

# Legislative Reform Advisory Group (LRAG) Meeting notes

27 May 2022

Teleconference (Teams meeting)

Advisory Group	Present	Adam Balen, Nina Barnsley, Gwenda Burns, Emily Jackson, Jackson Kirkson-Brown, Robin Lovell-Badge, Raj Mathur, Angela Pericleous-Smith, Francesca Steyn.  Peter Thompson (HFEA Chief Executive) Julia Chain (HFEA Chair, and Chair of LRAG meeting)
	Apologies	David Archard, Tim Child, Eddie Morris (Adam Balen attending instead).
Members of the executive	Present	Clare Ettinghausen (Director of Strategy and Corporate Affairs) Laura Riley (Head of Policy- Scientific) Ana Hallgarten (Public Policy Manager)

## 1. Welcome

- 1.1.** The Chair welcomed members to the third meeting of the Legislative Reform Advisory Group and thanked them for their involvement. The Chair briefly restated the context to this important work.

## 2. Donor anonymity and information provision discussion

- 2.1.** The HFEA Chief Executive outlined the issues in [the discussion paper](#). LRAG agreed that this is perhaps one of the most sensitive and potentially contested areas that they expected to discuss as a group, given that impacts of any change on individuals will range widely.
- 2.2.** The Chief Executive gave a general overview of the issues, including some of principles around how the HFEA currently works. He asked the group to consider how the Act might require clinics and the HFEA to operate in future around donor anonymity and managed information release, in the interests of donor-conceived people and their families, and donors, bearing in mind that donor anonymity can no longer be guaranteed, due to the huge uptake of direct-to-consumer DNA testing and matching services.

- 2.3.** Discussion began with a general exploration of the issues raised in the discussion paper. LLAG members had a range of responses and reflected that both patients and donors would be likely to have equally mixed views, depending on family circumstances, with no 'one size fits all' solutions. They suggested a new principle in the Act, that it should support parents to make the decisions that suits their child and family best.
- 2.4.** Other groups also use donor services: under the current Act, donors' own children can't apply to find formal information about their donor-conceived siblings, this information is not held on the HFEA register. All agreed that further consideration should be given to providing some information rights to donor's children in the Act.
- 2.5.** All agreed that the Act should continue to require clinic collection, and HFEA safekeeping, of all the data about children born from a donor, for the adult child/ren to request if wished. The Act should continue to make sure that consent is properly taken and in line with existing HFEA Code of Practice guidance, donors and recipients are properly informed about the changes to anonymity due to DNA testing and matching services. Parents should continue to decide when or if to tell their child aged under 18, about her or his donor-conceived status.
- 2.6.** Some LLAG members felt that the HFEA's legal relationship should focus only on the clinic and donor. Officially available, identifiable donor information relating to children *under* 18 years old shouldn't be dictated by the Act, but parents should decide when and if they approach a donor for childhood contact, and when or if to find out about or approach their child's siblings born from the same donor.
- 2.7.** Members felt that one of the merits of the [current age limits](#) of 16 years (for non-identifying donor information) and 18 years (for identifying information, only for donor conceived people born after 2005) is that it provided time for young people to reflect before contacting their donor. Some felt that some donors would not want to donate at all if they had to be potentially identifiable to a donor-conceived child in their childhood years- although all acknowledged the possibility of donors becoming identified informally via DNA testing and matching services at any time. Some felt it removed choices from both donor and parent for the law to make identifying donor information available in childhood.
- 2.8.** There were some concerns that a change in law could mean that parents (or their children) will feel they *should* make childhood contact with their donor, even though this might not be a good result for all families. Some LLAG members felt that funded emotional support would be needed for families considering making childhood contact with a donor, including peer support from other families via donor conception.
- 2.9.** Other members commented that the HFEA's role should be to provide the donor information, not a support service for those accessing information.
- 2.10.** LLAG members commented that if identifiable donor information became available at birth, some patients might want that information *before* conception, meaning that donation at clinics would have to work very differently.
- 2.11.** Turning to the core principles set out in section 4 of the discussion paper, LLAG members recommended that a further principle ought to be added, that any proposal did not impact on the availability of fertility treatment. If this were not addressed, then there was a concern that patients might then seek treatment overseas in less closely-regulated countries.
- 2.12.** Some felt that a change in the Act towards identifiable information-sharing during childhood could encourage a cohort of new donors, who had carefully considered the implications of their donation for the

donor conceived child. However, all noted that it was important that any change in policy did not impact negatively on some ethnic minority recipients and donors, given that some donor numbers relative to demand are already very low.

- 2.13.** Some LRAG members reported that fertility clinics serving specific faith communities can find that some patients from those groups find the concept of the HFEA holding a donor record to be a deterrent, and prefer to seek treatment abroad.
- 2.14.** LRAG members pointed out that people with white Northern European or North American ancestry are relatively overrepresented in the DNA testing and matching databases and are thus more likely to receive results of greater specificity, as well as perhaps being culturally more likely to use these services. People from other global majority ethnic backgrounds, or Eastern European or Southern European ethnic backgrounds are less well represented.
- 2.15.** Some LRAG members felt that given these aren't universally-used services in the UK, if there was no reason aside from the rise in DTC DNA testing to consider changing the Act, that it may be more appropriate to ask Government to look again at the regulation of Direct-to-consumer DNA testing and matching. Other members thought that because the option to allow donor information in childhood achieved by these services could be very valued by some patients and children, this justified their consideration around the Act.
- 2.16.** LRAG members wondered if in future, the Act could need to provide for recipients to choose a donor using information on the donors' genetics, by selecting a close match (or seeking a specific difference) to their own genetic information. They felt the Act may need to respond to growing demand for donors to have enhanced carrier screening. As polygenic risk scoring becomes more understood and reliable over the next decade, this could also radically change how recipients want to choose donors.

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### 3. Options discussion

- 3.1.** The Chief Executive of the HFEA outlined some initial thoughts on possible options for a new model (further detail in [the discussion paper](#)):
- 3.2.** **A) Status quo plus** –*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.*
- 3.3.** **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).*
- 3.4.** **C) Remove Anonymity completely**, *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*

**3.5. 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.

**3.6.** Continuing, the HFEA Chief Executive noted that options A and B rely on people not varying their consent, but it may be that some people will want to change their minds. Option C runs the risk of deterring people who would otherwise want to donate and could reduce access to treatment. Option D seeks to give donor and patient a choice on identifiable donor details by offering a double track system.

**3.7.** The Chief Executive invited comment on the four initial options. LLAG members said that:

<p><b>Option A: Status quo plus</b></p> <ul style="list-style-type: none"> <li>• Seeks to protect donor anonymity until the donor-conceived child is 18 years old, but there is always a risk of information being revealed informally, whether the donor-conceived person is younger or older than 18 years.</li> <li>• Someone must make a decision on the child’s behalf, which is best done by their parents.</li> </ul>	<p><b>Option B: Early identification by consent</b></p> <ul style="list-style-type: none"> <li>• Added more consent options on top of already complex consent requirements, which could be burdensome for some patients and clinics.</li> <li>• Would be resource intensive.</li> <li>• Donor-conceived people may find it difficult that their parents actively made a concealing choice - whereas where parents have no choice there can’t be blame. Counselling will be key.</li> </ul>
<p><b>Option C: Remove Anonymity completely</b></p> <ul style="list-style-type: none"> <li>• In New Zealand, donors are identifiable from birth.</li> <li>• Some people are already going online to find their donor in childhood- Why are 16 and 18 the right ages to reveal information.</li> <li>• Adoption in the UK has removed anonymity completely. Children know from an early age that they are adopted.</li> <li>• Not everyone will want to know about their biological or genetic origins, even when identifiable information is available.</li> <li>• Resource heavy, unsure how we would make it work in day to day terms.</li> </ul>	<p><b>Option D: A double track system</b></p> <ul style="list-style-type: none"> <li>• Seems to balance protections for those who need them, with offering more choices for those who want them.</li> <li>• The law should not push people toward less safe options. This option still contains the current strong advice that anonymity in childhood can’t be guaranteed, but it could allow as many people as possible to have regulated UK clinic treatment rather than going overseas for donor treatment or going online informally in the UK.</li> <li>• Parents should make all the choices and decisions for children, and they have to stand by them- nobody else can make those choices.</li> <li>• Sometimes parents change their mind about donor anonymity after the child is born, which</li> </ul>

	<p>may happen with this model that relies on consent at the outset</p> <ul style="list-style-type: none"><li>• It doesn't give all donor-conceived children equal rights.</li><li>• This option would need careful discussion with patients before treatment, when they may be having to take in a lot of other information already.</li></ul>
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## 4. Options decision

- 4.1.** The LRAG members did not support options B or C. There was support for continuity (option A) but on balance, members agreed that a consensus could be recorded that option D was their preferred option overall.

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## 5. Any other business

- 5.1.** None raised.
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