

# **Donor conception: ethical aspects of information disclosure**

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# Donor conception: ethical aspects of information disclosure

- This report is looking at families created through assisted reproduction using donated gametes, embryos or surrogacy
- The focus is on the significance of *information* about being donor-conceived or about the donor - it is not intended to include a wider consideration of 'what constitutes a family'



# Current legislation

- **Donor-conceived people** conceived after 1 April 2005 through treatment in a UK clinic can find out the identity of their donor at age 18 – so can make contact if they wish (also potentially with siblings)
- Non-identifying information available from 16 (and available earlier to **parents**)
- **Donors** are entitled to find out the number, sex and year of birth of any children born as a result of their donation but receive no other information unless the donor-conceived person makes contact later in life

# Key issues

- What 'information' is at stake?
  - The fact that a person is donor-conceived
  - Non-identifying information about the donor
  - Identifying information about the donor
- Ethical questions
  - how can the interests of all the various parties involved in donor conception be properly balanced?
  - what is the role of the state, the public sector, or health and social care professionals?

# Terms of reference

To consider the impact of the disclosure/non-disclosure of information about a person's genetic origins, with particular reference to:

1. the wide range of stakeholders involved, the complexity of the relationships between them, and the ethical values at stake
2. the quality of the evidence available as to both the medical and social importance of genetic information in this context
3. the support available to both donors and donor-conceived families
4. the role of the law and professional guidelines in determining the provision of information about donors to donor-conceived offspring and their families, and in intervening in families' decisions about disclosure.

# Consultation

- Open call for evidence: 130 responses
- Fact finding meetings with:
  - donor-conceived people
  - parents of donor-conceived people
  - donors
  - social work practitioners
  - healthcare professionals,
  - academics
  - those concerned with the law and regulation of donor conception services



# Emerging themes in research

- Early disclosure by parents is increasing
- However, the majority of donor-conceived people reach adulthood without knowing
- Outcomes if offspring are told early are generally good
- Outcomes less good if offspring are told late or find out accidentally
- Some donor-conceived adults wish to contact their donor (mainly out of curiosity) – but more interest in having relationships with their donor siblings

# Emerging ethical considerations

- Importance of focusing on **relationships** – the ways in which people’s interests are interwoven and interdependent
- Consideration of the mutual **responsibilities** that arise within these relationships
- Distinct roles of the state as **regulator** (intervening to prevent serious harm) and as provider of **support** (promoting well-being)



[www.nuffieldbioethics.org/donor-conception](http://www.nuffieldbioethics.org/donor-conception)

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