

# BMJ Open 'What's next?' The journey from hospital to community engagement from the perspectives of adults following severe acquired brain injury: a scoping review protocol

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## ABSTRACT

**Introduction** Community integration and social participation remain a challenge for many individuals following acquired brain injury (ABI) and the transition from hospital to home is a complex journey. It is important to conceptualise this transition from the perspective of people with ABI, to inform future research with the overall aim of improving the experience of community re-engagement and maintaining important relationships within social networks.

**Methods and analysis** The methodology outlined by Arksey and O'Malley and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis: extension for Scoping Reviews will be used to guide the review. A comprehensive electronic database search will be conducted in MEDLINE, CINAHL, Scopus, Embase and PsychINFO. The search will aim to locate only published, qualitative or mixed methods studies and will be limited to citations published in English, from January 2014 to the date of final search completion. Quality assessment using the Critical Appraisal Skills Programme will be completed and reported.

Data extraction will include participant and study characteristics.

Finally, qualitative data from each citation, including participant quotes, will be extracted and thematic analysis will be completed to support conceptualisation of community participation from those who have experienced the transition to the community following discharge from hospital. Three individuals with lived experiences of ABI will be engaged as paid consultants to review and comment on the findings of the review.

**Ethics and dissemination** It is intended that the findings from this review will be made available to relevant stakeholders through peer-reviewed publications and conference presentations. This scoping review does not require an ethics application.

## INTRODUCTION

Community integration and maintenance of social connections has been recognised as a complex and multifaceted issue for people following acquired brain injury (ABI).<sup>1</sup> Positive community and social outcomes are often

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review will conceptualise the transition from hospital to community and social engagement within contemporary health and disability contexts, from the perspectives of people with severe acquired brain injury (ABI), including close others for those who are unable to represent themselves due to the severity of their acquired disabilities.
- ⇒ A rigorous quality assessment process will be completed, and each paper will be classified as 'Core, Central or Peripheral' in relation to the review question.
- ⇒ A research librarian will be consulted regarding the development and completion of the review process. About 3–4 individuals with lived experience following ABI will be consulted to comment on the findings of this scoping review in the context of their experiences.
- ⇒ Studies published from January 2014 will be included in this scoping review, which excludes earlier exploration of this topic; however, we have chosen this starting point to align with the endpoint of a related published meta-synthesis.
- ⇒ 'Discharge planning' has not been included as a concept within the search strategy, which may exclude a sub-group that has reviewed the relationship between discharge planning processes and community integration. However, hand-searching will occur to ensure any key studies are included within this review.

considered to be the ultimate goals of rehabilitation after ABI (stroke, traumatic brain injury (TBI) and hypoxia).<sup>2</sup> Thus, with the recognition that these outcomes have a strong correlation with life satisfaction, emotional well-being and quality of life following ABI<sup>3</sup> they have gained a place in clinical practice guidelines globally.<sup>4–8</sup>

Acquired brain injury is one of the most common causes of disability in adults, often having a significant impact on a person's

physical, communication, cognitive and psychosocial functioning.<sup>9 10</sup> Brain injury frequently results in people requiring assistance for many aspects of their daily life, including accessing the community to participate in activities of their choosing.<sup>11 12</sup> Even with the provision of social insurance schemes for people with a life-long disability, such as the National Disability Insurance Scheme in Australia,<sup>13</sup> which enables individuals to have access to the support they require, community and social integration remains challenging for many individuals once they transition home following inpatient rehabilitation.<sup>14-16</sup> Rehabilitation efforts are often focused towards reducing the need for support; however for many, despite these efforts, lifelong support will be required. Return to previous community activities, including leisure and recreational pursuits, and social relationships are frequently disrupted.<sup>17-23</sup>

When exploring this topic, it is important to recognise the additional complexities associated with the physical, attitudinal, communication and societal barriers which can further constrain the ability of people with disability to access and engage in the community around them.<sup>11 24</sup> As people navigate the consequences of their brain injury, it is important to explore the challenges faced. It would be beneficial to gather information regarding strategies which could be implemented within inpatient rehabilitation, to support people as they transition to the community and adjust to their newly acquired disability.

A preliminary search of MEDLINE was conducted and no recent collation of the current qualitative literature to explore the experiences of people following ABI as they transition to life in the community was identified. Although Walsh and colleagues<sup>22</sup> completed a metasynthesis to examine the barriers and facilitators of community integration after stroke, this proposed scoping review will further explore this transition in a broader context. It will seek to determine if there is any relationship between functional capabilities and community integration from the perspectives of people with lived experience. In addition, the proposed review will expand the population of interest to include TBI and hypoxia, as well as stroke. Given people with ABI have identified the importance of achieving community integration and maintaining meaningful relationships with their family and friends,<sup>25-29</sup> further research is required to support positive progress in this area.<sup>30</sup>

### Review question

What are the experiences of people with severe ABI after they leave inpatient rehabilitation and transition to community engagement and social participation?

Overall, the aim of this scoping review is to:

1. Gather information regarding the lived experiences of people as they resume activities within the community with their loved ones, during the transition from hospital to home.

Additionally, we aim to:

2. Collate the perspectives of individuals with severe ABI to determine the factors that helped or hindered the transition from inpatient rehabilitation to community integration and social participation.
3. Conceptualise the journey following the discharge from hospital when moving on with life, from the perspective of people following ABI.

### METHODS AND ANALYSIS

The proposed scoping review will be conducted in accordance with the methodological guidelines outlined within the literature for scoping reviews<sup>31-33</sup> and will be presented in line with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist.<sup>34</sup> The anticipated start date for this scoping review is 1 September 2022 and finish date is 1 March 2023.

#### Identifying relevant studies

The search strategy has been developed by the authors in consultation with a research librarian and will aim to locate only published, qualitative studies. An initial limited search of MEDLINE and CINAHL was undertaken to identify articles on the topic and subsequent identification of keywords related to the topic. The keywords contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for MEDLINE (see online supplemental appendix 1). The search strategy, including all identified keywords and index terms, will be adapted for each included database. The reference list of all included sources of evidence will be screened for additional studies meeting eligibility. In addition, forward and backward author reference searching will be completed for key authors sourced in the final yield to gather any further studies of relevance.

The electronic databases to be included in the search are MEDLINE, CINAHL, Scopus, Embase and PsychINFO. The search strategy used for each of these databases is provided as supplementary material (see online supplemental appendixes 1-5).

Initially, the search will include two concepts related to 'acquired brain injury' and 'community participation', and a comprehensive list of search terms will be developed relating to these concepts. These two concepts will be combined with the Boolean operator 'AND' prior to the addition of a third concept related to the study design, 'qualitative'.

#### Study selection

This scoping review will consider studies that focus on using qualitative design including, but not limited to, phenomenology, grounded theory, action research OR data collection methodologies such as structured interviews, semi-structured interviews, focus groups, case studies, ethnography and qualitative description.

In addition, mixed methods studies will also be included if both the quantitative and qualitative components of the

**Table 1** Inclusion and exclusion criteria

Inclusion	Exclusion
Over the age of 18	Prior disability requiring support
People living in the community	Healthcare professional's perspectives
Stroke (ischaemic and haemorrhagic), TBI and hypoxic	Chronic presentations >4 years postonset
Severe ABI: spectrum of severity included if severe ABI is covered	Mixed neurological presentations
Close others representing those unable to participate due to severe communication and/or cognitive disability	Studies that focus on specific impairment-based interventions or tools
Up to 4 years postonset	Studies that do not include qualitative methodology
Community participation and/or social connection exploration	Systematic reviews or feasibility studies
Qualitative or mixed methodology	
Published in English	
Published from January 2014	
ABI, acquired brain injury; TBI, traumatic brain injury.	

study were designed and implemented to address related aspects of the same broad questions requiring real-life contextual understanding with the intention of integrating the results emerging from both approaches.<sup>35</sup>

The start date for the review is January 2014. This start date was selected to align broadly with the end date of the previously published review by Walsh and colleagues,<sup>22</sup> which commenced in 2000 and finished in August 2014.

Only studies published in English language will be included.

## Inclusion criteria

### Participants

Inclusion criteria (table 1) require that participants are over the age of 18, living in the community, with severe ABI (stroke (ischaemic and haemorrhagic), TBI and hypoxia). Those with injuries related to encephalitis and brain tumour resection will not be included as the outcome trajectory often differs and the associated focus of intervention is variable. Studies will be eligible if they covered the range of severity but studies that excluded people with severe ABI will not be eligible. Severity may be indicated at the time of episode by metrics derived from scales such as the Glasgow Coma Scale, Stroke Severity Scale or by using a functional measure, indicating the severity of residual disability, such as the Functional Independence Measure.

Studies that include the views of close others will also be included to ensure representation of those unable to

participate in qualitative research due to severe communication or cognitive disability.

### Concept

The core concept being examined is the lived experience of people as they adapt to a new life in the community following ABI. Given the purpose of this review is to identify evidence about factors that influence the experience of re-engaging in the community, we will not include studies that focus solely on specific impairment-based rehabilitation techniques and do not consider the implications of these on broader community re-engagement.

### Context

As this scoping review aims to gather information about the lived experience of people during their transition from hospital to home, only studies which include participants who have been discharged from inpatient rehabilitation, and are living in the community, will be eligible. Studies that focus on inpatient rehabilitation or include participants in the chronic stages after ABI will be excluded. For the purposes of this scoping review, chronic will be considered as greater than 4 years after injury onset, to ensure the perspectives gathered accurately reflect the transition from hospital to community re-engagement. Experience suggests that for many people the transition to the community and social participation can extend for many years following ABI, therefore including those up to 4 years postonset will offer the opportunity to reflect on those initial years as people adjust to life in the community.

Nil limitations will be made on geographical location, community support models or access to rehabilitation.

### Screening

Following the search, all identified citations will be collated and uploaded into EndNote X9 and Covidence where duplicates will be removed. Following a pilot test of 20 articles, titles and abstracts will then be screened by two independent reviewers (SC and JD) for assessment against the inclusion criteria for the review.

The full text of selected citations will be assessed in detail against the inclusion criteria independently by two reviewers (SC and JD). Reasons for exclusion of sources of evidence in the full text will be recorded and reported in the scoping review. Disagreements that arise between the reviewers at each stage of the review will be resolved through discussion or with the third reviewer (DW) where conflict cannot be resolved.

The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA-ScR flow diagram.<sup>34</sup>

### Charting the data

Data will be extracted from papers included in the scoping review using a data extraction tool developed collaboratively by the reviewers (SC, JD and DW).

The data extracted will include participant characteristics comprising age, gender, type of injury (differentiating



between stroke and non-stroke studies), the severity of the injury, time since injury, rehabilitation information (including length of stay), functional performance (mobility, communication and cognition), levels of informal or formal supports, and any cultural information provided. Data related to the study completion will be extracted, including sample size, study methodology and country of completion.

Finally, qualitative data from each citation, including participant quotes, relevant to the review question and objectives, will be extracted to support the conceptualisation of community participation from those who have experienced the transition to the community following discharge from the hospital. Quantitative data within mixed studies will not be extracted or analysed if it does not inform the qualitative findings.

The draft data extraction tool will be piloted by two independent reviewers (SC and JD) to ensure agreement regarding the information being extracted and ensure it will adequately meet the needs of the research question. It will then be modified and revised as necessary during the process of extracting data from each included evidence source. The data extraction form and subsequent modifications will be detailed in the scoping review.

A process of critical appraisal will be completed using the Critical Appraisal Skills Programme<sup>36</sup> to assess the methodological rigour of the individual sources of evidence. Each paper will be classified as 'Core, Central or Peripheral', proposed by Whiffin and colleagues,<sup>37</sup> adapted from a strategy originally used by Duggleby and colleagues.<sup>38</sup> This classification will reflect the relevance of the included studies against the applicability to the original research question.

The results of this quality and relevance assessment will be reported.

### Collating, summarising and reporting the results

The presentation of the evidence will be carefully considered to clearly answer the research questions and meet the objectives of this scoping review. Participant characteristic descriptors will be charted, whereas qualitative data will be mapped using thematic synthesis,<sup>39</sup> to represent commonalities in the literature while also ensuring a clear conceptualisation of the evidence related to lived experiences.

### Patient and public involvement

Following the completion of the thematic analysis, the authors will invite a small group of 3–4 people with severe ABI and close others to individually participate in a short interview. We will ask them to review a summarised report of the findings within this scoping review and comment on whether the findings reflect their experience of transitioning into the community.

The lived experience experts invited for this consultation process will reflect the diversity of presentations within this population group, including those who are non-ambulant, have cognitive or communication challenges, as well as diverse aetiology including stroke and TBI.

### ETHICS AND DISSEMINATION

An ethics application will not be required for this scoping review. The consultancy of people with lived experience will be a paid role, where we ask for the expertise of the 3–4 people with severe ABI and with their consent acknowledge their input to the review process.

The aim of this scoping review is to understand the experience of community re-engagement and social participation during transition from hospital to home from the perspective of people with severe ABI. We hope that this scoping review, alongside the completion of a larger project, will have impact in key ways, including to support people who are adapting to life after brain injury, encourage reflections by inpatient rehabilitation teams to enable them to better support people to feel prepared for the transition into the community and finally expand the knowledge of people working within the disability sector about the challenges faced by people as they engage in the community following severe ABI.

**Contributors** All authors (SC, JD and DW) have provided the domains of knowledge and made a substantial intellectual contribution, with SC leading the conceptualisation, of the scoping review. All authors (SC, JD and DW) made significant contributions to the design of the review, including the search strategy and methodology. All authors (SC, JD and DW) contributed to editing and revising the protocol and have given final approval for publication of this manuscript.

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**Patient and public involvement** 3–4 individuals with lived experience following ABI will be consulted to comment on the findings of this scoping review in the context of their experiences.

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