



Opening the HFEA Register to Families and Donors

HFEA Plans

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Overview

- Current access rights to information on the HFEA Register
- Changes proposed by the HF&E Bill
- HFEA arrangements to date

Current Access Rights: donor-conceived people

- From 2010 18 yr olds will be able to ask:
 - whether they are donor-conceived
- If so:
 - descriptive information about donor
 - existence of genetic half-siblings
- If donor recruited after 1/4/05 or re-registered as identifiable
 - donor's identity
- If planning to marry (no age specified):
 - related to intended spouse

Current Access Rights: parents and donors

- **Parents**

- Descriptive information about donors
- Number, sex and year of birth of half/full siblings

- **Donors**

- Number, sex and year of birth of donor-conceived children

New access rights HF&E Bill

- Age of access to all non-identifying information lowered to 16
- Access to donor identity remains at 18
- Also at 18:
 - New access right to identity of genetic half-siblings (if mutual consent)
- Consanguinity information extended to people who intend an intimate physical relationship or civil partnership
- Donors to be informed if identifying information requested

Current requests for information

- 1 October '07 to 29 September '08

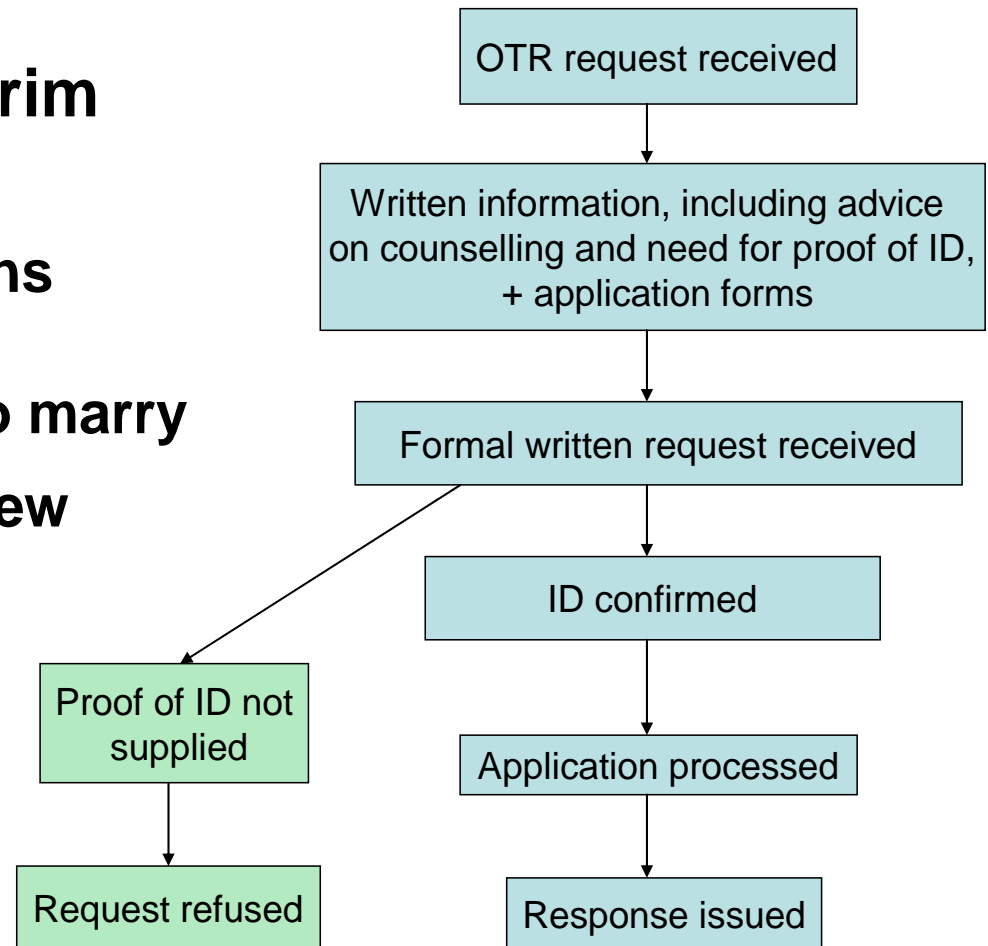
Parents	Donors	Egg sharers*	Donor conceived people	Total
43	16	2	0	61

*Submit combined Parent/Donor requests

- 90 donors recruited before 1/4/05 are registered as identifiable

HFEA Interim Policy:

- applications from those intending to marry
- pending new Act



Opening the Register policy group

- Develop a set of principles and a long term handling policy for applications for information contained on the HFEA Register
- Report back to the full Authority with recommendations
- Policy to be in place in 2009 to meet requirements of the new Act

Issues

- **The sensitivity of the information held**
 - Its personal meaning for applicants
 - Its potential impact on the families of those affected
- **Differentials** in what information can be accessed due to changes in legislation and regulations
- **Suitable counselling provision**
- **The training needs of front-line staff**
 - emotional and social issues for applicants
 - good communication and listening skills

Where we are now

- Interim policy in place
- Policy group established/work begun
- Welcome the speakers on this panel
 - contributions that will help inform policy development on the opening of the Register