

# Why do people apply to the Victorian donor conception registers?

VARTA Twilight Seminar 'Experiences of donor linking: research and personal perspectives'  
Monday July 9, 2018



Deborah Dempsey, PhD

Associate Professor in Sociology  
Swinburne University of Technology



# The Statement of Reason (SOR)

- A statement completed by applicants to the registers:
  - Suggested format: introductory statement, long and short-term goals
  - May be completed as part of the mandatory counselling and information session provided by VARTA
- If person the applicant wants to link with is located, SOR is forwarded to help them understand reasons for and expectations of linking

# Our research questions

- What kind of information are people seeking when they apply to the Central and Voluntary Donor Registers?
- What expectations do they have of the outcome?

# Methodology

- Eligible participants
  - Permission sought from those who submitted a SOR to the Voluntary or Central Donor Registers between June 2015 and March 2017
  - Email consent process
- De-identified SORs were analysed quantitatively and qualitatively
  - identification of the proportion of SORs with a particular theme
  - Strength and nuances of the theme (thematic analysis)

# Population and sample of SOR

	Population		Research sample	
Applicant		% (N=91)		% (N=42)
Donor	10	11%	6 (60%)	14%
Donor conceived	38	42%	17 (45%)	40%
Recipient parent	43	47%	19 (44%)	45%

<b>Demographic information</b>	<b>Sperm Donor (n=6)</b>	<b>Donor conceived (n=17)</b>	<b>Recipient parent (n=19)</b>	<b>Total (N=42)</b>
<b><i>Age group</i></b>				
29 years and younger	0	5	0	5
30-39 years	1	12	5	18
40-49 years	1	0	10	11
50-59 years	1	0	4	5
60 years and older	3	0	0	3
<b><i>Sex</i></b>				
Male	6	4	0	10
Female	0	13	19	32
<b><i>Relationship status</i></b>				
Single	0	1	14	15
Married/partnered	4	6	4	14
Divorced/separated	1	0	0	1
Not available/not applicable	1	10	1	12

# What information were applicants seeking?

Type of information sought	Donors (n=7)	Donor conceived (n=18)	Recipient parent (n=22)	Total (N=47)
Personality and personal information (e.g. interests, likes and dislikes)	4	15	18	37
Medical and genetic history	0	16	6	22
Photos	1	7	13	21
Family history and experiences	0	13	7	20
Physical characteristics and traits (e.g. hair and eye colour)	0	8	9	17
Education and occupation	0	6	4	10

# Personal information

- I do wonder about you and particularly wonder if you like to travel as I have travelled overseas extensively ...I enjoy playing tennis, cycling and skiing... I hope that by sharing a little bit about me with you, it will help you feel comfortable to share a little about yourself. (Donor 60+)
- ... I guess if there's any common personality similarities – I'm sociable, successful in my profession at a young age, independent, fit and a keen sports [person]. (DCP 30-39)

# Personal information

- I have read the donor profile provided to me by the clinic, however [child] asks me questions that I cannot answer such as 'What is your name?' and 'Where do you live?' (RP 30-39)
- There are interests my child has that don't appear to come from myself or my side of the family and it leaves us wondering (RP 40-49)

# Medical/genetic history

- I have struggled with a chronic illness that is likely to have come from my mother's side...I am keen for more medical information from your side so I can be further prepared. (DCP; 29 and younger)
- My main reason for wanting to make contact is to find out information about medical history. It's very important to be aware of any underlying conditions for my sake and my [children]. (DCP 30-39)
- At the time of donation I had good health. Since then there are a number of matters affecting me health wise that you should be aware of. (Donor 50-59)

# Physical characteristics

- There have been times in my life where I've wondered why I look the way I do or possess particular traits. For example, all my siblings have blonde hair, but I have brown hair. (DCP 30-39)
- In time, [my child] will have questions about their donor that the profile will not provide answers to, like whether their height comes from my genetics or yours or both. (RP 30-39)

# Photos

- It would be great to share some photos. Perhaps a photo of you as a younger child, as a teenager, one of you in your 20s/30s and if you are comfortable, a more recent one of yourself. We are happy to share some photos of the [girls] too. (RP 50-59)
- So far it is just 'the man' and it would be great to tell them the name of the man and perhaps a photo to put in their baby books, in the space where it says 'donor'. (RP 40-49)
- Do you have hazel eyes that look brown sometimes? ... Do you have a dimple on your chin? If you are willing to share an old photo that would be amazing. (DCP 30-39)

# Family history and experiences

- We became very curious about our paternal ancestry, our donor... Are you married or in a long-term relationship? Do you have children of your own? Did you grow up in a big family? (DCP 29 and younger)
- Although there were differences, I grew up in a very open, happy and loving family that is as crazy as the next and I understand my parents' decision to use a donor when creating their family... (DCP 30-39)

# Contact expectations

- Any contact or information exchange we might have will be under your control: information is power. I will respect your wishes above all else. (Donor 60+)
- I hope that over time you may be interested in some form of communication. All going well perhaps there could be some email exchanges, a Skype call, and maybe even have a coffee one day. (DCP 30-39)
- I believe it would be highly beneficial for my [child] to meet your family... The frequency would be guided by your wishes, my [child's] needs and of course, time. (RP 40-49)

# Summary

- Universal desire for contact as well as information
  - Less prominent in studies conducted overseas
  - Expectation management for those involved
- Similar and different information sought by DCP, sperm donors and RPs:
  - All applicant groups curious about the what the person is like
  - DCP: keener interest in medical/genetic history
  - RP: stronger views about the benefits of contact, particularly among single parent group

# Summary

- SORS as window on popular understandings of genetic inheritance:
  - Physical resemblances are emotionally powerful
  - Children as 'blend' of their biological parents
- Single mothers with children under six years old are the biggest group of applicants. What to make of this?
  - Stigma
  - Bigger support/family network for children

# Future directions for our research...

- What happens after links are made through the registers? (small interview based study)
- How is linking occurring through and beyond use of the formal registers? (large national project)

# Acknowledgements

- A big thank you to my collaborators on this research project:
  - Fiona Kelly, Briony Horsfall, Kate Bourne, Karin Hammarberg, Louise Johnston and Jennifer Power
- Our sincere thanks to:
  - The applicants to the Central and Voluntary Donor Registers who agreed to have their SOR included in this research
  - VARTA staff who assisted with research administration
  - La Trobe University School of Law for funding this research
- Ethical approval for this project was obtained through the Victorian Department of Health and Human Services, La Trobe and Swinburne Universities