LEGAL AFFAIRS AND SAFETY COMMITTEE

Members present:
Mr PS Russo MP—Chair
Ms SL Bolton MP
Mrs LJ Gerber MP
Mr JE Hunt MP (virtual)
Mr JM Krause MP
Mr JR Martin MP
Mr TJ Smith MP

Staff present:
Ms R Easten—Committee Secretary
Ms R Pye—Committee Support Officer

PUBLIC HEARING—INQUIRY INTO THE MATTERS RELATING TO DONOR CONCEPTION INFORMATION

TRANSCRIPT OF PROCEEDINGS

FRIDAY, 13 MAY 2022

Brisbane

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The committee met at 10.30 am.

CHAIR: Good morning. I declare open this public hearing of the Legal Affairs and Safety Committee's inquiry into matters relating to donor conception information. My name is Peter Russo. I am the member for Toohey and chair of the committee. I respectfully acknowledge the traditional custodians of the land on which we meet today and pay our respects to elders past and present. We are very fortunate to live in a country with two of the oldest continuing cultures in Aboriginal and Torres Strait Islander people, whose lands, winds and waters we all share. With me here today are: Laura Gerber MP, the member for Currumbin and deputy chair; Sandy Bolton MP, the member for Noosa; James Martin MP, the member for Stretton, substituting for Jonty Bush MP, the member for Cooper; Jason Hunt MP, the member for Caloundra, via videoconference; and Jon Krause MP, the member for Scenic Rim.

This hearing is a proceeding of the Queensland parliament and is subject to the parliament's standing rules and orders. Only the committee and invited witnesses may participate in the proceedings. Witnesses are not required to give evidence under oath or affirmation, but I remind witnesses that intentionally misleading the committee is a serious offence. I also remind members of the public that they may be excluded from the hearing at the discretion of the committee.

These proceedings are being recorded and broadcast live on the parliament's website. Media may be present and are subject to the committee's media rules and chair's direction at all times. You may be filmed or photographed during the proceedings and images may also appear on the parliament's website or social media pages. We ask that you please turn your mobile phones off or to silent mode.

GELBER, Professor Katharine, Private capacity

CHAIR: Good morning. I invite you like to make an opening statement, after which the committee will have some questions for you.

Prof. Gelber: Good morning, everybody. I thank the Queensland parliament for holding this inquiry on an issue that is very dear to my heart. Thank you for the opportunity to give evidence today. Obviously you will have read my written submission. I welcome any questions in relation to that material.

In my preliminary remarks I want to focus on two particular issues. The first is that the evidence shows that the NHMRC guidelines do not work in practice. We therefore need a statutory scheme to require compliance, because we are not getting compliance. The second is the issue of retrospectivity, which I understand is highly contentious but which nevertheless, in this instance, I think is warranted, legitimate, valid and ought to be pursued by the Queensland parliament.

As a preliminary comment I stress, as I did in my written submission, that this issue is at least 20 years behind adoption. Decades ago, everybody believed that adoption worked best if people did not disclose anything about it and if records were kept secret. Some organisations even wilfully destroyed records, believing at the time that it was in the best interests of the people they were serving. We now know that that was wrong. We now know that the best outcomes are when adoptees have access to identifying records about their birth families. Donor conception is similar in that respect.

When donor conception as an industry started in Australia about 40 years ago, everyone believed that anonymity was best. This was a new technology; it was a new industry. Clinics even deliberately destroyed records to keep identities secret. These days we know that this causes harm—in particular that this is harmful to the donor-conceived. We know, from extensive research in this area that the best practice is for donor-conceived people to have access to identifying information about their donors, regardless of when they were born.

This access is being denied in multiple ways. In some ways it is being denied legislatively, in jurisdictions which have an arbitrary date. If you were born before that date you do not have access to records and if you were born after that date you do have access to records, which is entirely unfair. In many cases, as you will have seen from the written submissions to this inquiry, access is being denied by the capricious behaviour of individuals who work in clinics. At the moment, a donor-conceived person's ability to access the information they even have a right to under the guidelines is arbitrarily controlled by the person on the other end of the phone. If you happen to have a friendly person on the end of the phone you will get information and if you happen to have a clinic like mine you will not. You will be stonewalled, lied to and deceived. That is simply unfair and unfathomable in today's society.

I start with the fact that the guidelines do not work. I hope that reading the submissions to this inquiry has convinced you that the guidelines—although they are well meaning and well drafted and since 2004 they have prohibited the use of anonymous gametes—are simply insufficient to tackle the issue that we are talking about today. The guidelines state that anonymous gametes should never be used. In practice, we know from the heartbreaking stories that you have been hearing that clinics are poor at record keeping, that today they still often obfuscate and block access to information when people request it and that a person's access to fundamental information about their biological heritage—information they should have a right to access—is often determined capriciously.

The records we are talking about are birth records. In all other areas of birth we have laws that require records to be kept in perpetuity in a safe environment by government. Those records need to be kept safe forever. Instead, right now in Queensland we are allowing these records to be kept by private clinics that have shown time and time again that they do not have the expertise or the commitment to do this safely. These clinics are routinely sold on to ever-larger clinics. Records then pass in ownership from the clinic a person may have received treatment from to two, three or four clinics further on. There is no guarantee at the moment that those records are kept safely.

Clinics are evidently, from the evidence you have seen in the written submissions, not dedicated to keeping records safe. Indeed, they are not even dedicated to keeping those records accurate. My son was born in New South Wales. Under the NHMRC guidelines and the practices of my clinic, I selected a donor who agreed to be identified and contacted. I was told when my son was five that the donor had changed his mind. I subsequently, through the New South Wales health department, contacted the clinic for records regarding the year of birth and the gender of any siblings of my donor-conceived son. I got this letter back, which I am happy to pass across the table. There are five children listed—the year of birth and the gender identity of those children.

After I received that letter, there was an amendment to the law in New South Wales that set up a register and that required clinics on request—not mandated—to provide relevant information to the register. I already had that information. Nevertheless, as a recipient parent I put in a request to the registrar for the year of birth and gender of siblings. I was anticipating getting exactly the same information back, but I did it because I knew that it would force the clinic to provide the information to the register and I wanted that information to be on the register and not held by the clinic. So I put in a second application for the same information for the sole purpose of forcing the clinic to provide the information to the register and I got this letter back. It lists 10 siblings. It does not match the first letter. When my clinic was required, under law, to provide accurate information to a register of donor conception, they did their due diligence. They checked and double-checked the information that they had, and I got an entirely different set of information from that first letter which I have circulated to you.

There are countless stories like this. You have read in the submissions of people who had the same donor and were told two different things and of people who were told that the clinic had lost contact with the donor and yet, years later, they make contact with the donor through other means and the donor says, 'The clinic never even tried to contact me. I still live at the same address I was living at when I donated. They made no attempt to contact me.' This happens all the time.

The second issue I want to talk about is retrospectivity. I realise that the issue of retrospectivity is challenging, partly because donors in the past were guaranteed anonymity. There are multiple responses to that. Times have changed. Our understanding of the harm to donor-conceived people of anonymity is far greater than it used to be. We were brave enough to change the law in adoption. We were brave enough, as the Office of the Information Commissioner has recognised, to limit the right to privacy of, for example, people who gave up children for adoption in order to do the right thing by adopted people. We need to do the same thing here. In fact, there are many donors, some of whom made submissions to this inquiry, who would prefer not to be anonymous but who were told that was their only option. Identifying information should be made available to all people regardless of when they were born and does not require contact. It is central to a person's identity and the donor-conceived have a right to that information.

My experience is that donor-conceived people are very respectful of the rights of donors. I recently met a young woman who had reached out to her donor in Victoria, prior to the change of law in Victoria in 2016 that mandated identity being open to everybody regardless of when they were born. At the time she reached out to her donor he declined to provide identifying information. He provided other information. I said to her, 'You do know that now you have a right to that information.' She said, 'Yes, I know I have a legal right to it, but he declined to give it to me in 2009 and I respect that, so I'm not going to pursue it.' That is my experience of donor-conceived people. They are very respectful of this situation. Without retrospectivity, there is an arbitrary date after which some people have access to a basic human right and others do not. That is why Victoria in 2016 legislated to make identifying information retrospective.

Queensland has the benefit of watching all the other states having done this before us. That means we can learn. We can learn from their mistakes and make sure that we have the best practice in this area. I urge the Queensland parliament to adopt the best practice in this area.

Mrs GERBER: Thank you. Professor, for coming and telling your story and giving us all that information. You may not be able to answer this question, but I am hoping that you can. Can you tell us what other jurisdictions have put in place in relation to regulating this area?

Prof. Gelber: Yes. Professor Sonia Allen can give you better information on that this afternoon. She ran the West Australian and South Australian inquiries. In a nutshell, Victoria has the best legislation. Victoria in 2016 mandated that everybody, regardless of when they were born, has the right to identifying information. They have a register but it is held by an independent body called VARTA, the Victorian Assisted Reproductive Treatment Authority. The problem with that is that the Victorian Assisted Reproductive Treatment Authority provides services both to the donor-conceived and to the fertility industry, and that creates a conflict of interest for them. That is why I have recommended, and Professor Allen has also recommended, that here we put the register in Births, Deaths and Marriages. Victoria allows identifying information. It allows donors to specify whether they wish contact or not.

South Australia has recently legislated as well. I believe that they are moving towards the removal of anonymity, although I am not sure if they have done it completely yet. Western Australia is doing the same. Tasmania has the weakest position of any state that has a statutory scheme. They have allowed the clinics to retain hold of the records. I believe that people can apply through the government department, but the clinics hold the records and there is no retrospectivity.

In New South Wales they amended the law in 2010. My son was born in 2006. New South Wales has a central register which is held by NSW Health, and donor-conceived people born before 2010 can voluntarily put themselves on that register. If they get any matches to either a donor or siblings, they can get access to siblings by mutual consent and the donor also by mutual consent through that register. Post 2010, all donor-conceived people in New South Wales have the right to access identifying information about their donors. They have an arbitrary line in the sand. My son was born in 2006.

Mrs GERBER: When you say 'identifying information about donors', is that defined differently between the jurisdictions?

Prof. Gelber: I do not believe so. I believe it means their name. I believe that is what it means—their name.

Mrs GERBER: I am trying to ascertain what 'identifying information' is defined as.

Prof. Gelber: I believe it is their name. Professor Allen will be able to answer that.

Ms BOLTON: Some other submitters have concerns about potential changes. One of those is that whatever laws arise from the inquiry may result in Queenslanders going overseas as an unintended consequence. Is this a reality?

Prof. Gelber: It is. The primary way that people access overseas gametes is by importing them, so it would be very important that any Queensland scheme closes that loophole and requires any internationally imported gametes to be subject to the same identification provisions as any gametes sourced from Australia. That is the primary way that people do it. It is obviously more expensive, difficult and time consuming to physically go to another country for reproductive services. If you close that loophole on the importation of gametes, at least you have covered most of the problem. In the end you cannot control everything, but having a good scheme that closes the loophole on the international importation of gametes would be the best way to achieve that important right.

Ms BOLTON: Within your submission you noted the intentional destruction of all donor conception records. Is that something that you believe would happen as a result of potential changes?

Prof. Gelber: No, I do not. I believe that the intentional destruction of records is a historical practice that no longer applies. Having said that, the way that records currently get destroyed or rendered inaccurate is primarily through negligence, as opposed to a deliberate act. Under the NHMRC guidelines that, on paper, clinics are required to adhere to in order to continue to receive a certificate to allow them to practise, they have to attend to their record keeping. It is my view that the majority of clinics would not wilfully and deliberately destroy records in order to get around this. What they may do is say that the provision of those historical records is time consuming and expensive and they may ask for a long window of time in order to retrieve and to check the accuracy of those records. That would be fine.

CHAIR: So there is also the danger that, in that process, some historical records may not be available to be lodged with Births, Deaths and Marriages?

Prof. Gelber: That is true, and that has been the case in other jurisdictions which have now legislated for the provision of those registers. Unfortunately, some people find, particularly from the very early days—late 1980s and early 1990s—that it is simply not possible to access records as the records no longer exist. It is very unfortunate. It is obviously not a reason to not legislate for retrospective access, because we can only do the best we can with the resources that are still available to us. Securing those records now and not waiting another 10 or 20 years is absolutely vital to people's wellbeing.

Mr KRAUSE: Professor, thank you for your submission. Am I correct in saying that you support the provision of identifying information to donor-conceived children but you also support the right of donors to opt out of contact?

Prof. Gelber: Yes.

Mr KRAUSE: It seems to me that the decision to opt out of contact could be usurped if people have identifying information about the donor, because they could unilaterally make contact. Have you considered that?

Prof. Gelber: Yes.

Mr KRAUSE: How would you respond to that concern, because I think it is a concern some donors would have?

Prof. Gelber: My experience, having worked in this area for 11 years now—there are others who have worked on it for longer—is that donor-conceived people are typically very respectful of their donors if they know that the donors have opted not to be contacted. I urge you to ask the donor-conceived people who are speaking to you today that same question.

Yes, there is a risk, but what is happening now is that people are using DNA databases and are using entirely informal mechanisms to make contact. Some of those stories have happy endings and some of those stories have tragic endings. At least if we have a properly funded system with appropriate counselling services and an ability to say, 'This is what the law says—yes, you can have identity but they can choose contact,' that is educative. It tells people that there is a difference between identity and contact and that even if you have been able to identify your donor that does not mean you should automatically contact them.

I realise that is a risk. I think it is an overblown risk. I think it is more a hypothetical risk than a real risk. I am not saying that it would never happen, but in the majority of cases I believe that somebody who knew that their donor did not want contact would not make contact. After all, anyone is allowed to refuse a human relationship. We cannot force relationships on people. Nobody wants to force relationships on people. It would not be very fruitful for somebody to try to force a relationship on somebody who has told them that they do not want that relationship. This situation is fraught and heartbreaking for donor-conceived people, and that option would put them in greater danger for their wellbeing. I think it is an overblown concern. I will not say that it would never happen, but I think it is not a reason not to legislate.

Mr KRAUSE: Thank you for your comments.

CHAIR: In relation to the letters you have provided to the committee, do you want those to be accepted by the committee but remain private so that they are not published?

Prof. Gelber: Yes, please. I do not want them published. They are my copies, but I am happy to provide a copy to you. I did not mean to give them to you to keep.

CHAIR: We do not need to accept them for the purposes of this hearing, unless you think it is vital to our deliberations. I believe it is not.

Prof. Gelber: I agree; it is not vital to your deliberations. I am just happy that you have seen them.

CHAIR: I think that you have explained it in your evidence quite distinctly.

Prof. Gelber: Thank you.

CHAIR: We will return those. Thank you for your time this morning and for your detailed submission.

Prof. Gelber: Thank you very much. I wish you all the best with the inquiry.

ROOS, Professor Daniel, Private capacity (via videoconference)

CHAIR: Good morning, Professor. I invite you to make an opening statement before the committee asks some questions.

Prof. Roos: I am not sure if you have a record of the statement I made, but I will briefly summarise.

CHAIR: We have your submission.

Prof. Roos: I will not repeat that. I sympathise with the need of donor children to understand their genetic origin. The reason for that is that I was adopted, so I needed to know the identity of both my mother and my father. For most donor children it is only father or mother. Having said that, my journey has made it very clear that there is a lot of unpredictability in the responses you get along the way from people involved in this process.

Some people are totally offended by the whole idea of identifying and meeting each other. That is something I cannot understand, as I feel completely the opposite. Whilst I think the primary aim or primary focus should be on the right of donor children to discover their genetic origins, there will be a small proportion of donors in the era which included me, when donation was meant to be an anonymous process, who will not wish to be identified. In those circumstances, I think that right also needs to be taken into account.

Mrs GERBER: Thank you for your appearance and your written submission as well as your oral evidence. In your written submission you provide us with an observation that you believe that the process should be publicly funded and that access should not be dependent upon ability to pay. Can you talk us through that issue? What is the cost at the moment and what are those pathways that you are talking about?

Prof. Roos: In my own experience there was no payment required at all, because two of my donor children discovered me via AncestryDNA. The cost of that is about $100. Subsequently with the other five, we discovered each other by the same process. We are talking here about a donor registry, and the infrastructure costs associated with that and the cost of accessing that is a state responsibility. That would be my personal view.

Ms BOLTON: This may be a personal question, but do you believe that the reason some donors do not wish to be identified is that they do not want to be identified or that they do not want to be contacted?

Prof. Roos: It could be either. I think it is critical for donor children to have answers to their questions—obviously, medical background or history of cancer in their donor parent. As much as is possible, that information should be mandated to be available. There will be a small subset of people who would be horrified by contact. I think that is the critical thing that needs to be respected. I guess what I am saying is: there can be legislation for a default situation, but there always needs to be an opt-out clause for the rare cases where people do not wish, for their own reasons, to take part in the process.

Mr HUNT: Where do you think the balance might lie between the right to access information and any sort of privacy protections, if any, around a donor? Is there a fulcrum between privacy and need?

Prof. Roos: As I said, I think biological aspects need to be accessible, but the right to meet is something that a few donors will not be comfortable with. To my mind, in terms of the meeting aspect—the identification, the ability to talk, finding out an address—there will be a few donors who will not want to be seen, let alone met.

Mr HUNT: Without putting words in your mouth, the balance, then, is provision of all of the information but the check is contactability? Is that where the balance lies?

Prof. Roos: Yes, in my mind. I am assuming that that will be only a small proportion of donors.

CHAIR: Professor, in relation to your personal experience, which you have articulated in your submission, is it fair to say that you were able to be contacted through other means when that occurred?

Prof. Roos: Yes. AncestryDNA, which is probably the most commonly utilised direct-to-consumer DNA private company, will automatically contact individuals who are on their registry when there is a match. If another one of my donor children chooses to submit their DNA to AncestryDNA, I will get an automatic notification that I have another donor child and vice versa. That does happen. I assume that the other direct-to-consumer DNA companies operate the same way. It is a bit scary in a way, because once you are in the process there does not seem to be a mechanism to stop that happening, although I could be wrong. There may be an opt-out clause, but I am not aware of that.

CHAIR: In that example we have just spoken about, isn't it a case where the law needs to catch up with the way modern technology works? Even if the law does not say that it is retrospective, isn't it occurring anyway through other means?

Prof. Roos: Yes, it is—very much so. I imagine that it is by far the most common way that donors and donor children are finding each other these days. It is a real pain, because there are several of these companies and donor children may have to submit their DNA to each of them in the hope that they would find their father.

CHAIR: Professor, thank you very much for making yourself available to the committee. Is there something that you feel we need to know or that we have not asked? Please feel free to contribute. If not, I will conclude this part of the hearing.

Prof. Roos: I am happy to contribute and I am glad that you are considering this.

SMITH, Mr Ian, Private capacity (via videoconference)

CHAIR: I invite you to make an opening statement, after which the committee will have some questions for you.

Mr Smith: The perspective that I can bring to your deliberations is threefold. I was a sperm donor myself in the 1980s, like Professor Roos, whom you have just spoken to, but I was in Melbourne. I have also been very involved in working with both donor-conceived people and donors over probably the last 10 years, so I have quite a rich perspective from that. The third perspective I offer is that I am currently conducting research into the policy dynamics, the socio-legal dynamics, behind the Victorian legislation, which, as you would know, is the first in Australia—in fact, the only place in the world where retrospective legislative has been carried to remove donor anonymity. I am looking at that from a research perspective, so I am bringing in all of those perspectives.

The first I would say, as I said in my submission, is that this is an incredibly complex area. You have medico-scientific practice. You have competing human rights: you have the human rights of the donor-conceived people and you have the human rights of donors. As you just said a moment ago, Chair, the law is catching up with the practice here and it is a really messy area. I would say that what it requires is a really nuanced approach to that complex dynamic. It is not a black-and-white issue. It requires a nuanced approach.

I will not go into the detail of my submission—you have it there—but I will pick out three things that I think are particularly worth considering. The first is this issue that is at the base of this discussion, which is the argument from donor-conceived people—which I essentially agree with—that they have a right to know their identity. That is extremely powerful. I agree with that. The issue from my perspective is: how do you go about achieving that in a way that recognises the needs, the rights and the wants of everybody involved? The donor-conceived people, the donors and the recipient parents are in that mix.

Again, as I said a moment ago, what I argue for is a nuanced approach to get an outcome that is the best possible outcome. My professional work has been in mediation and conflict resolution. Generally in those cases you will have two parties who both believe that their right is the most important one. If you have a win-lose situation then somebody loses. What I am arguing for is, if you can, to achieve the best possible outcome for as many people as possible. It may not satisfy everybody but it is about having a facilitated approach rather than a heavy-handed approach.

The second thing I would pick up on—a number of submissions have talked about it and it has been discussed this morning—is this issue of DNA. DNA testing, as many people have said in their submissions, has completely blown anonymity out of the water. It does not exist now, but you have the problem for historical donors like me. We were promised anonymity. DNA does effectively remove that.

Getting back to my point about taking a nuanced approach, I do not think it is just a matter of saying to donors like me, ‘Tough. Get over it. Get out of the way. We are doing this.’ I think DNA has a part in that. What I have suggested in my submission is that there is a possibility to use DNA in a very proactive and effective way—for example, in verifying records and ensuring correct matches are made. I think Professor Gelber mentioned that at the moment it can be done in a very clumsy fashion. There is the potential to use DNA quite productively.

A related issue to that which I have touched on is that I think there is a great need for a better national approach here. You have a complete patchwork. You picked it up in some of your questions before about what the different states and territories are doing. Federal-state coordination is not simple but I think it is really important.

The final point I would make is that one of your terms of reference is around the issue of private donations. These do exist. It is a growing area. It is really messy, but I think you have to recognise that it is happening. If you do set up a register in Queensland—which I would strongly recommend—allow people to register those private donation arrangements. You cannot control them but I think they should be recognised. I go back to the point of enabling donor-conceived people to find their identity. If you can help with that then I would advocate for including private donors in those registers. I will stop there. I am happy to take questions. I am happy to answer anything. Nothing is off limits with me.

Mrs GERBER: Thank you very much, Mr Smith, for your oral evidence as well as for your very comprehensive written submission. I just want to pick up on something you just said about private donations. I do not know what you are talking about when you say that. Are you able to explain for the committee the parameters around what you are talking about when you refer to private donations?

Mr Smith: Yes. You have the clinics who run the ART programs. Sperm donors and egg donors donate to those clinics. The records are held there. The register that exists in Victoria just deals with the sperm and egg donations that are made through a clinic. There is a whole other area of practice which is growing whereby people make their own arrangements for sperm or egg donations—more likely sperm donations. People have Facebook pages. There are Facebook groups that actively solicit people to be donors. That is what I am talking about—people who make arrangements outside the clinics. It results in donor-conceived people who run into exactly this problem that the clinic based donor-conceived people do of not being able to know their identity. What I am saying is that if you can find a way of helping with that then I think that is a good thing to do. Does that answer your question?

Mrs GERBER: It does. Has any other jurisdiction managed to deal with that yet?

Mr Smith: Not to my knowledge. Victoria is the one that I am most familiar with and, as I think we have said before, it is the most comprehensive. The legislation in Victoria does not allow for private donors to register themselves with the central registers that are maintained. I know of cases where private donors have attempted to do that and the legislation just does not allow for it.

Ms BOLTON: Obviously you are familiar with the Victorian model. When you spoke about the retrospective nature of what Victoria has done, have you found within the results that there have been any unintended consequences?

Mr Smith: It has been interesting to look at the experience in Victoria, because there was a lot of alarm at the time the Victorian legislation went through that there would be the kinds of things we have talked about this morning, of donors who did not want to be contacted—the donor-conceived people breaching contact vetoes, making unintended contact. In fact, if you look at the reports from the Victorian Assisted Reproductive Treatment Authority, to my knowledge there have been no instances of donor-conceived people who have been given the identity of their donor where the donor has lodged a contact veto—and there are a number of donors who have been in that circumstance who have said, ‘Okay I accept that my identity is being released.’

To answer the question that came up before, the donor-conceived person is given the name of the donor. That is the identity release. There is a provision in Victoria for donors to lodge a contact veto. A far as I am aware—and Professor Kelly, whom will be talking to you this afternoon, has also said this in her submission—there have been no instances of contact vetoes being breached.

There is an analogy with adoption. The same issue occurred there. When adoption records were opened up, some relinquishing parents were worried about their identity being released and there being unwelcome contact. Contact vetoes were put in place with the adoption legislation and it was the same experience. They were there as a safety net. As Professor Gelber said, donor-conceived people in my experience are very respectful. They are not about pushing a relationship on somebody who does not want a relationship with them. For many of them, knowing the name of that person is critical.

CHAIR: Dealing with the veto in the Victorian legislation, it is the case that, even though someone may have a contact veto, through alternative means they could still find that out.

Mr Smith: The technology exists. Once you have somebody’s name you can find out a lot about them, and donor-conceived people do. I know that that happens. In my experience the point at which they stop—they will find out information about their biological parent, their donor, but it is the unexpected knock on the door that some donors are worried about. I do not know of any instance where that has occurred.

Mr KRAUSE: Thank you for your submission and for your evidence this morning. I do not think it is covered in your submission, but can you tell the committee whether you are aware of any issues around the country that have come about in terms of succession law as a result of identity being disclosed and opened up?

Mr Smith: Yes. I am not a lawyer. I am doing a PhD in a law school but I am not a lawyer. I will say that up-front. The first thing I would say is that that is a frequent worry. It came up often in the debate in Victoria—and it has come up in some of the donors who were worried about this removal of identity—that they would be subject to claims on their estate. I think that is what you are getting at there. My understanding of the law, in Victoria at least, is that that is precluded. A donor-conceived person cannot, by force of law, make a claim on their donor’s estate. I am talking there about a donor such as myself who donated through a clinic. It is very clearly precluded.

This issue of private donations that we talked about before gets much more messy. There is a risk for people making those private arrangements—men who donate their sperm privately. They could potentially open themselves up to that kind of a claim. Again, I am not a lawyer; I am speculating there. In terms of donors donating through clinics, the legislation in Victoria at least—and the Victorian legislation is the most comprehensive—precludes that.

CHAIR: Just to be clear, you are talking about the donor-conceived legislation prohibiting claims under succession law?

Mr Smith: Correct.

Mr HUNT: I am going to ask you to speculate again, if you could, about potential private uptake of going onto a register. Do you think that would be utilised if that were an option—for people who are utilising the private channel to go onto a register as well?

Mr Smith: Yes, I think it would. The degree to which it would I do not know, but I do know of instances. The reason it is in my mind is that in Victoria I have been approached by somebody who was involved in a very cooperative private arrangement for donation who wanted to register himself on the Victorian register so that that information was collected and available to his donor-conceived daughter. He was told, 'No, we can't do it in Victoria; the legislation doesn't allow for it.' That is a sample of one. Beyond that, my sense is that, from talking to donors, including donors who are in these private arrangements, there would be some—almost certainly not all. My argument is: allow for it. Recognise that it is there. It is not going to go away. The point was made before by the chair: the law is catching up with what is going on here. Here is an opportunity to anticipate what might be a demand there.

Mrs GERBER: Why would someone choose to go through a private donation rather than a clinic? In order for to us regulate it or to set parameters around it, it is important for the committee to understand the motivations and the reasons people might do that. Are you able to give the committee any information about that?

Mr Smith: My first comment is that the demand for assisted reproductive technology is driven by a really profound desire by people who want to have children and are not able by natural means to do so. My observation is that in some cases people will do just about anything to achieve that aim. Earlier you touched on the fact that people will travel overseas for ART treatment or they will seek gametes from overseas. It is it is a variant on that. People will go outside the clinics if they can see a possibility of conceiving that way. For some of those people it might be a monetary issue. The cost of treatment through the clinics is very significant. If you can find a private sperm donor who will assist you, you may do that.

I go back to the fact that my observation is that people who want to have children, who cannot naturally, in some cases will go to any means and potentially put themselves in a dangerous situation. One of the problems with these private donations is that there are men out there, unfortunately, who are quite unscrupulous and who offer what is termed 'natural insemination'—in other words, having sex with women in order to impregnate them. There are all sorts of risks with that, but women will do it in order to achieve their aim. Does that go some way to answering your question?

Mrs GERBER: Some way, definitely. Can you give us an indication of how much it costs for someone to go through clinics for a donor-conceived child?

Mr Smith: I will not try to answer that because I am not across that detail. I do know that it is very expensive. You are talking to a clinic this afternoon, so ask them what they charge. It is a lot.

Mrs GERBER: Is there anything else that you wanted to share with the committee that we have not asked you about?

Mr Smith: Probably the other thing I would pick up on is the retrospectivity, as one of the committee members said before. It is a really tricky question. I have said in my submission that one of the difficulties with retrospective legislation is that it runs against a basic principle in law, that you can rely on the law as it is at the time that you act. Retrospectively changing legislation, such as happened in Victoria, runs directly contrary to that. It is one of the major concerns that I have heard from donors who were unhappy with the Victorian legislation. They say, 'We were made a promise at the time we were donors. We entered into that arrangement in good faith and now'—decades later in the case of Victoria—'you are shifting the goalposts.' The answer to that is, yes, that is happening and it has happened in Victoria, and it has happened for a very good and strong reason.

It goes back to the point I made at the start of my comments. I am sure that the donor-conceived people whom you will talk to later today—I think you have heard it already from Professor Gelber. The donor-conceived people in particular make the argument that it is their human right to know their identity. Notwithstanding the fact that people like me and Daniel Roos, whom you spoke to before, were promised anonymity when we signed up to be donors in the eighties, you have to weigh that against that really fundamental human rights argument that, ultimately, it is more important for the donor-conceived people to be able to know their identity. That makes the argument for making a retrospective change and going back on a promise that was made to people like me. Again, as I said before, I think you do it in a nuanced fashion. You do not just say to the donors who are anxious and worried about this, 'Well, too bad. We've changed the rules. Just get out of the way and get on with it.'

The other argument—Professor Gelber touched on this—is that the point of making this change retrospective is that—I cannot remember at what point anonymity was removed in Queensland; I believe it has been removed as a requirement for donors—

CHAIR: No.

Mr Smith: It is not? Okay.

CHAIR: Our inquiry is to look into the options.

Mr Smith: It is prospective? Okay. In Victoria there were several different tranches of legislation at different points in time that altered those rules around anonymity. What you had in Victoria—you will have it in Queensland—is donor-conceived people depending on not even when their conception occurred but when the donor donated. It may fall under different tranches of legislation. In Victoria you had four or five different sets of entitlements for donor-conceived people in terms of access to information. The argument to change this retrospectively was to say, 'We will create a level playing field for all the donor-conceived people. We will go right back to the beginning of clinic based donor conception and level the playing field.'

Retrospectivity is very contentious. It is not something that should be done lightly. There was an argument in Victoria, and I supported retrospectivity here. If you are going to do that, do it really carefully and sensitively and do not just sweep the rights of donors away. Deal with them respectfully. If you are going to make this retrospective change, explain to them why it is done and build in some protections. This goes back to the contact vetoes or whatever you choose. That was a quite contentious issue in Victoria. I have seen it in the submissions to this committee. Some donor-conceived people say, 'No, there should not be contact vetoes.' I argue that there is a place for that. I do not think they will be needed, based on the Victorian experience, but it provides that reassurance, for historical donors in particular, who are worried about that loss of identity. That was a long answer to your question about retrospectivity. Hopefully that is useful.

CHAIR: Just dealing with the private arrangements that you referred to, something occurred to me while you were talking about that. That could be covered, for example, by our Births, Deaths and Marriages. Obviously the form where you register would have to be adapted to take that in.

Mr Smith: Correct. It could be fairly simple. It is just a matter of allowing the option—for example, when somebody is registering a birth and it has occurred via a private sperm or egg donation outside of a clinic—for that could be registered and recorded. It becomes then part of the information that is available. The argument for having that information held by Births, Deaths and Marriages is that if the donor-conceived person comes along 20 years into the future looking for that information it is all there. It is not a matter of them having to go and search for it. I think it would be a fairly simple thing. In Victoria it was just that it had not been allowed for in the legislation so it cannot happen; it is not allowed to happen. If you build it in at the outset, that is what I am advocating.

CHAIR: Thank you for your time and for your written submission.

Mr Smith: Thanks for hearing me.

PAGE, Mr Stephen, Director, Page Provan

CHAIR: I invite you to make an opening statement, after which the committee will have some questions.

Mr Page: I would like to take up some of the points that Mr Smith raised, because I have knowledge of some of those matters directly. I want to thank the committee for inviting me to give evidence today. I acknowledge the traditional owners, the Jagera and Turrbal people.

I come here wearing a number of hats this morning—as a lawyer who specialises in this work, as a lecturer in ethics and the law in this field but, most importantly, as a parent through egg donation. My husband, Mitchell, and I have been fortunate to undertake surrogacy in Queensland with the assistance of two extraordinary women—our egg donor and our surrogate—and the assistance of two Queensland IVF clinics that we also had the assistance of, as required under the National Health and Medical Research Council ethical guidelines and the RTAC code of practice. I note that the NHMRC described it as a 'robust framework' of regulation; I would certainly agree.

An ANZICA counsellor provided donor counselling to our egg donor, Mitchell and me. As required under the Surrogacy Act, before entering into the surrogacy arrangement, there was a second ANZICA counsellor for our surrogate, Mitchell and me. As required under the Surrogacy Act, an assessment was undertaken after the birth by a third ANZICA counsellor for a surrogacy guidance report for the Children's Court.

We have embraced the principle of the Surrogacy Act of promoting openness and honesty about our daughter Elizabeth's birth parentage. She is entitled to know, in my view—as is everyone else—about where she has come from. It is a fundamental human right. Elizabeth goes to day care. She is almost three. Of the 100-plus families at the daycare centre, our family is the only one who has two dads. At the age of 18 months, Elizabeth recognised that, and at that point she started calling Mitchell 'Dad' and me 'Daddy', so I am forever 'Daddy'. Mitchell and I have commenced telling Elizabeth in an age-appropriate manner where she has come from, and we will continue to do so. It is a case of show and tell, not hide and seek.

On balance, I believe that it is important for there to be retrospective transparency for pre-2004 donations—and I will take up the question that the chair asked about anonymity—but if that occurs, officials should be writing direct to the donors and to the parents before notifying the children, as opposed to what happened in Victoria. It was the other way around, so kids discovered from a letter rather than from their parents, who had not told them. Ideally, there should be a national donor registry. It would be an improvement on the current situation in Queensland if there were a state donor registry to be run either by Births, Deaths and Marriages or by Queensland Health. I have nothing against Queensland Health, but I think that our registry is remarkably efficient. It is the most efficient in the country. It is responsive, it is self-funding on a user pays basis, it is low cost and it is a natural fit.

I would hope that there would be legislative and administrative measures enabling a Queensland central register to connect with those interstate, so that a donor-conceived adult can search in one place and have all of the records available to them. Queensland IVF clinics have gone from a secret squirrel type of model, where children have not been told where they have come from, to mandated transparency. Queensland now leads the world, in my view, with the quality of IVF and donor transparency, but retrospective transparency in a state central register would be even better.

I will take up the points that Mr Smith raised. I have not read his submission, but I am very familiar with his work and with him personally. The first issue I want to cover is anonymity; it is dead and buried. You can go on ancestry.com.au or 23andme.com and find out where you have come from. We are talking about enormous databases. In 20 years time, of course, the databases will be much greater than they are today. Anonymity was removed in Queensland as a matter of practice in 2004, because Queensland clinics are licensed under a Commonwealth-state scheme, which I have set out in length in my paper—I have set out the legislation so that it can be clearly read—the NHMRC ethical guidelines and the RTAC code of practice—that is, the Reproductive Technology Accreditation Committee of the Fertility Society of Australia and New Zealand. I am a director of the society; I am not a member of the RTAC committee.

Mr Smith talked about not being aware of any case of there being a knock in the door. You will see in my written submissions that I have seen such a case. In Queensland, an anonymous sperm donor received a message on Facebook from a third party—someone he did not know, a lesbian couple—to say, 'Here is your son.' He was in absolute shock. He wondered how that might have happened and I said that it could be one of three ways. The clinic could have leaked—my experience is that they do not; they take privacy very seriously—or there could have been some social interaction, either in person or via social media, where people recognise 'that child looks like mine'; I have seen cases like that. As I said in my submission, there has been such a case in Sydney. Thirdly, someone could have done one of those online searches. Guess what? He thought the clinic had leaked the information but the truth was that his mum had done a search through ancestry.com. There was the answer. One of the things I suggested was for him to go and see a fertility counsellor. He found that very helpful, because this was something which was confronting for him.

The third issue that was raised was about contact vetoes; that sounds very sensible. Victoria has certainly led the world in this area in terms of openness and retrospectivity and I would certainly endorse it. The fourth question that I cover is succession law. Just because someone is a genetic parent, that does not make them a parent as a matter of law; that is under the Status of Children Act or, as the High Court told us in Masson v Parsons in 2019, the Family Law Act. The Succession Act has a wide definition of ‘child’. I am not a succession lawyer—I am a family lawyer who did fertility law—but I would suggest looking at that.

The fifth thing I want to mention is donorsiblingregistry.com. This was started in the United States by a mum whose child wanted to know where she had come from. Queensland IVF clinics import sperm. Most Queensland sperm comes from the US, not locally. We do not have enough, we do not pay donors and we require transparency. They have to comply with Queensland requirements to import. Typically, there are about two or three sperm banks in the US that currently export here. All of our Queensland clinics who use US sperm have signed up.

On that question, Mr Smith mentioned private egg donation. It has to go through a clinic—medicine says that; you have to do IVF—but when you have a sperm donor, of course, it can be done privately. I have been doing private sperm donor agreements now I would guess for over 10 years but, lo and behold, there has been a sharp increase in about the last two or three years. I thought that it must be because of the Masson v Parsons ruling on who is a parent, which asks: is he a donor or is he a parent? No, that is an aside.

There have always been single women, principally single women and lesbian couples, who want to have some connection with the man who is providing the sperm so that there is a male role model—there is always that. Sadly, some want to achieve that by sexual intercourse and, as you could appreciate, my advice is to not do that, but what has happened in the last two or three years has been driven by COVID. This sounds surprising but because of COVID there is now a shortage of sperm donors in the United States and that ripple effect has, therefore, come here. Those who might have had a choice before of, say, a dozen sperm donors might only have one or two and so they have then gone to their friends who have said, ‘Yes, I will do it,’ so it is quite common.

A criticism I would have of the Victorian legislation, the Assisted Reproductive Treatment Act, is that a donor cannot ever be a parent. That is certainly inconsistent with what the High Court has told us in Masson v Parsons. You are at the forefront of changes in society at the moment. Are you familiar with Masson v Parsons? This was the case of a gay man who wanted to be a dad and he supplied his sperm in a private arrangement to a friend of many years who was a lesbian. Subsequently, she married her girlfriend. They had a child and his name, with his consent, was put on the birth certificate. Subsequently, the women had a second child through a clinic recruited sperm donor. Both girls called him ‘Daddy’. One day the women announced to the man, ‘We’re moving to New Zealand with the children.’ He was not too impressed by that, so he went to the Family Court to seek an injunction to stop them. The issue then became: was he a parent or only someone concerned with the care, welfare and development of the child? The latter enabled him to litigate, but there were balancing issues about being a parent.

The women ran the argument that they were a couple and, therefore, they were the only parents. That was rejected by the trial judge. They then said that under the New South Wales Status of Children Act the birth mother was the only parent and he was a donor and therefore not a parent. He ran the line that under the Family Law Act, federal legislation, ‘as a matter of fact I am a parent’ and the trial judge accepted that.

The women appealed. The Full Court of the Family Court said that the trial judge got it wrong—that there was a unitary scheme between the federal act and the state act and you look to the federal act first and then, if you are not there, go to the state act. He was not in either and it did not matter about genetics, intentions or parenting—tough luck. He then got special leave to appeal to the High Court. The High Court said that the Family Law Act reigns supreme. If there is a conflict with state legislation—there is no unitary scheme—it is a question of fact. He did not supply his sperm on the express or implied understanding not to be a parent; he supplied his sperm on the express or implied understanding to be a parent and put his name on the birth certificate because he wanted to be a parent and, lo and behold, he then parented.

Of the whole 80-odd paragraphs of the judgement, the two words that stood out to me were ‘or implied’, which said to me that the agreement between these parties was oral, so it is much better to have a written agreement. What is the status of this written agreement? It is uncertain, but those who contact each other through the websites that Ian Smith was talking about will rarely go and talk to a lawyer. It is cowboy country. How do you regulate it? Good luck. I think it is almost impossible to regulate. I think the idea of opting into a registry—I think Victoria made a mistake and probably did not envisage that this would happen—is great.

There was a question earlier about the cost. It is not that expensive. About three years ago, I was interviewed by Liz Hayes on *60 Minutes*. There was an awful man who went by the acronym of ‘Joe Donor’. Look him up; you will find him very easily online. I basically told him to stop. He had had 100 children by that stage, either by artificial insemination or by natural insemination. He was an American who came here to help women. Of course, it was ego driven and it was screwing up those kids. I wonder how many of them were called Robert, John or Peter if they were boys.

In any event, he ran the line, ‘Well, you either have to go with someone like me or spend lots of money going through an IVF clinic.’ If you go to an IVF clinic for a sperm donor, what are you paying for? You are paying for the sperm, which is most likely imported from the US. You are paying for artificial insemination—if you talk to the clinic they will use jargon such as intrauterine insemination, IUI, but that is artificial insemination—or you are paying for IVF, if you need to do IVF. If you manage to do IUI plus sperm, the sperm costs between $1,000 and $2,000. It is not much in the scheme of things. If you do IUI it is not much. If you do IVF there are a number of clinics, as QFG has pointed out in its submission. I think they call it ‘fertility centre’ bulk-bill. They might be able to bulk-bill or they might have a clinic they pay full rate. It might cost between $1,000 and $20,000 if they are paying for the full IVF cycle.

Mrs GERBER: That was amazing. That was very comprehensive. Thank you. You answered all of my questions to previous submitters. Thank you for your evidence. Thank you for your written submission as well.

Mr Page: I apologise that my written submissions are so long, but they set out the NHMRC guidelines rather than just a summary and they set out examples. These are real-life examples, not ones I have made up.

CHAIR: They were very helpful.

Mr KRAUSE: My question goes to your submission about succession law, which you touched on. In relation to that High Court case where, in the end, the Family Law Act prevailed and the gentleman was deemed to be a parent, how does that relate to different aspects of succession law around the country?

Mr Page: I am not a succession lawyer, but if he is a parent, under the Family Law Act, one would think he would be recognised as a parent for succession law. What the High Court has done is given us a dose of reality but also given us a curveball. The High Court has left open the possibility that there may be more than two parents. They comment on that under the Family Law Act. The assumption that we have—it has been set out clearly in Queensland legislation since the Surrogacy Act was enacted and amended the Births, Deaths and Marriages Registration Act—is two parents. That is what we clearly say in Queensland. Whether we like it or not, there are people who are creating children where they might be a throuple. I have seen a man and two women living together and creating a child, and an IVF clinic cannot refuse to provide treatment because of the Sex Discrimination Act. Who gets recognised as the parents? Only two of them, maybe—maybe only one. I have seen situations where gay men have provided sperm to single women or lesbian couples. Who gets recognised? This is a matter that gets unfortunately litigated too often in what is now the Federal Circuit and Family Court of Australia. It would be good to have some certainty about that. The High Court has thrown us a curveball because it is reality, but also you have to look at each case to then make a determination: is that person a parent?

Mr KRAUSE: It turns on those facts.

Mr Page: Yes.

CHAIR: How do you suggest legislation can deal with that curveball that the High Court has thrown us?

Mr Page: I think it is really covered under the Family Law Act. Under the Status of Children Act there is recognition, for example, of women with a de facto partner being recognised as parents—actually, I want to comment one brief thing about the Status of Children Act—but it does not recognise them if they are married. They are recognised under section 60H(1) of the Family Law Act as parents but not under our state legislation, so it would be good to update it. That came through before the federal changes to the Marriage Act.

With regard to section 23 of the Status of Children Act, I saw that Professor Allen did not refer to it by the section but referred to the phrase that 'the man has no rights or responsibilities for the child'. There has been a case in North Queensland in the Family Court which says that he is a parent, albeit one with no rights or responsibilities.

In our own surrogacy matter, that caused us grief because we had a single surrogate. Who was to be on the birth certificate beforehand? The standard view was only the surrogate. I can tell you: it gave me lots of grief as the lawyer as to which one. It is always a delight to have a test case except when they are your own. It gave me lots of grief as the lawyer as to who was to be on the birth certificate, and I came to the conclusion that the decision was wrong. Subsequently there has been a decision of the Childrens Court that says, no, it is wrong, and I have cited both of them in the paper. It would be good to have clarity.

Yesterday, I am delighted to say—I spent a lot of time working on this—the Northern Territory passed its Surrogacy Act. The Surrogacy Act amends the Northern Territory Status of Children Act which had the same provision in it and my advocacy was to please get rid of it; please make plain that the donor is not a parent.

I saw in some of the submissions that there was a reference to 'we don't know how this happened'—that the donor was not known, was anonymous. It was a conscious decision of IVF clinics, but it was also the conscious decision of this parliament.

When then attorney-general Clauson spoke to the amendment of the Status of Children Act to make recognition of sperm donors, he made it quite plain that sperm donors were not to be parents. The approach taken by then attorney-general Shine since then and the amendments under the Surrogacy Act have taken the same approach.

CHAIR: How do you fix it then?

Mr Page: I say in my submissions that it may be a COAG matter or a Commonwealth matter, but it would be useful to have agreements in place to identify who is a parent. In the Masson v Parsons case, they are reported to have spent approximately $4 million in total in litigation. The Full Court of the Family Court, special leave, the High Court: they spent $4 million to that point and then they went back to the Family Court for more. Most people cannot afford that. I did not act for any of them, but at one stage the father phoned me out of the blue and said that he had been eating a lot of canned beans and instant noodles to pay for it. It would be good to avoid that and all the stress associated with that. It would be good to have agreements in place that say very clearly what the respective roles are, but I suspect that is probably a federal matter with the Family Law Act.

CHAIR: But we could still deal with an aspect of it in the Status of Children Act?

Mr Page: Absolutely. It would be good to raise it and it would be good to have it certainly mentioned at COAG or the attorneys-general.

CHAIR: Leaving that to one side—and I am not saying that that is not a valid submission, but purely from the committee's point of view—if we were, for argument's sake, to make a recommendation, we could make a recommendation that there be amendment to the Status of Children Act. Even though that would not be a complete solution, it would be a step in the right direction?

Mr Page: It would be good to start so that these people who are confused about parentage and asking, 'What is my role?' have some guidance from parliament. That would be helpful.

Ms BOLTON: I asked Professor Gelber earlier regarding Queenslanders who go overseas instead, and there are concerns around that, and her response was that we need to close the loop on that. However, that does not stop someone physically going overseas. That was in your submission, so can you just expand on that?

Mr Page: In respect of closing the loop, we are now allowed to go back overseas, and people do go back overseas. What do we have a shortage of in Queensland? We have a shortage of sperm donors. That is relatively easily fixed; it is a technical thing. It is easy for men to produce sperm. Men produce sperm every day of the week. We have issues about caps—we have cap limits under the NHMRC ethical guidelines—and we have federal and state legislation about payment and similar matters; however, eggs are much more problematic. According to the American Society for Reproductive Medicine, the whole process of egg donation takes 50 hours of commitment and daily injections in the stomach—as opposed to a sperm donor, which is one hour, tops, including counselling. There is great psychological commitment. There is the potential risk, with the egg collection, of maybe dying, like any minor surgery. Therefore, egg donors here are as scarce as hen's teeth.

What have Queenslanders been doing? They have been going all over the world. They have gone to Argentina, the United States, Spain, Greece and all the countries where surrogacy has happened internationally. The idea that we can prevent them from doing so is fanciful. However, under our legislation we say that if you pay an egg donor a commercial amount you commit a criminal offence. We also say under section 12 of the Criminal Code that if part of the offence occurs in Queensland, or the effect occurs in Queensland, then that is a criminal offence in Queensland. The Commonwealth legislation, which also has a 15-year jail term, says clearly 'international trade and commerce'. They are potentially committing serious criminal offences. Most of them who do it do it in complete ignorance of that, but they will still do it. As I said, it is fanciful to think you can stop it.

It is better that we have greater flexibility here, and clinics are now taking up importing eggs from overseas. That has to be Commonwealth and Queensland compliant, so NHMRC and RTAC compliant. At the moment they only import from one source in the United States, but there was also another clinic in Ukraine that they were importing from—clearly not now.

CHAIR: Thank you, Stephen, for your written submission and also for coming today to present to the committee.

CLAY, Mx Sarah, Private capacity (via videoconference)

CHAIR: Good morning. I invite you to make an opening statement, after which the committee will have some questions.

Mx Clay: My name is Sarah Clay. I am a 38-year-old single parent to a 10-year-old child and work professionally as a youth mental health clinician. In January of this year I learned I was donor-conceived by VARTA donor-linking service. I thank you for the invitation to speak today as a donor-conceived person. Donor-conceived people are the most affected by this inquiry, and I understand that not many of us have been invited to present today. This is both a privilege and an immense amount of pressure on an individual to try to convey how strongly we feel.

I fully support the Queensland parliament allowing the right for donor-conceived people to be made aware of our biological families, including connecting us with both donors and siblings, and have our accurate medical history. I am not an academic expert on donor conception. I speak today as an expert by experience.

I am grateful that my child and I now have access to accurate medical history. My child has recently been diagnosed with dyslexia, autism and ADHD. I now know that neurodiversity is over-represented in my paternal genetics spanning generations. I would have been potentially able to access earlier intervention for her and better outcomes than being diagnosed with multiple disabilities at 10 years of age. Donor-conceived people in Queensland should have the same right to information as I have and be seen as humans worthy of consideration, honesty and integrity, which I feel has been denied to me for 37 years.

My first words to my biological father were ‘thank you’. My most recent were also of thanks as he had shared his story as a donor for this inquiry, supporting the rights of donor-conceived people in Queensland to know their genetic heritage and the establishment of a central registrar. My sister has also provided a submission today which speaks to the reasoning and advocacy to support my father in reaching out to his children. My father’s submission speaks more to the retrospective rights to override donor anonymity than I could give it justice.

These new relationships in no way diminish or detract from those from the family I grew up with. I have shared with my child the new family we share. As a parent, I believe that honesty and openness is paramount, part of my responsibility for her, and a way to reduce risk of multigenerational trauma resulting from the lies encouraged by the fertility industry for decades, denying us access to our family.

One of my initial concerns with my new status was around meeting an unknown sibling and forming a sexual relationship. I was assured by VARTA that that was statistically unlikely and that I could not have that information provided to me without cost, time delays and a pathway that did not really give me a feeling of autonomy. I have since discovered mutual friends shared with my new siblings, cousins attending a day care centre together and siblings who have lived less than 750 metres apart. If I had met a sibling randomly without knowing, the undeniable connection I felt with them would have previously been thought of as desire as I was drawn to them in a way that I would only describe as finding a soulmate, with intense attraction. I now have the knowledge that they are actually a part of me and we share our DNA, which is why our connection is so strong. My counsellor from VARTA was more of a case manager who was working with all of my new siblings and biological father, which I view as a conflict of interest and unethical, in my professional experience.

I also asked for consideration for support by donor-conceived peers be offered at initial point of notification via a support register. I found that the support from someone who has lived experience was far more valuable and genuine to me than my assigned counsellor, who appears to come from a legal background rather than one of lived experience or counselling. Support from people who have lived this journey was the only support that mattered to me or validated my feelings, hence my now involvement with Donor Conceived Australia. The support numbers provided prior to my appearance today seek to include one specific to donor-conceived people and from personal and professional experience are not safe for us nor knowledgeable about the unique needs of Australian conceived people.

If Queensland is to legislate for donors to have the right to contact their donor children through a government body, I ask that the initial and ongoing support provided to those donor-conceived people be trauma informed, evidence based, co-designed and delivered through the lens of lived experience. I ask for counselling to be in line with best practice without conflict of interest—so having an allocated counsellor not also providing counselling to other biological family members.

I ask for our information and rights to be shared with us, providing evidence of point of request and suitable access to accredited peer support from other donor-conceived people. This should be shared with us without financial burden. Financial status should not be a barrier for people who have become aware of their status as a donor-conceived person to access records, registers or DNA testing. I ask for us to have rights of access to our siblings. Sibling relationships are equally as important as that of donor and child.

Mrs GERBER: Thanks very much for your submission and for taking the time. I can see the emotional toll it may take on you, too, so thank you very much for coming before the committee and sharing your story. It is really important that we have all perspectives in this inquiry.

One of the balancing acts that has been presented to us by a number of submitters previously—and I am going to ask you for the perspective of a donor-conceived child or having a donor-conceived child as well—is the issue of the child's right to know identity and then contact. They are two separate issues that we have been presented with: the right to know identity and then the ability or right to make contact. One of the things that has been presented to us to balance is a contact veto as part of the regulation process, and I understand that is what occurs in Victoria. What is your perspective on contact vetoes? Do they work? Are they respected? Is it a safeguard that we could use in regulating this area?

Mx Clay: To clarify, my child is not donor-conceived; my child is from a former relationship. From my perspective, contact and information are two different things. I realise that I come from a place of privilege in that my biological father is now a part of my life and I am very much looking forward to meeting him. My siblings are wonderful people whom I am incredibly grateful to now have in my life. I do also have some siblings who have chosen to not become a part of our new extended family, and I fully respect that. It is a decision that each individual needs to make, but I do not feel it overrides my right to know my medical history and right to know where my identity comes from.

Ms BOLTON: To help me understand a little bit more about the perspective of a donor-conceived person, if laws were that ID and contact were all available, how would someone feel about the donor having the right to contact or know your identity? I am trying to figure out if this goes both ways.

Mx Clay: It is very important. My donor reached out. I fully agree with my sister's—Cate Smith—submission, which explains the process that she found, being the child reaching out and wanting to make that initial contact. At the end of the day, my father initially found out about his children via ancestry.com. It is about having that access to information available, regardless of what processes are put in place.

Ms BOLTON: From a donor-conceived person's point of view, do you think having a veto is important in case they do not want to be contacted by their donor?

Mx Clay: Yes. I feel that, like any other relationship that exists on earth, we all have the right to say that we do not want contact with a person. I feel that is something that we can do. I also think there should be more screening done moving forward for donors so they are be made aware they are making children and the impacts that can have on them in the future.

Mr HUNT: Thank you very much for your time and that testimony which, by the sound of it, comes from very deep down within you. Thank you very much. It is always challenging to talk about topics like that. So far this morning we have heard repeatedly about the impact of sites like ancestry.com and various DNA private testing facilities that make this almost a catch-up measure. Do you have any thoughts about those private testing facilities and how they have changed this landscape from what it was, say, five years ago?

Mx Clay: I am really glad you asked that. My biological father first found out about his children by ancestry.com. Without going through that pathway, I would not know my status or my child's medical history—not looking at the benefit of relationships. So much has changed from the eighties, when people agreed to anonymous donation. We cannot pretend that 40 years has not passed and science has not improved; human rights have developed and changed. In relation to ancestry.com, I have read other submissions that speak to using photo reverse Google searches and being able to find donor parents in that way. Anonymity does not exist these days.

CHAIR: Sarah, we are about three minutes ahead of time. Do you have anything else you feel the committee could benefit from in terms of your experience and knowledge that you would like to tell us?

Mx Clay: I feel, given my experience is quite new and quite raw—I found out four months ago today. It is one hell of a journey. The only thing I can really speak to is the need for genuine support to be offered to people when they find out. Whilst I am incredibly grateful that I now know, the emotional and mental toll at the start was very challenging and the support offered at the time was not suitable to my needs. Whilst I would not change knowing for anything in the world, I do wish that that stage had been more supportive and actually respected the experience of donor-conceived people.

CHAIR: That brings to a conclusion this part of the hearing. I would like to thank you, Sarah, for your written submission, for taking the time to present to the committee and also for how brave you are to have been able to do this. Thank you.

Mx Clay: Thank you for the opportunity.

MACMILLAN, Ms Caitlin, Private capacity (via teleconference)

CHAIR: Good afternoon, Caitlin. Would you like to commence by making an opening statement? After that, committee members will have some questions for you.

Ms Macmillan: I would, thank you. Good afternoon to all the members who are there today. I am sorry I was having difficulty joining virtually. Also good afternoon to all the witnesses and attendees today, and thank you to Ms Clay for reminding us about the emotions underlying this discussion. I think it is really important to remember that.

I am sure you are now well informed about donor conception's long and prevalent history from reading through the submissions. I saw that covered in a few submissions and it is covered in mine as well in some detail. I will not spend much more time on it, but I wanted to reiterate that donor conception is not new and it is not rare. When we talk about donor conception and donor-conceived people, we are not just talking about young people, who are often used to depict donor conception in the media; rather, we are talking about babies through to adults. I also want to caution against the use of the term 'donor-conceived children' that has been used by some of the members, no doubt unintentionally. We are talking about a practice that has been used successfully in humans since the 19th century, so we are referring to people of various ages, some of our peers and some of our elders. Similarly, the legislation therefore has intergenerational effects as a consequence of generations not inheriting a complete and accurate genetic history, including medical and ethnic history.

It feels like a matter of urgency—it has felt like a matter of urgency for quite some time—that we have this discussion. While it has taken some time, I do applaud the Queensland parliament and thank them for the opportunity to speak here today, and I urge other states to launch similar inquiries. It is my hope that nationally there is equality for donor-conceived people as soon as possible and that discrimination in legislation or created due to the lack of legislation is removed—discrimination based on method of conception, timing of conception and place of conception.

I am conscious of the challenges that have been discussed in balancing donors', parents' and donor-conceived people's rights to privacy. However, removing anonymity is in line with the United Nations Convention on the Rights of the Child, specifically articles 7 and 8, and the current Queensland framework is not able to fulfil these rights. It is unfortunate that for a long time practices have not aligned with these rights, and that is the reason we are in this position today.

Based on the submissions, however, donors and parents appear to be supportive of legislative reform, although I do acknowledge that some recipient parents, such as those surveyed and represented in Rainbow Families' submission, have some concerns. Some of their anecdotes which are presented and included in academic literature, documentaries and media are that some of these concerns are expressed by parents 20, 30 or 40 years later. Some parents have been concerned about maybe having information available, ambiguity about what is a parent and trying to protect against any misunderstandings. But as time goes on and parents are unable to facilitate their child's questions or facilitate them finding genetic information, it seems that down the track it is something they are supportive of.

Apparently, in order for donor-conceived people to obtain genetic information they need to know the name of the clinic, which assumes that a parent is alive, available, willing and remembers and that the clinic is still operational or contactable. If the clinic is still operational, the donor-conceived person has to navigate the clinic's policies to receive what information the clinic has and is willing to share, which, as Professor Gelber described this morning and has also been reported on in the academic literature, can really depend on the person who takes the call. The NHMRC guidelines provide no instruction and there is no consensus on what information should be collected by clinics, how long it should be kept for, how it should be stored or who can access it and how. There is also a lack of accountability or consequence when there is noncompliance.

Just as has been raised in similar inquiries in other states, there have been suggestions of voluntary registers as an alternative; however, as I have outlined in my written submission, there are a number of limitations to a voluntary register such as there being no consensus on what information is collected and how it is stored or made available. To make an application requires a person to have access to information allowing them to be matched and assumes that the information received from a clinic is accurate. As Professor Gelber also highlighted in her letters, different information can be received. It also requires a donor be aware that there are live births from the donation. In Queensland, historically they have not had access to this information or have been given inaccurate information to suggest maybe there were no live births.

What is happening instead is that people are relying on direct-to-consumer DNA testing such as ancestry.com. Through this there is a large amount of information available. There is confidence in the information that is available, there is less correspondence required, you do not need to make contact with a clinic and there is no back and forth. As of last week it was $99, so it is quite accessible, quite cheap. It is actually cheaper than the pay-as-you-go register in Victoria, which I think is about $140 to $170 for an application, and it does not require a donor to participate to be identified. If you are unfamiliar with the process of how DNA testing has been used in this space, I am happy to provide more detail. Basically, a term has been coined and used in the media that DNA stands for 'donor not anonymous'.

Donor-conceived people, irrespective of how old they are when they express an interest in learning their genetic history, need to access records after a considerable amount of time has passed, and the information is protected physically and legislatively. The consequences of not being able to access accurate or complete genetic information can create many challenges for families. I would like you to reflect on when you last had a check-up, visited an allied health professional or had appointment at the optometrist when they ask, 'Do you have a history of X?' It is a question that I think many of us take for granted, but it can cause a bit of anxiety for donor-conceived people when they do not know how to respond or how much information they are then willing to disclose to the professional. Notably, for some donor-conceived people in Australia and internationally there can be potentially avoidable but fatal outcomes, quite famously as in the story of Narelle Grech in Victoria. It is imperative that donor-conceived Queenslanders be afforded equal rights and are not faced with any disadvantages based on when they were conceived, where they were conceived and how they are conceived.

Just before I finish, I would like to reflect on Mr Page's account of potential unsolicited contact between families and offspring. I think that is a really good demonstration of there being no such thing as anonymity anymore. I am not aware of those accounts. I do not believe they are documented. It sounds like those accounts occurred in states where there is no option but to reach out blindly and there are no methods of facilitating contact. In Victoria a donor is given up to three months notice that his information is going to be released and in that time can express his contact preferences. I say 'his' only because the abolishment of anonymity applied to sperm donors in that there were not egg donors at the time. In states that do not have this, a donor-conceived person or their family may not realise their contact is not going to be received well but they have no way of checking that at this stage.

Ms BOLTON: We have heard a lot today from witnesses regarding the Victorian legislation and the retrospective provisions within it. What are your thoughts, and is there anything that you believe could be improved?

Ms Macmillan: That is a good question. It is legislation that in hindsight holds a lot of learning opportunities. I believe that in an ideal world there would be some way to include information when clinics have engaged in donor swapping or donor trading. What became apparent after the legislation was that when people who were conceived in Victoria, with parents who sought treatment from Victoria, would go to access information they would then discover that their clinic had engaged in donor swapping across borders. They might have found out that their donor was South Australian, for example. This meant that, despite being Victorian and having Victorian parents, the Victorian legislation was not able to help them or they were not governed by the Victorian legislation in that scenario. I do not have a solution for that. Considering that a lot of this is state based legislation, it is one of the reasons I think donor conception does need to be recognised in federal laws. I do not have a solution, but I think ideally there should be some way for donors who found out their sperm was used in other states to join these registries.

There is a lot of speculation about why people go and use private donors and why donors choose private avenues. One of the scenarios that has come up a bit in the media, particularly recently, is because some donors want there to be greater transparency in their information. By being a private donor they have the ability to provide detailed information, answer questions—because they are not going to know all the information that donor-conceived people are going to seek—and update their information. Assuming that a person knows their complete and accurate medical history when they are in their twenties or thirties, more information might come to light, particularly if they have their own children or their children have children, and some information at that level of genealogy and being able to distribute that just cannot happen when there is no ability to update information. When offspring cannot access information until they are 18 years of age, it means that, again, they are just going to have to go back and backdate their medical history if they make contact.

Ms BOLTON: You mentioned donor swapping. Sorry for my ignorance, but can you just clarify what that is?

Ms Macmillan: I think Sonia may be able to provide more detail on that this afternoon. Ian Smith, I think, knows quite a bit about it if you were to contact him again. I believe that what some clinics were doing was—maybe if they were short of donations they could contact other clinics in other states and they could either swap or they could import donations from other clinic. I am not sure whether they were paying for it. I am not sure if it was a supply and demand issue or why it went across borders. I am not too sure why it happened. There was a story of a donor being in Western Australia and travelling to South Australia and making a donation. He monitored the clinics to find out if there were any live births, only to discover much later that his donation was sent to Victoria. He did not know then to join things like the Victorian voluntary register, which was available before the central register.

Mr HUNT: I have asked this of a few other submitters and I will put this question to you as well. It has become quite apparent that DNA testing kits and private providers of DNA testing have made a lot of privacy provisions moot. Do you have a view on whether or not the existence of these things now has just completely circumvented a lot of privacy provisions?

Ms Macmillan: I think I got most of your question about the use of DNA and whether or not that circumvented privacy provisions. This is not directly answering your question but it is an observation about that. I do not believe that, even though they may express a preference to use DNA testing for information because there is greater accuracy and it is cheaper, that is actually the preference of donor-conceived people. It is daunting and a big task to put your DNA out into the world, send it off to what I believe is an American company, not knowing what is going to happen to that or how that information is used or stored. I do believe that donor-conceived people would also feel protected if there was a registry and the ability to contact or learn information, and potentially—if that is something they are interested in—contact donors through a local source that had some sort of legislation in place. It could benefit further from having the ability to check the information with DNA testing, such as was introduced in Victoria, where you still own your own genetic material and it is not going off and being used somewhere else.

In terms of privacy, when people do identify donors through Ancestry you have to remember that they are using publicly available information and learning things about their donor that have already been put out there. Although the donor may not have thought about it at the time, the donor has consented to that information being out in the universe. Maybe it is a newspaper article they participated in and their photo was included and now they do not want their photo released to the donor-conceived person, but they did consent at the time to that photo being put maybe in the *Australian* newspaper or something. Then you have things like LinkedIn, social media and maybe electoral records. It is really hard to know where that privacy line is. Are you breaching privacy by going and finding this information when you have a genetic relationship with this person? If you did not and you were just curious because that was your next-door neighbour, are you breaching privacy? I do not know. It is a really fine line. Knocking on the door if they are not happy for you to knock on the door—yes, that is breaching privacy. There are clear boundaries in terms of a consent process when there is a registry where someone can express their intentions, but through DNA it is a real unknown. I do not know if I answered your question, but I think it is just because it is a really hard question to answer.

Mr HUNT: I have asked that question a lot and there seems to be a fairly consistent line.

Ms Macmillan: I think too with DNA testing and privacy there have been some reports that donor-conceived people should not engage in Ancestry DNA and things like that to find out information when a donor has not consented to them knowing that information. We are talking about someone unravelling what is essentially 50 per cent of their own DNA, so who owns it and who has the right to information that relates to that DNA is a really contentious issue when it is inside the person.

CHAIR: Thank you. That brings to a conclusion this part of the session. I would like to thank you, Caitlin, for your written submission and making time available to address the committee.

Proceedings suspended from 12.30 pm to 1.30 pm.

ALEXANDER, Ms Matilda, Steering Committee Member, Rainbow Families Queensland

CORKHILL, Ms Heather, Steering Committee Member, Rainbow Families Queensland

CHAIR: Good afternoon. We would like to commence with you making an opening statement, after which the committee will have some questions for you.

Ms Corkhill: Thank you so much, committee. We will share that opening statement. I just wanted to start by acknowledging the traditional owners of the land on which we meet today, the Jagera and Turrbal people. We are so proud of our beautiful First Nations rainbow families who generously share their land and culture with us. Rainbow Families is here to advocate, celebrate and support LGBTQ+ parents and carers and their children across Queensland. We are a fully volunteer-run organisation and we act as a social and support network for parents and carers as well as their children.

I speak to you today as a proud mother of a seven-year-old daughter who was conceived through donor conception. We used an Australian anonymous donor who is open to be contacted after she turns 18 and will be identifiable after that point. We will be forever grateful to our donor for giving us a bright, empathetic and joyful daughter.

Ms Alexander: I speak to you today as one of the proud mothers of a four-year-old and a seven-year-old who were conceived through a clinic using a known donor who was the cousin of my partner and who is known to both of my children. They are familiar with him and have regular contact.

Ms Corkhill: Our interest in this inquiry is that most of our families are created through donor conception and that does also include surrogacy arrangements, as I know Stephen spoke to you about earlier today. We wish to give voice to donor-conceived children in our families and to parents but also wanted to note that some of us who are recipients of donations are also donors for other families. Because we recognise that there is such a diversity of experiences and views in our community, we decided to run a community survey on these issues in April this year. We heard from a large number of people, 112 people, 89 of whom were parents of donor-conceived children. About two-thirds had used or intend to use anonymous donors to conceive their children and about one-third had used or intend to use a known donor. It is a fairly good sample.

Some of our key findings were that our community strongly supported donor-conceived children having the right to access information about their genetic origins. While we are deeply empathetic to the experiences of people who had been misled or lied to in the past about being donor conceived, I think it is critical to point out that there are significant differences with our families. Our children do grow up knowing the truth about their origins in almost every situation. In practical terms, parents in same-sex relationships or single parents cannot hide the fact of our child’s donor conception, and our families are generally very well educated of the benefits of our children knowing where they came from. There is mandatory counselling for those who access clinics and there is also a wealth of information about the benefits of knowing where you came from. We also use age-appropriate information about donors for our children.

It is also important to note that about 18 years have now passed since 2004, when it was changed within the guidelines that there could even really be fully anonymous donations so that our children, like my own, are in the situation where once they turn 18 they can find out the identity of their donors anyway. Families with known donors also have varying degrees of ongoing contact, as Matilda here has just described. Their situation is extremely different again. Some families also have relationships with donor siblings, who are mostly found through social media online.

In our case, we started positive conversations about being donor conceived really from birth—certainly from the time that my daughter could speak. She knows that she has two mums, obviously that she is a bit different from some of the other children, even from kindergarten onwards. We are really open and comfortable talking about it with her. She is just really not that interested about it at the moment. When I tried to raise it in the context of this a few days ago she said, ‘Why are you talking to me about donuts?’ She got confused between donors and donuts. At seven years old she is not very interested, but we know that that absolutely could change and we are ready for those conversations. We will always have the comfort of knowing that her donor is open to contact with her when she turns 18.

There were fairly mixed views about a central register as a proposal. On the other hand, there was really significant support for a well-resourced, free-to-access, voluntary register, such as is available in Victoria, which may make it a better process to receive information and connect with donors and donor siblings as well and be a bit more regulated around that.

There were some views that we heard about counselling support and how absolutely critical it was at every stage—so when you are becoming a parent and then also for the child, perhaps when they are accessing information at the age of 18. We did find that there were mixed experiences with the counselling that we had received. It is really critical that they are inclusive and competent on issues regarding the LGBTIQ+ community and there should be high-quality, free or low-cost counselling options for donor parents and donor-conceived children.

Overall we recommend that there is a cautious and balanced approach taken to ensure that there is only the necessary additional regulation required to safeguard the child's important right to know where they came from, including critical medical and genetic information, but we do have some caution about whether there will be much impact on supply. We think it would be sensible to review the situation in five years to evaluate the impacts.

There is one other further point I would make because we heard some of the previous witnesses today. There had been a suggestion about having a notification or a note on the birth certificate if a child is a donor-conceived child. We are actually opposed to that because we thought that could have a stigmatising effect on the child and does not seem necessary, particularly in the context our families where things are very open anyway. Was there anything you wanted to add, Matilda?

Ms Alexander: No, just to welcome your questions today.

CHAIR: In relation to the suggestion about the birth certificate, it was not so much that that information would transfer to the birth certificate but that it would be recorded at the time of registration.

Ms Corkhill: I see. So that would be held in a separate location?

CHAIR: I do not know how physically it would work, but I think the idea was to enable collection of that information should someone ever want to access it. The machinations on how it would work in reality would be something that someone else hopefully would turn their mind to, but it was not so that when you got your birth certificate it said 'donor conceived'.

Ms Corkhill: I see. That is an important distinction.

CHAIR: I agree with you. That would not be the intent of gathering that information.

Ms Corkhill: That is good to hear.

CHAIR: Someone other than us would be working that out, based on our recommendations.

Mrs GERBER: I might just clarify that. Your organisation would not be opposed to Births, Deaths and Marriages holding the information should the donor person want to access information about themselves? The intention of the submission by that submitter was that Births, Deaths and Marriages—whether it is Births, Deaths and Marriages; it could be something else. It was for a central repository of the information for access.

Ms Corkhill: Yes, certainly. There were really mixed views, as I said, about the central register, but overall most people in our community did support it.

Mrs GERBER: I think your organisation is well placed to help the committee better understand the support services that perhaps could be looked at as part of the inquiry, both at the donor depositing stage—I am not sure that is the right word to use—and at the conception stage and then the accessing identity or contact stage. Can you talk us through what in your view would be the best support services to be put in place?

Ms Alexander: I think counselling and support services always work best where it is voluntary, where it is free and accessible and where it does involve specifically trained LGBTI-aware counsellors. Certainly the views from the survey, and my own personal experience, of the mandatory nature of the counselling are that it became a tick and flick and it was actually quite an offensive process because of the way it was undertaken. Because it was mandatory, there was a sense of expectation that we had to do this, that we had to pass it, in order to become parents, and certainly other people were told by the counsellors, 'You are not ready to become parents. Go away and come back when you are ready.' It became a kind of gatekeeping process. I think that is the danger of making it a mandatory counselling process. I think if you make it free and you make it accessible—what we found is that people are wanting to engage in this, they are wanting to know the best way forward, and if you provide that in a way that enables choice and control for the users then the good ones and the bad ones will be weeded out in that way.

Ms Corkhill: I think in contrast to that situation, I know some people who are contemplating a more informal arrangement yet cannot find anywhere that has free or low-cost counselling available for them that is suitable to their situation which is then deterring them from getting that counselling. I think that is even more key. The people who are getting the counselling are doing it as a bit more of a tick and flick in some cases because it is part of the clinical process. What we would want is one that is also open to private arrangements.

Ms BOLTON: You mentioned supply impacts, and earlier we had touched on the reasons for that, but also the concerns around what it will do should new legislation come into play on the importing of sperm but also what is available privately. Do you have any thoughts on what may be needed to—as I think Professor Gelber said—close that gap where more would be sought from overseas than within Australia because of lack of supply?

Ms Alexander: Certainly that was the feedback we got from people who had tried to conceive, say, in Victoria and changed jurisdictions because it was hard. With any kind of overregulation of the process, the impact will be a reduced amount of supply.

Ms BOLTON: That has been found in Victoria, has it, since the legislation came in?

Ms Alexander: We have definitely spoken to people for whom that was their experience. They felt like there were only a handful of people they could use within the Victorian system so they went across borders to conceive. You do not want to unintentionally do that by creating a system that provides legal and medical safeguards which actually just drive the problems over the border or into informal arrangements.

CHAIR: It is the case that Queensland is the last state to come on board with this form of legislation.

Ms Corkhill: I do understand, though, when it comes to donations from international donors. We happen to have an Australian donor but there were international donors available. They had to comply with exactly the same requirements. They had to be agreeable to being identified at the age of 18 anyway, so I am not absolutely sure that there is a loop that even needs to be closed there. It would just be codifying what is already happening within the clinics.

CHAIR: What about the issue that has come up in that the clinics are not the most reliable source for historical information where a person wishes to identify his or her heritage?

Ms Corkhill: I feel it is a question that is probably better answered by people who have had experiences of donor conception before 2004, because I definitely would not want to speak to their experiences, which are so different from now. To some extent, there was quite a lot of trust in clinics amongst people who answered the survey, with some saying that they could probably do it better than government and some on the other side of that. It is probably a better question for someone else.

Ms BOLTON: We spoke earlier about donor swapping and the difficulties encountered through that in terms of different states with different legislation. I am going back to that international donor. From what I understood, you said that the rules were the same for donations coming in, but I think we heard earlier that maybe they are not.

Ms Corkhill: I can only speak to my own experience from seven years ago. I am pretty sure it is the same, at least at QFG, which is the clinic we used. Based on the clinical guidelines, they needed to ensure the donors were going to meet the Queensland regulations, which are essentially through those clinical guidelines.

Mr HUNT: Do you have any very specific recommendations that you would like to see put in place around donor information accessibility and privacy safeguards? Can you identify any gaps?

Ms Corkhill: There will always be a bit of a necessary gap when it comes to informal arrangements. It might be necessary sometimes because they are so different in nature, especially if the children have ongoing contact with that person. In some cases it can be almost like a third parent to the child. That just does not seem like a gap you would even want to fill. There are also some issues around trying to overregulate. There are some informal arrangements. Perhaps people meet online. It would be almost impossible to actually regulate in that area. It reminds me of international surrogacy and that that will just continue, no matter what you do. You certainly would not want to criminalise those situations.

Ms Alexander: If you put a fine in place for not registering your private arrangement, people would probably prefer to pay the fine. Certainly there were members of our community who were reticent about government involvement in their private lives and felt like there was an equality issue: why are our relationships going to be subject to a higher level of regulation than, say, somebody who gets drunk at a pub one night, conceives and has a child? There is not an equity arrangement there.

Ms Corkhill: An important point that Stephen Page made earlier was that there was a gap in the Victorian legislation. If people want to have a private arrangement and then opt in, that is a wonderful thing. That should even be permitted, in our view.

Mr HUNT: Would you say there is a chance of overregulating the process?

Ms Corkhill: Undoubtedly. That is definitely the biggest risk that we have identified—absolutely.

Ms Alexander: Bearing in mind that unknown donors are not all coming through clinics. You might have a private arrangement. You might have an arrangement through a clinic using a known or unknown donor. Are you going to regulate all the unknown arrangements or are you going to regulate all the clinics? It is actually a separate question.

CHAIR: I have looked at your submission. I am some concerned about some aspects of it in the sense that a lot of the information we received has been driven by people wanting to access, not from the point of view of government trying to regulate. The driving force behind this is not government wanting to regulate people's lives but working out a way forward for people who want to access their heritage, know where they come from or find any medical information they need to understand some genetic issues. It is not about the big stick of government. There has been no suggestion from any submitters about having people fined for not complying.

Ms Corkhill: I completely understand the reasons for this inquiry and the huge benefits in there being safeguards on the child's right to know where they came from.

CHAIR: You summed it up better than me, Heather: the child's right to know.

Ms Corkhill: We completely understand that. We have really received a lot of mixed views. It is not even my own view, but some people feel that, as an LGBTIQ+ person, there has been a lot of interference in their private feelings and lives, even whether or not they can get married. There is a history there about distrust of government that I do not personally share, but that is where the feelings come from.

CHAIR: Which is completely understandable. That brings to a conclusion this part of the hearing. Thank you for your written submission and its candour. Thank you very much for attending today. Get home safely. There seems to be a bit of crazy wind out there.

Ms Corkhill: Thank you very much.

KELLY, Professor Fiona, Private capacity (via videoconference)

CHAIR: Welcome. Would you like to make an opening statement? After that, the committee will have some questions for you.

Prof. Kelly: Thank you very much. I thank the committee for inviting me to speak today. As noted, I am a professor of family law and health law and the dean of La Trobe University Law School. I have spent the past 15 years researching the legal regulation of assisted reproduction in both Australia and Canada with a particular focus on donor linking—that is, where donor-conceived people connect with their donor relatives. I have been watching the proceedings on and off during the day and I endorse what so many others have said. Donor-conceived people are harmed by donor anonymity and by a lack of supported access to identifying information about their donor relatives. This is clear from the donor-conceived people who have spoken to you today, but it is also well substantiated by research across the globe.

A growing number of jurisdictions are providing donor-conceived people with access to their donor's identifying information. As members of the committee have noted, Queensland is out of sync with these current trends. Queensland remains one of the small number of Australian states that does not yet have a legislative framework that enables this type of access, typically via a government-run register. Fertility clinics may be willing to share information with donor-conceived people. In research that I recently conducted with staff at Australian fertility clinics, including Queensland, I found that in Queensland the lack of a legislative directive meant that information disclosure was inconsistent and haphazard and that for those who requested the information there was a strong feeling of inequity and frustration, that it depended on who picked up the phone, which clinic you had conceived at or were conceived at and obviously which state you were born in.

I want to make three recommendations to the inquiry. First, I recommend that Queensland introduce legislation that regulates assisted reproduction and that key to this legislation should be the right of donor-conceived people to access their donor's identifying information when they reach a specified age or earlier with parental and donor consent. This is most effectively achieved by introducing a central register, akin to that found in states like Victoria, which operate prospectively so that children conceived after the commencement of the legislation are able to access their donor's identity when they reach the age requirement.

Secondly, I recommend the introduction of retrospective legislation that gives access to a donor's identity for those people who were conceived prior to the commencement of the legislation. However, I do recommend the inclusion of an option for a donor to file a no-contact preference. Data from Victoria, where retrospective legislation was introduced in March 2017, shows that more than half of the pre-1998 donors approached following a register application have agreed to some form of contact. The contact preference allows the donor to specify the parameters of that contact. For those who do not wish to have contact or wish to limit it, that contact preference can be lodged. Penalties apply if a no-contact preference is breached. There have been no instances of breach in Victoria since this was introduced.

I want to briefly go off script here, having listened to the previous presentation around the question of supply. I note that you asked the previous submitters whether this was an issue in Victoria following the introduction of this legislation. Donor numbers in Victoria have consistently risen over the past decade, including after this legislation was introduced. When you hear about donor shortages in Victoria, you are hearing about an increase in demand—not an increase in supply. Overall numbers are increasing for donors but we are also having a rapid increase in the number of primarily single women and lesbian couples. Heterosexual couples are the lowest users of donor sperm in Victoria.

The alternative that other states and, to some extent, Victoria have turned to are international donors, as the other witnesses noted. I want to clarify that when the sperm of international donors is brought into, say, Queensland, that donor has agreed to their identifying information being released to the child, as they are in Victoria, and they have had counselling that is Australian compliant. What we do not have control over is the number of children who are born as a result of that donor's sperm. While in Queensland you can have your 10-family or five-family limit—whichever state you are in—what you are not controlling is how many children are conceived in other countries using that same donor's sperm. It is not unusual for children who are currently conceived in Queensland using international sperm to have more than 50 donor siblings in other countries. There is a difference when you import sperm. It is why I would strongly recommend that there is a greater focus, and perhaps a greater demand by the government, on local clinics working harder to recruit local donors. Most fertility clinics in Australia have washed their hands of locating local donors. They consider it an expense that they no longer need to invest in because of the ease with which they can get international sperm but with little consideration of the impact on young people and adults as they discover the number of siblings they have overseas.

Finally—and I think this is very important—for a donor register to operate effectively in Queensland it must be accompanied by state funded support services. Given the highly emotional nature of the process of identity release, particularly in cases of retrospective access, donor-conceived people and donors should have access to counsellors who can provide support and facilitate the initial contact. Best practice demands that this service be well managed and funded by the state and preferably not outsourced. I think the Victorian model is the strongest one that we have in the country because of the in-house services that it provides.

If Queensland does not legislate and enable prospective and retrospective access to donor information, donor-conceived people and parents will locate their donors by other means, whether that is DNA testing, internet searches or social media stalking. Donor anonymity is dead and Queensland is simply catching up. My research demonstrates that when the state does not support donor linking parties will take matters into their own hands. It is not possible for the Queensland government to prevent that from happening, even when the donation has occurred as far as back as the 1960s or 1970s. However, what Queensland can do is facilitate that access to reduce the risk of poor outcomes. I recommend that Queensland adopt an active approach to this issue, ensuring that those involved are fully supported throughout the process.

Mrs GERBER: Thank you, Fiona, for your submission. You answered one of my questions straight up around supply and the anecdotal evidence we received from the last submitter. Thank you for clarifying that. If this legislation, or part of it, was retrospective, what would be your view on that? Do you think it should be retrospective or is there a middle ground? Are you able to give the committee your view on that?

Prof. Kelly: I do support retrospective legislation, provided it is well managed and you have that contact preference system in place. What we have seen in Victoria is: when you introduce retrospective legislation, what you discover by and large is that donors are happy to be contacted—the vast majority agree to contact—and that many have, in fact, wondered about their donor offspring over the years but have had no means by which to make contact or did not think it would be appropriate to search, given the nature of the relationship. There are certainly donors who do not wish to have contact. Perhaps they have not told their spouse about donating as a young man. I recognise that for them the release of identifying information they are obviously bound by, but they do not wish to have a relationship. Obviously that is a process that, again, the system in Victoria can assist the donor-conceived person to work through. But what we are seeing is that the vast majority go on to have positive relationships with their now-adult donor-conceived children.

What we have seen in Victoria since the change in the law and just the increased visibility of this to the public, because of all of the media when we had our version of this committee and the legislation that followed, is that in Victoria we now attract a different type of donor. The men who donate now are older, are more cognisant of the gravity of what they are doing and are often willing to be known when the child is younger, recognising that the child may have questions for them when they are under the age of 18, and I think that is a really positive thing. My concern, particularly around international donors, who are primarily from the US and very young, is that they sign up for this, they know their identity is going to be released and they have gone through that counselling, but they are 21 years old; they are not 30. The difference between a 21-year-old man and a 30-year-old man and their sense of what it is like to be an adult and have children and relationships is enormous. I think the benefit of this system is that everyone thinks more carefully about the child that is the ultimate point of the system and what their needs will be in the future.

CHAIR: I would like to acknowledge the presence of Tom Smith, the member for Bundaberg, who is replacing Jason Hunt, the member for Caloundra. At the end of your submission you talk about the rights for donors to apply for information. In that last paragraph, where you say 'I do not recommend'—you may have expanded on that within the body of your submission so forgive me if you have—are you able to expand on why you believe donors should not have access to the same information?

Prof. Kelly: In the arguments that support a donor-conceived person's right to know their donor's information, some people will cite the Convention on the Rights of the Child and a child's right to know one's biological origins. Others will cite the right to know and be cared for by both of their parents, which is in the federal Family Law Act as well as the Convention on the Rights of the Child. These are children's rights arguments. A donor is not the child in this, so when you look at the legal and, I would argue, moral imperative for this law, it is simply that the same argument does not apply to the donor. The donor has, with full consent, provided his sperm. The child has not given any form of consent. They are not a party to the contract. In terms of their rights to know their origins, the donor does not lack that right.

The right of a donor to apply has actually always been in the Victorian legislation, but until we had the amendments in 2017 it was clear that donors were not aware of it. We went from having maybe one or two applications every couple of years to having now up to 30 applications in a year by donors. If you think each donor has approximately 10 to 15 offspring, the resource implications, which I know is something government is concerned about, are obviously enormous, but at the same time the impact of that on donor-conceived people I think is quite different. My strong belief is that the right originates with the child who in this instance is now an adult and that those same legal and moral arguments do not apply to donors.

CHAIR: I have one more question in relation to succession law. I know that each state has different succession laws.

Prof. Kelly: I can say with absolute certainty that there is no risk. The risk only arises if a donor becomes a legal parent. That is not what is being proposed here. In most instances, by that point the individual is over the age of 18 anyway so you are not going to have any kind of parental conflict that might end up in the court. If you have a private arrangement, that is more complicated because parentage is not clear under the Family Law Act and, unfortunately, states cannot do anything about that. If you choose to have a known donor then there are legal risks associated with that, and one of them for the donor is definitely a risk around succession and also potential child support liability.

Ms BOLTON: With the Victorian legislation, do you see that there are any areas that could be improved on?

Prof. Kelly: The clear gap for me in Victoria is the inability of donor-conceived people to identify their siblings in an active way. They can put their names on the voluntary register and hope for a match, but at the moment the power to identify donor siblings ironically sits with donors. Because donors can initiate applications, they can find out the entire sibling group and then they can tell the offspring. I just think that is an odd centring of power in the donor for one, but, secondly, I think that is something that needs to be driven by the donor-conceived people themselves. I would certainly support a process where a donor-conceived person can apply for the identity of their donor siblings.

Mr SMITH: Professor, thank you for joining us. My question is around the anecdotal story of how someone decides that they are going to go along this journey to find out who the donor was: the DNA testing, the internet searching with social media stalking, as you have put it. How does that journey begin and what does it look like when they get to the end?

Prof. Kelly: It is a good question. I probably would say that everyone's journey would be different. I have just finished a study—unfortunately it has not been published yet or else I would provide it—where we interviewed 75 donor-conceived adults across Australia. For them the journey—because we are talking typically there about an older group, so they do not already have access to that information—obviously starts when they first discover that they are donor conceived. For some of them it is a positive story but for a lot of them it is negative. It gets disclosed inadvertently or they discover it by accident by doing a DNA test they got for Christmas or something like that.

Then I think it is really important to look at the motivations—that is really what you are asking about—for searching. Clearly, all of the research consistently finds that the No. 1 motivation is curiosity. I think we all can understand that. Very few will say that they are looking for a father, that they are looking to fill some terrible gap. They are curious about their origins. Even young people who have known from day one still search for donors. They are happy and well adjusted but they are curious about their origins. I think that is the thing that kicks off the process.

For those who have had a more traumatic experience, absolutely there is a desire to understand where they have come from, and the reason they will turn to something like DNA or internet—and I use the term 'stalking' because it is often the phrase that they themselves will use—is that there is nothing else. The state has enabled this. We permit children to be conceived in this manner. Now the vast majority of it is subsidised by Medicare, yet we do not look after them when they are born in terms of providing that key bit of information that most of us take for granted. That would be what I think will motivate them. We just take it for granted. For them it is that curiosity about where they come from.

CHAIR: That brings to a conclusion this part of the proceedings. Thank you, Professor, for attending. Thank you for your written submission. Have a good day.

DU TOIT, Ms Courtney, Member, Donor Conceived Australia

FAVARATO, Ms Kerri, Queensland Lead Representative, Donor Conceived Australia

SHACKLETON, Ms Aimee, Founder and Director, Donor Conceived Australia

CHAIR: I now welcome participants to make an opening statement, after which the committee will have some questions.

Ms Shackleton: Thank you for the opportunity to present to the committee today and thank you for the Queensland inquiry into matters relating to donor conception information. I have with me today representing Donor Conceived Australia Kerri Favarato, Queensland lead representative, and Courtney de Toit, member of Donor Conceived Australia and a lawyer who practises in family law, fertility law and succession law. We are all sperm donor conceived from two different states and we have all discovered this truth at different stages of our life. All three of us have different sets of legal rights to our genetic identity.

Donor Conceived Australia is a national not-for-profit charitable organisation led by donor-conceived people who volunteer their time to provide support, education and advocacy on behalf of people conceived via assisted reproductive treatments including sperm, egg and embryo donation throughout Australia. We currently do not receive any government funding, but we hope to receive funding in the future.

Our organisation comprises over 500 members conceived across all states and territories in Australia, with dates of conception as far back as the early 1970s. This means that our members are also subject to different rights to access their genetic information based on location and date of conception, just as the three of us are.

Donor Conceived Australia is guided by the United Nations Convention on the Rights of the Child and the Geneva Principles for Donor Conception and Surrogacy, which were provided to the UN Committee on the Rights of the Child by donor-conceived people on the 30th anniversary of the convention. This included Courtney, who is on our team today. A copy of the Geneva principles were provided in our submission to you.

Donor Conceived Australia advocates for a regulatory framework in which the rights of the child created are of paramount importance in all policy and practice related to assistive reproductive treatments. This includes the right to identifying information about their origins, including donor- and sibling-linking services, regardless of when or where they were conceived. We understand that legislating retrospectively is contentious. However, the Convention on the Rights of the Child is clear that knowing who you are is a fundamental human right.

You have heard today about the expensive direct-to-consumer DNA testing, which effectively removes anonymity, but you may not have heard about the countless hours, late nights and obsessive searching that goes along with that, not to mention the lack of support and resources as to how to go about this massive undertaking. For example, both Kerri and Courtney spent hundreds of hours working their way through complex DNA results as they were told there were no records to help them find their genetic family.

We are here today to speak on behalf of donor-conceived people from Queensland, who for many years have had no right to know their true genetic identity. Donor Conceived Australia recommends that Queensland establish a register and that the register be retrospective and linked to other state and territory registers. Furthermore, we recommend that this register include people conceived both privately and through a clinic.

In addition, we note that historical records have been intentionally withheld, tampered with or partially or even completely destroyed across multiple jurisdictions. We call for Queensland historical records to be gathered and retained in perpetuity, with heavy financial penalties for any person or entity found to be withholding or destroying any information or record pertaining to donor conception in Queensland.

Many of our Queensland members come to us after years of searching and hundreds of dollars spent on DNA testing. They require support to interpret technical data and to navigate complex outcomes. In fact, information and support are required for all parties affected by donor conception. The support network must extend beyond donor-conceived people and donors as the ripple effect can be far more wide reaching and will also likely have a multigenerational impact.

Donor Conceived Australia receives daily requests for immediate assistance from people affected by donor conception with a wide variety of complex issues relating to donor conception. There are currently no support services available to assist these people in Queensland that we can refer them to. Counselling currently exists predominantly for those affected by fertility issues, but donor conception issues are quite different. Support services which are tailored specifically to those affected by donor conception issues and, most importantly, counselling services which are impartial must be provided at no cost to the affected person.

Overall, we call for the rights of the child to be paramount in any policy and legislation created about them. Our submission addressed these and other issues. We would be pleased to elaborate further and answer any questions you have for us.

Mrs GERBER: Thanks for your submission. Thanks for taking the time to be here. I know that you have been here from the start. You spoke in your opening statement about wanting to see legislation that regulates both donations made through a private arrangement and donations made through a clinic. Can you point the committee to an example where another jurisdiction has been able to successfully do that?

Ms du Toit: Our submission pointed to allowing for people conceived through private donor conception to be on a register, not to actually legislate for that. I do not believe any jurisdiction has done so, no.

Mrs GERBER: We have heard that from a variety of other submitters today. That is helpful, thank you.

Ms BOLTON: Previously I have asked about the Victorian legislation and whether witnesses feel there could be improvements. The last witness talked about the inability in Victoria to identify siblings. That was one of the key areas they felt could be improved. From your perspective, what do you see that could be improved?

Ms Shackleton: We are calling for the ability to make contact with siblings—that is very important to our members—as a start.

Ms du Toit: I understand that there are costs each time an application is made to find out about a sibling. I am not actually able to use the registers of Victoria. This is just my understanding, but there are significant costs involved in applications for information. We definitely do not want our members having to pay for information that they should have a right to know immediately.

Ms Favarato: If I may expand on finding donor-conceived siblings, the reason having a register for that is so important in Queensland is that in my case I potentially have upwards of 300 donor-conceived half-siblings. That is how long my donor donated for. To date I have found six. There are so many others out there. When they find me, at the moment it is via DNA testing. My donor and I both have our DNA on one of the big sites. The half-siblings pop up and I am then responsible for giving them enough information so that they can then speak to their parents.

As Aimee said, there are no counselling services for me or for any of those donor-conceived siblings who randomly pop up looking for a bit of information. It is then left to me and that sibling to nut out the details of our relationship and try to work through the trauma that then comes from those people having lived a lie for 35 years or more, which is when my two recent ones have found out in their life.

Ms BOLTON: Having said that, do you think it would be better to have a national register than a state one?

Ms Favarato: Absolutely, but we are here for Queensland. That would absolutely be our goal, but at this point if we can get state based legislation underway that would be great.

Ms Shackleton: We will 100 per cent advocate for a national register, as per the federal inquiry that was held in 2011 or 2012; however, we are here to talk about Queensland, and we know that you have not a lot of say in a federal inquiry so we are focused on Queensland for today's presentation. That is what we are presenting on.

You have heard today about the handling of gametes interstate. That is a huge problem that we find with our members who find out when they do DNA tests. They may call a fertility clinic in the state they were conceived in and they are told, 'Yes, there were five births from your donor.' They might even be given the years of birth of those siblings. Then they do an Ancestry DNA test and another 10 show up in different states around Australia. Those people have been told there are only five in their state and only five in that state and none of these people are talking to each other.

Donor-conceived people are kind of putting the pieces together. The clinics are not talking to each other necessarily and there is no overall register that is looking at the full picture. Ideally, there either needs to be a national register or, as I mentioned, the individual state registers must be able to talk to each other.

Mr SMITH: Thank you so much for being here. Often when we talk about rights we think of them in a physical form, but really it is quite a cognitive function they are based on. As comfortable as you are, could you talk us through some of that cognitive process of finding out that you were donor conceived? Is it a curiosity? Is it that sense of biological connection? Is it asking the donor, 'Why did you decide to be a donor and not share in my childhood?' Are these things that come up quite often? If you are comfortable, could you maybe take me through some of your processes?

Ms Shackleton: Sure. I am going to mention that every donor-conceived person has a very different experience. I will note you have not heard from many donor-conceived people today. We have members who have known their whole life they were donor conceived, we have members who find out as teenagers and we have members such as my example—I found out at the age of 40, which is quite a late discovery. They are different experiences. Because we are here for Queensland, if you do not mind, I am going to throw that question over to Kerri, who is a Queenslander, to the answer that question.

Ms Favarato: I was conceived in 1981 and born in 1982. I found out the day before my 13th birthday that I was donor conceived. That has been obviously a very long time; I am almost 40. For me, this has made up a very large chunk of my life. There is no one response to it. The same as we all have very unique experiences, I do not have one unique way I have felt during this process. I felt confused initially because I did not understand—it was in 1995 when I found out. There was no internet. There was nothing. I had nothing whatsoever. When I did reach out to clinics I was met with, 'No. Records are gone. You have nothing.' I was never offered counselling. I was never offered to come in and speak to anybody. I was never offered a kind ear or a kind word. It was an instant shutdown.

I felt numb, angry and confused about why I wanted to know. That was always a question I asked myself, 'Why do I need to know this?,' and I did not have an answer. As a teenager—you all remember what it is like—you are so caught up in your own world you do not know what your feelings mean, so I lived my whole teenage life and my early twenties pretending I did not care, going, 'Oh, whatever. It doesn't matter,' and it did matter. I just did not have an opportunity or any support to discuss how I felt and to work through that trauma. Then not being able to talk through the trauma made the trauma worse.

As my experience has changed I have found other donor-conceived people in our support groups, some of the original people in our group. They have been the support that I should have had from clinics, from doctors, from counsellors from the very beginning. I have been let down in a monstrous way by that.

As I have gotten older and I have been more determined to find my answer, my viewpoint has changed. I have changed my mind about whether or not I like donor conception, about whether or not I want to know, about whether or not I want to have a relationship with my donor and half siblings. That continues to change and that will never stop, because even after finding my donor this story is a constant evolution and emotional ride for me and for many of us—all of us—as we try to navigate the emotional torment of these constant questions about why we need to know our fundamental existence.

It is not okay that I have gone through that alone, to now be in 2022 after I found out in 1995. I am a combination of—as you can probably hear—emotions: I am angry, I am disappointed and I am exhilarated by the opportunity that we are presented with today and in the next few weeks as you consider these things. This is an opportunity to make things right for people like me who were not a part of my creation—making it right for me. There are considerations for every donor-conceived person at this table and all of the donor-conceived members of our support groups. There have to be considerations for donors, but fundamentally I was created by this. My rights come first and I have to be the No. 1 priority.

In answer to your question, there is no answer. It is every emotion you can possibly imagine. It is every question you could even imagine being asked about your identity. If I asked you, 'Tell me about who you are as a person,' what would you give me as an example? Imagine not knowing half of your genetic history. It is an impossible thing to answer and it is an impossible thing to work through. This hopefully will lead to at least some rectification of the secrets of the past to help me and DC people navigate through those emotions, but at least feeling like we are supported through that process and receiving specialist counselling and seeing there is a change will make that a little more tolerable.

Mr SMITH: Thank you so much for sharing that. That is absolutely amazing. The advocacy that you are doing is very inspirational. Thank you.

CHAIR: Are there any more questions from the committee? I am conscious of the time. I would like to thank you for your written submissions, your attendance here today and answering our questions.

NEWTON, Ms Giselle, Private capacity (via videoconference)

CHAIR: Would you like to commence by making an opening statement to the committee? After that the committee will have some questions for you.

Ms Newton: Good afternoon. I would like to pay my respects to elders past, present and emerging and First Nations people. My name is Giselle Newton. I was conceived in Darwin with donor sperm from Perth in the early 1990s. My parents later sent sperm from the same donor to the Gold Coast to try and conceive another child. They were unsuccessful in that, so I guess in some ways I am also linked to Queensland.

I am among the few from my generation who grew up knowing that I am donor conceived, and over the last 3½ years I have been conducting social research on donor-conceived people's experiences via a doctoral program at UNSW Sydney. Through my research and experience it has become clear that there are three core views among donor-conceived people. These are largely undisputed. I think you have heard them over and over again today (1) the right to know one's donor-conceived status; (2) the right to accurate and identifying information about one's conception and biological family members to shed light on medical history and to avoid consanguineous relationships; and (3) the right to make contact with biological family members.

I suggest and recommend today that we centre these views in the following way. I also ask you to bear with me for a moment as I address some of your ongoing questions. Accurate birth certificates is one area in which we can address these things from the start. As we heard earlier today, it is really important that on birth certificates we continue to recognise both social and genetic parentage. I suggest there are two variables that we need to record on birth certificates; that is, social and genetic parents, and legal and non-legal parents. For example, a donor who donated with the understanding that he was the father to the child would be noted on the birth certificate as 'donor' or 'father and legal parent'; whereas the mother would be noted on the birth certificate as 'legal mother' and 'biological mother'. We need to recognise biological and social, legal and non-legal. I strongly but respectfully disagree with the comments earlier today that suggested that a transparent and open approach to birth certificates is stigmatising. This is transparency and openness in donor conception. We have the right to know the truth about who we are.

The second point we need to take into consideration is that we need an independent register that preserves all past and future records of donor conception. In the context of private donation, which we have spoken about today, this can be addressed via the birth certificate phase. If there is a private donation in the context of the home or wherever that might be, we can ask at the stage of the birth certificate for that person to be recorded whether they want to be a legal or non-legal parent. That means legal responsibilities such as any other parent, or non-legal, no responsibilities as a parent.

The third recommendation I have today is to legislate on the importation of gametes and what we call reprotourism. I am sure Professor Kelly has spoken to this. It is impossible to uphold the international human rights for donor-conceived people to have a meaningful relationship when gametes are being imported from Ukraine, from Argentina. Often donor-conceived people do not share a common language with their biological parent. We also have the case of the United States, as Professor Kelly outlined, where people donate dozens and hundreds of times. This means that donor-conceived people may have significant numbers of siblings, and this is not in the best interests of the child.

My fourth point relates to allowing all donor-conceived people the opportunity to negotiate relationships with their donor and donor-conceived siblings. The evidence shows that early disclosure and contact is beneficial, and many people may want this before they are 18 years old. Let's not legislate access to information from 18 years onwards. I suggest this occur without paternalistic oversight via a contact veto system.

There has been a lot of talk about Victoria, and rightly so, but I would like to draw your attention to South Australia. The Victorian legislation was world first; however, the contact preference system means that a person may be fined up to $8,000 for wanting to have contact with their biological parent. The South Australian government has matched and bettered this system by underpinning the system with the principle, as stated in the act, that 'the welfare of any child ... being of paramount importance, and accepted as a fundamental principle ... of this Act'. The act is not considered to be the appropriate place to make it an offence to make contact with another person through the register. There is existing legislation around harassment. Contact vetoes are stigmatising, paternalistic and harmful to donor-conceived people. We need to give people a window of opportunity to prepare themselves. We need to prepare parents and donors for the contact that inevitably is going to occur.

Most donor-conceived people overwhelmingly feel gratitude towards knowing the truth about their conception. My research has demonstrated that donor-conceived people have significant distrust in clinics and those regulating assisted reproduction. Whether there is legislation or not, donor-conceived people can sidestep oversight from these formal avenues. DNA testing exists. While legislation often lags, today we have the opportunity to create this progressive legislation. I encourage you to recognise donor-conceived people as equal citizens by enshrining donor-conceived people's rights in legislation with the best interests of donor-conceived people at the centre. Thank you for your time.

CHAIR: Can I just pick up on something you said earlier that I may have missed. You said the Victorian legislation has penalty provisions in it.

Ms Newton: That is correct, yes.

CHAIR: And the South Australian legislation does not. I know that everybody has been talking about how great the Victorian legislation is. Are you encouraging us to look at the South Australian legislation? Maybe the South Australian legislation has improvements that we could—

Ms Newton: That is exactly right. Later today you will speak to Sonia Allen, who has been conducting this work in South Australia, so you can hear it straight from her. This is improved legislation. It is still being finalised. I encourage you to read the discussion paper from the South Australian government. They have a lot of information on contact vetoes. They discourage the use of contact vetoes. They did not in 1988 introduce contact vetoes in adoption and therefore have discouraged the use of contact vetoes in donor conception. We know better. It is cruel to create this system for donor-conceived people.

Mrs GERBER: Thank you so much, Giselle, for your oral and written explanations. That was really helpful. I just wanted to unpack a bit more around the birth certificate requirements you talked about. Forgive my naivety, but I am just looking back to when I had my children and filled out their birth certificates. How in practice do you envisage that will work? There are also legal ramifications with some of the legal terminology you have used. Can you unpack that for us?

Ms Newton: Absolutely. I am not a legal expert and I again refer to Sonia Allen, who has been dealing with these issues in other states; however, we have talked about the issue of private donation and how people today have suggested that cannot be regulated. Every person in Australia is issued a birth certificate. We have this opportunity for every single person to recognise two, three or four parents on a birth certificate. I encourage us in considering this to allow people to use gender-neutral language as well if they wish to do so in this process. This means that we can allow people to have a social, biological or genetic parent listed on their birth certificate. This is incredibly important because it means and it guarantees that parents will disclose to their children because they know that that document is accessible to their children throughout their life. In Victoria the system is via an addendum. It is a separate document that comes with the birth certificate. It notifies a person they were donor conceived. It provides additional information. That might be one route to consider; however, I would be in favour of transparently, truthfully identifying the social or genetic parents of someone on their birth certificate.

CHAIR: You are very articulate in the way you put that together, but my first reaction, either correctly or incorrectly, is: could that information be used by some scurrilous people? The comment we heard earlier was, 'Why should the way I was conceived be on an official document?'

Ms Newton: I do understand that, and I understand that point of view. I guess we have a lot of assumptions about parentage. We all have assumptions that we have two parents, that they are both our genetic and social parents. As these people who have spoken to you today have revealed, sometimes at 35 or 40 years old those assumptions are turned on their head. We need to be very clear that you can have many important people in your life. Some of them are socially related to you—you have meaningful relationships with them throughout your life—and others are biologically related to you and perhaps also socially related to you. Why should this be regulated? Why should it be written down on birth certificates? Because it removes this issue that parents can decide to not disclose to children. A child might learn at 22 or 30 or 40. If it is on their birth certificate, it is all written on there with transparency and openness, and that is what we are here today to talk about.

Mrs GERBER: I wanted to then talk about perhaps the legal ramifications of some of that terminology. If a donor is named as a parent on the birth certificate, there could be child support implications, liabilities and succession law implications. What is your view on that?

Ms Newton: Again, I refer back to this case that was brought up by Stephen, I believe, this morning about $4 million being spent going through courts to address this issue. We know that birth certificates can be reissued and updated. Another point that I would also like to make is that lots of donor-conceived people would like to have an accurate birth certificate. Even if their initial birth certificate contained the names of the parents who were present at the time of their conception in the 1980s, they might wish to now ask for an accurate document. Therefore, they would like to have their three or four parents listed on their birth certificate. Yes, this does have ramifications, but those parents go into parenthood very carefully considering who is going to be part of a child's life. If they are not considering these very important questions of legal parentage, social parentage, how much of a role they are going to play and also if they want to share their inheritance with their children—these decisions need to be made before somebody becomes a parent and certainly before they issue a birth certificate.

Mrs GERBER: Are you referring to donors, in the sense you just outlined, so that the 21-year-old who decides to donate his sperm has made a conscious decision to become a parent? Is that your perspective?

Ms Newton: This is the whole issue with donation: we have biological parents. I have two biological parents like everyone else in this world. Some people have three biological parents now, with mitochondrial donation and with surrogacy. These decisions of the 21-year-old need to be made very carefully. This was the problem in the past. That is what we have seen with donor conception, that people did not think through the consequences of their decisions. That is why we are here. People got calls later. These donors might not want to have contact because they did not think these children would ever exist and turn into adults as we are here today. We are not children; we are adults, and we want to know the truth about our lives. Yes, it is important that a 21-year-old donor considers if they have to be listed on a birth certificate, they be listed as a non-legal biological parent, because that is what they are. They do not have legal responsibility, but they are a biological parent—that is the truth.

Mrs GERBER: Your submission is that if that is part of what is looked at as legislation or regulated then it would mean that we avoid the problems of the past?

Ms Newton: Exactly.

Mrs GERBER: We end up with donors, as one of the previous submitters talked about—how the type of people donating in Victoria has changed as a result of regulation.

Ms Newton: Yes, because they are conscious of being our biological parents.

Mrs GERBER: Thank you for your submission.

Ms BOLTON: Giselle, we talked earlier about supply and demand. It is possible that if somebody potentially has financial responsibility as a donor—if that is brought in—we could have an even greater shortage. At the moment we are having to bring donations from overseas. How do you view that for the parents who desperately want to have a child if there is such a shortage because legislation suddenly makes a donor responsible?

Ms Newton: I think Professor Kelly largely debunked the issue of there being a drop in donors. There has been an increase in donors, and evidence has shown that. We have an increase in families that want to access donated gametes. If somebody is not prepared to be identified as the parent of a child then they should not be donating. It is a very simple principle. If you do not want to have a relationship with a child, if you do not want to be identified, do not become a parent. Do not donate your gametes.

Ms BOLTON: My question was more about the legalities around your name being on a birth certificate and suddenly finding yourself having to pay support.

Ms Newton: That is why I suggested a non-legal parent or a legal parent. A non-legal parent has no financial responsibilities towards a child. There are no inheritance responsibilities. They are not legally responsible for the child.

Mr MARTIN: Returning to the Victorian system and the South Australian system and the veto process, if there is a situation where a donor has been contacted by the register, as I think in Victoria, and they are told, 'One of your donor-conceived children wants to have contact with you,' and that donor then replies, 'No, I do not want to have any contact,' what do you say to that? Do you say that the donor-conceived person still has a right to contact? What happens if the donor has said pretty clearly that they do not want contact?

Ms Newton: We have harassment laws. If, for example, somebody writes to me and says, 'Please don't make further contact with me,' and I continue to do so, whether that is a colleague, a friend or whoever it is in my life—if they have asked me not to contact them and I continue to do so, then that is covered by our current legislation. Why is donor conception any different? Why should we have this system of making special preferences in relation to our biological parents when for other people that does not exist?

A veto system is one system through legislation. Currently we have, as you heard today, DNA tests and people make contact regardless. Whether we legislate or not, people will continue to make contact by online means, social media and DNA testing. You can enforce $8,000 penalties upon donor-conceived people, but that is not a great system and it is harming donor-conceived people. We already have legislation on harassment. If a donor-conceived person wants to make contact—I would also point out that has never happened; there are no cases of this in Australia. We have heard today that donor-conceived people are extremely sensitive and respectful. I myself have not made contact with my donor because I am incredibly sensitive, worried and concerned at what will unfold. It is much harder being in this position. We are not out to get their money and take their livelihoods. We just want to know the truth about who we are. Does that answer your question?

Mr MARTIN: Yes, it does, thank you.

CHAIR: Thank you, Giselle. That brings to a conclusion this part of our hearing. Thank you very much for your written submission and for making yourself available to address the committee in such an articulate fashion.

Ms Newton: Thank you so much. I appreciate it. Good luck.

TURNER, Ms Sophie, Donor Conceived Aotearoa (via videoconference)

CHAIR: Welcome, Sophie. I invite you to make an opening statement, after which the committee will have some questions for you.

Ms Turner: I would like to begin by acknowledging the traditional owners of the land on which we meet today. I am appearing from Melbourne on the lands of, I believe, the Eastern Kulin nation. I pay my respects to their elders past, present and emerging, as well as the Jagera and Turrbal people in Brisbane, where you are meeting today.

My name is Sophie Turner. I am a donor-conceived person from Aotearoa, New Zealand. I consider myself both a Queenslander and a New Zealander, having lived in Queensland for 15 years. For the avoidance of doubt, I am a state government employee but I am not appearing in any capacity related to my employment. I am appearing both as a representative of Donor Conceived Aotearoa and as a donor-conceived person. Unless stated, my statements do represent the views of Donor Conceived Aotearoa. We are an advocacy group focused on ensuring that the rights and protections for donor-conceived people in New Zealand are at least maintained, but, more importantly, improved wherever possible.

Today I know I do not have much time for my statement, so I am taking it as read. I just want to present you with three key messages that apply to both retrospective and prospective changes that may be considered. The first is that information relating to genetic origins of donor-conceived people is of such personal significance that it is too important to be left in the hands of private companies. It must be subject to central oversight and management by government. I will discuss this further in the context of Maori beliefs and values that have helped shape the New Zealand model.

Secondly, the establishment of a register should not be the end objective. The ability for donor-conceived people to access information regarding their genetic origins, including connecting with members of their genetic family, should be the objective. Finally, donor-conceived people must be centrally involved in the development, implementation and governance of any reforms relating to donor conception.

With regard to the significance of information relating to genetic origins, I want to share this context about New Zealand. The values and beliefs of the Maori, the First Nations people of New Zealand, helped shape New Zealand's approach to assisted reproductive technology, including rights of donor-conceived people. There is a concept of whakapapa, which refers to one's genealogy and its sacred treasured nature. There is a Maori saying that people walk into the future backwards. This means that people should always be aware of their history. Maori culture views human gametes as the physical embodiment of whakapapa. This has influenced, we believe, New Zealand's attempt to develop donor conception approaches that focus on openness and altruism. It is one of the reasons New Zealand has a comparative degree of respect for the rights of donor-conceived people. I say 'comparative' as compared to Queensland and other jurisdictions. I want to stress: I am not saying that the New Zealand model is the best approach—there are many deficiencies—but you need to look to it. I am a non-Maori person from Aotearoa and I am borrowing these terms from Maori culture. I really wish the committee to note my respect for the impact that culture has had on shaping Aotearoa, New Zealand for the better.

I want the committee to consider the concept of whakapapa and understand the significance of information relating to donor conception. You have heard that from witnesses today who are donor conceived. This information is too sacred, too treasured, to solely be in the hands of private companies, and you, as the government, have a responsibility to ensure that information is protected and it is not held by companies—it is not solely the responsibility of private companies who drive profit from this treasured information.

My next point around the core objective: I am a public servant, as I have said. I believe we should celebrate the positive change government policies deliver for communities and individuals rather than celebrating the release of a policy. I will cry with joy and exhaustion if this government commits to a register, but the true celebration should be reserved for meaningful improvement that a register, or a similar mechanism, and a range of reforms brings about in relation to donor-conceived people's access to information regarding genetic origins. As a result, the committee must keep this end objective in mind. The processes and mechanisms that capture and retain information relating to donor conception must be designed to provide donor-conceived people meaningful access to the information they need to connect with genetically. It involves not only consideration of information that is collected but also the supporting processes, appropriate funding and powers to maintain the currency and security of this information and abilities to share best with donor-conceived people in a way that also supports their wellbeing. That includes providing access to appropriate counselling services for donor-conceived people and their families—not only their social family but also their genetic family.

New Zealand is approaching a really important milestone. The first wave of donor-conceived people to which the Human Assisted Reproductive Technology Act 2004 applies will soon be able to access information held in the mandatory register that was created by that act. Our organisation is concerned with the lack of commitment by the New Zealand government to provide appropriate independent counselling to these donor-conceived people to support their connection to their genetic origins. We have questions around the currency and functionality of the information that has been collected in that register, but only time will tell as this first cohort of New Zealanders come through the system. I encourage Queensland to look closely and take lessons from the New Zealand context.

Finally, donor-conceived people have to be centrally involved in this reform. Queensland Fertility Group is presenting after me. You know and you have heard the fertility industry. It is loud, it is well funded, it is well connected and it is an important stakeholder in this discussion. But have caution. They may claim to support donor-conceived people, but donor-conceived people are rarely, if ever, consulted or involved in a meaningful way in the development of policies or practices relating to donor conception or access to information.

The Queensland Fertility Group submission demonstrates this perfectly. They have had the gall to champion their person centred donor practices, for which they have helpfully provided a flow chart, which do not mention donor-conceived people once and end with a treatment and no consideration of the whole of life of a donor-conceived person or even their existence. A personal reflection here: I think the people in the person centred model provided by QFG would more likely be virtuous health directors, maybe then recipient parents, possibly donors somewhere at the end as an also exploited commodity, well before donor-conceived people even feature in their model. So, please, take their statements with caution.

I apologise for diverting and digressing. We have for too long been shouted over—you have heard that from others—by people who do not represent our interests. You have an opportunity to ensure donor-conceived people are not further marginalised, just simply being a product or a commodity in this discussion. If we are centrally involved in the development, implementation and governance of reforms, we will help ensure government-led reform actually delivers the objectives we are talking about. We do not want reform that purports to be for us but is actually being done to us and without us. That would be an absolute failure of government.

Today’s hearings and some of the submissions will have left your heads spinning. I have listened all day. It has been exhausting. As a donor-conceived person I want to remind you that the people this most deeply affects are donor-conceived people. The emotional labour associated with advocating for matters relating to your identity is exhausting, but we still do it. We fight for it. We welcome today’s discussion. So, please, when considering this information you have read and heard, I implore you to place the greatest weight on the views of donor-conceived people. I will end here. We have more donor-conceived people, I hope, on the agenda. They need to be heard. I welcome any questions from the committee about statements I have made or my personal experience, which I have not really spoken to, and, if time allows at the end, I do have some points in response to previous witnesses. Thank you.

Mrs GERBER: Thank you very much for your oral statement as well as your written one. Can you tell the committee: what are some of the lessons to be learned from the New Zealand model?

Ms Turner: It was 2004 that it was introduced. It covers assisted reproductive technology broadly. There are two sections: one relating to this mandatory register and the voluntary register. It was formed in 2004 with, I believe, very good intentions. It was miles ahead. It is 2022 and we are only just starting to have the conversation that they had all the way back then. Keep that in mind. I do not believe, though, that it truly involved that end objective. You create and you collect the information, but what do you do with it? Is it fit for purpose? Is the register fit for purpose? Are you supporting donor-conceived people? That is one of the biggest lessons.

The voluntary register is a failure. It is ineffective. We should have retrospective access. There are about 28 people on it, I believe. It is not functioning. It is really that point of: think of your end objective. Think how you want it to be used. The core thing is that it is not just holding information; it is not just a vault where you hold information. The purpose has to be connecting individuals with their genetic family. I will add, though, that from my personal position I do want to stress that, while it is not the perfect model, it means a lot that I know the New Zealand government has spent the time so long ago, when no-one else was touching this, to put something in place. That was really important.

Ms BOLTON: You mentioned this meaningful engagement or consultation for DC persons within the reform or any legislation developed. Can you outline what that should look like?

Ms Turner: Start the conversation with us. I do not know if donor-conceived people were consulted on the terms of reference for this inquiry. I was pleased to see that you have used humanising language. You have not called us donor offspring, for example. There has been dehumanising language used today by witnesses referring to supply and demand, making us a commodity. That would have been a starting point. Start your consultation with us. I think you have heard very clearly the human rights we have to our genetic information. It starts with us. It starts with exploring what good looks like, what better looks like and working back from there. I am not a legislative expert. I would suggest that is the first part.

In New Zealand I will note another key concern we have is that there are no donor-conceived people, for example, represented on ACART, which is the governing advisory body that makes decisions about applications under it. That is an example. It is fundamentally not supporting that end objective if we are not central to it. You do not know what we need and what is best until you ask us.

CHAIR: This may be an unfair question in the sense that we have heard that the Victorian legislation has some merit and it would be a point to start from. South Australia has not yet introduced this legislation—I think I am correct in saying that—but they are in the process of doing it and, as we heard from the last submitter, there are some positive aspects to that that we have been pointed to. I understand your evidence and I understand why you are telling us to look at the New Zealand example.

Ms Turner: On top of. Look at your other jurisdictions, yes, absolutely, but include New Zealand because they have had nearly 17 years of living this legislation. With the best intentions we started out, but we did not think ahead to what the individuals will look like. That is what has happened. They are now there. Those individuals are there to learn from—their views, their experiences. But absolutely consider Victoria and consider the other jurisdictions. I point to members of Donor Conceived Australia as being far more expert in that space than I am. I love their work.

I do just want to comment on Victoria, though, and the concept of vetoes. I want to strongly say that they are absolutely redundant in my mind and unnecessary. If a genetic parent, a donor—I refer to genetic parent—does not want to speak to or have contact with a donor-conceived person, all they have to do is say that. That gives such closure. It is an important piece of an individual's genetic story to hear that. I have not heard of a single donor-conceived person who has been rejected by their genetic donor, which does happen, who has then gone on to stalk them, harass them or harass their family. It is really important that donors simply say that. We do not need an archaic preventive veto to do that. It can be done in human interaction.

Mrs GERBER: I want to give you an opportunity to make some of the responses that you said you wanted to make at the start of your opening statement.

Ms Turner: Thank you. I want to give a big thanks to donor-conceived people who have spoken but also all the allies. Some of the comments we have heard are really challenging around supply, demand—that commoditisation of donor-conceived people. Thanks to Fiona Kelly. I strongly support all of her statements with the exception of the vetoes comment. In particular, on international donations I completely agree. It is false if recipient parents think that international donations come with anywhere near the protections. I ask committee members how on earth you think you would be enforcing those. A final point is that there are a whole lot of surrounding changes, birth certificates for one—you have heard about that—and the need for transparency. The register is so important, but it is not the only piece of this puzzle. All of this will be really hard, but it is worth doing and it has brought, as I said, immense joy to know that this committee is looking into this matter. Thank you.

Mr MARTIN: Could you provide the committee with a list of approved and supported terminology for the benefit of the report, to make sure that the language we use reflects contemporary language? I think that would be helpful.

Ms Turner: Every individual has their own view, but donor-conceived person, donor-conceived people—that person-centred use in the proper way—is appropriate. We are not offspring; we are not children. Even if you were referring to someone who is still actually a child, what is the harm in calling them a donor-conceived person? 'Recipient parents' is often how we refer to people who conceive using donation. Again, those people will have a term that they feel more comfortable with. Really, it is about asking that individual. If you are engaging with a donor-conceived person, for example, I prefer to identify my relationship to my genetic parents as being a genetic father, not being asked, 'Hey, who's your real dad?,' for example. It is just common practice but, really, donor-conceived people. Acknowledging our agency and our maturity is really important. Thank you for the question, though.

CHAIR: Unless you have anything else you would like to advise the committee of, I will close this session.

Ms Turner: No. I will let you get on to Queensland Fertility Group, keeping everything in context. Thank you, Chair.

YAZDANI, Associate Professor Anusch, Medical Director, Queensland Fertility Group

CHAIR: Welcome. I invite you to make an opening statement, after which the committee will have some questions for you.

Prof. Yazdani: Thank you. I have been the medical director for the Queensland Fertility Group for the last two years. I feel a little bit like I am stepping into a lion's den after the last witness. I am a subspecialist in reproductive endocrinology and infertility and I am in current clinical and private practice here in Brisbane. I was in public service for the last 25 years before this, so I do know a little bit about both types of medicine.

Thank you for allowing me to address the inquiry on behalf of QFG. Personally, I do want to thank you for allowing all of the stories of the donors and the donor-conceived individuals such an airing in a public forum, because it is really important. My remarks here really focus on the submission from QFG, but I will hopefully be able to answer some questions for you later on.

It is important to note that QFG was formed from a group of specialists working within fertility in Queensland and it remains such. QFG engages scientists, pathologists and labs but in fact does not employ any medical specialists at all. The services are provided on behalf of individual practices, and that forms part of the issues that have been discussed here today. We operate a modern, responsible donor program that supports the full disclosure of identifying information to donor-conceived persons, in line with the recommendations of NHMRC and RTAC. There is no anonymous donation of any type in our unit. There is no non-altruistic donation. There is a family limit on all donations and, in the absence of the federal registry, we are working within a national framework through Virtus Health to establish an appropriate limit.

Australian fertility clinics have robust, contemporary processes for managing all health information and we do this in a safe, transparent and accountable framework, as outlined by NHMRC and RTAC. Given the regulations that have been placed on managing all of this information, QFG questions the rationale for setting up a further government agency for the collection, retention and administration of health and clinical information in another registry that adds another level of complexity to the process as it is at the moment. We are concerned that the establishment of further legislative constraints would limit access to donors, increase the complexity and the cost for recipients and increase the health risks to donor-conceived individuals.

We do not support a blanket legislative release of identifying information for donors prior to 2004 as those arrangements occurred within a medical consultation, understanding that those identities would remain confidential. This is a problem for all of us, including for QFG.

QFG does not participate in any private donor arrangements, and we cannot provide any information on this, but I do highlight the risks that are inherent in terms of donor arrangements in this situation. Medicine, like any other profession, has evolved over time. While by current standards some of those practices may not be okay, such actions have to be seen within their historical context, particularly that those actions would have been taken by those individuals in an effort to assist the conception of those people they helped.

We absolutely recognise the importance of the information that donors want. If you asked me now today if you wanted to know who a donor is, I can give you that information in two minutes—on non-identifying information I can tell you who the person is and what their family history is—and within a day I can give you all of the identifying information, but for historical records that is a completely different situation. That has nothing to do with the unit or its structure; it has something to do with the way that medicine was practised 40 years ago, and that is all it is.

We are interested in engaging with all of the stakeholders in this. I completely accept some of the comments that were made just previous to this. We are happy to help and assist in trying to get the best outcome for donors, donor-conceived individuals and people accessing our services.

Mrs GERBER: Thank you for your submission. The committee has heard from a number of witnesses today. Overwhelmingly, those witnesses who are donor-conceived persons have said that the private sector has let them down in relation to providing information. I was really struck by the last submitter and her comments about the person centred approach. What do you say to that? I realise it is a difficult question, but I just think it is important for the committee to hear.

Prof. Yazdani: I absolutely agree. I think historically we have let donor-conceived persons down. There is no question about that at all. But you need to understand that if somebody now requests historical information—and, as you heard from Rainbow Families, a lot of this pertains to historical information, pre 2004, not something that any of us were involved with—absolutely the role of our organisation at this point is to facilitate contact. If you make contact with us to try to get information on your donor, we will take down all of your information. We offer support. That support is funded fully by QFG. There is counselling available to anyone who contacts our unit, and we try to get this matter resolved for them.

There is absolutely no hiding and no obfuscation—none of the techniques that people have said occur within the unit—from QFG, but it is difficult to access historical records. Those records exist in card formats. They are created by specialists. They involve more than one individual, and not just the donor-conceived individual. We have heard that we do not have the donor-conceived person at the centre [of the submitted flow chart]. I hate to tell you, but the donor-conceived person is not at the centre of the model when people to come and see us. The children are absolutely of paramount importance, but in fact the relationship is with the person who is coming to us as a patient, who sees me as their doctor. I am interested in her and in her family. Of course, her future and her future family is really important, but that is not the way that the practice has evolved or that the practice exists at the moment. That does not mean that they are any less important.

Ms BOLTON: Professor, earlier you mentioned the confidential nature. Obviously going back in time, we have heard about things like promises. You have said that 40 years ago it was very different in terms of records and that there is difficulty in terms of access. Do you have a problem with legislation that retrospectively allows that information to be accessed with contact preferences—so a donor may be happy for their identifiers to be released but may not want contact? We have heard that there is good respect for that. I am just trying to understand how you view that.

Prof. Yazdani: We are not the custodians of those records. That is what I was saying to you. The custodians of those records are the practitioners and specialists who hold those—not us. We are not employing or engaging any specialists. We are not providing medical services. This is part of the problem and this is the misunderstanding. If individual X contacts the unit and says, ‘I want to know about my donor,’ we actually do not know individual X. That is the problem. They are not registered. They are not under us. We do not know them. In order to access their record, we then need to find out who actually sought treatment. If it was mum, dad or whoever it was, we can put them in touch with the specialist who looked after them and then that information can be obtained. It is not possible to say, ‘This is donor X’ and cross-link it. It just does not exist, because the individual who is making the inquiry did not exist and is not registered.

Ms BOLTON: My question was: would you support legislation?

Prof. Yazdani: Do I have any concerns about it or do I support legislation to do that? It would absolutely simplify all of our interactions.

Ms BOLTON: Wonderful. Thank you.

Mr SMITH: Just to be absolutely sure, it is very difficult to find records prior to 2004 but it is not impossible?

Prof. Yazdani: No, it is not at all difficult; it is just that we do not have the records. QFG, for example, is a place where we provide the scientific services, but we do not hold the medical records. In some situations the medical records have been given to us, as specialists have retired and as they have stopped practice. Because we are such an old group, we now have a collection of medical records. Where we have those records, we will absolutely make every effort to make them available. I can guarantee you that, with our group now as it is, under absolutely no circumstance would we try and stand in the way of anyone trying to find information on their donor. We will link them as much as we can. There is absolutely no doubt about that at all. The problem is: if you are asking for a record from 1982, we may not have that record. That record is under the care of a specialist. If the donor-conceived person rings us and says, ‘I was conceived by donor 12058,’ then I have absolutely no problem with giving that information immediately because we have that information. We just may have what donor was used at that time in that situation.

There is this thought that everything has been in a central registry. It has not. That is not how medicine has been practised. Now, if somebody rings me and asks, ‘What donor was used on 20 July 2017?,’ I can give that information right now—no problem—and within a day I will give you the identifying information. I cannot do it for records that are 50 years old. It does not matter what legislation you put into place, the problem is the same. The problem is that of historical records; it is not of access to them.

Mrs GERBER: I want to change tack from historical records. We heard from a couple of submitters that, as a result of regulating and as a result of legislation, particularly in Victoria, the type of people choosing to become donors has changed in a positive way—in a way that is allowing for a more person centred approach. What is Queensland Fertility’s involvement in that and your perspective on that?

Prof. Yazdani: That is a really good point. The very first thing is that we are doing everything not to use international donors. I can tell you that international donors are a really big problem. We really do not want to use international donors. I heard the comment earlier in the day. We so do not want to use international donors. We want to use national donors. We want to have one national set of parents. We want to have a national family limit. There is no question about that at all. If we did not have to use unknown donors, that would be even better. If everybody just did known donations, that would be our preferred way. That is the first thing.

You were asking me about the nature of the donors. Yes, the nature of the donors has changed. The difference between international and Australian donors in particular is that they are absolutely older. That does not necessarily mean that they are doing it because there is a degree of maturity and they are more open to having more contact with children. It is potentially just about the type of person who is donating. They may see this as their opportunity to leave a legacy on earth that they would not have had in another way. It is not necessarily about a more mature, considered outlet; it may be that this is also the only outlet. I am absolutely not saying that that is what it is, but saying that being older does not necessarily make them better.

Certainly as you get older, there are potentially more problems. There are more problems for children conceived through older parents—all the issues that happen with age. You want to have younger donors as much as you can. We have to try and facilitate it and make it easier for Australian males to donate more easily and make donation much more accessible to them, because it is really important.

Mr MARTIN: The committee heard before that, in relation to the number of collections by local clinics, many local clinics have stopped trying to find local donors and that one of the consequences of this is that there were possibly large numbers of siblings around the world. Could you respond to that? Does QFG have any opinion on that? Is there anything you think should be included in regulations to increase the number of collections in Australian clinics?

Prof. Yazdani: We definitely are trying to push nationally. We want Australian donors. We do not want international donors. Everything you have said about international donors is absolutely correct. It is a much more unregulated market internationally. The international donors that we use in Australia have to meet all of the requirements that our Australian donors do. In Queensland we have a 10-family-unit limit. A 10-family-unit limit does not mean 10 children, though; it means 10 families. Some of those may be one and some of them may be two children. Our aspirational goal is to move to a five-family-unit limit across the whole of Australia and to only use Australian donors—full stop, end of story. There is no question. That is the plan.

Mr MARTIN: In your interaction with clinics, is there any feedback you can give the committee on what can be done to increase that number?

Prof. Yazdani: To increase the number of Australian donors?

Mr MARTIN: Yes. Is it just advertising? Is there some regulation that is in the way?

Prof. Yazdani: Advertising is part of it. Part of it is also that: the type of person you want to attract is younger, for the reason that the risk of medical disorders and medical problems and issues is lower at that point. There needs to be a balance struck between that and, as you heard before, suddenly recruiting a whole lot of 18-year-olds, which is a disaster because they do not have the maturity. There is a balance here. We have been trying to find that balance. You try and run more cheeky campaigns to get Australian donors in and then they do not speak well to older donors, so you wind up getting a whole lot of people ringing up with prank calls. I have to tell you that we have not found a formula yet to make that better. Australians are very family centred but on the old concept of the nuclear family that consists of a biological father, a biological mother and a biological child, whereas modern Australian families do not look like that. The more we dispel that myth the better it probably is, and we will probably see more donations as a result of that.

CHAIR: That brings to a conclusion this part of the hearing. We thank you for your time and for your written submission. Have a good afternoon.

Prof. Yazdani: Thank you.

BOOTH, Mr Paxton, Privacy Commissioner, Office of the Information Commissioner

RANGIHAEATA, Ms Rachael, Information Commissioner, Office of the Information Commissioner

CHAIR: Good afternoon. I invite you to start by making an opening statement, after which the committee will have some questions.

Ms Rangihaeata: Thank you for the opportunity to address the committee on this important and complex issue regarding the management of personal information associated with donor conception. I wish to acknowledge the traditional custodians of the land on which we meet today and pay our respects to elders past and present. I am appearing today with the Privacy Commissioner, Paxton Booth. I also acknowledge the expertise and the experience of those making submissions and appearing as witnesses today.

It goes without saying that the issues this inquiry raises are complex and there are different views on balancing the interests of the many parties affected by these issues. Our submission relates to right-to-information and privacy issues, noting that our jurisdiction is focused on information held by Queensland government agencies. From a privacy perspective, there are a number of important issues to consider but, firstly, it is important to understand that in Queensland privacy principles in the Information Privacy Act are subject to other laws. Should the parliament legislate to allow the disclosure of personal information of donors and donor-conceived individuals, that would, for the most part, operate outside the Information Privacy Act. To say it another way, the privacy principles are subservient to other laws which permit the collection and dissemination of personal information.

One important issue for the committee's consideration is whether identifying information should be released when the donation was made on the understanding that it would be anonymous. One approach to this issue is to only allow the communication of identifying information of donors and donor-conceived individuals when all parties agree or consent to the communication. We understand that this is currently the position in a number of jurisdictions, as outlined in many submissions and by witnesses today. That has the impact that some donor-conceived individuals have access to the information while others do not, depending on their date of birth.

Retrospective models, on the other hand, such as those in Victoria and South Australia, which in essence override a previous assurance that such information was confidential, give rise to a potential conflict between the rights of the donors and the donor-conceived individuals. Should a retrospective model be proposed to support the right to know identity and medical information, safeguards will be important to protect the privacy of individuals, even if their personal information is communicated to another without their consent.

In the event that it is proposed to allow access to donor conception information without the consent of the parties, this would be a significant incursion into those persons' privacy and, as such, other safeguards should be considered. There are five key initiatives, in our view, that should be considered relevant to those matters. The first is the creation of a central register to manage the information. This would simplify access and compliance for individuals and the current clinics that hold the information. It would provide a clearer pathway that is easier and reliable for those seeking information about donor conception whereby they can go to one agency to obtain information. It would also provide better governance of the personal information held by ensuring a consistent approach to data handling and management.

The second initiative is to provide an appropriate lead-in time to facilitate a strong community awareness campaign about the changes, to the extent to which they are retrospective in particular, to allow affected parties to prepare for any impact it may have on them and their family. The third is to consider how to best ensure the accuracy of any data that is held by clinics and, if recommendation 1 is followed, transmitted to a central register. Experiences in other jurisdictions, and indeed in the submissions provided to the committee, suggest there are likely to be gaps and inaccurate information within the current data. There are obvious significant risks if inaccurate information is released to parties about the donor or donor-conceived individual.

The fourth initiative is to ensure that donors and donor-conceived individuals have an ability to convey their wishes about contact by their genetic relative to the central register. This would be beneficial to both parties, as if contact was sought by one party they would understand the position of the other party and it may influence their decision to make contact. This would, of course, require the other party to be notified of the request for information prior to it being released. In Victoria, parties are given four months to reply to the request in order to provide time to convey their views about whether they wish to be contacted by the other party or their family. A variation to this, which offers a stronger privacy protection, would be to only permit contact where the other party is consenting. This would be consistent with the current model in Victoria, which allows donors to lodge a contact preference and a statement explaining their wishes. So while the identifying information is still provided to the other party, contact is only permitted if the other party has consented. The contact veto mechanism aims to achieve a balance between disclosing the identity of the donors to the donor-conceived persons. It will not mitigate all the privacy risks and the potential impacts. Lastly, a model that is similar to the Adoption Act in terms of managing the collection, storage and disclosure of information may serve as a useful model.

Restricting the use and disclosure of donor conception information, except as authorised by the legislated framework, would have several benefits. It would serve as a one-stop shop for all parties to understand what can and cannot be accessed; it would provide clarity in relation to the confidentiality provisions and in what circumstance the information sought by an applicant can be released; and it would stop a potential increase in formal right-to-information and information privacy access applications and subsequent review applications. Thank you. We are happy to take any questions you may have.

Mrs GERBER: Your submission is comprehensive, thank you. We have had some submissions from some stakeholders on not using the contact veto. I am not sure if you were able to tune in to those submissions, but I interested on your perspective on that issue—that it is not focused on the person and that it can be detrimental to donor-conceived persons. What is your view?

Ms Rangihaeata: We have been able to tune in to parts of today but unfortunately not all. Firstly, we know that most of the witnesses here today—I would say all of them—have a huge depth of experience. This is an area that we are examining from our particular expertise. We can see that there is years of personal experience as well. From our perspective, our work is all about striking a balance, often between relatively different perspectives, on whether information should or should not be released in a whole range of circumstances. That is in both parts of our work. Often we say that it is two sides of the same coin. It is about trying to get the right outcome in a very complex and difficult situation.

In Queensland, right to information comes down to pushing information out unless it would be contrary to the public interest to withhold it. At the same time, our Queensland privacy jurisdiction is about, essentially, protecting the community from harm in various ways. We have a range of privacy principles that cover off certain aspects of that. With the various permutations of personal interests and even various groups of individuals with common interest, it is very hard to come to a common single outcome; however, that is essentially what we do with a lot of our legislation on some aspects of access.

Some of the models of legislation are probably, from what we hear, reflective of the evolution in this area. Clearly there are a lot of aspects, including with technology and community expectations, around the right to know and generally around the right to access to information. There are changing expectations around privacy as well. Technology has certainly facilitated access to information, but it has also heightened privacy expectations in some areas. In other areas we know that people are willing to give up certain aspects of their privacy. It is difficult to achieve that balance when it is quite nuanced.

In terms of this particular area, we think some of the models, like the one in Victoria, are definitely well worth looking at—imposing some of those limitations where you can respect different wishes in certain situations and where you can consult, for example about contact preferences. There will always be some privacy risks. It is about to what point you are willing to mitigate those risks. What is the risk appetite, given the very important right to know this information and the public interest in the medical information and all the other issues that have been raised today in terms of the alternative ways that people find out this information and the impacts of doing it in that manner?

Mr Booth: I would convey it the sense that I think the rights of both the donors and the donor-conceived individuals can be seen as a pendulum. It started off decades ago in one spot and it is been swinging from everything being confidential towards things being more open and transparent and releasing more information. I think we have seen that particularly in Victoria, which has been spoken about numerous times today, where they have the ability now to have retrospective access to identifying information. The balance is the contact veto, which we have spoken about. It is swinging even further in South Australia, where they now have just a statement of wishes; there is no prohibition. There is certainly merit in both parties being able to put onto a central register a statement about their wishes of contact, as a minimum. I think there are benefits in that for all people. At the very least, you can go into that contact, if that is what you decide to do, knowing the other person's point of view.

That said, I still think there is merit in a contact veto consideration by this committee as an exercise in balancing the rights of these individuals who donated in a different time, in some cases decades ago, when there were different principles and different community expectations. It was a different world, where there was no internet and no ancestry.com. The idea of being identified was probably the furthest thing from their mind when they made that donation. Now there are changing expectations in the community which are pushing parliaments more towards the rights of the donor-conceived individuals, from my reading of and preparation for this exercise.

Mr SMITH: If a bill is drafted in Queensland that reflects legislation in Victoria and South Australia, are there elements of the Privacy Act that you envisage need to be changed, or is that a question that is better put on notice?

Mr Booth: The way the Privacy Act works is: if a law is passed by parliament which says, 'You can disclose this information for these purposes,' that then becomes an exemption for a large part of the privacy principle. It says, 'You can only use or collect or submit information for the purpose of the outline unless there is a law that authorises it.' In this case, if you pass a law that authorises it, it would take it out of the information privacy principles, by and large, to then be managed by whatever is allowed in the other legislation. The only one I can think of, off the top of my head, would be the obligation to secure data. That would probably still apply, depending on what was in the act. If it is excluded I would recommend, obviously, that there should be strong protections around that data and the need to maintain it in a secure manner.

Ms Rangihaeata: The one point with the Right to Information Act I made before was: with the Adoption Act we have a really strong administrative access scheme so that people do not have to make formal access applications. They can apply through an informal request, if you like, through that clear scheme, for the information, and they have clearer expectations around what they can and cannot access through that scheme. That means they are not having to make formal access applications, which is a longer process and takes more time and more resources at their end and is not ideal, given that we have the push model where that should be the last resort. As part of this you would expect that the relevant agency would set up a clear process that is visible and communicated well and that would ensure people know what to do. There are some relevant amendments to the right-to-information legislation that tie in to the legislation and support that framework, so I would probably consider a similar scheme.

Mr MARTIN: I take your point. You are trying to balance privacy rights with human rights and the rights of the child, and you are looking at this from that perspective. We have heard some pretty passionate submissions today from donor-conceived people, who basically say they should not have to go through a veto process. Why should they have to go to a register to contact the donor? That does not apply to another person who wants to contact any other member of the community. Do you have any response to that from a privacy point of view?

Ms Rangihaeata: Can I just clarify something? In terms of any other member of the community—

Mr MARTIN: Under a Victorian model, a donor-conceived person would have to contact a register to make contact with their donor. They have never met this person. It is an additional obligation that is put on a donor-conceived person that is not put on someone else who wants to contact any other member of the community. This is what I am hearing from them. It is an additional obligation that they have to comply with. Considering that you can bypass those rules pretty much altogether by going on ancestry.com or one of those private providers, I just wanted to hear your point of view. From a privacy angle, is that fair? Should a donor-conceived person have that extra obligation?

Ms Rangihaeata: The comparison is with going through the private route as opposed to a regulated route?

Mr MARTIN: Comparing that to any other member of the public who wants to contact somebody else.

Ms Rangihaeata: Track somebody down?

Mr MARTIN: For example, if I found out where an old friend from school lives, I can go to their house, knock on their door and say, 'Hey, it's me,' but someone who is trying to contact their donor cannot do that and can potentially be fined.

Ms Rangihaeata: There can be privacy implications for a range of contacts, and I guess this is one specific aspect that has been raised because of the sensitivity in this area. I understand the concerns that have been raised. Where there are concerns on both sides, I think it is appropriate to consider that it is necessary to look at appropriate safeguards for those who perhaps are not aware. We have looked at this previously through our work with putative father records and adoption records. It is very difficult, particularly when we cannot reach somebody to consult them about whether they want access, to know exactly how they will be affected. That is one of the difficult things to ascertain:

the impact. At the same time, I acknowledge that it is of considerable impact on the donor-conceived individual not to be able to contact. It is important to consider these safeguards as one option. Where the balance falls is a complex issue for this inquiry to consider. In relation to the private route of going through ancestry.com, I know that individual witnesses and submissions have also raised concerns about dealing with that information, whereas this provides a regulated route for people to manage the impacts of that.

Mrs GERBER: I know that our time is up, but I notice that in your submission you are proposing a new offence for destruction of records. Are you proposing that that be retrospective as well? I am only asking that because we have heard from a number of very passionate submitters that they could not access records because they were destroyed by the clinic. Whether or not they were destroyed intentionally is another matter, but there was an element of the destruction of personal records they wanted to access. That offence would alleviate it in future. I am just after a bit of an elaboration as to how you envisage that offence operating.

Mr Booth: When we wrote that, it was not intended to be retrospective. We are suggesting that it be a criminal offence. There would need exceptional circumstances under normal drafting guidelines for it to be retrospective.

CHAIR: That brings to a conclusion this part of the hearing. I would like to thank you for your attendance. Thank you for your written submission.

ALLAN, Professor Sonia, Private capacity (via videoconference)

CHAIR: If you would like to make a brief opening statement, following that the committee will have some questions for you.

Prof. Allan: You have my submission, so I thought I would just open by saying that I am not donor conceived and I do not have donor-conceived children but I have been looking at these issues since 2003, when I started working at the Victorian Law Reform Commission on a reference on access to assisted reproduction. That reference was about opening up donor conception and allowing single people, same-sex couples, access to donor conception.

In working for that reference, the first person I met was Narelle Grech, a young donor-conceived person who was looking for access to information. She had been looking for some time. I saw her wanting access to information dismissed. It was said that she was an angry teenager; she should feel privileged to have been wanted; it was not like adoption, where she had been given away. What really struck me was that people were failing to hear the lived experience of somebody who had been born as a result of donor conception and was telling us otherwise. She needed that information. It was important to her. That is where I started. I became very interested in hearing their voices and listening to the lived experience, and ever since I have worked in looking at the issues.

I have been listening all day. I wanted to pick up on some of the things that have been asked, if I may. First, obviously you have just heard from the Privacy Commissioner. I have privacy down on my list. If you take it from a human rights perspective, privacy is not absolute. It can be interfered with providing there is a legitimate cause and that any such interference is proportionate. Clearly, the legitimate cause here would be the rights of donor-conceived people to have access to information about their identity, to be able to preserve identity and family relations, so there is a legitimate reason to do so.

In terms of the retrospectivity issue, we started working on the model that was proposed very early on before the Senate committee inquiry in 2010. Donor-conceived people, recipients and donors had been calling for information for decades. Before I appeared on the scene they had been around for decades asking for information. My interest was to ask, ‘Can it be done?’ That was the first question: ‘You want retrospective release. Can we pass legislation that gives you the right to access information?’ The answer is yes, and we do so cautiously. We do not pass retrospective laws in criminal law, but we do pass retrospective laws. We did so with adoption and we have done so in the realm of assisted reproduction in relation to recognising legal parents, so there is good precedent for that.

There is a model of private donors, private arrangements. There is a model in South Australia that operated up until the establishment of the Donor Conception Register in November 2021. In the Births, Deaths and Marriages Registration Act, known donors or private donations were recorded on the birth registration document. When a person is born and they register the child, they record the known donor on the document. The provision in that act expired on the establishment of the Donor Conception Register, but South Australia, as I understand it, is looking at whether that provision can continue. That is section 14 of the Births, Deaths and Marriages Registration Act where people are registering known donations. The idea of that would be that that information could then be transferred on to a register. The inclusion of those details does not create legal parentage, but it does create a record of who the known donor was. I think that is very important to think about, because otherwise you leave a whole load of arrangements outside of what you are considering. Those children are entitled to access information as well. I will leave it at that for now.

CHAIR: In relation to the birth certificate in South Australia—sorry, you were not talking about the birth certificate; you were talking about the registration of the birth.

Prof. Allan: Yes.

CHAIR: If you applied for your birth certificate, would that information show up on your birth certificate?

Prof. Allan: Yes. As I understand it, you could have it on the back of the birth certificate, so it separates who the legal parent is from who the known donor was. Obviously people have different arrangements. It was a way of allowing it to be included somewhere. Now I think the consideration will be that the information can potentially be put onto the register, so they would have access to the information in that way.

If you look at birth certificates, what has happened in adoption around the country is this notion of integrated birth certificates. You have your original birth certificate and then you have an integrated birth certificate showing truths of everybody who was involved—conception and legal parents. That is also a possibility for donor conception. I see no reason why you could not have a parallel with adoption in terms of having integrated birth certificates for donor-conceived people. Then it is a choice: ‘Do I use my birth certificate that looks like everybody else’s or do I use my integrated birth certificate because that matters to me?’ It is a decision of the person it affects rather than a decision of somebody else.

CHAIR: I have been searching for that all day. It makes it clear. It would be a fair way to allow the person to make that decision as to which birth certificate they would like to rely on.

Prof. Allan: Yes.

Mrs GERBER: We have heard that you are a bit of an expert in relation to the development of the South Australian model. I wanted to explore that with you. We have heard a lot about Victoria. I want to hear about South Australia so that we can understand the learnings from South Australia.

Prof. Allan: I heard your question but if I may start with Victoria?

Mrs GERBER: Sure.

Prof. Allan: When we developed the model for Victoria—we gave it to the Victorian inquiry and they accepted it and that was the model that was implemented in Victoria—we did include a contact veto system because at the time everybody was scared. It was a bit like Chicken Little: the sky is going to fall in. This was a protection. It was mapped on a model of what had happened in adoption, but we never actually thought that a strict contact veto with penalty would be required because the risks were very low of breaching contact preferences. With that in mind, I would say that Victoria was the first to enact the legislation so they did so cautiously. What South Australia has been able to do is then look at the five years where this has been operational and think about what works and what does not and have some learnings in that regard.

What I must say is that the policy process is within the South Australian government. I do not know what the legislation will be in South Australia. That will be up to the South Australian parliament. In terms of the South Australian process and looking at how the register will operate, my observation is that it has been nothing but robust. The people in that team are looking at every single aspect. They work extensively, collaboratively and consultatively, and they are coming up with a model that is really aimed at facilitating and supporting people in this exchange of information and how that is going to look.

They are also working on a modern register, so one that is operational and accessible by people in ways that people operate now—so online, having a portal, having things that are very functional practically in terms of how this can work. I think a number of things are coming out of that. It is very important not just to look at the exchange of information between donors and donor-conceived people but also to think about the exchange of information between siblings. If you are talking about preserving family relations, it is not just parents but also genetic relatives. There are many good reasons to be thinking of siblings as well.

The support systems and who they would apply to is something that they are looking at. Victoria has a mandatory model: you must have mandatory counselling; you must engage with such-and-such services; you must have a statement of wishes. The feedback through extensive consultation with donor-conceived people and recipients is that often those sorts of mandatory systems—it is like with anything. If you go to counselling because somebody has told you that you must undertake it, there is a lot of research that says that there is no therapeutic benefit whatsoever, so why are you doing it? If you offer counselling as a choice then the people who need it will take it up.

You need to differentiate between intermediary services—perhaps the ‘search’, ‘find’ and ‘outreach’ services when you are looking for donors or donor-conceived people, as opposed to counselling, which is about psychological functioning or harm, dealing with problems. So you can have different functions available to people who are accessing the register.

If I am thinking about the practicalities, you did mention earlier today about having a national register. You have to be cognisant of the fact that donated gametes have moved across state borders and donor-conceived people and their families have moved around too. People travel interstate. The Senate committee inquiry in 2010 recommended a national register, but the federal government said that because the regulation of ART falls to the states it was a matter for the states. Their finding was that the states should act on this as a matter of priority. Their report was in 2011. Again, we are now 11 years after that report. Obviously it takes time. There have been reviews and inquiries. Victoria was the first. New South Wales was next. I led the reviews in South Australia and Western Australia, and they are now doing work on establishing their registers. It is a process.

I think South Australia, I am hopeful, depending on what happens in parliament, will be a really good model. I would encourage you to look at that. You do not really want a different register in every state of Australia. It is really complicated. It is made even more complicated when you start to see how differently they all operate.

CHAIR: You said there was a group working in South Australia to get this right. I have a two-pronged question. The legislation in South Australia has not been passed yet.

Prof. Allan: It has not.

CHAIR: Who is this group?

Prof. Allan: It is within the health department. You have principal policy officers, the legal team, people who are designated to look at operationalising—so IT people who are working on the infrastructure of the register. There is a team of people within the health department.

CHAIR: So you have a team of people within the health department?

Prof. Allan: Yes.

CHAIR: Do you have a team within Justice and Attorney-General or is it just Health?

Prof. Allan: No. Because of the way it was required in the legislation, it falls under the Minister for Health and Wellbeing. That is why the register will be within Health. Preferably, if you have the AG's department, you have Births, Deaths and Marriages as an option to put the register. Because of the way the legislation is in South Australia, it is within Health but birth registers will be linked to Births, Deaths and Marriages.

CHAIR: We could perhaps do away with a layer of bureaucracy by working within the Department of Justice and Attorney-General?

Prof. Allan: I also thought that, provided you get it operating properly. That is where everybody else's birth information is, right?

CHAIR: Yes.

Prof. Allan: If you want to do away with stigmatisation, if I go to get my birth certificate, I go to BDM. Why should a donor-conceived person go somewhere else? It is their birth information. You then need to have the right extended services to make sure that it can operate, because it is not as simple as me going to get my birth certificate. There are some added layers.

CHAIR: You talked about those in relation to support that can be offered to a person working through this.

Prof. Allan: Exactly.

CHAIR: That is why you mentioned that the mandatory aspect of it in Victoria is not as efficient as a voluntary system or being able to ask for help if you need it.

Prof. Allan: I think where the mandatory services may be required is to make sure that donors and recipient parents understand the importance of conveying this information to donor-conceived children. When you have people on the other end who are seeking information, I think you have to be careful of thinking that every person who is looking for information has suffered some kind of harm. Sometimes people look for information about their biological heritage because it is important to them. They do not need to be suffering. They do not need counselling. If I ask you, 'Who is your father?,' you will tell me. Is that your information? Is it important to you? Do you need counselling in order to have that information? That is the point. You do not need it in every case. Obviously in some cases it is different so it needs to be offered, but it does not need to be mandatory.

CHAIR: Thank you. Unless someone has a burning question, I would like to close this session. Thank you for your contribution. Thank you for your written submission. It has been very helpful to the committee.

LEISHMAN, Ms Anne, Private capacity

LEISHMAN, Mx Quill, Private capacity

CHAIR: I now welcome Anne Leishman and Quill Leishman. I invite you to make an opening statement, after which the committee will ask you some questions.

Mx Leishman: My name is Quill. I am 15. I was born right here in Brisbane and I have lived in Queensland my whole life. I am double-donor conceived, meaning that I was conceived through an egg donor and a sperm donor. I have always known that I am donor conceived thanks to my mum being open about it.

I have always wanted to know my genetic family, and my longing and interest in them has only grown over time. Very luckily, I have known two of my siblings since birth, my egg donor since I was seven and my sperm donor since I was 10. I met one of my siblings, my little sister, in person when I was three and she was two. She is the only person I am genetically related to who I have ever met in person.

When I was seven I FaceTimed my egg donor and when I was 10 I sent a letter to my sperm donor. I remember it well. I got some fancy paper and wrote with my neatest handwriting, I sent it off and waited. I got a response three months later and it was incredible. He wrote back. Finally knowing who he was, his job and any snippets of his personality was everything. As time went on, I got in contact with the rest of his family—his parents, my grandparents; his sisters, my aunts—and it was truly fulfilling.

A typical family always knows most of their genetic family. As most people always know their genetic family, they do not understand the longing of wanting to know who you are related to. Knowing my whole family is seen as a privilege that I have been afforded—something I might get if I am lucky and the cards play in my favour. It is something that is still debated to this day: should they be allowed to contact the donor? When should they be allowed to contact the donor? Should they even know they are donor conceived? So many people are so ready to debate this without actually thinking about donor-conceived people.

One of the main benefits of finding my donors—aside from finding them—is finding my extended family. Would you ever question whether someone is old enough to meet their cousins, their siblings or their grandparents? Because of my early contact, I was able to meet some of my family before it was too late. I knew my grandfather Michael before he died in 2018, I knew my great-grandfather Arthur before he passed in 2019 and I knew my great-grandmother Bonnie before she passed this January. With Arthur and Bonnie, I was the first great-grandchild they knew of. I am 15 and in most places I would have had to wait until I was 18 or I would have never been able to make contact at all. I would have never been able to know these people and it would have been far too late.

The Donor Sibling Registry helps increase the likelihood and ability of donor-conceived people to contact their donor families and siblings. People do resort to other methods such as DNA and private registries and they should be allowed to, but they should not have to. People should have the choice and the ability to discover what most people instinctively know. I was lucky to find my family, so I fully support a donor conception registry in Queensland. I ask you to please consider the impacts of donor conception on everyone involved and how you can help all Queenslanders.

Ms Leishman: I am Anne. I will address three points from your brief. The first is the right to know, the second is our lived experience as a family and the third is my opinion on a register for private or known donors. In terms of the right to know genetic relatives, I was informed by the United Nations Convention on the Rights of the Child, which was written 30 years ago, and then the working party in 2019, which expressly states that it applies to donor-conceived people. I think it is fundamental human nature to wonder about your family and culture. For Quill, it meant being able to know that her ancestry is Irish, Scottish, Balkans and Native American. That is all we knew for a while from profiles, but Native America has 500 nations. Now from having contact with the families, she knows that she is Choctaw and is even able to apply for citizenship.

Watching my donor-conceived child growing up, even the simplest questions are a bomb waiting to explode every single day. From age two, friends at preschool ask, 'Who is your dad? Where is your dad?' The questions are loaded. Quill started a new school this year. People ask, 'How many siblings do you have?' What is the answer? Is it, 'One. I am an only child', 'I have five siblings', or 'I do not even know; it's complicated'? Even if there is a hesitation before one of these answers, people wonder what is up. As for the five siblings, we know of five, possibly six siblings. We are very well aware that that is the tip of the iceberg and that very few siblings are registered anywhere that we know about. There might be 10 or there might be 30—who knows?—and we might never know all of them.

In terms of how open to be and how much detail, there were a number of times during primary school when I felt obliged to phone a parent and say, ‘Your child might come home saying the words “sperm donor” this evening and this is why,’ or friends or teachers think that word is inappropriate to be mentioned in schools, but it is their lived truth.

As for our lived experience, I decided to be open from the beginning, because if it was me I would be curious. I went to an organisation called the Donor Sibling Registry, which is in the USA. It is a private non-profit. If you look at their website you see a list people’s profiles. It is totally public—not their names but their usernames. There are 600 Queensland families who have applied to the Donor Sibling Registry in the US and seven Queensland clinics are listed there, with the full details. We were very lucky that we were able to find some siblings and know them from birth. There is also the California Cryobank. They have a sibling registry, as do many of the other American ones. It is hit or miss if anybody else is listed and even if they will contact us.

We went to America—you saw the picture. My child’s desire was to know her family from age two—the siblings, the dad, the aunts, the uncles, everyone. We found one of the donors through Google. Looking at an MTV documentary called *Generation Cryo* gave me some hints that some information was available in the US that you would not get here. I had the date of birth of the donor, I looked up California, I guessed the county and I found that donor within about 15 minutes.

The big issue is: it is not just what you can find; it is that I was supposed to have known that egg donor from the beginning. I met her, but the agency kept us from sharing our personal details and our contact information. Then they told me that I could not pass on any messages or ask at that time. She was told that I had just disappeared. If we had not found her when Quill was seven, each might have gone on thinking that the other did not want to know. That is very common. We found the other donor through DNA testing on Ancestry and 23andMe and then about two months of me spending every single night trying to figure out how a fourth cousin here, a second cousin here and a great aunt there fit into a family tree.

Reaching out is both anxious and very lonely. Much of the community and even some of the people today have said, ‘You shouldn’t reach out early’, ‘What about donor privacy?’ and ‘If they’re under 18, don’t reach out.’ There is condemnation that comes to you as a parent in trying to do what is right for your child.

We are lucky. I consider that Quill has three branches to her family tree—myself and my family and the other two. They are all supportive and in contact and it is great. We would have visited in 2020 but for COVID. We are hoping to go this year. I consider these other branches just like any other family around the room. One parent is related to the child one way; their child has relations with the family of the other parent. We call them ‘in-laws’. My child happens to have three branches. I have two sets of in-laws, and they have welcomed me as well and thanked me for bringing Quill to them.

As for my opinion on including known donors, a known donor from birth is what most donor-conceived people consider is ideal. They do not have to be an active parent but they are a genetic parent; they are a relative. Donor conception was originally a medical fertility treatment for heterosexual couples with fertility difficulties and the legal donor status was due to the filling of forms at a medical facility. The vast majority of people, especially needing sperm donors, are single mothers and same-sex couples, most of whom do not need nor want medical treatment, so they are outside of that legal framework where a donor goes through a medical facility.

If you have a donor registry in Queensland, make it open to known donors. It could be like when they had certified partnerships for people before there was same-sex marriage. It could give the legal certainty of donor status to people who register, whether it is prior to conception or prior to birth or even if they find out about it afterwards. Give the legal status of ‘donor’ so the donors are not afraid of being considered by Centrelink as a parent and the parents are not reluctant to enable family connections due to fears of opening the door to parental interference. It would at least enable you to get some record of the numbers.

I refer back to the legal case that I heard mentioned this morning. It puts the fear of God into parents, thinking that a donor might claim parenthood. In that particular case, the man agreed to provide his sperm on the basis that he was going to be a co-parent. He went on the birth certificate. He paid what any other parent would pay in terms of support for the child. He took them to school. He was known as a parent. He was a father. He was a co-parent, even if he did not live with the mother. He is not the donor case to make everybody else afraid of, but I think if you give legal certainty through the register it is a registered donor conception relationship. It protects the donors and it protects the families. Thank you.

Mrs GERBER: I do not have a question for you, but I did want to express my gratitude to Quill and Anne for their testimony. It was really helpful. Thank you so much for coming before us and giving us that perspective for the inquiry.

Mx Leishman: Thank you.

Ms Leishman: Thank you.

CHAIR: Do you have any ideas on what type of model the committee should be suggesting or looking at?

Ms Leishman: I think I said in my submission that you should have the record of the genetic parents, the raising parents and the donor-conceived people. I think in the Netherlands they register that, if it is a medical one, at the time of the transfer of the gametes. I think that is a model to consider, because in New South Wales there was an issue where there was an embryo donation and the recipient parent basically lied and said that the child was not born from the donation. That is a messy circumstance that can be avoided by having it registered at the time of the recipient receiving the donation. I think it is the Netherlands where that has been done. If there is not a pregnancy or it fails, people can then medically prove that and come off the register, if they are not trying again.

In terms of contact, a lot has been said about that. I think people in relationships have a right to be able to say, 'I want to spend time with you,' or 'I don't,' but donor families are no less than any other. Family relationships are messy: people get on for a while and they disagree for a while; they fall out and they get back together again. There will to be happy times, easy times, and there will be difficult times. A lot of people have said that we do not legislate for any other person whether you can or cannot see your family. If it becomes toxic or dangerous then there are orders that you can apply for to say, 'Really, do not contact me.'

CHAIR: There are other mechanisms.

Ms Leishman: There are other mechanisms already available, yes. Birth certificates is the other thing that has been mentioned. What would you like to see on your birth certificate?

Mx Leishman: I do not know much about birth certificates.

CHAIR: This was mentioned by the last witness. When you go and get your birth certificate, it contains information about your parents, where you were born and whether you have any other siblings. In relation to how to deal with this, there has been one suggestion that you could have two birth certificates—one that identifies all of your parents and another one that just has mum, dad et cetera. Then you as an individual would have the choice as to which one you would use, for example, to apply for a passport or apply to be on your local sporting team. That is one suggestion. The other suggestion has been that the additional information would be on the back of the certificate. Do you have a preference or is it something you have never really thought about?

Mx Leishman: It should definitely mention that the child is donor conceived as the bare minimum. I have not really thought about it much.

CHAIR: That is okay.

Ms Leishman: I moderate two Facebook groups for all parties about donor conception and it is something that is talked about often. There are several things. I think with the Victorian model now a note is put on the back that says 'more information available'. At least that gives somebody the chance to know that there is something if they have not been told. The biggest issue I have heard about the birth certificate is when you have an extra number of parents or whatever or your conception is noticed. People's birth certificates do not say 'was conceived in the back of the car', so there is a privacy aspect to that and an othering aspect. You mentioned passports. The passport form asks if there is another parent. As a single parent, I had to do a stat dec to say there was not. If there was a parent listed on the birth certificate, it might imply that the passport office wants it.

CHAIR: Yes, you need that permission.

Ms Leishman: That could be dealt with here in Australia, but then you go into America and they ask to see the birth certificate to make sure you have permission to travel alone with a child, and if there are extra names it could be complicated if the certificate had everything listed like that. We have discussed vaguely, now that we know the name of her genetic father, if we could put his name on the birth certificate and what are the implications of having that on. Do I need to wait until she is 17 years and 364 days to make sure there is no liability on that? I think there is a multitude of complications.

Some model that has a note that there is more information available is then recording all the information, which could be up to five different parents if you have two legal parents, two genetic parents and a surrogate, or another one if you do three-people donation. That should be available and recorded. It should be part of, if you like, the Births, Deaths and Marriages information. That information needs to be part of the record so that if somebody is looking at the birth information in 100 years time they can see all of it and figure it out and know why there are different branches and the legal family does not seem to follow the rest. As to whether it is visible, say you go and sign up for Little Athletics, the other parents can be looking at it and say, ‘Oh, that’s interesting,’ and talk about it. That, I think, is not necessarily helpful to an individual.

CHAIR: No, I agree.

Mx Leishman: If you were going to mention other people, I think it would be important to mention that they are like a donor. I do not really know the logistics of it, but it sounds like some of those issues could be a problem. If you specified that it was not a co-parenting situation—it was a donation—that could avoid some issues.

CHAIR: All right. Thank you. That brings to a conclusion this part of the hearing. I thank you for coming along and addressing the committee. It has been very helpful to hear from you both.

Ms Leishman: Thank you for the opportunity.

CHAIR: If you are out there on the roads, please drive safely.

Ms Leishman: Yes. We are not even sure if we are going home tonight. It is up to the Wide Bay.

CHAIR: Yes. Stay an extra night. Thank you.

DICKINSON, Ms Narelle, Clinical Psychologist and Fertility Counsellor, Independent Queensland Fertility Counsellors, Social Workers and Psychologists

CHAIR: Welcome. I invite you to make an opening statement, if you wish, and then we will have some questions for you. I am sorry you are last.

Ms Dickinson: Thank you. I just want to recognise what a long day you must have had and that you must be incredibly fatigued.

CHAIR: Does it show?

Ms Dickinson: No, but I can only imagine, so thank you for allowing me to present. Perhaps it is fitting that I am not a donor-conceived person, I am not a parent through donor conception and I do not have a vested interest, financial or business wise. I have been a psychologist for almost 30 years now. I have been working in the perinatal space for about 25 of those years and I have been working as a fertility counsellor for about 19 years, so I have been working in the industry since before the NHMRC changed into anonymity, and I can remember that changeover and what that was like. I guess what I am really aware of is how many competing interests there are when it comes to such a fraught topic as donor conception, but as a psychologist it is really important for me to not only hear the lived experiences of people such as the two very impressive people who just spoke but also look at the empirical evidence that sits around donor conception, and that is part of my job.

I am also a Churchill Fellow. I had the very good fortune of travelling the world about six years ago exploring surrogacy and donor conception in a whole range of places. I have actually subsequently been invited back to the United States to talk about the donor conception models we have here because they see us as world leaders in the way we go about things. The mental health professionals who work in this industry are very keen to see what we are doing and they know that it is really different to what happens there.

I am also a director of the Fertility Society of Australia and New Zealand. I am on the executive of ANZICA, which is the fertility counsellors, and I am also a board member of the psychologists registration board and the Prostitution Licensing Authority, so I have a bit of a sense of what it is to regulate individuals and also businesses, particularly somewhat specialised ones. It can be quite interesting to cross some of the parts of my world. Really importantly, I represent other Queensland counsellors, social workers and psychologists who work in this space, who worked with me to put the submission together, and a range of others who co-signed in support of the submission because they felt it really important that counsellors have a voice in this space.

I suspect that I am most useful in contributing in terms of the significance of counselling services in this area—and I think Professor Allan was talking about counselling—maybe to tease apart the difference in counselling as a therapeutic service versus a support service versus an implications counselling service, and that is part of what fertility counsellors do. We actually approach fertility counselling and donor conception from a range of different directions, and I can respond to more questions about that if that is of use to you.

I do feel that there is a need for a level of regulation. I think we have seen plenty of evidence over the years—and I am sure you have heard this discussed today—of times when the self-regulatory model has let down the people who are service users. Unfortunately, in an industry which is based on profits, it is in the interests of clinics to seek loopholes in self-regulatory models.

I also think that at the moment there are a significant number of people who are engaging in donor conception who are outside of the clinics. Anyone who is engaging in a home insemination—and it is an increasing number of individuals—is not coming under a clinic model and therefore is sitting outside of any of the protections which are afforded there, and that is dangerous. That is really dangerous for the individuals who were born as a result of those donor conceptions as well as for the parents and the donors. It is dangerous for everybody. I guess we have an opportunity to learn from the problems that have emerged in other models and legislative frameworks around Australia as well as elsewhere, and I really hope that Queensland can take what has been done elsewhere and do it better. I think any model that we come up with really has to help raise consistency in terms of the way treatment is done across the country.

We have talked about donor registers. You were asking Professor Allan about national registers. In an ideal world I think we would be seeing a national register, but a local register is still going to go some way towards meeting what is a big gap in Queensland. We need to make sure costs are kept down for the individuals who are using these services. Anyone who goes into a fertility clinic spends a lot of time, energy, emotional pain and money to have their families, and anything which adds to that burden is a problem. We need to try to minimise any further burden for them as well as for the children they have. We need to try to reduce confusion, because it is a really confusing place for people to walk, and at the moment there are a significant number of families who go overseas or who do their treatment outside of clinics because they think that is easier—they think it is better—and they do not understand that what they are really doing is opening a whole new minefield for themselves and for their kids.

Finally, and maybe I am following on from what the lovely family were just talking about, everyone has a birth story. Everyone has a story. I have one. I am the youngest of four, so I am the annoying little sister story. My elder family like to call me 'the accident' because I was a fair way behind the others, so everyone has a story. Actually, I think the donor conceived story and the surrogacy story, for what it is worth, are the best stories in the world because these are wanted kids; they are no accident. Anything that we can do that gives them their agency and really puts them front and centre in terms of whatever model ends up happening in Queensland is what we need to do.

CHAIR: Do you have a view about the retrospectivity of any proposed legislation?

Ms Dickinson: As Quill was referring to, people want to know and just because they were born prior to 2004 does not reduce their desire to know. It does not reduce the importance or their right to know. A few years ago I was working at a clinic and I had a young person exactly Quill's age come in. She was conceived prior to 2004. She came in and she said, 'My mum and my dad are okay with me getting my medical records. I want to know who my donor is,' and I had to say, 'Honey, I can't give you that information. I can't.' I really admired her tenacity because she said to me, 'That's okay. I've already found two of my donor siblings. I found them on Facebook and we're going to find the donor. We know his number. We'll find him.' I thought, 'Yeah, I think you probably will, actually,' because this kid was not going to stop until she figured it out. I know you would have heard other people tell stories of finding the donors through ancestry.com and whatever. Anonymity is dead, so anyone who thinks there is a protection afforded by previous anonymity is actually kidding themselves. What we are better off doing is serving the needs of the people who were conceived at that time and making it easier—making them feel like they do not have to go through back doors and cause distress unnecessarily. We just need to make it better for them.

CHAIR: As we heard from some of the evidence, there is a possibility that some of the historical records may not be available anymore for myriad reasons.

Ms Dickinson: Inevitably.

CHAIR: Yes, some legitimate and some—

Ms Dickinson: Not so much.

CHAIR: Yes, not so much, but you just have to do the best with what we have.

Ms Dickinson: Yes.

CHAIR: There is another thing I am interested in, and you may or may not have a view on this. There are varying models throughout Australia and we are the last jurisdiction to be looking at this. Is there one model that is a standout that you think we should look at more closely?

Ms Dickinson: I think there are positives in a range of the models and there are certainly flaws. The Victorian model has been revised because we saw that there were some restrictions there which were just completely inappropriate—things like police checks for people wanting to become parents. They are awful things to put in a donor conception model. It is probably the opportunity to cherrypick the best of what is around.

I do think that, without question, counselling has to be built in. The reality in Queensland is that we have not even begun to see donor linking start here yet, because we are just about to see those kids who were conceived since 2004 turn 18. That has not even happened here yet. The clinics have no idea what to do with what is about to happen. They are so ill prepared for that. We need a model which is going to support the donor-linking process that is about to begin here and also anyone who was conceived prior to 2004. We need to make sure that families are properly supported before they embark on donor conceptions—so they really are thinking about what it is they are doing.

I actually do not agree with the statement that people will seek counselling if they need it, even in terms of support counselling. If I bring it down to people with mental health problems such as anxiety, depression or whatever, when they are going through fertility treatment we see less than 23 per cent of people with a diagnosed health condition—I think that is the figure from the last paper I read—actually seek counselling while they are going through it or identify that they have those sorts of distresses. For people to walk into a clinic and say, 'I want counselling,' it just does not happen very often, and that is actually people in distress, so people who are not in distress are not going to necessarily seek out counselling, and clinics do not automatically offer it. The idea that that happens all of the time is not—

CHAIR: I am trying to play the devil's advocate. How do you take away the—

Ms Dickinson: The mandatory nature of it?

CHAIR: Yes. I do appreciate that telling someone they have to do something may not necessarily be the best model, but where do you land to make sure people avail themselves of that? I agree with you in this aspect: the people who need it the most may be the people who say, 'I don't need it.' How do you land with the model that would encourage someone to engage with the services available?

Ms Dickinson: I think to some degree it comes back to what I said in my introduction. As fertility counsellors we approach counselling in three ways: there is support counselling; there is treatment, which might be of someone who has that condition; and there is implications counselling. When I undertake an implications counselling session, I am aware that people walk through the door knowing that it is mandatory and they feel like they are forced to be there, whether they like it or not. They say, 'Are you going to assess me for being a good enough parent?' or whatever else. To be honest, it is my job to help them put that aside and I say, 'Actually, that is not why I'm here. I'm not assessing you. I'm helping you to think about what this will mean for you and your child and how you can do a great job'—just like the mum who appeared before me has done. Oh my goodness, I wish I could see more people like her.

There are different people. There are single mums where it is really obvious how the conception occurred. I would suggest that with same-sex female couples it is fairly obvious that there was a donor involved so the counselling has to shift. We have faced problems with that over the years. I have had many same-sex female couples walk in and say, 'You're assessing me to decide whether we deserve to be parents.' I say, 'No, that is not what this is about. We're going to talk about how you can deliver that information to your kids down the track and how you can help them tell the other kids in the playground why they don't have a dad and why they have two mums.' It is about the way the counselling is delivered and how that message is delivered to families as well.

CHAIR: Obviously time is always of the essence, and one of the things I have become acutely aware of since I have been in parliament is that everything takes longer than the general public would like. You said that there is a whole cohort of people who could be coming through the system which is going to create unique issues. What would be the ideal situation for this to be progressed?

Ms Dickinson: For time lines?

CHAIR: Yes.

Ms Dickinson: Well, 10 years ago when the Senate committee came through—or when it can. I think doing it right is better than doing it fast. Honestly, we have sat without legislation for a long time and we have sat without a register for a long time. I think we need a framework and we need a model here, but I would rather see it done properly.

CHAIR: There was a suggestion from an earlier witness that in South Australia there is a working group within Health. I think we are in a position where this would be within Attorney-General. How do you put together a working group to come up with the ideal model?

Ms Dickinson: I feel like I am not the best person to answer that question. It has to be representatives from people who work in all of the areas. There are always competing interests, as I said, and everyone does have a unique perspective. We as fertility counsellors are not huge fans of the health department model. I think we would see that something like Births, Deaths and Marriages makes a lot more sense and it is probably a reasonably inexpensive model to set in place as well in terms of maintaining registers. All of the different parties who have a role in treatment and who understand donor conception—whether it is people with lived experience or people who are working in the industry—have different perspectives and I think it is about making sure all of those perspectives are being represented, which is hard to do.

CHAIR: It is. I have monopolised the questions.

Mrs GERBER: That is all right; they were good questions. Is it mandatory for males who make donations to receive counselling?

Ms Dickinson: Yes.

Mrs GERBER: Can you talk me through that?

Ms Dickinson: Both intending parents and intending donors—whether it is known or not known—have mandatory counselling under the NHMRC and RTAC guidelines. There are a minimum of two sessions where they discuss the implications of being a donor for themselves, for their own family, for their own future family and for the donor-conceived person. Also, if it is known, if they know the recipients, it is thinking about the potential implications on those relationships and what sort of contact expectations there are. They are the sorts of things that are covered already.

Mrs GERBER: So it is already covered?

Ms Dickinson: Yes.

CHAIR: Unless anyone has a burning question, I would like to bring this hearing to a conclusion and thank you for your participation and written statement. That concludes this hearing. I thank everyone who has participated today. I thank the secretariat and Hansard. A transcript of these proceedings will be available on the committee's webpage in due course. There were no questions taken on notice. I declare the public hearing closed.

The committee adjourned at 4.52 pm.