Reconceptualising engagement: A relational practice with people experiencing communication disability after stroke

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Abstract

'Engagement' is a term increasingly used in healthcare and has commonly been conceptualised as a patient behaviour and responsibility. However, an emerging body of research indicates that the practitioner can influence engagement through their ways of relating, communicating and working with the patient. This doctoral research sought to explore the concept of engagement in stroke rehabilitation, and to develop rich, nuanced understandings of how practitioners engage people experiencing communication disability in this context.

A conceptual review explored how engagement was conceptualised in the healthcare literature, followed by two empirical qualitative studies utilising a Voice Centre Relational Approach. The first empirical study explored how people conceptualised engagement, by completing interviews with seven people experiencing communication disability and 14 rehabilitation practitioners. The second empirical observational study was a longitudinal exploration of how engagement was enacted in stroke rehabilitation services, observing 28 rehabilitation practitioners as they worked with three people experiencing communication disability. Together, these three studies helped develop in-depth understandings of engagement practices.

This research identified engagement to be a *process*, something facilitated through the practitioner's way of working, and as a patient *state*, evident in the patient's actions. The findings of this doctoral work propose that engagement is a relational practice, an intentional and reflexive way of thinking, working and being on the part of the practitioner. When enacting *engagement as a relational practice,* practitioners prioritised getting to know the patient and their needs, and used this knowledge to determine how best to work with them. This could see them emphasise relational or technical, disciplinary-based work depending on the patient' needs and priorities. Relational dialogue, an integrated approach to communication, was embedded

throughout their interactions. *Engagement as a relational practice* involved weaving together relational work and communication, together with technical, disciplinary-based work, and rehabilitation tasks. Practice was surrounded by a relational frame, a philosophy of practice. There was consistency and coherence between how the practitioner thought about engagement and how they enacted it. Engagement appeared co-constructed; each party's engagement was influenced by their perceptions of the other person's engagement. *Engagement as a relational practice* appeared a skilled, sophisticated way of working.

In explicating the recognisable elements of engagement practice, detailing communication patterns which appeared important for engagement, and demonstrating the need to consider practitioner (dis)engagement, this research makes significant contributions to knowledge. It challenges dominant understandings of which aspects of rehabilitation work and communication are legitimate and valuable when working to engage people experiencing communication disability in rehabilitation. This has implications for clinical practice, service development, and student education. These findings also serve as a base for on-going research into engagement. Re-conceptualising *engagement as a relational practice* may support practitioners to reflect on their understandings of engagement, their patient's engagement, on their ways of working, and perhaps most fundamentally, the frames and philosophies which surround and influence their practice.

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Transcription guide

Italics	Marks the speech of the researcher
… (pause)	Indicates a pause in the participant's speech
…	Indicates words removed from the original transcript
[ ]	Indicates words added by the researcher to clarify the meaning of the quote
" "	Indicates a direct quote from a participant or literature
' '	Indicates a quotation within the participant's direct quote
/ /	Indicates phonetic transcription of speech using the International Phonetic Alphabet, used when phonemic paraphasias were evident in speech

List of abbreviations

AHP	Allied health practitioner
CCI	Cognitive communication impairment
ESD	Early supported discharge
KPI	Key performance indicators
SLT	Speech language therapist

Attestation of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

……

Felicity Bright

30 November 2015

Co-authored works

Publications arising from this thesis

Bright, F. A. S., Kayes, N. M., Worrall, L., & McPherson, K. M. (2015). A conceptual review of engagement in healthcare and rehabilitation. *Disability & Rehabilitation, 37*(8), 643-654. doi:10.3109/09638288.2014.933899

Conference presentations arising from this thesis

Bright, F. A. S. (2014, November). *The role of the clinician in patient engagement.* Keynote presentation at Stroke Foundation South Island Seminar, Dunedin, New Zealand.

Bright, F. A. S., Kayes, N. M., Cummins, C., Worrall, L., & McPherson, K. M. (2014, May). *Voices of rehabilitation providers: Talking about engagement*. Poster presented at the meeting of the International Congress of Qualitative Inquiry, Champaign, IL.

Bright, F., Kayes, N. M., Worrall, L., & McPherson, K. M. (2014, May). *Voice(s) in action: Using the Listening Guide in observational research*. Poster presented at the meeting of the International Congress of Qualitative Inquiry, Champaign, IL.

Bright, F. A. S. (2013, May). *Does how we think about therapy matter? 'Voices' and values in speech language therapy.* Keynote address at the New Zealand Speech-Language Therapists' Association Professional Development seminar. Hamilton, New Zealand

Cummins, C., Bright, F. A. S., Kayes, N. M., & McPherson, K. M. (2013, March*). "I'm just lazy that's the problem": who is responsible for engagement in rehabilitation?* Presented at the New Zealand Rehabilitation Association Conference. Nelson, New Zealand.

Bright, F. A. S., Kayes, N. M., Cummins, C., McPherson, K. M., & Worrall, L. (2013, March). *"There needs to be some connectivity there": The role of therapeutic connections in facilitating engagement in rehabilitation.* Presented at the New Zealand Rehabilitation Conference 2013. Nelson, New Zealand.

Bright, F. A. S. (2012, July). *Rethinking engagement in rehabilitation: A critical review of the concept*. Presented at the meeting of the Rethinking Rehabilitation International Collaborative, Toronto, Canada.

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Ethics approvals

Ethical approval was obtained from:

- Northern X Ethics Committee (NTX/12/03/015) on 26 March, 2012
- AUT University Ethics Committee (12/88) on 18 April, 2012
- Health and Disability Ethics Committee (13/NTB/103) on 14 August, 2013
- AUT University Ethics Committee (13/243) on 28 August, 2013

Chapter One: Introduction

This thesis explores the concept of engagement in stroke rehabilitation and focuses specifically on engagement of people experiencing communication disability following stroke. The primary objective of this doctoral work is to develop understandings of how rehabilitation practitioners engage people experiencing communication disability. Engagement is increasingly referred to in the literature and in clinical practice, but as will be demonstrated within this thesis, there has been very little consideration of *what* engagement means to different stakeholders, nor *how* it occurs. This research was undertaken to better understand how engagement may be conceptualised by key stakeholders in stroke rehabilitation, how it may come about and how it may be enacted in practice.

Background to the research: Positioning the researcher

I have been interested in the concept of engagement since the early 2000's when I was a full-time practicing speech-language therapist in neurorehabilitation. This interest was sparked by Deborah Hersh's research on discharging people with aphasia from speech-language therapy (e.g. Hersh, 1998, 2001, 2003, 2009a, 2010a). Hersh (2009a) concluded one paper saying: "What happens at the close of therapy may be as important to our clients as the beginning of it" (p. 153). I recall reading this, thinking "but how should we *begin* therapy?" Commencing therapy and engaging people in their rehabilitation appeared to be hidden, a tacit aspect of practice (Byng, 1993; Fourie, 2011b). Yet as a practitioner, it was something I struggled with at times. Ten years later, I can still visualise patients who appeared to be struggling to engage. I recall my feelings of uncertainty, not knowing what I could do to help them engage. As I discharged one particular patient, I felt a sense of lost opportunity and I wanted to know what I could have done differently to better engage him in rehabilitation.

After leaving clinical practice, I worked as a clinical researcher, implementing different approaches to goal-setting in a randomised controlled trial of goal-setting interventions with people with traumatic brain injury (Bright, Boland, Rutherford, Kayes, & McPherson, 2012; Ylvisaker, McPherson, Kayes, & Pellett, 2008). Engaging participants in the interventions was an explicit component of treatment. Alongside my clinical research colleagues, we spent a significant amount of time reflecting on our ways of working, culminating in the publication of a co-authored autoethnography of practice (Bright et al., 2012). In this paper, we argued our client-centred approach to working was crucial in engaging participants in the intervention, enacted through listening, allowing time, supporting patients in prioritising what is meaningful, and viewing ourselves as supporters rather than doing interventions to them. When I reflected back to my clinical speech-language therapy practice, and to the patient who still stood out in my mind, I perceived these aspects of engagement were missing in my practice, or at best, enacted at a surface level.

While working in this research role, I completed my Masters of Health Science. This explored hope in people with aphasia (Bright, 2011). Findings from this study suggested a person's state of hope and their particular hopes may influence engagement. If they perceived rehabilitation gave them a sense of hope or might help them achieve their hopes, it was easier to engage. Those who reported struggling to engage appeared to tolerate rehabilitation as passive recipients, rather than as active, involved participants. The way the practitioner worked with a person's hope also appeared important in engagement.

As a result of my clinical and research experience, I contributed to undergraduate and postgraduate teaching on topics such as person-centred practice and engagement. I also provided a number of presentations on these topics to practitioners around New Zealand. While I could make a case for *why* engagement appeared important, I often

struggled to articulate *how* practitioners could work to improve patient engagement, strategies they could use.

Together, my clinical, research and teaching experiences created a real interest in further exploring engagement. As a practitioner, I wanted to know 'how can I better engage people in rehabilitation?' As a researcher, I wanted to know more about this sometimes nebulous and contested concept of engagement. As a lecturer and new clinical educator, I wanted to know 'what do I teach my students about engagement, their role in the process, and how engagement 'work' can be embedded within clinical practice?' Yet, as I will demonstrate in the conceptual review in Chapter Two, there was limited literature to guide me in answering these questions. The three years of doctoral study have been, in part, an exercise in learning more about engagement in order to help me become a better, more reflective and engaging practitioner and educator.

Engagement in stroke rehabilitation

Engagement is increasingly considered important for healthcare outcomes. In the context of rehabilitation, several authors have argued its benefits are limited if the patient is not fully engaged in the process (Kortte, Falk, Castillo, Johnson-Greene, & Wegener, 2007; Medley & Powell, 2010). Engagement has been associated with positive effects such as lower levels of depression and higher levels of positive affect, adherence, attendance, functional improvement during inpatient rehabilitation and level of functioning after discharge (Kortte et al., 2007; Lequerica & Kortte, 2010). Intrinsic patient factors such as motivation and self-efficacy have been described as core to engagement (e.g. Lequerica & Kortte, 2010). However, research from the mental health sector indicates that the interaction between the patient and rehabilitation practitioner can influence engagement (e.g. Addis & Gamble, 2004; Chase, Zinken, Costall, Watts, & Priebe, 2010; Drury & Munro, 2008; Staudt, Lodato, &

Hickman, 2012) as can the skills and actions of practitioners (e.g. Chase et al., 2012; Drury & Munro, 2008; Priebe, Watts, Chase, & Matanov, 2005; Staudt et al., 2012).

Communication disorders such as aphasia, apraxia of speech and dysarthria affect up to 65% of people after stroke (National Stroke Foundation, 2009). Aphasia and cognitive-communication difficulties commonly affect a person's ability to understand and process written and/or verbal information; these can affect a person's ability to express themselves and their needs, thoughts, emotions and priorities verbally and/or in writing. Communication disability[1] can also significantly impact on the *process* of rehabilitation, influencing how rehabilitation practitioners and patients communicate and interact. Some people experiencing communication disability reported a sense of not being listened to or understood (Dickson, Barbour, Brady, Clark, & Paton, 2008; Parr, Byng, Gilpin, & Ireland, 1997). One study indicated people with aphasia do not feel they are active participants in rehabilitation even when their therapists believe they are working collaboratively (Madonna, Armstrong, & Togher, 2002). While communication disability can present challenges in a healthcare interaction, people are often able to express *more* if their communication partners support communication using a range of communication strategies (Kagan, 1998).

Arguably, the responsibility to support communication and patient engagement sits with the rehabilitation practitioner (Simmons-Mackie & Damico, 2007). However, a practitioner's attitudes and behaviours may limit, rather than facilitate engagement. Practitioners may consider this patient group to be hard to communicate with. This can see them instead communicate with family or friends, which people experiencing communication disability often consider unacceptable (Dickson et al., 2008; Parr et al.,

[1] Communication disability refers to "the impairments, activity limitations, and participation restrictions that affect an individual's ability to interact and engage with the world in ways that are meaningful and fulfilling to them and their communication partners" (University of Queensland Communication Disability Centre, 2015).

1997). Practitioners may control conversation and focus on service requirements rather than the needs and perspectives of the individual patient (Dickson et al., 2008; Gordon, Ellis-Hill, & Ashburn, 2009). Given that engagement appears to be associated with interaction between the patient and practitioner (as described on page 3), and this can be significantly affected in the presence of a communication disorder, it seems reasonable to assume that there may be unique challenges in engagement when a person experiences communication disability.

As detailed above, engagement has been associated with improved rehabilitation outcomes (Kortte et al., 2007; Lequerica & Kortte, 2010). The presence of communication impairments, and in particular aphasia, is associated with poorer motor, functional and cognitive outcomes post-stroke (Gialanella, Bertolinelli, Lissi, & Prometti, 2011; Hilari, 2011), lower quality of life and higher levels of psychological distress (Hilari, 2011). People are more likely to discharge to residential care (Gialanella et al., 2011). If engagement is difficult because of the presence of communication disability, and if it is associated with rehabilitation outcomes as proposed, then arguably, this provides further justification for examining how practitioners can support engagement.

Understanding factors that may influence outcomes is becoming increasingly important with the growing demand for rehabilitation due to the ageing population, increasing chronicity and complexity of conditions, and advances in healthcare (Landry, Jaglal, Woodchis, & Ctt, 2006). For example, the number of people having stroke is increasing (Feigin, Forouzanfar, et al., 2014). In New Zealand, the rate of stroke amongst Māori[2] and Pasifika people is increasing. The burden of stroke is projected to increase significantly in the next ten years due to an increasingly ageing

[2] Māori are the Indigenous people of Aotearoa/New Zealand. Māori is also one of New Zealand's official languages.

population (Feigin, Krishnamurthi, Barber, & Arroll, 2014). With one in five New Zealanders being over 65 in 2031, compared with one in eight in 2009 (Statistics New Zealand, 2009), it is likely we will see an increase in annual costs to the health system (Feigin, Krishnamurthi, et al., 2014). However, this is occurring in a climate when funding pressures are increasing and costs of many treatments are increasing, leading to an imperative to maximise the benefits of healthcare services within limited resources (Ministry of Health, 2011; The Treasury, 2013). The rising costs of healthcare and the global economic climate have been suggested as core drivers behind a focus on patient engagement, particularly in the United States, in the last ten years (Barello, Graffigna, Vegni, & Bosio, 2014). There is also an increasing move toward promoting patient self-management as part of preventative healthcare (The Treasury, 2013), yet initiatives relevant to stroke show low levels of adherence and engagement (Feigin, Krishnamurthi, et al., 2014), indicating more work needs to be done. Helping practitioners improve patient engagement could arguably promote more efficient, effective use of healthcare resources as active patient participation is essential in many rehabilitation interventions.

Taken together, this brief review of the literature suggests people experiencing communication disability may face particular challenges in engaging in rehabilitation and there is a need to further consider engagement. While engagement is an emerging concept and not clearly defined or conceptualised, the literature suggests engagement may be an important factor in patient outcomes. Further research is required to explore what engagement means for people experiencing communication disability and those working with them in rehabilitation. Additionally, it appears it would be beneficial to have a better understanding of how engagement comes about, and in particular, the role the practitioner has in engaging people experiencing communication disability. Enhanced understandings of the meaning and process of engagement for people experiencing communication disability could arguably have a

number of effects, from supporting practitioners to reflect on and modify their practice as required, through to maximising patient outcomes and enhancing effective, efficient use of clinical resources.

Research aims

The primary objective of this research was to develop understandings of how practitioners engage people experiencing communication disability in stroke rehabilitation. However, a preliminary literature review undertaken prior to starting the PhD identified an apparent lack of clarity about what engagement might be. Accordingly, the primary objective of exploring practitioners' ways of working consisted of several specific aims. These were:

1. To examine how engagement was conceptualised in the healthcare literature and to propose a working definition to underpin the on-going research.
2. To explore how engagement in stroke rehabilitation was understood or conceptualised by people experiencing communication difficulties after stroke, and by rehabilitation practitioners working in stroke rehabilitation.
3. To develop understandings of how rehabilitation practitioners engaged people experiencing communication disability in stroke rehabilitation.

This research consisted of three distinct studies, each addressing a separate aim yet all contributing to the overall research objective as demonstrated in Figure 1.

Early in the PhD process, I undertook a systematic literature review (a conceptual analysis) to better understand the concept of engagement. At the same time, I completed a preliminary interview-based qualitative study exploring how people experiencing communication disability and rehabilitation practitioners viewed engagement. Key findings of these studies informed the focus and design of the final study, an in-depth observational study exploring how rehabilitation practitioners engage people experiencing communication disability in stroke rehabilitation

throughout the course of the person's rehabilitation. This comprehensive longitudinal observational study attended to how practitioners engaged, why they worked as they did and what this accomplished (Blumer, 1969). This focus was chosen as the practitioner's role appeared crucial in how people experiencing communication disability engage in rehabilitation and there has been limited attention paid to how the practitioner engages with the patient, and specifically, how they work. The intention of this study was to develop detailed, nuanced understandings of engagement practices which might support practitioners to reflect on ways of engaging people experiencing communication disability.

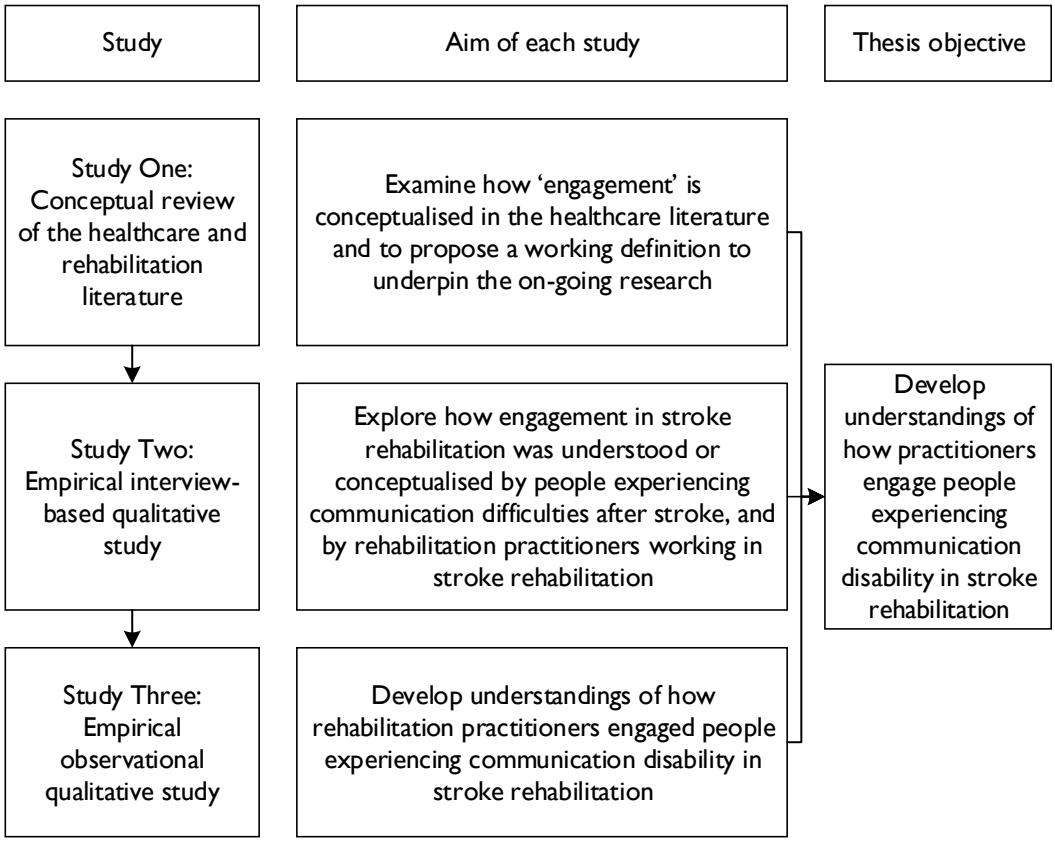


Figure 1: Research aims and components

Defining key terms

Seven terms are used repeatedly throughout the thesis and defined here: engagement, relational work, technical disciplinary-based work, patients, people experiencing communication disability, stroke rehabilitation and rehabilitation practitioners.

Engagement

Within the literature, the term *engagement* holds multiple meanings (e.g. Barello et al., 2014; Bright, Kayes, Worrall, & McPherson, 2015), which I explore in the conceptual review of engagement in Chapter Two. This review proposes a definition of engagement for the purposes of this research. The definition underpins the work undertaken in this thesis:

> Engagement is a co-constructed process and state. It incorporates a process of gradually connecting with each other and/or a therapeutic program which enables the individual to become an active, committed and invested collaborator in healthcare (Bright et al., 2015, p. 651).

Relational work

The term *relational work* refers to the process of developing a therapeutic relationship and in particular, the work the practitioner does to develop and maintain a relationship. Relational work involved combining a number of skills and techniques such as conversation, small talk, getting to know the patient, giving information about themselves, and coming to understand what the patient needs from the practitioner. This is done for the purposes of developing a relationship in order to engage the person in rehabilitation, or to maintain their engagement in rehabilitation.

Technical, disciplinary-based work

Technical, disciplinary-based work is often discussed alongside *relational work.* It refers to the work services require, such as assessment and goal-setting, and to the disciplinary-based work such as specific modes of treatment and education. Such work is commonly based on knowledge acquired in the course of professional training, or work that is mandated and prioritised by the rehabilitation services.

Patient

Within this thesis, I use the term *patient* to refer to the participants experiencing communication disability. 'Patient' commonly refers to people at the time they are receiving healthcare services. Many participants experiencing communication disability in the first empirical study were accessing rehabilitation at the time of their interview; all participants experiencing communication disability in the second empirical study were involved in rehabilitation during data collection. I use the term 'patient' reflecting that the participants were describing events that occurred while they were accessing rehabilitation services.

People experiencing communication disability

Communication disability refers to:

> the impairments, activity limitations, and participation restrictions that affect an individual's ability to interact and engage with the world in ways that are meaningful and fulfilling to them and their communication partners (University of Queensland Communication Disability Centre, 2015).

Within the context of this study, *people experiencing communication disability* refers to people who have specific communication impairments (namely, aphasia, dysarthria, apraxia of speech and/or cognitive-communication difficulties) who have been

diagnosed by a speech-language therapist, and whose communication impairment results from the stroke. In the context of this research, it does not include people with other forms of communication disability, such as those resulting from hearing or visual impairments, which may or may not have been present prior to the stroke.

Stroke rehabilitation services

Stroke rehabilitation services refers to the type of services patients were enrolled in at the time of the study. Within the New Zealand context, services are commonly organised as inpatient, outpatient and community-based rehabilitation services (McNaughton, McRae, Green, Abernathy, & Gommans, 2014; Stroke Foundation of New Zealand, 2010). *Inpatient service*s are residential and staffed by a team which may include any or all of: doctors, nurses, speech-language therapists[3], occupational therapists, physiotherapists, assistant staff (known by terms such as rehabilitation assistant, allied health assistant or healthcare assistant), psychologists, social workers, cultural support staff and pharmacists. Patients commonly receive daily therapy input. New Zealand guidelines indicate patients with physical impairments should receive a minimum of one hour/day of physiotherapy (Stroke Foundation of New Zealand, 2010) while other guidelines state patients should receive a minimum of 45 minutes/day of each required therapy (National Institute for Health and Care Excellence, 2013).

Outpatient rehabilitation services are clinic-based rehabilitation services. The patients reside at home but attend the clinic on a regular basis. These services are predominantly provided by allied health staff but may include nursing and medical staff as required. *Community-based rehabilitation services* are based in the patient's own home. Services may vary in intensity, with some practitioners providing intensive

[3] I use the term 'speech-language therapist' rather than 'speech-language pathologist', reflecting that 'therapist' is the preferred term in New Zealand.

input (several treatment sessions a week) while others provide a more consultative or monitoring approach, depending on the needs of the individual clients. As with outpatient rehabilitation services, these are predominantly provided by allied health staff but other disciplines may be involved on an as-required basis. Eighty-two percent of stroke rehabilitation units in New Zealand offer outpatient and/or community-based rehabilitation services, with18% offering an '*early supported discharge*' (ESD) programme (McNaughton et al., 2014). ESD programmes are designed for patients with mild-moderate disability who are able to reside at home with the support of family, and receive intensive (often daily) rehabilitation in their homes. Such programmes may be an alternative to inpatient rehabilitation for some patients, while for others, they may accelerate discharge from inpatient rehabilitation (Early Supported Discharge Trialists, 2005).

Rehabilitation practitioners

As detailed in the paragraph above, a wide range of professionals work in stroke rehabilitation. For the purposes of this study, *rehabilitation practitioners* refers to any staff member providing clinical care for a patient and includes all disciplines or designated positions stated on page 11.

Structure of the thesis

The structure of the thesis is illustrated in Figure 2. Within this chapter, I have provided an overview of the research topic: how rehabilitation practitioners engage people experiencing communication disability in stroke rehabilitation. This is a practice-oriented study, originating from a desire to develop my own practice and teaching. It is designed to inform how rehabilitation practitioners work, and reflects

my interest in the topic as a healthcare practitioner and as an educator with current and future healthcare practitioners.

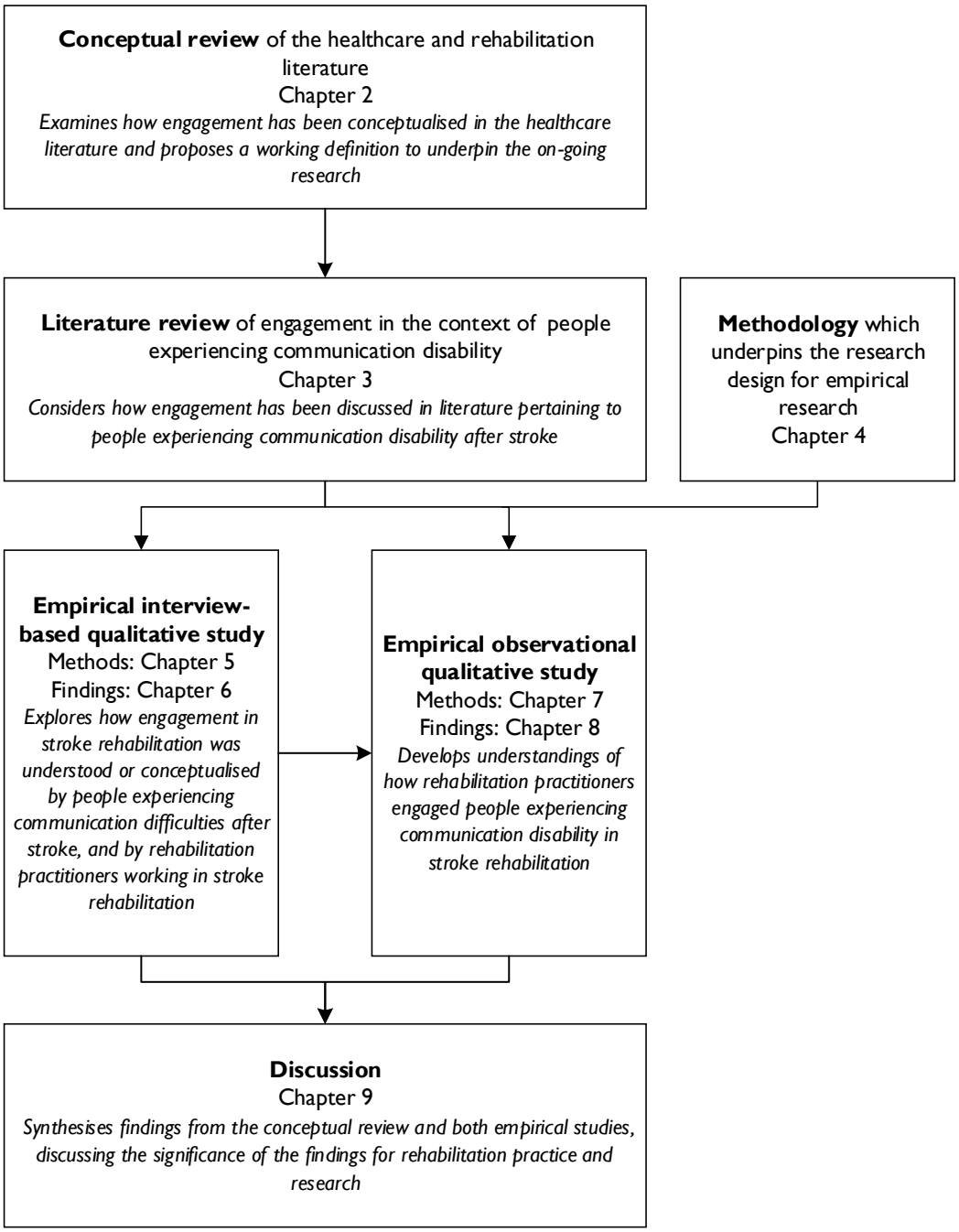


Figure 2: Thesis structure

Chapter Two presents the conceptual review of engagement undertaken early in the PhD to better understand how engagement was conceptualised in the literature

exploring engagement in healthcare. Chapter Three explores the communication disability literature, considering the current knowledge regarding engagement in people experiencing communication disability.

Chapter Four presents the Voice Centred Relational Approach, the methodology which underpins this doctoral study. I outline this methodology and its underlying theoretical framework before demonstrating how it informed the design of the doctoral research. I also introduce the Voice Centred Relational *Method*, the analytic method used throughout the two qualitative studies included in this thesis.

Chapter Five details the methods of the first exploratory interview-based qualitative study of this doctoral research. This study explored how people experiencing communication disability and rehabilitation practitioners conceptualised engagement. The findings are reported in Chapter Six. The methods for the second empirical study, a longitudinal observational study of how practitioners engaged people experiencing communication disability are detailed in Chapter Seven while the findings are presented in Chapter Eight. The findings bring together multiple data sources (including observations, stimulated recall and interviews) and perspectives from patient and practitioner participants to describe *engagement as a relational practice*, the central practice used to engage people experiencing communication disability.

Finally, in Chapter Nine, the Discussion, I draw together the results of the conceptual review and both empirical studies. I focus on the objective of this thesis, understanding how practitioners engage people experiencing communication disability in stroke rehabilitation. I consider how the findings advance existing knowledge of engagement and also how the research advances methodological knowledge through the innovative use of the Voice Centred Relational Method. The chapter considers the limitations of this doctoral study and makes suggestions regarding clinical practice and clinical education, and future research that may advance knowledge of engagement.

Chapter Two: A conceptual review of engagement[4]

This chapter considers how engagement has been conceptualised in the healthcare literature. Using a concept analysis methodology, it synthesises different understandings of engagement and identifies core elements from across the literature. Currently, the multiple uses of engagement are often somewhat dissonant. For example, meanings vary from patient enthusiasm (Kortte et al., 2007) to interaction between the healthcare practitioner and patient (Hitch, 2009) to a hospital's provision of electronic health records (Mattox, 2013). This presents challenges for researchers and practitioners alike. The purpose of the conceptual review was to synthesise literature which had explicitly explored the concept 'engagement', using this to propose a theoretically and empirically derived definition of engagement to inform the on-going research within this doctoral research.

Conceptual review methodology and methods

Over the last two decades, there has been an increasing focus on exploring 'taken-for-granted' concepts and terms. Researchers have sought to elucidate and clarify concepts to inform clinical practice and future research, and to challenge different ways they are understood (Morse, 1995, 2000; Rodgers & Knafl, 2000). This review drew on Morse's Pragmatic Utility approach to concept analysis (Morse, 2000; Weaver & Morse, 2006), which focuses on the clinical and research usefulness of the concept (Weaver & Morse, 2006). Concept analysis involves critical appraisal, coding, analytic questioning and

[4] A modified version of this chapter has been previously published. The full reference is: Bright, F.A.S., Kayes, N.M., Worrall, L., & McPherson, K.M. (2015). A conceptual review of engagement in healthcare and rehabilitation. *Disability and Rehabilitation, 37*(8), 643-654. doi:10.3109/09638288.2014.933899. Specific modifications are: (a) the published introduction is not included in this chapter;(b) a 'quality appraisal' column has been added to Table One; (c) greater discussion on quality is included in the body of the chapter; and (d) the published conclusion is not included in this chapter.

data synthesis to inform the development of a clinically applicable definition and/or conceptual model (Hawkins & Morse, 2014; Penrod & Hupcey, 2005).

The concept analysis approach was considered the most appropriate approach for this literature review because the purpose was to explore in detail *how* engagement had been conceptualised. Identifying conceptual maturity (i.e. whether it is well-defined and consistently applied across contexts) was beneficial for informing on-going research within this doctoral work (Morse, Hupcey, Mitcham, & Lenz, 1996; Morse, Mitcham, Hupcey, & Cerdas Tason, 1996). While there are multiple forms of conceptual analysis, Pragmatic Utility was selected due to its emphasis on the clinical usefulness and application of concepts (Morse, 2000; Weaver & Morse, 2006), consistent with the applied nature of this doctoral research.

Data sources

A systematic approach to literature searching was used. The search was conducted using EBSCO databases (specifically: Biomedical Reference Collection: Basic, CINAHL Plus, Health Business Elite, Health Source – Nursing/Academic Edition, MEDLINE, Psychology and Behavioural Sciences Collection, SPORTDiscus and Dentistry & Oral Sciences Source) and SCOPUS. The search terms are in Appendix A. A citation search was undertaken to capture articles not found in database searches. Citation lists of all included articles were reviewed; citation tracking was completed using SCOPUS.

Articles were included if they reported a theoretical or empirical study where the stated objective was to: (a) understand or describe the concept of patient engagement in hospital or community-based healthcare where there was an on-going therapeutic interaction, beyond medical testing and medication management; *or* (b) if the paper described the development of a measure of engagement for use in healthcare where there was on-going therapeutic interaction as defined above. Only articles published in

English-language, peer-reviewed journals between 1990 and 2012 were included, reflecting this review was undertaken at the start of the doctoral research. Articles were excluded if they: (a) solely sought to explore barriers and facilitators to engagement, or influencing factors of engagement without also explicitly providing a theoretically-informed or data-derived definition of engagement; (b) explored engagement in child or adolescent services given their engagement is likely to differ from adults accessing healthcare (Anderson & Wolpert, 2004); and/or (c) explored engagement in prison or forensic settings due to there being other complexities (such as mandated treatment) in these settings that distinguish them from standard hospital or community-based healthcare (Rempel & Destefano, 2002).

The titles and abstracts of all retrieved articles were reviewed to determine whether they possibly or probably met the inclusion criteria. The full text of these articles were retrieved and read to confirm eligibility for inclusion in the review. The primary supervisor (NK) reviewed a random selection of approximately 20% of the articles to confirm eligibility, while a second supervisor (KM) reviewed articles in cases of disagreement. Consensus was reached through discussion. Articles function as data for the purposes of conceptual review and as such, the use of 'data' in this chapter refers to the included articles.

Quality appraisal

Each included article was appraised for quality using an appropriate tool. Quality appraisal is not a required component in concept analysis and articles were not excluded based on quality (Morse, 2000). However, research quality is discussed here as it provides information about the current state of research and knowledge in this area. Articles reporting measures of engagement were appraised using Holmbeck and Devine's (2009) checklist, in particular the first section which focuses on the

conceptual basis of the measure. Qualitative papers were appraised with a Critical Appraisal Skills Programme (2010) assessment tool. Theoretical articles (including models of engagement, literature reviews and conceptual papers) were appraised using a checklist from the University of Melbourne (n.d.).

Data extraction and synthesis

Each included article was read in its entirety to gain a broad understanding of how engagement had been defined and/or conceptualised (Morse, 2000). Following this, analytic questioning (Morse, 2000; Weaver & Morse, 2006) prompted detailed analysis of how engagement was conceptualised, for example, querying how different stakeholders defined engagement, and asking what processes, outcomes and behaviours were associated with engagement. Findings were recorded on matrices, facilitating comparison within and between articles (Bright, Kayes, McCann, & McPherson, 2010; Hawkins & Morse, 2014). Two examples of matrices of analytic questions are provided in Appendix B. Core themes were extracted and refined using constant comparison (Charmaz, 2014). These core themes were synthesised to develop a theoretically-informed, data-derived definition of engagement.

Rigour

Multiple approaches to rigour were utilised. There was regular discussion regarding the emerging conceptualisation of engagement with supervisors and with external experts. Preliminary findings were presented to local rehabilitation practitioners (Bright, 2012a, 2012b) and to a panel of experienced rehabilitation researchers at the Rethinking Rehabilitation meeting in Toronto, Canada (Bright, 2012c). The published conceptual analysis underwent blind peer review (Bright et al., 2015). Each of these offered opportunities for peer review of methodology and interpretation (Mays &

Pope, 1995). Rigour is demonstrated by incorporating direct quotes within the review and through an audit trail completed while conducting the review.

Results

Literature search results

The search and subsequent screening process is illustrated in Figure 3 on page 20. In total, 1141 abstracts were retrieved and reviewed for relevance. Following initial review of abstracts, 1082 were excluded primarily because the paper did not seek to explore the concept of engagement or did not explore engagement in a therapeutic encounter. Many articles used the *word* 'engagement' without exploring it as a concept. For example, the word 'engagement' was used within a discussion of adherence to a physiotherapy program (Crook et al., 1998) and also in an article exploring compliance with HIV testing and medication management (E. M. Gardner, McLees, Steiner, Del Rio, & Burman, 2011). However neither article defined or explored the concept itself. The full text of 59 articles were retrieved following which a further 31 papers were excluded. Articles were excluded if they explored barriers and facilitators to engagement, or influencing factors of engagement without explicitly exploring the *concept* of engagement (Kayes, McPherson, Taylor, Schlüter, & Kolt, 2011). They were also excluded if they did not address engagement in an on-going therapeutic interaction, instead considering engagement in health service planning or medical consultations (McCabe, Heath, Burns, & Priebe, 2002).

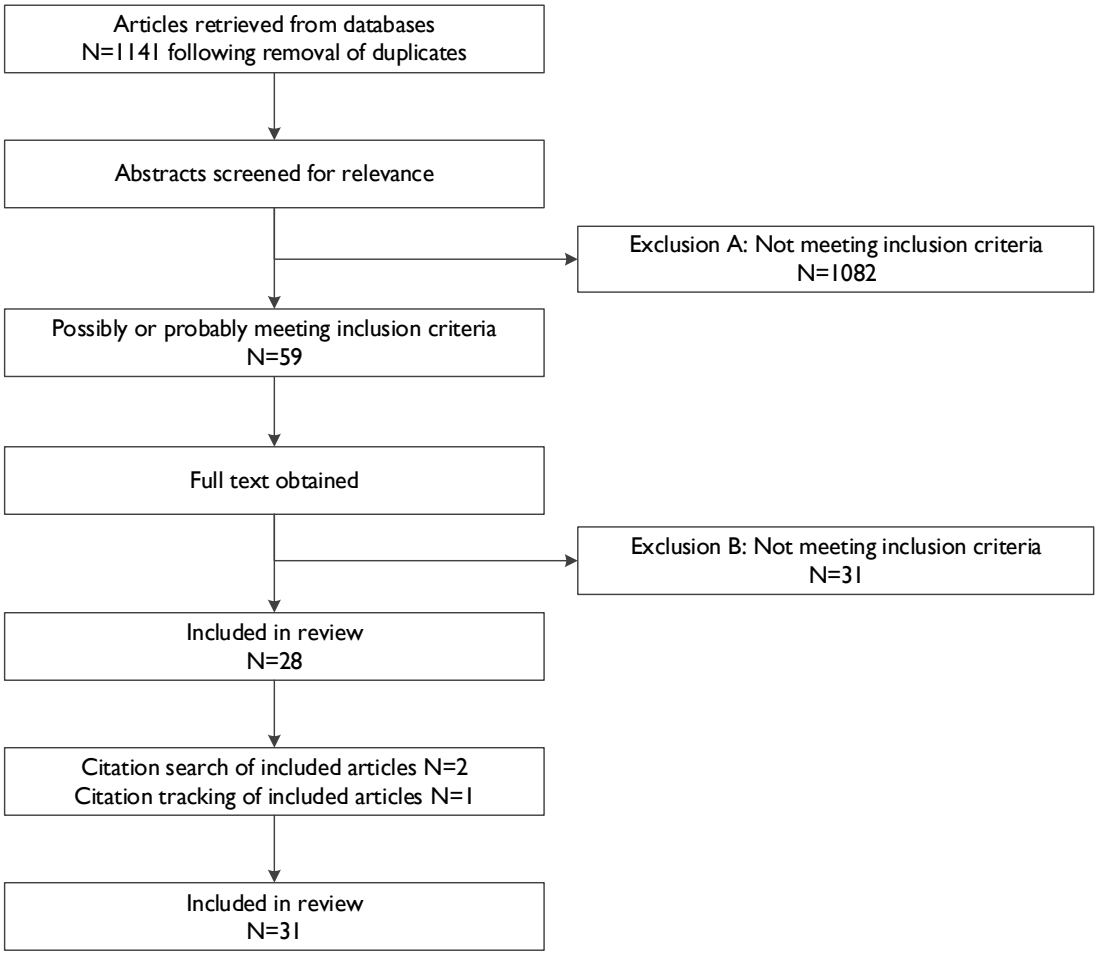


Figure 3: Literature search strategy and results

In total, 28 articles met the inclusion criteria. Two further articles were identified through citation searching (Chase et al., 2010; Priebe et al., 2005) and another identified through citation tracking (Drury & Munro, 2008). Thirty one articles were included in the review. These represented a range of designs including theoretical, measurement and qualitative studies. Seventeen articles were from mental health; the other 14 were from rehabilitation, speech-language therapy, chronic care, social work and primary care. Details of the included articles, including core information about how engagement was described within each, are summarised in Table 1 on pages 21-36.

Table 1: Summary of included papers

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Addis & Gamble, 2004	Explored nurses' understandings of engagement and experiences of engaging patients in assertive outreach services.	Assertive outreach Mental health	Qualitative Phenomenology Data collection: Interviews	N=7 nurses	Engagement occurred over time and involved connecting with the individual at a human level, requiring persistence and patience. Engagement did not always occur. It could be challenging and exhausting for staff. The practitioner's attitudes towards patients (e.g. 'caring for') was considered vital.	Strengths: Clear aim. Design consistent with aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear statement of findings. Findings extend current knowledge about engagement, in particular the practitioner's actions in engagement.
Chase et al., 2012	Explored the experience of people with mental illness engaged in community psychiatric services.	Community psychiatric services Mental health	Qualitative No defined methodology Data collection: Individual interviews	N=25 seemingly engaged people with severe, enduring mental illness	The human connection between patient and provider was perceived to be crucial. The practitioners' skills and attributes were considered vital, such as active listening and seeing them as an individual rather than a diagnosis. Service structures were perceived to impact on engagement. Participants indicated engagement differed from compliance. The latter could involve attending but not connecting with their practitioner or actively participating in care.	Strengths: Clear aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear statement of findings. Findings challenge and extend current knowledge about engagement, in particular challenging ideas of compliance and engagement. Limitations: Not underpinned by a defined methodology.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Chase et al., 2010	Explored the discourses of engagement and disengagement in the narratives of people accessing mental health services.	Assertive outreach Mental health	Qualitative Discourse analysis Data collection: Individual interviews	N=40 people diagnosed with psychosis; in assertive outreach services	The use of 'we' was considered a marker of engagement. Engaged patients positioned themselves as positive, expressing their ability to be active in the therapeutic relationship, communication and treatment. This active role could develop over time. Engaged patients spoke positively of the therapeutic relationship using terms such as "a balance, a level or a two-way process" (p. 49).	Strengths: Clear aim. Design consistent with aim. Data collection and analysis process detailed. Clear statement of findings. Findings extend current knowledge of phenomenon, in particular, subject positioning within engagement. Limitations: Little detail of process of rigour
Cumbie, Conley & Burman, 2004	Proposed model of nursing care to promote engagement of people with chronic illness based on a synthesis of the literature.	Chronic illness Nursing	Theoretical, drawing on existing literature	NA	Engagement was a process involving collaboration between patient and provider with the use of strategies to enhance engagement, based on a patient-centred approach to care. Engagement strategies included: making information and activities personally meaningful, understanding the patient's perspective, helping the patient develop model of their illness experience, co-establishing priorities, goals and action plans. The desired outcome was that the patient would identify and sustain strategies to manage their illness.	Strengths: The model of engagement drew on several models of nursing intervention. Written for clinical and academic audiences in persuasive manner. Paper well-structured. Findings prompt consideration of engagement as a way of working. Limitations: Model derived from several different studies previously completed by the authors, not all specifically related to engagement.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Danzl et al., 2012	Explored concept of engagement and its role in neurorehabilitation.	Neurological rehabilitation	Theoretical, drawing on existing literature	NA	Engagement was defined as an "increased motivation, attention and active participation in rehabilitation, grounded in and supported by the interaction and relationship between the patient and practitioner" (p. 36).	Strengths: Concept of engagement based on review of the literature. Written for clinical audience in a descriptive, persuasive manner. Paper well-structured. Findings prompt consideration of clinical implications of engagement in neurorehabilitation context. Limitations: Literature review pragmatic rather than systematic. Provides overview of concept.
Drury & Munro, 2008	Reviewed the role of engagement in crisis mental health; proposed strategies for promoting engagement from a Māori perspective.	Crisis services Mental health	Theoretical, drawing on existing literature	NA	The importance of therapeutic engagement was emphasised. Engagement could be dependent on the practitioner's actions and the resulting relationship between the patient and provider, through *manaakitanga* (the skill of hospitality, respecting the *mana* of all involved).	Strengths: Concept of engagement based on comprehensive review of the literature. Written for clinical and academic audiences in critical, persuasive manner. Paper well-structured. Findings prompt consideration of engagement within a Māori context, but are applicable to other contexts.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Duchan, 2009	Explored how the term engagement has been used in the literature with a focus on its application to speech-language therapy.	Speech-language therapy	Theoretical, drawing on existing literature	NA	Engagement was described as "a person's avid and active connection with another person", and/or the sense of being "drawn into and having connection with an activity" (p. 12). Multiple objects of engagement were identified including people, events or activities. Practitioners created a "climate of engagement" through their ways of working.	Strengths: Provides overview of concept of engagement, drawing on literature from different contexts. Written for clinical audiences in descriptive manner. Paper well-structured. Findings prompt consideration of different forms and indicators of engagement in clinical practice. Limitations: Literature review pragmatic rather than systematic. Review not exhaustive.
Gillespie et al., 2004	Reported the development and initial testing of a self-report measure of engagement in mental health services.	Assertive outreach Mental health	Measure development Modified existing measure to include self-report Psychometric testing	Testing: N=25 patient-practitioner dyads	Engagement was not explicitly defined. Measure contained domains of appointment keeping, patient-therapist interaction, patient communication/openness, perceived usefulness of treatment, and collaboration with treatment. Patient and practitioner rating of engagement were not consistently correlated.	Strengths: Provided rationale for developing measure. Limitations: Did not define engagement. Items generated from existing measure. Authors acknowledged items may not reflect construct of engagement as viewed by patients.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Godlaski et al., 2009	Explored what women with substance abuse related problems find most engaging about treatment.	Substance abuse services Mental health	Qualitative No defined methodology Data collection: Individual interviews	N=12 women accessing rural substance abuse treatment services	Engagement with providers, and others in the context of group treatment, was considered crucial in order to engage in treatment. It involved a sense of feeling safe, welcome and valued, and feeling understood. This was important in order for the women to openly and honestly participate in the treatment program.	Strengths: Clear aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear statement of findings. Findings extend current knowledge about engagement, in particular longitudinal nature of engagement. Limitations: Not underpinned by a defined methodology.
Hall et al., 2001	Reported the development of a measure of engagement in mental health services.	Community psychiatric and assertive outreach services Mental health	Measure development Developed through consultation with 13 mental health practitioners Psychometric testing	Testing: N=64 people accessing mental health services	Engagement was not explicitly defined. Measure contained domains of appointment keeping, patient-therapist interaction, patient communication/openness, perceived usefulness of treatment, and collaboration with treatment.	Strengths: Measure developed in response to lack of existing measures Limitations: Limited review of literature evident. Items generated from practitioners, not robust literature review or qualitative research. Measures practitioners' perception of engagement, not the patient's perception.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Hitch, 2009	Sought to capture the experience and meaning of engagement for staff and patients in assertive outreach teams.	Assertive outreach Mental health	Qualitative Phenomenology Data collection: Individual interviews	N=5 patients, 5 practitioners	Engagement had several forms: interpersonal, occupational (in meaningful activities) and service-oriented. Engagement was seen to be both a 'process' (the relationship and collaboration between patient and provider) and an 'outcome' (patient action – participation, initiation, self-initiated activity).	Strengths: Clear aim. Design consistent with aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear but brief statement of findings. Limitations: Limited findings about each form of engagement, reflecting study explored the multiple meanings of engagement
Kemppainen et al., 1999	Developed a scale of patient engagement in AIDS care.	AIDS care Chronic illness	Measure development Developed from previous qualitative research Psychometric testing	Testing: N=162 people with AIDs, currently receiving hospital care	Engagement was defined as the "level of involvement that patients demonstrate in nursing care" (p. 168). Scales focused on the patient's behavioural responses to their nurses. Factor analysis suggested the measure had two scales – the Participation Scale focused on positive engagement such as participation, respect and appreciation (e.g. I treated the nurses swell, I did what the nurses told me to do) and the Anger Scale in which interpersonal engagement was characterised by anger or aggression (e.g. I was irritable, I gave the nurses a terrible time).	Strengths: Clear rationale for developing measure. Items based on extensive qualitative research. Patient and practitioners contributed to face/content validity. Clear process of measurement development provided.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Konrad, 2009	Developed a model of therapeutic engagement in social work with grieving patients.	Social work	Theoretical drawing on existing research and researcher experience	NA	Engagement was discussed with regard to "relational engagement" (p. 407). Engagement was seen as a process which provided a foundation for therapeutic intervention and required practitioner skills and attitudes. These include a "willingness and desire to truly know" (p. 408), "emotional presence, responsively and empathy" (p. 409) and responsiveness to the emergent meaning in what the patient is saying. It requires practitioner engagement.	Strengths: Concept of engagement informed by disciplinary and professional perspectives (social work in trauma). Written for clinical and academic audiences in descriptive persuasive manner. Paper well-structured. Findings prompt consideration of the role of relationship in engagement, and of engagement as away or working and an intervention.
Kortte et al., 2007	Developed a measure of engagement in inpatient acute physical rehabilitation services.	Acute physical rehabilitation	Measure development Refined from existing measure of participation Psychometric testing	Testing: N=206 people with stroke, spinal cord injury, amputation or hip/knee replacement	Engagement was defined as "an interest in, and an intentional effort to, work toward the rehabilitation goals" (p. 878). Patients were measured on five scales: attendance, extent of prompting required, attitude toward treatment, acknowledgement of need for rehabilitation services/activities, extent of active participation in treatment.	Strengths: Based on review of literature. Construct defined. Limitations: Content based on related instruments and consultation with clinical experts.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Lequerica and Kortte, 2010	Proposed a theoretical model of engagement in physical rehabilitation.	Physical rehabilitation following physical injury or resulting from medical conditions	Theoretical drawing on existing literature	NA	Engagement was defined as "a deliberate effort and commitment to working toward the goals of rehabilitation interventions, typically demonstrated through active, effortful participation in therapies and cooperation with treatment providers" (p. 416). Engagement was conceptualised as a process and a state influenced by both the intrinsic variables within the patient such as willingness, self-efficacy and outcome expectancies, and their social and physical environment.	Strengths: Comprehensive model of engagement proposed, informed by theory and evidence. Written for clinical and academic audiences in an analytic manner. Paper well-structured. Findings prompt consideration of the *intrinsic,* on-going process of engagement. Limitations: Model informed by definition of engagement which emphasises patient state and actions.
Lequerica et al., 2006	Examined properties of measure of engagement in physiotherapy and occupational therapy in acute rehabilitation.	Acute physical rehabilitation	Measure development Developed from literature review and practitioner consultation Psychometric testing	Testing: N=75 people with acquired brain injury	Engagement defined as "a deliberate effort and commitment to working toward the goals of rehabilitation therapy" (p. 331). Items included intrinsic patient variables (e.g. expectations, interest, motivation, optimism) and patient behaviours (e.g. effort, responses to prompting and co-operation).	Strengths: Based on review of literature. Construct defined. Clear appropriate development process. Limitations: Limited details regarding format of measure.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Macgowan, 2006	Developed measure of engagement in group social work services.	Group treatment (drug and alcohol treatment. social work students, male sex offenders) Social work	Measure refinement Psychometric testing	Testing: N=224 people in various groups treatment programmes	Engagement was conceptualised as multi-dimensional including attendance, therapeutic alliance, participation, helping self and helping others. Measure included seven dimensions: attentions, contributing, relating to worker, relating to other members, contracting, working on own problems and working on others' problems. Measure was developed from literature review.	Strengths: Based on empirical study of engagement. Findings informed domains and indicators of domains. Tested in a variety of clinical contexts.
Mallinson, Rajabiun & Coleman, 2007	Explored the process by which people living with HIV/AIDS engaged in primary care for treatment.	Primary care Chronic illness (HIV)	Qualitative Grounded theory Data collection: Individual interviews	N=76 people living with HIV	Engagement in care was seen as a cyclical process which could involve times of disengagement. Perceptions of the relationship with the provider were a core element of the engagement process, either facilitating or impeding engagement. Engagement was facilitated through connection, validation and partnering; it was impeded through perceptions of paternalistic care. The practitioner's actions and attitudes appeared crucial.	Strengths: Clear aim. Design consistent with aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear statement of findings. Findings extend current knowledge about engagement, in particular the practitioner's role in engagement.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Meaden et al., 2012	Developed a measure of engagement in inpatient mental health rehabilitation services.	Inpatient psychiatric rehabilitation services Mental health	Measure development Developed from consultation with practitioners Psychometric testing	Testing: N=118 people with psychosis in residential care	Engagement was not explicitly defined. Measure consisted of seven domains: quality of relationships, patient communication and openness, goal-setting, perceived usefulness of rehabilitation, collaboration with rehabilitation, appointment-keeping and compliance.	Strengths: Clear rationale. Limitations: Modified existing measure of poor quality, integrating practitioner feedback. Did not provide definition of engagement.
O'Brien et al., 2009	Developed measure of engagement in mental health services in people with psychosis.	Community based mental health services Mental health	Measure development Developed from focus groups with researchers, practitioners and patients Psychometric testing	Testing: N=184 people with psychosis	Engagement was not explicitly defined. Measure consisted of ten items related to attendance, perceived need for treatment, adequacy and usefulness of providers and treatment, sense of being listened to and compliance.	Strengths: Clear rationale. Items generated and refined based on literature and consultation with experts. Limitations: Engagement not explicitly defined.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Padgett et al., 2009	Explored experiences of engagement and retention in mental health and substance abuse services in order to develop model of engagement.	Dual diagnosis services Mental health	Qualitative Grounded theory Data collection: Individual interviews	N=39 people accessing dual diagnosis services	Engagement was conceptualised as a process influenced by patient and systemic factors. Patient factors included severity and mental illness and substance abuse. Systemic factors included physical surroundings, rules and restrictions of services, staff actions and perceived kindness, and models of service provision. Engagement was considered to be entwined with 'retention' in care.	Strengths: Clear aim. Design consistent with aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear statement of findings. Findings extend current knowledge about engagement, in particular highlighting the role of both individual and environmental factors in engagement. Limitations: Grounded theory methodology not embedded in all aspects of design.
Park et al., 2002	Developed measure of engagement in homeless patients with mental illness.	Homeless people with mental illness Mental health	Measure development Developed from consultation with community mental health team Psychometric testing	Testing: N=112 people accessing mental health services	Engagement was defined as "a process during which the worker focuses on assuring that basic life support services (food and shelter) are in place while attending to the development of rapport to overcome barriers to further collaboration" (p. 855). Measure consisted of five ratings: patient attitudes toward provider, ease of engagement (i.e. contact with services), attitude to help, attitude to housing, and engagement with others (i.e. interpersonal interaction).	Strengths: Provided rationale for measure. Engagement clearly defined. Limitation: Items generated based on consultation with service providers.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Priebe et al., 2005	Explored views of engagement and disengagement held by patients of assertive outreach teams.	Assertive outreach Mental health	Qualitative No defined methodology Data collection: Individual interviews	N=40 people accessing assertive outreach services	Patients were most likely to have a relationship with services and service providers if they feel listened to and have a say in care decisions. Trusting therapeutic relationships appeared crucial. A sense of autonomy developed when patients were actively involved in decisions. Disengagement occurred as a result of a loss of autonomy and identity.	Strengths: Clear aim. Design consistent with aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear statement of findings. Findings extend current knowledge about engagement, in particular the process of disengagement from services and the role of practitioners in engagement. Limitations: Not underpinned by defined methodology.
Roy, Gourde & Couto, 2011	Sought to understand process of men's engagement in treatment groups through a review of the literature.	Group treatment Social work	Theoretical drawing on existing literature	NA	The definition of engagement was based on Macgowan's construct of engagement in groups. Engagement was influenced by multiple factors: participant factors such as attitudes and co-morbidities; treatment program variables such as therapeutic alliance and group dynamics; legal factors such as mandated treatment; and cultural and social values.	Strengths: Concept of engagement was based on descriptive review of the literature. Written for clinical and academic audiences in critical, persuasive manner. Paper well-structured. Findings prompt consideration of engagement at micro-, macro- and mesosystems in groups for men. Limitations: Literature review pragmatic rather than systematic. Review focused on very specific context.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Simmons-Mackie & Kovarsky, 2009	Reviewed concept of engagement in clinical interaction.	Speech-language therapy	Theoretical drawing on existing literature	NA	Engagement was defined as the "level of interpersonal involvement displayed by participants in social situations or interactive activities" (p. 6). Engagement could be demonstrated through verbal and non-verbal behaviours and was said to signal "commitment to and involvement in therapy" (p. 7).	Strengths: Concept of engagement based on review of the literature. Written for clinical and academic audiences. Paper well-structured. Findings prompt consideration of communicative aspects of engagement, and of different levels of engagement. Limitations: Article presents overview of engagement.
Staudt, Lodato & Hickman, 2012	Developed understanding of concept of engagement from perspectives of community mental health therapists.	Community mental health services Mental health	Qualitative No defined methodology Data collection: Focus groups	N=41 practitioners in 6 focus groups	"The affective relationship between therapists and clients defined engagement for the participants" (p.215), and involved establishing a 'safe environment' and a therapeutic connection. Engagement could be influenced by a number of patient, practitioner and/or service factors. Engagement was "conceptualized as a process that begins with patients accessing services and progressing to a successful therapeutic alliance, and ideally leaving services knowing there is an open door to return if and when needed" (p. 217).	Strengths: Clear aim. Design consistent with aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear statement of findings. Findings extend current knowledge about engagement, in particular practitioner's understandings of engagement, and the role of individual and systemic factors in engagement. Limitations: Not underpinned by defined methodology.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Tait, Birchwood & Trower, 2002	Developed measure of engagement in community health services.	Community mental health services Mental health	Measure development Measure developed from literature and discussion between researchers Psychometric testing	Testing: N=66 people with schizophrenia	Engagement was not explicitly defined. The measure consisted of four scales: patient availability, collaboration, help-seeking and treatment adherence.	Strengths: Clear rationale for developing measure. Limitations: Did not define engagement. Limited information given about item-generation.
Watkins, Shaner & Sullivan, 1999	Explored perceptions of engagement from the perspectives of those with dual diagnosis.	Dual diagnosis services Mental health	Qualitative No defined methodology Data collection: Individual interviews	N=21 people accessing dual diagnosis services	Engagement was defined as the process of seeking help and starting to make changes. Engagement was seen as an on-going cyclical process which could involve disengagement. Engagement was closely associated with retention in care. Practitioner actions could facilitate the engagement process.	Strengths: Clear aim. Clear statement of findings. Limitations: Not underpinned by defined methodology. Interview questions focused on concept of 'help' rather than engagement specifically. No information about rigour. Findings may be informed by focus on 'help' within data collection.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Woolhouse, Brown & Thind, 2011	Explored experiences of doctors engaging women who use substances	Family care	Qualitative Phenomenology Data collection: Individual interviews	N=10 doctors	Engagement was seen as a process in relationship development which was a necessary pre-cursor to maintaining the patient in medical care. Therapeutic relationships underpinned the engagement process; trust and presence were consisted crucial. Engagement was an on-going process which required the practitioner to closely read the patient in order to respond in a way that helped them stay engage in treatment.	Strengths: Clear aim. Design consistent with aims. Data collection and analysis processes detailed. Clear statement of findings. Findings extend current knowledge about engagement, in particular the role and nature of relationship in engagement. Limitations: Phenomenological methodology not embedded in all aspects of design. No information provided about rigour.
Wright, Callaghan & Bartlett, 2011	Explored nature and meaning of engagement for practitioners and service users in assertive outreach mental health services	Assertive outreach Mental health	Qualitative Hermeneutics Data collection: Individual interviews	N=14 mental health practitioners; 13 people accessing assertive outreach services	Engagement was considered an on-going process between the patient and provider. Contact between the two formed the 'building block' for on-going engagement. It was facilitated through dialogue (talking and active listening). This led to engagement *with* the other person. Have a user-led perspective was seen as important as was having a shared understanding of the patient's story and the service model. Patients emphasised the need to feel understood by the provider.	Strengths: Clear aim. Design consistent with aim. Data collection and analysis processes detailed. Several steps taken to promote rigour. Clear statement of findings. Findings extend current knowledge about engagement, in particular relational aspects of engagement and the perspectives of service users.

Reference	Study purpose	Study context	Methodology & Methods	Participant information	Key findings	Quality appraisal
Zubialde, Eubank & Fink, 2007	Proposed model of patient engagement in healthcare	Chronic illness	Theoretical based on existing literature and models of learning	NA	Patient engagement was conceptualised as being "mindful of their personal health needs within their life context, clear about their health related goals, and proactive in acquiring new capabilities and resources that help them meet their goals" (p. 355). It was based on the patient's story and context and sees the practitioner take a coaching role in service provision.	Strengths: Model of engagement proposed, informed by theory. Written for clinical and academic audiences in descriptive manner. Findings prompt consideration of engagement as an objective of practitioner intervention. Limitation: Model informed by adult learning theory, conceptualising engagement as a process of learning.

Quality of included papers

The quality of the included papers varied, as detailed in Table 1 above. Qualitative papers were of reasonable quality. Designs were consistent with aims, and studies appeared robust according to the CASP criteria (Critical Skills Appraisal Programme, 2010). Studies represented a range of methodologies, although several had no named methodology (Godlaski, Butler, Heron, Debord, & Cauvin, 2009; Priebe et al., 2005; Staudt et al., 2012; Watkins, Shaner, & Sullivan, 1999). Methodology guides decisions about research methods and adds to research rigour (Carter & Little, 2007). A mismatch between stated methodology and reported methods, evident in two papers (Padgett, Henwood, Abrams, & Davis, 2008; Woolhouse, Brown, & Thind, 2011), or a lack of discussion about rigour (Chase et al., 2012) may impact on the perceived trustworthiness of the study. Each qualitative study was undertaken in a very specific clinical population. While findings will not be generalisable to other clinical areas, they are likely transferrable and of value in understanding how engagement is conceptualised in different contexts (Tracy, 2013).

There were short-comings in the design of many measurement studies. Six of the ten measures lacked a robust conceptualisation of engagement, instead using practitioner and researcher definitions of engagement (Gillespie, Smith, Meaden, Jones, & Wane, 2004; Hall, Meaden, Smith, & Jones, 2001; Holmbeck & Devine, 2009; Lequerica et al., 2006; Meaden, Hacker, Villiers, Carbourne, & Paget, 2012; Park et al., 2002). For example, Hall and colleagues (2001) drew on an existing "client monitoring form" (p. 458) used by a clinical team together with discussions with team members. The face and content validity of this tool must be questioned given that patient perceptions were not considered. Four measures did not explicitly define engagement, despite it being the measured construct (Gillespie et al., 2004; Hall et al., 2001; Meaden et al., 2012; A. O'Brien, White, Fahmy, & Singh, 2009). Such limitations were somewhat

mediated by early trialling and refinement of some measures (Hall et al., 2001; Kemppainen et al., 1999; Meaden et al., 2012; Park et al., 2002). However, incorporating patient perspectives in the design process, and generating items from robust empirical and/or theoretical studies of engagement, as done by Macgowan (2006) and recommended by McDowell (2006), may improve the validity of these measures. While more questions remain about the psychometric properties, the focus of this quality appraisal is to understand the maturity and robustness of the current state of knowledge of engagement. It provides some indication that the concept 'engagement' is not mature; existing knowledge about engagement may be emerging rather than mature. Further conceptual analysis and further research may help develop conceptual knowledge (Morse, Hupcey, et al., 1996; Morse, Mitcham, et al., 1996).

The theoretical papers included in this review had a variety of objectives, from providing an introduction to the concept of engagement (Simmons-Mackie & Kovarsky, 2009) through to developing a comprehensive model of engagement (Lequerica & Kortte, 2010). There was wide variation in the design and depth of each paper. Papers which provided an overview of the concept utilised pragmatic literature searches (Danzl, Etter, Andreatta, & Kitzman, 2012; Duchan, 2009; Simmons-Mackie & Kovarsky, 2009). The reviews of engagement were not exhaustive, reflecting that the authors only intended to provide an overview of the concept. Several models of engagement were developed from a robust search of the literature, and integrated concepts related to engagement, demonstrating how these were aligned and related (Konrad, 2009; Lequerica & Kortte, 2010). This supports the finding that engagement is an emerging concept (Morse, Hupcey, et al., 1996; Morse, Mitcham, et al., 1996). It also highlights that research in engagement is in its infancy.

Conceptualising engagement: 'Engaging with' and 'Engaged in'

Engagement was conceptualised in two inter-related ways, as a process ('engaging with') and a state ('engaged in'). The process of engagement centred on developing a connection between the patient and practitioner or patient and service. The state of engagement was an internal state experienced by the patient and expressed through observable behaviours. These are summarised in Table 2 below.

Table 2: Core components of engagement: 'Engaging with' and 'engaging in'

Engaging with	Engaged in
Process of connecting with activity or person	Being with what you're doing, participating beyond talk
Practitioner's attitudes and behaviours crucial	Internal state: commitment, enthusiasm, effort, investment
Establishment of therapeutic relationship may precede state of engagement	Observable behaviours include participation, contribution, persistence
Fluid on-going process, may lead to state of engagement or disengagement	State of engagement: Both internal state and observable behaviours are present
Limited acknowledgement in engagement measures	Observable behaviours dominate engagement measures

The process of engagement: 'Engaging with'

The process of engagement involved a gradual, often "invisible" (Hitch, 2009) process of "being drawn in and having a connection to an activity or person" (Danzl et al., 2012, p. 35). Developing a mutually trusting relationship or 'connection' appeared crucial in facilitating a state of engagement (Addis & Gamble, 2004; Chase et al., 2012; Chase et al., 2010; Danzl et al., 2012; Drury & Munro, 2008; Gillespie et al., 2004; Konrad, 2009; Mallinson, Rajabiun, & Coleman, 2007; Priebe et al., 2005; Simmons-Mackie & Kovarsky, 2009; Staudt et al., 2012; Watkins et al., 1999; Wright, Callaghan, & Bartlett,

2011). Danzl and colleagues (2012) suggested this connection "grounded and supported" the patient's engagement in rehabilitation which established a "relational foundation" (Konrad, 2009, p. 408) for therapeutic intervention.

The relationship between the practitioner and patient needed to be developed before commencing the "therapeutic sequence" (Zubialde, Eubank, & Fink, 2007, p. 368). Such a relationship appeared to create an atmosphere of collaboration and connection which then supported the patient to take action (Addis & Gamble, 2004; Cumbie, Conley, & Burman, 2004; Danzl et al., 2012; Duchan, 2009; Konrad, 2009; Zubialde et al., 2007). This action could involve active participation in specific components of the therapy programme or intervention (Drury & Munro, 2008; Godlaski et al., 2009; Simmons-Mackie & Kovarsky, 2009), or simply continued attendance within the service (Woolhouse et al., 2011).

The practitioner appeared to have a crucial role in the process of engagement (Addis & Gamble, 2004; Chase et al., 2012; Drury & Munro, 2008; Mallinson et al., 2007; Padgett et al., 2008; Priebe et al., 2005; Staudt et al., 2012; Woolhouse et al., 2011; Wright et al., 2011). Communication between the patient and practitioner appeared central (Hitch, 2009; Wright et al., 2011). Patients reported it was important to feel they could talk and tell their story, sensing this was listened to (Chase et al., 2012; Konrad, 2009; Mallinson et al., 2007; A. O'Brien, White, et al., 2009; Wright et al., 2011). Also key to 'engaging with' were:

- responsiveness to the patient (Konrad, 2009);
- seeing them as an individual rather than focusing on their diagnosis or impairment (Chase et al., 2012; Cumbie et al., 2004; Duchan, 2009; Mallinson et al., 2007; Priebe et al., 2005; Staudt et al., 2012; Woolhouse et al., 2011; Wright et al., 2011);
- demonstrating a genuine interest in knowing the person and their story (Cumbie et al., 2004; Konrad, 2009);
- addressing core needs (Park et al., 2002; Watkins et al., 1999); and

- valuing patient expertise (Chase et al., 2010; Mallinson et al., 2007; Priebe et al., 2005; Watkins et al., 1999) and strengths (Drury & Munro, 2008).

Facilitating engagement could require significant skill (Drury & Munro, 2008; Konrad, 2009). As such, 'engaging with' was considered a way of working (Addis & Gamble, 2004; Chase et al., 2012; Cumbie et al., 2004; Drury & Munro, 2008).

Both patients and practitioners suggested the connection was enhanced if the practitioner was perceived to be engaged in the interaction (Mallinson et al., 2007) and in their work (Staudt et al., 2012). Practitioner engagement was demonstrated through behaviours such as sitting down with the patient to talk about their story, being present, respectful, attentive, going above and beyond, doing more than just the bare basics of the job (Drury & Munro, 2008; Mallinson et al., 2007; Woolhouse et al., 2011) and showing empathy (Godlaski et al., 2009). This resulted in the patient feeling known, respected and not judged (Woolhouse et al., 2011). Patients valued practitioners who they viewed as knowledgeable (Chase et al., 2012; Mallinson et al., 2007) and credible (Staudt et al., 2012). This helped establish trust (Kemppainen et al., 1999; Tait, Birchwood, & Trower, 2002; Woolhouse et al., 2011).

The process of engagement could start at, or before, the initial contact with the service and continue throughout the episode of care (Roy, Gourde, & Couto, 2011; Staudt et al., 2012; Wright et al., 2011). Engagement was fluid and could further develop or diminish over time (Addis & Gamble, 2004; Hitch, 2009; Lequerica & Kortte, 2010; Mallinson et al., 2007; Priebe et al., 2005; Wright et al., 2011). It was maintained through an internal feedback loop, which involved the patient making a conscious effort to remain engaged (Lequerica & Kortte, 2010), and through the practitioner's way of working (Woolhouse et al., 2011).

The interaction and relationship between practitioner and patient was considered within some of the published measures, for example, the 'quality of the relationship'

(Gillespie et al., 2004; Hall et al., 2001), 'attitudes toward staff' (Park et al., 2002), and the 'client's perception of being listened to' (A. O'Brien, White, et al., 2009). Of note however, items in the measures commonly focused on the patient's behaviours despite the literature emphasising the importance of the practitioner's actions and attitudes.

The state of engagement: 'Engaged in'

The state of engagement was described as a patient state of "being … within something you're doing" (Hitch, 2009, p. 487) and "participating … in action beyond talk" (Hitch, 2009, p. 488). It appeared to result from the process of engagement (Hitch, 2009; Priebe et al., 2005). The internal state of engagement could be accompanied by actions thought to indicate engagement. Roy and colleagues (2011) argued both the internal state and observable actions are necessary for the patient to be 'engaged'.

'Engagement' often appeared synonymous with active participation in treatment (Danzl et al., 2012; Hitch, 2009; Kemppainen et al., 1999; Lequerica & Kortte, 2010; Lequerica et al., 2006; Macgowan, 2006; Priebe et al., 2005; Roy et al., 2011; Tait et al., 2002) and treatment retention (Godlaski et al., 2009; Padgett et al., 2008). However, it was suggested that patients needed to do more than participate (Lequerica & Kortte, 2010; Roy et al., 2011). The state of engagement involved active commitment (Chase et al., 2012; Lequerica & Kortte, 2010; Simmons-Mackie & Kovarsky, 2009; Staudt et al., 2012), enthusiasm, energy and effort (Danzl et al., 2012; Kortte et al., 2007; Lequerica & Kortte, 2010; Lequerica et al., 2006). Some suggested an 'engaged patient' should have a high level of vested interest or investment in the activity or therapy (Kortte et al., 2007; Lequerica & Kortte, 2010; Simmons-Mackie & Kovarsky, 2009). A continuum of patient engagement appeared to be described across studies, from tolerating treatment (Addis & Gamble, 2004), agreeing to what is offered, being "involved in the proposed treatment" (Hall et al., 2001), collaborating and contributing to decision-

making for healthcare (Macgowan, 2006; Tait et al., 2002), actively participating in care (Danzl et al., 2012; Hitch, 2009; Kemppainen et al., 1999; Lequerica & Kortte, 2010; Lequerica et al., 2006; Macgowan, 2006; Priebe et al., 2005; Tait et al., 2002) and finally, being emotionally invested in the therapeutic encounter (Kortte et al., 2007; Lequerica & Kortte, 2010; Simmons-Mackie & Kovarsky, 2009; Staudt et al., 2012). In a group situation, engagement involved developing relationships with other patients and active collaborative work to address each other's needs (Macgowan, 2006). Patient engagement was said to be influenced by environmental factors such as the therapeutic environment (Godlaski et al., 2009; Lequerica & Kortte, 2010) and intrinsic factors such as accepting the need for treatment, perceiving the benefits of treatment (Lequerica & Kortte, 2010; A. O'Brien, Fahmy, & Singh, 2009) and self-efficacy (Godlaski et al., 2009).

A number of behaviours have been suggested as markers of patient engagement, predominantly evident in published measures of engagement. These included:

- willingness to participate (Park et al., 2002);
- contributions to the session (Macgowan, 2006);
- retention in a service (Padgett et al., 2008); and
- attendance at therapy (Hall et al., 2001; Kortte et al., 2007; Macgowan, 2006; A. O'Brien, White, et al., 2009; Tait et al., 2002).

Compliance with, and adherence to, recommendations have both been suggested as markers of engagement (A. O'Brien, White, et al., 2009; Staudt et al., 2012; Tait et al., 2002). However, such an interpretation is challenged by patient participants in a study of seemingly engaged mental health service users (Chase et al., 2012). Many reported they complied because they did not feel they had a choice and lacked the confidence to discuss the issues with their practitioners. Similarly, Roy and colleagues (2011) suggested attendance may demonstrate "pseudo-engagement" (p. 30). This may

indicate that agency may be important in engagement. Other markers of engagement included in published measures included:

- the quality of relationship and communication with the practitioner (Gillespie et al., 2004; Hall et al., 2001; Macgowan, 2006; Meaden et al., 2012; Tait et al., 2002);
- relationships with others (Park et al., 2002);
- attitudes toward help (Park et al., 2002);
- perceived attitude toward therapy (Kortte et al., 2007; Lequerica et al., 2006; Roy et al., 2011);
- perceived usefulness of treatment (Gillespie et al., 2004; Hall et al., 2001; Macgowan, 2006; Meaden et al., 2012; Tait et al., 2002);
- persistence and determination in activities (Lequerica et al., 2006);
- ability to assert their identity and individual experience (Chase et al., 2012); and
- collaboration in therapy planning (Meaden et al., 2012; Tait et al., 2002).

Simmons-Mackie and Kovarsky (2009) described a number of patient behaviours that may indicate engagement. These included gaze, tone, use of non-verbal behaviours such as gesture and body orientation, engrossment in an activity and attention to others present. Chase and colleagues (2012) proposed patient use of the pronoun 'we' when discussing engagement may be a linguistic indicator of an engaged relationship, signalling agency and an active role in the relationship. In contrast, pronouns 'them' and 'us' were considered a marker of disengagement with the patient positioned as a passive recipient of care compared with the "all-powerful" (Chase et al., 2012, p. 48) healthcare practitioners.

Engagement: A proposed definition

One objective of this review was to synthesise the findings of the review, using these to propose a definition of engagement. Synthesis of the core aspects of engagement as

detailed above resulted in a theoretically-informed and empirically-derived definition of engagement:

> Engagement is a co-constructed process and state. It incorporates a process of gradually connecting with each other and/or a therapeutic program which enables the individual to become an active, committed and invested collaborator in healthcare (Bright et al., 2015, p. 651).

Limitations of review

There are some limitations of this review which must be acknowledged. The term 'engagement' was not well-indexed in databases, making it less amenable to keyword searches. As a result, it is possible not all relevant articles were retrieved. Articles that simply explored barriers and facilitators to engagement without providing a definition of engagement derived from theory or data were excluded but it is possible further examination of this literature may refine understanding of engagement. The review focused on engagement in therapeutic interactions reflecting the focus of the doctoral research; exploration of engagement at other levels (e.g. a systemic level) may offer different perspectives on engagement. This review includes articles from diverse epistemological positions, from positivist measures of engagement through to critical discourse analysis. All papers have been included regardless of epistemology, not privileging some over others. In the future, a more critical review that explicitly attends to epistemology may provide more nuanced insight into the concept of engagement. However, this work has advanced knowledge by proposing a theoretically and empirically informed definition of engagement and highlighting the process of engagement and in particular, the relational aspect of engagement. It was also important in refining the focus of this doctoral research.

Conclusion

This review has identified engagement to be a complex, multi-dimensional concept involving both a co-constructed process and state. Engagement was defined and discussed in a number of ways in different contexts, suggesting it is not a mature, well-understood and universally applied concept. While engagement is commonly considered a patient behaviour, this review identified that practitioners played a pivotal role in the process of engagement. The process of engagement appeared to represent a way of working on the part of the practitioner. The therapeutic relationship between the patient and practitioner and the interpersonal communication between them appeared particularly important. The latter is particularly significant in the context of this research, given its focus on people with communication difficulty. In the next chapter, I specifically focus on engagement in the context of people experiencing communication disability, exploring the state of knowledge about engagement with this population.

Chapter Three: Literature Review

Engagement and people experiencing communication disability

Within this chapter I focus on engagement in the context of people experiencing communication disability after stroke. In 2009, Simmons-Mackie and Damico stated engagement appeared critical for clinical practice but there was "little specific guidance in the speech-language [therapy] literature" (p. 19) that would support practitioners in engaging patients in therapy. As this review will demonstrate, in the six years since, little has changed. Very few studies have considered engagement in, or engagement *of* people experiencing communication disabilities following stroke, despite it being described as a "necessary element" (Simmons-Mackie & Damico, 2009, p. 9) of therapy. This literature review focuses on this specific patient group, asking: (a) why we need to explore engagement in this context? and (b) how has engagement been studied in people experiencing communication disability to date? (see Figure 4).

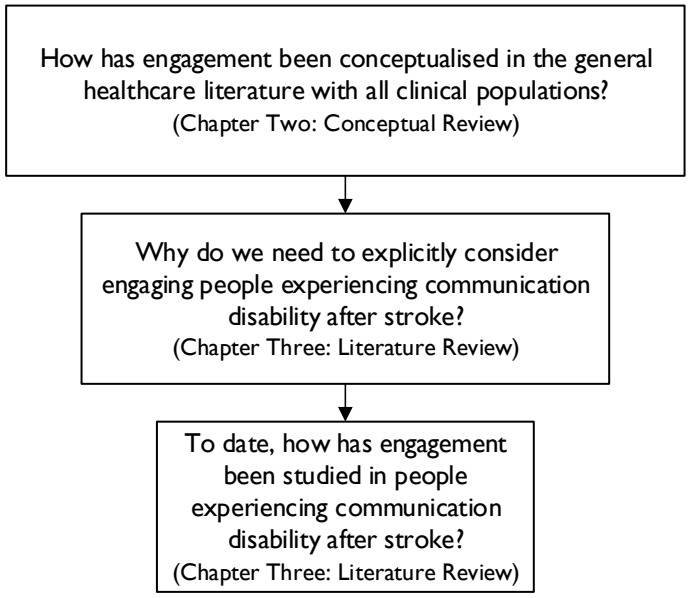


Figure 4: Literature review questions

The review presented within this chapter addresses the questions posed on the previous page. Firstly, I provide an overview of the literature exploring healthcare experiences of people experiencing communication disability and use this literature to demonstrate why engagement is important to consider for this specific group of patients. This is followed by a critical consideration of the small body of literature which has explicitly considered engagement in the context of communication disability after stroke, to understand the current state of knowledge around engagement. Finally, the core gaps in knowledge about engagement in this population are identified; these gaps informed the design of this doctoral research.

Patient experiences of healthcare relevant to engagement

Components of engagement may be more challenging when a person is experiencing communication disability, as suggested by studies exploring how this patient group experience healthcare services. Within this section, I explore concepts related to, or inherent within the process of engagement, specifically communication and therapeutic relationships which the conceptual review proposed were particularly important in the engagement process. I include literature from the broad communication disability field, including lifelong and acquired communication disability. This descriptive review is not intended to be an exhaustive review. Instead it provides an overview of the literature to demonstrate why engagement may be particularly challenging when experiencing communication disability.

Within the engagement process, communication performs multiple functions such as contributing to a therapeutic connection and relationship, supporting patient participation and collaboration in rehabilitation and facilitating engagement in specific activities (see page 40). Yet communication can be highly problematic when the patient has a communication disability. People experiencing communication disability have

described being excluded from interactions as staff defer to family and carers (Murphy, 2006; Parr et al., 1997). They report they are not listened to (Dickson et al., 2008; Parr et al., 1997), and feel isolated, excluded and unsafe (Nyström, 2009; Robillard, 1994). These subjective experiences contrast with core elements of the engagement process identified in the conceptual review in Chapter Two, such as feeling they can talk and be listened to, and that practitioners demonstrate a genuine interest in them, valuing their expertise (see page 40). Rather, these experiences reflect an asymmetric approach to communication which is common within healthcare (e.g. Parry, 2004), but is likely further exacerbated when the patient has communication difficulties.

The conceptual review indicated involvement, participation and collaboration may be important parts of both the *process* of engagement (see page 40), and of *enacting* engagement (see page 42). These actions are produced through communication (Entwistle & Watt, 2006; Thompson, 2007). Yet the literature indicates involvement and collaboration can be problematic when the person has a communication difficulty (C. Green & Waks, 2008; Parr et al., 1997), even when practitioners are experienced in working with people experiencing communication disability (Rodhe, Townley-O'Neill, Trendall, Worrall, & Cornwall, 2012). Speech-language therapists describe valuing interpersonal relationships, and involving and collaborating with patients in therapy processes (e.g. Hersh, 2003; Worrall et al., 2010). However this perception may not be shared by the patient, as evidenced in studies which incorporated perspectives of both the practitioner *and* the patient (e.g. Hersh, 2004; Madonna et al., 2002). This mismatch may result in therapy being perceived as irrelevant (Hersh, 2004, 2009b; Parr et al., 1997) or meaningless (Brady, Clark, Dickson, Paton, & Barbour, 2011), potentially influencing patient's motivation and engagement (Brady et al., 2011; Horton, 2008). This reinforces that core components of engagement may be challenging for people experiencing communication disability.

The healthcare practitioner[5] appears to play a central role in facilitating, or sometimes hindering engagement through their ways of communicating, their responsivity to the patient and whether they were considered knowledgeable and credible (see page 40). In the context of communication difficulties, the practitioner's role in engagement may arguably be even more important. When a person has a communication disability, they can depend on their communication partner (practitioners in the context of this research) to support communication, supporting them to both comprehend and be able to express themselves (Kagan, 1998; Simmons-Mackie & Damico, 2007; Togher, 2013). Yet it is recognised that the practitioner's communicative behaviours can sometimes negatively influence communicative success through actions such as talking too fast (Nyström, 2009), controlling interaction topics and conduct (Finke, Light, & Kitko, 2008; Gordon et al., 2009), focusing on physical needs or service requirements (Dickson et al., 2008; Gordon et al., 2009; Hemsley, Balandin, & Worrall, 2011a), speaking for the patient and assuming agreement (Talvitie & Reunanen, 2002), and ignoring a patient's attempts to communicate (Parr et al., 1997; Robillard, 1994). All of these actions are contrary to core elements of the engagement process.

The actions of the practitioner may reflect their level of knowledge and skill in communicating with people experiencing communication disability; actions may also reflect their underlying attitudes or values with regard to communication (Hemsley, Balandin, & Worrall, 2012; O'Halloran, Worrall, & Hickson, 2011; Sundin & Jansson, 2003). Healthcare practitioners commonly considered communication with this population to be difficult and time-consuming (Finke et al., 2008; Hemsley, Balandin, & Worrall, 2011b; Hemsley et al., 2012; M. Jones, O'Neill, Waterman, & Webb, 1997; Nyström, 2009; Sundin, Jansson, & Norberg, 2002). Those who reported prioritising taking time to communicate with their patients were more confident when

[5] I use the term 'healthcare practitioner' in this chapter, reflecting that the literature encompasses a range of healthcare contexts, not just rehabilitation.

communicating, and considered they had a role and an ethical imperative to support communication (Hemsley et al., 2012; Sundin & Jansson, 2003). In contrast, practitioners with lower levels of skill or knowledge about supporting communication (Hemsley et al., 2012; Murphy, 2006), or those who appeared to consider there was no need or time to communicate directly with the person with communication disability (Finke et al., 2008; Murphy, 2006) were less likely to attempt communication (Finke et al., 2008; Hemsley et al., 2012; Murphy, 2006). It is possible that deprioritising communication may impact on engagement because communication appears central in the engagement process.

The literature suggests communication is an integral part of developing a therapeutic relationship. This relationship appeared to be a core component of the engagement process, functioning as a foundation for engagement (see page 40). The therapeutic relationship is increasingly recognised as important in rehabilitation with people with communication difficulties (Fourie, 2009, 2011a; Grohn, Worrall, Simmons-Mackie, & Brown, 2012; Sundin & Jansson, 2003; Worrall et al., 2010; Worrall et al., 2011). In their phenomenological study of nurses caring for people with aphasia, Sundin and Jansson (2003) suggested communication underpinned relationship development, while Balandin and colleagues (2007) considered communication and relationship were entwined, stating "positive communication experiences depended to some extent on emotional connectedness" (p. 61). While communication is only one aspect of a therapeutic relationship (Cole & McLean, 2003), it is perhaps not surprising that developing a therapeutic relationship may be more challenging when a person has a communication disability. Communication behaviours considered important in developing a therapeutic relationship include listening, getting to know the patient, showing genuine interest in the patient as a person, putting the patient at ease, showing understanding and being empowering (Fourie, 2009; Walsh & Duchan, 2011). These behaviours are also important in engagement as demonstrated in the conceptual

review in Chapter Two. However, as demonstrated on previous pages, these communicative actions are often missing when working with a person experiencing communication disability. Additionally, practitioners may consider developing a relationship as demanding (Sherratt et al., 2011), perhaps because of limited knowledge about how to communicate (Sundin et al., 2002). Relational 'work' may be considered separate to therapy (Holland, 1998; Simmons-Mackie & Damico, 2011; Walsh & Duchan, 2011); practitioners may prioritise assessment over relational work (Fourie, 2011a). Relational work is also arguably skilled work and practitioners may have variable knowledge and skill in this (Ferguson & Elliot, 2001) as it is not well-conceptualised in this population (Fourie, 2009, 2011b) and may not be consistently incorporated into training. Clearly, there are the complexities in developing the therapeutic relationship when a person has communication disability, and it is evident that the practitioner's actions and beliefs may impact on the therapeutic relationship.

This overview of the patient experience literature demonstrates that core components of the process of engagement (in particular communication and therapeutic relationships) can be impacted when the patient has a communication disability. This supports the case for closer attention to the process of engagement when people are experiencing communication disability.

Engaging people experiencing communication disability

In the section that follows, another review of the literature is presented, this time utilising principles of systematic review in literature searching. The focus of this review was to critically consider the current state of knowledge regarding engagement of people experiencing communication disability within stroke rehabilitation.

Literature search

The aim of this search was to identify articles which explicitly defined or studied engagement in, or the engagement of people experiencing communication disability following stroke. To identify literature for this review, SCOPUS, PUBMED Nursing and Allied Health, and EBSCO databases (CINAHL and Medline) were searched using the following keywords: ((aphasia OR dysphasia) OR dysarthria OR ("communication disabil*" OR "communication difficult*" OR "communication impair*") OR apraxia) AND engag*. Publications were limited to those published before 2013 as articles published after that date did not contribute to developing the rationale for this research. Articles were included if the stated objective was to describe, understand or measure patient engagement in therapeutic interactions in stroke rehabilitation. Only peer-reviewed, English language articles were included. Articles were excluded if they did not address patient engagement in stroke rehabilitation, if they did not include people experiencing communication disability, or if they simply used the *word* engagement without discussing the *concept* engagement. Citation lists of the included articles were reviewed; citation tracking was completed using SCOPUS.

The search and screening process are illustrated in Figure 5 on page 54. The search retrieved 281 references. Titles and abstracts were screened for relevance, with 23 possibly meeting the inclusion criteria for this review. The full text of these articles were retrieved and read; two papers met the inclusion criteria. The primary reasons for exclusion were that articles used the 'word' engagement without referring to a concept, for example using 'engagement' to describe neurological activation related to the brain injury or neurological recovery (e.g. Wierenga et al., 2006); or that the engagement concept they referred to was engagement in social activities (e.g. Davidson, Howe, Worrall, Hickson, & Togher, 2008) or in personally meaningful activities such as hobbies (e.g. K. Brown, Worrall, Davidson, & Howe, 2011). The two

articles included in this review are summarised in Table 3 on page 55. Each paper was appraised using the National Institute for Health and Care Excellence tool (2012).

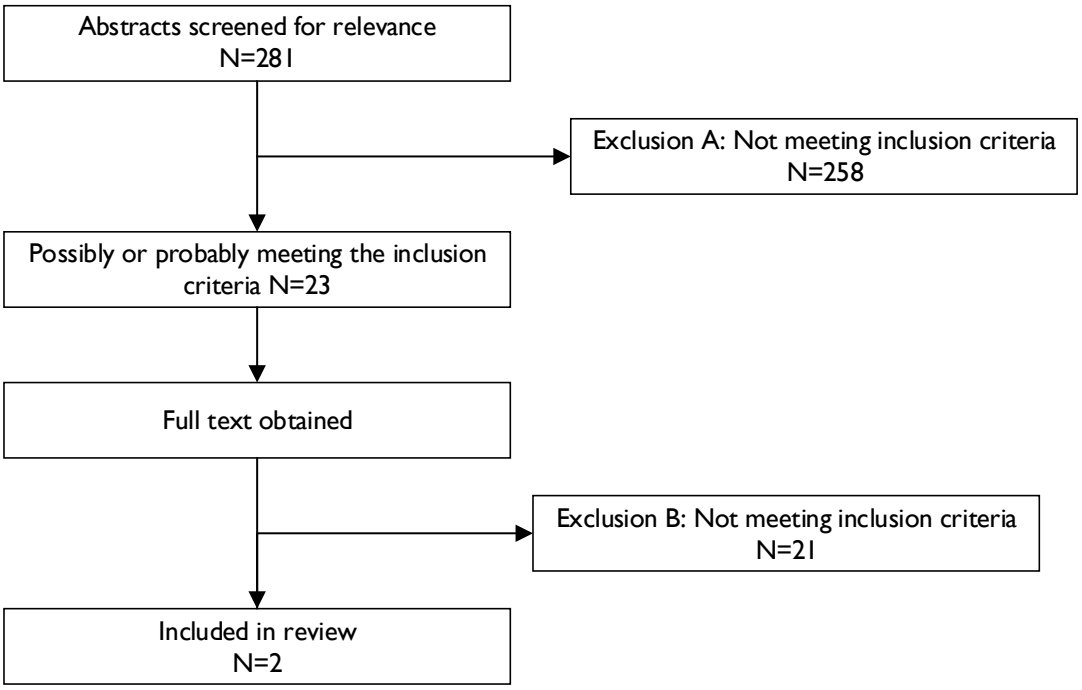


Figure 5: Literature search process and results

Table 3: Summary of included papers

	Horton et al. (2011)	**Simmons-Mackie and Damico (2009)**
Study aim	Explored how active participation and engagement were produced within stroke rehabilitation sessions	Investigated interactive resources used to manage engagement in group therapy
Study design	*Design:* Ethnography using multiple case studies *Data collection:* Observations of single sessions *Analysis:* Conversation analysis	*Design:* Multiple case study *Data collection:* Observation, transcription of interactions *Analysis*: Conversation analysis
Study populations	*Patients:* Aphasia and dysarthria *Practitioners:* Speech language and occupational therapists, and physiotherapists	*Patients:* Aphasia (group) *Practitioners*: Speech language therapists
Definitions of engagement (explicit and implicit)	Engagement was not explicitly defined but discussed in context of active participation in rehabilitation process Engagement was acknowledged as a co-constructed phenomenon, influenced by the practitioners' and institutional practices and values	Engagement was described as a process of managing interactions which implies a degree of engrossment in the process, evident through a variety of verbal and non-verbal actions. Engagement was considered to be co-constructed through interaction

	Horton et al. (2011)	Simmons-Mackie and Damico (2009)
Overview of paper	Data was gathered by observing interactions between two patients and six allied health practitioners. Engagement was considered important for learning and for skill acquisition. It saw patients take a more active role in the rehabilitation process. Engagement practices were socioculturally located, influenced by institutional values and practices. This could result in tensions between patient autonomy and accepted behaviour. Patient engagement (participation) was impacted by specific practitioner actions, including the instructional formats used (e.g. initiation-response-feedback) and activity types (e.g. impairment focused).	Data was gathered by observing two speech-language therapy group sessions. Practitioners played a crucial role in managing engagement. The practitioner's actions, including seating position within the group, their body language, gaze and body orientation appeared to either facilitate or inhibit patient engagement. The practitioner's own engagement (evident through their non-verbal behaviour) appeared to influence patient engagement, reinforcing the idea of it being co-constructed. This also suggested the practitioner held a position of power in the engagement process. Patients who were considered to be engaged actively contributed to interaction through verbal and non-verbal behaviours. Shared laughter was considered a marker of engagement. Disengaged patients were passive, making little contribution to interactions, appearing "bored", as observers within the group.
Conceptual critique	This study focused on the rehabilitation practitioners and how their interactions served to construct engagement/participation in rehabilitation. Analysis looked beyond the therapeutic dyad to also consider the broader sociocultural context surrounding the actions. The study considered interactions between people experiencing communication disability and practitioners from three allied health disciplines. The focus was on the interactions rather than the specific content of the disciplinary-based therapeutic task. The study was based on six single-session observations, providing insight into engagement within a session, rather than engagement in a broader process of rehabilitation.	Through its close attention to verbal and non-verbal behaviours (particularly the latter), the study focused on the 'micro' level processes of engagement. The paper provides detailed description of the behaviours associated with the process or enactment of engagement within a specific therapy session. The study only considered group speech-language therapy practice rather than other professional disciplines.

	Horton et al. (2011)	Simmons-Mackie and Damico (2009)
Methodological critique	Strengths: Appropriate methodology. Research design is defensible and clearly justified. Data collection appropriate and process clearly described. Role of the research detailed with some reflexivity evident. Research context described. Analysis procedure explicit. Findings are rich and convincing with good integration of data and analysis. Conclusions are plausible and coherent and clearly connected to findings. Implications of research are discussed. Findings enhance understandings of how engagement is interactionally and institutionally produced. Limitations: No clear definition of engagement provided. 'Engagement' appeared to be entwined with a number of complex concepts such as participation, learning and involvement. No explicit discussion of rigour or how analysis was conducted within the research team. Unclear why authors determined the presented data was "pertinent" (p. 272). Authors did not discuss limitations of research.	Strengths: Appropriate methodology. Research design is defensible and clearly justified. Data collection appropriate and process clearly described. Research context described. Analysis process briefly but concisely described. Findings are rich and convincing with good integration of data and analysis. Emergent themes relate to underlying definition of engagement. Conclusions are plausible and coherent and clearly connected to findings. Implications of research are discussed. Findings enhance understandings of how engagement and disengagement are interactionally achieved. Limitations: Sessions selected for analysis were determined to represent 'good' and 'bad' therapy but there was no indication of what criteria or reasoning informed these classifications. No explicit discussion of rigour or how analysis was conducted within the research team. Authors did not discuss limitations of research. Ethical considerations not addressed. No detail provided about consent process or ethical approval.

Engaging people experiencing communication disability

Engagement was discussed as a form of patient participation in rehabilitation (Horton, Howell, Humby, & Ross, 2011; Simmons-Mackie & Damico, 2009), a sense of commitment and involvement toward activities (Horton et al., 2011), and a form of interpersonal involvement and behaviour which "established, maintained or terminated an exchange" (Simmons-Mackie & Damico, 2009, p. 19). This interpersonal involvement reflected a level of engrossment in the interaction. Horton and colleagues (2011) suggested engagement had a cognitive component, which was important for learning and skill acquisition. Actions considered to reflect engagement included: participation in treatment activities (Horton et al., 2011), implementation of strategies or skills (Horton et al., 2011) and verbal and non-verbal behaviours such as gaze, body language and shared laughter (Simmons-Mackie & Damico, 2009).

Engagement was considered to be co-constructed through interaction between the patient and practitioner (Horton et al., 2011; Simmons-Mackie & Damico, 2009), and through interaction between the patient and *other* patients in rehabilitation (Simmons-Mackie & Damico, 2009). It was also influenced by patient-specific factors such as cognition or emotion (Simmons-Mackie & Damico, 2009). Practitioners were said to influence engagement through their own perceived engagement, their verbal and non-verbal behaviours such as eye gaze and body orientation (Simmons-Mackie & Damico, 2009) and how they verbally presented tasks and gave instructions (their instruction formats), and the type of activity selected such as impairment or functional activity (Horton et al., 2011). Horton and colleagues (2011) looked beyond *what* happened in the patient-practitioner interaction to also consider how this came to be, exploring how practice was socioculturally situated and in particular, how practice was influenced by institutional values and priorities. One such example was how an institutional focus on 'risk management' saw practitioners emphasise the 'acceptable' or 'correct ways' in

which patients should engage in rehabilitation. This resulted in an asymmetrical relationship between the patient and practitioner as practitioners were the arbiters in determining the 'right' way patients should engage.

In summary, these two studies suggested engagement could be viewed as a patient behaviour that was influenced by intrinsic patient factors, the actions of others, and the sociocultural context (Horton et al., 2011; Simmons-Mackie & Damico, 2009). Simmons-Mackie and Kovarsky (2009) proposed engagement research could occur at three levels: local (how engagement occurs within interaction), contextual (environmental factors influencing engagement) and sociocultural (the role of sociocultural practices on engagement). All three layers of research were evident in the articles in this review, although both focused on "the local level of engagement" (Simmons-Mackie & Kovarsky, 2009, p. 9), engagement within specific interactions.

Quality appraisal of both papers is detailed in Table 3 above. Both papers were methodologically robust and justifiable. The findings were rich and detailed, with good integration of data and analysis. The conclusions were coherent and clearly connected to both the aims of the study and to the findings. While each study had some limitations as detailed in Table 3, both enhanced understandings of engagement, in particular, by demonstrating how engagement was interactionally produced.

Implications for engagement research

The literature reviews in this chapter and in the previous chapter (the conceptual review) focused on three central questions:

1. How has engagement been conceptualised in the general healthcare literature?
2. Why do we need to explicitly consider engaging people experiencing communication disability (i.e. why might this population have specific needs or challenges?), and

3. To date, how has engagement been studied in people experiencing communication disability after stroke?

The conceptual review demonstrated that engagement has been conceptualised as a co-constructed process and a patient state, reflected in patient actions (see page 44). The conceptual review did not focus on people experiencing communication disability; instead it explored engagement within the general healthcare context, including patients accessing physical and/or mental health services. It highlighted that communication and the therapeutic relationship between the patient and practitioner were particularly important in the process of engagement. However, this chapter demonstrated how interpersonal communication and the therapeutic relationship could be problematic when a person experiences communication disability and accessing healthcare services. This raises questions about whether engagement may have unique challenges when a person is experiencing communication disability. Only two papers have explicitly considered engagement in people experiencing communication disability after stroke. No research has considered *how* patients or practitioners conceptualise engagement. Nor has any research explored how engagement occurs over time. As a result, there is very limited knowledge about the *process* of engagement with nothing known about the longitudinal process of engagement over the course of rehabilitation. Only slightly more is known about the *state* of engagement. Essentially, this reflects that research in this clinical population is in its infancy. The findings from this chapter and the previous chapter (the conceptual review), and the gaps in knowledge provide the rationale for the research within the remainder of this thesis.

There is a need to develop an understanding of how patients experiencing communication disability and practitioners conceptualise engagement in the context of stroke rehabilitation. Neither of the two studies which explored engagement sought to understand the meaning or process of engagement from the perspectives of those

experiencing communication disability, or from rehabilitation practitioners working with this population. Instead, they focused on how engagement was enacted and were based on the authors' conceptualisations of engagement. Within the conceptual review, studies exploring patient and practitioner perspectives of engagement in mental health services provided rich, nuanced descriptions of the engagement process, including descriptions of patient and practitioner actions within this process (see pages 40-41) which would likely not have emerged had their perspectives not been sought. Understanding how these groups conceptualise engagement may both broaden and deepen our knowledge of engagement in people experiencing communication disability.

People experiencing communication disability commonly experience stroke sequalae which require interaction with a variety of rehabilitation disciplines (e.g. Dickson et al., 2008; Horton et al., 2011; Parr et al., 1997; Talvitie & Reunanen, 2002). Practitioners may have different levels of knowledge and skill in working with people experiencing communication disability. The articles addressing engagement in people experiencing communication disability following stroke, considered it in the context of speech-language therapy group interactions (Simmons-Mackie & Damico, 2009), and between patients and four rehabilitation practitioners (Horton et al., 2011). In order to consider how best to facilitate engagement across the rehabilitation programme, attending to engagement with a range of other rehabilitation practitioners is essential.

Developing a more comprehensive understanding of the *process* of engagement is important for several reasons. There is little known about the process in people experiencing communication disability, and given communication is a core component in the process of engagement, it is not unreasonable to question whether the process of engagement is more challenging when a person has a communication impairment. Given that the process of engagement appears to lead to the state of engagement which

is considered important for rehabilitation outcomes (e.g. Kortte et al., 2007; Medley & Powell, 2010), a more comprehensive understanding of this process may be beneficial.

While the conceptual review proposed that engagement incorporated both a co-constructed process and a patient state (see page 44), the engagement literature in people experiencing communication disability did not consider how people become engaged in the rehabilitation programme over time, i.e. longitudinal studies of the engagement process. Instead, they provided detailed descriptions of practice, considering how people engaged in individual treatment sessions (Horton et al., 2011; Simmons-Mackie & Damico, 2009). However, studying engagement as a longitudinal process would allow for consideration of how the patient comes to engage, and how engagement might change over time.

While interview-based qualitative studies highlight the reported process-oriented nature of engagement, they provide limited insight into *how* the process occurs over time, the behaviours, interpretations and subsequent actions on the part of both parties. In contrast, an observational study of practice over the period of rehabilitation may be better placed to detail the process of engagement which arguably might assist practitioners to critically reflect on their practice and identify specific strategies they may be able to use to facilitate engagement. Drawing together the perspectives of patients and practitioners may provide a richer understanding of the process of engagement, and in particular, provide some understanding of how patients interpret and respond to practitioner actions.

Finally, the methodological approaches employed with this literature review focused on what a person (either the patient or the practitioner) did within a therapeutic interaction with some limited attention to why people acted as they did (Horton et al., 2011). Viewing engagement as an active process and a state without considering how these actions came to be provides a limited insight into human behaviour, arguably a

surface level understanding of engagement. Research from related areas such as patient adherence have emphasised the need to understand factors underpinning action such as beliefs, attitudes, supports and cultural context (Martin, Williams, Haskard, & DiMatteo, 2005). These may be important in engagement; the conceptual review suggested a person's engagement may be influenced by their interpretation of the practitioner's skills and engagement (see page 41). Research outside the engagement sphere indicates that a practitioner's knowledge, skills and attitudes can impact on interpersonal communication, a key aspect of the engagement process, when the patient has a communication disability (Hemsley et al., 2012; M. Jones et al., 1997; Murphy, 2006; O'Halloran et al., 2011; Sundin et al., 2002). The lack of research considering how patient behaviours come about, addressing both intrinsic and extrinsic factors, reflects that research in engagement in this clinical area is limited. Having a more comprehensive understanding of why people do or do not engage, or how and why engagement changes over time may help practitioners reflect on why a person is struggling to engage, and may support them to consider how they could facilitate engagement, a desired outcome of this doctoral research.

Conclusion

This chapter has extended the findings of the conceptual review by illustrating how people experiencing communication disability may experience particular challenges when engaging in stroke rehabilitation, and by detailing the very limited body of knowledge on engagement in this context. Research on engagement in people experiencing communication disability is in its infancy. The combined findings from these two reviews of the engagement literature underscore the need to explicitly focus on developing a more comprehensive understanding of how engagement is conceptualised and enacted in this context, exploring how these understandings and actions came to be as well as considering what they bring about in practice. Exploring

engagement with the rehabilitation practitioners across a range of professions and across a number of interactions while capturing perceptions, experiences *and* enactment of engagement is anticipated to contribute to further understanding of the process of engagement in people with communication difficulties. While the existing literature provides broad indications of how practitioners may act in order to facilitate engagement (for example, listening or taking time), this study intends to provide explicit, rich descriptions of how the engagement process can occur with this patient group. It is hoped this will support practitioners to reflect on their practice through providing examples of what is and what could be. It will help them identify what they do already, while also opening up possibilities of what they could do differently in order to engage with people experiencing communication disability in stroke rehabilitation.

Chapter Four: Methodology

This chapter discusses the Voice Centred Relational Approach, the methodology that underpins the empirical studies within this thesis. The Voice Centred Relational Approach brings together a theoretical framework consisting of a relational ontology, social constructionism and symbolic interactionism, and an established analytic method, the Voice Centred Relational *Method*. The Voice Centred Relational Approach functions as *a methodology*, the research strategy and plan for how the research will proceed (Crotty, 1998). This chapter is presented in three sections. Firstly, the history and more recent development of the Voice Centred Relational Approach are presented, before I discuss the interwoven ontology, epistemology and theoretical perspective (referred to as the 'theoretical framework') which underpins this research. Secondly, I demonstrate how the theoretical framework and analytic method (the Voice Centred Relational Method) were incorporated to develop the methodology for this specific research. Finally, I discuss the methodological issues involved in qualitative research with people experiencing communication disability, demonstrating how a relational approach to research facilitated their inclusion in the research. This chapter focuses on the principles that informed the research design; the details of *how* they were operationalised are contained in the relevant Methods chapters.

The Voice Centred Relational Approach: An overview

The Voice Centred Relational Approach is a qualitative methodology which emphasises the voices[6] of research participants. It is based on the premise that a person's 'voice' is "polyphonic and complex" (L. M. Brown & Gilligan, 1993, p. 15), that an individual might experience multiple, sometimes contradictory ways of thinking about and

[6] Voice refers to "perspectives" (L. M. Brown, Debold, Tappen, & Gilligan, 1991, p. 29; Sorsoli & Tolman, 2008, p. 497) or "stories" (Mauthner & Doucet, 1998) embedded within a person's communication.

understanding situations and concepts (L. M. Brown & Gilligan, 1993). In this approach, how a person speaks (and indeed, does *not* speak of themselves), their experiences and the relationships within their talk provides insight into their perceptions and experiences (L. M. Brown et al., 1991; L. M. Brown & Gilligan, 1993; Mauthner & Doucet, 2003). The Voice Centred Relational Approach emerged from Lyn Mikel Brown and Carol Gilligan's study of moral development in young women in the 1980s (L. M. Brown et al., 1991; L. M. Brown & Gilligan, 1992; Gilligan, Spencer, Weinberg, & Bertsch, 2005; Kiegelmann, 2009). Gilligan and colleagues (2005) argued voices were commonly missed or reduced in simple coding schemas yet they considered exploring the relationships within and between voices could offer a significant amount to understanding phenomenon. They considered voice to be influenced, and potentially silenced by the context surrounding the individual, such as relationships and societal and cultural frameworks (L. M. Brown & Gilligan, 1991). To become attuned to the multiplicity of voices within a person's narrative, they developed a four-staged Listening Guide which involves undertaking four sequential readings (or 'Listenings'[7]) to attend to the different voices and how they developed (L. M. Brown et al., 1991; L. M. Brown & Gilligan, 1991, 1992; Gilligan et al., 2005; Hamer, 1999; Mauthner & Doucet, 1998).

The Listening Guide is a central component of the Voice Centred Relational Approach. It is a flexible tool which can be customised to the researcher's theoretical perspective and the research question (Gilligan et al., 2005; Mauthner & Doucet, 1998; Sorsoli & Tolman, 2008). The first reading of data focuses on the broad story and context evident within the narrative while simultaneously considering the researcher's own response to this story. This makes the researcher's role in data construction overt, positioning them in relationship with the participant through the data. The second reading focuses

[7] The terms 'readings' or 'listenings' are used interchangeably in the literature. Throughout this thesis, I use the term 'readings', consistent with Mauthner and Doucet's (1998) approach.

on how the person speaks of themselves and the voices within the narrative. The third and fourth readings are where methodological diversity and analytic flexibility become apparent. The focus of these readings is determined by the researcher's theoretical perspectives and the research aims. For example, Mauthner and Doucet's work (2002, 2008; 1998, 2003) has consistently focused on reading for relationship (reading three) and reading for social contexts (reading four), linking "micro-narratives and macro-level structures and processes" (Doucet & Mauthner, 2008, p. 406). This approach is arguably inductive, reflecting the exploratory nature of their research, and represents a focus on relationships between *people* rather than relationships between *voices* within a person's narrative. In contrast, Brown and Gilligan (1992, 1993) have commonly focused on voices of care and justice, informed by earlier research which indicated these voices were consistently present in stories of moral development (see also L. M. Brown et al., 1991; Gilligan et al., 2005), and by two different moral theories, those of care and justice. Their analysis used *a priori* theory to focus on the relationships between *voices* of care and justice, a more abstract approach which builds on existing knowledge. Despite these divergences, in both instances ongoing analysis (i.e. after completion of the Listening Guide) attends to different relationships within the data. These examples demonstrate how the Voice Centred Relational Approach, through the use of the Listening Guide as the primary analytic tool, functions as a research *framework* rather than being a fixed prescription for how research must occur.

Historically, writing about the Voice Centred Relational Approach has focused on the analytic technique within the Listening Guide. As a new researcher at the start of my PhD, this left me uncertain about whether the Voice Centred Relational Approach could be considered a research methodology[8] in and of its own right, or if it was simply a

[8] I use the term 'methodology' based on Crotty's (1998) definition: that methodology is the "way of proceeding" (p. 13) in order to meet the research aims and is unique to the individual research project.

method, a data analysis technique used within a more common named methodology such as narrative inquiry. Researchers who have used this approach have positioned it within a number of theoretical perspectives – feminist standpoint theory, literary, narrative and relational theories to name a few (L. M. Brown et al., 1991; L. M. Brown & Gilligan, 1993; Gilligan et al., 2005; Mauthner & Doucet, 1998; Sorsoli & Tolman, 2008) but have not explicitly described it as a methodology in and of itself. The ontological and epistemological underpinnings of the approach have predominantly been implicit, embedded within methodological discussions but not explicitly addressed (Mauthner & Doucet, 2003), with little attention to how these are enacted within, or influence, the research process (Doucet, 1998). Over the last twenty years, Natasha Mauthner and Andrea Doucet have been the pre-eminent authors on the Voice Centred Relational Approach and have explicated the ontological, epistemological and theoretical underpinnings of this approach (Doucet, 1998; Doucet & Mauthner, 2002; Mauthner & Doucet, 1998, 2003). It is Mauthner and Doucet's writing, read in conjunction with the work of Brown and Gilligan which has most informed the development of the research methodology used within this thesis. This is for two reasons : (a) the emphasis on relationships between people as well as voices, something which appears important for engagement (see Chapter Two, conceptual review); and (b) the inductive approach to analysis (as opposed to drawing on *a priori* theory) which was considered appropriate for this exploratory research into engagement.

The decision of which methodology to use was made while the exploratory studies of this doctoral work were underway, i.e. the conceptual review and interview-based qualitative study. The decision was helped by refining the research purpose and question in response to the findings of the conceptual analysis. As the research purpose came to focus on exploring how practitioners worked to engage people experiencing communication disability in order to inform clinical practice, and as relationship increasingly appeared important but clearly was not well-researched, I sought a

methodology which was congruent with the relational focus, which would allow detailed description of practice that would support practitioners to reflect on their own practice and make changes where appropriate. While grounded theory was one possible methodology, I did not consider the study aims were compatible as the objective of grounded theory is to generate theory of processes. Secondly, grounded theory places a strong emphasis on coding and categories, abstracting the data (Corbin & Strauss, 1990). My previous experience with analysing data from people with aphasia highlighted the need to ensure the data were at the foreground throughout the analysis process in order to ensure their voice was not lost amidst the codes (Bright, 2011). Crotty (1998) emphasises the need to ensure that methodology is consistent with the study objectives. The Voice Centred Relational Approach fulfils this criteria.

Ontology, epistemology and theory: An overview

Within a Voice Centred Relational Approach, ontology, epistemology and theoretical perspectives are considered so closely entwined that each component is rarely discussed separately (Doucet & Mauthner, 2002; Mauthner & Doucet, 2003). This entanglement was evident as I addressed each area, considering how they could form a research strategy and be enacted. Within this section, ontology, epistemology and theoretical perspectives are each discussed separately to demonstrate what each contributes to the research design, before I bring them together to illustrate *how* they informed the research methods. The research and writing processes advanced my methodological understanding and reflections (see page 76 for more explanation). Accordingly, the detail provided within this chapter reflects my emerging understanding of ontology, epistemology and theoretical positions.

A relational ontology

The Voice Centred Relational Approach is based on a relational ontology (theory of being) (Doucet, 1998; Doucet & Mauthner, 2002; Mauthner & Doucet, 1998). Relational ontology holds that humans exist within relationship, embedded in both "intimate and larger social relations" (Mauthner & Doucet, 1998, p. 9). Humans are considered "interdependent rather than independent" (Tronto, 1995, p. 142). Relationships are important in developing humanity and form the basis of how we conceptualise ourselves, with the 'self' being seen as entwined with relationships with others and the cultures surrounding us (Gilligan et al., 2005). Douglas and colleagues (2015) recently argued that rehabilitation is "a social-relational affair" (p. 154) which occurs within relationship, consistent with earlier arguments for a relationship-centred approach to care (Beach & Inui, 2006; Tresolini & Pew-Fetzer Task Force, 1994; Worrall et al., 2010). This suggests rehabilitation can have a relational ontology.

A relational ontology results in relationship being valued throughout the research process. Within a Voice Centred Relational Approach, the researcher is considered in relationship with the participants not simply during data collection but also throughout the research process. Analysis is described as a relational act (L. M. Brown et al., 1991). The research process focuses on relational aspects of the phenomenon under consideration, closely attending to multiple forms of relationship: those within the data; between the voices in data; between the participant and those around them; and with the contexts in which they live (Doucet, 1998; Doucet & Mauthner, 2002; Mauthner & Doucet, 1998, 2003). As a result, Voice Centred Relational research has been described as having a "'relational filter'" (Doucet & Mauthner, 2002, p. 12) which involves reading for relationship in the data, prioritising relational issues within analysis, resulting in a relational interpretation.

A relational ontology appears consistent with the concept of engagement. The conceptual review in Chapter Two was completed at the same time as this theoretical framework was explicated. The review highlighted that relationship often appeared crucial in the process of engagement, yet there had been limited research explicitly exploring the relational processes within engagement. This methodology and its emphasis on relationship was considered a useful tool in opening up understandings of relational aspects of engagement.

A social constructionist epistemology

Epistemology, the theory of knowledge, requires consideration of what constitutes knowledge and how knowledge develops (Crotty, 1998). Berger and Luckman (1967) described knowledge as a person's certainty that something is 'real', arguing that what is 'real' is socially constructed through interaction and communication, and is historically, culturally and socially situated (Berger & Luckmann, 1967; Gergen, 1985). Reality, from this perspective, is considered to be not fixed or completely knowable; instead it is constructed and reconstructed through interaction (Berger & Luckmann, 1967). Within research, a social constructionist epistemology acknowledges multiple constructed realities. The research process and research knowledges emerge from interaction. Research considers the social locations of the researcher and participants, and considers that data and knowledge is constructed between the researcher and participants (Charmaz, 2008), consistent with the relational ontology detailed above.

Within a Voice Centred Relational Approach, knowledge is viewed as socially constructed. People are embedded within larger social relations; the knowledges participants hold are situated and constructed in interaction with social and cultural frameworks that surround them (Gilligan et al., 2005; Mauthner & Doucet, 1998). Knowledges are contextual and multi-layered (Mauthner & Doucet, 2003), reflecting

multiple constructed realities. Research knowledge is considered developmental, partial and situated in the context in which it was constructed between the researcher and participant/s (Mauthner & Doucet, 2003). Participants are only ever "incompletely known" (Mauthner & Doucet, 2003, p. 423); arguably it is not possible to claim to know the participant and their lived experience, instead only being able to "grasp something of their articulated experience and subjectivity" (Mauthner & Doucet, 2003, p. 423). Accordingly, knowledge claims within the research product need to reflect the partial, situated nature of co-constructed knowledge.

The researcher themselves is socially located (Doucet, 1998; Mauthner & Doucet, 2003). Doucet (1998) stated this influences how researchers "'see' and 'hear' the individuals [and] how we construct theory from their words, experiences and lives" (p. 54). The researcher actively constructs knowledge by attending to particular voices in the data (Doucet & Mauthner, 2002). They are in relationship with participants through the data collection and data analysis as they engage with the voices in the data. The relationship (recognised or not) continues in dissemination as the researcher shares findings and discusses the voices. Doucet and Mauthner (2002) described knowledge construction as responsive and relational, reflecting the relational ontology of the research, demonstrating how ontology and epistemology are closely entwined.

Social constructionism is closely aligned with early readings about engagement (both the concept of what *is* engagement, and the actual process of engagement). These readings indicated engagement and related therapeutic processes could be socially constructed (Crepeau, 2000; Lawlor, 2003; Simmons-Mackie & Damico, 2007). My thinking on this was captured in a memo: "[I see the] interaction of the person and society (and their context) create knowledge of the concept of engagement; they also serve to construct the experience of engagement[9]". The conceptual review undertaken

[9] Memo, 12 August 2012

as part of this doctoral work, and another recent conceptual analysis of engagement (Barello et al., 2014) both highlight how engagement is constructed in different ways by different stakeholders in healthcare. These reflections and readings indicate social constructionism is an epistemology congruent with engagement.

A symbolic interactionist perspective

The Voice Centred Relational Approach is said to be "firmly rooted … in a symbolic interactionist tradition" (Mauthner & Doucet, 1998, p. 27), a theoretical perspective aligned with a social constructionist epistemology (Crotty, 1998). Symbolic interactionism consists of three core premises: we act toward things based on the meaning objects have for us; this meaning comes from social interaction; and we modify these meanings through an internal interpretive process (Blumer, 1986). It views people as active contributors to meaning-making (Charon, 2010). Charon argued that to understand human action, we need to look beyond the action to consider how social interaction impacts on meaning-making, how we think (the process of interacting with the self), and how we define the situations we are in. The self is a socially constructed thinking 'object' that an individual attends to and acts toward; it can be named, imagined, visualised, talked about and acted toward (Hewitt & Shulman, 2011). Research within a symbolic interaction perspective requires close attention to the symbols (meaningful objects) people attend to, how they interpret these and how they act in response to this meaning (Charon, 2010). From a symbolic interactionist perspective, a key factor in meaning-making and thinking is seeing things from the perspective of others in the situation; this then influences how people interpret the situation and act. Charmaz (2004) suggested a theoretical perspective functions as a frame which "guides what we can look for and what we see – as well as what we do not look for or see" (p. 983).

While Mauthner and Doucet (1998) stated the Voice Centred Relational Approach reflected a symbolic interactionist perspective, there has been limited discussion of *how* this perspective underpins the approach. I suggest symbolic interactionism and the Voice Centred Relational Approach appear to particularly converge in their focus on the self and on relationships, and in the understanding that objects (e.g. people) and meanings are socially located. These influence what is attended to within analysis, particularly when using the Listening Guide consistent with Mauthner and Doucet's (2008; 1998) approach. For example, the 'self' is a central component of meaning-making attended to in analysis. People's meaning becomes evident in how they speak of themselves, their reflections and decision-making (Gilligan et al., 2005; Mauthner & Doucet, 1998). Accordingly, the Listening Guide can support the researcher to closely attend to the self by focusing on voices within the participant's narratives, considering how a person sees and presents themselves, the meanings they hold and how these developed (L. M. Brown et al., 1991; Mauthner & Doucet, 1998). Action emerges from meaning and also modifies meaning (Blumer, 1969). Attending to how people speak of themselves in action, understanding fluidity and how voices change in different situations are all parts of a Voice Centred Relational analysis (Gilligan et al., 2005).

The Listening Guide prompts a consistent focus on relationship, attending to how people talk of themselves and others within relationship, and how meaning arises from and is shared within relationship (Mauthner & Doucet, 1998, 2003). Relationships are considered a key context in which people construct meaning (Gilligan et al., 2005; Sorsoli & Tolman, 2008). This is similar to 'social interaction' (Blumer, 1969; Charon, 2010) where actors (which includes people and institutions or services) are seen to "take one another into account, symbolically communicate to one another and interpret each other's actions" (Charon, 2010, p. 138). 'Social interaction' reflects an on-going process of symbolic communication, interpretation, meaning-making and action. 'Social interaction' is also evident in the perspective that people are socially

located, something considered in reading four of the Listening Guide, as described by Mauthner and Doucet (2008; 1998). Incorporating symbolic interactionism into analysis prompts the researcher to consider the person and meaning-making within their social location. It requires attention to the social context and how this might influence the voices within a person's narratives. It prompts questions such as 'what meanings are shared or present within the voices?' and 'how did these voices come about?' (Mauthner & Doucet, 2003), and 'how might a person's social location relate to how people talk of themselves and others?' (Mauthner & Doucet, 1998). These connections demonstrate cohesion and coherence between the Voice Centred Relational Approach and symbolic interactionism.

The focus on meaning-making and action resonated with early reading on engagement which strongly focused on patient behaviours, with limited consideration of why people act in the way they do (Bright et al., 2015; Crepeau, 2000). This was also evident in the Literature Review (see page 62). I considered that attending to social interaction and joint action, to how patients and rehabilitation practitioners spoke of the self and of objects in their environment, understanding the process of meaning-making and on-going action may help "bring to life the essence and character of a [person's] experience and behaviour" (Halligan & Marshall, 1996, p. vii). Such aspects might be neglected by focusing only on behaviour. I also considered attending to these factors may contribute to a deeper, more complex and nuanced understanding of engagement. Additionally, symbolic interactionist principles of exploration (developing an understanding of what is happening) and inspection (detailed descriptions of what happens, how these actions relate to what people are thinking and considering the consequences of actions) (Blumer, 1969) were anticipated to contribute to meeting one of the research objectives, to develop understandings of how practitioners engage people experiencing communication disability; findings which might support

practitioners to reflect on patient engagement and ways of working which might facilitate engagement.

Ontology, epistemology and theory: A personal reflection

When reflecting on their understandings and implementation of the Voice Centred Relational Approach, Mauthner and Doucet described how their ontological, epistemological and theoretical positionings became more apparent as they gained distance from their doctoral research (Doucet, 1998; Doucet & Mauthner, 2002, 2008; Mauthner & Doucet, 2003). This is reflected in my own experiences of using this approach. I initially considered the Voice Centred Relational *Method* solely as an analysis technique rather than a research methodology underpinning the research approach. The depth of the approach only became apparent during the process of data analysis and while reflecting on the research process. The methodology for this PhD was developed over the course of the doctoral study, much of it occurring concurrently with the conceptual review and first empirical qualitative study. This has influenced the research process in different ways at different stages. It informed the analysis of the first empirical interview-based study (Chapters Five and Six), but informed both the design *and* analysis of the second observation-based study (Chapters Seven and Eight). My early understandings of the Voice Centred Relational Method focused on the epistemology and theoretical perspectives; the role of the relational ontology only became clear late in the research process and thus, had limited influence on the research design. While it would have been ideal to develop the methodology before commencing the research, it reflects that methodological development is an integral component of the research process in and of itself. It also reflects Mauthner and Doucet's (2003) statement that data analysis is a prime site for grappling with ontological, epistemological and theoretical issues.

The Voice Centred Relational Approach methodology

A research methodology functions as a bridge between the theoretical framework and the research methods including data collection and analysis. In this section, I link the key principles from the theoretical framework described above with the research methods, making explicit how I integrated these to provide the "map of action" (Crotty, 1998, p. 7) for the research, influencing the research process at different "decision junctures" (Koro-Ljundberg, Yendol-Hoppey, Smith, & Hayes, 2009, p. 688).

The central principles from relational ontology, social constructionism and symbolic interactionism that informed the methodology of this research are:

- The researcher and participants are in an on-going relationship throughout the research process.
- People exist in inter-dependent relationships, relationships with themselves, with others and with their context.
- Knowledge is constructed through interaction with the self, with others and with the broader context the individual researcher and participant/s are located in.
- People act in response to the meanings objects hold; these meanings are constructed through social interaction and can be ever-changing.
- Multiple constructed realities exist. Accordingly, knowledge is multi-layered and never complete. It is always partial and situated within the context it is constructed in.

These are summarised in Figure 6 in page 78.

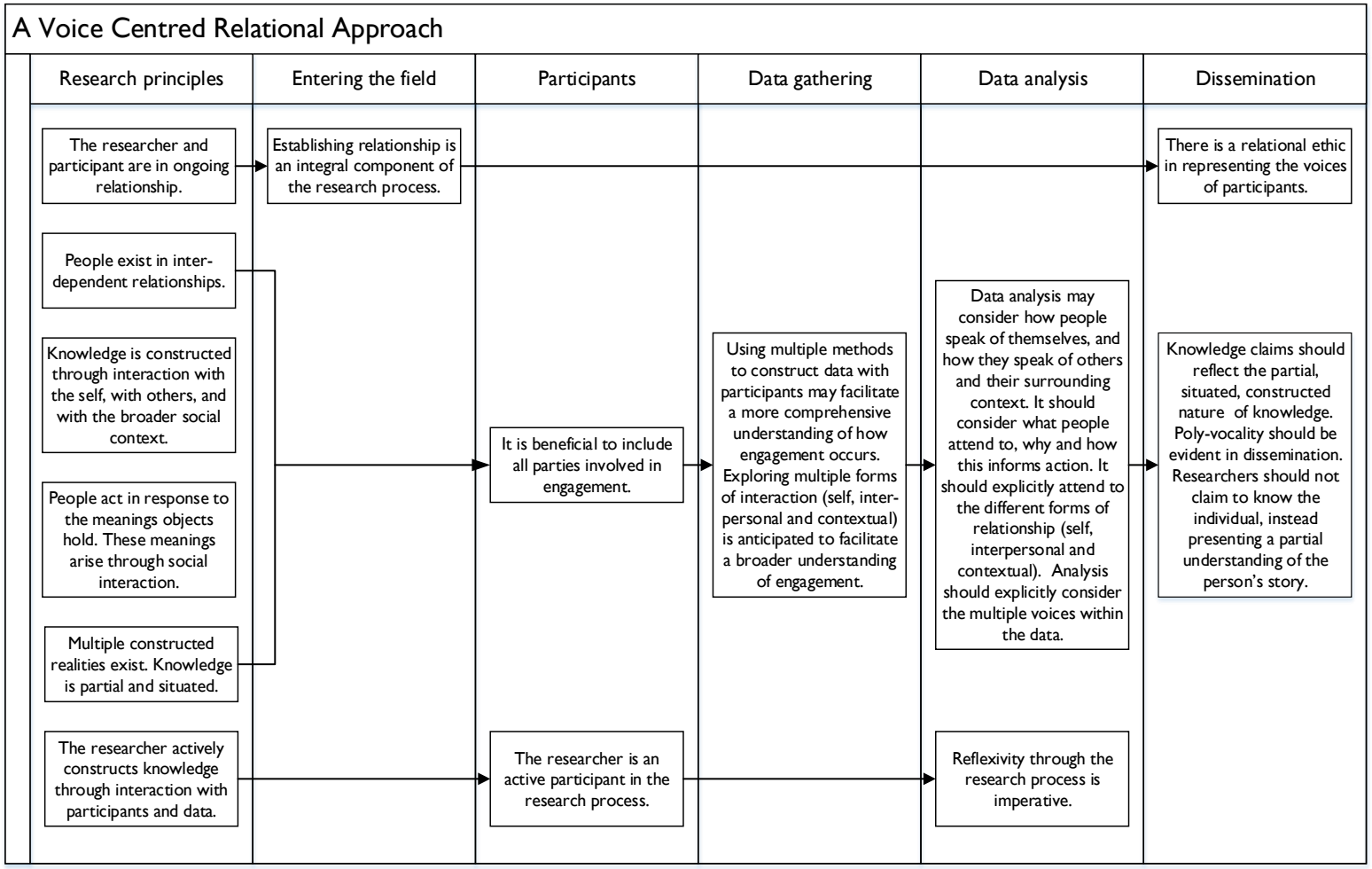


Figure 6: Demonstrating how the theoretical framework informs the methodology and methods

Entering the field: The researcher in relationship with participants

Relationships were integral throughout this research and influenced how I entered the field. I sought to develop relationships prior to collecting data through a process of *whakawhanaungatanga*[10], "allowing time and space to establish relationships" (R. Jones et al., 2006, p. 70) through informal interactions and sharing information and knowledge. While important for engaging people in clinical services (Drury & Munro, 2008), social constructionist researchers have suggested relationship facilitates open communication between parties throughout the research process (Jankowski, Clark, & Ivey, 2000; Morrow, 2005). Carol Gilligan commented the voices of individuals are very responsive to the outside world, that a tense research situation or relationship could constrain or flatten participant voices (Hamer, 1999).

The research process is a "relational encounter" (Kiegelmann, 2009, p. 6) with the researcher an active participant in the process (Gilligan et al., 2005). Creating an environment where participants felt comfortable sharing their experiences (Jankowski et al., 2000; Latimer, 2008) could enable a deeper, more nuanced understanding of their experiences (Charon, 2010). In a sense, this reflected a process of engaging research participants in the research process before then studying how they engaged in their rehabilitation. As well as developing relationship prior to commencing research, the relationship is also important in data gathering and analysis as will be discussed throughout this section.

Recruitment and sampling: Determining who were participants

Viewing people as existing in inter-dependent relationships prompted me to recruit people experiencing communication disability *and* their rehabilitation practitioners. A

[10] *Whakawhanaungatanga* is a Māori term defined as allowing time and space to establish relationships" (R. Jones, Crengle, & McCreanor, 2006, p. 70).

relational ontology considers people are entwined in relationship, therefore considering the relationship was important. Social constructionism and symbolic interactionism prompted consideration of how people acted together and separately as well as how they made meaning, interpretations and decisions about engagement based on their interactions within each person and between themselves (Blumer, 1969; Charon, 2010). Additionally, the vast majority of engagement research has focused on perspectives of practitioners *or* patients (Bright et al., 2015) rather than incorporating the perspectives of patients *and* practitioners, and there has been limited exploration of relational aspects of engagement.

Data gathering: Constructing knowledge with participants

Blumer (1969) stated direct examination of the participant's world is essential to understand how they make meaning and act. He suggested researchers may use any "ethically allowable principle" (p. 41) that might give a clearer understanding of what is happening. Because data gathering for the first qualitative study in this thesis occurred simultaneously with the development of this methodology, the theoretical framework and this resulting methodology was primarily applied to the second empirical study presented in Chapters Seven and Eight. While the first empirical study relied on interview data, the second empirical study combined multiple data collection methods, each of which enabled subtly different ways of eliciting and considering how people acted, how they constructed meaning and how they acted in relationship with others (Blumer, 1969; Charon, 2010; Mauthner & Doucet, 1998; Tronto, 1995). The exact methods are detailed in the Methods chapters of each study (Chapters Five and Seven).

Analysing data: Constructing knowledge(s) and understanding(s)

The Listening Guide was the primary method of analysis throughout this research. Within this section, I detail how the Listening Guide was developed and used as this applied to *both* empirical qualitative studies within this thesis. This specific Listening Guide was developed prior to analysis and was strongly influenced by the theoretical framework underpinning this study as detailed in Table 4 on page 82.

The first reading involved attending closely to the stories in the data and my own response to these, asking 'what is going on here?'(Mauthner & Doucet, 1998). Attending to the researcher's response makes their role in constructing knowledge explicit; this reflects the view that the researcher is in relationship with the participant and the data, and that their own social location influences how they construct the data (Doucet, 1998; Doucet & Mauthner, 2002; Mauthner & Doucet, 1998, 2003), consistent with the perspective that analysis is a relational act (L. M. Brown et al., 1991). The second reading focused on the voices of the participant, how they spoke of themselves, the different ways they acted and the roles they played (Berger & Luckmann, 1967; Gergen & Gergen, 2007). Analysis attended to how people created meaning and how these meanings influenced action (Blumer, 1969). Attending to poly-vocality within the data facilitated consideration of multiple realities (Gergen & Gergen, 2007) and multiple perspectives (Gilligan et al., 2005; Mauthner & Doucet, 1998)

Table 4: Questions guiding the Listening Guide analysis

Reading	Questions
Reading One: The story and response	What is going on here? What are the events, sub-plots, characters, metaphors, and recurrent phrases? What is my emotional & intellectual response to the participant?
Reading Two: Participant voices	Who is speaking and with what voice? How does the participant experience, feel, present and speak of themselves? How does the participant believe others see them? What are the emotions, reflections, opinions, actions, intentions within the stories? What pronouns does the person use when speaking of themselves? What are people saying and doing (acting)? How do they expect to act? How do they do things and how did they develop that knowledge? What roles are the participant playing? How do they perceive situations, words and actions (symbols)? How does this impact on action?
Reading Three: Others and relationships	Who is spoken about, the relationships, emotions, statements and stories associated with each? Who is related to who in what way? How are people positioned within the relationships and interactions? What are people saying and doing (acting)? How do they expect to act? How do they do things and how did they develop that knowledge? What roles are the participant playing? How do they perceive situations, words and actions (symbols)? How does this impact on action?
Reading Four: Context	What are the broader social, political, cultural, professional and structural contexts surrounding the participants' story, experiences, actions and interpretations? What is spoken and unspoken, overt and taken-for-granted within the context of the stories? Whose voices are heard informing the situation? What social values surround the interaction? Why do people act in some ways and not others? What is institutionalised? What is the 'right' way to do things? Where did this come from? How have different roles come about? What is privileged in talk and/or action?

The third and fourth readings were informed by the theoretical framework and Mauthner and Doucet's research (Doucet, 1998; Doucet & Mauthner, 2002, 2008; Mauthner & Doucet, 1998). The third reading focused on how the person spoke of the 'other' (people in their environment), relationship, and in particular, relationship between themselves and others in their environment. This reflected the relational

ontology underpinning the study as well as the position that knowledges are socially constructed through interaction (Berger & Luckmann, 1967; Blumer, 1969; Charon, 2010; Gergen & Gergen, 2007). The fourth reading focused on the socio-cultural context, considering interactions between individuals and their context (Blumer, 1969), asking what appeared to be taken-for-granted and how this came to be, what were dominant ways of working, and what was privileged and why this was, informed by Latimer's (2000, 2008) critical constructionism.

Constructing i-poems

I-poems are a core part of a Voice Centred Relational analysis (Gilligan et al., 2005). Focusing on the personal pronoun 'I' (or equivalent pronouns such as 'we', 'me' and 'my') has been suggested to help the researcher tune into how the person speaks of themselves and the voices they may speak with (Gilligan et al., 2005). In order to examine how people speak of others, I also used pronouns that referred to others such as 'they'. Creating these poems involves taking sections of transcripts which appear most data-rich (based on the second reading in the Listening Guide) to explore how people spoke of themselves (Gilligan et al., 2005; Mauthner & Doucet, 1998). The pronoun and accompanying text were extracted and constructed into poetic form (Gilligan et al., 2005). An example showing how interview data was constructed into an i-poem is shown in Appendix C. I-poems are created from the participant's words.

Presenting findings

Participants' perspectives are embedded throughout the research findings. This was done in part to ensure that the participant's voice was not dominated by my own voice, a key principle in presenting research in a Voice Centred Relational Approach (Mauthner & Doucet, 1998). It can be difficult for people experiencing communication

disability to be heard in research and practice (e.g. Parr et al., 1997); representing their perspectives was a personal ethical concern. The findings represent similarities and differences within and across participants, aiming to capture and represent poly-vocality, the multiple voices within an individual's stories (L. M. Brown et al., 1991; L. M. Brown & Gilligan, 1991; Gergen & Gergen, 2007; Gilligan et al., 2005; Mauthner & Doucet, 1998). Techniques such as i-poems and presenting contrasting voices highlight the different voices (Edwards, 2012; Gergen & Gergen, 2007; Mauthner & Doucet, 1998), helping us "hear *more* of [the participants'] voices and understand *more* of their perspective" (Mauthner & Doucet, 1998, p. 26), and helping understand how these came about and how they impact on action. As discussed in the Literature Review, current knowledge about engagement in people experiencing communication disability is focused on action with little consideration of how and why this came to be. Attending to meaning-making and action reflects the theoretical perspectives of the study and was anticipated to enhance knowledge about engagement.

Quality

Quality of the research was guided by Tracy's (2010, 2013) quality criteria: worthy topic, rich rigour, credibility, sincerity, resonance, ethical research, meaningful coherence and significant contribution. Tracy's criteria arise from a critical synthesis of a number of approaches to quality in qualitative research and build on debates which have gone before (Tracy, 2013). The framework she proposes synthesises core components of quality. One reason this approach appeared appropriate was the strong emphasis placed on reflexivity, something central to the Voice Centred Relational Approach (L. M. Brown & Gilligan, 1992; Doucet & Mauthner, 2002; Gilligan et al., 2005; Mauthner & Doucet, 1998, 2003). Within this section, I outline these criteria, detailing how they have been addressed, or will be addressed within the research. Further detail

of how these have been operationalised will be provided in the Methods chapters for each study.

Worthy topic requires that the topic is relevant, timely and worthy of investigation (Tracy, 2010, 2013). As outlined, engagement appears to be a complex phenomenon, constructed in different ways with very little research in the communication disability field despite it being considered an essential component of the therapeutic process (Simmons-Mackie & Kovarsky, 2009). *Rich rigour* requires the researcher to demonstrate the research has been carried out appropriately. This requires appropriate amounts and forms of data, appropriate sample sizes and robust data construction and analysis techniques. This will be evident in detailed description of the research process for each of the empirical studies conducted (see Methods chapters Five and Seven). Central to *sincerity* is reflexivity. Reflexivity is also central to the Voice Centred Relational Approach (L. M. Brown & Gilligan, 1992; Doucet & Mauthner, 2002; Gilligan et al., 2005; Mauthner & Doucet, 1998, 2003). Reading One of the Listening Guide prompts close attention to the researcher's responses to the participants and their stories, considering how these might affect understandings, interpretations and representations of data (L. M. Brown & Gilligan, 1992, 1993; Gilligan et al., 2005). Doucet and Mauthner (2002) identified the researcher may open up particular lines of enquiry and engage with some participant's data, or some voices, more than others depending on the specific research aims. Within their writing on the Voice Centred Relational Approach, they have consistently emphasised the need for reflexivity, describing data analysis "as a point where the voices and perspectives of the research respondents are especially vulnerable" (Mauthner & Doucet, 1998, p. 23). Techniques for promoting sincerity are detailed in the Methods chapters (pages 106 and 157).

Credibility refers to dependability and trustworthiness, and expression of knowledges which appear plausible (Tracy, 2010, 2013). Multiple techniques facilitate credibility.

Detailed description will be evident when presenting findings. Another technique, *multi-vocality,* akin to poly-vocality has been described throughout this chapter (see page 83). *Crystallisation* is key in ensuring credibility by opening up different ways of viewing and understanding situations (Ellingson, 2009). Richardson, an early pioneer of crystallisation described how it "provides us with a deepened, complex, thoroughly partial, understanding of the topic. Paradoxically, we know more and doubt what we know. Ingeniously, we know there is always more to know" (Richardson, 2000b, p. 934). Collecting multiple forms of data at multiple times, with multiple participants is said to "construct a multi-faceted, more complicated and therefore more credible picture of the context" (Tracy, 2013, p. 237). Member reflections are another technique in facilitating credibility (Tracy, 2010).

Tracy's (2013) three *ethical domains***,** procedural ethics, situational ethics and relational ethics, guided ethical considerations throughout the study. *Procedural ethics* refers to commonly prescribed ethical considerations such as doing no harm, informed consent and ensuring privacy and confidentiality. *Situational ethics* requires consideration of ethical issues specific to the study context and overlapped with procedural ethics in areas such as ensuring that the consent process was conducted ethically and appropriately given many participants experienced significant communication impairments. Finally, *relational ethics* prompts attention to the relationship between researcher and participant/s. Tracy (2010) described relational ethics as an "ethic of care" (p. 245) which recognises and values relationship. It sees research occur in a way which is respectful, relational and mindful of the participant and their context. The relational ethic in particular, is highly congruent with this research in light of its relational ontology, and its on-going focus on relationship.

Resonance requires meaningful research findings that impact on the audience. *Transferability* is a component of resonance, facilitating transfer of findings to the

readers' own situations (Tracy, 2010, 2013). This was congruent with one of the aims of this research: that readers may be able to use the findings to reflect on their own practice and ways of doing things. Tracy (2010) suggested this is achieved through writing with *aesthetic merit*, an engaging text that prompts readers to enter and respond to the worlds of the participants. *Meaningful coherence* requires coherence between the research process (design, data collection and analysis) and the theoretical framework underpinning the study. Coherence is demonstrated by explicitly stating the theoretical framework and relating this to the study methods in this chapter and subsequent Methods chapters (Chapters Five and Seven). Finally, research should demonstrate a *significant contribution* to knowledge. Tracy (2013) considered significant contributions could range from making a "little incremental addition or dent in the knowledge boundary" (p. 240), and could be practically, conceptually, methodologically or theoretically significant. This will be discussed in the Discussion (see page 202).

Research with people experiencing communication disability

Research with people experiencing communication disability requires the researcher to carefully consider how they can facilitate participation. Successful communication is co-constructed (Kagan, 1998). All parties in the communicative encounter contribute to the success of the interaction. When a person experiences communication disability, their communication partner (in this context, the researcher) holds greater responsibility for facilitating successful communication. This co-constructed, relational approach to communication is consistent with a relational ontology and a Voice Centred Relational Approach which considers the relationship between the researcher and participants is a site in which knowledges are created together (L. M. Brown et al., 1991; Doucet & Mauthner, 2002; Gilligan et al., 2005; Mauthner & Doucet, 1998, 2003).

The time spent developing relationships with potential participants when entering the research field was important for developing relationship. It also allowed me to understand the person's communication impairments and how I could best facilitate communication throughout the research process. This then informed how I approached the informed consent process. The presence of a communication disability can mask decision-making capacity (Kagan & Kimelman, 1995), making it difficult for people to understand information, to ask questions and to express their wishes (Kagan & Kimelman, 1995; Penn, Frankel, Watermeyer, & Muller, 2008), all of which are core components of the informed consent process. I ensured information was presented using techniques appropriate to the person's communication needs and utilised the knowledge and expertise of recruiting practitioners (usually the person's treating speech-language therapist) in the consent process. Full details about the consent process are detailed in the Methods chapters (see Chapters Five and Seven). Throughout the research process, supported communication techniques were used. These included: simplified language; writing, drawing and/or gesturing key words or concepts; asking questions to verify understanding; allowing time for the person to understand and/or formulate a response; and supporting the person to use alternative or augmentative communication approaches (Kagan, 1998). Prolonged engagement with participants was also important, allowing me to understand their communication disability and how best to support communication. Multiple interviews enabled me to check interpretation, ensuring I understood their meaning.

Data analysis presented particular challenges when a person's expressive language was significantly impacted and the participant had limited verbal output. This could require several levels of interpretation, first interpreting what the individual was meaning to convey, and then analysing using the Voice Centred Relational Approach. Using supported communication during data gathering and regularly checking my interpretation of the person's communication was crucial in this process. In one

instance, I constructed the interview data into a narrative and checked this with the participant and his wife to ensure my understandings reflected his intent.

While undertaking qualitative research with people experiencing communication difficulties can present some unique challenges, the vast majority of these challenges can be accounted for with preparation by the researcher. The flexibility of the Voice Centred Relational Approach, together with the relational foundations that underpinned the research process, facilitated research which was responsive to the specific communication needs of the participants.

Conclusion

The Voice Centred Relational Approach is a qualitative methodology which focuses on the ways of thinking and speaking within participant narratives. It is congruent with the research aim of understanding how practitioners engage people experiencing communication disability in stroke rehabilitation. Within this study, the emphasis on meaning-making, action and interaction was intended to facilitate consideration of why people act as they do with regard to engagement, moving beyond simply describing *what* they do. This was anticipated to open up in-depth, nuanced understandings of engagement, addressing the significant gaps in knowledge previously detailed in the literature review chapters (Chapters Two and Three). While I have demonstrated how this methodology informed key aspects of the research process, within the next chapter, I detail how this methodology was enacted in the methods of the first empirical study of this doctoral research which explores how people experiencing communication disability and rehabilitation practitioners conceptualised engagement.

Chapter Five: Methods

An empirical, interview-based study

The first empirical study of this doctoral research investigated how people experiencing communication disability, and rehabilitation practitioners, conceptualise engagement. This qualitative study was completed concurrently with the conceptual review presented in Chapter Two. Together, these studies provided a platform for ongoing research within this doctoral work. Within this chapter, I detail the research methods for this research.

Research aim

The purpose of this study was to explore how engagement in stroke rehabilitation was conceptualised by people experiencing communication difficulties after stroke, and by rehabilitation practitioners working in stroke rehabilitation.

Recruitment

People experiencing communication disability were recruited through multiple sources. The research was advertised through local rehabilitation services and in newsletters of local not-for-profit organisations. Potential participants either contacted me directly or gave their rehabilitation practitioner consent to give me their contact details. Rehabilitation practitioners were recruited through written and verbal advertising in local rehabilitation services, and through professional networks. Practitioners contacted me directly if they were interested in participating.

Sampling

Sampling for both participant groups was primarily purposive with convenience sampling used in recruiting for focus groups (Thorne, 2008). Sampling aimed for variation and diversity in participants to facilitate comprehensive understandings of how engagement was conceptualised rather than seeking saturation. Specific characteristics sought in people experiencing communication disability included: type and severity of communication impairment, time post-stroke, rehabilitation services used (inpatient, outpatient, community, and public and private services) and ethnicity. Justification for these characteristics are provided in Table 5.

Table 5: Sampling participants experiencing communication disability

Characteristics	Justification
Type and severity of communication impairment	The nature of communication impairment might affect different aspects of engagement, for example, comprehension impairments may impact understanding and inclusion in rehabilitation (Parr, Byng, Gilpin, & Ireland, 1997); expressive impairments may impact on expressing wishes, being heard by practitioners, and demonstrating autonomy in rehabilitation (Dickson, Barbour, Brady, Clark, & Paton, 2008; Parr et al., 1997).
Time post-stroke	A person's recall and interpretation of experiences may change over time (Kirkevold, 2002)
Rehabilitation services used	We hypothesised patient expectations may differ depending on funding and structure of the service, e.g. privately paying, using student-based service
Ethnicity	Māori have higher stroke rates (Stroke Foundation of New Zealand, 2010) and inequalities in access to services; engagement may be one factor in service access (Curtis, Harwood, & Riddell, 2007).

Sampling of rehabilitation practitioners aimed for diversity in clinical experience, profession and workplaces as outlined in Table 6 on page 92. Several practitioners were approached as key informants, people considered to have a "particular affinity for observing and thinking about the situations within which they found themselves rather

than simply living them" (Thorne, 2008, p. 91). They were practitioners with whom I had previously interacted, who appeared highly reflective about professional practice and were thought to be well-positioned to reflect specifically on engagement.

Table 6: Sampling rehabilitation practitioner participants

Characteristics	Justification
Clinical experience	Engagement may be a skill that develops with experience (King et al., 2007)
Profession	Different professional groups may have different levels of knowledge and skill in working with people experiencing communication disability.
Workplace	Engagement may be viewed and experienced differently depending on the location of the practitioner, based on the perspective knowledges are socioculturally situated.

Inclusion/exclusion criteria

People experiencing communication disability were eligible to participate if:

- Their communication disability was a result of a stroke;
- They were over 18 years of age;
- They were living in the greater metropolitan area the study was based in; and
- They were able to communicate with the researcher (with the use of supported communication and/or an interpreter).

People were excluded if unable to provide informed consent or unable to participate in interviews despite the use of supported communication and/or an interpreter.

Rehabilitation providers were eligible to participate if they provided stroke rehabilitation services, and were based in the greater metropolitan region in which the research occurred, or were able to travel to the research site for an interview.

Informed consent

Verbal and written information about the study was provided before consent was sought (see Appendix D for copies of participant information sheets). While information was often initially emailed, it was always followed up with face-to-face discussion. This face-to-face discussion allowed the use of supported communication techniques which supported participants to understand information about the research and to ask questions about the research in order to ensure the consent process was fully informed (Kagan, 1998) (see page 88). After the research was discussed and questions answered, written consent was sought (see Appendix E for copies of consent forms).

Participant characteristics

In total, seven people experiencing communication disability and 14 rehabilitation practitioners participated in the study. Their characteristics are summarised in Table 7 (people experiencing communication disability) and Table 8 (rehabilitation practitioners). The OHW speech, language and cognitive communicative scales (O'Halloran, Worrall, & Hickson, 2009) were used to describe the severity of communication impairment, ranging from no impairment to complete impairment. I intentionally provide only limited information about each individual participant. The research occurred in a geographic area with a finite number of stroke rehabilitation services. Ensuring anonymity and preventing deductive disclosure (i.e. ensuring readers cannot identify participants based on the traits described) was a concern (Kaiser, 2009).

Table 7: Characteristics of people experiencing communication disability

Name	Type of communication impairment	Severity	Time post-stroke	Rehabilitation services used	Ethnicity	Age
Raewyn	Aphasia	Moderate	> 12 months	Inpatient Outpatient/community Public and privately funded services	New Zealand European	45-64 years
Greta	Aphasia	Mild	<6 months	Inpatient Outpatient/community Public and privately funded services	Māori	>45 years
Geoff	Dysarthria	Mild	<6 months	Inpatient Public services	Māori	>65 years
John	Dysarthria (reported aphasia at time of stroke)	Mild	6-12 months	Inpatient Public services	New Zealand European	45-65 years
Matthew	Aphasia	Moderate	<6 months	Inpatient Outpatient/community Public services	New Zealand European	>65 years
David	Aphasia	Mild	<6 months	Inpatient Public services	New Zealand European	45-64 years
Peter	Dysarthria	Mild	>12 months	Inpatient Public services	New Zealand European	>65 years

Table 8: Characteristics of rehabilitation practitioners

Participant characteristics		
Clinical experience	<5 years:	4
	>5 years:	10
Profession	Speech-language therapists:	6
	Occupational therapy:	2
	Physiotherapy:	3
	Other (not defined):	3
Workplace	Inpatient:	2
	Outpatient/Community:	12

Gathering data with participants

Data were gathered through in-depth individual interviews and focus groups. In-depth interviews were used to develop an understanding of each participant's thoughts, feelings and subjective experiences of being engaged, or engaging others in stroke rehabilitation (Charon, 2010; Johnson, 2002; M. C. Taylor, 2005; Thorne, 2008). Interviews sought information about how people acted and how they constructed meanings about engagement, their role and the roles of others (Blumer, 1969; Charon, 2010; Mauthner & Doucet, 1998; Tronto, 1995). They were semi-structured, based on a brief interview schedule. This schedule was developed before starting the research and was revised throughout the process of data gathering to allow exploration of emerging findings. When interviewing people experiencing communication disability, questions were modified and presented using supported communication to maximise participation (Kagan, 1998). Table 9 contains examples of interview questions.

Table 9: Examples of interview questions

Participant population	Examples of questions
People experiencing communication disability	▪ Can you tell me about a time when you felt engaged in rehabilitation? ▪ Do you think your communication difficulties impacted on your engagement in rehabilitation? If so, how? ▪ Does it make a difference if your therapist seems engaged?
Rehabilitation practitioners	▪ Can you tell me what 'engagement' means to you? ▪ Can you tell me about a time when a client with communication difficulties was engaged in rehabilitation. Can you describe what was happening, what you were doing, what they were doing? ▪ When you think about how you engage your patients now as compared to when you were a new graduate, has anything changed? If so what? What do you think contributed to this?

Interviews lasted between 45 and 60 minutes. Interviews with people experiencing communication disability were audio-taped and video-taped to capture non-verbal data (Luck & Rose, 2007); interviews with rehabilitation practitioners were audio-taped. All were transcribed and annotated with non-verbal data. People experiencing communication disability were offered a second interview. It was intended that the first interview could serve to help me better understand their communication disability, develop individualised supported communication materials if required, and to explore the topic in more depth in the second interview. This approach also allowed me to check preliminary interpretation (Bright, 2011). Only two participants experiencing communication disability selected to have a second interview.

Four rehabilitation practitioner participants took part in individual interviews lasting between 75 and 120 minutes. These were audio-taped and transcribed. Focus groups were undertaken with ten rehabilitation practitioners. Focus groups enabled exploration of commonalities and differences across participants (Thorne, 2008). Two focus groups were conducted, the first with four participants, the second with six participants. They were carried out by locality, for the convenience of both the research team and the participants. Each focus group was attended by two researchers with one

acting as facilitator and the other as note-taker. Initial questions were similar to those used in the individual interviews (see Table 9 on page 96). Each focus group lasted between 45 and 80 minutes. Focus groups were audio-recorded and transcribed.

Analysing data

Data analysis was an iterative process. It started within the interviews as I listened to the participants' experiences, and continued through the process of writing this thesis (Mauthner & Doucet, 1998). Within this section, I focus on the structured analysis process based on the Voice Centred Relational Method[11]. Analysis occurred at three consecutive levels: the individual participant, within participant groups (i.e. people experiencing communication disability, and rehabilitation practitioners), and across groups. As this approach has not been used widely in rehabilitation or health research, in-depth detail is provided.

Analysing data: Individual level

Data analysis, at the individual level, primarily drew on the Listening Guide (described in the Methodology chapter, see page 81). I also used narrative construction, diagramming and i-poems (Gilligan et al., 2005) to explore engagement.

The Listening Guide

The Listening Guide involved four readings of each interview. Each transcript was imported into an Excel spreadsheet (see Table 10 on page 99 for an example). Analysis from each reading was recorded in four separate columns. For the early interviews in

[11] The Voice Centred Relational *Method* refers to the analytic methods associated with the Voice Centred Relational Approach. The Voice Centred Relational *Approach* refers to the broader *methodology* which was used in the second empirical study (see Chapters Seven and Eight).

the study, each reading occurred consecutively; reading one followed by reading two and so on. However, this process was very time-consuming as has been noted elsewhere (Mauthner & Doucet, 1998) and was modified as follows for subsequent interviews: reading one focused on their story and my response to this. Readings two to four were then done together, exploring the data for these three different topics within the text. This approach is consistent with that of Mauthner and Doucet (1998).

The first reading focused on the stories within the data: the characters, events, recurrent words, images and metaphors (Mauthner & Doucet, 1998) and the context surrounding the participant and their experiences (Gilligan et al., 2005). I also recorded my response to the data as I conducted the analysis (Gilligan et al., 2005), which Mauthner and Doucet (1998) described as reading for yourself within the story.

The second reading focused on how the participant spoke of themselves, their actions, meaning-making, thoughts and feelings. This involved close attention to personal pronouns such as 'I', 'we' and 'you'. When pronouns were not present in the narrative because of communication impairment, I added them in brackets in order to facilitate this analysis, for example, "up until now I haven't been involved in rehab before and this is new for now, [I was] a little bit apprehensive".

The third reading focused on how the participant spoke of others, and of their relationships with others. For those with communication disability, 'others' included other patients, rehabilitation practitioners or family members. For rehabilitation practitioners, this included patients, colleagues or students. I paid close attention to how they spoke of the interactions between themselves and the 'others', in particular.

Table 10: Sample of a completed Listening Guide

	Transcript	Reading 1: Story and researcher response	Reading 2: "I"	Reading 3: Other and relationship	Reading 4: Context
I2	So what tells you then? Obviously the communication may tell you, but what about their behaviour tells you that they're engaged?				
P1	Adherence in a word. Attention.	Doing what they're told. Attending to task. *From a physio; would be interesting to consider how different disciplines talk about it*		Behaviours valued.	Adherence is a valued commodity. Doing what they're told. Reinforcing therapist as expert. Medical model of practice. Power sitting with clinicians
P2	They're paying attention to what they're doing. They're not distracted. I think even if you can't know because of communication, cos we work with people with English as a second language a lot so it's not the same but it's a communication barrier and I think their distractibility and the level of attention they're giving sometimes tells you a lot, a lot of nonverbal. You can tell, can't you, sort of	Attention. Distractability. "You can tell, can't you, sort of" Complexity of engagement - you can tell, sort of … *Mirrors another participant – "there's a lot more I could say about it"*	Working with. Making judgements. Appraising. Taking messages from what people are doing/saying. Clinician as reader into behaviour	Ongoing process of reading people but clinicians don't seem entirely sure of what exactly it is (the x-factor) that they're reading	Behaviours and actions are valued and seem to impact on how clinicians think and act. What seems to be less valued is what is going on behind this behaviour, why it comes about.
P3	Initiation as well I think	Initiation of activities *So far, this feels like a shopping list of what the engaged patient looks like = tick, tick, tick …*			

The fourth reading focused on the broader context surrounding the participant and the others (L. M. Brown & Gilligan, 1992; Mauthner & Doucet, 1998). Examples of contexts included the rehabilitation context, patient-provider discourses, professions and health care structures. I listened for how these might have impacted on how the participant perceived the situation and acted within it.

Constructing i-poems

I-poems are a core part of a Voice Centred Relational analysis (Gilligan et al., 2005). Using personal pronouns 'I', 'we', 'me', 'my' and 'they', I selected data-rich sections of the transcript to explore how people spoke of themselves (Gilligan et al., 2005; Mauthner & Doucet, 1998). Some i-poems are 'composite i-poems', combining statements from several practitioners, used with transcripts from focus group interviews, while the example below is taken from one participant:

> You can have all the tools in your bag
> You might be the best therapist technically
> If you can't build that rapport with your patients
> You might as well have nothing
> I felt like it's more your relationships with your patient that's useful
> More useful than actually what you know and what you do

Constructing a written narrative

After completing the Listening Guide with each participant, I incorporated the analysis into a written narrative, as suggested by Gilligan and colleagues (2005). Initially, data and analysis from the first reading (in particular the broad story in the data) were constructed into narrative form. This was then supplemented by data and analysis from

each consecutive reading. Each reading was coded to help demonstrate the different aspects of engagement that emerged from each individual reading[12],[13].

> **Initial questions about engagement saw the participants focus on the behavioural aspects of engagement, specifically the patient's engagement and resulting behaviours. Engaged patients are seen as active participants** in the drivers' seat[2]_despite their impairments[18] **rather than passive recipients[10], who don't "take the easy route"[10] of simply receiving therapy in a passive way.** That those who are more passive may be seen to take the easy route is of interest[10]. (FB: Could this suggest that the active, compliant patient is privileged and preferable to work with?) Patients were positioned within the system, subject to its influence although engaged patients were said to be making the system work for them[2]. *While active participation was considered a crucial aspect of engagement, therapists still held the power as active participation was often considered as complying with therapy recommendations[5]. Valuing compliance and adherence reinforces the role of therapist as expert, that the power sits with the clinician[13].* **There was a strong emphasis on, almost urgency for "doing" therapy, doing the tasks, going through the motions[40], thinking positively[C40], even if patients did not feel like it.**

As the narrative developed, it was reorganised, resulting in different themes being constructed in response to the on-going analysis. The written narrative served as a 'case study' of each participant (Mauthner & Doucet, 1998).

Analytic questioning and diagramming

Analytic questions and diagrams were used to extend understandings of each participant's experience and conceptualisations of engagement. These first involved asking analytic questions of the data (Morse, 2000; Weaver & Morse, 2006), similar to the approach used in the conceptual review (see page 18). It involved interrogating the data with researcher-generated questions. These questions (shown in Table 11 on page 102) were informed by the conceptual review, the theoretical framework and the emergent analysis from the Listening Guide. The diagrams incorporated analysis from

[12] Within this thesis, different fonts are used to signify the different readings
[13] Reading one (reading for the story) is in bold. Reading one (my response) is in brackets. Reading two (reading for the self) is in italics. Reading three (reading for the other) is in grey.

the Listening Guide, narratives and analytic questioning, providing a visual summary of the data and analysis to date.

Table 11: Analytic questions guiding diagram construction

	Patients	Practitioners
Questions for all data	How did the person define or speak of engagement? Did they describe a process of engagement? If so, what did this process involve? Did they speak about disengagement? If so, how?	
Questions for specific populations	▪ How did patients speak of the practitioner's role in engagement? ▪ How did they speak about their own role, not just in engagement but also in rehabilitation? ▪ How did they talk about the presence of the communication difficulty? Did they consider it impacted on engagement? ▪ How did they talk about rehabilitation in general?	▪ How did practitioners speak of the patient's role? ▪ How did practitioners speak of learning about engagement? ▪ How did practitioners talk of engaging people with communication difficulties? ▪ What roles did they describe for themselves and for patients? ▪ What was spoken of and not spoken of? What appeared to be taken for granted? ▪ What tensions were evident in their data?

Labelling participant voices

The voices of participants are central to the Voice Centred Relational Approach (L. M. Brown et al., 1991; L. M. Brown & Gilligan, 1991, 1993; Gilligan et al., 2005; Hamer, 1999). After completing the analytic techniques already outlined, I returned to the Listening Guide, narrative and i-poems, asking "what voices are evident in the data?". These were labelled and memos summarising the 'voices' were developed. One example of a brief memo is provided:

> **In control, doing the work**
>
> The 'in control' therapist was one who valued their knowledge, the expertise that they brought to the encounter and the feeling of knowing what they were doing, comfortable with the rehabilitation process. This could appear as the 'technical' voice, focused on 'doing the work' of rehabilitation. Engagement was viewed as the patient doing and participating, following the rehabilitation process, showing engagement as the clinician expected them to show it. When patients failed to do so, this could result in the therapist using their knowledge and skills to 'move' and 'shift' them to where they needed to be. If this did not happen, it could result in the patient being discharged and sometimes 'dismissed' from the

therapist's mind. The clinician was somewhat engaged because they had the knowledge and process in mind. There was frequent use of "I", much of the talk was about what the clinician thought, prioritised and did.

Analysing data: Within participant groups

Following individual analysis, I synthesised findings within participant groups (i.e. people experiencing communication disability, and rehabilitation practitioners) to explore similarities and differences. This synthesis process centred on the voices and conceptualisations of engagement. Once these analyses had been completed, they were extracted into different forms to facilitate analysis, such as tables (see Table 12 for an example), and written narratives incorporating data from all participants.

Table 12: Comparing voices across participants: An example

Characteristics of the voice	
Voice	In control with a purpose (a "technical" therapy voice)
Values	Doing the work Sharing knowledge Fixing, finding solutions
How they speak of themselves	More engaged if seeing patient from the start Expert knowledge "I" dominant, clinician led
How they speak of the patient	Patient easier to engage if therapist feels in control
How they view engagement	Judge engagement as they expect to see it, through patient behaviours Following the process – goal-setting, therapy tasks. Potentially less focus on engagement, more on doing, complying. Those who don't engage as expected – more likely to be discharged/dismissed
How they work	"Normal" way of working – challenging to work outside it. Get help from experts "shifting" patient expectations to align with therapist perspective Gatekeeper to services – disengaged are discharged Focus on *what* they're doing rather than *how* they're doing it

Exploring voices within participant groups

Initially, all 'labelled' voices were placed on paper, then were organised into groups of similar voices. For example, with the practitioner data, the voice I described as 'mindful' was grouped with 'reflective' while 'deliverer' was grouped with 'fixer'. Grouping voices was an iterative process involving constant comparison (Charmaz, 2014), moving between analysis and transcripts (raw data) to explore characteristics of different voices and to ensure groupings reflected the characteristics in the original data. Once voices were grouped, more structured, detailed consideration occurred. Each voice was defined and associated with aspects such as:

- values that appeared to relate to the voice;
- meanings of engagement inherent within each voice, as evidenced in how they described engagement and in how they described their engagement-related actions;
- how participants viewed their own role and the roles of others in engagement
- how they acted in response to their interpretations of others' actions; and
- how they interpreted and acted in response to contextual factors.

Analysing data: Across participant groups

The final stage in the structured data analysis process involved bringing together the analysis from both participant groups – people experiencing communication disability and rehabilitation practitioners. The different conceptualisations of engagement held by people experiencing communication disability were 'mapped' onto the conceptualisations held by rehabilitation providers, showing areas of similarity and difference. Each of these was then explored in more detail, returning to the original transcripts and analysis tools (as detailed on pages 97 to 102) to consider each of these in more detail and further refine analysis, as appropriate. I focused on how the people experiencing communication disability spoke of practitioners, and vice versa, the

interaction between them, and the different voices that underpinned these views of engagement.

Ethical considerations

Ethical approval was gained from the University and National Health Ethics committees (see Appendix F). As detailed in the Methodology chapter, ethics was informed by Tracy's (2010, 2013) three forms of ethics – procedural, situational and relational. *Procedural ethics* of particular relevance to this research included gaining informed consent and confidentiality. The *informed consent* process was outlined on page 93. Participation was voluntary. Potential participants were invited to contact me directly. In the case of the key informants, after my initial approach, I did not contact them again, leaving it to them to contact me. To maintain *confidentiality*, material was securely stored, only accessible by myself, my supervisors or a transcriptionist who had completed a confidentiality agreement. Potentially identifying information was modified, including changing service details and personal characteristics. Limited demographic information is provided to prevent deductive disclosure (Kaiser, 2009). Some details have been modified (where this modification did not alter data interpretation) in order to maintain confidentiality.

Situational and relational ethics considered respectfulness to participants and to what they shared. For example, data from practitioner participants could, if taken out of context, be interpreted negatively (for example, descriptions of delaying care to people with particular conditions). I considered this a relational ethical issue. When considering this data and dissemination, I used several strategies. I considered the context surrounding the participant, asking why something might be said, not just *what* was said to help ensure data were understood within the context. I also asked myself "what if this particular participant read/heard what I was saying about them and what

they said?", a situation that actually occurred several times as I presented emergent findings to professional groups throughout the course of the research. I also considered whether presentation of particular data were necessary.

Quality

Quality considerations were guided by Tracy's (2010, 2013) writing on qualitative research quality as outlined in the Methodology chapter. Key quality issues within this study related to Tracy's domains of 'rich rigour, 'sincerity', and 'credibility'. *Rich rigour* was obtained by collecting data from multiple participants from different perspectives (i.e. rehabilitation practitioners and people experiencing communication disability) and using a range of theoretically informed analytic techniques as described in this chapter with constant reference to the data throughout analysis and writing. *Sincerity* was partly facilitated through the Listening Guide which requires researcher reflexivity. This helped me attend to my role in constructing knowledge. I regularly used memoing and supervision to reflect on on-going analysis. Finally *credibility,* reflecting dependability and trustworthiness of both the research process and findings, was achieved through offering a second interview to participants experiencing communication disability to check interpretation of data, thick description, situating data within context, exploring data from a range of perspectives and demonstrating poly-vocality, These have been highlighted as facilitating credibility and is consistent with the research framework (Edwards, 2012; Gergen & Gergen, 2007; Mauthner & Doucet, 1998). Member reflections were sought through presentations and discussions with different stakeholder groups, where their feedback on emergent analysis was sought. Crystallisation occurred by constructing data with multiple participants from multiple perspectives, conducting analyses using multiple yet coherent analytic tools, and presenting findings in a range of ways to facilitate reflection and understandings of engagement (Ellingson, 2009; Richardson, 2000).

Conclusion

This chapter outlined how this study of conceptualisations of engagement was conducted from the research question through to data analysis. While the Listening Guide is the central analytic tool for the Voice Centred Relational Method, there is little explicit guidance of how to advance analysis beyond using the Listening Guide. This chapter provided a comprehensive description of the analysis process. As demonstrated, analysis within and across participant groups was enhanced with a variety of analytic tools. These facilitated crystallisation, opening up different ways of viewing engagement. They also prompted attention to action and meaning-making, understanding how and why people understand engagement and how and why they act as they do. In the next chapter, I present the findings of this study, outlining the different ways in which people experiencing communication disability and rehabilitation practitioners conceptualised engagement.

Chapter Six: Findings

Conceptualisations of Engagement

This chapter explicates the findings of the first empirical study of this doctoral research which was undertaken to better understand how engagement was conceptualised in this specific population. It explored the perspectives of people with stroke experiencing communication disability and rehabilitation practitioners. Engagement was conceptualised as a process and as an action (see Figure 7).

Figure 7: Conceptualisations of engagement

The practitioner's actions and ways of working were central within the *process* of engagement. Within the *act* of engagement, the patient's actions were emphasised. The *process* of engagement appeared to involve three elements: developing interpersonal relationships, involving patients in rehabilitation, and working in a personalised way. The *act* of engagement was evident in patient actions such as complying, participating and taking charge of the rehabilitation process. The practitioner's role within these

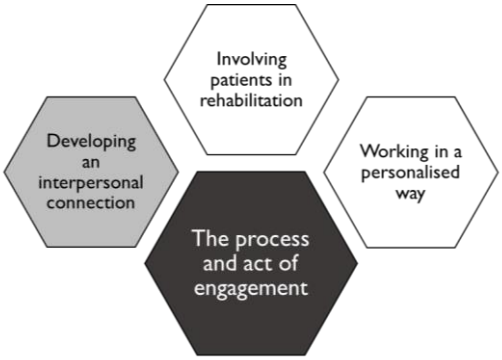
actions was less apparent. These findings both support and extend the existing engagement literature, shedding light on different understandings and components of engagement, identifying how these informed patient and practitioner action.

Within this chapter, I integrate data from people experiencing communication disability and rehabilitation practitioners. Quotes from practitioners are presented with a pseudonym and their workplace context (inpatient or community setting) while quotes from people experiencing communication disability are presented with a pseudonym. Brief information about each patient participant was provided on page 94.

Engagement as a process: Foregrounding the practitioner

The rehabilitation practitioner's actions appeared pivotal in the process of engagement. The specific actions were: developing an interpersonal relationship, involving the patient in rehabilitation; and working in a personalised way.

Developing an interpersonal relationship



Engagement was commonly developed through the patient-practitioner relationship. This was a reciprocal relationship with each person's actions impacting on the other, and on the patient's engagement. It was led by the practitioner, whose actions could convey the message that they valued relationship and that they encouraged the patient to relate with them on a personal level. Raewyn, a woman with chronic non-fluent aphasia talked of her practitioners showing an interest in her personally through actions such as kissing her on the cheek in greeting and being

"lovely" toward her. She also talked of how engagement was about more than just the practitioner though:

Felicity:	*Is it something they do or is it something you do?*
Husband:	They demonstrate and they assist you and you do it by yourself
Raewyn:	Yeah (hesitant tone)
Felicity:	*It's a bit more than that though, isn't it?*
Raewyn:	(points to self) yeah
Felicity:	*You're pointing to yourself. Is that because it's something inside you?*
Raewyn:	Yeah yeah
Felicity:	*So it's something you bring?*
Raewyn:	Yeah (emphatic tone)
Felicity:	*So is it a combination of what they bring in terms of setting up therapy and what you bring*
Raewyn:	Yeah

Viewing engagement as something that happened between the patient and practitioner, influenced by what they both brought to the encounter was echoed by Adele:

> Engagement is something that happens between us. It's not just something that's coming from the patient. It's a process between [us]. (Adele. Community practitioner)

Relational work, the process of developing an interpersonal relationship, was one component of the rehabilitation process. A community practitioner said: "I feel like it's more your relationship with your patient that's useful than actually what you know and what you do … [the relationship] is the cornerstone of therapy." This view was shared by many experiencing communication disability, who described relational skills to be as important as their technical, disciplinary-based knowledge and skills. When discussing this relational approach to engagement, participants gave primacy to the practitioner's role in developing the interpersonal relationship, attending to how their way of working promoted engagement.

The patient's perceptions of the practitioner's attitude toward them was important in forming an interpersonal relationship. People experiencing communication disability commented: "they come in and they know me", and "it's about the patient, not about how they do things". The practitioner's attitudes appeared particularly important when the patient was struggling to engage:

> It's the therapists' attitude and skills that helped me through and persistent [pause]. Them being persistent and their attitude that 'we can do it'. And and eye contact that made me feel like they were really caring. They care about me. Not just in it for the job but they're in it for me, going the extra mile. (Greta)

Greta's comment "they care about me" indicated she perceived the practitioner was interested in her as an *individual,* not just 'another patient'. This facilitated a sense of connection which she identified as helping her engage, enabling her to persist with and come to enjoy her rehabilitation. While perceptions of practitioner attitudes appeared important, *what* the practitioner did to develop relationship and facilitate engagement was often challenging for participants to describe.

Listening appeared to be one action crucial in developing a relationship:

> Listening to what is important to them, to understand her and her stories. Sometimes the stories are more what people don't say than what they say … I'd read between the lines and read the unspoken words. There's a lot of things people don't say that you need to be attuned to (Kate, community practitioner)

When working with people experiencing communication disability, listening could require significant time and effort from the rehabilitation practitioner. This did not always occur, with some practitioners suggesting it was an extraordinary way of working. It required them to value communication, considering it important: "believing they can [communicate], that they have something to contribute ... and to make that overtly obvious to the patient" (Manawa, community practitioner). Listening in the context of developing relationship and engagement involved close attention to the

person's words, reading the person, working out what they might need, considering what was and was not said, identifying how best to match communication styles and considering how best to relate to them. This demonstrates the complex, nuanced nature of communication when it was for the purposes of developing relationship.

Practitioners who emphasised relational work within their practice invested time and effort in developing relationship. They had a reflexive approach to practice. They saw themselves as an active 'ingredient' in engagement, believing their way of working influenced engagement as shown in an i-poem from Margaret's interview[14]:

> We developed quite a strong relationship quite quickly
> We found a connection, that connectivity
> We just started sharing each other's stories
> We found points of interest
> "Where is there a similarity between us"
>
> I'd ask questions to explore the topics more
> Narrative type questions
> My responses would open up her, the feelings aspect of it
> It was really important that we got a good rapport
> That she felt engaged
> We needed to springboard into a relationship so she could get the most out of it
> (I-poem. Margaret, community practitioner)

Within this i-poem, Margaret explicitly linked interpersonal relationship with patient engagement, describing this relationship as a therapeutic tool. This connection was echoed by Manawa, a Māori practitioner who talked of trying to develop relationship with a Māori patient: "I thought I'd try this relationship building, very deliberately this time which is a bit of an experiment … I'll introduce myself giving my pepeha[15]". Other practitioners working in this way reflected on their actions, considering how these might be interpreted and how they might "create an environment where you have that

[14] As detailed in the Methods chapter (see page 98), i-poems are constructed by the researcher, using participant data, and are centred around the pronouns they use to speak of themselves and others.
[15] Pepeha is a Māori term referring to a way of introducing yourself by talking about where you came from in terms of the land and genealogy.

[engaging] relationship" (Catherine, community practitioner). Triadic reflection, reflecting on the patient, themselves and the therapeutic environment, was a hallmark of practitioners who foregrounded relational work.

These practitioners considered relational work a legitimate rehabilitation intervention. In one focus group, a practitioner described her work with a patient who had been labelled non-compliant by the referring practitioner:

> I think she didn't want me to come in when I knocked on her door. I made the decision to not do our normal assessment, just to listen to her and that's when [her] whole [illness] belief system came up and I believe if I hadn't done that … I wouldn't have picked up on that … once she relaxed about all of that, she was better able to engage (Adele, community practitioner)

Prioritising the patient's social and emotional needs over the service's requirements or the technical work of rehabilitation saw relational work positioned as a legitimate therapeutic intervention because of its foundational role in engagement. What led some practitioners to view relational work as legitimate rehabilitation work was not clearly apparent in interviews, but appeared to reflect a philosophy of practice which saw interpersonal relationship as central in engagement.

Relationship and connection were problematic for some practitioners. While they stated it was important, these practitioners also described a simultaneous process of trying to maintain a distance from the patient:

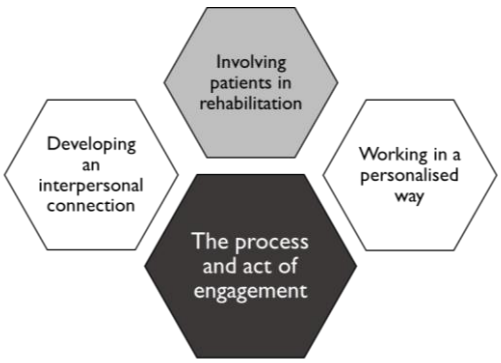
> It's ok for us to share a little bit of ourselves
> You've got to be really careful and keep that professional [hat] on
> Us as a team are quite focused on self-management
> Making sure they don't become too dependent on us
> We want them to engage in rehab and not necessarily in us
> Not those really intense connections with us
> (Composite I-poem. Community practitioners)

Some practitioners emphasised the relationship or connection should be with the rehabilitation *programme* instead of the rehabilitation *practitioner.* This was primarily

evident in interviews with community-based practitioners, perhaps reflecting their role as the final rehabilitation service available to stroke patients; many prioritised self-management and patient autonomy. This could suggest clinical and professional contexts influenced views of engagement and engaging processes. This will be discussed in detail on page 127. As well as suggesting there is a risk of so-called over-engagement and dependency, practitioners expressed concerns about losing objectivity and being "emotionally involved", something one community-based practitioner considered "unhealthy". While they stated relationship was important, they sought a balance between relationship and professional distance, fostering a relationship primarily with the rehabilitation *programme* not the *practitioner*, while attempting to manage issues of objectivity and dependency.

Involving patients in rehabilitation

Interviewer:	*How would I engage you in rehabilitation? What's the trick?*
Geoff:	With me, talk to me as if you know what you're talking about and as if you really want to know what I think.



Being involved in the rehabilitation process helped people experiencing communication disability engage in rehabilitation. It required practitioners address areas meaningful to the patient by eliciting and responding to their perspectives. It also required that the person experiencing communication disability was able to understand what was happening. Communication was central to involving

the patient in rehabilitation. Because patients had communication impairments, involvement could be problematic if communication was not supported.

Identifying what was meaningful

Identifying what was meaningful to patients was one component of involving people in rehabilitation. Patients considered this important for setting the direction of therapy; it also helped them feel they were part of the rehabilitation process. Communication and conversation were crucial for finding out what was meaningful as illustrated in John's comment: "it was important that they talked to me because they found out the next level that I wanted to work on". The process of talking about what was meaningful, and also sensing the practitioner was responsive to this appeared important. Perceiving their "views were understood and I [was] not left behind" as Greta described, reportedly facilitated engagement. While practitioners consistently stated that working on what was meaningful was important, the primary purpose for some was less about creating a sense of being involved, as prioritised by the patients, but more about stimulating a response, "getting the best out of [the patient]" as Mark, an inpatient practitioner described. In this way, identifying what was meaningful was a strategic tool used in an attempt to facilitate patient action. Such practitioners consistently emphasised the importance of patient compliance and participation in rehabilitation, considering this facilitated "re-engagement with life" as one described. In contrast, other practitioners spoke of first addressing the patient's priorities, even if they did not share these priorities, as a way of engaging the patient in rehabilitation. They considered this responsive way of working helped develop a relationship so the patient would then allow them to address the areas the practitioner considered important. Clearly, identifying and working on what was meaningful to the individual could be done for many reasons. However, it appears important to note that patients and practitioners may have different and potentially competing reasons for wanting the

patient to be involved, with patients wanting a sense of inclusion in what was happening, while some practitioners appeared to involve the patient to foster patient achievement and outcomes.

When identifying what was meaningful, the process of listening, gathering information and incorporating this into rehabilitation needed to be overt, readily apparent to the person experiencing communication disability. It appeared this did not consistently happen in practice. Manawa, a community practitioner mentioned "talking around goals" while other community-based therapists used more indirect means of inferring what was meaningful, "drawing on cues" such as photographs in the person's home as indicators of the patient's interests. This implicit, practitioner-driven approach to identifying patient priorities could be problematic, with Caitlyn, a community practitioner describing a patient "who for the first few months wasn't engaging in therapy at all … I didn't realise his complete and utter love of computers and it wasn't till I found that out that he got a lot more enthusiastic about things". It may be that a lack of direct conversation about what was meaningful and of interest to the person experiencing communication disability meant engagement was challenging.

Communicating: Understanding and being understood

When seeking to identify what was meaningful, the presence of communication impairments presented unique challenges for patients and practitioners. Matthew, who had a marked non-fluent aphasia said:

> I couldn't speak anything
> I couldn't even speak
> I couldn't anything
> I didn't have much of a say
> I didn't know what I was talking about
> If I don't [pause] begin my [speech] therapy, I don't talk
> [I couldn't] tell the doctors [what I needed to tell them]
> (I-poem. Matthew)

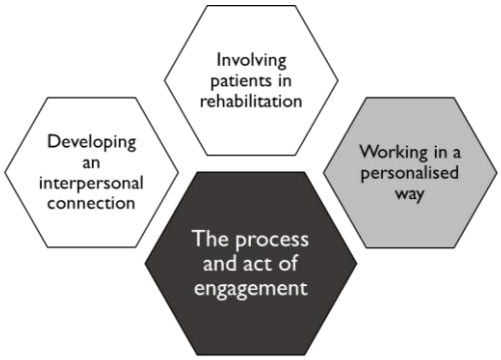
As a result, he considered he didn't have as much of a say in his rehabilitation as he wished, an experience shared by all participants with moderate and severe expressive communication impairments, with consequences for engagement. David believed "if I didn't have a problem with English [referring to his non-fluent aphasia], [engaging in rehabilitation] wouldn't have been so hard". Matthew and David's experiences contrasted with Raewyn's positive experiences of supportive staff, describing her most engaging practitioners as those who sought and understood "mine /pɜ:sept/ [perspective]". The practitioner's communicative behaviours, communicative success, patient involvement and subsequent engagement may be entwined.

Along with being able to express themselves, people experiencing communication disability talked of needing to understand what was happening. However, the very presence of a communication disability meant understanding was often difficult. John described his comprehension difficulties as his "biggest issue", saying "I couldn't understand what was actually happening". This meant not understanding rehabilitation planning discussions or family meetings, meaning discharge was unexpected. He considered family meetings were run by practitioners, where practitioners conveyed their perspectives and their plans. He described it as "that meeting where they have a discussion about your future". The use of personal pronouns "they" and "your" suggested practitioners were positioned, or perhaps positioned themselves as decision-makers, and he was positioned as present but not part of the meeting and the decision-making that occurred within it. This illustrates how communication difficulties may exacerbate the likelihood people have a passive role in rehabilitation.

Being involved in rehabilitation, understanding what was happening and being understood by practitioners, saw the patient depend on the practitioner to support their communication. However, this appeared to be done inconsistently. Some practitioners (across *all* professional disciplines) were perceived to not foster

communication, for example, by talking with family members or not seeking patient perspectives. Some people experiencing communication disability considered staff did not have sufficient time, while other participants (both patients and practitioners) considered it an attitudinal issue: "[communication] is seen as too much hard work" (Manawa, community practitioner). This appeared linked to professional confidence. If practitioners perceived communication might not be successful, some might avoid communication rather than risk "failing" (Manawa, community practitioner). However, some practitioners, often those who prioritised relationship, emphasised the importance of taking time to communicate and demonstrating interest in the patient. They suggested this signified commitment, care and respect, showing that they valued the patient and their input. It appeared that the practitioner's communication could facilitate, or could potentially limit patient involvement in rehabilitation, impacting on their engagement.

Working in a personalised way



Working in a personalised way, matching the practitioner's way of working with the patient's needs of the practitioner, required the practitioner to identify how best to work, thinking critically about who and how they needed to be at any particular time. This represented a reflective, individualised way of working. While most practitioners considered this way of working important, only a few were able to articulate their practice in detail.

Working in a way that matched the patient's needs saw practitioners bring together their relational *and* technical, disciplinary-based skills, emphasising different skills at

different times in different contexts. Some practitioners perceived patients required evidence of both skills in order to trust in the practitioner, considering this facilitated engagement:

> Trusting from a technical perspective that you know what you're talking about, that you have experience … but also trust that you are going to do the best for them and that you're doing to them also as a person – trusting that it's a mutual thing (Catherine, inpatient practitioner)

The need for the practitioner to bring together yet selectively emphasise relational and technical, disciplinary-based skills was echoed by people experiencing communication disability. Geoff described the need for "professionalism" and "semi-professionalism", concepts equated with technical skills and relational skills respectively which he described as "they're the vital part, coming from here [pointing to his heart]". These skills were commonly prioritised by people experiencing communication disability, reflected in comments such as "she's my best trainer. Not the most knowledgeable but she's the best trainer ... probably because she is a, she's more in touch with me, more in touch". In contrast, several patients emphasised technical skills and gave little, if any reference to relational skills. This suggests practitioners need to match ways of working with the patient's needs in order to best facilitate engagement.

Working in a personalised way to facilitate engagement could see practitioners perform a metaphorical dance, as in Catherine's description of the process:

> I would say I'm a gentle pusher
> I'm giving people the choice as well you know
> It is kind of cajoling them along
> It depends on the patient
> On this patient I can use sense of humour
> I'm also aware that he gets frustrated very quickly
> If I do things that are too easy he gets annoyed
> If it's too challenging then he gets annoyed because he can't do it
> I think that he feels inadequate
> I have to pitch it quite right and that's sometimes hard

It's a bit of a shuffle
You're constantly recalibrating
What can you get away with
You're adjusting as you go
(I-poem. Catherine, community practitioner)

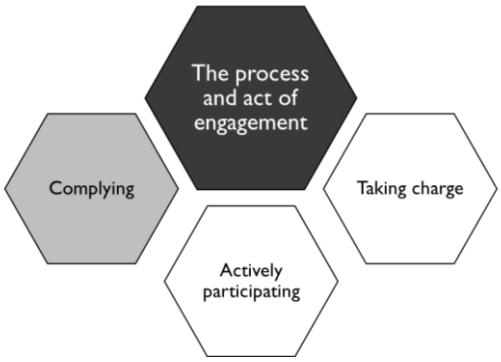
Complexity is inherent within Catherine's description. This way of working was a personalised approach to practice which involved an on-going process of reflection on herself and her patient, her way of working and how this might be interpreted and acted on by the patient. It highlights the process of facilitating engagement could be on-going and ever-changing on the part of both parties in the interaction. Responding to the patient's preferred style of working could be challenging, particularly when it required the practitioner to work in a way that was contrary to their values, for example, by being task-focused rather than using their preferred "exploratory narrative approach" as Margaret, a community practitioner, described. This close attention to their own practice, considering and modifying their own way of working was only evident in several of the experienced, highly reflective and relationally-oriented practitioners, suggesting it may be an advanced way of working.

It appeared challenging for many practitioners to reflect on how they identified how best to work with any one patient. This limited reflection suggests that engagement commonly appeared to be a sub-conscious process involving implicit interpretation of the patient's actions: "you get to know fairly quickly how you are going to act with that person … you give them what they need because you've read the signs" (Adele, community practitioner). However, what practitioners attended to and how they interpreted these "signs" was often unspoken with practitioners unable to offer further information when prompted. This suggests that identifying how best to work with the patient in order to facilitate engagement is an implicit and complex process.

Engagement as action: Foregrounding the patient

The second way engagement was conceptualised was as a patient action. This focuses on the behaviours of the person experiencing communication disability, and in particular, their participation in the therapeutic activities of rehabilitation. When conceptualising engagement as an action, the patient's actions are emphasised and the practitioner's actions less obvious or not considered in either practitioner or patient data. Engagement was considered to be enacted in three ways: complying, actively participating and taking charge. These different forms of engagement appeared to sit on a continuum with actively participating and taking charge being seen as the desired, or sometimes *required* form of engagement. Enacting engagement appeared to come easily for some patients, while for others it followed a sometimes lengthy process of becoming engaged.

Complying: Doing what you're told



Compliance involved patients doing as they were told, putting in effort and persisting when this was difficult. This was commonly the minimum practitioners expected of patients; it was also the minimum patients expected of themselves and other patients. Those who did not comply were viewed negatively: "they [the patients who were "dripping and whinging and carrying on"] are just not trying, they don't want to be part of the group" (John).

Compliance could be long lasting, or it could reflect that the patient was tolerating rehabilitation while coming to a point of feeling engaged. Greta described several weeks of attending and complying with rehabilitation:

> Going there, I thought:
> I wonder what's going to happen?
> Am I doing the right thing?
> Is it the right place to go?
> After the first few visits I felt really welcome and comf-comfortable,
> I just blended in and went along with the programme
> Sometimes I think 'I've already done this, why am I doing it again'
> I know being there is reinforcement and repetition
> I have to realise that
> (I-poem. Greta)

Greta described struggling to cognitively and emotionally engage, however her attendance and compliance kept her within the rehabilitation process and programme while she became engaged. This process was facilitated through the practitioner's actions and through a sense of achievement:

> After going through three, two or three times I caught the vision
> [I] felt "oh this is really helping me, I'm glad we're doing this"
> I was involved
> The good thing was I knew exactly who these people were
> I was involved cos they understood my views, I wasn't left behind
> It's the therapists' attitudes, positive attitude
> 'We can do this'
> The therapist and their listening
> Their flexibility in being able to work with me
> Even if I wasn't quite feeling there
> They had the ability to change it
> It was hard work but at the end, I felt a huge, I was invigorated
> I just got excited
> After that, I wanted to give them a big hug
> I can do this
> I can keep going now
> (I-poem. Greta)

It appeared that compliance, or as one person experiencing communication disability said, "going through the motions", was not 'engagement' in and of itself, but in fact, could be one stage in the process of becoming engaged.

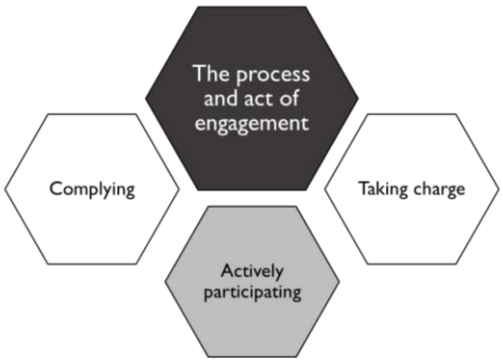
It was not uncommon for rehabilitation practitioners to conflate engagement with compliance, with some descriptions of engagement focusing solely on complying with instructions and completing therapeutic activities. These practitioners paid little

attention to the *process* of engagement, or to whether the patient was cognitively and emotionally engaged. One inpatient practitioner spoke of the importance of doing rehabilitation even when the patient did not want to participate: "[people] can't wait till they get better till they do rehab, they have to do it now ... this is a really good time to be working on this even if you feel crap all of the time". Another described "enforced engagement … they would bring [the patient] down so she'd be sitting here and the only way she could get away was if we did some therapy". The view that patients must comply was shared by a number of people experiencing communication disability who considered compliance was their responsibility, that they had to "push through", as David said. When engagement and compliance were viewed synonymously, the patient appeared to be given the responsibility for their engagement.

When practitioners considered compliance was synonymous with engagement, there was little attention to their own role in facilitating engagement. At times, this saw them deflect any responsibility. Eloise (an inpatient practitioner) described a "disengaged patient" saying "I'm really busy and I can't waste an hour trying to get someone out of bed each time". When practitioners did reflect on their role, their reflections did not represent the complex interpersonal process of engagement described earlier in this chapter. They often considered that educating the patient would prompt compliance and engagement, "helping them understand why you think they should be engaged and why you think it's important from your perspective … because you have expertise in that area" (Mel, inpatient practitioner). They emphasised the specialist knowledge they held, taking a directorial approach to rehabilitation. This approach may have emerged through professional socialisation in pre-qualifying training. Several practitioners suggested student training and assessment may emphasise *doing* and *knowing* rather than *being* and *connecting*, the latter more closely related with the process of engagement described earlier in the chapter. This socialisation could lead to a perception that practitioners are teachers and holders of expert technical knowledge,

and may contribute to some practitioners emphasising patient action (compliance and participation) as core components of engagement. Practitioner expertise was also discussed by people experiencing communication disability. Several described practitioners as holders of specialist knowledge, emphasising the knowledge and power differential between the two parties: "they [rehabilitation practitioners] had the power. They knew what was going on so I just went along with whatever they said" (John). Conceptualising engagement as compliance saw both parties emphasise patient action, considering this the bare minimum expected from the patient. If a patient was "non-compliant", they were also often considered "disengaged" which could result in discharge. It is apparent the different understandings and values around compliance, action and engagement could have implications for a patient's rehabilitation.

Actively participating in rehabilitation



Active participation in rehabilitation involved patient action *and* an internal state of engagement. The latter was key in distinguishing compliance from active participation. The internal state of engagement was characterised by a desire to progress, being "eager for input" (David) and being cognitively occupied in tasks. Rehabilitation practitioners described engaged patients as being "committed" (Kate, inpatient practitioner), "working together with a shared goal" and showing "their heart's in it" (Manawa, community practitioner). Similar language was used by people experiencing communication disability, terms such as "commitment" (Peter) and "flow" (Greta). Active participation involved both physical *and* cognitive action.

Active participation appeared to come easily when patients perceived they were progressing in areas important to them. This was evident in one description of physiotherapy: "Physiotherapy [unintelligible] I couldn't do a thing [points to leg] I couldn't do a thing. They gave me tips [of what to do]. Walking, it made me feel good … It's great, great" (Matthew). Significant enjoyment and satisfaction were evident within his non-verbal expression, his tone of voice, repetition and emphasis of 'great' and his facial expression. It appeared easier for patients to participate, to apply effort and to enjoy rehabilitation when working on what was meaningful, areas such as dressing, texting their partner or using the computer. When this connection was not apparent, engagement was more challenging. Greta said: "I think if if I feel like it's going to be helpful to me, I engage and if it doesn't, I don't engage as well. I try to push through but it's harder". This latter scenario could see the patient perhaps "go through the motions", complying but not investing significant energy or effort in the activity. Participation was facilitated when the practitioner offered information to help the patient understand how activities connected with what was meaningful to the patient.

Rehabilitation practitioners also discussed active participation in conjunction with working on what was meaningful, but more commonly, referred to patient goals, using 'goals' synonymously with 'what was meaningful'. Structured, specific goals were required by services they worked within and were highly valued by individual practitioners, one of whom said she would continue to set goals even if it was not mandated as they gave direction to rehabilitation. Goals appeared to function as a measure of engagement, as indicated by Lesley (community practitioner):

> I think if someone's engaged, you're going to have an active rehab goal and be working strategically toward that and therefore you're going to be keeping them in therapy because you're working toward the goal. If I've tried to set goals with someone and they've said 'oh I want to be able to talk again' and we've talked around 'can you be more specific, who do you want to talk to, in what context, is there any other forms of communication we can use', all that stuff and we

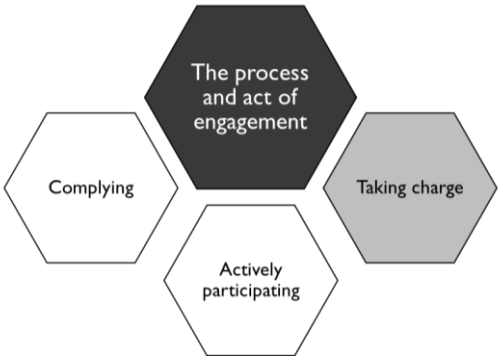
> still haven't come up with any environment in which they'd like to be able to talk, any person they'd like to be able to talk to, just this non-specific thing, we start to go well what are we going to do with you … if we don't have goals, we're just wasting our time because we're not really worked toward anything in particular.

Goals informed on-going decisions about rehabilitation. Lesley's comments suggested she privileged goals which were consistent with her perception of what a goal involved, in particular, specificity which allowed her to monitor progress. While working on what was meaningful appeared important to all parties, practitioners emphasised goals with specific, clearly defined objectives, while people experiencing communication disability emphasised addressing broad areas or activities that were personally meaningful.

Practitioners who valued active participation reported their engagement was enhanced when they perceived their patients were engaged, i.e. were actively participating in rehabilitation. "You engage more when they're engaging" said one community practitioner, who then went on to say "I don't like to say that but it's true", suggesting it was a tacit aspect of care which contained a number of tensions. Similarly, other practitioners said "it's also easier for us to engage with them because you can see they're keen and they want to be there". In contrast, when they perceived the patient as disengaged or not participating, practitioners described feeling inadequate and could then be prone to disengagement themselves. This highlights the co-constructed nature of engagement. Each person's engagement was influenced by their perceptions of the other's engagement, and more fundamentally, by how they constructed engagement.

Patient taking charge

The patient taking charge of rehabilitation was one way practitioners conceptualised engagement. Inpatient and community practitioners described engaged patients:



> They're proactive
> They know what they want
> They tell the nurse 'I've got a session at this time, you have to help me get dressed'
> They're making sure the system works in their favour
> They are more likely to do any home practice you set for them
> They comment on what they're doing
> That shows me they're thinking about what they're doing
> They'll tweak what you gave them
> They're paying attention to what they're doing
> They're not distracted
> It's easier for us to engage with them because you can see they're keen and they want to be there
> They're in a place where they can engage with you
> They're an active participant not a passive participant
> It's easy to be a passive participant
> (Composite i-poem. Focus group)

Practitioners focused on patient actions (as evidenced through the pronoun 'they') and assumed attitudes. However, the practitioner appeared to be a silent party in this process, perhaps reflecting an unspoken assumption that the patient was responsible for engagement. There was little reflection on their own role beyond prescribing activities and feeling engaged because the patient appeared engaged.

Engaging by 'taking charge', particularly in community settings, was perhaps seen as the ideal because patients were close to discharge. The practitioner's focus was on self-management, the patient managing their own recovery. When focusing on self-management, practitioners appeared to simultaneously distance themselves from the patient, with one saying "we want them to engage in rehab and not necessarily in us …

[we] are quite focused on self-management, in making sure they don't become too dependent on us" (Peta, community practitioner). The consequence of ascribing responsibility to the patient was that there was no consideration of *how* patients became able to take charge, or of the practitioner's role in that process.

Two participants experiencing communication disability emphasised agency and assertiveness when discussing engagement. This reflected a 'taking charge' approach. These men considered they were responsible for their own success:

> I felt I was in control of my destiny
> Even from day one I felt they wouldn't help me
> If they said they couldn't help, I would have gone to someone else
> I would have tried to find out from someone else
> (I-poem. Peter)

Peter considered he was responsible for his rehabilitation and recovery. He and John had backgrounds in the military and sports management, areas where personal responsibility and discipline dominated. This possibly influenced how they viewed engagement. Peter and John were also the participants with the mildest communication impairments which may have made it easier for them to 'take charge', as taking charge appeared to involve communication, assertiveness and information-seeking: "I asked questions a lot … so that might have alerted them to the fact I was certainly interested in my rehabilitation and not just doing it because they wanted to" (Peter). Yet these actions can be challenging in the context of communication disability, raising questions about whether people experiencing communication disability might be perceived as disengaged if unable to demonstrate engagement in the way practitioners expect.

While some practitioners valued 'taking charge', patients indicated their attempts to do so could be restricted by healthcare practitioners. These restrictions were evident in descriptions of inpatient settings where multiple discourses were in play, including those of risk, of acceptable behaviour and of independence. Actions such as showering

without first being assessed by an occupational therapist or going to the local shops with friends resulted in reprimands for breaching unspoken rehabilitation rules which were centred on risk management:

> [I got] a bollocking from the nurses when I was there because I went out with one of my mates. We ended up at [name of shops] and they said (tapping on table) 'no, no, you are not allowed to do that'. I went 'why?' I said 'I was just out with my mate and we just looked at the shops and we were allowed to get out and about' and they said 'you might fall over'. (John)

John's example highlights tensions between risk discourses, perhaps more common in inpatient settings where safety is a core concern, and rehabilitation discourses in which independence is encouraged, although so is compliance. The setting may be significant. In a community setting, taking initiative may be desirable, associated with "getting back into life" which one community-based practitioner considered a marker of engagement. 'Taking charge' may be valued differently in different contexts, or perhaps which *forms* of 'taking charge' are accepted may vary across contexts.

Summary and conclusion

This chapter has highlighted that engagement was conceptualised in two core ways: as a process facilitated by the rehabilitation practitioner, and as a state and behaviour evident in patient action. The process of engagement functioned as a way of working on the part of the practitioner. Practitioners appeared to intentionally work in particular ways in order to facilitate engagement. Their actions, and the patient's interpretations and responses to these appeared crucial in facilitating engagement, and appeared particularly important when the patient was struggling to engage. The practitioner's actions however, were informed by their own values, skills and attitudes, and by the systems in which they worked, making the process of facilitating engagement an involved, multi-layered and often hidden process. In demonstrating that engagement

was a practitioner action as much as it was a patient action, and in making some of the tensions explicit, this study has opened up new understandings of engagement. The central role of the practitioner contrasts with much of the engagement literature. In fact, no studies have explicitly explored the practitioner's role and action in engagement. It is therefore appropriate and in fact necessary to attend to the practitioner's role in more detail in order to enhance understandings of engagement, and to support practitioners to reflect on practice. An observational study was anticipated to allow for more in-depth investigation of some of the tensions inherent within engagement, and might provide insight into how practitioners managed the different tensions within engagement. The next two chapters will detail the second empirical study of this doctoral research which explored how rehabilitation practitioners engaged people experiencing communication disability.

Chapter Seven: Methods

An empirical, observational study

The second empirical study of this doctoral research considered the process of engagement, and focused particularly on how the rehabilitation practitioner engaged the person experiencing communication disability in rehabilitation. The intention of the study was to develop understandings of engagement practices, ways of working undertaken to facilitate engagement. Observational methods were used to develop rich, nuanced descriptions of practice which might support rehabilitation practitioners to reflect on how they do, or could work. Within this chapter, I detail the research methods, demonstrating how the Voice Centred Relational Approach underpinned, and was enacted throughout this study of engagement practice. I also provide information about the participants and the data collected given these details provide context for the description of the iterative process of data collection and analysis.

Research aim

The purpose of this study was to develop understandings of how rehabilitation practitioners engaged people experiencing communication disability in stroke rehabilitation.

Overview of study design

This research explored the engagement practices of 28 rehabilitation practitioners by studying their interactions with three people experiencing communication disability throughout four separate episodes of rehabilitation, each lasting between two and 14 weeks. Details of participants are on page 140. The study design was informed by the Voice Centred Relational Approach detailed in Chapter Four, together with the

conceptual review (Chapter Two) and the first interview-based empirical study (Chapter Six). The key principles from the Voice Centred Relational Approach were applied at each of the 'decision junctures' within the research (Koro-Ljundberg et al., 2009), as illustrated in Figure 8 on page 133.

This study was based in 'real life situations' of rehabilitation services where both interpersonal interactions and individual meaning-making could be explored (Charon, 2010). Data were gathered through observations, interviews and stimulated recall interviews which helped develop understandings of rehabilitation practitioner's engagement practices, how these came to be and how they impacted on patient engagement. These data gathering approaches enabled direct examination of the participants' worlds (Blumer, 1969), and comprehensive understandings of individual perspectives (Charon, 2010). Data analysis was iterative and was centred on the Listening Guide as described by Mauthner and Doucet (1998) and Gilligan and colleagues (2005). Research ethics and quality were underpinned by Tracy's (2010, 2013) guidelines.

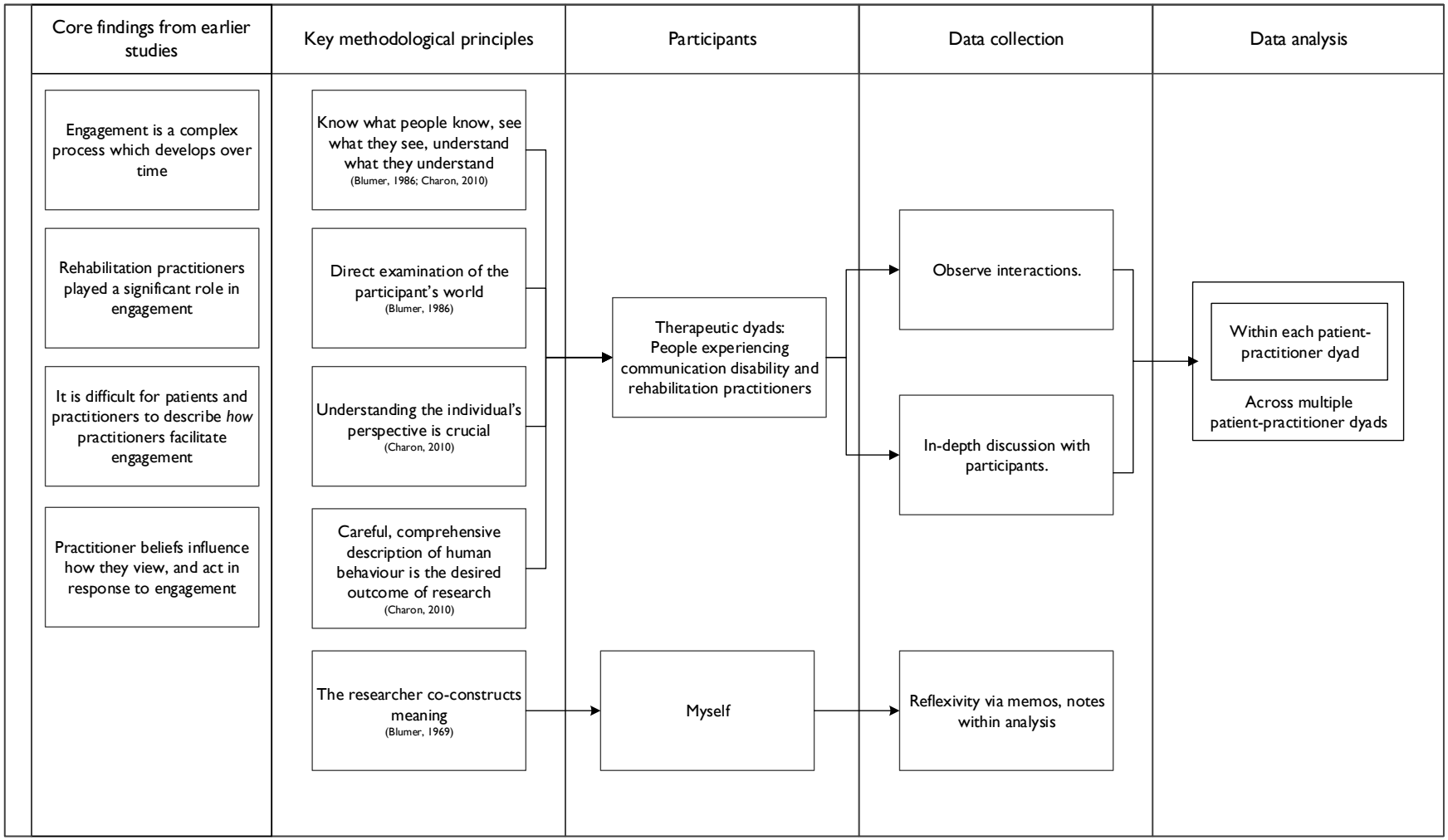


Figure 8: How earlier research and methodological framework influenced study design

Entering the field: Developing relationships with participants

When designing this study, a number of stakeholders were consulted to ensure it was methodologically robust, feasible and respectful toward potential participants. These included potential localities, Māori advisors and people experiencing communication disability. The key discussion points are summarised in Table 13 below.

Table 13: Summary of consultation process

Form of consultation	Issues raised
Consultation in localities	Recruitment: ▪ Feasibility of staff and patient recruitment ▪ Recruitment processes Service processes: ▪ Patient transfer between services Ethical issues: ▪ Privacy for non-participants ▪ Disclosure in event of harm ▪ Dissemination and participant confidentiality
Consultation with Māori	Whanaungatanga: ▪ Importance of relationship when entering the field and while conducting observations Support for participants: ▪ Process of obtaining informed consent to both initially participate in research, and in ensuring *ongoing* consent throughout data collection
Consultation with people with communication difficulties	Research burden: ▪ Negotiating research burden with participants Family/whanau participant: ▪ Linking with family and whanau through consent and data collection processes

I met with several potential localities, talking with managers and senior practitioners to discuss the proposed study and to gain feedback on both the design and the acceptability and feasibility of implementing in their localities. A meeting was held with the Matauranga Māori committee at AUT University which discussed issues to consider when working with Māori participants; many of these were relevant to all participants regardless of ethnicity. I spoke with several people living with aphasia who I knew

through my professional networks and sought their feedback regarding the study design, and in particular, the recruitment and observation processes. Consultation helped develop relationships with staff and management in potential recruiting localities. Stakeholder feedback resulted in the research protocol being refined in response to situational ethical concerns (Tracy, 2010, 2013). The primary modifications made were:

- re-considering the researcher role, changing from mostly silent passive observer to prioritising relationship development before and during the research process;
- meeting staff at the final recruiting locality prior to starting the study to ensure they understood the study and to discuss any challenges they foresaw might arise throughout the research; and
- specifying a process for ensuring privacy for non-participants, and for disclosing any harmful activities observed.

Relationships were also important in the early stages of conducting research. I focused on building relationship with participants both before the consent process, and throughout the research. This involved meeting with participants several times prior to completing the consent process, ensuring I spent some time attending to our relationship during data collection by spending time talking with them and their families outside periods of data collection, and sharing some information about myself. I considered the relationships helped create a relational research environment which might facilitate communication and understanding of people's experiences (Jankowski et al., 2000; Latimer, 2000; Morrow, 2005).

Locality of the research

This research occurred within a public regional rehabilitation service in an urban area in New Zealand. The service offered rehabilitation for people aged 16 and over in inpatient and community settings. Patients commonly were discharged from the

inpatient service directly into the care of the community service. The community service offered both short-term intensive rehabilitation (on average, a two week episode of care) and longer-term, less intensive rehabilitation (on average, patients had an eight-to-ten week episode of care).

Recruitment

People experiencing communication disability (also referred to as 'patient participants') were recruited in acute wards and inpatient rehabilitation units. Treating speech-language therapists initially approached eligible patients to discuss the study, seeking consent to provide their details to the researcher, after which I made an appointment to come and meet with the patient and their family. The speech-language therapist was the liaison between myself, the patient and the family until we met face-to-face. Participants experiencing communication disability were offered the opportunity to involve their significant other/s in research, supporting them during data collection. While the significant other's role was primarily to support communication, they were considered a participant in their own right. Only one patient wanted family involved; others reported not wanting to burden their family members and/or stated that their family were rarely present during rehabilitation. Rehabilitation practitioners were approached after the patient participant had consented. 'Rehabilitation practitioner' was defined as any staff member providing clinical care to a patient, such as a healthcare assistant, allied health practitioner, nurse or doctor. All staff were aware of the study as a result of the earlier consultation process (see page 134) and had had the opportunity to opt-out from this approach.

Sampling

Initial sampling of patient participants was purposive, while convenience sampling was utilised for practitioner participants (Thorne, 2008). I sought variation and diversity in participants, while also seeking specific characteristics informed by the literature review and the previous qualitative study. Specific characteristics sought in participants experiencing communication disability were: severity of communication difficulty, ethnicity and diversity in rehabilitation service used. The rationales for these are provided in Table 14.

Table 14: Sampling participants experiencing communication disability

Characteristics	Justification
Severity of communication impairment	Engagement may be more challenging when the person has a severe communication impairment
Ethnicity	Māori have higher stroke rates (Stroke Foundation of New Zealand, 2010) and inequalities in access to services; engagement may be one factor in service access (Curtis, Harwood, & Riddell, 2007).
Rehabilitation service	Practitioners working in different rehabilitation settings may conceptualise engagement differently. Patients may experience different engagement challenges in different clinical contexts.

In recruiting rehabilitation practitioners, convenience sampling was initially used (Thorne, 2008). Sampling criteria were derived from existing literature and research, and from emergent analysis. Initially, all practitioners were approached and all those who volunteered to participate in the study were included. As the study progressed, purposive sampling was used, sampling for professional discipline, experience and models of care as detailed in Table 15.

Table 15: Sampling rehabilitation practitioner participants

Characteristics	Justification
Specific disciplines	Exploring disciplines which appeared to have particular approaches to, or challenges in engaging patients. For example, nursing rosters frequently changed meaning they had intermittent interaction with the patient across their length of stay; speech-language therapists considered supported communication was essential in engagement; occupational therapists reported valuing engaging through doing.
Years of experience	Several participants indicated engagement skills may be influenced by clinical experience.
Models of care (e.g. consultative approach or low frequency interaction)	Different models of care (in particular the frequency of interaction and associated interpersonal relationship) appeared important factors in the engagement process.

Inclusion/exclusion criteria

People experiencing communication disability were eligible if they were:

- over 18 years of age;
- accessing rehabilitation in designated rehabilitation services;
- able to communicate with the researcher with the use of supported communication or interpreter;
- living at a home (i.e. not in residential care) in the catchment area of the specific rehabilitation services involved in the research at the time of the stroke, and if they were anticipated to return to this location (inpatients) or were residing in this home during their episode of community rehabilitation;
- able to discuss their experiences of services with support if required; and
- had four or more practitioners participating in the research (inpatients) or two or more practitioners participating (community) consent to take part in this research.

Rehabilitation practitioners were eligible if they were working with a patient participant.

Informed consent

Verbal and written information about the study was provided before written consent was sought. Copies of the participant information sheets are provided in Appendix G. Supported conversation techniques facilitated the consent process as detailed in Chapter Five (see page 93) (Kagan, 1998; Kagan & Kimelman, 1995). Practitioners had received information about the study prior to being approached as part of the early consultation process; this information was reviewed before consent was sought. Copies of the written consent forms are provided in Appendix H.

Participant characteristics

In total, 33 people participated in the research: three people experiencing communication disability, two family/whānau members of one participant, and 28 rehabilitation practitioners participated. One person experiencing communication disability participated twice, once as an inpatient and once within a community rehabilitation service. The latter was treated as a separate episode of rehabilitation and so this study incorporated data from participants in four rehabilitation episodes, two inpatient episodes and two community episodes. The OHW speech, language and cognitive communicative scales (O'Halloran et al., 2009) were used to describe the severity of communication impairment. Participant characteristics are summarised in Table 16 and Table 17. Throughout the thesis, 'dyad' refers to each patient-participant pair, of which there were 28.

Table 16: Characteristics of people experiencing communication disability[16]

	Betty	**Ryan**	**Betty**	**Arthur**
Type of communication impairment	Aphasia	Aphasia; apraxia of speech	Aphasia	Cognitive-communication impairment; dysarthria
Severity at start of rehabilitation	Moderate	Severe	Mild	Severe (speech) Moderate (CCI)
Severity at end of rehabilitation	Mild	Moderate	Mild	Severe (speech) Moderate (CCI)
Time post-stroke at start of research	<2 weeks	2 weeks	6 weeks	16 weeks
Rehabilitation service	Inpatient	Inpatient	Community	Community
Ethnicity	NZ European	NZ European	NZ European	Cook Island Māori
Age	>65 years	45-65 years	>65 years	45-65 years
Length of care	2 weeks	3 months	3 months	2 weeks
Number of dyads participating	8	12	4	4
Family participating	0	2	0	0

Table 17: Characteristics of rehabilitation practitioners

Participant characteristics		
Clinical experience	<5 years	13
	>5 years	15
Profession	Speech-language therapists	5
	Occupational therapists	5
	Physiotherapist	4
	Doctors	4
	Nurses	7
	Rehabilitation or healthcare assistants	3
Workplace	Inpatient	20
	Outpatient/Community	8

[16] Betty is referred to twice. The first column refers to her inpatient episode of rehabilitation. The second column refers to her community rehabilitation.

Gathering data with participants

Participant observation, stimulated recall, and informal and formal interviews with both parties were used to explore how rehabilitation practitioners engaged people experiencing communication disability in stroke rehabilitation. These methods were informed by the literature and the earlier interview-based empirical study (Chapter Six) as summarised in Table 18.

Table 18: Data gathering methods and rationales

Principles of data gathering	Rationale for data gathering approach
Multiple methods of data gathering may reduce communicative burden	Presence of communication impairment presents challenges in describing engagement process *Source: Study one findings*
Collecting perceptions close to time of interaction may best capture interpretation of events	Nature of retrospective recall may mean recollections differ from perceptions at the time *Source: Literature (Kirkevold, 2002)*
Observing interactions may allow for detailed description of practice Multiple data gathering methods may support participants to describe/reflect on engagement Need to collect detailed data over course of rehabilitation episode	Difficult for all participants to detail process of engagement *Source: Study one findings*
Observing interactions and using stimulated recall may support practitioners to describe/reflect on their practice	Practitioner self-report may reflect a desire to present events in a particular light, recall issues and/or lack of conscious awareness because practice is habitualised *Source: Literature (Mays & Pope, 1995; Wottrich, Stenstrom, Engardt, Tham, & Koch, 2004)*

Combining different approaches to data gathering facilitated crystallisation (see page 86), and allowed close consideration of how people acted, how they constructed meaning and how they acted in relationship with others (Blumer, 1969; Charon, 2010; Mauthner & Doucet, 1998; Tronto, 1995). Each method is discussed in detail below. Table 19 provides details of types and amount of data collected.

Table 19: Data gathering types and amount

	Observations	Stimulated recall	Informal interviews	Formal interviews
Number	160	5	93	15
Hours	147	6.5	27	20

Observations

Observing interactions allowed for examination and detailed description of actions. The data collected from observations also enabled consideration of how participants constructed meaning within interactions, what behaviours they attended to and acted on, what roles they took and what actions accomplished (Blumer, 1969; Charon, 2010). The observations enabled a focus on the relational aspects of engagement, in particular, relationships between participants within each dyad, and between participants and their context (Doucet, 1998; Doucet & Mauthner, 2002; Mauthner & Doucet, 1998, 2003). Observing people within their real-life situations gave some insight into the social and cultural frameworks surrounding and influencing them (Gilligan et al., 2005; Mauthner & Doucet, 1998).

Participant observations formed the largest dataset for this study, with 160 individual periods of observation throughout the course of the research. An average of 5 observations were completed with each dyad (range 1-17). While I intended to observe at least two interactions between each dyad, this was not possible with seven of the 28 due to the schedules of the patient, practitioner and/or myself, or because there was only one interaction between the patient and practitioner (e.g. Betty was discharged from physiotherapy after one visit).

Time and purposive sampling determined which interactions were selected for observation. Time sampling involved observing interactions over a specified time period (Croll, 2004) to allow for exposure to a broad range of interactions between the

person experiencing communication disability and many practitioners. In the *inpatient services*, three four-to-six hour observational periods were completed within the first week; in *community services*, 75% of interactions between each dyad were observed over the first two weeks of rehabilitation. These observations provided insight into who the patient interacted with, in what ways and about what. On-going sampling was informed by these observations together with the informal interviews. This sampling involved purposefully selected events to be observed, for example, formal scheduled interactions such as ward round, planned therapy sessions, informal interactions such as those that occurred in the corridor, or nursing cares. Some interactions were sampled to facilitate detailed exploration and inspection of common interactions or practices, while others were sampled because they were considered 'surprising' (Emerson, Fretz, & Shaw, 2011; Tracy, 2013). Examples included dyads in which both parties expressed a significant change in engagement (from highly engaged to disengaged, and vice versa), dyads where both parties reported being highly engaged, and dyads who had irregular contact and inconsistent engagement.

Initial interactions between each dyad were observed and audio-recorded. Most purposefully-sampled interactions were video-recorded, allowing for analysis of verbal and non-verbal behaviours. These recordings were also used for stimulated recall interviews (see page 144). Regardless of whether videoing occurred, fieldnotes were recorded during and/or after observations, capturing non-verbal and contextual data. Following many observations, individual participants were asked about their perception of the interaction, their own engagement, their perception of the other person's engagement; and the impact of my presence. While these interviews took between five and fifteen minutes, they were not always feasible due to fatigue or the participant's schedule. Following each period of observation and after reviewing the video-recording, fieldnotes were extended to incorporate my reflections on the interactions, key points to consider, future sampling strategies and emergent analysis

(Emerson et al., 2011). Two types of fieldnotes are presented in the Findings chapter: *descriptive* fieldnotes which incorporate verbatim text, a description of actions or events, and my own impressions of the interaction; and *verbatim* fieldnotes which solely present a transcript of the interaction.

While observing interactions, my role was slightly removed, not initiating conversation but responding in a socially and contextually appropriate way (Davidson, Howe, et al., 2008). This reflected that research was a "relational encounter" (Kiegelmann, 2009, p. 6). However, this relationship was balanced by the need to have minimal influence on the interaction and the developing relationship between members of the dyad.

Stimulated recall

Stimulated recall is a method of eliciting the reasoning and thinking that underpinned action (Gass & Mackey, 2000). External stimulus (in this case, videos of interactions between the patient and practitioner) provided the stimulus or reference point for the interview. Stimulated recall interviews allowed for close examination of what patient and practitioner participants perceived as critical in the process of engagement. Eliciting participants' thought processes and feelings using this approach (Coleman & Murphy, 1999; Gass & Mackey, 2000; Saba et al., 2006) provided insight into the objects people attended to, how they interpreted them and how they responded (Blumer, 1969; Charon, 2010; Gilligan et al., 2005; Mauthner & Doucet, 1998; J. O'Brien, 2006). Stimulated recall videos were completed within 48-72 hours of the interaction in order to support recall (Gass & Mackey, 2000).

Each stimulated recall interview focused on a ten minute video of a recent interaction selected using a form of critical incident sampling (Lyle, 2003). Interactions were selected for several reasons: patients and/or practitioners identified the interaction as significant in enhancing or diminishing engagement; the interaction was considered

'typical' for the dyad; or the interaction was perceived to be markedly different to usual sessions, by participants or by myself. The specific ten minute video stimulus was selected for reasons such as: the patient reported struggling to engage, or a time when the practitioner was intentionally working to engage the patient, as identified through previous observations or informal interviews. This video could include two contrasting or distinct moments within the interaction.

Prior to the stimulated recall interview, its purpose was explained. Participants were invited to stop the recording at any point to comment (Gass & Mackey, 2000; Saba et al., 2006). Participants commonly commented on the video as it played although the intention was to show the recording once to orient the participant before repeating it to capture their reflections. I paused the recording at points I wished to explore in detail (e.g. instances which appeared significant in engagement). In three sessions, the first viewing took 60 minutes as the participant commented while viewing the recording (60 minutes was the time allocated for interview), so the second viewing did not occur. Interviews were recorded and transcribed onto a table which captured the events on the recording *and* the data from the stimulated recall session.

Stimulated recall was completed with four rehabilitation practitioners but only one dyad (practitioner *and* patient separately), a total of five stimulated recall interviews. It was intended that at least half of practitioner participants would complete stimulated recall videos, anticipating this might offer rich insights into engagement practices. There were several reasons this did not occur as planned: there was often insufficient time to edit the video of the interaction for use within the stimulated recall interview, and/or, it was not possible to schedule the stimulated recall interview within the recommended 48-72 hours (Gass & Mackey, 2000) given the schedules of all parties involved. Stimulated recall interviews were conducted with only one patient

participant. Two patient participants commonly declined, with one saying they "didn't want to do it". No reason was given for this refusal, and I did not pursue an explanation.

Informal and formal interviews

Interviews explored each participant's experiences and perceptions of engagement, enabling in-depth exploration of knowledge development (Berger & Luckmann, 1990), meaning-making and action (Charon, 2010) and structures influencing rehabilitation (Gergen & Gergen, 2007). These interviews were classified as informal and formal interviews. Informal interviews (n=93) occurred after observed interactions (see page 142 for details of the procedure), or during the research process, such as when sitting with patients in between rehabilitation interactions. The latter conversations explored the patient's broader experiences of engagement in rehabilitation, such as experiences I may not have observed and their broad sense of engagement. These interviews were brief, lasting between 5 and 15 minutes. Notes from the informal interviews were recorded in fieldnotes. Formal interviews (n=15) considered experiences and perceptions of engagement over the course of rehabilitation and occurred after the patient was discharged from the rehabilitation service. These formal interviews were completed with practitioners who were observed four or more times, or those where previous data gathering suggested an interview may assist in developing a more comprehensive understanding of engagement practices. All patient participants were invited to participate in a final interview though two declined this, with one saying (after three months of data gathering): "I think we've covered everything really". Each interview lasted between 30 and 90 minutes. Interviews were audio-recorded (all participants) and video-recorded (patient participants). They were transcribed by myself or a transcriber who had completed a confidentiality agreement. A sample (n=4) from the transcriber were checked for accuracy.

Significant others could participate in informal and formal interviews to support the participant's communication. They themselves were not the subject of the interview (i.e. questions were not directed at them unless I was seeking to clarify the patient participant's meaning). If they offered information within the interview that was not clarifying a participant's statement, or was not expanded by the participant (verbally or non-verbally), it was not considered data and was not analysed.

Demographic information

Gender, ethnicity and age were collected for all participants. Other data collected to enable participant description were:

- Patient participants – date of stroke;
- Family/whanau –relationship with patient participant, and
- Practitioners – profession, year of qualification and number of years working in stroke rehabilitation.

Analysing data

Data analysis was an iterative process. Analysis occurred at different levels: *within* data from each patient-practitioner dyad and *across* all participants. As described in the Methodology chapter (see page 65), the Voice Centred Relational Approach is an analytic framework, offering a flexible, principle-based approach to analysis (Gilligan et al., 2005; Kiegelmann, 2009; Mauthner & Doucet, 1998). Both the Voice Centred Relational Approach and the Listening Guide have been used with relatively small sets of interview-based data. There has been little (if any) research applying this approach in large data sets with multiple data sources. As a result, a number of processes and strategies were trialled prior to commencing the structured analysis process detailed within this chapter.

Overview of analysis process

Prior to conducting analysis, all data from each dyad were collated into one physical file (i.e. all transcripts and fieldnotes of observations, stimulated recall sessions, informal and formal interviews, and any memos written during data collection). Each of the 28 files was considered an individual dataset for analysis. Data analysis occurred in three stages.

1. The first stage focused on the first 12 dyads recruited into the study. The practitioner within each dyad was relatively representative of all dyads by profession and years of experience. It was considered this data would likely provide a robust overview of how practitioners engaged people experiencing communication disability which could then be developed in the next stage of analysis (Tracy, 2013).
2. The second stage focused on a further eight dyads which were theoretically selected in response to the emergent analysis, selected because it was considered they would further extend understandings of ways of working. This was based on my detailed knowledge of all the data, and the emergent informal analysis that occurred in the process of collecting data and writing memos and fieldnotes (Mauthner & Doucet, 1998).
3. The final stage of analysis focused on the remaining eight dyads, from whom there was limited data (most had 1-2 interactions).

Each stage involved a subtly different analysis process as will be outlined below. The question 'how do rehabilitation practitioners engage people experiencing communication disability in stroke rehabilitation?' remained at the forefront of analysis, with close attention paid to the practitioner's actions or ways of working.

Stage one of data analysis: Structured analysis of 12 dyads

This stage of data analysis involved multiple steps. Firstly, four datasets were analysed using the Listening Guide as demonstrated in Figure 9. As this method has been

described in earlier chapters (see pages 81 and 97), within this section it is only briefly summarised, focusing on how it was applied in this current study.

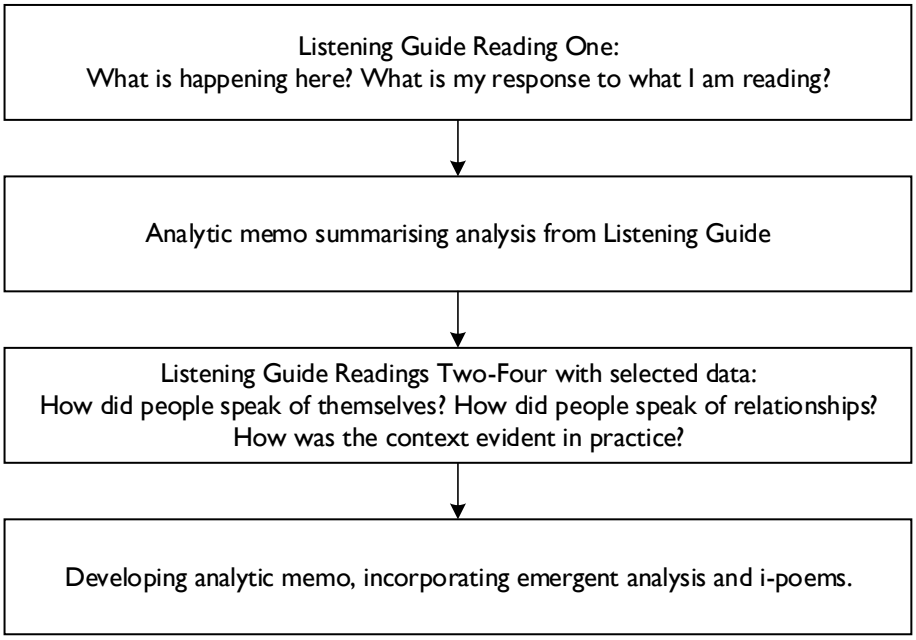


Figure 9: Analysis process for individual datasets

The first reading of the Listening Guide with each dataset was consistent with that detailed in previous chapters, attending to the broad story of 'what is happening here?' and 'what is my response to what I am reading?' (Gilligan et al., 2005; Mauthner & Doucet, 1998). The reading was then summarised into a memo:

> When Betty continues to ask "maybe I can go home", the content of Mike's talk focuses on the rehabilitation process with comments such as "it's part of the deal here I'm afraid", "But we'd like all of the MDT to have a chance to assess you over a period of days and then we'll all meet with the family and the medical team and the disciplines and then we'll try and make a plan" and "we usually like to have a bit more time to assess you before we make definitive decisions". The rehabilitation process dominates, with talk of assessments, meetings and plans.

Memos documented areas such as similarities and differences across the dataset; what practitioners *did* with patients (talk-in-action) and how they talked about what they did (talk-about-action); and practitioner talk and action in different contexts, such as with

the patient, in team meetings or in family meetings. Analysis focused on the practitioner and the patient's response to them and their actions, reflecting the study's overall focus on understanding how rehabilitation practitioners engaged people experiencing communication disability. Memos captured recurring themes, surprising findings and areas for further consideration. They included raw data and contained hyperlinks back to the original dataset, ensuring analysis remained grounded in data.

Following memoing, the remaining readings of the Listening Guide were completed concurrently with selected data (Mauthner & Doucet, 1998). The data were selected for several reasons, including:

- A participant considered an event to be of particular significance;
- Data appeared to offer particular insight into engagement practices;
- There were inconsistent ways of working across the patient's episode of rehabilitation;
- There were a range of data sources for a particular interaction (e.g. observation, patient reflection, practitioner reflection and/or stimulated recall session); or
- There were marked contradictions between talk-in-action and talk-about-action.

The second reading attended to how people spoke about themselves. Within the analysis, attending to body language and tone of voice prompted consideration of how people spoke of themselves in talk and in action. The third reading considered how participants spoke (and didn't speak) of the 'other' and of relationships in both their verbal and non-verbal action. This reading considered who was present and included in interactions, whose opinions appeared to hold weight or who was silenced. The fourth and final reading focused on how contextual factors were evident in, and appeared to influence practitioners' ways of working. This included considering how profession-based and organisational structures and the physical environment were evident in practitioner and patient talk, action and meaning-making. The emergent analysis of

each dataset was collated in a four-column grid, refocusing on the Listening Guide questions:

- What is happening here?
- How do people speak of themselves?
- How do they speak of others and relationship?, and
- How do they speak of the context?

Analyses from the latter three readings were incorporated into the original memo in order to develop analytic thinking as occurred in the first study[17]:

> **When Betty continues to ask "**maybe I can go home**", the content of Mike's talk focuses on the rehabilitation process with comments such as "**it's part of the deal here I'm afraid**", "**But we'd like all of the MDT to have a chance to assess you over a period of days and then we'll all meet with the family and the medical team and the disciplines and then we'll try and make a pla**n" and "w**e usually like to have a bit more time to assess you before we make definitive decisions**".** *In this, Mike positions himself as an empathiser, but not a negotiator (e.g. 'it's part of the deal I'm afraid),* and Betty as someone who is expected to go with the flow. **The rehabilitation process dominates, with talk of assessments, meetings and pans**. THE REHAB PROCESS IS ALMOST AN ENTITY OF ITS OWN. REHABILITATION IS ABOUT ASSESSMENT; WHAT IS NOT CLEAR IS WHAT IS BEING ASSESSED AND WHAT THE BENCHMARK OR TARGET IS – IT ALL FEELS VERY NEBULOUS AND NON-NEGOTIABLE. THE LANGUAGE USED IS THE SYSTEM'S LANGUAGE – THE "MDT"; the patient is relatively silent, especially when Mike talks of the meeting: "we'll all meet with the family and the medical team and the disciplines and then we'll try and make a plan". Is she included in the "we"? It is all about her after all – Betty is positioned as having responsibility for the decision about going home – responsibility in the terms of 'If you keep making progress, it won't be long'. If she wants to go home, she needs to progress. It is interesting to see who is not spoken of – Betty. There is no mention of her as a player other than as a subject of assessment.
>
> If YOU keep making progress, it won't be long
> WE'D like all of the team to assess YOU
> Then WE'LL meet with the family and the medical team and the disciplines
> Then WE'LL make a plan.

I-poems (see page 83) were created to enable more detailed consideration of how participants spoke of themselves and others. Finally, within each memo, I also reflected on the research aims, asking 'how do rehabilitation practitioners engage people

[17] Reading one (reading for the story) is in bold. Reading two (reading for the self) is in italics. Reading three (reading for the other) is in grey. Reading four (reading for the context) is in capitals. Underlined words contain hyperlinks which link to the original transcript. The final lines contain an i-poem; the emphasis was added.

experiencing communication disability in stroke rehabilitation?' summarising how practitioners' worked, how and why they worked as they did and what this accomplished, and started to explore the engagement practices evident within the data. This analytic memo then formed the basis for analysis across participants.

After analysing four datasets, I commenced comparative analysis across participants following the process illustrated in Figure 10.

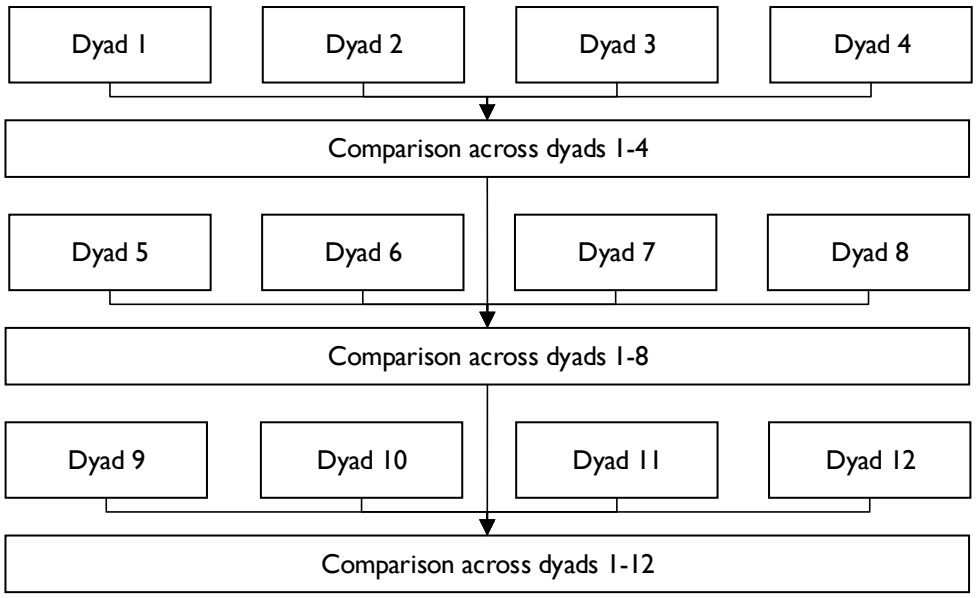


Figure 10: Process of comparative analysis across first 12 datasets

Memoing (Charmaz, 2014; Tracy, 2013) and mind-mapping were central in this process with detailed memos incorporating emergent analysis and raw data. An example of an early memo and mindmap are provided in Appendix I. Analysis continued in an iterative process of constant comparison (Charmaz, 2014), moving between analysing individual participant datasets and comparative analysis between datasets until the first 12 datasets were analysed. While initially four behaviours appeared to be used when practitioners were working to facilitate engagement, over the course of analysis, understandings of how practitioners worked were challenged, developed and modified. This process was supplemented by regular critical reflection with supervisors. The

emergent findings informed sampling decisions, specifically, which participants' data to sample in the next stage of analysis.

Stage two of data analysis: Theoretically sampled participants

The second stage of analysis aimed to further develop and refine the emergent analysis. It was completed with eight theoretically sampled datasets which were selected for several reasons including:

- the practitioner reported intentional conscious attempts to engage the patient, or there was minimal reflection on engagement and their way of working, even when explicitly asked;
- the dyad reported significant challenges in engagement; and
- the practitioner reported having to work in ways inconsistent with their preferred way of working in order to engage the patient.

This stage of the analysis process occurred as detailed for Stage One above, except that the four readings of the Listening Guide were completed concurrently and then integrated into a memo. Comparative analysis continued as detailed in Stage One of data analysis. The twin tools of memoing and constant comparison resulted in increasingly complex, nuanced understandings of how practitioners worked to engage the patient in stroke rehabilitation. Mindmaps were used to visually represent relationships between actions, and between ways of thinking and acting. They arose from memos, fostering constant comparison, and helping refine analysis within later memos. This cyclical, iterative process of mindmapping and memoing advanced and refined thinking throughout the analysis process. Example of mindmaps and memos from early and late in the analysis process are provided in Appendix I.

Stage three of data analysis: Final eight dyads – constant comparison

Data from the final eight dyads were primarily used for constant comparison. In several instances, the dyads had small amounts of data (for instance, one had a three minute interaction between the dyad followed by one ten minute interview with the practitioner). These dyads were often observed during the initial time-sampling period of data collection (see page 142), but did not have on-going interaction (for example, a nurse who was not scheduled to work with the participant between when the initial observation occurred and when the patient was discharged), or an allied health practitioner who only saw the patient once or twice before discharging them, a situation most commonly seen in community rehabilitation.

Datasets were reviewed and brief notes were taken. These focused on the Listening Guide questions of 'what is happening here?', 'how do they speak of themselves?', 'how do they speak of others and of relationships?' and 'how do they speak of the context?'. These summaries were then compared with the analysis completed to that point. While the new data did not identify any new ways of working, most resulted in detail being added to the existing ways of working.

Ethical considerations

This study received ethical approval from the local Regional Ethics Committee and from the AUT University Ethics Committee, and from the recruiting health services. Ethics approvals are attached in Appendix J.

As detailed in the Methodology chapter, Tracy's (2010, 2013) three primary forms of ethics (procedural, situational and relational) formed the ethical framework for this study. *Procedural ethics* of particular relevance were informed consent, privacy and confidentiality. The initial *informed consent* process was detailed on page 139. In

addition to that initial consent process, I considered gaining and retaining consent was a process occurring over time (Dewing, 2007), and was mindful participants likely only understood what the study involved as it occurred. Accordingly, I sought consent for data gathering on a daily basis and regularly discussed each person's continued participation in the study, explicitly providing opportunities for them to withdraw. My concerns for *patient privacy* meant I removed myself from situations which might be considered particularly intrusive, such as personal cares. *Participant confidentiality* was maintained through a number of mechanisms: all transcription was completed by myself or a transcriptionist who had completed a confidentiality agreement, and any information that might identify participants was stored in locked file or stored on a password-protected computer folder.

Situational ethics, ethical concerns specific to the study (Tracy, 2013) centred on confidentiality and conducting observational research in a shared environment with many non-consenting people in that environment. *Participant confidentiality*, both during the research and when disseminating findings, was a primary concern of mine. Dyadic research meant internal confidentiality was critical, not disclosing what one participant said about another or enabling participants to identify each other (Kaiser, 2009; Tolich, 2004). During data gathering, I was conscious of the risk of disclosure. This was a particular concern as I had previously worked with several rehabilitation practitioner participants as a colleague and was conscious it could be easy to fall into conversation about patient participants in this capacity, rather than as a researcher-participant interaction. Strategies to minimise this risk included taking notes when talking to staff to provide a visual reminder of my position as a researcher, and memoing reflections and tensions in the process. Ensuring dyadic confidentiality was essential as it demonstrated to participants that their comments were confidential. Preventing *deductive disclosure* requires all participants maintain both external *and* internal confidentiality when the study findings are published and discussed (Kaiser,

2009; Tolich, 2004). Without care, participant descriptions might identify individual participants, or hint at their identity, leading people to think they know who the participants were. It might also result in one member of a dyad identifying comments the other made about them and their interactions (Kaiser, 2009; Wiles, Crow, Heath, & Charles, 2008). For this reason, limited non-identifying information about the research participants and rehabilitation contexts is provided both within this thesis and when discussing the research in other contexts (e.g. conference presentations). At times, descriptive information has been altered to prevent identification, so long as this did not alter data interpretation.

Another situational ethics concern related to any *unsafe or unethical action* that might be observed. The process agreed with staff and management before commencing the study was that I would first discuss the situation with my supervisors and if collectively we agreed it met the threshold for breaking confidentiality, it would be discussed with the service manager. This issue never arose. Finally, ensuring *privacy of non-participants* was a concern, given much data gathering occurred in shared spaces where non-participants were present. When in shared spaces, nursing staff commonly provided information about why I was present to other patients. I ensured other patients were not visible on recordings; if this was not possible, I took fieldnotes instead. When observing team meetings, participating patients were discussed first; I left the meeting after the discussion. Only data from participating staff was transcribed.

Relational ethics informed the study design from early consultation through to dissemination. My *relationship with participants* was a primary concern. I was mindful the research involved close examination of practitioners' ways of working, as well as close attention to patient experiences at a challenging, vulnerable time in their lives. I worked to develop relationship with all participants, viewing research as a relational

process. This reflected *whanaungatanga*[18], being together in relationship with the participants. Accordingly, there was often a process of getting to know one another in the early stages of the research. Even when data gathering was complete, I considered the relationship was still important when discussing findings, that dissemination should continue to demonstrate relationship toward participants and their experiences. I drew on the same strategies used in the first study (see page 105) such as being mindful toward how the findings might be interpreted, situating findings within the sociocultural location and the broader context of the participants, and attending to *why* people acted as they did, not simply describing their behaviour.

Quality

Tracy's (2010, 2013) approach to quality guided quality considerations as detailed in the Methodology chapter. Rigour, sincerity and credibility were key issues within this study. Collecting multiple forms of data from multiple participants in multiple contexts over a prolonged period of time facilitated *rich rigour*. Data analysis was robust and theoretically informed, and involved prolonged immersion in the data throughout analysis and writing. There was regular discussion about the research process and data analysis with my supervisors. *Sincerity* was facilitated through multiple means. The Listening Guide prompted reflexivity, and required attention to my reaction to data. My thoughts and emotions were captured within fieldnotes and analytic memoing and these were regularly discussed with supervisors. *Credibility* (dependability and trustworthiness) was achieved through thick description, incorporating data into the analysis, considering the contexts surrounding practice and using a variety of data analysis and representation tools. Crystallisation was central in ensuring credibility. Multiple forms of data from multiple sources at multiple time points helped develop a

[18] *Whanaungatanga* is a Māori term meaning "a relationship through shared experiences and working together which provides people with a sense of belonging" (www.maoridictionary.com)

comprehensive, yet partial understanding of the different facets and nuances of engagement practice (Ellingson, 2009; Tracy, 2013). This multi-layered data enabled rich description of practice in the Findings and also enabled production of a multi-layered, multi-vocal text.

Conclusion

This chapter detailed the design and conduct of this observational study of engagement. It provides comprehensive description of the process of data gathering and data analysis. Multiple methods of data gathering facilitated crystallisation, gaining multiple though partial perspectives on the phenomenon of engagement. The data analysis process is a unique process developed in order to operationalise the Voice Centred Relational Approach with a large data corpus, consisting of multiple data types from multiple sources over a prolonged period of time. Within the next chapter, I present the findings of the research, detailing *engagement as a relational practice*, a relational approach to engagement which was evident when practitioners worked intentionally and successfully to engage a person in stroke rehabilitation.

Chapter Eight: Findings

Engagement as a relational practice

Within this chapter, I discuss how rehabilitation practitioners engaged people experiencing communication disability. *Engagement as a relational practice* was a relational approach to engagement which was evident when practitioners worked intentionally and successfully to engage a person in stroke rehabilitation. It involved practitioners weaving together eleven different ways of working and being in order to engage people in rehabilitation. These are depicted in Figure 11. When enacting this practice, practitioners reported they foregrounded engagement within their ways of thinking about and providing rehabilitation. Within early interactions, the practitioner appeared to focus on *getting to know* the patient to identify how best to work with them to engage them in rehabilitation while also *developing a two-way relationship* by getting to know *each other* as people, not just in their defined roles of patient and practitioner. The practitioner focused on *identifying and responding to the patient's priorities*. By *integrating relational and/or technical disciplinary-based work*, practitioners appeared responsive to the specific needs and priorities of the patient. Enacting *engagement as a relational practice* involved *working purposefully and reflexively*. Engagement appeared to be influenced by perceptions of the other person's engagement (or disengagement); each party was involved in *co-constructing each other's engagement.*

Communication between the practitioner and person experiencing communication disability was integral in enacting *engagement as a relational practice*. It involved practitioners *facilitating two-way interaction* between themselves and the patient, *purposefully using particular approaches to communication*, each for different purposes. Within interactions, practitioners were *actively listening to know and understand* the patient and their experiences. It involved them *threading subtle communication*

throughout interactions. Communication was complex in the context of communication disability. Practitioners enacting *engagement as a relational practice* were consistently *responding to the presence of communication disability*, supporting the patient to communicate and participate as much as they could.

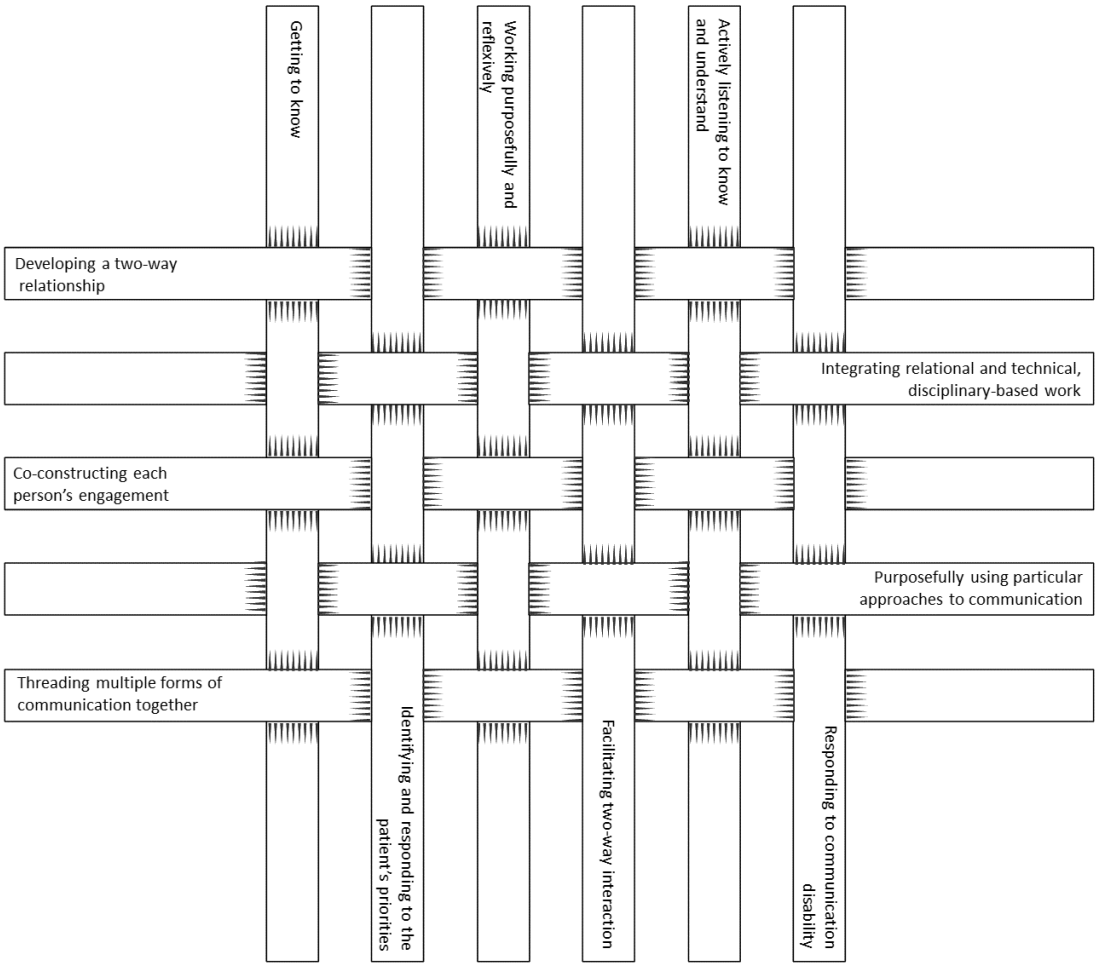


Figure 11: Core components of *engagement as a relational practice*

Within this chapter, I detail each strand of *engagement as a relational practice*, and how *together,* these ways of working comprise a practice. *Engagement as a relational practice* required practitioners to work relationally and intentionally to engage the patient, evidenced in how practitioners *worked* with people experiencing

communication disability (their talk-in-action[19]), and in how they *talked* about engagement and rehabilitation, their role and the patient's role in engagement and rehabilitation (their talk-about-action[20]). Practices which appeared non- or dis-engaging are also discussed given they provide further insight into how and why practitioners worked to engage people experiencing communication disability in stroke rehabilitation.

A relational approach to engagement

> I'm just walking alongside him and the family
> It's a person-centred approach to practice
> Empowering him
> Showing him that I am here to walk
> We're helping with rehab but we shouldn't be calling all the shots
> We shouldn't be telling people what to do anyway
> It's us together not us and them
> We're all on the same page,
> We're not here to have a different perspective to them.
>
> It's making that connection
> It's talking about what matters
> Gradually building rapport
> At the moment he can't tell us
> But letting him know that we know about it and who he is
> We try and have him as part of it
> You're working on what they've established as being important
> They've made clear that toileting is really important
> I'm here to try and help them with strategies
> To get where they want to go is more important
> To get him in a car, one of the key goals
> He's a proud man, it's about helping to give him his dignity back
> That's how I show person-centred care
> It's working alongside, it's not me dictating
> It's what we're working on
> (I-poem from informal interviews, Catherine, inpatient allied health practitioner (AHP))

[19] *Talk-in-action* refers to how the practitioner communicated (verbally or non-verbally) when interacting with the person experiencing communication disability

[20] *Talk-about-action* refers to how the practitioner *spoke* about their practice within interviews outside the 1:1 interaction with the patient. *Talk-about-action* represented the practitioner's reported perceptions of and reasoning about their practice.

Engagement as a relational practice is represented in this i-poem on the previous page. This way of working was comprised of eleven different strands (five of which pertained specifically to communication) and each of these is discussed in detail below.

1. Getting to know: Who are you and how should I work with you?[21]

The first interactions between the patient and practitioner were described as important in developing a relationship. *How* these first interactions occurred, and what practitioners prioritised within them varied across practitioners. These interactions occurred at a time when services required assessments, education and rehabilitation interventions to occur within specified time periods. Practitioners had multiple priorities. When enacting *engagement as a relational practice,* practitioners emphasised getting to know the patient to understand how they needed to work to engage the patient, something evident in their talk-in-action and their talk-about-action. When practitioners emphasised their own needs and the activities mandated by their services, engagement did not appear to be prioritised; it appeared more challenging for each person involved.

When enacting *engagement as a relational practice,* practitioners commenced rehabilitation by gaining an understanding of the person they were working with, developing a sense of who they are and were before their stroke, and their experiences since their stroke. They reflected on the patient's perspectives and experiences:

> I know they've had a really bad experience on the ward and have been really disappointed in the care they've received … This is a tough time for them. (Informal interview, Tim, inpatient AHP)

> I'm also really sympathising. [They are] just so exhausted and I do worry that a lot of things are [them] being exhausted and stressed

[21] The interwoven figure shown in Figure 11 will gradually be developed in a small illustration as each component of *engagement as a relational practice* is discussed

> and quite traumatised by the whole thing … I can see where she's coming from. I'm married and it would be so hard seeing your husband so vulnerable. (Informal interview, Catherine, inpatient AHP)

Practitioners gathered this information through conversation, sitting down with the patient and talking about what was important to them on a daily basis and in their lives. This opened up understandings of the person, their needs and their priorities. Practitioners appeared to take this knowledge and consider 'how do they need me to work with them?', which informed the actions they gave primacy:

> For me, it's really important to give them a positive experience, trying to find something that would leave them with a positive experience. You want them to leave with the feeling that he's done something, got something out of it and that he's enjoyed it. (informal interview, Tim, inpatient AHP)

Early success was considered important in facilitating patient engagement. Tim, an inpatient AHP suggested success helped "get them on board" and accordingly, was a priority in the first days of rehabilitation. He worked purposefully to "try and give him a positive experience … [to] make him feel he'd done something … trying to find something that would leave them with a reasonable experience" (informal interview), facilitating movements and actions that the patient had not been able to do previously. This created trust in the practitioner and their skills. Both the patient and his family suggested this contributed to his engagement:

> Tim just makes you achieve, he helps you do it
> He doesn't push you but helps you through it
> You get that sense of achievement
> (I-poem from informal interview, Ryan)

Practitioners could emphasise technical disciplinary-based action *or* relational work, or, more commonly, blend the two together. Tim described trying to create success in therapy while with the same patient, Catherine talked of developing a relationship by spending time talking with and listening to him and his family. Both practitioners

emphasised the need to establish trust. They suggested trust arose from a combination of patient success within therapy sessions, the patient's perception of their therapeutic knowledge and the presence of a relationship between them. Knowing the patient and understanding how best to work helped practitioners consider how they should work to facilitate engagement in rehabilitation.

A contrasting starting point for rehabilitation evident in the data was 'what do I need to do?' In these instances, the practitioner focused first on what they perceived they needed to do, often allocating little time to get to know the patient or develop a relationship. Relationship appeared to be backgrounded while practitioner-prioritised tasks were foregrounded. Within interviews, practitioners did not describe working intentionally to facilitate a relationship or patient engagement. This practitioner-driven approach commonly reflected what appeared to be habitualised and often mandated patterns of rehabilitation work. This work was centred on assessment, goal-setting and discharge planning. As assessments were required by service protocols, they could dominate initial interactions. The content and structure of assessments influenced what the practitioner knew of the patient. This knowledge was often limited and partial. Knowledge was commonly about facts rather than meaning, current functioning rather than interpretations or experiences. This limited partial knowledge was reflected in an informal interview with two practitioners after an initial assessment session:

> *Felicity:* *What was your priority within that session?*
>
> Practitioners: We wanted to find out information today … [Assessment] takes a lot longer and we're by no means finished. We needed to see her walk and get on and off the toilet. We didn't do those in our safety screen yesterday … We didn't touch on [Betty's needs and wants]. We didn't ask the question of what are the biggest concerns. But I don't think we completed the assessment. We'll get to that tomorrow. (Informal interview, Lorna and Bridget, inpatient AHPs)

When I revisited this session with Lorna three weeks later, asking "Did you have a sense of her priorities?" she said: "No ... That's probably something I failed to look back on." (interview). The practitioner and the service's requirements shaped what was spoken of and what became known. While Lorna and Bridget described the patient's perceptions and priorities as important, these appeared lost or backgrounded while service priorities were foregrounded.

The rehabilitation practitioner's starting point could be a site of tension between their own priorities and preferences and the service's requirements. Assessment was an initial service priority with key performance indicators (KPIs) attached. An early emphasis on getting to know the patient and developing a relationship could result in some assessment-related KPIs not being met. However, practitioners enacting *engagement as a relational practice* justified their focus on relationship, discussing the limitations of the KPIs as well as the benefits of relational ways of working. Tim (inpatient AHP) said of assessments: "We have an assessment form and it has to be filled out within 24 hours and you just end up writing stuff because you can't assess him in one, in five sessions". He described his initial priorities, saying: "The first couple of sessions are really about getting them on your boat, getting them on board", a form of relational work which responded to the patient's need for a positive experience. Understanding the limitations of assessment and surrounding policies *and* having a clear rationale for prioritising other activities helped practitioners justify their decision to focus on getting to know the patient and engaging them in the rehabilitation process. Systems and structures appeared to create tensions which some practitioners were able to work with, while other practitioners appeared to struggle with these tensions and appeared to default to activities reflected in the service KPIs. Practitioners who prioritised relationship in both their talk-in-action and talk-about-action appeared able to work with the tensions.

Some practitioners had co-existing priorities, wanting to work relationally, responding to the patient's needs, while also wanting to complete the tasks they considered important, or perceived needed to be done. This was evident when Anna talked of prioritising both relationship and assessment:

> Building rapport and the therapeutic relationship is what I love the most, it's so important in therapy. This really should be the focus of the first few sessions, but should also be there all the time when working with them. I'm quite chatty and focus on what the patient is saying. This is the priority in my first sessions with a patient.

> Assessment is the most important thing we can do so we can provide strategies. Obviously therapy is important as well but [it] can be carried on at home.
> (Informal interview, Anna, inpatient AHP)

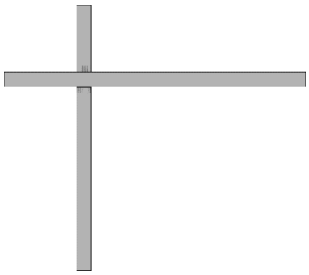
Anna's early intervention focused on assessment. Her patient Betty later commented that she didn't know what Anna was doing with her, perceiving "[Anna] had a brief [of what she had to do]" and "she had lots of forms" but felt "I don't think [she] really listening to me". Betty did not see the value in the interactions which made her reluctant to stay as an inpatient, even when Anna wished for her to stay longer. Anna's internal priorities co-existed alongside and were likely influenced by external service priorities and discourses about what rehabilitation work should be prioritised. She suggested her way of working had been influenced by feedback from the therapists who saw her patients after discharge. Of note is her comment about her own disengagement in response to perceived pressures:

> In the past I have had lots of feedback from the [community team] and there's been boxes that haven't been ticked. So maybe it does become a lot more tick boxy as well. I guess you become more task focused rather than patient focused … When there are time pressures, like for discharge, you can disengage from your role of being therapist, or more disengage from doing therapy. You become

> a bit more matter of fact with a patient and say "ok this is what is happening" (Informal interview, Anna, inpatient AHP)

Anna's co-existing priorities reflected the complexity of clinical practice, with relational work co-existing alongside other priorities. The presence of multiple practice priorities, both those *within* a practitioner and those seemingly placed *on* a practitioner appeared to influence how practitioners worked with the patient, and could result in a focus on 'what do I need to do?' Engagement was recognised as important but in this context, appeared challenging to enact. As discussed above, these tensions were not unique to individual practitioners. However, the tensions did not appear so problematic for those enacting *engagement as a relational practice*. It appeared that the relational frame these practitioners brought to their practice changed how they viewed the complexities, seeing them as something they could work with by enacting a relational approach to care. Their way of working was consistent and congruent with their relational frame.

2. Developing a two-way relationship



Developing a relationship was a two-way process. It involved getting to know the patient and demonstrating a genuine interest in them to help them engage in rehabilitation. Practitioners gave something of themselves so that the patient could get to know them as a person, not 'just' a healthcare practitioner. This gave a "sense of who people [practitioners] are" which Betty, a patient participant, described as important for her engagement. Practitioners perceived the relationship engendered trust in the practitioner, offering a sense of emotional safety. Trust and safety were considered to facilitate engagement. Relational work and the resulting relationship had therapeutic value:

> We've got the relationship. They know me. I don't beat around the bush, I tell them things straight up, but we've got rapport … Once

> you've got that, it opens the door to future conversations - you can ask them, you can follow up more, you can ask different questions (informal interview, Myra, inpatient nurse)

Myra's comments suggested relationship served as a springboard for other aspects of rehabilitation. Because of this, relational work was considered a legitimate form of rehabilitation work, worthy of time and effort.

Relational work appeared particularly important when the patient was struggling to engage. Betty reported feeling "cared for, they care about you", while Ryan said of one allied health practitioner: "they see me as a person first, not just a patient". It seemed that the combination of the practitioner's behaviours and the attitudes the patient perceived underpinned this behaviour, contributed to a sense of relationship and facilitated engagement in the broader rehabilitation process with Ryan saying:

> I hate what I have to do
> I hate needing help
> But if it had to be with anyone, it should be with her
> She always focused on you
> She always says hi
> A person, she treats you like a person
> Not a number
> (I-poem from informal interview, Ryan and Violet[22])

Ryan and Violet's quotes within the i-poem demonstrate how the relationship between the patient and practitioner, and in particular the actions of the practitioner might create a therapeutic environment which supported engagement in rehabilitation.

Some practitioners considered getting to know the patient was sufficient for relationship development:

[22] Violet was Ryan's wife, and consented to participate in the research as a 'significant other'

> I focused on getting to know her
> I spent a lot of time just getting to know her
> What is she interested in
> What she needs from me – like her goals
> (I-poem from informal interview, Kelly, community AHP)

However, developing a relationship in order to facilitate engagement often required the practitioner to do more than this. Most patient participants indicated an engaging relationship was a two-way relationship where they knew (aspects of) the practitioner. Betty, the patient Kelly was referring to in the i-poem above, described their relationship saying "Maybe I'm just an old lady but I like to know what people do and what people are. There's a very defined line between Kelly and me". This made her feel slightly removed from her practitioner. Within rehabilitation, she reported doing what she was told but often considered herself "disengaged". In contrast, when Betty described her engagement with Elise, an allied health practitioner, she commented:

> I like to see her
> I like being with her
> She's given quite a lot of herself
> Given various aspects of herself
> I feel lucky I've got her
> (I-poem from informal interview, Betty)

Having some knowledge of the practitioner appeared important in helping Betty engage. This appeared to be facilitated by Elise's actions and disclosure which partly arose from Elise's sense of connection with Betty, reflecting an iterative, two-way relationship:

> I think I just connected with her in such a way I felt that I could give some of my personal stuff, not a lot … it's not always a lot … They don't always want to just talk about themselves, they like to know about you as well. (Interview, Elise, community AHP)

Developing this two-way relationship did not require detailed disclosures from the practitioner. Instead, giving a little of themselves was evident in subtle comments such as "you're like me, I look at my wife when someone asks me a question" (Tim, inpatient

AHP), "we did some paddle-boarding on the weekend at the staff Christmas do"(Catherine, inpatient AHP) and "I love walking on that beach. I took the kids there when they were little" (Elise, community AHP). By intentionally sharing limited personal information, practitioners positioned themselves as people rather than a disconnected professional which appeared to help build relationship.

The two-way relationship between the patient and practitioner was evident not just in words but through non-verbal communication such as laughter, touch, body position, maintaining eye contact and pausing while the person experiencing communication disability spoke. All these non-verbal acts conveyed a sense of interest in the other, of two people being in relationship together as evident in this interaction between Myra (a nurse) and Betty, who was lying in bed at the time:

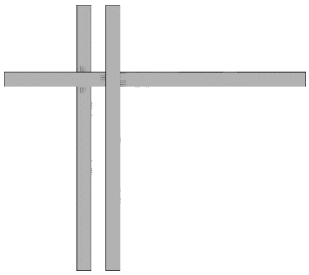
> Myra comes in to do the afternoon observations. Betty and I are talking and she joins in the conversation, saying "they [observations] can wait for a bit". She leans over the bed. She makes continuous eye contact with Betty, making suggestions when she is unable to get the words out, giving positive feedback when she is able to communicate her message. (Descriptive fieldnote)

Communication will be explored further from page 184. It was central to developing a two-way relationship and a key aspect of *engagement as a relational practice*.

3. Identifying and responding to patient priorities

> I love the fact we work on what the patient wants to work on
> And that can be anything
> We work together with [the patient]
> It's not me going in and dictating what to do
> I would have liked to do things in the kitchen but he wasn't keen
> I didn't want to push it
> You can't push it

It's important to ask what's important to him
There's no point pushing it if it's not important
If it's not meaningful to him then there's not point
I wanted to see if he might be interested
You have to make it meaningful for him
(i-poem from informal interview, Xanthe, community AHP)



Seemingly informal conversations were crucial in identifying patient priorities. While many services required practitioners to complete structured goal-setting activities, those who enacted *engagement as a relational practice* appeared to gain an understanding of what was important through conversations during rehabilitation. Catherine, an allied health practitioner often sat with the patient and family to talk about their experiences of rehabilitation and their concerns. Through listening to the patient's concerns about care (such as irregular showers) and comments about his embarrassment at needing assistance with personal cares, she identified early priorities for her work with him:

You're working on what they've established as being important
They've made clear that toileting is really important
I'm here to try and help them with strategies
To get where they want to go is more important
Toileting and showering are things that are important
Ryan's always been very dignified, well-presented
Those are part of him as an individual
He's a proud man, it's about helping to give him his dignity back
(I-poem from informal interview, Catherine, inpatient AHP)

While these priorities were then documented and discussed within the formalised goal-setting process, what appeared consistent within *engagement as a relational practice* was that patient priorities were identified through interaction and relational work, in particular through listening to the patient and getting to know what they needed from the practitioner rather than through the service's formalised goal-setting process.

Structured goal-setting processes were consistently used within rehabilitation services and were often linked to service KPIs. One practitioner considered goal-setting

facilitated engagement, by “helping the patient feel motivated”. The same practitioner also considered it an educational tool that demonstrated person-centricity: “it is helpful in making sure she knows what rehab is for, it’s for her and without her, we won’t be able to do anything”. However, structured, formalised goal setting processes could fail to elicit patient priorities, or could override them. Some patients appeared unaware of the goals that had been set. This reflected that goals were sometimes set by practitioners and then presented to the patient for approval, as was observed with one patient; it could also reflect that the goal-setting process was not understood by the patient. This was evident with one patient, when a practitioner attempted to use a functional activity checklist as a goal-setting tool:

> Kelly says "I'll leave this [functional activity checklist] with you and I’ll ask Elise to help you fill this form out. If you haven't finished it with her, I'll help you with it. If you want to finish it, read through these and fill it out. So if something is important, you have to be able to rate it if you're able or if it's difficult or you're unable and question mark if you're not sure." She writes down the rating scale. "I mean, you don't have to do it without me. Try it, we've only got two goals. If I'm able to help you with more activities that you would be able to do independently then why not?" shrugging as she talks. She starts packing up her materials as she talks. Betty asks "I don't know what do I need, what do I need?" Kelly points to the form and says "mmm, this might give you some ideas. It's up to you, I'll be back. I’ll leave you these, no pressure, just make sure it’s here when Elise or I visit.” (Descriptive fieldnote)

Betty’s confusion was evident in her language and in her puzzled facial expressions, yet this did not appear to be addressed by Kelly. Practitioner statements such as “no pressure” but “make sure it’s here” were in contrast with each other, adding to Betty’s confusion. After this session, Kelly and Betty gave different reflections on the interaction process. Betty commented: “I don't really know what they expect of me”. In contrast, Kelly commented:

> Kelly: It's not always easy goal-setting with someone with communication difficulties but I think the [functional activity checklist] helped her.

Felicity: *Do you think she gets the point of what you're doing?*

Kelly: Um, yeah I kind of do. I don't think I repeated myself, I did explain why we're involved initially but really I can't remember telling her again in the last couple of sessions that I had with her but I think that's something that she probably realised. (Interview)

These statements highlighted the practitioner and patient had different understandings of the goal-setting process, and quite different impressions of how involved the patient felt. In this instance, Kelly appeared to assume the process was meaningful to Betty because of her compliance throughout the assessment, yet Betty's comments suggested she did not understand the process or the purpose – she was tolerating the activity. While goal-setting was *said* to be important in facilitating engagement, this is one example of how it did not achieve engagement.

In contrast with the structured goal-setting process above, *engagement as a relational practice* involved practitioners finding out what was important to the patient then drawing together their knowledge of the patient, the patient's experiences and priorities to plan the rehabilitation programme, matching what they did and how they worked to the patient's needs. This might see an emphasis on technical, disciplinary-based work as with Arthur below, or they may prioritise relational work. Matching ways of working and responding to Arthur's priorities was evident when Helena, a community physiotherapist worked with Arthur:

> After a quick chat about how Arthur has been doing in the last two days, Helena says "let's do some work". She asks Arthur what he'd like to work on, giving him several options – working on his hand, his walking, or stretching. *This gives Arthur a say, albeit in a somewhat controlled way*[23]. Arthur talks about walking with a pole. She comments that he's not quite ready yet. His daughter offers to get a walking stick in – "ok, give us a look" Helena says. "Let's do some walking then we'll have a look at the stick". (Descriptive fieldnote, Helena, community AHP and Arthur)

[23] The use of italics within fieldnotes reflects researcher opinion at the time of writing the fieldnote.

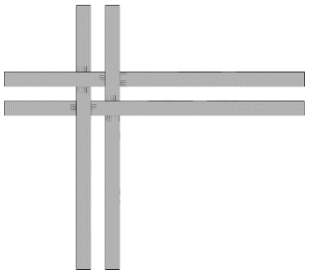
The congruence between Helena's physiotherapy profession and Arthur's focus on walking was thought to help engagement: "He knows I'm the walking person and he really wants to walk and get his arm and leg working and I'm the one who does that so he's happy to engage with me" (informal interview). However, Arthur's focus on physical function presented challenges for Jessica, his speech-language therapist. She talked of being on the "back foot", unable to address walking as this was "outside her remit". She struggled to know how best to engage him in speech-language therapy. Arthur did not identify any specific communication-related goals, although he presented with significant communication issues, including <50% intelligibility in conversation and difficulty communicating with family. In an intentional approach to engagement, Jessica drew together multiple forms of knowledge:

- her knowledge of his priorities, saying "he really just wants to work on his walking";
- her professional knowledge of his impairments, prognosis and the most effective therapeutic approaches, saying "it's hard to know what we'll achieve given he's had four months of intensive therapy already … I know for the most success, we need to have the family"; and
- her previous clinical experience including working with patients who struggled to engage, saying "he needs to have some enjoyment".

Jessica combined these different forms of knowledge with her professional values of relationship, connection and engagement. She intentionally showed interest in him by responding to his comments and drew on his immediate environment (grandchildren and photographs of family) to talk with him about his roles as a father and grandfather. The actions arose from her plan to engage him by adding value, specifically, helping him participate in activities important to him: "I want to be able to have him feel some success. I feel I'm doing something worthwhile, I'm adding value to him". These priorities formed the basis of rehabilitation, incorporated with the intention of facilitating engagement. Had Jessica not worked in this way, addressing what was

important to Arthur and adding value, engagement may have been more problematic. Understanding and responding to patient priorities appeared important when enacting *engagement as a relational practice.* When patient priorities were not readily apparent, adding value appeared to be a useful tool in helping engagement.

4. Integrating relational and technical, disciplinary-based work



Relational work occurred alongside work focused on service requirements and technical, disciplinary-based activities. This integrated approach to rehabilitation appeared to be primarily achieved through an interactive approach to communication. It was commonly evident during physical activities such as having a conversation while completing physiotherapy exercises or a bed bath, or while completing goal-setting or structured assessments. One example of this was captured in a fieldnote from a therapy session:

> After hoisting the patient onto the plinth in the gym and making him comfortable, Tim starts moving the patient's legs as if testing his hip function. Catherine, the occupational therapist initially watches then starts conversation with the patient: "The weather's been lovely, hasn't it". She talks about the events of the weekend: "we swam this weekend – well paddleboarded". She went onto explain it was the work Christmas do which she and the physiotherapists attended. Tim continues to palpate and move the patient's hips, but quietly joins in the conversation talking about where they went and what they did. (Descriptive fieldnote, Tim and Catherine, inpatient AHPs)

Embedding small talk and conversation *throughout* interactions and rehabilitation was one way in which relational work occurred. These helped develop the relationship between the practitioner and person experiencing communication disability.

This integrated practice contrasted with the work of practitioners who appeared to view relationship building as a standalone action which needed to be 'done' rather than being considered a core component of rehabilitation. In these instances, relational

work was discussed as "building rapport", evident in several minutes of chat at the start of interactions, informal talk about the week or talk about what the patient had been doing, before the practitioner marked the change of space with bridging language such as "right well, what we're going to do today is …". Such language indicated a move to doing the work the practitioner had planned for the session. In these interactions, building rapport was a discrete activity, contrasting with *engagement as a relational practice*, where relational work was embedded within and throughout all interactions.

Practitioners who described relationship as important in engagement enacted relational work throughout all their scheduled and unscheduled interactions with patients. They communicated in *some* way, sometimes with only a smile or "hello" regardless of the context in which the two had contact. Within their reflections on practice, they consistently acknowledged the relationship between themselves and their patient. Their interactions presented a seemingly authentic, consistent approach to relational work. In contrast, some who did not prioritise relationship confined relationally-oriented work to defined, scheduled interactions. When they saw the patient outside these contexts, there was little communication from the practitioner. As captured in a fieldnote, the relationship between them appeared absent:

> I am sitting in Betty's room, next to the bed which Betty is lying on. Bridget [inpatient AHP] walks past the room and I call to her, asking if she is seeing Betty today, as Betty had expressed uncertainty earlier in the day. Bridget comes over to me and says "yes, I just have to work out what time". She didn't look at Betty or address her at all. After she leaves, Betty shrugs her shoulders. (Descriptive fieldnote, Betty and Bridget, inpatient AHP)

This contextually-bound relationship was also evident in the actions of some staff who were not scheduled to work with the patient on a particular day. Such actions included not acknowledging the patient when passing them in the hall or when working next to them in the shared lounge space. This suggests a perception that, for those

practitioners, relationship building was a discrete, time- and context-bound action rather than an on-going process embedded throughout rehabilitation.

Another way in which relational and technical, disciplinary-based work occurred together was by starting with the patient's agenda. Within activities, practitioners enacting *engagement as a relational practice* commonly started interactions through open-ended questions such as "how are you?" and "do you have any concerns?", even when the patient had severe communication disability and little verbal language. These actions reflected particular perspectives on practice, as described in this interview:

> I like to find out how they're doing. And if there's anything that concerns them, they've go to the top of their priority list, I try and address that … I think it's important they feel the doctor's working for them, not just at them. (Informal interview, Linda, inpatient doctor)

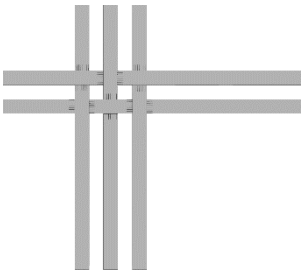
When introducing therapeutic activities, practitioners proposed session plans using language such as "I was thinking about doing [activity A] or [activity B]. What do you think?". In these cases, the plan could be negotiated and modified as required, based on the patient's knowledge of themselves, their limits and their concerns, as occurred in this physiotherapy assessment:

> When assessment tasks became more complex and Betty declined to do it, Harriet rephrased the request once or twice but finished by saying "that's ok, you need to feel safe, if you're not comfortable then that tells us something". As tasks became harder, she explained them then sought Betty's perspective on how she felt about it. When Betty was reluctant to stand on one leg with her eyes closed, Harriet negotiated and proposed alternatives - could you try it with your eyes open, could you do it with me holding you. She tried to find out why Betty was reluctant to do it. (Descriptive fieldnote, Betty and Harriet, inpatient AHP)

These practitioners also *acted* on the patient's verbal and non-verbal responses, demonstrating respect for the patient's perspective. Attending to the patient's needs

and preferences seemed to help them determine which forms of work to emphasise at which times, giving the patient some control over their own rehabilitation.

5. Working purposefully and reflexively



When enacting *engagement as a relational practice,* practitioners worked purposefully and reflexively to engage the person experiencing communication disability. Practitioners reflected on what they needed to do to engage the patient, and attended to their own actions and how these impacted on engagement during and after interactions as evident in an interview with Tim, an inpatient physiotherapist:

> *Felicity:* *How did the session go?*
>
> Tim: There was a lot of flapping around at the start [referring to discussions between himself and the OT regarding the plan for the session]. It feels like you're wasting time but it's just the way it is. You're weighing up what gives the most time to treat the patient, working out the logistics of getting him into a hoist and onto a plinth, whether it's best in the gym or on the ward. Unfortunately that meant there was a lot of flapping. I also know the family have been a bit disappointed with the care in the stroke unit - the last thing you want is to look like you don't know what you're doing. He seemed to enjoy and session and seemed to be engaging in what we were doing. One example of that is when I talked about the short term goal of being able to transfer without the hoist, his eyes lit up. The first couple of sessions are really about getting them on your boat, getting them on board. It's good when you know about the hobbies - you can talk about that, involve them in discussion - that's one way to do it. The first few sessions are all about getting them on board. You want him to leave with the feeling that he's done something, got something out of it and that he's enjoyed it (Informal interview)

Nuanced, detailed reflections on engagement and relationships saw practitioners closely attend to their way of being and acting with the patient (what and why they worked as they did and how this was interpreted), as well as attending to the relationship between themselves and the patient. They saw themselves as active ingredients in developing a relationship which they considered pivotal in engaging the patient. Reflections on practice covered multiple aspects of engagement: the practitioner, the patient, the family and the service. Reflections were prospective (for example, how they planned to work to address particular aspects of engagement) and retrospective (for example, reflecting on why they performed particular actions or what consequences these had). Characteristic of these engaging practitioners was that they questioned their own practice and explicitly attended to both the positive and negative consequences of their ways of working. One example of this was in Jessica's reflections on working with Arthur. She considered their interaction was important in facilitating a relationship, but she also reflected on the unintended consequences of focusing on the relationship and engagement between Arthur and herself, rather than the relationship between Arthur and the rest of his family: "now I realise the pressure that I put on getting that success between us is taking away from him having success with his family which is taking away from his quality of life – I need to think about that" (informal interview). Practitioners attended to the patient's positive and negative experiences, reflecting on how they needed to work in response to these. This was evident in Catherine and Tim's comments on page 162 when they reflected on Ryan's lack of trust, using this knowledge to inform a therapeutic approach centred on engagement.

In contrast, some practitioners appeared to assume the relationship would develop naturally: "I think that having a good working relationship with [Betty] every day, that we would naturally build a relationship. I don't think there's anything formal I would do, I would hope it would come naturally" (informal interview, Mike, doctor). He also

assumed engagement would naturally occur and that he was skilled at this: "As a doctor, you're always practicing engagement and communication with people with different needs so you do it [communication and engagement] all the time to some extent", raising questions of whether engagement work was somewhat unquestioned and was assumed to occur, rather than being critically considered and reflected on. Several practitioners described themselves as relational and engaging, however their descriptions of practice were broad and non-specific:

> I would say I think [I am a] relational [therapist]
> Like at the beginning obviously I focused on getting to know her
> Building that relationship so she would actually trust me
> Then we will have a good client-therapist relationship
> And obviously part of that would be being responsive as well
> At the beginning I think this relational [work] here is very important
> Otherwise you are not going to get anywhere with a patient
> (I-poem from interview with Kelly, community AHP)

When asked for more detail about how she built a relationship or why she considered relational work important, Kelly struggled to provide more detail. Assumptions about practice were evident in statements such as "I think [I am a] relational [therapist]" and terms such as "obviously" yet she gave few specific examples to support this perception. Some speech-language therapists assumed their communication skills were pivotal in engaging the patient, and considered themselves experts in engagement:

> And we studied for four years to be speech therapists plus we learnt on the job when we get here so it's probably not something we can expect everyone to pick up on quickly (Informal interview, Anna, inpatient AHP)

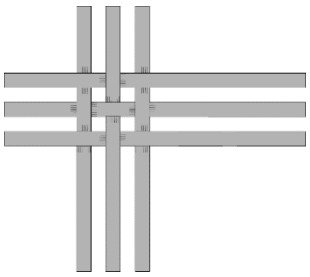
However, such expertise was not necessarily perceived or valued by patients with Betty reporting she was not particularly engaged with Anna. This suggests engagement might require broader communicative and relational action not just specific communicative techniques. It also raises questions about whether perceived expertise or communicative skills may limit a practitioner's reflection on their practice.

Yet other practitioners defined their relationship with the patient within the context of disciplinary work rather than being a specific intervention done in order to engage:

> *Felicity:* *In terms of his engagement in rehab, what is your role in trying to engage him in rehab?*
>
> Patrick: That's actually a difficult question. I was always taught that there is partially, with post-stroke patients, my role is to make sure he's not depressed then if he's not depressed, everything should click into place (Informal interview, Patrick, inpatient doctor)

Clearly, practitioners held a range of perspectives on the role of relationship in engagement, and in particular, had different understandings of their role in facilitating a relationship in order to engage a patient. The reflections of practitioners who did not enact *engagement as a relational practice* were commonly broad statements consisting of assumptions about their work rather than a detailed critique of themselves and their way of working. In contrast, practitioners who enacted *engagement as a relational practice* did not assume a relationship would automatically develop, nor did they consider it solely in the context of their disciplinary work. Instead, they appeared to purposefully and reflexively consider *how* they worked and how they could facilitate relationship development.

6. Co-constructing each person's engagement



Engagement appeared to be co-constructed. Within dyads, engagement was often influenced by a person's perception of the other person, their behaviour and their engagement. This was particularly apparent when practitioners spoke of their own engagement. Interviews with Nadia, an allied health practitioner working with Ryan, illustrated how her engagement changed over time, as did Ryan's. Attending to her narrative and to Ryan's narrative together illustrates how engagement could be co-constructed:

Week Two of rehabilitation

I hate [therapy]
(i-poem, Ryan, informal interview)

A mediocre session
There's a bit of engagement but not a lot
He sort of shut off
I hit a brick wall
In physio they go past the communication but yeah
You're focusing on something really hard with him
It's almost like 'why try?'
I feel like I'm trying to engage
It's probably affected by …
When he's not engaging I think 'what am I doing wrong'
I think more about myself than him
(Nadia, allied health practitioner)

Week Four of rehabilitation
Hate it, didn't want to try
If she'd backed off
If he'd been able to achieve, it would have been easier
I'm just tolerating it
Feeling negative
Getting nowhere
(i-poem, Ryan, informal interview)

I didn't want to come back after Christmas
It's just been too hard
He's not engaged
He's not enjoying it
I'm not sure what to do
(Nadia, allied health practitioner)

Week Eight of rehabilitation
I'm achieving
Before now, it was too difficult
I'm rapt
It's magic
I'm finally feeling positive
I didn't realise what she was doing
She was doing something but I didn't realise
I do now
Now, now it's good
(I-poem, Ryan, informal interview)

It's such a nice feeling
He was so interested to talk to me
It was so natural, so nice
My engagement is a lot easier
I can feel the success
I can see the change, the progression
I feel that what we're doing makes a difference
So I feel more engaged
(Nadia, inpatient rehabilitation)

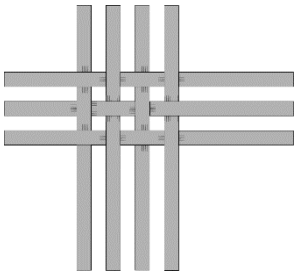
Ryan and Nadia's words highlight how limited success and perceived disengagement can impact on each party within the dyad. When rehabilitation and engagement were difficult, patients appeared to *tolerate* rehabilitation, rather than indicating any investment, and at times, any understanding of what they were doing and why. Ryan's engagement challenges were evident not just in his language (above), but in his non-verbal language in sessions as noted in fieldnotes written during sessions. This included a lack of eye contact with the practitioners, turning his body away, responding with yes/no responses only (if at all), requiring significant verbal cueing and encouragement before attempting tasks, and flat affect. His apparent disengagement was mirrored in Nadia's struggle to engage. Nadia also detailed how she felt more engaged when she perceived Ryan was engaged, illustrating how engagement could be co-constructed, influenced by the other's actions and their interpretation of the other person's engagement.

Each party, patient or practitioner, could sometimes appear to deliberately disengage in response to the other person's behaviour. Toni, who initially reported being very engaged with Ryan, reported a change in her engagement toward the end of his episode of care:

> At the start I probably would have treated him like I treat all my patients but to be honest the further I have got through his care the more careful I have been with him … Half of it is probably so he doesn't get overloaded and angry and half of it is probably my just protecting myself personally, like I don't want to be sworn at or have a patient be angry at me. (Informal interview)

She was mindful of Ryan's mood and behaviour and appeared to intentionally disengage for two reasons: to reduce the cognitive load on Ryan and reduce potential for anger, and to protect herself from his emotional responses. Of note, Ryan also reported disengaging from Toni in response to what he perceived was a breach of trust, being left alone in the shower without any means of calling for help. Another instance of this occurred between Ryan and Patrick, a doctor. Ryan reported losing faith in Patrick after an interaction; his disengagement appeared obvious in an observed interaction between the two: "Ryan is looking down; he appears reluctant to look up at the doctors. His initial responses are short and curt" (descriptive fieldnote, observation). These examples highlight the dynamic co-constructed nature of engagement, which could be influenced by perceptions of the other person's actions as well as perceptions of that person's engagement.

7. Facilitating two-way interaction



When practitioners enacted *engagement as a relational practice,* they drew on a dialogic approach to communication which involved two-way communication flow. The flow of interactions bore similarities to regular conversation with both parties contributing, both seeking and sharing information. The patient appeared to be viewed as a legitimate, valued communication partner. The two-way interaction reflected the relationship between the practitioner and person experiencing communication disability, a connection between two *people*, not two disconnected parties solely defined and known by their roles and positions within rehabilitation.

When participating in two-way interaction, patients were supported to participate even when their verbal output was limited:

> Jessica checks facts as he talks, identifying he was living with his sister. She encourages him to take the pen. He writes his previous address. When he gets stuck, she writes down options which facilitate ongoing discussion. Jessica draws on her knowledge of Arthur to support conversation - his sister's name, that he was a builder. This sees them go into a conversation about him going into building after leaving school. Jessica has been writing key words down; she refers back to these as they have the conversation - "I think you're telling me something about losing your hearing while you were a builder". There is a lot of reflecting back. This leads into a conversation about his family - brother and sister, Arthur as the self-described baby of the family. This conversation gives a lot of knowledge about Arthur the person, his whanau, his context. (Descriptive fieldnote, Arthur and Jessica, community AHP)

This was a holistic, conversational approach to communication which represented *relational dialogue*. Practitioners combined a range of communicative behaviours: communication *techniques* consistent with supported communication such as writing and gesture; *content* or topics, both clinical and non-clinical; communicative *conduct* such as body language and responsiveness to patient communication; and communicative *acts* such as joking, chatting or questioning as evident in this interaction between Tim, an inpatient AHP and Ryan:

> Tim says "I was just going to ask some questions. What was, oh yeah, the car. Let's see if you can read my writing." He writes some words on paper. Violet [Ryan's wife] gets the reading glasses out. Tim laughs: "they're not bright pink are they?!" To Ryan he says, "just have a go at pointing .. actually the first thing is can you read my writing?!" He works through what kinds of transmission the car is, offering the option of manual (then pausing) then automatic, at which point Ryan nods. Tim looks over at me saying "it's like a test, having a speech therapist watching". He writes some more words down. "Sorry, it's a constant test of if you can read my writing. When you play golf, do you use left handed or right handed clubs?" Ryan tries to clarify, his answer isn't overly clear and he looks to Violet. "You're like me, I look at my wife all the time when someone asks me a question" he says. Ryan looks puzzled when reading the words Tim had written on paper and doesn't answer. Tim turns the page and writes down the two words (right and left) again. Violet suggests asking him what hand he throws darts with. "Oh, you're a darts player!" Tim says. (Descriptive fieldnote, Ryan and Tim, inpatient AHP)

In the examples above, Jessica and Tim's communication supported the patients to understand and express themselves. Their communication also facilitated communicative flow between the two parties. Strategies including allowing time for the patient to understand and respond, asking questions in ways the patient could understand, asking questions to better understand Arthur and Ryan, and actively working to clarify meaning to support the patients to express themselves. In the interaction between Tim and Ryan, informal comments such as "you're like me, I look at my wife all the time when someone asks me a question" deflected from Ryan's communication difficulties. Tim took the spotlight and possibly the pressure off him which demonstrated dignity and respect for Ryan while still maintaining a conversational flow. In giving a little information about himself, Tim fostered a sense of relationship and two-way dialogue. *Relational dialogue* was an interactional approach to communication which created a space where information was shared and understandings were constructed.

Relational dialogue contrasted with *practitioner-centred monologue*, a communicative approach which was evident when practitioners controlled the process of information-seeking and information-sharing. Patients supplied or received the requisite information. The practitioner's verbal and non-verbal behaviour could minimise the patient's role resulting in the patient's needs and preferences being sidelined or only briefly acknowledged to the degree to which the practitioner allowed as evident in this interaction between Kelly and Betty:

> Kelly moves onto the final outcome measure which is based on a thermometer. "I want you to think how you're feeling in terms of your overall health, what you can do or are having difficulty with, your mood, your overall health. 0 is very bad 100 is very well. Where do you put yourself now?" Betty gives a narrative response: "Particularly now, afternoon is when I really am going right down and I think that is because I'm obviously building no I'm not really, it's just entertaining people it's very weary". While Betty is talking, Kelly sighs several times and looks at her watch. (*This gives the*

> *impression of being in a hurry and distracted, not particularly interested in what Betty is saying, instead focusing on getting the outcome measure completed*). Kelly refines the question but does not respond to Betty's comments: "So right now, how are you feeling about everything now, where would you put yourself now?" Betty responds 40-50. Kelly says "so 45 then". She briefly laughs while saying "sorry about that, we just need to do it for the outcome measure". (Descriptive fieldnote, Betty and Kelly, community AHP)

Kelly's focus on her own priorities and her actions such as sighing and looking at her watch effectively sidelined Betty and her concerns within this interaction. This positioned Betty as a recipient of what Kelly perceived she needed to do, which Betty commented on:

> She obviously had a lot of questions to ask
> She has a route she has to work with
> Does she come in with a script she needs to go through with me?
> She's going to be here for an hour –
> This is what she's got to finish?
>
> I think I'm not really quite sure what she is talking about
> I feel like she's the teacher and I'm not coping as her pupil
> I really am trying my best but it's not quite what she is expecting
> She's trying to get something into me
> But I'm not working very well for her
> (i-poem, Betty, informal interview)

Within *practitioner-centred monologue*, practitioners controlled the *content* and *conduct* (who was spoken to and when) of the interaction. Communication *topics* were clinically oriented and often focused on stroke-related impairments. The primary communicative *acts* were questioning, focused on finding out the specific information they needed to know, or telling what was going to happen. Within the example of Betty and Kelly above, Kelly's style of questioning, specifically her use of yes/no questions in a rapid request-response format contributed to a transactional form of communication centred on the practitioner's needs. As a result, Betty's needs and perspectives were sidelined.

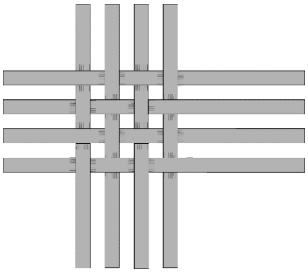
At its most extreme, practitioner-centred monologue could involve minimal interaction between the patient and practitioner, making the patient a 'ghost patient', someone physically present but invisible in interactions:

> Patrick and the consultant walk into the bedspace with the nurse. Patrick is carrying the folder. He doesn't say 'hello' or talk to Ryan. *Patrick seems to be in the role of scribe.* Ryan is looking down; he appears reluctant to look up at the doctors. His initial responses are short and curt … At one point, Patrick leans over to the consultant: "I have noticed, I was observing him trying to write the other day and Ryan has a very interesting situation and he knows what he wants to write and he starts it but then he perseverates and he can't complete it. He needs a lot of guidance, he knows if he's done right or wrong but he can't complete the task which is an interesting problem." He leans back. … The doctors talk together about medications. Ryan says something about his pain. The doctors don't respond to this comment. The nurse explains they're talking about medications. Patrick crosses medications off ... The doctors finish. They turn around and walk out. (Descriptive fieldnote, Ryan and Patrick, inpatient doctor)

Ryan was rendered silent and opaque through Patrick's verbal and non-verbal communication including the lack of greeting and eye contact, and his overt exclusion from discussions. Subtle exclusionary markers in practitioner-centred transactions between this dyad, and other patient-practitioner dyads, included ignoring or paying minimal attention to the patient, not participating in basic social rituals such as greeting or farewelling, interrupting the patient while talking, or signifying busyness or distraction (such as loud sighing while the patient is talking). Following this interaction, Ryan appeared resigned to this interactional pattern, shrugging his shoulders and saying he was used to it although he also said "[it's] destructive, so bloody destructive. He kept telling me what I can't do. I know I can't do it. I'm not bloody stupid. I don't know what came over him, it was bloody rough". He did however, perceive expertise within their action: "I'm pretty disappointed in them, that's for sure. But they're thorough" (informal interview). This way of working appeared to reflect hierarchy, a position as a distant doctor-as-expert, a practitioner-centred approach to care. The

patient was sidelined, positioned as an object of attention rather than an active participant in not just the interaction, but in their own rehabilitation. Foregrounding technical expertise distanced the practitioner and patient, resulting in disconnection and disengagement rather than connection and engagement.

8. Purposefully using particular approaches to communication



Within *engagement as a relational practice,* practitioners intentionally and reflexively utilised particular communicative approaches. Practitioners perceived interpersonal communication was important in establishing and maintaining a relationship and thus was also important in engagement. Non-clinical communication was an important aspect of engagement-oriented communication. In community services, practitioners started therapy sessions or interactions by talking about items in the home such as photographs or the local area. In hospital services, they attended to items in the patient's bedspace, not simply commenting on artifacts, but asking questions, initiating conversation in ways that enabled the patient to respond. This was apparent in an early interaction between Ryan and Catherine, an allied health practitioner:

Catherine:	I saw that cool picture in the dining room (referring to Ryan driving a racing car). You look good Ryan, it's a cool photo. Did you get to go ride on the track? (gesturing driving)
Ryan:	Yip
Violet:	2012 for his birthday
Catherine:	How fast did they go? (pause for ~5 seconds, maintaining eye contact)
Ryan:	Maybe .. (unintelligible)
Catherine:	(pause 2 seconds) Faster than 100kph? (surprised intonation)
Ryan:	Oh yeah
Catherine:	Pretty up there? (raised eyebrows, raised intonation)
Ryan:	Yip

Catherine: Like 150 or something?
Ryan: Mmmm (neutral tone)
Catherine: No – lower?
Violet: Higher
Catherine: Errgh – speedy (surprised intonation)
(Transcribed interaction, verbatim fieldnote, Catherine and Ryan)

Within this interaction, Catherine used pauses, facial expression, simple questions, tone of voice and gesture to support Ryan to understand and respond to her questions. Ryan appeared to want to participate, responding verbally and non-verbally, maintaining eye contact with Catherine and using gesture to point to himself in the picture. She supported him to actively participate by directing all questions to him. She maintained eye contact throughout their discussion and persisted in the conversation, seeking to understand his experiences. In the context of enhancing engagement, two other things appeared significant: selecting conversational topics beyond her own disciplinary-based concerns by attending to environmental cues that provided information about Ryan, and her animated tone of voice which suggested genuine interest (rather than asking as a form of politeness). When asked "within that session, what did you do to try and engage him?", Catherine explained:

> I think the main thing [for relationship and engagement] is reminding him we do know about other things he likes like his car, his boat and his daughters, that's why we joke around because it's been such a big part of his life so at the moment he can't tell us but letting him know that we know about it and who he is and try and have him as part of it - when we're talking about setting goals and so on, it's us together not us and them, that they can be on the same, we're all on the same page, we're not here to have a different perspective to them. (Informal interview, Catherine, inpatient AHP)

This form of communication seemed to be an intentional, reflexive approach to communication done for the purposes of relationship and engagement.

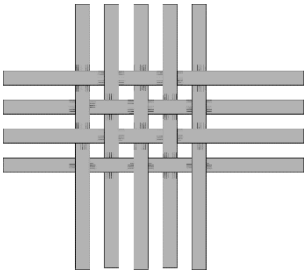
Practitioners who commonly enacted relational dialogue regularly reflected on their *own* communication, considering how it might influence the patient and their

engagement. One such example was given by Toni, who talked of being more "jokey" when Ryan appeared to be down:

> He needs a bit more encouragement, it looks like he's a bit down about the whole thing. It looks like with a bit of joking around he should be a bit better. It depends on the nurse - if you get a European nurse who will joke, that's fine but if you get an Indian nurse who doesn't speak much, he won't get that. I mean, I'll do that this week and I think I've got him most of the week and I'm happy to do that. (Informal interview. Toni, inpatient nurse)

Toni used communication as a therapeutic tool. This intentional approach to communication demonstrates a close reading of the patient's internal state (by attending to the patient's verbal and non-verbal responses) and reflection on their own way of working. Practitioners who appeared most successful in engaging patients appeared closely attuned to the patient's non-verbal communication, modifying their way of working accordingly. Relational dialogue was responsive, with staff changing their approach to best meet the patient's needs.

9. Actively listening to know and understand



The act of listening appeared crucial within *engagement as a relational practice.* Listening involved physical and communicative action, sitting or being physically together, listening for the meaning of the patient's verbal and non-verbal communication rather than hearing and responding to the words or facts immediately evident in the person's message.

> Elise looks at Betty and asks "How are you, Betty?" Betty replies, telling her all about her visit to daycare the other day, a long rather comprehensive response. While she is talking, Elise stays in the same position, leaning forward slightly, hands folded on her lap, just watching quietly. This allows Betty time to talk, to find her words and construct her sentences - 'gentle watching'. She occasionally asks follow up questions such as 'did they not do activities?' When

> Betty talks about the lack of activity at the daycare, Elise responds to Betty's humour (e.g. when she comments on the 'lazy me' just sitting still and not talking to anyone). While Elise's main role is listening, she does comment, question and reflect back, such as 'it sounds like you might need a more active or lively group' when Betty describes a group who all had severe speech and language difficulties. She leaves several seconds silence before initiating comments or responses. She explains she used to visit family in another local rest home and talked about the activities that seemed to be the favourites there. (Descriptive fieldnote, Betty and Elise, community AHP)

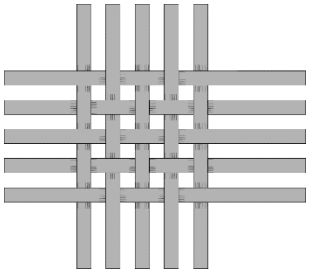
While actively listening, there were periods of silence in which the practitioner was attuned to all of the patient's communication modalities, processing this information, and working out how best to respond. Listening was reflected in a fieldnote of an interaction between a nurse and Ryan, when he and his family raised concerns about care:

> She doesn't respond to *what* the patient says, instead she focuses on *how* she is saying it, acknowledging the agitation, distressed tone and tears. While they are talking, she sits back, leaning back in the chair, watching and listening. She makes eye contact. A brief touch on the hand when he expresses anger. Waiting two, three, four seconds before talking. There is silence, a lot of silence, letting the person talk. (Descriptive fieldnote, Melody, inpatient nurse)

After the interaction, Melody commented: "[to develop the relationship with them] I'm really listening to the things she says are important ... It's about trying to listen". Listening was an intentional, disciplined act which allowed a space for a connection to develop, for a patient (and/or family) to feel heard and understood, and was considered to have therapeutic value. Catherine, an inpatient AHP talked of working with a patient and family who were concerned about their rehabilitation. She described using communication and listening in particular as tools in developing a relationship and engaging them in rehabilitation: "I try and make sure I poke my head in [to talk with them]… it only takes five minutes but it's so important" and "[I'll make time] to sit with [family member] and let her vent, if that helps. I'm quite happy for her to have those vents, she can have them as much as she likes" [Informal interview]. "Poking my

head in" and letting a patient "vent" may not be prioritised by all practitioners, but when done as a component of *engagement as a relational practice*, listening, knowing and understanding experiences were considered important therapeutic work.

10. Threading subtle communication throughout interactions



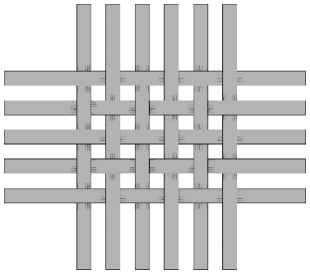
Interpersonal communication was threaded through interactions and therapeutic activities when practitioners enacted *engagement as a relational practice.* This likely reflected the relational approach these practitioners prioritised; it also reflected an understanding that developing relationships to engage was an on-going process. Observing interactions highlighted the constant yet unobtrusive role interpersonal communication played. It was subtle, evident in body positioning, touch, eye contact, pauses, how the practitioner held their head and more as indicated:

> Throughout the session, Tim's communication is very subtle - checking, gesturing, guiding him physically, regular but not constant eye contact, periods of silence while completing assessments or when the patient was completing an activity, quiet feedback but more effusive when there is a significant effort or action, explanations of what is happening. (Descriptive fieldnote, Tim, inpatient AHP)

Sitting alongside the patient, being at their level was often observed in practitioners enacting *engagement as a relational practice*. There was intermittent physical contact, a brief touch when saying hello or goodbye or when acknowledging emotional distress. There were often periods of silence within interactions, particularly when completing therapy activities such as physiotherapy sessions or personal cares. The use of quiet jokes, regularly checking the patient's perception of progress, sitting together and talking; all these communicative acts all gave the sense of an engaging environment. When *engagement was a relational practice*, the two parties, patient and practitioner,

were engaged together through communication and were also engaged in the therapeutic activity.

11. Responding to the presence of communication disability



A person's communication disability could be exacerbated or reduced by the actions of those working with them; it was also influenced by the communicative environment. Practitioners enacting *engagement as a relational practice* integrated supported communication within their interactions, such as Jessica on page 185 or Catherine on page 189.

Within some interactions, the use of a restricted range of supported communication techniques had the effect of limiting the person's communication and their ability to meaningfully participate as a conversational partner:

> Bridget: Do you have hobbies?
> Betty: Yes
> Bridget: Do you go out regularly?
> Betty: Yes
> Bridget: Oh, is that to Toastmasters?
> Betty: Yes
> Bridget: What night is that?
> Betty: Wednesday
> Bridget: How do you get there?
> Betty: I drive
> Bridget: OK
> (Transcribed interaction, verbatim fieldnote, Betty and Bridget, inpatient AHP)

Limiting interactions to yes/no questions appeared to be a strategy used to help the rehabilitation practitioner gather information and to reduce the communicative demands on the patient. However, when communication was centred on clinical information-seeking (i.e. when there was an absence of other elements of relational

dialogue), this could result in the practitioner controlling the topic and conduct of interaction.

While selective use of supported communication could be problematic, so too was the *absence* of supported communication. When practitioners failed to modify communication to enable a patient to participate, the patient was sidelined within the interaction. One patient expressed they were in pain during a ward round with doctors. The doctor responded, saying:

> You're in pain right? Pain is a natural mechanism but it is natural to have pain in response to an injury, it's a drive to protect the body. However this all depends on having an intact brain. Because stroke usually happens in the elderly outside the normal reproductive ages, the pain mechanism after stroke has not evolved to deal with stroke. The response to it isn't anatomic. (Transcribed interaction, verbatim fieldnote, Ryan and Patrick, inpatient doctor)

At the time of this interaction, Ryan's comprehension was limited; he required simplified language and extra time to process language. Patrick's communication suggested a limited understanding of communication difficulties and the practitioner's role in facilitating communication. This was also evident when Zara, an inpatient nurse reflected on an interaction with Betty. The interaction was characterised by missed understandings, when neither Betty nor Zara understood what the other was saying. Zara said: "there's nothing I can do [when Betty doesn't understand. She's very lost" (informal interview), suggesting a lack of knowledge and skill in supporting communication and interaction. A lack of staff communication was noted by Ryan:

> They're not crash hot
> They need to listen to us
> Listen to us you know
> Give us information
>
> They keep telling me what I can't do
> I know I can't do it
> I'm disappointed in them
> It was not nice

> They scurry over and turn me
> They walk away not even putting the bed rails up
> I have to ask them to do it
> They don't want to talk
> I think they feel awkward because I can't talk back
> They've not even tried
> (I-poem, informal interview, Ryan)

A number of practitioners appeared to have limited knowledge of how to operationalise communication techniques. I observed four different practitioners responding to a speech-language therapist's sign by the patient's bed which stated "Communication recommendations: Use whiteboard":

> One practitioner wrote down key words and suggested the patient point to them to convey her response to questions. Another wrote her questions on the whiteboard and gave them to the patient to read. The third handed the whiteboard to the patient when she had word-finding difficulties, saying "here is your communication, write it down". Yet another said "write your questions down here and I'll come and look at them later". (Memo)

In contrast with the unskilled and perhaps unconfident approach to communication described above, practitioners enacting *engagement as a relational practice* demonstrated an understanding of the person's communication impairment, their role in reducing the communication disability and skills in implementing a broad range of supported communication techniques to facilitate communication.

Systemic factors may have contributed to communication challenges. For example, there was little handover about communication between acute and rehabilitation services beyond "patient has aphasia" as stated by a nurse and occupational therapist working with Betty. There was no handover about how the aphasia affected Betty or how staff could facilitate communication. Accordingly, rehabilitation practitioners described using early interactions to assess communication as well as completing their disciplinary assessment: "I was also seeing if she can follow as it has a big impact on how we do treatment … I don't think she's someone who I need to run to the SLT and

get advice" (informal interview, Bridget, inpatient AHP). In inpatient services, speech-language therapists provided communication recommendations at the bedside and in the clinical notes. However bedside recommendations were not updated despite changes in patient communication. Nurses reported not reading the recommendations in the clinical notes:

> I could if I wanted to, sit down at 7.30 and read all the notes but then I could be showering a patient in that time …so it's what you choose to do. (Informal interview, Toni, inpatient nurse)

Written information about strategies was not sufficient to educate staff. Speech-language therapists provided verbal recommendations, mostly to allied health staff:

> Our whole allied health team they just all want to take on strategies for communication and what can I ask them to do in therapy that's going to help, you know generalise and stuff. And we try and do that for each other. (Informal interview, Nadia, inpatient AHP)

In contrast, there was little talk of working with nursing or medical staff to support communication as Penny, a nurse noted: "I feel we don't have much interaction with the SLT because everyone is busy all the time" (informal interview). Yet sidelining the patient (excluding the patient through the practitioner's communication) was predominantly evident in interactions between doctors and nurses. Speech-language therapists appeared reluctant to address these breakdowns with other staff members, even when aware they were impacting on the patient's engagement in rehabilitation. Nadia described her reasoning during a session where Ryan complained about a doctor's communication:

> We had to be really careful about agreeing with [Ryan's] point of view to a point where he thinks you're on his side. … I still have to be faithful to my multidisciplinary team and I wasn't in the situation [that the patient was describing] and I can't say 'it was terrible, he had no right' in case I break that professional boundary. You want people with communication difficulty to have trust in you and I feel I'm an advocate for them cos they can't get their message across but I know in the past it hasn't always been well received, just in

> terms of, I feel I'm fighting the rest of the team. (Stimulated recall interview, Nadia, inpatient AHP)

Supporting and challenging staff communication appeared complex in the context of team relationships, power dynamics (doctors-allied health and senior staff member-junior staff member) and mixed roles and duties (patient advocate-communication specialist-team member). As a result, Nadia appears somewhat torn in her loyalties. This gives an indication of the complexity inherent in supporting communication, particularly when it is perceived to be challenging the actions of other staff members. Responding to communication disability and supporting communication was a complex process, influenced by a number of factors including individual knowledge and skills, team dynamics, systemic factors such as time and communication processes, and perceptions of value of communication.

Summary and conclusion

Engagement as a relational practice was a complex, multi-layered approach to engagement. It was enacted by combining eleven ways of working and being. These were evident in how practitioners worked within interactions, and in how they talked about how they worked. By addressing the patient's priorities in ways which were meaningful, and continually critically reflecting on their own practice, rehabilitation practitioners were able to successfully engage patients in their rehabilitation. Practitioners who enacted *engagement as a relational practice* closely attended to their way of being and acting with the patient. They saw themselves as active ingredients in engagement, conscious their way of working impacted on patient engagement. *Engagement as a relational practice* required the practitioner to do more than *say* they valued engagement. It required them to critically reflect on how their work impacted on engagement, and to enact practices which facilitated engagement. The eleven ways of working representing *engagement as a relational practice* combined four key aspects

of rehabilitation practice: communication, relationship, technical knowledge and skills, and rehabilitation tasks. All four were legitimate forms of practice, which when combined together and personalised to the patient were able to respond to the social, emotional, physical and communicative needs of that individual patient. This way of working was skilled and nuanced. Central to *engagement as a relational practice* was the practitioner's professional values or philosophy of practice. This informed each person's understandings of rehabilitation practice, including the role of engagement and relational work, the practitioner's role in these, whose knowledges and experiences were valid and valuable, what elements of care were important in rehabilitation, and what forms of rehabilitation work were valued and considered legitimate. When enacting *engagement as a relational practice,* the practitioners' ways of working were explicit, coherent and intrinsically consistent. *Engagement as a relational practice* involved a complex interplay of philosophy and practice, requiring consistency between these, and between the practitioner's way of working and the patient's needs and priorities. It was a unified, connected approach to engagement.

Chapter Nine: Discussion and conclusion

The primary objective of this doctoral research was to develop in-depth understandings of how practitioners engage people experiencing communication disability in stroke rehabilitation. In order to do so, it was necessary to first understand how engagement was conceptualised in the literature, and by people experiencing communication disability and practitioners working in stroke rehabilitation. A literature-based investigation of engagement explored how engagement was conceptualised in the health and rehabilitation literature (Chapter Two). Following this review, two empirical studies were undertaken. The first was an interview-based study which explored how people experiencing communication disability and rehabilitation practitioners conceptualised engagement (Chapter Six), while the second, an observational study, explored how practitioners worked to engage patients (Chapter Eight). Within this chapter, I draw together the key findings of these three studies, discussing the novel contributions this doctoral study offers, demonstrating how these challenge and/or add to current knowledge of engagement. Implications for research and practice are discussed while also acknowledging the limitations of the research.

Summary of key findings

Findings from this research have augmented understandings of engagement and engagement practices, with novel findings emerging from each study within this doctoral research. The conceptual review demonstrated that engagement was co-constructed, consisting of both a process and a state. It highlighted the role practitioners held in engagement, indicating their actions could influence patient engagement. These findings were echoed in the first empirical study, which suggested engagement was a process facilitated by the practitioner, as well as a patient state evident in their actions. Patient engagement seemed to be clearly influenced by the

practitioner's actions. These actions appeared to be underpinned by the practitioner's values, skills and attitudes, and influenced by the systems they worked within. The practitioner's engagement or disengagement could influence their ways of working and thinking about their practice.

While both studies highlighted the importance of the practitioner's actions, they offered limited detail about *how* they worked to influence engagement. The final study, an observational study, addressed this gap and developed rich, nuanced understandings of how practitioners worked to facilitate engagement. Exploring what happened in the interactions between the patient and practitioner, considering how these interactions came about and how they impacted on engagement suggested engagement was a relational practice, a combination of ways of saying, doing, and relating (Kemmis, Wilkinson, et al., 2014). Engagement required the practitioner to weave relationship and communication (relational work), together with technical, disciplinary-based work and rehabilitation tasks (see Figure 12), emphasising one or more depending on the specific needs of the individual patient. Accordingly, this appeared a flexible, responsive way of working.

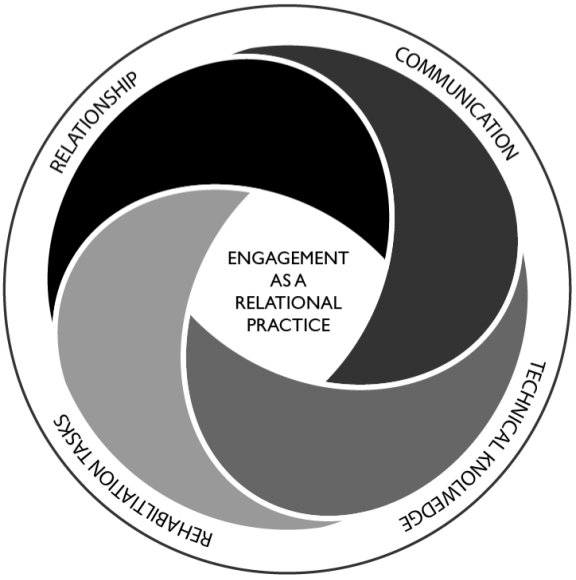


Figure 12: Engagement as a relational practice

When enacting *engagement as a relational practice,* practitioners appeared to attend to and prioritise relationships and communication; such factors often appeared crucial in patient engagement. Practitioners included the patient within interactions, constructing them as a successful communicator and supporting them to be an equal communication partner. When reflecting on the practice that appeared relational, practitioners described walking alongside the patient, and sharing knowledge and expertise rather than taking a position of practitioner-as-expert. Relational work appeared particularly important when the person experiencing communication disability was struggling to engage. Observations suggested engagement was co-constructed, with each person's engagement influenced by how they perceived the other person's engagement. Practitioner reflexivity appeared to be a hallmark of *engagement as a relational practice*. Practice appeared to be surrounded by a relational frame which informed how the practitioners thought about engagement and rehabilitation, and their role within both. This frame also informed their ways of working and being with the patient. There was consistency and congruence between their ways of thinking and talking about practice and how they worked with their patients. Proposing *engagement as a relational practice* was a key finding for this study. It is consistent with, and extends the findings from the earlier research within this thesis, including the literature included in the reviews (Chapters Two and Three) and the findings of the first empirical study (Chapter Six).

Novel contributions to knowledge

This research has made several novel contributions to knowledge about the concept of engagement and how practitioners work to engage people experiencing communication disability. Within this section, I focus on four key contributions.

First, I propose engagement is a relational practice, a highly skilled and intentional way of working underpinned by the practitioner's beliefs and values. This relational approach to engagement foregrounds relational work, suggesting it to be a legitimate and at times, essential form of rehabilitation work. The practitioner's actions and their ways of working are central to patient engagement. This contrasts with much literature which emphasises the patient's actions and their state of engagement. These findings detail the "recognisable elements" (Simmons-Mackie & Damico, 2011, p. 37) of what happens within the interactions when practitioners are working to facilitate engagement. As a result, engagement moves from being a somewhat invisible and often assumed process to one that is more transparent, complex and nuanced.

Second, I argue *relational dialogue* is an important aspect of communication when working intentionally to engage people experiencing communication disability. Communication disability literature often discusses supported communication (e.g. Ackermann, Mathiak, & Riecker, 2007; L. R. Jensen et al., 2014; Kagan, 1998; Rayner & Marshall, 2003) yet my thesis is that supported communication *techniques* in isolation are insufficient for promoting engagement, and at times, may be a barrier to engagement. Instead, it appears that the combination of relational dialogue *and* supported communication are important for engagement.

Third, the findings from these three studies indicated *practitioner engagement* was perhaps an important but often silent factor in the engagement process, influencing how practitioners worked and how patients engaged with them. Finally, this research has advanced methodological knowledge by demonstrating how the Voice Centred Relational Approach can be applied when working with large datasets, with multiple participants, and with multiple forms of data (e.g. interview and observational data). Each of these contributions will now be addressed in detail.

Engagement as a relational practice

Engagement appeared relational, a deliberate way of working in which the therapeutic relationship was valued and prioritised. Engagement emerged within and because of relationship, as described by Ells and colleagues (2011). Practitioners in this doctoral research spoke of valuing patient engagement and considered how their way of working could or did influence engagement. Placing relationship at the centre of rehabilitation is consistent with arguments that relationship is not something 'nice to have', an optional add-on to therapy (Kayes, Mudge, Bright, & McPherson, 2015). Relationship was considered to have therapeutic benefit in its own right, rendering it a legitimate and arguably, essential way of working. The practitioner's ways of thinking about and enacting engagement appeared to be surrounded by a relational frame, one that valued relational work within rehabilitation. Such a frame could guide what people look for and see, i.e. how they make sense of situations and practice (Crotty, 1998). Relational work involved combining multiple skills and techniques to develop a relationship to engage the person experiencing communication disability in rehabilitation. This represented a form of *bricolage* (Shaw & Deforge, 2012), working in a highly skilled and individualised manner akin to "praxis artistry" (Higgs, McAllister, & Whiteford, 2009, p. 102), consistent with previous descriptions of expert practitioners (G. M. Jensen, Gwyer, Shepard, & Hack, 2000).

However, viewing *engagement as a relational practice* offers a novel perspective on engagement in stroke rehabilitation. It shifts the focus from the *patient* state or behaviours as currently emphasised in much of the literature exploring engagement in rehabilitation (e.g. Kortte et al., 2007; Lequerica & Kortte, 2010). As demonstrated in the conceptual review, engagement is commonly discussed as a patient state and/or behaviour, with disengagement (or failure to engage) portrayed as a *patient* 'problem' and responsibility. This ignores the role of the practitioner, therapeutic process or

environment in disengagement, factors which this research suggests are important for engagement. Viewing *engagement as a relational practice* supports other literature which argues against related concepts such as motivation and compliance being viewed as individualist, solely attributable to the patient (Crepeau, 2000; Maclean & Pound, 2000; van Hal, Meershoek, Nijhuis, & Horstman, 2012; Watkins et al., 1999). Indeed, this research shines a light on the practitioner's role and opens up different understandings of engagement, contributing to a more nuanced conceptualisation of engagement than has been previously detailed in the literature.

The nature and role of relationships are receiving increasing attention in the literature. Relationship-centred care is a values-based model of practice (Beach & Inui, 2006; Tresolini & Pew-Fetzer Task Force, 1994; Worrall et al., 2010) which is said to be desirable in aphasia rehabilitation (Worrall et al., 2010). This bears many similarities to *engagement as a relational practice.* For example, relationship-centred care explicitly recognises the personhood of the patient and the practitioner (Beach & Inui, 2006); e*ngagement as a relational practice* emphasises the need for the practitioner to give something of themselves, positioning themselves as a person in relationship not a detached professional (see page 167). Relationship-centred care values authenticity (Beach & Inui, 2006), meaning the practitioner's way of working is consistent with what they say they value and what they say about how they work. This was evident within *engagement as a relational practice*. These approaches to care share a desired outcome of relationally-oriented practice: patient engagement.

Viewing relationship as skilled, legitimate rehabilitation 'work'

A relational view of engagement is consistent with the call for care and rehabilitation to be considered within a relational framework (L. M. Brown & Gilligan, 1992; Douglas et al., 2015; Ells et al., 2011; Noddings, 2003). Douglas and colleagues (2015) argued that

rehabilitation is by definition, a relational encounter. Viewing rehabilitation as relational prompts a shift from a 'practitioner-as-expert and patient-as-passive-recipient' model of care to one that positions both parties in a caring relationship together (Noddings, 2003). Douglas and colleagues (2015) demonstrated interpersonal interactions could influence the patient's relational schema (how they experience themselves in relation to others), impacting on their engagement. Integral to a relational approach is the perspective that relational work is skilled, legitimate rehabilitation work. The current doctoral research, however, highlighted the tensions in enacting a relational approach to engagement, which relates to what work is valued and legitimised within rehabilitation.

Practitioners who enacted *engagement as a relational practice* valued relational work, considering it a legitimate and valuable way of working. Not all participants valued relational work despite it appearing important in facilitating engagement although within this doctoral study, all parties valued technical knowledge and skills. A number of the participating practitioners appeared to give primacy to traditional modes of intervention, prioritising assessment and treatment within their ways of working. This reflects a 'technical-rational' approach which emphasises scientific theory and knowledge (Bradley, 2009; Schön, 1983) and technical knowledge and skill (B. Green, 2009; Plack, 2005). This may reflect different understandings of what forms of work are considered legitimate rehabilitation work. Historically within healthcare, a technical, disciplinary-based way of working has been valued and prioritised within training and practice (Schön, 1983, 1987). The dominant medical model emphasises scientific knowledge; this has influenced which knowledges other professions prioritise (e.g. Byng, Cairns, & Duchan, 2002; Fourie, 2011a; Trede & Higgs, 2008; Walsh & Duchan, 2011). Trede and Higgs (2005) argued that an emphasis on technical skills and knowledge can lead to a practitioner-centred approach to care; such an approach which emphasises the practitioner's knowledge and their position of power. This was evident

in the practitioner-driven approaches to engagement within the empirical studies of this doctoral research; such approaches commonly emphasised doing the work of rehabilitation, complying and participating in the rehabilitation programme set by the practitioner who was considered the expert in rehabilitation. Practitioners who gave primacy to technical knowledge and skills rarely discussed relational work. Those who gave primacy to relational work in their talk-in-action and talk-about-action[24] appeared able to combine both relational work *and* technical knowledge and skills, considering they were both legitimate forms of rehabilitation work which could be used separately or together at different times over the course of rehabilitation, for different purposes.

It is perhaps unsurprising that some practitioners emphasised technical, disciplinary-based knowledge and skills. Not only do these dominate professional training as discussed above, they dominate rehabilitation research and practice guidelines. For instance, researchers seeking to unpack the so-called 'black box' (Whyte & Hart, 2003) or 'Russian doll' (DeJong, Horn, Conroy, Nichols, & Healton, 2005) of rehabilitation focused on the specific mechanisms of rehabilitation and delivery of therapy tasks in order to "objectively verify [the] contents of therapy" (Whyte & Hart, 2003, p. 639). This focuses on *what* the practitioner does; *how* the practitioner works is seemingly neglected. Arguably, their actions are seen as something that needs to be controlled for rather than being seen as mechanism of therapy (Kayes et al., 2015). Regional stroke management guidelines (National Stroke Foundation, 2010; Stroke Foundation of New Zealand, 2010) also reinforce technical, disciplinary-oriented work. Therapeutic relationships were mentioned once in each guideline, in the context of considering cultural and spiritual beliefs "in order to enhance the therapeutic relationship" (Stroke Foundation of New Zealand, 2010, p. 15) and as a mechanism for behaviour change in the presence of behavioural issues (National Stroke Foundation, 2010). Within the

[24] Talk-in-action refers to what practitioners *did* with patients while talk-about-action refers to how they *talked* about what they did.

observational study (Chapter Eight), practice appeared strongly influenced by service KPIs which focused on assessments, structured processes and/or formal events. The combination of professional training, dominant models of practice, literature and research priorities, stroke management guidelines and service KPIs can construct particular understandings of what work is considered valuable and valid. Questions must be asked about what is excluded when technical work is given primacy. This research suggests relational work may be hidden or absent, and has demonstrated what this might mean for patient engagement.

In the context of engagement, the findings of this research demonstrate relational work was often given primacy by people experiencing communication disability and by those practitioners enacting *engagement as a relational practice.* This is a site of tension. On one level, practitioners needed to fulfil mandated roles which focus on and measure specific skills and tasks. Indeed, practitioners understandably value the technical, disciplinary-based knowledge they bring (Noddings, 2012; Schei, 2006; Sherratt et al., 2011). At the same time, relational work, reflecting values of care and relationship (Noddings, 2003) was highly valued by patients and some practitioners within this study and others (e.g. Bright et al., 2015; Fadyl, McPherson, & Kayes, 2011; Fourie, 2009; Worrall et al., 2010). Such values are reported to attract people into the healthcare professions (Byng et al., 2002; Nicholls & Gibson, 2010; Sayer, 2011). Working in this way is a nuanced, highly skilled way of working, reminiscent of Schei's (2011) description of good doctoring:

> A relational competence, where empathic perceptiveness and creativity render doctors capable of using their personal qualities, together with the scientific and technologic tools of medicine, to provide individualized help, attuned to the particular circumstances of the patient (p. 394-5).

Engagement as a relational practice required practitioners to blend relational and technical, disciplinary-based work together, prioritising different work at different

times depending on the specific needs and priorities of the patient (Fadyl et al., 2011). Practitioners also demonstrated skill in working in this way. If professional training emphasises technical knowledge and skills, and if the dominance of scientific knowledge is reinforced through professional socialisation in clinical education and clinical practice as Byng and colleagues suggested (2002), it may be that some practitioners do not have the skills necessary to work in this individualised manner, a claim previously made by Ferguson and Elliot (2001).

Perhaps the indicator of practitioners who enact *engagement as a relational practice* is that they perceive relational and technical, disciplinary-based work as co-existing and complementary, as discussed by Altun:

> Someone who takes account of the specificities of the people they interact with, their particular capacities, needs and vulnerabilities, as well as other specificities of the situation. ... [taking] into account their particular characteristics, constraints and resources, including their vulnerability and fallibility, and "reasonable behaviour" also suggests some degree of emotional sensitivity to others … to be able to imagine things from other people's standpoints—in other words, to be willing to take the standpoint of the other (Altun, 2002, p. 65).

This way of working demonstrated "praxis artistry" (Higgs et al., 2009, p. 102), high quality graceful care in which different acts, values and requirements are mindfully combined to facilitate engagement.

Critically reflecting on practice

Reflection was integral to *engagement as a relational practice.* Practitioners who worked intentionally and successfully to engage people experiencing communication disabilities consistently reflected on *what they did*. More than this, they reflected on *how they were* with the patient. They considered how they needed to be and work in order to engage, reflecting prospectively and retrospectively and implementing these

understandings within their on-going actions. Their reflections were specific and focused, incorporating information from what happened and also their understandings of the patient and their context. Their reflections-on-action (Schön, 1983, 1987) were consistent with what was observed in practice. Practitioners did not assume; they critically interrogated their practice. They considered their way of working could impact on engagement which influenced how they reflected on the impact of their actions, and on whether their intentions were realised.

Engagement as a relational practice required the practitioner to do more than say they valued engagement. It required them to critically reflect on how their work impacted on engagement, and to enact practices which facilitated engagement. Several different layers or forms of reflection have been proposed in the literature. Taylor (2010) suggested three predominant forms of reflection: technical (empirically and theoretically-described skills and knowledge); practical (interpersonal interactions) and emancipatory (power relations and the social context surrounding and constructing practice). Practitioners who enacted *engagement as a relational practice* demonstrated comprehensive reflections comprised of all three forms above. The combined focus on themselves as a practitioner, their interactions with the patient and the patient's needs, and the social context surrounding practice resulted in sophisticated, nuanced reflections on engagement and clinical practice. In contrast, different patterns of reflection were evident when engagement did not appear to be prioritised, or when it was problematic. Some practitioners appeared to assume engagement occurred, while others did not reflect on their practice even with prompts (i.e. interview questions). Those who assumed engagement occurred often provided broad statements about practice rather than detailed reflections, suggesting a lack of nuanced understanding of practice (Simmons-Mackie & Damico, 2011). These limited reflections might occur for several reasons which I will explore in the following paragraphs. I suggest these reasons might include a lack of training about reflection,

limited frameworks that facilitate reflection on engagement specifically, and the cognitive load involved in practice.

Reflection is described as a learned skill of thinking about practice and knowledge both in the moment (reflection-in-action) and after the moment (reflection-on-action) (Schön, 1983, 1987). It involves making tacit knowledge explicit and using this awareness to enliven and make changes to practice (Schön, 1987). Within education programmes and healthcare services which may emphasise technical rationalist skills (see above), reflection may not be considered important, or may be discussed primarily in the context of reflection on technical, disciplinary-based service delivery (Day & Andereson, 2011). This was evident in practitioners who prioritised technical, disciplinary-based work; their reflections centred on *what* they did, rather than *how* they did it or how the patient may have perceived it. Within this research, only practitioners enacting *engagement as a relational practice* attended to the emotional aspects of practice and the social context surrounding practice, such as the impact of service requirements and KPIs. These areas are important as both the emotional and social context often significantly impact on practice but their influence is hidden and not critically considered (Jameton, 1984; McCarthy & Deady, 2008; McLaughlin, Lincoln, & Adamson, 2008; B. J. Taylor, 2010). The practice of those practitioners who focused on technical, disciplinary-based work often appeared somewhat "routine and unremarkable" (Lofland, Snow, Anderson, & Lofland, 2006, p. 123), raising the possibility that their practice was ritualised and seemingly unexamined (Cott, 1998; B. Green, 2009; Liberati et al., 2015). Jameton (1984) suggested this can contribute to reflection being superficial and focused on action or meeting governmental requirements. Limited reflection can also maintain dominant perspectives and ways of working, rather than facilitating the critical transformation which is said to be important for practice development and change (Austin, Goble, Leier, & Byrne, 2009; Jameton, 1984; Kilminister, Zukas, Bradbury, & Frost, 2010).

Some authors have suggested standardised reflection processes such as reflective cycles used in student training, or mandatory reflections for professional registration may constrain how a practitioner reflects and what they reflect on (Austin et al., 2009; Jameton, 1984; McCarthy & Deady, 2008). They suggest automated reflection can result in a mechanistic approach which consolidates the status quo (Austin et al., 2009) rather than critically reflecting and examining assumptions, knowledge and the impact of the sociocultural context and considering what could be (Austin et al., 2009; Jameton, 1984; McCarthy & Deady, 2008). The latter has been described as the transformative component of reflection (Austin et al., 2009) which enables practitioners to "remake their work practices" (King et al., 2007, p. 56). Schön (1987) considered this reflection-in-action a hallmark of practice artistry. Within my research, an automated reflection was reflected in broad statements about practice rather than detailed, specific examination of the practitioner's way of working (see page 178). The latter included thinking about how to proceed in the future, the transformative nature of reflection (Austin et al., 2009).

As evident in the conceptual review (Chapter Two) and the literature review (Chapter Three), there is currently very limited knowledge about engagement, and indeed, about therapeutic processes more broadly (Kayes et al., 2015; Simmons-Mackie & Damico, 2011). The lack of a theoretically- or empirically-derived conceptual framework may limit reflection (Fourie, 2009; Hersh, 2010b; Hersh & Cruice, 2010). Practitioners who enacted *engagement as a relational practice* appeared to have a relational frame or philosophy of practice which influenced their conceptualisations of engagement, perceiving it as relational and considering they had a significant role in engagement. This influenced what they reflected on. In contrast, those who conceptualised engagement as intrinsic to the patient, enacted through patient behaviour did not consider engagement was constructed through their own actions and therefore, they did not consider their own behaviour when they reflected. Again, this might lead to

consolidation of the status quo (Austin et al., 2009). Many practitioners assumed engagement was occurring although this was not reported by the patient involved in the interaction, nor was it supported by observations. Some practitioners within the second empirical study did not necessarily identify difficulties when they did occur, or when difficulties were perceived by the patient. This might hinder reflection as Dewey (1933) and Schön (1987) suggested reflection occurred when difficulties occurred. While Fourie (2011a) suggested a lack of a conceptual framework might inhibit reflection, it may be that descriptions of engagement proposed in this research may support practitioners to think through the process and act of engagement, considering both the patient and themselves and whether engagement difficulties might exist. Of course, there is a risk this might promote a mechanistic approach to reflection as discussed on the previous page.

Finally, it could be queried whether practitioners' reflective capacity might be limited by the cognitive load involved in enacting practice and reflecting-in-action. Clinical practice is by definition cognitively complex, requiring high levels of cognitive stacking and frequent cognitive shifts (Boud, 2010). Burger et al. (2010) demonstrated how nurses had different levels of capacity to manage the cognitive load. For some (those described as 'advanced beginners'), "all they could do was complete the required care" (Burger et al., 2010, p. 503). Cognitive load has been shown to increase when working with people with English as a second language (Saltiel, 2010). Given patients in this study had communication disability and communication was challenging, this might also impact on capacity for reflection. Some authors have suggested capacity for reflective practice (a form of meta-cognition) may increase, and style of reflective practice may change (intuitive vs. conscious) as the practitioner's expertise develops (e.g. Collier, 2010; G. M. Jensen et al., 2000).This literature raises the question of whether cognitive capacity is a factor in practitioner reflection on engagement.

Communicating for engagement: Relational dialogue

Communication was central to *engagement as a relational practice.* The communication practices in this way of working were constitutive (Frost, 2010), facilitating relationships and engagement and helping people develop a sense of safety with, and trust in the rehabilitation practitioners. This form of communication was relational, underpinned by professional values and a relational philosophy of practice. Inherent in relational dialogue was a sense of "openness-to the other" (Frost, 2010, p. 5), being open to hearing the other, seeing concepts and situations from their perspective, and changing their way of being-with and working as needed. Relationship underpinned, and was embedded throughout, interactions. Relational dialogue was a creative approach to communication tailored to the communicative, emotional and relational needs of the patient. It involved two-way information-sharing and relationship-building. This approach to communication supports Salmon and Young's (2011) argument that clinical communication is a skilled, creative, values-based act rather than a series of discrete communication techniques. In keeping with Baxter (2004) and Stewart and Zediker's (2000) descriptions of dialogue, communication within *engagement as a relational act* was entwined with professional values and philosophies of practice, a multi-stranded, multi-factored way of working.

Within this section, I focus on three characteristics which appeared important within relational dialogue and which may need special consideration within a dyad impacted by communication disability: small talk, interactional flow and active listening. Following this, I discuss how these characteristics could be integrated with supported communication, arguing that it is the *combination* of these characteristics *and* supported communication, when used consistently over time *together* with the relational frame of the practitioners that makes this multi-stranded approach to communication engaging and relational.

Small talk

The "tiniest, most transient events" (Karben & Smith, 2010, p. 204), such as greetings in the corridor or a shared space, or small talk within clinical interactions appeared important to people experiencing communication disability. These so-called 'mundane' communication events are recognised as important in developing and maintaining relationships (Davidson, Worrall, & Hickson, 2008; Frost, 2010; Potter et al., 2005), something also evident in this current research. Such communication was more than an exchange of niceties. It was interactive, with both parties sharing information, and getting to know each other. It created a sense of solidarity and alignment between the two parties, a shared understanding and sense of being together, consistent with other research in clinical communication (Burnard, 2003; Crawford & Brown, 2011; Gafaranga & Britten, 2003; Prusak, 2003). Data from the observational study (Chapter Eight) suggested meaningful small talk involved conversational flow rather than being a brief nicety performed at the start of each session through questions such as 'how are you?' (with no follow up conversation) or 'do you remember what we did last time?' (a transactional, question-answer exchange in which the response was already known by both parties). Togher and colleagues (2013) described the latter as a marker of non-collaborative communication support. In meaningful small talk, practitioners attended to cues within the patient's speech, following their content instead of controlling the interaction themselves, something Burnard (2010) suggested was a marker of a skilled communicator. Previous research suggests the importance of small talk is not always recognised in clinical interactions (Walsh, 2007) and that a lack of it may result in a sense of isolation or being ignored (Rolfe, 1997). Accordingly, small talk appeared one important component of relational dialogue, reflecting Burnard's (2010) assertion that "ordinary chat might be as important as therapeutic conversation" (p. 682).

Interactional flow

Interactional flow was evident within *engagement as a relational practice*. The person experiencing communication disability and the rehabilitation practitioner were both active participants in the exchange, seeking and providing information. Flow was created through a combination of communicative *content,* namely communicating about a range of topics not only clinically related topics, and communicative *acts* such as laughter, joking and small talk. There was joint involvement and input within the interaction (Walsh & Duchan, 2011), reflecting a communicative dance in which each person responded to the explicit words and implicit meanings evident within interaction, "together [shaping] the therapeutic conversation" (Rober, 2005, p. 389). Interactional flow occurred *within* and *across* interactions, evidence of a "living conversation" (Cunliffe & Eriksen, 2011, p. 1435). Interaction was present across the meetings between patient and practitioner, regardless of whether they were scheduled interactions or informal passings in the dining room or hall. The latter acknowledged and reinforced the relationship between the parties, not limiting it to defined rehabilitation work. Over a number of shared experiences, the dyads appeared to develop "chronotopic similarity" (Baxter, 2004, p. 4), a collection of shared time-space experiences. Within this current research, the emergent shared history of each dyad contributed to developing a relationship between the parties, as well as a shared identity of two people being together in a partnership.

This *interactional* communication contrasted in very real ways with the *transactional* communication common within practitioner-centred monologue (see page 186). Transactions were asymmetrical; the practitioner was in control of the interaction. Several authors have discussed this as a practitioner-centric approach to communication (Durning, Artino, Pangaro, van der Vleuten, & Schuwirth, 2011; Simmons-Mackie & Damico, 2011; Stewart & Zediker, 2000). While there were times of

transactional communication evident in communication with practitioners enacting *engagement as a relational practice* and people experiencing communication disability, this did not appear problematic because there were times of interaction and there was an interpersonal relationship between the patient and practitioner. This pattern is consistent with Baxter's (2010) description of times of mundane interactions which are interspersed with dialogue. Interactional communication positioned the two parties in relationship together, reinforcing this relationship on an on-going basis.

Active listening

A third strand of relational dialogue was listening. The findings of this study support the idea that listening is values-based, influenced by how the practitioner conceptualises clinical practice and their own professional role (Baxter, 2004; Davis, 2013) and whether they value listening as a therapeutic activity (Baxter, 2004; Buber, 1970; Davis, 2013; West, 2010). When practitioners considered their role was to 'treat' or to fix, listening appeared somewhat mechanistic and involved listening for the facts which the practitioner considered important. Practitioners focused on what was said rather than the holistic form of listening which the literature suggests is important for relationship and engagement (Baxter, 2004; Buber, 1970; Davis, 2013; Mundle & Smith, 2013). Practitioners who enacted *engagement as a relational practice* appeared more likely to prioritise listening and consider it an active intervention in its own right, something also seen in expert physiotherapists and child mental health practitioners (Davis, 2013; King, Servais, Bolack, Shepherd, & Willoughby, 2012). When listening within *relational dialogue,* the practitioner was an active participant in the interaction. Rober (2005) suggested such active listening involved listening and preparing for how to respond, taking the words and then processing them, participating in an inner conversation to understand the person and their meaning, and using this knowledge to understand how to go on. He suggested active listening enables the practitioner to

know "how to go on" (p. 388) with the patient, creating space for different voices, perspectives and opinions within their interactions. This form of listening is consistent with approaches seen in person-centred care (Bright et al., 2012), and represents stereophonic listening, which involves hearing "the body and the person who inhabits it" (Simmons-Mackie, 2013, p. 97). Within this doctoral research, active listening involved practitioners engaging with the meaning the patient was trying to convey, using this to inform their on-going interaction and rehabilitation planning, using knowledge to understand how best to go on with the patient and how best to engage them in treatment. Accordingly, it was central to *engagement as a relational practice.*

Barrow (2011) argued listening is "at the heart of working practice" (p. 22), as it provides a therapeutic space in which the patient-practitioner dyad can work. King and colleagues (2012) described it as a therapeutic process in its own right. Within this current research, listening was a valued, skilful act. As an active process, the practitioner had to place their clinical agenda to one side, to listen for what the patient is and is not saying. Active listening has been described as 'embodied' listening (Buber, 1970; Mundle & Smith, 2013), obvious in silence and body language, and in what was responded to (Mundle & Smith, 2013; Scott, Scott, Miller, Stange, & Crabtree, 2009). Within the observational study reported in Chapter Eight, active listening was evident in multiple forms of action: *physical* such as touch and positioning, *cognitive* such as supporting the person to co-construct their story and attending to verbal and non-verbal messages and *affective* such as attending to the patient's emotions and their own emotions, suggestive of a process of attunement (Buber, 1970; Mundle & Smith, 2013; Scott et al., 2009). It enabled openness to the other, opening up understandings of the other person's worlds. A seemingly advanced form of communication, listening appears central to many components of engagement: developing relationship, understanding what is important, finding out how to go on together, and individualising rehabilitation to respond to the needs of the individual patient.

Integrating supported communication and relational dialogue

Relational dialogue was an integrated approach to communication which combined small talk, interactional flow and active listening. In this study of engaging people experiencing communication disability, it also involved the use of supported communication techniques. To date, a reasonable amount of literature on communication between people experiencing communication disability and rehabilitation practitioners has focused on supporting the person to communicate in interactions, through the use of supported communication techniques for example. This study suggested that supported communication techniques needed to be used *together* with other aspects of relational dialogue to be engaging.

There were times that the communication supports the practitioner implemented had the unintended consequence of over-directing the interaction and/or focusing on what the practitioner wanted to hear, as demonstrated on page 194. As such, the encounter changed from one of interaction to one of transaction with an emphasis on information seeking or information giving. Communication acts such as active listening were backgrounded. Practitioners often did not appear aware of this. Some speech-language therapists described themselves and others in their profession as engaging because they knew how to support communication by implementing supported communication *techniques* and were experts in communication. This assumption has been challenged by several authors (Ferguson & Armstrong, 2004; Fourie, 2011a; Holland, 1998). Certainly the findings of this study indicated engaging communication was not the purview of any one profession. In the context of engagement, it appeared that supported communication techniques *together* with a 'package' of relational dialogue (small talk, interactional flow and active listening) were important for engagement

This research suggests there is a need to critically reflect on how communication occurs. In particular, there is a need to consider how supported communication

techniques might constrain or hide the aspects of communication which appeared important for engagement such as those discussed earlier in this section and in the previous chapter (pages 184 to 198). Foucauldian researchers argue there is a need to consider not simply what it is that one does, but what the doing does (e.g. Fadyl, 2013; Foucault, 1983). There is a need to interrogate assumptions about practice, a nuanced, critical reflection on what is done and what this brings about.

The disengaged practitioner: Implications for care

Viewing engagement as relational and co-constructed prompts attention to each person's engagement. While existing literature has considered patient engagement, the practitioner's engagement has not been considered in the engagement literature to date. This doctoral research demonstrated that practitioner disengagement was not uncommon and could impact on the patient's access to services and on how the practitioner worked with them while in rehabilitation. Several papers have indicated patient engagement can be influenced by their perception of the practitioner's engagement (Mallinson et al., 2007; Staudt et al., 2012), and that practitioner behaviours may influence engagement (Simmons-Mackie & Damico, 2009), something evident within the findings of this doctoral research. This reciprocal nature of relationship and engagement is consistent with earlier discussions of clinical practice as relational, with each person influencing the other (Beach & Inui, 2006; Douglas et al., 2015). It demonstrates the importance of attending to the practitioner's engagement.

Practitioner disengagement appeared most evident when practitioners perceived they were unable to make a difference to the patient and when they perceived the patient was disengaged. Underlying this were tensions between ideal and real practice as described by Hersh (2010b), an ideal that the practitioner 'should' be able to engage patients and 'should' make a difference (ideal practice), yet this did not always occur in

real practice with individual patients. Practitioners who appeared disengaged within this study of engagement appeared to have a limited understanding of *how* they could facilitate engagement however, and had a limited repertoire of strategies to draw on. They also appeared to have a limited repertoire of strategies to facilitate their own engagement, not just the patient's engagement.

There was complexity and contradiction within the practitioner participants' descriptions of engagement in both qualitative studies in this research. This was an example of complex polyphonic voices (L. M. Brown & Gilligan, 1992). At one level, these practitioners did not appear to consider engagement resulted from a practitioner's way of working. Instead they described engagement as an individualistic trait, outside their influence, something also described in Maclean and Pound's (2000) study of motivation in stroke patients. Some practitioners suggested disengagement was unamenable to change; this appeared to result in a sense of helplessness and disengagement. However, the data also suggested some of these same practitioners perceived patient disengagement as a personal failing on their part, with interviews and observations suggesting an implicit understanding that they *could* influence engagement. This is similar to ideas discussed by Maclean and colleagues (2002) who described feelings of guilt and helplessness when the patient was not motivated for stroke rehabilitation. While practitioners rarely talked of emotional components of disengagement, these were sometimes evident in their talk and actions such as tearfulness or a stated desire to stay away from work. Because of this, I suggest engagement-work could be considered emotional work. The emotional work inherent within rehabilitation practice has been the focus of only limited research (Kayes et al., 2015; Kolehmainen & McAnuff, 2014) although studies in the healthcare arena have indicated emotions can impact on how people enact care and make clinical decisions (e.g. McSherry et al., 2012; Michie et al., 2007). Within speech-language therapy, Hersh (2009a, 2010b) demonstrated discharge planning in aphasia therapy has an emotional

component which can impact on clinical reasoning. Consistent with this research's findings regarding disengagement, Hersh (2010b) and Kolehmainen and McAnuff (2014) indicated emotional aspects of professional practice were most apparent when practitioners perceived a tension between 'ideal' and 'real' practice. The seemingly hidden emotional aspects of engagement evident within this doctoral research appeared to impact on how the practitioner worked with the patient and thus, are arguably worthy of increased attention in future research, and in clinical practice.

The Voice Centred Relational Approach

This research has advanced methodological knowledge in two ways, making the *methodology* of the Voice Centred Relational Approach explicit, and detailing how this approach can be used with large datasets. While the Voice Centred Relational Approach is an established research approach, and has been most commonly used as an analytic *technique*, the methodology and theoretical framework that underpins the research has commonly been implicit (Mauthner & Doucet, 2003) despite these being essential in developing and implementing research methodology (Crotty, 1998). This study has explicated the theoretical underpinnings of the Voice Centred Relational Approach and shown how they directly informed how the research was planned and proceeded. This is likely to be of use to those considering and/or utilising this approach in the future.

With the exception of Mikel Brown and Gilligan's (1992) longitudinal study of moral development, the Voice Centred Relational Approach has primarily been utilised with relatively small set of interview-derived data. The large number of datasets and multiple forms of data in this study posed some challenges as there was a lack of specific guidance on *how* to enact this approach in a robust, methodical manner. Modifying the process to intentionally capture and compare verbal and non-verbal communication, and to compare action, talk-in-action and talk-about-action enabled

close examination of practice and facilitated crystallisation. Applying this methodology to observational research helped develop rich, nuanced understandings of practice, enhancing and extending findings from interview-based research. It highlighted the tensions and complexities in practice. As such, this methodology appears to be useful in examining practice. Detailing *how* this methodology was applied will be useful for those conducting observational research in the future. Using the theoretical underpinnings of the Voice Centred Relational Approach to develop a robust analytic process for the data has strengthened the analysis, provided nuanced insight into engagement practices, and has contributed to methodological development.

Limitations

Within this research, there are some limitations which must be acknowledged. The findings of this research are highly contextualised. The first qualitative study (reported in Chapter Six) primarily involved people experiencing communication disability and practitioners who were community-based; the second study (reported in Chapter Eight) primarily involved people who were inpatient-based or who had only recently discharged from hospital. The findings from the first empirical study suggested that practitioners' understandings of engagement may be influenced by the contexts in which they practice. The relational nature of engagement was particularly strong in the second empirical study; this may reflect the context in which they worked, that patient participants had only recently had a stroke and that they had moderate-severe communication disability. It might also reflect that only a small number of people experiencing communication disability were included in the research and those people particularly valued relationship. While participants in the first empirical study accessed or worked in a range of rehabilitation services (public, private, inpatient and community-based), those in the second empirical study were located within two connected services within the same health board. As such, I would promote caution

when considering the direct transferability of findings to other rehabilitation contexts and across the continuum of care. Rather, these findings may provide a starting point for reflecting on engagement and engagement-related practices within the practitioner's specific context.

The relational approach to research which underpinned this study likely contributed to the strong relational findings as relationship was one area explicitly considered within the Listening Guide analysis. This does not mean that the findings are not valid, however, it should prompt a tentativeness about them. The relational nature of engagement is *one* aspect of engagement and appears important for many but not all people experiencing communication disability. It could be anticipated that a different methodology or theoretical framework might illustrate additional understandings of engagement. Researchers and practitioners should maintain an openness to a range of ways of conceptualising engagement, recognising that these findings focus on one facet of engagement.

It is important to consider whose voices are missing or are limited within the data. Across data sets, all except for two patient participants were New Zealand European; all except for four were aged under 65 years of age. They cannot be considered representative of the stroke population (Stroke Foundation of New Zealand, 2010). The majority of practitioner participants were of New Zealand European or Asian ethnicity. Several disciplinary groups were either not represented because they were not able to be recruited, or only minimal data was collected because of the logistics of data collection. It could be anticipated that social workers and psychologists, for example, may provide particular insights into engagement as anecdotal reports suggest engagement was more likely to be considered within training and patients were often referred to these professionals if they were perceived to be struggling to engage in rehabilitation. Senior doctors were not well-represented yet hold a significant role in

rehabilitation. Exploring their perspectives and practice might have provided additional insights into engagement.

There are limitations within the observation process. Observations were not continuous and did not capture every interaction between each dyad. Other observations may have provided alternate understandings of engagement processes. While the observational study provided rich insights into how practitioners engaged people experiencing communication disability, practitioners may have modified how they work because they were being observed, the Hawthorne effect (Landsberger, 1958). However, it has been argued that it is unlikely such behaviour change would be sustained over a period of time (Gwyn, 2002; Myers, 2000) and it is likely practitioners acted how they *thought* they should act to facilitate engagement (Gwyn, 2002), meaning the data still provides insight into how practitioners work to engage people experiencing communication disability in rehabilitation. It is possible that observations of speech-language therapists (in particular, junior therapists) may have been influenced by my position as an experienced speech-language therapist. The difference in our roles and positions may have impacted on their perceptions of the situation and their actions and reflections. They may have felt self-conscious about being observed, or may have been reluctant to voice their reflections.

Data collection did not always occur as planned. For example, the number of stimulated recall sessions completed was significantly lower than intended. The logistics of completing observations, editing recordings and scheduling times to complete the stimulated recall sessions within the suggested timeframes meant it was not feasible to do more. This is somewhat disappointing as the sessions provided rich understandings of how practitioners thought about their practice. Completing stimulated recall sessions with more patient participants would have likely provided more nuanced understandings of engaging practice however most patient participants declined to

complete these sessions. The sheer amount of data, particularly in the second empirical study, meant that analysis was not as in-depth as it might have been with a smaller dataset. However, the approach taken to manage data was theoretically informed, based on the writings of leading qualitative researchers (Charmaz, 2014; Mauthner & Doucet, 1998; Tracy, 2013), which added rigour to the analysis process.

Within this thesis, I have predominantly focused on engagement processes and practices within the patient-practitioner dyad. Accordingly, there is a risk engagement challenges may be ascribed to the individual practitioner. However, service influences on practice were clearly evident. Greater attention to the context in which rehabilitation occurred might have provided a more nuanced understanding of practice, and would have better elucidated *how* practice is socioculturally located. Further research to better understand practice in the context is important and may further our understandings of professional practice.

Finally, there are some assumptions about engagement inherent within this work. Implicit within this research is an assumption that engagement is good and necessary, yet the evidence for this is currently in its infancy. It is not known if engagement is necessary with every practitioner, or perhaps if it is important with some key practitioners. Further research to further develop the conceptual base for engagement, to explicate core components of engagement, and to examine the relationship between engagement and outcomes is clearly necessary.

While the research presented in this thesis has a number of limitations, it has made substantial contributions to understandings of engagement, communication and qualitative research methodologies. As a practice-oriented study, the findings have a number of implications for practice which will be detailed below. Many of these limitations open up areas for future research, as will be detailed on page 239.

Implications for practice

A number of clinical implications arise from this research, and in particular, from the three substantive novel contributions emphasised within this chapter. There are implications for multiple levels of practice, from the one-to-one interaction between the person experiencing communication disability and the practitioner, through to an organisational level, as summarised in Figure 13.

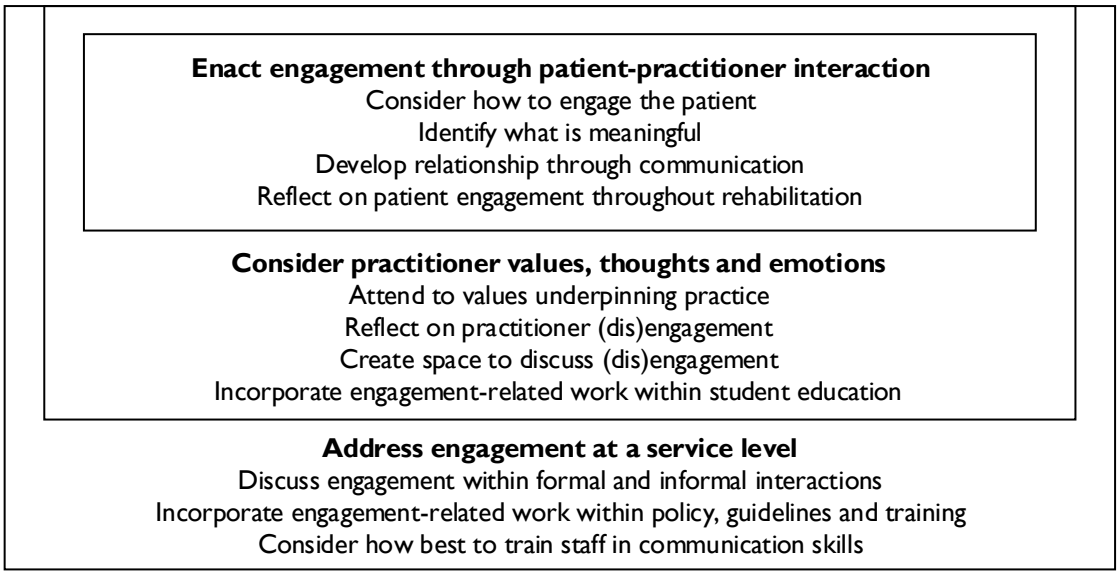
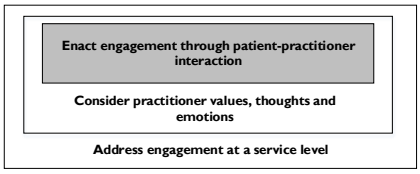


Figure 13: Implications for practice

Enact engagement in clinical practice



Viewing *engagement as a relational practice* has implications for how practitioners work throughout the rehabilitation episode, prompting practitioners to explicitly attend to patient engagement and consider how they could work to facilitate engagement. Drury and Munro (2008) proposed practitioners might view themselves

as hosts, valuing the act of *manaakitanga*[25], considering how they might welcome the patient within the services and how they might work to enhance the *mana*[26] of the patient as they work together. Framing engagement in this way opens up ways of viewing the practitioner's role, shifting from being a provider of technically-oriented services to giving primacy to creating an environment which is engaging for the patient and responds to who they are and what they need.

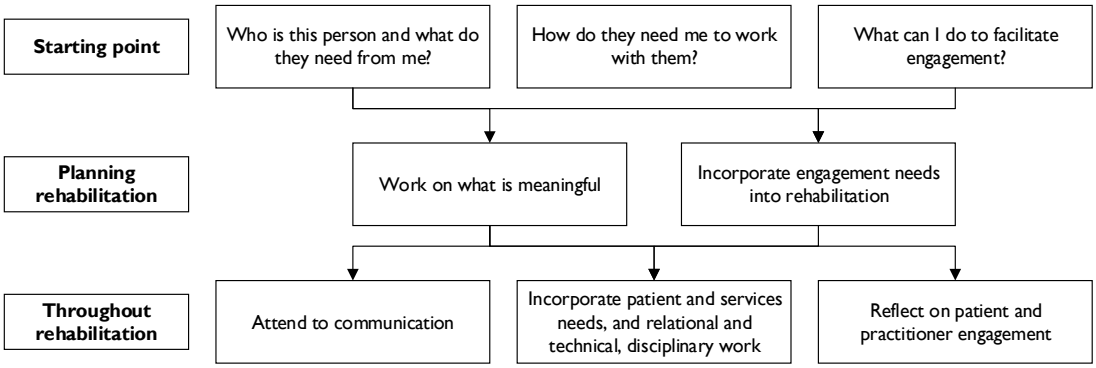


Figure 14: Enacting engagement in clinical practice

When starting rehabilitation and focusing on engagement, practitioners might consider:

- Who is this person and what do they need from me?,
- How do they need me to work with them? and
- What can I do to facilitate engagement?'.

Having these questions as a starting point may see the patient's needs and priorities be given primacy over the requirements of the practitioner and the service. This starting point requires the practitioner to be open to a range of needs and consequently, a variety of ways of working. For instance, the patient may need to develop trust, or may need an environment to express their fears or concerns. Alternatively, they may want

[25]*Manaakitanga* is a Māori term and refers to hospitality, kindness, generosity, support - the process of showing respect, generosity and care for others (www.maoridictionary.com)
[26] *Mana* is a Māori term and refers to prestige, authority, control, power, influence, status, spiritual power, charisma - *mana* is a supernatural force in a person, place or object (www.maoridictionary.com)

to focus on technical, disciplinary-based activities. This reflects that different individuals, at different times, may emphasise technical, disciplinary-based work, or relational work, or a combination of both (Fadyl et al., 2011). Each requires different responses from the practitioner. Considering the questions above may help the practitioner consider how they need to work with the patient in order to facilitate engagement (Bishop, 2015; Bright et al., 2012; Drury & Munro, 2008). The practitioner may then act as *bricoleur*, selecting from a range of tools and strategies in order to best respond to the needs of the individual patient, a creative and reflexive approach to practice (Murray, 2015; Shaw & Deforge, 2012).

It may be challenging for practitioners to identify what the patient needs from them in order to engage. One reason for this is that engagement can be conceptualised in multiple ways. Understanding what engagement means to each individual may be valuable, by asking questions such as:

- Tell me about a time you were engaged/disengaged in therapy/rehabilitation?
- What was happening?
- What was the practitioner doing? What were you doing? How were you feeling?
- Why was that [activity/therapy] engaging for you?
- How would I have known you were engaged?

Within the first empirical study of this research (Chapter Six), patient participants suggested the state of engagement and associated behaviours may exist on a continuum from 'doing the work' through to 'taking charge', a concept examined in stroke rehabilitation literature (Harwood et al., 2012; McPherson, Brander, Taylor, & McNaughton, 2004). This was not dissimilar to the continuum proposed in the conceptual review (see page 42). This current work highlighted that discussing this continuum with the patient, asking where they are currently on the continuum, where they perceive they want and need to be, and what might help them get to this place might be another way of starting a conversation about engagement, and understanding

what engagement means for that individual. While these conversations might need to be explicitly about engagement, also having broader conversations with the patient about their experiences of care to date might also give the practitioner an understanding of what the person needs from them. Listening to their stories in order to understand requires a disciplined, mindful way of listening, reading between the lines, listening to what is said and what is not said as discussed in earlier work (Bright et al., 2012), as described and observed in the second empirical study. This form of listening represents a therapeutic form of listening and can be useful for knowing how best to work; it is also useful for creating a therapeutic environment which the patient perceives to be safe and responsive to their needs and perspectives (Shipley, 2010).

Patients in this research consistently reported that working on what is meaningful and having the sense that rehabilitation is adding value was important in facilitating and maintaining engagement, something also evident in the literature (McPherson, Kayes, & Kersten, 2014). While rehabilitation services commonly require goal-setting and have structured processes in place to elicit goals (McNaughton et al., 2014), the current research indicates such processes did not necessarily appear to facilitate engagement. Instead, informal interaction between the patient and practitioner appeared important. Doing this required the practitioners to spend time talking with the patient, getting to know them, what they enjoyed, their priorities and concerns. Observations of practice indicated these conversations happened over a period of days rather than within a designated goal-setting session or meeting. In order to address what is meaningful, practitioners also need to attend to and act on what patients said, as opposed to privileging what they considered was achievable or important (Levack, Dean, Siegert, & McPherson, 2011). It appears important that practitioners do not assume goal-setting, or indeed any other single action or strategy will facilitate engagement in and of itself; instead this research demonstrated that engagement develops through multiple means

and in fact, there may be a risk that processes such as goal-setting may be disengaging if they are not understood by, and meaningful to the patient.

In addition to working on what is meaningful, having the sense that rehabilitation is valuable and having an impact is important. This might see the practitioner intentionally select activities that the patient succeeds in. However, given that task challenge has been suggested to be important in motor learning and neuroplasticity (Muir, Jones, & Signal, 2009), this research highlights there may be difficulties in finding the optimal challenge point for the individual (Guadagnoli & Timothy, 2004), when practitioners seek to balance task challenge and therapeutic success. In this instance, attending to *how* tasks are introduced and discussed, ensuring that patient progress is able to be seen by the patient and being mindful of how task complexity might impact on engagement appears important.

Communication was central to *engagement as a relational practice.* Communication patterns evident within this research were multi-dimensional and required the practitioner to bring together a variety of communicative content, conduct and acts. In the context of engagement, *communicative content* involved both clinical and non-clinical communication, and technical, disciplinary-based conversation as well as interactional, relational communication. This may be facilitated by using open-ended questions to explore patient experiences and perspectives, discussing the person's life not just their stroke-related impairments, offering small amounts of information about themselves, and engaging in small talk. Attending to *communicative conduct* requires practitioners to reflect on *how* communication occurs. When enacting supported communication, for example, practitioners should consider how this impacts on the patient's ability to actively participate, whether the techniques facilitate participation or whether they constrain it. While closed questions might reduce the linguistic demands on the patient as they only need to reply with a verbal or non-verbal 'yes' or

'no', it might also limit their ability to contribute new information or to discuss topics or questions other than those introduced by the practitioner. While patients with severe expressive language difficulties may struggle to *verbally* respond to open-ended questions, their non-verbal responses to questions such as "how are you today?", "have you got any concerns?" or "how do you feel about this plan?" can convey important information that can then be explored further. In order to critically consider *communicative conduct*, practitioners might reflect on *how* communication occurs, the types of questions they ask, how the patient is or is not able to contribute to interactions, how the patient and practitioner are positioned through the practitioner's communication, and how practitioners respond to all verbal and non-verbal communication from the patient.

A variety of communication *acts* were evident when engaging people experiencing communication disability in rehabilitation. These included asking questions, providing information, small talk, joking, touch, eye contact, pausing and laughter. Relational work was commonly subtle, evident in small talk, interaction and dialogue, and in non-verbal communication. These actions do not necessarily add significant time to interactions, a common concern of practitioners (Bright et al., 2012). Mesquita and de Carvalho (2014) suggested person-centred approaches to communication added less than one minute to general practice consultations while Crawford and Brown (2011) found communicative behaviours associated with relational work can be enacted in interactions lasting less than five minutes. Listening appeared to be an important communicative act. Practitioners could critically reflect on *how* they listen, and the depth of this, whether they are listening to understand what is said, or listening for meaning, to understand emotions, concerns and experiences. All of these communicative acts were evident across the interactions when practitioners were enacting *engagement as a relational practice* although were not necessarily within every interaction. Reflecting on what forms of communication are used or were not

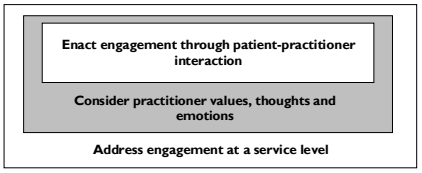
used might help practitioners consider whether they could draw on other communication acts in order to facilitate engagement.

While working to engage the patient, the practitioner may need to balance both the needs of the patient and the (mandated) needs of the service. One way this can be done is to explicitly attend to *how* activities occur, not just *what* activities occur. For example, while services might require assessments to be completed within a specified timeframe, *how* these are conducted is under the practitioner's control. Assessments and other activities can be completed in ways which recognise and arguably facilitate the practitioner-patient relationship. This current research suggests this can occur through communication behaviours such as open questions and exploring patient comments, through intonation and non-verbal behaviours, and through sitting alongside as opposed to standing over the patient. Starting interactions with open-ended questions that elicit the patient's perceptions and concerns as opposed to the practitioner's agenda is another way of incorporating engagement-related work into rehabilitation. While engagement work might require dedicated action, within this research, practitioners did not necessarily do *either* engagement work *or* rehabilitation work; in order to engage patients, both forms of work were necessary. This research supports arguments that attending to *how* rehabilitation occurs as well as *what* rehabilitation occurs (Kayes et al., 2015) can help ensure engagement-related work is embedded throughout rehabilitation practice.

Engagement as a relational practice involved critically reflecting on the patient's engagement. While some practitioners appeared to consider compliance was a marker of engagement, this research challenges the idea that the two are synonymous. Indeed, compliance may be an indicator of disengagement, with some patients reporting 'going through the motions' and practitioners describing times of 'enforcing engagement' (i.e. compliance) when the patient is disengaged. Critically reflecting on whether the patient

is 'going through the motions' or whether they are indeed engaged may be beneficial. While this research did not attempt to identify universal indicators of engagement *across* participants, observations of individual patients *across* therapeutic interactions in the second empirical study suggested body language, facial expression, use of and response to humour and contributions to interactions might be indicators of engagement. Patient temperament and non-verbal communication across situations might also give some indication of their level of engagement in individual interactions. However, it is perhaps more important and reliable to ask the person about their engagement and how they perceive rehabilitation. The continuum of engagement (discussed on page 229) may provide a framework for having that conversation. While individual practitioners might struggle to have these conversations, particularly if the relationship between the patient and practitioner is not strong, it may be appropriate for a designated team member (for example, the person with whom the patient appears most engaged) to regularly review the patient's engagement in their rehabilitation. This, of course, requires that action can result from the patient's feedback. This research demonstrated some practitioners found it difficult to challenge other staff members, and that engagement was not universally valued across practitioners. In order for such conversations to be meaningful and not pay lip service to the patient's perception, this process needs to be valued by the service as well as individuals working within it.

Consider the practitioner's values, thoughts and emotions



This doctoral research into engagement highlighted that the practitioner's values, thoughts and emotions appeared to underpin their actions and how they worked to facilitate engagement. Accordingly, it is important to attend to these within clinical practice.

It may be beneficial to explicitly attend to the values which underpin professional practice, influencing how practitioners view and enact engagement. One way a practitioner could explore assumptions and values is to use a critical reflection approach (Fook & Gardner, 2007; F. Gardner, 2009; Savaya & Gardner, 2012). This approach supports practitioners to explore critical incidents, which in the context of engagement might include times of engagement or disengagement, or engagement-related challenges, drawing on critical theory and post-modern and post-structural thought to consider missing perspectives, dominant discourses and power relations. Such an approach is intended to support practitioners to unpack and articulate the assumptions and values underpinning their practice while also identifying areas of conflicting values, such as conflicts between organisational and personal values. Whilst practitioners *migh*t state the values they give primacy to, the literature suggests people may not always be aware of the values influencing their thought and action (Higgs et al., 2009; Savaya & Gardner, 2012) as many are tacit rather than explicit, sub-consciously absorbed through exposure in different situations (Schatzki, 2012).

Practitioner engagement and disengagement appears worthy of attention both in conjunction with patient (dis)engagement and in its own right. This doctoral research raised questions about whether patient disengagement may impact on practitioner disengagement and vice versa. Patient disengagement should prompt practitioners to reflect on:

- their own engagement;
- whether their engagement may be influencing patient (dis)engagement;
- their response to the situation; and
- whether their response might be influenced by the patient's disengagement.

Additionally, practitioner disengagement should prompt practitioners to reflect on what is happening and why they are experiencing disengagement. While patient engagement can be explored by asking questions about previous experiences of

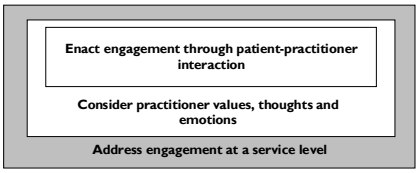
engagement (see page 229), asking the same questions of practitioners may provide some insight into how they view engagement. Such questions might provide a starting point for discussing engagement or disengagement, and might help explore how and why these states come about.

Practitioner disengagement also appeared influenced by a lack of training, support and low self-efficacy (in particular, the sense they could make a difference for the patient). Some practitioners indicated that their disengagement influenced clinical decision-making, and that research has linked patient experiences of care with staff experiences at work (Maben et al., 2012; Mundle & Smith, 2013) there is arguably a need to closely attend to disengagement. Ensuring staff are able to reflect on their practice in a safe, supportive environment appears imperative if practitioner disengagement is to be addressed, and if staff are able to explore the reasons behind this disengagement. While some staff have regular professional supervision, not all do. For instance, medical and nursing staff do not consistently have access to professional supervision (Lipworth, Morrell, & Kerridge, 2008). Even when supervision occurs, it is recognised that self-disclosure may be limited (Savett, 2011). Supervision may focus on the technical delivery of care rather than the emotional aspects of providing care (A. C. Jones & Cutcliffe, 2009), a managerial approach rather than supportive. Reviewing the different functions supervision performs and ensuring supervisory arrangements meet the different needs of the individual also appears important (A. C. Jones & Cutcliffe, 2009). Techniques such as the Schwartz Rounds (Luterman, 2011; Stickley & Freshwater, 2006) or Balint Group Training (Kurtz, 2002) may provide the necessary space for practitioners to reflect on *how* care occurs and the emotional work involved in providing rehabilitation.

Developing knowledge about engagement and skills in engaging patients should arguably start within student education, framing it as a set of skills which can be

learned and taught rather than being an inherent trait that the practitioner either does or does not have. Engagement may be implicit or potentially side-lined within teaching for several reasons. Education may focus on technical skills and knowledge reflecting a technical rationalist approach (Bradley, 2009; Schön, 1983). There is also currently a very limited evidence base to guide teaching on engagement and relational work. Making engagement explicit within education may support students to become more aware of engagement, to develop their skills in both engaging patients and in reflecting on how their practice may impact on engagement. This requires attention to engagement within the university classroom and in the workplace while on placements, in student feedback, assessment and marking structures. This may require supervisors to consider how they conceptualise engagement and the practitioner's role in engagement, as this will likely influence how they educate and support students. It also requires attention to the education environment and how this might impact on student values. One study reported medical students believed they lost their values of person-centred practice throughout training due to a lack of self-efficacy, barriers such as time, and a lack of role modelling (Liberati et al., 2015). Developing further knowledge about engagement will likely be beneficial for informing clinical education in this area.

Address engagement at a service level



If engagement and relational work is to be a legitimate form of rehabilitation, this must be supported at a service level. This research demonstrated that patient engagement needs to be proactively considered, addressed and reviewed throughout rehabilitation. Incorporating engagement and relational work into KPIs or guidelines, perhaps modifying these to reflect engagement-related work can require a significant investment of time in the early stages of rehabilitation,

might be one step that could be taken. Proactively discussing engagement and ways of working within team meetings or patient handovers rather than reacting to situations when disengagement has occurred might also see this way of working valued as legitimate and important, and also as a tangible aspect of rehabilitation. Services could also offer training in engagement-related work, supporting staff to develop skills in these areas. The challenge is in supporting engagement-related work without mandating it, which risks it becoming a tick-box activity. This would be contrary to the findings of this research which indicated engagement is an individualised approach to practice, informed by a philosophy of practice.

While the recommendations so far have focused on engagement and different aspects of practice, this research also highlighted how communication disability may not be discussed in interactions between practitioners, which could influence how practitioners work to engage the patient. Within handovers, explicitly discussing both the presence and type of communication disability *and* sharing information about how to support communication might help patients and practitioners alike. The findings of this research have implications for how speech-language therapists support other healthcare professionals to communicate with people experiencing communication disability. Communication training should perhaps incorporate personal values, principles underpinning supported communication *and* communication techniques as all three of these together were important in engaging people experiencing communication disability. Personal values and understandings of the principles of communication support appeared to impact on how techniques were enacted. It is worthwhile considering who receives training and support and *how* these occur. Within this research, while speech-language therapists appeared to give specific communication advice to allied health practitioners, doctors and nurses appeared to have a number of communication challenges. In order to develop skills and change behaviour, a range of interventions are likely required, and these need to be tailored to

the needs of the individuals within their specific context (Baker et al., 2015; Grol, 2002). Inservices, which therapists considered useful for training, may not be the most effective means of training and facilitating practitioner behaviour change. Drawing on the implementation science literature might also help therapists design interventions to improve communication skills. One strategy may be to buddy with a doctor or nurse, using these opportunities to model communication and support the practitioner to communicate may be more effective due to its authentic, relevant nature. Additionally, this approach might support speech-language therapists to work with the patients without focusing on assessment and treating communication impairments, which was sometimes problematic for the engagement of both parties (see page 181). Arguably, this way of working also facilitates patient participation and inclusion in other aspects of their rehabilitation, an approach consistent with a social approach to therapy (Byng & Duchan, 2005).

Implications for research

A number of areas for further research emerge from this doctoral work. Given the populations who were missing in this research study, exploring this topic with broader ethnic, cultural and professional groups, in a variety of clinical contexts may provide further understandings of engagement practices. Working with Māori researchers, using kaupapa Māori research[27] may support more detailed understandings of how practitioners engage with Māori in stroke rehabilitation.

The observational study of this research was centred on three people experiencing communication disability and the 28 practitioners working with them. While the focus was on the practitioner's way of working, data collection was centred around the

[27] Kaupapa Māori research is a research approach which privileges Māori knowledge and ways of knowing (Tuhiwai Smith, 2012)

patient. This provided detailed understandings of engagement practice but did not examine how each practitioner worked across a larger number of patients across their caseloads, attending to how (or indeed *if)* they personalised practice to meet the specific engagement needs of each individual, and how and why they worked as they did. An observational study which positioned the practitioner as the central unit, focused on several practitioners working with a number of patients, could be anticipated to augment understandings of clinical reasoning and would further enhance the knowledge base on professional practice in rehabilitation.

As a practitioner-researcher, I have an interest in exploring *how* the findings of this research might impact on practice. One such study could utilise a participatory action research design (Kemmis, McTaggart, & Nixon, 2014; Kemmis, Wilkinson, et al., 2014). Drawing on the idea of 'transformative communities' (Nicholson, 2013), researchers could work alongside a group of practitioners who are interested in considering the findings of the study within their context, taking the knowledge from this research and associated readings to critically reflect on their own engagement practices. As well as enabling critical consideration of engagement in practice and exploring how knowledge could be implemented, a critical participatory action research approach would also allow exploration of sociocultural factors which influence practice, an area briefly addressed in this research, but not explored in detail. Such research is an example of how utilising different theoretical frameworks and methodologies might enable new or different understandings of the phenomenon. Of course, exploring sociocultural factors influencing engagement is an area worthy of investigation in its own right (i.e. not solely in conjunction with a critical participatory action research study).

Inherent within these suggestions for research is an assumption that engagement is positive and important for rehabilitation outcomes. Further research is required to support this assertion. Further critical exploration of the *state* of engagement, seeking

to differentiate it from related concepts such as participation might enable researchers to develop theoretically and conceptually derived measures of engagement. Additionally, I suggest it is essential to develop measures completed by the patient rather than by practitioners as there are clearly difficulties in judging another person's engagement. These might enable quantification or measurement of engagement or disengagement which would enable further exploration of the relationship between patient engagement and patient outcomes. As indicated in the conceptual review, no measures address practitioner engagement. Yet this research has indicated *practitioner* engagement may be important in patient engagement and in clinical service delivery. Further exploring the practitioner's engagement and considering how best to measure their engagement might be important in developing clinically-oriented understandings of engagement.

Finally, there are several implications for research which arise from my personal learnings and questions over the course of the PhD. While these may not be anticipated to make a significant contribution to advancing knowledge of *engagement*, they are possible research topics which reflect my personal interests as a researcher-practitioner and as a researcher-educator. For instance, the Voice Centred Relational Approach has highlighted one area for research. Feedback from conference presentations where I presented i-poems suggested these i-poems may be useful in prompting reflection on practice. This raises questions about whether the Voice Centred Relational Approach may be a useful technique for fostering practitioner reflection, not simply being an analytic technique in qualitative research. Using the Voice Centred Relational Approach in this way could possibly advance research on practitioner reflection, while also extending use of i-poems and the Listening Guide, further contributing to methodological advancement.

With regard to health professional education, the findings suggest exploration of how engagement is addressed within student education is warranted. As a researcher-educator, there are two distinct perspectives that seem of particular relevance. First, it could be asked how engagement could best be addressed within the curriculum to support students to critically reflect on engagement, and to develop skills and strategies in engaging patients. My second interest comes from my teaching experiences during my PhD in which I worked with students who were struggling to engage with their clinical supervisors. Without consciously intending to do so, I found myself implementing the core components of *engagement as a relational practice*, working to get to know the student and how they needed me to work with them, prioritising relational work, and developing a two-way relationship. These strategies appeared effective in engaging the students and creating environments where we could have difficult and/or personal conversations and where we could work intensively on their clinical or relational skills. These experiences have led me to question whether the core components that underpin patient engagement (relationship and communication, and technical, disciplinary-based knowledge and specific tasks) could be utilised in student engagement.

Conclusion

This doctoral research started with my desire to know how I could better engage people experiencing communication disability in stroke rehabilitation. Implicit within this was an understanding that practitioners could influence engagement, and in fact, had a responsibility to consider engagement within their practice. In order to answer this question, I needed to consider what engagement might mean to different parties in rehabilitation, as well as considering how it was successfully enacted in practice.

A conceptual review of the literature (Chapter Two) and an empirical qualitative study with people experiencing communication disability and rehabilitation practitioners (Chapter Six) suggested engagement was a multi-faceted concept. It could be viewed as a process occurring between the patient and practitioner, and a patient state. This research has highlighted the practitioner's central role in engagement, a role that appears particularly pivotal when a patient is struggling to engage. The process of engagement, and in particular, the practitioner's ways of working were the focus of the second empirical study within this doctoral research. This study suggested practice was informed by a relational frame; practitioners working in this way valued relationship and engagement and this informed how they thought about and enacted practice. Enacting *engagement as a relational practice* was a nuanced complex way of working in which practitioners valued and enacted both relational and technical, disciplinary-based ways of working. Practitioners working in this way considered they had an important, if not central role in facilitating engagement, and utilised relationship and communication as therapeutic resources. There was consistency and congruence between how they talked about engagement, relationships and rehabilitation practice, and how they worked. There were complexities inherent within engagement work and this research has provided some understanding into why some practitioners may not view *engagement as a relational practice*, or why they might struggle to address engagement within their ways of thinking about and enacting clinical practice. In particular, the frame that surrounds a practitioner's ways of thinking about and enacting engagement and rehabilitation appears central in how, or in fact *if* the practitioner managed such tensions.

By elucidating different aspects of engagement, the findings (and my dissemination of these) will hopefully prompt researchers and practitioners to attend to the multiple meanings engagement can hold. A number of research questions have emerged from this research; these could help advance knowledge on engagement. The detailed

explanations of practice may support practitioners to reflect on their own practice (their values, and stated and enacted ways of working) to consider whether their ways of working are consistent with those described as *engagement as a relational practice.* These may also provide some engagement strategies which practitioners could draw on when working to engage people experiencing communication disability. The findings should prompt universities and clinical services to consider how engagement is considered and legitimised or backgrounded within policy, practice and training.

Overall, this research has significantly advanced existing understandings of engagement. It indicates engagement is multi-faceted and strongly influenced by the practitioners' way of thinking about and enacting practice. This challenges the idea that engagement is an intrinsic patient state and behaviour. Engagement is complex, both conceptually and in practice. This research indicates it warrants greater consideration in education and in practice, as something we explicitly attend to and reflect on. Elucidating how engagement is constructed through relationships rather than solely being an intrinsic patient state and responsibility, may guide practitioners in understanding and reflecting on their practice. It is hoped the findings of this research open up different ways of "springboarding into a relationship" and engaging people experiencing communication disability in stroke rehabilitation.

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Appendix A

Search terms

EBSCO search terms

[(therap* N10 engag*) OR (treatment* N10 engag*) OR (rehabilit* N10 engag*) OR (physiotherap* N10 engag*) OR ("mental health" N10 engag*) OR (speech N10 engag*) OR ("allied health" N10 engag*) OR (nurs* N10 engag*) OR (doctor N10 engag*) OR (physician N10 engag*) OR (patient* N10 engag*) OR ("clinical practice" N10 engag*) OR ("social work" N10 engag*) OR ("assertive outreach" N10 engagement)] AND [(review N5 engag*) OR (measure* N5 engag*) OR (assess* N5 engag*) OR (perception* N5 engag*) OR (experience* N5 engag*) OR (model* N5 engag*) OR (construct N5 engag*) OR (concept* N5 engag*)] in abstract, title or keywords

SCOPUS search terms

[(therap* W/10 engag*) OR (treatment* W/10 engag*) OR (rehabilit* W/10 engag*) OR (physiotherap* W/10 engag*) OR ("mental health" W/10 engag*) OR (speech W/10 engag*) OR ("allied health" W/10 engag*) OR (nurs* W/10 engag*) OR (doctor W/10 engag*) OR (physician W/10 engag*) OR (patient* W/10 engag*) OR ("clinical practice" W/10 engag*) OR ("social work" W/10 engag*) OR ("assertive outreach" W/10 engagement)] AND [(review W/5 engag*) OR (measure* W/5 engag*) OR (assess* W/5 engag*) OR (perception* W/5 engag*) OR (experience* W/5 engag*) OR (model* W/5 engag*) OR (construct W/5 engag*) OR (concept* W/5 engag*)] in abstract, title or keywords

Appendix B

Example of analytic matrices

How does the paper define engagement?

Author	Definition
Drury	Do not explicitly define
Godlaski	Defined in a number of ways – therapeutic alliance, behavioural outcomes (intensity & duration of Rx participation), retention Influenced by range of: client variables – motivation, employment, clinician's interpersonal skills – empathy, perceived usefulness of therapy Imply that factors may include (or should be researched): patient variables, counsellor variables, programme and environmental factors Need to consider the client's ability to engage with him/herself, to engage with own strategies, capacities and talents – self-efficacy Use "engaging" in a number of ways. A quality of a service (what do clients find engaging about services), a state or experience (bring therapeutically engaged), an action (difficulty engaging in treatment) Did not provide a specific definition of engagement
Hall	Complex and multi-faceted, appointment keeping as well as what occurs within and between sessions
Hitch	Occupational engagement – participation in activities that form parts of the individual's identity Service engagement – initial or subsequent participation in any programme of assistance or intervention for people with MH problems. Author considers it multi-faceted – may include intrinsic and extrinsic influences, therapeutic relationship and relationship to health – all need to be explored Refers to CAOT – engagement is an enablement skill that involves clients in doing, in participating, that is to say, in action beyond talk by involving others and oneself to become occupied
Horton	Somewhat synonymous with participation and learning Involves sense of commitment and involvement on the part of all parties Interactionally managed May be hindered by cognitive, communicative, attitudinal or knowledge issues

How does engagement develop or diminish?

Author	Data
Drury	Through practitioner skill – "as a host, I need to figure out how we are to go on together in a manner which is beneficial and enhancing to both of us, and does not trample on the mana of either of us. This is the art of manaakitanga (hospitality) – enhancing the mana of each of us" (p. 320). This can be seen as a performance talent which may be useful for crisis negotiation. Based on respect.
	Refer to Signs of Safety approach for building partnerships – what is worrying, what is working well, what needs to happen. Collaborative relationships (which appear synonymous with engagement though not explicitly said) likely to happen when focusing on strengths, what is working well and what the problems of concern are. Suggest (p. 321) that a strengths based approach is more likely to engage or to reduce the chance of one 'taking flight' or becoming defensive
	Manaakitanga is one tool – deliberate atmosphere generated, everyone listened to respectfully and responsively
Godlaski	Feelings of anxiety lessened in first two sessions due to warm and welcoming attitude of staff and other clients, and being with other women whose experience was similar to theirs
	What made them feel comfortable in treatment – an accepting situation where they could express their experiences without undue fear of judgement; staff treated them with respect and listened to their understanding of their experience; being with others whose experiences were the same
	Number of factors that created accepting environment – welcoming, honesty, felt at ease, not judge or disapproved of, trust, welcome, accept. Empathetic, respectful attitude of staff was an important factor – not being contradicted or judged, too concerns seriously, helped them get assistance
	Hearing other women's stories – not alone or isolated, understood or accepted.
	Feeling comfortable important as they gave the participants a sense of acceptance by others leading to self acceptance and a sense of hope that things could be better
	Self-disclosure could also be an obstacle to engagement
	Not everything has to be perfect in order to be engaging (e.g. groups) – authors suggest there is a threshold of +ve experience for engagement; lack of negative thinking
	Key things to engage someone: other women; inviting and welcoming physical and relational environment; accept and value others who are different; Requires sense of autonomy – authors suggest this is a pre-requisite for engagement

Appendix C

Constructing an i-poem

Sample of rehabilitation practitioner focus group

Felicity: *From your perspective when you're working with people with stroke, if you could describe someone who looked like they were really engaged or involved in their rehab, what would that look like to you?*

Practitioner 1: We have patients on the inpatient ward who when they're really engaged, **they tell the nurse that I've got the session at this time**, you have to help me get dressed before then. **They're** very **proactive** in terms of therapy, **they know what they want** out of therapy, **they're making sure the system works in their favour**

Practitioner 2: They're generally well and medically stable and, yeah, on the whole

Practitioner 3: Yip

Practitioner 4: **They tend to be more likely to do any home practice you set for them** as well. It's a little bit harder for me because of the way I work with these people … Often **they** are the ones who will, in my experience, ask questions or **comment on what they're doing** which **shows me they're thinking about what they're doing**, not just doing what they're told. It doesn't have to be a lot but they'll occasionally ask or say something that shows you they're reasoning and processing and have got some insight or are trying to understand how this will help or why it's hard

Practitioner 2: Yip

Practitioner 5: Or **they'll tweak what you gave them** and say "That worked but I've been thinking about this and have done ….

Practitioner1: "I've thought about this and decided … you know"

Practitioner 4: **They're an active participant not a passive recipient**. **It's easy to be a passive recipient** but these participants are actively involved and adapt things and give feedback.

Sample of i-poem constructed from participant data

They're proactive
They're know what they want
They tell the nurse 'I've got a session at this time, you have to help me get dressed'
They're making sure the system works in their favour
They are more likely to do any home practice you set for them
They comment on what they're doing
That shows me they're thinking about what they're doing
They'll tweak what you gave them
They're an active participant not a passive participant
It's easy to be a passive participant
(Composite i-poem. Focus group)

Appendix D

Participant information sheets

INVOLVEMENT AND PARTICIPATION IN REHABILITATION:
WHAT HELPS OR HINDERS?

AUT UNIVERSITY

PARTICIPANT INFORMATION SHEET: People with Stroke

An invitation

You are invited to take part in a study of people's experiences of stroke rehabilitation.

You can choose if you want to take part in the research. It is entirely **voluntary** (your choice).

If you decide to not take part, **it will not affect care or treatment** you are receiving.

If you do take part, **you can change your mind at any time.** You do not have to give a reason.

This information sheet will give you **information about the study.** It may help you decide if you would like to take part. Please **tell us** if it is **difficult to understand** or if you have any **questions.** If you **need an interpreter**, we can arrange one.

This study is coordinated by the Person Centred Research Centre at AUT University in Auckland and will form part of Felicity Bright's PhD. It will take place between 1 January 2012 and 31 December 2012.

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Who can take part in the study?

We are inviting **18-24 people with stroke** to take part in this study.

What are the aims of this study?

We are trying to learn more about **people's experience of taking part in rehabilitation**.

In particular, **we will ask you** about:

- What made you **feel involved**, or engaged in rehabilitation
- **What helped** you feel involved in rehabilitation
- **What stopped** you feeling involved in rehabilitation

What happens if I decide to take part?

You will be asked to take part in **an interview**. If you have **communication difficulties**, these will take place over **two sessions**.

You are welcome to have a **family member or friend present** to help you communicate.

Each interview will take **60-90 minutes**.

We would like to **tape record and video** the interviews to make sure we don't miss important details.

The interview can take place where you choose. It may be at your home, at AUT or somewhere else. If it costs you to travel to the interview, we will **reimburse you**.

We will also ask if you would like a **family/whānau member to take part** in our study. If you give us permission to contact them we would need to tell them you are taking part in this study.

We would like to **ask them about two things**:

(1) their views of ***your*** **involvement in rehabilitation**, and

(2) their views of ***their own*** **involvement** in your rehabilitation.

We would be talking to them in a **focus group situation**, i.e. with family members of other people with stroke. This would **involve them sharing their views in this group**.

We will ask all focus group members to **maintain confidentiality**, but cannot completely guarantee this.

You **do not need to nominate a family/whānau member** for this study. This will not prevent *you* from taking part in the study.

What happens with the results of the study?

The results will be presented at **conferences**. They will also be published in **professional journals.**

We can give you a **copy of the results** if you would like.

How can I volunteer to take part in this study?

You can **contact the researchers** directly to **find out more** about the study or to **volunteer** to take part.

Felicity Bright (Research Officer) 921 9999 x 7097

What future research are you doing?

We plan to do several studies related to this one. These are:

1) Talking with **family/whānau** about involvement in stroke rehabilitation (engagement)
2) Talking with **rehabilitation providers** about engagement
3) Developing a **guide to help therapists** engage/involve people in rehabilitation
4) Developing an **assessment** to determine a person's level of engagement

We will use the findings from this study to underpin our future research.

If you or your family/whānau would like to find out more about this research, please let us know.

Confidentiality

What you say **is confidential**.

Only the members of the research team will know what you say. **You will not be identified** in research findings.

If you are Māori, we may ask our Māori advisors to help us make sure we have interpreted what you say correctly. They will not know who you are.

Your information will be **securely stored at AUT University**. Computer files will be password protected.

Your information will be stored for **ten years**. All future use of information will be strictly controlled and is bound by the Privacy Act.

Your rights

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Freephone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.govt.nz

How will the study affect me?

Taking part will take some of your **time**.

Benefits to you:

You may find it **helpful to talk about your experience**.

Benefits to others:

This study will help us understand how to improve patient involvement in rehabilitation. This should help improve their outcomes from rehabilitation

Risks:

There should **not be any risks** from taking part in the study.

You may find the interviews **tiring**. If you are tired, we can **take a break**.

Some people may find it **difficult to talk about their experiences**.

If you feel distressed by any questions, **you do not have to answer** and we can stop the interview.

Support services

If you **experience distress** from taking part, **please let us know** so we can help arrange support for you.

You may wish to talk with someone at the **Stroke Foundation.**
Stroke Foundation: 475 0070

Alternatively, you can access **free counselling at AUT University** if taking part in the research causes you distress:
AUT Health, Counselling and Well-being: 921 9998

To ensure ongoing cultural safety Nga Kai Tataki - Maori Research Review Committee Waitemata DHB encourage those who identify themselves as Maori and who are participating in health research or clinical trials to seek cultural support and advice from either Mo Wai Te Ora – Maori Health Services or their own Kaumatua or Whaea.

For assistance please contact the Services Clinical Leader for Mo Wai Te Ora – Maori Health on 09 486 1491 ext: 2324 or the Maori Research Advisor on 09 486 1491 ext: 2553

If you have concerns about how the research is conducted, you can contact
Dr Rosemary Godbolt (Executive Secretary, AUT Ethics Committee)
Phone: **921 9999 x 6902**
Email: rosemary.godbolt@aut.ac.nz

Please keep this brochure for your information.
Thank you for reading about this study.

This study has received ethical approval from the Northern X Regional Ethics Committee, ethics reference number NTX/12/03/015 and AUT Ethics Committee (reference number: 11/305)

Participant Information Sheet: Rehabilitation Providers

Date Information Sheet Produced:

19 March 2012

Project Title

Involvement and participation in rehabilitation following stroke: What helps or hinders?

Researcher Contact Details:

Felicity Bright	felicity.bright@aut.ac.nz	921 9999 x 7097

Project Supervisor Contact Details:

Dr Nicola Kayes	n.kayes@aut.ac.nz	921 9999 x 7309
Prof Kath McPherson	katmcp@aut.ac.nz	921 9999 x 7110

An Invitation

You are invited to take part in a research project entitled: *Involvement and participation in stroke rehabilitation services: What helps or hinders?*, which is being undertaken by Dr Nicola Kayes, Felicity Bright and Professor Kathryn McPherson who are researchers in the Person Centred Research Centre at AUT University, and Dr Linda Worrall of the University of Queensland. It will take place between 1 January and 31 December 2012. The findings from this study will contribute to Felicity Bright's PhD.

To help you decide whether to take part it is important for you to understand why the research is being done and what it will involve. This information sheet sets out answers to some of the questions you may have about the study. Read the information carefully. Please ask us if there is anything that is not clear or if you would like more information. Your participation is entirely voluntary. If you do agree to take part you may withdraw at any time without having to give a reason.

What is the purpose of this research?

This study is seeking to understand what makes a person feel involved, or engaged in rehabilitation services, and what might help or hinder this process. We are talking to people with stroke, their family/whānau and rehabilitation providers about this.

We are hoping to talk to 8-12 rehabilitation providers who are currently working with people with stroke. We will primarily do this through focus groups but may also conduct some individual interviews. These discussions will focus on your perceptions and experiences of engaging people with stroke in rehabilitation.

How was I chosen for this invitation?

We are inviting a number of rehabilitation providers from a variety of professional backgrounds to participate in this study.

What will happen in this research?

If you consent to take part in this research, you will be invited to take part in a focus group and/or individual interview. The interviews will focus on your perceptions and experiences of engaging people with stroke in the rehabilitation process.

Focus groups will involve up to six participants and will last between 60 and 90 minutes. We will aim to hold the focus groups at a time and venue that is convenient to you.

Individual interviews are likely to take approximately one hour, and will be held at a time and location convenient to you.

Both focus groups and individual interviews will be audio-taped and transcribed for analysis, and will only be available to members of the research team.

What are the benefits?

Benefits to you: Discussing your perceptions and experiences of engaging people with stroke may help you critically reflect on your practice.

Benefits to others: We are hoping that this study will help us understand how to improve patient participation and involvement in rehabilitation services, which should improve their outcomes from rehabilitation. Your views and experiences will contribute to the development of a guideline for rehabilitation providers, to help them reflect on, and respond to engagement-related issues.

What are the discomforts and risks?

We do not expect there to be any risks to you from participating in this study. It is possible that reflecting on your clinical practice may cause discomfort. If you wish to access supports after participating in this study, you are able to access three free counselling sessions through AUT Health, Counselling and Wellbeing Centre and also through the Employee Assistance Programme (EAP). Their contact details are on page 3.

How will my privacy be protected?

Your information will be confidential to the research team. Only the investigators of the study and research assistants will see the transcripts of the interviews although for participants who identify as Māori, we may show sections of anonymised transcripts (with no identifying information) to our Māori advisors to ensure the *wairua* of what is said is captured in our analysis.

All information is confidential. Material will be stored securely in locked cupboards or password-protected computer files. Your personal information will be kept in separate to the transcripts of the interviews. Data will be kept securely for ten years and then destroyed.

While some of your quotes from the focus groups or interviews may be used in reports your details will be altered so you cannot be recognised.

For the focus groups, the researchers will explain to all participants that what each person says should not be talked about outside the group but this cannot be guaranteed.

What happens to the results of the study?

The findings will be written up to be presented at appropriate conferences and published in professional journals. If you wish to receive a summary of the findings please supply your name and address or email address to the researcher.

What other related research will be happening in the future?

We intend to use the findings of this study, and the broader study of engagement, to underpin future research we do. Specifically, we hope to develop: (1) a guide to clinical practice for rehabilitation providers to help them engage people in rehabilitation and (2) an assessment that will enable researchers and clinicians to measure levels of engagement.

What are the costs of participating in this research?

There are no costs associated with this research except your time which is likely to be between 60 and 90 minutes. If you travel to take part in the focus groups or interviews, your travel costs will be reimbursed.

How do I agree to participate in this research?

You are welcome to contact the research staff directly to find out more about the study, or to volunteer to take part. Their contact details are at the bottom of the page.

Will I receive feedback on the results of this research?

Yes. If you would like to receive a summary of findings you can indicate this on the consent form. If so, we will send you a written summary on completion of the study (this is likely to be in March/April 2013). If you wish to discuss the summary findings with one of the research team, we are happy to meet with you or discuss them with you over the telephone.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Nicola Kayes, *n.kayes@aut.ac.nz*, 921 9999 x 7309

Support Services

AUT Health, Counselling and Well-Being Services	09 921 9998
EAP Counselling	09 358 2110 or 0800 327 669.
Health and Disability Advocate	0508 555 050

To ensure ongoing cultural safety Nga Kai Tataki - Maori Research Review Committee Waitemata DHB encourage those who identify themselves as Maori and who are participating in health research or clinical trials to seek cultural support and advice from either Mo Wai Te Ora – Maori Health Services or their own Kaumatua or Whaea.

For assistance please contact the Services Clinical Leader for Mo Wai Te Ora – Maori Health on 09 486 1491 ext: 2324 or the Maori Research Advisor on 09 486 1491 ext: 2553

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Freephone: 0800 555 050
Free fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.govt.nz

This study has received ethical approval from the Northern X Regional Ethics Committee, ethics reference number NTX/12/03/015'

Appendix E

Consent forms

AUT UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Consent Form: People with Stroke

Project title:

Involvement and participation in rehabilitation following stroke: What helps or hinders?

Project Supervisor: Dr Nicola Kayes n.kayes@aut.ac.nz 921 9999 x 7309
Researcher: Felicity Bright felicity.bright@aut.ac.nz 921 9999 x 7097

	REQUEST FOR INTERPRETER		
English	I wish to have an **interpreter.**	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
NZ Sign Language	I wish to have a sign language interpreter	Yes	No
Samoan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

1. I have **read the Information Sheet (dated 19 March 2012)** *or* someone has read it to me.

2. I have **been able to ask any questions** I have.
   I am happy with the answers given.

3. I have been able to **talk about the study with family** or friends

4. I understand that the interview will be **audio-taped and video recorded** and transcribed.

5. I know I can **choose to not answer** questions.
   I know I can also **stop being in the study** at any time.
   If I withdraw, all information about me will be destroyed.
   I know that this will in no way affect my future health care.

CF: People with stroke Version 2: 19 March 2012 1

6. I understand that everything I say is **confidential**.
I know that no material that could identify me will be used in any reports on this study.

I agree to take part in this research	Yes/No
I wish to receive a transcript of the interview	Yes/No
I wish to receive a recording of the interview	Yes/No
I wish to receive a copy of the report of the research	Yes/No
I agree to the researchers contacting my family member (named below), telling them that I have taken part in the study, and giving them information about the study	Yes/No
I agree that my family member can discuss their views of my Involvement in rehabilitation in a focus group	Yes/No
I would like to be contacted in the future to get more information about the broader study of engagement that is planned	Yes/No

Family member name: _____

Address: _____

Telephone: _____

Email: _____

Participant's signature: .....

Participant's name: .....

Participant Contact Details (if applicable):

.....

.....

.....

.....

Date:

This study has received ethical approval from the Northern X Regional Ethics Committee, ethics reference number NTX/12/03/015

Note: The Participant should retain a copy of this form.

Consent Form: Rehabilitation Providers

Project title:

Involvement and participation in rehabilitation following stroke: What helps or hinders?

Project Supervisor:	Dr Nicola Kayes	n.kayes@aut.ac.nz	921 9999 x 7309
Researcher:	Felicity Bright	felicity.bright@aut.ac.nz	921 9999 x 7097

1. I have read the Information Sheet dated 19 March 2012.
2. I have been able to ask any questions I have and I am happy with the answers given.
3. I understand that the focus group or interview will be audio-taped and transcribed.
4. I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.
   I understand that although confidentiality in the focus group will be encouraged this cannot be guaranteed.
5. I know I can also stop being in the study at any time.
   If I participate in *a focus group*, I understand that while it may not be possible to destroy all records of the focus group discussion of which I was part, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used.
   If I participate in *an interview*, I know that all information about me will be destroyed.
6. I know that no material that could identify me will be used in any reports on this study.

I agree to take part in this research	Yes/No
I agree to keep the contents of the focus group discussions confidential	Yes/No
I wish to receive a copy of the report of the research	Yes/No
I would like to be contacted in the future to get more information about the broader study of engagement that is planned	Yes/No

Participant's signature: .....

Participant's name: .....

Participant Contact Details (if applicable):

.....

.....

.....

.....

Date:

This study has received ethical approval from the Northern X Regional Ethics Committee, ethics reference number NTX/12/03/015

Note: The Participant should retain a copy of this form.

Appendix F

Ethical approval: Regional Health Ethics

Health and Disability Ethics Committees

Northern X Regional Ethics Committee
Private Bag 92522
Wellesley Street
Auckland 1141
Phone: (09) 580 9105
Fax (09) 580 9001
Email: northernx_ethicscommittee@moh.govt.nz

26 March 2012

Ms Nicola Kayes c/- Ms Felicity Bright
Rehabilitation and Occupation Studies
AUT North Shore Campus
Room AA272 AA Building
Private Bag 92 006 Auckland 1142

Dear Nicola

Re:	Ethics ref:	**NTX/12/03/015** (please quote in all correspondence)
	Study title:	Exploring engagement in rehabilitation in people with stroke. PIS/Cons v#2, 19/2/12
	Investigators:	Ms Nicola Kayes (Principal/Supervisor), Ms Felicity Bright, Professor Kathryn McPherson, Professor Linda Worrall
	Localities:	Auckland University of Technology, Counties Manukau DHB, Waitemata DHB

Thank you for your response received 21 March 2012 with the amended documents. The study has received ethical approval from the Northern X Regional Ethics Committee. Please provide locality assessments from Counties Manukau DHB and Waitemata DHB when available. A list of members of the Committee is attached.

Please note the Chairperson's comments:

> "The Chair is satisfied with your detailed response. We recognise that people who have taken part in the study may wish to be kept informed on developments in stroke rehabilitation which we recognise is a separate issue from recruiting people for future studies. We ask you to, however, exercise care in handling the databases with contact numbers on them. It is permissible to use these databases to inform people of research and upcoming studies provided these databases are not used to actively recruit selected individuals. Any future studies will of course require separate ethics applications."

Approved Documents

- Protocol number [undated, received 28/2/12]
- Participant Information sheet/Consent form version [version 2, dated 19 March 2012]
- Family and Whanau Information sheet/Consent form version [version 2, dated 19 March 2012]
- Family and Whanau (of people with stroke) Information sheet/Consent form version [version 2, dated 19 March 2012]
- Information sheet/Consent form (Rehabilitation Providers) version [version 2, dated 19 March 2012]
- Invitation version [2, dated 19 March 2012]

This approval is valid until 30 March 2013, provided that Annual Progress Reports are submitted (see below).

The following required documents were reviewed:

- Locality assessment from Auckland University of Technology
- Letter of Maori support from Waitemata DHB MRRC

Access to ACC

For the purposes of section 32 of the Accident Compensation Act 2001, the Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out. Participants injured as a result of treatment received in this trial will therefore be eligible to be considered for compensation in respect of those injuries under the ACC scheme.

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by **30 March 2012**. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Requirements for the Reporting of Serious Adverse Events (SAEs)

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

- are *unexpected* because they are not outlined in the investigator's brochure, and
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and
- if the study involves blinding, result in a decision to break the study code.

There is no requirement for the individual reporting to ethics committees of SAEs that do not meet all of these criteria. However, if your study is overseen by a data monitoring committee, copies of its letters of recommendation to the Principal Investigator should be forwarded to the Committee as soon as possible.

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

Statement of compliance

The committee is constituted in accordance with its Terms of Reference. It complies with the *Operational Standard for Ethics Committees* and the principles of international good clinical practice.

The committee is approved by the Health Research Council's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990.

We wish you all the best with your study.

Yours sincerely

Cheh Chua
Administrator
Northern X Regional Ethics Committee

cc: Waitemata DHB
CMDHB Research Office

Ethical approval: University Ethics

AUT UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

MEMORANDUM

Auckland University of Technology Ethics Committee (AUTEC)

To: Nicola Kayes
From: **Dr Rosemary Godbold** Executive Secretary, AUTEC
Date: 18 April 2012
Subject: Ethics Application Number 12/88 **Exploring engagement in rehabilitation in people with stroke.**

Dear Nicola

I am pleased to advise that the Chair of the Auckland University of Technology Ethics Committee (AUTEC) and I have approved your ethics application. This delegated approval is made in accordance with section 5.3.3.2 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 30 April 2012.

I advise that as part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/research/research-ethics/ethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 17 April 2015;
- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/research/research-ethics/ethics. This report is to be submitted either when the approval expires on 17 April 2015 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact me by email at ethics@aut.ac.nz or by telephone on 921 9999 at extension 6902. Alternatively you may contact your AUTEC Faculty Representative (a list with contact details may be found in the Ethics Knowledge Base at http://www.aut.ac.nz/research/research-ethics/ethics).

On behalf of AUTEC and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

Dr Rosemary Godbold
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Felicity Bright felicity.bright@aut.ac.nz, Katherine McPherson

From the desk of ...
Dr Rosemary Godbold
Executive Secretary
AUTEC

Private Bag 92006, Auckland 1142
New Zealand
E-mail: ethics@aut.ac.nz

Tel: 64 9 921 9999
ext 8860
Fax: 64 9 921 9902

Appendix G

Participant information sheets

Participant Information Sheet

Engaging in stroke rehabilitation

Investigators:

Felicity Bright — Speech Language Therapist
PhD Candidate, AUT University
Phone: 921 9999 x 7097
Email: felicity.bright@aut.ac.nz

Dr Nicola Kayes — Senior Lecturer, AUT University

Prof Kath McPherson — Professor of Rehabilitation
AUT University

Prof Linda Worrall — Professor of Speech Pathology
University of Queensland

You are invited to take part in stroke rehabilitation research

Kia ora

You are invited to **take part** in a **research project.** We are doing research into **how rehabilitation providers work with (engage) people in stroke rehabilitation.** This is part of **Felicity Bright's PhD.**

What is the research about?

- We want to learn **how rehabilitation providers help people** engage in stroke rehabilitation
- We are focusing on how they help **people who have communication difficulties**
- We want to watch how the staff work with you

You can choose if you want to take part in the research. **It is your choice.** If you decide to not take part, this **will not affect your care** at [locality].

If you do take part, **you can change your mind** at any time. You do not have to give a reason.

This information sheet gives you **information about this study.** It may help you decide if you would like to take part. **We will go through it with you.** Please **ask questions** at any time.

You **do not have to decide now** about taking part in the study. Please **talk with family or whānau** first if you wish.

What does the research involve in [name of inpatient service]?

A. Observing how staff work with you each week

- We would like to **observe you and the staff** [name of clinical service].

- **Week one:** Observe for **2 days.**
- We will **audiotape** you and the staff.

- **Every week after that:** Observe for up to **4 hours each week.**
- We will **videotape** you and the staff.

We don't want to intrude. If you are busy with visitors, or **need privacy**, or **need rest**, or **don't want us there** for <u>any</u> reason, you can ask us to leave.

B. Interviews each week

- We would also like to **talk with you** each week about how you are engaging in rehabilitation.

- We would also like to **interview you after you leave** [clinical service].

- We would like to videotape these interviews.

C. Talking through videos every 2-3 weeks

Together with you, we would like to **watch a short video of you and different staff working together**. We will **ask you questions** about what you were thinking at the time.

D. Talking with your rehabilitation providers each week

We will also **talk with your rehabilitation providers** about how they are working with you. We will **watch the same videos** with your rehabilitation providers

F. Reviewing your medical records

We would like to **review your medical records** to see how the staff talk about how they worked with you

What does the research involve once I am home?

If you have rehabilitation from [name of service], we would like to do the same things (observations, interviews, watching videos).

The only difference is that we would observe all rehabilitation sessions in the first two weeks.

We will ask if you would like to **stay involved** in the study.

Frequently asked research questions

Can anyone else be with me when I am doing the research?

- **Absolutely!** Your **family or whānau or friends are welcome to be with you** at any time during the study.

How does this research benefit me?

- This is **not speech therapy or rehabilitation.** You **may not benefit** from this study.
- You may find **talking about your rehabilitation** can be helpful.
- You will be **helping us learn** how we can work better with other people with stroke in the future.

Are there any risks?

- There are **no physical risks** in doing this study.
- Talking about stroke might be **upsetting** for some people
- It can be **hard to watch yourself on video.** If it is too hard, or if you don't want to do it, we won't watch the videos.
- If you feel the research is **getting in the way of your rehabilitation, we can stop.**
- **If you find the research difficult, we can stop.** You might find it helpful to talk with a Māori support worker, social worker or psychologist if you wish.

Who pays for the study? Do I get paid for taking part?

- This research will not cost you money.
- We will give you **gift vouchers to say thank you** for taking part.

How do the researchers keep information private?

We will keep your information **private and confidential.** This means:

- Your information will be stored in **locked or password protected files.**
- **We will not use your name** or any identifying information when presenting findings unless we specifically ask you and you say yes.
- Only researchers will have access to your information.
- Information will be kept at AUT University.

In the future, we may ask you if we can **use specific parts of a video.** We may want to use it in Felicity's thesis or for teaching. **You are welcome to say no.**

Note: We will not use any videos unless you explicitly agree to this.

What happens after the study?

- All information will be kept securely at **AUT University for 10 years.** After 10 years, all audio- and video-tapes will be destroyed.

Will I find out the results?

- **Yes!**
- We will meet you and give a **summary of our early analysis.** We will ask for your thoughts, **whether you think we are on the right track.**
- We will give you a **summary of the findings at the end of the study** – in **2015.** We can do this face-to-face, or we can send you a copy of the findings.

Contact details

Who do I contact for more information?

- If you want **more information**, please contact **Felicity Bright.**
  - Phone: 921 9999 x 7097
  - Email: felicity.bright@aut.ac.nz

What do I do if I have concerns about the research??

Any concerns regarding the nature of this project should be notified in the first instance to Dr Nicola Kayes (research supervisor). Her phone number is 921-9999 x 7309 and her email is nkayes@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, 921 9999 ext 6902.

Who else can I contact for support?

- If you want to **talk to someone who isn't involved with the study**, you can contact an independent health and disability advocate on:

  Phone: 0800 555 050
  Fax: 0800 2 SUPPORT (0800 2787 7678)
  Email: advocacy@hdc.org.nz

- For **Maori health support** please contact :

- You can also contact the **health and disability ethics committee** (HDEC) that approved this study on:

  Phone: 0800 4 ETHICS
  Email: hdecs@moh.govt.nz

Ethics and locality approval details

Approved by the Auckland University of Technology Ethics Committee on 28 August 2013. AUTEC Reference number 13/243

Approved by Health and Disability Ethics Committee on 14 August 2013. HDEC Reference number 13/NTB/103

Participant Information Sheet

Research study: **Engaging in stroke rehabilitation**

Investigators:

Felicity Bright	Speech Language Therapist and PhD Candidate, AUT University
Dr Nicola Kayes	Senior Lecturer, AUT University
Prof Kath McPherson	Professor of Rehabilitation, AUT University
Prof Linda Worrall	Professor of Speech Pathology, University of Queensland

Kia ora

You are invited to take part in a research project. We are exploring how rehabilitation providers engage people with communication difficulties in stroke rehabilitation. This study contributes to Felicity Bright's PhD.

Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect your employment. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. You are welcome to talk with other people before making your decision.

If you agree to take part in this study, you will be asked to sign a Consent Form. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 5 pages long. Please make sure you have read and understood all the pages.

What is the purpose of the study?

This study forms part of a broader study of engagement in stroke rehabilitation services. This study focuses specifically on how rehabilitation providers engage people with communication difficulties in stroke rehabilitation. Through exploring rehabilitation providers' clinical practice and the influencing factors, the study aims to help us better understand how engagement occurs and how clinicians may be able to better engage patients if they are struggling to engage.

Why have I been invited to participate in this study?

Your patient _____ has consented to take part in the study. We are inviting all of his/her rehabilitation providers to participate in the study.

What does the research involve?

If you agree to take part in the research, you will be asked to sign a consent form. This research will take place over a six month period, although your involvement will only be for as long as your patient _____ is in your service.

If you agree to participate, the research will involve observations of normal clinical interactions, and interviews. It may also involve participating in a stimulated recall session. We will also ask you to comment on our early analysis.

A. Observations of patient-clinician interactions each week.

In the patient's first week in rehabilitation, we will observe patient-clinician interactions over a two day period. You don't need to do anything different to usual – we are looking at who is interacting, how and about what. These interactions will be audiotaped.

After the first week, observations will happen twice a week for a maximum of four hours. We will purposefully select which interactions to observe – such as particular clinicians, particular types of interactions (e.g. education vs therapy). We will let you know this in advance.

Please note:

- Patient safety and care is paramount. If the patient is busy, needs privacy or rest, we will not intrude.
- If you feel our presence has the potential to, or is impacting on patient care, we will leave.

B. Interviews

We would like to talk with you every two weeks about how rehabilitation is going. This would take between 5 and 15 minutes and would be at a time convenient to you. We may also ask you to participate in an interview after your patient leaves your service. This would take about an hour. We would like to audiotape these interviews.

C. Reviewing videos of sessions (stimulated recall)

We may ask you to participate in one stimulated recall session. This involves reviewing a ten minute video of an observed session and talking it trhough with the researcher. This would take up to one hour.

What are the potential benefits of the study?

Benefits to you: Discussing your perceptions and experiences of engaging people with stroke may help you critically reflect on your practice.

Benefits to others: We are hoping that this study will help us understand how to improve engagement in rehabilitation services, which should improve their outcomes from rehabilitation.

What are the potential risks of the study?

We do not expect there to be any risks to you from participating in this study. It is possible that reflecting on your clinical practice may cause discomfort. If you wish to access supports as a result participating in this study, you are able to access three free counselling sessions through AUT Health, Counselling and Wellbeing Centre and also through the Employee Assistance Programme (EAP). Their contact details are on page 5.

Will taking part in this study cost me anything and will I be paid?

Participation in this study will not cost you. We will give you a gift voucher to say thank you for taking part.

How will my privacy be protected?

Your information will be confidential to the research team. Only the researchers, or transcriptionists who have signed confidentiality agreements will see the transcripts of the interviews. Material will be stored securely in locked cupboards or password-protected computer files. Your personal information will be kept in separate to the transcripts of the interviews. Data will be kept securely for ten years and then destroyed.

It is possible the researchers would like to use sections of videotapes in the future, for example, as part of Felicity Bright's PhD thesis, or as part of a workshop on engagement. If this is the case, we will ask you to consent to the use of the tape. We will identify what we want to use and how we intend to use it. You are free to say no to this as it will identify you.

What happens to the results of the study?

We will give you a copy of the findings of the study. This is likely to be in 2015.

The findings will be written up to be presented at appropriate conferences and published in professional journals. They will be incorporated into Felicity Bright's PhD thesis.

Who do I contact for more information or if I have concerns?

If you want more information, please contact Felicity Bright.

Phone: 921 9999 x 7097 Email: felicity.bright@aut.ac.nz

What do I do if I have concerns about the research??

Any concerns regarding the nature of this project should be notified in the first instance to Dr Nicola Kayes (research supervisor). Her phone number is 921-9999 x 7309 and her email is nkayes@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, 921 9999 ext 6902.

Who else can I contact for support?

If you want to **talk to someone who isn't involved with the study**, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

For Maori health support please contact :

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Support and counselling is also available through:

AUT Health, Counselling and Well-Being Services	09 921 9998
EAP Counselling	09 358 2110 or 0800 327 669.

Ethics and locality approval details

Approved by the Auckland University of Technology Ethics Committee on 28 August 2013.
AUTEC Reference number 13/243.

Approved by Health and Disability Ethics Committee on 14 August 2013.
HDEC Reference number 13/NTB/103.

Appendix H

Consent forms

Consent Form

Research study: Engaging in stroke rehabilitation

Researcher:	Felicity Bright	felicity.bright@aut.ac.nz	921 9999 x 7097
Project Supervisor:	Dr Nicola Kayes	n.kayes@aut.ac.nz	921 9999 x 7309

I _____ (full name) agree to take part in this study.

I have had time:

- To think about **whether I want to participate**
- To **talk with family and whānau** about taking part

I understand:

- I **do not have to take part.** It is my choice.
- I can **change my mind.**
- I can **ask questions** at any time.
- I can **stop the research** at any time.

I understand what is involved:

- The researcher will **observe me working with some of my rehabilitation providers** in [redacted]

- **I will be interviewed** about my rehabilitation
- I will watch **videos of me and some of my rehabilitation providers** while talking with the researcher

- Most interviews and observation sessions will be **video-taped**; the others will be **audio-taped**

- The **research will happen each week** while I am receiving rehabilitation
- My participation is **confidential**; no one will know I have participated.
- If the researchers want to use any videotapes publically, they will tell me what video they would like to use, and what they would like to use it for. I can say no.

I agree that the researcher can:

- **Tell my rehabilitation providers** that I am taking part
- **Talk with my rehabilitation providers** about how they are working with me
- **Review my medical records**
- **Contact me** in the future if they would like to **use any videos that might identify me**

If I want to ask any questions about the study, I need to contact

Felicity Bright

Phone: 921 9999 x 7097 Email: felicity.bright@aut.ac.nz

I understand what this research is about	YES	NO
I agree to take part in this research	YES	NO
I agree the researchers can ask me if they want to use videos in the future	YES	NO
I would like to receive a summary of the results	YES	NO

Participant's name: _____

Participant's signature: _____

Date: _____

Declaration by researcher: I have explained the research project, what it will involve, and the potential risks. I have answered the participant's questions. I have offered to discuss the study with family and whānau. I believe the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Researcher's signature: _____

Date: _____

Ethical approvals

Approved by the Auckland University of Technology Ethics Committee on 28 August 2013. AUTEC Reference number 13/243

Approved by Health and Disability Ethics Committee on 14 August 2013. HDEC Reference number 13/NTB/103

Consent Form

Research study: Engaging in stroke rehabilitation

Researcher:	Felicity Bright	felicity.bright@aut.ac.nz	921 9999 x 7097
Project Supervisor:	Dr Nicola Kayes	n.kayes@aut.ac.nz	921 9999 x 7309

Please tick to indicate you consent to the following

I have read and I understand the Participant Information Sheet.	Yes ☐	No ☐
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	No ☐
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes ☐	No ☐
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my employment.	Yes ☐	No ☐
I understand that observations will be audio-taped in the first week, and all observations, interviews and stimulated recall sessions will be video-taped.	Yes ☐	No ☐
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study unless I have explicitly consented to this, after the researchers have told me what they wish to use and for what purpose.	Yes ☐	No ☐
I agree the researchers may contact me in the future if they wish to use any video data that might identify me	Yes ☐	No ☐

I agree the researchers may contact me in the future about research related to engagement in stroke rehabilitation	Yes ☐	No ☐
I know who to contact if I have any questions about the study in general.	Yes ☐	No ☐
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature: Date:

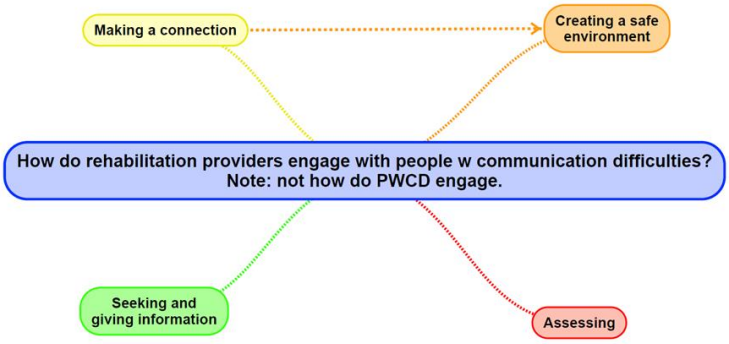
Ethical approvals

Approved by the Auckland University of Technology Ethics Committee on 28 August 2013. AUTEC Reference number 13/243

Approved by Health and Disability Ethics Committee on 14 August 2013. HDEC Reference 13/NTB/103

Appendix I

Early mindmap and analytic memo



Creating a safe environment

Creating a sense of safety is a priority for some clinicians. They recognise and respond to the emotional experience of the patient and consider they have a role in creating an environment in which the patient can feel safe and able to trust the practitioner. They do this by looking for indicators of the patient's emotions, through verbal reassurance and quiet questioning, through light touch to physically reassure. They provide opportunities for the patient to talk without placing expectation on them by leaving pauses and time, by commenting without quizzing.

In contrast, other practitioners consider safety and communication to be two separate entities. In this situation, safety is prioritised over communication. Ward tasks that are considered central to safety (which appear to be medications, falls prevention, toileting) take priority on the task list of these practitioners. Even within a task (e.g. giving medications, taking observations), the task is foregrounded and communication is not seen to be a priority. If there is intentional communication, it is centred on mechanics of the specific task rather than there being any interaction or relational dialogue alongside, preceding or following the task.

Creating a safe environment as an intentional practice may be an important practice as the patient with 'just' a communication difficulty is a vulnerable patient in the context of an inpatient ward. Patients who are physically mobile and independent with activities of daily living 'need' little input from nursing staff in particular, who are likely to be prioritising 'heavy' or 'bell-heavy' patients. This means there are less formal (or informal) opportunities for interaction and connection. This may lead to a predominantly task-based approach to interaction and connection. These patients are also vulnerable because there is a perception (that some perceive) inpatient rehabilitation is for patients

Late section of mindmap and analytic memo

Creating a [safe] therapeutic environment

> "The first couple of sessions are really about getting them on your boat, getting them on board. It's good when you know about the hobbies - you can talk about that, involve them in discussion - that's one way to do it. The first few sessions are all about getting them on board. You want him to leave with the feeling that he's done something, got something out of it and that he's enjoyed it."

Creating an environment that facilitates engagement is a leading concern for some rehabilitation practitioners. As an active verb, 'creating' involves a process of making something out of what is, using what is in the environment. "Creating" a therapeutic environment sees the practitioner position themselves as an active ingredient in the engagement process, mindful of how their actions, their way of working, might influence the patient. Their starting point is the patient's needs rather than the system's requirements, functioning as a bottom up approach. While there is not a recipe for creating an environment, because it is individualised, there are some core ingredients.

Tim sees creation of a therapeutic environment essential. He takes Ryan's previous experiences into account, knowing they have had a "rough time" on the acute stroke ward and that his family do not trust the staff and are reluctant to leave Ryan unattended. Tim is also aware of the shock that comes from stroke, a sudden shift from wellness and independence, to disability and dependence, to some extent putting himself in Ryan's shoes, viewing the situation from their perspective. In this, he is interpreting Ryan and his wife's behaviour, looking for the story behind the actions, looking at 'why?' and 'how did this come to be?', not just 'what?'. In looking behind actions, he also opens up the space for critical reflection on the rehabilitation

environment, which includes his role, actions and attitudes as a rehabilitation practitioner. Looking at 'what' the patient and family are doing can, in contrast, lead to a focus on the patient and family, seeking the behaviour as acontextual, or the patient's problem, something **they** (the patient and family) have to change.

Creating a therapeutic environment starts from day one. Tim describes these early days saying "*the first couple of sessions are really about getting them on your boat, getting them on board ... You want him to leave with the feeling that he's done something, got something out of it and that he's enjoyed it*". This way of thinking about working appears to function as a frame or a template, shaping the practitioner's way of working. It also shapes what they view as a successful outcome. For Tim, a successful outcome is establishing trust, that Tim's wife will feel able to leave him with the rehabilitation practitioners, knowing he is in safe hands. He describes this saying "*kind of impress them in a way, just to gain their trust really".* One way to facilitate trust is through demonstrating competence, giving the impression the practitioner knows what they're doing. To do this, Tim actively works to facilitate success, facilitating movements that Ryan has been unable to do before (and which are not particularly functional), "*playing to the audience and making him and his wife feel that he'd done something, seen something different … trying to find something that would leave them with a reasonable experience"*, consistent with his aim of having the patient "*leave with the feeling that he's done something".* Developing a therapeutic relationship is another aspect of creating a therapeutic environment as the relationship helps the patient be "*more comfortable with you and you know them more*". Harriet emphasises communication skills such as listening, using communication tools, allowing time for responses or moving on when appropriate.

While Tim's description and conduct of practice reflect a focus on 'what' is done and the resulting product (satisfaction, trust), they reflect his view that he is responsible for facilitating this, that who he is with Ryan, and what and how he does it matters. He is an active participant, mindful of the impact of his actions. He reflects on what he brings and his own engagement in the moment: *"My engagement is quite important - you have to be in the moment, constantly monitoring change, seeing if I do x, what does he do, how does he react?"*. This reflects a mindful approach to practice, considering what the patient needs from him and how he needs to act in response. Tim constantly monitors how his engagement is enacted in response to constant reading of the patient's engagement, balancing the two to get his desired result, that with some patients "*the last think you want to do is ramp them up so you quieten them down, talking quietly. Then others, you want to get them going*". While this mindful reflection on his practice is a hallmark of a highly-engaging practitioner, it highlights the complexity of clinical practice and the multiple forms of clinical reasoning that might be undertaken in the moment.

Harriet emphasises creating a safe environment in the moment, a space where her patient feels supported and comfortable to do the activities she wants to do. This is an environment that encourages Betty to act but does not require it – opportunity without expectation (a theme that comes up when discussing communication as well). When Betty feels unsure, she is reassured: "*that's OK, you need to feel safe. If you're not*

comfortable then that tells us something", and Harriet uses several strategies to encourage her to try. These include informing her about the task by explaining and demonstrating it, using physical touch to support her and encouraging her verbally, but also moves beyond this to try and understand why Betty is uncomfortable, seeking her perspective. Harriet reflects on her actions after the fact: "*if they're reluctant, you make them comfortable and then they do it for you*", highlighting the role of the practitioner in creating a safe therapeutic environment for the patient.

What is a therapeutic environment?

What is a therapeutic environment? Trust and safety are evident in a therapeutic environment, facilitated through interaction. I contrast Tim's practice (as a 'therapeutic environment') and Kelly's (perhaps a 'clinical environment'). With Tim, Ryan feels involved and informed, talked to as an individual, reporting Tim is focused and caring. But more than this, there is supported achievement: "*he helps you through it so you achieve ... he backs off if needed".* In this context, Ryan appears to want to do therapy. In contrast, with Kelly, Ryan talks of feeling "*anti*", although reports "*I didn't realise what [therapy] I was doing … I couldn't be bothered*". He reported "*there was no connection*" with Kelly or with the therapy tasks. While he took responsibility for this "*I was just negative … it was me you know*", he also commented Tim was "*positive*" and that if Kelly "*had just backed off the hard stuff so you could do some easier things, then it would have been fine*".

A therapeutic environment, especially a safe therapeutic environment, might be more than just the 1:1 clinical environment. Tim takes an active role in challenging other team members who seek to attribute disengagement and dissatisfaction to the patient and his family. In taking this role in team meetings, removing the issue from the individual patient and elevating it to a systemic level, he depersonalises the issue and prompts the team to reflect on 'why' not 'what': *"To be fair, this has been a long time coming … There seems to be a lot of difference between what patients receive on the weekend compared to during the week. This isn't a bad thing to be honest, if it gets us looking at what is happening on the weekend".*

When is a therapeutic environment not a therapeutic environment?

A practitioner may talk the talk, describing themselves as an active player in patient engagement, aspiring to help the "*feel a bit safer maybe in the environment they are in, given it's obviously a scary time*", yet the majority of their (observed) interactions were practitioner-driven, focused on their agenda or 'to-do' list for the session. Sitting alongside Lorna's narrative of patient-centredness (which 'creating a therapeutic environment' is part of), is a competing narrative of service constraints. Helping someone feel safe "*comes with time*" and when time is limited, there is less time for relational aspects of care – instead, the doing of the work is prioritised. That is not to say the practitioner does not try to work in a way that facilitates safety and comfort,

but this might be backgrounded while completing assessments and preparing for discharge might be prioritised.

Appendix J

Ethical approval: Regional Health Ethics

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
C/- MEDSAFE, Level 6, Deloitte House
10 Brandon Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

14 August 2013

Ms Felicity Bright
Person Centred Research Centre (PCRC)
Health & Rehabilitation Research Institute
AUT University | North Shore Campus
90 Akoranga Drive, Northcote
Auckland 1142

Dear Ms Bright

Re:	Ethics ref:	13/NTB/103
	Study title:	Engaging people with communication difficulties in stroke rehabilitation

I am pleased to advise that this application has been *approved* by the Northern B Health and Disability Ethics Committee. This decision was made through the HDEC-Full Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern B Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at *a given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Participant access to ACC

The Northern B Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or

distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Raewyn Sporle
Chairperson
Northern B Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted

Document	*Version*	*Date*
CV for CI: CV for Felicity Bright	1	03 July 2013
Evidence of scientific review: Scientific review at AUT	1	03 July 2013
Protocol	1	03 July 2013
PIS/CF: PIS forms - introductory PIS to be given by nurse specialist, full PIS for patient, staff and family participants	PIS 1	03 July 2013
PIS/CF: CF for patient, staff and family participants	CF 1	03 July 2013
Demographics form	1	03 July 2013
Application		

Appendix B
Statement of compliance and list of members

Statement of compliance

The Northern B Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008715) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*	*Present on 06/08/2013?*	*Declaration of interest?*
Mrs Raewyn Sporle	Lay (the law)	01/07/2012	01/07/2015	Yes	No
Mrs Maliaga Erick	Lay (consumer/community perspectives)	01/07/2012	01/07/2014	Yes	No
Mrs Mary Anne Gill	Lay (consumer/community perspectives)	01/07/2012	01/07/2015	Yes	No
Mrs Kate O'Connor	Non-lay (other)	01/07/2012	01/07/2015	Yes	No
Mrs Stephanie Pollard	Non-lay (intervention studies)	01/07/2012	01/07/2015	Yes	No
Dr David Stephens	Lay (consumer/community perspectives)	01/07/2012	01/07/2014	Yes	No
Dr Paul Tanser	Non-lay (health/disability service provision)	01/07/2012	01/07/2014	Yes	No
Ms Kerin Thompson	Non-lay (intervention studies)	01/07/2012	01/07/2015	Yes	No

http://www.ethics.health.govt.nz

Ethical approval: University Ethics

AUTEC
SECRETARIAT

28 August 2013

Nicola Kayes
Faculty of Health and Environmental Sciences

Dear Nicola

Re Ethics Application: **13/243 Engaging people with communication difficulties in stroke rehabilitation.**

Thank you for submitting your application for ethical review. I am pleased to confirm that the Chair and I from Auckland University of Technology Ethics Committee (AUTEC) have approved your ethics application for three years until 28 August 2016.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/researchethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 28 August 2016;
- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/researchethics. This report is to be submitted either when the approval expires on 28 August 2016 or on completion of the project;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within their.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Felicity Bright

Auckland University of Technology Ethics Committee
WA507 Level 5 WA Building City Campus