

# A review of Australian health privacy regulation regarding the use and disclosure of identified data to conduct data linkage

## Abstract

**Objective:** To review Australian legislation about privacy, focusing on provisions within the regulations to conduct health research using identified data and lobby for regulatory change in the ACT.

**Method:** A systematic review of Commonwealth and jurisdiction health privacy regulation.

**Results:** Australia has a number of regulations for the protection of privacy of health information. In addition to Commonwealth privacy laws, there are jurisdictional regulations concerning protection of health information. These range from no specific legislation in Western Australia, to a code of practice in South Australia, and Commonwealth legislation that deals with use and disclosure of identified health information to conduct health research (Sections 95 and 95A of the Privacy Act 1988). At the time of this review, all but one jurisdiction, the Australian Capital Territory (ACT), had provisions for disclosing identified health information for health research.

**Conclusion:** The ACT's Health Records (Privacy and Access) Act was inconsistent with the other Australian regulation concerning the use of identified health data in health research.

**Implications:** The information from the review was used to inform the ACT Government that the health privacy regulations in place were inconsistent with the rest of Australia and resulted in regulatory change in the ACT. ACT legislation was amended to include provisions for the disclosure of identified health information for health research under controlled circumstances. The amendments were passed in December 2005, facilitating future health research involving data linkage in the ACT.

**Keywords:** Medical Records Linkage, Privacy, Indigenous identifier, Indigenous health.

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At the beginning of 2005 an attempt was made to assess the level of under identification of Indigenous status in the Australian Capital Territory's (ACT's) public hospital system by linking data from Winnunga Nimmityjah Aboriginal Health Service (the ACT's Aboriginal Community Controlled Health Service) with data held by ACT Health. As part of this investigation an extensive literature review related to data linkage and Commonwealth and State and Territory Privacy legislation was performed to understand how the process could be facilitated. Several meetings with senior public servants at ACT Health occurred in light of the reviews findings, resulting in a review of the ACT Health Records (Privacy and Access) Act.

## Use of data linkage in health research projects

In Australia, identified health information has been used in the past, particularly

in Western Australia (WA), to explore issues such as determining whether health assessment improves health outcomes,<sup>1</sup> risk factors for recurrence of ischemic stroke after hospitalisation,<sup>2</sup> levels of gastroenteritis amongst infants,<sup>3</sup> prevalence of intellectual disability,<sup>4</sup> and measuring incidence and prevalence of chronic disease such as end stage renal failure and diabetes rates.<sup>5-6</sup> This research was done using linked data. Record linkage is simply the integration of information from two independent sources. Records from the two sources that are believed to relate to the same individual are matched in such a way that they may then be treated as a single record for that individual. Records brought together in this way are said to be linked.<sup>7</sup> A number of States and the Australian Institute of Health (AIHW) and Welfare have worked on developing privacy-protecting linkage protocols and the AIHW.<sup>8</sup>

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## The process of undertaking data linkage in health research

The AIHW published the *Statistical Data Linkage in Community Services Data Collections* in 2004 as a guide to developing and implementing processes and mechanisms for the linkage of data. This report was particularly concerned with links between the community services sector who often have their own discrete electronic information systems for collecting and storing client information.<sup>9</sup> The AIHW publication is a good guide for a linkage research project because it spells out a step-by-step process and ensures involvement with stakeholders. It also addresses the privacy and ethical concerns of data linkage projects.

## Methods

A systematic review of nine pieces of Commonwealth and jurisdiction health privacy regulation was undertaken, in Canberra during January-July 2005, to identify provisions for use and disclosure of identified data for health research. Information was accessed through the Office of the Federal Privacy Commissioner (OFPC). The OFPC website has links to each jurisdiction and the Commonwealth health privacy regulations.<sup>10</sup> An analysis of the similarities and differences in health privacy regulation was conducted. Specifically, sections of the regulations where health research using data linkage may be permissible were examined.

## Results

In Australia, there is a number of regulations for the protection of privacy of health information.<sup>11</sup> In addition to Commonwealth privacy laws, the States and Territories have their own regulations concerning protection of health information.<sup>10</sup>

## Review of Legislation

### Section 95 of the Commonwealth Privacy Act's Guidelines

Section 95 of the Commonwealth Privacy Act applies to 'medical research' only, including epidemiology or epidemiological studies.<sup>12</sup> Human Research Ethics Committees (HRECs) may approve research that involves the use or disclosure of personal information held by Commonwealth agencies without the consent of individuals to whom the information refers. However, before such research is approved the HREC must consider whether the public interest in the research outweighs, to a substantial degree, that of the privacy of individuals.<sup>13-14</sup>

### Section 95A of the Commonwealth Privacy Act's Guidelines

Section B of the section 95A guidelines relates to the collection, use and disclosure, without consent of the individuals to whom the information refers, of health information held by private sector organisations, for the compilation or analysis of statistics, relevant to public health or public safety.<sup>14-15</sup> This means that researchers can use section 95A guidelines to collect, use or disclose health information without the consent of individuals to whom the information refers, if it is deemed relevant to public health or safety by a HREC.

### State and Territory legislation and regulations

There is also regulation at State and Territory level that may have a bearing on whether personal information can be used in health research and the way in which proposed research must be conducted. The regulation may be in the form of legislation related to privacy generally, administration of government and private agencies or in administrative codes of practice. Some jurisdictions have stricter limitations on the handling of personal information as part of the administrative structure of health departments and agencies. Legislation, standards and codes that impact on health research and that applied across the jurisdictions at the time of the review are shown in Table 1.

**Table 1: Australian Privacy Legislation and Development (November 2005).**

Jurisdiction	Legislation title	Basis	Health research provisions	Year enacted
Commonwealth	Privacy Act	Information Privacy Principles & National Privacy Principles	Yes	1988
ACT	Health Records (Privacy and Access) Act	Information Privacy Principles	No <sup>a</sup>	1998
New South Wales	Health Records and Information Privacy Act	Health Privacy Principles	Yes	2004
Northern Territory	Information Act	Information Privacy Principles	Yes	2002
Queensland	Information Standard 42	Information Privacy Principles	Yes	2001
South Australia	Code of Fair Information Practice	Information Privacy Principles	Yes	2004
Tasmania	Personal Information and Protection Act	Information Privacy Principles	Yes	2005
Victoria	Victorian Health Records Act	National Privacy Principles	Yes	2002
Western Australia	No Law – Discussion paper released 2001	N/A	Yes	N/A

Notes:

Source: 10-11

(a) Changes to the ACT Legislation were passed by the Legislative Assembly in December 2005 creating a provision for health research.

*Similarities and differences amongst health privacy regulation*

At the time of our review most jurisdictions had similar provisions for disclosure and use of health information for health research (Table 2). The provisions were made up of three broad criteria. Identified data may be released if:

- They are to be used for the compilation of statistics or production of health research and that the statistics/health research is in the public interest; and
- It is impractical to seek consent from the person who the health information concerns; and
- That the recipient of the health information does not disclose the health or personal information derived from that information in an identifiable form.

Identified data may be used or disclosed, if the above conditions are met, and the research is approved by an HREC approved by the National Health and Medical Research Council.

**Discussion**

Our 2005 research revealed that across Australia there were some similarities in health privacy legislation where identified data may be used in health research. There were also some differences in regulations which were highlighted by those between the ACT and WA. At the time of the review the ACT had legislation covering health information privacy but no provisions to use or disclose health information for health research.<sup>16</sup> This was in contrast to WA where there was no regulation covering use and disclosure of health information.<sup>10-11</sup> This may explain why data linkage has been used there for a number of years in a variety of research areas.<sup>1-6</sup>

The ACT Government determined that further provisions were required relating generally to health research. The ACT legislation was amended and is now along similar lines to that of the NSW Health Records and Information Act 2002. This states that *health information may be used or disclosed for health research, or the compilation or analysis of statistics, in the public interest and either:*

- A) that purpose cannot be served by the use of information that does not identify the individual or from which the individual's identity cannot reasonably be ascertained and it is impracticable for the organisation to seek the consent of the individual for the use, or
- B) reasonable steps are taken to de-identify the information, and
- (ii) if the information could reasonably be expected to identify individuals, the information is not published in a generally available publication, and
- (iii) the use of the information is in accordance with guidelines, if any, issued by the Privacy Commissioner for the purposes of this paragraph.<sup>17</sup>

A decision was also made to include amendments which would allow controlled research using identified data.

The amendments to the ACT Health Records (Privacy and Access) Act were tabled in the Legislative Assembly in September 2005 and passed on 13 December 2005.<sup>23</sup> The amendment to Principle 10 to allow for the disclosure of identifiable data for research purposes in controlled circumstances is consistent with the model provisions in the National Health Privacy Code as well as with current best practice.

**Table 2: Provisions in health privacy regulation where identified health data may be released for health research, by Jurisdiction (November 2005).**

Jurisdiction	Section/part of regulation	May be released for the compilation of statistics in the public interest	May be released if impractical to seek consent	May be released if de-identified or when published does not identify individuals
Commonwealth <sup>12,15</sup>	Section 95, 95A	✓	✓	✓
ACT <sup>16</sup>	Not permissible	☒ <sup>a</sup>	☒ <sup>a</sup>	☒ <sup>a</sup>
New South Wales <sup>17</sup>	Schedule 1, under Health Privacy Principles 10	✓	✓	✓
Northern Territory <sup>18</sup>	Part 5 – Protection of Privacy No. 71 under Information Privacy Principles 2	✓	☒	✓
Queensland <sup>19</sup>	Information standard 42A under National Privacy Principles	✓	✓	✓
South Australia <sup>20</sup>	Use and disclosure of health information for research purposes 2.1 (d)	✓	✓	✓
Tasmania <sup>21</sup>	Schedule 1, Personal Information Protection Principles (2) use and disclosure	✓	✓	✓
Victoria <sup>22</sup>	Principle 2 Use and disclosure	✓	✓	✓
Western Australia <sup>10-11</sup>	No regulation	✓	✓	✓

*Note:*  
 (a) Changes to the ACT Legislation were passed by the Legislative Assembly in December 2005 where identified health data may be released for the purpose of health research.

## Conclusion

There are considerable benefits of using identified health information in health research involving data linkage; however the benefits must be achieved while maintaining and respecting privacy and ethical concerns. If the currently accepted protocols are followed there are minimal privacy issues. While most Australian jurisdictions have rules governing use and disclosure of health information, there are inconsistencies that can impact on research where identified data are required. Once these inconsistencies are identified, however, it is positive to see movement forward to rectify them in the form of regulatory change. The amendment to the Health Records (Privacy and Access) Act introduced in the ACT in 2005 will be of benefit to future research projects where identified data are required, and which otherwise accord with ethical requirements.

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