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Cohort Profile: The Acquired Brain Injury Community Rehabilitation and Support Services Outcomes Cohort (ABI-REStART) Study, Western Australia, 1991-2020

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Cohort Profile: ABI-REStART, 1991-2020

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**Cohort Profile: The Acquired Brain Injury Community Rehabilitation and Support
Services Outcomes Cohort (ABI-REStART) Study, Western Australia, 1991-2020**

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Abstract

Purpose: Transition into the community following acute management of acquired brain injury (ABI) is a critical part of recovery. Post-acute rehabilitation and transitional care can significantly improve outcomes. The Acquired Brain Injury Community REhabilitation and Support Services OuTcomes CohoRT (ABI-REStART) is a novel whole-population cohort formed to better understand the needs of individuals with ABI receiving post-acute rehabilitation and disability services in Western Australia (WA), and to improve their outcomes. To do this a unique combination of i) internal clinical/rehabilitation data, and ii) externally linked health data from the WA Data Linkage System was used, including hospitalisations, emergency department presentations, mental health service use, and death records, to measure longitudinal needs and outcomes of individuals with ABI over 29 years, making this the largest, most diverse post-acute ABI cohort in Australia to date.

Participants: Whole-population cohort of individuals ($n = 1,011$) with an ABI who received post-acute community-based neurorehabilitation or disability support services through Brightwater Care Group from 1991-2020.

Findings to date: Comprehensive baseline demographic, clinical and rehabilitation data, outcome measures and linked health data have been collected and analysed. Non-traumatic brain injury (e.g. stroke, hypoxia) was the main diagnostic group (54.9%, $n=555$), followed by traumatic brain injury (34.9%, $n=353$) and eligible neurologic conditions (10.2%, $n=103$). Mean age at admission was 45.4 years, and 67.5% were male ($n=682$). The cohort demonstrated significant heterogeneity, socially and clinically, with differences between ABI groups across a number of domains.

Future plans: ABI-REStART is a dynamic whole-population cohort that will be updated over time as individuals enrol in the service. Future analyses will assess longitudinal brain injury outcomes, the changing health and social needs of individuals with ABI, and evaluate and inform post-acute services to best support these individuals.

Registration: This cohort is not linked to a clinical trial, and is not registered.

Article Summary

- ABI-RESTART is the largest Australian post-acute neurorehabilitation and disability support cohort to date with a 29 year follow-up period.
- The combined use of internal clinical and rehabilitation data and linked health data provides a detailed picture of ABI that could not be derived from a single data source, with key measures including functional independence, health status and comorbidities, goal attainment, mental health and well-being, quality of life, and mortality, offering a unique, holistic understanding of the needs and outcomes of individuals with ABI
- The cohort represents a diverse and complex population including individuals with non-traumatic brain injury, traumatic brain injury, and eligible neurologic conditions, providing a diverse range of brain injury experiences.
- The unique study framework follows each cohort member from pre-injury to long-term follow-up after discharge from post-acute services, with a minimum 10-year lookback period (starting from 1981) and a mean follow-up time of 8.4 years following discharge.
- A state-based data linkage register was used, so pre-admission or post-discharge follow-up data for cohort members based interstate or overseas will not be captured, and all clients were accessing services at a single organisation which may reduce the generalisability of findings.

Introduction

Acquired brain injury (ABI) is one of the leading causes of death and disability in Australia¹. Defined as any damage to the brain occurring after birth, ABI can be traumatic (caused by extrinsic forces to the head) or non-traumatic (e.g. stroke, drug misuse, tumour, hypoxia/anoxia). Estimates suggest 2% of the population of Western Australia (WA) are living with an ABI². The consequences of ABI are complex and difficult to predict, but often lead to a range of impairments in cognitive, physical and psychosocial functioning¹⁻⁴. Up to 75% of brain injuries occur in adults under 65 years of age³, resulting in difficulties that can impact working ability, social engagement and community integration⁵⁻⁷.

Regaining independence and/or meaningful participation in life following an ABI is achievable. Transition back into the community following acute management of ABI in hospital is a critical phase of recovery, and adjustment during transition predicts longer-term outcomes and overall recovery from brain injury^{8,9}. Post-acute care is important throughout this often difficult and stressful transition period⁹. Individuals with inadequate supports risk poorer outcomes including development of a depressive disorder⁸, re-hospitalisation or institutionalisation⁹ and reduced likelihood of returning to work⁵.

Despite the importance of post-acute care for individuals with an ABI, little empirical evidence is available to enable service planning and policy development for this poorly-understood cohort. A number of community-based neurorehabilitation cohort studies examining the outcomes of individuals with ABI after rehabilitation exist in Australia¹⁰⁻¹³. While this research has demonstrated the value of community-based rehabilitation, these cohort studies have small samples (<200), and short follow-up times (<3years). Long-term research examining the experiences of individuals accessing post-acute ABI services and the effectiveness of different types of post-acute care is required to ensure the best outcomes for individuals.

The Acquired Brain Injury Community REhabilitation and Support Services

Outcomes Cohort (ABI-REStART) study is the largest in Australia to date. This cohort includes 1,011 people with ABI who received post-acute rehabilitation or support services at Brightwater Care Group in WA from 1991-2020. Brightwater has been a main provider of post-acute community-based disability services for people with acquired brain injury in WA since 1991¹⁴, with the goal to support people to meaningfully 'restart' their lives in the community after ABI.

The ABI-REStART research program uses a unique combination of internal clinical and rehabilitation data and externally linked hospital, emergency department, mental health and mortality data from the West Australian Data Linkage System¹⁵. This enables longitudinal examination of the needs and outcomes of individuals with ABI over 29 years, making this the longest follow-up of individuals with ABI undergoing post-acute care in Australia to date¹⁰⁻¹². This novel framework follows each cohort member from pre-injury, through acute injury, to long-term community-based follow-up after discharge from post-acute services. The aim of the ABI-REStART research program will focus on understanding the complex health and social needs of people with ABI during post-acute care, and identify predictors of short- and long-term outcomes to facilitate effective service planning and delivery.

This cohort profile paper: 1) describes the background and formation of ABI-REStART, 2) outlines data sources, key variables and outcomes, 3) presents baseline sociodemographic and clinical characteristics, and 4) outlines planned research for the cohort.

Cohort Description

Cohort Design and Eligibility

ABI-REStART is a retrospective whole-population cohort comprising all clients of Brightwater Care Group's ABI programs and services (excluding respite) from inception on March 15, 1991 to December 31, 2020 ($n=1,011$). Each individual's entry date into the cohort represents the date of their index admission to Brightwater's community-based ABI services. The study cohort will be periodically updated with new admissions to allow a dynamic cohort of individuals to be followed through changing services over time, a unique possibility not seen in previous cohorts.

The cohort consists of individuals with diverse brain injuries, including traumatic brain injuries (TBI), non-traumatic brain injuries (NTBI) and eligible neurologic conditions, defined by the Australian Rehabilitation Outcomes Centre (AROC) impairment codes¹⁶. Each individual's AROC diagnosis represents their primary brain injury diagnosis at entry to Brightwater, and not necessarily their index brain injury, meaning that individuals may have had prior brain injuries. Table S1 displays the AROC diagnoses eligible for Brightwater admission. Individuals with congenital neurologic conditions (e.g. cerebral palsy, spina bifida) or intellectual disabilities are eligible for services at Brightwater, but were excluded from the cohort. Admissions are accepted any time since injury, most often in the sub-acute (3-12 months post-injury) or chronic phases (>12 months post-injury)^{17,18}.

Cohorts, Setting and Programs

The overall cohort is comprised of four sub-cohorts based on year of admission to services: 1991-2002, 2003-2007, 2008-2013, and 2014-2020. These sub-cohorts reflect periods of service delivery change across the different programs. The five different community-based programs are summarized below, ranging from full-time residential neurorehabilitation to casual home-based supports.

Transitional Rehabilitation Program

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3 The *Oats Street* rehabilitation centre is a purpose-built community-based residential
4 facility providing evidence-based post-acute transitional rehabilitation services for
5 individuals with ABI and/or eligible neurologic conditions. The program is funded by the
6 West Australian Department of Health and can support up to 43 live-in residents aged 18-65,
7 across 8 group houses and 8 independent living units, plus 10 additional home-based clients.
8 The Transitional Rehabilitation Program has a typical duration of 12-24 months, and aims to
9 enable clients to regain the skills to live independently in the community. Clients participate
10 in person-centred rehabilitation tailored to their individual goals, and are supported by an
11 integrated multidisciplinary team of medical and allied health professionals.
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24 The Transitional Rehabilitation Program is based on a novel model of care: Staged
25 Community-Based Brain Injury Rehabilitation. Post-acute therapy and care services are
26 provided in a stage-based approach to support a client's continued recovery from ABI over
27 time¹⁹⁻²¹. On admission, clients are allocated to a house with levels of assistance appropriate
28 for their needs, from 24 hour continuous care to full independence, and graduate through
29 stages with decreasing levels of support as their independence and functional abilities
30 improve²¹. The program is able to support all stages of brain injury rehabilitation, from
31 profound physical disability (including those minimally conscious) to higher-level cognitive
32 rehabilitation.
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45 ***Transitional Accommodation Program***

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47 The Transitional Accommodation Program is funded by the West Australian
48 Department of Health and provides short-term support for individuals with ABI who are
49 medically stable following hospital discharge. Referrals must come from a Perth metropolitan
50 public hospital, and clients receive transitional care and short-term accommodation while
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they are supported to seek longer-term accommodation or make adjustments to existing homes²².

Supported Independent Living

Supported Independent Living is a supported accommodation program for individuals with ABI, with the Australian Government's National Disability Insurance Scheme (NDIS)²³ or private funding, who require additional supports but do not seek neurorehabilitation²⁴.

Individuals in this program live across 8 shared houses for people with disability throughout the Perth metropolitan area and access supports appropriate for their lifestyle and goals.

Capacity Building

Capacity Building offers home-based supports to individuals with ABI with NDIS funding. Supports include specialist neurorehabilitation therapy services, support coordination, equipment and assistive technology, and behavioural assessment and support. Capacity Building clients have individually tailored rehabilitation or lifestyle goals that are achieved while living off-site.

Home and Community Care Social Skills

The Home and Community Care Social Skills program provides support, privately or with NDIS funding, for social engagement and activities as well as in-home care as required. This program is for individuals with ABI who are at risk of social isolation or need support around the home to maintain their independence.

Data Sources and Follow-Up Time

Figure 1a summarizes the data sources for ABI-REStART. The study uses a unique combination of internal clinical and rehabilitation data, and externally linked data collections from the WA Department of Health. Internal electronic medical records for each cohort

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3 member were probabilistically linked through the WA Data Linkage System¹⁵ to four
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5 external health data collections. We obtained data on hospitalizations (hospital morbidity data
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7 collection; 1981-2020), emergency department (ED) presentations (ED data collection; 2002-
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9 2020), deaths (mortality register, 1991-2020) and mental health (mental health information
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11 system; 1981-2020). The combination of internal and external data sources allows
12
13 triangulation of information to ensure higher accuracy, continuity, and completeness than
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15 could be derived from a single source.
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19 Figure 1b summarizes the ABI-REStART study design and follow-up time. The
20
21 unique study framework follows each cohort member from pre-injury, acute care, post-acute
22
23 care and long-term follow-up after discharge from post-acute services. For all cohort
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25 members, a minimum 10-year pre-admission lookback period is available to examine pre-
26
27 injury morbidity patterns and acute care details. Linked data are obtained up to December 31,
28
29 2020, with a mean follow-up time of 8.4 years (range 0y-29.2y) following discharge from
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31 community-based services for each cohort member. The study cohort and data linkage will be
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33 periodically updated with new admissions to allow cohort growth and dynamic follow-up.
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37 **Key Measures, Variables and Outcomes**

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39 Key measures and variables available for the ABI-REStART study are summarized in
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41 Table 1. Variables are primarily derived from clinical and administrative data collected as
42
43 part of routine service provision. Key variables span five categories (Admissions,
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45 Demographics, Clinical, Rehabilitation, and Psychosocial), offering a unique, holistic
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47 understanding of the needs and outcomes of individuals with ABI. Outcomes for each cohort
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49 member include functional independence, health status and comorbidities, goal attainment,
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51 mental health and well-being, quality of life, and mortality, the most comprehensive set of
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53 measures available for a cohort of this kind to date.
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Ethics

Clients provided consent for their de-identified information to be used for research purposes as part of the conditions of service upon admission. Ethics approval for this study was granted by the University of Western Australia Human Research Ethics Committee (RA/4/1/9232) and the West Australian Department of Health Human Research Ethics Committee (RGS0000002894).

Statistical Analysis

Extraction and analysis of baseline data was completed in February 2021. Baseline data were analysed using STATA 16.0²⁵. Primary analyses were tested against an alpha level of 0.05 (uncorrected, two-tailed). Descriptive statistics were calculated and presented as mean \pm standard deviation, or count (percentage). Independent samples t-tests, two-way ANOVAs and χ^2 analyses were used to compare differences in continuous and categorical outcomes, respectively. Bonferroni correction was used for multiple comparisons.

Patient and public involvement

Patients or public were not involved in the development of the research question and study design or conducting the present study.

Findings to date

Sociodemographic Characteristics

Table 2 summarizes the baseline sociodemographic characteristics of ABI-REStART. Mean age at admission was 45.4 ± 15.5 years (range: 14.9y–93.2y), with 6.2% aged over 65 (n=63). Male clients (67.5%) outnumbered female clients (32.5%). The relatively young age and predominantly male cohort is consistent with other profiles of individuals seeking ABI services^{10–12}. The majority of the cohort was born in Australia (64.7%), with 3.4% of clients of Indigenous and/or Torres Strait Islander background. Most of the cohort lived in a major

city (84.3%) and were between *average disadvantage* and *least disadvantaged* levels of the IRSD before admission (76.5%).

Brain Injury Characteristics

Table 3 summarizes AROC diagnostic categories for the cohort. The majority had an NTBI (54.9%; 555 of 1,011) with stroke (52.6%; 292 of 555) comprising over half of NTBI diagnoses. TBI accounted for 34.9% of the cohort (353 of 1,011).

Table 4 summarizes brain injury characteristics for the cohort. There were significant differences in gender composition of the diagnostic groups ($p < 0.001$), with more male than female clients with TBI and stroke. Gender differences were smaller in the other NTBI and neurologic groups.

There were significant differences in age at admission and ABI type ($p < .001$). Clients with TBI were significantly younger than those in all other ABI groups at admission (largest corrected $p < 0.001$). Consistent with prior literature, TBI clients were more likely to be male and significantly younger than those with other ABIs^{26,27}. Those presenting with stroke and neurological conditions were significantly older than those with other NTBI (largest corrected $p < .006$), likely reflecting increasing age-related stroke risk^{28,29}.

Clients with neurologic conditions or TBI primarily entered post-acute rehabilitation in the chronic injury phase, whereas most clients with stroke entered services during the sub-acute phase. This may be related to longer hospital admissions for TBI clients, but may also demonstrate the benefits of specialized stroke services in managing acute stroke³⁰, quickly directing people to rehabilitation. Bilateral injuries (58.9%) were the most common overall, and for TBI (62.3%), other NTBI (80.2%) and neurologic condition groups (97.1%). The majority of strokes were unilateral (72.9%), with left hemispheric more common than right hemispheric stroke. Seventy-six clients had another brain injury prior to their admission

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3 injury (7.5%). Individuals with a stroke diagnosis represented 54.0% of those clients (41 of
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5 76). The presence of these individuals with prior injuries is consistent with evidence that
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7 recurrent TBI is associated with increased disability³¹, and prior stroke is a significant risk
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9 factor of recurrent stroke³².

12 The median length of acute hospital stay for the cohort was 5.0 months (IQR 2.8mo-
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14 8.0mo), with TBI clients having significantly longer acute stays (largest corrected $p < 0.001$).
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16 Although it is not clear why this was the case, evidence suggests that accompanying injuries
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18 and complications are associated with longer hospital stays for patients with TBI³³.
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20 Fortunately, rehabilitation appears to be effective in improving independence despite longer
21
22 periods between injury and rehabilitation admission³⁴.

26 External causes of injury – defined as environmental events, circumstances or
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28 conditions that are external to the body – are shown in Table 5. Internal causes (e.g. medical
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30 conditions) are not included. Half of the cohort sustained their ABI due to an external cause
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32 (50.6%, 512 of 1,011). Accidents were the leading external cause of injury (60.2%; 308 of
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34 512), with motor vehicle accidents (MVA; 33.6%) the most common accident type. Clients
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36 aged below 30 were most likely to have sustained an ABI due to motor vehicle accidents (77
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38 of 172, 44.8%), with a median age of 23.7 years (IQR 19.1y-37.7y), whereas clients aged
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40 from 40-60 were most likely to have been injured in accidental falls (35 of 61, 57.4%),
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42 corrected $p < 0.001$. Abnormal reaction during surgical or medical procedure was the leading
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44 external cause of stroke (82.4%), while poisoning and toxic effect of substances was the
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46 leading external cause of other NTBI (48.6%).

51 52 **Admission Characteristics**

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The majority of TBI (65.4%), stroke (63.7%) and other NTBI (54.8%) clients were admitted for post-acute transitional rehabilitation. The majority of neurologic clients were admitted to Supported Independent Living (43.7%).

Median time from injury to admission to community-based services was 10.5 months (IQR 5.7mo-27.1mo). Clients with neurologic conditions took significantly longer to access services than other ABI groups (largest corrected $p < 0.001$). Those in the stroke group accessed services significantly faster than the TBI group ($p < 0.001$) but did not differ from the other NTBI group ($p = 0.40$).

Similar numbers of clients were admitted from hospital and home. There were significant differences in ABI group and admission source ($p = 0.001$), with 71.1% of individuals with neurologic conditions admitted from home, 52.9% of the TBI group, 45.3% of the stroke group, and 39.8% of the other NTBI group. The overrepresentation of individuals with neurological injury in admissions from home is likely the result of slow onset of neurological injuries relative to acute injuries like stroke or TBI.

Future Directions

The main focus of the ABI-REStART research program is to measure the short- and long-term outcomes of cohort members following discharge from post-acute services. The heterogeneity of the cohort, and the scope and quantity of longitudinal health data available provides a unique opportunity to identify the predictors of outcomes. Findings will enable greater understanding of personal and structural factors influencing outcomes, providing valuable evidence for clinicians to generate effective, personalized post-acute programs.

Health comorbidities of the cohort will also be examined to understand the complex needs of people with ABI and facilitate effective person-centred care. Comorbidities—i.e. chronic condition(s) co-existing with an index disease³⁵—are common following ABI.

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Complex or mismanaged comorbidity can affect the course and outcome of rehabilitation and result in poorer functional outcomes, longer stay, and higher use and costs of healthcare services³⁶⁻³⁸. Better understanding of comorbidities can support a focus on the whole person, not only neurologic recovery, which is critical for effective community re-integration.

Mental health disorders are common for those with ABI^{27,38}. Individuals with mental health comorbidities present before or after ABI have poorer outcomes than those without^{38,39}. Research using 263 ABI-REStART members found that mental health comorbidities were present in 55.8% of the sample ($n=106$), representing the most common comorbidity²⁶. The ABI-REStART study provides the opportunity to examine the prevalence of mental illness, specific mental health needs, and its impact on rehabilitation outcomes to inform policy and services for mental health and ABI.

Strengths and Limitations

ABI-REStART is the largest post-acute community-based ABI cohort study in Australia. The unique design provides novel opportunities to examine the longitudinal needs of people living with ABI, and to evaluate the efficacy of post-acute rehabilitation and support programs offered. The cohort was formed over 29 years, allowing the effects of policy and treatment changes over time to be examined. The use of both internal clinical data and linked health data produces a detailed picture of brain injury that is more complex than could be derived from a single source, allowing complex questions around the nature of ABI and the individualized client requirements to be examined.

As ABI-REStART is comprised of individuals from a single organization, this population differs from the ABI population in Western Australia in some ways. The cohort is relatively young, with only 6.2% of clients aged 65 years or above. This underrepresentation reduces the conclusions that can be drawn from this cohort around older adults. Similarly,

only 3.4% of the study cohort were of Aboriginal or Torres Strait Islander background despite Indigenous Australians being overrepresented in TBI cases in Western Australia^{2,40} and having elevated stroke risk relative to non-Indigenous Australians^{41,42}. Research is needed to examine the factors impacting the engagement of Indigenous Australians with post-acute services. Finally, the use of a State-based data linkage register is limited, as pre-admission or post-discharge follow-up data for cohort members based interstate or overseas will not be captured in the WA Data Linkage System data collections.

Collaboration

Researchers interested in collaborating on cohort analyses should contact the corresponding author to express their interest. Initial planned data analyses and publications will be conducted by the primary ABI-REStART study investigators; however the research team is open to potential collaboration on future analyses. Access to the data is only possible with express permission of the University of Western Australia and West Australian Department of Health Human Research Ethics Committees and data custodians, and may require a data sharing agreement. Analysis of linked data is currently authorised to occur at only one location in Perth, Western Australia, owing to ethical considerations.

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Competing interests

None declared.

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Author Contribution

GM performed the data collection, wrote the statistical analysis plan, analysed the data and drafted and revised the paper. **LT** designed and supervised the study, provided analytical input, and drafted and revised the paper. **JW** provided clinical and service input, and revised the draft paper. **AM** designed and led the study, obtained linked data, obtained funding for the study and revised the draft paper.

Data sharing statement

Data may be made available upon reasonable request. Access to the data is only possible with express permission of the WA Department of Health Human Research Ethics Committees and data custodians, and may require a data sharing agreement. Analysis of linked data is currently authorised to occur at only one location in Perth, Western Australia, owing to ethical considerations.

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Table 1. Data sources, key measures and variables available for the ABI-REStART study

	Date	Data Source/Type	Description	Key Variables
	1991 - 2020	Admissions	<ul style="list-style-type: none"> Admission & discharge date Facility Programs Referral source 	<ul style="list-style-type: none"> Time since injury to admission Admission source Admission program Admission and discharge dates Age at admission
	1991 - 2020	Demographics	<ul style="list-style-type: none"> Demographics Social background 	<ul style="list-style-type: none"> Age at injury Gender Indigenous status Country of birth Usual occupation SEIFA IRSD⁴³ ASGS Remoteness Area⁴⁴
	1991 - 2020	Clinical	<ul style="list-style-type: none"> Diagnoses Vital signs / observations Medications Investigations (pathology, radiology) Medical & allied health consultation notes Medical correspondence and referrals 	<ul style="list-style-type: none"> ABI type (TBI, NTBI, neurologic) Injury location (unilateral, bilateral) Cause of injury Severity (Glasgow Coma Scale⁴⁵, post-traumatic amnesia, loss of consciousness) Injury phase (acute, subacute, chronic)
	1991 - 2020	Rehabilitation	<ul style="list-style-type: none"> Australasian Rehabilitation Outcomes Centre (AROC) Impairment Code Outcome measures 	<ul style="list-style-type: none"> FIM+FAM⁴⁶ MPAI-4⁴⁷ GAS⁴⁸
	1991 - 2020	Psychosocial	<ul style="list-style-type: none"> Mental health Quality of life Behavioural Well-being 	<ul style="list-style-type: none"> QOLIBRI^{49,50} NPTDA⁵¹ HADS⁵²
EXTERNAL	1981 - 2020	Hospital (HMDC)	<ul style="list-style-type: none"> Hospital admissions and separations for all public and private hospitals in WA 	<ul style="list-style-type: none"> Comorbidities Comorbidity severity Surgical procedures Health service use patterns
	2002 - 2020	Emergency department (EDDC)	<ul style="list-style-type: none"> ED presentations at all public and private hospitals in WA 	
	1981 - 2020	Mental health (MHIS)	<ul style="list-style-type: none"> Inpatient and outpatient community mental health presentations 	
	1991 - 2020	Deaths	<ul style="list-style-type: none"> All deaths occurring in WA 	<ul style="list-style-type: none"> Cause of death Time to death

Note: SEIFA IRSD = Socio-Economic Indexes for Areas Index of Relative Socioeconomic Disadvantage; ASGS = Australian Statistical Geography Standard; FIM+FAM = Functional Independence Measure + Functional Assessment Measure; MPAI-4 = Mayo-Portland Adaptability Inventory; GAS = Goal Attainment Scale; QOLIBRI = Quality of Life After Brain Injury; NPTDA = Northwick Park Therapy Dependency Assessment; HADS = Hospital Anxiety and Depression Scale.

Table 2. Sociodemographic characteristics for the ABI-REStART cohort at admission to post-acute community-based brain injury support programs, 1991-2020 (n=1,011)

Characteristics	Total, n=1,011	1991-2002, n=231	2003-2007, n=145	2008-2013, n=220	2014-2020, n=415
Sex, n (%)					
Male	682 (67.5)	150 (64.9)	108 (74.5)	156 (70.9)	268 (64.6)
Female	329 (32.5)	81 (35.1)	37 (25.5)	64 (29.1)	147 (35.4)
Age at admission, mean \pm SD					
Total	45.4 \pm 15.5	44.1 \pm 21.5	39.5 \pm 12.5	44.2 \pm 12.8	48.8 \pm 12.9
Male	44.2 \pm 14.6	39.8 \pm 18.0	39.9 \pm 12.8	44.7 \pm 12.3	48.0 \pm 13.3
Female	47.9 \pm 17.1	51.9 \pm 25.0	38.3 \pm 11.6	43.0 \pm 13.9	50.2 \pm 12.1
Age category at admission, n (%)					
<18 years	15 (1.5)	8 (3.5)	3 (2.1)	-	4 (1.0)
18-29	190 (18.8)	66 (28.6)	36 (24.8)	40 (18.2)	48 (11.6)
30-39	161 (15.9)	46 (19.9)	32 (22.1)	34 (15.5)	49 (11.8)
40-49	223 (22.1)	43 (18.6)	43 (29.7)	54 (24.6)	83 (20.0)
50-59	274 (27.1)	19 (8.2)	26 (17.9)	78 (35.5)	151 (36.4)
60-69	102 (10.1)	7 (3.0)	5 (3.5)	14 (6.4)	76 (18.3)
\geq 70 years	46 (4.6)	42 (18.2)	-	-	4 (1.0)
Indigenous, n (%)					
Total	34 (3.4)	2 (0.9)	-	13 (5.9)	19 (4.6)
Male	24 (70.6)	1 (0.5)	-	11 (84.6)	12 (63.2)
Female	10 (29.4)	1 (0.5)	-	2 (15.4)	7 (36.8)
Mean age \pm SD	38.8 \pm 13.6	31.0 \pm 0.8	-	40.0 \pm 15.2	38.8 \pm 13.4
Marital Status, n (%)					
Single	444 (43.9)	101 (43.7)	76 (52.4)	99 (45.0)	168 (40.5)
De Facto	38 (3.8)	3 (1.3)	2 (1.4)	12 (5.5)	21 (5.1)
Married	253 (25.0)	73 (31.6)	30 (20.7)	50 (22.7)	100 (24.1)
Separated	59 (5.8)	13 (5.6)	10 (6.9)	12 (5.5)	24 (5.8)
Divorced	133 (13.2)	14 (6.1)	20 (13.8)	35 (15.9)	64 (15.4)
Widowed	30 (3.0)	16 (6.9)	1 (0.7)	3 (1.4)	10 (2.4)
Unknown	54 (5.3)	11 (4.8)	6 (4.1)	9 (4.1)	28 (6.8)
Country of Birth, n (%)					
Australia (and external territories)	654 (64.7)	162 (70.1)	98 (67.6)	120 (54.6)	274 (66.0)
New Zealand	31 (3.1)	9 (3.9)	5 (3.5)	5 (2.3)	12 (2.9)
Maritime South-East Asia	27 (2.7)	3 (1.3)	1 (0.7)	6 (2.7)	17 (4.1)
Mainland South-East Asia	13 (1.3)	3 (1.3)	2 (1.4)	2 (0.9)	6 (1.5)
Southern Asia	11 (1.1)	-	-	3 (1.4)	8 (1.9)
Chinese Asia	9 (0.9)	2 (0.9)	-	2 (0.9)	5 (1.2)
Southern and East Africa	18 (1.8)	-	2 (1.4)	3 (1.4)	13 (3.1)
The United Kingdom	84 (8.3)	28 (12.1)	12 (8.3)	14 (6.4)	30 (7.2)
Western Europe	11 (1.1)	2 (0.9)	1 (0.7)	4 (1.8)	4 (1.0)

Cohort Profile: ABI-REStART, 1991-2020

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Southern Europe	11 (1.1)	2 (0.9)	-	3 (1.4)	6 (1.5)
Other	44 (4.4)	7 (3.0)	4 (2.8)	9 (4.1)	24 (5.8)
Unknown	98 (9.7)	13 (5.6)	20 (13.8)	49 (22.3)	16 (3.9)
Usual Occupation, n (%)					
Managers	26 (2.6)	1 (0.4)	4 (2.8)	9 (4.1)	12 (3.0)
Professionals	49 (4.9)	5 (2.2)	3 (2.1)	11 (5.0)	30 (7.2)
Technicians and Trades Workers	80 (7.9)	3 (1.3)	9 (6.2)	24 (10.9)	44 (10.6)
Community and Personal Service Workers	34 (3.4)	2 (0.9)	6 (4.1)	8 (3.6)	18 (4.3)
Clerical or Administrative Workers	20 (2.0)	1 (0.4)	2 (1.4)	5 (2.3)	12 (2.9)
Sales Workers	10 (1.0)	-	1 (0.7)	-	9 (2.2)
Machinery Operators and Drivers	31 (3.1)	4 (1.7)	2 (1.4)	10 (4.6)	15 (3.6)
Labourers	48 (4.8)	5 (2.2)	6 (4.1)	12 (5.5)	25 (6.0)
Not in workforce	206 (20.4)	7 (3.0)	15 (10.3)	42 (19.1)	142 (34.22)
Unknown	507 (50.2)	203 (87.9)	97 (66.9)	99 (45.0)	108 (26.0)
Accommodation Type, n (%)					
Private Residence	318 (31.5)	7 (3.0)	31 (21.4)	74 (33.6)	206 (49.6)
Public Rental	56 (5.5)	4 (1.7)	1 (0.7)	20 (9.1)	31 (7.5)
Family Home	40 (4.0)	3 (1.3)	11 (7.6)	1 (0.5)	11 (2.7)
Supported Accommodation	19 (1.9)	-	-	1 (0.5)	18 (4.3)
Residential Aged Care	9 (0.7)	-	-	1 (0.5)	6 (1.5)
Temporary Housing	15 (1.5)	-	-	1 (0.5)	14 (3.4)
Crisis Accommodation	5 (0.5)	-	-	1 (0.5)	4 (1.0)
Hospital	3 (0.3)	-	-	-	3 (0.7)
Institutional care	2 (0.2)	-	-	-	2 (0.5)
No fixed address	20 (2.0)	-	3 (2.1)	6 (2.7)	11 (2.7)
Unknown	526 (52.0)	217 (94.9)	99 (68.3)	101 (45.9)	109 (26.3)
ASGS – Remoteness Area, n (%)					
Major city	814 (84.3)	179 (77.5)	113 (77.9)	167 (75.9)	355 (85.5)
Inner regional	57 (5.9)	12 (5.2)	10 (6.9)	19 (8.6)	16 (3.9)
Outer regional	45 (4.7)	16 (6.9)	13 (9.0)	9 (4.1)	7 (1.7)
Remote	28 (2.9)	6 (2.6)	1 (0.7)	11 (5.0)	10 (2.4)
Very Remote	14 (1.5)	7 (3.0)	1 (0.7)	1 (0.5)	5 (1.2)
Migratory & Offshore	8 (0.8)	6 (2.6)	2 (1.4)	0	0
Missing	45 (4.5)	5 (2.2)	5 (3.5)	13 (5.9)	22 (5.3)
SEIFA – Index of Relative Social Disadvantage, n (%)					
Q1 – Most disadvantaged	141 (14.0)	61 (26.4)	37 (25.5)	18 (8.2)	25 (6.0)
Q2 – More disadvantaged	83 (8.2)	6 (2.6)	10 (6.9)	25 (11.4)	42 (10.1)
Q3 – Average	216 (21.4)	22 (9.5)	19 (13.1)	68 (30.9)	107 (25.8)

Cohort Profile: ABI-REStART, 1991-2020

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Q4 – Less disadvantaged	291 (28.8)	68 (29.4)	41 (28.3)	53 (24.1)	129 (31.1)
Q5 – Least disadvantaged	224 (22.2)	63 (27.3)	28 (19.3)	43 (19.6)	90 (21.7)
Missing	56 (5.5)	11 (4.8)	10 (6.9)	13 (5.9)	22 (5.3)

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Table 3. Brain injury diagnoses and Australasian Rehabilitation Outcomes Centre (AROC) Impairment Codes for the ABI-REStART cohort, 1991-2020

AROC Code, Category and Diagnosis	n (%)
Non-traumatic (Stroke)	292 (28.9)
1.1 Stroke – Haemorrhagic	81 (8.0)
1.2 Stroke – Ischemic	178 (17.6)
1.0 Stroke – Unspecified	33 (3.3)
Non-traumatic (other - excluding stroke)	263 (26.0)
2.11 Subarachnoid haemorrhage	58 (5.7)
2.12 Anoxic brain damage	78 (7.7)
2.13 Encephalitis	18 (1.8)
Meningitis	6 (0.6)
Neoplasm/tumour of brain, meninges or cranial nerves	32 (3.2)
Intracranial abscess	2 (0.2)
Hydrocephalus	5 (0.5)
Toxic encephalopathy	35 (3.5)
Metabolic encephalopathy	7 (0.7)
Other non-traumatic brain dysfunction	22 (2.2)
Traumatic	353 (34.9)
2.21 Traumatic, open injury	50 (5.0)
2.22 Traumatic, closed injury	280 (27.7)
2.2 Traumatic, unspecified	23 (2.3)
Neurologic	103 (10.2)
3.1 Multiple sclerosis	16 (1.6)
3.2 Parkinsonism	17 (1.7)
3.3 Polyneuropathy	3 (0.3)
3.4 Guillain-Barré Syndrome	1 (0.1)
3.8 Neuromuscular Disorders	13 (1.3)
3.9 Extrapyramidal and abnormal movement disorders	2 (0.2)
Spinocerebellar disease	3 (0.3)
Epilepsy	31 (3.1)
Other neurologic and neurodegenerative disorders	17 (1.7)

Table 4. Brain injury and admission characteristics for the ABI-REStART cohort at admission to community-based brain injury services, 1991-2020 (n=1,011)

Characteristics	Total, n = 1,011	Traumatic, n=353	Non-traumatic		Neurologic, N=103
			Stroke, n=292	Other NTBI, n=263	
<i>Sociodemographic</i>					
Age at injury, mean ± SD (years)	42.3 ± 16.5, n=853	33.4 ± 14.9, n= 303	51.0 ± 13.4, n=265	43.0 ± 15.0, n=226	46.8 ± 18.9, n=59
Gender, n (%)					
Male	682 (67.5)	283 (80.2)	197 (67.5)	142 (54.0)	60 (58.3)
Female	329 (32.5)	70 (19.8)	95 (32.5)	121 (46.0)	43 (41.8)
Indigenous, n (%)					
Total	34 (3.4)	16 (4.5)	10 (3.4)	5 (1.9)	3 (2.9)
Male	24 (3.5)	13 (4.6)	8 (4.1)	2 (1.4)	1 (1.7)
Female	10 (3.0)	3 (4.3)	2 (2.1)	3 (2.5)	2 (4.7)
<i>Clinical</i>					
Injury location, n (%)					
Right	114 (11.3)	24 (6.8)	76 (26.0)	13 (4.9)	1 (1.0)
Left	145 (14.3)	38 (10.8)	97 (33.2)	10 (3.8)	-
Unilateral – side unspecified	101 (10.0)	42 (11.9)	40 (13.7)	19 (7.2)	-
Bilateral	595 (58.9)	220 (62.3)	64 (21.9)	211 (80.2)	100 (97.1)
Unknown	56 (5.5)	29 (8.2)	15 (5.1)	10 (3.8)	2 (1.9)
Length of acute hospital stay, mean ± SD (months)	6.0 ± 4.8, n=740	7.0 ± 5.3, n=273	5.1 ± 3.5, n=236	5.9 ± 4.9, n= 206	4.8 ± 6.7, n= 25
Previous ABI, n (%)	76 (7.5)	15 (4.3)	41 (14.0)	19 (7.2)	1 (1.0)
Injury phase, n (%)					
Acute (>3 months)	56 (6.0)	12 (3.5)	21 (7.5)	20 (8.3)	3 (4.1)
Subacute (3 – 12 months)	410 (43.7)	134 (39.2)	158 (56.2)	109 (45.0)	9 (12.3)
Chronic (> 12 months)	472 (50.3)	196 (57.3)	102 (36.3)	113 (46.7)	61 (83.6)
<i>Admission</i>					
Age at admission, mean ± SD (years)	45.4 ± 15.5	37.8 ± 14.5	52.6 ± 13.2	45.4 ± 14.5	50.9 ± 15.8
Time post-injury, n (%)					
< 1 year	466 (49.7)	146 (42.7)	179 (63.7)	129 (53.3)	12 (16.4)
1 – 2 years	161 (17.2)	68 (19.9)	48 (17.1)	40 (16.5)	5 (6.9)
> 2 years	311 (31.1)	128 (37.4)	54 (19.2)	73 (30.2)	56 (76.7)
Program, n (%)					
TRP	546 (54.0)	232 (65.7)	168 (57.5)	140 (53.2)	17 (16.5)
TAP	121 (12.0)	36 (10.2)	28 (9.6)	41 (15.6)	16 (15.5)
CAPB	107 (10.6)	32 (9.1)	24 (8.2)	30 (11.4)	21 (20.4)
HACC Social Support	70 (6.9)	25 (7.1)	26 (8.9)	14 (5.3)	5 (4.9)
SIL	167 (16.5)	39 (11.1)	46 (15.8)	38 (14.5)	44 (42.3)
Admitted from, n (%)					
Home	435 (43.0)	165 (46.7)	120 (41.1)	96 (36.5)	54 (52.4)
Hospital	437 (43.2)	139 (39.4)	140 (48.0)	136 (51.7)	22 (21.4)
Other	22 (2.2)	8 (2.3)	5 (1.7)	9 (3.4)	-
Unknown	117 (11.6)	41 (11.6)	27 (9.3)	22 (8.4)	27 (26.2)

Note. TRP = Transitional Rehabilitation Program; TAP = Transitional Accommodation Program; CAPB = Capacity Building; HACC = Home and Community Care; SIL = Supported Independent Living

Table 5. Known external causes of brain injury for the ABI-REStART cohort (n=1,011)

Cause of ABI, n (%)	Total, n=1,011	Traumatic, n = 353	Non-traumatic		Neurologic, n=103
			Stroke, n=292	Other NTBI, n=263	
<i>Individuals with known external causes of injury</i>	512	347	51	111	4
Accidents					
Accidental fall	61 (11.9)	58 (16.7)	1 (2.0)	2 (1.8)	-
Motor vehicle accident (incl. pedestrian)	172 (33.6)	167 (48.1)	-	4 (3.6)	1 (33.3)
Motorbike accident	29 (5.7)	29 (8.4)	-	-	-
Cycling accident	14 (2.7)	13 (3.8)	-	1 (0.9)	-
Quad bike accident	4 (0.8)	4 (1.2)	-	-	-
Railway accident	3 (0.6)	3 (0.9)	-	-	-
Drowning and submersion	3 (0.6)	1 (0.3)	-	2 (1.8)	-
Other accident	12 (2.3)	9 (2.6)	1 (2.0)	2 (1.8)	-
Unspecified accident	10 (1.9)	8 (2.3)	-	2 (1.8)	-
Poisoning and toxic effect of drugs, medicaments, or gases					
Accidental overdose	12 (2.3)	-	1 (2.0)	11 (9.9)	-
Intentional overdose	19 (3.7)	-	1 (2.0)	18 (16.2)	-
Unknown intent	9 (1.8)	-	-	9 (8.1)	-
Complication of chronic substance use	20 (3.9)	-	3 (3.9)	16 (14.4)	1 (33.3)
Intentional self-harm (excl. poisoning)					
Hanging or strangulation	4 (0.8)	-	-	4 (3.6)	-
Jumping from high place, or in front of moving object	7 (1.4)	7 (2.0)	-	-	-
Drowning	1 (0.2)	-	-	1 (0.9)	-
Unspecified suicide	2 (0.4)	1 (0.3)	-	1 (0.9)	-
Complications of medical and surgical care					
Abnormal reaction during surgical or medical procedure	78 (15.2)	2 (0.6)	42 (82.4)	33 (29.7)	1 (33.3)
Adverse effects of drugs, medicaments and biological substances during therapeutic use	2 (0.4)	-	1 (2.0)	1 (0.9)	-
Assault	50 (9.8)	45 (13.0)	1 (2.0)	4 (3.6)	-
<i>Individuals with known internal or unknown causes</i>	499	6	241	152	99

Note. Percentages for each group were calculated using the number of individuals with known external causes of injury recorded as the denominator. Individuals with known internal or unknown causes were not included in the count.

Cohort Profile: ABI-REStART, 1991-2020

31

Figure 1. Data Sources and Study Design for the ABI-REStART Study, 1991-2020. (a) Internal and External Data Sources and, (b) Study Design

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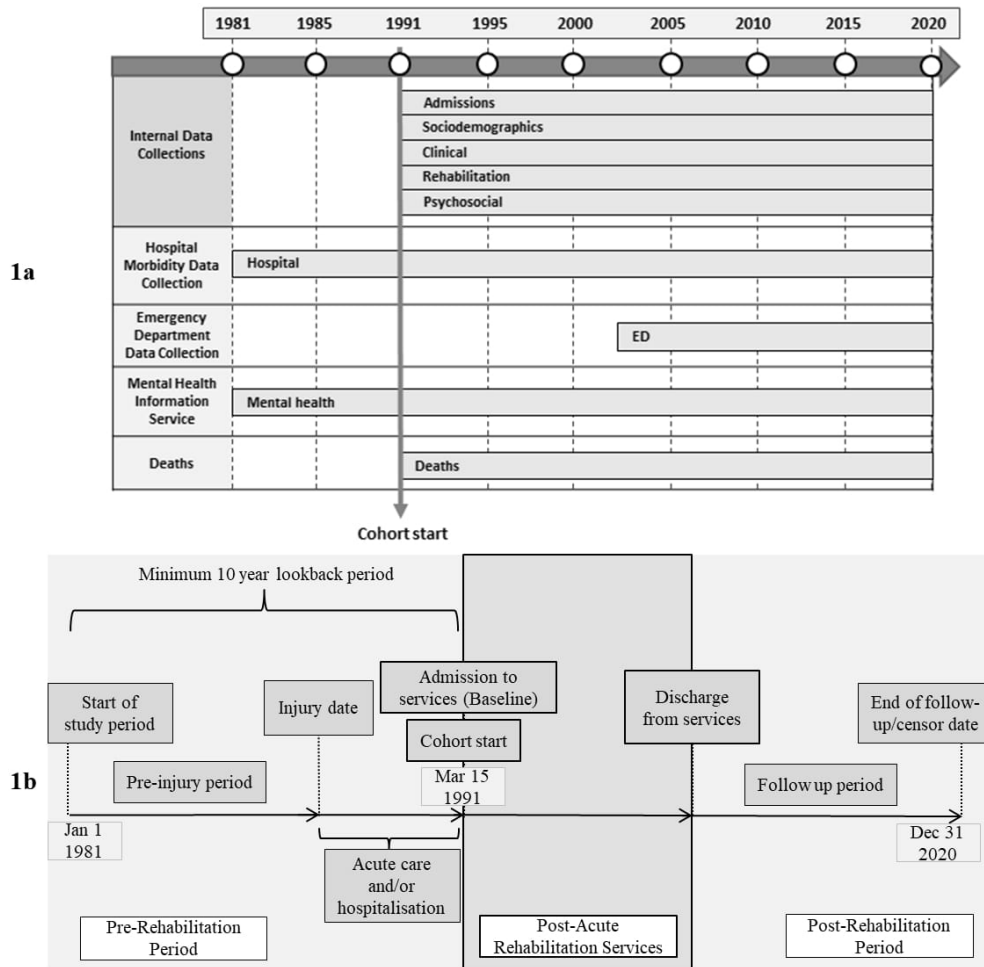


Figure 1. Data Sources and Study Design for the ABI-REStART Study, 1991-2020. (a) Internal and External Data Sources and, (b) Study Design

401x391mm (72 x 72 DPI)

Table S 1. AROC codes and diagnoses eligible for admission to Brightwater services.

AROC Impairment Group	AROC Impairment Group Code
Haemorrhagic Stroke	1.11 Left Body Involvement (Right Brain)
	1.12 Right Body Involvement (Left Brain)
	1.13 Bilateral Involvement
	1.14 No Paresis
	1.19 Other Stroke
Ischemic Stroke	1.21 Left Body Involvement (Right Brain)
	1.22 Right Body Involvement (Left Brain)
	1.23 Bilateral Involvement
	1.24 No Paresis
	1.29 Other Stroke
Brain Dysfunction	2.11 Non-traumatic Subarachnoid Haemorrhage
	2.12 Anoxic Brain Damage
	2.13 Other Non-traumatic Brain Dysfunction
	Encephalitis
	Meningitis
	Neoplasm/tumour of brain of meninges – malignant or benign (includes secondary tumours)
	Neoplasm/tumour of cranial nerves
	Intracranial abscess
	Hydrocephalus
	Toxic encephalopathy
<i>Metabolic encephalopathy*</i>	
2.21 Traumatic, Open Injury	
2.22 Traumatic, Closed Injury	
Neurologic Conditions	3.1 Multiple Sclerosis
	3.2 Parkinsonism
	3.3 Polyneuropathy
	3.4 Guillain-Barré Syndrome
	3.8 Neuromuscular Disorders
	Post poliomyelitis/post-polio syndrome
	Motor neurone disease
	Muscular dystrophies and other myopathies
	3.9 Other Neurologic Disorders
	Other extrapyramidal disease and abnormal movement disorders
Spinocerebellar disease	
Disorders of the autonomic nervous system	
<i>Epilepsy*</i>	
Other demyelinating diseases of the central nervous system	

Note. * indicates a diagnosis included in the cohort that was not taken from the AROC code

STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation	Page No
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	1,2 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6-8
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up (b) For matched studies, give matching criteria and number of exposed and unexposed	8,9 n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Table 1
Bias	9	Describe any efforts to address potential sources of bias	n/a
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9,10
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, explain how loss to follow-up was addressed (e) Describe any sensitivity analyses	10
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	6 n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	10-13 Tables 2,4,5 9
Outcome data	15*	Report numbers of outcome events or summary measures over time	n/a

1	Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
2			(b) Report category boundaries when continuous variables were categorized	Table 4
3			(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
4	Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a
5	Discussion			
6	Key results	18	Summarise key results with reference to study objectives	n/a
7	Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
8	Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14
9	Generalisability	21	Discuss the generalisability (external validity) of the study results	n/a
10	Other information			
11	Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	15

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.

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Cohort Profile: The Acquired Brain Injury Community Rehabilitation and Support Services Outcomes Cohort (ABI-REStART), Western Australia, 1991-2020

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Cohort Profile: ABI-REStART, 1991-2020

1

**Cohort Profile: The Acquired Brain Injury Community REhabilitation and Support
Services OuTcomes CohoRT (ABI-REStART), Western Australia, 1991-2020**

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Abstract

Purpose: Transition into the community following acute management of acquired brain injury (ABI) is a critical part of recovery. Post-acute rehabilitation and transitional care can significantly improve outcomes. The Acquired Brain Injury Community REhabilitation and Support Services OuTcomes CohoRT (ABI-REStART) is a novel whole-population cohort formed to better understand the needs of individuals with ABI receiving post-acute rehabilitation and disability services in Western Australia (WA), and to improve their outcomes. To do this a unique combination of i) internal clinical/rehabilitation data, and ii) externally linked health data from the WA Data Linkage System was used, including hospitalisations, emergency department presentations, mental health service use, and death records, to measure longitudinal needs and outcomes of individuals with ABI over 29 years, making this the largest, most diverse post-acute ABI cohort in Australia to date.

Participants: Whole-population cohort of individuals ($n = 1,011$) with an ABI who received post-acute community-based neurorehabilitation or disability support services through Brightwater Care Group from 1991-2020.

Findings to date: Comprehensive baseline demographic, clinical and rehabilitation data, outcome measures and linked health data have been collected and analysed. Non-traumatic brain injury (e.g. stroke, hypoxia) was the main diagnostic group (54.9%, $n=555$), followed by traumatic brain injury (34.9%, $n=353$) and eligible neurologic conditions (10.2%, $n=103$). Mean age at admission was 45.4 years, and 67.5% were male ($n=682$). The cohort demonstrated significant heterogeneity, socially and clinically, with differences between ABI groups across a number of domains.

Future plans: ABI-REStART is a dynamic whole-population cohort that will be updated over time as individuals enrol in the service. Future analyses will assess longitudinal brain injury outcomes, the changing health and social needs of individuals with ABI, and evaluate and inform post-acute services to best support these individuals.

Registration: This cohort is not linked to a clinical trial, and is not registered.

Strengths and Limitations

- ABI-RESTART is the largest Australian post-acute neurorehabilitation and disability support cohort to date with a 29 year follow-up period.
- The combined use of internal clinical and rehabilitation data and linked health data provides a detailed picture of ABI that could not be derived from a single data source, with key measures including functional independence, health status and comorbidities, goal attainment, mental health and well-being, quality of life, and mortality, offering a unique, holistic understanding of the needs and outcomes of individuals with ABI
- The cohort represents a diverse and complex population including individuals with non-traumatic brain injury, traumatic brain injury, and eligible neurologic conditions, providing a diverse range of brain injury experiences.
- The study framework follows each cohort member from pre-injury to long-term follow-up after discharge from post-acute services, with a minimum 10-year lookback period (starting from 1981) and a mean follow-up time of 8.4 years following discharge.
- A state-based data linkage register was used, so pre-admission or post-discharge follow-up data for cohort members based interstate or overseas will not be captured, and all clients were accessing services at a single organisation which may reduce the generalisability of findings.

54 Introduction

55 Acquired brain injury (ABI) is one of the leading causes of death and disability in
56 Australia¹. Defined as any damage to the brain occurring after birth, ABI can be traumatic
57 (caused by extrinsic forces to the head) or non-traumatic (e.g. stroke, drug misuse, tumour,
58 hypoxia/anoxia). Estimates suggest 2% of the population of Western Australia (WA) are
59 living with an ABI². The consequences of ABI are complex and difficult to predict, but often
60 lead to a range of impairments in cognitive, physical and psychosocial functioning¹⁻⁴. ABI
61 can cause long-term physical disability and complex neuro-behavioural effects. These can
62 include neurological impairment (e.g. motor function, sensory loss), medical complications
63 (e.g. spasticity, epilepsy), cognitive impairment (e.g. memory deficits, language impairments,
64 reduced consciousness), personality and behavioural changes (e.g. impaired social skills) and
65 lifestyle consequences (e.g. loss of independence, reduced quality of life)⁵. Up to 75% of
66 brain injuries in Australia occur in adults under 65 years of age³, resulting in difficulties that
67 can impact working ability, social engagement and community integration⁶⁻⁸.

68 Regaining independence and/or meaningful participation in life following an ABI is
69 achievable. Transition back into the community following acute management of ABI in
70 hospital is a critical phase of recovery, and adjustment to the cognitive, physical and
71 behavioural impairments associated with ABI during transition predicts longer-term
72 outcomes and overall recovery from brain injury^{9,10}. Post-acute care is important throughout
73 the transition from acute services, such as hospitalisation, to home or community care, with
74 clients and families often reporting the transition to be difficult and stressful¹⁰. Individuals
75 with inadequate supports risk poorer outcomes including development of a depressive
76 disorder⁹, re-hospitalisation or institutionalisation¹⁰ and reduced likelihood of returning to
77 work⁶.

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3 78 Post-acute care is defined as care occurring after the acute care period, with
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5 79 individuals who have achieved acute recovery, are medically stable, and no longer requiring
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7 80 hospitalisation¹¹. Post-acute care may occur immediately following discharge from hospital
8
9 81 or at any time after the individual has achieved medical stability¹². The focus of post-acute
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11 82 care is on functional improvement and/or to support individuals to achieve meaningful
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13 83 participation in life, as distinct from physiological recovery.
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17 84 Despite the importance of post-acute care for individuals with an ABI, little empirical
18
19 85 evidence is available to enable service planning and policy development for this cohort. A
20
21 86 number of community-based neurorehabilitation cohort studies examining the outcomes of
22
23 87 individuals with ABI after rehabilitation exist in Australia¹³⁻¹⁶. Two of these studies involved
24
25 88 retrospective analysis of client data at discharge from community-based brain injury services
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27 89 in which individualized rehabilitation care was provided. The first study showed that ABI
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29 90 clients (n=63) who received rehabilitation services in Queensland between 2017-2018 had
30
31 91 significantly improved physical outcomes compared with a historical ABI cohort who did not
32
33 92 receive rehabilitation services between 2007-2009 (n=124)¹⁴. The second study, conducted
34
35 93 with 47 ABI clients in South Australia from 2010-2013, demonstrated that outpatient
36
37 94 rehabilitation significantly and immediately improved physical and psychosocial outcomes,
38
39 95 although social wellbeing declined in the follow-up period¹³. Client experiences of
40
41 96 community-based rehabilitation have also been examined, with one study surveying clients (n
42
43 97 = 79) and their families (n = 39) experiences following attendance to a brain injury
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45 98 rehabilitation unit in New South Wales from 2015-2017. This study indicated that person-
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47 99 centred care was critical to an individuals' experience of care across a number of post-acute
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49 100 services¹⁵. While this research has demonstrated the value of community-based rehabilitation,
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51 101 these cohort studies have small sample sizes (<200), and short follow-up times (<3years).
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53 102 Longer-term research examining the experiences of individuals accessing post-acute ABI
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103 services and the effectiveness of different types of post-acute care is required to ensure the
104 best outcomes for individuals.

105 **ABI-REStART**

106 The Acquired Brain Injury Community REhabilitation and Support Services
107 OuTcomes CohoRT (ABI-REStART) is the largest research cohort of people with ABI who
108 received post-acute rehabilitation or support services in Australia to date. The cohort is a
109 whole-population cohort comprising of all individuals who received brain injury services
110 through Brightwater Care Group in WA, from 1991-2020. Brightwater has been a main
111 provider of post-acute community-based disability services for people with acquired brain
112 injury in WA since 1991¹⁷, with the goal to support people to meaningfully '*restart*' their
113 lives in the community after ABI.

114 The ABI-REStART research program uses a unique combination of internal clinical
115 and rehabilitation data and external linked health data collections from the WA Data Linkage
116 System¹⁸. This enables longitudinal examination of the needs and outcomes of individuals
117 with ABI over 29 years, making this the longest follow-up of individuals with ABI
118 undergoing post-acute care in Australia to date¹³⁻¹⁵. The aim of the ABI-REStART research
119 program will focus on understanding the complex health and social needs of people with ABI
120 during post-acute care, and identify predictors of short- and long-term outcomes to facilitate
121 effective service planning and delivery.

122 **Aims**

123 This cohort profile paper aims to: 1) describe the background and formation of ABI-
124 REStART, 2) outline data sources and , key variables, 3) present baseline sociodemographic
125 and clinical characteristics, and 4) outline planned research for the cohort. Future publications
126 will examine the specific outcomes of the cohort.

127

128 Cohort Description

129 Cohort Design and Eligibility

130 ABI-REStART is a retrospective whole-population cohort comprising all clients of
 131 Brightwater Care Group's post-acute brain injury programs and services (excluding respite)
 132 from inception on March 15, 1991 to December 31, 2020 ($n=1,011$). Each individual's entry
 133 date into the cohort represents the date of their index admission (first episode of care) to
 134 Brightwater's community-based brain injury services.

135 The cohort consists of individuals with diverse brain injuries, including traumatic brain
 136 injuries (TBI), non-traumatic brain injuries (NTBI) and eligible neurologic conditions,
 137 defined by the Australian Rehabilitation Outcomes Centre (AROC) impairment codes¹⁹.
 138 Table 1 summarises AROC diagnostic categories for the cohort. NTBI were the leading
 139 diagnostic category in the cohort (54.9%; 555 of 1,011) with stroke (52.6%; 292 of 555)
 140 comprising over half of NTBI diagnoses. TBI accounted for 34.9% of the cohort (353 of
 141 1,011).

142 **Table 1. Brain injury diagnoses and Australasian Rehabilitation Outcomes Centre**
 143 **(AROC) Impairment Codes for the ABI-REStART cohort, 1991-2020**

AROC Code, Category and Diagnosis		n (%)
Non-traumatic (Stroke)		292 (28.9)
1.1	Stroke – Haemorrhagic	81 (8.0)
1.2	Stroke – Ischemic	178 (17.6)
1.0	Stroke – Unspecified	33 (3.3)
Non-traumatic (other - excluding stroke)		263 (26.0)
2.11	Subarachnoid haemorrhage	58 (5.7)
2.12	Anoxic brain damage	78 (7.7)
2.13	Encephalitis	18 (1.8)
	Meningitis	6 (0.6)
	Neoplasm/tumour of brain, meninges or cranial nerves	32 (3.2)
	Intracranial abscess	2 (0.2)
	Hydrocephalus	5 (0.5)
	Toxic encephalopathy	35 (3.5)
	Metabolic encephalopathy	7 (0.7)

	Other non-traumatic brain dysfunction	22 (2.2)
Traumatic		353 (34.9)
2.21	Traumatic, open injury	50 (5.0)
2.22	Traumatic, closed injury	280 (27.7)
2.2	Traumatic, unspecified	23 (2.3)
Neurologic		103 (10.2)
3.1	Multiple sclerosis	16 (1.6)
3.2	Parkinsonism	17 (1.7)
3.3	Polyneuropathy	3 (0.3)
3.4	Guillain-Barré Syndrome	1 (0.1)
3.8	Neuromuscular Disorders	13 (1.3)
3.9	Extrapyramidal and abnormal movement disorders	2 (0.2)
	Spinocerebellar disease	3 (0.3)
	Epilepsy	31 (3.1)
	Other neurologic and neurodegenerative disorders	17 (1.7)

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Each individual's AROC diagnosis represents their primary brain injury diagnosis at index admission to Brightwater, but not necessarily their index brain injury. It is possible for individuals to have had prior brain injuries for which they did not access Brightwater services. Individuals with congenital neurologic conditions (e.g. cerebral palsy, spina bifida) or intellectual disabilities are eligible for services at Brightwater, but were excluded from the cohort. Admissions are accepted any time since injury, most often in the sub-acute (3-12 months post-injury) or chronic phases (>12 months post-injury)^{20,21}.

Cohorts, Setting and Programs

The overall cohort is comprised of four service delivery periods based on year of index admission to services: 1991-2002, 2003-2007, 2008-2013, and 2014-2020. These periods reflect significant change to service delivery programs. Key changes are specified in Table 2.

158 **Table 2. Key changes to programs across four service delivery periods.**

Service Period	Program (start date)	Service Changes
1991-2002	TRP (1991)	1) Commencement of the Transitional Rehabilitation Program on the Oats Street site (24 beds). 2) Inclusion for TRP: a. No more than 1 support worker; b. At least 1 personally-relevant goal; c. Some supportive social network; d. No interfering comorbid health conditions; e. Able to independently complete basic self-care.
	SIL (1998)	3) Commencement of long-stay brain injury accommodation.
2003-2007	TRP	1) Increase in number of TRP beds and program expands to two sites (Oats Street and Marangaroo). 2) Introduction of staged approach to ability-based graduation through houses at Oats Street.
2008-2013	TRP	1) Increase in number of beds to include on-site independent living units for more independent clients. 2) Change in inclusion criteria: a. Reduced restrictions around comorbid health conditions; b. No requirement for self-care ability; c. More than 1 support worker permitted (inclusion of minimally conscious clients).
	TAP (2008)	3) Transitional Accommodation Program introduced.
	HACC SS (2009)	4) HACC Social Support Program introduced.
2014-2020	TRP	1) Increase in number of beds to 43. 2) Transitional Rehabilitation Program reduced to a single site (Oats Street).
	CAPB (2016)	3) Capacity Building Program introduced.
	HACC SS	4) HACC SS clients began transitioning into CAPB program and HACC program closed down.

Note. TRP = Transitional Rehabilitation Program; SIL = Supported Independent Living; TAP = Transitional Accommodation Program; HACC SS = Home and Community Care Social Support; CAPB = Capacity Building

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3 159 Clients are able to be re-referred to Brightwater programs, or transferred between
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5 160 programs, as their goals and abilities change, and therefore can have multiple episodes of
6
7 161 care. However, clients can only be enrolled in a single program at any one time.
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10 162 All programs accept clients between the ages of 18-65 years, however acceptance to
11
12 163 each program is on a case-by-case basis. As such, some individuals outside of those age
13
14 164 ranges have been admitted throughout the duration of the programs. The five different
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16 165 community-based programs are summarized below, ranging from full-time residential
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18 166 neurorehabilitation to casual home-based supports.
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22 167 ***Transitional Rehabilitation Program***

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24 168 Beginning in 1991, the Transitional Rehabilitation Program was Brightwater's first
25
26 169 post-acute service for individuals with ABI and/or eligible neurologic conditions. The
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28 170 program is delivered at the *Oats Street* rehabilitation centre, a purpose-built community-
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30 171 based residential facility. The program is funded by the WA Department of Health and can
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32 172 support up to 43 live-in residents, across 8 group houses and 8 independent living units, plus
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34 173 10 additional home-based clients.
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38 174 The Transitional Rehabilitation Program has a typical duration of 12-24 months, and
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40 175 aims to enable clients to regain the skills to live independently in the community. Clients
41
42 176 participate in evidence-based, person-centred neurorehabilitation that is tailored to their
43
44 177 individual goals, and are supported by an integrated multidisciplinary team of medical and
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46 178 allied health professionals.
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50 179 The Transitional Rehabilitation Program is based on a novel model of care called
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52 180 Staged Community-Based Brain Injury Rehabilitation, whereby post-acute therapy and care
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54 181 services are provided in a stage-based approach to support a client's continued recovery from
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56 182 ABI over time²²⁻²⁴. On admission, clients are allocated to a house with levels of assistance
57
58 183 appropriate for their needs, ranging from 24 hour continuous care to full independence, and
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3 184 graduate through stages with decreasing levels of support as their independence and
4
5 185 functional abilities improve²⁴. The program is able to support all stages of brain injury
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7 186 rehabilitation, from profound physical disability (including those in a minimally conscious
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9 187 state, in which there is reduced consciousness with evidence of environmental awareness²⁵)
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12 188 to higher-level cognitive rehabilitation.
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15 189 ***Supported Independent Living***

16
17 190 Beginning in 1998, Supported Independent Living is a supported accommodation
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19 191 program for individuals with ABI who are funded by the Australian Governments' National
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21 192 Disability Insurance Scheme²⁶ (NDIS; from 2016), or Disability Service Commission (DSC;
22
23 193 prior to 2016), or with private funding, and who require additional supports to carry out
24
25 194 activities of daily living but do not seek neurorehabilitation²⁷. Individuals in this program live
26
27 195 across 8 shared houses for people with disability throughout the Perth metropolitan area.
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31 196 ***Transitional Accommodation Program***

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33 197 The Transitional Accommodation Program commenced in 2008 and is funded by the WA
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35 198 Department of Health as a step down from hospital service²⁸. Referrals must come from a
36
37 199 Perth metropolitan public hospital, and clients receive transitional care and short-term
38
39 200 accommodation while they are supported to seek longer-term accommodation or make
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41 201 adjustments to existing homes. This program operates in a socio-medical model, using short-
42
43 202 term therapy, nursing and care supports to keep clients healthy and medically stable to
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45 203 promote natural recovery but does not involve comprehensive active rehabilitation. Clients in
46
47 204 the program can utilise NDIS funding to engage in activities and have sustainable discharge
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49 205 options. The Transitional Accommodation Program often involves setting up support
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51 206 structures for people with complex disabilities, including nursing and psychosocial
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53 207 complexity.
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208 ***Home and Community Care Social Skills***

209 Commencing in 2009, the Home and Community Care Social Skills program
210 provided support, privately, with Commonwealth Department of Health funding, for social
211 engagement and activities as well as in-home care as required. This program was for
212 individuals with ABI who were at risk of social isolation or needed support around the home
213 to maintain their independence. This program began to be phased out in 2016 when the
214 Capacity Building program began, with no new clients accepted into the program after June
215 2019²⁹.

216 ***Capacity Building***

217 The Capacity Building program was launched in 2016 to replace the Home and
218 Community Care Social Skills program. Capacity Building offers home-based supports to
219 individuals with ABI who have NDIS funding. The supports on offer include specialist
220 neurorehabilitation therapy services, support coordination, equipment and assistive
221 technology, and behavioural assessment and support. Capacity Building clients are able to
222 access services on an ad-hoc basis as determined by the client themselves, and have
223 individually tailored rehabilitation or lifestyle goals that are achieved while living off-site.

224 **Data Sources and Follow-Up Time**

225 Figure 1a summarizes the data sources for ABI-REStART. The research program uses
226 a combination of internal clinical and rehabilitation data, and externally linked data
227 collections from the WA Department of Health. Internal electronic medical records for each
228 cohort member were probabilistically linked through the WA Data Linkage System¹⁸ to four
229 external health data collections. We obtained data on hospitalizations (hospital morbidity data
230 collection; 1981-2020), emergency department (ED) presentations (ED data collection; 2002-
231 2020), deaths (mortality register, 1991-2020) and mental health (mental health information
232 system; 1981-2020). The combination of internal and external data sources allows

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3 233 triangulation of information to ensure higher accuracy, continuity, and completeness than
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5 234 could be derived from a single source.

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7 235 Figure 1b summarizes the ABI-REStART design and follow-up time. The study
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9 236 framework follows each cohort member from pre-injury, acute care, post-acute care and long-
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11 237 term follow-up after discharge from post-acute services. For all cohort members, a minimum
12
13 238 10-year pre-admission lookback period is available to examine pre-injury morbidity patterns
14
15 239 and acute care details. Linked data are obtained up to December 31, 2020, with a mean
16
17 240 follow-up time of 8.4 years (range 0y-29.2y) following discharge from community-based
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19 241 services for each cohort member.
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23 242 **Key Measures, Variables and Outcomes**

24 243 Key outcome measures and variables available for ABI-REStART are summarized in
25
26 244 Table 3. Study variables are primarily derived from clinical and administrative data collected
27
28 245 as part of routine service provision. Key variables span five categories (Admissions,
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30 246 Demographics, Clinical, Rehabilitation, and Psychosocial), offering a unique, holistic
31
32 247 understanding of the needs and outcomes of individuals with ABI. Outcomes for each cohort
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34 248 member include functional independence, health status and comorbidities, goal attainment,
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36 249 mental health and well-being, quality of life, and mortality.
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251 **Table 3. Data sources, key measures and variables available for the ABI-REStART study**

	Date	Data Source/Type	Description	Key Variables
	1991 - 2020	Admissions	<ul style="list-style-type: none"> Admission & discharge date Facility Programs Referral source 	<ul style="list-style-type: none"> Time since injury to admission Admission source Admission program Admission and discharge dates Age at admission
	1991 - 2020	Demographics	<ul style="list-style-type: none"> Demographics Social background 	<ul style="list-style-type: none"> Age at injury Gender Indigenous status Country of birth Usual occupation SEIFA IRSD³⁰ ASGS Remoteness Area³¹
	1991 - 2020	Clinical	<ul style="list-style-type: none"> Diagnoses Vital signs / observations Medications Investigations (pathology, radiology) Medical & allied health consultation notes Medical correspondence and referrals 	<ul style="list-style-type: none"> ABI type (TBI, NTBI, neurologic) Injury location (unilateral, bilateral) Cause of injury Severity (Glasgow Coma Scale ³², post-traumatic amnesia, loss of consciousness) Injury phase (acute, subacute, chronic)
	1991 - 2020	Rehabilitation	<ul style="list-style-type: none"> Australasian Rehabilitation Outcomes Centre (AROC) Impairment Code Outcome measures 	<ul style="list-style-type: none"> FIM+FAM³³ MPAI-4³⁴ GAS³⁵ RCS³⁶
	1991 - 2020	Psychosocial	<ul style="list-style-type: none"> Mental health Quality of life Behavioural Well-being 	<ul style="list-style-type: none"> QOLIBRI^{37,38} NPTDA³⁹ NPDS⁴⁰
EXTERNAL	1981 - 2020	Hospital (HMDC)	<ul style="list-style-type: none"> Hospital admissions and separations for all public and private hospitals in WA 	<ul style="list-style-type: none"> Comorbidities Comorbidity severity Surgical procedures Health service use patterns
	2002 - 2020	Emergency department (EDDC)	<ul style="list-style-type: none"> ED presentations at all public and private hospitals in WA 	
	1981 - 2020	Mental health (MHIS)	<ul style="list-style-type: none"> Inpatient and outpatient community mental health presentations 	
	1991 - 2020	Deaths	<ul style="list-style-type: none"> All deaths occurring in WA 	<ul style="list-style-type: none"> Cause of death Time to death

Note: SEIFA IRSD = Socio-Economic Indexes for Areas Index of Relative Socioeconomic Disadvantage; ASGS = Australian Statistical Geography Standard; FIM+FAM = Functional Independence Measure + Functional Assessment Measure; MPAI-4 = Mayo-Portland Adaptability Inventory; GAS = Goal Attainment Scale; RCS = Rehabilitation Complexity Scale; QOLIBRI = Quality of Life After Brain Injury; NPTDA = Northwick Park Therapy Dependency Assessment; NPDS = Northwick Park Dependency Score

252

253 Table 4 outlines the availability of key outcome measures data for the cohort. As the
 254 cohort is a retrospective pragmatic cohort, available outcome measures data for each client
 255 differs depending on the service period, the outcome measures used at the time, and the
 256 program the client was admitted to. Comprehensive outcome measures were introduced
 257 across services in 2011, therefore, only a subset of the cohort have complete outcome measures.

258 **Table 4. Key ABI-REStART outcome measures and data availability, 1991-2020**
 259 **(n=1,011)**

Key Outcome Measures and Data	Years Available	Clients with data		
		Total number, n	Of total cohort, %	Over years available, %
Internal Data				
Functional Independence Measure and Functional Assessment Measure (FIM+FAM) ³³	2011–2020	383	37.9	57.0
Mayo-Portland Adaptability Inventory-4 (MPAI-4) ³⁴	2011–2020	468	46.3	69.6
Goal Attainment Scale (GAS) ³⁵	2011–2020	362	35.8	53.8
Quality of Life After Brain Injury Inventory (QoLIBRI) ³⁸	2015–2020	94	9.3	19.0
Northwick Park Dependency Score (NPDS) ⁴⁰	2011–2020	405	40.1	60.3
Northwick Park Care Needs Assessment (NCPNA) ³⁹	2011–2020	405	40.1	(60.3
Rehabilitation Complexity Scale (RCS) ³⁶	2012–2020	354	35.0	56.9
External Data				
Hospital admissions				
Pre-admission	1981–2020	1,011	100	-
Post-discharge (follow-up)	1991–2020	829	81.9	-
Emergency department presentations				
Pre-admission	2002–2020	692	68.4	-
Post-discharge (follow-up)	2002–2020	342	33.8	-
Mental health information system	1981–2020	TBD	-	-
Death	1991–2020	TBD	-	-

260 *Note.* TBD = To be determined. Mental health data not yet received. Updated death data not yet received.

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264 **Data Extraction, Storage and Security**

265 Clinical records for active and historic ABI clients are stored within a secure internal
266 clinical application (iCare). This data can only be accessed by users with appropriate security
267 clearance, such as the researchers involved on the project, and relevant clinical and
268 administrative staff. Archived historic client data is retained by the organisation and used for
269 service evaluation and research purposes as needed.

270 Researchers extracted demographic, clinical and outcome measures data for the ABI-
271 RESTART members from the iCare data warehouse using structured query language (SQL).
272 Linked hospital and ED data were used to validate clinical diagnosis details, date of injury
273 and cause of injury. For historic clients, researchers manually extracted admissions,
274 demographic, clinical and outcome measures data from scanned documents (PDF) uploaded
275 into the client's clinical records. Researchers created a master ABI-RESTART database
276 specifically for this study. This database is stored on a secure internal network drive which
277 can only be accessed by the study investigators.

278 **Ethics**

279 Clients provided consent for their de-identified information to be used for research
280 purposes as part of the conditions of service upon admission. Ethics approval for this research
281 was granted by the University of Western Australia Human Research Ethics Committee
282 (RA/4/1/9232) and the West Australian Department of Health Human Research Ethics
283 Committee (RGS0000002894).

284 **Statistical Analysis**

285 Extraction and analysis of baseline data was completed in February 2021. Basic
286 demographic and brain injury characteristics at index admission are presented in the current
287 cohort profile. Subsequent research will examine the health status, service use, and outcomes
288 of the cohort in detail.

289 Baseline data were analysed using STATA 16.0⁴¹. Primary analyses were tested
 290 against an alpha level of 0.05 (uncorrected, two-tailed). Descriptive statistics were calculated
 291 and presented as mean \pm standard deviation, or count (percentage). Independent samples t-
 292 tests, two-way ANOVAs and χ^2 analyses were used to compare differences in continuous and
 293 categorical outcomes, respectively. Bonferroni correction was used for multiple comparisons.

294 **Patient and public involvement**

295 Patients or public were not involved in the development of the research question and
 296 project design or conducting the present study.

297 **Findings to date**

298 **Sociodemographic Characteristics**

299 Table 5 summarizes the baseline sociodemographic characteristics of ABI-REStART.
 300 Mean age at admission was 45.4 ± 15.5 years (range: 14.9y–93.2y), with 6.2% aged over 65
 301 (n=63). Male clients (67.5%) outnumbered female clients (32.5%). The relatively young age
 302 and predominantly male cohort is consistent with other profiles of individuals seeking ABI
 303 services^{13–15}. The majority of the cohort was born in Australia (64.7%), with 3.4% of clients
 304 of Indigenous and/or Torres Strait Islander background. Most of the cohort lived in a major
 305 city (84.3%) and were between *average disadvantage* and *least disadvantaged* levels of the
 306 Socio-Economic Index for Areas Index of Relative Socioeconomic Disadvantage (SEIFA
 307 IRSD) before admission (76.5%).

308 **Table 5. Sociodemographic characteristics for the ABI-REStART cohort at index**
 309 **admission to post-acute community-based brain injury support programs, 1991-2020**
 310 **(n=1,011)**

Characteristics	Total, n=1,011	1991-2002, n=231	2003-2007, n=145	2008-2013, n=220	2014-2020, n=415
Sex, n (%)					

Cohort Profile: ABI-REStART, 1991-2020

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Male	682 (67.5)	150 (64.9)	108 (74.5)	156 (70.9)	268 (64.6)
Female	329 (32.5)	81 (35.1)	37 (25.5)	64 (29.1)	147 (35.4)
Age at admission, mean \pm SD					
Total	45.4 \pm 15.5	44.1 \pm 21.5	39.5 \pm 12.5	44.2 \pm 12.8	48.8 \pm 12.9
Male	44.2 \pm 14.6	39.8 \pm 18.0	39.9 \pm 12.8	44.7 \pm 12.3	48.0 \pm 13.3
Female	47.9 \pm 17.1	51.9 \pm 25.0	38.3 \pm 11.6	43.0 \pm 13.9	50.2 \pm 12.1
Age category at admission, n (%)					
<18 years	15 (1.5)	8 (3.5)	3 (2.1)	-	4 (1.0)
18-29	190 (18.8)	66 (28.6)	36 (24.8)	40 (18.2)	48 (11.6)
30-39	161 (15.9)	46 (19.9)	32 (22.1)	34 (15.5)	49 (11.8)
40-49	223 (22.1)	43 (18.6)	43 (29.7)	54 (24.6)	83 (20.0)
50-59	274 (27.1)	19 (8.2)	26 (17.9)	78 (35.5)	151 (36.4)
60-69	102 (10.1)	7 (3.0)	5 (3.5)	14 (6.4)	76 (18.3)
\geq 70 years	46 (4.6)	42 (18.2)	-	-	4 (1.0)
Indigenous, n (%)					
Total	34 (3.4)	2 (0.9)	-	13 (5.9)	19 (4.6)
Male	24 (70.6)	1 (0.5)	-	11 (84.6)	12 (63.2)
Female	10 (29.4)	1 (0.5)	-	2 (15.4)	7 (36.8)
Mean age \pm SD	38.8 \pm 13.6	31.0 \pm 0.8	-	40.0 \pm 15.2	38.8 \pm 13.4
Marital Status, n (%)					
Single	444 (43.9)	101 (43.7)	76 (52.4)	99 (45.0)	168 (40.5)
De Facto	38 (3.8)	3 (1.3)	2 (1.4)	12 (5.5)	21 (5.1)
Married	253 (25.0)	73 (31.6)	30 (20.7)	50 (22.7)	100 (24.1)
Separated	59 (5.8)	13 (5.6)	10 (6.9)	12 (5.5)	24 (5.8)
Divorced	133 (13.2)	14 (6.1)	20 (13.8)	35 (15.9)	64 (15.4)
Widowed	30 (3.0)	16 (6.9)	1 (0.7)	3 (1.4)	10 (2.4)
Unknown	54 (5.3)	11 (4.8)	6 (4.1)	9 (4.1)	28 (6.8)
Country of Birth, n (%)					
Australia (and external territories)	654 (64.7)	162 (70.1)	98 (67.6)	120 (54.6)	274 (66.0)
New Zealand	31 (3.1)	9 (3.9)	5 (3.5)	5 (2.3)	12 (2.9)
Maritime South-East Asia	27 (2.7)	3 (1.3)	1 (0.7)	6 (2.7)	17 (4.1)
Mainland South-East Asia	13 (1.3)	3 (1.3)	2 (1.4)	2 (0.9)	6 (1.5)
Southern Asia	11 (1.1)	-	-	3 (1.4)	8 (1.9)
Chinese Asia	9 (0.9)	2 (0.9)	-	2 (0.9)	5 (1.2)
Southern and East Africa	18 (1.8)	-	2 (1.4)	3 (1.4)	13 (3.1)
The United Kingdom	84 (8.3)	28 (12.1)	12 (8.3)	14 (6.4)	30 (7.2)
Western Europe	11 (1.1)	2 (0.9)	1 (0.7)	4 (1.8)	4 (1.0)
Southern Europe	11 (1.1)	2 (0.9)	-	3 (1.4)	6 (1.5)
Other	44 (4.4)	7 (3.0)	4 (2.8)	9 (4.1)	24 (5.8)
Unknown	98 (9.7)	13 (5.6)	20 (13.8)	49 (22.3)	16 (3.9)
Usual Occupation, n (%)					
Managers	26 (2.6)	1 (0.4)	4 (2.8)	9 (4.1)	12 (3.0)
Professionals	49 (4.9)	5 (2.2)	3 (2.1)	11 (5.0)	30 (7.2)
Technicians and Trades Workers	80 (7.9)	3 (1.3)	9 (6.2)	24 (10.9)	44 (10.6)
Community and Personal Service Workers	34 (3.4)	2 (0.9)	6 (4.1)	8 (3.6)	18 (4.3)
Clerical or Administrative Workers	20 (2.0)	1 (0.4)	2 (1.4)	5 (2.3)	12 (2.9)
Sales Workers	10 (1.0)	-	1 (0.7)	-	9 (2.2)

Cohort Profile: ABI-REStART, 1991-2020

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Machinery Operators and Drivers	31 (3.1)	4 (1.7)	2 (1.4)	10 (4.6)	15 (3.6)
Labourers	48 (4.8)	5 (2.2)	6 (4.1)	12 (5.5)	25 (6.0)
Not in workforce	206 (20.4)	7 (3.0)	15 (10.3)	42 (19.1)	142 (34.22)
Unknown	507 (50.2)	203 (87.9)	97 (66.9)	99 (45.0)	108 (26.0)
Accommodation Type, n (%)					
Private Residence	318 (31.5)	7 (3.0)	31 (21.4)	74 (33.6)	206 (49.6)
Public Rental	56 (5.5)	4 (1.7)	1 (0.7)	20 (9.1)	31 (7.5)
Family Home	40 (4.0)	3 (1.3)	11 (7.6)	1 (0.5)	11 (2.7)
Supported Accommodation	19 (1.9)	-	-	1 (0.5)	18 (4.3)
Residential Aged Care	9 (0.7)	-	-	1 (0.5)	6 (1.5)
Temporary Housing	15 (1.5)	-	-	1 (0.5)	14 (3.4)
Crisis Accommodation	5 (0.5)	-	-	1 (0.5)	4 (1.0)
Hospital	3 (0.3)	-	-	-	3 (0.7)
Institutional care	2 (0.2)	-	-	-	2 (0.5)
No fixed address	20 (2.0)	-	3 (2.1)	6 (2.7)	11 (2.7)
Unknown	526 (52.0)	217 (94.9)	99 (68.3)	101 (45.9)	109 (26.3)
ASGS – Remoteness Area, n (%)					
Major city	814 (84.3)	179 (77.5)	113 (77.9)	167 (75.9)	355 (85.5)
Inner regional	57 (5.9)	12 (5.2)	10 (6.9)	19 (8.6)	16 (3.9)
Outer regional	45 (4.7)	16 (6.9)	13 (9.0)	9 (4.1)	7 (1.7)
Remote	28 (2.9)	6 (2.6)	1 (0.7)	11 (5.0)	10 (2.4)
Very Remote	14 (1.5)	7 (3.0)	1 (0.7)	1 (0.5)	5 (1.2)
Migratory & Offshore	8 (0.8)	6 (2.6)	2 (1.4)	0	0
Missing	45 (4.5)	5 (2.2)	5 (3.5)	13 (5.9)	22 (5.3)
SEIFA – Index of Relative Social Disadvantage, n (%)					
Q1 – Most disadvantaged	141 (14.0)	61 (26.4)	37 (25.5)	18 (8.2)	25 (6.0)
Q2 – More disadvantaged	83 (8.2)	6 (2.6)	10 (6.9)	25 (11.4)	42 (10.1)
Q3 – Average	216 (21.4)	22 (9.5)	19 (13.1)	68 (30.9)	107 (25.8)
Q4 – Less disadvantaged	291 (28.8)	68 (29.4)	41 (28.3)	53 (24.1)	129 (31.1)
Q5 – Least disadvantaged	224 (22.2)	63 (27.3)	28 (19.3)	43 (19.6)	90 (21.7)
Missing	56 (5.5)	11 (4.8)	10 (6.9)	13 (5.9)	22 (5.3)

Note. ASGS = Australian Statistical Geography Standard; SEIFA = Socio-Economic Index for Areas.

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313 **Brain Injury Characteristics**

314 Table 6 summarizes brain injury characteristics for the cohort. There were significant
 315 differences in gender composition of the diagnostic groups ($p < 0.001$), with more male than
 316 female clients with TBI and stroke. Gender differences were smaller in the other NTBI and
 317 neurologic groups.

318 **Table 6. Brain injury and admission characteristics for the ABI-REStART cohort at**
 319 **index admission to community-based brain injury services, 1991-2020 (n=1,011)**

Characteristics	Total, n = 1,011	Traumatic, n=353	Non-traumatic		Neurologic, N=103
			Stroke, n=292	Other NTBI, n=263	
<i>Sociodemographic</i>					
Age at injury, mean \pm SD (years)	42.3 \pm 16.5, n=853	33.4 \pm 14.9, n= 303	51.0 \pm 13.4, n=265	43.0 \pm 15.0, n=226	46.8 \pm 18.9, n=59
Gender, n (%)					
Male	682 (67.5)	283 (80.2)	197 (67.5)	142 (54.0)	60 (58.3)
Female	329 (32.5)	70 (19.8)	95 (32.5)	121 (46.0)	43 (41.8)
Indigenous, n (%)					
Total	34 (3.4)	16 (4.5)	10 (3.4)	5 (1.9)	3 (2.9)
Male	24 (3.5)	13 (4.6)	8 (4.1)	2 (1.4)	1 (1.7)
Female	10 (3.0)	3 (4.3)	2 (2.1)	3 (2.5)	2 (4.7)
<i>Clinical</i>					
Injury location, n (%)					
Right	114 (11.3)	24 (6.8)	76 (26.0)	13 (4.9)	1 (1.0)
Left	145 (14.3)	38 (10.8)	97 (33.2)	10 (3.8)	-
Unilateral – side unspecified	101 (10.0)	42 (11.9)	40 (13.7)	19 (7.2)	-
Bilateral	595 (58.9)	220 (62.3)	64 (21.9)	211 (80.2)	100 (97.1)
Unknown	56 (5.5)	29 (8.2)	15 (5.1)	10 (3.8)	2 (1.9)
Length of acute hospital stay, mean \pm SD (months)	6.0 \pm 4.8, n=740	7.0 \pm 5.3, n=273	5.1 \pm 3.5, n=236	5.9 \pm 4.9, n= 206	4.8 \pm 6.7, n= 25
Previous ABI, n (%)	76 (7.5)	15 (4.3)	41 (14.0)	19 (7.2)	1 (1.0)
Injury phase, n (%)					
Acute (>3 months)	56 (6.0)	12 (3.5)	21 (7.5)	20 (8.3)	3 (4.1)
Subacute (3 – 12 months)	410 (43.7)	134 (39.2)	158 (56.2)	109 (45.0)	9 (12.3)
Chronic (> 12 months)	472 (50.3)	196 (57.3)	102 (36.3)	113 (46.7)	61 (83.6)
<i>Admission</i>					
Age at admission, mean \pm SD (years)	45.4 \pm 15.5	37.8 \pm 14.5	52.6 \pm 13.2	45.4 \pm 14.5	50.9 \pm 15.8
Time post-injury, n (%)					
< 1 year	466 (49.7)	146 (42.7)	179 (63.7)	129 (53.3)	12 (16.4)
1 – 2 years	161 (17.2)	68 (19.9)	48 (17.1)	40 (16.5)	5 (6.9)
> 2 years	311 (31.1)	128 (37.4)	54 (19.2)	73 (30.2)	56 (76.7)
Program, n (%)					
TRP	546 (54.0)	232 (65.7)	168 (57.5)	140 (53.2)	17 (16.5)
TAP	121 (12.0)	36 (10.2)	28 (9.6)	41 (15.6)	16 (15.5)
CAPB	107 (10.6)	32 (9.1)	24 (8.2)	30 (11.4)	21 (20.4)
HACC Social Support	70 (6.9)	25 (7.1)	26 (8.9)	14 (5.3)	5 (4.9)

SIL	167 (16.5)	39 (11.1)	46 (15.8)	38 (14.5)	44 (42.3)
Admitted from, n (%)					
Home	435 (43.0)	165 (46.7)	120 (41.1)	96 (36.5)	54 (52.4)
Hospital	437 (43.2)	139 (39.4)	140 (48.0)	136 (51.7)	22 (21.4)
Other	22 (2.2)	8 (2.3)	5 (1.7)	9 (3.4)	-
Unknown	117 (11.6)	41 (11.6)	27 (9.3)	22 (8.4)	27 (26.2)

Note. TRP = Transitional Rehabilitation Program; TAP = Transitional Accommodation Program; CAPB = Capacity Building; HACC = Home and Community Care; SIL = Supported Independent Living

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321 Significant differences in age at admission and ABI type ($p < .001$) were also present.

322 Clients with TBI were significantly younger than those in all other ABI groups at admission

323 (largest corrected $p < 0.001$), which is consistent with prior literature. Those presenting with

324 stroke and neurological conditions were significantly older than those with other NTBI

325 (largest corrected $p < .006$), likely reflecting increasing age-related stroke risk^{42,43}.

326 *Clinical Characteristics*

327 Clients with neurologic conditions or TBI primarily entered post-acute rehabilitation

328 in the chronic injury phase, whereas most clients with stroke entered services during the sub-

329 acute phase. This may be related to longer hospital admissions for TBI clients, but may also

330 demonstrate the benefits of specialized stroke services in managing acute stroke⁴⁴, quickly

331 directing people to rehabilitation. Bilateral injuries (58.9%) were the most common overall,

332 and for TBI (62.3%), other NTBI (80.2%) and neurologic condition groups (97.1%). The

333 majority of strokes were unilateral (72.9%), with left hemispheric more common than right

334 hemispheric stroke. Seventy-six clients had another brain injury prior to their admission

335 injury (7.5%). Individuals with a stroke diagnosis represented 54.0% of those clients (41 of

336 76). The presence of these individuals with prior injuries is consistent with evidence that

337 recurrent TBI is associated with increased disability⁴⁵, and prior stroke is a significant risk

338 factor of recurrent stroke⁴⁶.

339 The median length of acute hospital stay for the cohort was 5.0 months (IQR 2.8mo-

340 8.0mo), with TBI clients having significantly longer acute stays (largest corrected $p < 0.001$).

341 Although it is not clear why this was the case, evidence suggests that accompanying injuries

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3 342 and complications are associated with longer hospital stays for patients with TBI⁴⁷. However,
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5 343 rehabilitation appears to be effective in improving independence despite longer periods
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7 344 between injury and rehabilitation admission⁴⁸.
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10 345 ***Cause of Injury***

11 346 External causes of injury – defined as environmental events, circumstances or
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13 347 conditions that are external to the body – are shown in Table 7. Internal causes (e.g. medical
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15 348 conditions) are not included. Half of the cohort sustained their ABI due to an external cause
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17 349 (50.6%, 512 of 1,011). Accidents were the leading external cause of injury (60.2%; 308 of
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19 350 512), with motor vehicle accidents (MVA; 33.6%) the most common accident type. Clients
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21 351 aged below 30 were most likely to have sustained an ABI due to motor vehicle accidents (77
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23 352 of 172, 44.8%), with a median age of 23.7 years (IQR 19.1y-37.7y), whereas clients aged
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25 353 from 40-60 were most likely to have been injured in accidental falls (35 of 61, 57.4%),
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27 354 corrected $p < 0.001$. Abnormal reaction during surgical or medical procedure was the leading
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29 355 external cause of stroke (82.4%), while poisoning and toxic effect of substances was the
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31 356 leading external cause of other NTBI (48.6%).
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Table 7. Known external causes of brain injury for the ABI-REStART cohort (n=1,011)

Cause of ABI, n (%)	Total, n=1,011	Traumatic, n = 353	Non-traumatic		Neurologic, n=103
			Stroke, n=292	Other NTBI, n=263	
<i>Individuals with known external causes of injury</i>	512 (50.6)	347 (98.3)	51 (17.5)	111 (42.2)	4 (3.9)
Accidents					
Accidental fall	61 (11.9)	58 (16.7)	1 (2.0)	2 (1.8)	-
Motor vehicle accident (incl. pedestrian)	172 (33.6)	167 (48.1)	-	4 (3.6)	1 (33.3)
Motorbike accident	29 (5.7)	29 (8.4)	-	-	-
Cycling accident	14 (2.7)	13 (3.8)	-	1 (0.9)	-
Quad bike accident	4 (0.8)	4 (1.2)	-	-	-
Railway accident	3 (0.6)	3 (0.9)	-	-	-
Drowning and submersion	3 (0.6)	1 (0.3)	-	2 (1.8)	-
Other accident	12 (2.3)	9 (2.6)	1 (2.0)	2 (1.8)	-
Unspecified accident	10 (1.9)	8 (2.3)	-	2 (1.8)	-
Poisoning and toxic effect of drugs, medicaments, or gases					
Accidental overdose	12 (2.3)	-	1 (2.0)	11 (9.9)	-
Intentional overdose	19 (3.7)	-	1 (2.0)	18 (16.2)	-
Unknown intent	9 (1.8)	-	-	9 (8.1)	-
Complication of chronic substance use	20 (3.9)	-	3 (3.9)	16 (14.4)	1 (33.3)
Intentional self-harm (excl. poisoning)					
Hanging or strangulation	4 (0.8)	-	-	4 (3.6)	-
Jumping from high place, or in front of moving object	7 (1.4)	7 (2.0)	-	-	-
Drowning	1 (0.2)	-	-	1 (0.9)	-
Unspecified suicide	2 (0.4)	1 (0.3)	-	1 (0.9)	-
Complications of medical and surgical care					
Abnormal reaction during surgical or medical procedure	78 (15.2)	2 (0.6)	42 (82.4)	33 (29.7)	1 (33.3)
Adverse effects of drugs, medicaments and biological substances during therapeutic use	2 (0.4)	-	1 (2.0)	1 (0.9)	-
Assault	50 (9.8)	45 (13.0)	1 (2.0)	4 (3.6)	-
<i>Individuals with known internal or unknown causes</i>	499 (49.4)	6 (1.7)	241 (82.5)	152 (57.8)	99 (96.1)

Note. Percentages for each group were calculated using the number of individuals with known external causes of injury recorded as the denominator.

Individuals with known internal or unknown causes were not included in the count.

Cohort Profile: ABI-REStART, 1991-2020

Admission Characteristics

The majority of TBI (65.4%), stroke (63.7%) and other NTBI (54.8%) clients were admitted for post-acute transitional rehabilitation. The majority of neurologic clients were admitted to Supported Independent Living (43.7%).

Median time from injury to admission to community-based services was 10.5 months (IQR 5.7mo-27.1mo). Clients with neurologic conditions took significantly longer to access services than other ABI groups (largest corrected $p < 0.001$). Those in the stroke group accessed services significantly faster than the TBI group ($p < 0.001$) but did not differ from the other NTBI group ($p = 0.40$).

Similar numbers of clients were admitted from hospital and home. There were significant differences in ABI group and admission source ($p = 0.001$), with 71.1% of individuals with neurologic conditions admitted from home, 52.9% of the TBI group, 45.3% of the stroke group, and 39.8% of the other NTBI group. The overrepresentation of individuals with neurological injury in admissions from home is likely the result of slow onset of neurological injuries relative to acute injuries like stroke or TBI.

Future Directions

The main focus of the ABI-REStART research program is to measure the short- and long-term outcomes of cohort members following discharge from post-acute services. The heterogeneity of the cohort, and the scope and quantity of longitudinal health data available provides a unique opportunity to identify the predictors of outcomes. Findings will enable greater understanding of personal and structural factors influencing outcomes, providing valuable evidence for clinicians to generate effective, personalized post-acute programs.

To ensure that change over time can be examined into the future, the cohort will be periodically updated with new admissions to allow a dynamic cohort of individuals to be followed through changing services over time, a possibility not seen in previous cohorts of this type.

Health comorbidities of the cohort will also be examined to understand the complex needs of people with ABI and facilitate effective person-centred care. Comorbidities—i.e. chronic condition(s) co-existing

Cohort Profile: ABI-REStART, 1991-2020

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with an index disease⁴⁹—are common following ABI. Complex or mismanaged comorbidity can affect the course and outcome of rehabilitation and result in poorer functional outcomes, longer stay, and higher use and costs of healthcare services^{50–52}. Better understanding of comorbidities can support a focus on the whole person, not only neurologic recovery, which is critical for effective community re-integration.

Mental health disorders are common for those with ABI^{52,53}. Individuals with mental health comorbidities present before or after ABI have poorer outcomes than those without^{52,54}. Prior research using a retrospective convenience sample of 263 ABI-REStART members admitted to the service from 2009 - 2018 found that mental health comorbidities were present in 55.8% of the sample ($n=106$), representing the most common comorbidity⁵⁵. ABI-REStART provides the opportunity to examine the prevalence of mental illness, specific mental health needs, and its impact on rehabilitation outcomes to inform policy and services for mental health and ABI.

Strengths and Limitations

ABI-REStART is the largest post-acute community-based ABI cohort in Australia. The research design provides novel opportunities to examine the longitudinal needs of people living with ABI, and to evaluate the efficacy of post-acute rehabilitation and support programs offered. The demographic and outcomes data at Brightwater has been collected over 29 years, which will allow the effects of policy and treatment changes over time to be examined. The use of both internal clinical data and linked health data produces a detailed picture of brain injury that is more complex than could be derived from a single source, allowing complex questions around the nature of ABI and the individualized client requirements to be examined.

As ABI-REStART is comprised of individuals from a single organization, this population differs from the ABI population in Western Australia in some ways. The cohort is relatively young, with only 6.2% of clients aged 65 years or above. This underrepresentation reduces the conclusions that can be drawn from this cohort around older adults. Similarly, only 3.4% of the cohort were of Aboriginal or Torres Strait

Cohort Profile: ABI-REStART, 1991-2020

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Islander background despite Indigenous Australians being overrepresented in TBI cases in Western Australia^{2,56} and having elevated stroke risk relative to non-Indigenous Australians^{57,58}. Research is needed to examine the factors impacting the engagement of Indigenous Australians with post-acute services. Finally, the use of a State-based data linkage register has limitations, as pre-admission or post-discharge follow-up data for cohort members based interstate or overseas will not be captured in the WA Data Linkage System data collections, and it is not possible to distinguish these cases from individuals who remained in WA but did not access services captured by data linkage systems.

Collaboration

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Researchers interested in collaborating on cohort analyses should contact the corresponding author to express their interest. Initial planned data analyses and publications will be conducted by the primary ABI-REStART study investigators; however the research team is open to potential collaboration on future analyses. Access to the data is only possible with express permission of the University of Western Australia and West Australian Department of Health Human Research Ethics Committees and data custodians, and may require a data sharing agreement. Analysis of linked data is currently authorised to occur at only one location in Perth, Western Australia, owing to ethical considerations.

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Competing interests

None declared.

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Cohort Profile: ABI-REStART, 1991-2020

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Author Contribution

GM performed the data collection, wrote the statistical analysis plan, analysed the data and drafted and revised the paper. **LT** designed and supervised the study, provided analytical input, and drafted and revised the paper. **JW** provided clinical and service input, and revised the draft paper. **AM** designed and led the study, obtained linked data and revised the draft paper.

Data sharing statement

Data may be made available upon reasonable request. Access to the data is only possible with express permission of the WA Department of Health Human Research Ethics Committees and data custodians, and may require a data sharing agreement. Analysis of linked data is currently authorised to occur at only one location in Perth, Western Australia, owing to ethical considerations.

Cohort Profile: ABI-REStART, 1991-2020

Figure 1. Data Sources and Study Design for the ABI-REStART Study, 1991-2020. (a) Internal and External Data Sources and, (b) Study Design

For peer review only

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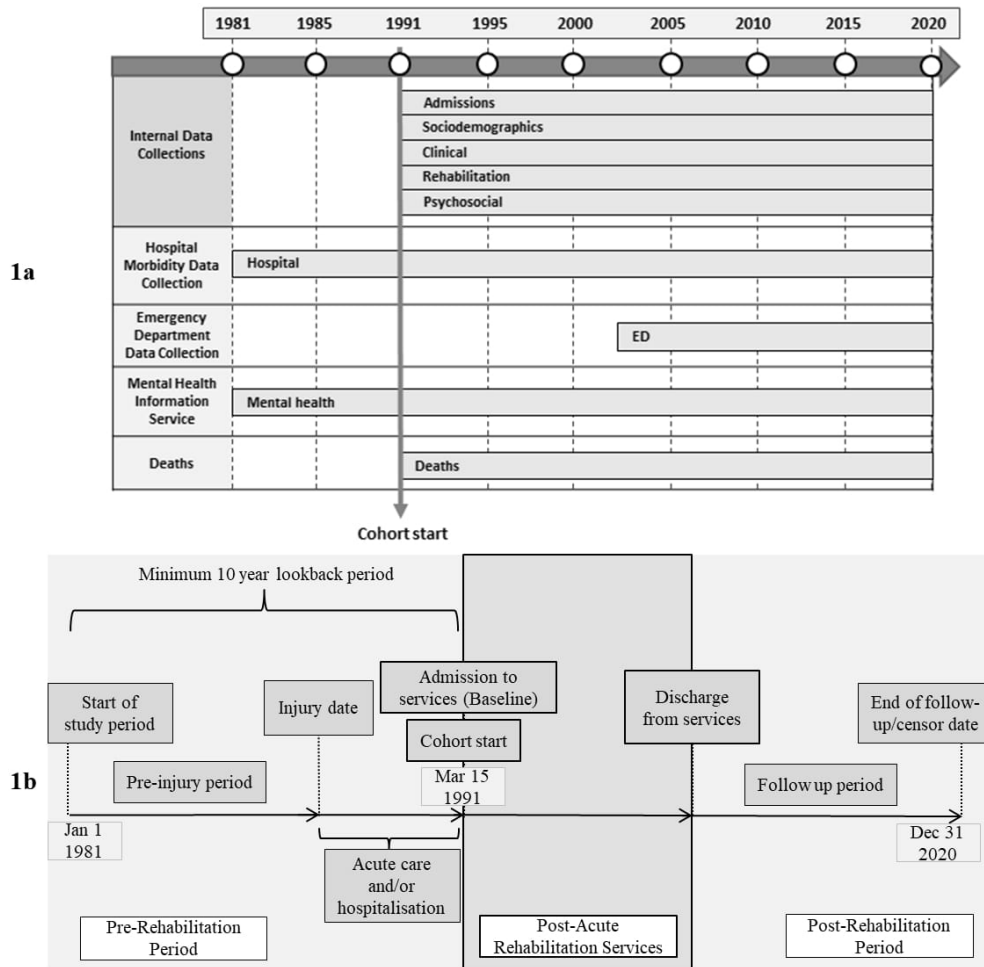


Figure 1. Data Sources and Study Design for the ABI-REStART Study, 1991-2020. (a) Internal and External Data Sources and, (b) Study Design

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STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation	Page No
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found	1,2 2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6-8
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up (b) For matched studies, give matching criteria and number of exposed and unexposed	8,9 n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Table 1
Bias	9	Describe any efforts to address potential sources of bias	n/a
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9,10
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, explain how loss to follow-up was addressed (e) Describe any sensitivity analyses	10
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	6 n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	10-13 Tables 2,4,5 9
Outcome data	15*	Report numbers of outcome events or summary measures over time	n/a

1	Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
2			(b) Report category boundaries when continuous variables were categorized	Table 4
3			(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
4	Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a
5	Discussion			
6	Key results	18	Summarise key results with reference to study objectives	n/a
7	Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	14
8	Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	14
9	Generalisability	21	Discuss the generalisability (external validity) of the study results	n/a
10	Other information			
11	Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	15

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.