



THE UNIVERSITY OF
WESTERN AUSTRALIA
Achieve International Excellence

School of Anatomy, Physiology & Human Biology

Mail Bag Delivery Point 309
The University of Western Australia
35 Stirling Highway
Crawley Western Australia 6009

T +61 8 64881527
F +61 8 6488 1051
E kathy.sanders@uwa.edu.au
CRICOS Provider Code: 00126G

Attitudes to Disclosure of Donor Conception

Participant Information Sheet

Please read this information sheet before deciding to take place in this study. Please retain a copy of this information sheet for your records.

Why are we doing this study?

In the past conception involving sperm, egg or embryo donation was seldom discussed. Donors were almost always anonymous and few donor-conceived children were told of the manner of their conception. However, in recent years more countries/states (e.g. Sweden, Netherlands, UK, New Zealand and the Australian states of New South Wales, Victoria and Western Australia) have legislated for open-identity donor systems whereby children born of sperm, egg or embryo donation can access identifying information about their donor on reaching maturity.

The purpose of this study is to examine the attitudes of donors and recipients to issues surrounding the release of information about a child's conception. Currently little is known about whether recipients of donated sperm, eggs or embryos inform their family and friends about their treatment; similarly whether donors disclose to their family. We seek to understand the reasons why people choose to tell or not to tell others in their family and social network of their involvement in donor conception, and the factors that influence these decisions. This information will provide a greater understanding of the broader family context in which donor conception takes place. We hope the information gathered from this study will be used to guide clinical and counselling practice in donor conception programs across Australia.

Who is carrying out this study?

This study is being conducted by Ms. Iolanda Rodino (PhD Candidate/Clinical Psychologist), Dr Kathy Sanders and Dr Debra Judge (School of Anatomy, Physiology & Human Biology, The University of Western Australia) together with Dr Peter Burton (Concept Fertility Centre, Subiaco, Western Australia).

Who can participate in this study?

- Recipients of donated sperm, eggs or embryos. Women currently in treatment, on waiting lists for treatment, or having completed treatment are welcome to participate. Partners of recipients are also able to participate.
- Donors of sperm, eggs or embryos. We welcome the views of current donors and of those who have donated in the past.

Please note, participation in this study is voluntary. Your decision to participate or not will not influence your access to donor conception programs now or in the future.

What will this study involve?

Should you agree to take part in this study, you will be invited to complete an anonymous online (or paper) questionnaire which will take approximately 15-20 minutes of your time. The questionnaire seeks information about your:

- demographic characteristics (e.g. age)
- the type of donor program you are/were involved in (e.g. sperm / egg / embryo; anonymous or known donor; year of last treatment); motivation for donation (donors only)
- attitudes and intentions towards disclosure to children born of donor conception
- attitudes and intentions towards disclosure to other people in your life including family and friends
- experiences in close relationships with family and friends

Most questions are multiple choice style. There are spaces for you to write comments or elaborate on answers should you wish to do so. Please note that depending on your circumstances not all questions may be applicable to you.

What will be done with the information?

The information obtained from this questionnaire will be kept confidential and only used for the purpose of this project. It will not be released by the researcher to a third party unless required to do so by law. Responses from all participants are anonymous and analyses will be done on grouped data. We aim to publish the findings in relevant journals and communicate them at conferences. Your anonymity is assured at all times.

How do I find out more about this study?

We are very happy to answer any questions you may have about this study. Please see the contact details of the investigators listed on the next page.

How do I participate in this study?

Once you have read this information sheet and are satisfied that any questions about the project have been answered, you can access the questionnaire by going to the following webpage / link.

<http://www.thinkfertility.com/donor>

Please note that the completion and submission of the questionnaire will be taken as evidence of your consent to participate in the study. As the questionnaire is anonymous, once you have clicked the submit button you will not be able to withdraw your data from the study. However, you may choose to exit from the questionnaire at any time before submission, in which case none of your responses to questions will be saved.

If you would prefer a pencil and paper version of the questionnaire, please phone or email Ms. Iolanda Rodino (see details below) and leave your postal or email address. Please note this information will not be retained and will be used only to send you the questionnaire.

THANK YOU FOR YOUR TIME

Please see over for contact details of the investigators

Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time.

In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Research Ethics Office at the University of Western Australia on (08) 6488 3703 or by emailing to hreo-research@uwa.edu.au All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.

Attitudes to disclosure of donor conception

Investigators' contact details:

Dr Kathy Sanders

Assistant Professor
School of Anatomy, Physiology &
Human Biology
The University of Western Australia
Ph. (08) 6488 1527
E: kathy.sanders@uwa.edu.au

Ms Iolanda Rodino

Clinical Psychologist
School of Anatomy, Physiology
& Human Biology
The University of Western
Australia
Ph: (08) 9389 7212
E: iolanda@thinkfertility.com

Dr Debra Judge

Assistant Professor
School of Anatomy, Physiology &
Human Biology
The University of Western Australia
Ph: (08) 6488 3304
E: debra.judge@uwa.edu.au

Dr Peter Burton

Scientific Director
Concept Fertility Centre
Subiaco, Western Australia
Ph. (08) 9382 2388
E. pete@conceptfert.com.au