

## Appendix 2

### MAPPING THE LAW AND POLICY CONTEXT

Our interview study was informed by a policy-mapping exercise. We conducted an analysis of the regulatory context in which post-2005 UK donors donate, an attempt to map out the laws and policies which frame what it means to donate in an ‘open’ context. Findings from our policy analysis are detailed in Chapter 1 and inform our analysis throughout the book.

Between January and May 2017, we identified 61 policy documents in which the rights, roles and obligations of donors, or donors’ families, were either directly discussed or implicated (summarised in [Table 2.1](#)).<sup>1</sup> These included legal documents, public consultations, transcripts of parliamentary debates, professional guidance to infertility counsellors and a range of documents published by the HFEA. The documents were identified and selected via prior knowledge of the regulatory context, consultation of socio-legal academic studies in this area, browsing the HFEA website, discussion with HFEA staff and through contacts with British Infertility Counselling Association (BICA) members.

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<sup>1</sup> Policy documents published since this period have not been included in our policy analysis. However, the commercial and technological context is changing rapidly, and there have been calls for legal and regulatory review in relation to new developments. These include the rise in direct-to-consumer genetic testing, which enabled contact between ‘donor relatives’ (Darroch and Smith, 2021), expanded genetic carrier testing for donors and improvements in egg vitrification techniques which make ‘egg banks’ and the import and export of eggs more viable (Hudson et al., 2020).

**Table 2.1. Documents Analysed by Category.**

Category	Document	Publisher	Date
Legal documents	• HFE Act 1990	HMSO*	1990
	• HFEA (disclosure of donor information) regulations	HMSO	2004
	• HFE Act 2008	HMSO	2008
Policy development	• ‘Opening the Register Policy’ and minutes/papers from meetings where it was discussed	HFEA	2009–2016
	• Review of the HFE Act	Department of Health	2006
	• Parliamentary debates of HFEA (disclosure of donor information) regulations	Hansard	2004
	• General committee debates of the HFE Act, 2008	Hansard	2008
	• Sperm, Egg and Embryo Donation SEED report	HFEA	2005
HFEA forms	• HFEA application forms for donors, recipients and donor-conceived people requesting access to information	HFEA	2016
	• Historic and current HFEA donor registration forms	HFEA	1991–2015
Codes of Practice	• HFEA Codes of Practice	HFEA	1991–2016
	• Chairs’ letters to clinics advising of updates to Code of Practice	HFEA	1991–2017
	• BICA Practice guidelines	BICA	2012
	• BICA Opening the Record	BICA	2003
Information leaflets	• Leaflets provided on the HFEA website linked to application for information forms	HFEA and Life cycle	2016

\*Her Majesty’s Stationary Office.

The documents were read and coded with the support of NVivo software. The first stage of coding was descriptive, identifying which aspects of policies were relevant to donors and categorising how exactly they were implicated. For example, different codes were used to categorise where and how policies discussed the donor’s role in relation to various aspects of the process (e.g. payment, testing of gametes, selection of donors). The researchers read the data, looking for patterns and anomalies in the ways that laws and policies positioned donors. HFEA working papers and parliamentary debates were then read and coded in an attempt to explain patterns identified and to trace the logic and discourses behind the final policy decisions made.