

Appendix 1

INTERVIEW STUDY WITH DONORS, DONORS' RELATIVES AND FERTILITY COUNSELLORS

The data discussed in this book were produced as part of an ESRC-funded qualitative study, 'Curious Connections: The Impact of Donating Egg and Sperm on Donors' Everyday Lives and Relationships' (grant number: ES/N014154/1), conducted at the University of Manchester between 2017 and 2021 and led by the first author. It focuses on the experiences of UK donors, and their relatives, who donated in an era of increased openness in donor conception. It explores how 'openness' is operationalised through laws, policies and interactions in clinics as well as how it is experienced by donors and their relatives. The project used an exploratory qualitative methodology in order to understand the processes through which donation is made meaningful in people's lives. In this appendix, we discuss the methods used in relation to interviews with donors, donors' relatives and clinic staff. Appendix 2 outlines our methods of policy analysis.

RECRUITMENT

We took a flexible and varied approach to recruitment. We collaborated with staff in three fertility clinics in England to advertise the research to current

and former donors. We shared information about the project through existing personal and professional networks, including via participants in previous projects who we knew were in contact with donors and the Donor Conception Network (a support group for families through donor conception). We recruited (mostly non-clinic and known) donors via private Facebook groups and websites designed for donor and recipient matching, and by directly contacting people who posted about their donations on public social media sites. [Table 1.1](#) summarises the recruitment routes used and how many donors we were able to recruit through these different routes.

Recruiting the relatives of donors proved more challenging and, after attempting various strategies to contact the partners and parents of donors directly (e.g. advertising through fertility counsellors or adverts on forums), we relied heavily on snowballing through donor participants, in order to advertise the project to this group. As our resulting sample shows (see below), this strategy proved more successful in recruiting the relatives of egg donors (particularly their partners) compared to sperm donors. The sperm donors we interviewed were more often single and less likely to have disclosed their donation to parents or wider kin. In addition, during our interviews, we discovered that five of the donors who had contacted us were also partners of donors and our interviews therefore covered their experiences of both being a donor, as well as a partner of one (often it was hard to separate the two).

Recruiting fertility counsellors and donor coordinators was relatively simple in comparison. Online leaflets were emailed via a gatekeeper to members of the British Infertility Counselling Association (BICA) and paper leaflets were given out at Progress Education Trust (PET) event. Counsellors and donor coordinators were also identified and contacted, where possible, via the staff pages of fertility clinic websites or by snowballing from previous participants.

THE SAMPLE

In total we conducted 88 interviews including 52 interviews with donors, 23 with donors' relatives and 18 with fertility counsellors or donor coordinators. Five donors were also partners of donors, hence the numbers for each group do not total 88.

Table 1.1. Numbers and Percentages of Donors Recruited Through Different Routes.

Recruitment Route	Clinics		Online Networks		Personal/ Professional Networks		Support Organisations		Snowballing		All Routes	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Sperm donors	10	38.5	8	30.8	5	19.2	1	3.8	2	7.7	26	100
Egg/embryo donors	4	15.4	12	46.2	6	23.1	4	15.4	0	0.0	26	100
All donors	14	26.9	20	38.5	11	21.2	5	9.6	2	3.8	52	100

Donor Participants

Among the donor participants, there was an equal split between men and women. All the men had donated sperm and all but one of the women had donated eggs. The one remaining female participant had donated ‘spare’ embryos having used ‘double donation’ to become a solo parent herself. To maintain confidentiality, her data are included with that of egg donors in the tables below.

The overwhelmingly majority of donors we interviewed had donated in the UK since 2005, the year new regulations came into effect in the UK, meaning that new donors would be required to consent to their identity being released to potential donor-offspring (see Chapter 1). As [Table 1.2](#) shows, the median year of first donation was 2012, meaning that most participants had had time to reflect on their donation and its consequences. Five had donated prior to 2005, including two outliers who had donated in the 1980s. These participants made contact with, or were introduced to, the researchers and were included in the sample for theoretical reasons as it was expected they would offer particular insights into experiences of being a donor in the context of openness. For example, two originally anonymous sperm donors had since chosen to become identity-release donors and one anonymous egg-share donor was considering re-registering as an identity-release donor, at the time of the interview. All participants lived in the UK and all but two had donated here (the two exceptions had both donated in European countries).

As explained in Chapter 2, ‘sperm donation’ and ‘egg donation’ are terms used to describe transfers of gametes; however, the circumstances of sperm and egg donation can vary considerably, and in relation to multiple dimensions (e.g. location or relationship to recipient). We refer to these as different

Table 1.2. Timing of Donors’ First Donation (Year).

		Sperm Donors ^a	Egg and Embryo Donors	All Donors ^a
Year of first donation	Range	1981–2018	2003–2017	1981–2018
	Median	2009	2014	2012

^aMissing Data for four donors (all sperm donors).

donation pathways, and [Table 1.3](#) shows the numbers of donors who had experienced different pathways. We report these in relation to multiple dimensions, including the categories generally used in clinics: ‘egg share donation’ – where women donate half of their eggs in exchange for reduced cost IVF treatment for themselves; ‘known donation’ – where a donor donates to someone they already know and ‘altruistic donation’ – where donors are donating to someone they do not know and are not involved in an egg (or sperm-) sharing programme. We also report the relative proportions of participants who donate within and outside of clinics, the different systems of information management they enter into (anonymous, identity-release and known to recipient) and the method through which they found, or were matched to, recipients. Many donors had experienced more than one of these routes into donation.

These statistics are reported in order to inform the reader about our sample and therefore the types of donation experiences we can (and cannot) report on. Our sample is not statistically representative of the UK donor population and the proportions we report here cannot be separated from the recruitment methods we adopted.

It should also be noted that we have taken an inclusive approach to categorising donation pathways. This means we have included those who had taken steps to pursue a particular donation pathway for any length of time, even if it was discontinued for some reason or not yet completed at the time of interview.

[Table 1.4](#) summarises the donation outcomes for the donor participants we interviewed. More than 80% knew that at least one child had been born as a result of their donations, a situation that was more common for sperm donors than egg donors. In the case of the two sperm donors who had donated in the 1980s, they understood that their donations must have been successful because they had been allowed to remain in the donation programme after more than a year. Two egg donors had been told that their donations were unsuccessful and the remaining donors (just under one-fifth) did not know the outcome of their donation, either because they were awaiting this news because they did not want to know and so had not asked or had been refused this information.

Among egg donors who knew their donation had been successful, most reported that five or fewer children had been born from their donation. For sperm donors, this number was, on average, higher, and more likely to be

Table 1.3. Numbers and Percentages of Donors Who Have Experienced Particular Donation Pathways.

		<i>n</i> (Sperm Donors)	% 1.d.p.	<i>n</i> (Egg and Embryo Donors)	% 1.d.p.	<i>n</i> (All Donors)	% 1.d.p.
Clinic pathway	Altruistic	16	61.5	16	61.5	32	61.5
	Known	14	53.8	8	30.8	22	42.3
	Egg-share	0	0.0	11	42.3	11	21.2
Information management	Anonymous	5	19.2	2	7.7	7	13.5
	Identity-release	13	50.0	22	84.6	35	67.3
	Known to recipients	14	53.8	8	30.8	22	42.3
Donation location	Clinic donation	19	73.1	26	100.0	45	86.5
	Non-clinic donation	13	50.0	0	0.0	13	25.0
Matching	Known (personal networks)	6	23.1	2	7.7	8	15.4
	Known (online matching)	9	34.6	4	15.4	13	25.0
	Known (agency)	0	0.0	3	11.5	3	5.8
	Anonymous (via clinic or agency)	16	61.5	24	92.3	40	76.9

Table 1.4. Donation Outcomes.

		<i>n</i> (Sperm Donors)	% 1 d.p.	<i>n</i> (Egg/Embryo Donors)	% 1 d.p.	<i>n</i> (All Donors)	% 1 d.p.
Donation outcome	Knowledge of at least one birth	24	92.3	19	73.1	43	82.7
	Unknown (awaiting outcome)	1	3.8	3	11.5	4	7.7
	Unknown (not disclosed)	0	0.0	1	3.8	1	1.9
	Unknown (not requested)	1	3.8	1	3.8	2	3.8
	Unsuccessful (no births expected)	0	0.0	2	7.7	2	3.8
Number of donor offspring	Unknown/not stated	4	15.4	2	7.7	6	11.5
	0	1	3.9	5	19.2	6	11.5
	1–5	9	34.6	19	73.1	28	53.8
	6–30	9	34.6	0	0.0	9	17.3
	31+	3	11.5	0	0.0	3	5.8

Table 1.5. Median and Range of Donors’ Age at Time of First Donation.

		Sperm Donors	Egg/Embryo Donors	All Donors
Age at first donation	Range	22–58	21–40	21–58
	Median	36.5	33	34

slightly uncertain or unknown to them. A small number of men who had donated outside of clinics reported that more than 30 children had been born from their donations (the highest estimate being 130). However, even among those who had donated outside clinics, the vast majority of sperm donors reported that they had 30 or fewer donor offspring.

As [Tables 1.5 and 1.6](#) show, in terms of the age at which they donated, household income, sexual orientation and parental status, the donors we interviewed came from a wide range of backgrounds and circumstances. This was particularly true in terms of sexuality; two-thirds of donors identified as straight, and one-third as gay, lesbian or bisexual. However, there was very little diversity in our sample in relation to ethnicity; all but two of the donors we interviewed identified themselves as white. The two donors identifying as being from an ethnic minority in the sample were both sperm donors. When compared to the limited information we have about recent UK clinic donors (HFEA, 2005, 2014) and the partial snapshot we have of ‘online’ sperm donor demographics (Freeman et al., 2016), it seems likely that the sample under-represents egg donors from non-white ethnic backgrounds and sperm donors who already have their own children.

Donor Relatives

[Table 1.7](#) provides information about the donor relatives we interviewed. As [Table 1.8](#) shows, in terms of household income and ethnicity, the sample of donor relatives is very similar to that of the donors we interviewed, reflecting the fact that the overwhelming majority were recruited via a donor who also participated in the study. Donor relatives were more likely to have their own children, compared with donors. This partly reflects the aim of recruiting donors’ parents and partly a greater tendency for partners or siblings with their own (or shared) children to take part and/or be referred by donors.

Table 1.6. Donors' Identity and Circumstances.

		<i>n</i> (Sperm Donors)	% 1 d.p.	<i>n</i> (Egg and Embryo Donors)	% 1 d.p.	<i>n</i> (All Donors)	% 1 d.p.
Sexual orientation	Straight	17	65.4	17	65.4	34	65.4
	Gay/lesbian/bisexual	8	30.8	9	34.6	17	32.7
	Missing data	1	3.8	0	0.0	1	1.92
Household income (at interview)	< £24k	4	15.4	4	15.4	8	15.4
	24,000–49,999	11	42.3	6	23.1	16	30.8
	50,000–99,999	3	11.5	11	42.3	14	26.9
	≥100k	4	15.4	4	15.4	8	15.4
	Missing data	4	15.4	1	3.8	5	9.62
Ethnicity	White British	20	76.9	23	88.5	43	82.7
	White European/White other	4	15.4	3	11.5	7	13.5
	Black African/Black Caribbean/Black British	1	3.8	0	0.0	1	1.9
	Asian/Asian British	1	3.8	0	0.0	1	1.9
	Other or mixed/multiple ethnicities	0	0.0	0	0.0	0	0
Parental status	Own children at time of donation	5	19.2	13	50.0	18	34.6
	Own children at time of interview	8	30.8	19	73.1	27	51.9

Table 1.7. Summary of Donor Relative Participants.

		<i>n</i>	% 1 d.p.
Relationship to donor	Partner	15	65.2
	Parent	5	21.7
	Sibling	3	13.0
Substance donated	Sperm	8	34.8
	Egg	15	65.2
Gender of donor relative	Male	9	39.1
	Female	14	60.9

Table 1.8. Demographic Information About Donor Relative Participants.

		Partners	Parents	Siblings	All Donor Relatives
Parental status (at interview)	own children at time of interview	12	5	3	20
	no children	3	0	0	3
Ethnicity	white British	11	3	2	16
	white other	2	1	1	4
	mixed/multiple	2			2
	missing data		1		1
Household income	<24k	1	1		2
	24,000–49,999	3	1	2	6
	50,000–99,999	6	1	1	8
	100,000+	4			4
	missing data	1	2		3

Clinic Staff

Given the small populations involved, in order to maintain confidentiality, we do not report demographic details about the two donor coordinators and 16 fertility counsellors who participated in interviews. For the same reasons,

we do not give details about the organisations in which they work. However, all had worked directly with donors who had donated via licensed UK clinics since the shift to identity-release donation in 2005.

THE INTERVIEWS

Interviews with donors took place during 2018 and 2019. They usually lasted between 90 and 120 minutes (ranging from 35 to 160 minutes of audio recorded conversation) and took place either in participants' homes, a public place (such as a café) or a workplace (either the participant's or at the university). We took an in-depth, loosely structured approach to interviewing donors, beginning with a variation on the request, 'tell me how you became a donor?' Interviewers then encouraged participants to tell their 'donation stories' in their own words, focussing on the topics they considered most important. A topic guide was used to probe for areas of particular interest and ensure topics of interest, not spontaneously raised, were covered. Such topics included: talking to others about their donation, thoughts about the possibility of future (or ongoing) contact with recipient families, experiences of the process of donation and finding out (or not) about the outcome of the donation.

Interviews with donor relatives and with clinic staff (counsellors and donor coordinators) were often shorter (averaging approximately an hour in both cases) and slightly more structured, partly because these participants often seemed to have less of a pre-existing story to tell. Interviews with clinic staff began earlier than with donors (from 2017 to 2019) and those with donor relatives continued longer (2018–2020). For practical reasons, a minority of the interviews with clinic staff and donor relatives were conducted via telephone, at the request of participants.

Interviews with family members began by asking how they first found out their relative was considering donating/had donated, how that had been presented to them and what their reaction had been. As well as asking relatives to recount their relative's 'donation story', we also asked who they had told about the donation and their thoughts about the future.

Interviews with fertility counsellors and donor coordinators focussed on their work with donors. We asked about their aims and approach in the work

they (and their organisations) did with donors and tried to establish the kinds of topics that these professionals covered in their conversations with them and the reasons these were considered important. In addition, we asked questions about their impressions of donors they had worked with, e.g. what kinds of people came forward to donate and what kinds of issues or questions did they generally raise.

Donor and donor relative participants were also asked to complete a short questionnaire at the end of their interview. This questionnaire was used to collect demographic information about them and the circumstances of the donation(s) in question.

DATA ANALYSIS

With two exceptions, all interviews were audio recorded, with the consent of the participant, and transcribed verbatim. In addition, the interviewer wrote an anonymised summary of each interview. With regard to the two exceptions, detailed notes were recorded after the interview by the interviewer. Subsequently, identifying features of the interviews (for example, names of people or places) were redacted or changed.

Anonymised transcripts, notes and summaries were uploaded to NVivo (a computer-assisted qualitative data analysis software programme) and coded thematically using both descriptive codes (mapping onto the themes covered in the topic guides) or more abstract codes of analytical interest derived from our literature review and policy analysis (i.e. narratives of secrecy and openness). Separate coding frames were used to code transcripts from interviews with donors, donor relatives and clinic staff. The researchers analysed the data through repeated readings of the data in various themes, looking for common themes, causal processes, patterns and anomalies.

ETHICS

This study was approved by the University of Manchester Research Ethics Committee 5 (Ref: 2017-0782-2169). Participants were provided with detailed information about the study and an opportunity to ask questions

before consent to take part was recorded (either written or audio consent given). Names and identifying details have been changed or redacted in order to protect the identities of participants (some pseudonyms were selected by participants, others by the interviewer, depending on preference). As an additional safeguard, where multiple members of the same family have taken part in interviews, these interviews were conducted by different members of the team. Particular care has also been taken when citing from these interviews, and we do not directly compare data from members of the same family in this book.