

Donor anonymity and information provision

Introduction

1. The legislative framework underpinning the legal disclosure of gamete and embryo donor information taking place at licensed clinics in the UK was established in 1991 under the Human Fertilisation and Embryology Act 1990 (the Act). The Act requires the HFEA to keep a database (the register) of every IVF treatment carried out, which includes all cycles and use of donated eggs, sperm and embryos since that date. The Act envisaged no contact between the donor and the donor-conceived person. People born as a result of donation could only access non-identifying information about the donor at age 18, via the HFEA, as the sole provider of this information.
2. The rationale for this was established in the Warnock report, where protecting the anonymity of all parties was believed to protect all parties from emotional difficulties and to minimise the risk of legal complications.
3. Following *Rose v Secretary of State for Health and the HFEA* [2002] EWHC 1593, (a test case brought by Joanna Rose, born via donor conception before the Act was passed), the government decided to remove donor anonymity in the UK via the Disclosure of Donor Information Regulations 2004. This was on the basis that donor-conceived people should be able to have information about their genetic origins, should they want it. This came into effect in 2005, for applicants aged over 18 years old. This means that the first applicants will be able to apply to the HFEA for identifiable donor information in 2023.
4. Donors who donated prior to these changes were also able to voluntarily re-register with the HFEA to become identifiable. To date, just over 220 donors who donated anonymously between 1991 and 2005 have re-registered with the HFEA to be identifiable. Donors who did not re-register and who donated prior to 2005, remain anonymous within the provisions of the Act.
5. Statutory access rights were extended in 2008 (when the Act was updated) to allow donor-conceived people aged 16 and above to apply for non-identifying information about their donor. These amendments allowed the HFEA to establish and run the [Donor Sibling Link](#), facilitating donor-conceived adults, born post-1991, to share their contact details with others who share the same donor. The law also requires the HFEA to provide a suitable opportunity for applicants seeking information 'to receive proper counselling about the implications of compliance with the request', in recognition of the potential significant impact of HFEA Register information on the recipient. A very small proportion of applicants take up the offer of counselling provided.
6. Records of donor conception treatments prior to the implementation of the Act in 1991 are not centrally held. Historically, many such records were destroyed by clinics. The UK-based, voluntary [Donor Conceived Register](#) (DCR), currently funded by the HFEA, matches people who donated in a UK clinic or who were conceived following treatment in a UK clinic before August 1991 and donor-conceived people sharing the same donor, using accredited DNA testing. It also provides counselling and peer support. People who were conceived (or who donated) after August 1991 may also find matches on DCR, including if their donor had also donated before the HFEA was set up. Registrants of the DCR also have their own independent [website](#).
7. The evolving rules around the managed release of donor information reflect changes in attitudes within the UK around openness, confidentiality, and the balance between the rights of donors, parents

and of donor-conceived people. The central question this paper raises is whether the emergence of affordable and accessible DNA testing and matching websites, and the near universal use of social media with personal identifiers, means that the current rules are no longer appropriate or effective.

8. The remainder of this paper begins with a short summary of the current situation in Section 1, followed by an identification of the issues where the Act is under tension in Section 2 and some detail about DNA testing and matching websites and their impact in Section 3. Section 4 looks at how the HFEA currently manage the changing landscape around the Act's provisions on donor anonymity via our Code guidance information provisions, and Section 5 looks at published views on whether the status quo in the Act is sustainable in this altered landscape of much wider access to genetic relatedness information. Section 6 considers some possible principles and practices to underpin a new model, and queries whether some aspects of the current model may offer important principles to retain, to some people involved in donor conception as currently provided, and what new challenges to principle might arise from providing identifiable donor conception information at an earlier stage in the child's life.
9. Section 7 offers some initial suggestions of options for change, and Section 8 explores some possible impacts of moving to wholly identifiable donation. The aim of the paper is to provoke debate on the merits of those options.
10. Section 9 summarises issues for LLAG to consider.
11. The Appendix sets out some possible further impacts, broken down by specific groups within the donor conception relationship, if the law changed to provide identifiable donor conception information at an earlier stage in the child's life.

1. The current situation

12. ***For donor-conceived people***

Currently the law allows donors to remain anonymous until any children resulting from their donation are 18, at which point they can request identifying information about their donor from the HFEA. Donor-conceived people are also able to receive the following information:

- anonymous information about the donor and any donor-conceived genetic siblings, from the age of 16;
- identifying information about donor-conceived genetic siblings, with mutual consent, from the age of 18;
- information about the possibility of being related to the person they intend to marry or enter into a civil partnership with, at any age; and
- information about the possibility of being related to the person they intend to enter into an intimate physical relationship with, from the age of 16.

13. ***For patients/parents of donor conceived people***

The law is silent on what information should be disclosed to parents of donor-conceived children, this is up to the HFEA. The Code of Practice advises that once patients give birth to a child they can access:

- all non-identifying information about the donor;

- information about the number, sex and year of birth of their children's genetically related donor-conceived siblings.

However, many clinics enable patients to access a much larger amount of non-identifying information about donors during the process of selecting a donor.

14. *For donors*

Currently the law provides for donors to find out the number, sex and year of birth of any children born.

In view of the statutory right of access of donor-conceived people and donors to information held on our Register with some limitations under the Act; the HFEA provides the Opening the Register (OTR) services based on verified data held on the Register. The HFEA also funds the voluntary Donor Conceived Register (DCR) service for pre-1991 donors who want to provide their identifiers and for donor-conceived people who want to access these, or to seek out other people who were born from the same donor. The HFEA also currently offers and funds some professional counselling support to enquirers around these services, though this is not a statutory requirement.

2. Issues

15. Fundamental questions now arise for the future of the managed system of information release with emotional support as envisaged under the Act. The HFEA remains legally situated by the Act as the access point to donor information, with the Register as central repository of this information. However, in practice, other routes are increasingly available to individuals to gather information about genetic relatedness. This is because of the exponential rise in use of direct-to-consumer DNA testing and matching websites, and the ubiquity of identifiable personal information available on social media. In combination, these can directly, or by inference, identify donors and donor-conceived people to each other - and allow third parties to make these links.
16. Anonymity in relation to donor conception can therefore no longer be assured to donors or to donor-conceived people and to their genetic relatives, regardless of when donations were made, or relevant consents given and whether this information is sought intentionally or is discovered unexpectedly. The future of donor conception information under the Act raises some of the most sensitive, challenging, and complex questions for the HFEA as the regulator.
17. Policymakers only have a limited amount of social research to draw on regarding the various possibilities for future regulation. Ultimately, Parliament will need to try to balance views from the lived experience of donor conceived children and adults, with those of recipients, donors and their families, and the public interest in maintaining the paramount principle of the welfare of children.

3. DNA testing and matching websites

18. Donor-conceived people and their parents are highly likely to be able to access, or to infer, potentially identifying information about donors outside the framework of the Act at any time after the child is born, online via 'matched' results from **DNA testing and matching websites** (often used in combination with identifiable **social media** footprints). A [2018 Authority paper explains](#) how these links can be made. Some donor-conceived people (and/or their parents) proactively search for

information about their donors hoping to make contact and/or to begin to form a relationship with the donor, at any point from the child's birth

19. Multiple commercial direct-to-consumer genetic testing websites with millions of members offer users DNA-based information for family history or ancestral ethnicity purposes, or for generalised health information, including Ancestry.com, 23andMe, MyHeritage and FamilyTree DNA.com. Customers send the company a saliva sample from which their DNA is extracted, receiving their results directly within a secure website or in a written report. Many DNA testing websites also offer optional additional services to help identify genetic relatedness between their users, by 'matching' them with other users in their database. DNA testing and matching websites are increasingly affordable and easy to use. They have seen a huge increase in users in recent years (over 40 million people globally in 2021¹), allowing greater numbers of more accurate 'matches'. This can result in donors, donor-conceived people and their genetic relatives identifying each other, either deliberately by using matching websites for that purpose, or inadvertently (e.g. when using the sites primarily to find out information about health or ancestry and opting in to matching services; or through their close genetic relatives using the sites and opting in to matching services, and information then being revealed to them).
20. Donors, donor-conceived people, or their close genetic relatives who have not consented to be registered, tested, and matched on a DNA testing website can still potentially have their identity inferred through further searching of publicly available identifiable information, provided a confirmed genetic match has been made with a close genetic relative of theirs. Harper et al (2016)², explain how the different types of direct-to-consumer genetic tests can be used to track down genetic relatives, for example: *"In 2005, a 15-year-old boy tracked down his father after taking a Y chromosome test with a commercial ancestry company. His father was not in the database but was identified through a match with another man sharing the same rare surname."*
21. Further information about recipient and donor preferences may also be available from the use of **imported gametes**, which sometimes offer much richer donor information than is available to recipients as typically offered about UK donors via licensed clinics, and where this increased detail available may be preferred by some patients. Furthermore, **introductory services online** such as informal Facebook groups or introduction websites such as Pride Angel, are already putting prospective donors in touch with prospective recipients, making it perhaps already more common at clinics that some 'known' donors may have become only quite recently known to the recipients. These services are likely also facilitating completely informal unregulated 'donation' (that is, outside of the legal definition of donation in the Act), or co-parenting arrangements which take place outside of the ambit of licensed clinics or the HFEA, adding to the changing expectations and landscape of donation within the UK.

4. HFEA activity so far

22. DNA 'matching' services and their impact on donor anonymity was brought to the Authority's attention and first discussed [in 2018](#). Guidance was added to the [Code of Practice](#) in 2019 about the

¹ <https://www.dataminingdna.com/who-has-the-largest-dna-database/>, as referenced by Debbie Kennett <https://www.hfea.gov.uk/about-us/30th-anniversary-expert-series/anonymity-for-donors-until-children-turn-18-can-this-be-maintained/>

² <https://pubmed.ncbi.nlm.nih.gov/27073260/>

information that donors and patients considering donor conception should be given about the impact of these services. Extracts from Guidance note 20 of the Code of Practice are below:

- “Given the growing use of direct to consumer DNA testing and matching websites, it is now also possible that donors and donor-conceived people, and/or their close genetic relatives, may become identifiable to each other outside of the HFEA’s managed system of information provision.”
- “The centre should explain that this could be through intentional searching using direct to consumer DNA testing and matching services possibly in combination with social media sites, or inadvertently, when the donor or donor-conceived person is using these services or sites for another purpose, such as researching their family ancestry, ethnicity, or seeking genetic health information.”
- “People who are not aware that they are donor-conceived may become aware of their donor-conceived status for the first time through their use of direct to consumer DNA testing and matching services. Furthermore, neither the donor nor the donor-conceived person themselves necessarily need to be signed up to such a service for a genetic link, and possibly even their identity, to be inferred. If a donor or donor-conceived person’s close genetic family members have opted into genetic matching services, but not the donor or donor-conceived person themselves, then it is still possible (in combination with information from other sources) that other wider genetic relationships may be inferred, which could include the donor or a donor-conceived person. The centre should make clear that the use of direct to consumer DNA testing and matching services has greatly increased over the last few years, which may increase the likelihood of such matches or inferences being made.”

5. Is the status quo sustainable?

23. As should be clear from the discussion above the Act’s framework of anonymity as default with managed information release via the HFEA risks being overtaken by technological change. It gives assurances to donors, donor conceived people and their parents that their status in relation to donor conception, their identity and other information will stay confidential until the legal framework permits it to be disclosed, while in reality, the independent exchange of relevant information can freely and legally take place outside of the Act’s control.
24. What limited social science research there is supports this conclusion. In an [article by genetic genealogist Debbie Kennett](#), in a 2020 survey from We Are Donor Conceived, 78% of respondents reported that they had successfully identified their donor through direct to consumer DNA testing. *“There are many reports of people testing and being matched immediately with a family of donor siblings. Furthermore, those who have not been told of their donor origins can take a DNA test and accidentally find out they were donor conceived. Neither the donor nor the donor-conceived person necessarily needs to have taken a DNA test. Discoveries can be made inadvertently because of other close relatives testing. For example, a DNA test can reveal that your parent was donor conceived even if the parent was unaware”.*³ Kennett concludes that *“The genie is well and truly out of the bottle.*

³ <https://www.wearedonorconceived.com/2020-survey-top/2020-we-are-donor-conceived-survey/>

Direct-to-consumer testing is here to stay. Now it is time to rewrite the existing legislation to reflect the new reality.”

25. This position is consistent with the conclusions reached in an opinion paper by Joyce Harper et al, published in 2016 *“the spread of genomic testing is likely to make anonymous gamete donation and parental non disclosure highly problematic. The likelihood is that such testing will change the way fertility clinics, as well as the general public, perceive the acceptability of non-disclosure⁴.”*
26. Given this, the central issue is how should the law respond to these societal and scientific developments, so that the welfare of donor-conceived children can continue to be paramount, whilst balancing the rights of donors and interests of patients/parents?

6. Principles and practices for a new model

27. Before considering options for change, it is sensible to reflect on the current principles and practices which underpin the existing scheme and agree which of these should remain. These can be summarised as follows:
- a) The **welfare of the child**. It is important for children to know, at an early age, of their donor-conceived origins. Patients should continue to be encouraged and prepared to be open with their children about how they were conceived.
 - b) There should continue to be **professional emotional support** offered to donor-conceived people and donors. How such support might be funded is a separate question.
 - c) That an **official, central record/repository of information about donor conception** (donor information, donation and treatment cycles, births etc) should still stand, so donor-conceived people (independent of their parents) continue to have an official, non-commercial channel to find out information about their donor-conceived status, their donor and their donor siblings. It cannot be presumed that all parents would pass this information onto their children, or that it would emerge via another route. The same applies for donors, to have an official channel to find out the outcome of their donation.
 - d) That **nobody, including parents, should be legally required to inform donor-conceived children/adults of their donor-conceived status or of their genetic parentage**, since this is not routinely legally mandated for children born in other circumstances (although they may be able to discover some information from their official documentation while aged under 18, e.g. in UK adoption an adoption certificate replaces the original birth certificate).
 - e) That **nobody should be legally sanctioned for seeking or revealing information discovered or inferred via direct to consumer DNA testing and matching services**, nor sanctioned for contacting other people on the basis of this information.
28. We should also consider whether there are there any principles or benefits offered by the current system of donor anonymity until the child is 18. Those involved and wider society may value, and/or benefit from retaining some of these, whilst acknowledging that of itself direct to consumer DNA testing and matching may already have disrupted many norms in this space. For example, that some recipient families and donors may value the requirement for the parents/family to have a family life

⁴ <https://pubmed.ncbi.nlm.nih.gov/27073260/>

throughout childhood without the involvement of the donor. For some families and donors, the expectation of anonymity and no prospect of contact could be pre-requisite to their involvement with donor conception at all.

29. Some donor-conceived people may value the option to seek increasing levels of detail of information on their donor only via the HFEA as they grow older, but not feel any interest in contacting her or him and/or may feel that the anonymised and managed system protects them from being reached out to by their donor. Careful thought will need to be given to establishing any new principles which should be reflected in a potential new model for donor conception, for example around safeguarding issues, or any welfare of the child considerations specific to known donation/coparenting situations.

7. Options for change

30. The following are initial thoughts on possible options for a new model:

- a) **Status quo plus** – although the existing system is clearly under strain, there are still good arguments why some of the concerns that underpin it remain important (see section 7 above). It would be possible to keep the current statutory position where all donors must remain anonymous until resulting child is 18 after which the donor-conceived person may seek their identity from HFEA if they wish to, and amend the Act so that clinics must inform donors and recipients about the risk that any children born from their donation could find out the donor's identity before they are 18, including as part of the consent process. This position would make the existing Code of Practice guidance mandatory. However, there would remain the high likelihood of information coming to light outside of the consented process and the need for provision in the Act for managing that eventuality.
- b) **Early identification by consent** – introduce guidance for clinics and a voluntary system for donors to become identifiable earlier on, perhaps under agreed terms about the level of contact/localised arrangements (either from the outset or at any point before children born from their donation are 18 with the consent of the parents, or consent varied by the child after a certain age). This could allow for bespoke identifiable donation in line with the parents' or the child's readiness and goes a little further towards allowing donor-conceived people to access their genetic parentage information as early as possible. Consideration would need to be given to who would manage this voluntary system and support the participants in it, and how disagreements about actioning next steps in the pathway might be resolved in it. This position relies on all parties sticking to a voluntary agreement around contact and requires long-term good communication. However, this option does not permit a uniform set of options for all donor-conceived people, and the 'choice' for donors may not be realistic because information could still emerge by other routes and supporting voluntary agreements would be very resource intensive.
- c) **Remove Anonymity completely, with increased emotional support for all parties** – Amend the Act so that legally, donors' details must be made identifiable to the recipients from the outset: whether from the time of considering all donors, so donor details are always identifiable, or after selecting a specific donor, or when treatment commences, or upon pregnancy, or birth? What are the benefits or risks of facilitating donors and recipients to be known to one another from the time of considering or selecting a donor, when treatment commences, upon pregnancy, or birth, including for any resulting child and all parties' wider families? Is this likely to prompt greater demand for UK donors in the UK and see patients coming from overseas for treatment in the UK, or will more UK recipients seek potentially very risky informal donation arrangements, or travel to

have overseas treatment to avoid these changes? How should the UK's law and regulation respond to those prospects? Consideration would need to be given to how/if this position interacts with the current provisions for known donation. Also, questions arise as to how/if it would apply retrospectively to trying to provide historical donors' identities, as has been done in Victoria, Australia. What additional support will be needed for all parties over time, including those affected by previous legal models of donation, and how will this be resourced?

- d) **A double track system** – in which donors must choose between the status quo (i.e., donor identifiable information available when the child is 18) and being identifiable from the outset (to be defined in new legislation). Patients could choose between donors who wish to be identifiable and those who do not. This could provide more autonomy to donors and patients in deciding the type of information/contact they want. However, where patients opt for the status quo, donor-conceived people still might wish to find out details about their donor earlier than 18. This option has the advantage of choice for the patients but the disadvantage of not permitting a uniform set of options for all donor-conceived people. And as with options 1 and 2, the 'choice' for donors may not be realistic because a high likelihood remains of information coming to light outside of the consented process, with the need for provision in the Act for managing that eventuality.

8. Issues and impacts to consider: identifiable donation

31. The impact of moving to a system of identifiable donation would require careful consideration. The end of managed information sharing around donor anonymity or donor conception is a significant change for donor-conceived people, for recipients and donors themselves even as these developments have gradually been emerging. There are different and far-reaching implications for people trying to discover information about their donor and their donor's identity via DNA testing and matching websites, as opposed to using the managed OTR or DCR services that HFEA currently provides.
32. In considering this issue further, it may be helpful to learn more of the experiences of the increasing number of families who have used known donors, including donors who have recently become 'known', through introductory services such as Pride Angel, for example how they have navigated the involvement of the donor in the child's life, what the impacts have been on the wider family (e.g., the donor's family members). In time, a review of relevant research and social science projects, such as [the ongoing ConnectedDNA research project](#), exploring how people involved in donor conception use, and are impacted by, the rise in online DNA testing and [the Curious Connections research project](#), the first major study of egg and sperm donors since the move towards identity-release donation in UK clinics; and others, will need to be carried out to ensure any proposed options for change are, as far as possible, evidence-based and take account of the experiences and interests of all parties.
33. Previous changes in the law have come about after hearing the experiences of donor-conceived people. Their voices must remain central to the development of new approaches. As the first cohort of donor-conceived 18-year-olds will be able to access their identifiable donor details in 2023, more research would help to establish their experiences of identifiable donors.

9. Summary

34. The Legislative Reform Advisory Group is asked to consider:

- Whether the status quo (i.e., donor anonymity until the child is 18) is tenable.
- Agree on the principles and practices which should form the basis of any new model: the importance of children knowing of their donor conceived origins, the importance of professional emotional support, having an official record of information about donor conception. Any more to carry forward from the current system, or to newly establish?
- The options for change and to characterise any preferred model
- The issues and impacts to consider if a model of earlier identifiable donation is to be legally adopted.

Appendix

These are some initial impact considerations. We invite the group to expand on these and suggest new considerations to be made:

1. Impact on the donor (of option b, c, d)

- Potential donors may decide against donating if the only option is to be identifiable.
- The type of person donating may change: increased number of donors interested in establishing a relationship with children conceived from their donation, rather than adults.
- Consider impact on their family/personal life: the increased chance of donor conceived children contacting the donor when they are under 18. This will also have implications for the donor's family and how relationships will be managed (e.g., the expectations on the donor's own children and parents – genetic half siblings and genetic grandparents). There may be particular considerations relating to egg share donors e.g., how would they feel about donor conceived children making contact if they do or don't have their own children from the same treatment cycle.
- Consider what extra information identifiable donors could be asked to, or may wish to, provide e.g., photos, videos.
- Consider what information the donor should be entitled to.
- Consider whether donors' (and surrogates') own biological children should be able to access information about their donor-conceived siblings/surrogate born children.
- How would this affect historical donors i.e., those who donated anonymously (prior to 2005) and have not re-registered, those who donated from 2005 to currently? If the terms under which they previously donated change consideration will need to be given to what support is needed.

2. Impact on donor conceived people (of option b, c, d)

- It is likely that a significant number of donor conceived people have not been told of their status. If a model of identifiable donation is established there is a risk that even fewer families will tell children about their donor conceived status for fear of them wanting to contact their donor and establish a relationship. Parents may see this as an unwanted complication or risk to their family life.
- On the other hand, for the families who decide to tell their children of their donor conceived status, there is evidence that knowing early on, with openness to discussion, about your genetic origin is preferable and having as much information as possible before 18 will help with that.
- Welfare of the child/impact on family life for the child will need to be considered: reflect on experiences of known donation/co-parenting with parents who have used e.g., online recipient and donor introductory services or informal social media groups with that aim.

3. Impact on patients/parents of donor conceived people (of option b, c, d)

- Risk that if all UK donors are required to be known this will reduce the number people willing to donate. That may lead to an increased number of imported donations to the UK, perhaps making it more complex for the donor conceived adult to build a relationship in future with the donor if they want that, and perhaps involving donors from countries where there are different family limits to donate to. If patients seek donor treatment abroad this may or may not be on an anonymous donor basis.

4. Impact on patients/parents of donor conceived people (of all options)

- If parents choose to tell their child of their donor conceived status: consideration needs to be given to how they help their child navigate possible unexpected information emerging, making contact/establishing a relationship with their donor whilst they are a child, impact on child's family dynamic etc

5. Impact on clinic staff and operations (of option b, c, d)

- Administrative burden of providing extra information about the donor.
- Administrative burden of possibly managing an increased number of coparenting situations.
- Administrative burden of managing a double track system.
- Consider what level of support and services would need to be provided e.g., increased uptake of counselling, welfare of the child/supportive parenting considerations, potentially helping to put in place arrangements for donors and parents of donor conceived children to make contact.

6. Impact on HFEA (of option b, c, d)

- Consider what level of support and services need to be provided e.g., impact on register requests, Donor Sibling Link.
- Clinics may need more guidance and support e.g., on the rights and responsibilities of all parties involved in donor conception, and supporting the practical arrangements needed.
- A UK donor recruitment campaign may be needed.
- As outlined above an official record/repository of information about donor conception (donor information, donation and treatment cycles, births etc) should still stand, presumably continuing to be the responsibility of the HFEA. Consideration would need to be given to adapting how this service is provided, to take account of any changes to the Act.
- The HFEA will need to consider its position regarding its role in providing emotional support to donors, donor conceived people and their families via professional counselling. This is partly because the HFEA may be increasingly likely not to be the first point of learning of new information about a donor conception. The HFEA may become more of a confirmatory source in future. There is also a discussion to be had about whether the HFEA is the right body to both deliver information from the register and offer informal support from our staff and refer for funded professional counselling support as needed, as it currently does.