



United Nations Convention on the Rights of the Child

Submission

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1. General principles

Right to life, survival and development (article 6)

Child injury hospitalisations in Australia

During 2001-02 to 2011-12, there were 686,409 injury-related hospital admissions of children aged ≤ 16 years in Australia, with an injury hospitalisation rate of 1,489 per 100,000 population (95%CI: 1485.3-1492.4). The direct hospital treatment cost was estimated at \$2.1 billion. This equates to almost 69,000 injury hospital admissions each year, with an annual cost of \$212 million.

During the 10 year period (i.e. 2001-02 to 2011-12), there has been no decrease in injury hospital admissions of children in Australia. There was a higher risk of death within 30 days of an injury-related hospital admission for children who were aged < 10 years, who were more seriously injured, who were injured in transport incidents or following near-drowning/submersion/threats to breathing or following self-harm, for children who resided in regional/remote Australia, and for children with a head injury.

- Mitchell R. Curtis K. Foster K. A ten-year review of child injury hospitalisations, health outcomes and treatment costs in Australia. <http://injuryprevention.bmj.com/content/early/2017/07/26/injuryprev-2017-042451>

The ten-year review of child injury hospitalisations in Australia involved analysing linked hospitalisation and mortality data from 8 Australian jurisdictions. The process of obtaining the multiple linked data extracts was time consuming and took over 4 years to complete (see Appendix A). Having accurate and timely information on child injury hospitalisations in Australia using linked hospitalisation and mortality data will allow timely monitoring of the burden of hospitalised child injury and evaluation of child injury prevention initiatives.

Injury hospitalisations only represent one piece of the child injury burden in Australia, there are many more children who present to emergency departments, general practitioners or allied health for treatment following an injury. After sustaining an injury, many children can face ongoing limitations related to their injury, including chronic pain, physical disabilities and psychological issues, such as post-traumatic stress disorder.

There is no current national child injury prevention strategy in Australia and the development of such a strategy for Australia is long overdue.

2. Violence against children

Abuse and neglect, including physical and psychological recovery and social reintegration (articles 19 and 39)

Child assault hospitalisations in Australia

During 2001-02 to 2011-12, there were 13,877 assault-related hospital admissions of children aged ≤ 16 years in Australia at an estimated direct hospital treatment cost of \$60.6 million. The male hospitalisation rate for assault (40.5 per 100,000) was twice that of females (18.7 per 100,000).

- Mitchell R. Seah R. Ting, H. Curtis K. Foster K. Intentional self-harm and assault hospitalisations and treatment cost of children in Australia over a 10-year period. Australian and New Zealand Journal of Public Health - <https://onlinelibrary.wiley.com/doi/abs/10.1111/1753-6405.12782>

Children aged ≤ 16 years in Australia living in more disadvantaged socioeconomic quintiles during 2001-02 to 2011-12 were more likely to be hospitalised for an injury sustained by assault (Incident Rate Ratio range 1.40 to 3.64).

- Seah R. Lystad R. Curtis K. Mitchell R. Socioeconomic variation in injury-related hospitalisations in Australian children ≤ 16 years: a 10-year population-based cohort study. Submitted

Intentional injury often affects vulnerable groups in society. National coordination of intentional child injury prevention efforts should be undertaken through the development and implementation of a national child injury prevention strategy, along with adequate resourcing for strategies designed to reduce intentional injury in Australia.

3. Disability, basic health and welfare

Health and health services, in particular primary health care, especially section E regarding the 'prevention of accidents' and section F regarding 'develop preventive health care' (article 24)

National child injury prevention policy

While injury prevention has been a priority health area in Australia for 30 years – since 1986 when the Better Health Commission published *Looking Forward to Better Health*. Injury prevention policy in Australia has been limited by poor stakeholder involvement, and inadequate resourcing and implementation. Australia's most recent injury prevention and safety promotion plan expired in 2014.

- Mitchell R. McClure R. (2006) The development of national injury prevention policy in the Australian health sector: and the unmet challenges of participation and implementation. Australian and New Zealand Health Policy, 3: 11.

While the health sector has the responsibility for treating injured individuals, many risk factors for injury and the development and implementation of policy aimed at injury

prevention lie with other government agencies, including transport, work safety, sport and recreation, family and community services, local government, and maritime. A 'whole of government' approach is needed for injury prevention with government agencies working collaboratively to reduce the burden of injury in Australia. A whole of government approach would reduce duplication of effort, focus limited resources, and strengthen cross-government networks and partnerships. A whole of government approach to injury prevention policy is possible as New Zealand have adopted a cross-government approach to address injury prevention, with reporting on the New Zealand injury prevention strategy occurring directly to the New Zealand Cabinet.

Injuries are preventable. However, injuries remain the leading cause of death and hospitalised morbidity of children aged 1 to 18 years in Australia.

4. Education, leisure and cultural activities

Rest, play, leisure, recreation and cultural and artistic activities (article 31)

Child sport-related injury hospitalisations in Australia

During 2001-02 to 2011-12, there were 130,167 sport injury-related hospital admissions of children aged ≤ 16 years in Australia at an estimated direct hospital treatment cost of \$39.6 million per year. There has been no decline in the hospitalisation rate for sport-related injuries of children during the 10-year period examined. Team-ball sports and wheeled-non-motor sport accounted for almost two-thirds of sport injury hospitalisations. Injuries to the elbow and forearm and the head were the most frequent body locations of injured.

As there has been no decline in the hospitalisation rate for sport-related injuries of children in Australia, there is a need for a national strategy for child injury prevention that includes preventing sports injury among Australian children. Within New Zealand, the experience of the Accident Compensation Corporation system over the past 30 years indicates that a national sports injury prevention programme can be cost-effective, if it is supported and managed systematically by government.

It is essential that key stakeholder groups (e.g. health and sport government agencies, peak sports governing bodies, sports medicine professional bodies, and injury prevention experts) are involved in the development and implementation of sports safety policies and programmes to reduce the burden of sports injury among Australian children.

- Lystad R. Curtis K. Browne G. Mitchell R. Incidence of sports injury-related hospitalisations in Australian children over a ten-year period: a nationwide population-based cohort study. Submitted.

Appendix A

1. National hospitalisation data access issues

1.1 Background: Hospitalisation data in Australia

Hospitalisation data in each Australian jurisdiction is recorded as episodes of care. For example, if a child is injured and hospitalised in a rural hospital, then transferred to a paediatric trauma centre, then admitted to the intensive care unit (ICU), then admitted to the children's ward, and then transferred back to the rural hospital for rehabilitation, that represents 5 episodes of care in the hospitalisation data for the one injury event (For example, the episodes of care in the above example would represent 5 rows of data in Microsoft Excel™).

Prior to the availability of record linkage, hospitalisation data was analysed by excluding these 'statistical separations' (e.g. movement from ICU to ward) and any hospital transfers. This was done to avoid double counting these episodes of care as 'new' injuries. However, this process was not ideal. It also created problems for calculating hospital length of stay, as in the example above, the child's hospital length of stay should be the sum of their length of stay for their 5 episodes of care related to their injury.

1.2 Record linkage of hospitalisation (and other) data collections

In order to identify which episodes of care are related to the one injury event, the hospitalisation data can be linked to itself (to identify all episodes of care for the one individual). The hospitalisation data can also be linked to other data collections, such as mortality data, to identify deaths after hospital discharge (otherwise only in-hospital deaths can be identified).

1.2.1 Record linkage process

The record linkage process is undertaken by a third party (i.e. one of the data linkage centres in Australia, such as the Centre for Health Record Linkage: CHReL). The data custodian of a data collection will provide the data linkage centre with the records to be linked (based on the requirements of the researcher) and a unique identifier for each episode of care. The data linkage centre is only provide with the an individual's unique identifying information (such as first name, last name, date of birth, address) that are used to link the episode of care records. The data linkage centre does not have access to any health or treatment information.

The data linkage centre usually uses probabilistic linkage techniques to identify the same episodes of care relating to the same individual using the identifying information. The data linkage centre will then provide each individual in the data extract a unique personal project number and this is attached to each episode of care record belonging to that individual. The data linkage centre then provides the person project number and the unique identifier back to the data custodian (e.g. the hospitalisation data custodian within a Health Department). The data custodian then attaches the person project number to the health information (i.e. age, sex, admission and separation dates, diagnoses, procedures etc) and provides this information to the researcher via a secure and encrypted data transfer portal. The

researcher does not have access to the identifying information, such as name and address, they are only provided with the information needed to answer their research question(s).

The researcher receives multiple data extracts from all of the data custodians (e.g. hospitalisation, mortality, police-reported crash records) and uses the person project number and various other data variables (including episode start/end dates, separation mode, hospital) to 'link' all the data extracts together for analysis. This 'relinkage' can take some time as there usually is lots of data cleaning and organisation to do. For further information on the potential for injury surveillance in Australia using data linkage, see:

- Mitchell R. Cameron C. Bambach M. (2014) Data linkage for injury surveillance and research in Australia: Perils, pitfalls and potential. *Australian and New Zealand Journal of Public Health* 38 (3) 276-281.

The hospitalisation data can be linked to other data collections to obtain additional information regarding the circumstances of the injury event, such as linking the hospitalisation data to the police-reported information on road crashes. The hospitalisation data contain information regarding a child's injuries and treatment and the police-report road crash data can provide information regarding the circumstances of the injury event, such as was the child wearing a seat belt/ helmet, speed of vehicle, type of collision, wet/sunny conditions. For an example of what information is available using linked hospitalisation and police-reported crash data, see:

- Mitchell R. Senserrick T. Bambach M. Mattos G. (2015) Comparison of novice and full licenced driver common crash types in New South Wales, Australia, 2001-2011. *Accident Analysis and Prevention* 81, 204-210.
- Mitchell R. Bambach M. Foster K. Curtis K. (2015) Risk factors associated with the severity of injury outcome for paediatric road trauma. *Injury* 46, 874-882.

1.3 National hospitalisation data at the Australian Institute of Health and Welfare

In terms of national hospitalisation data, the AIHW holds the *National Hospitalised Morbidity Dataset (NHMD)*. As part of the *National Healthcare Agreements*, each Australian jurisdiction is required to provide the AIHW with some agreed data variables from their hospitalisation data and this is what forms the NHMD. However, these data variables do not currently include any of the unique identifying information (such as first name, last name, date of birth, address) that are needed to conduct record linkage.

In order to conduct research that requires national record linkage, for example by linking national hospitalisation data records to the National Death Index (NDI), each state and territory health department must provide unique person identifiers from their hospitalisation data to the AIHW Data Linkage Unit, along with a state unique identifier for each episode of care. Some jurisdictions are equipped to do this in a more timely fashion than others. At this stage, Western Australia (WA) has been unable to provide any unique identifying information out of their state.

Before any record linkage can occur, the researcher must obtain Human Research Ethics Committee (HREC) approval from each state and territory and the AIHW HREC and also approval from all state and territory health data custodians.

1.3.1 HREC approval

For national research that involves health record linkage, having one national HREC that had the jurisdiction to provide ethics approval would be ideal. Currently, using the NHMD to NDI linkage example, a best case scenario is that ethics approval from all jurisdictions (except WA) and the AIHW HREC could be obtained in 9 months. Note that most HRECs will meet once a month and the AIHW HREC only meets 4 times a year.

The Queensland Health HREC is currently the only HREC that will ratify an existing HREC approval, while the University of Tasmania HREC has an expedient approval process, if a researcher already have one HREC approval. All other jurisdictions require a full HREC review.

Research that involves multi-jurisdiction clinical trials are able to get HRECs to comply with the NHMRC's national approach to single ethics review (<https://www.nhmrc.gov.au/health-ethics/national-approach-single-ethical-review-multi-centre-research>), so it would be helpful if the single ethics review approach was also identified as applying to record linkage studies and promoted to the HRECs in all Australian jurisdictions.

1.3.2 Health data release procedures by the AIHW

When reporting information from the hospitalisation data, there is a concern that individuals could be identified within the published information. To prevent identification cell sizes are usually shown as ≥ 5 (or in some cases ≥ 3). For example, if you have a Table where you want to show the number of males in Western Sydney who were aged ≤ 4 years who were hospitalised following a near-drowning in a backyard swimming pool, the number of males could be < 5 and, therefore, this information would not be able to be disclosed.

To prevent individuals being able to identify small numbers of hospitalisations, the AIHW Data Linkage Unit is applying the '1,000 denominator rule' to the release of health data from the NHMD (i.e. *patient level data should not be provided with a combination of demographic data items that distinguishes groups with an estimated population of less than 1,000*). In the majority of cases, the release of unit record linked hospitalisation data contravenes this data release policy.

The '1000 denominator rule' is not a data release policy of the jurisdictions who regularly provide their jurisdiction-based health data for research projects. The exception is the Northern Territory Health Department that does consider potential sample size in any release of their hospitalisation data, due to their low number of admissions. Application of the '1,000 denominator rule' by the AIHW to the release of linked hospitalisation data means that the AIHW requires each data custodian to re-state via email or letter their approval to provide their jurisdictions' hospitalisation data to a researcher.

1.3.3 Application processes in each jurisdiction

While jurisdiction-based legislation around data accessibility for research needs to be adhered to, there still needs to be consistent health data access across jurisdictions. The WA Health Department's 2012 *Information Access and Disclosure policy* requires researchers who need information at the hospital level (i.e. where a hospital is named) to write to each WA hospital Chief Executive (CE) for their permission to access data recorded by their hospital. It is not reasonable to require this of researchers, especially as no contact details

for the hospitals or CEs are able to be provided by the WA Health Department and up to 109 hospitals (public and private) can need to be contacted.

Information on the hospital is required for injury research as researchers often want to be able to take into account in their analyses whether or not the child received their definitive treatment at a *paediatric trauma centre* or not. Previous research has identified that seriously injured children who received definitive care at a paediatric trauma centre in NSW had a survival advantage than if they had received care at an adult trauma centre.

- Mitchell R. Curtis K. Testa L. Holland A. Soundappan SVS. Adams S. (2017) Differences in survival outcome for severely injured paediatric trauma by type of trauma centre. *Paediatrics and Child Health* 53 (8) 808-813

The additional requirement that all research that uses linked data in WA should also have a WA researcher on the team is also an unnecessary restriction. If researchers do have any specific data queries regarding WA data, then the WA data custodian(s) are able to provide advice.

1.3.4 Confidentiality agreements

Prior to a researcher receiving any hospitalisation data, confidentiality agreements are required to be signed with each Health Department. It would be helpful if there was one size fits all confidentiality agreement between the jurisdictions. Despite jurisdiction-specific privacy legislation, this should be possible to achieve. NSW has the most streamlined approach, with the chief investigator receiving information regarding any data restrictions and signing the confidentiality agreement on behalf of all investigators. South Australia (SA), WA and Victoria require each investigator to sign a confidentiality agreement. In SA, the 'Deed of Confidentiality Agreement' is with the SA Crown and the language of Section 7.2 requires researchers to be personally and legally responsible for data security, if anything untoward happens to the data. This is an unreasonable request. Data is housed securely on university servers or within the Secure Unified Research Environment (SURE).

Within each agreement, is a stipulation that the researcher provide a copy of their manuscript/report/conference abstract to the Health Department between 12-15 working days prior to any public release.

1.3.5 Research timeframes

For research that involves national record linkage, the HREC approval process, each jurisdiction's health data application process, the waiting period for each jurisdiction to provide their unique person identifiers for linkage, the legal review of confidentiality agreements, the conduct of the linkage and the provision of data extracts back to the researcher for analysis all take extended periods of time to occur. This impacts on the timeliness of the research results.

For example, a case-comparison study examining adult hospitalised injury in NSW, SA and Queensland took 4 years to achieve. The example of linking the NHMD to the NDI also took 4 years to achieve. These timeframes are not unusual for research involving health record linkage. See Productivity Commission 2017 Report on *Data Availability and Use* report at: <https://www.pc.gov.au/inquiries/completed/data-access#report>

For a description of the conduct of national data linkage in Australia and some of the issues see:

- Mitchell R. Cameron C. McClure R. Williamson A. (2015) Data linkage capabilities in Australia: practical issues identified by a Population Health Research Network “Proof of concept project”. *Australian and New Zealand Journal of Public Health* 39 (4) 319-325.

2. Australian Government Public Data Policy Statement

The *Public Data Policy Statement* was released on 7 December 2015 by Prime Minister Turnbull. It appears the government is committed to providing access to public data and for public data to be used to inform improvements in service delivery and public policy for the benefit of the Australian public. However, a guarantee of ‘timely access to public data’ for public health research purposes has not been identified.

https://www.pmc.gov.au/sites/default/files/publications/aust_govt_public_data_policy_statement_1.pdf

The current 4 year timeframe to access linked national hospitalisation (and other national data collections) is too long to wait for researchers. Most Commonwealth-funded research career fellowships are only of 4 years duration.