

PARTICIPANT INFORMATION SHEET

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RESEARCH PROJECT: *ENHANCING REPRODUCTIVE OPPORTUNITY IN AUSTRALIA: RECONSIDERING CONSENT, ALTRUISM AND THE LEGAL STATUS OF EMBRYOS*

(1) What is the study about?

This project examines the impact of current laws and policies on the decisions and choices people make about the use and donation of their stored embryos created through IVF.

Through our online and written survey and/or interviews with you and other current and former users of Assisted Reproductive Technology (ART), we will explore the actual choices and opportunities available to prospective parents and donors of embryos. We want to explore possible reforms to law and policy to address the concerns of those who are most affected: you, and those closest to you.

(2) Who is carrying out the study?

The study is being conducted by Professor Jenni Millbank, Associate Professor Anita Stuhmcke and Professor Isabel Karpin at The University of Technology, Sydney.

(3) What does the study involve?

Participation in this study involves undertaking an online or written survey and/or a short semi-structured interview. The latter will be conducted either in person (at a **location you select** or at the University of Technology Sydney) or by telephone.

We would like to hear from you to help understand what kinds of choices people with stored embryos would like to have about issues such as:

- how long to store embryos;
- whether to donate unused embryos to other infertile people so that they can try to have children;
- what to do with stored embryos if a couple separates;
- whether embryos can be used by one partner if the other partner dies; and
- whether to undergo a farewell process for embryos that are being discarded.

The survey: Your participation in the survey will be confidential. The survey can be completed either online or by hand (the written survey). If you would prefer to participate in the survey online, it can be accessed through our website at www.allabouttheembryo.net. Alternatively, if you would like to complete the survey by hand, we would be more than happy to send you a copy with a reply paid envelope attached. In this case, please contact us either by email at allabouttheembryo@uts.edu.au or by phone (02) 9514 3118 and provide us with your preferred postal address.

The interview: If you participate in an interview, it will be recorded, subject to your consent, to allow subsequent analysis. You will be provided with a written transcript of your interview for verification and correction. Following this, any identifying information will be completely removed from the interview

transcripts. You will also be offered the opportunity to receive a one-page report on the progress of the study at the end of 2010 and 2011.

(4) How much time will my participation take?

The survey is estimated to take between 20 to 40 minutes to complete.

The interview is expected to take between 30 minutes and an hour to complete.

(5) Can I withdraw?

Being in this study is completely voluntary - you are not under any obligation to consent.

The survey: As we are not collecting any identifying information in the survey, once you submit your survey we will not be able to identify your responses to withdraw them from the study.

The interview: If you participate in an interview you may withdraw your consent to participate at any time without affecting your relationship with the service provider that you may have received this information from, the University of Technology, Sydney, or the researchers.

You may also stop the interview at any time if you do not wish to continue. If this is the case, the audio recording will be erased and the information provided will not be included in the study.

(6) Will anyone else know the results?

All aspects of participation will be strictly confidential (except as required by law) and only the researchers will have access to information collected. A number of papers analysing the results of the study will be submitted for publication, but individual participants will not be identifiable in such papers.

(7) Will the study benefit me?

While there are no direct benefits to participants, we hope that this project will ultimately benefit individuals with embryos in storage and those involved in or considering donation. We want changes to rules governing the storage and donation of embryos to be informed by the needs and interests of people who have had personal experience with these issues. We intend the study results to inform future improvements in legal and clinical frameworks around the storage and donation of eggs, sperm and embryos.

(8) Can I tell other people about the study?

Yes. If you have friends or acquaintances who may also be interested in participating in the study, we encourage you to invite them to our website, www.allabouttheembryo.net or email us at: allabouttheembryo@uts.edu.au

(9) More information?

For more information please email us at allabouttheembryo@uts.edu.au, visit our website www.allabouttheembryo.net or call us on (02) 9514 3118.

NOTE: This study has been approved by the University of Technology, Sydney Human Research Ethics Committee. If you have any complaints or reservations about any aspect of your participation in this research which you cannot resolve with the researcher, you may contact the Ethics Committee through the Research Ethics Officer (ph: +61 2 9514 9772 Research.Ethics@uts.edu.au) and quote UTS HREC reference number HREC 2009-262A. Any complaint you make will be treated in confidence and investigated fully and you will be informed of the outcome.

This information sheet is yours to keep.