

Donor Conception Network Research Policy and Checklist

Introduction

The Donor Conception Network (DCN) receives many requests from researchers asking if they can approach members of the DCN to take part in their research. As we have a duty to protect the interests of our members, we have set up a research group to consider all applications to undertake research involving our members.

This information is important if:

- you wish to conduct a piece of research involving members of the DCN (please note the DCN research group require a minimum of 30 days' notice to review a proposal)
- you have been asked to participate in a research project

Donor Conception Network research policy statement

The DCN recognizes that research is a valuable tool for learning, empowerment, and improving services for:

- parents with children conceived with donated gametes
- adult offspring
- people contemplating or undergoing treatment

The **aims** of this policy are to ensure that all research undertaken within the DCN:

- **promotes best practice** in research and research-related activity
- **contributes to genuinely evidence-based policy**
- **safeguards the dignity, rights, safety and well-being of participants** as the primary consideration for all research studies and helps to avoid unacceptable risk to the researchers
- **promotes equality in line with the Equality Act 2010** (which identifies discrimination as unlawful if it is based on: age, disability, gender reassignment, marriage and civil partnership, pregnancy, maternity, race, religion or belief, sex, sexual orientation)
- **adheres to data protection requirements**
- **promotes efficiency** and reduction of 'consultation fatigue' by avoiding where possible duplication of research activity (i.e. a project is less likely to be approved by the research committee if a similar one has recently been undertaken)
- **improves dissemination** of current and future research findings
- **ensures free and comprehensive access to information on research** in progress and on completed research findings undertaken through the DCN
- **facilitates greater public acceptance** where necessary for any research undertaken

We believe that there are **three key principles** central to carrying out research ethically:

1. Obtaining informed consent

DCN members need to be able to make an informed decision about whether or not to take part in research. To be able to do this, they will need to know and understand the purpose of the research and what it involves.

2. Protecting participants from harm

Both those taking part in the research and doing the research should be safeguarded from harm (both physical and psychological).

3. Maintaining confidentiality and anonymity

The confidentiality and anonymity of participants should be protected when storing and handling data.

What does this policy mean for DCN members asked to take part in research?

The DCN has developed a checklist to try to ensure that research involving the DCN is conducted appropriately and is relevant to our members. Although it is not possible to cover all potential issues, the research checklist has been developed to highlight some that might arise. Hopefully DCN members will feel confident that any research they are asked to take part in is a good and necessary piece of work and will help towards understanding the various issues associated with donor conception. The research should be explained to DCN members clearly, and once the study is finished they should be told about the results.

If DCN members have been asked to take part in a research project and have any questions about it, they should contact the researcher.

What does this policy mean for researchers wanting to conduct a research project?

- If a research project involves collecting information from or about members of the DCN **researchers must complete the checklist.**
- If the proposed research has been approved by a Research Ethics Committee such as an NHS institution or University, **please send a copy of the approval and supporting documents.**
- In addition to Research Ethics Committee approval, the proposal will still require operational approval from the DCN Research Group. A proposal can be approved, amendments suggested or further information required. In some cases a proposal can be rejected.
- It is the **researcher's responsibility to ensure that the research is carried out in accordance with approval from the appropriate Research Ethics Committee.**
- Once the research has taken place the researcher must ensure that there is **easy access to the findings when they are published** e.g. the researcher is encouraged to write a piece for the newsletter or present them at a DCN meeting. **Summaries of findings and publications will be placed on our website.**

What does this policy mean for the DCN?

- Before the research takes place, the DCN is responsible for ensuring that the **research group has reviewed the checklist and submitted research documentation and that a response is provided to the researcher within 30 days. As stated above, this can be approval for the research to take place** under the auspices of the DCN, a request for amendments or further information or a rejection. The DCN is **NOT responsible for carrying out the research, nor ensuring that it follows the approval of the Research Ethics Committee, or for any implications of its findings. This is the sole responsibility of the researcher.**

Further information

If you have any further questions, please contact the DCN at: research@dcnetwork.org