

**Investigation of community participation outcomes for adults with acquired brain injury after discharge from post-acute rehabilitation: A mixed-methods study protocol paper**

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## Abstract

**Background:** Staged Community-Based Brain Injury Rehabilitation (SCBIR) has been found to improve functional and psychosocial outcomes for people who have sustained an acquired brain injury (ABI), however, research is required to establish longer-term outcomes after discharge. Transition into the community following discharge from SCBIR is poorly documented with limited evidence for community participation outcomes.

**Methods:** The aim of this research is to investigate community participation outcomes for adults with ABI after discharge from SCBIR. A mixed-methods exploratory research design will be used. The project will be undertaken in three sequential phases employing both quantitative and qualitative methods. Phase 1: A scoping review will be conducted to identify relevant factors impacting community participation. Interviews will be conducted with adults with ABI, their family member/s or carers, and Oats Street staff providing post-acute neurorehabilitation. Thematic analysis will be used to guide the analysis of interview data. Phase 2: Community participation outcomes for Oats Street clients will be measured at discharge (T0), 4 months (T1), 8 months (T2) and 12 months (T3) following discharge. Phase 3: A series of multilevel mixed effect regression models will be used to analyse changes in community participation outcomes and to develop and test a community participation explanatory model.

**Discussion:** This research will facilitate a better understanding of community participation for adults with ABI and will add high-quality evidence to support SCBIR. Findings may be used to improve the transition of SCBIR clients into the community after discharge.

**Keywords:** brain injury, staged community-based brain injury rehabilitation, neurorehabilitation, outcome measurement, discharge, community integration, transition.

## **Background**

Over 500 000 people have an ABI in Australia, with around 1 in 45 people experiencing activity and participation limitations related to their ABI (1). The lifetime costs of care for people with ABI are high, with an estimated \$2 600 000 for moderate cases and \$5 000 000 for severe cases (2). Transition into the community following acute management of ABI is a critical period in the recovery and long-term adjustment to brain injury (3). Post-acute rehabilitation and transitional care has been shown to effectively enhance outcomes for people with ABI (4) and deliver significant cost-savings for service providers and insurers over the long term (5).

Participation and re-integration into the community is an important part of post-acute rehabilitation for people with ABI (3). The International Classification of Functioning, Disability and Health (ICF), describes participation as ‘involvement in life situations’ (6) . The ICF is an internationally recognised conceptual framework for health and disability (7) that can be applied in the context of ABI (8). Evidence suggests that difficulties transitioning from post-acute rehabilitation to the community can be reduced by developing interventions that target outcomes in community participation (9). The term ‘community participation’ has been found to be inconsistently defined in the literature and is commonly associated with the term ‘community integration’ (9). Current research defines community participation as being multi-dimensional and involves the dynamic interactions between personal and environmental factors on a person’s ability to participate in activities on a community level (10). Community participation involves factors such as managing a home, independence in activities of daily living, engaging in social networks, as well as participating in self-care, leisure and productive activities (11).

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People with ABI often experience many barriers to community participation after discharge from rehabilitation that can negatively impact their overall health and wellbeing (12).

Restrictions to community participation for people with ABI has been found to reduce quality of life (13) and increase long-term costs of care in the community (10). In addition, decreased community participation can lead to higher risks of people with ABI becoming socially isolated and experiencing mental health conditions such as depression and anxiety (14).

Brightwater Care Group has been one of the main providers of post-acute neurorehabilitation in Western Australia since 1991. The Oats Street Rehabilitation Centre '*Oats Street*' in East Victoria Park is based on a novel model of care called Staged Community-Based Brain Injury Rehabilitation (SCBIR), in which post-acute therapy is provided in a stage-based approach to support a client's continued recovery over time (15). Central to this model is the provision of person-centred rehabilitation that is tailored to individual clients' needs and goals (16), supported by an integrated multidisciplinary team of medical and allied health professionals (17). The Oats Street rehabilitation model aims to support people with ABI to regain independence and meaningful participation in the community as much as possible following neurological injury (15). Oats Street provides community-based residential rehabilitation, consisting of 8 shared houses and 8 independent living units (16). As clients develop their skills and become more independent, they 'graduate' from house to house through the stages of care with each stage providing less support (16). At discharge, clients are supported to find appropriate accommodation in the community and assisted throughout the transition process (18). Multiple outcome measures are completed to assess functional and psychosocial outcomes as well as to identify if individual client goals have been met (18). This study will focus on the final component of the model, 'Integration into an established local community', and its impact on community participation outcomes after discharge for Oats Street clients (19).

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Emerging research supports the effectiveness of the Oats Street rehabilitation model (15-18) with studies to date showing that clients demonstrate significant functional gains at discharge from Oats Street when compared with their functional status at admission (15). However, further evidence is needed to fully quantify the impact of the Oats Street rehabilitation model on the short-term (3 months after discharge) and long-term (4-12 months after discharge) outcomes of people with ABI. In particular, there is a current evidence gap surrounding the longer-term impact of this model in relation to the community participation outcomes of adults with ABI following discharge. Evidence suggests that a lack of consistent long-term follow up can deter or prevent appropriate care being provided (20). Research is needed to investigate whether functional gains made over the course of rehabilitation translate to improved community participation outcomes after discharge from Oats Street and if they can be sustained over time.

Current research in this area is limited, with many studies using the broader term 'post-acute rehabilitation', rather than SCBIR. The procedures of post-acute rehabilitation used in these studies differ from the specific model of SCBIR used at Oats Street. In addition, most studies were retrospective in nature (21), and focussed on measuring specific outcomes such as functional independence (22), rather than the broader concept of community participation. Furthermore, most studies reported on specific ABI populations such as traumatic brain injury (TBI) or stroke and do not include the broader range of ABI diagnoses in their research (23).

The ABI-REStART research program led by Brightwater Research Centre, is a novel retrospective whole-population cohort study that measures the short- and long-term outcomes of Brightwater ABI clients following discharge from post-acute rehabilitation over 29 years (18). This unique program of research comprises six individual studies that utilise

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Brightwater's internal clinical and rehabilitation data along with externally linked hospital, emergency department, and death data from the WA Department of Health (18). The research program aims to measure the longitudinal health outcomes and needs of the Brightwater ABI cohort over time, including from pre-injury to long-term follow up (1-year, 5-year, 10-years) after discharge (18). As part of the ABI-REStART research program, this research project will investigate community participation outcomes for adults with ABI in the first 12 months following discharge from the Oats Street Rehabilitation Centre.

The overarching aim of this research is to investigate community participation outcomes for adults with ABI after discharge from SCBIR. This research project will develop and implement a research protocol to identify relationships between factors impacting community participation. These factors are to be modelled to determine which variables have an effect on community participation outcomes and to what extent. The specific objectives of the study are to: (1) Identify factors that influence community participation including relevant outcome measures for people with ABI living in the community, (2) measure community participation outcomes for adults with ABI following discharge from SCBIR; and (3), to evaluate predictors of community participation outcomes to after discharge from SCBIR for adults with ABI.

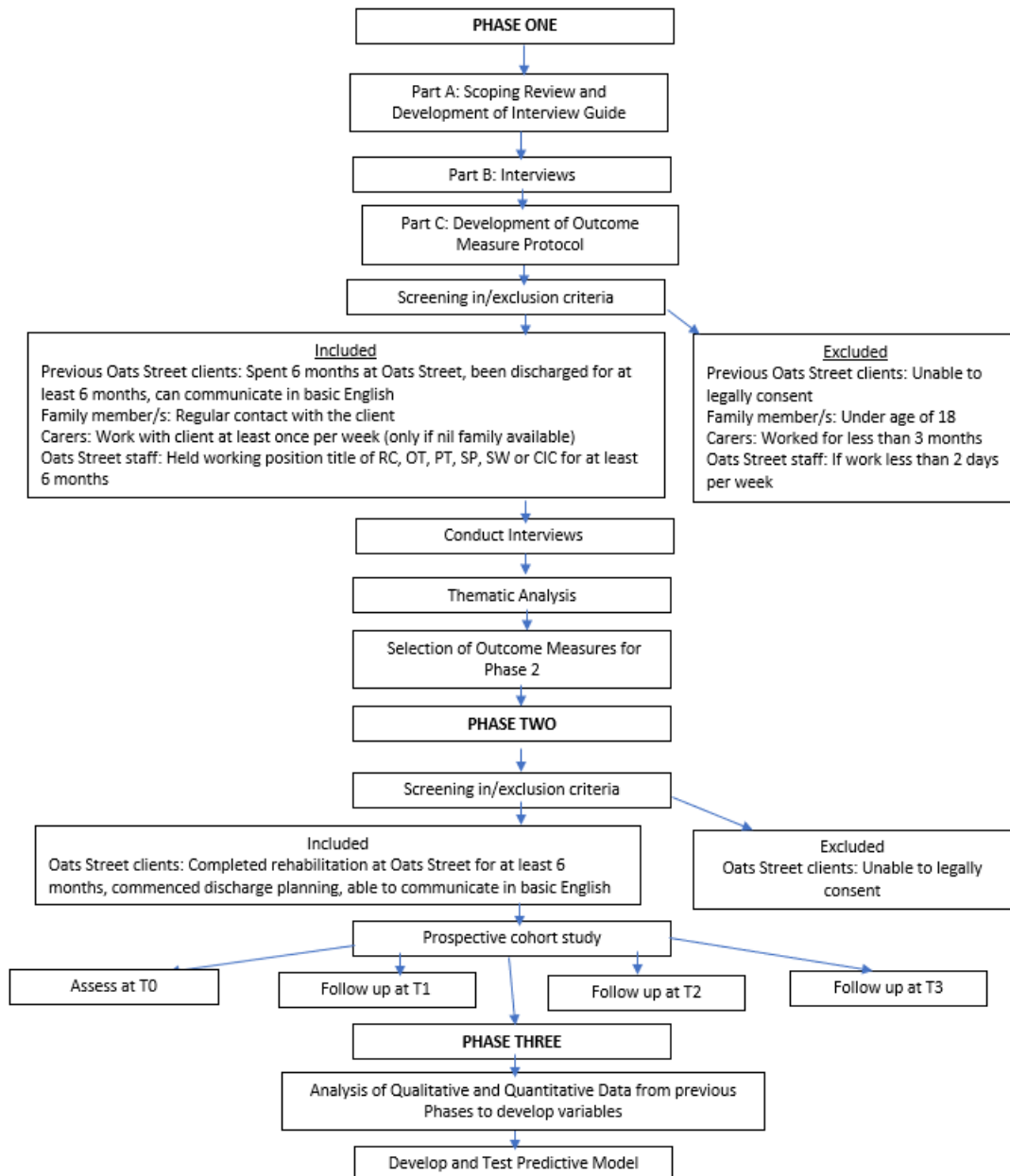
## **Methods**

### ***Research Design***

This exploratory research project will consist of three sequential phases using a mixed-methods approach (24). See Figure 1 for a flow diagram of the research. A Consumer Reference Group will be formed prior to commencing the phases to acknowledge the value that lived experience from consumers can bring to research (25). Participants will be encouraged to provide input and feedback to the researchers throughout the research process

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to guide the study in areas such as recruitment, study design, data analysis, and research dissemination (26). The Consumer Reference Group will include 2-3 staff members from the Oats Street facility involved in the discharge process, 2-3 discharged Oats Street clients, and their family or carers. Meetings will occur every two to three months throughout the project.



**Figure 1:** Flow diagram of research procedures

## **Phase 1**

### ***Research Protocol Development: Identification of factors influencing community participation for adults with ABI.***

Phase 1 will consist of three consecutive parts (Parts A, B, and C) for the development of the quantitative and qualitative tools to measure community participation outcomes in Phase 2.

#### **Part A: Scoping Review**

A scoping review of the literature will be completed to identify the most important factors that influence community participation outcomes for adults with ABI.

**Procedures:** This scoping review will follow the five framework stages originally outlined by Arksey & O'Malley in 2005 (27). A literature search will be conducted using the following electronic databases: MEDLINE, CINAHL, PsycINFO, Proquest and Scopus. The review will be registered with PROSPERO. A search strategy was prepared in collaboration with a trained university librarian. A combination of three separate concepts (Acquired Brain Injury, Community Participation and Adult), will be included in the search strategy alongside specific key words and medical subject headings (MeSH). The search strategy will initially be created for the MEDLINE database first for testing and confirmation. Once the search strategy is deemed to be appropriate, it will subsequently be adapted for use in the other databases described above.

Research Screener will be used in the initial stages of the systematic review to semi-automate abstract screening (28). Research Screener is a new online systematic review system that has been found to significantly reduce the workload for systematic reviews (28). Two reviewers (LC and CH) will complete abstract screening with the assistance of Research Screener. Full-text PDFs of all potentially relevant articles will then be reviewed independently for suitability according to the chosen inclusion and exclusion criteria by three reviewers (LC,



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CH, NG). These same three reviewers will then complete data extraction and analysis. Any disagreements will be resolved by discussion until a consensus is reached. If the disagreement is unable to be resolved by discussion alone, a fourth party will be asked to provide input.

### *Development of Interview Guide*

Findings from the scoping review will be used to develop the interview guide for Part B. Questions will be designed to ask participants about their experiences related to the key factors identified in the systematic review and any other factors that may also influence community participation for adults with ABI. Draft interview questions will be provided to the Consumer Reference Group for feedback. Questions will be then modified as required by an interactive process between the Consumer Reference Group and the research team.

### **Part B: Qualitative Interviews**

Part B will involve face-to-face semi-structured interviews over a four-week period to supplement systematic review findings and provide an in-depth understanding of the experience of community participation for adults with ABI following discharge from SCBIR.

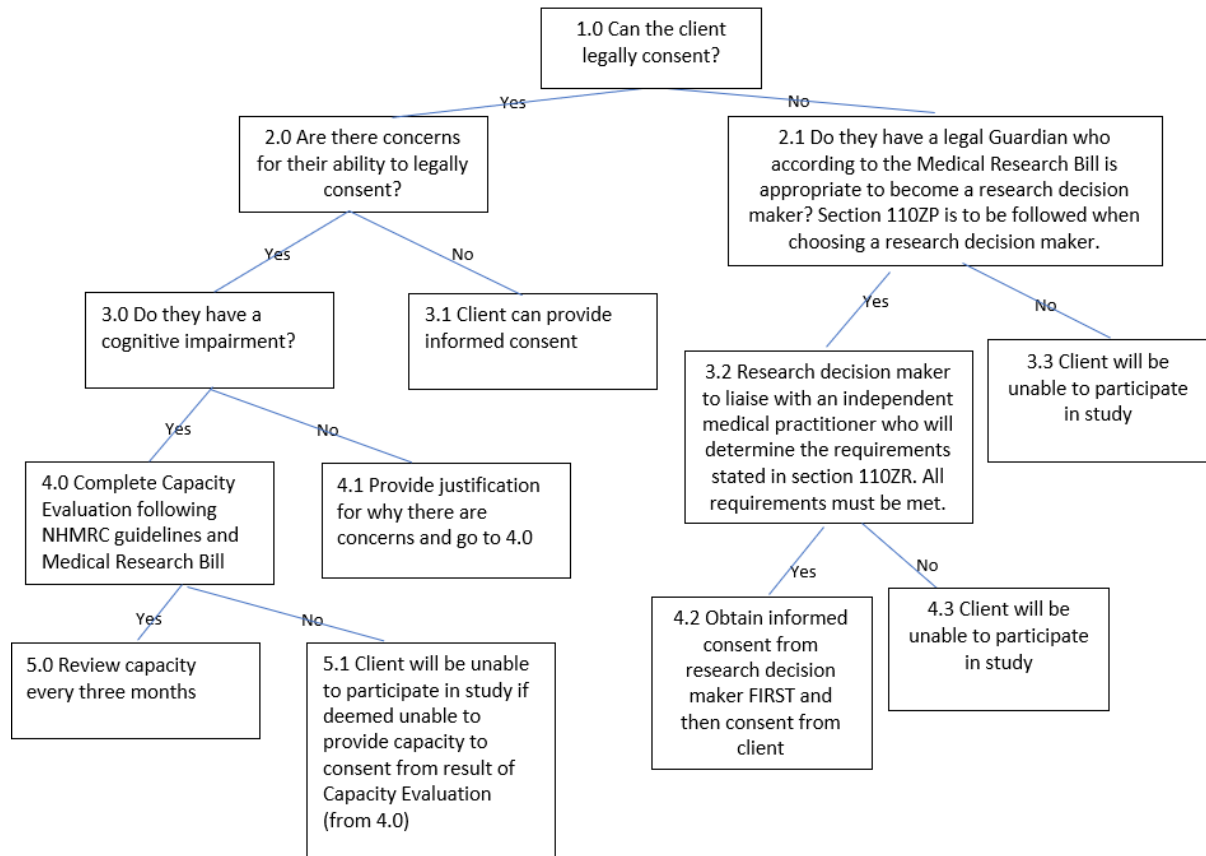
### *Participants and Recruitment*

Three participant groups will be recruited: (1) Previous Oats Street clients ('Clients'), (2) their family member/s or carers ('Family'), and (3) Oats Street Staff members ('Staff'). Purposive sampling will be utilised to recruit participant groups (29).

Clients: Oats Street discharge records will be used to identify eligible participants. Eligible participants will be individuals who have: 1) completed SCBIR at Oats Street with a minimum length of stay of 6 months, 2) been discharged for at least 3 months, and 3) are able to communicate in basic conversational English. Clients will be excluded if they do not have

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capacity to consent or do not have a legal guardian who can provide informed consent on their behalf. See Figure 2 for the process of determining capacity to consent.



**Figure 2:** Ethics Decision Tree for Capacity to Consent

A recruitment email will be provided to Brightwater Oats Street who will then forward this email on to eligible clients. If clients are happy to participate, they will give consent to Oats Street to pass on their details to the research team. Clients will then be invited to participate in the interviews via email. One researcher (LC) will meet with clients who express interest in person to provide further information and details of participation. Clients will be given the opportunity to ask questions and have them answered. Informed consent will be obtained from interested clients. If the client has formal guardianship orders in place, their legal guardian will be asked to provide informed consent on their behalf.

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*Family:* Clients and/or their legal guardians will provide consent for the researcher to contact family member/s and carers by email. Family members aged  $\geq 18$  years will be included if they have regular contact with the client. Carers who have worked with the client at least once per week for more than 3 months will be invited to participate if the client does not have an eligible family member. Family members will be identified from the primary contact list at Oats Street.

*Staff:* Oats Street staff members including Rehabilitation Coordinators, Occupational Therapists, Physiotherapists, Speech Pathologists, Social Workers, and Community Integration Coordinators (whose role is to assist clients with organising formal and informal supports, prepare housing applications and liaise with other agencies during the discharge process) who have been employed for at least 6 months will be invited via email to participate in the study. One researcher will meet in a private meeting room at the Oats Street facility with staff members who express interest to obtain their informed consent.

### ***Expected Sample Size***

One researcher (LC) aims to interview approximately 10-12 participants from each group or until the saturation of themes is reached.

### ***Procedures***

Semi-structured interviews will be conducted with participants individually to identify enablers and barriers to community participation after discharge from SCBIR. Interviews with family members will be held separately from clients to minimise contamination of results. Open-ended questions will be asked to promote in-depth responses. A prompt guide will be included as part of the interview guide. Interviews will be conducted in a quiet environment at a time and location convenient to each participant (at home or at a private Oats Street room) and will run for approximately 45-60 minutes.

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With consent from interviewees, interviews will be audio-recorded via a Dictaphone. Each audio recording will be transferred as audio files to the secure drive for the processes of transcription and subsequent analysis. Interviews will then be transcribed verbatim by researcher and use of transcription services. The researcher will use Otter.ai (Business Plan), a speech to text transcription service, to assist with the transcription process. All interviewees will be given copies of the transcripts to verify that they were accurate.

### *Qualitative Data Analysis*

A thematic analysis approach will be undertaken following the six-phase procedure defined by Braun and Clarke (30) to identify and understand the most relevant themes from the interviews. NVivo 12 qualitative data analysis software will be used to manage and code interview transcriptions. Patterns among the codes will be identified and then used to develop preliminary themes. These themes will be shared with all interviewees and the Consumer Reference Group to obtain their input. Themes will be clearly defined to accurately reflect the dataset. A thorough audit trail will be maintained throughout the coding process to ensure consistency between data and the overall findings. Member checking will be conducted throughout this process to first clarify transcripts and then preliminary findings. A formal peer-review process will be completed by the research team to improve the dependability of the research findings (31).

### **Part C: Research Protocol Development: Measuring Community Participation**

Findings from Part A and B will be used alongside a literature review to identify key outcome measures to measure community participation outcomes in Phase 2. Outcome measures with a strong evidence base for assessing factors influencing community participation will be chosen. This will include evaluating the psychometric properties of each outcome measure.

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### *Structured Survey*

Findings from the systematic review and interviews will be used to design a structured quantitative survey to measure other key factors influencing community participation that may not be assessed through the outcome measures (e.g., access to funding, living situation). For example, if funding is identified as an important contributing factor, a survey item will be designed to measure the type and level of funding. The Consumer Reference Group will be asked to provide feedback on the draft survey, which will be modified as required. Survey data will be collected via an online survey (Qualtrics), or paper based.

### **Phase 2: Prospective Follow-Up following discharge from SCBIR**

This prospective cohort study will measure community participation outcomes for adults with ABI in the first 12 months following discharge from SCBIR. Data collection will be undertaken over 24 months (2022-2024).

### *Participants and Recruitment*

#### *Inclusion and Exclusion Criteria*

Clients will be eligible for participation if they have: 1) completed rehabilitation at Oats Street with a minimum length of stay of 6 months, 2) commenced discharge planning, and 3) are able to communicate in basic English. Clients will be excluded if they do not have the capacity to consent or have a legal guardian who can provide informed consent on their behalf. Clients must be aged between 18-65 to participate in the Oats Street program as this is a Department of Health funding requirement.

#### *Recruitment*

Clients who are within approximately four weeks of discharge from the service will be informed of the study by their Brightwater Case Coordinator. One researcher (LC) will meet with clients who express interest in the study at the Oats Street facility to obtain informed

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consent and enrol clients into the study. If the client has formal guardianship orders in place, their legal guardian will be asked to provide informed consent on their behalf. Initial discharge assessments will then be completed with confirmed participants (see Procedures).

### *Sample Size Calculation*

Based on client discharge numbers from 2018-2020, we expect approximately 26 (range: 20-31) discharges per year, or 52 (range: 40-62) discharges over the 24-month study follow-up period. Factoring in an expected response/attrition rate of 20% based on similar studies in the literature (23, 32, 33), the total number of participants expected to fully complete the study is 41 (range: 32-50).

### **Procedures**

After study enrolment, participants will be assessed at four time points over the study period: T0 (discharge), T1 (4 months), T2 (8 months) and T3 (12 months) post-discharge.

Assessments will include administration of 1) core outcome measures (see Materials), 2) any additional outcome measures identified in Phase 1, and 3) the structured survey developed in Phase 1. Data will be analysed in Phase 3.

#### Discharge (T0)

Discharge assessments will take place at Oats Street 1-2 weeks prior to discharge. The core outcome measures (See Materials) will be completed by Oats Street staff members.

Additional outcome measures identified from the systematic review and the structured survey will be completed by the researcher in private Oats Street rooms.

#### Follow-Ups (T1-T3)

Follow-up assessments will be conducted over one week at the participant's preferred location (their own home or at a private room at Oats Street). If these locations are not suitable, they will be able to choose a location suitable to them. To reduce participant fatigue,

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assessments will be completed during multiple 60-minute meetings over the one-week period. Participants will be reminded that they can take breaks if needed and that they are able to stop the assessment at any time. All assessments will be completed by one researcher (LC). The researcher will implement participant retention strategies to reduce attrition over the follow-up period (34). Participants will be contacted one month before each time point to prepare suitable times for assessment via phone and email. Once the dates have been confirmed, a reminder text and email will be sent two weeks before the start date. The researcher will maintain regular contact with participants throughout the follow-up period via phone and email.

### **Materials**

#### ***Core Outcome Measures***

Five core outcome measures are currently used at Oats Street to measure client progress throughout rehabilitation and will be completed at discharge and follow-ups to measure continuation of results after discharge from SCBIR.

#### **Community Integration Questionnaire (CIQ)**

The CIQ assesses an individual's ability to integrate into their community after sustaining an ABI (35). The 15-item questionnaire is made up of three subscales that include Home Integration, Social Integration, and Productive Activity; multiple studies support its reliability and validity (36). It has been translated and validated in multiple countries (37, 38) and is commonly used in ABI research to measure community participation (23).

#### **UK Functional Independence Measure and Functional Assessment Measure (UK FIM+FAM)**

The UK FIM+FAM is a valid and reliable measure of disability and functional independence for people who have sustained an ABI (39). The tool consists of 30 items that evaluate motor and cognitive functioning (15). An additional six items assess extended activities of daily

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living. There is extensive research evidence supporting the sound psychometric properties of the UK FIM+FAM (39) and it is commonly used in ABI rehabilitation settings to evaluate client progress (15, 40, 41).

### Mayo-Portland Adaptability Inventory (MPAI-4)

The MPAI-4 is a tool primarily used in post-acute rehabilitation settings to evaluate global functioning for people with ABI (42). A total of 29 items are included across three subscales (Ability Index, Participation Index, and the Adjustment Index) with established psychometric properties (43). The MPAI-4 has been found to be a reliable measure of ABI rehabilitation progress (43) and is also commonly used in many rehabilitation settings (15). Multiple studies have found the MPAI-4 to be a valid measure when used with ABI clients in SCBIR settings (42, 44, 45).

### Goal Attainment Scale (GAS)

The GAS is a person-centred outcome measure that evaluates the degree to which individual rehabilitation goals have been achieved after intervention (46). The GAS is best utilised in conjunction with other standardised outcome measures to quantify rehabilitation intervention outcomes (47).

### Quality of Life after Brain Injury (QOLIBRI)

The QOLIBRI was developed to measure the quality of life of individuals who have sustained a brain injury (von Steinbüchel et al., 2010). A total of 37 questions cover six dimensions of health-related quality of life (von Steinbüchel et al., 2010). Developed and validated on an international scale, the QOLIBRI has been found to have strong psychometric properties in multiple language versions including English (48). It has also been validated in an Australian population (49).

## **Phase Three: Explanatory Modelling**



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The final phase of the research will involve the development and testing of a community participation explanatory model using the follow-up data (outcome measures and survey responses over T1, T2 and T3) collected in Phase 2.

Statistical analysis will be completed using the Statistical Package for the Social Sciences (SPSS) Version 22.0. Descriptive statistics (mean, median, standard deviation, and range) will be calculated to summarise baseline demographic and clinical characteristics, length of rehabilitation stay, and time since discharge. Raw outcome measure scores will be adjusted to normative units utilising normative data published in peer reviewed studies for each outcome measure for analysis.

### ***Community Participation Outcomes***

#### *Statistically Significant Change*

A series of multilevel mixed-effects regression models will be used to analyse any statistically significant change in community participation outcomes (UK FIM+FAM, MPAI-4, GAS, QoLIBRI, CIQ) at T1, T2 and T3 after discharge from SCBIR. These models have been found to be effective when working with small sample sizes (50). Each model will adjust for multiple covariates (demographic and clinical) to address heterogeneity of participants. Multilevel modelling will be used to account for fixed and random factors that that may affect overall outcomes.

#### *Clinically Significant Change*

In addition, clinically significant change in outcomes will be examined according to the Minimal Clinically Important Difference (MCID) recommended in published standard studies for each outcome measure. The MCID represents the smallest measurable difference in outcome score that translates into clinically meaningful change for individuals (51). The MCID thresholds are 5T for the MPAI-4 (52) and 8.0 points for the UK FIM+FAM motor

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scale and 7.0 points for cognitive scale (41) The GAS has its own validated scale that is able to calculate clinical change (46). The QOLIBRI and CIQ do not yet have a published MCID, therefore the research team will follow the analysis methods of recent peer-reviewed studies for these two outcome measures.

### *Explanatory Modelling*

Finally, three multilevel mixed-effects regression models will be used to evaluate predictors of community participation (CIQ Total score) at T1, T2, and T3 after discharge from SCBIR. Predictor variables will include demographic variables (e.g., age, gender, marital status), clinical variables (e.g., ABI diagnosis, time since injury, length of stay, time since discharge), outcome measures (e.g., UK FIM+FAM, MPAI-4, GAS, QoLIBRI), and other key variables identified (e.g., level of funding, level of social supported). A data-driven model selection approach will be used to select the final combination and number of fixed and random predictors which account for the largest proportion of variance in CIQ score (53).

### *Power Calculation*

An *a priori* power analysis was conducted using G\*Power to determine the approximate number of predictors to be included in the final multilevel model. Based on an estimated sample size of 41 participants (range: 32-50), an alpha-level of 0.05, power (1-  $\beta$ ) of 0.80, and an anticipated large effect size (Cohen's  $f^2 = 0.35$ ) based on similar studies in the literature (23, 32), a limit of four predictors (range: 2 to 7) can be included in the final model.

### *Missing Data*

To account for any missing data or attrition, an intention-to-treat (ITT) analysis will be completed, which will consist of all participant data including any drop-outs (54). A per-protocol (PP) analysis will then be conducted to only include participants who fully complete

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all components of the study (54). These will be compared to identify any statistically significant differences between groups and examine trends in the data sets (55).

### **Discussion**

There may be some practical issues involved in performing this research project due to the ever-changing impact of COVID-19 as there is a potential risk of participants being unwell or restrictions being put in place in the research project setting (Perth, Western Australia).

Although face-to-face interviews would be ideal, there is the option to move to an online interview process if COVID-19 restrictions impact the current protocol. Online videoconferencing services may also be required for some components of outcome measures if restrictions persist. The results of this research project will be disseminated through online and in-person conferences, publications, and presentations.

The research presented in this protocol paper will address the current gap in ABI research by exploring factors influencing community participation outcomes for adults with ABI as a broader diagnosis compared to more specific conditions such as stroke or TBI. Results will identify the enablers and barriers to community participation for this specific population which may subsequently be used for better service planning and provision. This research will also bring together existing literature that is currently not clearly defined or linked to community participation to provide a better definition of this term for use in rehabilitation research. Furthermore, research findings will identify the most relevant outcome measures to assess community participation, as previous studies have reported the difficulty of measuring this term due to its ambiguity (10). Future studies may then have a better understanding of which outcome measures to use for a more consistent approach to community participation research.

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Results from this research project will provide important evidence for community participation outcomes after discharge from SCBIR for adults with ABI. There is currently limited evidence for community participation outcomes for this population related to SCBIR as it is a novel model of care, and these results will contribute to the much-needed knowledge base in this area. Understanding community participation outcomes may also demonstrate the need for further research in relation to community participation interventions and rehabilitation planning.

Findings from this research will add high-quality evidence to the SCBIR model used at Oats Street Rehabilitation Centre and identify the long-term impact and subsequent community translation of their rehabilitation model. Insights gained from the multiple studies may then be used to make modifications to the current model to improve discharge planning and subsequent transition into the community. In addition, an explanatory community participation model will be developed and tested to facilitate a better understanding of community participation for adults with ABI. This may promote better long-term community participation outcomes such as improved quality of life, functional independence, and overall engagement in society for adults with ABI after discharge from SCBIR. Furthermore, improving community participation outcomes may reduce future financial costs associated with long-term support services.

There are some limitations to this research project that need to be addressed. Firstly, the research project is restricted to the researcher team's PhD timeframe and therefore the follow-up period for each participant is limited to 12 months, in comparison to other studies that completed 18-month to five-year follow-up periods. In addition, there are risks of participants being lost to follow-up over the 12-month period which may negatively affect results. The researchers acknowledge the relatively small sample size estimated for the Phase 2 of the research project, which may reduce the statistical power of the study. However, the

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multi-level mixed effects regression model was specifically chosen for data analysis as it has been found to be effective with small sample sizes. The sample size is restricted by the number of potential participants being discharged from Oats Street and there is the potential for the sample size to be too small to utilise for modelling. The researchers will then modify the study protocol as required to a research design more suitable for a small sample size. Although there are potential limitations, this research will be of value for post-acute rehabilitation discharge planning and community participation interventions. To further enhance this research protocol, a qualitative study exploring the experiences of community participation for adults with ABI over time would be beneficial as a future addition.

### **Declarations**

#### *Ethics approval and consent to participate*

Statement confirming ethics approval and consent. Ethics approval was sought from the Curtin University Human Research Ethics Committee (HREC) and Brightwater Care Group. This proposal has been developed according to the National Statement on Ethical Conduct in Human Research (56).

#### *Availability of data and materials*

The datasets generated and analysed during the proposed research project will not be publicly available due to ethics and confidentiality requirements but are available from the corresponding author on reasonable request.

#### *Competing interests*

One researcher (LC) received scholarship funding from Brightwater Care Group to conduct research. The authors declare that they have no other competing interests.

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### *Acknowledgements*

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### *List of abbreviations*

ABI: Acquired Brain Injury

SCBIR: Staged Community Based Brain Injury Rehabilitation

### References

1. Australian Institute of Health and Welfare. Disability in Australia: Acquired brain injury 2007. Report No.: Bulletin no. 55.
2. Ponsford JL, Spitz G, Cromarty F, Gifford D, Attwood D. Costs of care after traumatic brain injury. *Neurotrauma*. 2013;30(17):1498-505.
3. Fortune DG, Walsh RS, Waldron B, McGrath C, Harte M, Casey S, et al. Changes in aspects of social functioning depend upon prior changes in neurodisability in people with acquired brain injury undergoing post-acute neurorehabilitation. *Frontier Psychology*. 2015;6:1368-.
4. Oddy M, da Silva Ramos S. The clinical and cost-benefits of investing in neurobehavioural rehabilitation: A multi-centre study. *Brain Injury*. 2013;27(13-14):1500-7.
5. Griesbach GS, Kreber LA, Harrington D, Ashley MJ. Post-acute traumatic brain injury rehabilitation: Effects on outcome measures and life care costs. *Journal of Neurotrauma*. 2015;32(10):74-711.
6. World Health Organization WHO. International classification of functioning, disability and health (ICF). Geneva: Geneva: World Health Organization; 2001.
7. Ditchman N, Sheehan L, Rafajko S, Haak C, Kazukauskas K. Predictors of social integration for individuals with brain injury: An application of the ICF model. *Brain Injury*. 2016;30(13-14):1581-9.
8. Bilbao A, Kennedy C, Chatterji S, Üstün B, Vásquez Barquero JL, Barth JT. The ICF: Applications of the WHO model of functioning, disability and health to brain injury rehabilitation. *NeuroRehabilitation*. 2003;18(3):239-50.
9. Lee D, Heffron JL, Mirza M. Content and effectiveness of interventions focusing on community participation poststroke: A systematic review. *Archives Physical Medicine Rehabilitation*. 2019;100(11):2179-92.e1.
10. Kersey J, McCue M, Skidmore E. Domains and dimensions of community participation following traumatic brain injury. *Brain Injury*. 2020;34(6):708-12.
11. Parvaneh S, Ghahari S, Cocks E. Community integration for after acquired brain injury: A literature review. *Iranian Rehabilitation Journal*. 2014.
12. Abrahamson V, Jensen J, Springett K, Sakel M. Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: A qualitative study. *Disability Rehabilitation*. 2017;39(17):1683-94.
13. Gerber GJ, Gargaro J, McMackin S. Community integration and health-related quality-of-life following acquired brain injury for persons living at home. *Brain Injury*. 2016;30(13-14):1552-60.
14. Stalder-Lüthy FMA, Messerli-Bürgy NP, Hofer HP, Frischknecht EP, Znoj HP, Barth JP. Effect of psychological interventions on depressive symptoms in long-term rehabilitation after an acquired brain injury: A systematic review and meta-analysis. *Archives Physical Medicine Rehabilitation*. 2013;94(7):1386-97.
15. Jackson D, Seaman K, Sharp K, Singer R, Wagland J, Turner-Stokes L. Staged residential post-acute rehabilitation for adults following acquired brain injury: A comparison of functional gains rated on the UK Functional Assessment Measure (UK FIM+FAM) and the Mayo-Portland Adaptability Inventory (MPAI-4). *Brain Injury*. 2017;31(11):1405-13.
16. Williams E, Martini A, Jackson H, Wagland J, Turner-Stokes L. Time between acquired brain injury and admission to community-based rehabilitation: Differences in cognitive and functional gains. *Brain Injury*. 2020;34(6):713-22.

## Protocol Paper for ANZCTR

17. Williams E, Jackson H, Wagland J, Martini A. Community rehabilitation outcomes for different stroke diagnoses: An observational cohort study. *Archives Rehabilitation Research Clinical Translation*. 2020;2(2):100047-.
18. Mann G, Troeung L, Wagland J, Martini A. Cohort profile: The acquired brain injury community rehabilitation and support services outcomes cohort (ABI-RESTaRT), Western Australia, 1991–2020. *BMJ*. 2021;11(9):e052728-e.
19. Brightwater. Rehabilitation for life: The Oats Street Model for acquired brain injury rehabilitation. 2018.
20. Juengst SB, Terhorst L, Nabasny A, Wallace T, Weaver JA, Osborne CL, et al. Use of mhealth technology for patient-reported outcomes in community-dwelling adults with acquired brain injuries: A scoping review. *International Journal Environmental Resource Public Health*. 2021;18(4):1-19.
21. Sander AM, Roebuck TM, Struchen MA, Sherer M, High Jr WM. Long-term maintenance of gains obtained in postacute rehabilitation by persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation*. 2001;16(4):356-73.
22. Curran C, Dorstyn D, Polychronis C, Denson L. Functional outcomes of community-based brain injury rehabilitation clients. *Brain Injury*. 2015;29(1):25-32.
23. Seale GS, Caroselli JS, High WM, Becker CL, Neese LE, Scheibel R. Use of the Community Integration Questionnaire (CIQ) to characterize changes in functioning for individuals with traumatic brain injury who participated in a post-acute rehabilitation programme. *Brain Inj*. 2002;16(11):955-67.
24. Creswell JW. *Research design: Qualitative, quantitative, and mixed methods approaches*. 4th ed. Thousand Oaks: SAGE Publications; 2014.
25. McKenzie A, Alpers K, Heyworth J, Phuong C, Hanley B. Consumer and community involvement in health and medical research: Evaluation by online survey of Australian training workshops for researchers. *Research Involvement and Engagement*. 2016;2(1):16-.
26. McKenzie A, Hanley B. *Planning for consumer and community participation in health and medical research* 2014.
27. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International journal of social research methodology*. 2005;8(1):19-32.
28. Chai KEK, Lines RLJ, Gucciardi DF, Ng L. Research screener: A machine learning tool to semi-automate abstract screening for systematic reviews. *Systematic Reviews*. 2021;10(1):93-.
29. Campbell S, Greenwood M, Prior S, Shearer T, Walkem K, Young S, et al. Purposive sampling: Complex or simple? Research case examples. *Journal of Research in Nursing*. 2020;25(8):652-61.
30. Clarke V, Braun V, Hayfield N. Thematic Analysis. In: Smith JAe, Braun Va, Hayfield Na, editors. *Qualitative psychology: A practical guide to research methods*. 3rd ed: SAGE; 2015. p. 222-48.
31. Kelly J, Sadeghieh T, Adeli K. Peer review in scientific publications: Benefits, critiques, & a survival guide. *EJIFCC*. 2014;25(3):227-43.
32. Geurtsen GJM, van Heugten CMMP, Martina JDMD, Rietveld ACMP, Meijer RMDP, Geurts ACM DP. A prospective study to evaluate a residential community reintegration program for patients with chronic acquired brain injury. *Archives of Physical Medicine and Rehabilitation*. 2011;92(5):696-704.



## Protocol Paper for ANZCTR

33. Foy CML. Long term efficacy of an integrated neurological and vocational rehabilitation programme for young adults with acquired brain injury. *Journal of Occupational Rehabilitation*. 2014;24(3):533-42.
34. Abshire M, Dinglas VD, Cajita MIA, Eakin MN, Needham DM, Himmelfarb CD. Participant retention practices in longitudinal clinical research studies with high retention rates. *BMC Medical Research Methodology*. 2017;17(1):30-.
35. Willer B, Ottenbacher KJ, Coad ML. The community integration questionnaire: A comparative examination. *American Journal of Physical Medicine Rehabilitation*. 1994;73(2):103-11.
36. Sander AM, Fuchs KL, High WM, Hall KM, Kreutzer JS, Rosenthal M. The community integration questionnaire revisited: An assessment of factor structure and validity. *Archives Physical Medicine Rehabilitation*. 1999;80(10):1303-8.
37. Ioncoli M, Berardi A, Tofani M, Panuccio F, Servadio A, Valente D, et al. Crosscultural validation of the community integration questionnaire—revised in an Italian population. *Occupational Therapy International*. 2020;2020:8916541-7.
38. Fraga-Maia HMS, Werneck G, Dourado I, Fernandes RdCP, Brito LL. Translation, adaptation and validation of “community integration questionnaire”. *Ciencia e Saude Coletiva*. 2015;20(5):1341-52.
39. Turner-Stokes L, Siegert RJ. A comprehensive psychometric evaluation of the UK FIM + FAM. *Disability Rehabilitation*. 2013;35(22):1885-95.
40. Nayar M, Vanderstay R, Siegert RJ, Turner-Stokes L. The UK functional assessment measure (UK FIM+FAM): Psychometric evaluation in patients undergoing specialist rehabilitation following a stroke from the National UK Clinical Dataset. *PLoS One*. 2016;11(1):e0147288-e.
41. Wilson FC, Wheatley-Smith L, Downes C. Analysis of intensive outpatient neuro-rehabilitation outcomes using FIM+FAM UK. *NeuroRehabilitation*. 2009;24(4):377-82.
42. Malec JFPA-CR, Kean JP, Altman IMPMBA, Swick SMA. Mayo-Portland Adaptability Inventory: Comparing psychometrics in cerebrovascular accident to traumatic brain injury. *Archives Physical Medicine Rehabilitation*. 2012;93(12):2271-5.
43. Malec JF, Kragness M, Evans RW, Finlay KL, Kent A, Lezak MD. Further psychometric evaluation and revision of the Mayo-Portland Adaptability Inventory in a national sample. *Journal of Head Trauma Rehabilitation*. 2003;18(6):479-92.
44. Guerrette M-C, McKerral M. Validation of the Mayo-Portland Adaptability Inventory-4 (MPAI-4) and reference norms in a French-Canadian population with traumatic brain injury receiving rehabilitation. *Disability and Rehabilitation*. 2021:1-7.
45. Kean J, Malec JF, Altman IM, Swick S. Rasch Measurement Analysis of the Mayo-Portland Adaptability Inventory (MPAI-4) in a Community-Based Rehabilitation Sample. *Neurotrauma*. 2011;28(5):745-53.
46. Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: A practical guide. *Clinical Rehabilitation*. 2009;23(4):362-70.
47. Krasny-Pacini AMD, Evans JP, Sohlberg MMP, Chevignard MP. Proposed criteria for appraising goal attainment scales used as outcome measures in rehabilitation research. *Archives Physical Medicine Rehabilitation*. 2016;97(1):157-70.
48. von Steinbüchel N, Wilson L, Gibbons H, Hawthorne G, Hoefler S, Schmidt S, et al. Quality of life after brain injury (QOLIBRI): Scale validity and correlates of quality of life. *Neurotrauma*. 2010;27(7):1157-65.

## Protocol Paper for ANZCTR

49. Hawthorne G, Kaye AH, Gruen R, Houseman D, Bauer I. Traumatic brain injury and quality of life: Initial Australian validation of the QOLIBRI. *Journal of Clinical Neuroscience*. 2010;18(2):197-202.
50. Holden JE, Kelley K, Agarwal R. Analyzing Change: A Primer on Multilevel Models with Applications to Nephrology. *American Journal of Nephrology*. 2008;28(5):792-801.
51. McGlothlin AE, Lewis RJ. Minimal clinically important difference: Defining what really matters to patients. *JAMA*. 2014;312(13):1342-3.
52. Malec JF, Kean J, Monahan PO. The minimal clinically important difference for the mayo-portland adaptability inventory. *Journal of Head Trauma Rehabilitation*. 2017;32(4):E47-E54.
53. Hsiu-Ting Y. Applying linear mixed effects models with crossed random effects to psycholinguistic data: Multilevel specification and model Selection. *Tutorials in Quantitative Methods for Psychology*. 2015;11(2):78-88.
54. Tripepi G, Chesnaye NC, Dekker FW, Zoccali C, Jager KJ. Intention to treat and per protocol analysis in clinical trials. *Nephrology (Carlton)*. 2020;25(7):513-7.
55. Field AP. *Discovering statistics using SPSS for Windows: Advanced techniques for the beginner*. London: Sage Publications; 2000.
56. Council NHaMR. *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*. Canberra: Commonwealth of Australia; 2018.