

Response to the HFEA consultation – April 2023

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This submission reports data collected as part of the Young Adults Study, a social scientific investigation into the perspectives and experiences of donor conceived adults, led by researchers at the Thomas Coram Research Unit, UCL. The study is funded by the Economic and Social Research Council [REF: ES/S015426/1].

The submission focusses on findings from in-depth interviews conducted between November 2020-September 2021 with 33 young adults, all of whom were conceived via sperm donation and aged between 18-31 (Mean= 24; S.D.= 4.31). Twenty-five participants (76%) were female and 8 (24%) were male. In terms of family type at birth, 24 participants (73%) were born to mums and dads; 6 (18%) to solo mums; and 3 (9%) to two mums. Further demographic information about the sample is available on request.

Participants were primarily recruited to the study via the Donor Conception Network, who contacted all eligible individuals or their parents. Information about the study was also shared widely on social media, including through the Donor Conceived Register.

The findings of the study largely support the HFEA's proposals relating to access to donor information and also suggest further areas for changes to the law in this area. Below, we address both aspects under the following topics: donor identifiability; DNA testing; and counselling.

Donor identifiability

All participants were asked about their views of the current law with respect to donor information. Most participants were supportive of the current legislation (post-2005), with some variation within the sample, including those in favour of anonymous donation (n= 5, 15%), and those supportive of the retrospective removal of donor anonymity (n= 5, 15%). A minority of participants advocated an end to international and/or private donation involving anonymous donors. A minority of participants advocated the release of identifiable information immediately after the birth of a child; the 'two-track' system that is being proposed was not mentioned.

In terms of their access to donor information, most participants (n= 27, 82%) could request non-identifying donor information from the HFEA; 6 (18%) could not. However, all participants (n= 33, 100%) stated the importance of having access to medical information about the donor, and the majority (n= 25, 76%) expressed an interest in other types of information or contact. Several participants made comparisons between themselves and other donor conceived people (i.e., those conceived prior to 1991; those conceived post-2005) with respect to their rights in law (/lack thereof).

The findings from our study thus suggest that the proposals with respect to donor identifiability do not go far enough. Further proposals for change include:

- The legal requirement that where practicable (i.e., post-1991), donors be proactively contacted to update their medical information, and strongly encouraged to re-register as identifiable (see also Hodson et al., 2023);
- The legal right of donor conceived individuals conceived prior to 2005 to access, free of charge, DNA testing for health.

DNA testing

All participants were asked if they had made use of any DNA testing websites or services (e.g., Ancestry and MyHeritage, 23andMe, King's College via the Donor Conceived Register), and their experiences of doing so. Nineteen participants (58%) had used at least one DNA testing website or service, through which:

- 3 participants (9%) had inadvertently learned about their donor conception;
 - 5 participants (15%) had identified their donor, in some cases with support from additional organisations (e.g., Finding Families, Search Angels). Of these, 4 participants had contacted the donor;
 - 8 participants (24%) had identified a half-sibling (other donor conceived individuals);
 - 4 participants (12%) had not identified a match at the time of interview;
 - 3 participants (9%) were awaiting their results.
- (N.B. One participant had identified both the donor and a half-sibling through DNA testing.)

Participants aware of their donor conception had primarily used DNA testing websites or services to look for half-siblings, the donor, or both.

Reasons for not using DNA testing websites or services among those who had not done so included: no interest; felt that it was unlikely to yield results; preferred to consult the HFEA for information first; felt that it was unlikely to have a positive outcome; prohibited by the cost of services.

Participants who inadvertently learned of their donor conception through DNA testing differed in the extent to which they found the information distressing (from very distressing to not at all distressing).

Feelings of disappointment were expressed by some of the participants who had not identified a match through DNA testing, and by those whose donors did not respond positively to being contacted after having been identified in this way. These findings should be read alongside empirical research from Australia (Newton et al., 2023), which has similarly identified the possibility of no matches from DNA testing, and the bioethical literature on donor expectations (see e.g., Zadeh, 2016).

The findings from our study therefore suggest that the proposals with regards to DNA testing are to be welcomed. However:

- Such a legal requirement must be accompanied by detailed and nuanced guidance that ensures that clinic staff communicate this range of possible outcomes of DNA testing, especially in discussing with recipients the possibility of children identifying donors, e.g., that donor identification and contact *may or may not* result from DNA testing.

Further proposals for change include:

- The legal right of donor conceived individuals conceived prior to 2005 to be considered for means-tested funding for DNA testing for ancestry.

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Counselling

In terms of the age at which participants had been told/found out about their donor conception, 16 (48%) had always known; 3 (9%) had been told before the age of 10; 4 (12%) had been told or found out between the ages of 11-20; and 10 (31%) had been told or found out aged 20+.

Participants were not explicitly asked for their views about disclosure; it is noteworthy that the majority, irrespective of their own circumstances, mentioned the importance of parents sharing information about donor conception with their children from a young age. A minority suggested that information about donor conception should be included on the birth certificate. A minority advocated mandatory disclosure as a legal requirement.

In terms of access to counselling for themselves, participants overall showed limited knowledge of the offering from the HFEA via the Hewitt Fertility Centre counselling team. Some participants who had received counselling from this service stated that they felt they would benefit from ongoing, specialist support, provided by an independent service. Most participants seeking information and support had consulted the Donor Conception Network and/or the Donor Conceived Register via social media.

The findings generally support the proposal to introduce mandatory implications counselling for parents and donors. Further recommendations for change include:

- The legal right of donor conceived individuals of all birth dates to access, free of charge, specialist, independent counselling services, if and for as long as required;
- The legal requirement that centres actively and publicly promote the sharing of information about donor conception with children by parents, irrespective of year of treatment (see also the recommendations of the Nuffield Council on Bioethics, 2013).

Summary of recommendations

In conclusion, the findings largely support the HFEA's current proposals and also suggest further areas for changes to the law, as follows:

- The legal requirement that where practicable (i.e., post-1991), donors be proactively contacted to update their medical information, and strongly encouraged to re-register as identifiable;
- The legal right of donor conceived individuals conceived prior to 2005 to access, free of charge, DNA testing for health;
- The legal right of donor conceived individuals conceived prior to 2005 to be considered for means-tested funding for DNA testing for ancestry;
- The legal right of donor conceived individuals of all birth dates to access, free of charge, specialist, independent counselling services, if and for as long as required;
- The legal requirement that centres actively and publicly promote the sharing of information about donor conception with children by parents, irrespective of their year of treatment



Finally, based on the empirical evidence presented, it must be acknowledged that the assumptions underpinning the HFEA's proposals for change to donor information access (namely regarding parental disclosure of children's donor-conceived status) remain contested. Moreover, the possibility that the current (prospective) proposals will deepen the inequities that exist between different groups of donor conceived people (i.e., based on date of birth and/or parental decision-making), with implications for how individuals feel about their donor conception and/or donor's status, cannot be overlooked.

The findings of the Young Adults Study are currently being written up for publication; further information about any aspect of this submission can be provided on request.

References

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