

Participant Information Sheet

Project title: The choices people make after being declined for NHS-funded IVF

Invitation paragraph

We would like to invite you to take part in our research project. Before you decide whether to participate, we would like you to understand why the research is being conducted and what it would involve for you. Talk to others about the study if you wish. Please ask us questions if anything is unclear. The contact details for the study organiser are available at the bottom of this information sheet.

What is the purpose of the project?

The purpose of this project is to find out what steps (if any) people take to have children after being declined for NHS-funded In Vitro Fertilisation (IVF).

The NHS and the UK government do not currently record data for how potential parents choose to have a family if they are declined NHS-funded IVF. This project aims to get an overview of what choices people make to have a child (or if they choose not to), so that we can explore possible consequences of declining to fund IVF that the NHS may not be considering.

This research is being used for a thesis for an Masters of Research in Bioethics project. The data will be published in the University of Bristol Research Data Storage Facility and available for use in further publications.

Why have I been invited to participate?

If you are somebody who has been declined for NHS-funded IVF in the past, then we are interested in hearing what your next steps were (if any) to have a family.

You should also be aged over 18 and be someone who has access to free NHS care.

Unfortunately we cannot accept responses from single men or men who wished to access fertility services with another man; the NHS does not provide access to the same fertility services for these groups of people, and therefore are not being assessed in this project.

We also cannot accept responses from transgender people who have tried to access IVF through non-traditional routes (such as via gender identity clinics). This is because the funding structure for this group of people is assessed differently and is not being reviewed in this project. If you are transgender but were able to request (even if it was declined) IVF via the standard fertility clinic pathway, then you may complete the survey.

Do I have to take part?

The survey is completely voluntary.

If you have questions prior to taking part, you can email the organiser of the study. If you agree to take part, you will be asked to answer a question at the start of the survey that indicates you have read and understood the information presented here and agree to take part.

You are free to withdraw at any point during the survey by closing the survey, and any data you have entered up to that point will not be saved. By submitting the survey, you are consenting to us using the data you have submitted. You will not be able to withdraw your data after submission, as it is submitted completely anonymously and we will not be able to identify the data that is yours.

What will happen to me if I take part and what will I have to do?

You will be asked to fill in a survey about your experiences after being declined for NHS-funded IVF.

The survey length is dependent on your experience and how many methods you may have used to have a family. Most participants will find that the survey will take 10-20 minutes to complete, however it could take up to 45 minutes. You can stop the survey at any time and change your mind without submitting your answers if you no longer wish to participate. Unfortunately, it is not possible to save your answers to complete the survey at a later time, but you can submit your answers at any point if you are unable to complete the entire survey. This survey will remain open until 31st July 2023.

What are the possible disadvantages and risks involved in taking part in the project?

This survey asks you to answer questions that are personal in nature, including questions about your age, race and sexuality, and questions that are about your personal life, including your sex life. The questions are not mandatory and you do not have to answer anything you do not wish to. The survey is completely anonymous, and you will not be identifiable. The survey may be difficult to answer in parts, as we appreciate this is about a sensitive topic. If you find any of the survey distressing, you do not have to continue or complete it. If you require further support regarding this topic, charities such as [the Fertility Network](#), [British Infertility Counselling Association](#) and [Life Charity](#) offer a range of support services.

What are the possible benefits of taking part?

There are no personal benefits to taking part in the project. However, we hope this data will add to the broader conversation about the ethical implications of the availability of IVF under the NHS, and that it could give us information that could be used to suggest changes that would benefit other people.

Will my participation in this project be kept confidential?

Your data will remain anonymous and cannot be linked back to you. Identifiable information is not asked for in the course of this questionnaire, and any potentially identifying information will be removed before the research data is published. The data will be collected via Microsoft Forms, and is immediately stored on University of Bristol computer servers. After conclusion of the project, the anonymised data will be published in Bristol's Research Data Storage Facility. This will be published as open data, and so will be available to anyone interested in the research, or who wishes to conduct their own analysis. We have no control over how others use the data, but the anonymisation of it means you would not be identifiable as a participant to anyone. Sharing research data is considered best scientific practice and is a requirement of many funding bodies. As most research is publicly funded, the outcomes of the research should be made publicly available.

What will happen to the results of the research project?

The results of this survey will be presented as part of an overall Masters of Research in Bioethics project. The results will be submitted for assessment as part of a master's dissertation to be written by the organiser of the survey. The results will be published by Bristol's Research Data Storage Facility, and can then be cited in journals. If you wish to know the results of the project, you may contact the organiser at the email address given below. Your email address will not be collected during the course of the survey, so we regret that we cannot inform anyone of the results if they do not request it.

Who is organising and funding the research?

The Centre for Ethics in Medicine at the University of Bristol Medical School is funding this project via a Master's Programme award from the Wellcome Trust.

Who has reviewed the study?

Dr Zuzana Deans, Prof Jonathan Ives and has been given a favourable opinion by the University of Bristol Health Sciences Student Research Ethics Committee (REF: 12799).

Further information and contact details

If you would like any further information about the study, please contact the lead organiser (Dr Molly Nobes) at mn12815@bristol.ac.uk

If you have any concerns related to your participation in this study, you can contact the University of Bristol Research Governance Team: research-governance@bristol.ac.uk