

**RUNNING HEAD: Psychosocial evidence on gamete donation and information sharing**

**TITLE: Gamete donation, information sharing and the best interests of the child: an overview of the psychosocial evidence**

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## ABSTRACT

This paper overviews key empirical findings from social science research regarding the impact of gamete donation on child wellbeing. In particular, the paper addresses current regulatory debates concerning information sharing and the best interests of the child by considering psychosocial aspects of telling - or not telling - children about their donor conception and the identity of their donor. The paper identifies three core sets of empirical, ethical and policy concerns underpinning these debates relating to (i) the psychosocial impact of gamete donation *per se* on child wellbeing, (ii) the psychosocial impact of parental disclosure decisions on child wellbeing, and (iii) the psychosocial implications of donor identification for donor-conceived offspring. The paper illustrates how these concerns are framed by ideas about the significance – or not – of ‘genetic relatedness’; ideas which have come to the fore in contemporary discussions about the potential consequences of donor-conceived individuals gaining access to their donor’s identity. By drawing together research findings that may be pertinent to the regulation of gamete donation and information sharing, a further aim of this paper is to explore the potential use and misuse of empirical ‘evidence’ in ethical and policy debates. Whilst this paper starts from the premise that psychosocial data has a vital role in grounding normative discussions, it seeks to contribute to this dialogue by highlighting both the value and limitations of social science research. In particular, the paper argues for a cautious approach to applying psychosocial evidence to ethical issues that is sensitive to the caveats and nuances of research findings and the changing cultural and regulatory context.

## INTRODUCTION

The history of gamete donation is often presented as a history of technological advancement, social controversy and ethical debate. However, beneath this public rhetoric, the history of gamete donation also lies in the rich and diverse experiences of the rising numbers of children and families who have been created in this way. There is growing awareness that bringing together these different realms can be a valuable, if complex, task. Indeed, in recent years there have been various calls for empirical ‘evidence’ about the realities of donor conception families to inform ethical and regulatory discussions about gamete donation. In particular, the agreed standard for guiding these debates, that is the protection of the ‘best interests of the child’, is deemed to require some consideration of psychosocial outcomes for children within different reproductive scenarios. It is here that social science research can make a critical contribution, providing descriptions and evaluations of the impact of gamete donation on child wellbeing grounded in empirical observation and measurement, as well as illuminating the meaning of these experiences from the perspectives of those involved. Indeed, a key strength of such research is the ability to counter assumptions about psychosocial aspects of donor conception and family life that may be based on prejudice, speculation, anecdote or abstract reasoning alone. At the same time, applying empirical evidence to ethical debates is intrinsically problematic. Findings are open to misrepresentation, misinterpretation and over-simplification: the same evidence may be used to support different normative arguments and, as I shall argue, there are ethical questions that no amount of empirical data can resolve.

In this paper, I will outline key empirical findings concerning the psychosocial impact of gamete donation on child wellbeing that may be brought to bear on central ethical and policy concerns in this field. Whilst my primary focus is on current regulatory debates within the UK around information sharing, particularly regarding the disclosure to donor-conceived

offspring of both the fact of their donor conception and their donor's identity, I hope that taking a broader historical view of the research will illustrate the interplay between ethical concerns, empirical findings, social contexts and regulatory developments.<sup>1</sup> The three sets of empirical issues that I shall address concern (i) the psychosocial impact of gamete donation *per se* on child wellbeing, (ii) the psychosocial impact of parental disclosure decisions on child wellbeing, and (iii) the psychosocial implications of donor identification for donor-conceived offspring. The empirical insights under discussion are predominantly drawn from psychological research that assesses child wellbeing in gamete donation families by examining aspects of children's psychological development and family relationships.

At the outset, it is important to consider both the definition of child wellbeing that is being operationalised within these studies as well as the measures employed, as these have a critical bearing on the interpretation of the findings. Indeed, these studies cannot claim to be capturing all dimensions of child wellbeing but rather work with a particular understanding based on the observation of children's social and emotional development and family processes. The underlying premise is that quality of parenting and parent-child relationships impact on children's psychological wellbeing (Golombok 2000, forthcoming); for example, high levels of parental warmth, control and communication have been found to be beneficial for children's socio-emotional wellbeing (Macoby and Martin 1983).<sup>2</sup> Similarly, the quality of parents' couple relationships and own psychiatric state may also affect child outcomes by impacting on parents' capacity to parent. The assessment of children's social and emotional development may include identifying the prevalence of psychological disorders amongst a sample, reporting both their severity and type. A variety of measures including standardised interviews, questionnaires and observational measures may be used to assess children's

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<sup>1</sup> I have restricted the primary focus of this article to the UK because regulatory and cultural perspectives on gamete donation vary widely across countries. However, the empirical and ethical issues raised are of broader relevance and furthermore, even within a given national setting, there may be a diversity of views.

<sup>2</sup> This paradigm develops the foundational work on parenting of Baumrind (1991).

psychological adjustment and the quality of parent-child interaction as well as the parents' psychological state and the quality of spouse relationships.<sup>3</sup> These measures are conducted with parents and children; others such as teachers may provide additional assessments of children's behaviour. These measures are all standardised and allow for systematic comparisons amongst sub-groups (e.g. comparing families where children are conceived by sperm donation, egg donation or 'natural conception' or comparing families where parents have told their child about their donor conception with those where parents have not). Where relevant, the data may also be compared against population norms (e.g. comparing the prevalence of emotional or conduct problems against the general population). Thus when discussing the research findings, it is important to bear in mind that statements concerning the impact of gamete donation and information-sharing on child wellbeing must be understood as referring to specific observable aspects of children's psychological adjustment and family functioning that are deemed to be of significance for children's socio-emotional development.

Beyond these definitional issues, the nature of these research findings can sometimes become lost in translation when applying empirical 'evidence' to ethical discussions, owing in part to the intrinsic difficulty of this enterprise encapsulated by the 'is-ought' problematic. Although evidence is valuable in ethical debate, psychological research aims to describe what 'is' and not answer ethical questions about what 'ought' to be. Indeed, it may undermine the quality of psychological research for those who report empirical data to present normative conclusions; conversely, bioethicists involved in normative debate may oversimplify research findings or make false assumptions about psychosocial outcomes that have no empirical grounding. Therefore, a secondary aim of this paper is to highlight some of the nuances and complexities of these research findings that need to be borne in mind when evaluating their

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<sup>3</sup> Further discussion of these measures can be found in Golombok (2000, forthcoming), as well as in the published reports of individual studies which contain detailed descriptions of the measures, including their reliability.

significance. By arguing that empirical findings require interpretation in relation to the changing personal, social and cultural frameworks that shape the meaning of individual experience, I also aim to highlight further issues raised by using empirical data as ‘evidence’ from a broader sociological perspective. In particular, a key theme of this paper is the centrality of the meaning of ‘genetic relatedness’ to contemporary discussions about gamete donation and information sharing. Individual and cultural perceptions of relatedness and the significance - or not - placed on genetic connections between people are fundamental to understanding how questions around the psychosocial impact of gamete donation, parental disclosure and donor identification are framed. To this end, the paper highlights the importance of reflecting on the caveats and complexities of research findings and the cultural and regulatory context when utilising empirical insights in ethical and regulatory debates.

## THE PSYCHOSOCIAL IMPACT OF GAMETE DONATION

Some three decades ago, with the increased availability of assisted reproductive techniques involving sperm donation and the introduction of egg donation, there was a fundamental concern about whether gamete donation in itself would have a negative impact on child wellbeing. As more possibilities for parents to conceive using other people’s gametes opened up, psychological research began to address the question of whether the absence of ‘genetic relatedness’ between a child and their parent(s) in donor conception families would negatively affect their psychological development and family relationships. There is now a growing body of research<sup>4</sup> that indicates that this absence of genetic relatedness does not have a detrimental impact on child adjustment and family functioning. Rather, it has been found that children in gamete donation families are faring as well as their counterparts in

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<sup>4</sup> It is noteworthy that the majority of this research has been conducted by one research team. As well as meaning there are relatively few studies in this area, there is also a need for studies to be replicated by other research teams.

other family forms. This has been consistently shown in longitudinal studies comparing outcomes in families created through different reproductive means, such as sperm donation, egg donation, embryo donation, natural conception, *in vitro* fertilisation (IVF) and surrogacy (Golombok et al. 1995, 1996, 1999, 2002a,b, 2004, 2005, 2006; MacCallum et al. 2007; Murray et al. 2006; Shelton et al. 2009). For example, the European Study of Assisted Reproduction Families compared heterosexual-couple families created by sperm donation and IVF with those with naturally conceived children or children adopted in infancy, following over one hundred families in each group from the UK, Spain, Italy and the Netherlands at age 6 and 12 years. No differences in emotional or behavioural problems were found when comparing children conceived by sperm donation and the other family types.<sup>5</sup> Where differences in parent-child relationships were observed, the quality of parenting was found to be more positive in sperm donation families than natural conception and adoptive families (Golombok et al. 1995, 1996, 1999, 2002a,b).<sup>6</sup>

What conclusions can be drawn from such pioneering longitudinal research for contemporary regulatory debates around gamete donation? The overall finding that there is no evidence of the absence of genetic relatedness to parent(s) in gamete donation families in itself having negative outcomes for child wellbeing remains significant. Indeed, whilst the psychological health of donor-conceived children may now be taken for granted in some realms, it is important not to lose sight of this empirical finding as it provides a crucial benchmark for future debates. For example, when discussing the relative merits of informing – or not informing – children about their donor conception, the underlying premise that children conceived from gamete donation are doing well should not be overlooked. More generally, this research yields the fundamental insight that parenting and family environment

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<sup>5</sup> A smaller sample of egg donation families was also recruited from the UK and yielded similar findings concerning the lack of association between egg donation and difficulties in child adjustment (Murray et al., 2006).

<sup>6</sup> Parents in the UK sample were also seen at age 18 years and similar observations were made concerning positive aspects of parent-child relationships in sperm donation families (Owen and Golombok 2009).

are more important to child wellbeing than family structure (Golombok 2000, forthcoming); that is, that it matters more *how* a child is parented than *who* they are parented by. Again, whilst this appeal to the value of the quality of parenting may appear self-evident to some, it continues to hold great relevance for contemporary debates concerning gamete donation families. One pertinent example concerns the diversification of family forms enabled by gamete donation, including those parented by lesbian couples, solo mothers and, more recently, gay male couples and single men. Any such development almost inevitably evokes well-versed ethical and social anxieties about the potential psychosocial damage inflicted by ‘non-traditional’ family structures on child wellbeing. Thus far, compatible conclusions about the saliency of ‘good’ parenting have also been drawn from comparative studies of sperm donation families headed by heterosexual couples and those headed by lesbian couples (Bos et al. 2007; Gartrell et al. 2012) and single mothers (Murray and Golombok 2005). Emerging work on gay male parenting is also yielding positive findings about the capacity of people to parent well in contexts other than the traditional nuclear family norm (Golombok et al. 2014).

One of the most important caveats for interpreting findings from early ‘benchmark’ studies of gamete donation families is that these children were generally unaware of their donor conception. In the European Study, no sperm donation family had disclosed when the child was 6 years old, less than 10% had disclosed at 12 years and, in a UK follow-up, less than 10% had disclosed at 18 years (Golombok et al. 2002a,b; Owen et al. 2009). These findings therefore indicate that non-disclosure of donor conception does not interfere with children’s psychological development and parent-child relationships whilst begging the question of what the psychosocial outcomes would be if children were informed of their origins. However, a key limitation that requires consideration is that there may be sample biases in terms of the families who agree to take part in these studies as suggested by the relatively low response rates: little is known about child outcomes in those families who do



not take part and, as I shall discuss, this ‘hidden’ donor conception population should not be overlooked. Furthermore, these findings should be interpreted within a particular cultural context when there were deeply engrained social taboos around gamete donation, and sperm donation in particular, with rates of parental disclosure being very low. Indeed, non-disclosure was the norm, at least for families headed by heterosexual couples, with the professional advice parents received from clinics being not to tell their children – or indeed anyone else - about their use of donor gametes. In this context, the belief that it was in a child’s best interests not to be told of their donor origins and, by implication, their donor’s identity, was reflected by parents’ disclosure decisions and by the policy of donor anonymity. In extrapolating these findings to contemporary questions around parental disclosure it should therefore be borne in mind that not being told about one’s donor conception may carry very different meanings in a context where non-disclosure was the norm compared to the openness expected of parents today. This culture of non-disclosure attributed contradictory significance to genetic relatedness, especially with regards to sperm donation. On one level the ‘genetic’ connection between a child and their sperm donor was not given any individual or social recognition. On another, the assumption that ‘genetic’ connection is of fundamental significance to determining male parenthood underpinned the perceived necessity to conceal the father’s lack of genetic relatedness with their child.

## THE PSYCHOSOCIAL IMPACT OF PARENTAL DISCLOSURE DECISIONS

The question of whether parental openness around gamete donation would have a negative impact on child wellbeing became a more pressing concern as the numbers of families being created in this way rose and the ethics of parental secrecy began to be questioned. As a research question, this concern was framed in terms of assessing whether a child’s awareness of the absence of genetic relatedness with their parent(s) in gamete donation families

negatively affects their psychological development and family relationships. As with the previous concern about the impact of gamete donation, there is a fairly substantial body of research in this area which supports the general finding that the psychological wellbeing of children who are aware of their donor conception is not compromised by this knowledge (Golombok 2013; Nuffield Council on Bioethics 2013). This is apparent in both post-2000 longitudinal studies of gamete donation families (Golombok et al. 2004, 2005, 2006, 2011a,b, 2013) and comparative studies of disclosing and non-disclosing gamete donation families (Nachtigall et al. 1997, 1998; Lycett et al. 2004, 2005; Freeman et al. 2012b). Again, the research focus tends to be on heterosexual-couple families;<sup>7</sup> not least because for social and regulatory reasons, these have historically formed the large majority of gamete donation families, at least within the clinical context, and also because disclosure rates are typically lowest in this group (Appleby et al. 2012).

The overall finding is that families in which there is openness about gamete donation are generally functioning as well as ‘non-disclosing’ families. For example, findings from a longitudinal study initiated in 2000 including 50 sperm donation and 51 egg donation families indicate that parental disclosure does not in itself have a detrimental impact on child adjustment, with children conceived by gamete donation faring well overall (Golombok et al. 2004, 2005, 2006). Some differences between disclosing and non-disclosing families emerged with regards to parent-child relationships. During the preschool stage, 46% of sperm donation parents and 56% of egg donation parents reported planning to tell their child about their donor conception (Golombok et al. 2005). By middle childhood, only 28% and 41% respectively had disclosed (Readings et al. 2011), and parent-child relationships in disclosing families were found to be more positive in some respects than in non-disclosing families:

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<sup>7</sup> There are some studies that compare child psychological adjustment in non-disclosing and disclosing families in different family types. See for example Chan et al. (1998)’s study which includes lesbian couple and single mother families.

specifically, disclosing families showed more positive mother-child interaction and lower levels of mothers' emotional distress (Golombok et al. 2011a,b). These findings are in line with a later UK study of 46 sperm donation families recruited from a clinic endorsing openness around donor conception, of which 13% of parents had disclosed to their children at age 4-8 years. Whilst no group differences were found at this age regarding children's psychological adjustment, some aspects of parent-child relationships were more positive in families where parents were open with children about their donor conception: in particular, there was less mother-child conflict than in non-disclosing families (Lycett et al. 2004). A follow-up study at early adolescence (age 10-14 years) by which time 33% of the parents had disclosed again found no significant differences in the psychological adjustment of children in relation to whether or not they were aware of their donor conception, although disclosure appeared to be associated with more positive parent-child relationships with regards to lower levels of mother-son conflict (Freeman et al. 2012b). Adolescents who were aware of their donor origins reported less warmth in their relationship with their father but they also described their lack of genetic relatedness with him as being unimportant (Blake et al. 2014, Freeman in press). For these adolescents, the social relationship between with their father and his enduring presence in their lives effectively eclipsed the significance of the genetic connection with the absent donor. In common with most studies on the impact of parental disclosure decisions to date, these sperm donors were anonymous and essentially untraceable.

When reporting and interpreting research findings concerning differences between disclosing and non-disclosing families, several caveats and complexities should be taken on board. First, whilst there is a tendency to focus on significant differences between families, this should not obscure the greater number of similarities between families: in other words, an absence of significant difference should also be viewed as an important finding. The typically small sample sizes also need to be taken into account as this may limit their

statistical power, just as the sometimes low response rates may lead to potential sample biases; in particular, non-disclosing and/or ‘dysfunctional’ families may be reticent to participate. Where differences are observed, it is also critical to recognise that these are not necessarily indicative of dysfunction. Indeed, the variation in parent-child relationships in the studies cited above fell within the normal range and was not reflected by differences in children’s psychological wellbeing. Furthermore, any observed differences cannot necessarily be directly attributed to parents’ disclosure decisions. Rather, differences in psychosocial outcomes may reflect other differences between ‘disclosing’ and ‘non-disclosing’ families, for example concerning parenting style and communication between family members. Overall, the extent and significance of differences in psychosocial outcomes between disclosing and non-disclosing families should therefore not be over-stated.<sup>8</sup>

Another important insight that is sometimes lost when communicating these research findings is that parents’ disclosure decisions - and their outcomes - are not static. Parents’ considerations and feelings about disclosure may change over time, just as the significance for their children may rise and fall. At present, most is known about children’s responses to first learning of their donor conception in early childhood, a time when children have been found to have a very limited understanding of the process and implications of egg and sperm donation (Blake et al. 2010). There is now a recognition that children’s level of understanding of, and interest in, their donor origins may fluctuate in accordance with their emotional and cognitive development. For example, children will likely develop a fuller understanding of the implications of donor conception at adolescence, a developmental phase when identity issues and conflict within parent-child relationships may also become more prevalent (Freeman and Golombok 2012b). Similarly, in adulthood, being donor conceived may take

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<sup>8</sup> For further discussion of the limitations of these studies, see Golombok (forthcoming).

on different meanings; for example, becoming a parent oneself may lead to an enhanced interest in one's own parentage and 'genetic' origins (Freeman et al. 2014c).

Whilst more research is required to ascertain the impact of gamete donation at adolescence and beyond, what can be gleaned from current empirical work is that the circumstances of disclosure are integral to understanding the outcomes, and that a child's age, sex, family structure and the manner and circumstances of disclosure may play a significant role in how any individual child responds (Jadva et al. 2009). In this vein, a finding that has gained particular currency within ethical and policy discussions is that 'early disclosure' tends to be associated with more positive outcomes: if children are to be informed of their donor conception, the most favourable situation is to be told from an early age so they are never shocked by discovering this knowledge. Donor conception therefore becomes part of a family narrative that is 'always known', with the commonly preferred mechanism for communicating this information being age-appropriate books relaying the story of the child's creation. Conversely, donor offspring who find out during adulthood or under more adverse situations, such as parental death, divorce or arguments, may respond more negatively and report their parents' secrecy about their origins to be a source of psychological harm (Turner et al. 2000; Jadva et al. 2009). Furthermore, just as with adoption, individual personality, identity issues and communication processes within the family may also be of significance to how donor-conceived children adapt to information about their origins (Skinner-Drawz et al. 2011; Wrobel et al. 2013), an area that is beginning to be examined in donor conception research.

Just as children's feelings about their donor conception may change over the life course, so can parents' orientations towards, and feelings about, disclosure. As the findings of the European Study indicate, a significant proportion of parents who report intending to tell their children do not actually go on to do so. Not only does this highlight the difficulties of

ascertaining disclosure rates amongst donor conception families, it also points to a further conceptual limitation of studies of parental disclosure decisions; that is, the tendency to work with a fixed dichotomy between ‘disclosed’ and ‘non-disclosed’ families that conceals fluctuation and variation both within and between these groups. Longitudinal analysis of parents’ disclosure status at different time points has revealed transitions towards both increased secrecy and increased openness (Freeman forthcoming); for example, not only do parents who report intending to tell their child find that they never do so, but conversely parents who state that they have decided against telling may be prompted to do so at a later stage, with their perspectives on disclosure shifting in relation to their changing personal, familial and cultural circumstances. Indeed, the closer one observes the disclosure process, the more complexities arise. For example, recent findings include high levels of ‘partial’ disclosure, that is, where parents have told their children about the fertility treatment whilst omitting information about the use of donor gametes (Readings et al. 2011), and significant discrepancies in parents’ disclosure decisions and their child’s knowledge of their conception, for example, where one parent tells a child without the other parent’s knowledge or where a child simply ‘forgets’ the information they have been told (Freeman in press).

In recent years, there has been a tidal shift in public perceptions of the ethical and social issues raised by donor conception. This is exemplified by the overturning of the concern about the impact of *telling* children about their donor conception with that of *not telling* children. Calls for increased openness are evident across the public realm, with professional advice having now turned full circle from advocating parental secrecy towards the emerging consensus that parental disclosure is in a child’s best interests. Under this new ethics of genetic transparency, the doctrine of donor anonymity has been called into question and in several jurisdictions including the UK, anonymous donation has been replaced by identity-release donation (Freeman et al. 2012a). This reflects a wider cultural preoccupation

with ‘genetic identity’, with increased attention being given to the significance of the ‘genetic connection’ between donor and child in a context in which individuals are viewed as having a right to knowledge of their ‘genetic origins’ (Appleby et al. 2012; Freeman and Richards 2006). Whilst this emphasis on transparency has affected regulatory approaches towards both sperm and egg donation, cultural meanings ascribed to the genetic connection to a sperm donor and to an egg donor are inherently gendered, with the former assuming particular significance given the historical association of fatherhood with the provision of sperm (Rothman 1989, Richards 2014). Indeed, the longstanding cultural and socio-legal identification of fatherhood with biological paternity in comparison to the association of motherhood with the act of giving birth has rendered the female genetic contribution via the egg relatively invisible in comparison to the cultural potency of the sperm (for further discussion, see Freeman 2014b).

How does the empirical evidence from comparative studies of disclosing and non-disclosing families sit within these debates? What can be said about ‘non-disclosure’ in a cultural climate where parental openness is widely perceived as the ideal? First, the observation that non-disclosure does not in itself appear to have identifiable negative outcomes for children’s psychological wellbeing, at least during childhood, raises an immediate caveat that not disclosing carries a risk of ‘accidental’ disclosure which may have profoundly detrimental effects. Indeed, whilst parents may decide not to tell their children about their donor conception, this information may be inadvertently revealed at a later stage. There are numerous scenarios in which this might occur: common hypothetical examples highlighted in the literature include children being told by family members or friends with whom the parents may have confided or if a donor-conceived person’s genetic parentage is revealed through genetic testing. The actual level of the risk of accidental disclosure is unquantifiable and the extent to which these inadvertent discoveries have occurred is

unknown. However, this should be set against the finding that the discovery of donor conception at later age, especially under adverse circumstances, can have negative outcomes (Jadva et al. 2009), with the risk of accidental discovery remaining a real concern for parents as they negotiate their disclosure decisions

The second caveat is that whilst disclosure is also generally not associated with negative outcomes, this insight has largely been derived from studies where first disclosure occurred during early childhood. Indeed, rather less is known about the consequences of both disclosure and non-disclosure in adolescence and adulthood. For example, on reviewing the empirical evidence, a working party for the Nuffield Council on Bioethics (2013) concluded that that disclosure is ‘usually’ in a child’s best interests when couched in the following terms:

‘When, if and how to disclose should remain a private decision for families to take, but evidence suggests that it will usually be better for children to be told, and to be told at an early age.’

I shall return to the implicit dichotomisation between early disclosure as positive and late disclosure as potentially problematic later but for now, it is of interest to note the divergences of opinion that these caveats can create. Indeed, whilst there may be an overriding consensus that telling children about their conception is in their best interests, there are discrepancies around whether disclosure is *always* in the best interests of a child: as the papers in the present volume attest, some advocate disclosure in some circumstances whilst others maintain a general preference for non-disclosure. A key ‘exceptional’ circumstance currently being voiced where parents may reasonably decide that disclosure is not in their child’s best interests is where religious and cultural perspectives on donor conception may lead to the families’, parents’ and/or children’s stigmatisation within their local communities (Nuffield Council on Bioethics 2013: 96). Whilst such an appeal to the significance of social context is



both valuable and, to a certain extent, substantiated (Hudson and Culley 2014), there is a need for further critical evaluation and empirical enquiry to explore the role of culture, ethnicity and religion, especially given that the vast majority of UK studies of disclosure in donor conception families have focused on the majority white population. For example, it is critical to unpack how different ethnic and religious groups perceive gamete donation and the potential taboos raised around infertility, illegitimacy, adultery and masturbation. Another caveat worth reiterating is that, by and large, empirical insights on disclosure have thus far been derived from research with families who have used unidentifiable, anonymous donors. Perhaps one of the most significant shifts in the broader social context that may play a role in shaping the meaning and impact of parents' disclosure decisions is the introduction of identity-release donation in several countries around the world. It is to the implications of the disclosure of the donor's identity that I shall now turn.

#### THE PSYCHOSOCIAL IMPLICATIONS OF DONOR IDENTIFICATION

There is currently a call for empirical evidence regarding the psychosocial implications of donor identification, particularly regarding information exchange, contact and potential relationships between offspring, donors and families who share the same donor. Indeed, in jurisdictions such as the UK where donor anonymity has been removed, the policy transition towards identifiable donors has, perhaps inevitably, been taken with limited knowledge of the consequences for all concerned. Whilst it is too early to grasp fully what the implications of donor identification may be, there are two current areas of research concerning the psychosocial outcomes of gamete donor that are of relevance. The first addresses children's responses to the disclosure of their donor conception: if there is a concern about what may happen if donors are no longer anonymous, then it is reasonable to ask first if donor-conceived children express any interest in their donor and obtaining his or her identity. The

second research area concerns one potential outcome of donor identification, that is, contact between ‘donor relations’.<sup>9</sup> What happens if donor-conceived individuals seek and make contact with their donor? What happens if families who share the same donor meet each other?

With regards to responses to disclosure, children told about their donor conception in preschool years have been found to respond with indifference or curiosity rather than distress (Blake et al. 2014), a stance that continues into early adolescence (Freeman and Golombok 2012; see also Ilioi and Golombok in press). At adolescence, some offspring may express a degree of interest in their donor, often in terms of curiosity about potential physical and personality resemblances. However, as may be expected, there are likely to be multiple factors that impact on if, when and to what extent a child may develop an interest in their donor, such as their age, gender and the quality of their relationship with their parent(s). Furthermore, whilst historically, much research has focused on children in heterosexual couple families conceived by anonymous sperm donation, it is now recognised that family structure (e.g. heterosexual couple, lesbian couple, solo mother) and donor type (e.g. sperm or egg donor; anonymous, identifiable or known) may influence both the likelihood of disclosure and the child’s perception of the donor. For example, considerably more sperm-donor conceived offspring express an interest in their donor than egg-donor conceived offspring and an increased interest in sperm donors has been found amongst families where there is no social father, especially solo mother families (Freeman et al. 2014c). Further research is required to explore individual differences in children’s feelings about their donor,

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<sup>9</sup> By ‘donor relations’, I am referring to anyone who may be ‘genetically’ connected via donor conception. Typically interest has focused on the relationship between a donor-conceived individual and their donor, and between donor-conceived individuals in different families who share the same donor (commonly referred to as ‘donor siblings’). However, in recent years there has been increasing consideration of the wider network of ‘genetic’ and ‘social’ kin relationships that may be created through gamete donation.

including the significance – or not – of having an identifiable or known donor compared to an anonymous one.

Turning to more recent studies exploring meetings between donor relations, an initial observation is that worldwide, there have been relatively few cases where donor offspring have established contact with their donors and those cases are restricted predominantly to sperm donors.<sup>10</sup> One particular forum where contact has been facilitated and which has become the subject of research is the US-based online registry, the Donor Sibling Registry (DSR).<sup>11</sup> In line with earlier research on children's responses to disclosure, offspring and parents who seek their hitherto anonymous sperm donors via the DSR identify curiosity as a key reason for searching (Freeman et al. 2009; Jadvá et al. 2010). For some, this curiosity underpinned a wish to meet the sperm donor although they did not usually express a desire to form a relationship with this person (Jadvá et al. 2010). Comparable findings were reported in Scheib et al. (2005)'s study of adolescents with identity-release sperm donors: most were curious about the donor and planned to request identifying information and pursue contact, and a small minority sought a paternal relationship with him.

Whilst there is some knowledge of what may interest sperm donor-conceived offspring about their donor, the factors that may prompt them to go on to seek his identity or make contact requires further research. In the relatively rare instances where contact has been established, most parents and offspring report favourable outcomes; for example, describing how meeting the sperm donor increased the child's sense of self and family (Jadvá et al. 2010; Freeman et al., 2009, 2012a). Similarly, in terms of contact between families who share

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<sup>10</sup> Note that this section refers to contact with previously unknown sperm donors who donated via a sperm bank or clinic, rather than the increasing number of donors who may be known to recipients from the outset, whether as friends, family members or through connection websites facilitating private arrangements between donors and recipients.

<sup>11</sup> The DSR was founded in 2000 by Wendy Kramer and her donor-conceived son to facilitate contact between donor offspring and their donors and donor siblings. It is the largest global network of this kind and currently has approximately 45,000 members, including donors, parents and donor-conceived people.

the same donor, overwhelmingly positive findings are reported: for example, in the first DSR surveys, 85% of offspring and 95% of parents who had contacted ‘donor siblings’ rated this as a positive experience. However, despite the overall positive picture that the available research may paint of these meetings, little is known of the longer term outcomes regarding the development of these relationships over time (Freeman et al. forthcoming). Indeed, there is some evidence that the experience of meetings between donor offspring and their donor is not always entirely positive for those involved and may invoke conflicting and ambivalent emotions (Jadva et al. 2010). For example, in Victoria, Australia, which has one of the most advanced systems of mediating contact between offspring and their donors, the outcomes have been variable, with a lack of communication regarding expectations and boundaries between those seeking contact being one source of the more problematic aspects (Freeman et al. 2014c): for example, cases where one party desires a high level of contact whilst the other wants none or a very limited information exchange could lead to disappointment for all involved. Thus whilst it may be concluded that contact between donor-conceived offspring and their donor may be beneficial for a child’s wellbeing, this finding is not generalizable and more in-depth research is required to ascertain what mechanisms contribute to positive and negative outcomes. Likewise, whilst meetings between donor siblings have been reported in more positive terms, the limitations of these research findings should be taken into account.

Thus far, research on contact between donor relations is primarily limited by the relatively low numbers who have made contact, particularly in terms of contact with donors. As such, most research has focused on people’s motivations and expectations prior to contact rather than the process of making contact itself, and on contact between donor siblings rather than donors and offspring (Scheib et al. 2008; Freeman et al. 2009; Jadva et al. 2010; Hertz et al. 2011; Blyth 2012). Very few studies report on face-to-face meetings between donor relations and those that do contain a relatively small number of cases: for example, of the 791

parents in the first DSR study, 3% and 23% reported that their child had met their donor or donor sibling respectively (Freeman et al. 2009). Whilst issues concerning sample size, bias and representativeness need not impede qualitative analysis, there is a tendency within policy and ethical debate to seek to generalise and quantify such insights. As such, it is important to note that such issues are intrinsically problematic in this research area. A reliance on survey data may produce self-selected samples representing specific interest groups. When interpreting data from the DSR studies, for example, the extent to which these samples are representative of the donor-conceived population as a whole has been questioned. However, this is rather misleading and the data from these samples may be better viewed as giving valuable insights into the experiences of sperm donation families – and parents in particular – who are actively seeking donor relations rather than the donor conception population as a whole. As the large membership of this website attests (see footnote 14), a considerable number of parents and offspring are expressing such an interest although this must be set against the significant proportion of donor conception families where gamete donation is not disclosed. This links to perhaps the most important caveat when considering the implications of donor identification, that is, that the relatively low numbers of donor offspring who meet their donor represent just the tip of the ice berg of the donor conception population. As illustrated in Figure 1, only a proportion of the donor-conceived population are aware of their donor origins, of those only a proportion will be interested and able to seek contact with their donor and so on, leading to a very small minority who go on to meet this person. Thus in considering the evidence about the implications of donor identification, it is vital not to forget the silent majority of donor-conceived individuals whose voices are not represented and who will never be in the situation of meeting their donor.

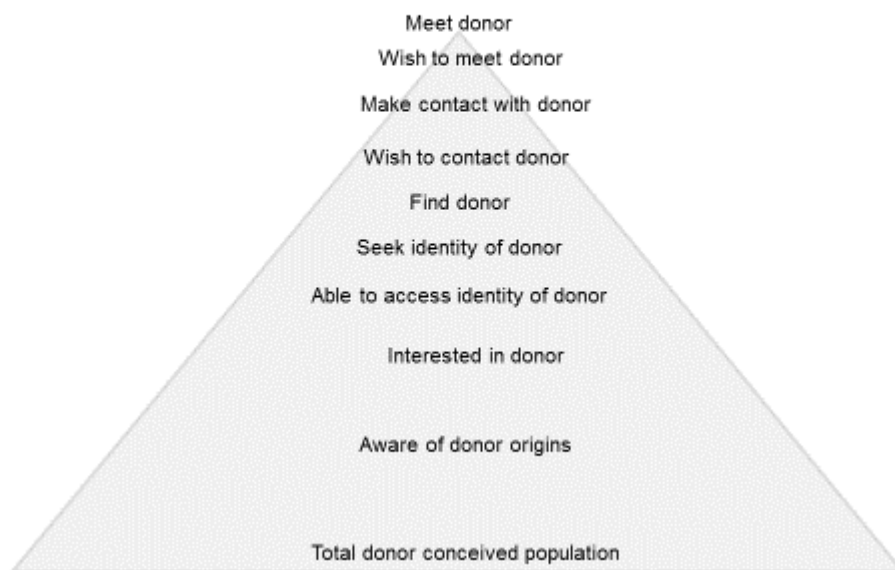


Figure 1. The tip of the iceberg: schematic representation of the proportional impact of donor identification on the donor-conceived population.

In this light, it should also be noted that whilst there is some, albeit by no means conclusive, evidence that the removal of donor anonymity may concur with rising rates of disclosure, identity-release donation does not necessarily lead to parental disclosure and in fact, the prospect of having an identifiable donor may deter some parents from telling their children about their donor conception (Appleby et al. 2012; Freeman et al. 2013). Similarly, our ongoing research indicates that parents may disclose to children the circumstances of their donor conception whilst withholding the fact that their donor is identifiable (Freeman et al. 2013). Thus whilst there is a tendency in ethical and regulatory debates to focus on the implications of donor identification as being an inevitable result of the introduction of identity-release donation, it is important to tease apart these trends.

## CONCLUSIONS

As this overview has illustrated, psychological research on donor conception families has yielded valuable insights into the impact of gamete donation, parental disclosure decisions and donor identification on child wellbeing that have many potential applications to contemporary ethical and regulatory debates. Overall, the findings do not raise any fundamental concerns about the ethics of genetic transparency that is currently being promoted in the UK. Rather, this body of research may be used to support the importance placed upon disclosure and information sharing by finding that a child's awareness of their donor conception and the potential identification of their donor are not inherently detrimental to their interests, at least during childhood: the overall conclusion being that for those minority of donor offspring who are aware of their origins, some - although by no means all - may be interested in finding out about their donor and if contact is sought, this may have favourable outcomes. However, the way such general insights are interpreted and applied to ethical debate differs, and the same evidence may be used in different ways. For example, in discussions about whether to limit the number of offspring to be conceived using one donor, the findings from the DSR studies have been used in arguments for (e.g. Sawyer 2010) and against (e.g. Janssens et al. 2011) lowering these limits: the current paucity of evidence of 'negative' outcomes of meetings with donors and with donor siblings being seen as both a reason for and against the exercise of caution in this field (Freeman et al. forthcoming).

Furthermore, this discussion has also highlighted a number of caveats and complexities that should be considered alongside these findings, particularly concerning the limitations of the samples and the variation in outcomes across different individual, familial and cultural contexts. One significant area of variation that has only been touched upon in this paper is that of the qualitative difference between sperm and egg donation (Richards 2014): most of the empirical research and ethical discussion is implicitly or explicitly focused

on sperm donation and yet regulation tends to generalise to both egg and sperm donation, or ‘gamete donation’. Discrepancies between egg and sperm donation are likely to become more significant in the context of donor identification (Freeman et al. 2014c). Another significant variable is donor offspring age. Indeed, most research has been conducted with children in early to middle childhood. Less is known about the longer term impact of gamete donation, disclosure and donor identification in adolescence and beyond, and the changing meaning of donor conception over the life course.

Related to this, a key argument of this paper is that understanding shifting psychological, social and cultural meanings attributed to genetic relatedness is pivotal to understanding these research findings: in other words, the significance placed on being donor conceived and knowing the identity of the donor is shaped by complex and sometimes contradictory individual and cultural meanings attributed to genetic connection. These contradictions can be illustrated by the research findings. The overall finding that gamete donation children and families are functioning well implies that genetic relatedness is less important than the quality of the parent-child relationship. However, searching for the donor and other ‘donor relations’ does seem to be important for some. This gives rise to the paradox whereby genetic relatedness is held to be insignificant regarding parent-child relationships and child adjustment whilst significant in terms of the connection with the donor and ‘donor siblings’. This perception of the relative (in)significance of genetic relatedness has, of course, changed over time. The genetic connection between a donor-conceived offspring and their donor was once considered ‘best forgotten’: now it is being brought under the spotlight as a fundamental aspect of one’s identity that offspring have a right to discover, whether for medical, psychological or ethical reasons. In itself, the introduction of systems of donor identification ascribes significance to the genetic connection between a child and their donor; likewise, the identification of the relationship between those who share the same donor as



‘half siblings’ ascribes kinship significance to these ‘genetic’ connections in social terms. The framing of questions around gamete donation and information sharing in both empirical research and ethical debates play a role in this process, with the regulation of donor conception likewise influencing how much significance is attributed to the various genetic connections involved (see Freeman et al. forthcoming).

Whilst the caveats and complexities involved in assessing the impact of gamete donation and information sharing may be eclipsed by what is sometimes presented as a unanimous call for openness as being in the best interests of the child, some, as is apparent in this present volume, argue alternatively for donor anonymity and/or non-disclosure. As the topic of information sharing and donor conception can yield such strong and opposing ethical standpoints, it is important to recognise both the value and limitations of empirical studies in providing ‘evidence’ in these debates. As I have suggested, this touches on the fundamental ‘is-ought’ problematic that lies at the heart of empirical bioethics: whilst psychological studies focus on reporting what ‘is’, ethical debate moves beyond this to consider what ‘ought’ to be. Empirical research may guide normative discussion and provide much needed grounding in face of speculation and abstract reasoning: indeed, a critical awareness of the limitations of studies of donor conception families need not detract from the conviction that some data is usually better than none. However, empirical evidence cannot – and indeed should not - be expected to provide all the answers. For example, even where there is no evidence of parental disclosure decisions having observable negative outcomes, whether or not parents disclose *remains* an ethical question. An absence of evidence of psychological ‘harm’ should not be equated with an absence of evidence of psychological ‘wrong’. Conversely, , a negative outcome cannot necessarily be equated with a ‘wrong’: for example, a negative experience of making contact with one’s donor may still be valued and constitute an important part of one’s personal narrative and identity formation.

More than this, I would argue that it is important not to lose sight of the fact that it is ultimately parents, children, donors and families who live through and experience the consequences of these complex ethical dilemmas. In this sense, whilst it is not my intention to question the validity of the generally accepted conclusion that disclosure is usually in a child's best interests, it is perhaps useful to reflect on how the simple message that early disclosure is in a child's best interests may be communicated and received in different contexts. What are the implications of the implicit dichotomies (disclosure as right c.f. non-disclosure as wrong; early disclosure as positive c.f. late disclosure as potentially problematic) for those they impact on? I am thinking here in particular of parents with adolescent and young adult children who are unaware of their donor origins who have lived through these great cultural and policy transitions, first concurring with professional advice not to tell their child about their conception in order to protect their wellbeing and now hearing a clear message that disclosure in early childhood is the best means of avoiding psychological harm to your child. Similarly, whilst policy makers, researchers and ethicists alike are seeking to understand the implications of donor identification, most donor-conceived people who are aware of their donor origins will face the reality that their donors will remain anonymous and unknown. In such a complicated and changing area, it is essential to continue to seek the stories of these families and to take a step back to consider how the sometimes contradictory messages that arise from ethical, regulatory and policy debates may impact on those whose lives are under discussion.

## ACKNOWLEDGEMENTS

The empirical research presented in this paper is largely based on studies conducted at the Centre for Family Research, University of Cambridge, UK, and funded by grants awarded to Susan Golombok by the Wellcome Trust and the Nuffield Foundation. I would like to thank Susan Golombok and Vasanti Jadva for our frequent discussions of the issues covered in this paper and for their comments on the draft. I would also like to thank the two anonymous reviewers for their feedback. As ever, we are extremely grateful to all the families who have taken part in these studies.

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