# Further details of methods and sample

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The archived data was 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). It was conducted at the University of Manchester between 2017 and 2021 and led by Dr Petra Nordqvist. The project investigates the experiences of UK donors, and their relatives, focussing on how they experience a cultural and legal context in which openness is widely promoted as ‘best practice’ and donors are usually traceable. It explores the ways in which ‘openness’ is re(produced) and operationalised through laws, policies and interactions in clinics as well as how it is experienced by donors and their relatives. An exploratory qualitative methodology was used with the aim of understanding the practices and processes through which donation is made meaningful in people’s lives. This document details the methods used in relation to interviews with donors, donors’ relatives and clinic staff.

Please note that, due to the limitations of anonymization in relation to unusual cases and non-consent from some participants, some transcripts produced as part of this project have not been archived with the UKDS. In addition, a number of the transcripts and further details of the cases are available only following request, and after review by, the PI. This report provides information about the whole sample with the aim of providing some context to the archived data.

# Recruitment

Given that egg and sperm donors are a ‘hard to reach’ population and our intention to speak to donors who had undertaken donation through various routes, we took a flexible and varied approach to recruitment. We collaborated with staff in three fertility clinics in English cities to advertise the research to some of their current and former donors. We also advertised the project through our existing personal and professional networks, including via participants in previous projects who we knew were in contact with donors and via the Donor Conception Network (a support group for families through donor conception). The Internet also provided opportunities to recruit those who had donated via less ‘official’ routes. In particular, we had some success in recruiting 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 summaries the recruitment routes used and how many donors we were able to recruit through these different routes.

### 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 | |
|  | n | % | n | % | n | % | n | % | n | % | n | % |
| 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 |

Recruiting the relatives of donors proved more challenging and 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). 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), 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 infertility counsellors or donor coordinators. Five donors were also partners of donors, hence the numbers for each group do not total 88.

## Donor Participants

Amongst 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 is 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. 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. All participants lived in the UK and all but two had donated here (the two exceptions had both donated in European countries).

### Table 1.2: Timing of Donors’ First Donation (Year)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Sperm donors\*** | **Egg and embryo donors** | **All donors\*** |
| Year of First Donation | Range | 1981-2018 | 2003-2017 | 1981-2018 |
| Median | 2009 | 2014 | 2012 |

\*Missing Data for 4 donors (all sperm donors)

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 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 find, or are matched to, recipients. Many of the donors we spoke to had experienced more than one of these routes into donation, several men had donated both in and out of clinics and known donors might get to know multiple recipients in different ways. As Table 1.3 demonstrates, there were differences between sperm and egg donors in terms of the different donation pathways they had experienced or pursued.

### Table 1.3: Number and % of donors who have experienced particular donation pathways

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | **n (sperm donors)** | **% 1.d.p.** | **n**  **(egg and embryo donors)** | **% 1.d.p.** | **n**  **(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 |

We should highlight here that these statistics are reported here in order to inform the reader about our sample and therefore the types of donation experiences we can (and cannot) report on. They are not intended as a report on the proportions of different donor ‘types’ in the UK donor population more broadly. Our sample is not statistically representative of the UK donor population (indeed, it would be impossible to say what that would look like because there are no records of the numbers of donations which take place outside of licensed clinics) and the proportions we report here cannot be separated from the recruitment methods we adopted.

We should also note here that we have taken an inclusive approach to categorising the donation pathways donors had experienced. 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. For example, Gavin is recorded as having experienced both a clinic and out-of-clinic pathway because he initially pursued donation via a clinic but was turned down (due to issues with his sperm surviving the freeze-thaw process) but then, at the time of interview, was in the process of donating to a lesbian couple he had met online.

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, in the case of the embryo donor who had donated abroad, had been refused this information. For those with knowledge of the success rates of egg and sperm donation, these may appear surprisingly high percentages of live births. However, it is important to bear in mind that these are birth dates per donor rather than per donation; many donors had donated more than once, sometimes to more than one recipient. The stated focus of our project on the impact of sperm and egg donation and traceability may also have been of greater interest to those with knowledge of at least one birth resulting from their donation, and so such donors might have been more likely to agree to participate in the project.

Amongst 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 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 amongst those who had donated outside clinics, the vast majority of sperm donors reported that they had 30 or fewer donor offspring.

### Table 1.4: Donation Outcomes

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | n (sperm donors) | % 1 d.p. | n (egg/embryo donors) | % 1 d.p. | n (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 |

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. 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.

### 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 |

### Table 1.6: Donors’ Identity and Circumstances

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | n (sperm donors) | %  1 d.p. | n  (egg and embryo donors) | %  1 d.p. | n  (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 |

## Donor Relatives

Table 1.7 provides information about the donor relatives we interviewed. It shows that we were more successful in recruiting the relatives of egg donors compared to sperm donors and donors’ partners compared with their other relatives. This reflects the particular challenges in recruiting sperm donors’ relatives and relatives other than partners. The first challenge was linked to the greater tendency amongst our participants for sperm donors to be single and/or to keep their donations to themselves. The second challenge partly reflects the view we sometimes encountered from donors, or feeling amongst non-partner relatives, that this would not be *their* story to tell.

### Table 1.7: Summary of Donor Relative Participants

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | n | % 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 |

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 1.8: 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 | 0 | 0 | 2 |
| missing data | 0 | 1 | 0 | 1 |
|  |  |  |  |  |  |
| household income | <24k | 1 | 1 | 0 | 2 |
| 24000-49999 | 3 | 1 | 2 | 6 |
| 50000-99999 | 6 | 1 | 1 | 8 |
| 100000+ | 4 | 0 | 0 | 4 |
| missing data | 1 | 2 | 0 | 3 |

## Clinic Staff

Given the small populations involved, in order to maintain confidentiality, we do not report demographic details about the 2 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 an office (usually at the donor’s workplace but on two occasions 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, 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 took place from 2017 to 2019 and those with donor relatives were conducted in 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. This was often considered easier by some participants, who on occasion considered it inappropriate for the researcher to travel long distances to talk to them, and counsellors were often used to working with clients via telephone.

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, what were their reasons for doing so, how did they respond to the possibility of being traced and what kinds of issues or questions did they generally raise.

# Data Analysis

With two exceptions, all interviews were audio recoded, with the consent of the participant, and transcribed verbatim. 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.

# Ethics

This study was approved by a 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). Written informed consent for archiving anonymised data was either given prior to interview or afterwards via email (see supporting documents). 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 should be taken when citing from linked interviews (i.e. those where we have interviewed both a donor and their relative) and data from these linked cases should not be directly compared.

# References

Freeman, T., V. Jadva, E. Tranfield, and S. Golombok. 2016. ‘Online Sperm Donation: A Survey of the Demographic Characteristics, Motivations, Preferences and Experiences of Sperm Donors on a Connection Website’. *Human Reproduction* 31 (9): 2082–89. https://doi.org/10.1093/humrep/dew166.

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