**Old consent and new developments: health professionals should ask and not presume**

We thank Lucy Frith for her thought-provoking response(1) to our paper, where we argued that it would be ethically acceptable to contact an anonymous egg donor to help facilitate diagnostic genetic testing for a donor-conceived child(2). Whilst we read Frith’s commentary with interest, we still think that the egg donor should be contacted in the case that we describe. Frith raises concerns as to whether contact would constitute ‘*overriding consent*’, thus ’*potentially set[ting] a dangerous precedent*’ for existing gamete donors and donor-conceived children. In contrast, we consider that contacting the egg donor would not override her consent, as her views on contact in the instance that has now arisen were never sought. Our view is that given we do not currently know what she might want, contacting her is a more legitimate way of respecting her autonomy than trying to anticipate her likely answer. We strongly agree with Frith’s suggestion that future consent discussions around gamete donation should make explicit ‘*the possibility of being contacted in the future if there is a relevant reason for doing so*’.

**Limitations of consent**

Frith expresses a concern that contact would constitute ‘*overriding [the egg donor’s] consent*’, meaning that we have to ‘*justify contacting the egg donor against her previously stated wishes not to be contacted*’. However, our argument is that the egg donor was never asked whether or not she was happy to be contacted in the circumstances that have now arisen. Thus there is no consent to be overridden, given that she never gave or withheld it in the first place. Frith rightly acknowledges that her arguments therefore ‘*[do] not fully address [our] 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’*. However she concludes that ‘*the balance of probabilities suggests that she does not want to be contacted*’. Whilst we appreciate Frith’s focus on the importance of respecting the egg donor’s wishes, we are concerned that conjecturing the egg donor’s likely answer is paternalistic. Our suggestion is to contact her to enable her to make a decision for herself; we feel that any other approach risks significantly undermining her autonomy.

Frith argues 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*’. However, our arguments do not rely on genetic exceptionalism – we highlight that narrow models of consent are unsuited to many decisions around genomic medicine, not by virtue of it being ‘genomic’ *per se*, but because genomic medicine has qualities that mean historical narrow consent as sole arbiter of future decisions is often inappropriate. Of course, these qualities may be shared with other areas of medicine and Garrison *et al* recently proposed a concept of ‘genomic contextualism’, which encompasses the notion that genomic information has some qualities that overlap with other kinds of medical information, and some that are distinct(3). Insofar as other areas of medicine ‘*involve complex medical information, present uncertainties and could have unforeseen consequences*’, we should not automatically subscribe to the precedent of using narrow consent in such situations either. Perhaps the lessons learnt from genomic medicine in reconsidering the appropriateness of regarding consent as a one-off, definitive event might be usefully applied elsewhere.

Frith makes a convincing point that ‘*we allow people to make future binding choices… 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*’. Whilst we acknowledge this, we argue that the analogies that Frith uses to illustrate her argument have key differences to the case under consideration here. When you make a will, your solicitor does not regularly contact you to check you are still happy with it, but in this scenario, you would have awareness of the changing contexts that might influence your decisions regarding your legacy; the egg donor in our case does not.

Frith also argues that ‘*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*’, and we acknowledge that this is often the case. However, when individuals have made previous decisions around theoretical future treatments, for example an advanced decision, and circumstances evolve such that the treatment in question would now be actually indicated, or a new alternative treatment that has never been discussed becomes available, usual practice would involve checking with a patient that they still wish to refuse treatment, rather than ignoring that possibility on the basis that they had already made their decision. Frith raises a question as to whether contacting the egg donor may ‘*press healthcare professionals’ duties to inform patients far over what is either ethically demanded or practical*’. We agree that establishing a duty to contact in such cases is beyond the scope of our article, but whether contact is required in all cases and whether it is ethically defensible in a particular case are two different questions; here we are concerned with the latter.

**Balancing the interests of the donor and the child**

Frith reviews our argument that the choices made by the egg donor might impact on the donor-conceived child, and agrees that this issue needs careful consideration. She accurately states that ‘*the HFEA has always been clear that it is paramount to get consent and respect that consent from all parties involved in gamete donation*’, but goes on to argue from this that ‘*overriding the freely given consent of a donor… could potentially set a dangerous precedent*’. We think this concern is perhaps based on a misunderstanding of our argument as we highlighted earlier: we are not advocating overriding the egg donor’s ‘*freely given consent*’ – in contrast, we want to ask her for her consent in relation to the newly arisen situation, instead of second guessing what her answer will be, and so denying her the opportunity to exercise her autonomy. We acknowledge Frith’s concern that in practice, shifts in policy around contact in such situations ‘*could create unease among potential donors and recipients*’. We think that further discussion of such issues among relevant stakeholders will be important and necessary in responding to this concern, but our view is that we should not pre-empt the outcome of such discussions by automatically saying ‘no’ to contacting donors in unforeseeable future situations where there is a pressing medical reason for doing so.

Whilst this was not a key focus of our original article nor of the response, it is interesting to reflect on how the protections around donor anonymity are shifting over time, outside the context of recontact for medical reasons. In 2005, UK law changed such that future donor-conceived children could receive information about their donor when they turned 18(4) – so in the case we discuss, in donating, the egg donor had to accept the possibility of contact in the future. Increasing uptake of commercial genetic testing is changing this landscape further(5), given the possibility of finding genetic relatives through ancestry testing. For example, five days after our initial article was published online, the Progress Educational Trust held an event entitled ‘Anonymous no more?’(6), where one of the key questions explored was ‘*where there is a delay between the birth of a donor-conceived child and the donor’s identity having to be made available, could this arrangement be made impractical by the advent of direct-to-consumer genetic testing?*’

**Conclusion**

We are grateful to Lucy Frith for engaging with our article and giving us a useful opportunity to reflect on our arguments. We still hold that it would be ethically acceptable to contact the egg donor in the case that we describe: we consider that this eventuality was not covered during the consent process and that the potential harm to the donor-conceived child from not contacting the donor also needs to be factored in. The limitation of the consent process in this instance presents a useful opportunity to consider more widely the limitations of consent in the context of complex medical interventions. Frith’s call for a policy change such that future donors are warned of the possibility of future contact as part of the process of gamete donation, is very welcome and timely. We too believe that this would pre-empt such difficulties arising in the future, although we think it is important that this potential for contact is clearly presented as a possibility not a choice. It would be unfair to give potential donors the illusion of veto unless we are sure that in every situation we would be able to honour it; as this is not the case, we agree with Frith that ‘*if donors do not want to sign up to these conditions, they can simply not donate*’.

**References**

1. Frith L. 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. Journal of Medical Ethics. 2019:medethics-2019-105629.

2. Horton R, Bell B, Fenwick A, Lucassen AM. Is it acceptable to contact an anonymous egg donor to facilitate diagnostic genetic testing for the donor-conceived child? Journal of Medical Ethics. 2019;45(6):357.

3. Garrison N, Brothers KB, Goldenberg AJ, Lynch JA. Genomic Contextualism: Shifting the Rhetoric of Genetic Exceptionalism. The American Journal of Bioethics. 2019;19(1):51-63.

4. HFEA. Finding out about your donor and genetic siblings <https://www.hfea.gov.uk> [Available from: <https://www.hfea.gov.uk/donation/donor-conceived-people-and-their-parents/finding-out-about-your-donor-and-genetic-siblings/>.

5. Kennett D. Personal genetic testing and the implications for the donor conception community <https://www.bionews.org.uk/page_96385>: BioNews  939; 2018 [

6. Progress Educational Trust, University of Liverpool, European Sperm Bank, London Women's Clinic. Anonymous no more? Donor conception and direct-to-consumer DNA testing2019; University of Liverpool (London campus).