

**The Possible Selves of Individuals with an Acquired Brain Injury**

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### **Thesis abstract**

**Context:** The biopsychosocial approach to understanding brain injury has allowed for greater scope to understand subjective experience and how such experiences affect adjustment to brain injury. This thesis portfolio focuses on two aspects of subjective experiences in those with a brain injury, health-related quality of life and ‘possible selves’.

**Aim:** The broad aim of this thesis portfolio is to explore ways in which rehabilitation, through both identification of need and intervention, can be improved through exploration of subjective experiences. Two papers are presented: a systematic review which explores predictors of long-term health-related quality of life in those with a traumatic brain injury and a mixed methods research study which pilots the use of the possible selves interview in those with an acquired brain injury.

**Results:** The findings from the systematic review provide support for the biopsychosocial model of adjustment. However, they also indicate a need to better understand how brain-injury specific health consequences that arise after a TBI impact quality of life. The results of the research paper indicate that the possible selves interview is a feasible measure to use in those with a brain injury. This finding paves the way for future research to expand upon the use of possible selves in rehabilitation, as a way to combine areas relating to identity, motivation and goal-setting.

**Conclusions:** The overall thesis emphasises the importance of the subjective experiences of those with a brain injury in rehabilitation. Both health-related quality of life and possible selves require further research to best understand their utility in shaping assessment and intervention in those with a brain injury.

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This thesis is dedicated to all those who live with an acquired brain injury.

“Rivers know this: there is no hurry. We shall get there some day.” – AA Milne, Winnie the Pooh.



## **CHAPTER 1: Introduction to Thesis**

### **Chapter Overview**

This chapter provides a general overview of the thesis portfolio and introduces the rationale behind it.

Word count: 1523

### **1.1. Acquired Brain Injury**

Acquired brain injury (ABI) is an umbrella term that refers to damage to the brain that has occurred since birth that is non-degenerative in nature (Headway, 2019). There are many causes of ABIs including traumatic brain injuries (TBI), strokes and encephalitis. ABIs are relatively common; it is estimated that there are around 1.3 million individuals living with TBI-related disabilities and another 1.2 million stroke survivors in the UK (Stroke Association, 2018; Parsonage, 2016). There is a significant financial burden accompanying ABIs as they are associated with premature death, health and social care costs, reduced employment and continuing disability; as such TBIs alone are thought to cost the UK around £15billion a year (Parsonage, 2016).

Although the symptoms and severity of ABIs vary according to the location and diffusion of the injury within the brain, the subjective impact of an ABI varies depending on wider personal and contextual factors. The neuropsychological and functional impairments associated with ABIs can have debilitating effects across multiple domains (Biderman, Daniels-Zide, Reyes, & Marks, 2006). This includes physical, cognitive, behavioural and emotional impairments that are associated with a greater risk of mental health difficulties (Andelic et al., 2010), reduced social integration (Lefebvre, Cloutier & Levert, 2008) and increased offending behaviour (Williams, Cordan, Mewse, Tonks & Burgess, 2010); these difficulties can have a marked impact on a person's quality of life.

For those with more severe injuries, these difficulties can be chronic and persist beyond discharge from inpatient care (Ponsford, Olver & Curran, 1995).

Despite this, families are usually the individuals who provide ongoing support (Kreutzer et al., 2009).

## **1.2. Neuropsychological rehabilitation**

Rehabilitation after brain injury is broadly concerned with helping individuals who have suffered an ABI live fulfilled lives that hold personal value and purpose. Assessment, goal setting, intervention and reassessment are key aspects of rehabilitation and help provide structure to rehabilitation (Wade, 2005). Within neuropsychological rehabilitation, psychosocial, emotional, behavioural and cognitive difficulties are commonly targeted (Wilson, 2008). However, a holistic, integrated and multidisciplinary approach to rehabilitation is emphasised, which aims to address the needs of individuals across multiple domains (Stroke Unit Trialists' Collaboration, 2013; Semlyen, Summers & Barnes, 1998).

Rehabilitation continues to be structured in this way because current perspectives emphasise the way in which individuals interpret, respond and adjust to a brain injury is idiosyncratic and is influenced by a dynamic and complex interaction of factors (Gracey & Ownsworth, 2012). This has been conceptualised as the biopsychosocial approach to ABI (Williams & Evans, 2003). This is reflected in the World Health Organisations' (2001) International Classification of Functioning framework which emphasises the role of contextual factors on bodily functioning, participation and activities after the onset of a health condition.

Broadly, there has been support for the biopsychosocial perspective with research emphasising the contribution of neuropathology, personal and psychological characteristics and the social environment to psychosocial outcomes (Haslam et al., 2008; Yeates, Gracey & Mcgrath, 2008; Rutterford & Wood, 2006).

Such perspectives allow for greater scope and flexibility within rehabilitation settings since they represent a shift away from permanent, biologically determined outcomes e.g. damaged neural substrates, towards an understanding of more flexible outcomes that are influenced by individual and social contexts (Wright, Zeeman & Biezaitis, 2016). The aim of interventions is therefore tailored to meet holistic needs using a multidisciplinary approach to identify and address relevant biopsychosocial factors.

### **1.3. Subjective experience and ABI**

Of growing interest within the biopsychosocial approach and within the domain of neuropsychological rehabilitation are areas relating to subjective experiences; particularly, subjective interpretation of brain injury symptoms and identity-related issues (Ownsworth & Haslam, 2016; Gracey & Ownsworth, 2012). A better understanding of these issues may help inform rehabilitation and ongoing support over the long-term.

Identity has wide-ranging meaning within psychology and is a broad concept. Self-identity can be defined as a person's self-knowledge relating to their values, qualities and inner-sameness (Ownsworth, 2014). The social identity theory posits that individuals have multiple social identities, derived from their various social group memberships (Tajfel & Turner, 1979). These group memberships hold value and meaning and can influence how individuals behave across different social contexts. The self-categorisation theory (Turner, 1999) suggests that individuals hold both personal and social identities which may become more or less salient depending on the context and the particular social interactions that are occurring.

The development of both personal and social identity are likely to be influenced by both intrapersonal and social influences. For example, ‘personal attributes’ such as personality type are influenced by the cultural context, while more ‘social attributes’ such as group membership only gain importance once an individual personally identifies with them (Vignoles, 2017).

Identity can be greatly affected by an ABI, both on an individual and social level. Levack, Kayes and Fadyl (2010) completed a qualitative metasynthesis which identified eight themes reflecting the ways in which the lived experience of individuals with a brain injury are affected. These were mind-body disconnect; disconnect with pre-injury identity; social disconnect; emotional sequelae; internal and external resources; reconstruction of self-identity; reconstruction of a place in the world and reconstruction of personhood. The ‘rupture’ in the continuity of the self after a brain injury has been linked to higher levels of anxiety and poorer adjustment (Cantor et al., 2005; Ellis-Hill & Horn, 2000). Reconstruction of identity, both on a personal and social level, therefore becomes an important part of adjustment after a brain injury.

If identity is strongly influenced by both social and intrapersonal processes, then the subjectively salient aspects of these processes are important in how individuals perceive themselves across different contexts (Walsh, Fortune, Gallagher & Muldoon, 2012). As identified by Levack et al. (2010) the neuropsychological impairments associated with ABI can affect identity on both a social and personal level by interfering with both social and intrapersonal processes. The extent to which this affects identity may be linked to individuals’ experience of the salience of their brain injury symptoms across different aspects of their life.

As such, understanding the subjective experience of brain injury symptoms may be important to understanding both identity-related constructs and adjustment to brain injury. Subjective experiences of the impact of brain injury symptoms can be quantified using measures of health-related quality of life (HRQoL). Such measures provide an indication of the extent to which the self is viewed as being affected by the presence of a brain injury. HRQoL may therefore be more informative than functional measures of wellbeing e.g. cognitive functioning, depressive symptoms, because they consider the personal sensitivity to certain brain injury symptoms.

Consideration of subjective experience of both identity and brain injury symptoms has implications for the way in which we view and measure adjustment to brain injury (e.g. Gracey & Ownsworth, 2012; Muenchberger, Kendall, & Neal, 2008; Nochi, 1998). Although neuropsychological rehabilitation programmes increasingly consider identity and self-experience as key to interventions, they do not often evaluate outcomes in terms of changes to self-concept (Ownsworth & Haslam, 2016). This is of concern as changes to functional measures do not necessarily capture the extent to which individuals have been able to integrate their post-injury status into their sense of self and this therefore tells us little about the subjective experiences of those with a brain injury (Secrest & Zeller, 2007). If the perceptions of people with a brain injury are not shared in this way, then rehabilitation is less likely to be successful at meeting their broader needs.

Interestingly, rehabilitation does not always attain the hoped-for level of improvement, perhaps reflecting that the broader needs of people with a brain injury are indeed not always met. Goal setting and attainment and long-term psychosocial outcomes are identified as particular areas of need within rehabilitation (Dahm & Ponsford, 2015; McPherson, Kayes & Weatheral, 2009) suggesting that current

theoretical perspectives do not consistently have the ecological validity to translate to meaningful interventions for some people with a brain injury. There consequently remains questions around how to understand, identify and meet the psychological needs of individuals living with a brain injury.

#### **1.4. Rationale for empirical paper and systematic review**

Given the documented importance of subjective experience in rehabilitation, more could be done to understand and integrate aspects of lived experience, including identity-related issues and health-related quality of life, within the assessment and rehabilitation process.

The current portfolio therefore presents research which highlights the importance of subjective experience in exploring areas relating to rehabilitation. Firstly, the systematic review uses a narrative synthesis approach to explore factors associated with long-term health-related quality of life after a traumatic brain injury. Results are explored in the context of relevant theory, including the biopsychosocial approach. A discussion around the clinical implication of the findings is also presented.

Secondly, the empirical paper presents a mixed-methods pilot study trialling a methodology to assess future self-identity in those with a brain injury, through the use of the 'possible selves' interview. This paper focuses on assessing the feasibility of the possible selves approach in those with a brain injury with the aim of delineating the construct through which identity-related issues can be further explored and objectified. Finally, a critical review discusses the limitations of applying such constructs to individuals with a brain injury and suggests direction for future research.

## **CHAPTER 2: Systematic Review**

What are the predictors of long-term health-related quality of life in individuals with a traumatic brain injury?

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**What are the predictors of long-term health-related quality of life in individuals  
with a traumatic brain injury?**

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### Abstract

**Objectives:** The aim of this review was to critically evaluate longitudinal studies investigating psychosocial, demographic and injury-related factors associated with long-term health-related quality of life (HRQoL) following a traumatic brain injury (TBI).

**Methods:** Four databases were searched using keywords for articles published up until June 2018. Longitudinal studies assessing factors associated with HRQoL in TBI participants who were more than one year post-injury were included. Data extraction was based on the Strengthening the Reporting of Observational Studies in Epidemiology guidelines. Methodological quality was assessed using the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies. A narrative synthesis approach using PRISMA guidelines was taken due to the heterogeneity across study design and objectives.

**Results:** Searches yielded 16 studies which were deemed eligible for inclusion. 1250 unique participants with mild-severe TBI were followed for between 0-20 years post-injury. There were a range of factors investigated in relation to HRQoL. The strongest evidence related to depressive symptoms predicting mental HRQoL and functional ability, including community integration, predicting overall HRQoL. Gender, age, pre-morbid employment and time since injury also had associations with long-term HRQoL. There was some but inconsistent evidence for the impact of injury severity. Due to variation in methodological quality and predictive factors selected across the reviewed studies, it is hard to draw firm conclusions. Further research is required to address these limitations

**Clinical implications:** Early assessment is required to identify those with early risk factors associated with poor long-term HRQoL. Injury severity does not necessarily directly impact HRQoL.

Systematic review registration number: CRD42018086823

**Keywords:** traumatic brain injury, health-related quality of life, systematic review, neuropsychology, rehabilitation

## **1. Introduction**

### **1.1. Rationale**

Traumatic brain injury (TBI) occurs when the brain suffers an injury as the result of an external trauma. Common causes include road traffic accidents, falls and assault. TBIs are relatively common; The National Institute of Health and Care Excellence (2014) estimates that around 1.4 million people visit A&E with a head injury every year. While many of these individuals make full recoveries, for others the effects of a head injury can be chronic and debilitating, with the World Health Organisation (WHO) (2006) estimating that by 2020 TBI will rank third in terms of burden of disease. Given the chronic and disabling nature of some TBIs, it is pertinent that rehabilitation programmes and treatments are based on a strong evidence base and the factors supporting optimal recovery are well understood.

The nature and severity of TBIs vary and in part depend on the location and diffusion of the injury within the brain. Individuals may consequently struggle with the effects of a TBI across multiple domains (Yeates, Gracey & Mcgrath, 2008). Evidence has also highlighted the personal impacts of a TBI; research capturing the subjective experience of those with a TBI indicates that changes to perceived sense of self, relationships and quality of life are common experiences (Muenchberger, Kendall & Neal, 2008; Crisp, 1994).

More optimistically, there is also evidence of post-traumatic growth following a TBI. Post-traumatic growth can be defined as the positive change experienced after a life-changing event which may allow individuals to achieve a higher state of psychological functioning after a TBI (Karagiorgou, Evans & Cullen, 2018; Grace, Kinsella Muldoon, Fortune, 2015). In their systematic review, Grace et

al. (2015) found that post-traumatic growth was possible even in those with a severe TBI and suggested that factors such as education, employment, age, beliefs and mental wellbeing were all related to the occurrence of post-traumatic growth.

The evidence therefore indicates that adjustment post-TBI is not determined purely by markers of severity; it appears that difficulties associated with severe TBI may sometimes be offset by psychological or social resources, or exacerbated by the environmental context (Powell, Gilson & Collin, 2012). As Nochi (1998) highlighted, people with a brain injury actively interpret their symptoms, and are not passive participants to biological damage. A biopsychosocial perspective has been used to suggest that the interplay of brain pathology, psychological and behavioural characteristics and the social environment influence adjustment to brain injury (Williams & Evans, 2003). Impairments to social, emotional and cognitive abilities may therefore differentially affect individuals with a TBI.

However, although it is generally agreed that there is an interactive effect, the precise nature of the interplay between biopsychosocial factors is less well understood. Many studies only provide correlational data, thereby failing to provide causal inference. Gracey and Ownsworth (2012) suggested that prospective longitudinal studies may be better placed to understand the adjustment process over a period of time.

The trajectory of quality of life after a TBI may be a useful way in which to assess the factors predicting adjustment post-TBI, especially as it provides a broad scope from which to consider wellbeing across multiple domains. However, there is little consensus on the definition or measurement of 'quality of life' (Sartorius, 1993). One difficulty with this is that there have been different means to assess

quality of life. Assumptions about the impact of TBI on quality of life are sometimes made on the basis of commonly observed difficulties post-TBI. For example, functional impairments such as communication difficulties, mood and poor memory and attention have been considered to be a sign of poorer quality of life in those with a brain injury (Shukla, Devi & Agrawal, 2011). However, such functional assessments fail to capture the subjective experience of how a brain injury impacts quality of life across different domains. Indeed, poor levels of functioning do not necessarily mean an individual experiences or believes they have a poor quality of life. Polinder, Haagsma, van Klaveren, Steyerberg and Van Beeck (2015) suggested that using functional means to determine quality of life actually only captures health status. In many ways the subjective experience relating to the impact of a brain injury may therefore be more useful to investigate than functional markers alone.

WHO defines ‘quality of life’ holistically, suggesting it is an individual’s *perceived* position in life across multiple social, physical and emotional domains, embedded within a wider systemic and value-based context (WHO, 1995). From this perspective, when considering TBI, it is the subjective view of the impact of disability, not the level of functioning per se that defines quality of life.

A specific type of quality of life, health-related quality of life (HRQoL) captures this subjective experience of health; it refers to a person’s perception of their quality of life by considering how their health has affected their social, physical and mental functioning. HRQoL is therefore a multidimensional construct. Investigating HRQoL may be one way in which to consider the idiosyncratic impact of a person’s head injury, without making assumptions about the impact on the basis of biological, social, cognitive or mood markers.

Recovery trajectory is steepest in the first year post-TBI (Jennett, Snoek, Bond & Brooks, 1981) and many studies have focused exclusively on outcomes within the first year post-TBI. For example, observational studies have indicated that in the early stages post-TBI there are associations between HRQoL and factors such as awareness deficits, depression, anxiety and employment status (Sasse et al., 2013; Soberg et al., 2013). However, understanding the trajectory of HRQoL over time and beyond the first year of injury may reveal factors that predict sustained HRQoL as well as how these factors interact.

The growing interest and number of studies investigating HRQoL in those with a TBI suggests that it may now be feasible to complete a systematic review into the factors that predict better long-term HRQoL in individuals with a TBI. This could provide further direction to identifying those at an early stage of injury who may be at high risk of chronically poor HRQoL. Additionally, it has implications for early decision making during rehabilitation efforts; understanding the factors that predict long-term HRQoL may provide direction to early treatment management in terms of the focus that rehabilitation should take.

## **1.2. Objectives**

The systematic review aimed to investigate the following question:

“Amongst individuals with a traumatic brain injury, what is the evidence that psychosocial, demographic and injury-related factors predict long-term health-related quality of life?”

## **2. Methods**

### **2.1. Protocol and registration**

The review is registered with PROSPERO: International prospective register of systematic reviews (registry ID CRD42018086823). The review was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement (Moher, Liberati, Tetzlaff & Altman, 2009).

## **2.2. Eligibility criteria**

Eligibility criteria for inclusion within the systematic review is outlined using PICOS (participants, interventions, comparisons, outcomes, and study design), as recommended by The PRISMA Statement (Moher et al., 2009). As the studies included in this systematic review are observational, ‘interventions’ and ‘comparisons’ are renamed ‘predictive factors’. Rationale and further detail of the eligibility criteria are reported below.

### **2.2.1. Participants.**

#### ***Inclusion Criteria.***

- Participants aged 16 years and over at time of injury
- Participants with a primary diagnosis of mild-severe traumatic brain injury, with reference to a Glasgow Coma Scale score or other validated measure

#### ***Exclusion Criteria.***

- Participants under 16 years of age at time of injury, including studies with a subset of participants within this age range
- Participants with general acquired brain injuries
- Participants with a neurodegenerative condition

### **2.2.2. Predictive factors.**



***Inclusion Criteria.***

- Psychosocial factors, broadly encompassing personal psychological attributes and/or wider systemic factors (Singh-Manoux, 2003)
- Demographic and injury-related factors

***Exclusion Criteria.***

- Intervention studies e.g. randomised control trials

**2.2.3. Outcome.*****Inclusion Criteria.***

- HRQoL as reported on by a validated quantitative measure

***Exclusion Criteria.***

- Measures of generic quality of life
- Qualitative measures of HRQoL
- Non-validated measures of HRQoL

**2.2.4. Study Design.*****Inclusion Criteria.***

- Longitudinal observational studies, with at least one predictive factor recorded prior to the HRQoL measure
- At least one measure taken more than 1 year post-injury
- Studies in the English language

***Exclusion Criteria.***

- Intervention studies, including randomised control trials
- Cross-sectional designs

- Case studies

### **2.3. Information sources**

PubMed, PsycINFO, CINAHL Complete and Web of Science were the databases used to complete the search.

### **2.4. Search Strategy**

The PICOS-style question “Amongst individuals with a traumatic brain injury, what is the evidence that psychosocial, demographic and injury-related factors predict long-term health-related quality of life?” was used to structure the search strategy.

The term ‘brain injury’ was used to identify participant group. ‘Traumatic brain injury’ was also considered but was removed after it limited search results. ‘Quality of life’ and ‘health-related quality of life’ were used for the outcome of interest. ‘Predictive’ ‘psychosocial’, ‘demographics’ and ‘injury-related’ were initially considered for terms for predictive factors, however inclusion of any of these terms resulted in a limited number of search returns. Predictive factors were therefore removed from the final search terms. ‘Longitudinal’ was considered as a term for study design. However, this too significantly reduced search returns and so was excluded from the final searches. Filters to include only studies in the English language, with adult and adolescent participants and human subjects were included.

The specific search strategies used varied across different databases, but all search strategies used both the identified participant term and outcome of interest terms. The search terms for each database can be viewed in Appendix A. Each use a

Boolean strategy. Appendix B shows the development of the search strategy for PubMed as an example.

## **2.5. Data Collection Process**

A data extraction template was developed based on the Strengthening the Reporting of Observational Studies in Epidemiology guidelines (STROBE) (von Elm et al., 2007). STROBE details the information that should be reported in an observational study for completeness and accuracy. Key details from included studies, such as research question, design, participants' diagnoses, measures and results, are reported in Table 1 alongside a rating of methodological quality. A narrative synthesis was deemed the most suitable approach to the systematic review; study heterogeneity in terms of study design and assessment tools meant that a meta-analysis was not feasible.

## **2.6. Assessment of Methodological Quality**

The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (QATOCCS) (National Heart, Lung and Blood Institute, 2014) was used to rate the methodological quality of the studies. The QATOCCS is a 14-item tool which allows the rater to answer each question with 'yes', 'no', 'cannot determine', 'not reported', or 'not applicable'. There is an accompanying guidance document which supports the rater in determining the best response to each question. This therefore allows the rater to summarise and critically evaluate the studies on the basis of these responses. A final rating of 'good', 'fair' or 'poor' is given on the basis of the rater's judgement of the impact of the responses on bias. A second rater, another trainee clinical psychologist, also rated 50% of the studies using the

QATOCCS. This served as a measure of inter-rater reliability. Cohen's  $\kappa$  was run to determine inter-rater reliability with results indicating that there was moderate agreement (McHugh, 2012) on the ratings ( $\kappa = 0.67, p = 0.002$ ). The studies selected were chosen at random. In instances where the quality rating differed, a discussion was had to agree on the final quality rating.

The final quality rating was influenced by the extent to which the studies could reliably answer this systematic review's question.

Table 1

*Summary of Study Characteristics*

<b>First Author &amp; date</b>	<b>Research Question/ Aim</b>	<b>Study Design</b>	<b>Participants (N)</b>	<b>TBI sample (severity measure)</b>	<b>HRQoL Measure</b>	<b>Relevant findings</b>	<b>Quality Rating</b>
1. Forslund (2013)	Describe HRQoL two years after TBI and to identify its predictors	Prospective-Predictive 3 time points: 0,1 & 2 years post-TBI	91 (70 males)	Moderate-Severe TBI (GCS)	SF-36	<i>Prospective findings:</i> Effect of age at injury, community integration, injury severity & Marshall Classification on PCS ( $p \leq 0.05$ ). Changes in depressive scores and depression at year 1 predicted MCS score at 2 years ( $p < .001$ ). Hierarchical regression model predicted 38% of variance for PCS and 65% of variance for MCS.	Good
2. Hu (2012)	Assess HRQoL two years after TBI and to identify its determinants	Prospective-Predictive 4 time points: at discharge & 6,12 & 24 months post-discharge	312 participants with TBI (257 males), 381 controls	Moderate-Severe TBI (GCS)	SF-36	<i>Prospective findings</i> Significant effect of age on physical component score ( $p < 0.05$ ), Significant effect of gender on mental component score ( $p < 0.05$ )  Significant effect of time and GCS score on all SF-36 domains ( $p < 0.05$ ).	Good

3. Andelic (2018) follow-up of Andelic (2009)	Describe functional outcomes and HRQL in individuals with TBI 20 years post-injury.	Prospective-Predictive	44 (33 males)	Moderate-Severe (GCS)	SF-36	<i>Prospective findings</i> Time since injury had significant effect on bodily pain and role limitations due to emotional health subscales of SF-36 Significant effect of community integration & depression on both MCS & PCS domains on SF-36 and gender on MCS ( $p < 0.05$ ). Regression model showed 29% & 45% variance explained by these factors for PCS & MCS respectively.	Good
4. Dawson (2003)	Examine whether cognitive recovery markers in the acute period predict outcomes up to four years post TBI	Prospective-Predictive 3 time points, admission, 1 year post-injury, 4 years post-injury	47 participants (25 males), 15 controls	Mild-Severe TBI (GCS)	SIP (psychosocial domain)	<i>Prospective findings</i> Pre-injury work stability, GCS, attention & passive memory retrieval predicted psychosocial component on SIP at 1 year ( $p \leq 0.05$ ) Gender, length of stay, active memory retrieval and attention predicted psychosocial component on SIP at 4 years ( $p \leq 0.05$ )	Fair
5. Grauwmeijer (2018) (Follow-up to	Evaluate cognitive function ten years after	Prospective-Predictive 8 time-points discharge, 3,	50 (34 males)	Moderate-Severe TBI (GCS)	SF-36	<i>Prospective findings</i> No significant effects of cognitive functioning at discharge or time since injury at 10 years post-injury	Fair

Grauwmeijer (2014)	moderate-severe TBI and to investigate the associations between cognitive function, depression and HRQoL	6, 12, 18, 36 & 120 months post-injury				<i>Correlational findings</i> Depression and subjective cognitive functioning at 10 years significantly associated with both MCS & PCS at 10 years. Two measures of objective cognitive functioning (trail making test and memory recall test) significantly associated with MCS	
6. Williamson (2013)	Examine the predictive associations of family satisfaction, functional impairment, pain, and depression on HRQoL among persons with TBI	Prospective-Predictive 5 time-points 0,12,24,48, 60months post-discharge	131 (89 males)	Moderate-Severe/Critical TBI (HAIS)	SIP	<i>Prospective findings</i> Direct effects of physical independence, family satisfaction & pain ( $p < 0.001$ ) and depression ( $p < 0.05$ ) on HRQoL. Indirect effects of physical independence & pain ( $p < 0.05$ ) on overall HRQoL mediated by depression	Fair
7. Grauwmeijer (2014)	Investigate longitudinal HRQoL after TBI and to	Prospective-Predictive 7 time-points discharge, 3, 6, 12, 18, 24	97 (70 males)	Moderate-Severe TBI (GCS)	SF-36	<i>Prospective findings</i> Length of stay, time since injury & functional independence predicted physical component.	Fair

	identify its predictors.	& 36 months post-TBI.				Age at injury, $p < 0.05$ ) depression & length of stay ( $p < 0.01$ ) predicted mental health component	
8. Wielenga-Boiten (2015)	Investigate health locus of control in individuals with TBI and to determine its relationship to HRQoL over time	Prospective-Predictive 3 time points: 0, 12 & 36 months post-TBI	85 (59 males)	Moderate-Severe TBI (GCS)	SIP-68	<i>Prospective findings:</i> Chance health-related locus of control, physical and cognitive functioning, discharge destination & psychiatric condition significantly associated with total HRQoL ( $p < 0.05$ ), length of stay with physical HRQoL ( $p < 0.05$ )	Fair
9. Andelic (2015) (Follow-up to Forslund et al., 2013)	Investigate physical HRQoL changes after TBI and its association with whether demographic and injury can predict its trajectory	Prospective-Predictive 4 time points: 0,1,2&5 years post-TBI	97 (76 males)	Moderate-Severe TBI (GCS)	SF-36 Physical health scales only	<i>Prospective findings:</i> Significant effects of pre-morbid education, pre-morbid employment, time & length of post-traumatic, Marshal classification and injury severity on different physical subscales ( $p < 0.05$ ). Gender significantly associated with Role-Physical ( $p = 0.014$ ) and bodily pain & general health ( $p = 0.04$ )	Fair
10. Ulfarsson (2014)	Investigate pre-morbid unemployment	Retrospective-Predictive	51 (38 males)	Severe TBI (GCS)	SF-36	<i>Retrospective findings</i>	Fair



and sick leave on long-term HRQoL and functioning in people with TBI

Pre-injury data collected retrospectively, HRQoL assessed 2-11 years post-TBI

Pre-morbid unemployment and sick leave significantly predicted worse physical HRQoL, ( $p = 0.02$ )

11. Teasdale (2005)	Examine quality of life in those with a head injury, and the injury and post-injury demographic factors predictive of long term quality of life	Retrospective -Predictive 2 time-points 0 months after TBI and either 5, 10 or 15 years after TBI	126 with cranial lesions (73 males) and 114 with cerebral fracture and no lesion	Mild-Severe TBI (GCS)	EBIQ	<i>Retrospective findings:</i> Cognitive functioning on discharge and age at injury associated with lower core score for patients with cerebral lesions ( $p < 0.01$ ) Length of post-traumatic amnesia associated with motivation and communication subscales ( $p < 0.05$ )	Fair
12. Andelic (2009)	Describe functional outcome and HRQoL ten years after TBI	Retrospective -Predictive 2 time points: at admission & approx. 10 years after TBI	62 (35 males)	Moderate-Severe TBI (GCS)	SF-36	<i>Retrospective findings</i> No significant effect of injury severity <i>Cross-sectional findings:</i> Gender associated with mental health component ( $p < 0.01$ ), epilepsy on vitality & role limitations due to emotional health ( $p = 0.01$ ), employment on role limitations due to	Poor

						physical health ( $p \leq 0.01$ ) and depression with all domains ( $p < 0.01$ ). Functional outcome associated with all domains other than bodily pain ( $p < 0.05$ )	
13. Tomberg (2007)	Investigate longitudinal changes in psychosocial factors and HRQoL in people with TBI	Prospective-Predictive 3 time-points 0 months, approx. 2.3yrs & approx. 5.7yrs after TBI	31 (25 males)	Moderate-Severe (GCS)	SF-36	<i>Prospective findings:</i> Education associated with all domains of SF-36 ( $p < 0.05$ ). <i>Cross-sectional findings</i> Satisfaction with social support, adjustment to work and current employment status ( $p < 0.05$ ) all associated with all domains of HRQoL, avoidant coping strategy associated with lower scores social functioning subscale ( $p < 0.05$ ). Age associated with physical component ( $p < 0.05$ ).	Poor
14. Beseoglu (2013)	Study the long-term QoL and socio-professional reintegration after mild TBI	Retrospective -Predictive 2 time-points admission and 3 years post injury	36 (24 males)	Mild TBI (GCS)	SF-36	<i>Retrospective factors</i> No significant effect of CT scan results on any SF-36 subscales  <i>Cross-sectional factors</i> No significant effect of employment status on any SF-36 subscales	Poor

15. Jaeger (2014)	Assess the long-term outcome in severe TBI patients and explore the prognostic values of initial clinical and paraclinical parameters	Retrospective -Predictive 2 time-points admission and 2-4 years after injury	18 (gender ratio not reported)	Severe TBI (GCS)	QoLBRI	<i>Retrospective findings</i> More severe GCS and longer post-traumatic amnesia associated with poorer overall HRQoL ( $r = 0.66$ & $-0.76$ respectively, $p < 0.05$ ).	Poor
16. Ahman (2013)	Investigate the impact of TBI on post-concussion symptoms, post-traumatic stress, and quality of life and to investigate the differences between the genders	Retrospective -Predictive/ mixed design 3 time points: at admission, 3 years and 11 years post-TBI	163 (95 males), 10 followed up at 11 years (gender ratio not reported)	Mild TBI (GCS)	SF-36	<i>Mixed findings:</i> Females had significantly lower scores on limitations due to emotional health, role limitations due to physical health and mental health scales than males ( $p < 0.05$ ), no significant effect of time since injury on all domains of SF-36	Poor

**GCS** = Glasgow Coma Scale; **HAIS** = Abbreviated Injury Scale of the head region; **SF 36** = Short-Form Survey 36; **MCS** = Mental component score on SF-36; **PCS** = Physical component score on SF-36; **SIP** = Sickness Impact Profile; **EBIQ** = The European Brain Injury Questionnaire; **QoLBRI** = Quality of Life After Brain Injury Scale; **CFQ** = Cognitive Failure Questionnaire; **GOAT** = Galveston Orientation and Amnesia Test; **SCID-I** = The Structured Clinical Interview for DSM-IV Axis I Disorders; **BPRS** = The Brief Psychiatric Rating Scale; **HADS**: Hospital

Anxiety and Depression Scale; **FIM + FAM** = The Functional Independence Measure + Functional Assessment Measure; **FSS** = The Family Satisfaction Scale; **SSQ** = The Social Support Questionnaire; **LOS** = The Life Orientation Scale; **WSRS** = The Wimbledon Self-Report Scale; **GOS & GOS-E** = Glasgow Outcome Scale & Glasgow Outcome Scale-Extended; **BI** = Barthel Index; **ISS** = Injury Severity Score; **BDI** = Beck Depression Inventory; **Multidimensional HLC Scales** = The Multidimensional Health Locus of Control Scales; **CIQ**: Community Integration Questionnaire

### 3. Results

#### 3.1. Study selection

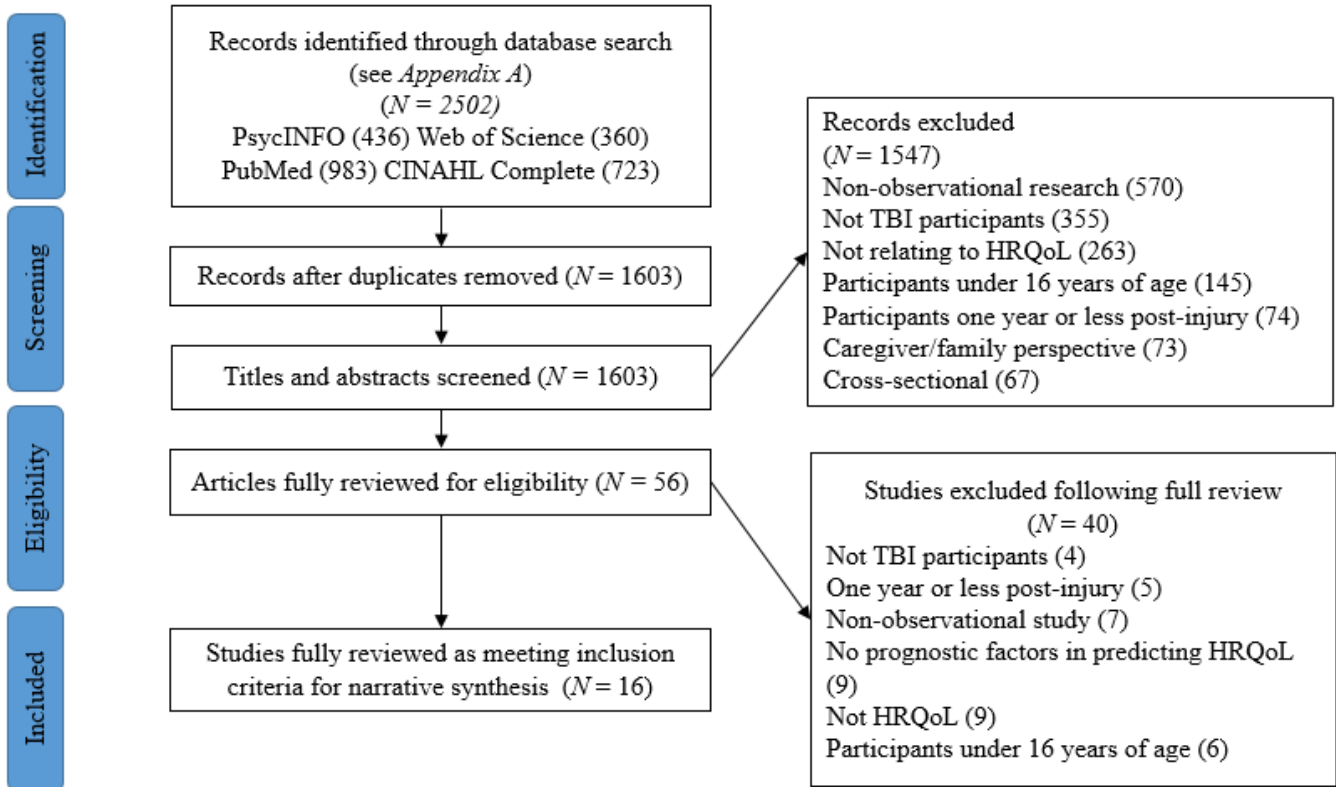


Figure 1. Study selection procedure

As outlined in Figure 1, 2502 studies were identified from searching the databases. All duplicates were removed ( $N = 899$ ) and studies were subsequently screened on the basis of their title and abstract. 2446 studies were excluded at this stage. Where there was insufficient detail within the abstract to determine eligibility, the full article was accessed and read. At the eligibility stage, 56 studies were accessed in full as it was not possible to ascertain inclusion or exclusion on the basis of the abstract alone.

16 studies were deemed to be eligible for the systematic review. All studies analysed predictive factors HRQoL in those aged 16 years or over with a TBI. All

studies followed participants who were more than one year post-injury either at the start or end of data collection.

### **3.2. Study characteristics**

Study characteristics are explored as a way to examine study heterogeneity and how this may influence outcomes. These are outlined according to the PICOS criteria, including detail on study size and follow-up period.

#### **3.2.1 Participants.**

Across the 16 studies, a total of 1441 participants with a TBI were recruited, however only 1250 were unique participants as some studies were follow-ups of earlier research (Andelic et al., 2018 & Andelic et al., 2009; Andelic et al., 2015 & Forslund, Roe, Sigurdardottir & Andelic, 2013; Grauwmeijer et al., 2018 & Grauwmeijer, Majanka, Heijenbrok-Kal & Ribbers, 2014). The same cohorts are included in this review because of the differences in aims and to allow for reporting of the most up-to-date date for the cohort.

Out of the 1250 unique participants, 860 (69.8%) were males and 372 (30.2%) were females. Jaeger et al. (2014) did not report on gender ratios and so the gender of 1.4% of participants is unknown. The range of TBI samples were from mild-severe on the Glasgow Coma Scale and moderate-severe or critical injury on the head section of the Abbreviated Injury Scale (Gennarelli & Wodzin, 2005). Only four studies included participants with a mild TBI.

Most of the studies had relatively small sample sizes; the largest study had 312 participants (Hu et al., 2012), and the smallest had 18 participants (Jaeger et al., 2014). Most studies ( $N=13$ ) had under 100 participants by final data collection.

### **3.2.2. Study Design.**

All included studies were longitudinal observational studies in the English language. All the studies assessed participants either prospectively or retrospectively and followed them beyond one-year post-injury. Out of the studies, 10 had prospective designs (Andelic et al., 2018; Grauwmeijer et al., 2018; Andelic et al., 2015; Wielenga-Boiten, Heijenbrok-Kal & Ribbers, 2015; Forslund et al., 2013; Grauwmeijer et al. 2014; Williamson et al., 2013; Hu et al., 2012; Tomberg, Toomela, Ennok & Tikk, 2007; Dawson, Levine, Schwartz & Stuss, 2003).

The remaining six studies had retrospective designs (Jaeger et al., 2014; Ulfarsson, Lundgren-Nilsson, Blomstrand & Nilsson, 2014; Ahman, Saveman, Styrke, Björnstig & Stålnacke, 2013; Beseoglu, Roussaint, Steiger & Hänggi, 2013; Andelic et al., 2009; Teasdale & Engberg, 2005).

Most of the studies recruited from western populations, with 13 studies recruiting from Europe and two from North America. Only one study recruited from Asia.

Only five studies explicitly sought to determine predictors of HRQoL in TBI using prospective or retrospective observational designs (Grauwmeijer et al., 2014; Ulfarsson et al., 2014; Forslund, et al. 2013; Williamson et al., 2013 and Hu et al., 2012). These five studies were therefore directly relevant to this systematic review's question.

### **3.2.3. Predictive Factors.**

A range of psychosocial, demographic and injury-related factors were assessed as potential predictors of HRQoL. The most commonly investigated factors

were time since injury followed by injury severity and age. Levels of functioning, depressive symptoms, gender, education level and employment were also commonly investigated, although often using different assessment tools and methods. The different predictive factors, and the means to assess them, are outlined alongside study characteristics in Table 1.

#### **3.2.4. Outcome of Interest.**

The majority of the studies used the Short-Form Survey (SF-36 or SF-12) (Ware & Sherbourne, 1992) as the main measurement of HRQoL ( $N=11$ ). The SF-36 provides a mental component score and a physical component score, representing HRQoL across both domains. One of the studies only used the physical component score or physical scales, and therefore did not report on the mental component score (Andelic et al., 2015). Three studies used the Sickness Impact Profile (SIP) (Wielenga-Boiten et al., 2015; Williamson et al., 2013; Dawson et al., 2003). The SIP measures HRQoL across 12 subscales, but can be summed to provide an overall score, a psychosocial score and a physical score. Dawson et al. (2003) only used the psychosocial score.

Only two studies, Jaeger et al. (2014) and Teasdale and Engberg (2005), used a brain-injury specific measure of HRQoL, the European Brain Injury Questionnaire (EBIQ) (Teasdale et al., 1997) and the Quality of Life After Brain Injury Scale (QoLIBRI) (Tazopoulou, Truelle, North & Montreuil, 2005) respectively. The EBIQ is a brain-injury specific measure of HRQoL, capturing a range of common symptoms after brain injury and the subjective impacts of them. The QoLIBRI was developed to specifically capture HRQoL after a TBI. It is comprised of 37 items, across six domains of HRQoL.



### **3.3. Quality Assessment within Included Studies**

Table 2 summarises the risk of bias across the 16 studies using the QATOCCS. Andelic et al. (2018), Forslund et al. (2013) and Hu et al. (2012) were all rated as a 'good' quality studies. All three relied on largely prospective data and used either logistic or hierarchical regression, thereby controlling for some confounding variables. The studies all specifically looked at predictors of long-term HRQoL and provide good quality evidence for factors associated with HRQoL.

Table 2

## Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (National Heart, Lung and Blood Institute, 2014)

Criteria	First Author Date	Dawson (2004)	Williamson (2013)	Forslund (2013)	Ulfarsson (2014)	Tomberg (2007)	Andelic (2018)	Andelic (2009)	Jaeger (2014)
1. Clear research question?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Clearly defined study population?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
3. Participation rate of eligible persons at least 50%?		Yes	No	Yes	No	Yes	Yes	Yes	Yes
4. Clear inclusion and exclusion criteria applied?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5. Sample size justified?		No	No	No	No	No	No	No	No
6. Exposure measured prior to outcome?		Yes	Yes	Yes	Yes	Some	Yes	Some	Some
7. Sufficient timeframe between measures?		Yes	Yes	Yes	Yes	Yes & No	Yes	Yes & no	Yes
8. Different levels of exposure?		Yes	Some	Some	Yes	Yes	Some	Some	Yes
9. Valid exposure measures?		Yes	Some	Yes	Yes	Some	Yes	Yes	Yes
10. Was the exposure(s) assessed more than once over time?		Yes	No	No	Yes	Some	Yes & No	No	No
11. Valid outcome measure?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
12. Assessors blinded to the exposure?		No	No	No	No	No	No	No	No
13. Loss to follow-up after baseline 20% or less?		No	Yes	Yes	N/A	No	Yes	N/A	N/A
14. Confounding measures controlled for?		Yes	Yes	Yes	Yes	No	Yes	No	No
Quality Rating		Fair	Fair	Good	Fair	Poor	Good	Poor	Poor

Criteria	First Author Date	Grauwmeijer (2018)	Grauwmeijer (2014)	Teasdale (2005)	Ahman (2013)	Wielenga-Boiten (2015)	Andelic (2015)	Hu (2012)	Beseoglu (2013)
<b>1. Clear research question?</b>		Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
<b>2. Clearly defined study population?</b>		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>3. Participation rate of eligible persons at least 50%?</b>		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unknown
<b>4. Clear inclusion and exclusion criteria applied?</b>		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>5. Sample size justified?</b>		No	No	No	No	No	No	No	No
<b>6. Exposure measured prior to outcome?</b>		Some	Yes	Yes	Yes	Yes	Yes	Yes	Some
<b>7. Sufficient timeframe between measures?</b>		Yes & No	Yes	Yes	Yes	Yes	Yes	Yes	Yes & No
<b>8. Different levels of exposure?</b>		Yes	Some	Yes	N/A	Some	No	No	No
<b>9. Valid exposure measures?</b>		Yes	Some	Yes	Yes	Yes	Yes	Yes	Yes
<b>10. Was the exposure(s) assessed more than once over time?</b>		Yes	Yes	No	No	Yes	No	Yes & No	No
<b>11. Valid outcome measure?</b>		Yes	Yes	Some	Yes	Yes	Yes	Yes	Yes
<b>12. Assessors blinded to the exposure?</b>		No	No	No	No	No	No	No	No
<b>13. Loss to follow-up after baseline 20% or less?</b>		No	No	N/A	No	No	No	Yes	N/A
<b>14. Confounding measures controlled for?</b>		No	Yes	No	No	Yes	Yes	Yes	Yes
<b>Quality Rating</b>		<b>Fair</b>	<b>Fair</b>	<b>Fair</b>	<b>Poor</b>	<b>Fair</b>	<b>Fair</b>	<b>Good</b>	<b>Poor</b>

### **3.4. Results of individual studies**

Generally, studies considered HRQoL as multidimensional, rather than as a unitary construct. HRQoL was commonly broken down into the ‘mental’/‘psychosocial’ and ‘physical’ components. Broadly, mental HRQoL related to mental health, role limitations due to emotional health, social interaction, communication and recreational activities, while physical HRQoL referred to mobility, physical functioning, limitations due to physical difficulties and general health although the precise meaning varied according to the assessment tool used. The terms ‘mental’ and ‘physical’ HRQoL are used throughout this review. Only the EBIQ and QoLIBRI considered brain injury specific physical and mental health consequences. Some studies reported the results of individual scales, which provided a more detailed breakdown of the results.

#### **3.4.1. Depression and psychiatric symptoms.**

The most consistent and perhaps strongest predictor of long-term mental HRQoL was depression. Forslund et al. (2013) found depressive symptoms were associated with poorer mental HRQoL; Andelic et al. (2018) found depression to be associated with both physical and mental HRQoL. In their regression analysis, Andelic et al. (2018) found that their overall model predicted 29% and 45% of the physical and mental component scores of the SF-36 respectively, while Forslund et al. (2013) found 65% of the variance in the mental component score could be explained by their overall model.

All other studies which investigated depression also found it to be significantly associated with HRQoL. Results were mixed as to whether depression

predicted physical HRQoL, but all studies found an association with mental HRQoL. Consequently, there is stronger evidence for an association between depression and mental HRQoL.

### **3.4.2. Age at injury.**

All participants were over 16 years of age at the time of injury and the majority were under 70 years of age at the time of the study. Forslund et al. (2013) and Hu et al. (2012) found that lower age at injury was associated with better physical HRQoL. Findings by Grauwmeijer et al. (2014) and Tomberg et al. (2007) also found associations between lower age and better physical HRQoL. Only two studies, Andelic et al. (2015) and Andelic et al. (2009), did not find an association between age and physical HRQoL, and one study reported a small effect of greater age at injury on better HRQoL (Teasdale & Engberg, 2005). Interestingly, Andelic et al. (2015)'s study is the five year follow-up of Forslund et al. (2013)'s two year follow up study, which suggests that age at injury may become less important as the time since injury increases.

### **3.4.3. Time since injury.**

Forslund et al. (2013) and Hu et al. (2012) differed in their results in relation to the effect of time since injury on HRQoL, although this may be because of the different time scales measured. Hu et al. (2012) found that all subscales of the SF-36 improved over the first two years post-injury. Forslund et al. (2013) found that scores between one and two years post injury were relatively stable, although a subset of 26% of participants reported some improvement in their HRQoL. Findings in the studies generally indicated an improvement in HRQoL when the first year post-injury was included in analysis, especially for physical HRQoL (Wielenga-

Boiten et al., 2015; Grauwmeijer et al., 2014; Hu et al., 2012; Dawson et al., 2003).

There was far less evidence that HRQoL continues to improve over the longer-term; Andelic et al. (2018), Grauwmeijer et al. (2018), Ahman et al. (2013), Tomberg et al. (2007) and Teasdale and Engberg (2005) followed participants for a maximum of 11-20 years and found no association between time since injury and HRQoL. This may suggest a 'plateau' in HRQoL for people with a TBI, with significant improvements in HRQoL over the first year of injury more likely.

#### **3.4.4. Gender.**

Generally there was evidence that females have poorer mental HRQoL over the long-term following a TBI. Both Hu et al. (2012) and Andelic et al. (2018) reported finding that females had lower mental component scores. Forslund et al.'s (2013) finding of no association between gender and HRQoL could be due to the low proportion and number of females in the study.

Overall of the nine studies that analysed gender, six found significant effects of gender. Andelic et al. (2015) found females had poorer physical-HRQoL, Andelic et al. (2009), Hu et al. (2012) and Dawson et al. (2003) found females had poorer mental/psychosocial HRQoL and Ahman et al. (2013) found females had lower scores across both domains of HRQoL. However, three studies found that there was no association between gender and HRQoL (Grauwmeijer et al., 2014; Forslund et al., 2013; Teasdale & Engberg, 2005). The relatively low proportion of females across studies may account for the variability across studies.

#### **3.4.5. Injury severity and injury-severity related variables.**

Overall the effects of injury-related variables were mixed. Hu et al. (2012) reported that more severe GCS score was associated with poorer overall HRQoL.

However, of the other studies that investigated the role of GCS score, none other than Hu et al. (2012) and Jaeger et al. (2014) found significant associations in their final models. There was no clear indication that HRQoL was influenced by the range of injury severity included within each study.

Other markers of injury severity were also investigated, including presence of abnormalities on CT scans, Marshall CT scan score, injury severity score and coma duration at admission. However, the direction of the effect varied and results were not consistently significant between studies. There was some evidence that longer duration of post-traumatic amnesia was associated with poorer long-term HRQoL in some domains (Andelic et al., 2015; Jaeger et al., 2014; Teasdale & Engberg, 2005; Dawson et al., 2003), although this effect did not remain significant in the Forslund et al. (2013) study once control variables, such as community integration and physical functioning, were accounted for.

#### **3.4.6. Functioning.**

There was strong evidence that functional ability influences overall long-term HRQoL after a brain injury. This is a broad term and level of functioning was defined differently across different studies. However, the strongest effects of ‘functional ability’ were found when functioning was defined as community integration and physical and cognitive independence.

Physical and cognitive independence were often measured using the FIM+FAM, however various objective cognitive measures were also used to assess cognitive functioning. In relation to findings of predictive influence of physical independence, Forslund et al. (2013) found that higher levels of physical independence were associated with better HRQoL on some subscales; physical

functioning, role limitations due to physical health, general health and social functioning. Grauwmeijer et al. (2014), Williamson et al. (2013), Andelic et al. (2009) and Wielenga-Boiten (2015) found physical independence was associated with overall HRQoL.

Grauwmeijer et al. (2014) Andelic et al. (2009) and Wielenga-Boiten (2015) also used the FAM to assess cognitive functioning and found that higher levels of cognitive functioning were associated with better HRQoL over the long-term. Teasdale and Engberg (2005) found that cognitive functioning at discharge predicted overall HRQoL at a later stage post-injury. Similarly, Dawson et al. (2003) found that performance on cognitive batteries at baseline were predictive of long-term psychological and social HRQoL at follow ups. On the other hand, cross-sectional data indicated that cognitive functioning on only two out of nine cognitive batteries were associated with mental HRQoL; however perceived cognitive functioning was associated with overall HRQoL (Grauwmeijer, 2018).

Both Andelic et al. (2018) and Forslund et al. (2013) found that better community integration predicted better overall HRQoL. Forslund et al. (2013) found a significant association between increased overall physical HRQoL at 2 years and better community integration at 1 years post-injury. In their follow-up study, Andelic et al. (2018) found this effect was sustained for longer, with those 20 years post-injury benefiting from better overall HRQoL.

#### **3.4.7. Employment.**

Overall, there was mixed evidence for the role of employment in predicting long-term HRQoL after a brain injury. Forslund et al. (2013) reported that pre-morbid employment predicted better HRQoL in 6/8 subscales on the SF-36, but it



was not significant in their final model for predicting either the overall physical or overall mental component of the SF-36.

Ulfarsson et al. (2014) investigated the role of pre-morbid employment and found evidence that those with pre-morbid unemployment or history of sick leave had poorer physical HRQoL. They added that this may be reflective of poorer socioeconomic status, which in turn may represent a risk factor for poorer HRQoL post-TBI. Similarly, Dawson et al. (2003) found that pre-morbid work stability predicted better psychosocial HRQoL at 1 year post-injury, although this effect was no longer significant at 4 years. Andelic et al. (2015) also found pre-morbid employment predicted higher physical HRQoL but only on one scale. There was less evidence for the protective effect of current employment on HRQoL; neither Grauwmeijer et al. (2014) nor Beseoglu et al. (2013) found any association.

Overall the results on employment are therefore mixed, with stronger evidence for pre-morbid employment being a protective factor than current employment.

#### **3.4.8. Other psychological and social factors.**

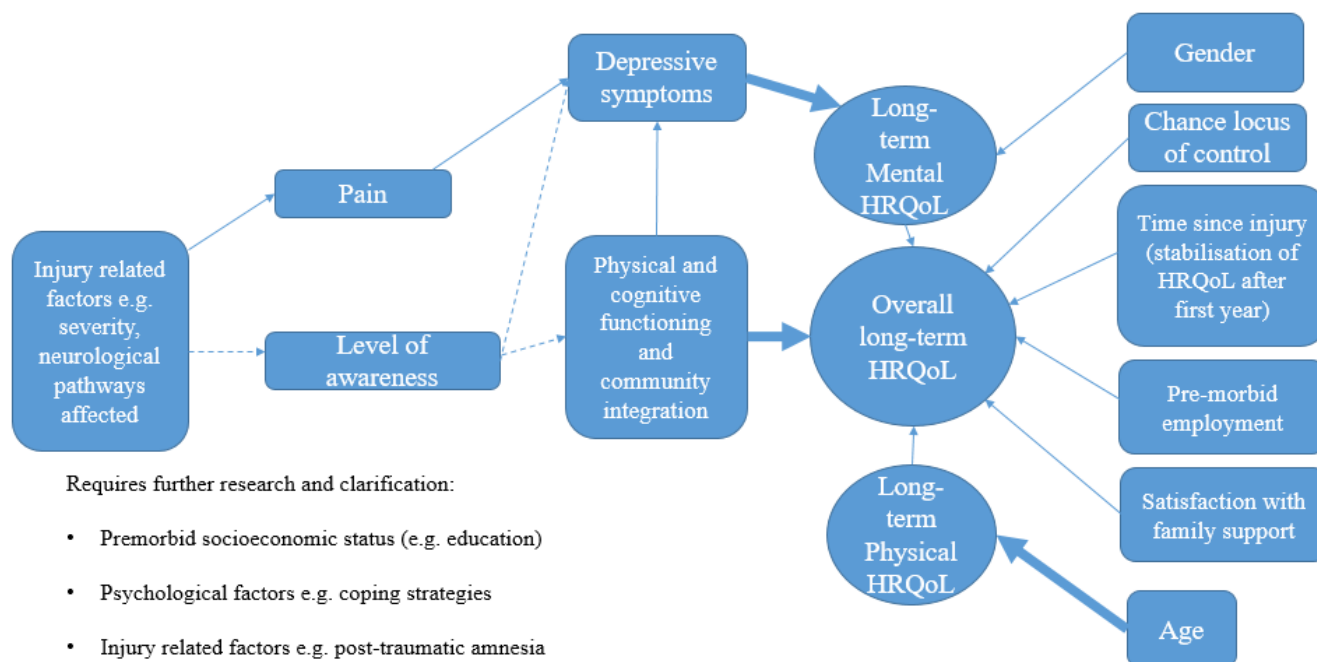
There is some limited evidence for the role of psychological factors in post-TBI HRQoL, however these were not widely investigated. There was evidence that a higher level of chance health-related locus of control was associated with poorer long-term HRQoL (Wielenga-Boiten et al., 2015). Health-related locus of control was defined as the extent to which an individual believes that their health is controlled by chance, for example luck or fate (Rotter, 1966). Avoidant coping strategies were associated with poorer social functioning HRQoL, although the

methodological design for this study was rated as weaker for the purposes of answering this review's question (Tomberg et al., 2007).

In relation to social factors, Williamson et al. (2011) found lower satisfaction with the family was related to poorer HRQoL and Tomberg et al. (2007) reported that greater social support was associated with better overall HRQoL.

### 3.5. Synthesis of Results

A theoretical diagram synthesising and summarising the key results is outlined in Figure 2. As outlined in the diagram, not all factors predicted overall long-term HRQoL, but rather some were predominately associated with either 'mental' or 'physical' HRQoL. Hypothesised relationships between level of awareness and other factors are included and explored in the discussion.



*Figure 2. Theoretical synthesis of findings. Note. Thin solid lines denote the associations found in this review, thicker lines represent stronger evidence based taken from studies rated as being of 'good' quality. Dotted lines denote hypothesised associations identified through related literature. The bullets points represent evidence that was either mixed or not strong enough to include in the model*

## 4. Discussion

### 4.1. Summary of evidence

This systematic review sought to review the literature on factors predicting long-term HRQoL in adults with a TBI and to evaluate this evidence using a narrative synthesis approach. The systematic reviewed identified 16 longitudinal observational studies that met criteria. The quality rating of the studies ranged from poor to good, although only three studies were considered 'good' quality. There was a large amount of heterogeneity in the study designs, aims and results. It is therefore difficult to draw firm conclusions, however a general pattern of findings has emerged from the results, which supports a biopsychosocial perspective on factors that predict long-term HRQoL after a TBI.

Depressive symptoms, levels of cognitive, physical and community functioning and age appear to have the strongest links to long-term HRQoL after a TBI. However, the interplay of factors is complex and it is likely that there are a number of confounding factors that were not identified in the reviewed studies. These issues should be considered when developing a predictive model of long-term HRQoL.

#### **4.1.1. Psychological factors.**

Some of the strongest evidence was for the role of depression in negatively affecting long-term HRQoL; this link was particularly strong to mental HRQoL. This is consistent with current understanding of the impact of depression, whereby symptoms of depression, such as low mood, lack of motivation and tiredness influence a person's subjective experience of their quality of life. Gaynes, Burns, Tweed and Erikson (2002) found that depression can exacerbate the effects of existing generic medical conditions; it theoretically follows that depression may also amplify the effects of TBI and impair HRQoL.

Acquiring a TBI is considered a risk factor for depression and other psychiatric conditions in itself (Kim et al., 2007; Kreutzer, Seel & Gourley, 2001). However, not all individuals with a TBI become depressed and factors associated with the development of depression after a TBI were not frequently investigated in the reviewed studies. There was some evidence suggesting that pain and impaired functioning may indirectly affect HRQoL through depression after a TBI (Williamson et al., 2011). Discharge to a nursing home and psychiatric rehabilitation were also found to be linked to long-term depression in one of the reviewed studies (Grauwmeijer et al., 2018). However, this would need to be studied further before being linked to HRQoL.

Given the high rates of depression among those with a brain injury, "diagnostic overshadowing" may need to be considered, whereby depression after a TBI is considered a normal reaction to a devastating event. This can result in a lack of treatment, potentially worsening the depression (Diaz et al., 2012). Future research may benefit from investigating the indirect effects of certain factors on

HRQoL through depression so that predictors of depression over the longer-term may be identified.

Outside of HRQoL, research investigating the rates of depression in TBI patients suggests that a pre-morbid history of depression may be a significant risk factor for depression up to 12 months after injury (Bombardier et al., 2010). Ownsworth and Oei (1998) developed a model which indicated pre-existing psychiatric conditions, left anterior region injuries, poor insight into deficits and attempts to resume pre-injury roles leading to significant failure were associated with depression after TBI. Malec, Brown, Moessner, Stump and Monahan (2010) also found a link between depression after TBI and functional ability and self-appraisal. Unfortunately pre-morbid depression was not modelled in the studies included in the current review, and so the findings cannot be extended to HRQoL.

The role of other psychological factors beyond mental health were not as frequently investigated in the reviewed studies, and the limited evidence as to the role of health locus of control and coping strategies in predicting HRQoL should be expanded upon. There is a long-existing body of evidence that coping and locus of control influences other emotional outcomes in brain injury (Godfrey, Knight & Partridge, 1996; Moore & Stambrook, 1995). Self-blame, denial and worry have been associated with both anxiety and depression post-TBI (Curran, Ponsford & Crowe, 2000). Coping strategies have found to influence outcomes (Moore & Stambrook, 1995; Anson & Ponsford, 2006).

Adopting particular psychological stances or strategies may influence the extent to which individuals can adjust to changes post-TBI. It has been suggested that avoidant coping strategies are safety-seeking behaviours in that they help the

person with TBI to avoid perceived personal or social threats and maintain an identity coherent with their pre-injury self (Gracey, Longworth & Psaila, 2016). However, over the long-term avoidance prevents engagement in meaningful social activities or opportunities to relearn skills, thus affecting outcomes (Gracey et al., 2015).

Tomberg et al. (2007) found similar results between avoidant coping and HRQoL. However, they also highlighted that those with better earlier physical HRQoL and higher level of sociability were more likely to later use task-focused coping. Those with disputes within the family were more likely to use avoidant strategies. This is consistent with findings elsewhere in the literature that suggest that social group membership is adaptive post-brain injury not only due to emotional support, but because of the instrumental and practical support others can offer (Haslam et al., 2008). Thus, the quality of social support after a brain injury may influence the coping strategies that people adopt after a brain injury, which in turn may impact on HRQoL. However, due to methodological considerations, further rigorous, prospective research is needed to establish this link.

#### **4.1.2. Biological factors**

The extent to which individuals may be able to use or learn psychological strategies may be influenced by the severity of their injury and subsequent cognitive ability. Interestingly, GCS did not appear to consistently predict HRQoL in the reviewed studies and when it did, the direction of the effect varied. Other studies have suggested that both social and personal factors may mediate the impact of injury severity on other measures of wellbeing (Jones et al., 2011). Contextual factors may therefore also reduce the perceived impact of brain injury symptoms,

which may explain the general lack of association found between injury severity and HRQoL in the current systematic review.

Although it is generally accepted that more severe injuries are generally more likely to result in poorer neurocognitive functioning (Dikmen, Machamer, Powell & Temkin, 2003), TBIs are highly heterogenic in nature. There are varying effects of injury severity, dependent on the specific neurological pathways affected. Thus, diffusion and location of the injury within the brain could potentially differentially affect HRQoL across different domains such as cognition or physical ability (Lingsma, Roozenbeek, Steyerberg, Murray & Maas, 2010). Theoretically, this could contribute to the lack of direct effect between injury severity and HRQoL observed in the reviewed studies.

Poor awareness, for example, may mediate the impact of injury severity on HRQoL. A significant number of individuals with moderate-severe TBIs appear to struggle with some aspects of awareness into the impact of their injury (Morton & Barker, 2010). In other studies, lack of insight has been viewed as a protective factor for HRQoL after the first year of injury (Sasee et al., 2016). Over the long-term, however, it can lead to repeated failure to achieve unrealistic goals, thereby causing repeated negative feedback and poorer outcomes (Ownsworth & Clare, 2006). In relation to HRQoL, people with awareness deficits may have difficulty attributing their difficulties to their brain injury thereby resulting in higher HRQoL than those aware of the challenges they face as a consequence of their injury. However, none of the studies investigated awareness deficits in this review. Future studies therefore need to consider the impact of awareness deficits on HRQoL.

Interestingly, duration of post-traumatic amnesia, which has been considered as a measure of injury severity (McMillan, Jongen & Greenwood, 1996), was more strongly linked to long-term HRQoL in the reviewed studies. It is therefore arguable that multiple measures of injury severity may be best placed to predict long-term HRQoL. One example of this is the Mayo Classification system (Malec et al., 2007) which assesses injury severity according to a number of different markers, including GCS, PTA and loss of consciousness.

Younger age at injury appears to be associated with better physical HRQoL. However, it should be noted that even within the general population, lower age is associated with better HRQoL (Huber, Felix, Vogelmann & Leidl, 2017) and so this result should be interpreted with caution. There was a broad trend for women to experience poorer HRQoL over the long-term. Females were underrepresented in the sample, however this may be due to the increased prevalence of males with a TBI rather than a skewed sample (Slewa-Younan et al., 2008).

#### **4.1.3. Independence, social and cognitive functioning.**

Other areas of functional ability at different stages of injury also appeared to be strong predictors of long-term HRQoL. Impaired functioning, especially in terms of cognitive and physical independence and community integration, was predictive of long-term HRQoL. It is possible that lack of independence and poor community integration affect individuals' sense of self-efficacy, identity and belonging. This is consistent with the social identity theory which suggests that a person's identity is derived from group membership (Tajfel, 1979). Having a valued, integrated identity after a TBI is closely linked to feeling as though one has a valued place in the world, feeling autonomous of oneself and one's future and social engagement with others



(Levack et al., 2014; Jetten, Haslam & Haslam, 2008); poor functional ability could interfere with this by hindering opportunities to access chances that would typically help a person reconnect with or adjust their identity. This is important because establishing a coherent post-injury identity may be associated with post-traumatic growth, the experience of positive psychological change after injury (Grace et al., 2015).

The results of the review also indicated that there are some social and demographic factors which may place certain groups of individuals at higher risk of experiencing poor HRQoL. Ulfarsson et al. (2014) suggested that individuals from poorer socioeconomic backgrounds face multiple risk factors from a biopsychosocial perspective that may make them both more vulnerable to a TBI and impede post-injury HRQoL. However, the findings of the role of education and employment, both markers of socioeconomic status, provided mixed results in their predictive power for HRQoL. Overall, there was stronger evidence for the protective role of pre-morbid employment on post-injury HRQoL than pre-morbid educational attainment.

There was mixed evidence as to whether HRQoL improves over time. However, closer inspection of these findings suggested that significant improvements in HRQoL were generally observed when the first year-post injury was included in analyses. Long-term findings which started recording HRQoL beyond one year of injury generally did not observe significant improvements in HRQoL. This suggests that there could be a 'plateau' in HRQoL, meaning that HRQoL appears to improve most rapidly during the first year post-injury and subsequently begins to stabilise after the first year. This is consistent with research that indicates recovery trajectories in TBI slow by the end of the first year post-injury (Christensen et al., 2008). As physical health plateaus, psychosocial factors,

which may influence the way in which individuals respond to their health difficulties, may be more influential across the long-term. This highlights not only the importance of early rehabilitation efforts for long-term benefits, but continued psychological support.

#### **4.2. Limitations**

There are a number of limitations of this review which should be considered. The decision to include only longitudinal studies, rather than cross-sectional studies, was made in order to identify higher quality studies that could identify predictors of long-term HRQoL. This was to help identify relationships between factors across time, assess long-term HRQoL and avoid the biases associated with measuring at one time point only.

However, it should be noted that a number of the studies, despite their longitudinal designs, measured some factors cross-sectionally. This was particularly the case for psychosocial factors; while injury-related factors were recorded at the onset of injury, thereby providing the 'longitudinal' design label, subsequent information regarding relationships between psychosocial factors and HRQoL were measured concurrently. Therefore, the relationship between some factors and HRQoL were not measured across time, which prevents the interpretation of temporal relationships. Given the emphasis on the importance of social contextual factors on adjustment to brain injury (Walsh, Fortune, Gallagher & Muldoon, 2012), developing the understanding of issues such as family and social support on HRQoL across time would be important.

The quality of these studies were therefore considered poorer than studies that analysed relationships prospectively across time. Less emphasis was

subsequently placed on these studies throughout the review. However, this does not mean that the findings from these studies are incorrect but rather that further research is required to help establish the validity of the findings across time.

Generally, the methodological quality of studies was rated as fair to poor. Small sample size was a common issue. These studies may not have had the power to detect significant effects of factors on HRQoL, particularly for detecting interactive effects of factors on HRQoL. None of the studies discussed issues of power or the limitations associated with small sample sizes. Lack of consideration of the impact of small sample sizes further reduced the quality rating of the studies. Future longitudinal studies should seek to justify their sample sizes and interpret results in the context of this so that more robust conclusions can be drawn from each study.

An additional consideration is that of causality. Causality is difficult to ascertain in observational studies. It is therefore quite possible that greater levels of HRQoL cause lower levels of depression or better levels of functioning, rather than vice versa. However, it is likely that the factors identified in the systematic review have a bidirectional influence on HRQoL, which would suggest that targeting them in interventions would remain beneficial to individual's HRQoL.

There is perhaps also more opportunity to consider a wider range of factors. With the growing interest in identity-related experiences, it would be of interest to consider whether identity-related measures, e.g. pre-post injury self-discrepancy, relate to HRQoL. Similarly, issues regarding self-awareness were not investigated in any of the reviewed studies. Consideration of both of these factors could help

contribute to the literature regarding the integration of social and neuropsychological perspectives (Walsh et al., 2012).

It is also noted that the majority of studies used generic measures of HRQoL, with only a few using brain-injury specific measures. Polinder et al. (2015) suggested that use of disease-specific instruments may allow for specific TBI-related health concerns to be explored e.g. memory difficulties, communication. Generic questionnaires on HRQoL do not capture these issues, and so some brain-injury related issues, such as fatigue and pain, may not have been thoroughly explored in the reviewed studies. Use of brain-injury specific HRQoL questionnaires could enable the ‘unpacking’ of HRQoL in order to determine the specific factors that may impair the improvement of HRQoL over time. This may make the tentative model outlined here more applicable to those with a brain injury.

The idea of ‘unpacking’ HRQoL perhaps highlights an issue with the term ‘HRQoL’ more broadly; as a multidimensional construct, it covers multiple aspects of a person’s life. It has been argued that the varying definitions of HRQoL mean that measures of HRQoL may actually measure different constructs e.g. health status, quality of life or self-perceived health (Karimi & Brazier, 2016). As such, results from studies are likely to vary dependent on the measure and type of HRQoL used. Greater consistency and agreement on what is meant by HRQoL may be needed in order for the concept to be of greater use. The future use of the QoLIRBI may in part help address this issue, as it specifically asks participants how ‘satisfied’ or ‘bothered’ they are by brain injury symptoms, rather than objectively assess health. This seems more in keeping with the WHO’s definition of HRQoL.

Another issue related to the use of generic measures of HRQoL and of the varying definitions of the concept mean that there is likely to be overlap between predictor factors and measures of HRQoL. Levels of depression and physical functioning, for example, may both share common factors with the mental and physical scales of the SF-36. Furthermore, the EBIQ assesses both cognitive and physical difficulties such as depression; as such the same or similar predictor factors are likely to have a significant association with such measures of HRQoL. While some studies acknowledged the overlap in the constructs, all the studies would benefit from discussing levels of collinearity further.

A meta-synthesis was deemed unsuitable to review due to the large variation in the studies aims, design and factors analysed. A narrative synthesis approach was therefore chosen as the preferred alternative. Although efforts were taken to reduce subjective bias, extracting information and placing emphasis on results will have been influenced by subjective views of relative importance to at least some extent. Narrative syntheses have been criticised for being opaque in their interpretations, which has led to questions about the validity of their conclusions (Campbell, Katikireddi, Sowden, McKenzie & Thomson, 2018). In order to address these concerns, the current study has followed the guidelines set out in PRISMA and used the STROBE framework in order to be transparent about the data analysed and the reasons for the quality ratings given.

Finally, it is acknowledged that only 50% of the studies included in this review were co-rated for quality. This could mean that the quality ratings provided are biased by the author's interpretation. The final rating on the QATOCCS is based on the rater's opinion on how much each point may influence the overall bias within each study, therefore being a subjective activity. Furthermore, quality ratings were

influenced by the extent to which they answered the review's question; this requires further subjective interpretation. Subjective interpretation of the quality of the evidence collected will have influenced the tentative model of factors predicting HRQoL outlined here, as evidence from 'good' rated studies were emphasised over lower-rated quality studies.

### **4.3. Conclusions**

There is evidence for the role of a range of biopsychosocial factors in predicting long term HRQoL in those with a TBI. The strongest evidence suggests depressive levels predict mental HRQoL and levels of functioning, particularly in terms of independence and community integration, predicting overall long-term HRQoL. It should be noted that these conclusions are influenced by the quality of the studies and so more emphasis has been placed on these findings. There was also evidence for male gender, younger age and pre-morbid employment acting as protective factors for HRQoL, with the first year post-injury being an important time-frame for early intervention.

These preliminary findings outline a broad profile of the risk factors associated with poor long-term HRQoL after a TBI. Early intervention could identify 'high-risk' individuals and target the malleable factors associated with HRQoL, such as community integration, family support and depressive symptoms.

Identifying factors associated with HRQoL, rather than relying on objective measures of functioning, will continue to delineate the meaningful and subjective experience of people with a TBI. Future research should focus on high quality longitudinal studies of HRQoL in order to build on the existing research, particularly the role of psychological factors such as coping strategies. Additionally, it may be

prudent to consider the role of awareness deficits and utilise brain-injury specific HRQoL questionnaires in order to capture issues that are relevant to those who have sustained a TBI. This may help to clarify and expand on the preliminary model reported in this review.

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## **7. Appendices**

Appendix A: Search terms for all databases.

Appendix B: Search Terms for PubMed

**Appendix A: Search terms for all databases.**

<b>PsycINFO:</b> (MA brain injur* OR SU brain injur*) AND (MA quality of life OR SU health related AND SU quality of life) [436 results]
<b>Web of Science:</b> (TS=(health-related quality of life)) AND (TS=(brain injur*)) OR (TI=(brain injur*)) AND LANGUAGE: (English) [360 results]
<b>PubMed:</b> ((((quality of life[MeSH Terms]) OR quality of life[Title/Abstract]) OR ((Quality of life[Title/Abstract]) AND Health-related[Title/Abstract]))) AND (((brain injuries[MeSH Terms]) OR brain injuries[Title/Abstract]) OR brain injury[Title/Abstract])) [983 results]
<b>CINAHL Complete</b> ([SU] brain injur* OR [AB] brain injur*) AND ([SU] quality of life OR TI health-related quality of life OR AB health-related quality of life) English language [723 results]

**Appendix B: Search Terms for PubMed**

Search no	Search terms and number of results
Participants	
<b>Search 1</b>	brain injuries[MeSH Terms]: 59262
<b>Search 2</b>	brain injury[Title/Abstract]: 50969
<b>Search3</b>	traumatic brain injury[Title/Abstract]: 28203
<b>Search 4</b>	brain injury [Title/Abstract] AND traumatic brain injury [Title/Abstract]: 50969 <i>Remove traumatic brain injury, does not render additional studies</i>
<b>Search 5</b>	brain injuries [Title/Abstract]: 5296
<b>Search 6</b>	traumatic brain injuries [Title/Abstract]: 1728
<b>Search 7</b>	(brain injuries[Title/Abstract]) OR traumatic brain injuries[Title/Abstract]: 5296 <i>Remove traumatic brain injuries, does not render additional studies</i>
<b>Search 8</b>	(brain injuries[Title/Abstract]) OR brain injury[Title/Abstract]: 53813
<b>Search 9</b>	((brain injuries[MeSH Terms]) OR brain injuries[Title/Abstract]) OR brain injury[Title/Abstract]): 84656
Outcome of interest	
<b>Search 10</b>	Quality of life[MeSH Terms]: 153956
<b>Search 11</b>	Quality of life [Title/Abstract]: 211669
<b>Search 12</b>	Quality of life AND health-related "[Title/Abstract]): 35868
<b>Search 13</b>	((quality of life[MeSH Terms]) OR quality of life[Title/Abstract]) OR ((Quality of life[Title/Abstract]) AND Health- related[Title/Abstract]): 263233
<b>Search 14</b>	((((Quality of life[Title/Abstract]) AND Health- related[Title/Abstract])) OR quality of life[MeSH Terms]: 165030
Study Design, Participants and Outcome of Interest	
<b>Search 15</b>	(longitudinal) AND brain injuries[MeSH Terms] 1381
<b>Search 16</b>	((((longitudinal) AND brain injuries[MeSH Terms])) AND quality of life[MeSH Terms] 81

	<i>Remove design as too few results</i>
Predictive Factors and Participants	
<b>Search 17</b>	(predictive) AND brain injuries[MeSH Terms] 2124
<b>Search 18</b>	(brain injuries[MeSH Terms]) AND psychosocial 673
<b>Search 19</b>	((predictive) AND brain injuries[MeSH Terms]) AND psychosocial 40 <i>Remove psychosocial as too few results</i>
<b>Search 20</b>	((predictive) AND brain injuries[MeSH Terms]) AND quality of life[MeSH Terms] 58 <i>Remove predictive factors as too few results</i>
Traumatic Brain Injury and Quality of life	
<b>Search 9 &amp; 13</b>	1639 results
<b>Search 9 &amp; 13</b>	with English language, species 'human' and 'adult' & 'adolescent' participants: 983
<b>Final search terms</b>	(((((quality of life[MeSH Terms]) OR quality of life[Title/Abstract]) OR ((Quality of life[Title/Abstract]) AND Health-related[Title/Abstract]))) AND (((brain injuries[MeSH Terms]) OR brain injuries[Title/Abstract]) OR brain injury[Title/Abstract])) Sort by: Best Match Filters: Humans; English; Adolescent 13-18 years; Adult: 19+ years 983 results

### **CHAPTER 3: Bridging the systematic review and empirical paper**

#### **Chapter Overview**

This chapter provides a summary of the systematic review and leads into the rationale for the empirical paper.

Word Count: 309

The systematic review considered the psychosocial, demographic and injury-related factors associated with long-term HRQoL in individuals with a brain injury. This indicated broad support for the biopsychosocial model. Such findings are important for identifying individuals who are at high risk of poor HRQoL.

Results such as these highlight that a number of individuals face enhanced risk factors that make them vulnerable to poor psychosocial outcomes post brain injury. The evidence that some individuals continue to experience poor HRQoL after brain injury highlights more to be done to understand the best ways in which to support individuals through the rehabilitation process and beyond.

In more recent years, neuropsychological research has highlighted the importance of identity-related issues in adjustment post brain injury. It has been suggested that identity may be a way in which to link together the social and neurobiological aspects of the biopsychosocial model (Walsh, Fortune, Gallagher & Muldoon, 2012), as sense of self and identity-related constructs are affected by both neurological damage and social, contextual factors. Furthermore, identity-related issues appear of importance to individuals post brain injury (Levack et al., 2014). As such, there may be particular utility in assessing identity-related issues and harnessing identity-related constructs as a medium for change (Ylvisaker McPherson, Kayes & Pellett, 2008). It would be of interest to identify whether identity-related constructs linked to health-related quality of life.

The empirical paper pilots a method, “the possible selves interview”, which has been used to analyse future self-identity in other clinical and non-clinical groups. The aim of the empirical paper is to assess the feasibility and acceptability of the possible selves method in those with a brain injury and provide direction for future

studies. This adds to a body of work regarding identity and ABI, which has a broader aim of improving the rehabilitation process and meeting the psychological needs of those with an ABI.



**CHAPTER 4: Empirical Paper**

**The Possible Selves of Individuals with an Acquired Brain Injury**

Prepared for Neuropsychological Rehabilitation

Word Count: 8000 (excluding references and appendices)

**The Possible Selves of Individuals with an Acquired Brain Injury**

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Word Count: 8000 (excluding references and appendices)

## 1. Abstract

Possible selves reflect future self-identity, providing concrete form to an individual's hopes, fears and expectations. They enable insight into aspects of motivation, adjustment and identity; key topics within the acquired brain injury (ABI) literature. The primary aim of this mixed methods pilot study was to investigate the feasibility and acceptability of the possible selves method in participants with an ABI for the first time.

21 participants with an ABI completed an adapted version of Clarke's (2016) possible selves interview and two questionnaires relating to health-related quality of life and current-ideal self-discrepancy.

All participants were able to describe some possible selves, although a large proportion of 'expected' possible selves were not given. Results indicated good inter-rater reliability of the coding and participant-rated acceptability of the method. Exploratory analyses revealed no significant associations between balance of possible selves, strategies to achieve hopes and brain injury possible selves enmeshment and psychosocial outcomes. However, when brain injury references were re-coded, participants who had 'pre-injury-focused' possible selves i.e. a focus to return to pre-injury functioning, reported higher levels of current-ideal self-discrepancy. Effect sizes are reported to provide future direction for hypothesis testing.

Future studies should look to refine the possible selves method as applied to those with an ABI. The results of the current study suggest that the possible selves approach could be a useful construct to explore identity and goal-setting in people with a brain injury.

Keywords: Acquired brain injury, possible selves, identity, pilot study, rehabilitation

## 2. Introduction

### 2.1. Acquired Brain Injury

The consequences of ABIs cause unique complexities in rehabilitation. Common neuropsychological deficits relating to attention, goal-directed behaviour, memory, language, planning, and emotion regulation may all interfere with patients' understanding and engagement across the rehabilitation process and beyond (Ylvisaker & Szekeres, 1989; Prigatano, Roueche & Fordyce, 1985). Individuals' capacity to benefit from rehabilitation efforts, and ongoing community support, varies in part because of these complications (Ponsford, 2013).

Goal-setting and attainment has been a widely used approach to provide structure to rehabilitation and evaluate its progress and outcome for people with a brain injury (Hurn, Kneebone & Cropley, 2006). The premise of goal-setting is largely based on Locke's (1968) theory on motivation which suggests goals direct attention and increase motivation towards a specified end-point.

However, much of the original goal-setting research was based on non-clinical populations who do not have the neurological impairments seen in those with a brain injury (Ylvisaker, McPherson, Kayes & Pellett, 2008). Therefore, despite being considered 'best practice' in rehabilitation, the most effective way to use goal-setting within ABI rehabilitation settings is poorly understood (McPherson, Kayes & Weatherall, 2009). Reviews of the use of different methods of goal-setting have indicated only short-term benefits during rehabilitation or little observed benefit at all in those with an ABI (Plant, Tyson, Kirk & Parsons, 2016; Levack et al., 2006).

Theories of self-regulation may be better placed to understand the conditions under which goal-setting may fail or succeed in individuals who have a brain injury.

Most theories of self-regulation highlight the important role of meta-cognitive skills, such as awareness, motivation and goal-directed behaviour, which can be harnessed to detect and reduce discrepancies between current and ideal states (Locke & Latham, 2002; Carver & Scheier, 1998). It is not uncommon for these cognitive abilities to be impaired in those with a brain injury, accounting for some of the observed difficulties with goal-directed behaviour (Whyte, Skidmore, Aizenstein, Ricker & Butters, 2011).

Theories of self-regulation also make a distinction between ‘higher-order’ and ‘lower-order’ goals (Emmons & Kaiser, 1996). Goals which are framed at a concrete level, with clear behavioural implications, are termed ‘lower order’ goals. ‘Higher order’ goals are more abstract and connected to a sense of identity and values (Emmons & Kaiser, 1996).

Some theories suggest that the goals that individuals generally engage with are derived from important aspects of the self, and new goals represent new ways in which core values of the self can be met (Brands, Wade, Stapert & van Heugten, 2012). In this way ‘higher order’ goals that link to a person’s identity may be as important as relearning skills for lower-order tasks. Arguably then, identity-related issues should be considered a cornerstone of goal-setting and attainment.

## **2.2. ABI and Identity**

The physical, social and cognitive changes that occur post-brain injury can disrupt self-experience and therefore identity. The perceived sense of ‘self-discrepancy’ that arises, particularly between current and pre-injury selves, is thought to negatively impact wellbeing (Gilligan, 2015; Cantor et al., 2005; Higgins, 1987; Tyerman & Humphrey, 1984). Discrepancy is maintained when individuals continue to seek unrealistic goals associated with their pre-injury identity. When

these goals are no longer attainable in the context of post-injury abilities, a negative feedback loop is created whereby attempts to attain goals are unsuccessful, resulting in poorer psychosocial outcomes (Cantor et al., 2005).

During rehabilitation, the pre-injury goals held by patients may be misaligned with clinicians' goals. Clinicians may take an 'expert stance' and facilitate goals that may be clinically important but are not consistent with patients' wishes. This may be especially prevalent in the brain-injured population, as neuropsychological deficits may interfere with a person's ability to articulate their wishes (Van den Broek, 2005).

It has consequently been argued that goal-setting should involve not only developing task-oriented skills (Hart & Evans, 2006; Emmons & Kaiser, 1996) but also understanding and developing a person's values, identity and personally meaningful goals (Ylvisaker et al., 2008). The identity-related literature suggests that goal-setting should aim to reconstruct a sense of identity through maintaining personal values and creating meaning for individuals post-ABI (Gracey, Evans & Malley, 2009). Better understanding how identity and goals relate to one another could help improve outcomes in those with an ABI.

### **2.3. Possible Selves**

One way to bring together aspects of identity and goals is through 'possible selves', a concept first introduced in Markus and Nurius' (1986) seminal paper. Possible selves are representations of the self in the future. They refer to the self-relevant cognitions of hopes, fears and expectations that individuals hold about their future and provide organisation and direction to these aspects of self-knowledge (Markus & Nurius, 1986).

Possible selves that are frequently activated in the self-knowledge component of working memory are thought to be relevant to self-representation and subsequent behaviour (Markus & Kunda, 1986). Salient possible selves are thought to promote striving behaviours towards goals and avoidance behaviours to prevent fears from being realised. Possible selves are self-evaluative as they are thought to highlight discrepancies between current and future selves, thereby promoting approach and avoidance behaviour (Markus & Nurius, 1986).

There are a number of means to measure possible selves, including closed questionnaires and open-ended interviews to elicit possible selves (Oyserman & Markus, 1990). Clarke (2016) used an open-ended possible selves interview based on the work by Oyserman and Markus (1990).

As possible selves are thought to be malleable, a number of studies have used these findings and applied various forms of possible selves methodology to enhance goal-attainment with the overarching aim of improving quality of life (Hoyle & Sherill, 2006; Oyserman, Bybee & Terry, 2006; Oyserman et al., 2004). As such it may be expected that aspects of possible selves may correlate with psychosocial outcomes.

### ***Balanced Possible Selves***

Oyserman and Markus (1990) proposed that a hoped-for possible self will have the greatest motivational influence when it is balanced by a feared possible self in the same domain, and vice versa. When possible selves complement each other in this way, they activate both approach and avoid mechanisms at the same time. Activation of both approach and avoid goals are thought to be more motivational than the activation of just one or the other (Nikitin & Freund, 2010; Elliot & Church,

1997). Frazier, Hooker, Johnson and Kaus (2000) suggested balanced possible selves represent more important and salient aspects of future-identity.

### *Plausible Strategies in Possible Selves*

Possible selves are also thought to have a greater motivational influence when they are accompanied by specific and plausible strategies that guide behaviour; such possible selves have been referred to as 'roadmaps' and have been associated with greater goal attainment. (Oyserman, Bybee, Terry & Hart-Johnson, 2004; Oyserman, Terry & Bybee, 2002). Furthermore, broadening the range of possible selves has been associated with more positive academic outcomes for students (Hock, Deshler & Schumaker, 2003). It could therefore be predicted that undertaking plausible strategies to achieve hopes may be associated with lower levels of current-ideal self-discrepancy.

### *Enmeshment in Possible Selves*

In the possible selves literature, enmeshment has been used to describe a high number of negative references to ill-health within reported possible selves following the onset of chronic illness (Morley, Davies & Barton, 2005). It has been suggested that possible selves that are 'enmeshed' with illness may be associated with less optimal adjustment to chronic pain and Alzheimer's disease (Morley et al., 2005; Cotrell & Hooker, 2005). Hoped-for and feared possible selves that both focus on declining health may be linked to unhelpful cognitive strategies such as rumination, rather than motivating behaviour (Smith & Freund, 2002). In brain injury, it is therefore possible that a high level of enmeshment is linked to lower levels of quality of life and greater current-ideal self-discrepancy.

## **2.4. Acquired Brain Injury and Possible Selves**



The possible selves construct brings together goal-setting, self-regulation and identity and therefore may be well placed to understand issues of adjustment and goal planning in those with an ABI. An understanding of the content and type of possible selves may provide meaningful information on the ‘motivational landscape’ of those with an ABI. Given the current issues surrounding goal setting in the ABI population, this is of clinical relevance. As possible selves are thought to be flexible, they could also offer scope through which to affect and direct change.

However, the possible selves construct has not yet been applied to individuals with a brain injury. There is uncertainty about the methods used to assess the content and nature of possible selves in people with an ABI due to the nature of the cognitive demands that may be involved, such as autobiographical memory, future thinking and executive functioning. Similarly, it is unclear whether the possible selves construct, in terms of the influence of ‘enmeshed’, ‘balanced’ and ‘road-mapped’ possible selves, influences outcomes in the same way it does in the non-brain-injured population that it has been tested on.

It is therefore important to establish the feasibility and acceptability of the approach in this population. Such a pilot study could delineate the feasibility of the methods and operationalise the key constructs within the possible selves theory, while also providing a first-look at the nature of the possible selves held by individuals with a brain injury.

## **2.5. Aims**

The current study therefore aims to undertake a pilot analysis to assess the feasibility and acceptability of the possible selves method when applied to individuals with an ABI. A secondary aim is to provide an initial description of the

content and types of possible selves held by people with an ABI. The following research questions are based on these aims:

1. Is it feasible to apply the possible selves construct to the ABI population? This question is answered in three parts:
  - 1.1 Are participants with a brain injury able to generate possible selves?
  - 1.2 Broadly, are the patterns observed in the possible selves literature between aspects of possible selves (balance, enmeshment and plausible strategies) and outcome measures (health-related quality of life and current-ideal self-discrepancy) observable in the brain injured population? It was expected that there would be an association between these aspects of possible selves and health-related quality of life and current-ideal self-discrepancy.
  - 1.3 What is the inter-rater reliability for the coding of the possible selves interview when applied to the brain injury population?
2. Is the possible selves construct acceptable for the ABI population group?

Participants will be asked a number of questions at the end of the possible selves interview regarding their experience of the possible selves interview.
3. What is the content of the possible selves of those with an acquired brain injury?

### **3. Materials and methods**

#### **3.1. Design**

A cross-sectional, mixed-method acceptability and feasibility design was best suited for the aims of the current study. Both qualitative and quantitative approaches answered the research questions regarding the nature of possible selves and the feasibility and the acceptability of the approach within the brain-injured sample.

Descriptive, correlational and independent measure designs were utilised to answer the first two research questions regarding the feasibility and acceptability of applying the possible selves construct to those with an ABI. For the final research question, content analysis was used to determine the nature and content of the possible selves reported. Initial content analysis was based on Clarke's (2016) manual, which provides scoring of a semi-structured possible selves interview. Further inductive content analysis completed to assess for sub-domains within these themes. Content analysis was chosen as this employs a low level of interpretation (Sandelowski & Barroso, 2003).

### **3.2. Participants**

Participants were individuals who had sustained an ABI and were at least one year post-injury. Participants were recruited between May and October 2018 from two NHS community brain injury services and one third-sector organisation.

Inclusion criteria were as follows:

- Participants with a diagnosed ABI. For those with a traumatic brain injury (TBI) this had to be a moderate-severe brain injury, as classified by the Mayo Classification system (Malec et al., 2007). Under the Mayo Classification System, moderate to severe TBIs are defined as 'definite' TBIs. Definite TBIs are injuries whereby the individual had a Glasgow Coma Scale (GCS) of 12 and under, loss of consciousness for 30 minutes or more and post-traumatic amnesia lasting for 24 hours or more.
- Age 18 years and over
- Participants had to be at least 1 year post-injury. Recovery rates slow considerably after one year meaning there is a clearer understanding of functioning post-injury (Chamberlain, 2006).

Exclusion criteria were as follows:

- A significant communication impairment that compromised ability to verbalise possible selves
- Mild TBIs, as defined by the Mayo Classification System: a Glasgow Coma Scale of 13 and above, loss of consciousness for less than 30 minutes, post-traumatic amnesia for less than 24 hours and no observable injury on brain scans
- Insufficient fluency in English to either understand or communicate aspects of the interview and questionnaires
- Lack of capacity to understand the nature of the study and to be able to give informed consent

Consistent with other research applying the possible selves construct to a novel population group (Bardach, Gayer, Clinkinbeard, Zanjani & Watkins, 2010), 21 participants were recruited. Participant demographics are reported in Table 1.

### **3.3. Materials**

#### **3.3.1. Possible Selves Interview.**

The possible-selves interview is an open-ended, semi-structured interview designed to elicit future self-representations about one's hopes, fears and expectations, initially developed by Oyserman and Markus (1990) and adapted by Clarke (2016). As per the protocol reported in Clarke (2016), participants were asked to generate three expected, three feared and three hoped-for possible selves. The possible selves were audio recorded and subsequently coded into one of five primary domains: personal development, possessions, interpersonal relations,

emotional/physical wellbeing or not given. Appendix A shows the possible selves interview form. Inductive content analysis was completed to identify sub-domains.

The coding manual in Appendix B provides the full details of the coding procedures, which were adapted from Clarke (2016) for use with participants with a brain injury. Participants were asked to detail any strategies they were currently undertaking, or planned to undertake, to help them achieve their hoped-for possible selves. A 'plausible strategy' score was calculated based on the number of plausible strategies participants were able to outline for each hope.

To assess enmeshment between possible selves and brain injury, the number of brain injury references during the possible selves interview were recorded. In order to control for verbosity, for each given possible self, brain injury references were rated as either present or absent so that no more than one brain injury reference per possible self was counted.

Balance was coded for hoped-for and feared-possible selves; each hoped-for and feared-possible self was coded as balanced if it was counterbalanced by a hope or fear in the same area. A total score of three (all hopes and fears balanced) was therefore possible.

Following the possible selves interview, participants were asked four questions to assess the 'acceptability' of the interview. These consisted of three Likert-scaled questions and one open-ended question: 1: It was easy for me to give answers to the interview; 2: I had no difficulty understanding what the questions meant; 3: I felt that the questions were important for people with a brain injury. These questions were scored between 1 (strongly disagree) and 5 (strongly agree). A final open-ended question asked participants whether they had any additional comments on the research interview.

### **3.3.2. Quality of Life after Brain Injury Questionnaire.**

The Quality of Life after Brain Injury Questionnaire (QoLIBRI) (von Steinbüchel et al., 2010) is a 37-item questionnaire that captures health-related quality of life (HRQoL) following a brain injury. The QoLIBRI was designed for use with people who have suffered a brain injury and provides an indication of the extent to which these individuals feel that the injury has impacted on their quality of life. The questionnaire consists of six scales which capture HRQoL across cognition, self, daily life and autonomy, social relationships, emotions and physical problems. The scale has been found to have good test-retest reliability (ICC = 0.91) and internal consistency (alpha = 0.95) (von Steinbüchel et al 2010).

Only the total score was used in the current study.

### **3.3.3. The Head Injury Semantic Differential Scale-III.**

The Head Injury Semantic Differential Scale-III (HISDS-III) (Tyerman & Humphrey, 1984) is a measure of self-discrepancy following a brain injury. Self-discrepancy can be measured between pre-injury, current and ideal states. The possible selves interview is concerned with future selves only. The HISDS-III was therefore selected in order to test validity of the possible selves methods and constructs against a measure that is validated in brain injury and associated with emotional outcomes, while also providing a rating of current self.

The HISDS-III lists 18 personal qualities, with each quality being made up of word pairs that reflect the positive and negative end of the spectrum i.e. 18 semantic differential items. Participants are asked to denote on a 7-point scale where they believe they fall for each determined state i.e. current, pre-injury or ideal self. It was developed for and is commonly used in the brain injury population (Ellis-Hill & Horn, 2000; Tyerman & Humphrey, 1984), making it suitable for the current study.

Ellis-Hill and Horn (2000) found a Cronbach's coefficient alpha of 0.93 indicating good internal reliability.

For the current study, participants were asked to rate attributes of their current selves and their ideal selves.

#### **3.3.4. Demographic information sheet.**

Participants were asked to complete a demographic information sheet which detailed their gender, age, type of injury, time since injury and marital status (Appendix C). If participants had a TBI they were asked questions about their injury severity and this was followed up with confirmation from the referring service, where possible.

#### **3.4. Procedure**

The principles of the British Psychological Society's (2010) Code of Human Research Ethics were applied to the development and undertaking of the current study. Ethical approval was sought and provided by an NHS Research Ethics Committee and the Health Research Authority.

Local collaborators identified suitable participants within the research sites and subsequently referred participants to the study after potential participants had given their consent to be contacted by the primary researcher. All participants were given an information sheet by local collaborators to help them decide whether they would like to be involved in the study, prior to being contacted by the primary researcher. Interviews were carried out by the researcher at the University of East Anglia, at the referring service or at the participant's home. The researcher completed all questionnaires and forms with participants in the research interview in written format. The possible selves interview was also audio-recorded to ensure accuracy of content.

Participants were shown all the session paperwork as a visual prompt to aid attention and memory throughout the interview. Information was given in simple and short sentences to support with any processing and working memory difficulties.

The order of completion for the possible selves interview and questionnaires was counter-balanced to account for order-effects. Breaks were given as needed to account for fatigue often experienced in those with a brain injury.

### **3.5. Data Analysis Plans**

Data were analysed using SPSS version 25 and Excel 2013.

Where relevant, distribution of quantitative data and identification of potential outliers were assessed through visual inspection of the data on stem and leaf plots and the Shapiro Wilk test. Levene's test was used to assess for equality of variance between groups. Non-parametric analyses were used when data did not meet the assumptions of parametric tests.

Where possible, effect sizes are provided in order to note the magnitude of hypothesised trends and provide direction for future research.

Data analyses are reported for each research question below:

- 1.1 To assess the ability of participants to describe possible selves, descriptive data on the numbers of possible selves reported are described. Descriptive data on balance of possible selves, brain injury references and plausible strategy scores are also reported.
- 1.2 Spearman's rank correlations were used to assess the relationship between aspects of possible selves (brain injury-possible selves enmeshment and plausibility score) and psychosocial outcome measures (health-related quality of life, as measured by the QoLIRBI and current-ideal self-discrepancy, as measured by the HISDS-III). Due to the low number of higher balance scores,



for the purposes of statistical analysis, balance scores were separated into ‘balanced’ (at least one balanced possible self) and ‘unbalanced’ (no balanced possible selves). A Mann-Whitney test was used to assess the differences on the same outcome measures between participants with ‘balanced’ and ‘unbalanced’ possible selves.

1.3 Cohen’s  $\kappa$  was run to determine the level of inter-rater reliability of the adapted coding manual. Categories of agreement were based on McHugh (2012). Inter-rater reliability was assessed for domain type, balance, plausible strategy score and brain injury references.

2. Descriptive data were reported to capture participant responses to acceptability questions relating to the possible selves method and construct in those with a brain injury.

3. The nature and content of possible selves were investigated primarily using content analysis. The content analysis used by Clarke (2016) identifies four broad domains of possible selves, plus a ‘not given’ category. The proportion of domains reported by each participant per type of possible self was calculated. For example, a participant with a proportion score of 0.66 for hopes in the personal development domain would have reported two hoped-for possible selves in that domain. This ensured independence of data to meet statistical assumptions. Comparisons of these proportions were compared using sign tests.

Further inductive content analysis of the domains was completed in order to identify sub-domains. Consistent with the conventional approach to content analysis, categories were derived directly from the data and pre-conceived themes were avoided (Hsieh & Shannon, 2005; Kondracki & Wellman, 2002). This approach was chosen due to the novel nature of the study and the lack of established theoretical

framework (Hsieh & Shannon, 2005). Broad codes were assigned to each possible self in order to identify the key theme of each possible self. Relationships among these codes were identified and from this categories were derived.

#### 4. Results

Participant demographics are reported in Table 1. The participant sample was heterogeneous, particularly in regards to age and time since injury.

Table 1  
*Participant Demographics*

	<i>Mean (SD)</i>	<i>Range</i>
Age	50 years (13.74)	25-76 years
Time since injury	10 years (8.08)	1-27 years
	<i>N</i>	<i>%</i>
Gender		
male	15	71.4
female	6	28.6
Cause of injury		
Stroke	12	57.1
Traumatic brain injury (severe TBI)	7	33.3
(moderate TBI)	6	28.6
Encephalitis	1	4.8
	2	9.5
Employment status		
Employed	3	14.3
Volunteering	5	23.8
Unemployed	7	33.3
Retired	6	28.6
Marital Status		
Married	3	14.3
In a relationship	2	9.5
Single	16	76.2

#### 4. 1. Is it feasible to apply the possible selves construct to people with a brain injury?

##### 4.1.1. Are people with a brain injury able to articulate their possible selves?

Overall, 138 possible selves were recorded out of a total possible number of 189. This was 73% of the total possible number of possible selves. All participants were able to generate at least two possible selves.

Across the whole sample of participants, the median overall number of possible selves given was 7. However, only six (28.6%) participants were able to generate all nine possible selves. Of these six participants, four had had a stroke, one encephalitis and one had suffered a moderate TBI.

One participant was unable to complete the possible selves interview due to memory and attentional difficulties. This participant had suffered a severe TBI 26 years ago and was unable to work. They self-reported significant executive dysfunction as a result of their brain injury.

Overall, 51 possible selves were 'not given'. 'Not given' possible selves were most common in the expected-selves domain ( $N = 31$ ) accounting for 60.8% of the overall 'not given' possible selves.

The median balance score was 1, comparable with the balance reported by Oyserman and Markus (1990). The most common balanced domains were interpersonal relationships ( $N=9$ ) and emotional and physical health ( $N=7$ ). These may reflect the more important aspects of future self-identity (Frazier et al., 2000).

The median plausibility score was 2.17, suggesting most participants were able to describe one strategy for each hoped-for possible self. Out of the 20 participants who described plausible hoped-for possible selves, only two participants were unable to describe any strategies to help them achieve those possible selves.

On average, individuals made nearly four brain injury references each and there were 0.56 brain injury references per possible self. Brain injury references were present in all types of possible selves.

#### **4.1.2. Do aspects of possible selves relate to psychosocial outcome in the brain injured population, as they do in other population groups?**

Exploratory, two-tailed tests were used throughout as directional hypotheses were not being investigated. One participant was removed from analysis, as they were unable to complete the possible selves interview or questionnaires. This left 20 complete sets of data to be included in the analyses. As outlined below, there was no significant association between aspects of possible selves (balance, enmeshment and plausible strategy score) and HRQoL or current-ideal self-discrepancy and the hypotheses regarding these associations were not supported.

*Is there a relationship between current-ideal self-discrepancy (HISDS-III score) and a) brain injury references b) plausible strategies to achieve hoped-for possible selves?*

Age and plausible strategy score had a significant association with HISDS-III current-ideal self-discrepancy score and were therefore controlled for. A partial Spearman's rank correlation did not show a statistically significant association between brain injury references and HISDS-III current-ideal self-discrepancy score  $r_s(16) = 0.23, p = 0.36$ , with the effect size being small. There was no significant association between HISDS-III current-ideal self-discrepancy score and plausible strategy score,  $r_s(17) = -0.41, p = 0.08$ , although a medium-large effect size was observed.

*Is there a relationship between health-related quality of life (QoLIBRI score) and a) brain injury references b) plausible strategies to achieve hoped-for possible selves?*

A bivariate Spearman's rank correlation found no significant correlation between QoLIBRI score and plausible strategies score,  $r_s(18) = 0.33, p = 0.16$ , with a

small effect size observed. A second Spearman's Rho correlation found no significant correlation between QoLIBRI score and brain injury references, and a negligible effect size was observed,  $r_s(18) = -0.10, p = 0.67$ .

***Is there a relationship between balance of possible selves and a) health-related quality of life b) current-ideal self-discrepancy score to achieve hoped-for possible selves?***

A Mann-Whitney test indicated that there was no significant difference between participants with balanced possible selves ( $mdn = 45.00$ ) and unbalanced possible selves ( $mdn = 23.00$ ) on HISDS-III current-ideal self-discrepancy score,  $U = 33.0, p = 0.32$ , a small effect size was observed  $r = -0.22$ . An independent-samples t-test indicated that there was no significant difference between QoLIBRI score between the balanced ( $mean = 48.27, SD = 18.74$ ) and unbalanced ( $mean = 58.39, SD = 22.80$ ) groups, ( $t = 1.07, p = 0.299$ ) and a small-medium effect size was observed-  $d = 0.44$ .

#### **4.1.3. Can good inter-rater reliability be established for the possible selves method in those with a brain injury?**

A second rater, with experience of rating possible selves interviews, also rated all possible selves for domain, balance, enmeshment (brain injury references) and plausible strategy score. This was used to determine the inter-rater reliability of the manual. The second rater used the manual to code and discrepancies were discussed and resolved. Sub-domains and themes, as are outlined later in this paper, were not second-rated as they were not a part of the manual.

To determine the inter-rater reliability of categories of possible selves, 50 codes of '0, not given' were removed from analysis, to avoid skewing the inter-rater reliability score. This is because these were already coded as 0 by the virtue of there

not being any data to code. Any articulated possible self was kept, even if it was subsequently coded as 0 e.g. because the meaning was unclear. This left 140 possible selves from 21 participants.

Table 2 shows the inter-rater reliability scores, which ranged from moderate-strong.

Table 2

*Inter-rater Reliability for the Different Aspects of the Possible Selves Interview*

Possible Self	Inter-rater reliability ( $\kappa$ )	$p$	Category of agreement
Categorical Domain	0.78	<0.001	Moderate
Plausible Strategy Score	0.81	<0.001	Strong
Brain Injury References	0.86	<0.001	Strong
Balance	0.90	<0.001	Strong

#### 4.2. Is the possible selves approach acceptable to those with a brain injury?

At the end of the possible selves interview participants were asked three Likert-scaled questions on their perception of the interview. Answers were scored on a scale of 1-5, from strongly disagree to strongly agree. Responses relate to the 20 participants who completed the possible selves interview and are reported in Table 3.

Table 3

Question	$M (SD)$	Range
1	3.55 (1.57)	1-5
2	4.00 (1.17)	3-5

3	4.70 (0.66)	3-5	<i>Participant</i>
<hr/>			<i>Responses</i>

*to Acceptability Questions*

*Note.* Question 1: It was easy for me to give answers to the interview; Question 2: I had no difficulty understanding what the questions meant; Question 3 was: I felt that the questions were important for people with a brain injury.

A final open-ended question asked participants whether they had any additional comments on the research interview. Most individuals opted not to answer this question, however those that did indicated that they found the interview to be a positive experience. The comments collected were:

*“The interview was quite long and I was feeling tired.”*

*“Would it be useful to ask what might help [people to achieve their hoped-for selves]?”*

*“I find it hard to understand things now, so the interview was difficult.”*

*“I see real potential and benefit in this study for me.”*

*“I liked talking about my brain injury. I would like to be expand my story and let people know what life is like after a brain injury”*

*“It was a good interview, it’s good to talk.”*

*“It was relevant and useful. This sort of research is important for modern therapy, something I have benefited from.”*

### 4.3. What are the possible selves described by people with a brain injury?

#### 4.3.1. Domains of possible selves (based on Clarke, 2016).

Table 4

*Reported Domains of Possible Selves Based on Clarke (2016).*

	Hoped-For PS		Expected PS		Feared PS	
	$N_{ps}$	%	$N_{ps}$	%	$N_{ps}$	%
<b>Personal Development</b>	27	42.8	11	17.5	3	4.8
<b>Possessions</b>	2	3.2	1	1.6	3	4.8
<b>Emotional/Physical</b>	18	28.6	14	22.2	19	30.1
<b>Wellbeing</b>						
<b>Interpersonal</b>	10	15.9	6	9.5	24	38.1
<b>Relationships</b>						
<b>Not given</b>	6	9.5	31	49.2	14	22.2

*Note.*  $N_{ps}$  refers to the number of possible selves. Percentages are given for proportion of total hoped-for, expected, and feared possible selves.

Table 4 highlights the domains of possible selves using the coding manual based on Clarke (2016). The most common domain of possible selves was ‘personal development’ for hopes, ‘unable to give/not given’ for expectations and ‘interpersonal relationships’ for fears. These results were further analysed to assess for statistical significance.

Sign tests indicated a significantly higher median proportion of hopes relating to personal development than both hopes relating to interpersonal relationships,  $p = 0.014$  and fears relating to personal development,  $p < 0.001$ . There was a significantly higher median proportion of fears relating to interpersonal



relationships compared to both fears relating to personal development,  $p = 0.002$  and hopes relating to interpersonal relationships,  $p = 0.012$ .

There was also a significantly higher proportion of expectations that were not given compared to hopes,  $p < 0.001$  and fears  $p = 0.013$ . These results indicate significant differences between the most prominent domains across hopes, fears and expectations.

#### 4.3.2. Inductive content analysis of possible self themes

Further inductive content analysis was conducted to explore themes within the domains that may be more specific and relevant to individuals with a brain injury. The results of the inductive content analysis are reported in Table 5. Appendix D provides a more detailed description of the identified sub-domains.

Table 5

##### *Themes from Inductive Content Analysis*

Domain <i>Sub-domain</i>	Hopes ( $N_{ps}$ )	Expectations ( $N_{ps}$ )	Fears ( $N_{ps}$ )
Personal Development			
<i>Employment/volunteering</i>	9	2	1
<i>Meaningful activities &amp; general skills</i>	14	4	1
<i>Rehabilitation and functional skills</i>	4	3	1
<i>Change in living arrangement</i>	0	2	0
Possessions			
<i>Ownership</i>	1	1	0
<i>Financial strain</i>	1	0	3
Emotional/physical wellbeing			
<i>General wellbeing</i>	7	5	7
<i>Brain injury-related health concerns</i>	3	5	8
<i>Return to pre-injury functioning</i>	7	1	0
<i>Have another brain injury</i>	1	1	3
<i>Post-traumatic growth</i>	0	2	1
Interpersonal relationships			
<i>Building relationships with others</i>	8	6	10
<i>Wellbeing of others</i>	2	0	4
<i>Others as a threat</i>	0	0	7
<i>Burdening others</i>	0	0	3
No possible self			

<i>Unable to give (self-reported)</i>	3	8	7
<i>Unclear meaning and unable to code</i>	0	1	0
<i>Not given</i>	3	22	7

Note.  $N_{ps}$  refers to the number of possible selves.

Of the personal development hopes, the most common sub-theme related to engaging in meaningful activities, including travelling and learning new skills, such as driving ( $N_{ps} = 14, 51.9\%$ ); finding a paid job or volunteering was also common ( $N_{ps} = 9, 33.3\%$ ). This is consistent with the high number of participants who were either unemployed or volunteering ( $N = 12, 57.1\%$ ) and it was common for participants to report that their brain injury had disrupted their occupational pursuits.

Within the wellbeing domain, the most common subdomain were hopes relating to general wellbeing ( $N_{ps} = 7, 38.9\%$ ) and hopes to recover fully ( $N_{ps} = 7, 38.9\%$ ). Some hopes also referenced concerns regarding desire to improve the physical and emotional symptoms of their brain injury ( $N_{ps} = 3, 16.7\%$ ).

Expected possible selves were harder for participants to articulate, with some participants ( $N = 7, 33.33\%$ ) indicating that they could not generate any 'expectations' at all. Some expected possible selves were not given due to self-reported cognitive difficulties ( $N_{ps} = 8, 25.81$ ) while the majority of expected possible selves were not given because participants reported that they did not have any expectations to give, without giving a clear reason why ( $N_{ps} = 21, 67.74\%$ ). Only one possible self was not interpretable due to an unclear meaning.

Interpersonal feared-possible selves were often related to fears of being alone and failure to create meaningful relationships with others ( $N_{ps} = 10, 41.7\%$ ), a similar number to the hopes to be in a relationship ( $N_{ps} = 8, 80.0\%$ ). Some participants recognised that their brain injury caused emotional dysregulation which they feared pushed people away.

#### 4.3.3. Possible Selves-Brain Injury Enmeshment

Although not initially planned in data analysis, it was decided to use the results from the inductive content analysis to compare participants who fell into different themes. Participants were categorised as ‘pre-injury-focused’ ( $N = 5$ ) when they indicated a preoccupation with a complete return to pre-injury functioning in all areas, in at least one possible self. ‘Improvement-focused’ participants ( $N = 7$ ) indicated a desire to show some improvement in brain injury symptoms but not a complete return to pre-injury functioning. A final group of participants did reference changes to their brain injury symptoms and these participants were categorised as “no change” ( $N = 8$ ). These three groups were compared on measures of HRQoL and self-discrepancy.

This analysis was chosen as it was felt these possible selves may reflect different levels of adjustment to injury and current-ideal self-discrepancy. It is acknowledged that these analyses are highly tentative, undertaken in an exploratory manner to identify potential direction for future research.

Two one-way ANOVAs were conducted to determine if health-related quality of life (QoLIBRI score) and current-ideal self-discrepancy (HISD-III score) were different between the “pre-injury-focused”, “improvement-focused” and “no change” groups. There were no significant differences on HRQoL between the ‘no change’ group ( $M = 55.09$ ,  $SD = 23.37$ ), the ‘improvement-focused’ group ( $M = 54.90$ ,  $SD = 18.23$ ) and the ‘pre-injury-focused’ group ( $M = 42.24$ ,  $SD = 18.43$ ),  $F(2, 17) = 0.722$ ,  $p = 0.50$ . A medium effect size was reported,  $\eta^2 = 0.078$ .

In the one-way ANOVA for current-ideal self-discrepancy, an outlier was detected prior to analysis; the ANOVA was run with and without this outlier. Removal of the outlier did not affect the detection of a significant result and it was therefore subsequently included in the analysis. There was a significant difference between HISDS-III score between the ‘no change’ group ( $M = 29.75$ ,  $SD = 19.30$ ), the

‘improvement-focused’ group ( $M = 27.71$ ,  $SD = 17.22$ ) and the ‘pre-injury-focused’ group ( $M = 61.40$ ,  $SD = 15.92$ ),  $F(2, 17) = 6.30$ ,  $p = 0.009$ , with a large effect size observed  $\eta^2 = 0.426$ .

Tukey post hoc analysis revealed that the mean difference in HISDS-III score between the ‘return to pre-injury functioning-focused’ group to the ‘no reference’ group was 31.65, 95% CI [5.58, 57.72], which was statistically significant, ( $p = 0.016$ ). The mean difference in HISDS-III between the ‘pre-injury-focused’ group to the ‘improvement-focused’ group and was 33.69, 95% CI [6.91, 60.46], which was also statistically significant,  $p = 0.013$ . There was no significant difference between the ‘no change’ group and ‘improvement-focused’ group,  $p = 0.974$ .

## 5. Discussion

The current study investigated the types of possible selves held by a small sample of participants with an ABI, aiming to assess the feasibility and acceptability of the possible selves methodology in this participant sample. A secondary aim was to provide an initial description of the possible selves held by people with a brain injury.

### 5.1. Ability to report possible selves

All participants were able to describe some possible selves. However, there was large variation in the ability to generate all nine possible selves asked of participants in the interview, and one participant was unable to complete the interview. Level of cognitive ability and neuropsychological consequences of brain injury are likely to have an impact on individual’s ability to describe and engage with their possible selves and associated strategies. Although cognitive ability was not formally assessed in the current study, a number of participants reported

cognitive difficulties that hindered their ability to articulate responses to the possible selves interview, despite adaptations to make the approach more suitable.

Difficulty in generating possible selves was especially prevalent for expected possible selves. Clarke (2016) reported a greater number of expected possible selves from participants with first-episode psychosis which suggests difficulty generating expected possible selves is not universal. This may be a feasibility issue of applying the possible selves method to individuals with particular neuropsychological profiles.

Analysis of the acceptability questions indicated most participants reported finding the possible selves interview easy to understand and relevant to people with a brain injury. Difficulty appeared to lie in generating answers to the possible selves interview. Attempting to generate expected possible selves may place an additional cognitive demand on executive functioning, over and above hopes and fears. Expectations have been thought of as 'ideal expectations' and 'predicted expectations' (Thompson & Sunol, 1995). The latter type of expectation relies on understanding of probability (Leung, Silviu, Pimlott, Dalziel, & Drummond, 2009) and access to autobiographic memory (Schroots, Dijkum & Assink, 2004), abilities often affected by a brain injury (Piolino et al., 2007; Stuss & Levine, 2002). This may in part account for the large number of 'not given' expected possible selves.

Given all this, the possible selves interview may need to be further adapted to facilitate the generation and expression of possible selves, particularly expected possible selves. In the current study, participants had the possible selves questions in front of them, as a visual prompt, and the options to write or verbalise responses were both available. In other studies, visual and gestural aids have supported the articulation of person-centred goals (Leach, Cornwell, Fleming & Haines, 2010).

Ylvisaker et al., (2008) used metaphorical identity mapping as a form of external graphical organiser to help individuals with TBI build a visual representation of their identity.

It could be possible to develop visual representations of possible selves, based on some of the metaphorical identity mapping ideas utilised by Ylvisaker et al., (2008). Alternatively, visual representations could be used to support the development of possible selves. The latter idea could, for example, help individuals map out their values and interests which could then serve as prompts to develop possible selves associated with these areas.

## **5.2. Review of the coding manual**

Inter-rater reliability of the coding of possible selves, based on the adapted manual, was generally strong, indicating the reliability of the manual to code different aspects of possible selves. The manual relies on contextual information to support the coding of the possible selves and it would be important to continue using this in ambiguous situations. Further flexibility may come in allowing multiple categorical domains to be coded for the same possible self which may improve the inter-rater reliability for the coding of categories.

There were no statistically significant results between psychosocial constructs (HRQoL and current-ideal self-discrepancy) and aspects of possible selves (balance, plausible strategies and possible selves-brain injury enmeshment) once age had been accounted for. However, the medium-large effect size observed between plausible strategy score and current-ideal self-discrepancy and the small-medium effect size between plausible strategy score and HRQoL may warrant further investigation in better powered studies. However, it is acknowledged that the small sample size in the current study may have inflated these effect sizes.

Only very small effect sizes were observed between outcomes and brain injury references. The methodology to code brain injury-possible selves enmeshment may need reviewing to detect differences in the type of brain injury references, rather than a simple numerical count. For example, a measure that takes account of positive-negative valence in brain injury references may be a more suitable way to consider the types of brain injury enmeshment.

Interestingly, when brain injury references within possible selves were recoded, those with a focus on aiming for pre-injury functioning' had higher levels of current-ideal self-discrepancy compared to those who made no references to changes to functioning and those who aimed to make some improvement to functioning. This suggests that possible selves could provide useful insights into the adjustment process, but the way in which brain injury references are coded needs to be amended to make it more nuanced and relevant. Furthermore, it supports the literature that understanding the personal meaning attached to the presence of brain injury symptoms within identity is important (Gracey, Longworth, & Psaila, 2016).

Balanced possible selves are thought to be important in identifying the most personally meaningful possible selves, while also motivating behaviour, thus helping to reduce current-ideal discrepancy (Frazier et al., 2000). However, in the current study, no impact of balance on self-concept or HRQoL was observed, and the association, although not significant, was in the opposite direction to that expected.

A high proportion of balanced possible selves focused on health-related content, consistent with findings in those with dementia (Hooker & Cotrell, 2005). Balanced hoped and feared possible selves that focus on returning to pre-injury levels of functioning, for example, may be personally meaningful, but may not also be plausible or reflect optimal adjustment. Repeated failure to achieve possible

selves in this way could result in more negative psychosocial outcomes, including rumination. The extent to which the concept of balance translates to clinical health populations could therefore be questioned, although to investigate this is beyond the scope of this pilot study.

### **5.3. Types of Possible Selves**

The type of possible selves described by participants indicated a large variety of domains and subdomains. Interestingly, there was a large variation in the domains and subdomains described across hopes, expectations and fears. Most participants' hopes related to personal development; finding employment or something meaningful to do with one's time, although these possible selves were not always well-defined. These sorts of hopes may be described in rehabilitation settings; findings elsewhere in the literature suggest that patient-driven rehabilitation goals tend to be broad, with a focus on return to function over the long-term (Brown et al., 2014).

However, these hopes were not matched by feared possible selves. A statistically greater proportion of feared-possible selves related to interpersonal relationships than personal development. Concerns around interpersonal relationships may be especially relevant for the current sample, most of whom reported being single. Interpersonal fears were distinguished from hopes by the number of fears specifically about the danger and judgement of others, indicating a level of distrust of other people or concern about stigma. Developing the therapeutic relationship in order to promote engagement during goal-setting may therefore be especially important.

However, there is a slight bias in the possible selves interview; the focus within the transcript of eliciting feared possible selves focuses more on 'being like'



rather than ‘doing’. It may be that participants were encouraged to focus less on personal development fears, which often reflect behaviours, and more on interpersonal fears, which may reflect more ‘being like’. This could also account for the lack of balanced possible selves. The provision of a prompt sheet indicating participants should consider what they might be like and/or be doing in the future could have addressed such biases. However, more systematic ways of addressing potential bias should be considered in future research.

In clinical practice failure to achieve rehabilitation goals is not uncommon (van den Broek, 2005). Given that feared possible selves were qualitatively different to hopes, it may be useful to consider feared possible selves, as well as hopes within rehabilitation. Feared possible selves may influence behaviour and emotional wellbeing in ways that are different to hopes. Holding a feared possible self may indicate that the fear is within the realms of possibility, or that the individual may feel that they are already engaging in behaviour that indicates they are capable of fulfilling that fear (Pierce, Schmidt & Stoddard, 2015). Consideration of feared possible selves could help to better understand the motivations and emotional wellbeing of those with a brain injury. Developing plausible strategies to avoid fears may be as useful as developing strategies to achieve goals.

Similarly, supporting individuals to move from an orientation of ‘pre-injury functioning focused’ to ‘improvement-focused’ may be useful to reduce levels of current-ideal self-discrepancy, which may have an impact on overall wellbeing. As malleable constructs (Markus & Kunda, 1986), possible selves may be a useful means through which rumination about preinjury functioning could be targeted.

#### **5.4. Limitations**

The exploratory approach in this study aimed to identify broad trends within the data, in order to establish preliminary feasibility of the possible selves method and provide direction for future studies. One of the challenges of this study was to balance the use of inferential statistics in order to highlight potentially interesting results against over-interpreting the data. However, it acknowledged that the use of a more liberal approach to analysis limits the interpretability of the results. In particular, there may be a number of confounding factors not identified or analysed that would account for the effect sizes and some of the findings reported here. The small sample size means that smaller effects will not have been identified as significant, and so there is a risk of type 2 errors.

The small sample size is also unlikely to be representative of the wide spectrum of ABIs. Although injury severity was recorded for participants with TBIs, the cognitive profile of participants was widely unknown. Similarly, type of stroke was unknown for some participants. It is quite possible that level of cognitive impairment and the type of brain injury sustained had a significant impact on the ability of participants to generate meaningful possible selves. It therefore remains uncertain what profiles of participants would be best suited to the possible selves interview. Furthermore, the study did not distinguish between types of ABI; to do so may be important for understanding the interaction between neuropsychological profiles and identity-related constructs (Walsh, Fortune, Gallagher, & Muldoon, 2012).

The current study assesses the possible selves methodology, not the possible selves theory. A more thorough investigation into how the possible selves theory translates to those with a brain injury is perhaps warranted. This is particularly

relevant as, while the possible selves theory has been used in clinical populations, many of the findings are based on non-clinical samples.

### **5.5. Conclusion**

The current study analysed the application of the possible selves methods to people with a brain injury. Results of this pilot study would suggest that the possible selves method is both feasible and acceptable to apply to individuals with a brain injury. However, there remains areas of the method that need to be further developed. Future research should focus on undertaking a larger-scale study, which could further develop the method outlined here.

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## **7. Appendices**

Appendix A: Possible Selves Interview (adapted from Clarke, 2016)

Appendix B: Possible Selves Coding Manual

Appendix C: Demographic Information Sheet

Appendix D: Description of Sub-domains of Possible Selves from Inductive Content Analysis

**Appendix A: Possible Selves Interview (adapted from Clarke, 2016)****Possible Selves Interview**

I would like you to think about yourself in the future. Who will you be in the future? Each of us has some image or picture of what we will be like and what we want to avoid being like in the future.

**Hoped-for Possible Selves**

Think about what you would **ideally like** to be doing or be like in the future. Please describe to me three descriptions of what you would like to be in the future:

I hope to:

Strategies for working towards future:

I hope to:

Strategies for working towards future:

I hope to:

Strategies for working towards future:

**Expected Possible Selves**

Think about what you expect to be like or be doing in the future. Please describe to me three **expectations** of yourself in the future:

I expect to:
I expect to:
I expect to:

**Feared Possible Selves**

In addition to expectations and expected goals, we all have images or pictures of what we don't want to be like; what we don't want to do or want to avoid being or doing. Describe ways in which you would **not** like to be in the future -- *things you are concerned about or want to avoid being like.*

I fear I will:
I fear I will:
I fear I will:

## **Appendix B: Possible Selves Coding Manual**

### **Coding Manual for Possible Selves**

Possible Selves will be coded for the following:

- Domain (from Clarke, 2016)
- Brain injury references (adapted from Clarke, 2016)
- Plausible strategies (adapted from Oyserman et al., 2004)
- Balance (Oyserman and Markus, 1990)

### **Domain and brain injury references coding (Clarke, 2016)**

#### **0 Not Given**

When the participant is not able to respond with any possible self then it is included in this group.

If the participant answers in the past or present tense, score 0 (if there is a clear indication that they are not talking about the future tense).

#### **1 Personal Development**

When the content of the possible self is related to any personal development it is included in this category. Development can be in any area in which learning or time spent planning or working is necessary. Personal development is defined as:

- Educational references either occupationally or for personal interests. (E.g. Hobbies, college/university courses, travel.)
- Occupational references. (E.g. Work, jobs, earning)
- Functional skills/learning skills for independence, completing rehabilitation

#### **2 Possessions**

When the content of the possible self relates to material possessions it is included in this category. Possessions are defined as the following:

- Ownership/lack of any material object (E.g. Home, car)
- Financial references (E.g. Money, debt)



### **3 Emotional/Physical Well Being**

When the content of the possible self relates to any physical or mental wellbeing it is included in this category. This includes emotionally related experiences and specific mental health concerns. This category includes the following:

- Feelings/emotions. (E.g. Being sad, happy, bad, lonely)
- Physical health. (Physical illness, injuries, severe accidents)
- Mental health references or brain injury references

\*An additional note should be made when a specific brain injury reference is made. Place a ‘\*’ in the designated column if present. Score a maximum of one brain injury references per possible self, even if the brain injury is referenced more than once per possible self. See brain injury references section below for further detail on coding.

### **4 Interpersonal Relations**

When the content of the possible self relates to other people it is included in this category. As well as references to relationships with family and friends this also includes being alone. This includes the following:

- Family
- Friends.
- Spending time with others

#### **Additional information on coding:**

- When rating the possible selves there should be as little subjective decision on the content of the possible self. Only rate the words, as they are in the possible self.
- If the participants refers to the past or present tense, score 0. There should be a clear lack of future thought to score 0.
- If the participant provides more than 1 possible self for each possible self asked for, code the first one given

### **Brain Injury References**

- An additional note should be made when a specific brain injury reference is made within the possible self.
- Brain injury references can also be made in the strategies for achieving hoped for possible selves
- Possible selves that are scored as 0 (e.g. because they are clearly not future-focused) cannot be scored as having a brain injury reference
- Score a maximum of one brain injury references per possible self (including strategies), even if the brain injury is referenced more than once per possible self and in strategies. The total brain injury references can therefore not be more than 9 (if 3 hoped, expected and feared possible selves are reported).
- Brain injury references may include the specific words ‘brain injury’ or ‘stroke’ or any other specific type of acquired brain injury, but may also include less specific references such as ‘disability’, ‘accident’ and ‘injury’ where these refer to the consequence of the brain injury. Consequences of brain injury are wide reaching and therefore could include ‘pain’, ‘memory’, ‘thinking’, ‘language’, ‘emotional dysregulation’, ‘awareness’ ‘mobility issues’ etc and should be coded as a brain injury reference
- References to changes to life or identity could also be considered a brain injury reference e.g. ‘Wanting life to be like *before*’. When unsure the context of the possible self and the strategy, if there is one, can support in making this decision.
- References that clearly refer to non-brain related consequences e.g. orthopaedic damage following a car crash, do not count as a brain injury reference. However, references to physical consequences as a result of stroke or traumatic brain injury do e.g. reduced movement in arm following stroke.

Use the context of the possible self and the participant to help guide this judgement.

- The number of brain injury references must be divided by the total number of possible selves to provide an average score.

### **Balance (Oyserman and Markus, 1990)**

Once the possible selves are coded into domains, participants will be coded for level of balance between hoped-for and feared possible selves, on a scale of 0-3. Each hoped-for possible self will be considered to be balanced if it is matched by a feared possible self in the same specific area. For example, a possible self would be considered balance if the hope fell into the domain of ‘wanting to get a job’ and the fear was ‘not having a job’. It would be considered unbalanced if the fear fell into the same broad domain i.e. personal development but related to another specific area e.g. I hope to learn to drive and I fear I will be able to complete my education. Each participant will be scored on a scale of 0-3, which 0 representing no balanced possible self and 3 being all three hoped-for possible selves matched by a fear. This is based on the procedure described by Oyserman and Markus (1990).

### **Plausible strategies (adapted from Oyserman et al., 2004)**

The Oxford Dictionaries (2018) define plausible as an ‘argument or statement seeming reasonable or probable’. This is an important construct, as it is thought that possible selves that detail plausible strategies offer better self-regulation and therefore help individuals to achieve their goals. The rater must decide, on balance, whether it would be probable or reasonable to expect that the strategy might help the individual to achieve or work towards their hoped-for possible self.

The rater should also consider whether the possible self is plausible. This is difficult to determine as the consequences of a brain injury are wide ranging and what may be achievable/plausible for one person may not be for another. Therefore, consider whether the participants believes the possible self is plausible. When the participant clearly believes the possible self is unachievable or where the possible self is clearly a physical impossibility then rate the possible self as implausible. In all other instances rate the possible self as plausible.

A procedure based on Oyserman et al. (2004) will be used to analyse number of strategies given. Participants will be allocated a score of 0-3 per possible hoped-for self.

- A score of 0 reflects no possible self and no strategy. Also score 0 if the possible self-described is not plausible. In order to determine this, consider from the strategy whether the participants believes the possible self is plausible using their strategies. If the participant is clear that they don't think the possible self is plausible, score 0. Additionally, if the possible self is clearly an impossibility (e.g. I want to live forever) score 0.
- A score of 1 reflects a plausible possible self with no plausible strategy
- A score of 2 reflects a plausible possible self with 1 plausible strategy
- A score of 3 reflects a plausible possible self with more than 1 plausible strategy.

A maximum score of 9 is therefore possible, based on a maximum score of 3 for each of the 3 hoped for-possible selves. The total score must then be divided by the number of hoped-for possible selves given. This provides an average score.

**Appendix C: Demographic Information Sheet**

**Demographic Information Sheet**

Age.....

Gender: Male/Female

Time since injury: Years.....months.....

Employment status: Employed            Volunteering            Unemployed

Marital Status: Single            Cohabiting            Married            Civil  
Partnership

**TBI patients only: Mayo Classification (Malec et al, 2007):**

(a) Moderate-Severe (Definite) TBI

(b) Mild (Probable) TBI

(c) Symptomatic (Possible) TBI

## **Appendix D: Inductive Content Analysis of Possible Selves – Description of identified sub-domains**

Descriptions of the subdomains that were identified from the inductive content analysis are provided below.

### **Personal Development**

#### **Employment/Volunteering**

Any possible self that refers to paid employment or volunteering. This may include beginning, maintaining or losing paid employment or volunteering.

#### **Meaningful Activities and general skills**

The broad concept is about doing something personally meaningful and developing personal skills (or fearing the loss of these things). This includes taking up, continuing or discontinuing hobbies; going on holiday or travelling; and learning new skills that are unrelated to rehabilitation of functioning skills following a brain injury.

#### **Rehabilitation and functional skills**

Referring to relearning, maintaining or losing skills as a consequence of brain injury. These references include engaging in rehabilitation or fear of loss of skills associated with brain injury. These refer to references of *skills* or rehabilitation exercises.

#### **Change in living arrangement**

Referring to moving elsewhere e.g. emigrating abroad, move to a care home. This does not include the *purchase* of a house.

### **Possessions**

#### **Ownership**

Referring to buying something or the hope/fear/expectation to own something in the future e.g. buying a house.

**Financial strain**

Referring to financial concerns, including the hope to address financial strains or the fear/expectation that financial concerns may arise in the future

**Emotional/physical wellbeing****General wellbeing**

References to health that are not explicitly related to having had a brain injury e.g. a hope to be generally well in the future

**Brain injury-related health concerns**

References to brain injury symptoms that are affecting either mental or physical health and the concern that these may continue to impact on emotional or physical wellbeing in the future, or the hope that their symptoms improve.

**Pre-injury functioning focused**

Referring to the hope or expectation of complete removal of all brain injury symptoms or a return to pre-injury life, or the fear that this will not be possible. This category does not include possible selves that refer to *improvement* of symptoms.

**Have another brain injury**

Possible selves that refer to the fear or expectation of having another brain injury, or the hope that this does not happen.

**Post-traumatic growth**

Attributing future positive changes specifically as a result of having had a brain injury

**Interpersonal relationships****Building relationships with others**

Referring to hope or expectation to forge future friendships, romantic or other relationships, or the fear that one will fail to do this or lose these relationships. This includes fears of being alone.

**Wellbeing of others**

Referring to concerns about the physical and emotional wellbeing of other people

**Others as a threat**

Referring to distrust of others or concern that others are a source of potential emotional or physical threat. Concerns regarding stigma from others.

**Burdening others**

Referring to concerns of being a burden to others in the future

**No possible self**

**Unable to give (self-reported)**

When no possible self is given because the participant indicates that they are unable to generate any or any more possible selves due to cognitive difficulties associated with their brain injury

**Unclear meaning and unable to code**

When the participant articulates a response to the possible self question but the interviewer is unable to understand the meaning of the possible self because the response is unclear.

**Not given**

When the participant does not articulate a possible self but does **not** indicate that this is because they are unable to do so because of their brain injury.



## **CHAPTER 5: Additional Methodology**

### **Chapter Overview**

This chapter details additional methodology not included in the main empirical paper. This includes a more detailed discussion about the ethical considerations of the empirical study and the process for deriving categories for the content analysis.

Word count: 1191

## **1. Ethical Considerations and participants**

As a pilot study applying the possible selves construct to people with a brain injury for the first time, careful consideration of methodology was required. A pilot study was selected as an ethical way of applying the possible selves construct to a novel population. This enabled a small sample of participants to be studied to ensure the feasibility and acceptability of the approach.

To develop a suitable and ethical pilot study using the possible selves approach, service users of brain injury support services were actively involved in the development of the research protocol. The current study contributes to a programme of work being undertaken on issues of identity and wellbeing following brain injury within the University of East Anglia. Previous discussions with people with a brain injury had therefore established that subjective sense of changes to identity is a significant concern, thereby providing an initial rationale for the acceptability and ethics of the current study.

Services users of brain injury groups were actively involved in developing the participant information sheet and consent form for the current study. Feedback suggested the need for easy-to-read information, including large font and use of short and simple sentences. Both service users and staff from local brain injury services suggested keeping the interview to a maximum of one hour, where possible. Included questionnaires were therefore kept to a minimum. Both the HISDS-III and the QoLIBRI were selected because of their validation with people with a brain injury and their relatively short completion time.

The nature of the current study meant that participants were asked personal questions which were potentially sensitive in nature. All referring services were given

the participant information sheet (Appendix A) and staff information letter (Appendix D) so that they were aware of the study parameters. Participants were approached by staff at the referring services and asked if they were interested in taking part in the study. If so, they were provided with information sheets and consent to contact forms. If these consent to contact forms were signed and returned to the primary researcher, participants were contacted via telephone by the primary researcher in order to discuss the study in more depth and determine whether they would still like to take part in the study. It was ensured that all participants had read the information sheet and all participants were given at least 24 hours to read the information sheet prior to the telephone call. At the end of the telephone call, if potential participants remained interested in taking part then a time and date was arranged to meet.

On the day of the interview session, participants were reminded again of the nature of the study. All participants were informed that they could withdraw at any time during the session and did not have to answer any questions that they did not want to answer. Participants signed the consent form on the day of the study, prior to commencing the interview. The consent form is shown in Appendix B.

A risk management protocol was developed (Appendix E) should participants become distressed or disclose any risk-related information. All interview sessions were conducted during the working hours of the referring service, so that staff were available to consult if necessary.

Participants were not paid for taking part in the study. However, they were asked whether they would like the chance to take part in a £20 Amazon voucher prize draw (Appendix C). At the end of the study, one participant number was

generated at random and the chosen participant was contacted via email. Participants were also asked whether they would like to receive feedback on the outcome of the study.

## **2. Process of deriving categories for content analysis**

This section of the chapter relates to the conceptual inductive content analysis that was completed to identify subdomains of possible selves, which aimed to complement the primary domains established by Clarke (2016). Primary domains (personal development; possessions; emotional/physical wellbeing; interpersonal relationships; not given) were coded using Clarke's (2016) approach and so the process of deriving these domains is not presented.

The aim of the content analysis was to establish subcategories of possible selves that could fit within the domains already established by Clarke (2016). This aimed to provide a more detailed insight into the possible selves of those with a brain injury. The coding of the content analysis was based on the eight principles outlined by Carley (1993). This process was used as a way to maintain rigour and trustworthiness (Bengtsson, 2016).

Transcripts of each given possible self were typed out so that analysis was completed for each given possible self. Phrases within possible selves were identified as the level of analysis. This was chosen in order to provide wider context than single words and enable identification of broader concepts (Carley, 1993). The analysis coded for existence, rather than frequency, of categories as many of the possible selves were quite short and so only contained limited content. Clarke (2016) indicated that, in the case that possible selves were longer, the primary domains should be based on the first category given, rather than the most common. All subdomains were therefore

also coded in this way. This ensured that the domains and sub-domains were consistent with one another. One sub-domain was identified for each possible self.

A level of implication was allowed so that words and phrases relating to the same topic could be coded under the same category e.g. ‘get better completely’ and ‘I hope to recover’ could both be categorised as ‘pre-injury functioning focused’. The transcripts of possible selves were condensed into key phrases to identify the meaningful aspects of the text. Irrelevant information was deleted. Key phrases were coded to concisely identify the condensed meaning units. This allowed comparison between the codes of different possible selves to be easily compared (Erlingsson & Brysiewicz, 2017). Comparison of the codes allowed identification of categories which broadly related to similar issues. Rules for categorisation were established in order to maintain consistency. An example of the process is presented in Table 1 below, demonstrating how two different but linked codes were categorised under the same heading.

Table 1

*Examples of Deriving Codes for Inductive Content Analysis*

Full possible self transcript	Honestly I expect long-term the health condition will always be there. I think any significant recovery or progress is behind me unfortunately. So that is factored into where I see myself.
Condensation	I expect the long-term health condition will always be there. Significant recovery or progress behind me.
Coding	Continued brain injury symptoms in future
Sub-domain (primary domain, possible self type)	Brain injury related health concerns (Emotional/physical wellbeing, expected possible self)

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Full possible self text	What worries me is, as I live on my own, if this gets worse, am I going to be immobile? Because I've got stairs, I am in a house. But you can go on and on, it's not helpful to worry about it
Condensation	If this gets worse, am I going to be immobile?
Coding	Decline in brain injury symptoms in future
Sub-domain (primary domain, possible self type)	Brain injury related health concerns (Emotional/physical health wellbeing, feared possible self)

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## **CHAPTER 6: Additional Results**

### **Chapter Overview**

This chapter relates to additional results from the empirical paper. Additional analyses on the possible selves is presented by type of ABI. Secondly transcripts are presented which provide examples of the possible selves given by participants.

Word Count: 1431

### **1. Possible Selves by type of ABI**

Number of overall and expected possible selves, balance and plausibility scores and brain injury references were investigated by type of ABI. Stroke and encephalitis participants were grouped together as ‘other ABIs’ due to the low number of participants with encephalitis, and the distinct neuropsychological profile often associated with TBIs (Levin & Krauss, 1994).

Due to the low number of higher balance scores, for the purposes of statistical analysis, balance scores were separated into ‘balanced’ (at least one balanced possible self) and ‘unbalanced’ (no balanced possible selves). Effect size was not possible to calculate for balance, due to the use of Fisher’s exact test.

Wilcoxon signed rank tests were used to investigate the association between type of ABI and overall and expected possible selves and plausibility score. An independent t-test was used to assess the association between type of ABI and brain injury references as the data met the necessary assumptions. Due to the nominal nature of the balance coding, Fisher’s exact test was used to assess the relationship between balance score and type of ABI.

As shown in Table 1 cause of ABI was not significantly associated with type or number of possible selves reported. However, there was a small-medium effect size of type of ABI on number of overall possible selves and number of expected possible selves.



Table 1

*Aspects of Possible Selves by Cause of ABI*

	TBI ( <i>N</i> = 8)	Other ABIs ( <i>N</i> = 13)	<i>P</i>	Effect size
	<i>Mdn</i> (range)			
Number of overall possible selves	6 (1-9)	8 (3-9)	0.14	<i>r</i> = -0.32
Number of expected possible selves	0.50 (0-3)	2 (0-3)	0.13	<i>r</i> = -0.33
Balance score	0 (0-3)	1 (0-3)	0.16	N/a
Plausibility score	2.33 (0-3)	2.00 (0.67- 3)	0.66	<i>r</i> = 0.10
	<i>M</i> ( <i>SD</i> )			
Brain injury references	0.55 (0.30)	0.56 (0.27)	0.84	<i>r</i> = -0.04

*Note.* Brain injury references are reported as mean averages per possible self, as per the coding manual.

## 2. Example transcripts from possible selves interview

### 2.1. Brain Injury-possible selves enmeshment.

Examples of brain injury references included:

Hoped-for possible self: “*To cure the physical consequences of my stroke*”

Expected possible self: “*I’m terrified of having another stroke. I think each one is usually worse. I’ve had two, realistically, you know...I do expect it.*”

Feared: *“I don’t want to be the person I was before the stroke which was....I wouldn’t say I was materialistic but I would say I was striving towards the wrong goals. Wealth doesn’t necessarily mean you’re successful. Position in society doesn’t necessarily mean you’re successful...or that you’re happy. I think I put too much priority on those goals beforehand.”*

## **2.2 Balance.**

Examples of balanced possible selves included:

Hope: *“To improve the way I am now to become more the way I was before this happened. I hope that physically I am better.”*

Fear *“If things stay as they are, if you come back in 6 months’ time, I fear I’m not going to be as I am now. I’m not as I was a year ago.”*

## **2.3. Plausibility.**

Example of a plausibility score of 3 (plausible possible self with at least two strategies attached):

*“Mainly to be happy, given my circumstances” with attached strategy: “One of the main things for me is sleep, so related to fatigue. So that’s all fatigue management or sleep and err managing that better because that has such a big impact on mood. My current strategy is really good. I’d say being active also helps. I’ve been very active over the past week and I took my bicycle with me to get there [holiday location]. From when I first did my physio diary it became very obvious that exercise improves mood and improves fatigue.”*

Example of a plausibility score 2 (plausible possible self with only one strategy attached):

*“To have movement in my right arm” with strategy “I have exercises to do from the physiotherapist. I keep to them.”*

Example of a plausibility score of 1 (plausible possible self but no attached strategy)

*“My ideal hope for the future is to meet someone who understands my brain injury. I have a brain injury and I have pain in my leg every day. I find it hard talking about things...I would like to meet someone who understand brain injury, if she’s a friend or a girlfriend. A friend would be more better because you can build on it.”* when prompted for a strategy *“No, been put off a bit and lost my confidence. My confidence is gone and it’ll take some getting back”*

Example of a plausibility score of 0 (non-plausible possible self):

*“Have a new body. I wish I could just not have this pain or this awkwardness of difficulty.”*

### **Assumptions for statistical analysis**

This section details how the data from the empirical paper was inspected for its suitability for different statistical tests. Non-parametric tests were selected when the data breached the assumptions required for parametric testing.

Table 2

#### *Assessment of Parametric Assumptions for Correlations*

Correlation	Outliers	Normal distribution of data (Shapiro Wilk)	Statistical test used
HISDS-III & brain injury references	Yes	$p > 0.05$ for both scales	Spearman’s rank

HISDS-III & plausible strategy score	Yes	Plausible strategy score $p = 0.025$	Spearman's rank
QoLIBRI & brain injury references	Yes	$p > 0.05$ for both scales	Spearman's rank
QoLIBRI & plausible strategy score	Yes	Plausible strategy score $p = 0.025$	Spearman's rank

None of the correlations met assumptions for use of parametric analysis due to the presence of outliers, ordinal data and non-normal distribution of some data. Spearman's rank correlations were therefore used. This was chosen as it is less affected by outliers, can be used when data is not normally distributed and is suitable for exploratory analyses (Gauthier, 2001)

Table 3

*Assessment of Parametric Assumptions for Statistical Analysis of Comparisons between Groups*

Grouped by	Outcome measure	Normal Distribution (Shapiro Wilk)	Homogeneity of Variances (Levene Statistic)	Outliers	Statistical Test used
Type of ABI (other ABIs & TBI)	Number of possible selves	'Other ABI group' $p < 0.05$	$p = 0.806$	Present in TBI group	Mann-Whitney
Type of ABI (other ABIs & TBI)	Number of expected possible selves	'Other ABI group' $p < 0.05$	$p = 0.650$	None present	Mann-Whitney
Type of ABI (other ABIs & TBI)	Plausible Strategy Score	Both groups $p > 0.05$	$p = 0.152$	None present	Mann-Whitney

Type of ABI (other ABIs & TBI)	Brain injury references	Both groups $p > 0.05$	$p = 0.940$	None present	Independent t- test
Balance (balanced & unbalanced possible selves)	QoLIBRI*	Both groups $p > 0.05$	$p = 0.716$	None present	Independent t- test
Balance (balanced & unbalanced possible selves)	HISD-III*	Both groups $p > 0.05$	$p = 0.525$	Present in balanced group	Mann-Whitney
Focus (pre- injury, improvement & no reference)	QoLIBRI*	All groups $p > 0.05$	$p = 0.653$	None present	One-way ANOVA
Focus (pre- injury, improvement & no reference)	HISD-III*	All groups $p > 0.05$	$p = 0.779$	Present in pre-injury focused group**	One-way ANOVA

*Note.* Non-parametric tests used where data are ordinal, have non-normal

distribution, outliers are present or there is insignificant homogeneity of variances.

\*Treated as continuous data for the purpose of statistical analysis \*\*One outlier was removed for testing and results on the ANOVA remained significant. It was decided that the score was a genuinely occurring score and was left in analysis as it did not impact the results' significance.

For the purposes of the statistical analyses, data from both the QoLIBRI and HISDS-III were considered continuous. This is consistent with research indicating that Likert-scale results can produce reliable results when used in parametric tests and when there are at least five data-points (Lubke & Muthen, 2004; Glass, Peckham & Sanders, 1972)

As show in Table 3, the majority of data did not meet the assumptions of parametric testing. Comparison of the 'TBI' and 'other ABI' groups on number of possible selves, number of expected possible selves and plausible strategy score were analysed using three Mann-Whitney tests, due to either the presence of outliers or non-

normal distributions. Comparison of HISDS-III scores between the balanced and unbalanced groups was also analysed using a Mann-Whitney test due to the presence of outliers.

There were outliers detected within the 'preinjury functioning-focused' and 'no reference' groups in relation to HISDS-III score, as indicated by inspection of boxplots. A one-way ANOVA was run with and without the outliers, with both ANOVAS remaining statistically significant. Further inspection of the data indicated that the data were genuinely occurring scores. The decision was therefore taken to include the outliers in analysis, using the ANOVA as the statistical test of choice. This is presented in the main empirical paper.

## **CHAPTER 7: General discussion and critical review**

### **Chapter Overview**

This chapter summarises the findings from both the systematic review and the empirical paper. A critical appraisal of themes within the papers is presented in the context of relevant literature

Word Count: 4083

## 1. Main findings

This section focuses on bringing together the main findings of both the systematic review and empirical paper and discussing this in light of recent literature in the area. Both papers link to ideas regarding self-identity and subjective reality and the extent to which brain injury related schema interact with these aspects of the self.

The systematic review highlights broad support for the biopsychosocial model of adjustment post-ABI, with a range of factors identified as predicting long-term HRQoL. As HRQoL reflects the subjective interpretation of the impact of a brain injury across a range of health-related domains, these are important findings. However, no identity-related constructs were included in any of the reviewed studies, despite identity-related issues being pertinent in both the ABI literature and rehabilitation (Ownsworth & Haslam, 2016; Gracey & Ownsworth, 2012). Many studies focused on demographic and injury-related factors, despite the growing evidence regarding subjective experiences and identity.

Identity-related issues may affect subjective interpretation of brain injury symptoms. Post-traumatic growth, for example, may be associated with positive changes to sense of identity, which may offset some of the negative consequences of illness (Park, Chmielewski & Blank, 2010). It follows that subjective experience of brain injury symptoms may also be influenced by the extent to which individuals are able to positively integrate their brain injury into their ongoing sense of self.

There therefore appears to be a gap in the literature assessing the relationship between identity-related issues and HRQoL over the long-term. However, it is possible that some of the factors identified in the systematic review link to identity-



related constructs. Social identity theory posits that health and wellbeing is strongly influenced by one's social identity and group membership (Jetten, Haslam & Haslam, 2012). In the current systematic review, depression, community integration and level of independence were important predictors of HRQoL. All these factors are associated with identity-related concepts; depression is closely linked to loss of or lack of social identity (Cruwys, Haslam, Dingle, Haslam & Jetten, 2014), while both poor functioning and lack of community integration may also affect group membership. It could therefore be hypothesised that some of the factors identified in the systematic review broadly link to group membership and therefore social and personal identity; it follows that a coherent sense of identity may link to HRQoL through group membership and social interactions. Jones et al. (2011) found that personal and social identity factors were able to buffer the impact of injury on life satisfaction; whether this is the same for HRQoL could also be ascertained.

Such research would support Ownsworth and Gracey's (2012) suggestion that a key aspect of rehabilitation should be social connection with others; they suggest that this provides the opportunities for individuals to re-establish self-representations and identities (e.g. Levack et al., 2014; Tajfel, 1979). Increasingly research is identifying the importance of social connection and participation for health and wellbeing outcomes after brain injury (Walsh, Muldoon, Fortune & Gallagher, 2015).

However, HRQoL as an outcome in relation to identity remains important to investigate further. Measures of HRQoL could be thought of as a more honest picture of quality of life than typical functional measures, e.g. depression inventories, which may make assumptions about the subjective impact of brain injury symptoms. Given the more recent emphasis on understanding the social

reality of those with a brain injury, it is arguable that HRQoL should be a key outcome measure in both future studies and interventions.

The possible selves methodology offers a means through which to analyse aspects of current and future identity. Themes of searching for meaningful activities and forging new relationships were relatively common in the possible selves reported by participants. Possible selves such as these may reflect the way in which individuals strive to re-establish their sense of self post injury, given the many changes that had occurred since acquiring their brain injury e.g. changes in the dynamics of their relationships, loss of work, changes to hobbies.

Furthermore, the empirical paper's findings suggested that individuals with 'preinjury functioning-focused' possible selves i.e. a complete focus to return to pre-injury lifestyle and functioning to the exclusion of other goals, experience the highest level of current-ideal self-discrepancy. This may suggest difficulty integrating aspects of their post-injury identity into their sense of self.

With further amendments to the possible selves methodology, it is possible the possible selves interview could be used in a larger, powered study as a means to assess links between identity and HRQoL. Furthermore, it could become the basis of interventions aimed at helping people to re-establish their identities post-brain injury. Although as highlighted in the empirical paper, it would be important to continue to validate and refine the method before large-scale longitudinal studies are carried out.

## **2. Evaluation of possible selves theory and health-related quality of life**

### **2.1. Critical discussion on health-related quality of life**

Historically, much of what was captured about recovery and adjustment after a brain injury was clinician or family-reported (Pagulayan, Temkin, Machamer &

Dikmen, 2006). There was therefore not the understanding of the personal impact of brain injury on functioning and quality of life.

However, this has begun to change and it is thought that clinicians and researchers are increasingly seeking to understand personal experience of brain injury, particularly to outcome interventions (von Steinbuechel et al., 2012). Quantitatively, HRQoL is a well-placed measure of patient-rated outcome because it describes the personal effects of brain injury on quality of life. As outlined in the systematic review, there is scope to develop models that highlight the interactive effect of biopsychosocial factors for predicting HRQoL outcomes.

Over the past decade, the growing interest in HRQoL has been reflected in the development of the QoLIBRI, a brain-injury specific measure of HRQoL. However, a number of the longitudinal studies outlined in the systematic review relied on generic measures of HRQoL, usually the SF-36. This may be because many of the longitudinal studies included in the review began recording outcomes prior to the introduction of the QoLIBRI.

Interestingly, Wilde et al. (2010) recommended the SF-36 as a measure of global outcome, but not as a measure of HRQoL. Carlozzi, Tulskey and Kisala (2010) compared qualitative themes of HRQoL generated by participants with a brain injury to constructs on generic measures of HRQoL. While they found some overlap between the qualitative and quantitative constructs, they suggested that the generic measures failed to capture the complexity of HRQoL after brain injury. Further to this, some authors have argued that the SF-36 is not a measure of HRQoL because it places a large emphasis on physical and emotional functioning, rather than the satisfaction associated with either of these areas (Guyatt, 1997). This is

problematic in the sense that this fails to capture a key aspect of subjective experience of brain injury.

Another issue with the reliance on generic measures of HRQoL is that such measures may capture the impact of pre-existing health complaints on quality of life because the items are not disease-specific. This may reduce the usability of such measures in targeted interventions during rehabilitation. The use of the QoLIBRI, or other brain-injury specific measures of HRQoL, therefore need to be translated over to longitudinal studies investigating factors relating to HRQoL. The tentative model outlined in the systematic review could perhaps be further developed with the use of brain-injury specific measures of HRQoL.

Dirven et al. (2013) critiqued the use of HRQoL as a measure in those with brain tumours. They highlighted the potential difficulty of using patient-rated data in situations where participants have severe brain injuries and associated cognitive impairments. The authors suggested the use of proxy-rated HRQoL to complement or replace patient-rated HRQoL. This decision needs to be balanced with the importance of understanding patient-perspectives. Furthermore, there are also risks associated with overreliance on proxy-measures; levels of agreement between patient and proxy quality of life ratings are not always good, particularly in those with more severe injuries or when HRQoL is neither very high or low (Hwang, Chen & Lin 2017; Brown et al., 2008; Sneeuw et al., 1998)

## **2.2. Critical discussion on possible selves theory**

The empirical paper set out to evaluate the application of the possible selves method to those with an ABI. This broadly highlighted the feasibility of the approach, but with the need for further development of the possible selves manual.

However, an evaluation of the possible selves theory was not within the scope of the empirical paper. Some of the observations within the empirical paper warrant a discussion within the context of the possible selves theory.

The idea of balanced possible selves requires some consideration. The term has largely been applied to non-clinical populations, with ‘academic’ possible selves of youths being a particular area of interest (Oyserman et al., 2006; Oyserman et al., 2004; Oyserman & Markus, 1990). Research has suggested that balanced possible selves are optimal for goal attainment and psychosocial outcome (Frazier et al., 2000; Oyserman & Markus, 1990).

The precise mechanism through which balance may affect change remains debatable (Clarke, 2016). Oyserman and Fryberg (2006) suggested that balanced possible selves provide a clear, positive goal to strive towards, while also making the consequences of failure salient to the individual. Oyserman and Markus (1990) also suggested that balanced possible selves enabled individuals to refine their strategies to achieve their possible selves, so that only the strategies that could be used to simultaneously achieve and avoid the possible selves are attempted.

However, not all studies find balance to significantly influence outcomes (Clarke, 2016; Oyserman et al., 2004). Part of the variation in findings could be due to the poorly defined definition of ‘balance’ and issues around its construct validity (Quinlan, Jaccard & Blanton, 2006). Balance has been differentially defined as matched hopes and fears, while others have defined it as matched positive expectations and fears (Clarke, 2016; Oyserman & Markus, 1990).

While there remains a question about the theoretical construct of balance, there is also a question around the extent to which it can be applied to clinical

populations, including people with ABI. Markus and Nurius (1986) argued that possible selves, since they are future based and so have not yet been realised, do not necessarily have to be within the realms of possibility. This arguably gives a far broader scope for future identity than both current and past identities. As discussed in the empirical paper, if possible selves focus on health-related content that is not feasible in the context of the person having a permanent disability i.e. recovery, then these possible selves move attainment out of the realm of possibility. Having ‘balanced’ possible selves that focus implausible hopes and fears could be viewed as maladaptive.

The extent to which the construct of ‘balance’ within the possible selves theory translates over to individuals with an ABI therefore warrants further investigation. As a starting point for future hypothesis testing, Cotrell and Hooker (2005) suggested that both a range of health and non-health possible selves may reflect optimal adjustment to dementia. This could also be investigated in relation to ABI participants. Should the null hypothesis, that having a range of health and non-health possible selves is not associated with adjustment to ABI, be rejected, then this could provide direction for interventions that look at ways to support people with a brain injury to expand their repertoire of possible selves and develop attainable ‘balanced’ possible selves.

### **3. Evaluation of general line of inquiry**

The International Classification of Functioning Disability and Health (ICF) (WHO, 2001) describes an integrated model of health. It reflects the move away from a disability-based view of health towards a more integrated biopsychosocial model which considers the impact of environmental and personal contextual factors

on health, rather than rely on diagnoses alone. Such a position is reflected in the more recent ABI literature, which has increasingly placed an emphasis on lived and subjective experiences and how this impacts on level of wellbeing and adjustment to brain injury (e.g. Yeates, Gracey & Mcgrath, 2008; Williams & Evans, 2003).

This thesis portfolio has sought to explore ways in which the subjective experiences of individuals with a brain injury might be further utilised in assessment and rehabilitation. However, when applying the ICF framework to ABI, how the neuropsychological and emotional consequences of an ABI affect the generation and expression of subjective experiences must be considered. This section therefore provides comment on the use of subjective experience to inform interventions more broadly in those with a brain injury.

### **3.1. Consideration of cognitive impairments**

A major consideration in exploring subjective experiences in those with a brain injury is the impact of self-awareness deficits and how this may influence self-report. In those with a brain injury, self-awareness can be defined as the capacity to recognise areas of difficulty or impairment through integrating external reality with inner experience (Fleming, Strong & Ashton, 1996). Since all measures and interviews depend to varying degrees on individuals being able to recognise and report on their subjective experiences, deficits in self-awareness can affect the validity of self-report measures. This needs to be considered, particularly when assessing the feasibility of a new method or when using subjective experiences to form the basis of interventions.

The injuries resulting from an ABI can have a significant impact on cognitive functioning and therefore self-awareness (Sherer, Madison, Hannay, 2000).

Executive dysfunction, passivity and lack of motivation are known issues in the ABI literature (Ylvisaker, & Szekeres, 1989; Powell, Al-Adawi, Morgan, & Greenwood, 1996) and may restrict the extent to which individuals are able to introspect or identify and pursue meaningful values and goals. Indeed such cognitive deficits have been identified as barriers to goal-setting and attainment in rehabilitation (Leach et al, 2010; Seigert & Taylor, 2004; Hanks, Rapport, Millis & Deshpande, 1999). At times, cognitive deficits may give rise to disparity between clinicians' level of motivation or perception of important goals and those of the clients.

A person's identity is also intertwined with a person's lived experiences. Autobiographical memory is key to identity (Rose Addis & Tippet, 2004) and therefore is important in being able to express identity-related ideas and beliefs. As described by Wilson and Ross (2003), 'we are what we remember' (p137); it is thought that loss of autobiographical memory could impact identity by interfering with the continuity of the self and our memories of who we are (Hirst, 1994). This could be a barrier for assessments and interventions that seek to place identity as a cornerstone to promoting adjustment to brain injury. In relation to the empirical paper reported here, for example, possible selves are contextual and linked to current self-identity (Markus & Nurius, 1986). Therefore cognitive deficits that create a vague sense of current self may impede ability to generate possible selves or impair the quality or elaboration of possible selves.

More broadly then, difficulty in accessing autobiographical memory may lead to the underreporting of symptoms 'in the moment', if specific incidents of difficulty are not encoded or recalled efficiently. Therefore, attempting to capture subjective experiences that consistently provide an indication of what is needed or valued can be complicated in those with a brain injury.



### **3.2.Consideration of emotional response to brain injury**

In addition to the cognitive deficits as a consequence of neuronal damage, psychological factors may also impede self-awareness and motivation to engage in rehabilitation. There is thought to be an emotional cost to articulating subjective experience after a brain injury. Gracey, Longworth and Psaila (2015) highlighted the importance of identifying the personal meanings and cognitive processes associated with changes caused by an ABI. They suggested a number of transdiagnostic processes underpin emotional distress in those with an ABI. These centred on the broad concept of ‘threats to self’ (Shields, Ownsworth, O’Donovan & Fleming, 2015). Situations which may challenge a person’s sense of coherence in relation to their social, practical or intrapersonal identity might be experienced as threatening and lead to defensive denial or avoidance. Gracey et al. (2015) posited this as a type of defensive strategy, which is used to avoid threats to one’s perceived social identity or personal standards and which may arise ‘in the moment’ as a threat is perceived, either consciously or unconsciously. In rehabilitation settings, this may therefore present as avoidance or minimising of difficulties.

Ownsworth et al. (2007) also identified a typology of awareness deficits associated with psychologically poor awareness as a result of a defensive strategy. They suggested that this was employed as a strategy to avoid the emotional distress of acknowledging deficits associated with ABI. Avoiding articulating difficulties or engaging in certain rehabilitation tasks may therefore be a defensive, protective strategy for some individuals, aimed at minimising perceived self-discrepancy (Gracey et al., 2009).

Such a response may be particularly relevant in those with low self-esteem (Riley, Dennis & Powell, 2010), or those with particular pre-injury coping strategies or pre-injury experiences leading to low trust in others (Gracey et al., 2015). It is also thought that defensive responses as described above have a bidirectional relationship to cognitive deficits (Krpan, Stuss & Anderson 2011). Situations that are stressful to manage as a result of cognitive deficits, and therefore represent a threat to the self, may therefore be managed by avoidance, which in turn reduces the ability to learn effective coping strategies.

The concept of ‘threats to self’ arguably overlaps with aspects of self-discrepancy (Shields et al., 2015). Such approaches would indicate the importance of identity-related constructs across the spectrum of rehabilitation in order to promote engagement and motivation.

### **3.3.Adaptations to rehabilitation**

Given the above concerns regarding ability to generate and express subjective experiences in those with a brain injury, the accuracy and reliability of self-report measures in this population has already been questioned and reviewed (Powell, Machamer, Temkin & Dikmen, 2001). Inability to recognise behavioural or social difficulties appears more common than difficulties recognising physical impairments (Bach & David, 2006; Prigatano & Altman 1990). This may mean that poor self-awareness may be a particular issue within neuropsychological rehabilitation, as this area of rehabilitation has a greater focus on intrapersonal and social adjustment than physical health. This may make collaboration and understanding of client need within rehabilitation more difficult. Indeed, poor awareness has been associated with

poorer outcomes in therapy and functional status, and difficulty in goal-setting (Fischer, Gauggel & Trexler, 2004; Trudel, Tryon, & Purdum, 1998).

Given this, and the additional difficulties in the brain injury population relating to both organic and psychological factors, the use of subjective experience in assessment, formulation and intervention in neuropsychological rehabilitation needs to be carefully considered within the broader biopsychosocial model. Clearly, the medical understanding and the viewpoints of staff and family members also need to be considered within rehabilitation, particularly in cases where there is suspected poor self-awareness. Including family members in rehabilitation and supporting healthy family functioning are thought to be important components for promoting positive outcomes in TBI participants (Foster et al., 2012; Sander et al., 2002).

However, it remains important in rehabilitation to understand how individuals understand and express their subjective reality, regardless of the extent to which this matches the external reality. This enables an understanding of how clients understand themselves, in relation to their goals and values as well as the meaning they place on their own identity and group identity (Ylvisaker et al., 2008; Walsh, Muldoon, Fortune & Gallagher 2017). While this also provides the opportunity to help individuals engage in meaningful functional activities, it may provide an indication of awareness difficulties, or the extent to which individuals have integrated the brain injury into their sense of self; this therefore provides a starting point in neurorehabilitation from which to understand motivations and current self-identity.

Such a position is also tenable because self-awareness is not thought to be all or nothing; self-awareness has been found to improve over time, particularly as

people return to their pre-injury environment and the changes that have occurred become more salient (Powell et al., 2001). This would indicate that individuals could be supported to develop their self-awareness, whether this be due to defensive factors or neurological damage or both. Indeed, motivational interviewing techniques may be well placed to promote self-awareness prior to engaging in therapy (Hsieh et al., 2012; Medley & Powell, 2010). Further to this, Cox et al. (2003) indicated that motivational interviewing helped clinicians understand brain injury clients' emotional needs on a more individual level, indicating further benefits of the approach.

Another consideration moving forward is the way in which individuals with a brain injury are supported to share their experiences and values, particularly in the context of neuropsychological impairment. Difficulty providing a response could theoretically be a greater issue for open ended or semi-structured interviews, such as the possible selves interview. This could be due to attentional, memory or other cognitive or emotional difficulties (Paterson & Scott-Findlay, 2002).

However, there is the opportunity to use the possible selves methodology and other interviews creatively in those with a brain injury. In clients with certain cognitive profiles, generating concrete forms to possible selves or other aspects of cognition may be difficult. Gracey et al. (2015) discussed the distinction made within the Interacting Cognitive Subsystems framework (ICS) (Teasdale & Barnard, 1993) between concrete, semantic meaning and autobiographical meaning amassed through multisensory input, termed 'propositional meaning' and 'implicational meaning' respectively. The authors indicated implicational meanings could be explored through 'felt senses' in therapeutic settings since some clients with a brain injury

may have difficulty expressing concrete cognitive ideas. They suggested visualization techniques may be useful with individuals with such cognitive profiles.

Such ideas could be applied to help understand the possible selves in this population group. Previous studies have supported the expression of possible selves through both imaginative (Murru & Ginis, 2010) and visual representation (Ylvisaker et al., 2008). The means through which interviews are adapted must not be prescribed, but instead person-centred and based on an understanding of the person's strengths and difficulties.

On questionnaires, difficulties expressing self representations may also be exacerbated by the use of generic measures of wellbeing which do not provide prompts to discuss issues relating specifically to brain injury (von Steinbüchel et al., 2010). As previously discussed, brain injury-specific measures may provide the scaffolding needed for some people with an injury to think about areas of difficulty that are associated with their brain injury. There may therefore need to be a move away from generic measures, towards brain-injury specific measures that help individuals with a brain injury provide more accurate pictures of their experiences.

### **3.4. Future directions**

There are challenges when working therapeutically with individuals with a brain injury. These include understanding subjective experiences and using this understanding to help individuals set and achieve meaningful goals.

More recently, it has been suggested that a transdiagnostic approach to understanding emotional distress post-brain injury may be beneficial to promoting wellbeing and supporting rehabilitation success (e.g. Gracey et al., 2015; Shields et al., 2015). This model places 'threats to self' as one of the common factors

underlying mental health difficulties such as anxiety and depression. Identity-related issues are therefore also key to neuropsychological rehabilitation. However, there remains room for a theoretically coherent model which is able to predict when or under what conditions differences in adjustment or rehabilitation success or failure may occur.

The introduction of the possible selves permits a person-centred yet conceptually coherent model to be applied in a way that integrates issues of goal setting, motivation for rehabilitation and identity. It permits a formulaic approach which is perhaps more suited to a transdiagnostic model of emotional wellbeing after ABI. The approach lends itself to this approach since it may provide a lens through which ‘threats to self’ can be explored. Such a model therefore provides space in rehabilitation to shape personally meaningful goals and develop strategies. At present, the literature deals with the issues of motivation, goal-setting and identity as parallel issues; the possible selves approach allows them to be conceptually integrated which could be of value to clinical practice.

It could also be argued that HRQoL could be used to identify ‘threats to self’ using quantitative means. In particular, the QoLIBRI questionnaire could be used to identify the specific areas of health that the client perceives has been most impacted by their brain injury e.g. cognitive, physical, relationships. In some individuals, this means of assessing ‘threats to self’ may be more suitable than open-ended interviews.

Continuing to explore subjective experience therefore remains important in rehabilitation, although necessary adaptations such as the use of brain injury-specific

measures and creative methods may be needed. In this way, it is possible to continue to explore and understand the best ways to support individuals with a brain injury.

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**Appendices for Overall Thesis Portfolio**

Appendix A: Participant Information Sheet

Appendix B: Participant Consent Form

Appendix C: Prize Draw Form

Appendix D: Staff Information Letter

Appendix E: Risk Management Protocol

Appendix F: Neuropsychological Rehabilitation Journal Instruction for Authors

Appendix G: Letter of Approval from Health Research Authority

## **Appendix A: Participant Information Sheet**

### **The Possible Selves of Individuals with an Acquired Brain Injury**

#### **What's the study about?**

- We would like to invite you to take part in our research study. We are looking for people with an acquired brain injury.
- The research is being done as a part of the researcher's doctoral clinical psychology course at UEA
- If you have been given this sheet then it's because your clinician/support worker thinks you may like to take part.

#### **What will the study aim to do?**

- The study would like 40 people with a brain injury to take part.
- The study aims to ask people about their hopes, fears and expectations for the future. Researchers haven't looked at this in the brain injury population before.
- We want to know if how people think about their future is linked to wellbeing in the present. We know that in some groups of people, how they see their future helps them in the present e.g. helps them achieve goals and helps them to adjust to illness. We want to know if this is the same for people with a brain injury.

- We want to know how people with a brain injury find answering questions about their future. If they find it doable, we could develop more research into talking about the future with people with a brain injury. This could lead to research which aims to help people with a brain injury to achieve more of their goals.

### **What would taking part involve?**

- You will meet the researcher at your local service, at the University of East Anglia or at your home for around an hour. However, we can take breaks if needed or have a longer or more than one session if needed.
- The researcher will ask you about your hopes, fears and expectations for the future. This is called the 'possible selves' interview. This part of the session will be audio recorded. The recording will be transcribed, removing any identifiable information. Recordings will be deleted after transcription.
- We are keen to know what your thoughts are on these questions, since 'possible selves' hasn't been explored in people with a brain injury before. We hope that your responses to the questions will tell us if it is feasible to do



more research on possible selves in those with a brain injury.

- Possible selves have been explored in people with other conditions, like dementia and chronic pain. It helped researchers learn about adjustment to illness. We hope that studying possible selves in people brain injury will also tell us about adjustment to the injury.
- You will also be asked to complete two more questionnaires that will ask you questions about yourself and your life.
- We will ask you if we can check your medical records that your support service hold on you, only to confirm your diagnosis and better understand what type of brain injury you have. This is your choice and if you do not want us to do this, you can still take part.
- Unfortunately, we cannot pay expenses for taking part. However, you will be entered into a £20 Amazon voucher draw as a way to say thank you for taking part.

### **Are there any benefits to taking part?**

- There are no direct benefits to taking part in this study. However, this is the first study of its kind to be done with people with a brain injury. The research could lead to future research that might help other with a brain injury.

**Are there any disadvantages to taking part?**

- The session will involve questions about hopes, fears and questions about you and your life. Some people may therefore find some of the questions to be sensitive. You do not have to answer any questions that you do not want to and are free to withdraw from the study before or during the session.
- Should you feel upset either during or after the session then we encourage you to seek support from either your care team or GP. We will also provide you with contact details of organisations that operate outside of normal working hours at the end of the session.
- You may feel tired during the interview. If this is the case we can stop at anytime to have a break. You can also do the interview over more than 1 session.

**What about confidentiality?**

- It is part of the law that we keep all information you give the researcher confidential. This means that no one outside of the research team will know your personal details or responses.
- Any personal information will be kept in a locked cabinet at the University of East Anglia. It will be destroyed as long as it is no longer needed.

- All of your responses in the interview will be anonymised. Your responses will be recorded by a random participant number instead of your name which means that your responses alone will not be able to identify you. Your responses will be kept for 10 years in line with the University of East Anglia's policy and then destroyed.
- Confidentiality will only be broken in the event that you give information to the researcher that would indicate you or someone else is at risk of harm. In this instance, the researcher has a duty of care to act in order to prevent harm.

### **What will happen after the session?**

- The research is being completed as part of the Clinical Psychology Programme at the University of East Anglia. The information collected in the interviews will be analysed and written up.
- It is planned that the research will be completed by May 2019 and will be submitted to the relevant research journal. There is the option, should you be interested, to receive feedback on the results of the study around this time point. We can send you a summary of the research.
- The study will be sent to a journal for publication and to research conferences. All personal information will be removed in all analyses, reports and publications.

- The prize draw for the £20 Amazon voucher will happen once the study is completed.

### **What if I would like to take part?**

- Whether you would like to take part is entirely your decision and you do not have to take part in this research. You may like to speak to your family, friends or a trusted professional to help you decide whether you would like to take part.
- Should you decide that you would like to take part then the professional who approached you with this information sheet will give you a consent form for you to sign. This consent form will indicate that you are happy for the researcher to contact you with a date for completing the session.
- You are free to withdraw from the study any time before the interview session with the researcher. After the interview your responses will be anonymised. It therefore will not be possible to withdraw your data from the study.
- The researcher will then contact you to arrange to meet with you at the referring service, at the University of East Anglia or at your home.
- There will be no impact on your medical care if you decide not to take part.

## Contact

For further information please contact:

Laura Barnes, Chief Researcher [laura.barnes@uea.ac.uk](mailto:laura.barnes@uea.ac.uk)

Dr Fergus Gracey, Supervisor [f.gracey@uea.ac.uk](mailto:f.gracey@uea.ac.uk)

In case of concerns or complaints please contact:

Professor Ken Laidlaw [k.laidlaw@uea.ac.uk](mailto:k.laidlaw@uea.ac.uk)

## Appendix B: Participant Consent Form

### Participant Consent Form

IRAS ID: 230004

Participant Identification Number:

#### CONSENT FORM

Title of Project: The Possible Selves of Individuals with an Acquired Brain Injury

Name of Researcher: Laura Barnes, Trainee Clinical Psychologist

Please initial:

1. I confirm that I have read the information sheet dated..... for the above study. I have had time to think about the information, ask questions and have had these answered well.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
  
3. I consent to the researcher accessing my medical records to confirm my diagnosis of acquired brain injury and to record clinical information relating to that diagnosis only.
  
4. I agree to the session being audio recorded, listened to only by the researcher and the anonymised transcript read by additional researcher at the University of East Anglia
  
5. I understand that all my responses will be kept confidential unless there is indication of harm to self or others, in which case the researcher will have a duty of care to report these concerns.
  
6. I consent to my General Practitioner being informed of my participation in the study
  
7. I understand that the data I provide will be anonymised and stored securely at the University of East Anglia in line with the Data Protection Act (1998).
  
8. I understand that data from this research session may be checked by auditors at the University of East Anglia to ensure quality of the research.

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

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person  
taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Appendix C: Prize Draw Form**

**The Possible Selves of Individuals with an Acquired Brain Injury**

Please initial as appropriate:

I would like to enter the prize draw for a chance to win a £20 Amazon Voucher

I would like to receive feedback on the overall findings of the study

I agree to my GP knowing about my involvement in the study

**Print Name:** \_\_\_\_\_

**Signed:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

**Name and address of GP** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



**Appendix D: Staff Information Letter**

Dear Staff Member,

**Re: The Possible Selves of Individuals with an Acquired Brain Injury  
Laura Barnes, Trainee Clinical Psychologist**

Thank you for taking the time to read this information regarding the above thesis and for your ongoing support with the project. It really is genuinely appreciated. The following outlines what the research study is about, what it involves and service users who would be eligible to take part.

What is the research about?

This research is looking at how people with an acquired brain injury see themselves in the future. We all have hopes, fears and expectations for how our future may play out; we may hope that we become a parent, or fear that we may be lonely. Our hopes, fears and expectations for ourselves in the future have been termed our 'Possible Selves'. Our possible selves our part of our identity, and have strong links to our motivation and goals.

There has been lots of research using possible selves in the past. Interestingly, in other groups of people, some types of possible selves are linked to better adjustment to illness. Some research has also found that some types of possible selves help people to achieve their goals. Both adjustment and achieving goals are relevant to the brain injury population, as a brain injury can understandably have a big impact on a person's sense of identity and this can affect people's motivation to achieve rehabilitation goals.

By looking at the possible selves of those with an ABI, we hope to learn more about what motivates people with a brain injury, and under what types of possible selves people with a brain injury experience a better quality of life and more positive sense of self. It is hoped that this will be relevant for services such as yourselves by providing insight into the 'motivational landscape' of those with an ABI.

The possible selves construct has never been applied to the ABI population before. This research study is therefore a small scale, pilot research study. It aims to collect initial findings around how people with a brain injury describe their possible selves. It also aims to investigate whether it is actually feasible to apply the possible selves construct to the brain injury population. It is hoped that this could lead to further research in the area, with data from this study informing it.

What does it involve?

I am looking to recruit around 40 participants from a range of NHS and non-NHS services who support people with any form of Acquired Brain Injury e.g. stroke, traumatic brain injury etc. The full inclusion and exclusion criteria is included on a separate sheet in this letter.

Should you know any service users within your service that you think may like to take part, then these participants may be approached and asked whether they may

like to be involved. Participants who want to take part must sign a consent to contact form which give permission for the researcher to contact participants directly. Participants can then be given a participant information sheet which your service should have. The information sheet explains the study.

Once these consent to contact forms have been signed, the researcher is able to contact participants directly. The researcher will contact the participant and explain the nature of the study, and confirm that the participant understands and consents to taking part.

Should the participant still wish to take part, then the researcher will arrange the research session. When the researcher meets with the participant for the research session, full informed consent will be gathered and an informed consent form signed. As a part of this, the researcher will seek consent from the participant for the researcher to check a recent assessment or discharge documentation held by your service (if applicable/held by your service) to confirm the type of diagnosis they have and clinical information associated with the diagnosis.

The research session will last for around 1-1.5hrs and involve participants answering questions about their hopes, fears and expectations for the future. This part of the session will be audio recorded. It will also involve answering two questionnaires, one on current quality of life and one on how close people feel to achieving their hopes for the future.

There are no direct benefits for participants, however all participants will be offered a chance to enter a prize draw to win a £20 Amazon voucher as a token of gratitude for taking part. Participants will also be asked if they would like feedback on the study outcome. Both the prize draw and outcome will be conducted around April 2019. All participating services will also be offered feedback on the study's findings.

Should you have any further queries then please do contact either:

Laura Barnes, Trainee Clinical Psychologist [Laura.Barnes@uea.ac.uk](mailto:Laura.Barnes@uea.ac.uk)

Dr Fergus Gracey, Consultant Clinical Neuropsychologist  
[Fergus.Gracey@uea.ac.uk](mailto:Fergus.Gracey@uea.ac.uk)

In case of complaints please contact: Professor Ken Laidlaw [k.laidlaw@uea.ac.uk](mailto:k.laidlaw@uea.ac.uk)

Yours sincerely,

Laura Barnes

Trainee Clinical Psychologist & Lead Researcher

## **Appendix E: Risk Management Protocol**

### **Risk Management Protocol**

- Risk management will be conducted throughout the study, during pre-screening conversations and eligibility criteria with referring services, screening, in session and post-session.
- All referring professionals will be informed of the eligibility and exclusion criteria, and will be advised that individuals should not be approached to participate should they present with any severe mental health condition or have a recent history of violence.
- All referring professionals will be aware of the nature of the possible selves interview and the questionnaires so that they can use their professional judgement when considering whether individuals would be suitable to participate.
- Consent will be sought to inform GPs of participants' involvement in the study.

### **In session or post-session risk**

- Should participants become distressed during the session, they will be responded to sensitively to check whether they are ok, a short break taken if needed and they will be reminded that they have the right to withdraw from the study during the session should they want. Participants will have the choice as to whether they would like to continue with the study or not.
- Should participants verbalise or behave in way that would indicate that the participants was at risk of harm from others or risk of harm from themselves or towards others then the person will first be reminded what they are saying

is concerning and might warrant the researcher to inform someone, due to concerns about them/others. If this continues then session will be aborted

- Participants will be advised to seek support from the appropriate service such as their care team, GP or organisations such the Samaritans
- The appropriate individuals within the referring service will be informed immediately
- The researcher's supervisor the University of East Anglia will also be informed immediately so that appropriate advice in the situation can be given
- All research sessions will be conducted within the working hours of the referring service so that staff at the site are available to support if needed. A buddy system will also be in place so that the researcher is in contact with another Trainee Clinical Psychologist before and after the research session. The buddy will contact the researcher should the buddy not hear from the researcher after 30 minutes of the session ending. Should the researcher not respond, the buddy will contact staff at the referring service.

**Appendix F: Neuropsychological Rehabilitation – Instruction for authors**

The screenshot shows the Taylor & Francis Online website interface. At the top, there is a blue navigation bar with the Taylor & Francis logo, 'Taylor & Francis Online' text, and links for 'Log in', 'Register', and 'Cart'. Below the navigation bar, the journal title 'Neuropsychological Rehabilitation > An International Journal' is displayed in a large, dark blue font. To the left of the title is a small thumbnail image of the journal cover. To the right of the title is a search bar with the placeholder text 'Enter keywords, authors, DOI etc.' and a dropdown menu labeled 'This Journal'. Below the title and search bar, there are five buttons: 'Submit an article' (green), 'Journal homepage' (blue), 'New content alerts' (blue with an envelope icon), 'RSS' (blue with an RSS icon), and 'Citation search' (blue with a quote icon).

**Instructions for authors**

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our [Author Services website](#).

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**About the Journal**

Neuropsychological Rehabilitation is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Neuropsychological Rehabilitation accepts the following types of article: original articles, scholarly reviews, book reviews.

Neuropsychological Rehabilitation is an international, peer-reviewed journal, publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy. Please note that this journal only publishes manuscripts in English. This journal accepts the following article types: original (regular) articles, scholarly reviews, and book reviews.

### Peer Review and Ethics

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### Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

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There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, and references. Further details may be requested upon acceptance.

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Author details. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) [requirements for authorship](#) is included as an author of your paper. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCIDiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. [Read more on authorship](#).

Should contain an unstructured abstract of 200 words.

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This work was supported by the [Funding Agency] under Grant [number xxxx].

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### Queries

Should you have any queries, please visit our [Author Services website](#) or contact us [here](#).

**Appendix G: Letter of Approval from Health Research Authority****Health Research Authority**

Miss Laura Barnes  
 Trainee Clinical Psychologist  
 Cambridgeshire and Peterborough NHS Foundation Trust  
 Norwich Medical School  
 Department of Clinical Psychology, University of East Anglia  
 Norwich  
 NR4 7TJ

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

21 March 2018

Dear Miss Barnes

**Letter of HRA Approval**

<b>Study title:</b>	<b>The Possible Selves of Individuals with an Acquired Brain Injury</b>
<b>IRAS project ID:</b>	<b>230004</b>
<b>Protocol number:</b>	<b>1</b>
<b>REC reference:</b>	<b>18/LO/0312</b>
<b>Sponsor</b>	<b>University of East Anglia</b>

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further from the HRA.

**How should I continue to work with participating NHS organisations in England?**

You should now provide a copy of this letter to all participating NHS organisations in England, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of HRA assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

**How should I work with participating NHS/HSC organisations in Northern Ireland, Scotland and Wales?**

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HRA Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland, Scotland and Wales.

If you indicated in your IRAS form that you do have participating organisations in one or more devolved administration, the HRA has sent the final document set and the study wide governance report (including this letter) to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with Northern Ireland, Scotland and Wales.

**How should I work with participating non-NHS organisations?**

HRA Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**I am a participating NHS organisation in England. What should I do once I receive this letter?**

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Sarah Green

Tel: 01603 59 1721

Email: [sarah.green@uea.ac.uk](mailto:sarah.green@uea.ac.uk)

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **230004**. Please quote this on all correspondence.

Yours sincerely

Aliki Sifostratoudaki

Assessor

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

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Copy to: *Ms Sarah Green, University of East Anglia, Sponsor Contact*  
*Ms Vivienne Shaw, Cambridgeshire Community Services, R&D Contact*

IRAS project ID	230004
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### List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Covering letter re amendments ]	1	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance documentation from sponsor]		23 January 2018
GP/consultant information sheets or letters [Appendix M CCS Letter to GP ]	2	12 February 2018
GP/consultant information sheets or letters [Appendix M NCHC Letter to GP ]	2	12 February 2018
GP/consultant information sheets or letters [Appendix M Headway Letter to GP ]	2	12 February 2018
HRA Schedule of Events [230004_SOE_research sites_Assessed by HRA]	1	05 February 2018
HRA Statement of Activities [230004_SOA_research sites_Assessed by HRA]	1	05 February 2018
IRAS Application Form [IRAS_Form_29012018]		29 January 2018
Letter from sponsor [Insurance documentation from sponsor]		23 January 2018
Non-validated questionnaire [Demographic Information Sheet CCS]	1	29 January 2018
Non-validated questionnaire [ Demographic Information Sheet Headway]	1	29 January 2018
Non-validated questionnaire [ Demographic Information Sheet NCHC]	1	29 January 2018
Other [Appendix L CCS Staff Info Letter ]	3	28 February 2018
Other [Appendix L Headway Staff Info Letter ]	3	28 February 2018
Other [Appendix L NCHC Staff Info Letter ]	3	28 February 2018
Participant consent form [Appendix C CCS Consent form-1]	2	12 February 2018
Participant consent form [Appendix C Headway Consent form]	2	12 February 2018
Participant consent form [Appendix C NCHC Consent form]	2	12 February 2018
Participant consent form [Appendix B NCHC Consent to contact V1]	1	29 January 2018
Participant consent form [Appendix B CCS Consent to contact V1]	1	29 January 2018
Participant consent form [Appendix K Headway Prize Draw]	2	12 February 2018
Participant consent form [Appendix K NCHC Prize Draw]	2	12 February 2018
Participant consent form [Appendix B Headway Consent to contact V1]	1	29 January 2018
Participant consent form [Appendix K CCS Prize Draw]	2	12 February 2018
Participant information sheet (PIS) [Appendix+A+Headway+Participant+information+sheet+]	2	12 February 2018
Participant information sheet (PIS) [Appendix+A+NCHC+Participant+information+sheet+]	2	12 February 2018
Participant information sheet (PIS) [Appendix+A+Participant+Info+sheet+CCS]	2	12 February 2018
Research protocol or project proposal	2	12 February 2018
Summary CV for Chief Investigator (CI) [Laura Barnes]		
Summary CV for supervisor (student research) [Dr Fergus Gracey]		09 June 2017
Summary CV for supervisor (student research) [Dr Joanne Hodgekins - Jan 2017]		
Summary CV for supervisor (student research) [LOUIS RENOULT]		

IRAS project ID	230004
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Summary, synopsis or diagram (flowchart) of protocol in non technical language [Appendix D CCS Risk management]	1	29 January 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Appendix D Headway Risk management]	1	29 January 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Appendix D NCHC Risk management]	1	29 January 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Appendix E Timeline]	1	29 January 2018
Validated questionnaire [Appendices G and H Possible Selves Interview and coding]	1	29 January 2018
Validated questionnaire [Appendix I Qolibri-Questionnaire]	1	29 January 2018
Validated questionnaire [Appendix J Head Injury Semantic Differential Scale]		29 January 2018