CORRECTED VERSION

LAW REFORM COMMITTEE

Inquiry into Access by Donor-Conceived People to Information about Donors

Melbourne— 17 October 2011

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Rev Dr G. Gleeson, Member of NHMRC’s Australian Health Ethics Committee, and

Mr M. Sammels, Director of Health and Research Ethics Section, National Health and Medical Research Council (NHMRC).

The CHAIR — Thank you for coming in. My name is Clem Newton-Brown, I'm the Chairman of the Law Reform Committee, and Jane Garrett is Deputy Chair. Also with me today is Russell Northe and Anthony Carbines. Donna Petrovich wasn't able to stay for this afternoon's session. We've been given Terms of Reference by Parliament to report back after we've investigated, so thank you very much for your submission and for coming in today to assist us in that process.

Just before we begin, you should be aware that anything you say here is protected by Parliamentary privilege but not outside the room. If you could perhaps start with your full names and professional addresses for the stenographer, and then launch into what you would like to tell us.

Mr SAMMELS — My name is Matthew Sammels, I'm the Director of the Health and Research Ethics Section at the NHMRC, I'm here in a support function to Reverend Dr Gleeson, and I will hand over to Reverend Dr Gleeson.

Rev. GLEESON — I'm Gerald Gleeson, I'm a member of the NHMRC's Australian Health Ethics Committee. I come from Sydney, I teach philosophy at the Catholic Institute of Sydney.

The CHAIR — Could you perhaps start by telling us a bit about what the National Health and Medical Research Council is?

Rev. GLEESON — I can have a go; Matthew may be better. The NHMRC is the Federal Government's Health and Medical Research body that oversees funding and regulation.

The CHAIR — It's a government committee?

Mr SAMMELS — Yes. So the NHMRC is a statutory agency under the Federal Government, we're a portfolio agency of the Department of Health and Ageing.

The CHAIR — And you provide ethical advice to hospitals or researchers?

Mr SAMMELS — No; one of the functions of the NHMRC under its Act is to develop ethical guidelines and advice on ethical issues relating to health and medical research, and that's where these particular issues are dealt with, and it is the responsibility of the Australian Health Ethics Committee of the NHMRC, which Gerry is a member of, to develop a particular guideline for.

The CHAIR — How long have you been in existence?

Mr SAMMELS — NHMRC has been in existence for 75 years but in its current form as a statutory agency it's been there since 2006.

The CHAIR — When was the first time that you've had any input into this issue?

Mr SAMMELS — Into the development of Ethical Guidelines?

The CHAIR — Or has there been any input — this whole issue was developing back in the 70s and 80s, was there any input then?

Mr SAMMELS — The National Health and Medical Research Council developed what was called a supplementary note, and it was dealing with issues relating to medical research at that point in time; obviously IVF was relatively new, late 70s early 80s, and the first time we actually developed guidelines to deal with clinical practice of assisted reproductive technology was in 1996, and that was a fairly thin document, and then subsequent to that point in time we've had a revision in 2004 and another one in 2007.

The CHAIR — Your submissions to this Committee, is this the first time that your organisation has turned its corporate mind to the issues in relation to pre-88 donors?

Rev. GLEESON — I think to pre-88 in particular, yes, it would be the first time but the ART Guidelines, the thicker book which Matthew has, that of course has a certain legal standing because under the ART Federal Act clinics have to operate according to the ART Guidelines, both in research and in clinical practice, so this is a quasi legal document. The most recent revisions were in the light of the changes to the Federal legislation to do with cloning and so on.

The CHAIR — Thanks for that. I'll let you launch into it.

Rev. GLEESON — There was a brief submission from Professor Anderson, the CEO of the NHMRC. Just listening to the presenters before this, I guess many of the common themes come through. These Guidelines, I should say, are specifically ethical in nature although, as I said, they have a certain legal authority but AHEC deliberately doesn't give legal advice, it gives ethical advice but, as I say, in this particular area the ethical advice has a legal standing.

One of the principles there, of course, is that donor-conceived persons are entitled to know their genetic parents; this is accepted as one of the fundamental principles. As it says, the welfare of the people born through the use of ART is a paramount ethical consideration. On the other hand, ART clinics must not release identifying information without the consent of the person to be identified. As everyone recognises, and as was recognised in the Interim Report of this Inquiry, there is this tension between the desires and the rights of the donor-conceived people and what was often a practice of anonymity, particularly before 1988, and seemingly the right of those donors not to be identified. That, I take it, is the hard issue that's before this Committee. That was the issue that I thought, if you're willing, I would say a few things about because I think it is the hard one. In the NHMRC and the AHEC deliberations, we haven't formulated an official response to this dilemma: what should you do? Everyone says there's two rights and you're balancing two rights, but we haven't developed formal advice as to how to settle that issue. If I can just offer a few suggestions about that.

The first is that as a philosopher rather than a lawyer I actually think the language of rights is not the most helpful way of thinking about these problems. I know that for lawyers perhaps it's the most natural way and even for some ethicists, but I think it's actually easier to think about people's responsibilities. The limitations with the rights analysis is that precisely when you encounter a conflict of rights there is no way of settling it. In any case as we go through life, simply exercising our rights is not always the right thing to do. People may have rights but it's not necessarily right to actually exercise those rights, so I think we need a broader way of thinking about it in terms of responsibilities.

That would suggest, I think, that the pre-1988 donors, from an ethical point of view, should be willing to be contacted and to reveal the kind of information that the donor-conceived person requests. However, there are clearly cases where doing that would involve serious burdens and occasion other harms to people, perhaps to the donor, perhaps to their families and so on, so it's not an unqualified duty to be contactable. And that's about all you can say about it, that in an ideal world the donors would be willing to be contacted, but clearly in some cases in fact it wouldn't be right because of the harm that that involves.

The other thing to say I think is that in all of the submissions, certainly the number we've looked at, no one is suggesting that pre-1988 donors should be compelled to reveal their identity.

Ms GARRETT — Some have said that; those directly affected.

Rev. GLEESON — Have they said that?

Ms GARRETT — Very clearly.

Rev. GLEESON — I think in terms of the ethical principles in these Guidelines and in the national statement it would be very hard to make that case out, that you actually have to unmask people, as it were. What I think people are suggesting is that there needs to be a mechanism which enables as much communication and contact as is possible for the people involved, a system whereby the donors can access information; analogous to the adoption arrangement. That seems to be the safe minimum that people can think possible, allowing for the fact that some donors may refuse to cooperate.

The CHAIR — Just in relation to your last sentence in the first paragraph: "There can be no right to something that is recognised, even if belatedly, to be unethical", is it not possible to have a right that's unethical?

Rev. GLEESON — It depends then on your philosophy of rights. If you took a purely legalistic view of rights then the government could pass a law which gave people certain rights, which in a sense would be legal rights, but many might argue in fact what they're doing is unethical or wrong. Yes, if you think of the right in that narrow, legal way then you could have a right to do what is unethical. And it's why the word "right" is so ambiguous. Whereas if you're thinking of an ethical right, I don't have a right to tell lies, for example, it doesn't make sense.

The CHAIR — I suppose there should be no right to something that's unethical; is that what you're — —

Rev. GLEESON — Perhaps that would be a better way to put it.

The CHAIR — It's an interesting analysis because you're right, we are having this balancing thing and it's another way of looking at it.

Ms GARRETT — I suppose whether you would define it as a right or an ethical responsibility, you've set it out very clearly in your view and I think it's very clearly set out whether it's a right or ethical responsibility, that at the end of the road there comes a clash of those two things if there is a situation where a donor-conceived person feels absolutely fundamental to their identity is understanding their genetic origin and a donor who perhaps, for whatever reasons, feels very strongly that their anonymity should be protected. Whatever scheme you have, somebody's ethical situation or right is going to trump the other one's by necessity when they clash.

The CHAIR — What's your resolution to that dilemma?

Rev. GLEESON — Well, I think at the end of the day if the donor is unwilling to be contacted we have to live with that fact. I'd resist saying that the donor has a right to remain anonymous because that makes it sound as if the donor is doing a good thing, but I think of it more as the fact that I don't have the right to invade that donor's privacy. You might have stolen my property but I don't have the right to break into your house and get it back, as it were, even though it's mine. Even if I've got a right to know, I could exercise that right in ways that are not in fact ethically defensible, and that would be the case here; you'd be invading the privacy of the other person.

The CHAIR — In essence, I suppose, the donor trumping the other right, do you take into consideration the likely unsatisfactory nature of any contact that would be made if the donor didn't want to be contacted, does that figure in the weighing up?

Rev. GLEESON — I was thinking of the situation where perhaps the donor is now a public figure, their family situation, etcetera, etcetera. It might be that if it suddenly emerged that I've fathered a child somewhere, this could have massive repercussions on an existing family and a person's position and so on. So I suppose I wondered whether in a case like that, if you had this intervening agency where in fact the donor could write a letter saying: "look, I'm sorry, I would love to make contact but I really can't." And without identifying the reasons sort of give an explanation that at least said to the person: "look, I'm in a situation where my family couldn't deal with this so I'm sorry; I'm not able to do it." I think for the donor-conceived person that kind of an explanation might be acceptable, they might say: "okay, I'd like to make contact but clearly it would have a lot of ramifications."

The CHAIR — Should the donors be compelled to give non-identifying information?

Rev. GLEESON — Yes, I think again most agree that that's pretty fair. The debate there seems to be that giving medical histories and so on seems to be fine. It's where the donor-conceived person actually wants to get to know the donor, they don't just want a medical history, they want to meet you, that's where it's more difficult.

Mr NORTHE — Reverend, just on the scenario we've just played out before you were here, we spoke about Narelle Grech, for example — —

Rev. GLEESON — I'm not familiar with that.

Mr NORTHE — Narelle is a donor-conceived person who is trying to find her donor, biological father, she basically has a terminal illness, it may be genetic related, and she isn't able to do so. What might the position be of your organisation with someone like Narelle on medical grounds? I guess ethical grounds is trying to find her donor and I guess the scenario I played in reverse to Roger before, he's a donor and might have a genetic illness trying to contact a donor-conceived person. How do those two scenarios play?

Rev. GLEESON — I don't know if Matt has any thoughts. The intermediary mechanism, which at least gets as much of that information available as possible is what I would see.

Mr SAMMELS — There's a particular ethical guideline which the NHMRC has released in relation to Section 95AA of the Privacy Act which deals with reporting of serious genetic conditions back to people who may have basically an interest in hearing about that particular genetic abnormality or whatever. It gives direction to physicians as to how they should go about trying to track down, or at least release information to, genetic relatives. That would be how we would see this particular process you're talking about progressing via at least the process there of disclosure through Section 95AA.

Mr NORTHE — So you're saying it provides an obligation?

Mr SAMMELS — It provides a process of thinking about information giving and receiving. Again, anything which the NHMRC releases is more of a guidance nature only rather than regulatory.

The CHAIR — For example, Narelle's siblings who may also be carrying a genetic problem, does the doctor have an obligation to do everything possible to contact those siblings?

Mr SAMMELS — It depends obviously on the nature of the particular illness as Section 95AA Guidelines do classify them into serious and non-serious illnesses. The doctor would have an obligation, but obviously within limits. If there was an absence of records the doctor couldn't actually go out there and be an investigator in trying to find everyone who may potentially have an interest, failing obviously placing an advert in the newspaper. But it just outlines a particular process whereby doctors can consider reporting this information back to those who may have an interest due to their genetic relations.

Rev. GLEESON — And it protects the doctor.

Mr SAMMELS — Yes.

Rev. GLEESON — Because normally they're prohibited from breaching privacy in that way. But I suppose those guidelines don't mention this case where in fact you don't know the identity, unless you were to go through some register or organisation, so you wouldn't be able to find the person which I suppose it gives an added reason for the need for some intermediary mechanism like the adoption register. I'm not familiar with it but VARTA is the Victorian authority in this area. It sounds as if they're fulfilling this role; is that right? No?

Ms GARRETT — It's been shifted. In terms of where the ethical responsibility of the donor, or the right of the donor, stems from, in your mind it's from those initial agreements pre-88 which guaranteed anonymity or spoke of anonymity?

Rev. GLEESON — This is on the donor's part?

Ms GARRETT — Yes.

Rev. GLEESON — Well, as I say, I'm hesitant to speak of the donors having a right to anonymity but it's true they acted on the assumption that they would remain anonymous and the information that they are the parent of this person, that I would take it is personal medical information, to which they're entitled to privacy. That's why I don't think that can be invaded, or should not be invaded. I mean, they should be encouraged to make contact, all of those things should happen, but at the end of the day I cannot see that you could have a system whereby you went around revealing people's identity against their will.

Ms GARRETT — So what is the answer to those donor-conceived people who obviously didn't choose their circumstance who say: my life has been completely and utterly shattered or thrown up. I need this information to feel like I can fulfil — —

Rev. GLEESON — I think they are entitled to the information, they're entitled to know who their parent was, but in exercising that entitlement there are limits, as there are to exercising lots of our entitlements and one of the limits is I may not invade the privacy of another person.

Ms GARRETT — What's become clear, at least to me, over the course of these hearings is that that concept of the anonymity has really dominated a lot of how this has unfolded, how the clinics have approached the situation, and we've had evidence from major clinics that until recently they wouldn't even attempt to contact donors to see whether they would be willing to consent to information, non-identifying or identifying, because their view was that the agreement they had reached was so strict on anonymity that even contacting them was a breach of that, and I think that seems to have pervaded much of the records are in different places, some of them are incomplete. The evidence we've received from donor-conceived people and their families and agents representing them is that it's very hit and miss as to how you received what information, there's not a lot of transparency about whether there has been attempts made, genuine attempts, and who those people are. I'm making a statement really, aren't I? What's my question?

That it has been quite, I suppose, skewed in that anonymity and that's seeped into a lot of things and perhaps centralising and enhancing the VARTA model may address some of those issues. What's your view on whether you agree with that analysis that it's been skewed, and how you would address that?

Rev. GLEESON — I guess it has and just hearing the presenters before us shows, I think, some sort of change of our cultural sensibility in relation to this, that contact, communication, openness, access to information, I think these are the things we now expect. No one is suggesting that we would go back to the practices of anonymous donation. Granted that cultural shift, which I think is a good thing, I think you can't make it directly retrospective in a sense that you now go back and say: okay, we're going to identify people. Nonetheless, I think it's got an implication for how we relook at what was happening, as I guess happened with adoptions as well.

Ms GARRETT — Although with adoption they are given now retrospective access to identifying information.

Rev. GLEESON — To identifying, have they?

Ms GARRETT — Yes. So the arguments before this Committee have been that donor-conceived people should be treated the same as adoptees.

The CHAIR — Any other questions or comments?

Mr NORTHE — Not from my perspective. Very interesting.

Rev. GLEESON — Good luck. One of the issues that was raised was about registries and I think we did want to just make a point that it's not an NHMRC — —

Mr SAMMELS — No, the NHMRC doesn't have a legislative mandate to maintain any particular registers. This occasionally comes up when Assisted Reproduction Technologies acts are up for review, as they have just recently under New South Wales. The only particular register that we can actually hold under any particular act is a register of licences granted out to undertake research on human embryos under the research involving human embryos legislation, and that's it.

Rev. GLEESON — It's a state matter really.

The CHAIR — Just interested in your views from an ethical perspective of the idea of us, if we were just hypothetically to require that all the information that we had was collected into one Registry, that all the donors that were able to be identified were identified by an independent body, and that they were required to give non-identifying information, which could be provided to any offspring, just going that far does that still pass the ethics test?

Rev. GLEESON — I would think it does, yes, it's the minimum that the donor-conceived person is entitled to along with perhaps an invitation to the donor.

The CHAIR — Obviously that would be the ultimate outcome you would try for.

Rev. GLEESON — But I think, at the very least, yes the non-identifying.

Mr SAMMELS — Yes.

The CHAIR — Okay. Thank you very much. Thanks for your help; you've given us another perspective.

Rev. GLEESON — Good. All the best.

Witnesses withdrew.