COMMENTARY

The Case for Reframing Known Donation

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ABSTRACT

Contemporary UK egg and sperm donation exists in two predominant forms: (i) clinic-based, identity-release donation; and (ii) known donation, which can take place either inside or outside of the clinic context. Regulatory and clinical discussions of the latter currently focus, almost exclusively, on risk whereas identity-release is widely presented as the default route for both donors and recipients. Consequently, there is little support available for those potential donors and recipient parents who might prefer a known donor arrangement. In this commentary, we reflect on our sociological research with donors and parents through donor conception and argue that there are a number of reasons why known donation may, in some contexts, offer advantages over identity-release donation. Whilst this research also demonstrates that there can be challenges involved in known donation, these are not inevitable nor are challenges absent from identity-release routes. It is timely and important to question whether the current de-valuing of known donation compared with identity-release donation holds up to academic scrutiny. We argue for a more balanced approach in which the benefits and challenges of *both* known and identity-release routes are discussed with donors and recipients and for increased support for known donation in clinics and by regulatory bodies.

Keywords: known donation; egg donation; sperm donation; donor conception; self-arranged insemination; open donation

Introduction

Known donor conception is a form of donor-assisted reproduction where the donor and recipient have personal knowledge of one another, prior to conception. Some are relatives or friends. Others get to know each other for the purposes of donor conception. This often happens after registering with agencies or websites (e.g., Pride Angel, Coparenting.co.uk) or via social media groups which facilitate communication and meetings between potential donors and intended parents. Known donor conception can take place within clinics or entirely outside of clinics (e.g., Freeman et al., 2016; Jadva et al., 2018). We do not know how common this form of donor conception is in the UK as this information is not routinely collected. However, the growing popularity of 'matching' websites and Facebook groups for would-be donors and recipients suggest this practice is on the rise (Bergen & Delacroix, 2019; Freeman et al., 2016) and known donor conceptions may now outnumber their more traditional (unknown) equivalents (Harper et al., 2017).

Known donor conception can be contrasted with 'unknown' forms, where donor and recipient(s) do not know one another's identity at the time of donation. This includes anonymous donation, where the intention is that the donor and recipient family will remain permanently unknown to one another. This form of anonymous donation is no longer permitted in UK clinics and it has been argued it is no longer ethical (due to the donor conceived person's 'right to know' the identity of their donor (Besson, 2007; Frith, 2013; Giroux et al., 2012)) or viable (due to the increasing availability of direct-to-consumer genetic testing (Darroch & Smith, 2021)). In the UK, and a growing number of other jurisdictions, permanently anonymous donation has been replaced with temporarily anonymous donation, also known as identity-release donation. This is where identifying information about donors is made available to people conceived from their donation at maturity (in the UK, at the age of eighteen), *if* requested by the donor conceived person, who would therefore need to be aware of their donor

conception. In most jurisdictions, parents and donors are not able to access identifying information about the other parties.

Despite the rising popularity of known donation, UK policies and clinic practices widely present identity-release donation, as the default option. Known donor conception, particularly but not only when practised outside of clinics, is widely discouraged and framed as intrinsically risky and complicated in comparison with identity-release donation (see e.g., HFEA, 2022c).

In this commentary article, we first illustrate and then challenge this presentation of known donation. Our challenge is informed by our own and others' research with both donors and recipients of donated gametes (encompassing known and unknown arrangements) which collectively demonstrate the potential and experienced advantages of known donor conception arrangements. We argue that policy and practice should provide a more balanced framework for considering the risks *and* potential benefits of both known and identity-release routes.

Regulatory framings of known donor conception

Known donor conception is permitted under UK law and, to our knowledge, UK clinics will generally facilitate it when recipients present with a donor. However, our analysis of the UK regulator's (the Human Fertilisation and Embryology Authority, HFEA) website content shows that known donor conception is predominantly presented as risky, particularly but not exclusively when practised outside of clinics. In comparison, identity-release donor conception is presented as safer, more straightforward and the 'standard' option in clinics.

In a section of the HFEA website (HFEA, 2022c) aimed at people considering the use of donated gametes to conceive, the text highlights four 'options for finding a donor': 'through a licensed fertility clinic', 'a friend, relative or someone else you know', 'a UK or international

egg or sperm bank' or a 'donor introduction website'. It also describes how it can be arranged 'privately, without attending a clinic'.

This section of the website repeatedly and explicitly describes 'private' or self-arranged insemination as medically and legally risky:

> *If you don't have treatment with a licensed clinic the situation is more complicated. There's a risk that your donor will be considered a parent by law – with all the rights and responsibilities that brings. Talk to a solicitor to find out more about how this applies to you.*

> *It's always safer to have treatment with donor sperm at a licensed clinic. (HFEA, 2022c)*

It particularly highlights the risks associated with using donor introduction websites:

> *There are an increasing number of websites which offer services which match women with sperm donors. Donors and recipients may then meet and arrange insemination privately, without attending a clinic. If you are considering using these services it is important to bear in mind the very real risks and consequences of obtaining sperm in this way (HFEA, 2022c).*

A linked webpage advises readers using such websites to:

> *Always meet someone you are matched with in a public place and take a friend along with you.*

Never agree to natural insemination (ie. sex), even if the donor says that it has a higher success rate.

Never accept a donor who is not prepared to have health screening (for infectious and inherited diseases) and make sure you have written evidence of the results.

Don't agree to pay a donor (only expenses are acceptable) (HFEA, 2022a).

We agree these are sensible considerations and it is important to acknowledge that there is evidence of abusive and/or coercive behaviour perpetuated by some acting or advertising themselves as donors (Taylor et al., 2022). However, the website text phrasing portrays 'online' donors, in general, as predatory and themselves disinterested in the donations and conceptions being as legally and medically safe as possible. An alternative phrasing might have been 'always ensure donors undergo health screening' or 'it is illegal to pay for sperm in the UK but it is acceptable to cover a donor's expenses'. Such phrasing provides the same advice without positioning online donors as automatically morally suspect and the use of such websites as intrinsically risky.

Another sub-section of the same webpage (HFEA, 2022a) is titled 'using a known donor'. This section is accompanied with a text box, warning readers considering this option to 'be clear on how much involvement the donor will have with your child'. The words 'be clear' are in a larger font, underlined and in bold. This section advises readers to 'think carefully about how [known donation] would work in practice,' suggests drawing up an agreement

(whilst acknowledging, ‘it won’t be legally binding if you get into a dispute’) and ends with a link to a solicitor’s website which describes ‘examples of legal cases involving disputes over parental rights’ (HFEA, 2022a).

Again, this is sensible advice; known donors and recipients should make clear their expectations of relationships following donation and it is a good idea to ‘think carefully’ about conceiving with a donor via any route (or indeed about having a child, in general). However, we wish to highlight the lack of balance here. Nowhere does the website discuss the perceived benefits of known donation (or indeed self-arranged insemination) or the reasons why a person might prefer this option over identity-release donation.

Furthermore, whilst the social and emotional risks associated with known donation are highlighted, there is no suggestion that there could be any risks with identity-release donation. One such risk would be that, whilst identity-release donation enables donor conceived people, who are aware of their donor conception, to access the identity of their donor when they are eighteen, recipients do not know what that person is like or what their expectations might be of contact. Just as different expectations in this regard could result in ‘disputes’ in cases of known donation, it could also be the case in identity-release donation, particularly since direct-to-consumer genetic testing means there is no longer any guarantee that donor anonymity will be maintained until a donor conceived person is eighteen. Arguably the possibility of conflicting expectations between recipients and donors is greater in identity-release donation since there is no possibility to meet, draw up an agreement or discuss expectations in advance.

In summary, the HFEA website positions identity-release, (UK) clinic donation as the default, risk-free option and frames known and non-clinic donation as uniquely risky and best avoided. Whilst a full review of all websites with guidance on known donor conception is beyond the scope of this paper, our preliminary analysis of UK fertility clinic websites found

similar content and links for information about donor conception often led, by default, to information about identity-release donor conception.

The (largely unacknowledged) benefits of known donation

In this section, we reflect on findings from our own research with donors and parents through donor conception, as well as other research in this area, to identify, potential, perceived and experienced, benefits of known donation for donors, recipients and their families.

We particularly draw on four UK-based studies of the impact of donor conception on everyday relationships, that we have worked on, both separately and together. The first 'Conceiving Together' (CT) study, 2006-2009 was Nordqvist's doctoral study and explored lesbian couples' experiences of donor conception (see Nordqvist, 2014). The second 'Relative Strangers' (RS) study, involved Nordqvist only, was led by Carol Smart and explored the experiences of parents and grandparents of donor conceived children (see Nordqvist & Smart, 2014). The third study, Gilman's doctoral research, 'Qualifying Kinship' (QK), 2012-2016, investigated the views and experiences of UK identity-release sperm and egg donors (Gilman, 2017). The fourth study, 'Curious Connections' (CC) (2017-2021) involved both authors and explored the impact of sperm and egg donation for donors and their families (Nordqvist & Gilman, 2022). In total, across all studies, we conducted 76 in-depth interviews with egg/sperm donors and 69 interviews with parents through donor conception. In each study, a significant minority of participants had experience of known donation, specifically 48% and 18% respectively of couples/solo parents in the CT and RS studies and 33% and 42% of donors in the QK and CC studies.

Reflecting on our findings in these studies, as well as other research in the field, we have identified the following advantages of known donation for donors and parents. Some advantages were directly articulated by participants. Others are potential advantages which we

have identified based on the broader values, interests and desires expressed by participants, as well as the challenges they faced with unknown pathways. This list is not exhaustive, but we hope it demonstrates how the exclusively risk-focussed discussions of known donation in current UK policy contexts are limited by their omission.

The donor conceived child's 'right to know'

The shift to identity-release donation in UK clinics in 2005, as well the moral imperative to tell donor conceived children about their conception, are often described in relation to the donor conceived person's 'right to know' about their origins and identity (Besson, 2007; Frith, 2001; Gilman & Nordqvist, 2018). For many of the known donors we interviewed for the CC study into donors' experiences, known donation was felt to be more in keeping with the spirit of this ethical and legal shift, when compared to identity-release donation. Assuming they are aware of their donor conception, known donation enables children to contact, or ask questions of, their donor when they wish and not to have to wait until they are adults to do this (Nordqvist & Gilman, 2022). Findings from both the CT and RS studies with recipient parents confirm that some choose a known donor for this very reason (Nordqvist, 2014; Nordqvist & Smart, 2014). In recent years, a group of donor and surrogate conceived people who presented at a UN conference to celebrate the 30th anniversary of the UN Convention on the Rights of the Child, advocated for 'open donation', a term often used for known donation, (from any age) using a similar logic (Cummerford & Dingle, 2019).

Avoiding the politics of waiting

Identity-release donors do not know whether, how or when they might be contacted by someone conceived from their donation. Most donors interviewed as part of the CC and QK studies were relatively comfortable with this uncertainty. However, for one egg donor, this

dynamic of waiting for a 'big reveal' (which might never come) was one of the reasons she opted for known donation. As she explained, knowing her donor offspring throughout their lives would be 'less intense' than meeting them as a young adult.

The dynamics of waiting were also found to impact recipient families, sometimes negatively. Some recipient parents in the CT and RS studies had chosen known donation to avoid their children having to wait to find out (Nordqvist & Smart, 2014). Many parents who had identity-release donors spoke of the need to manage 'the wait' for themselves and their children (ibid); the study also documented that having very limited information about the donor could enable fears and/or fantasies to develop. Empirical research from Australia also suggests that donor conceived people meeting (until then anonymous) donors in adulthood may not be positively experienced (Dempsey, Nordqvist & Kelly, 2021). Our studies indicate that both recipient parents and donors may prefer known donation because of these issues.

A sense of connection

Many of the donors we interviewed in the CC and QK studies who had donated to known recipients spoke of a sense of satisfaction with knowing the families their donations had helped to create and thus seeing the positive impact their donation had made (see also Goedeke et al., 2021; Goedeke & Daniels, 2017; Shaw, 2007). We found that known donor conception could cement existing friendships or lead to new and meaningful connections in peoples' lives (Nordqvist & Gilman, 2022). Several identity-release donors in the QK and CC studies expressed an interest in making themselves contactable to recipient families. Similarly, some parents who took part in the CT and RS studies, would seek out and celebrate connections formed through (initially unknown) donor conception (e.g., Nordqvist, 2014). Some searched for donor relatives after the donation with the aim of building extended kin and support networks for themselves and their children (see also Andreassen, 2017; Hertz & Nelson, 2019).

Lesbian parents, in particular, were found to want children to know who 'dad' is, even if he is not enacting a parental role (Nordqvist, 2014) and this can be a motive for choosing a known donor (Haimes & Weiner, 2000).

Personal connection and compatibility

In identity-release (or anonymous) donation, clinic staff usually match donors and recipients according to shared physical traits (Homanen, 2018). In some contexts, recipients can also select a donor from anonymised profiles, according to their own preferences, which usually includes matching (based on physical appearance, personality, or skills) with the intended parent(s) but can also be based on approval of, or sense of connection with, a particular donor, based on their profile (Ravelingien et al., 2015; Scheib, 1994). In both the CT study (with recipient parents) and the CC study (with donors), often both parties valued feeling a sense of affinity with the other, even if their identity was unknown; those who had donated to known recipients typically spoke about the importance of 'feeling a connection' with their recipient (Nordqvist & Gilman, 2022); and some recipient parents preferred known donation for the very reason that they could 'get a feel' for who that person was (Nordqvist, 2014). Known donor conception creates circumstances in which donors and recipients can more easily choose one another based on feelings of affinity, a sense of personal connection or compatibility, alongside or instead of the matching of physical and personality traits (see Freeman et al., 2016; Jadva et al., 2018). In particular, it allows potential donors and recipients to discuss relational expectations, prior to any donation (as advised by the HFEA website) and it enables prospective parents to assess the suitability of potential donors as someone who will have an ongoing genetic (and perhaps social) connection to their child. Known donation may thus help to avoid future conflicts (as detailed in e.g., Dempsey et al., 2021) where it is clear from initial conversations that donor and recipient expectations are incompatible.

Increased equality of access

Intra-Uterine Insemination (IUI) with donor sperm can cost upwards of £2,000 per cycle in a fertility clinic (Marshall, 2021). IVF typically costs around £5,000 per cycle in the UK (HFEA, 2022b). Patients typically require multiple treatment cycles. NHS funding for treatment costs is varied across the country and limited. For those that do not qualify, the costs are simply unaffordable for many, with lesbian couples being shown to face particular barriers to accessing treatment (Marshall, 2021).

Although there may be some donors who (illegally) charge, our research suggests there are men who are prepared to donate outside of clinics for free or for travel costs (see also Bergen & Delacroix, 2019; Freeman et al., 2016). Some of the donors interviewed for the CC study chose to act in a known capacity explicitly to counteract the fact that some recipient parents are excluded from high-cost clinical treatment.

Some drawbacks and counterarguments

Our research, as well as existing literature, highlights that people also perceive or experience challenges with known donation and we do not wish to ignore these. Below we engage with four key perceived risks.

Donors prefer anonymity

It is certainly true that not every donor wants to know their recipient(s) from the outset. In the CC and QK studies, we found that many donors who had donated via the anonymous or identity-release pathway said they would not like to donate to someone they knew (see also Graham, 2021). Such arrangements were often described as ‘more complicated’. A few donors

thought it would be difficult to remain appropriately detached if they saw the recipient family frequently (Gilman, 2017; Nordqvist & Gilman, 2022).

That said, our research, as well as the growing numbers connecting via donor introduction websites demonstrate that there is a significant subsection of the population who are willing to act as known donors. For some, for various combinations of the reasons outlined above, this was their preferred option (see also Graham, 2021) and we interviewed a significant minority of donors who had donated to both known and unknown recipients, often progressing from identity-release to known donation because of the perceived benefits of the latter and/or challenges of the former.

Blurred boundaries

One of the reasons known donation was often described as 'complicated' by donors in the CC and QK studies was the perceived blurring of social (and sometimes legal) boundaries between the donor's and the recipient's families. For recipients, and particularly for non-genetic parents, the donor may be an ambivalent figure and someone who might be viewed as unsettling their own family relationships (Nordqvist, 2010; Nordqvist & Smart, 2014) or raising the stigma associated with (particularly male factor) infertility (Gannon et al., 2004). In certain circumstances, if known donation takes place outside of a licensed clinic, it can also give rise to uncertainties about the legal status of the donor and any non-genetic social parent (Smith, 2013). In a world where non-genetic and non-heterosexual families continue to largely lack social and legal recognition (Dempsey et al., 2021), these are important considerations and may mean recipients will prefer a donor who is, at least initially, anonymous to them.

However, it is important to remember that, with the introduction of identity-release legislation and increased access to genetic testing, all donors are potentially identifiable. Many of the social risks associated with known donor conception are arguably therefore no longer

contained by initial anonymity but rather postponed or made uncertain. An unknown donor might therefore appear to resolve some of these issues at the time of conception but it could actually exasperate them if a donor becomes known years later, perhaps unexpectedly and not necessarily after the donor conceived child is eighteen (e.g. Dempsey et al., 2021).

Health risks to recipients and donor conceived people

As detailed above, the HFEA website highlights the increased health risks associated with non-clinic donor conception to argue that conceiving in a licensed clinic is the 'safer' option. Clinic donors undergo rigorous testing for sexually transmitted diseases and infections, genetic testing for certain inheritable conditions and are required to give a family medical history (Clarke et al. 2019). This significantly reduces any risk to the health of the recipient and any child conceived.

However, testing is not unique to clinic donations. Interview data from the CT and CC study suggests that, when donation is arranged outside of a clinic, many sperm donors undergo testing for STIs and STDs, either via one of the many web-based services available, or at an NHS walk-in clinic. In our studies, non-clinic donors saw this as a duty of 'good donors' and routinely provided evidence of their sexual health to potential recipients. Negative results from such tests do not rule out the possibility that a donor could pass on an STD; unlike in clinic donation, sperm donated outside of clinics cannot be quarantined. We also found genetic testing was not the norm for non-clinic donations, although family medical histories were often discussed. It is therefore the case that physical risks are higher in non-clinic donation, but the use of testing can arguably reduce them to then a lower level than might be expected in a typical 'natural' conception, although this does rely on the trustworthiness of the donor.

Non-adherence to the 'ten family' limit

A further risk which the HFEA website also highlights regarding non-clinic donor conception, is the lack of regulation of the number of families any one donor can donate to and the associated risk of donor-related people entering into sexual or romantic relationships with one another. This risk is not mentioned in relation to other routes to finding a donor.

We take issue with the implication that this risk is unique to non-clinic donor conception. Using a clinic donor is no guarantee that the UK 'ten family' limit will be adhered to, nor that a donor conceived person will be able to avoid the risk of consanguineous relationships. Graham et al.'s (2019) survey of online and clinic donors, as well as our own interviews with donors in the CC and QK study found significant overlap between clinic and non-clinic sperm donors. One of the participants in the CC study had donated via a clinic and then went on to donate to more than 80 further recipients he had met online. Although this was a rather unusual case in terms of numbers, it was fairly common for donors in this study to transition between different 'pathways' of donation (Nordqvist & Gilman, 2022). Using 'official' channels, a donor conceived person would only be able to identify donor siblings from clinic-based donations and not those in other families, and then only at age eighteen by mutual consent. The risk of consanguineous relationships therefore remains.

We found in the CC study that, in many cases, known donation actually enabled donors and recipients to discuss whether the donor had donated to any other families and, if so, how communication between recipient families might take place.

Reframing and Supporting Known Donor Conception

In highlighting some of the benefits of known donor conception, we are not arguing that known donation is intrinsically 'better' than identity-release donation. Nor are we suggesting that there are no legal, physical, or social-emotional risks involved. Instead, our aim is to shift the framework in which both known and unknown donor conception are discussed. Based on our

empirical evidence, we propose that clinics and policymakers should move away from talking about known and non-clinic donations exclusively as 'risky' and acknowledge some of the benefits of these pathways. Furthermore, such discussions should recognise the risks and challenges associated with identity-release pathways, bearing in mind that, with the rise of direct-to-consumer genetic testing, even temporary anonymity cannot be guaranteed (Darroch & Smith, 2021; Harper et al., 2016). It is neither helpful nor appropriate to position known/unknown and clinic/non-clinic donor conception as neat binaries mapping onto complicated/straightforward and safe/risky. Reframing the discussion in this way would enable donors and recipients to make more informed decisions about the pathways which are best for them and their (potential) children, in the context of their wider networks of relationships and material constraints.

In order to make such discussions and choices meaningful, known donor conception needs to be better supported by clinics and regulatory bodies and to be more accessible to donors and recipients. Currently, identity-release pathways are the default option in UK clinics unless donors and recipients present together. We offer the following recommendations (some of which would require legal reform in the UK context):

1. The option of finding or being a known donor should be discussed with all donors and potential recipients who present at clinics rather than assuming an identity-release pathway as the default option. Information about known and unknown pathways should also be made available on clinic websites and patient/donor literature. The benefits and risks of both options should be discussed.

2. To support those who, after such discussions, decide known donor conception is their preferred choice, clinics could provide matching and introduction services for known

donors and recipients. Alternatively, clinics could partner with agencies or websites which enable known donors and recipients to contact one another.

3. UK laws and clinic policies should be amended to enable greater flexibility to share information between recipients and donors, where this is desired. Specifically, it should be possible for donors and recipients who begin donation, initially anonymously, to register an interest in becoming known and for contact information to be shared by mutual consent.

4. Clinics should offer packages to support those who wish to conceive with a sperm donor outside of a clinic. Such packages could include sexual health and genetic screening tests for donors, semen analysis, counselling, advice on conception methods and (crucially) the signing of consent forms, similar to those used in clinic-based donor conception, which make clear who the legal parents of any child conceived from the arrangement will be. This would reduce the legal and medical risks which can accompany non-clinic donation without unnecessarily medicalising the process of conception and increasing costs.

5. Regulatory bodies (in the UK, the HFEA) should operate voluntary donor registers for donor conceptions which take place outside of licensed clinics, or enable the inclusion of self-arranged donor conceptions on a central donor registry (as is permitted with the new Donor Conception Register in South Australia (yourSAy, 2021)). This would enable donor sibling linking between non-clinic and clinic donor conceived people.

This is not an exhaustive list. However, we hope these broad suggestions show how laws, clinic policies and practices could be reformed in order to re-frame and support known donor conception, alongside identity-release, as a valid choice for both donors and recipients.

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