



Office of the Victorian Privacy Commissioner

May 2011

**SUBMISSION TO  
THE VICTORIAN LAW REFORM COMMISSION  
IN RESPONSE TO THE  
GUARDIANSHIP CONSULTATION PAPER**

**I. Introduction**

The appointment of a substitute decision-maker, by its nature, raises privacy issues. When a substitute decision-maker is appointed, whether by an individual who has capacity to appoint a person of their choice, or by a third party on behalf of the person who does not have that capacity, the decision-maker will have access to a great deal of personal information about the person he or she represents. Under the *Information Privacy Act 2000*, a substitute decision-maker can consent to the collection, use or disclosure of an individual's personal information, the transfer of that personal information to someone outside of Victoria and can exercise access and correction rights to the individual's personal information.<sup>1</sup>

The right to privacy is a fundamental human right enshrined in the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights. In addition, it is one of the express rights under the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities.

The major part of this submission is directed at the chapters of the Consultation Paper dealing with the proposed Register of Personal Appointments and Advance Directives.

**II. New General Principles [5.101 – 5.122]**

I support the Commission's draft General Principles as they reflect the right of all adults to the same basic human rights. In particular they reflect the fact that an impaired decision-making capacity may be only temporary and that any decision made on behalf of another, should reflect that person's wishes as far as possible. This is consistent with section 64(4) of the *Information Privacy Act* which specifically requires an authorised representative not to give consent where that representative knows or believes the consent does not accord with the wishes of the individual before that person became incapacitated.

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<sup>1</sup> Section 64 *Information Privacy Act 2000*

### III. Collection of Data [6.99 – 6.104]

It is proposed that data be collected and made available about the operation of guardianship laws, to assist in undertaking evidence-based law reform and to test the success of reforms when they are implemented.<sup>2</sup>

The Commission has noted that the proposed register of personal appointments and advance directives could be a valuable tool for gathering such information.<sup>3</sup> While I recognise the public interest in collecting such data, any use or publication of such information should occur in a de-identified or statistical form only, in accordance with the existing provisions of the Victorian *Information Privacy Act*,<sup>4</sup> which allows for use and disclosure of personal information except for publication in an identifiable form where the information is for research or statistical analysis in the public interest and it is impracticable to obtain the individual's consent and a third party recipient of the information will not disclose it further.

### IV. Register of Personal Appointments and Advance Directives [8.140 – 8.144, 9.100 – 9.101]

A Register of Personal Appointments and Advanced Directives raises a number of privacy considerations. However, such a register can also be privacy enhancing, since it will provide organisations with confirmation that a substitute decision-maker is validly appointed and can properly be given information about the individual they are representing.

Nevertheless, it is important that the privacy issues relating to any registration system are properly considered and the system is properly designed and administered in order to ensure the protection of the personal information collected and contained on the register, especially if, as recommended, registration is mandatory. Safeguards need to be built in to any legislation that establishes the register.

#### a. Privacy laws and public registers

Section 16(4) of the *Information Privacy Act* (IPA) provides that a public register must be administered consistently with the Information Privacy Principles set out in the IPA, so far as reasonably practicable.

Privacy laws do not apply to individuals who are acting in a private capacity, and therefore privacy laws, including the IPA, will not place obligations on individuals who have access to information contained in a public register. In addition, the *Privacy Act 1988 (Cth)* only applies to private sector organisations with an annual turnover of three million dollars or more. Therefore many private sector organisations are not subject to any privacy regulation.

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<sup>2</sup> Victorian Law Reform Commission, Guardianship Summary Paper, p20

<sup>3</sup> Victorian Law Reform Commission, Guardianship Consultation Paper, para 6.100.

<sup>4</sup> Information Privacy Principle 2.1(c) Schedule 1 *Information Privacy Act 2000 (Vic)*

**b. Why is the register being created?**

The Commission has indicated that it is proposing that the register be created to establish whether personal appointments exist or are current.<sup>5</sup>

It is noted that the Victorian Parliament Law Reform Committee recommended the creation of a register,<sup>6</sup> that registration be mandatory for all documents creating and revoking enduring powers of attorney (financial) and enduring powers of attorney (guardianship),<sup>7</sup> that registration be required at the time the documents are created,<sup>8</sup> and that any act performed under a document which had not been registered would have no legal effect.<sup>9</sup>

It was also recommended by the Victorian Parliament Law Reform Committee that documents creating and revoking general (non-enduring) powers of attorney be able to be registered.<sup>10</sup>

**c. Creating an online register**

The Commission has recommended that an online registration system would be more effective than a paper-based register, as it would be more readily searchable, and provides 24 hour access.<sup>11</sup>

The Commission has also recognised that an online system would require safeguards to ensure an individual's privacy is protected while allowing appropriate people to access the information.<sup>12</sup>

While there are great benefits in enabling ready access to registers, once information is available online, without restriction, it is capable of being collected, incorporated with other publicly available information, and misused by people with no legitimate interest in or use for the information, including for criminal activity such as identity fraud and identity theft.

As noted above, individuals who have access to any information contained in a register may not have any privacy obligations in relation to how they use or disclose the information they obtain.

A balance needs to be struck between the public interest in the free flow of information - in this case the ability to access information to verify the validity or existence of a power of attorney document - and the public interest in protecting individuals' privacy as recognised by the Commission.<sup>13</sup>

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<sup>5</sup> Victorian Law Reform Commission, Guardianship Summary Paper, p 24.

<sup>6</sup> Law Reform Committee, Parliament of Victoria, *Inquiry into Powers of Attorney (2010)* Recommendation 66.

<sup>7</sup> Ibid, Recommendation 67.

<sup>8</sup> Ibid, Recommendation 69.

<sup>9</sup> Ibid, Recommendation 70. Note that it was also recommended that VCAT have the ability to extend the time for registration of a document if VCAT believed the document was valid.

<sup>10</sup> Ibid, Recommendation 68.

<sup>11</sup> Victorian Law Reform Commission, Guardianship Consultation Paper, para 8.142.

<sup>12</sup> Ibid.

<sup>13</sup> Privacy Victoria has published guidance on the creation of public registers addressing privacy issues, especially in the context of an online register – see Public Registers and Privacy – guidance for the Victorian Public Sector Office of the Victorian Privacy Commissioner August 2004

d. **Who should have access to a register?**

It is my view that there should be a 'layered approach' to access to information contained on the register.

*No open access*

I do not believe that there is need or public interest benefit in allowing the general public to have open (unrestricted) access to the register.

If registration was mandatory and the public had open access to information contained in the register, donors with concerns about the disclosure of their personal information may be discouraged from making a personal appointment. Additionally, appointees whose information would be contained in the register may be similarly discouraged from agreeing to accept an appointment. Discouraging people from making advance arrangements for their affairs to be managed by a trusted person in the event of incapacity would not be in the public interest.

*Establishing a valid reason to access*

I consider that there should be a requirement that, in order to access information on the register, an individual or organisation must be able to establish that it is necessary - that the individual or organisation has a valid reason for obtaining access to that information.

*A layered approach to access to information*

Where an individual or organisation is able to establish it is necessary to obtain access to information contained in the register that individual or organisation should only have access to the minimum amount of information which is required for that purpose or reason.

For example the register could operate, as a minimum, as a type of 'document verification system'. When an individual or organisation needs to check whether a power of attorney document exists and is current, they provide basic information about the document presented and the system responds by verifying with a 'yes' or 'no' whether the document exists and is current.

When this type of verification is available, for example, it may not be necessary for an organisation (for example, a bank or other financial institution) to have access to additional personal information which might be contained in the register, such as the donor's date of birth or address, or whether the donor has made an appointment in relation to his or her medical treatment, and any directions or restrictions in relation to that appointment.

However, and as an example of another 'layer', it may be appropriate for a hospital or other health service provider to be able to verify the nature of an appointment, for example, whether an enduring power of attorney (medical treatment), has been made by an individual, who has been appointed to this role, and whether there are any specific directions or restrictions on any such appointment. This will be particularly relevant if the scope of instructional directives is extended to encompass wishes about medical decision making.

The level of access to information contained in the register and provided to other individuals or organisations should be aligned with their need to access the information.

**e. Data security**

The amount of information to be included in the register and accessed should be given thorough consideration. The register should only contain the minimum amount of information necessary to achieve its purpose.

However, it may be necessary for the entire register to contain detailed information such as full names, dates of birth and addresses of donors and substituted decision-makers as well as types of appointments and details of directions or restrictions in relation to appointments.

Given the amount of information which the register will potentially contain, adequate security mechanisms will need to be put in place to assist in protecting that information from misuse or unauthorised access, modification or disclosure.<sup>14</sup>

If appropriately implemented, the concept of 'layered access' referred to above will work to provide a level of data security. While the entire register may contain extensive amounts of information, individuals or organisations will only have access to a minimal level of information required for their particular purposes.

If the register includes health information, the obligations contained in the *Health Records Act 2001 (Vic)* also need to be considered.

**f. Data quality**

Consideration also needs to be given to mechanisms to ensure that the personal information which is collected as part of the register, and subsequently disclosed to and used by others, is accurate, complete and up to date.<sup>15</sup>

The legislation should, for example, require that documents appointing or revoking personal appointments are registered within a certain period after their creation.

In addition it will be important to ensure that the information contained on the register is kept up to date. Simply expecting individuals to do this may not be effective. Automatic reminders could be sent to individuals whose information is contained in the register, prompting them to update information (for example, an annual reminder), with provision for an entry to be removed after a period of time if the entry is not renewed.

**g. Notice**

It is important to ensure that appropriate notice is given to both individuals and substituted decision-makers about the purpose for which information about them is being collected to be included in the register, their ability to access and update that information, to whom and in what circumstances that information will be disclosed to other individuals and/or organisations, and the consequences of not providing the information. These are all matters provided for under current privacy legislation. However, it may be preferable for these obligations to be incorporated into the legislation creating the register.

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<sup>14</sup> See *Information Privacy Act 2000 (Vic)* Sch 1 – Information Privacy Principle 4 – Data Security

<sup>15</sup> See *Information Privacy Act 2000 (Vic)* Sch 1 – Information Privacy Principle 3 – Data Quality

#### **h. Penalties for misuse**

Given the detailed nature of the information contained in the register, and the potential implications if that information is inappropriately accessed or disclosed, it is my view that any amendments to the law should set out strict rules to regulate the circumstances in which access will be provided, and what can be done with the information which is obtained from the register.

There should be incorporated into the law specific penalties for inappropriate access to information from the register, or for misuse of information obtained from the register. This is particularly important where individuals or small businesses obtain information from the register. As previously stated, individuals or small businesses are not currently subject to any privacy laws to regulate that person's or organisation's use or disclosure of the information (See above (IV)(a)).

### **V. Confidentiality [Chapter 18]**

The Commission has rightly pointed out that there is a difference between confidential and personal information that is private. Confidential information may include non-personal information. Not all personal information remains private and the *Information Privacy Act* permits use and disclosure of personal information by organisations in a number of instances, including consent of individuals or their substitute decision-maker.

As noted above, a substitute decision-maker may not be subject to any privacy legislation, yet they will have authority to access very private information about an individual they are representing. I support the proposal of the Commission that all substitute decision-makers have access to confidential and private information about the represented person only on a need to know basis and that disclosure of such information should only occur if reasonably necessary to provide the information to a third person in order to perform the functions of a substitute decision-maker, or required or permitted by law.

The Commission has proposed under the new accountable mechanisms for substitute decision-makers [19.41 – 19.54] that several penalties could be introduced for all substitute decision-makers who misuse or abuse their powers. Since the decision-makers may not be subject to privacy laws (as noted above), such penalties could include misuse of the personal information of the individual.

I note that some submissions made to the Commission suggested that sometimes guardians and administrators experience difficulties gaining access to information about the person they are representing,<sup>16</sup> and further that some guardians and administrators misuse privacy laws to deny family members access to information.<sup>17</sup>

As stated previously and noted by the Commission in the Consultation Paper,<sup>18</sup> the *Information Privacy Act 2000 (Vic)*<sup>19</sup> gives a guardian or administrator the same rights to access and correct information as the person they are representing. The attorney or guardian also has the same ability to consent to, and therefore to also refuse, disclosure of information to certain persons as provided for in Information Privacy Principle 2.1(c).

Therefore, it should not be the case that a guardian or administrator is denied access to information about the person they are representing "because of privacy". Such a result is due to a misunderstanding of privacy laws.

<sup>16</sup> Victorian Law Reform Commission, Guardianship Consultation Paper, at para 18.21.

<sup>17</sup> Ibid, para 18.23.

<sup>18</sup> Ibid, para 18.14.

<sup>19</sup> *Information Privacy Act 2000 (Vic)* s 64.

Additionally, where a guardian or attorney denies family members access to information, this is because the attorney 'stands in the shoes' of the represented person and is therefore able to restrict access to information on that basis, rather than because of a "misuse" of privacy laws.

## **VI. Conclusion**

Whilst the creation of a Register of Appointments and Advanced Directives is an admirable proposal, there are important privacy impacts which need to be specifically addressed in the legislation which creates the Register.

It is vitally important that members of the public, guardians, administrators and appointees, and individuals and businesses that are using and accessing the Register are confident that the Register is both useful and functional but also secure, with appropriate privacy protections established.

Considering such matters at an early stage allows the Register to have privacy protections 'built in' to its development, rather than attempting to 'retro-fit' privacy protections at a later stage.

The privacy considerations involved in creating this Register are significant but not insurmountable if appropriate time, thought and consideration to privacy issues occurs.

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