

# CORRECTED VERSION

## LAW REFORM COMMITTEE

### **Inquiry into access by donor-conceived people to information about donors**

Melbourne — 8 September 2011

#### Members

Mr A. Carbines  
Ms J. Garrett  
Mr C. Newton-Brown

Mr R. Northe  
Mrs D. Petrovich

Chair: Mr C. Newton-Brown  
Deputy Chair: Ms J. Garrett

#### Staff

Executive Officer: Dr V. Koops  
Research Officers: Ms V. Shivanandan and Ms A. Gordon  
Administrative Officer: Ms H. Ross-Soden

#### Witnesses

Ms H. Versey, Privacy Commissioner, and  
Mr S. May, Policy and Compliance Officer, Office of the Privacy Commissioner.

**The CHAIR** — Thank you very much for coming in to make your submission to the Committee. I am the chair of the Law Reform Committee which is a cross-party committee set up by Parliament. Your evidence will be taken down and will become a public document once you have given it. Whatever you say here today is protected by parliamentary privilege but not what you say outside this room. If you are contacted by a journalist as a result of your evidence, just be aware that you do not have that privilege. You are asked to give an oral presentation, which is a run-down of your submission, highlighting the key points. We generally have a fair few questions to ask and we will fire those at you as you are speaking, if that is okay. Could you start by stating your full names and addresses; your business address is fine.

**Ms VERSEY** — My name is Helen Versey, I am the Victorian Privacy Commissioner, and my address is level 11, 10-16 Queen Street, Melbourne.

**Mr MAY** — My name is Scott May, and I am a Policy and Compliance Officer at the Privacy Commissioner's office with the same business address.

**The CHAIR** — What would you like to tell us?

**Ms VERSEY** — First of all I should say that Scott was the person who drafted our submission, which is why he is here today. He did all the hard work on it. At the time we put in the submission I was overseas so I have come into the submission late. Our submission essentially summarises the privacy issue as we see it. I should say that of course I am really focused on the privacy issue so I freely admit that I am not going to have expertise in a lot of the other areas being covered here. I should also add that strictly speaking I think the records regarding donors would probably come under the *Health Records Act* rather than the *Information Privacy Act*. The *Information Privacy Act* only regulates organisations, and that is public sector organisations, in relation to non-health information. The *Health Records Act* regulates both the public and private sector in relation to health-related information.

Health-related information includes non-health information which is collected in the course of providing a health service, so there is a possibility that the donor issue is regulated by the *Health Records Act* rather than the *Information Privacy Act*. But I think what I can say is that the principles of the two acts are very similar. There are some variations to do specifically with health information, and I think the general principles relating to privacy and the collection and handling of information would basically be regarded as the same. I just wanted to make that qualification to the Committee to show that I am not necessarily going to be an expert in all areas regarding health information.

I think the first issue that the submission emphasised in summary is one that I am sure others have emphasised — that is, that of course the pre-1988 donors had entered into an arrangement and provided their sample on the basis that they would and had to remain anonymous. They equally agreed not to seek the identity of any children conceived as a result of their donation. To now release their information to a donor-conceived child clearly takes away what was their legally assured privacy and anonymity. On the other hand, access to one's own personal information is a very strong privacy right which has been denied to the pre-1988 donor-conceived persons.

I also want to acknowledge that I recognise that the *Infertility Treatment Act 1995* clearly states that it is the welfare and interest of the persons born under a procedure which is paramount rather than that of the donors. It is clearly a very difficult balancing act on the two privacy rights. The submission by the deputy commissioner supported the recommendation of the Law Reform Commission that where a request is received from a donor-conceived person then the donor's consent should be obtained. I think if there is going to be access allowed then the proper balance would be on the basis of obtaining the consent of the donor, given the circumstances in which they gave their sample.

**The CHAIR** — Do you consider it a breach of privacy simply for the request, 'Do you consent?' to be made to the donor?

**Ms VERSEY** — It does raise privacy issues because the very act of approaching a donor potentially — and I say 'potentially' because it obviously depends on the different facts of the case — raises privacy issues if, for example, through the approach the fact that the donor had made a donation in the past became known to, say, his family who were otherwise unaware of it.

**The CHAIR** — If the government set up a body other than the treating clinic to make these approaches, would you have concerns as far as privacy goes with that body being provided with the information?

**Ms VERSEY** — I do have concerns. I think it would depend very much on the body and I was going to make some comments regarding who you might think about or what considerations you might take into account when thinking about what body could be the one to approach. I think under the submission that our office made regarding the use of consent there was a heading 'Notes of caution'. I would like to emphasise those notes of caution and make these points that I really do urge the Committee to carefully consider. I think the interim report of the parliamentary committee highlighted that the donor records, or the records, were pretty patchy. They varied enormously in quality, so data quality, which is a fairly significant privacy principle, is a significant issue which could, in my view, adversely impact on both the donor and on the donor-conceived person; and as the standard of records are very mixed, you have to consider that at the time they were being collected there was probably very minimal collection of identifying information, because the whole idea was that the donor would remain anonymous.

I do not know, but you might want to consider whether some donors might even have given their correct name. If you are trying to seek a donor from these records with very minimal information, for example, with only the name David Brown, there are a lot of David Browns around in Victoria. Two people may have the same name and the same date of birth, so you have to consider that if you have only got very minimal information in these records that have been very poorly kept, possibly, there is a real data quality issue which could affect both the donor and also the donor-conceived person if they happen to be given a match and it is the wrong person. I do not think that can be dismissed as a possibility with poor quality records. In fact I have to say that when I was considering this, if you have got very inaccurate records, it occurs to me that really to be sure that you are making the right match — and I am not sure how you can do it without doing a DNA match in circumstances with poor quality records — that obviously could be quite a traumatic road to go down for both the donor-conceived person and also the donor if there are expectations raised and then it becomes clear that it is not a correct match. As I have said, so far as the donor is concerned, you do have to consider that if you are allowing this to be done without consent, you have no idea what the circumstances of the donor are if you are allowing someone to make that contact without the donor's consent.

I am conscious that regarding adoption, of course, it was permitted to allow adopted persons to have access to information about their real parents, or certainly their real mother. But I think this situation does need to be distinguished from adoption in that with adoption, because a birth had to be registered, the mother's name appeared on the original birth certificate and there were some standards in governance around the collection of that information for the purpose of registering the birth. In addition there was likely to have been a court process with court documents you would have, and even if, as they did, open up those records, you were much more likely to have had accurate records. It is not quite the same situation of simply opening up these records without the consent of the donor, so I do not think the same problems regarding data quality apply in adoption as they would do in this situation.

**The CHAIR** — So your concerns with data quality are that the donor may be incorrectly identified?

**Ms VERSEY** — That is one of my concerns, yes, or one of the major concerns, that the lack of quality records makes it much more likely that a mistake might be made in terms of trying to trace the donor.

**The CHAIR** — I understand that concern, but is that relevant to the issue of privacy?

**Ms VERSEY** — Yes, it is. Data quality is one of the privacy principles, so if you are going to give people access to records which are in fact inaccurate records, then data quality has an impact on privacy. One of the principles is that records should be complete and accurate and up to date. It can cause harm to people if they are not accurate, and therefore incorrect matches can be made.

**Ms GARRETT** — This is primarily in the context of suggesting that if there was a view that perhaps access should be given regardless of consent in circumstances where the issue is — most people who have made a submission to date, this year and today, have not suggested that people should be given access to information without consent, although there may be others coming with a different view. I appreciate that you are talking about giving access without consent, but in terms of looking at it in the context of giving access with consent, I

note in the submission you say that even with the contacting of the donor there is no privacy, and I respect that. On balance, though, do you think the data quality access is an issue with that?

**Ms VERSEY** — It is going to be an issue even if you go down the road of consent, in that if you have a third party who is seeking to make the match and he is contacting people to make that initial approach, you have still got some issues in relation to your data quality in that you may be contacting basically the wrong person. I think that is something you have to consider even with consent because of the likely poor quality of the pre-1988 records. One of the things that struck me when I was considering this submission is that the existing records appear to be scattered around the place, and you might want to consider whether the records should be transferred to some central agency. I think that was suggested in recommendation 1 of the interim report.

**Mr MAY** — I think it was actions to preserve.

**Ms VERSEY** — To preserve the records.

**The CHAIR** — Was that recommendation for all the records or just those that are not held by an institution that has got good record-keeping capacity?

**Ms VERSEY** — It may be just the records; that is obviously a matter for the Committee. But what I was considering was that if you had your records centrally, you could at least perhaps also have some proper analysis of the quality of the records you are actually dealing with, because at the moment you do not really know. I would have thought it would have been helpful if, firstly, they were preserved, and secondly, that whilst a decision clearly is going to be made as to whether any access is to be given at all — obviously that is a matter for the Committee — it seems to me that perhaps there should be some analysis of whether the records are in a good enough state to really be worth allowing someone or some attempt to make a match even with consent.

The other thing is that I know there is consideration of having a third party who would assist the donor-conceived person, or both the donor and donor-conceived person, to make the match. While I recognise the arguments in favour of that in that then there is some proper counselling and support for the making of the match, I would just issue one caution that you might want to consider as to which agencies are appropriate to do that. If those agencies are going to be given access to these records and potentially apply for access to the electoral rolls, then they need to be agencies who themselves have proper records management. There are some not-for-profit organisations whose record-keeping is not good and also may not be subject to any privacy legislation at all.

**The CHAIR** — Can you give any suggestions as to whom we might consider?

**Ms VERSEY** — Obviously Births, Deaths and Marriages in terms of holding records.

**Ms GARRETT** — We hope it is good.

**Ms VERSEY** — I feel reasonably confident that they are very good at holding records, keeping them secure and understanding about keeping registers secure. Indeed I think it is obvious; they already hold the present registers, both the compulsory one and the voluntary one. The only issue about that would be that they are not a counselling service, although they would probably have to provide some counselling in the course of having to deal with people who are registering deaths, et cetera. That may be an issue, but I suppose if they were given the responsibility then that could be adjusted. I do think it is important to consider, whatever organisations provide the service, that at least they are subject to privacy legislation and are capable of keeping these records secure.

**Mrs PETROVICH** — Thank you very much for your presentation. You talked about a central facility and you also talked about the anonymity and how we guarantee the contract that was given to those donors about ensuring their privacy. If we go to a central agency, how then do we guarantee that privacy on behalf of the agency which originally created that contract, and is it transferable?

**Ms VERSEY** — That is obviously an issue that you would need to consider. I would have thought that if you legislate for the records to be transferred then, yes, it is transferable. We are talking about pre-1988 records, of course. The other issue is that you could build into your legislation the protections around the confidentiality of the records. You could put stricter privacy protections onto those records than you actually have under either the *Health Records Act* or the *Information Privacy Act*. You could actually put the safeguards into the

legislation around the records. That might get over necessarily having to have an organisation that is subject to privacy legislation, although I have to say it does help because they are usually attuned to the issues and have obligations anyway in terms of secure record-keeping.

**Ms GARRETT** — Just as an extension of that point, in your experience, taking into account health records, is there something in a similar vein that may be able to be achieved by creating some mapping, standards or something about what the existing clinics could do to preserve the records that exist within their keeping?

**Ms VERSEY** — Yes. I will have to think about that, but one of my concerns is that it is a bit of an unknown as to what the quality of the records are, which is why my thought was that if you centralised and preserved the records, you would have someone who could actually assess what the quality of the records are. Some of these clinics may have been really quite small, and some records do not exist at all; they are probably likely to have been destroyed. But I suppose it was just the idea of someone who can properly manage those records. It is a bit like the Guthrie cards, where there was quite a big push to get those cards managed properly. It was in my lifetime at the Privacy Commission when there was quite a lot of media publicity about who was managing the records. They eventually became declared public records. They are managed now in accordance with the *Public Records Act*. There was quite a lot of concern expressed in the media about the management of those cards.

**Mr CARBINES** — VARTA, in its submission and presentation, talked about a number of records that are of a high quality, and that obviously relates to their experience in the past in dealing with a particular role. What is your assessment and how widespread would that be? Are you saying that perhaps the quality of records would have a bearing on one of your contentions?

**Ms VERSEY** — I am expressing that it is a concern having read the previous information, and I acknowledge that there may well be some records which are perfectly well kept depending on the nature. It just seems to me that there is quite a patchwork. It may be that it is another possibility — and I suppose I am just floating ideas for the Committee to consider — that those that have got good quality records and can manage the records can retain them. The difficulty with that is if you have two different rules, someone has got to decide whether the records are being kept properly, and which ones are of poor quality and have not been kept properly.

**Mr CARBINES** — Then in the end the quality of the records does not change the contention you are putting in your submission that there should be donor consent before information is made available in regard to the quality of the records?

**Ms VERSEY** — No, my submission is that it should only be done with donor consent, given the basis upon which they were collected and the assurances given that, for them, make it retrospective. That raises some real issues.

**Mr CARBINES** — I want to pick up on your earlier comments on adoption matters. We are again talking about the records because when people have tried to pursue information around their adoption records there have been inconsistencies about the quality of the information that is available to them to be able to pursue getting answers about birth mothers, or what have you. Do you have a view about that?

**Ms VERSEY** — I think the only thing is that at least there was a minimum and that was a birth certificate. One would expect that the birth certificate at least would have some accurate information. What I am saying is that that is very different from a situation where a donor is given an assurance of anonymity, and there probably was not the rigour around making sure that at least you have that initial record of whom you were dealing with, so you may not even have a right to pursue; you may not have an accurate record of whom you were actually dealing with.

**Mr CARBINES** — It is good that you have raised that point because it comes up in the deliberations of the Committee and in some of the submissions we have received when there are other aspects involved. Do you think people are trying to draw conclusions from the changes around adoption information? We talked about information collection, but do you think there are any other aspects that define the difference between what has happened in recent times around adoption information practices and what we are considering — that is, when people are saying, ‘You could do what has happened there’, are there other reasons that you think what has happened there does not apply? Is it not as simple as that?

**Ms VERSEY** — One of the things that strikes me about this situation and adoption is that there may have been myriad reasons why someone might have decided to donate. It could have been a university student without any thought about what the consequences were, just wanting to make \$50 or whatever. I think the previous reports all gave a variety of scenarios where people made the decision to donate.

I think that is quite a different circumstance to a woman who conceives a child that may have been a pure chance or mistake, but then gives birth to the child and makes that decision to give it up for adoption, or may have been forced to because she was young and under family pressure. Nevertheless when I say that more thought went into it, there was much more that went into that than to someone who never even considered the consequences that at the end of the day there may be a child born from giving a donation and they did not have any conception of what the long-term consequences were. They were told they were going to remain anonymous. They agreed they would not try to contact the child, and they may have agreed to that for all sorts of different reasons when making the donation. That is quite an important difference between the adoption situation and the donor situation.

**The CHAIR** — Scott, do you have anything you want to add? Was everything covered?

**Mr MAY** — No. I think I am all right.

**Mrs PETROVICH** — I have just one more question on that point. I think it is rather interesting, but it may have been a sexist point you just made actually.

**Ms VERSEY** — I was not meaning it to be sexist.

**Mrs PETROVICH** — No, I was just being facetious. When those donations were made there was an agreement that there would be no contact to seek the child, maybe without any thought that there was going to be a child. How do we protect the rights of the donor-conceived person now whereby their privacy might be breached when their donor realises that they may have a family, or several families, out there?

**Ms VERSEY** — That is actually a very good point because we have been somewhat concentrating on the donor-conceived person's rights. I think that is why it should really be by consent. If there is going to be identifiable information released to the donor-conceived person, it really should be with the consent of the donor. I think that would meet that concern because of the assurances they were given.

**Mrs PETROVICH** — Because pre-1988 some of these people may not even have been aware that they were donor-conceived.

**Ms VERSEY** — Exactly, yes.

**The CHAIR** — Thank you very much for your attendance.

**Committee adjourned.**