



UNIVERSITY OF
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Patient-Centred Design for Engineering- Based Research on Mild and Moderate Traumatic Brain Injury: Informing Fellowship Research Priorities

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Authors and acknowledgements

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Collaborators

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Overview

In January 2026, two online focus groups were conducted with members of the public affected by mild and moderate traumatic brain injury (TBI) – either those with a diagnosis or their family members. The focus groups explored experiences of living with TBI, particularly in-hospital monitoring and discharge processes, as well as prognosis trajectories.

The aim of the focus groups was to help shape research priorities by identifying the most difficult aspects of acute and ongoing TBI diagnosis and gathering views on potential engineering interventions or monitoring improvements.

The focus groups identified five research themes to consider during all stages of research design and development, which are presented and discussed in the following sections.

The five themes identified were:

- Information and communication gaps in healthcare
- Inadequate recognition and assessment of brain injuries
- Transition support from hospital to home
- Information needs across the injury timeline
- Patient and family perceptions around prognosis and outcome prediction

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Introduction

Brain injury is one of the most common yet misunderstood conditions in both medicine and the wider community. It is estimated that half of the global population will experience at least one traumatic brain injury during their lifetime (1). Unlike many medical conditions where the path to recovery follows a predictable trajectory, brain injuries are profoundly heterogeneous – each patient's journey is unique, shaped by the nature and severity of their injury, their pre-existing health, and factors we do not yet fully understand. This unpredictability extends to prognosis: clinicians struggle to accurately predict outcomes, leaving patients and families in a state of profound uncertainty.

The consequences of brain injury extend beyond the acute medical crisis. Patients face a constellation of challenges – cognitive impairment, debilitating fatigue, communication difficulties, and personality changes – that are largely invisible to others yet profoundly disabling. These "hidden" injuries are under-recognised both in the healthcare system and in the wider world. For family caregivers, the burden of injury is also life-changing.

Advances in digital health technology offer an array of possibilities for transforming brain injury care. These include wearable devices, smartphone applications, and big data analysis for prognostic accuracy.

However, ensuring that such technologies address real needs, respect privacy and dignity, remain accessible to diverse populations, and complement rather than replace existing care requires meaningful input from those who will use them.

Patient and Public Involvement and Engagement (PPIE) is essential to ensure that innovation in brain injury care is meaningful, ethical, and effective. Those who have lived through brain injury – as patients or caregivers – possess irreplaceable knowledge about what works, what fails, and what matters most.

In 2024, the NIHR published its [Strategic Commitments for Public Partnerships](#) (2025–2030), reinforcing the principle that research is stronger when shaped by the people it aims to help (2). Public involvement is now embedded across NIHR-funded research, reflecting a growing recognition that lived experience is essential to research (3).

The perspectives of patients and caregivers must shape research priorities, guide technological development, and inform clinical practice.

Aim and objectives

Aim

Two online focus groups were conducted to ensure ease of access for participants across the UK, particularly in the East of England. The aim was to develop an in-depth understanding of the difficulties faced by patients and their families, as well as their attitudes towards clinical and potential engineering interventions both in the acute setting and at home. There was a total of 11 participants across both groups, of which 2 were carers, plus one additional participant who was unable to attend on the day contributing by email.

Objectives

Specific objectives were explored as follows:

- To explore patient and caregiver difficulties in order to identify key research priorities.
- To understand the impact of poor prognostic capability, and the potential benefits and costs of providing more prognostic information.

Focus Group 1: Systemic Difficulties

The first focus group took place via Zoom on 14th January 2026. The activity was funded by NIHR Biomedical Research Centre. Recruitment was supported by the NIHR BRC Patient and Public Engagement (PPIE) team through mailing lists and support groups. The focus group was professionally facilitated and explored patient experiences from the time of injury through to the present. There were 6 participants in this focus group, one of whom was a carer.

Over the course of the discussion, three key themes emerged from this first focus group. These were:

- Information and communication gaps in healthcare.
- Inadequate recognition and assessment of brain injuries.
- Transition support from hospital to home.

The key issues, potential effects, potential engineering-based solutions identified by participants are reported, along with recommendations on what this could mean for future engineering research on TBI.

1. Information and communication gaps in healthcare

Problem: Inadequate communication about diagnoses, prognosis, and available support

Participants expressed concerns about misdiagnosis and the lack of early information about their condition, particularly about the physical and emotional impacts of brain injury. Many also recognised the need for better coordination across different parts of the healthcare system and clearer treatment plans, particularly around the transition to home.

Effects

These information gaps led to substantial mental health consequences, with lack of early information impacting patients' mental wellbeing and inadequate recognition in emergency departments causing long-lasting impacts on both patients and their personalities.

Participant-proposed solutions

Participants suggested digital interventions for monitoring recovery at home and communicating health status to employers, alongside individualised digital advice for patients and families. However, solutions for improving early diagnostic communication and prognosis delivery remain underexplored.

“I might have the brain injury, but I say the family has the brain injury because it impacts them as well, just as much if not more than me.”

“It's quite a lot, really, that I think we should have had being told to us right from the start.”

2. Inadequate recognition and assessment of brain injuries

Problem: Dismissal of brain injury and resulting changes

Participants detailed the experience of being dismissed by healthcare professionals both at the point of admission and in later phases, despite the need for overnight monitoring and clear personality changes.

Effects

This dismissal contributed to mental health deterioration and left families unprepared to manage severe personality changes, including aggression and communication difficulties, without professional guidance or validation of their experiences.

Participant-proposed solutions

Participants emphasised the need for individualised care plans tailored to each patient's specific needs rather than one-size-fits-all approaches, alongside comprehensive assessments that recognise cognitive and personality changes as legitimate medical concerns.

“Healthcare professionals, when I tried to raise it with them, kept telling me I was the problem.”

3. Transition support from hospital to home

Problem: Gap in support when moving from hospital care to home recovery

Participants noted the lack of support and resources for transitioning from hospital to home, including assessment of the home environment and necessary aids. The group emphasised the importance of preparing homes for discharge and providing walking aids to ensure the safety and dignity of patients living with brain injury.

Effects

Poor transition planning created physical safety risks, fear of falling, and challenges managing incontinence and sleep disturbances without adequate professional support. The caregiver burden was particularly profound, with family members providing intensive around-the-clock care and making significant modifications to the home environment – all with minimal preparation or healthcare system support, effectively transferring the burden of recovery management from professionals to unprepared families.

Participant-proposed solutions

Participants proposed comprehensive home environment assessments prior to discharge to identify necessary modifications, provision of appropriate mobility aids (such as wheelie walkers) at the point of discharge, and physical adaptations including rails and bathroom modifications. They also suggested technology-enabled solutions such as personalised exercise apps, sleep monitoring using wearable devices, structured fatigue management courses, and task management apps to support daily living and reduce caregiver burden.

“They just kind of assume that you’re somehow going to pick up the pieces... but they don’t tell you what support the person’s going to need.”

Focus Group 2: Outcome Prediction

The second focus group took place via Zoom on 28th January 2026. As with Focus Group 1, the activity was funded by the NIHR Cambridge Biomedical Research Centre and recruitment was supported by the NIHR BRC Patient and Public Engagement (PPIE) team via mailing lists and support groups. The professionally facilitated focus group explored patient experiences and views on information, communication and prognostic capability in the hospital setting and beyond. In Focus Group 2, there were 5 participants, one of whom was a carer. One additional participant who was unable to attend on the day contributed by email.

Over the course of the discussion, two key themes emerged. These were:

- Information needs across the injury timeline.
- Patient and family perceptions around prognosis / outcome prediction.

These themes are explored in two parts: first, what information is needed, by whom, and at what stage of the injury timeline; and second, whether and how predictions of outcome should be delivered to patients and families and the implications of receiving this information.

4. Information needs across the injury timeline

Participants identified that information gaps exist not just at diagnosis but throughout every stage of the injury pathway. Like the findings from Focus Group 1, at admission, injuries could be missed or minimised; at discharge, patients often received little or no guidance on what to expect or where to seek support.

In the community, signposting to vocational rehabilitation, benefits, and mental health services was often absent. Families and carers were particularly underserved, frequently left to advocate and navigate the system alone.

Much of this difficulty in getting information stems from the nature of brain injury itself: each person and their injury are different, making it hard for clinicians to predict how someone will recover. This uncertainty may contribute to poor communication. Without confidence in what lies ahead, clinicians default to providing vague or minimal information, leaving patients and families without clear direction. Participants felt that a better ability to predict recovery could unlock better information at every stage of the injury timeline.

"Who are you trying to give what level of information to and what is the outcome of that?"

"I found it very difficult to get information on anything, really, prognosis or how [the patient] would be, in the very early days, even whether she would live through it."

5. Patient and family perceptions around prognosis and outcome prediction

A further point was raised by a participant about the need to protect clinicians— if predictions are given in good faith but recovery does not follow the expected course, there should be an understanding that this reflects the inherent uncertainty of brain injury, not clinical error. The concern that doctors could face legal consequences for giving the wrong information was perceived as a barrier to clinicians sharing predictions.

Overall, participants recognised that more information at all stages of the injury pathway would help to guide patients and carers through the difficult, chronic experience of brain injury, particularly when combined with smaller, time-bound recovery targets. However, different ways in which outcome predictions can be received highlight that the same information, delivered the same way, can help one person and harm another.

Participants emphasised that any tool which improves the ability to predict recovery must also consider how that information is framed, who receives it, and at what point. The effect of a prediction depends as much on the injured person and their current situation as on its accuracy.

“Having smaller targets for a day was a lot better for me... as memory improved, goals subsequently elongated to a few days and then week targets.”

Summary and recommendations

Some prediction of recovery, even if imperfect, is better than none. The absence of prognostic information was linked to poor communication, lack of direction, and mental health deterioration across both focus groups.

How predictions are delivered matters as much as their accuracy. The same information can motivate one person and devastate another. Who receives it, when, and how it is framed should be considered alongside the prediction itself.

Small, evolving targets can be preferred over a single long-term prediction. Daily goals in the early stages, extending to weekly as recovery progresses, reflect the chronic and evolving nature of brain injury.

One-size-fits-all approaches were rejected across both groups. Care should be personalised to the individual and their injury.

There is strong patient appetite for digital tools to monitor and communicate recovery. Participants saw value in apps and wearables to track progress, share status with family and employers, and provide personalised lifestyle prompts.

Clinicians need legal and professional protection to share predictions in good faith. Without frameworks that distinguish honest uncertainty from clinical error, doctors may continue to default to minimal information— which patients and carers identified as one of the biggest gaps in their care.

Researcher's reflections

From these two focus groups, I was struck by the disconnected nature of brain injury treatment and recovery between hospital and community settings, as well as the lack of prognostic information at each stage, particularly in a form that could be easily digested by patients and their families.

The fact that carers also found getting information difficult shows that this lack of information is not only experienced by patients with amnesia. In the acute hospital setting, it reflects both the lack of concrete predictions that clinicians have, and the legal and social difficulties of communicating information to families that might turn out to be wrong. In the community, it reflects the disconnect between hospital and home settings and the sad novelty of the experience for patients and families – it is hard to advocate for what you or a loved one needs if you aren't yet aware of the most pressing needs.

Along with improving patient outcomes, outcome prediction is a 'golden goose' of brain injury – something that many researchers are working on, but which is inherently difficult to achieve. From Focus Group 2, patients and carers felt that having some prediction of recovery, even if imperfect, was better than no information at all.

The absence of prognostic information left people without direction and was linked to poor communication throughout the injury timeline.

Additionally, the way that predictions are communicated is just as important as their accuracy. What helps one person may harm another – overly optimistic outcome predictions may reinforce feelings of failure or highlight the disconnect between current abilities and what someone could do before the injury. However, a reductive or pessimistic outcome prediction may limit people from reaching their full potential after injury.

One carer shared that her loved one was not expected to speak again, but she noticed signs of speech and embarked on an intensive, self-directed speech and language therapy programme, with the result that her loved one can now talk. This story highlights that predictions, while valuable, should not define the ceiling of what someone can achieve, and that the people closest to the patient may recognise potential that discrete clinical assessments miss.

Across both groups, one-size-fits-all approaches were consistently rejected, whether for rehabilitation, exercise advice, or prognostic information.

Collectively, this reinforces the importance of a personalised medicine approach. Predictions should be tailored to the individual, taking into account their personality, their role (patient or carer), and their stage of recovery.

Brain injury is a chronic condition, so predictions of outcome should evolve over time by setting small, graduated targets; daily goals in the early stages, extending to weekly as recovery progresses may be preferable to a single long-term prediction. This reflects the evolving nature of brain injury recovery, as well as providing a means by which outcome prediction can be adjusted over time.

From an engineer's perspective, current clinical practice for prognosis prediction does not make use of engineering or physics-based information about the injury, despite traumatic brain injury being caused by physical forces. I believe that incorporating mechanical injury patterns into clinical tools could improve the ability to form an initial recovery prediction, as well as influence subsequent outcome predictions as the brain injury evolves. It is hoped that this could increase access to predictive information for people living with brain injury, their carers, and their healthcare team, and provide a greater sense of agency at a time when so much feels beyond control.

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