Taking pART online

Participant Information Leaflet

Taking pART Online: Understanding what influences the decision to consent to data use for fertility research

This sheet explains why we are doing this study and what we are inviting you to do.

What is the purpose of the study?

Under UK law the Human Fertilisation and Embryology Authority must keep a record of all cycles of infertility treatment such as IVF. This includes details about the patient (name, date of birth, place of birth), about their fertility diagnosis and subsequent treatment. Information is also kept on the outcome of any pregnancy resulting from fertility treatment. This data is used for monitoring success rates and safety. In certain circumstances it can also be used for research to help us learn more about the consequences of fertility treatment. Since 2009, the HFEA has asked patients for consent to allow this data to be used in research – this includes consent for their data to be used, for linkage to other records, and for their details to be available for future contact for research. To be a really useful resource for research, it is important that many people agree to this, but at the moment only about half the people undergoing treatment in the UK say yes to allow their HFEA data to be used for research.

The aim of this study is to find out why people accept or refuse to allow their data to be used in infertility research.

Why have I been asked to help?

You have been asked to help because you have experience of infertility treatment and the consent procedures that the HFEA requires for all those undergoing treatment.

Do I have to take part?

No, you can choose whether you want to take part in this study.

If I do agree to take part, what will happen next?

If you would like to take part you can complete the online survey available on our study website. There are five questions to answer about your experiences of completing the consent forms, what choice you made and why, and the option to tell us about your fertility story. This information is collected anonymously, so we will not know who you are.

How long will it take?

This depends on how much you have to say! In general, we would expect it to take about 10 minutes to complete.

How will the researchers use my survey responses?

If you choose to respond to this survey, then your responses would be analysed alongside other survey responses and interviews from people who have also undergone fertility treatment or are staff at a fertility clinic. The results of the study will be published in reports, academic journals and presented at conferences. You will never be identified in any publication. All the data that you give us for analysis will be confidential, and have no personal information with it so you cannot be traced. It will be used strictly within the terms of the Data Protection Act.

What if I change my mind? Can I withdraw after completing the survey?

You can withdraw from the study until you press the 'submit survey' button – at this point we would not be able to remove your responses because we will not be able to tell which ones they are (your name and details are not saved with your responses).

Are there any benefits or risks in taking part?

Participants may feel that by taking part they may influence how researchers or clinics speak to new patients about the consent process. People who have taken part in similar studies have said that they valued the opportunity to share their thoughts, and have found the experience a positive one.

Although the focus of the survey is about consent and participation in research, we will give you the option to tell us about your experiences of infertility and treatment. You may find this distressing, but you will have control over what you tell us about and do not have to answer this question if you don't want to. You will be able to stop at any point during the survey if you wish to.

What will happen if there is a problem?

Given the nature of this study is very unlikely that you will suffer harm by taking part. However, the University of Oxford has insurance in place to provide for harm arising from participation in a study for which the university is the Research Sponsor. If you are unhappy about the way that you have been approached or treated during this study, you should contact Dr Claire Carson on (01865) 289755 or you may

contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224 or, email ctrg@admin.ox.ac.uk.

Who has reviewed this study?

This study has been reviewed by the Central University Research Ethics Committee, at the University of Oxford.

Who is organising and funding the study?

This research is based at the National Perinatal Epidemiology Unit, which is part of the Nuffield Department of Population Health at the University of Oxford. This study has been funded by the Medical Research Council as part of a fellowship grant to Dr Claire Carson.

Who are the research team?

The study team at the University of Oxford comprises: Dr Claire Carson, Prof Jennifer Kurinczuk and Prof Maria Quigley at the National Perinatal Epidemiology Unit, and Dr Lisa Hinton in the Health Experiences Research Group.

For further information –

We hope that this information sheet has told you what you need to know before you decide whether to take part in this study. If you do have any questions or wish to talk to someone about this study, please contact Claire Carson at the National Perinatal Epidemiology Unit on (01865) 289755.

If you would like to take part in the study please click on the link and answer the questions online.

If you have questions OR would like to volunteer to be interviewed without completing the survey, you can contact the research lead, Dr Claire Carson, by telephone on (01865) 289755 or by email at (claire.carson@npeu.ox.ac.uk).

Many thanks for reading this leaflet.

Taking pART online

National Perinatal Epidemiology Unit
Nuffield Department of Population Health
University of Oxford
Richard Doll Building
Old Road Campus
Headington
Oxford
OX3 7LF
T: (01865) 289755
E: claire.carson@npeu.ox.ac.uk