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

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

The British Association of Social Workers (BASW) Project Group on Assisted Reproduction, PROGAR (Project Group on Assisted Reproduction (PROGAR) - **https://bit.ly/4dBheN9** - has since the 1980s campaigned on matters concerning assisted reproduction, including surrogacy, in the UK and overseas. Over the years, we have worked variously in partnership with donor-conceived adults, Barnardo's, Children's Society, Donor Conception Network, Donor Conceived UK, British Infertility Counselling Association (BICA), British Association for Adoption and Fostering (BAAF), National Association of Guardians ad Litem and Reporting Officers (NAGALRO), Children and Family Court Advisory and Support Service (Cafcass), Children and Families Across Borders (CFAB), Surrogacy UK and UK DonorLink (now known as Donor Conceived Register

PROGAR does not take a stance for or against egg donation and egg freezing. Rather, its focus is on the ethical and human rights of those impacted, in particular the lifespan implications for donor conceived people, their families and networks and those of the other parties affected, including donors (and surrogates where they are involved). The field of reproductive medicine carries major implications for anyone conceived as a result. There is a long 'tail' to interventions and history tells us that not all are foreseen. By building in attention at the outset to lifespan implications at the core, risks are at least minimised.

Social work has a strong professional interest in this sector for a number of reasons, including the fact that some social workers are employed in this work. There are also many parallels between this sector and adoption and alternative care services, not least in relation to understanding of personal identity in complex family relationships. In addition, social work has decades of experience of where there are family problems and breakdowns and social workers are involved in providing mental health services to people who have suffered trauma related to their identity and in supporting children and families when relationships fall apart. The experience of social workers is therefore of crucial importance to decision-making and risk assessment in relation to both policy and practice in this field.

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 PROGAR'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 worded, this question appears to be primarily concerned with medical counselling. Our interest lies in psychosocial implications counselling and we have responded with that focus. We consider such counselling to be hugely important to ensure that informed consent is secured. As such we believe that psychosocial counselling for those contemplating egg donation and those considering egg freezing for social reasons should be mandatory and form part of the 'treatment/donation/cryopreservation' pathway with the counselling cost included (we do not currently have a position in relation to counselling prior to egg freezing for medical reasons other than where this is prior to transitioning which we cover below). Within this pathway, patients should be able to receive the amount of sessions that they and the counsellor deem appropriate rather than an amount predetermined by clinic policy. Consent cannot be deemed valid without these safeguards. It is especially crucial that women considering egg donation (as donors or recipients) are able to understand the lifetime responsibilities that are invoked, and the central importance of the human rights of those who could be conceived or otherwise impacted. These include the right to identifying and non-identifying information about the donor (their genetic mother) and their related rights to the [voluntary] exchange of information with any donor-related siblings. Although some donors will see their donation as a 'gift' to those who are involuntarily childless, they also need to engage with the fact that their donation could result in the creation of human beings who are rights holders (including from childhood) and who may wish to exercise those rights, in particular their right to receive information about the donor, their genetic mother.

Egg donation also comes in many different forms – 'altruistic'; donation where financial compensation is a key driver; donation to a family member or a friend who was previously known to the recipient; donation where the parties have met specifically to enter into such an arrangement (can include co-parenting); donation as part of an egg sharing arrangement; donation for a gestational surrogacy arrangement (either as a 'known' donor or as an identity-release release). Given this range, the provision of psychosocial implications counselling is a skilled task that needs to be tailored to the particular situation.

We also believe that mandatory preparation sessions should be provided as part of the pathway for prospective donors and prospective recipients of donated gametes (including in surrogacy). This together with mandatory implications counselling better reflects the need for additional scrutiny and preparation for all parties involved in bringing into being a person with lifespan interests and needs.

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

This is a contested area in which the UK has always come down in favour of altruism though it is fair to say that the boundary between altruism and other motivations is not always clear cut (for example egg sharing; where donors are attracted by compensation; where donors feel obliged or coerced). Given the arguments against commodifying children, we support the principle of altruism. We also believe this fits with reports by the UN Special Rapporteur on the Sale and Trafficking of Children[1] in which she made clear that pre-birth surrogacy contracts (which increasingly include egg donation) should never be legally enforceable and that 'payment' to a surrogate-born baby should never be conditional on her 'handing over' the baby. While this is not made explicit in relation to the release of donated gametes in any donor conception related reports of which we are aware – although we note there are EU prohibitions on payments and new (2024) ESHRE guidance at

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[1] Children **risk being "commodities" as surrogacy spreads, UN rights expert warns (2018)** https://www.ohchr.org/en/press-releases/2018/03/children-risk-being-commodities-surrogacy-spreads-un-rights-expert-warns **and** her two reports - Report of the Special Rapporteur on the sale of children, child prostitution and child pornography (2018) and Safeguards for the protection of the rights of children born from surrogacy arrangements (2019)

https://share.google/gjh5bGytMIKWId4p2 - we believe that it could be, and that a person's human right to dignity extends to their creation not being subject to monetary exchange.

We are also aware of the ways in which the landscape in DC services has changed rapidly in recent years. In the UK today, the majority of services are privately provided which in turn means that profits are made on the back of women donating their eggs. There are important physical risks in producing eggs for donation and some low income women may be motivated financially regardless of risk by what may appear to others to be fairly low levels of 'compensation'. However, this does not in our view mean that children's rights should be secondary to those of potential egg donors.

PROGAR has always taken the stance that decisions about ARTs should not be based on 'supply and demand', a market-based approach, as is sometimes argued. It is important to note that in international law there is no 'right to have a child' (for adults) but there are clear legal rights for children.

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

There is little research in this aspect of either egg donation or egg freezing. The UK is relatively unusual in allowing egg sharing which in some other jurisdictions is banned for its potential encouragement of low income women to undertake ARTs through this route with the additional emotional risk that it might result in success for the recipient but not them. There are also concerns about some women feeling a sense of obligation to assist another; or about women feeling coerced into doing so. This is an area that highlights the importance of mandatory psychosocial implications counselling and preparation even though that is of course no guarantee of uncovering such situations. Interestingly, a recent UN Special Rapporteur Report on Surrogacy[2] 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 key comment in relation to 'advertising' is that anything that commodifies children is unacceptable, including where it highlights/foregrounds the compensation rates or the 'gift' aspect.

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[2] A/80/158: The different manifestations of violence against women and girls in the context of surrogacy - Report of the Special Rapporteur on violence against women and girls, its causes and consequences (2025) - https://www.ohchr.org/en/documents/thematic-reports/a80158-different-manifestations-violence-against-women-and-girls-context

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?

PROGAR was heavily involved in the campaign to lift donor anonymity. We have also long argued for the importance of peer and professional support services from post conception onwards as well as in the pre-treatment/donation stages. Our experience, supported by research – including from the related field of adoption - is that some parents and donors struggle to be open with their children without support; and that there are particular risks associated with non-disclosure followed by late disclosure, especially if unplanned. There is also growing awareness of the complexity of managing the lifespan implications of being donor conceived, or of being a donor. This includes the fact that there can be multiple 'siblings' who are being/were raised in multiple families[3]; that those impacted are regularly having to make decisions throughout their lifespan about who to tell, when and why; and that accidental and late disclosure brings additional complications.

As access to commercial DNA testing services has exploded, so have instances of donor-conceived people (DCP) becoming aware of their origins through this route; of DCP and donors being able to trace each other without the need to access the HFEA Register; and of donors being 'outed' to their family members.

Alongside these developments, the very limited funding for professional support that the HFEA had made available to those approaching its Register has now been removed, primarily on the grounds that they have insufficient resources to cope with rising demand. This leaves the only option for professional support coming from fee charging services (unless someone is able to access, say, non-specialist GP counsellors or mental health services). This introduces inequity.

The shift to commercial providers of treatment services has made little or no difference to their acceptance of any duty of care for the consequences of ARTs.

There is also the newer phenomenon of the rapid growth in the use of gestational surrogacy arrangements where an egg donor is used. Emerging research suggests that parents may be open about their use of a surrogate but not about the involvement of a donor. So the stage is set for all the risks associated with accidental or late disclosure that have been identified for DCP where surrogacy was not involved.

We also identify the need for the following legislative changes:

- <u>Birth registration</u> – there is currently nothing recorded in the UK birth registration system that enables a DC person or a surrogate-born person to learn of their genetic and/or gestational origins as well as their legal parentage. We have supported the proposals from the UK Birth Registration Campaign Group on this and were pleased when these were largely included in the Law Commissions' 2023 Report on Surrogacy Law Reform.
- We would like there to be <u>mandatory psychosocial implications counselling</u> from a qualified counsellor for anyone contemplating being an egg donor (including within surrogacy arrangements); or social egg freezing; or egg freezing prior to transitioning

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[3] Although the presence of multiple half-siblings is more associated with sperm donation, the growing use of egg banks will lead increasing numbers of women to donate multiple times leading to higher numbers of offspring.

(and see below) or using egg donation (including within surrogacy) as a route to family life. The number of sessions should be determined by the counsellor and patient/client but must fit with mainstream understanding in other fields of the need for informed decision-making to routinely build in time for reflection and follow up.

- We would also like to see mandatory preparation sessions for prospective donors and prospective recipients of donated gametes (including in surrogacy). This together with mandatory implications counselling better reflect the need for additional scrutiny and preparation for all parties involved in bringing into being a person with lifespan interests and needs.
- <u>Access to the HFEA Registers for DCP</u> –
    - we agree with the HFEA that the time has come for the age limits for accessing donor information to be abolished – but with appropriate professional support in place;
    - non-DC offspring of donors, i.e. the genetic half siblings of DCP should be allowed to join the voluntary Donor Sibling Register;
    - there should be retrospective rights to access identifying details of their parent(s)'s donor granted to all DCP conceived with the use of anonymous donations. This means all conceived between August 1991 and April 2005 plus all those conceived with anonymous donations in the post 2005 transition period. There is precedent for this from the State of Victoria in Australia – which also affords some protection to donors who do not wish to have subsequent contact from their DC offspring;
    - professional psychosocial support and intermediary services for those accessing the Register should be reinstated;
    - there is also the need for review of the operation and requirements of both HFEA Registers, given that there is recent evidence of inaccurate information sometimes being released from both Registers[4].
- <u>Collection of donor information</u>, including biographical details, should be <u>mandatory</u>
- <u>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.</u> At present, the HFEA is restricted by having to stick to the letter of the law in this and other areas 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 donors.
- There is scope for making the <u>rights of children</u> more prominent in the legislation. The right to identity is not optional in international human rights frameworks, for example.
- <u>Legal parenthood</u> – even following the court cases around legal parenthood in which the relevant forms had been incorrectly completed by HFEA clinics, there remain some instances of mistakes with regard to form filling. The requirement on clinic staff to complete forms affording legal parenthood needs revisiting – in no other field is such a responsibility placed on health professionals.

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[4] https://donorconceiveduk.org.uk/a-statement-from-dcuk-on-incorrect-donor-information-in-response-to-channel-4s-investigation/

- Inspection regime - we are aware that the HFEA would like to lighten its regime. We believe it should be maintained and with a mandated upper limit to the length of time between inspections. Our experience drawn from both the fertility sector and the children's social care sector is that things can change rapidly for the worse (for example with staffing changes, financial pressures) and without regular inspections and with an over-reliance on self-reporting the HFEA could fail to pick up on actual or pending problems. Inspection is an essential safeguard and in the private and public environments which characterise this sector, a loose touch inspection could result in a fall in standards. It is not reasonable to rely on market factors for regulation because the consequences of poor practice may not be seen for a generation. We therefore veer towards supporting stronger inspection frameworks that are proportionate, in particular from the viewpoint of the person who may be conceived.
- 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.
- Conflict between rights of DCP to identifying information under the HFE Acts and rights of adults under Gender Recognition Act – although no doubt wholly unintentional, If a person donated their gamete(s) for the use of others prior to being awarded a gender recognition certificate, then the DCP would be unable to trace them as their previous birth registration records are sealed. This needs amendment to secure the rights of DCP. And if this fails, then no-one should be allowed to donate their gamete(s) for use by anyone other than themselves prior to entering a transitioning process.
- mitochondrial donation: when agreement for this to go ahead was being sought through Parliament, we argued – and still hold the view – that there are implications for the offspring that were given too little weight in deciding that access to identifying information about the donor was unnecessary because 'too little DNA' was involved. This discounted the potential need for some people conceived through this route to have access to identifying and non-identifying information for non-medical reasons: in other words, for them to have the right to decide what was important to them. We were interested that much of the recent media coverage of children born as a result of mitochondrial donation referred to 'children born with 3 parents' – they failed to point out that they will only have the legal right to learn about two of them!

Whether the existing legislative framework, including the Human Fertilisation and Embryology Act 1990, is effective in safeguarding the best interests of those undergoing treatment for egg donation or egg or embryo freezing?

As we set out at the start of this response, our primary concern is with the lifespan implications for donor-conceived people (DCP) and hence what is in their best interests. As part of that, DCP will not want to learn that their genetic mother has suffered adverse outcomes from their involvement, including from any exploitation of her. This also includes any inadequate processes for her assessment and preparation as part of her decision-making or for her preparation and support during and after the egg retrieval process. PROGAR has long advocated greater attention to preparation and support processes.

PROGAR has also expressed concerns about the inadequacy of the current Welfare of the Child process. Our concerns have focused in particular on the use of a self-declaration checklist which fails to ask for any pending child protection/police investigations against the potential donor or recipient, only those in the past. We also believe that there is a need for attention to legal aspects of the sharing of Welfare of the Child information by, and with, other organisations. For example we are aware that there have been instances of a prospective donor deemed unsuitable for treatment in one clinic on WoC grounds going to another clinic and being accepted without disclosing the relevant information. There are currently prohibitions on the first clinic being able to share their information. These are of course challenging areas to discuss but discussion is needed with the input of children's safeguarding services.

Attempts failed during the process of the HFE 2008 Bill to remove the requirement in the 1990 Act for patients and donors to give their formal consent to the treating clinic to inform other health professionals of their involvement in ARTs. This was despite widespread support, including from PROGAR. This remains a potential barrier to safeguarding.

Finally, we've argued above for the need for later information to be able to be shared where there are genetic implications for those genetically related through DC 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 or become incapacitated as a result of a genetically transmissable condition. We believe this to be a safeguarding matter.