Article:

Gilman, L. orcid.org/0000-0002-4697-6485 and Nordqvist, P. (2018) Organizing openness: how UK policy defines the significance of information and information sharing about gamete donation. International Journal of Law, Policy and the Family, 32 (3). pp. 316-333. ISSN 1360-9939

https://doi.org/10.1093/lawfam/eby014

International Journal of Law, Policy and The Family, 2018, 32, 316–333
doi: 10.1093/lawfam/eby014
Advance Access Publication Date: 28 September 2018
Article

OXFORD

Organizing Openness: How UK Policy Defines the Significance of Information and Information Sharing about Gamete Donation

Leah Gilman* and Petra Nordqvist**

*Department of Sociology, University of Manchester, Manchester, UK, Email: leah.gilman@manchester.ac.uk
**Department of Sociology, University of Manchester, Manchester, UK

ABSTRACT

'Openness' is increasingly held up as a self-evident virtue, presented as inherently positive and progressive in both the public and personal sphere. This article examines how this ideal is realized in the regulation of gamete donation in the UK; what exactly is it that people are expected to be open about and with whom? Through an analysis of the policies and texts via which information about gamete donation is managed, we demonstrate that sharing information about the donor with donor offspring is prioritized, whilst other trajectories of information often remain forbidden or unconsidered. We argue that these policy discourses and decisions both reflect and reproduce a dominant framing of gamete donation as significant in terms of its reproductive consequences and specifically the interest donor offspring may have in their origins. However, as we demonstrate, this is not the only way in which donation information can be significant to those implicated. It can also, for example, be viewed as a gift or form of bodily donation connecting donors and recipients. We argue for closer analysis of the ways in which social policies organize openness along particular trajectories and how this in turn shapes the social and relational significance of the events being disclosed.

I. INTRODUCTION

In recent decades, a broad cultural change has taken place; in the UK and Euro-America more broadly, 'openness' is now viewed as a self-evident virtue, idealized in both the public and personal spheres (Klotz, 2014). Whilst in the past, it might have been seen as best to 'let sleeping dogs lie', family secrets are increasingly framed as inherently destructive of personal relationships (Smart, 2009, 2011) with sharing and honesty perceived as essential for healthy family relationships. As Smart (2010) explains, there is now a legal presumption that it is best for a child to know the 'truth' of his or her genetic origins, reflected in cases where DNA testing is ordered to attribute paternity and in the move towards openness in adoption practices (see also Jones, 2016). An ideal of openness and transparency now also permeates various everyday relationships. For example, Giddens (1992) describes the contemporary ideal of the 'pure relationship'; one conducted between equals and based on openness and mutual disclosure, now seen as the foundation of intimate relationships (rather than status or tradition). Similarly, Faircloth and Gürtin (2017) note the increasing expectation of non-hierarchical relationships within families, characterized by mutual information sharing between parents and children. In reality, couples and families often struggle to materialize this ideal. Nevertheless, it remains a powerful social discourse which frames experiences of lived relationships (Jamieson, 1999).

Drawing on Strathern (1999b), Klotz (2014) argues that the idealization of openness in our personal lives draws upon a broader valorization of 'transparency' in the political sphere (see also Moore, 2017). Bound up with neoliberal aspirations to create informed and choosing consumers, she points to such initiatives as evidence-based policy-making, freedom of information regulations and 'audit cultures' as examples of the ways in which increased availability of information is seen as progressive, just and efficient. As Klotz (2014) highlights such is the dominance and pervasiveness of this ideal of transparency that it can be difficult to recognize its cultural and historical specificity.

This ideal of openness raises some interesting sociological questions because it is one thing to agree that openness is a good thing in the abstract, but quite another to translate openness into practices (Nordqvist, 2014; Nordqvist and Smart, 2014a). Decisions have to be taken about what information needs sharing and what can be withheld. Decisions also need to be made about who should be on the receiving end of information, and who can be excluded. Thus, at the point at which the ideal of openness is enacted, complicated questions arise.

A useful site to explore such questions is the field of donor conception; the practice whereby men and women provide egg, sperm, or embryos to enable others to conceive and carry a child. This is an area where the rhetoric of openness has had a significant impact on UK laws, policies, and practices. Whilst previously secrecy was the norm, the sharing of information about donor conception is now, not only encouraged by professionals, but also managed centrally via the Human Fertilization and Embryology Authority (HFEA) and the HFEA Register. Exploring how such information sharing is framed and organized provides a window into exploring values and understandings in contemporary personal life more broadly because, as Edwards (2005) has demonstrated, these new reproductive practices do not necessarily produce 'new' ideas; instead they often intensify existing ideas and make explicit that which is usually implicit. The social, cultural, and legal management of donor conception is thus indicative of wider understandings, and values, circulating within society (see Edwards, 2000).

In this article, we explore gamete donation from a policy perspective: examining the rules and texts which govern and frame how information sharing is managed in this context. Taking a similar approach to Haimes (1993), Turkmendag et al (2008, 2012), and Klotz (2014), who have also examined policy-making in this area, we analyse the norms and assumptions which are embedded within such texts and which they reproduce. Our analysis builds from the understanding that the law (and its translation into other forms of policy and regulation) constructs, as well as reflects, social actions and imagination (Geertz, 1983). On the one hand, legal and policy decisions and discourses are likely to reflect dominant social norms, values, and assumptions in the social cultural context to which they apply, particularly those of legislators and others with the power and resources to make their voices heard in the process of policy development (see Turkmendag et al (2008) for further discussion in the context of gamete donation policy). At the same time, laws are of analytical interest because of the ways in which they produce meaning and shape imagined, as well as enacted, possibilities (Melhuus, 2012: 8–10). Our analysis therefore not only tells us about the norms which have shaped and constrained policy-making in this area but it also tells us something about the way in which people are likely to understand gamete donation because of the influence laws and policies have on the way we come to think about and enact particular actions and events.

Specifically, we aim to explore the particular forms and trajectories of openness which are legitimated and encouraged in UK gamete donation policy: what information is deemed important to share, and with whom. Crucially, we also consider when information sharing is still *not* considered best, or indeed not considered at all. We show that the particular form of openness embraced in UK policy prioritizes information sharing about donors with their donor-conceived offspring. Further potential paths of disclosure or communication, such as between donors and recipients and their wider networks, remain largely forbidden or unconsidered (contact between donor-conceived siblings being a significant exception). We argue that by mandating for openness of a particular form, UK donation policy risks imposing a singular truth about the kind of act gamete donation is and the relationships it could, or should, entail; it frames gamete donation as significant only in terms of its reproductive potential and the interest donor-conceived people may have in learning more about their origins. Whilst we do not wish to deny the significance of gamete donation as a (potentially) reproductive act, we hope to draw attention to the way in which organizing openness only in this particular way excludes another way in which donation may have relational significance: as a gift relationship or form of bodily donation between donors and recipients.

II. OPENNESS IN DONOR CONCEPTION

Donor conception is a field where the increased valorization of openness is highly visible and has resulted in significant changes to family and medical practices, as well as policy and regulations. Historically, in the UK (and many other Western jurisdictions), the issues arising from donor conception were managed through secrecy. This included the widespread destruction, or minimal recording, of donor details prior to the 1990s and the norm of donor anonymity prior to 2005 (Haimes and Daniels, 1998; Frith, 2001). The practice of matching physical characteristics (including blood types) of the donor to the intended non-genetic parent also enabled, arguably encouraged, recipients to ‘pass’ as genetic parents to their donor-conceived children and avoid disclosure to both their children and their wider social circle (Haimes, 1992).

However, in recent decades, such practices increasingly came to be viewed as harmful, resulting in comprehensive changes to policy and practice in this area. Arguably, the most fundamental of these changes is the abolition of absolute donor anonymity. Since April 2005, those donating in UK clinics must consent to their identity being released to any donor offspring who request this information after the age of 18. Similar identity-release policies have been implemented in a range of

European jurisdictions, beginning with Sweden in 1985, as well as some Canadian provinces and Australasian states (Blyth and Frith, 2009). In the UK, this regulatory amendment was introduced following lobbying by donor-conceived people and those advocating on their behalf, including academics. Beginning in the late 1980s, it was increasingly argued that donor offspring had a 'right to know' both the circumstances of their conception and identifying details about their donor, on the basis that such information was relevant to their 'biological identity' (eg Daniels, 1995; Freeman, 1996; McGee et al, 2001; see also Turkmendag, 2012). Such statements were frequently supported through comparison with the experiences of adopted persons (Turner, 1993; McWhinnie, 1996; Blyth et al, 2001) and specifically the concept of 'genealogical bewilderment' – a term coined by Sants (1964) referring to the psychological damage he perceived to adopted people through the lack of information available to them about their genetic history.

Telling donor-conceived children about the circumstances of their conception is now widely encouraged (Crawshaw et al, 2012; Klotz, 2014; Freeman, 2015). Support groups and pictures books have been developed with the specific aim of supporting parents to disclose donor conception to their children in age-appropriate ways. As Klotz's (2014) ethnographic study found, the stated aim of these groups is that children should feel they have 'always known' they were donor-conceived, rather than experience this as a revelation. Parliamentary debates prior to the abolition of donor anonymity frequently focused on whether the proposed changes risked decreasing parental disclosure – an outcome seen as self-evidently negative (see Turkmendag et al, 2008). As Klotz (2014) highlights, non-disclosure by parents is now frequently described with the morally loaded terms, 'secrecy' or 'lying'. Although not implemented in UK policy, the push towards truth-telling can be seen in recent proposals for a person's donor-conceived status to be indicated on their birth certificate, meaning that parents would not be able to 'undermine' their children's rights to access information about their conception and donor by failing to tell them about the manner in which they were conceived (Blyth et al, 2009; Crawshaw et al, 2017).

Much previous academic research on openness in gamete donation has been conducted in the fields of social psychology and social work, often using survey or interview data to examine the impact policies and practices of openness or secrecy have in donor-conceived families (eg Turner and Coyle, 2000; Lycett et al, 2004; Scheib et al, 2005; Golombok et al, 2006; Jadva et al, 2010; Ravelingien et al, 2013) and very often mobilized in support of the drive to openness (Daniels and Taylor, 1993; McGee et al, 2001; Crawshaw et al, 2017). Undoubtedly, it is important that research seeks to understand the impact of openness/secrecy for those implicated by donation. However, in this article, we instead seek to problematize the practice of being 'open'. Our approach builds on Klotz's (2014) ethnographic study of donor conception in Britain and Germany. Like her, we examine gamete donation through the lens of 'information' and consider how particular regimes of information management shape the significance which donation comes to have for those involved. In addition, by systematically comparing the information which is (and is not) made accessible to donors, recipients and donor-conceived people, we also highlight the particular version of openness which is being advocated and explore the consequences of openness being organized in this way and not another.

III. DATA AND METHODS

The data analysed in this article were collected as part of a wider study investigating the impact of donating egg and sperm for donors and their families, in the context of the move towards 'openness' in donor conception. The first stage of data collection reported here comprised an analysis of the regulatory context in which post-2005 UK donors donate – an attempt to map out the laws and policies which frame what it means to donate in an 'open' context.

The UK context is particularly amenable for policy analysis in this area. Here, gamete donation and donor conception are highly regulated areas. The first Act of Parliament regulating provision of assisted conception was the Human Fertilization and Embryology (HFE) Act 1990, after which the HFEA, a governmental 'arms-length body', was established in 1991. The HFEA has a remit to regulate and monitor the activities of clinics which carry out research or treatment using human gametes and embryos. This centralized approach to the regulation of reproductive technologies in the UK means that there is a wide range of policies to which all UK fertility clinics are subject; the HFEA publishes regular codes of practice which interpret relevant legislation to provide both mandatory and 'best practice' guidance for clinic staff, as well as providing patients, donors, donor-conceived people and publics with information about fertility treatment, donation and research. In 2006, a review of the HFE Act was conducted prior to the revised HFE Act 2008 being passed, writing into law the abolition of donor anonymity previously implemented via the 2004 changes to HFEA regulations. This relatively centralized and prescriptive approach to the regulation of donor conception in the UK provided a helpful source of policy documents, official forms and clinic directives with which to explore how 'openness' is mobilized in this policy area.

Between January and May 2017, we identified 61 policy documents in which the rights and obligations of donors, or donors' families, were either directly discussed or implicated (summarized in Table 1). These included legal documents, public consultations, transcripts of parliamentary debates, professional guidance to infertility counsellors, and a range of documents published by the HFEA. The documents were identified and selected via prior knowledge of the regulatory context, consultation of socio-legal academic studies in this area, browsing the HFEA website, discussion with HFEA staff and through contacts with British Infertility Counselling Association (BICA) members.

The documents were read and coded using Nvivo. The first stage of coding was descriptive, identifying which aspects of policies were relevant to donors and categorizing how exactly they were implicated. For example, different codes were used to categorize where and how policies discussed the donor's role in relation to various aspects of the process (eg payment, testing of gametes, and selection of donors). In this article, we focus largely on data coded as either, 'information *about* donors' or 'information *for* donors'. At this stage of the analysis, it became clear that in order to fully understand what regulatory 'openness' means in this context, mentions of information sharing with or about recipients or donor-offspring would also need to be analysed, since these were a key focus of policy discussions and had direct implications for donors. Further codes were then created: 'information about/for recipients' and 'information about/for donor-offspring'. We then sought to compare the precise rules governing information transfer between those in this donation triad, how such

Table 1. Documents analysed in each category

Category	Document	Publisher	Date
Legal documents	• HFE Act 1990 • HFEA (disclosure of donor information) regulations • HFE Act 2008	• HMSO • HMSO • HMSO	• 1990 • 2004 • 2008
Policy development	• ‘Opening the Register Policy’ and minutes/papers from meetings where it was discussed • Review of the HFE Act • Parliamentary debates HFEA (disclosure of donor information) regulations • General committee debates HFE Act 2008 • Sperm, Egg and Embryo Donation SEED report	• HFEA • Dept. of Health • Hansard • Hansard • HFEA	• 2009–2016 • 2006 • 2004 • 2008 • 2005
HFEA forms	• HFEA application forms for donors, recipients and donor-conceived people requesting access to information • Historic and current HFEA donor registration forms	• HFEA • HFEA	• 2016 • 1991–2015
Codes of Practice	• HFEA Codes of Practice • Chairs’ letters to clinics advising of updates to Code of Practice • BICA Practice guidelines • BICA Opening the Record	• HFEA • HFEA • BICA • BICA	• 1991–2016 • 1991–2017 • 2012 • 2003
Information leaflets	• Leaflets provided on the HFEA website linked to application for information forms	HFEA and Lifecycle	2016

HMSO, Her Majesty’s Stationary Office.

sharing was framed and also any explicit or implicit justifications given for the policy decisions made. This final stage of the analytical process involved reading and coding of HFEA working papers and parliamentary debates in an attempt to trace the discourses behind the final policy decisions made.

IV. HOW OPENNESS IS REALIZED IN UK POLICY

As noted above, when analysing UK policy on donor conception, it quickly became apparent that donor conception is imagined to primarily affect three parties: the recipient(s), the donor, and any donor-conceived offspring. It is between these three persons that information sharing is discussed and supported (or hindered) in various ways. In order to demonstrate and compare how UK policy conceptualizes openness in this 'triad', our analysis takes each group in turn, analysing both the information which current regulation makes accessible to them and the ways in which the significance of this information is framed in policy texts.

1. Donor-Conceived Offspring

UK regulations state that, at age 16, donor offspring are able to access non-identifying information about their donor. This includes all information recorded in the standardized HFEA donor registration form, excluding the donor's name and contact details. These forms record the donor's 'ethnic group', their physical characteristics (height, weight, hair, eye, and skin colour) religion, occupation, interests, skills, and reasons for donating. In addition, there is space for donors to write a 'good will message' to offspring and a freehand personal description of themselves (sometimes referred to as the 'pen portrait'). Any information deemed potentially identifying would be redacted by HFEA staff. At age 18, those whose donors donated after April 2005 or who donated prior to this date but have re-registered as identifiable, are able to also access this identifying information, alongside their donor's name and last known address.

Upon reaching the age of 16, donor offspring can also access basic information about any other donor-conceived offspring conceived from the same donor as themselves. This is limited to the number of any such 'donor siblings', their year of birth, and their sex. However, if two donor-conceived people, 16 or over, are considering entering into an 'intimate physical relationship', they may submit a joint application to the HFEA to ascertain whether or not they are genetically related via a shared donor. At age 18, donor offspring can also apply to register with Donor Sibling Link, a facility through which they can, by mutual consent, share information and make contact with donor-conceived genetic siblings.

The HFEA provides postal application forms and advice leaflets for donor-conceived people who wish to access information held on the register. More than simply collecting the necessary information for the HFEA to access and report the relevant information, these procedures and documents also frame the significance of this information in particular ways. HFEA texts depict accessing information as a 'big decision' with profound emotional consequences. A HFEA leaflet explains that accessing information about donors and donor siblings can raise 'unexpected feelings' and that is important to 'prepare' themselves before embarking on the application process:

> It's important to prepare for this and how to deal with the various feelings you might have. That's why we encourage you to talk to someone you trust such as a family member or friend, a professional or other people who have already been through a similar experience. We recommend you take advantage of our free confidential support service which gives you the chance to talk things through with a specialist donor conception support worker. (HFEA application for information about your donor or donor-conceived siblings, 2016a)

Although the same application enables access to information about both donor siblings and the donor, what is portrayed as emotionally complicated about this information is largely framed in terms of information about the donor rather than any other donor relation. This is evidenced in the list of questions which the accompanying leaflet (HFEA, 2016b) suggests donor-conceived people consider before making a decision. Several of these refer directly to information about the donor, for example, 'Is this a good time in your life to get information about your donor?' 'What if your donor seems totally different to you?' 'Will I ever be able to find my donor?'. Only one refers to information about donor-related siblings: 'Have you got any expectations about how many donor-conceived genetic siblings you may have?' Other questions listed could be viewed as referring to information about either the donor, donor-related siblings, or others in the donor's family, but the accompanying text links the question only to information about donors. For example, the question 'What do you expect to find out from us?' is followed by a discussion of the varied quality of information available about donors and the advice that donors may not have been aware of the significance this information might have had to offspring.

Policy decisions and texts imply that donor offspring (more than recipients or donors) are particularly vulnerable to the emotional issues raised by accessing information about donation:

> The Working Group felt that a primary duty of care is owed to donor-conceived people. This is due to the lack of control this group have over the circumstances of their birth and the potential significant impact the release of information could have on their sense of identity. (Opening the register policy: a principled approach, HFEA, 2009)

This sentiment is borne out in the HFE Act 2008 which places a statutory requirement upon the HFEA to offer counselling to this group (but not to recipients or donors). As the above citation shows, the particular emotional significance which donation information is seen to have for donor-conceived people is tied to the impact it is perceived to have on their sense of identity. Such statements reflect the arguments put forward in the parliamentary debates preceding the introduction of identity-release donation (see also Turkmendag, 2012):

> Knowing who one's biological parents are is part of one's identity, and it is important to have that information, if it is available. I do not think it is relevant only on medical grounds so it is not adequate to have only the non-identifying information available. (UK Parliament, 2004, c.352)
>
> The purpose of allowing donor-conceived people access to information about their donor is to fill a gap in the knowledge that they have about themselves. Many donor-conceived people feel they are missing important information about who they are and where they came from, because one set of genetic information is missing. (UK Parliament, 2008, c.154)

These arguments reference the broader idea in Euro-American cultures that information about reproduction has a 'constitutive' character (Strathern, 1999b; Carsten, 2007; Klotz, 2014). As Strathern (1999b) explains, for persons inhabiting this cultural universe, finding out about one's ancestry is assumed to have automatic implications for both kinship and identity. Knowledge about ancestry is constitutive in that the very act of knowing creates a relationship which in turn impacts on and alters already existing relationships. Framing this policy wording is thus the belief that knowledge about our own reproduction is knowledge about ourselves.

The above extract from the House of Lords debates suggests that this information is deemed significant in terms of its genetic character. This would seem to support the view that the 2004 changes to HFEA regulations can be seen as part of a wider 'geneticization' of parenthood and identity (see Donovan, 2006). However, it should be noted that although this emphasis was common in the parliamentary debates, HFEA policy documents tend to be more open-ended with regard to the significance that information about the donor may have for donor offspring. For example, donors are encouraged to complete a 'goodwill message' and also record their reasons for donating as part of the information that can be accessed by donor offspring. In this sense, although HFEA policies emphasize that information about donation is significant to offspring primarily in terms of finding out 'where (or from whom) they came from', they do not configure that information in genetic terms only.

Given the emphasis on enabling donor-conceived people to find out 'where they came from', the provision in the HFE Act 2008 for the creation of the Donor Sibling Link service appears something of an anomaly. However, it should be noted that this decision was given much less attention in parliamentary and policy debates than the equivalent decision about donor information and there seems to be much less consensus on its significance. In parliamentary debates, brief mention was made of this provision in order to avoid consanguineous relationships between donor-conceived people but there was no discussion as to why the law was extended to allow for the creation of the Donor Sibling Link, building on the previous provision for donor-conceived people to find out if they were related to one another.

2. RECIPIENT PARENTS

Recipients of donor gametes are able to access non-identifying information about donors whose gametes have been (or are planned to be) used in their treatment. Though not a statutory requirement, HFEA policy states that they are permitted access to the same information available to 16-year-old donor offspring and this can be made available to them prior to treatment, as well as afterwards (see HFEA, 2009). Recipients can also apply to the HFEA to access basic information about the number, approximate age, and sex of any donor-related siblings to their own children.

The fact that the information available to recipients mirrors that which will later be available to their 16-year-old children is no coincidence. Policy documents frame information about donors and donor siblings as significant to recipients in their role as parents (or potential parents) of donor-conceived children and not as *directly* meaningful to themselves as recipients of donated gametes. In other words, openness in this context is seen to operate with the same aim as described in the Section IV.1: information about donors should flow to the donor-conceived child. Explanatory notes on the HFEA's donor information forms explain that, although recipients may read their goodwill message and personal statement, this will be in order that they can discuss the information contained with their children:

> You may wish to provide in these sections a goodwill message and description of yourself. This information is not compulsory but it is recommended you complete these sections as the information you provide can help parents tell children about their origins and answer some questions a donor-conceived person may have. (HFEA donor information form version 4, 2015).

Similarly, the HFEA application form for recipients applying for information about donors is quite explicit that this information is ultimately for their children; they are being permitted access specifically in order that they can pass it on:

> We give this information to you so that it can be passed onto your donor-conceived child. [. . .] You may wish to access professional support groups to help you to have these conversations in an open and sensitive way. (HFEA Application for information about your child(ren)'s donor and/or donor-conceived genetic siblings version 4, 2016c).

Note that the title of this application form states that the information they seek is about their 'child(ren)'s donor' and not, as might be equally legitimate, *their* donor, therefore reinforcing the idea that in seeking this information they are acting on their child's behalf. To the extent that accessing this information is seen to create social or emotional issues for recipients themselves, this seems to be limited to discussions about how they might pass that information on to their children and it is in relation to this issue that they are advised to seek professional support. To our knowledge, there is no equivalent leaflet to that discussed above for donor-conceived people which discusses the emotional implications and questions to consider before accessing this information for recipients.

3. Donors

Donors are able to access basic non-identifying information about any person that has been born from their donation; the HFE Act 2008 makes it a statutory right for donors to request and be informed of the number of offspring born from their donation, their years of birth, and their sexes. Our analysis of policy documents and parliamentary debates found no significant discussion regarding why this clause was inserted into the revised HFE Act suggesting that its inclusion was seen as non-contentious and not seen to be in need of justification.

One reason for its apparently non-contentious status in the 2008 debates may have been that it had already become 'best practice', prior to it being written in law. In 2004, a letter from the chair of the HFEA to licensed clinics suggested that basic information about donor offspring should be disclosed to donors on the basis that it would enable donors to prepare themselves and their families for contact. At this time, the provision of information to donors was recommended by the HFEA but not a statutory requirement:

> Providing information [to donors or the parents of donor-conceived people] may benefit those concerned, for example by allowing parents to make informed decisions about the controlled disclosure of information to their children and by allowing donors to prepare themselves and their families for possible contact with a donor-conceived person and their family. (HFEA Chair's letter, 2004).

Here, the disclosure of information about offspring to donors seems to be valued not for its own sake but as a means of preparing for information to be shared about donors with offspring. Openness *with* donors is therefore framed as means of ensuring that openness *about* donors is successful and that any implied disruption it might cause to their families is minimized.

In line with this finding, the transfer of information to donors is not conveyed as having the same emotional significance as when this information is relayed in the opposite direction. This is partly evident in the comparative lack of information available to donors vis-à-vis donor offspring. In addition, there is no statutory requirement on the HFEA to offer counselling to donors seeking information about their offspring, suggesting that the decision to access this information is seen as less complex or problematic than the other way around. That said, it is HFEA policy to recommend that donors 'talk things through' with someone else before going ahead with their application to request information and the form recommends this alongside directions to clinics and other organizations who may be able to support them.

V. AN ORIGINS FRAMEWORK AND ITS CONSEQUENCES

Looking at the information trajectories which are accessible, and the ways in which these are framed, it is clear that the 'openness' legitimized in UK policies on donor conception has limits and is realized primarily in one particular way. Policy texts focus on the provision of information to donor offspring about their donor; this is framed as information about their origins and therefore about 'who they are'. Although donors and recipients are also able to access (non-identifying) information about the donation, this is framed as part of donor offspring's ability to access this origins information. For donors, accessing information about offspring is said to enable them to prepare for future contact from their offspring and for recipients, information about donors is provided in order that they can communicate it to their donor-conceived children. It is therefore the case that donor conception policy facilitates openness specifically in relation to information about offspring's origins and not a more generalized commitment to openness regarding information about gamete donation and donor conception, and the connections they do (or could) create.

It may seem common sense that policy in this area should emphasize the importance of origins information to donor offspring. After all, there is now a considerable body of academic literature which demonstrates the importance of this information to donor-conceived people (Turner and Coyle, 2000; Scheib et al, 2005; Jadva et al, 2010) and the reasoning of the HFEA that donor-conceived people (more than recipients or donors) lack agency in the decision to be part of a donor conception rings true (see findings in 'donor offspring' section). We are not seeking to deny that information about their donor may be of significance to donor-conceived people.

However, we wish to highlight that the emphasis on this information trajectory, and the exclusion of others, constructs a particular version of reality (Berger and Luckmann, 1966) which in effect forecloses alternative or additional ways in which gamete donation and donor conception might be seen to matter. It is possible that openness *could* be different; donation information could matter in multiple ways, including but not limited to that about origins.

Neither are we suggesting that UK policy on donor conception imposes the view that origins information will *necessarily* be important to donor offspring. We are in agreement with Klotz's (2014) contention that HFEA policy aims to create agency for donor-conceived people to decide if this information matters to them or not. Rather we are suggesting that by facilitating and framing openness along particular trajectories, they create a framework for understanding in what sense donor conception information could be made to matter. Or to put it another way, if information about donor conception is going to be of *any* significance then, the policy implies, it is going to be significant in this way to these people.

To explain and explore further the implications of this finding, it is helpful to consider one information trajectory which is excluded under current UK policy; there is no acknowledgement of the direct interest donors and recipients may have information about one another. At no stage can these two parties find out identifying information about each other; such information searching missions can only be initiated by the donor-conceived person. Currently, non-identifying information about the donor can be provided to recipients, but only with the understanding that they will then pass that information on to their donor- conceived child(ren). Likewise, donors are not able to access any information about their recipients, nor is there any facility through which donors and recipients, anonymous at the time of donation, can later make contact with one another by mutual consent.

This situation is somewhat at odds with the findings of studies which have sought to explore donors' and recipients' views of one another. A recent interview study with donor-conceived families found parents were often interested in donors as people, not only as potential genetic parents to their offspring; recipients wanted to know why donors were motivated to donate and it was often important that they could imagine liking them (Nordqvist and Smart, 2014b). Previous research also suggests that egg donors often value or desire contact with, or information about, recipients (Graham et al, 2016), sometimes explained as a way of personalizing or acknowledging the gift they have given (Shaw, 2007, 2008; Gilman, 2017). Both Gilman's (2017) interview study of identity-release donors and Konrad's (2005) work with UK egg donors found that information about the outcome of the donation (ie whether a pregnancy was achieved and a baby born) was valued as a means of finding out if their gift had been a success; in effect, information about donor offspring was valued primarily as a means of finding out if they had achieved their aim of helping the recipients become parents, rather than whether they themselves had become 'donor parents'.

The possibility of contact between donors and recipients was not considered in any of the debates or consultation papers analysed. The lack of consideration is anomalous when we consider policy decisions which have been made in relation to some other forms of bodily donation; there are procedures via which organ donor families and bone marrow donors and recipients can make contact with one another (British Transplant Society, 2015; NHS Blood and Transplant, 2017; Anthony Nolan Trust, 2017a,b). These policies set out procedures via which facilitating organizations should manage these communications and dictate that contacts should begin anonymously before face-to-face contact is arranged after a period of time, if that is mutually desired. However, in UK gamete donation, the interest donors and recipients may have in one another remains unacknowledged. This renders invisible an alternative or additional framework for making sense of gamete donation and information about those involved; rather than thinking about donation exclusively as a reproductive act, we might also view it as an act of bodily donation, connecting donors and recipients, not only via a potential donor-conceived person, but also as givers and receivers of this material.

The exclusive emphasis on a reproductive framework for understanding gamete donation is partly explained by the particular symbolic status which gametes and conception have in Euro-American society. Schneider's (1984) *Critique on the Study of Kinship* highlighted the ethnocentricity underpinning the anthropology of kinship to that date. He argued that the centrality of understandings of sexual reproduction to Euro-American kinship led his colleagues to impose this a priori assumption in their analysis, examining how the 'biological facts' of human reproduction were recognized within different kinship systems, rather than considering that reproduction might not have such a central position in their kinship reckonings or social organization more broadly. The 'new kinship studies' have since gone beyond this critique, highlighting the importance of culture and context regarding not only *whether* 'biology' matters to understandings of kinship but also the mutable status as to what is meant by 'biological' (eg Strathern, 1992; Thompson, 2005). However, Schneider's analysis remains relevant to this discussion in that it highlights the symbolic importance of conception to Euro-American kinship and what we can overlook when we see the world through this lens. We suggest that in the UK, such is the centrality of biological reproduction to our understandings of kinship and identity that the significance of gamete donation as a (potentially) reproductive act screens out additional ways in which this act may carry meaning.

Of course, it is not surprising that a reproductive framework is used to make sense of what is significant about gamete donation. After all, what distinguishes this form of bodily donation is that gametes are donated for the purpose of enabling another's fertility treatment and therefore with the explicit intention that a new life will be created. However, what Schneider's (1984) work helps to explain is the extent to which this framework is applied to the exclusion of others. In effect, why it is that the substance of *what* is donated is emphasized whilst the *way* in which it is transferred is side-lined? Or to put it another way, the particular symbolic status of the moment of conception, explains why the *gamete* in 'gamete donation' is emphasized to the exclusion of the *donation*.

Furthermore, even within a reproductive framework, UK policy organizes openness around the idea that particular kinds of reproductive information and relationships are significant, whilst others are attributed less importance, or ignored altogether. Specifically, the focus is on reproductive information as origins information about where the donor-conceived person has come from, rather than, as may also be of interest, information about what has been passed on or shared ancestry. This is reflected in the lack of discussion in parliamentary debates or HFEA working papers given to donors' potential interest in finding out about their donor-conceived offspring (other than to prepare themselves and their families for contact (see findings section on donors)). In addition, whilst an amendment to the HFE Act 2008 was proposed (though not passed into law) which would have given children of donor-conceived offspring the right to trace their parent's donor, no consideration was given to the interests that the parents of donors might have in their children's donor-conceived offspring (as evidenced by some in Beeson et al's (2013) study).

With regard to shared ancestry, the provision of the Donor Sibling Link would suggest that politicians and policy-makers have responded to research findings which demonstrate the importance donor-conceived people sometimes attribute to connections with 'donor siblings' (Jadva et al, 2010; Hertz and Mattes, 2011; Blyth, 2012). However, as noted earlier, there has been much less debate and discussion regarding the significance of these lateral ties. In addition, the interest donors' own children might have in finding out about their donor-conceived genetic half-siblings (see Blyth et al, 2017) has been largely overlooked. This topic was not discussed in the parliamentary debates and, although a HFEA working group did consider the possibility of donors' 'naturally conceived' children joining the Donor Sibling Link, this was not implemented due to concerns that to do so would overstep their remit as stated in the HFE Act 2008 (HFEA, 2009). The emphasis on the transfer of information downwards from one generation to the next is explicable through the particular significance attributed to knowing one's origins in Euro-American kinship systems. As Edwards (2000) and Strathern (1999a,b) explain, to know about one's origins is perceived as an important way in which people are connected to the past, a way of rooting oneself in the present and providing ontological security (Carsten, 2000). Conversely, to not know one's origins is perceived to leave a person at risk of being disconnected and the feeling that something is 'missing' (Edwards, 2000). With regard to knowledge about origins, cultural tropes are plentiful – this information is said to tell us 'who we are and where we came from', to constitute the 'something missing' in our identity and 'our roots'. There is arguably less of an established cultural narrative about the significance of knowledge about lateral connections and it is perhaps for this reason that, even within a reproductive framework, openness tends to be organized around the transfer of origins information rather than reproductive information more widely.

VI. CONCLUSIONS

We have shown that, by organizing openness along particular trajectories and side-lining others, UK policies construct the meaning of gamete donation and the relationships it sets in train in a particular way. These texts foreground the significance which donation information may have to donor-conceived people as information about their donor and therefore 'where they come from'. However, in doing so, they side-line alternative or additional ways in which gamete donation may be understood and the connections gamete donation could (and does) create between people. In this article, we have highlighted the way in which the exclusion of the donor-recipient trajectory from this particular organization of openness side-lines an understanding of gamete donation as a gift or bodily donation and the possibilities for how such a connection might be imagined or enacted. In addition, we have drawn attention to the tendency in UK policy to configure reproductive information as information about origins, rather than information about 'passing on' or shared ancestry.

Given the pervasiveness of the ideology of openness, increased availability of information is often viewed as inherently positive and equated with increased freedom and choice. However, what we hope to highlight is that the sharing of information is rarely, if ever, value-free and can constrain, as well as enable, choices about social relationships (see also Carsten, 2007). When policy-makers mandate that certain kinds of information ought to be accessible, judgements have to be made about *what* and *who* that information is about. It is therefore crucial that we examine what is included and excluded in this drive to disclose. What kind of information is deemed necessary to tell and to whom? In short, what form of openness is being advocated? We suggest that this is an important line of inquiry because, when we encourage 'openness' along particular trajectories and not others, we shape the meaning of that which we are being open about and so alternative or additional understandings can be foreclosed, ignored, or devalued. As Smart (2009) explains, we need to examine what kind of 'truths' are being told when particular categories of information are deemed (legally) necessary to tell. We would add that close attention also needs to be paid to the trajectories along which openness is encouraged, or hindered, and the ways in which this shapes the social relationships which can be imagined or enacted between people.

It has not been our intention to suggest that donor offspring should not be able to access information about their donor, nor are we necessarily suggesting that donors, recipients, and offspring should all have equal access to information. However, we hope to raise questions about the information trajectories available to those implicated by donation, as well as the way these are framed and whether this might be done in ways which enable multiple 'truths' about the kind of act gamete donation is and the connections it creates.

ACKNOWLEDGEMENT

The authors are grateful to the ESRC for funding the research we report here (grant number ES/N014154/1). Thanks also to the 'Curious Connections' advisory board and the anonymous reviewers for helpful feedback on this article and the ideas expressed within.

REFERENCES

Anthony Nolan Trust (2017a) *'Getting in touch with your donor: what are the rules?'* See https://www.anthonynolan.org/patients-and-families/recovery-after-first-year/getting-touch-your-donor.

Anthony Nolan Trust (2017b) *'How is the person I helped?' Anthony Nolan Trust*. See https://www.anthonynolan.org/8-ways-you-could-save-life/donate-your-stem-cells/support-donors/how-person-i-helped.

Beeson, D., Jennings, P. and Kramer W. (2013) 'A new path to grandparenthood parents of sperm and egg donors', *Journal of Family Issues* **34**(10), 1295–316.

Berger, P. and Luckmann, T. (1966) *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*, New York: Doubleday.

Blyth, E. (2012) 'Genes r us? Making sense of genetic and non-genetic relationships following anonymous donor insemination', *Reproductive Biomedicine Online* **24**(7), 719–26.

Blyth, E., Crawshaw, M., Frith, L. and van den Akker, O. (2017) 'Gamete donors' reasons for, and expectations and experiences of, registration with a voluntary donor linking register', *Human Fertility* **20**(4), 268–78.

Blyth, E., Crawshaw M., Haase, J. and Speirs, J. (2001) 'The implications of adoption for donor offspring following donor-assisted conception', *Child & Family Social Work* **6**(4), 295–304.

Blyth, E., and Frith, L. (2009) 'Donor-conceived people's access to genetic and biographical history: an analysis of provisions in different jurisdictions permitting disclosure of donor identity', *International Journal of Law, Policy and the Family* **23**(2), 174–91.

Blyth, E., Frith, L., Jones, C. and Speirs, J. (2009) 'The role of birth certificates in relation to access to biographical and genetic history in donor conception', *The International Journal of Children's Rights* **17**(2), 207–33.

British Transplant Society (2015) *Consent for Solid Organ Transplantation in Adults: British Transplant Society Guidelines*, British Transplant Society. See https://bts.org.uk/wp-content/uploads/2016/09/12_BTS_NHS_Consent_April_2013-1.pdf (accessed 6 April 2018).

Carsten, J. (2000) '"Knowing where you've come from": ruptures and continuities of time and kinship in narratives of adoption reunions', *The Journal of the Royal Anthropological Institute* **6**(4), 687–703.

Carsten, J. (2007) 'Constitutive knowledge: tracing trajectories of information in new contexts of relatedness', *Anthropological Quarterly* **80**(2), 403–26.

Crawshaw, M.A., Blyth, E.D. and Feast, J. (2017) 'Can the UK's birth registration system better serve the interests of those born following collaborative assisted reproduction?', *Reproductive Biomedicine & Society Online* **4**(June), 1–4.

Crawshaw, M., McCrystal, P., Hunt, J., Monach, J. and Pike, S. (2012) *BICA Practice Guidelines*, BICA Publications. See http://bica.net/ (accessed 5 April 2018).

Daniels, K. (1995) 'Information sharing in donor insemination: a conflict of rights and needs', *Cambridge Quarterly of Healthcare Ethics* **4**(02), 217–24.

Daniels, K.R. and Taylor, K. (1993) 'Secrecy and openness in donor insemination', *Politics and the Life Sciences* **12**(2), 155–70.

Donovan, C. (2006) 'Genetics, fathers and families: exploring the implications of changing the law in favour of identifying sperm donors', *Social & Legal Studies* **15**(4), 494–510.

Edwards, J. (2000) *Born and Bred: Idioms of Kinship and New Reproductive Technologies in England*, Oxford and New York: Oxford University Press.

Edwards, J. (2005) "Make-up': Personhood through the lens of biotechnology', *Ethnos* **70**(3), 413–31.

Faircloth, C. and Gürtin, Z.B. (2017) 'Fertile connections: thinking across assisted reproductive technologies and parenting culture studies', *Sociology*, 03 April. http://journals.sagepub.com/doi/abs/10.1177/0038038517696219 (accessed 8 September 2018).

Freeman, M. (1996) 'The new birth right', *International Journal of Children's Rights* **4**, 273.

Freeman, T. (2015) 'Gamete donation, information sharing and the best interests of the child: an overview of the psychosocial evidence', *Monash Bioethics Review* **33**(1), 45–63.

Frith, L. (2001) 'Gamete donation and anonymity: the ethical and legal debate', *Human Reproduction* **16**(5), 818–24.

Geertz, C. (1983) *Local Knowledge: Fact and Law in Comparative Perspective*, New York: Basic Books.

Giddens, A. (1992) *The Transformation of Intimacy: Sexuality, Love and Eroticism in Modern Societies*, Stanford, California: Stanford University Press.

Gilman, L. (2017) *'Qualifying Kinship: How Do UK Gamete Donors Negotiate Identity-Release Donation?'*, Edinburgh: University of Edinburgh.

Golombok, S., Murray, C., Jadva, V., Lycett, E., MacCallum, F. and Rust, J. (2006) 'Non-genetic and non-gestational parenthood: consequences for parent–child relationships and the psychological well-being of mothers, fathers and children at age 3', *Human Reproduction* **21**(7), 1918–24.

Graham, S., Jadva, V., Freeman, T., Ahuja, K. and Golombok, S. (2016) 'Being an identity-release donor: a qualitative study exploring the motivations, experiences and future expectations of current UK egg donors', *Human Fertility* **19**(4), 230–41.

Haimes, E. (1992) 'Gamete donation and the social management of genetic origins', in Stacey M. (ed), *Changing Human Reproduction: Social Science Perspectives,* London: Sage, 119–47.

Haimes, E. (1993) 'Issues of gender in gamete donation', *Social Science & Medicine* **36**(1), 85–93.

Haimes, E. and Daniels, K. (1998) 'International social science perspectives on donor insemination: an introduction', in E. Haimes and K. Daniels (ed), *Donor Insemination: International Social Science Perspectives,* Cambridge: Cambridge University Press, 1–6 .

HFEA (2004) '*Chair's letter: CH (04) 07 Disclosure of information relating to gamete donation*'. See http://hfeaarchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/2675.html (accessed 20 May 2017).

HFEA (2009) *'Opening the register policy: a principled approach'*. See http://hfeaarchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/docs/AM_Item_9_Jan09.pdf (accessed 20 May 2017).

HFEA (2015) *Donor Information Form Version 4*. London: HFEA. See http://hfeaarchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/docs/HFEA_Form_Donor.pdf (accessed 20 May 2017).

HFEA (2016a) 'Application for information about your donor or donor-conceived genetic siblings', Version 4. See http://hfeaarchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/docs/20160629_Application_for_information_about_your_donor_and_or_donor_conceived_genetic_siblings.pdf (accessed 20 May 2017.)

HFEA (2016b) 'Preparing to access non-identifying information about your donor and donor-conceived genetic siblings', version 2. See http://hfeaarchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/docs/Preparing_to_access_non-identifying_information_about_your_donor_and_donor-conceived_genetic_siblings(5).pdf (accessed 20 May 2017).

HFEA (2016c) 'Application for information about your child(ren)'s donor and/or donor-conceived genetic siblings', version 4. See http://hfeaarchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/docs/20160704_Parent_application_for_information_about_your_childrens_donor_and_or_donor_conceived_genetic_siblings.pdf (accessed 20 May 2017).

Hertz, R. and Mattes, J. (2011) 'Donor-shared siblings or genetic strangers: new families, clans, and the internet', *Journal of Family Issues* **32**(9), 1129–55.

Jadva, V., Freeman, T., Kramer, W. and Golombok, S. (2010) 'Experiences of offspring searching for and contacting their donor siblings and donor', *Reproductive BioMedicine Online* **20**(4), 523–32.

Jamieson, L. (1999) 'Intimacy transformed? A critical look at the`pure relationship', *Sociology* **33**(3): 477–94.

Jones, C. (2016) 'Openness in adoption: challenging the narrative of historical Progress' *Child & Family Social Work* **21**(1), 85–93.

Klotz, M. (2014) *(K)information: Gamete Donation and Kinship Knowledge in Germany and Britain.* Volume **32**. Frankfurt and New York: Campus Verlag.

Konrad, M. (2005) *Nameless Relations: Anonymity, Melanesia and Reproductive Gift Exchange between British Ova Donors and Recipients,* Oxford: Berghahn Books.

Lycett, E., Daniels, K., Curson, R. and Golombok, S. (2004) 'Offspring created as a result of donor insemination: a study of family relationships, child adjustment, and disclosure', *Fertility and Sterility* **82**(1), 172–79.

McGee, G., Brakman, S.-V. and Gurmankin, A.D. (2001) 'Gamete donation and anonymity: disclosure to children conceived with donor gametes should not be optional', *Human Reproduction* **16**(10), 2033–36.

McWhinnie, A.M. (1996) '*Families Following Assisted Conception: What Do We Tell Our Child?*', Dundee: University of Dundee Social Work Department.

Melhuus, M. (2012) *Problems of Conception: Issues of Law, Biotechnology, Individuals and Kinship,* New York and Oxford: Berghahn Books.

Moore, S. (2017) 'Towards a sociology of institutional transparency: openness, deception and the problem of public trust', *Sociology* **52**(2), 416–30.

NHS Blood and Transplant (2017) *'Donor Family and Recipient Contact'*, NHS Blood and Transplant. See http://www.odt.nhs.uk/transplantation/recipient-coordination/donor-family-and-recipient-contact/.

Nordqvist, P. (2014) 'The drive for openness in donor conception: disclosure and the trouble with real life', *International Journal of Law, Policy and the Family* **28**(3), 321–38.

Nordqvist, P. and Smart, C. (2014a) 'Relational lives, relational selves' in Freeman. T, Graham. S, Ebtehaj. F and Richards M. (eds) *Relatedness in Assisted Reproduction*, Cambridge: Cambridge University Press, 296–311.

Nordqvist, P. and Smart, C. (2014b) *Relative Strangers: Family Life, Genes and Donor Conception*, Basingstoke and New York: Palgrave Macmillan.

Ravelingien, A., Provoost, V. and Pennings, G. (2013) 'Donor-conceived children looking for their sperm donor: what do they want to know?' *Facts, Views & Vision in Obstetrics and Gynaecology* **5**(4), 257.

Sants, H.J. (1964) 'Genealogical bewilderment in children with substitute parents', *British Journal of Medical Psychology* **37**(2), 133–42.

Scheib, J.E., Riordan, M. and. Rubin, S. (2005) 'Adolescents with open-identity sperm donors: reports from 12–17 year olds' *Human Reproduction* **20**(1), 239–52.

Schneider, D. (1984) *A Critique of the Study of Kinship*, Michigan: Michigan University Press.

Shaw, R. (2007) 'The gift-exchange and reciprocity of women in donor-assisted conception', *The Sociological Review* **55**(2), 293–310.

Shaw, R. (2008) 'The notion of the gift in the donation of body tissues', *Sociological Research Online* **13**(6), 4.

Smart, C. (2009) 'Family secrets: law and understandings of openness in everyday relationships', *Journal of Social Policy* **38**(04), 551–67.

Smart, C. (2010) 'Law and the regulation of family secrets', *International Journal of Law, Policy and the Family* **24**(3), 397–413.

Smart, C. (2011) 'Families, secrets and memories', *Sociology* **45**(4), 539–53.

Strathern, M. (1992) *After Nature: English Kinship in the Late Twentieth Century*, Cambridge and New York: Cambridge University Press.

Strathern, M. (1999a) *Property, Substance and Effect: Anthropological Essays on Persons and Things*, London: Athlone Press.

Strathern, M. (1999b) *Property, Substance and Effect: Anthropological Essays on Persons and Things*, London: Athlone Press, 64–86.

Thompson, C. (2005) *Making Parents: The Ontological Choreography of Reproductive Technologies*, Cambridge and Massachusetts: The MIT Press.

Turkmendag, I. (2012) 'The donor-conceived child's "right to personal identity": the public debate on donor anonymity in the United Kingdom', *Journal of Law and Society* **39**(1), 58–75.

Turkmendag, I., Dingwall, R. and Murphy, T. (2008) 'The removal of donor anonymity in the UK: the silencing of claims by would-be parents', *International Journal of Law, Policy and the Family* **22**(3), 283–310.

Turner, A.J. and Coyle A. (2000) 'What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy', *Human Reproduction* **15**(9), 2041–51.

Turner, C. (1993) 'A call for openness in donor insemination', *Politics and the Life Sciences* **12,** 197–99.

UK Parliament (2004) Human Fertilisation and Embryology (Disclosure of Donor Information) Regulations 2004 [HL] 09 June 2004 vol 662 c. 344–663.

UK Parliament (2008) Human Fertilisation and Embryology Bill [Public Bill Committee Debate] 05 June 2008 c. 152–166.