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# The Australian and New Zealand brain injury lifespan cohort protocol: Leveraging common data elements to characterise longitudinal outcome and recovery

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## ABSTRACT

**Introduction** Cognitive, behavioural, academic, mental health and social impairments are common following paediatric traumatic brain injury (TBI). However, studies are often reliant on small samples of children drawn from narrow age bands, and employ highly variable methodologies, which make it challenging to generalise existing research findings and understand the lifetime history of TBI.

**Method and analysis** This study will synthesise common data sets from national (Victoria, New South Wales, Queensland) and international (New Zealand) collaborators, such that common data elements from multiple cohorts recruited from these four sites will be extracted and harmonised. Participant-level harmonised data will then be pooled to create a single integrated data set of participants including common cognitive, social, academic and mental health outcome variables. The large sample size (n=1816), consisting of participants with mild, moderate and severe TBI, will provide statistical power to answer important questions that cannot be addressed by small, individual cohorts. Complex statistical modelling, such as generalised estimation equation, multilevel and latent growth models, will be conducted.

**Ethics and dissemination** Ethics approval was granted by the Human Research Ethics Committee (HREC) of the Royal Children's Hospital (RCH), Melbourne (HREC Reference Number 2019.168). The approved study protocol will be used for all study-related procedures. Findings will be translated into clinical practice, inform policy decisions, guide the appropriate allocation of limited healthcare resources and support the implementation of individualised care.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The process of data harmonisation allows for integration of information across multiple data sets, increasing the integrity and utility of findings.
⇒ Pooling of data sets will provide opportunities for research to be conducted more rapidly and at a lower cost, increasing capacity for translation of findings into clinical practice.
⇒ The harmonisation and pooling of data sets will allow for a larger sample size and the possibility to answer questions not possible with smaller data sets.
⇒ Harmonisation and pooling require time-consuming data management and analysis. Furthermore, the literature to guide and support these processes is limited.

## INTRODUCTION

TBI, which comprises mild, moderate and severe levels of injury, represents a significant, worldwide public health issue with an estimated 69 million people affected per year.[1] For a TBI sustained in adulthood, the lifetime costs can be substantial, with estimates per individual at levels up to $5 million for more severe injuries.[2] No such estimates are available for childhood TBI. Given the risk of greater impairment with injury to the immature brain, it is reasonable to assume that lifetime costs (60 years+ if injured as a preschooler), are likely to be substantially greater.[2] Despite substantial improvements in acute treatment and management, there exists no cure for damage sustained following a TBI. As such, patients and their families are typically left to manage chronic, often lifelong, challenges in areas such as cognition, behaviour, mental health and psychosocial functioning.[3–7] The lifetime history of consequences of TBI can only be fully understood by examining data from large data sets with common data elements which allows the integration of data from large numbers of participants. Unfortunately, in this largely clinical field, study data are rarely combined, are usually overseen by small research groups, use varying methodologies and address diverse research questions.

One approach for making sense of findings from diverse studies is to integrate data into a common metric for each domain of interest, via data pooling and harmonisation.[8]

### Child outcomes following TBI sustained in childhood and adolescence

TBI is a major cause of mortality and disability worldwide and is associated with a threefold increase in functional disability.[9] In Australia, approximately 2.8 per 100 children experience TBI each year, and one in every 30 newborns suffers a TBI by age 16.[10] Despite these figures, long-term consequences of child TBI remain poorly understood. Until recently, it had been argued that young children's brains are 'plastic' and that functions subsumed by damaged brain tissue may be transferred to undamaged tissue with no observable loss of function.[11] Research findings from our team lead the field and challenge this traditional plasticity notion, demonstrating that, where brain damage is diffuse, such as with a TBI, a younger age at injury increases vulnerability.[12] Children injured at a young age have poor outcomes acutely and long-term, in areas including intellectual ability,[4] attention,[13 14] memory,[15] executive functioning,[16 17] socialisation[7 18 19] and functional outcomes.[20] However, these findings are often based on cross-sectional studies, with limited sample size and therefore potential sample bias, with a reliance on group-level data and with no focus at an individual level.

### Long-term outcomes following TBI in childhood and adolescence

The impact of childhood TBI in the very long-term is poorly understood. Unfortunately, opportunities to follow children with TBI into adulthood are hampered by loss to follow-up with children transitioning to adult services, moving out of the education system or leaving the family home. To date, only a limited number of studies have followed children who sustained TBI into adulthood,[6 19 21 22] with somewhat conflicting results, possibly due to inherent methodological problems of longitudinal research, including sample attrition and bias. Following mild TBI in childhood, results are inconsistent, with some suggesting few major long-term neurobehavioural consequences[15] and others suggestive of significant ongoing problems.[23] More consistent results follow more severe TBI in childhood, indicating long-term medical and physical problems,[19] cognitive deficits,[20] vocational difficulties,[3] as well as lowered educational attainment, unemployment, psychiatric disturbance, substance abuse, delinquency and social isolation reported in adulthood.[6] At a social and policy level, the lack of prospective long-term data from childhood cohorts has translated into poorly developed and inadequate services following childhood brain insult.

### Predictors of shorter-term and longer-term outcomes following childhood TBI

One of the major challenges faced by professionals working with children with TBI is the difficulty in predicting outcome and determining priorities for intervention. Research evidence and clinical impressions suggest that outcome is highly variable and multidetermined: (1) premorbid or 'constitutional' factors in areas including behaviour, learning and/or psychiatric status are often major determinants of postinjury function;[13] (2) injury-related findings demonstrate a clear dose–response relationship for severity and outcome, particularly for cognitive skills;[11] (3) developmental factors (eg, age and developmental stage at TBI), where earlier age at TBI or TBI at critical times of development is associated with poorer outcomes[4 24] and (4) psychosocial factors including lower socioeconomic status, low levels of parental education, parental mental health problems, family dysfunction, preinjury behavioural and psychosocial problems have all been linked to poor outcome.[5 25] While preinjury and injury-related risk factors are often not modifiable, they allow us to identify children most 'at risk' and therefore a preventative approach to intervention can be implemented. Children with these risk factors are often vulnerable to persisting, long-term impairments, so they may be invited to take part in intervention programmes aiming to prevent and/or reduce difficulties such as attention, memory and executive impairments.[5 26 27] Other factors may be more modifiable, including parent mental health and family dysfunction, where direct resources (eg, psychoeducation in the form of parenting programmes) may improve child behaviour and reduce parental anxiety.[28]

### Pooling and harmonisation of data to overcome limitations of individual data sets

While meta-analysis may be considered appropriate to address the knowledge gaps in TBI, it is based on combining estimates at the study level, rather than at the individual participant level, meaning investigation is limited by low sample size and power. The unit of analysis in meta-analysis is typically the study, whereas more power can be derived if the unit of analysis is the study participant.[8] To address this limitation is to invest in new, large, prospective studies, capable of providing the power needed to examine less frequent events. However, such studies take decades to mature are extremely costly and necessarily delay the emergence of important health knowledge.[8] An alternative approach, with both clinical and statistical advantages, is to identify common data elements across studies in an effort to pool and harmonise individual participant data across individual cohorts.

In a review by Menon and Maas,[29] it was observed that one of the more important recent developments in the TBI field was the initiation of a series of clinical studies that form part of the International Initiative for Traumatic Brain Injury Research. These studies make use of common data collection standards. They draw on a community of researchers specific to the adult TBI field across the USA, Canada and Europe, to deliver combined study cohorts, therefore increasing sample size and providing opportunities to answer research questions unable to be investigated

by individual samples. Following this review,[29] Meeuws *et al*[30] aimed to quantify the degree of harmonisation of common data elements from three multicentre studies (which included paediatric studies), with a focus on acute hospitalisation and moderate–severe cases, conducted within the International Initiative for TBI Research. The high degree of harmonisation of study variables among these studies demonstrated the importance and utility of common data elements,[31] in TBI research. Kassam-Adams *et al*[32] reported on the development of an international data repository which included prospective studies of acute child trauma and recovery to allow researchers to better examine the nature and course of children's responses to acute trauma exposure. Kassam-Adams *et al*[32] described the harmonisation of key variables, key-study and participant level variables and examined retention to follow-up across studies. It was concluded that the project demonstrated the feasibility and value of merging research data and making it available for re-use.

In accordance with these approaches, our proposed study intends to leverage common data elements employed by the Chief Investigators (Australian and New Zealand based contexts) in our team. While the harmonisation of data can be challenging (eg, ensuring differing assessment tools are capturing the same outcome domains, converting outcome data to a common metric), a multicohort consortium approach, such as we propose, provides a number of advantages including: (1) efficiency in the use of existing data, time and resources; (2) the capacity to bring together expert knowledge from across a range of disciplinary boundaries; (3) increased opportunity for knowledge translation and dissemination; (4) the increased generalisability afforded by combining data collected by different researchers on different samples and (5) the opportunity to combine data from a number of studies to answer questions that cannot be answered in individual cohorts.[8] Uniquely, our samples comprise TBI data across all TBI severity levels (ie, mild, moderate and severe) sustained in childhood (preschool, primary school-age and adolescents), with a longitudinal designs that offer an unparalleled opportunity to characterise longitudinal outcome and recovery of TBI across the lifespan.

In summary, the pooled data sets have clinically relevant individual-level data, with multiple sources of data available (eg, cognitive, behavioural, speech, adaptive, participant and parent reports, genetic data, MRI brain scans and biomarkers). These data are essential for the evaluation of risk and protective factors in recovery, to inform and guide the implementation of intervention models into standard clinical care. Most importantly, this rich data set will inform clinical practice, intervention and rehabilitation, allowing for an organised and uniform approach in clinical care, to ultimately improve the lives of TBI survivors and their families across the lifespan. The study aims to:

1. Identify trajectories of outcome and recovery across multiple domains such as age, severity and sex, with a focus on identifying risk, resilience and protective factors that explain individual variation in these outcomes across the lifespan
2. Identify diagnostic and prognostic methods that will best predict recovery
3. Determine patterns of recovery and challenges to recovery in the context of early TBI
4. Assist in identifying critical periods during which brain disruption will result in poorest outcomes and highlight windows for intervention.
5. Individualising care with more targeted use of health resources, therefore intervening and reducing impairments that impact everyday functioning.

## METHODS AND ANALYSIS

### Ethics

Approval was obtained by the Royal Children's Hospital Ethics Committee in October 2019 (HREC Reference Number: 2019.168).

### Data transfer

Data Transfer Agreements for data sharing were developed by the Murdoch Children's Research Institute's (MCRI) Legal Department for the sharing of data between the MCRI and the Universities of Queensland, Sydney and Canterbury. All documents were completed and approved by all parties by May 2021.

### Study design

This multinational cohort study will harmonise and pool data from multiple, existing cohort studies initiated in Australia and New Zealand, and establish a strong evidence base for the identification, prediction and prevention of risk factors for adverse outcomes in TBI. Once data sets are obtained from all study collaborators (see table 1), common data elements across cohorts will be synthesised and extracted and participant-level harmonised data from the cohorts will then be pooled to create a single integrated data set of participants. Our study team have worked closely together and thus have developed a shared understanding of the relevant common data elements. Outcomes to be measured include data in areas such as cognition, behaviour, mental health, socialisation, academic achievement, employment and overall quality of life. While data on oculomotor and physical outcomes would add to the comprehensiveness of the data set, such data were not available. The integrated data set will provide a rich data source from which the study aims can be addressed.

#### Patient and public involvement statement

These data were collected prior to the current process of including patient and public involvement in study proposals.

### Data storage

Digital copies of data will be securely stored at MCRI under restricted access. The pooled and harmonised

**Table 1** Data sets to be integrated

| Existing cohort | | | | | Measurement domains | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | Outcomes§ | | | | | | Predictors¶ | | | | | | | | |
| Sample size (n); C=controls | Study site location* | Age at injury (year) | Study design† | Injury severity‡ | a | b | c | d | e | f | g | h | i | j | k | l | m | n | o |
| 52 (C=18) | VIC | 0–3 | L | ** | ✔ | | ✔ | | | | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | | |
| 131 (C=35) | VIC | 1–7 | L | ** | ✔ | ✔ | ✔ | ✔ | ✔ | | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ |
| 76 | VIC | 8–12 | L | ** | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ |
| 120 (C=30) | VIC | 5–16 | C | ** | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | |
| 326 (C=128) | NZ | 0–25 | L | ** | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | | |
| 205 | QLD | 7–15 | L | ** | ✔ | | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | | |
| 31 (C=15) | VIC | 7–15 | L | ** | ✔ | | ✔ | ✔ | ✔ | | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | | |
| 84 (C=9) | VIC | 13–18 | C | ** | ✔ | ✔ | ✔ | | ✔ | | ✔ | ✔ | | ✔ | ✔ | | ✔ | | |
| 525 (C=125) | VIC | 5–18 | L | †† | ✔ | ✔ | | | ✔ | | ✔ | ✔ | | ✔ | | ✔ | ✔ | ✔ | |
| 50 | VIC | 18–42 | R | ** | ✔ | ✔ | | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | | ✔ | | |
| 92 (C=38) | NSW | 5–15 | C | ** | | ✔ | | | | | | ✔ | | | | | | ✔ | |
| 36 (C=17) | VIC | 12–19 | L | ** | ✔ | ✔ | ✔ | | | | | | | ✔ | | ✔ | | | |
| 48 (C=5) | VIC | 3–12 | C | ** | ✔ | ✔ | | | | | | ✔ | | ✔ | ✔ | ✔ | ✔ | | |
| 40 (C=20) | VIC | <1 year post | C | ** | ✔ | | | ✔ | ✔ | | ✔ | ✔ | | ✔ | | | | | |
| Total TBI: 1412<br>Total controls: 404<br>Total N: 1816 | | | | | | | | | | | | | | | | | | | |

*Study site location: VIC=Victoria, Melbourne; NSW=New South Wales, Sydney; QLD=Queensland, Brisbane; NZ: New Zealand, Christchurch.
†Study design: L=longitudinal; C=cross-sectional; R=retrospective.
‡Injury severity.
§a=cognition; b=mental health; c=socialisation; d=academic achievement; e=quality of life; f=employment.
¶Predictors: g=preinjury status; h=injury characteristics; i=developmental aspects; j=cognition (full scale IQ); k=environmental distal (socioeconomic status); l=environmental proximal (family function); m=time since injury; n=MRI; o=genetics.
**Mild, moderate and severe.
††Mild.
TBI, traumatic brain injury.

data set will be stored as indicated in the Memorandum of Understanding which was developed in collaboration with each contributing organisation and signed and approved by all sites as per the legal requirements of MCRI. The merged data set will only be accessed by the research team as specified in the approved ethics application (Human Research Ethics Committee (HREC) of the Royal Children's Hospital (RCH) Reference Number 2019.168).

### Data analysis

The increase in sample size (and statistical power) will enable more complex statistical modelling, such as generalised estimation equation, multilevel and latent growth models. These models will accommodate multiple levels of clustering (state, hospital), as well as adjustment for both time-varying and invariant covariates. Most independent and dependent variables are collected and recorded in a standard and common fashion across data sets, and time-varying predictors and outcomes (eg, age, IQ or time itself) permit flexibility of modelling in different ways. As an example, age is expected to be normally distributed, but is also able to be categorised for clinical age groups, or polynomially extended to model curvilinear patterns and pathways. Moreover, time can be modelled as predetermined data collection time points, or as a timeseries/panel predictor. Of importance to the longitudinal data sets, models such as Generalised Estimating Equation and Random Effects models have the ability to circumnavigate the complete case requirement of most F-tests. These models can analyse all available data without case wise exclusion, provided that the data are missing at random or completely at random. For this reason, we do not expect a dramatic reduction in sample size due to attrition.

### Examples of leveraging common data elements

For the intellectual outcome domain, we will extract standardised Full Scale Intelligence Quotient (FSIQ) scores (M=100; SD=15) from the databases housed at each of the individual sites. For the social outcome domain, we will harmonise data collected from the Child Behavior Checklist (CBCL) Social Competence Scale (M=50; SD=10) and the Vineland Adaptive Behvaior Scale (VABS) Socialisation Scale (M=100; SD). For this analysis, the CBCL Social Competence and VABS Socialisation measures will be independently rescaled as a z-score metric (M=0; SD=1), and then merged into one variable. A similar process will need to be repeated depending on the variables requiring harmonisation. To illustrate the benefit of pooled data, Ordinary Least Squares multiple regression models will be run on the data sets independently, and then a multilevel mixed model adjusted for study source.

## ETHICS AND DISSEMINATION

In Australia, for a TBI sustained in adulthood, the lifetime cost per individual adult is $5 million for a severe injury and $3.7 million for a moderate injury, and it can only be assumed that for a child, with a lifetime ahead of them, the costs will only be greater.[2] Despite the significant functional implications of postinjury sequelae, study data are rarely combined in order to fully understand the lifetime history of consequences. An approach that will support the integration of data sets, by unifying data into a common metric for each domain of interest, is via pooling and harmonisation.[8]

Our approved ethics proposal will allow us to address our objective, to pool and harmonise data from multiple, existing cohort studies initiated in Australia and New Zealand and to establish a strong evidence base for the identification, prediction and prevention of risk factors for adverse outcomes in TBI. Our unique data set will provide a rich, comprehensive source of knowledge in areas such as cognition, behaviour, mental health, socialisation, academic achievement, employment and overall quality of life. It will also allow us to identify predictors [(preinjury, injury-related, developmental, environmental, mental health, diagnostic (imaging, genetic, biomarkers)] of outcome. As this large data set will lend itself to sophisticated statistical techniques, such as machine learning, it will allow us to answer questions that cannot be answered in individual cohorts.[8] The information gained will guide and inform the individualisation of care across the lifespan.

In summary, these data are essential for the evaluation of risk and protective factors in recovery following an TBI sustained in childhood. Our findings will be published in highly regarded journals in our field, be presented at national and international conferences, be translated into clinical practice, inform policy decisions and guide the appropriate allocation of limited healthcare resources. Such an integrated knowledge-base and clinical service will underpin health and quality of life improvements for child TBI survivors and their families via a uniformed approach to clinical care.

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manuscript. CC, VA, JK, SL, AM, LC, CS and NTS contributed data sets. All authors provided critical feedback and helped shape the research and analysis plan and the final manuscript. CC was responsible for the overall study content and, as guarantor, had responsibility for the conduct of the study, had access to the data and monitored the decision to publish.

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