



## Australian Government

### Australian Law Reform Commission

**Professor Rosalind Croucher AM**  
**President**

Mr Stephen Finnimore  
Research Director  
Legal Affairs and Community Safety Committee  
Parliament House  
George Street  
BRISBANE QLD 4000

22 July 2016

Dear Mr Finnimore,

#### **Submission to inquiry into Health and Other Information Legislation Amendment Bill 2016**

The Australian Law Reform Commission (ALRC) welcomes the opportunity to make a submission to the inquiry being conducted by the Legal Affairs and Community Safety Committee's inquiry into the Health and Other Legislation Amendment Bill 2016.

The bill proposes to amend the *Hospital and Health Boards Act 2011* (Qld) to allow the disclosure of confidential information following consent by a substitute decision maker in circumstances where the person has impaired capacity for consenting to participate in the research. A designated person may disclose confidential information in such circumstances if the chief executive of the Department of Health or Hospital and Health service gives written approval for the research. Two ALRC reports about privacy, and decision making by representatives may therefore be of particular interest to your inquiry: *For Your Information: Australian Privacy Law and Practice*, Report 108 (2008) and *Equality, Capacity and Disability in Commonwealth Laws*, Report 124 (2014).

In the 2008 report, the ALRC relevantly stated that where a third party is appointed under an enduring power of attorney, or guardian by a tribunal or board, to the extent that the instrument authorises the representative to make decisions related to personal information, agencies and organisations should allow the person to act as the substitute decision maker for the person.

The ALRC also recommended that the research exceptions should extend to allow the disclosure of confidential information where it is unreasonable to seek consent (Recommendation 65-5). For this to apply, other safeguards relating to research exceptions must be met, including in relation to whether the public interest in the research outweighs the public interest in maintaining the level of privacy protection maintained in the *Privacy Act 1988* (Cth). The National Privacy Principles in place at the time of writing of the report allowed for the use and disclosure of health information for research without consent where it was *impracticable* to seek an individual's consent prior to use or disclosure. In making the recommendation, the ALRC acknowledged that the reference to 'impracticable' denotes an emphasis on the means of obtaining consent, rather than the impact of obtaining consent. The National Health and Medical Research Council noted in its submission to the ALRC inquiry that requiring specific consent for the disclosure of information for a particular study may be quite unnecessary and inefficient in circumstances where the person has given

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consent in general terms for use of their health information in future similar research study. This is similar to the stated rationale for the bill for consideration before the committee that requiring an additional application for approval to obtain a person's confidential information is an unnecessary burden in circumstances where the research has ethics approval, the project has been authorised by the relevant chief executive and a substitute decision maker has provided consent where the person has impaired decision making in relation to the giving of consent to the disclosure of their information

In the 2014 report, the ALRC considered consent for medical treatment and recommended that legislation relating to informed consent to medical treatment be consistent with the National Decision-Making Principles and the Commonwealth decision-making model. The model acknowledges that a representative may obtain and disclose personal or other information on behalf of the person (Recommendation 4-7).

Under the National Decision Making Principles (Recommendation 3-3), such a decision must:

- give effect to the person's will and preferences; or
- if the person's current will and preferences cannot be determined, the representative must give effect to what the person would likely want; or
- if it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's human rights and act in a way least restrictive of those rights.

We trust this submission is of assistance. If you require any further information, please do not hesitate to contact the ALRC.

Yours sincerely,



**Professor Rosalind Croucher AM**