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Identification of sources of injury outcomes data in Australia

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Accompanying documents to this research brief	
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A joint initiative of

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Contents

Abbreviations

ABI	Acquired Brain Injury
AIS	Abbreviated Injury Scale
AQoL	Assessment of Quality of Life
AROC	Australasian Rehabilitation Outcomes Centre
ASCIR	Australian Spinal Cord Injury Register
ASDI	Acute Stress Disorder Interview
AUDIT	Alcohol Use Disorders Identification Test
BDI	Beck Depression Inventory
BIRP	Brain Injured Rehabilitation Program
CAPS	Clinician-Administered PTSD Scale-IV
CHART	Craig handicap Assessment and Reporting Technique
CIDI	Composite International Diagnostic Interview
DASS	Depression, Anxiety, Stress
DRS	Disability Rating Scale
DSM-IV	Diagnostic and Statistical Manual
ED	Emergency Department
FIM/	Functional Independence Measure
FSIQ	Full Scale IQ
GHQ-28	General Health Questionnaire – 28 item
GOAT	Galveston Orientation and Amnesia Test;
GCS	Glasgow Coma Scale
GOSE	Glasgow Outcome Scale Extended
GPE	Global Perceived Effect
HADS	Hospital Anxiety and Depression Scale
HAQ	Health Assessment Questionnaire
HRQoL	Health Related Quality of Life
IES	Impact of Event Scale
ICU	Intensive Care Unit
IQR	Inter-Quartile Range
ISS	Injury Severity Score
LEFS	Lower Extremity Functional Scale
MINI	Mini International Neuropsychiatric Interview
LHSORC	Liverpool Hospital Surgical Outcome Research Centre
MOT-Q	Motivation for Traumatic Brain Injury Rehabilitation Questionnaire
MPAI	Mayo-Portland Adaptability Inventory
MPQ	McGill Pain Questionnaire
MTS	Major Trauma Service
OMAS	Olerud and Molander Ankle Score
PTA	Post-Traumatic Amnesia
PTC	Post-Traumatic Checklist
PTSD	Post Traumatic Stress Disorder
RSC	Rapid screen of Concussion
RTA	Road Traffic Authority (RTA)
SCI	Spinal Cord Injury
SCID	Structured Clinical Interview for DSM-IV
SD	Standard Deviation
SES	Socio-economic Status

SF-12/36	Short Form Health Survey 12/36
SGIC	State Government Insurance Commission (SA)
SIC	State Insurance Commission
SIPw	Sickness Impact Profile (work subscale)
SPRS	Sydney Psychosocial Reintegration Scale
TAC	Transport Accident Commission (Vic)
TBI	Traumatic Brain Injury
UEFI	Upper Extremity Functional Index
VOTOR	Victorian Orthopaedic Trauma Outcomes Register
VSTR	Victorian State Trauma Registry
WeeFIM	Functional Independence Measure (for children)
WHODAS II	World Health Organization Disability Assessment Schedule II
WHOQoL	World Health Organization Quality of Life

1. Background

The burden of injuries requires knowledge of a broad range of deficits that can occur following injury.[1] Information pertaining to injury outcome is necessary to guide the public health response to injury, identify and inform priorities, assist with policy setting and strategic health services planning, and to monitor the impact of changes in care and interventions.[2-4]

The Transport Accident Commission (TAC) has identified improving client outcomes as a key strategic goal in their Strategy 2015. The state of Victoria operates a regionalised, inclusive system for trauma care. Implementation of the Victorian State Trauma System has led to a significant reduction in the adjusted odds of mortality after severe injury[5], increasing the importance of monitoring outcomes in addition to mortality. Worldwide, systematic approaches to measuring outcomes other than mortality have been rare[6]. Data pertaining to injury outcomes have largely stemmed from research studies of subsets of the population.[7] A coordinated approach to identifying sources of injury outcomes data, both routinely collected and research-based, would have significant benefits for injury stakeholders such as the TAC, including reduced duplication of effort in collecting outcomes data and a greater understanding of data that may be used for organisational performance monitoring. However, there is currently a lack of clarity regarding the extent, type and quality of injury outcomes data within Victoria.

2. Project aim and objectives

The primary aims of this project were to:

a. Identify sources of injury outcome data collected in Australia over the past 10 years (2000- April 2011).
b. Describe the existing sources of injury outcomes data, specifically focusing on perceived gaps in the context of the injury List Of All Deficits (LOAD) framework[1] and the World Health Organisation's International Classification of Functioning (ICF).[8]
c. Highlight data and data sources that may be used for TAC performance monitoring.
d. Establish priority areas for future injury outcomes research for Victoria

3. Methods

This project was separated into three components:

1. Systematic review of the injury literature
2. Searches of the World Wide Web, and examination of relevant web sites
3. Informal interviews with expert local informants

3.1 Systematic review of the injury literature

3.1.1 Eligibility criteria

A structured literature search was undertaken to identify all studies published in peer and non-peer reviewed (grey) literature and conference abstracts between January 2000 and March 2011. It was decided *a priori* to allow the inclusion of all study types, including; randomised controlled trials, quasi-randomised controlled trials, cohort studies, case-control studies, retrospective case series and case studies. Studies were considered eligible for review if the study: (1) investigated injuries among individuals of any age; (2) assessed outcomes consistent with current concepts of general disability, including but not limited to; functional limitations, psychosocial and behavioural consequences, reduced quality of life; (3) and/or investigated the impact on society or the family of those injured (see Table 1). No language restriction was imposed when searching electronic databases.

Table 1 Review inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Relevant to the review theme	Duplicate articles
Study involving human subjects	Did not follow participants over time
Population of any age	
Investigated injury AND assessed relevant outcome	
And/or investigated impact on family or society	
All study types	

3.1.2 Search strategy

A number of databases relevant to the project topic were searched and these are presented in Table 2. The search strategy used keywords such as child, adolescent, paediatric, accident, injury, trauma, disability, morbidity, health status, outcome, and related MeSH terms. The major search strategies (Medline and Cochrane) are listed in appendix 1 and 2. Reference lists of identified articles were manually searched.

Table 2 Databases searched

Database
Medline
Embase
PsychInfo
SocioFile
Cinahl
Cochrane
Transport, Road, Science Citation Index

3.1.3 Mapping included studies to the LOAD framework and ICF classifications

The LOAD framework describes the elements that contribute to the burden of injury across the family, individual and societal domains,[1] and is particularly useful in assessing the comprehensiveness of injury studies, and identifying research gaps and opportunities. The framework is presented diagrammatically as Figure 1.

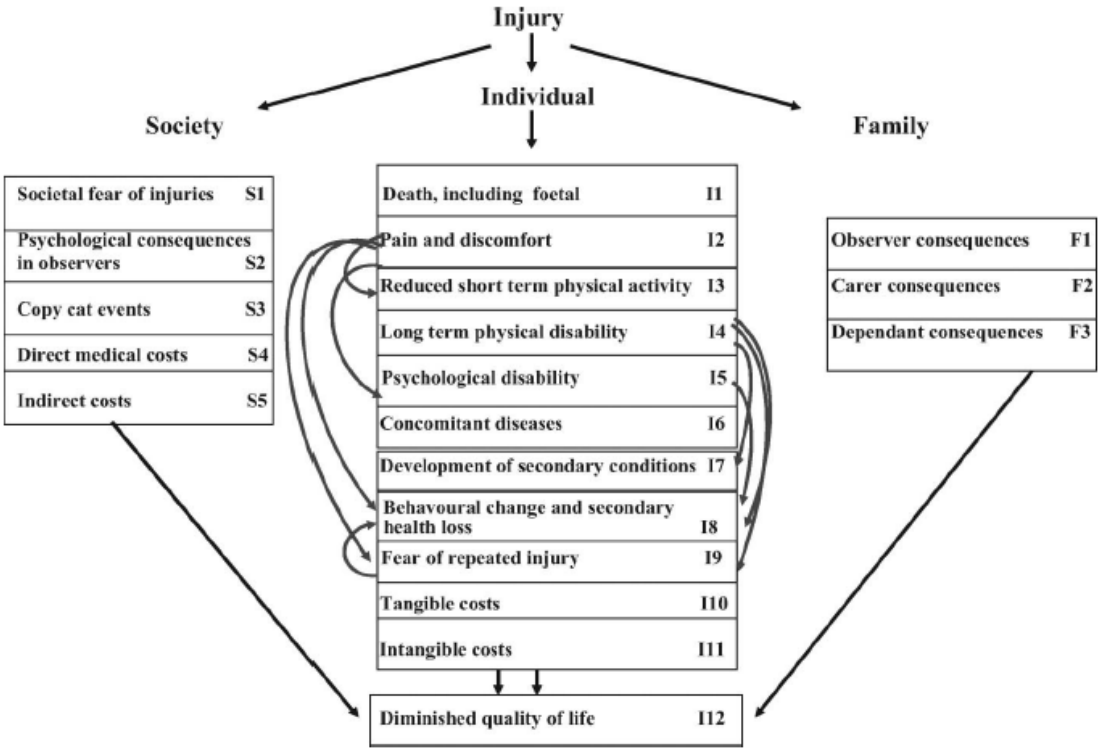

Figure 1 LOAD Framework
Source: Lyons R.A. et al, International Journal of Injury Control and Safety Promotion, Vol 17, No 3 2010, pg 149

The LOAD framework consists of a number of key components within each domain, coded as S1-S5, I1-I12 and F1-F3 (Figure 1). Each included study was mapped against the LOAD framework and the relevant key component that the study was measuring identified. All existing and proposed studies should be examined in the context of the LOAD and ICF frameworks when assessing comprehensiveness and potential study quality and worth.

The ICF is another useful conceptual classification designed to establish a common language for describing health-related[8] and disability states.[9] It complements the LOAD framework well by offering a broad classification, discriminating between 'Body Functions and Structures' and Activities and Participation' (Figure 2). The key difference between the ICF and LOAD is that the LOAD framework is specific for injury.

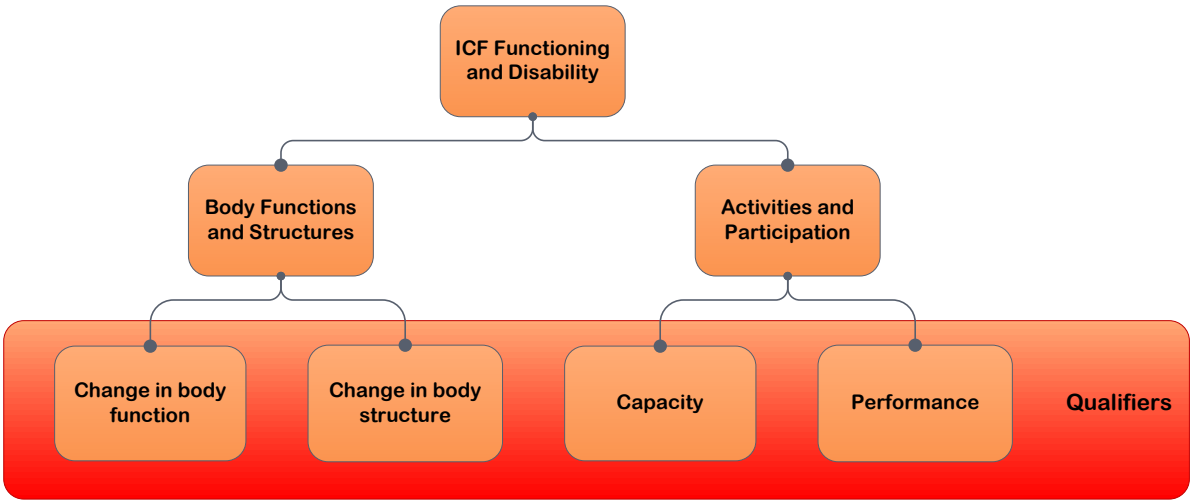

Figure 2 Structure of ICF highlighting qualifiers

Again, the outcome measure of each included study was mapped against the ICF qualifier.

The ICF, whilst not as intuitive or discriminative as the LOAD framework, remains a useful tool to broadly describe the focus of injury studies based on an internationally understood and accepted classification.

3.2 Searches of the World Wide Web

A number of websites were searched with the aim of identifying any relevant missed studies or grey literature which had not yet been published. Websites were chosen to be reviewed if they were deemed relevant by the investigators or if they were recommended by the expert informants. See Table 3 below for included websites and URLs.

Table 3 List of websites and URLs of sites reviewed

Websites reviewed	URL
Australian Rehabilitation Outcomes Centre	http://chsd.uow.edu.au/aroc/index.html
Australian Research Council	http://www.arc.gov.au/
National Health and Medical Research Council	http://www.nhmrc.gov.au/
WorkSafe	http://www.worksafe.vic.gov.au/
Transport Accident Commission (TAC)	http://www.tac.vic.gov.au/
Victorian Neurotrauma Initiative	http://www.vni.com.au/
Institute for Safety, Compensation and Recovery Research	http://www.iscrr.com.au/
Victorian Orthopaedic Trauma Outcomes Registry	http://www.med.monash.edu.au/epidemiology/traumaepi/orthoreg.html
Victorian State Trauma Outcomes Registry	http://www.med.monash.edu.au/epidemiology/traumaepi/traumareg.html
NSW Government Lifetime care & support	http://www.lifetimecare.nsw.gov.au/Brain_Injury.aspx
The University of Adelaide – Discipline of Orthopedics and Trauma	http://health.adelaide.edu.au/ot/rah/research/trauma/

3.3 Interviews with expert informants

Informants were selected by the authors based on their key roles within the Victorian injury research community, their experience in sourcing injury data and have been investigators on projects which collect data first hand from study participants. A purpose designed interview comprising five open ended questions was provided to all informants at the time they were invited to participate (Appendix 3).

4. Results

4.1 Literature review

The search strategy yielded a total of 1444 references (Figure 3). Of these, 1383 references were excluded as they did not meet the inclusion criteria (Table 1). Of the 61 articles shortlisted for abstract or full text review, 38 were confirmed as meeting the inclusion criteria, and are summarised in Appendix 4.

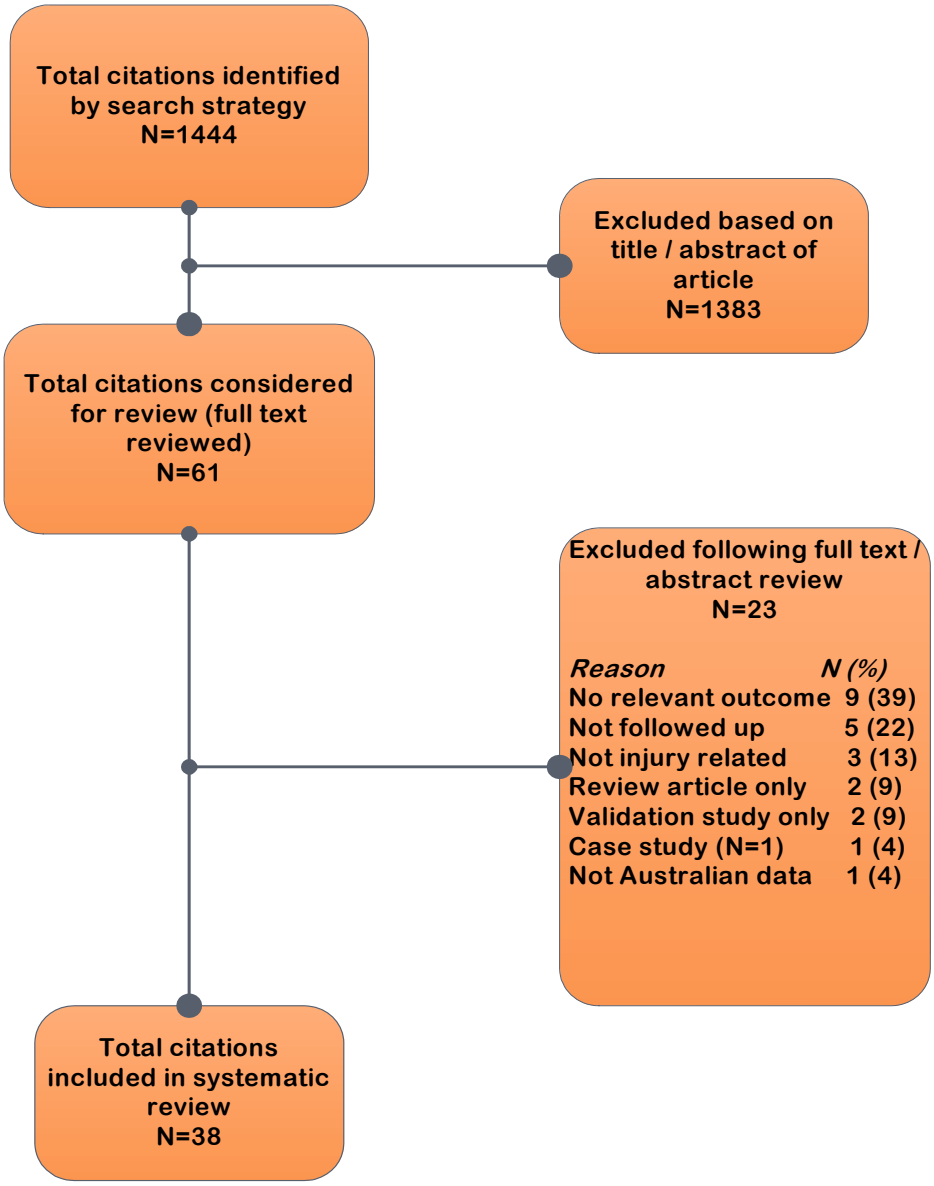

Figure 3 Flowchart indicating the number of articles identified and excluded

4.2 Study design

The majority of included studies were a prospective cohort design. There were only two randomised controlled trials (Holmes et al 2007[10] and Kenardy et al 2008[11]). One study was a matched case-control study (Hawthorne et al 2009[12]).

4.3 Data repositories

The origin of each of the included studies are summarised in Figure 4. The majority of studies originated from Victoria. There were no included studies originating from the Australian Capital Territory, Northern Territory, or Tasmania.

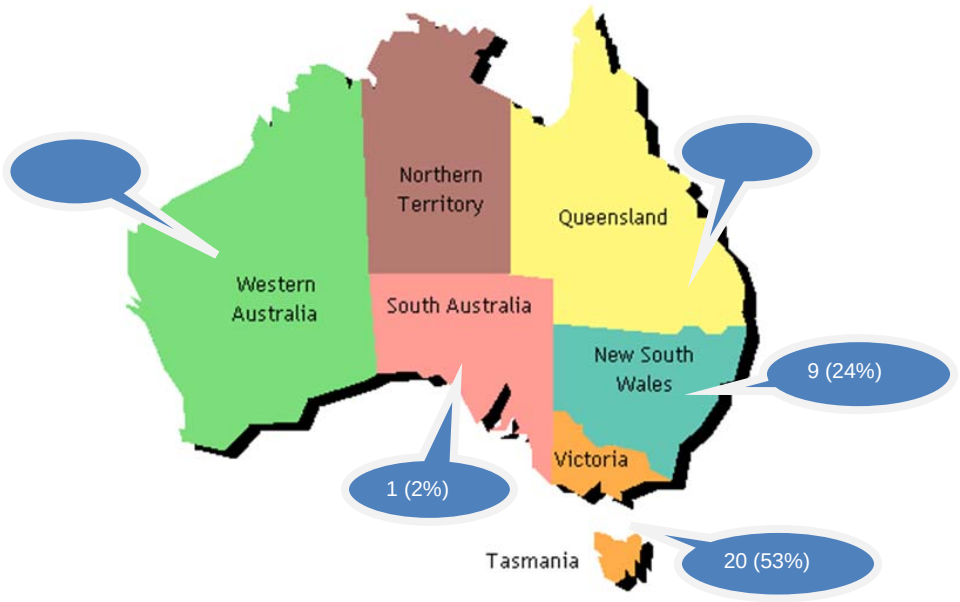

Figure 4 Number (%*) of studies contributed by each state
(* Does not equal 100 due to rounding; n=3 (8%) - multiple states; 1 (2%) – unclear)

Nine dedicated data sources (registries or databases) were identified from the included studies. Almost half of the studies utilised data from single sites (e.g. hospital department, ED, ICU, Outpatient Clinic, etc) or from specialist clinics (e.g. Physiotherapy, Occupational Therapy) (Table 4). Just over one quarter of the studies used data from the Victorian Orthopaedic Trauma Outcome Registry (VOTOR) or the Victorian State Trauma Registry (VSTR).

Table 4 Data source used for study

Data Source	Number of Studies (%)
Single site data	18 (47)
VOTOR	6 (16)
VSTR	4 (11)
SCI Registry	3 (8)
BIRP Centre	1 (3)
Head Injury Database (Epworth)	1 (3)
LHSORC	1 (3)
Paediatric Trauma Registry (NSW)	1 (3)
SGIC (SA)	1 (3)
RTA (NSW)	1 (3)
Unclear	1 (3)
Total	**38 (103*)**

(* Does not equal 100 due to rounding)

4.4 Study population

Just under one third (11/38; 29%) of the studies recruited an adult trauma population for inclusion in their study (Table 5). Cohorts recruited from motor vehicle crashes accounted for only 11% of the included studies.

Table 5 Study population used for study

Population / mechanism	Number of Studies (%)
Adult trauma	11 (29)
Adult TBI	8 (21)
Adult orthopedic trauma	8 (21)
Motor Vehicle Crash	4 (11)
Paediatric TBI	2 (5)
All age SCI	2 (5)
Paediatric orthopaedic trauma	1 (3)
Paediatric trauma	1 (3)
Adult SCI	1 (3)
Total	**38 (101*)**

(* Does not equal 100 due to rounding)

4.5 Instruments / Outcome measures

Over 60 different outcome measures or instruments were used by the 38 studies. The five most commonly used instruments are summarised in Table 6. These measures were used in almost 80% (30/38) of all included studies.

Table 6 Five most commonly used outcome measures or instruments

State	Number of Studies (%)
Mortality (following hospital discharge)	8 (21)
SF-36	7 (18)
SF-12	5 (13)
Pain Score	5 (13)
GOSE	5 (13)

SF-36 – Short Form Health Survey 36 items; SF-12 – Short Form Health Survey 12 items; GOSE – Glasgow Outcome Scale Extended.

Appendix 4 includes each of the outcome measures / instruments used in the included studies within the summary table.

4.6 Year of study publication

Over the last 10 years, there has been an overall increase in the number of studies published in Australia which examine medium to long term outcomes following injury. Figure 5 shows the growth in the number of published studies, peaking with 10 studies in 2008, and six published studies in 2009 and 2010.

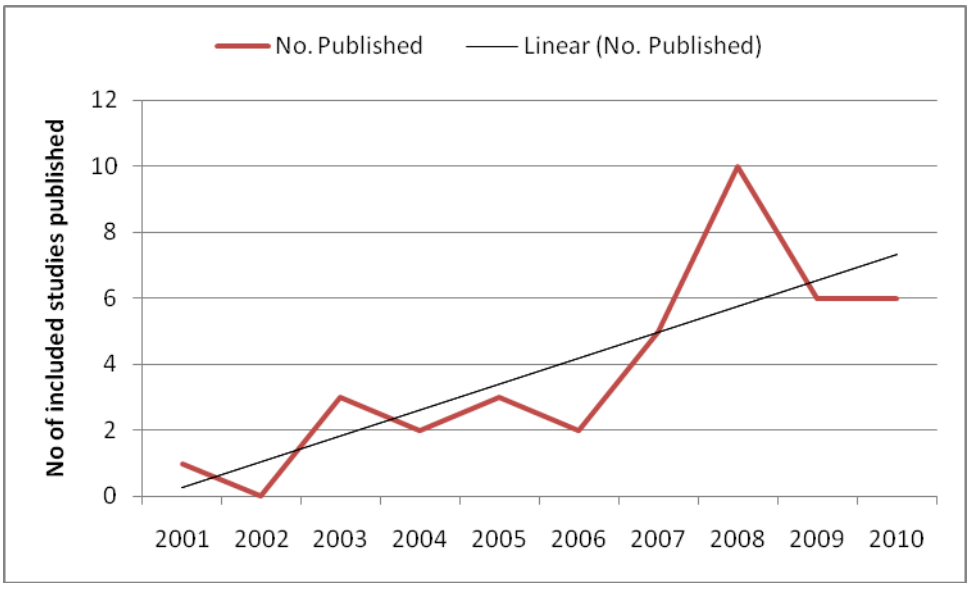

Figure 5 No. of included studies published by year, over the past 10 years

4.7 List of all deficits (LOAD) framework

The 38 studies focused on a total of 115 LOAD framework key components. The majority of studies reported outcomes related to the individual (91%; 105/115). Only a few studies included analysis on the impact of injury on society (9%; 9/115), and the family (1%; 1/115) (See Figure 6).

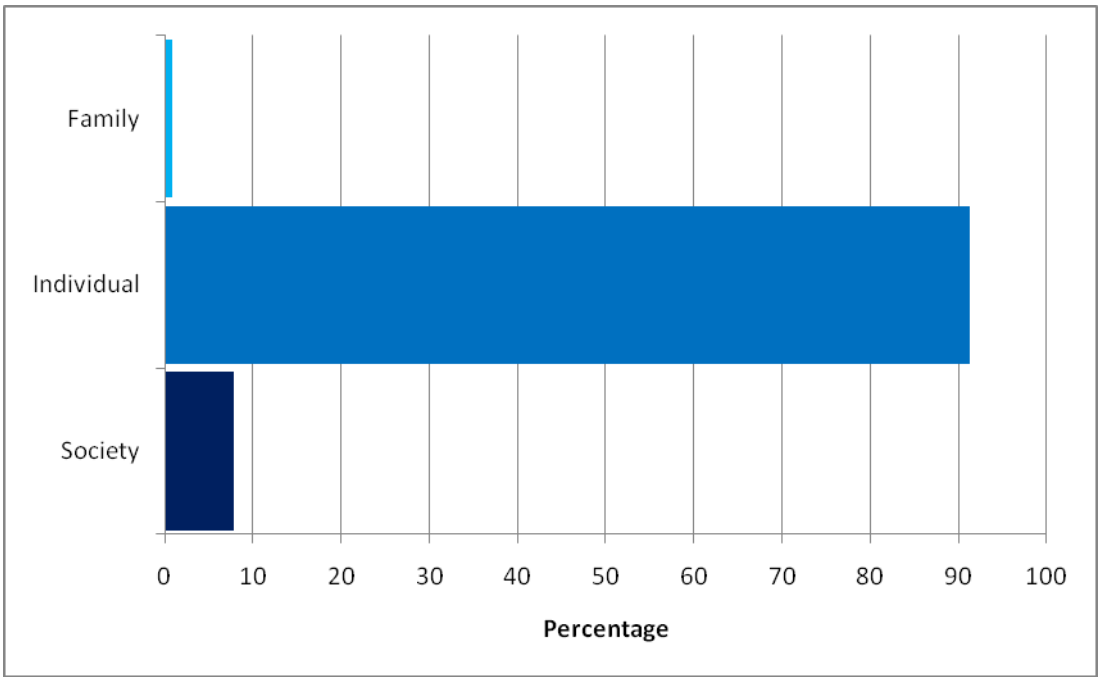

Figure 6 Study focus based on LOAD framework category

There was variability even within major LOAD framework categories (Figure 7). The single study which examined the impact of injury on the family focused solely on 'dependant consequences'. The nine studies which reported the impact of injury on society focused on the economic costs to society. The remaining studies focusing on the impact of injury on the individual predominately administered outcome metrics aimed at measuring 'long term physical disability', 'diminished quality of life' and 'psychological disability'. 'Intangible costs' and 'concomitant disease' were not measured.

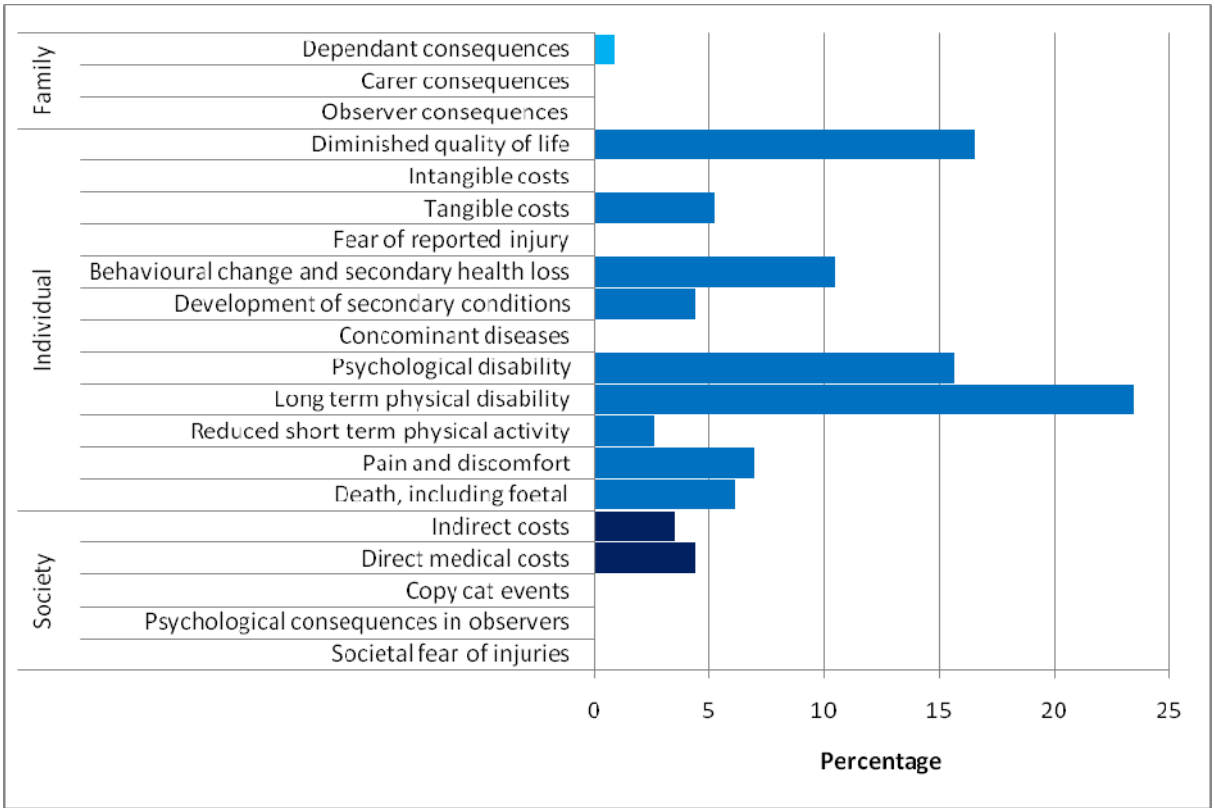

Figure 7 Study focus based on detailed LOAD framework category

4.8 International Classification of Functioning (ICF) Categories

The 38 included studies were classified into four ICF 'constructs/qualifiers' categories based on the focus of the reported outcome. The majority of studies examined the 'activities and participation' component, equally focusing on the subjects 'performance' and 'capacity' following injury (both 36%; 32/90). No studies focused on 'change in body structure', however 29% (26/90) studies reported outcomes relating to 'change in body function' (Figure 8).

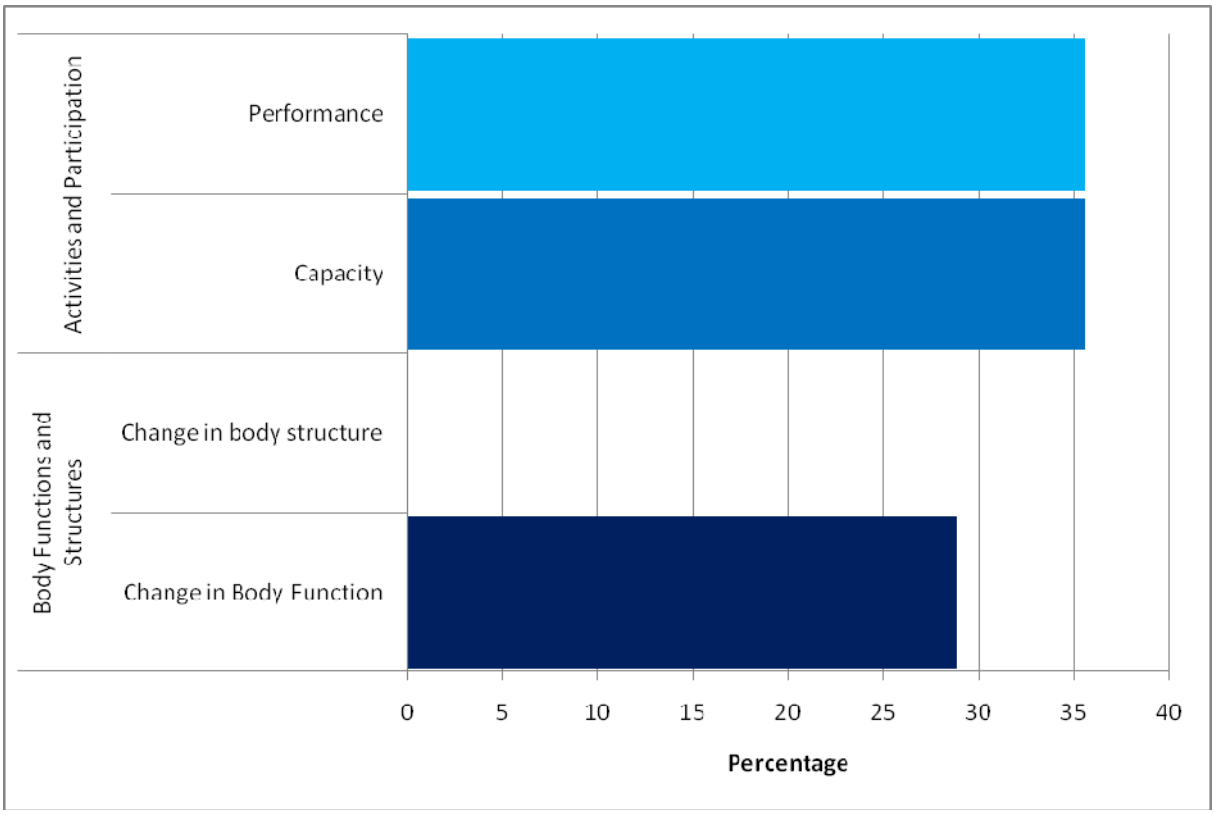

Figure 8 International Classification of Functioning (ICF) Functioning and Disability categorization of included studies

4.9 Website review

Eleven websites were reviewed (Table 3) and this yielded eight additional data sources, available within Australia, that were not identified within the literature review (Table 7). Four sources were based in Victoria; the Compensation Research Database (CRD), TAC Client Outcomes Survey, The Alfred Hospital's Intensive Care Traumatic Brain Injury Database and the Victorian Population Health Survey.

Table 7 Additional sources of injury outcome data identified by website review

Source
Australasian Rehabilitation Outcomes Centre
Compensation Research Database
TAC Client Outcomes Survey
The Macquarie University, Mild Traumatic Brain Injury Clinic
The Alfred Hospital's Intensive Care Traumatic Brain Injury database
Orthopaedic trauma management and outcomes documentation program and database
Queensland Trauma Registry
Victorian Population Health Survey

A summary of the other source websites can be found in Appendix 5, including the websites from which the sources originate and relevant web links.

4.10 Interviews with informants

Eight key Victorian informants were invited to participate in the interview. Five (62%) informants were either interviewed in-person or provided a written response to the interview questions.

The informants who responded to the interview came from university, compensation and clinical research settings, each with a very strong understanding of injury research from their respective sectors.

There were six additional data sources identified through the informant interviews which were not identified by either the literature review or the website review. These are summarised in Table 8.

Table 8 Additional sources of injury outcome data identified by informant interview

Source
Australian Bureau of Statistics – Work-related Injuries Survey
Medicare
National Injury Surveillance Unit (NISU)
Safe Work Australia national dataset
WorkSafe internal claims database (ACCTION)
WorkSafe Injured Worker Survey (IWS)

In addition, the informants were asked to identify the strengths and weaknesses of the data sources that they were familiar with. These are summarised in Table 9.

Table 9 Strengths and weaknesses of data sources identified by key informants

Strengths	Weaknesses
Regularly updated, contemporary	Universal lack of consistency in diagnostic coding between databases
Often relevant to the population from which data is collected (eg. TAC / WorkSafe)	'Long term data' unavailable
Much of the data can be linked with other regsitries	Some lack detailed information (eg. return to work information / clinical information)
	Potential response bias where data not collected from an independent body.
	Some data reliant on 'Self Report'
	Difficult to access
	Some incomplete datasets

The informants were asked to state any gaps they perceived in injury outcomes research in Australia. These are summarised in Table 10.

Table 10 Perceived gaps in injury outcomes research in Australia as identified by key informants

Perceived gaps
What measures should be used for; function, quality of life (specific or general)?
Most appropriate time(s) of outcome measure in relation to injury?
How to best measure pre-injury health status (especially in children)?
The magnitude of contribution family socio-economic factors, family attitudes and developmental stages impact of a child's outcome?
Detailed information on return to work outcomes, particularly the type of work people go back to following their injury
Comprehensive Spinal Cord Injury registry with minimal but regular follow-up data
Long term health care data

4.11 Final list of injury outcome data sources identified

The following table lists each of the sources of injury outcome data that was identified through the literature review, website review or key informant interview.

Table 11 Final list of injury outcome data sources identified

Data Source	Summary	Status
Australian Bureau of Statistics – Work-related Injuries Survey	Reports adults aged 15 years and older, who worked at some time in the last 12 months and experienced their most recent work-related injury or illness in that period	Ongoing
Australasian Rehabilitation Outcomes Centre	Reports rehabilitation data from all rehabilitation units who are members of AROC	Ongoing
Australian Spinal Cord Injury Registry (ASCIR)	Reports health data for all spinal cord injuries managed by a spinal cord injury unit in Australia	Ongoing
BIRP Centre	Provides comprehensive Brain Injury Rehabilitation Services to the population of NSW	Ongoing
Head Injury Database (Epworth)	Records data from the ABI rehabilitation units located at Epworth hospital (Richmond and Camberwell campuses)	Ongoing
ISCRR Compensation Research Database	Contains client compensation and health service utilisation data	Ongoing
LHSORC	Contains data of all trauma patients who present to the Liverpool Hospital, NSW	Unclear
Medicare	Contains comprehensive health service utilisation and health cost information	Ongoing
National Injury Surveillance Unit (NISU)	Collect data relating to injury in the state of South Australia	Ongoing
NSW Trauma Registry (including paediatrics)	Collects data about seriously injured people admitted to trauma centres in NSW	Ongoing
Orthopaedic trauma management and outcomes documentation program and database (SA)	Provides data to support evidence based clinical practice for the orthopaedic trauma patient	Unclear
Queensland Trauma Registry	Collects data about seriously injured people admitted to trauma centers in QLD	Ongoing
RTA (NSW)	Collect information relating to road safety, registration of vehicles and road network / travel time information	Ongoing

Data Source	Summary	Status
Safe Work Australia national dataset	Collects a standard set of data items for inclusion in workers' compensation systems operating in Australia	Ongoing
SCI Registry (NSW and QLD)	Reports health data for all spinal cord injuries managed by a spinal cord injury unit in NSW and QLD (respectively)	Ongoing
SGIC (SA)	Contains client compensation and health service utilisation data	Ongoing
TAC Client Outcomes Survey	Contains data relating to compensation client experiences and satisfaction	Ongoing
The Alfred Hospital's Intensive Care Traumatic Brain Injury Database	Collects data about people admitted to trauma to the Alfred Hospital's ICU with traumatic brain injury	Unclear
The Macquarie University Mild Traumatic Brain Injury Clinic	Collection of data relating to patients who are referred to the clinic following mild traumatic brain injury	Unclear
VOTOR	Contains data of all patients who are admitted with orthopaedic injury to four health services within the state of Victoria	Ongoing
VSTR	Contains data of all major trauma patients who present to all trauma services within the state of Victoria	Ongoing
WorkSafe internal claims database (ACCTION)	Contains client compensation, injury and health service utilisation data	Ongoing
WorkSafe Injured Worker Survey (IWS)	Contains data relating to compensation client experiences and satisfaction	Ongoing

5. Discussion

The purpose of this project was to identify sources of injury outcome data. This project has highlighted that over the last 10 years there has been limited injury outcome research focusing on medium to long term functional and quality outcomes. There has, however, been an increase in the number of studies published, particularly in the last half of the previous decade.

A number of data sources were identified across Australia. Most of the studies originated from a single site, related to a single cohort study where a limited number of participants were recruited and followed-up for a finite period. There were, however, a number of studies which recruited from multiple centres, utilising predominantly registry data (e.g VSTR, VOTOR, SCI Register). The majority of studies have originated from Victoria, with VOTOR and the VSTR being the main source of published clinical, long term functional, return to work and health related quality of life data.

There was wide variability in the populations studied, with most focusing on adult trauma, adult traumatic brain injury and adult orthopaedic injury. Likewise, the majority of data sources focus predominately on severe injuries. These studies have focused on injuries which have required a period of hospitalisation or operative intervention. In contrast, the majority of compensation claims are for mild injuries. The TAC Client Outcomes Survey is one data source which focuses on clients in the Recovery claims division, comprises mild and moderate injuries, and is cross-sectional in nature.

The most appropriate time to study outcomes following injury is not clear.[13] Baldry Currens & Coats (2000)[13] suggest that outcomes should be measured 12-months following injury. Any time prior to this may be confounded by the varying rates of recovery between individuals, and any time beyond this risks loss to follow-up.[13] However, a consensus guideline suggest three time points for follow-up; 3, 12 and 24-months for assessment of quality of life following multiple injuries.[14] The length of follow-up of the included studies reviewed was typically less than 24-months, and in most cases, 12-months or less. This is a limitation of these studies from the point of view of investigators, clinicians, and other stakeholders (e.g. TAC) who are interested in long term outcomes. Other studies suggest that even 24-months following injury, many still show large deficits from full recovery measured by pre-injury status or against population norms.[7] This represents an opportunity for future research examining outcomes beyond the 12-month time frame, to assess their validity and utility. Within Victoria, several data sources provide the opportunity to do longer-term follow up, including the VSTR, VOTOR and the Epworth head injury database. Each of these databases has well established and successful data collection methodologies. The VSTR and VOTOR have demonstrated high follow-up rates,

particularly for transport-related trauma patients. The Epworth Head Injury Database has data pertaining to extended follow-up periods many years after sustaining a TBI.

There was a wide variety of instruments used to assess outcomes following injury. A lack of consensus on the optimal health-related quality of life instruments exist as evidenced by the large number of outcome metrics used across the studies. Overall, there were over 60 different health related quality of life and functional measures used across the 38 included studies. Whether this should be seen in a negative light is questionable given the broad foci of the studies, addressing many of the key LOAD components, at least across the individual domain. The five most commonly administered outcome measures were not unexpected. Mortality following hospital discharge remained the most common outcome measure among the included studies, however there is a need to measure the quality of survival given the potential for long term disability following injury.[3] The ability to follow a patient's recovery over time and report on their function and quality of life provides a far more comprehensive description of patient outcomes.[3] While a number of consensus statements have been published,[14-16] they have not been well adopted by Australian studies, potentially due to contextual issues in implementing the recommendations in the local setting. For example, the most recent consensus statement recommends the use of the EQ-5D which was developed in Europe and has no available population norms for Australia. In contrast, there are Australian population norms for the SF-12 (Version 1 and more recently Version 2 as a result of work the TAC commissioned by A/Prof Graeme Hawthorne) and the SF-36 (Versions 1 and 2). It is therefore not surprising that the SF-36/SF-12 were commonly employed to measure functional health and well-being in this review of injury outcome sources. The intensity of persistent pain and global functional outcome using the GOS-E were also common. The SF-36, SF-12, GOS-E and pain are potentially over-represented in the results as these are the outcomes routinely measured by the trauma registries which have had the greatest output during the last decade. After removing the studies utilising data from the trauma registries, the remaining studies use a wide range of different outcome measure, further supporting the lack of consensus for outcome measurement instruments. It is also worth noting that the various Victorian agencies engaged in injury outcomes research regularly interact, and this may explain the consistency of the use of some measures (e.g. the SF-12) across studies and data sources.

This project categorised the outcome assessment focus of included studies according to the injury List Of All Deficits (LOAD) framework[1] and the ICF. The LOAD framework was specifically designed to identify the important outcomes from injury, providing a disease-specific framework to complement the broader WHO developed ICF. The LOAD framework and the ICF provided the means by which to assess the comprehensiveness of injury studies, and identify research gaps and opportunities. The majority of included studies examined the impact of injury on the individual. Studies most commonly focused on assessing long term physical activity,

diminished quality of life, psychological disability, and behavioural change and secondary health loss.

Studies focusing on the family and societal domains are underrepresented in Australia. The family domain challenges investigators to focus on the consequences experienced by family, close friends and carers of individuals who have sustained an injury. These consequences include psychological, economic and quality of life impacts. Often dependants are adversely impacted where the main earner in the family is injured or killed, both through a reduction in family income, and the ability of the parent to engage with their children. The burden of injury can be manifest more broadly than the individual and family. Society can be impacted in a number of ways; increasing fear of injury when injury is broadcast through traditional and social media, psychological distress and sequelae in observers, copy cat events, and direct and indirect costs. Only a few of the studies included in this project examined direct (eg. patient care costs such as ED, prehospital, nursing home care) and indirect costs (eg. reduced productivity). The contribution of compensation data could have a direct and notable effect on the ability of investigators to analyse and report pertinent economic cost to both the individual and society into the future.

There were several obvious gaps in the individual domain. These included; intangible costs (a theoretical monetary value placed on the diminished well-being of individuals due to physical, mental and behavioural problems following injury), fear of reported injury (fear of the injury occurring again leading to the individual returning to pre-injury level of activity), and concomitant diseases. One explanation for the lack of reporting of these may be the 'theoretical nature' of each key component, making the data more difficult to collect than traditionally collected outcome data. Each of these categories would provide valuable information to compensation organisations, specifically informing costs associated with injury and potential reasons for delayed recovery and return to work.

The focus of outcome measures were also considered in the context of the International Classification of Functioning (ICF), functioning and disability categorisation.[3, 8] The ICF is a useful conceptual classification designed to establish a common language for describing health-related[8] and disability states.[9] In this project, it provided a useful classification to broadly assess each of the included studies against, and to categorise the focus of the outcome measures used. Of the ICF functioning and disability parts, included studies consistently focused on activities and performance outcomes, and changes in body function following injury. No studies focused on the 'change in body structure' qualifier. As the name suggests, change to body structures requires information on the nature of the change in the respective body structure. It is possible that investigators were comfortable that such 'disability' may be picked up when assessing body function, capacity and performance.

A recent addition to the sources of data about the Victorian injury community is the ISCRR Compensation Research Database. Compensation databases have the potential to add considerable benefit, complementing existing clinical and outcome databases. They could provide researchers with an insight into the provision of healthcare by medical and paramedical providers to injured persons in the many months and years following their injury.[17] The sole use of hospital clinical and administrative databases risks limiting the health service utilisation and economic information available to the researcher.

The website review and expert informant interviews were important for identifying established sources of injury outcome data. Both of these components of the project yielded additional sources which were not identified through a systematic review of the injury literature. There are a number of outcome data sources within Australia, and the majority of sources originating from Victoria. In fact, the largest, most robust injury datasets internationally (VOTOR and VSTR) are maintained within Victoria.

The expert informant interviews proved useful in both identifying additional sources of injury data, and in providing potential data source strengths and weaknesses and informant perceived gaps in injury outcomes research. There were commonly held beliefs that many sources lacked long term follow-up data. In some cases, the data sources were limited as data was incomplete, or lacked specific or detailed information; the lack of detailed return to work information was provided by one informant as an example. In terms of research gaps, the informants reinforced the lack of clarity around the most appropriate outcome metrics to assess physical function, quality of life and pre-injury health status (particularly in children). The informants also suggested that there is potentially more work to be done on how family socio-economic factors, and family attitudes and developmental stages, impact a child's outcome.

5.1 Data sources that are of potential value to the Transport Accident Commission

We believe that the following six data sources are of high potential value to the TAC and contain data that can be accessed, following consultation with the appropriate groups, due to their involvement in data collection or funding of the project:

I. VOTOR
II. VSTR
III. Compensation Research Database
IV. Head Injury Database (Epworth)
V. Client Outcomes Study (TAC)
VI. TAC Claims Data

We believe that the following six data sources may be of value. It is unclear whether the TAC will be able to access the data from these sources, but further investigation may be warranted:

I. Australasian Rehabilitation Outcomes Centre
II. Australian Spinal Cord Injury Registry
III. Medicare
IV. National Injury Surveillance Unit
V. Spinal Cord Injury registries (NSW & QLD)
VI. Alfred ICU Brain Injury Database

The remaining 11 are not of value to the TAC as they are unlikely to contain any TAC client data, either because they are from other states or include participants injured in non-transport-related events.

5.2 Limitations

There were several limitations associated with this project.

The studies reviewed report outcomes from a variety of injury mechanisms. No studies focussed exclusively on compensable clients or motor accident victims, although some do have a large proportion of participants from such groups (eg. the Gabbe studies[18-20]).

The majority of compensation claims are for mild injuries, yet most of the data sources focus on severe injuries, such as those that have required a period of hospitalisation or operative intervention. Despite this being a limitation for comparison between populations, combining the TAC data sources with the larger injury registries ensures a comprehensive capture of case-mix.

It is possible that some studies, which may have been of value to this project, have not been identified through the systematic review process as they are currently underway, in press, or recently published. A strength of this project was the 'mixed methods' approach to identifying data source, which included searches or potentially relevant web sites and semi-structured interviews with key informants.

6. Recommendations and priority areas for future injury outcomes research for Victoria

I. The LOAD framework has highlighted a number of areas where injury research is lacking. Focus of research has largely been on the individual, rather the domains of family and society. Future research should consider the effect of an individual's injury on the family and society. Furthermore, future injury research would benefit from the focus on the individual being broadened to include analysis of the tangible and intangible costs, and prevalence and burden of concomitant disease.

II. Long term outcome metrics, measured at clinically appropriate time periods are critically important. Every effort should be made to support the ongoing development of such data repositories.

III. The utility of extended (5-10 years) follow up by registries such as VSTR, VOTOR and the Epworth Head Injury Database should be investigated. Currently information is collected from patients up to 24-months following injury for the VSTR, and to 12-months for VOTOR. We note that the Epworth Head Injury Database has some data up to 20 years post-injury. Extended follow-up beyond the existing 12-24 months may then also align with key indicators for compensation agencies such as litigation outcomes and health service costs. The true value of collecting data at these longer time periods (eg, 10 years post-injury) still needs to be established.

IV. The contribution of compensation database data in outcomes research in this country is still in its infancy, but has the potential to add value to existing injury outcomes data sources. The true utility of compensation data warrants further investigation.

V. The systematic identification of state data sources is both feasible and important to those involved in the prevention or care of the injured. This process should be repeated regularly, and given the rapid increase in the number of studies being published in this area over the last five years, should be repeated at least bi-annually, to ensure the information remains up to date, and that research funds are channeled to address gaps in knowledge and high priority outcomes.

7. Conclusions

This project has highlighted that over the last 10 years there has been limited injury outcome research focusing on medium to long term functional and quality outcomes.

A coordinated approach to identifying sources of injury outcomes data, both routinely collected and research-based, has significant benefits for injury stakeholders, including reduced duplication of effort in collecting outcomes data and a greater understanding of data that may be used for organisational performance monitoring.

There is opportunity for TAC to partner with other research organisations to focus on a range of research areas which would be of potential benefit to both the TAC and the injury community. Areas identified that require investigation include; analysis of tangible and intangible costs associated with injury, prevalence and burden of concomitant disease, the utility of extended (5-10 years) follow-up by injury outcomes registries.

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Appendices

Appendix 1. Medline search strategy and yield (As of 20/04/11)

Number	Key word	Result
1	exp "Wounds and Injuries"/	601791
2	injur$.mp.	614614
3	exp Health Status Indicators/	149002
4	exp Disability Evaluation/	31572
5	exp Health Status/	79820
6	accident.mp.	37878
7	disability.mp.	77512
8	exp "Outcome Assessment (Health Care)"/	509666
9	outcome.mp.	876588
10	exp "Quality of Life"/	88132
11	health status evaluation.mp.	39
12	health status measure.mp.	207
13	exp Morbidity/	288412
14	exp Australia/	80660
15	exp Victoria/	5015
16	exp "Recovery of Function"/	20355
17	1 or 2 or 6 or 7	962946
18	3 or 4 or 5 or 8 or 9 or 10 or 11 or 12 or 13	1357746
19	17 and 18	158901
20	14 and 19	1947
21	15 and 19	264
22	limit 20 to (humans and yr="2000 - Current")	1394
23	limit 21 to (humans and yr="2000 - Current")	197

Appendix 2. Cochrane search strategy and yield (As of 20/04/11)

Number	Key word	Result
1	MeSH descriptor Wounds and Injuries explode all trees	13027
2	MeSH descriptor Health Status Indicators explode all trees	13290
3	MeSH descriptor Disability Evaluation explode all trees	31572
4	MeSH descriptor Health Status explode all trees	79820
5	MeSH descriptor Outcome Assessment (Health Care) explode all trees	509666
6	MeSH descriptor Quality of Life explode all trees	88132
7	#1 OR #2 OR #3 OR #4 OR #5 OR #6	101212
8	MeSH descriptor Australia explode all trees	2065
9	injur*:ti,ab,kw	17272
10	#7 AND #8 AND #9	87
11	#10, from 2000 to 2011	74

Appendix 3. Interview questions

1. What **sources** (i.e. specific registries, specific databases, collected firsthand from study participants, health records) of injury outcome data have you used in your research?

2. Of the sources of injury outcome data you are familiar with (and have already described), could you please identify the **strengths and weaknesses of these datasets**, from your personal perspective/experience?

3. Are you aware of any **other sources** of injury outcome data in Australia that you have not used in your research?

4. What types of **outcome data do you think is currently lacking** in Australia?

5. What do you think are the **gaps in injury outcomes research** in Australia?

Appendix 4. Summary of studies describing the post-injury outcomes of injured people in Australia

Study	Design	Study Population	Enrolment proportion	Major exclusions	Study Centre / database	Age at injury	Instruments / outcomes	Post-injury Time Points	LOAD Categories	ICF Category (constructs / qualifiers)
Anderson 2009a[21]	Retrospective cross-sectional design	124 Adult survivors of childhood TBI	41% of those eligible	History of neurological, developmental or psychiatric disorder	RCH (Vic)	Mean 9.9 [SD 2.6]	-30 item participant functional outcome questionnaire -SPRS	Mean 13.7 year following injury	I4 I5 I7	Change in body function
Anderson 2009b[22]	Prospective longitudinal study	54 Children aged between 2 and 7 years with TBI	64% of those eligible	Non-accidental TBI Penetrating head injury Previous TBI Pre-existing neurologic or developmental disorder	RCH (Vic)	2 – 7 years	-Bayley Scales of Infant Development -Wechsler Preschool Primary Scale of Intelligence -Revised Wechsler Intelligence Scale -FSIQ	12 months 30 months 5 years	I3 I4	Change in body function
Andrew 2008[23]	Prospective cohort study	366 Adults admitted to two level 1 trauma centres	71.9% of those eligible	Nil	VOTOR (Vic)	15 – 74 years	-SF-12v1	12 months	I4 I5	Change in body function
Bryant 2003[24]	Prospective cohort study	171 Motor vehicle accident patients consecutively admitted to hospital were assessed for acute stress disorder	78% of those eligible	Dissociative amnesia	Unclear	Male mean 30.0 [SD 11.5] Female mean 33.4 [SD13.3]	-ASDI -PSTD module from the CIDI	Up to 1 month 6 months	I5 I7	Capacity Performance

Study	Design	Study Population	Enrolment proportion	Major exclusions	Study Centre / database	Age at injury	Instruments / outcomes	Post-injury Time Points	LOAD Categories	ICF Category (constructs / qualifiers)
Bryant 2010[25]	Prospective cohort study	1084 randomly selected adult trauma patients from recent admissions to four major trauma hospitals	All	Mod or Severe brain damage Psychotic or suicidal Non-Australian visitors Under police guard	4 major trauma hospitals (Aus)	18+ years	-ISS -MINI -CAPS -DSM-IV -WHOQOL-AV	3 months 12 months	I4 I5	Change in body function Capacity Performance
Cameron 2008[5]	Population based cohort study	Major trauma (ISS>15) presentation to both Level 1 adult trauma centres in Victoria	Nil	Nil	VSTR (Vic)	Median 40 (IQR 24-62)	-Mortality -Incidence	Yearly	I1	Change in body function
Catroppa 2008[26]	Prospective longitudinal	48 injured children and 17 healthy controls who presented with TBI	57% of those eligible	Nil	RCH (Vic)	2.0-6.11 years	-FSIQ	6 months 30 months 5 years	I5 I8	Capacity Performance
Chan 2003[27]	Prospective cohort study (survey)	3088 victims of motor vehicle accidents who made a claim through the State Insurance Commission, South Australia	13% response rate to survey	Suspected fraud claim Claim made >1yr after accident	SGIC, (SA)	Mean 39.11 [SD 13.11] (age at follow-up)	-GHQ-28 -PTSD Checklist-Civilian Version -Dissociative Experiences Scale	9 months	S4 S5 I5 I7 I10	Capacity Performance
Chia 2004[28]	Retrospective cohort study	120 children with pelvic fractures presenting to The Children's Hospital at Westmead	96% of those eligible	Nil	The Children's Hospital Westmead (NSW) Paediatric Trauma Registry(NSW)	Median 9 (range 1-16) years	-Mortality -Adverse events -?Reported persistent and behavioral problems	Mean 36 (range 7 - 156) months	I1 I4 I5 I8	Change in body function Capacity Performance

Study	Design	Study Population	Enrolment proportion	Major exclusions	Study Centre / database	Age at injury	Instruments / outcomes	Post-injury Time Points	LOAD Categories	ICF Category (constructs / qualifiers)
Clay 2010[29]	Multicentre prospective cohort	168 adult patients with a range of non-life-threatening orthopaedic injuries presenting to 1 of 4 Victorian hospitals	All	Intentional injury Significant TBI	4 Victorian Hospitals (Vic)	18 – 64 years	-Short-form MPQ -SF-36 -DASS – 21	2 weeks 6 months	I2 I3 I4 I5 I7 I12	Capacity Performance
Czech 2010[30]	Cross-sectional study	Road traffic accident unit record data for the period 2001 to 2007	All	Nil	RTA (NSW)	All	-Alcohol related crashes -Aus Gov Bureau of Transport Economics (2000)	Not applicable	S4 S5	
Dorsett 2008[31]	Longitudinal panel	51 adult patients with acute traumatic SCI discharged from a QLD SCI service	46/53 (87%)	Nil	SCI Service (QLD)	16-72 years	-Mortality -The Life Situation Questionnaire	6 months 12 months 24 months 36 months 10 years	I1 I4 I7 I10	Change in body function Capacity Performance
Faux 2008[32]	Prospective controlled study	100 sequential admissions to a level 2 ED in Sydney with mild traumatic brain injury (100 minor injury controls)	All	Nil	ED (NSW)	17 + years	-GOAT -modified Westmead PTA scale -modified RSC	1 month 3 months	I2	Capacity Performance
Ferguson 2008[33]	Prospective cohort study	60 patients with isolated tibial shaft fractures treated at two adult trauma centres in Victoria	All	Nil	VOTOR (Vic)	16 – 77 years	-Pain score -SF-12v1 -SIPw	1 year	I2 I4 I12 S5	Capacity Performance
Fitzharris 2007[34]	Prospective cohort study	62 otherwise healthy adults admitted to hospital following traffic crashes	43% of all admissions in Vic	Serious head or spinal injury	1 trauma centre and 2 metropolitan teaching hospitals (Vic)	18 – 59 years	-Pain score -SF-36 -HAQ	2 months 8 months	I2 I4 I12	Change in body function Capacity Performance

Study	Design	Study Population	Enrolment proportion	Major exclusions	Study Centre / database	Age at injury	Instruments / outcomes	Post-injury Time Points	LOAD Categories	ICF Category (constructs / qualifiers)
Gabbe 2007a[18]	Prospective cohort study	2388 orthopaedic trauma patients admitted to one of two level 1 adult trauma centres.	77% of eligible participants	Serious head injury (AIS>2), non-English speaking, dementia, mental illness	VOTOR (Vic)	Median 44.8 IQR 21.1-64.5 years	-SF-12v1	6 months 12 months	I4 I8 I12	Change in body function Capacity Performance
Gabbe 2006[19]	Prospective cohort study	1102 major trauma patients definitively managed at an adult MTS	67.1% of eligible participants	Survived 12 months from injury	VSTR (Vic)	Median 40 IQR 15-94 years	-Living status -Return to work -Modification of the FIM	6 months	S5 I4 I8 I10 I12	Change in body function Capacity Performance
Gabbe 2007b[20]	Prospective cohort study	707 patients with orthopaedic injuries funded by no-fault compensation scheme for transport-related injury or deemed non-compensable	68.8% of eligible participants	Died during hospitalisation Non-English speaking, dementia, mental illness Covered by worker's compensation	VOTOR (Vic)	18-64 years	-SF-12v1 -Return to work	12 months	S4 I4 I8 I12	Change in body function Capacity Performance
Hall 2001[35]	Prospective cohort study	123 patients with severe trauma admitted to ICU at the Royal Perth Hospital	All	Nil	Royal Perth Hospital ICU (WA)	Median 29 IQR 20-38 years	-Mortality -Active rehabilitation	6 months	I1 I4 I12	Capacity Performance
Hancock 2005[36]	Prospective cohort study	62 consecutive adult patients seen in 2 orthopaedic clinics following ankle fracture	All	Compensable Not weight bearing	2 orthopaedic clinics (NSW)	17-83 years	-OMAS -LEFS -GPE	6 weeks 6 months	I3	Change in body function Capacity Performance
Haran 2005[37]	Prospective cohort study	305 patients with SCI at recruitment to a randomised control trial	9% of those on the register	Nil	SCI register (NSW)	1 mo – 61 years	-SF-36	Mean interval since SCI 14±12 years	I4 I8 I12	Change in body function Capacity Performance

Study	Design	Study Population	Enrolment proportion	Major exclusions	Study Centre / database	Age at injury	Instruments / outcomes	Post-injury Time Points	LOAD Categories	ICF Category (constructs / qualifiers)
Harradine 2004[38]	Longitudinal, prospective multicentre study	198 patients with severe TBI from 11 participating rehabilitation units	All	Previous TBI, ABI or past medical history which may affect recovery	Brain Injured Rehabilitation Program (BIRP) centres (NSW)	Mean 32.1 [SD 12.2]	-DRS -MPAI -SPRS -GHQ-28 -SF-36	Rehab admission 18 months	I4 I5 I8 I12	Change in body function Capacity Performance
Harris 2008[39]	Prospective cohort study	731 consecutive adult patients presenting to a major trauma centre with accidental major trauma	All	Nil	Liverpool Hospital Surgical Outcome Research Centre (Registry) (NSW)	19-91 years	-ISS -SF-36 -SES -Compensable status	1-6 years	I4 I5 I8 I12 S4	Change in body function Capacity Performance
Harris 2009[40]	Retrospective cohort study (survey)	355 adult major trauma patients who had previously presented to a NSW major trauma facility	61% of those eligible	Nil	Trauma Centre (NSW)	19-91 years	-ISS -SES -Compensable status	Unclear	I10 S4	Capacity Performance
Hawthorne 2009[12]	Prospective matched case – control	66 randomly sampled patients with TBI matched to non-trauma controls.	61% of those eligible	GOSE<3 SCI Terminal illness Non-English speaking	RMH Trauma Regsitry (Vic)	Mean 39 [SD 15]	-SF-36 -HRQoL -GOSE	3 mths to 15 years	I4 I5 I8 I12	Change in body function Capacity Performance
Homes 2007[10]	Randomised controlled trial	117 adult patients admitted to one of two level 1 trauma centres following major trauma	80% of those eligible	History of prior head injury Non-English speaking Attempted self-harm Psychiatric illness Died	Alfred RHM (Vic)	Mean 37 [SD 14.7]	-SCID -BDI -HADS -PTC -AUDIT	3 months 6 months	I5 I8	Capacity Performance

Study	Design	Study Population	Enrolment proportion	Major exclusions	Study Centre / database	Age at injury	Instruments / outcomes	Post-injury Time Points	LOAD Categories	ICF Category (constructs / qualifiers)
Kenardy 2008[11]	Cluster randomised controlled trial	104 children admitted to paediatric units following accidental trauma.	All	Suspected physical or sexual abuse Head injury	Mater Children's and Royal Children's (QLD)	7-15 years	-Child IES -IES -DASS - 42 -Subjective account of reaction	1 month 6 months	F3 I5	Capacity Performance
Kingston 2010[41]	Retrospective, exploratory design (survey)	65 people who had experienced a major traumatic hand injury and were treated at the OT department at a major regional hospital	33% of those who were mailed a survey	Nil	A hospital (QLD)	Mean 45.9 [SD 15.3]	-Mailed survey -UEFI	1-3 years following injury	I2 I4 I12	Change in body function Capacity Performance
Myburgh 2008[42]	Prospective inception cohort study	635 adult patients from 16 centres with TBI admitted to the ICU of major trauma centres.	All	Nil	16 tertiary referral trauma centres in Aus and NZ (NSW/Vic)	Mean 41.6 [SD 19.6]	-Mortality -GOSE	6 months 12 months	I1 I12	Capacity Performance
O'Mullane 2009[43]	Retrospective cohort study	803 adults with assault related trauma who were admitted to hospitals in Victoria	All	Nil	VSTR (Vic)	15+ years	-GOSE	6 months	I4 I12	Change in body function Capacity Performance
O'Donnell 2010[44]	Longitudinal cohort study	391 randomly selected injury patients with moderate to severe injuries.	29% of those eligible	Mod or Severe brain injury Compensable workplace injury Psychotic Deliberate self harm Current misuse of illicit substance	Royal Melbourne Hospital & Alfred Hospital (Vic)	Mean 38.2 [SD 13.2]	-Compensable status -CAPS -HADS -WHODAS II -WHOQOL-Bref -Pain score	24 months	I2 I4 I5 I8 I12	Change in body function Capacity Performance

Study	Design	Study Population	Enrolment proportion	Major exclusions	Study Centre / database	Age at injury	Instruments / outcomes	Post-injury Time Points	LOAD Categories	ICF Category (constructs / qualifiers)
Saltapidas 2007[45]	Prospective cohort study	70 patients with TBI from English speaking and CALD backgrounds	All	Neurological disorder apart from TBI Psychiatric disturbance, including drug and alcohol abuse, requiring treatment	Head injury database at Epworth Rehabilitation Centre (Vic)	17-72 years	-MOT-Q -CHART	4-89 months following injury (mean = 27 months)	I4 I5 I12	Change in body function Capacity Performance
Slewa_Younan 2008[46]	Prosepctive multi-centred group comparison study	25 women (matched to 45 men) admitted for treatment following non-penetrating moderate to severe TBI.	69% of those eligible	History of prior head injury Psychiatric disturbance Significant alcohol / substance abuse	5 major trauma centres in Sydney (NSW)	15-50 years	-Serum endogenous sex hormones -GOSE -GCS -PTA	7 days 3 months	I4 I8	Change in body function Capacity Performance
Spinecare 2003[47]	Prospective cohort study	80 football players with documented spinal cord injury	85% of those eligible	Injuries from outside Australia	6 spinal cord injury units (Aus)	Mean age at injury 23.5 years	-Frankel grade -Mortality	Unclear	I1 I4	Change in body function Capacity Performance
Urquhart 2006[48]	Prospective cohort study	1181 patients following treatment for orthopaedic trauma	90.6% of those eligible	Died during hospitalisation Non-English speaking, dementia, mental illness Less than 6 months post injury	VOTOR (Vic)	15-100 years	-Pain score -SF-12v1 -SIPw	6 months	I2 I4 I5 I10 I12	Change in body function Capacity Performance
Utomo 2009[49]	Prospective cohort study	428 older adults (age > 64 years) with isolated TBI from the VSTR	All	Nil	VSTR (Vic)	65+ years	-Mortality -GOSE	6 months	I1 I4	Change in body function

Study	Design	Study Population	Enrolment proportion	Major exclusions	Study Centre / database	Age at injury	Instruments / outcomes	Post-injury Time Points	LOAD Categories	ICF Category (constructs / qualifiers)
Watson 2005[50]	Validation (AQoL) study	221 admitted injury patients from four major Victorian metropolitan hospitals	11% of estimated equivalent population	Non-English speaking Self-inflicted injury Head injury with neurological deficit	4 major hospitals (Vic)	18-74 years	-AQoL -SF-36	12 months	I4 I5 I12	Change in body function Capacity Performance
Yang 2010[51]	Prospective cohort study	264 patients following treatment for orthopaedic trauma	76.7% of those eligible	Pathological fractures Isolated orthopaedic injury managed by another unit	VOTOR (Vic)	Median 38 years	-Pain score -SF-12v1 -Global outcome questions -Return to work or study	12 months	I2 I4 I5 I10 I12	Change in body function Capacity Performance

Appendix 5. Summary of Website sources of describing the post-injury outcomes of injured people in Victoria

Website	URL	Source	Data Source	State of Origin	Studies
Institute for Safety, Compensation and Recovery Research	http://www.iscrr.com.au/news.html	Web page – News article	Compensation Database	Victoria	Elbers 2011[52]
NSW Government Lifetime care & support	http://www.lifetimecare.nsw.gov.au/Brain_Injury.aspx	Web based report	The Macquarie University, Mild Traumatic Brain Injury Clinic (Mild TBI Clinic)	NSW	Batchelor 2005[53]
Google.com	http://cicm.org.au/journal/2001/september/Outcome1.pdf	Journal article	The Alfred Hospital's Intensive Care Traumatic Brain Injury database	Victoria	Henzler 2001[54]
The University of Adelaide – Discipline of Orthopedics and Trauma	http://health.adelaide.edu.au/ot/rah/research/trauma/	Web page	Orthopaedic trauma management and outcomes documentation program and database	South Australia	Not Available
The Victorian Neurotrauma Initiative	http://www.vni.com.au/sitebuilder/about/knowledge/asset/files/99/final_vni_report_22julsml.pdf	Web based report	Australasian Rehabilitation Outcomes Centre	NSW	Access Economics Pty Limited[55]
The Victorian Neurotrauma Initiative	http://www.vni.com.au/sitebuilder/about/knowledge/asset/files/99/final_vni_report_22julsml.pdf	Web based report	Queensland Trauma Regsitry	Queensland	Access Economics Pty Limited[55]
The Victorian Government Health Information	http://www.health.vic.gov.au/healthstatus/vphs.htm	Web page	Victorian Population Health Survey	Victoria	Not Available

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Summary of Research Findings - No. *0711-006-R1B*

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Identification of sources of injury outcomes data in Australia

What are the implications for TAC?

- **Identification of data sources.** A coordinated approach to identifying sources of injury outcome data has significant benefits for injury stakeholders. The benefits include reduced duplication of effort in collecting data and a greater understanding of data that may be used for organizational performance monitoring.
- **Data source availability.** There are six data sources within Victoria that are considered to be of high potential value to the TAC for performance monitoring. The TAC already has strong involvement with these six datasets. A further six data sources were of possible value to the TAC and further investigation of these may be warranted.

What issues were addressed?

- **Identification of injury outcome data sources.** Australian injury outcome data sources were identified using several complimentary methods; systematic literature review, searches of the World Wide Web, and key informant interviews.
- **Studies identified were classified according to LOAD and ICF frameworks.** Each of the studies identified were mapped to the injury List of All Deficits (LOAD) and Work Health Organization's International Classification of Functioning (ICF) frameworks for the purpose of describing the research focus and identifying gaps.
- **Identification of data sources that may be used for TAC performance monitoring.** Data sources were identified as being of either of 'high potential value', 'possible value', or 'unlikely to be of value' to the TAC.
- **Recommendations and priority areas.** Recommendations and priority areas for future injury outcomes research for Victoria were provided, based on the findings of this work.

What are the research findings?

- **Data sources.** There has been an increase in the number of studies published in the area of injury outcomes over the past decade. Most studies originated from a single site, and participants were followed-up for a finite time period. The majority of studies have originated from Victoria, with VOTOR and the VSTR being the main sources of outcome data.
- **Populations studied.** There was wide variation in populations studied. Most data sources focus on severe injury, whereas the majority of compensation claims are for mild injuries.
- **Time periods.** The length of follow-up of the included studies reviewed was typically less than 24-months, and in most cases, 12-months or less.
- **Instruments used to measure outcomes.** There was a wide variety of instruments used to assess outcomes following injury. The SF-36, SF-12, GOS-E and pain were the most commonly used metrics, possibly as these are the outcomes routinely measured by the trauma registries which have had the greatest output during the last decade.

- **LOAD and ICF framework.** The LOAD and ICF framework were used to describe the research focus and identify potential gaps in injury outcomes research.
- **Valuable, local data sources.** Six data sources were identified which were deemed to be of high potential value to the TAC. These were; VOTOR, VSTR, Compensation Research Database, Head Injury Database (Epworth), Client Outcomes Study, and TAC Claims Data.

What do the findings mean?

- **Data source availability.** A number of data sources are available to the TAC locally, and can be accessed following consultation with the appropriate groups. Other data sources are of potential value and may warrant further investigation.
- **Opportunities for future research.** There is opportunity for TAC to partner with other research organisations to focus on a range of research areas which would be of potential benefit to both the TAC and the injury community. Areas identified that require investigation include; analysis of tangible and intangible costs associated with injury, prevalence and burden of concomitant disease, the utility of extended (5-10 years) follow-up by injury outcomes registries.

What methods were used?

- **Systematic review of the injury literature.** Several relevant literature databases were systematically searched for studies examining injury outcomes over the previous decade.
- **Searches of the World Wide Web.** A number of potentially relevant web sites were examined to identify additional sources of injury outcomes data
- **Informal interviews with expert local informants.** Eight key informants were invited to respond to an informal interview, seeking additional sources of injury outcome data, strengths and weaknesses of existing data sources and potential research gaps.

Who were the authors?

- Mr Paul Jennings – Monash University Department of Epidemiology and Preventive Medicine
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Where can I get further information?

A detailed research report is appended to this document. Copies of this research brief and the associated detailed report can also be obtained by contacting ISCRR directly:

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Accompanying documents to this research brief	
Title	**Report number**
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