

CHAPTER 3

Establishment of a national register

3.1 This chapter examines whether the establishment of a national register to retain information about donor conception practices would address issues in relation to the current management of donor conception data. In particular, this chapter discusses:

- arguments in support of a national register;
- suggested approaches for a national register, including:
 - the role of the register;
 - what information could be captured;
 - how the register should be administered;
 - how the register would operate;
 - the need for donor conceived people to access information about their biological siblings; and
 - whether the register should be retrospective;
- opposition to the establishment of a national register; and
- the role of a voluntary register and an associated DNA database in enabling donors and donor conceived people whose records have been destroyed to locate one another and any donor siblings.

Support for the establishment of a national register

3.2 The majority of submitters and witnesses supported the establishment of a national register in place of state-based registers.¹ Support for a national register generally resulted from concerns about the current management of data in relation to donor conception. Such concerns stem from differences in legislation and regulation, and access to information for donor conceived people (and their families) across Australia, along with concerns about compliance with the NHMRC Guidelines and RTAC clinic accreditation processes.

¹ See, for example, Mr Callum Lorbach, *Submission 3*; Mr Adam Quinlivan, *Submission 12*, p. [2]; Ms Karen Boyd, *Submission 16*, p. 2; Mr Michael and Mrs Laureen Dempsey, *Submission 27*, p. [2]; *Submission 29 (name withheld)*, p. [2]; Dr Sonia Allan, *Submission 30*, p. 3; Ms Helen Kane, *Submission 32*, p. 2; Mr Damian Adams, *Submission 38*, p. [2]; Miss Lauren Burns, *Submission 40*, p. 2; *Submission 54 (name withheld)*, p. 4; *Submission 59 (name withheld)*, p. 2; *Submission 60 (name withheld)*, p. [2]; *Submission 89 (name withheld)*, p. 2; DCSG, *Submission 122*, p. 137; SMC Australia, *Submission 99*, p. 7; Mrs Leonie Hewitt, DCSG, *Committee Hansard*, 2 November 2010, p. 7; Dr Damien Riggs, *Committee Hansard*, 2 November 2010, p. 37; Ms Marianne Tome, Victorian Infertility Counsellors Group, *Committee Hansard*, 3 November 2010, pp 72-73.

Historical record-keeping practices

3.3 A number of submissions indicated that record-keeping practices in the early days of donor conception were very poor, with clinics only retaining records for a limited period.² This approach reflected the view which existed during the 1970s and 1980s that donor anonymity should be maintained. As Mr Michael Williams, a donor conceived person, informed the committee:

I contacted the doctor who practised at the clinic at which [I] was conceived...[The] junior doctor...told me that all records of my donor had been destroyed. He was very nice to me. He apologised that attitudes in the early 1980s were different and that a policy of secrecy between offspring and parents and between the medical profession and the state and offspring persisted.³

3.4 Mr Warren Hewitt of the DCSG also noted:

[t]he...people, whose records were destroyed, came about because clinics had made guarantees to donors that their identity would never be revealed and clinics became afraid that they [would] be in a position of conflict, so they destroyed the records.⁴

3.5 Ms Kimberley Springfield asserted that such attitudes reflected the view that records relating to donor conception should be treated in the same way as any other medical records.⁵ Dr Sonia Allan made a similar point:

[t]he retention of information on donors has traditionally been within the sole discretion of medical clinics and doctors performing donor conception. State and territory legislation specifies a period in which medical records must be retained but, after this period, information on donors may be destroyed. It is therefore common for donor-conceived individuals, when informed of their donor-conceived status and curious for information about their donor, to be informed by the clinics at which they were conceived that such information has been destroyed.⁶

Variations in record-keeping

3.6 While record-keeping practices have improved since the 1970s and 1980s, there is still wide variation between jurisdictions regarding record-keeping requirements. In Victoria, New South Wales and Western Australia, which have registers, clinics are required to provide information about donors, donor recipients

2 See, for example, Ms Lynette Mason, *Submission 24*, p. 2; Dr Sonia Allan, *Submission 30*, p. 12; Ms Kate Dobby, *Submission 103*, p. 3.

3 *Committee Hansard*, 3 November 2010, p. 7.

4 *Committee Hansard*, 3 November 2010, p. 5.

5 *Submission 52*, p. [1].

6 *Submission 30*, p. 6.

and children conceived through donor conception procedures to the Registrar of Births, Deaths and Marriages, or a similar body, for entry into a central register.⁷ It appears that in states and territories without registers, these births are only reported to the Australian Institute of Health and Welfare's National Perinatal Statistics Unit.

3.7 Ms Kate Dobby, a submitter who worked for four years at the Donor Registers Service in Victoria, noted the difficulties in accessing information across jurisdictions because of the variations in record-keeping practices:

[o]ne of the main difficulties that I encountered in my work was the inability to access the information (whether held by a Victorian or interstate clinic, hospital or other body holding records) that was needed in order to fulfil the management of the Registers. This was not just because there has been a history of this information being destroyed or haphazardly collected by practitioners and clinics, but was also a direct result of the lack of specific provision in legislation and regulations to enable the Regulator to have the authority to access relevant information, whether in making provisions for access to records relating to a clinic or agency which had closed, or to access records held interstate by a body outside of jurisdiction (but involving records of patients or donors relating to the requesting jurisdiction). This had implications for my ability to release information to people [to] whom the legislation granted rights of access.⁸

Record-keeping under NHMRC Guidelines

3.8 The NHMRC Guidelines apply in jurisdictions where there is no legislation specifically regulating the management of data in relation to donor conception.⁹ The NHMRC Guidelines specify that clinics should store all relevant information about participants indefinitely, in a way that is secure but is accessible to all participants (under the conditions set out under the NHMRC Guidelines).¹⁰

3.9 In particular, the NHMRC Guidelines provide the following advice on data management:

[c]linics should have the following overall arrangements for record-keeping:

...

7 Sections 49, 51, 53 and 70 of the *Assisted Reproductive Treatment Act 2008* (Vic); Regulation 14 of the *Assisted Reproductive Treatment Regulations 2009* (NSW); subsection 44(4) and section 45 of the *Human Reproductive Technology Act 1991* (WA).

8 *Submission 103*, p. 3.

9 The guidelines apply to South Australia in this respect by operation of subregulation 8(2) of the *Assisted Reproductive Treatment Regulations 2010* (SA), which specifies that a condition of registration of an assisted reproductive technology provider is compliance with the NHMRC guidelines.

10 Paragraph 10.3.4 of the NHMRC's *Ethical Guidelines on the Use of Reproductive Technology in Clinical Practice and Research* (2007).

- arrangements to store relevant information about participants in a procedure involving the use of donated gametes or embryos in a way that is secure but accessible to the persons born as a result of the procedures, and the participants, under the conditions described in paragraphs 6.10 to 6.13 [these paragraphs relate to entitlements to information by donor conceived people, including medical information and personal information, and providing donors with information about children born from their donations];
- arrangements to ensure transfer of records to a suitable person or location when a clinic closes or a practitioner ceases to practise (such arrangements should ensure that records stay with the gametes and embryos to which they relate); and
- provision to keep records indefinitely (or at least for the expected lifetime of any persons born).¹¹

3.10 While the NHMRC Guidelines specifically provide for the transfer of records, Mrs Caroline Lorbach from the DCSG argued that these obligations do not assist where:

...those records...are being held perhaps in garages, in storage from doctors who have retired or doctors who have died. Their children are probably holding on to some records. So we have a lot a very valuable records being held outside clinics. One of our son's records are being held by a pharmaceutical company.¹²

3.11 Mrs Lorbach went on to explain that, in relation to her son:

[w]hen we first approached the clinic where we conceived him, we wanted to write a letter to the donor to say thank you and...to ask whether in future he might be willing to answer any questions. The clinic said they would contact the donor for us but we got a reply...saying that they could not find him, that he was not at the address he had registered. So we left it for a while...We then spoke to a counsellor and asked again could she try to find the donor and could she use other means of finding him, perhaps electoral rolls. She said yes, that they would do that. She got back to us quite quickly and said that she had found the donor at the address the clinic had—he had never moved. Our only conclusion was that the clinic had lied to us when they told us that they had tried to contact him. What happened then was that the donor did not want to have any contact with us but he was willing to give the counsellor a good amount of information which we could pass on to our son. To get the basic information, to contact that donor the counsellor had to then go to the pharmaceutical company to get the contact information which was in storage there.¹³

11 Paragraph 10.1.1 of the NHMRC Guidelines.

12 *Committee Hansard*, 2 November 2010, p. 5.

13 *Committee Hansard*, 2 November 2010, p. 6.

3.12 A number of submissions noted that records about donor conception need special protection and should be held permanently for donor conceived people (and their children) to access easily.¹⁴

Variations in nature of data recorded

3.13 As noted earlier in this report, the NHMRC Guidelines require clinics to keep information from gamete donors (or gamete providers for donated embryos), such as the donor's name, date of birth, address, details of physical characteristics and details of their past medical and family history.¹⁵

3.14 However, submissions from SMC Australia and others highlighted that there is great variation between states and territories, and even between clinics within the same jurisdiction, in relation to the recording and release of information about donors and any offspring conceived as a result of their donation.¹⁶

Tracking past donors

3.15 Some submissions noted that most treating clinics and doctors do not have the expertise or the facilities to keep track of past donors and patients, or to facilitate contact between donors and donor conceived people. However, there is an implicit obligation to do so where they hold records relating to donor conception.¹⁷

3.16 The NHMRC Guidelines place the onus on donors to keep clinics updated:

[c]linics should tell gamete donors (or gamete providers for donated embryos) that it is their ethical responsibility to keep the clinic informed about any changes to their health that may be relevant to the persons born or the recipients of their donation, and about changes to their contact details.¹⁸

3.17 However, on the basis of evidence received during the inquiry, it would appear that donors are not keeping clinics updated. To illustrate this point, Ms Fiona Hearne of SMC Australia provided the following example:

14 See, for example, Miss Laura Burns, *Submission 40*, p. 1; Ms Kimberley Springfield, *Submission 52*, p. [2]; DCSG, *Submission 122*, p. 137. It is also worth noting that, in the Netherlands, records are required to be retained for 80 years and may be accessed by donor conceived people and their direct relatives. Similarly, in the case of adoption, many records, particularly birth certificates, in Australia are accessible by adopted people and their close relatives, and there is a requirement that these records be kept in perpetuity.

15 Paragraph 10.3.1 of the NHMRC Guidelines.

16 *Submission 99*, p. 5. See, also, Rainbow Families Council, *Submission 73*, p. 2; Ms Elizabeth Hurrell, *Submission 101*, p. 3.

17 Public Interest Law Clearing House (PILCH), *Submission 125*, p. 8; see, also, Ms Kate Dobby, *Submission 103*, p. 3.

18 Paragraph 10.3.2 of the NHMRC Guidelines.

[w]e have a member with a child who is not yet one year old. She has asked her clinic to see whether her donor would be open to receiving a letter, which he indicated on his form. The clinic have told her that they have lost contact with him. This is not a donor who would have donated 10 or more years ago; this is a recent donation.¹⁹

3.18 Many submissions noted that there is substantial variation in relation to the handling of requests for information or for assistance in facilitating contact. For example, some submissions noted that the clinics they had encountered were reluctant to assist because they were not legally empowered to provide information or facilitate contact.²⁰ Others highlighted that many clinics do not have any procedures or guidelines in place on how to handle such requests, and that requests are handled on an ad hoc basis, with the level of assistance provided often depending on the willingness of the particular individual handling the request to assist.²¹

3.19 Some submitters indicated that the lack of clear procedures to locate donors can leave individuals having to personally pursue various avenues to try to locate information about their donor. For example, after being told by the Infertility Treatment Authority (ITA) (which held the relevant records) that it could not write to her donor to see if he was willing to disclose his identity, Miss Lauren Burns personally tracked down the doctor who facilitated her conception, who subsequently agreed to write to her donor.²²

3.20 Ms Robyn Bailey of SMC Australia advised the committee that clinics vary in the amount of effort they are willing to make to assist parties to locate donors.²³ However, Mrs Leonie Hewitt of the DCSG indicated the Royal Hospital for Women went to 'extraordinary lengths' to assist her family, and 'need to be commended for that'.²⁴ Further:

[the Royal Hospital for Women] have set up their own voluntary register—sadly, it is hidden on their website. We did some publicity for that years ago. They did electoral checks. They did an internet search Sydney-wide and Australia-wide. They sent letters out to people with the same surname. They have his surname but no date of birth. So they did an awful lot...²⁵

19 *Committee Hansard*, 2 November 2010, p. 44.

20 Miss Lauren Burns, *Submission 40*, pp 3-4; Public Interest Law Clearing House (PILCH), *Submission 125*, p. 8.

21 See, for example, Miss Lauren Burns, *Submission 40*, pp 3-4; Mrs Caroline and Mr Patrice Lorbach, *Submission 76*, p. 5; Mr Michael Adams, *Committee Hansard*, 3 November 2010, p. 7.

22 *Submission 40*, p. 4.

23 *Committee Hansard*, 2 November 2010, p. 44.

24 *Committee Hansard*, 2 November 2010, p. 11.

25 *Committee Hansard*, 2 November 2010, p. 11.

3.21 Dr Martyn Stafford-Bell of the Canberra Fertility Centre indicated that, if his clinic was approached by a donor conceived child, 'then we would make every possible effort to contact the donor'.²⁶

Need for national consistency

3.22 SMC Australia argued that the current system of 'jurisdictional differences and industry intransigence related to donor data management have combined to produce outcomes which are demonstrably inequitable, inefficient, unfair and unreasonable'.²⁷

3.23 At the public hearing in Sydney, Ms Robyn Bailey of SMC Australia expanded on this argument:

...at best, clinic governance is ad hoc and, at worst, non-existent around Australia. Obviously it varies between the states. SMC Australia members [support] a national donor conception framework that upholds the rights of all humans. This must include a national register that is complete, accurate, current and retrospective and which provides a sound basis to ensure that all children are treated the same, regardless of birthplace or date.²⁸

3.24 The DCSG also argued that any national register must be 'independent of service providers' and should 'store the identity of gamete and embryo donors, recipient parents and donor conceived people past and present'.²⁹

3.25 At the public hearing in Melbourne, Ms Marianne Tome, from the Victorian Infertility Counsellors Group, stated that her organisation recognises the rights of 'all donor conceived individuals in Australia to have access to information about their biological parents and genetic siblings', and that 'access to such information should be through a national central register such as that established in Victoria'.³⁰

3.26 In her submission, Dr Sonia Allan noted that Sweden, Austria, Switzerland, the Netherlands, Norway, the United Kingdom, New Zealand and Finland all have legislation that provides for the disclosure of donor identity. She advised:

[i]n all [these] jurisdictions, since the inception of their respective legislation, a prospective donor is required to consent to the release of his or her identity to any offspring who requests this information and such consent is secured in advance of the collection and use of gametes or embryos.

26 *Committee Hansard*, 29 October 2010, p. 7.

27 *Submission 99*, p. 7.

28 *Committee Hansard*, 2 November 2010, p. 40.

29 *Submission 122*, p. 137.

30 *Committee Hansard*, 3 November 2010, p. 72.

Information is then held on a registry that may be accessed by donor conceived individuals.³¹

Suggested approaches for a national register

3.27 Several different approaches for a national register were suggested during the course of the committee's inquiry. Issues canvassed in this regard include:

- the role of the register – whether it should simply be a repository of information that individuals are able to access in certain circumstances, whether it should also have a role in facilitating contact between donors and donor conceived people and their families, and further, whether the body responsible for the register should have a regulatory role in enforcing compliance by clinics with their obligations;
- what information could be captured – whether both non-identifying and identifying information should be stored, the type of information, and specific requirements for clinics, doctors and private individuals to report information about donor conception to the register;
- who should administer the register – whether it should be administered by the private sector, by state and territory governments, or by the Australian Government, and, if administered by government, which body within the relevant government would be responsible for its administration; and
- how the register would operate – the type of information individuals will be able to access and in what circumstances, and whether the register would be retrospective.

Role of the register

3.28 There were differing views on what role a national register should perform. Many submissions argued that the establishment of a national register would provide a

31 *Submission 30*, p. 15. In the United Kingdom, the Human Fertilisation and Embryology Authority records all births as a result of ART procedures in all licensed UK clinics from 1 August 1991. Donor conceived people born before 1991 can only access information through clinics, or through UK DonorLink or Donor Sibling Link. UK DonorLink manages a voluntary register, facilitates DNA testing, provides support and counselling to those affected by donor conception, and facilitates contact between donor conceived people (over 18 years of age), their siblings, and donors. In the Netherlands, a register was created in 2002, from which donor conceived children, born after 1 June 2004, may obtain non-identifying information from age 12, and identifying information from age 16, about their donor. DNA testing may be used. If a donor's circumstances have changed, the donor may object to the release of identifying information. This information will be released to the donor conceived child unless strong considerations apply. If necessary, a court may determine the matter.

central repository of information about donors and donor conceived people, as well as a central place for people to access that information.³²

3.29 It was also submitted that a national register should not only be a repository of information, but should also have a role in facilitating contact with people affected by donor conception.³³ For example, Miss Laura Burns commented:

[t]he keystone to the functioning of a reformed system based on openness and honesty is resourcing the Authority managing the National Donor Register to offer donor linking services with specialised counselling available in each state to any person who requests it. The Authority must be properly resourced to employ counsellors who are able to act as intermediaries, facilitating contact between donors, donor conceived people and their half-siblings.³⁴

3.30 As an example of a service that could be provided by a national register, some submitters referred to the letterbox service in place in Victoria which acts as an intermediary to enable people to exchange letters in a non-identifying manner, rather than, or preceding, meeting with the other party.³⁵

3.31 Another submitter suggested that it may be appropriate and helpful for donor recipients to be able to contact the donor, 'to ensure that the sperm donor is a decent person before embracing him with our children'.³⁶

3.32 The register could also play a role in arranging contact with other relatives of the donor. Mr Adam Quinlivan, a donor conceived person, suggested that, even where a donor chooses not to have contact with a donor conceived child, the decision of a donor not to have contact should not prevent other members of the donor's family from having contact with the donor conceived person.³⁷

3.33 Some submissions suggested that, where records no longer exist, a national coordinating body should be proactive in finding past donors.³⁸ Submitters also noted the importance of ensuring that information on the register is kept up-to-date if it is to be of any use. It was specifically suggested that there should be capacity to add

32 See, for example, Mr Michael and Mrs Laureen Dempsey, *Submission 27*, p. [1]; Mr Damian Adams, *Submission 38*, p. [2]; *Submission 89 (name withheld)*; p. 2; DCSG, *Submission 122*, p. 138.

33 See, for example, Ms Helen Kane, *Submission 32*, p. 2; Victorian Infertility Counsellors Group, *Submission 68*; p. 2; Ms Antonia Clissa, *Submission 105*, p. 2; DCSG, *Submission 122*, p. 139.

34 *Submission 40*, p. 2.

35 See, for example, Miss Lauren Burns, *Submission 40*, p. 2; Victorian Infertility Counsellors Group, *Submission 68*, p. 2.

36 Tonia, *Submission 7*, p. 2.

37 *Submission 12*, p. 1.

38 See, for example, SMC Australia, *Submission 99*, p. 12; Ms Kylie Dempsey, *Submission 114*, p. [3]; DCSG, *Submission 122*, p. 139.

updated medical histories and contact details of both donors and donor offspring to the register.³⁹ Some submitters suggested that the register should accord donor conception records with special protection and that these records should be held permanently.⁴⁰

3.34 There were also suggestions that a central repository of information would make it possible to oversee and enforce compliance by clinics with their obligations, such as enforcing limits on the number of people that donors are permitted to assist.⁴¹

Information to be recorded

3.35 The committee received evidence that a national register should retain records of the numbers of donor conceived people born through ART procedures undertaken in both clinics and private arrangements,⁴² and that the quality of the information kept about donors should be improved.⁴³

3.36 The DCSG suggested that, in order for a national register to resolve the shortcomings which currently exist with clinic or state-based registers, there should be mandatory reporting by all people using donor conception practices about the use of donated gametes and embryos, and live births which result.⁴⁴ Several submissions noted that the same reporting obligations should also apply in relation to international donations⁴⁵ and private arrangements.⁴⁶

3.37 In addition, some submitters suggested that there needs to be better consistency regarding the level of detail and amount of information recorded, to improve access to information for donor conceived people.⁴⁷ Some submissions emphasised that improving the amount of information collected is important so that donor conceived people are given sufficient information about the donor's medical

39 See, for example, *Submission 54 (name withheld)*, p. 4; *Submission 89 (name withheld)*, p. 2; SMC Australia, *Submission 99*, p. 7.

40 See, for example, Ms Kimberley Springfield, *Submission 52*, pp [1-2]; DCSG, *Submission 122*, p. 138.

41 See, for example, Ms Kate Dobby, *Submission 103*, p. 1; Mrs Leonie Hewitt, DCSG, *Committee Hansard*, 2 November 2010, p. 7; Dr Damien Riggs, *Committee Hansard*, 2 November 2010, p. 37.

42 See, for example, Dr Damien Riggs, *Submission 19*, p. 1; *Submission 29 (name withheld)*, p. [2]; DCSG, *Submission 122*, p. 137; *Submission 157 (name withheld)*, p. 2.

43 See, for example, *Submission 64 (name withheld)*, p. [1]; Victorian Infertility Counsellors Group, *Submission 68*, p. 2; *Submission 108 (name withheld)*, p. [2].

44 *Submission 122*, p. 137.

45 See, for example, *Submission 29 (name withheld)*, p. [2]; SMC Australia, *Submission 99*, p. 12.

46 See, for example, Dr Damien Riggs, *Submission 19*, p. 1; *Submission 29 (name withheld)*, p. [2]; *Submission 157 (name withheld)*, p. 2.

47 See, for example, *Submission 64 (name withheld)*, p. [1]; Victorian Infertility Counsellors Group, *Submission 68*, p. 2; *Submission 108 (name withheld)*, p. [2].

history in order to assist them to most effectively manage their health.⁴⁸ Retaining sufficient information is also important in circumstances where, for example, a donor becomes untraceable or dies.⁴⁹

3.38 Dr Sonia Allan advised the committee of the types of information that she thought should be retained:

Identifying information:

Name

Date of birth

Address

Occupation

Medical History (personal and familial to the extent to which it is known) – this should be updated every five years. The onus to update such information should fall to the clinics or registry rather than the donor (who may not follow up).

Non-identifying information such as:

Education (level and qualifications)

Eye colour

Hair colour

Height

Weight

Marital status

Number of children (if any)

Sex

Year of birth

Place of birth

Nationality/culture with which the donor identifies

Religion (if any)

Reason for becoming a donor

Number of offspring born through other donations

Identity of other offspring born through other donations

Interests/hobbies/sporting activities

****Anything else the donor considers central to their personality would also be useful for a donor conceived individual to know.⁵⁰**

48 Dr Sonia Allan, *Submission 30*, p. 12; Mr Damian Adams, *Submission 38*, p. 8; *Submission 97 (name withheld)*, p. [1].

49 *Submission 127 (name withheld)*, p. 6.

3.39 Ms Robyn Bailey of SMC Australia made a suggestion along similar lines:

[f]ully identifying information including name, address, contact details, email address and that sort of thing is kept for later use, and the information on health, eye colour, hair colour and all that sort of thing is what we are getting at the moment. There needs to be something put in place so that contact is not lost in 16 or 18 years time or whenever a child goes looking.⁵¹

How could a national register be administered?

3.40 Some submitters felt that, given the importance and sensitivity of information regarding the identities of people involved in donor conception (including medical information), information would be best safeguarded by being held by a government authority, rather than by private individuals.⁵² Mrs Caroline and Mr Patrice Lorbach suggested that medical professionals are not trained in record-keeping and therefore should not have a controlling interest in this area.⁵³

3.41 A number of submissions suggested that the Commonwealth should be responsible for administering the register.⁵⁴ Mrs Myfanwy Cummerford, a donor conceived person, suggested that the Commonwealth has a responsibility with respect to ensuring that donor conceived people have access to information about their donors by virtue of the Commonwealth's facilitation and funding of the practice of donor conception.⁵⁵

3.42 Mrs Lorbach of the DCSG endorsed the model of the Victorian Government and stated that the previous Infertility Treatment Authority (ITA) (now the Victorian Assisted Reproductive Technology Authority (VARTA)), was 'world leading in the way it was being run'. In her view, people with appropriate expertise should run the register:

I would trust the government to look after this information more than I would trust a company to look after it. I do not think a company, a place of business, is the appropriate place for what is in effect birth certificate type

50 Answer to questions on notice, received 8 November 2010, pp [6-7].

51 *Committee Hansard*, 2 November 2010, p. 44.

52 See, for example, Mr Damian Adams, *Submission 38*, p. [4]; Mrs Caroline and Mr Patrice Lorbach, *Submission 76*, p. 9; Ms Kate Dobby, *Submission 103*, p. 3; DCSG, *Submission 122*, p. 137.

53 *Submission 76*, p. 2.

54 See, for example, Mr Michael and Mrs Laureen Dempsey, *Submission 27*, p. [1]; Dr Sonia Allan, *Submission 30*, p. 17; Mrs Myfanwy Cummerford, *Submission 63*, p. [1]; DCSG, *Submission 122*, p. 137.

55 *Submission 63*, p. [1].

information. I think it would be much easier for a clinic to be broken into and have information taken from it than for a government department.⁵⁶

3.43 However, the Canberra Fertility Centre's submission suggested that a centralised register, rather than local registers, may deter some people from donating because they may prefer for their identifying information to be held outside government departments due to confidentiality concerns. The Centre recommended maintaining the management of data involved in donor conception by individual clinics.⁵⁷ At the public hearing in Canberra, Dr Martyn Stafford-Bell elaborated:

[p]eople feel that if their data is kept on a register run by professionals in the field with vast experience then it is handled sensitively and in confidence. It is like going to see your doctor. They are very afraid, rightly or wrongly, of having their intimate details on a government register to which they believe any Tom, Dick or Harry living around the corner can log in and gain access. Whether or not that is true I do not know, but it is the perception of the general public.⁵⁸

3.44 He suggested that if the Commonwealth were to establish a central register:

...the [Fertility Society should]...run a central register. There are certain advantages from this that I would see. No. 1 is that the patients would not be afraid or have any horror of a register run by the [Fertility Society]. No. 2 is that it would be run by people with great experience in the field. No. 3 is that it would be run with great sensitivity, and No. 4 is that it would be very, very much cheaper than a government run central registry.⁵⁹

3.45 The Commonwealth Office of the Privacy Commissioner (Privacy Commissioner) also raised a number of privacy issues with the creation of a national registry:

[g]enerally speaking, centralised databases of 'personal information' can be tempting to hackers and organised crime (e.g., as material for potential identity theft). Further, the administrators of centralised data repositories are sometimes subjected to pressure to use, or allow the use of, the repository for purposes that are unrelated to the reason it was established ('function creep').⁶⁰

3.46 The Privacy Commissioner also suggested that any organisation or agency administering a national register would be obliged to put in place appropriate security measures, and should also put in place measures to prevent 'function creep'.⁶¹

56 *Committee Hansard*, 2 November 2010, p. 8.

57 *Submission 48*, p. [4].

58 *Committee Hansard*, 29 October 2010, p. 7.

59 *Committee Hansard*, 29 October 2010, p. 13.

60 *Submission 151*, p. 7.

61 *Submission 151*, p. 8.

Who should be able to access information and in what circumstances?

3.47 Some submitters supported donor conceived people being able to access identifying information about their donor once they reach the age of 18 years, without the need for parental permission.⁶² However, some individuals suggested that donor conceived people should have access to identifying information about their donor before the age of 18 to reduce identity issues.⁶³

3.48 Ms Romana Rossi, a parent of a donor conceived person and member of TangledWebs, suggested that there should be visitation rights for the donor conceived person to be able to establish a relationship with their biological family before they reach 18 years of age. She noted that '[t]he adoption experience has shown that it is nearly impossible to have a parental/child relationship with someone you meet in adulthood'.⁶⁴

3.49 Dr Sonia Allan suggested that donor conceived people should be able to access information after they reach the age of 16 years, and that they should be permitted to access the information earlier if they do so under the guidance of a counsellor, youth worker, parent, guardian or other responsible adult.⁶⁵ SMC Australia similarly supported a system in which contact between donors, recipients and donor conceived people is facilitated where there is a mutual desire to do so before the donor conceived child turns either 16 or 18 years of age.⁶⁶

3.50 A number of submitters also suggested that donor conceived people should be able to access information about their donor's medical history from an early stage.⁶⁷ Some submissions noted that the lack of detailed medical history in relation to donors may hinder medical treatment throughout a child's life, and may exclude them from being able to take preventative measures in relation to any health conditions.⁶⁸

3.51 It was also suggested by one submitter that the register should be publicly accessible, to enable potential recipients to check how many families each donor has assisted, prior to deciding whether or not to use that donor.⁶⁹

62 See, for example, *Submission 89 (name withheld)*, p. [4]; Ms Kylie Dempsey, *Submission 114*, p. [4].

63 See, for example, Mr Adam Quinlivan, *Submission 12*, p. 1; Dr Sonia Allan, *Submission 30*, p. 20; Ms Romana Rossi, *Submission 75*, p. 3.

64 *Submission 75*, p. 3.

65 *Submission 30*, p. 20.

66 *Submission 99*, p. 7.

67 See, for example, *Submission 4 (name withheld)*; Mr Michael and Mrs Laureen Dempsey, *Submission 27*, p. 2; Mr Damian Adams, *Submission 38*, p. [2].

68 Mr Michael and Mrs Laureen Dempsey, *Submission 27*, p. 2; Dr Sonia Allan, *Submission 30*, p. 12; Mr Damian Adams, *Submission 38*, p. [9].

69 *Submission 93 (name withheld)*, p. 5.

Sibling register

3.52 Many submitters and witnesses supported the establishment of a donor registry model that also enables donor siblings to contact each other, similar to the Donor Sibling Registry in the United States of America.⁷⁰ Ms Cheryl Fletcher of SMC Australia emphasised the benefits that children may have from having contact with their siblings:

[t]here are quite a few people around the country where the siblings meet at birthdays and at Christmas, and they love that extended family. That is the benefit of a register too.⁷¹

3.53 Ms Fiona Hearne, also of SMC Australia, advised the committee:

[m]y daughter is in touch with one of her siblings. Our clinic has always given us a list of the sex and the year a child was born...A month or so ago I got a list of all the birth dates and the sex of the children born from our donor. That is really unusual. I am hoping that it becomes a bit more of a standard. We know the number of siblings but, at the moment, if my daughter decides that she wants to be put in touch with siblings the clinic is not interested in helping us until she is at least 18.⁷²

3.54 The DCSG suggested that donor conceived people and the children of donors should be able to access the year of birth and the sex of all of their half-siblings or full siblings. It also suggested that donor conceived people, their half and full siblings, and the children of donors should be able to share information or make contact with each other on a voluntary basis through a register. At the public hearing in Sydney, Mrs Leonie Hewitt of the DCSG spoke of her eldest child's half-siblings:

[w]e talk a lot about the donors and making contact with them, but in the case of our eldest child there is no donor to contact. For her there needs to be a register for the half-siblings to make contact. There is nothing in place for them to meet those half-siblings.⁷³

3.55 Mr Adam Quinlivan, a donor conceived person, also proposed that different sets of parents who used the same donor should be able to contact each other, to allow half-siblings to meet while they are children.⁷⁴

70 Ms Fiona Hearne, SMC Australia, *Committee Hansard*, 2 November 2010, p. 50; DCSG, *Submission 122*, p. 138. The Donor Sibling Registry assists donor conceived individuals to contact others with whom they share genetic ties, including half-siblings and donors.

71 *Committee Hansard*, 2 November 2010, p. 47.

72 *Committee Hansard*, 2 November 2010, p. 47.

73 *Committee Hansard*, 2 November 2010, p. 11.

74 *Submission 12*, p. 1.

Retrospective operation of the register

3.56 The committee received evidence both in support of, and against, the retrospective operation of a national register.

Arguments in support of a retrospective national register

3.57 A number of submissions were in favour of retrospective disclosure of information.⁷⁵ For example, Dr Sonia Allan advocated providing donor conceived people with access to all identifying and non-identifying information that is held by clinics, hospitals or doctors, regardless of when conception took place.⁷⁶

3.58 Further, the Victorian Infertility Counsellors Group submitted:

[u]p until the [*Assisted Reproductive Treatment Act 2008* (Vic)], fertile women had to travel interstate to seek treatment and did therefore not come under Victorian legislation. These women and their children therefore do not have the same access to information about their donor origins as do donor conceived offspring in the rest of the Victorian community. These women find it particularly difficult not to be able to provide their children with up to date and accurate information about their donor, often only having a few lines of information to share with their child. A retrospective national register would assist in rectifying this inequality.⁷⁷

3.59 In support of retrospective release of donor's identifying information, many donor conceived people who made submissions to the inquiry noted that they were never a party to the secrecy agreement with the donor, and that they should be entitled to know information about their own genetic history.⁷⁸

3.60 TangledWebs argued that the rights of a donor conceived child to information must prevail over the rights of the donor to anonymity:

[t]he child cannot have his or her rights limited by an implied contract to which they were not a party.⁷⁹

3.61 Some submissions suggested that all past donors could be re-contacted to see whether they are now willing to be identified, as it is not necessarily the case that past donors wish to remain anonymous.⁸⁰ The DCSG submitted that a number of former

75 See, for example, DES Action Australia – NSW, *Submission 18*, pp 3-4; Dr Sonia Allan, *Submission 30*, p. 3; Mr Damian Adams, *Submission 38*, p. [2]; DCSG, *Submission 122*, p. 137.

76 *Submission 30*, p. 15.

77 *Submission 68*, pp. 6-7.

78 See, for example, Mr Damian Adams, *Submission 38*, p. [2]; TangledWebs, *Submission 61*, p. [2]; Miss Narelle Grech, *Submission 107*, p. 2.

79 *Submission 61*, p. [2].

80 Rainbow Families Council, *Submission 73*, p. 2; DCSG, *Submission 122*, p. 139.

sperm donors had sought out the DCSG to discover the results of their donations.⁸¹ The DCSG quoted from a former sperm donor who stated:

I was a sperm donor during 1997-1998. [M]y donations were during the period when [d]onors had to sign away any future contact. This was a condition of participation and I only wanted to help people – but at the back of my mind was the hope that the rules would change to allow the resultant children to trace their donor fathers, if they wished to do so [footnote omitted].⁸²

3.62 Similarly, Mr Michael Linden, who donated sperm anonymously in the late 1970s, argued that it is wrong to necessarily assume that donors do not care to know whether their donations resulted in any offspring:

[f]rom the donor's perspective, the fundamental lie is, that apart from being the source of a much-prized commodity, once his job is done he simply doesn't count.

And worse, by some perverse corollary, with regard to the fate of his children, it is assumed that he really doesn't care.⁸³

3.63 Ms Robyn Bailey of SMC Australia emphasised the importance of counselling in cases where anonymous donors may be reluctant to provide information:

...it would be good if there was a staggered counselling process where donors could go away and have some counselling, and mull it over for a year or so. I do not think there is a need to rush the retrospective register. I do not agree with anonymous donors being dragged out immediately and forced to meet. That would be against the interests of all parties involved.⁸⁴

3.64 Mr Richard Egan of FamilyVoice Australia indicated that his organisation supported legislation mandating retrospective disclosure of donor details:

[t]hat legislation would require a national register because you need to collect the data before clinics go out of business. Some of it will be very patchy going back to the 1970s and so on, but we need to get that information into a central registry before it is too late. Some people may not start looking for their donor father until they are 30 or 40, so these things come up at different times in people's lives. So: [it is our view that there should be] an absolute right to know.⁸⁵

81 DCSG, *Submission 122*, p. 71.

82 DCSG, *Submission 122*, p. 74.

83 *Submission 9*, p. 2.

84 *Committee Hansard*, 2 November 2010, p. 46.

85 *Committee Hansard*, 29 October 2010, pp 19-20.

3.65 Mr Egan also commented that, if legislation establishing a national register was retrospective, contact vetoes could be put in place the way they are in adoption cases:⁸⁶

[n]o-one wants to force themselves on someone else, but they do have a right to know where they come from, who they are, who their relatives are and so on. That should include the ability to track donor siblings so you know who your brothers and sisters are. That seems to me a fundamental human right. That is the 'right to know' stuff.⁸⁷

3.66 Miss Lauren Burns concurred with this view:

[a]fter donor-linking and counselling has been supplied by the intermediary Authority, donor conceived people should be permitted to apply for identifying information about their donor, but be required to comply with any contact vetoes placed by the donor.⁸⁸

Analogy with adoption

3.67 Drawing an analogy with adoption, the Victorian Adoption Network for Information and Self Help Inc (VANISH) noted that, despite the initial anxiety surrounding the retrospective release of information regarding adoption, it is now well accepted that it is normal for adopted people to want information about their birth parents.⁸⁹

3.68 The committee notes that all states and territories have legislation which sets out the rights that adopted people have to information about their birth parents. Appendix 2 to this report outlines what information is available to adopted people in each state and territory and at what age.

3.69 All state and territory legislation provides adopted people with the right to identifying information about their biological parents, including their original birth certificate. However, legislation is not consistent between states and territories and, additionally, not all adoption legislation in Australia is retrospective. For example, in South Australia and Queensland, birth parents and adopted people may veto the release of identifying information, and any contact, if the adoption was finalised prior to the commencement of the relevant legislation in those states.⁹⁰

86 Generally, state and territory legislation has retrospectively removed anonymity for parents whose children were adopted. However, birth parents and adopted people may place vetoes on contact or the release of identifying information, dependent on provisions in relevant legislation. See Appendix 2.

87 *Committee Hansard*, 29 October 2010, pp 19-20.

88 Miss Lauren Burns, *Submission 40*, p. 2.

89 VANISH, *Submission 62*, p. 3.

90 Australian Institute of Health and Welfare, *Adoptions Australia 2008-09*, Child Welfare Series No. 48, February 2010, pp 66-67 and 68.

Arguments against the retrospective operation of a national register

3.70 The committee also received a number of submissions that did not support retrospectively releasing identifying information about anonymous donors⁹¹ because, in the past, sperm donors often signed a contract which assured the donor of anonymity.⁹² For example, the Fertility Society suggested that retrospectivity would be a 'grievous violation' of the privacy of donors who previously entered into such confidential agreements in good faith.⁹³

3.71 The Office of the Information Commissioner Queensland agreed:

...if donors provided sperm or eggs on the understanding that their identities would remain confidential, that should not be overridden by any new laws without evidence that the presumptions of benefit are shown to be erroneous or that any detriment that is shown to arise overrides the benefits of the policy to an extent where it becomes desirable to change the rules.⁹⁴

3.72 Similarly, the Canberra Fertility Centre advised:

[we are] emphatically opposed to any retrospective legislation regarding disclosure of identifying information, as this would seem unfair to donors who donated under the impression that they would remain anonymous. It may also be devastating to a child or the recipient parents if their attempt at contact with the donor was rebuffed.⁹⁵

3.73 One submitter, who had been a donor in the late 1980s, strongly opposed the retrospective release of identifying information about himself.⁹⁶ In his submission, he stated that he had signed a contract which provided that he 'would have no legal rights as a donor' and would have 'total anonymity with no legal obligation to the normal parents and their child'.⁹⁷ Although he donated for altruistic reasons, he also advised the committee that when the law changed in Victoria to provide greater access to information by donor conceived individuals, he ceased donating because he did not want to be identified.⁹⁸

3.74 This submitter had provided non-identifying information about himself and his family, including photographs of family members, to the Victorian Voluntary

91 See, for example, Office of the Information Commissioner Queensland, *Submission 20*, p. 3; Canberra Fertility Centre, *Submission 48*, p. [7]; Fertility Society, *Submission 106*, p. [11].

92 Dr Sonia Allan, *Submission 30*, p. 16.

93 *Submission 106*, p. [11].

94 *Submission 20*, p. 3.

95 *Submission 48*, p. [7]. See, also, Office of the Information Commissioner (Queensland), *Submission 20*, p. 3.

96 *Submission 160 (name withheld)*.

97 *Submission 160 (name withheld)*, p. [1].

98 *Submission 160 (name withheld)*, p. [1].

Register, written a letter to any child that may have been conceived as a result of his donation, explaining why he wished to remain anonymous, and offered to be contacted should a medical emergency arise where the child needed a biological parent to provide an organ donation, for example.⁹⁹

3.75 Noting that he had his own children, he advised the Registrar of the Voluntary Register that:

[m]y wife and I have had many debates about the wisdom of revealing my identity and the possible flow on effects to our family, friends, the donor conceived children and their natural parents. After much agonizing we have decided on balance that it is for the best if I maintain my silence about my IVF involvement and accordingly I ask that my identity continues to be protected by your department.¹⁰⁰

3.76 The Western Australia Department of Health raised some issues which would require further consideration in relation to a national register covering retrospective release of identifying information:

[f]or example, in terms of the clinics, it could be said that health professionals are under a legal and ethical duty not to disclose confidential information concerning a patient which has been identified in the course of their professional attendance upon that patient. That legal duty may arise in contract or in equity. A third party who comes into possession of confidential information which he or she knows is confidential falls under an obligation not to pass that information on to anyone else.¹⁰¹

Campaign to increase awareness of register

3.77 Submitters suggested that, if a national register is established, there could be nationwide campaigns run to advertise the register, to encourage past donors to come forward, and to raise awareness about donor conception more generally.¹⁰² The committee was advised during the public hearing in Melbourne that the campaign run by VARTA, *Time To Tell*, had been very successful in raising awareness of these issues.¹⁰³

3.78 Similarly, Ms Robyn Bailey of SMC Australia suggested:

...there could be national advertising of a register and people could be invited to come forward and the public could be educated like they have done very successfully in Victoria...We could inform the public about the

99 *Submission 160 (name withheld).*

100 *Submission 160 (name withheld)*, p. [4].

101 *Submission 126*, p. [3].

102 See, for example, PILCH, *Submission 125*, p. 2; DCSG, *Submission 122*, p. 139.

103 Ms Marianne Tome, Victorian Infertility Counsellors Group, *Committee Hansard*, 3 November 2010, pp 72-73.

benefits for donor conceived offspring of knowing their donors and encourage past donors to come forward. We could search electoral rolls. There are many things we could do in a staggered and considered way, not rushing into it. I think that would be of great benefit to the families and the donors.¹⁰⁴

3.79 However, the Public Interest Law Clearing House (PILCH) suggested that, while there is a voluntary register in Victoria for past anonymous donors, there is an absence of widespread knowledge of its existence. This means that only very limited information is available about donor treatment procedures which occurred before 1998.¹⁰⁵

Opposition to the establishment of a national register

3.80 The Fertility Society did not support the establishment of a national register, with Associate Professor Peter Illingworth advising the committee that, in his view, state and territory variations were only 'very minor'.¹⁰⁶ The Fertility Society suggested that reform of donor conception practices would be best made by further development and refinement of the existing local state-based systems, and that there is no evidence that a national approach will provide significant advantages in this very difficult area.¹⁰⁷

3.81 In addition, Dr Martyn Stafford-Bell of the Canberra Fertility Centre stated at the Canberra public hearing that he was 'completely opposed to a register of donor conceived children'.¹⁰⁸ He explained that, in his view, state and territory and federal registers do 'no appreciable good and certainly no good over and above that which is presently being done' by clinics.¹⁰⁹

3.82 Some submissions argued that, even if no national body or register is to be created, mandatory requirements should be developed and enforced for clinics in relation to how they record and maintain donor data, and how they facilitate contact between donors, recipients and donor conceived people.¹¹⁰ Similarly, regardless of whether or not a national register is established, many submissions suggested that all clinics should increase the amount and type of information they collect.¹¹¹ As noted

104 *Committee Hansard*, 2 November 2010, p. 46.

105 PILCH, *Submission 125*, p. 7.

106 *Committee Hansard*, 3 November 2010, p. 63.

107 *Submission 106*, p. [14].

108 *Committee Hansard*, 29 October 2010, p. 3.

109 *Committee Hansard*, 29 October 2010, p. 3.

110 See, for example, Mr Michael and Mrs Laureen Dempsey, *Submission 27*, pp [1], [2]; SMC Australia, *Submission 99*, p. 7.

111 See, for example, Victorian Infertility Counsellors Group, *Submission 68*, p. 2; Rainbow Families Council, *Submission 73*; Ms Elizabeth Hurrell, *Submission 101*, pp [3]-[4]; *Submission 108 (name withheld)*, p. [2].

earlier in this report, the type of information currently provided can range from a brief physical description to a number of personal characteristics, interests and family history.¹¹²

Voluntary register

3.83 The establishment of a voluntary register was supported by the majority of submitters who commented on the issue of a register.¹¹³ A voluntary register was viewed as being particularly beneficial in circumstances where records have been destroyed or in order to locate half-siblings.¹¹⁴ If any national register was not made retrospective, a voluntary register was also seen as a way to enable donors who may have donated anonymously in the past to identify themselves.¹¹⁵

3.84 The Fertility Society supported the establishment of 'voluntary retrospective registries' including in states which do not currently have registries.¹¹⁶ Some submissions further proposed that, where records no longer exist or cannot be accessed, a voluntary register should also contain a DNA database and testing facility, as DNA testing would be the only way to accurately link donors and donor conceived people.¹¹⁷ For example, Mr Damian Adams stated that a DNA register should be established 'to allow those with no records or records that have been destroyed the ability to connect with their biological family'.¹¹⁸ There were suggestions that the database could be similar to the United Kingdom's DonorLink service.¹¹⁹

3.85 In this context, the DCSG argued that donor conceived people who need to use DNA testing to obtain a match with a donor because of the destruction of records must not incur a charge for such a service.¹²⁰

112 SMC Australia, *Submission 99*, p. 5.

113 See, for example, Mr Adam Quinlivan, *Submission 12*, p. 1; Ms Lynette Mason, *Submission 24*, pp 1-2; Mr Damian Adams, *Submission 38*, p. [4]; Fertility Society, *Submission 106*; Liberty Victoria, *Submission 153*, p. 4.

114 See, for example, Mr Damian Adams, *Submission 38*, p. [4]; Liberty Victoria, *Submission 153*, p. 4.

115 See, for example, the Fertility Society, *Submission 106*; Liberty Victoria, *Submission 153*, p. 4.

116 Fertility Society, *Submission 106*, p. [2].

117 Ms Lynette Mason, *Submission 24*; Fertility Society, *Submission 106*; Liberty Victoria, *Submission 153*, p. 4; DCSG, *Submission 122*, p. 138.

118 *Submission 38*, p. [4].

119 See, for example, Mr Adam Quinlivan, *Submission 12*, p. 1; Ms Kate Dobby, *Submission 103*, p. 1; see, also, UK DonorLink, *UK Voluntary Information Exchange and Contact Register Following Donor Conception Pre 1991*, <http://www.ukdonorlink.org.uk/>, accessed 31 August 2010. UK DonorLink is a voluntary contact register set up to enable people conceived through donated gametes, their donors and half-siblings to exchange information and, where desired, to contact each other.

120 DCSG, *Submission 122*, p. 138.