**CONTACTING GAMETE DONORS TO FACILITATE DIAGNOSTIC GENETIC TESTING FOR THE DONOR-CONCEIVED CHILD – WHAT ARE THE RIGHTS AND OBLIGATIONS OF GAMETE DONORS IN THESE CASES? A RESPONSE TO HORTON et al.**

**ABSTRACT**

In their paper Horton et al 1 argue that it is acceptable to contact an anonymous egg-donor to facilitate diagnostic genetic testing for the donor conceived child, despite the donor, ‘indicating on a historical consent form that she did not wish to take part in future research, and that she did not wish to be informed if she was found to be a carrier of a ‘harmful inherited condition’.’ 1 There are a number of claims embedded in Horton et al’s position that it is acceptable to contact the donor and request that she at least think about participating in genetic testing. In this response. I will go through their main claims and argue that the area of genomic medicine does not justify exceptions to general consent conditions as the authors suppose and conclude that the donor should not be contacted. I will then go on to suggest a policy change that would address Horton et al’s concerns but would not involve overriding any previously expressed wishes.

**THE CASE**

Horton et al use the example of a child born from egg donation in the UK, and presumably their arguments would apply to children born from sperm donation, who presents with a health problem that might be caused by a rare genetic condition. In order to get a possible diagnosis the child could be entered into a hybrid clinical-research project, such as the 100,000 Genomes Project, and have trio genome testing, where the genome sequence of the child is compared with their biological parents. In order to do this, the egg donor needs to supply a sample. However, the donor had not consented to any future contact and therefore the clinic, where treatment had taken place, refused to contact the donor. The regulations concerning contacting donors are clear. The HFEA Code of Practice states: ‘At registration, donors should indicate whether or not they wish to be notified if the centre learns (e.g, through the birth of an affected child) that they have a previously unsuspected genetic disease or they are a carrier of a harmful inherited condition….Their wishes should be recorded in the donors’ medical records.’ 2

**WHY IS IT JUSTIFIABLE TO OVERRIDE THE DONOR’S WISHES NOT TO BE CONTACTED?**

Horton et al advance a number of arguments to justify contacting the donor against her previously stated wishes not to be contacted. First, arguments about consent: what determines valid consent, in terms of information provision, debates over exactly what she consented to, i.e. did she refuse consent to research or to tests that might have a therapeutic benefit, and specifically, did she refuse consent to what is being asked of her now? And a temporal aspect, are decisions taken at one time point binding at future time points? Second, arguments around how the interests of the donor-conceived child interact with those of the donor, how should the donor-conceived child’s interest in their own health information be weighed up against the donor’s interest in, or right to, privacy?

**Consent**

Horton et al’s central argument to justify overriding consent is that: her consent has become out dated; there have been significant material changes in the circumstances under which the donor gave consent. Genomic medicine is a rapidly changing area and trio-testing is now available and could increase the likelihood of a diagnosis for the child’s health condition. Consequently, the state-of-the-art in genomic medicine, when the egg donor made her decision about any future contact was very different and, therefore, her consent can be called into question. As Horton et al put it, ‘we cannot conjecture what her current answer maybe.’ Therefore, contacting her is not going against her wishes, as we do not know what her current wishes are.

The authors argue that the usual narrow model of consent is unsuitable for consenting to rapidly changing technologies such as genomic medicine. It is impossible to present all the possible options or outcomes and therefore, ‘in situations where by virtue of a near infinite number of possible outcomes or because of unpredictable evolution in technology, consent in such cases is better seen as an ongoing and dynamic process.’1 rather than a one off definitive event. There are two elements to this argument, first: the information in genomic medicine is very complex, and second, genomics will evolve so, ‘no-one can truly understand, retain or weigh all the relevant information in the depth we might consider historically necessary for valid consent.’ 1 To take the first element, that genomic information is inherently complex, I find this argument unpersuasive. Many choices that people are required to make concerning medical treatment involve complex medical information, present uncertainties and could have unforeseen consequences. Even the cases that the authors use of straightforward medical decisions, taking statins or having a knee replacement can be complicated, with unforeseen consequences and uncertainties. For instance, what are the long-term side effects of statin use? How do they interact with other medication? And choosing to manage high cholesterol through statins could act as a disincentive to engage in behavioural changes, such as increasing exercise and improving diet, that might result in other forms of harm. Therefore, I would argue that choices in genomic medicine do not always warrant distinctive consent procedures and maybe we need to rethink the forms of genetic exceptionalism that this argument presupposes.3

However, it is undeniable that genomic medicine is a fast changing area and this second element raises more concerns. Genomic medicine has evolved so that trio testing to help diagnose any child born from the donation is now possible, this was not an option at the time the donor chose not to be contacted. For the case at hand, the important element is making decisions that determine choices in the longer-term. So as Horton et al rightly point out, deciding to have a particularly surgery is a time-locked, binary choice (although in reality this is probably simplifying this kind of choice). Whereas the egg donor’s choice not to be contacted is one that is likely to extend far into the future. These are concerns that the donor’s choice might not represent her views now, that she might change her mind in the light of the new developments in genomic medicine, if given the opportunity.

These are important points to consider, however, we allow people to make future binding choices, 4 such a marriage, in spite of the inevitable changes in circumstances there will be in the longer term. And generally, we do not go back and check if people are happy with their choices, we wait for them to ‘opt out’ of the arrangement. For example, when you make a will, you can go back and change it whenever you want, however, your solicitor does not regularly contact you to check you are still happy with the future binding decisions you made. Medically, we wait until people present at the doctors to check any choices and treatment plans, rather than regularly initiating contact to check they are happy with their previously expressed choices or to tell them about new treatment regimes.

However, this does not fully address the author’s main worry that the donor’s wishes are essentially unknown, as she was not asked about this specific situation and therefore, in effect, she has not refused or consented to contact. The authors argue that we need to go back and check this as we are uncertain about exactly what she has refused and why. We do know that she indicated that she did not want to be contacted about future research. She also indicated that she did not wish to be notified if it was found that she had a previously unsuspected genetic disease, or if she was found to be a carrier of a ‘harmful inherited condition’. While I partially agree with the authors that we cannot be 100% sure what her views on the new situation might be, she has refused to be contacted in a very broad range of situations. She has refused contact in: the case of research; knowledge that might be of clinical benefit to her; and knowledge of her carrier status that might be of benefit to others. Therefore, I would argue that the balance of probabilities suggests that she does not want to be contacted.

It should also be noted that the donor could revisit her decision not to allow any contact if she wanted. She could go back and ask to update her previously stated preferences. The HFEA allows such revisiting of choices and, on the consent form for egg donation, the donor signs a declaration that states, ‘I understand that I can make changes to, or withdraw, my consent at any point until the eggs or embryos have been transferred, used in training, or have been allowed to perish.’ 5 Thus, the HFEA does allow a form of ‘consent as an ongoing process’ 5 as Horton et al advocate. It could be countered that the donor may not know about the relevant advances in genomic medicine and therefore rather than relying on her to come forward she should be given the opportunity to be informed about them, as Horton et al argue. However, as noted above, we rarely pursue people to ensure they are fully informed about all their options, but wait for them to contact us (i.e. go to the solicitor about their will, or go to the doctor), and this seems to press healthcare professionals’ duties to inform patients far over what is either ethically demanded or practical.

**Interests of the donor, interests of the child**

One key argument for not respecting the egg donor’s wishes and contacting her is that it potentially harms the donor-conceived child. At the time of her making her original decision it affected her and only potentially affected someone else, now there is a specific person that her actions may be harming. If we put concerns with the quality of the consent aside, accept for the purposes of this argument that the donor gave valid consent not to be contacted and this was a fully autonomous decision, an argument could be made that this decision could still be overridden on the grounds that it harms, or potentially harms others. There has been considerable debate in the literature about the ‘right not to know’ genetic information about one’s self, 7,8 and how this right might cash out in cases where it potentially might harm others. As Laurie notes, respecting someone’s right not to know, in the form of respecting their privacy can be overridden in cases where there is a, ‘likelihood of serious and foreseeable familial harm to an identifiable person.’ 8 In the case under discussion, we can see that there is a clear case of potential harm to the donor-conceived child if the donor exercises their right not to know.

The arguments for overriding consent here are strong, however, the HFEA has always been clear that it is paramount to get consent and respect that consent from all parties involved in gamete donation.9 Therefore, overriding the freely given consent of a donor, despite evidence of harm to the donor-conceived child, could potentially set a dangerous precedent and the clinic should respect the donor’s wishes not to be contacted. In the UK, the conditions under which one donates are clearly specified and later deviation from this could create unease among potential donors and recipients. For example, in the debates over the law change in the UK, from anonymous to non-anonymous donation in 2005, it was argued that the interests of the donor conceived should take precedence over the donor’s right to privacy in the form of anonymity.10  However, this policy change was not applied retrospectively to donors who had previously consented to donate under conditions of anonymity.

**POSSIBLE SOLUTIONS: POLICY CHANGES**

I would like to suggest a policy change that would prevent this situation in the future and address some of the concerns raised by Horton et al about the complexity and changing nature of genetic information. Gamete donors, arguably, have some form of moral obligation to any child produced from their donation.10 Consequently, I suggest that the HFEA Code of Practice should be changed so that prospective donors are informed, as part of the consent process, that they may be contacted in the future, if needed, and be asked if they would agree to genetic testing, or for another, as yet unknown, medical purpose. At that point they are free to decline to participate, but they have to consent to the possibility of future contact. By becoming a gamete donor people enter into a clearly defined arrangement and one that comes with certain obligations to any child produced from the donation. It is often countered that the privileging of the donor-conceived child’s rights is unfair on the donor, but gamete donation is a voluntary activity, which people enter into freely (leaving aside debates over egg sharing).11 If donors do not want to sign up to these conditions, they can simply not donate.

This change in the HFEA Code of Practice would alleviate issues with the rapid evolution of genomic testing that, arguably, makes valid consent at the time of donation difficult, as Horton et al argue, and presents the donor with a clear choice at a specific time. An argument could be made for making agreeing to future genetic tests a condition of donating; however this is a question for another discussion. Horton et al merely suggest it is acceptable to contact the donor not that it is acceptable to force her to participate in testing. At the very least the donor, at the time of donation, should be required to accept the possibility of being contacted in the future if there is a relevant medical reason for doing so, over and above the existing provisions for the later identity release of donors. 10

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