FINAL VERSION 3RD JAN 2025

Women and Equalities House of Commons Select Committee Inquiry into egg donation and freezing questions:

https://committees.parliament.uk/call-for-evidence/3784/

Following Donor Conceived UK's extensive Consultation in 2023 with our stakeholders and the Donor Conceived community, the existing Donor Conceived Register Registrants Panel (DCR RP) established Donor Conceived UK**.**

Donor Conceived UK is a peer-led charitable organisation that represents donor conceived people, donors and others affected by donor conception practices in the UK.

We work in partnership with donor conceived adults, historical donors, others affected by donor conception, The Human Fertilisation & Embryology Authority (HFEA), Department of Health & Social Care (DHSC), Donor Conception Network (DCN), British Infertility Counselling Association (BICA), SurrogacyUK, British Association of Social Workers (BASW) Project Group on Assisted Reproduction (PROGAR) and The Donor Conceived Register (DCR) currently run by Liverpool Women's Hospital.

Donor Conceived UK does not advocate for or against egg donation or egg freezing. Instead, it centres its work on the ethical and human right considerations of all those affected. This includes, in particular, the lifelong implications for donor conceived people, as well as anyone intergenerationally affected, and the impacts on other parties involved, including donors (and surrogates where applicable).

Reproductive medicine has profound and enduring consequences for those conceived through its practices. Interventions in this field often carry a long and sometimes unpredictable legacy, and history shows that not all effects can be anticipated at the time of conception. By placing careful attention on lifespan implications from the outset, and embedding these considerations at the core of policy and practice, potential risks can at least be reduced.

We are the UK's only national, peer-led organisation by, and for, donor conceived people.

Our founder, trustees, and leadership are all donor conceived themselves. This gives us unmatched authenticity, credibility, and clarity of purpose: to speak with, and for, the Donor Conceived community.

What are the short and long-term health impacts of donating or freezing eggs and embryos and to what extent are they sufficiently researched and understood?

This is outside of Donor Conceived UK's specific area of interest.

Whether the counselling provided ahead of egg donation is adequate to ensure informed consent, including of potential health impacts?

As currently framed, this question appears to focus primarily on medical counselling. Our response instead addresses psychosocial implications counselling, which is where our principal concern lies. We regard such counselling as essential to securing genuinely informed consent.

Donor Conceived UK believe that robust psychosocial counselling for those contemplating egg donation, must be mandatory. It must be an integral part of the donation pathway, with the cost of counselling included. Within this pathway, intending parents should be able to access the number of counselling sessions that they and the counsellor consider appropriate, rather than being limited by a number set by clinic policy. Without these safeguards, consent cannot be considered valid. One session is not deemed sufficient, and it should be made clear where historical donors can turn to in the years and decades that follow donation, to ensure they are appropriately supported by professionals trained in this latter life work.

Egg donation takes many different forms, including so-called ‘altruistic’ donation; donation where financial compensation is a significant motivating factor; donation to a family member or friend already known to the intending; arrangements where the parties meet specifically to enter into an egg donation agreement (which may include co-parenting); donation as part of an egg-sharing arrangement; and donation within a gestational surrogacy arrangement, whether involving a known donor or an identity-release donor.

Given this diversity of arrangements, the provision of psychosocial implications counselling is a skilled and complex task that must be carefully tailored to the specific circumstances of each situation.

We also believe that mandatory *preparation sessions* must form part of the pathway for donors and prospective recipients of donated gametes, including in surrogacy arrangements. Combined with mandatory implications counselling, this more accurately reflects the need for additional scrutiny and thorough preparation for all those involved in bringing into being a donor conceived person (DCP) with lifelong interests, rights, and needs. This approach also recognises the many parallels between this sector and adoption, particularly in relation to the development and understanding of personal identity within complex family relationships.

What level of compensation / payment should be provided to egg donors, if any?

This is a contested area in which the UK has traditionally favoured an altruistic model. However, the line between altruism and other motivations is not always clear, as seen in egg-sharing arrangements, in cases where compensation is a significant incentive, or where donors may feel obliged or pressured to donate.

Donor Conceived UK firmly oppose financial compensation for donors above the fair reimbursement for loss of earnings and medical expenses in line with the Oviedo Convention of 1997.

‘Donor Conceived UK takes the position that decisions about the use of donor conception should not be shaped by a supply-and-demand or market-based approach. Donor conceived people (DCP), in particular, have consistently articulated strong opposition to the commodification of their lives and of the relationships created through donor conception, including concerns about kinship loss and the creation of very large sibling groups in the absence of international family limits.

It is also important to note that international law does not recognise a “right to have a child” for adults, while it does clearly establish legal rights for children.

https://donorconceiveduk.org.uk/legal/geneva-principles/

/gjh5bGytMIKWId4p2 ESHRE Guidance

What evidence is there, if any, of vulnerable women being encouraged into egg donation or egg freezing?

Donor Conceived UK has anecdotal evidence of men and women undergoing fertility treatment being coerced into donating their gametes, feeling a sense of obligation to assist another- The high cost of IVF is often a factor in egg sharing agreements. Women historically being given discounts when they are vulnerable and desperate to be able to afford their own treatment.decisions they may not have made had they not been in such an emotionally charged period of their lives. The UK is relatively unusual in permitting egg sharing, a practice that is prohibited in some other jurisdictions.

The recent UN Special Rapporteur Report on Surrogacy did reflect anecdotal evidence of coercion and similar for some surrogates, especially in commercial international surrogacy, and attracted criticism from parts of the fertility and surrogacy world for doing so.

Is the regulatory regime on advertising as it applies to egg donation and people wishing to freeze their eggs or embryos sufficient?

Our main point regarding ‘advertising’ is that any approach that commodifies humans is unacceptable, including promotions that emphasise compensation rates or the idea of donation as a ‘gift.’ A recent example of this was the London Sperm Bank and influencer The Ribbon Box running a competition to ‘win’ a ‘free’ vial of sperm in April 25.

What has been the impact of changes to the release of donor information, including support for the families involved, and whether further legislation is required?

It is critical that Donor Conceived people (DCP) can access information about their genetic origins and family medical history, and that donors can ensure any new medical information which comes to light later must be passed on to the donor conceived person by fertility clinics.

We also wish to raise the concerning trend of gametes and embryos being imported and exported to and from the UK and ask the Committee to consider this issue from the point of view of the Donor Conceived person (DCP).

The effect of changes to the release of donor information is relatively minor compared to the profound impact of commercial genetic testing services such as AncestryDNA and 23andMe. https://sites.manchester.ac.uk/connecte-d-n-a/about/ These services have effectively ended donor anonymity, regardless of the legislation in place at the time, and have led to a surge of “late discovery” misattributed parentage events (MPEs) among donor conceived adults. At the same time, they have empowered Donor Conceived people (DCP) to take agency and seek answers about their genetic origins. Donor conceived people (DCP) are grateful for these tools having experienced brick walls and unanswered questions from official routes for decades.

For Donor Conceived people (DCP) to be applying to the HFEA for identifying or non-identifying information, they need to first know that they are donor conceived. There are still huge question marks over how many parents are disclosing the truth to their children, as stated in Human Reproduction journal 2016:

‘The majority of heterosexual couples who have conceived through anonymous sperm or oocyte donation decide against disclosure or are uncertain about whether or not to do so, or report intentions to tell which are generally not borne out in practice.’

When you look at the HFEA figures of those who do apply for information from the registers, one must ask the question ‘how many UK citizens are living their lives oblivious that this is their truth?’

Law Reform is therefore key in ensuring the rights of donor conceived people are centred.

‘An over-arching focus on patient protection cannot be achieved while the HFEA uphold the principle that ‘parents should not be legally required to disclose to their children that they are donor conceived.’

(-exert from DCUK response to HFEAs proposals to modernise fertility law)

Donor Conceived UKs full response to the HFEAs proposals can be read here: UK Legislation – Home The experiences of DCP should be of the upmost importance in adequately reforming and ‘future proofing’ fertility law in the UK.

We cannot overstate the importance of both peer and professional support services, not only after conception but also during the pre-treatment or donation stages. Our experience (supported by research, including findings from the related field of adoption) shows that some parents and donors struggle to be open with their children at any age without support. Non-disclosure followed by late or unplanned disclosure carries particular risks.

There is also growing recognition of the complexity involved in managing the lifelong implications of being donor conceived or of being a donor. This includes navigating relationships with multiple “siblings” raised in different families, making ongoing decisions about if, when and how to share information, and dealing with the complications that arise from accidental or late disclosure.

Donor Conceived UK (DCUK) fills a critical gap in the fertility landscape: We exist to ensure that those of us conceived through donation aren’t left to navigate identity, emotional impact or complex family realities alone - often many decades after conception. As more people discover their origins via DNA and seek answers, and the numbers of people using donor gametes to create their family increases, this need is only growing.

The UK government, regulator and fertility industries focus has remained squarely on their duty of care in relation to the period surrounding treatments and donor recruitment and have largely avoided accepting any duty of care for the psycho-social fallout from the lifespan implications of creating life in this way,

Back in January of last year (2024), the HFEA made the decision to remove funding for support services for Donor Conceived people (DCP) and donors within the Opening the Register (OTR) cohort. This decision took effect in September 2024, and affects all those conceived or donating post-August 1991. Donor Conceived UK hope to be part of the solution for future support needs of this community, but we cannot do this alone. We are a tiny volunteer team doing big work and we need allies in government to take a stand and centre the rights and needs of Donor Conceived people (DCP) in future legislation affecting the fertility industry.

There is scope for making the rights of children more prominent in the legislation. The right to identity is not optional in international human rights frameworks for example. We also ask the Committee to consider our following recommendations on the issue of donor conception:

1.Further protections should exist to discourage Britons to return to the UK pregnant with anonymous gametes, undermining UK fertility regulations and placing donor conceived children at a disadvantage.

2.Commercial surrogacy abroad disproportionately exploits low-income women in developing countries, a practice that should not be facilitated by UK regulations or legislation permitting the export of gametes and embryos.

3.Anyone purchasing donor gametes from UK fertility clinics or egg banks, or seeking to import or export gametes and embryos, should undergo criminal record checks. Individuals with a history of violent or sexual offences should be prohibited from accessing, importing, or exporting donor gametes.

4.The anonymous use of donor gametes arranged informally between strangers via social media in the UK must be criminalised, and social media companies held accountable for hosting such content. This practice continues the birth of children from anonymous donors without proper health or STI screening and has, in some cases, resulted in women being subjected to sexual violence by men insisting on penetrative sex to “donate” sperm.

5.The current UK embryo storage limit of 55 years, introduced by the previous government, should be reduced to ten years, with ongoing storage permitted only upon renewal every five years. The 55-year limit is excessive and raises serious psychological concerns for Donor Conceived people (DCP),who may be unable to trace their genetic parents because they are likely to have passed away. This extended storage period primarily benefits fertility clinics financially, rather than prioritising the welfare of the future child. Some clinics have also raised concerns about the adequacy of long-term storage facilities, suggesting the 55-year policy was implemented without sufficient planning or consideration.

6. Being open to dialogue around how the law about birth registration and birth certificates must be changed to ensure that they are complete and accurate, by recording the identity of everyone involved in a birth. Any donor or surrogate as well as the legal parents must be included on birth certificates. This is often viewed as a way to solve the many problems DCP encounter, including finding half-siblings.

7. Addressing the historical legacy of damaging fertility practices including anonymous donation. The fertility industry was built on secrecy and the premise that ‘the world would never know’.

8. Launching regular publicity campaigns to encourage historical donors to lift their anonymity and recipient parents to ‘tell’ if donated gametes or embryos were used to conceive.

9. Currently the Act(s) only allow for the provision of genetic information from the donor to the recipients and only in limited circumstances. This needs addressing. Legislation should allow for information to be passed directly to DCP; for DCP (or their parents when they are minors) to pass on information to the donor and others to whom they are genetically related; and for family members to pass on information when the person concerned has died or lost mental capacity.

10. There is room for legislative improvement in the responsibilities of the HFEA to trace donors when identifying information is released so that up to date information can be provided to the DCP. At present, the HFEA is restricted by having to stick to the letter of the law in this, rather than having enough flexibility to respond to the changing landscape. This also applies to their ability to make changes to the information held on the HFEA Register when inaccuracies are confirmed, as has been the case recently in relation to some historic records Exclusive: Wrong genetic info given to people born by sperm donation – Channel 4 News.

11. We are aware that the HFEA has indicated a desire to lighten its inspection regime. We believe that the inspection framework should be maintained, with a mandated upper limit on the length of time between inspections. A lighter-touch approach risks a deterioration in standards.

It is not reasonable to rely on market forces as a substitute for effective regulation, as the consequences of poor practice may not become apparent for a generation. We therefore tend towards supporting stronger inspection frameworks that are proportionate, particularly when considered from the perspective of the person who may be conceived.

12. There is a strong need for medical information, that comes to light later, to be able to be shared where there are genetic implications for those genetically related through donor conception and for this to be consented for at the time of treatment or donation (for recipients, donors and surrogates). This also needs to allow for family members to provide information to be shared, for example where a donor has died of a genetically transmissable condition. We believe this to be a safeguarding matter.