Submission to the Victorian Parliament’s Scrutiny of Acts and Regulations Committee in relation to the –

Assisted Reproductive Treatment Bill 2008

November 2008
SUBMISSION TO THE VICTORIAN PARLIAMENT’S
SCRUTINY OF ACTS AND REGULATIONS
COMMITTEE

in relation to

THE ASSISTED REPRODUCTIVE TREATMENT BILL 2008

The Committee’s attention is drawn to the Assisted Reproductive Treatment Bill (‘the Bill’).

Certain clauses relating to the collection, use and disclosure of information under the
Bill may fall outside the scope of the Information Privacy Act 2000 (Vic) (‘IPA’). For
example, assisted reproductive treatment (ART) providers that are not Victorian
public sector organisations or contracted service providers (within the meaning of
section 9 of the IPA) are not subject to the Victorian Information Privacy Principles
(‘IPPs’). However, any clauses relating to information management by the Registry
of Births Deaths and Marriages (‘BDM’), the Department of Human Services (‘DHS’)
and Victoria Police are subject to the jurisdiction of the IPA. While it is not the
intention of the IPA to restrict appropriate release of personal information, an overly
invasive ability to require the provision of personal information from an individual or
an ill defined ability to share data between organisations may interfere with an
individual’s right to privacy unless appropriate checks and balances are in place.

The proposed legislation unduly requires or authorises acts or practices that may
have an adverse effect on personal privacy within the meaning of the Information
Privacy Act 2000 (Vic) - section 17(a)(iv), Parliamentary Committees Act 2003 (Vic)
(‘PCA’); &

Is incompatible with the human rights set out in the Charter of Human Rights and
Responsibilities (‘the Charter’) – s17(a)(viii) PCA.

I. Consent requirements for treatment procedures

1. For woman to receive treatment, cl. 11(1)(c) of the Bill requires that the consent
provided by her and her partner (if any) to receipt of that treatment must include a
statement by the counsellor (who has provided the woman and her partner with
mandated ART counselling under cl. 13) confirming that the counsellor has
sighted a criminal records check in relation to the woman and her partner. Clause
11(1)(d) also requires the consent to include permission from the woman and her
partner (if any) for a child protection order check to be conducted in relation to them.

2. Under cl. 11(2), the persons from whom consents are obtained must cause the consents to be given to their ART provider, or to the doctor in charge of their treatment. When permission is granted, the Secretary of the Department of Human Services must then provide the ART provider with details of any custody to the Secretary orders, third party orders or any guardianship to the Secretary orders in relation to the applicants.

3. If the criminal records check reveals that either that the applicant has charges proven for an offence under clauses 1 or 2 of Schedule 1 of the Sentencing Act 1991, or that the child protection order check reveals an order has been made removing a child from custody or guardianship of the applicant, then a presumption against providing the woman with an ART procedure applies (: cl. 14). A person may then apply to the Patient Review Panel to review this presumption under cl.15.

4. The above consent provisions (which apply in a similar manner to surrogacy arrangements under cl. 42) may have a number of adverse effects on privacy under the IPA and may be considered arbitrary under the Charter. These include –

   a. The definition of ‘criminal records check’ in cl. 3 of the Bill effectively requires an applicant to allow Victoria Police to prepare a statement that releases large amounts of their sensitive criminal history information. This includes general convictions recorded against the person, any findings of guilt with or without conviction, and any outstanding charges. Such a release – mandated under the Bill in order to obtain assisted reproductive treatment – goes far beyond the type of information required to assess whether the applicant has any charges for an offence under clauses 1 and 2 of Schedule 1 of the Sentencing Act 1991 which would result in a presumption against treatment.

   b. Information Privacy Principle 1.1 (Collection) requires that personal information only be collected where it is necessary for one or more of an organisation’s functions or activities. The Bill’s requirement for an individual to effectively consent to Victoria Police releasing sensitive information that goes beyond what is necessary under the Bill to assess eligibility for treatment, creates doubt about whether the individual’s consent is voluntary, as is required under IPP 2.1(b) (Use and Disclosure). Further, the validity of the consent is also undermined due to its lack of specificity, as (b)(iv) of the definition allows a police member to include ‘any other matter the member considers relevant’ on the statement, making it impossible for an individual to know what information they are consenting to release. This gives Victoria Police unfettered discretion to release criminal record details, creating not only an unnecessary emotional burden on an applicant, but an unnecessary and ill-defined administrative burden on Victoria Police.

   c. The manner in which criminal records and child protection order checks are collected and assessed under the Bill is also a matter of concern. It is not clear, for example, why the criminal records check must be produced to a counsellor, while the child protection check must instead be released by DHS to an ART provider.
d. If it is intended that ART counsellors harvest information from an applicant in relation to the criminal check in order to assess whether any listed offences result in a presumption against treatment, there is an obvious question about the appropriateness of a counsellor – in light of their professional obligations – using counselling sessions to glean such information from a patient and conduct such an assessment. It is also not clear from the Bill what details about the criminal records check – if any – are then required to be given to the ART provider. On its current drafting, and in light of the broad definition of a ‘criminal records check’ the Bill may result in a lot of sensitive and delicate personal information released by Victorian Government flowing without certainty or necessity between an applicant for treatment, ART providers and counsellors.

e. It is important to note that the Victoria Law Reform Commission (VLRC) expressed concern about the use of police records checks in its *Assisted Reproductive Treatment: Final Report*, stating:

   ‘A police check would be overly invasive as it might reveal convictions that are irrelevant to the health and wellbeing of children...’

The VLRC also raised concerns about the use of counselling sessions to question patients about their criminal background.

f. While there is a need to identify applicants who pose an unacceptable risk to the health, wellbeing and best interests of a child, the Bill on its current drafting, does not strike an appropriate balance between these interests and the interests of privacy.

g. In light of the above, any checks done should be limited and strict controls on the flow of sensitive and delicate information should be put in place. It is preferable, for example, that one specialist body be in receipt of and assess any checks in relation to applicants; and that applicants have the ability to explain the results of checks in the first instance, rather than on review of a refusal to grant treatment.

**II. Information and advice**

5. Clause 19 requires ART providers to provide donors with written advice about: the rights of people born as a result of donor treatment procedure and the parents of those persons and others to access information under Division 3, Part 6; the nature of information about the donor that is recorded on the Central Register; the donor’s rights to obtain information under Divisions 2& 3 of Part 6; and the existence and function of the Voluntary Register.

6. Clause 25 mirrors the notice provisions in cl. 19 but provides that similar notices must be given to both women undergoing donor treatment and their partner, if any.

   a. Clauses 19 and 25 promote transparency in information handling by requiring donors, women undergoing treatment and their partners, to all be informed of the manner in which their personal information may be accessed once on the Central Register maintained by BDM, and their own rights to access such information. However, it is also desirable that these individuals be informed of their right to correction on the Central Register granted under
cl. 54, which does not fall within Divisions 2 or 3 of Part 6 of the Bill. Requiring individuals to be advised of this right of correction may promote better data quality in the information held by BDM on the Central Register, in line with IPP 3 (Data Quality). It is also desirable for individuals to be notified as to what personal information of theirs will be placed on the ART Registers (under cl.49 or 50); what information may be transferred by ART provider (and doctors) under cl. 51 & 52 to BDM; and for donors, that their consents may be transferred between ART providers under cl. 23.

III. Information contained on Registers

7. Clause 49 and 50 require registered ART providers and doctors carrying out artificial insemination to keep registers that include the ‘prescribed information’ in relation to certain information about donors, parents and children born as a result of ART procedures. However, the Bill does not define ‘the prescribed information.’

   a. It is important to limit the definition of this type of information to what is necessary for each register to achieve its purpose in line with IPP 1 (Collection) and that that information is detailed within the Bill itself.

8. Clause 51 requires each registered ART provider to give the Registrar of BDM personal information about: the birth of anyone or any pregnancy that occurs as a result of a donor treatment procedure; and each donor treatment procedure carried out by the registered ART provider if the outcome of the procedure is unknown. These requirements are mirrored under cl. 52 in relation to doctors carrying out artificial insemination treatments.

   a. While these information requirements may be aimed at ensuring information about children born as a result of a treatment procedures are recorded by BDM, it is not clear from the Bill what BDM’s obligations are in regard to the use and management of this information.

   b. The collection of information about each treatment procedure – and any pregnancy that occurs as a result – irrespective of whether a birth has actually occurred or not (if this is not known) is highly privacy intrusive. The purpose of collection should be expressed and limits placed on the use and period of retention of the information.

9. Divisions 2 and 3 of Part 6 of the Bill contain clauses which allow identifying information about individuals to be accessed from ART providers and BDM where consent (e.g. cls. 55, 58, 59) for release of that information has been provided by the relevant individual.

   a. In order to ensure that such disclosures are made within the parameters of these consents (and therefore being authorised disclosures within the meaning of IPP 2.1 (Use and Disclosure)), ideally, any consents should be obtained by ART providers and BDM in writing. Consideration should be given to placing this requirement within the Bill itself.

   b. Ensuring specificity in what is and is not to be released will place less of an administrative burden on organisations obliged to maintain and administer registers.
c. To be effective, consent needs to be current. Consideration should also be given as to how such consents should be obtained in practice and whether it is appropriate to prescribe a length of time for the consent to remain valid.

10. **Clause 58(2)** allows the Registrar of BDM to disclose information about a child born as a result of a donor treatment procedure to his/her parent or donor parent where the child has indicated to the Registrar that he/she does not want identifying information about him/herself released, if the Registrar considers it reasonable to do so in the circumstances.

a. Allowing the Registrar to disclose personal information about a child born as a result of ART against their expressly stated wishes clearly raises privacy issues. Under the IPA, a child has privacy rights. In order to limit the invasiveness of this disclosure ability, consideration should be given to requiring the Registrar in making his/her decision to take into account whether the child has sufficient understanding and intelligence to understand the consequences of refusing to provide access to the relevant information. If the child is deemed to have sufficient understanding, the child’s wishes should be paramount.

IV. **General Provisions**

11. **Clause 68** exempts documents containing information about or provided by a donor, a woman receiving ART treatment (or her partner), or a person born as a result of a treatment procedure from the jurisdiction of the *Freedom of Information Act 1982*. In my view, provided that children born as a result of ART, their descendents, donors and parents receive proper access to personal information on the Registers under Part 6, there is no apparent need for other individuals to have access to the information and I support the exemption.

12. **Clause 124** of the Bill gives the Governor in Council the ability to make regulations for or with respect to:

   (g) the giving of information by registered ART providers and doctors to the Register, the Patient Review Panel and the Authority; and

   (h) the disclosure of information from the Central Registrar, Voluntary Register and other registers and records kept under the Bill.

a. It is submitted that provisions dealing with the collection, use and disclosure of personal information on registers under Part 6 of the Bill, are more appropriately articulated within the Bill itself, rather than left to a general regulation making power.

HELEN VERSEY
Privacy Commissioner