

NSW INJURY RISK MANAGEMENT RESEARCH CENTRE

DATA CONFIDENTIALITY AND PRIVACY POLICY

1.0 INTRODUCTION

The NSW Injury Risk Management Research Centre (the Centre) was officially established in September 1999 when a Deed of Agreement (the Agreement) was signed by its four funding partners - NSW Health, the Roads and Traffic Authority (RTA), the Motor Accidents Authority (MAA) and the University of New South Wales (UNSW). The Agreement contained specific clauses concerning the purpose of the Centre, the obligations of the funding partners and data confidentiality. As part of the Agreement, the funding partners were obligated to provide copies of their data to be used for injury research purposes by the Centre and to allow their data to be stored in the Centre's data repository. A new funding agreement was signed in May 2003. The issue of confidentiality was covered in clause 21, page 16 of the new Agreement and reads:

The Centre acknowledges that during the course of providing the Services to the partners it may become acquainted with or have access to information owned by a partner which the partner wishes to keep confidential and the Centre agrees to maintain the confidence

2.0 DEFINITIONS

Authorised Research Scientist- Staff or Student of the Centre authorised to *collect and/or analyse* Personal Information for research purposes of the Centre and who has been trained to *collect and/or analyse* Personal Information in an ethical manner

Authorised User- user granted permission by the Centre to access *existing* Data, usually only IRMRC Authorised Research Scientist

Centre- NSW Injury Risk Management Research Centre

Code of Conduct- document detailing measures designed to protect the confidential nature of Personal Information and Data obtained or held by the Centre and which all IRMRC staff and students are required to sign and abide by

Confidentiality Agreement- document detailing measures designed to protect the confidential nature of information obtained from the Centre which all collaborators and Third Party users of the IRMRC data resources are required to sign and abide by (yet to be developed)

Consent- permission obtained from an Individual to collect Personal Information about them

Data- unit record data currently held by the Centre

Individual- any person who is contacted for the purposes of obtaining Personal Information for a research project conducted by the Centre

Partner- one of the four centre core funders - NSW Health, the Roads and Traffic Authority (RTA), the Motor Accidents Authority (MAA) and the University of New South Wales (UNSW)

Personal information- any information or an opinion about a person whose identity is apparent (unique identifying information) or can reasonably be ascertained from the information or opinion (potentially identifiable information). Unique identifying information include items such as name and address, photographs, biometric information including fingerprints and genetic characteristics, will always be Personal Information.

Potentially identifiable information includes a range of other information that can also become personal information, if it is viewed in combination with other information, which together are sufficient to allow a person's identity to be 'reasonably ascertained'. Items/characteristics which may fall into this category include age, date of birth, ethnicity and diagnosis. The potential for these types of general information to become identifying is higher when dealing with a small population, or dealing with unusual or rare clinical conditions.

Secure Environment- secure data server and storage cabinet maintained in a locked office in the Centre that can only be accessed by Authorised Users

Staff- person directly employed by, or working at, the Centre

Student- person undertaking a research project at the Centre for educational purposes, under the supervision of senior Centre staff

4.3 *Access*

5.2 Reports

1. In cases where Personal Information is collected and analysed for research purposes of the Centre, the information will be reported in a manner that prevents the identification of any subject.
2. In cases where existing Data is analysed, the information will be reported in a manner that prevents the identification of any individual. The manner of reporting will be the following. In general, data will not be released where there are five or fewer cases per cell in a data table or figure (i.e. the 5 cell rule). This is based on the premise that, due to the small numbers involved, it may be possible to identify the identity of one or more of the reported cases, and/or the statistical significance may be affected. As this general rule may not protect the identity of individuals in all cases, a judgement needs to be made in all cases on the adequacy of this rule to ensure individual privacy and confidentiality. Alternative approaches should be used where there is any doubt, including:
 - making the data cover a wider field (e.g. aggregating data across a number of council areas such as on a regional basis); or
 - providing only an overview of data rather than specific details.

6.0 LINKAGE OF ADMINISTRATIVE DATASETS

The Privacy Commissioner has taken the view that use of Personal Information is necessary for research for the purposes of prevention of, or amelioration of the effects of, injury then it is clearly in the public interest to promote such research. However, it is also recognised that the use of identified data also has the effect of enhancing the data collected, particularly when it can be linked to other sources. Enhanced data is more valuable and hence there is a greater risk of the information being used outside the bounds of the original research project.

In the case of linkage of administrative datasets, Personal Information is used to identify data subjects in at least two sets of data, each of which contains personal identifiable information. The two sets of data are cross-matched and, where it can be ascertained that the two data sets relate to the same individual, an enhanced data set can be formed. Once the enhanced data set is formed, it is de-identified for the purpose of further use and distribution as part of a research project. The University is judged to be a suitable agency for conducting such a cross matching exercise and holding the resulting data sets, as its sole interest is for research.

Other agencies may have potentially wider interests in the information and there is an associated risk that the information will be used for other purposes. Any such data linkage needs to conform to the current directives of the NSW Privacy Commissioner.

The current (2003) directives are summarised as follows:

- 6.1 The Centre should, wherever possible, be responsible for producing and retaining the 'enhanced' data as it has no further interest in the enhanced data, other than for addressing the *a priori* stated research purpose/s. Other Partners who provided the data potentially have a greater use for the data, if it can enhance their own data collections.
- 6.2 The proposed research must be an approved research project where a research ethics committee has specifically approved the collection from a third party. This would then allow:
 - the principle that collection of Personal Information be directly from the individual or guardian to be modified to allow collection from third parties or other agencies participating in the research proposal, so long as the research ethics committee has specifically approved the collection from the third party
 - the principle that use must be directly related to the purpose for which it was collected to be modified to allow for use for approved research project purposes

- disclosure of non-sensitive Personal Information may be made to:
 - an agency or agencies identified in an approved research project (defined at Part 2 of the Draft Code) or to a supervisor or assessor of that project; and
 - an entity which can assist in the research but which was not named specifically in the research

- 6.4 Contracts and protocols for linkage research projects will bind parties so that use and disclosure outside the terms of the research project can only be made:
- (i) where lawfully authorised to do so under the PPIP Act; and
 - (ii) where compelled by law to do so.
- 6.5 Agreements between the University and any participant who obtains new Personal Information (including enhanced Personal Information) as a result of the research should include specific clauses with respect to the need to ensure that Personal Information is only used and disclosed for purposes outlined in the research proposal. This would entail inclusion of the following clauses:
- no uses can be made outside the terms of the ter