

Evidence call: summary

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Introduction

In March 2012, the Working Party for *Donor conception: ethical aspects of information disclosure* launched a call for evidence in order to seek the views of the wider public in the context of the issues raised by the project.

Respondents were given the choice of two documents on which to base their response to the call for evidence. The first was a set of 12 in-depth questions published on the Nuffield Council's website (set A). The second was a set of eight briefer questions hosted by the Survey Monkey website, designed to offer respondents a less time-intensive method of responding (set B), and also aimed at people with a direct personal experience of donor conception.¹ Responses helped inform the Working Party's deliberations as it drafted its final report. In total, 38 people submitted responses to set A, and 90 to set B.²

This summary is intended to give an overview of the responses received by the Working Party, and aims to summarise issues raised by respondents to questions posed in both sets A and B. It does not, however, aim to be an evaluation of the views expressed: rather it is a report of such views. This summary does not, therefore, represent the views of the Working Party.

¹ Each set of questions is listed at Annex A of this document.

² One respondent used the Survey Monkey tool to submit their response, but asked to be quoted via the respondent's form to set A. In addition, the Working Party received evidence submissions in the form of journal articles and other literature which did not directly address the questions in either set but were relevant to the Terms of Reference of the Working Party. These respondents have been recorded as submissions to set A.

Analysis of responses

Ethical concerns

Question 1 of set A asked for respondents to state which ethical concerns arise in the disclosure or non-disclosure of information in connection with donor conception. A range of ethical concerns were raised by respondents, some of which focused specifically on the donor-conceived person, whereas others focused on their parents, the donor, and other parties.

The impact on the donor-conceived person

The impact on the donor-conceived person was an issue raised by several respondents to both set A and set B. For example, Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors, drew attention to the potential psychological impact on the donor-conceived person if information about their conception is withheld, and the Trustees and Steering Group of the Donor Conception Network commented that “the primary concern is the welfare of the person conceived.” Dr Sonia Allan noted that the impact on that person could be significant, and identified four different forms this impact could take: affecting a person’s ability to develop a sense of self; subjecting the person to a risk for forming consanguineous relationships; denying the person access to medical history; and preventing the person from having an opportunity to choose for themselves whether or not they want further information. Similarly, Dr Maggie Kirkman, The Jean Hailes Research Unit, Monash University, Australia commented that “the primary concern in not disclosing is the potential harm done to a person who may remain ignorant of significant medical history and who may experience psychological harm through discovery in later life under adverse circumstances.”

The child’s rights as paramount

Several respondents felt that an ethical concern arose from the need to recognise that the donor-conceived child’s rights are paramount. For example, the British Infertility Counselling Association (BICA) expressed the view that the primary ethical concern should be the welfare of donor-conceived children, and that “the emotional and physical well being needs of children – who did not choose to be conceived in this way – are paramount.” BICA also suggested that there could be a comparison with the current state of affairs in the context of adoption: “The current situation of being careful not to infringe the rights of the donors and parents is unique when compared to other forms of family building, e.g. adoption.”

A personal account which focused on ‘rights’ was submitted by one respondent who made the following comment:

“I have this in front of me as I write: the clinic logo at the top and the neatly handwritten information, such that it is. It is heartbreaking to watch my son, now 13, read this document. I almost felt ashamed to give it to him, as it was so little, but it was all I had... As we drive around, he sometimes says to me, ‘that person could be my father, or that one, or that one.’ This cannot be right... everyone in their right mind knows that a child has a right to basic knowledge about their biological parents.”

Anonymous respondent, responding to the Working Party's call for evidence

Describing the child's rights as 'paramount' was also the approach taken by Andrea Powell, who noted that "the child born from donor conception has not chosen to be so. Therefore... that child's rights should supersede the rights of any parties who knowingly entered into the process that created the child." An anonymous respondent similarly noted that "it seems that we as adults sometimes forget that a child is also a future adult with rights and responsibilities like the rest of us and also with the same need for security and trust." Progar (Project Group on Assisted Reproduction, British Association of Social Workers) argued strongly for this 'paramountcy' approach:

"The primary ethical concern is that the welfare of those who are most likely to be affected, donor-conceived offspring, is not afforded paramountcy within the 'groups' affected, i.e. parents, donors, and donor-conceived people except where surrogacy arrangements have been involved... Where other parties claim that their rights are being infringed with respect to any aspect of information disclosure, the absence of paramountcy means that fruitless debates are opened time after time about whose rights should prevail."

Identity issues

Some respondents felt that the issue of the impact of being donor-conceived on a person's identity was a matter of ethical concern, and raised several points in support of this argument.

One anonymous respondent, for example, noted that "[we] know that a strong and steady sense of identity is an important feature in becoming a stable adult. People benefit from having a sense of belonging and being accepted and respected, in their family and community. Finding out that your true biological origins have been kept secret will undermine confidence and self-esteem."

The argument that identity could be undermined was made by a significant number of respondents, and some expressed the view that identity was a relevant *ethical* concern, as non-disclosure of donor conception could mean that a person's identity could be compromised, potentially causing them future harm.

Balancing interests and best interests

Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors, stated that one ethical concern was "to balance the interests of parents and the extent of their legal parental autonomy." Other respondents made similar points, for example:

"The health and social welfare of children/people born as a result of gamete donation should take priority but this has to be balanced with the needs of the people for whom this is the only option to have a child and the needs of the gamete donors and their families."

Anonymous respondent, responding to the Working Party's call for evidence

Professor Marilyn Strathern highlighted the complexity inherent in considering family interests, noting that “as far as family interests are concerned, interpersonal relations are diffuse, and do not rest only with the parents and children involved (there may well be grandparents, other siblings, etc.).” Professor Strathern further commented that “the law does not know what to do with interpersonal relations... So the issue is likely to come down to an opposition between (the ‘rights’ of) autonomous individuals...”

Other respondents felt that the current system did not serve any parties’ interests well:

“[The] best interests of all parties to donation are not so well served in relation to the content of information that is available. There is a donor information questionnaire but the HFEA does not make it mandatory for all sections to be completed so that many parents and children will be deprived of information that children are likely to need to complete their sense of identity.”

Jennie Hunt, Senior Accredited Member of BICA, responding to the Working Party's call for evidence

Deception and secrecy

Several respondents felt that non-disclosure of the fact that a person was donor-conceived lead to a situation where a donor-conceived person was deceived in some way. This, they suggested, was a key ethical concern.

Governmental collusion in this ‘deception’ was a point raised by a handful of respondents. Dr Sonia Allan, for example, commented: “That there is not only awareness that parents may not tell their children, but at times active encouragement not to tell is very questionable (both ethically, and I would argue legally).”

Other respondents, such as BICA couched ethical concerns in this category in terms of ‘secrecy’ observing that “it has long been established that secrets are damaging to relationships and it seems inconceivable that the current legislation still allows for deception regarding a person’s origins.” The British Fertility Society similarly noted that ‘secrets’ can be damaging to relationships and Dr Thérèse Callus commented that “evidence is available as to the damage that secrecy in a family may cause and the feeling of deception when the truth becomes known.”³

The British Medical Association (BMA) drew attention to the distinctions between secrecy and anonymity, stating that it “does not support secrecy but does support anonymity. Although the two concepts are often conflated they are very different. The BMA believes parents should be open with their offspring about donor

³ Dr Callus cites the following article in support of her argument: Haimes E (1988) ‘Secrecy’: what can artificial reproduction learn from adoption? *International Journal of Law, Policy and the Family* 2: 46-61.

conception but has concerns about the removal of anonymity from donors and did not support this move.”

Trust

In association with concerns about ‘secrecy’ or ‘deception’, respondents also highlighted trust as an area of ethical concern.

Progar (Project Group on Assisted Reproduction, British Association of Social Workers), for example couched its comments in terms of the relationship between ‘trust’ and ‘secrecy’:

“Whether parents tell their children or not about their conception status raises the issue of trust between parents and children. Not telling their children suggests that children are not being trusted with the information by their parents, as though the matter must be kept a secret. It is significant that heterosexual couples are less likely to tell their children than single parents and same sex couples. The belief in the need for secrecy often derives from the shame of male infertility.”

PROGAR (Project Group on Assisted Reproduction, British Association of Social Workers), responding to the Working Party’s call for evidence

Privacy

Dr Thérèse Callus highlighted the importance of privacy in relation to the status of a person’s fertility, noting that to force parents to disclose “to a third party” that they have used donor gametes to conceive “amounts to an interference with an individual’s privacy.” However, Dr Callus argues that the privacy of parents “may be legitimately interfered with for the greater need to allow the offspring to be informed of the fact” that they are donor-conceived. This argument is based on the fact that all of the adult parties who take part in donor conception are aware that the donor-conceived child is genetically related to a donor. This, she argues, is unlike a situation where a child is conceived as a result of an affair (and so lacks a genetic relationship with one of their parents) as, unlike donor conception, this situation does not involve state intervention.

Further points about privacy were also submitted in responses from academic researchers.

“It is important to consider the need some families may have for privacy. Some parents [in the study] chose to keep the information very private, and might tell only the child and a select few. For example, one lesbian couple we interviewed lived on a very deprived housing estate and they felt that their child might suffer if his status as donor-conceived became known... Moreover, some felt that the information ‘belongs’ to the child and they felt it was not their right to place it in the public domain.”

Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester, responding to the Working Party’s call for evidence

A more conceptual question about the *nature* of privacy was raised by Professor Marilyn Strathern, who noted that “what is personal to someone is not necessarily private (e.g. their birth dates), so there is nothing axiomatic about designating the details of donor conception as a ‘private’ matter. The question is what is served in particular instances by the concept (value) of privacy.”

The right to choose

The Christian Medical Fellowship felt that an important ethical question was the issue of whether donor-conceived people should have a right to choose knowledge about their genetic history, identity, and genetic family. The same respondent felt that the issue of whether parents should have the right to withhold information from their donor-conceived child was also an important issue to address.

The availability of support services

The availability of support services was raised by a significant number of respondents as an ethical concern, most of whom stated that they currently work in health or social care, or represent a charity, support group, or professional body.

For example, BICA highlighted the lack of support services for all parties in the context of donor conception, including donors, parents, and offspring. Its response highlighted the work of the voluntary sector organisation, the DCN, and in particular their ‘Telling and Talking’ workshops, although it also noted that the DCN “are unable to offer consistent support, and don’t offer counselling, due to the continual lack of certainty regarding funding for the work they do.” This gap in counselling services is, argues BICA, an anomaly which needs to be addressed. This view was directly echoed by the British Fertility Society, which stated that “although the charity Donor Conception Network provides some support (e.g. ‘Telling and Talking workshops’ for parents), they are unable to offer consistent support, and cannot offer counselling, due to the lack of funding for the work they do.”

BICA also drew attention to its stance on counselling for potential parents, arguing that the counselling services available to this group do not match those available to parents who adopt a child, and suggesting that “counselling on the social, ethical, medical [and] legal... implications of this treatment should be mandatory.” In addition, they argue that donors should receive similar mandatory counselling “in order to prepare them for the life-long implications of donation.”

A response submitted by Progar (Project Group on Assisted Reproduction, British Association of Social Workers) also stated that provision of support services was an ethical concern.

“The UK Parliament has legislated to allow a range of donor conception treatments, but has failed to mandate the provision of support services for people with a personal involvement. Research, practice experience and the views of donor-conceived people, their parents and donors all make clear that some of them are affected adversely at some stage during their lifetime and that there are others who would benefit from professional support during information disclosure or contact with genetic relatives, but there are no dedicated professional support services available for them.”

Progar (Project Group on Assisted Reproduction, British Association of Social Workers), responding to the Working Party's call for evidence

The issue of consent: donors and donor-conceived people

A small number of respondents highlighted issues of consent as warranting ethical concern. For example, the Christian Medical Fellowship felt that the question of 'what are the implications of the child's inability to consent?' was an important issue to be addressed by the Working Party. Other respondents, such as BICA, highlighted the issue of retrospective removal of donor anonymity, and its implications for the donor's original consent.

Retrospective disclosure

BICA argued that a right for donor offspring to access identifying information for their donor must apply to all donor-conceived people, regardless of the date which they were born. They state that "either all people or none have this right", and go on to draw attention to the recent recommendations of the Victoria Law Reform Committee, which recommended retrospective disclosure of the donor's identity, with appropriate safeguards. Progar (Project Group on Assisted Reproduction, British Association of Social Workers) also felt that there should be a debate about retrospective disclosure in the UK.

Should people always be told that they are donor-conceived?

Question 1 of set B asked whether donor-conceived people should always be told about the circumstances of their conception. Every person who submitted a response to set B answered this question. Responses varied significantly, and the complexity and sensitivity of this issue was highlighted in a summary of recent research with donor-conceived families:

"Our research suggests that parents want to be 'honest' but that total openness and complete loss of control over information was usually far too worrying. One interviewee spoke of 'gentle lies' which captured the difficult tightrope parents had to walk."

Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester, responding to the Working Party's call for evidence

People should always be told that they are donor-conceived

The majority of people who answered this question took the view that donor-conceived people should *always* be told about the circumstances of their conception. A range of explanations were put forward in support of this view.

Withholding information would impact negatively on the donor-conceived person

Several respondents expressed the concern that withholding information could have a detrimental effect on the donor-conceived person, with comments echoing some of the points made earlier on ethical concerns arising in donor conception:

"There has been research to suggest that keeping secrets in a family can be damaging. The child could find out in later life, and would feel betrayed for not being told sooner."

Respondent to set B

“Advances in medicine mean that a donor-conceived child may find out at some point in the future in an unplanned way, which could be a huge shock and have a devastating effect on them.”

Respondent to set B

“There is a risk that discovering the lie later in life can have a serious detrimental impact. This in turn could lead to the DC person feeling negative or resentful about their origins. As an egg donor, I can’t imagine anything worse than having gone through an IVF cycle in good faith... only to be contacted by a donor-conceived person who is displeased at being lied to.”

Respondent to set B

Withholding information would impact negatively on the parent(s)

A small number of respondents also highlighted the potential impact of non-disclosure on parents of donor-conceived people. One respondent, for example, stated that “not telling will potentially create constant stress on the parents for being constantly concerned about possible suspicion by [their] child that there is something underlying or that the child’s, teenager’s, or young adult’s behaviour is interpreted by parents as a possible sign that he or she knows or suspects something.”

Identity argument

Several respondents stated that a person’s sense of identity could be compromised by the non-disclosure of donor conception. Again, some of these comments echoed those made in response to question 1 of set A.

“The revelation of this fundamental lie about a person’s identity can be devastating for sense of self and confidence in their ‘functional’ parents who have deliberately concealed this information.”

Respondent to set B

“It is a basic human condition to want to know where we come from and who we are, which is derived from our progenitors.”

Respondent to set B

The importance of honesty

Several respondents felt that withholding information about donor conception would be dishonest, and would therefore potentially compromise the person’s trust in their family.

“...a good parenting relationship starts with being open and honest with your child. If you conceal, you appear defensive.”

Respondent to set B

“I think it is morally wrong to keep this information from a child... Keeping this information from them is essentially lying to them and I don’t understand how parents can lie to their children like that.”

Respondent to set B

“Having your parents lie to you over something so important as how you came into existence could be psychologically damaging if discovered at a later date, and would almost certainly have a detrimental effect on that relationship.”

Respondent to set B

Legal considerations

Other respondents such as the Church of England: Mission and Public Affairs Council (responding to set A) referred to the UN Convention on the Rights of the Child and, in particular, Article 8, which declares that children have a right to the preservation of their identity. The Mission and Public Affairs Council suggests that “some knowledge of their biological parents may be seen as an important way of helping to achieve this.”

The non-disclosure of donor conception to the donor-conceived person was also portrayed in terms of a human rights issue by a number of respondents to set B. Responses included: “it is a human rights issue and these children should not be treated differently from adopted children” and “they have a natural right to know their parents and they have a civil right to know their genetic heritage.”

Medical considerations

Several respondents stated that children should always be told that they are donor-conceived for medical reasons. Responses received included:

“[A] risk may be minimised in terms of genetically inherited traits from the donor (e.g. the donor’s family has a history of heart disease or high blood pressure) [...It] is vital that the child knows what they might potentially inherit.”

Respondent to set B

“Donation can have serious medical implications: the offspring’s view of his/her health risks can be significantly changed by knowing his/her donor status.”

Respondent to set B

“It is important for children to know if their genetic origins are different from those of their parents. Medical records often ask if there are any hereditary illnesses in the family (such as diabetes, asthma, heart disease). A donor-conceived person needs to know their parents’ genetic weaknesses do not apply to them.”

Respondent to set B

“My father died when I was a child and I do not know his medical history. I feel awkward and frustrated each time on a medical questionnaire, when I am asked about my family’s medical history and genetic conditions.”

Respondent to set B

The high number of respondents which took the view that disclosure was important for medical reasons illustrates the importance placed by respondents both on the 'medical history' taken by physicians, and on genetic testing for hereditary conditions.

Avoiding consanguineous relationships

Concerns about donor-conceived people inadvertently entering into consanguineous relationships were raised by a small number of respondents to this question.

"I personally plan to tell my children they were conceived via a donor... when they grow up and date, marry, have children of their own, they should know they need to be prepared to ask about their partner's origins on the hugely improbable chance they were both donor-conceived children from the same sperm donor."

Respondent to set B

"Alerting donor offspring to their donor status will minimise the risk of involuntary incest: this risk may not be minor, given that some donors in the past have produced over a hundred children, who may well live in the same geographical area."

Respondent to set B

"The chance of accidental incest between donor-conceived siblings from different families is often downplayed by the promoters of donor conception, but experience from adoption has shown that it is possible. Disclosure would make accidental incest less likely."

Respondent to set B

While no examples were cited of direct experience of this issue occurring, fear of the possibility was clearly very present in respondents' submissions.

Religious authority

Very few responses made reference to religious authority as an argument in favour or against disclosure. However, the Working Party received a communication from the Board of Deputies of British Jews which made the following point about the view of Jewish law in the context of disclosure.

"In the classic Jewish tradition the core Talmudic ruling linked to this particular topic... prohibits producing children when it is clear that their legal father's identity will remain secret. The reasons given for this include not only to a potential human right to trace origins, but also to prevention of incest and of the genetic diseases related to consanguinity."

The Board of Deputies of British Jews, responding to the Working Party's call for evidence

The same respondent noted by contrast that "there are groups represented by the Board who feel that there are societal and ethical values and issues of confidentiality which override this."

There is a right to know

Rachel Pepa put forward the view that donor-conceived people “have the right to know where they come from. Any meaningful entitlement to a family life includes an entitlement to know who that family is.” This view was also supported by a number of respondents to set B, including:

“It is their right to know where they came from. Children from two biological parents know they came from them, so why should donor-conceived children deserve any less information?”

Respondent to set B

“Everyone has a right to know their origins and there is firm evidence that adopted children, for example, are better adjusted if this is a known fact from an early stage in their lives.”

Respondent to set B

People should not always be told that they are donor-conceived

Far fewer respondents felt that people should not always be told that they are donor-conceived. However, a number of respondents argued that the disclosure of donor conception to the donor-conceived person was essentially a private matter for the family, which needs to be addressed by a case-by-case approach. One respondent, for example, was of the opinion that people – and specifically children – should not be told in all instances as some may not have the capacity to understand the information. The same respondent stated that “it is best practice for children to be told but they should be given access to that information at the time that their parents feel is right.”

Similar comments included:

“It has to be decided in the individual family and their individual circumstances. There may be cultural, financial, emotional or social reasons why it is not in the child’s best interest for them to be told. There might not be any information available about anonymous donors from abroad and this could be more damaging to a child.”

Respondent to set B

“It depends on the individual family and their dynamics. It is difficult to suggest that families should ‘always’ tell as for some this may not be the right thing to do.”

Respondent to set B

“Disclosure or non-disclosure is an individual decision (one of thousands) that is made by the parents in view of the best interests of their child.”

Respondent to set B

“I think that it is a decision for each family to make. In an ideal world, the family would feel supported to be open and tell the children but families are complex entities and there needs to be the freedom for each family to decide how to bring up their child.”

Respondent to set B

Another respondent simply stated that people should not necessarily always be told as “they can be happy without knowing.”

Who should disclose?

Question 2 of both set A and set B focused on the question of *who* should decide about disclosure, and whether other parties – apart from the parents of the child – should have a role in making the decision to disclose, or indeed withhold information.

Parents only

The vast majority of respondents who answered this question in set B stated that parents should make the decision to disclose donor conception status. Several respondents who chose to address the questions posed by set A also made unequivocal statements that the matter of disclosing donor conception is a matter for only parents to decide.

“It absolutely has to be up to the parents. I’m very sure on this point! It is the parent who has gone through the absolute hell of infertility and is left with this option only to create a family. It’s no one else’s business but theirs; it is their body that gives birth to the child and it is their name on the birth certificate. It is up to them and them alone to make that decision.”

Respondent to set B

“The evidence from adoption is that disclosure about a child’s genetic origins is best handled by parents at their own speed. Children mature at different rates and can absorb, understand and contextualise complex information at different ages. Parents are best placed to understand their child’s level of development and to choose the right time to decide.”

The British Medical Association, responding to the Working Party’s call for evidence

“My children will know from the beginning, in age appropriate language, but that’s my decision that I’m making for my children. I am vehemently opposed to anyone else involving themselves in either the decision itself, or the process of informing my children.”

Respondent to set B

In addition, The Christian Medical Fellowship responded to this question by noting that “the law currently preserves the social parents’ ‘decisional privacy’”.

Parents - but support might be needed

Other respondents emphasised the role of parents but also highlighted their potential need for support. For example, the Trustees and Steering Group of the Donor Conception Network commented: “DC Network supports the right of children to know that they are donor-conceived... We would prefer that all parents come to this position through a combination of education, awareness raising and preparing for being a donor conception family.”

The difficulties which arise for parents were highlighted by some respondents who are themselves parents of donor-conceived children. One respondent, for example, noted that “once they [the parent(s)] are no longer attending the fertility clinic, it is far too easy to distance themselves from the truth.” Additionally, a response to set B noted that “some families with male infertility issues may be reticent about this [disclosure], especially if they have gone to some lengths to pick a sperm donor with similar physical characteristics to the male/non-biological father.” A response which highlighted a recent piece of social research also highlighted difficulties which parents are faced with.

“...we can represent the views of families who are broadly in favour of disclosure and yet who find the process both difficult and challenging in practice... Thus our most important recommendation would be that any decision about whose responsibility it is to reveal information about donor conception must consider the complex and social consequences that disclosure can have for families and relationships.”

Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester, responding to the Working Party's call for evidence

The same respondents also noted that they “were not able to find parents who were completely against disclosure.”

In order to assist parents in disclosing, the Church of England: Mission and Public Affairs Council felt that parents should receive counselling before the donor conception takes place “during which the desirability of disclosure ought to be emphasised.” This was a view which was supported by several other respondents, one of whom commented that “equally important is the routine availability of ongoing support for the parents after conception such as that offered by DC networks.” A respondent to set B also noted that “there will be parents who delay and prevaricate about telling their children, [so] there should also be help and encouragement available, based on the premise that, if left, the truth is more likely to come out in the middle of a row or other unfortunate circumstance.” Another respondent to set B also commented:

“Counselling is very important to the future welfare of the child and the family unit that they will grow up within. Therefore it is important that DC takes place within licensed centres that have specialist counsellors that have experience of working with infertile and donor conception families. Once couples have had this counselling then it is up to them to decide if they are going to tell the child or not.”

Respondent to set B

A small number of respondents suggested that fertility clinics have a specific obligation to encourage parents to disclose their offspring's donor conception. The Christian Medical Fellowship, for example, made the following observation:

“The Government should give more thought to how it will encourage clinics... as clinics have the most obvious opportunity and role to help parents to tell their children about their origins.”

Christian Medical Fellowship, responding to the Working Party's call for evidence

Not just the parents

Dr Maggie Kirkman, from The Jean Hailes Research Unit, Monash University, Australia felt that, should the donor-conceived person's right to know about their conception be accepted, then “the decision cannot be left to individual families. Parents should have access to guidance on how best to manage sharing this information with their children.” Progar (Project Group on Assisted Reproduction, British Association of Social Workers) expressed similar views, stating that it was *not* up to parents to decide whether to disclose to either the child or other parties, noting that “the principles that children have the right to know of their origins and that this is important for their emotional, mental and physical wellbeing means that information-giving or withholding is not a ‘lifestyle choice’ for parents.” This view was supported by Rachel Pepa, who stated that “the disclosure of a child's donor conception is *not* a matter for each individual family to decide, because the child has the right to know where they come from. If the family can't or won't tell their child that they are donor-conceived then the state has a responsibility to ensure that the child's rights are upheld.”

Venessa Smith, Donor Services Coordinator, The London Women's Clinic, noted that “all families are different, with very specific needs and attitudes. However, the rights of young adults, regardless of their background, remains the same.” Rachel Pepa echoed this latter point, stating that “if donor-conceived people have the right to know they have the right to know, it's not ok to lie to them just because they're from a certain religious or ethnic background.” Conversely, one respondent to set B noted that “there are many cultural and religious issues that mean that in some families it would not be in the best interests of the child to be told that they were donor-conceived.”

The state and the role of birth certificates

Several respondents felt that parents should be given a nudge towards disclosing to their offspring that they are donor-conceived via amendments to the current birth certification system in the UK. Reference was made to the system in the Australian state of Victoria, where birth certificates may be annotated to indicate that a person is donor-conceived. When the child becomes an adult at 18, and applies for the birth certificate, they are then notified that additional information about them is held by the birth registry. These individuals can then choose whether to access that information.

A revision of the current process of birth certification was also suggested by the Christian Medical Fellowship, as “the right of donor-conceived people to such information will otherwise remain at the discretion of their parents.” Other respondents felt that, in choosing not to recognise a person’s donor-conception on a birth certificate, there could be a suggestion that the process is somehow shameful.

A response from the BMA took a different view, noting that by using formal mechanisms such as birth certification to record a person’s donor-conception status “means that parents could lose control over the timing of disclosure. This could result in more unplanned disclosures which the literature suggests can be very damaging to the donor-conceived child or adult.” Moreover, the BMA also felt that “adding ‘donor-conceived’ or similar to the birth certificate would also result in the young person having no control over who has access to the information given that birth certificates are used for a range of purposes including often at commencement of work with a new employer and can be accessed by others.” This view was supported by a small number of respondents who submitted responses to set B, one of which stated, “I *don’t* think anyone else should be involved, unless there is clear and present medical danger. I *don’t* think donor conception should be noted on the birth certificate.”

Other respondents also felt that adding further information to birth certification was inappropriate. One anonymous respondent, for example, felt that some sort of formal record of donor conception was necessary, but that birth certificates should not be the vehicle for this information due to concerns about privacy.⁴

One respondent to set B suggested that the state should contact donor-conceived people directly:

“The state should advise donor offspring at the age of 16 that they are donor-conceived, and thus have certain rights in law. By this stage, however, the person should have known for many years about his/her conception, as the parents should themselves have communicated this fact to the child. Knowing that the state will, in any event, inform the offspring of his/her donor conception and consequent legal rights should encourage the parents to be more open on the subject at an earlier age.”

Respondent to set B

Where there are disagreements within the family

The question also asked for respondents to comment on a situation where family members disagree about disclosure.

Professional interventions

The British Infertility Counselling Association argued that disagreements emerge within families because they currently have a choice about whether to disclose to their offspring, commenting: “If people started donor gamete treatment with the knowledge that they must disclose, and the appropriate support to enable them to do this well, disagreements and conflict within families about disclosure wouldn’t arise.”

⁴ A more detailed system of recording donor conception on birth certificates was discussed at factfinding meetings held by the Working Party.

The role of professional support raised by other respondents, one of whom – a parent of a donor-conceived person – made the following point:

“If there are disagreements between the parents (or other adults in the extended family), there needs to be skilled and accessible support services to help them recognise the priority of the child’s needs. Ideally, this should happen before they go ahead with conceiving their children.”

Anonymous respondent, responding to the Working Party’s call for evidence

Another respondent stated that “if there were disagreement within the family it would be an excellent approach to discuss it with a professional.” One anonymous respondent, however, felt that more time should be taken to consider these options before external intervention is considered.

Families need to ‘work it out’

A different approach, however, was submitted by Maren Klotz from Maren Klotz, Lecturer, European Ethnology, Humboldt University Berlin, and Honorary Fellow at the Egenis Centre, University of Exeter:

“I do not think families-by-donation should be treated differently from any other family. Hence, even though there might be disagreement among family members it should not be the regulator’s task to force families to disclose.”

This approach was supported by the Progress Educational Trust, who stated that “if there is disagreement about disclosure within the family, then it is incumbent upon family members to negotiate the matter themselves.”

What information do parents need about a donor?

Question 3 of both sets A and B addressed the issue of what information, if any, parents need about a donor in order to carry out their parenting role, and take care of their child.

The response submitted by the Human Fertilisation and Embryology Authority (HFEA) outlined the non-identifying information it currently seeks on its donor registration form:

- the donor’s parents’ ethnic group;
- whether the donor was adopted;
- the donor’s marital status;
- how many children the donor already had (if applicable) and the gender of those children;
- any physical illness or disability, history of mental illness or learning difficulties and any known medical conditions within the donor’s biological family;
- a goodwill message; and
- a description of themselves as a person (pen-portrait).

This question elicited a range of suggestions for information which parents may need about a donor. Some of these reflect the current state of affairs, as outlined by the HFEA response, whereas others state that further types of information might be needed by parents. These types of information can be split into identifying and non-identifying information.⁵

Identifying information

- The donor's name
- Donor's place of birth
- The address of the donor
- Identity of other offspring
- Education
- Donor's date of birth

Non-identifying information

- Occupation of the donor
- Medical history or family history of inheritable disease
- Education
- Physical characteristics, such as eye and hair colour, weight, and height
- Marital status
- Number of children
- Nationality
- Financial status
- Sexual orientation
- Cultural or religious background
- Number of offspring conceived through donations/how many other people the donor has donated to
- Information about the donor's own parents, and whether he or she was adopted, or donor-conceived.
- General interests, such as hobbies, sports played.
- Why the donor chose to donate
- How the donor feels about future contact
- The traits that the donor has inherited from their family

Most respondents provided these suggestions in the form of lists. However, others made more substantive comments about the need for certain types of information, and also drew distinctions between information which was needed to help raise the child or respond to their questions in the future, versus the use of information for *choosing* the donor.

Respondents also commented on specific types of information in more detail, and opted out of providing a list of information requirements. For example, one respondent commented on the need for information about ethnicity.

⁵ Some types of information may appear in both categories. For example, the donor's place of birth could be seen to be identifying information if they live in a hamlet where just a handful of people reside, whereas if the donor's address is in a major city, that information may be non-identifiable.

“There are many clinical factors that have a differing effect on people from different races and ethnicities, certain medical treatments are more effective on particular races. Culture and religion may be more important information to the child when of age to make informed decisions, this may impact on their psychological development.”

Respondent to set B

The majority of respondents to set B, however, felt that information about the medical history was key. These responses included:

“All the parents really need is updated health history in order to help give the child the best medical care possible. In choosing a donor, health information seems most important.”

Respondent to set B

“That the donor is healthy. That is all I need or want to know. They are not the parents of the child, they have simply donated a cell.”

Respondent to set B

One respondent also felt that information about the intelligence of the donor was necessary. This view was not, however, shared by other respondents.

“I think it would help for them to know about the basic intelligence of the parent, so if they have a child with a very different intelligence level to the family, this can be managed and dealt with so the child has the support it needs without them feeling odd.”

Respondent to set B

A response from ANZICA (the Australian and New Zealand Infertility Counsellors Association) also noted that many parents are “interested to learn more about the donor who helped them become a family and in our experience many wish to do so while their children are young so they can grow up knowing this information. Many are moved to thank the donor for the joy they have given them.” The Trustees and Steering Group of the Donor Conception Network highlighted how “some parents seek out donors from the USA where considerably more information about donors is available, often including photographs [and] voice recordings”, demonstrating the importance placed by some parents on donor information.

The Working Party also received several submissions from parents of donor-conceived people in response to this question, including:

“I would like much more detail about the father both from the perspective of medical information but mainly about him, what sort of person is he? Why did he donate? What is he doing now?... It just seems incredible to me that you can give someone life but then to all intents and purposes you don't exist to those you give life to.”

Anonymous respondent, responding to the Working Party's call for evidence

“We have very limited information on the donor. This hasn’t particularly impacted on us as parents yet. However, it was useful to know that the donor was fairly tall as our daughter outgrew her father, and also helpful to be able to give her the small amounts of information we had when she asked. The greatest impact would be regarding lack of medical background.”

Andrea Powell, responding to the Working Party’s call for evidence

Parents of donor-conceived people also noted specific instances where the lack of medical information had appeared problematic:

“In the first few days/weeks of my son’s life I was asked if there was family history of tongue tie and neonatal jaundice, but I could only answer from my side of the family. It would be good if there was a means to ask the donor questions like this through the clinic so that one can care for their child properly.”

Respondent to set B

“I would have liked more medical history information – my older son has astigmatism and glasses, so when I’m asked if there’s family history of slight problems I can’t answer 50 per cent of the information.”

Respondent to set B

The Church of England: Mission and Public Affairs Council also suggested that safety and expectation may play a role in the information needs of parents.

“Certain ‘non-genetic’ information is relevant to the well-being of donor children. For example, information with regard to any donor convictions for serious crime (murder, rape, violent crime) ought to be made available to parents as this will assist them in providing early support to their children.”

Church of England: Mission and Public Affairs Council, responding to the Working Party’s call for evidence

In recognising both this sort of information, and also other types of information which parents might need about donors, the Mission and Public Affairs Council added a caveat, namely that it would “represent an invasion of donor privacy to insist that such information *ought* to be made available.”

A different approach was taken by respondents who made a distinction between what parents need to know, and what they would *like* to know.

“Technically, the parents need to know nothing about the donor to carry out their parenting role. In practice, however, new parents usually find they would like to know some of the basic things that one knows about extended family such as appearance, bodyweight, interests, academic achievements, aptitudes, personality characteristics and special talents.”

Anonymous respondent, responding to the Working Party's call for evidence

"I do not believe the parents need any information to carry out their role. However some information such as how the procedure was carried out, preparation of [the] donor/ the child's birth/ creation story [might be helpful.]"

Lynda Mizen, responding to the Working Party's call for evidence

Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors, expressed a similar view, noting that "it is arguable that parents need very little information about a donor to carry out their parenting (leaving aside issues about access to medical information) and that parenting is far more about nurture than nature." However, Ms Ghevaert also noted that "it can be helpful for parents to have some information about their donor... to share with their child on an age appropriate bases and to shape their family history and story in light of this." Such information was described by one respondent, themselves a donor:

"In my case I included additional information in the file for the recipients. Both the parents and the child. So, there were photos of me growing up, ending with a photo of me as I was on the day of writing the file. I tried to get across a bit of my personality... The reason I left this information behind is [that] I don't know what the future holds. So I wanted to leave enough behind to answer the questions these people will have in the future: why do I look like this? Why do I think this way?"⁶

Mr James Martin, responding to the Working Party's call for evidence

Very few respondents who submitted responses to both set A and set B took the view that parents need no information. One example of such a response, however, is that which was submitted to set B by a parent of a donor-conceived person.

"My initial reaction is none at all. I presume major genetic conditions would have already been ruled out. Other things such as autism, dyslexia, asthma would arise and be dealt with as they would with any other child. Every child runs the gauntlet of the genetic lottery... Too much information can be a bad thing and leads to the accusation of designer babies [and] not many people have a blemish-free family medical history."

Respondent to set B

A similar response was received from a respondent who works as a clinical geneticist:

"Little or none I imagine, but it is important to know that a reliable system is in place to trace a donor in case genetic issues crop up –

⁶ Under the provisions of the HFE Act, any information provided by donors that is deemed to be 'identifying' will not be made available to the parents, but released on request to the donor-conceived person once they reach the age of 18.

either with the child conceived from a donor gamete or with the donor.

Respondent to set B

What information does a donor-conceived person need about the donor?

Question 4 of both sets A and B asked respondents for their views about what information a donor-conceived person might need about the donor, either during childhood or adulthood. Again, a wide range of suggestions were made for the type of information that a donor-conceived person might need about the donor, many of which mirrored the list presented above at question 3. However, additional types of information were also noted:

- A photograph of the donor
- The gender and age of donor-conceived half siblings
- Information about the donor's family background
- Information about the donor's own children

A number of respondents made more detailed comments in response to this question. For example, several respondents highlighted the importance of medical information: Dr Sonia Allan, for example, suggested that this should include personal and familial history, to the extent to which it is known. She also suggested that this information should be updated on a five-yearly basis, and that the “onus to update such information should fall to the clinics or registry rather than the donor.” Dr Thérèse Callus also commented that, “in light of the increased probability of the use of medicine *à la carte* developed according to each individual's genetic make-up, it can be argued that it is more important than ever to make disclosure of donor conception status the norm.” In addition, Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors felt that medical information could benefit a donor-conceived person if they became ill, and also for medical screening purposes “to assist with their own family building plans (e.g. to assess the risks or prevent the passing on of a genetic condition)”.

Andrea Powell, a parent of a donor-conceived person, also felt that medical information about the donor was very important, noting that “the donor-conceived person should have access to the donor's blood group and medical background, and on a continuing basis. Even if we had medical details at the time he donated, this is unlikely to be sufficient as our daughter gets older.”

The Donor Sibling Registry drew on its own survey of 751 people, and concluded that “participants explained that they simply wanted to see what their donor looked like.” A similar view was taken by a parent of a donor-conceived child:

“I think this varies from child to child and from situation to situation. Many children just need a back story to explain why they are as they are. My son is very sporty but there is no history of sport in our family so it looks like it came from the donor.”

Respondent to set B

Focusing on the donor's reasons for donating, an anonymous respondent highlighted the importance of donor's pen portrait on HFEA form D. This view was echoed by a respondent to set B, who suggested that the donor-conceived person "is likely to want to have an understanding of who the donor is, where they come from, what they do and why they made the decision to help that child come into the world." Similarly, another parent of a donor-conceived person stated, "I would have liked it if there was a personal letter from the donor directly addressed to the future child explaining his reasons for donating. This would help when the inevitable questions come about what he's like."

Obtaining information about donor siblings was also the subject of a number of comments the Working Party received in response to this question, some of which expressed concerns about the formation of incestuous relationships with these siblings. Some of these questions echoed concerns stated in response to question 1 of set A.

"It is by no means inconceivable that donor-conceived people could unwittingly start a relationship with a half sibling. There has been at least one case that we are aware of, of twins who married without realising they were siblings and a case of another set of twins who nearly got married. In both cases the twins in question had been separated at birth and adopted by separate families without realising that they had a twin."

Christian Medical Fellowship, responding to the Working Party's call for evidence

"Donor-conceived children should also be made aware of the identity of other children of the same donor to prevent the risk of children forming personal relationships with their own half-siblings.

Respondent to set B

"They need to be informed about the risks of genetic sexual attraction (GSA) that can occur between donors, their children and their half siblings, prior to any reunion after puberty... donor children should be counselled about this before they think about reunions."

Respondent to set B

This issue of 'accidental incest' was also raised by the Donor Sibling Registry (DSR). Drawing on the experiences of its members, it stated that "despite the fact that the larger sperm banks ship sperm across the US and to many other countries, we hear of many random meetings on the DSR. These meetings take place at summer camp, at school functions, at parks, on cruises, at parties – just about anywhere. And offspring can be any age when these meetings occur."

The British Infertility Counselling Association noted that the *type* of information a donor-conceived person needs will change over time, "for example, medical and family history will not be so important for a child, but will become more important when the donor-conceived person is considering having a family of his or her own,

or if they develop medical problems.” This view was echoed by the Church of England: Mission and Public Affairs Council, which noted that “the type of information that younger children will receive will depend on what their parents consider to be in their best interests. Adolescents, incrementally, ought to have the same access to information as their parents, but this will vary according to individual circumstances.”

One respondent also argued that what donor-conceived children need to know, and what they want to know were two different points (a point the same respondent made for the question of what parents need to know). This respondent noted:

“Again, technically the child does not need to know any particular information. However... many donor-conceived offspring very much want to know if they do have biological relatives and if they might connect with them. Of course some do not, but I believe that most want to know.”

Anonymous consultation respondent, responding to the Working Party’s call for evidence

One respondent, however, explicitly argued in favour of the *status quo* in the UK.

“[Within] the now non-anonymous British set-up, the current basic information on the donor is sufficient. There is no need to produce a highly artificial ‘time capsule’ with information trying to convey his [or her] personality, because children interested will eventually be able to contact their donor and find out what he or she is like as a person.”

Maren Klotz, Lecturer, European Ethnology, Humboldt University Berlin, and Honorary Fellow at the Egenis Centre, University of Exeter

As with views expressed in response to question 3, very few respondents stated that the donor-conceived child needed no information at all. One respondent, however, stated that “I don’t think donor-conceived children really need any information about their donor” while another felt that “[information] doesn’t offer any particular benefit to the child, and puts off a lot of donors.”

A distinct viewpoint was also provided by a respondent to set B, a parent of donor-conceived children: “They will accept what they are told from an early age. I can tell them what I know. I will take them to the country of their conception and show them where my treatment took place. They will always know they can’t find out any more about their donor and as they grow up with this knowledge, I am sure they will be satisfied with it.”

Interests of the donor and the donor’s family in the context of information about offspring

Question 5 of set B and question and question 9 of set A asked respondents to comment on what information, if any, a donor and the donor’s family might want to

receive about a child born as a result of their donation. Suggestions by respondents included:

- The number of live births resulting from the donor's donation, i.e. whether the treatment was a success
- The sex of any children born
- The wellbeing of the child; that they are happy and healthy
- Information with regard to the offspring's physical and mental well-being
- The area in which any offspring live, in order to reduce risk of GSA
- Interests and educational achievements
- Medical information which may be pertinent to the donor's own health
- Appearance, such as hair and eye colour
- Basic details about other family members and siblings
- Contact information

In regard to the suggestion that donors may wish to know the number of live births arising from their donation, Mr John B. Appleby and Dr Lucy Blake from the Centre for Family Research at the University of Cambridge drew attention to a recent study which found that the majority of donors feel that it is important to know how many children were born as a result of their donation.⁷

The Working Party also received the view of an egg donor and also a sperm donor about what they would like to know.

“As an egg donor I wanted to know about the recipient couple to ensure they are able to deal with a potentially bright child. I also wanted to ensure that their life principles were roughly in accordance with mine. I personally wanted to see that their life principles were roughly in accordance with mine. I wanted to see a baby picture and to know that the child is happy. My main worry would be that a child I had helped to create would have an unhappy life, or would not have a fulfilled life and I would have a maladjusted embittered teenager coming to find me 18 years later.”

Respondent to set B

“As a male sperm donor I would like to know how many children have been conceived from my donations. Just to know the numbers and if all was ok. I would want to know if any child had serious medical issues.”

Respondent to set B

Another respondent put themselves in the position of a donor, and concluded:

“I guess if I had donated I would want to know the children are healthy and happy and loved, the sex and ages and whether the

⁷ Jadva V, Freeman T, Kramer W, and Golombok S (2010) Sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor offspring *Human Reproduction* **26**: 638-45.

parents were going to tell them about me. I might be curious about colouring and personality.”

Respondent to set B

Possible future health-related obligations from donors to offspring were raised by another respondent who felt that the donor would want to know “if the child was born disabled, handicapped or had some life-threatening condition, in case the child would need an organ donation, blood, bone marrow or some other donation in later life that the biological parent would be one of the few matches for.”

An anonymous respondent also noted that “from our experience, working mainly with egg donors, there is usually an existing relationship with the recipients and an anticipated relationship with the child. Our limited experience of sperm donors who are unknown to the recipient suggests that, at the very least, they would want to know if the treatment has been successful.” However, a parent of a donor-conceived child stated that “in my experience, they aren’t that interested.” Another parent felt that “although the importance of the donor’s contribution should be acknowledged, they should be entitled to any information about any children conceived as a consequence. Blood, kidney and other organ donors/recipients remain mutually anonymous. The same should be true of the donated ‘seeds of life’.

The Church of England: Mission and Public Affairs Council, however, made a distinction between information which donors may like to have, and information they *ought* to have. This respondent also noted that “donation ought to be viewed as an altruistic act and not as a means of ‘remote parenting’.”

The interests of the donor and the donor’s family

Question 9 also focused on the idea of the *interests* of the donor and the donor’s family in receiving information about offspring.

Interests of the donor

Responses ranged between those which stated that donors would want to receive a substantial amount of information, and those which took the view that the donor would want to be removed from the prospect of further information being provided.

One anonymous respondent, for example, suggested that:

“[A] mentally and emotionally healthy donor would likely want information about their genetic offspring. Genetic connections are profound. One piece of evidence for this profundity is the very lengths to which couples and individuals go to conceive children that are genetically related to at least one of them.”

Anonymous respondent, responding to the Working Party’s call for evidence

Other respondents distinguished between donors who are known or unknown to the recipient. The British Infertility Counselling Association, for example, noted that “recent legal cases have highlighted that some so-called ‘known donors’ do have an interest not only in receiving information about donor-conceived children, but being involved in their life.” A response from Mr John B. Appleby and Dr Lucy Blake from

the Centre for Family Research at the University of Cambridge similarly noted an Australian study of 45 potential donors, which revealed that 80 per cent of donors considered contact with offspring conceived through their donation, although many would only consider one-off contact in order to answer any questions about family origin.⁸

The situation of 'egg-share' donors was, however, seen as a different case by The British Infertility Counselling Association, who suggested that "many express a wish pre-treatment not to know the outcome [of the recipient's treatment] and to not have any further involvement in the recipient's life. Inevitably their primary concern is to have a child of their own, and at the pre-treatment stage they often cannot accommodate any feelings they may have towards resulting donor-conceived offspring."

Dr Maggie Kirkman also expressed a view that "although a case can be made for the need of the donor and her or his family to learn about the person conceived as a result of the donation, the fulfilment of their need is dependent on the welfare and decisions of the donor-conceived adult (or child's parents in consultation with the child)."

Interests of the donor's family

Respondents also made comments about the donor's families, and their potential interests.

"The majority of our sperm donors do not inform their family of their donations. Those that have regularly mentioned the difficulties that some parents have in knowing about grandchildren that they will never meet and the fact that their son has provided the families' genetic material to anonymous benefactors. One particular donor, who is himself childless, has had to deal with this for many years from his mother who liked to keep tabs on the ages of children that he has helped create... I have also unfortunately witnessed the breakdown of a number of relationships as soon as the donor reveals to his partner that he was part of the donation program which has resulted in live births."

Venessa Smith, Donor Services Coordinator, The London Women's Clinic, responding to the Working Party's call for evidence

"[The] donor's future children (or existing children, if there were any) have the same need to know about the existence of half-siblings as the donor offspring. It is important when they are making decisions about future partners and starting their own families, and to avoid the risk for future disclosure that could threaten trust and respect within the family."

Anonymous respondent, responding to the Working Party's call for evidence

⁸ Godman KM, Sanders K, Rosenberg M, and Burton P (2006) Potential sperm donors', recipients' and their partners' opinions towards the release of identifying information in Western Australia *Human Reproduction* **21**: 3022-6.

Other respondents also felt that children of the donor should know that they have half-siblings, and the British Infertility Counselling Association made an observation about the information needs of surrogates and their families, suggesting that further research is needed into what information should be available to this group. However, Progress Educational Trust felt the asymmetry in information provision for donors' families as opposed to donor conception families to be "entirely appropriate," arguing that "donation should be made in a spirit of generic good faith, without there being a concomitant expectation of specific information about any resulting offspring."

The complexity of relationship structures in the context of donor conception was highlighted by Professor Carol Smart and Dr Petra Nordqvist from The University of Manchester. Professor Smart and Dr Nordqvist – in providing a summary of their research on families who use donor gametes – noted that "in cases of substantial involvement [of the donor in the recipient family's life] we found that the donor's parents could also become important figures in the life of the child... When discussing disclosure, and who should make decisions about disclosure, it is important to consider the complexities of these families. Disclosure involves the lives of people beyond a narrowly conceived nuclear family."

The significance of the donor's medical history

Question 5 of set A asked respondents to comment on the significance of information about the medical history of the donor and the donor's family in the context of the health and wellbeing of the donor-conceived person. Respondents were also asked if they were aware of any examples or evidence in this area.

A number of respondents felt that the donor's medical history was extremely significant and expressed concern that, without access to this history, donor-conceived offspring might be at a disadvantage.

"UK DonorLink reports that the historical prevalence of non-disclosure has had detrimental effects on the health and decision-making of donor-conceived offspring. For example, where the father is known to have had cancer or other diseases that can be linked to genetics, sperm donor-conceived offspring have incorrectly believed that they are at a greater risk of cancer. This is becoming increasingly important, as more developments in genetic causes or propensity of particular genes to increase the likelihood of disease, become known."

The British Infertility Counselling Association, responding to the Working Party's call for evidence

"The donor-conceived adults whom I have met through UK DonorLink and DC Network have talked of their anxiety about lack of medical information and the fear that they carry genetic conditions of which they have no knowledge but which could affect their own future health, that of their children and might affect their children's own plans to form a family."

Jennie Hunt, Senior Accredited Member of BICA, responding to the Working Party's call for evidence

“[It is] very important. We know from the work of UK DonorLink that people ‘linked’ to genetic relatives on its register have learned that there has been early sudden death from heart disease in the ‘other’ family, prompting the need for tests... It is also very important for recipients who nearly always want a good deal of reassurance that the medical history of the donor does not increase the risk of their child having medical problems.”

PROGAR (Project Group on Assisted Reproduction, British Association of Social Workers), responding to the Working Party’s call for evidence

The importance of the donor’s medical history was also highlighted by the Christian Medical Fellowship, which stated: “although there has been a proliferation of predictive genetic tests for serious illnesses, medical geneticists still often rely in practice on family history and knowledge rather than DNA analysis.” Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors highlighted the importance of the donor’s medical history *after* a donor-conceived person becomes ill, noting that “such information may assist with an effective medical diagnosis and treatment plan and could be the difference between life or death.”

The DSR – drawing on its experience in the United States – noted that some clinics are “resolutely refusing to test donors for genetic illness.” Specifically, the DSR states that “in an era where Tay Sachs has almost been completely eradicated from the Jewish population through premarital genetic testing, there are still children being born via gamete donation with the illness.”

Other respondents exhibited caution in regard to the importance of medical history. The Progress Educational Trust, for example, stated that “it is always a remote possibility that medical information about the donor and their family will be significant for the health and well-being of donor-conceived people, but it is far from likely.” The same respondent also highlighted that medical information could create unnecessary anxiety for the donor-conceived person and their families. This may be especially so if the information is not “properly contextualised.”

Venessa Smith, Donor Services Coordinator, The London Women’s Clinic also noted that although the medical history of the donor is important, “with the strict screening regime and selection prior to joining the donation programme, patients should feel reassured that their medical interests have been taken care of. It is of course impossible to screen for everything, but a good base level of medical information can always be made available to patients if they have any concerns.”

One respondent queried the usefulness of much family history information on a more general basis:

“Another possibility would be to raise awareness among physicians that asking for medical history can actually be a problematic experience for many groups of people, not only the donor-conceived, and that it should only become an issue in the rare cases where this would be of relevance. From my limited medical

knowledge on this issue it seems to me that... medical history information is for a large majority of people not actually crucial medical information.”

Maren Klotz, Lecturer, European Ethnology, Humboldt University Berlin, and Honorary Fellow at the Egenis Centre, University of Exeter

Examples of the significance of medical history

Specific examples of instances where the donor's medical history might be important were also raised by respondents. The Christian Medical Fellowship, for example, noted that “a history of glaucoma in the family qualifies an individual for free screening for this at age 40.” An anonymous respondent noted that “if a donor's family have a history of heart disease, this would be relevant to the child who could take precautionary measures in diet and lifestyle.”

One respondent also provided the Working Party with an example from her own personal experience.

“When I was 20 my dad was diagnosed with kidney failure as the result of Polycystic Kidney Disease (PKD). There is a 50 per cent chance somebody afflicted with this will pass it on to their offspring, about half of people with PKD ultimately develop kidney failure and there is no conclusive test for the PKD gene. Consequently, not knowing I was donor-conceived and so believing I could be affected, I went for a course of genetic counselling and yearly ultrasound scans of my kidneys until the truth came out when I was 25.”

Rachel Pepa, responding to the Working Party's call for evidence

A number of respondents also drew attention to an instance of an Australian woman who might have had her genetically-linked bowel cancer diagnosed earlier than stage 4 had she known to seek screening at an earlier stage. One of these respondents was the Victorian Assisted Reproductive Treatment Authority, which also highlighted the examples of “a donor whose father had a potentially fatal hereditary disorder, and a donor who had a serious heart condition which can result in sudden death with a 50 per cent chance of passing this on to offspring.” The same respondent also noted the “experience of one donor applying to the central register in order to pass on important medical genetic information to the person conceived as a result of their donation. The donor had a terminal condition and wanted the person to know so that they could have regular testing.” Similar concerns on the part of a donor were reported by a respondent to set B;

“I recall hearing of an Australian sperm provider some years ago whose father and older brother went on to die of prostate cancer and he wished that his male offspring could be alerted to this fact in order to have regular screening and early treatment. He informed the fertility clinic to which he had provided sperm on an anonymous basis but they were not interested in this development as there was no vehicle for passing on such information. Parental confidentiality took precedence over any perceived health benefits to the donor-conceived person.”

Respondent to set B

The Trustees and Steering Group of the Donor Conception Network also noted “a reported incidence in the US, via the Donor Sibling Registry (DSR), of aortic aneurism in a donor that also affected a proportion of offspring; some having life-saving surgery as a result of knowing what had happened to their donor.”

An example from Japan was provided by Tsuyoshi Sotoya, Graduate School of Social Sciences, Hitotsubashi University, who described a case where a “woman conceived via donor insemination [has said] that she feels bad when asked about her father’s medical history in the hospital because she does not know about it at all and cannot answer this type of question (in Japan, since there is no law regarding assisted reproductive technologies such as donor insemination which protects donor-conceived offspring’s right to know about their origins, it is impossible for them to know about the donor’s information even if they want it.)”

Disclosure of inherited medical risk post-donation

Question 6 of both sets A and B focused on the issue of the disclosure of information about inherited medical risk *after* the donation has taken place. It asked respondents to comment on who should be told about the medical risk, and by whom.

Should donors pass on information about the manifestation of genetic conditions?

Set B asked respondents to comment on the question as to whether donors should try to pass on information about genetic conditions which manifest after the donation has taken place. The overwhelming response to this question was “yes”, although relatively few respondents offered explanations for why this ought to be so, or identified particular circumstances in which this might be appropriate or possible. Examples of substantive responses include:

“Donors are altruistic in nature and I would hope this concern continued beyond the actual period of donation.”

Respondent to set B

“This would depend on the condition. If it is life threatening with a strong likelihood that it may be passed on to any offspring then the donor should try and pass on this information.”

Respondent to set B

“This would be helpful information to both the parents and the children. However it would be difficult to find a mechanism for doing this when most [donor-conceived people] are not aware that they are donor-conceived. Would the donor only be able to contact those families that have been open with their offspring?”

Respondent to set B

“This calls into question the honesty of the donor. To my knowledge, the genetic health of the donor is assessed based on self reporting. This cannot be reliable. How a requirement to report later in life can be enforced is difficult to see.”

Respondent to set B

Of the very few respondents who felt that the donor should not disclose about the manifestation of genetic conditions, the following comments were made:

“Generally speaking, no, as it is important for a separation to take place and for the new parents and child to make the best of the rest of their life. In extreme cases, the possibility of early intervention and treatment may provide a convincing argument for some to have this information, but I would like to think that this would be rare as screening should take place beforehand.”

Respondent to set B

The British Infertility Counselling Association also noted that in a situation where a donor-conceived person finds out that they have an inherited medical risk, the donor should also be notified of the risk. The Association states: “it would be unethical not to inform donors, whether or not they had disclosed the fact that they had donated to their family, as this knowledge would prompt donors and their own children to have tests.”

How should information about inherited medical risk be passed on?

Importance of this information reaching donor-conceived people and their parents

Very few respondents who responded to either set A or set B took the view that no one should be informed. The British Infertility Counselling Association, for example, took the view that donor-conceived people, or their parents if they are under the age of 18, should have a right to information about inherited medical risk, regardless of whether or not the parents have disclosed, or intend to disclose, that they are donor-conceived.

Role of health professionals and clinics

The Church of England: Mission and Public Affairs Council felt that relevant information should be given to health professionals, who should then give either parents or the offspring (if they are an adolescent or adult) an opportunity to be made aware of this information.

The role of skilled professional help in passing on information once an inherited risk had been discovered was also highlighted by a number of respondents. Dr Sonia Allan, for example, felt that counsellors “should be engaged in the process of telling the family of the risk”, while an anonymous respondent stated that “although the information will come via the registry (wherever that resides), it needs to be dealt with sensitively and respectfully, by trained professionals.”

The BMA argued that where clinics become aware of a “significant medical history after donation has occurred, a procedure should be in place for ensuring that the information is reviewed and that the necessary steps are taken to ensure that information is given to the parents of any children born following the donation (or the

offspring themselves if they are sufficiently mature) in a timely and sensitive manner.”

One respondent described the policy of her own clinic:

“Unfortunately, this situation has occasionally arisen as a result of the LWC [London Women’s Clinic] being a regular provider of donor gametes. The policy at LWC is to analyse the risk to other offspring before deciding whether it is necessary for the information to be provided to other parents or the donor.”

“Often parents with an affected child do want other families to be aware of medical problems. The need to inform other families is carefully assessed but it does need to be remembered that this may be related to their own anxiety rather than any benefit this information will give to other families.”

Venessa Smith, Donor Services Coordinator, The London Women’s Clinic, responding to the Working Party’s call for evidence

The Victorian Assisted Reproductive Treatment Authority (VARTA) provided the Working Party with a case study which was included in the Victorian Law Reform Committee Inquiry Report, where a clinic was contacted by a donor who was concerned about the risk of passing on a serious medical condition to the genetic offspring of his donation. The clinic was aware that these offspring, who at this point were in their late 20s, may not have been told that they were donor-conceived. It therefore made the decision to contact their parents to inform them of the medical risks and the need for medical testing. This, note VARTA, “needed to be done very sensitively as secrecy was the norm at the time of donor treatment. For one family, there was a great reluctance to inform their son and it took four years for them to do so. He was a pilot and did in fact inherit the serious heart condition. There were serious concerns raised as to what may have happened if he had died suddenly whilst flying.”

The Trustees and Steering Group of the Donor Conception Network highlighted how it might also be necessary to pass on information to donor-conceived people and their families if the donor were to die:

“New information about a health risk that is reported to the HFEA should be conveyed to parents, offspring or donors in a sensitive manner, ideally by a member of an intermediary services team. If the HFEA is informed that a former donor has died, donor-conceived adults and parents of under 18s should be informed, whether the death was medically relevant or the result of an accident, as it may change expectations for offspring.”

Trustees and Steering Group of the Donor Conception Network, responding to the Working Party’s call for evidence

However, a response from the Progress Educational Trust warned that “it would be an exceptional scenario in which it [medical risk] were discovered after donor conception had taken place... given the unlikelihood of this scenario... we would be

reluctant to suggest any generic provision for such a scenario.” The same respondent noted the case of only one example in the UK of which it was aware:

“Anecdotally, we know of only one relevant instance in the UK, in which a donor-conceived child was born with a condition that meant that clinicians felt duty-bound to notify the relevant sperm donor of possible risk to himself and/or his existing or prospective offspring.”

Progress Educational Trust, responding to the Working Party’s call for evidence

Progar (Project Group on Assisted Reproduction, British Association of Social Workers) also stated that “health authorities should have protocols and guidance in place. We assume that the personnel involved might include geneticists, genetic counsellors, family doctors and psychosocial professionals such as counsellors, and social workers with training in disability and mental health.”

The relevance of the age of disclosure

Question 7 of set A required respondents to comment on the impact of donor-conceived individuals finding out about their donor conception at different ages. It suggested that respondents might breakdown their comments to focus on the impact in three specific areas: medical, psychological, and social. However, Professor Marilyn Strathern suggested that these categories were “impossible to disentangle – indeed one probably should not want to.”

The vast majority of people who chose to respond to this question took the view that donor-conceived people should be told about the circumstances of their conception at an early age. For example, the Australian and New Zealand Infertility Counsellors Association stated that “It is the experience of ANZICA counsellors that families who talk to their children about how they became a family with the assistance of a donor; especially if they do so early and in a loving manner fare much better than those who do not.” An anonymous respondent similarly observed:

“Most of the children I know never ‘found out’ about their donor conception, rather it’s just a fact that they have always known, in the same way that children grow up knowing they have a cousin or they live at no. 19.”

Anonymous respondent, responding to the Working Party’s call for evidence

Drawing on its own survey which received 751 responses, the Donor Sibling Registry stated that the majority of these respondents stated that early disclosure was important, and cited one of its survey respondents as stating: “I would say please, please, please be honest with your child about their origins from day one... I can’t tell you how big a shock it was to discover at the age of 25 that the man I think of as my dad isn’t my biological father.” Trustees and Steering Group of the Donor Conception Network made similar observations:

“Starting to ‘tell’ later than age eight or so carries a risk of a child being shocked by the information and this sense of shock always being associated with information about donor conception. The risk of this happening increases as a child gets older. Developmentally, probably the worst time to tell a child is during early teenage years as they are beginning to separate and differentiate themselves from parents, but do not yet have a secure sense of new individual identity.”

Trustees and Steering Group of the Donor Conception Network, responding to the Working Party’s call for evidence

Dr Sonia Allan made reference to a forthcoming literature review, where it was concluded that “it is clear... that some (though not all) donor-conceived people experience great and long-lasting distress in discovering the circumstances of their conception later, rather than earlier, in life.”⁹ She also referred to the findings of the Victorian Law Reform Committee in Australia, which concluded that “some donor-conceived people suffer substantial distress... if told of their donor-conceived status later in life.” Similar conclusions were also reached by Dr Maggie Kirkman, who noted that “learning from infancy but certainly before puberty appears to be ideal. When they find out later than this, donor-conceived people can feel that they lose trust in their parents... and lose the sense of identity that they have constructed all their lives.” A response from the Victorian Assisted Reproductive Treatment Authority (VARTA) also drew attention to “emerging research [which] suggests that parents who tell their children while they are young that they are donor-conceived are more at ease with the process than parents choosing a later time for disclosure.”¹⁰

Professor Carol Smart and Dr Petra Nordqvist from the University of Manchester highlighted how disclosure may be a process rather than a one-off event:

“Our study shows that telling the child and others is not a one-off event, but has to be done repeatedly. Surprising as it may seem, young children (as well as others of course) can forget, and need to be reminded. This ‘forgetting’ is understood where young children are concerned and parents are advised that they need to tell their children often and in age appropriate ways.”

Professor Carol Smart and Dr Petra Nordqvist, the University of Manchester, responding to the Working Party’s call for evidence

Examples or evidence for the relevance of the age of disclosure

Question 7 of set A also asked respondents as to whether they were aware of any examples or evidence pertinent to the question of the age of disclosure. ANZICA (the Australian and New Zealand Infertility Counsellors Association) provided the following examples:

⁹ since published as: Blyth E, Crawshaw M, Frith L and Jones C (2012) Donor-conceived people’s views and experiences of their genetic origins: a critical analysis of the research evidence *Journal of Law and Medicine* **19** (forthcoming). [update ref]

¹⁰ MacDougall K, Becker G, Scheib JE, and Nachtigall RD (2007) Strategies for disclosure: how parents approach telling their children that they were conceived with donor gametes *Fertility and Sterility* **87**: 524-33.

“To give some examples, we have heard of people finding out from their parent at the time of the parent’s separation, from a third party who may be a relative or friend of the family (this may be told kindly or in some cases vindictively), or who have guessed due to blood group or genetic information or an appearance very different to their father’s, where the parents has developed dementia and told inadvertently, where the young person has worked in a doctor’s surgery and looked up her mothers’ records. In some instances, they have learned of their donor-conception after their non-biological parent has died and so have not had the opportunity to resolve this with them and tell them that they loved them whether they were biologically related or not.”

Australian and New Zealand Infertility Counsellors Association, responding to the Working Party’s call for evidence

The relevance of the age of disclosure on the parents of the donor-conceived child was also highlighted by The British Infertility Counselling Association, which noted: “it has... been well documented that parents rarely regret telling their children in infancy, but others often regret not telling and live with considerable distress about the secrecy for the rest of their life.”

Other respondents made the following observations:

“Keeping a secret of such magnitude over many years has enormous consequences for the entire family. Furthermore, all too often the offspring finds out at a time of family crisis such as death or a divorce... Even if they are told later in life at a time of calmness, it appears that most people in that situation feel betrayed that they were lied to about such important information by those whom they trusted most.”

Anonymous consultation respondent, responding to the Working Party’s call for evidence

“I can only draw on the parallels of my adoption. I was told at a young age that I was adopted. In fact my first book that I can remember was called ‘I am adopted’. A nice simple book to help the child know that there is nothing wrong with being adopted.”

Mr James Martin, responding to the Working Party’s call for evidence

“My son has always known. My own view is that the psychological impact is the greatest, and the evidence shows that being told, e.g. as a teenager, that you are adopted or donor-conceived can be incredibly damaging. Apart from anything else, the child will realise that his/her family has been hiding a secret for all those years, and that everyone was in on it – grandparents, aunts and uncles, family friends. Not a great start in life, in my view.

Anonymous respondent, responding to the Working Party’s call for evidence

“... one young adult had found out about his conception through discovery of some early medical records. This was devastating for him. Not because he was donor-conceived but because he felt lied to.”

Venessa Smith, Donor Services Coordinator, The London Women's Clinic, responding to the Working Party's call for evidence

“Our daughter is donor sperm conceived, and she has known since she was around four ([she] doesn't remember not knowing). She is very comfortable in her own skin, and unfazed by/about her origins, and has a good relationship with her father.”

Andrea Powell, responding to the Working Party's call for evidence

Other respondents – particularly those who work with donor-conceived people in a professional capacity – also drew attention to their own experiences of late disclosure, with several highlighting instances of donor-conceived people being told after their childhood years, and experiencing feelings of betrayal.

“Teenagers and young adults who speak at the Time to Tell seminars, who have learned of this early and who can't remember ever not knowing, commonly describe their situation as 'not a big deal'... The contrast between these young people and those who discovered later is marked. They commonly describe the shock and disbelief they felt when learning of their origins, feeling they had been lied to and deceived. They have described taking years to process the information and incorporate it into their identity.”

Victorian Assisted Reproductive Treatment Authority, responding to the Working Party's call for evidence

This view was supported by a submission from Mr John B. Appleby and Dr Lucy Blake from the Centre for Family Research at the University of Cambridge, who drew attention to an online study of donor-conceived people which found that those who discovered the nature of their conception at the age of 18 were more likely to report feeling shocked, confused, upset, numb and angry than those who learnt of their donor origins before the age of 18, although they were also more likely to report feeling relieved.¹¹

The same respondents, however, noted that “late disclosure does not necessarily lead to negative reactions, just as early disclosure may not always lead to positive or neutral reactions.” In particular, they draw attention to a study suggesting that the mental health of the mother, the quality of the relationship between parent and child, and the quality of donor conception-related communication may also influence the impact on the donor-conceived person.¹²

¹¹ Jadvá V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24**: 1909-19.

¹² Mahlstedt PP, LaBounty K, and Kennedy WT (2010) The views of adult offspring of sperm donation: essential feedback for the development of ethical guidelines within the practice of assisted reproductive technology in the United States *Fertility and Sterility* **93**: 2236-46; Paul MS,

Some respondents drew attention to the relatively small amount of research on the impact of age of disclosure. The Christian Medical Fellowship, for example, stated that “qualitative evidence in this area is limited, however the testimony of donor-conceived adults is increasingly being heard, and generally confirms the benefits of parents being open from an early age, yet such evidence is often dismissed on the grounds that it is anecdotal. More controlled research therefore needs to be done.”

The impact on the donor-conceived individual making contact with the donor and half-siblings

Question 8 of set A focused on the impact of the donor-conceived individual making contact with either the donor, or any previously unknown half-siblings. The HFEA provided some background information about the UK-based register, the Donor Sibling Link (DSL):

“There are now 19 people registered to share their contact details with their donor-conceived genetic siblings, should any of them join the register. To date there have been no matches on the DSL, but all the processes and protocols are in place for future use. This service gives donor-conceived people the opportunity to share experiences with someone in the same position as they are, and as more donor-conceived people register the likelihood of finding a match will increase.”

HFEA, responding to the Working Party’s call for evidence

A clarificatory point was also made by Progar (Project Group on Assisted Reproduction, British Association of Social Workers), who noted that “‘contact’ is not only with donors and siblings but also often with all the family members/networks of these individuals, including children and grandchildren of donors and donor offspring.”

Making contact with the donor

The Victorian Assisted Reproductive Treatment Authority commented that at present research into donor-conceived people making contact with donors – or indeed half-siblings – was limited.

An anonymous respondent commented on the experiences of a contact who was unable to provide her three donor-conceived children with any identifiable information about the donor. This respondent notes “how upsetting it is for her to know so very little about her children’s biological father. She has described the information that she has (height, weight, eye colour, hair colour) as being what is wanted on a ‘wanted poster’.”

Similar frustration was exhibited by another respondent.

and Berger R (2007) Topic avoidance and family functioning in families with young adult children conceived with donor insemination *Fertility and Sterility* **88**: S249-S50, respectively.

“I have narrowed where I was conceived down to two clinics. One said it couldn’t release any information without getting my mother’s consent to look at her medical records. She gave her consent but then it said that it couldn’t release any information because it was a breach of confidentiality (whose confidentiality wasn’t clear). The man I spoke to on the phone about this was very rude and hung up on me... The other clinic looked in their records and said they couldn’t find anything. The woman I spoke to there admitted the records were a mess and said she would take a second look, but I never heard from her again.”

Rachel Pepa, responding to the Working Party’s call for evidence

Making contact with half-siblings

Several respondents focused on the impact of a donor-conceived person making contact with half-siblings.

Highlighting how donor-conceived people may have different expectations of sibling relationships, The British Infertility Counselling Association noted that “some [donor-conceived people] simply want to see what the donors/half-siblings look like whereas others hope for an ongoing relationship.” Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors, however, noted that such contact “can also stop them worrying about the possibility of forming an intimate relationship with someone to whom they are genetically related.”

One anonymous respondent noted that “for many, it [making contact with donor siblings] fills a ‘blank’ in their lives, and makes them more peaceful, simply to have met and talked to someone related to them.”

Jennie Hunt, Senior Accredited Member of BICA, raised concerns about the lack of support services, noting that: “as yet we have no system in place for intermediary and support services that can enable both donors and donor-conceived people, siblings and parents to prepare appropriately for contact.” A similar point was raised by Andrea Powell, who – referring to contacting her daughter’s donor or donor siblings – stated, “I have no idea how we would handle contact with her donor or her siblings, but feel strongly that for all parties, counselling for all, and a third party making initial contact would make things easier in preparing for likely outcomes.”

Specific examples

Respondents were also invited to tell the Working Party about any examples or evidence in regard to this question. Dr Maggie Kirkman suggested that there was a “full range of possible outcomes, from extremely happy continuing friendships to disappointing single encounters.”

Positive examples of the impact of contact, with half siblings

“[I know] a mother of young twins who spent a week’s holiday meeting up with a family with a single child from the same donor. The children were under five and had a good time and played happily together, despite not speaking the same language. The experience was highly valued by all parents, and continued contact is planned, though visits will be infrequent due to distances.”

Anonymous respondent, responding to the Working Party's call for evidence

"I have interviewed one 26 year old woman who had made contact with her previously unknown donor half-brother. Over a two year period, the two had developed a relationship with hardly any face-to-face interaction or interaction in larger groups of friends or family, but were on the phone to each other every week and also emailing back and forth... The woman described this as an extremely positive relationship, where she could share some of her concerns about being donor-conceived. She also underlined how the half-siblings were now trying to locate their donor together."

Maren Klotz, Lecturer, European Ethnology, Humboldt University Berlin, and Honorary Fellow at the Egenis Centre, University of Exeter

"Again I only have the similarities of my life to go on from an adoption standpoint. For me, it was a very positive experience... I couldn't say for certain that this would be the case for others."

Mr James Martin, responding to the Working Party's call for evidence

"[I know] three teenage half-sisters, all only children, who have made contact and have close relationships, calling each other sisters, and seeing each other most long holidays despite not living in the same city. The families regularly take all three girls away on holiday, which has enriched their lives in many ways, giving them the opportunity to visit places they would otherwise not have seen and to learn about life in different families."

Anonymous respondent, responding to the Working Party's call for evidence

"The one young adult I have met who has got in contact with his half-siblings has worked very hard to build a relationship with them. However, it will always be more like a distant cousin than with a true sibling. In his situation, his half-siblings lived quite remote from one another so most contact was via email and this is not always satisfactory. Even so, he does feel these relationships are crucial to him understanding who he is."

Venessa Smith, Donor Services Coordinator, The London Women's Clinic, responding to the Working Party's call for evidence

Negative examples of the impact of contact, or no contact, with half siblings

"I know two families who know of a half-sibling, but the other family does not want the children to have contact. In both cases, the child who knows would like to know more and meet the other child, and this causes some sadness and bewilderment. In both cases, the children are older (over 10), and the other family has not explained their withdrawal from contact. This inevitably leaves room for doubt

that the withdrawal may be for personal reasons such as disapproval.”

Anonymous respondent, responding to the Working Party’s call for evidence

Evidence basis

Some respondents felt that there is currently a lack of evidence concerning the impact of making contact with the donor or with half siblings. Comments received by the Working Party included:

“[There] is a distinct lack of hard evidence on this issue. Most is anecdotal evidence. More qualitative research is required to reveal the complexity of relational dynamics in families with non-biological children.”

Christian Medical Fellowship, responding to the Working Party’s call for evidence

Responsibilities arising in connection with the disclosure of information, and the support needed in the context of these responsibilities

The question of responsibilities that might arise in connection with the disclosure of information about donor conception was raised by question 10 of set A and question 7 of set B, which specifically focused on support. Both of these questions also asked respondents to comment on where they thought such responsibilities lie.

Which responsibilities arise?

The British Infertility Counselling Association felt that the responsibility arising in connection with the disclosure of information was for the government to “bring donor conception into line with all other UK children’s legislation in determining children’s rights to information about their identity as paramount.” The Association also suggested that donor-conceived people who are conceived outside the UK should have the same rights to information as those people conceived in the UK.

Progar (Project Group on Assisted Reproduction, British Association of Social Workers) stated that “there is a [moral] responsibility for professional support services to be provided to families with young children including recipient families and donors’ families to assist them with disclosure/information sharing and to support them throughout what may be a long process.”

Progress Educational Trust felt that “the principal responsibility that arises in connection with the disclosure of information is the responsibility of an authorised body to maintain a central and secure register of information pertaining to donor conception.”

Where do responsibilities lie?

The question also asked where responsibilities might lie, giving suggestions such as the Government, fertility clinics, professionals or families.

Government and governmental bodies

A significant number of respondents who chose to address this question felt that responsibilities for the disclosure of information should lie with government, or with statutory bodies such as the HFEA. Different respondents emphasised diverse forms such a responsibility might take, including providing for the support needs of those affected by donor conception, legislating in connection with openness in donor conception, and specific responsibilities that might arise towards the people born as a result of donor conception. The British Infertility Counselling Association, for example, argued that, in terms of child welfare, family welfare and adult mental health, there is a case to be made for the Government to acknowledge the responsibility it has to all people affected by donor conception. The Christian Medical Fellowship expressed concerns that “equity in the preservation of personal identity [for donor offspring] has not received as much attention as the rights of adults to fertility treatment.”¹³

Some respondents, such as the Christian Medical Fellowship, felt that the Government has a responsibility to “give consideration to how it will encourage parents to be open with their children about their origins.” An anonymous respondent similarly commented:

“[The] need for donor-conceived children to access the truth about their origins should be a matter for public policy, and if at all possible, for public services as well. I do not think that providing services takes away the responsibility of parents, but rather that it must complement it and back it up with practical help.”

Anonymous respondent, responding to the Working Party’s call for evidence

The Victorian Assisted Reproductive Treatment Authority drew attention to how – in light to changes to legislation in the context of donor conception in the state of Victoria – the Victorian Government had “provided funding for sensitive education so that the general public could be informed of changes to legislation.” Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors similarly suggested that “it would be helpful to introduce public campaigns designed to raise awareness of infertility and assisted conception in all its forms. This would help people to better understand the issues, support family building and protect family life.”

Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors suggested there was a need for “expert legal advice and help in the preconception states and ongoing legal support for parents throughout their child’s minority”. Another respondent felt that there needs to be a “clear legal system that protects the children and their parents, including: access to information about the child’s origins (particularly medical), protection against potentially unscrupulous donors, a legal framework that clearly defines who their parents are an – crucially – strict rules governing how fertility clinics should operate.”

Other comments relating to governmental responsibility included:

¹³ In support of this view, the Christian Medical Fellowship cites: Almond B (2006) *The fragmenting family* (Oxford: Oxford University Press), p118.

“Governments should enact legislation that provides for the donor-conceived person to be alerted to the method of conception, and that further information is available to them.”

Dr Sonia Allan, responding to the Working Party’s call for evidence

“There is an absolute moral responsibility on clinics and the HFEA to ensure that full information is provided by the donor and practice currently falls far short of what is needed. The HFEA do not require donors to complete all sections of the donor information form and do not require all donors to have counselling.”

Jennie Hunt, Senior Accredited Member of BICA, responding to the Working Party’s call for evidence

Fertility clinics

The British Infertility Counselling Association felt that fertility clinics also have responsibility “to acknowledge the life-long implications of family creation through donor conception and to ensure that processes are in place at the donation and treatment stage to assist patients and donors in meeting the long term needs of all who are affected.” The response from the Association also stated that fertility clinics should provide the finance necessary for the provision of post-donation support services. A respondent to set B similarly felt that the medical profession could assist in a separate way, by setting up support groups: “Banks could facilitate setting up the groups in various areas – offering to help make connections if desired, but shouldn’t have to fund or run them – perhaps even a forum online would work.”

The responsibility of fertility clinics was also raised by the Christian Medical Fellowship, which took the view that “more efforts should be made by clinics to follow up on patients (current and previous patients) and to collect data on the various forms of treatments, particularly new methods, so that we have good information on the effects of treatment upon the resultant children, rather than continuing blindly with this social experiment.”

Potential responsibilities of clinics were also highlighted by the Trustees and Steering Group of the Donor Conception Network, who emphasised the role played by the culture of individual clinics. They stated: “fertility clinics need to come more strongly on board with the ‘telling’ message... A clear and consistent message from all staff, from consultants to receptionists is needed.”

Parents of donor-conceived people

However, many respondents took the view that responsibilities lie with parents of the donor-conceived people. For example, one respondent noted that “disclosure is not simply a one-off event in which parents tell their child that he or she was donor-conceived,” and that parents should do “their best” to answer any questions their child may have as they grow up. From another perspective, it was noted that “the parents of donor-conceived children need support before, during and after treatment with donor gametes.” Similarly, another respondent stated: “Parents have to struggle with several stages in creating a donor conceived family, beginning with the loss of the possibility of a genetically-linked child to one or both parents. Counselling is invaluable at every stage of their journey and I believe should be a requirement of all

people seeking to conceive this way: this should be funded by the clinics helping the parent(s) with their treatment. Having become parents to a donor conceived child, the struggle is in the” telling and talking”

The medical profession

The Christian Medical Fellowship stated that the medical profession should consider marking the medical notes of donor-conceived people so that a “GP would therefore know and be able to counsel, or direct towards counselling, the parents as they bring up the child.”

However, another respondent to set B noted that not all medical professionals had the knowledge basis needed in order to provide adequate levels of support:

“My GP, for example, when I went to speak to her at the beginning, about my desire to go down the donor conception route, told me I had to have sex with my partner for six months before she could refer me – even though I’d clearly told her I was single! She obviously knew what her protocol was for couples, but I had to educate her on single mothers by choice. She did eventually refer me.”

Respondent to set B

The responsibility does not lie with one party

Some respondents noted that support should be multidisciplinary. Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors, for example, stated that “no one group should act in isolation since it is and will continue to be difficult to balance the needs of donors, donor-conceived children and parents and adapt to developments in medical science and changing attitudes and structures associated with family life.”

Support needed in connection with these responsibilities

Question 11 of set A then asked respondents to comment on support which might be needed in the context of these responsibilities. Question 7 of set B also fed into this question. One comment from a respondent to set B highlighted the inherent sensitivities involved, noting that “this [donor conception] is venturing into a world where the most private/intimate situation in your life is suddenly turned into a cross-cultural medical transaction with strangers being involved.”

Counselling

A significant number of respondents stated that support should be given in the form of counselling. The Donor Sibling Registry, for example, commented that “There needs to be education and counselling for both donors and future parents about the impact of using donor eggs and sperm. This needs to come from a third party, not one provided by the clinic or sperm bank.” Similar comments included:

“[There] is a form of pre-counselling that is given when adopted children are searching for their birth parents. Something similar would be helpful, particular in relation to looking for half-siblings.”

Anonymous respondent, responding to the Working Party’s call for evidence

“Counselling should be available, but not mandatory, for donors and for the parents of donor-conceived children before and after donor conception. Such counselling should be provided by clinics as a condition of their license to perform fertility treatment.”

Progress Educational Trust, responding to the Working Party’s call for evidence

A respondent to set B also felt that a “mediation model would work well... [where] counsellors with correct training and experience provide the support service.”

The timing at which such support should take place was also felt to be important by a number of respondents who stated that counselling was needed. For example, one respondent stated “ideally counselling should be offered to children when they have been told and are old enough to understand. Patients should be counselled well before they go into treatment... Donors should also be counselled at the time of screening with respect to their legal and moral obligations and be adequately prepared for their decision to donate.”

Support networks

A range of suggestions for support networks were made by respondents, a number of whom emphasised the need for funding for peer support networks such as the Donor Conception Network. Peer support was clearly valued by respondents: for example one respondent to set B noted that, “from my own experience, the very best ‘support’ in all matters pertaining to donor conception has come from others who share my donor conception status. The pooling of information, ideas and experiences with those who truly understand the problems has been invaluable.” Similarly, the value of websites such as anonymousus.org (which is aimed at donor-conceived people) was noted by respondents.

One anonymous respondent, however, suggested that “support needs to go beyond what can be provided by self-help groups such as the Donor Conception Network,” arguing that “although the service it provides is wholly commendable, it does not reach many families who may feel alienated for a variety of reasons, and I believe that a more formal/impersonal service such as a helpline would be invaluable.” Other respondents who submitted responses to set B also suggested that a helpline would be useful, with others calling for an ‘unbiased’ support service

Some respondents envisaged that support would come from government. One respondent, for example, suggested a “centrally-funded counselling service, probably on a regional basis, with close links with post-adoption services... It may be that those providing donor services should contribute alongside the HFEA or its successor.” Another respondent felt that “there needs to be a government agency coordinating essential support.”

The need for intermediary services to support those contemplating contact was also emphasised by a number of respondents. The British Fertility Society, for example, commented:

“The BFS feel that the introduction of a national support network delivered by appropriately trained professionals for all who are

affected by donor conception to include intermediary services, professional support works and counsellors is required.”

British Fertility Society, responding to the Working Party’s call for evidence

“[There] needs to be a national post-donation support and intermediary services that is fully funded. This could also become the home of the voluntary register (UK DonorLink) in preference to the unfortunate decision to allow the National Gamete Donation Trust to manage it...”

Jennie Hunt, Senior Accredited Member of BICA, responding to the Working Party’s call for evidence

The suggestion that support was needed at all, however, was questioned by one respondent to set B, who stated that “as a potential parent of a donor-conceived child I do not feel I need any help or support in being a parent to a child – at least, no more support than any parent of any child needs.”

Other comments

Question 12 of set A and question 8 of set B gave respondents the opportunity to give the Working Party any other comments not covered by responses to specific questions.

The clarity of data concerning donors was raised by a response from the BMA, which made the following point.

“Although data from the Human Fertilisation and Embryology Authority about new donors appears reassuring, the published data do not distinguish between known or directed donors (who will only donate to one person or couple) and those willing to donate to anyone, where up to ten families can be helped. This makes a difference in terms of the number of people able to receive treatment.”

The British Medical Association, responding to the Working Party’s call for evidence

In a letter submitted to the Working Party, ANZICA stated: “modern infertility practice using donated gametes should be based on an understanding of the needs of donor-conceived individuals and the consequent principles of being open with all participants about future identification and the consequences that follow from that.”

The different case of overseas treatment

Concern was expressed by a significant number of respondents about situations where people seeking treatment with donor gametes travel abroad for that treatment. In this case, the information available to all parties may change, and may bring about further ethical concerns. Comments received included:

“[As] increasing numbers of people cross borders for fertility treatment this creates issues and varying experiences, for example

the conception of a child in one jurisdiction using an anonymous donor that is then parented in a jurisdiction where donors are identifiable and the additional challenges this may bring.”

Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors, responding to the Working Party’s call for evidence

“People having treatment abroad and using donated gametes is a great concern for those receiving treatment, those conceived and the donors who may be exploited and not have the level of information and support which is offered in the UK (though this could be much better). Much more attention should be paid to educating people in the UK about the medical and social ‘risks’ and potential consequences as going abroad for treatment cannot be prohibited.”

Anonymous respondent, responding to the Working Party’s call for evidence

Other comments on the situation of overseas treatment were also offered by an anonymous respondent, who stated that there should be “an expectation that if there are financial benefits [to UK clinics who use donors from other countries], these should be conditional on the UK service setting a standard of service equivalent to that which their patients would receive if they stayed in the UK.”

The difference in cost between treatment in the UK and overseas was also noted by respondents. In particular, one respondent to set B noted that “known donors are more expensive so I opted for the cheap version. Donors do a fantastic job and it should be cheaper in the UK to access donors and be inseminated. I go to Denmark because it is cheaper even if you factor in air fares.”

Public awareness

PROGAR (Project Group on Assisted Reproduction, British Association of Social Workers) felt that “there needs to be a sustained public awareness campaign about the importance of donor information, encouraging former donors to update their files on the HFEA register and educating them about the need to re-register as identifiable if they donated prior to 2005.”

Variation in quality of donor information

A response from the HFEA noted that information which is given by donors to clinics may be of varying quality. In particular, “goodwill messages containing identifying information, poor spelling and grammar, possibly problematic content, or foreign language.” In light of this concern, the HFEA notes that it plans “to carry out future work with the [fertility] sector to improve the quality of donor information and this work will be a core aim of the HFEA’s new National Donation Strategy Group.”

The value of such goodwill messages was raised by the Anscombe Centre, which stated that “a goodwill message from the donor may also be valuable, as going some way to alleviating the sense of abandonment some children – not unreasonably – feel.”

The importance of language

The Donor Sibling Registry (DSR) highlighted the importance of language, and how 'parent' terminology is used by recipients. The Registry stated:

"Parents need to be very, very careful about their own bias, and to let the language be child driven. It should be them that define the relationship between them and their genetic relatives, not us, the parents. To many parents, the donor is just a 'piece of genetic material', or a 'donated cell', but to our children, the donor is often viewed very much differently."

DSR, responding to the Working Party's call for evidence

The importance of counselling

A number of respondents used this question as an opportunity to highlight the importance of counselling. Responses received include:

"It is essential that the counselling that prospective donors and parents are given, prior to them deciding to participate in donor-conception programmes, adequately covers the full implications of this practice. If participants are enabled to recognise and consider all that donor-conception may entail, they will be better equipped to deal with difficult issues, should they arise at a later date."

Church of England: Mission and Public Affairs Council, responding to the Working Party's call for evidence

Other questions to address

Some respondents chose to highlight 'other issues' in the form of questions. These included the following, which were submitted by the HFEA:

- What role should the regulator play in information disclosure?
- Should the regulator go beyond the statutory minimum to provide information and if so, how far should the regulator go?
- What role should centres play in helping donors provide better information about themselves for future families? Do centres have a responsibility to submit good quality donor information to the HFEA?
- The role of guilt in the situation where donor-conceived children ask for information which their parents are unable to give them.
- What role should professional bodies play in providing guidance on information disclosure to people affected by donation?
- What is the role of the regulator in ensuring good practice in:
 - Good quality donor information?
 - Good counselling?
 - Emphasis on 'openness'?

Annex A: List of questions in the evidence call

Set A

1. What ethical concerns arise in the disclosure, or not, of information in connection with donor conception?
2. Is the disclosure of a child's donor conception essentially a matter for each individual to decide? What if there is disagreement within the family? Who else should have a role in making this decision?
3. What information, if any, do parents need about a donor in order to enable them to carry out their parenting role? Please explain.
4. What information might a donor-conceived person need about the donor, either during childhood or once they become adult? Please explain.
5. How significant is information about the medical history of the donor and the donor's family for the health and wellbeing of donor-conceived offspring? Do you know of any examples or evidence in this area?
6. Where information about inherited medical risk becomes apparent after donation has taken place, who should be told, and by whom?
7. What is the impact on donor-conceived offspring of finding out about their donor conception at different ages: for example medically, psychologically and socially? Do you know of any examples or evidence in this area?
8. What is the impact on donor-conceived offspring of making contact with either the donor or any previously unknown half siblings? Do you know of any examples or evidence in this area?
9. What interests do donors and donors' families have in receiving any form of information about a child born as a result of the donation?
10. What responsibilities arise in connection with the disclosure of information? Where do these responsibilities lie? (for example with government, fertility clinics, professionals or families?)
11. What support is required in connection with these responsibilities?
12. Do you have any other comments? Please highlight any relevant areas you think we have omitted, or any other views you would like to express about information disclosure in the context of donor conception.

Set B

1. Should children always be told that they are donor-conceived? If so, why?
2. Who should decide whether, and if so when, to tell a child that they are donor-conceived? Is this a decision only the parents can take – or should anyone else be involved?
3. What information do the parents of donor-conceived children need about the donor to help them look after the child? Why?
4. What information about the donor do donor-conceived children need? Why?
5. What information (if any) might an egg, sperm or embryo donor want about a child as a result of their donation? Why?
6. If a donor finds out later that they have a genetic condition, should they try to pass on this information to the child conceived with their egg/sperm?
7. What support might donors, donor-conceived children and parents of donor-conceived children need? Who do you think ought to provide it?
8. Do you have any other comments?