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Trauma Data Scoping Project

final report

This document was prepared by the Qld Trauma Data Scoping Project Team:

Australian Centre for Prehospital Research
(Queensland Ambulance Service and the University of Queensland)

Queensland University of Technology
(including the National Centre for Classification in Health)

Trauma Clinical Network

Royal Australasian College of Surgeons

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AUSTRALAN CENTRE FOR PREHOSPITAL RESEARCH

TRAUMA DATA SCOPING PROJECT: FINAL REPORT

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Trauma Data Scoping Project **Investigators and Project Team**:

A/Professor Vivienne Tippett	Director, Australian Centre for Prehospital Research (ACPHR)
Professor Gerry FitzGerald	Queensland University of Technology
Dr Cliff Pollard	Chairman, National Trauma Registry Consortium (NTRC)
Professor Michael Schuetz	Chair of Traumatology (PAH)

Trauma Data Scoping Project **Steering Committee**:

Professor Leanne Aitken	Griffith University
Professor Nick Bellamy	Director, CONROD (University of QLD)
Mr John Hand	Commissioner, MAIC
Mr Jim Higgins*	[Former] Commissioner, QAS & Steering Committee Chair
Ms Kim Birch	Managing Director, MAIC
A/Professor Rob Pitt	Director, QISU
Dr Daryl Wall	Chair, Trauma Committee (QLD RACS)
Ms Barbara Williams	Director, Community Engagement Unit (Strategic Policy and Executive Services, DES)
Professor Andrew Wilson**	Executive Director; Policy, Planning and Resourcing Division (QLD Health)
*Mr David Melville	[Current] Commissioner, QAS & Steering Committee Chair
**Represented by:	Ms Faileen James, Senior Director

Trauma Data Scoping Project **Working Group**:

Project Manager	
Dr Kerrianne Watt	ACPHR
Expert Advisors	
Dr Cate Cameron	School of Medicine (Griffith University)
Ms Tamzyn Davey	NTRC and CONROD (UQ)
Ms Emma Enraght-Moony	ACPHR & National Centre for Classification in Health (NCCH) (QUT)
Dr Kirsten McKenzie	NCCH (QUT)
Ms Debbie Scott	NCCH (QUT)
Mrs Sue Walker	Director, NCCH (QUT)
Research Assistant	
Ms Ruth Taylor	QUT

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1.0 INTRODUCTION

In early 2007, the Trauma Plan for Queensland was endorsed in principle by the Queensland Emergency Medical System Advisory Council (QEMSAC) and Queensland Cabinet. Among other key targets for development, the Trauma Plan recognised the need for improvement to the current system of injury data collection in Queensland. The Trauma Data Scoping Project was funded by the Motor Accident Insurance Commission as an extension of the Queensland Trauma Plan Project (2001- 2006) in May 2007. The project was commissioned to:

- Scope existing injury and trauma data sets across the continuum of care from event to rehabilitation and discharge;
- Conduct a critical analysis of the national and international literature on trauma data;
- Identify impediments to the efficient and effective coordination and use of injury data;
- Identify options for improvements in the system of injury data collection; and
- Develop recommendations in consultation with stakeholders to facilitate a sustainable system of data collection, collation and interrogation to inform prevention and system improvement, and progress the intended objectives of the Trauma Plan in relation to data.

1.1 BACKGROUND TO THE TRAUMA DATA SCOPING PROJECT

In 2001, with funding from the Motor Accident Insurance Commission, the Queensland Trauma Plan Project was funded to collect and collate information on the impact of trauma on the Queensland population, and to describe and evaluate the Queensland trauma management system. The Project provided evidence to support the development of a formal trauma plan for the State which would:

- guide the future development of initiatives in Queensland aimed at reducing the impact of trauma on the community; and
- improve the means by which trauma patients are managed in the Queensland emergency prehospital and health care systems.

This project was completed in 2006 [1], and prompted a subsequent series of multi-agency consultative forums led by the Royal Australasian College of Surgeons (QLD Trauma Committee). The result of these consultative processes was the presentation to government of the document *A Trauma Plan for Queensland* [2]. The Plan was endorsed in principle by QEMSAC and by the Queensland Cabinet for further development. To facilitate these steps, an Interdepartmental Committee chaired by QLD Health was established in September 2006. The role of this committee was to consider the recommendations made in the Plan and develop an appropriate strategy for funding of core aspects of the plan and its sequential development over

subsequent years. In mid-2007, the state budget delivered $28.3m over four years to progress priority aspects of the Trauma Plan, including the establishment of the Queensland Injury Prevention Council and the Trauma Clinical Network.

No specific allocation was made for data improvement in the first year of implementation of the Plan, although it was acknowledged that the collection of accurate and relevant data is critical to the evidence-based approach to system development, and to ensuring optimal outcomes for patients. The current trauma data scoping project was designed to bridge the immediate gap in developmental progress towards improvements in data capture, analysis, systems monitoring and broader injury reporting to support the Trauma Plan.

During consultations conducted for the Trauma Plan Project and the development of a Trauma Plan for Queensland, it was generally agreed that comprehensive data are required to:

- inform policy and strategic development for both injury prevention and health management (including rehabilitation);
- inform system development and measure the impact of policy change;
- evaluate outcomes; and
- ensure reliable information for quality improvement processes.

One of the issues noted in these consultations was the current state of trauma data:

> *"The collection of injury data is currently fragmented with no corporately endorsed coordination between the various data collecting agencies. Consequently, the data are not being used to their full potential."* [2]

These issues are not new. A previous report of the Queensland Health Injury Advisory Taskgroup (2001) made similar comment. This project identified and described the variety of sources of data and noted:

> *"The solution to the question of data requirements to support Queensland Health's involvement in injury prevention and control lies not in the creation of new data sources but in overcoming the fragmentation of existing activities."* [3]

Most recently, the Trauma Plan recommended the conduct of a 2-year project to undertake a review of the system of injury data collection, as well as dedicated ongoing funding for data acquisition and management to facilitate the development of an integrated data collection and information exchange system. The Plan made preliminary comment on the concept of a data warehouse in which data from a variety of sources could be collated to present a comprehensive picture of the cause, management and impact of traumatic injury in Queensland.

The Trauma Plan further identified a staged approach to delivering improvements to the system of data collection. The proposed aim of Stage 1 of this approach was to design and develop detailed recommendations for a more coordinated and sustainable system of data collection and collation. To enable this process, it was considered necessary that recommendations should canvass the spectrum of care from injury prevention through injury management and rehabilitation.

1.2 THE TRAUMA DATA SCOPING PROJECT

The Trauma Data Scoping project was designed to be a highly consultative process. This process was structured to allow sequential refinement of potential options for the future development of an injury data system in QLD, such that a level of consensus among stakeholders for one of these options could be attained.

The Trauma Data Scoping Project has yielded two key developmental products.

1. The Issues Paper (Appendix A) was released for consultation in October 2007, as the first phase of the Project. Current sources of injury data in Queensland were described and known limitations of the current system of data collection, data management, interrogation and reporting were identified.

2. Following release of the Issues Paper, a comprehensive round of Stakeholder consultations occurred. The findings of the consultation process informed the Discussion Paper (Appendix B), which was released for feedback in March 2008.

   A summary level document, the Discussion Paper described the feedback provided by stakeholders in relation to the Issues Paper. Preliminary analyses of impediments to achieving an integrated injury data system encompassing the full spectrum of care were provided in the Discussion Paper. Options for improvement to the current system of data collection and management were also presented. Following release of the Discussion Paper, a second, targeted round of strategic consultations were conducted to determine priorities for subsequent system development.

   Thematic analysis of the Stakeholder consultations together with a critical analysis of the national and international literature was included in the Discussion Paper.

   Several formal written responses to the Discussion Paper were provided to the Project Team, and these are included in Appendix C.

1.3 PROJECT GOVERNANCE

The Trauma Data Scoping Project was comprised of an Investigator Team and a Working Group. Both groups met frequently throughout the project. The project was overseen by a Steering Committee, whose role was to monitor the timeline and to provide expert input. The Steering Committee met on a quarterly basis throughout the project.

1.4 PURPOSE AND STRUCTURE OF THE FINAL REPORT

The purpose of this report is to describe the process and key outcomes of the products described above, and the level of attained consensus around strategies for moving forward.

The report is provided in four sections complemented by four appendices (A-D). Section 2 of the report provides a detailed description of the applied methodology. Section 3 describes the results, including an assessment of the attained level of Stakeholder consensus together with an endorsed statement of intent. Section 4 describes the next steps which will be required to facilitate further progress in this area.

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1. Tippett V, FitzGerald G, Pollard C, Clark M, Schuetz M, Geraghty T, Aitken L, Kassulke D, Bellamy N, McClure R, Elcock M. (2006). *Trauma Plan Project 2001-2005*. Australian Centre for Prehospital Research, Brisbane.

2. Trauma Plan Working Group for Queensland Emergency Medical System Advisory Committee (QEMSAC) and Royal Australasian College of Surgeons (RACS). (2006). *A Trauma Plan for Queensland*. Brisbane.

3. Spinks A; & McClure R. (2001). Strategic Direction for Injury Surveillance for Injury Prevention and Control: Discussion paper for the Queensland Health Injury Advisory Taskgroup, Brisbane.

2.0 METHODOLOGY

2.1 INTRODUCTION

The methodology applied to this task was highly consultative and involved several phases of discussion with stakeholders in Queensland and interstate. A rolling review of the literature on this issue was conducted over the life of the Project, as well as an analysis of systems in place interstate. An overview of the relevant Legislation governing data capture and sharing in Queensland was also conducted, together with an assessment of the Legislative environment in which linkage initiatives have been implemented elsewhere, most noticeably in Western Australia.

2.2 PROCESS

2.2.1 Project timetable

A summary of the consultation that occurred during the project is provided in the following table.

Table 1: Consultation Timetable

Activity	Consultation	Date
Circulation of Issues Paper	Working Group	Aug 2007
	Chief Investigators	Sep 2007
	Steering Committee	Sep 2007
	Stakeholders / Key Informants	Oct 2007
Consultations	Stakeholders	Nov 2007 - Feb 2008
	Key Informants	Nov 2007 - Apr 2008
Circulation of Discussion Paper	Working Group	Feb 2008
	Chief Investigators	Feb 2008
	Steering Committee	Feb 2008
	Stakeholders / Key Informants	Mar 2008
Formal feedback requested	Stakeholders	Mar 2008
Circulation of options	Steering Committee	May 2008
Final Consultation (Options)	Strategic Stakeholders	Jul 2008
Circulation of revised “hybrid” option	Chief Investigators	Jul 2008
Circulation of revised “hybrid” option for endorsement	Strategic Stakeholders	Jul 2008
Circulation of Final Report	Working Group / Chief Investigators	Sep 2008

2.2.2 Phase 1 – Development of the Issues Paper

Phase 1 of the Project was the development of an Issues Paper to canvass the key challenges facing the system. The Issues Paper was first released to the Steering Committee for comment in September 2007.

After incorporating feedback, the Issues Paper was released to Stakeholders electronically and via hard copy in October 2007. The list of Stakeholders (see Discussion Paper - Appendix B) was identified by the Project Team and the Steering Committee. Included were representatives from various government, academic and research sectors, and providers across the spectrum of interest, from prevention through prehospital and inpatient care to rehabilitation. Additional Stakeholders were included through the "snowballing" technique. A list of key informants was also developed by the Project Team and Steering Committee. Key informants were identified for their capacity to provide feedback at a federal or interstate level.

2.2.3 Phase 2 – Consultation Round 1

Stakeholders were invited to participate in face-to-face small-group or individual consultations with a member of the Project Team. Stakeholders who could not attend a consultation were invited to submit written feedback either electronically or in hard copy to the Project Manager. Consultations were able to be conducted with 58 out of the 80 identified stakeholders, between November 2007 and February 2008.

Consultations were semi-structured, took approximately 2 hours each, and guaranteed informants anonymity. Consultations followed a proforma, circulated to Stakeholders prior to the consultation, which was comprised of four main topic areas:

1. **Data capture** - targeted at those Stakeholders who operate injury data systems. Questions were aimed at details regarding the nature of data collected (years covered, exclusion / inclusion criteria); purpose of data collection; further uses of data; funding / governance arrangements; and, definitional / coding structures used.
2. **Data access** - targeted at both end-users and collectors of injury data to identify issues affecting data retrieval and interpretation. Questions focused on experience in accessing / providing data; procedures for accessing data; factors that enable / impede access (including legislation); associated time lags with accessing data; and, suggestions for how to improve data access for the future.
3. **Data coordination** - evaluated the comparability, and interoperability, of data sets across the treatment continuum. Discussion points included processes for updating coding systems; documentation of data changes; variations between disparate data collections that impact on data use; views regarding the value of data coordination; and, approaches for achieving better interoperability.

4. **Data linkage** – focused on the value of linkage of trauma data across providers, and identified barriers which may exist to prevent linking of trauma data. Stakeholders were asked about their experiences in relation to linkage of data in Queensland (including how linkage was achieved); impediments to linkage (including technical / classification issues, privacy concerns and legislation); the capacity for reduction of duplication; and, perceptions about improved interoperability due to recent / future improvements in electronic capture of data.

During consultations, Stakeholders were also given the opportunity to identify any other issues that they felt required emphasis or consolidation.

Following the consultation, a written summary was provided to the Stakeholder for authorisation and to provide further opportunity for comment. Transcript contents were then entered into a spreadsheet to facilitate thematic analyses.

2.2.4 Phase 3 – Development of the Discussion Paper

The Discussion Paper was developed on the basis of comments provided by Stakeholders and Key Informants in the first consultation phase. This was a summary level document that reflected their perceptions about issues relating to the collection and use of injury data in Queensland, as well as impediments and facilitators to developing a cohesive system.

The Discussion Paper concluded with four options for achieving a comprehensive system of injury data collection in QLD. These options were developed from feedback obtained from Stakeholders and Key Informants during the consultation phase.

The Discussion Paper was first circulated for comment to the Steering Committee for feedback in February 2008, and disseminated electronically to Stakeholders and Key Informants in March.

2.2.5 Phase 4 – Consultation Round 2

An invitation to provide formal feedback from Stakeholders was issued with the Discussion Paper. Several formal responses were provided by Stakeholders, these are presented in Appendix C.

A final Steering Committee meeting was held to obtain further input regarding the four options that were presented in the Discussion Paper. Feedback obtained from the Steering Committee was used to refine the options, which were then presented for endorsement by Strategic Stakeholders at the final consultation.

A list of Strategic Stakeholders (see Appendix D) was developed by the Project Team in consultation with the Steering Committee. This group was primarily comprised of attendees with the capacity to make an "in principle" commitment on behalf of their organisation, to one of the presented options for advancing an integrated system for trauma data collection in Queensland.
Feedback obtained from Round 2 consultations was used to inform the development of a Revised Option for progressing of an injury data system in Queensland. This option was then circulated to the strategic stakeholders who attended the Final Consultation, and their endorsement sought. Feedback also informed the Recommendations and proposed ‘next steps’ described in this report.

3.0 RESULTS

3.1 INTRODUCTION

This Section is divided into five Sections, complemented by Appendices A (Issues Paper) and B (Discussion Paper). Section 1 provides an overview of the relevant literature as previously reported in the Discussion Paper. Section 2 describes the agreed principles underpinning improvements in future data systems. Section 3 provides the endorsed consensus statement, followed by an assessment of impediments and facilitators to achieving this objective.

3.2 THE LITERATURE

In 2001, the Queensland Health Injury Advisory Taskgroup produced a Discussion paper outlining a strategic direction for injury prevention and control. The document highlighted the need for adequate data on occurrence and management of injury in Queensland, in order to:

- effectively inform and evaluate injury prevention and policy;
- assess the performance of the health system in the management of injury;
- inform and measure the impact of policy on injury management within the health system; and
- inform health system needs (with regard to injury).

Over a decade ago the Taskgroup described the state of injury data in Queensland as being fragmented with limited coordination between the various injury data sources. There has been little improvement in this regard, with minimal coordination between organisations collecting injury data, and duplication of data collection and effort across injury data sources.

This situation does not make the best use of the data and the limited resources available to injury data collection, and does little to facilitate a comprehensive overview of injury, injury management, and the outcomes of injury.

A literature review was conducted as part of the development process for the Discussion Paper (Appendix B), to identify potential options for improvement of the injury data system in Queensland. Two systems in use nationally and internationally for construction of integrated data systems, designed for more effective utilisation of existing data collections, are data linkage and data warehousing. An overview of the mechanisms, benefits and considerations of each technique are presented following.

3.2.1 Record / Data Linkage

Record linkage involves the unification of multiple, separately assembled records

(or parts of records) which belong to one individual. [1,2] The advent of the computer in the early 1960's increased the scope for linking medical records for epidemiology, and research into health services and health service management. [2] The first formal linkage of health records began in England around this time, with the establishment of the Oxford Record Linkage System. [3] Record linkage systems followed in Canada, Scotland, North America, Scandinavia, and Australia. [4] The data sources most commonly used in health record linkage systems are birth and death registers, hospital inpatient data, physician contacts, cancer notifications / registries, laboratory services data, pharmaceutical benefits data, residential care data, domiciliary care, mental health services data, and socio-demographics data from the Census. [4] The linkage of health records has served several purposes, including: the evaluation of health system performance; public health surveillance; measuring participation in health services; determining burden of disease and disease outcome; and, assessing adverse treatment effects and outcomes. [4-9]

There are two main techniques used in data linkage, deterministic and probabilistic.

Deterministic linkage requires agreement on a sufficient number of identifying variables (between two or more records) before a match / link is made. [1] Deterministic linkage is most often used where a unique patient identification number is available. [1] In Scotland, for example, all patients who are registered with a general practitioner are assigned a community health number which is a unique identifier. [5] Records of all patients are maintained centrally and updated as the patient moves through the healthcare system. [5] Variations of a unique patient identification number exist in health systems across the world. In its simplest form deterministic linkage requires that all identifiers (for example, unique patient identification number; name; date of birth; and address) are required to agree across two (or more) records before a match/link is made. [1] More flexible variations can be used whereby a pre-defined subset of identifiers (for example, three out five identifiers) is required to determine a match of records. [1] A major limitation of this method of linkage is that it deems each identifier to be of equal value in determining a match. [1] This does not take into account the potential for missing or incorrect values, or that some identifiers may be more accurately and reliably recorded than others. [1]

Probabilistic linkage also requires agreement on a number of variables across records to determine a match, but unlike deterministic linkage, the variables are not always identifying (although in most cases they are); they are non-unique (gender, name, address); and the potential for inaccurately recorded variables, is taken into account. [8] Probabilistic methods were used in a New Zealand study to anonymously link mortality and census data. [10] While most linkage is based on identifying variables such as name, this study used only geocodes (computer readable coordinates of geographic location in terms of area, state etc.); sex; ethnic group; country of birth; and data of birth, to match patients on mortality and Census data. [10] Probabilistic linkage accounts for discrepancies in the recording of variables due to error or change in status (for example, maiden name change), and uses a computer

algorithm to calculate the probability that two (or more) records belong to the same individual. [8] This method typically has an accuracy of between 98-99% and is a widely accepted and valid technique to use in the absence of a unique patient identifier. [7,8,10]

Proponents of population-based record linkage argue that record linkage is essential to enable comprehensive assessment of the performance and safety of a health system and that this represents its main purpose and value. [3,4] Other major reasons cited for the use of record linkage include being able to use the same data repeatedly to address various epidemiology and health service questions. [12] Considering the cost of conducting several cohort or case-control studies, and the already substantial investment made in the collection of routine data, record linkage systems represent a relatively cost-effective research resource. [3,12-15] Likewise, purpose-designed health registers, which are becoming increasingly popular, are expensive and may only represent a sample of the population. [12] Using administrative data which is already collected by the health system (and other relevant bodies) and made interpretable through record linkage to meet the required need, is comparatively more cost effective. [13] Several studies have been undertaken to compare the sensitivity and efficiency of relevant record linkage data sets with disease-specific registers. [5,13] In a study on diabetes in a Scottish community, the authors concluded that the linked data set was more sensitive in identifying cases of diabetes than the general practice register of diabetes, and that it was able to identify an additional proportion of the population who were at risk of diabetes (history of hyperglycaemia) and who might have warranted screening for undiagnosed diabetes. [5] Similarly, Brameld et al. (1999) found that a linked data set produced estimates of the incidence and prevalence of end-stage renal failure which were comparable to those acquired through the disease register. [13]

The large sample sizes available in record linkage systems facilitates more accurate generalisation of results to the wider population and results are available more rapidly than they would be if they required ad hoc data collection. [12,13] Using linked data sets also reduces selection bias which can occur in the use of case-control and cohort studies. [12] Studies using data linkage sets may be less intrusive because in many cases patients and health professionals do not need to be contacted if the required data already exists through the linked data set. [12] The West of Scotland Coronary Prevention Study Group (1995) reported in their study that record linkage was as effective in ascertaining adverse events (death and nonfatal myocardial infarction), as direct follow-up with patients. [16] Recall bias is also lessened with linkage studies (when compared with case-control and cohort studies) because the data are collected in ignorance of (or before) the outcome of interest. [12] Being able to analyse changes in the health status of the population over time is another important benefit of linked data systems, especially as health status seldom responds immediately to interventions. [17]

Limitations inherent in record linkage data sets

The use of data linkage systems is generally limited by the extent and relevance of the data available in the respective data set. [3] There is a finite range of analyses possible from one data set. [3] A lack of specific important data points which may be required as key exposure, outcome, or confounding variables, may render the use of particular linked data sets useless.[12] The Oxford Record Linkage Study, for example, has been criticised for not having sufficient detailed data concerning the history, severity and management of diseases, because it is based on routinely collected, administrative data. [18] There are also extensive difficulties inherent in large-scale record linkage for research in the field of health, mainly because of the need for long-term forecasting to facilitate inter-agency cooperation and coordination of data sets. [4] The majority of health data linkage sets use administrative data, collected routinely for purposes other than research, and this has led to concerns about the quality of the data. [18-22] For example, disease diagnosis codes recorded for hospital billing purposes, may have been done in such a way as to merely satisfy the minimal requirement for payment, or even so as to maximise payment. [19] Without concern for the use of such codes in the context of clinically and/or epidemiologically relevant purposes, skewed or incorrect conclusions may be drawn from the results of research using such data. [19] Another quality concern with the use of administrative data sets is the high number of missing data codes, which may lead to under or over estimations of the prevalence of a particular disease or cause. [20,22,23] A technique has, however, been developed to correct (to some degree) this problem. [23] The capture-recapture technique assumes the relevant data set is missing data and estimates the margin of error (with confidence intervals) to allow comparison of the total population of persons with the relevant disease and the number of persons in the data set who have been recorded as having the disease. [23]

Acknowledging the limitations inherent in data linkage sets, Sorenson et al. (1996) proposed a guide highlighting the scientific and practical considerations for the use of record linkage data sets in health research. [24] This includes checking for duplicate records on one individual, within the data set; consideration of whether the study requires counts of individuals or events (and whether the particular linked data set is able to provide the required data); and consideration of accuracy and completeness of the data contained in the linked data set. [24] In deciding to use a particular data linkage set, the time period covered by the data; accessibility to the data set; costs of access; format of the data; and the size of the data set (and whether a subset of records will suffice), are all essential considerations. [24] Another important consideration for the use of data linkage sets, particularly when the study intends to draw conclusions about, for example, relative risk following the exposure of interest, is completeness of population coverage or whether a population registry is linked into the data set. [24,25] A data set which is linked to a population registry, enables selection of a matched comparison group, and thus allows for adjustments to be made for relevant confounders such as socio-economic status and co-morbidities. [25] Cameron et al. (2007) argue that outcomes research using linked data sets which do not include a population registry, may result in invalid conclusions. [25]

Privacy and legal issues

In the community, the concept of linked health records may raise privacy concerns based on the incorrect assumption that data linkage systems contain centrally stored, comprehensive profiles on individuals. [26] Rather, linked data systems bring together separate data files, only temporarily, to generate ad hoc data sets for the express purpose of answering a particular research question. [26] The conduct of record linkage studies requires prior approval from, and is overseen by, the relevant institutional review boards (or ethics committees). [27] As well as this, details relating to the matching of data files, and the management and storage of data, have to have been specified in a research proposal and (in Australia) conform to National Health and Medical Research Council guidelines. [27] A record linkage study that is properly planned and conducted according to such guidelines should pose only minimal risk to privacy. [26,27] As mentioned previously, the use of data linkage sets may in some instances help to preserve patient privacy because identifying information which is necessary for patient follow-up may not be required for a particular study if the data already exists (through a linked data set). [12]

Community concerns for privacy and confidentiality with regard to record linkage are reflected in current legislation in Australia, which specifies that personal information shall not be disclosed unless that individual is aware that the information is usually passed on to a particular agency; the individual consents to disclosure of personal (identifying) information; or the relevant agency deems disclosure of personal information is required to prevent or reduce danger to health or the individual's life. [27] These legislative clauses present substantial challenges to data linkage because it would not be feasible to get consent from all the relevant individuals for the purpose of linking medical records at a population level. There are, however, exceptions to be made in that the relevant national and/or State authorities can approve record linkage it they believe that the public interest in the disclosure of personal information substantially outweighs the public interest in privacy. [27] Such exceptions have been made with numerous instances of record linkage which have been undertaken for special research purposes in Australia, and of note, with the establishment in 1995 of a comprehensive population-based system in the Western Australia Data Linkage System - the first and only of its kind in Australia. [4] This successful and internationally recognised data linkage system was enabled by a supportive legal framework (in the State of Western Australia) which specifically authorises record linkage for public interest research. [4]

Injury and data linkage

Traditionally, record linkage systems have not focussed on injury prevention (or trauma management) research. [28] There is growing recognition, however, of the potential value of data linkage in this area because of the conventionally disparate nature of injury data sources. [28] Data sources such as police crash data; pre-hospital (ambulance) service; emergency department presentations; hospital separations; insurance claims; and death records, each contain valuable information, but are

limited in their ability to provide a comprehensive overview of injury. [28] A more complete picture of the experience of the injured individual, from events leading up to the injury to the long-term outcomes of injury, are essential to inform effective and timely policy on injury prevention; to implement and evaluate injury prevention strategies; to improve the quality of management of the injured patient within the health system; and, to measure improvements in management over time. A study in the UK linking police traffic crash reports and hospital admission data concluded that the use of police road traffic crash data alone was biased in estimating the prevalence of road traffic crashes. [22] In New South Wales, Boufous and Williamson (2006) linked worker's compensation data to police crash data in order to provide a more comprehensive picture of work-related traffic crash characteristics. [29] The USA Crash Outcome Data and Evaluation System is an example of a comprehensive system of linked data on injury; specifically injury which is the result of a motor vehicle crash. [30] This system uses probabilistic methods to link multiple data sets including traffic crash, health-related (hospital separations) and vital statistics (death records) data. [30] This system is used to assess the patterns, costs, and outcomes of road traffic crash injuries, and to evaluate the cost-effectiveness of intervention strategies. [30]

Challenges to the linkage of injury data which are not already covered under the general heading of "Limitations inherent in data linkage sets" (above) include the diversity of injury data sources across the continuum of the injury 'experience' compared with the data sources relevant to chronic or infectious diseases. [28] Chronic and infectious disease registries in the most part glean information from similar sources using largely comparable coding schemes, for example, hospital data, death certificates, and pathology results. [28] Injury data sources, on the other hand, are more diverse with information coming from beyond the health system and often with incompatible coding schemes, for example, insurance databases, transport authorities, and police reports. [28] This presents some challenges for the data linkage process especially from a data coordination and privacy perspective. [28] Organisations are generally apprehensive about sharing data which contains personal information, and data linkage may require multiple ethical approvals adding to the already complex and confusing privacy legislation. [28]

The challenges to linkage of the relevant injury data sources are not insurmountable and the advantages are numerous. In addition to the aforementioned benefits in terms of policy and practice, and being able to calculate rates of injury (where linkage is population-based), linkage of injury data sources may provide access to a larger number of cases, allow for the assessment of confounders (eg. co-morbid conditions), and provide a means of validating aspects of research data. [31]

3.2.2 Data Warehousing

Data warehousing as a concept is not as easily defined as data linkage because it does not follow a particular method. Rather, it loosely describes the technical process

of 'integrating' data to meet the particular information needs of a specific organisation or section of an organisation. Generally, it contains an organisation's data in a centralised repository, to: provide easy access to appropriate users; fulfil reporting and analysis requirements; and, provide decision support. [32] Data warehousing was traditionally focussed on assembling the financial and operational data for "non-health" organisations. [33] It has more recently been recognised as a valuable tool which enables healthcare organisations to access data from disparate sources in order to create a more integrated vision of the organisation's activities and inform better business and clinical decisions. [34]

Technical considerations

There is no "one fits all" method / technique for establishing a data warehouse. Each data warehouse is developed with the needs and idiosyncrasies of the particular organisation in mind. Scheese (1998) outlined five key (general) considerations in the development of a data warehouse: 1. identify the needs of the end-users; 2. scale the warehouse project according the needs of the organisation; 3. assign key managers/executives who play visible roles in the organisation as sponsors; 4. source skilled and experienced technical expertise; and, 5. design adequate security (especially in the case of sensitive data which will potentially be made available to a large number of employees in the organisation). [33] More specific considerations include establishing a dictionary of data descriptions, and identifying and/or designing tools to extract, translate, and integrate data from disparate data sources. [35] Once established, the data warehouse needs to be updated regularly to ensure that the format of the data corresponds with the end-users' evolving data needs. [35] The design of a data warehouse also needs to allow for additional data sources to be added subsequent to establishment of the original data warehouse. [35] Privacy with respect to individual patient data is of crucial importance in the design of a data warehouse. [35] Ensuring the confidentiality of the activities of the individual agencies supplying the source data is also of the utmost importance. [35]

Data warehousing as a health data integration solution

In health organisations where there are large amounts of data stored in various information systems across the organisation, end users have traditionally been limited in their ability to access this data. [33] Data warehousing provides the tools to facilitate access to data stored in the various systems across an organisation. [33] Data warehousing allows for existing legacy systems to be maintained as data from these systems is consolidated into one coherent data set. [35] Other advantages to data warehousing include data quality improvement (by extension of the process of consolidation), and importantly, quick and efficient access to information by end users for clinical research, clinical quality improvement, and decision support. [35,36] While the value of the data is maximised, end users cannot, however, directly query the source data, and in this way the security and privacy of the data sources are protected. [35] Limitations / disadvantages of data warehousing are largely similar to

those cited for data / record linkage, and pertain largely to the complexity of consolidating and coordinating data from disparate sources and the quality of data not originally intended for research (in other words, administrative or insurance data sources). [35,36] Other concerns include the time and resources required to undertake such a project, and the difficulty of designing a system and being able to adequately anticipate future usage and needs. [35]

How has data warehousing been used?

Data warehousing in the health domain has been used to centralise the business and financial administration of organisations, review clinical data, and provide access to data for clinical research and clinical decision making. [37,38] Data warehousing has been used to instigate collaboration between relevant groups/stakeholders, such as academic institutions, that have an interest in particular health areas.

3.3 PRINCIPLES UNDERPINNING FUTURE DATA REQUIREMENTS

Based upon the findings of this project, the following principles have been identified as a basis for any future trauma data system in QLD:

1. A comprehensive system of injury data collection should include at a minimum:

- Data on the frequency and nature of injured persons presenting to health services, including demographic and other person-related characteristics;
- The frequency and nature of known risks;
- A representative sample of all injured patients to identify and quantify the causes of all injuries;
- A representative sample of seriously injured patients to identify the differential causes of serious injury and the effect of treatment on patient outcomes; and
- System-wide performance indicators for benchmarking and evaluation purposes.

2. Ownership of data to be retained by the individual agencies, which also retain responsibility for data collection and data quality.

3. Agencies agree in principle to the sharing of data and commit to improving the system of data collection so that the data are accessible and meaningful.

4. Injury data definitions and coding standards should ideally be standardised. There should be a standard data dictionary developed, agreed upon and applied in Queensland, for cases involving injury. This should align with national approaches wherever possible. Where agency requirements do not allow standardisation of particular data points, these should at a minimum be mapped to standardised terms.

5. Data should be collected on key elements in a format that allows for extraction of data with equivalent meaning across "core" agencies (e.g., QAS; EDIS; QISU; QHAPDC; QTR).

6. A centralised, easily accessible, well structured, clearly defined source of aggregate data should be available to those with a bona fide reason for accessing data, including:

- Policy makers
- Clinicians and care providers (for clinical review)
- Researchers
- Public sector agencies (e.g., QHealth Central Office)

This would facilitate access to information on the frequency and nature of risks, incidents and injured persons; and would also ensure that data are provided in a manner which is usable and interpretable for all agencies/users.

7. Data on injured persons linked at person-level (provided in a de-identified format) should be accessible to bona fide users for the purposes of policy development, performance monitoring/quality assurance, benchmarking, and research. Methods to enhance accessibility of data to agencies should be progressively developed.

8. Agencies will work together under the auspices of the Queensland Injury Prevention Council and the Trauma Clinical Networks to develop system-wide indicators of performance, and facilitate monitoring and benchmarking of trauma care in Queensland.

9. Lack of data on patient outcomes must be addressed, with additional strategies for enhancing available data to be developed in collaboration with stakeholder agencies. Follow-up data on seriously injured patients is recommended at a minimum, with an "opt-off" system (similar to that which operates in Victoria) being strongly recommended. Additional areas for future consideration may include: data on hospital mortality; data from insurance sources; and coroner's data.

3.4 CONCEPTUAL ENDORSEMENT

A final consultation with Strategic Stakeholders (see Appendix D) was held on Tuesday 8th July, 2008. At this consultation, four options for the future of trauma data collection in QLD were suggested by the Project Team, and were discussed by participants.

Subsequently, final endorsement of the following revised option statement was achieved:

> *"We, the stakeholders, agree to the following concepts:*
>
> - *regular, frequent linkage of data from core databases; and,*
> - *linkage of noncore databases on a project-by-project basis.*
>
> *We also agree, in principle, to the following option in relation to the future of injury data in QLD:*
>
> *a system of data collation using standard data dictionaries and consistently defined common parameters. Core agencies will submit data for linkage key generation on a frequent and regular basis, to facilitate provision of person level, de-identified linked data for comprehensive reporting on the patterns of injury, injury causation and outcomes. Linkage of noncore databases will occur on a project-by-project basis. This system is similar to the Western Australian Data Linkage System, and to the systems that have been adopted by SA and NSW.*
>
> *It is further recommended that once established, the system be "tested" using several research questions that require linked data from agencies across the continuum of care, to assess the completeness and accuracy of links and the integrity of linked datasets."*

Level of consensus among the strategic stakeholders is described in Table 2.

Table 2: Consensus Assessment

Stakeholder	Response
Health Statistics Centre, QLD Health	Endorsed
Epidemiological, Statistical and Library Services Centre	Endorsed
QLD Transport	Commitment to follow-on projects depends upon project feasibility and associated costs as outlined in their respective business plans.
NCCH	NCCH would like to be assured that consideration has been given to the involvement of the proposed Queensland Data Service Centre which has been recommended as a resource for health data linkage as part of the proposed NCRIS population health roadmap.
Department of Child Safety	Endorsed
Information Division, QLD Health	Endorsed
QISU	Endorsed
QTR	Endorsed
MAIC	MAIC endorses this option subject to each agency independently verifying the legal and legislative status to support such initiatives.
QAS	Endorsed

3.4.1 Impediments and Facilitators

One of the main benefits associated with adopting the above option, as endorsed by Stakeholders, is the ability of each agency to retain data ownership whilst facilitating linkage across the continuum of care. Equally important is the fact that similar systems already operate in other parts of Australia (i.e., West Australian Data Linkage System (WADLS) [39], which has been adopted by SA and NSW. These precedents provide a useful platform on which Queensland could progress development of its own system.

The Western Australian experience has demonstrated that early involvement and agreement of stakeholders is crucial to development of a robust system. Establishing a code of practice and guidelines, to be described in an overarching MOU, is critical to success and facilitates the development of secondary agreements / guidelines with each participating agency, and/or for individual projects.

Also found to be crucial is the early involvement of a well-respected spokesperson.

3.4.2 Overview of WADLS

The West Australian Data Linkage System (WADLS) is comprised of core population health data sets that can be linked (birth, death and marriage registrations; hospital separations; mental health contacts; cancer notifications; midwives' notifications; ED presentations; electoral roll). Data are linked through personal identifying information derived from each of the contributing data sources. However, the actual health details are stored and managed separately by delegated data custodians for that agency, so the agencies retain control of their own data. These linkages are created and maintained using rigorous, internationally accepted privacy preserving protocols, probabilistic matching and extensive clerical review.

The Western Australian Data Linkage System consists of chains of links where each link is associated with a record in one of the core data sets. All links in a particular chain have been associated with the same individual through the process of probabilistic record linkage. This method of linkage relies on the availability of similar demographic information (e.g. name, gender, date of birth, address) in each data source. [39]

The linkage protocol consists of four distinct steps: 1. linkage staff create linkage keys using confidential personal demographic information; 2. linkage staff assign and encrypt linkage keys for each particular project; 3. encrypted linkage keys are provided to data custodians so they can be added to clinical or service details for a particular project; 4. researchers receive deidentified clinical or service details separately from each data custodian, and use the encrypted keys to connect the details across data sets for their analyses. [39]

Using this linkage methodology, access to identifying information is restricted to a specialised linkage team who perform the first and second steps of the process. Data custodians are involved in the third step. Researchers are only involved in the last step, and at no stage does any party have access to both the confidential personally identifying details and the data to be linked.

Predictably, linkage success is positively related to the number of data fields that are available for linkage. However, a higher degree of success is achieved using as many of the following variables as possible:

- name;
- date of birth;
- gender;
- address;
- date of event;
- county of birth; and,
- any unique identifiers that are present.

Most core data sets are updated monthly to ensure that the linked information in the complete core data sets remains current. Initially, agencies were incorporated on a

project-by-project basis, however over time agencies realised the benefits of being involved in the system and they became adopted as “core agencies”.

Governance

The WADLS is overseen by a Data Linkage Advisory Board that meets quarterly. The Board consists of high level representatives from the collaborating institutes (i.e. UWA, WA Department of Health, Curtin University, Institute of Child Health Research), and a representative from WA Health Consumer’s Council. Governance arrangements have changed responsively to reflect the needs of data custodians and users. The committee is flexible in its governance approach, and focuses on facilitating research project proposals rather than impeding them. A key factor related to the success and acceptability of the system in WA is the requirement that linkage requests describe explicitly the reasons for linkage in terms of the ‘public good’.

Access

Within WADLS there is a Data Linkage Unit and a Client Services Group. Expressions of interest are submitted to the Client Services Group who liaise with the applicants to ensure that the proposal is appropriate. When the proposal is in a format that contains as few variables as necessary to satisfy the needs of the applicant, the Client Services Group prepare a brief report on the proposal (purpose, aims, researchers involved, etc). This report is then provided to the data custodians involved for their approval. Ethics approval is required before this can occur. Currently ethics approval occurs through the WA Health Department’s Ethics Committee, however previously this was achieved through individual university or hospital ethics committees. Custodian approval for the project can be dependent on the potential for data to be identifiable at the person level when it is combined with other datasets. WADLS takes a proactive approach to providing data, with requests rarely being refused outright. Modifications to the original data request are common.

Approval of a data request takes approximately 2 months, and data are provided approximately 3 months after approval (i.e. a total processing interval of approx 5 months). The process can take longer if new linkage is required, as opposed to data extraction from routinely linked data sets.

WADLS requires recipients of data to provide copies of any arising papers / reports before they are published in order to ensure that the process of data linkage and access is accurately described.

Costs

WADLS is funded by the Department of Health WA, the Australian Government Department of Health and Ageing, the University of Western Australia (via NHMRC

and ARC grants), Curtin University of Technology and the Telethon Institute of Child Health Research. The Insurance Commission of WA also contributes funding.

Running costs are estimated at approximately $1.5-2M per annum, and primarily consist of staff costs. Funding is provided through specific positions, infrastructure, and specific projects. Approximately 20 full-time positions are required to staff WADLS. The majority of these positions are public servant (WA Health) positions, although some are university-based.

WADLS is currently working towards a cost-recovery system. It is estimated that the cost of an average linkage project will be $110 per hour (vs. $160 per hour charged by AIHW), however this will be negotiable. Cost will depend on the number of records, time period over which data are to be linked, the number of variables, and the number of data sets to be linked.

Other benefits

Because only the linkage keys are stored by WADLS, there is no “database” that requires storage. In addition, this system removes the requirement for databases from different agencies to be interoperable.

As WADLS expanded, the number of requests for identified data in WA reduced substantially. Between 1995-2003, 279 data requests were made to WADLS, which resulted in 721 outputs (journal articles, reports, conference presentations, etc).

3.4.3 Legislative environment

There appears to be nothing unique to the legislative environment in WA that facilitated the development of WADLS. Consultation conducted in Western Australia during the project identified the fact that no specific changes were required to the WA Legislation prior to the implementation. As is the case elsewhere, collection of data is covered by the Legislation that is relevant to each participating custodian. Providing that the legislation relevant to each custodian allows for disclosure / access of information for research purposes, no additional legislation is required to link the data using the described mechanism.

Review of the relevant legislation in QLD, as described in the Discussion Paper (Appendix B), illustrates that there is nothing in the legislative environment in Queensland which would impede the implementation of such a system.

4.0 NEXT STEPS

The Trauma Plan, endorsed by Cabinet in 2007, identified a staged approach to delivering improvements to the system of injury data collection:

Stage 1 Scoping of trauma data sources; critical analysis of the national and international literature on trauma data; identification of options for improvements in data items pertinent to trauma; and the development of a strategic Business Plan in consultation with stakeholders (12 months)

Stage 2 Develop instruments and testing mechanisms for the linking and integrating of data sources to convert data into usable information for injury management and injury prevention research and policy decisions (12 months)

Stage 3 Management, monitoring and review of changes to systems by design and implementation of new arrangements and support instruments; including, data dictionaries, minimum data sets, and classification systems (2 years).

Stage 4 Consolidation of the new arrangements and ongoing management.

This project comprises several components of Stage 1, as detailed above. At the conclusion of this project, a high core level of agreement has been achieved amongst identified key stakeholders. While this level of agreement is indicative of significant will to advance data developments specific to trauma, due to movements at a national level, the sectors are not yet poised to prepare a comprehensive business plan.

Specifically, the project has achieved the following:

- scoping of current trauma data collections (Issues Paper);
- critical analysis of national and international literature (Discussion Paper);
- identification of impediments to progress (Discussion Paper and Final Report);
- identification of options for improvement including new business rules and governance structure (not achieved and would be completed as part of the development of the proposed Business Plan); and
- establishment of key stakeholder consensus regarding how to progress Queensland trauma data into the future (in principle endorsement of the characteristics of a sound data system and agreement regarding routine and special case linkage which would be progressed through the proposed Business Plan).

To make real the endorsement of stakeholders and progress the development of improved trauma data systems, progress will need to be achieved in the following key areas:

- Identification of an appropriate, mutually agreed lead agency;
- Identification of specific data items for inclusion in an injury specific data dictionary and, where necessary, mapping of definitions where agency definitions cannot be altered. This task necessarily needs to be cognisant of the National Health Data Dictionary and other established definitional agreements across the stakeholder group;
- Identification of structures to facilitate more efficient data collection methods and data warehousing concepts;
- Identification of both pilot and long term funding models and funding sources; and
- Development of governance structure arrangements which include specification of data access and utilisation and reporting mechanisms which facilitate an evidence base for trauma policy and planning, performance monitoring and evaluation.

Once this work has been completed, development of a detailed business plan is possible and Stages 2-4 as described above could then be progressed.

In relation to the preparation of a strategic Business Plan, it is vital to highlight the notable and growing number of statewide and national initiatives in the areas of trauma management, health information systems and infrastructure. Any future strategic development in coordinating trauma and injury data must be developed in the context of currently evolving strategies, such as the:

- National Collaborative Research Infrastructure Strategy (NCRIS);
- Qld Health Statewide eHealth Strategy and Emergency Department Information System (EDIS) update;
- Qld Ambulance Service Strategic Information Management Initiative (SIMI Project) with electronic data collection (eARF);
- data standards/classification & coding development work by the National Centre for Classification in Health (NCCH);
- National Trauma Registry Consortium (NTRC);
- data linkage research by the CSIRO's eHealth Research Centre (EHRC);
- objectives of the Statewide Trauma Clinical Network (STCN); and
- Queensland Injury Prevention Council (QIPC).

In particular, planning and implementation of future developments in trauma data must occur with cognisance of the significant work on data linkage and integration being conducted with Commonwealth funds through NCRIS. The NCRIS population health and clinical data linkage capability aims to:

- enhance the linkage and integration of health-related data collected in Australia;
- provide improved accessibility to data for research; and
- support development of improved data collection systems.[40]

NCRIS population health and data linkage initiatives are under development, and are evolving. It is vital that any strategic business plan based upon the principles endorsed by the Stakeholders be designed in alignment with new national strategies. It is equally essential that such national strategies be designed with awareness of the identified needs of injury and trauma stakeholders.

A key objective of this project has been to identify the level of stakeholder support for development and improvement of the current disparate systems for trauma data collection, collation and integration within Queensland. As a consequence of the level of agreement achieved by the project the current environment would support advancement in this area, given appropriate leadership.

Fundamental to the success of these intentions will be the identification of a central agency to negotiate with the current state and national initiatives described above, on behalf of agencies involved in trauma management, for the inclusion of trauma in key pieces of work. Currently, the new Board of the Queensland Trauma Registry with support from the Statewide Trauma Clinical Network (STCN), or its data subcommittee, and the Queensland Injury Prevention Council (QIPC) are currently the most appropriate agents to provide direction in positioning trauma-related data as a focus of existing and evolving strategies; and to thereby progress future development in this area.

CONCLUSION

This project delivers a significant portion of Stage 1 of the Queensland Trauma Plan (described above) recommendations regarding delivery of improvements to the system of injury data within Queensland.

There is considerable parallel impetus across government to advance this issue, as evidenced by the significant number of national and state strategies surrounding health information systems. It would be of benefit to injury and trauma interest groups to engage collaboratively with these initiatives. In particular, consideration within government of shared information platforms, through initiatives such as NCRIS, provides a potentially valuable vehicle through which the data objectives of the trauma plan could be delivered.

Within the direct emergency health services environment the developments in the National Trauma Registry Consortium require close engagement and collaborative contribution. There are strategic synergies with existing data developments across

government and external agencies which should be utilised to progress the needs of service providers, policy makers and researchers from across the trauma spectrum.

Strong leadership will be essential to facilitate widespread recognition of injury and trauma data needs in the future. There is a need to either identify or designate an agency with decision making capability that encompasses both the interests and requirements of data custodians. This agent must have a sufficient level of seniority to enact the evident level of agreement that this project has demonstrated. In the current environment, the establishment of both the STCN and QIPC, in close collaboration with new board arrangements of QTR, could provide such direction.

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APPENDIX A – ISSUES PAPER

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October 2007

Trauma Data Scoping Project

issues paper

This document was prepared by the Qld Trauma Data Scoping Project Team:

Australian Centre for Prehospital Research
(Queensland Ambulance Service and the University of Queensland)

Queensland University of Technology
(including the National Centre for Classification in Health)

Trauma Clinical Network

Royal Australasian College of Surgeons

This paper is for discussion purposes only, and has been circulated for general comment. Any views or opinions expressed in the paper do not necessarily represent the views or opinions of the Queensland Government, any policy position or representation of a Government department, or of any proposed course of action.

AUSTRALAN CENTRE FOR PREHOSPITAL RESEARCH

TRAUMA DATA SCOPING PROJECT: ISSUES PAPER

Project Funded by: **Motor Accident Insurance Commission**

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TABLE OF CONTENTS

INTRODUCTION

In early 2007, the Trauma Plan for QLD was endorsed in principle by the Queensland Emergency Medical System Advisory Council (QEMSAC) and Queensland Cabinet. Among other key targets for improvement, the Trauma Plan recognised the need for improvement to the current system of injury data collection in Queensland. Following endorsement of priority aspects of the Queensland Trauma Plan, the aim of the ***Trauma Data Scoping Project*** is to:

- Scope existing injury and trauma data sets across the continuum of care from event to rehabilitation and discharge;
- Identify impediments to the efficient and effective coordination and use of data; and
- Develop recommendations for a sustainable system of data collection, collation and interrogation to inform prevention and system improvement.

The ***Trauma Data Scoping Project*** is funded by the Motor Accident Insurance Commission as an extension of the ***Queensland Trauma Plan Project*** (2001- 2006). The Project commenced in May 2007 and is due for completion by May 2008. This Issues Paper is the first phase of the ***Trauma Data Scoping Project***. The purpose of the Issues Paper is to describe the current sources of injury data in Queensland, and canvass through consultation and feedback the limitations of the current system of data collection and interrogation. Preliminary analysis of impediments to achieving an integrated injury data system that encompasses the spectrum of care from injury prevention through to injury management and rehabilitation will occur.

TIMEFRAME AND CONDUCT OF THE PROJECT

The Trauma Data Scoping project will be a highly consultative process. Over the course of the project (May 2007 – May 2008), the project team will facilitate several individual consultation sessions, focus groups and consultative forums. The project team will meet with key stakeholders and interest groups in government, the academic and research sector, and providers across the spectrum of interest from prevention through prehospital and inpatient care to rehabilitation and beyond.

The first phase of the project commences with this Issues Paper. Consultation will be conducted to inform the development of a Discussion Paper that will describe recommendations for improvement in the current system of data collection and management.

The Discussion Paper is planned for release in late 2007. Following release of the Discussion Paper, a second round of consultation (forums) will be conducted to determine priorities for subsequent development. The final report on the project is due to be provided to the funder in May 2008.

During the life of the Project, the project team will visit key interstate informants and systems to identify possible opportunities for improvements that may be applicable to Queensland. In addition, a critical analysis of the national and international literature is being conducted to inform the final report for the Project.

HOW CAN I CONTRIBUTE?

A member of the Trauma Data Scoping project team will contact you very shortly to arrange a consultative session. These sessions can be conducted at an individual level, or in small groups with colleagues from your immediate work area who are eager to contribute. The purpose of these consultations is to discuss this Issues Paper, identify any issues that have not been canvassed to date, and map the existing system of collection and coordination against known best practice principles.

Your attendance at one of these groups is welcomed. If you are unable to attend a forum, you are welcome to provide written comments to the team through the Project Manager:

Dr Kerrianne Watt
Australian Centre for Prehospital Research

✉ **PO Box 1425, Brisbane, QLD, 4001**
☎ **(07) 31097943**
💻 **kwatt@emergency.qld.gov.au**

All comments and contributions are welcome but we would specifically value your feedback in relation to the following:

1. **Does this Issues Paper encompass the issues related to injury data that are important to you?**

2. **What is / isn't possible with the injury data that you collect / use?**

3. **When people come to you with requests for data, what factors make it difficult for you to retrieve/collate/disseminate the data?**

4. **On occasions when you have required injury-related data, what factors have impacted on data availability (i.e., barriers / enablers)?**

5. **Are there other issues that you believe require emphasis and consolidation?**

BACKGROUND TO THE TRAUMA DATA SCOPING PROJECT

In 2001 with funding from the Motor Accident Insurance Commission, the Queensland Trauma Plan Project was launched to collect and collate information on the impact of trauma on the Queensland population, and to describe and evaluate the Queensland trauma management system. The aim of this project was to provide evidence to support the development of a Trauma Plan for Queensland. This plan was intended to guide the future development of initiatives in Queensland aimed at reducing the impact of trauma on the Queensland community and to improve the manner in which patients are managed within the Queensland emergency prehospital and health care systems.

This project was completed in 2006 [1], and prompted a subsequent series of consultative forums led by the Royal Australasian College of Surgeons (QLD Trauma Committee). The result of these collaborative processes was the presentation to government of *A Trauma Plan for Queensland* [2]. The *Trauma Plan for Queensland* (attached) was endorsed in principle by QEMSAC and endorsed by Queensland Cabinet for further development. To facilitate these steps, an Interdepartmental Committee chaired by QLD Health was established in September 2006 to consider the recommendations made in the Plan and develop an appropriate strategy for sequential development and funding of core aspects of the plan.

As a consequence, the 2007 state budget delivered $28.3m over four years to progress priority aspects of the Trauma Plan. No specific allocation was made for data improvement, although it was acknowledged that the collection of accurate and relevant data is critical to the evidence-based approach to system development and to ensuring optimal outcomes for patients.

It is generally agreed that comprehensive data are required to:

- Inform policy and strategic development for both injury prevention and health management (including rehabilitation);
- Inform system development and measure the impact of policy change;
- Evaluate outcomes; and
- Ensure reliable information for quality improvement processes.

One of the issues noted in consultation during preparation of both the Queensland Trauma Plan Project Report and the Trauma Plan, was the current state of trauma data:

> *"The collection of injury data is currently fragmented with no corporately endorsed coordination between the various data collecting agencies. Consequently, the data are not being used to their full potential."* [2]

These issues are not new. A previous report of the Queensland Health Injury Advisory Taskgroup in 2001 made similar comment. This project identified and described the variety of sources of data and noted:

> *"The solution to the question of data requirements to support Queensland Health's involvement in injury prevention and control lies not in the creation of new data sources but in overcoming the fragmentation of existing activities."* [3]

Most recently, the Trauma Plan recommended the conduct of a 2-year project to undertake a review of the system of data collection as well as dedicated ongoing funding for data acquisition and management to facilitate the development of an integrated data collection and information exchange system. The Plan made preliminary comment on the concept of a data warehouse (real or virtual) in which data from a variety of sources could be collated to present a comprehensive picture of the cause, management and impact of trauma in Queensland.

The Trauma Plan further identified a staged approach to delivering improvements to the system of data collection. The proposed aim of Stage 1 of this approach was to design and develop detailed recommendations for a more coordinated and sustainable system of data collection and collation. To enable this process, it was considered necessary that recommendations should canvass the spectrum of care from injury prevention through injury management and rehabilitation.

This Issues Paper has been developed to commence the first stage of the project proposed by the Trauma Plan which will:

- Scope the existing data sources;
- Conduct a critical analysis of the national and international literature on trauma data;
- Identify options for improvements in the system of data collection pertinent to trauma; and
- Develop a strategic plan in consultation with stakeholders to progress the intended objectives of the Trauma Plan in relation to data.

CHARACTERISTICS OF A GOOD DATA SYSTEM

While there are multiple sources of injury data in QLD, there is little linkage of data across the spectrum from injury event to rehabilitation and beyond . While it is acknowledged that over the years both the Queensland Trauma Registry and the Queensland Injury Surveillance Unit have continued to expand their collection sites across the State, there is no comprehensive state-wide reporting function which informs the full trajectory of care. Opportunities for systemic performance improvement are limited as a consequence of:

- Fragmentation of organisation-specific data collections;
- Data quality;
- Variable definitions for key data points; and
- Inability to link data.

Efficient and effective systems of data collection and management should arguably meet the following criteria:

- Common data dictionaries and formats across agencies to enable semantic interoperability of datasets;
- Facilitated linkage between organisations and datasets and adoption of a minimum core dataset to facilitate linkage between disparate databases;
- Whole of government strategy and data warehousing;
- Currency of data (reduced lag times) to enable timely access and rapid utilisation of information and identification of emerging issues;
- Enhanced accessibility through improved mechanisms for routine and ad-hoc reporting of data especially across agencies so as to support evaluation of the implementation of the Trauma Plan and to inform service planning; and
- Governance arrangements which ensure maintenance of data integrity, privacy and confidentiality.
- Relevance – a description of how the data collection meets the needs of its clients. To do this effectively it will be necessary to define both the collection and the potential end users of the data collected.
- Interpretability – the availability of information to support the understanding and use of the dataset.

The solution to the question of data requirements to support improvements in injury control probably does not lie in the creation of new data sources but in overcoming the fragmentation of existing activities. Integrating the existing information will result in more comprehensive characterisation and monitoring of the public health problem of injury, and create a valid and balanced picture on which appropriate policy development and program implementation can be based.

In addition to integrating existing injury data sources, a mechanism for enabling centralised analysis of all databases for the purpose of injury control is required. Such an integrated system could enable contextual interpretation of analyses from logically complementary databases.

One scenario that may merit consideration would involve formal linkages between the databases. Integrated analysis would facilitate dramatically enhanced value from existing data sources. Importantly, if cost effectiveness of injury prevention and improved injury management within health systems can be demonstrated by this improved system of data collection, then a percentage of these savings could be returned to the system to increase the resources available for enhancement of the data collection.

The Trauma Plan makes reference to the data warehousing concept as another possible solution for consideration. It would be essential that any data warehouse is shaped by the various end users (i.e., policy makers, practitioners and researchers, from both Government and public sector agencies) by means of properly formulated queries. The results of the analysis would in turn feed back to the end users to inform their ongoing activity. Proper functioning of this integrated information system implies that data collection, question formulation and program implementation are seen as a whole and that no one part of the system operates in isolation. End users must contribute to and be responsible for appropriate queries, and for supplying information for which they are responsible to the collection system in an agreed and appropriate format. Similarly, they must be committed to the appropriate use of the subsequent results. Most effective use of this information system will be achieved where end users are enabled to have direct access to the data to enable them to perform their own analyses. The extent to which the data would be made available to the end users will depend on permissions by the various ethics and confidentiality committees and the level of clearance these end users possess. In achieving this level of access a system would be able to compound its productivity and optimally integrate the data needs of policy makers, practitioners and researchers.

CURRENT INJURY DATA SOURCES

Preliminary assessment of the current and potential sources of injury data in QLD are described in Table 1 (Appendix 1). The data sources are classified according to the point at which most of the data are (or would potentially be) collected. For instance, data from the Queensland Injury Surveillance Unit (QISU) are obtained from ED records, so this database has been categorised under treatment, even though most of the data relates to pre-event and injury event. The custodian of the data is also listed in the table, together with a brief description of the population included in the database, and the data elements.

This table highlights the duplication of data elements, but also the capacity for linkage of data across agencies. Inconsistencies in data collected across databases are also highlighted – for example, data pertaining to risk factors for injury are present in very few databases.

Please refer to Table 1 (Appendix 1)

WHAT ARE THE ISSUES?

The collection of injury data in QLD is currently fragmented with no corporately endorsed coordination between the various data collecting agencies. Consequently, the data are probably not being used to their full potential. Analysis of the information captured in the various databases is largely conducted with respect to specific administrative needs of the collecting agency, and little reference is made to data from other sources. Although there are examples within some agencies/organisations where injury data are used to inform development of intervention programme activity, overall there appears to be sporadic, cross agency consultation. There is currently no comprehensive facility for statistical interpretation of injury epidemiology in Queensland. Consequently, funding for and effectiveness of injury control program activities are compromised.

Policy documents at both State and Federal levels have highlighted the need for improved injury surveillance information as a necessary basis for advancing efforts in injury control. Several reports have been commissioned by the Commonwealth to advise on how best to collect the necessary data and calls have been made for health departments across each of the states to initiate coordinated efforts to improve national injury surveillance. Given the status of injury as a major public health issue, and the fact that Queensland is developing a national reputation in the area of injury prevention, it is an opportune time for key agencies to capitalise on our existing strengths and lead the way in addressing this issue. Queensland can provide a working demonstration of a best practice model of injury surveillance by integrating its existing injury information collections and ensuring that personnel are available to analyse and interpret the data and to then develop and implement programs based on these analyses.

Three main issues related to collection of injury data were identified during consultation for development of the Trauma Plan. These were:

1. **Coordination**
2. **Linkage**
3. **Access.**

Some of the key issues related to each of these points are described below.

1. COORDINATION

In order that data can be shared, data must be comparable. Considerations for comparability will include data definitions, scope of the collection, any changes within that collection over time (e.g., a change in the collection of a particular variable that combines two other variables, or a change in the data collection process or population base), and the time period in which the data were collected.

- There is an apparent lack of coordination between agencies. *Is it possible to harmonise the collection of injury data across the treatment continuum to ensure more effective and efficient data collection and provide an information source for prevention activities?*
- There is a need to reduce the number of disparate data sources*. Is it possible to standardise data definitions and coding/classification systems?*

2. LINKAGE

The advantages of linking several data sets vs using a single data set have been previously described [4]. An example is the Crash Outcome Data and Evaluation System (traffic collision; EMS, hospital discharge, and vital statistics data at state and national level) that has been used in the US to ascertain more accurate estimates of incidence, costs and outcomes of road crashes, as well as identifying risk factors [5]. In Australia, another useful example of the importance of linked data is VISU (Victorian Injury Surveillance Unit), where coroners' records are matched with hospital admissions and ED presentations for surveillance of injury mortality and morbidity [6].

- Currently, there is no linkage across episodes of care for a single injury event. This may result in multiple counting of some injuries, and consequently, hospitalisations resulting from injuries are likely to be overestimated. *Is there capacity to obtain patient-based data (to facilitate linkage of data pertaining to an injury event), while retaining the episode-based frameworks that currently exist in most databases?*
- There is duplication of variables, or collection of similar information. *Is there capacity in the current system of injury data collection to reduce duplication of information? How might this be achieved?*
- Probabilistic linkage vs unique identifier*. What option would best suit the systems of data collection in QLD?*
- The public are concerned about data linkage, and the potential for misuse. *How can the public be reassured that data linkage will enhance research and prevention activities and not compromise privacy?*
- Privacy issues revolving around legislative impediments to linkage*. What are the legislative issues relating to linkage of data, and how can data linkage be facilitated in the current legislative framework? What, if any, legislative changes are required to facilitate data linkage?*

3. ACCESS

There are a number of agencies responsible for injury data collection in Queensland. Each of these collections was developed to suit the unique needs of the collecting organisation. Injury research is not always the primary purpose of the data collection and so using the data for statistical interpretation or injury research is not always feasible. Accessibility for outside organisations is variable according to the data held and the reasons for the data collection. Some databases hold detailed information that, if easily accessible by outside sources, could violate the privacy of individuals or compromise the purposes of that data collection. For example, the police database holds information on any event that is of operational interest to the police. Details on injury location, those involved in the injury event and mitigating factors are held. Much of this information would be of interest to injury prevention practitioners. However, the database is also a repository for police intelligence and would be compromised if open access to other organisations was granted. Typically data remain within the agency responsible for data collection, and are not accessible to other agencies.

The collection, use, storage and disclosure of personal information by agencies within the Queensland Public Sector is regulated **by Information Standard 42** [7]. QLD Health complies with a different Information Standard (**IS42a**) [8]. However, Statutory bodies that are governed by the Minister of Health comply with **IS42**. In Queensland, privacy is implemented administratively, and is therefore policy-based. Thus, where legislation exists that relates to the collection, use, disclosure or storage of information that is inconsistent with **IS42** or **IS42a**, the legislation overrides the policy. In addition, in some instances (e.g., Commission for Children and Young People and Child Guardian, CCYPG) legislation relevant to one agency has jurisdiction over the legislation in other agencies.

Importantly, there is a time-lag associated with the collection of the majority of injury-related data. For instance, a period of approximately 18 months exists between a patient episode and the completion of documentation, coding and data entry into the electronic QHAPDC (Queensland Health Admitted Patients Collection) database. Routine deaths data are typically not provided until almost a full calendar year afterwards [9]. Consequently, estimates of injury occurrence are compromised. For instance, the frequency of suicidal deaths may be underestimated because of ICD-10 coding rules that require a determination by a coroner or doctor that a death is suicide or intentional. Delays in coronial processes mean that the determination and reporting of intent may not occur for up to 18 months after a death. If this does not occur before the ABS books are closed off, these deaths are currently coded to "accidental" by default.

Finally, if data that are released are not well understood, there is a risk of misinterpretation of the dataset. For example, an apparent upward or downward trend in a particular injury type may reflect an increase or decrease in ascertainment in a database, or a change in how cases are coded, rather than a true change. The sharing of data with other agencies may inadvertently result in an inaccurate interpretation of the data, and result in poorly designed injury prevention initiatives or policies.

- There are important issues relating to privacy / confidentiality legislation that must be considered*. What changes are required to current legislation, policies, etc to facilitate improved access to data in QLD? Would a whole-of-government approach facilitate or impede this?*
- Organisational sensitivity to releasing data that may be interpreted as reflecting upon clinical performance of the relevant institutions*. What is required to increase an understanding of the issues specific to each organisation and reduce anxiety/concerns around these organisational sensitivities?*
- There are currently time-lags associated with collection of most injury-related data. *Can the time-lags associated with current access to data be feasibly reduced? What is required to reduce these time-lags?*
- Proprietary data systems that use proprietary coding schemes present barriers to external organisations accessing and interpreting data*. What can be done to assist agencies with facilitating access and interpretation of data by external agencies/organisations? Is there a common format that will facilitate data sharing that doesn't require access to proprietary systems?*

WHAT ARE THE KEY IMPEDIMENTS TO CHANGE?

Consultations for the Queensland Trauma Plan Project and the resultant Trauma Plan, as well as commentary in historic documents [3] suggest that the following issues may well be key impediments to change.

- **Absence of a unique patient identifier to facilitate linkage?**
- **Legislative impediments?**
- **Privacy concerns?**
- **Lack of standardisation of inclusion criteria?**
- **Lack of standardisation of data points?**
- **Lack of standardised coding mechanisms?**
- **Technical interoperability (IT hardware and software applications that enable rapid interface are required)?**
- **Semantic interoperability: common definitions, mappable codings to enable meaningful linkage?**
- **Lack of resources for information management and storage of data?**
- **Linkage methodology decisions – e.g., patient-based, or episode-based?**
- **To what extent have recent changes to Privacy and Confidentiality Legislation to facilitate inter-agency performance analysis improved opportunities to address these issues?**
- **Has any progress been made by your agency in addressing these issues?**
- **Are there forums known to you that are addressing these Issues?**
- **Have improvements in electronic capture of data (e-ARF, EDIS etc) provided opportunity to improve inter-operability?**

COMMENTS:

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The Trauma Data Scoping Project Team comprises:

Investigator Team

A/Professor Vivienne Tippett	Director, Australian Centre for Prehospital Research (ACPHR)
Professor Gerry FitzGerald	Queensland University of Technology
Dr Cliff Pollard	Chairman, National Trauma Registry Consortium (NTRC)
Professor Michael Schuetz	Chair of Traumatology, PAH

Working Group

Dr Cate Cameron (Expert Advisor)	School of Medicine; Griffith University
Ms Tamzyn Davey (Expert Advisor)	NTRC and CONROD (UQ)
Ms Emma Enraght-Moony (Expert Advisor)	ACPHR and National Centre for Classification in Health (NCCH), QUT
Dr Kirsten McKenzie	NCCH, QUT
Ms Debbie Scott (Expert Advisor)	NCCH, QUT
Ms Ruth Taylor (Research Assistant)	QUT
Mrs Sue Walker	Director, NCCH, QUT
Dr Kerrianne Watt (Project Manager)	ACPHR

The Trauma Data Scoping Project Steering Committee comprises:

Jim Higgins (Chair)	Commissioner, Queensland Ambulance Service
Professor Leanne Aitken	Griffith University
Professor Nick Bellamy	Director, CONROD (University of QLD)
John Hand	Commissioner, MAIC
Kim Birch	Managing Director, MAIC
Professor Rob Pitt	Director, QISU
Dr Daryl Wall	Chair, Trauma Committee, QLD RACS
Barbara Williams	Director, Community Engagement Unit; Strategic Policy and Executive Services, DES
Professor Andrew Wilson*	Executive Director - Policy, Planning and Resourcing Division, QLD Health

*Represented by Faileen James (Senior Director, and Gillian Priest, Senior Planning Officer)

The project team wishes to acknowledge the contribution of a previous document to this Issues Paper: Spinks A; McClure R. (2001). Strategic Direction for Injury Surveillance for Injury Prevention and Control: Discussion paper for the Queensland Health Injury Advisory Taskgroup. Brisbane.

Appendix 1 - Pre-consultation Map of Potential Data Sources

Notes: Databases are classified according to the point at which most of the data are collected. For instance, QISU data are obtained from ED records, so this database has been categorised under treatment, even though most of the data relates to pre-event and injury event.
Some information is incomplete. It is intended that this information will be further clarified during consultation sessions with stakeholders.
Potential data sources are asterisked *

	CUSTODIAN	DATABASE	DATA
PRE-EVENT / INJURY EVENT	Queensland Police	QPRIM	*People involved in "Events of operational interest":* Identifying info; demographics; event description; location; limited injury description.
	Department of Transport	QLD Road Crash Information System – traffic crashes only	*All major crashes on public roads:* Identifying info; demographics; location; crude injury severity; event description
	QLD Health - Health Information Centre	ESU (Omnibus survey)	Sample - Survey data; collected periodically ('98; '01; '02; '06).
TREATMENT	Queensland Ambulance Service	AIMS / EARF	*All patients attended by QAS:* Identifying info; demographic info; event description; treatment; injury description (mechanism; location; activity)
	QISU	Injury surveillance (ED)	*ED data (sample)*: Demographics; injury info (event; activity; location; e-code; mechanism; diagnoses; triage; separation)
	CONROD	QTR	*Patients in hospital >24hrs - sample:* Identifying info; demographics; injury description (e-code; location; AIS; ISS); mode of transport to hospital; treatment; outcome; disposal; length of stay
	QLD Health, Health Information Centre	QHAPDC	*Admitted patients – all hospitals:* Identifying info; demographics; injury description (principal diagnoses; procedure; e-code; location – all ICD10-AM); separation date

	CUSTODIAN	DATABASE	DATA
TREATMENT, cont..	Poison Information Centre	Queensland Poisons Information Statistics (QPIS)	*All phone calls to centre*: Some demographics (age, gender), presenting symptoms, treatment; poison details, time frame from the ingestion, phone numbers and area.
	General Practice *	-	TBC
	QLD Health	EDIS	*State-wide – ED patients* Identifying info; demographics; injury data (mechanism; activity; location; ICD10; mode of transport; separation; principal diagnoses)
	ICU Departments in selected Hospitals; and Australian and New Zealand Intensive Care Society (ANZICS)	ICU (local) ANZICS database (national)	*All patients admitted to ICU at selected hospitals* Identifying information; demographics; broad body region injured; treatment; separation. Aggregated (de-identified) data are then supplied by participating ICUs to ANZICS.
	RBWH	Burns	*Burns patients (adult and children) RBWH and RCH:* Demographics; severity; event information
	RFDS	RFDS	*Patients treated/transported by RFDS (eg – clinics in remote areas) – incident based* *Identifying info; demographics; history; primary and additional provisional diagnoses; ICD10 codes (chapter headings); e-code.*
	PAH	Spinal Unit	*TBC*

	CUSTODIAN	DATABASE	DATA
POST-EVENT	QCOMP	-	*All people injured in capacity of work (state-wide)* *Demographics (including occupation); Injury info (type; Date/ time; mechanism); outcome (death; permanent impairment; Ongoing capacity for work; medical expenses attached to claim)*
	MAIC	Personal Injury register and Database	*Insurance claims from MVCs – state-wide* Identifying info; demographics; crash details (vehicle details; location; time; circumstances); injury codes (AIS); claims payments including legal and rehabilitation costs.
	NCIS	Coronial data	*State-wide (informs national) – reportable deaths* Identifying; demographics; cause of death (ICD-10); injury info where primary cause of death (ICECI) (mechanism; activity; intent); autopsy; toxicology; police narrative
	ABS	Mortality Data (from BDM and NCIS)	*State-wide (informs national) - all registered deaths* Demographics; Medical cause of death; ICD-10 (underlying and multiple causes of death)
	AIHW	NHMD (National – derived from QHAPDC)	*State-wide – hospital separations* Hospital type; demographics (gender; DOB; Age, Country of birth; ATSI; Area of residence; LOS (admission and separation dates); Principal diagnosis; Additional diagnoses; Procedures; DRG; Estimated average DRG cost DRG; Care type; Admission mode; Separation mode; Injury info (E-code; location; Activity
	QHealth (HIC)	Allied Health records (SNAP) – from QHAPDC	State-wide, as per QHAPDC (additional in-hospital treatments)
	Medicare *		TBC

	CUSTODIAN	DATABASE	DATA
POST-EVENT, continued..	Commission for Children, Young People and Guardians	Child Death Review	*State-wide –all child deaths* Demographics (age, gender, geographic distribution; SES; ATSI); injury info (intent; mechanism; event; time; location; coronial cause of death); history of child (whether previously known to Dept Child Safety, family abuse etc).
	Private Health insurers *		TBC
	Commonwealth Rehab Services Australia *	TBC	TBC
	Centrelink *	TBC	TBC
	Special Projects E.g., James Cook University (CARRS-Q)	Road Traffic Crash study	*Road crash patients* (15yrs+; admitted to: The Townsville Hospital, Cairns Base Hospital, Atherton Hospital, Mt Isa Base Hospital; >24 hours (1 March 2004 and 30 June 2007). Data collected: Demographics; Revised Trauma Score; Emergency response times, LOS; injuries and interventions; plus fatalities (from Coroners Data).

TBC= To be clarified

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APPENDIX B – DISCUSSION PAPER

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March 2008

Trauma Data Scoping Project

discussion paper

This document was prepared by the Qld Trauma Data Scoping Project Team:

Australian Centre for Prehospital Research
(Queensland Ambulance Service and the University of Queensland)

Queensland University of Technology
(including the National Centre for Classification in Health)

Trauma Clinical Network

Royal Australasian College of Surgeons

This paper is for discussion purposes only, and has been circulated for general comment. Any views or opinions expressed in the paper do not necessarily represent the views or opinions of the Queensland Government, any policy position or representation of a Government department, or of any proposed course of action.

AUSTRALAN CENTRE FOR PREHOSPITAL RESEARCH

TRAUMA DATA SCOPING PROJECT: DISCUSSION PAPER

Project Funded by: **Motor Accident Insurance Commission**

Suggested citation:
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CONTENTS

Glossary

ABS	Australian Bureau of Statistics
eARF	electronic Ambulance Report Form
CAD	Communications Ambulance Dispatch
CCYPG	Commission for Children and Young People and Child Guardian
ED	Emergency Department
EDIS	Emergency Department Information Service
HBCIS	Hospital Based Corporate Information System
ICD	International Classification of Diseases
ICU	Intensive Care Unit
MAIC	Motor Accident Insurance Commission
MOU	Memorandum of Understanding
NCRIS	National Collaborative Research Infrastructure Strategy
PAH	Princess Alexandra Hospital
QAS	Queensland Ambulance Service
QCC	QEMS Coordination Centre
QEMS	Queensland Emergency Medical Services
QEMSAC	Queensland Emergency Medical Services Advisory Council
QHAPDC	Queensland Hospital Admitted Patient Data Collection
QISU	Queensland Injury Surveillance Unit
QTR	Queensland Trauma Registry
RBWH	Royal Brisbane and Women's Hospital
RCH	Royal Children's Hospital
RFDS	Royal Flying Doctor Service
URN	Unit Record Number
VSTORM	Victorian State Trauma Outcomes Registry
WADLS	Western Australian Data Linkage System

BACKGROUND

In early 2007, the Trauma Plan for Queensland was endorsed in principle by the Queensland Emergency Medical System Advisory Council (QEMSAC) and Queensland Cabinet. Among other key targets for improvement, the Trauma Plan recognised the need for improvement to the current system of injury data collection in Queensland. Following endorsement of priority aspects of the Queensland Trauma Plan, the ***Trauma Data Scoping Project*** was commissioned to:

- scope existing injury and trauma data sets across the continuum of care from event to rehabilitation and discharge;
- identify impediments to the efficient and effective coordination and use of data; and
- develop recommendations for a sustainable system of data collection, collation and interrogation to inform prevention and system improvement.

The ***Trauma Data Scoping Project*** is funded by the Motor Accident Insurance Commission (MAIC) as an extension of the ***Queensland Trauma Plan Project*** (2001- 2006) [1]. The Project commenced in May 2007 and is due for completion by May 2008. An Issues Paper was released for consultation in October 2007, as the first phase of ***Trauma Data Scoping Project***. Current sources of injury data in Queensland were described in this Issues Paper, and known limitations of the current system of data collection, data management, interrogation and reporting were identified. This ***Discussion Paper*** is the second key product of the Project.

PURPOSE OF THE DISCUSSION PAPER

The Trauma Data Scoping project has been designed to be a highly consultative process. Since the release of the Issues Paper in October 2007, a comprehensive round of stakeholder consultations has occurred. During the consultation phase, the project team visited key interstate informants to observe systems and identify possible opportunities for improvements that may be applicable to Queensland. The findings of the consultation process have been used to inform development of this Discussion Paper. In addition, a critical analysis of the national and international literature has been conducted and is included in this Discussion Paper (Appendix A). It is important to note that this Discussion Paper is a summary level document designed to:

a) describe feedback provided by stakeholders in relation to the Issues Paper; and
b) provide options for improvement in the current system of data collection and management.

The Discussion Paper also provides preliminary analysis of impediments to achieving an integrated injury data system that encompasses the full spectrum of care. A second round of strategic and targeted consultation forums will be conducted to determine priorities for subsequent development.

How can I continue to contribute?

The project team welcome written commentary from stakeholders. All comments should be referred to the Project Manager, Dr Kerrianne Watt, by email at kwatt@emergency.qld.gov.au or by telephoning 3109 7943. The date(s) and venue(s) for the proposed face-to-face forum will be advised in April 2008.

STAKEHOLDER CONSULTATION FEEDBACK - SUMMARY

PROCESS

Stakeholders in government, academic and research sectors, and providers across the spectrum of interest from prevention through prehospital and inpatient care to rehabilitation, were identified by the working group and the Steering Committee. Consultations were able to be conducted with 58 out of the 80 identified stakeholders between October 2007 – January 2008 (see Appendix B).

Consultations were conducted face to face, and were facilitated by members of the working group. Consultations were semi-structured, and took approximately 2 hours. Consultations followed a proforma that was circulated to stakeholders prior to the consultation (Appendix C), comprised of four main topic areas:

1. **Data capture** - targeted at those stakeholders who operate injury data systems. Questions were aimed at identifying details regarding nature of data collected (years covered, exclusion/inclusion criteria); purpose of data collection; applications of data; funding / governance arrangements; and definitional/coding structures used.
2. **Data access** - targeted at both end-users and collectors of injury data to identify issues affecting data retrieval and interpretation of data. Questions focused on experience in accessing / providing data; procedures for accessing data; factors that enable / impede access (including legislation); associated time lags with accessing data; and suggestions for how to improve data access issues.
3. **Data coordination** - the comparability or interoperability of data sets across the treatment continuum. Discussion points included processes for updating coding systems; documentation of changes; variations between data collections that impact on data use, and views regarding the value of data coordination and approaches for achieving better interoperability.
4. **Data linkage** – focused on the value of linkage of trauma data across providers and identified barriers which may exist to linking trauma data. Stakeholders were asked about their experiences in relation to linkage of data in Queensland (including how linkage was achieved); impediments to linkage (including technological / classification issues, privacy concerns and legislation); the capacity for reduction of duplication; and perceptions about improved interoperability due to recent / future improvements in the electronic capture of data.

During consultations, stakeholders were also given the opportunity to identify any other issues that required emphasis or consolidation.

After the consultation, a written summary of the consultation was provided to the stakeholder for authorisation and to provide further opportunity to comment. Comments were then entered into a spreadsheet to facilitate thematic analyses.

SUMMARY FINDINGS

1. DATA CAPTURE

Consultations with stakeholders identified gaps in understanding of the full spectrum of data sources and data elements that exist in relation to injury. There was recognition that there is currently no overarching purpose for injury data collection, as each data base exists to service the clinical, operational and reporting priorities of the collecting agency. Stakeholders considered that it is imperative to collect a formally agreed upon set of core data elements derived from key sources such as prehospital, Emergency Department (ED), admitted patients, and outcome data (including coroner's data), with development towards collection from supplementary sources. A preliminary summary of current injury data sources is provided in Appendix D.

An important gap in injury data capture identified by stakeholders is that of rehabilitation data. The capacity to measure morbidity in Queensland is minimal, as very little rehabilitation data are routinely collected. Data are collected by MAIC and QCOMP in relation to motor vehicle crashes and workers' compensation claims, but this is possible only under specific legislation relevant to those organisations. Some data on outcomes are collected in specific databases (such as the burns database at RBWH, and the Spinal injuries database at PAH). These data are used to improve patient care, and injury prevention activity. There was some suggestion by stakeholders with a clinical interest that data on clinical indicators (such as the haemodynamic status of patients; pathophysiology; organ failure; and comorbidities) were difficult to obtain. Only limited information is available on variables such as previous injuries, with limited or no apparent access available to other variables such as comorbidities and disability status.

2. ACCESS

Stakeholder Experience in Accessing Data

Feedback from stakeholders indicated that their experience obtaining any kind of epidemiological data is difficult, but that obtaining data on injury is particularly difficult. Overall, stakeholders expressed disappointment and frustration about the under-utilisation of current injury data sources in Queensland and the inability to secure available data in a timely manner.

Seven of the agencies consulted during the consultation process reported past experience with difficulties in accessing data from the Queensland Trauma Registry (QTR). The key issues raised by stakeholders include:

- lack of transparency regarding the reasons for refusing data requests;
- time delay in the provision of data;
- poor marketing of the services provided by QTR and the data that are accessible, resulting in limited knowledge of the usefulness of this source; and
- the inaccessibility of data at the individual hospital level (e.g., Queensland Health central office has only recently gained limited access to data from individual hospitals through QTR).

A recent internal review of formal requests to QTR in 2007 demonstrated refusal of only two requests on the basis of not collecting the data requested or not having ethical clearance to access information. An external review of QTR canvassed these and related issues and at the time of writing, the Registry was working actively with its funding agencies to redress these challenges.

It does appear that many stakeholders who could, or should, have ready access to the QTR data are not aware that the data are available and consequently are not considering potential application of this information source to injury management/injury prevention activities. There is some known and historic resistance from some hospitals to providing data to the Registry if facility level information is known to be provided to staff and researchers external to the facility in which the data are collected. This issue would appear to require negotiation.

The QTR has faced some difficulty in regard to continuity of staff at QTR collection sites and stakeholders expressed concern about the potential impact of the loss of skilled capture and coding activities if these positions are not supported into the future.

Whilst stakeholders described more streamlined processes for obtaining data from the Queensland Injury Surveillance Unit (QISU), the lack of representation and quality of the available data was identified as an area of concern. An ongoing source of concern for QISU is that it is currently unable to comprehensively fulfil its primary role of injury surveillance due to limited participation by EDs in the data collection process. Whilst the data collected by QISU were recognised by stakeholders as extremely valuable (e.g., risk factor identification, cause of injury) the validity of the data and the application to injury prevention was cited by some stakeholders as a reason for not accessing these data. The data currently available are considered inadequate for application to development of population level interventions/strategies. Broader capture and population level data (or at least data that are representative of the population) are required.

Identified Impediments

Agencies that collect data raised concerns related to confidentiality and privacy issues where small numbers of cases are involved, so that releasing data risks possible identification of individuals. These agencies also cited concerns about possible misinterpretation of data as a reason for reluctance of data release. Appropriate application and interpretation of the data requires explicit understanding of what the data means, restrictions on how data are collected/defined, and the classification and grouping systems used. However, provision of this information requires resources. End-users of data also identified this as a concern and indicated a level of discomfort with the level of advice currently received with data provision, specifically with regard to the limitations of the data provided. Collectively, end-users of data were strong advocates for an interface between data users and collectors that could guide users on what, where and how data should be accessed and applied.

End-users of data recognised that timeliness of access to data is a crucial issue, particularly in relation to quality assurance processes (e.g., trauma review), and service provision analyses. Collectors of data agreed that resources and processes are urgently required to reduce the current timelags.

Suggestions for Improvement
A central, easily accessible source of aggregate data was recognised by the wider group of stakeholders as a useful tool. The concept of a well-structured database with clear definitions that was accessible to agreed stakeholders is supported. The majority of stakeholders argued that unequivocal access of injury-related data should be available (with care taken in relation to identifying information provided – for example, replace age with age group), in a timely and usable manner, to:

- those with a bona fide reason for accessing data (policy makers, practitioners)
- researchers
- care providers (for the purposes of reviewing patient care)
- public sector agencies (including Queensland Health Central Office)

For clinical purposes, a "real time" function for data entry / download (i.e., electronic capture of data) was expressed as the ideal solution that would, over time, also address issues of duplication (discussed in the section on linkage). For non-clinical purposes, regular provision of summary data (vs the very large and more detailed annual reports that are provided after significant delays) was identified by stakeholders as a possible mechanism for improving access to data. Larger, more detailed annual reports that are currently provided by agencies such as QTR could then be provided less frequently (e.g,. 3 years).

3. COORDINATION

Comparability - Definitions / Coding Systems
Stakeholders recognised that there is minimal comparability between injury data sets in Queensland. There was recognition by data collectors and end-users that the disparity in current data definitions prevents interoperability. For example, the Department of Transport defines "serious injury" as an injury where transportation via ambulance to hospital is required. This definition differs markedly from other definitions of serious injury. For example, the Queensland Trauma Registry (QTR) defines serious injury as those injuries that result in a patient being admitted to hospital for more than 24 hours (serious injury is further defined as major and minor injury, where major injury describes those patients with an ISS score of >15).

Agencies responsible for collecting data agreed that urgent changes in the consistency of data definitions and coding systems are required. Stakeholders agreed that any changes that occur must take into consideration the various national perspectives in relation to definitions and coding systems. Stakeholders stressed that definitions should be agreed upon by all relevant stakeholders so that the resulting definitions and core data elements fulfil the organisational (and usually administrative) requirement of each data collection.

There is acknowledgement that this task continues to be challenging and that previous attempts to improve interoperability of key definitions have reached only partial consensus. However, there is strong consensus that standard data formats must be agreed upon and used by core agencies (e.g., name; date of birth; etc) if effective interoperability is to be achieved.

Suggestions for improvement

It is acknowledged that negotiation and development of consistent data definitions that apply to all injury data sets is likely to be a difficult and lengthy process. However, in the short term (i.e., 5-10yrs), a more realistic goal may be to ensure that key organisations share definitions and coding systems. At a minimum, most stakeholders agreed that the following organisations should collect data on key data points in a format that allows for extraction of data with equivalent meaning: QAS; EDIS; QISU; Queensland Health; QTR. Stakeholders suggested that the national standards on injury surveillance should be used to guide the development of standard definitions and coding.

Once common data definitions and coding systems are in place, significant resources will be required to establish interoperable information technology and infrastructure to support them. Both of these are crucial. There is a perception among clinicians that interoperability between databases within hospitals is limited, thereby making linkage of data from different systems difficult (e.g., EDIS, QHAPDC, ICU). However, deterministic linkage of data from the different systems that operate within the same hospital is possible and performed routinely. Conversely, linking the full health care experience of individuals within the same agency is complicated, and this impacts considerably on time lags associated with data provision. For example, in Queensland Health there is no unique patient identifier across hospitals. Thus, in cases of interhospital transfers, probabilistic linkage is required to track patient care, and this can only be done retrospectively. There are processes currently in place to improve this system for public hospitals.

Those stakeholders who collect data were adamant that any changes must also be accompanied by stringent quality checks to ensure that data definitions and coding systems are being applied so that data are truly comparable. This requires significant training and education resources. Regardless of the system used, it should be highly structured so that interpretation on an individual basis is limited, in order to reduce the need for ambiguity in the selection of suitable codes. There is an overall agreement among those who currently collect injury data in Queensland that the coding systems used in many organisations are open to interpretation, reducing the comparability of data.

4. LINKAGE

Stakeholder perspectives

Overwhelmingly, stakeholders were supportive of linking patient data across the continuum of care, on the basis that patient care will be improved, and that better quality data will be available for injury prevention.

There is general agreement that linked data will better facilitate system-wide performance measurement to assess the impact of trauma management on patient outcomes.

There are precedents for data linkage in Queensland. For example, data linkage at unit record level is routinely performed in Queensland by several agencies (e.g, MAIC; QCOMP). Both of these agencies link data using probabilistic methods (name; date of birth; date of injury), and are claim-based, which allows linkage from point of injury (e.g, MAIC – crash; QCOMP – work injury) to various outcome measures (e.g., – amount spent on

physiotherapy). In both cases, private insurers are required by legislation to provide data on a regular (e.g., monthly) basis, or risk financial penalty. Where data from several agencies are required (e.g., QAS, Queensland Health), this is achieved through an inter-agency Memorandum of Understanding (MOU).

Some databases have detailed patient-based linked information (including outcome measures). Examples include the Spinal Injuries Unit database (PAH), and the burns databases (RBWH and RCH). Data from these units are used for clinical research and injury prevention purposes. These units are dedicated treatment facilities where the information collected is also used to inform treatments protocols. It is important to recognise that these databases have been implemented because there is no capacity in the current system to collect the information required by the units in their absence. Data points relate to patient groups that are often not included in the QHAPDC (and therefore QTR), or QISU. Supporting these data bases requires a dedicated resource. These databases are considered to be under-resourced and consequently neither of these systems are electronically based.

Capacity for Data Linkage

The Health Information Centre in Queensland Health collates admitted patient data at the episode level, and requires the current episode-based framework to be retained. An episode is defined as a phase of treatment, thus a patient may experience several episodes within a hospital stay (e.g., acute; rehabilitation; maintenance). This is a national standard and there is no scope to change this. However, there is capacity in the current system to obtain event or patient-based information (i.e., information pertaining to the patient, or to one specific event) from the episode-based system. Data relating to different episodes for the same patient within one hospital can be linked deterministically using the Unit Record Number (URN). Data on episodes of care at different hospitals can be linked through probabilistic methods, matching on patient identifying information such as name, gender, date of birth, address, etc. Data on admitted patients can also be linked to data from other sources (e.g., Coroner; QAS) using probabilistic linkage, but the accuracy of the data linkage depends on the completeness and accuracy of patient identifying information in the various datasets. This process can also be time consuming for large datasets. Currently, in their data cleaning processes, both QISU and QTR convert episode-based information provided by Queensland Health into an approximation of event-based or patient based information. When patients have episodes at more than one hospital, matching is performed on patient name, age, time of presentation, etc, to reduce over counting of patients who present to multiple hospitals. However, these processes are extremely time-intensive and not necessarily infallible.

Duplication of Data / Duplication of Roles

In addition to capturing patient data across the continuum of care, linkage of data was also seen by some stakeholders as a tool to reduce the perceived duplication of information that exists in the current system. Clinicians were strongly supportive of an electronic record that would reduce the need for repeated entry of patient information (e.g., administrative information and medical history). Clinicians indicated that there is a high level of frustration experienced by both staff and patients at this repetition.

There was also recognition among the wider stakeholder group that there is some overlap in roles of staff responsible for coding injury data. For example, some stakeholders expressed concern that at sites where both QISU and QTR operate, there are separate coding staff for each agency. In consultation with QISU and QTR, both agencies expressed support for the

idea of sharing coding staff, and suggested that any savings actualised could be redirected to maintaining agency costs, or health services. There was also an understanding that there is some overlap in the information collected by QISU and QTR (in relation to seriously injured patients), and that there is room for greater cooperation to address this. A linked data system that contains information across the continuum of care would remove this overlap, and also bridge the current information gaps.

Emergency Department Data Interfaces

While data from EDIS and QHAPDC (through Hospital Based Corporate Information System - HBCIS) within the same hospital can be linked retrospectively, the current system does not facilitate straightforward "real-time" communication between these two databases. As previously mentioned, when patients are transferred to another hospital after first presenting at an ED, retrospective data linkage can occur through probabilistic matching. Recent changes in Queensland Health (e.g., distributed electronic health record) should allow greater electronic capture of data, and therefore potentially facilitate better opportunities for "real-time" data linkage. In addition, Queensland Ambulance Service and Queensland Health are working on changes that will allow linkage of data pertaining to patients in the prehospital environment with EDIS and with QHAPDC (where patients are not admitted through the ED or where EDIS is not used by a hospital). The eARF (electronic Ambulance Report Form) number was added to EDIS (and QHAPDC) in late 2007. It is also planned that data from CAD (Communications Ambulance Dispatch) will interface with the eARF. These changes should better facilitate linkage of patient data from the prehospital stage to discharge, but the process must be carefully monitored. There are issues related to the purpose of these databases (administrative vs clinical), and about quality of the data in these databases – these issues are addressed in the section on Access in this Discussion Paper.

It is important to note that while there are elements of core data collected from EDs across the state, several different data collection systems are in operation (e.g., EDIS; HBCIS emergency module, ERIC). A further problem is that prior to 2003, data elements from EDIS were unique to each hospital. Standardised EDIS data elements and codes have been used by Level 3 hospitals or above since 2003, and in all hospitals with EDIS from 2008. Aside from issues of system interoperability, there are issues related to multiple presentations by one person, or to presentations at multiple hospitals (e.g., interhospital transfers) which need to be considered when exploring data linkage capabilities. Currently, each of these presentations is entered as a separate episode. It is important for such issues to be addressed, possibly through forums such as the Client Directory Project and the Statewide Provider Directory.

During the consultation process, particular difficulties were described in relation to data on patients involved in interhospital transfers. Some of the data fields (time of scene departure; time of arrival at hospital) required by QTR are not present on forms used by some retrieval agencies (e.g., Royal Flying Doctor Service - RFDS). Efforts are currently being made to address this situation.

Currently, there is substantial duplication of data across agencies involved in inter-hospital transfers (Queensland Health; QAS; Careflight; RFDS; QCC – Queensland Clinical Coordination Centre). Problems are also experienced with the retrieval of clinical data for quality assurance purposes (e.g., trauma review committees) in cases of patients who visited multiple facilities. Stakeholders indicated that a real time, electronic health record would be enormously beneficial in this sense, and would help eliminate the current duplication of data

currently collected, and fill the gaps regarding data on patients at different sites. Significant efforts have been made recently by QCC to develop a clinical coordination database. Binary endpoints (e.g., mortality) are considered to be a sub-standard mechanism for measuring trauma outcomes and facilitate quality improvement. For example, the current system allows examination of deaths, but not "near misses".

Method of Linkage

The majority of stakeholders are supportive of linkage through a unique patient identifier, although there is acknowledgement that this step has proven historically difficult to secure. Current e-health initiatives in Queensland Health have the potential to address the unique identifier issue and facilitate more efficient linkage of data.

Some stakeholders firmly believe that only a system based on a unique identifier will work. Proponents of this view argue that probabilistic linkage methods fail due to human error. Such a system is heavily reliant on accurate recording of precise information with respect to name, date of birth, gender and location. If linkage methods rely on precise information, and information is not entered precisely, then linkage via any means other than a unique identifier is likely to result in higher levels of linkage error.

On balance, there is also an acknowledgement that probabilistic methods would be workable. Certainly, interstate linked data sets have been successful using this approach. The Western Australian Data Linkage System (WADLS) uses probabilistic linking techniques, and this approach will be used by South Australia when they introduce their linked data set late in 2008.

Identified Impediments

The area of most consistent concern related to linkage is not the process itself but the security of the system used to house the data post-linkage. Stakeholders stressed that a failure to describe strict security parameters and effective systems for protecting patient privacy and confidentiality would result in reluctance or refusal to provide data for the purposes of linkage.

Related to this are concerns expressed by the majority of stakeholders about public reaction to the concept of linked data. Some clinicians suggested that this concern should be balanced with the frustration expressed by patients about the excessive repetition required of them about their personal information and medical history, throughout their treatment. Overall, stakeholders were optimistic that with appropriate education about the uses and benefits of linked data (vs what data can not be used for), combined with illustrations of possible applications of the data, and how linked data systems operate in other states and internationally, the public would be receptive. Stakeholders expressed the need for cooperation and good will by all agencies involved, but primarily there was a belief that strong governance frameworks and commitment to data security could affect current public perception. Careful consideration of how this has been achieved in other Australian states is required.

A further barrier to linkage of data across the continuum of care is the lack of available data on outcome following injury. There is no central repository of data related to rehabilitation in Queensland, thus there is no database to link to. Some stakeholders expressed that this is

primarily due to lack of funds, multiple providers of rehabilitation services, and multiple definitions of “rehabilitation”.

Currently, legislation prevents contacting patients after treatment. As such, agencies such as QTR can not routinely contact patients to measure outcomes post-discharge. Follow-up for the purposes of research is allowed only under specific circumstances where special ethical approval has been secured, and this is done on a project by project basis. Processes for securing these arrangements are described by stakeholders as frustrating, overly bureaucratic and very time consuming.

Alternative systems have been constructed to facilitate longer-term follow-up. For example, the Victorian Trauma Registry (VSTORM) uses an opt-off system, where consent to follow-up of patients at 6 and 12 months following discharge is implied unless actively refused. Less than 1% of patients refuse consent in this system, and outcome measures are obtained for approximately 80-87% of patients captured in the registry. Patients are informed by posters present in EDs and hospitals, as well as through letters and verbal explanations during hospital visits. Follow-up measures include: Extended Glasgow Outcome Scale; SF12; pain; return to work; additional care at home; disability.

Suggestions for improvement

Significant effort is being directed towards addressing issues that are currently considered impediments to data linkage. Commonwealth funding is being sought through the National Collaborative Research Infrastructure Strategy (NCRIS) toward building the research infrastructure that will facilitate data linkage. Trauma has been identified as a priority area under this proposal, which is based on the West Australian model (WADLS). Significant financial resources have been allocated by Queensland Health toward the e-health strategy. The electronic health record has been identified as a priority, and this should facilitate data linkage. Allocation of a statewide unique identifier may be part of this process. This unique identifier would be additional to, not instead of, the current hospital-based URN. In addition, the introduction of Transition 2 (T2) is likely to facilitate linkage of data that are collected in hospitals. Specifically, T2 allows linkage of any data that are captured in systems (e.g., EDIS, ICU, Pharmacology, Radiology) that operate in the 33 casemix hospitals.

5. LEGISLATION

Stakeholder perspectives

Stakeholders perceive privacy and confidentiality legislation as significant impediments to sharing / accessing / linking data, however little commentary on the specific aspects of the current legislation that required change was provided. The current situation regarding legislation and its application to data access does not appear to be well understood. Injury data in Queensland is necessarily multi-jurisdictional and covered by associated Acts (e.g. RFDS – Commonwealth Act, Queensland Health – Health Act, Health Services Act, Public Health Act, Private Health Facilities Act; QAS – Ambulance Service Act). Stakeholders suggested that a Whole of Government approach would require facilitation by a group that is capable of instituting change.

Currently, the majority of stakeholders perceive that the Legislation allows for health data to be shared if it relates to continuing care of the patient, and that the legislation allows for

provision of data to external agencies (e.g., police) if that agency is made a "prescribed entity" (via inter-agency MOUs). This is the strategy used in instances where data are currently linked in Queensland (e.g., MAIC; QCOMP; ABS). Stakeholders perceive the current environment to be overly bureaucratic, and many suggested that overarching legislation is required to facilitate data sharing and linkage. Some stakeholders observed that significant effort is required to change attitudes across government if a system of linked data is to be embraced. There is a perception that government agencies have a highly conservative perspective on data linkage. This may be because the utility of linked data (politically and scientifically) has not have been well described.

One specific piece of legislation relating to access of Coronial data was identified by a range of stakeholders as problematic. Current legislation (Section 53, Coroners Act 2003 [2]) prevents provision of information "*while a coroner is investigating the death to which the document relates*". This can result in significant time lags. The delay in access to Coronial Data reduces the available information (especially pre-event information) about injuries. Access to the injury information that is unlikely to change or be impacted on by the result of the Coronial inquiry prior to closure of the case would help improve the situation. This would require a change to the current Coronial legislation.

Some stakeholders were of the opinion that the main impediment to sharing data, rather than perceived legislative constraints, are organisational sensitivities around data being used for unfavourable or ill-informed comparisons.

Agencies such as MAIC and QCOMP reported no difficulties in accessing the data required from multiple other agencies (e.g., Queensland Transport, QAS, private organisations) due to legislation drafted specifically for their purposes. Additional MOUs exist between agencies where required, which detail specifically the data that are required, the timeframe, and the purposes for which the data can be used. These agencies represent possible models for the way in which legislation can be used to assist with access to injury data (e.g., an overarching legislation that relates specifically to collection of and access to injury data).

Key Standards and Legislation

Due to the apparent confusion described by stakeholders around the provision of confidential patient information for the purposes of data sharing and linkage, a brief description of the relevant regulations and Legislation is now provided.

The collection, use, storage and disclosure of personal information by agencies within the Queensland Public Sector is regulated by Information Standard 42 [3]. IS42 is issued by the Queensland Government Chief Information Office within the Department of Public Works. IS42 is based on the information privacy principles established by the Commonwealth Government. Queensland Health complies with a different Information Standard (IS42a) [4]. However, Statutory bodies (including Health Portfolio Statutory bodies[1]) that are governed by the Minister of Health comply with IS42. In Queensland, privacy is implemented

[1] Health Portfolio Statutory bodies in Queensland include: Bundaberg Health Services Foundation; Far North Queensland Hospital Foundation; Gold Coast Hospital Foundation; Ipswich Hospital Foundation; Princess Alexandra Hospital Foundation; Royal Children's Hospital Foundation; Royal Brisbane Hospital Research Foundation; Royal Women's Hospital Research and Development Foundation; Sunshine Coast Health Services Foundation; Townsville District Health Foundation; Toowoomba Hospital Foundation

administratively, and is therefore policy-based. Thus, where legislation exists that relates to the collection, use, disclosure or storage of information, the legislation and not the relevant clauses under IS42a apply (e.g., Part 7, Section 62 of the Health Services Act 1991; Chapter 6, Part 4 of the Public Health Act). In addition, in some instances (e.g., Commission for Children and Young People and Child Guardian - CCYPG) legislation relevant to one agency has jurisdiction over the legislation in other agencies.

Under IS42A, "*with respect to persons who are or have received a public sector health service, the principal duty of confidentiality is under section 62A of the Health Services Act 1991. A key exception to a statutory duty of confidentiality is where another legislative provision requires or permits personal information to be given to another person or body. Many of the provisions listed below are authorities or requirements to make such disclosures*."

There are notable exceptions to IS42A, as defined in the Queensland Health Privacy Plan [5]. Prior to 2006, exceptions that came under the Health Act 1937 [6], allowed the provision of information to a person involved in an investigation or inquiry into a matter relating to public health (Section 15(4)). Section 20(2) allowed the Chief Executive to "*collect copies of annual reports (that may contain personal information) of medical reports of medical officers of health of local governments in relation to the public health of the local government area and its inhabitants*". Part 5 of the Health Act also allowed for provision of information to authorised persons for approved research and studies (Section 154M). In 2006, the Public Health Act was introduced. The Public Health Act supercedes the parts of the Health Act that relate to privacy and confidentiality of identifiable (or potentially identifiable) patient data in relation to research. The Queensland Health Privacy Plan (2005) has not yet been updated to reflect the introduction of the Public Health Act.

Because other legislation over-rides IS42 or IS42A where it exists, relevant legislation is briefly summarised below in order to clarify the current situation regarding provision of confidential patient information in Queensland, and how this may impact on the issues of access and linkage.

Public Health Act 2005

Of primary relevance to the provision of confidential patient information (including identified information) is the Public Health Act (2005) [7]. One of the purposes of the Act is described as "*collecting and managing particular health information, and establishing mechanisms for health information held by the department to be accessed for appropriate research, and inquiring into serious public health matters*".

Section 281 of the Public Health Act permits provision by the Chief Executive or relevant person of confidential patient information (including identifiable information) for the purposes of research (clinical and applied; epidemiological; evaluation and planning; monitoring and surveillance). In addition, the Chief Executive or a relevant person may give the information despite any other provision of this Act or any provision of another law that deals with confidentiality, including the *Health Services Act 1991 (* Section 62A), or the *Private Health Facilities Act 1999* (Part 11, Section 147) - see below. A relevant person is described as a person who has access to health information held by the department (e.g., health service employee; public service employee). Provision of this information must be sought by written application to the Chief Executive, and the application must be accompanied by the relevant supporting documentation (Sections 282 and 283). Under Section 284 of the Public Health

Act, the Chief Executive is required to consider the application "*as soon as practicable and either grant or refuse the application"*. The application may only be approved if the Chief Executive is satisfied that the research is in the public interest (i.e., will provide increased knowledge and improved health outcomes; and that the privacy of individuals will be protected). This section specifically requires that provision of identifying information is only allowed if the identifying information is necessary for the research. Provision of confidential information may be granted subject to conditions (including: reasonable reimbursement to the state for associated costs; assurance that information will be handled confidentially and securely; ethical conduct of researchers and use of information; feedback provided to Chief Executive regarding progress and results).

Health Services Act 1991

Under Part 7, Section 62A(1) of the Health Services Act [8], patient information obtained about patients in the course of receiving treatment must not be disclosed if there is a possibility that the information can identify the patient. However, there are important exceptions to Section 62A(1). Specifically, Section 62A(1) does not apply in relation to disclosure of confidential patient information if the disclosure is under the following circumstances:

- Data collection and public health monitoring - where the disclosure is to another designated person, to give effect to or manage a funding arrangement for a public sector health service; or for analyses, monitoring or evaluating public health; and the other designated person is authorised in writing by the Chief Executive to receive the confidential information. [Section 62G]
- Health Services - where the disclosure is to another designated person, to evaluate, manage, monitor or plan health services. Note: disclosure is also allowed to an entity prescribed under a regulation for this paragraph for evaluating, managing, monitoring or planning health services as stated in the regulation. [Section 62H]
- Approved quality assurance - where the disclosure is to a committee declared under section 31(1) to be an approved quality assurance committee, or to a person authorised by the committee to receive the confidential information, to enable the committee to perform its functions. [Section 62M]
- Use by Coroner - where disclosure is to a person requiring the information to perform a function under the Coroners Act 2003, other than the preparation of an annual report. [Section 62P]

Additionally, disclosure of confidential information by the Chief Executive to the Commonwealth, another State or Commonwealth or State entity is provided for by Section 62N, where there is an agreement or requirement. Entity of the State includes a department and an entity established under an Act for a public purpose. Provision of information must be prescribed under a regulation for this paragraph; and considered by the Chief Executive to be in the public interest. The Commonwealth, a State or entity that receives confidential information must not share this information with other parties unless allowed to do so by the agreement or in writing by the Chief Executive; and must ensure the confidential information is used only for the purpose described in the agreement.

Section 62B of the Health Services Act indicates that Section 62A(1) does not apply if the disclosure of information is required or permitted by an Act or another law.

Private Health Facilities Act 1999
The Health Services Act relates to information pertaining to patients in Public Hospitals. Separate legislation exists for Private Health Facilities (the Private Health Facilities Act, 1999 [9]). Part 11, Section 147 prohibits the provision of Personal Health Information. However, this does not apply if provision of the information is to "*an entity prescribed under a regulation for this subparagraph for the purpose of evaluating, managing, monitoring or planning health services as stated in the regulation*".

Ambulance Service Act 1991
In its current form, Section 49 of the Ambulance Service Act (1991) [10] restricts provision of identifiable information, with the following exceptions:

- where provision of that information is permitted under any other Act, or where required by operation or law;
- patient consent is provided;
- information is provided to hospital medical staff, or to a medical practitioner; and
- where information is required in connection with the further treatment of a patient in accordance with the recognised standards of the medical profession.

Provision of de-identified information for the purposes of research that has been approved by an appropriate ethics committee is allowed under Section 49 of the Ambulance Service Act, but this section does not allow for provision of identified patient data.

Legislation - Summary
There is capacity in the current legislative framework (Public Health Act; Health Services Act; Private Health Facilities Act) for collection and provision of identified patient data for the purposes of data collection and public health monitoring (i.e., injury surveillance); as well as quality assurance. Even where provision of information is not explicit (e.g., Ambulance Service Act), relevant Acts contain clauses that allow for provision of information where it is required by other Acts, or law.

6. DATA QUALITY

Poor data quality was raised as an issue of concern by the majority of stakeholders. There is recognition that "*energy and understanding of the importance of the data collection*" is required for it to be done well, and that this energy and understanding may be lacking in many of those who are charged with the responsibility of collecting data in the current system (i.e., clinicians). A high level of tolerance was expressed by stakeholders in relation to the significant pressures that already exist for clinicians, and an understanding that placing extra pressure on them to collect accurate data is perhaps unworkable. There is a perception that the quality of data collected in EDs for injury purposes is not high as a consequence of non-user friendly systems.

There are three important issues related to the accuracy of data capture in EDs. Firstly, in EDIS, the code and presenting complaint are not always related to diagnoses / outcome. Some coding is based on information collected at time of presentation. Therefore, coding is

based on the condition of the patient at the time of presentation to the ED. This is often not representative of the actual patient presentation/condition, in terms of details of the presentation, and severity of presentation. For instance, the triage category allocated upon arrival at the ED can change from a 1 to a 5 once the condition of the patient is accurately assessed, however this change is not reflected in EDIS. This could be overcome by the addition of extra fields in EDIS to reflect triage code upon assessment and discharge.

Secondly, details of the presentation often vary markedly from what is initially described at presentation (e.g., a patient's initial presentation details may be coded as "sore foot" and therefore not necessarily be coded as an injury, even though the final diagnosis may be fractured ankle due to fall. Similarly, a patient's initial presentation may indicate "fall" where final diagnoses may reveal that the patient had low blood pressure and fainted). There should be some capacity for the coded data to capture final diagnoses rather than initial presentation details.

Thirdly, there are issues with diagnoses-based codes (e.g. ICD10-AM codes). The treating clinician is responsible for assigning ICD10-AM codes, and it is perhaps unreasonable to expect already overburdened ED clinicians to assign codes. Accurate ICD10-AM coding is complex, and ED clinicians do not have ready access to complete information required to accurately assign codes. Codes that are available to clinicians do not reflect all ICD diagnoses, so often require an educated judgement call. Even if complete ICD10-AM coding books were available in all EDs, motivation and time to accurately assign the correct code is often lacking. Stakeholders suggested that a better method may be for a dedicated and appropriately trained coder to be present in EDs to code relevant clinical information for each ED presentation.

For these reasons, stakeholders cautioned that current practice related to collection of injury data from EDs are likely to result in inaccurate data with respect to planning and service provision.

There are also concerns relating to the quality of data provided on the electronic Ambulance report Form (eARF). The eARF has historically been used as a reporting tool. There are issues related to missing data on these eARFs. However, the utility of information collected in the prehospital environment is well recognised (especially in relation to identification of injury risk factors), and these issues must be considered if data from eARFs are to be linked with data from other health systems.

DESIRED FEATURES OF A BETTER SYSTEM OF DATA COLLECTION

A number of consistent themes have been identified in the consultation. Any future data system should address these features.

DATA STANDARDS AND SCOPE

- A set of formally agreed upon, defined, core data elements are required from core agencies (e.g., pre-hospital; ED; admitted patients; mortality), supported by Memoranda of Understanding between relevant agencies to provide these elements in a timely manner for specified purposes.

- Standard definitions/coding standards should be developed and used across the system. These standards should be nationally or internationally consistent wherever possible to facilitate benchmarking. (Note: Queensland Health is working with other states in Australia toward a national agreement of National standards and definitions.)

- The National Data Standards for Injury Surveillance (NDS-IS v2) should also be considered and applied wherever possible.

- Consideration should be given to the collection of data on those patients who are currently either not represented in databases such as QISU and QHAPDC (and therefore QTR), or on whom very little data are collected in these databases. For example, burns or orthopaedic patients are often treated as outpatients, so are not recorded in the QHAPDC. Data are collected on these patients, but the databases are dedicated databases that were established because the capacity to collect information on these patients does not exist in the current system.

- Collection of core data elements could be supplemented by annual cross-sectional surveys that would allow specific investigation of every major injury subgroup and demographic. If this is not possible, the cross-sectional surveys could be rotated by major injury subgroup every 3-4 years, so that all subgroups would be covered in that time frame. These cross-sectional surveys would use standardised instruments, and include detailed information on outcomes (e.g., SF36 for quality of life). These surveys should be completed by independent researchers. Alternatively, additional data may be collected in EDs (EDIS has the capacity for “add-on” components, that can supplement the basic data collected).

DATA LINKAGE

- Linkage of data across the continuum of care was endorsed by all stakeholders. Data pertaining to the same event for each injured patient from point of injury to final treatment is highly desirable.

- Measurement of outcomes should be implemented and these should be linked.

- Relevant legislation facilitates data linkage for specified purposes related to the provision of information to authorised persons for approved research and studies and for the purposes of quality improvement (see both Linkage and Legislation Sections).

- It is crucial to provide education about the data linkage process (to those within government, collecting agencies, and the general public). There is a generally conservative view to data linkage throughout the system. Significant effort is required to change attitudes if a system of linked data is to be embraced. The utility of linked data (politically and scientifically) must be translated at all levels of government.

DATA COLLECTION

- The core data elements should be available in a centralised location (e.g., registry of injury). This registry would not be limited to seriously injured patients, but may contain data on those injured patients who present to medical services (such as EDs). This registry would comprise the following data: standard demographic descriptors; mechanism and nature of injury; severity of injury; and body regions affected. Such a system would allow every injury death to be cross-coded with ICD10 Nature of injury (chapter XIX) and External cause of injury (chapter XX) codes (so that nature of injury and cause of injury could be linked). This would allow identification of matrices for analysis (e.g., head injuries in males in specified age group caused by road traffic crash).

- Several options for organisational and funding arrangements have been canvassed. It is clear that strong governance, stable funding and close relationships with clinical and operational providers are critical to the success and utility of a register. Options include:
    a) stakeholders contribute to the costs of establishment and maintenance of the registry. Relevant agencies may include: Universities, relevant government departments (health; communities; attorney general); other government and non-government agencies (MAIC; private health insurance companies);
    b) a model similar to that of the Victorian Trauma Registry (VSTORM) which is governed by a Steering Committee comprised of major trauma services; an epidemiologic unit based at an academic institute, and interested clinicians. The data are held by the university-based epidemiology unit, which has a "competitively renewable" contract.

- The importance of collecting agencies retaining their independence must also be considered. For instance, QISU often acts in an educative and/or advisory capacity. Some of the current functionality of QISU may be lost if QISU is not independent from its funder.

- Dedicated and appropriately trained clinical coders are required at all participating hospitals (whether information is obtained on ED or admitted patients).

- EDs participating in data collection would be supplied with appropriate resources (e.g., dedicated triage support nurse trained in coding). In order to address the perceived additional burden this may place on EDs, the participation may be on a 3 year rotational basis, with some permanent participating EDs.

- Data collection activities should be supported by a coordinated training programme across all data sets (i.e., all medical staff, coding staff, etc, for QISU, QTR, QAS).

- Better use of the free text fields on the EDIS screen would be valuable, as would the implementation of software to code information directly from data contained in EDIS.

- Commitment is required from senior bureaucrats in relevant government jurisdictions to the collection of injury data as core business, rather than additional supplementary activity.

- Strategies are required to reduce interpretation errors in relation to times recorded by aeromedical and ground clinical teams (e.g., time to definitive care; time left hospital a; time arrive hospital b).

DATA ACCESS AND USE

- These data must be accessible by those who have a bonafide reason, including research and quality improvement purposes (e.g., care providers who want to review the care provided to patients), and Queensland Health Central Office.

- Different levels of access to data could be provided according to needs.

- Frequent, regular reporting of aggregate level of data to relevant stakeholders, and less frequent more detailed descriptions of data (e.g., triennial QTR reports).

CONSENT

- Currently, prospective consent from patients is required. Opt-off consenting by patients that would allow follow-up of patients for research should be considered. An opt-off system operates in Victoria for the purposes of their Trauma Registry, and there is a refusal rate of <1%.

DATA AWARENESS

- Consultations demonstrated that the data currently collected in Queensland are not well understood. This could be addressed by establishing a central point of contact or referral for people who require injury data. They can then be referred to the appropriate data source / provider. This referral point could also assist with interpretation of data, and descriptions of limitations of the data once it is received. As an alternative to assistance with data interpretation, this point of contact could assist with monitoring the quality of interpretation that is provided with data.

SYSTEMS AND STRUCTURES

- Jointly establish an additional academically-based research unit that employs a range of epidemiologists, and injury prevention specialists. Involvement with EDs must be retained. Some initiatives that could support this proposal are already in motion. For example, in association with the University of Queensland, the Queensland Ambulance Service has established a Chair of Injury Prevention which will commence mid-year. This position will also have clinical loading.

- Monitoring of the recently implemented system where incentives are provided to hospitals for provision of timely and accurate data is required. Ideally, this incentives-based system should facilitate linkage of EDIS data into the HBCIS system within hospitals, and provision of that information to Queensland Health.

- In developing improvement to the system, special attention must be paid to patients requiring retrievals and/or interhospital transfers. Currently there are issues with: obtaining clinical information for trauma review where more than one hospital is involved; absence of data required by QTR on retrieval forms (RFDS); and issues related to the current episode-based systems that operate in both Queensland Health and QAS.

- These issues need to be addressed in close collaboration with QCC as a matter of priority. At a minimum, all relevant data should be available and accessible on one system. This may require an agreement that one agency (e.g., QCC) holds the primary data set. After this, mandatory data fields can be made explicit. One possibility is that funding arrangements can be made dependent upon the provision of these data points.

- Agencies involved with collection of data should provide clearly articulated, transparent processes for approving access to data. A standardised request protocol/procedure across all databases could facilitate this process. The independent referral agency described above could act as an agency that processes data requests. If this is not possible, the independent agency could function as an avenue for moderation for cases where data requests are denied by the agency.

- Currently, there are no data available that measure the performance of the system (i.e., the proportion of patients who reach the right facility, and receive the right treatment). Such a system measure is desperately needed. Efforts are underway by many agencies (including QAS) to determine systemic performance measures. The current KPIs are not functional in this respect.

FUTURE DEVELOPMENTS

- An electronic, downloadable electronic health record for use within Queensland Health hospitals would assist with reduction in duplication and timelag.

- Any changes that are made must be made in relation to relevant national agendas. A national collection of comparable data should be a parallel aim.

- A standard indigenous code should be used in all datasets so that data are comparable.

A FUTURE SYSTEM OF TRAUMA DATA COLLECTION

The following quote provides a summary of the viewpoint of the wider group of stakeholders:

"Data on injury has enormous scientific value, and is currently the most under-utilised data source. An extraordinary and obvious opportunity exists to develop an injury database in a way that would allow us to describe injury across the continuum of care that is comprehensive, comprehensible, and usable."[2]

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A comprehensive, comprehendible and usable system of trauma data collection and analysis is required to meet a number of strategic and operational needs.

1. Firstly, data are required to inform injury prevention strategies. Injury prevention strategies will depend on identification of factors that influence the risk of injury including the:

    a. Nature and frequency of risks as identified by data such as transport infringements (Police) or Occupational Health and Safety breaches.
    b. Nature and frequency of injuries; both serious and minor.
    c. Detailed understanding of the causative factors that contribute to risk, incidents or injuries.

2. Secondly, data are necessary to inform health and emergency services system planning, development and resource allocation. There is a requirement for data on the risks of major incidents as well as the frequency and extent of injuries. These data may include: the frequency and timing of injuries; severity of injuries; and geographical dispersal of injuries.

3. Thirdly, data are necessary to inform the care of injured patients. These data should inform the patterns of injuries associated with various incidents and the impact of treatments on injury outcomes.

4. Finally, data are required to inform system evaluation and performance.

Ideally, fully linked data regarding incidents would also be linked to an automated electronic medical record that permits comprehensive analysis of incidents and their impact on injury outcomes. In the absence of a fully automated electronic record system, it may not be possible to collect data on all patients or on all incidents. Such a system may be inefficient and ineffective. Any future data collection system should therefore include:

- Population-level data where appropriate and possible; and
- Representative sample data when population-level data are not available.

[2] Professor Alan Lopez, Personal Communication.

To meet these broad needs, data should be collected and made available to policy makers, planners, managers and evaluators. These data could be derived from:

- Data on the demographics of the community and the demographics of the subpopulation of injured persons, in order to identify the characteristics of those most at-risk for injury. This would facilitate better targeting of injury prevention strategies and health services.

- Data on the risks of injury and risk-taking behaviours that contribute to injury to identify individuals most at-risk for injury. This would facilitate better targeting of injury prevention strategies and compliance monitoring.

- Data on the causes of injury including both physical and behavioural causes, to inform injury prevention programmes and design of community infrastructure and physical objects.

- Data on the patterns of injuries and the relationship between particular causes and particular injuries, to assist with informing injury prevention programmes, as well as diagnostic and therapeutic standards and guidelines.

- Data on treatment and outcomes of patients to inform the development of clinical diagnostic and treatment standards.

- Data on the efficiency and effectiveness of the system of injury prevention and injury management, to inform future system-wide design and investments.

FUTURE OPTIONS

A comprehensive system of trauma data collection should include as a minimum:

- The frequency, risk and nature of risks.
- Data on the frequency and nature of injured persons presenting to health services.
- A representative sample of all injured patients to identify and quantify the causes of all injuries.
- A representative sample of seriously injured patients to identify the differential causes of serious injury and the effect of treatment on outcomes of patients.
- System-wide performance indicators for benchmarking and evaluation purposes.

The options for achieving a comprehensive approach to this include:

1. A dispersed model (similar to the model that exists now), but with standard data dictionaries and possible data linkage utilising consistently defined common parameters.

2. A central collaborative model in which agencies contribute aggregate data to a central location where data are linked to produce a comprehensive report on the patterns of trauma and the risk of injury (i.e., data warehouse).

3. A centralised interrogative model in which inquisitive and linking software is able to interrogate individual databases to produce a comprehensive picture of injury causation and outcomes (i.e., virtual data repository, such as the CSIRO's E-Health Research Centre).

4. A central repository of all information utilising a consistent system of data collection (similar to the model used by WADLS).

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The Trauma Data Scoping Project Team comprises:

Investigator Team

A/Professor Vivienne Tippett	Director, Australian Centre for Prehospital Research (ACPHR)
Professor Gerry FitzGerald	Queensland University of Technology
Dr Cliff Pollard	Chairman, National Trauma Registry Consortium (NTRC)
Professor Michael Schuetz	Chair of Traumatology, PAH

Working Group

Dr Cate Cameron (Expert Advisor)	School of Medicine; Griffith University
Ms Tamzyn Davey (Expert Advisor)	NTRC and CONROD (UQ)
Ms Emma Enraght-Moony (Expert Advisor)	ACPHR and National Centre for Classification in Health (NCCH), QUT
Dr Kirsten McKenzie	NCCH, QUT
Ms Debbie Scott (Expert Advisor)	NCCH, QUT
Ms Ruth Taylor (Research Assistant)	QUT
Mrs Sue Walker	Director, NCCH, QUT
Dr Kerrianne Watt (Project Manager)	ACPHR

The Trauma Data Scoping Project Steering Committee comprises:

Professor Leanne Aitken	Griffith University
Professor Nick Bellamy	Director, CONROD (University of QLD)
John Hand	Commissioner, MAIC
Kim Birch	Managing Director, MAIC
Professor Rob Pitt	Director, QISU
Dr Daryl Wall	Chair, Trauma Committee, QLD RACS
Barbara Williams	Director, Community Engagement Unit; Strategic Policy and Executive Services, DES
Professor Andrew Wilson*	Executive Director - Policy, Planning and Resourcing Division, QLD Health

*Represented by Faileen James (Senior Director)

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Appendix A: Literature Review

Options for Data Integration in Queensland: Outline of the Literature on Record/Data Linkage and Data Warehousing

BACKGROUND

The Queensland Health Injury Advisory Taskgroup produced a Discussion Paper in 2001 that outlined a strategic direction for injury prevention and control. The document highlighted the need for adequate data on injury and the management of injury in Queensland in order to effectively inform and evaluate injury prevention and policy; assess the performance of the health system in the management of injury; inform and measure the impact of policy on injury management within the health system; and inform health system needs (in relation to injury). This Taskgroup described the state of injury data in Queensland as being fragmented with limited coordination between the various injury data sources. There appears to have been little improvement in this regard, with minimal coordination between organisations that collect injury data, and duplication of data collection and effort across injury data sources. This situation does not make the best use of the data and the limited resources available to injury data collection, and does little to facilitate a comprehensive overview of injury, injury management, and the outcomes of injury.

The Trauma Data Scoping Project was commissioned as a consequence of the recognition of an ongoing need for a more integrated injury data system in Queensland. This section provides an overview of the literature on two possible options for data integration which have been widely applied in the health domain: 1) record/data linkage; and 2) data warehousing.

RECORD/DATA LINKAGE

What is record linkage?

Record linkage involves the unification of multiple, separately assembled records (or parts of records) which belong to one individual[1,2]. The advent of the computer in the early 1960's increased the scope for linking medical records for epidemiology and research into health services and health service management[2]. The first formal linkage of health records began in England around this time, with the establishment of the Oxford Record Linkage System[3]. Record linkage systems followed in Canada, Scotland, North America, Scandinavia, and Australia[4].

In the health sector, record linkage has been most commonly used in birth and death registers, hospital inpatient data, physician contacts, cancer notifications/registries, laboratory services data, pharmaceutical benefits data, residential care data, domiciliary care, mental health services data, and socio-demographics data from the Census[4]. Linkage has served several purposes including: the evaluation of health system performance; public health surveillance; measurement of participation in health services; determining burden of disease and disease outcome; and assessment of adverse treatment effects and outcomes[4-9].

Main Linkage Techniques

There are two main techniques used in data linkage: 1) deterministic linkage; and 2)probabilistic linkage.

Deterministic linkage requires agreement on a sufficient number of identifying variables (between two or more records) before a match/link is made[1]. Deterministic linkage is most often used where a unique patient identification number is available[1]. In Scotland, for example, all patients who are registered with a general practitioner are assigned a community health number which is a unique identifier[5]. Records of all patients are maintained centrally

and updated as the patient moves through the healthcare system[5]. Variations of a unique patient identification number exist in health systems across the world. In its simplest form, deterministic linkage requires that all identifiers (for example, unique patient identification number; name; date of birth; and address,) are required to agree across two (or more) records before a match/link is made[1]. More flexible variations can be used whereby a pre-defined subset of identifiers (for example, three out five identifiers) is required to determine a match of records[1]. A major limitation of this method of linkage is that it deems each identifier to be of equal value in determining a match[1]. This does not take into account the potential for missing or incorrect values, or that some identifiers may be more accurately and reliably recorded than others[1].

Probabilistic linkage also requires agreement on a number of variables across records to determine a match, but unlike deterministic linkage, the variables are not always identifying (although in most cases they are); they are non-unique (gender, name, address); and the potential for inaccurately recorded variables is taken into account[8]. Probabilistic methods were used in a New Zealand study to anonymously link mortality and census data[10]. While most linkage is based on identifying variables such as name, variables such as geocodes (computer readable coordinates of geographic location in terms of area, state e.t.c.); gender; ethnic group; country of birth; and date of birth were used in this study to match patients on mortality and Census data[10]. The advantage of probabilistic linkage is that it accounts for discrepancies in the recording of variables due to error or change in status (for example, maiden name change), and uses a computer algorithm to calculate the probability that two (or more) records belong to the same individual[8]. Accuracy in matching of between 98-99% is typically yielded by this method, and it is therefore a widely accepted and valid technique to use in the absence of a unique patient identifier [7,8,10].

Advantages of instigating record linkage

Proponents of population-based record linkage argue that record linkage is essential to enable comprehensive assessment of the performance and safety of a health system, and that this represents its main purpose and value [3,4]. Other major reasons cited for the use of record linkage include being able to use the same data repeatedly to address various epidemiology and health service questions[12]. Considering the cost of conducting several cohort or case-control studies, and the already substantial investment made in the collection of routine data, record linkage systems represent a relatively cost-effective research resource [3,12-15]. Likewise, purpose-designed health registers, which are becoming increasingly popular, are expensive and may only represent a sample of the population [12]. Using administrative data that is already collected by the health system (and other relevant bodies) and made interpretable through record linkage to meet the required need, is comparatively more cost effective[13]. Several studies have been undertaken to compare the sensitivity and efficiency of relevant record linkage data sets with disease-specific registers[5,13]. In a study on diabetes in a Scottish community, the authors concluded that the record linked data set was more sensitive in identifying cases of diabetes than the general practice register of diabetes, and that it was possible to identify an additional proportion of the population who were at risk of diabetes (history of hyperglycaemia) and who might have warranted screening for undiagnosed diabetes, using the linked data set[5]. Similarly, Brameld and colleagues found that estimates of the incidence and prevalence of end-stage renal failure using a linked data set were comparable to those acquired through the disease register [13].

The large sample sizes available in record linkage systems facilitates more accurate generalisation of results to the wider population. Results can also be more rapidly acquired than by ad hoc data collection[12,13]. Using linked data sets also reduces selection bias which can occur in the use of case-control and cohort studies[12]. Studies using data linkage sets may be less intrusive because in many cases patients and health professionals do not need to be contacted if the required data already exists in the linked data set[12]. The West of Scotland Coronary Prevention Study Group reported that record linkage was as effective in ascertaining adverse events (death and nonfatal myocardial infarction), as direct follow-up with patients[16]. Recall bias is also reduced with linkage studies (when compared with case-control and cohort studies) because the data are collected in ignorance of (or before) the outcome of interest[12]. Being able to analyse changes in the health status of the population over time is another important benefit of linked data systems, especially as health status seldom responds immediately to interventions[17].

Limitations inherent in record linkage data sets

The use of data linkage systems is generally limited by the extent and relevance of the data available in the respective data set[3]. There is a finite range of analyses possible from one data set[3]. A lack of specific data points (e.g., exposure, outcome, or confounding variables) may prohibit the use of particular linked data sets for answering specific research questions[12]. The Oxford Record Linkage Study, for example, has been criticised for not having sufficient detailed data concerning the history, severity and management of diseases, because it is based on routinely collected, administrative data[18]. There are also extensive difficulties inherent in large-scale record linkage for research in the field of health, mainly because of the need for long-term forecasting to facilitate inter-agency cooperation and coordination of data sets[4].

The majority of health data linkage sets use administrative data, collected routinely for purposes other than research, and this has led to concerns about the quality of the data[18-22]. For example, disease diagnosis codes recorded for hospital billing purposes may have been recorded to merely satisfy the minimal requirement for payment, or even to maximise payment[19]. Without concern for the use of such codes in the context of clinically and/or epidemiologically relevant purposes, skewed or incorrect conclusions may be drawn from the results of research using such data[19]. Another concern with the use of administrative data sets is the high number of missing data codes, which may lead to under or over estimations of the prevalence of a particular disease or cause[20,22,23]. However, a technique has been developed to correct this problem to some degree[23]. This technique is referred to as "*capture-recapture technique*". This technique assumes that there is missing data in any relevant data set, and estimates the margin of error (with confidence intervals) to allow comparison of the total population of persons with the relevant disease and the number of persons in the data set who have been recorded as having the disease[23].

In acknowledging the limitations inherent in data linkage sets, Sorenson et al., proposed a guide highlighting the scientific and practical considerations for the use of record linkage data sets in health research[24]. This includes checking for duplicate records on one individual within the data set; consideration of whether the study requires counts of individuals or events (and whether the particular linked data set is able to provide the required data); and consideration of accuracy and completeness of the data contained in the linked data set[24]. In deciding to use a particular data linkage set, the time period covered by the data; accessibility

to the data set; costs of access; format of the data; the size of the data set (and whether a subset of records will suffice), are all essential considerations[24]. Another important consideration for the use of data linkage sets is completeness of population coverage or whether a population registry is linked into the data set – this is particularly important when the study relates to estimation of risk following the exposure of interest. [24,25]. A data set that is linked to a population registry enables selection of a matched comparison group, and thus allows for adjustments to be made for relevant confounders such as socio-economic status and co-morbidities[25]. It has been argued that outcomes research using linked data sets which do not include a population registry may result in invalid conclusions[25].

Privacy and legal issues

In the past the concept of linked health records has raised privacy concerns based on the incorrect assumption that data linkage systems contain centrally stored, comprehensive profiles on individuals[26]. In reality, linked data systems bring together separate data files, only temporarily, to generate ad hoc data sets for the express purpose of answering a particular research question[26]. The conduct of record linkage studies requires prior approval from and is overseen by the relevant institutional review boards (or ethics committees) [27]. As well as this, details relating to the matching of data files, management, and storage of data must be specified in a research proposal and (in Australia) conform to National Health and Medical Research Council guidelines[27]. A record linkage study that is properly planned and conducted according to such guidelines should pose only minimal risk to privacy[26,27]. As mentioned previously, the use of data linkage sets may in some instances help to preserve patient privacy because identifying information which is necessary for patient follow-up, may not be required for a particular study if the data already exists (through a linked data set) [12].

Community concerns for privacy and confidentiality with regard to record linkage are reflected in current legislation in Australia, which specifies that personal information shall not be disclosed unless that individual is aware that the information is usually passed on to a particular agency; the individual consents to disclosure of personal (identifying) information; or the relevant agency deems disclosure of personal information is required to prevent or reduce danger to health or the individual's life[27]. These protective clauses present substantial challenges to data linkage because it would not be feasible to get consent from all the relevant individuals for the purpose of linking medical records at a population level. There are, however, exceptions to be made in that the relevant national and/or State authorities can approve record linkage if they believe that the public interest in the disclosure of personal information substantially outweighs privacy considerations[27]. Such exceptions have been made with numerous instances of record linkage for special research purposes in Australia. An exception was also made to facilitate the establishment of a comprehensive population-based system in the Western Australia Data Linkage System - the first and only of its kind in Australia – in 1995[4]. This successful and internationally recognised data linkage system was enabled by a supportive political and legal framework (in the State of Western Australia) which specifically authorises record linkage for public interest research[4].

Injury and data linkage

Traditionally, record linkage systems have not focussed on either injury prevention or trauma management research[28]. There is growing recognition, however, of the potential value of data linkage in this area because of the conventionally disparate nature of injury data sources[28]. Data sources such as police crash data; pre-hospital data (Ambulance Services);

Emergency Department presentations; hospital separations; insurance claims; and death records, each contain valuable information, but are limited in their ability to provide a comprehensive overview of injury[28]. A more complete picture of the full experience of the injured individual (pre-event circumstances through to post-discharge and long-term sequelae of injury), is essential to inform effective and timely policy on injury prevention; implementation and evaluation of injury prevention strategies; improvements in the quality of management of injured patients within the health system; and measurement of the impact of changes in management and system configuration over time.

There have been several key examples of the utility of data linkage that demonstrate the importance of more comprehensive approaches to critique of these events. In a UK study that linked police traffic crash reports and hospital admission data, it was concluded that the use of police road traffic crash data alone was biased in estimating the prevalence of road traffic crashes[22]. In 2006 in New South Wales, researchers linked workers' compensation data to police crash data in order to provide a more comprehensive picture of work-related traffic crash characteristics[29]. The USA Crash Outcome Data and Evaluation System (CODES) is another example of a comprehensive system of linked data on injury, specifically injury that results from motor vehicle crash[30]. This system uses probabilistic methods to link multiple data sets including traffic crash, health-related (hospital separations) and vital statistics (death records) data[30]. This system is used to assess the patterns, costs, and outcomes of road traffic crash injuries, and to evaluate the cost-effectiveness of intervention strategies[30].

The diversity of injury data sources across the continuum of the injury 'experience' represents a unique challenge to linkage of injury data. By comparison, chronic and infectious disease registries in the most part glean information from similar sources using largely comparable coding schemes - for example: hospital data; death certificates; and pathology results[28]. Conversely, injury data sources are more diverse with information coming from beyond the health system and often with incompatible coding schemes - for example, insurance databases; transport authorities; and police reports[28]. This presents some challenges for the data linkage process especially from a data coordination and privacy perspective[28]. Organisations are generally apprehensive about sharing data that contains personal information, and data linkage may require multiple ethical approvals adding to the already complex and confusing privacy legislation[28].

Summary

The challenges to linkage of the relevant injury data sources are not insurmountable and the advantages are numerous. Apart from the aforementioned benefits in terms of policy, practice, and being able to calculate rates of injury (where linkage is population-based), linkage of injury data sources may provide access to a larger number of cases; allow for the assessment of confounders (e.g., co-morbid conditions); and provide a means of validating aspects of research data[31].

Please refer to Appendix A2 for a description of some of the major and relevant data linkage systems in Australia and overseas.

DATA WAREHOUSING

What is data warehousing?

Data warehousing as a concept is not as easily defined as data linkage because it does not follow a particular method. Rather, it loosely describes the technical process of 'integrating' data to meet the particular information needs of a specific organisation or section of an organisation. Generally, it contains an organisation's data in a centralised repository established to: provide easy access to appropriate users; fulfil reporting and analysis requirements; and provide decision support[32]. Data warehousing has traditionally focussed on assembling the financial and operational data for "non-health" organisations[33]. It has more recently been recognised as a valuable tool which enables healthcare organisations to access data from disparate sources in order to create a more integrated vision of the organisation's activities and inform better business and clinical decisions[34].

Technical considerations

There is no "one fits all" method/technique for establishing a data warehouse. Each data warehouse is developed with the specific needs and idiosyncrasies of the particular organisation in mind. Scheese (1998) outlined five key (general) considerations for the development of a data warehouse: identify the needs of the end-users; scale the warehouse project according to the needs of the organisation; assign key managers/executives who play visible roles in the organisation as sponsors; source skilled and experienced technical expertise; and design adequate security (especially in the case of sensitive data that will potentially be made available to a large number of employees in the organisation) [33]. Other imperatives include the establishment of a data dictionary and the identification and/or design of tools to extract, translate, and integrate data from disparate data sources[35]. Ideally, a data warehouse is a dynamic tool and needs to be updated regularly to ensure that the format of the data corresponds with the end-users' evolving data needs[35]. The design of a data warehouse should also allow for additional data sources to be added subsequent to establishment of the original data warehouse[35]. Privacy with respect to individual patient data is of crucial importance in the design of a data warehouse, and resistance within an organisation may need to be addressed and managed with sufficient resources and strong management support [35],[36]. Also of the utmost importance is ensuring the confidentiality of the activities of the individual structures supplying the source data[35].

Data warehousing as a health data integration solution

In health organisations where there are large amounts of data stored in various information systems across the organisation, end users have traditionally been limited in their ability to access this data[33]. Data warehousing provides the tools to facilitate access in these operational environments[33]. Data warehousing allows for legacy systems to be maintained as data and consolidated into one coherent data set[35].

The major advantages of data warehousing include data quality improvement (by extension of the process of consolidation); and importantly, quick and efficient access to information by end users for clinical research, clinical quality improvement, and decision support[35,36]. Data warehousing maximises the value of the data but because end users do not directly query the source data, the security and privacy of the data sources are protected[35].
Limitations/disadvantages of data warehousing are largely similar to those cited for

data/record linkage, and primarily relate to the complexity of consolidating and coordinating data from disparate sources with data not originally intended for research (i.e., administrative or insurance data sources) [35,36]. Other concerns include the time and resources required to undertake such a project, and the difficulty of designing a system and being able to adequately anticipate future usage and needs[35].

How has data warehousing been used in the health domain?

Data warehousing has been used to: centralise the business and financial administration of health organisations; review clinical data; and provide access to data for clinical research and process improvement[36-38]. Data warehousing has also been used to provide access to timely data to support administrative and clinical decision making[36]. In addition, health systems and health-related organisations have reported the utility of data warehousing for education; to assess and evaluate clinical outcomes and resource requirements; and to instigate collaboration between relevant groups/stakeholders that have an interest in particular health areas[36,39].

Summary

It is widely recognised that there is an ongoing need for a more integrated injury data system in Queensland[40, 41]. There are two options for data integration in the health domain: 1) record/data linkage; and 2) data warehousing. This literature review was designed to provide an overview of these options in order to improve understanding about data integration, and to facilitate discussion around options for improving the injury data system in Queensland.

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Appendix A2:

Major and Relevant Data Linkage Systems

Appendix A2. Major and Relevant Data Linkage Systems

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Western Australia Data Linkage System	• Birth Records. • Midwives Notification System. • Cancer Register. • Hospital Morbidity Data System. • Mental Health Services Register. • Mortality Records. • Hospital inpatient data. • WA Electoral Role. • Domiciliary Nursing. • Emergency Centres. • Ambulance. • Alcohol and Drug Services. • Medical Benefits Claims. • Pharmaceutical Benefits Claims. • Aged Care (community and residential). • Genealogical Database Staes 1-3 (Probands born from 1950). • Research Databases[*].	Probabilistic	• Utilisation and patterns of care in people with chronic illnesses. • Various research applications (e.g., health care quality and adverse events indicators; evaluations of surgical procedure and technology; epidemiology, and management of coronary heart disease and major cancers; trends in incidence; utilisation and outcome in people with alcohol and illicit drug dependence)	• Uses administrative data, which often lack necessary data and can be inaccurate due to recording/coding errors. • Database can not be linked to census data. • Database doesn't contain information about GP services; pharmaceuticals; or state hospital admissions information. • None of the datasets used by WADLS can distinguish between diagnostic and therapeutic procedures.	• Personal identifiers: name; age; gender; date of birth; parent's names; address; full demographics. • Injury Data: ICD-9/10 codes for principle and other injuries; event dates; external cause; deaths. • Hospital Care: principle and other procedures; complications; doctors; urgency of admission[†]; public/private; source/destinations. • Continuing Care: Prescriptions.

[*] Research databases that have been linked to the WADLS include (but are not limited to): Busselton Surveys 1966-87, Road Injury 1987-2001, MONICA Heart Disease 1984-93, Risk Factor Surveys 1978-94, Crime Research 1984-95, Pregnancy Cohort 1989-92, Child Health Surveys 1993, 2001-2, Twin Registry 1980-98, Birth Defects 1980-2002, Intellectual Disability 1980-2002, Cerebral Palsy 1956-2002, Autism 1999-2002.

[†] The Urgency of Admission Code is a number (1,2,3,9) based on the National Health Data Dictionary. The code depends on whether urgency status has been assigned and whether admission occurred on an emergency basis.

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Centre for Health Record Linkage (NSW)	• NSW Admitted Patient Data Collection. • NSW Emergency Department Data Collection. • NSW Midwives Data Collection. • NSW Perinatal death review database. • NSW Central Cancer Registry. • NSW Pap Test Register. • NSW Registry of Births, Deaths and Marriages birth and death registration data, ABS. • Mortality Data and ABS Perinatal Mortality Data. • The 45 and up study[‡].	Probabilistic	• Assess the quality of health care. • Assess the effectiveness of preventative interventions (i.e., screening). • Obtain follow-up information on participants in research studies and surveys. • Monitor trends in patterns and costs of health care. • Studies of risk factors for disease and injury.	• Uses administrative data prone to errors, duplications and information gaps. • See Limitations section in body of Background for general limitations inherent in data linkage sets.	• Personal Identifiers: date of birth; gender; country of birth; area of residence. • Injury Data: ICD codes; activity when injured; place of injury; deaths due to injury. • Hospital Care: admission/separation date/time; source of referral; facility transferred from, urgency of admission[§]; intended length of stay; care type; diagnoses; diagnosis related group; major diagnostic category. • Continuing Care: days of leave required.

[‡] The 45 and Up Study is a large, general population cohort study designed to investigate healthy ageing. It aims to recruit 250,000 men and women aged 45 and over from NSW and will link data collected prospectively and longitudinally from participants with population health databases on health and health service use.

[§] The Urgency of Admission Code is a number (1,2,3,9) based on the National Health Data Dictionary. The code depends on whether urgency status has been assigned and whether admission occurred on an emergency basis.

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Oxford Record Linkage Study (1963-1999)	• Inpatient care records from general and psychiatric NHS hospitals (in the former Oxford Regional Health Authority area). • Birth Records. • Death Records. • Maternity Records (in hospital and at home).	Probabilistic	• Studies of long-term trends in hospital admission rates for individuals and clinical conditions. • Studies of age, period and cohort effects. • Studies in post-operative mortality and other adverse outcomes of care. • Studies of perinatal factors and the development of disease and use of hospital care in later life.	• Study population is restricted to Oxfordshire, Buckinghamshire, Berkshire and Northamptonshire. Therefore, cannot be considered completely representative of entire UK population. • Very few records collected as raw data. • Reliability of coding of conditions and interventions has not been tested. • The system was not designed as a rapidly responding, up-to-date file capable of dealing with day to day management and clinical enquiries.	• Personal Identifiers: forenames; surnames; parents; gender; date of birth; postcode; NHS numbers. • Injury Data: ICD-10 injury codes; external cause E-codes. • Hospital Care: admission/discharge dates; admission category (elective/emergency); principle and secondary diagnoses (ICD-10); operations/procedures; days in ICU and HDU.
Scottish Record Linkage System (SMR01 Linked Database)	• General Hospital Discharge Records. • Psychiatric Inpatients. • GRO death records. • Scottish Cancer Register. • GRO Birth Records. • Maternity. • Neonatal. • GRO Still Births/Infant Deaths. • Scottish Birth Record.	Probabilistic	• Used to support clinical auditing and effectiveness within the NHS in Scotland. • Analyses in response to demand placed on health services and medical research community. • Studies of short-term/long-term patient outcomes.	• Uses administrative data, which often lack necessary data and can be inaccurate due to recording/coding errors. • Possibilities of errors using probabilistic matching. • Clerical checking is required to prevent false positive data matches.	• Personal Identifiers: age; birth-date; gender; post code. • Injury Data: ICD-10 codes; External cause of injury codes (E800-E988); circumstance; event specific agent that lead to injury; diagnosis codes; deaths due to injury. • Hospital Care: Diagnoses (ICD-10); operations (using OPCS-4 classification); deprivation; length of stay (total, pre/post operative days); emergency admission/planned admission; transfers/discharges.

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Manitoba Health Research Data Repository	• Manitoba Health Population Registry. • Manitoba Health Hospital Discharge data. • Manitoba Physician and GP claims data. • Personal care home data. • Nursing Home Data. • Prescriptions data. • Vital Statistics Data. • Immunization Monitoring Data. • Canadian National Deaths Registry. • Communicable Diseases Register. • Work Cover. • Social and Educational Data. • Aging in Manitoba Study. • Heart Health Survey. • Cancer Registry. • Inflammatory Bowel Disease Database. • Sleep Lab Clinical Data. • Alcoholism Panel Surveys. • Diabetes Education Resource Database.	Unique identifier (PHIN – Personal Health Identification Number. This number is used on almost everything from health to education to work cover etc).	• Identifies study cohorts for research on health care utilization. i.e defines cohorts by parent-child or sibling relationships. • Easily compares data with those generated by disease-specific registries (e.g., comparing with cancer registry). • Add date-specific values for marital status, residence, and other characteristics to databases that do not report them (e.g. files for nursing home residents). • Study interventions longitudinally. • Compare regions, areas, and hospitals. • Combine information on patients and physicians. • Add up expenditures for different services within the Canadian Health-care system. • Examine the determinants of health using education and family services data in conjunction with health related information.	• Uses administrative data that were primarily developed for accounting purposes. • Data in original format does not always directly represent research needs. • Changes in registry details (due to marriage/name change) often lead to individuals with multiple PHIN numbers, thus leading to difficulties in accurately linking their files. • Registry relies on self-reporting of info such as treaty status and changes through marriage, divorce, moving etc. A lag time also exists between the occurrence and the info becoming accessible in the different data sources.	• Personal Identifiers: date of birth; gender; postal code; aboriginal treaty status. • Injury Data: ICD-CM injury codes; deaths due to injury. • Hospital Care: Diagnosis (based on ICD-CM); type of service; procedural information; physician details; length of stay separation data. • Continuing Care: dates of assessment; admission and separation details; level of care; ongoing changes to case status; diagnostic information; hospital discharge data; prescriptions; GP diagnostic codes and Pharmaceutical data.

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF INJURY DATA
British Columbia Linked Health Database	• Medical Service Plan Records. • PharmaCare Files. • Hospital Separations File. • Continuing Care Files. • British Columbia Cancer Agency Incidence File. • WorkSafe BC. • Births File. • Deaths File. • Mental Health.	Probabilistic	• Able to address changes over time in health service utilization within the population as a whole or in subgroups defined by age, gender, area of residence or income (ecological). • Linkage between data sets to enhance detail and quality of data.	• BCLHD files are linkable, but *not* linked. • Linkage with external data not always possible. • Data is sometimes incomplete and is not linkable across years. • Individual descriptors (e.g., gender, birth date) may vary over time and across data files. • Different services code differently (e.g., hours vs. visits), limiting comparability.	• Personal Identifiers: birth date; gender; postal code. • Injury Data: accident type code [**]; ICD-9 codes; body region; date of injury; nature of injury [††]; external cause of injury codes (E800-E988). • Hospital Care: hospital code; level of care; entry/exit/death codes; admission/separation dates; transfer codes; patient service code; ICU/CCU/rehabilitation days. • Continuing Care: level of care; type of assessment; hospital of referral.

[**] The accident type code is used by *Worksafe BC* to uniquely identify an accident type. Code descriptions for 'accident type code' field may be found at the following URL: http://www.chspr.ubc.ca/files/data/wcb_AccidentType.htm

[††] A classification of the injury in terms of its principle physical characteristics. Also used by 'BC Worksafe'.

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Alberta, Canada (Alberta Ministry for Health & Wellness)	• Inpatient (hospital morbidity). • Ambulatory Care Classification System (ACCS). • Day Procedures. • Long Term Care. • Alberta Health Care Insurance Plan Payments. • Alberta Health Care Insurance Plan Registry. • Alberta Blue Cross. • Acute Care Dataset. • Ambulatory Care Dataset. • Continuing Care Dataset. • Pharmaceuticals & Extended Health Benefits Dataset. • Community Health Services Dataset.	Unique identifier	• Operational – funding health care. • Government quality improvement and utilization studies. • Academic research. • Business planning for health organizations such as hospitals. • Regional business planning. • Aggregate information for industry research.	• Virtually all data collected is for administrative purposes such as management of the Alberta Health Care Insurance Plan and determining funding for the regional health authorities. • Some of the data collected are submitted to the regions (no source records). • The Ministry has information collected about publicly funded programs and services. There is no information for those outside the public system.	• Personal Identifiers: age; gender; address; • Injury Data: ICD-10 codes. • Hospital Care: Ambulatory Care data - day surgeries/procedure; emergency room visits. Inpatient data - Services; diagnoses; procedures; interventions; morbidities. • Continuing Care: Provider and care requirements for auxiliary hospitals; nursing homes; acute care facilities patients; prescription doses; prosthetics/orthotics; chiropractic services.

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Rochester Epidemiology Project	• Ambulatory[‡‡]. • GP services data. • Social Services. • Hospitals . • Emergency Departments. • Home Visits. • Laboratory. • Psychiatry/Psychology. • Test results.	Probabilistic	• Provides accurate incidence data for almost any serious condition. • Supports population-based analytic studies of disease causes and outcomes. • Population-based historical studies to assess long-term outcomes. • Random sampling of the population for prospective evaluations. • Comparisons of the disease experience of the urban residents of Rochester with that of the rural portion of Olmstead County.	• Study population is restricted to Rochester and Olmstead County.	Data are collected on all aspects of routine medical care (no specified data collection for injury). Specific injury data: TBC

[‡‡] Self-presentations to Emergency Departments.

Crash Outcome Evaluation System (USA)	• Traffic Records Crash Data. • Emergency Department. • Hospital inpatient Acute Care. • Rehab and Long Term Care. • Non-hospital Outpatient. • Insurance Claims. • Death Certificates.	Probabilistic	• Determine crash outcome in terms of mortality, injury, severity, and health care costs.	• None specifically described.	• Personal Identifiers: name; gender; date of birth; postcode. • Injury Data: ISS, ICD-9 codes; Type of crash; contributing factors; type of roadway; actions; injured occupants; use of safety devices such as belts and helmets; time of. • Hospital Care: Status; treatment; disposition; procedures and diagnoses. • Continuing Care: Admission/separation details; functional status; level of impairment; vital signs.

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Denmark (Note: there are over 80 registries which may serve as potential data sources to researchers in Denmark. There is no central repository/data linkage system but linkage of these data sources may be undertaken using the unique identifier. The following list contains those registries considered most significant for researchers)	• Central Person Registry. • The Danish Conscription registry. • Danish Patient Registry. • Cause of Death Registry. • Birth Registry. • Abortion Registry. • Danish Congenital Malformation Registry. • Provider Registry. • Registry of GP Services. • Danish Amputation registry. • Registry of Psychiatric Demography. • Multiple Sclerosis Registry. • Danish Cancer Registry. • Danish Registry of Heritable Eye Diseases. • Danish Accident Registry. • Occupational Registry of Danish Statistical Institute. • Registry for Education Statistics. • Danish Registry of Fohlings Disease. • Danish Twin Registry. • Danish Cytogenic Registry. • Central Blood Bank Database.	Unique identifier (PRN)	• Epidemiological research. • Case-control studies on disease incidence. • Pharmaco-epidemiologic research. • National Surveillance of Diseases and Health problems. • Examples of research questions: used to probe contradictions raised by smaller studies and following disease progression. Useful for unravelling complex diseases such as schizophrenia by teasing out the relative contributions of genetic and non-genetic factors, thereby pointing to possible strategies for preventing disease. • Used to marry advances in genetics with the vast database resources.	• Resource intensive. High costs are associated with maintaining existing databases, and extra funds are needed to expand and update existing databases to keep them accurate. • The use of 120 demographic databases overseen by 'Statistics Denmark' is tightly restricted. This red tape is hampering studies that require correlation of health and demographic data.	• Personal Identifiers: age; gender; date of birth; occupation; residency; marital status; income; parental relationships. • Injury Data: ICD-10 codes;. • Hospital care: Discharge; operative procedures; deaths.

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Norway	• The Norwegian Patient Registry. • The Cause of Death Register. • The Cancer Registry of Norway. • The Medical Birth Registry of Norway. • The Norwegian Surveillance System for Communicable Diseases (MSIS). • The Tuberculosis Registry. • The Childhood Vaccination Register (SYSVAK). • The Norwegian Prescription Database.	Unique identifier	• Health Surveillance. • Epidemiological Research. • National, population-based studies.	• The registration of both the unique identification number and injury variables are newly introduced, and the quality of the information registered may not be sound in the first months.	• Personal Identifiers: age; gender; address. • Injury Data: date/time of injury; intent (unintentional, self-inflicted, violence); road traffic (yes/no); product-related injury (yes/no); activity (activity when the injury occurred; work, education, sport, ravelling); place (road, home etc); injury mechanism; injury severity (AIS); place (the name/number of the municipality where the injury occurred). • Hospital Care: hospital, department, diagnoses; surgical procedure(s); dates of admission/ discharge/procedure(s).

NAME OF DATABASE	DATA SOURCES	METHOD OF LINKAGE	APPLICATIONS	LIMITATIONS	TYPE OF DATA
Sweden	• The Cancer Register. • The Medical Birth Register. • The Swedish Birth Defect Registry. • Hospital Discharge Register. • The Cause of Death Register. • The Prescribed Drug Register. • The Abortion statistics (no personal identification number). • Smoking habits of parents of newborns. • Registration of breast-feeding. • Registration of assisted reproduction. • The Acute Myocardial Infarction. Register • The Injury statistics	Unique identifier	• Uncover causes and consequences of disease. • Epidemiological, social and public health research.	None specifically described	• Personal Identifiers: personal identification number; gender; age; place of residence. • Injury Data: intentional/ unintentional; cause of Injury; external cause of injury. • Hospital Care: date of admission; date of discharge; length of stay; acute/planned admission; admission/discharge disposition; main diagnosis; secondary diagnoses; surgical procedures.

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Appendix B: Stakeholder List

Name			Position	Organisation	
Prof	Leanne	Aitken	Professor Critical Care Nursing	School of Nursing and Midwifery	Griffith University
Dr	Peter	Aitken	Senior Staff Specialist Emergency Department	Emergency Department	Townsville Hospital
Ms	Robyn	Allen	Executive Officer	Kidsafe	
Ms	Kerry	Armstrong	Principal Advisor, Policy	Queensland Transport	
Ms	Helen	Atkinson	Manager, Program Development and Planning Team	Office for Children	Department of Communities
Dr	Michael	Barnes	State Coroner		
Prof	Nicholas	Bellamy	Director, CONROD	School of Medicine	University of Queensland
Dr	Matt	Brandt	Principal Medical Officer	Workcover	
Ms	Judith	Brennan	Trauma Nurse Coordinator	Townsville Hospital	
Mr	Ian	Callow	Manager	Statewide Trauma Clinical Network	Princess Alexandra Hospital
Dr	Cate	Cameron	Research Fellow, Epidemiology and Biostatistics Unit	School of Medicine	Griffith University
Ms	Julia	Carter	Health Information Manager	Royal Flying Doctor Service	
Ms	Anita	Champion	Manager	Poisons Information Centre	
Ms	Sue	Cornes	Director	Health Information Centre	Queensland Health
Prof	Ross	Crawford	Medical Engineering	Faculty of Built Environment and Engineering	Queensland University of Technology
Dr	Chris	Cunneen	Senior Medical Advisor	QCOMP	
Mr	Jamie	Cupples	Executive Director	Farmsafe	
Ms	Melissa	Dale	Trauma Nurse Coordinator	RBWH	
Ms	Corelle	Davies	Senior Director	Maternity, Child Health and Safety Branch	Queensland Health
Mr	John	Dickinson	Executive Director	Brain Institute Association of Queensland	

Name			Position	Organisation	
Ms	Cassie	Dransfield	Manager, Scheme Analysis	QCOMP	
Dr	Stephen	Duckett	Executive Director	Reform and Development Division	QLD Health
Mr	David	Eeles	AC, Resource Planning	Queensland Ambulance Service	
Dr	Mark	Elcock	Director	Clinical Coordination Centre	QEMS
Dr	Richard	Franklin	National Manager, Research and Health Promotion	Royal Life Saving Society Australia	
Mr	Neil	Gardiner	Director, Client Services Unit	Health Information Centre	QLD Health
Dr	Tim	Geraghty	Director, Rehabilitation	Spinal Injuries	QLD Spinal Cord Injuries Service
Mr	Noel	Gillard	Director	Emergency Management Unit	Queensland Health
Ms	Kelly	Grimmond	A/Manager, Product Safety Division	Department of Tourism, Fair Trading and Wine Industry Development	
Mr	John	Hand	Commissioner	Motor Accidents Insurance Commission	Queensland Treasury
Dr	Dale	Hanson	Snr Lecturer Clinical Adjunct Senior Lecturer	School of Public Health Trop Medicine & Rehabilitation Sc.	
Mr	Alan	Head	Principal Planning Officer	Planning and Coordination Branch	Policy, Planning and Resourcing Division
Mr	Jim	Higgins	Commissioner (Former)	Queensland Ambulance Service	
Ms	Lulu	Hill	Acting Director	Planning and Coordination Branch	Policy, Planning and Resourcing Division
Dr	Brett	Hoggard	Principal Medical Coordinator	QLD Clinical Coordination Centre, North	
Mr	Adrian	Horth	Project Director, ED and OT Information Systems	Clinical Informatics, Information Directorate	Queensland Health
Mr	Tony	Hucker	Manager, Clinical Education	School of Ambulance and Paramedic Studies	QAS
Ms	Josie	Istvandity	Assistant Analyst, Statutory Authorities	Commission for Children and Young People and Guardians	
Ms	Faileen	James	Senior Director	Policy Planning and Resourcing	Queensland Health
Dr	Trisha	Johnston	Acting Director	Epidemiology, Statistical and Library Services Centre	Queensland Health
Dr	John	Kastrissios	President	QLD General Practice Board	
A/Prof	Roy	Kimble	Director	Burns Unit	RCH
Ms	Emma	King	Manager	Child Death Review	Commission for Children and Young People and Guardians
Dr	Steven	Lake	Senior Advisor (Research)	Strategic Policy and Research Branch	Department of Child Safety

Name			Position	Organisation	
Prof	Fred	Leditschke	Paediatrics and Child Health	RCH / Kidsafe	
Ms	Pam	Longland	Senior Project Officer	Community Engagement Unit; Strategic Policy and Executive Services	Department of Emergency Services
Prof	Alan	Lopez	Head, School of Population Health	University of Queensland	
Sup.Intndt	Paul	Lostroh	Officer in Charge	Disaster and Major Event Planning	Queensland Police Service
Ms	Dale	Mason	Trauma Nurse Coordinator		PA Hospital
Mr	Des	McConachy	Manager, Information Support Unit	Queensland Ambulance Service	
Mr	Geoff	Meers	Director	Infrastructure Program	Queensland Transport
A/Prof	Michael	Muller	Burns, Trauma and Critical Care Research Centre	RBWH	
A/Prof	Jim	Nixon	Paediatrics and Child Health	RCH / Kidsafe	
Mr	John	O'Brien	Director, Information Use	IBMB	Queensland Health
A/Snr Sgnt	Sean	O'Neill	Project Manager, NQDL & Road Safety Initiatives	State Traffic Support Branch	Queensland Police Service
Ms	Laura	Pareezer	Senior Planning Officer	Planning and Coordination Branch	Policy, Planning and Resourcing Division
Mr	Lachlan	Parker	Flight Intensive Care Paramedic	Queensland Ambulance Service	
Prof	Tony	Parker	Human Movement Studies	Faculty of Health	QUT
Ms	Kiley	Pershouse	Spinal Outreach Team (SPOT)	QLD Spinal Cord Injuries Service	
Ms	Cathy	Pilecki	Manager, Information and Education	Motor Accidents Insurance Commission	Treasury Department
Prof	Rob	Pitt	Director, QISU	Mater Children's Hospital	
Dr	Cliff	Pollard	Chairman	National Trauma Registry Consortium	Royal Australasian College of Surgeons
Dr	Steve	Rashford	Medical Director	Queensland Ambulance Service	
Dr	Richard	Williams	Chair, Queensland Branch	Australian Orthopaedic Association	
Prof	Mary	Sheehan	Director	CARRS-Q	School of Psychology and Counselling; Faculty of Health
Dr	Niall	Small	Director, Emergency Department	Townsville Hospital	
Ms	Kate	Smith	Senior Project Officer/ Injury Prevention	Health Promotion Unit	Queensland Health
Ms	Dawn	Spinks	Manager	Queensland Injury Surveillance Unit / Queensland Safe Communities Support Centre	
Mr	Michel	Tilse	Director	Health Promotion Unit	Queensland Health

Name			Position	Organisation	
Dr	Susan	Urquhart	Senior Medical Officer	QLD Spinal Cord Injuries Service	PA Hospital
Mr	Paul	Vardon	Principal Project Officer, Health Issues Team	Health Promotion Unit	Queensland Health
Dr	Paul	Varghese	Director, Geriatric Medicine	PA Hospital	
Dr	Daryl	Wall	Director, General Surgery	PA Hospital	
Ms	Freya	Walton	Child Safety Director	Strategic Policy and Partnerships Directorate	Department of Aboriginal and Torres Strait Islander Policy
Ms	Belinda	Wallis	RCH Burns Research Group	Paediatrics & Child health - University of Queensland	
Ms	Helen	Warneke	A/Director	Office of Child Safety	Department of Communities
Ms	Barbara	Williams	Director, Community Engagement Unit;	Strategic Policy and Executive Services	Department of Emergency Services
Prof	Andrew	Wilson	Executive Director	Policy, Planning and Resourcing	QHealth
Ms	Maryann	Wood	A/Director, Population and Social Statistics	Australian Bureau of Statistics	
Ms	Nicky	Woodman	Manager, Data Analysis	Queensland Transport	
Dr	Jeanette	Young	Chief Health Officer	Queensland Health	

Appendix C: Consultation Proforma

1. Does this Issues Paper encompass the issues related to injury data that are important to you?

2. *Data capture*. For <u>those who operate injury data systems</u>

- What are the years covered by the database?
- What are the exclusion/inclusion criteria?
- What variables are collected (discrete variable info)
- What is the (current) main purpose of the data collection?
- What was the initial main purpose (if different to current purpose)?
- Does the data collection serve purposes additional to the main purpose?
- How are the data used?
- Who is the funder?
- Who owns the data?
- Is there a data dictionary? If so, is it unique or based on an existing data dictionary?

3. Data access (collectors). When people come to you with requests for data, what factors make it difficult for you to retrieve/collate/ disseminate the data?

- What are the procedures for accessing data?
- What are the levels of access? Who has access? How is access obtained?
- How do the current processes around access to data enable or impede use of data?
- Are there sensitivities on release of information (e.g., possible misinterpretation)?
- What is required to increase an understanding of the issues specific to each agency and reduce anxiety/concerns around organisational sensitivities?
- What are the legislative / ethical impediments to sharing data?
- Can the current time lags associated with access to data be feasibly reduced? How (what's required?)
- What would you like to happen (in relation to access to data?)

4. Data Access (users). When you seek data, what factors make it difficult for you to retrieve/interpret the data?

- What is your experience in accessing data?
    - what data have you tried to access / would be useful if you could access it)?
- How do the current processes around access to data enable or impede use of data?
- What are the legislative / ethical impediments to sharing data? What changes are required to facilitate improved access to data in QLD (legislation, policies etc.). Would a Whole of Government (W.O.G) approach facilitate or impede this?
- What can be done to assist agencies with facilitating access and interpretation of data by external agencies / organisations? Is there a common format that will facilitate data sharing that doesn't' require access to proprietary systems?
- Can the current time lags associated with access to data be feasibly reduced? How (what's required?)
- What would you like to happen (in relation to access to data?)

5. Coordination: What is / isn't possible with the injury data that you collect (and/or use) [this question is about comparability /interoperability of data sets across the treatment continuum e.g., data definitions; scope of collection; changes over time taken into account; alignment of time periods]

- If you make changes within your database/collection system do you document it? How? What detail do you include?
- How are the changes to data collection (new variables added, for example) formally documented? For e.g updating data dictionary/manual
- Do you have a process for updating coding systems?
- Are you aware of the variations between the data collections which are relevant to your purposes?
- What would you like to happen? Do you think comparability across data sets is necessary/ would be useful?

6. Linkage

- What is your opinion on data linkage?
- If data linkage occurs, what are the processes?
- What are the Impediments to data linkage? Consider:
    - unique patient identifier vs probability linkage?
    - Standardised coding definitions and coding/classification systems
    - Legislative issues (privacy) and public perception of data linkage
    - To what extent have recent changes to Privacy and Confidentiality Legislation to facilitate inter-agency performance analysis improved opportunities to address these issues?
    - How can data be linked in current legislative framework?
    - What legislative changes are required to facilitate data linkage?
    - IT issues (resources for info management)
- Is it possible to obtain patient-based info while retaining current episode based framework?
- Capacity to reduce duplication? How?
- Has any progress been made by your agency in addressing these issues?
- Are there forums known to you that are addressing these Issues?
- Have improvements in electronic capture of data (e-ARF, EDIS etc) provided opportunity to improve inter-operability?

7. Are there other issues that you believe require emphasis and consolidation (i.e,. wish list)?

Appendix D:

Preliminary Table of Existing Data Sources

Note: Databases are classified according to the point at which most of the data are collected. For instance, QISU data are obtained from the ED records, so this database has been categorised under treatment, even though most of the data relates to pre-event and injury event.

PRE-EVENT / INJURY EVENT			
Custodian	**Queensland Police**	**QLD Transport**	**QLD Health - Health Information Centre**
Database	QPRIM		Epidemiology Services Unit (Omnibus survey).
Sample	People involved in "Events of operational interest".	Crashes on public roads in QLD	Population-based sample (CATI).
Demographic	Identifying information; demographics.	Age; gender; given names; family names; postcode; address; town/city; state.	Age; gender; marital status; employment status; education level; ATSI status; income level; locality; number of adults (18+) in the house.
Event information	Event description; location.	Type of vehicle (car, truck, motor cycle); road user type (driver; passenger; pillion; bike rider; pedestrian); cause of crash (inattention; inexperience; alcohol related; illegal manoeuvre; fail to give way/stop; rain/wet road; fatigue related; speed related; age - lack of perception; dangerous driving); seatbelts worn (Y/N); nature of crash (Multiple vehicle – angle, head-on, rear-end, sideswipe. Single Vehicle - hit object, overturned, hit parked vehicle, fall from vehicle); time of day (also light/dark outside); day of week; geographical location of crash (includes CBD, suburban etc); roadway features and traffic control relating to crash (e.g., stop/giveway signs at T junction, bridges).	Falls data (only for participants aged >65yrs) - perceptions of falling; last fall; activity prior to fall.
Injury Information	Limited injury description (tbc).	Nature of injury (e.g., fracture, laceration, burn); body location of injury (e.g., arm, neck, head & face); severity of injury (e.g., fatal, serious, minor).	Injury type; hospitalisation resulting from fall; medical treatment required; contributing factors to fall; time period since fall; effect of fall (movement/activities; time period affected).
Main and additional purposes of the data collection	Record of events of operational interest.	The main purpose of the database is to improve road safety and reduce road trauma. Data are also used to inform injury prevention (around road crashes), and to evaluate injury prevention interventions.	The main purpose of the database is to collect population level data for estimating prevalence at specific points in time and to develop time series data.
Exclusion/inclusion criteria	TBC	All crashes on public roads that involve injury and/or car/s towed and/or where there was property damage in excess of $2,500.	
Owners	QLD Police	Qld Transport.	QLD Health.
Funder	QLD Police	Qld Police and Qld Transport.	QLD Health.
Years covered by database	TBC	The database started in 1986 but reliable data are available from 1991 onwards.	The data are collected periodically – '98; '01; '02; '06.
Treatment	N/A		
Administrative	TBC	Vehicle registration number; driver's licence number; vehicle configuration; speed at time of crash; if car failure what type (e.g., weld, seam, puncture).	
Additional Clinical	N/A	N/A	

TREATMENT			
Custodian	**QAS (Information Services Unit)**	**QAS (Information Services Unit)**	**QISU**
Database	eARF	CAD	QISU
Sample	Cases that are attended by a QAS Paramedic.	Patients requiring transport or assistance by QAS (000 calls and other requests for service)	Persons presenting with an injury to EDs at participating hospitals.
Demographic	First Name; surname; Date of Birth; age; gender; residential address; ethnicity.	Gender; approx age; incident address.	Age; gender; postcode; country of birth; language; ethnicity; employment status.
Event information	Date and time of injury (if known - text); geographical location; activity at time of injury (descriptive text); other factors (Alcohol/drug use); social situation (e.g. homeless, self care functioning); scene findings (dangers on scene, patient position - e.g. sitting, lying, trapped, walking); prior care management (bystander first aid); patient history (including allergies).	Date and time of injury (if known - text); geographical location; activity at time of injury (if known- descriptive text); circumstances leading to injury (if known - text).	Time and date of injury; geographical location of injury; activity at time of injury; object associated with injury.
Injury Information	Injury type; mechanism of injury; body region injured (specific anatomical structure); in case of MVC - additional info such as position in vehicle; vehicle details; side airbags; position of vehicle; helmet; vehicle impact details; extrication.	Patient conscious level (y/n); breathing (y/n); injury type; mechanism of injury; body region injured (specific anatomical structure); blood present.	Text description of injury; nature of injury; body location injured; mechanism of injury; indication of severity; triage code; intent of injury; ICD10-AM code..
Main and additional purposes of the data collection	Patient care record. Data are also used for research purposes, and for service planning.	A record of incidents resulting in calls to QAS. The database is also used to prioritise incidents, dispatch appropriate resources; and to manage scene safety.	QISU data are primarily collected for injury surveillance. The data are used to inform injury prevention and policy at many levels. QISU data are also used to advocate for change to reduce injuries, and QISU often acts as a contact point for injury-related queries (i.e. media, general public, etc).
Exclusion/inclusion criteria	All cases attended and/or treated by a QAS Paramedic. This includes patients who refuse transport.	All incidents created by calls to QAS (i.e., requests for attendance by QAS, including patient transport service).	Inclusion: any injured person presenting for initial treatment of an injury at the ED of a participating hospital. The 14collecting hospitals cover 3 regions in QLD: Metropolitan (Brisbane); Regional (Mackay and Moranbah districts); and remote (Mount Isa).
Owners	QAS.	QAS.	The data are owned by Queensland Health and stored on the Mater server (covered under Mater insurance policies)
Funder	Qld Government.	Qld Government.	QISU is funded by Queensland Health, and sits under the Health Promotion Unit (Injury Prevention). The Mater provides admin/IT/logistical support. Some QISU employees are Mater-based.
Years covered by database	E-ARF Partial collection commenced Jan 2006 (Pilot); Full electronic collection Jan 2007.	Communications Data (QACIR) 1 July 2003.	The database originated in 1989, however easily accessible data are only available from 1998. The number of participating hospitals and data fields has increased over this time period.
Treatment	Procedures performed (e.g., pressure bandage; haemorrhage control; spinal immobilisation; IV access); medication administered; referral (e.g. assessment team; police).	In cases where patients are not transported to hospital, minor treatments are described (text); and sometimes advice provided (in minor cases where QAS attendance not required); pre-QAS arrival (e.g., 1st aid) and post-dispatch instructions.	N/A

TREATMENT			
Custodian	**QAS (Information Services Unit)**	**QAS (Information Services Unit)**	**QISU**
Administrative	Case number; dispatch code (describes urgency of case); transport category (describes urgency of case); receiving facility; location at dispatch; date; time of dispatch; time patient call received; dispatch time; time on case; time arrive at scene; time arrive at patient; time depart scene; time hospital notified (if applicable), time at hospital; time of handover; billing type (e.g. DVA; interhospital transfer).	Incident number; dispatch code (describes urgency of case); time/date incident created; transport category (describes urgency of case); location of dispatched vehicle at dispatch; date; time of dispatch; time patient call received; dispatch time; time on case; time arrive at scene; time arrive at facility; time off case; skill level of unit dispatched; response code; response determinant.	Discharge status from ED (including admission); method of arrival at hospital.
Additional Clinical	Blood Pressure; temperature; pulse; Glasgow Coma Score; Heart Rate; Respiratory Rate; Oxygen saturation; pain score; BSL; Pupil size / reactivity; ECG where required; End-tidal CO2. Time of these observations is also recorded.	N/A	N/A

TREATMENT			
Custodian	**Department of Communities (Child Care)**	**Spinal Injuries Unit**	**QCC**
Database	TBC	Spinal Injuries Unit.	CCRIS (Clinical Co-Ordination & Retrieval Services Information System).
Sample	Children injured whilst attending a child care facility (including out of school hours school care).	All patients admitted to the Spinal Injuries Unit and most outpatients treated at the SIU.	Patients requiring retrieval and/or transport coordinated through QCC (QAS; Careflight; RFDS; various community helicopter providers).
Demographic	Full Name; Date of Birth; gender.	Gender; Name; Age; Home Region (SLA).	UR Number; name; date of birth; gender; location.
Event information	Date and time of injury; date and time of medical treatment; activity at time of injury (text description).	Date of injury; geographical location of injury.	Date; time of injury.
Injury Information	Injury severity (serious; hospitalisation; permanent injury; fatal); type of Injury (bite from child; cut/laceration; poisoning; bite/sting; dislocation; respiratory; bruise; fracture/break; unconscious; bump/knock; hearing loss; other; burn/scald); cause of Injury (bite; person falling; other; caught in/between; running/jumping; falling off equipment; stepping on/in; object falling/flying; struck by/against); body region; body diagram.	Injury type (canal stenosis; crush; disc disease; diving/watersports; fall; football; gymnastics; impact with motor vehicle; impact with other hazard; motor bike; MVA; other non-traumatic; pedestrian/pushbike; transverse myelitis; tumour; vascular; violence); Injury level (e.g., C or T); other injuries (text field); mechanism of injury.	Cause and details of injury (text description).
Main and additional purposes of the data collection	The database records instances of serious injury/death that occur while children are in child care, for the purposes of monitoring the quality of the care at child care providers.	The purpose of the data collection is to inform and improve clinical care of patients.	The database serves as a centralised record of all episodes of patient care that are managed through QCC. Additionally, the data are used for state-wide health retrieval services planning.
Exclusion/inclusion criteria	Any child who sustains an injury whilst at a child care facility in QLD.	All patients admitted to SIU and most outpatients (may include admitted patients from other hospitals who seek outpatient treatment from SIU).	N/A
Owners	Department of Communities.	PAH.	OCHO
Funder	Department of Communities.	PAH (and some occasional limited external funds).	OCHO funds the CCRIS database. The database administrators are located in the Information Division of QHEALTH. The Business Area Administrator belongs in the Integrated Patient Transport Reform Project (IPTRP).
Years covered by database		The database has been in operation from 1973 onwards, and computerised since mid 1990s.	Reasonable data are available from 2006 onwards.
Treatment	Type of Treatment (Ambulance; First Aid; Doctor); Text Description of treatment sought.	Operations; Interventions performed; rehabilitative procedures.	Interventions / treatment administered; medication administered.
Administrative		Length of stay in spinal unit; accommodation type at discharge; transfer method; referral region (SLA); status at discharge (e.g., death); primary means of mobility at discharge; other factors (mental health); equipment used in rehab; complicating factors; FIM scores.	Incident ID; incident date; urgency; distance; road travel time; time at scene; time arrive at referring hospital; time arrive at receiving hospital; time depart receiving hospital; mode of transport.
Additional Clinical			Vital stats.

TREATMENT			
Custodian	**CONROD**	**QLD Health (HIC)**	**Poisons Information Centre**
Database	Queensland Trauma Registry.	Queensland hospital admitted patient data collection (QHAPDC).	Poisons Information database
Sample	Patients with serious injuries admitted to QLD hospitals.	All admitted patient separations from recognised public hospitals, licensed private hospitals, and day surgery units.	All received phone calls.
Demographic	UR number; ED number; surname; first name; date of birth; gender; ATSI status; address.	UR number; surname; given name; gender; dob; address; Medicare eligibility; marital status; country of birth; Indigenous status.	Age; gender; weight of child.
Event information	Date/time of injury; narrative description of injury event; geographical location of injury; activity at time of injury (ICD10-AM).	Place of occurrence; activity when injured.	Product details (generic); route of exposure; size/quantity of exposure.
Injury Information	External cause of injury (ICD10-AM); intent; nature of injury; type(s) injury (AIS codes); body location (AIS codes); injury severity (ISS); trauma and injury severity score (TRISS); revised trauma score (RTS); outcome..	External cause of injury; principle and other diagnoses (ICD coded); procedures (ICD coded).	Time since exposure; signs and symptoms present at time of call.
Main and additional purposes of the data collection	QTR is a research-oriented, university based centre that undertakes activities that support quality assurance processes in QHealth hospitals. QTR data is also used to inform service provision/planning (e.g., rehab), and to inform methods of injury prevention.	QHAPDC is a monthly collection of unit record data. The data collected is used for: strategic planning; resource allocation; performance measurement; benchmarking; epidemiological and medical research; and to optimise QLD Health's own revenue through fee-paying patients and provision of relevant treatment information to support funding claims.	The database is primarily an administrative tool to record call details to the PIC, but is also used for education purposes; and to identify trends and issues as they arise.
Exclusion/inclusion criteria	All patients admitted to Queensland hospitals for a period of 24hrs or greater; or who have ISS>16.	QHAPDC includes all admitted patient separations from recognised public hospitals; licensed private hospitals; and day surgery units.	All calls to PIC line are recorded.
Owners	The data are owned by QHealth, but the software ad intellectual prowess is the intellectual property (content knowledge) of QTR.	QLD Health.	QLD Poisons Information Centre.
Funder	MAIC	QLD Health.	QHealth (RCH).
Years covered by database	QTR started in 1998 (RBH, PAH, RCH, and MCH); and became state-wide in 2002.	The database has been in operation since 1985.	The database has been in operation since July 2004. Data were collected prior to this date, but it is very difficult to access.
Treatment	Operations/interventions performed during hospital stay; rehabilitate procedures.	Procedures (ICD coded).	Initial treatment rendered prior to call; advice given.
Administrative	Hospital name; presentation date/time; mode of arrival; means of referral; operation types/dates/times; ICU days; length of stay; transfers.	Admission date/time/number; care type; source of referral/transfer; separation date/time/number; discharge status; facility transfers; admission ward/unit; treating doctor; eARF; length of stay; patient activity during stay; AR-DRG; MDC; palliative care; rehabilitation care.	Date; time of call; caller type (lay, ambulance, nursing, medical etc).
Additional Clinical	Vital stats: Pulse rate; Sp02 rate; respiratory rate; systolic BP rate; Diastolic BP; Glasgow Coma Score; temperature.	A wide variety of indicators are produced from this data source.	N/A

TREATMENT			
Custodian	**QLD Health (HIC)**	**RCH Burns Unit**	**RBH (Adult) Burns Unit**
Database	EDIS	Burns Database.	
Sample	Patients who present for treatment at EDs in QLD.	RCH Burns Unit Patients.	RBH Burns Unit patients.
Demographic	Surname; first name; gender; age; date of birth; postcode; ED visit number.	UR number; gender; date of birth; age months; suburb.	Name; date of birth; gender; nationality; religion; marital status; employment status; size of household (no. of adults/children); type of housing; formal education.
Event information	Date/time of injury; location at time of injury; activity at time of injury.	Date/time of burn; geographical location of injury.	Date/time of injury; location at time of burn (home; vehicle; work); injury witnesses; attempts to extinguish fire (Y/N); circumstances of burn (text).
Injury Information	Text description of injury; cause of injury; Intent; diagnoses (ICD10-AM); severity (triage code).	Date of injury; type of burn (scald/chemical/contact/friction); burn category; cause of burn (for some); burn size (%); burn location (on body); burn depth; intent of burn (accidental/ intentional). Additional event and injury data are collected periodically as part of specific studies.	Cause of burn (specific definition, not normal cause of injury code, as this not specific enough); total burn size; total burn depth; mechanism of burn (scald; flame; contact; chemical; electrical; friction); accidental/non-accidental; predisposing conditions (normal; physical conditions; mental conditions; drug alcohol; other); morbidities associated with burn injury (infections etc, renal failure).
Main and additional purposes of the data collection	Primarily administrative - record of patient attendance and care.	The primary purpose of the database is to inform patient care; but data are also used for injury prevention purposes (interventions, research).	The data are collected to determine morbidity associated with burns; and examine quality measures of outcomes after burns injuries (functional, physical, and psychological). The data also support injury prevention.
Exclusion/inclusion criteria	Patients presenting to EDs at most QLD hospitals.	Any burns patient referred to RCH burns Unit aged 0 - 14. The catchment area includes QLD, the Pacific, TI and Northern NSW.	Adults who are treated for burns at the burns unit at RBWH. Data are collected while patients are in the burns unit, and then during episodic care (return treatments).
Owners	QLD Health.	The Burns Unit.	Burns Unit, RBWH.
Funder	QLD Health.	RCH Foundation.	Burns Unit, RBWH.
Years covered by database	TBC	The database has been in operation since 2000.	Paper records have been collected since 1972 and electronic record since 1997.
Treatment	Treatments; interventions; medications administered whilst in ED.	First aid details (who, what - excluding QAS); other treatment (who, what); details of surgery (date, procedure); details of other interventions.	Initial treatment (cool water; ice; silvazine); surgical interventions (number of operations; types of operations); blood products used; use of non-autologous wound coverage; physiotherapy; occupational therapy.
Administrative	Admission status; method of arrival at ED; triage code; date/time arrival; discharge details (time/disposition); transfers.	Admission date/time; interventions/operations; consultant; number of visits; number of day visits; insurance status (public v private); discharge date/time till complete re-epitheliase; long-term scar management (>1 month).	Date/time of admission; length of stay (number of days in ICU, +/_4C, other wards); place of initial treatment (ambulance; GP; RBH; other hospital); persons administering treatment; referrals to RBH; date/time of discharge/death.
Additional Clinical	Vital stats.	Some additional clinical data are collected from time to time, for specific research projects.	TBC

	TREATMENT	POST-EVENT	
Custodian	**Royal Flying Doctor Service**	**QCOMP**	**MAIC**
Database	Health Aeromedical Logistics (HAL)	QCOMP	
Sample	All patients transported or treated by the RFDS.	Workers compensation claims lodged by injured workers in QLD.	Personal injury claims and related information regarding at-fault MVCs in QLD or involving a QLD vehicle.
Demographic	Surname; given names; date of birth; age; address; state; postcode; country (if not Australia); gender; ethnicity (Indigenous; non-Indigenous; Unknown); Insurance (travel; public liability; workers compensation; third party; veteran affair; other).	Industry (NOT occupation - Occupation is coded by OESR); gender; age; address.	Surname; middle initial; first name; date of birth; employment status; usual occupation; weekly earnings; employer.
Event information	Mechanism of injury (MVC - driver/passenger; seatbelts Y/N; motorbike -rider/pillion; helmet Y/N); pedestrian; animal incident; fall; assault; stabbing; gunshot; other; geographical location of injury.	Time of injury; day of injury; circumstances leading to injury (text).	Accident date; accident time; location; accident circumstance; date reported to police; vehicles involved; persons involved.
Injury Information	Injury type (fracture; burns; abrasion; laceration; haemorrhage); provisional diagnosis; external cause of morbidity and mortality; patient severity on contact/uplift (critical; high dependency; low dependency; no dependency; not applicable); Patient transfer outcome (improved; unchanged; deteriorated; transport not required; refused transport; died prior to arrival; died prior to transport; died in transport).	Narrative description of injury; mechanism of injury (coded by OESR using a set of Workers' compensation specific codes used Australia wide which are based on ICD10); agent (e.g., power drill); location and nature of injury (coded by insurers; rule based); fatal / permanent impairment information (i.e., individual permanent impairment assessment – this is the proportion of the body that is permanently impaired and is based on body regions – e.g., upper limb; lower limb; general disfigurement).	Demonstrable injury; injury code (AIS - up to 5); ISS; body region; hospital admission; ambulance transportation; time off work.
Main and additional purposes of the data collection	The database is primarily a patient care record, but data are also used for clinical review / improvement; legal documents; reporting to funders; research; trends analysis (no capacity to currently undertake this, planned for the future).	The primary role of the database is to facilitate maintenance of workers compensation claims and to regulate the scheme. WH&S access the data through DEIR for injury prevention purposes.	The purpose of this data collection is to monitor the Compulsory Third Party (CTP) insurance scheme, and regulate and set insurance premiums. Data are also used for injury prevention-related research; and some private applications (e.g., taxis; private insurers).
Exclusion/ Inclusion criteria	All patients treated and/or transported by RFDS crew (includes clinical cases & helicopter escorts).		Personal injury claims and related information regarding at-fault MVCs in QLD or involving a QLD vehicle.
Owners	RFDS.	Insurers own the data.	MAIC.
Funder	DOHA, Qld Health, OATSI, COAG, multiple contracts (Aeromedical, Clinics, telehealth), donations.	Fully funded by levies from Workers compensation (i.e., insurers).	MAIC is funded by a levy on car insurance premiums.
Years covered by database	The database has been in operation since July 04. The data in legacy system (pre-July 04) is not readily accessible due to system constraints.	Comprehensive electronic records exist since mid 90's.	The database has been in operation since Sept 1994.
Treatment	Clinical procedures / interventions performed.	Treatment received related to claim (type, total cost).	Treatment received related to claim (type, total cost).
Administrative	Transport type (primary; clinic; transfer; repat; onsite); flight priority (immediate; urgent; semi-urgent; non-urgent); evacuation details (date of decision; time of decision); activation details (date of activation; time of activation); patient handover (date of handover; time of handover); cabin altitude; clinical coordinator details; site of first contact with patient; attending flight nurse & attending medical officers; past medical and surgical history; current medication; allergies; examination; management; patient's last food; last fluid; and last tetanus injection.	Number of work days lost; associated medical payments (to item #).	Ambulance transportation; hospitalisation; time off work; total gross payment; net payment.
Additional Clinical	GCS; motor response; pupil reactivity; pupil size; BP; pulse; respiration; O2 L pm; O2 Saturation; MAP; CVP; cardiac rhythm; other (e.g., Colour, BSL); extremity observations (time; colour; warmth; peripheral pulses; movement/sensation; limb splints).	N/A	N/A

POST-EVENT		
Custodian	**Victorian Institute of Forensic Medicine**	**ABS Population and Statistic Program**
Database	NCIS (National Coronial Information System)	Registered Deaths
Sample	QLD coronial cases (Data are collected by Coroner and provided to NCIS).	All registered deaths in Australia.
Demographic	Names; date of notification of death; age; gender; date of birth; place of usual residence; period of residence in Australia (if not residents); country of birth; employment status; usual occupation; marital status; indigenous identification.	Year of death; age at death; gender; usual residence of the deceased; country of birth; Aboriginal and Torres Strait Islander status; marital status; occupation.
Event information	Time/location of incident; activity at time of incident; if MVC - vehicle type; driver/passenger; context; user; police narrative of circumstances.	Date/time death.
Injury Information	ICECI is used to code the following: Mechanism of injury (primary, secondary, tertiary); object or substance involved (primary, secondary, tertiary); intent (e.g., accidental, self-inflicted); nature of injury (e.g., burns, drowning); ICD-10 Codes; deaths.	ICD-10 codes for deaths where the underlying cause was identified as an external cause (injury or poisoning); multiple causes of death; circumstances of injury; nature of injury; Years of potential life lost; other conditions reported on the death certificate.
Main and additional purposes of the data collection	The primary role of the NCIS database is to assist coroners in their roles of investigating deaths. Secondarily, the database is used for injury prevention research by approved government and research agencies.	The collection is the key source of mortality data for Australia. The data are also used for reporting to WHO, and for research; informing policy, and informing injury prevention.
Exclusion/inclusion criteria	All coronial cases in QLD (NCIS).	All deaths within Australia are registered (irrespective of citizenship). Excluded are: deaths of Australian citizens who die overseas; missing persons where no body is found or where no inquest occurs; still births; foetal deaths.
Owners	All data is owned by the relevant state coroner, but NCIS administers the data.	ABS.
Funder	Commonwealth and State/Territory Agencies.	Federal Government (ABS).
Years covered by database	The database began operation in 2001.	The data dates back to early 1900's; electronic data set from 1960's; ICD-10 on multiple cause of death since 1997.
Treatment	All information from the medical record as required by the coroner to complete the coronial inquest.	N/A
Administrative	N/A	N/A
Additional Clinical	N/A	N/A

Appendix E: Relevant Legislation

PUBLIC HEALTH ACT 2005

Part 4 RESEARCH

Division 1 - Definitions

In this part—**biomedical study** means a study of the biological determinants of health and disease that establishes the biological basis for preventing, treating and curing disease.

clinical and applied study means a study of the effectiveness of strategies to diagnose and treat disease or illness.

epidemiological study means a study of the distribution and determinants of health-related states or events in particular populations.

evaluation and planning study means a study for—(a) appraising or measuring the value of a health intervention; or (b) designing and projecting current and future health services.

monitoring and surveillance study means a study for keeping watch over the health of the population or individuals to control the spread of disease and maintain health and well-being.

register means the Research Register.

research means systematic investigation for the purpose of adding to knowledge about human health and well-being and includes the following—
(a) a biomedical study;
(b) a clinical and applied study;
(c) an epidemiological study;
(d) an evaluation and planning study;
(e) a monitoring and surveillance study.

Research Register see section 288(3).

Division 2 - Health information held by the department for research

Section 281 Chief executive may give information (1) The chief executive may give information under this part. (2) To enable the chief executive to give information under this part, a relevant person may give information under this part to the chief executive.
(3) The chief executive or a relevant person may give the information despite any other provision of this Act or any provision of another law that deals with confidentiality, including, for example, the Health Services Act 1991, section 62A.
(4) In this section— **relevant person** means a person who has access to health information held by the department, including, for example, a health service employee or a public service employee.

Section 282 Application to chief executive for information (1) A person may apply in writing to the chief executive to be given health information held by the department for research being conducted by the person or by an entity of which the person is a member.
(2) The application must state the following— (a) a description of the research that includes— (i) the purpose of the research; and (ii) the methodology of the research; (b) the type of information required, including whether information identifying a person is required; (c) if information identifying a person is required— (i) the reasons the identifying information is required; and (ii) how the privacy of an individual identified will be protected; (d) if the information will be needed at intervals during the research, details of the intervals; (e) the name of the person or entity proposing to conduct the research; (f) the names of all persons who will be given the information for the research; (g) the duration of the research; (h) the views of a human research ethics committee about the research including contact details for the committee.

Section 283 Further information or documents to support application (1) This section applies if the chief executive considers further information is required to help the chief executive decide an application for health information held by the department. (2) The chief executive may, by notice given to the applicant, require the applicant to give the chief

executive, within the reasonable time stated in the notice, further information or a document about the application. (3) The requirement may only relate to information or a document that is necessary and reasonable to help the chief executive decide the application. (4) If the applicant fails to comply with the requirement within the stated time, the applicant is taken to have withdrawn the application.

Section 284 Decision about application (1) The chief executive must consider the application for health information held by the department as soon as practicable and either grant or refuse the application. (2) The chief executive may grant the application only if the chief executive is satisfied the giving of the health information held by the department is in the public interest, having regard to— (a) the opportunities the research will provide for increased knowledge and improved health outcomes; and (b) the privacy of individuals to whom the health information relates. (3) If the application asks for information identifying a person, the chief executive may grant the application only if the chief executive is satisfied the identification of the person is necessary for the relevant research. (4) If the chief executive decides to grant the application, the chief executive must immediately give notice of the decision under section 285 to the applicant. (5) An application may be granted subject to the conditions the chief executive considers necessary or desirable including, for example, the following— (a) that the person or entity conducting the research must pay the State's reasonable costs of giving the information; (b) that information given for research must be handled in a confidential and secure way; (c) that measures must be put in place to ensure researchers are aware of and comply with ethical requirements relevant to the conduct of the research; (d) that measures must be put in place to provide feedback to the chief executive on the progress and results of the research. (6) If the chief executive decides to grant an application subject to conditions, the chief executive must immediately give the applicant notice of, and the reasons for, the conditions. (7) If the chief executive decides to refuse the application, the chief executive must immediately give the applicant notice of the refusal and the reasons for the refusal.

Section 285 What notice must state (1) The notice under section 284(4) must state the following— (a) the name of the person or entity conducting the research; (b) the names of all persons who may be given the information for the research; (c) a description of the research, including the purpose and methodology of the research; (d) the type of information to be given and, if the information is to be given at intervals, details of the intervals; (e) if the application was granted subject to conditions, the conditions; (f) the period for which the application has been granted. (2) If an application is granted subject to a condition, the applicant must comply with the condition, unless the applicant has a reasonable excuse.
Maximum penalty for subsection (2)—50 penalty units.

Section 286 Notification of change of persons being given information (1) This section applies if the names of persons who will be given the information for the research changes. (2) The person for the time being in charge of the research must give notice to the chief executive as soon as practicable after the change.
Maximum penalty—20 penalty units.

Section 287 Chief executive may rescind decision to give information (1) This section applies if this part is contravened in relation to health information given under this part. (2) The chief executive may rescind the chief executive's decision to give the information.

HEALTH SERVICES ACT 1991

Part 7, Section 62 CONFIDENTIALITY

62A Confidentiality

(1) A designated person or former designated person must not disclose to another person, whether directly or indirectly, any information (***confidential information***) acquired because of being a designated person if a person who is receiving or has received a public sector health service could be identified from the confidential information.

Designated person means a person who is— (a) a public service employee employed in the department; or (b) a health service employee; or (c) the chief health officer; or (d) the director of mental health appointed under the *Mental Health Act 2000*; or (e) a health professional (other than a person mentioned in paragraphs (a) to (d)) engaged in delivering a public sector health service on behalf of the department, whether at a public sector health service facility or another place; or (f) a person (other than a person mentioned in paragraph (a) or (b)) engaged temporarily to provide administrative support services for the department; or (g) a person being educated or trained at a public sector health service facility as part of the requirements for— (i) registration, enrolment or other authorization (however described) to practise as a health professional; or (ii) completion of a course of study qualifying a person for registration, enrolment or authorization mentioned in subparagraph (i); or (h) a person providing education or training at a public sector health service facility to a person mentioned in paragraph (g); or (i) a volunteer carrying out duties at a public sector health service facility on behalf of the department; or (j) another person prescribed under a regulation for this paragraph to be a designated person.

62B Disclosure required or permitted by law

Section 62A(1) does not apply to the disclosure of confidential information by a designated person if the disclosure is required or permitted by an Act or another law.

62G Disclosure for data collection and public health monitoring

Section 62A(1) does not apply to the disclosure of confidential information by a designated person if— (a) the disclosure is to another designated person; and (b) the disclosure and receipt of the confidential information is— (i) to give effect to or manage a funding arrangement for a public sector health service; or (ii) for analysing, monitoring or evaluating public health; and (c) the other designated person is authorised in writing by the chief executive to receive the confidential information.

62H Disclosure for purposes relating to health services

Section 62A(1) does not apply to the disclosure of confidential information by a designated person if— (a) the disclosure is to another designated person for evaluating, managing, monitoring or planning health services; or (b) the disclosure is to an entity prescribed under a regulation for this paragraph for evaluating, managing, monitoring or planning health services as stated in the regulation.

62M Disclosure to approved quality assurance committee

Section 62A(1) does not apply to the disclosure of confidential information by a designated person if the disclosure is to a committee declared under section 31(1) to be an approved quality assurance committee, or to a person authorised by the committee to receive the confidential information, to enable the committee to perform its functions.

62N Disclosure to Commonwealth, another State or Commonwealth or State entity

(1) Section 62A(1) does not apply to the disclosure of confidential information by the chief executive if— (a) the disclosure is to the Commonwealth or another State, or an entity of the Commonwealth or another State and the disclosure— (i) is required or allowed under an agreement— (A) between Queensland and the Commonwealth, State or entity; and (B) prescribed under a regulation for this paragraph; and (ii) is considered by the chief executive to be in the public interest; or (b) the disclosure is to an entity of the State and the disclosure— (i) is required or allowed under an agreement— (A) between the chief executive and the entity; and (B) prescribed under a regulation for this paragraph; and (ii) is considered by the chief executive to be in the public interest. (2) The Commonwealth, a State or entity that receives confidential information under an agreement under subsection (1)— (a) must not give it to anyone else unless allowed to do so by the agreement or in writing by the chief executive; and (b) must ensure the confidential information is used only for the purpose for which it was given under the agreement. (3) In this section — entity of the State includes a department and an entity established under an Act for a public purpose.

62P Disclosure to person performing function under Coroners Act 2003

Section 62A(1) does not apply to the disclosure of confidential information by a designated person to a person who requires the confidential information to perform a function under the Coroners Act 2003, other than the preparation of an annual report.

62Q Necessary or incidental disclosure

Section 62A(1) does not apply to the disclosure of confidential information by a designated person that is necessary or incidental to a disclosure of confidential information otherwise permitted under this part. For example the disclosure of confidential information to advise the chief executive about authorising the disclosure of confidential information in the public interest under section 62F or to collect confidential information for the purpose of a prescribed agreement under section 62N.

PRIVATE HEALTH FACILITIES ACT 1999

Part 11, Section 147 CONFIDENTIALITY OF INFORMATION

(1) This section applies to the following persons— (a) a person who is, or was, the chief executive, the chief health officer or an authorised person; (b) another person who is, or was, involved in the administration of this Act, including, for example, as a health service employee or public service employee; (c) a member of an advisory committee; (d) a person who was involved in the administration of the repealed division.

(2) This section applies to information obtained by a person to whom this section applies in the course of performing the person's functions under this Act or under the repealed division.

(3) The person must not disclose the information if— (a) the disclosure of the information would be likely to damage the commercial activities of the person to whom the information relates; or (b) the information is personal health information; or (c) the information is contained in a report under section 16.16

(4) Subsection (3) does not apply if—

(a) the information is disclosed: (i) in the performance of functions under this Act; or (ii) with the written consent of the person to whom the information relates; or (iii) to the person to whom the information relates; or

(b) the information is otherwise publicly available; or

(c) the information is given in the following circumstances— the chief executive gives the information to the Commonwealth or another State, or an entity of the Commonwealth or another State (the recipient), under an agreement with the recipient; (ii) the agreement is prescribed under a regulation for this paragraph; (iii) the chief executive is satisfied the giving of the information is in the public interest; or

(d) the information is disclosed to the chief executive to allow the chief executive to act under paragraph (c) or (h) or subsection (6); or

(f) the disclosure of the information is required or permitted by an Act or another law; or

(g) the disclosure of the information is authorised by the chief executive under subsection (6); or

(h) the disclosure of the information is— (i) to a person authorised in writing by the chief executive to receive the information for evaluating, managing, monitoring or planning health services; Or 16 Section 16 (Criminal history reports for investigation); (ii) to an entity prescribed under a regulation for this subparagraph for the purpose of evaluating, managing, monitoring or planning health services as stated in the regulation.

(6) For subsection (4)(g), the chief executive may authorise, in writing, the disclosure of information to a person if the chief executive believes, on reasonable grounds, the disclosure is in the public interest.

(7) The Commonwealth, other State or entity that receives information under subsection (4)(c)—

(a) must not give the information to anyone else, unless allowed to do so— (i) under an agreement mentioned in subsection (4)(c); or (ii) by the written consent of the chief executive; and

(b) must ensure the information is used only for the purpose for which it was given.

(8) If the chief executive authorises the disclosure of the information to a person under subsection (6), the person—

(a) must not give the information to anyone else; and

(b) must ensure the information is used only for the purpose for which it was given.

(9) The chief executive must include in the department's annual report under the Financial Administration and Audit Act 1977 a statement about authorisations by the chief executive under subsection (6), including general details about—

(a) the nature of the information given to persons under the authorisations; and
(b) the purpose for which the information was given to the persons.

(10) The statement under subsection (9) must not identify any person.

(11) In this section—
commercial activities means activities conducted on a commercial basis.
information includes a document.
personal health information means information about a person's health that identifies, or is likely to identify, the person.

147A Application of section 147 to person under Coroners Act 2003
Section 147 does not apply to the disclosure of information to a person who requires the information to perform a function under the Coroners Act 2003, other than the preparation of an annual report.

AMBULANCE SERVICE ACT 1991

Section 49 Confidentiality

(1) A service officer or agent of the service must not give, directly or indirectly, to any other person any information acquired as such an officer or agent in respect of a person who could be identified from the information as a person who has received prehospital care or ambulance services. Maximum penalty—50 penalty units.

(2) Subsection (1) does not apply—
(a) to information that an officer or agent is expressly authorised or permitted to give under this or any other Act or that is required by operation of law; or
(b) to information given with the prior consent of the person to whom it relates or, if the person has died, with the consent of the spouse or senior available next of kin of the person; or
(c) to information concerning the condition of a person who has received ambulance services if the information is communicated by an ambulance officer to— (i) a member of the medical staff of a hospital; or (ii) a medical practitioner; or (iii) another ambulance officer or a member of an ambulance service (or similar body providing ambulance services) from outside Queensland; or (iv) the next of kin or a near relative, including a spouse, of the person; in accordance with the recognised standards of medical practice; or
(d) to information given to the Australian Red Cross Society for the purpose of tracing blood, or blood products derived from blood, infected with any disease or the donor or recipient of any such blood; or
(e) to information required in connection with the further treatment of a patient in accordance with the recognised standards of the medical profession; or
(f) to information used in the conduct of research which has the approval of an appropriate ethics committee which will not identify individual patients.

(3) In subsection (2**)— medical practitioner** includes a person registered under a law of another State that provides for the same matter as the Medical Practitioners Registration Act 2001 or a provision of that Act.

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APPENDIX C – FORMAL WRITTEN RESPONSES TO DISCUSSION PAPER

QUEENSLAND INJURY
SURVEILLANCE UNIT

Disseminating Queensland data
for Queensland injury prevention

Level 2
Mater Community Services Building
39 Annerley Road
WOOLLOONGABBA Q. 4102
Phone: 07 3163 8569
Fax: 07 3163 1684
Email: mail@qisu.org.au

27/05/2008

The Queensland Trauma Data Scoping Project Team

Re: Discussion Paper: March 2008

We are writing with concerns regarding some of the material contained within the recently released discussion paper. Whilst the process of obtaining information to prepare this discussion paper appears to have been exhaustive and comprehensive, there are some errors and omissions in the final document. Our concerns are as follows:

1. **The Discussion Paper does not clearly reflect the varied reasons for collecting injury data.** No one injury data set can be all things to all users, and the current array of injury data collectors reflects the varying purposes for which data is collected. Whilst a summary statement on page 20 of the discussion paper does accurately outline the various purposes for which injury data is collected, this framework is not utilised throughout the document. The result is that different data collection services are discussed throughout the document without reference to their purpose.

2. **The discussion paper is weighted towards collection of clinical data.** Whilst informing injury prevention strategies is identified as an operational need, most discussion revolves around provision of clinical data sets to inform pre-hospital and in-hospital health care (see Appendix D: Preliminary Table of Existing Data Sources). The QISU data set is predominantly concerned with collecting data on the pre-event/event agent/environment factors of the Haddon injury paradigm with some personal and post-event data (see below). Interestingly, the QISU data set is the only data set not included in appendix D: and therefore a direct comparison of the QISU data set to other data sets is not possible.

3. **The QISU database is misrepresented within the discussion paper.** In the initial TDSP Issues Paper, October 2007, Appendix A, QISU is incorrectly identified as providing predominantly treatment data. Whilst QISU does collect data on the triage category, nature of injury (ICD code) and hospital separation, it collects no data on treatment of the individual patient. As stated above, the bulk of data in the QISU data base refers to the pre-event and event (age, external cause, major injury factor, location of injury, intent). This data is used to understand injury mechanisms and inform injury prevention strategies.

4. **There is a lack of understanding of the operational structure and methodology of QISU:** Page 7 of the discussion paper states that “at sites where both QISU and QTR operate, there are separate coding staff for each agency”. This is incorrect as QISU data is entered by emergency department nurses or clerical staff and cleaned centrally at

QISU. On page 14, there is an extended discussion relating to poor quality of injury data obtained from emergency departments. As the primary collectors of this data the implication is that this concerns QISU data specifically. The discussion refers to the high burden on clinicians (doctors) in collecting data. This is again misleading as clinicians do not collect any additional data to that collected in a normal medical record. Clinicians are responsible for providing the diagnosis in the QISU data but this is the exact same ICD-10 code (patient diagnosis) that they have to provide QH as part of their medical record. The EDIS system is designed to assist and simplify ICD-10 coding by medical staff and QISU benefits from this technology. Although there are well recognised minor problems with identification of some injuries within the ED, this reflects a small percentage of the overall injury data set obtained by QISU.

5. **There is a lack of understanding of the nature and purpose of injury surveillance:** The discussion paper states:

   Whilst data collected by QISU were recognised by stakeholders as extremely valuable (e.g., risk factor identification, cause of injury) the validity of the data and the application to injury prevention was cited by some stakeholders as a reason for not accessing these data. The data currently available are considered inadequate for application to development of population level interventions/ strategies.

   QISU operates a surveillance unit under the terms of a Service Agreement with QH. That agreement specifies a sample of convenience selected to represent metropolitan, provincial, rural and remote communities in Queensland. QISU estimates that current reporting reflects 20-25% of injury presentations in the state. The surveillance process is designed to identify new injury patterns and changes in existing patterns and QH has perceived sufficient benefit to maintain continuous funding and support for 20 years. The level of data collected allows analysis of injury mechanisms that can inform injury prevention strategies and policy recommendations. Although QISU is not funded to review every ED injury presentation within Queensland it does have the methodology, experience, expertise and tools to do so if needed.

Whilst we agree with the ultimate conclusions drawn from the discussion paper, We are anxious to correct some of the misinformation and improve the clarity of focus within the existing discussion paper. We look forward to further discussions on this topic.

Yours Sincerely,

Dr Rob Pitt **Dr Ruth Barker** **Dawn Spinks**

Formal feedback regarding the Discussion Paper was received via email from:
Dr Dale Hanson, Senior Lecturer, School of Public Health, Tropical Medicine and Rehabilitation Sciences, James Cook University

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I am well aware the hard task is to get everybody's thoughts on paper in a coherent way. The easy task is to critique what is written. I also am well aware this paper represents the view of those you consulted & not necessarily your own views.

I agree with the general thrust of what you are saying, but I do have some concerns - particularly relating to page 15.

1. I think the idea of a retrospective triage score is a contradiction in terms. The Australian Triage Score (ATS) is a clinical tool designed to PROSPECTIVELY prioritise clinical work in an ED, nothing more, nothing less. It is not a research tool. If researchers find the triage score inadequate for their needs, then they should invent another index more appropriate for their needs. we shouldn't try to turn triage into something it was never intended to be. Unfortunately, there is a lot of misunderstanding about the tool by those who don't work in the ED. Most importantly, the difference between priority or urgency and severity. The triage tool was not designed to judge severity, but to prioritise clinical work load.
Sure, severe things will often be urgent, but not necessarily. For example, a dislocated little finger is very painful & best treated urgently and so would score a triage score of ATS 3, but it is hardly life threatening/severe. Where as lung cancers presenting as a chronic cough is most definitely a life threatening problem (severe), yet because it is a chronic problem will be score ATS 5. Sure, having taken a full history and examination and reviewed investigation results, I may in retrospect decide the condition may be more or less urgent - but this is not the point!!!! Triage is to prioritise workload. A good example might be an infant presenting with a fever and rash. The life threatening question here is might this be meningococcal sepsis (to which the answer is yes it might). For that reason, the triage sister will categorize this sort of presentation as ATS 3 or even ATS2 depending on circumstances. The fact that I as the ED doctor later retrospectively decide it was a viral upper respiratory tract infection (a trivial non life threatening problem) in no way negates that decision of the triage sister that this is clinical problem is a high priority presentation for the ED to rapidly assess. So I think the idea of retrospective triage is an oxymoron.
As I said, If researchers need a different more robust tool to retrospectively judge urgency/severity - thats fine(they should goahead and create a new index), but it is not triage.

2. I think the presentation of the utility of different datasets is extremely unbalanced. QISU cops a lot of criticism but the strengths and weaknesses of other datasets go unquestioned. I don't disagree with the weaknesses of the QISU data set as stated, however this is not balance by a discussion of the strengths and limitations of ED data sets. There is no critique of other data sets. Their utility, strengths and weaknesses remain unexplored. I for one think it is most misleading (by omission) to imply that other data sets are somehow perfect. Surely the whole point or the argument of this paper is that different data sets have their strengths and weaknesses and that by merging data we will be able to get a better overall picture of what is going on. I know you can only report what your respondents have said. However, I think ED data sets properly resourced are very important for

prevention as they give a much better feel for where and how these incident occur and so how they can be prevented. So I don't know how to rectify what I consider to be a seriously unbalanced presentation of the pro & cons of the different data sets, as it may represent the views of those you consulted. I think this is particularly important as I am not so naive as to believe that everybody reading this reports sole motivation is to improve trauma reporting whatever the cost. there will be those reading the report looking for opportunity costs - things that can be rationalised to save money. Frankly, i fear that unless your report become more balanced QISU is unlikely to survive. I think this would be a great shame & I don't think this is what you intend. I have already been on two committee's over the years who's unwritten political task was to rationalise QISU (that is remove funding from QISU). Lets not unintentionally fuel this fire.

Formal feedback regarding the Discussion Paper was received via email from:

Nicky Woodman, Land Transport & Safety Division, Queensland Transport

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Thank you for the opportunity to provide feedback and comment on the Trauma Data Scoping discussion paper.

The paper appears to focuses mainly on the duplication of detailed injury data collected by various agencies such as Health, Emergency services and MAIC.

Information in the RoadCrash database focuses on characteristics of crashes leading up to the event and only has two fields relating to injuries sustained by casualties involved. The RoadCrash database contains nature of injury and the severity of injury rated as one of four attributes (namely fatality, hospitalised, medically treated, and minor injury).

It should be noted that there is a degree of error with the casualty severity data in RoadCrash due to the nature of the data capture. Some casualties maybe classed as hospitalised whereas in fact this may not have been the case.

The trauma data scoping project offers to enable the clarification of the casualty severity discrepancy; however this information would be delayed by years after the crash and therefore offers limited value.

The cost of this exercise includes

- Lag time in acquiring the data
- Serious changes to crash records up to 24 months after the initial reporting by police resulting in changes to reports.
- Estimated additional cost of $50,000 per year in crash data coding to check and update records with more accurate casualty severity data.

Advantages

- More accurate determination of injuries sustained and injury severity of road casualties.

Overall this project offers little benefit to the Data Analysis Unit and road crash reporting as this level of improved accuracy would have limited or no effect on road safety strategy.

Formal feedback regarding the Discussion Paper was received from the following representatives of Queensland Trauma Registry (QTR) via a series of written and verbal communications:

Professor Nicholas Bellamy, Director, CONROD (UQ) &
Ms Jacelle Lang, Research Officer, QTR, CONROD (UQ)

SUMMARY OF QTR CONCERNS FROM MINUTES OF STEERING COMMITTEE MEETING, 30 MAY 2008:

- Concerns around page 3, "Access" section.

- Specifically the dot points on the bottom of page 3. The context around these points is missing and QTR would prefer positives presented with these points to provide balance.

- QTR accepts that these dot points are a summary of the opinions expressed by stakeholders but still would prefer a context. This document will be distributed statewide and there is concern that this may impact negatively (and unfairly) on perceptions of QTR. An example is the dot point of "Time delay in the provision of data." QTR would prefer that these comments be balanced with the KPIs that they are obliged to fulfil – eg Queensland Health KPI for provision of data is 50% within 5 days and 85% within 3 months.

- An additional concern are the dot points relating to the provision of data and poor marketing. QTR publishes annual reports that are widely circulated.

Response from Project Investigator (Assoc Prof Vivienne Tippett) at Steering Committee Meeting, 30 May 2008:

- We are happy to resolve these issues and to provide some commentary and additional contextual information in the final report. However it needs to be understood that these comments have been provided outside of the commentary phase for the Discussion Paper. The Discussion Paper has been signed off by the Steering Committee and circulated, as agreed at the last Steering Committee meeting (March 3rd).

Following a series of discussions with representatives of Queensland Trauma Registry (QTR)*, the following revisions were agreed upon via email with Ms Jacelle Lang [representing Prof Nicholas Bellamy] for inclusion with the Trauma Data Scoping Project Final Report:

"Seven of the agencies consulted during the consultation process reported past experience with difficulties in accessing data from the Queensland Trauma Registry (QTR). The key issues raised by stakeholders include:

- lack of transparency regarding the reasons for refusing data requests

QTR Formal Response:

[QTR reported that between 2001 and October 2007, 222 formal requests for data were made, and 12 were refused. Reasons for refusal of data generally include: not permitted under legislation, not permitted under existing ethics approvals; data not collected by QTR].

- time delay in the provision of data

QTR Formal Response:

[QTR are required to meet the following Key Performance Indicators (KPIs) set by Queensland Health regarding timeliness of data provision: 50% of data requests within five days, and 85% of requests within three months, except in extenuating circumstances. These targets are regularly exceeded - e.g., of the 118 requests for data that were received between 1st November 2005 and 31st December 2007, 70% were met within 5 working days, and 98% were met within three months].

- poor marketing of the services provided by QTR and the data that are accessible, resulting in limited knowledge of the usefulness of this source; and

- inaccessibility of data at the individual hospital level.

QTR Formal Response:

[There appear to have been communication inefficiencies that have resulted in inaccessibility of data by a central agency. These issues have now been resolved and under the current funding agreement, QTR is required to provide Queensland Health with data on all entered cases within 28 days].

An external review of QTR canvassed these and related issues and at the time of writing, the Registry was working actively with its funding agencies to redress these challenges. “

***[Professor Nicholas Bellamy, Director, CONROD (UQ) & Ms Jacelle Lang, Research Officer, QTR, CONROD (UQ)]**

APPENDIX D – STRATEGIC STAKEHOLDER LIST

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Strategic Stakeholders invited to the Final Consultation

Strategic Stakeholder	Agency
David Melville (Chair)	Commissioner, QAS
John Hand	Commissioner, MAIC
Ruth Barker for Dawn Spinks	Queensland Injury Surveillance Unit (QISU)
Nick Bellamy	Director, CONROD
Ray Brown	Information Division, QHealth
Sue Cornes	Health Statistics Centre, QHealth
Faileen James (apology)	Planning and Coordination Branch, QHealth
Roy James	Service Integration, Information Operations, Information Division, QHealth
Trisha Johnston	Epidemiology, Statistical and Library Services Centre, QHealth
Stephen Lake	Department of Child Safety
Rob Pitt	Queensland Injury Surveillance Unit (QISU)
Sue Walker (apology)	NCCH
Nicky Woodman	Data Analysis Unit, QLD Transport

Also invited were the **Project Team** members:

Chief Investigators	Vivienne Tippett (apology)
	Gerry Fitzgerald
	Michael Schuetz
	Cliff Pollard
Project Manager	Kerrianne Watt
Expert Advisors	Debbie Scott
	Emma Enraght-Moony