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**Egg and Sperm Donation: Your Views and Experiences**

Participant Information Sheet (PIS)

This PIS should be read in conjunction with [The University privacy notice](http://documents.manchester.ac.uk/display.aspx?DocID=37095)

You are invited to take part in a research study which examines how sperm and egg donation impacts on the everyday lives and relationships of donors, their partners and parents. Before you decide whether to take part, it is important that you understand why the research is being carried out and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. Please get in touch if there is anything that is not clear or if you would like more information.

**Who will conduct the research?**

This study is being conducted by Dr Petra Nordqvist and Dr Leah Gilman, sociologists working at the University of Manchester. It is being conducted independently of any medical institution and is funded by the Economic and Social Research Council.

**What is the purpose of the research?**

The study aims to explore and understand the experiences of people who donate egg or sperm, as well as their partners and parents, and how donation impacts on their everyday lives and relationships.

**Why have I been chosen?**

We are interested in speaking to anyone who has donated egg or sperm (including embryo donors) since April 2005, as well as the partners or parents of any such donors.

**What would I be asked to do if I took part?**

Taking part would involve a one-off, informal interview with one of the researchers, in a time and place which suits you. This could be your own home, workplace or a public place, such as a café. It will last between one and two hours. The interview will take the form of a guided conversation and the researcher will ask about your views and/or experiences of egg, sperm or embryo donation. We will not be following a strict list of questions and so other related topics are likely to be discussed. With your permission, the interviews will be recorded using a digital voice recorder. If you wish to stop the interview, take a break or re-schedule, you can request this at any time.

We are interested in speaking to parents and partners of donors, as well as people who have donated themselves. It is very difficult to contact parents and partners directly so, if you are a donor, another very valuable way in which you could support the project would be to pass on information about the study to family members. If you think that your partner or one of your parents might be willing to take part in an interview, please pass on this information sheet to them and explain that they should get in touch with the researcher if they are willing to participate. Also, should you choose to contact the researchers, they may ask if you are willing to participate in this way. However, you are under no obligation to do so and willingness to speak to family members is not a requirement of participating in the research.

. In the case of embryo donation, the person who contacts the researchers will be offered the choice of an individual or joint interview.

Where appropriate, interpreters (including for sign language as well as languages other than English) can be arranged to attend interviews. Audio recordings of written documents can also be provided. Please contact the researchers if you believe these would be helpful.

At the end of the interview, you will be invited to complete a very short, tick-box questionnaire which collects basic information about you and your circumstances at the time of donation (e.g. age, relationship status, age(s) of any children, date of donation(s)). If you do not wish to complete the questionnaire, it is still possible to take part in the interview.

**What will happen to my personal information?**

In order to undertake the research project we will need to collect the following personal information/data about you in order to arrange an interview:

* Name and contact details (email and/or phone number)

The questionnaire collects the following personal information as well as details about your donation. However, these will be stored securely (in a locked drawer on university premises) separately from your name and contact details:

* Date of birth
* Relationship status
* Sexual orientation
* Household income
* Age(s) of any children
* Religion
* Ethnicity
* Highest educational qualification
* Household type
* Nationality

We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is “public interest task” and “for research purposes” if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our [Privacy Notice for Research Participants](http://documents.manchester.ac.uk/display.aspx?DocID=37095).

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained and your data will be looked after in the following way:

Only members of the research team would have access to your personal details (name and contact details) and the information requested on the questionnaire. These are stored securely in a locked drawer on university premises.

Audio recordings will be accessible to the research team and, in some instances, a university-approved transcriber. After the interview, the conversation would be transcribed. Transcriptions are stored securely on a password protected folder on university computers and kept separate from any identifying details, so that what you have said remains confidential and your participation in the research remains anonymous. As soon as is practically possible, transcriptions will be anonymised (i.e. any identifying features such as names or places would be removed or changed). With your permission, we would then like to use anonymous quotations from your interviews for educational and research purposes, including academic publications.

Audio recordings and non-anonymous transcriptions are deleted as soon as anonymous transcriptions have been completed. Consent forms and the anonymised files are then kept for 5 years after the project is completed. With your express permission, and if deemed appropriate, the anonymised data files may also be archived with the UK Data Archive as they may be helpful to other researchers in the future. With your express permission, your name and contact details will be stored by the researchers in order to contact you about related and follow-up research studies which you may be interested in.

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our [privacy notice for research](http://documents.manchester.ac.uk/display.aspx?DocID=37095) and if you wish to contact us about your data protection rights, please email [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL. at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner’s Office](https://ico.org.uk/concerns), Tel 0303 123 1113

**Will my participation in the study be confidential?**

Your participation in the study will be kept confidential to the study team and those with access to your personal information as listed above.

Where multiple persons in the same family/couple participate in interviews, particular care will be taken to ensure that the issues discussed in the interview are treated in the strictest confidence. To avoid any risk of accidental disclosure, these interviews will be conducted by different members of the research team.

To maintain anonymity and confidentiality, any data which could identify you is stored securely, in line with the University of Manchester’s data security policy. All audio recordings are deleted from the recording device as soon as possible and then stored in a password protected folder on university computers. An encrypted online system is used when transferring audio files to university approved transcribers. Anonymous questionnaires and your personal details (name and address) would be stored in a locked drawer in university offices and would only be accessed by members of the research team. During the transcription of interviews, all identifying details, like names and places, are removed and replaced with pseudonyms in some cases. It is these anonymised transcripts which are then used for analysis and in reporting of the research.

**What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. You can also decline to answer any question and/or stop the recording at any point. However, it will not be possible to remove your data from the project once it has been anonymised and forms part of the dataset as we will not be able to identify your specific data. This does not affect your data protection rights.

If you prefer that your interview is not audio recorded if would still be possible to take part in the study. Equally, if you do not wish to complete the questionnaire or any particular question on it, participation is still possible.

**Will my data be used for future research?**

With your permission, the researchers will retain your contact details (securely stored as stated above) for the purposes of contacting you about research outcomes and details of follow-up and related studies that you may be interested in. You can decline your consent for such communications from the outset or you can withdraw your consent at a later date by following the information in any email received.

**Will I be paid for participating in the research?**

It is not possible to pay participants in this study.

**What is the duration of the research?**

Interviews are expected to last between 1 and 2 hours but the precise timings vary according to the amount that participants have to say. The questionnaire usually takes less than 5 minutes to complete.

**Where will the research be conducted?**

Interviews take place at a place and time to suit you. This can be in participants’ homes, their work place or a public place, such as a café.

**Will the outcomes of the research be published?**

We anticipate that we will publish the findings in academic journals such as The Journal of Sociology of Health and Illness, Sociology, and British Journal of Sociology. We will also write shorter articles in professional journals as well as information leaflets to social policy makers, practitioners and the general public. Findings will also be published in a book aimed at academics, policy-makers, practitioners and other member of the public with an interest in the topic.

**Who has reviewed the research project?**

This project has been reviewed by the University of Manchester Research Ethics Committee 5.

**What if I want to make a complaint?**

**Minor complaints**

If you have a minor complaint then you need to contact the researcher(s) in the first instance (see contact details at the end of this information sheet)

**Formal Complaints**

**If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact**

TheResearch Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk)  or by telephoning 0161 275 2674.

**What Do I Do Now?**

If you do not wish to take part in the study, you do not need to take any further action. You will not be contacted as part of this project again.

If you would like to take part or would like further information, please contact one of the researchers using the following details:

**Dr Leah Gilman**, [leah.gilman@manchester.ac.uk](mailto:leah.gilman@manchester.ac.uk), 0161 306 6881

**Dr Petra Nordqvist**, [petra.nordqvist@manchester.ac.uk](mailto:petra.nordqvist@manchester.ac.uk) 0161 275 0262

Alternatively, if you have received this leaflet via post, you can return the contact details form in the pre-paid envelope provided and one of the researchers will contact you to discuss the project further and/or arrange an interview.

For further information about the project, you can also consult our web page: [www.manchester.ac.uk/egg-and-sperm-donors](http://www.manchester.ac.uk/egg-and-sperm-donors)

**This Project Has Been Approved by the University of Manchester’s Research Ethics Committee (ref: 2017-0782-1600)**