The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.

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ABSTRACT

Background: Rehabilitation is most likely to be effective when it aims to promote independence, autonomy and social engagement in line with the person's wishes, to enhance their quality of life. Patients who experience acquired brain injury (ABI) receive multiple interventions to assist them in recovering from physical, cognitive, emotional, behavioural, and social impacts of their brain injury. Inpatient rehabilitation enables skilled professionals to provide an intensive and comprehensive treatment and intervention to help them regain their skills which in turn improves their function and quality of life. Despite the importance of these interventions, tensions can arise when making ethical decisions relating to risk taking and safety. This study seeks to explore the role and perspective of the social worker within the multidisciplinary team (MDT). There is a need to address the research gap in brain injury social work within rehabilitation settings, offering new insights into this field.

Methods: A qualitative approach using semi structured interviews with 12 participants across three participant groups: patients, family/informal carers and professionals.

Findings: Four themes were identified from the interview data using interpretive phenomenological analysis: 1) Promoting patients' right to autonomy and self-determination, 2) Differing perspectives of patient, family and professionals on risk, 3) The legal and ethical considerations in decision making, 4) Discharge planning and resource constraints: Role of the social worker.

Discussion: The research identified several key recommendations for policy and practice in addressing the needs of patients with ABI and their families including shared risk taking amongst the MDT, enhanced patient and family involvement, balance autonomy with tailored risk assessment, foster open communication and shared decision making, ABI training for social workers who undertake mental capacity assessments, standardised shared decision making framework, trauma informed practice and effective multidisciplinary team working.

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This work is in loving memory of my Aunty O who is no longer with us, you didn't get to witness me finish this project, but your prayers and love live on.

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LIST OF ABREVIATIONS

ABI	Acquired Brain Injury
MDT	Multidisciplinary team
HRA	Health Research Authority
NVivo	Software program for Qualitative data analysis
IRAS	Integrated Research Application System
IPA	Interpretative Phenomenological Approach
NHS	National Health Service
UK	United Kingdom
CINHAL	Cumulative Index to Nursing and Allied Health Literature
CQC	Care Quality Commission
MCA	Mental Capacity Act
CRPD	Convention on the Rights of People with Disabilities
SDT	Self-determination theory
BINI	Brain Injury Needs Indicator
UN	United Nations
LA	Local Authority
BASW	British Association of Social Workers
NICE	National Institute for Health and Care Excellence
SCIE	Social Care Institute for Excellence
OT/OTs	Occupational therapists
EbE	Expert by Experience
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation and Research Type.
PICO	Population, Intervention, Comparison and Outcome
BISWG	Brain Injury Social Work Group
NIHR	National Institute for Health and Care Research

DEFINITION OF TERMS

Services Users v Patients

For the purposes of this dissertation service users will be referred to as patients. This reflects the hospital setting, and the term used within the multidisciplinary team. It also highlights the dominance of the medical model over the social model within this setting. Social work profession uses labels to describe the people, they work with, such as, clients, customers, service users and experts by experience (McLaughlin, 2009). The words we use to describe people that use our services are an indication of how we perceive them; and they all evoke different meanings, relationship and power dynamics between those that use services and the providers (McDonald, 2006). As a social worker working within a health care setting, it was initially alien for me to describe people as “patients”. However, this was the only way anyone who received medical care was referred to and I had to quickly accept the use of the term. It can be challenging for multidisciplinary teams to develop a common language that is inclusive of all disciplines without dominance of one discipline over others (McLaughlin, 2009).

The term that was most prevalent when I was working as a social worker in a local authority setting was “service user” which has become more popular in describing people using health and social care services, particular people with disabilities. The use of this term has also faced criticism, deemed to present people as passive and consumerist and actively stigmatizing (Christmas & Sweeney, 2016).

Expert by Experience (EbE) v Brain injury survivor

Most recently, the term ‘expert by experience’ appears to have a more collaborative connotation. It denotes the person as an equal within the power dynamics of those that use services and providers where one expert is acquired through educational training and the other through their individual experience (McLaughlin, 2009). In the context of Acquired Brain Injury (ABI) experts by experience are people who either have a diagnosis of ABI or an informal carer for someone with ABI. This term recognizes that people with lived experience have valuable contributions to make and are “experts” of their own situation. This term enables both the positive and negative experiences of “expert by experience” to help inform practice (McLaughlin, 2009). However, who is deemed to be an expert by experience is subjective.

McLaughin (2009) has asked, how long should they be deemed an expert and by whom? For the purposes of this research EbE starts from the point of diagnosis, so one can argue that you become an expert once you are diagnosed with ABI. Experts by experience are people who have recent personal experience of using services and can be a person with an acquired brain injury (CQC, 2025).

'Brain injury survivor' is also a common term used in literature to describe people with ABI, and this reinforces empowerment and recognizes the person's experience. Using the term 'patient' in this study emphasizes the context of the service and setting. The identifier survivor of acquired brain injury is a preferred term because it puts the person first and the condition second rather than the other way round (Brain Injury Network, 2023). Those who use services should choose how they wish to be addressed. It is important to be mindful of the power that words or labels have and to continue to reflect and challenge the social constructs, and the impacts those terms have on how the people who use services are perceived.

Informal carers/family

This study refers to informal carers as either a family member or a friend.

Multidisciplinary team

The term 'multidisciplinary team' as used here is interchangeably with 'professionals' and 'ward staff' working in the inpatient rehabilitation ward. A multidisciplinary team model within rehabilitation consists of professionals from different disciplines who uses their own approaches and skill set to support the patient and the consultant communicates with each professional (Singh et al., 2018).

CONTENT SUMMARY

Chapter 1: Introduction –This chapter provides a background on Acquired Brain Injury (ABI), a definition of ABI, size of the phenomena, what brain injury rehabilitation entails. The research question, aims and objectives are also set out.

Chapter 2: Literature review –This chapter presents a review of existing literature relating to how professionals explore issues of patient autonomy, risk and self-determination.

Chapter 3: Research Methodology – This Chapter outlines qualitative research and the epistemological position of the study. There is an exploration of being an insider researcher, followed by research design as well as consideration of other methods, ethical considerations, study setting and recruitment. Sampling strategies, data collection and data analysis are also discussed.

Chapter 4: Findings – This chapter provides an interpretative phenomenological analysis of the in-depth interviews across the three participants groups of patients (n=4) family (n=1) and professionals (n=7) experiences of how patients' autonomy and issues of risks are managed in brain injury inpatient rehabilitation.

Chapter 5: Reflexivity – This chapter presents an overview of reflexivity and its use in IPA. It provides an explanation of the reflexive processes used to enhance the quality of the study. There is an exploration of insider practitioner researcher role whilst exploring the study from the lens a social worker. That is examining information from the perspective of social work values.

Chapter 6: Discussion, Recommendations and Conclusion - This chapter provides a detailed discussion of the salient findings, recommendation for future research, limitations and conclusion.

CHAPTER 1: Introduction

1.1 Background

"Many stories matter. Stories have been used to dispossess and to malign. But stories can be used to empower, and to humanize. Stories can break the dignity of a people. But stories can also repair that broken dignity" (Adichie, 2009).

Acquired Brain Injury (ABI) is a leading cause of death and disability in the United Kingdom, and it remains a significant issue for long term care (Holloway & Tasker, 2019). Although people living with ABI are now living longer due to developments in health care provision, some continue to have complex needs, which are often life-long (Holloway & Tasker, 2019). ABI can result in several different cognitive, behavioural, emotional and physical effects, as well as leading to executive function loss, coma, reduced awareness state, communication problems, fatigue, hormonal imbalance, and post traumatic amnesia (Headway, 2023). For these reasons, ABI is an area of research that needs more recognition and attention. In recent years, there has been advancement in social work research within the field of ABI which highlights the challenges that people with ABI and their families face, for example, poor level of involvement in decisions regarding provision of health and social care services (Holloway & Tasker, 2019). However more insight is required from a social work perspective with the aim of adding to the existing knowledge base.

1.2: Definition of ABI

An Acquired Brain Injury is defined as a non-degenerative injury to the brain occurring since birth (Department of Health & Social Care, 2022). The term 'Acquired Brain Injury' includes both traumatic and non-traumatic brain injuries (Department of Health & Social Care, 2022). Traumatic brain injury is an injury to the brain caused by trauma to the head (Headway, 2023). This includes road traffic accidents, assaults, falls and accidents at home or at work. Non-traumatic brain injury includes brain tumour, stroke, brain haemorrhage, brain aneurysm, carbon monoxide poisoning, hydrocephalus, hypoxic and anoxic brain injury, meningitis, and encephalitis (Headway, 2023).

1.2.1: Size of the Phenomena and importance of rehabilitation

Headway, a brain injury charity compiled a list of datasets on all Acquired Brain Injury (ABI) related hospital admissions in the UK (Headway, 2023). In 2019-2020, there were 356,699 UK admissions to hospital with ABI (Headway, 2023). All ABI admissions in the UK increased by 12% since 2005-2006 (Headway, 2023). Brain injury continues to rise at an alarming rate in the UK (Headway, 2023). Statistics from 2019-20 highlight that there is one admission to hospital for brain injury every 90 seconds, one head injury every three minutes and one stroke every four minutes in the United Kingdom (Headway, 2023). The reason for the increase is not immediately clear, and more research is needed to understand why the number of ABI diagnosis keeps increasing (Tennant, 2018). In the UK, 1.3 million people live with an ABI related disability (Linden et al., 2023).

There are often long-term issues associated with brain injury. The nature and intensity of the rehabilitation will depend on the stage the person has reached in their recovery process (The Disabilities Trust, 2023). Hence, brain injury rehabilitation is imperative in enabling people to access the specialist support they need at crucial stages. Royal College of Physicians and British Society of Rehabilitation Medicine (2003) published a national clinical guideline on rehabilitation which suggests that there is growing evidence for the effectiveness and cost benefits of rehabilitation, especially when the multidisciplinary team professionals work collaboratively towards a common goal.

1.2.2: Effects of ABI

The brain controls everything we do, and the effects of ABI can have devastating physical/motor, sensory, social, emotional, behavioural and cognitive consequences for both the individual and their family (Ponsford, 2013). The effects of brain injury vary between patients and depend on how severe the injury was and the areas of the brain that were affected (Headway, 2024). In severe brain injury individuals, complete recovery is rare, and so, in many cases, despite prolonged periods of inpatient rehabilitation, these people remain impaired and require significant care and support in the long term to meet their ongoing care needs (Latchem-Hastings, 2023). Some people with less severe injuries may go through the stages of rehabilitation quickly and return to their daily routine whilst others with severe brain

injuries would need care and treatment for a longer period or even years after their diagnosis (Headway, 2024).

A common effect of brain injury is executive dysfunction, which causes difficulties with motivation and initiation, organisation, flexible thinking, problem solving, impulsivity and difficulties with planning (McDonald et al., 2002; Headway, 2023). This can be worsened as some individuals with brain injury may not be aware of their executive dysfunction and may not have insight into the effect of their brain injury. This is called the frontal lobe paradox because the person may appear unimpaired when they are assessed. However, in their everyday life, patients experience difficulties with learning new ways of carrying out daily living activities tasks such as dressing, cooking, administering their medication or managing their appointments or correspondence (Chung et al., 2013; George & Gilbert, 2018). Issues with executive dysfunction not only impacts the person, but also their families and friends may be affected when the person refuses support to manage the effects (Headway, 2022). It can also affect other areas of their lives such as returning to work or education, managing relationships, finances and maintaining a residence (Perna et al., 2012). This study highlights that whilst ABI is defined by medical diagnosis, its effects are social.

It is important to recognise the psychological and social impact ABI can have not only on the patient but also on their family systems. This includes the impacts on their relationships, environment, vocational/educational situation and their emotional wellbeing (Scottish Acquired Brain Injury Network, 2025). Some of the psychosocial effects of ABI are, loss of role and identity, reduced ability to understand and manage social interactions, impaired social skills, risk of social isolation, risk of unemployment or reduced educational performance and change in financial situation. This view is supported by research undertaken by Headway (2025) which showed that 70% of brain injury survivors saw a deterioration in their social life post brain injury. It is therefore imperative that the patient and their families receive appropriate support to address their social situation, exploration of families/carer needs, spiritual care, financial support, vocational needs and housing needs (Scottish Acquired Brain Injury Network, 2025). This is where the role of the social worker is critical within the rehabilitation process by ensuring patients and families

receive early intervention and access to services in the critical stages. Although the role of the social worker is varied within neurorehabilitation, it aligns with the principles of social work in supporting social difficulties, promoting human rights and protecting vulnerable people from harm (British Association of Social workers, 2023).

1.3: Multidisciplinary team working in neurorehabilitation

Due to the complex needs of patients with ABI, they require specialist intervention by professionals with knowledge, experience and skills in management of brain injury. Consequently, the staffing provision must be adequate to meet the needs of the rehabilitation service (Turner-Stokes & Wade, 2004). Within a brain injury rehabilitation setting, the team typically consists of professionals including consultant and doctors, nurses, occupational therapists, physiotherapists, speech and language therapists, neuropsychologists, neuropsychiatrists, dietitians, activities coordinator, rehabilitation assistants and social workers. Brain injury inpatient rehabilitation involves specialist rehabilitation for people who are unable to return home following their discharge from an acute hospital setting. Neurological rehabilitation centres provide a setting where specialist structured rehabilitation is in place throughout the day (Headway, 2023). Rehabilitation is a process of assessment, treatment, and management by which the individual, family and carers are supported to achieve their maximum potential (NHS England, 2013).

This first stage following a brain injury is often a critical period, medically, as ABI may be life threatening for some patients hence this stage requires skilled doctors and health professionals. The multidisciplinary team and in particular the social worker make a crucial contribution in the rehabilitation stage and particularly the care planning stage. During these two latter stages, as the role of the social worker increases, tensions can arise between the medical and social model. Social worker training prioritizes empowering patients and advocates a strengths-based approach which can conflict with the priorities of medical practitioners (Caiels & Brown, 2021).

During their initial admission, the professionals will complete their assessments of the person. This is to explore how the brain injury has affected the patient, including physical, cognitive, emotional, behavioural, and social difficulties that the team and patient may identify. Rehabilitation should be person-centred, meaning it is tailored

to the needs to the individual's needs, preferences, and values thereby optimising the persons experiences with care and fully involving their perspectives into their care (Jesus et al., 2016). This includes considering the patients' views, cultural background and pre-morbid lifestyle (Turner-Stokes & Wade, 2004). The aim of rehabilitation is to improve functional outcomes by restoration, compensation, and adaptation (Lowry et al., 2022). Rehabilitation helps the brain relearn other ways of working to reduce the long-term impact of brain injury (Headway, 2023). It is crucial to note that the benefit of rehabilitation is to also help the patient and their family to cope successfully with the remaining disabilities (Headway, 2024). Research based evidence shows that rehabilitation in specialist settings for people with ABI is effective in reducing length of stay in hospital and costs of long-term care (NHS England, 2013). Additional support for specialist teams was identified by Odumuyiwa et al., (2019) who further stressed the need for specialist, person-centred, and multidisciplinary care provided by trained professionals with experience of working with those with ABI and their families.

Teamwork is an important aspect of a rehabilitation team and an essential part of high-quality patient care (Korner, 2010). Literature shows that there are three types of team approaches, multidisciplinary, interdisciplinary and transdisciplinary. Multidisciplinary teams consist of work undertaken with other disciplines in parallel with clear role definitions (Wade, 2015; Korner, 2010). Interdisciplinary teamwork entails work undertaken jointly with other disciplines where professional meetings take place regularly to discuss patient's goals and devise treatment plans (Wade, 2015; Korner, 2010). Professionals in Transdisciplinary teams work within integrated systems across many disciplines and work is undertaken collaboratively (Wade, 2015).

Multidisciplinary team working in neurorehabilitation involves a combination of team-based goals and interdependency of treatments, which is an important factor for effective functioning of the team (Wade, 2015). The interventions provided by the MDT are often connected or closely related (Van der Veen et al., 2024). It is recognised that social workers are a key part of the multidisciplinary team especially in relation to service provision and without them, service efficiency and effectiveness are likely to be markedly reduced (Wade, 2015; Linden et al., 2023). Social workers

work with patients who have health conditions which result in difficulties living independently or who have impairments impacting their daily life (Freymuller et al., 2014). Although the role of the social worker in MDT setting is seen as positive, role clarity is a perceived issue with some team members lacking understanding of the social workers professional role leading to inappropriate tasks or underutilisation of the professional role (Glaser & Suter, 2016). Further, Glaser & Suter's (2016) study revealed a perceived lack of respect for social work ideology and practice with social workers ascribing this to limited understanding and recognition of the difference between social work and other medical professions. Literature indicates that social work practice within rehabilitation can vary across services. However, in the context of this research, the social work role involves carrying out psychosocial assessments, having the knowledge and skills to manage the needs of patients with ABI, addressing crisis management, devising strategies for coping with trauma and knowledge of welfare services and legislation (Hogsnes et al., 2026). The social worker's role within inpatient rehabilitation primarily focuses on return to community living, with the MDT relying heavily on the social worker to facilitate a safe discharge (McDermott, 2023).

1.4: Key concepts: Risk, autonomy and self-determination

Due to complex needs of patients with ABI, the potential for conflict can arise amongst those seeking to identify care needs. The professionals, patient, their carer and families, all need to be heard when exploring ongoing support post rehabilitation. This is particularly so when issues of risk, autonomy and self-determination are being considered during transition from inpatient rehabilitation to home/community. The terms autonomy relates to independence and freedom to make one's choices and decisions (Schipper et al., 2011) and people should be treated as autonomous unless there is a specific reason for the contrary. This echoes the government's response to greater public involvement and more choice, which called on NHS staff to create opportunities for patients and their families to be involved in decisions about their care (Department of Health & Social Care, 2012). Despite rehabilitation's integral contribution to promoting independence, the tension between promoting safety and respecting the choice to live at risk is not well understood (Andreoli, 2010). Decisions relating to risk taking lies at the centre of brain injury rehabilitation,

furthermore, the decisions about risk taking are influenced by conflicting values, systems and patients' abilities (Andreoli, 2010).

While not unique to social work, a key part of the social worker's role within the multidisciplinary team is to help balance issues of risk with self-determination. Social workers are trained to ensure that self-determination is at the forefront of their practice. Self-determination remains a key principle within the social work profession. The Code of Ethics for Social work recognises respect to self-determination as an integral part of social work practice. "*Social workers should respect, promote, and support people's dignity and rights to make their own choices and decisions, irrespective of their values and life choices, provided this does not threaten the rights, safety and legitimate interests of others. Social workers ensure that any limitations on a person's rights are necessary and proportionate and are for a legitimate purpose"* (BASW 2012, p.7). One of the principles of the National clinical guidelines for rehabilitation following acquired brain injury denotes that patients with ABI and their families should be provided with appropriate information at all stages and be supported to be fully involved in decisions regarding their care and support needs (Turner-Stokes & Wade, 2004). Balancing risk, autonomy and self-determination can be challenging for the multidisciplinary team due to tensions that can arise from perspectives on the medical model versus social model, individual/family value systems, as well as legal and ethical considerations.

To address the limited research in this area, this study seeks to explore how professionals balance risk, autonomy as well as involvement of patients and families in making decisions about what level of support a person with ABI needs. The study will explore decisions around discharge destination/support following patients' rehabilitation and the degree to which they contribute towards the decision-making process. It also seeks to examine the factors that can influence decision-making of professionals within the rehabilitation setting. Exploring the tensions that can arise in the team when navigating the decision-making process is pivotal in understanding how decisions are made. Finally, it will explore risk issues and patient's autonomy in preparation for discharge.

1.5: Research Question: How does the multidisciplinary team balance patients' risk, autonomy and self-determination when making decisions about the discharge outcome following inpatient brain injury rehabilitation?

1.6: Aims & objectives

Aims: The aim of this study is to better understand the tensions that arise for the patients, family and multidisciplinary team when balancing patients' risk, autonomy and self-determination during inpatient rehabilitation; and how this affects decision-making about post-rehabilitation discharge.

Objectives:

1. To explore the factors influencing multidisciplinary team (MDT) decision-making during discharge planning for patients with Acquired Brain Injury (ABI).
2. To understand the lived experiences of patients, families, and professionals regarding risk, autonomy and self-determination during inpatient rehabilitation.
3. To examine the role of the Mental Capacity Act (MCA) 2005 and other legal/ethical frameworks in MDT decision-making.
4. To understand the role and perspective of professionals including the social worker within the MDT.

CHAPTER 2: Literature Review

2.1 Review type

A narrative review approach was taken to explore the current literature. This method was chosen over other types of literature review because it facilitates synthesising evidence from a broad range of sources, including empirical, grey and theoretical literature, to shed light on current understanding of the topic from a broad range of perspectives, identify gaps and connections within in the current evidence base (Sukhera, 2022; Agarwal et al., 2023; Cronin et al., 2008; Gordon, 2018). However, narrative reviews have been criticised for lacking rigour, failing to disclose inclusion criteria and not providing evidence-based synthesis for focused questions (Sukhera, 2022; Byrne, 2016). This study has mitigated this by using clearly defined inclusion criteria and providing a rigorous thematic synthesis of the literature.

A narrative review involves these steps: define topic and audience, search and re-search the literature, be critical and find a logical structure and finally reviewing your review (Gregory & Denniss, 2018). With reference to the research question: *How does the multidisciplinary team balance patients' risk, autonomy and self-determination when making decisions about the discharge outcome following inpatient brain injury rehabilitation?* The literature review seeks to identify the salient features of this topic and to identify gaps in current research knowledge. I used a search strategy to find relevant research, and I also integrated theoretical perspectives in my discussion of the findings from the literature review.

2.2: Methods

Qualitative evidence synthesis requires the use of comprehensive searches which are necessary and valuable to answer health services research questions (Methley et al., 2014). I explored qualitative and mixed methods original research in my approach to searching for evidence. When devising a search strategy, the search tool is used as an organising framework to list the terms by the main concept in the search question (Methley et al., 2014). The SPIDER search strategy was deemed to be the most appropriate as qualitative and mixed methods studies could be searched. This search strategy was designed following difficulties in using PICO when searching for qualitative and mixed methods research (Cooke et al., 2012).

PICO enables researchers to define their quantitative research question and search terms for a search strategy (Cooke et al., 2012). Thus, SPIDER was found to be an optimal search strategy for mainly searching for qualitative and mixed methods studies (Cooke et al., 2012).

PICO	SPIDER	Justification
P – Population/problem	**S** – Sample	Smaller groups of participants tend to be used in qualitative research than quantitative research, so this term was deemed more appropriate.
I – Intervention/exposure	**PI** – Phenomenon of Interest	Qualitative research aims to understand the how and why of certain behaviours, decisions, and individual experiences. Therefore, an intervention/ exposure per se is not always evident in qualitative research questions.
C – Comparison	**D** – Design	The theoretical framework used in qualitative research will determine the research method that is used. As inferential statistics are not used in qualitative research, details of the study design will help to make decisions about the robustness of the study and analysis. In addition, this might increase the detection of qualitative studies in the databases in which titles and abstracts are unstructured.
O – Outcomes	**E** – Evaluation	Qualitative research has the same end result as quantitative research methods: outcome measures. These differ depending on the research question and might contain more unobservable and subjective constructs when compared to quantitative research (e.g., attitudes and views and so forth), so evaluation was deemed more suitable.
	R – Research type	Three research types could be searched for: qualitative, quantitative, and mixed methods.

Table 1: The construction of the SPIDER search tool from the PICO search tool (Cooke et al., 2012)

A search strategy was employed to identify the current research in this area. Search terms (including synonyms and other similar words) are presented in Table 2 below. The commonly used databases for health and social care research that were used were Scopus, Google scholar, CINAHL and PubMed. Sources such as CINAHL and Scopus were in the list of academic journal and online search engines thought to provide relevant materials for social care research (McGinn et al., 2014). There was no limitation on date range or study design; this was done to provide access to more literature.

Search Terms

"Multidisciplinary team"	"Brain injury inpatient"	"Social worker"	"Rehabilitation"	"Risk"
"MDT"	"Acquired Brain injury"	"Social work"	"Rehab"	"Autonomy"
"Interprofessional team"	"Brain injury patient"	"Social care"	"Therapy"	"Self-determination"
"Interdisciplinary team"	"Traumatic brain injury"	"Social services"	"Rehabilitation unit"	"Safety"
"Multiprofessional team"	"Non-Traumatic brain injury"	"Case work"	"Rehabilitation ward"	"Decision-making"

“Transdisciplinary team”	“Head injury”	“Case manager”	“Inpatient rehabilitation”	“Risk-taking"
“Multi-disciplinary team”	“Mild head injury”		“Neurorehabilitation”	“Independence”
“Carers”	“Client”			“Autonomous”
“Families”	“Service user”			“Free-will”
“Friends"	“Customer”			“Choice”
Informal carers”				“Freedom”
“Next of kin”				

Table 2: Search terms

2.3: Inclusion and Exclusion criteria

The inclusion criteria should provide information on the type of sources of evidence which will be considered for inclusion (Peters et al., 2020). PCC (Population, concept and context) type of sources of evidence is explained below (Peters et al., 2020):

Population	18 years and above Multidisciplinary team professionals, patients and families/informal carers
Concept	Autonomy, risk and safety issues in brain injury rehabilitation
Context	Hospital and community settings
Type of evidence	Qualitative data, theoretical literature, all types of literature including grey literature

Table 3: Inclusion and Exclusion criteria

The inclusion criteria were studies involving patients, 18-year-old and over, brain injury diagnosis, inpatient rehabilitation and social work-related studies on brain injury. The inclusion criteria also included studies on multidisciplinary team working, risk, autonomy and self-determination, some papers included community cases to ensure a thorough understanding of the phenomena. The literature search also

included UK and international studies. There was also no limitation to the age of the papers. This was done to provide comprehensive information on the phenomenon, provide insights which are not confined by rigid frameworks of other types of knowledge synthesis and to help identify research gaps (Hall, 2024).

The exclusion criteria were, children/under 18s, and studies which were not written in English. The initial search elicited 145 records. After screening of titles and abstracts, these were narrowed down to 57 records to be read in full. The papers excluded after screening related to children/adolescents, and papers heavily focused on scientific aspect of ABI. The final number of research papers included in this review was 29 (excluding grey literature) See Appendix 18.

Databases

Scopus	Large abstract and citation database of peer-reviewed literature, including scientific journals, books, and conference proceedings
CINAHL	Cumulative Index to Nursing and Allied Health Literature
PubMed	Biomedical and life sciences literature
Google scholar	Web-based search engine that indexes scholarly literature from a wide range of academic sources
Hertfordshire University Online library	Electronic library search

Table 4: Databases

As a result of my review, I identified key themes based on my research question across the literature included in this review. This involved exploring literature in relation to autonomy, risk and self-determination – using the search terms listed in Table 2. The literature review is structured around the core themes identified below:

1) Models of Disability
2) Collaborative practice
3) Approaches to autonomy
4) Self-determination theory and engagement
5) Approaches to risk assessment
6) Human right issues

7) Mental Capacity Act 2005, legal and ethical considerations
8) Transition from hospital to home

2.4: Core themes identified across the literature

Models of Disability

For the patient in a rehabilitation setting, the brain injury journey to 'recovery' usually starts with diagnosis and treatment, leading to rehabilitation, and finally, discharge care planning. This first stage of the patient's journey is the medical treatment which by its nature is based on the medical model of disability, focusing primarily on the patient's impairments, diagnosing and treating symptoms through medical intervention. Under the medical model disability is perceived to be impairments resulting from disease, injury or health conditions (Palmer & Harley, 2012). By comparison, the social model of disability looks at what accommodations the person needs, emphasizing the problems people face because of external factors/barriers in society rather than their physiological impairments (Palmer & Harley, 2012). Duffy's (2022) paper on disability rights stresses that advancing the disability rights as universal rights, to protect everyone in the community will ensure that everyone has a contribution to make to society which in turns makes everyone a beneficiary and everyone a contributor.

It can be argued that traditionally, inpatient neurorehabilitation sits within a medical model. Consequently, the medical model has more hegemony in a rehabilitation setting. Although this may be attributed to the professional culture of the relevant multidisciplinary team, the traditional medical model is often viewed by social workers as limiting and defines the person in terms of their illness and disabilities and does not acknowledge the disabling effects of societal norms in comparison to the social model which defines disability as caused by society or the environment (Wiseman, 2011). The medical model focuses on action and outcome rather than on relationships, as opposed to the social work model which places greater value on self-determination (Reese & Sontag, 2001). A biopsychosocial model may be preferred when diverse professionals work collaboratively in conducting multidisciplinary assessments and can identify the specialist support needed which is then tailored to the needs of the individual (Wiseman, 2011).

Collaborative practice

Patients with ABI can feel excluded from decision-making and receive conflicting information regarding treatment (Kivunja et al., 2018). Kivunja et al's (2018) study of ABI patients' experiences of nursing care found that the care they receive may not be as person-centered as nursing staff believed and attributed the mismatch to lack of staffing, task-focused care and time constraints which limited their ability to engage patients with brain injury and provide an individualized care approach (Hunter et al., 2016). There is recent guidance for health care professionals such as the NICE (2021) guidance on shared decision making which is a collaborative process that involves joint working between the person and their health care professionals to make decisions about their care. Social Care Institute for Excellence (2025) concurs that supporting people in decisions about their care and treatment should be at the forefront of health and social care services. This way of working encourages health care professionals to explain the different options through information sharing and discussions thus empowers people to make decisions for themselves.

In exploration of the role of the "interdisciplinary team", Singh et al., (2018) emphasizes that conflict is inevitable when people work together and should be expected and even embraced. Working jointly towards a common goal can improve patients' outcomes, including mortality (Singh et al., 2018). The individual skills and expertise which each discipline brings has many benefits to the team. However, teamwork is not without its challenges, for instance disagreements in professional knowledge may occur which could undermine a team member. This could be overcome by having shared team goals and working cohesively to promote better patients' outcomes rather than working towards one's own individual specialty (Singh et al., 2018). Collaboration between team members is essential in neurorehabilitation and can be fostered when team members feel free to express their opinions and share ideas without fear of negative consequences (Van der Veen et al, 2024).

Approaches to autonomy

The philosopher John Stuart Mill's conception of autonomy, and the "liberty-limiting principle" in his work', 'On Liberty' asserts that the ability to develop one's own individuality and lead a self-chosen life is paramount and ultimately the individual is

the final judge. Mill argued that the only way power can be exercised over another member of society, against his will, is to prevent harm to others (Bavetta et al., 2014). In essence, Mill was fiercely opposed to paternalism. Hence his work laid the foundation of what we know today as liberal approach to autonomy. A relational approach on the other hand, emerged mainly from feminist thinkers in the late 20th century and is based on the conviction that people are socially embedded by social determinates such as race, class, gender and ethnicity. This approach analyses the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy (Mackenzie & Stoljar, 2000).

Andreoli's (2010) study highlights the difference between a relational approach and liberal approach to risk taking and autonomy. They identify how a relational approach to autonomy, which addresses the individual's decision and functional abilities within their social contexts, is more favourable than a liberal individualist approach to autonomy. Andreoli (2010) maintains that a liberal individualist approach to autonomy is based on patients' ability to make decisions based on their own needs and values. In contrast, relational autonomy challenges this view and instead argues that self-direction is driven by a network of dependent and interdependent relationships of the patient (Andreoli, 2010). This study concluded that relational autonomy may help clinicians make better decisions that balance risk-taking and safety, decisions that are committed to the principles of respecting autonomy and advancing safety (Andreoli, 2010). Arguably, a liberal approach to autonomy is more in line with social work values which emphasises the importance of respecting service users right to self-determination and ability to make their own choices and decisions.

Cardol et al's (2002) paper on autonomy and participation in rehabilitation also echoed similar findings; asserting that rehabilitation professionals can guide the person in determining the most appropriate options and strategies through provision of information, allowing time and creating an environment where autonomy is respected and encouraged to the extent of the persons abilities. However, this is debatable as patients should be encouraged to make decisions as much as possible irrespective of their abilities. This is more in line with the principles of autonomy and self-determination which sits more with social work perspectives. Hunt & Ells (2011)

goes further in the definition of relational autonomy as an approach based on person-centred rehabilitation care; asserting that multidisciplinary team professionals should work in partnership with the individual and family in exploring risk and autonomy. Constraining autonomy can be an ethical problem even when clinicians are acting in an individual's best interests (Macciocchi & Stringer, 2001). Thus, professionals that work within the multidisciplinary team should be aware of the ethical issues that arise when exploring risk.

Similarly, Hunt & Ells' (2011) paper which explored risky choices and relational autonomy highlighted the challenges health care professionals face when patients want to make "risky" choices which are contrary to the rehabilitation goals. When health care professionals pay attention to the patient's individual goals, history, social context and preferences, they can engage patients better through communication. It is therefore crucial that working in a person-centred way with the patient and family to develop their care plan results in a partnership towards autonomy between the patients and professionals (Hunt & Ells, 2011).

Prior to the Hunt & Ells (2011) paper, Bowen et al., (2010) emphasised relationships as a crucial vehicle for change within a relational approach to rehabilitation. They considered the first step was to address the uneven power dynamics of the biopsychosocial model and extend the definition to include a bio-psycho-social-family perspective. It recognises the importance of the biological/physical, psychological and social aspects following a disability and adjusting rehabilitation to meet the individual's bio-psycho-social needs (Glintborg & Hansen, 2016). The bio-psycho-social model is based on the interaction between the patient, relatives, professionals and the community (Engel, 1977). Whereas the bio-psycho-social-family perspective further seeks to highlight the role of the family within the biopsychosocial formation. If the patient is disadvantaged in the level of support they have from family systems, this can impact their recovery especially post discharge, in comparison to another person who has a robust family support network in place (Lindlof et al., 2024). As Bowen et al., (2010) noted, understanding the family factors helps to have a holistic picture of the patient, such as the distributions of roles, communication style, attachment patterns and whether they have experience of being care givers. Additionally, exploring the history of ill health within the family and how this has been

managed in the past provides an understanding of the family systems (Bowen et al., 2010). This perspective is in keeping with social work intervention which does not assess issues in isolation but from a strength-based approach which is holistic and involves a comprehensive view of the patient's life (Department of Health & Social Care, 2019).

Self-determination theory and engagement

Issues relating to reluctance to participate in rehabilitation activities often referred to as engagement, is sometimes observed in patients with a brain injury. Consequently, engagement can limit the functional gains during the critical early stages of recovery (Ownsworth & Clare, 2006). Self-determination theory (SDT) is effective in understanding human engagement and motivation (Kusec et al., 2019). It provides insight into how people's experiences are related to their behaviour and motivation. Figure 1 below illustrates Self-determination theory's three basic psychological needs: autonomy, competence and relatedness to others (Ryan & Deci, 2000). Satisfying the psychological needs promotes autonomy (Michalovic et al., 2019). SDT can contribute to positive outcomes for patients and equally contributes to the ethical ideas of promoting patients' autonomy in decision-making and interventions (Ryan & Deci, 2000). Self-determination theory can be used to measure how individuals become motivated during rehabilitation and how professionals can engage them in rehabilitation (Kusec et al., 2019).

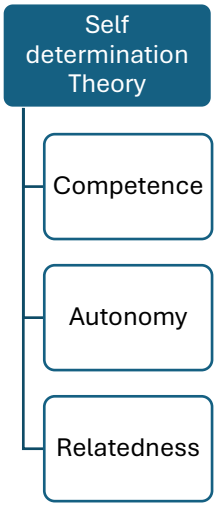

Figure 1: Self-determination theory (Ryan & Deci, 2000)

DeHope & Finegan (1999) go further to demonstrate how self-determination model aids in developing self-awareness for patients. The first step is educating patients

about their brain injury and to become more aware of their difficulty with social rules and interactions. Impaired self-awareness is also referred to as lack of insight and has been linked to reduced participation during rehabilitation (Medley & Powell, 2010). Therefore, professionals should seek to complete brain injury education both individually and in groups. Arguably, case law on CT v London Borough of Lambeth & Anor [2025] identifies insight as a clinical concept which professionals should be mindful of particularly when issues of capacity is being explored. The summary in this case is that a person may still be able to make a particular decision even if they lack insight into their general condition.

Education about decision making can empower and develop the patients' sense of self-determination (DeHope & Finegan,1999). The next step is practicing in a safe, structured environment which helps with developing awareness where the patient can be provided feedback on their communication. Finally, ensuring the patient has the opportunity of learning through real life situations and consequences. The goal is for the patient to eventually progress towards being more independent in their interactions in social situations and experience the natural consequences of their actions which may in turn help promote their autonomy. This approach is also favored by Medley & Powell (2010) who argue that constructive feedback and structured experiences promote self-awareness. Which in turn leads to progressing through the determination and action stage where the patient commits to meaningful goals while being supported to work through their feelings of loss and grief (Medley & Powell, 2010).

A systematic review conducted by Oyesanya & Bowers, (2017) highlighted the limited literature in this area but noted that patients and families wanted to be more involved in the rehabilitation process and both patients and family members reported unmet information needs. Panday et al‘s (2022) qualitative study highlighted that people with traumatic brain injury experience a lack of autonomy as inpatients. Whilst other studies argue that autonomy as self-determination has become an important core value in caring for people with disabilities (Schipper et al., 2011). There has been an improvement compared to the period where dependency and protection were the dominant values, leading to paternalism and a belittling attitude of professionals towards people with disabilities (Schipper et al., 2011). The study on

citizenship paradigm conducted by Schipper et al., (2011) embraces autonomy as self-determination and that all people have the right to make their own decision based on their subjective values. This view is also echoed in a study on choice and control in daily life for people following brain injury conducted by Murray et al., (2022); that the person with ABI should be engaged in choice and control and a tailored and collaborative approach should be used in rehabilitation. Communicating with the individual and their family members about their options, educating them and involving them with the decision-making process further enhances the persons autonomy (Panday et al., 2022). Gridley et al's (2014) study on good practice within the English social care services for adults with disability identified several positive factors. This included the importance of ongoing professional support either through a specialist key worker or case manager to coordinate the various services and ensure good practice at each organisational level (Gridley et al., 2014). Despite the move towards personalisation in adult social care and the shift of power imbalance from professionals to patients, the paper argues that participants still valued the importance of professional support.

Approaches to risk assessment

To ensure all aspects of a patients needs are addressed both socially and medically, a systemic approach to risk assessment and management is required within acquired brain injury service provision (Corrigan et al., 2004). Risk assessment is a process of determining the probability and likelihood of risk occurring and this consist of risk identification, risk analysis and risk evaluation (NHS England, 2024). Risk assessment requires a collaborative approach, drawing on variety of sources including case notes and functional assessment to ensure that the disciplines involved in patients' care can contribute their expertise and knowledge on the issue being explored (Weatherhead et al., 2012). Risk assessment is central to social work practice, it is multi-faceted, incorporating the seriousness of a specific harm as well as the factors surrounding it (Copstick et al., 2022).

To help social workers make the specialist assessment needed to assess people with ABI, the Brain Injury Needs Indicator (BINI) was developed (Copstick et al., 2022). BINI is referenced in the Care Act 2014 as a tool to be used as part of an assessment process to identify the deficits of people with suspected or diagnosed

ABI (Department of health, 2025). This enables social workers to assess the recovery, support needs and overall risk after ABI. The BINI uses information provided by the patient, their support network and professionals in determining the level of insight the person has on their brain injury and their risk level. When there are disagreements between the patients' view of their needs, the support network or professionals, the BINI aids in understanding the care needs of the person (Copstick et al., 2022). It is crucial to note that involving the support network aids in understanding the issues around insight, thus increasing the validity of the results, additionally it is a precursor to identifying the needs of the informal carers which is in line with the Care Act 2014 (Copstick et al., 2022) which compels assessors to ensure that a more detailed assessment takes place as part of the exploration of a person's wider needs or deficits. Even so, the needs of those with ABI and their families are not always completed appropriately (Copstick et al., 2022).

Neurorehabilitation services tend to be less risk averse with focus on increasing functioning and community participation (Weatherhead et al., 2012). Knox et al., (2013) noted that risk is often depicted negatively as something that must be avoided. However, being able to take risk may hold positive meanings to an individual and a qualitative study exploring notions of risks by Lupton & Tulloch (2002) showed that risk taking was associated with self-improvement and control. According to Knox et al., (2013), it is important for professionals to recognise the person's right to take risks, and the views of the person about the nature and acceptance of the risk must be considered. Risk assessment should therefore guide professionals to assess the person's strengths, needs and wishes (NICE, 2022). Patients with ABI have a right to make decisions about their lives, and it is the role of the multidisciplinary team to assess potential and actual risk. Social workers should support people to reach informed decisions about their lives and promote their autonomy and independence (BASW, 2012). Figure 2 below is an example of a Risk Matrix (NHS England, 2024) which is commonly used in the rehab site where this study is based to balance patient's safety with their recovery and independence. Although, a risk matrix can be helpful in facilitating discussions for complex decisions, it can be argued that risk matrix tools are subjective because they inherently rely on the assessor's judgement which can be open to interpretation rather than an objective measurement (Lemmens et al., 2022).

Likelihood

Consequence	Rare 1	Unlikely 2	Possible 3	Likely 4	Almost certain 5
5 Severe	Medium 5	High 10	Very high 15	Extreme 20	Extreme 25
4 Major	Medium 4	Medium 8	High 12	Very high 16	Extreme 20
3 Moderate	Low 3	Medium 6	Medium 9	High 12	Very high 15
2 Minor	Very low 2	Low 4	Medium 6	Medium 8	High 10
1 Minimal	Very low 1	Very low 2	Low 3	Medium 4	Medium 5

Figure 2: Risk Matrix (NHS England, 2024)

Stanley et al's (2022) study on physiotherapists and occupational therapists highlighted some of the tensions facing professionals in their decision making. These include needs versus resources, privacy versus exposure, crisis versus routine, care versus production, autonomy versus authority, experience versus expertise, treatment versus punishment and rhetoric versus reality. Professionals need to balance issues, such as, the wishes of the person, (including concerns over patients' safety) public safety, and their legal organisational and professional obligations (Stanley et al., 2022). This supports Mill's harm principle which asserts that the only real reason society should interfere with a person's freedom is to prevent harm to themselves or others (Bell, 2021).

Stanley et al's (2022) study concluded that the process of decision making requires a collaborative approach which is person-centred between the professionals and the person. Emphasis is placed on effective management of power dynamics between the relationship to reduce violation to the person's dignity and subsequent harm to the health and wellbeing of the person with a brain injury. However, it can be argued that professionals hold significant power in making decisions around goal setting, timetabling and post ABI care (Murray et al., 2022). Discussions with the patient, their family and professionals assist with shifting the power imbalance to that of a shared model and this can be achieved by involving the patient in their goal setting so that they can have more choice and control on the support they receive (Stanley et al., 2022). A study by Murray et al., (2022) explored the perspectives of choice and control in daily life following ABI conveyed that therapists need to utilise a

person-centred collaborative approach during goal setting which involves weighing up risks and autonomy with emphasis on empowerment, support and advocacy. Education, understanding, and shared decision making can ensure empowerment throughout the rehabilitation process (Murray et al., 2022).

Human Rights Issues

Human rights for people with disabilities is embedded in international law and legislations, notably The United Nations (UN) Convention on the Rights of People with Disabilities (CRPD), the Humans Rights Act 1998 and Equality Act 2010 in the UK. The Equality Act 2010 recognizes acquired brain injury as a disability; health care services are required to make suitable adjustments for patients. Tyerman (2023) explores the challenges a patient with ABI faced in engaging with health care consultations which indicates that this remains an issue for patients with ABI. The CRPD stipulates that disabled people including people with a brain injury have a right to participate in decision making that affects all areas of their lives and should be actively involved in the decision-making process (United Nations, 2007). Recent publications show that ongoing work is needed in this area as Tyerman (2023) calls for professionals to make appropriate adjustments to ensure good communications with patients with ABI. For health and social care professionals, it is imperative to maintain the FREDA (freedom, respect, equality, dignity and autonomy) principles according to CQC (2024); this is a human rights-based approach to protect the rights of individuals and ensure they have choice and control over their lives.

Brain injury policy and practice have been historically focused on rehabilitation and restoration of function however it is well established that people often have long term impairments because of their brain injury (Knox, 2013). This means that multidisciplinary teams involved in their care across all areas from hospital to community, need to understand their role in assisting people become as empowered as possible in participating and being involved in decision-making process (Knox, 2013). This is aligned with the UN convention which recognises the need for people with disabilities to have autonomy and independence as well as the freedom to make their own choices. Thogersen et al., (2025) study on rehabilitation professionals' perspective on psychological rehabilitation stresses that professionals can adapt their approaches to the needs of the patient thus improving the relationship,

providing better self-awareness, leading to better collaboration and lessening conflict.

Mental Capacity Act 2005, Legal and ethical considerations

There are ongoing ethical and legal implications to consider, such as the Mental Capacity Act (MCA) 2005. The Mental Capacity Act 2005 sets out five core principles which underpin the legal framework for making decisions on behalf of someone who lacks capacity (Department for Constitutional Affairs, 2007). The 5 principles are: presumption of capacity, individuals must be supported to make their own decisions, people have a right to make unwise decisions, decisions for someone who lacks capacity must be made in their best interest and utilising the least restrictive option (SCIE, 2022). The MCA was designed with the aim of promoting and safeguarding decision making within a legal framework.

The MCA 2005 needs to be considered when determining whether individuals with a brain injury can make decisions about their care and support needs or discharge destination. It is crucial that individuals are involved as much as possible in making both short-term and long-term decisions. The person must be assumed to have capacity unless there is evidence to support otherwise and if they are not, it is still crucial to ensure that their views and wishes are considered (Clark-Wilson & Holloway, 2015). The challenge for professionals is to manage the tension between promoting people's rights and the duty to protect them from risk (SCIE, 2023). If too much emphasis is placed on rights, this can lead to safety issues and similarly a risk-adverse approach can impose unnecessary restrictions on people's rights and freedom. The Mental Capacity Act 2005 supports a move from a model of protection and paternalism towards a model of enablement and empowerment (SCIE, 2023).

The Social work model uses an ethos of empowerment and a strength-based approach with the responsibility given to social workers to holistically conduct assessments from a person-centred perspective to advocate appropriately for their needs (Linden et al., 2023). Differences between health professionals and social care professionals can result in some professionals who have difficulties with empowerment being labelled as risk-averse or paternalistic which has been seen to result in missing vulnerabilities or not safeguarding patients with ABI or patients with

ABI being wrongly assessed as having capacity (House of Lords, 2014; Flynn, 2016; Norman, 2016; George & Gilbert, 2018). A toolkit developed for practitioners exploring capacity in cases of suspected exploitation of people with cognitive impairment, recommends that MCA and related safeguarding decisions should involve multiple professionals and information gathering (Lambert & Fyson et al., 2025).

In exploration of equality under the law, a study on brain injury and mental capacity legislation conducted by Moore et al., (2019) argues that the MCA is not appropriately applied to safeguard people with brain injury particularly during the assessment process. The study identified that issues around executive dysfunctions (which causes issues with motivation, initiation, planning) and insight which are common effects of brain injury are often not considered (McDonald et al., 2002; Headway, 2023). This has resulted in people with brain injury making decisions which can be unintentionally self-harming or self-sabotaging (Moore et al., 2019). The study concluded that changes need to be made to the assessment process of the MCA in ensuring that the assessment does not rely only on what the person says but also on what they do (Moore et al., 2019). In addition to this, capacity issues are not set in stone and is a dynamic process. A patient may be capable of making decisions relating to a particular task but may not be capable of making decisions about a different activity or tasks (Lush, 2001).

The issue of executive dysfunction in the context of the MCA 2005 came under the spotlight and is critiqued in the case of TB v KB and LH [2019], where executive dysfunction was found to affect the person's ability to use or weigh up information to decide on a specific decision leading to a lack of capacity. This case emphasised that executive dysfunction is not a lack of capacity and care must be taken before finding that a person is unable to use or weigh up relevant information based on executive dysfunction. It is therefore crucial to follow the guidance set out in the MCA. The judge in this case suggested that support strategies could have been used to help P overcome the deficits of executive function.

Others such as George & Gilbert (2018) still argue that there is a flaw in the current MCA assessment process. In some cases, the MCA assessment is conducted by the

decision makers who are the Local Authority (LA) social workers in cases of post discharge care and support needs. The report pointed that these professionals may not be fully trained to understand the frontal lobe paradox. The person with brain injury may perform very well in the interview process of the MCA but in real function, are not able to manage the things they say they can. This can result in the patient's impairments and vulnerabilities being overlooked as they are masked by preserved language and verbal reasoning skills (George & Gilbert, 2018). Using corroborating information from family members has shown to be more in line with the assessment of the patient's deficits, compared to individuals rating themselves as less impaired (Sherer et al., 1998). As the LA are the final authority, they can overturn the outcome of the MCA assessment previous completed by other trained professionals within the multidisciplinary team (George & Gilbert, 2018). An assessment tool mentioned earlier, the Brain Injury needs Indicator (BINI) can be useful when there are concerns about the patient's capacity to make decisions about their care and treatment, when they refuse to engage in services, or when there are concerns about self-neglect or being unresponsive to interventions (Copstick et al., 2022). The BINI promotes collaboration amongst the MDT thus enabling social workers and other professionals to recognise the areas of deficits of the patient with ABI such as the effect on their cognition and recovery (Copstick et al., 2022).

From a practitioner's perspective, a study conducted by Foulkes et al., (2024) showed that health care professionals found it challenging to assess decision making capacity of people with ABI who have communication difficulties. This study highlighted the importance of presenting options to enable patients make an informed decision. Some professionals were observed not to present patients with options, instead they presented them with recommendations which they could either accept or decline. This is not in line with the NICE (2025) guidelines that the assessor should present options available in relation to the decision and the options should be presented in a balanced and non-leading way. It is noteworthy to be aware of the limitations of this study being small scale with 10 participants and the limited diversity in the professional group, there were no doctors, nurses or social workers in this study. Nonetheless, the study gave spotlight to the fact that health care professionals conducting mental capacity assessments require robust training. Similarly, George & Gilbert (2018); Odumuyiwa et al., (2019) and Cameron et al.,

(2022) conducted studies which stress the need for further training and development for social work practitioners to have greater understanding of those with ABI. Other studies have echoed this; Norman et al., (2020) paper into professional understanding of brain injury in the UK showed a lack of knowledge and understanding of ABI amongst a range of health and social care professionals. The findings show that to improve the outcomes for patients and families, professionals need to improve their knowledge of ABI and its long-term consequences (Norman et al., 2020).

Brown (2024) introduces the concept of a social model of capacity for social workers. It recognises the complex context of mental capacity and identifies autonomy as a key concept. The use of a social constructivist approach can enable professionals to challenge the unspoken assumption within the Mental Capacity Act 2005 that autonomy involves decision making in isolation from other people (Brown, 2024). Social workers can promote autonomous decision making (Brown, 2024) through the assessor's relationship with the person and their support network. There are several studies which explore the ethical issues during capacity assessments as identified by (Graham & Cowley, 2015) however there is limited literature which shows the assessment process, or the skills and experience needed for it to be carried out effectively. The main factor for quality assessment is ensuring relationships are at the centre of decision making and that supported decision making is good practice which is recognised both in the UK and internationally (Brown, 2024). Further, tensions between the duty to safeguard and uphold autonomy could be addressed through good communication, meaningful involvement and engagement of people during the assessment process (Brown, 2024). Panday et al., (2022) study also supports this viewpoint; that patient's autonomy can be increased by communicating with the patients about choice, educating patients and family members on the multidisciplinary team's decision-making process, providing consistent and up to date information to patients and their families. This is in line with the MCA 2005 that people can be supported with making decisions by providing them with all the relevant information that they need. Additionally, some patients with ABI may require support from a family member, carer or advocate hence, it is imperative to include the appropriate support network of the patient.

Cameron et al's (2022) paper into staff's perception and capability to carry out mental capacity assessment for people with ABI recognized that it is crucial that the most appropriate professional/discipline to carry out the assessment is identified. In local authority settings, social care professionals tend to carry out MCAs in silos, yet most have little or no knowledge of ABI and its effects. The health care professionals in Cameron et al., (2022) study reported that although social care professionals were competent in conducting capacity assessments; they were not experts in ABI and would need clinical support to carry out these assessments. The findings in a study on staff perception and capability to assess people with ABI showed that assessments by social care professionals with non-specialist knowledge of ABI are unlikely to be sufficient thus, a multidisciplinary approach is needed where specialist professionals who have knowledge of ABI support the assessment process (Cameron et al., 2022). Within a multidisciplinary team where there are social workers, the assessment can be jointly carried out with another professional within the MDT if it is in relation to ongoing care decisions or discharge plans. For instance, Neuropsychologist are trained in ABI and its effects on cognition, social workers and neuropsychologist can carry out the assessment together, considering real life examples also of how the person has evidenced what they say they can do. The participants in the Cameron et al., (2022) paper reiterated that the clinical expertise of an MDT approach was ideal, and that clinical psychologists have the skills to support this due to their knowledge in ABI effects on cognition, the MCA principles and the assessment process.

Transition from hospital to home

O'Shannessy et al., (2023); Odumuyiwa et al., (2019) have all stressed how the transition from hospital to home is a critical and challenging part of rehabilitation. They noted how it involves detailed planning between the patient, family and professionals. The findings of this study on experiences of people with ABI and their families during rehabilitation showed that communication and being involved in the decision making and discharge planning was a key positive experience for those involved. However, areas that could be improved were in relation to inconsistences in care, accessing information in easy-to-understand form and staff communication style (O'Shannessy et al., 2023). The study undertaken by O'Shannessy et al., (2023) utilized a thematic approach to analyze the data, whereas I would argue that

as the focus was on lived experiences, the qualitative part of the data would be better analyzed using a phenomenology approach to provide more in-depth insight into the experiences of the participants.

Other papers such as Odumuyiwa et al., (2019) have similar findings to that of O'Shannessy et al., (2023): that people with ABI require specialist long term care that is tailored to their individual needs which require effective communication, information sharing and inclusion of families and carers where appropriate as well as effective multidisciplinary working. This is where the role of the social worker during the period of community reintegration and assessment for long term support is essential in ensuring that the person receives appropriate community education, assessment of ongoing needs, signposting to specialist ABI services in the community, support with adjustment in the community, referral to support groups, advocacy as well as support for families and informal carers (Simpson et al., 2002). In supporting patients with ongoing needs, a diagnosis of ABI should automatically trigger specialist social care assessment over a period of time rather than a one off (Holloway & Fyson, 2016).

2.5: Summary

This chapter explored the current literature on risk, autonomy and self-determination as well as some of the ethical dilemmas that the multidisciplinary team may face. There was also an exploration of the role of the Mental Capacity Act 2005 in guiding professionals in assessing decision making as well as some of the limitations of the MCA in exploring the needs of people with ABI specifically in relation to executive dysfunction. The role of the social worker within the MDT was also explored during rehabilitation and planning for discharge back to the community.

CHAPTER 3: Research methodology

Chapter Overview

This Chapter starts by outlining qualitative research and the epistemological position of the study. This is then followed by exploring my role as an insider researcher. I then set out the research design as well as consideration of other methods, ethical considerations, study setting and recruitment. Finally, I discuss sampling strategies, data collection and data analysis.

3.1: Qualitative research

Qualitative research is used by researchers to understand human experiences and realities, through contact with the individuals in their natural environments and producing data which enables us to understand their experiences (Munhall, 2012). This study utilized a qualitative approach to understand the phenomena with emphasis on the meanings, experiences and views of the participants. Qualitative methods aid in prioritising and providing deeper insights into real world issues and the participants perspectives to increase further understanding of the phenomena (Tenny et al., 2022). This approach provided the experiences of the patients, families and professionals in decision making and further insights into how the multidisciplinary teams work together.

Qualitative methods enable researchers to bridge knowledge, understand meaning and emotions, generate tangible experiences, and reflective understanding (Carey, 2012). This type of research seeks to address social phenomenon, aid understanding of the context and circumstances in which we practice and provide an opportunity to gain insight into issues relating to policy, legislation, political, economic, or cultural influences which may impinge on the way we practice (Carey, 2012). Qualitative data focuses on depth as opposed to quantity of findings and helps to answer why, how and what the participants were thinking, feeling and experiencing compared to a quantitative approach which can be difficult to capture experiences, attitudes and behavior (Tenny et al., 2022).

Qualitative research is concerned with subjective experiences rather than objective facts, and findings are recorded in a written format as opposed to numerical and statistical forms (Tenny et al., 2022) Importantly for this study, qualitative methods

can give voice to marginalized and disempowered groups (Leeming, 2018). For example, Abrahamson et al., (2017) used qualitative methods in their study into the experiences of people with an acquired brain injury and their carers. This approach is common amongst social scientists and enables the researchers to examine the narratives of the participants, create meaning, capture nuances and context to their unique perspectives and experiences (Lim, 2025).

3.2: What is Phenomenology?

Phenomenology is a form of qualitative research which seeks to describe the phenomenon by exploring it from the perspective of those who have experienced it, in essence, lived experiences. It is a powerful approach of inquiry and aims to describe the meaning of the experience and is focused on the "what" and "how" of human experience (Neubauer et al., 2019).

The overarching research question guided the choice of methods and methodology. The aim of this study is to better understand the tensions that arise for the multidisciplinary team when balancing patients' risk, autonomy and self-determination during inpatient rehabilitation; and how this affects decision-making about discharge following rehabilitation. As this study sought to hear about lived experiences of patients, families and professionals, it was concluded that a phenomenology approach would be the most suited method to apply in this research. The next section will discuss the chosen theorist and rationale.

3.3: Philosophical foundations of Phenomenology

The epistemological position of this study is underpinned by a phenomenological approach, which is well-suited to address the research gaps that have been highlighted. Edmund Husserl, the founder of phenomenology, began his phenomenological research into the consciousness from the standpoint of the individual, (Moran, 2005). Husserl focused on bracketing with emphasis on philosophers setting aside their presuppositions (Neubauer et al., 2019). Heidegger challenged Husserl's idea, arguing that this was impossible as we live in a world where we all have pre-existing believes which shape our understanding of the world around us (Horrigan-Kelly et al., 2016). My approach in this study is therefore in line with Heidegger as shown in Figure 3 below. Utilizing a Hermeneutic

phenomenological approach as a social worker encourages engagement with the participants in a meaningful way, allowing the researcher to clarify and try out interpretations in a way that creates a broader understanding of the phenomena (Newberry, 2012).

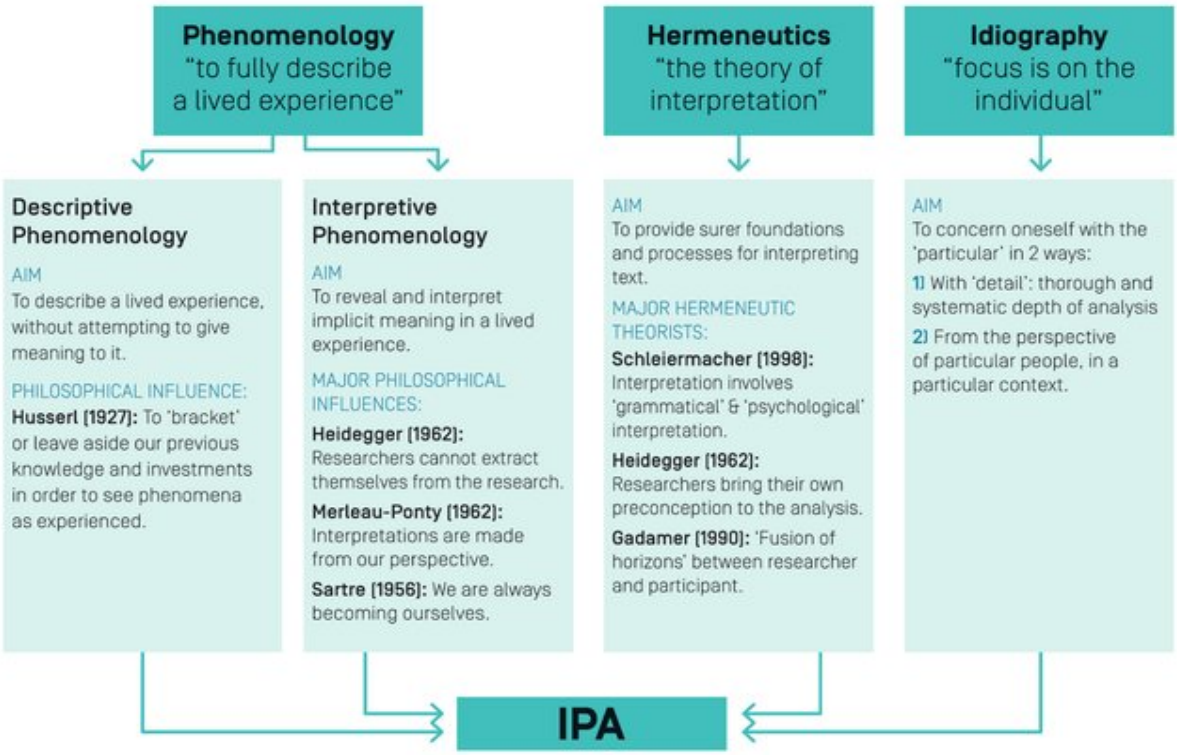

Figure 3: The three influences of IPA (adapted from Smith et al., 2009)

Phenomenology is a type of qualitative research based on the study of an individual's lived experiences within the world (Neubauer et al., 2019). As this study seeks to understand human experience, phenomenology was deemed to be most suited to this study. The study conducted by Andreoli (2010) utilised a grounded theory approach but acknowledged that questions of risk and safety could be explored with a phenomenology approach. Grounded theory was not deemed suitable for this study as it aims to develop new theory to explain a social process relating to an experience (Denzin & Lincoln, 2018) whereas, phenomenology seeks to deeply understand lived experiences. IPA aligns with my study objectives because it helps to gather rich data on the tensions that arise for the patient, family and professionals in decision making. IPA helps to understand how patients, families and professionals make sense of autonomy and risk. IPA's focus on lived experiences and meaning making correlates directly with the study's objectives.

3.4: Ethics

This study considered ethical issues in relation to participants including patients living with ABI to inform the recruitment and data collection process. Mentioned earlier was the need to be sensitive to participants, particularly patients with ABI who are still dealing with the effects of trauma. This section considers two main issues. First, the process of seeking ethical approval for the research. Secondly, issues relating to the selection and recruitment of participants to help ensure their wellbeing. Prior to the study commencing, IRAS project 343988 was completed and authorisation/approval was obtained from the Health Research Authority Research Ethics Committee (Reference 24/YH/0249) (See Appendix 3, 4 & 5). This ensured that the research proposal was in line with the guidance and principles set by the (Health Research Authority, 2023). The university also issued a Protocol number UH protocol number aHSK/PGR/NHS/02325(1) as the Sponsors (See Appendix 6).

The participants of the study were provided with a Participant Information Sheet (See Appendix 8, 9 &10). with the clear purpose of the research, benefits and risks of participation, assurances about confidentiality, and information on how to withdraw from the research at any point. Participants were reminded that their decision to participate or not will have no bearing on their care or ongoing relationship with the multidisciplinary team. Participants were then asked to sign a Consent form (See Appendix 11,12 &13) if they wanted to participate. The needs of patients with ABI were considered by ensuring that the information provided was verbally explained in a simplified way to ensure understanding of the process. Rather than excluding participants based on diagnosis, patients' ability to consent to interview was also considered in line with the Mental Capacity Act 2005 where appropriate. The researcher is a trained social worker with experience of conducting mental capacity assessments and anyone deemed to lack capacity to consent was excluded from the study.

Participants' wellbeing was considered throughout the data collection phase. The study sought to contribute positively to patients and society. It was recognised that reflecting on life changing diagnosis of ABI can be distressing for participants. Patients with ABI may become more emotionally labile therefore participants who were tearful and emotional during the interview were offered the opportunity to stop

the interview process, contact family/friends or professionals for support and, if necessary, withdraw from the study (UK Research and Innovation, 2023). There was a potential participant who was not recruited due to the researcher's insider practitioner role and knowledge of a potential safeguarding investigation. It was decided that the participant was going through a challenging time and therefore participating in research at that point was not deemed appropriate.

Additionally, the duration of the interview process was considered for patients with ABI as fatigue can be limiting, participants were offered a suitable interview time to meet their individual needs and breaks were offered if needed. Participants were also informed that any safeguarding concerns will be reported in line with the organisational policy and procedures.

The participants' data was collected, stored and processed in compliance with the requirements of the Data Protection Act 1998. The researcher and all investigators ensured that the principle of the Act is upheld. The data custodian was the Chief investigator and the researcher.

Due to resource limitations, the audio interviews were transcribed by the researcher and the use of Otter transcription tool (Approved by HRA). I went through each audio recording and transcripts to check for accuracy, and corrections were made as needed. Transcriptions were stored in a password-protected data management database folder specifically set up for the study and only accessible by the researcher. Personal identifiers and direct identifiers were removed from the transcripts and replaced with codes to protect the identities of participants and anyone else mentioned in the interview or observation (Stam & Diaz, 2023). Research data generated from the study may be kept for up to 10 years.

3.5: Study setting and structure of the team

The study took place in an inpatient Neurorehabilitation ward within an NHS hospital in Greater London. The ward offers rehabilitation for adult patients with ABI and other neurological conditions, across Southeast London. The rehabilitation team is led by a Consultant rehabilitation medicine physician working with a multidisciplinary team (MDT) consisting of ward doctors, nurses, occupational therapists,

physiotherapists, speech and language therapists, neuropsychologists, neuropsychiatrist, dietitians, activities coordinator, rehabilitation assistants and social worker. As part of the admission and discharge planning process, the MDT also liaises with external services such as ophthalmology, orthotics, neurosurgery, neuro-urology, integrated care boards, neuro-navigation service, social services, housing, community rehabilitation teams and charities.

Patients within the setting have a named rehabilitation coordinator who was the key person responsible for sharing information between the patients, family and the multidisciplinary team. During their initial admission, the MDT professionals complete a holistic assessment of the patient. This is to explore how the brain injury has affected the patient, including physical, cognitive, emotional, behavioural, and social difficulties that the team and patient may identify. The MDT work collaboratively to set patient-centred goals. Some sessions are completed jointly with other members of the MDT for example, if specialist support is needed from Speech and Language therapist due to the patient's communication needs. The MDT work within a rehabilitation pathway which is tailored to the needs of individual patients. Patients have several meetings with the MDT for information sharing along the rehabilitation pathway such as initial family meetings, mid-way meetings and discharge planning meetings. Patients and families attend these meetings and participate in discussions about their rehabilitation progress and support needed post discharge. At times, these meetings involve other external professionals such as social services especially during the discharge planning phase. Information is also shared amongst MDT in various forums such as handover meetings. Multidisciplinary team meetings take place biweekly to enable the MDT to collaboratively review each patient's progress, discuss barriers, update goals, escalate and resolve issues pertaining to discharge planning.

The practitioner researcher's study was conducted on a Level 2b neurorehabilitation ward, which serves patient with high but not complex needs compared to the Level 1b ward were the researcher works as a social worker. This distinction was made to avoid researching patients under my direct care. The length of stay for patients on the Level 2b ward was up to 12 weeks.

3.6: Sampling technique

Purposive sampling is defined as a strategy used to select participants that are most likely to yield useful information based on the aims and objectives of the study (Campbell et al., 2020). The patient participant group was chosen because this study is about them, and their experiences and it is important to ensure that their voice is heard. The family/carers are also important during the rehabilitation process, and they are involved in the decision-making process of the patient. It is also crucial to hear from the MDT professionals involved as they make recommendations about the ongoing needs of patients. Hearing from the MDT professionals would be useful in highlighting some of the professional differences/cultures between the team members and how this can influence their decision making.

3.7: Recruitment

In keeping with the Data Protection Act (1998) and Hospital Policy, accessing patient personal data directly for the purposes of research was avoided by working with the ward team to identify eligible patients. In addition, the ward staff advised on which patients were well enough to be approached about the study. That is, that they were not currently acutely unwell. As noted earlier, some patients with brain injury may also be going through a difficult time emotionally, so it was important to check with the ward staff that it was appropriate to meet with them to avoid any additional distress. The process was that patients/family were first given an invitation letter by the ward staff to gain their consent for me to approach them about this study. Secondly, if they agreed, I approached them and gave them information about the study and the provided them with the Participant Information Sheet (See Appendix 8,9 &10), so they had time to reflect on whether they wished to participate. Participants were given at least 48 hours before following up on whether they wished to proceed. For professional team members, I was able to directly approach them, although, the process was similar as regards to information giving and the Participant Information Sheet.

The researcher obtained signed consent prior to any interviews being conducted (See Appendix 11,12 &13). The patient participant group having sustained an acquired brain injury required issues of capacity, (under the Mental Capacity Act 2005) to be considered. The researcher is a registered social worker, and trained in

assessment of capacity, therefore, able to assess their ability to consent to the study. Patients who lacked capacity were not included in the study as they would not be able to provide consent. Additionally, it was planned that, if a patient had fluctuating capacity and they lose capacity during participation, the researcher would terminate the interview. Fortunately, this situation did not arise. Similarly, it was stressed to participants that if they would wish to withdraw from the research at any point, they would be supported to do so, that is, their rights, dignity, and wishes would be fully respected.

Participants (Inclusion/exclusion criteria), participant recruitment

Eligibility criteria	Inclusion criteria	Exclusion criteria
• Patients with a Brain injury diagnosis admitted to the ward for inpatient rehabilitation. • Family/Carer of a patient with Brain injury. • MDT professionals must work within the neurorehabilitation ward.	• Gender: ANY • Age range: 18 and over • Ethnicity: Any Ethnicity • Any Socio-economic grouping • Clinical condition: Brain injury diagnosis • Capacity to consent • Location: Inpatient rehabilitation	• Outside of stated age range • Outside stated of location • Outside of clinical condition • Medically unwell to take part • People who lack capacity • People who are non-English speakers or needed specialist Speech and language therapy support

Figure 4: Participants eligibility criteria, Inclusion criteria and Exclusion criteria

3.8: Data Collection (Interview procedure, development of topic guides & Participant demographics)

Interview procedure

Face-to-face semi-structured interviews were conducted with three cohorts of participants: patients with ABI, their family/carers, and professionals. Face-to-face interviews were deemed better suited as it allows the interviewer to select a conducive environment and create a positive atmosphere (Opdenakker, 2006). It is well known that distractions can be problematic for patients with ABI so, remote interview where the researcher has little or no control over the external environment can be disruptive (Deakin & Wakefield, 2014). For other participants groups such as

professionals and families, remote option was considered as some participants may feel more comfortable in familiar environment and be able to share their experiences better (Hanna, 2012; Orchard & Fullwood, 2010). However, face to face interview allows the researcher to pick up on body language and other nonverbal body cues which humans rely on to communicate effectively may not be possible via other methods such as telephone or video interviews (McConnon, 2020). The interviews were recorded via a digital audio recorder.

The aim of the study was to explore the factors that influence patients, families and the multidisciplinary team when balancing risk, autonomy and self-determination. As the study utilized phenomenology, interviews was identified as the best method to use to elicit information from the participants. Semi-structured interviews were deemed to be the most appropriate method to answer the research question as it relies on participants reflection of their experiences (Lauterbach, 2018). By utilizing a Phenomenological approach, researchers can examine the lived experiences of participants explicitly yet flexibly through the structure that Phenomenology provides (Bevan, 2014).

Semi structured interviews offer a flexible framework through combining a set of questioning directives with open ended approach thus enabling a thorough investigation of the participants lived experiences, consisted with the principles of phenomenology (Ruslin et al., 2022). Semi-structured interviews are a process of obtaining the experiences of the interviewee with the aim of interpreting the meaning of the identified phenomena (Brinkmann, 2014). This approach has been successfully employed in similar qualitative studies by Andreoli (2010) and O'Shannessy et al., (2023) both arguing that this approach enabled the experiences of participants to be further explored. In comparison to unstructured interviews, the interviewer can guide conversation on areas which are deemed important as part of the research project.

The interviews took place at the NHS hospital site in a private room. The interviews were recorded by audio with participant consent. The interviews were up to 45 minutes in length. Participants were given the opportunity to have breaks if required. Some participants were emotional and supported with tissues and the interviews

were paused as needed and then continued as per the wishes of the participants involved. Reflecting on experiences of living with ABI can cause participants to experience emotional distress (Carlsson et al., 2007). An awareness of this allowed me to be prepared to provide adequate support to participants as needed. (See Interview Topic Guides for all participants in Appendix 14,15 &16).

Development of interview topic guides

The interview topic guides were developed after conducting the literature review and finalizing the aims and objectives of the study. With the support of my academic supervisors, the questions were checked to ensure that they would answer the research question. The topic guides were in line with phenomenology research consisting of open-ended exploratory questions (See Appendix 14,15 &16) allowed participants to focus on their lived experiences whilst focusing on the core of the research questions (Tavakol & Sandars, 2025). Although there were predetermined questions, the semi-structured method was flexible enough for me to be able to probe further to delve into the participants unique experiences.

Participant demographics

Specific demographics such as age, ethnicity or gender was not asked of the participants to protect participants privacy. Information about the roles of professionals, previous jobs or professions of patients/families arose in the interview. Due to the nature of the research being qualitative, the focus was on exploring findings from specific groups of people, in this case patients with ABI, and their families and professionals who work in the rehabilitation wards.

Qualitative research provides a processed based, narrated data closely linked to human experience, hence there is a degree of trust one has for the researcher (Stahl & King, 2020). Qualitative research requires four general criteria to ensure trustworthiness: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Credibility is assured by engaging with different types of participant groups to meet the study aims and using reflexivity to acknowledge personal biases (Ahmed, 2024). The concept of transferability in qualitative research is a process of abstraction used to apply findings from a specific study that can be applied to other contexts, settings or group of people; it is not commonly discussed in social sciences

and social work literature (Drisko, 2024). This study ensured transferability by describing the steps taken in the research process, data collection and analysis as well as any potential biases due to being an insider researcher. Dependability is about detailing the research procedures and providing an audit trail of the study process (Ahmed, 2024). Finally, confirmability requires the researcher to keep track of thoughts, biases and reflections throughout the research process to provide insight into the researcher's subjectivity thus contributing to the confirmability of the findings (Ahmed, 2024)

Table 5 below shows:
12 Semi-structured interviews conducted across three participants groups.
Patients N=4
Family/carer N= 1
MDT professionals N=7

Patients with Acquired Brain Injury	Family	Professionals
• 4 - All Brain injury diagnosis	• 1	• 1 Dietitian • 1 Doctor • 2 Nurses • 1 Occpational therapist • 1 Psychologist • 1 Social worker

Table 5: Participants demographics

3.9: Qualitative Data Analysis Methodology

Interpretative Phenomenological Analysis

The data analysis was guided by Interpretative Phenomenological Analysis (IPA). IPA was used in this study because the research objectives focused on the understanding the participants lived experiences in the context of ABI. It is useful for examining topics which are complex and emotionally laden (Smith & Osborn, 2015). IPA is rooted in phenomenology and provides an examination of a person's lived

experience, the meaning of this experience to the participants and how they make sense of it (Smith & Osborn, 2015). IPA is often described as a double hermeneutic or dual interpretation process because the participants try to make sense of their world and then the researcher tries to decode meaning to make sense of how the participant made sense of their world (Smith & Osborn, 2008). IPA is in line with the Heideggerian philosophy with the underpinnings guided by three theoretical influences: phenomenology, hermeneutics and ideography (Shinebourne, 2011).

In a similar study which used IPA, exploring the impact of traumatic brain injury on those close to the survivor, such as, a family member or friend, the researchers practiced reflexivity by referring to the interview transcript to ensure that the interpretation of the data was valid (Townshend & Norman, 2018). I used reflexivity and supervision which are vital components of a holistic approach to IPA (Vicary & Ferguson, 2024) which involves self-awareness, looking inwards and exploring what is happening from different angles. Reflexivity needs to be an authentic aspect of the IPA process, to be aware of our own emotions, ethics, boundaries and biases (Vicary & Ferguson, 2024). I used the annotations function on NVivo software when completing the data analysis to reflect on what was going on, make initial observations and notes. NVivo data management system works well with a range of qualitative research designs such as phenomenology (Zamawe, 2015).

Uprichard (2009) study into the experiences of the process of adjustment to a brain injury used IPA to present the participants experiences. The use of IPA by Owen et al., (2017) in their study on decision making capacity also explored the data translation in an interpretative way, paying close attention to the in-depth interview data from patients with ABI. Reflexivity enables the researcher to demonstrate transparency and the audit trail of data collection and analysis process and contributes to trustworthiness ((Vicary et al., 2017; Lincoln & Guba, 1985).

Figure 5: The seven-steps of IPA data analysis (Charlick, McKellar, Fielder, & Pincombe, 2015 adapted from Smith et al., 2009

Within this study, I used the 7 steps of IPA outlined by Charlick et al., (2015) who adapted it from Smith et al., (2009). IPA was used to identify patterns, themes and meanings and understand how the participants make sense of their experiences (See Figure 5 on the 7 steps of IPA data analysis). Comparisons were also made between the experiences of the MDT professionals and how their professional values/culture influences their approach to balancing patients' risk, autonomy and self-determination. IPA enables researchers to understand the intricate experiences of those affected by societal challenges (Hartman & Squires, 2024). This study offers a social workers perspective and IPA is suited to the skill base of social workers; in the traditions of double hermeneutics, social workers complete interviews in an open way and then critically analyze the information (Vicary & Ferguson, 2024). IPA fits with social work professional values and allows the researcher to become immersed or immerse themselves in the subjective worlds of participants. A critique of IPA from a social work perspective is its psychological depth and that other factors may not be considered; Todorova (2011) suggested that its application needs to be broadened to allow for socio-cultural factors to be considered.

3.10: Data transcription

Transcription is a crucial part of qualitative research. Transcription is the process of reproducing spoken words from an audio recorded interview into written text; a record of what a participant said in response to a question, in their own words

(Halcomb & Davidson, 2006; Saunders et al., 2019). A similar viewpoint is that data transcription is a part of qualitative research which seeks to capture the meanings of occurring phenomena in social encounters and that these phenomena can be best captured through talking or stories constructed by the participants and the researcher (Widodo, 2014).

In this study, the interview was recorded on a digital recorder. I then listened to each interview, went through the transcript to ensure accuracy. The first step in transcription involves careful listening of the data, paying attention, being familiar with the data and being open to what is there rather than what is expected (Bailey, 2008). Data transcription must be congruent with the methodological design and theoretical underpinnings of the study (Halcomb & Davidson, 2006) and in this case, the essence was to capture the lived experiences of the participants.

3.11: Coding

A computer software program called NVivo was used to code, manage and analyse the qualitative data (Dhakal, 2022). Using the seven steps of IPA, I analysed the data as follows:

Step 1: Reading and re-reading

I began by familiarising myself with the data again. I listened to the audio recording of each participant individually then went through each individual transcript and made corrections and where names of people were mentioned, this was removed. I then printed out the transcripts and read each transcript again. I created a title for my project on NVivo and imported each transcript on to NVivo. I also created a Project Journal on NVivo to provide an audit trail of each step I took within the process and when.

Step 2: Initial noting

I used a combination of digital (NVivo) and paper-based approach. I manually selected one transcript at a time and used a highlighter to highlight key areas/segments of the transcript. I then did this on NVivo, highlighting key areas of each individual transcript and then using codes to capture initial meanings and concept of each case by using a descriptive phrase. After creating the individual

codes on each transcript, I then used annotation on NVivo to make exploratory and reflexive notes of my thoughts as well as the initial interpretations of the participants experiences. These notes were my initial thoughts on what the participants were saying.

Step 3: Developing emergent themes

Coding/codes are used to break down participants experiences into small parts for detailed analysis and understanding of their lived experience. In NVivo, coding is used to put together extracts (across documents) that are related to each other (Zamawe, 2015). After coding all the transcripts, I then developed the initial codes into higher level emergent themes to represent the participants lived experiences. I created a code structure to organise the themes and sub-themes.

Step 4: Searching for connections across emergent themes

I finalised the higher-level codes to represent the experiential themes across the entire dataset. I also used NVivo concept map to visualise the themes. (See Appendix 17: NVivo Qualitative Data Analysis)

Step 5: Moving to the next case

I then repeated the process by moving on to the next transcript and repeated the steps.

Step 6: Looking for patterns across cases

After analysing each transcript individually, I then looked for patterns across each participant group. i.e. for all patients and all professionals. I only had one participant for families and was able to explore this in detail.

Step 7: Taking interpretations to deeper levels

I had various supervision sessions with my supervisory team during each step of the IPA process to discuss the lived experiences of the participants. This enabled me to delve into the meanings of the participants experiences and how their experiences shaped their understanding. Conducting post interview debriefing also enhanced reflexivity and enabled me to explore my own emotional response that may be blocking understanding of the participants lived experiences. For example, I

discussed the role of the social worker within the MDT but had to ensure that I focused on the participants experiences rather than my own practitioner role. This was at times challenging and supervision enabled me to explore the nuances within the data, with a genuine focus on staying true to the voice of the participants.

I explored the interpretations, identified the commonalities and differences within the participant groups and made interpretations of the lived experiences of the participants. I then wrote down my findings. I was able to visualise the data using the coding stripes on NVivo. I extracted the text coded to a specific theme along with supporting participant quotes which will be presented in the findings section. (See Appendix 17 for NVivo Qualitative data analysis).

CHAPTER 4: Findings

This chapter presents the findings from the interviews using an interpretative analysis approach from in-depth interviews across the three participants groups of patients (n=4) family (n=1) and professionals (n=7) experiences of how patients' autonomy and issues of risks are managed in brain injury inpatient rehabilitation. The chapter presents a narrative of my findings supported with relevant direct quotations from the interview data. I present the factors which influence decision making as well as issues of risk and safety.

Table 6 below is an overview of the 12 participants and the names given to them to maintain confidentiality.

Patients	Family	Professionals
P001	F001	S001
P002		S002
P003		S003
P004		S004
		S005
		S006
		S007

Table 6: Participants

Based on all the interviews, the following 4 overarching themes were identified through review of the transcripts, and these are: promoting patients' right to autonomy and self-determination, differing perspectives of patient, family and professionals about risk, legal and ethical considerations in decision making and discharge planning, resource constraints and the role of the social worker. 3 of the overarching themes had subthemes based on the lived experiences of the participants (See table 7).

Findings Themes & Subthemes			
Theme 1: Promoting patients' right to autonomy and self-determination	**Theme 2: Differing perspectives of patient, family and professionals about risk**	**Theme 3: Legal and ethical considerations in decision making**	**Theme 4: Discharge planning and resource constraints: Role of the social worker**
Subtheme 1.1: Professionals and patients' perspectives on Autonomy and self-determination	Subtheme 2.1: Attitude to Risk		Subtheme 4.1: Discharge discussions and resource constraints
Subtheme 1.2: Participation and patient engagement in recovery	Subtheme 2.2: Hierarchy/Power imbalance and Culture of the team		Subtheme 4.4: Role of the Social worker
Subtheme 1.3: Family involvement and support network	Subtheme 2.3: Risk assessment and management		

Table 7: Findings Themes and Subthemes

Theme 1: Promoting patients' right to autonomy and self-determination

Promoting patients right to autonomy and self-determination in rehabilitation is centred on empowerment and supported decision making. The following subthemes will be explored in detail: professionals and patient's perspectives on autonomy and self-determination, participation and patient engagement in recovery and family involvement and support network.

Subtheme 1.1: Professionals and patients' perspectives on Autonomy and self-determination

The concept of autonomy and self-determination was viewed as an important aspect of rehabilitation across the professional interviews. However, there was recognition of the need to balance these with patient safety and risk management.

Professionals recognised the need for patients to be involved in making decisions about their care and that patients need to be involved in setting their own personal goals and take ownership of their own recovery for example during goal setting. This indicated an approach of patients having free will, choice and control over their care and goals.

> *"I make sure that the patient have freedom to be where he is, have freedom and a free choice of what he would have, what care he would choose". S001 (Doctor)*

> *"So in terms of autonomy, in general practice and evidence based practice, there's a real push about service user autonomy, so we include that here as much as possible, and things like goal setting, making sure our programs try and support autonomy. We include it in so goal setting, our therapy should be supporting autonomy where possible". S002 (Occupational therapist)*

Patients had their own personal views on what was important to them in respect of their autonomy. The approach of goal setting was affirmed by a patient participant who described goal setting sessions; that they enable patients to prioritise what was important to them and allowed this participant to feel active in their own care.

> *"Yeah I had goal setting every week, which I did, like, achieve my goals in less time than I was given. Right? Normally do it every two weeks, but I was doing it within a week because I push myself. But yeah, they always ask me what I want to do in my sessions. Very supportive and allow me to make my decisions, rather than just tell me". P002 (Patient)*

To achieve patient autonomy, professionals need to be aware of what is important to patients and what goals they are trying to achieve. For one participant, walking was

a goal along with the need to get feelings back in their arm which indicated feelings of grief and loss.

> *"I need to be walking again. I need my feeling back in my left arm. I don't have feelings in my left arm. I want feelings". P001 (Patient)*

According to a professional participant, a person-centred approach is used to promote patients' autonomy, which is in line with social work practice. Understanding the personal view of the patients enables professionals to understand their perception of the patient's own needs.

> *"We promote autonomy by ensuring that the process, the processes that are needed to be put in place to work with patients, because it's actually a person centered approach for the patients we use, so we ensure the working together from a multi disciplinary team promotes autonomy for the patient". S003 (Social worker)*

A patient participant described that personal dignity was affected due to the stroke especially in relation to managing personal care tasks. Being able to manage this independently was important to the patient hence involving patients in care planning discussions is central to promoting independence and choice. They commented on finding the loss of personal dignity "extremely difficult to cope with" which shows not just the physical implication of the stroke, but the emotional effects which drove self-determination of wanting to be independent in this area.

> *"For me, I wanted to be independent as possible, particularly on personal care, because as far as I was concerned, the whole having a stroke thing took away my dignity, and I found that extremely difficult to cope with. So when I came here, the first thing I wanted to do was be able to get to the point where I could have a shower by myself. I could go to the toilet, not necessarily by myself, but they would leave me in the toilet". P004 (Patient)*

Patients are encouraged to make decisions about their own care even if it goes against professional's advice or clinical information. Professionals reported that patients are supported with making informed decisions on the basis that they have the right information about the pros and cons of the decision.

“So with autonomy regarding sort of patient care, I would feel like we need to be able to provide, let patients make their own decision around their care, because they are the patient at the end of the day, and they should be able to make their own decision, however sound or unsound it might feel to us, if we provide them with the right sort of advice, present with the pros and cons and things like that, we still should be let them make that final decision around their care”. S004 (Dietitian)

Patients are encouraged to make independent choices and decisions during aspects of their nursing care according to a nurse participant. The word “challenge” denotes that patients need great mental and physical effort to become more independent.

“I'm trying to challenge this patient to realize how they could be more independent of the situation that they are in the moment”. S005 (Nurse)

Some patients however didn’t always meet their rehabilitation goals. The family member participant reflected that their relative who had a brain injury couldn’t walk independently but still needed support and that they felt let down by the lack of progress in the patient’s recovery.

“He feels, he feels a bit let down because he thought he was going to be walking when he came out of here. He can walk with a quad stick, but still with assistance of one” F001(Family)

There was consensus amongst professionals that were interviewed about what autonomy meant. Professionals prioritised autonomy as being fundamental for psychological health, a sense of purpose and recovery. When patients are supported to make decisions and direct their own care, they are more likely to be engaged in their rehabilitation (Hickmann et al., 2022). Professionals emphasised the importance of fostering patient’s independence and involving them in decisions around their care so that they feel more empowered to work towards their rehabilitation goals.

“So autonomy is it's so important in the sense of, for me, it's about the sense of personal control to direct your life, to be able to feel a sense of ownership over the

things that you're doing, where you're heading for and it's psychologically it's really important for people's sense of themselves and kind of psychological well-being really". S006 (Neuropsychologist)

"I think basically just means independence, really, and then, being a rehab ward, we kind of like involve patients to be to be autonomy in their in their day to day activities. That is why they've come into the rehab unit in the first place. So to make sure they're able to do things on their own, we kind of like prompt them to be able to carry out the activities that do aid their early discharge out of the rehab for them to achieve what they have come on the ward really". S007 (Nurse)

Subtheme 1.2: Participation and patient engagement in recovery

The interviews for both patients and professionals showed that participation and patient engagement during rehabilitation are important components to recovery.

A patient said they took ownership of their own recovery, such as going to the therapy gym when needed.

"And I'm also allowed to go in the gym by myself, as long as someone else is there, and use the facilities however much I like, which I do, when I don't go in there all day, every day, they like sending out the search parties". P002 (Patient)

Patients expressed that they were involved in their care, and one patient discussed the importance of their medication being administered at a specific time, highlighting their sense of achievement at making their own decision and being listened to. Active participation such as these may motivate patients and foster independence and a sense of ownership in the rehabilitation process.

"I've been involved in my care. I've been open, and I've always left feeling that okay, this is what I need to do. P003 (Patient)

"I actually requested from one of my blood pressure tablets to be moved to 8pm instead of 10pm because my blood pressure was spiking at the end of the day, where I'm so active, So I said, bring it forward. And they did it. So that was my decision". P002 (Patient)

Some patient participants emphasised that having the “right attitude” was essential for successful recovery and engagement in rehabilitation. They stressed that determination made a great difference and provided an example of working with the professionals on skills to aid independence even if initially they questioned it.

> *“If you've not got the right attitude, you'll never get better anyway. You gotta be 100% determined and 100% positive as much as you can. Nobody can be it all the time. Even I couldn't do it all the time. I did. I have tried, but I couldn't. But providing you can do it the majority of the time, and you try everything that they suggest” P004 (Patient)*

One patient participant highlighted the importance of personal engagement and building positive relationships with staff, which in turn fosters a supportive environment. They credited their own active participation for achieving greater independence such as the example of cleaning out the cupboards and cutting onions and didn’t particularly enjoy being told what to do. There was a sense of fierce independence in how this participant spoke about their experience.

> *“They had me cleaning out the cupboards in the kitchen, and I'm standing there thinking, what? I'm cutting up onions? Yeah, I'm thinking, but I can cut up… onions. I'm 54, years old. I think I've cut a lot of onions in my life and then when you think about it, it's not about what you're doing, it's about how you do it. And they're trying to make you safe in your environment” P004 (Patient)*

Professionals reported that patients were encouraged to practice their skills during and outside of therapy sessions. An occupational therapist spoke about how they promoted self-management and gave examples of exercise programs given to patients to complete outside of their therapy session.

> *“There might be exercise programs where possible, getting the patients to be doing those sorts of things you have practice outside of therapy sessions”. S002 (Occupational therapist)*

A nurse participant agreed that patients are given exercises to practice at the weekend as therapists are not available over the weekend. Another professional explained that evidence shows that repetition was helpful in aiding patient recovery. These ways of working are in line with promoting independence, collaboration and patient involvement.

> *"To do exercises on Saturday, Sunday. We don't have therapies, but we are encouraging the patients to do the exercises and to ask the therapist for some exercises, to give them during the weekend and not to stay and wait for 30 minute session on the day, just to work towards the discharge". S005 (Nurse)*

> *"The evidence suggests that you know, for example, a physical aspect of recovery and, you know, or sensory plasticity, that repetition is what's needed so often, that is helpful As well, on lots of different ways. Yeah, so that, you know, people are not it's not just a therapist doing something to that person and they're taking some control ownership". S002 (Occupational therapist)*

Professionals reported that families were encouraged to be involved in patient care so that they are prepared for what to expect on discharge. A nurse participant acknowledged some challenges around discharge and talked about the fear of the unknown and how this can cause anxiety around the time of discharge. The statement "looking for every opportunity to delay the discharge" however indicates some frustrations that some professionals may experience when they try to balance the patients' needs versus the needs of the service.

> *"But as the discharge is coming up, fear of unknown. Patient is quite anxious and not wanting to go really looking for every opportunity to delay the discharge. But at least we will be able to speak to family. You say home is home, home environment is home environment. And these are the things that could be happening at home and actually involve them in the patient care while in so that they know exactly how home is going to be like". S007 (Nurse)*

Some barriers to participation and engagement were noted with some patient participants reporting factors such as communication difficulties, fatigue, and

emotional distress. Staff need to be flexible and adapt based on the needs of the patients.

> *"It's okay. I've got emotional liability now, where my emotions are moving to the surface". P002 (Patient)*

> *"One of the major factors of having a stroke is that you get tired unbelievably quick". P004 (Patient)*

> *"Yeah, but I do get all fatigue. It's like post stroke fatigue, yes, but I push myself and then I crash like, just crash out". P002 (Patient)*

> *"I've become a toddler. And because that's, that's what it felt like, because I had to start learning how to speak". P003 (Patient)*

Subtheme 1.3: Family involvement and support network

Family involvement is an important part of brain injury recovery (Bogner, et al., 2019). A family member valued being included in the rehabilitation programme. The participant mentioned "his short-term memory is not very good". This could be related to still going through an adjustment period of trying to understand how the brain injury presents for their loved one.

> *"Don't think there's anything that I could be more included in basically, because I'm here for a lot of his sessions, whether it be speech therapy, physio, occupational therapist, I do try to be here because part of the reason is like I say his short term memory is not very good, and if I asked him how he got on with a certain session, he might not remember exactly what he did or the information he gives me, it might be what he wants me to hear and not what the truth was". F001 (Family)*

Other patient echoed the importance of family involvement and emphasised how a strong support network provided them with emotional and communication support.

> *"My daughter's been, she's my rock"…… "She's been involved in everything all the way through. So she can, she's probably the first, is the early, earliest person to understand what the things that I'm trying to say". P003 (Patient)*

Professionals highlighted the complex roles family members play particularly parents in patient care and decision making. A neuropsychologist participant emphasised the need to respect patients' autonomy and ability to make informed decisions whilst ensuring the family does not substitute decision making that could undermine the patient's legal rights. This participant reflected on their own mothers' maternal instincts of protection and care and the universal tension that arises between protection and the freedom to make decisions.

> *"So there was a mother involved, and she was very strongly against all of the drug use and the influence, the sort of circle of influence around that, the risk with that was that she she almost became the sort of proxy decision maker. And again, it was that just because she seems to be making these sort of maternal instincts, but equally, would anybody else want their mother making all their decisions for them? Because, you know, my mother would wrap me up in cotton wool and would say, you know, oh, don't go to work if you don't feel… And actually, we all know that we want to make our own decisions". S006 (Neuropsychiatrist)*

Families are also impacted by the brain injury as highlighted by a family participant who reported the financial impact of closing their joint business. "It's hard work" showed the detrimental effects of brain injury. The family participant became emotional during the interview, and I had to provide a break which she had, and she wanted to continue. This emotional response highlighted the continued impact of brain injury for family members, and I reflected on my professional instinct to offer solutions at this point, but I had to maintain my stance as a researcher, not a practitioner and so I continued the interview as per the participants wishes.

> *"It's hard work. I'm trying to because we had our own business. We've closed that down now, so I've had to deal with all that. I've been dealing with finances". F001 (Family)*

There were other examples about how family members were included in discussions with the patients and the professionals.

> *"My husband and my daughter were included in, in the discussions that were had. Yeah, and they still are being included". P004 (Patient)*

"We tell the family exactly what we are doing, reasons why we are doing them, and what we expect them to do in the community". S007 (Nurse)

A family member's search for meaning was evident, "you've got to find something to blame". It also highlighted the adjustment and the gradual shift of coming to terms with the reality of the situation.

"Is there anything I could have done to prevent it? Was it my fault? Should I have made him take more time off work and everything, you know, no, but that's you start to blame yourself after a while, and because you seem so different, you know, you've got to find something to blame, even though you know it probably wasn't your fault". F001 (Family)

Theme 2: Differing perspectives of patient, family and professionals on risk

Throughout the interviews across all participants groups, there was emphasis that patients, family and professionals had differing perspectives on risks often due to personal and professional priorities. This will be examined in more detail within the identified subthemes: attitude to risk; hierarchy/power imbalance and culture of the team; risk assessment and management.

Subtheme 2.1: Attitude to risk:

It was clear across the three participant groups that risk was viewed differently. Patients, family and professionals had differing attitudes to risk, and this can create tension between the patient and professionals' dynamics as well as between the team.

For patients and families, there were discussions around attitudes to risk prior to the brain injury. A family member reported their loved one was in construction which is a job with a lot of physical risks attached to it. They took more risks than the average person. Having a job role which involved risks however did not necessary mean that the patient took more risks than others. Understanding the patient's attitude to risks is important in assessing their attitude to risk prior to their brain injury.

"Being…., we have scaffolding up and things like that. And there'd be times where I wouldn't feel safe going up scaffolding because there was something not right, or something Yeah. And he'd say, oh, it's alright. Don't worry. Let me go up. And he'd go and do it whatever it needed doing, you know? So yeah, he would take risks and that." F001 (Family)

Another participant who was in construction made a comparison between their previous job and being told to wait for nurses before mobilising. Understanding the job role of participants may help professionals understand why they may be "taking risks" on the ward. "Compared to what I'm doing here, it's nothing" the patient's perception of going up on roofs in comparison to attempting to transfer without supervision provides an insight into how they viewed risks.

"I'm up on roofs every day, so do I take risks, all roofers do. We all take risks; we risk our lives every day" P001 (Patient)
"Compared to what I'm doing here, it's nothing' P001 (Patient)

Some professionals had different attitudes to risk, and some made comparisons about how they viewed risks in their personal lives in comparison to their job role. A nurse participant felt that positive risk taking was an important part of their job. This is a term often linked to choice and control and promoting independence. A neuropsychologist felt that their attitude to risk was somewhere in the middle.

"I believe that our job is positive risk taking" S005 (Nurse)

"I think in my own appetite for risk is well, fairly mixed bag, I suppose, and probably somewhere in the middle" S006 (Neuropsychologist)

A participant mentioned that some professionals feel anxious about patient risk taking and that risks should be a collaborative process between the team and should not fall on one person. This argument is in line with the way professionals reported they assessed risks in their interviews, which involves different disciplines working together to identify the risks and how they can be mitigated.

“I think a lot of it just comes from anxiety. So those who are less likely to take the risk that comes from an anxiety and that's really uncomfortable. So if you are that clinician with that patient who's taking all those risks, you need the support of the whole team to sort of validate that this is, this is okay. I don't think it should fall to one individual” S006 (Neuropsychologist)

A medical professional discussed issues around a patient being aggressive and how they would always try to have “zero risk”. This indicates their personal value on aggressive behaviour and reflects the organisations zero tolerance of violence to staff. However arguably, it is not clear how any risk can be removed completely especially when there are challenging behaviours to staff.

“I will always try to make the risk zero against myself and against my staff”. S001 (Doctor)

Subtheme 2.2: Hierarchy/Power imbalance and Culture of the team:
There were issues around hierarchy and power imbalance amongst professionals which they felt could affect decisions around risk for patients. The participants spoke about their role within the team and how they perceived decisions were being made and which professional group had more say.

For one nurse participant, the views of therapists were given more weight within the team and indicates the perceived dominance of this professional group. This could lead to other professionals in the team feeling that their professional opinion isn’t as respected amongst the others or in comparison to others.

“If I've assessed, and I think from my side, this patient can actually be discharged home, and the therapist feels its unsafe, I'm going to step back, because if anything happens, they’re going to go, oh the therapist did say the patient was unsafe.” S007 (Nurse)

Other professionals felt that risk should be shared. This can however be cumbersome if there is no consensus on how risk is shared.

“I think as OTs, we often feel like there is, that there is a bit of an unbalance in that we are often having to deal with risk more than others, which, again, we understand is part of our role. But you know, sometimes there's things that the team are not thinking about. You know, for instance, you know, overnight care or risk overnight you know, often that is not really, it's often very much left to be led by the OTs.” S002 (Occupational therapist)

Some participants felt that certain professional groups were very hierarchical with decisions made by their managers which can limit professional autonomy. Professionals who have given professional advise within the team may also feel that they are not listened to and this is not helpful within the context of multidisciplinary team working. Some participants felt that nursing staff may not feel empowered to make decisions. This indicates some level of tension amongst the team due to the systemic structure within the nursing discipline.

“Particularly within the nursing profession, the hierarchy is such, you know, prominent part of that organised, that sort of organisational structure that, without the backing of the next level up in the hierarchy, people feel very exposed, very worried, I think, and even, even in moments where I've advised about something which may have a perceived risk attached to it and it impacts nursing practice, it's very much the response has very much been, I need to get my senior backing on this that I can't just take this from you”. S006 (Neuropsychologist)

“That the team will ask the therapists about the risk, particularly the nursing staff and they and that they don't feel empowered to make a decision around that themselves’. S002 (Occupational therapist)

Some participants reflected on how decisions are made within their professional group. A neuropsychologists reported that their team members would be able to use their professional judgements to make decisions without the need for their managers backing. This reflects that within the multidisciplinary team, the different disciplines or professionals have their nuanced culture, and this can be reflected in the way they interact with other team members.

“But I wouldn't feel that I needed to get that sort of backing on everything, on every situation, and I think neither would my team, they would feel able to make those judgments and draw on the evidence and best practice guidance in the law to actually make an informed decision about something” S006 (Neuropsychologist)

One participant also referenced blame in respect of delayed discharges which can hinder the cohesiveness of the team. On the other hand, this was not reflected in the other interviews with other professionals. They also felt that OTs were seen as risk averse in an example. This highlights the personal experience of this participant and how this perception can influence the way they view the team. One professional did however acknowledge that when things go wrong, the blame shouldn’t lie on one person. This does echo some concerns around how professionals may feel when patients take certain risks which may potentially cause them harm.

“There's been a real push to get the patient home, and then the OTs being blamed for delaying discharge because of the like getting a bed sensor in”. S002 (Occupational therapist)

“It's been sort of put on the OTs that they've been the ones that have been too risk averse” S002 (Occupational therapist)

“Nobody should have to be that one person, that if the patient harms themselves, behind the curtain, it's on them”. S006 (Neuropsychologist)

A participant reflected on what influences staff to make decisions on restrictions to patients and how staff struggle with the balance. They shared their nuanced view and tried to make sense on the drivers of the decisions being made and whether they were indeed for patients’ safety or for staff.

“Sometimes to separate out what is, what is the part of this picture that's about the client and their autonomy and their rights, their human rights, and what about this situation is also about the members of the team on the ground and actually their safety and their rights, sometimes things collide, and actually it's quite difficult to delineate sometimes what which is, what's the driver of this current so if we're going to enhance someone's support or we're going to place a restriction on them. What's

the driver of that? Is it for the client, or is it for the staff? And where is that coming from?" S006 (Neuropsychologist)

There was also exploration of shared understanding of risk within the team. Although all disciplines gave examples of team working, there was report that risks were assessed differently based on the professional role of each staff member.

"I learned a lot from that case because I thought we had more of a shared understanding until that case, which is quite recent, and after that case, I think my view shifted that we we don't, and it makes me even more aware of needing to be very clear in what you say and how things are put across". S006 (Neuropsychologist)

Other professionals indicated that it was everyone's responsibility to highlight risks even if the risks do not necessary pertain to their professional role. This is in line with risks being a dynamic process which needs to be reviewed regularly.

"We've all got our own roles, and we should always be flagging at risk where this is related to my profession, or where it's related to somebody other's profession. So I mean, if I have observed risks, then obviously speaking to the team". S004 (Dietitian)

There was consensus from some participants, about how different professionals within the MDT assess risks as this is linked to their varying expertise, professional training and the specific area of risk being assessed. This highlights the strength of multidisciplinary team working and how each professional brings a set of unique skills and clinical knowledge to the assessment process.

"So every discipline has their, has their has their way of assessing risk". S007 (Nurse)

"I think this is an example of where the MDT is quite important, because there can be risks that, you know, a particular discipline might not consider". S002 (Occupational therapist)

Team working was also championed amongst the professionals which suggests the interest of working towards a common goal during the patient's rehabilitation.

"Within the MDT, it's very difficult to work alone as a social worker within this setup". S003 (Social worker)

"We made an arrangement as a team, because we work as a team". S001 (Doctor)

"We work as a team, is an MDT approach to each patient". S007 (Nurse)

Subtheme 2.3: Risk assessment and management

Risk assessment and management was discussed in interviews across all participant groups as being part of the patient's rehabilitation.

Patients gave examples of how issues of risk were managed and the advice given to them by professionals on safety.

"We think you need to sit down, because it was risk they were risk averse because they didn't want me to hurt myself. Now, whether I listen or whether I don't is my choice, but I try to take on board soon as they're the experts that maybe I should listen, because they know this is new to me". P004 (Patient)

Some patients valued the advice of the professionals. There is an awareness of risks and safety issues from the patients.

"Fair enough I will wait for help. That's what they want me to do, that's what I'll do". P001 (Patient)

"Like, when I say to physio that I've been practicing without stick. They know I'm being safe, and I'll do it in the bathroom, where I know that there's bars everywhere I can hang on to or around my bed, you know, things like that, that's how I've practice. They know I am very safe". P002 (Patient)

Across patients and family participant groups, the expertise of professionals was valued however decisions were shown not to be made in isolation, rather collaboratively with patients and their families. A family member gave an example of wanting to take their loved one with brain injury to a relative's home however the OT advised against that because there was no grab rail support to enable personal care

to be completed safely. During the interview, the family member was able to problem solve the need for their loved one to come home for home leave temporarily by going to a different location which had the necessary aids.

> *"But Occupational therapist didn't want me to take him there because there's no grab rails in the bathroom and things like that" F001 (Family)*

There was agreement amongst both an occupational therapist and a social worker about the need to complete a risk assessment document where there are complex issues around risk for patients who are being discharged. This helps to inform the discharge destination and whether it is safe for patients to be discharged home with support or into an alternative setting such as a care home. Both reported that the risk assessment tool was completed collaboratively all members of the multidisciplinary team.

> *"A risk document, which can be really helpful to identify some of the risks, and this is completed by the MDT, and highlights the potential risks that could occur or that the team would be concerned about, given the patients, you know often would be their cognitive difficulties, and might be about insight, etc, and that sort of highlights and allows for that discussion. S002 (Occupational therapist)*

> *"We robustly cover risk from a risk assessment perspective for all our patients that need that document, especially when we are the point of transfer of care. We do it as part of our assessments when we are ongoing, but the MDT documents that covers the risk assessment". S003 (Social worker)*

Theme 3: The legal and ethical considerations in decision making

All the professionals interviewed referenced the Mental Capacity Act 2005 (MCA) as a framework for assessing and exploring patients' decision-making ability. The Act applies to everyone involved in the care, treatment and support for people with the aim of promoting and safeguarding decision making within a legal framework. Across all professional participants, the decisions tend to be around care and support needs, discharge destination, feeding or nutritional intake.

"….Act 2005 and it's clearly instruct and inform every person who's dealing with the patient, that's when it comes to health, that if I have any suspicion, or anybody else have suspicion that the patient doesn't have the capacity to decide on certain aspect of his care, including his desire to choose a decision, then I would apply the…Act". S001 (Doctor)

Some professionals gave examples where the MCA is completed jointly with other professionals. This is usually based on the patients' individual needs. For example, a social worker and speech and language therapist may jointly carry out assessments on care and support if the patient has a speech impairment. These decisions are made by the MDT to identify who will be best placed to carry out such assessments.

"If there are particular issues, once they've been given certain information, and we would then look at doing a Capacity Assessment, which is includes the therapy therapists that are working, particularly with this patient, on this decision so often, for instance, if it's about autonomy and risk at home, it would be with social work, potentially with neuropsychology, OT, and obviously, depending if the patient required, you know, speech support as well". S002 (Occupational therapist)

"For example, a lot of our patients have got cognitive impairment by the time we decide to say they need an MCA Mental Capacity Assessment, it's either a disturbance of brain or mind, and we feel we will get most especially the occupational therapist, involved, because it's also about their care needs, their functional needs". S003 (Social worker)

There were different instances where capacity assessments are considered such as decisions around nutritional intake which required certain professional skill set to lead on completion of the capacity assessments.

"If I am not sure if they have capacity, I would definitely ask the medical team to do a formal Capacity Assessment, just to make sure the patient understands the risks and a benefits like, for example, we had somebody who haven't been eating for a long time, and then we have to outweigh whether they fully understand the risks of going home still having reducing nutritional intake and essentially slowly wasting away, or would they be somebody that might not have capacity, and we have to act in their

best interest, and potentially think of long term feeding options such as gastrostomy feeding tube". S004 (Dietitian)

Reference was also made to how the MDT considered best interest decisions. If someone lacks capacity to make a specific decision, the MCA states that the decision must be made in their best interest. A participant gave an example where best interest decisions are made about discharge destination.

"We've got even now patient that wants to go home, but actually can't manage himself, then you're raising the concern that this patient have to be assessed for capacity, because it is not only to take decision that this man doesn't have capacity or this lady, the team have to assess him, to take decision if this person doesn't have capacity, and after that on best interest of the person, we can take decision as a team where this person could be discharged to meet his needs". S005 (Nurse)

A professional discussed the challenges that professionals may have on what is considered the best for the person and that it was vital to go back to the best interest checklist and the legal framework. Objective information was crucial regardless of the other factors surrounding the individual, and that the legal framework must be adhered to and one must always go back to the MCA 2005 to protect patient's rights. There may be some complex scenarios, requiring skilled professionals to refer to best practice. This can be a challenge for professionals as different factors can influence what is considered a best interest decision for the patient however, the Mental Capacity Act 2005 sets out the framework on how patients can be supported.

"But in a work context, I always try to just come back to the to the framework that we're working in, to the legal framework that actually, despite and the best practice guidelines, there's so many best practice guidelines on this, and sometimes, if you feel really stuck with a case, it's just helpful to go back to that checklist of what makes a really good assessment of capacity. And have I covered all of these things? Is there something that I've missed? Because that's that objective information that doesn't change depending on the pushes and pulls with that particular person, these particular team members that are involved with this case". S006 (Neuropsychologist)

A professional viewed the system as protectionist and discussed the “protection impulse” as a major influence on professionals, as they can end up prioritising patient’s safety concerns over their right to autonomy. This worry comes from several factors such as anxiety over negative outcomes, professional accountability and a culture which values safety and risk aversions. The neuropsychologist acknowledged the protection impulse within health settings and the phrase “you recognize it in yourself” indicates self-awareness that this can impact anyone but also professionals need to be careful of impinging on patient’s rights and autonomy and to always return to the legal framework.

> *“We need to act within this framework. It is very clearly laid out, and whilst it feels uncomfortable and uncertain, we need to come back and remain close to this and examine these things very carefully before we jump to protection the protection impulse, as I think it's been referred to in some of the court judgments, the protection impulse health professionals is a real thing, and you recognize it in yourself”. S006 (Neuropsychologist)*

A participant explored the challenges that professionals can have with balancing risk issues and the drivers of the decisions being made, whether this is indeed to protect the patient, themselves or whether it is about the organisation’s reputation. Professionals must exercise caution against letting fear override lawful and ethical decision making. This participant acknowledged the challenges professionals may face to avoid risks, they advocate for the legal and ethical framework to reconcile some of the conflicting pressures that professionals may face.

> *“I think people often get pulled in different directions so that, you know, wanting to make sure that there's no risk because their reputation and the trust's reputation and the consequences of you know, acting in a way that might not protect that patient at all costs can feel really scary territory, but again, reminding us that one of the key aspects of our role is to just bring people back to this is the law. We need to act within this framework”. S006 (Neuropsychiatrist)*

An example was provided by a dietitian where positive risk taking was provided within the legal framework. This patient within this example was informed about the risks and benefits of choosing meals with egg but despite the egg allergy, the patient

still wanted to choose those meals and made an informed decision. Professionals may have grappled with protection in this case and may have felt uncomfortable about this risk taking, however the legal framework is there for professionals to refer to.

> *"I have had somebody who have stated that they have egg allergy, but they have got capacity to choose their own meals, but they still have chosen meals that still contain egg and they have got capacity to outweigh the risks and the benefits and choose those meals. So as long as we have highlighted that for the rest of the team, and everybody's aware it is patient's decision at the end of the day". S004 (Dietitian)*

Theme 4: Discharge planning and resource constraints: Role of the social worker

Discharge planning is often a complex process for the MDT. This is particularly the case for the social worker who strives to bridge the gap between hospital rehabilitation and community integration whilst navigating resource constraints and upholding and the needs of the patient and family. This section relates to the subthemes on discharge discussions and resource constraints, and role of the social worker.

Subtheme 4.1: Discharge discussions and resource constraints

There were statements from participants that supported patients were included in discussions around their discharge. This shows collaboration between the professionals and patients in discussing the next steps.

> *"Yes we had a family meeting, which my husband and my daughter are at, as well as me and all the all the doctors, all the occupational therapists, all the physiotherapists, they all gave their view, and we discussed discharge, and we discussed what it was going to be like. We discussed what the next steps were". P004 (Patient)*

A patient described challenges with discharge such as issues with housing and not having a discharge destination. They discuss having an allocated Social worker and being involved in care arrangements.

“Yeah, because I'm on a step down programme now, which means I have less sessions as I'm due to be discharged. So I'm ready for discharge, but I'm just waiting on housing”. P002 (Patient)

“I've got a social worker. She's arranged one carer a day. Because I can do personal care and just be helping with meal prep. So, like, big, major things like striping the bed sheets and things like that”. P002 (Patient)

Some patients have temporary home leave. Whilst this provides some level of normality for patients, this type of home leave also presents the opportunity for patients to have an idea of home life and what to expect on discharge.

“Yeah, he did come home last Saturday. Came home for the day. It was his birthday, so I arranged for him to come for the day”. F001 (Family)

For some patients, there are discharge challenges such as the home environment not being fully accessible and for a patient participant who enjoys cooking, this may pose as a restriction on ability to remain independent. The participant said, “if I can’t cope then what do I do”, this indicates the worry this patient is facing having to think beyond the hospital setting. There were also references made by the participant that the home was assessed by professionals which shows some ongoing issues with accessibility. This type of concerns highlighted by the patient participant highlights some of the system and resource constraints that can arise at the discharge planning phase.

“They know the wheelchair do not go in the kitchen and she's still saying the social worker I will still go back there. I will go back there, if I can’t cope then what do I do they have to come and move me”. P001 (Patient)

“I like to cook, always have done. Even when my kids were growing up I’ve always cooked”. P001 (Patient)

“I have spoken to someone in a rehab team, and they've been there and look at their situation. And none of the doorways could be widened, because they're all main supporting walls”. P001 (Patient)

Professionals emphasised the importance of early discharge planning. Delayed discharges can impact patients who are keen to move on to the next steps, additionally it can impact on patient admission flow for the service.

> *"I suppose one of the things from an occupational therapy perspective is that we, as early as we can, actually, we start looking at the discharge". S002 (Occupational therapist)*

> *"This patient needs placement, Whereas, to me, from the time the patient was impulsive and all that its about checking, who does this patient have at home. What happens in between? The care in between. Should we approach this patient about care, placement? so is that keeping this patient all these months to. Think the patient is not going home, patient is going to care". S007 (Nurse)*

A professional highlighted the challenges of institutionalisation and prolonged hospital stays due to delayed discharges. The hospital environment can create complex behavioural issues for patients and the bulk of that falls on nurses due to the nature of their role, "the nurses are the ones that get a lot of this passion". This statement highlights the perception that as nurses are mostly there to provide round the clock care, some behaviour which challenge staff end up being most directed at them. It is therefore crucial that support is provided to the staff that are impacted by the challenges daily.

> *"Some of the patients, really, they become very impulse, very aggressive. There'll be challenging behaviours, because I call it, they become institutionalised. And when they're institutionalised, you know, a lot of things, a lot of things happen. I normally will say the nurses are the ones that get a lot of this passion, because they are the ones with the patients 24 hours. So they're the one that actually more close, more intimate, so they get the behaviours more". S007 (Nurse)*

For some patients, they had an awareness of the ongoing support available on discharge. These are based on the patients' individual needs and for some patients, speech therapy was important, whereas others needed occupational therapy and physiotherapy input on discharge.

“I'm quite clear that when I leave here I will have to continue speech therapy. So I've already sort of been asking about where I can access that in my area, or somewhere close, but because, to me, that's the bit for me that I have to keep doing just to get this back to some a better shape, a better shape”. P003 (Patient)

“I'm going to get referred to the community stroke team so that I can have physiotherapy and occupational therapy in the home and in the community. So this is not a just because I'm being discharged, it doesn't end. P004 (Patient)

Professionals also discussed how patients are supported around discharge discussions. The statement, “so we looked at other ways” suggests some feelings of unease that professionals had with the patient declining support. Others who agreed to have support are provided with relevant information for follow up. This suggests that discharge support needs to be person-centred and tailored to individual needs.

“So we asked, for instance, if they wanted the rapid response team to go in. They said no. So we so we looked at other ways, like, for example, if you'd be agreeable for us to contact him the day, you know, that on the same day as his discharge to contact him the day after, to check, he declined equipment”. S002 (Occupational therapist)

“So we would discuss that with a patient, explain what available options and flavours are there, provide community dietician number as well, just in case, if there's any issues, just to let them know, more or less, sort of put in patient and the family at ease to make sure that there is some sort of follow up in the community”. S004 (Dietitian)

There was a consensus between professionals that communication and information sharing was vital in discharge discussions and that patients are allowed to make informed decisions.

“In the meantime, if they need nutritional supplements, we would request a GP prescription for that on discharge, but we would discuss that beforehand with the patient”. S004 (Dietitian)

"So communication really is very vital in on the ward. So kind of like communicate with patients day to day, the activities the patients are doing, and then what home is going to look like". S007 (Nurse)

Some patients face some challenges with transitioning from the security of the hospital setting to home. Leaving the structured environment of a hospital setting may create feelings of anxiety for some patients. Professionals must manage tensions between patient safety, bed management and system constraints without compromising on patient's care. There is a need for the MDT to balance bed flow with person-centred discharge planning, best addressed through earlier, shared planning across the MDT with robust risk assessments.

"You know what happens is when they are in their comfort zone, when they are within the hospital and all that there are staff out there, so the moment of truth comes in when they are now going to be discharged. So they are anxious about different things, and because I had a conversation with him on Friday, and he was quite reluctant, so I would like to go home on Monday. So I'm like, I wish we actually have those decisions in our hands. I've got patients out there waiting for the bed. So if everything, like I said, I said, everything, I said, we normally don't do failed discharge, so we tick all boxes if your care is in place, for a PM visit, we will discharge you, I said, but if it's not in place, we will not discharge you. And unfortunately, the care wasn't there, so we couldn't discharge the patient". S007 (Nurse)

Subtheme 4.2: Role of the Social worker

The Social worker has an important role to play throughout the rehabilitation journey, including assessing need, assessing mental capacity, assessing risk and safeguarding (Mantell, 2010). Social workers work collaboratively with patients and in accordance with their wishes such as providing consent and being involved in decisions around their discharge.

"I as a social worker, especially when it comes up to discharge, goes to meet with the patient, get the family involved through their consent, because some families, some patients do not want their family involved for various reasons, but once we get the consent, then we then convene what we call a family meeting" S003 (Social worker)

A family member highlighted the important role social workers play in discharge arrangements.

> *“Because the social worker said the other week, she said, with his discharge date coming up, she said, you're going to be seeing a lot more of me now”. F001 (Family)*

There were challenges identified regarding being a social worker within the MDT versus local authority. Local authority social workers have specific roles in relation to the Care Act assessment which are specifically carried out by the local authority social workers, and not the social worker based within the MDT. The statement “I would say in most cases, they’ve been in agreement with us” suggests there has been conflict between the recommendations of the MDT and what social services provide. This can have an impact on discharge outcomes for patients and requires skilful negotiations and discussions with the external services involved.

> *“I came from local authorities. So immediately I'm talking about local authority processes. Then I realized that our role mainly is to give the clear recommendation, because the patient has been with us, but the local authority also comes in to carry out, probably care needs assessment, and then tells us the eligibility criteria, but I would say in most cases, they've been in agreement with us, yes, over 90% okay of times”. S003 (Social worker)*

Transparency is required in managing patient’s expectations about their ongoing care. Social services are the budget holder and authority for decisions around ongoing care needs largely falls outside of the MDT’s control. Patients need to be aware of whom will be responsible for their ongoing care and support needs.

> *So as a social worker, I am able to be able to say, these are the options we feel your needs could be best met with when you leave here, and again, you're entitled to have a local authority social worker who will even give me broader insights as to all other options that you might have, because they are the budget holder, they are the decision makers. S003 (Social worker)*

The team empowers patients to be involved in decisions around their rehabilitation through several meetings. The social worker refers to “person centred” approach

which supports people to develop the knowledge, skills and confidence they need to make informed decisions about their own care (British Association of Social Workers, 2023). This approach is rooted in social work practice, and it is something which I reflected on as a social work practitioner as being key in promoting collaboration with patients.

> *As a social worker, working within the multidisciplinary team, we have processes in place that we call, either initial family meeting, Midway family meeting or discharge family meeting within that process, the patient has the autonomy to be able to be this person centred in the meetings. So we tend to give them a pre information beforehand to say you are free to tell us how you feel or what you want out of this process of discharge that is about to take place. S003 (Social worker)*

A patient participant highlighted the role of the social worker in relation to ongoing care and support needs. Some patients experience worries around care arrangements and how they will manage. Patient involvement in discussions around discharge arrangement is important in reinforcing person-centred care.

> *“I've got a social worker. She's arranged one carer a day. Because I can do personal care and just be helping with meal prep. So, like, big, major things like stripping the bed sheets and things like that”. P002 (Patient)*

Patients are involved in their care in collaboration with other agencies however the reality is that resource boundaries or constraints can inevitably impact patients’ true autonomy and sense of choice. The communication with patients is helpful but it also highlights the tension between person-centred care and the broader systemic constraints that impact discharge outcomes.

> *“So as a social worker, I am able to be able to say, these are the options we feel your needs could be best met with when you leave here, and again, you're entitled to have a local authority social worker who will even give me broader insights as to all other options that you might have, because they are the budget holder, they are the decision makers. But our recommendation as a team is that you are going to be placed or you are going to go back to your home, and these are the things we want to put in place. So I think for me as a social worker, I'm always finding myself I might*

sound repetitive when we finished a meeting, even with the therapist, but I always find that communication open with my patients to actually go and say more, or give insightful kind of processes or pathways as to, especially how the local authority will be involved in our transfer of care". S003 (Social worker)

Summary

This chapter outlined the four themes identified through the analysis of the transcripts using IPA approach. The themes captured the lived experiences across all three participants groups (patients, family and multidisciplinary team) and highlighted their views on how professionals balance patients' autonomy, self-determination as well as issues of risks in rehabilitation. The interviews demonstrate that a collaborative person-centred approach that values patients' independence and safety concerns without undermining autonomy is central to the rehabilitation process. Balancing these tensions is not a static process, but involves ongoing dialogue, assessment and teamwork between patient, family and professionals.

CHAPTER 5: Reflexivity

5.1: Introduction

Reflexivity is an important aspect of Interpretative Phenomenological Approach (IPA). This chapter presents an overview of reflexivity and its use in IPA. It provides an explanation of the reflexive processes used to enhance the quality of the study. This is followed by an analysis of the insider practitioner researcher role, examining its influence on this study through a social work lens.

Researchers use reflexivity to improve transparency and trustworthiness of qualitative research (Robinson, 2014). Reflexivity is an account of the way the researchers personal view of the world affects the research. It shows how the researcher engages with the process of designing the study, analysing the data and reporting the findings (Lipp, 2007). The benefit of engaging in reflexivity as a researcher is that it provides transparency and an audit trail of the data collection and analysis process (Vicary et al., 2017). Parallel to social work practice, reflexivity enabled me to be in a continuous self-awareness state and be attuned to my own feelings, assumptions and biases during the research process.

5.2: IPA and Reflexivity

Reflexivity is an important aspect of social work practice which involves self-awareness, looking inwards and exploring what is happening from all angles during the research process (Vicary & Ferguson, 2024). IPA researchers need to be mindful of their own beliefs, emotions and biases so that they can enrich their interpretation of how the participants make sense of their experiences (Peat et al., 2019). IPA uses intersubjective reflexivity which aims to explore the dynamics between the researcher and the participants (Peat et al., 2019). For instance, the pre-existing role of being an insider researcher where I know some of the professional participants in a work capacity prior to engaging in the research. Conducting reflexivity improves transparency and the ethical quality of the research (Vicary & Ferguson, 2024; Peat et al., 2019). Having said this, data interpretation is inevitably a subjective process, but reflexive approaches can improve the data reliability (Braun & Clarke, 2021).

I utilized supervision to explore some of my interpretation of the data by delving into the experiences of the participants, exploring their backgrounds and roles.

Discussing this with my supervisors allowed me to reflect on some of my interpretations of the participants experiences and what they mean. I also tried to ensure that my own personal experiences or beliefs did not influence my interpretation of the data, mainly due to my insider role, so that the data interpretation stayed true to the participants voices. However, this was difficult as data interpretation is a subjective process.

5.3: Identity as an Insider researcher

Insider or work-based research simply put means the research is based within the researchers own practice (Costley et al., 2010). As a practicing Social worker working in neurorehabilitation, this unique position means I already have knowledge of the phenomena. This aligns with the philosophical approach of this study which is phenomenology. As an insider researcher with lived experiences of being a practitioner, I already have my own expertise experience in the field to be able to investigate the issue from an informed perspective.

Whilst undertaking this study, I worked as a Senior Social worker in one of the rehabilitation wards in the hospital. The study, however, took place on another ward where I was not based to reduce any conflict between my role as a practitioner vs researcher. My identity as an insider researcher is not without its challenges and benefits (Doyle, 2019). The challenge that I faced was not going into practitioner mode to offer advice to participants, I was there to listen to their views and experiences, so I had to maintain this during the interviews. The benefits of being an insider researcher meant that I was aware of the structure of the team including the team dynamics, roles, and the language used within the team. This enabled me to have a smoother path in gaining access to participants and carrying out my research (Doyle, 2019). Additionally, I conducted a presentation to senior managers within my service to inform them about the proposed study; this was made possible due to my insider role.

Knowledge or experiences of the insider researchers apply not only to the organisation's dynamics but also the lived experience of the researcher's own organisation which in essence is the underpinnings of Phenomenology (Brannick & Coghlan, 2007). I had some knowledge of "high profile" cases within the team via

forums where these were discussed. I would not have been privy to this information if I was not an insider researcher. For example, the ward staff had approached a patient who was willing to participate in the research, however I had knowledge that they had just disclosed a safeguarding issue which was very fresh. My social work values guided me in this instance because although I was eager to have another patient participant, I knew that they were actively experiencing some emotional challenges, and I did not think it was the right time for them to be interviewed. As regard to completing the research, it may also be considered a disadvantage of being close to the data as I would have been ignorant of the situation if I was not an insider researcher and continued with the interview. On the other hand, if I was ignorant to their situation, I would have proceeded with the Mental Capacity Act 2005 to guide me as to their capacity to engage with the interview. This links in with reflexivity which focuses on interrogating the researchers subjective experience and understanding how knowledge is constructed (Ide & Beddoe, 2023).

It is therefore crucial that professionals who because practitioner researchers use reflexivity to explore the implications and the impact being an insider has on the research. Doing this at early stages enables the researcher to be mindful of their primary role as a researcher rather than a practitioner.

5.4: Reflexive account

I used the Annotations section in NVivo to make initial thoughts and reflection whilst I was analyzing the data. This enabled me to record my initial feelings and analysis on the lived experience of the participants within the software package. Below are some examples of the reflexive notes I made:

What did I notice?

I reflected on the feelings that this participant may have, being disappointed about not achieving their goals, due to the expectations that their relatives had. This initial thought enabled me to reflect on how this can affect patient's engagement.

> *Appears family and friends had expectations that he would be walking - patient may feel disappointed and upset that he wasn't able to achieve this despite still making*

progress as described by relative. (Created 8th August 2025 – Extract on reflection of F001 interview)

How did emotions affect what was going on?

The family member was emotional during the interview. The report that they were dealing with multiple grief issues was impactful. Recognising the losses and the carer strain made me reflect on my own practice whilst acknowledging the importance of supporting family members. During the interview, I was mindful not to slip into practitioner mode in this instance by immediately offering solutions. I felt a sense of unease doing this as this is not in line with my values as a social worker. On the other hand, I had to remind myself of being a researcher so instead, I offered the participant a break and they wanted to carry on. I reflected that the interview also offered an opportunity for the participant to express themselves fully to someone outside of the treating team.

Carer strain noted here with relative loosing their own parent and still being there for patient and juggling a lot. Additionally, the financial impact of the stroke - they lost their business as they worked together previous to the stroke. (Created 8th August 2025 – Extract on reflection of F001 interview).

What have I learnt from this?

I reflected on the discussion about patient's need for privacy and a patient not wanting to be observed by staff. On a personal level, I was able to identify with the participants reports that as human beings we all crave a sense of privacy. I reflected on how hospital settings must be for patients whose privacy is limited, most are in an open ward, with curtains opened. Having been in a hospital setting when having my children, I reflected that I also craved privacy, thus I can empathise with patients on this level.

S006 provides insight on need for privacy as an inherent thing for humans - explore theory on this. Reflected on hospital setting and how patient's privacy and dignity is impacted. (Created 17th August 2025 – Extract on reflection of S006 interview)

Summary

Reflexivity not only enables the researcher to reflect on their thought processes whilst immersed in the data but implore questions which serve as a way for the practitioner researcher to develop their skills (Vicary & Ferguson, 2024). Engaging in reflexive practice is a vital component of social work practice and central to my role as a social worker. I have personally found the process of reflexivity to be a useful ongoing process throughout the research journey.

CHAPTER 6: Discussion, Recommendations & Conclusion

This chapter starts by restating the research aims and objectives, followed by a discussion about how the objectives were met based on the key findings of this research. In particular, the following will be discussed: Participation and patient engagement in recovery, Family involvement and support network, Hierarchy/Power imbalance and Culture of the team, Legal and ethical considerations in decision making and the Role of the social worker. These findings are pertinent to understanding the tensions that arise when balancing patient's risk, autonomy and self-determination. The limitations of the study are set out as well as the recommendations for policy and practice. The suggestions for further research are also outlined. Based on the qualitative analysis, it can be concluded that the research aims were largely met.

Aims: The aim of this study was to better understand the tensions that arise for the patients, family and multidisciplinary team when balancing patients' risk, autonomy and self-determination during inpatient rehabilitation; and how this affects decision-making about post-rehabilitation discharge.

Objectives:

1: To explore the factors influencing multidisciplinary team (MDT) decision-making during discharge planning for patients with Acquired Brain Injury (ABI).
2: To understand the lived experiences of patients, families, and professionals regarding risk, autonomy and self-determination during inpatient rehabilitation.
3: To examine the role of the Mental Capacity Act (MCA) 2005 and other legal/ethical frameworks in MDT decision-making.
4: To understand the role and perspective of professionals including the social worker within the MDT.

6.1: Participation and patient engagement in recovery

Objective 1: To explore the factors influencing multidisciplinary team (MDT) decision-making during discharge planning for patients with Acquired Brain Injury (ABI).

Objective 2: To understand the lived experiences of patients, families, and professionals regarding risk, autonomy and self-determination during inpatient rehabilitation.

Patient engagement is a continuous process that requires ongoing review in accordance with the patient's shifting goals, expectations and emotional needs (Knutti et al., 2022). There were discussions raised in the interviews by professionals about the importance of patients taking an active role in their recovery through engagement in goal setting and development of individualised plans tailored to their needs. The aim of rehabilitation is usually established in goal setting which is a one-to-one session between patients and their key worker, patients decide on their short term and long-term goals (Baird et al., 2010). It is reflected in literature that interventions which promote active participation in rehabilitation increases engagement and motivation (Brett et al., 2017; Knutti et al., 2022).

Rehabilitation goals should be created with the patient directly affected by the intervention (Knutti et al., 2022). From a social work perspective, this is in line with a person-centred approach that places a value on service user autonomy, ensuring the needs of the person are at the forefront (Murphy et al., 2013). My findings indicate that patients' value when professionals listen, include and involve them in decisions relating to care planning, risk assessment and discharge planning. There was also evidence to suggest that professionals promoted patient participation and engagement. Nevertheless, there are factors which can affect or limit engagement such as patients' cognitive, communication, social, environmental and emotional factors (Larsson et al., 2013; Knutti et al., 2022; Haggstrom & Larsson-Lund, 2008). Emotional and social factors had an influence on the level of participation by patients with traumatic brain injury (Larsson, et al., 2013). My research noted that patient participants listed emotional difficulties following their brain injury. Common consequences of ABI such as executive difficulties, behavioural and emotional changes are often less easy to understand and assess (Holloway & Fyson 2016).

Patients need to maintain ownership of their own recovery, with some participants citing that having the right attitude was crucial, as well as building positive relationship with staff. Active participation during inpatient rehabilitation fosters the

skills, independence and confidence needed post discharge (Aldosary et al., 2024). Figure 6 below shows an illustration of the care team within the research study site with the patient central whilst being supported by the multidisciplinary team. This illustration is a typical example and may not reflect all settings.

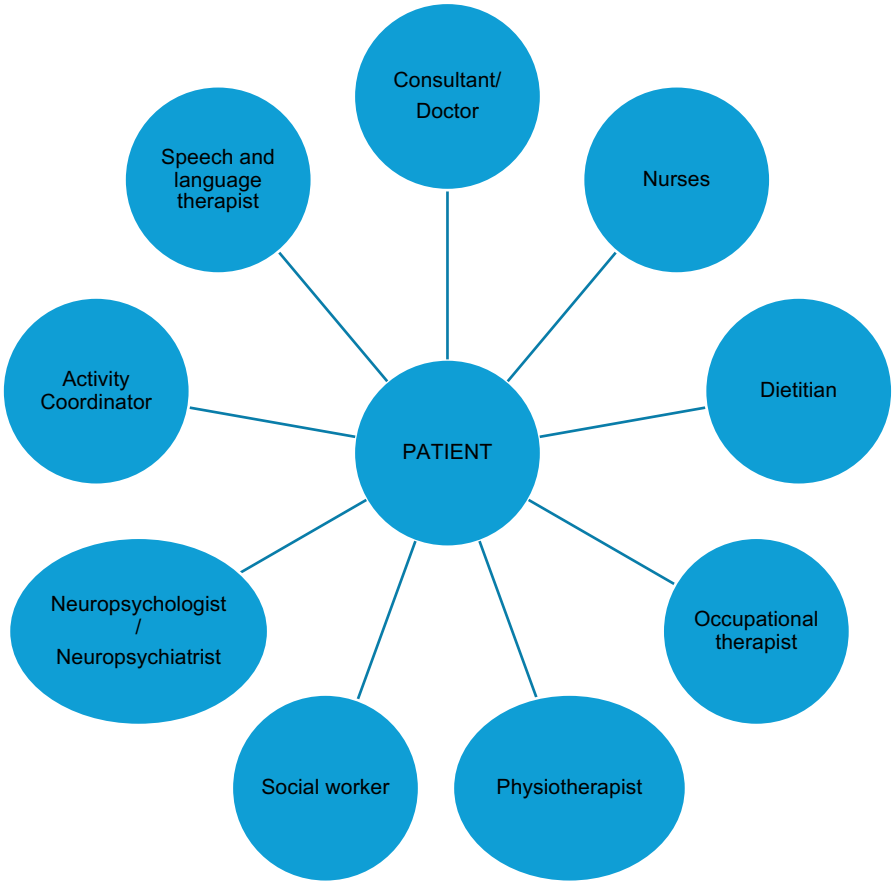

Figure 6: Patient in the centre of their care team (Devised by the Author of this thesis)

In line with the objectives of this research, patient participation and engagement impacts discharge planning. My research showed that patients' engagement can be promoted through individualised care plans, in keeping with research by Coulter et al (2015), multidisciplinary team collaboration, self-management programmes outside of therapy sessions and a focus on preparation for life beyond the hospital setting.

6.2: Family involvement and support network

Objective 2: To understand the lived experiences of patients, families, and professionals regarding risk, autonomy and self-determination during inpatient rehabilitation.

The effect of ABI is not only felt by the patient but also felt across the family. There has been criticism of work practices that have not captured and responded to the needs of family members (Holloway et al., 2019). The findings from my study show that families and informal carers are impacted by brain injury, and their needs must be considered in the rehabilitation journey and post rehabilitation. The consequences of ABI on family members include difficulties in coping and adapting, concerns for the future and increased risk of loneliness and depression (Townshend & Norman, 2018). A study by Holloway et al., (2019) supports this view, emphasising the importance of supporting family members, showing empathetic understanding of the condition, genuine inclusion of family and awareness of their grief process.

Family involvement and support network was repeatedly cited in my interviews as a vital component for patient engagement, increasing motivation, supporting routine, providing emotional support and bridging the gaps in communication between patients and staff. Other studies have also identified the importance of family involvement and the central role they play in improving patients' rehabilitation outcomes (Keegan, 2021; Foster et al., 2012; Oyesanya & Bowers, 2017). My research showed that those with active family involvement provided professionals with better understanding of patients' preferences and life pre-brain injury and patients were better supported with decisions around transition from hospital to community life. The significance of this approach for social workers lies in adopting a whole family perspective as referenced in the Care Act 2014. This involves undertaking holistic assessment, ensuring that the impact on family members and support networks is identified and addressed alongside the adult's care needs (Department of Health & Social Care, 2025). This aligns with the findings of this research which showed that the patient should not be assessed in isolation but holistically involving the family, for instance, through patient and family meetings.

Involving family/informal carers will enable professionals to fully consider the patient's needs in relation to risk, autonomy and self-determination which is one of the objectives of this research. Considering the needs of family was imperative and professionals in my research emphasised the need for targeted education for families around patient care and brain injury, as well as preparation for discharge. To remain sustainable, the needs of family and informal carers must be recognised, and better overall service coordination is needed within the health and social care systems (Hollway & Tasker, 2019). It is therefore essential that professionals recognise the challenges which may need additional multidisciplinary team input or community input to ensure that family/informal carers receive holistic support to meet their needs.

6.3: Hierarchy/Power imbalance and Culture of the team

Objective 2: To understand the lived experiences of patients, families, and professionals regarding risk, autonomy and self-determination during inpatient rehabilitation.

The study setting was within a multidisciplinary model which utilises the skills and experience of different disciplines who work in parallel with the consultant having a leading role in coordinating the patients care (Li et al., 2021). A multidisciplinary team requires collaboration among a diverse range of professionals; however, issues of hierarchy, power imbalance and culture of the team can be argued as inevitable (Van der Veen et al., 2024).

In line with the research question, knowledge of hierarchy/team culture can aid in understanding the tensions that occurs for professionals when balancing issues of risk and autonomy for patients with ABI. The synthesis of my research findings show that these factors were present and can shape the dynamics within the multidisciplinary team. A professional participant reported issues relating to hierarchy in decision making, where the occupational therapy perspectives on discharge was prioritised over the nursing perspective. The participant reported that nurses would step back their opinion particularly in scenarios where they felt a patient was safe to go home but the therapist disagreed. The existing literature recognises power dynamics and hierarchical systems within teams, particularly those involving more

esteemed professions can foster an environment in which other team members perceive their contributions as less valuable (Van der Veen et al., 2024; Essex et al., 2023; Fernandopulle, 2021).

The nursing profession was reported to be hierarchical in this research with a professional participant explaining that nurses sought their superior's backing on decisions which could have been made autonomously. As evidenced in literature, hierarchy in health care systems are inevitable, and noted within and across different professions such as nursing (Vehvilainen et al., 2024; Rogers et al., 2023). Power sharing, collaborative power or work empowerment within hierarchical systems where the leadership team encourages and promotes MDT working fosters an environment and culture of learning, values the expertise of patients, families and professionals (Vehvilainen et al., 2024; Rankinen et al., 2009). Conversely, a culture that has no power sharing can create an environment of fear and blame which influences the ability of shared decision making, positive risk taking and effective MDT working (Vehvilainen et al., 2024).

There is potential for tensions between the medical and social model within a medically dominated hierarchy, but improvement in role clarity and valuing the contributions of the diverse professionals will strengthen MDT working (Carpenter et al., 2003). Despite its challenges, literature shows that the benefit of multidisciplinary teamwork leads to comprehensive coordinated care, patient centred service and improved patient outcome (Suddick & De Souza, 2006). Teamwork can be improved by compassionate leadership culture which nurtures inclusion, respect, civility and shared power to promote positive work environment for health and social care professionals (West, 2021).

6.4: Legal and ethical considerations in decision making

Objective 3: To examine the role of the Mental Capacity Act (MCA) 2005 and other legal/ethical frameworks in MDT decision-making.

The Mental Capacity Act 2005 provides a comprehensive framework designed to promote and safeguard decision making by empowering people to make decisions for themselves where possible and protecting people who may lack capacity to make

decisions (Health Research Authority, 2021). It was evident from this study that professionals applied this Act when exploring patient ability to make decisions. Professionals must abide by the principles of the MCA which is a key part of social work training. Social workers play a crucial role in carrying out mental capacity assessments and it is crucial that the principles are adhered to, focusing on the right to make decisions and starting with the presumption of capacity; every effort must be taken to support the person in making decisions themselves (SCIE, 2025). However, this study identified challenges in practice with implementing the Act, such as subjective interpretation and disagreements even within experienced team members. A review of the body of literature on the application of the MCA suggest that health professionals do not always have the knowledge and confidence to accurately assess mental capacity (Marshall & Sprung, 2017). In cases where mental capacity fluctuates, this could result in professionals concluding a lack of mental capacity, impacting patient's autonomy and ability to make their own choices (Taylor, 2014). A professional participant cited issues of paternalism which is also evident in literature, where professionals exercised paternalism rather than promoting autonomy (Marshall & Sprung, 2017).

Although social workers are skilled in conducting capacity assessments, literature notes that social workers may also need specialist clinical support to complete MCA for people with ABI (Cameron et al., 2022; Acquired Brain Injury and Mental Capacity Act Interest Group, 2014). Several studies have identified a lack of understanding of the MCA particularly around issues of executive functioning difficulties where capacity assessments do not reflect performance under real life demands (Holloway & Norman, 2022; Fisher-Hicks et al., 2021; George & Gilbert, 2018; Ryan-Morgan, 2021). It can be argued that executive dysfunction may be better understood within MDT settings due to the specialist knowledge of ABI within the team. My research indicated that mental capacity assessments were completed collaboratively with skilled multidisciplinary team members around various decisions. Additionally, executive functioning difficulties are well known pervasive clinical concepts within neuropsychology and therapy specialties (Rabinovici et al., 2015). On the other hand, studies have shown that social workers who lacked knowledge of ABI were often unaware of issues around executive impairments (Holloway & Norman, 2022; Cameron, 2022). Literature highlights that social care practitioners will benefit from

further guidance on the application of the MCA with ABI population, particularly where there are concerns about the person's ability to understand, apply and use information outside of an assessment setting (Cameron, 2022). There is important professional learning about the way the MCA is utilised although the issue of lack of understanding of executive impairments did not arise from research participants, largely due to professionals working within this setting having specialist knowledge in this area.

Literature reveals that a lack of patient's insight is an issue in relation to ABI (Di Somma & Fleming, 2024). People with ABI may have impaired self-awareness (insight) which can affect their ability to observe and reflect on their own thoughts and actions (Headway, 2023). Importantly, a lack of insight into one's ABI does not automatically mean a lack of capacity (NICE, 2018). The MCA has limitations in terms of its use and application as identified by the report "Making the Abstract Real" which addresses the difficulties associated with using the MCA on behalf of people with ABI (Acquired Brain Injury and Mental Capacity Act Interest Group, 2014). Concepts such as lack of insight is not mentioned in the MCA, although commonly cited in the application of the MCA in clinical practice and there is a risk that concepts such as insight may become substitute for legal decisions (Moore et al., 2019; Allen, 2009). From my professional practice, I have learnt that issues of insight are important to reference, there were reports from participants about the way the MCA is utilised and a reminder that professionals must always refer to the code of practice of the MCA. In the case CT v London Borough of Lambeth & Anor [2025] it was determined that insight is a clinical concept, whereas decision making capacity is a legal concept. This is an important distinction because it prevents conflating clinical diagnosis such as lack of insight with the legal test for capacity ensuring that professionals adhere to the principles and statutory requirements of the MCA and prevent someone from being presumed to lack capacity due to insight which could undermine their autonomy (Mental Capacity Law and Policy, 2025).

Health and social care professionals within the decision-making process must be aware that use of insight may in fact conflict with the autonomy promoting principles of the MCA (Case, 2016). Assessors must be aware that a person may be able to make a particular decision even if they are described as lacking insight into their

general condition (CT v London Borough of Lambeth & Anor [2025]; Case, 2016). Legal and ethical considerations within neurorehabilitation is grounded in the adherence of the guidance set out in the Mental Capacity Act (NICE, 2025). This research showed that professionals can struggle with the ethical tensions whilst trying to balance patients' autonomy, safety, family perspectives and legal requirements. Ultimately, the team must always return to best practice set out within the statutory framework.

6.5: Role of the social worker

Objective 4: To understand the role and perspective of professionals including the social worker within the MDT.

This section examines the role and professional perspective of the social worker within the multidisciplinary team. Social workers have a significant role to play in addressing the psychosocial needs that arise following ABI. Grant (2023), a researcher with lived experience of brain injury, identified the crucial role brain injury social worker intervention had on his life. The social worker recognised no human being should be excluded or left behind (Grant, 2023). Social workers not only support during the rehabilitation journey but also have a key role in ensuring the right support is in place in transition from hospital to the community. The experience of Grant (2023) mirrors those of the patient participants where social work support was crucial, particularly in the discharge planning phase.

My research showed that the social worker within the MDT worked collaboratively with other disciplines in addressing the needs of patients with ABI and their families. However, social workers outside of the clinical setting such as those working in local authority context may not necessarily have the experience or training in understanding the needs of patients with ABI. Studies have shown that social workers who support patients with ABI and their families need to have appropriate training and understanding of ABI as effective assessment requires skilled and specialist knowledge (Linden et al., 2023; Holloway & Fyson, 2016). There is a call for social workers to have training of ABI to address this need and the Heads together project; a project funded by the National Institute for Health and Care Research (NIHR) aims to provide a fully accessible training platform for social

workers (Department of Health and Social Care, 2024). The online courses are now live on the Brain Injury Social Work Education platform and provides social workers, families and people with lived experience of brain injury with information and resources on ABI (BISWG, 2025).

Additionally, social workers' awareness of trauma informed practice places them in a useful position as part of the MDT to explore the impact of ABI on patients and their families (Office for Health Improvement & Disparities, 2022). Trauma informed practice is defined as an approach to health and care interventions which aids in understanding that trauma exposure can impact an individual's neurological, biological, psychological and social development (Office for Health & Improvement Disparities, 2022). Trauma informed practice offers opportunities for professionals within this study to improve the accessibility and quality of service by working collaboratively with people to help them make choices about their health and wellbeing, particularly when exploring decision making. Social workers are integral to the rehabilitation team, their expertise in addressing psychosocial needs, discharge planning, family support and knowledge of the legal framework is crucial for addressing the needs of patients with ABI and their families (Freymuller et al., 2024).

6.6: Recommendations for policy & practice

This study has resulted in several key recommendations for policy and practice in addressing the needs of patients with ABI and their families. The recommendations for health and social care professionals and policy makers include:

1) Shared risk taking amongst the multidisciplinary team: Professionals should collectively discuss and document risk. These should be appropriately documented and reviewed as needed. Professionals should agree on action plans that promote independence and balances self-determination with safety concerns. Professionals should consider the use of a standardised Risk matrix within MDT settings.
2) Enhanced patient and family involvement: Professionals should work collaboratively with patients and family in providing clear, accessible information throughout their rehabilitation journey. The needs of the patient and family should be considered holistically.

3) Balance autonomy with tailored risk assessment: Professionals should devise tailored care plans which promote patients' independence considering individual preferences. Patients should be empowered to make choices whilst ensuring appropriate contingency plans to account for risk.
4) Foster open communication and shared decision making: Professionals should work closely with patients and families in devising goal setting, care plans, risk assessment and discussing discharge plans. Patients should always be central to the decision making.
5) Mental capacity assessment: Social workers undertaking mental capacity assessments must be skilled and trained professionals who have knowledge/experience or training on ABI.
6) Standardised Shared decision-making framework: Patients with ABI to be kept well informed and supported with making decisions throughout their rehabilitation. Whilst there is no universal standardised toolkit in the context of ABI, a useful tool is the Brain Injury Needs Indicator (BINI) available from BrainKind (2025) is designed to enable social workers and other professionals to identify how well someone has recovered from their brain injury and what social care support they need.
7) Trauma informed practice: Professionals should improve accessibility to services for patients with ABI and their families.
8) Effective multidisciplinary team working: Professionals should recognise and value the expertise that different specialities bring to the team. There should be an acknowledgement of professional differences, but all professionals should work toward a common goal in striving to improve patient care and outcomes.

Balancing patient's risk, autonomy and self-determination requires implementation of the above recommendations and a personalised approach from the whole multidisciplinary team.

6.7: Strengths & Limitations

This research sought to understand the tensions and dilemmas that arise for the patients, family and MDT when balancing patient's risk, autonomy and self-determination during patient rehabilitation. The research objectives outlined in the

introduction have been achieved through the detailed insights of the research participants into their experiences. The approach of IPA using semi-structured interviews enabled in-depth examinations of the participants unique and personal lived experiences (Smith & Osborn, 2015). The findings of this study show that collaboration between patient, family and MDT is essential in managing risks issues, promoting patient's autonomy and self-determination.

The focus on patient's and family experiences addressed the gap in literature to enable greater understanding of the lived experiences of patients with ABI and their families. Additionally, the professional participants also offered new insights and additional knowledge into the challenges that the MDT face when seeking to balance issues of risk whilst promoting patient's autonomy and self-determination.

The small-scale study was conducted in a single centre comprising 12 interviews across the three participant groups, although ideal for IPA does not allow for broader generalisation. The recruitment of family members was challenging and as a result only 1 family member was interviewed in the study, limiting the wider understanding of the family or informal carers' perspective. The insider researcher nature of the study was a potential strength due to knowledge of ABI and the setting, but it may also have potentially introduced some biases in the recruitment process as the study was based in a single centre.

This study provides benefits to the social work communities of practice by promoting evidence-based practice, therefore fostering a culture of continuous learning and reflection and strengthening the social work professional identity.

6.8: Recommendations for further research

Despite the small-scale nature of the study, this research was able to shed light on a social worker's viewpoint on the factors that influence the multidisciplinary team in balancing patients' risk, autonomy and self-determination. Whilst the study addressed potential gaps and knowledge, there is scope for further research in the future to explore the following:

- The needs of minority ethnic groups with ABI who are often underrepresented in research.

- Studying the role of family/support networks in brain injury recovery and methods to optimise family engagement.
- Research on the Mental Capacity Act 2005 and its application within ABI practice.
- Decision making framework or toolkit for assessing mental capacity in the context of ABI practice.
- Finally, any future research will need to be scaled up to multi-centre for broader understanding of the phenomena.

6.9: Conclusion

This study advances the existing literature by offering a social work perspective and providing evidence-based practices that can inform policy and practice discussions particularly for those working within multidisciplinary teams within ABI practice. The findings extend understanding about multidisciplinary team practice and social work in ABI rehabilitation settings, highlighting the need for collaborative holistic interventions to address the needs of patients and their families through involvement of the multidisciplinary team and external agencies.

The literature surrounding the lived experiences of people with ABI from a social work perspective is limited and this research gathered unique perspectives from patients, family and professionals about how these important components are explored during inpatient rehabilitation. The use of IPA and reflexivity complements social work research and enhances in-depth understanding of the lived experiences of participants whilst also improving data trustworthiness and rigour.

The findings from this study offers insight into the experiences of patients, family and the MDT when exploring issues of risk, autonomy and self-determination. Balancing risk, autonomy and self-determination requires ongoing communication, tailored risk assessments, shared decision making and most importantly, a person-centred approach from the whole multidisciplinary team. Joined up MDT working which honours both autonomy and safety concerns are imperative for improving patients' outcomes during rehabilitation and the transition beyond hospital. Multidisciplinary teams should actively reflect on outcomes to improve practice.

The study offers understanding on the social worker's role in providing psychosocial support to address the practical, legal and emotional aspects of rehabilitation so that patients can transition back to community living after brain injury.

The study identified several areas which warrant further research to increase insight into the needs of minority ethnic groups with ABI who are often underrepresented in research, the role of family/support networks in brain injury recovery and methods to optimise family engagement and research on the Mental Capacity Act 2005 and its application within ABI practice.

The next steps following submission of this dissertation will be to disseminate the findings to the NHS Trust and publish the results to provide better understanding on how patients with ABI, family and multidisciplinary team can address risk whilst balancing autonomy and self-determination during inpatient rehabilitation.

STATUTES & CASE LAW

STATUTES

Care Act 2014

Data Protection Act 1998

Equality Act 2010

Humans Rights Act 1998

Mental Capacity Act 2005

CASE LAW

CT v London Borough of Lambeth & Anor [2025] EWCOP 6 (T3).

TB v KB and LH [2019] EWCOP 14

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APPENDIX 1: Letter of invitation

LETTER OF INVITATION TO BE CONTACTED ABOUT A RESEARCH STUDY

Hello, my name is Basirah Oloko. I am a student at the University of Hertfordshire currently completing a Masters by Research study to find out how patients with a brain injury and their families/informal carers are supported with making decisions during their rehabilitation.

My study is called **'The role of the multidisciplinary team in balancing patients' risk, autonomy and self-determination during brain injury inpatient rehabilitation: a social worker's perspective'**

I would like to meet with you to give you an information sheet about the study as your experiences are relevant to my research.

Please note that agreeing to receive information about the study (by signing this letter) does NOT mean you are agreeing to participate in the research.

Are you happy for me to meet with you and provide you with an information sheet about my study?

Yes [ ]

If yes – please write your name and sign.

Name: .....

Signature: .....

Date: .....

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APPENDIX 2: Research participant poster

APPENDIX 3: HRA favourable opinion

Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

31 January 2025

Dr Jennifer Lynch
Centre for Research in Public Health and Community Care, University of Hertfordshire
Health Research Building, College Lane
Hatfield
AL10 9AB

Dear Dr Lynch

Study title:	**The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.**
REC reference:	**24/YH/0249**
Protocol number:	**TBC**
IRAS project ID:	**343988**

Thank you for your recent correspondence, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

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

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

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

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

Where a deferral is agreed we expect the sponsor to publish a minimal record on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, a minimum research summary will still be published in the research summaries database. At the end of the deferral period, we will publish the full research summary.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: Research summaries - Health Research Authority (hra.nhs.uk)

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

After ethical review: Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

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

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Brain injury research poster]		31 January 2025
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor insurance]	1	30 July 2024
Interview schedules or topic guides for participants [Interview topic guides]	1	11 October 2024
Interview schedules or topic guides for participants [Interview topic guides Families/Informal Carers]	1	11 October 2024
Interview schedules or topic guides for participants [Interview topic guides Professionals]	1	11 October 2024
Interview schedules or topic guides for participants [Interview topic guides Patients]	1	11 October 2024
IRAS Application Form [IRAS_Form_03122024]		03 December 2024
Letter from sponsor [Research in principle sponsorship letter]	1	10 October 2024
Letters of invitation to participant [Invitation letter]	1	21 November 2024
Organisation Information Document [Organisation information document]	1	19 September 2024
Other [Response to HRA Ethical Review additional information]	1	02 December 2024
Participant consent form [Consent form Patients]	2	14 November 2024
Participant consent form [Consent form Professionals]	2	14 November 2024
Participant consent form [Consent form Families/Informal Carers]	2	14 November 2024
Participant information sheet (PIS) [Participant Information Sheet Patient]	2	14 November 2024
Participant information sheet (PIS) [Participant Information Sheet Professionals]	2	14 November 2024
Participant information sheet (PIS) [Participant Information Sheet Families/Informal Carers]	2	14 November 2024
Research protocol or project proposal [Protocol]	2	14 November 2024
Response to Additional Conditions Met		
Response to Request for Further Information		
Schedule of Events or SoECAT [IRAS Schedule of events]	1	11 October 2024
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	2	11 October 2024
Summary CV for student [Student CV]	1	11 October 2024

Statement of compliance

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

User Feedback

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

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 343988	**Please quote this number on all correspondence**

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

Yours sincerely

PP H Hendry

Sheila MacLennan
Chair

Email: bradfordleeds.rec@hra.nhs.uk

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

[IF REC ONLY STUDY - REC Staff in England and Wales please insert link to the standard conditions, see links below. Staff in Scotland and Northern Ireland to delete this section but reminded to attach the conditions to the approval email.

After ethical review guidance for sponsors and investigators – Non CTIMP Standard Conditions of Approval]

Copy to: Ms Leire Caselles Vallejo

APPENDIX 4: HRA approval letter

Dr Jennifer Lynch
Centre for Research in Public Health and Community Care, University of Hertfordshire
Health Research Building, College Lane
Hatfield
AL10 9ABN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

31 January 2025

Dear Dr Lynch

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.**
IRAS project ID:	**343988**
Protocol number:	**TBC**
REC reference:	**24/YH/0249**
Sponsor	**Univeristity of Hertfordshire**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) 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 relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW 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 standard conditions 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.

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 **343988**. Please quote this on all correspondence.

Yours sincerely,

Hayley Henderson
Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Ms Leire Caselles Vallejo*

List of Documents

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

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Brain injury research poster]		31 January 2025
Interview schedules or topic guides for participants [Interview topic guides Families/Informal Carers]	1	11 October 2024
Interview schedules or topic guides for participants [Interview topic guides Professionals]	1	11 October 2024
Interview schedules or topic guides for participants [Interview topic guides Patients]	1	11 October 2024
IRAS Application Form [IRAS_Form_03122024]		03 December 2024
Letters of invitation to participant [Invitation letter]	1	21 November 2024
Other [Response to HRA Ethical Review additional information]	1	02 December 2024
Participant consent form [Consent form Patients]	2	14 November 2024
Participant consent form [Consent form Professionals]	2	14 November 2024
Participant consent form [Consent form Families/Informal Carers]	2	14 November 2024
Participant information sheet (PIS) [Participant Information Sheet Patient]	2	14 November 2024
Participant information sheet (PIS) [Participant Information Sheet Professionals]	2	14 November 2024
Participant information sheet (PIS) [Participant Information Sheet Families/Informal Carers]	2	14 November 2024
Research protocol or project proposal [Protocol]	2	14 November 2024

IRAS project ID	343988

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Research activities and procedures as per the protocol and other study documents will take place at participating NHS organisations.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type.	Study funding arrangements are detailed in the Organisation Information Document	A Principal Investigator should be appointed at participating NHS organisations.	Where an external individual who does not already hold an NHS employment contract will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold an Honorary Research Contract. External staff holding pre-existing NHS employment contracts should obtain a Letter of Access. These should confirm Occupational Health Clearance. These should confirm enhanced DBS checks appropriate barred list checks.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

APPENDIX 5: HRA approval following amendment

NHS
Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee

NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

17 November 2025

Dr Rosemary Godbold
Principal Lecturer
University of Hertfordshire
4 Saffron Close
Downham Market
Norfolk
PE38 9UP

Dear Dr Godbold

Study title:	**The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.**
REC reference:	**24/YH/0249**
Protocol number:	**TBC**
Amendment number:	**SA 01**
Amendment date:	**15 October 2025**
IRAS project ID:	**343988**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment tool]	2	07 November 2025
Other [IRASForm-4]		07 November 2025
Summary CV for Chief Investigator (CI) [R Godbold CV]		

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

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

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 343988:	**Please quote this number on all correspondence**

Yours sincerely

pp. Gigi Chan

Mr Peter Atkinson

Chair

E-mail: bradfordleeds.rec@hra.nhs.uk

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Ms Leire Caselles Vallejo*

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 18 November 2025 in correspondence

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mr Peter Atkinson (Chair)	Retired Consultant Ophthalmic Surgeon	Yes	
Dr Hanif Ismail	Patient and Public Involvement Manager	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Gigi Chan	Approvals Administrator

APPENDIX 6: Protocol number

Dear Basirah,

The Chair of the Health, Science, Engineering and Technology ECDA has confirmed that you may quote the amended UH protocol number **aHSK/PGR/NHS/02325(1)** on your submission paperwork and exam arrangements form in line with the substantial amendment attached.

Best wishes,
Erin

Erin Archer (she/her)
Ethics Administrator, Research and Enterprise Services
Office of the Vice-Chancellor

University of Hertfordshire
Hatfield AL10 9AB
UK

Chat with me in Teams

LGBTQ+ Ally

If it is helpful for you to share your pronouns with me, please do so.

Ethics Approval Canvas Site for UG/PGT Students:
https://herts.instructure.com/courses/105037
HertsHub Ethics Approval Site for Doctoral Students and Staff:
https://herts365.sharepoint.com/sites/UHResearch/SitePages/UH-Ethics-Approval---studies-involving-human-participants.aspx

Ethics email address:
ethicsadmin@herts.ac.uk

APPENDIX 7: Permission for research from the NHS Trust

Dear **Jennifer Lynch**,

IRAS Ref: 343988
Study Title: The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective
KCH Ref: KCH24-213
Sponsor: University of Hertfordshire
Location: Orpington Hospital [CPMS code: RJZ70]
Target Recruitment: 15-17 participants overall (5 patients, 5 family members, 5-7 multidisciplinary team members)
Protocol Version: V2

Please review your experience working with R&D (click here)

This email confirms that **KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST** has the capacity and capability to deliver the above referenced study. Please find attached our signed Organisation Information Document as confirmation.

We agree to start this study **when the sponsor gives the green light to begin**.

NB: Principal Investigator and research team, please note that *capacity and capability* has been issued; however, recruitment must not start until you receive confirmation from the sponsor that you are able to begin.

Dear **Basirah Oloko**,

The study has been registered as **KCH24-213**. Please quote this reference in any communications with the R&D Office regarding your project.

A condition of the approval is to upload your recruitment data in real time into the study record in EDGE. Please contact our data central email address kch-tr.data@nhs.net if you need assistance with training or EDGE account activation.

If you would like help from the R&D office, have any concerns regarding the study or want advice, please contact us via our central inbox kch-tr.research@nhs.net. I have also enclosed the R&D structure with contact details.

The R&D Facilitator allocated to your study was: Olatunde Tijani
The RDU Lead for your clinical area, who can also provide support, is: Professor Ashkan Keyoumars

Wishing you all the best with your research; we thank you for leading research at KCH for the benefit of patients and families. We look forward to working with you on this study.

King's College Hospital NHS Foundation Trust Research & Development team are keen improve the services offered to our sponsor's, investigators and stakeholders. Please take a minute to complete our 60 seconds 3 question survey and let us know how we did (click here)

Kind regards,
Olatunde

Olatunde Tijani - (O L A T U N D E)
Assistant Research Facilitator
The R&D Office I First Floor Coldharbour Works I 245A Coldharbour Lane I Brixton I London SW9 8RR
✉: a.tijani1@nhs.net 📱: 07779 554 829 ☎: 0203 299 6634 (ext: 36634)

APPENDIX 8: Participant information sheet for patients

University of Hertfordshire UH

UNIVERSITY OF HERTFORDSHIRE

FORM EC6: PARTICIPANT INFORMATION SHEET FOR PATIENTS

1 **Title of study**

The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.

2 **Introduction**

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 **What is the purpose of this study?**

The study seeks to find out how patients with a brain injury, their families/informal carers and professionals make decisions during their stay in rehabilitation.

4 **Do I have to take part?**

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you must complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive.

5 **Are there any age or other restrictions that may prevent me from participating?**

Participants must be aged 18 and over to take part.
Participants must have an Acquired Brain injury diagnosis.
Participants must have capacity to be able to decide whether or not to take part in the study.

6 **How long will my part in the study take?**

If you decide to take part in this study, you will be invited to take part in an interview process which could last up to 45 minutes.

7 **What will happen to me if I take part?**

You will be asked to sign a consent form after you have read the Participant information sheet and wish to take part in the study. The researcher will meet with you in a quiet room where you will be asked some questions. The interview will be recorded via audio and later transcribed. Some quotations of your answers may be used in the study however your identity will be anonymized, and no personal identifiable information will be used in the study.

8 **What are the possible disadvantages, risks or side effects of taking part?**

(Note: Please also note that circumstances may arise that could result in the need for you to withdraw from the study; should such circumstances occur, the investigator will discuss the matter with you.)

There may be positive and negative experiences which you may have to discuss. The researcher will check in with you during the interview if you wish to stop for a break or if you wish to be supported by someone during the interview process.

9 **What are the possible benefits of taking part?**

You can share your lived experience as a person with a Brain injury.

10 **How will my taking part in this study be kept confidential?**

Participant data will be kept confidential. All names or identifiable information will be removed from the data and the document linking participant codes to participant details will be kept separately. All participants will be guaranteed confidentiality in written reports and summaries of data analysis. Participant data will be stored safely and not shared with other participants or staff.

11 **Audio-visual material**

The interview will be recoded on audio and will be saved, and password protected on a computer device. The data may be referenced in future studies.

12 **What will happen to the data collected within this study?**

In this research study we will use information from you and the ward staff. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it.

We will make sure no-one can work out who you are from the reports we write.

You can find out how your information is used on the Health Research Authority Website:

https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/

The data collected will be stored electronically, in a password-protected environment, for up to 5 years, after which time it will be destroyed under secure conditions.

The data will be anonymized prior to storage.

The data will be transcribed, and quotations may be used within the study. Personal data of participants will be anonymized.

Should a participant choose to withdraw from the study, or they lose mental capacity during the study, the data collected up to that point will remain in the study but no further data will be collected.

13 **Will the data be required for use in further studies?**

The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymized.

14 **Who has reviewed this study?**

This study has been reviewed by:
The Health Research Authority (REC reference 24/YH/0249)
The UH protocol number is HSK/PGR/NHS/02325

15 **Factors that might put others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.
Please note if any safeguarding issues become apparent, the researcher has a duty of care to follow these up in line with policy and procedure.

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me by phone:
Basirah Oloko Telephone: 07929786176

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane

University of Hertfordshire UH

Hatfield
Herts
AL10 9AB
s.harrison-barker@herts.ac.uk

If you suspect a Data Protection Act breach has occurred, please contact
dataprotection@herts.ac.uk

Thank you very much for reading this information and considering taking part in this study.

APPENDIX 9: Participant information sheet for families/informal carers

University of Hertfordshire UH

UNIVERSITY OF HERTFORDSHIRE

FORM EC6: PARTICIPANT INFORMATION SHEET FOR FAMILIES/INFORMAL CARERS

1 **Title of study**

The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.

2 **Introduction**

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 **What is the purpose of this study?**

The study seeks to find out how patients with a brain injury, their families/informal carers and professionals make decisions during their stay in rehabilitation.

4 **Do I have to take part?**

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you must complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive.

5 **Are there any age or other restrictions that may prevent me from participating?**

Participants must be aged 18 and over to take part.
Participants must be a family member/friend or informal carer of a patient admitted for neurorehabilitation.

6 **How long will my part in the study take?**

If you decide to take part in this study, you will be invited to take part in an interview process which could last up to 45 minutes.

7 **What will happen to me if I take part?**

You will be asked to sign a consent form after you have read the Participant information sheet and wish to take part in the study. The researcher will meet with you in a quiet room where you will be asked some questions. The interview will be recorded via audio and later transcribed. Some quotations of your answers may be used in the study however your identity will be anonymized, and no personal identifiable information will be used in the study.

8 **What are the possible disadvantages, risks or side effects of taking part?**

(Note: Please also note that circumstances may arise that could result in the need for you to withdraw from the study; should such circumstances occur, the investigator will discuss the matter with you.)

There may be positive and negative experiences which you may have to discuss. The researcher will check in with you during the interview if you wish to stop for a break or if you wish to be supported by someone during the interview process.

9 **What are the possible benefits of taking part?**

You will have the opportunity to share your experience as a family/friend or informal carer of a patient with a Brain injury.

10 **How will my taking part in this study be kept confidential?**

Participant data will be kept confidential. All names or identifiable information will be removed from the data and the document linking participant codes to participant details will be kept separately. All participants will be guaranteed confidentiality in written reports and summaries of data analysis. Participant data will be stored safely and not shared with other participants or staff.

11 **Audio-visual material**

The interview will be recorded on audio and will be saved, and password protected on a computer device. The audio will be transcribed and anonymized. Only the researcher will have access to the personal data. The anonymized data may be referenced in future studies.

12 **What will happen to the data collected within this study?**

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it.

We will make sure no-one can work out who you are from the reports we write.

You can find out how your information is used on the Health Research Authority Website:

https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/

The data collected will be stored electronically, in a password-protected environment, for up to 5 years, after which time it will be destroyed under secure conditions.

The data will be anonymized prior to storage.

The data will be transcribed, and quotations may be used within the study. Personal data of participants will be anonymized.

Should a participant choose to withdraw from the study, or they lose mental capacity during the study, the data collected up to that point will remain in the study but no further data will be collected.

13 **Will the data be required for use in further studies?**

The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymized.

14 **Who has reviewed this study?**

This study has been reviewed by:
The Health Research Authority (REC reference 24/YH/0249)
The UH protocol number is HSK/PGR/NHS/02325

15 **Factors that might put others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.
Please note if any safeguarding issues become apparent, the researcher has a duty of care to follow these up in line with policy and procedure.

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me by phone:
Basirah Oloko Telephone: **07929786176**

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during this study, please write to the University's Secretary and Registrar at the following address:

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University of Hertfordshire
College Lane

University of Hertfordshire UH

Hatfield
Herts
AL10 9AB
s.harrison-barker@herts.ac.uk

If you suspect a Data Protection Act breach has occurred, please contact
dataprotection@herts.ac.uk

Thank you very much for reading this information and considering taking part in this study.

APPENDIX 10: Participant information sheet for professionals

University of Hertfordshire UH

UNIVERSITY OF HERTFORDSHIRE

FORM EC6: PARTICIPANT INFORMATION SHEET FOR PROFESSIONALS

1 **Title of study**

The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.

2 **Introduction**

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 **What is the purpose of this study?**

The multidisciplinary team clearly plays a critical role in rehabilitation of brain injury individuals. However, there is limited literature on how professionals, patients and families explore risk, autonomy and self-determination within brain injury rehabilitation. This study seeks to explore how professionals make ethical and clinical decisions relating to safety and autonomy.

4 **Do I have to take part?**

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you must complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you may receive.

5 **Are there any age or other restrictions that may prevent me from participating?**

Participants must be aged 18 and over to take part.
Participants must work within a brain injury neurorehabilitation team.

6 **How long will my part in the study take?**

If you decide to take part in this study, you will be invited to take part in an interview process which could last up to 45 minutes.

7 **What will happen to me if I take part?**

You will be asked to sign a consent form after you have read the Participant information sheet and wish to take part in the study. The researcher will meet with you in a quiet room where you will be asked some questions. The interview will be recorded via audio and later transcribed. Some quotations of your answers may be used in the study however your identity will be anonymized, and no personal identifiable information will be used in the study.

8 **What are the possible disadvantages, risks or side effects of taking part?**

(Note: Please also note that circumstances may arise that could result in the need for you to withdraw from the study; should such circumstances occur, the investigator will discuss the matter with you.)

There may be positive and negative experiences which you may have to discuss. The researcher will check in with you during the interview if you wish to stop for a break or if you wish to be supported by someone during the interview process.

9 **What are the possible benefits of taking part?**

You can share your experience as a professional working in neurorehabilitation. Further light will be shed on the role of the multidisciplinary team in balancing patient's risk, autonomy and self-determination.

10 **How will my taking part in this study be kept confidential?**

Participant data will be kept confidential. All names or identifiable information will be removed from the data and the document linking participant codes to participant details will be kept separately. All participants will be guaranteed confidentiality in written reports and summaries of data analysis. Participant data will be stored safely and not shared with other participants or staff.

11 **Audio-visual material**

The interview will be recoded on audio and will be saved, and password protected on a computer device. The data may be referenced in future studies.

12 **What will happen to the data collected within this study?**

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it.

We will make sure no-one can work out who you are from the reports we write.

You can find out how your information is used on the Health Research Authority Website:

https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/

The data collected will be stored electronically, in a password-protected environment, for up to 5 years, after which time it will be destroyed under secure conditions.

The data will be anonymized prior to storage.

The data will be transcribed, and quotations may be used within the study. Personal data of participants will be anonymized.

Should a participant choose to withdraw from the study, or they lose mental capacity during the study, the data collected up to that point will remain in the study but no further data will be collected.

13 Will the data be required for use in further studies?

The data collected may be re-used or subjected to further analysis as part of a future ethically approved study; the data to be re-used will be anonymized. The data will be kept for up to 5 years.

14 Who has reviewed this study?

This study has been reviewed by:
The Health Research Authority (REC reference 24/YH/0249)

The UH protocol number is HSK/PGR/NHS/02325

15 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.
Please note if any safeguarding issues become apparent, the researcher has a duty of care to follow these up in line with policy and procedure.

University of Hertfordshire UH

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me by phone:
Basirah Oloko Telephone: 07929786176

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB
s.harrison-barker@herts.ac.uk

If you suspect a Data Protection Act breach has occurred, please contact
dataprotection@herts.ac.uk

Thank you very much for reading this information and considering taking part in this study.

APPENDIX 11: Consent form for patients

University of Hertfordshire UH

UNIVERSITY OF HERTFORDSHIRE

FORM EC3
CONSENT FORM FOR PATIENTS

I, the undersigned *[please give your name and contact details here, in BLOCK CAPITALS]*

NAME:……

CONTACT DETAILS……

hereby freely agree to take part in the study entitled: **The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: A social worker's perspective.**

……

(UH Protocol number HSK/PGR/NHS/02325)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice audio will take place and I have been informed of how/whether this recording will be transmitted.

4 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used, including the possibility of anonymised data being referenced in future studies.

5 I confirm that my personal data can be retained for the purposes of receiving a summary of the study results.

6 I understand that if there are any safeguarding issues which arise, the researcher as a duty of care to report it in line with the safeguarding policy and procedures.

University of Hertfordshire UH

Signature of participant……..…Date……

Signature of (principal) investigator……Date……

Name of (principal) investigator *[in BLOCK CAPITALS please]*

……

APPENDIX 12: Consent form for families/informal carers

University of Hertfordshire UH

UNIVERSITY OF HERTFORDSHIRE

FORM EC3
CONSENT FORM FOR FAMILIES/INFORMAL CARERS

I, the undersigned *[please give your name and contact details here, in BLOCK CAPITALS]*

NAME:……

CONTACT DETAILS: ……

hereby freely agree to take part in the study entitled: **The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: A social worker's perspective.**

(UH Protocol number HSK/PGR/NHS/02325)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

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5 I confirm that my personal data can be retained for the purposes of receiving a summary of the study results.

6 I understand that if there are any safeguarding issues which arise, the researcher as a duty of care to report it in line with the safeguarding policy and procedures.

University of Hertfordshire UH

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me by phone:
Basirah Oloko Telephone: 07929786176

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

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s.harrison-barker@herts.ac.uk

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Thank you very much for reading this information and considering taking part in this study.

APPENDIX 13: Consent form for professionals

University of Hertfordshire UH

UNIVERSITY OF HERTFORDSHIRE

FORM EC3
CONSENT FORM FOR PROFESSIONALS

I, the undersigned *[please give your name and contact details here, in BLOCK CAPITALS]*

NAME:……

CONTACT DETAILS: ……

hereby freely agree to take part in the study entitled: **The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: A social worker's perspective.**

(UH Protocol number HSK/PGR/NHS/02325)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

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5 I confirm that my personal data can be retained for the purposes of receiving a summary of the study results.

6 I understand that if there are any safeguarding issues which arise, the researcher as a duty of care to report it in line with the safeguarding policy and procedures.

University of Hertfordshire UH

Signature of participant……..…Date……..

Signature of (principal) investigator……Date……

Name of (principal) investigator *[in BLOCK CAPITALS please]*

……

APPENDIX 14: Interview topic guides for patients

Question topic guides for Patients

The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.

Questions are designed to explore risk, autonomy and self-determination. This a guide on the types of questions I will be asking.

Introduction: My name is Basirah Oloko. Once again thank you for taking part in this study. I will be asking you about your brain injury, how it has affected you and how you are supported in making decisions.

Reminder to stop for breaks.

1) Can you tell me about your brain injury and what led to your admission to this ward.

2) What was important to you during your stay here. Do you think this was important to the people that were looking after you?

3) What decisions have you had to make during your stay and how you were supported in making those decisions?
Prompt: Who was involved in those decisions? i.e. friend/family/informal carer / professionals etc?

4) Since your stay here, has anyone told you that what you are doing is unsafe or risky?
If yes – how did you feel about that?
Who told you that it was unsafe and what reason did they give?

5) Where will you be going when you leave hospital?
Can you explain whether you were given choices/options during this process/by whom?

6) Is there anything we haven't covered yet about how you can be best supported to make decisions?

Thank you for taking time to meet with me.

APPENDIX 15: Interview topic guides for families/informal carers

Interview topic guides for family/informal carers

The role of the multidisciplinary team (MDT) in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.

Questions are designed to explore autonomy, self-determination and risks. This a guide on the types of questions I will be asking.

Introduction: My name is Basirah Oloko. Once again, thank you for taking part in this study. I will be asking you about X's brain injury, then move on to talk about safety and decision making and your role within this.

Reminder to stop for breaks.

1) Can you tell me about your understanding of X's brain injury.

2) What led to X being admitted for inpatient rehabilitation?

3) Since, X had their brain injury, have they done anything that could be seen as risky or unsafe?
   If yes – Is this out of character for X?
   If no – are there any behaviours, you would be worried about?
   Is this something you would have been concerned about before X's brain injury?

4) Where you at any point concerned about X ability to make decisions about his/her discharge? If so, describe the situation and how was X supported with that decision.

5) When it came to discussing discharge and the supports available, did you feel included in the decision-making process?
   If yes – how did the MDT include you in the decision-making process for X?
   Prompt: What information were you provided on available options.
   Prompt: How were you guided on the pros and cons of the options.
   If no – how could they have included you?

6) Is there anything the team looking after X could do to include you in the decision-making process?

Thank you for taking time to meet with me.

APPENDIX 16: Interview topic guides for professionals

Interview topic guides for multidisciplinary team professionals.

The role of the multidisciplinary team in balancing patients' risk, autonomy, and self-determination during brain injury inpatient rehabilitation: a social worker's perspective.

Questions are designed to explore autonomy, self-determination and risks. This a guide on the types of questions I will be asking.

Introduction: My name is Basirah Oloko. Once again thank you for taking part in this study. I will be asking you about your role and the first couple of questions will be about autonomy and decision making. Then we will move on to risks.

Reminder to stop for breaks.

1) Can you tell me about your role in this ward.

2) What do you understand by the term "autonomy".
   How do you include this in your day-to-day practice with patients and their families.
   Prompt: "Promoting independence"

3) How do you include patients and families in making decisions about their discharge and ongoing care?
   Prompt: If you had any concerns about a patient's ability to make decisions, what steps do you take? And how do you involve them even when there are concerns about their mental capacity.

4) Can you describe a situation where a patient was taking "risks" or doing something unsafe?
   Prompt: How did you respond?

5) How would you describe yourself in terms of your attitude to risk. Do you think this affects your work with patients? Tell me more or give examples.

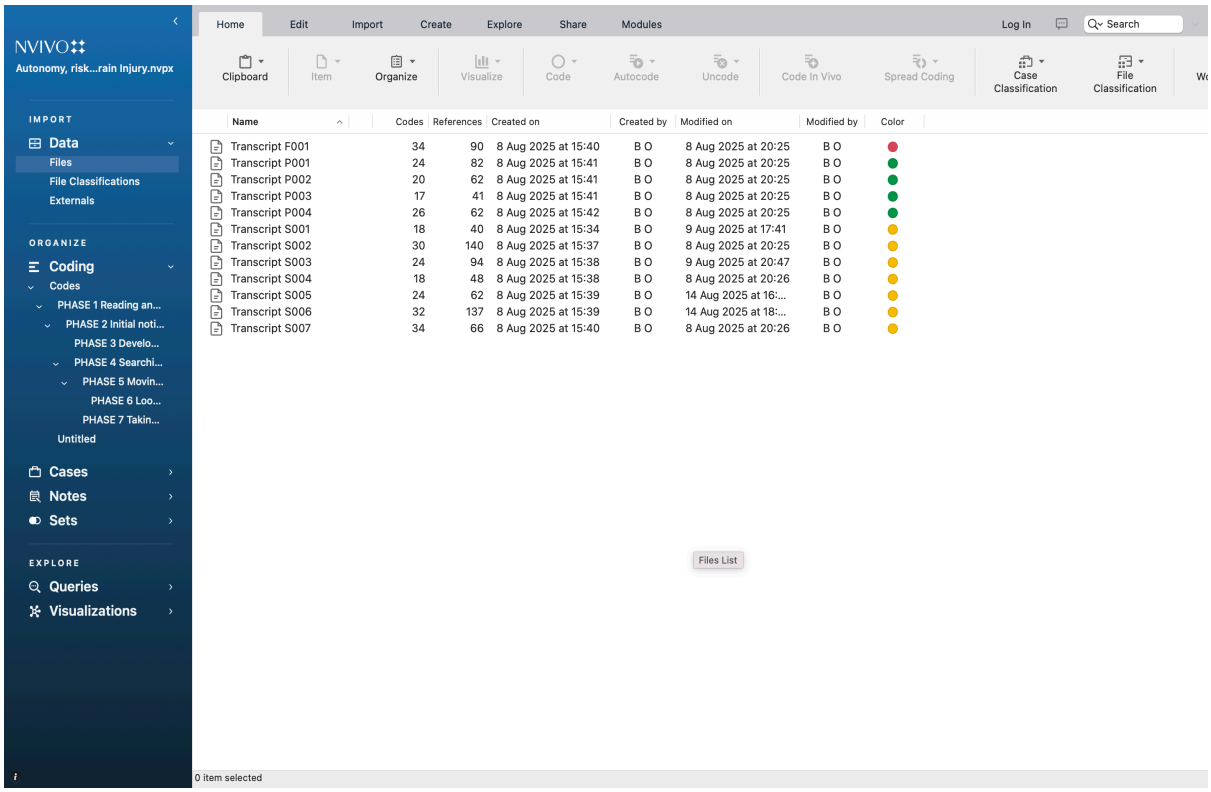
6) Do you think there is a shared understanding of risk within the team?

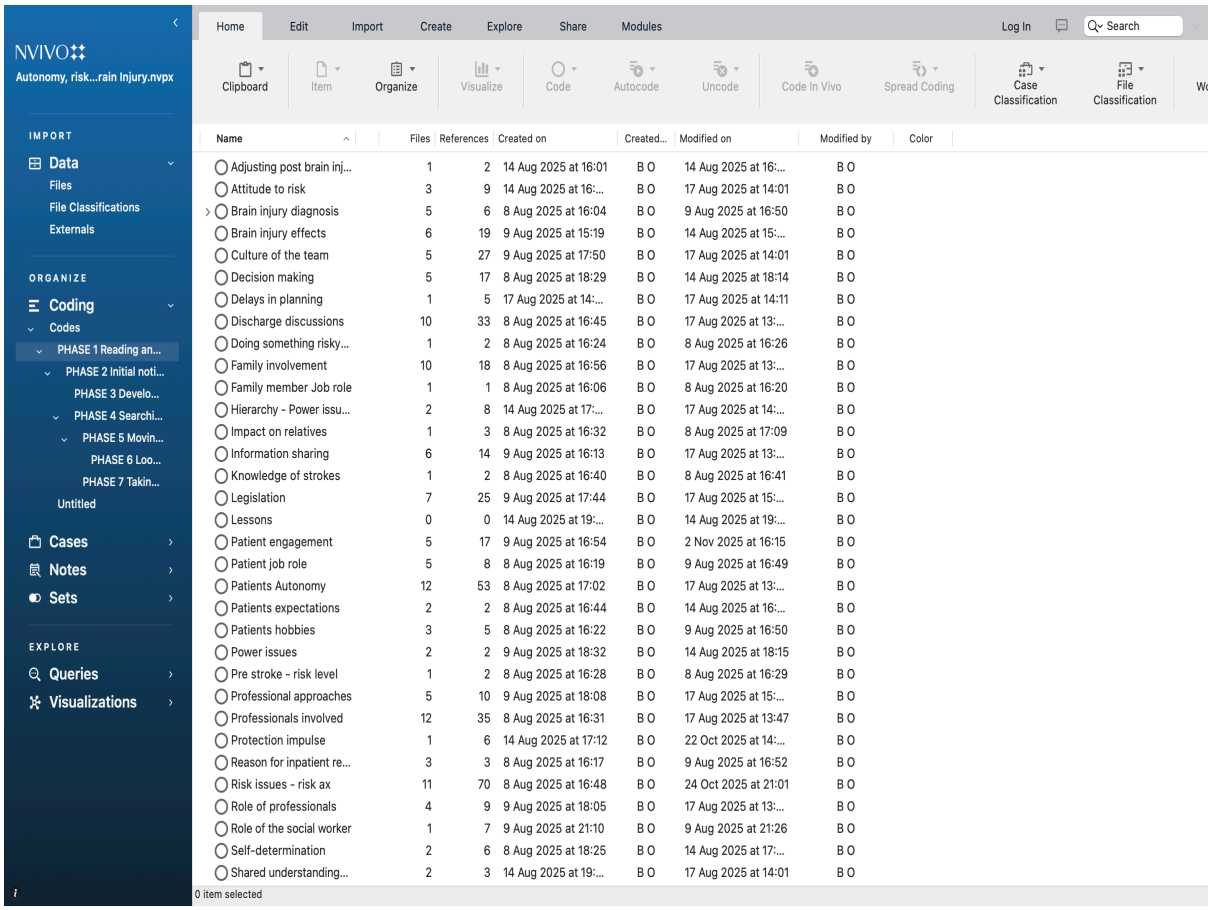
   Prompt: Could you describe the team's culture in regard to risk and does this fit in with your perception of risk).

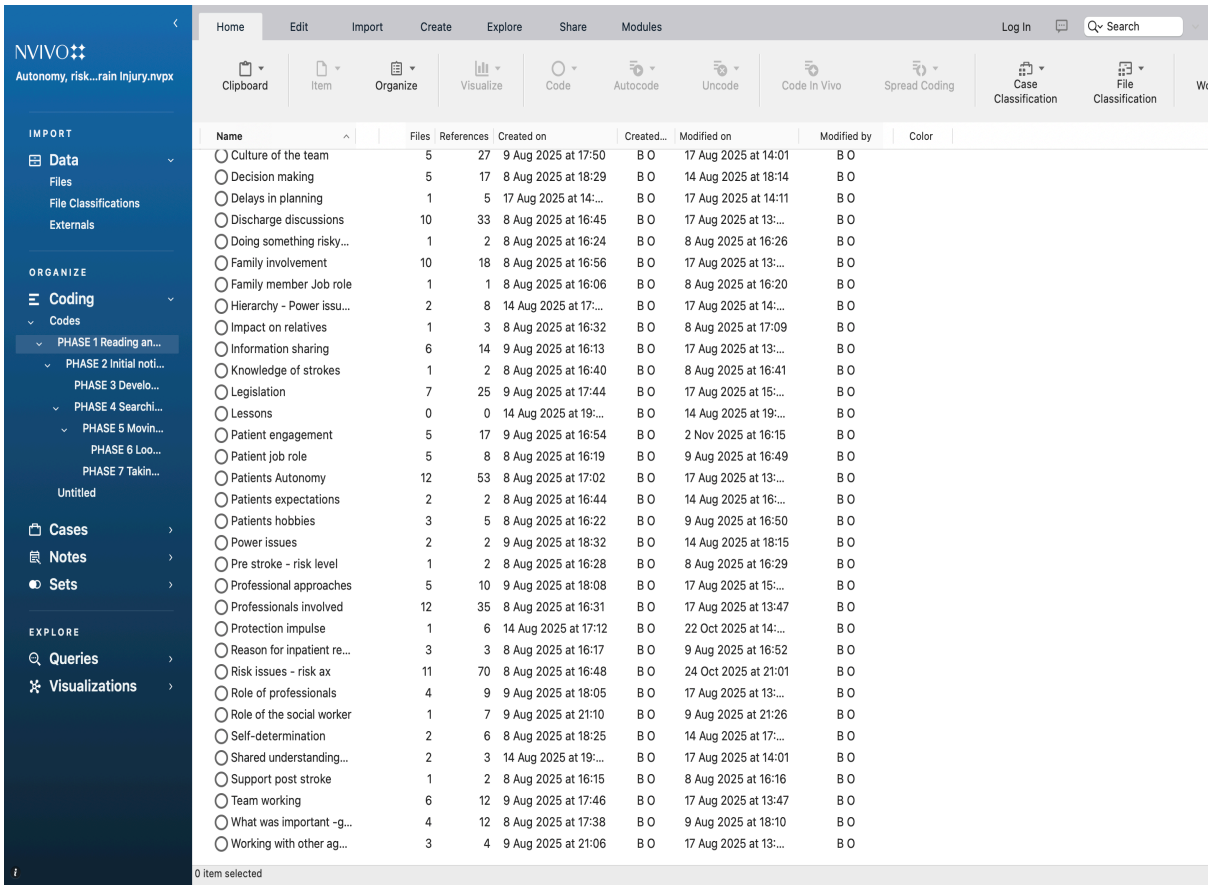
7) Thinking about risk and autonomy. Has there been occasions regarding risk and autonomy when you would have liked to have a different outcome? If so can you explain in more details.

Thank you for taking time to meet with me.

APPENDIX 17: NVIVO Qualitative Data Analysis






NVIVO
Autonomy, risk...rain Injury.nvpx
Home
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Modules
Log In
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Visualize
Code
Autocode
Uncode
Code In Vivo
Spread Coding
Case Classification
File Classification
IMPORT
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Culture of the team 5 27 9 Aug 2025 at 17:50 B O 17 Aug 2025 at 14:01 B O
Decision making 5 17 8 Aug 2025 at 18:29 B O 14 Aug 2025 at 18:14 B O
Delays in planning 1 5 17 Aug 2025 at 14:... B O 17 Aug 2025 at 14:11 B O
Discharge discussions 10 33 8 Aug 2025 at 16:45 B O 17 Aug 2025 at 13:... B O
Doing something risky... 1 2 8 Aug 2025 at 16:24 B O 8 Aug 2025 at 16:26 B O
Family involvement 10 18 8 Aug 2025 at 16:56 B O 17 Aug 2025 at 13:... B O
Family member Job role 1 1 8 Aug 2025 at 16:06 B O 8 Aug 2025 at 16:20 B O
Hierarchy - Power issu... 2 8 14 Aug 2025 at 17:... B O 17 Aug 2025 at 14:... B O
Impact on relatives 1 3 8 Aug 2025 at 16:32 B O 8 Aug 2025 at 17:09 B O
Information sharing 6 14 9 Aug 2025 at 16:13 B O 17 Aug 2025 at 13:... B O
Knowledge of strokes 1 2 8 Aug 2025 at 16:40 B O 8 Aug 2025 at 16:41 B O
Legislation 7 25 9 Aug 2025 at 17:44 B O 17 Aug 2025 at 15:... B O
Lessons 0 0 14 Aug 2025 at 19:... B O 14 Aug 2025 at 19:... B O
Patient engagement 5 17 9 Aug 2025 at 16:54 B O 2 Nov 2025 at 16:15 B O
Patient job role 5 8 8 Aug 2025 at 16:19 B O 9 Aug 2025 at 16:49 B O
Patients Autonomy 12 53 8 Aug 2025 at 17:02 B O 17 Aug 2025 at 13:... B O
Patients expectations 2 2 8 Aug 2025 at 16:44 B O 14 Aug 2025 at 16:... B O
Patients hobbies 3 5 8 Aug 2025 at 16:22 B O 9 Aug 2025 at 16:50 B O
Power issues 2 2 9 Aug 2025 at 18:32 B O 14 Aug 2025 at 18:15 B O
Pre stroke - risk level 1 2 8 Aug 2025 at 16:28 B O 8 Aug 2025 at 16:29 B O
Professional approaches 5 10 9 Aug 2025 at 18:08 B O 17 Aug 2025 at 15:... B O
Professionals involved 12 35 8 Aug 2025 at 16:31 B O 17 Aug 2025 at 13:47 B O
Protection impulse 1 6 14 Aug 2025 at 17:12 B O 22 Oct 2025 at 14:... B O
Reason for inpatient re... 3 3 8 Aug 2025 at 16:17 B O 9 Aug 2025 at 16:52 B O
Risk issues - risk ax 11 70 8 Aug 2025 at 16:48 B O 24 Oct 2025 at 21:01 B O
Role of professionals 4 9 9 Aug 2025 at 18:05 B O 17 Aug 2025 at 13:... B O
Role of the social worker 1 7 9 Aug 2025 at 21:10 B O 9 Aug 2025 at 21:26 B O
Self-determination 2 6 8 Aug 2025 at 18:25 B O 14 Aug 2025 at 17:... B O
Shared understanding... 2 3 14 Aug 2025 at 19:... B O 17 Aug 2025 at 14:01 B O
Support post stroke 1 2 8 Aug 2025 at 16:15 B O 8 Aug 2025 at 16:16 B O
Team working 6 12 9 Aug 2025 at 17:46 B O 17 Aug 2025 at 13:47 B O
What was important -g... 4 12 8 Aug 2025 at 17:38 B O 9 Aug 2025 at 18:10 B O
Working with other ag... 3 4 9 Aug 2025 at 21:06 B O 17 Aug 2025 at 13:... B O
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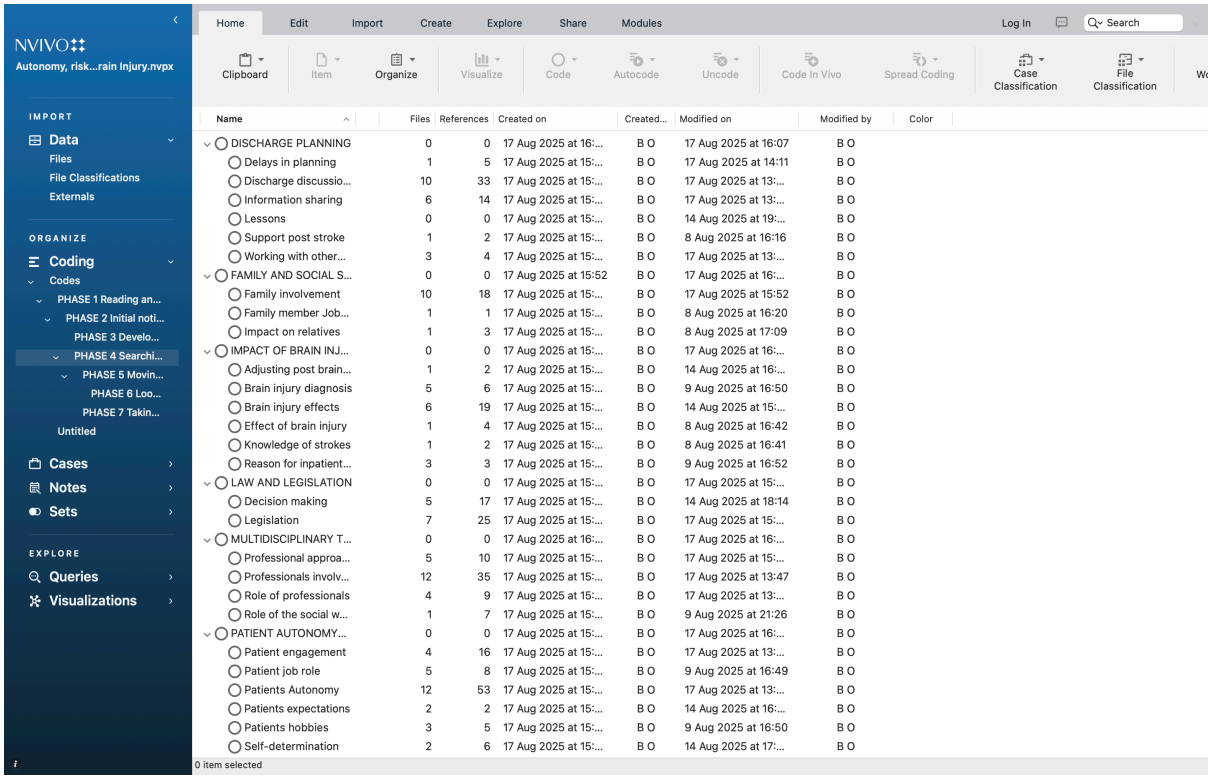
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Autonomy, risk...rain Injury.nvpx
Home
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DISCHARGE PLANNING 0 0 17 Aug 2025 at 16:... B O 17 Aug 2025 at 16:07 B O
Delays in planning 1 5 17 Aug 2025 at 15:... B O 17 Aug 2025 at 14:11 B O
Discharge discussio... 10 33 17 Aug 2025 at 15:... B O 17 Aug 2025 at 13:... B O
Information sharing 6 14 17 Aug 2025 at 15:... B O 17 Aug 2025 at 13:... B O
Lessons 0 0 17 Aug 2025 at 15:... B O 14 Aug 2025 at 19:... B O
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Family involvement 10 18 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:52 B O
Family member Job... 1 1 17 Aug 2025 at 15:... B O 8 Aug 2025 at 16:20 B O
Impact on relatives 1 3 17 Aug 2025 at 15:... B O 8 Aug 2025 at 17:09 B O
IMPACT OF BRAIN INJ... 0 0 17 Aug 2025 at 15:... B O 17 Aug 2025 at 16:... B O
Adjusting post brain... 1 2 17 Aug 2025 at 15:... B O 14 Aug 2025 at 16:... B O
Brain injury diagnosis 5 6 17 Aug 2025 at 15:... B O 9 Aug 2025 at 16:50 B O
Brain injury effects 6 19 17 Aug 2025 at 15:... B O 14 Aug 2025 at 15:... B O
Effect of brain injury 1 4 17 Aug 2025 at 15:... B O 8 Aug 2025 at 16:42 B O
Knowledge of strokes 1 2 17 Aug 2025 at 15:... B O 8 Aug 2025 at 16:41 B O
Reason for inpatient... 3 3 17 Aug 2025 at 15:... B O 9 Aug 2025 at 16:52 B O
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Role of professionals 4 9 17 Aug 2025 at 15:... B O 17 Aug 2025 at 13:... B O
Role of the social w... 1 7 17 Aug 2025 at 15:... B O 9 Aug 2025 at 21:26 B O
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Patients Autonomy 12 53 17 Aug 2025 at 15:... B O 17 Aug 2025 at 13:... B O
Patients expectations 2 2 17 Aug 2025 at 15:... B O 14 Aug 2025 at 16:... B O
Patients hobbies 3 5 17 Aug 2025 at 15:... B O 9 Aug 2025 at 16:50 B O
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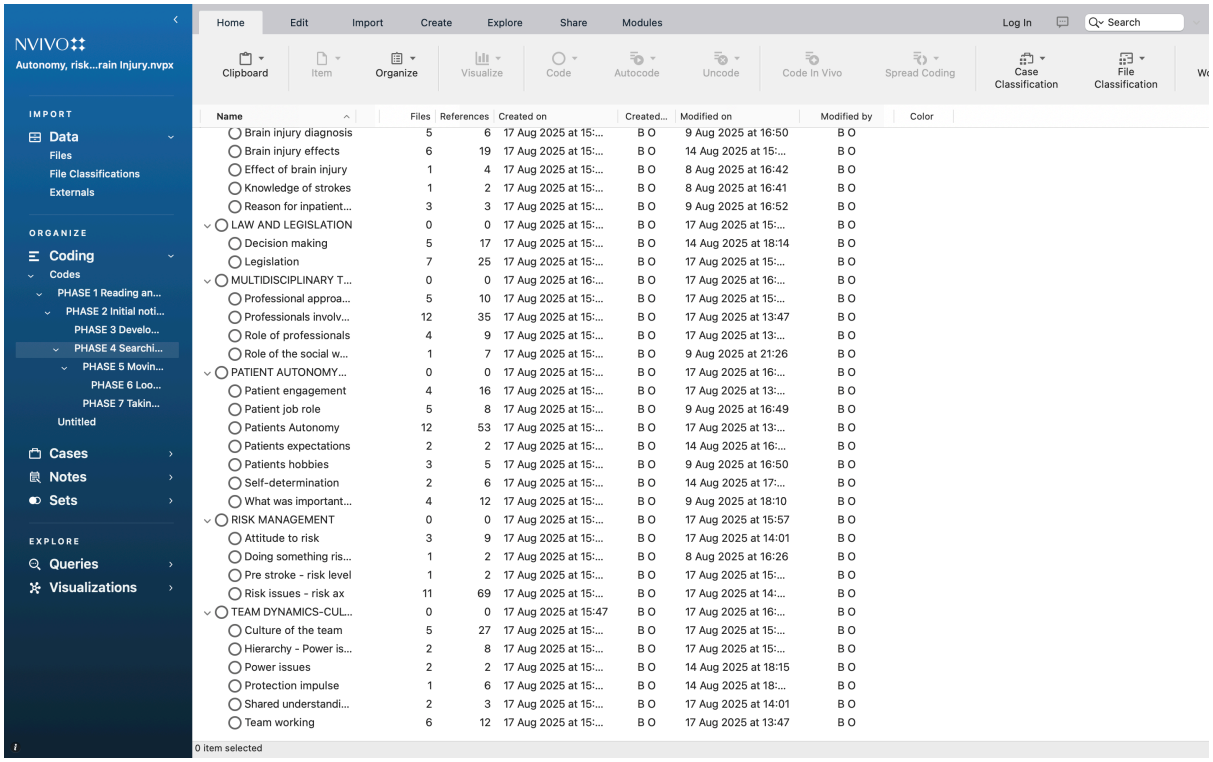
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Autonomy, risk...rain Injury.nvpx
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PHASE 5 Movin...
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Clipboard
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Spread Coding
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Brain injury diagnosis 5 6 17 Aug 2025 at 15:... B O 9 Aug 2025 at 16:50 B O
Brain injury effects 6 19 17 Aug 2025 at 15:... B O 14 Aug 2025 at 15:... B O
Effect of brain injury 1 4 17 Aug 2025 at 15:... B O 8 Aug 2025 at 16:42 B O
Knowledge of strokes 1 2 17 Aug 2025 at 15:... B O 8 Aug 2025 at 16:41 B O
Reason for inpatient... 3 3 17 Aug 2025 at 15:... B O 9 Aug 2025 at 16:52 B O
LAW AND LEGISLATION 0 0 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:... B O
Decision making 5 17 17 Aug 2025 at 15:... B O 14 Aug 2025 at 18:14 B O
Legislation 7 25 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:... B O
MULTIDISCIPLINARY T... 0 0 17 Aug 2025 at 16:... B O 17 Aug 2025 at 16:... B O
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Professionals involv... 12 35 17 Aug 2025 at 15:... B O 17 Aug 2025 at 13:47 B O
Role of professionals 4 9 17 Aug 2025 at 15:... B O 17 Aug 2025 at 13:... B O
Role of the social w... 1 7 17 Aug 2025 at 15:... B O 9 Aug 2025 at 21:26 B O
PATIENT AUTONOMY... 0 0 17 Aug 2025 at 15:... B O 17 Aug 2025 at 16:... B O
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Patient job role 5 8 17 Aug 2025 at 15:... B O 9 Aug 2025 at 16:49 B O
Patients Autonomy 12 53 17 Aug 2025 at 15:... B O 17 Aug 2025 at 13:... B O
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Patients hobbies 3 5 17 Aug 2025 at 15:... B O 9 Aug 2025 at 16:50 B O
Self-determination 2 6 17 Aug 2025 at 15:... B O 14 Aug 2025 at 17:... B O
What was important... 4 12 17 Aug 2025 at 15:... B O 9 Aug 2025 at 18:10 B O
RISK MANAGEMENT 0 0 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:57 B O
Attitude to risk 3 9 17 Aug 2025 at 15:... B O 17 Aug 2025 at 14:01 B O
Doing something ris... 1 2 17 Aug 2025 at 15:... B O 8 Aug 2025 at 16:26 B O
Pre stroke - risk level 1 2 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:... B O
Risk issues - risk ax 11 69 17 Aug 2025 at 15:... B O 17 Aug 2025 at 14:... B O
TEAM DYNAMICS-CUL... 0 0 17 Aug 2025 at 15:47 B O 17 Aug 2025 at 16:... B O
Culture of the team 5 27 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:... B O
Hierarchy - Power is... 2 8 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:... B O
Power issues 2 2 17 Aug 2025 at 15:... B O 14 Aug 2025 at 18:15 B O
Protection impulse 1 6 17 Aug 2025 at 15:... B O 14 Aug 2025 at 18:... B O
Shared understandi... 2 3 17 Aug 2025 at 15:... B O 17 Aug 2025 at 14:01 B O
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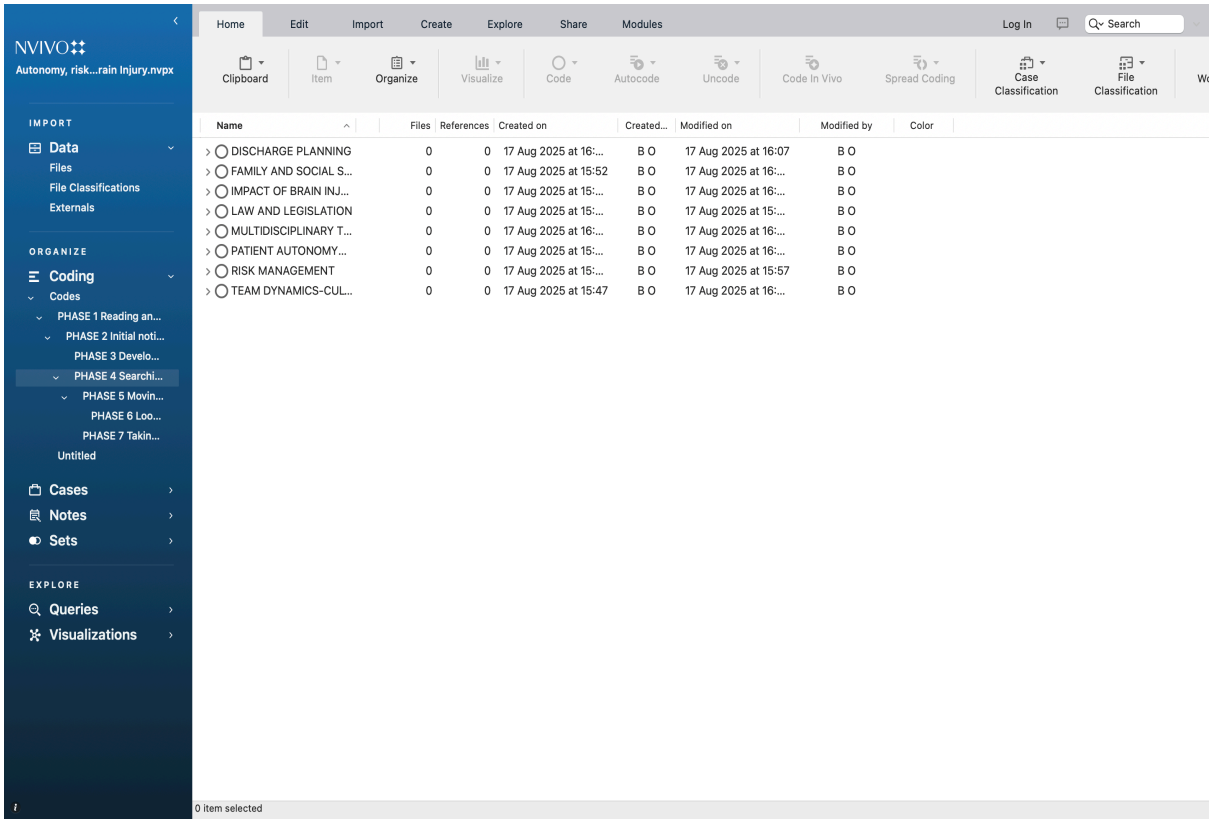
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Code In Vivo
Spread Coding
Case Classification
File Classification
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IMPACT OF BRAIN INJ... 0 0 17 Aug 2025 at 15:... B O 17 Aug 2025 at 16:... B O
LAW AND LEGISLATION 0 0 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:... B O
MULTIDISCIPLINARY T... 0 0 17 Aug 2025 at 16:... B O 17 Aug 2025 at 16:... B O
PATIENT AUTONOMY... 0 0 17 Aug 2025 at 15:... B O 17 Aug 2025 at 16:... B O
RISK MANAGEMENT 0 0 17 Aug 2025 at 15:... B O 17 Aug 2025 at 15:57 B O
TEAM DYNAMICS-CUL... 0 0 17 Aug 2025 at 15:47 B O 17 Aug 2025 at 16:... B O
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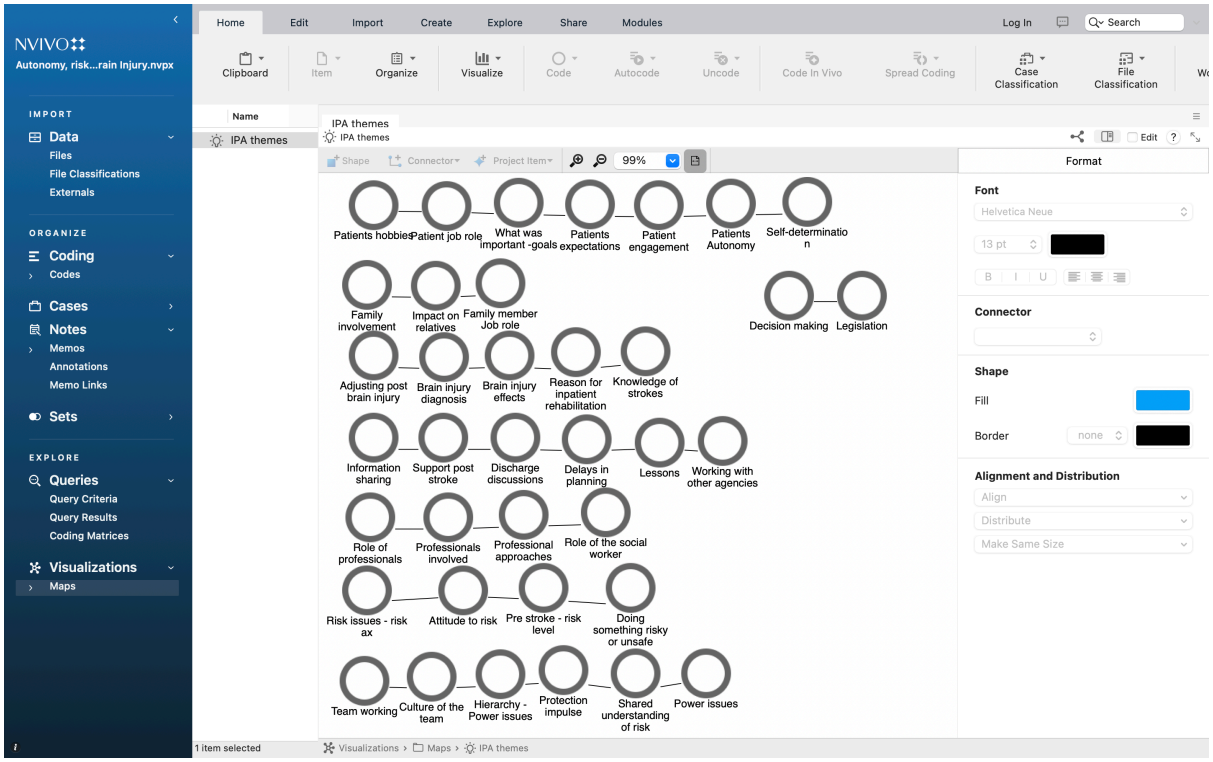
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Patient engagement
Patients Autonomy
Self-determination
Family involvement
Impact on relatives
Family member Job role
Decision making
Legislation
Adjusting post brain injury
Brain injury diagnosis
Brain injury effects
Reason for inpatient rehabilitation
Knowledge of strokes
Information sharing
Support post stroke
Discharge discussions
Delays in planning
Lessons
Working with other agencies
Role of professionals
Professionals involved
Professional approaches
Role of the social worker
Risk issues - risk ax
Attitude to risk
Pre stroke - risk level
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Hierarchy - Power issues
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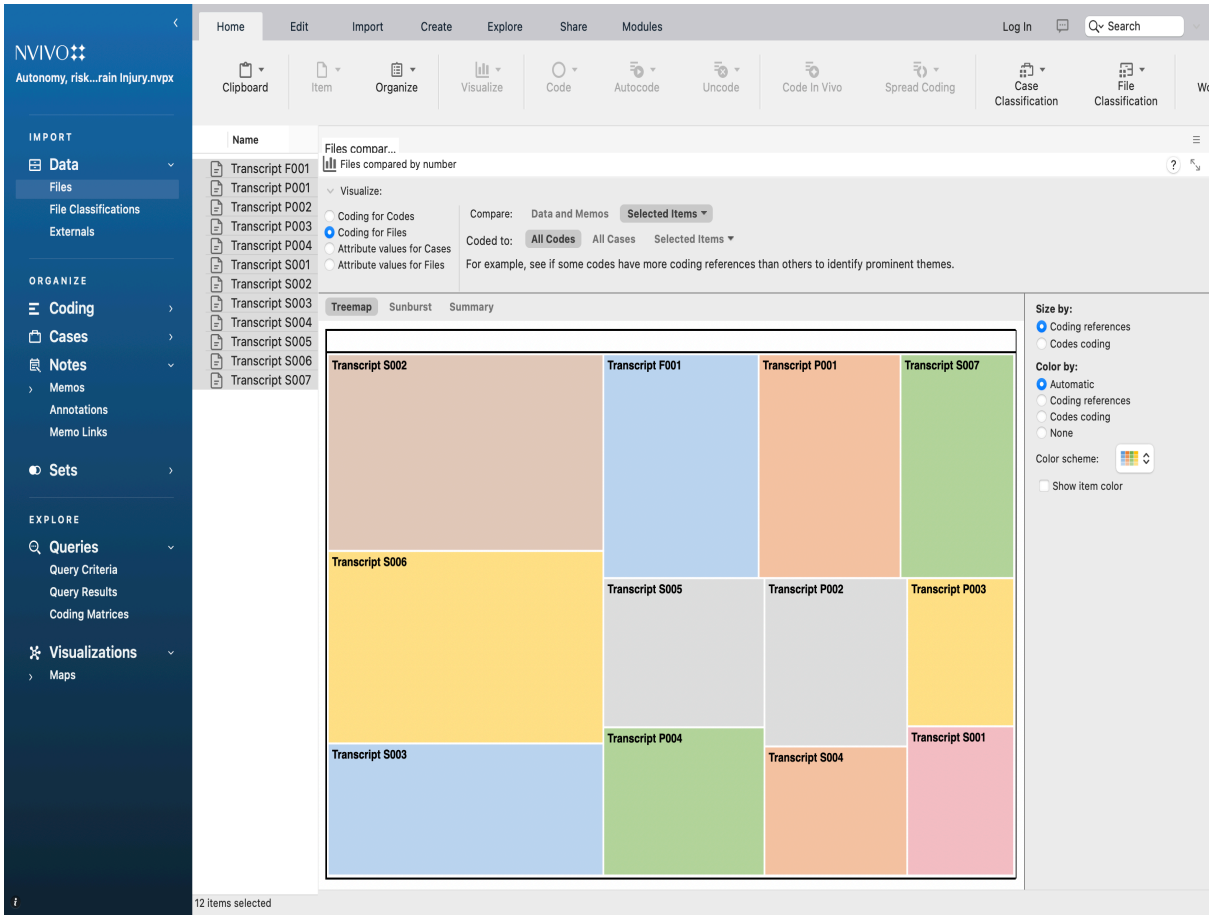
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Transcript S004
Transcript S005
Transcript S006
Transcript S007
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Visualize:
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Coding for Files
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Attribute values for Files
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All Cases
Selected Items
For example, see if some codes have more coding references than others to identify prominent themes.
Treemap
Sunburst
Summary
Transcript S002
Transcript F001
Transcript P001
Transcript S007
Transcript S006
Transcript S005
Transcript P002
Transcript P003
Transcript P004
Transcript S001
Transcript S003
Transcript S004
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Color by:
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Codes coding
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Show item color
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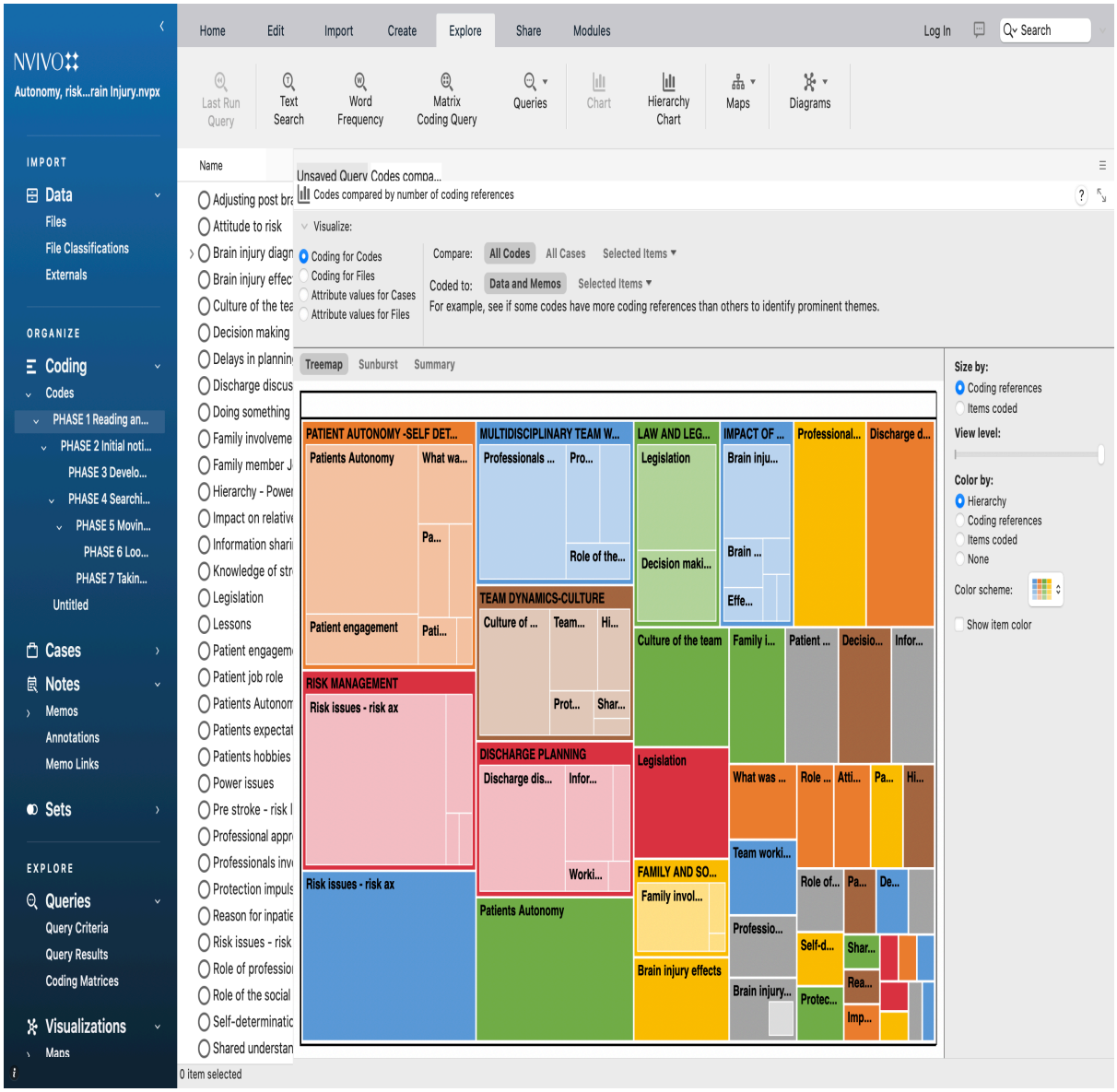
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Patients Autonomy
Discharge discussions
Family involvement
Patient engagement
Culture of the team
Hierarchy – Power issues
Information sharing
Working with other agencies
Legislation
Role of professionals
Attitude to risk
Shared understanding of risk
Team working
Professionals involved
Professional approaches
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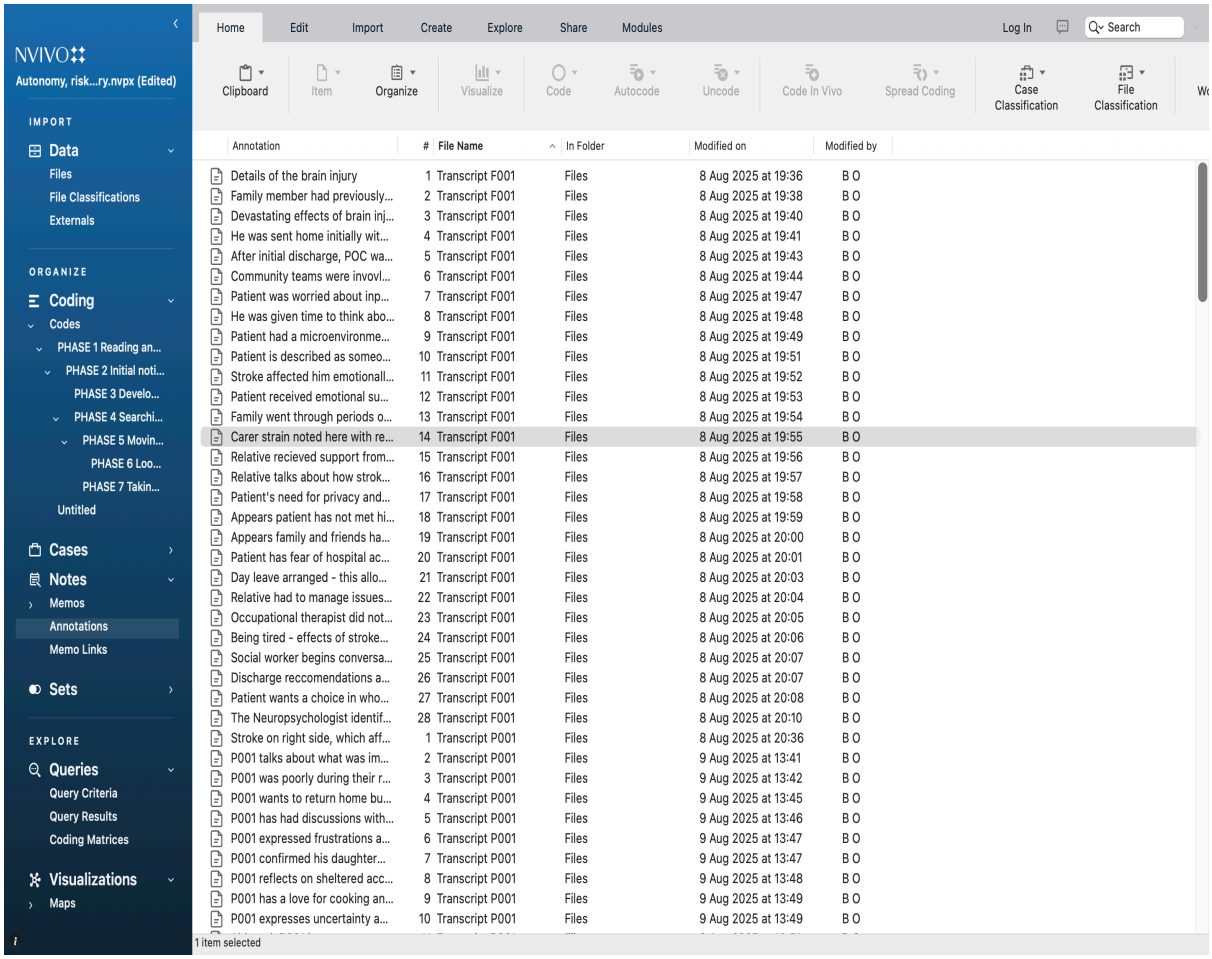
Transcript S007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Details of the brain injury 1 Transcript F001 Files 8 Aug 2025 at 19:36 B O
Family member had previously... 2 Transcript F001 Files 8 Aug 2025 at 19:38 B O
Devastating effects of brain inj... 3 Transcript F001 Files 8 Aug 2025 at 19:40 B O
He was sent home initially wit... 4 Transcript F001 Files 8 Aug 2025 at 19:41 B O
After initial discharge, POC wa... 5 Transcript F001 Files 8 Aug 2025 at 19:43 B O
Community teams were involvl... 6 Transcript F001 Files 8 Aug 2025 at 19:44 B O
Patient was worried about inp... 7 Transcript F001 Files 8 Aug 2025 at 19:47 B O
He was given time to think abo... 8 Transcript F001 Files 8 Aug 2025 at 19:48 B O
Patient had a microenvironme... 9 Transcript F001 Files 8 Aug 2025 at 19:49 B O
Patient is described as someo... 10 Transcript F001 Files 8 Aug 2025 at 19:51 B O
Stroke affected him emotionall... 11 Transcript F001 Files 8 Aug 2025 at 19:52 B O
Patient received emotional su... 12 Transcript F001 Files 8 Aug 2025 at 19:53 B O
Family went through periods o... 13 Transcript F001 Files 8 Aug 2025 at 19:54 B O
Carer strain noted here with re... 14 Transcript F001 Files 8 Aug 2025 at 19:55 B O
Relative recieved support from... 15 Transcript F001 Files 8 Aug 2025 at 19:56 B O
Relative talks about how strok... 16 Transcript F001 Files 8 Aug 2025 at 19:57 B O
Patient's need for privacy and... 17 Transcript F001 Files 8 Aug 2025 at 19:58 B O
Appears patient has not met hi... 18 Transcript F001 Files 8 Aug 2025 at 19:59 B O
Appears family and friends ha... 19 Transcript F001 Files 8 Aug 2025 at 20:00 B O
Patient has fear of hospital ac... 20 Transcript F001 Files 8 Aug 2025 at 20:01 B O
Day leave arranged - this allo... 21 Transcript F001 Files 8 Aug 2025 at 20:03 B O
Relative had to manage issues... 22 Transcript F001 Files 8 Aug 2025 at 20:04 B O
Occupational therapist did not... 23 Transcript F001 Files 8 Aug 2025 at 20:05 B O
Being tired - effects of stroke... 24 Transcript F001 Files 8 Aug 2025 at 20:06 B O
Social worker begins conversa... 25 Transcript F001 Files 8 Aug 2025 at 20:07 B O
Discharge reccomendations a... 26 Transcript F001 Files 8 Aug 2025 at 20:07 B O
Patient wants a choice in who... 27 Transcript F001 Files 8 Aug 2025 at 20:08 B O
The Neuropsychologist identif... 28 Transcript F001 Files 8 Aug 2025 at 20:10 B O
Stroke on right side, which aff... 1 Transcript P001 Files 8 Aug 2025 at 20:36 B O
P001 talks about what was im... 2 Transcript P001 Files 9 Aug 2025 at 13:41 B O
P001 was poorly during their r... 3 Transcript P001 Files 9 Aug 2025 at 13:42 B O
P001 wants to return home bu... 4 Transcript P001 Files 9 Aug 2025 at 13:45 B O
P001 has had discussions with... 5 Transcript P001 Files 9 Aug 2025 at 13:46 B O
P001 expressed frustrations a... 6 Transcript P001 Files 9 Aug 2025 at 13:47 B O
P001 confirmed his daughter... 7 Transcript P001 Files 9 Aug 2025 at 13:47 B O
P001 reflects on sheltered acc... 8 Transcript P001 Files 9 Aug 2025 at 13:48 B O
P001 has a love for cooking an... 9 Transcript P001 Files 9 Aug 2025 at 13:49 B O
P001 expresses uncertainty a... 10 Transcript P001 Files 9 Aug 2025 at 13:49 B O
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APPENDIX 18: Summary of studies included in Narrative literature review (Excluding grey literature)

Autor/Year	Title	Study Aims	Design/Methods
Andreoli, 2010	Balancing risk-taking and safety among patients, families and clinicians during transition in care from brain injury rehabilitation.	The aim of this study is to explore the ethical and clinical factors that influence how patients, families, and clinicians make decisions about risk-taking and safety.	Qualitative: Interviews
Cameron et al., 2022	Staff perceptions and Capability in using the Mental capacity Act to assess decision making in those with acquires brain injury and executive dysfunction.	To establish the perceptions and capability of social care professionals in using the MCA 2005 to assess decision making in those who have executive dysfunction and frontal lobe paradox in comparison to health care professionals.	Qualitative: Interviews
Flynn, 2016	The death of Tom: a serious case review.	Safeguarding case review.	Case review
Foulkes et al., 2024	Using conversation analysis to explore assessments of decision-making capacity in a hospital setting.	Using Conversation Analysis (CA), to explore how real-life capacity assessments were conducted in a hospital setting with patients with acquired brain injury (ABI)-related communication difficulties. A second aim was to establish the feasibility of using CA to advance knowledge of the conduct of capacity assessment.	Qualitative: Conversation Analysis
Glintborg & Hansen, 2016	Bio-psycho-social effects of a coordinated neurorehabilitation programme: a naturalistic mixed methods study.	This study investigates bio-psycho-social outcomes and perceptions of a coordinated rehabilitation programme.	Mixed methods: Quantitative data, questionnaire and Interviews

Gridley et al., 2014	Good practice in social care: the views of people with severe and complex needs and those who support them.	This study reports findings drawn from a study of good practice in English social care for adults with disability and older people with severe and complex needs.	Qualitative: Interviews
Holloway & Fyson, 2016	Acquired Brain Injury, Social Work and the Challenges of Personalisation.	To provide information about ABI and discussing some of the challenges which social workers may face when working with this service user group, particularly in the context of personalisation.	Qualitative: Case study
Holloway et al., 2019	Experiences of challenges and support among family members of people with acquired brain injury: a qualitative study in the UK.	To explore how families are affected and integrate their views on the formal/informal support received as a consequence of ABI.	Qualitative: Interviews
Kivunja et al., 2018	Experiences of giving and receiving care in traumatic brain injury: An integrative review.	To synthesise the literature on the experiences of giving or receiving care for traumatic brain injury for people with traumatic brain injury, their family members and nurses in hospital and rehabilitation settings.	Integrative literature review
Knox et al., 2013	Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury.	To raise professional awareness of factors that may influence the support offered by clinicians to people with acquired brain injury (ABI), and to consider the potential implications of these factors in terms of post-injury rehabilitation and living.	Case studies
Linden et al., 2023	Social workers and acquired brain injury: A systematic review of the current evidence-base.	To systematically explore the evidence, base to examine how social workers have been prepared to work with their clients with brain injury.	Mixed methods

Lindlof et al., 2024	Empowering Support for Family Members of Brain Injury Patients in the Acute Phase of Hospital Care: A Mixed-Methods Systematic Review.	To identify and synthesize empowering support for the family members of patients in the acute phase of traumatic brain injury hospital treatment.	Mixed methods: Systematic review
Lupton & Tulloch, 2002	Life would be pretty dull without risk: voluntary risk-taking and its pleasures.	To explore the meanings given to risk & the discourses used to express ideas about risk.	Qualitative: Interviews – should I include this?
Macciocchi & Stringer, 2001	Assessing risk and harm: The convergence of ethical and empirical considerations.	To provide an introduction to problems commonly faced by clinicians and to present a model for making ethically and empirically informed clinical decisions.	Qualitative: Case studies
Moore et al., 2019	Behind the cloak of competence: brain injury and mental capacity legislation.	To explore the application of the Mental Capacity Act (MCA) and its guidance when applied to ABI survivors.	Mixed methods: Interviews
Murray et al., 2022	Perspectives of choice and control in daily life for people following brain injury; A qualitative systematic review and meta-synthesis.	To analyse and integrate international research exploring perspectives of choice and control in daily life following ABI.	Qualitative
Norman, 2016	A preventable death? A family's perspective on an adult safeguarding review regarding an adult with traumatic brain injury.	To review the care management of a man with a traumatic brain injury (TBI) from a family member's perspective.	Case study
Norman et al., 2020	Accepting what we do know: A need to improve professional understanding of brain injury in the UK.	To understand the ABI knowledge base of professionals across a range of organisations within the UK, and to identify areas for improvement.	Mixed methods: Questionnaire
Odumuyiwa et al., 2019	Improving access to social care services following acquired brain injury: a needs analysis.	To improve understanding of 1) the long-term community rehabilitation needs of ABI survivors and their families, and	Mixed-method, predominantly qualitative, approach was employed using questionnaires and semi-structured interviews

		2) their experiences of community health and social care provision within the United Kingdom.	
O'Shannessy et al., 2023	Mixed methods study to understand the experiences of adults with acquired brain injury and their family members who receive specialised rehabilitation.	To explore inpatients' and their family members' experiences of a specialist ABI rehabilitation service.	Mixed methods: Interviews
Owen et al., 2017	Clinical assessment of decision-making capacity in acquired brain injury with personality change.	To translate between these recent neuroscience constructs and the "appreciation" or "use and weigh" abilities in decision making capacity law to improve practical strategies for decision making capacity assessment in patients with organic personality disorder.	Qualitative: Interviews
Ownsworth & Clare, 2006	The association between awareness deficits and rehabilitation following acquired brain injury.	To examine empirical evidence concerning the issue of whether awareness of deficits is necessary for rehabilitation gains and provide guidelines to assist clinical decision-making.	Empirical studies
Oyesanya & Bowers, 2017	I'm trying to be the safety net: Family protection of patients with moderate-to-severe TBI during the hospital stay.	To describe family caregivers' experience of protecting patients with TBI during the hospital stay.	Qualitative: Interviews
Panday et al., 2022	Experiences of inpatient rehabilitation from the perspective of persons with acquired brain injury.	To explore the experiences, needs, and preferences of patients from an ABI inpatient rehabilitation program in Ontario.	Qualitative: Interviews
Schipper et al., 2011	Citizenship and autonomy in acquired brain injury.	To explore how these concepts of autonomy are combined in theory in the citizenship paradigm, and how this turns out in the	Case study: Interview

		practice of care for people with acquired brain injury.	
Stanley et al., 2022	Occupational therapists and physiotherapists weighing up the dignity of risk for people living with a brain injury: grounded theory.	To explore the tensions between dignity and management of safety risks.	Qualitative: Interviews
Thogersen et al., 2025	Rehabilitation professionals' perspectives on rehabilitation psychology in neurorehabilitation.	To explore the perspectives of rehabilitation professionals on the possible added benefits of psychological rehabilitation in combination with existing comprehensive rehabilitation.	Qualitative: Interviews
Weatherhead et al., 2012	Brain injury professional's perspectives on risk assessment	This research explores professionals' perspectives on those risks, focussing on how psycho-social risks are assessed and managed.	Mixed methods: Questionnaire
Wiseman, 2011	Transdisciplinary working: the social worker as case manager.	To explore the practice experience and dilemmas of being a social worker in a case management role in relation to brain injury.	Case study