

Donor Conceived UK's response to the Human
Fertilisation & Embryology Authority's Recommendations
to Government on Modernising Fertility Law

The DCUK Advocacy Subcommittee
Donor Conceived UK
5 February 2024

Contents

Introduction	3
Proposal 5: <i>The Act should be revised to include an over-arching focus on patient protection</i>	6
The HFEA's Problematic Definition of 'Patient'	6
The Incompatibility of Patient Protection and Insufficient Medical Records	7
Addressing the Entangled Relational Legacy of Donor Conception	8
Proposal 8: <i>The Act should be amended to enable the removal of donor anonymity from the birth of any child born from donation</i>	8
Retrospective reform is the way forward	8
Proposal 9: <i>Clinics should be required by law to inform donors and recipients of the potential for donor identity to be discovered through, for example, DNA testing websites, social media or further means other than the HFEA Register</i>	11
Birth Certificate Reform	11
Proposal 10: <i>The Act should require all donors and recipients to have implications counselling before starting treatment</i>	12
Proposal 12: <i>The Act should be updated to require automatic record-sharing between clinics and the NHS central records systems as the default position. This would support more joined-up and safer patient care at hospitals and within primary care. Patients could be able to opt out of this record sharing</i>	13
Appendix A: DCUK responses to the original HFEA Consultation	16

INTRODUCTION

We would first like to bring to your attention our transition to 'Donor Conceived UK' (DCUK).

When we submitted our prior response to the consultation into modernising fertility law, we were known as the Donor Conceived Register Registrants Panel (DCRRP). Henceforth, we should be referred to as Donor Conceived UK, with the DCRRP as part of the organisation's wider remit ambitions.

In their role as Co-Chairs of the DCRRP Laura Bridgens and Roy Davis launched a consultation early 2023 exploring proposals to establish a new peer-led organisation.

We will continue to represent registrants of the DCR service, funded by the HFEA and run by Liverpool Women's Hospital Trust, but intend to also officially represent users of the Donor Sibling Link (DSL), the HFEA record management services and the 'Open ID at 18' cohort (otherwise referred to as Opening The Register).

This new name will reflect our widening remit ambitions in terms of support, education and advocacy and will also enable clearer signposting opportunities to ensure those who require support can find it easily.

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DCUK'S RESPONSE TO HFEA'S MODERNISING FERTILITY LAW CONSULTATION REPORT

DCUK were very disappointed to read the HFEA's proposals that were released in November 2023, after their public consultation earlier in the year. The proposals do not go far enough and there is a palpable inattention to the voices and experiences of donor-conceived people (DCP).

Such has been the extent of secrecy and lies in the lives of Donor Conceived People in the UK that nobody in authority knew the identity of any UK born adult donor conceived people who could be brought before the Warnock Committee to give evidence of their experiences. The Warnock Report of the Committee of Inquiry into Human Fertilisation and Embryology of 1984 ultimately led to the Human Fertility and Embryology (HF&E) Act of 1990. When modernising fertility law now, we respectfully urge for the overarching focus of the Act to be that of the donor conceived person.

The HFEA have failed, in both their proposals and consultation report, to incorporate the views of the donor-conceived community. The experiences of donor-conceived persons should be of the upmost importance in adequately reforming and 'future-proofing' fertility law in the UK. Not only does this fail to recognise the historic trauma related to the donor-conceived experience, but also goes against articles 3,7 and 8 of the UN Convention on the Rights of the Child. Donor-conceived people constitute an untapped wealth of knowledge, vital to inform the achievement of 'best practices' and adequate implications counselling for recipient parents. DCUK implores the HFEA to utilise this and amplify the voices of those who have experienced the impacts of the fertility industry the most.

This outcome cannot be achieved without the HFEA's acknowledgement of the entangled relational legacy left by the historical practices of the fertility industry with regards to donor conception. The HFEA is presiding over catastrophic ethical and public health failings which must be remedied.

True 'patient protection' and safety cannot be achieved without ensuring the safety of donor-conceived people. The current and proposed regulations are insufficient in obtaining this goal. Donor-conceived persons must be protected by the HFEA from the potential significant mental and physical harms evident from the fertility industry's practices. These mental and physical harms can be mitigated against through robust processes ensuring early disclosure of a child's identity as donor-

conceived and a guarantee of up-to-date, accurate and complete medical records in accordance with this transparency.

Aside from the lack of focus on the donor-conceived experience, the HFEA's proposals are insufficient to truly 'future-proof' the UK's fertility laws. The emergence of direct-to-consumer genetic testing (DTCGT) and the global legal trend towards full genetic transparency will continue to transform the landscape of donor conception and the unrealistic nature of donor anonymity. The HFEA's proposals address changes such as DTCGT, but fail to acknowledge its full implications. Ultimately, this will result in more outdated laws and unnecessary legal complexity.

DCUK advocates for:

1. An over-arching **focus on the experiences of existing donor-conceived people** to inform all future reform.
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2. **Accurate medical records** for donor-conceived people throughout their lives, which includes their genetic origins and any related genetic medical history.

The HFEA can achieve this through:

1. Placing reform with **retrospective effect** on the table for discussion.
2. Being open to dialogue around how the law about birth registration and birth certificates could 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. This is often viewed as a way to solve the many problems DCP encounter, including finding half-siblings.

3. **Robust implications counselling** for all recipient parents and donors, informed by the experiences of existing donor-conceived adults.
4. **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’.
5. Launching regular publicity campaigns to **encourage former donors to lift their anonymity** and recipient parents to ‘tell’ if donated gametes were used to conceive.

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PROPOSAL 5: THE ACT SHOULD BE REVISED TO INCLUDE AN OVER-ARCHING FOCUS ON PATIENT PROTECTION

DCUK advocates for the care and protection of donor-conceived people and believes the Act should be revised with an overarching focus on the best interests of the child. We are guided by the United Nations Convention on the Rights of the Child (the CRC) and the Geneva Principles on Donor Conception and Surrogacy, which were provided to the UN Committee on the Rights of the Child by donor conceived people on the 30th anniversary of the CRC. Fertility treatment’s unique position in modern healthcare and its intergenerational effects, as outlined above, must not be forgotten. Legislation and industry practices should be guided by this moral and legal compass to ensure that the rights of donor-conceived people are observed and respected.

The HFEA’s Problematic Definition of ‘Patient’

In order to achieve this focus, ‘patient’ needs redefining for clarity of intention. In the HFEA’s data collation for this consultation report, donors, surrogates and donor conceived people were all defined as patients. This is a problematic starting point for

Proposal 5, failing to define 'patient protection' sufficiently. Intended parents, donors, surrogates and donor-conceived people are likely to have conflicting interests and should not be agglomerated in this way. Donor-conceived people are not 'patients' but the key stakeholder that the fertility industry should centre its principles around. To define 'patient' in this way artificially simplifies the matter and disregards the conflicts of interest involved.

DCUK is disappointed that the needs and protection of donor-conceived people are not acknowledged more explicitly in the consultation report. The report describes 'a lack of focus on the needs and protection of patients' which is 'out of step with modern healthcare'. While we recognise the importance of 'medical' patient protection, defined via research such as the Cumberlege Report, this does not explicitly recognise the need for a greater focus on donor-conceived persons. Classifying donor-conceived people as 'patients' along with recipient parents and donors contradicts this very idea of 'focus' and fails to recognise their fundamental rights.

The Incompatibility of Patient Protection and Insufficient Medical Records

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.' DCUK are dismayed that the HFEA continue to uphold this principle.

This principle puts donor-conceived people at risk. By withholding vital information about one's genetic origins, knowledge of which is a fundamental human right, the medical records of donor-conceived people are incomplete and incorrect. The seriousness of this issue cannot be ignored.

The HFEA, a body answerable to the Department of Health and Social Care, has made it impossible for donor-conceived people to receive appropriate medical advice. This

is an egregious breach of medical ethics. It has already led to catastrophic health outcomes for donor-conceived people, and will continue to do so. The HFEA must enforce financial penalties to clinics not supplying accurate medical information to donor-conceived individuals.

Addressing the Entangled Relational Legacy of Donor Conception

If the HFEA truly wishes to encourage ‘a positive culture of best practice’, as outlined in its recommendations, it must also acknowledge the relational legacy left by historical practices. As the Progress Educational Trust stated, ‘the special status of medical secrecy that applies to assisted reproduction has long ceased to be justifiable.’

DCUK unequivocally repudiates the idea of ‘patients as consumers’, along with clinics operating in a ‘competitive market’. The best interests of the child cannot be sufficiently focused on while upholding ‘consumer interests’. There is an inherent conflict of interest here with the fertility industry being predominantly privately funded and about profit making as apposed to being principle led.

PROPOSAL 8: THE ACT SHOULD BE AMENDED TO ENABLE THE REMOVAL OF DONOR ANONYMITY FROM THE BIRTH OF ANY CHILD BORN FROM DONATION

Retrospective Reform is the Way Forward:

We at DCUK believe that *any* child born from donation, including those born prior to when the Act is changed, should have access to their donor’s identifying information.

It has been stated, by Peter Thornton and other HFEA colleagues, that retrospective reform is outside this consultation’s remit. We believe this is a grave oversight and a missed opportunity to future-proof the Act. The HFEA’s own reasons for the consultation apply equally to all donor-conceived individuals, regardless of when they were born.

DTCGT was cited by the HFEA as one of the reasons for these proposals: 'anonymity... can no longer be assured to donors or to donor-conceived people and to their genetic relatives, regardless of when donations were made.' The HFEA admitted that this 'undermines the integrity of the current legislative framework.' The impact of DTCGT is often underestimated by the fertility industry: a donor does not have to have taken a DNA test in order for a DCP to find them through family connections. In addition, with very minimal regulation from the test providers, recipient parents are ordering DNA tests for their children prior to them turning 18. Anonymity in any capacity is no longer realistic. This impacts both existing and future donor-conceived individuals equally. In light of this, why is the HFEA negating its duty of care to existing donor-conceived people by not considering retrospective identity release?

The HFEA has also cited a change in professional advice and attitudes as one reason for change:

'When the Act was first introduced there was a **general presumption** that donation should be anonymous. Over time **attitudes** have changed, but **the law does not fully reflect these changes**. The current professional advice is that **children benefit from learning from a young age that they have been conceived using donor gametes**.'

('Modernising the Act Report' section 2, para 1).

The HFEA owes a duty of care to those born via anonymous donation under this 'presumption', which has caused irreversible damage. The best way to mitigate against future damage, following the HFEA's own evidence, is to allow for retrospective donor-identification.

There already exist three groups of donor-conceived individuals with differing legal rights: those born pre-August 1991, those born between August 1991 and August

2005, and those born after April 2005. Should the HFEA's proposals go ahead, a fourth group will be created. This will further complicate the legal landscape and fragment the rights of the donor-conceived community. These issues would be avoided by retrospective legislation.

In disregarding the case for retrospective removal of donor anonymity, the HFEA cites the need to 'respect' donors. This language is offensive and damaging, insinuating that the pursuance of knowing one's own genetic origins is not respectful and portraying donor-conceived individuals as a threat. This plays on the unconscious bias that places the rights of the donor and the parents desire for a child above that of the DCPs right to know their origins and have autonomy over the meaning placed on genetic connections. DCUK asks the HFEA to be more sensitive in their use of language surrounding donor conception.

Again, this prioritises the wishes of donors over the rights of donor-conceived people. The judge presiding over a landmark ruling in Belgium last year, brought by donor-conceived woman Anke Wesenbeek (June 2023), articulated this lack of adequate balance. A paternity test was ordered for the suspected donor, citing the DNA test to be a sufficiently minor breach of the defendant's right to privacy and physical integrity (Article 8 ECHR) when weighed against the claimant's fundamental right to know her genetic origins. The judge also considered elements of international jurisprudence, acknowledging the trend towards greater recognition of the importance of knowing one's genetic history. There was a similar outcome in The Netherlands for the descendants of Dr Jan Karbaat when his late wife refused to comply with the legal case seeking to confirm his paternity via DNA. Retrospective reform is the future.

The Australian state of Victoria has already recognised this, passing 'Narelle's Law' in 2016 which allows all donor-conceived people access to identifying information about their donors. State by State the rest of Australia are introducing Assisted

Reproductive Technology Bills, which would create a national retrospective register allowing all donor-conceived individuals to identify their donor.

The nature of donor conception was earlier outlined as a long-term social intervention with intergenerational effects. A more useful comparison would be adoption than medical treatments. Under the Adoption Act 1976 (section 51(1)), adopted children over the age of 18 years are entitled to disclosure of their birth records. In passing this legislation, the UK government recognised the importance of the right to know one's own genetic origins.

The HFEA's proposals are out of step with the emerging legal prioritisation of donor-conceived peoples' right to know their genetic origins globally. Now is the time for change.

PROPOSAL 9: CLINICS SHOULD BE REQUIRED BY LAW TO INFORM DONORS AND RECIPIENTS OF THE POTENTIAL FOR DONOR IDENTITY TO BE DISCOVERED THROUGH, FOR EXAMPLE, DNA TESTING WEBSITES, SOCIAL MEDIA OR FURTHER MEANS OTHER THAN THE HFEA REGISTER

First, DCUK would like to challenge the specifics of this proposal. Any information given to donors and recipients must be comprehensive and informed by the existing experiences of donor-conceived people. In the absence of these elements, this requirement becomes a futile 'tick-box' exercise and does nothing to improve the practices of the fertility industry. Again, DCUK would like to highlight the frequent underestimation of DTCGT from within the fertility industry.

Birth certificate reform

DCUK believes this question does not go far enough. Transparency surrounding a child's donor-conceived origins should be legally mandated from birth, facilitated by the HFEA through early donor identification and birth certificate reform. Robust

disclosure protocols for donor-conceived people is the key to any hope of adequate reform in this area.

Mandating birth certificate registration of a person's donor-conceived origins would encourage a culture of openness towards donor conception, turning the tide on an industry built on secrecy and social stigma.

The trauma associated with discoveries of donor-conceived status can be enormous and we believe the HFEA is in dereliction of its public duties by leaving historical donor conceived persons to discover that a donor was involved in their conception through sudden and mistaken discoveries or via commercial DNA tests. People are discovering all the time that they are donor-conceived and are in need of support from us. This is DCUK's reason for being and we know all too well the damage that this secrecy can cause. The real scandal is the amount of donor-conceived people who do not yet know.

The power to know one's donor-conceived origins should lie solely with the donor-conceived individual. Recipient parents should not be given the power to conceal such information. By not legally requiring parents to disclose their child's donor conceived origins or enacting birth certificate reform to ensure complete transparency, the HFEA is complicit in keeping these damaging secrets from donor-conceived persons.

PROPOSAL 10: THE ACT SHOULD REQUIRE ALL DONORS AND RECIPIENTS TO HAVE IMPLICATIONS COUNSELLING BEFORE STARTING TREATMENT

DCUK believes this proposal is futile if not implemented sufficiently. As seen from our response to the original consultation in April 2023, there *is* a vital need for patients to have counselling pre- and post- pregnancy to focus on the implications of having a

donor-conceived child. However, the HFEA must elaborate on the specifics of this requirement.

In developing this implications counselling, DCUK advocates for an approach informed by donor-conceived adults, with a focus on their experiences of being donor conceived. Such counselling should consist of a series of sessions and conversations, ensuring that recipient parents truly understand the nature of donor conception as a long-term social intervention.

If such counselling is done right, DCUK hopes for a brighter future in which charity sector intervention is not needed to repair the mistakes of the past.

PROPOSAL 12: THE ACT SHOULD BE UPDATED TO REQUIRE AUTOMATIC RECORD-SHARING BETWEEN CLINICS AND THE NHS CENTRAL RECORDS SYSTEMS AS THE DEFAULT POSITION. THIS WOULD SUPPORT MORE JOINED-UP AND SAFER PATIENT CARE AT HOSPITALS AND WITHIN PRIMARY CARE. PATIENTS WOULD BE ABLE TO OPT OUT OF THIS RECORD-SHARING.

DCUK welcomes the call for full automatic record-sharing between clinics and the NHS central records systems, including the sharing of medical information where there are genetic implications for those created through donor conception. There is also a need to allow for family members and extended family members to provide information to be shared, for example when a donor or close family member of the donor is diagnosed, or has died from, an inherited genetic condition. Serious legal consequences must be applied if these genetic implications are not shared.

Adequate record-sharing between clinics and NHS central records should extend to DCP too. Our own safety cannot be disregarded. As articulated by a consultation response, 'patient safety is endangered by the fact that [patients'] fertility medical records are not able to be accessed by other medical professionals outside of the fertility service.'

Medical knowledge of a person's donor-conceived status is essential to achieve safer 'patient' care for donor-conceived persons when they are in a health/medical setting.

The historical use of the 'clean slate' theory must be replaced with the modern knowledge and understanding we now have in regard to the importance and significance of genetics. This is reflected in current adoption practices and encourages an understanding of healthy identity formation, which the HFEA and fertility industry must also promote.

The HFEA must record share, not only between clinics and the NHS, but also with the DCPs they hold records for. By colluding in the deception of post-1991 DCP as to their true origins, the HFEA is presiding over a gradually unfolding ethical and public catastrophe. It must urgently rectify this before it grows into a significant public scandal. As a community we believe this is the right thing to do, but are also aware the realities of this would have far reaching implications. DCUK does not therefore believe in disclosing to DCP 'en-masse'. As much as many of us we would like for this to happen, we are aware of the significant mental health issues disclosure presents, and the significant lack of trained mental health professionals and trauma counsellors currently available. Telling a lot of people all at once would also put too much pressure on the charity sector, which would not cope.

However, in order to achieve truly safe patient care for donor-conceived individuals, retrospective reform would be the best ethical decision to take and should also see NHS records updated accordingly. This would ensure the highest levels of patient safety across the board.

At this time we would support a public consultation about regulatory reform to consider a wider range of options in relation to the removal of anonymity than has to date been considered in the remit of this consultation.

In addition, full record-sharing of this kind would help to encourage openness about fertility treatment and donor conception. As stated by the Progress Educational Trust in response to this proposal, 'the special status of medical secrecy that applies to assisted conception has long since ceased to be justifiable.' Transparency surrounding fertility treatment is key to addressing the relational legacy of secrecy and shame which has had such damaging impacts on the donor-conceived community.

Appendix A – DCUK responses to the original HFEA Consultation questions (Modernising the regulation of fertility treatment and research involving human embryos) in April 2023

11. If you are responding on behalf of an individual sharing professional views, or an individual sharing professional and personal views, or on behalf of an organisation please complete the following:

Which of the following best describes your organisation? (please select only **ONE** option)

- A professional or clinical group or organisation
- A research group or organisation
- Academic group or organisation
- A group, organisation, or charity representing patients or others

- Other, please specify:**

Laura Bridgens and Roy Davis took over as Co-Chairs of the Donor Conceived Register Registrants Panel in September 2022, and have begun to consider the future direction of the DCP UK community. It is strongly felt that there is significant disconnect around what the DCR is and who we are as a community. As a result, it is believed there is a need to establish an official organisation, with a proper DCP-led legal structure which aims to support, educate and advocate for DCP, and those affected by DC practices here in the UK.

A consultation was launched in January 2023 <https://www.donorconceivedregister.co.uk/consultation2023> and a collaborative participatory study has since been conducted. A report of trends, findings and recommendations is due to be published in May 2023.

Whatever the outcome of the regulatory changes proposed in this HFEA consultation, an open dialogue and fertility industry support and acknowledgement for the project being undertaken would be welcomed.

Patient safety and promoting good practice

Proposal 1: The HFEA should have greater freedom to decide the regularity and form of inspections.

12. To what extent do you agree or disagree that the HFEA should have greater freedom to vary its inspection regime? (please select only **ONE** option)

Strongly agree

Question 12:

Inspections into implications counselling need to be strengthened to hold clinics to a higher standard of counselling. Counselling should be robust and independently delivered to avoid conflicts of interest. Clinics should not oversee/control this counselling as they are not impartial (i.e. their agenda is to encourage donations and for RP to pay for their services).

Implications counselling should consist of multiple sessions and conversations, with strong focus on the welfare of the DCP.

Inspections also need to ascertain if clinics are helping to facilitate anonymous donations abroad, and penalties (financial/license loss) should be applied if they are. Any anonymous donations abroad need to be recorded. The law should be changed so that clinics can share donor information before the DCP turns 18, when RPs and Donors are mutually willing to share this information.

Proposal 2: There should be the possibility of appointing Deputy PRs and PRs with a broader range of qualifications or experience.

13. To what extent do you agree or disagree that there should be more flexibility in the appointment of clinic leaders, for example introducing the option of a deputy PR, and broadening the criteria for the qualifications and experience required to be a PR? (please select only **ONE** option)

Prefer not to answer

Question 13:

We need clarity into what the responsibilities of a deputy Person Responsible are. Would a widening of the recruitment pool lead to a watering down of responsibility to the patient or other stakeholders?

Proposal 3: The HFEA should have a broader and more proportionate range of regulatory enforcement powers.

14. To what extent do you agree or disagree that the HFEA should have a broader, more effective range of powers to tackle non-compliance? (please select only **ONE** option)

Agree

Question 14:

Non-compliance of standards must be tackled. There is a need for good, solid regulation that protects the person who may be conceived, as well as those undergoing treatment or donating gametes. For example, poor or non-compliance incompletion of donor health information.

Proposal 4: The HFEA should have the power to impose financial penalties.

15. To what extent do you agree or disagree that the HFEA should have a broader range of powers to impose financial penalties across the sector? (please select only **ONE** option)

Strongly agree

Question 15:

See the answer to question 14. Financial penalties should be applied when clinics make decisions that assist their need for 'supply and demand' without consideration for the resulting DCP.

Proposal 5: The Act should be revised to include an over-arching focus on patient protection.

16. To what extent do you agree or disagree that there should be an explicit duty on the HFEA and clinics to act to promote patient care and protection? (please select only **ONE** option)

Strongly agree

Question 16:

Donor Conceived People should be included in the promotion of patient care and protection. The term 'patient' removes focus from the rights of DCP, who may later approach the clinic for help. Clinics lose sight of the long-term implications for DCP and we must be considered underneath the umbrella of care and protection. The trauma associated with discoveries of donor-conceived status can be enormous and we believe the HFEA is in dereliction of its public duties by leaving historical DCPs to discover that a donor was involved in their conception through sudden and mistaken

discoveries or via commercial DNA tests. The HFEA must take steps to sensitively inform and protect DCP. The Fertility Industry itself should be providing a budget to remunerate the trauma caused to DCP.

We strongly need implication counselling and counselling pre and post-pregnancy for Patients with focus on the implications of having donor conceived children. We should follow the lead of adoption pathways' compulsory education.

To end the ethical and public health catastrophe that the HFEA is currently presiding over the following must happen. 1. The HFEA must urgently trace all DCPs over the age of 18 for whom it holds records of and must sensitively inform them of their genetic origins 2. Birth certificates must be reformed to accurately record the circumstances of conception for DCPs.

Furthermore, in compliance with the state's human rights obligations to facilitate family life, the HFEA must also begin a publicity campaign to encourage former donors to lift their anonymity.

Proposal 6: The Act should be revised to accommodate developments in the way fertility services are provided.

17. To what extent do you agree or disagree that the HFEA should have a broader range of powers to tackle related fertility services not taking place in licensed clinics? (please select only **ONE** option)

Disagree

Question 17:

HFEA should not have a broader range of powers but should strongly encourage education around the ethical and moral implications of using anonymous gametes.

Proposal 7: The appeals process in the Act (and associated Regulations) should be amended to allow for challenges to licensing decisions to be resolved in a more efficient and proportionate way.

18. To what extent do you agree or disagree that the current appeals process should be changed? (please select only **ONE** option)

Prefer not to answer

19. To what extent do you agree or disagree that there should be more flexibility for the HFEA to make rules governing the setting of standard license conditions? (please select only **ONE** option)

Unsure

Question 19:

The long-term implications of people conceived through donor conception must inform the setting of standard license conditions. The best interest of the child should be paramount.

20. If you would like to comment further on issues related to patient protection and how the HFEA regulates, please tell us more.

Access to donor information

21. To what extent do you agree or disagree that clinics should be required by law to inform donors and recipients of potential donor identification through DNA testing websites? (please select only **ONE** option)

Strongly agree

Question 21:

This question doesn't go far enough. The Donor Conceived community pushes for transparency from day one. RPs must be encouraged to inform DCP of their origins from birth. Meantime, HFEA must facilitate early donor identification when desired by the Donor Conceived Person. In the era of commercial DNA testing, the false promise of anonymity is farcical. In line with this, birth certificate reform must be supported by the HFEA. We require full transparency, across the board, from day one.

By withholding vital information re genetic origins the medical records of donor conceived people are incomplete and incorrect. The HFEA (a body responsible to the Department of Health and Social Care) has made it impossible for DCPs to receive (and for their doctors to give) apt and appropriate medical advice. This is an egregious breach of medical ethics. It has already led to catastrophic health outcomes for DCPs, and will continue to do so. The HFEA must enforce financial penalties to clinics not supplying accurate medical information to DCP.

22. To what extent do you agree or disagree that the Act should be amended to provide parental and donor choice to opt for anonymity until age 18 or identifiable information after the birth of a child? (please select only **ONE** option)

Strongly disagree

Question 22:

This is not an and/ OR question. Donor conceived people must be allowed to access their correct genetic information from birth. The Act should not be amended to provide parents or donors to opt for anonymity until the DCP's age of 18. The age of

18 is arbitrary -- the fact that people below this age may serve in the UK military but may not have access to their genetic records is insulting.

Giving donors the option to choose to opt-in or opt-out is prioritising their needs and wishes over the rights of the DCP, and will create two tiers of donor conceived people -- those who have information and those who must wait until adulthood. We strongly oppose this. Parental and donor preferences must not override/limit the rights of the donor conceived person. Again, we strongly encourage nothing but transparency from birth.

However, we welcome the acknowledgment from the HFEA that the current laws are no longer fit for purpose. However, the HFEA also has a duty of care to look at what can still be improved for DCPs living now (i.e. retrospective removal of anonymity).

The HFEA seems determined to ignore the rights of the humans created by this practice. Patient focus ignores our rights and our perspectives. The donor conceived person has a fundamental human right to know who they are and where they came from. What is in the best interest of the child, as stated in international law, must be paramount.

23. To what extent do you agree or disagree that the Act should require all donors and recipients to have implications counselling before starting treatment? (please select only **ONE** option)

Strongly agree

Question 23:

Counselling must be mandatory for both Donors and Recipients. Counselling must be robust and must focus on the welfare of the Donor Conceived Person being created. There is a conflict of interest if the counselling is conducted by the clinic.

The Act must allow access to the Donor Sibling Link (DSL) for non-DC offspring of Donors, who are also impacted by the implications of donation. The Act must allow DCP who are under the age of 18 to have access to the DSL enabling them to connect with their UK donor siblings before reaching adulthood.

The Act must allow retrospective right of Donor Conceived Adults conceived between 1991-2005 to be able to access identifying information about their genetic parent, in line with 'Narelle's Law' in Australia.

The HFEA must be supportive of Birth Certificate reform to allow Donor Conceived people to be able to access information about their genetic origins and parentage. For RPs and donors, social and psycho-social risks and potential harms for the future need to be appropriately communicated.

24. If you would like to comment further on issues related to access to donor information, please tell us more.

Consent

25. To what extent do you agree or disagree that the current consent regime could be simplified (for example to an 'opt out' model) in ways that continue to provide protection to patients? (please select only **ONE** option)

Unsure

Question 25:

Any decisions must be made based on the best outcome for the Donor Conceived Person. Donor conception is not a treatment, in the same way that adoption is not a

treatment. Instead it is a long-term social intervention. Success should not be measured by the take-home baby rate... but the intergenerational affect.

The fertility industry must be run on principles and not 'supply and demand'.

26. To what extent do you agree or disagree that the sharing of fertility patient data in a non-fertility medical setting should be brought in line with the current regulations for the sharing of other patient/medical data between healthcare providers? (please select only **ONE** option)

Strongly agree

Question 26:

There is a legal obligation for medical information to be shared where there are genetic implications for those created through donor insemination. There is a need to also allow for family members and extended family members to provide information to be shared, for example when a Donor or close Donor family member is diagnosed, or has died from, an inherited genetic condition. Serious legal consequences must be applied if these genetic implications are not shared.

The historical use of the 'clean slate' theory must be replaced with the modern knowledge and understanding we now have in regard to the importance and significance of genetics. This is reflected in current adoption practices and encourages an understanding of healthy identity formation, which the HFEA and fertility industry **MUST** also promote.

By colluding in the deception of post-1991 DCP as to their true origins, the HFEA is presiding over a gradually unfolding ethical and public catastrophe. It must urgently rectify this before it grows into a significant public scandal. The HFEA must record

share, not only between clinics and the NHS, but also with the DCPs they hold records for.

27. To what extent do you agree or disagree that consent for donating embryos should be extended to allow patients who wish to, to give consent to research embryo banking? (please select only **ONE** option)

Prefer not to answer

28. If you would like to comment further on issues related to consent, please tell us more.

Scientific developments

29. To what extent do you agree or disagree that the Act should explicitly give the HFEA greater discretion to support innovation in treatment? (please select only **ONE** option)

Prefer not to answer

Question 29:

The best interest of the child must be paramount. Unless research is primarily driven and informed by the “best interest” of the donor conceived person, we oppose research that is likely to result in dubious consequences for future generations.

30. To what extent do you agree or disagree that changes should be made to the Act to allow Regulations to be made (by secondary legislation or statutory instruments) to enable future amendments and extensions? (please select only **ONE** option)

Strongly agree

Question 30:

The statutory framework that governs the work of the HFEA is too rigid and unresponsive to meet the needs of DCP's. The DC community would welcome more discretion being given to the Secretary of State to update the framework by secondary legislation or statutory instruments in the interests of DCPs.

Regulations and Statutory Instruments need to have a lifespan that is long-sighted, in keeping with the intergenerational impact of donor conception. At every point in the process, the best interests of the donor conceived person MUST be paramount. Most regulations and laws abruptly stop at the moment of conception, whereas that is where our lives begin. "Nothing about us, without us."

A lot of literature and commentators fail to see the distinct, systematic and often purposeful failures of the fertility industry as opposed to the mere inevitabilities of family situations such as adoption or parental estrangement. Awareness of this is required to avoid future harm to DCP.

The fact that we as DCP were not directly included in drafting the consultation nor directly asked to respond to it makes me wonder whether the HFEA want to recognise us as stakeholders who need appropriate representation. I wonder if the HFEA is fit for purpose to adequately represent Donor Conceived People...The way the questions have been framed in this consultation survey completely exclude DCP concerns. An agency or body MUST be launched that prioritises our needs. Additionally, DCP MUST be properly represented on the boards of and as trustees of the HFEA and fertility industry clinics.

31. If you would like to comment further on issues related to scientific developments and how the HFEA regulates these, please tell us more.