The experience of being supported to participate in decision making after severe traumatic brain injury

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Abstract

The right to make decisions about one's own life is a fundamental tenet of the United Nations Convention on the Rights of Persons with Disabilities and a central aim of contemporary disability policy. To date, there has been limited investigation into how people with traumatic brain injury (TBI) and those in their social support network participate in the decision-making process. Without this knowledge, people with TBI will not have access to decision-making support that meets their needs and supports their participation.

The aim of this doctoral inquiry was to explore the experiences of adults with severe TBI and those around them in making decisions about their lives after injury in order to inform practice. Constructivist grounded theory methods were used. Eight adults with TBI and eleven nominated decision-making supporters participated. Supporters included spouses, parents, support workers and a friend. Each participant was interviewed at least twice over a 12-month period.

The research yielded four published articles and one submitted manuscript. The overarching finding from the data reflected the relational nature of decision-making participation for adults with TBI and captured the relationship between three key constructs: *giving and receiving support, constructing the decision-making space,* and *conceptualising self*. Several factors were identified that supported a positive support relationship, including knowing the person well, understanding the impact of the brain injury and taking a positive approach to risk. Based on these findings, a series of recommendations for clinical practice are presented.

This is the first body of research to simultaneously explore the experiences of adults with TBI and those around them in making decisions about life after injury. It highlights the critical role that supporters play in supporting decision-making participation and provides guidance for those supporting adults with TBI regarding how they can maximise the person's participation.

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This thesis represents a collaborative effort and I am privileged to have had the support of many people over the course of its development and completion.

To the participants who so willingly and generously gave their time to me, I hope that I have done your stories justice. Thank you for teaching me so much about life after brain injury.

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Finally, to my husband Daen, this thesis belongs to us. Your love, support and generosity have sustained me through the many ups and downs along this journey. Along with our darling Sabine, I hope that we will share many wonderful post-thesis adventures.

For Sabine,

May you learn from the wisdom of those who have walked a different path.

Statement of Authorship

This thesis consists primarily of work by the author that has been published or accepted for publication as described in the text. Except where reference is made in the text of the thesis, this thesis contains no other material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

Lucy Christine Knox

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Publications and presentations arising from this thesis

Publications included in this thesis

Knox, L., Douglas, J., & Bigby, C. (2013). Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury. *Disability and Rehabilitation, 35*(22), 1926-1932. doi: 10.3109/09638288.2013.766270

Knox, L., Douglas, J., & Bigby, C. (2015). Becoming a decision-making supporter for someone with acquired cognitive disability following TBI. *Research and Practice in Intellectual and Developmental Disabilities.* Advance online publication. doi: 10.1080/23297018.2015.1077341

Knox, L., Douglas, J., & Bigby, C. (2015). 'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI. *Brain Injury, 29*(6), 745-757. doi: 10.3109/02699052.2015.1004753

Knox, L., Douglas, J. M., & Bigby, C. (2016). "I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents. *Neuropsychological Rehabilitation, 26*(2), 236-260. doi:10.1080/09602011.2015.1019519

Knox, L., Douglas, J., & Bigby, C. (2016). "I've never been a yes person": Decision-making participation and self-conceptualisation after severe traumatic brain injury. *Disability and Rehabilitation.* Advance online publication. doi: 10.1080/09638288.2016.1219925

Related publications completed during candidature not included in this thesis

Douglas, J., Bigby, C., Knox, L., & Browning, M. (2015). Factors that underpin the delivery of effective decision-making support for people with cognitive disability. *Research and Practice in Intellectual and Developmental Disabilities, 2*(1), 37-44. doi: 10.1080/23297018.2015.1036769

Douglas, J., Drummond, M., Knox, L., & Mealings, M. (2015). Rethinking social-relational perspectives in rehabilitation: Traumatic brain injury as a case study. In K. McPherson, B.E. Gibson, A. Leplege (Eds.), *Rethinking rehabilitation: Theory and practice* (pp.137-162). Boca Raton, FL: CRC Press.

Conference papers

Knox, L., Douglas, J., & Bigby, C. (2015, July). *"I'm considered unable to make decisions… not capable": The subjective experience of decision making after severe TBI.* Paper presented at the 5th Pacific Rim Conference of the International Neuropsychological Society/Australasian Society for the Study of Brain Impairment, Sydney, Australia.

Foster, A., Lanyon, L., and Knox, L. (2015, April). *"I'm still a person… and I have an opinion": Novice researchers' experiences of engaging with people with communication impairments within a social constructivist paradigm.* Paper presented at Qualitative Methods Conference, Melbourne, Australia.

Knox, L., Douglas, J., & Bigby, C. (2014, December). *"The underlying things are still the same": Moving into the role of decision-making supporter for a person who has an acquired cognitive disability following severe TBI.* Paper presented at the 8th Disability Round Table, Melbourne, Australia.

Knox, L., Douglas, J., & Bigby, C. (2014, May). *"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents.* Paper presented at 37th Annual Brain Impairment Conference, Perth, Australia.

Knox, L., Douglas, J., & Bigby, C. (2014, May). *"In the end, I just be a passenger to the things that go on around me": Understanding the role of communication in decision-making participation after severe TBI.* Paper presented at Speech Pathology Australia National Conference, Melbourne, Australia.

Knox, L., Douglas, J., & Bigby, C. (2014, March). *"Even when I say we, it was a decision that I made": The experiences of adults with severe TBI and their partners in making decisions about life after injury.* Paper presented at the 10th World Congress on Brain Injury, San Francisco, USA.

Knox, L., Douglas, J., & Bigby, C. (2013, July). *"There's more to it than what you see on the CT scan": The experience of decision-making impairment after severe traumatic brain injury.* Paper presented at 10th International Symposium on Neuropsychological Rehabilitation, Maastricht, Netherlands.

Knox, L. & Douglas, J. (2013, May). *"There's a lot of things that I just know I can't influence": The experiences of adults with severe TBI and their partners in* *making decisions about life after injury.* Paper presented at 36th Annual Brain Impairment Conference, Hobart, Australia.

Knox, L., Douglas, J., & Bigby, C. (2012, October). *Managing the tensions associated with supporting decision making after severe acquired brain injury: Results from a pilot study.* Paper presented at the 2nd World Congress on Adult Guardianship, Melbourne, Australia.

Knox, L., Douglas, J., & Bigby, C. (2012, May). *Exploring tensions associated with supported decision making after severe traumatic brain injury.* Paper presented at the 7th World Congress for NeuroRehabilitation, Melbourne, Australia.

Knox, L., Douglas, J., & Bigby, C. (2012, October). *Exploring the impact of communication impairment on the experience of decision making following severe traumatic brain injury: A case study.* Poster presented at the 15th International Aphasia Rehabilitation Conference, Melbourne, Australia

Chapter 1:

Thesis Overview

What's good about someone making decisions for you? Nothing. Because you should be able to make them yourself. It's frustrating, it's annoying... It really, really pees you off. I should be able to do it but I can't.

(Mick - Interview 2)

Many of us take the right to make decisions in our own life for granted. In making decisions, we demonstrate to others who we are and what we value. Our decisions shape the course of our lives. However, there is a long history of people with disabilities being denied the right to make decisions for themselves. For people with cognitive disabilities, being able to make decisions not only requires having this right acknowledged and upheld, but also having access to support that enables participation.

New conceptualisations of disability that have emerged in recent decades emphasise the individual as expert in their own life, and acknowledge the impact of social and cultural factors in shaping their experience. As a result, legal and policy frameworks that seek to acknowledge and counteract the ways in which society contributes to the disablement of people with disability have been developed and implemented. However, although necessary, legal and policy changes are insufficient to fully enable participation in decision making.

There is equivocal evidence that the practical and attitudinal changes that were imagined have been achieved, and that people with traumatic brain injury (TBI) have greater scope to shape the course of their lives. Although current thinking about disability emphasises giving people opportunities to make choices, there remains little examination of the experiences of people with TBI, and those around them, in making decisions in their lives after injury. In particular, the factors that support and hinder participation in both routine and major decision making are yet to be explored.

Using a constructivist grounded theory approach, I sought to understand the experiences of adults with TBI and those around them in making decisions about their lives after injury in order to inform clinical practice. Eight adults with severe TBI and 11 nominated decision-making supporters participated in this study. Nominated supporters included spouses, parents, support workers and a friend. Each participant took part in at least two in-depth interviews over a 12-month period.

This inquiry yielded four published articles and one submitted manuscript. Each of these manuscripts elucidated different aspects of decision-making participation, contributing to the overarching aim of the research. Three major constructs emerged across the data. The first construct reflected the *saliency of the person's relationships* with those in their support network in facilitating decision-making participation. Several factors emerged as facilitating a positive support relationship in which the individual was at the centre of decision making. These include knowing the person well, understanding the impact of the brain injury in the context of the person, sharing an appreciation of what is important to the person, and taking a positive approach to risk. The results also highlighted the changing nature of the relationship in response to shared decision-making experiences. The second construct revealed the interface between the self and the support relationship to construct the space where *decisions* were made. The third construct related to the dynamic and recursive relationship between the experience of decision-making participation and *self-conceptualisation* for adults with severe TBI. These three constructs interacted within a context that is changing and influenced by social, legal and political environments.

In line with the constructs described above, a series of recommendations for clinical practice are presented. The purpose of these recommendations is to support rehabilitation practitioners to maximise the decision-making participation of adults with TBI.

Organisation of the thesis

This thesis comprises eight chapters. The thesis is by publication and consists of five papers concerned with the experience of decision-making participation after TBI. Four of these papers are published and the fifth has been submitted for publication. Each of these is presented as a self-contained paper that includes a literature review, description of research methods, results, discussion and references. References for the remainder of the thesis are included in the reference list at the end of the thesis document. In line with the nature of a thesis by publication, some repetition of information may be noted, particularly in relation to methodological aspects of the research.

A brief summary of each of the chapters is provided below. A visual guide to the thesis is presented in Figure 1-1, which outlines how each of the remaining chapters contributes to the aims of the investigation.

Chapter 1 has provided a brief introduction of the problem addressed in this thesis. It also contains an outline of the literature, aims, methods and results.

Chapter 2 provides a discussion of the literature relevant to this research. I introduce the topic of decision-making participation and outline the factors that have influenced contemporary thinking in relation to the necessity of providing decision-making support. The challenges that TBI may pose to decision-making participation are also examined. This chapter contains the first article of the thesis, published in *Disability and Rehabilitation*. In this paper, we reviewed the literature in order to identify factors that influence the decision-making support provided to individuals with acquired brain injury (ABI). Two clinical case studies from the literature are presented in order to highlight how clinicians' hidden assumptions and perceptions of risk may influence the decision making support they provide and shape long-term outcomes for individuals with ABI.

Chapter 3 outlines the research methods used in this research. A rationale for selection of a qualitative approach is provided, and my decision to adopt a constructivist grounded theory approach is justified. The research design is presented, including methods of data generation and a description of participants. An overview of data analysis techniques is included.

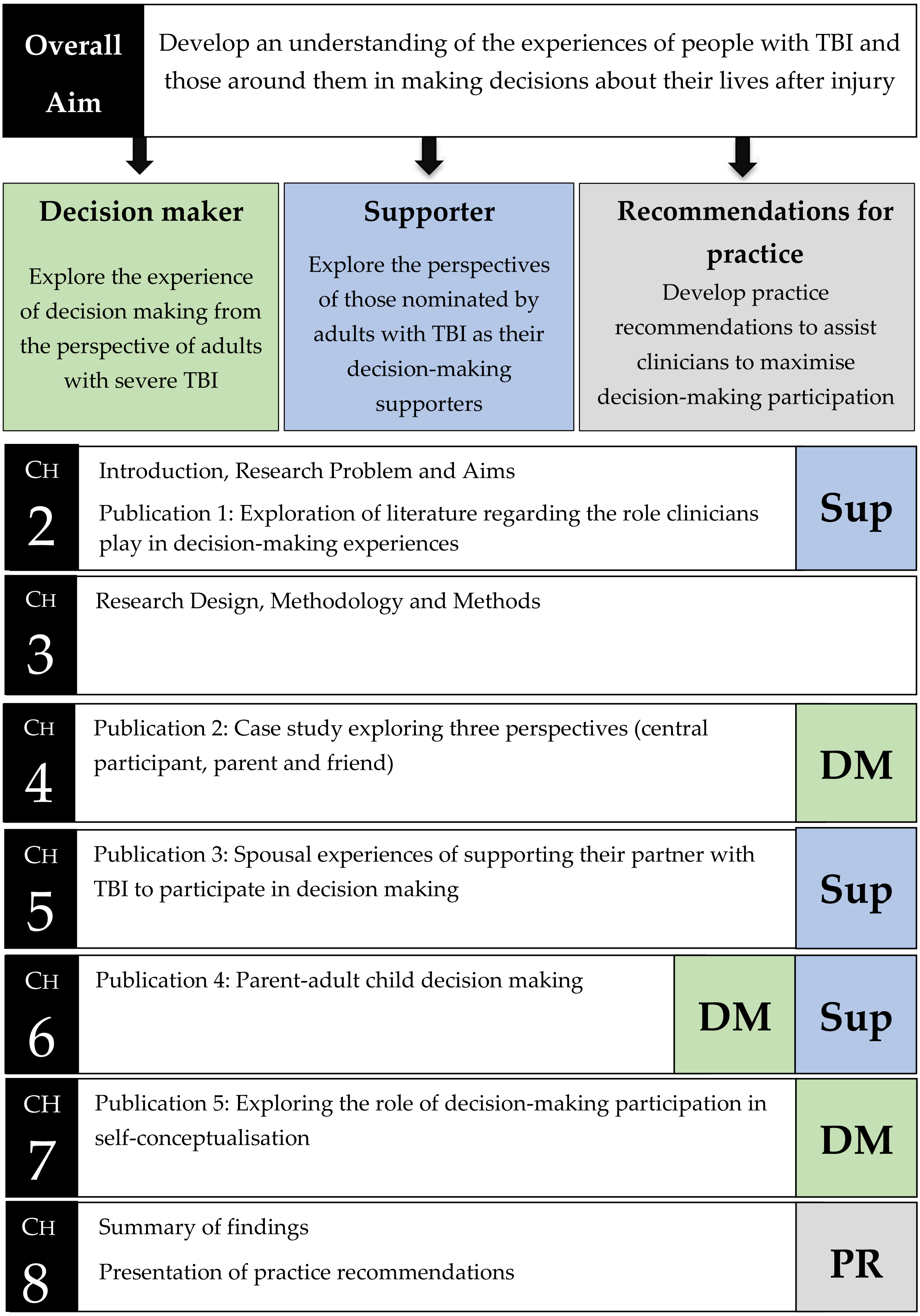
Chapters 4-7 each contain a publication reporting the results of this research.

Chapter 4 presents a case study of a central participant and two participants he nominated as his decision-making supporters. This paper was published in *Research and Practice in Intellectual and Developmental Disabilities.* A single case from the research was explored in order to develop an in-depth understanding of the evolution of decision-making support over time from multiple perspectives. The key findings in this paper highlighted that understanding the person and what is important to them and having a shared focus on maximising autonomy contribute to positive decision-making support.

Chapter 5 presents the findings of a study that explored the perspectives of spouses of adults with TBI. This paper was published in *Brain Injury*. This study aimed to understand how the spouses of individuals with severe TBI experienced the process of supporting their partners with decision making. The findings suggested that spouses experience decision making as a complex multi-stage process underpinned by a number of relational factors.

Chapter 6 includes a publication exploring processes used by adults with severe TBI and their parents in making decisions about life after injury. This paper was published in *Neuropsychological Rehabilitation*. The findings proposed that participants' approaches to decision making were guided by their vision of a "reimagined future" and again emphasised the relational underpinnings of decision making.

Figure 1-1: A visual guide to the thesis



Overall Aim

Develop an understanding of the experiences of people with TBI and those around them in making decisions about their lives after injury

Decision maker

Explore the experience of decision making from the perspective of adults with severe TBI

Supporter

Explore the perspectives of those nominated by adults with TBI as their decision-making supporters

Recommendations for practice

Develop practice recommendations to assist clinicians to maximise decision-making participation

CH 2	Introduction, Research Problem and Aims Publication 1: Exploration of literature regarding the role clinicians play in decision-making experiences	Sup
CH 3	Research Design, Methodology and Methods	
CH 4	Publication 2: Case study exploring three perspectives (central participant, parent and friend)	DM
CH 5	Publication 3: Spousal experiences of supporting their partner with TBI to participate in decision making	Sup
CH 6	Publication 4: Parent-adult child decision making	DM Sup
CH 7	Publication 5: Exploring the role of decision-making participation in self-conceptualisation	DM
CH 8	Summary of findings Presentation of practice recommendations	PR

Chapter 7 consists of the fifth and final manuscript that is currently under review. In this paper, the interface between decision-making participation and self-conceptualisation was explored. The findings of this study highlighted the recursive relationship between participation in making decisions and the dynamic conceptualisation of self following TBI. Additionally, data revealed that the relationship between decision-making participation and self-conceptualisation is mediated by an individual's social support network.

Chapter 8 draws together the findings described in the earlier chapters. A series of practice recommendations for rehabilitation clinicians working with people with TBI and those around them is presented. The thesis concludes with a description of the methodological strengths and weaknesses of the overall project and directions for future research.

Chapter 2:

Introduction,

Research Problem and Aims

The aim of this chapter is to review the contemporary literature across three domains central to this research. First, adults with TBI are positioned in the literature. An overview of the consequences of TBI, including for decision making, is provided. Second, decision making is defined and its importance outlined. The differing conceptualisations of decision making across three contexts relevant to the experiences of adults with TBI are presented. Specifically, decision making is explored from two service perspectives (health and rehabilitation, and disability support) and from a legal and political standpoint. Third, the role of support in decision-making participation is considered. This is explored in the first manuscript of the thesis, which forms part of this chapter. In this publication, the role of rehabilitation professionals in shaping the decision-making experiences of adults with TBI is highlighted. The chapter concludes with delineation of the research problem and description of the research aims that guided this doctoral project.

Locating adults with TBI in the literature

The focus of this research is the experiences of adults with TBI. TBI is the most common form of brain injury, and results from an external force hitting the skull, resulting in an altered state of consciousness (National Institute of Neurological Disorders and Stroke, 2011). It is considered a high-prevalence injury (Khan, Baguley, & Cameron, 2003), and has been described as a significant public health issue internationally (Corrigan, Selassie, & Orman, 2010; Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). The annual incidence of TBI in most Western communities has been estimated at between 200 and 500 individuals per 100,000 (Hillier, Hiller, & Metzer, 1997; Sorenson & Kraus, 1991; Tagliaferri, Compagnone, Korsic, Servadei, & Kraus, 2006). In Australia, the most recent data indicated that 22,710 individuals were hospitalised (in 2004-05) due to a primary diagnosis of TBI (Helps, Henley, & Harrison, 2008).

Risk factors for TBI include age, gender and socioeconomic status. The incidence of TBI is frequently reported to be two to three times higher among males than females (Helps et al., 2008; Ylvisaker, Szekeres, & Feeney, 2001). Young people are at particular risk of injury, with a peak in occurrence among those aged 15- to 24-years old (Feigin et al., 2013; McKinlay et al., 2008; O'Connor, 2002). As a result, TBI is often a source of lifelong disability, with consequent economic and social costs to the individual, family and community. Taking into account healthcare costs, productivity losses and carer burden, it has been estimated that the lifetime costs of a severe TBI average $4.8 million in Australia (Access Economics, 2009).

Brain injury severity exists on a continuum from very mild, where there may be little or no lasting side effects, to profoundly severe TBI resulting in prolonged coma or permanent vegetative state (Lezak, Howieson, & Loring, 2004). The measures used most frequently to determine brain injury severity are the Glasgow Coma Scale (GCS) and length of post-traumatic amnesia (PTA). Duration of PTA has long been considered a more reliable predictor of functional outcomes, and has been shown to correlate with both functional outcome and cognitive recovery (Brown et al., 2005; Fleming, Tooth, Hassell, & Chan, 1999; Kosch, Browne, King, Fitzgerald, & Cameron, 2010; Tate et al., 2006).

Significant advances have been made in the acute management of individuals with TBI over recent decades. These advances have led to an increase in the number of survivors, particularly those who have sustained very severe brain injuries (Ghajar, 2000). As a result, there are an increased number of individuals with TBI who have survived severe or profound injuries and are living with associated long-term consequences, including chronic disability and complex medical issues.

The impact of TBI

Significant evidence demonstrates that the consequences of TBI are broad and far-reaching. Individuals commonly experience changes in their cognitive, behavioural, emotional, and/or psychosocial functioning, which lead to longer-term disability (Ponsford et al., 2014; Tate et al., 2006; Teasdale & Engberg, 2005). Specifically, researchers have presented consistent evidence that moderate to severe TBI is associated with increased social isolation and difficulties in interpersonal relationships, lower levels of community integration, higher rates of unemployment, and decreased independence (Colantonio et al., 2004; Dawson & Chipman, 1995; Hoofien, Gilboa, Vakil, & Donovick, 2001; Jacobsson, Westerberg, Söderberg, & Lexell, 2009; Jourdan et al., 2015; Mazaux et al., 1997; Ponsford et al., 2014; Tate et al., 2006).

Individuals with TBI frequently present with complex support needs. A national survey found that individuals with a brain injury most commonly required support with cognitive and emotional tasks (Australian Bureau of Statistics, 2004). Analysis of the survey data highlighted that, compared with other people with an impairment, people with a brain injury more frequently required assistance with at least one of the three core identified activities (mobility, self-care, communication) and across a greater number of core activities (Australian Institute of Health and Welfare, 2007).

Decision making after severe TBI

Research has demonstrated how impairments associated with TBI impact on a person's decision-making abilities. From a biological perspective, the nature of these changes can be considered across three interconnected areas: cognition, emotional regulation and communication (Johnson-Greene, 2010; Mackenzie, Bennett, & Cairney, 2011; Mantell, 2010; Mazaux et al., 1997). Cognitive changes impacting on decision making primarily relate to damage of the frontal lobes of the brain, a defining feature of TBI. Frontal lobe damage is associated with decreased behavioural self-regulation, contributing to increased difficulties in decision making (Hornak, Rolls, & Wade, 1996; McHugh & Wood, 2008).

Researchers have utilised an experimental paradigm involving patients with lesions in specific brain areas in order to study decision making, examining the factors that may explain participants' failure to adhere to expectations based on rational choice theory (Mellers, Schwartz, & Cooke, 1998). A key finding is that the prefrontal cortex (particularly the ventromedial region) plays a critical role in an individual's use of somatic (emotion-related) cues to guide decision-making (Bechara & Damasio, 2005; Bechara, Damasio, & Damasio, 2000; Bechara & Van Der Linden, 2005). More recently, researchers have aimed to identify the biological substrates underlying cognition, with a focus on the neural substrates of specific mental processes involved in decision making, such as judgment and working memory (Barbey, Koenigs, & Grafman, 2013; De Bourbon-Teles et al., 2014; Fellows, 2007; Fellows & Farah, 2007; Heekeren, Marrett, & Ungerleider, 2008). The difficulties in translating these research findings into daily life relate to the ecological validity of tasks used in studies and their broader application to the substantial variety of decisions that individuals make. However, one of the most important contributions of the research is further evidence of the central role that emotion plays in decision making (Bechara & Damasio, 2005).

Emotional changes are a common consequence of TBI and can appear almost paradoxical; including increased emotional lability and reduced ability to experience different emotional states (Hornak et al., 1996; Prigatano, 1986; Saunders, McDonald, & Richardson, 2006). Although decision making has historically been considered to be a cognitive process, evidence suggests that a person's emotional state and emotional processing may impact their decision making (Bechara, 2011). Emotional disturbances have been found to impact on higher level cognitive processes, including judgment and risk perception (Blanchette & Richards, 2010). Further, high-emotion or stressful situations can influence a person’s approach to decision making (Starcke, Polzer, Wolf, & Brand, 2011; Youssef et al., 2012).

It has been proposed that having the ability to understand relevant information and clearly express choice are imperative for decision making (Appelbaum & Grisso, 1988). Communication difficulties are a well-established consequence of moderate-severe TBI (Struchen, Pappadis, Sander, Burrows, & Myszka, 2011), and may include motor speech impairments, word finding difficulties and impaired pragmatic skills (Dahlberg et al., 2006; Douglas, 2010; McDonald, Togher, & Code, 1999; Snow, Douglas, & Ponsford, 1998). Although relatively little is known about the impact of communication impairment on decision making after TBI, it has been suggested that the autonomy of individuals with neurological communication disorders may be at risk due to their communication impairments because their ability to contribute to decision making may be underestimated (Ferguson, Worrall, & Sherratt, 2009).

The changes described above can assist us to build an understanding of the nature of decision making after brain injury. However, there are a number of other factors that may influence the decision-making processes used by people with TBI and those around them. First, the nature of TBI means that they are likely to be faced with a range of new and/or unanticipated decisions (Zuscak, Peisah, & Ferguson, 2016). Such decisions may include health and financial matters, rehabilitation goals, and decisions about their employment, relationships and living arrangements. These decisions may be made in an unfamiliar context with its own requirements and constraints on decision making.

Second, the composition of a person's support network is likely to have changed after injury. Adults with TBI frequently report difficulties in their personal relationships, and evidence suggests that these difficulties may increase over time (Ponsford et al., 2014). As a result, they may find that they have a smaller social network to seek support from or may find that they are now relying on different supporters for decision-making support.

Finally, it has been proposed that an individual's values may also undergo a process of change following a ''biographical disruption'' (Bury, 1982; Williams, 2000), such as severe TBI. Specifically, having survived a life threatening event and learned to live with the consequences of a severe TBI, it could be presumed that individuals may question the worth of activities, roles and values that they previously took for granted (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). For example, authors have identified that individuals with chronic illness, including TBI, report that they may develop aspects of their lives that they had previously ignored, including pursuing different activities or interests that assist them to make sense of their illness or injury and setting new life goals (Collicutt McGrath, 2011; Fraas & Calvert, 2009). Values-based reasoning has received relatively little attention in the literature relating to decision-making. Although many authors acknowledge the importance of values in informing decision making, there remains limited understanding of how this change in values may influence decision making after TBI, and how this may influence perceptions of a person’s decisional capacity (Karel, Gurrera, Hicken, & Moye, 2010).

Decision making

In practical terms, making decisions is something we do throughout each day. Our decisions reflect who we are, what we value and our goals for the future (Douglas, Drummond, Knox, & Mealings, 2015). Some of our decisions may seem minor or inconsequential, such as what we eat or what we wear. Others may have greater consequences for our lives, such as where we choose to live or with whom we enter into a relationship.

In a formal sense, the World Health Organisation (WHO), in the International Classification of Functioning, Disability and Health (ICF), defines decision making as “making a choice among options, implementing the choice, and evaluating the effects of the choice…” (2001, p. 128). This definition highlights the complex nature of decision making, which is characterised by a number of discrete steps involving cognitive, emotional and valuation processes. It demonstrates that making decisions requires both thought (in generating alternatives and determining the preferred option) and action (in implementing the decision). However, by focusing on the process of decision making, it is important to ensure that the context in which decision making occurs is not overlooked.

The context for decision making may include factors such as the person’s living environment, the supports that are available to them, their previous experience of making decisions and their stage of life. In order to develop an understanding of the experience of decision making and the factors that shape that experience, it is necessary that attention is paid both to the process and the context, and the relationship between them is explored. In this research, a broad view of decision making has been adopted which acknowledges the process, as outlined in the WHO definition above, and the context.

The importance of decision-making participation

All people being able to make decisions in their lives is a principle that is central to contemporary human rights. This principle reflects the value placed on individual autonomy, particularly in Western societies, and research that highlights the role decision making plays in personal wellbeing. The ability to make decisions about oneself has been associated with increased self-determination (Nota, Ferrari, Soresi, & Wehmeyer, 2007), improved quality of life (Brown & Brown, 2009) and psychological wellbeing (Deci & Ryan, 2008). It has been proposed that we assert our identity through the choices that we make (Jenkinson, 1993). Further, Buchanan and Brock (1989) argue that the individual is in the singular position of being able to make decisions that align with their aims and personal values.

Decision making in health and rehabilitation: Building independence

Immediate care after TBI is provided in an acute setting, where the primary goal is the maintenance of life and mitigation of further complications (Smith, 1996). Once medically stable, a person with TBI is likely to be transferred to a rehabilitation setting. Historically, the practice of clinical rehabilitation after TBI has been focused on rehabilitation and the restoration of function after injury (Wade & De Jong, 2000). The philosophies underpinning rehabilitation are diverse and can be contradictory (Muenchberger, Kendall, & Collings, 2011). The goals of rehabilitation have variously been described as achieving maximum possible physical functioning, enabling an individual to resume important roles within the home and social environments, and increasing independence, participation and general life satisfaction (Cicerone, 2004; Wallace, Evans, Arnold, & Hux, 2007; Young & Sullivan, 2001). Despite this variation, there is a consistent acknowledgement across the literature of the multifaceted nature of brain injury rehabilitation and its role in facilitating an individual's autonomy in the context of their changed physical and cognitive functioning.

The concept of autonomy, frequently referred to in discussions of decision making, involves a diffuse set of meanings (Agich, 2004). In health and medical settings, autonomy is generally understood in the liberal individualist tradition as the ability of an individual to make and act on decisions without interference (Beauchamp & Childress, 2009; Stiggelbout et al., 2004). For clinicians to support a patient to exercise autonomy in line with such a view, their role invariably involves providing information to allow the patient to decide on an appropriate course of action. Such a perspective presents many problems in brain injury rehabilitation. First, it relies on an "idealised image of a rational patient" (Donchin, 2001, p. 368), which does not reflect how most of us act in reality (Quinn, 2010). It therefore fails to provide guidance in situations where a person requires decision-making support. Additionally, it advocates rehabilitation staff taking a narrow and immediate view of their roles in the lives of those they work with.

Hunt and Ells (2011) have argued for a broader conceptualisation of autonomy in rehabilitation. They propose that respect for autonomy must consider how a person's actions are shaped by their dynamic connections to other people and the world around them. These connections include relations between people (such as between patient and clinician or patient and family member) and relations with other factors that shape these connections, including law and policy, the rehabilitation environment, the person's self-conceptualisation and understanding of and attitudes towards their disability. Such an approach reflects a *relational* view of autonomy.

Theories of relational autonomy presume that human beings are social creatures and make decisions within the context of their social environments (Andreoli, 2010; Entwistle, Carter, Cribb, & McCaffery, 2010). Within a healthcare context, the adoption of such a perspective would require clinicians to take a more complex and nuanced view of autonomy, place an onus on them to understand the person's social context and ensure that the patient’s autonomy is promoted with this context in mind (Stoljar, 2007; Walker, 2008).

The aim of the first manuscript of the thesis was to investigate how those around the person with TBI supported them to make decisions and influenced their decision-making opportunities. In particular, I chose to focus on understanding how the approaches taken by rehabilitation clinicians have the potential to shape the person’s decision-making experiences. Through the exploration of two clinical case studies drawn from the literature, I explored two specific factors that may influence the way clinicians provide decision-making support. Following this manuscript, I consider how decision making is conceptualised in legal/policy and disability support contexts in the remainder of the introduction.

Publication

Knox, L., Douglas, J., & Bigby, C. (2013). Whose decision is it anyway? How clinicians influence decision-making participation after acquired brain injury. *Disability and Rehabilitation, 35*(22), 1926–1932. doi:10.3109/09638288.2013.766270

Statement of Contribution

As co-authors of the following manuscript titled *Whose decision is it anyway? How clinicians influence decision-making participation after acquired brain injury*, we confirm that Lucy Knox has made the following contribution:

- The study was designed by the candidate in collaboration with her primary supervisor Professor Jacinta Douglas and associate supervisor Professor Christine Bigby.
- The candidate was responsible for reviewing and analysing the relevant literature.
- The candidate was responsible for writing the complete first draft of the manuscript.
- Professors Jacinta Douglas and Christine Bigby critically appraised the manuscript and Lucy's subsequent revisions of it.

Signed: Date: 6/05/16

Lucy Knox

Signed: Date: 6/05/16

Professor Jacinta Douglas

Signed: Date: 6/5/16

Professor Christine Bigby

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Legal and political perspectives on decision making: The rise of supported decision making

One of the most significant influences on our approaches to decision making is the United Nations Convention on the Rights of Persons with Disabilities [CRPD] (U.N. General Assembly, 2007). The CRPD came into force in 2008 and has been ratified by 161 countries since its inception, making it one of the most widely accepted human rights treaties of this century (Skempes & Bickenbach, 2015). The purpose of the CRPD is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (U.N. General Assembly, 2007). As such, the CRPD aims to translate traditional concepts of human rights into a specific disability context, by obliging countries that have ratified it to ensure that people with a disability have access to the support they require to exercise their rights and freedoms.

The CRPD is firmly grounded in the social model of disability, in which disability is understood as resulting from interaction between a person (and their impairments) with the social and economic structures in their environment (Oliver, 2009; Shakespeare, 2014). In relation to decision making, social model approaches emphasise that definitions of capacity should consider not only an individual's decision making impairment, but also the "social, economic, and legal barriers" that a person may face when making decisions. The onus is then on ensuring that the supports that are required given the individual's decision making abilities are in place (Bach & Kerzner, 2010, p. 18).

The right to make decisions about one's own life is central to the CRPD, and is reflected both in the General Principles and body of the Convention. Specifically, Article 12 obliges governments to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (U.N. General Assembly, 2007). These obligations have seen a growing interest in the concept and practice of supported decision-making. In line with the CRPD, supported decision making has been proposed as the preferred response under international law when a person requires decision-making support due to a cognitive disability (Gooding, 2012).

In one sense, supported decision making refers to an approach where one or more people support another to make decisions and communicate those decisions (Series, 2015). However, it also refers to a legal concept that provides an alternative to guardianship or substitute decision-making for adults with a cognitive disability who require decision-making support (Gooding, 2015). Supported decision making ensures that the person retains their legal status and the rights, powers and responsibilities associated with it (Gordon, 2000).

In recent years, several significant reviews of the law relating to decision making and guardianship have taken place both in Australia and internationally (Australian Law Reform Commission, 2014; Carney, 2015b; Davidson et al., 2016; Glen, 2015; Victorian Law Reform Commission, 2012). A consistent focus across these reviews has been on the introduction of frameworks that provide legal recognition to a support person chosen by the individual (Series, 2015). However, our knowledge of supported decision making practice is still developing. Carney (2014) has warned of the danger involved in significant legal changes that precede a thorough understanding of practice. Additionally, there is little evidence that attempting to change practice through legal avenues will result in the long-term changes that are required.

In order to develop the practice of supported decision making, pilot programs have been run across a number of jurisdictions in Australia. The findings of these programs have identified the importance of tailoring decision-making supports to the individual rather than employing a ‘one size fits all’ approach (Carney, 2014). Further, these programs have demonstrated how a lack of resources can hamper a person’s ability to make decisions and put these decisions into action. For example, the South Australian trial identified that case management support was often required to ensure that participants were able to have their wishes enacted (Wallace, 2012). However, evaluations were not well embedded or rigorously designed in several of the trials. Consequently, it is difficult to accurately discern the impact of the programs and identify the components of support which were most useful to participants. This situation is further complicated by the fact that there has been a lack of consistency in relation to the support approaches used, disability groups included, and the nature of the support providers.

The term 'supported decision making' has been used to describe a range of different support approaches. However, Browning and her colleagues (2014) argued for the need to differentiate between *supported decision making* and *support with decision making*. The authors recognise the important - but informal - role played by those around the person with cognitive disability, but argue that the concept of supported decision making should be focused on the maintenance of legal capacity.

Adults with ABI constitute a small but significant group of people who have formally appointed substitute decision makers. In 2014-15, adults with ABI made up almost 16 percent of adults with newly appointed guardians from the Victorian Public Advocate (Office of the Public Advocate, 2015).

However, as noted by Carney (2015b), the supports used by many people with cognitive disability exist outside of the law, in relationships with friends, family or via other civil society networks (such as advocacy programs). In recognising this, he called for the need to better understand how informal decision-making support is provided. Regarding adults with TBI, this knowledge is particularly important as most are unlikely to enter into formal supported decision making agreements.

As well as shaping significant changes in the law, the CRPD has driven significant changes to disability policy both in Australia and internationally. In Australia, the importance of participation in decision making has been highlighted in several recent policy documents. The *National Disability Strategy 2010-2020* calls for 'choice and control' to be central to government policy and program redesign (Council of Australian Governments, 2011). The high level principles for a National Disability Insurance Scheme (NDIS) include the statement that a future scheme will ensure that "people with disability will be able to exercise more choice and control in their lives, through a person-centred, self-directed approach to service delivery" (Council of Australian Governments, 2012, p. 1). However, it has been argued that some of the provisions of the NDIS Act, such as those that allow for the appointment of nominees, might limit the ability of scheme participants to make decisions on their own (Australian Law Reform Commission, 2014).

More recently, the final report of the Australian Law Reform Commission's inquiry into *Equality, Capacity and Disability in Commonwealth Laws* proposed four National Decision Making Principles (Australian Law Reform Commission, 2014). The Commission proposed the use of the Principles as a "conceptual overlay" (p.53), consistent with the CRPD, to be used in any future reviews of relevant Commonwealth, state and territory laws. The proposed principles acknowledge the importance of adults making decisions for themselves and having access to the support they require to enact their will and preference. Despite this recommendation, questions remain about whether such high-level changes will result in the practical and attitudinal changes that had been imagined, particularly in the lives of individuals with TBI (Muenchberger et al., 2011).

Making decisions about disability services and support: Exercising choice and control

A person with severe TBI is likely to experience lifelong deficits that require a shift from a medical treatment model to a patient-centered support model that recognises psychosocial and environmental needs, particularly as patients and families transition from rehabilitation to home (Whyte, Laborde, & DiPasquale, 1999). In Australia, some adults with TBI may access the disability support system in order to meet their long term needs after leaving hospital. The majority of disability supports can be categorised as accommodation, community support (such as therapy and case management), community access, respite and employment support (Australian Institute of Health and Welfare, 2015).

When exploring how decision making is conceptualised in the disability sector, it is important to recognise that people with TBI have historically been under-represented users of disability support services in Australia (Price Waterhouse Coopers, 2010). In the state of Victoria, it has been noted that the disability service system was primarily designed to provide services to people with intellectual disability and the majority of users of disability services have a primary diagnosis of intellectual disability (Stringer, 2007; Victorian Law Reform Commission, 2012). Consequently, disability service providers often lack knowledge of the unique needs of adults with TBI. In particular, a lack of understanding about the need for access to rehabilitation over the long term has hampered the ability of people to access services to meet their ongoing needs.

It is unsurprising in this context that most of the literature exploring choice and decision making from a disability support perspective is based on the experiences of adults with intellectual disability (Winkler, Callaway, Sloan, & Holgate, 2015). Many of these studies reflect the experiences of participants moving from institutional living to community based housing (Emerson et al., 2000; Heller, Miller, & Hsieh, 2002; Wehmeyer & Bolding, 2001; Young, 2006). Although the findings of these studies indicate that people generally have more opportunities to make decisions about their lives in smaller, more home-like environments, it is the organisation and practice of frontline workers that influence outcomes (Bigby, Clement, Mansell, & Beadle-Brown, 2009; Felce & Emerson, 2001). A recent study exploring the experiences of adults with severe ABI moving from residential aged care to smaller-scale disability housing in the community found that both the built environment and the practices of support staff shaped their choice-making opportunities (Winkler et al., 2015). Participants reported more individualised, person-centred support in the community which equated to greater choice-making opportunities.

Although the vast majority of adults living with chronic TBI do not live in disability-funded accommodation, the current literature contains a dearth of information about the experiences of decision-making for individuals with chronic TBI living in the community. One exception is a study undertaken by McCluskey, Johnson and Tate (2007). The authors explored how decisions about care were made following TBI by interviewing 14 individuals with a brain injury and 37 ‘others’ who coordinated or provided care. None of the individuals with TBI were identified as the primary decision maker, with this role being typically assumed by family members. Further, the findings highlighted that adults with TBI who lived alone with less care experienced greater autonomy than those who did not.

There remains little known about the experience of decision making for adults with TBI who access the disability support system. It has been argued that the introduction of the NDIS will invite radical changes in the way that disability support is being provided (Dowse et al., 2015) and provide participants with greater opportunities to exercise choice and control (Productivity Commission, 2011). However, the current lack of evidence may mean that practice changes are difficult to measure and achieve.

The current problem

Across the contexts that shape the experiences of people with TBI, there is a shared recognition of the fundamental right of individuals to make decisions in their lives. There is also an acknowledgement that individuals with TBI may require support to exercise this right. At present, there is limited knowledge about how this support can best be provided. Until the practice of supporting decision-making is given the same weight as the right to make decisions, tangible improvements in the lives of people with TBI will be limited.

The publication presented in this chapter (Knox, Douglas, & Bigby, 2013) highlighted the complex and multidimensional nature of support and the decision-making experience. However, little is known about how decisions are made in the lives of people with a brain injury, the decision-making approaches used, or the roles played by those who support the decision-making process. Further, empirical evidence exploring methods or strategies to maximise decision-making participation is limited. The aim of this thesis is to contribute to an emerging evidence base from which to develop practice that maximises decision-making participation for adults with severe TBI.

Aims of the research

With the ultimate goal of maximising the participation of people with TBI in making decisions in their lives, this research project was designed to explore the experiences of people with TBI and those around them in making decisions about their lives after injury.

The primary aim of this research was to build an understanding of the experience of decision making after brain injury from the perspective of adults with severe TBI living in the community. In recognising the role that those around the person play in shaping their decision-making opportunities and experiences, the perspectives of members of the person's support network (both in a formal and informal capacity) were also included as crucial to the research process. Based on an understanding of the decision-making process from a range of perspectives, a further aim of this research was to develop recommendations to guide clinical practice across the health and disability sectors.

Chapter 3:

Research Design

The research design involves the "intersection of philosophy, strategies of action and specific methods" (Creswell, 2009, p. 5). In this chapter, I present an overview of the research approach and methods I used in this investigation. I outline the reasons for electing to use a qualitative research approach and its congruence with my ontological and epistemological beliefs. I provide an overview of grounded theory, including the constructivist approach that was adopted and its use with individuals with TBI. Finally, I describe the research methods used, including participant recruitment, data generation and analysis. Although a summary of this information is included in individual publications, my aim for this chapter was to provide a more comprehensive overview of the research design to allow readers to assess the quality of the research and the appropriateness of the methods selected (Patton, 2002).

Qualitative research

It has been argued that "questions of method are secondary to questions of paradigm" (Guba & Lincoln, 1994, p. 105). A paradigm comprises the worldview or belief system that guides the research (Annells, 1996). My previous research experience had been grounded in a positivist paradigm. However, my primary interest in undertaking this research was to develop a deeper understanding of the experiences of adults with TBI and those who shape their lives in significant ways. In line with these aims, I selected a qualitative approach. This was most appropriate as the aim of the research was to build an understanding of a given experience in the social world in which the research participants live and to make sense of that experience (Denzin & Lincoln, 2008).

Qualitative research is well suited to investigating areas that are poorly understood (Morse & Richards, 2002). Despite a prominent human rights agenda that advocates the right of all individuals to make decisions about their own lives, little was known about how adults with acquired cognitive impairments actually experienced the process of making decisions after their injury. Both the research topic and strategy were influenced by my personal beliefs and values, which in turn have been shaped by various experiences, including my training as a speech pathologist and professional experience in roles including speech pathology, advocacy and case management with adults with brain injury. The decision to undertake qualitative research reflects an appreciation of the nature of truth in the lives of people with whom I have worked and a desire to respect and honour their experiences. This research therefore sets out to create meaning and develop theory grounded in the experiences of adults who have acquired a severe brain injury in making decisions about their lives following their injury and, from this, develop strategies to maximise their participation in decision making.

Selection of a research strategy

A broad range of research strategies may be adopted by the qualitative researcher, each of which are associated with varying assumptions and procedures. Grounded theory was chosen as the research strategy to be applied, for several reasons. First, grounded theory has been described as an exploratory research strategy and is therefore well suited to areas of research where there is limited existing knowledge (Grbich, 2007). Rather than testing predefined concepts and theories, grounded theory allows concepts to emerge from data. The limited existing knowledge of the experience of decision making following brain injury provides further justification for the choice of grounded theory as the method of inquiry.

Second, grounded theory has been demonstrated to be an appropriate methodology to explore the experiences of individuals after severe ABI. Previous areas for research have included the experience of adjusting to disability and reconstructing self-narratives after brain injury (Nochi, 1998a, 2000), the processes and conditions of care management after severe ABI (McCluskey et al., 2007), and the transition experiences of young people moving from aged care facilities to community living environments (Winkler, Farnworth, Sloan, & Brown, 2011).

Finally, Annells (1997) advises researchers considering using grounded theory to determine whether there is a social process to be investigated. Grounded theory is considered an appropriate choice where research questions involve "social interactions or experiences" (Kennedy & Lingard, 2006, p. 103). The research questions in this research encompassed both of these elements - the experiences of making decisions, and the social processes and interactions that surround these experiences.

Definition of grounded theory

Glaser and Strauss (1967, p. 2) define grounded theory as "the discovery of theory from data systematically obtained from social research". It is a technique of "explication and emergence" (Charmaz, 2008, p. 156), which emphasises the process of analysis and theoretical development. Rather than setting out to verify an existing theory through their research, grounded theorists allow theory to emerge through an iterative process of data generation, analysis and conceptual theorising (Strauss & Corbin, 1998). The resulting theory or model, which is 'grounded' in the data, provides an explanation of the social phenomena being studied and explains the main concern of the participants and the way in which this concern is managed (Glaser, 2002; Strauss & Corbin, 1998).

Since Glaser and Strauss first described the method in 1967, grounded theory has been adapted by a number of researchers and there are at least three primary modes currently in existence: Glaserian, Straussian and Constructivist (Mills, Bonner, & Francis, 2006a). However, there are several foundation techniques across these methods, including constant comparison and theoretical sampling (Holton, 2007). The constant comparison method involves concurrent data generation and analysis using codes and categories (Birks & Mills, 2011). Theoretical sampling involves the researcher making sampling decisions based on emerging codes and concepts in order to develop their emerging theory (Draucker, Martsolf, Ross, & Rusk, 2007). As grounded theory methods have sought to account for individuals' subjective experiences of reality, the framework underpinning the method is consistent with symbolic interactionism (Corbin & Strauss, 1990).

Symbolic interactionism

Symbolic interactionism is both a theory and methodological approach to exploring human behavior and interaction with its roots in American pragmatism (Annells, 1996). A number of social psychologists and sociologists have contributed to the development of this perspective, although many of its shared assumptions are based in the work of George Herbert Mead and his student Herbert Blumer (Schwandt, 2007). The Blumer-

Mead view of symbolic interactionism (Blumer, 1969) has the following three principles as its foundation:

- individuals' actions towards things (such as other individuals, institutions and situations) are determined by the meaning that they apply to these things;
- meaning is a social product, derived from social interaction; and
- these meanings are used and revised through an interpretive process.

The influence of pragmatism in symbolic interactionism is reflected in the proposition that individuals are active agents in their lives who constantly adapt as a result of their interactions with others (Schwandt, 2007). A symbolic interactionist perspective, therefore, requires the researcher to explore and construct the ways in which individuals view the world, and the influence of their past experiences and interactions on their realities, in order to understand their actions (Blumer, 1969). Grounded theory provides a systematic means for doing this (Kendall, 1999).

Research strategy

The epistemological position of grounded theory has been described as a continuum (Charmaz, 2007). At one end lies the classical approach described by Glaser (1998), which developed from positivist assumptions. Strauss and

Corbin's methods (1998) have been labelled post-positivist (Mills, Chapman, Bonner, & Francis, 2007). Recently, constructivist versions of the method have been described by Charmaz (2006, 2014) and Clarke (2009). Given my epistemological position and its influence on the research area for investigation, I chose constructivist grounded theory as my methodological approach.

Constructivist grounded theory

Constructivism is the view that knowledge is constructed by human beings through a process of interaction within the world and with others (Crotty, 1998). Constructivists believe there are multiple social realities and that knowledge about these realities is mutually constructed by the viewer and the viewed, rather than reality existing in a unitary form simply to be found and uncovered (Charmaz, 2003a). Researchers adopting a constructivist approach are therefore interested in the multiple realities that humans inhabit. Constructivists also acknowledge that meaning is created through shared interaction, and that the use of language is central to this process (Charmaz, 1990).

With this knowledge in mind, several authors have described the key differences between constructivist grounded theory and the classical approaches developed by Glaser and Strauss (Annells, 1996; Bryant &

Charmaz, 2007; Mills, Bonner, & Francis, 2006b). The first of these relates to assumptions regarding the position of the researcher. For example, Glaser (1978) stressed the importance of the objectivity of the researcher in the discovery of theory, reflecting the positivist philosophical underpinnings of his approach. In contrast, a constructivist approach acknowledges the generation of data through the researcher's "past and present involvements and interactions with people, perspectives and research practices" (Charmaz, 2006, p. 10).

According to Charmaz (2003a, p. 273), constructivist grounded theory appreciates that the "viewer creates the data and ensuing analysis with the viewed". Hence, data are not created or discovered but built through a process of interaction, with appreciation of "temporal, cultural and structural contexts" (2003a, p. 273). Constructivist grounded theory redefines the relationship between researcher and participant and "brings the centrality of the researcher as author to the methodological forefront" (Mills et al., 2006b, p. 9). The subsequent constructivist grounded theory therefore also acknowledges the role of the individual (researcher) as a participant in the research process.

When interviewing participants in a constructivist study, Charmaz (2006) stresses the importance of "reciprocities" with research participants (p.110).

By doing so, researchers respect and value participants, thereby providing a means of developing a level of understanding that extends beyond presumed or surface meanings (Charmaz, 2003a). Researchers must be prepared to build a relationship with participants that will allow them to tell their story. Therefore, researchers must be finely attuned to the presence of cues and structures that may prevent participants from speaking openly (Charmaz, 2003a).

Charmaz has written extensively about the treatment of data and analytical outcomes in constructivist grounded theory (Mills et al., 2006b). Specifically, Charmaz (2006) stresses the importance of the narrative of participants remaining at the core of the final research outcome. One of the strategies advocated by Charmaz in order to achieve this is the coding of data using gerunds to maintain the actions and experiences of participants. Gerunds also enable the researcher to "see implicit processes, make connections between codes, and keep analyses active and emergent" (Charmaz, 2011, p. 368). Further, constructivist grounded theorists should ensure that their writing is both analytical and evocative of participants' experiences (Mills et al., 2006b). The emphasis placed on the participant's voice again demonstrates the inherent value that the researcher places on participants as co-constructors of the final theoretical product.

Criticism has been directed at grounded theory for its focus on human experience and interaction, and the limited attention paid to the broader social context in which it occurs (Holloway & Todres, 2006). In particular, Layder (1982) and MacDonald (2001) criticised grounded theory and its symbolic interactionist underpinnings for its failure to incorporate the influence of macro-level social structures, such as gender and culture. However, more recent modes of grounded theory, such those described by Charmaz (2003a, 2006, 2011) and Clarke (2005) have adopted strategies to address this criticism within a postmodern stance. In line with these approaches, I have tried to ensure that the rapidly changing socio-political context for decision-making participation remained present in the process of analysis.

Personal Perspective

In acknowledgment of the need for qualitative researchers to locate themselves within their research, Charmaz (2006) notes that “we are not passive receptacles into which data are poured” (p.15). My personal and professional experiences have shaped my interest in the topic under investigation and the way that I have approached and undertaken the research. I am a speech pathologist with over ten years’ experience working with adults with acquired brain injuries. Prior to undertaking this project, I had worked in a range of direct service roles, including as an advocate, speech pathologist and case manager with adults with TBI. Across these diverse roles, I became interested in the gap that was often evident between policy and practice in working with people with brain injury. I observed that good practice was rarely measured well and that staff often lacked the time, resources and knowledge to support their clients to make meaningful choices about their services and supports. Despite an influx of policy documents citing the need for clients to exercise increased choice and control, I was concerned by the lack of participation by people with ABI in shaping these documents and wondered how change would occur given the limited practice-level knowledge about the decision-making supports that worked for people with ABI. My practice experience also highlighted the importance of understanding the views of adults with TBI *and* those around them, in recognising that it is often the families of people with TBI who influence and support change in the lives of their loved ones.

As a speech pathologist with a belief that communication is the “stuff of relationships”, it may not be surprising that I felt most closely aligned with a constructivist paradigm to underpin this research. I have long held the belief that effective communication has its basis in attempting to understand the perspective of others and how their views have been shaped by their own experiences. When designing this research, I read broadly about a range of methodological approaches and was drawn to Charmaz’s approach. In particular, I was attracted by her emphasis on the need for researchers to consciously reflect on their relationships with participants, to maintain a sense of reciprocity in the process of meaning making, and to seek to ensure that participants’ voices are central through the process of analysis.

In addition to reflecting upon and acknowledging how my own beliefs and experiences have shaped the research process, I also understood the importance of reflexivity throughout this process. In this research, reflexivity was encouraged through regular supervision sessions in which we explored and discussed my interviewing style and approach (including my responses to topics raised by participants that were unexpected or personally challenging), and how these encounters shaped my understanding and interpretation of participants’ experiences.

Research methods

The following section details the design of this research. The selection of participants and my approach to data generation and analysis are described. Finally, the strategies I applied in order to maximise research quality are outlined.

Participants

Two groups of participants were recruited to participate in this research: a group of *central participants*, comprising adults with severe TBI living in the community, and a group of *involved others*, people nominated by individuals with TBI as those who participate in the decision making process with them.

Central participants

Eight central participants were recruited to participate in the research. Central participants were recruited through community-based services and service provider networks for people with acquired brain injuries, and were required to meet five inclusion criteria:

1. Severe TBI (defined as more than seven days of post-traumatic amnesia);
2. TBI acquired at 16 years or older;
3. Aged between 18-55 years at the time of initial interview;
4. Living in the community; and
5. Able to communicate responses verbally or in writing during a 30 minute interview.

Table 3-1 provides an overview of central participants' demographic details.

Table 3-1: Demographic details for central participants

Name	Age	Years Post Injury	Injury-related impairments reported by participant	Level of disability (GOSE)*	Status when included in research	Involved other/s
John	51	29	Physical/mobility, speech	SD-	Single, living in supported accommodation, not in paid employment	Accommodation Manager Accommodation staff member
Anna	47	17	Cognitive (memory/attention), speech	SD-	Living with partner and children, not in paid employment	Spouse Mother
Mick	42	19	Memory	SD+	Living with partner, not in paid employment	Spouse
Peter	46	8	Memory, speech	MD-	Living with partner and child, not in paid employment	Spouse
Beau	35	7	Physical, memory, speech, reduction of social network	MD-	Single, living alone with support, not in paid employment	Father Friend
Rhys	27	10	Physical weakness, speech, reduction of social network	MD+	Single, living alone with support, part-time employment	Mother
Cameron	31	9	Memory, reduction of social network	MD+	Single, living with family, part-time employment	Mother
Rose	43	14	Physical/mobility	SD-	Living with partner, not in paid employment	Spouse

* Level of Disability (Wilson, Pettigrew, & Teasdale, 1998): SD+ (Upper severe disability), SD- (Lower severe disability), MD+ (Upper moderate disability), MD- (Lower moderate disability

Sampling

A number of sampling strategies were used in tandem in order to identify and select central participants. Initially, a purposive sampling strategy was used to identify central participants. Purposive sampling is used to identify individuals who are most likely to provide the most relevant data about the phenomenon under investigation, including recruitment of individuals with diverse characteristics representing a range of relevant experiences (Corbin & Strauss, 1990; Maykut & Morehouse, 2000; Patton, 2002). Variation for participants with TBI was therefore sought across the variables of age, gender, access to compensation, use of formal or informal supports for decision making, living situation, and rural or metropolitan location.

As the study progressed, theoretical sampling was used to explore emerging categories through the recruitment of participants with similar and divergent experiences and follow up interviews with participants (Draucker, Martsolf, Ross, & Rusk, 2007). Theoretical sampling is one of the defining features of grounded theory, and involves actively sampling new data to develop the emerging theory (Tweed & Charmaz, 2012). Theoretical sampling is not considered only in relation to participants but in relation to the entirety of data (Coyne, 1997). Repeat interviews with participants therefore provided opportunities to further explore and refine emergent themes throughout the process of data generation.

Participants differed across a range of characteristics, but also displayed some similarities. Participants ranged in age from 27-51 and had a range of living arrangements, including living alone, living with family, and living in disability-specific accommodation. Six of the eight central participants were male and two were female. Three participants had received compensation following their injuries, a further two participants were in receipt of a package of disability support funding. The majority of participants (6/8) lived in metropolitan areas. All experienced moderate-severe disability, as measured on the GOSE and no participant was employed full-time. These similarities were not unexpected given the severity of participants' injuries.

Involved other participants included parents, spouses, accommodation support staff, and a friend. Two participants had formal decision makers appointed to manage their financial and legal affairs. However, neither of these participants identified their relationship with their formally appointed decision makers as positive and, consequently, neither wished the researcher to speak to them. Although this points to the challenges of maintaining positive relationships within formal decision-making structures, the views and experiences of formal decision-makers would provide a different and additional insight into the decision-making process.

Central participants were selected according to a process that developed during the study. John was the first central participant to be recruited. John had limited social support and relied on the limited support provided by staff at his accommodation facility for decision-making participation. Despite having had a financial administrator appointed, John did not identify the administrator as a decision-making supporter and did not wish them to be interviewed. In interviewing John and his identified supporters, several questions arose regarding how the experiences of individuals with stronger informal support might differ from John's experiences.

In adopting a purposive sampling strategy, Anna was recruited next. Anna had wide social support network and described engaging with a range of people in her network in seeking support in making decisions. Despite this, Anna described a relatively poor relationship with her spouse. Analysis of the data raised questions about how decision-making support was influenced by the nature of the relationship between the person being supported and their supporter.

At this stage, I wished to examine more deeply the experience of support within spousal relationships, and two further central participants who were in spousal relationships were recruited. Both Mick and Peter were in domestic partnerships which had commenced following their injuries. Both reported relatively little decision-making support outside that received from their spouses. However, their relationships differed across a range of other features. Mick was in a long-term same-sex relationship which had commenced in Mick's early twenties. He and his spouse had owned and run a business together. Peter had moved countries and married his partner after meeting her overseas. He was twice divorced and had two older children to his first marriage (living in his home country). He and his partner had a young child together. Strong themes began to emerge regarding the leadership role taken by supporters, and the construct of giving and receiving support began to take shape.

Beau was the next participant recruited. Despite the extremely severe injury he had sustained, Beau described his outcome as positive. The focus that both he and his supporters placed on 'achieving independence' highlighted the critical role of the self (as understood by the person themselves and by their supporters).

This was further examined with the sixth and seventh central participants, Rhys and Cameron, and in follow up interviews with earlier participants. Both Rhys and Cameron were striving to increase their independence. Both identified their mothers as their main source of decision-making support. The eighth and final central participant, Rose, was recruited to further explore the role of formal supporters (financial trustee). Her experiences also contrasted with other participants with a spouse, as she had been in a committed relationship with her spouse prior to her injury.

Involved other participants

Eleven involved others were also recruited to participate in this research. This group of participants was identified by asking central participants to nominate the people who participate with them in making decisions. After involved others were nominated by the central participant, they were contacted by mail and/or telephone and provided with written information about the research and a consent form.

Four central participants nominated one involved other. The remaining four participants nominated two involved others, although one declined participation. When I commenced recruitment for the research, I had expected to recruit a greater number of “formal” decision-making supporters (such as paid support staff, clinicians, guardians or financial administrators). Despite several central participants having formal/paid supporters in their lives, the majority nominated informal supporters. The only participant to nominate paid support staff as his decision-making supporters (John) described that he did not have family or friends from whom he sought support. Further, although two central participants had financial administration orders in place (a court order giving a third party responsibility for managing the person's legal and financial affairs) neither of these participants reported a positive relationship with the administrator and did not provide consent for them to be interviewed as part of the research. While this means that the experiences of formal decision-makers are largely absent from the research, the recruitment process highlighted the challenges faced by adults with TBI in maintaining mutually constructive and respectful relationships with formally appointed decision makers.

Data generation and analysis

There are no rules about the type of data that can or cannot be included in a grounded theory study (Glaser, 1998). Instead, a variety of data sources may be included. In this study, the primary methods of data generation were in-depth interviews and field notes.

In-depth interviews

One of the primary methods of data generation I used in this research was qualitative interviews. Interviews have been described as a "construction site of knowledge" (Kvale, 2006, p. 2), with knowledge created through interactions between the interviewer and interviewee. Birks and Mills (2011) have argued that interviews are particularly suited to grounded theory studies that seek to understand the world from the perspective of the individual, which was one of my aims. Additionally, when undertaking constructivist grounded theory, interviews provide researchers with greater control over the co-construction of data and therefore greater analytic control (Charmaz, 2003b).

Interviews may be structured, semi-structured, or unstructured (DiCicco-Bloom & Crabtree, 2006). Structured interviews have been likened to questionnaires conducted verbally and, as such, are rarely used in qualitative research. Unstructured interviews provide the participants with maximum control and are the most common type used in qualitative research (Morse & Richards, 2002). At the outset of this research, I planned to use a semi-structured interview approach. I expected this approach would be most appropriate to gather relevant information and provide structure to central participants in order to maximise their participation in interviews. As such, topic guides were developed to provide a general direction in initial interviews (see Appendices A-B). I did not use any specific wording or follow a set order of questions. In practice, many of the interviews had a largely unstructured format. Additional topics were often raised by participants and covered over the course of interviews. Structure was more often provided by the interviewer by way of prompts or assistance to address cognitive and/or communication issues. Data generation via interviews occurred in the period between August 2012 and May 2014.

Once I began conducting the interviews, I felt it was important that participants be able to determine what decision making meant to them and how they defined its place in their lives. By undertaking a series of interviews with participants, I was able to clarify gaps or murky areas that were uncovered during transcription and analysis in subsequent interviews. Each participant took part in at least two interviews, with a period of approximately 12 months between initial and final interviews.

There were two key reasons for scheduling follow up interviews. First, second and/or subsequent interviews will provide a further opportunity to discuss and explore recent decisions that have occurred in the participant's life. Second, these interview provide an opportunity to check interview data and discuss emerging themes and theory with participants. Five central participants who were among the first to agree to be interviewed took part in three interviews, reflecting a focus on identifying and refining topics and questions of interest in the early phases of the project. Later interviews were both open and structured in parts, as these interviews had several purposes: to collect further data (by discussing more recent decisions made by participants), to clarify points from previous interviews, and to elucidate key issues and concepts that had emerged from the data in the process of analysis.

Interview procedure

Once potential participants had expressed an interest in the research and prior to the interview, I made contact with them by phone. During this initial contact I provided a brief summary of the research and invited the participants to ask questions about the research and myself. Participants were asked to nominate an interview time and venue that was suitable for them. The majority of participants, including all but one of the central participants, elected to be interviewed in their own homes. Three participants requested that interviews be held in a quiet café, and three others were interviewed in a private room or office in their workplaces. The timing of interviews was also chosen by participants in order to fit into their schedules.

Upon meeting participants for the first time, I spent time learning more about them and discussed the broad purpose of the research before completing the documentation relating to project information and informed consent (see Appendices C-F). A number of participants were keen to know more about my professional background and my motivations for undertaking the research. I answered all questions as fully as possible. I also informed the participants that I was not currently affiliated with any health service or rehabilitation provider and they were free to speak honestly about their experiences, including in rehabilitation.

Interviews lasted between 45 and 155 minutes. I was guided by individual participants regarding the length of interviews. I ensured that I had ample time following interviews for further conversation and did not appear rushed. Participants were encouraged to ask me any questions they wished. Interview length varied greatly between participants. I was particularly conscious of watching for signs of fatigue in participants with TBI, but allowed participants to determine when they wished to stop.

As a speech pathologist, I was keen to support the communication of central participants in interviews while remaining mindful of not acting as a therapist. I used a range of both general and specific communication strategies to enhance communication, such as trying to minimise noise and other distractions during the interview, using simple language, and bringing participants back to the broad purpose of interview when necessary. I also sought clarification from participants through the discussion of direct examples and prompts to elicit autobiographical memory (for example, using questions such as “Can you tell me about a time when…?”).

Audiotaping and transcription

All interviews were digitally recorded with the permission of participants. Although there are conflicting views in the literature regarding the necessity of recording (Glaser, 1998; Patton, 2002), I made the decision to record interviews in this research for two reasons: (1) it allowed me to attend more fully to the context of the interview and what was being communicated by the interviewee, including their non-verbal communication, and (2) it provided me with an accurate record of the interview for analysis.

Written permission for recording was obtained from individual participants prior to commencement of the first interview. Verbal permission was sought prior to the recorder being turned on at subsequent interviews. During the course of one interview, a participant asked me to turn the recording off (which I promptly did), as he wished to make some statements "off tape". Once he had done so, he consented to the recording being turned back on. On this occasion and in line with the participant's request, his "off tape" statements were not transcribed nor included in analysis. There were a small number of occasions during interviews when participants started to become upset when discussing their experiences. At each of these times, I offered to turn the recording off temporarily (though this was generally refused) and ensured that my questioning did not exacerbate the person's distress.

I transcribed each interview verbatim as soon as possible after the interview to ensure that the context was retained. Although the process of transcription is lengthy, it provided a form of initial data analysis (Gibbs, 2007; Kvale, 2007). As such, I made the decision to transcribe the interviews myself. This allowed me to reflect on my interviewing style, undertake a preliminary form of open coding of the data, and make note of topics or areas for follow up in further interviews. Transcripts included non-word utterances (e.g., um, ah) and lengthy pauses.

Field notes

Field notes are "accounts describing experiences and observations that the researcher has made while participating in an intense and involved manner" (Emerson, Fretz, & Shaw, 1995, pp. 4-5). There were several reasons for making field notes in this research: as insurance against the failure of a recording device, as a record of observations or discussions not captured via the recording of interviews, and as a means of placing data collected through interviews within a broader context which contributes to creating a "thick description".

I made only minimal notes during the interviews, generally in the form of key words, but recorded key observations immediately after interactions with participants, either in written note form or via an audio recording. My notes included both impressions of the interview and general observations (for example, about the physical environment, participants' appearance and/or interaction). In addition, I often noted my perceptions of the interview and ideas for improvement, particularly in the earlier stages of the research. An example of field notes made during an interview is available in Appendix H.

Ethical approval

Prior to the commencement of data collection, ethical approval for this research was obtained from the La Trobe University Human Ethics Committee (approval number: 12-063; see Appendix I).

Data management

The volume of data collected during this research necessitated the use of a data management system. The NVivo 9 software program (QSR International Pty Ltd, 2010) was used to assist with data management. All data (including transcribed interviews, field notes, and diary entries) was imported into NVivo, and read line-by-line during the coding process.

Data analysis

Grounded theory allows for a variety of data to be generated, and detailed strategies for coding, analysing and synthesising the data have been documented (Birks & Mills, 2011). In this research, data analysis occurred in line with the constant comparison method and followed an approach most closely aligned with that described by Charmaz (2006). Analysis occurred alongside data generation over a period of several years, and followed themes and construct of interest emerging from the data. First, the practical experiences of clinicians, described in the first paper, highlighted the need for an exploration of decision making and the supporters who assist in this area. One participant, Beau, was supported by two committed decision makers, so his case was explored in more detail (see Chapter 4). One key theme to emerge was the relational nature of decision-making and the interaction. For this reason, the role of different decision supporters was explored, leading to two other papers focused on parents and spouses (Chapters 5 and 6). Throughout this analysis, the link between decision-making participation and the self for adults with TBI emerged and this was also explored further (Chapter 7). Finally, the major constructs emerging across the study are drawn together in Chapter 8.

Coding

A code in qualitative research is "a word or short phrase that symbolically assigns a summative, salient, essence-capturing and/or evocative attribute for a portion of …data" (Saldana, 2009, p. 3). Coding is an active process that combines the phenomena under investigation, the researcher's knowledge and existing theory (Birks & Mills, 2011). In grounded theory, it occurs in an iterative process that commences as soon as the first data is generated (Strauss & Corbin, 1998).

According to Charmaz (2003b), the coding process involves at least two steps: (1) initial or open coding, whereby the researcher pays close attention to the data and starts to make analytic decisions about it; and (2) focused coding, where the researcher uses the most frequently occurring open codes to synthesise and conceptualise the data in its entirety. In practice, the iterative nature of coding means that the coding process did not always follow such distinct stages.

Glaser (1978, p. 57) suggests that the first question for grounded theorists to pursue in the process of coding is "What is happening in the data?". To commence the process of initial coding, I carefully examined interview transcripts and their accompanying field notes. As I read sentence by sentence, I labelled each segment of data. I used gerunds for these initial codes in order to maintain focus on the actions and processes at hand (Charmaz, 2006, 2008) and, where possible, I used participants' own words (in vivo codes) to label the data (Saldana, 2009). I also used the process of initial coding to identify where further data was required.

Focused codes are more general, selective and conceptual than initial codes (Charmaz, 2006; Glaser, 1978). They represent reoccurring themes and cut across interviews and observations, allowing the researcher to check their preconceptions about the topic (Charmaz, 2006, p. 59). As I moved between and across transcripts and my interpretation of the data, I refined codes and concepts to form categories. Charmaz (2008, p. 164) argues that theoretical categories consist of codes that “carry the weight of the analysis”. These categories are then integrated into a theoretical analysis of the area being studied to form a grounded theory (Clarke, 2003). An example of part of the coding process for the concept “Conceptualising Self” (presented in Chapter 7) is provided in Appendix I. Although this provides an illustration of the development of codes relating to one process in the integrated model, it does not reflect the complex and messy nature of the coding process in actuality.

Memo writing

Memos provide the infrastructure for grounded theory and act as the central process by which the researcher fully engages with the data in order to develop a theory that is 'grounded' in it (Lempert, 2007). They have been described as a record of the researcher’s internal dialogue and an essential tool in increasing the abstraction of the researcher’s ideas (Strauss, 1987). Throughout the process of analysis, I used memos to note my thoughts about particular or interesting aspects of the data, raise questions for further exploration, describe possible codes, and explore how codes might differ or fit together. In addition to memos, I regularly used the process of diagramming to explore the relationships between codes and discuss my evolving ideas with my supervisors. Examples of memos and diagrams from have been included in Appendices J-K.

The grounded theory product

The aim of this grounded theory research was to develop an understanding of the experience of participating in decision making after TBI. This understanding is presented as a figure containing three major constructs in Chapter 8. These constructs are grounded in the data, originate from a specific area of inquiry, and aim to represent the voice of the population from whom it derived (Grbich, 2007; Holloway & Todres, 2006; Strauss & Corbin, 1998). Comparative analysis of the findings from this research across groups and contexts is required to deepen the explanatory power of the findings described in Chapter 8.

Assessing the quality of this research

Lincoln and Guba (1985) proposed four criteria to measure quality when assessing qualitative research. Table 3-2 outlines these criteria and their meaning. The strategies that were adopted in this research have also been included in this table and their application is briefly outlined below.

(1) Prolonged engagement

Prolonged engagement increases the researcher's chances of understanding the phenomena being studied and should be the goal of every qualitative researcher (Onwuegbuzie & Leech, 2007). It allows the researcher to build greater rapport with participants, and provides increased opportunity to make incidental observations relevant to the research. In this research, prolonged engagement was achieved by conducting a series of interviews with both groups of participants with a period of approximately 12 months between penultimate and final interviews. Undertaking a series of interviews also allowed a form of member checking (Elliott & Lazenbatt, 2005), by giving me an opportunity to summarise and seek feedback from participants regarding my understanding and interpretation of previous interviews, and to clarify key issues and concepts that had emerged during analysis.

Table 3-2. Assessing quality in this research (from Lincoln & Guba, 1985)

Criteria	Explanation	Strategies Applied
Credibility	Results are credible from the perspective of the participant	• Audio recording of interviews and verbatim transcription • Prolonged engagement • Field notes and personal journal • Recording of joint analysis and supervision sessions • Peer debriefing and scrutiny of the findings through manuscript review • Examination of previous research findings during analysis and preparation of publications
Transferability	Readers are able to determine whether results can be generalised or transferred to other settings	• Thick description of research assumptions and context (setting, participants, experiences) • Comparison with the literature
Dependability	There is an audit trail which allows external scrutiny	• Field notes and personal journal • Memos and records of emerging codes and themes • Recording of joint analysis and supervision sessions

Confirmability	Results are able to be confirmed or corroborated by others	• Sampling of negative cases • Memos • Reflective commentary evidenced through publication of findings over the course of the research • Description of study limitations

(2) Peer debriefing

Peer review involves "discussion of the researcher's conclusions and interpretations with others" (Johnson, 1997, p. 283) and was achieved in several ways in this research. First, verification of initial and focused codes was achieved by asking the researcher's two supervisors, both of whom are experienced in using the grounded theory method, to comment on emerging codes and diagrams depicting relationships. I participated in regular face-to-face supervision meetings with my supervisors and kept notes relating to the decision making processes we used (Lincoln & Guba, 1985). Additionally, I presented the emerging findings to peers at national and international conferences in the areas of rehabilitation and supported decision-making, and at brain injury service provider networks. Finally, credibility was established through peer scrutiny of the findings through the review of manuscripts, particularly in the later stages of the research process.

(3) Field notes and personal journal

Field notes have been described as a crucial element of qualitative research that are at the centre of the trustworthiness of a study (Lincoln & Guba, 1985). As described earlier, both field notes and a personal journal were maintained throughout the study, and were used to illustrate the context of interviews, provide for thick description, and evidence researcher reflexivity. Reflexivity was also evidenced by reflective commentary evidenced through publication of findings over the course of the research.

(4) Thick description of research assumptions and context

Thick descriptions are "deep, dense, detailed accounts" (Denzin, 1989, p. 83). The purpose of thick description is to establish credibility by enabling readers to 'experience' the events described in a study and therefore make their own interpretations (Creswell & Miller, 2000). Although I have limited the amount of detail that I have included in the thesis itself for the sake of brevity, I have used thick description in writing up the results of the research for publication. For example, a detailed account of each of the spousal relationships is provided in Chapter 6.

(5) Sampling of negative cases

Qualitative researchers also look for negative cases or "disconfirming evidence" (Creswell & Miller, 2000, p. 127). Negative cases allow researchers to explore why these differences are so. In constructivist research, negative cases can also assist the researcher to understand the multiple realities that may be associated with a social process (Creswell, 1994). In the process of developing and reviewing the emerging themes, I have sought to identify significant differences in the participant characteristics. Examples of this include comparing and contrasting the experiences of three couples who had commenced their relationship following brain injury with one couple with a longstanding relationship in Chapter 5, and exploring how John's experience differed compared to participants with a strong social network in Chapter 7.

Summary

This qualitative grounded theory inquiry aimed to explore the experience of making decisions about life about TBI from a variety of perspectives. This chapter has outlined the approach utilised in this research, and presented a rationale for its selection. In the following four chapters, the findings emerging from this research are presented in their published format. These chapters consist of a case study exploring decision-making participation from three different perspectives, and three studies exploring the spousal experience, the process of decision making within parent-adult child relationships, and the interface between decision-making participation and self-conceptualisation after TBI.

Chapter 4:

Shifting roles - A case study

Overview of chapter

The first publication presenting the results from the experiential component of this research describes the case study of a central participant, Beau, and his two nominated decision making supporters. In this paper, I explored how the relationship between the person with TBI and those around them changes when decision-making support becomes part of their interactions. This paper arose from a presentation at the 8th Disability Round Table in 2014.

Of the eight central participants who participated in this research, Beau and his supporters were chosen as the focus of this case study for a number of reasons. First, despite having sustained an extremely severe TBI, Beau described his outcome after injury as a positive one. This case study therefore provided an opportunity to explore the "active ingredients" of support and consider how these factors contributed to Beau's current life situation. Second, Beau nominated two decision-making supporters, a parent and a friend. Beau and his supporters described that they were motivated by a shared goal of maximising his autonomy. However, their experiences illustrate how the nature and composition of support can change over time and according to the decision to be made.

The overarching theme that emerged from this case study was the *dynamic* and *relational* nature of decision making. Implications for practice included the importance of supporters having a deep knowledge of the person they are supporting and understanding their own motivations and interests in the decision-making process.

Publication

Knox, L., Douglas, J., & Bigby, C. (2015). Becoming a decision-making supporter for someone with acquired cognitive disability following TBI. *Research and Practice in Intellectual and Developmental Disabilities.* Advance online publication. doi:10.1080/23297018.2015.1077341

Statement of Contribution

As co-authors of the following manuscript titled *Becoming a decision-making supporter for someone with acquired cognitive disability following TBI*, we confirm that we made the following contributions:

- The study was designed by the candidate in collaboration with her primary supervisor Professor Jacinta Douglas and associate supervisor Professor Christine Bigby.
- The candidate was solely responsible for data collection and analysis.
- The candidate was responsible for writing the complete first draft of the manuscript.
- Professors Jacinta Douglas and Christine Bigby critically appraised the manuscript and subsequent revisions of it.

Signed: Date: 6/05/16

Lucy Knox

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Professor Jacinta Douglas

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Professor Christine Bigby

The following article (pp 86-95) has been removed for copyright reasons.

Knox, L., Douglas, J., & Bigby, C. (2015). Becoming a decision-making supporter for someone with acquired cognitive disability following TBI. *Research and Practice in Intellectual and Developmental Disabilities, 3*(1), 12-21.

This article can be accessed via the following link:

http://dx.doi.org/10.1080/23297018.2015.1077341

Chapter 5:

Spousal experiences of supporting decision-making participation

In Chapter 4, the nature of decision-making support for one of the central participants and his involved others was investigated and described. Analysis of the data from participants across the study highlighted that the role held by the decision-making supporter shaped their approach and motivation within the process. In Chapters 5 and 6, the experience of decision-making in two different relationships - spousal relationships and parent-child relationships – is explored.

Overview of chapter

Four central participants from the overall research program nominated their spouse as their involved other. The publication in this chapter reflects an investigation of the experiences of spouses in providing decision-making support to their partners with severe TBI. The findings of this study provided evidence of the iterative relationship between decision-making support and participation for adults with TBI. The experience of spousal participants suggested that decision-making is conceptualised as a complex, multi-stage process that is frequently led by the non-injured spouse

Publication

Knox, L., Douglas, J., & Bigby, C. (2015). 'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI. *Brain Injury, 29*(6), 745-757. doi:10.3109/02699052.2015.1004753

Statement of Contribution

As co-authors of the following manuscript titled *'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI*, we confirm that we made the following contributions:

- The study was designed by the candidate in collaboration with her primary supervisor Professor Jacinta Douglas and associate supervisor Professor Christine Bigby.
- The candidate was responsible for data collection and analysis.
- The candidate was responsible for writing the complete first draft of the manuscript.
- Professors Jacinta Douglas and Christine Bigby critically appraised the manuscript and subsequent revisions of it.

Signed: Date: 6/05/16
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Professor Jacinta Douglas

Signed: Date: 6/05/16
Professor Christine Bigby

The following article (pp 99- 111) has been removed for copyright reasons.

Knox, L., Douglas, J., & Bigby, C. (2015). 'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI. *Brain Injury, 29*(6), 745-757.

This article can be accessed via the following link:

http://dx.doi.org/10.3109/02699052.2015.1004753

Chapter 6:

The decision-making experiences of adults with TBI and their parents

Overview of chapter

Four central participants from the larger study nominated a parent as their involved other. This study reflects analysis of the data from these parent-adult child dyads. In contrast to the experiences of spousal involved others (as reported in Chapter 5), decision-making participation within the parent-child relationship was future focused. The overarching construct that emerged from the data was a process of *reimagining the future*. This construct guided participants' integration of the brain injury into their lives and their changing approach to decision making over time. Although participants described an initial period of joint decision making, their revised vision of the future motivated participants to increasingly seek opportunities for the person with TBI to exercise greater autonomy with a reduced level of parental involvement. Additional sources of motivation for parental participants reflected an acknowledgment that they would not be able to provide support to their adult child indefinitely, and a desire to regain their own independence. The findings highlighted that participants used a number of conscious strategies to reduce parental involvement in decision making

Publication

Knox, L., Douglas, J. M., & Bigby, C. (2016). "I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents. *Neuropsychological Rehabilitation, 26*(2), 236-260. doi:10.1080/09602011.2015.1019519

Statement of Contribution

As co-authors of the following manuscript titled *"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents,* we confirm that we made the following contributions:

- The study was designed by the candidate in collaboration with her primary supervisor Professor Jacinta Douglas and associate supervisor Professor Christine Bigby.
- The candidate was responsible for data collection and analysis.
- The candidate was responsible for writing the complete first draft of the manuscript.
- Professors Jacinta Douglas and Christine Bigby critically appraised the manuscript and subsequent revisions of it.

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Signed: Date: 6/05/16

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Signed: Date: 6/5/16

Professor Christine Bigby

The following article (pp 115-139) has been removed for copyright reasons.

Knox, L., Douglas, J. M., & Bigby, C. (2016). “I won't be around forever”: Understanding the decision-making experiences of adults with severe TBI and their parents. *Neuropsychological Rehabilitation, 26*(2), 236-260.

This article can be accessed via the following link:

http://dx.doi.org/10.1080/09602011.2015.1019519

Chapter 7:

Decision-making participation and self-conceptualisation

Overview of chapter

The final manuscript included in this thesis focused on the experiences of the eight central participants. In seeking to understand the decision-making experiences of central participants, it emerged that participants' decision-making experiences were intricately linked with the process of self-conceptualisation after injury. In recognising the central role of self-concept in shaping (and being shaped by) decision-making participation, this study aimed to elucidate the interaction between these two concepts. The findings indicate that experiences of participating in making decisions play a significant role in shaping the self, and that social support plays an important role in mediating this relationship. In discussing this finding, this manuscript brings together three overarching themes evident throughout this doctoral investigation: self-concept, decision-making participation, and social support.

Publication

Knox, L., Douglas, J., & Bigby, C. (2016). *"I've never been a yes person": Decision-making participation and self-conceptualisation after severe traumatic brain injury*. Manuscript submitted for publication.

Statement of Contribution

As co-authors of the following manuscript titled *"I've never been a yes person": Decision-making participation and self-conceptualisation after severe traumatic brain injury*, we confirm that we made the following contributions:

- The study was designed by the candidate in collaboration with her primary supervisor Professor Jacinta Douglas and associate supervisor Professor Christine Bigby.
- The candidate was solely responsible for data collection and analysis.
- The candidate was responsible for writing the complete first draft of the manuscript.
- Professors Jacinta Douglas and Christine Bigby critically appraised the manuscript and subsequent revisions of it.

Signed: Date: 6/5/16

Lucy Knox

Signed: Date: 6/05/16

Professor Jacinta Douglas

Signed: Date: 6/5/16

Professor Christine Bigby

The following article (pp 143-196) has been removed for copyright reasons.

Knox, L., Douglas, J., & Bigby, C. (2016). "I've never been a yes person": Decision-making participation and self-conceptualisation after severe traumatic brain injury. *Disability and Rehabilitation.* Advance online publication.

This article can be accessed via the following link:

http://dx.doi.org/10.1080/09638288.2016.1219925

Chapter 8:

Findings in Context

The aim of this doctoral inquiry was to explore the experiences of people with TBI and those around them in making decisions about their lives after injury, in order to inform rehabilitation practice. The purpose of this chapter is to present an integrated view of the findings across the manuscripts included in the thesis. The chapter is broadly organised into four sections. First, a brief summary of the findings from each of the five manuscripts is presented and their contribution to the literature is discussed. Second, a summary of the findings across this investigation is described. Next, practice recommendations for clinicians working with people with TBI and those around them are proposed. Finally, the strengths and limitations of the current research and possible future directions are highlighted.

Summary and contribution of publications

During the research process, five manuscripts were prepared and submitted for publication. Four of these papers are published and the fifth is under review. Each of these papers contributed to the aim of the overarching project, which was to build an understanding of the experience of participating in decision making after severe TBI from a range of perspectives. The five papers reflected different aims and research questions, following the development and evolution of the research over time. I will now discuss the overarching significance of the findings of this research and significance of each of the five papers that make up this thesis.

Changes to international and domestic law over the last two decades have seen a burgeoning interest in the concept of supported decision making. To date, most of the literature on the topic remains descriptive or conceptual in nature (Arstein-Kerslake, 2016; Browning et al., 2014; Carney, 2014; Glen, 2015; Gooding, 2012; Kohn & Blumenthal, 2014; Series, 2015). Only a small number of researchers have published peer-reviewed empirical research about the practice of supported decision making, and most of this has occurred very recently (Douglas, Bigby, Knox, & Browning, 2015; Gooding, 2015; Watson, 2016). The findings of this research therefore make a significant contribution to knowledge about how the practice of decision making is understood and experienced, both from the perspective of those being supported or those who have taken on the support role.

The first publication (Knox et al., 2013) presented an overview of the issues for clinicians in supporting decision making participation after brain injury. The primary aim of this paper was to explore the ways in which professionals' actions shape the decision-making experiences of adults with TBI with whom they work. Specifically, clinical case studies were used to explore how clinicians' hidden assumptions and perceptions of risk influence their clinical practice. At the time of publication, the literature regarding decision-making participation for adults with acquired disabilities was limited. This manuscript responded to this gap in the literature by exploring the concept of decision making from a clinical perspective. It encouraged clinicians to consider the long term implications of their actions within a rehabilitation context, and presented a tool to assist them to identify factors that influence their provision of decision-making support.

The second publication was the first to present findings emerging from the qualitative investigation. This paper, *Becoming a decision-making supporter for someone with acquired cognitive disability* (Knox, Douglas, & Bigby, 2015a), focused on the experiences of Beau, a central participant, and his two nominated supporters. In this article, I explored how decision-making support had evolved within these relationships following Beau's injury. The contribution of the paper was in detailing the way that participants worked together and separately to make decisions in line with a shared long-term vision for Beau. It documented the emergence of concepts in relation to the support relationship and decision-making process that were further developed in later manuscripts. In particular, the findings emphasised the importance of a positive support relationship being based on a deep knowledge of the person. This knowledge included an understanding of Beau's self-concept. The findings of the case study also highlighted the important role that Beau's supporters played in facilitating his decision-making participation. For example, supporters described how they adjusted the processes they used based on the decision, and built a network of people around Beau who were able to enhance his decision-making opportunities. Evidence of the challenges faced by supporters in their roles was also presented. This is a topic which had largely been overlooked in the literature.

The next two publications highlighted how the role of the supporter can influence their approach to support. Although researchers have previously investigated the differences in stress, strain and burden experienced by family caregivers in different roles, this research contributed a new perspective in exploring how a decision-making supporter's role might influence their motivations and action. In particular, the findings highlighted that spouses were focused on the 'here and now', whereas the support provided by parents tended to focus on growing the person's independence in the future. These findings have important implications for the development of a person's social support network after injury.

The third manuscript included in this thesis, *'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI* (Knox, Douglas, & Bigby, 2015b), provided an insight into the experiences of spouses nominated as involved other participants. The aim of the study was to develop an understanding of the experiences of spouses supporting a partner with decision-making participation after severe TBI. A model developed from the findings of the study provided a basis for making recommendations to support the ongoing adjustment of spouses in the post-injury period. The significance of the study reflects its extension of the current literature on couples by describing how the process of decision making influences the development and maintenance of the relationship after injury.

The findings elucidated how the nature of the spousal relationship shapes (and was shaped by) the decision-making process. A number of relationship factors that supported decision-making participation were identified. Several of these, including communicating effectively, being committed to the relationship and holding your partner in positive regard, aligned with factors previously highlighted in maintaining positive spousal relationships (Blais & Boisvert, 2007; Gill, Sander, Robins, Mazzei, & Struchen, 2011; Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011). The findings add further weight to the need for clinicians to explore these factors in intervention with couples. Further, this study extends the literature regarding decision-making interventions after TBI. Rather than focusing remediation efforts at the level of the individual, it emphasises the importance of understanding and incorporating the perspectives of those in the person's social support network, in maximising participation.

In this study, decision making emerged as a complex process consisting of several discernable phases. The insights of spousal participants suggested that they generally led the process, for both major and everyday life decisions. The process described in the article provides a starting point for clinicians in talking to adults with TBI and their spouses about how decision making occurs within their relationship. Further, these findings may influence clinical practice in emphasising the need for explicit reflection on the decision-making processes adopted within a relationship and its implications for participation for the person with TBI.

In addition, this study provided new insights into the experiences of spouses who have commenced a relationship with their partner following TBI. The voices of these individuals have been largely absent from the research literature. In particular, this study has highlighted how a lack of long-term support and follow-up for adults after TBI can impact on newly formed relationships.

The next paper, *"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents* (Knox, Douglas, & Bigby, 2016b), explored how decision-making participation was experienced and conceptualised within parent-adult child dyads. The key finding to emerge in this study was an overarching construct of *reimagining the future*. This construct described how adults with TBI and their parents came to develop an understanding of the impact of the brain injury on the person's life course. In response, they adapted the decision-making processes they used over time to reflect a new vision for the person's life. The findings of this study provide further insights for clinicians regarding the role of contextual factors when negotiating decision-making support for a person after TBI. In particular, when family caregivers take on a support role, attention needs to be paid to both the family life cycle and the person's current life stage.

In line with the previous studies described above, shared participation in decision making relied on the presence of a number of relational factors. In particular, the pre-injury relationship shaped the dyad's approach to decision making, highlighting the importance of clinicians exploring how the pre-injury relationship would be characterised by those involved in the process. The findings again emphasised the need for brain injury education that is provided in the context of the person and their life.

The study provided further insight into the assessment of risk in the decision-making process. It highlighted several particular types of risk which have the potential to impact on decision-making participation. In particular, physical and financial risk were assessed as posing the most significant danger. The results suggest that development of positive strategies to allay decision-making supporters' concerns in these areas will be necessary in order to maximise decision-making participation.

Participants described a range of strategies that they used to increase decision-making independence and reduce the support role provided by parents. Identification of these strategies may assist clinicians working with adults who are being supported by ageing parents to explore methods of reducing parental input and introduce alternative sources of support. The findings highlight the need to start a conversation with parents about long-term sources of support for their adult child.

The fifth and final article, *"I've never been a yes person": Decision-making participation and self-conceptualisation after severe traumatic brain injury* (Knox, Douglas, & Bigby, 2016a), explored the interface between decision-making participation and self-conceptualisation after TBI. The significance of the findings reflected the pivotal role that decision-making participation plays in shaping self-concept after severe TBI. In the process of re-establishing autonomy after injury, decision making was conceptualised as a medium through which the self is continuously refashioned. Alongside this process, and in a recursive fashion, self-concept contributed to the experience of making decisions by shaping the individual's goals, attitudes and approach to the decision-making process. An individual's social support network emerged as an important mediator in this process. Those around the individual directly and indirectly supported their development of a positive self-concept and played a direct role in facilitating their participation in making decisions. As such, interview data exemplified the negative impacts that a lack of social support can have for both decision-making participation and self-concept.

The findings of this paper contribute to the literature by highlighting the potential role that decision-making participation plays in shaping the self after injury. Further, the findings highlight the need to ensure that adults with TBI are given support, based in knowledge of who they are and what is important to them, to participate in personally meaningful decisions. As support is provided in the context of an individual's social support network, the importance of supporting individuals with TBI to develop and maintain relationships is also emphasised. Finally, data illustrated that support for decision making can be delivered in a variety of forms. The concept of a 'continuum of support' that varies according to the decisional context can guide discussion with people with TBI and those around them in relation to the practice of decision-making support.

The experience of decision making participation after severe TBI

This thesis set out to explore the experience of decision-making participation from the perspective of those with severe TBI and those around them. This inquiry has yielded five manuscripts. Across these five manuscripts, three major constructs emerged: (1) giving and receiving support, (2) constructing the decision making space, and (3) conceptualising self. Together these constructs describe how people with severe TBI, and those around them who support them, engage in the decision making process in their respective roles.

The findings of this research provide clear evidence that decision-making participation for people with severe TBI occurs within the context of meaningful relationships. The nature of the relationship between the person with TBI and their supporters influenced the overall outlook on decision making and number and nature of decision-making opportunities that the person was supported to participate in. In order to maximise decision-making participation, support was both freely given by supporters and willingly received by adults with TBI.

In engaging in the decision-making process together, adults with TBI negotiated a goal of increased autonomy with recognition of the benefits of support. At the same time, supporters balanced their understanding of the person's right to participate, and the benefits of their increased independence, against their perceptions of risks associated with the decision. The space in which decision making took place was therefore shaped by those within the support relationship.

As well as interactions between the individuals engaged in the decision-making process, the decision-making space reflected the goals, beliefs and previous experiences of the individuals within the support relationship. Making decisions therefore played a pivotal role in contributing to the process of self-conceptualisation for adults with TBI. Through an ongoing process of engaging in decision making and evaluating the outcomes of those decisions, participants fashioned their self-concept.

Each of the three major constructs, represented in Figure 8-1, is now discussed in turn below. The implications of the current legal, political and practice contexts on the interaction between these constructs is also explored.

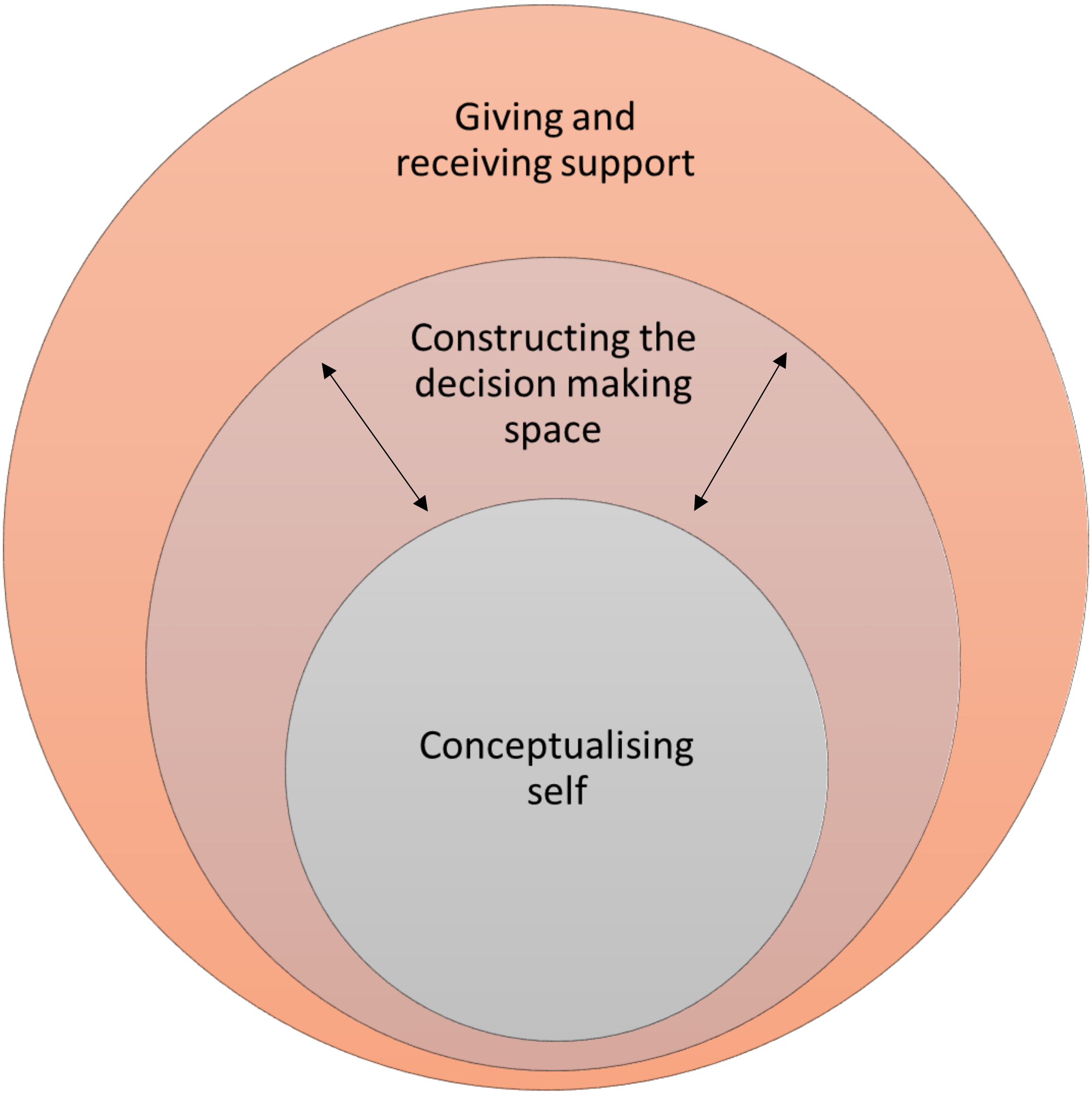


Figure 8-1: Decision-making participation after TBI – Major constructs

Construct 1: Giving and Receiving Support

The findings emphasise the interactive relationship between the person being supported and their decision-making supporters. It was clear that support was not simply provided, but was both given and received with an evolving relationship. Within this shared context, both parties influenced the nature of support.

Participants with TBI described varied sources of social support. Decision-making support was most often provided by family caregivers, particularly parents and spouses. The findings highlight that the nature of the relationship between the person and their supporters influenced the overall outlook on decision making. For example, when compared with spousal supporters, parental supporters focused on developing the person's ability to make decisions without them by seeking to provide learning opportunities. In addition, although participants rarely named paid professionals as their 'decision making supporters', it was clear that their actions and interactions with adults with TBI directly and indirectly shaped their decision-making opportunities.

The support relationship provided a space in which decision making was able to occur. Within this space, decision making support played out in a number of ways. The functions fulfilled by supporters included creating opportunities, providing expert advice, acting on the person's behalf, motivating and acknowledging achievement, and recruiting others to join the person's social support network, either on an ongoing basis or to provide support or expert input in relation to a particular decision.

A positive support relationship is characterised by a number of features. These included trust, closeness, honest and effective communication, mutual respect and a commitment to the long term nature of the relationship. Providing positive, person-centred support also required supporters to have a deep understanding of the person at the centre of the support relationship. Doing so required supporters to know the person in terms of their personal characteristics and their self-narrative. These features contributed to the quality of the relationship and, they were also important in providing a relational context for decision-making participation.

Research provides clear evidence that the consequences of TBI can significantly disrupt relationships (Brunsden, Kiemle, & Mullin, 2015; Douglas & Spellacy, 2000; Gill et al., 2011; Hammond et al., 2011; Kao & Stuifbergen, 2004; Sander, Maestas, Clark, & Havins, 2013). This can have consequences for the provision of decision-making support. Examples from this research highlighted that when support relationships are poor, collaboration is avoided which, in turn, leads to a reduction of decision making opportunities. Additionally, people with limited support may find that they have very few opportunities to make decisions. The literature contains few evidence-based strategies to increase the decision-making participation of those in this situation.

The findings also offer some evidence regarding the potential benefits of having more than one person acting as decision-making supporter. Central participants with several supporters described that having access to a network of support provided them with the opportunity to seek and reflect on a range of different views during the process. It also empowered them to make choices about who they sought support from in relation to particular decisions. Additionally, supporters commonly described that they experienced burden resulting from a significant sense of responsibility associated with their role making decisions with the person with TBI. Having a network of supporters around them may reduce the feelings of burden and isolation experienced in their role. However, the findings demonstrate the need to remain aware of the risk of collusion by groups of supporters that excludes the person with TBI from the decision-making process.

Finally, this investigation has provided insights into the changing nature of the support role over time. In line with a previous study with stroke survivors (Proot, ter Meulen, Abu-Saad, & Crebolder, 2007), participants described a period of intensive decision making support in the early phase post-injury. Following this, participants described needing varying levels of support. For some participants, their need for support continued to decrease incrementally over time. For others, their support requirements had reduced but now remained static. Some participants described that they had consciously adopted strategies to increase the level of independence of the person being supported. Providing opportunities to build the person's abilities to make decisions remains an important aspect of the supporter's role.

Construct 2: Constructing the decision making space

The second major construct therefore reflects the construction of the decision making space between the self and the support relationship. Although decision making is frequently conceptualised as an individual task, the findings of this research emphasise the need to consider decisions in the context of the relationships within which they occur.

The findings illustrate that decision-making opportunities may originate in either the self or support spheres. Decision-making supporters identified that they often initiated the decision-making process, and it was evident that their ability to identify decision-making opportunities was shaped by their own cognitive and emotional reserves, and parallel responsibilities. For example, several instances of decision-making opportunities being overlooked in order to reduce the burden experienced by supporters were evident.

Decision-making opportunities were embedded in the everyday, but varied in their size and scope. Some decisions described by participants were major life decisions, such as entering and ending relationships with an intimate partner, making a decision to have children, and deciding where to live. Other decisions were seemingly mundane, such as what clothes a person chose to wear on a particular day or what food they ate.

Importantly, the size and scope of decisions did not reflect their level of importance to the person. This finding was neatly summarised by Beau: *"The feeling I got from after achieving a small goal and, to no-one else it would be worth anything, but to me, it was good."* Although the literature has traditionally focused on the importance of support with major life decisions (Brown & Marchant, 2013; Davidson et al., 2016), the findings highlight that a broader conceptualisation of decision making, taking into account a range of decisions, is required. Minor decisions may have significant implications for the person in the context of their life and their goals for the future. In doing so, consideration needs to be given to the availability of support for people who require it across a range of decisions that have meaning in their lives.

The decision-making process was also shaped by participants' previous experiences. In particular, positive experiences resulting from a particular approach reinforced that approach. In contrast, where a given approach caused negative interactions or an undesirable outcome, an alternative approach was sought. It was evident that there were times when previous negative experiences caused those around the person to withdraw from the decision-making process or, alternatively, resulted in the person with TBI having minimal input into a decision.

Construct 3: Conceptualising Self

The findings of this research capture the recursive relationship between decision-making participation and self-conceptualisation for adults with TBI after injury. Researchers have previously described that the self consists of knowledge components and evaluative components (Campbell, 1990; Douglas, 2013; Ylvisaker & Feeney, 2000). In this research, self-concept emerged as consisting of two central components: knowledge about self (who I am) and feelings about self (how I feel about myself). Both of these aspects of self were refashioned through participation in decision making, the outcomes of this participation and their interactions with others through this process.

Knowledge of self reflected participants’ attributes and goals for the future. Participants described that many of their attributes remained constant despite their injury. Decision-making participation provided them with an opportunity to reinforce these continuous aspects of self and demonstrate independence. Goals reflected how their engagement in previous decision-making processes had shaped the self and the outcomes of these processes influenced their personal aspirations. Participants' goals shaped the decision-making opportunities that they sought out and engaged in. Regardless of their current requirements for support, all participants described a goal to re-establish a sense of autonomy that had been diminished through their injury.

The evaluative component of self comprised the person's attitudes towards self and their achievements. Attitudes to self were shaped by evaluations made on multiple levels, including comparisons against the pre-injury self, peers, others with TBI, and how they perceived they were viewed by others. Their achievements spanned a range of life roles and domains. Over time, achievements became attributes and shaped the decisions they made. Together, these factors shaped their motivations for decision making, the types of decisions they made and the support they sought in making decisions.

The influence of changing approaches to decision making

The findings describe participants' experiences within a context. Further, the data has been considered in light of the changing sociopolitical context for decision making, in line with contemporary grounded theory methods (Charmaz, 2011; Clarke, 2007). In this research, the context for decision making reflected a range of factors: participants' environment ('living in the community'), stage in their rehabilitation journey (chronic phase), and social support structures. A broad range of other factors will influence an individual's participation, including the person's life stage and community norms and attitudes towards brain injury (Block, West, & Goldin, 2016; Fleming, Nalder, Alves-Stein, & Cornwell, 2014; King et al., 2003; Whiteneck, Gerhart, & Cusick, 2004).

The sociopolitical context for decision making, both locally and internationally, is currently in flux. Over the course of this research, several significant legal inquiries were completed and policy documents released in Australia alone (Australian Law Reform Commission, 2014; Council of Australian Governments, 2011, 2012; Victorian Law Reform Commission, 2012). It is, as yet, unclear what impact these changes will have in shaping decision-making participation. Although scholars have focused on the critical role that legal and political structures play in shaping individual experience (Flynn & Arstein-Kerslake, 2014), the findings of this research highlight the challenges in ensuring that policy and legislative change leads to positive outcomes for individuals.

Recommendations for clinical practice

The results of the current inquiry have been extended to create a series of recommendations for clinical practice. The aim of these recommendations is to maximise the clinical application of the findings of this research for practitioners working with adults with TBI and those around them. The recommendations were developed around practice principles relating to the three major constructs described above. Consideration has also been given to the changing external context in which decision making takes place. Reference to relevant literature has also been made where appropriate. Some overlap between categories may be noted, reflecting the dynamic and interactive relationship between them.

Giving and receiving support: Practice recommendations

The findings of this research capture the central role of the support relationship in facilitating decision-making participation. Table 8-1 presents a series of practice recommendations related to four key findings regarding the support concept evident in the data.

Finding 1: Decision making occurs in the context of relationships

A finding that consistently emerged throughout the data was the relationally based nature of decision making. Given that previous qualitative research has described a loss of autonomy as a common experience for adults after brain injury (Chamberlain, 2006; Gelech & Desjardins, 2011; Schipper et al., 2011; Strandberg, 2009), this research provides evidence that positive relationships provide a vehicle for people with TBI to increase autonomy and exercise control in their lives. Recognising this, it is vital that rehabilitation and long-term support after injury takes an inclusive and supportive approach towards the person's social support network.

There are a range of approaches that professionals can use to support the maintenance of social relationships post injury. For example, providing support or intervention in the person's real life context provides incidental opportunities for others to learn about the injury. Where a person's social support is poor, they may have few opportunities to participate in decision making. In these circumstances, professionals can play a role in exploring opportunities for new relationships via mutual interests and/or formal support programs.

Communication plays an essential role in developing and maintaining satisfying personal relationships (Dindia & Timmerman, 2003). However, communication problems have been identified as one of the most challenging long-term sequelae associated with TBI. There is a growing body of evidence for intervention targeting communication impairment after TBI, including those that aim to improve the communication skills of the person with TBI and their communication partners (Cicerone et al., 2011; Dahlberg et al., 2007; Douglas, Knox, De Maio, & Bridge, 2014; Finch, Copley, Cornwell, & Kelly, 2015; Togher, McDonald, Code, & Grant, 2004; Togher et al., 2014). Interview data highlighted that making decisions together can be difficult and, at times, can result in interpersonal conflict. Communication partner training could provide an opportunity for those who act as decision-making supporters to develop their communication skills for such situations (Togher, McDonald, Tate, Rietdijk, & Power, 2016).

Several participants described how previous experiences within their relationship shaped the way that they engaged in the decision-making process together. Where supporters had an established relationship with the person prior to the injury, their prior experiences shaped their views about what was important to the person and which communication strategies might be most effective. For adults with TBI, these experiences shaped their expectations of the support they expected to receive. These insights suggest that, by facilitating a discussion of their previous experience of decision making and what has or has not worked well in this context, clinicians can support participants to develop a shared understanding about the decision-making approaches that support positive participation in the process.

Finally, recognising the chronic nature of brain injury, further consideration needs to be given to the provision of long-term professional support. Several authors have argued for a continuing role for rehabilitation and support services over an extended period of time after injury (Douglas, 2013; Kao & Stuifbergen, 2004; Paterson & Stewart, 2012; Ponsford et al., 2014; Sander et al., 2013; Ylvisaker & Feeney, 2000). Although such changes are restricted by funding and service arrangements and current conceptualisations of the role of rehabilitation, this research highlights the need for services to develop innovative ways of making support available on an ongoing and ad hoc basis to support the maintenance of social networks and formation of new relationships.

Finding 2: Decision-making supporters bring their own motivation, values and beliefs when providing support

The first publication of this thesis explored how assumptions held by those around the person with TBI shaped their approach to decision making. The experiential component of the research revealed that the actions of those participating in the decision-making process with adults with TBI reflected their own values and beliefs. This finding has previously been reported in relation to people with dementia (Reamy, Kim, Zarit, & Whitlatch, 2011; Smebye, Kirkevold, & Engedal, 2012) and intellectual disability (Dunn, Clare, & Holland, 2010). It highlights the importance of supporters being able to reflect on their own values and identify what drives their approach to decision making. It also points to the difficulty of supporters being able to adopt a completely neutral stance when the outcomes of decisions are shared (Martin et al., 2012).

Providing decision-making support that aligns with the CRPD and the proposed national decision-making principles requires those acting in a support role to act according to the person's will and preferences rather than their best interests. The findings of this research suggest that supporters remain unaware of this distinction. Supporters commonly described that they provided support in line with their understanding of the person, their goals and "what's best for [them]" (as described by Beau's support Adrian). Taking a best interests perspective also reflected their desire to minimise risk to the person. In particular, they acted to shape the outcome of decisions where they perceived a risk of financial loss or physical harm. A study of caregivers' perceptions of the ability of adults with TBI to exercise judgment identified financial management as one of two main areas of concern (Kreutzer et al., 2009). Given these findings, financial decision making should be an area of particular interest for professionals in order to ensure that risks are proactively managed and adults with TBI are provided with opportunities for skill development and increased independence over time.

It has been acknowledged that the distinction between these concepts is not always as clear as suggested by legal scholars (Carney, 2015a). However, there is a need for them to be better understood by rehabilitation and disability professionals. This would provide them, in turn, with the ability to discuss the terms and the support approaches associated with them with those who have taken on the support role. Within a rehabilitation context, professionals could model an approach that reflects the person's will and preferences. Further, real-life scenarios could be used to distinguish how these different approaches may look in practice and assist supporters to identify what factors influence their provision of support in relation to particular decisions.

Finding 3: Supporters report that providing decision-making support can be an onerous and burdensome task at times

Arksey and Glendinning (2007) have proposed that choice needs to be considered in a social context, rather than in individual terms. The findings of the current investigation highlight that while those providing support to the person with TBI draw benefit and satisfaction from their role, it may also result in their own choices and decisions being constrained. This finding highlights the importance of ensuring that supporters have opportunities to discuss their experiences, either informally in discussion with others in a similar position, or more formally, as a planned topic in a caregiver support group.

In response to these challenges, involved others reported that they relied on routines and advance planning in order to reduce the burden of being responsible for the majority of day to day decisions. The benefits of routine in increasing the autonomy of people with brain injury have previously been documented (McCluskey, 2003; Ylvisaker, Jacobs, & Feeney, 2003). In her investigation of care management after ABI, McCluskey and her colleagues (2007) proposed that routines acted to provide structure and purpose to participants with ABI. As a result of repeated practice, participants’ skills improved and they were able to exercise increased autonomy. The central participants in this research provided a range of examples where they also relied on routines in order to enact their decisions and exercise a level of control in their lives. However, there were also times when this routine constrained their ability to make decisions. This finding suggests that families may need support to discuss and negotiate the role of routine in their lives. The evolving nature of support post-injury suggests that this topic needs to be regularly revisited by the person and those who support them.

Finding 4: Knowledge of brain injury assists those around the person to tailor their support

The existing literature has highlighted that family caregivers report that they are provided with insufficient information about brain injury across the recovery continuum (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012; Gan, Gargaro, Brandys, Gerber, & Boschen, 2010; Keenan & Joseph, 2010; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007; Yeates, Henwood, Gracey, & Evans, 2007). A central finding that emerged in this research was the importance of having an understanding of brain injury in order to better tailor decision-making support. For people with TBI, this knowledge provided an understanding of their own limitations and assisted them to develop an awareness of particular situations in which they may need additional support. For involved others, this knowledge guided their support. It influenced when they chose to intervene in the decision-making process, their selection and use of support strategies and how they delivered this support.

Decision-making supporters described that knowing the person well was an essential component of understanding the brain injury. For clinicians, this finding highlights the need to better tailor support and education that reflects the needs of the individual and their family. Rather than discussion of abstract concepts, informational counselling and the provision of feedback regarding a person's assessment results need to reflect an understanding of who the person is and what is important to them. For those around the person, inclusion in team meetings and therapy sessions may provide opportunities for them to build an understanding of the impacts of the brain injury in the context of activity.

As highlighted earlier, these findings provide further evidence for the need for long-term support for adults with TBI. Although rehabilitation and support is often intensive and focused in the early stages of recovery, TBI is a chronic condition. Access to education and support may assist the development and maintenance of positive relationships with the person, both for those who have entered a new relationship and those who have a long standing relationship.

Table 8-1: Practice recommendations related to the 'giving and receiving support' construct

Findings	Evidence	Principle/s	Recommendations
Decision making occurs in the context of relationships	Knox et al. (2015a, 2015b, 2016a, 2016b) *Supporting evidence:* Amado (2013) Douglas (2012) Togher et al. (2004) Togher et al. (2016)	Relationships provide a vehicle for developing autonomy after TBI Communication is the means through which relationships are negotiated The nature and history of relationships shapes the decision-making approach used within these relationships	• Use a social network tool to assess the person's past and present social relationships and networks • Support the maintenance of valued relationships and explore opportunities for the development of new relationships • Provide communication partner training to those who may act as decision-making supporters • Explore mechanisms for support beyond hospital discharge • Facilitate discussion of previous decision making experiences – Decision making processes used – What has and has not worked well

Decision-making supporters bring their own motivation, values and beliefs when providing support	Knox et al. (2013, 2015a, 2015b, 2016b) *Supporting evidence:* Dunn et al. (2010) Martin et al. (2012) Kreutzer et al. (2009)	Regular self-reflection and review are essential components of effective decision-making support	• Use previous decision-making experiences to assist supporters to identify how their goals and values influence their approach – Reflect on how the process may have been different if they held different goals or values • Discuss the differences between taking a 'best interests' approach and one that is based on the person's 'will and preference'
Supporters report that providing decision-making support can be an onerous and burdensome task at times	Knox et al. (2015a, 2015b, 2016b) *Supporting evidence:* Arksey and Glendinning (2007) McCluskey (2003)	Those providing decision-making support require support in their roles	• Introduce support and education for those who have taken on the role of decision-making supporter – Include as a topic in caregiver support groups – Provide opportunities for peer mentoring for caregivers • Discuss the advantages and limitations of routine in supporting autonomy

Knowledge of brain injury assists those around the person to tailor their support	Knox et al. (2015a, 2015b, 2016b) *Supporting evidence:* Gan et al. (2010) Yeates et al. (2007)	Effective support reflects an in-depth knowledge of who the person is and the impact of the brain injury on their behaviour	• Provide brain injury education that is tailored to the individual • Incorporate supporters in therapy sessions in order to provide opportunities to develop their knowledge of TBI • Individuals with TBI require access to therapy and support over the long term in order to assist them to develop and maintain important relationships

Constructing the decision making space: Practice recommendations

The second major construct reflected broad range of decisions that reflected their varied roles, responsibilities and interests. Table 8-2 presents a series of practice recommendations related to two key findings that have emerged from this research.

Finding 5: Every decision is a new experience

The findings of this research highlight the value of supporters approaching each decision as a new experience. Although supporters' previous experience can provide them with skills and knowledge to draw on when providing support, there is also a need for supporters to be prepared to put aside their assumptions when commencing a new decision-making process. In particular, the current research has highlighted that a person's need for decision-making support will change over time and in response to a range of different factors, such as the nature of decision, its significance to the person, and their familiarity with the issues involved.

The findings also demonstrated that people with TBI and their supporters may work together to alter the nature of support over time. For example, they may seek opportunities to allow the person with TBI to increase their level of independence and reduce the level of support provided by their supporters. This changing approach may be adopted in response to the motivations and desires of the participants and/or the family life cycle.

Antaki and colleagues (2009) previously argued that the policy discourse around choice for people with cognitive impairment does not reflect the real life decisions available to them. The findings of the research demonstrated a discrepancy between the size or significance of a decision and how important participation in that decision was to the individual. This finding underscores the importance of decision-making support reflecting a deep knowledge of the person with TBI and what is important to them. Clinicians could facilitate the development of this knowledge through conversations that explore the relative importance of a defined set of decisions and collaboration with the person and their supporters. This would enable decision-making opportunities to be structured in line with the individual's preferences.

Finding 6: The decision making process consists of a number of stages

The findings of this research highlight that the decision-making process involves a number of steps. Although the WHO definition presented in Chapter 2 identifies three steps, the evidence from this research suggests that this may be an overly simplistic characterisation of the process. The decision-making model illustrated in Chapter 5 captures the spousal experience of the decision-making process. It highlights that decision-making supporters may undertake a number of pre-decisional steps. In particular, supporters described having responsibility for identifying decision-making opportunities and evaluating their involvement in the process prior to engaging with the person they are supporting. Spousal supporters also described evaluating the decision in terms of its outcome and the impact of the process on their relationship.

Diagrammatic models may assist a dyad or group to conceptualise the decision-making process as they work through it. They may assist those involved to develop an awareness of the steps involved and work their way through the multiple components involved in making a decision. In addition to diagrammatic models, structured decision-making aids may also be helpful. A recent Cochrane Review noted that there is a strong evidence base that decision aids can "improve people's knowledge regarding options and reduce their decisional conflict…" (Stacey et al., 2014, p. 3). Several of these are publicly available. For example, the Ottawa Personal Decision Guide for Two (O'Connor, Stacey, & Jacobsen, 2015) has been developed to assist dyads in the process of working through a decision. The evidence from this research highlighted that participation in a decision may mean being involved in all parts of the decision or having responsibility for one part of the decision. Using a model may assist those involved to transparently negotiate their preferred levels of involvement.

Table 8-2: Practice recommendations related to the 'constructing the decision-making space' construct

Findings	Evidence	Principle	Recommendations
Every decision is a new experience	Knox et al. (2015a, 2016a, 2016b) *Supporting evidence:* Antaki et al. (2009)	Every decision is a potential opportunity for participation	• Recognise that the need for decision making support will change over time and according to the decision • Structure opportunities to participate in decision making in line with the person's preference
The decision making process consists of a number of stages	Knox et al. (2015b, 2016b) *Supporting evidence:* Stacey et al. (2014)	Support may be needed at any or all stages of a decision Decisions may be composed of multiple smaller decisions	• Diagrammatic models and decision aids can be used to discuss the process with person and those around them to: – Elucidate the decision-making process – Analyse the components of a decision – Identify how a particular decision might contribute to a longer term vision – Trigger discussion about how the dyad is moving through the decisional process – Identify how the person wishes to participate in a particular decision

Conceptualising self: Practice recommendations

The significance of the relationship between decision-making participation and self-conceptualisation was a key finding emerging from this research. The recommendations relating to this finding are outlined in Table 8-3 and discussed below.

Finding 7: Decision-making plays a pivotal role in shaping the self after injury

There is increasing interest in the process of self-conceptualisation after injury (Douglas, 2013; Gracey et al., 2008; Levack et al., 2014; Muenchberger, Kendall, & Neal, 2008; Nochi, 1998a; Ylvisaker & Feeney, 2000). The findings of this research clearly indicate the significant role of decision-making participation in contributing to the ongoing process of self-conceptualisation after TBI. Rehabilitation professionals have a critical role in supporting the autonomy of the individuals they are working with in order to support them to develop a positive self-concept.

Despite an active focus on engaging people in the rehabilitation process, findings from the literature suggest that many individuals feel excluded from meaningful decision-making participation in this context (Lawson, Delamere, & Hutchinson, 2008; Lefebvre, Pelchat, Swaine, Gélinas, & Levert, 2005; O'Callaghan, McAllister, & Wilson, 2010). In response, it has been suggested that the multidisciplinary team should focus their intervention around the concept of self-identity (Thomas, Levack, & Taylor, 2014; Ylvisaker & Feeney, 2000). Doing so would require the team to consider whether their interactions contribute to a context in which the person actively participates and feels that they are valued by team members for doing so.

In line with the findings of this research, it is recommended that rehabilitation professionals regularly seek feedback from the person on a regular basis about their perceived level of involvement in decision-making, as well as their thoughts and feelings about the processes around decision making. This may require the use of both formal and informal methods. Informal methods could include regular conversations about how involved the person feels in decision making and/or repeated measurement of the person’s perceived level of participation via a visual analogue scale. Relevant items of the Resident Choice Scale (Hatton et al., 2004) could be used to measure decision making participation across a range of life areas from different perspectives. In addition, clinicians could support an individual and their supporters to complete a visual map of life decisions across valued life roles and domains.

Finding 8: Conceptualisation of self is a dynamic process

Existing literature highlights the dynamic and iterative nature of self-conceptualisation (Douglas, 2013; Muenchberger et al., 2008; Strandberg, 2009). The findings of this research add further weight to this evidence, and have several key implications for rehabilitation professionals. In particular, they emphasise the need to understand how the person conceptualises self at the point of intervention. They also underscore the need for professionals to maintain awareness of the constantly changing nature of the person's self-concept. In particular, clinicians should consider whether rehabilitation activities reinforce the self and reflect the person's life goals (Martin, Levack, & Sinnott, 2015).

An understanding of the person's functional status may be obtained by talking to them and observing them, and these observations can also assist the clinician to develop their knowledge of the person and what is important to them. Using a tool such as the self-conceptualisation framework, first described by Douglas (2013) and expanded in this research, could frame further discussion with the person. Conversational prompts include, for example, questions in relation to the person's attributes (What are 3 things that are really important to know about you?), their achievements (Tell me about an achievement you are most proud of?), their attitudes to self (How would your friends or family describe you?) and goals. Answers can then inform a number of rehabilitation processes such as goal setting, team meetings, and intervention planning. This knowledge can also inform practitioners about the context in which the person is attending therapy and the issues of greatest concern and importance to them in the current phase of their life.

Finding 9: Adults with TBI report that they are assumed by others to be "incapable"

It has been proposed that the negative labels attached to a person by others can threaten their views of self and shape their actions (Nochi, 1998b). All of the central participants in this research reported that there were times when they were assumed to be unable to make decisions in their own lives. This assumption reflected their perceptions of the views of a range of people, including those close to them. This finding extends the literature which describes that adults with brain injury report a *loss of self in the eyes of others* (Nochi, 1998a) by highlighting how decision-making participation (and exclusion) can contribute to this process.

Recognising the role of social interactions in shaping the self, the actions of rehabilitation professionals can reinforce or oppose the labels given to the person by others. Actions that support a positive sense of self could include emphasising the person's strengths (for example, when presenting assessment results) and working alongside them to develop strategies that can assist them to manage their impairments. Developing a positive identity map, as suggested by Ylvisaker and colleagues (2008), provides an opportunity for therapy to be grounded in "the self" and directed by the person's goals. In addition, concrete reminders of positive gains and feedback over the course of intervention provide tangible evidence of the person's capabilities.

Finding 10: Being "independent" is a key goal for many people with TBI

Many participants in this research described that increasing their independence was an important goal for them. In a rehabilitation context, independence has traditionally been defined in a functional sense (for example, being independent in personal care) (Reindal, 1999; Schipper, Widdershoven, & Abma, 2011). However, it is important to note that this is not how independence was defined by the participants in this research.

Independence, as described by participants, aligned more closely with a definition of autonomy. Participants described that they wanted to be able to make decisions about their lives that reflected their life goals. Functional independence in some tasks was necessary to achieve this. However, participants described the important roles played by those in their social support network. The participants in this research defined "independence" as being able to make and act on decisions about their lives *(autonomy)* while recognising the important role that others play in their lives *(interdependence)*. This highlights the importance of clinicians understanding the social context for activity after TBI and exploring the personal meaning of independence in order to inform goal development and intervention planning.

A focus on functional independence in rehabilitation settings reflects a broader conceptualisation of what intervention is and how outcomes are measured. The first manuscript of the thesis described how such an approach can pose risks to a person's autonomy and social participation. Although current funding arrangements present a barrier to services shifting their focus towards maximising autonomy, there is a role for team discussion about the difference between these concepts and consideration of how they are valued within that setting. As proposed by Hunt and Ells (2011), approaching intervention from a relational perspective can support clinicians to consider how they can maximise the decision-making autonomy of those they work with.

Table 8-3: Practice recommendations related to the 'conceptualising self' construct

Findings	Evidence	Clinical Principle/s	Recommendations
Decision-making plays a pivotal role in shaping the self after injury	Knox et al. (2016a) *Supporting evidence:* Thomas et al. (2014) Entwistle and Watt (2006) Hatton et al. (2004)	The context of rehabilitation can support or diminish autonomy Rehabilitation practice should facilitate participation in personally meaningful decisions	• Understand that all opportunities to participate in decision making have value • Use a visual map of life decisions to explore with the person which decisions are of greatest importance to them • Regularly seek feedback about the extent to which the person feels included in decision making
Self-conceptualisation is a dynamic process	Knox et al. (2015a, 2016a) *Supporting evidence:* Douglas (2013) Martin et al. (2015)	Intervention and support should reflect a thorough understanding of who the person is and how they see themselves at that particular time	• Understand how the person conceptualises self by: – Talking to and observing the person – Talking to those around the person who are important to them • Use the self-conceptualisation framework to guide therapy and relationship building

			• Recognise that a person's life goals are dynamic and will change based on their experiences and social context
Adults with TBI report that they often feel they are assumed by others to be "incapable"	Knox et al. (2016a) *Supporting evidence:* Douglas (2013) Douglas (2015) Nochi (1998a) Nochi (1998b) Ylvisaker et al. (2008)	Interactions with the person with TBI should maximise their strengths and recognise their capabilities	• Model interaction that assumes capacity • Provide feedback (e.g. from assessments) that highlight the person's strengths • Highlight and record the person's achievements • Explore the person's understanding of their own limitations
Being "independent" is a key goal for many people with TBI	Knox et al. (2015a, 2016a) *Supporting evidence:* Schipper et al. (2011) Hunt and Ells (2011)	We all rely on others to exercise autonomy	• Take time to discuss what the concept of independence means to the person with TBI • Explore team members' understanding of the concepts of independence and autonomy • Ensure that the person is included in an ongoing process of assessing personally relevant outcomes

Responding to the changing context: Practice recommendations

Finally, in recognising the role of the social, political, legal and cultural environments on decision making, Table 8-4 present practice recommendations reflecting a need for professionals to maintain an awareness of a broad range of contextual factors.

Finding 11: The decision-making process is shaped by the context within which it occurs

Participants' lack of engagement with changes in the broader sociopolitical context highlights the need for greater collaboration across disciplines and professions in order to maximise decision-making participation for people with TBI. This collaboration is important in ensuring support is tailored to meet the needs of the individual, and in assisting professionals to meet their legal and ethical obligations.

Supported decision making is a concept that will have increasing relevance for professionals across the health, rehabilitation and disability service sectors. The first manuscript included in this thesis highlighted that new legal frameworks will require clinicians to radically reconsider their approach towards decision-making assessment. This body of research has demonstrated that particular consideration needs to be paid to the relational and socially mediated nature of the process. The roles of those around the person are likely to be more formally recognised and greater opportunities for collaborative decision-making will be required to be embedded in practice.

Given these findings, two key practice recommendations are made. First, there is a need for professional development for rehabilitation clinicians to build their knowledge of the current state of policy and practice across the range of contexts relevant to people with TBI. For example, clinicians should have a basic working knowledge of the United Nations Convention on the Rights of Persons with Disabilities and the concept of supported decision making, and an understanding of its impact on their practice.

Second, more opportunities for multidisciplinary knowledge-sharing and collaboration are required across legal, political and practice sectors. Currently, the majority of the literature in relation to supported decision making occurs within a philosophical and legal context (Arstein-Kerslake, 2016; Browning et al., 2014; Carney, 2014; Glen, 2015; Gooding, 2012), and has limited practical application to those working to support people with cognitive impairments. Conversely, there is very limited rehabilitation research relevant to the implementation of human rights (Skempes, Stucki, & Bickenbach, 2015). Collaboration across these disciplines, through research and education, will be required to ensure that the context for people with TBI is structured in a way that maximises their participation in decisions that are important to them.

Table 8-4: Practice recommendations reflecting a need to respond to the changing context

Finding	Evidence	Principle	Recommendations
The decision-making process is shaped by the context within which it occurs	Knox et al. (2013, 2016a) *Supporting evidence:* Gooding (2015) Skempes et al. (2015)	Support should reflect the will and preferences of the person (rather than a single professional approach)	• Rehabilitation professionals require knowledge of the current state of policy and practice across contexts relevant to people with TBI • Opportunities for increased multidisciplinary knowledge-sharing and collaboration are needed

Research strengths and limitations

A number of methodological considerations and limitations should be taken into account when considering the findings of this investigation. Although these issues have been discussed within the manuscripts comprising chapters 4-7, a summary is now provided.

The overall strength of this research lies in its qualitative design. In-depth interviews generated rich, complex data that provided insight into participants' experiences and allowed for a deep understanding of the processes underpinning decision making in the lives of adults with TBI and those around them. Conducting a series of interviews over the course of the research allowed the exploration of decision making as a dynamic process shaped by the changing goals and beliefs held by individual participants. It also provided an opportunity to explore how decision-making opportunities altered over time and what drove these changes.

This research is the first to explore decision making after brain injury by seeking to understand the experiences of a number of people who are involved in the process. However, there are number of alternative data generation methods that could have been used to gain different insights into the process. Examples of alternative methods include dyadic interviewing and participant observation.

Dyadic or group interviewing could provide a more nuanced understanding of how interactions between the involved parties shape the decision-making process and its outcome (Eisikovits & Koren, 2010). Observing participants in the process of making decisions could provide deeper insights into how the process takes place (Kawulich, 2005). Although the focus of this research was building an initial understanding of how participants experienced the process, these alternative methods could form the basis of future investigations.

Adopting a constructivist stance in this research allowed for the valuing of participants' stories and experiences. Despite post-injury sequealae (including reduced awareness, memory impairment and perseveration) have been noted as challenges for research participation (Paterson & Scott-Findlay, 2002), the experience of this research demonstrated that these can be overcome. Participants provided rich and detailed accounts of their own experiences and the impact that these experiences had on their lives.

A range of strategies have been used to strengthen the quality of the findings from this research. For example, the findings have been formally presented at national and international conferences in the areas of rehabilitation and supported decision-making, and informally to service provider networks and other health and rehabilitation professionals. Feedback in these forums has confirmed the relevance and fit of the findings to the experiences of those working in the area (Glaser, 1998).

The research was designed to develop and describe an understanding of the experience of participating in decision making after TBI, in order to inform clinical practice. The recommendations presented in this chapter provide a guide for rehabilitation professionals and case managers working with people with TBI in order to maximise their decision-making participation. As such, the initial aims of the research have been met. However, no claims are made about the generalisability of the findings. Further, the findings are limited by the scope of what is possible within a doctoral research program, and comparative analysis of research findings across groups and contexts will be required to raise the findings emerging from this research to the level of a formal theory (Glaser & Strauss, 1967)

Strauss and Corbin (1994) noted that grounded theories need to be considered within their temporal, social and political contexts. All of the participants in this research lived in the Eastern states of Australia and were interviewed in 2012-2014. The legal and political context for decision making varies significantly across international jurisdictions, and this is one factor that would be expected to impact on experience. As the context continues to change, the model emerging from this research will need to continue to evolve. Further, issues relating to rehabilitation access, community-based support and disability funding are context-specific and likely to shape a person’s experience.

The total number of participants in this research, although comparable to other studies, was relatively small. Nineteen participants took part in a total of 42 interviews. Saturation was reached in relation to the experiences of central participants, with no new concepts seen to emerge from their interviews in the final stages of the research. However, the diversity of the roles of involved others means that there is still more to understand about their experiences. Nonetheless, concepts were identified that explained similarities and differences between participants, accounted for the majority of their experiences and described how they managed the decision-making experience (Creswell, 2007).

All of the central participants in this research had sustained a severe TBI and were living with the chronic effects of brain injury. Although all lived in the community, one participant (John) lived in a supported residential setting. His experience highlighted the particular needs of those living with minimal family support and how this impacted on his ability to make decisions about his life and set goals for the future. Further exploration of the decision-making support needs of this group is required. In line with the overarching philosophy of this research, central participants were asked to nominate the involved other participants who would be invited to participate in this research. Throughout interviews with participants, it was clear that there were a number of other people in their lives who influenced their decision-making opportunities and experiences. In some cases, participants expressed that they did not wish particular individuals to speak to the researcher because they did not have a positive relationship with them. Given this, it is important to acknowledge that the findings reflect the experiences of preferred decision-making supporters. Little remains known about the experiences of those who participate in the process where significant conflict is involved.

Finally, all of the participants in this research were from English speaking backgrounds. None were indigenous Australians. People from other cultures may have a different understanding of decision making, both in terms of process and outcomes (Nisbett, Peng, Choi, & Norenzayan, 2001; Weber & Hsee, 2000). Further, as indigenous Australians have historically been over-represented in terms of TBI and underrepresented in relation to post-injury services and support (Gauld, Smith, & Kendall, 2011; Helps & Harrison, 2006), it will be important to expand the findings of this research to account for their experiences in the future.

Directions for future research

This research has highlighted several areas for further investigation. The first and most obvious of these is the need to examine and extend the constructs that have emerged from this research in a range of different contexts. This could be achieved by seeking to understand the views of adults with TBI and their supporters living in different geographic locations or exploring the decision-making experiences of different but related groups. Although one participant in the current research lived in a supported residential environment, seeking to understand the experiences of those in institutional and/or residential aged care environments would allow further exploration of the context and support concepts that have emerged and provide greater insight into the role of the living environment in facilitating decision-making participation. Investigating the decision-making experiences of adults with mild or moderate TBI could extend our understanding of the *conceptualising self* construct. Further, all of the participants in this research were in the chronic phase post-injury and examining the experiences of those earlier in the injury trajectory could help to extend our understanding of the constructs emerging from this investigation.

Although this research provided some insight into the role of rehabilitation in influencing decision-making participation after TBI, more research is required to understand this relationship in greater detail. A longitudinal qualitative study of decision-making participation commencing earlier in the post-injury journey (for example, in inpatient rehabilitation) would provide greater insight into the role of rehabilitation in shaping decision-making opportunities over the longer term. Such a study could also explore how the changing nature of the relationships around the person impacts on their decision-making opportunities and whether this relates to changes in the perceived availability of decision-making support.

All but one of the central participants in this research nominated either a parent or spouse as a decision-making supporter. The critical role that family members play in providing instrumental and expressive support after brain injury has been well documented (Degeneffe, 2001; Jumisko, Lexell, & Söderberg, 2007; Kozloff, 1987; Lefebvre, Cloutier, & Levert, 2008; Serio, Kreutzer, & Gervasio, 1995; Turner et al., 2007). However, this also highlights the need to better understand (a) how adequate support can be provided to those who do not have strong family ties, and (b) the experiences of others from outside the immediate family who take on the role of decision-making supporter.

The need to consider the decision-making support needs of those who are socially isolated has been highlighted previously (Carney, 2014). At least one of the supported decision-making trials undertaken in Australia recruited volunteers previously unknown to the person to act as decision-making supporters in such situations (Office of the Public Advocate, 2016). At the completion of this trial, the project manager noted that the "development of a trusting and respectful relationship…was often a very slow process" (Burgen, 2015, p. 23) and the program did not continue beyond its 18-month trial. Given that the findings of this research have highlighted the need for supporters to have a deep understanding of the person they are providing support to, thorough evaluation of such an approach is needed. If such an approach is found to be a viable alternative, evidence will be needed regarding strategies to support the maintenance of such relationships.

Several participants highlighted the influence of formal supporters in shaping their lives, including rehabilitation clinicians and paid support staff (such as disability support workers and accommodation staff). Additionally, exploration of the experiences and motivators of those who are appointed as proxy decision-makers, such as guardians and financial administrators, is needed.

One participant nominated a friend as one of his decision-making supporters. In interviews, several other participants provided examples of times when friends had supported them through a decision. Friends often act as a sounding board in our everyday relationships (Goldsmith & Fitch, 1997) and their role in supporting decision-making participation requires further attention.

As highlighted earlier, different methods could augment our understanding of how decision-making participation takes place within relationships. Suggested methods include observation of a dyad or group making decisions, or the use of critical discourse analysis to analyse dyadic interviews to provide insight into the influence of broader social and cultural structures on the decision-making process (Locke, 2004).

Finally, although the findings emerging from this research may provide a guide for clinicians working with adults after TBI, further research using mixed methods is required to transform these findings into practical tools. Quantitative measures could include changes in the number and type of decision-making opportunities, and the measurement of the person's satisfaction with decision making participation over time. In depth interviews with practitioners could provide additional data regarding barriers and facilitators to decision-making participation (both from a relational and environmental context). This knowledge could be used to develop training materials and practical tools for use.

Concluding statement

This research is the first to explore the experience of decision making from the perspectives of those being supported to make decisions and those providing support. The findings revealed that participation in decision making is a complex, cross-contextual process reflecting individual, relational and decision-specific factors. The rapidly changing nature of the sociopolitical context will continue to shape how this process plays out in the lives of adults with brain injury.

The findings of this research emphasise the importance of decision-making participation in people's lives. Being active in making decisions provides a vehicle for people to participate as full and active members of society. The findings highlight that there is more to be done, and this work must be done.

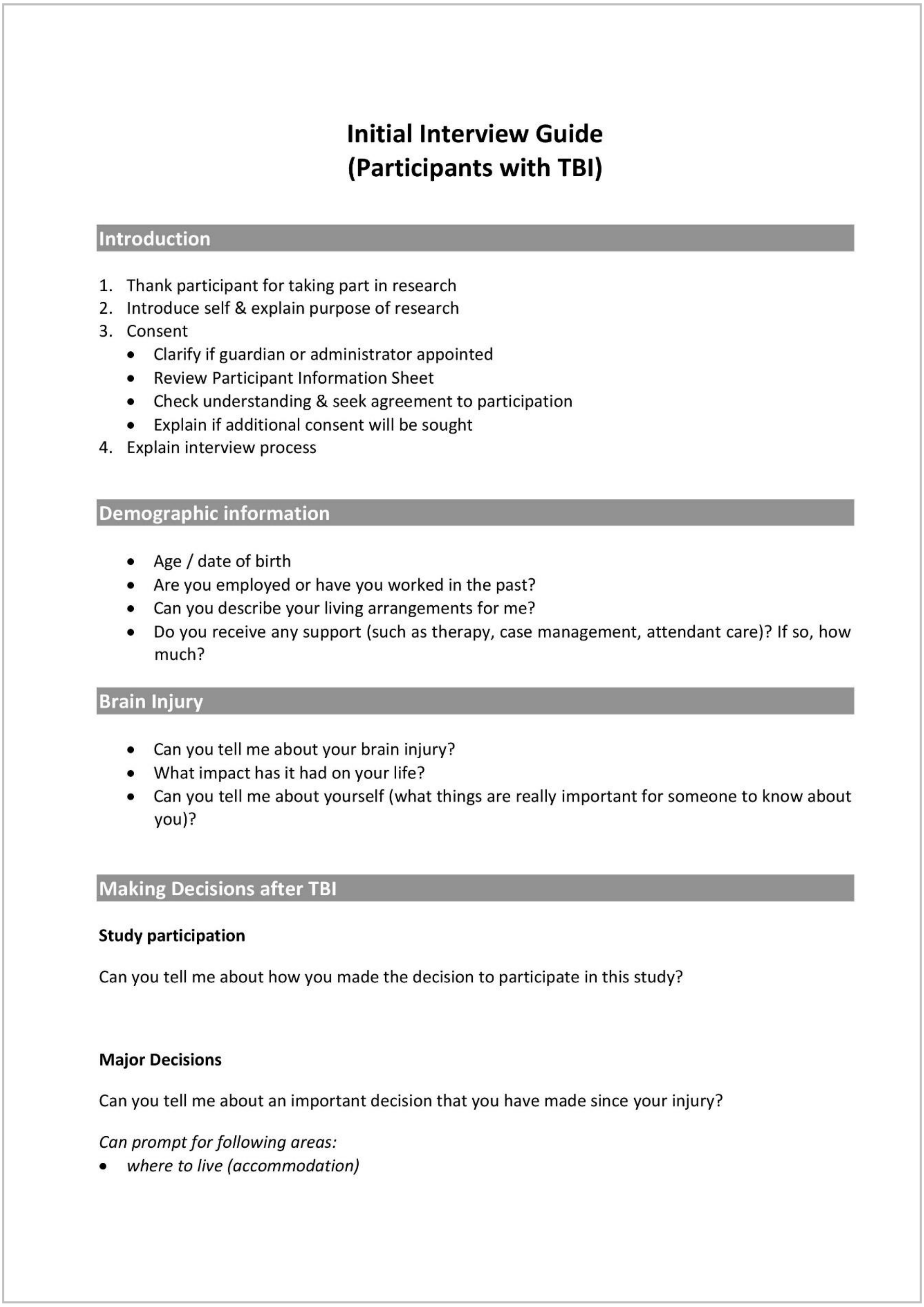
> *I always wanted to contribute…feel like I was a valued part of what makes [things] work. And there's this massive change since the accident… everything was turned on its head… But through time, over the last 2 or 3 years, claw [my] way back.*
>
> *There are times when it's too much effort, but with encouragement from family, friends and loved ones, it's worth it. There's no what's right for one person is right for anyone else. It's gotta be up to them to decide they want to do it. And they need support and encouragement to do it.*

Peter (Interview 2)

APPENDICES

APPENDIX A

Initial interview guide - Central Participants



Initial Interview Guide
(Participants with TBI)

Introduction

1. Thank participant for taking part in research
2. Introduce self & explain purpose of research
3. Consent
    - Clarify if guardian or administrator appointed
    - Review Participant Information Sheet
    - Check understanding & seek agreement to participation
    - Explain if additional consent will be sought
4. Explain interview process

Demographic information

- Age / date of birth
- Are you employed or have you worked in the past?
- Can you describe your living arrangements for me?
- Do you receive any support (such as therapy, case management, attendant care)? If so, how much?

Brain Injury

- Can you tell me about your brain injury?
- What impact has it had on your life?
- Can you tell me about yourself (what things are really important for someone to know about you)?

Making Decisions after TBI

Study participation

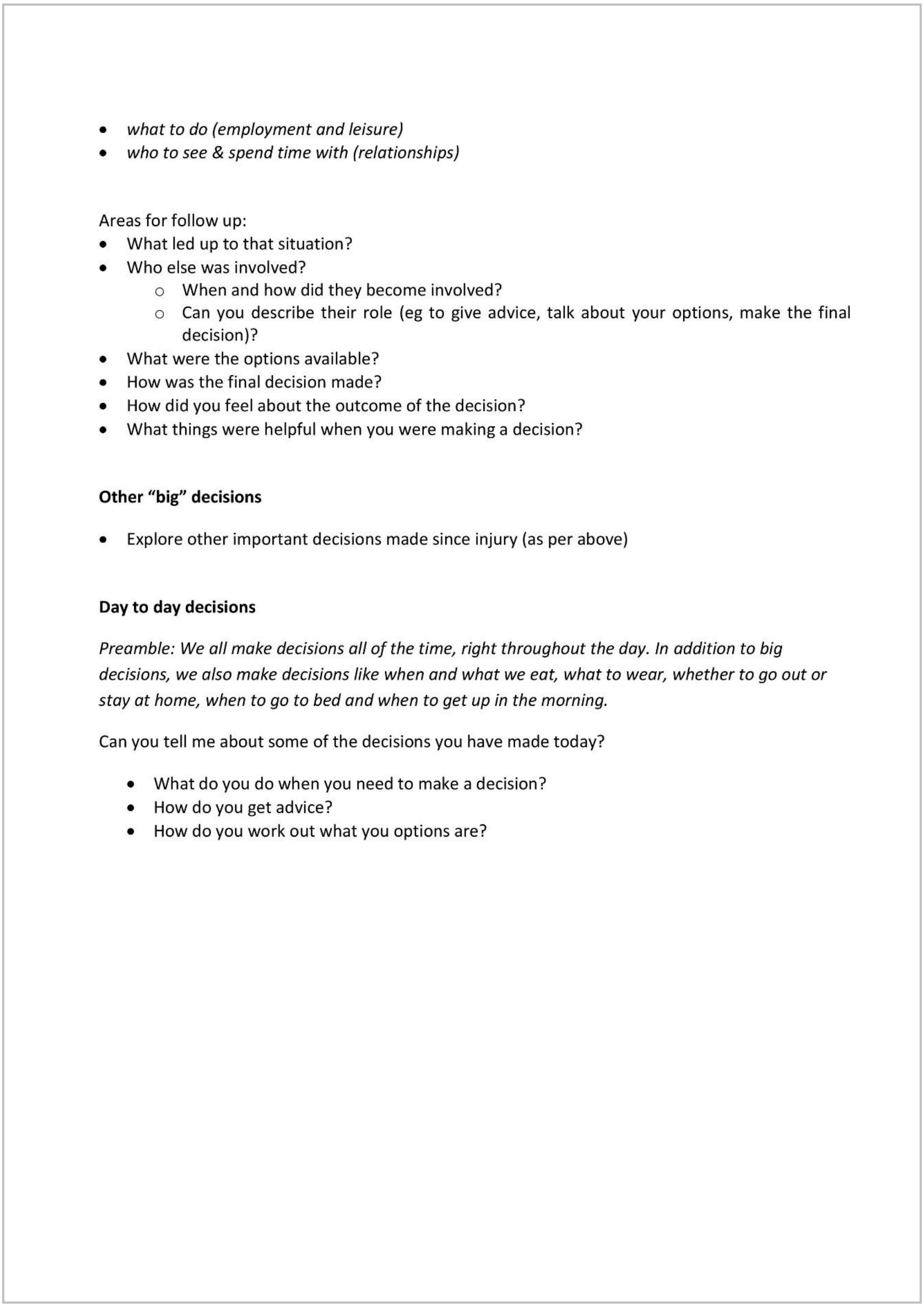
Can you tell me about how you made the decision to participate in this study?

Major Decisions

Can you tell me about an important decision that you have made since your injury?

Can prompt for following areas:

- *where to live (accommodation)*



- *what to do (employment and leisure)*
- *who to see & spend time with (relationships)*

Areas for follow up:

- What led up to that situation?
- Who else was involved?
    - When and how did they become involved?
    - Can you describe their role (eg to give advice, talk about your options, make the final decision)?
- What were the options available?
- How was the final decision made?
- How did you feel about the outcome of the decision?
- What things were helpful when you were making a decision?

Other "big" decisions

- Explore other important decisions made since injury (as per above)

Day to day decisions

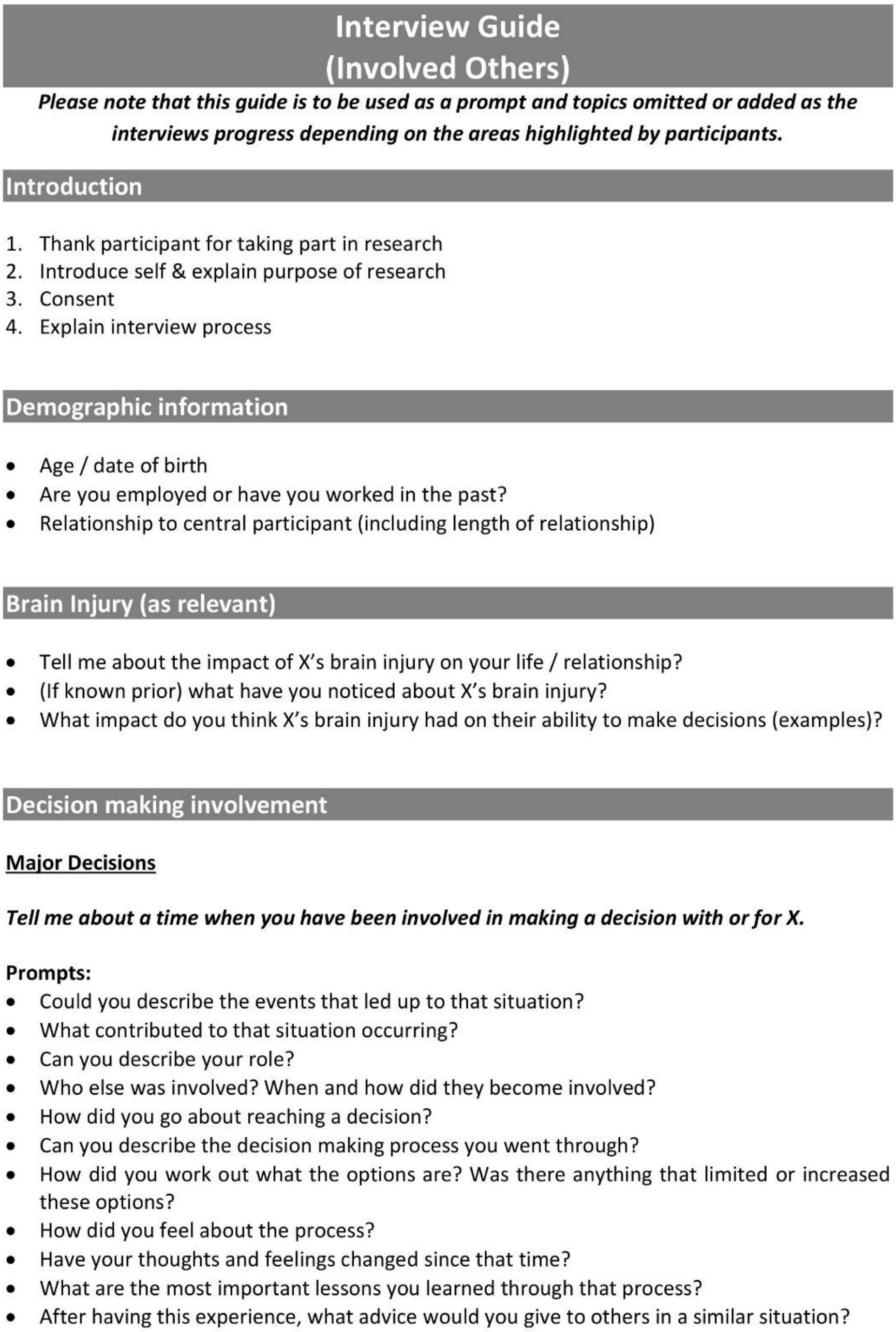
Preamble: We all make decisions all of the time, right throughout the day. In addition to big decisions, we also make decisions like when and what we eat, what to wear, whether to go out or stay at home, when to go to bed and when to get up in the morning.

Can you tell me about some of the decisions you have made today?

- What do you do when you need to make a decision?
- How do you get advice?
- How do you work out what you options are?

APPENDIX B

Initial interview guide – Involved others



Interview Guide
(Involved Others)

Please note that this guide is to be used as a prompt and topics omitted or added as the interviews progress depending on the areas highlighted by participants.

Introduction

1. Thank participant for taking part in research
2. Introduce self & explain purpose of research
3. Consent
4. Explain interview process

Demographic information

- Age / date of birth
- Are you employed or have you worked in the past?
- Relationship to central participant (including length of relationship)

Brain Injury (as relevant)

- Tell me about the impact of X's brain injury on your life / relationship?
- (If known prior) what have you noticed about X's brain injury?
- What impact do you think X's brain injury had on their ability to make decisions (examples)?

Decision making involvement

Major Decisions

Tell me about a time when you have been involved in making a decision with or for X.

Prompts:
- Could you describe the events that led up to that situation?
- What contributed to that situation occurring?
- Can you describe your role?
- Who else was involved? When and how did they become involved?
- How did you go about reaching a decision?
- Can you describe the decision making process you went through?
- How did you work out what the options are? Was there anything that limited or increased these options?
- How did you feel about the process?
- Have your thoughts and feelings changed since that time?
- What are the most important lessons you learned through that process?
- After having this experience, what advice would you give to others in a similar situation?

- (For formal supporters) Does policy influence the way that you support X's participation in decision making?

Everyday decisions

- Can you tell me about the difference between decision making about the 'big' decisions and decisions about everyday events?
- Are there any decisions that X cannot make on his/her own?

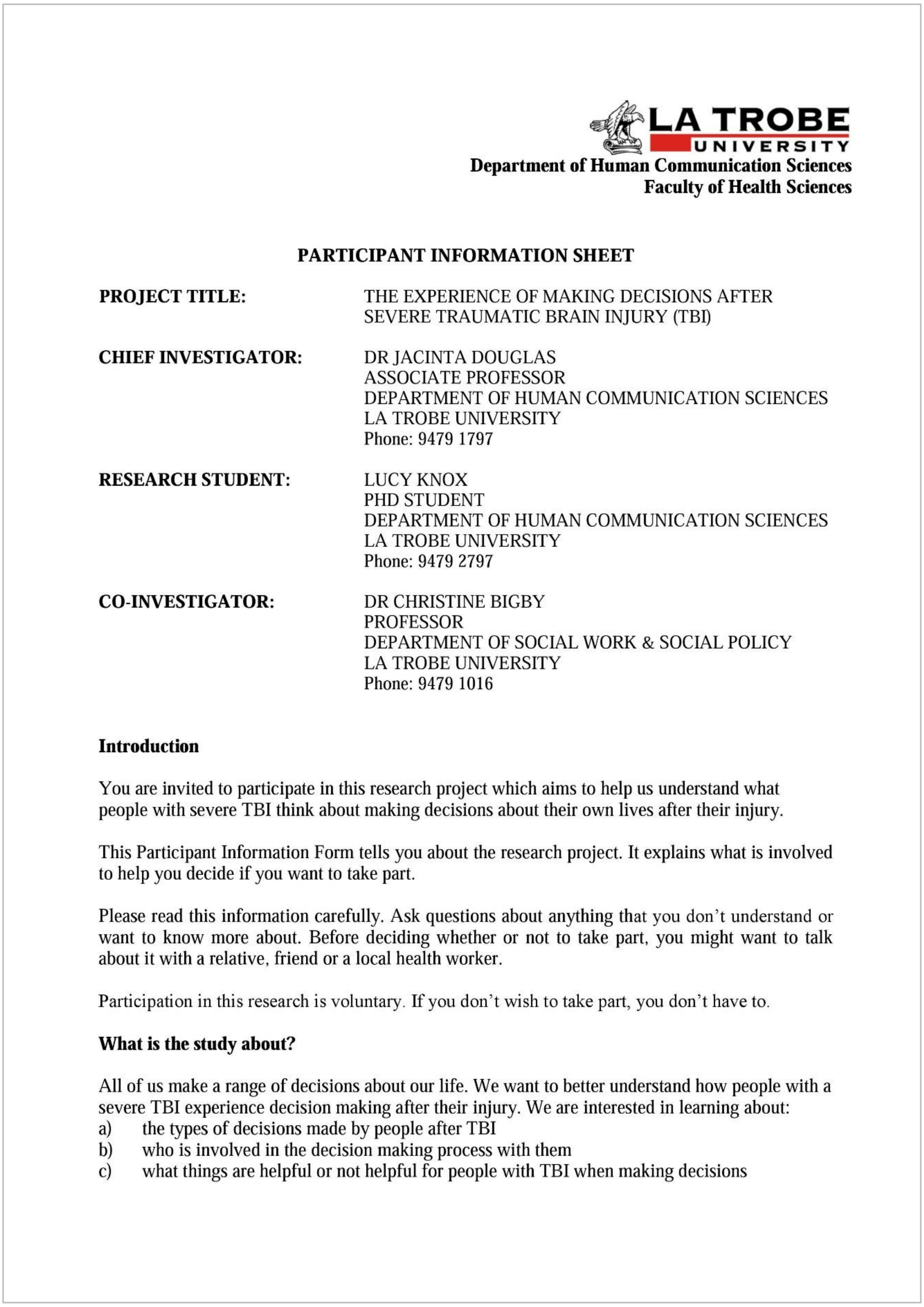
Debriefing

Provide brief verbal summary of interview.

- Anything else you would like to discuss, or add?

APPENDIX C

Participant Information Sheet - Central Participants



Department of Human Communication Sciences
Faculty of Health Sciences

PARTICIPANT INFORMATION SHEET

PROJECT TITLE:	THE EXPERIENCE OF MAKING DECISIONS AFTER SEVERE TRAUMATIC BRAIN INJURY (TBI)
CHIEF INVESTIGATOR:	DR JACINTA DOUGLAS ASSOCIATE PROFESSOR DEPARTMENT OF HUMAN COMMUNICATION SCIENCES LA TROBE UNIVERSITY Phone: 9479 1797
RESEARCH STUDENT:	LUCY KNOX PHD STUDENT DEPARTMENT OF HUMAN COMMUNICATION SCIENCES LA TROBE UNIVERSITY Phone: 9479 2797
CO-INVESTIGATOR:	DR CHRISTINE BIGBY PROFESSOR DEPARTMENT OF SOCIAL WORK & SOCIAL POLICY LA TROBE UNIVERSITY Phone: 9479 1016

Introduction

You are invited to participate in this research project which aims to help us understand what people with severe TBI think about making decisions about their own lives after their injury.

This Participant Information Form tells you about the research project. It explains what is involved to help you decide if you want to take part.

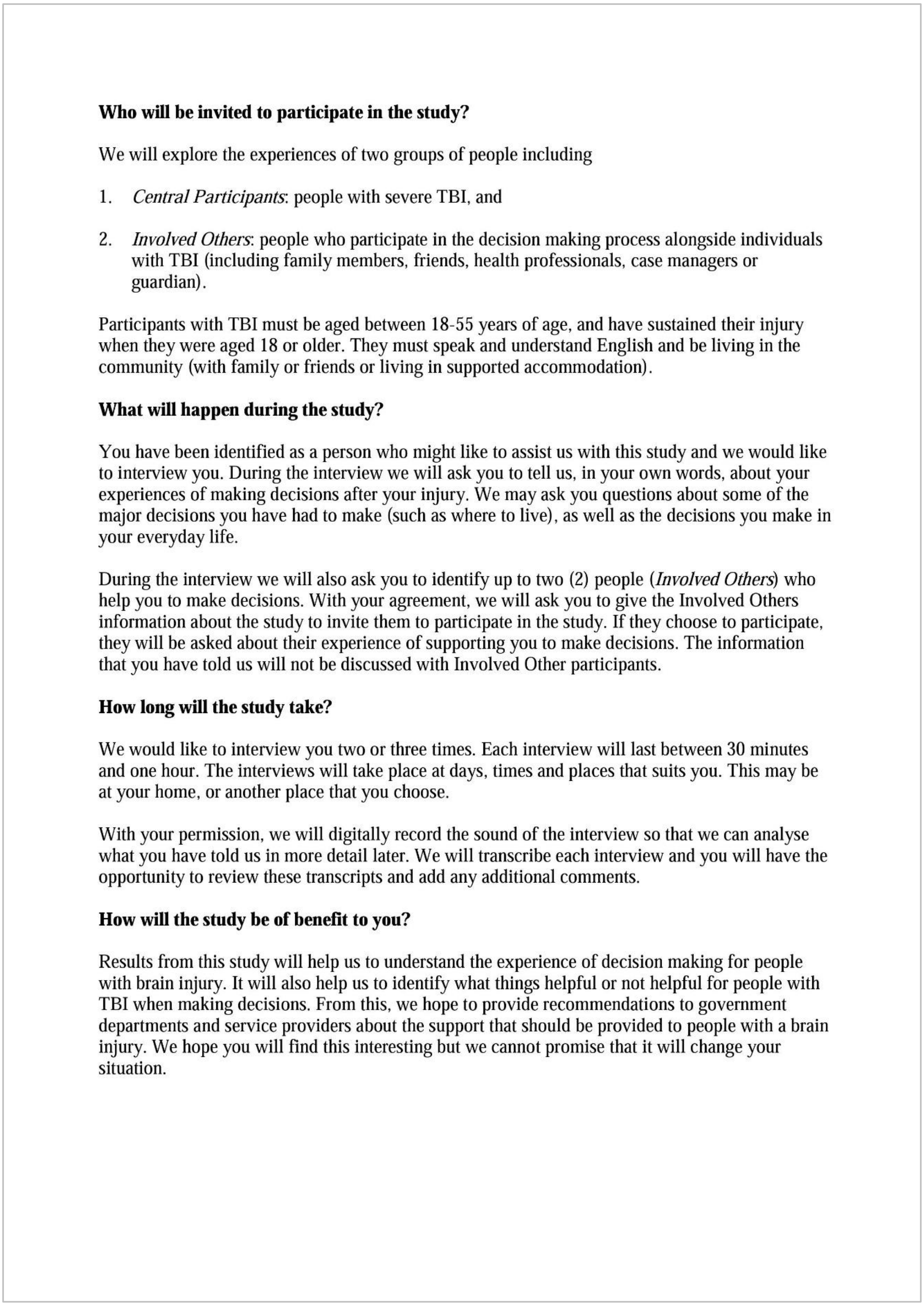
Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or a local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

What is the study about?

All of us make a range of decisions about our life. We want to better understand how people with a severe TBI experience decision making after their injury. We are interested in learning about:

a) the types of decisions made by people after TBI
b) who is involved in the decision making process with them
c) what things are helpful or not helpful for people with TBI when making decisions



Who will be invited to participate in the study?

We will explore the experiences of two groups of people including

1. *Central Participants*: people with severe TBI, and
2. *Involved Others*: people who participate in the decision making process alongside individuals with TBI (including family members, friends, health professionals, case managers or guardian).

Participants with TBI must be aged between 18-55 years of age, and have sustained their injury when they were aged 18 or older. They must speak and understand English and be living in the community (with family or friends or living in supported accommodation).

What will happen during the study?

You have been identified as a person who might like to assist us with this study and we would like to interview you. During the interview we will ask you to tell us, in your own words, about your experiences of making decisions after your injury. We may ask you questions about some of the major decisions you have had to make (such as where to live), as well as the decisions you make in your everyday life.

During the interview we will also ask you to identify up to two (2) people (*Involved Others*) who help you to make decisions. With your agreement, we will ask you to give the Involved Others information about the study to invite them to participate in the study. If they choose to participate, they will be asked about their experience of supporting you to make decisions. The information that you have told us will not be discussed with Involved Other participants.

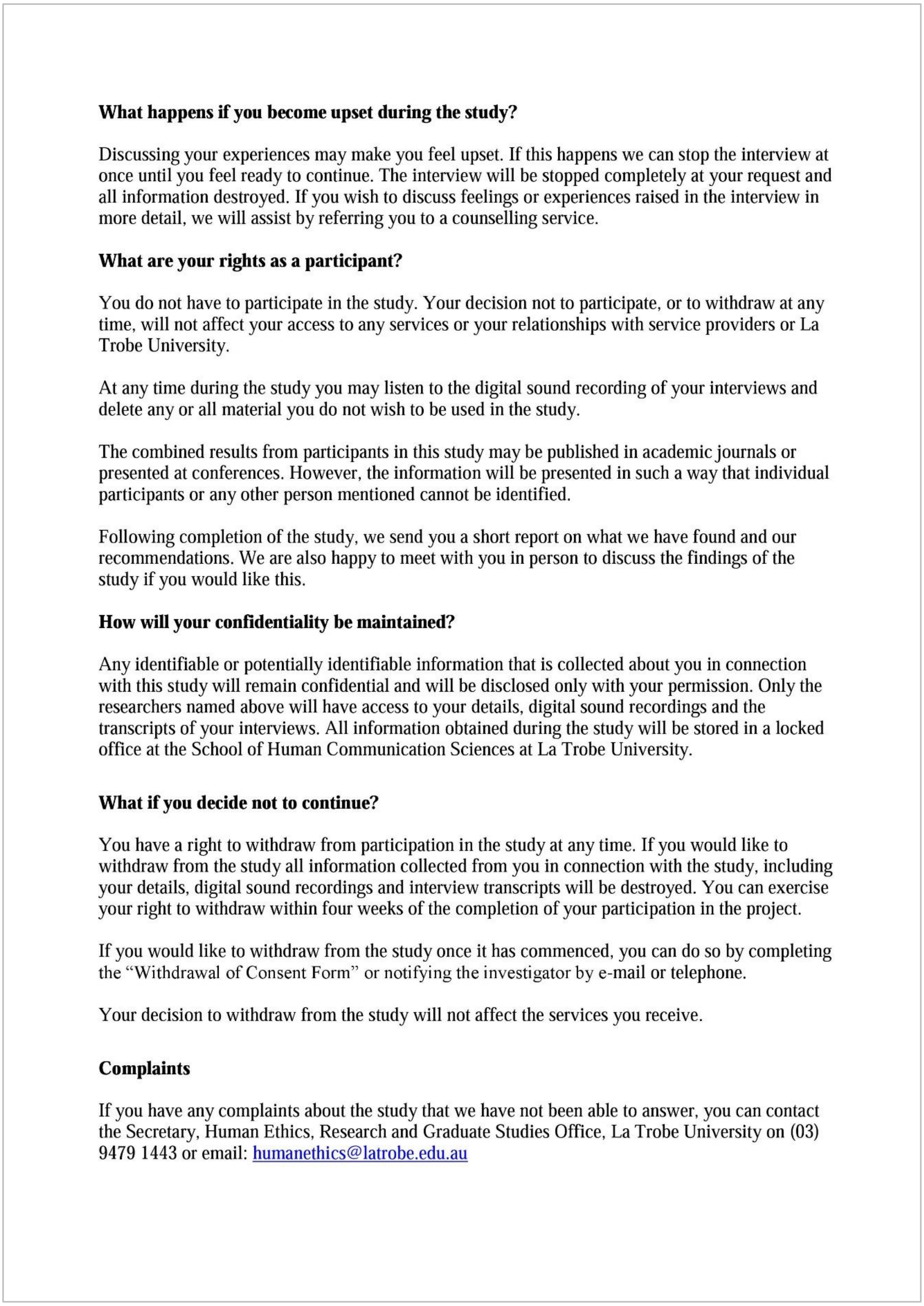
How long will the study take?

We would like to interview you two or three times. Each interview will last between 30 minutes and one hour. The interviews will take place at days, times and places that suits you. This may be at your home, or another place that you choose.

With your permission, we will digitally record the sound of the interview so that we can analyse what you have told us in more detail later. We will transcribe each interview and you will have the opportunity to review these transcripts and add any additional comments.

How will the study be of benefit to you?

Results from this study will help us to understand the experience of decision making for people with brain injury. It will also help us to identify what things helpful or not helpful for people with TBI when making decisions. From this, we hope to provide recommendations to government departments and service providers about the support that should be provided to people with a brain injury. We hope you will find this interesting but we cannot promise that it will change your situation.



What happens if you become upset during the study?

Discussing your experiences may make you feel upset. If this happens we can stop the interview at once until you feel ready to continue. The interview will be stopped completely at your request and all information destroyed. If you wish to discuss feelings or experiences raised in the interview in more detail, we will assist by referring you to a counselling service.

What are your rights as a participant?

You do not have to participate in the study. Your decision not to participate, or to withdraw at any time, will not affect your access to any services or your relationships with service providers or La Trobe University.

At any time during the study you may listen to the digital sound recording of your interviews and delete any or all material you do not wish to be used in the study.

The combined results from participants in this study may be published in academic journals or presented at conferences. However, the information will be presented in such a way that individual participants or any other person mentioned cannot be identified.

Following completion of the study, we send you a short report on what we have found and our recommendations. We are also happy to meet with you in person to discuss the findings of the study if you would like this.

How will your confidentiality be maintained?

Any identifiable or potentially identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission. Only the researchers named above will have access to your details, digital sound recordings and the transcripts of your interviews. All information obtained during the study will be stored in a locked office at the School of Human Communication Sciences at La Trobe University.

What if you decide not to continue?

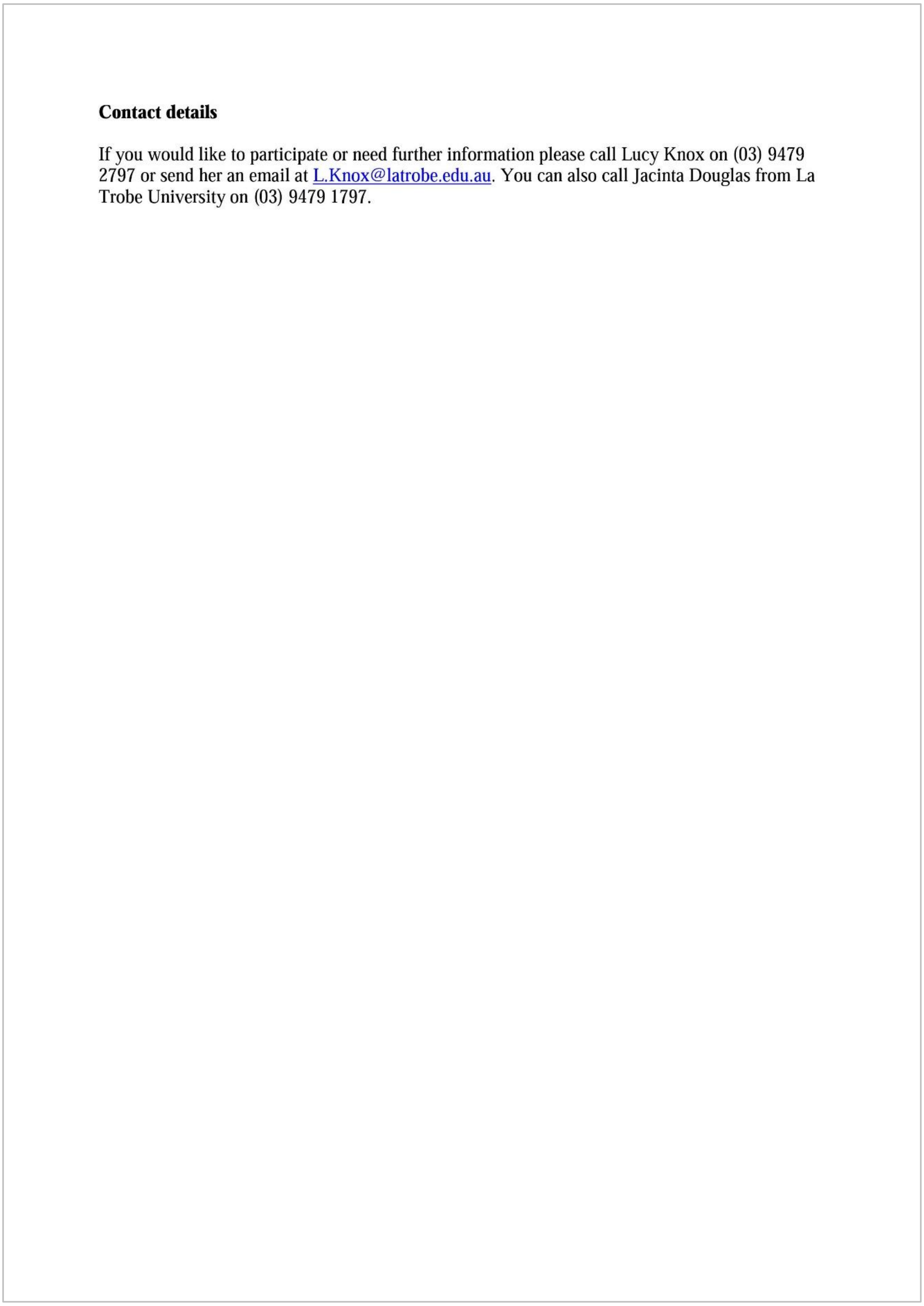
You have a right to withdraw from participation in the study at any time. If you would like to withdraw from the study all information collected from you in connection with the study, including your details, digital sound recordings and interview transcripts will be destroyed. You can exercise your right to withdraw within four weeks of the completion of your participation in the project.

If you would like to withdraw from the study once it has commenced, you can do so by completing the "Withdrawal of Consent Form" or notifying the investigator by e-mail or telephone.

Your decision to withdraw from the study will not affect the services you receive.

Complaints

If you have any complaints about the study that we have not been able to answer, you can contact the Secretary, Human Ethics, Research and Graduate Studies Office, La Trobe University on (03) 9479 1443 or email: humanethics@latrobe.edu.au

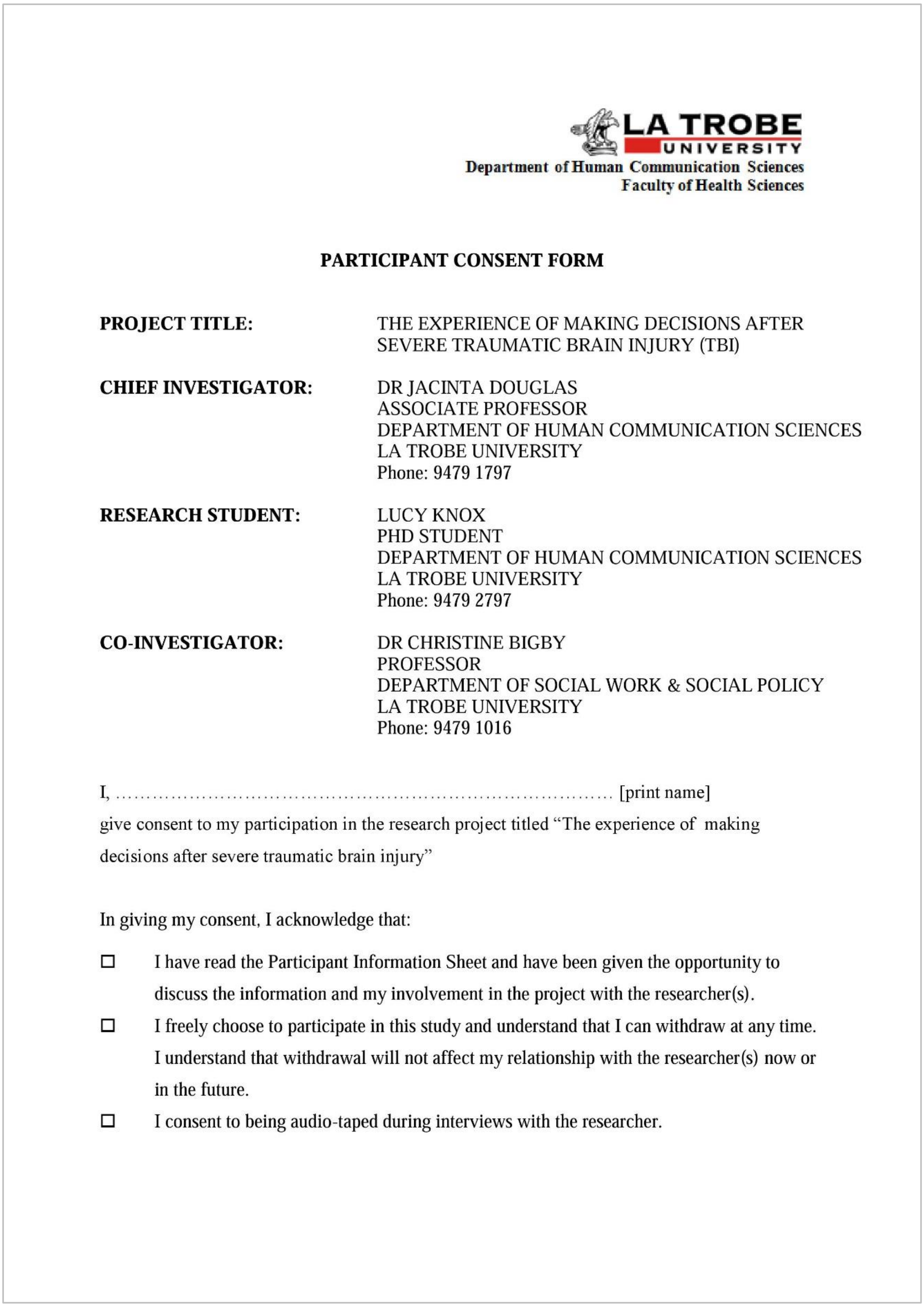


Contact details

If you would like to participate or need further information please call Lucy Knox on (03) 9479 2797 or send her an email at L.Knox@latrobe.edu.au. You can also call Jacinta Douglas from La Trobe University on (03) 9479 1797.

APPENDIX D

Participant Consent Form - Central Participants



LA TROBE
UNIVERSITY
Department of Human Communication Sciences
Faculty of Health Sciences

PARTICIPANT CONSENT FORM

PROJECT TITLE:	THE EXPERIENCE OF MAKING DECISIONS AFTER SEVERE TRAUMATIC BRAIN INJURY (TBI)
CHIEF INVESTIGATOR:	DR JACINTA DOUGLAS ASSOCIATE PROFESSOR DEPARTMENT OF HUMAN COMMUNICATION SCIENCES LA TROBE UNIVERSITY Phone: 9479 1797
RESEARCH STUDENT:	LUCY KNOX PHD STUDENT DEPARTMENT OF HUMAN COMMUNICATION SCIENCES LA TROBE UNIVERSITY Phone: 9479 2797
CO-INVESTIGATOR:	DR CHRISTINE BIGBY PROFESSOR DEPARTMENT OF SOCIAL WORK & SOCIAL POLICY LA TROBE UNIVERSITY Phone: 9479 1016

I, ………………………………………………………………………… [print name]
give consent to my participation in the research project titled "The experience of making decisions after severe traumatic brain injury"

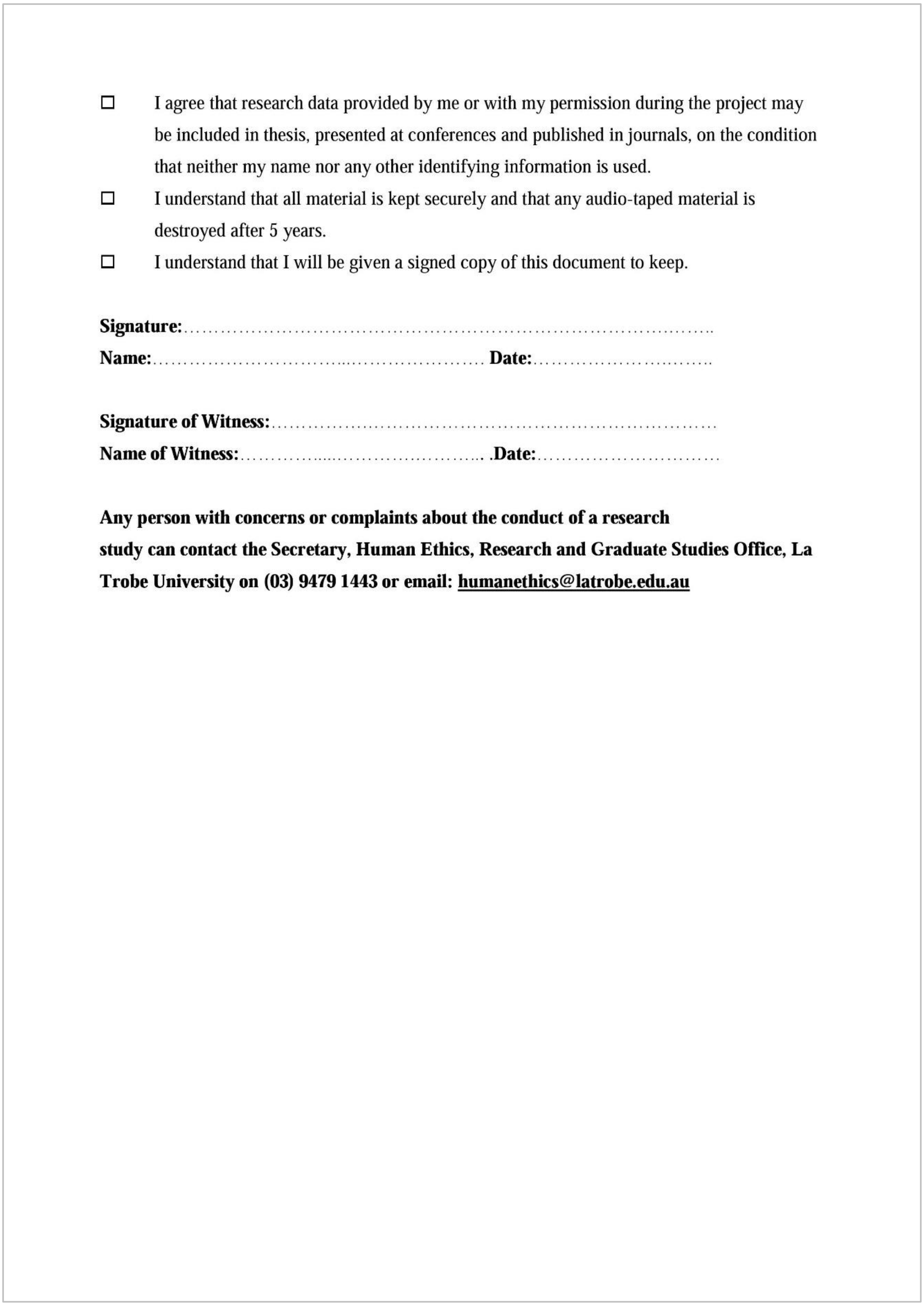
In giving my consent, I acknowledge that:

☐ I have read the Participant Information Sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher(s).

☐ I freely choose to participate in this study and understand that I can withdraw at any time. I understand that withdrawal will not affect my relationship with the researcher(s) now or in the future.

☐ I consent to being audio-taped during interviews with the researcher.

APPENDIX D



☐ I agree that research data provided by me or with my permission during the project may be included in thesis, presented at conferences and published in journals, on the condition that neither my name nor any other identifying information is used.

☐ I understand that all material is kept securely and that any audio-taped material is destroyed after 5 years.

☐ I understand that I will be given a signed copy of this document to keep.

Signature:…………………………………………………………………………….……..

Name:…………………………...………………….. **Date:**…………………….……..

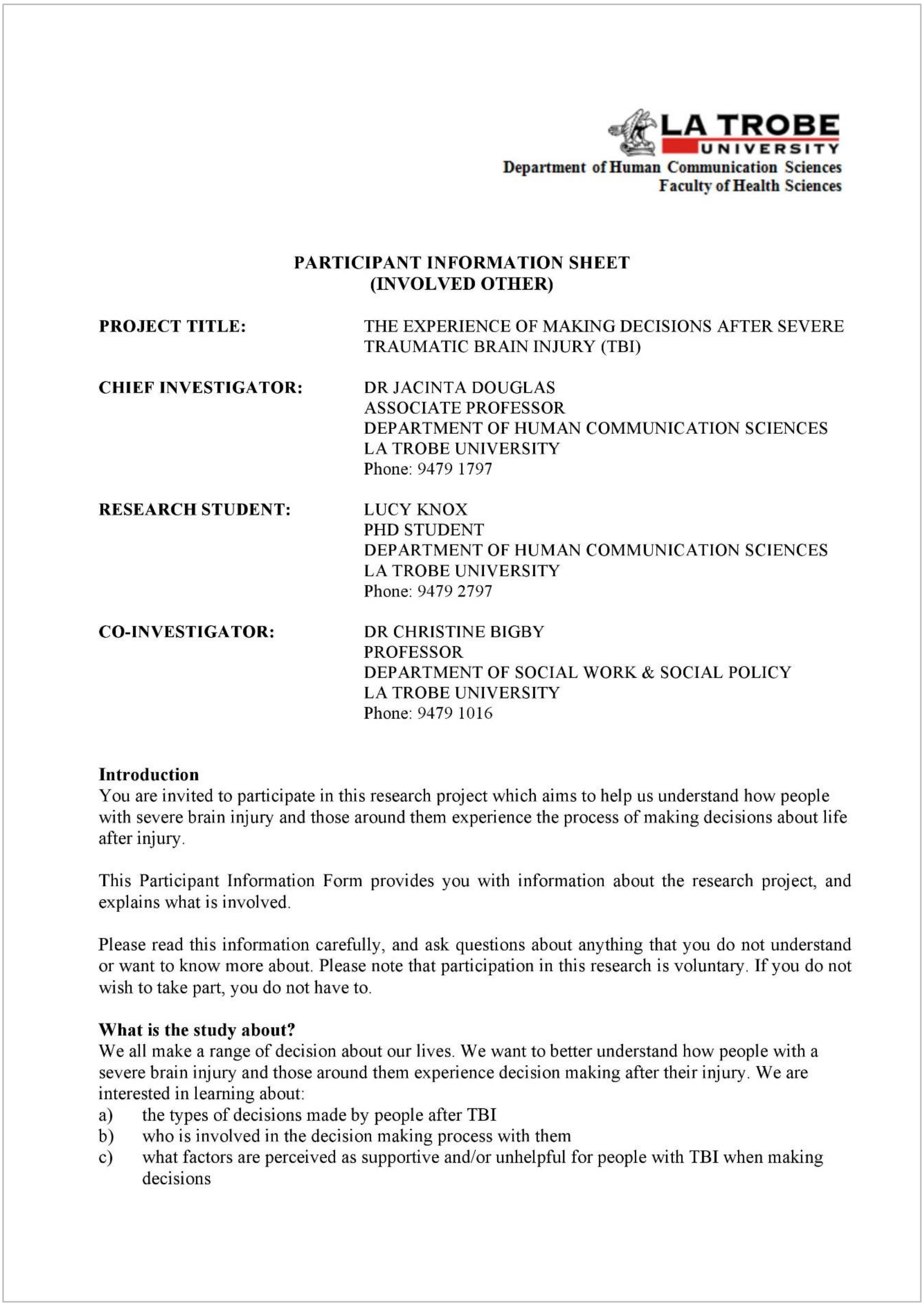
Signature of Witness:……………….……………………………………………………

Name of Witness:…………......……………….……….. .**Date:**…………………………

Any person with concerns or complaints about the conduct of a research study can contact the Secretary, Human Ethics, Research and Graduate Studies Office, La Trobe University on (03) 9479 1443 or email: humanethics@latrobe.edu.au

APPENDIX E

Participant Information Sheet - Involved Others



LA TROBE UNIVERSITY
Department of Human Communication Sciences
Faculty of Health Sciences

PARTICIPANT INFORMATION SHEET
(INVOLVED OTHER)

PROJECT TITLE:	THE EXPERIENCE OF MAKING DECISIONS AFTER SEVERE TRAUMATIC BRAIN INJURY (TBI)
CHIEF INVESTIGATOR:	DR JACINTA DOUGLAS ASSOCIATE PROFESSOR DEPARTMENT OF HUMAN COMMUNICATION SCIENCES LA TROBE UNIVERSITY Phone: 9479 1797
RESEARCH STUDENT:	LUCY KNOX PHD STUDENT DEPARTMENT OF HUMAN COMMUNICATION SCIENCES LA TROBE UNIVERSITY Phone: 9479 2797
CO-INVESTIGATOR:	DR CHRISTINE BIGBY PROFESSOR DEPARTMENT OF SOCIAL WORK & SOCIAL POLICY LA TROBE UNIVERSITY Phone: 9479 1016

Introduction
You are invited to participate in this research project which aims to help us understand how people with severe brain injury and those around them experience the process of making decisions about life after injury.

This Participant Information Form provides you with information about the research project, and explains what is involved.

Please read this information carefully, and ask questions about anything that you do not understand or want to know more about. Please note that participation in this research is voluntary. If you do not wish to take part, you do not have to.

What is the study about?
We all make a range of decision about our lives. We want to better understand how people with a severe brain injury and those around them experience decision making after their injury. We are interested in learning about:

a) the types of decisions made by people after TBI
b) who is involved in the decision making process with them
c) what factors are perceived as supportive and/or unhelpful for people with TBI when making decisions

Who will be invited to participate in the study?
We will explore the experiences of two groups of people including

1. *Central Participants*: people with severe TBI, and
2. *Involved Others*: people who participate in the decision making process alongside individuals with TBI (including family members, friends, health professionals, case managers or guardian).

What will happen during the study?
You have been nominated as an *Involved Other* participant who may be able to assist us with this study and we would like to interview you. Even though you have been nominated to participate in this study, you are under no obligation to participate if you do not wish to.

If you choose to participate, we will ask you to tell us about your experiences of supporting someone with a brain injury to make decisions in their life. In particular, we are interested in talking to you about what you did to help the person make decisions, and what challenges were involved in that process. You will be provided with a copy of each of your interview transcripts and given an opportunity to check what you told us. If you wish, you can add any further information you feel is important.

How long will the study take?
We would like to interview you twice. These interviews will last for up to an hour and will be private and confidential. The interviews will take place at a day, time and place that suits you. This may be at your home, workplace or another place that you choose.

With your permission, we will digitally record the sound of the interview so that we can analyse what you have told us in more detail later. We will transcribe each interview and you will have the opportunity to review these transcripts and add any additional comments.

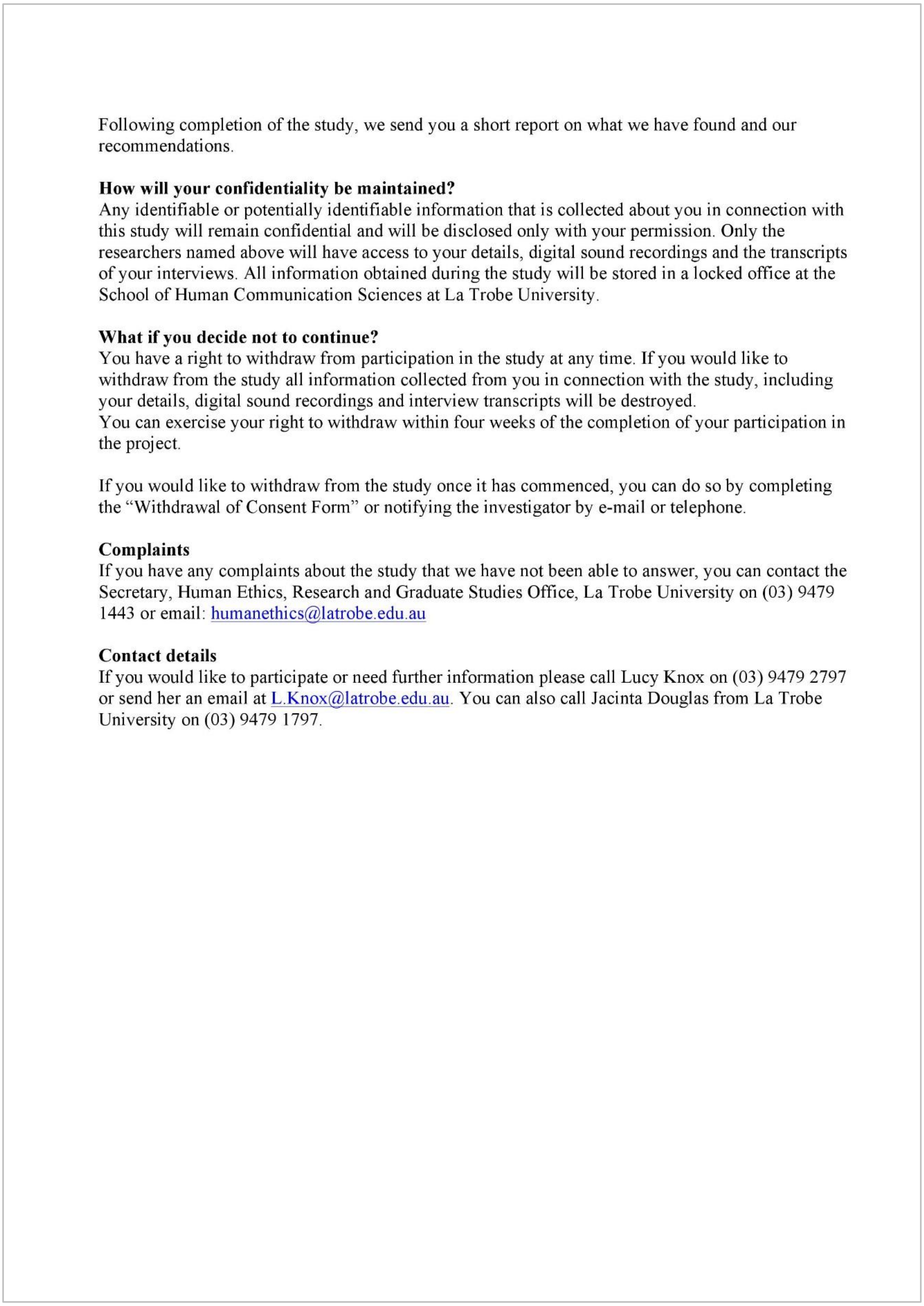
How will the study be of benefit to you?
Results from this study will help us to better understand the experience of decision making for people with brain injury and those individuals who participate in the process with them, and identify factors that are supportive and unhelpful for people with TBI when making decisions. From this, we hope to provide recommendations to government departments and service providers about supports that may be provided to people with a brain injury.

What are the risks of participating in this project?
Discussing your experiences may make you feel upset. If this happens we can stop the interview at once until you feel ready to continue. The interview will be stopped completely at your request and all information destroyed. If you wish to discuss feelings or experiences raised in the interview in more detail, we will assist by referring you to a counselling service.

What are your rights as a participant?
You do not have to participate in the study. Your decision not to participate, or to withdraw at any time, will not affect your relationships with service providers or La Trobe University.

At any time during the study you may listen to the digital sound recording of your interviews and delete any or all material you do not wish to be used in the study.

The combined results from participants in this study may be published in academic journals or presented at conferences. However, the information will be presented in such a way that individual participants or any other person mentioned cannot be identified.



Following completion of the study, we send you a short report on what we have found and our recommendations.

How will your confidentiality be maintained?
Any identifiable or potentially identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission. Only the researchers named above will have access to your details, digital sound recordings and the transcripts of your interviews. All information obtained during the study will be stored in a locked office at the School of Human Communication Sciences at La Trobe University.

What if you decide not to continue?
You have a right to withdraw from participation in the study at any time. If you would like to withdraw from the study all information collected from you in connection with the study, including your details, digital sound recordings and interview transcripts will be destroyed.
You can exercise your right to withdraw within four weeks of the completion of your participation in the project.

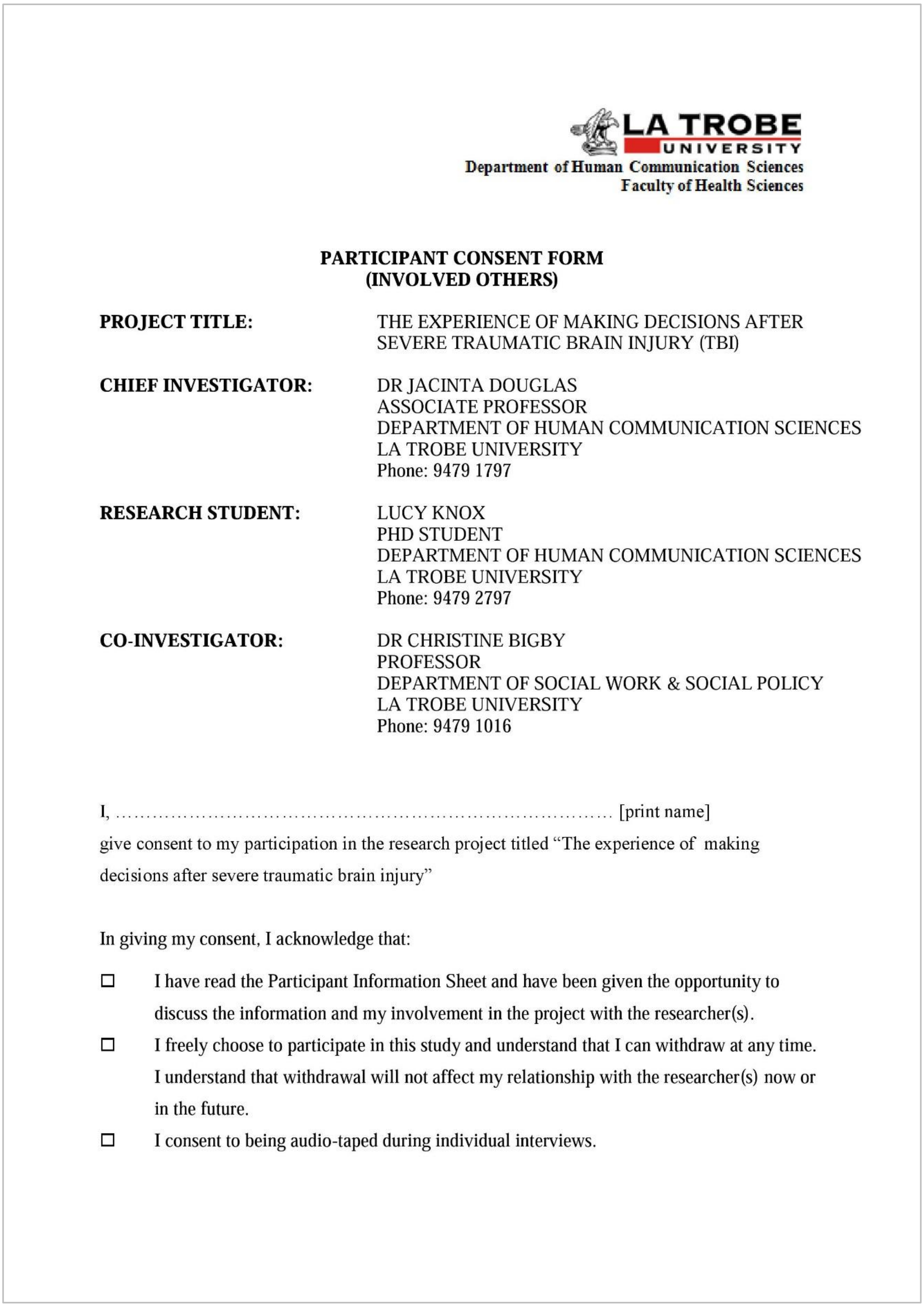
If you would like to withdraw from the study once it has commenced, you can do so by completing the “Withdrawal of Consent Form” or notifying the investigator by e-mail or telephone.

Complaints
If you have any complaints about the study that we have not been able to answer, you can contact the Secretary, Human Ethics, Research and Graduate Studies Office, La Trobe University on (03) 9479 1443 or email: humanethics@latrobe.edu.au

Contact details
If you would like to participate or need further information please call Lucy Knox on (03) 9479 2797 or send her an email at L.Knox@latrobe.edu.au. You can also call Jacinta Douglas from La Trobe University on (03) 9479 1797.

APPENDIX F

Participant Consent Form - Involved Others



LA TROBE
UNIVERSITY
Department of Human Communication Sciences
Faculty of Health Sciences

PARTICIPANT CONSENT FORM
(INVOLVED OTHERS)

PROJECT TITLE:	THE EXPERIENCE OF MAKING DECISIONS AFTER SEVERE TRAUMATIC BRAIN INJURY (TBI)
CHIEF INVESTIGATOR:	DR JACINTA DOUGLAS ASSOCIATE PROFESSOR DEPARTMENT OF HUMAN COMMUNICATION SCIENCES LA TROBE UNIVERSITY Phone: 9479 1797
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I, ……………………………………………………………………………… [print name]
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☐ I consent to being audio-taped during individual interviews.

- ☐ I agree that research data provided by me or with my permission during the project may be included in thesis, presented at conferences and published in journals, on the condition that neither my name nor any other identifying information is used.
- ☐ I understand that all material is kept securely and that any audio-taped material is destroyed after 5 years.
- ☐ I understand that I will be given a signed copy of this document to keep.

Signature:……………………………………………………………………….……..
Name:……………………………...…………………… **Date:**……………………….……..

Signature of Witness:……………….……………………………………………………
Name of Witness:……………....………….………... .**Date:**…………………………

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APPENDIX G

Excerpts from field notes

Field Notes: Interview 1 - John

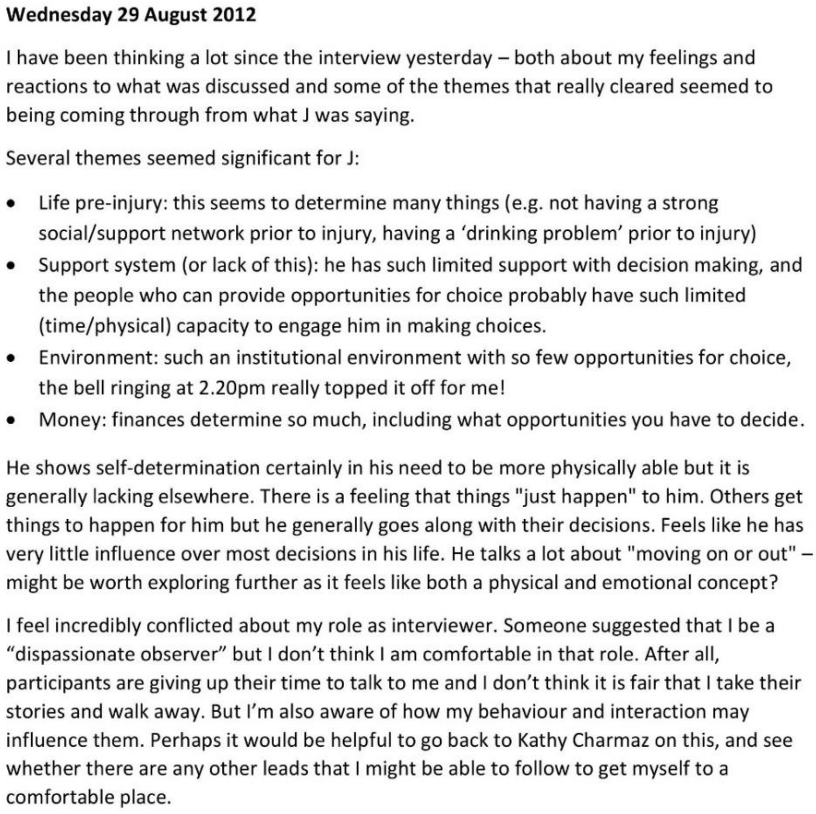
29 August 2012

So I'm feeling pretty shell shocked after that first interview. J was incredibly honest about what he's been through but really he's experienced a lot of tragedy in his life. And particularly the story that he told me about him and his friend who died, I found really difficult to listen to.

In terms of the environment, [redacted] is like lots of other SRSs that I've been to. There are residents hanging round. So at the entrance there are several random plastic chairs around and ashtrays. When I arrived, J was actually outside just finishing a cigarette and waiting for me. This is perhaps a sign of how few visitors he has. But there are other residents who are also just hanging around the entrance or the long driveway. The building itself is several stories and there is a second building behind the main one that is also double or triple storey.

J himself was quite neatly dressed today, especially in comparison to many of the other residents that I saw. He was wearing a t-shirt and windcheater with a pair of pants, but his clothing appeared clean and tidy. It looks like he hadn't shaved for a few days but he had combed his hair. He had a little disposable plastic bag that he carried with him that contained cigarette butts. When I was talking to him about smoking and whether he had money to be able to purchase cigarettes, he said that he does get to spend a little bit of his fortnightly allowance on cigarettes but he smokes chop chop because it means that the cigarettes are cheaper. Again, that issue of having money to make choices is a really big. He said that it only costs him twenty five cents a cigarette rather than fifty or sixty cents a cigarette (for tailor mades).

When I arrived, J went and got one of the staff members who took us into a strange but quiet little room. This is the room where J informed me that the doctor normally sees residents. It was good in that we had a quiet space, but the room itself had a very cold feeling. There were several chairs that had a plastic type coating on them, like you would expect to see in a doctor's surgery, obviously to enable the chairs to be wiped down with antiseptic.



Wednesday 29 August 2012

I have been thinking a lot since the interview yesterday – both about my feelings and reactions to what was discussed and some of the themes that really cleared seemed to being coming through from what J was saying.

Several themes seemed significant for J:

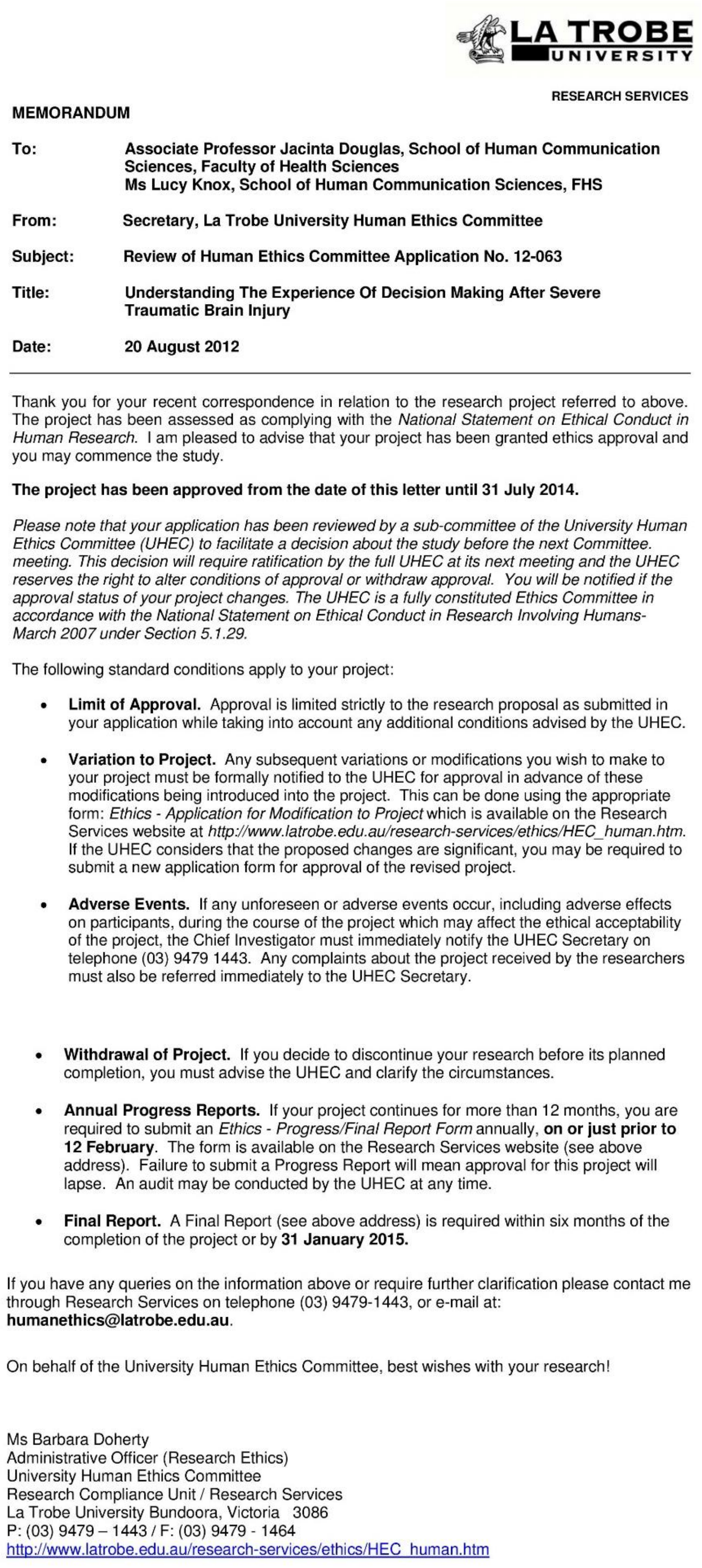
- Life pre-injury: this seems to determine many things (e.g. not having a strong social/support network prior to injury, having a 'drinking problem' prior to injury)
- Support system (or lack of this): he has such limited support with decision making, and the people who can provide opportunities for choice probably have such limited (time/physical) capacity to engage him in making choices.
- Environment: such an institutional environment with so few opportunities for choice, the bell ringing at 2.20pm really topped it off for me!
- Money: finances determine so much, including what opportunities you have to decide.

He shows self-determination certainly in his need to be more physically able but it is generally lacking elsewhere. There is a feeling that things "just happen" to him. Others get things to happen for him but he generally goes along with their decisions. Feels like he has very little influence over most decisions in his life. He talks a lot about "moving on or out" – might be worth exploring further as it feels like both a physical and emotional concept?

I feel incredibly conflicted about my role as interviewer. Someone suggested that I be a "dispassionate observer" but I don't think I am comfortable in that role. After all, participants are giving up their time to talk to me and I don't think it is fair that I take their stories and walk away. But I'm also aware of how my behaviour and interaction may influence them. Perhaps it would be helpful to go back to Kathy Charmaz on this, and see whether there are any other leads that I might be able to follow to get myself to a comfortable place.

APPENDIX H

Ethical approval and amendment



LA TROBE
UNIVERSITY

RESEARCH SERVICES

MEMORANDUM

To: **Associate Professor Jacinta Douglas, School of Human Communication Sciences, Faculty of Health Sciences**
Ms Lucy Knox, School of Human Communication Sciences, FHS

From: **Secretary, La Trobe University Human Ethics Committee**

Subject: **Review of Human Ethics Committee Application No. 12-063**

Title: **Understanding The Experience Of Decision Making After Severe Traumatic Brain Injury**

Date: **20 August 2012**

Thank you for your recent correspondence in relation to the research project referred to above. The project has been assessed as complying with the *National Statement on Ethical Conduct in Human Research*. I am pleased to advise that your project has been granted ethics approval and you may commence the study.

The project has been approved from the date of this letter until 31 July 2014.

Please note that your application has been reviewed by a sub-committee of the University Human Ethics Committee (UHEC) to facilitate a decision about the study before the next Committee. meeting. This decision will require ratification by the full UHEC at its next meeting and the UHEC reserves the right to alter conditions of approval or withdraw approval. You will be notified if the approval status of your project changes. The UHEC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans-March 2007 under Section 5.1.29.

The following standard conditions apply to your project:

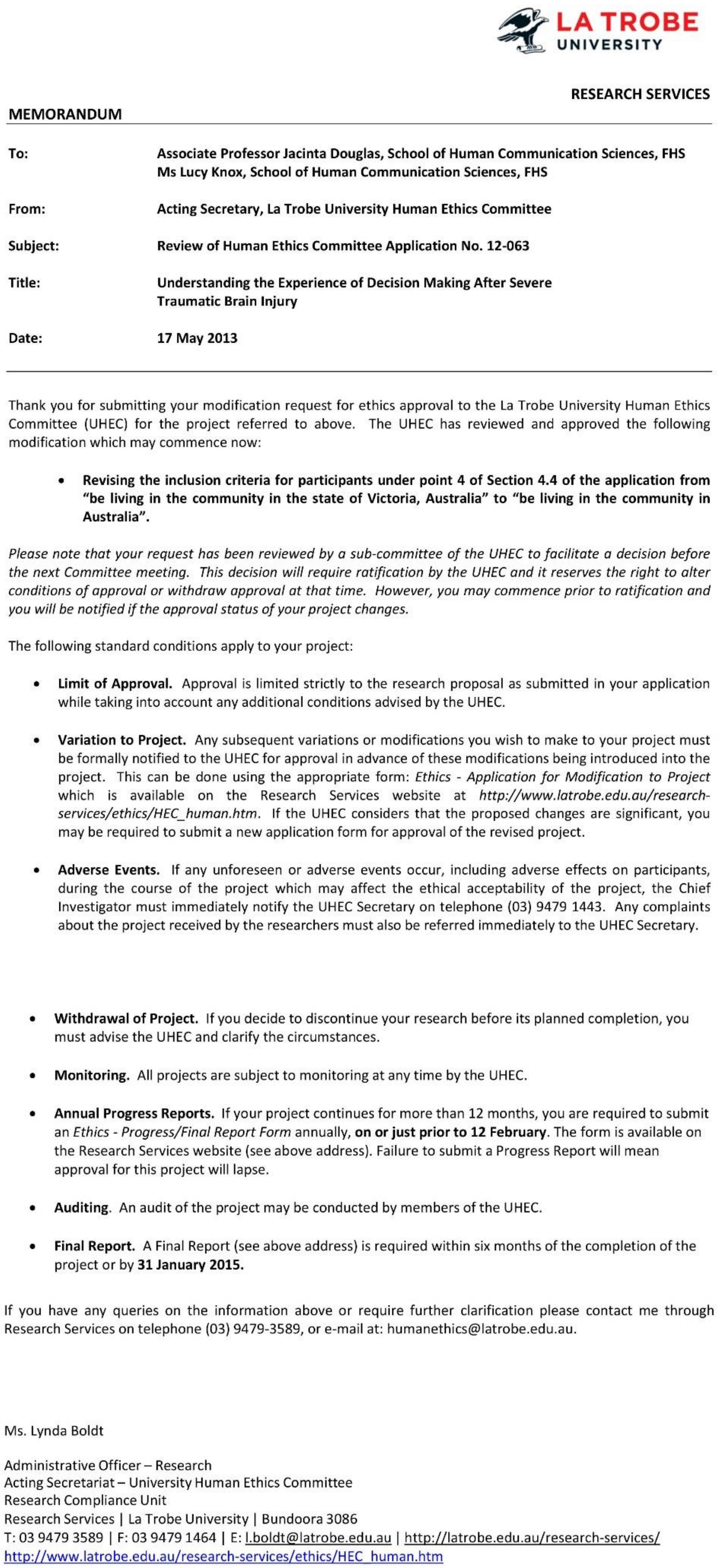
- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the UHEC.
- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the UHEC for approval in advance of these modifications being introduced into the project. This can be done using the appropriate form: *Ethics - Application for Modification to Project* which is available on the Research Services website at *http://www.latrobe.edu.au/research-services/ethics/HEC_human.htm.* If the UHEC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.
- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the UHEC Secretary on telephone (03) 9479 1443. Any complaints about the project received by the researchers must also be referred immediately to the UHEC Secretary.
- **Withdrawal of Project.** If you decide to discontinue your research before its planned completion, you must advise the UHEC and clarify the circumstances.
- **Annual Progress Reports.** If your project continues for more than 12 months, you are required to submit an *Ethics - Progress/Final Report Form* annually, **on or just prior to 12 February**. The form is available on the Research Services website (see above address). Failure to submit a Progress Report will mean approval for this project will lapse. An audit may be conducted by the UHEC at any time.
- **Final Report.** A Final Report (see above address) is required within six months of the completion of the project or by **31 January 2015.**

If you have any queries on the information above or require further clarification please contact me through Research Services on telephone (03) 9479-1443, or e-mail at: **humanethics@latrobe.edu.au**.

On behalf of the University Human Ethics Committee, best wishes with your research!

Ms Barbara Doherty
Administrative Officer (Research Ethics)
University Human Ethics Committee
Research Compliance Unit / Research Services
La Trobe University Bundoora, Victoria 3086
P: (03) 9479 – 1443 / F: (03) 9479 - 1464
http://www.latrobe.edu.au/research-services/ethics/HEC_human.htm

APPENDIX H



LA TROBE UNIVERSITY

RESEARCH SERVICES

MEMORANDUM

To: **Associate Professor Jacinta Douglas, School of Human Communication Sciences, FHS**
Ms Lucy Knox, School of Human Communication Sciences, FHS

From: **Acting Secretary, La Trobe University Human Ethics Committee**

Subject: **Review of Human Ethics Committee Application No. 12-063**

Title: **Understanding the Experience of Decision Making After Severe Traumatic Brain Injury**

Date: **17 May 2013**

Thank you for submitting your modification request for ethics approval to the La Trobe University Human Ethics Committee (UHEC) for the project referred to above. The UHEC has reviewed and approved the following modification which may commence now:

- **Revising the inclusion criteria for participants under point 4 of Section 4.4 of the application from "be living in the community in the state of Victoria, Australia" to "be living in the community in Australia".**

Please note that your request has been reviewed by a sub-committee of the UHEC to facilitate a decision before the next Committee meeting. This decision will require ratification by the UHEC and it reserves the right to alter conditions of approval or withdraw approval at that time. However, you may commence prior to ratification and you will be notified if the approval status of your project changes.

The following standard conditions apply to your project:

- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the UHEC.
- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the UHEC for approval in advance of these modifications being introduced into the project. This can be done using the appropriate form: *Ethics - Application for Modification to Project* which is available on the Research Services website at *http://www.latrobe.edu.au/research-services/ethics/HEC_human.htm*. If the UHEC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.
- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the UHEC Secretary on telephone (03) 9479 1443. Any complaints about the project received by the researchers must also be referred immediately to the UHEC Secretary.
- **Withdrawal of Project.** If you decide to discontinue your research before its planned completion, you must advise the UHEC and clarify the circumstances.
- **Monitoring.** All projects are subject to monitoring at any time by the UHEC.
- **Annual Progress Reports.** If your project continues for more than 12 months, you are required to submit an *Ethics - Progress/Final Report Form* annually, **on or just prior to 12 February**. The form is available on the Research Services website (see above address). Failure to submit a Progress Report will mean approval for this project will lapse.
- **Auditing**. An audit of the project may be conducted by members of the UHEC.
- **Final Report.** A Final Report (see above address) is required within six months of the completion of the project or by **31 January 2015.**

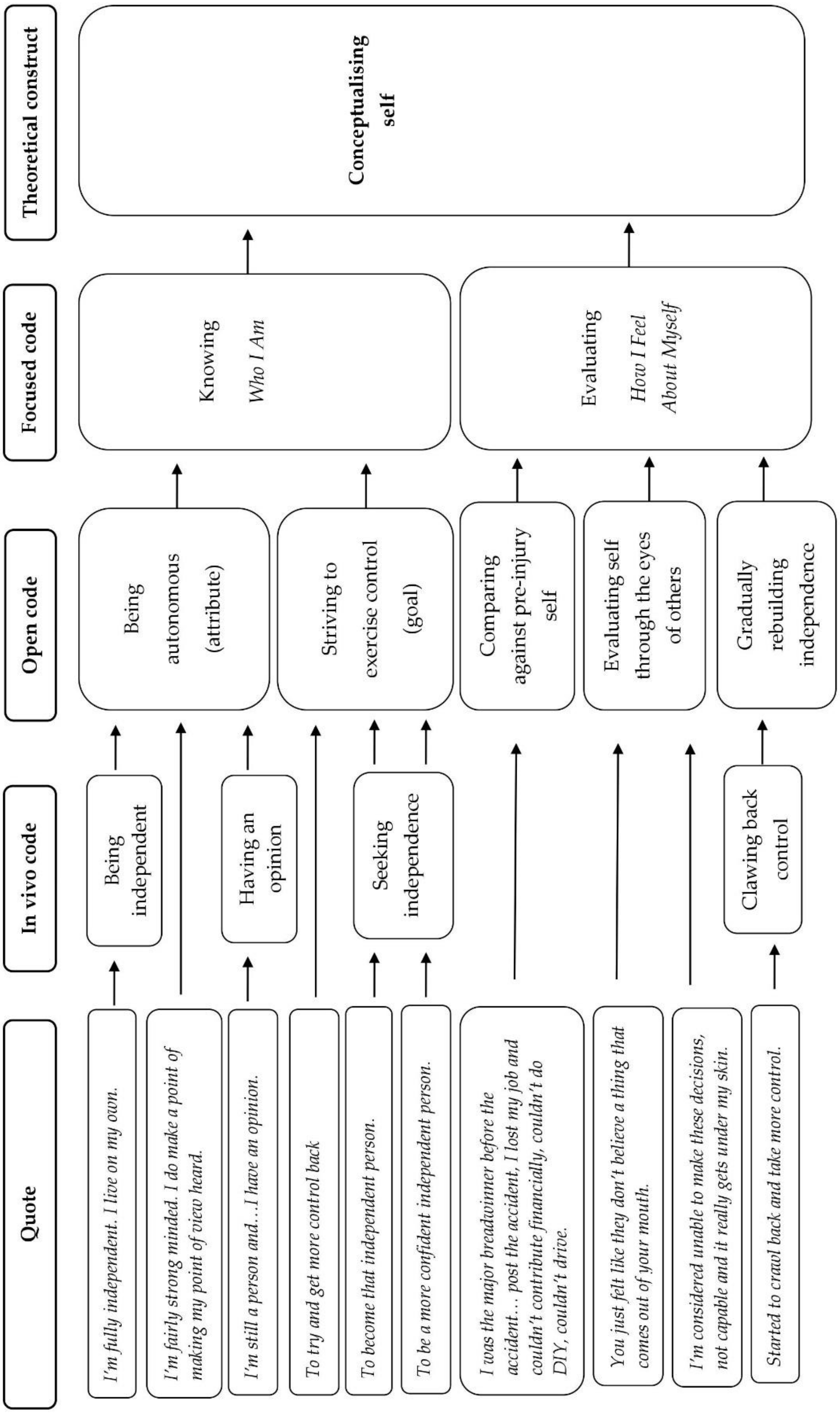
If you have any queries on the information above or require further clarification please contact me through Research Services on telephone (03) 9479-3589, or e-mail at: humanethics@latrobe.edu.au.

Ms. Lynda Boldt

Administrative Officer – Research
Acting Secretariat – University Human Ethics Committee
Research Compliance Unit
Research Services | La Trobe University | Bundoora 3086
T: 03 9479 3589 | F: 03 9479 1464 | E: l.boldt@latrobe.edu.au | http://latrobe.edu.au/research-services/
http://www.latrobe.edu.au/research-services/ethics/HEC_human.htm

Coding example

Example of Coding Process: Conceptualising Self



I'm fully independent. I live on my own.

I'm fairly strong minded. I do make a point of making my point of view heard.

I'm still a person and…I have an opinion.

To try and get more control back

To become that independent person.

To be a more confident independent person.

I was the major breadwinner before the accident… post the accident, I lost my job and couldn't contribute financially, couldn't do DIY, couldn't drive.

You just felt like they don't believe a thing that comes out of your mouth.

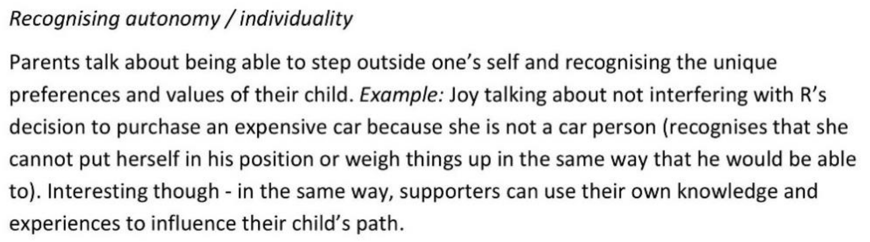
I'm considered unable to make these decisions, not capable and it really gets under my skin.

Started to crawl back and take more control.

APPENDIX J

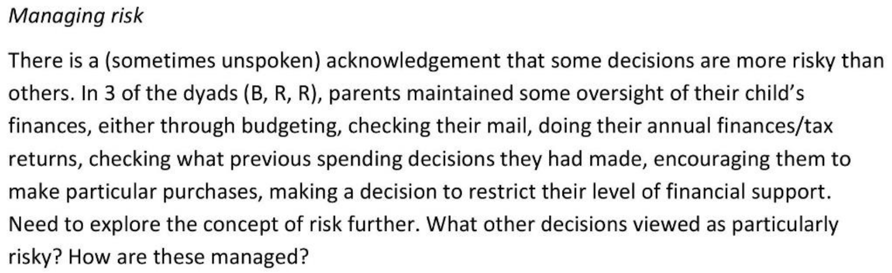
Example memos

Emerging themes: Parents (10/09/2013)



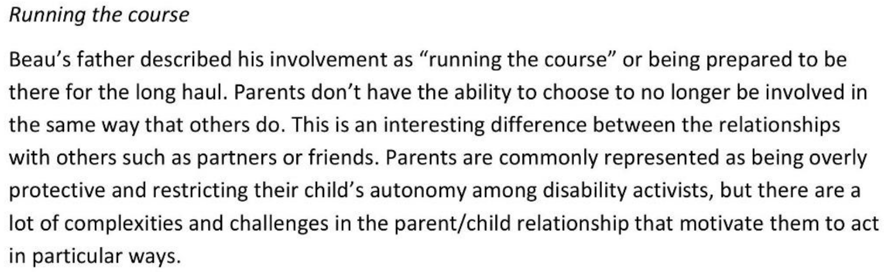
Recognising autonomy / individuality

Parents talk about being able to step outside one's self and recognising the unique preferences and values of their child. *Example:* Joy talking about not interfering with R's decision to purchase an expensive car because she is not a car person (recognises that she cannot put herself in his position or weigh things up in the same way that he would be able to). Interesting though - in the same way, supporters can use their own knowledge and experiences to influence their child's path.



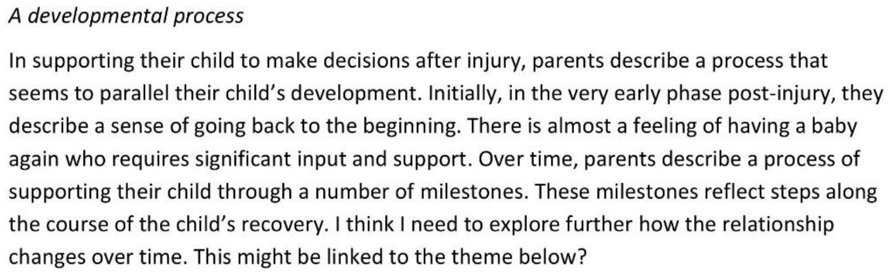
Managing risk

There is a (sometimes unspoken) acknowledgement that some decisions are more risky than others. In 3 of the dyads (B, R, R), parents maintained some oversight of their child's finances, either through budgeting, checking their mail, doing their annual finances/tax returns, checking what previous spending decisions they had made, encouraging them to make particular purchases, making a decision to restrict their level of financial support. Need to explore the concept of risk further. What other decisions viewed as particularly risky? How are these managed?



Running the course

Beau's father described his involvement as "running the course" or being prepared to be there for the long haul. Parents don't have the ability to choose to no longer be involved in the same way that others do. This is an interesting difference between the relationships with others such as partners or friends. Parents are commonly represented as being overly protective and restricting their child's autonomy among disability activists, but there are a lot of complexities and challenges in the parent/child relationship that motivate them to act in particular ways.



A developmental process

In supporting their child to make decisions after injury, parents describe a process that seems to parallel their child's development. Initially, in the very early phase post-injury, they describe a sense of going back to the beginning. There is almost a feeling of having a baby again who requires significant input and support. Over time, parents describe a process of supporting their child through a number of milestones. These milestones reflect steps along the course of the child's recovery. I think I need to explore further how the relationship changes over time. This might be linked to the theme below?

Exploring self-concept (5/08/13)

Finding a 'place' after brain injury

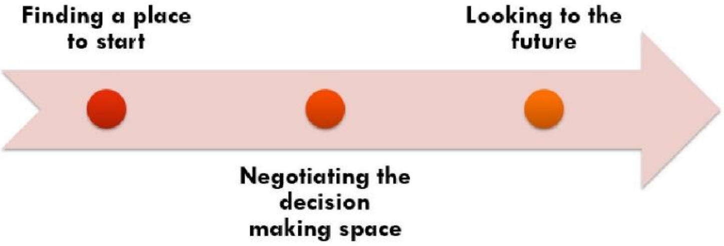
P described being unsure how he fits into this world "as Peter, the ABI…". There is an overarching theme of *needing to find your place in the world again*. Roles that were important have been taken away. P values the role of being able to provide for his family (being the main breadwinner) and he experiences his inability to do this as failure. This failure is also experienced in being unable to meet other's expectations (eg those of his wife). He wonders how he can function conventionally in this world (earning a living, supporting his wife and daughter, being part of the community, being fit, having friends). The Men's Group seems to have provided something that starts to fill this gap for him. He is able to be open about his injury, he doesn't need to conceal it. And P appears to have made an active decision not to conceal his injury, but rather to talk about. The issue of others not knowing about his injury and making assumptions about him and his behavior is one that has been a constant throughout his interviews ("They see me as this big, sick, secret guy"). All of the participants with TBI describe this tension between people not understanding this injury (sometimes because they cannot see anything different about the) and, at the same time, being viewed as different and feeling a constant sense of exclusion.

Need to explore decision making and this sense of finding a place in the world. What P was describing was that his decisions were limited by his brain injury, but when he makes decisions this can also give him back a sense of establishing a new place in the world?

Example diagrams

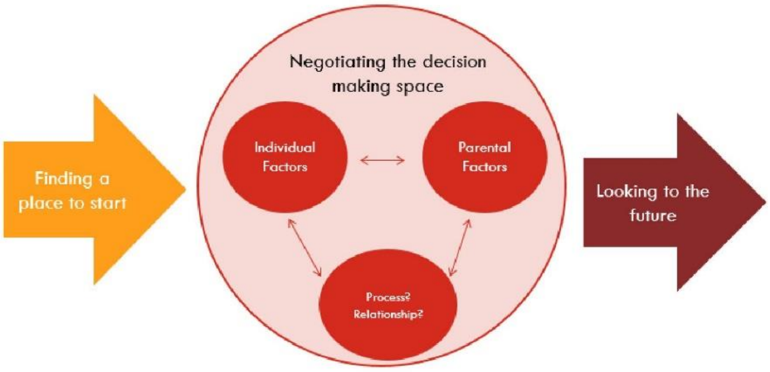
Parent-adult child decision making: Evolution of decision-making process through diagramming

17 April 2014



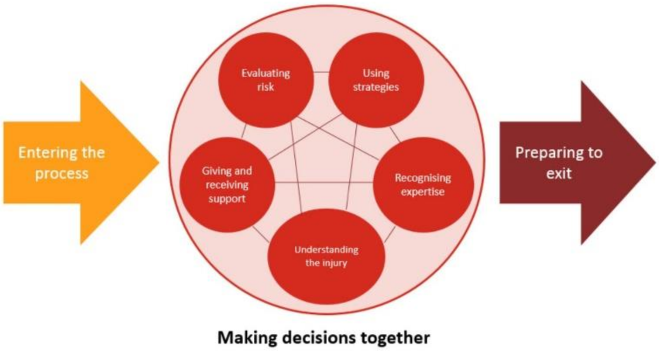
2 May 2014

6 May 2014

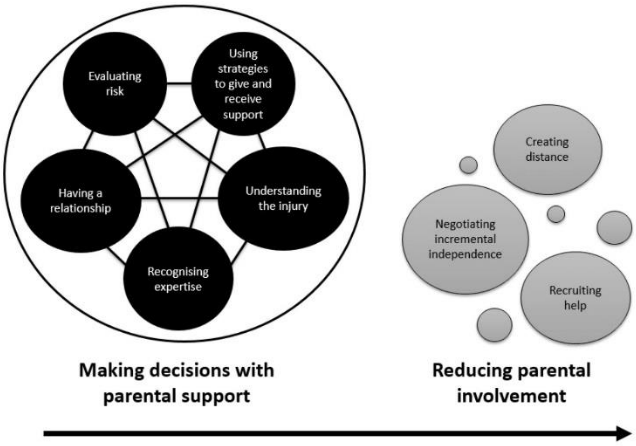


APPENDIX K

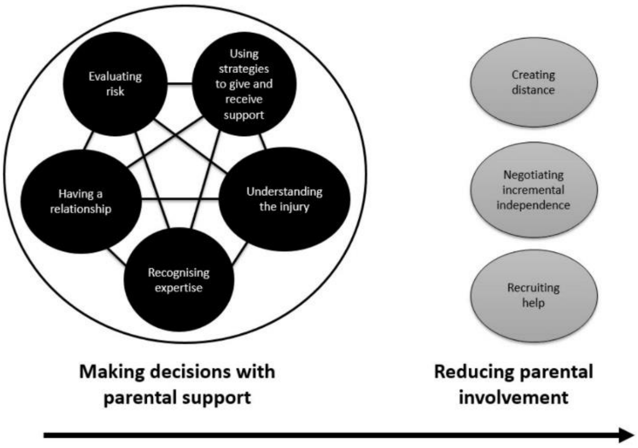
10 May 2014



23 June 2014



22 December 2014



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