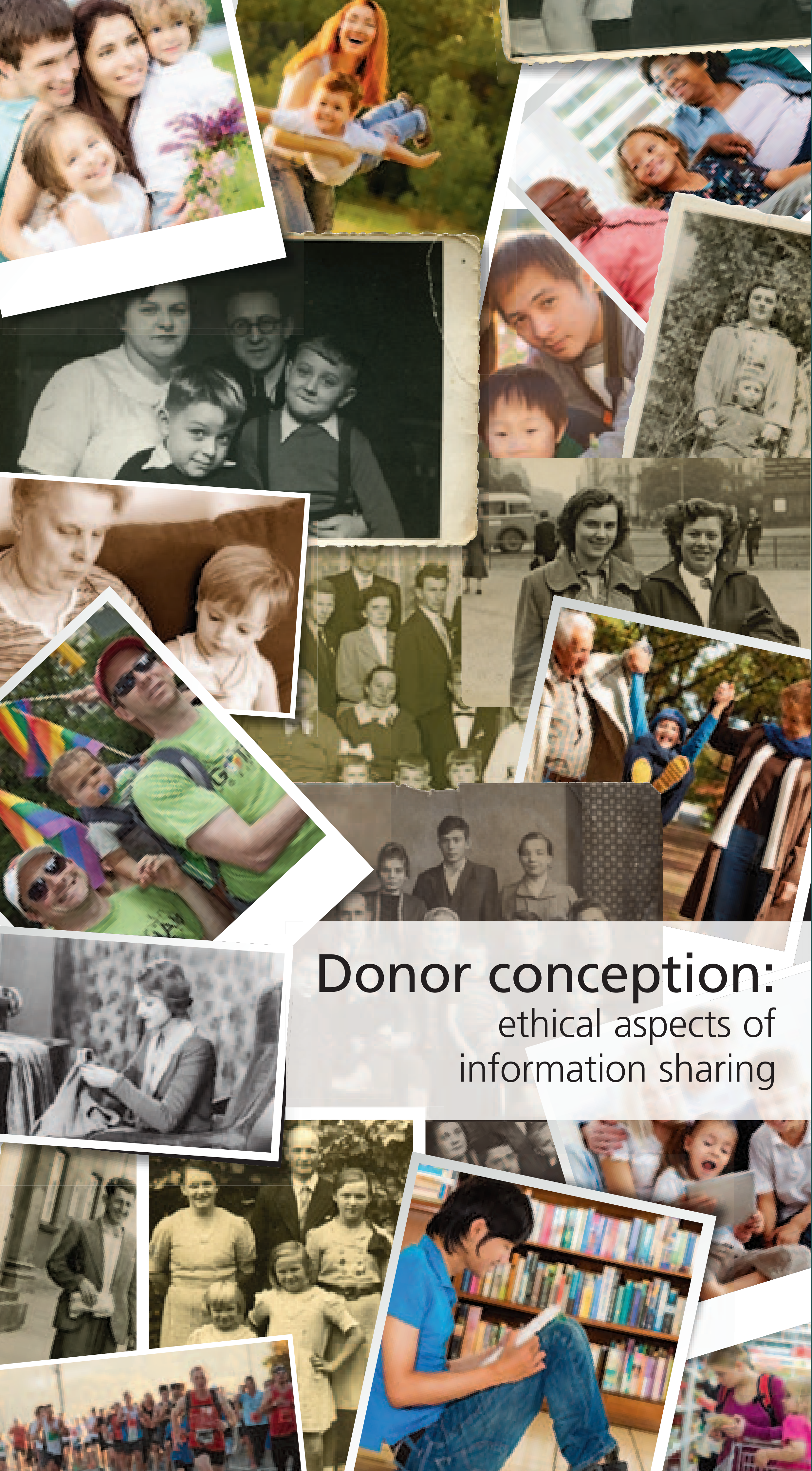

# Donor conception:
## ethical aspects of information sharing

NUFFIELD
COUNCIL ON
BIOETHICS

Published by
**Nuffield Council on Bioethics**
**28 Bedford Square**
**London WC1B 3JS**

Telephone: 020 7681 9619
Email: bioethics@nuffieldbioethics.org
Website: http://www.nuffieldbioethics.org

ISBN: 978-1-904384-28-1

April 2013

**To order a printed copy, please contact the Nuffield Council on Bioethics or visit the website.**

£10 per report (where sold)
Developing countries: Free

Web references throughout this report were accessed in March 2013.

Printed in the UK by:
ESP Colour Ltd.
Elgin Drive
Swindon
Wiltshire
SN2 8XU
**http://www.espcolour.co.uk**

FSC
www.fsc.org
MIX
Paper from responsible sources
FSC® C006509

Printed using vegetable based inks on FSC® certified paper. The printer holds the environmental standard ISO 14001.

# Donor conception: ethical aspects of information sharing

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**The Nuffield Council on Bioethics is funded jointly by**
**the Medical Research Council, the Nuffield Foundation, and the Wellcome Trust**

# Acknowledgments

The Working Party would like to express their gratitude to all those who contributed to the production of this report, through responding to the open call for evidence or online survey, attending factfinding sessions to share their knowledge and debate issues directly with the Working Party, or acting as external reviewers of the draft report (see Appendices 1 and 2). In addition to contributing in these ways, a number of people were particularly generous with their time and expertise, and we would like to offer special thanks to: Joanne Anton, John Appleby, Lucy Blake, Marilyn Crawshaw, Tabitha Freeman, Nicky Hudson, Wendy Kramer, Susannah Merricks, Walter Merricks, Olivia Montuschi, Juliet Tizzard and Sophie Zadeh.

# Foreword

It is said that there is nothing new under the sun. However, when one looks at the ethical aspects of information sharing in donor conception it intuitively feels that there *is* something new. While sperm donation has a long history in the Western world, innovative reproductive techniques using donor eggs, embryos and even wombs are all recent technological developments. With these new technologies come new ethical challenges. These new challenges are compounded by the increased availability of, and access to, information – both medical and social. In the area of donor conception in the UK what information is available, and to whom, is well regulated. However not all donor conception takes place within a regulated system, and new technologies have enabled access to information in new ways. For example, medical genetics has allowed individuals to identify those to whom they may be related and the internet has facilitated access to, and enabled linking of, information in ways that have not previously been possible. As a result, donor-conceived people are now making links with donors and donor-conceived siblings in new ways. But what are the ethical aspects of information sharing in donor conception? Is there really anything new under the sun? While the Working Party found that new technologies did pose new ethical questions, many of the key issues are ages old, for information sharing in the context of donor conception has, at its heart, people. It is about families, kinship and relationships.

In the early stages of developing this project, it became apparent that there were many interests at stake, and also very different heartfelt views on this issue, even amongst people coming from a similar perspective. A Working Party representing the full diversity of these views would have been too large to be practical. A small expert Working Party was therefore brought together, establishing a consultation process to ensure that the Working Party would hear, and could take full account of, the multiplicity of views and the diversity of contexts in which reproductive donation occurs. It was essential for the Working Party to consider the different perspectives of those affected by donor conception, being aware that in each corner of the 'donor conception triangle' – donor, recipient parent/s and donor-conceived offspring – opinions were not uniform, and indeed could be poles apart. The Working Party also needed to consider the wider network of family, kin and cultural groupings impacted by, and impacting on, the 'donor conception triangle', bearing in mind how all these interdependent relationships change over time. It also needed to consider throughout the one group it could not hear from – those who are donor-conceived, but who are unaware of this.

The word 'information' is used in many different ways in donor conception. It can, for example, be information relating to the fact that an individual is donor-conceived. It can also be information about the donor themselves – information about their medical history, their genetic makeup, and who they are as people. It was important to the Working Party to identify the benefit or harm that knowing certain information might confer on the different parties, as well as when and how this information could be shared most effectively. For example, the Working Party found that there was sufficient evidence to point to the conclusion that it is usually better for children to be told by their parents, at an early age, that they are donor-conceived.

In exploring the ethical considerations of information sharing, as in other areas relating to donor conception, the use of language is important. The language of 'rights', which tends to start with conclusions, seemed too adversarial, not permitting the more nuanced approach needed in dealing with the complex interdependent networks of relationships of family and kin. The Working Party has therefore used the language of 'interests' and explored how these interests, together with the responsibilities of those involved in donor conception, can lead to a more individualised context-dependent analysis and approach. The Working Party places the onus on recipient parents to decide if, when, how and what information relating to donor conception should be shared with their offspring, seeing responsibility for these decisions as being a key part of the parental role.

The Working Party also considered how different values impact on these relationships, and concluded that openness to children about the means of their conception is important in so far as it contributes to the quality of relationships within the family, and to the well-being both of parents and of donor-conceived people. The Working Party considered the need to ensure that useful information is collected and made available, that support for all those involved in accessing and sharing this information is provided, and that structures are in place to ensure any essential medical information can reach those who need to receive it.

As the cover of this report demonstrates, the ethical aspects of information sharing in donor conception are about people and relationships. I hope that this report will be useful to those considering donation or donor conception, to those providing and regulating care, and to those involved in donor-conceived kinship relationships.

On a personal note I would like to thank everyone who so willingly contributed to the consultation and factfinding meetings. This enabled the Working Party to understand the complexity and diversity of experiences and viewpoints in this area. I would also like to thank the members of the Working Party for their hard work, wisdom and unfailing involvement throughout the project. I am sure too that the Working Party would like me to thank the Council, and particularly the Council subgroup, for their feedback and comments through successive drafts, and the external reviewers who helped identify areas in need of further development in the later stages of the project.

Finally, I would like to thank the secretariat, without whom this report would not have come into being. I would particularly like to thank Katharine Wright and Kate Harvey, whose time, intellect, hard work and dedication, have enabled the expertise of the Working Party and of all those who have contributed to the consultation to be brought together in exploring the ethical dimensions of this complex issue, and in the ultimate production of this report.

Rhona Knight

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# Terms of reference

In the context of families created through assisted reproduction using donor gametes, the Working Party will consider the impact of the disclosure/non-disclosure of information about a person's genetic origins, with particular reference to:

1. the wide range of stakeholders involved, the complexity of the relationships between them, and the ethical values at stake;

2. the quality of the evidence currently available as to both the medical and social importance of genetic information in this context;

3. the support available to both donors and donor-conceived families, for example in connection with future contact; and

4. the role of the law and professional guidelines in determining the provision of both general and specific information about donors to donor-conceived offspring and their families, and in intervening in families' decisions with respect to disclosure.

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# Executive summary

## Introduction

1. The task for this Working Party has been to consider questions of information sharing in practices of donor conception in the UK. Its primary focus has thus been on issues of privacy, openness, and access to information, and the implications of each of these for the individuals, families and groups affected by donor conception.

## Chapter 1: Families created through donor conception

2. The development of assisted reproduction services, and the willingness of people to donate their sperm, eggs and embryos for the treatment of others, has made it possible for many people who would otherwise have remained childless to create families of their own. Prospective parents may consider using donor gametes to conceive because of fertility problems or in order to avoid transmission of a serious genetic condition; donor gametes may also be used in the creation of 'non-traditional' family forms such as families created by same-sex couples or single people. Donors may be known or unknown to their eventual recipients, and may sometimes themselves be receiving fertility treatment. Since the introduction of regulation in 1991, over 35,000 children have been born in the UK as a result of donated gametes; many more donor-conceived people will have been born as a result of sperm donation outside of licensed clinics, or of treatment in overseas clinics.

3. Families formed through the donation of gametes or embryos ('donor-conceived families') can be viewed alongside other diverse family forms in the UK, including families created through adoption, single parent families, and 'reconstituted' families including step-children. The word 'family' is used for a wide range of relationships, referring not only to the unit of one or more parents and their children (however conceived), but also to a wider set of relations sometimes referred to as the 'extended' family. Our notions of what constitutes 'our family' are flexible and cover a wide variety of combinations of relationships.

4. Despite this broad understanding of the notion of 'family', we suggest that the concept of 'kinship' might provide a better way of addressing the complex and contested issues emerging from questions of donor conception and disclosure. The concept of kinship can embrace the ways in which people *know* themselves to be related to each other. This is not universally the same the world over, but is culturally and historically shaped. Dominant understandings of kinship in the UK emphasise both biological and social relations: kinship bonds may arise as a result of biological connection and/or may be forged through care and nurture. From one perspective, the link between a donor and a donor-conceived person may be indisputably there, while from another it is self-evidently absent. Such a pluralism of opinion and understanding clearly emerged in both the research literature and in the views and attitudes of those sharing their personal experience with the Working Party.

5. The increasing emphasis in the UK on the significance of disclosure about the use of gametes in conception, and for access to information about the donor, comes at a time when the discussion of genes and genetic connection is prevalent in society, and where genetic explanation has become increasingly prominent in seeking to describe and understand disease, disorder, identity and relatedness. It is also occurring at a time when a high societal value is placed more generally on 'openness' and 'transparency'; and in a context where the internet and ever-expanding technologies of communication and social networking are challenging the boundaries of privacy.

## Chapter 2: Law and practice in the UK

6. The fundamental premise underpinning both the existence of treatment services using donor gametes, and the UK regulation of these services, is that the ‘recipient’ parent or parents will be the child’s real parents from the beginning. Where treatment is provided in licensed clinics, the law makes provision for the donor to be excluded from the legal status of parent, and for the recipients to acquire that status, even where they have no biological connection with the child. While donors are excluded from any parental responsibility in this way, information about them is, however, collected and retained by the regulatory authority (the Human Fertilisation and Embryology Authority (HFEA)), so that it can be provided later to donor-conceived people on request. Donors are encouraged, although not required, to provide biographical information about themselves, for example in the form of a ‘pen portrait’, and to write a message for the future donor-conceived person or persons.

7. While such information is anonymised, so that it can be provided without identifying the donor, fully-anonymous donation was abolished in the UK in 2005. Donor-conceived people born as a result of treatment with gametes donated after April 2005 will be able, when they reach the age of 18, to obtain identifying information about their donor. Those conceived before that date will not be able to obtain identifying information unless their donor chooses to make themselves identifiable. Those conceived before statutory regulation began in 1991 do not have access to any information via the HFEA and often have little, if any, information about their donor from paper records, although the possibility exists of being ‘matched’ (using DNA testing) with their donor or donor-conceived siblings via a state-funded voluntary register if their donor or donor-conceived siblings have also chosen to register.

8. In the past, most clinics providing treatment with donor gametes encouraged the prospective parents to forget about their treatment, once pregnancy was achieved, with disclosure to donor-conceived children about their means of conception being strongly discouraged on the basis that it was both unnecessary and potentially harmful. In the light of changing social and professional attitudes, this advice has reversed: reference to the “importance” of early disclosure to children has now been incorporated in the legislation, and is strongly recommended in the HFEA *Code of practice*.

9. It has been argued that the state should take further action to *ensure* that donor-conceived people know of the circumstances of their birth so that they are in a position to access the information held on their behalf by the HFEA: for example through some indication on a person’s birth certificate. It has similarly been argued that the legal provisions enabling donor-conceived people to access identifying information about their donor should be made retrospective, so that all donor-conceived people, whenever born, have access to this information where held. The Government has not, however, accepted the need for any such change to date. While Article 8 of the European Convention on Human Rights (the right to respect for a person’s private and family life) is cited in favour of recognising a ‘right to know’, it is argued in response that the Article 8 rights of recipients and donors are also engaged in any policy in this area, and that the competing interests of all concerned must be properly weighed.

10. Other countries both inside and outside Europe take widely differing stances on access to information for donor-conceived people, with some insisting on anonymous donation (in some cases excluding also the possibility of ‘known’ donation from a friend or relative), while others like the UK have taken steps to require all donors in the future to be identifiable when donor-conceived people reach adulthood. Just one jurisdiction, the Australian State of Victoria, requires the use of donor gametes to be indicated on a person’s birth certificate and, at the time of writing, is further considering whether changes to donor anonymity should be made retrospective.

11. In the UK, it is a legal requirement that potential donors and prospective parents must first be given a “suitable opportunity” to receive proper counselling about the implications of donation or treatment, and also “provided with such relevant information as is proper”. There is considerable variation in the extent to which clinics routinely encourage potential donors and prospective

parents to engage with such counselling services. With the exception of this support available through clinics at the point of donation or treatment, and information provided on the HFEA's website, the primary sources of support for people affected by donor conception are found in the voluntary sector. There is a further statutory requirement that donor-conceived adults applying to the HFEA's Register for information about their donor should be given a "suitable opportunity to receive proper counselling about the implications of compliance with the request" before the HFEA complies. There are at present no specialist services for donor-conceived adults in this position.

## Chapter 3: Medical information and family history

12. Family histories of particular conditions are often assumed to be much more predictive than they really are. The Working Party heard of many examples where donor-conceived people or their parents had been asked for family history information that would not, in fact, have made any significant difference to the care provided. It is important that all health professionals, in their routine practice, regularly question the basis for seeking information about a person's family history, and only do so where this information will be genuinely useful in the person's care.

13. Lack of information about the medical history of the donor is a source of much concern among donor-conceived people and their parents. However, in most cases, such information would be of little medical relevance for the donor-conceived person because of the screening and assessment that potential donors undergo before being accepted as donors, and because of the low predictive value of much family history information. If a donor does not have an inherited condition him or herself, then there will only be very rare situations where a family history of a condition will be medically significant to the donor-conceived person.

14. Potential donors will be excluded from donating altogether if their personal or family medical history could pose significant health risks to future offspring. It is important that details of the major conditions that have been 'screened out' in this way before a donor is allowed to donate are provided to prospective parents in an easily accessible and comprehensible format, in order to provide substantial reassurance that their child will have a low risk of inheriting a serious genetic condition from their donor. A clear explanation should also be provided that the donor has no known family history of any other condition that would pose a serious risk to the health of any resulting person. Some parents of donor-conceived children may interpret 'no information' about the donor's family history as resulting from a lack of willingness to share information, rather than as reassurance that there is no relevant information to provide. Clear communication on this point is essential.

15. The situation may, however, occasionally arise where factors in the donor's own medical history or family history are insufficient to exclude the donor from donating, but may be of future relevance to the health care of the donor-conceived person. Disclosure of such information to prospective parents should be encouraged and facilitated. Given the developing nature of knowledge in this area, however, parents should not place undue weight on such information, as information that is believed to be potentially relevant at the time of donation may later prove not to be so. A sound evidence base underpinning what information should be sought from donors in their clinic assessment is essential, so that donor-conceived people and their parents may be confident that information that may indeed be clinically relevant for the donor-conceived person's health care will be collected before donation and passed on appropriately. It is not useful to collect and share information about the health of the donor or their family that is unlikely to have any effect on the donor-conceived person's health or health care.

16. Circumstances may arise where significant medical information only comes to light after donation: for example in the case of the diagnosis of a serious late-onset strongly heritable condition in the donor. Such cases may also arise in reverse, where a donor-conceived person is diagnosed with a serious inherited condition, information about which could be relevant to their donor, their donor's own family, and any donor-conceived siblings. In such cases, it is

beneficial both for donors and donor-conceived people for there to be a clear and easily accessible mechanism through which such information may readily be communicated.

## Chapter 4: Knowledge of donor conception and access to donor information

17. The evidence on the experiences of donor-conceived people, parents, and donors with respect to the sharing of information about donor conception is patchy, and some things (such as the views of those who do not know they are donor-conceived) cannot be known. Almost all of what is known about the views and experiences of donor-conceived adolescents and adults relates to those conceived as a result of sperm donation, and hence very little is known about those conceived through egg or embryo donation.

18. Until recently, parents were advised not to tell their children that they were donor-conceived, and most parents followed this advice. The number of parents who do share this information with their children is increasing, with the latest figures suggesting that over three quarters of parents intend to tell their child about their means of conception, although intentions to tell do not inevitably lead to disclosure. Solo mothers and same-sex couples are more likely to tell their children about their means of conception than heterosexual couples.

19. Longitudinal studies of systematic samples of families indicate that both ‘disclosing’ and ‘non-disclosing’ families function well up to early adolescence. Little is known about the functioning of families in later adolescence and adulthood.

20. Children who learn that they are donor-conceived when they are very young appear to assimilate this information without difficulty. However, some adults who found out later in life, or inadvertently through disclosure from a third party, that they were conceived through sperm donation have reacted negatively. It is unknown how often inadvertent or unplanned disclosure occurs.

21. Some donor-conceived people are interested in obtaining information (both non-identifying and identifying) about their donor: reasons include finding out what kind of person the donor was and their motivation for donating; identifying features or characteristics in common; and accessing medical information. Such information may help some donor-conceived people integrate their donor into their existing life story. The evidence in this area is currently limited to sperm donation.

22. Studies of people on the Donor Sibling Registry (DSR), conceived as a result of sperm donation, show that some donor-conceived people (and also some parents of younger children) have high levels of interest in contacting both their donor and any donor-conceived siblings. It is not known, however, what proportion of donor-conceived people who are aware of their origins join the DSR. Whilst most people who search for their donor do not wish to form a ‘parental’ relationship with their donor, some do wish to form a ‘family like’ relationship with their donor siblings.

23. Parents who do tell their children about their means of conception rarely appear to regret this decision. While some non-disclosing parents have described finding ‘secrecy’ within the family to be a burden, the majority of non-disclosing parents do not appear to regret their decision.

24. Despite concerns that the regulatory change in 2005, requiring future donors to be potentially identifiable to their adult offspring, would prevent donors coming forward, clinics with an active donor recruitment programme appear to be successful in finding sufficient donors.

25. The experience to date of contact between sperm donors and donor-conceived people through voluntary contact registers is reported to be positive. Such contact also has a potential impact on donors’ own families.

## Chapter 5: Ethical considerations

26. Donor conception is first and foremost about *people*. The Working Party takes the view that any debate about the ethical considerations that should inform public policy on donor conception should start, not with the analysis of abstract principles, but with the people concerned, and the reality of their lives. 'People', in turn, do not exist in isolation but within a web of relationships with one another: such webs extend out beyond the family into the wider communities in which people live.

### Rights and interests

27. Much of the contemporary ethical and legal debate on information sharing in donor conception has been phrased in the language of *rights*. These rights claims seek to protect important *interests* for each of the parties involved: the significance placed by many on knowledge of, and contact with, those with whom they have close biological links; the value placed on having children and the autonomy of the family unit; the privacy associated with personal information; the need for boundaries beyond which public/state interference is not acceptable; and the significance placed on the keeping of promises and honouring of contracts.

28. Starting from the language of rights, however, is effectively to start with *conclusions*: the conclusion that particular interests are of sufficient importance to impose duties on others to ensure that the right-holder is able to enjoy the interest in question. Using the language of interests, on the other hand, enables us first to 'unpack' what we know about the nature of those interests, and then go on to consider at a second stage the extent to which others might be held to bear responsibilities in connection with the promotion or protection of those interests. It is not the role of this Working Party to make any judgment as to the appropriate degree of importance to be attached by any individual to any interest. However, the extent to which these interests are widely expressed and shared is relevant to the degree of moral responsibility that this creates in others. In turn, this is relevant in determining what action may be demanded on the part of public bodies.

### Values

29. Many of these interests arise specifically in the context of the relationships (actual and potential) that may exist between the different parties. A number of values embedded in those relationships, in particular *trust* and *honesty*, are widely regarded as playing a central part in promoting well-being within families. A further value that is often put forward in the context of relationships is that of *openness* or transparency. While these terms may at times be used synonymously with 'honesty' or 'truthfulness', we suggest this need not be the case: a person who chooses not to share information is choosing not to be 'open' but is not necessarily being dishonest. It is not, for example, usually considered 'dishonest' to choose not to disclose private information.

30. Difficulties arise in disentangling what (in the context of information about donor conception) may be rightly regarded as private, and what constitutes a secret from which the donor-conceived person is dishonestly or disrespectfully excluded. The very nature of that information is that it is about relationships, or potential relationships: thus, information relating to donor conception may both be said to be personal information relating to each of the parties involved, and 'interpersonal' information, in that more than one person has a stake in it. Non-disclosure of information about oneself (by a parent, or by a donor) could be characterised as an action based on concern for privacy, while non-disclosure of information about the other (by a parent about their donor-conceived offspring) could equally well be characterised as secrecy or dishonesty. Neither can provide a clear ethical guide to action, because the information is at one and the same time information about all of these people.

31. Rather than starting from the point that 'openness' in donor conception is intrinsically valuable, it is helpful to seek to identify more precisely what it is that an emphasis on openness seeks to promote. **The Working Party takes the view that openness to children about their means of conception is important in so far as it contributes to the quality of relationships within the family, and to the well-being both of parents and of donor-conceived people** (paragraph 5.33). Thus, openness may or may not be beneficial, depending on the context. In many cases, openness within the family will undoubtedly contribute significantly to the well-being of family members and to the relationships between them. In some cases, however, openness about donor conception may potentially have the opposite effect, particularly where families created through donor conception come from communities where donor conception itself is not widely accepted, or where 'openness' more generally is not necessarily given the same value as it currently has in Euro-American societies.

### Weighing interests

32. While in some cases the interests of those connected through donor conception have the potential to coincide, in others they will conflict and it will not be possible to satisfy them all. The Working Party takes the view that there is no one right place to start when analysing these conflicts of interest; and in particular that the interests of one party to a relationship should not, as a matter of principle, automatically take precedence over any others. Accordingly, the interests of different parties always have to be weighed. In practice, it will fall to the parents of donor-conceived children to weigh the interests in any particular decision regarding disclosure, unless the risk of harm to others is sufficient to justify external intrusion into family life by third parties. Such power on the part of parents must be exercised responsibly.

### Responsibilities

33. The parents of donor-conceived children have a moral responsibility to avoid, where reasonably possible, any harmful consequences that may follow for their children from the fact that they were donor-conceived. While the possibility of harm arising from inadvertent disclosure or discovery is not sufficient to justify the conclusion that parents act wrongly if they use donor gametes without committing to openness in advance, there *is* sufficient evidence to point to the conclusion that, **other things being equal, it will usually be better for children to be told, by their parents and at an early age, that they are donor-conceived. The Working Party takes the view that the parents of donor-conceived children thus have a responsibility to give careful consideration to the question as to whether or not they should be open with their children about how they were conceived. In particular, we suggest that this responsibility includes a willingness both to take account of the evidence available, and to engage as necessary with professional support, when determining what is best in their particular circumstances** (paragraphs 5.46 and 5.47). Parents also owe responsibilities to donors given the possibility for future contact between donor-conceived people and donors: in particular to include consideration of the potential impact on the donor as a factor in their decisions regarding disclosure.

34. Responsibilities also arise for donors and for donor-conceived people. In donating gametes in the knowledge that such donation may lead to the creation of a future person, donors have a responsibility to think carefully about the consequences: for themselves and their own families; for the recipients of the donated gametes; and for the resulting person. In turn, donor-conceived people have a responsibility, commensurate with their age and understanding, to do their best to understand the reasons why their parents chose to create a family through treatment with donated gametes, and why they made the decisions they did about disclosure: in short to be aware that parents, too, may be vulnerable. Similarly, we suggest that, if seeking contact with their donor, donor-conceived adults have a responsibility to consider the impact on others and to be sensitive in their approach.

35. Third parties, including both professionals and the state in its regulatory role, potentially also have responsibilities, in particular in connection with preventing or limiting harm to those who are potentially vulnerable. The Working Party endorses the approach that it *is* acceptable for

third parties to take account of the welfare of any future child in providing reproductive treatment services, whether or not donor gametes are also used, even though in such cases there is no possible 'alternative life' for the prospective child. However, the standard used in making such welfare judgments is clearly crucial and will have a direct bearing on how rarely, or otherwise, the welfare of the future child will be of legitimate concern to third parties. In the context of determining the threshold at which intervention by third parties can be justified, **we believe that the HFEA has taken the right approach in focusing on factors that are "likely to cause a risk of significant harm or neglect" to future children, a standard of harm that is likely only rarely to be fulfilled, and reiterate that we do not believe that a failure to disclose to children that they are donor-conceived should be regarded as constituting such a risk** (paragraph 5.62).

### The stewardship role of the state

36. More generally, the state has a 'stewardship' role to *facilitate* what are seen as beneficial behaviours: to provide conditions, whether physical or social, that help and enable people in making their choices. We suggest that, in enabling and endorsing donor conception as a means of creating a family, **the state should also be concerned to take action that is likely to promote the welfare of people affected by donor conception, where this can be achieved without unreasonably interfering with the interests of others**. In the light of the evidence that inadvertent or late disclosure may be harmful for donor-conceived individuals, we therefore consider that **the state is justified in taking steps to try to ensure that parents are informed about the best available evidence about disclosure, and to support them in considering this evidence both before conception and, where applicable, in their later preparations for disclosure as their child grows up**. We further suggest that the state could take on a 'facilitative' role in promoting the well-being of people affected by donor conception by **encouraging a social environment where the creation of families through donor conception is seen as unremarkable: as just one way among a number of others of building a family**. Such a role should not be understood as promoting 'special arrangements' for particular family forms, but rather as one of inclusivity: encouraging the acceptance of diversity both in the way people become parents, and in the plethora of ways in which they create 'kin' (paragraphs 5.69 to 5.71).

## Chapter 6: Implications for regulation in the UK

37. In considering the various proposals for policy or legal change put to us during the course of this enquiry, the Working Party has taken the view that, wherever possible, measures that aim to support, encourage and empower those making decisions are preferable (both ethically and practically) to measures that seek to limit or remove choice. We set out our conclusions with regard to areas of policy as they might affect particular groups, although inevitably there will be considerable overlap between each set of considerations.

### Prospective parents

38. Proposals for policy change put to the Working Party that would affect the environment in which prospective parents contemplate treatment with donor gametes included: the introduction of a 'screening' process for prospective parents seeking access to treatment with donor gametes, in order to exclude those not committed to telling their children at an early age that they were donor-conceived; mandating disclosure either through direct communication with donor-conceived people or indirectly through changes to birth certification; increasing the levels of support available to prospective parents; and revisiting the decision to prohibit anonymous donation.

39. Earlier we concluded that, other things being equal, it is better for children to know from an early age that they are donor-conceived. However, other things will *not* always be equal. Some families will have good reason not to disclose, at least in early childhood, and with rare

exceptions, only parents know enough about their own family situation to judge what they, in their particular circumstances, should do with respect to disclosure. Moreover, only factors that are "likely to cause a risk of significant harm or neglect" to future children justify interference by third parties in reproductive decisions.

40. We conclude that **it would be inappropriate to introduce any form of additional 'screening' of prospective parents other than through the application of the existing 'welfare of the child' criterion for all assisted reproduction treatments (not just those involving donor gametes) as currently interpreted by the HFEA** (paragraph 6.4). We similarly take the view that **it is not the role of state authorities, whether through direct contact with donor-conceived people as they reach adulthood, or through the use of official documentation such as birth certificates, to intervene to ensure that all donor-conceived people know of the circumstances of their conception** (paragraph 6.8).

41. However, it *is* part of the professional responsibility of clinics, and the professionals working within them, to take into account prospective parents' need for information and support, not only in connection with the clinical procedures involved, but also in connection with the bigger picture of what is being undertaken: that is, the creation of a future person. We suggest that this professional responsibility includes ensuring that the needs of the prospective parents for information, for therapeutic support, and for preparation for non-genetic parenthood, are met as an intrinsic part of the process of treatment.

42. **We recommend that, as a matter of good professional practice, clinics should present counselling sessions as a routine part of the series of consultations undertaken before treatment with donated gametes or embryos begins. Clinics can thus be confident that their patients have had access to the information and support that they may need in order to make a properly informed decision to go ahead with treatment. Prospective parents should clearly understand that such sessions will be treated as confidential and that their counsellor is not involved in making any judgments about their suitability as parents. Given the importance of a trusting relationship between counsellors and their clients, prospective parents should also be able to see an alternative counsellor if, for whatever reason, they do not feel comfortable with the counsellor whom they first see. We recommend that these requirements should be professionally mandated by the relevant professional bodies, including the British Fertility Society and the British Infertility Counselling Association** (paragraph 6.17). In making this recommendation, we emphasise that the various functions that the counsellor may be undertaking in these sessions – sharing information necessary for consent, offering therapeutic support, and helping prospective parents prepare for parenthood – should be distinguished. Where prospective parents are attending such appointments as a routine part of their treatment, the emotional support that they receive, and the extent to which they are encouraged to 'prepare for parenthood', must be led by *their* needs.

43. The provision of information about the implications of treatment, on the other hand, is not client-led in quite the same way, given the statutory requirements to provide such information. It is therefore important that information about the benefits of early disclosure is *not* presented in such a way as to make prospective parents feel that they cannot engage honestly with the counsellor and discuss their own situation and their own feelings. We emphasise that **it is the professional duty of the counsellor, and other relevant professionals, to ensure that they provide information and support in a non-judgmental and understandable manner that encourages prospective parents to engage with the issues of disclosure and non-disclosure. It is crucial that prospective parents are able to feel confident about expressing their own anxieties, views or concerns about disclosure, to seek advice and guidance without fear of being judged, and to 'own' their ultimate decisions about disclosure or non-disclosure with regard to the well-being of their future family. We recommend that the HFEA should, in the next edition of its *Code of practice*, explicitly encourage such an ethos within clinics** (paragraph 6.21).

44. We further highlight the very important point that prospective parents' need for information and support should be regarded as a *process*, rather than as a one-off event. It is often very difficult for prospective parents (particularly those who have had a long experience of infertility investigations and treatments) to focus on the more practical aspects of non-genetic parenthood until a pregnancy has been well established: until that point prospective parents may not let themselves believe in the reality of the future child. **We recommend that clinics, in recognition of their wider role in helping create a child, should routinely offer parents an additional support session that could be taken up either later in pregnancy or in the first few years of the child's life, the cost of which should be included within the overall treatment fee** (paragraph 6.22).

45. We note further that it will occasionally happen that a donor is later diagnosed with a serious strongly heritable condition, and that information about that diagnosis may be highly relevant to the care the donor-conceived person should receive. While such circumstances may be rare, by definition it cannot be foreseen when they may arise. **We recommend that the possibility of such information being passed on from the donor (and the importance in such cases of the donor-conceived person, who may by then have reached adulthood, receiving that information so that they can choose how to act upon it) should be raised within counselling sessions so that prospective parents are able to take this issue, too, into account when considering their disclosure options** (paragraph 6.24).

46. Finally, in response to arguments that anonymous donation should be permitted if both donors and recipients prefer such an option, we concluded that **it is the proper role of a stewardship state to ensure that donor information, including identifying information, will be available for those donor-conceived people who know about about the means of their conception and request it**. **We therefore do not recommend reintroducing the option of anonymous donation through UK clinics** (paragraph 6.30).

**Parents and offspring during childhood and into adulthood**

47. One role of a stewardship state is to encourage a social environment where the creation of families through donor conception is seen as just one way among a number of others, of building a family. A crucial aspect of this inclusive approach must be found in better provision for the support of donor-conceived families through mainstream NHS services: in particular through maternity, child health and GP services that are sensitive to the possibility that a child may have been conceived with donor gametes. In many cases this may be primarily a matter of awareness, so that professionals do not make assumptions that are perceived by parents of donor-conceived children as excluding or sidelining them. We suggest that one very practical way both of providing information and support to the parents of donor-conceived babies, and of raising awareness of donor conception among professionals involved with babies and young children, would be to ensure that references to donor conception and associated support groups are included within the various information sources routinely available to pregnant women and new mothers. **We recommend that the Department of Health should encourage those providing information and advice to pregnant women and new parents through NHS-sponsored methods to include reference to donor conception, and to organisations that support donor-conceived people and their families, in their materials** (paragraph 6.33).

48. The primary sources of expert support for donor-conceived families are currently found in the voluntary rather than the state sector. The Working Party does not find this balance of provision problematic in itself, noting that voluntary organisations in the health and social care sphere are often established and run by those with extensive personal experience of the issues in question, and the support that they offer to parents and families is enormously valued precisely because it is user-led. Nor, in the current economic climate, do we think it unreasonable that those using such services should be expected to contribute to their costs, through organisational membership fees or charges for particular services or events. Nevertheless, **we take the view that the state, which has chosen through regulatory action both to promote donor**

**conception as a legitimate means of creating a family, and actively to encourage early disclosure to resulting children, retains an ultimate responsibility for ensuring that donor-conceived families continue to be able to access specialist support where this is needed. This responsibility would include stepping in financially, if necessary, to ensure that the specialist advice and resources provided by voluntary organisations in this field continue to be generally available to those who need them** (paragraph 6.34).

49. We further suggest that this responsibility of the state with respect to specialised support for donor-conceived families also extends to the provision of information and support for those families who are unable to access support from the voluntary sector, for example because they do not feel comfortable with the underpinning approach of particular organisations. **We recommend that the HFEA, as the public body with most expertise in this field, should expand and make more easily available the information it provides to all those directly affected by donor conception, for example through the creation of a dedicated donor conception website, distinct from the main HFEA website** (paragraph 6.35).

50. The question of possible contact between donor-conceived people and their donors raises further issues concerning support needs. While there is a statutory requirement that those applying to the HFEA Register should have been given a suitable opportunity to receive counselling about the implications of their decision, at present there are no generally available services specialising in such support. Moreover, the support needs of people in this situation may be better described as 'intermediary work', helping both parties think through the implications of possible contact, and facilitating such contact where mutually desired, rather than 'counselling' the individual. **The Working Party takes that the view that the state, in legislating for a system where identifiable information about donors is seen as desirable, has a responsibility to make sure that those affected are appropriately supported. This means that the state should take an active role in ensuring that an appropriate intermediary and counselling service (that is, one whose role is to support both the donor-conceived person and the donor in possible contact) should be made available. Such a service could also potentially incorporate the service currently available to facilitate contact between donor-conceived siblings** (paragraph 6.38).

51. While the legal entitlements of donor-conceived people to information differ depending on when they were conceived, all may potentially have a need for support where information from either the HFEA Register or the pre-1991 voluntary register provides for the possibility of contact with their donor. Indeed, those relying on the voluntary register may have additional support needs, in that, in the absence of paper records, links may only be made through DNA 'matches' and as a result connections may often be made on a basis of likelihood rather of certainty. **We welcome the fact that the Department of Health has committed itself to future funding of the voluntary register that facilitates contact between pre-1991 donor-conceived people, donors and siblings at least for the immediate future; but emphasise the importance of the future of this service being secured on a long-term basis** (paragraph 6.39). While those conceived before 1991 may, because of the legal provisions in place at the time, inevitably have lesser access to information about their donor, there is all the more reason for ensuring that where there is a prospect of contact between a donor-conceived person and their donor, appropriate levels of intermediary support are in place.

52. We further note that some parents, donor-conceived people and donors would welcome the possibility of contact during the donor-conceived person's childhood. Such contact is, of course, possible where a known donor is used; moreover 'known' donors are not limited to close friends and family but may be found through advertising and matching websites. Desire for such contact is also sometimes cited as a reason for donors and recipients to consider unregulated sperm donation. Given the apparent appetite for such an interchange, and the potential benefits to be gained by encouraging more people to access donor gametes via regulated, rather than unregulated, routes, we suggest that that this is an issue worthy of further consideration. **We therefore recommend that the HFEA's National Donation Strategy Group should look specifically at the question of whether the potential benefits of early information**

**exchange and possible contact between donors and donor-conceived families would be sufficient to justify proposals to change the law to permit this** (paragraph 6.42).

53. In addition to ensuring that those affected by donor conception receive the support they may need, we further suggested that the state could take on a broader, facilitative role in the welfare of those affected by donor conception, by encouraging a social environment where the creation of families in this way is seen as just one way among a number of others of building a family. We suggest here that **a key function of a stewardship state is to promote an inclusive and accepting environment for individuals becoming parents in different ways: where what is seen as valuable in family life is the nature of the relationships created and not the particular means by which those relationships first came into being**. We acknowledge that there are no simple, single methods to achieve this aim, although the various methods for increasing public awareness of donor conception recommended elsewhere in this report could play a part (paragraph 6.44).

54. Finally, we consider the question of access for donor-conceived people and their parents to medical information about the donor. **We reiterate that details of the major conditions that have been 'screened out' before donors are allowed to donate should be provided to the parents in an easily accessible and comprehensible format that they can retain for later reference** (paragraph 6.45). Such information, clearly set out, should provide parents with considerable reassurance that the risks of their child developing a significant heritable condition through their donor are very low. Nevertheless, it should be made clear that it is currently impossible to exclude all such serious conditions, given the number of possible strongly heritable conditions and the late onset of some such conditions.

55. The current donor information form also provides space in which to provide 'relevant' information about the donor's health and family history. In the view of the Working Party, such information is 'relevant' only where it would be likely to have an impact on the health or health care of any future offspring. Given that there appears to be considerable confusion as to what information about the donor's family history may, or may not, be relevant for the health care of future offspring, **we recommend that the HFEA, in association with relevant professional bodies, establish a multidisciplinary working group to review and update the assessment and screening guidance issued in 2008, including input from a wide range of health professionals with experience in genetic medicine, and making explicit recommendations as to what information, if any, about a donor's family history should usefully be collected from donors and provided on the form** (paragraph 6.48).

56. Situations may also arise where significant medical information with respect to the donor becomes available only *after* donation, for example where a donor is diagnosed with a serious late-onset strongly heritable condition. Similar issues might arise where the donor-conceived child is diagnosed with a serious inherited condition, where this information may be of relevance to the donor, the donor's own family, and any other donor-conceived siblings. **We recommend that the HFEA should take responsibility for ensuring that a clear, well-publicised, route for sharing significant medical information is established, either via fertility clinics or via the HFEA's own Register, to make it as easy as possible for donors, or donor-conceived people and their families, to pass on such information where it arises. We further recommend that the UK's NHS clinical genetic services are involved in such communications** (paragraph 6.49).

### Donor-conceived adults who do not have access to information

57. It has been suggested that, building on the legal change in 2005 that prospectively abolished anonymous donation, the law should further be changed *retrospectively*, so that those adults born as a result of treatment with donor gametes before 2005 are also statutorily entitled to identifying information about their donor. Such change has been resisted on the basis that it would undermine the legitimate expectations of privacy of those who donated at a time when

anonymous donation was the norm. Quite aside from the issue of the interests of such donors, however, we note that the interests of pre-2005 donor-conceived people who desire such information would not in fact be promoted in any significant way if the state were to provide the identifying details of a donor who was not open to further information exchange or ongoing contact. In other words, in order for the interests of donor-conceived adults in this position to be furthered, the donor must be willing and able to engage in at least minimal contact. Yet, such willingness is simply not something that can be created through legislation.

58. Drawing on our stance that, wherever possible, measures that aim to support, encourage and empower those making decisions are preferable to measures that seek to remove choice, **we suggest that the state, rather than regulating retrospectively for the removal of anonymity, should instead take action to increase awareness among past donors that a willingness on their part to become identifiable would be highly valued by some donor-conceived adults**. In this context, we note that, although no such cases have been reported, legal advice obtained by UK DonorLink in 2011 highlighted the possibility that under Scots law a person conceived before 1991 as a result of sperm donation could be entitled to share in the donor's estate on death. **We recommend that the Scottish Law Commission investigate this possibility and consider what, if any, action is required to ensure that past donors living in Scotland do not, by making themselves known, incur any unexpected financial obligations** (paragraph 6.56).

59. We do not consider it appropriate to invite clinics directly to contact past donors: such contact entails serious concerns about breach of confidentiality and could only be justified where the information being communicated is sufficiently important to the person being contacted, such as information about a relevant and significant medical diagnosis in donor offspring. However, a public campaign, raising awareness of the possibility of 're-registering' as identifiable on the HFEA Register or joining the voluntary register (now known as the Donor Conceived Register), would serve the dual purpose of prompting past donors to consider the possible impact for themselves and their families of such registration, and of raising awareness more generally of donor conception. **We recommend that the HFEA, in conjunction with the Donor Conceived Register, should initiate a public information campaign about donor conception and the possibility for past donors to make themselves identifiable if they wish** (paragraph 6.57).

60. We also draw attention to the role of professionals and clinics with respect to the non-identifying information they may hold about pre-1991 donors. We recognise that in many cases records may be in a poor condition, or indeed no longer in existence. However, we do not think it acceptable that, where records do exist, donor-conceived adults appear to receive such variable responses to requests for non-identifying information about their donor. **We recommend that the HFEA should issue guidance to clinics setting out what is expected of them with respect to making information from pre-1991 records available to applicants** (paragraph 6.58). The Working Party can see no reason why, where non-identifying information about donors exists in old treatment records, this information should not be disclosed (if necessary after seeking the consent of the person's mother where the information forms part of her health records) to a donor-conceived person seeking this information.

61. Finally on this point, we note that the question of differential access to donor information is not purely a historic one: not all prospective parents use UK-regulated clinics in order to access treatment with donor gametes or embryos. **We reiterate our earlier recommendation, that the HFEA should ensure, for example through the creation of a dedicated donor conception website, that factual information about the implications of seeking treatment with donor gametes abroad or through unregulated methods, is readily accessible to those contemplating these routes** (paragraph 6.60).

### Donors

62. In making a donation that may lead to the creation of a person, donors have a responsibility to think carefully about the consequences for all those concerned: for themselves and their

families, for recipients, and for their donor-conceived offspring. Just as it is important for prospective parents to have access to proper information and support to help them decide whether creating a family with donor gametes is the right way forward for them, we emphasise here the importance of equivalent information and support being made available to donors. **We recommend that clinics should ensure that sessions with a counsellor are scheduled as part of the routine series of appointments that donors attend before deciding whether or not to go ahead with donation. We further recommend that, where donors have partners, clinics should strongly encourage partners to attend these sessions. Such an approach to the counselling support available to donors should be required of clinics as a matter of good professional practice by the relevant professional bodies, including the British Fertility Society and the British Infertility Counselling Association** (paragraph 6.63).

63. The interest that recipients and future donor-conceived people may have in the information provided by donors differs significantly. While it would be possible to match donors and recipients on the basis of their informational wishes, clearly it is impossible to predict in advance whether any donor-conceived person is likely to find it important to know about their donor or not. **We therefore conclude that, in deciding to donate, donors have a responsibility to think seriously about how they provide information about themselves, in the knowledge that for some recipients, and in particular for some donor-conceived people, this information will be very important. We further conclude that clinics have a responsibility not only to encourage donors to engage seriously with the provision of information about themselves, but also to provide appropriate support in doing so where required. Filling in the donor form should not be perceived as a brief administrative task** (paragraph 6.64).

64. However, the question still remains as to how ‘much’ information is an acceptable minimum, or the right amount, or even too much. The ‘one-off’ nature of the opportunity to provide information both emphasises the importance of giving it serious attention, but also demonstrates the limitations of such information: it can only try to present the donor at one moment in time which will gradually become more and more out-of-date. Moreover, it is important for all concerned to understand that ‘narrative’ information, apart from specific factual details, is never a straightforward ‘truth’: how a person tries to describe themselves in a few paragraphs will always be a selective narrative. Taking these factors into account, the Working Party did not feel that it had sufficient evidence to recommend a particular ‘information set’ that all donors should provide. **We recommend that the HFEA’s National Donation Strategy Group should consider further the question of how much and what kind of information should be expected on the donor information form, drawing on the expertise of a range of interested parties** (paragraph 6.66).

65. We conclude this report by recalling our discussion of the wider role of the state in encouraging an environment where donor conception would be seen as one way among a number of others of creating a family of one’s own, and where donor-conceived families would feel ‘ordinary’ and included. Such a society would also have a high value for donors, and their generosity in making donor-conceived families a reality.

# Introduction

The task for this Working Party has been to consider questions of information sharing in practices of donor conception in the UK. Its primary focus has thus been on issues of privacy, openness, and access to information, and the implications of each of these for the individuals, families and groups affected by donor conception. While its remit was not to investigate the ethics of donor conception *per se*, the Working Party nevertheless received evidence of a wide range of views and attitudes towards the use of donated gametes as a means of creating families. At one end of the spectrum, some people, including some donor-conceived adults, believe that donor conception should not be allowed at all. Both this view, and the opposing one that donor conception is a legitimate means of creating a family and of having children of 'one's own', hinge on the relative significance placed on biological or 'blood' connection between parents and their children. This issue of the significance of biological connection in family relationships, and in the identity of the individual, has also proved to be central to questions about whether donor-conceived people should always be informed about the means of their conception, how much information about their donor they should be able to obtain, and whether they should be able to find out the identity of their donors, with the possibility of such identifying information leading to contact.

References to 'disclosure' in the context of donor conception tend to conflate two separate issues: 'openness' by parents about the use of donor gametes in conception (donor-conceived people knowing about the circumstances in which they were conceived), and access to information (identifying or non-identifying) about the particular donor. It is, however, very important that these two issues should be distinguished. It is possible for a parent to be open with their child in the context of anonymous donation. It is not, however, possible for a donor-conceived person to exercise any entitlement to information about their donor in the absence of information about the circumstances of their conception. It should also be noted that, in contemporary social life in the UK, 'openness' has acquired positive connotations and is axiomatically thought to be desirable. The Working Party has been compelled to think carefully about the language it uses in order to convey not only the complexity of the issues raised in sharing information in the context of donor conception, but also the diversity of views and opinions on its implications.

These issues have been contentious for many years, as the Working Party's factfinding meetings and responses to its call for evidence have illustrated. The Working Party is acutely aware of how many, potentially competing, interests are at stake – and of how much these issues matter to those whose lives are affected by donor conception. Because of the variety and complexity of these views, the Council, in establishing this enquiry, sought to provide a forum where all voices could be heard; and it was felt that this would best be enabled through consultation rather than seeking to represent this vast spectrum of opinion on the Working Party itself. Input from as wide a range of interested and concerned individuals and organisations as possible was thus sought through an open call for evidence, an online survey, a series of face-to-face meetings, and external review of the draft report by diverse stakeholders. Further details of the Working Party's way of working are set out in Appendices 1 and 2.

As noted above, the Working Party has been primarily concerned with the UK. It should be noted however that there are other, and different, regulatory and ethical regimes across the world which inevitably impact upon the UK. Not only might ethnically diverse populations within the UK be informed by cultural and ethical imperatives in their countries of origin, but people regularly opt to travel overseas for fertility treatment, and it is also possible to import gametes to treatment in a UK clinic. In addition, UK regulatory frameworks do not cover the 'informal' arrangements people make outside the clinic to donate and acquire sperm both in the UK and abroad. The Working Party is aware that there are distinctive national IVF and donor conception cultures that are emerging and changing,[1] and that this needs to be kept in mind in any discussion of donor conception and information sharing whose primary focus is the present situation in the UK.

## Structure and key questions to be considered in this report

The main issues around information sharing that arose throughout the Working Party's consultative and factfinding activities included:

- The interests that donor-conceived people may have, both in knowing the fact that they were conceived with donor gametes or a donor embryo, and in accessing information about their donor;
- How these interests should be balanced with the interests that parents and donors may themselves have in connection with sharing this information;
- What responsibilities parents may have to their children with regard to information sharing; and what other responsibilities may arise in the context of donor conception;
- What evidence there is about the impact both on donor-conceived people and on their families if parents do, or do not, disclose the fact that they were conceived with donor gametes or embryos;
- What evidence there is as to the importance of biological connections, and knowledge about those connections; and the extent to which significance placed on such connections may be influenced by culture;
- The extent to which information about the medical 'family history' of the donor may be significant for the donor-conceived person's health care, and the means by which relevant information might be passed on;
- What evidence there is as to the interests donors, and their wider families, may have in having access to information about people born as a result of their donation;
- What role 'third parties' such as professionals and the state should take in seeking to influence particular approaches to disclosure, or access to information.

In order to address these questions, the report will begin with a short overview of the circumstances in which people seek treatment with donated gametes or embryos, and of how the families thus created fit into the wider understandings of 'families' and 'kinship' that are dominant in the UK (*Chapter 1*). *Chapter 2* will summarise the current state of UK law and practice on the collection, retention and disclosure of information about donor conception and about donors, and on the support available to those affected by donor conception. *Chapters 3 and 4* focus on the evidence currently available regarding, firstly, the medical significance of information about the donor for the donor-conceived person (and in some cases vice-versa); and, secondly, the experiences of donor-conceived people, parents and donors of disclosure/non-disclosure, and the impact that access to information, or the withholding of information, has had on all concerned.

In the final two chapters, the Working Party draws on the legal and evidential background laid out earlier in the report to set out its own approach to these questions. *Chapter 5* discusses the ethical concerns that arise with respect to disclosure and puts forward the Working Party's preferred ethical approach. *Chapter 6* takes forward these ethical considerations and applies them to more detailed questions of policy, setting out the Working Party's conclusions and recommendations for policy-makers and others.

Finally, we note that, while surrogacy arrangements are necessary for some forms of donor conception, we received very little evidence about the value placed by people conceived through surrogacy arrangements and surrogate mothers on information about, or contact with, each other. In this report, we therefore include reference to surrogacy arrangements to the extent that this is necessary to include all forms that donor-conceived families may potentially take, without coming to conclusions or making recommendations about surrogacy in particular.

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[1] See, for example, contributors to Knecht M, Klotz M, and Beck S (2012) *Reproductive technologies as global form* (Frankfurt/New York: Campus Verlag) and Inhorn MC (2007) *Reproductive disruptions: gender, technology, and biopolitics in the new millennium* (Oxford: Berghahn Books).

# Chapter 1

## Families created through donor conception

# Chapter 1 – Families created through donor conception

## Chapter 1: overview

- The donation of sperm, eggs and embryos makes it possible for many people who would otherwise have remained childless to create families of their own. Since the introduction of regulation in 1991, over 35,000 children have been born in the UK as a result of donated gametes; and many more donor-conceived people will have been born as a result of unlicensed sperm donation, or of treatment in overseas clinics.
- Prospective parents may consider using donor gametes to conceive because of fertility problems or in order to avoid transmission of a serious genetic condition. Donor gametes may also be used in the creation of 'non-traditional' family forms such as families created by same-sex couples or single people.
- Donors may be known or unknown to their eventual recipients, and may sometimes themselves be receiving fertility treatment.
- Families formed through the donation of gametes or embryos ('donor-conceived families') can be viewed alongside other diverse family forms in the UK, including families created through adoption, single parent families, and 'reconstituted' families including step-children. The word 'family' is used for a wide range of relationships, referring not only to the 'nuclear' unit of one or more parents and their children, but also to a wider set of relations sometimes referred to as the 'extended' family. Our notions of what constitutes 'our family' are flexible and cover a wide variety of combinations of relationships.
- Despite this broad understanding of the notion of 'family', however, the concept of 'kinship' may provide better traction in addressing the complex and contested issues emerging from questions of donor conception and disclosure. The concept of kinship can embrace the ways in which people *know* themselves to be related to each other, and is culturally and historically shaped. Dominant understandings of kinship in the UK emphasise both biological and social relations: kinship bonds may arise as a result of biological connection or may be forged through care and nurture. From one perspective, the link between a donor and a donor-conceived person may be indisputably there, while from another it is self-evidently absent. Such pluralism of opinion emerged clearly in both the research literature and in the views and attitudes of those sharing their personal experience with the Working Party.
- The increasing emphasis in the UK on the significance of disclosure about the use of gametes in conception, and for access to information about the donor, comes at a time when the discussion of genes and genetic connection is prevalent in society, and where genetic explanation has become increasingly prominent in seeking to explain and understand disease, disorder, identity and relatedness. It is also occurring at a time when a high societal value is placed more generally on 'openness' and 'transparency'; and in a context where the internet and ever-expanding technologies of communication and social networking are challenging the boundaries of privacy.

## Creating a family through donated gametes and embryos

1.1 The development of assisted reproduction services, and the willingness of people to donate their sperm, eggs and embryos for the treatment of others, has made it possible for many people who would otherwise have remained childless to create families of their own. While the donation of sperm is not new (children have been born as a result of medically-assisted artificial insemination using donated sperm for over 100 years[2]), conception using donated eggs or embryos first became possible only after the development of *in vitro* fertilisation (IVF) techniques, with the first reported use of donated eggs and embryos taking place in the early 1980s.[3] Medical involvement with surrogacy arrangements, and hence the possibility of such

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[2] Hard A (1909) Artificial impregnation *Medical World* **27**: 163. See also: Barton M, Walker K, and Wiesner BP (1945) Artificial insemination *British Medical Journal* **1(4384)**: 40-3. The earliest report of donor insemination with medical assistance was in 1884: see Gregoire A, and Mayer RC (1965) The impregnators *Fertility and Sterility* **16**: 130, cited in Allan S (2012) Donor conception, secrecy and the search for information *Journal of Law & Medicine* **19(4)**: 631-50.

[3] Craft I, McLeod F, Green S *et al.* (1982) Birth following oocyte and sperm transfer to the uterus *Lancet* **2(8301)**: 773; Trounson A, Leeton J, Besanko M, Wood C, and Conti A (1983) Pregnancy established in an infertile patient after transfer of a donated embryo fertilised in vitro *British Medical Journal (Clinical Research Edition)* **286(6368)**: 835-8.

arrangements using IVF techniques, has been regarded as professionally acceptable since the early 1990s.[4]

1.2 While the reason that prospective parents consider donor conception may often be because of fertility problems experienced by either or both heterosexual partners, donor conception services (combined where necessary with the use of surrogacy arrangements) are also increasingly used in order to enable the creation of 'non-traditional' family forms: for example families created by same-sex couples, single women, or, less commonly, single men.[5] Donor conception may also be considered in order to avoid the passing on of a serious heritable condition from parent to child.

1.3 The circumstances in which people donate eggs, sperm or embryos to others, or act as surrogates, similarly differ. 'Known' donors and surrogates may be friends or relatives of the prospective parent, as, for example, where one sister donates eggs or acts as a surrogate for another.[6] In such cases, there is likely to be ongoing contact between the parents of any resulting child and the donor or surrogate, although the nature of this contact will depend on those concerned. 'Unknown' donors, on the other hand, usually have no prior connection with the recipient, and choose to donate through a clinic for the benefit of unknown recipients whom they may never meet. In cases of unknown donation, both the professionals involved in providing treatment services, and the state in its regulatory role (see Chapter 2) potentially have an important part to play in determining and controlling what information is made available between the parties involved.

1.4 These two categories of 'known' and 'unknown' donation may, however, become blurred. In some cases potential donors and recipients may identify each other in advance (for example through personal advertising) and present themselves for treatment services as a 'known' donor-recipient pair, even though there is no longstanding connection between them. In such cases, despite the lack of prior friendship or relationship, the possibility of information exchange and contact between donor and recipient after the birth of any resulting child clearly exists. Such open arrangements similarly arise, inevitably, in the case of surrogacy arrangements where the surrogate and prospective parents are initially unknown to each other: the nature of the arrangement is such that they will become known to each other by the time of a child's birth. 'Matching services' also exist that link potential egg donors with recipients, and provide detailed non-identifying information about the donor, without donor and recipient ever meeting.[7] On the other hand, relationships between recipients and longstanding 'known' donors may break down, or simply fade away over time, with the result that the child born as a result of the donation may have no knowledge of the donor, despite the latter's prior connection with the recipient parents. Thus, from the perspective of the resulting donor-conceived person, the question as to whether a 'known' or 'unknown' donor was involved in their conception may in some cases be of little importance.

1.5 Donors may also themselves be undergoing fertility treatment. The possibility of embryo donation, in particular, only arises in the context of fertility treatment, where women or couples

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[4] See: Brazier M,Campbell A and Golombok S (1998) *Surrogacy: review for health ministers of current arrangements for payments and regulation*, available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4014373.pdf, at paragraph 1.6.

[5] See, for example, The Telegraph (12 June 2008) *Single, male, broody?*, available at: http://www.telegraph.co.uk/education/3356441/Single-male-broody.html; Pride Angel (6 November 2012) *Single man becomes a dad through surrogacy in UK*, available at: http://prideangel.blogspot.co.uk/2012/11/single-man-becomes-dad-through.html.

[6] 'Known donors' are sometimes described as 'identifiable donors': however this latter term may also, confusingly, be used for anonymous donors whose identity may be released when the donor-conceived person reaches adulthood. In this report, we will use the term 'known' donors for those who are known to the prospective parents at the time of treatment, and 'identity-release' donors for those who can be identified only when the donor-conceived person reaches adulthood.

[7] See, for example, Altrui (2012) *Altrui homepage*, available at: http://www.altrui.co.uk/.

may be asked to consider donating ‘spare’ embryos (that is, embryos that they will not be using for their own treatment) for the treatment of others. Under ‘egg-sharing’ arrangements, women may also donate some of the eggs they produce as part of their own fertility treatment to another woman, in return for free or reduced-cost treatment. ‘Sperm-sharing’ arrangements, in which the male partner in a couple undergoing fertility treatment donates sperm for the treatment of others in return for free or reduced cost treatment, or so that the couple may gain priority on the waiting list for donor eggs, may similarly be made available by some clinics.

1.6 In the case of sperm donation, medical assistance for donation and insemination is not essential, although it is strongly recommended in order to facilitate screening for infections or significant genetic conditions in the donor (see paragraphs 3.11 to 3.18). Women or couples seeking a sperm donor outside the clinic system may thus make arrangements either with someone known to them, or with a stranger contacted via third parties or the internet. In such cases, the amount of information available later to the donor-conceived person about the donor will depend entirely on the arrangements between donor and recipient at the time.

1.7 Initially, clinics offering assisted reproductive treatment, including treatment with donated gametes or embryos, were not subject to any special regulation or oversight by the state, and it is therefore not known how many children were born as a result of these procedures.[8] However, this changed in 1991, with the enactment of the Human Fertilisation and Embryology Act 1990: this created a new legal framework governing all forms of assisted reproduction services, and established the Human Fertilisation and Embryology Authority (HFEA) as a regulatory oversight body. Since 1991, all clinics offering assisted reproductive services must by law be licensed and inspected by the HFEA, and operate in accordance with the HFEA’s *Code of practice*.[9]

1.8 In the period between 1992 (the earliest date from which official figures are available) and 2009, over 35,000 children were born of parents who received donated eggs, sperm or embryos in UK-licensed clinics.[10] The actual number of people conceived as a result of donated gametes and living in the UK will be significantly higher: as noted above, there are no official figures for those conceived before 1991, and there are also no records of those conceived as a result of treatment outside the UK or of those conceived through ‘informal’ donor insemination, where a woman uses donated sperm without assistance from a clinic. These fall outside the regulatory framework created by the 1990 Act, and hence are not included in the figures collected by the HFEA.

## Family and kinship

1.9 Families formed through the donation of gametes or embryos, which we will call, for present purposes, ‘donor-conceived families’, can be viewed alongside the emergence of other diverse family forms in the UK. The bigger picture also includes families created through adoption (both national and transnational), single parent families, and ‘reconstituted’ families that include step-children.[11] Despite high divorce rates, the idea of family and marriage remain popular and rates of remarriage are also high.[12]

1.10 The ‘family’ is of central concern to the questions that the Working Party has been addressing. But what do we mean by family? Donated gametes and embryos are used explicitly to create a

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[8] However, guidance for artificial insemination was published by the Royal College of Obstetricians and Gynaecologists prior to 1991. See: Royal College of Obstetricians and Gynaecologists (1979) *Artificial insemination* (London: Royal College of Obstetricians and Gynaecologists).

[9] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf.

[10] Human Fertilisation and Embryology Authority (2011) *Donor conception: births and children*, available at: http://www.hfea.gov.uk/donor-conception-births.html. These figures include surrogacy arrangements as such arrangements are legally classed as treatment using donor gametes.

[11] Simpson B (1994) Bringing the ‘unclear’ family into focus: divorce and re-marriage in contemporary Britain *Man* **29(4)**: 831-51; Simpson B (1998) *Changing families: an ethnographic approach to divorce and separation* (Oxford: Berg Press).

[12] OnePlusOne (2012) *Understanding 21st Century relationships: a compendium of key data*, available at: http://www.oneplusone.org.uk/wp-content/uploads/2012/07/Keydatachapter1.pdf, at page 32.

family, but they also have the potential to create a variety of 'family' connections beyond parents and their children: for example, between the ensuing child and the family of the donor, between the donor and the recipients (and their wider family), or between donor siblings. The potential for donated gametes both to make a family and to connect people who would otherwise be unrelated, underlines two dominant meanings attached to the term 'family' in the UK. Family can be used to describe a family unit of one or more parents and their children, or it can refer to a wider set of relatives. It can be one's birth family and/or the family in which one is raised and connected. Here we begin to unpack the dominant meanings attached to family and also to note the diversity of family forms in contemporary UK society. We move on to suggest that the anthropological concept of *kinship*, which includes the family but is not synonymous with it, may provide better traction from which to address the complex questions that have emerged in discussion of, and consultation about, donor conception and information disclosure.

1.11 Today, in the UK, families come in many shapes and sizes, and there is a rich social vocabulary to describe this diversity of family forms. The term 'nuclear family' is often used to refer to two parents and their children; while it can be narrowly defined as a cohabiting, married couple and their children, it can also refer to two adults in civil or common law partnerships and their children. There are also many forms of single-parent families, created by choice or unplanned, or arising after the death of a partner, or after divorce or separation; as well as combined and reformed families that include children from previous marriages or partnerships. In these examples, it is children who make a family, and these children can be conceived naturally or through assisted reproductive technologies, or they can be adopted or brought into families from previous marriages or partnerships. Additionally, married or cohabiting couples in permanent relationships without children may consider themselves a family.[13] The word family, in English, then, is used for a wide range of relationships. It refers not only to the unit comprising one or more parents and their children (however and wherever conceived), but also to a wider set of relations sometimes referred to as the 'extended' family. One's own family can be confined to a partner and/or offspring or extended to close and distant relatives. In its extended form it can also include in-laws and step-relatives: that is, relatives through marriage or partnerships. Very close friends are sometimes referred to as being 'part of the family'. In ordinary and everyday parlance the sociological terms for the diversity of family forms are largely irrelevant and all of them are embraced by the term 'family'. Our notions, then, of what constitutes 'our family' are flexible and cover a wide variety of combinations of relationships.

1.12 Despite this flexibility of the notion of the family, however, we suggest that the concept of 'kinship' might provide better traction than 'family' for addressing the complex and contested issues emerging from questions of donor conception and disclosure. The concept of kinship can embrace the ways in which people *know* themselves to be related to each other. It is not universally the same the world over, but is culturally and historically shaped. Across the UK, for example, at different times in history, and in different populations and classes, various conventions of birth, marriage, cohabitation, nurture and inheritance, as well as ideal ways of maintaining appropriate family relationships, have been emphasised. Islamic law, for example, divides kinship into three parts: relations through blood, through marriage, and through milk.[14] In many societies, nurture as well as shared substances, including food, forge enduring kinship connections over time.[15] Starting from kinship rather than family frees us from assuming particular family forms and from knowing in advance what a 'family' looks like on the ground.

1.13 Kinship not only encompasses relatedness (of different kinds) but also includes different cultural understandings of how both persons and kin are brought into being. It may be true to say that

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[13] This is especially the case when couples are choosing, or accepting, a future without children. Experience from counselling services suggests that, for some couples, defining themselves as a family, in which there is mutual care and nurture, reinforces their lifelong commitment to one another and contributes to the reshaping of a future life vision.

[14] Clarke M (2009) *Islam and new kinship: reproductive technology and the Shariah in Lebanon* (Oxford: Berghahn Books).

[15] Carsten J (2004) *After kinship* (Cambridge: Cambridge University Press).

human beings the world over are reproduced biologically and that this is, indeed, a universal aspect of human being. But it is also true to say that people the world over do not necessarily attach the same meaning or significance to either the biological facts of reproduction or to the notion of biological relatedness. In some societies, kinship relations through the female 'line' of descent may be more significant than the male 'line', or vice versa: one's name, identity, property and so forth may be passed on from one's mother or father. The Working Party heard in one of its factfinding meetings, for example, that Jewish people may attach a quite different meaning to 'mitochondrial donation'[16] from that ascribed by non-Jewish people because of the value placed on the maternal line of inheritance.[17] In other societies, kinship may be traced through both the mother's and the father's 'side', but different kin terms might be used with, and different kinship obligations expected from, kin on different 'sides'. In yet other societies, no emphasis is placed at all on biological kinship, and links are forged through conventions of naming and nurture.[18]

1.14 If we turn to what might be considered dominant understandings of kinship in the UK, there has been an emphasis on both biological and social relations. Biological relatedness in this kind of kinship thinking has usually been described in idioms of blood, such as 'blood ties' and 'blood relatives' and, in common parlance, 'blood is thicker than water'. More recently, and perhaps increasingly, idioms of genes and genetics are used to refer to biological kin, with reference, for example, to genetic fathers or genetic families. Some scholars have argued that genetic relatedness is supplanting other ways of understanding kinship and is part and parcel of what they refer to as the 'geneticisation' of social life where genetic explanation is becoming more and more prominent in describing complex social phenomena (see paragraph 1.27).[19]

1.15 Others have suggested that genetic relatedness connotes something different from earlier versions of biological relatedness. The idea of the 'genetic family', it is argued, marks a shift away from the notion of families "as units of love, solidarity and lasting commitment",[20] because genetic connection is self-contained and can exist without the exercise of choice or the activation of family bonds. In the 'genetic family' the knowledge of kinship is carried in the genes themselves, and can exist independently of family relationships.[21] Another example that underlines a perceived difference between biological and genetic kinship emerges from surrogacy arrangements. Many people consider a fetus to be biologically related to a surrogate mother even where the intended mother's egg has been used. This relatedness is said to be forged, amongst other things, through the role of the surrogate mother in feeding the fetus and is also often imagined in terms of shared blood. [22] Similarly, a woman who has successfully used donated eggs to conceive a child, while not genetically related to her child, usually considers herself to be biologically related through gestation and birth.

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[16] The donation of mitrochondria (small organelles, sometimes described as the 'batteries' of the cell), as distinct from the nuclear DNA in the egg. See: Nuffield Council on Bioethics (2012) *Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review*, available at: http://nuffieldbioethics.org/mitochondrial-dna-disorders.

[17] Factfinding meeting on regulatory aspects of donation, 22 June 2012. For a discussion of Halakhic principles of paternity, see: Kahn S (2000) *Reproducing Jews: a cultural account of assisted conception in Israel* (Durham, NC: Duke University Press). In the context of orthodox thinking, non-Jewish sperm does not establish paternity.

[18] Carsten J (2000) *Cultures of relatedness: new approaches to the study of kinship* (Cambridge: Cambridge University Press); Sahlins M (2013) *What kinship is - and is not* (Chicago: University of Chicago Press).

[19] Lippman A (1991) Prenatal genetic testing and screening: constructing needs and reinforcing inequities *American Journal of Law and Medicine* **17(1-2)**: 15-50; Lippman A (1992) Led (astray) by genetic maps: the cartography of the human genome and health care *Social Science & Medicine* **35(12)**: 1469-76. See also: Finkler K (2000) *Experiencing the new genetics: family and kinship on the medical frontier* (Philadelphia: University of Pennsylvania Press). For a counter-argument, see: Hedgecoe A (1998) Geneticization, medicalisation and polemics *Medicine, Health Care and Philosophy* **1(3)**: 235-43. For an overview, see: Edwards J (2006) *Reflecting on the 'Euro' in 'Euro-American' kinship: Lithuania and the United Kingdom*, available at: http://briai.ku.lt/downloads/AHUK_13/13_129-139_Edwards.pdf.

[20] Strathern M (2005) *Kinship, law and the unexpected: relatives are always a surprise* (Cambridge: Cambridge University Press), at page 73, citing a personal communication with Janet Dolgin.

[21] Ibid: Marilyn Strathern fruitfully expands on the work of legal scholar Janet Dolgin who tracks the emergence of 'the genetic family' (which Strathern characterises as "[r]elatedness without relatives"), in recent court cases in North America.

[22] See also the role of fetomaternal microchimerism: Maloney S, Smith A, Furst DE *et al.* (1999) Microchimerism of maternal origin persists into adult life *Journal of Clinical Investigation* **104(1)**: 41-8.

1.16 Others again use the language of genetic connection simply as a synonym for 'biological' or 'blood' connection, without placing any particular significance on the choice of idiom. The implications of the changing language with which understandings of kinship are formulated are relevant to the arguments put to the Working Party both for and against the disclosure of information after donor conception. While it is fair to say that metaphors of blood, biology and genes are nowadays intermingled, and all are deployed to describe an aspect of kinship that is also said to be 'natural', *which* of these metaphors is deployed in particular situations may matter. In what follows we use the term 'biological' to capture this specifically 'natural' aspect of kinship, while recognising that no choice of term can be entirely neutral (see paragraph 1.32 below).

1.17 One accepted general understanding of kinship in the UK is that we also create kinship bonds through care and nurture. Thus kinship can be forged through desire, will and intention, and in this way adopted and step-children, for example, are made one's 'own'. At the same time the givenness of biological kin (who it is said cannot be chosen) can fade without due care and attention: thus, at times, people who are biologically 'close' to us may play no part in our lives and may no longer be reckoned by us as kin. There have been legal cases where parenthood has been disputed by donors and recipients and granted by the courts to non-genetic parents on the basis of their desire and intention to create a family and their existing relationship with the child;[23] in other cases the biological link, rendered visible in the idiom of genetics, has been privileged and deemed unassailable.[24] The kinship thinking with which we are concerned in this report relies on an interweaving of biological and social strands. Indeed, the biological aspects of kinship are also deeply social insofar as they are given meaning and made more or less significant in different societies.

1.18 Successful assisted reproductive technologies, including donor conception, not only result in the birth of an individual child but also *create* kin and kinship. The individual or couple who have successfully conceived a child using donated gametes become parents, and their parents become grandparents, and their siblings aunts and uncles, whether the biological disconnection is known or not. The English kin terms 'aunt' and 'uncle' usually refer to people who act in these roles, so that people without a biological link are frequently made into an aunt or an uncle. For many UK families these kin terms are also used as markers of respect between younger and older persons. We could see these examples as a 'fictive' kinship, or as persons acting 'as if' they were an aunt or an uncle. However that would not do justice to all the ways in which families in the UK appropriate aunts and uncles, as social roles, for various emotional and pragmatic reasons.

1.19 This raises a question for the relationship between the donor-conceived person and the donor and his or her family. Are the donor's siblings automatically aunts or uncles to the donor-

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[23] For example, in *TJ v CV & Ors* [2007] EWHC 1952 (Fam), an application by a sperm donor who sought contact and parental responsibility for the offspring, who was part of his sister's same-sex family, was denied. No parental responsibility order was made, and a limited contact order was granted. In addition, the judgment stated that the lesbian couple should not "feel assailed and undermined in their status as parents." See: Family Law Week (2008) *TJ v CV & Ors [2007] EWHC 1952 (Fam)*, available at: http://www.familylawweek.co.uk/site.aspx?i=ed999.

[24] See: BioNews (8 May 2012) *Birth mother v non-birth mother*, available at: http://www.bionews.org.uk/page_143453.asp, for an account of two cases where the courts have prioritised biological connection between parents and child. In *T v B* [2010] EWHC 1444 (Fam), a lesbian non-birth mother who had previously been deemed to have parental responsibility for a child was *not* held to be accountable for financial provision for the child once the relationship between the non-birth mother and the birth mother had dissolved. In *Re G* [2006] UKHL 43 (1), the High Court and the Court of Appeal were overruled by a House of Lords judgment which found that the lower courts' decision to award primary care of two children to the non-birth mother of a lesbian couple had not given sufficient weight to the fact that the birth mother was the genetic mother of the children, despite the fact that the latter had deliberately acted to obstruct her former partner's relationship with their children. The House of Lords concluded that the children should continue to live with their genetic mother. See also: *S v D & E* [2013] EWHC 134 (Fam), which ruled that sperm donors who knew the parents (in this case, lesbian couples) to whom they had donated could apply for contact with the resulting children, although under the Human Fertilisation and Embryology Act 2008, in each case both women in the couple had legal status as parents. The judgment highlighted the fact that in each case the child's parents had chosen a donor who lived in close proximity, and had facilitated early contact between child and donor. See: http://www.bailii.org/ew/cases/EWHC/Fam/2013/134.html.

conceived person? Or does the relationship need to be 'activated' socially in order for them to be perceived as 'true' aunts or uncles? The point to make is that both are possible. They can be perceived either axiomatically as an aunt or an uncle by virtue of being biologically related to the donor, whether they have a relationship with the donor-conceived person or not; or evidently unrelated insofar as no relationship is activated and therefore they play no aunt or uncle role in the life of the donor-conceived person. Similarly the donor can be seen to be a mother or a father upon the successful use of their gametes, without knowing the child, or indeed without knowing that their donation had resulted in a child being born. The donor can also be seen as quite unrelated: as merely providing the raw material that allowed another set of parents to become parents. The same donor can also be understood as a 'true' parent to (and by) their own non-biologically related children, such as their adopted or step-children.

1.20 Thus, the notion of kinship is flexible and allows for an emphasis on either its biological or social aspects. Depending on how one looks at it, the link between a donor and a donor-conceived person may be indisputably there, or self-evidently not, or indeed 'there' in some subtle way that is in between these two positions. This was highlighted in the Council's earlier report *Human bodies: donation for medicine and research*, which identified the range of views expressed by consultation respondents on the specialness or otherwise of gametes. Some respondents argued there was no difference between gametes and other bodily materials, while others pointed to a radical difference between them because of the potential of gametes to create new life.[25] Ethnographic studies have also shown a variety of views on the status of gametes: as "just" or "merely" bodily fluid and alienable,[26] or with the potential for creating unbreakable, albeit diffuse, links between people.[27] The *Human bodies* report notes that the consultation responses to this issue "demonstrate vividly the pluralism of opinion with which policymakers in the UK must grapple".[28]

1.21 This pluralism of opinion was echoed in the consultation exercise and factfinding meetings carried out by this Working Party. In looking at who should be responsible for making decisions about disclosure, one respondent to the online survey put it emphatically: "It is for the birth parents to decide what is best for their child, it is for them to decide what to tell the child, how much to tell them and when. In the end, a donor gives a single cell. It is the birth mother who carries the child, grows it and nourishes it from *her* blood and then gives birth and nurtures and teaches the child. Genetics do not make the parent!" Another respondent equally emphatically took the opposing view: "Some donors of my acquaintance (both egg and sperm) have regretted the act of what they have later come to regard as 'giving away their own children' into the hands of unknown strangers."[29]

1.22 Similarly, variations in how 'one's own' family is defined emerged in factfinding meetings with people with personal experience of donor conception. One parent told us that where a family includes donor-conceived and naturally-conceived children, there is no question of difference: "the donor-conceived child is 'mine', from the second they are born". Similarly, a donor commented that when they meet a child conceived from their gametes they do not feel "they're mine" or that they are "50 per cent me".[30] However, another donor-conceived person argued that "you can't just ignore the genetic side of things – that matters too." This person went on to highlight how often donor-conceived siblings (those conceived as a result of gamete donation by the same donor) find many similarities with each other when they meet for the first time, and

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[25] Practitioners, too, take a variety of stances on this point: see, for example, Wainwright SP, Williams C, Michael M, Farsides B, and Cribb A (2006) Ethical boundary-work in the embryonic stem cell laboratory *Sociology of Health & Illness* **28(6)**: 732-48.

[26] Edwards J (2000) *Born and bred: idioms of kinship and new reproductive technologies in England* (Oxford: Oxford University Press).

[27] Konrad M (2005) *Nameless relations: anonymity, melanesia and reproductive gift exchange between British ova donors and recipients* (Oxford: Berghahn Books).

[28] Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research*, available at: http://nuffieldbioethics.org/donation, at page 50.

[29] Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

[30] Factfinding meetings with people personally affected by donor conception, 27 April 2012.

how positive such connections with siblings can be.[31] As we have seen, gametes create not only life but also kin; but they do neither on their own.

## Comparisons with other family forms

1.23 Families created through donor conception are often compared with families created through adoption: indeed, comparisons with adoption provided a significant spur to the recent change in UK policy regarding access by donor-conceived people to identifiable information about their donor (see paragraph 2.9). There are conflicting views as to how meaningful these comparisons are: for some the fact that donor-conceived families usually have biological links between one parent and offspring demonstrates a self-evident difference from adoptive families; while others point to the absence of that biological link between one parent and offspring as demonstrating an equally self-evident similarity between the two family forms. Others suggest, in this context, that embryo donation is more similar to adoption than egg or sperm donation.[32] Clearly adoption does not disaggregate the component parts of kinship in the same way that donor conception does: there is no doubt that children who are later adopted are nonetheless biologically related to the parents who conceived them. Nonetheless, there is also no doubt that the child then becomes, legally, emotionally and socially, the child of the adoptive parents, just as the donor-conceived child is legally, emotionally and socially the child of the 'recipient' parents from conception and birth. Another similarity, from the perspective of the parents, may be that, both in cases of adoption and of donor conception, prospective parents require external assistance in order to build a family.

1.24 Significant differences may, however, be found between adoptive and donor-conceived families in that adoption involves the placing of existing children, born into one family (often in the context of adoption referred to as the 'birth family') into a new family, while donor-conceived children are usually born directly, and by design, into the family where they will be brought up. Thus, except in cases involving surrogacy, in donor conception there is no 'relinquishment' on the part of birth parents (either voluntarily or through the involvement of others) and no associated difficulty for children in understanding why their birth parents were unable or unwilling to bring up their own child. Families created through surrogacy arrangements may be perceived as more like adoptive families in that the child is 'relinquished' by the surrogate mother at birth (and legal intervention is required to reassign legal parenthood – see paragraph 2.1); or more like naturally-conceived families in that in some cases of surrogacy both egg and sperm may come from the 'intended' parents.

1.25 Research with donor-conceived adolescents and adults indicates that some donor-conceived offspring are interested in obtaining information about their donor, and in understanding their reasons for donation (see paragraph 4.25). Such interest has clear parallels with the interest some adopted adolescents and adults have in finding out about their birth parents, although the *nature* of the information sought (the extent to which value is placed on biological kinship, as opposed to curiosity about biological connection) is likely to vary widely within both groups.[33] It

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[31] Factfinding meeting with Rachel Pepa, 24 April 2012.

[32] MacCallum F, and Widdows H (2012) Ethical issues in embryo donation, in *Reproductive donation: practice, policy and bioethics*, Richards M, Pennings G, and Appleby J (Editors) (Cambridge: Cambridge University Press), for example, argue that embryo donation raises distinctive ethical concerns and that as the recipient couple will "rear a child that is genetically unrelated to them" and the child may also have full genetic siblings, it resembles adoption more than egg or sperm donation.

[33] See: Howell S (2003) Kinning: the creation of life trajectories in transnational adoptive families *Journal of the Royal Anthropological Institute* **9(3)**: 465-84; and Melhuus M, and Howell SL (2009) Adoption and assisted conception: one universe of unnatural procreaction. An examination of Norwegian legislation, in *European kinship in the age of biotechnology*, Edwards J, and Salazar C (Editors) (Oxford: Berghahn Books). In the context of transnational adoption in Norway, Signe Howell writes of how policy-makers and social commentators constantly attempt to bring to the fore biogenetic understandings of relatedness, emphasising the need of adopted children to know, and to know of, their birth families and their 'cultural heritage'. However, Howell argues that an emphasis in these quarters on the enduring and essentialist nature of biological connectedness (with culture mapped on to it) is at odds with the more nuanced and

is also the case that what drives curiosity in the case of each may also differ and be related to when and how people know they are adopted or donor-conceived.

1.26 Parallels may also be drawn between donor-conceived families and other family forms where one biological parent (usually the father) is unknown. This may arise in cases where the biological father has never played any role in their child's life: in such cases, the child may have limited or no information about him. In other cases, children may be brought up in families where both they and their father believe themselves to be biologically-connected but in fact are not: in such cases of 'misattributed paternity', the mother may be aware that her child's biological father is not her partner, but chooses not to disclose this.[34] Families in this latter situation are often compared with donor-conceived families where the parents opt not to tell their offspring of the means of their conception, although they also differ in that fathers, as well as offspring, assume incorrectly that they are biologically connected.

## Current context

1.27 The call for disclosure, and for access to information, in connection with donor conception comes at a particular moment when genes, genetic connection, and genetic explanation are prominent in society.[35] The promises of developments in genetic medicine are reported and debated extensively in the mass media as well as the specialist press, and experiences, views and information (accurate and inaccurate) circulate about genetic testing and the genetic basis of various diseases and disorders. The potential to provide personalised drug treatments and gear medicines to genotypes (pharmacogenetics) is an avenue of research that solicits and attracts attention. The current availability of 'over-the-counter' or 'via the internet' DNA tests also raises the profile of genetics in social life. The same companies that offer paternity tests also offer DNA test kits to enthusiasts of family history and genealogical research.[36] At the same time, television, literature and film (fact and fiction) are saturated with the potential of DNA profiling to aid criminal investigations.[37] Many scholars have identified such examples, among others, as part of a wider process of a 'geneticisation' of social life where genetic explanation has become increasingly more prominent in explanation of disease, disorder, identity and relatedness.[38]

1.28 We noted above, however, that a more nuanced analysis of the place of genetics in kinship is necessary (see paragraphs 1.14 to 1.16). It is not given the same value universally, and it appears, at least in the UK context, that as genetic connection has become more prominent (explicit), so too has social connection.[39] An emphasis on genetic relatedness thus runs

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contingent understandings of relatedness expressed by adoptive parents and their families who appear to have numerous ways of making kin of the children they adopt.

[34] Estimates vary as to how often this arises: current best estimates are one to three per cent of all families: see, for example, Sykes B, and Irven C (2000) Surnames and the Y chromosome *The American Journal of Human Genetics* **66(4)**: 1417-9; Voracek M, Haubner T, and Fisher ML (2008) Recent decline in nonpaternity rates: a cross-temporal meta-analysis *Psychological Reports* **103(3)**: 799-811; Wolf M, Musch J, Enczmann J, and Fischer J (2012) Estimating the prevalence of nonpaternity in Germany *Human Nature* **23(2)**: 208-17. See also: Lucassen A, and Parker M (2001) Revealing false paternity: some ethical considerations *The Lancet* **357(9261)**: 1033-5.

[35] See, for example, Freeman T, and Richards M (2006) DNA testing and kinship: paternity, genealogy and the search for the 'truth' of our genetic origins, in *Kinship matters*, Ebtehaj F, Lindley B, and Richards M (Editors) (Oxford: Hart Publishing), for the role of the Human Genome Project in 'geneticising' the way we think.

[36] DNA Worldwide, for example, offers male and female 'ancestry tests' and 'ethnic ancestry tests'. See: DNA Worldwide (2013) *DNA Worldwide homepage*, available at: http://www.dna-worldwide.com/.

[37] For a discussion of the role of the UK National DNA Database, see: Nuffield Council on Bioethics (2007) *The forensic use of bioinformation: ethical issues*, available at: http://www.nuffieldbioethics.org/bioinformation.

[38] Lippman A (1991) Prenatal genetic testing and screening: constructing needs and reinforcing inequities *American Journal of Law and Medicine* **17(1-2)**: 15-50; Lippman A (1992) Led (astray) by genetic maps: the cartography of the human genome and health care *Social Science & Medicine* **35(12)**: 1469-76; Finkler K (2000) *Experiencing the new genetics: family and kinship on the medical frontier* (Philadelphia: University of Pennsylvania Press); Finkler K (2001) The kin in the gene: the medicalization of family and kinship in American society *Current Anthropology* **42(2)**: 235-63. See also: Weiss M (2011) Strange DNA: the rise of DNA analysis for family reunification and its ethical implications *Genomics, Society and Policy* **7**: 1-19.

[39] Strathern M (1992) *Reproducing the future: anthropology, kinship and the new reproductive technologies* (Manchester: Manchester University Press).

alongside an emphasis on relatedness forged through care, attention and time. This dual focus on both genetic/biological and social connection is found also in English family law: while, for example, biological connection is taken to have overriding importance in cases such as absent fathers' obligation to pay child maintenance (regardless of any meaningful relationship with the child), by contrast courts have at times emphasised the importance of social relatedness and care-giving over biological connection, when determining where a child should live or with whom they should have contact (see paragraph 1.17 above).[40] As we will see in Chapter 2 (see paragraph 2.3), courts awarding 'parental orders' for intended parents in surrogacy arrangements may only do so if there is a biological connection with at least one parent – and yet that biological connection is insufficient itself (without the order) to confer any parental rights or responsibilities on a genetically-connected intended parent.[41]

1.29 The emphasis on disclosure and access to information is also occurring at a time when a high societal value is placed more generally on 'openness' and 'transparency'. The internet and ever-expanding technologies of communication and social networking, such as Facebook and Twitter, have presented us with unprecedented means of 'disclosure' in all spheres of social life, including, potentially, the ready sharing of individuals' genetic information.[42] This burgeoning of information and communication possibilities is challenging the boundaries of privacy: both in the sense of changing (some) individuals' sense of what is private, and in increasing the likelihood of private information being inadvertently made available to others. The popularity of the television programme *'Who do you think you are?'*, devoted to the family history of celebrities, is enhanced by the growing capacity of interested people to trace their origins, ancestors and heritage.[43] These social phenomena, and others, are threads in the cultural fabric of the beginning of the 21st Century and they mutually shape and inform each other. The Working Party has found it helpful to be reminded of the contemporary value placed on 'openness' and 'transparency' in many social domains.

1.30 The political lobby for disclosure in the context of donor conception also appears to be stronger in 'Euro-American' societies[44] than elsewhere, and there is detailed ethnographic evidence from other parts of the world that the issue of disclosure in donor conception is not as high on the agenda of concerns as it is in the UK. Ethnographers highlight, for example, the stigmatisation of infertility in some societies (especially of male infertility) which compels people not only to hide the fact of infertility but also not to reveal the use of assisted conceptive technologies.[45] In some societies, the mixing of sperm with the egg of a married woman is not only shameful but

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[40] For a more detailed discussion of how the courts deal with conflicts between biological and social relatedness, see: Fortin J (2009) Children's right to know their origins-too far, too fast? *Child and Family Law Quarterly* **21(3)**: 336-55. Fortin highlights how a 'right to know' on the part of the child claimed in such disputes often has less to do with the child's needs or interests than with the needs or interests of those surrounding the child.

[41] For further discussion of this point, see: McCandless J, and Sheldon S (2013) The determination of legal parenthood in assisted conception, in *Perceptions of relatedness in assisted conception families*, Freeman T, Ebtehaj F, Graham S, and Richards M (Editors) (Cambridge: Cambridge University Press), forthcoming.

[42] See, for example, Wired.com (9 November 2012) *Social codes: sharing your genes online*, available at: http://www.wired.com/wiredscience/2012/11/social-codes/ for a discussion of the potential for sharing genetic data routinely via social media.

[43] The programme is in its ninth series in the UK and has spawned ten international adaptations in the USA, Canada, Netherlands, Finland, Norway, Finland, Sweden, Germany, Australia and South Africa. See: BBC (2012) *Who do you think you are?*, available at: http://www.bbc.co.uk/programmes/b007t575.

[44] The concept of 'Euro-American' societies indicates not a geographical area, but rather a world view which is prevalent in Northern European and North American cultures and includes other white settler societies such as Australia, New Zealand, South Africa, and Israel. Euro-American, in this context, indicates shared models rather than a population and points to idioms rather than places; it gives us a descriptive language with which to track dominant ideologies that are not confined within socio-political borders of nation states. At times, it is glossed more generally as 'Western' or, more specifically, as 'Anglo Euro American'.

[45] Paxson H (2003) With or against nature? IVF, gender and reproductive agency in Athens, Greece *Social Science & Medicine* **56(9)**: 1853-66; Inhorn MC (2007) Masculinity, reproduction, and male infertility surgery in the Middle East *Journal of Middle East Women's Studies* **3(3)**: 1-20; Edwards, J (2010) *Bodies bridging borders*, available at: http://www.eastbordnet.org/working_papers/open/documents/Edwards_Bodies_Bridging_Borders100522.pdf.

also forbidden:[46] parents using donor gametes to conceive go to great lengths not to disclose the facts of conception and have no interest in maintaining – or maintaining the possibility of – a relationship between their child and the donor. The emphasis on the importance of openness is also stronger in the UK than in some other European countries,[47] and the differential interest in donor identity across Europe translates into different legal frameworks and policies on donor anonymity (see paragraphs 2.30 and 2.31). Moreover, in the context of attitudes towards openness and transparency within families, not only do we need to take into account differences between Northern and Southern European societies, but also the religious and cultural diversities within them. It is further the case that factors such as openness and transparency within families may be valued differently across social classes.[48]

## Choice of language in donor conception

1.31 During the factfinding meetings that the Working Party held with a wide range of stakeholders (see Appendix 2), it became apparent that the vocabulary used in donor conception is very influential: particular terms are used in different ways by different people, and it is therefore essential to ‘unpack’ what is meant in particular cases. We have already noted the way that the language of genetics is increasingly being used in the context of family and identity, and that while some will use the language of ‘genetic’ connection to mean something quite specific (see paragraphs 1.14 to 1.16), others will use it synonymously with ‘blood’ or ‘biological’ connection. In a meeting with practitioners and researchers working with donor-conceived families, for example, we were told that when people talk about their ‘genetic origin’, this should not be narrowly understood as concern about their ‘genetic’ inheritance, or that they understand their identity as genetically determined. It should be understood, rather, much more broadly in terms of ‘their own story’, including their biography, background and family connections: how, in other words, information about the circumstances in which they were conceived is integrated into their own narrative.[49]

1.32 For the sake of clarity, therefore, in this report we will use the broader term ‘biological’ for this aspect of kinship which includes ‘genetic’, unless our respondents state otherwise. We confine use of the term ‘genetic’ to discussion of medical information that relates specifically to genes and genetic mutations. In our discussions of kinship, we will also distinguish between ‘connections’ where a biological link exists (regardless of what value is placed on that link by any party) and ‘relationships’ where that connection has been ‘activated’ by choice, or has been created through care and attention. In line with the underlying premise of creating donor-conceived families, we will refer to the legal parents of donor-conceived people as ‘parents’ (regardless of the absence of biological connection); to those who provide gametes or embryos as ‘donors’; and to those hoping to create a family using surrogacy arrangements as ‘intended parents’. We include egg, sperm and embryo donation when referring to donor conception unless otherwise specified. Donors’ own biological children are referred to as ‘donors’ children’

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[46] For example, Professor Marcia Inhorn notes that “Islam is a religion that privileges – even mandates – biological descent and inheritance. Preserving the “origins” of each child, meaning his or her relationships to a known biological mother and father, is considered not only an ideal in Islam, but a moral imperative.” However, she also notes that, in recent times, fatwas have allowed infertile Shi’ite Muslim couples to donate and accept donated gametes in IVF clinics. See: Inhorn MC (2006) “He won’t be my son” *Medical Anthropology Quarterly* **20(1)**: 94-120.

[47] Maren Klotz has compared the debate around donor conception and disclosure in Germany and the UK in a thesis entitled: *[K]information. Gamete donation and the constitution of kinship through knowledge-management in Britain and Germany: an ethnographic exploration* (2012) Berlin: Humboldt University. There she identifies how privacy, connectedness and information are being renegotiated in morally significant ways. She points to the way in which concerned groups in the UK, as opposed to those in Germany, have multiple entry points into policy and decision-making processes. Klotz also found that the focus of activist groups in Germany tends to be on the form of the family, whereas in the UK it tends to be on the means of conception. She cites work from the USA which relates the call for disclosure to an emphasis on the centrality of ‘the genetic family’ in conservative movements which underline its ‘naturalness’ (and hence ‘unnaturalness’ of any kind of family other than heterosexual married nuclear family).

[48] The white middle classes in the UK, for example, put a high premium on ‘truthfulness’ and openness with children from an early age as part of parental responsibility for educating and socialising autonomous individuals with rights and entitlements: “To be self-conscious about knowledge is in Britain a largely middle-class predilection” - Strathern M (2005) *Kinship, law and the unexpected: relatives are always a surprise* (Cambridge: Cambridge University Press), at page 4.

[49] Factfinding meeting with practitioners and researchers, 30 May 2012.

or ‘donors’ (adult) children’, as appropriate; and we use the term ‘donor-conceived siblings’ to refer to the connections between the offspring of the same donor (sometimes also described as ‘donor-conceived communities’), while recognising that this ‘sibling’ connection differs in many ways from that of brothers and sisters who share the same family life from birth. Finally, we note that the terms often used in the context of information sharing in donor conception, including ‘openness’, ‘honesty’ and ‘secrecy’ inevitably convey moral sentiments both positive and negative, a point to which we return in our ethical considerations in Chapter 5.

# Chapter 2

## Law and practice in the UK

# Chapter 2 – Law and practice in the UK

### Chapter 2: overview

- The aim of donor conception services is to enable recipient parents to have a ‘family of their own’. Where treatment is provided in licensed clinics, UK law makes provision for the donor to be excluded from the legal status of parent, and for the recipient parents to acquire that status, even where they have no biological connection with the child.
- Information about donors is nevertheless collected and retained by the regulatory authority (the HFEA), so that it can be provided later to donor-conceived people on request. Donors are encouraged, although not required, to provide biographical information about themselves, for example in the form of a ‘pen portrait’, and to write a message for the future donor-conceived person.
- While such biographical information is anonymised, so that it can be provided without identifying the donor, fully-anonymous donation was abolished in the UK in 2005. Donor-conceived people born as a result of donations made after April 2005 will therefore be able, when they reach the age of 18, to obtain identifying information about their donor.
- Those conceived before that date will not be able to obtain identifying information unless their donor chooses to make themselves identifiable. Those conceived before regulation began in 1991 do not have access to any information via the HFEA and often have little, if any, information about their donor from paper records, although the possibility exists of being ‘matched’ (using DNA testing) with their donor or donor-conceived siblings via a state-funded voluntary register if their donor or donor-conceived siblings have also chosen to register.
- In the past, most clinics providing treatment with donor gametes encouraged the prospective parents seeking treatment to forget about their treatment, once pregnancy was achieved, with disclosure to donor-conceived children about their origins being seen as unnecessary and potentially harmful. In the light of changing social and professional attitudes, this advice has reversed: reference to the “importance” of early disclosure to children has now been incorporated in the legislation, and is strongly recommended in the HFEA *Code of practice*.
- It has been argued that the state should take further action to *ensure* that donor-conceived people know of the circumstances of their birth so that they are in a position to access the information held on their behalf by the HFEA: for example through some indication on a person’s birth certificate. It has similarly been argued that the legal provisions enabling donor-conceived people to access identifying information about their donor should be made retrospective, so that all donor-conceived people, whenever born, have access to this information where held.
- The Government has not accepted the need for any such change to date, rejecting arguments based on Article 8 of the European Convention on Human Rights (the right to respect for a person’s private and family life) because of the competing interests of others concerned. Legal approaches to anonymity and disclosure vary considerably both inside and outside Europe.
- In the UK, it is a legal requirement that potential donors and prospective parents must first be given a “suitable opportunity” to receive proper counselling about the implications of donation or treatment, and also “provided with such relevant information as is proper”. There is considerable variation in the extent to which clinics routinely encourage potential donors and prospective parents to engage with such counselling services.
- The primary sources of support for people affected by donor conception, particularly for families once treatment is in the past, are found in the voluntary sector. There is a further statutory requirement that donor-conceived adults applying to the HFEA’s Register for information about their donor should be given a “suitable opportunity to receive proper counselling about the implications of compliance with the request” before the HFEA complies. There are, at present, no specialist services for donor-conceived adults in this position.

## Collecting and accessing information about donors

2.1 The fundamental premise underpinning both the existence of treatment services using donor gametes, and the UK regulation of these services, is that the ‘recipient’ parent or parents will be the child’s real parents from the beginning.[50] Prospective parents seek treatment in order to have their own family, and donors are encouraged to come forward on the basis that they will

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[50] The Working Party is aware of the view held by some donor-conceived adults that this premise is simply wrong: that donor conception as a practice separates offspring from their true biological parents from before birth, and is unacceptable: see, for example, TangledWebsUK (2011) *TangledWebsUK*, available at: http://www.tangledwebs.org.uk/tw/. Similar concerns were expressed to the Working Party through responses to the call for evidence from the Christian Medical Fellowship and the Anscombe Centre. This report, however, starts from the position that donor conception is a generally-recognised means of building a family: the key issue the Working Party was asked to address related to the ethical implications of information sharing in connection with donor conception.

not have any form of parental responsibility for the resulting child.[51] The Human Fertilisation and Embryology Act 2008[52] sets out detailed provisions relating to legal parenthood after treatment in the UK with donor gametes that aim to ensure that these objectives are achieved in practice. Thus, under the current law, where children are born as a result of licensed treatment in the UK, the following provisions ensure that there is no doubt about their parents' status:

- The woman who gives birth to a child is always the legal mother, regardless of whether her own egg, or a donor egg or embryo, has been used in conception.[53]
- If the mother is married, her husband will automatically be the legal father, and if she is in a civil partnership, her female partner will automatically become the child's legal parent.[54]
- Where the mother is not married or in a civil partnership but has a partner (male or female), then that partner will be the legal father/parent of the resulting child, if both parties notify the clinic treating them that this is their wish.[55]
- Where treatment is provided through a UK-regulated clinic, the law explicitly excludes the possibility of the sperm donor being treated as the father of the resulting child;[56]
- However, where sperm is donated and used *outside* the regulated system, the position of the sperm donor will not be prescribed in this way, and if no other second legal parent exists (for example where donating to a single woman or an unmarried couple) he may be treated as the legal father. Similarly, the protections in the Act do not apply to pre-1991 conceptions.[57]

2.2 Although the regulatory framework governing donor conception services thus clearly seeks to exclude the donor from the legal responsibilities that might otherwise arise in connection with one's biological offspring, and emphasises the full legal parenthood of the recipient parent(s), nevertheless, from the beginning the Human Fertilisation and Embryology Authority (HFEA) has collected and retained information about donors in such a way as to enable that information to be connected with any resulting offspring. Over the 20 years in which the HFEA has been in existence, understandings of the value placed on that information, by both donor-conceived people and by prospective and actual parents, have changed considerably. We return in Chapters 3 and 4 to a more detailed account of the concerns and interests that all parties to donor conception may have in connection with 'information', understood both in the sense of knowledge that a person is donor-conceived, and in terms of access to biographical information about others with whom they share close biological connections. In this chapter we focus on UK regulatory and professional arrangements as these relate to the collection of, and subsequent access to, information relating to donor conception;[58] and to the support that should be available to (prospective) parents, donor-conceived people and donors in connection with information sharing.

2.3 We note briefly here two exceptions to the circumstances in which donors are distanced from legal parenthood. First, while surrogacy arrangements are treated under the HFE Act as

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[51] See, for example, the information provided on the National Gamete Donation Trust website: http://www.ngdt.co.uk/donation-and-the-law, which demonstrates how donors may be encouraged to donate.

[52] The 2008 Act amended and extended the original provisions in the 1990 Act of the same name.

[53] Section 33 of the 2008 Act.

[54] Sections 35 and 42 of the 2008 Act. The only circumstances in which a husband or civil partner would not be the legal father/parent would be where he/she had not consented to the treatment with donor gametes.

[55] Sections 36-7 and 43-4 of the 2008 Act.

[56] Section 41 of the 2008 Act. However, the HFEA *Code of practice* highlights the fact that there is no specific provision to prevent a male embryo donor being considered the legal father, if the recipient is a single woman, and warns potential donors to seek independent legal advice. See: Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at 11.31.

[57] For potential financial and inheritance implications arising out of pre-Act conceptions, see: UK DonorLink (2011) *Guidance on financial implications for those who may wish to trace family members through the UK DonorLink Register*, available at: http://www.ukdonorlink.org.uk/UKDL_Financial_Implications_Leaflet_June_2011.pdf. This reproduces legal advice given to UK DonorLink in 2011, indicating that under Scots law a person has an automatic entitlement to inherit from their biological father, regardless of the lack of any social relationship. No such cases have, however, been reported.

[58] See: Human Fertilisation and Embryology Authority (2009) How legislation on fertility treatment developed, available at: http://www.hfea.gov.uk/1319.html#1333 for a useful timeline of regulatory change.

treatment involving donor gametes (as the surrogate mother is the ‘patient’ receiving donor gametes as part of her treatment and hence one or both the intended parents are regarded as ‘donors’), the legal parenthood provisions involving surrogacy arrangements differ significantly from those in other donor conception arrangements. The surrogate mother, by virtue of being the birth mother, is the legal mother regardless of whether or not her own egg has been used; and, if she is married, her husband will therefore be the legal father, unless he demonstrates he did not consent to the surrogacy arrangement. Nevertheless, the law has recognised the relevance of the intentions of the intended parents and surrogate, through the creation of a ‘fast-track’ adoption process known as a parental order, which may be granted by a court to intended parents, as long as at least one intended parent has contributed gametes to the resulting child.[59] Complications may, however, arise where UK-based intended parents use an overseas surrogate, both in establishing parental status and in bringing the child back to the UK, since laws assigning parenthood differ significantly between countries; and early legal advice is strongly advised.[60]

2.4 Second, although the law makes provision for donors to be excluded from any legal responsibility for children conceived as a result of their donation, some parents may *choose* to enter into more flexible ‘co-parenting’ arrangements with their donor.[61] Co-parenting arrangements may be of particular relevance to gay people or single women: for example, a potential mother without a partner might want her child to have a clearly-recognised father figure in their life, and may therefore choose to ‘co-parent’ with a friend or acquaintance who agrees to donate sperm to her for insemination.[62] Similar arrangements may be initiated by male same-sex couples, or single men, who would prefer their child to have both mother and father figures in their life, and hence opt for a co-parenting arrangement rather than surrogacy.[63] Whether or not the ‘co-parent’ has legal status as a parent will then depend on a number of factors, including whether or not donation and insemination takes place in a licensed clinic (see paragraph 2.1 above). Indeed, it has been suggested that some recipients and donors may consciously choose informal donation, without the intervention of a licensed clinic, because they envisage the donor having a greater role in the upbringing of the resulting child.[64]

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[59] Section 54 of the 2008 Act. A parental order avoids the need for formal adoption proceedings to reassign legal parenthood; such an order is, however, only available to couples (not single parents) and at least one parent must be biologically connected to the child. In principle, at least, there is a further requirement that the surrogate must only have received ‘expenses reasonably incurred’. In practice, however, since a court must make the child’s welfare its paramount concern, an order may be made even if excessive expenses are deemed to have been paid: *Re L (a Minor)* EWHC [2010] 3146 (Fam).

[60] The HFEA’s *Code of practice* states that the centre should advise all patients considering surrogacy arrangements to seek legal advice, given that surrogacy arrangements are not legally enforceable. In addition, the Code recommends that the centre should advise patients intending to travel to another country for the purpose of entering into a surrogacy arrangement not to do so until they have sought legal advice about the legal parenthood of the prospective child, and the adoption of parental orders procedures for that country. See: Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraphs 14.2 and 14.3. See also: Natalie Gamble Associates (2012) *International surrogacy*, available at: http://www.nataliegambleassociates.co.uk/page/International-surrogacy/36/.

[61] For examples of co-parenting arrangements, see: Pride Angel (2013) *Co-parent law: for co-parents and involved donors*, available at: http://prideangel.com/p97/fertility-pregnancy/Fertility-Law/Co-parent-Law.aspx. The complexities of co-parenting arrangements were also highlighted by Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors, responding to the Working Party’s call for evidence.

[62] For more information on co-parenting, see: Pride Angel (2013) *Co-parenting*, available at: http://www.prideangel.com/p60/faqs/Co-parenting.aspx and Natalie Gamble Associates (2013) *Sperm donors (known donors and co-parents)*, available at: http://www.nataliegambleassociates.co.uk/page/knowndonor/16/. Also see: The Telegraph (31 July 2011) *Meet the co-parents: friends not lovers*, available at: http://www.telegraph.co.uk/family/8659494/Meet-the-co-parents-friends-not-lovers.html.

[63] Herbrand C (2008) Les normes familiales à l’épreuve du droit et des pratiques: analyse de la parenté sociale et de la pluriparentalité homosexuelles *PhD Thesis*: Université Libre de Bruxelles.

[64] See, for example, the discussion on BBC Radio 4 (15 November 2012) *Woman’s Hour: sperm donors and the CSA*, available at: http://www.bbc.co.uk/programmes/p01165sg; Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

### The HFEA's Register

2.5 We noted in Chapter 1 (see paragraph 1.3) that in the case of 'unknown' donors, professionals and regulatory authorities act as intermediaries between donors and recipients, not only in connection with the initial donation and treatment with donated gametes, but also in connection with the collection and management of information: information about the donor and, in cases where donation leads to a successful pregnancy, information about the resulting child. Unlike known donors and recipients who have the potential to make their own arrangements as to how much information they share with each other and with any resulting children, unknown donors, recipient parents and any people born as a result of donation are entirely reliant on third parties (clinics and the HFEA) both for how much information is collected, and on the extent to which they may access that information.[65] Access to information for donor-conceived people, whether from known or unknown donors, will further depend on whether or not their parents tell them that they are donor-conceived: while the HFEA holds and makes available information as described below, and actively encourages parents to disclose to their children (see paragraphs 2.20 and 2.21) it does not itself act to contact donor-conceived people in connection with the information it holds.

2.6 Since 1991, the HFE Act has required the HFEA to maintain a 'Register of information' which records all notified births resulting from treatment services, including those where donated gametes and embryos were used, and also holds information about gamete donors.[66] While information about donors' physical characteristics (eye and hair colour, height, weight and ethnic group) has been collected from the beginning, the emphasis on the potential significance of personal and biographical information about donors has changed over time. In 1991, the donor information form included an optional section inviting donors "to give a brief description of yourself as a person",[67] and the HFEA's *Code of practice* emphasised the optional nature of this section, stating that donors should be encouraged to provide as much other non-identifying biographical information about themselves "as they wish[ed]".[68] The approach of clinics in encouraging donors to provide biographical information in this way also varied considerably.[69] Since 2003, however, the emphasis in the HFEA's *Code of practice* has changed to include the expectation that clinics would encourage donors to provide as much information "as possible".[70] Information that must now be collected by clinics about donors and transmitted to the HFEA includes the physical characteristics cited above, donors' medical background, information about any screening tests carried out, and donors' contact details.[71] The latest version of the standard donor information form invites donors to provide optional additional information in the form of biographical information about themselves such as details of their occupation, interests and religion, and their reason for donating, as well as providing the opportunity to write a goodwill message to their future offspring and a pen portrait providing a fuller description of themselves.

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[65] As noted in paragraph 1.4, 'known' donors may, of course, lose contact with the recipient family, and in some cases offspring born as a result of their donation may only be able to obtain information via the HFEA (depending on their parents' willingness to share information with them). Nevertheless, where known donors have a longstanding prior relationship with recipient parents, those parents are not dependent on clinics and the HFEA for information in the same way as those conceiving through the assistance of unknown donors.

[66] Section 31 of the 1990 Act, as amended; section 24 further requires the HFEA to issue directions to clinics, requiring them to provide information to the HFEA, including the details of people receiving regulated treatment, people born as a result of such treatment, and donors.

[67] Human Fertilisation and Embryology Authority (1991) *Donor information form 91(4)* (London: Human Fertilisation and Embryology Authority).

[68] Human Fertilisation and Embryology Authority (1991) *Code of practice 1st edition*, available at: http://www.hfea.gov.uk/docs/1st_Edition_Code_of_Practice.pdf, at paragraph 3.37.

[69] See, for example, Blyth E, and Hunt J (1998) Sharing genetic origins information in donor assisted conception: views from licensed centres on HFEA donor information form (91) 4 *Human Reproduction* **13(11)**: 3274.

[70] Human Fertilisation and Embryology Authority (2003) *Code of practice 6th edition*, available at: http://www.hfea.gov.uk/docs/Code_of_Practice_Sixth_Edition.pdf, at paragraph 4.4.

[71] Human Fertilisation and Embryology Authority (2012) *Donor information form: version 4*, available at: http://www.hfea.gov.uk/docs/HFEA_Form_Donor.pdf.

2.7 While the form makes clear that these later biographical sections are optional, it recommends that donors should fill them in, commenting that: "the information you provide can help parents tell children about their origins and answer some questions a donor-conceived person may have."[72] However, the Working Party was told that these sections are not consistently filled in, or filled in only sketchily;[73] one respondent to the call for evidence also noted that, in her research, she had observed how donors sometimes intended to fill these parts of the form in at home, precisely because they were seen as being more important or complicated, but then never returned them.[74] Clinics may also edit information if they are concerned that it is in some way inappropriate,[75] while the HFEA will redact any information that it deems potentially identifiable.[76] At the time of writing, the HFEA's National Donation Strategy Group is in the process of developing a leaflet for donors, offering guidance on what information they might provide.[77]

2.8 Initially, the intention behind collecting such donor information was to enable limited *non*-identifying details about donors to be released to donor-conceived people, on request, when they reached the age of 18. Donor-conceived people aged 16 or over would also be able to contact the HFEA to ensure that they were not biologically connected to the person they intended to marry.[78] It was not envisaged that any identifying information would be released at any stage: potential donors were encouraged to come forward and donate gametes under assurances of anonymity, and their donation was conceptualised as a one-off gift with no future implications of any kind. However, this approach to the collection, and future sharing, of information was not unchallenged, with the British Association of Social Workers' Project Group on Assisted Reproduction (Progar) drawing on comparisons with adoption to argue from the beginning that the regulation of donor conception services should include access by donor-conceived people to identifying information about their donor.[79]

2.9 Following extended campaigning by Progar and the Children's Society, the Department of Health announced in December 2000 that it would be undertaking a consultation on the amount of information that should be made available to donor-conceived people, and to their parents during their childhood.[80] Before the promised consultation document was published, a case was brought by a donor-conceived adult (Joanna Rose) and a donor-conceived child (EM) under the *Human Rights Act 1998*, in which it was argued that under Article 8 of the European Convention on Human Rights, states had an obligation to ensure that "certain vital non-identifying information about donors is collected and made available to [donor-conceived] offspring both on maturity and to parents such as those of EM who wish to bring up their child in openness about the circumstances of its conception."[81] By the time that the case was heard, in May 2002, it was agreed that it would be appropriate to defer consideration of many of the issues raised, until

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[72] Human Fertilisation and Embryology Authority (2012) *Donor information form: version 4*, available at: http://www.hfea.gov.uk/docs/HFEA_Form_Donor.pdf.

[73] Factfinding meeting with professionals involved at the time of donation, 22 June 2012.

[74] Maren Klotz, Lecturer, European Ethnology Humboldt University Berlin, and Honorary Fellow at the Egenis Centre, University of Exeter, responding to the Working Party's call for evidence.

[75] Laura Witjens, personal communication, 29 January 2013; the Working Party was also told in the factfinding meeting with professionals involved at the time of donation (22 June 2012) that one clinic includes extra information which records the staff impression of the donor, because of concerns that some donors do not necessarily 'write well' about themselves.

[76] Human Fertilisation and Embryology Authority (2012) *1 October 2012: the way we provide donor information is changing*, available at: http://www.hfea.gov.uk/7479.html.

[77] Human Fertilisation and Embryology Authority (6 September 2012) *National Donation Strategy Group (NDSG) meeting minutes*, available at: http://www.hfea.gov.uk/docs/NDSGSeptember-minutes.pdf, at paragraph 5.11.

[78] Section 31(6) and (7) of the HFE Act 1990, as originally passed; this provision was later extended to allow access to this information for donor-conceived people aged 16 or over who were proposing to enter a civil partnership or were intending to enter into an 'intimate physical relationship', so that they could check that they were not biologically related to their proposed partner (section 31ZB of the HFE Act 1990, as amended).

[79] Wincott E, and Crawshaw M (2006) From a social issue to policy: social work's advocacy for the rights of donor conceived people to genetic origins information in the United Kingdom *Social Work in Health Care* **43(2-3)**: 53-72.

[80] For a fuller discussion of the events leading up to the change in the law, see: *R v Secretary of State for Health* (2002) EWHC 1593 ('the Rose judgment'); Wincott E, and Crawshaw M (2006) From a social issue to policy: social work's advocacy for the rights of donor conceived people to genetic origins information in the United Kingdom *Social Work in Health Care* **43(2-3)**: 53-72; Turkmendag I (2012) The donor-conceived child's 'right to personal identity': the public debate on donor anonymity in the United Kingdom *Journal of Law and Society* **39(1)**: 58-75.

[81] *R v Secretary of State for Health* (2002) EWHC 1593, at paragraph 15.

ministerial decisions relating to the consultation process had been announced, and the judgment itself concentrated primarily on whether Article 8 was 'engaged' (but not at this stage whether it had been 'breached').[82] It was noted in the judgment that, while the claimants had limited themselves to asking for non-identifiable information about the donor (in order to enable them to "build up pictures about themselves"), in reality they would also like *identifying* information but were aware that because of confidentiality concerns they were most unlikely to be able to force disclosure. However, in coming to the conclusion that Article 8 *was* engaged, the judge held that the distinction between identifying and non-identifying information was "not necessarily an easy line to draw", and thus in coming to his conclusion he had looked "at the concept of information about donors regardless of whether it falls on the identifying or non-identifying side of the line". He noted, however, that should any future court consider whether Article 8 had been breached, then the distinction between non-identifying and identifying information would become much more significant in balancing the various interests at stake.

2.10 Following the consultation and the *Rose* case, the Department of Health announced a policy change in order to enable future donor-conceived adults to access identifying information, if they wished, about their donor. As a result of the *Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004*, anonymous donation was abolished, and any person conceived as a result of gametes donated after 1 April 2005 will be entitled, at the age of 18, to obtain identifying information about their donor.[83] The age for accessing *non*-identifying information about the donor was reduced from 18 to 16 in 2009, for all donor-conceived people conceived since 1991.[84] Those born between 1991 and 2005, however, will not be able to access identifying information about their donor unless the latter has chosen to 're-register' with the HFEA as an identifiable donor: that is, unless they actively choose to waive their right under the legislation to remain anonymous.[85] At present, any donor-conceived person in this group who wants to find out if their donor has re-registered in this way will have to resubmit their request for information on a regular basis, as no mechanism exists to alert people whose donor re-registers *after* the initial request for information was made; however, the HFEA told us that it was in the process of developing a means whereby donor-conceived people would be able be able to check more easily, on a quarterly basis.[86] The lack of retrospectivity with regard to access to information similarly meant that those born before 1991 were not affected by this policy change relating to anonymity (see paragraphs 2.15 and 2.16).

2.11 Changes have also taken place with respect to how the non-identifying information provided on donor information forms, and subsequently held by the HFEA, may be made available to others affected by donor conception. Following the introduction of the 2004 Regulations, the HFEA broadened its approach more generally to the disclosure of information: the parents of donor-conceived children were given access to non-identifying information from the Register, in recognition of the importance attached by some parents to sharing information about the donor with their child as they grew up; and donors were able to find out the number, sex, and year of birth of any people born as a result of their donation. The HFEA told us that, in making policy in

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[82] If Article 8 were held to be 'engaged', then a second question would arise as to whether it had been 'breached': this would depend on whether any interference with the interests protected by Article 8 could be justified by reference to the rights and interests of others. The interference must also be necessary, and a proportionate means of achieving the desired outcome.

[83] Note that clinics were given until 1 April 2006 to make use of their existing stocks of donated gametes, so that some people born as a result of treatment with donor gametes between 1 April 2005 and 1 April 2006 will not be able to access identifying information about their donors. See: Human Fertilisation and Embryology Authority (2005) *Information for centres on transitional period for use of gametes from anonymous donors: CH(05)01*, available at: http://www.hfea.gov.uk/docs/transitional_period_for_gametes_embryos_version1.pdf.

[84] Section 31ZA Human Fertilisation and Embryology Act 1990, as amended.

[85] The HFEA's website includes information about the possibility of past donors re-registering in this way: Human Fertilisation and Embryology Authority (2012) *Re-register as an identifiable donor*, available at: http://www.hfea.gov.uk/1973.html. It is not known how many donors are aware of this possibility; pro-active advertising has not been undertaken and most clinics have been reluctant to contact past donors to invite them to re-register because of data protection and confidentiality concerns.

[86] HFEA (Juliet Tizzard), personal communication, 18 January 2013.

this way, and allowing access to non-identifiable information above and beyond what was required at the time by the Act, they sought to balance the importance of maintaining the confidentiality of the donor, with the importance of ensuring that parents who wished to share information with their child, as they grew up, were able to do so.[87]

2.12 In 2009, the HFEA developed its *Opening the Register* policy, setting out a broad framework for processing requests for donor information, determining who can receive what information, and identifying the core principles (described as "protection of the right of applicants to access information"; "duty of care"; "treating all applicants sensitively"; and "statutory compliance") that should underpin the release of such information.[88] This reaffirmed the existing policy of giving parents non-identifying information so that they could share it with their child, and also further extended access rights to allow *prospective* parents (that is, those considering treatment with donor gametes) to receive non-identifying information about available donors from the clinic where they were receiving treatment.[89] The 2008 Act (coming into force in 2009) further enshrined in law the existing policy of giving donors access to information about the number, sex and year of birth of children born as a result of their donation.[90]

2.13 While UK regulation and HFEA policy have thus gradually changed over the years to encourage greater information provision by donors and greater access to that information by prospective and actual parents, the time-lag inevitable in prospective regulatory change in such an area means that there is little experience to date of donor-conceived people themselves accessing information direct from the HFEA. Only in 2008 would the first donor-conceived young people, born as a result of treatment regulated by the 1991 Act, have reached 16 and be able to access (non-identifying) information from the HFEA Register. Only in 2024 will those born since the abolition of anonymous donation in 2005 be entitled to receive identifying information from the Register, although, as noted above, it is possible that such information may in the meantime be obtained by those born under the original regulatory regime whose donors have chosen to re-register as identifiable. However, as we discussed in Chapter 1 (see paragraph 1.29), technological and social developments, in particular the research capabilities provided by the internet and the use of social networking, are increasingly enabling people to obtain information about donors, donor offspring and donor-conceived siblings *outside* regulated channels.

2.14 We describe later the role of voluntary-sector databases, such as the US-based Donor Sibling Registry (DSR), that exist to facilitate such connections (see paragraph 4.25), but examples have also been reported of individuals 'tracking down' their donor through the use of online DNA testing, combined with further research based on little more than their knowledge of the location of their parents' treatment clinic.[91] Moreover, easy access to personal information through the internet may increasingly challenge the distinction between 'identifying' and 'non-identifying' information: apparently mundane information provided by a donor about the university where they studied, followed by the city in which they now practise law, for example, may quickly lead to the possibility of identification. Social networking may similarly enable donors potentially to be identified from apparently anonymised biographical information. The current role of the HFEA as the 'gatekeeper' of identifiable information about donors may thus gradually be forced to evolve in recognition of the extent to which such information may be obtainable in other ways.

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[87] Factfinding meeting on regulatory aspects of donation, 22 June 2012.

[88] Human Fertilisation and Embryology Authority, responding to the Working Party's call for evidence. For more information, see: Human Fertilisation and Embryology Authority (2009) *Information access for donor-conceived people [and] donors*, available at: http://www.hfea.gov.uk/535.html and Human Fertilisation and Embryology Authority (2009) *Authority paper: opening the Register policy – a principled approach*, available at: http://www.hfea.gov.uk/docs/AM_Item_9_Jan09.pdf.

[89] Human Fertilisation and Embryology Authority, responding to the Working Party's call for evidence.

[90] Section 24 of the HFE Act 2008, inserting new section 31ZD into the 1990 Act.

[91] New Scientist (3 November 2005) *Anonymous sperm donor traced on internet*, available at: http://www.newscientist.com/article/mg18825244.200-anonymous-sperm-donor-traced-on-internet.html. For a discussion of this issue, see: Cahn N (2012) Legal parent versus biological parent: the impact of disclosure *Journal of Law and Medicine* **19(4)**: 790-802, at 799. See also: New Scientist (24 January 2013) *Matching names to genes: the end of genetic privacy?*, available at: http://www.newscientist.com/article/dn23088-matching-names-to-genes-the-end-of-genetic-privacy.html.

### *People conceived through donated gametes before 1991*

2.15 The HFEA Register does not hold information about people conceived before 1991, and hence the primary source of information for this group of donor-conceived adults is the clinic where their mother's treatment took place. The Working Party was told that clinics varied considerably in their attitude to requests, with some going to considerable trouble to try to locate any information they still held (with the consent of the patient to whom the files related, as necessary), while others appeared to the donor-conceived adults approaching them to be unhelpful or even obstructive.[92] In some cases, the original files may no longer exist, because clinics have closed, or lead clinicians have retired. In others, documents may still exist but may be stored or filed in a way that makes accessing them difficult. In the Working Party's factfinding meeting with professionals involved in providing donor conception services, it was clear that, where files are still accessible, clinics do indeed take different stances on how to respond to information requests: while, for example, one clinic was happy to contact past donors and ask them to consider providing further information and/or contact details, another clinic felt that such contact was unfair to past donors who had donated under assurances of anonymity, and also to past patients who had received treatment with the same expectations.[93]

2.16 Recognising that some donor-conceived people born as a result of treatment before the implementation of the 1991 Act have a strong desire to find out about their donor, the Department of Health has, since 2004, funded a voluntary register to facilitate contact, where desired, between donor-conceived adults, donors and donors' own (adult) children. Given the lack of a clear 'paper-trail' linking donors and donor-conceived people, 'matches' between donor-conceived people and donors, or between donor-conceived siblings, can only be made through DNA testing. This brings additional challenges, given that such testing cannot provide absolute certainty of biological connections, especially those between donor-conceived siblings. Matches can also clearly be made only if both parties have chosen to join the voluntary register. By the end of June 2012, 174 donor-conceived adults, 82 donors, and four adult children of donors were fully registered on the database, with a further 183 donor-conceived adults, 85 donors, and seven adult children of donors who had started, but not as yet completed, the process of registration. Six links had been made between donor and donor-conceived adults, and 35 probable sibling links (including groups of 11, five and three siblings).[94]

2.17 Between 2004 and 2012, the voluntary register, known as UK DonorLink (UKDL), was run by After Adoption Yorkshire.[95] Since 1 January 2013, following a decision by the Department of Health to amalgamate its financial support for the promotion of gamete donation with its support for the voluntary register into a single contract,[96] the register has been provided by the National

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[92] Factfinding meeting with Rachel Pepa, 24 April 2012; factfinding meetings with people personally affected by donor conception, 27 April 2012. For example, one person was advised that their mother's consent was required to access the records relating to the mother's treatment, but was then turned away even with that consent. Others, however, had more positive experiences.

[93] Factfinding meeting with professionals involved at the time of donation, 22 June 2012.

[94] Crawshaw M, Gunter C, Tidy C, and Atherton F (2013) Working with previously anonymous gamete donors and donor-conceived adults: recent practice experiences of running the DNA-based voluntary information exchange and contact register, UK DonorLink *Human Fertility*: e-published ahead of print, 5 February 2013.

[95] For more information about UK DonorLink, see: http://www.ukdonorlink.org.uk; Crawshaw M, and Marshall L (2008) Practice experiences of running UK DonorLink, a voluntary information exchange register for adults related through donor conception *Human Fertility* **11(4)**: 231-7; Crawshaw M, Gunter C, Tidy C, and Atherton F (2013) Working with previously anonymous gamete donors and donor-conceived adults: recent practice experiences of running the DNA-based voluntary information exchange and contact register, UK DonorLink *Human Fertility*: e-published ahead of print, 5 February 2013. See also: Adams D, and Lorbach C (2012) Accessing donor conception information in Australia: a call for retrospective access *Journal of Law and Medicine* **19(4)**: 707-21 for further discussion of the practicalities of DNA matching.

[96] See: TED (2012) *UK-London: health services - contract notice: 2012/S 211-347874*, available at: http://ted.europa.eu/udl?uri=TED:NOTICE:347874-2012:TEXT:EN:HTML.

Gamete Donation Trust as part of a 'national gamete donation service' and renamed the Donor Conceived Register.[97]

### People conceived through treatment abroad, or through non-regulated treatment in the UK

2.18 The information available via the HFEA Register for those conceived since 1991 is collected by UK-licensed clinics at the time of donation and treatment, and passed on to the HFEA. It therefore relates only to those conceived in UK-licensed clinics. This means that two further groups of donor-conceived people, in addition to those conceived before 1991, do not have access to information via the HFEA Register: those conceived through treatment abroad, and those conceived in the UK through informal arrangements between sperm donor and recipient. In many cases, particularly where a person has been conceived as a result of informal known sperm donation from a donor who has played an active part in their life, donor-conceived people may have *more* information than they might otherwise have had via the HFEA. Similarly, depending on the jurisdiction where treatment was sought, donor-conceived people born after treatment overseas may have significantly more information about their donor than is routinely collected in the UK.[98] However, given the variation in regulation in Europe alone, some people born as a result of treatment outside the UK may have access to little or no information about their donor, and anonymous donation with no facility for later disclosure of identifying information is widely practised (see paragraph 2.31).

## Early disclosure to donor-conceived people

2.19 Initially, most clinics providing treatment with donor gametes encouraged the prospective parents seeking treatment to forget about their treatment, once pregnancy was achieved. Disclosure to donor-conceived offspring about their origins was strongly discouraged on the basis that this was both unnecessary, and also potentially very harmful: there was concern that such information would disturb or distress the donor-conceived person with no compensatory benefit, and that the best outcome would be for children to grow up assuming that they were biologically-related to both their parents.[99] Such concerns arose in an environment where sperm donation, in particular, was equated by some with adultery, and viewed with some suspicion and mistrust.[100] Moreover, until 1988, openness about the use of donated sperm could potentially override the presumption that the mother's husband was the child's legal father, adding concerns about illegitimacy to other pressures on parents.[101]

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[97] See: Donor Conceived Register (2013) *Donor conceived register homepage*, available at: http://www.donorconceivedregister.org.uk/.

[98] US sperm banks, for example, often collect very detailed personal and biographical information about donors. Whether or not identity-release or anonymous donors are used, however, varies. See: The President's Council on Bioethics (2004) *Reproduction and responsibility: the regulation of new biotechnologies*, available at: http://bioethics.georgetown.edu/pcbe/reports/reproductionandresponsibility/_pcbe_final_reproduction_and_responsibility.pdf, at page 148. See also: ASRM forty-fifth annual postgraduate program (21 October 2012) *Examining the genetic link: course 16*, available at: http://www.asrm.org/2012_PG16_Examining_The_Genetic_Link/, where it was noted that over half of US sperm banks have open-identity donation.

[99] See, for example, Bloom P (1957) Artificial insemination (donor) *The Eugenics Review* **48**: 205-7 where a physician notes: "For the child's sake particularly I prefer that absolutely nobody but the parents themselves and myself should know of the insemination therapy." Bloom further states: "Two separate donors are used on alternate days at each estimated ovulatory period. Not only does the donor not know the patient but it is my practice never to tell the donors whether the insemination is successful or not. Even I do not know which of the two donors was responsible, and as I keep no records of which donors come for which patients I am usually in the position of not knowing which of quite a number of donors was responsible. I believe it is better that way."

[100] See, for example, concerns about the sperm donation as "tantamount to adultery" and the view that "[t]he intrusion of the seed of a third is as contrary to the proper meaning of the marriage bond as is the intrusion of the illicit affection for body of a third": Archbishop of Canterbury (1948) *Artificial human insemination: the report of a commission appointed by His Grace the Archbishop of Canterbury* (London: SPCK); Hansard (1958) *Artificial insemination of married women: vol. 206, cc926-1016*, available at: http://hansard.millbanksystems.com/lords/1958/feb/26/artificial-insemination-of-married-women.

[101] Section 27, Family Law Reform Act 1987, which came into force on 4 April 1988. See: The Family Law Reform Act 1987 (Commencement No. 1) Order 1988.

2.20 Over the past 20 years, social policy and professional practice in this area has changed significantly. As we note elsewhere in this report, a number of different factors are likely to have influenced these changes in attitude both to the significance of disclosure about the use of donor gametes, and to the provision of information, particularly identifying information, about donors. These include increasing awareness of the value found by some adopted adolescents and adults in finding out about their birth families, and the similar experiences of some donor-conceived people (see paragraphs 1.25, and 4.22 to 4.25); campaigning by donor-conceived people, parents and professionals advocating for greater openness and access to information; evolving social attitudes in the UK and elsewhere that have contributed to the increasing social acceptability of the diversity of family forms; legal clarity with respect to paternity and inheritance;[102] some lessening in the stigma attached to infertility and assisted reproduction; and developments in genetic medicine that have increased awareness of and attention to biological connections (see paragraph 1.27). The view that it is good practice for donor-conceived children to be told of the means by which they were conceived from an early age is now widely held by professionals and support groups. Indeed, since 2009, clinics providing treatment with donor gametes or embryos have been legally required to provide their patient with “such information as is proper about (a) the importance of informing any resulting child at an early age that the child results from the gametes of a person who is not a parent of the child, and (b) suitable methods of informing such a child of that fact”.[103]

2.21 The HFEA provides further guidance on how these legal requirements should be interpreted in its *Code of practice*:

> “The centre should tell people who seek treatment with donated gametes or embryos that it is best for any resulting child to be told about their origin early in childhood. There is evidence that finding out suddenly, later in life, about donor origins can be emotionally damaging to children and to family relations.
>
> The centre should encourage and prepare patients to be open with their children from an early age about how they were conceived. The centre should give patients information about how counselling may allow them to explore the implications of treatment, in particular how information may be shared with any resultant children.”[104]

## Legal challenges to the law on disclosure

2.22 Although the change in the law in 2004 established a new system of donation in the UK, under which donors can be identified to their donor offspring when the latter reach the age of 18, for some this legal change is seen as only the first step. As we noted above (see paragraph 2.5), the HFEA provides information about donors to donor-conceived offspring only on request and no provision is made to alert people to the fact that this information exists. There has been considerable debate in Parliament as to whether further regulatory change should be implemented with the aim of actively ensuring that *all* donor-conceived people know that they are donor-conceived.[105] Specific proposals for achieving this aim that were highlighted to the

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[102] Allan S (2012) Donor conception, secrecy and the search for information *Journal of Law & Medicine* **19(4)**: 631-50.

[103] Section 13(6C) of the 1990 Act, as amended. This requirement is a condition of the clinic’s licence to be permitted to provide treatment services involving donor gametes or embryos.

[104] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraphs 20.7-8.

[105] See, for example, House of Commons Science and Technology Committee (2005) Human reproductive technologies and the law: fifth report of session 2004-5 - volume I, available at: http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/7/7i.pdf; House of Lords and House of Commons Joint Committee on the Human Tissue and Embryos (Draft) Bill (2007) *Human tissue and embryos (draft) bill: volume I - report*, available at: http://www.publications.parliament.uk/pa/jt200607/jtselect/jtembryos/169/169.pdf; Secretary of State for Health (2007) *Government reponse to the report from the Joint Committee on the Human Tissue and Embryos (Draft) Bill*,

Working Party included direct communication from the HFEA with donor-conceived people when they reach the age of 18;[106] putting reference to donor conception on a person's birth certificate;[107] and introducing 'adoption-style' screening of prospective parents before treatment to ensure that only those committed to disclosure are permitted access to treatment.[108] Retrospective access by donor-conceived people to identifying information – that is, applying the post-2005 provisions to all donor-conceived people regardless of when they were born – has also been advocated.[109]

2.23 In many cases such proposals are put forward on the basis that donor-conceived people have a 'right' to access information about their donor, that such a right may be meaningfully exercised only if they know in the first place that they are donor-conceived, and that this right must apply equally to donor-conceived people whenever born. We return in Chapter 5 to a discussion of the Working Party's own view on whether 'rights' or 'interests' provide a more helpful analysis of the competing concerns generated by donor conception (see paragraphs 5.2 to 5.5). In this chapter concerning regulation, we provide more detail on two proposed regulatory changes that have generated particular debate – the inclusion on a person's birth certificate of some indication that they were donor conceived, and retrospective access to identifying information about donors – and then summarise the human rights arguments used to support them.

### Birth certification

2.24 Proposals that a child's birth certificate should make some reference to the use of donated gametes date back to the Warnock Report in 1984, where it was suggested that "consideration should be given as a matter of urgency to making it possible for the parents registering the birth to add 'by donation' after the man's name."[110] However, while most of Warnock's recommendations were carried straight through to the Human Fertilisation and Embryology Act 1990, this particular proposal was not, because of concerns that it would be stigmatising for the donor-conceived person.[111] A number of alternative models for reforming birth certification have since been put forward, including:

- the use of a discreet symbol on the birth certificate itself;
- indication on *all* birth certificates that further information about the person might potentially be available on other registers, such as that held by the HFEA;
- the creation of an Appendix to the long birth certificate (discloseable only to the individual and their parents), indicating that the person is donor-conceived; and

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available at: http://www.official-documents.gov.uk/document/cm72/7209/7209.pdf; House of Lords and House of Commons Joint Committee on Human Rights (2008) *Legislative scrutiny: fifteenth report of session 2007-08*, available at: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf.

[106] Factfinding meeting with people with personal experience of donor conception, 27 April 2012. This view was also put forward by Dr Thérèse Callus, responding to the Working Party's call for evidence: "if reform of the birth certificate as proposed is not acceptable, the alternative method of enforced disclosure would be by way of an information letter to the offspring upon their attaining majority."

[107] The International Donor Offspring Alliance, responding to the Working Party's call for evidence; Dr Sonia Allan, responding to the Working Party's call for evidence; factfinding meeting with Rachel Pepa, 24 April 2012; factfinding meetings with people with personal experience of donor conception, 27 April 2012; factfinding meeting with practitioners/researchers, 30 May 2012. See also: International Donor Offspring Alliance (2008) *International Donor Offspring Alliance Human Fertilisation and Embryology Bill birth certificates: the case for reform - briefing for members of the House of Commons*, available at: http://web.jaguarpaw.co.uk/~tom/idoa-briefing-latest.pdf.

[108] Factfinding meeting with people with personal experience of donor conception, 27 April 2012.

[109] Factfinding meetings with: Rachel Pepa, 24 April 2012; people with personal experience of donor conception, 27 April 2012; practitioners/researchers, 30 May 2012; and Christine Whipp, 16 July 2012. See also: Allan S (2012) Donor identification 'kills gamete donation'? A response *Human Reproduction* **27(12)**: 3380-4; Parliament of Victoria Law Reform Committee (2012) *Inquiry into access by donor-conceived people to information about donors: final report*, available at: http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/DCP_Final_Report.pdf; BioNews (2 April 2012) *Victoria's secret (or 'V' for victory)*, available at: http://www.bionews.org.uk/page_137523.asp.

[110] Department of Health and Social Security (1984) *Report to the Committee of Inquiry into Human Fertilisation and Embryology [The Warnock Report]*, available at: http://www.hfea.gov.uk/docs/Warnock_Report_of_the_Committee_of_Inquiry_into_Human_Fertilisation_and_Embryology_1984.pdf, at paragraph 4.25.

[111] HL Deb 13 February 1990 cc1254-71 and c1353. See also: Frith L (2001) Gamete donation and anonymity: the ethical and legal debate *Human Reproduction* **16(5)**: 818-24.

- wholesale reform of the birth and adoption certification system, so that everyone, however conceived, has a certificate of their legal parentage to be used for any official purposes (‘part A’), while a separate ‘part B’ would indicate whether the person was biologically connected to their legal parents, and where further information, if appropriate, could be sought.[112]

2.25 The issue was debated in Parliament again in 2007, when the Joint Committee responsible for scrutinising the *Human Tissues and Embryos (Draft) Bill* expressed deep concern about “the idea that the authorities may be colluding in a deception” but also recognised “that this is a complicated area involving the important issue of privacy, as well as issues of human rights and data protection.”[113] The Committee therefore recommended further Government consideration of this matter “as a matter of urgency.” The Department of Health, however, was not convinced of the need for change. In a letter to the Joint Committee on Human Rights in 2008, the Department expressed concern about the possible impact on the privacy of both the donor-conceived person and their parents if changes to the birth certification procedures were to be introduced, given that birth registers are public documents and there was a range of reasons, including applications for passports or in some cases jobs, why people might be asked to submit ‘full’ birth certificates. The Department took the view that a more proportionate way forward was to encourage parents to tell their children that they are donor-conceived and to enable donor-conceived people to obtain information from the HFEA on request from the age of 16, although it noted that it would continue to keep this approach under review.[114] The Joint Committee on Human Rights was satisfied with this approach, concluding that: “We consider that the registration process should only be changed if there is objective evidence that it is necessary and that the change will not have a disproportionate impact on the ability of donor-conceived people to keep their birth status private if they wish to do so.”[115]

### Retrospective access to identifying information about donors

2.26 Concern has also been expressed about the inequality amongst donor-conceived people regarding their access to information, depending on the year in which they were conceived; and the Working Party heard arguments that, in order to avoid discriminatory treatment of donor-conceived people based on year of birth, donor anonymity should be removed retrospectively from *all* donors, regardless of when they donated (see paragraph 2.22). Comparisons with adopted people (who have access to information about their birth parents, regardless of when they were adopted) have similarly been made to support the argument for retrospective change in the legislation governing anonymity. While, to date, no jurisdiction has introduced such retrospective access to donor information, the Government of the Australian State of Victoria is currently considering proposals from its Parliamentary Law Reform Commission to legislate to achieve this aim (see paragraph 2.32).

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[112] See: Blyth E, Frith L, Jones C, and Speirs JM (2009) The role of birth certificates in relation to access to biographical and genetic history in donor conception *The International Journal of Children’s Rights* **17(2)**: 207-33 for a detailed account of the various proposals put forward both in the UK and elsewhere. The proposal for universal reform of birth certification involving a ‘part A’ and ‘part B’ certificate was put forward at the Working Party’s factfinding meeting with practitioners/researchers, 30 May 2012.

[113] House of Lords and House of Commons Joint Committee on the Human Tissue and Embryos (Draft) Bill (2007) *Human tissue and embryos (draft) bill: volume I - report*, available at: http://www.publications.parliament.uk/pa/jt200607/jtselect/jtembryos/169/169.pdf, at paragraph 276. Concerns about state ‘collusion’ in parental deception were raised directly with the Working Party by The International Donor Offspring Alliance, who argued in response to the Working Party’s call for evidence that, while individuals are not bound by human rights conventions (which apply to the states which sign them), and that states cannot prevent people from circumventing legal requirements (for example, by going abroad for treatment), states do have a duty not to “collude” with parents who do not wish to disclose.

[114] House of Lords and House of Commons Joint Committee on Human Rights (2008) *Legislative scrutiny: fifteenth report of session 2007-08*, available at: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf, pp123-4 (citing the Department of Health’s response to a query from the Joint Committee on how they had responded to the Draft Bill Committee’s recommendation).

[115] House of Lords and House of Commons Joint Committee on Human Rights (2008) *Legislative scrutiny: fifteenth report of session 2007-08*, available at: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf, at paragraph 4.33.

2.27 At the time that the *Human Fertilisation and Embryology Bill* was being scrutinised by Parliament, the Department of Health took the view that it would not be appropriate to make retrospective changes with respect to information about donors, commenting:

> "Where the donor-conceived person was born before the 2004 Regulations prevented donors from donating anonymously (before 1 April 2005), they will only be able to obtain non-identifying information about their donor, unless the donor re-registers as identifiable. The Government considers that this position strikes a fair balance between the interests of the donor-conceived person and the donor. The Department considers that it is justifiable, in the interests of protecting the Article 8 rights of the donor, and public confidence in the regulatory system, not to force donors to become identifiable to people born as a consequence of their donation before donor identification became compulsory. The Department takes the view that this approach is fair in view of the fact that the donor would have provided the donation on the understanding that they would remain anonymous and disclosure of this information to a donor-conceived person without donor consent could have very detrimental effects on their family life or perhaps their psychological health. The legislation does not prevent a donor from re-registering as identifiable where they wish to. Where a donor chooses to take this step then people conceived as a result of their donation will be able to obtain identifying information about the donor. Whether or not the donor chooses to re-register, the donor-conceived person is able to obtain non-identifying information about the donor once they reach the age of 16."[116]

### Human rights arguments

2.28 As the summary above indicates, much of the discussion around possible further legislative change in this area is based on human rights arguments, in particular on the relevance of Article 8 of the European Convention on Human Rights which protects an individual's right to respect for their private and family life. We noted above (see paragraph 2.9) that the judge in the *Rose* case held that Article 8 was 'engaged' by the desire of donor-conceived people to have information (identifying or non-identifying) about their donor, but, given the policy announcement from the Department of Health that was pending at the time, made no finding as to whether or not a failure on the part of the state to provide that information would 'breach' Article 8. In determining in any case whether interference with an Article 8 right constitutes a 'breach', courts are required to consider whether the interference can be justified on the basis that it constitutes a 'proportionate' means of protecting the rights and freedoms of others.

2.29 While those advocating the recognition of a moral and ethical 'right to information' emphasise the significant part such information may potentially play in the private and family lives of some donor-conceived people, those resisting further legislative change point to the potential impact on others (for example on parents who feel threatened by mandatory disclosure, or past donors who donated on the clear understanding that they would remain anonymous), and to alternative more 'proportionate' ways forward involving the encouragement, rather than the imposition, of information sharing. The Government's current view on these human rights arguments – in brief that neither the European Convention nor other human rights treaties establish a clear right to information – is summarised in Box 2.1 below. There has been no further case-law on this point in the English courts since the *Rose* case, and no case in the European Court of Human Rights has considered the specific question of access by donor-conceived people to information about their donor.

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[116] House of Lords and House of Commons Joint Committee on Human Rights (2008) *Legislative scrutiny: fifteenth report of session 2007-08*, available at: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf, Appendix 9, pp115-6.

### Box 2.1: Government response to human rights arguments

During the scrutiny of the *Human Fertilisation and Embryology Bill* (which went on to become the 2008 Act) the Department of Health set out its position with respect to human rights arguments as follows:

> "The Government does not consider that Article 8, or any of the UK's other international human rights obligations, creates a right for donor-conceived people to know the identity of their biological parents. In the *Rose* case, Justice Scott Baker found that article 8 was engaged in relation to the claimants' case. He stated however that the fact that Article 8 is engaged is far from saying that there has been a breach of it. Whilst Justice Scott Baker found that donor-conceived people have a right to obtain information about their biological parent, he did not go as far as saying that they had a right to receive identifying information or that they should be able to obtain information at any given age. He recognised, as did the claimants in the Rose case, that the distinction between identifying and non-identifying information was likely to be very relevant when it came to the important balancing exercise of the other considerations in Article 8(2). The Government considers that the interests of the donor-conceived person's legal parents are engaged when considering whether to disclose information about a donor to a donor-conceived person, as are the donor's where the information is identifying. The Government considers that it has struck a fair balance between those competing interests."[117]

In a subsequent exchange of letters with the parliamentary Joint Committee on Human Rights[118] the Department of Health elaborated on the question of how the rights protected by Article 8 might apply in the case of donor conception:

> "While the High Court has decided that Article 8 of the Convention is engaged in relation to a donor-conceived person's right to know information about their biological parent(s), … disclosure of information, whether non-identifying or identifying, to a donor-conceived person about their donor would also engage the Article 8 rights of the person's legal parents, because it would reveal to the donor-conceived person that their parents received treatment services, and that one of them at least is not their biological parent. It would also engage the Article 8 rights of the donor if the information is identifying information. The Department has sought to strike a balance between those potentially competing rights."[119]

The Joint Committee on Human Rights concluded:

> "In our view the provisions in the Bill concerning access to donor information are unlikely to give rise to a significant risk of incompatibility with the Convention, either in terms of the right to private life (Article 8 ECHR) or the right to enjoy that right without discrimination (Article 14 ECHR)."[120]

## *Legal provisions regarding disclosure in other jurisdictions*

2.30 As we have noted earlier in this report, attitudes to information sharing in the context of donor conception vary significantly around the world, and indeed between communities within particular jurisdictions. These differences are demonstrated clearly by the very different approaches to regulation taken by countries that, in other respects, may seem to share many similarities. A number of European countries (Austria, Finland, the Netherlands, Norway, Sweden and Switzerland) have, like the UK, legislated to provide statutory access to both identifying and non-identifying information about donors for donor-conceived people, and have prohibited anonymous donation.[121] In the Netherlands, for example, donor-conceived people have a statutory right to request identifying information about their donor from the age of 16,

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[117] House of Lords and House of Commons Joint Committee on Human Rights (2008) *Legislative scrutiny: fifteenth report of session 2007-08*, available at: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf, Appendix 9, at page 116.

[118] A committee made up of members of both the House of Commons and House of Lords, responsible for scrutinising proposed legislation to ensure that it is compatible with the European Convention on Human Rights.

[119] House of Lords and House of Commons Joint Committee on Human Rights (2008) *Legislative scrutiny: fifteenth report of session 2007-08*, available at: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf, Appendix 9, at page 114.

[120] House of Lords and House of Commons Joint Committee on Human Rights (2008) *Legislative scrutiny: fifteenth report of session 2007-08*, available at: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf, at paragraph 4.14.

[121] See: Allan S (2011) *A cross-jurisdictional study of regulatory requirements and practice regarding the recording of donor information and its release to donor-conceived people* (Canberra: Winston Churchill Memorial Trust of Australia); Allan S (2012) Donor conception, secrecy and the search for information *Journal of Law & Medicine* **19(4)**: 631-50.

and non-identifying information from the age of 12; non-identifying information about the donor's physical characteristics and social background is available on request to parents of children under the age of 12. Medical information, by contrast, may only be provided to the donor-conceived person's GP.[122]

2.31 In Belgium, Bulgaria, the Czech Republic, Denmark, France, Greece, Portugal and Spain, by contrast, the anonymity of donors is protected by law, with exemptions in some countries, but not others, for known gamete donation.[123] In Belgium, for example, fertility professionals are required to make identifiable information about donors 'inaccessible' and all those working within the clinic are bound by professional secrecy. The exceptions to this rule cover information about the physical characteristics of the donor which may be shared by recipients when choosing a donor; medical information which may be shared with a GP at the donor-conceived person's request; and circumstances where donor and recipient mutually request non-anonymity (i.e. in known donation).[124] In France, a strict application of the requirement of anonymity means that those who bring their own donor may only be helped through a cross-donation programme in which donors are exchanged between recipient couples.[125] Some European countries prohibit or restrict donation: egg donation, for example, is prohibited in Austria (although, as noted above, identity-release sperm donation is permitted), Germany and Norway, while Italy does not permit any form of gamete donation and France only permits treatment for married couples.[126] A wide range of approaches to the acceptability of anonymous, identity-release, or indeed donation in any circumstances, is thus found within countries, many of which are subject to the same European Directives on the donation and use of tissues and cells,[127] and between whom there is sufficient professional consensus on other aspects of reproductive care for there to be shared professional guidelines.[128]

2.32 Outside Europe, there are similar disparities of legal approach between a number of 'Western' or 'Euro-American' jurisdictions (see paragraph 1.30). In both the USA and Canada, donors may choose whether they wish to donate on an anonymous or identity-release basis;[129] and a high profile court decision in British Columbia in the *Pratten* case, that would have outlawed anonymous donation within this Canadian province, has recently been overturned by the British Columbia Court of Appeal, thus restoring the status quo.[130] New Zealand, on the other hand, has, since 2005, required donors to be potentially identifiable once their donor offspring reach

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[122] Overheid (2004) *Wet donorgegevens kunstmatige bevruchting (The Artificial Insemination (Donor Information) Act)*, available at: http://wetten.overheid.nl/BWBR0013642/geldigheidsdatum_04-02-2013; Winter HB, Dondorp W, Ploem MC *et al*. (2012) *Evaluatie embryowet en wet donorgegevens kunstmatige bevruchting*, available at: http://www.zonmw.nl/uploads/tx_vipublicaties/embryowet-wdkb_webversie.pdf.

[123] Blyth E, and Frith L (2009) Donor-conceived people's access to genetic and biographical history: an analysis of provisions in different jurisdictions permitting disclosure of donor identity *International Journal of Law, Policy and the Family* **23(2)**: 174-91; Garcia-Ruiz Y, and Guerra-Diaz D (2012) Gamete and embryo donation: a legal view from Spain, in *Reproductive donation: practice, policy and bioethics*, Richards M, Pennings G, and Appleby J (Editors) (Cambridge: Cambridge University Press).

[124] Ejustice.just.fgov.be (2007) *Loi relative à la procréation médicalement assistée et à la destination des embryons surnuméraires et des gametes*, available at: http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&cn=2007070632&table_name=loi.

[125] Pennings G (2005) Gamete donation in a system of need-adjusted reciprocity *Human Reproduction* **20(11)**: 2990-3.

[126] Shenfield F, de Mouzon J, Pennings G *et al.* (2010) Cross border reproductive care in six European countries *Human Reproduction* **25(6)**: 1361-8; Van Hoof W, and Pennings G (2012) Extraterritorial laws for cross-border reproductive care: the issue of legal diversity *European Journal of Health Law* **19(2)**: 187-200.

[127] Eur-Lex (2004) *Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells*, available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32004L0023:EN:NOT.

[128] See, for example, Shenfield F, Pennings G, De Mouzon J *et al.* (2011) ESHRE's good practice guide for cross-border reproductive care for centers and practitioners *Human Reproduction* **26(7)**: 1625-7.

[129] Ethics Committee of the American Society for Reproductive Medicine (2013) Informing offspring of their conception by gamete or embryo donation: a committee opinion *Fertility and Sterility*: E-published ahead of print, 7 March 2013; Parliament of Canada (2006) *Reproductive technologies: surrogacy, and egg and sperm donation*, available at: http://www.parl.gc.ca/Content/LOP/researchpublications/prb0035-e.htm.

[130] See: BioNews (3 December 2012) *British Columbia Court of Appeal reverses decision on sperm donor anonymity*, available at: http://www.bionews.org.uk/page_221579.asp?dinfo=k4xM7kuEjsxuIJs3htzUEUTk&PPID=221859.

the age of 18,[131] with similar provisions enacted in a number of Australian states.[132] The Australian State of Victoria has gone further than any other jurisdiction in enacting legislation to promote, or indeed mandate, information sharing: in addition to ensuring that identifying information about donors is available on request to donor-conceived people when they reach the age of 18, donors, too, are entitled to request identifying information about their donor-conceived offspring, although the donor-conceived person's consent must be obtained before this information is provided. Since 2010, the legislation has also required that the fact of donor conception be included on an appendix to the birth certificate.[133] The Victorian Government is currently considering further proposals from the parliamentary Law Reform Committee, published in 2012, recommending that retrospective access to such identifying information should be given to all donor-conceived people.[134] In recognition of the concerns that some past donors might have about such information being provided, it is suggested that donors would be able to lodge 'contact vetoes', in response to individual requests for contact by a donor-conceived person, although they would not be permitted either to issue a pre-emptive veto applying to all potential applications, or to prevent the information itself being provided. They would, however, be able to indicate – in advance of any information being shared – their *preferences* regarding contact. The response of the Victorian Government to these proposals is still awaited.

## Support for people affected by donor conception

2.33 One common theme that emerged throughout the Working Party's factfinding meetings and in the responses to the call for evidence and online survey, was the need for greater support for people affected by donor conception: whether as donor-conceived people assimilating information about their conception or considering contacting those with whom they are biologically connected, parents considering whether, and how, to talk to their children about donor conception, prospective parents contemplating treatment with donor gametes, or donors and their own families. Below we summarise the support currently available in the UK: we note here, as elsewhere, that the support available via licensed clinics by its nature only applies to prospective parents who seek UK-licensed treatment, and that, for those seeking overseas treatment, the arrangements and requirements for pre-treatment support will inevitably differ from country to country.

2.34 With the exception of the support provided by clinics to prospective parents and donors at the point when they are considering treatment/donation, and information provided on the HFEA's website,[135] the primary sources of support for people affected by donor conception come from the voluntary sector, albeit, in some cases, with public funding. The main source of family support is the Donor Conception Network (DCN), established in 1993 by a number of families with donor-conceived children committed to openness within families about donor conception,[136]

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[131] Part 3 of the Human Assisted Reproductive Technology Act 2004, available at: http://www.legislation.govt.nz/act/public/2004/0092/latest/DLM319241.html?search=ts_act_human_resel&sr=1. However, the Government rejected a recommendation by the Law Commission to include reference to donor gametes on birth certificates: see Ministry of Justice, New Zealand (2006) *Government response to Law Commission report on new issues in legal parenthood March 2006*, available at: http://www.justice.govt.nz/publications/global-publications/g/government-response-to-law-commission-report-on-new-issues-in-legal-parenthood-march-2006/law-commissions-recommendations-and-government-response, at paragraphs 39-42.

[132] Allan S (2011) *A cross-jurisdictional study of regulatory requirements and practice regarding the recording of donor information and its release to donor-conceived people* (Canberra: Winston Churchill Memorial Trust of Australia).

[133] For further details of the Victorian system, see: Parliament of Victoria Law Reform Committee (2012) *Inquiry into access by donor-conceived people to information about donors: final report*, available at: http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/DCP_Final_Report.pdf.

[134] Parliament of Victoria Law Reform Committee (2012) *Inquiry into access by donor-conceived people to information about donors: final report*, available at: http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/DCP_Final_Report.pdf.

[135] See: Human Fertilisation and Embryology Authority (2012) *For donor-conceived people and their parents*, available at: http://www.hfea.gov.uk/23.html; Human Fertilisation and Embryology Authority (2013) *For donors*, available at: http://www.hfea.gov.uk/egg-and-sperm-donors.html.

[136] Donor Conception Network (2013) *Donor Conception Network homepage*, available at: http://www.dcnetwork.org.

while the National Gamete Donation Trust (NGDT) promotes donation and provides web-based information and informal support both for donors and for potential recipients of donor gametes.[137] The organisations COTS[138] and Surrogacy UK[139] fulfil a similar function with respect to those considering surrogacy arrangements either as an intended parent or surrogate, and specialist legal websites also provide extensive information about the legal implications of donor conception and surrogacy.[140] Since the beginning of 2013 the NGDT has been responsible, under a Department of Health contract, for running the voluntary register that provides support for pre-1991 donor-conceived people and donors seeking contact (see paragraphs 2.16 and 2.17). Peer support may also be found in a large number of internet-based groups, including those concerned more generally with fertility issues[141] and those established by donor-conceived adults both for networking/mutual support and for campaigning purposes.[142]

## Information provision

2.35 The HFEA *Code of practice* spells out in some detail the information that patients and donors should be offered before they are asked for their consent to proceed, and makes very clear that "the provision of information should be clearly distinguished from the offer of counselling".[143] 'Information' for prospective parents is used in this context to refer both to knowledge about the regulatory framework and requirements, and to the descriptive and biographical information provided by the donor. Thus prospective parents should be provided with the non-identifying information given by the donor, should be advised of the likelihood of a resulting child inheriting physical characteristics, and should receive an explanation of the screening tests that donors undergo, and of the limitations of such tests. On the 'regulatory' side, they should be advised of the legal provisions governing parenthood, and the legal entitlements of any resulting children with respect to access to information about their donor. They should also be advised that "it is best for any resulting child to be told about their origin early in childhood"; be encouraged to "be open with their children from an early age about how they were conceived"; and be given "information about how counselling may allow them to explore the implications of treatment, in particular how information may be shared with any resultant children".[144] Similar requirements covering information relating to the legal and practical implications of donation or surrogacy are set out in the *Code of practice* as a prerequisite before donation or surrogacy arrangements may proceed.[145]

2.36 As professionals working in fertility services highlighted to the Working Party in a factfinding meeting, prospective parents, donors and surrogates approach clinics with very differing degrees of initial knowledge: some may simply have skimmed the clinic's homepage before

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[137] National Gamete Donation Trust (2013) *National Gamete Donation Trust homepage*, available at: http://www.ngdt.co.uk/.

[138] Childlessness Overcome Through Surrogacy (COTS) (2011) *COTS homepage*, available at: http://www.surrogacy.org.uk/About_COTS.htm.

[139] Surrogacy UK (2013) *Surrogacy UK homepage*, available at: http://www.surrogacyuk.org/.

[140] See, for example, Natalie Gamble Associates (2013) *Natalie Gamble Associates homepage*, available at: http://www.nataliegambleassociates.com/ and Porter Dodson (2013) *Porter Dodson Fertility and Parenting Law homepage*, available at: http://www.porterdodsonfertility.com/.

[141] See, for example, Fertility Friends (2012) *Fertility Friends homepage*, available at: http://www.fertilityfriends.co.uk/; Infertility Network UK (2012) *Infertility Network UK homepage*, available at: http://www.infertilitynetworkuk.com/; Baby Centre (2013) *Getting pregnant: all you need to know about trying for a baby*, available at: http://www.babycentre.co.uk/getting-pregnant.

[142] International Donor Offspring Alliance (2013) *International Donor Offspring Alliance homepage*, available at: http://www.idoalliance.org/; Yahoo! Groups (2013) *People conceived via donor insemination (PCVAI)*, available at: http://groups.yahoo.com/group/pcvai/. See also: paragraphs 4.25 to 4.28 for details about the work of the US-based DSR, an organisation which provides a forum for donor-conceived people to search for their donor and/or any donor-conceived siblings.

[143] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 4.1. Section 13(6) of the Human Fertilisation and Embryology Act 1990, as amended, requires women (or couples where they are being treated together) to be "provided with such relevant information as is proper" before treatment services are provided.

[144] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraphs 20.1-8.

[145] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraphs 11.30-7 and 14.1-3.

making the first appointment, while others may have undertaken detailed research.[146] In addition to informing themselves through the various web-based resources described above (see paragraph 2.34), prospective parents and donors may also have obtained more extensive information through support groups: the DCN, for example, facilitates two-day *Preparing for DC parenthood* workshops for prospective parents, providing the opportunity for those considering treatment with donor gametes to obtain extensive information.[147] Recognising the significant variation in the amount of information prospective parents or potential donors might need, the distinction drawn by the HFEA between 'information' and 'counselling' was strongly supported by professionals attending the Working Party's factfinding meeting: while counselling sessions might be one means of ensuring that the information legally required before treatment could proceed had been provided,[148] it was argued that counselling sessions were also crucial in providing the time and space to explore the implications of that information for a person's particular situation, and to work through any existing fears and concerns. We return to the question of the role of counselling in more detail below (see paragraph 2.39).

2.37 The emphasis of clinics and the HFEA's *Code of practice* relates naturally to the information required for prospective parents and potential donors and surrogates to make their initial decisions regarding treatment or donation. However, there is also a need for information further down the line, as parents think through whether and, if so how, they should approach talking to their children about the way they were conceived; donors similarly think about whether or how to tell their partner (particularly in a new relationship) about their past donation; or donors consider whether or how to share information with their own children about the existence of donor-conceived siblings. The DCN provides a number of support services for families encouraging openness: these include *Telling and talking* workshops for parents of children aged 0-7,[149] *Telling and talking* leaflets for parents of children of different ages, and *My story* and *Our story* children's books to support talking to very young children.[150] The DCN is currently also developing materials aimed at older children.[151] It was clear from responses to the Working Party's call for evidence that these materials are highly valued by parents who have decided to tell their children that they are donor-conceived, but who do not necessarily find it easy (see also paragraph 4.11).

2.38 Donor-conceived people, parents and donors may of course also choose to make use of both public and private web-based forums, and these may provide opportunities to share information and seek advice from others in a similar situation. The DCN's annual meetings, and the networking opportunities offered through membership of the Donor Conceived Register (formerly UKDL) for people born before 1991, provide further such opportunities for mutual support, especially for those who have, in the past, felt isolated as a donor-conceived person.[152]

## *Counselling before treatment or donation*

2.39 'Counselling', as described by the British Association of Counselling & Psychotherapy (BACP), is an umbrella term for a range of 'talking therapies' where trained practitioners "work with people over a short or long term to help them bring about effective change or enhance their

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[146] Factfinding session with professionals involved at the time of donation, 22 June 2012.

[147] See: Donor Conception Network (2013) *Preparing for DC parenthood*, available at: http://www.dcnetwork.org/workshop/preparation.

[148] See, for example, the detailed advice on information provision set out in British Infertility Counselling Association (2012) *Guidelines for good practice in infertility counselling: third edition* (York: BICA Publications).

[149] See: Donor Conception Network (2013) *Telling and talking workshops*, available at: http://www.dcnetwork.org/workshop/telling-talking and Crawshaw M, and Montuschi O (2013) Participants' views of attending parenthood preparation workshops for those contemplating donor conception parenthood *Journal of Reproductive and Infant Psychology* **31(1)**: 58-71 for more detail about these workshops.

[150] See: http://www.dcnetwork.org/catalog/books-and-pdfs for details of DCN publications.

[151] For more information, see: Montuschi O (25 November 2012) *DCN works towards another world first*, available at: http://oliviasview.wordpress.com/2012/11/25/dcn-works-towards-another-world-first/.

[152] Factfinding meeting with Rachel Pepa, 24 April 2012, and with people with personal experience of donation, 27 April 2012.

well-being".[153] It has traditionally been viewed primarily as a service that people only use when they cannot find ways of helping themselves. However, it can also be seen as a way of promoting and maintaining well-being, and of finding out more information about a complex issue in a protected and supportive environment. This latter approach is supported by the HFEA *Code of practice* which emphasises that the availability of counselling in assisted reproduction clinics, for both prospective parents and for those contemplating donation or acting as a surrogate mother, should be understood and presented to patients as a 'routine' part of clinic practice.[154] Professionals participating in a factfinding meeting with the Working Party similarly emphasised the important role they considered counselling can play in supporting those contemplating donation or treatment with donor gametes (see paragraph 2.36). It is a legal requirement that any woman, and where applicable her partner, considering IVF or any treatment using donated gametes or embryos, must first be given "a suitable opportunity to receive proper counselling about the implications of her being provided with treatment services of that kind, and have been provided with such relevant information as is proper".[155] The same requirement applies to those considering donating gametes or embryos for the treatment of others, and to those considering acting as surrogates.

2.40 Counselling provided in the context of treatment or donation at an HFEA-licensed clinic is often described as 'implications counselling', because of this legal requirement. However, counselling in the context of donor conception may encompass considerably more than the consideration of the implications of treatment or donation. The British Infertility Counselling Association (BICA) describes infertility counselling as offering prospective parents "an opportunity to explore their thoughts, feelings, beliefs and their relationships in order to reach a better understanding of the meaning and implications of any choice of action they may make; counselling may also offer support to them as they undergo treatment and may help them to accommodate feelings about the outcome of any treatment."[156] Thus, the aim of counselling for prospective parents in the context of donor conception is not solely to provide an opportunity for them to think through the implications of various courses of action with the support of an informed professional, but also, where necessary, to provide therapeutic support in handling the difficult emotions that infertility may generate. Those who consider treatment with donated gametes for reasons other than medical infertility, including single women, same-sex couples and those seeking to avoid passing on a serious genetic condition, may have different support needs, as will those contemplating 'egg-share' arrangements.[157]

2.41 Counsellors working in HFEA-licensed centres are required to be accredited members, or working towards accredited membership, of their professional body (BICA) or be able to demonstrate equivalent, accredited specialist training and experience, and to abide by the BICA *Guidelines for good practice in infertility counselling* and the HFEA *Code of practice*. Within these requirements there is considerable flexibility, allowing the counsellor to work according to their own philosophy. The BICA guidelines emphasise that while "counselling can increase a client's ability to make choices and change aspects of their situation… [it] does not involve giving advice or directing a client to take a particular course of action."[158] Counselling in licensed clinics should thus be predominantly 'client-centred' with a focus on the well-being and needs of the individuals engaging with the counsellor. An important aspect of counselling sessions is their confidentiality: the BICA guidelines emphasise the importance of maintaining client consent and

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[153] British Association for Counselling and Psychotherapy (2012) *BACP homepage*, available at: http://www.bacp.co.uk/.

[154] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 3.2.

[155] Section 13(6) of the HFEA Act 1990, as amended.

[156] British Infertility Counselling Association (2013) *About BICA*, available at: http://www.bica.net/about-bica.

[157] See: British Infertility Counselling Association (2004) *Implications counselling for people considering donor-assisted conception: BICA practice guides* (York: BICA Publications) and British Infertility Counselling Association (2012) *Counselling and surrogacy in licensed clinics in the UK: BICA practice guides* (York: BICA Publications) for further material for this section and below. Note also that donors may have complex reasons for donating.

[158] British Infertility Counselling Association (2012) *Guidelines for good practice in infertility counselling: third edition* (York: BICA Publications), at paragraph 1.1.

confidentiality and of respecting "client self-determination, dignity and privacy".[159] They also highlight that the provision of counselling should be kept quite distinct from any 'assessment' of prospective patients undertaken by the clinic in connection with the legal requirement to take account of the welfare of any future child before providing treatment: 'counselling' sessions may not be used for this purpose.[160]

2.42 Prospective heterosexual parents who have already spent time trying to conceive naturally, and who have undergone fertility investigations and – in some cases – treatments, may find it difficult to engage with what is termed 'preparation for parenthood': their fears around never having a baby are likely to outweigh concerns they may have about the reality of parenting a donor-conceived child. One of the aims of counselling in such cases is to provide a forum in which they can express their feelings without fear of criticism or judgment, and to allow an exploration of the possibility of creating a different family and future from the one they had originally envisaged for themselves. Counsellors may also find that some prospective parents referred for counselling present initially with mental health issues, such as depression associated with infertility, shock and trauma at diagnosis, multiple loss (past, current and anticipated), and grief.[161] Considerable time may be needed to work through issues relating to prospective parents' inability to have a child who is genetically related to both of them. Prospective parents in this position may benefit from exploring these feelings before considering the ways in which the complicated issues associated with donor conception treatments may affect their future and that of any child conceived.[162]

2.43 While the circumstances bringing prospective parents to counselling at this point may thus vary significantly, the BICA guidelines to counsellors provide a helpful summary of the main issues that are likely to be covered in counselling sessions. These suggest that counselling sessions may explore factors such as:

- "[the clients'] feelings about the medical diagnosis and cause of infertility
- their initial reactions to the option of using donation and/or surrogacy and changes to attitudes and feelings over time
- their acceptance, emotional preparedness and expectations of parenthood through donation and/or surrogacy
- the implications of differences and similarities between their feelings and those of their partner (if they have one) to the option of donation and/or surrogacy
- the personal implications of donation and/or surrogacy for them in the short and longer term including cultural issues
- the impact on their wider family and social relationships
- their attitudes to and preparation for sharing biographical and genetic origins information with children conceived by donation and/or surrogacy

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[159] British Infertility Counselling Association (2012) *Guidelines for good practice in infertility counselling: third edition* (York: BICA Publications), at paragraph 2.2.

[160] British Infertility Counselling Association (2012) *Guidelines for good practice in infertility counselling: third edition* (York: BICA Publications), at paragraph 5.2. BICA emphasises that counsellors need to make their own independent decisions about whether or not to undertake 'welfare of the child' assessments, and that if they do so, they should make very clear to patients that, in this case, they are acting on behalf of the clinic and not as a counsellor. The clinic should also have an arrangement to ensure that prospective parents may access counselling support from a different counsellor.

[161] Domar AD, Broome A, Zuttermeister P, Seibel M, and Friedman R (1992) The prevalence and predictability of depression in infertile women *Fertility and Sterility* **58(6)**: 1158-63; Monach J (2006) Stresses and distresses *Therapy Today* **17(8)**: 24.

[162] BICA (2004) *Implications counselling for people considering donor-assisted conception: BICA practice guides* (York: BICA Publications), pp13-5; Pike S, and Grieve K (2006) Counselling perspectives on the landscape of infertility *Therapy Today* **17(8)**: 28-32; Hammarberg K, Carmichael M, Tinney L, and Mulder A (2008) Gamete donors' and recipients' evaluation of donor counselling: a prospective longitudinal cohort study *Australian and New Zealand Journal of Obstetrics and Gynaecology* **48(6)**: 601-6. See also: Hakim LZ, Newton CR, MacLean-Brine D, and Feyles V (2012) Evaluation of preparatory psychosocial counselling for medically assisted reproduction *Human Reproduction* **27(7)**: 2058-66, where it was found that a high proportion of both men and women participating in counselling before assisted reproduction treatment (in this case with their own gametes) found the sessions 'important' and 'helpful'.

- their attitudes to, and preparedness for, sharing with their children that they might have half or full siblings being raised in another family
- the welfare of children and families in relation to the manner and timing of sharing information on genetic origins
- the implications for parents and donor-conceived children of the current use and potential development of genetic testing."[163]

2.44 Similarly, the BICA guidelines suggest that the purpose of counselling in relation to donors, those donating through 'sharing' arrangements (see paragraph 1.5) and surrogates is to encourage the person or couple to reflect upon and understand:

- "their reasons for wanting to provide gametes or embryos or act as surrogates
- their attitudes and possible feelings towards any resulting children
- the implications for any current or future partner they may have
- the implications for themselves and their own family where it is likely or anticipated that they will maintain contact with the recipients or intended parents as the child(ren) grow up
- the needs of resultant children for full biographical information and the importance of providing such information on the HFEA Register form, in a sensitive manner, including the optional sections on 'goodwill message' and 'pen picture'
- the needs of such children when they reach adulthood and the possibility of future contact
- the importance to their own existing or future children of information about the donation or surrogacy and these children's potential needs
- the importance of sharing information wherever possible with their own parents and wider family
- the implications with embryo donation of resulting children being full genetic siblings to their own children
- the possibility that treatment will fail or that pregnancy-related difficulties will arise".[164]

2.45 As noted above (see paragraph 2.39), the Human Fertilisation and Embryology Act makes it compulsory for clinics to provide a 'suitable opportunity' for counselling before providing treatment involving donated gametes or embryos or enabling a person to donate. It does not, however, *require* clinics to provide such counselling in all cases, or prospective parents or donors to take it up: the obligation is to enable those who wish to take advantage of it to do so. The HFEA *Code of practice* states that, where the question of treatment with donated gametes or embryos arises, clinics "should allow people enough time to consider the implications of using donated gametes or embryos, and to receive counselling before giving consent".[165] It further requires that "if a person who has previously donated gametes or embryos, or received treatment, requests further counselling at any point, the centre should take all practicable steps to help them obtain it".[166]

2.46 Professionals involved in donation who contributed to the Working Party's factfinding meetings and call for evidence illustrated the different ways in which these requirements have been interpreted.[167] A number of clinics, for example, include counselling appointments routinely among a standard series of initial appointments for prospective parents and donors. As a result, participation in the session is effectively mandatory, although not described as such, and rarely if ever queried by participants. Other clinics presented the opportunity for counselling as a

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[163] British Infertility Counselling Association (2012) *Guidelines for good practice in infertility counselling: third edition* (York: BICA Publications), at paragraph 6.6. The list should not be seen either as exhaustive or as compulsory given the inevitable differences in clients' circumstances.

[164] British Infertility Counselling Association (2012) *Guidelines for good practice in infertility counselling: third edition* (York: BICA Publications), at paragraph 6.7.

[165] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 20.9.

[166] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 3.5.

[167] Factfinding meeting with professionals involved at the time of donation, 22 June 2012; Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

choice for some groups but not for others: one clinic, for example, told us that they required known donors to attend counselling appointments, both on their own, and together with the prospective parents, but did not have a similar requirement for unknown donors. An informal survey carried out in 2011 among BICA members found that 92 per cent of the 27 clinics who responded made counselling mandatory for known or identity-release egg donors, 94 per cent made counselling mandatory for egg-share donors, and in most cases partners also attended sessions.[168] However, similar figures for sperm donors are not available, and anecdotally it seems that these are much more variable. The Working Party was also told that clinics vary considerably in the number of counselling sessions that they are willing to include within the overall treatment fee, hence potentially affecting accessibility for those with more complex or longer-term support needs. A further informal survey carried out in January 2013 among BICA members found that nine of the 15 clinics responding offered unlimited access to counselling for prospective parents, while the remaining six offered between one and three sessions free, with fees charged for additional sessions. NHS and private clinics were represented in both groups. Few clinics had calculated specific costings for counselling sessions: one NHS clinic had, however, added £7.50 to all treatment package costs to cover the costs of providing unrestricted access to counselling (based on estimated take-up of 25%), while a counsellor in a private clinic had made a similar calculation (based on 15% take-up) and proposed adding £12.75 to the fees for all treatment packages.[169]

### *Support and counselling in connection with information disclosure to a donor-conceived person*

2.47 When a donor-conceived adult applies to the HFEA's Register for information (whether identifying or non-identifying) about their donor, there is a statutory requirement that "the applicant has been given a suitable opportunity to receive proper counselling about the implications of compliance with the request" before the HFEA complies.[170] The HFEA "strongly recommends" that donor-conceived people wishing to access the Register seek counselling or similar support services before making a formal application,"[171] and told us that it has "taken steps to encourage the sector to provide adequate provision of appropriate counselling to donor-conceived applicants".[172] At the time of writing, all applications to the Register by donor-conceived individuals have been for *non*-identifying information, since identifying information will only be statutorily available from 2024 when the first of those born as a result of treatment after the 2005 legislative changes reach the age of 18. While identifying information may potentially be provided before 2024, in cases where a donor 're-registers' as identifiable and their donor-conceived offspring subsequently requests identifying information, no such approaches to the HFEA's Register have yet been made.[173]

2.48 Although the HFEA's website provides some general information and guidance for donor-conceived people contemplating contact with their donor,[174] and provides links to the websites of BACP[175] and BICA,[176] it would not be straightforward for a donor-conceived person to identify

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[168] Sheila Pike, personal communication, 31 July 2012 (survey conducted to inform a session on pre- and post donation counselling for egg donors at 'The Psychology and Counselling Special Interest Group pre-congress course on third party reproduction', ESHRE annual meeting (2011) Stockholm).

[169] Sheila Pike, personal communication, 21 January 2013.

[170] Section 31ZA3(b) of the HFE Act 1990, as amended.

[171] Human Fertilisation and Embryology Authority, responding to the Working Party's call for evidence.

[172] Human Fertilisation and Embryology Authority, responding to the Working Party's call for evidence. This included hosting a meeting in June 2009, in the context of the HFEA's *Opening the Register* policy, with relevant people in the counselling professions, to explore ways in which they could provide appropriate counselling to donor-conceived applicants: HFEA (Juliet Tizzard), personal communication, 18 January 2013.

[173] At the time of writing, 116 previously anonymous donors had re-registered with the HFEA as identifiable, but no requests for information about these donors had been made, and hence no donor-conceived person has been provided with identifiying information: HFEA (Juliet Tizzard), personal communication, 18 January 2013.

[174] Human Fertilisation and Embryology Authority (2012) *Get support & advice*, available at: http://www.hfea.gov.uk/114.html.

[175] British Association for Counselling and Psychotherapy (2013) *BACP homepage*, available at: http://www.bacp.co.uk/.

[176] British Infertility Counselling Association (2013) *BICA homepage*, available at: http://www.bica.net/.

a specialist counsellor via this route: the therapist listings on BACP's website do not include specific reference to donor conception (unlike, for example, adoption or relationships counselling, both of which are listed), while BICA's focus is primarily on counselling in connection with fertility issues (that is with prospective donors and parents, including those who decide not to pursue treatment), rather than with donor-conceived adults. Although BICA published a report in 2003 recommending the establishment of specialist counselling services to support those approaching the HFEA Register,[177] the only specialist service currently providing support in relation to contact between donor-conceived people, donors and donor-conceived siblings is that provided through the voluntary register for pre-1991 donor-conceived people and donors, now known as the Donor Conceived Register (see paragraphs 2.16 and 2.17). The professionals involved in providing that service up to 2012 emphasised to the Working Party the difference between such 'intermediary' work, in which the professional works with both parties contemplating contact, and 'counselling' understood as therapeutic support for an individual: while some individuals contemplating contact may additionally seek counselling support, the main focus of the support provided around the voluntary register is intermediary work.[178]

## *Contacting siblings*

2.49 The 2008 amendments to the HFE Act also made it possible for the HFEA to establish the Donor Sibling Link (DSL), a service to help adult donor-conceived siblings contact each other if they wish to do so.[179] People who are over the age of 18 and were conceived after 1 August 1991 are entitled to sign up to the DSL in order to share and receive contact details of donor-conceived siblings who have also signed up. The HFEA website recommends that potential registrants first approach the HFEA Register to establish if they have any donor-conceived siblings, and "strongly recommends" that potential registrants receive counselling or similar support before joining. Questions that the HFEA prompts people to consider at this stage include:

- Are you ready to potentially meet any donor-conceived genetic siblings?
- What if there is a lot more or a lot less information available than you expect?
- Do you want to initiate contact or are you happy for others to contact you?
- Would you be disappointed if none of your siblings joined the DSL? Many donor-conceived people may be unaware of their origins, may not know about the register, or simply may not be interested in meeting other donor-conceived genetic siblings.
- What if you contact your donor-conceived genetic siblings and they don't respond?

2.50 At the time of writing, 24 donor-conceived adults had registered with the DSL, and no matches had been made.[180] These numbers are much lower than those of UK-based registrants with the US-based DSR (see paragraph 4.25): however, the DSL differs from the DSR in that membership is limited to donor-conceived adults and is hence not open to the parents of younger donor-conceived children.

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[177] BICA (2003) *Opening the record: planning the provision of counselling to people applying for information from the HFEA register* (Sheffield: BICA Publications).

[178] Factfinding meeting with practitioners/researchers, 30 May 2012.

[179] Human Fertilisation and Embryology Authority (2010) *Donor Sibling Link*, available at: http://www.hfea.gov.uk/donor-sibling-link.html.

[180] HFEA (Juliet Tizzard), personal communication, 18 January 2013.

# Chapter 3

## Medical information and family history

# Chapter 3 – Medical information and family history

## Chapter 3: overview

- Family histories of particular conditions are often presumed to be much more predictive than they really are. It is important that all health professionals, in their routine practice, regularly question the basis for seeking information about a person's family history, and only do so where this will be genuinely useful for the person's care.
- Lack of information about the medical history of the donor is a source of much concern among donor-conceived people and their parents. However, in most cases, such information would be of little medical relevance for the donor-conceived person because of the screening and assessment that potential donors undergo before being accepted as donors, and because of the low predictive value of much family history information. If a donor does not have an inherited condition him or herself, then there will only be very rare situations where a family history of a condition will be medically significant to the donor-conceived person.
- Potential donors will be excluded from donating altogether if their personal or family medical history could pose significant health risks to future offspring. Details of the major conditions that have been 'screened out' in this way before a donor is allowed to donate should be provided to prospective parents in an easily accessible and comprehensible format, thus providing substantial reassurance that their child will have a low risk of inheriting a serious genetic condition from their donor. A clear explanation should also be provided that the donor has no known family history of any other condition that would pose a serious risk to the health of any resulting person. Some parents of donor-conceived children may interpret 'no information' about the donor's family history as resulting from a lack of willingness to share information, rather than as reassurance that there is no relevant information to provide. Clear communication on this point is essential.
- The situation may, however, occasionally arise where factors in the donor's own medical history or family history are insufficient to exclude the donor from donating, but may be of future relevance to the health care of the donor-conceived person. Disclosure of such information to prospective parents should be encouraged and facilitated. Given the developing nature of knowledge in this area, however, parents should not place undue weight on such information, as information that is believed to be potentially relevant at the time of donation may later prove not to be so.
- A sound evidence base underpinning what information should be sought from donors in their clinic assessment is essential, so that donor-conceived people and their parents may be confident that information that may indeed be clinically relevant for the donor-conceived person's health care will be collected before donation and passed on appropriately. It is not useful to collect and share information about the health of the donor or their family that is unlikely to have any effect on the donor-conceived person's health or health care.
- Circumstances may arise where significant information only comes to light after donation. In such cases, it is beneficial both for donors and donor-conceived people for there to be a clear and easily accessible mechanism through which such information may readily be communicated.

## Introduction

3.1 One particular concern that arises repeatedly in connection with access to information about the donor by donor-conceived people and their parents relates to the potential relevance of medical information about the donor for the future health and health care of the donor-conceived person.[181] The Working Party concluded from the evidence available to it that the value of such information in the context of licensed treatment is in fact widely overestimated, and that only in rare cases will a lack of personal or family medical history about a donor make any significant difference to the health or health care of the donor-conceived person. However, given the degree of concern that the question of access to medical information clearly generates, the Working Party found it helpful to set out its findings on this issue in a separate chapter. For some people, it may also be the case that an interest in knowing about the medical history of

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[181] See, for example, Hershberger PE (2007) Pregnant, donor oocyte recipient women describe their lived experience of establishing the "family lexicon" *Journal of Obstetric, Gynecologic, & Neonatal Nursing* **36(2)**: 161-7; Cushing AL (2010) "I just want more information about who I am": the search experience of sperm-donor offspring, searching for information about their donors and genetic heritage *Information Research* **15(2)**: 1; Ravitsky V (2012) Conceived and deceived: the medical interests of donor-conceived individuals *Hastings Center Report* **42(1)**: 17-22. See also: Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

their donor constitutes part of their more general interest in 'knowing about' their donor in a biographical sense, rather than because of concerns about the impact on their own health, and we discuss the interests of donor-conceived people and others in obtaining such 'narrative' information about donors in the next chapter. In this chapter, we focus more narrowly on issues relating to the clinical relevance of personal or family medical information from the donor for donor-conceived people: that is, on circumstances in which a failure to provide information about the family history of the donor might be detrimental to a person's health or health care.

3.2 Concerns raised by donor-conceived people and their parents about their lack of access to such medical information fall into two broad categories, as illustrated in Box 3.1 below. The first area of concern relates to general requests for information about a person's family history. Anyone who comes in contact with health services will be asked at some point for details of their 'family history', and both parents and donor-conceived people themselves report how difficult they find it to respond to such questions, when they feel they know nothing about one part of that 'family history'. We discuss below (see paragraphs 3.7 and 3.23) why such questions may be asked, and the potential relevance of the donor assessment and screening progress in responding to them. A separate set of concerns, however, arise in the context of the possibility of donor-conceived people inheriting rare but significant conditions from their donor: in such cases, the donor-conceived person could potentially be at a medical disadvantage compared with a person who has full genetic links with both their parents, as they will be unable to benefit from the earlier diagnosis and treatment that might be available to those who are aware of a significant diagnosis in their immediate family.[182] This latter category of concern may also arise in reverse: it is possible that information about a genetic condition diagnosed in a donor-conceived person may also be relevant for the future health care of their donor, his or her family, and any donor-conceived siblings. Donors are, of course, tested far more thoroughly than a person who has a child through a natural conception (see paragraph 3.11). Despite this, however, examples of donor-conceived people inheriting major genetic conditions from their donor still occur (and indeed, as we note later, screening must always have its limitations), and this issue was raised repeatedly with the Working Party as a major source of concern for donor-conceived people.[183]

3.3 For donor-conceived people, anxieties about conditions or dispositions to disease that they may have inherited from their donor can clearly only emerge if and when they find out that they are donor-conceived. Separate issues arise for donor-conceived people who do *not* know that they are donor-conceived, in that they may provide information to doctors about their non-genetic parent's medical history: at best this will be irrelevant, and at worst may be harmful by, for example, leading to unnecessary investigations. False reassurance deriving from a non-genetic parent's medical history may potentially also lead to a lost opportunity of an earlier diagnosis. Such issues similarly arise for those who are in this position for other reasons (such as misattributed paternity – see paragraph 1.26 – or who do not know that they are adopted): the potential disadvantage relates not to the fact of donor conception itself, but rather to an incorrect belief about genetic connection with a social parent.

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[182] We note here that this is distinct from questions of the 'right not to know', in the sense of a person choosing not to be tested for a particular serious genetic condition because they prefer not to obtain that information. Donor-conceived people are not in a position to exercise such a 'right not to know' if they have no means of knowing about the diagnosis in the donor.

[183] Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering. See also: Daily Mail (7 March 2012) *'I didn't want children to die': a mother's mission to save sperm donor's 35 kids never told about his fatal, genetic illness*, available at: http://www.dailymail.co.uk/news/article-2111623/Sperm-Donors-35-Kids-Never-Told-About-Fatal-Genetic-Illness.html; New York Times (14 May 2012) *In choosing a sperm donor, a roll of the genetic dice*, available at: http://www.nytimes.com/2012/05/15/health/in-sperm-banks-a-matrix-of-untested-genetic-diseases.html?_r=1&pagewanted=all.

### Box 3.1: Concerns raised about lack of medical information about the donor

**Concerns about lack of 'family history' information in general health care**
"[I]n 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." – *Respondent to Working Party's online questionnaire*

"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 sight problems I can't answer 50% of the info." – *Respondent to Working Party's online questionnaire*

"[Information which] gives some information about medical conditions that either develop or might develop (such as allergy, eczema, asthma etc)." – *Respondent to Working Party's online questionnaire*

"The greatest impact would be regarding lack of medical background. We can only answer for my half of the family, and I think there is a risk that 'unknown' for a condition might be interpreted as 'not present' at a critical moment." – *Andrea Powell, responding to the Working Party's call for evidence*

(See paragraph 3.23 below for a discussion of the extent to which such information, if available, would affect a person's health care)

**Concerns about inheriting a serious genetic condition from the donor**
"In another recent case, a sperm donor did not notify the three sperm banks through which he helped conceive 24 offspring that he had been diagnosed with a genetic heart defect. The mother of one of these children looked for information about the donor, discovered his identity, and subsequently learned about his medical condition. Following these discoveries, her son's asymptomatic aortic aneurysm – which could have ruptured at any moment – was also diagnosed, and surgery was performed that probably saved his life."[184]

"I know several instances of this – two severely autistic children, twins with an inherited skin condition, Narelle Grech, who has been very active in the Australian Donor Conception Support Group and might have had her genetically linked bowel cancer diagnosed earlier than Stage 4, had she known to seek screening." – *anonymous respondent to the Working Party's call for evidence*

"I'd also like continued health updates on diseases/conditions that developed later in life that may be hereditary." – *Respondent to Working Party's online questionnaire*

**Inappropriate care arising out of belief that non-genetic parent was genetically-related**
"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 DC [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*

## Background on genetic information and family history

3.4 Inherited medical conditions may be associated with a mutation in a single gene ('single gene' or 'Mendelian' conditions), or with a complex combination of genetic mutations or variations in many genes and environmental factors ('multifactorial' conditions). Both types of conditions may become apparent at different stages in life.

3.5 There are thousands of different single gene conditions, and while most of them are individually rare, collectively they are significant.[185] Such single gene conditions may be recessive (a person will only develop the condition if they inherit the particular gene mutation from both parents) or dominant (the condition will manifest itself in a person if they inherit the particular gene mutation from either parent).[186] Identifying the presence of a particular gene mutation within a genetic family allows for accurate testing of relatives to see whether or not they have inherited the condition. Knowledge of the particular familial mutation reduces the risk of 'false negative' results in unaffected relatives because it allows clinicians to test specifically for that mutation.

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[184] Ravitsky V (2012) Conceived and deceived: the medical interests of donor-conceived individuals *Hastings Center Report* **42(1)**: 17-22. See also: ABC News (21 July 2011) *Sperm donor's 24 kids never told about fatal illness*, available at: http://abcnews.go.com/Health/sperm-donors-24-children-told-fatal-illness-medical/story?id=14115344.

[185] Approximately one in 17 people will be affected by a rare condition, although not all these are single gene conditions: see Rare Disease UK (2013) *Rare Disease UK homepage*, available at: http://www.raredisease.org.uk/.

[186] 'X-linked' conditions, where the condition is due to a mutation on the X chromosome, can have different manifestations in males (who have just one X chromosome) from those in females (who have two).

Although accurate genetic testing is currently available only for a small proportion of the many single gene conditions, the risk that an individual with no family history of a particular condition, and no signs or symptoms of it, will transmit a strongly heritable condition to their offspring is usually extremely low.

3.6 Many common conditions such as cancer and heart disease are 'multifactorial' diseases: that is they result from the interaction of several different genetic variations with several different environmental factors. Only if certain groups of variants and factors are present in a particular combination will the condition eventuate (a comparison might be a highly complex fruit machine). Each variation and each factor alone may have only a small, if any, effect, and hence it may not be particularly helpful to identify one or some of the variations (such as a particular gene mutation) in an individual, especially as the environment in which they happen to exist will also be influential. The pre-birth environment in the womb, amongst others, is likely to affect how certain genes are switched 'on' or 'off' so that the same gene mutation may be 'silent' in one person, but result in clinical effects in another.[187] In one family a particular mutation (for example of a gene influencing electrical impulses in the heart) may confer a high probability of sudden cardiac death; in others it might be present in many family members without any clinical effects. Using a mutation as a predictor of a condition depends on knowing what the other components of the 'fruit machine' are, and in most common diseases this is still unknown.

3.7 There is thus a spectrum of 'genetic' conditions: from dominant or recessive single gene conditions (such as cystic fibrosis, haemophilia and Huntington's disease) where the presence of a particular mutation has high predictive value, to multifactorial conditions (such as many forms of heart disease, cancer and diabetes), where the presence of any one gene mutation or variation will have only low predictive value. In between these two poles are a number of subgroups of common conditions such as certain cancers or types of heart disease, where a single gene mutation confers a considerable risk, but additional risk factors are necessary before the effects of this gene mutation are seen. In this case, the number of factors that need to coincide (as in the 'fruit machine' metaphor above) is lower, and hence the presence of a particular mutation may have moderate predictive value. For example a 'BRCA 1 or 2' gene mutation will tell a woman she has a 60-80 per cent chance of developing breast cancer (as opposed to ten per cent in the general population). However, it is not yet known why 20-40 per cent of those with the mutation do *not* develop cancer. Although there have now been several decades of successful research discovering links between DNA variations and particular diseases, their individual predictive powers in the clinical setting will remain low until the particular combination of risk factors for that disease has been discovered. Often the predictive value of such gene associations is still less than that from taking a detailed medical family history. One of the reasons why patients are routinely asked about their family history of conditions such as heart disease and cancer is thus with the aim of identifying people who may fall into one of these higher-risk groups, rather than because *any* history of heart disease or cancer in the family will necessarily affect decisions about the patient's care.

3.8 While the study of the human genome has become much faster and cheaper (the 'thousand dollar genome')[188], clinical interpretation still lags behind. Genetic testing in the clinical setting is changing from one where only certain genes, based on particular signs and symptoms or on family history, are tested, to one where the whole genome is tested to look for *any* abnormality. These new genomic technologies are highly effective at obtaining much more data at a much lower cost than previously possible. However, not enough is yet known about the functions or interactions of many genes to interpret the data that come from such testing: for example in analysing what is a normal variation (such as those causing differences in hair or eye colour) and what variation increases the chance of disease; or how important any particular variant may

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[187] See, for example, Bird A (2007) Perceptions of epigenetics *Nature* **447(7143)**: 396-8.

[188] The Telegraph (10 January 2012) *Entire DNA sequence now available for less than £700*, available at: http://www.telegraph.co.uk/science/science-news/9004186/Entire-DNA-sequence-now-available-for-less-than-700.html.

be in predicting anything about that condition. The move from targeted testing to whole genome testing not only means that the clinical significance of the results are often harder or impossible to determine, but can also raise ethically difficult decisions if unexpected or 'incidental' findings about, for example, future cancer risks, are found.[189]

3.9 It is a common assumption that more genetic screening of donors would provide more information for donor-conceived offspring and their families. However, the rarity of individual single gene conditions combined with the multifactorial nature of most common conditions as described above, means that the predictive value of such screening, in the absence of particular symptoms or family history in the donor, is likely to be low. Most early-onset strongly heritable conditions can be excluded in a donor if he or she is well at the time of donation and has no close family with a history of the condition. Later-onset conditions may be more difficult to exclude, but the absence of a family history in previous generations will nevertheless be of significant reassurance.

3.10 Many common diseases may also be present in more than one family member, simply because they *are* common. To say something 'runs in the family' is not the same as saying that it is a genetic condition, or that a relative has a high chance of also developing the condition. Families may share environmental risk factors: for example, a family of heavy smokers may find that lung cancer 'runs' in the family.

## Law and guidance on medical screening and selection of donors

3.11 Potential donors are required to undergo detailed medical screening before they are accepted by clinics. The primary rationale for such screening is the provision of good quality care to the prospective parents, coupled with the responsibility of fertility professionals to take into account the welfare of the future child (see paragraphs 5.57 to 5.62). In this context, good quality care includes avoiding the use of gametes that might increase the chance of an inherited condition in the donor-conceived child, even if that chance is small. Obviously, excluding *all* conceivable risks would not be reasonably possible without undermining the practice of donor conception, as no suitable donors would then be left. The fact that donors are screened in a way that those seeking reproductive help with their own gametes are not,[190] can be justified on the basis that donors are in a quite different position from prospective parents. Helping people have a child with their own gametes implies accepting the risks that may be inherent in their combined genetic material: although, in cases of a known familial risk of transmitting a serious genetic condition, prospective parents may be informed of prenatal or preimplantation genetic testing options, it would not be regarded as acceptable to advise them to look for a different partner. By contrast, donors are, in principle, replaceable. Donors may also be excluded if there is concern about the effect of donating on their own health, for example concern about the risk of OHSS (ovarian hyper stimulation syndrome) in egg donors.

3.12 The HFEA *Code of practice* sets out a number of legally binding 'licence conditions' with respect to testing potential donors for infectious diseases.[191] All donors must be negative for HIV,

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[189] See: Joint Committee on Medical Genetics (2011) *Consent and confidentiality in clinical genetic practice: guidance on genetic testing and sharing genetic information - a report of the Joint Committee on Medical Genetics*, available at: http://www.bshg.org.uk/consent_and_confidentiality_2011.pdf; PHG Foundation (2012) *Whole genome sequencing in health services*, available at: http://www.phgfoundation.org/pages/wholegenome.htm.

[190] Note, however, that as part of the requirement for clinics to take account of the welfare of a future child before providing any assisted conception treatment, clincs are required to consider factors that may cause a risk of significant harm to the child, including circumstances that are likely to lead to prospective parents being unable to care for a child throughout their childhood. Examples cited of where such circumstances could arise include a medical condition in the parent, or a family medical history indicating that "any child who may be born is likely to suffer from a serious medical condition": Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 8.10.

[191] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, Chapter 11. See also: Commission of the European Communities (2006) *Commission Directive 1006/17/EC (the EU Tissue and Cells Directive)*, available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2006:038:0040:0052:EN:PDF, at Annex III; Advisory Committee on the Safety of Blood, Tissues and Organs (2011) *Guidance on the microbiological safety of human organs, tissues and cells*

hepatitis B and C, syphilis and (for sperm donors) chlamydia. In addition, the *Code of practice* notes that additional testing may be required, depending on donor's geographical area of origin or their own medical history.[192] These additional tests primarily relate to further infectious diseases, such as the Human T Cell lymphotrophic viruses (HTLV) or malaria. Donor sperm must ordinarily be quarantined for a minimum of 180 days, after which repeat testing is routinely required.[193]

3.13 Apart from these mandatory tests, the *Code of practice* requires clinics to consider the suitability of the prospective donor, with particular attention paid to their personal or family history of heritable conditions and their personal history of transmissible infection; and specifies that "donors of gametes and embryos should be screened in accordance with current professional guidance produced by the relevant professional bodies" (see paragraph 3.14).[194] Finally, the *Code of practice* highlights the legal requirement that donors must not be chosen precisely because they *have* a particular genetic or chromosomal abnormality, even if this abnormality exists in the prospective parents.[195]

3.14 Professional guidance on the assessment and screening of (sperm) donors dates back at least to 1979, where information on artificial insemination provided by the Royal College of Obstetricians and Gynaecologists for prospective parents explained that donors are "carefully selected" and are required to be "fit and healthy and on questioning to have given no family history of hereditary disease."[196] The "current professional guidance" referred to in the latest *Code of practice* was produced in 2008 by the Association of Biomedical Andrologists in partnership with the Association of Clinical Embryologists, British Andrology Society, British Fertility Society, and Royal College of Obstetricians and Gynaecologists.[197] These guidelines require clinics to undertake a detailed clinical assessment of potential donors, through face-to-face interviews, as well as through reference to medical records as necessary. They note that "this assessment should consider the age of the potential donor, as well as relevant medical and surgical history, reproductive and sexual history, genetic history, family genetic history and the risk of transmissible disease including blood-borne viral infections and spongiform encephalopathies. It should also include a physical examination."[198] All donors should also have their blood group and rhesus status recorded for matching purposes where required.

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*used in transplantation*, available at: http://www.bts.org.uk/Documents/Publications/Guidance%20on%20the%20microbiological%20safety%20of%20human%20organs,%20tissues%20and%20cells%20used%20in%20transplantation.pdf, pp12-5.

[192] For example, HTLV-1 antibody testing must be performed for donors living in or originating from high incidence areas (or whose partners or parents originate from those areas); and testing for RhD, malaria and T. cruzi may be required depending on the donor's history and the characteristics of the gametes being donated.

[193] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, Chapter 11, licence condition T53c. If the blood donation sample is additionally tested by the nucleic acid amplification technique (NAT) for HIV, HBV and HCV, quarantining of the gametes and re-testing of a repeat blood sample is not, however, required.

[194] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraphs 11.14 and 11.21.

[195] HFE Act 1990, Schedule 3, as amended, T55. This might arise, for example, in the case of deaf prospective parents preferring a deaf child.

[196] Royal College of Obstetricians and Gynaecologists (1979) *Artificial insemination* (London: Royal College of Obstetricians and Gynaecologists). More detailed guidance was subsequently issued, including reference to the requirements for laboratory screening for a number of sexually transmitted diseases: Royal College of Obstetricians and Gynaecologists (1992) *Recommendations for centres using donor semen and those planning to set up a donor insemination service* (London: Royal College of Obstetricians and Gynaecologists).

[197] Association of Biomedical Andrologists, Association of Clinical Embryologists, British Andrology Society, British Fertility Society, and Royal College of Obstetricians and Gynaecologists (2008) UK guidelines for the medical and laboratory screening of sperm, egg and embryo donors (2008) *Human Fertility* **11(4)**: 201-10.

[198] Association of Biomedical Andrologists, Association of Clinical Embryologists, British Andrology Society, British Fertility Society, and Royal College of Obstetricians and Gynaecologists (2008) UK guidelines for the medical and laboratory screening of sperm, egg and embryo donors (2008) *Human Fertility* **11(4)**: 201-10, at 202. In addition to the infectious diseases singled out in the *Code of practice*, these guidelines further state that the donor should screen negative for gonorrhoea, and should be screened for the cytomegalovirus (CMV). CMV negative donors are stated to be preferable, although CMV IgG positive (IgM negative) donors may be used for CMV IgG positive recipients.

3.15 With respect to heritable conditions, the guidelines state that potential donors should not have a "significant heritable condition: this being defined as one that has a major adverse effect on lifestyle or life prognosis". Enquiries should be made to establish that the donor has not been diagnosed with:

- "familial disease with a major genetic component" (cited examples include cleft lip or palate, congenital heart malformation and neural tube defects);
- "any significant Mendelian disorders" (such as haemophilia, haemoglobin disorders, or tuberous sclerosis);
- "familial disease with a known or reliably indicated major genetic component" (cited examples include juvenile diabetes mellitus or rheumatoid arthritis); or
- "a chromosomal rearrangement that may result in unbalanced gametes"; that is, a chromosomal rearrangement that, while it might carry no health consequences for the donor, could result in any offspring having an imbalance of their chromosomes with associated and significant health or developmental problems.

3.16 The guidance further requires that enquiries should be made regarding the potential donor's family history (to include their genetic parents, siblings and offspring), in order to make sure that these members of the potential donor's family are free of:

- any of the familial diseases with a major genetic component cited above;
- "non-trivial disorders showing Mendelian inheritance" that are autosomal dominant (such as Huntington's disease), X-linked (such as haemophilia), or autosomal recessive, particularly if there is a high frequency in the relevant population (such as cystic fibrosis in Northern European populations);
- a chromosomal abnormality;
- a history of mitochondrial disorders (egg and embryo donors only).

If there is evidence of any of the above, the potential donor should be offered a referral to a clinical genetic service who can arrange relevant testing.

3.17 All donors should further be subject to laboratory screening for chromosomal abnormalities ('karyotyping'), and should screen negatively for relevant autosomal recessive conditions depending on their family's geographical area of origin:

- $\alpha^0$- and β-thalassaemia (Mediterranean, Middle East, Indian subcontinent);
- sickle-cell anaemia (African and Afro-Caribbean);
- Tay-Sachs disease (Jewish of Eastern European descent);
- cystic fibrosis (Northern European).

3.18 In order to facilitate future monitoring and surveillance, the guidance recommends that, as a matter of best practice, serum and/or DNA from all donors should be stored "in order to facilitate the future provision of genetic information to the donor-conceived in the event that advances in technology meant that information about late onset genetic diseases became available after the time of donation". Recruitment centres should "have mechanisms in place to manage any information they may generate", and should closely monitor all donor pregnancies so that any birth abnormality may be "carefully documented and discussed with a clinical geneticist so that the risk to other donor-conceived siblings and the donor's own children (if applicable) can be assessed". The decision to inform a donor or parents about any new genetic information "should be a matter of clinical judgement".

3.19 The requirements of the *Code of practice* and current professional practice described above apply to gamete donors who donate through UK-licensed clinics. Prospective parents who travel abroad for treatment cannot assume that the screening and assessment regime will be exactly the same in other countries, although broadly similar professional guidance is likely to be in place.[199] The position is rather different where prospective parents obtain sperm informally from known donors or through 'dating-agency' type websites, without involving a licensed clinic. While the donor may be willing to provide detailed information about his personal and family medical history, no medical screening will take place (unless separately arranged) and recipients will not have the additional reassurance of knowing that the sperm has been quarantined for 180 days (see paragraph 3.12 above).

## Access to medical information by donor-conceived people and parents

3.20 The 'donor information form' requires the clinic to list "any screening tests other than HFEA mandatory tests carried out for this donor", and also includes space to "list any physical illness or disability, history of mental illness or learning difficulties" and "any known medical conditions within the donor's biological family".[200] The guidance accompanying the form more specifically states that "any known relevant medical conditions within the donor's biological family background" should be included, but does not indicate how 'relevance' is to be determined.[201]

3.21 Parents of donor-conceived children now have access to the donor information form completed by the donor and clinic; indeed 'prospective parents' considering the possibility of treatment with donor gametes are similarly able to access the information contained in the form (see paragraphs 2.11 and 2.12). The information that parents, and subsequently donor-conceived people themselves, will be able to access in future is thus determined first by the level of information sought by the doctor undertaking the health assessment of the donor, and secondly by the level of information transferred on to the form, or conveyed to parents in other ways (for example through a clear explanation of what has been excluded through the screening process). It should, however, be noted that the policy on sharing information included on the donor information form, and indeed the design of the form itself, has evolved considerably in recent years, and hence parents of older donor-conceived children may have less medical information about their child's donor than that encouraged through the current policy. Donor-conceived people who have already reached adulthood may have potential access to little, if any, information.

3.22 Clinicians with expertise in genetic medicine who contributed to a factfinding meeting on the medical significance of information about a person's donor were of the view that the tests donors currently undergo, and the information sought from them, were "extensive", and that this screening should identify most potential donors with any form of serious disease, genetic or otherwise. As a result, parents should be reassured that in the vast majority of cases the risk that their children would inherit a significant condition from their donor would be very low.[202] It was felt to be very important that this information should be clearly conveyed to parents, perhaps in the form of a letter explaining that their child's donor was assessed for a range of serious heritable conditions (and that these conditions had hence specifically been 'screened out'), that they could keep and refer to in the future. The HFEA *Code of practice* currently emphasises that clinics should "give people seeking treatment with donated gametes or embryos information about genetic and other screening of people providing gametes" including "details about the sensitivity and suitability" of the tests used and "information that explains the

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[199] See, for example, the ASRM guidance in the US: The Practice Committee of the American Society for Reproductive Medicine and the Practice Committee of the Society for Assisted Reproductive Technology (2012) *Recommendations for gamete and embryo donation: a committee opinion*, available at: http://www.asrm.org/uploadedFiles/ASRM_Content/News_and_Publications/Practice_Guidelines/Guidelines_and_Minimum_Standards/2008_Guidelines_for_gamete%281%29.pdf. See also the requirements of the EU Tissues and Cells Directive that apply to all member states of the European Union.

[200] Human Fertilisation and Embryology Authority (2010) *Donor information form*, available at: http://www.hfea.gov.uk/docs/HFEA_Form_Donor.pdf.

[201] Human Fertilisation and Embryology Authority (2012) *HFEA donor information form (v2012): completion guidance notes*, available at: http://www.hfea.gov.uk/docs/HFEA_form_guidance_-_Donor_Info_Form.pdf.

[202] Factfinding meeting on the medical significance of information about the donor, 2 October 2012.

limitations of testing procedures".[203] However, it would appear from the very widely-expressed concerns about lack of medical information that the reassurance that such information should provide is not being clearly communicated.

3.23 Given the assurance that should be provided by the level of screening currently carried out, it was suggested in the factfinding meeting that in most cases, a desire for more information would be related to anxiety rather than because such information would, in practice, have a significant medical impact. As described above, the multifactorial nature of most familial conditions is such that knowledge about the possibility of increased risk for one particular factor associated with a condition has little direct relevance for the health care of the individual, while inherited conditions where gene mutations have greater predictive weight (as in some forms of cancer and heart disease described above) should have been identified, and hence excluded, by a competently-taken family history at the time of the donor assessment (see paragraph 3.7). In many cases answers to the question "Is there a family history of…?" asked of donor-conceived people or their parents (examples of which are set out in Box 3.1 above) would not, in fact, significantly affect the health care they are likely to receive. Indeed, it was noted as a general point that health professionals needed to challenge their own practice, and to consider before asking the question about family history whether or not the answer would in fact make any difference to the subsequent care provided.

3.24 Thus in most cases, the fact that a donor has been carefully screened and assessed, coupled with the very low predictive value of much family history information[204] will mean that there is no 'relevant' information (other than the fact of their having been screened for numerous conditions) to include on the donor information form for the future use of parents and donor-conceived people. Occasionally, however, there may be circumstances where particular medical information about a donor *could* potentially influence health care decisions in a significant way for future offspring, even though that information would not be regarded as sufficiently serious to justify excluding the donor from donating in the first place. The clinicians contributing to the Working Party's factfinding meeting on these issues highlighted the importance of a clear evidence base to underpin decisions that particular medical information about a donor might in the future be relevant to offspring's health care, and recognised, too, that such an evidence base would continue to evolve. It was agreed that where there *is* a clear evidence base that information about a particular condition might be relevant for a donor-conceived person's future care (while being insufficiently serious to exclude the donor from donating in the first place), then such information should be sought and documented in the original pre-donation screening so that it is available for the future for parents and offspring. Given the extent of pre-donation screening and the low predictive value of much family history information, however, those present at the meeting were not able to identify specific circumstances when this might arise.

3.25 Given that the medical information routinely available to parents, and subsequently to donor-conceived people themselves (including the reassurance that there is no significant information to impart), is based on the clinical assessment and screening of the donor undertaken by the clinic, participants in the factfinding meeting emphasised the importance of the *form* of this assessment: the face-to-face interview recommended in the current guidance was thought to be essential, and it was suggested that the history taken should cover three generations of the donor's family, in line with the standard approach of clinical genetic services. It would clearly be important that those undertaking such assessments were encouraged to liaise as necessary with clinical genetic services to help assess the significance of particular family histories.

3.26 The situation may also arise where significant information only becomes available after donation: particularly in the context of the donor developing a late onset strongly heritable condition (see paragraph 3.9 above). It is clearly important that in such cases there is a clear

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[203] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraphs 20.3-4.

[204] See, for example, National Institutes of Health (2009) *NIH state-of-the-science conference statement on family history and improving health*, available at: http://consensus.nih.gov/2009/Fhx%20images/familyhistory_final_stmt.pdf.

route of communication from the donor to the donor-conceived person and/or their parents, as envisaged by the current professional guidance (see paragraph 3.18 above).[205] Similar issues will arise where the donor-conceived person is diagnosed with a serious inherited condition, where this information may potentially be of relevance to the donor, their family, and any other donor-conceived siblings.[206] Examples were cited in the factfinding meeting, where methods had, in practice, been found for communicating this information, via the fertility clinic, as recommended in the HFEA *Code of practice*.[207] However, it was felt to be very important that the system by which this should be done should be as clear and straightforward as possible, and well-publicised to prospective parents and donors, to maximise the likelihood of it being used in the rare cases where it might be necessary. In the case of informal sperm donation outside the clinic setting, donors and donor-conceived people will clearly be reliant on any existing information channels to share such information, as contact will not be possible either via a clinic or the HFEA.

3.27 As we noted at the start of this chapter, rather different issues related to medical history arise for donor-conceived people who do not know that they are donor-conceived: in particular, if asked for information about their 'family history', they will inevitably provide doctors with incorrect information relating to the parent with whom they have no biological link. In many cases such misinformation will not significantly affect their own health care: however in some it may potentially lead either to false reassurance about the person's own risk of developing a particular condition (although this should not be overstated given the assurance provided by screening), or to the person undergoing unnecessary tests or preventive measures because of an identified 'risk factor' that in fact is irrelevant (see example in Box 3.1 above). This latter concern becomes particularly pertinent in circumstances where parents chose to conceive using donor gametes precisely in order to avoid the risk of transmitting a serious genetic condition. Exceptionally, cases may arise where it becomes absolutely crucial for the donor-conceived person to learn information about risk factors that they may have inherited from their donor (as where a serious treatable late-onset strongly heritable condition is diagnosed in the donor), and in such cases the clinicians participating in the meeting felt strongly that a means must be found for ensuring that the information reaches the person concerned, regardless of their parents' earlier decisions regarding non-disclosure. We return to this point in Chapter 6.

## Conclusions on access to medical information

3.28 The primary focus of the pre-donation clinical assessment and screening of potential donors is to ensure that those who might pose a significant health risk to potential recipients or resulting children are 'screened out'. The Working Party supports the current threshold for such screening, on the basis that donors, unlike natural conception parents, are 'replaceable', and that it is justifiable to set a minimum health threshold with respect both to infectious diseases

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[205] See, for example, Callum P, Messiaen LM, Bower PV *et al.* (2012) Gonosomal mosaicism for an NF1 deletion in a sperm donor: evidence of the need for coordinated, long-term communication of health information among relevant parties *Human Reproduction* **27(4)**: 1223-6. See also: BioNews (1 August 2011) *Sperm donor had 24 kids and a fatal genetic mutation*, available at: http://www.bionews.org.uk/page_102689.asp?hlight=cardiomyopathy; Hansen A (2012) Danish sperm donor passed neurofibromatosis on to five children *BMJ* **345**: e6570. If the condition is one that will not manifest in childhood, the child would not usually be offered testing until theIf the condition is one that will not manifest in childhood, the child would not usually be offered testing until they were older. See: The British Society for Human Genetics (2010) *Report on the genetic testing of children 2010*, available at: http://www.bshg.org.uk/GTOC_Booklet_Final_new.pdf, although it will still be important for the information to be communicated to parents, so that they are aware of the future implications. If a mechanism *is* in place to inform the parents, this will put the parents in the same position of knowledge as they would have been if the diagnosis had been made in a biologically-connected member of the social family. They can then make their own choices on how to respond to that information.

[206] See, for example, Ravitsky V (2012) Conceived and deceived: the medical interests of donor-conceived individuals *Hastings Center Report* **42(1)**: 17-22, which notes that in 2006, "a sperm donor passed a rare and dangerous genetic condition – severe congenital neutropenia – to five children born to four couples. The sperm bank could not contact the donor and warn him not to make additional donations because contact with him had been lost."

[207] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraphs 11.27-9. One way in which such requests are handled is via 'The Genethics Club': www.genethicsclub.org.

and serious strongly heritable conditions when helping create families through the use of donated gametes. We note here, however, that such screening should *not* be confused with proactive recruitment of donors with particular characteristics. Moreover, regular review of the guidance on screening will inevitably be required, as knowledge about the clinical implications of particular genetic mutations and variations develops.

3.29 The current level of screening, and the assurance provided thereby that there is no known family history of serious genetic disease, is likely in most cases to mean that there will be no further medical information about the donor or the donor's family that is relevant to the health of any resulting donor-conceived person. It is clearly important that information about the screening tests undertaken, and an explanation that the donor's family history contains no known serious genetic conditions, should be provided to the parents in an easily accessible and comprehensible format. This should provide substantial reassurance of a 'negative family history' for donor-conceived people, although it should also be noted that it is never possible to exclude all risks (see paragraphs 3.9 and 3.22).

3.30 On occasion, in the process of undertaking the donor assessment, information about the health or family history of the donor may be obtained that is likely to be of value in future decisions regarding the donor-conceived person's health care, while not constituting sufficient reason for excluding the donor. Such information should be regarded as 'relevant' medical information, and included on the donor information form as currently advised (see paragraph 3.20). However, much clearer guidance, supported by a clear evidence base, is required as to what constitutes such 'relevant' information, a point to which we return in Chapter 6 (see paragraphs 6.47 and 6.48). It is not helpful to include information about the personal or family medical history of the donor that is highly unlikely to affect the health or health care of any resulting donor-conceived people.

3.31 Circumstances may arise where significant information only comes to light after donation, and it is important that a clear and easily accessible mechanism is established to ensure that such information may be communicated, both from donor to the donor-conceived person, and vice-versa. Particular difficulties may arise where the person does not know that they are donor-conceived, and we return to this point in Chapter 6.

# Chapter 4

## Knowledge of donor conception and access to donor information: the evidence

# Chapter 4 – Knowledge of donor conception and access to donor information: the evidence

### Chapter 4: overview

- The evidence on the experiences of donor-conceived people, parents, and donors with respect to the sharing of information about donor conception is patchy, and some things (such as the views of those who do not know they are donor-conceived) cannot be known. Almost all of what is known about the views and experiences of donor-conceived adolescents and adults relates to those conceived as a result of sperm donation, and hence very little is known about those conceived through egg or embryo donation.
- Until recently, parents were advised not to tell their children that they were donor-conceived, and most parents followed this advice. The number of parents who do share this information with their children is increasing, with the latest figures suggesting that over three quarters of parents intend to tell their child about their means of conception, although intentions to tell do not inevitably lead to actual disclosure. Solo mothers and same-sex couples are more likely to tell their children about their means of conception than heterosexual couples.
- Longitudinal studies of systematic samples of families indicate that both 'disclosing' and 'non-disclosing' families function well up to early adolescence. Little is known about the functioning of families in later adolescence and adulthood.
- Children who learn that they are donor-conceived when they are very young appear to assimilate this information without difficulty. However, some adults who found out later in life, or inadvertently through disclosure from a third party, that they were conceived through sperm donation have reacted negatively. It is unknown how often inadvertent or unplanned disclosure occurs.
- Some donor-conceived people are interested in obtaining information (both non-identifying and identifying) about their donor: reasons include finding out what kind of person the donor was and their motivation for donating; identifying features or characteristics in common; and accessing medical information. Such information may help some donor-conceived people integrate their donor into their existing life story. The evidence in this area is currently limited to those conceived through sperm donation.
- Studies of people on the US-based Donor Sibling Registry (DSR), conceived as a result of sperm donation, show that some donor-conceived people (and also some parents of younger children) have high levels of interest in contacting both their donor and any donor-conceived siblings. It is not known, however, what proportion of donor-conceived people who are aware of their origins join the DSR. Whilst most people who search for their donor do not wish to form a 'parental' relationship with their donor, some do wish to form a 'fraternal' relationship with their donor siblings.
- Parents who do tell their children about their means of conception rarely appear to regret this decision. While some non-disclosing parents have described finding 'secrecy' within the family to be a burden, the majority of non-disclosing parents do not appear to regret their decision.
- Despite concerns that the regulatory change in 2005, requiring future donors to be potentially identifiable to their adult offspring, would prevent donors coming forward, clinics with an active donor recruitment programme appear to be successful in finding sufficient donors.
- The experience to date of contact between sperm donors and donor-conceived people through voluntary contact registers is reported to be positive. Such contact also has a potential impact on donors' own families.

4.1 This chapter summarises the evidence regarding the impact of disclosure, or non-disclosure, of information in the context of donor conception, drawing on the academic research literature, material submitted in response to the Working Party's call for evidence, and information presented in the Working Party's factfinding meetings (see Appendix 2). We note here that the research literature currently available presents only a partial picture, and there is much that is not known: some qualitative studies are based on small samples such as members of support groups whose experiences and views may not generalise to those who do not join such groups; most studies provide 'snapshots' in time and hence may reflect experiences influenced by past attitudes and cultures; almost all studies of donor-conceived adults relate to those conceived via sperm donation rather than egg or embryo donation; some studies rely on reporting from third parties, such as parents reporting on their children; some people affected by donor conception are less likely to participate in research than others; there are no longitudinal studies of the impact of donation on donors and their own families;[208] and so forth. Where appropriate, this report highlights where further research would be beneficial in adding to our understanding of this area. However, it is inevitably the case that we cannot have any data relating to the views of one group of those affected by donor conception, namely donor-conceived people who do not know they are donor-conceived, and hence a 'full picture' of the impact of non-disclosure cannot be achieved.

4.2 In coming to our conclusions, we have taken these limitations into account, noting also that the valuable personal insights provided to the Working Party by those contributing to its consultative exercises similarly do not constitute 'representative research', but rather served to alert the Working Party to a wide range of perspectives and experiences. Below, we first look at what is known about how many people know they are donor-conceived, and the factors affecting their parents' decision to disclose or not. We then look at the evidence on the impact of these disclosure decisions on donor-conceived people themselves, on family functioning, on parents, and on donors. As Chapter 3 has already discussed the question of the significance of medical information about the donor for the health and health care of donor-conceived people, this aspect of information will not be covered further in this chapter, although we note that, for some, information about aspects of their donor's health may be of interest in the same way as other forms of biographical information, even where it has little or no predictive value for their own health.

### Box 4.1: Views from donor-conceived people

"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." – *Donor-conceived adult, cited in a response to the Working Party's call for evidence by the Donor Sibling Registry.*

"Donor-conceived people may think about their conception very rarely: like most people, they do not constantly think about how they were conceived." – *Donor-conceived adult, taking part in a factfinding meeting with the Working Party*

"The joy I felt upon learning my identity reminds me of the intense relief which ensues when an illness or pain finally passes." – *Donor-conceived adult, cited in a response to the Working Party's call for evidence from The International Donor Offspring Alliance*

"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 Working Party's online questionnaire*

"People have a fundamental need to make sense of their lives in terms of story: from grand religious and national narratives to highly personal, family-based anecdotes, we establish our connection with the past, the present and the future by seeing ourselves and those connected with us as a part of a continuing story."[209]

"The background to all this is one key question. Don't I feel something is *missing*? And my answer is – why would I?… What is it about biology that is supposed to give meaning to our lives? What about me that's a meaningful part of who I am could be a direct product of my sperm donor?"[210]

"Donor-conceived children should be given as much information as possible about their donor, assuming they are interested in having said information… Most of the time, the information these children are seeking is benign, for example, 'My second toe is longer than my big toe, and my mom's aren't. Did I get that from my donor?' Why should children *not* be able to have answers to these questions?" – *Respondent to Working Party's online questionnaire*

"When I was growing up I thought that I was the only child on the planet conceived in such a way. Whereas we are all much more aware nowadays children need to meet others who share their experiences. It is important for a sense of identity; not to feel different from their friends and their wider family" – *Donor-conceived adult contributing in writing to a*

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[208] With the exception of a longtidudinal study on surrogate mothers: see Jadva V, Blake L, Casey P, and Golombok S (2012) Surrogacy families 10 years on: relationship with the surrogate, decisions over disclosure and children's understanding of their surrogacy origins *Human Reproduction* **27(10)**: 3008-14.

[209] International Donor Offspring Alliance (2008) *International Donor Offspring Alliance Human Fertilisation and Embryology Bill birth certificates: the case for reform - briefing for members of the House of Commons*, available at: http://web.jaguarpaw.co.uk/~tom/idoa-briefing-latest.pdf, at page 5.

[210] Daily Life (4 April 2012) *The so-called 'missing piece'*, available at: http://www.dailylife.com.au/health-and-fitness/dl-wellbeing/the-socalled-missing-piece-20120403-1w9rf.html.

*factfinding meeting*

### Box 4.2: Views from parents

"I think this [information a donor-conceived person needs] 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 Working Party's online questionnaire*

"A woman I met told her children when they were ten and 14. She had wished to for a long time, but her husband was very afraid of rejection by the children. I gather that when they were told, it was not received well by the older child who has had a difficult time adjusting to the idea. In the husband's mind, this has confirmed that they should never have told them." – *Respondent to the Working Party's call for evidence*

"Our daughter is donor sperm conceived, and she has known since she was around four (doesn't remember not knowing). She is very comfortable in her own skin, happy and unfazed by/about her origins, and has a good relationship with her father." – *Respondent to the Working Party's call for evidence*

"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 the child." – *Respondent to the Working Party's online questionnaire*

"It would be abhorrent to me that anyone but the parents make the decision to tell the child and when and how to do so. As much as I strongly believe that the child has a right to know, I am also strongly against any outside interference in what I believe is a private family matter." – *Respondent to the Working Party's online questionnaire*

"I have several friends who have made contact with their children's half siblings. The experience varies according to the age of the child, but I know of no negative outcomes, except where the other family has withdrawn, causing confusion and regret." – *Respondent to the Working Party's call for evidence*

"When the facts are too uncomfortable, be it for blame or shame, they can become like the proverbial elephant in the middle of the room: everyone is aware of something important, some members know the details, but the rest just know it is unmentionable, and the effect is underlying anxiety." – *Respondent to the Working Party's call for evidence*

"We have always talked about him [donor] as being kind, to have donated sperm so that I [recipient] could have a child. As we drive around, he sometimes says to me: 'that person could be my father, or that one, or that one.'" – *Respondent to the Working Party's call for evidence*

### Box 4.3: Views from donors

"Once a donation has been made, any resulting successful pregnancy becomes part of the woman or couple it has been donated to, and therefore… donors shouldn't want any information as the child is not theirs." – *Respondent to the Working Party's online questionnaire*

"It is so important to let donors know that there has been a positive outcome to their donation, and that a baby has been born thanks to their selfless act." – *Respondent to the Working Party's online questionnaire*

"As an egg donor, I can't imagine anything worse than having gone through an IVF cycle in good faith that the couple I was helping would raise their child to the best of their ability, only to be contacted by a donor-conceived person who is displeased at having been lied to." – *Respondent to the Working Party's online questionnaire*

"… I have mentally cleared a space in my future for about 15 to 20 years' time onwards, should any of these [donor-conceived] people want to come and say hello." – *Respondent to the Working Party's call for evidence*

"As a 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 the Working Party's online questionnaire*

"I think there ought to be a safe way to share more information between donors and recipients. It can help to know about a child's personality if you know about their parents." – *Respondent to the Working Party's online questionnaire*

"I think they [donors] should be notified by the parents of their plan of action, like if they plan to tell their child or not." – *Respondent to the Working Party's online questionnaire*

"My wife seems to feel threatened by it and hit the roof when she found out I had told our kids about their half-brothers/sisters… I think subconsciously she has concerns that family resources would be diverted to these children."[211]

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[211] 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(3)**: 638-45.

## Disclosure decisions: overview

### *How many people know they are donor-conceived?*

4.3 Until recently, parents tended not to tell their children they were donor-conceived. In a study of four systematic samples of children born in the late 1980s through donor insemination in Spain, Italy, the Netherlands and the UK, none of the 111 parents who participated had disclosed the donor insemination to their child by early school age;[212] less than ten per cent of parents had done so by early adolescence;[213] and a follow up of the UK sample showed that no further children had been told by age 18.[214] A similar pattern was found for egg donation families[215] and for families created through embryo donation.[216] Investigations in the US produced comparable findings.[217] In Sweden, where legislation giving donor offspring the right to obtain information about the donor's identity came into force in 1985, levels of disclosure were still low more than a decade later.[218]

4.4 In recent years there has been a significant rise in the number of parents who intend to tell their children about their donor conception, with the most recent figures (again from Sweden) showing that 78 per cent of parents of children conceived through sperm or egg donation intend to tell their child.[219] Intentions to tell, however, do not inevitably translate into actual disclosure. In a longitudinal study of children born in the UK in 2000 as a result of sperm or egg donation, for example, only around half of those who said when their child was age one that they intended to disclose, had in fact done so by the time their child was seven.[220] Moreover, some of the parents who reported that they had 'disclosed' to their children had discussed the use of fertility treatment but not the use of donated eggs or sperm.[221] Similar partial disclosure arises in surrogacy: children may be told about the surrogacy arrangement, but not about the use of a donor egg.[222] However, the Working Party was also told of the reverse experience of the Donor

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[212] Golombok S, Brewaeys A, Cook R *et al.* (1996) The European study of assisted reproduction families: family functioning and child development *Human Reproduction* **11(10)**: 2324-31.

[213] Golombok S, Brewaeys A, Giavazzi MT *et al.* (2002) The European study of assisted reproduction families: the transition to adolescence *Human Reproduction* **17(3)**: 830-40.

[214] Owen L, and Golombok S (2009) Families created by assisted reproduction: parent-child relationships in late adolescence *Journal of Adolescence* **32(4)**: 835-48.

[215] Murray C, and Golombok S (2003) To tell or not to tell: the decision-making process of egg-donation parents *Human Fertility* **6(2)**: 89-95; Murray C, MacCallum F, and Golombok S (2006) Egg donation parents and their children: follow-up at age 12 years *Fertility and Sterility* **85(3)**: 610-8.

[216] MacCallum F, and Golombok S (2007) Embryo donation families: mothers' decisions regarding disclosure of donor conception *Human Reproduction* **22(11)**: 2888-95; MacCallum F, and Keeley S (2008) Embryo donation families: a follow-up in middle childhood *Journal of Family Psychology* **22(6)**: 799-808; MacCallum F, and Keeley S (2012) Disclosure patterns of embryo donation mothers compared with adoption and IVF *Reproductive BioMedicine Online* **24(7)**: 745-8.

[217] Nachtigall RD, Becker G, Quiroga SS, and Tschann JM (1998) The disclosure decision: concerns and issues of parents of children conceived through donor insemination *American Journal of Obstetrics and Gynecology* **178(6)**: 1165-70.

[218] Lindblad F, Gottlieb C, and Lalos O (2000) To tell or not to tell-what parents think about telling their children that they were born following donor insemination *Journal of Psychosomatic Obstetrics & Gynecology* **21(4)**: 193-203. Eleven per cent of parents of donor-conceived children born between 1985 and 1997 had disclosed to their child that they were donor-conceived.

[219] Isaksson S, Sydsjö G, Skoog Svanberg A, and Lampic C (2012) Disclosure behaviour and intentions among 111 couples following treatment with oocytes or sperm from identity-release donors: follow-up at offspring age 1-4 years *Human Reproduction* **27(10)**: 2998-3007 (part of the Swedish Study on Gamete Donation). Sixteen per cent of parents had begun this process by the age of four.

[220] Readings J, Blake L, Casey P, Jadva V, and Golombok S (2011) Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy *Reproductive BioMedicine Online* **22(5)**: 485-95. Seventeen out of 36 sperm donor parents intended to tell and nine had done so by age seven; 20 out of 32 egg donor parents intended to tell and 11 had done so by age seven. Follow-up interviews with these parents when their children were ten showed hardly any change: Lucy Blake, personal communication, 6 July 2012.

[221] Readings J, Blake L, Casey P, Jadva V, and Golombok S (2011) Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy *Reproductive BioMedicine Online* **22(5)**: 485-95, at page 491.

[222] Jadva V, Blake L, Casey P, and Golombok S (2012) Surrogacy families 10 years on: relationship with the surrogate, decisions over disclosure and children's understanding of their surrogacy origins *Human Reproduction* **27(10)**: 3008-14. All the families who had used genetic surrogacy were found to have disclosed about the use of a surrogate, but only 58 per cent had told the child that a donor egg had been used.

Conception Network (DCN) who are sometimes contacted by families who had not planned to tell but who changed their minds when their child was between five and ten.[223]

4.5 The UK-based studies published to date all relate to children born via donor conception *before* the removal of donor anonymity in 2005. Hence, while there is anecdotal evidence that an increasing number of parents are being open with their children about the circumstances of their conception,[224] as yet there are no published research data tracking the effect of the regulatory change in a representative sample.[225] It should also be noted that disclosure rates are affected by family type: children brought up in families headed by solo mothers or same-sex couples are more likely to know that they are donor-conceived than those brought up in families headed by heterosexual couples. Disclosure rates in lesbian households have been reported to be as high as 100 per cent,[226] while over 90 per cent of solo mother intend to tell.[227] Within heterosexual households, parents are more likely to disclose where a donor egg has been used than donor sperm.[228] Many of the parents who do not intend to tell their children that they are donor-conceived nevertheless tell at least one other person about their use of donor gametes.[229]

### Reasons underpinning parents' disclosure decisions

4.6 A number of studies have explored the factors underpinning parents' decisions about disclosure. In addition to the impact of family type, noted above, a number of characteristics have been found to be relevant to disclosure decisions. Levels of distress about infertility, and perceived stigma surrounding infertility and assisted reproduction have been linked with lower levels of disclosure.[230] Where parents feel able to disclose to their wider family, by contrast, disclosure rates to children are higher.[231] Other factors such as professionals' attitudes to disclosure within the fertility clinic, how 'progressive' an area is where the family lives, religious

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[223] Walter Merricks, personal communication, 7 February 2013. Similarly, in a New Zealand study (Daniels KR, Grace VM, and Gillett WR (2011) Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception *Human Reproduction* **26(10)**: 2783-90), seven out of 44 respondents were reported to have changed their minds and now wished to disclose, although it is not clear how many went on to do so.

[224] See, for example, the way that the DCN has developed from its establishment by a handful of parents, promoting openness contrary to prevailing medical advice, to a network of 1,600 families. The Working Party was told that over the past 20 years the DCN has had contact with over 5,000 parents or potential parents of donor-conceived people. The Working Party was also told at its factfinding meetings with people with personal experience of donor conception, 27 April 2012, that attitudes on sperm donation websites had shifted significantly in recent years towards favouring identity-release donation; the same point was made at a Progress Educational Trust debate on 24 January 2013 relating to attitudes expressed via parenting and fertility websites.

[225] Preliminary findings from a study being carried out by Freeman T, Zadeh S, Smith V and Golombok S suggest that the removal of anonymity has not had an immediate impact on disclosure rates: Tabitha Freeman, personal communication, 11 February 2013.

[226] Vanfraussen K, Ponjaert-Kristoffersen I, and Brewaeys A (2001) An attempt to reconstruct children's donor concept: a comparison between children's and lesbian parents' attitudes towards donor anonymity *Human Reproduction* **16(9)**: 2019-25.

[227] Murray C, and Golombok S (2005) Going it alone: solo mothers and their infants conceived by donor insemination *American Journal of Orthopsychiatry* **75(2)**: 242-53. Preliminary findings in an ongoing study of solo mothers of children aged between four and eight are that 70 per cent have disclosed, and that 27 per cent intend to disclose: Tabitha Freeman and Sophie Zadeh, personal communication, 11 February 2013.

[228] Readings J, Blake L, Casey P, Jadva V, and Golombok S (2011) Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy *Reproductive BioMedicine Online* **22(5)**: 485-95.

[229] Golombok S, Brewaeys A, Cook R *et al.* (1996) The European study of assisted reproduction families: family functioning and child development *Human Reproduction* **11(10)**: 2324-31 (75% of mothers had decided not to tell their child, and a further 13% were undecided, but 56% had told a friend or family member); Lalos A, Gottlieb C, and Lalos O (2007) Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking *Human Reproduction* **22(6)**: 1759-68 (61% had told their child or children, but almost all had told another person).

[230] Nachtigall RD, Tschann JM, Quiroga SS, Pitcher L, and Becker G (1997) Stigma, disclosure, and family functioning among parents of children conceived through donor insemination *Fertility and Sterility* **68(1)**: 83-9; Salter-Ling N, Hunter M, and Glover L (2001) Donor insemination: exploring the experience of treatment and intention to tell *Journal of Reproductive & Infant Psychology* **19(3)**: 175-86.

[231] Shehab D, Duff J, Pasch LA *et al.* (2008) How parents whose children have been conceived with donor gametes make their disclosure decision: contexts, influences, and couple dynamics *Fertility and Sterility* **89(1)**: 179-87.

belief, and the extent to which the donor-conceived child resembles others family members may also affect parents' willingness or inclination to disclose.[232]

## Why parents decide to disclose

4.7 Parents generally choose to disclose to their children that they are donor-conceived because they believe that it is important to avoid 'secrets' within families or because they believe that the child is entitled to know about the way in which they were conceived.[233] Concerns have also been expressed that non-disclosure could lead to their child's "sense of self" being undermined.[234] A very practical reason given for disclosure is the fear that, if parents do not tell their child, this may leave them vulnerable to accidental disclosure from a third party,[235] with parents expressing the view, for example, that "I would hate for them ever to find out any other way besides our telling them".[236] In the case of families headed by solo mothers or lesbian couples, mothers are further prompted to tell because of the practical question of how they explain the child's arrival to others, and how they respond to the child's questions about their father from an early age. In such cases, there is also no father to 'protect' from disclosure of donor conception.[237]

## Why parents decide not to disclose

4.8 Many of the characteristics of families that are associated with disclosure decisions, summarised in paragraph 4.6 above, relate to the broader social environment in which donor-conceived families live: the extent to which parents feel that their wider family and community would support or be hostile to the idea of the use of donor gametes or embryos in conception. We return to some of these factors, particularly concerns about stigma, below (see paragraphs 4.33 to 4.40). However, research exploring with non-disclosing parents the reasons for their decision generally focuses on their concerns that disclosure may have a negative effect on their child's psychological well-being, with a common reason for non-disclosure being to avoid either

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[232] Becker G, Butler A, and Nachtigall RD (2005) Resemblance talk: a challenge for parents whose children were conceived with donor gametes in the US *Social Science & Medicine* **61(6)**: 1300-9; Hargreaves K, and Daniels K (2007) Parents' dilemmas in sharing donor insemination conception stories with their children *Children & Society* **21(6)**: 420-31; Shehab D, Duff J, Pasch LA *et al.* (2008) How parents whose children have been conceived with donor gametes make their disclosure decision: contexts, influences, and couple dynamics *Fertility and Sterility* **89(1)**: 179-87. Indeed, all parents, regardless of whether or not they wish to share information about their use of donor gametes, will have to grapple with the issue of how to respond to comments or questions about family resemblances.

[233] See, for example, Baetens P, Devroey P, Camus M, Van Steirteghem AC, and Ponjaert-Kristoffersen I (2000) Counselling couples and donors for oocyte donation: the decision to use either known or anonymous oocytes *Human Reproduction* **15(2)**: 476-84; Lycett E, Daniels K, Curson R, and Golombok S (2005) School-aged children of donor insemination: a study of parents' disclosure patterns *Human Reproduction* **20(3)**: 810-9; Golombok S, Murray C, Jadva V *et al.* (2006) Non-genetic and non-gestational parenthood: consequences for parent-child relationships and the psychological well-being of mothers, fathers and children at age 3 *Human Reproduction* **21(7)**: 1918-24; Murray C, MacCallum F, and Golombok S (2006) Egg donation parents and their children: follow-up at age 12 years *Fertility and Sterility* **85(3)**: 610-8; Hargreaves K, and Daniels K (2007) Parents' dilemmas in sharing donor insemination conception stories with their children *Children & Society* **21(6)**: 420-31; Lalos A, Gottlieb C, and Lalos O (2007) Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking *Human Reproduction* **22(6)**: 1759-68.

[234] Shehab D, Duff J, Pasch LA *et al.* (2008) How parents whose children have been conceived with donor gametes make their disclosure decision: contexts, influences, and couple dynamics *Fertility and Sterility* **89(1)**: 179-87. No figures are given as to how many parents expressed this concern.

[235] Leeb-Lundberg S, Kjellberg S, and Sydsjö G (2006) Helping parents to tell their children about the use of donor insemination (DI) and determining their opinions about open-identity sperm donors *Acta Obstetricia et Gynecologica Scandinavica* **85(1)**: 78-81; MacCallum F, and Golombok S (2007) Embryo donation families: mothers' decisions regarding disclosure of donor conception *Human Reproduction* **22(11)**: 2888-95; Shehab D, Duff J, Pasch LA *et al.* (2008) How parents whose children have been conceived with donor gametes make their disclosure decision: contexts, influences, and couple dynamics *Fertility and Sterility* **89(1)**: 179-87; Readings J, Blake L, Casey P, Jadva V, and Golombok S (2011) Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy *Reproductive BioMedicine Online* **22(5)**: 485-95.

[236] Hahn SJ, and Craft-Rosenberg M (2002) The disclosure decisions of parents who conceive children using donor eggs *Journal of Obstetric, Gynecologic, & Neonatal Nursing* **31(3)**: 283-93.

[237] Vanfraussen K, Ponjaert-Kristoffersen I, and Brewaeys A (2001) An attempt to reconstruct children's donor concept: a comparison between children's and lesbian parents' attitudes towards donor anonymity *Human Reproduction* **16(9)**: 2019-25.

distressing the child or jeopardising their positive relationship with their non-genetic parent. Other reasons given include not knowing how, when or what to tell.[238]

4.9 Concern about the possible impact of disclosure on the child may also be expressed in terms of anxiety that disclosure will only serve to 'confuse' donor-conceived children.[239] Closely linked to these anxieties about negative impacts on children are concerns that disclosure will lead to offspring rejecting the parent who is not biologically connected to them:[240] such anxieties being vividly expressed by a mother worrying whether her daughter would "run screaming out of the house and never see [me] again."[241] Other parents do not disclose because they simply do not think it necessary to do so, or do not 'see the point'.[242]

## *Timing of disclosure*

4.10 Where parents decide to be open with their children about their donor conception, the question then arises as to when is the best time to start the process of disclosure. The advice given by the regulator, the Human Fertilisation and Embryology Authority (HFEA), and by the DCN, is that disclosure at an earlier age is better although it is never too late to tell.[243] The DCN, for example, comments in its *Telling and talking* booklets for parents that: "a number of donor-conceived adults who learned of their origins later in life have spoken of feeling that their lives were blighted by having no explanation for their sense of disconnection from the rest of their family, until they found out about their donor conception. On the other hand, some young people who were told from early on have spoken about enjoying a 'sense of specialness' as a result of being donor-conceived."[244] The DCN recommends that: "the ideal time to start the process [of telling] is before the age of five. The two best windows of opportunity are when your child is a baby or when children show curiosity about where babies come from and how they themselves were made".[245]

4.11 While identifying these 'windows of opportunity', the DCN also notes how difficult many parents find it to choose the right time or the right words with which to discuss donor conception with

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[238] Cook R, Golombok S, Bish A, and Murray C (1995) Disclosure of donor insemination: parental attitudes *American Journal of Orthopsychiatry* **65(4)**: 549-59; Lycett E, Daniels K, Curson R, and Golombok S (2005) School-aged children of donor insemination: a study of parents' disclosure patterns *Human Reproduction* **20(3)**: 810-9; Murray C, MacCallum F, and Golombok S (2006) Egg donation parents and their children: follow-up at age 12 years *Fertility and Sterility* **85(3)**: 610-8; Daniels K, Thorn P, and Westerbrooke R (2007) Confidence in the use of donor insemination: an evaluation of the impact of participating in a group preparation programme *Human Fertility* **10(1)**: 13-20; Lalos A, Gottlieb C, and Lalos O (2007) Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking *Human Reproduction* **22(6)**: 1759-68.

[239] Greenfeld DA, and Klock SC (2004) Disclosure decisions among known and anonymous oocyte donation recipients *Fertility and Sterility* **81(6)**: 1565-71.

[240] Leiblum S, and Aviv A (1997) Disclosure issues and decisions of couples who conceived via donor insemination *Journal of Psychosomatic Obstetrics & Gynecology* **18(4)**: 292-300; Lindblad F, Gottlieb C, and Lalos O (2000) To tell or not to tell-what parents think about telling their children that they were born following donor insemination *Journal of Psychosomatic Obstetrics & Gynecology* **21(4)**: 193-203; Hahn SJ, and Craft-Rosenberg M (2002) The disclosure decisions of parents who conceive children using donor eggs *Journal of Obstetric, Gynecologic, & Neonatal Nursing* **31(3)**: 283-93; MacCallum F, and Golombok S (2007) Embryo donation families: mothers' decisions regarding disclosure of donor conception *Human Reproduction* **22(11)**: 2888-95; Frith L, Sawyer N, and Kramer W (2012) Forming a family with sperm donation: a survey of 244 non-biological parents *Reproductive BioMedicine Online* **24(7)**: 709-18.

[241] Daniels KR, Grace VM, and Gillett WR (2011) Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception *Human Reproduction* **26(10)**: 2783-90.

[242] Golombok S, Murray C, Brinsden P, and Abdalla H (1999) Social versus biological parenting: family functioning and the socioemotional development of children conceived by egg or sperm donation *Journal of Child Psychology and Psychiatry* **40(4)**: 519-27; Murray C, and Golombok S (2003) To tell or not to tell: the decision-making process of egg-donation parents *Human Fertility* **6(2)**: 89-95. In a factfinding meeting with Lucy Blake, 6 July 2012, Dr Blake quoted comments from her own research with parents of donor-conceived children, including: "Well, he's their father… I just don't see any… he's on the birth certificate, he's the one what was there rubbing my back when I was throwing up, holding my hand when I had them, I mean, I just don't see the point"; and "unless anybody asks, we just didn't feel the need to tell."

[243] See, for example, Human Fertilisation and Embryology Authority (2012) *Talk to your child about their origins*, available at: http://www.hfea.gov.uk/116.html; Donor Conception Network (2013) *Telling and talking workshops*, available at: http://www.dcnetwork.org/workshop/telling-talking .

[244] Donor Conception Network (2006) *'Telling' and talking about donor conception with 0-7 year olds: a guide for parents* (London: Donor Conception Network), at page 4.

[245] Donor Conception Network (2006) *'Telling' and talking about donor conception with 0-7 year olds: a guide for parents* (London: Donor Conception Network), at page 6.

their young child.[246] Examples of these difficulties have emerged from the longitudinal studies of the experiences of families formed through donor conception: in one, parents who had not disclosed commented that they regretted not having told their child from the start, but felt that telling them now that they were older would be too much of a shock.[247] Similarly, a number of solo mothers (who tend to be more inclined to disclosure than heterosexual couples – see paragraph 4.5) had not begun the process of disclosing donor conception to their child between the ages of four and eight, not so much because of fears about how the child would react, but rather because of concerns that their child was too young to understand.[248] Other research has indeed shown that young children will not fully absorb what they are told at first: in one study, of six children told before the age of four that they were conceived through donor insemination, only two demonstrated that they had some understanding of their donor conception three years later.[249] The DCN guidance emphasises that disclosure is a process, not a one-off event, and suggests that by "starting to sow the seeds of information early" parents may ensure that the child cannot remember a time when they did not 'know', even though the depth of understanding of what is 'known' will develop over time.[250]

4.12 All the donor-conceived people who attended factfinding meetings with the Working Party agreed that early disclosure was best, although some who had been told when they were older (for example in their mid-20s) were understanding about why this had happened, noting for example, that in the 1980s when the general advice was 'not to tell', it could have been much harder for open families because of the lack of general understanding.[251] However it was thought that finding out very late (in old age or on the deathbed of a parent), or discovering that you were the 'last to know', would be particularly hard to cope with.[252] It was also suggested that donor-conceived children may often 'pick up' in childhood that they are different in some way, for example wondering if they were adopted;[253] school biology lessons, for example, may prompt questions within the family about physical similarities and characteristics associated with dominant and recessive genes.[254] Qualitative studies investigating the views of donor-conceived adults similarly emphasise the importance of early disclosure, both as a means of avoiding any problems "posed by deception and secrecy" and also as providing an "opportunity for offspring to affirm their parents' choice of donor conception as a means of family building."[255]

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[246] Donor Conception Network (2006) *'Telling' and talking about donor conception with 0-7 year olds: a guide for parents* (London: Donor Conception Network). See also: Cook R, Golombok S, Bish A, and Murray C (1995) Disclosure of donor insemination: parental attitudes *American Journal of Orthopsychiatry* **65(4)**: 549-59; and Daniels K, Thorn P, and Westerbrooke R (2007) Confidence in the use of donor insemination: an evaluation of the impact of participating in a group preparation programme *Human Fertility* **10(1)**: 13-20, where it is suggested that parents who do not feel confident may be less likely to disclose their use of donor insemination to their child and to other people.

[247] Golombok S, MacCallum F, Goodman E, and Rutter M (2002) Families with children conceived by donor insemination: a follow-up at age twelve *Child Development* **73(3)**: 952-68.

[248] Tabitha Freeman and Sophie Zadeh, personal communication, 15 February 2013.

[249] Blake L, Casey P, Readings J, Jadva V, and Golombok S (2010) 'Daddy ran out of tadpoles': how parents tell their children that they are donor conceived, and what their 7-year-olds understand *Human Reproduction* **25(10)**: 2527-34.

[250] Donor Conception Network (2006) *'Telling' and talking about donor conception with 0-7 year olds: a guide for parents* (London: Donor Conception Network, at page 4.

[251] Factfinding meeting with people with personal experience of donor conception, 27 April 2012.

[252] Ibid.

[253] Factfinding meeting with Christine Whipp, 16 July 2012; factfinding meeting Rachel Pepa, 24 April 2012. See also: Daniels KR, Grace VM, and Gillett WR (2011) Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception *Human Reproduction* **26(10)**: 2783-90.

[254] Daniels KR, Grace VM, and Gillett WR (2011) Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception *Human Reproduction* **26(10)**: 2783-90.

[255] Blyth E (2012) Discovering the 'facts of life' following anonymous donor insemination *International Journal of Law, Policy and the Family* **26(2)**: 143-61. See also: Kirkman M (2003) Parents' contributions to the narrative identity of offspring of donor-assisted conception *Social Science & Medicine* **57(11)**: 2229-42.

## Impact of disclosure on donor-conceived people

### *Emotions associated with disclosure*

4.13 How donor-conceived people are affected by disclosure depends to an extent on their age when the process of disclosure begins. Children who are told in their preschool years about the use of donor eggs or sperm in their conception have been found to respond neutrally, with curiosity, or even sometimes with pleasure, rather than with distress.[256]

4.14 In contrast, some of those who were told (or found out) that they were conceived using donor sperm as adolescents or adults, speak of 'shock', 'anger' or 'confusion' in response to their discovery.[257] Larger-scale studies of adolescents and adults conceived through sperm donation, recruited via the US-based Donor Sibling Registry (DSR), have also found significant associations between feeling shocked, angry or confused and an older age of disclosure,[258] although one smaller study of adults born through sperm donation recruited through support groups found no association between age of disclosure and the participant's general attitude towards their means of conception.[259] People conceived through sperm donation may be more likely to feel shocked or confused if they have been brought up in two-parent heterosexual households where they had no reason to think they were not biologically connected to both their parents, rather than in same-sex or solo mother households.[260] While studies of DSR registrants suggest that both shock and confusion may fade considerably over time,[261] anger appears to be more persistent, with 13 per cent of people conceived through sperm donation reporting that that they still felt angry at the time the research took place (down from 19% at point of disclosure).[262] People conceived through sperm donation also report feeling 'relieved' as a

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[256] Rumball A, and Adair V (1999) Telling the story: parents' scripts for donor offspring *Human Reproduction* **14(5)**: 1392-9; Lycett E, Daniels K, Curson R, and Golombok S (2005) School-aged children of donor insemination: a study of parents' disclosure patterns *Human Reproduction* **20(3)**: 810-9; Leeb-Lundberg S, Kjellberg S, and Sydsjö G (2006) Helping parents to tell their children about the use of donor insemination (DI) and determining their opinions about open-identity sperm donors *Acta Obstetricia et Gynecologica Scandinavica* **85**: 78-81; Blake L, Casey P, Readings J, Jadva V, and Golombok S (2010) 'Daddy ran out of tadpoles': how parents tell their children that they are donor conceived, and what their 7-year-olds understand *Human Reproduction* **25(10)**: 2527-34. See also: 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(3)**: 524-33, where parents of children conceived through donated eggs or sperm who use 'seed planting' strategies for disclosure at a young age report that children take the information in their stride.

[257] Turner AJ, and Coyle A (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy *Human Reproduction* **15(9)**: 2041-51 (16 donor-conceived adults aged between 26 and 55, who found out about their donor conception during adolescence and adulthood); Blyth E (2012) Discovering the 'facts of life' following anonymous donor insemination *International Journal of Law, Policy and the Family* **26(2)**: 143-61 (eight participants aged between 44 and 65 who found out about their donor conception between the ages of 11 and 56.).

[258] Jadva 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(8)**: 1909-19 (165 participants aged between 13 and 61, of whom 114 were told after the age of three and the remainder had 'always known'.); Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24 (741 participants aged between nine and over 40). In this study, 45.7 per cent of offspring of heterosexual parents compared with 79.3 per cent of offspring of lesbian parents reported that they have always been aware that they were donor-conceived.

[259] 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(7)**: 2236-46, which included 85 adult offspring of sperm donation recruited through internet-based support networks. The authors note that this finding was unexpected and contrasts with that of other studies with donor-conceived people. Almost half (47%) of respondents learned about their donor conception when they were over 18 years old; 19 per cent learned between ages ten and 18 years; and 34 per cent learned before the age of ten years. The majority were told by their mothers (69%) during a planned conversation (64%), while 37 per cent learned after an argument with a parent, from someone other than their parents, or worked it out themselves.

[260] Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24: 33 per cent of participants with heterosexual parents said they felt confused at the point of disclosure, compared with seven per cent of those with lesbian parents.

[261] Jadva 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(8)**: 1909-19; Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24.

[262] Jadva 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(8)**: 1909-19.

result of disclosure; again such feelings were more common in those who discovered the nature of their conception in adulthood.[263] Such relief has been associated with very different feelings: with pleasure at being able to disassociate oneself from dysfunctional relationships with the non-biological parent;[264] or, more positively, with understanding why certain things have felt confusing for a donor-conceived person in the past.[265] Others again said that they felt 'indifferent' at the point of disclosure of their donor conception.[266]

4.15 Curiosity is reported as a common reaction to disclosure of conception as a result of sperm donation, and unlike shock or confusion, levels of curiosity appear to remain relatively stable over time: one of the studies of members of the DSR reported that 72 per cent of donor-conceived people felt curious at the point at which the use of donor sperm was disclosed, compared with 69 per cent at the time the research was carried out.[267] There is, however, no way of knowing what percentage of *all* those conceived via donor sperm (or indeed of those conceived through egg or embryo donation, about whom very little is reported) feel such curiosity, or any of the other reactions to disclosure described in this section, as membership of organisations such as DSR is likely to indicate some degree of interest in one's biological connections. Such curiosity may range from a desire for a little 'narrative' information about the donor, to enable the donor-conceived person to form a picture of them, to a desire to meet and potentially build a lasting relationship (see paragraphs 4.21 to 4.28). Curiosity about the donor may have implications for relationships between donor-conceived people and their parents: fathers of people conceived through sperm donation may, in particular, interpret such interest as rejection of themselves.[268] As a result, donor-conceived people may sometimes hesitate to be open with their parents about the extent of their curiosity.[269]

## Longer term impact of disclosure

4.16 Concern is often raised about the longer-term impact of disclosure on donor-conceived people, particularly where disclosure takes place after early childhood. Two particular issues emerged a number of times in response to the Working Party's call for evidence, and during factfinding meetings with people with personal or professional experience of donor conception: the issue of

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[263] Jadva 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(8)**: 1909-19.

[264] Turner AJ, and Coyle A (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy *Human Reproduction* **15(9)**: 2041-51. Comments included: "The man I thought was my dad was such a creep that it was nice to know I wasn't genetically related to him."

[265] Response to the Working Party's call for evidence from Venessa Smith. Donor Services Coordinator, The London Women's Clinic: "… [O]ne 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. Interestingly, he found the fact that his brother was from a different donor a great relief because he felt that this explained the physical and emotional differences between them that they had both always found very confusing."

[266] Jadva 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(8)**: 1909-19. Eleven per cent of donor-conceived adults in this study said that they felt indifferent at the point of disclosure. See also: Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24, where it was found that 16 per cent of offspring with two heterosexual parents, and 34 per cent of offspring with two lesbian parents indicated that finding out about their donor conception made 'no difference' to them.

[267] Jadva 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(8)**: 1909-19. See also: Cushing AL (2010) "I just want more information about who I am": the search experience of sperm-donor offspring, searching for information about their donors and genetic heritage *Information Research* **15(2)**: 1.

[268] Lycett E, Daniels K, Curson R, and Golombok S (2005) School-aged children of donor insemination: a study of parents' disclosure patterns *Human Reproduction* **20(3)**: 810-9.

[269] Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24: around a quarter of offspring in this study indicated that their father was unaware of their curiosity about the donor.

trust, and the impact of disclosure on the identity or self-esteem of the donor-conceived person.[270]

4.17 Issues relating to trust arise in the context both of disclosure and non-disclosure: one reason why parents may decide to disclose is to avoid the risk of their child finding out inadvertently and subsequently feeling that they were deceived (see paragraph 4.7); but parents may also find it hard to make a disclosure when their child is past early childhood because they fear that this disclosure itself may lead to a loss of trust.[271] Research evidence on how disclosure may in practice affect relationships of trust within families is very limited, as this question has not been explored in the larger quantitative studies of donor-conceived adolescents and adults. The limited evidence available does point again to the relevance of the timing of disclosure: concerns about compromised trust emerged in a qualitative study with 16 donor-conceived adults who found out in adolescence or adulthood,[272] while a study of 45 mothers of donor-conceived children concluded that the most common outcome of disclosure was that "telling had created a sense of trust in the child, because s/he knew his or her mother would always inform him or her of reality."[273]

4.18 While there is similarly little empirical research that focuses on how disclosure affects a donor-conceived person's 'sense of identity', that which does exist suggests that disclosure may have an impact on how donor-conceived people understand themselves and how they now 'fit in' with those around them. Again the age of disclosure appears to be relevant. One donor-conceived person taking part in a qualitative study commented: "I would say that being told at a young age and being raised in openness has contributed to me having a stable sense of self, and feeling secure in my familial relationships"; by contrast, the author of this study also notes that "those who learn as adults that they were donor-conceived may experience disruption to their identity and a sense of not being the person they thought they were. This is readily comprehensible in narrative terms: the story of where I came from and who I am, constructed, developed, and amended on the assumption of consistent social and genetic parentage, has been shown to be based on a false premise."[274] Similar concerns about 'disruptions' to one's sense of identity emerge in other qualitative studies with people who found out they were donor-conceived in adolescence or later;[275] and a survey of 47 people conceived through sperm donation, carried out by a donor-conceived person for a high school project, found that 27 of her respondents

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[270] Factfinding meetings with people with personal experience of donor conception, 24 April and 16 July 2012; factfinding meeting with practitioners/researchers, 30 May 2012. See also responses to the Working Party's call for evidence, including the response from a person with personal experience of donor conception: "[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": Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

[271] Mr John B. Appleby and Dr Lucy Blake, Centre for Family Research, University of Cambridge, responding to the Working Party's call for evidence.

[272] Turner AJ, and Coyle A (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy *Human Reproduction* **15(9)**: 2041-51. One respondent, for example, stated: "I now have a total distrust for my mother [following disclosure], and have realised that it is very hard for me to totally trust someone else." See also: Hewitt G (2002) Missing links: identity issues of donor conceived people *Journal of Fertility Counselling* **9(3)**: 14-9, where it is is reported that 16 out of 47 respondents to a survey felt compromised in their ability "to form trusting, open, honest relationships with others".

[273] Scheib JE, Riordan M, and Rubin S (2003) Choosing identity-release sperm donors: the parents' perspective 13-18 years later *Human Reproduction* **18(5)**: 1115-27, at 1121. See also: Daniels K, and Meadows L (2006) Sharing information with adults conceived as a result of donor insemination *Human Fertility* **9(2)**: 93-9.

[274] Kirkman M (2003) Parents' contributions to the narrative identity of offspring of donor-assisted conception *Social Science & Medicine* **57(11)**: 2229-42: study involving 55 recipient parents and 12 donor-conceived people, encompassing sperm, egg and embryo donation.

[275] Turner AJ, and Coyle A (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy *Human Reproduction* **15(9)**: 2041-51; Blyth E (2012) Genes r us? Making sense of genetic and non-genetic relationships following anonymous donor insemination *Reproductive BioMedicine Online* **24(7)**: 719-26.

reported "confusion about identity" at the time of disclosure, and 13 said that they "frequently" experienced feelings of an incomplete identity.[276]

4.19 While these concerns about the impact on donor-conceived people's identity are raised both in qualitative research and in individual reports, it was suggested to the Working Party that more work needs to be done to understand what is meant, both psychologically and ethically, by 'harm to identity' in the context of donor conception.[277] It is not known what proportion of all donor-conceived people experience either temporary or more long-term difficulties in absorbing the fact that they were donor-conceived (and any associated information about their donor) into their understanding of themselves and their relationships to others, since the evidence available relates only to those sufficiently interested to join support groups or contact registers. Recent research carried out by a donor-conceived adult with 12 individuals conceived through sperm donation recruited via the DCN found a link (although not necessarily a causative one) between more deterministic approaches to life and discomfort with one's identity as a donor-conceived person: those of her informants who placed considerable emphasis on the importance of information about their donor (for example that "knowing who I am... means being able to attribute my physical characteristics and abilities to my family members") were those who were least comfortable with their identity as a donor-conceived person. Others reported that finding out that they were donor-conceived had a positive effect on their sense of identity, in that they felt freed to make their own choices, not constrained by ideas as to the kind of person they 'should' be because of their genetic inheritance.[278] The author argued there are "potentially hazardous consequences to regarding biological connection as fundamental to 'who we are'" and that more research with a much wider range of donor-conceived adults was required to inform policy and to challenge prevalent assumptions as to the importance of such connection (see also paragraphs 1.27 to 1.30).

### *Indifferent or positive attitudes to donor conception*

4.20 The sections above summarise the evidence available, both through quantitative and qualitative studies and from the personal experience of those who responded to the Working Party, on the impact disclosure may have on donor-conceived people. While many of the concerns that arise in connection with disclosure relate to potentially detrimental effects (particularly at the point of disclosure), it is important to note that, for many donor-conceived people, knowing that they are donor-conceived may make very little difference to their lives, or may be perceived in a positive light. Twenty one per cent of the people conceived through sperm donation responding to one of the DSR surveys reported feeling 'indifferent' about being donor-conceived at the time the research took place, while 24 per cent felt 'content' and 22 per cent 'happy' about being donor-conceived.[279] Similar positive outcomes (including positive relationships with their mother, and feeling loved and wanted) emerged in a smaller qualitative study with 25 people conceived

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[276] Hewitt G (2002) Missing links: identity issues of donor conceived people *Journal of Fertility Counselling* **9(3)**: 14-9. Participants were recruited via the Donor Conception Support Group of Australia and via the internet.

[277] Mr John B. Appleby and Dr Lucy Blake, Centre for Family Research, University of Cambridge, responding to the Working Party's call for evidence.

[278] Merricks S (2012) Who do you think you are? An exploration of the relationship between identity and genetic information drawn from the experiences of donor-conceived people *Unpublished undergraduate thesis*: Goldsmiths, University of London.

[279] Jadva 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(8)**: 1909-19. The authors of the report also provided a breakdown of these feelings toward being donor-conceived according to the age at which disclosure had occurred. For offspring who were under the age of 18 when disclosure had occurred, 24 per cent felt 'indifferent', 27 per cent felt content, and 23 per cent felt happy. For offspring who were over the age of 18 when disclosure occurred, nine per cent felt indifferent, 13 per cent felt content, and 19 per cent felt happy. See also: Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24, where it was found that 16 per cent of offspring with two heterosexual parents, and 34 per cent of offspring with two lesbian parents indicated that finding out about their donor conception made 'no difference' to them.

through sperm donation.[280] Very few people conceived through sperm donation, regardless of their attitude to the means of their conception, wish that they had never found out: just four per cent of DSR members responding to this question described themselves as feeling this way when they first found out, and this figure fell to one per cent at the time the research took place.[281] It is important to reiterate, however, that it is not known how representative members of the DSR are of donor-conceived people who are aware of their means of conception, and also that none of these studies included people conceived through egg or embryo donation.

### *What kind of information is sought?*

4.21 Where a donor-conceived person knows that they were conceived as a result of donated gametes, the amount of information available to them about their donor will vary significantly depending on their circumstances, in particular the regulatory framework governing donor conception at the point when their parents had fertility treatment. Moreover, their interest in obtaining information will depend on their own attitudes to donor conception and the value to be placed on biological connection. As we note in Chapter 2 (see paragraph 2.5), people conceived as a result of ‘unknown’ donation (whether such donors remain permanently anonymous or whether their identity may be released at 18 as is now the case in the UK) are dependent on third parties for access to any information that may have been collected. The amount of information potentially available to any donor-conceived person also clearly depends on how much information the donor has decided to provide, and on any regulatory requirements placed on donors, either to provide or limit particular forms of information. We have already listed in Chapter 2 the information that UK donors are currently required, or invited, to provide (see paragraph 2.6). We list in Box 4.4 below the forms of information that those responding to the Working Party’s call for evidence suggested donor-conceived people might want or need:[282]

**Box 4.4: Examples cited of information a donor-conceived person might want or need about the donor: responses to the Working Party’s call for evidence and online survey**

Name
Address
Place of education/qualifications
Number of children
How many people the donor has donated to
Hobbies and sports practised
Date of birth
Occupation
Physical characteristics, including a photograph
Financial status
Information about the donor’s parents
Reasons for donating
Place of birth
Medical history
Marital status
Sexual orientation
Circumstances of donor’s birth (i.e. adopted, donor-conceived)
The gender and age of the donor’s own children

4.22 The question of what sort of information a donor-conceived person might want or need about their donor, and why, was discussed during a number of factfinding meetings with people with

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[280] Scheib JE, Riordan M, and Rubin S (2005) Adolescents with open-identity sperm donors: reports from 12-17 year olds *Human Reproduction* **20(1)**: 239-52. The study involved 29 participants of whom 25 answered this question.

[281] Jadva 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(8)**: 1909-19.

[282] Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering. These responses were in reply to the question: “what information might a donor-conceived person need about the donor, either during childhood or once they become adult? Please explain.” See also: Turner AJ, and Coyle A (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy *Human Reproduction* **15(9)**: 2041-51; Rodino IS, Burton PJ, and Sanders KA (2011) Donor information considered important to donors, recipients and offspring: an Australian perspective *Reproductive BioMedicine Online* **22(3)**: 303-11; Crawshaw M, and Dally J (2012) Producing sperm, egg and embryo donors’ pen portraits and other personal information for later use by donor offspring: an exploratory study of professional practices *Human Fertility* **15(2)**: 82-8.

personal or professional experience of donor conception. In one meeting, for example, most donor-conceived adults present had basic non-identifying information such as the donor's height, eye colour and hair colour, but said that they would also like to know more, particularly about the donor's medical history (see Chapter 3 for further discussion of medical information), and about the donor's motivation.[283] The reasons commonly cited for wanting such information is to give the donor-conceived person a sense of the kind of person the donor is or was, in order to help absorb him into the donor-conceived person's existing life story, and to identify features or characteristics in common.[284] As one donor-conceived person explained to the Working Party: "My biological father was long dead when I finally found out his identity but his acknowledged son has been a great source of information, photos, anecdotes and jokes. What I at one time thought could only be a dream, to know his identity and more, has become a wonderful reality. I now feel that I understand and accept myself more."[285] Other donor-conceived people, by contrast, report little or no interest in information about their donor.[286]

4.23 As the quotation above suggests, while the information collected on the donor information form may now provide more biographical information for donor-conceived people than was available for those conceived in the 1990s and earlier, some people will, in addition, strongly desire identifying information about their donor, with the associated possibilities for contact, or at least further information sharing. Another reason raised on a number of occasions with the Working Party for desiring identifying information is the fear on the part of donor-conceived people of embarking involuntarily on an incestuous relationship. The Working Party was told that, while the actual risks of such a relationship might be very small, the fear among donor-conceived people, particularly those conceived before the introduction of regulations limiting the number of families that may be created with the assistance of one donor, is very real.[287]

4.24 Donor-conceived people are likely to have different attitudes to information about their means of conception at various points in their lives: the information needs and desires of a young child, for example, will be very different from those of an adult who has children of their own. Despite this speculation, however, most evidence about the informational needs of donor-conceived people represents a 'snapshot in time', as this question has not been addressed in longitudinal studies. It may also be the case that, for some donor-conceived people, a key issue is not so much what information may potentially be available, but rather that they do not have any choice about whether or not to access it because it is being withheld by third parties.[288] One donor-conceived person who spoke to the Working Party, for example, commented that they did not know what they would do with information about their donor if they were able to obtain it, but that it was immensely frustrating knowing that others were controlling access to whatever little

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[283] Factfinding meeting with people with personal experience of donor conception, 27 April 2012.

[284] Factfinding meetings with people with personal experience of donor conception, 27 April 2012 and with practitioners/researchers, 30 May 2012. See also: Scheib JE, Riordan M, and Rubin S (2005) Adolescents with open-identity sperm donors: reports from 12-17 year olds *Human Reproduction* **20(1)**: 239-52, where 82 per cent of participants indicated that they would like to know what their donor was like; Jadva V, Freeman T, Kramer W, and Golombok S (2010) Experiences of offspring searching for and contacting their donor siblings and donor *Reproductive BioMedicine Online* **20(4)**: 523-32, where "[w]ith regard to searching for their donor, the most common reason, reported by 89% (113) of offspring, was curiosity about the characteristics of the donor"; and Rodino IS, Burton PJ, and Sanders KA (2011) Donor information considered important to donors, recipients and offspring: an Australian perspective *Reproductive BioMedicine Online* **22(3)**: 303-11. For a discussion of the information needs of adults who are donor-conceived, see: Daniels K, and Meadows L (2006) Sharing information with adults conceived as a result of donor insemination *Human Fertility* **9(2)**: 93-9.

[285] Information provided following a factfinding meeting with people with personal experience of donor conception, 27 April 2012.

[286] Factfinding meetings with people with personal experience of donor conception, 27 April 2012; Daily Life (4 April 2012) *The so-called 'missing piece'*, available at: http://www.dailylife.com.au/health-and-fitness/dl-wellbeing/the-socalled-missing-piece-20120403-1w9rf.html.

[287] Factfinding meeting with practitioners/researchers, 30 May 2012.

[288] Scheib JE, and Ruby A (2006) Impact of sperm donor information on parents and children *Sexuality, Reproduction and Menopause* **4(1)**: 17-9; Merricks S (2012) Who do you think you are? An exploration of the relationship between identity and genetic information drawn from the experiences of donor-conceived people *Unpublished undergraduate thesis*: Goldsmiths, University of London.

information was retained.[289] The same participant noted that their partner, who was adopted, was not at all interested in accessing information about their birth family. Similar points about the importance of feeling in control over information relating to oneself, regardless of what use would actually be made of it, were made to the Working Party by practitioners.[290]

4.25 In the absence of 'official' sources of information for some groups of donor-conceived people, voluntary linking services have emerged, enabling donor-conceived offspring, donors and donor siblings to try to identify each other either through anonymous 'donor numbers' where available, or potentially through DNA testing (see paragraph 2.16 for information about the UK-based voluntary register for those conceived before 1991). The DSR, based in the US but open for anyone to join, provides a forum for donor-conceived people to search for their donor and/or any donor-conceived siblings, and, in January 2013, had 38,000 registered members, of whom 1,800 are egg or sperm donors.[291] Since the DSR was established in 2000, more than 9,700 matches have been made between donor offspring and their donor connections: most of these matches are between donor-conceived sibilngs, with around 700 instances of matches between donors and offspring.[292] Approximately 400 registrants are from the UK, almost 100 of whom have matched with half siblings either in the UK or in other countries such as Denmark and the US.[293]

4.26 Recent surveys of DSR members provide an insight into the nature of donor-conceived people's interests in knowing about their donor relations, although it should be noted that the experiences of those who join a contact register cannot necessarily be extrapolated to the wider group of people conceived through donor gametes. Donor-conceived participants in the studies have also, to date, all been conceived through sperm donation, rather than egg or embryo donation (see paragraph 4.28 below with reference to family registrants). More than 80 per cent of DSR members conceived via sperm donation who participated in a recent (2011) survey indicated a desire to have contact with their donor at an unspecified time in the future, with the main reasons cited as being curiousity about the donor's looks, learning about ancestry and learning about medical history.[294] Similar findings emerged from an earlier (2010) survey of 165 DSR members: 77 per cent were searching for their donor, with the reasons most commonly cited as being curiosity about the donor's characteristics, a better understanding of ancestral history, family background and genetic make-up, a better understanding "of why I am who I am", and a desire to meet the donor.[295] Despite the interest in meeting, it appears that few donor-conceived people envisage such contact with their donor as leading to a 'parental' relationship with him: none of those responding to the 2010 survey cited "desire to form a relationship" as being their main reason for searching, although 38 per cent included it as one of their

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[289] Factfinding meetings with people with personal experience of donation, 27 April 2012; concern about 'control' of information, and the effect of information being withheld, emerged independently at two of these sessions.

[290] Factfinding meeting with practitioners/researchers, 30 May 2012. Drawing on comparisons with adoptive people seeking information, Dr Gary Clapton – a social worker and academic with a particular interest in the role of birth fathers in adoption – suggested that: "If information is power then a lack of it promotes powerlessness. Adopted people experience a form of infantalisation during the process of enquiring, discovering about and searching for information relating to their origins."

[291] The Donor Sibling Registry (2012) *The Donor Sibling Registry: homepage*, available at: https://www.donorsiblingregistry.com/; Wendy Kramer, personal communication, 17 January 2013.

[292] Wendy Kramer, personal communication, 17 January 2013. These figures will underestimate the numbers of actual 'matches' made, as they rely on individuals adding postings to the website: for example, there are only around 50 postings relating to the largest group of donor-conceived siblings which is known to include almost 200 members.

[293] Wendy Kramer, personal communication, 17 January 2013. No breakdown is available as to the number of non-UK donors were used by these families, or whether treatment took place abroad. The match rate is unexpectedly high given that over 35,000 donor-conceived people have been born in the UK in the past 20 years, suggesting that those finding a match may predominantly be those using clinics or sperm banks who promote awareness of the DSR.

[294] Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24: 518 out of 741 participants expressed an interest in contact with their donor. See also: Bos HMW, and Gartrell NK (2011) Adolescents of the US National Longitudinal Lesbian Family Study: the impact of having a known or an unknown donor on the stability of psychological adjustment *Human Reproduction* **26(3)**: 630-7, at page 635, where 67 per cent of 17-year-olds with identity release donors in the US National Longitudinal Lesbian Family Study stated that they planned to meet their donor.

[295] Jadva V, Freeman T, Kramer W, and Golombok S (2010) Experiences of offspring searching for and contacting their donor siblings and donor *Reproductive BioMedicine Online* **20(4)**: 523-32.

reasons.[296] While relatively low numbers succeed in making contact, the majority of those who do describe it as a positive experience.[297]

4.27 Seventy-eight per cent of those participating in the 2010 DSR survey were also searching for their donor-conceived siblings. One third of these were successful, and almost all had subsequently been in contact.[298] The main reasons given for searching for siblings were curiosity (for example about similarities in appearance and personality) and "to know and understand a 'missing' part of me", and as with the contact with donors, the majority describe their experience of contact with siblings as positive.

4.28 Membership of the DSR is also open to parents who wish to make contact either with their child's donor or with their donor-conceived siblings before their child reaches adulthood, and indeed a majority of DSR members fall into this category, including 750 egg donation families and 80 embryo donation families.[299] A survey of 791 parent registrants found that a high proportion of those searching for both donors and siblings were solo mothers, followed by lesbian couple parents, and then a much smaller proportion of heterosexual couple parents.[300] The survey found that parents' main motivation for searching for their child's donor was for their child to have a "better understanding of who she/she is", to give their child "a more secure sense of identity", curiosity about the donor's characteristics, or to thank the donor. The main reasons for searching for their child's donor-conceived siblings similarly included curiosity, providing the child with a better understanding of themselves and to give the child a more secure sense of identity.[301] Nearly twice as many parents were interested in finding the child's donor-conceived siblings than their donor, and while it appeared to be the case that many parents valued knowing 'about' the donor more than actually knowing the donor, contact with donor siblings was rated very highly. Relationships between the families of donor-conceived siblings were commonly described in terms of family or friendship, such as "extended family", "one big family" or "connected to a larger community".[302]

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[296] Jadva V, Freeman T, Kramer W, and Golombok S (2010) Experiences of offspring searching for and contacting their donor siblings and donor *Reproductive BioMedicine Online* **20(4)**: 523-32: additional comments written by respondents included "I don't expect any 'father-daughter' relationship. I would be fine with just an exchange of pictures and a letter possibly". Similarly, of the 68 people in Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24 who had made contact with their donor, only six described their donor as "like a parent to me", while the same number described him as "a complete stranger to me".

[297] Jadva V, Freeman T, Kramer W, and Golombok S (2010) Experiences of offspring searching for and contacting their donor siblings and donor *Reproductive BioMedicine Online* **20(4)**: 523-32: 11 of those searching (9% of the sample) found their donor, of whom ten had been in contact. Seven described this as a very positive experience, one as fairly positive, one as neutral and one as fairly negative. The larger survey reported in 2011 similarly found that nine per cent of those searching were able to make contact with their donor: Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24.

[298] Jadva V, Freeman T, Kramer W, and Golombok S (2010) Experiences of offspring searching for and contacting their donor siblings and donor *Reproductive BioMedicine Online* **20(4)**: 523-32. See also: Blyth E (2012) Genes r us? Making sense of genetic and non-genetic relationships following anonymous donor insemination *Reproductive BioMedicine Online* **24(7)**: 719-26.

[299] Wendy Kramer, personal communication, 31 January 2013.

[300] Freeman T, Jadva V, Kramer W, and Golombok S (2009) Gamete donation: parents' experiences of searching for their child's donor siblings and donor *Human Reproduction* **24(3)**: 505-16: 46 per cent of those searching for donors were solo mothers, 32 per cent were lesbian-couple parents, and 22 per cent were heterosexual parents. Similar patterns were also found for parents searching for donor siblings: 43 per cent were solo mothers, 38 per cent were lesbian-couple mothers, and 19 per cent were parents who were heterosexual couples. These figures reflect the breakdown of membership on the DSR as a whole: approximately 50 per cent of family registrants are solo mothers, 33 per cent are lesbian couples, and 17 per cent are heterosexual couple families (Wendy Kramer, personal communication, 17 January 2013).

[301] Freeman T, Jadva V, Kramer W, and Golombok S (2009) Gamete donation: parents' experiences of searching for their child's donor siblings and donor *Human Reproduction* **24(3)**: 505-16, which reports that 688 out of 791 parents registered with the DSR were seeking their child's donor siblings. See also: Scheib JE, and Ruby A (2008) Contact among families who share the same sperm donor *Fertility and Sterility* **90(1)**: 33-43, where it was suggested that contact among families who share the same donor created an "extended family for the child and may also help answer questions about the donor."

[302] Freeman T, Jadva V, Kramer W, and Golombok S (2009) Gamete donation: parents' experiences of searching for their child's donor siblings and donor *Human Reproduction* **24(3)**: 505-16, at 512. Similar themes emerged in a survey of 596 mothers belonging to the organisation Single Mothers by Choice: Hertz R, and Mattes J (2011) Donor-shared siblings or genetic strangers: new families, clans, and the internet *Journal of Family Issues* **32(9)**: 1129-55.

## Impact of non-disclosure and disclosure on family functioning

4.29 The research and personal accounts described above inevitably focus on the impact of disclosure on donor-conceived people who have been told, or found out about, the circumstances of their conception. By definition, as we noted at the start of this chapter, no equivalent studies can take place with respect to those who do *not* know. However, a limited number of studies have investigated factors such as children's psychological adjustment and family relationships, both in families where children are unaware of their donor conception and in 'disclosing' families, in some cases comparing outcomes with other family types such as adoptive families, families created through IVF using the parents' own gametes, and natural conception families.

### *Non-disclosing families*

4.30 The European Study of Assisted Reproduction Families, a longitudinal study that used in-depth interview assessments with mothers and fathers, and standardised questionnaires administered to parents and teachers, found no differences in emotional or behavioural problems between children conceived by either sperm or egg donation (very few of whom had been told that they were donor-conceived) and comparison groups of IVF, naturally conceived, and early-adopted children at early school age[303] and again at age12.[304] The children generally showed high levels of psychological adjustment. More positive parenting was shown in assisted reproduction than natural conception families when the child was aged six. Although differences in parenting quality were no longer apparent by age 12, the families continued to function well. Similarly, studies of children born through embryo donation found that the families were characterised by positive parent-child relationships and that children were faring well.[305] In a further study that used parent questionnaires to compare sperm donation, egg donation, embryo donation and surrogacy families (most of whom were likely to be non-disclosing families) with families created by assisted reproductive procedures using the parents' own gametes, no differences in the psychological adjustment of five to nine-year old children were found.[306] Similar results emerged from an Australian study of children aged five to 13 conceived through sperm donation (65% of whom were unaware that they were donor-conceived) included within a large-scale family study of natural conception couple families, solo mother families and step-father families.[307] These studies indicate that donor-conceived children who are unaware of the nature of their conception do not appear to be at increased risk of developing psychological problems or difficulties in parent-child relationships despite concerns by some to the contrary. However, the conclusions that may be drawn are limited, as, with the exception of the UK sample from the European Study who were followed up at age 18,[308] little is known about the psychological well-being of these children in later adolescence or adulthood. Moreover, the possibility can never be

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[303] Golombok S, Brewaeys A, Cook R *et al.* (1996) The European study of assisted reproduction families: family functioning and child development *Human Reproduction* **11(10)**: 2324-31. See also: Golombok S, Cook R, Bish A, and Murray C (1995) Families created by the new reproductive technologies: quality of parenting and social and emotional development of the children *Child Development* **66(2)**: 285-98; Golombok S, Murray C, Brinsden P, and Abdalla H (1999) Social versus biological parenting: family functioning and the socioemotional development of children conceived by egg or sperm donation *Journal of Child Psychology and Psychiatry* **40(4)**: 519-27.

[304] Golombok S, Brewaeys A, Giavazzi MT *et al.* (2002) The European study of assisted reproduction families: the transition to adolescence *Human Reproduction* **17(3)**: 830-40. See also: Golombok S, MacCallum F, Goodman E, and Rutter M (2002) Families with children conceived by donor insemination: a follow-up at age twelve *Child Development* **73(3)**: 952-68.

[305] MacCallum F, Golombok S, and Brinsden P (2007) Parenting and child development in families with a child conceived through embryo donation *Journal of Family Psychology* **21**: 278-87; MacCallum F, and Keeley S (2008) Embryo donation families: a follow-up in middle childhood *Journal of Family Psychology* **22(6)**: 799-808.

[306] Shelton KH, Boivin J, Hay D *et al.* (2009) Examining differences in psychological adjustment problems among children conceived by assisted reproductive technologies *International Journal of Behavioral Development* **33(5)**: 385-92. Data were not collected on whether or not parents had or intended to tell children they were donor-conceived.

[307] Kovacs GT, Wise S, and Finch S (2012) Functioning of families with primary school-age children conceived using anonymous donor sperm *Human Reproduction* **28(2)**: 375-84. Donor insemination families in the study functioned as well, or better than, the comparison groups.

[308] Owen L, and Golombok S (2009) Families created by assisted reproduction: parent-child relationships in late adolescence *Journal of Adolescence* **32(4)**: 835-48.

excluded that donor-conceived people may find out about their donor conception at a later point in their life.

### Disclosing families

4.31 In the first study to compare the functioning of families where parents had told or intended to tell their children that they had been conceived by donor insemination with those who had not disclosed this information, the differences that were identified reflected more positive outcomes for the disclosing families when the children were aged between four and eight years old.[309] However, only six out of 46 of the children had actually been told about their donor conception at the time of study. In a follow up of the families when the children were aged ten to 14 years, ten out of 30 had been told about their donor conception.[310] The disclosing families continued to function well in terms of parent-child relationships and child adjustment, and in-depth interviews with the adolescents revealed the relative unimportance attributed to the non-genetic link with the father.

4.32 A longitudinal study initiated in the year 2000[311] provided an opportunity to compare children born through donor insemination and egg donation who were aware of their biological origins by age seven, the age at which most adopted children understand the meaning and implications of being adopted, with those who were not.[312] As in the earlier European study (see paragraph 4.30), the families showed positive parent-child relationships, with no differences between those formed through egg donation and donor insemination. However, the donor conception mothers who had kept their child's origins secret showed higher levels of emotional distress than those who had been open with their child about their origins (see paragraph 4.44). In addition, interview and observational assessments of mother-child interaction revealed less positive interaction in the families in which parents had not disclosed the donor conception to the child.[313] However, it should be noted that the differences identified were not indicative of maternal psychiatric disorder or dysfunctional family relationships in the non-disclosing families, but instead reflected variation within the normal range. Moreover, there was no evidence of elevated levels of psychological problems among the children in non-disclosing families. Although the findings suggest that disclosure may be associated with more positive outcomes for family relationships it is not clear whether this resulted from openness about the donor conception in particular or open communication in the family more generally. It should also be noted that these families have not yet been followed into the children's adolescence.

### Fears of stigmatisation by third parties

4.33 Concern about stigma arises both in non-disclosing and disclosing families: such concerns may be a factor in a decision not to disclose, or may emerge after disclosure. Parents may fear that their children will be ostracised or bullied, with anxieties expressed, for example, that children might "[feel] isolated in a world where there is still social stigma about having been conceived via donor gametes,"[314] or would draw attention to themselves at school and elicit negative

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[309] Lycett E, Daniels K, Curson R, and Golombok S (2004) Offspring created as a result of donor insemination: a study of family relationships, child adjustment, and disclosure *Fertility and Sterility* **82(1)**: 172-9.

[310] Freeman T, and Golombok S (2012) Donor insemination: a follow-up study of disclosure decisions, family relationships and child adjustment at adolescence *Reproductive BioMedicine Online* **25(2)**: 193-203.

[311] Golombok S, Lycett E, MacCallum F *et al.* (2004) Parenting infants conceived by gamete donation *Journal of Family Psychology* **18(3)**: 443-52.

[312] Golombok S, Readings J, Blake L *et al.* (2011) Children conceived by gamete donation: psychological adjustment and mother-child relationships at age 7 *Journal of Family Psychology* **25(2)**: 230-9.

[313] Golombok S, Readings J, Blake L *et al.* (2011) Children conceived by gamete donation: psychological adjustment and mother-child relationships at age 7 *Journal of Family Psychology* **25(2)**: 230-9.

[314] Shehab D, Duff J, Pasch LA *et al.* (2008) How parents whose children have been conceived with donor gametes make their disclosure decision: contexts, influences, and couple dynamics *Fertility and Sterility* **89(1)**: 179-87 (study of 141 couples, although the numbers subscribing to this view are not given).

reactions from classmates.[315] Such anxieties may extend to fear of disapproval from the child's friends and relatives.[316] Fears are also sometimes raised that openness about donor conception may lead to the parents, particularly fathers, being stigmatised or humiliated for their infertility, which has in the past, or in some communities, been associated with virility or masculinity.[317] An assessment of actual experiences of stigma, however, suggested that concerns about stigmatisation may not necessarily be borne out in practice, with parents who had disclosed having lower scores on stigma (measured in terms of their experience of levels of perceived discomfort, superiority and avoidance by third parties) than those who were undecided and those who had not disclosed.[318] However, those least likely to experience stigma may have been more likely to disclose. Intended parents in surrogacy arrangements also have to deal with the reactions of others, given the difficulties involved in keeping surrogacy arrangements completely private. One study of 42 couples with a one-year-old child born through a surrogacy arrangement found that the majority of reactions of their wider family networks to disclosure about surrogacy were either positive or neutral, with only three couples reporting any negative reactions.[319] However, the fact that people may go to significant lengths to disguise surrogacy, for example by going abroad for extended periods of time, suggests that concerns about how others may react to surrogacy are clearly influential for some.[320]

4.34 While stigma is clearly feared by some parents, both in relation to themselves and their child, the current evidence base relating to actual experiences of stigma is very small. Concerns about stigma are particularly likely to be dependent on the environment and community in which prospective parents live, and the extent to which donor conception is seen as an acceptable way of building a family (see also paragraphs 4.6 and 4.12). The Working Party heard of concerns about donor conception from a number of cultural and religious perspectives, including Muslim,[321] Sikh,[322] Jewish,[323] Hindu,[324] and Christian[325] that could potentially affect parents' decisions with regard to openness, both because of concerns as to the impact of such disclosure on themselves and/or their child.

4.35 The strongest concerns expressed to the Working Party came from those with knowledge of Sikh and Muslim communities in the UK, where notions of honour and shame are important, and where it was considered highly unlikely that parents would want to reveal to their extended

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[315] Hunter M, Salter-Ling N, and Glover L (2000) Donor insemination: telling children about their origins *Child and Adolescent Mental Health* **5(4)**: 157-63 (a study of 83 disclosing parents). See also: Hershberger P, Klock SC, and Barnes RB (2007) Disclosure decisions among pregnant women who received donor oocytes: a phenomenological study *Fertility and Sterility* **87(2)**: 288-96 (study of eight pregnant women: while concerns about possible bullying in school were expressed, only one woman said, at this point, that this would affect her disclosure decision).

[316] Lalos A, Gottlieb C, and Lalos O (2007) Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking *Human Reproduction* **22(6)**: 1759-68. See also: Cook R, Golombok S, Bish A, and Murray C (1995) Disclosure of donor insemination: parental attitudes *American Journal of Orthopsychiatry* **65(4)**: 549-59.

[317] Laruelle C, Place I, Demeestere I, Englert Y, and Delbaere A (2011) Anonymity and secrecy options of recipient couples and donors, and ethnic origin influence in three types of oocyte donation *Human Reproduction* **26(2)**: 382-90 (18 of the 52 couples taking part expressed concern about parental stigma). See also the discussion in Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24, at 2422.

[318] Nachtigall RD, Tschann JM, Quiroga SS, Pitcher L, and Becker G (1997) Stigma, disclosure, and family functioning among parents of children conceived through donor insemination *Fertility and Sterility* **68(1)**: 83-9 (82 fathers and 94 mothers of donor-conceived people who resided in the San Francisco area and were predominantly white, highly educated, affluent, white-collar professionals).

[319] MacCallum F, Lycett E, Murray C, Jadva V, and Golombok S (2003) Surrogacy: the experience of commissioning couples *Human Reproduction* **18(6)**: 1334-42; Jadva V, Blake L, Casey P, and Golombok S (2012) Surrogacy families 10 years on: relationship with the surrogate, decisions over disclosure and children's understanding of their surrogacy origins *Human Reproduction* **27(10)**: 3008-14.

[320] See, for example, ABC News (24 December 2012) *Documentary special: surrogacy secrets*, available at: http://www.abc.net.au/news/2012-12-21/documentary-special-surrogacy-secrets/4442510.

[321] Dr Morgan Clarke, written contribution to factfinding meeting on regulatory aspects of donation, 22 June 2012; factfinding meeting with academics, 30 May 2012.

[322] Factfinding meeting on regulatory aspects of donation, 22 June 2012.

[323] Factfinding meeting on regulatory aspects of donation, 22 June 2012; The Board of Deputies of British Jews, responding to the Working Party's call for evidence.

[324] Hindu Council UK, responding to the Working Party's online survey.

[325] Anscombe Centre, responding to the Working Party's online survey; The Christian Medical Fellowship, responding to the Working Party's call for evidence.

family or wider community that they had used donor gametes to conceive.[326] It was reported that husbands and wives who do not conceive naturally may feel that they are a 'failure', and that within the Sikh community (and also more widely among other South Asian communities in the UK), the more obvious 'solution' to infertility might be divorce, thus enabling the fertile partner to 'start again'. It was also suggested to us that while many members of the Sikh community, particularly in the younger generation, will take the view that the use of donated gametes, where necessary, is a perfectly acceptable way of conceiving a child – perhaps arguing that it is God's will that techniques to assist with infertility are available – those holding this view will still need to take account of how their wider family and community may react.

4.36 Similarly, from Muslim perspectives, the Working Party was told that matters of assisted conception are often sensitive and meant to be kept private. In some cases, analogies are made between the use of donated sperm and adultery. It should be noted, however, that there are differences between Sunni and Shia principles on this issue, and between different religious leaders within the main branches of Islam. There are examples of how Shia ethical reckoning accommodates the use of donated gametes and surrogacy.[327] It was suggested to the Working Party that the importance placed by Muslim communities (and South Asian communities more generally), on 'lineage', as traced through the paternal line, raised particular concerns for people conceived through sperm donation, and that non-disclosure in such cases protects the child in the eyes of the outside world. It was also pointed out that 'openness' could lead to stigma and ostracism for the family, and would damage the child's future marriage prospects.[328] Yet it is clear that, despite the views of some religious scholars, some people from communities that overtly reject donor conception do, nevertheless, seek treatment with donated gametes in order to have a family.[329]

4.37 Recent research on attitudes to gamete donation conducted in three UK cities with focus groups involving 100 men and women of Indian, Pakistani and Bangladeshi origin (including Muslim, Sikh and Hindu participants) similarly found some widely-held perspectives and concerns among participants, although the authors emphasised that it was misguided to assume that there could be a single generalisable 'South Asian' viewpoint on gamete donation.[330]

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[326] Factfinding meeting on regulatory aspects of donation, 22 June 2012.

[327] See, for example, Tremayne S (2006) Not all Muslims are luddites *Anthropology Today* **22(3)**: 1-2; Clarke M (2009) *Islam and new kinship: reproductive technology and the Shariah in Lebanon* (Oxford: Berghahn Books); Tremayne S (2009) Law, ethics and donor technologies in Shia Iran, in *Assisting reproduction, testing genes: global encounters with new biotechnologies*, Inhorn MC, and Birenbaum-Carmeli D (Editors) (Oxford: Berghahn Books).

[328] Factfinding meeting with academics, 30 May 2012. The importance on 'lineage' was echoed in the contribution submitted after the factfinding meeting on regulation on 22 June, where it was highlighted how those Muslim scholars who *do* find the use of donor gametes to be permissible may hold that under Islamic law the donor as the genetic parent should have the responsibilities and duties of a legal parent: such an approach is clearly compatible with (indeed depends on) openness about donation but may be felt to undermine the rationale for prospective parents to seek donor gametes in the first place. See also Leila Afshar and Alireza Bagheri's account of embryo donation in Iran, where they note that while techniques such as treatment with donated gametes and surrogacy are available in Iran (primarily in Tehran), only embryo donation has a statutory basis, and some of the Shi'ite religious leaders both inside and outside Iran disagree with the relative permissiveness of Iranian practice: Afshar L, and Bagheri A (2012) Embryo donation in Iran: an ethical review *Developing World Bioethics*: e-published ahead of print, 18 June 2012. Afshar and Bagheri note, in particular, that the legislation governing embryo donation is deliberately silent on the question as to whether the parents of a child conceived through embryo donation have the same rights and duties as the parents of naturally-conceived children, because of concerns by the Guardian Council that this would contradict Islamic Shari'a.

[329] For example, the Working Party was told that in Punjab, from where many British Sikhs originate, billboards advertise egg and sperm donation, and other fertility services: Factfinding meeting on regulatory aspects of donation, 22 June 2012. See also: BioNews (21 January 2013) *Donor conception in the UK: the seldom-heard voices of minority ethnic communities*, available at: http://www.bionews.org.uk/page_243313.asp?dinfo=k4xM7kuEjsxuIJs3htzUEUTk&PPID=243263.

[330] Culley L, and Hudson N (2009) Constructing relatedness *Current Sociology* **57(2)**: 249-67. See also: Hudson N, Culley L, Rapport F, Johnson M, and Bharadwaj A (2009) "Public" perceptions of gamete donation: a research review *Public Understanding of Science* **18(1)**: 61-77; Hampshire KR, Blell MT, and Simpson B (2012) 'Everybody is moving on': infertility, relationality and the aesthetics of family among British-Pakistani Muslims *Social Science & Medicine* **74(7)**: 1045-52; BioNews (21 January 2013) *Donor conception in the UK: the seldom-heard voices of minority ethnic communities*, available at: http://www.bionews.org.uk/page_243313.asp?dinfo=k4xM7kuEjsxuIJs3htzUEUTk&PPID=243263.

Childlessness was widely seen as socially unacceptable and also stigmatised,[331] and IVF using the couple's own gametes was regarded as relatively uncontentious. However, all participants felt that gamete donation would be disapproved of within their communities. Disclosure of the use of donor gametes (particularly sperm) was regarded as "highly risky", leading to problems of stigma for both parents and child in the wider community. However, the authors of the research emphasise the way in which opinions and perspectives shifted within focus groups, and ambivalent or contradictory views were expressed by the same participants depending on the perspective taken: for example, despite the general feeling that disclosure both to the child and the wider community would be "highly risky", a minority of participants also felt that the child had a 'right' to know about the nature of their conception, while others expressed concern about inadvertent disclosure at some point in the child's life and the resulting potential for harm both for the child and relationships with parents.

4.38 While Muslim participants in these focus groups expressed their concerns primarily with reference to religious acceptability, no Hindu and Sikh participants discussed specifically religious objections, and indeed the Hindu Council UK responded to the Working Party's online survey by emphasising the importance of disclosure and access to information about the donor, because of the need in Hinduism for there to be no 'family' connection between married couples going back at least seven generations.[332] The Board of Deputies of British Jews similarly emphasised to the Working Party the importance of being aware of how 'religious' and 'cultural' concerns within a community may pull in different directions: while interpretation of Jewish law leads to a clear conclusion that transparency is important and that the identity of sperm donors, in particular, should be known to offspring (because of the Talmudic prohibition on keeping a father's identity secret), concerns about stigma for the child and their family lead to a preference for non-disclosure.[333] We were told that, given anxieties about stigma, most people in the UK's Jewish community would be surprised to hear that Jewish religious law would lean towards disclosure. A parallel disjunction between religious law and culture in Israeli regulation in this area was described to the Working Party: we were told that attempts to establish a formal registry to record information about donors had been abandoned because of an understanding that both patients and professionals would not comply.[334]

4.39 The responses the Working Party received from those associated with Christian churches in the UK demonstrated further the complex ways in which people may be influenced by their religion. Both the Christian Medical Fellowship (which holds to an evangelical basis of faith) and the Anscombe Bioethics Centre (a Catholic institution) argued for openness about donor conception in their responses to the Working Party's call for evidence – but did not agree that the use of donor gametes was an acceptable way of creating a family at all.[335] Thus, it seems likely that some members associated with Catholic or evangelical Protestant churches who wish to create a family through donor conception may hesitate to reveal their decision to do so. The Church of England: Mission and Public Affairs Council, by contrast, made no comment on the acceptability of donor conception in its response, but advocated encouragement to openness and emphasised the importance of counselling for prospective parents of the longer-term implications of their decisions.[336] It was also suggested to the Working Party that members of the Orthodox Christian churches are unlikely to wish to tell others that they have used donor

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[331] This should not be understood simplistically in coercive terms: almost all British Pakistani men and women participating in research in the North East of England were in favour of early, high fertility (most regarding four children as their ideal), quite apart from any pressure from extended families: Hampshire K, Blell M, and Simpson B (2012) Navigating new socio-demographic landscapes: using anthropological demography to understand the 'persistence' of high and early fertility among British Pakistanis *European Journal of Population* **28(1)**: 39-63.

[332] Hindu Council UK, responding to the Working Party's online survey.

[333] Board of Deputies of British Jews, responding to the Working Party's call for evidence; factfinding meeting on regulatory aspects of donation, 22 June 2012.

[334] Factfinding meeting on regulatory aspects of donation, 22 June 2012.

[335] The Anscombe Centre, for example, set out their view that it is "morally wrong to conceive a child deliberately, even with the most generous of motives, whom one has no intention of parenting oneself", while the Christian Medical Fellowship stated that "we… do not support gamete donation in principle". The catechism of the Catholic Church, approved in 1992, posits donor conception as "gravely immoral": see Vatican (1992) *Catechism of the Catholic Church*, available at: http://www.vatican.va/archive/ENG0015/__P86.HTM, at paragraph 2376.

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

gametes: one prospective parent told the Working Party that she feared exclusion both from the community and from the church if the use of donor gametes became known.[337]

4.40 While the research with members of the UK's South Asian communities described above highlights some of the culturally specific ways in which gamete donation may be understood, the authors also emphasise that many of the concerns raised by participants are not specific to particular populations or faith communities. Embarrassment about male infertility, for example, is widespread, and many people express disapproval of creating non-traditional families, such as those headed by same-sex parents, for reasons completely unconnected with religious teaching. Some parents are able to challenge family and wider social expectations: one donor-conceived person, for example, pointed out to us how her own parents ignored clinicians' advice and were open with her about the use of donor sperm, even though the UK in the 1950s was hardly an easy environment for discussing such matters.[338] Others may feel far less able to challenge the cultural norms in the community where they live, or the attitudes and expectations of their wider families.[339] While recognising that (as the example of the UK in the 1950s demonstrates) wider environmental influences can and do change over time, such factors clearly have the capacity to shape parents' perceptions of stigma, and the likely impact of disclosure on both their own lives and the lives of their child.

## Impact on parents and prospective parents of donor-conceived people

4.41 At the start of this chapter we summarised what is known about *why* parents of donor-conceived people choose to disclose or not disclose donor conception to their offspring (see paragraphs 4.6 to 4.8). Below we consider the evidence as to how these parents are affected by their decisions.

### *Disclosing families*

4.42 Parents who decide to disclose to their children generally appear to find this a positive or neutral experience. Despite parents' fears described earlier about the potential impact of disclosure on children or family relationships (see paragraph 4.8), studies of disclosing families suggest that families rarely regret having made the decision to tell their children that they were donor-conceived.[340] Some parents describe themselves as feeling 'good'[341] or feeling 'relieved',[342] although they may also feel mixed emotions, such as sadness because of the reminder that conception had not been 'normal'.[343] Some feel that disclosure is 'no big deal'.[344] It has also

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[337] Factfinding meeting with a prospective parent, 16 July 2012.

[338] Additional contribution following the factfinding meetings on 27 April 2012.

[339] See, for example, Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester, responding to the Working Party's call for evidence, who cited an example from their own research of a lesbian mother with a donor-conceived child, whose own parents so strongly disapproved of her sexuality that they kept it secret from other family members and lied about the child's origins. As the mother relied on her parents for both support and childcare, she feared that openness, and resulting disruption to relationships, could have severe consequences for both her and the child.

[340] 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(3)**: 524-33 (study which included 38 families who had disclosed, where it was concluded that "although parents reported a variety of feelings after disclosing that ranged from neutral to a profound sense of relief, no parents expressed regret or reported a negative outcome after having initiated disclosure"); Blyth E, Langridge D, and Harris R (2010) Family building in donor conception: parents' experiences of sharing information *Journal of Reproductive and Infant Psychology* **28(2)**: 116-27 (study of 15 families who disclosed by the age of five, where it was reported that "no parent in our study regretted their decision to tell their child").

[341] Rumball A, and Adair V (1999) Telling the story: parents' scripts for donor offspring *Human Reproduction* **14(5)**: 1392-9 (57% of 54 participants).

[342] Blake L, Casey P, Readings J, Jadva V, and Golombok S (2010) 'Daddy ran out of tadpoles': how parents tell their children that they are donor conceived, and what their 7-year-olds understand *Human Reproduction* **25(10)**: 2527-34; Landau R, and Weissenberg R (2010) Disclosure of donor conception in single-mother families: views and concerns *Human Reproduction* **25(4)**: 942-98.

[343] Blake L, Casey P, Readings J, Jadva V, and Golombok S (2010) 'Daddy ran out of tadpoles': how parents tell their children that they are donor conceived, and what their 7-year-olds understand *Human Reproduction* **25(10)**: 2527-34, at 2531.

[344] Rumball A, and Adair V (1999) Telling the story: parents' scripts for donor offspring *Human Reproduction* **14(5)**: 1392-9, at 1396 (13% of 54 disclosing parents).

been suggested that sharing information about donor conception with their children may have a positive impact on couples' own relationships with each other.[345]

4.43 Longer term anxieties that are expressed following disclosure appear to be more about donor conception in general, rather than disclosure: examples include concern that donor-conceived offspring will not be able to find out who their donor is, or "guilt that our problem has been passed on to a child who will know about half of his genetic background. This didn't occur to me until he was born."[346] There may also be more immediate impacts on family relationships in children's responses to what they have been told: while younger children are likely to be neutral or curious (see paragraph 4.13), the most common reaction reported by adolescents on being told that they were conceived through sperm donation is anger with their mother 'at being lied to'; by contrast the most common response to fathers is 'sympathetic'.[347] Concerns may also sometimes arise more broadly about relationships with the non-biological side of the family: one mother, for example, reported that "my mom is really into saying who the other grandchildren look like… I think she's downgrading our children because she can't find her family in them."[348]

### *Non-disclosing families*

4.44 Concerns were expressed to the Working Party that parents who decide not to disclose are likely to find this a burden within their family life: that they are living "with the burden of deceit" or "with their fingers crossed".[349] Surveys of parents who chose not to tell their children that they were donor-conceived find that most do *not* in fact regret or feel 'guilty' about their decision, suggesting that the likelihood of such difficulties should not be overstated.[350] Nevertheless, it is clear both from empirical research, and from the experience of organisations such as the DCN, that some parents may later experience difficulties with regard to their initial decision not to disclose. A number of parents report that they wish they had told their child when they were younger but felt it was now 'too late' (see paragraph 4.11); and non-disclosing mothers were found to have higher levels of psychological distress (albeit not reaching clinical levels) than disclosing mothers in a longitudinal study of children born in 2000, although it is not possible to demonstrate a causative connection between such distress and the decision not to disclose.[351] Some parents participating in qualitative studies have also described how they had found 'secrecy' within the family to be a burden.[352] Those who do intend to disclose but have not yet managed to do so may also find this stressful, with one parent, for example, commenting: "It's

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[345] Lalos A, Gottlieb C, and Lalos O (2007) Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking *Human Reproduction* **22(6)**: 1759-68 (20 of the 22 people taking part in this study, corresponding to 13 families).

[346] Hunter M, Salter-Ling N, and Glover L (2000) Donor insemination: telling children about their origins *Child and Adolescent Mental Health* **5(4)**: 157-63.

[347] Jadva 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(8)**: 1909-19.

[348] Becker G, Butler A, and Nachtigall RD (2005) Resemblance talk: a challenge for parents whose children were conceived with donor gametes in the US *Social Science & Medicine* **61(6)**: 1300-9.

[349] Factfinding meeting with practitioners, 30 May 2012.

[350] van Berkel D, van der Veen L, Kimmel I, and te Velde E (1999) Differences in the attitudes of couples whose children were conceived through artificial insemination by donor in 1980 and in 1996 *Fertility and Sterility* **71(2)**: 226-31 (83% of the 110 participants did not feel guilty about their decision, and only 2% reported 'often' feeling guilty: study carried out in the Netherlands); Lycett E, Daniels K, Curson R, and Golombok S (2005) School-aged children of donor insemination: a study of parents' disclosure patterns *Human Reproduction* **20(3)**: 810-9 (14 of the 20 non-disclosing participants reported that they had no concerns about their decision: study carried out in UK). See also: Blake L, Casey P, Jadva V, and Golombok S (2012) Marital stability and quality in families created by assisted reproduction techniques: a follow-up study *Reproductive BioMedicine Online* **25(7)**: 678-83, which found that couples in families created through egg or sperm donation, or surrogacy were functioning well; and makes the suggestion that "[o]f interest to future researchers in this field will be the relationship between marital quality and parents' decisions as to whether to tell the child about their donor conception."

[351] Golombok S, Blake L, Casey P, Roman G, and Jadva V (2012) Children born through reproductive donation: a longitudinal study of psychological adjustment *Journal of Child Psychology and Psychiatry*: e-published ahead of print, 23 November 2012.

[352] Daniels KR, Grace VM, and Gillett WR (2011) Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception *Human Reproduction* **26(10)**: 2783-90. See also: Paul MS, and Berger R (2007) Topic avoidance and family functioning in families conceived with donor insemination *Human Reproduction* **22(9)**: 2566-71 and Berger R, and Paul M (2008) Family secrets and family functioning: the case of donor assistance *Family Process* **47(4)**: 553-66 where it is suggested that 'topic avoidance' by parents on the question of donor conception may have a negative effect on family functioning.

hard, we can't talk about it… it feels as if we've failed, we had decided that xxx would be told by now, at the latest…".[353]

## *The option of treatment overseas for prospective parents*

4.45 Where prospective parents experience difficulties in accessing treatment with donor gametes in the UK, in some cases they may consider travel abroad for treatment. As the HFEA does not collect data on the number of UK residents who seek fertility treatment abroad, the total number of those doing so is unknown, although during the course of a factfinding meeting with clinicians, the Working Party were told that difficulties in recruiting black and minority ethnic donors in particular, coupled with discomfort with the idea of asking family or friends to be known donors, meant that many potential patients are likely to go abroad.[354]

4.46 A snapshot of the reasons why prospective parents may go abroad for treatment is provided by a recent study by the European Society of Human Reproduction and Embryology (ESHRE) of the 'cross-border reproductive care' provided by 46 clinics in Belgium, the Czech Republic, Denmark, Slovenia, Spain, and Switzerland.[355] Of the 1,230 patients participating in the survey, 53 travelled from the UK to one of these clinics for treatment, citing reasons of: previous treatment failures (20 patients); access difficulty at home (18 patients); the perception that treatment abroad would be "better quality" (15 patients); and "legal reasons" (five patients).[356] Most of those travelling from the UK were seeking treatment with donated gametes, and of these over a quarter stated that they wished to access an anonymous donor.[357] Detailed interviews with a different group of 29 women from the UK who had been, or were planning to go, overseas in the near future for treatment found that by far the most common reason cited for travelling abroad was donor shortage, with 27 participants citing this reason. Seven participants cited reasons of cost, and the same number indicated that success rates overseas were a reason for travelling for treatment.[358] While few reported that their main reason for choosing overseas treatment was to obtain an anonymous donor, some were content that the regulatory regime governing their chosen clinic meant that their future child would have no prospect of access to their donor's identity, while others would have preferred treatment in the UK, with the associated access to identifying information, if this had been feasible for them. For three participants in the study, on the other hand, the prospect of obtaining detailed information about the donor played an important part in determining their choice of country.[359] We return to the question of the number of donors available in the UK in paragraph 4.48.

4.47 HealthTalkOnline, a website which enables patients to share their experiences of health-related conditions and illnesses illustrates the positive reasons why people may choose to travel abroad for treatment in its recording of the experiences of a couple who chose to travel to Spain for treatment with donor gametes. The woman in the couple noted that "the waiting lists were a lot shorter and the success rates are a lot, lot higher as well." These reasons for travelling abroad were reiterated by her husband who also noted that "people talk about overseas as if it's one

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[353] Lalos A, Gottlieb C, and Lalos O (2007) Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking *Human Reproduction* **22(6)**: 1759-68, at 1763. Similar examples of anxiety or uncertainty, taken from interviews with families, were cited to the Working Party in a presentation on 6 July 2012 by Lucy Blake, Centre for Family Research, University of Cambridge (see appendix 1).

[354] Factfinding meeting with professionals involved at the time of donation, 22 June 2012. See also: Shukla U, Deval B, Jansa Perez M *et al.* (2013) Sperm donor recruitment, attitudes and provider practices - 5 years after the removal of donor anonymity *Human Reproduction* **28(3)**: 676-82.

[355] Shenfield F, de Mouzon J, Pennings G *et al.* (2010) Cross border reproductive care in six European countries *Human Reproduction* **25(6)**: 1361-8.

[356] More than one reason could be cited per patient.

[357] Eight patients were seeking treatment with donor sperm, 33 with donor eggs, and six with donor embryos: some (unspecified number) with both donor egg and donor sperm. 26.4 per cent indicated a wish for an anonymous donor.

[358] Culley L, Hudson N, Rapport F *et al.* (2011) Crossing borders for fertility treatment: motivations, destinations and outcomes of UK fertility travellers *Human Reproduction* **26(9)**: 2373-81. The 29 participants who travelled, or planned to travel, abroad for treatment with donor gametes were able to indicate more than one reason for their decision to do so.

[359] Nicky Hudson and Lorraine Culley, personal communication, 21 December 2012.

place, you know, it's bad overseas, it's not regulated – but where precisely are we talking because it's not one place. And that [is] a point that I would immediately keep making, because 'overseas' isn't this deregulated nightmare that people sometimes paint the picture of."[360] The shortage of donors in the UK has been acknowledged by the HFEA in its review of donation policies in the UK where it concluded that "long waiting times for suitable donors is one of the main reasons people give for going abroad, where it can be easier to access donor treatment."[361]

## Impact on donors and potential donors

### *Potential donors*

4.48 The removal of donor anonymity in 2005 (see paragraph 2.10) has led to debate about how the supply of gametes from donors has been affected, with considerable concern expressed that the removal of anonymity would discourage potential donors from coming forward.[362] However the statistics available present a rather more complicated picture. The number of treatment cycles involving insemination with donor sperm has reduced by more than half over the past ten years, with 3,878 cycles performed in 2010, falling from 6,892 in 2004 and 8,328 in 2000,[363] although it is difficult to separate out the effect of donor shortage from the fact that the development of intra-cytoplasmic sperm injection (ICSI) has resulted in significant decrease in demand for insemination with donor sperm from heterosexual couples.[364] The number of IVF treatments using donor sperm, by contrast, has risen in recent years, with 1,200 cycles in 2010, compared with 998 in 2004 and 1,093 in 2000.[365] Figures from the past ten years published by the HFEA show that there has been a steady *increase* in the number of people who register as sperm donors (see Table 4.1 below).[366] However, the correlation between the number of new donors coming forward and the number of cycles of treatment using donor sperm is made more complex by the fact that some donors (in particular 'known' donors) may choose to limit their donations to one particular family.[367]

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[360] HealthTalkOnline.org (2012) *Naomi: interview 28*, available at: http://www.healthtalkonline.org/Womens_health/Infertility/Topic/4230/Interview/2986/Clip/20988/topicList; HealthTalkOnline.org (2012) *Martin: interview 29*, available at: http://www.healthtalkonline.org/Womens_health/Infertility/People/Interview/2987/Category/555.

[361] Human Fertilisation and Embryology Authority (2011) *The changing landscape of donation*, available at: http://www.hfea.gov.uk/6190.html.

[362] See, for example, Fortescue E (2003) Gamete donation – where is the evidence that there are benefits in removing the anonymity of donors? A patient's viewpoint *Reproductive BioMedicine Online* **7(2)**: 139-44. See also an Australian study of sperm donors which found that over half said that they would not donate if donor anonymity were to be removed: 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(11)**: 3022-6.

[363] Human Fertilisation and Embryology Authority (2012) *Donor conception: patients and treatments*, available at: http://www.hfea.gov.uk/donor-conception-treatments.html. Figures for 2011 show a further slight increase to 4,091, see: Human Fertilisation and Embryology Authority (2013) *Fertility treatment in 2011*, available at: http://www.hfea.gov.uk/docs/HFEA_Fertility_Trends_and_Figures_2011_-_Annual_Register_Report.pdf, at page 16.

[364] Human Fertilisation and Embryology Authority (2006) *Sperm, egg and embryo donation (SEED) policy review: findings of the clinic survey*, available at: http://www.hfea.gov.uk/docs/Clinics_survey_Seed_review.pdf, at paragraph 2.4: "The most frequently cited past trend, identified by 30% of clinics (n=15), was a reduction in demand for donor sperm due to the development of ICSI". See also: British Fertility Society (2008) *Working party on sperm donation services in the UK*, available at: http://www.britishfertilitysociety.org.uk/news/documents/2008_02_Sperm%20Donation%20Services.pdf, which states: "the advent of intra-cytoplasmic sperm injection (ICSI) has transformed the treatment of male infertility, and without doubt has accounted for a significant reduction in treatment cycles with donated sperm since the mid 1990s", at page 5.

[365] Human Fertilisation and Embryology Authority (2012) *Donor conception: patients and treatments*, available at: http://www.hfea.gov.uk/donor-conception-treatments.html. Figures for 2011 show a further slight increase to 2,212, see: Human Fertilisation and Embryology Authority (2013) *Fertility treatment in 2011*, available at: http://www.hfea.gov.uk/docs/HFEA_Fertility_Trends_and_Figures_2011_-_Annual_Register_Report.pdf, at page 16.

[366] Human Fertilisation and Embryology Authority (2012) *UK and overseas donors*, available at: http://www.hfea.gov.uk/3413.html.

[367] See the explanatory notes to Human Fertilisation and Embryology Authority (2012) *New donor registrations*, available at: http://www.hfea.gov.uk/3411.html; and Pacey A (2010) Sperm donor recruitment in the UK *The Obstetrician & Gynaecologist* **12(1)**: 43-8. Sperm donors whose sperm is imported from abroad are also included in the HFEA figures of new donor registrations.

4.49 Reductions can also be observed in the number of treatment cycles with donor eggs: in 2010, 1,506 cycles were carried out, compared with 1,915 in 2004 and 2,067 in 2000. Embryo donation, by contrast, is higher than it has ever been, with 325 cycles with donor embryos in 2010, compared with 244 in 2004, and 266 in 2000.[368] In terms of new donor registrations, Table 4.1 illustrates that, for the past ten years, the number of new egg donors have remained relatively steady. However, the division between 'egg share' donors and 'non-patient' donors has changed during the same period: in 2000, for example, 601 egg share donors were used in HFEA clinics, compared with 791 non-patient donors. However, ten years later, the balance between the two has shifted, with clinics relying increasingly on 'egg share' arrangements.

**Table 4.1: Donor registrations: 2000-10**[369]

| **Year** | **Sperm donors (new registrations)** | **Egg donors (new registrations)** | **Egg donors (egg share, used in HFEA licensed clinics)** | **Egg donors (non-patient, used in HFEA licensed clinics)** | **All egg donors used in HFEA licensed clinics** |
|---|---|---|---|---|---|
| 2000 | 323 | 1,241 | 601 | 791 | 1,392 |
| 2001 | 327 | 1,302 | 625 | 742 | 1,367 |
| 2002 | 288 | 1,174 | 731 | 601 | 1,332 |
| 2003 | 257 | 1,032 | 836 | 513 | 1,349 |
| 2004 | 239 | 1,107 | 999 | 510 | 1,509 |
| 2005 | 272 | 1,023 | 760 | 541 | 1,169 |
| 2006 | 303 | 803 | 655 | 514 | 1,169 |
| 2007 | 360 | 1,024 | 695 | 501 | 1,196 |
| 2008 | 405 | 1,167 | 681 | 554 | 1,235 |
| 2009 | 438 | 1,202 | 728 | 541 | 1,269 |
| 2010 | 480 | 1,258 | 776 | 592 | 1,368 |

4.50 As the preceding section illustrated, it is clear that some people do experience difficulties in accessing treatment with donated gametes, even though the actual number of those registering as donors has not fallen in the way often assumed. However, in the course of factfinding meetings, the Working Party learned that, although patients tend to assume that donors will not be available, in some UK clinics, patients are offered a wide choice of sperm donors,[370] while one London clinic told the Working Party that it could routinely find a suitable egg donor within six months.[371] There have also been reports in the press that waiting times for fertility treatment

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[368] Human Fertilisation and Embryology Authority (2012) *Donor conception: patients and treatments*, available at: http://www.hfea.gov.uk/donor-conception-treatments.html.

[369] The numbers of egg donors used in HFEA licensed clinics are higher than the numbers listed in the "egg donors (new registrations)" column. This is due to the fact that donors under the "new registrations" column are counted only once when they are first registered. If a donor goes on to donate in a subsequent year, they are counted again under the "all egg donors used in HFEA licensed clinics" column. See explanation at: Human Fertilisation and Embryology Authority (2012) *Egg share donors and non-patient egg donors*, available at: http://www.hfea.gov.uk/3412.html. See also: Human Fertilisation and Embryology Authority (2012) *New donor registrations*, available at: http://www.hfea.gov.uk/3411.html.

[370] Factfinding meeting with professionals involved at the time of donation, 22 June 2012. See, for example, London Sperm Bank (2013) *Donor search*, available at: http://www.londonspermbankdonors.com/ and London Fertility Centre (2013) *LFC's sperm bank catalogue* available at: http://www.spirehealthcare.com/london-fertility-centre/sperm-donation/lfc-sperm-bank-catalogue/.

[371] Factfinding meeting with professionals involved at the time of donation, 22 June 2012.

with donor eggs have halved to an average of less than seven months since the rate of compensation for egg donors rose to £750 in October 2012.[372] It appears, therefore, that the issue is not now so much about the removal of anonymity – although the dip in 2004-5 demonstrates that it certainly had an initial effect on some possible donors[373] – but on the extent to which clinics are willing, and have the resources, to put considerable effort into donor recruitment.[374] It was suggested to the Working Party that the position of private clinics is thus likely to be rather different from that of NHS and mixed NHS/private clinics.[375]

4.51 It may also be the case that the demographic of donors changes depending on whether they can donate anonymously or as identity-release donors. Two studies of UK clinics published several years before the removal of anonymity found that students were routinely targeted as sperm donors.[376] By 2004-5, however, the HFEA reported that two out of three sperm donors were aged over 30 and two out of five had children of their own, compared with donors in 1994-5 where donors were most commonly aged between 18 and 24 (with less than a third over 30) and only one in five already had children of their own.[377]

## *Donors and their families*

4.52 Decisions by parents to disclose, or not disclose, information about donor conception may also have an impact on people who have already donated, and on their families. However, there is very little empirical evidence that addresses the effect of disclosure or non-disclosure on donors. That which does exist focuses on two main types of impact, namely on donors' own relationships, and feelings of curiosity or concern about the donor-conceived person.

### Donors' families and relationships

4.53 The potential effect of disclosure on members of the donor's family, and the implications for family relationships, was brought up by several responses to the Working Party's call for evidence, and in factfinding meetings.[378] The Working Party, for example, was told by a donor services coordinator that the majority of sperm donors in her clinic do not inform their family of their donations, and that she had witnessed the breakdown of a number of relationships when the donor later revealed to his partner that he was part of a donation programme that had

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[372] The Telegraph (26 November 2012) *Fertility treatment waiting times halve after increased payments to donors*, available at: http://www.telegraph.co.uk/health/healthnews/9696083/Fertility-treatment-waiting-times-halve-after-increased-payments-to-donors.html. The Telegraph contacted a total of 97 fertility clinics, and found that the average waiting time for treatment with donor eggs was 13.1 months in October 2011 compared with 6.75 months in October 2012. See also: Manchester Fertility Services (10 January 2013) *Donor eggs ready now for immediate IVF treatment*, available at: http://www.manchesterfertility.com/blog/item/donor-eggs-ready-now-for-immediate-ivf-treatment/, where it is reported that "if you need a donor egg to have a baby, then we have donors ready and waiting for you at our clinic. Despite some media reports and the continued, common misconception that infertility clinics still have lengthy waiting lists for donor eggs, at our clinic we actually have more than enough donors to meet current demand."

[373] Sweden, the first country to remove donor anonymity, appeared to have a similar experience: see Daniels K, and Lalos O (1995) Ethics and society: the Swedish insemination act and the availability of donors *Human Reproduction* **10(7)**: 1871-4.

[374] See, for example, BioNews (11 July 2011) *Sperm, smoking, screening and more*, available at: http://www.bionews.org.uk/page_101473.asp.

[375] Factfinding meeting with professionals involved at the time of donation, 22 June 2012.

[376] Murray C, and Golombok S (2000) Oocyte and semen donation: a survey of UK licensed centres *Human Reproduction* **15(10)**: 2133-9. Forty-three per cent of clinics recruited students as sperm donors; no information is provided as to the percentage of clinics who recruited egg donors who were students. See also: Murray C (1999) *Recruitment and supply of egg and semen donors in the UK: a qualitative report* (Bury, Lancashire: National Gamete Donation Trust), where comments from clinic staff included: "We've found that leaflets in student bars work better than any other methods", and "We tried hospital radio, but it didn't work. They best population [to target] is students" (at page 115). The same report also addressed the motivations of older men, citing the observations of clinic staff that they "just want to help. Often their wives have just given birth and they are so overwhelmed that they want to give other people the chance to experience this", and that "a lot of them [older men] have friends who have gone through fertility treatment and realise the need for donors" (at page 118).

[377] See: Human Fertilisation and Embryology Authority (2005) *Who are the donors? An HFEA analysis of donor registrations and use of donor gametes over the last 10 years*, available at: http://www.hfea.gov.uk/docs/Who_are_the_donors_factsheet.pdf, at page 5.

[378] Factfinding meetings with people with personal experience of donor conception, 27 April 2012; with practitioners, 30 May 2012; and with professionals involved at the time of donation, 22 June 2012.

resulted in live births. She also noted that some sperm donors who do tell their families about their donation find that their parents are distressed by the idea that they have grandchildren that they will never meet.[379]

4.54 This experience in one clinic is not, of course, necessarily representative of wider donor experience; clinics that actively encourage potential sperm donors with partners to involve those partners in their decision-making may prompt very different experiences.[380] The experience of egg donors may also potentially differ considerably from that of sperm donors at the time of donation, given the very different kind of procedures involved. In one clinic-based study of egg donation, all but one of 31 donors had told someone that they had donated; almost all partners were described as "very supportive", and more than half of the donors' mothers and fathers were also "very supportive."[381] However, some participants did report more negative reactions, with one lesbian donor, for example, noting that "all were supportive, except that mother took a long time to accept that if any children were conceived they would not be anything to do with me." Another donor's mother felt that the donor had 'given away' her grandchildren, and three (two of whom were known donors) felt that donation had had a negative impact on their relationships.

4.55 By contrast with the experience of sperm donors described above of a London clinic, over 90 per cent of partnered respondents in a 2012 survey of sperm donors (predominantly members of the US-based DSR) had told their partner that they were a donor.[382] While most of the wives/partners of donors in this survey were open to the idea of their partner connecting with donor-conceived offspring, 15 out of 103 donors said that their partners were not open to such contact, and a further 17 made additional comments noting partners' reservations. Examples of concerns that were feared by, or actually experienced by, partners included the anxiety that "my desire to contact or meet my offspring is a sign that they (my wife and my daughter) are not enough" and "my wife had feelings of jealousy when I would spend time online chatting with my donor child's mother".[383] The issue of boundaries, both in terms of online and face-to-face contact, was clearly important in cases where contact had been made, and the authors of the survey suggest that "for a donor with his own family, it may be helpful to think of two families engaging with each other, rather than a donor and his offspring".[384]

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

[380] Indeed, in the Australian State of Victoria, where a potential donor has a spouse, written consent from the spouse is required before donation may go ahead. See: Johnson L, Bourne K, and Hammarberg K (2012) Donor conception legislation in Victoria, Australia: the "Time to tell" campaign, donor-linking and implications for clnical practice *Journal of Law & Medicine* **19**: 803-19.

[381] Fielding D, Handley S, Duqueno L, Weaver S, and Lui S (1998) Motivation, attitudes and experience of donation: a follow-up of women donating eggs in assisted conception treatment *Journal of Community & Applied Social Psychology* **8(4)**: 273-87. Eighty-four per cent of the 30 egg donors' partners were described as "very supportive"; 56 per cent of the women's mothers were also deemed to be very supportive, and 55 per cent of the women's fathers.

[382] Daniels KR, Kramer W, and Perez-y-Perez MV (2012) Semen donors who are open to contact with their offspring: issues and implications for them and their families *Reproductive BioMedicine Online* **25(7)**: 670-7: 73 per cent of participants were recruited via the DSR with the remainder contacted via internet-based groups such as a Yahoo group called 'Sperm donors'. Almost two thirds of these donors (primarily US-based) indicated that they had shared this information before they became seriously involved with their partner, while a number (unspecified) commented that the decision to donate had been a joint one. An earlier study in Australia of 22 sperm donors found that the majority of donors in a relationship assessed their partner as feeling either neutral or unenthusiastic about their being a donor; and only six of the 13 donors who were not in relationships at the time of the study stated that they would tell their future partner about their donation: Daniels KR (1991) Relationships between semen donors and their networks *Australian Social Work* **44(1)**: 29-35. Slightly more positive results were indicated by a later study which found that nine out of 19 donors suggested that their partner approved of their donation: Daniels KR, Ericsson HL, and Burn IP (1996) Families and donor insemination: the views of semen donors *International Journal of Social Welfare* **5(4)**: 229-37.

[383] Daniels KR, Kramer W, and Perez-y-Perez MV (2012) Semen donors who are open to contact with their offspring: issues and implications for them and their families *Reproductive BioMedicine Online* **25(7)**: 670-7, at 673 and 674.

[384] Daniels KR, Kramer W, and Perez-y-Perez MV (2012) Semen donors who are open to contact with their offspring: issues and implications for them and their families *Reproductive BioMedicine Online* **25(7)**: 670-7, at 676.

4.56 As the quotations above highlight, the impact of contact with donor offspring may extend beyond the sperm donor and his partner to other members of their family: in particular to their own children. Thirty-three donors participating in the study (out of the 95 donors with children) had, at the time, told their own children about the existence of donor-conceived siblings; 38 others said that their children were too young to tell, and most of these intended to tell them later. Of the 33 families where the children had been told, 23 were interested in meeting donor-conceived siblings, while ten were not. An earlier (2010) survey of DSR registrants, in which 63 sperm donors and 11 egg donors participated, also made brief reference to the reactions of donors' parents: two of the qualitative responses cited referred to the donor's mother or parents being "thrilled" with "these additions to the family" or "their new granddaughter".[385]

4.57 By definition, donors who join contact registers indicate a willingness to engage in some form of contact with, or provide further information for, people born as a result of their donation. By contrast, the image that donor-conceived people may "knock on the door" or "turn up on the doorstep" 18 years or more after donation is widely deployed to suggest that such contact may be experienced as unwanted or disruptive.[386] Such a scenario was strongly resisted by one donor-conceived person who contributed to the Working Party's factfinding meetings and who emphasised that there was no reason to think that donor-conceived people would 'force themselves' on to a donor who did not wish to meet them.[387] The fact that some donors who donated anonymously in the past have since joined contact registers (see paragraphs 2.16 and 4.25) demonstrates the willingness on the part of some to facilitate contact even where this was never envisaged when they first donated, although these numbers remain very small compared with the total number of past donors. A survey of past donors from one London clinic in the context of the development of the UK voluntary register (see paragraph 2.16) reported that more than three quarters of those willing to be interviewed were in favour of the creation of a voluntary register, and most of these would consider joining it if their partner agreed.[388] The proportion of these donors who in fact went on to register is not known. Some respondents to this survey also suggested that they might be willing to be contacted for information even if they had not chosen to register,[389] although the anecdotal experience of clinics cited to the Working Party in factfinding meetings suggested that past donors who donated anonymously are not necessarily responsive to such requests.[390]

4.58 Where the creation of a family through donor conception also involves surrogacy arrangements, the further question arises as to the impact of that arrangement on the surrogate's own family. A survey in 2012 of 'parental order reporters' (social workers who write court reports in connection with intended parents' applications for parental orders) reported concerns that insufficient attention was given to the effect on surrogates' children of their mother having a baby and then "giving it away".[391] Research conducted with 34 surrogate mothers one year after the birth of the surrogate child, however, found that, of the 32 surrogates who had their own child at the time, 26 reported that their child felt positively about the surrogacy arrangement during the

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[385] 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**: 638-4, at 643.

[386] An example of the strength of this image is found in a *Guardian* article from September 2012 where it was erroneously assumed that the removal of anonymity in 2005 applied retrospectively: "The concern is that 18-year-olds will be turning up out of the blue on doorsteps all over the country to meet their biological fathers and disrupting family life. Far from what your average altruistic donor anticipates at the time of providing a service designed to help infertile couples conceive". See: The Guardian (11 September 2012) *Dividing marital assets: is sperm included?*, available at: http://www.guardian.co.uk/law/2012/sep/11/marital-assets-sperm.

[387] Factfinding meeting with Rachel Pepa, 24 April 2012.

[388] Crawshaw MA, Blyth ED, and Daniels KD (2007) Past semen donors' views about the use of a voluntary contact register *Reproductive BioMedicine Online* **14(4)**: 411-7.

[389] It was also suggested that donors may want to be approached, but do not want to make the 'first move': Factfinding meeting with practitioners and researchers, 30 May 2012.

[390] Factfinding meeting with professionals involved at the time of donation, 22 June 2012.

[391] Crawshaw M, Purewal S, and van den Akker O (2012) Working at the margins: the views and experiences of court social workers on parental orders work in surrogacy arrangements *British Journal of Social Work*: e-published ahead of print, 10 April 2012.

pregnancy, while five said that their children's reaction was either neutral or ambivalent.[392] Both at the point of disclosure, and also at the point of 'handover', no children showed a negative response, according to their mothers. A follow-up of these surrogate mothers and their families approximately nine years later found that family relationships were functioning well. Almost all surrogates' own children (96%) and most partners (88%) reported positive views of surrogacy and said that they felt "proud" of the surrogate.[393]

**Curiosity or concern about the outcome of the donation**

4.59 Just as many donor-conceived people are curious about their donor (see paragraph 4.15), donors may experience curiosity about the outcome of their donation. In the 2012 US survey of sperm donors cited above (see paragraph 4.55), 'curiosity' about offspring was cited as a predominant theme, centred around how many children there were, their state of health and happiness, and whether there was any physical likeness between them and the donor. Research with 32 anonymous egg donors similarly emphasised curosity, for example with respect to appearance, although eight donors stated they never thought about the children who might have been born as a result of their donation.[394] A questionnaire survey of 48 donors who took part in an egg-sharing programme found that the majority (65%) of these donors, whether successful or unsuccessful with their own treatment, were willing to meet their donor offspring in the future. Just two of donors in this group expressed the view that they would prefer not to be contacted. The authors note, however, that this finding may lead to some donors feeling disappointed if donor offspring choose not to contact them in the future.[395]

4.60 In the 2010 survey of DSR registrants cited above, many donors expressed no "concerns" about being a donor.[396] However, just over a quarter of the 63 sperm donors said that they worried about their donor offspring's well-being, and almost as many mentioned concerns about possible legal or financial ramifications of donation, wanting to be able to contact donor offspring and not being able to, and how their own child might feel. None of the egg donors, by comparison, expressed anxiety about how their own child might feel, although three were concerned about wanting to contact donor offspring and not being able to. Just one sperm donor and no egg donors raised concerns about what parents and friends would think if they knew that the participant was a donor.

## Conclusions about evidence

4.61 The evidence available to the Working Party regarding the impact of disclosure or non-disclosure derives primarily from empirical studies of donor-conceived families; qualitative studies of the experiences of donor-conceived adolescents and adults; surveys of donor-conceived people, parents and (to a lesser extent) donors; and the experience of those working with donor-conceived people, their families and donors, in particular the DCN. This evidence points towards the conclusion that children whose parents begin to talk to them about their donor conception from an early age generally seem to integrate this information into their

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[392] Jadva V, Murray C, Lycett E, MacCallum F, and Golombok S (2003) Surrogacy: the experiences of surrogate mothers *Human Reproduction* **18(10)**: 2196-204. The remaining mother felt that her child was too young to understand during the pregnancy, but subsequently explained to him.

[393] Imrie S, Jadva V, and Golombok S (2012) The long-term psychological health of surrogate mothers and their families *Fertility and Sterility* **98(3), supplement**: S46.

[394] Fielding D, Handley S, Duqueno L, Weaver S, and Lui S (1998) Motivation, attitudes and experience of donation: a follow-up of women donating eggs in assisted conception treatment *Journal of Community & Applied Social Psychology* **8(4)**: 273-87.

[395] Gürtin ZB, Ahuja KK, and Golombok S (2012) Emotional and relational aspects of egg-sharing: egg-share donors' and recipients' feelings about each other, each others' treatment outcome and any resulting children *Human Reproduction* **27(6)**: 1690-701.

[396] 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(3)**: 638-45. Twenty-nine of the 63 sperm donors and seven of the 11 egg donors expressed no concerns.

developing sense of self, whereas donor-conceived people who discover their origins in adolescence or adulthood are more likely to be distressed, and this may impact detrimentally on the relationship with their parents. Thus it appears that, where parents aim to disclose to their children the facts of their conception, the optimal time is in their preschool years. Such early disclosure also avoids any risk of later harm arising as a result of unplanned disclosure or inadvertent discovery by the donor-conceived person of the means of their conception. However, while some parents who choose not to tell their children at an early age that they are donor-conceived later come to regret this decision, studies following the welfare of donor-conceived families have found that such families nevertheless function well up to early adolescence. There is little evidence at present from systematic longitudinal studies on how donor-conceived families function in later adolescence and into adulthood; and the qualitative studies of donor-conceived adolescents and adults relate almost entirely to those who have joined support networks or contact registries (primarily US-based), and who were conceived via sperm donation. Little is known of the attitudes and experiences of donor-conceived people who are not involved in such networks, or of those conceived through egg or embryo donation. The personal experiences of those who do not know they are donor-conceived remain, of course, unknowable.

# Chapter 5

## Ethical considerations

# Chapter 5 – Ethical considerations

## Chapter 5: overview

- Ethical consideration of the principles that should govern information sharing in donor conception should start from a focus on people, and relationships, rather than from abstract principles.

**Interests and rights**

- Important interests arise for each of the parties involved in donor conception: the significance placed by many on knowledge of, and contact with, those with whom they have close biological links; the value placed on having children and the autonomy of the family unit; the need for boundaries beyond which public/state interference is not acceptable; the privacy associated with personal information; the significance placed on the keeping of promises and honouring of contracts. These are often expressed in the language of ‘rights’.
- Using the language of ‘interests’, rather than ‘rights’, however, enables us first to ‘unpack’ what we know about the nature of those interests, and then go on to consider at a second stage the extent to which others might be held to bear responsibilities in connection with those interests.
- It is not the role of this Working Party to make any judgment as to the appropriate degree of importance to be attached by any individual to any interest. However, the extent to which these interests are widely expressed and shared is relevant to the degree of moral responsibility that this creates in others. In turn, this is relevant in determining what action may be demanded on the part of public bodies.

**Values**

- Many interests arise specifically in the context of relationships, and widely-valued characteristics of those relationships include *trust* and *honesty*. ‘*Openness*’ is also valued by many. Openness, however, is not necessarily synonymous with ‘honesty’: in particular, choosing not to disclose private information is not usually considered to be dishonest. Difficulties arise in the context of ‘openness’ in donor conception because information about donor conception may be simultaneously private information about the parents or donor, and information about the donor-conceived person. Openness in this context should not be regarded as intrinsically valuable, but rather as important in so far as it contributes to the quality of relationships within the family, and to the well-being both of parents and of donor-conceived people.

**Weighing interests**

- Where interests potentially conflict, the interests of one party to a relationship should not, as a matter of principle, automatically take precedence over any others. Accordingly, the interests of different parties always have to be weighed. In practice, it will fall to the parents of donor-conceived children to weigh the interests in any particular decision regarding disclosure, unless the risk of harm to others is sufficient to justify external intrusion into family life by third parties. Such power must be exercised responsibly.

**Responsibilities**

- The parents of donor-conceived children have a responsibility to avoid, where reasonably possible, any harmful consequences that may follow for their children from the fact that they were donor-conceived. Such responsibilities include a willingness both to take account of the evidence available regarding disclosure, and to engage as necessary with professional support, when determining what is likely to be best for their donor-conceived child in their particular circumstances.
- Responsibilities also arise for donors and for donor-conceived people. In choosing to donate, donors have a responsibility to think carefully about the consequences: for themselves and their own families; for the recipients of the donated gametes; and for the resulting person. In turn, donor-conceived people have a responsibility, commensurate with their age and understanding, to do their best to understand the reasons why their parents chose to create a family through treatment with donated gametes, and why they made the decisions they did about disclosure. Where the prospect of contact arises, donor-conceived people and donors each have a responsibility to be sensitive to the needs of the other, including the potential for impact on the other’s own family.
- Third parties, including both professionals and the state in its regulatory role, also have responsibilities. It is acceptable for third parties to take account of the welfare of any future child in providing reproductive treatment services, even though in such cases there is no possible ‘alternative life’ for the prospective child. However, interventions to prohibit treatment can only be justified where there is a risk of significant harm or neglect to future children. A failure to disclose to children that they are donor-conceived should not be regarded as constituting such a risk. Given the evidence of the importance attached by some donor-conceived people to information about their donor, both professionals and the state have a responsibility with respect to the collection and retention of such information.

**The stewardship role of the state**

- The state has a ‘stewardship’ role in providing conditions, whether physical or social, that help and enable people in making their choices. Having enabled and endorsed donor conception as a means of creating a family, the state should also be concerned to take action that is likely to promote the welfare of people affected by donor conception, where this can be achieved without unreasonably interfering with the interests of others. This should include encouraging a social environment where the creation of families through donor conception is seen as unremarkable: as one way among a number of others of building a family.

## Introduction: people and relationships

5.1 As the evidence reviewed in Chapter 4 reminds us, donor conception is first and foremost about *people*: the people who are conceived through donor gametes or surrogacy; the people who seek treatment with donor gametes in order to realise their wish to become parents; the people who donate eggs, sperm or embryos, or act as surrogates, in order to enable others to create families; and people who are close to those directly affected by donor conception. The Working Party takes the view that any debate about the ethical considerations that should inform public policy on donor conception should start not with the analysis of abstract principles, but with the people concerned, and the reality of their lives. 'People', in turn, do not exist in isolation but within a web of relationships with one another: such webs extend out beyond the 'family' (see paragraph 1.11) into the wider communities in which people live, work, play, go to school, socialise, worship and so forth. Within those relationships, individuals may have multiple roles: the Working Party heard from parents of donor-conceived offspring who are themselves donors, from an adopted person who became a donor, and of a donor-conceived person who himself became a donor, to name only a few such examples. More broadly, of course, roles and relationships evolve and change over time in all families and communities, as children grow up, take on adult roles in their communities, and themselves become parents.

### Box 5.1: People and relationships – quotes from donor-conceived people, parents, and donors

"No amount of 'information' about gamete providers can ever replace the role of the displaced and marginalised 'third party', biological parent. It is perfectly normal and understandable for a child to want to know simple and seemingly inconsequential things, such as if their father or mother owned a pet dog and what was it called, or at what age their parents learned to swim, or if they ever fell out of a tree and broke their arm. Such questions about a gamete provider cannot be answered from the data on a fertility clinic tick-box questionnaire. Parents represent family and family is about relationships, not about information." [Donor-conceived adult]

"I'd always known something wasn't quite right that there was something different about me but I just didn't know what, it was such a relief when I was finally told that I was donor-conceived. This meant all the feelings and suspicions I'd had were real. It didn't change the way I felt about my dad at all but I still want to know more. I'd love to know about my genetic family, to trace my family tree as well as draw a connection to my half siblings." [Donor-conceived adult]

"When people ask, 'who's your real father?', I pedantically stop them and say, 'My real father is the man who raised me.' That's *real* to me… There's a sperm donor and a parenting father and these roles both exist." [Donor-conceived adult]

"I carried him, felt him kick, gave him life. I am the mother and will love him so much that he will never question. I would have never had him if I had to tell." [Mother of child conceived through egg donation]… "I'm worried he's going to find out one day and turn against both of us because of our deceit. If I had 100% certainty [that he would never find out] it would never be an issue, it would be ok; but we don't and it's hanging over me, over us, like a big cloud." [Father of same child]

"Coming from a family background of secrets and lies, I was determined that no child of mine would ever be brought up like that. We had decided before even starting treatment that any child we had would be told the truth from an early age. It was easy to tell and I loved spending time making books to show and explain; as our son got older, we told him more details and answered all questions honestly. It feels really good to know that he knows about his genetic background. It has never been a problem or an issue!" [Mother of child conceived through egg donation]

"[Disclosure] is a decision that only the parents can take. It is no one else's business. No one undertakes the treatment needed to secure a donor-conceived baby lightly." [Prospective parent of donor-conceived child]

"My wife and I share a relationship with our children borne of bandages for scuffed knees, bedtime stories, and piggyback rides in the park. I treasure this. But someday they may want to meet you. Maybe someday you'll want to meet these wonderful people you helped to create." [Father of child conceived through sperm donation in 'Letters to my donor']

"The donor contributes an incredible gift to make this mission possible, at little or no benefit to themselves, and since anonymity ceased they live with the knowledge that at some point in the future, they may be contacted by a person who is their genetic offspring and half sibling to their own children and this is a massive responsibility to live with and not one I feel donors take lightly." [Egg donor]

"I have always treasured the knowledge that out there, somewhere, are my offspring. In my head I have kept a little calendar, ticking off your years… In a perfect world my donor-conceived children have no need of me, feel no gap, no distress, and no desire to find me. But for those that do, then I wish to be there for them, and willingly." [Sperm donor]

## Rights, interests, values and responsibilities

5.2 Much of the contemporary ethical and legal debate on information disclosure in donor conception has been phrased in the language of *rights*: the right of a donor-conceived person to know the truth about their origins and have information about, or contact with, their donor; the right of individuals or couples to become parents; the right of parents to decide for themselves how to bring up their children; the rights of individuals to their privacy (variously defined); the right of donors to have the original terms under which they donated honoured.[397] These rights claims seek to protect important *interests* for each of the parties involved: the significance placed by many on knowledge of, and contact with, those with whom they have close biological links; the value placed on having children and the autonomy of the family unit; the need for boundaries beyond which public/state interference is not acceptable; and the significance placed on the keeping of promises and honouring of contracts.[398] In turn, these interests are strongly associated with *values* or *goods*, such as love, trust, and openness within relationships.[399]

5.3 Starting from the language of rights, however, is effectively to start with *conclusions*: the conclusion that particular interests are of sufficient importance to impose duties on others to ensure that the right-holder is able to enjoy the interest in question.[400] Using the language of interests, on the other hand, enables us first to 'unpack' what we know about the nature of those interests, and then go on to consider at a second stage the extent to which others might be held to bear responsibilities in connection with the promotion or protection of those interests.

5.4 We note also that the language of rights is often perceived as one of conflict: of asserting the claims of one individual against another, with the intention that the rights of one will be held to 'trump' or extinguish the rights of the other.[401] It is also a language that encourages a focus on the individual: of one person's rights being isolated and pitted against another's. And yet, as we postulated above, a fundamental feature of all families (whether created through donor conception or otherwise) is that of complex, interweaving relationships, where action taken by one person, or impacting on one person, will have inevitable effects both on others and on the relationships between them. The language of 'interests', by contrast, offers a less adversarial tool for exploring what is at stake for the many different parties to donor conception and in the relationships that exist between them, and for identifying where interests coincide, as well as where they conflict. The language of interests is flexible: while the language of rights may suggest immutability and the need for enforcement, people's perceptions both of their own interests and those of others may change over time, allowing for mutual resolution.

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[397] For a summary of 'rights'-based claims, see: Jones C (2010) The identification of 'parents' and 'siblings': new possibilities under the reformed Human Fertilisation and Embryology Act, in *Rights, gender and family law*, Wallbank J, Choudhry S, and Herring J (Editors) (Abingdon: Routledge).

[398] By way of contrast, we note here the prominence of Hart's 'choice theory' of rights, which he developed in response to the Benthamite or 'interest theory': Hart HLA (1984) Are there any natural rights?, in *Theories of rights*, Waldron J (Editor) (Oxford: Oxford University Press), 77-90, at page 81. However, we have found an approach to rights that hinges, in part at least, on the notion of interests to be more appropriate to the subject matter here. In any event, Hart himself acknowledged that the choice theory cannot adequately explain either all legal rights or, more particularly, those which are part of social and political morality: Hart HLA (1973) Bentham on legal rights, in *Oxford essays in jurisprudence (second series)*, Simpson AWB (Editor) (Oxford: The Clarendon Press), as noted by Waldron J (1984) *Theories of rights* (Oxford: Oxford University Press), at page 9.

[399] Such values may understood to be intrinsic (ends in themselves) or as instrumental (contributing to another intrinsic good) - see paragraphs 5.22 to 5.33.

[400] See, for example, the discussion of 'interest theories' of rights in Waldron J (1984) *Theories of rights* (Oxford: Oxford University Press).

[401] We note that this is in the context of the language of rights being deployed rhetorically, or in the sense of rights as 'trumps'. International human rights law, by contrast, distinguishes between 'absolute rights' and 'qualified rights': interference with a person's qualified rights can be justified by reference to the rights and interests of others. We return to this point at the end of this chapter (see paragraph 5.72); our critique here relates to the rhetorical use of rights where no 'balancing' of competing rights claims is envisaged. For a discussion of the language of rights and the different ways in which it may be deployed, see: Tobin J (2012) Donor-conceived individuals and access to information about their genetic origins: the relevance and role of rights *Journal of Law & Medicine* **19**: 742-57.

5.5 This chapter will therefore consider the issues at stake first in terms of the *interests* of all the people concerned and the *values* associated with these interests, and then of the *roles and responsibilities* of those (both people and organisations) to whom one might potentially look for the protection, or promotion, of those interests. In some cases, an interest could be thought sufficiently strong to ground a moral right, with a corresponding moral duty on another to ensure that right is protected. Moreover, depending on the strength of the interest, it may then be considered appropriate to seek to protect that right in law, thus supplementing a moral duty with a legal one. We will therefore go on to consider, in Chapter 6, the implications of these interests and responsibilities for regulation within the UK, and in particular whether the nature and weight of any of those interests points to the need for regulatory change to provide for legally enforceable rights and duties in particular areas.

## Interests

5.6 We alluded above to the many parties involved in donor conception. We set out below a number of these parties, and the interests they may have in connection with the disclosure of information about donor conception, drawing on the research evidence currently available and the evidence presented to the Working Party, as summarised in Chapter 4. We note here that, depending on the individual, the strength of these interests ranges from the expression of a mild preference to the identification of essential conditions for the person in question. Some go further and claim that what is at stake is not limited to something they themselves feel strongly about, but something to be regarded as a universal or objective interest for any human being: an essential condition for 'human flourishing'. We take the view that it is not the role of this Working Party to make any judgment as to the appropriate degree of importance to be attached by any individual to any interest: as we noted in Chapter 1, there is tremendous plurality of opinion within the UK alone as to the meaning to be ascribed to gametes and the biological connections they create (see paragraphs 1.20 and 1.21), and we have demonstrated in Chapter 4 a similar range of feeling among donor-conceived people as to what it means to be donor-conceived (see paragraphs 4.13 to 4.20). However, the extent to which these interests are widely expressed and shared *is* relevant to the degree of moral responsibility that this creates in others and, in turn, to the required policy response. In this connection, the claim to objectiveness or universality can be understood as an assertion that the interest in question is one that deserves, or even demands, special consideration by others.

### *Donor-conceived people*

5.7 As we have seen in Chapter 4, some donor-conceived people have expressed very strongly the view that knowledge of their biological origins, in the sense both of the truth about the circumstances of their conception and of knowledge of their donor, is essential to both their sense of self and to their social identity: their understanding of 'who they are', and of where they fit in the world.[402] For some, this knowledge is so important that seeking it has become a major focus of their adult lives, and 'information' alone is not enough: what is really desired is contact, with the subsequent possibility of forming meaningful relationships with their donor. Indeed, it has been argued in the literature on donor conception that a child's knowledge of, and relationship with, their biological progenitors is "a basic good on which most people rely in their pursuit of self-knowledge and identity formation".[403] For others, what might be described as 'biographical' information about their donor, information that would help contribute towards a 'back story' or 'narrative' for their life and give them an idea of the kind of person who provided half their biological material, is valuable and significant, without necessarily being regarded as

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[402] Haslanger helpfully distinguishes between a sense of 'self', concerning "the cluster of basic traits that allow an individual to function as an agent, some of which are measured by the notion of 'personal identity'… and 'social identity' to refer to a person's reference group orientation": how one navigates one's relationship with one's reference group. See: Haslanger S (2009) Family, ancestry and self: what is the moral significance of biological ties? *Adoption & Culture* **2(1)**.

[403] Velleman JD (2005) Family history *Philosophical Papers* **34(3)**: 357-78, at 365.

vital to their well-being. Others again express very little interest at all in information about their donor (see paragraph 4.22). However, a much clearer message emerges with respect to being told in the first place that they are donor-conceived: in a survey of members of the Donor Sibling Registry (DSR), only one per cent of donor-conceived adolescents and adults said that they wished they had never been told, indicating a very strong preference for having this information even where the initial experience of finding out may be negative (see paragraphs 4.14 to 4.20).

5.8 It is clearly not possible to say that *all* or *most* donor-conceived people, if aware of the fact that donor gametes were used in their conception, regard information about their donor, or the possibility of subsequent contact, as being of overwhelming importance in their lives and crucial for their ability to flourish as an individual. The wide spectrum of opinion even among the relatively small number of donor-conceived people who spoke in person to the Working Party (a spectrum reflected also in surveys of donor-conceived people belonging to the DSR - see paragraph 4.14) suggests that it is hard to substantiate the claim that information about one's biological connections is a 'basic good' in the sense of something that is *essential* for human flourishing, for having any kind of 'good life'. It does, moreover, seem likely that the environment in which a person grows up, and in particular the value placed both by the person's family and their wider community on the importance of biological connection and the influence of genetic inheritance on life choices, will affect how donor-conceived individuals conceptualise information about their donor (see paragraphs 1.27 to 1.29 and 4.19). Nevertheless, it is certainly the case that *some* donor-conceived people do view such information, and contact, as absolutely core to their sense of self and their social identity, and have suffered harm as a result of not knowing until later in life that they were donor-conceived, or in not having access to the information that they have sought. The possibility of contact with, and possibly a lifelong relationship with others conceived through the same donor ('donor-conceived siblings') is clearly also found by some to play an important part in their life (see paragraph 4.25).

5.9 It is, of course, impossible to know how donor-conceived people who do *not* know how they were conceived would judge their own interests. While we know from the longitudinal studies of non-disclosing families that these function well, at least into early adolescence (see paragraph 4.30), we cannot know how the donor-conceived people concerned would value the opportunity to know about their means of conception or about their donor, and we cannot judge how 'never knowing' may affect a person's flourishing as an individual. All that can be noted on this point is that very few donor-conceived people (albeit of a sample of those joining a contact register) wish that they had not been told; and that those who are told very young appear to have positive experiences of absorbing the fact of being donor-conceived into their life narrative, without being exposed to the risk of shock from inadvertent disclosure or discovery. The possibility that donor-conceived people may feel some sense of "genetic disconnection" and hence begin to have doubts about their biological connection with their parents is also raised in some qualitative studies.[404]

5.10 More generally, donor-conceived people, like all people, have a strong interest in a happy, well-functioning family life during childhood and beyond, and in family relationships that will help them develop into well-adjusted adults. Both during childhood and later, they also have an interest in knowing that they are not at significant risk of developing serious genetic conditions from their donor, and in not providing misleading 'family history' (i.e. that belonging to their non-biologically-connected parents) to their doctors; they also have an interest in receiving other medical information about their donor if this would have an impact on the health care they receive (see paragraphs 3.24 and 3.26).

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[404] See, for example, Daniels KR, Grace VM, and Gillett WR (2011) Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception *Human Reproduction* **26(10)**: 2783-90. Similar points were made to us by Rachel Pepa and Christine Whipp (factfinding meetings on 24 April 2012 and 16 July 2012). However, adolescents in natural conception families may also experience doubts as to whether they 'belong' with their families. See, for example, the views expressed at Experience Project (2013) *I feel like I don't belong*, available at: http://www.experienceproject.com/groups/Feel-Like-I-Dont-Belong/33530.

## Prospective parents

5.11 The desire to have children, to create a family 'of one's own', is widely recognised as a very powerful human drive. While a minority of people do not feel any such desire and actively choose not to have children, the lengths to which some individuals and couples will go in order to have a child provides some indication of the strength of feeling engendered, and the role played by the creation of a family in a lifetime narrative. Infertility has been described as a rupture in the life trajectory that people have imagined for themselves. All societies structure the life course around phases with attendant expectations. Partnership or marriage and having children are a significant part of the imagined trajectory of social life, which is not to say that all members of a society subscribe to, or desire, that 'phase' (which for some confers adulthood) but that it is widely disseminated as an ideal. Infertility disrupts life plans: it breaks a perceived continuity into the future.[405] The expectations of an older generation to have grandchildren, and the desire of peers to share similar experiences, adds additional social pressure. The distress of involuntary childlessness may be acute, and those who do not go down the route of bypassing infertility, through assisted reproduction or adoption, have to reconfigure their life stories and their senses of self in ways that project them into a different future from the one they had previously imagined.

5.12 Before the development (and general availability) of treatment services involving donor gametes, the only other option open to those who wanted a family, but who were unable to conceive with their own gametes, was adoption. However, as noted earlier (see paragraphs 1.23 and 1.24), comparisons between adoption and donor conception are not straightforward. In particular, it has never been appropriate to regard adoption as a simple 'solution' to infertility, in that adoption services are essentially services for *children*, not for prospective parents. The placing of children for adoption may indeed enable couples and individuals who have been unable to have a biologically-related child to have the family life they strongly desire. However, this is not the primary purpose of adoption services, which is rather to make the best possible arrangements for the particular child for whom those services have responsibility, rather than to meet the needs and desires of prospective adoptive parents. Those who wish to adopt will not necessarily always be able to do so.

5.13 Treatment with donor gametes, by contrast, leads to the birth of a child, who would not otherwise have existed, directly into that child's social and legal family. Thus the wider availability of treatment services involving donor gametes, combined also with changing social attitudes to parenting by same-sex couples and single women, has opened up the possibility of a new kind of parenthood for many couples and individuals who, in the past, would have been obliged to accept the impossibility of creating their own family. This form of parenthood differs from adoptive parenthood further through the existence, for the most part, of a genetic link with one of the child's parents,[406] as well as through the experience of pregnancy, birth and early nurture. Any proposed action that might limit access to such services (whether through any form of screening of those eligible to access services, or through reduced availability of donor gametes) would therefore have the potential to affect, or indeed to prevent altogether, the realisation of the reproductive interests of those for whom these services provide their only route to parenthood.

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[405] Becker G (1999) *Disrupted lives: how people create meaning in a chaotic world* (Berkeley: University of California Press).

[406] In embryo donation, or 'double donation' of egg and sperm, no such genetic link will, however, exist; it is also possible for there to be no genetic link between children born as a result of a surrogacy arrangement and their social family, although in the UK such a link is required for a parental order to be made. Equally, it is possible for there to be full genetic links between the legal parents and the child, where a surrogate mother carries a child conceived from the gametes of both intended parents.

## Parents (and their wider families)

5.14 While the interests of prospective parents are firmly focused around the establishment of a pregnancy, once a child is born the ‘prospective’ parents become parents, who share the same interests as parents in any other family. Such general ‘parental’ interests include respect for the privacy and autonomy of family life, reflecting the importance placed on being able to bring up one’s children in accordance with one’s own values, perhaps with support on request from professionals or state services but without such support being forced on them against their will. While the nature of this ‘respect’ for parental control of family life will vary significantly in different societies, and over time (we note, in particular, greatly varying cultural attitudes to the role of extended family members in the bringing up of children), we suggest that respect for the autonomy of family life, however defined, may be considered to be essential for the well-being both of the parents and of their offspring, and that hence this interest demands special attention (see paragraph 5.6).[407] Parents of donor-conceived children may also have a strong interest in being seen as the ‘only’ or ‘real’ parents of their child (see paragraph 2.1), and in being able to leave behind them the often difficult and stressful period of fertility treatment. For some, the possibility of their child later identifying the donor, resulting in potential contact with both the donor and the donor’s wider family, may be perceived as an unwelcome intrusion into their own family space.

5.15 Parents of donor-conceived children may, on the other hand, have interests in accessing information about the gamete donor who enabled them to become parents. However, as was the case in relation to the views of donor-conceived adults, responses to the Working Party’s consultative activities demonstrated a very wide range of views by parents as to the nature of this interest: from those who felt that parents needed to know little or nothing about the donor (because they were looking for “just a bit of genetic material that matched [partner]”[408]), to those who felt that detailed biographical information was crucial in order for them to help their children absorb the fact of their being donor-conceived into their understanding of themselves.[409] All parents, however, have an interest in being reassured that their child’s donor has been appropriately screened for significant genetic conditions and hence the risk of the transmission of serious conditions is very low; they also have an interest in receiving medical information about the donor if such information has implications for the health care of their child, and hence for their ability to parent (see paragraphs 3.24 and 3.26).

5.16 A few respondents went beyond emphasising the importance of biographical information about their child’s donor to suggest that ongoing contact with the donor, donor-conceived siblings, or both, would be in the interests of both parents and offspring during the donor-conceived person’s childhood, particularly where children were being brought up in single parent households.[410] The number of parents of donor-conceived offspring signing up to contact registers such as the DSR while their child is still young illustrates that such contact is regarded positively by a significant number of donor-conceived families, particularly those headed by solo mothers or same-sex couples (see paragraph 4.28). Such a focus on ‘family to family’ contact emphasises how the wider family or kinship network may also potentially have interests arising out of the sharing of information about donor conception. The Working Party was told of ongoing research with the grandparent generation in donor-conceived families, which highlighted the possibilty of generational differences with respect to privacy and openness about donor conception leading to family conflict: some grandparents, for example, “frankly could not

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[407] See, for example, how experimental social models such as kibbutzim have shifted back from fully communal arrangements to a greater focus on the family: http://www.jewishvirtuallibrary.org/jsource/Society_&_Culture/kibbutz.html (‘raising children’). See also the discussion of the ‘goods’ found in familial relationships in: Brighouse H, and Swift A (2009) Legitimate parental partiality *Philosophy & Public Affairs* **37(1)**: 43-80.

[408] Factfinding meeting with people directly affected by donor conception, 27 April 2012.

[409] Factfinding meeting with people directly affected by donor conception, 27 April 2012.

[410] Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

understand the need to talk about it in the first place".[411] In contrast, some grandparents reported finding it a burden being required to maintain the secret about treatment with donor gametes: for example where women undergoing treatment confided in their mothers for emotional support but asked them to tell no one else.[412]

## *Donors (and their wider families)*

5.17 Two very different sets of interests might be identified for donors: those that arise in connection with the original terms under which they donated gametes; and those that arise in connection with the possibility of a relationship with their donor-conceived offspring (and potentially also the donor-conceived person's family). People who donated gametes before the change in the law in the UK in 2005 donated on the understanding that their identity would never be made known to any resulting offspring, and may feel strongly that such understandings (whether or not they legally constituted a contract) should be honoured. Such an interest may be defined narrowly, in terms of 'fair dealing' with donors, or more broadly in terms of the importance of maintaining trust in health care systems (whether private or NHS). Whether or not the relationship between donors and clinics may be strictly defined as a 'patient'/professional relationship, it is clear that donation takes place in a clinical relationship involving expectations of confidentiality and trust, and that both the donors involved, and the wider health care system, have interests in the trust in that system being maintained.[413]

5.18 The way in which donors view their interests with respect to their donor-conceived offspring is likely to be strongly affected by the environment in which they donated (see paragraph 5.34). Those who donated at a time when the culture of donation was based on anonymity and non-disclosure may feel that they have few, if any, interests in knowing about the future welfare of any offspring (see paragraph 4.59). Those, on the other hand, who donated on the basis that their donor-conceived offspring would be able to obtain identifying information about them on reaching the age of 18, are more likely to have thought carefully about the future person or persons who might be created as a result of their donation, and to feel that they have an interest in being reassured about their future well-being (see paragraph 4.59). Such donors also have an interest in being able to prepare for the possibility of future contact, both psychologically and practically, for example through telling their own family about the existence of donor-conceived offspring. In the context of such potential contact, donors further have an interest that any people conceived as a result of their donation have been able to integrate the knowledge of their conception well into their lives, and do not have expectations of the donor (for example of a 'parental' relationship) that the donor is unable to meet.

5.19 Some donors would go further, and claim an interest in actively ensuring the welfare of their donor-conceived offspring during their childhood: for example by specifying the kind of home in which the child may be brought up, or through direct and ongoing contact during their offspring's childhood.[414] In some cases of known donation, these interests are explicitly recognised in the terms of the agreement between the donor and recipient parent(s) (see paragraph 2.4). The

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[411] Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester, responding to the Working Party's call for evidence. The end of their research project, which is entitled 'Relative strangers', was marked by a conference on 'Genetic identities, personal lives and assisted donor conception', which took place on 22 March 2013. See: http://www.socialsciences.manchester.ac.uk/morgancentre/events/2012-13/relative-strangers-manchester/index.html. See also: Morgan Centre for the Study of Relationships and Personal Life, University of Manchester (2013) *Relative strangers*, available at: http://www.socialsciences.manchester.ac.uk/morgancentre/research/relative-strangers/index.html.

[412] Nordqvist P, and Smart C (2013) Relational lives, relational selves: assisted reproduction and the impact on grandparents, in *We are family? Perceptions of relatedness in assisted conception families*, Freeman T, Ebtehaj F, Graham S, and Richards M (Editors) (Cambridge: Cambridge University Press).

[413] See: Rees A (2012) Keeping mum about dad: 'contracts' to protect gamete donor anonymity *Journal of Law & Medicine* **19(4)**: 758-68 for a more extended discussion of the legal basis on which understandings about anonymity might rest, and the extent to which there might be public policy reasons for respecting them.

[414] Factfinding session with people with personal experience of donor conception, 27 April 2012. The desire on the part of some donors to control the environment in which a child, born as a result of their donation, will grow up is also found in the restrictions placed by some donors on the use of their donated gametes, for example in specifying particular family forms.

current regulated system of 'unknown' donation, on the other hand, excludes the legal recognition of any such interest: the underpinning premise of the provisions in the Human Fertilisation and Embryology Act and associated regulations is that those donating gametes or embryos to strangers have no claim in respect of, or responsibility for, any resulting offspring. In legislating in 2004 to ensure that future donor-conceived offspring would be able to contact their donor at the age of 18, the Government recognised the potential for donor-conceived adults to have an interest in contacting, and possibly developing a relationship with, their donor. However, it did not acknowledge any corresponding interests on the part of donors, other than a statutory entitlement from 2008 to know the number, sex and year of birth of any offspring born as a result of their donation.

5.20 Donors' own families – in particular their partners and children – also potentially have interests arising out of the sharing of information about donor conception and potential contact between donor-conceived people and donors. While the extent to which donors' partners are involved in the decision to donate, or are told of an earlier donation varies considerably, all partners have an interest in ensuring that contact with donor-conceived offspring does not have a negative impact on their own family unit (see paragraphs 4.53 to 4.55). The strength of feeling that donation may potentially engender in some donors' partners is demonstrated by recent representations put to the Human Fertilisation and Embryology Authority (HFEA) that donation should not be permitted without the consent of the donor's partner.[415] Similarly, donors' own children may or may not welcome the idea of contact with their parent's donor-conceived offspring (see paragraph 4.56); those who do desire contact cannot initiate it, but must wait for the donor-conceived person to do so if they wish. Donors' parents may feel a sense of loss that they have grandchildren whom they cannot see grow up, and/or actively embrace a grandparental role where the sharing of identifying information makes contact possible (see paragraphs 4.53 and 4.56).

5.21 Finally, donors and their families also have an interest in being informed in the exceptional case where a donor-conceived person has been found to have a serious genetic condition (see paragraph 3.26). Information about such a diagnosis (which does not of itself need to involve any identifying information about the donor-conceived person) could have medical implications both for donors themselves, and for any other genetic offspring, whether their 'own' or donor-conceived.[416]

## Values in relationships

5.22 We have identified above some of the interests that may be at stake in connection with information disclosure about donor conception for each party affected: for donor-conceived people (both as children and as adults); for prospective parents; for parents; for donors; and for the wider families of all the above. However, many of these interests arise specifically in the context of the relationships (actual and potential) that may exist between these different parties. As we saw in Chapter 4, when people speak about the interests at stake in donor conception, they often refer to *values* that they regard as essential in shaping those relationships, and we now turn to a consideration of these values.[417]

5.23 Both *trust* and *honesty* are often identified as being aspects of relationships that are highly valued as playing a central part in promoting well-being within families. We saw earlier how

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[415] Daily Mail (26 August 2012) *Wife whose husband became secret sperm donor calls for change in the law to require partners' consent*, available at: http://www.dailymail.co.uk/news/article-2193780/Sperm-donation-Wife-man-secretly-donated-sperm-calls-spouses-consent-mandatory.html.

[416] See also: Raes I, Ravelingien A and Pennings G (2 July 2012) *Abstract book of the 28th EHSRE annual meeting: ethics of donation and surrogacy (session 21) - the right of the gamete donor to know his/her genetic offspring (O-o85)*, available at: http://humrep.oxfordjournals.org/content/27/suppl_2/ii32.full for a more extended discussion of the interests of donors and their families.

[417] We note here that, while the 'values' we identify may also be considered to be virtues, in the sense of character traits of people (the extent to which individuals are trustworthy, honest, etc.), our focus here is on the characteristics of *relationships*, and what it is that is valued in them by those who have a stake in donor conception.

concerns about trustworthiness and truth-telling within parent-child relationships may influence parents' decisions to disclose or not disclose the use of donor gametes in conception, and in the reactions of some donor-conceived people when they found out late or inadvertently about the circumstances of their conception (see paragraphs 4.16 and 4.17). Similarly, references to trust and honesty arose in the evidence given to the Working Party when respondents explained the reasons underpinning their own decisions to disclose or not. The value placed by many on kinship relationships founded on trust and honesty may be explained by the nature of those relationships: predicated on intimacy, the shared vulnerability of an interconnected life, and the inherent dependency of children, when young, on those who care for them (a dependency which over time may invert, as parents age and children grow up and take on adult roles).[418]

5.24 A further value that is often put forward in the context of relationships is that of *openness* or *transparency*. While these terms may at times be used synonymously with 'honesty' or 'truthfulness', we suggest this need not be the case: a person who chooses not to share information is choosing not to be 'open' but is not necessarily being dishonest. We explore this distinction further below.

5.25 Some of those who shared their experiences with the Working Party saw openness within relationships (contrasted explicitly with 'secrecy' or 'deception') as inherently good: for example it was argued that an absence of such openness creates a 'secret system' of those who decide to keep information secret, those who become secret-holders, and those who are unaware and hence excluded from the secret.[419] Often it is people directly affected by the information who belong in this excluded 'unaware' group: as one donor-conceived adult commented forcefully: "You can't make a decision about whether or not to tell somebody something you don't know yourself".[420] Some of the parents to whom the Working Party spoke emphasised that they saw information about their child's conception as information that they as parents 'held in trust' for that child, with a duty to pass it on appropriately during childhood, until the child was mature enough to take on ownership of it for themselves.[421] On such a view, openness about donor conception is seen as something automatically owed by the parent to the child because of the nature of the information at stake. Sharing information is thus seen as the good or right thing to do in and of itself, regardless of broader consequences, whether good or bad.

5.26 The views on openness expressed by some of the parents and practitioners who came to meet the Working Party also appear in the literature on donor conception: it has been argued that "deception of this nature" (that is, failure to disclose to children that they were conceived through donated gametes) "constitutes a wrong in that it violates the respect owed to that child", regardless of any consequential harmful outcome.[422] Such a categorical wrong may be understood as an 'existential lie' (a 'Lebenslüge'); a fundamental deception on the part of parents about the nature of their children's being, that cannot in any case be justified and is inherently disrespectful.

5.27 Others, however, question whether there is a simple physical 'truth' that should automatically take precedence over other kinds of 'truth' (such as those arising from gestation or from active caring and love), noting that openness and secrecy within families are not simply matters of personal integrity but also of social, legal and cultural context.[423] It is argued that 'family

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[418] We note here, however, that such an understanding of kinship relationships cannot be claimed to be universal: in some cultures, much greater weight may be placed on, for example, authority, devotion or obedience. See: Montgomery H (2009) *An introduction to childhood: anthropological perspectives on children's lives* (Chichester: Wiley-Blackwell).

[419] Factfinding meeting with practitioners, 30 May 2012.

[420] Rachel Pepa, responding to the Working Party's call for evidence.

[421] Factfinding meeting with people directly affected by donor conception, 27 April 2012. Similar views were expressed in the meeting with practitioners on 30 May 2012.

[422] See, for example, Cowden M (2012) 'No harm, no foul': a child's right to know their genetic parents *International Journal of Law, Policy and the Family* **26(1)**: 102-26.

[423] Smart C (2009) Family secrets: law and understandings of openness in everyday relationships *Journal of Social Policy* **38(4)**: 551-67; Smart C (2011) Families, secrets and memories *Sociology* **45(4)**: 539-53. See also: Bowlby R (2013) *A child*

secrets', while not necessarily good things, may be felt to be necessary for the preservation of relationships; and that physical or genetic truth may be less important than stabilising fictions. The perceived need for secrecy about particular things at particular times may be understood as a response to social vulnerability, and it is suggested that "an emergent insistence on genetic truth and transparency may simply create other forms of vulnerability, especially if cultural mores and familial norms have not changed greatly".[424] Some respondents to the Working Party's call for evidence similarly challenged the notion that openness or transparency should automatically be seen as a positive value in itself, noting that while concealment allows for the option of future disclosure, openness does not allow for an option of future concealment.[425] The concern about the irrevocability of disclosure underlies the hesitancy experienced by a number of parents about disclosing to their donor-conceived offspring when they are very young: the fear that young children cannot be expected to keep this information to themselves – and yet that when they are older they themselves may wish that they had been more reticent.[426] As one prospective parent put it to us: "Once information is 'out', there is no way of putting it back 'in' again: a child who discloses to others when they are young cannot recreate their own privacy."[427]

5.28 The difficulty, if not impossibility, of making a limited disclosure only to the donor-conceived person himself or herself brings into consideration a further value often cited in the context of relationships, that of *privacy*: openness with a young child inevitably entails openness within a much wider family and community circle. Thus, in addition to concerns that parents may have as to their children's own future wishes about sharing information about donor conception, privacy concerns also arise more directly at the time of disclosure, in terms of the impact on the parents, on the child, and on other close family members. Openness between parents and child is highly likely to lead to information that parents may regard as deeply private being publicly discussed – for example by other parents at the child's nursery or school. At worst, this wider disclosure may lead to stigmatisation and even exclusion from the parents' broader family or social or religious community. The way in which the sharing of information within the family cannot be separated out from disclosure to the wider community was emphasised to us in a response to our call for evidence based on an ongoing research project looking at the experiences of parents and grandparents of donor-conceived people: it was commented that "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".[428]

5.29 The terms 'truth', 'honesty', 'openness', 'transparency', 'privacy', 'secrecy', 'deception' and 'lies' arise repeatedly in research with people affected by donor conception when describing attitudes to disclosure and non-disclosure. Each of these terms carries with it particular moral connotations associated with the perceived desirability of disclosure or acceptability of non-disclosure. In particular, the term 'privacy' (with its connotations of justifiable constraints on information sharing) and the term 'secrecy' (with its implications of cover-up and intent to deceive) may be used by different people to justify or criticise the same decision not to disclose; and it may be very difficult to distinguish between what is legitimately private and what is inappropriately secret. It was suggested to the Working Party that one way of making this distinction was to define secrecy as "withholding information that is vital to a child's identity formation or well-being, hence causing detriment to the child".[429] Such a definition, however, again takes as its starting point the vital importance of information about donor conception to donor-conceived people in all cases, which, as we have already noted, is a claim that is not

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*of one's own: parental stories* (Oxford: Oxford University Press), in particular chapter 12, *Parental secrets in Thomas Hardy's The Mayor of Casterbridge*.

[424] Smart C (2009) Family secrets: law and understandings of openness in everyday relationships *Journal of Social Policy* **38(4)**: 551-67, at 564.

[425] Professor Marilyn Strathern, responding to the Working Party's call for evidence.

[426] Factfinding meeting with researchers, 30 May 2010.

[427] Factfinding meeting with prospective parent, 17 July 2012.

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

[429] Factfinding meeting with practitioners, 30 May 2012.

substantiated (see paragraph 5.8). A very different argument might also be made: that if a parent believes that there is 'nothing to tell' (see paragraph 4.9), then there is no 'secrecy' or 'deception' involved in not disclosing. However, this argument, too, cannot stand alone: just because the parent regards the information as 'nothing', this does not mean that their children would regard its value in the same way, if ever put in a position to make such a judgment.

5.30 The difficulties encountered in disentangling what (in the context of information about donor conception) may be rightly regarded as private, and what constitutes a secret from which the donor-conceived person is dishonestly or disrespectfully excluded, brings us back again to the central significance of relationships in donor conception. Information that a person is donor-conceived is indisputably information *about* that person; it is also, however, information *about* their legal parents, and potentially also *about* the donor if the information serves to identify them.[430] Where treatment with donor gametes was sought because of infertility on the part of one or both of the legal parents, that information may be regarded as particularly sensitive personal information. Just as it would be wrong to dismiss the anger and distress of many donor-conceived people about the way information has been withheld from them just because not every donor-conceived person shares these views, it would also be wrong to downplay the extent to which, for some parents, personal information about the circumstances in which their children were conceived is deeply private.

5.31 Similarly, while UK donors are now recruited with a very clear understanding that identifying information about them will be shared, on request, with any resulting offspring at the age of 18 (and non-identifying information shared with the prospective parents even before treatment), donors recruited before 2005 donated on the clear understanding that identifying information would *not* be given out to anyone. Many of these may feel strongly that this personal information is private to them (see paragraph 4.57). As the different examples cited above demonstrate, the way in which information about donor conception may be regarded by a number of different parties as 'their' (personal) information relates both to the fact of donor conception (and in many cases the associated infertility) and to identifying information about the donor. *Non*-identifying information about the donor, on the other hand, may fall into a different class of information, in that it could potentially be shared with both parents and offspring without risk of the donor's privacy being breached, although the increasingly fine line between 'identifying' and 'non-identifying' information should be noted (see paragraph 2.14).

5.32 Thus, information relating to donor conception may both be said to be personal (in many cases also regarded as private) information relating to each of the parties involved, and 'interpersonal' information, in that more than one person has a stake in it. Moreover the very nature of that information is that it is about relationships, or potential relationships: relationships created in the absence of biological connection, and the possibility of future relationships created in adulthood on the basis of that biological connection. Non-disclosure of information about oneself (by a parent, or by a donor) could be characterised as an action based on concern for privacy, while non-disclosure of information about the other (by a parent about their donor-conceived child) could equally well be characterised as secrecy or dishonesty. Neither can provide a decisive ethical guide to action, because the information is at one and the same time information about all of these people.

5.33 Rather than starting from the point that 'openness' in donor conception is intrinsically valuable, it is helpful to seek to identify more precisely what it is that an emphasis on openness seeks to promote. **The Working Party takes the view that openness to children about their means of conception is important in so far as it contributes to the quality of relationships within the family, and to the well-being both of parents and of donor-conceived people**. Thus, openness may or may not be beneficial, depending on the context. In many cases, openness

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[430] The way in which information may be both 'personal' and 'shared' is also recognised in data protection law: see Taylor M (2012) *Genetic data and the law* (Cambridge: Cambridge University Press).

within the family will undoubtedly contribute significantly to the well-being of family members and to the relationships between them. In some cases, however, openness about donor conception may potentially have the opposite effect, particularly where families created through donor conception come from communities where donor conception itself is not widely accepted, or where 'openness' more generally is not necessarily given the same value as it currently has in Euro-American societies.

### *The role of the environment*

5.34 As we noted earlier (see, for example, paragraphs 1.27 to 1.29), the wider social and legal environment in which parents bring up their children exercises a substantial influence both on what is seen as acceptable, and what is, or should be, valued in family relationships. Research with donor-conceived families brings to light the concerns expressed in the early days of donor conception that the use of donor gametes, or indeed of any reproductive technology such as IVF, would be immoral or 'unnatural';[431] and such attitudes seem highly likely to have influenced both past professional advice to parents not to tell anyone about their treatment, and parents' own levels of comfort with the way in which they created their family. The extent to which the use of donor gametes is regarded as an acceptable way of creating a family (a key factor influencing the extent to which it will, in practice, be feasible for families to be open if they wish) continues to vary considerably between and within communities (see paragraphs 4.33 and 4.40). Stigma is still widely associated with infertility, especially male infertility.

5.35 As the significant shift in professional and legal attitudes to questions of openness and information sharing in donor conception has demonstrated, this wider social 'environment' in which parental decisions are made can, and does, change. Technological developments enabling the easier sharing of information, and also potentially contributing to inadvertent discovery of genetic discontinuity between parent and child, also have the capacity to change the basis on which parents make decisions about withholding or sharing information (see paragraph 2.14). While, as we noted earlier, the influences behind the shift in attitudes over the past 20 years in the UK are multiple and complex (see paragraph 2.20), we highlight here the potential role that the state may play in this area. While it is not, in the view of the Working Party, the role of the state actively to challenge the views of individuals or faith communities with respect to the acceptability of donor conception, the state does have a potential role in promoting an environment in which negative views about particular family forms *can* be challenged, and where an acceptance of diversity is encouraged. We return to this point in paragraphs 5.66 to 5.71 below.

## Weighing interests

5.36 Earlier in this chapter, we identified many of the interests that those concerned with donor conception have in connection with information disclosure – whether information about the use of donor gametes in conception, non-identifying information about the donor, or identifying information that would make it possible for a donor-conceived person to make contact, and potentially form a relationship, with their donor. We have based this analysis on what people with personal experience of donor conception have told us about what matters to them, and on the research evidence reviewed in Chapter 4. It is clear that these interests overlap and may, in specific cases, either coincide or conflict. This is unsurprising, given that the use of donor gametes creates a complex and interwoven network or web of actual and potential relationships.

5.37 We have already highlighted the wide variety of experiences and attitudes to the significance of information about biological connections. A further point to note is that the summary of interests above does not (and indeed, could not) include the views of those who are donor-conceived but

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[431] See, for example, Golombok S, Brewaeys A, Cook R *et al.* (1996) The European study of assisted reproduction families: family functioning and child development *Human Reproduction* **11(10)**: 2324-31.

do not know. From what the Working Party learned from people who found out that they were donor-conceived later in life or in adverse circumstances, it is clear that such inadvertent disclosure or discovery may have harmful long-term consequences. However, whether it is better to know or not know (and never find out) is a different question that cannot be answered on the basis of these testimonies (see paragraph 5.9). The Working Party was struck by the fact that at one meeting with a group of people with personal experience of donor conception, the donor-conceived people present did not feel it was harmful *never* to find out one's origins (emphasising, rather, the harm of inadvertent disclosure or discovery); these attitudes contrasted with those of many of the recipient parents in the same meeting, who felt strongly that non-disclosure itself constituted a wrong.[432] They were not, however, shared by other donor-conceived people who contributed to the Working Party's deliberations, who took the view that non-disclosure was inherently harmful.[433]

5.38 When the interests in question coincide, it is possible, in principle, to handle issues relating to information disclosure in a way that satisfies the interests of all those concerned. For instance, when parents of donor-conceived children regard openness about donor conception as an important basis for a trusting relationship with their children, difficult questions may still arise with regard to the practicalities as to when and how to tell, but a clear basis exists for resolving these issues in a way that serves the interests of all members of the family. Similarly, if donors and the people born from their donated gametes have the same wishes with regard to possible contact, this may still be a sensitive matter and a potential ground for both illusions and disillusions, but in such cases there is, at least, a basis for having the interests of both parties satisfied. However, it is clear that in other cases the interests in question may conflict. If, for example, the donor does not want to engage in the kind of contact the donor-conceived person very much desires, the interests of the latter will be frustrated. Where interests conflict, it will not be possible to satisfy both.

5.39 Here we come to the heart of the problem: how to handle questions relating to information sharing, and in particular relating to disclosure of the use of donor gametes, if there is no way in which this can be done without frustrating the interests of one of the parties. This problem is exacerbated by the fact that the competing interests differ in kind: interests at stake including what might be described as 'identity' interests, privacy interests and (in the exceptional cases where medical information will significantly affect health care) medical interests. One view that was put to the Working Party was that the only way of dealing with these conflicts is always to prioritise the interests of donor-conceived individuals, regarding these as 'paramount', in the same way that courts regard the welfare of children as 'paramount' when called upon to make decisions about their upbringing or future.[434] Arguments for this position include the fact that, without ever being asked for their own views, donor-conceived people find themselves facing the potentially far-reaching implications of their parents' decisions; and the belief that donor-conceived people are the ones most affected.[435] An alternative view recommends that it should be the interests of prospective and then actual parents that should be prioritised, as without their (successful) use of donor gametes, subsequent individuals would not exist in the first place.[436]

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[432] Factfinding meetings with people with personal experience of donation, 27 April 2012.

[433] Factfinding meeting with Rachel Pepa, 24 April 2012; factfinding meeting with Christine Whipp, 16 July 2012.

[434] See, for example, the response to the Working Party's evidence call from PROGAR (Project Group on Assisted Reproduction, British Association of Social Workers). See also the use of this principle of 'paramountcy' in the Australian state of Victoria: Parliament of Victoria Law Reform Committee (2012) *Inquiry into access by donor-conceived people to information about donors: final report*, available at: http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/DCP_Final_Report.pdf.

[435] Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

[436] Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

5.40 We return here to the fact that a key feature of reproduction in general, and the use of donor conception in particular, is the creation of connections and relationships between people. Against this backdrop, the Working Party takes the view that there is no one right place to start when analysing these conflicts of interest; and in particular that the interests of one party to a relationship should not, as a matter of principle, automatically take precedence over any others.[437] Accordingly, the interests of different parties always have to be weighed. The question then arises as to *how* such a process of weighing interests may be undertaken and, very importantly from a policy perspective, *who* could or should be responsible for undertaking it. We have suggested above that some degree of autonomy in family life, of being free to make decisions about what is right for one's own family, is objectively important for the well-being of both parents and their offspring (see paragraph 5.14). In the case of decisions relating to disclosure of the use of donor gametes, such 'family' autonomy must be understood as 'parental' autonomy, given that, by definition at this point, parents are in control of what their children know. The notion of 'weighing' interests may imply a neutral third party making a judgment, and parents clearly are not 'neutral', in that their own interests, as well as those of their children, are at stake. Yet the idea of a third party, such as a health or social care professional (whether acting in accordance with a professionally-agreed code of practice, or mandated via state regulation) being responsible for determining whose interests should prevail in a particular case, suggests a degree of external intrusion into family life that is regarded as unacceptable in almost all other circumstances.

5.41 The way in which we respond to this conundrum depends on how we conceptualise the roles and responsibilities of those concerned. Below, we consider first the responsibilities that arise, on a personal level, within the various relationships created through the use of donor gametes in conception, noting how these are inherently reciprocal by nature of the fact that they arise in relationships. We then go on to consider the responsibilities of third parties connected with donor conception: the professional responsibilities of the professionals who help create donor-conceived families; and the responsibilities of the state both in its role as regulator of assisted reproduction and in its wider functions.

## Reciprocal responsibilities within relationships

### *Responsibilities of parents to their donor-conceived child*

#### Responsibilities to future children

5.42 It is generally agreed that parents have a moral responsibility to promote the well-being of their children. Having that responsibility is part of what it means to be in a parental role. At the outset, since at one point in time there are only prospective parents and prospective children, the strength of parents' obligations to tell children about their means of conception needs to be considered in relation to the ethical debate about responsible reproduction. Are there any circumstances where prospective parents who know at the time they are considering treatment that they will be unable or unlikely to disclose the use of donor gametes to any resulting child ought, ethically, to refrain from seeking treatment altogether?

5.43 The key issue at stake here is the nature and extent of the harm that might result from having children in these circumstances.[438] There is considerable ethical and legal discussion as to what

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[437] We note here, that while 'paramountcy' has a role in the Children Act when judicial decisions affecting a child's welfare are required, on an ethical (and even legal) level there can be no expectation that parents should completely sacrifice their interests when these compete with their children's. Indeed, any such requirement to treat one child's interests always as paramount would be impossible for parents with more than one child. We also note that such a principle is not helpful in determining the competing interests of adults: see Chisholm R (2012) Information rights and donor conception: lessons from adoption? *Journal of Law & Medicine* **19(4)**: 722-41.

[438] Some would argue that a preliminary question is whether for children born to parents not committed to openness, a different life (one with disclosing parents) would have been possible at all. If not, then it could be argued that creating any life, other than a 'life not worth living at all' is a morally acceptable outcome of fertility treatment, an argument we consider further in paragraph 5.58. Where a 'different life' *would* be possible (i.e. where the parents could, in fact, choose to

degree of harm to prospective children might be considered to be sufficiently serious to trigger action by third parties, and we consider this later as we discuss the possible role of professionals or the state in controlling or restricting access to treatment services in such cases (see paragraphs 5.56 to 5.62). However, we return here to the evidence that we have reviewed in Chapter 4, where we saw that families in which parents choose not to disclose to their offspring that they are donor-conceived have been found to function well into early adolescence although much less is known about families with older offspring (see paragraphs 4.29 to 4.32). Harms may potentially arise if donor-conceived people find out late, or inadvertently, although from the limited survey data available it would appear that in many cases initial negative reactions will fade over time (see paragraph 4.14); moreover, we have no way of knowing how often in practice such inadvertent disclosure or discovery arises. We do not underestimate the distress experienced by some donor-conceived offspring whose parents have chosen not to be open with them about their use of donor gametes, and who later feel betrayed. However, based on the evidence, it does not appear that the level of this risk, or the extent of the potential harm, is so great that prospective parents could be held to be acting wrongly if they seek treatment with donor gametes without being sure that they can commit in advance to openness. While we recognise that the evidence in this area (particularly with respect to families with older donor-conceived children) is still limited, and that the risks of inadvertent disclosure or discovery may potentially increase as a result of technological and social developments (see paragraphs 1.27 to 1.30), nevertheless we suggest that much clearer proof of likely harm would be required to justify the claim that parents act intrinsically wrongly in creating a family without being able to commit in advance to openness about the means used to conceive.

5.44 We need now to move beyond discussion of the circumstances in which prospective parents might be held to be acting wrongly or irresponsibly in having children in the first place, and consider the separate question of how those children are cared for after birth. That is, in the light of the above discussion, our primary concern in relation to parents' responsibilities towards their donor-conceived children relates to how extensive these responsibilities may be to an actual, rather than prospective, child. Such responsibilities arise primarily after birth, in their care of the child; however, as we note below, responsibilities may also arise in the way that parents prepare for parenthood, once they have made the decision to create a family with donor gametes.

### Responsibilities to children

5.45 After a child has been born, we suggest that parents have obligations to do their best to promote the welfare and personal development of their children in a way that will enable them, so far as parents can reasonably achieve this, to grow into autonomous, considerate and responsible adults with a high degree of well-being. In doing so, parents are also entitled to take account of their own interests, and those of others for whom they have responsibility such as dependent relatives. We consider that most people would broadly agree with this approach.

5.46 In the course of parenting, particular obligations may arise in particular circumstances. The Working Party takes the view that, in the light of the evidence reviewed in Chapter 4, the parents of donor-conceived children have a moral responsibility to avoid, where reasonably possible, any harmful consequences that may follow for their children from the fact that they were donor-conceived. We argued above that the possibility of harm arising from inadvertent disclosure or discovery is not sufficient to justify the conclusion that parents act wrongly if they use donor gametes without committing to openness in advance. However, there *is* sufficient

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disclose), then the possibility of this 'alternative life' becomes relevant: the responsibilities of parents once a child has been born and questions of disclosure become 'real' are discussed in paragraphs 5.45 to 5.49. The Working Party encountered one example where parents actively delayed treatment with donor gametes until the change in the law with respective to anonymity, thus ensuring a 'different life' (one with access to information about the donor) would be possible for their child: Factfinding meetings with people with person experience of donor conception, 27 April 2012.

evidence to point to the conclusion that, **other things being equal, it will usually be better for children to be told, by their parents and at any early age, that they are donor-conceived** (see paragraph 4.61). In not telling their children early on, parents not only run the risk of harm arising from later disclosure in adverse circumstances; they also lose the opportunity of using disclosure as a positive means of affirming their decision to create a family using donor conception and helping their child absorb their origins into their personal narrative. Moreover, many of the reasons parents give for not disclosing, in particular concerns about negative impacts both on their child and on family relationships, have been demonstrated to be unfounded (see paragraphs 4.31, 4.32, 4.42 and 4.43). We noted above that, in practice, it will almost inevitably be parents who undertake the 'weighing of interests' involved in making decisions about disclosure, despite the fact that they cannot be a neutral party in this decision, and are in a position of power in relation to their offspring with respect to the information they hold. Such power has to be exercised responsibly.

5.47 **The Working Party takes the view that the parents of donor-conceived children thus have a responsibility to give careful consideration to the question as to whether or not they should be open with their children about how they were conceived. In particular, we suggest that this responsibility includes a willingness both to take account of the evidence available, and to engage as necessary with professional support, when determining what is best in their particular circumstances**. In suggesting such a responsibility (moral not legal) on the part of parents, we note that this must be matched by parallel responsibilities on the part of the state and professionals as to the level of support available and the manner in which that support is provided (see paragraphs 5.64 and 5.70).

5.48 However, it does not necessarily follow from the above discussion that it is never justifiable to withhold knowledge from children about the use of donor gametes. In some cases, parents may have strong reasons for not telling that may override the initial presumptions that such openness is likely to promote their child's welfare. For instance, the Working Party heard anxieties from some religious and cultural perspectives as to the potential for very negative reactions to the use of donor gametes in reproduction (see paragraphs 4.34 to 4.40). In such circumstances, openness may lead to stigmatisation within the parents' community, so that parents may feel that the hazards – both for themselves *and* for their children – of disclosure may be much greater than those of non-disclosure. In such cases, there may well be a *coincidence of interest* in not disclosing early, in that the parents' concerns are to avoid harm to their family unit as a whole. It is, however, important to acknowledge that concerns about the stigmatisation of infertility or the fear of social disapproval of the use of donor gametes, may arise or not in a variety of circumstances, and that social pressures or expectations are not homogenous within particular communities. Parents, regardless of their social or cultural background, will need to consider their own specific situation in making their decisions about disclosure.

5.49 Some parents may thus find that they have strong reasons for not telling their children that they were conceived using donor gametes. For instance, they may be concerned about the impact of such disclosure both on their children's welfare, and on the welfare of the family unit as a whole. In other cases, parents who have had a long and painful struggle with fertility issues may feel that their fertility problems are a private matter, and that they have a justifiable interest in protecting these from the scrutiny of others. Where these privacy concerns on the part of the parents, as opposed to concerns about the welfare of the child or the family unit as a whole, constitute the main reason for non-disclosure, the interests of the parents and offspring may no longer coincide, and the challenge of weighing competing (and potentially incommensurable), interests arises.

5.50 Since, as we have argued, disclosure is in most cases likely to be the best option for the child, parents have a responsibility to consider whether any reasons they may have for not telling are significant enough, in their circumstances, to justify non-disclosure. Some of those who decide not to disclose do so from a fear of consequences that may turn out to be unfounded: indeed, the available evidence suggests that almost all who eventually decide to disclose are glad that they did so (see paragraph 4.42). This suggests that there is a potential role for professionals in helping and supporting parents to overcome any fears that may stand in the way of choosing what in many cases may be the best option for themselves and their child. Ultimately, however, making such decisions is an inherent part of the parental role, and indeed only parents will usually know enough about their own family situation to judge what they, in their particular circumstances, should do with respect to disclosure. Only in very exceptional cases, where there is reason to fear the child might suffer significant harm, may third party intervention be justified in such decision-making. We return in Chapter 6 to consider the exceptional circumstances in which such harm might arise (see paragraphs 6.24 and 6.50). We also consider below the role of the state in promoting and encouraging an environment where parents who want to disclose feel able to do so without fears of negative consequences either for themselves or for their children (see paragraphs 5.70 and 5.71).

## *Responsibilities that arise as a recipient to a donor*

5.51 Donation of gametes is frequently described as a gift, with donors ultimately giving the 'gift of life'. It is not surprising, given what is known about the compulsion to reciprocate a gift, that people should consider 'repayment' in some way. However it is also the case in the UK that there has been a general reluctance to commodify body parts: it is often argued that human biological materials such as blood and organs should be kept out of the market, and that in the context of bodily material altruistic gifts, without expectation of remuneration, are preferable. The Council's earlier report on *Human bodies* highlighted a more mixed response to donated bodily material with some people arguing that payment in these circumstances was also ethically appropriate. Nonetheless, as in the findings of that report, the gift is a powerful image in the discussion of donated gametes and surrogacy. In donated gametes the gift can also signify a complete handover of bodily material with no further claim or expectation of reciprocity, or it can signify an ongoing relationship whereby return is expected, albeit not necessarily directly. As one donor wrote: "A huge thank you to the wonderful lady who has donated her eggs to help us start a family. I'll never know you but your generosity is something I can only aim to match in the future. You have given us a true gift."[439] In this case, the recipient aims to 'match' the donor's generosity in some way in the future.

5.52 Another less predictable way of reciprocating the gift of donation was presented to the Working Party in terms of the *responsibilities* a recipient may owe to their donor. It was noted that the way in which the recipient told their offspring of the facts of their conception, or the way in which they talked about the donor, would impact on how the donor-conceived person perceived the facts of their conception, which would in turn impact on how they perceived the donor. This might have implications for how the donor-conceived person related to the donor in the event of later contact. This was described to us in two ways: first, that failure to disclose was not fair to donors given the possibility of inadvertent disclosure and later contact; second, that if the donor-conceived person were told badly, then they might be angry with, or resentful of, the donor – which again would be unfair to the donor. The Working Party agrees that, in accepting eggs or sperm from a donor, whether known or unknown, recipients thereby incur a responsibility towards that donor to ensure that their gift does not later rebound on them. Such a responsibility would require, in particular, that recipient parents include the donor's interests as one of the factors to be taken into account in their considerations about disclosure, and that they act to minimise the risk of any possible future harm arising for the donor as a result of their donation.

## *Responsibilities that arise as a donor (to donor-conceived offspring, recipients and the donor's own family)*

5.53 In donating gametes in the knowledge that such donation may lead to the creation of a future person, donors have a responsibility to think carefully about the consequences: for themselves and their own families; for the recipients of the donated gametes; and for the resulting person.

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[439] Metro (22 May 2012) *Good deed feed*, available at: http://e-edition.metro.co.uk/2012/05/22/15.html.

While some of donors' responsibilities to recipients and future offspring might be held to be discharged through the practice of donating through a licensed clinic, with the associated protections, we suggest that donors themselves, in choosing to donate, nevertheless incur a number of responsibilities that cannot be discharged by others: for example the responsibility of participating frankly and honestly in the medical screening procedure; of giving serious consideration to the way they provide information about themselves and their motivations for both recipients and future resulting people to read; and of giving due consideration to the possibility of future contact. We discuss further in Chapter 6 the extent of these responsibilities, including the possibility of providing additional information at a later stage in the rare cases where serious medical information of relevance to the donor-conceived person emerges after donation (see paragraphs 6.63 to 6.66). In recognising these responsibilities, however, we reiterate that the fundamental premise of donor conception is that the recipients of donated gametes will become the true and only parents of the resulting child, and that the only circumstances in which donors should be considered to have ongoing responsibilities during the childhood of the person resulting from the donation (with the exception of the rare medical cases cited above) is where such responsibility forms part of the agreement with the recipients. In some such cases, indeed, it may be more appropriate to refer to a 'co-parent' rather than a 'donor' (see paragraph 2.4).[440]

5.54 In choosing to donate, donors also have a responsibility towards their own families, in particular (where applicable) their partner and their children. We have noted earlier the potential impact, both positive and negative, that identity-release donation may have on the donor's own family, whether contact is made with the donor-conceived person and their family during childhood, or not until adulthood (see paragraphs 4.53 to 4.58). Just as prospective parents have a responsibility to give careful consideration to the question of whether or not they should tell their children they are donor-conceived (see paragraph 5.47), potential donors have a responsibility to take account of the potential impact of donation on their own close family members, including the possibility that any future contact may affect a future partner and as-yet unborn children.

### *Responsibilities as donor-conceived person: to parents and donor*

5.55 Donor-conceived people, unlike both their parents and their donor, did not have any choice at all in connection with decisions about the use of donor gametes in conception. Nevertheless, it could be argued that they, like all offspring, have responsibilities towards their parents, and just as particular parental obligations arise in particular circumstances, so may particular obligations arise for donor-conceived people. We recognise that those who find out late, or inadvertently, that they were donor-conceived may feel distressed and angry that their parents have not been open with them (see paragraph 4.14), and that, in such circumstances, the use of donor gametes may cause strong feelings within families. Nevertheless, we suggest that donor-conceived people have a responsibility, commensurate with their age and understanding, to do their best to understand the reasons why their parents chose to create a family through treatment with donated gametes, and why they made the decisions they did about disclosure: in short to be aware that parents, too, may be vulnerable. Just as we suggest that parents' responsibilities to take account of their disclosure decisions on the well-being of their children are matched by responsibilities on the part of professionals and the state to ensure that support is available, support should also be available, where necessary, to help donor-conceived people understand the facts of their donor conception from the perspective of the other actors involved (see paragraph 6.34). Similarly, we suggest that, if seeking contact with their donor, donor-conceived adults have a responsibility to consider the impact on others and to be sensitive in their approach; and that, in turn, they should be able to turn to external sources of support to help them in what may be a difficult and emotional process (see paragraph 6.38).

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[440] For a contrary view on the responsibilities of donors, see: Benatar D (1999) The unbearable lightness of bringing into being *Journal of Applied Philosophy* **16(2)**: 173-80.

## Responsibilities of third parties

### *The role of professionals and fertility clinics*

5.56 We have discussed above the moral responsibilities that may arise for each of the parties directly involved in donor conception. A separate question then arises as to the possible role of third parties in 'intervening' in connection with these responsibilities, with the aim of preventing or limiting harm to those who are potentially vulnerable, particularly children. Before discussing the role of the state (whose role in intervening to protect the welfare of children is well-established), we point to the special role that clinics and professionals have in this context. We note, however that these two roles may in practice be interrelated: that depending on the regulatory framework established in any particular country, the responsibilities of professionals may be guided entirely by professional codes of practice and ethics or may, additionally, be subject to specific requirements set down by law. Thus, in the UK, professionals working in the fertility field are bound to act in accordance with statutory requirements and, in particular, with the statutory *Code of practice* published by the HFEA.[441] Hence their actions are guided by dual (if in practice generally overlapping) requirements: to act in accordance with their professional responsibilities, and additionally to act, where necessary, to ensure that the requirements specified by the state are met.[442]

5.57 Clinics and professionals who provide fertility treatment services involving the use of donor gametes, embryos or surrogacy are not only providing 'medical treatment' to the 'patient' in front of them: they are causally and intentionally involved in creating a child. It is widely accepted that it is therefore part of their professional responsibility to take into account the welfare of the child who would not exist but for their help (see paragraph 5.61). This means that there may come a point where professionals should not provide the reproductive assistance requested. However, there is less consensus about *when* this should be the case.[443] For our discussion, the question is whether professionals should refuse treatment to patients who are not fully committed in advance to openness.

5.58 According to one relatively mainstream ethical view, professionals should refuse fertility treatment only in the very rare cases where the resulting child would have a life that was so miserable that any reasonable person would rather not have existed at all. This is sometimes called the 'wrongful life standard'.[444] It is based on the argument that, excluding the rare cases of a truly miserable life, a child cannot be harmed by being brought into the only existence he or she could possibly have.[445] We note that some donor-conceived individuals have indeed asserted that it would be better for prospective parents not to have children at all, than to use

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[441] The HFEA includes lay as well as professional membership, and the statutory requirements set out in the HFE Acts derive from parliamentary consideration of wider public concerns regarding assisted reproduction/use of donor gametes, and hence again are not limited to, although clearly overlap with, considerations of professional responsibility.

[442] Practice may vary considerably between clinics and professionals, despite the fact that they are operating under the same regulatory regime and guidance. See, for example, in a related context, how professionals draw on their own social and ethical perspectives when following professional guidelines in order to classify embryos as 'spare': Ehrich K, Williams C, and Farsides B (2010) Fresh or frozen? Classifying 'spare' embryos for donation to human embryonic stem cell research *Social Science & Medicine* **71(12)**: 2204-11. However, the HFEA *Code of practice* acts to constrain some aspects of professionals' discretion in making judgments based on their own values, for example by specifying that "staff at the centre must not unlawfully discriminate against patients or donors by allowing their personal views to affect adversely the professional relationship with them, or the treatment they provide or arrange": Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 29.7.

[443] Pennings G (1999) Measuring the welfare of the child: in search of the appropriate evaluation principle *Human Reproduction* **14(5)**: 1146-50.

[444] See, for example, Buchanan A, Brock D, Daniels N, and Wikler D (2000) *From chance to choice: genetics and justice* (Cambridge: Cambridge University Press), at page 235.

[445] With regard to our discussion, this argument is primarily relevant only to cases where prospective parents really have no option at all of disclosing to their child the means of his or her conception. Where the parental decision not to tell is susceptible to change, the alternative to 'life with non-disclosing parents' is not non-existence but rather life with 'disclosing' parents.

donated gametes to conceive.[446] Based on the evidence, however, it is fair to say that this is not a typical perspective on the impact of being donor-conceived. Indeed, the kinds of circumstances that are thought to give rise to a serious risk of a life that an individual would think not worth living are very rare, and typically associated, for example, with the most rare, painful and disabling forms of disease. So we may conclude that in cases where the reasoning behind the wrongful life standard applies, this standard does not lead to the conclusion that professionals should refrain from offering fertility treatment with donor gametes to prospective parents who do not intend to tell.

5.59 The 'wrongful life' standard has been criticised as expressing a too minimal understanding of both parental and professional responsibility.[447] In its guidance for professionals, the European Society of Human Reproduction and Embryology (ESHRE) has proposed instead the "reasonable welfare" standard, according to which the criterion for ethically acceptable (assisted) reproduction is the absence of "a high risk of serious harm", where "serious harm" is taken to refer to a seriously diminished quality of life, regardless of whether for this particular child a better life would have been possible.[448] In the UK, the HFEA similarly interprets the legal requirement that clinics should take account of the welfare of any resulting child by requiring them to "consider factors that are likely to cause a risk of significant harm or neglect" to a future child.[449] Again we do not consider that the evidence reviewed in Chapter 4 demonstrates that there is a 'high' risk of 'serious' or 'significant' harm to offspring whose parents choose not to be open about their use of donated gametes in their conception. So we may conclude that on the standards followed by ESHRE and the HFEA, there are also no grounds for saying that professionals should not provide fertility treatment involving the use of donor gametes to those not committed to disclosure.

5.60 In the debate about assisted reproduction, some seem to adhere to a third standard, according to which reproduction is only acceptable if it can be expected that the child will have an optimal life.[450] This 'maximum welfare' standard entails using the same criteria that are also used in the context of adoption, where the only consideration is the need to find the best possible home for a particular child who has already been born. However, it is hard to justify third party intervention to prevent prospective parents from choosing to reproduce where their children cannot grow up in the best possible circumstances. Such a claim would imply, for instance, that parents should be prevented from having children when they are poor, or when one of the parents is ill or disabled, or when an existing child is ill or disabled (so that the parents may have to put extra time into caring for another child). As it is generally not considered morally irresponsible for parents in these circumstances to have children, it would be discriminatory to use this standard to refuse fertility treatment to those who cannot reproduce naturally.[451]

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[446] See, for example, TangledWebsUK (2013) *Why we believe donor conception is harmful*, available at: http://www.tangledwebs.org.uk/tw/WhyWrong/.

[447] See, for example, Steinbock B, and McClamrock R (1994) When is birth unfair to the child? *Hastings Center Report* **24(6)**: 15-21, where a principle of "parental responsibility" is suggested, under which it is not morally acceptable to have a child unless it can be given "a decent chance of a happy life" (pp17-8), since "bringing children into existence under very adverse conditions is unfair to the children themselves" (at page 19).

[448] Pennings G, De Wert G, Shenfield F *et al.* (2007) ESHRE Task Force on Ethics and Law 13: the welfare of the child in medically assisted reproduction *Human Reproduction* **22(10)**: 2585-8.

[449] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 8.10.

[450] See Pennings G (1999) Measuring the welfare of the child: in search of the appropriate evaluation principle *Human Reproduction* **14(5)**: 1146-50 for a discussion of all three standards. Recent analysis compatible with the idea of a "maximum welfare standard" can also be found in Savulescu J (2001) Procreative beneficence: why we should select the best children *Bioethics* **15(5-6)**: 413-26. As our analysis demonstrates, we reject an argument to the effect that parents have a duty, when making reproductive decisions, to 'maximise' the interests of their future children, or to select 'the best possible child', as put forward in Savulescu. For criticism of Savulescu's approach see, for example, Glover J (2006) *Choosing children: genes, disability and design* (Oxford: Oxford University Press) at page 54, and Scott R (2007) Why parents have no duty to select 'the best' children *Clinical Ethics* **2(3)**: 149-54.

[451] We note that refusal by professionals to provide treatment differs in some respects from active 'third party intervention' in family life, as found, for example, in child protection measures. However, given that such treatment is licensed and made available to the public as a whole through state regulation, prospective parents are highly likely to perceive any such refusal of treatment as 'intervention' in their desire to create a family.

5.61 Indeed, the argument has been made that the whole idea that third parties (whether acting in accordance with professional norms or in order to implement statutory requirements) should be able to intervene in the reproductive choices of others is inherently discriminatory: how can such intervention be justified in the case of those needing assistance to conceive, when it would be seen as unacceptably intrusive to intervene with the reproductive choices of those able to conceive without assistance?[452] In response to arguments such as these, the HFEA has tightened its interpretation of the 'welfare' clause in order to make it clear that clinics may only refuse treatment in the most serious of circumstances: the examples of "risk of significant harm or neglect" being cited in the latest *Code of practice* include such circumstances as previous convictions involving children, child protection measures taken regarding existing children, or a history of family violence, along with circumstances (such as serious ill-health or addiction) that are likely to lead to the parent being unable to care for the child throughout childhood.[453] The rationale for including *some* form of 'welfare' provision within the Human Fertilisation and Embryology Act, however, is defended on the grounds that, where third party involvement is required in reproduction, there is a duty on those providing that assistance to consider the longer-term implications.[454]

5.62 The Working Party takes the view that it *is* acceptable for third parties (in this case both the professionals involved in assisted reproduction and the regulator, under whose guidelines professionals must operate) to take account of the welfare of any future child in providing treatment services, whether or not donor gametes are also used in treatment. However, the standard used in making such welfare judgments is clearly crucial and will have a direct bearing on how rarely, or otherwise, the welfare of the future child will be of legitimate concern to third parties. **We believe that the HFEA has taken the right approach in focusing on factors that are "likely to cause a risk of significant harm or neglect" to future children, a standard of harm that is likely only rarely to be fulfilled, and reiterate that we do not believe that a failure to disclose to offspring that they are donor-conceived should be regarded as constituting such a risk**. A policy decision to deny treatment to prospective parents on these grounds could only be justified by evidence that children born in such circumstances are indeed likely to suffer serious harm. As we have discussed in Chapter 4, the evidence does not bear out this claim, notwithstanding the distress and difficulties that some individuals have undoubtedly experienced.

5.63 As we stressed above, clinics and professionals who provide treatment services involving the use of donor gametes, embryos or surrogacy are not simply providing 'medical treatment' to the 'patient' in front of them: they are causally and intentionally involved in creating a child. In addition to what has been said above about the responsibility to take account of the welfare of the child before providing treatment, it is therefore part of their professional responsibility to take into account the prospective parents' need for information and support not only in connection with the clinical procedures involved, but also in connection with the bigger picture of what is being undertaken. Such a professional responsibility is particularly important given the asymmetry of knowledge that inevitably exists between clinics and patients, particularly when patients are first contemplating treatment; and in the light of the potentially conflicting interests (financial interests, reputational interests and so forth) that clinics may have in the way they run services, recruit donors, and provide options to patients.

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[452] Jackson E (2002) Conception and the irrelevance of the welfare principle *The Modern Law Review* **65(2)**: 176-203.

[453] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, guidance note 8. Compare with guidance in earlier versions of the *Code of practice*: for example in the sixth edition, factors to be taken into account included "the commitment to raise children" and "the ability to provide a stable and supportive environment for a child/children". See: Human Fertilisation and Embryology Authority (2003) *Code of practice 6th edition*, available at: http://www.hfea.gov.uk/docs/Code_of_Practice_Sixth_Edition.pdf, at paragraph 3.12.

[454] See, for example, the views of professionals expressed in Lee E, Macvarish J and Sheldon S (2012) *Assessing child welfare under the Human Fertilisation and Embryology Act: the new law* (Canterbury: University of Kent), available at: http://blogs.kent.ac.uk/parentingculturestudies/files/2012/06/Summary_Assessing-Child-Welfare-final.pdf.

5.64 One way in which clinics currently meet this professional obligation is through the provision (or offer) of pre-treatment counselling sessions to enable prospective parents to consider the implications of their treatment options. As part of this, prospective parents should have the opportunity to express their thoughts and concerns about disclosure, find out about the research evidence available on disclosure (demonstrating that many of the anxieties of parents about disclosure have been shown to be unfounded), and explore the risk of inadvertent disclosure or discovery and the related potential for harm. They should be aware that it may not be possible to ensure that their child will never find out about their means of conception, and that a decision not to disclose necessarily entails both the risk of possible later harm from inadvertent discovery, and also the lost opportunity to use early disclosure as a positive way of affirming their decision to create a family using donor conception and helping their child absorb their origins into their personal narrative (see paragraph 5.46). However, it should also be acknowledged that parents may have other reasons that, for them, are more weighty, such as (but not limited to) the impact of a stigmatising environment. The proper outcome of such pre-treatment counselling is that prospective parents should be supported in making a decision that is truly their own, in the light of the best evidence available, and after taking the opportunity to explore their own situation and concerns with a person who is both well-informed and non-judgmental.

5.65 Clinics also have a responsibility both to recipients (and indirectly through them to future donor-conceived people) and to donors, in their role of ‘information collector/information provider’. As we discussed earlier in the particular context of medical information, the only information about the donor potentially available to recipients and donor-conceived people under the age of 18 is that provided on the donor information form (see paragraph 3.21). The approach that clinic staff take to the importance of the information thus provided is likely to influence how donors regard this task, and how much trouble is taken in fulfilling it. We return to the question of the role of clinics in supporting donors, both in thinking through their intention to donate and in providing information about themselves, in Chapter 6 (see paragraphs 6.63 and 6.64).

### *The role of the state: the stewardship model*

5.66 We have discussed above the role of third parties in intervening in the reproductive decisions of others: in practice these third parties are the health professionals working in fertility clinics. Depending on the regulatory system in place, the actions of such professionals may be guided entirely by their own professional standards and codes of conduct, or they may also be subject to additional regulatory guidance mandated by the state. Thus, in the UK, this area is governed by the Human Fertilisation and Embryology Act 1990 (as amended by the Human Fertilisation and Embryology Act 2008), and the HFEA is tasked with key regulatory functions (see paragraph 1.7).

5.67 However, whether or not the *regulatory* role with respect to the governance of assisted reproduction services is exercised by professional organisations or by bodies established for the purpose by the state, states also potentially have a wider role with respect to donor conception and the support of families created through donor conception. The nature and extent of this role depends on rather wider considerations of the proper role of the state. The Nuffield Council, in its earlier report *Public health: ethical issues*, presented what it described as a ‘stewardship model’ of the state, distinguishing such a model both from a *laissez-faire* libertarian approach to state responsibilities, and from an overly-intrusive ‘nanny state’:

> “The concept of stewardship means that liberal states have responsibilities to look after important needs of people both individually and collectively. Therefore, they are stewards both to individual people, taking account of different needs arising from factors such as age, gender, ethnic background or socio-economic status, and to the population as a whole... In our view, the notion of stewardship gives

> expression to the obligation on states to seek to provide conditions that allow people to be healthy, especially in relation to reducing health inequalities."[455]

A key aspect of the role of the 'stewardship' state is thus to *facilitate* what are seen as beneficial behaviours: to 'provide conditions', whether physical or social, that help and enable people in making their choices, while avoiding active intrusion in those choices unless there is very strong evidence to justify such intrusion for the benefit of others.

5.68 The Council advocated this stewardship model of the state initially in the context of the state's public health duties, and, in a modified form, in the context of promoting the donation of bodily materials to benefit others.[456] We suggest here that this concept of the state, which explicitly recognises the 'important needs' of both individuals and people collectively with respect to their health, and emphasises the role of the state in 'providing conditions' that promote healthy behaviour, may also provide a helpful guide in considering what role the state ought to play with respect to the regulation of donor conception services and the associated questions of information collection, retention and disclosure. While we have concluded above that neither the state (in its regulatory role), nor professionals, are justified in preventing assisted conception, other than in circumstances of potentially significant harm, this leaves open the degree to which the state might take action to promote the interests of those affected by donor conception, where this can be done without placing an undue burden on others. In considering what burdens might be 'undue', both the interests of others also concerned in donor conception, and also the interests of wider society in terms of the allocation of scarce resources, need to be considered.

5.69 In the UK context, we note that the state has chosen to regulate, in both NHS and private clinics, how treatment services are provided, the circumstances in which gamete and embryo donation is permitted, and the information that must be retained about donors. As a result of statutory regulation, only those donors who can contemplate becoming identifiable when their donor-conceived offspring reach the age of 18, may now donate. The publicly-funded NHS provides some (limited) access to treatment services using donor gametes. We therefore suggest that, in enabling (through legal provisions regarding parenthood, for instance) *and* endorsing in this way donor conception as a means of creating a family, **the state should also be concerned to take action that is likely to promote the welfare of people affected by donor conception, where this can be achieved without unreasonably interfering with the interests of others**.

5.70 In particular, the state, through its regulator the HFEA, has the opportunity both to *influence* the way prospective parents view the prospect of raising donor-conceived children and to *support* them in this process. Such action may promote the welfare of donor-conceived individuals by ensuring that their parents are well-placed to make a decision based on full consideration both of the evidence of the impacts of disclosure and their own personal family circumstances, without unjustifiably intruding into the reproductive decisions of prospective parents. In the light of the evidence that inadvertent or late disclosure may be harmful for donor-conceived individuals, we therefore consider that **the state is justified in taking steps to try to ensure that parents are informed about the best available evidence about disclosure, and to support them in considering this evidence both before conception and, where applicable, in their later preparations for disclosure as their child grows up**. We consider further in Chapter 6 how these responsibilities might be implemented in practice.

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[455] Nuffield Council on Bioethics (2007) *Public health: ethical issues*, available at: http://nuffieldbioethics.org/public-health, at paragraph 2.41.

[456] Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research*, available at: http://nuffieldbioethics.org/donation.

5.71 We further suggest that the state could take on a 'facilitative' role in promoting the well-being of people affected by donor conception by **encouraging a social environment where the creation of families through donor conception is seen as unremarkable**: as one way among a number of others of building a family.[457] Such a role should not be understood as promoting 'special arrangements' for particular family forms, but rather as one of inclusivity: encouraging the acceptance of diversity both in the way people become parents, and in the plethora of ways in which they create 'kin'. We return in Chapter 6 to consider in more detail how our suggestion of a stewardship state might help determine a policy response to the various proposals put forward, both to the Working Party and elsewhere, to the current regulation of donor conception.

5.72 Finally, we note in this chapter that the state, under its international human rights obligations (codified in UK law through the Human Rights Act 1998), is required to ensure that the human rights of all those within its jurisdiction, as set out in the European Convention on Human Rights, are properly protected. We have argued throughout this report for an analysis of the competing concerns of those personally affected by donor conception in terms of 'interests' and 'responsibilities' rather than of 'rights'. We conclude by highlighting how the interpretation of human rights law, despite the terminology of 'rights', similarly has at its heart both the weighing of potentially conflicting interests, and the consideration of the proportionality of any interference on the part of the state with those interests. Our conclusions coincide closely with current interpretations of the human rights obligations established by the European Convention on Human Rights (see paragraphs 2.28 and 2.29).

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[457] See, for example, Haslanger S (2009) Family, ancestry and self: what is the moral significance of biological ties? *Adoption & Culture* **2(1)**. Haslanger highlights the importance of cultural 'schemas' in providing social bases for healthy identity formation, and argues that rather than reify particular schemas, such as the traditional nuclear family, the dominance of these schemas should be challenged and alternatives constructed. See also: Archard D (2012) The future of the family *Ethics and Social Welfare* **6(2)**: 132-42.

# Chapter 6

## Implications for regulation in the UK

# Chapter 6 – Implications for regulation in the UK

## Chapter 6: overview

**Overarching approach**

- Wherever possible, measures that aim to support, encourage and empower those making decisions are preferable (both ethically and practically) to measures that seek to limit or remove choice.

**Policy affecting prospective parents**

- It would be inappropriate to introduce any form of additional 'screening' of prospective parents by reference to disclosure plans; nor is it the role of state authorities to intervene (for example through indications on the birth certificate) to ensure that all donor-conceived people know of the circumstances of their conception.
- As a matter of good professional practice, clinics should present counselling sessions as a routine part of the series of consultations undertaken before treatment with donated gametes or embryos begins, in order to ensure the best possible support for those contemplating treatment. Information should be provided in a non-judgmental manner that enables prospective parents to engage with the issues of disclosure and non-disclosure. Clinics should provide access to an additional support session later in pregnancy or after the birth of the child.
- The option of anonymous donation should not be reintroduced.

**Policy affecting parents and donor-conceived people during childhood and into adulthood**

- Reference to donor conception, and to organisations that support donor-conceived people and their families, should be included in materials routinely available to pregnant women and new parents.
- While most support for donor-conceived families is provided by the voluntary sector, the state retains a responsibility to ensure that donor-conceived people and their families are able to access the support they need. This would include stepping in financially if necessary to ensure the continuance of such services.
- The state should take an active role in ensuring that an appropriate intermediary service is in place for those who in future will contact the HFEA for identifying information about their donor. The future of the voluntary register connecting pre-1991 donor-conceived people and donors should be secured on a long-term basis.
- Parents should be provided with clear and comprehensible information about the significant heritable conditions that have been 'screened out' in the donor assessment process, so that they may be reassured that the risk of their child inheriting such a condition is very low.
- A multi-disciplinary group should review and update the 2008 guidance on the screening and assessment of donors, and recommend what family history information, if any, will be relevant to the donor-conceived person's health care (while not being sufficiently serious to rule out donation), and hence should be recorded on the donor information form. A clear, well-publicised mechanism should be established so that any significant medical information arising at a later stage may be shared between donors and donor-conceived people.

**Policy affecting donor-conceived adults who do not have access to information**

- Rather than regulating retrospectively for the removal of donor anonymity, the state should take action to increase awareness among past donors that a willingness on their part to become identifiable would be highly valued by some donor-conceived adults.
- The HFEA should issue guidance to clinics setting out what is expected of them with respect to making information from pre-1991 records available to donor-conceived adults.
- The HFEA should ensure, for example through the creation of a dedicated donor conception website, that factual information about the implications of seeking treatment with donor gametes abroad or through unregulated methods, is readily accessible to those contemplating these routes.

**Policy affecting donors**

- Clinics should ensure that sessions with a counsellor are scheduled as part of the routine series of appointments that donors attend before deciding whether or not to go ahead with donation. Where donors have partners, clinics should strongly encourage partners to attend these sessions.
- Donors have a responsibility to think seriously about how they provide information about themselves, and clinics have a responsibility to provide appropriate support in doing so where required. Filling in the donor informationform should not be perceived as a brief administrative task.
- The HFEA's National Donation Strategy Group should consider further the question of how much and what kind of information should be expected on the donor information form, drawing on the expertise of a range of interested parties.

6.1 In this final chapter, we draw on the evidence summarised earlier in the report, and on the ethical considerations set out in the preceding chapter, to discuss the variety of proposals for policy or legal change that have been put to us during the course of this enquiry, and to note the areas where further research or investigation would be valuable. For clarity, we have drawn together areas of policy as they might affect particular groups, although inevitably, given the significance of the connections and relationships between all those involved in donor conception, there will be considerable overlap between each set of considerations. We begin with prospective parents; move on to families with donor-conceived children, and to donor-conceived people once they reach adulthood; and finally consider the position of donors. Reflecting again the immensely diverse experiences and expectations of people affected by donor conception, we begin each section with a brief sketch of the range of attitudes and approaches that may be taken by people who, at first sight, appear to be in a very similar situation.

## Prospective parents

### Box 6.1: Prospective parents: scenarios[458]

- Jonathan and Eleanor have a seven-year-old daughter, Sophie, conceived through sperm donation. While initially convinced she wanted Sophie to be aware of the means of her conception, Eleanor is now concerned about how telling will impact on Sophie's relationship with Jonathan.
- Emily and Anna have two children conceived using donor sperm from the same donor. Now Henry and George are four they want to tell them they were donor-conceived, but are unsure how to do this in the most effective way – particularly as the children are very different.
- Leah and Lysander have always been open about their use of donor eggs. They believe that the fact of donor conception should be noted on the birth certificate, and that donor-conceived people should have easy access to information about their donor. Transparency is the only way to remove the stigma of infertility.
- Maria is single, and wishes to get pregnant, but she wants to ensure that there is no way at all that any child she has will be able to get in contact with the sperm donor. She sees the donation as a purely financial transaction, and wonders if the only option she has is to go abroad for this.
- Bhavna and Dilip have a daughter, Hema, through embryo donation. They have not told anyone at all. They are part of a Hindu community, and are very scared about anyone in the community finding out, and worry when family members try and work out who Hema looks like.

6.2 We consider in this section a number of proposals for policy change in the UK that would have an impact on the circumstances in which treatment with donor gametes might be made available to prospective parents, and the support that is available to them. In coming to our conclusions, we have sought to take into account the interests of all concerned, and the potential for these both to come into conflict but also at times, and over time, to coincide (see paragraphs 5.36 to 5.41). In considering what responsibilities may arise in response to these interests, we have also taken the view that, wherever possible, measures that aim to support, encourage and empower those making decisions are preferable (both ethically and practically) to measures that seek to limit or remove choice.

### *Screening of parents pre-conception*

6.3 The Working Party was urged by a number of respondents to our call for evidence and participants at factfinding meetings to recommend the introduction of a 'screening' process for prospective parents seeking access to treatment with donor gametes, with the specific aim of ensuring that only prospective parents who were committed to telling their children at an early age that they were donor-conceived should be able to access UK-regulated treatment.[459] This

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[458] This box highlights hypothetical scenarios to illustrate a range of possible situations.

[459] Factfinding meeting with people with personal experience of donor conception, 27 April 2012; additional comments submitted following the factfinding meeting with practitioners, 30 May 2012. See also: PROGAR (Project Group on

view was primarily supported through comparisons with current adoption practice, where prospective adoptive parents must first undergo an extensive 'approval' process by social workers before being matched with children available for adoption. It will already be clear from our analysis in Chapter 5 that we do not believe that there can be any justification for creating such a hurdle for accessing treatment with donor gametes. While we have concluded that, other things being equal, it will usually be better for children to know from an early age that they are donor-conceived (see paragraph 5.46), we have also concluded that there is insufficient evidence of harm resulting from a parental decision not to tell to justify the creation of such a hurdle to access treatment (see paragraph 5.62). Some form of 'screening' process for prospective *adoptive* parents can be justified on the grounds that the state is actively intervening to remove parental responsibility from birth parents and confer it on the adoptive parents, and in the process has an active duty to the child in question to treat his or her welfare as paramount. Treatment with donor gametes, by contrast, is concerned with the creation of a child who will be born directly into the prospective parents' family, and for whom no alternative 'future' could be envisaged. The two situations are not parallel. Moreover, the Human Fertilisation and Embryology Act already makes general provision, in connection with *all* regulated assisted reproduction treatments, for treatment to be withheld if clinics believe that any future child would experience significant harm or neglect (see paragraph 5.62).

6.4 **We therefore conclude that it would be inappropriate to introduce any form of additional 'screening' of prospective parents other than through the application of the existing 'welfare of the child' criterion for all assisted reproduction treatments (not just those involving donor gametes) as currently interpreted by the HFEA**. We consider in more detail below the quite separate question of what support might be required to help prospective parents think through the implications of using donor gametes or embryos to create their family, and to be confident that this is the best way forward for them.

### *Mandating disclosure*

6.5 Another approach put to the Working Party, to ensure that donor-conceived people should be able to find out that they had been conceived with donor gametes regardless of their parents' wishes regarding disclosure, was to mandate disclosure by some means. It was suggested that this could be achieved directly, via a letter (for example from the HFEA) to the donor-conceived person at 18, or indirectly, by indicating on the birth certificate either that the person was donor-conceived or that more information about the person's birth was available, should they wish to access it (see paragraph 2.22). Our respondents suggested that, if one of these proposals were implemented, parents would be much more likely to tell their children that they were donor-conceived, because they would know that they could not prevent later disclosure. However, if parents still chose not to tell, then the letter at 18, or the annotations on the birth certificate, would make it (almost) certain that the donor-conceived person would find out in the end, and hence not be deprived of this knowledge. As this summary implies, the primary rationale underpinning these proposals is the argument that donor-conceived people have a 'right to know' that they were conceived with donor gametes. A further argument put forward in favour of citing the fact of donation in some way on the birth certificate relates to the role and responsibility of the state: it was put to us that it was not right for the state to 'collude' with parents who chose not to tell by recording biologically inaccurate information on the birth certificate.[460] Finally, the Working Party was told that some parents would actively prefer to have the option of including reference to a gamete donor on the birth certificate: for example some

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Assisted Reproduction, British Association of Social Workers), responding to the Working Party's call for evidence, where it suggests that "no one should be accepted for treatment if they stated their intention to withhold information from children".

[460] The International Donor Offspring Alliance, responding to the Working Party's call for evidence.

solo mothers by choice would prefer this option, thus avoiding the implication that the father was simply 'unknown'.[461]

6.6 As we discuss in Chapter 2 (paragraph 2.25), much of the political and legal debate regarding the merits of changing the birth certification system to include reference to the use of donor gametes in conception has focused on concerns about privacy, and on how such marking on the birth certificate may potentially be experienced as stigmatising by some of those concerned. However, there seems no reason why a system of birth certification that would avoid these concerns could not be devised: we referred earlier, for example, to the proposal to include an Appendix to the 'long' birth certificate, indicating the availability of further information from the HFEA on request (see paragraph 2.24). By ensuring that the Appendix could only be supplied to the person to whom the certificate related, or to their parents, privacy could be effectively protected. The alternative means of achieving the same aim suggested to the Working Party at factfinding meetings (that of changing the entire birth certification system so that everyone, however conceived, would have an 'A' certificate for public use and a separate private 'B' certificate which need never be disclosed to others, containing information about donor conception, surrogacy or adoption) would work in the same way (see paragraph 2.24). A system involving a letter from the HFEA to the donor-conceived person as they reached the age of 18 would similarly not entail any direct risk of stigma, in that it would be private, and not publicly-disclosed, unless the donor-conceived person chose to share the contents more widely.

6.7 Questions of privacy and risk of stigmatisation, however, are not the only issues at stake when considering the creation of a system of third party disclosure. The issue also arises as to the potential for such a step to have adverse unintended consequences: in particular of people suffering harm as a result of finding out that they are donor-conceived through a route other than via their parents.[462] While those advocating such a system may assume that parents will be bound to tell their children they were donor-conceived because of the inevitability of later discovery, this will not necessarily be the case, given how difficult parents often find it to start the process of disclosure, even where they are fully committed to it (see paragraph 4.11). Moreover, if such a system were to be based on parents' own willingness to report the use of donor gametes, it might even lead to parents finding it harder to tell: they might feel 'boxed in' by an initial hasty decision made in the first few weeks of a baby's life not to declare the use of donor gametes to the registration authorities, and as a result find it much harder gradually to change their minds and start the process of disclosure. However, even before considering these wider issues of potential, if unintended, harm, there is a further preliminary issue to consider: that of whether it is appropriate in the first place for the state to take action to ensure that donor-conceived people have documentary 'evidence' about the circumstances of their conception.

6.8 We have already concluded that, other things being equal, it will usually be better for children to be told, by their parents and at an early age, that they are donor-conceived (see paragraph 5.46). However, we have also concluded that other things will *not* always be equal, that some families will have good reason not to disclose, at least in early childhood, and that ultimately making such decisions with respect to disclosure is an inherent part of the parental role (see paragraph 5.50). Moreover, we do not believe that this position changes significantly when the donor-conceived person reaches the age of 18. While parental 'authority' as such may lapse once a child is no longer a minor, the autonomy of family life continues to be important:

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[461] Factfinding meetings with people with personal experience of donor conception, 16 July 2012. A survey carried out by the DCN of its own members, however, found that 82 per cent of respondents opposed the idea: Walter Merricks, personal communication, 11 January 2013.

[462] Such concerns were expressed in Parliament of Victoria Law Reform Committee (2012) *Inquiry into access by donor-conceived people to information about donors: final report*, available at: http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/DCP_Final_Report.pdf, at page 64. However, the report did not call for any changes to be made in light of this observation, stating: "However, the Committee does not believe it is appropriate to repeal existing mechanisms by which the state may inform a donor-conceived person of his or her status."

parent/child relationships continue to evolve, and develop (and ultimately invert as parents age) throughout the lifetimes of all parties. Interference with such relationships in adulthood arguably requires an even higher level of justification than during childhood, since the protective duties of the state towards minors can no longer be invoked. **We therefore take the view that it is not the role of state authorities, whether through direct contact with donor-conceived people as they reach adulthood, or through the use of official documentation such as birth certificates, to intervene to ensure that all donor-conceived people know of the circumstances of their conception**.

6.9 Indeed, given the importance placed by many donor-conceived people on finding out from their parents, we suggest that such third party intervention runs the risk of causing actual harm in some circumstances. We recognise that there will be some people who feel very strongly that, in their case, it would have been better for them to have found out earlier, if necessary through state intervention, that they were donor-conceived. We do not underestimate the anger and distress they personally may experience as a result of their parents' decisions and the lack of such intervention. However, just as we concluded that the evidence on potential harm from non-disclosure is insufficient to justify any form of additional screening of prospective parents (see paragraph 6.4 above), similarly we conclude that the currently-available evidence of harm is insufficient to meet the threshold necessary for state intervention on a universal basis in decisions that are the proper domain of the family.[463] We return below to the rare cases where the diagnosis of a serious strongly heritable condition in the donor may require an exception to this conclusion (see paragraph 6.24).

6.10 The issue of 'collusion' by the state in permitting what may be understood as inaccurate information on birth certificates is a separate point, and an important one to address. The central question here is *what* it is that birth certificates are understood to record. If birth certificates are understood straightforwardly as a record of a person's biological genitors, then, clearly, omitting to mention the use of donor gametes is misleading at best. However, birth certificates are not 'simply' a biological record. They are a record of *legal* parentage which usually, but not invariably, arises as a result of that biological connection. This distinction has been made explicit in a number of statutory changes in the context of donor conception, most vividly in the Human Fertilisation and Embryology Act 2008 which enabled both partners in a lesbian couple who have a child through gamete or embryo donation to be listed on the birth certificate, as 'mother' and 'parent' respectively.[464] However, these provisions of the Human Fertilisation and Embryology Acts do not represent a radical break with the past: the longstanding legal presumption that a woman's husband is the father of her child unless the contrary is proven, for example, demonstrates how 'legitimacy' has long been regarded as important for social, as well as legal, reasons, regardless of strict biological 'truth'. A wider understanding of what it is that birth certificates record would clearly be beneficial.

6.11 Any decision to make birth certificates a record of biological connection rather than (or indeed as well as) a record of legal parentage, would lead logically to the necessity of paternity testing before the birth of any child could be registered, given the estimated prevalence of 'misattributed paternity' (see paragraph 1.26).[465] We note again how the differences between adoption and donor conception explain the difference of approach in this area of certification: in adoption, legal parenthood is reassigned through the actions of the court and it is inevitable that this change is documented. In donor conception, the child's parents are the legal parents from

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[463] This absence of justification for such interference in parental decision-making also applies to the more general proposal that *all* birth certificates should include a reference to more information potentially being available from the HFEA or on adoption registers – see paragraph 2.24. While it would be possible to provide the *option* of 'by donation' on birth certificates, as suggested by some solo mothers, such an option could lead to uncertainty on the part of all recipient parents as to whether or not they were required to fill it in, and could also (unless accompanied also by wholescale reform of the birth certification process) lead to privacy concerns on the part of some donor-conceived people.

[464] Section 42, Human Fertilisation and Embryology Act 2008.

[465] Draper H (2005) Why there is no right to know one's genetic origins, in *Philosophical reflections on medical ethics*, Athanassoulis N (Editor) (Basingstoke: Palgrave Macmillan). See also: Ravelingien A, and Pennings G (2013) The right to know your genetic parents: from open identity gamete donation to routine paternity testing *American Journal of Bioethics*: forthcoming.

birth and no such revised documentation is required. Where donor conception also involves the use of surrogacy, by contrast, legal intervention *is* required to reassign parenthood, and this is indeed currently documented through the parental order.

## *Support in considering the implications of disclosure decision*

6.12 We have argued above that, exceptional cases aside (see paragraphs 6.9, 6.24 and 6.50), it is not the role of the state to take action to ensure that a person knows they are donor-conceived. Prospective parents should thus be able to access treatment with donor gametes without being ‘screened’ with regard to their intentions about early disclosure, and in the knowledge that disclosure will not be forced upon them. Nevertheless, in Chapter 5, we have already concluded that the parents (and prospective parents) of donor-conceived children have a responsibility to give serious consideration to the question as to whether or not it is best, in their circumstances, to be open with their children about how they were conceived (see paragraph 5.47). Precisely because parents are in a position to control what information they share with their children while they are young, they have a moral responsibility to think through their disclosure decisions carefully. The question thus arises as to what the professionals involved in donation, and the state in its regulatory role, may reasonably do in order to support and empower prospective parents in these considerations about future disclosure.

6.13 We have summarised earlier in this report the various forms of information provision and support that are required, or should be offered, under the Human Fertilisation and Embryology Act 1990, the HFEA’s *Code of practice*, and professional guidelines, before treatment with donor gametes goes ahead (see paragraphs 2.35 to 2.46). We suggest here that it is helpful to distinguish between three distinct functions of such information provision and support, even though, in practice, some or all may be provided by the same professional at the same time. These three functions may be summarised as follows:

- *The provision of sufficient information about treatment with donor gametes so that prospective patients are in a position to provide valid consent to treatment*. Under the common law, this is defined as information about the ‘nature and purpose’ of the treatment, and may thus be understood as encompassing primarily the *physical* aspects of treatment, along with brief reference to the implications of conceiving, and subsequently bringing up, a child using donor gametes. The statutory provisions under the HFE Act 1990, however, additionally require that the prospective parents “have been provided with such relevant information as is proper” (see paragraph 2.35). By including the patient’s partner (where applicable) in this requirement, the statutory provisions thus allow for the information in question to be defined rather more broadly, and hence to encompass concerns beyond the immediate and physical implications of treatment. Such information would include both the legal ramifications of donor conception (such as the provisions as to legal parenthood, and the future child’s entitlement to access information from the HFEA from the age of 16), and a broad overview of the evidence currently available about the impact of telling or not telling a child that they are donor-conceived (see paragraph 6.19 below).

- *The provision, or offer, of counselling*. In line with generally-accepted definitions of counselling, we define this as client-led, therapeutic support, provided by a qualified counsellor, whose aim is to help prospective parents think through what course of action is right for them, and to provide the support necessary to deal with difficult emotions around fertility and fertility choices. Such counselling should provide prospective parents with a safe and quiet space in which to express and explore their feelings with a sensitive, trusted and non-judgmental third party. It should offer an opportunity, where necessary, to mourn the loss of a longed-for shared biological child and the future that prospective parents had imagined for themselves, and to reconstruct a different future for themselves, with or without children. Where people are considering treatment with donor gametes for reasons other than infertility, for example single women, same-sex partners, or couples where one party has a serious genetic condition (see paragraph 1.2), other needs for support may emerge. However, the defining characteristic of this aspect of support is that it relates primarily to the needs of the prospective parents themselves.

- *Preparation for parenthood*, where the focus of the information provision and support relates to the practical aspects of bringing up a donor-conceived child: for example thinking through such day-to-day matters of how parents will deal with comments about resemblance from outsiders, how others in the same position have managed the process of disclosure to the child and at what age; or, alternatively, of thinking through and managing the implications of non-disclosure. Such preparation may be relatively brief, overlapping to a degree with the information required for consent, or it may be quite extensive, as in the two-day 'Preparing for DC parenthood' workshops offered by the DCN to prospective parents considering treatment with donor gametes (see paragraph 2.36). Again, the extent of support offered in this area should be led by the needs and wishes of the prospective parents.

6.14 The extent to which particular prospective parents have access to, and engage with, all three of the above forms of information-giving and support will depend both on the individuals themselves, and on the practice of the clinic where they are seeking treatment. Prospective parents' existing levels of knowledge and need for emotional support when they first approach a clinic will vary considerably. Clinics themselves also vary in how they offer support, and in particular the extent to which the statutory 'offer' of counselling is presented as being a routine part of the treatment process or as something more exceptional (see paragraph 2.46). Similarly, while some clinics will place no limit on the availability of counselling sessions, others may include only one session within the overall treatment price (where treatment is being provided on a private basis), and expect patients to pay for any additional sessions provided.

6.15 The Working Party concluded earlier that it is part of the professional responsibility of clinics, and the professionals working within them, to take into account prospective parents' need for information and support, not only in connection with the clinical procedures involved, but also in connection with the bigger picture of what is being undertaken: that is, the creation of a future person (see paragraph 5.63). We suggest that this professional responsibility includes ensuring that the needs of the prospective parents for information, therapeutic support, and preparation for non-genetic parenthood, as described above, are met as an intrinsic part of the process of treatment. Clearly, these needs will vary considerably, depending on the circumstances of the prospective parents themselves. We also note that, while all clinicians in a clinic will have some degree of responsibility for ensuring that patients have sufficient information before they are asked for their consent to treatment, counsellors are particularly well-placed to ensure that prospective parents not only have access to information but have the opportunity to consider the implications of that information for their own particular situation, and to explore these implications with a knowledgeable third party without fear of being judged.

6.16 It has been suggested that one way of ensuring that all prospective parents are sufficiently prepared before starting treatment would be through making counselling sessions mandatory for all prospective parents.[466] This proposal was rejected by the House of Commons Science and Technology Committee in 2005 who commented that "forcing people to be counselled could easily be considered an infringement of liberties and might be counterproductive if the parents felt that it had been forced on them."[467] We agree that including a statutory requirement that prospective parents should attend counselling sessions is inappropriate, for the reasons (both ethical and practical) cited by the Committee. We also suggest that such a proposal is wrongly targeted, in that it focuses on prospective *parents*, rather than on the responsibility of

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[466] See, for example, the discussion in House of Commons Science and Technology Committee (2005) *Human reproductive technologies and the law: fifth report of session 2004-5 - volume I*, available at: http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/7/7i.pdf, pp74-6. See also: The British Infertility Counselling Association's response to the Working Party's call for evidence, where it states that: "Counselling on the social, ethical, medical, legal etc. implications of this treatment should be mandatory", at paragraph 1e of its response.

[467] House of Commons Science and Technology Committee (2005) *Human reproductive technologies and the law: fifth report of session 2004-5 - volume I*, available at: http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/7/7i.pdf, at paragraph 166.

*professionals*. Moreover, if such a statutory requirement were to be created, not only might it be counterproductive with respect to the prospective parents, but it might also risk encouraging a ‘tick-box’ mentality within clinics, where ‘seeing the counsellor’ would be one more administrative task to be ticked off before patients could be treated. What is required, rather, is the encouragement of a *culture* within clinics where the opportunity for prospective parents to discuss the implications of possible treatment options in a safe and quiet space is valued by all clinicians, understood to underpin and safeguard professional and legal requirements for consent, and seen as central to good treatment.

6.17 The Working Party was impressed by the approach of some clinics, cited above, of ensuring that all prospective parents meet with the counsellor by making this appointment part of a series of routine appointments that patients are expected to attend before treatment can commence. In this way, counselling sessions are ‘de-stigmatised’, in that they are presented, and understood, as a normal part of the treatment ‘work-up’. **We recommend that, as a matter of good professional practice, clinics should present counselling sessions as a routine part of the series of consultations undertaken before treatment with donated gametes or embryos begins. Clinics can thus be confident that their patients have had access to the information and support that they may need in order to make a properly informed decision to go ahead with treatment. Prospective parents should clearly understand that such sessions will be treated as confidential and that their counsellor is not involved in making any judgments about their suitability as parents. Given the importance of a trusting relationship between counsellors and their clients, prospective parents should also be able to see an alternative counsellor if, for whatever reason, they do not feel comfortable with the counsellor whom they first see. We recommend that these requirements should be professionally mandated by the relevant professional bodies, including the British Fertility Society and the British Infertility Counselling Association**.

6.18 In making this recommendation, we emphasise that the various functions identified above that the counsellor may be undertaking in these sessions – providing information necessary for consent, offering therapeutic support, and helping prospective parents prepare for parenthood – should be distinguished. Where prospective parents are attending such appointments as a routine part of their treatment, the emotional support that they receive, and the extent to which they are encouraged to ‘prepare for parenthood’, must be led by *their* needs. The provision of information about the implications of treatment, on the other hand, is not client-led in quite the same way. We have already argued that fertility professionals should regard their role not simply as one of helping establish a pregnancy but more broadly as helping create a future child. They thus have a professional, as well as statutory, duty to ensure that parents have been provided with sufficient information about the future implications of treatment before giving consent to that treatment.

6.19 The question thus arises as to how much information about the ‘implications’ of treatment with donor gametes should be regarded as sufficient before treatment may go ahead, particularly (in the context of this report) with respect to information about disclosure; and the manner in which that information should be imparted. The Human Fertilisation and Embryology Act itself specifies that the information provided “must include such information as is proper about (a) the importance of informing any resulting child at an early age that the child results from the gametes of a person who is not a parent of the child, and (b) suitable methods of informing such a child of that fact.”[468] The HFEA interprets this statutory requirement as follows:

> “The centre should tell people who seek treatment with donated gametes or embryos that it is best for any resulting child to be told about their origin early in childhood. There is evidence that finding out suddenly,

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[468] Section 13(6C) of the HFE Act 1990, as amended.

> later in life, about donor origins can be emotionally damaging to children and to family relations.
>
> The centre should encourage and prepare patients to be open with their children from an early age about how they were conceived. The centre should give patients information about how counselling may allow them to explore the implications of treatment, in particular how information may be shared with any resultant children."[469]

6.20 After reviewing the evidence currently available about the impact of disclosure and the associated ethical arguments about the responsibilities of parents, the Working Party has already concluded that early disclosure generally appears to result in better outcomes (see paragraph 5.46). However, we have also concluded that there may be circumstances where such disclosure may *not* be in a child's best interest, and that ultimately this is a matter for parents to judge (see paragraphs 5.48 to 5.50). We strongly agree that the information given to prospective parents at this stage should include making them aware of the research evidence on disclosure: in particular that children who find out whilst young that they are donor-conceived generally appear to assimilate this information without difficulty, while in some cases those who find out later may be distressed and angry (see paragraphs 4.13 to 4.20). However, it is important that this information is *not* presented in such a way as to make prospective parents feel that they cannot engage honestly with the counsellor and discuss their own situation and their own feelings.

6.21 We have already suggested that the (prospective) parents of donor-conceived children should be willing to take account of the evidence available regarding the impact of disclosure/non-disclosure, and to engage as necessary with professional support when determining what is likely to be best for their donor-conceived child in their particular circumstances (see paragraph 5.47). We emphasise here that **it is the professional duty of the counsellor, and other relevant professionals, to ensure that they provide information and support in a non-judgmental and understandable manner that encourages prospective parents to engage with the issues of disclosure and non-disclosure. It is crucial that prospective parents are able to feel confident about expressing their own anxieties, views or concerns about disclosure, to seek advice and guidance without fear of being judged, and to 'own' their ultimate decisions about disclosure or non-disclosure with regard to the well-being of their future family. We recommend that the HFEA should, in the next edition of its *Code of practice*, explicitly encourage such an ethos within clinics**.

6.22 Finally, we turn to the question of the extent of the support that clinics, through their counsellors and other clinicians, offer to prospective parents. We endorse the practice of some clinics of not placing a specific limit on the number of counselling sessions available to prospective parents: while we recognise that this has a cost implication for clinics, we also note that counselling costs form a very small percentage of overall clinic costs, and that the number of prospective parents taking up an extended series of appointments is likely to be small (see paragraph 2.46). We further highlight the important point that prospective parents' need for information and support should be regarded as a *process*, rather than as a one-off event. In particular, it was drawn to the Working Party's attention that it is often very difficult for prospective parents (particularly those who have had a long experience of infertility investigations and treatments) to focus on the more practical aspects of non-genetic parenthood until a pregnancy has been well established: until that point prospective parents may not let themselves believe in the reality of the future child.[470] Thus many parents may not be in a position to benefit as fully as they would

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[469] Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraphs 20.7-8.

[470] Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering. See also: Landau R, Weissenberg R, and Madgar I (2008) A child of "hers": older single mothers and their children conceived through IVF with both egg and sperm donation *Fertility and Sterility* **90(3)**: 576-83.

have liked from the information and support available from the clinic, particularly as regards the more practical aspects of preparing themselves for parenthood. **We recommend that clinics, in recognition of their wider role in helping create a child, should routinely offer parents an additional support session that could be taken up either later in pregnancy or in the first few years of the child's life, the cost of which should be included within the overall treatment fee** (where treatment is being provided privately). The session could be provided either by the clinic counsellor, or by another clinician such as a specialist nurse with whom the parents had developed a supportive relationship. Clinics should similarly ensure that parents, before they leave the clinic, have been given appropriate written information about other sources of advice and support as their child grows up.

6.23 By ensuring in this way that prospective parents know they have access to future support, fertility professionals would provide a 'bridge' between the treatment services provided (usually on a private basis) by the clinic, and the mainstream NHS services which most parents will use for maternity and early years health care. Given that the 'twin pillars' of the regulatory system set up by the Human Fertilisation and Embryology Act 1990 have been described as 'consent' and the 'welfare of the child',[471] we consider that the provision of such a bridge to universal services, focusing on the needs of the parent with respect to their future child, legitimately comes within the role of clinics providing treatment services with donor gametes. We return later to the question of how routine NHS maternity and child health services should ensure that donor-conceived families are appropriately and inclusively treated (see paragraphs 6.31 to 6.33).

6.24 Finally, in our consideration of the support that should be made available to prospective parents before, during, and following treatment, we highlight a further issue that should be raised with prospective parents when they are provided with information about disclosure to a future child. We noted earlier in this report that, despite the screening that prospective donors undergo, it will occasionally happen that a donor is later diagnosed with a serious strongly heritable condition (see paragraph 3.26). Similarly, a donor-conceived person might themselves be diagnosed with such a condition. When a person receives such a diagnosis, clinicians will then ordinarily discuss with them the importance of sharing this information with their 'first degree relatives' because of the likelihood of such relatives having the same gene mutation as the affected person.[472] We discuss below what steps might be taken to ensure that a donor-conceived person could also receive this information from their donor (or vice-versa), in order to minimise the impact on their own health (see paragraphs 6.49 and 6.50). While such circumstances may be rare, by definition it cannot be foreseen when they may arise. **We recommend that the possibility of such information being passed on from the donor (and the importance in such cases of the donor-conceived person, who may by then have reached adulthood, receiving that information so that they can choose how to act upon it) should be raised within counselling sessions so that prospective parents are able to take this issue, too, into account when considering their disclosure options**.

## *Revisiting anonymity*

6.25 We have discussed above the question of how parents could be supported and empowered in making their decisions about whether and how to disclose to their children that they are donor-conceived. However, as we noted in the Introduction to this report, the question of whether parents should tell their children that they are donor-conceived is a quite distinct question from whether or not donor-conceived people should have access to information about the identity of

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[471] See, for example, *Evans* v *Amicus Health care Ltd and Others (Secretary of State for Health and Another intervening), Hadley* v *Midland Fertility Services Ltd and Others (Secretary of State for Health and Another intervening)* [2003] EWHC 2161 (Fam), at paragraph 148.

[472] See, for example, Joint Committee on Medical Genetics (2011) *Consent and confidentiality in clinical genetic practice: guidance on genetic testing and sharing genetic information - a report of the Joint Committee on Medical Genetics*, available at: http://www.bshg.org.uk/consent_and_confidentiality_2011.pdf, at page 1.

their donor, although these issues are often conflated under general references to ‘openness’. While the change in the law in 2004 meant that all those donating in UK-regulated clinics from April 2005 onwards would be potentially identifiable to their adult donor-conceived offspring, this change was far from uncontroversial. In particular, it has been suggested, among others by the House of Commons Science and Technology Committee in 2005, that a “twin track approach” should be made available, providing donors and recipients with the choice of donation on the basis of anonymity or on the basis (as now) of future identity release.[473] Given that, even within Europe, legal approaches to anonymity and disclosure differ markedly between countries, the Working Party felt it appropriate to reconsider the ethical issues at stake with regard to permitting anonymous donation in the UK.

6.26 A number of arguments can be made in favour of permitting anonymity where this is the preferred option of both prospective parents and donor. One is that the moral basis for third party reproduction has always been, and can only be, that the donor ‘just’ contributes the reproductive material that then enables the recipient couple to become the true and only parents of their child. The fear is sometimes expressed that this underpinning basis of donor conception services may be fundamentally undermined by what is perceived as a conflicting message: that the donor will always remain connected to the donor-conceived person as their biological (and therefore, in the eyes of some, ‘real’) parent. Calls for mandatory openness and even the retrospective lifting of donor anonymity are seen as inevitable further steps along this path that eventually will leave no room for the recipient couple to have their ‘own’ family.[474] In response to these concerns, however, it could be argued that dominant ideas of kinship, in the UK and elsewhere, are flexible enough to cope with the idea of an identifiable donor without threatening the primary relationship between parents and their children (see paragraphs 1.12 to 1.22, and 6.29).

6.27 A second argument that has often been made in the past in favour of permitting anonymity is based on the concern that the possibility of reproduction with donor gametes may be affected in a more direct way: by leading to a shortage of donors.[475] However, despite the concerns that the legislative changes taking effect in 2005 would have precisely this effect, it now seems clear that, where UK clinics actively seek to recruit donors, they are able to do so. While shortages of donors do continue to exist, this cannot be directly attributed to the move away from anonymous donation (see paragraphs 4.48 to 4.50).

6.28 Finally, there is the argument that, as no particular child can be said to be made worse off by the choice of their parents to conceive with the help of an anonymous donor (because if other gametes from an identity-release donor had been used, ‘this’ child would not exist and a different child would have been born[476]) the decision to ban anonymous donation is an unjustified infringement of reproductive freedom.[477] In other words, if donors are willing to donate, and prospective parents to receive, gametes on an anonymous basis, what is the justification for intervention in their choices? Considered more closely, however, this third argument seems to protect a rather abstract notion of reproductive freedom. Is this freedom really significantly infringed if prospective parents can only make use of a non-anonymous donor? As long as donors are available (and treatment is successful), prospective parents will

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[473] House of Commons Science and Technology Committee (2005) *Human reproductive technologies and the law: fifth report of session 2004-5 - volume I*, available at: http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/7/7i.pdf, at paragraph 158.

[474] Pennings G (2012) How to kill gamete donation: retrospective legislation and donor anonymity *Human Reproduction* **27(10)**: 2881-5.

[475] Fortescue E (2003) Gamete donation – where is the evidence that there are benefits in removing the anonymity of donors? A patient’s viewpoint *Reproductive BioMedicine Online* **7(2)**: 139-44; Turkmendag I, Dingwall R, and Murphy T (2008) The removal of donor anonymity in the UK: the silencing of claims by would-be parents *International Journal of Law, Policy and the Family* **22(3)**: 283-310. See also: Paul S, Harbottle S, and Stewart JA (2006) Recruitment of sperm donors: the Newcastle-upon-Tyne experience 1994–2003 *Human Reproduction* **21(1)**: 150-8.

[476] This is known as the ‘non-identity’ problem: where no alternative life can be envisaged for *this* particular child (on the basis that any child conceived at a different time or with different gametes will be a different child) can *this* child be said to be harmed unless their life is not worth living? See also the discussion at paragraph 5.43.

[477] Cohen IG (2011) Prohibiting anonymous sperm donation and the child welfare error *Hastings Center Report* **41(5)**: 13-4.

be able to have a child and establish a family. We have already concluded that the state should not mandate telling donor-conceived people of the means of their conception, and hence it will still be open for parents to choose not to disclose. There may be a small group of prospective parents who (perhaps because of concerns about the possibility of inadvertent disclosure) would *only* consider treatment with anonymously donated gametes and who now have to travel from the UK to other European countries for such treatment. With this exception, it is hard to conclude that prohibiting anonymity has resulted in material incursions to the reproductive interests of prospective parents.

6.29 In itself, therefore, this third argument does not amount to a convincing reason why the state could not, as a matter of 'stewardship' policy, decide that all gamete donation should take place on an identity-release basis because of the known interests of some donor-conceived people in finding out more about their donor. We should, however, take seriously the first argument, that emphasis on the donor may risk undermining the role of the recipient parents. Even if there are still enough donors, reproductive freedom may be more subtly undermined if those who need the help of a donor are led to fear that the focus on the significance of the donor may prevent them from establishing a family of their own. The challenge that we face is to shape practices that serve the interests of donor-conceived individuals, while allowing 'true' families to be created through donor conception.

6.30 It is clear that some donor-conceived people feel a very strong need to find out information (including identifying information) about their donor. It is also clear that the evidence for the concern that the removal of anonymity has caused difficulties in recruiting donors is not compelling. Given that we have already rejected the idea of mandatory openness (thus leaving open the option that parents may in some circumstances choose not to disclose to their child), **we suggest that it is the proper role of a stewardship state to ensure that donor information, including identifying information, will be available for those donor-conceived people who know about the means of their conception and request it. We therefore do not recommend reintroducing the option of anonymous donation through UK clinics**. We consider later in this chapter how much information it is appropriate for the state, through its regulatory mechanisms, to require donors to provide, both for the use of parents (prospective and actual) and for donor-conceived people (see paragraphs 6.65 and 6.66). However, we emphasise here that the *way* in which the collection, and possibility of accessing, this information is presented to all those affected by donor conception is critical. It is not the case that all prospective parents, parents and donor-conceived people will find information about the donor meaningful or useful (see paragraphs 5.7 and 5.15). The extent to which information is wanted, or indeed found to be essential, will depend entirely on the individuals concerned. While the state, in its stewardship role, has a duty to ensure that information is available for those who might feel an interest in or need for it, this duty should not be interpreted as an endorsement of the position that people affected by donor conception *must* or necessarily *do* want or need it.

## Parents and donor-conceived people during childhood and into adulthood

### Box 6.2: Support as donor-conceived children grow up: scenarios[478]

- Jonathan and Eleanor's daughter, Sophie, is now a lively 12-year-old, and they have decided to tell her that she is donor-conceived – however, they are unsure how to do this, and would value support.
- Gabriella and Marcus had their son, 14-year-old Jeremy, using egg donation. They had decided at an early stage that they would not tell their son he was donor-conceived. They still do not wish their son to know, but would value support in dealing with awkward questions.
- Leah and Lysander would like to know what support their son, Elliott, will be able to access if and when he decides to

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[478] This box highlights hypothetical scenarios to illustrate a range of possible situations.

make contact with his donor and donor siblings.

- Emily's father has been diagnosed with bowel cancer and Emily has been asked to see her doctor about being screened. Anna, whose eggs were used to conceive Henry and George, wonders how similar information could be made available to the boys if the sperm donor developed a similar problem to Emily's father.
- Malcolm is a known sperm donor and has contact with the children conceived using his sperm. He finds this valuable and wonders whether this might have been possible if he had donated through a clinic.
- Maria went to Spain for fertility treatment using donor sperm. With developments in genetics and information-linking, she wants to discover what information her son, Jake, might be able to access, if he wishes to do so.

### *Support for families while children are growing up*

6.31 We have discussed above the information and support that prospective parents may need when they are considering creating a family through gamete donation. We have also suggested that clinics, in recognition of their involvement not just in the establishment of a pregnancy but also in the creation of a child, should provide further support to parents, at least on a one-off basis, once the longed-for child has become a reality (see paragraph 6.22). However, we do not think it appropriate for clinics to be expected to extend their role beyond this point. The question thus arises as to where else the parents of donor-conceived children, and donor-conceived people themselves as they grow up, should find support, if and when they come to need it.

6.32 We argued in Chapter 5 that one role of a stewardship state is to encourage a social environment where the creation of families through donor conception is seen as unremarkable: as one way among a number of others of building a family (see paragraph 5.71). We suggest that a crucial aspect of this inclusion of donor-conceived families must be found in better provision for their support through mainstream NHS services: in particular through maternity, child health and GP services that are sensitive to the possibility that a child may have been conceived with donor gametes. In many cases this may be primarily a matter of awareness, so that professionals do not make assumptions that are perceived by parents of donor-conceived children as excluding or sidelining them. Where parents feel that professionals such as health visitors or GPs are knowledgeable about, and accepting of, a variety of family forms, they are more likely to feel comfortable sharing the information that their child is donor-conceived, hence reducing the risk of any future misunderstandings in connection with the lack of shared medical history with the non-genetic parent (see paragraph 6.51). Awareness on the part of GPs and health visitors that a child has been donor-conceived will also place these professionals in a better position to respond positively if parents do have subsequent needs for support.

6.33 We suggest that one very practical way both of providing information and support to the parents of donor-conceived babies, and of raising awareness of donor conception among professionals involved with babies and young children, would be to ensure that references to donor conception and associated support groups are included within the various information sources routinely available to pregnant women and new mothers, such as the Bounty Packs distributed through the NHS,[479] the NHS Start4Life website,[480] and the pregnancy and baby guide included on the NHS Choices website,[481] as part of their general function to provide information and support for all kinds of families. **We recommend that the Department of Health should encourage those providing information and advice to pregnant women and new parents through NHS-sponsored methods to include reference to donor conception, and to organisations that support donor-conceived people and their families, in their materials**. We note that including such references within universally-available maternity materials in this way has the additional advantage of reaching UK-based women and couples who travel abroad

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[479] See: Bounty (2013) *Free Bounty Packs for you*, available at: http://www.bounty.com/packs?WT.ac=lhn_favourites_freepacks.

[480] See: Start4Life (2013) *Healthy tips and advice for pregnant women, new mums, dads-to-be, friends and family*, available at: http://www.nhs.uk/start4life/Pages/healthy-pregnancy-baby-advice.aspx.

[481] See: NHS Choices (2012) *Your pregnancy and baby guide*, available at: http://www.nhs.uk/conditions/pregnancy-and-baby/pages/pregnancy-and-baby-care.aspx#close.

for treatment, or who become pregnant through informal donation arrangements not involving a UK clinic.

6.34 We alluded above to the organisations that support donor-conceived people and their families. As we described earlier (see paragraph 2.37), at present such support in the UK is primarily provided by voluntary sector organisations, although these organisations may also receive varying degrees of public funding, either for the provision of core services, such as the tender awarded in December 2012 to the National Gamete Donation Trust to run the pre-1991 voluntary register (Donor Conceived Register),[482] or on a more *ad hoc* basis for the provision of specific services, such as past Department of Health funding of DCN workshops for parents.[483] The Working Party does not regard it as problematic that the primary sources of expert support for donor-conceived families are found in the voluntary rather than the state sector: indeed, voluntary organisations in the health and social care sphere are often established and run by those with extensive personal experience of the issues in question, and the support that they offer to parents and families is enormously valued precisely because it is user-led. Nor, in the current economic climate, do we think it unreasonable that those using such services should be expected to contribute to their costs, through organisational membership fees or charges for particular services or events. Nevertheless, **we take the view that the state, which has chosen through regulatory action both to promote donor conception as a legitimate means of creating a family, and actively to encourage early disclosure to resulting children, retains an ultimate responsibility for ensuring that donor-conceived families continue to be able to access specialist support where this is needed. This responsibility would include stepping in financially, if necessary, to ensure that the specialist advice and resources provided by voluntary organisations in this field continue to be generally available to those who need them**.

6.35 We further suggest that this responsibility of the state with respect to specialised support for donor-conceived families also extends to the provision of information and support for those families who are unable to access support from the voluntary sector, for example because they do not feel comfortable with the underpinning approach of particular organisations. **We recommend that the HFEA, as the public body with most expertise in this field, should expand and make more easily available the information it provides to all those directly affected by donor conception, for example through the creation of a dedicated donor conception website, distinct from the main HFEA website**. Such a website could draw on examples of good practice from other countries: the creation of podcasts, for example, by people with personal experience of donor conception covering a variety of viewpoints and approaches, could be particularly valuable for those who prefer not to actively engage in support networks but still value knowledge about other people's experiences.[484] We have already noted that the role of the HFEA with regard to the 'safekeeping' of information about individual donors is changing, and will continue to change, because of the increasing possibilities for parents and donor-conceived people to use means such as social networking to access such information directly (see paragraph 2.13). In such circumstances, the provision of an easily-accessible, centralised source of general advice and information about donor conception from a respected neutral party such as the HFEA becomes particularly important, so that those affected by donor conception are empowered to make their own choices and decisions on the basis of accurate information. We note below a number of circumstances in

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[482] See: UnitedKingdom-Tenders.co.uk (2012) *The National Gamete Donation Service*, available at: http://england.unitedkingdom-tenders.co.uk/31637_The_National_Gamete_Donation_Service_2012_London for the Department of Health's contract notice, tendering for a combined National Gamete Donation Service to include promotion of gamete donation and the voluntary contact register for pre-1991 donor-conceived people.

[483] See, for example, the promise of such funding in House of Lords and House of Commons Joint Committee on Human Rights (2008) *Legislative scrutiny: fifteenth report of session 2007-08*, available at: http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/81/81.pdf, Appendix 9, at page 115.

[484] See, for example, the podcasts provided by the Victorian Assisted Reproductive Treatment Authority: http://www.varta.org.au/personal-stories-podcasts-and-transcripts/.

which this role of neutral and respected information-provider will be particularly important (see paragraph 6.60 below).

### Support for contact between donor-conceived offspring and donors

6.36 We have discussed above the needs of parents and their donor-conceived children as they are growing up. As donor-conceived children reach adolescence, however, their needs may gradually become distinguished from those of their parents, and once they reach the age of 18 they will (if conceived after April 2005) be legally entitled to access information from the HFEA about the identity of their donor. As we discuss in Chapter 2, those conceived before the change in the law became effective in April 2005 will not have the same rights to identifying information, and will only be able to access such information if their donor volunteers to provide it (see paragraphs 2.10, 2.15 and 2.16). However, the fact that some of these earlier donors *are* volunteering to be identifiable means that, while general access to identifying information will not open up until 2024, action needs to be taken promptly to ensure that appropriate procedures are in place for dealing with requests for this identifying information from the HFEA Register.

6.37 While there is no reason why the HFEA-sponsored website suggested above in paragraph 6.35 should not provide information and resources for donor-conceived adolescents and adults on an equivalent basis to that provided for parents of younger children, the question of possible contact between donor-conceived people and their donors raises rather different concerns about support. As we noted earlier, there is a statutory requirement that those applying to the HFEA Register (whether for identifying or non-identifying information) should have been given a suitable opportunity to receive counselling about the implications of their decision, and the HFEA strongly recommends that applicants should obtain such counselling before going ahead with their request (see paragraph 2.47). At present, however, there are no services specialising in such support available for people born since 1991,[485] and the HFEA website signposts users to the website of the British Association of Counselling and Psychotherapy (BACP) for listings of non-specialist services. Moreover, those involved in the support of donor-conceived adults and donors seeking contact through the pre-1991 voluntary register emphasised to us that much of their role was better described as 'intermediary work', helping both parties think through the implications of possible contact, and facilitating such contact where mutually desired, rather than counselling the individual, although some individuals may also additionally need such therapeutic support.[486]

6.38 **The Working Party takes that the view that the state, in legislating for a system where identifiable information about donors is seen as desirable, has a responsibility to make sure that those affected are appropriately supported. This means that the state should take an active role in ensuring that an appropriate intermediary and counselling service (that is, one whose role is to support both the donor-conceived person and the donor in possible contact) should be made available. Such a service could also potentially incorporate the service currently available to facilitate contact between donor-conceived siblings** (see paragraph 2.49). One possible model that has been put forward by the British Medical Association (BMA) is that the HFEA might train, and accredit, a small group of staff with intermediary skills, who would then work at a regional level allowing for face-to-face contact and ongoing support as and when required.[487] In making this suggestion, the BMA noted that some of the savings that the HFEA is currently being expected to make could be diverted to this activity. An alternative approach, put forward by the British Fertility Society, is that of a 'Post Donation Care Service' providing similar functions but run independently of the HFEA.[488] The

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[485] The one service with specialist expertise in this area, the Donor Conceived Register (formerly UKDL), is a service for people conceived before 1991: see paragraphs 2.16 and 2.17.

[486] Factfinding meeting with practitioners, 30 May 2012.

[487] British Medical Association (2012) *Consultation on proposals to transfer functions from the Human Fertilisation and Embryology Authority and the Human Tissue Authority: response from the British Medical Association* (London: British Medical Association).

[488] British Fertility Society (2012) *Response to the Department of Health: consultation on proposals to transfer functions from the Human Fertilisation and Embryology Authority and the Human Tissue Authority*, available at:

Working Party does not take a view on which organisation would be best placed to provide such a service but is firmly of the opinion that it is the responsibility of the state to ensure that an adequate service is provided in some form. Indeed, we note that the HFEA is only required to comply with a request for identifying information if "the applicant has been given a suitable opportunity to receive proper counselling about the implications of compliance with the request" (see paragraph 2.47), and hence it could be argued that such a service *must* be in place before any identifying information is released under the Act. Moreover, whichever organisation undertakes that responsibility would need to ensure that the services provided met an appropriate standard of care: inadequate provision falling below that standard of care could potentially lead to legal claims in negligence if, at some point in the future, identifying information provided from the HFEA Register were to be held to play a role in causing psychiatric harm to either a donor-conceived person or a donor.[489]

6.39 While the legal entitlements of donor-conceived people to information differ depending on when they were conceived, all may potentially have a need for support where information from either the HFEA Register or the pre-1991 voluntary register (the Donor Conceived Register) provides for the possibility of contact with their donor. Indeed, those relying on the voluntary register may have additional support needs, in that, in the absence of paper records, links may only be made through DNA 'matches' and as a result connections may often be made on a basis of likelihood rather than certainty (see paragraph 2.16). **We welcome the fact that the Department of Health has committed itself to future funding of the voluntary register that facilitates contact between pre-1991 donor-conceived people, donors and siblings (see paragraph 6.34), at least for the immediate future; but emphasise the importance of the future of this service being secured on a long-term basis**. While those conceived before 1991 may, because of the legal provisions in place at the time, inevitably have more limited access to information about their donor, there is all the more reason for ensuring that where there is a prospect of contact between a donor-conceived person and their donor, appropriate levels of intermediary support are in place.

6.40 It was also suggested to the Working Party during factfinding sessions, that some people would appreciate the possibility of contact, either with the donor, or with donor siblings, or both, before the donor-conceived person reached the age of 18. Indeed, as we noted in Chapter 4, many of the parents joining the US-based Donor Sibling Registry (DSR) do so in the hope of making early contact with their child's donor siblings and their families so that the children would grow up knowing each other (see paragraph 4.28). Such contact is possible for those who received treatment in the US, as they are provided with a donor's unique reference number: this enables the offspring of the same donor to identify each other, without identifying the donor, and also enables the donor to make themselves findable via the DSR if they wish to do so. However, the position for those receiving gametes from unknown donors through regulated treatment in the UK is different because the HFEA is prevented by statute from sharing potentially identifiable information before the donor-conceived person reaches the age of 18 (and then only to that person himself or herself). Indeed, the HFEA stopped the practice of providing donor codes to families in 2009 because of concerns that this could effectively result in the legal provisions governing possible contact being bypassed.[490]

6.41 Contact in the UK between families and donors is, of course, possible where a known donor is used. As we noted in Chapter 1, 'known' donors are not limited to close friends and family but may be found through advertising and matching websites, and hence there may be little or no

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http://www.fertility.org.uk/practicepolicy/documents/12-10_BFS%20Response%20to%20DH%20consultation.pdf, at paragraphs 65-9.

[489] See, for example, *AB & others v Tameside & Glossop Health Authority & Another* [1997] PNLR 140 for a discussion of the legal responsibilities that may arise in the context of sharing sensitive information with patients, particularly with reference to the standard of care with which the communication is handled.

[490] Human Fertilisation and Embryology Authority (2009) *Authority paper: disclosure of donor codes to gamete and embryo recipients - evaluation and review of HFEA policy*, available at: http://www.hfea.gov.uk/docs/AM_Item_10_Jan09.pdf.

prior acquaintanceship between such known donor-recipient pairs. One reason for seeking such a 'known' donor is to provide for the possibility of more information and contact than is available via the unknown donor route. Similarly, one of the reasons cited why people consider 'unregulated' sperm donation is to make such early information sharing and contact with the donor possible (see paragraph 2.18). The question thus arises as to whether it would be desirable for the Human Fertilisation and Embryology Act to be amended, so that donors and recipients could access identifying information from the HFEA's Register *before* the donor-conceived person reached 18 if all the parties requested this. Such a change would enable parents and donors to have the option of a more open interchange of information, with the possibility of contact, while the children were still very young, where this was desired.

6.42 Given the apparent appetite for such an interchange demonstrated by the various approaches to known donation described above, and the potential benefits to be gained by encouraging more people to access donor gametes via regulated, rather than unregulated, routes, we suggest that that this is an issue worthy of further consideration. We are aware that enabling early contact via the regulated route of anonymous identity-release donation would have consequences: in some cases contact, once initiated, might be found to be problematic; and the potential implications of choosing this option would need to be thought through carefully by both recipients and donors before commencing treatment or donation. **We therefore recommend that the HFEA's National Donation Strategy Group should look specifically at the question of whether the potential benefits of early information exchange and possible contact between donors and donor-conceived families would be sufficient to justify proposals to change the law to permit this**.

## *The promotion of a social environment more accepting to donor conception*

6.43 In our analysis of the role of the state in Chapter 5, we concluded that a stewardship state should be concerned to take action that is likely to promote the welfare of people affected by donor conception, where this can be achieved without unreasonably interfering with the interests of others (see paragraph 5.69). In addition to ensuring that those affected by donor conception receive the support they may need, we further suggested that the state could take on a broader, facilitative role, by encouraging a social environment where the creation of families in this way is seen as unremarkable: as one way among a number of others of building a family (see paragraph 5.71). Earlier in this chapter we discussed the consequences of this approach for support services for parents of donor-conceived children as they grow up: that it was crucial for mainstream NHS services to be sensitive and responsive to their needs, so that they do not feel excluded from what should be a universal service (see paragraph 6.32). Similar issues may arise in the context of other universal services, in particular in schools, where a lack of awareness on the part of teachers of the possibility of children being donor-conceived may result in children being made to feel awkward or 'different'.

6.44 **We suggest here that a key function of a stewardship state is to promote an inclusive and accepting environment for individuals becoming parents in different ways: where what is seen as valuable in family life is the nature of the relationships created and not the particular means by which those relationships first came into being**. We acknowledge that there are no simple, single methods to achieve this aim, although the various methods for increasing public awareness of donor conception recommended in this chapter (see paragraphs 6.33 and 6.56) could play a part. Other possible means of increasing awareness, and hence inclusion, of donor conception suggested to us included the development of authoritative guidance for health professionals and teachers, and the inclusion of donor-conceived children in children's literature. The rhetoric used in public life, for example by policiticians, when talking about 'the family' will also play a part. While we recognise that encouraging and promoting an inclusive culture in these and other ways is a long-term and in some ways intangible task, we suggest that such an inclusive approach is the proper role of a pluralistic state, particularly in the context of state-provided or state-funded services, and indeed is entirely compatible with the wider approach taken to diversity in the UK as exemplified in the Equality Act.[491] Such an approach of promoting inclusion and the acceptance of diversity might further serve, over time, to encourage less stigmatising attitudes to donor conception among those in the UK who do not currently support donor conception as a legitimate means of building a family.

## *Access to relevant medical information*

6.45 We discussed in Chapter 3 the extent to which potential donors are subject to clinical assessment and screening, in order to ensure that those whose gametes might present a significant health risk either to the recipient woman or to any future offspring should not be permitted to donate (see paragraph 3.11). **We reiterate that details of the major conditions that have been 'screened out' before donors are allowed to donate should be provided to the parents in an easily accessible and comprehensible format that they can retain for later reference**. While this information is currently available to prospective parents via the donor information form, it may be that it could be provided in a clearer, more accessible way, for them to retain for future use. This could, for example, take the form of a separate document provided by the clinic at the time of treatment, explaining in lay language what the clinical assessments and various screening tests can, and cannot, exclude; and why particular conditions are tested for, while others are not. Such information, clearly set out, should provide parents with considerable reassurance that the risks of their child inheriting a significant condition from their donor are very low. Nevertheless, it should be made clear that it is currently impossible to exclude *all* such serious conditions, given the number of individual strongly heritable conditions and the late onset of some such conditions.

6.46 The current donor information form also provides space in which to provide 'relevant' information about the donor's health and family history. It became very obvious to the Working Party during its enquiry that there is widespread confusion as to what might constitute such 'relevant' information. While many of those responding to our call for evidence cited examples where lack of information about the donor's family history had been felt to be problematic, the clinicians with experience in genetic medicine who participated in a factfinding meeting with the Working Party struggled to identify specific circumstances in which (given the donor assessment and screening procedures that exclude many potential donors for health reasons) such information about the donor would in fact have a significant impact on a person's health care (see paragraph 3.23). Indeed, it was suggested that health professionals are perhaps too ready to ask patients if there is a family history of a particular condition, even where that information will have little or no impact on the patient's subsequent treatment.

6.47 The Working Party takes the view that, if the situation arises where aspects of the donor's family medical history *would* be likely to have an impact on the health care of any future offspring (while not being sufficiently serious to exclude the donor from donating), this information should be regarded as 'relevant' and included on the donor information form so that it is available to (prospective) parents and hence, later, to donor-conceived people. However, we do not believe that there is any justification for including on the form health-related information about the donor that is *not* likely to affect the health or health care of any future offspring. Indeed, the inclusion of this information may lead to undue emphasis being placed on perceived 'risks' that are in fact very low indeed.

6.48 Given the confusion noted above as to what information about the donor's family history may, or may not, be relevant for the health care of future offspring, **we recommend that the HFEA, in association with relevant professional bodies, establish a multidisciplinary working group to review and update the assessment and screening guidance issued in 2008,**

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[491] The Equality Act 2010 brought together more than 100 separate pieces of legislation into a single Act to provide a legal framework protecting individuals from unfair treatment and promoting a fair and more equal society: see http://www.equalityhumanrights.com/legal-and-policy/equality-act/what-is-the-equality-act/.

**including input from a wide range of health professionals with experience in genetic medicine, and making explicit recommendations as to what information, if any, about a donor's family history should usefully be collected from donors and provided on the form**. Such updated guidance, in an area where knowledge is continually evolving, would help ensure that there is a clear evidence base for the information sought from potential donors before they are accepted, and consequently for the information made available to families via the donor information form. Where information is *not* likely to be of relevance for the health care of future offspring, it should not be collected. We note that such a recommendation makes explicit what is currently implicit in the donor information form: that the medical screening and assessment of potential donors has the dual purpose of 'screening out' those whose health status means that they are not suitable as donors, and of obtaining and documenting that information (if any) that may be clinically relevant for the health care of any future offspring. The establishment of such a working group would also enable the current advice on what conditions can, and should, be 'screened out' in donors to be reconsidered in the light of developments in genetic testing.

6.49 We also highlighted in Chapter 3 that situations may arise where significant medical information with respect to the donor becomes available only *after* donation, for example where a donor is diagnosed with a serious late-onset strongly heritable condition. It is clearly important that in such exceptional cases there is a clear route of communication from the donor to the donor-conceived person and/or their parents.[492] Similar issues might arise where the donor-conceived child is diagnosed with a serious inherited condition, where this information may be of relevance to the donor, the donor's own family, and any donor-conceived siblings. We were told of anecdotal cases where methods have been found for communicating this information, via the fertility clinic, but also of other circumstances (not necessarily in the UK) where this has not been possible.[493] **We recommend that the HFEA should take responsibility for ensuring that a clear, well-publicised, route for sharing significant medical information is established, either via fertility clinics or via the HFEA's own Register, to make it as easy as possible for donors, or donor-conceived people and their families, to pass on such information where it arises. We further recommend that the UK's NHS clinical genetic services are involved in such communications**.

6.50 The Working Party is aware that there are a number of practical ramifications of this recommendation that require further consideration: in particular the question of what information might be considered sufficiently 'significant' to be shared. We note, however, that there is well-established guidance for clinical genetics services on when and how to share information about a genetic diagnosis with relatives who may be at risk, so that those relatives may make their own choices about testing or treatment, as appropriate (see paragraph 6.24). The aim of the disclosure route recommended above must be to ensure that donors and donor-conceived offspring are similarly put in a position to make their own choices about their health care after a significant strongly heritable condition has been diagnosed in someone with whom they have a close biological connection. Particular difficulties arise in contacting a donor-conceived adult to provide this information if there is any possibility that they do not already know that they are donor-conceived. In such cases it may be impossible to alert them that they are potentially at risk, without thereby also disclosing to them the manner in which they were conceived. We recommend that the manner in which such communication should be handled should be further considered by the working group recommended in paragraph 6.48 above. We also reiterate here our earlier conclusion that the possibility, albeit rare, for such information to come to light

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[492] The aim of providing such a route of communication would be to ensure that donor-conceived people and donors are placed in the same position with respect to their diagnostic and health care choices as they would have been, had the relevant diagnosis been made in a biologically-connected member of their social family. They can then make their own choices on how to respond to that information. The provision of such a route therefore does not interfere with any 'right not to know' about one's genetic predispositions.

[493] See, for example, Ravitsky V (2012) Conceived and deceived: the medical interests of donor-conceived individuals *Hastings Center Report* **42(1)**: 17-22, which cites cases in the US where the destruction of records by the egg donation broker or the sperm bank made such communication impossible.

should be routinely raised with prospective parents in pre-treatment counselling sessions (see paragraph 6.24).

6.51 Finally, we consider here the role of health professionals much more widely. We have alluded earlier in this chapter to the importance of GPs and others being sensitive to the possibility that, even where families present as a traditional 'nuclear' family, genetic links may not be fully present (see paragraph 6.32). Indeed this applies not only to donor-conceived families but to other family forms such as adoptive and reconstituted (step) families. Despite recent policy encouraging early disclosure, there are, and are likely to continue to be, many donor-conceived children who do not know that they are donor-conceived. Health professionals need to be aware of the importance of not making automatic assumptions of biological connections between children and their parents, and of bearing this in mind when using a family history to aid diagnoses or clinical management. It is important that they only use family history where it is directly relevant to a patient's care, making clear whether they are concerned with strong biological/genetic connections, or more generally about environmental factors such as family eating habits. Similarly, health professionals who discuss with patients whether and how they should share a diagnosis of a significant genetic condition with relevant family members should take account of the diversity of family forms so that, for example, a donor would be prompted to think of the relevance of their diagnosis for anyone born as a result of their donation.

## Donor-conceived adults who do not have access to information

**Box 6.3: Access to information for donor-conceived people born before 2005: scenarios**[494]

- Sam was born in 2004; his brother Josh was born in 2006. His parents have been open about the fact that he was donor-conceived, and Sam is now asking them about what he and Josh can find out about their sperm donors.
- Julia was born in 1988. Her parents divorced last year, and her mother has told her that she was conceived using sperm donation. She is eager to find out information about the sperm donor, but does not know how to access this. She would also like to find out if she has any donor siblings, and would value meeting people who have had similar experiences.
- Raymond was conceived abroad using anonymous donation. His parents are now concerned that they have very little information about the egg donor, and have been told that there is no method for them to find out any more.
- Tallis was born in 1979 through non-regulated sperm donation. His mother has not seen the donor since. Tallis would like to find out more about the sperm donor, but doesn't want to upset his mother.

### *Donor-conceived people born through UK-regulated treatment before 2005*

6.52 In the section above we have considered how a stewardship state should best support donor-conceived families: both the family unit of parents and their young donor-conceived children, and donor-conceived people themselves as they reach adolescence and adulthood. Our primary focus, however, has been looking forward: taking as our starting point the current legal provisions that give prospective parents access to the information on the donor information form so that they can share it with their children, and enable donor-conceived people at 18 to access identifying information about their donor if they wish. However, these considerations inevitably do not take into account the concerns and interests of those who were born as a result of treatment with donated gametes *before* these provisions came into force, and whose statutory access to information is correspondingly lower or non-existent. Donor-conceived people in this position fall into two distinct groups: those conceived between 1991 and 2005, who will be able to access only non-identifying information about their donor from the HFEA Register at the age of 16; and those conceived before the implementation of the Human Fertilisation and

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[494] This box highlights hypothetical scenarios to illustrate a range of possible situations.

Embryology Act in 1991, who have no statutory rights to information at all. We noted earlier that while people conceived before 1991 might potentially be able to access non-identifying information about their donor from the clinic where their mother was treated, in practice access via this route was very patchy and many records no longer exist (see paragraph 2.15). Identifying information about a donor is only potentially available to donor-conceived people in these situations if their donor has chosen to re-register as an identifiable donor on the HFEA Register (for those who donated between 1991 and 2005) or joins the Donor Conceived Register (for those who donated before 1991).

6.53 We noted in Chapter 2 that arguments have been made to change the law further, so that the provisions requiring identifiable information about donors to be made available to their adult offspring on request should apply retrospectively to all donors (see paragraphs 2.26 and 2.27). Indeed, such a recommendation was made in 2012 by the Law Reform Committee in the State of Victoria in Australia (see paragraphs 2.30 to 2.32), with the proposed protection for donors that they would be able to veto contact from their offspring if they wished, albeit via a relatively cumbersome procedure. Those arguing in favour of such legal change point to the very strong interest that some donor-conceived adults have in obtaining more information about, and the possibility of contact with, their donor; and the injustice that access to such information is determined by the accident of a person's date of conception. Those against point to the equivalent injustice of retrospective change to the terms on which donors agreed to donate, with the potential for disruption to their current family life, particularly where the donor's partner and other close family members may not know even of the possibility of donor offspring. Concerns are also expressed as to the impact on trust in doctors and reproductive health services more generally, if explicit promises made by professionals come to be regarded as breakable.[495]

6.54 The human rights arguments put forward on both sides of this debate have been summarised in Chapter 2 (see paragraphs 2.28 and 2.29). We note here, as elsewhere, that the 'balancing' of qualified human rights involves much the same process as the approach of weighing competing interests that we discuss in Chapter 5 (see paragraph 5.72). Clearly, some donor-conceived adults experience a very strong need for information about their donor, which they are currently unable to meet. Equally clearly, some past donors will feel very strongly that retrospective legal change in this area is both potentially harmful to their current relationships and fundamentally unfair, given that the assurance of anonymity was a standard part of the terms on which they had agreed to donate at the time. These interests do not, and cannot, coincide, and action to meet the interests of one group will inevitably be damaging to the interests of some of the other.

6.55 However, we suggest that a constructive way forward from this impasse may be achieved by considering in more depth the nature of the interests of donor-conceived adults who desire, but do not have, identifying information about their donor. Those interests lie in obtaining information in order to find out more about their donor as a person (for example to help them assimilate the fact of being donor-conceived into their sense of self), and potentially also in the hope of developing a meaningful relationship. However, it is hard to see how these interests would be promoted in any significant way if the state were to provide the identifying details of a donor who was *not* open to further information exchange or ongoing contact. In other words, in order for the interests of donor-conceived adults in this position to be furthered, the donor must be willing and able to engage in at least minimal contact. Yet, such willingness is simply not something that can be created through legislation. Thus not only does retrospective legal change potentially damage the interests of some donors, it would also, in at least some cases, fail to achieve its objective of promoting the interests of donor-conceived adults.

6.56 Drawing on our stance that, wherever possible, measures that aim to support, encourage and empower those making decisions are preferable to measures that seek to limit or remove choice (see paragraph 6.2), **we suggest that the state, rather than regulating retrospectively for the removal of anonymity, should instead take action to increase awareness among past**

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[495] See, for example, Pennings G (2012) How to kill gamete donation: retrospective legislation and donor anonymity *Human Reproduction* **27(10)**: 2881-5.

**donors that a willingness on their part to become identifiable would be highly valued by some donor-conceived adults**. Such a campaign should also alert parents to the possibility of their son or daughter finding out the identity of their donor, even though this had not been foreseen by the parents at the time of their treatment. We recognise that some parents will feel that their own interests have been infringed by such increased awareness of the possibility of donor re-registration – for example where they find the idea of an identifiable donor threatening to their family life. However, we take the view that, once donor-conceived people reach adulthood, their explicit wishes regarding access to information which their donor is willing to provide cannot be subject to a parental veto. We also note that, although no such cases have been reported, legal advice obtained by UK DonorLink in 2011 highlighted the possibility that under Scots law a person conceived before 1991 as a result of sperm donation could be entitled to share in the donor's estate on death (see paragraph 2.1). **We recommend that the Scottish Law Commission investigate this possibility and consider what, if any, action is required to ensure that past donors living in Scotland do not, by making themselves known, incur any unexpected financial obligations**.

6.57 We do not consider it appropriate to invite clinics to contact past donors directly: such contact entails serious concerns about breach of confidentiality (especially where donors' partners or children do not know of past donations) and could only be justified where the information being communicated might be of sufficient importance to the person being contacted, such as information about the medical diagnosis in donor offspring of a serious but treatable condition (see paragraph 6.49). However, a public campaign, raising awareness of the possibility of 're-registering' as identifiable on the HFEA Register or joining the Donor Conceived Register, would serve the dual purpose of prompting past donors to consider the possible impact for themselves and their families of such registration, and of raising awareness more generally of donor conception. **We recommend that the HFEA, in conjunction with the Donor Conceived Register, should initiate a public information campaign about donor conception and the possibility for past donors to make themselves identifiable if they wish**. Such a campaign should make clear that donors willing to make themselves identifiable in this way would have access to a supportive intermediary and counselling system before any contact was made (see paragraphs 6.38 and 6.39), and should also take into account any advice available from the Scottish Law Commission, as suggested above. We further note that the HFEA should take steps to ensure that, where a pre-2005 donor re-registers as identifiable *after* any person conceived from their donation has already contacted the Register for information, the donor-conceived person should be alerted (see paragraph 2.10). Donor-conceived adults should not be expected to contact the Register repeatedly in order to find out whether their donor has re-registered since their previous contact.

6.58 We also draw attention to the role of professionals and clinics with respect to the non-identifying information they may hold about pre-1991 donors. We recognise that in many cases records may be in a poor condition, or indeed no longer in existence. However, we do not think it acceptable that, where records do exist, donor-conceived adults appear to receive such variable responses to requests for non-identifying information about their donor. Such responses may indeed add to the perception that information is being deliberately withheld. **We recommend that the HFEA should issue guidance to clinics setting out what is expected of them with respect to making information from pre-1991 records available to applicants**. The Working Party can see no reason why, where non-identifying information about donors exists in old treatment records, this information should not be disclosed (if necessary after seeking the consent of the person's mother where the information forms part of her health records) to a donor-conceived person seeking this information.

## *Donor-conceived adults conceived outside UK-regulated clinics*

6.59 We have discussed above the situation of those conceived before the current regulatory framework in UK clinics took its current form. However, the problems arising out of the differential access to information that inevitably result from legal developments, are not simply historic ones that will gradually affect fewer and fewer people. As we discussed in Chapter 2 (see paragraph 2.18), not all prospective parents use UK-regulated clinics in order to access treatment with donor gametes or embryos. Some seek treatment abroad, while others have the option of obtaining access to donor sperm without assistance from a clinic. In neither case will the HFEA hold information about the donor, or be able to disclose that information on request to donor-conceived adults conceived via these routes. The information potentially available to donor-conceived adults in such cases will thus depend on the information available to their parent(s) at the time they were conceived, and (in the case of unregulated treatment) whether contact has been maintained with their sperm donor. As we noted earlier, treatment abroad may in some cases result in the donor-conceived person having significantly more non-identifying information about their donor than those conceived in the UK; however it is highly likely that they will not have access to identifying information. In some cases, they may have access to little or no information at all.

6.60 The question thus arises as to what action a stewardship state, concerned to promote the welfare of those affected by donor conception, should take in such cases. The HFEA cannot provide information about donors that it does not itself collect. Nor, in our view, is it either practical or desirable to seek to prevent prospective parents from seeking treatment abroad or informal sperm donation in the UK, although we have suggested action above that might encourage more donation in the UK to come within the regulated sector (see paragraph 6.42). Indeed, we are aware that some prospective parents feel that they have little choice other than to go abroad because of the higher costs of private treatment in the UK (see paragraph 4.46). However, we suggest that it *is* within the remit of the state, in this case exercised through the HFEA as the regulator, to act to ensure that prospective parents who choose these routes to donor conception, do so on the basis of clear, unbiased information. **We reiterate our earlier recommendation, that the HFEA should ensure, for example through the creation of a dedicated donor conception website, that factual information about the implications of seeking treatment with donor gametes abroad or through unregulated methods, is readily accessible to those contemplating these routes** (see paragraph 6.35).

## Donors

### Box 6.4: Supporting donors: scenarios[496]

- Faizal is a student, who sees an advertisement in his medical school looking for sperm donors from ethnic minority groups. He is wondering what the implications for his family and for himself might be if he were to donate.
- Richard is considering donating sperm, but is concerned about the amount of information he is being asked to provide. He is also unsure how to complete a pen picture when he has no idea what the resulting children will be like.
- Karen and Jonathan used egg donation to conceive Francis. Francis has been diagnosed with epilepsy, and the doctor has indicated that the type of epilepsy is more likely to be inherited from the mother. Karen and Jonathan wonder if they should feed this information back to the fertility clinic so that the donor can be made aware of this.
- Jeffery donated sperm in 2006. He realises that, from 2024, he may be contacted by people born as a result of his donation. He is now married with two children, and wants to know how this whole process will be managed, so that he can prepare his own family, who do not know he was a donor.

### *Support for donors in considering the implications of donation*

6.61 This final section of this report considers the role, responsibilities, and needs of donors – without whom donor conception would self-evidently be impossible. We argued earlier that, in making a donation that may lead to the creation of a person, donors have a responsibility to think carefully about the consequences for all those concerned: for themselves and their families, for recipients, and for the people born as a result of their donation (see paragraph 5.53). Just as we have discussed the importance of proper information and support being made available to

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[496] This box highlights hypothetical scenarios to illustrate a range of possible situations.

prospective parents to help them decide whether creating a family with donor gametes is the right way forward (see paragraphs 6.12 to 6.17), we emphasise here the importance of equivalent information and support being made available to donors. Like prospective parents, prospective donors need information about both the short-term and long-term implications of donation: both the immediate physical aspects, and the longer-term consequences. Since the change in the law in 2005, these longer term consequences for unknown donors include accepting that a biologically-connected person will be growing up, for whom the donor has no parental responsibility, and with whom they have no prospect of early contact – and yet from the age of 18 that person might (or might not) wish to make contact. Such uncertainty may, in particular, cause difficulties for donors with respect to managing the expectations of their own children, whether born at the time of the donation or conceived many years later, in connection with the possibility of later contact.

6.62 'Known' donors will have to think through different implications, in conjunction with the recipients' wishes and intentions, regarding the extent to which they will, or will not, have contact with any future child, and what role they will be understood to be playing in their offspring's lives.[497] Those considering donating gametes through 'sharing' arrangements or donating embryos that are no longer required for their own treatment (see paragraph 1.5) will have different considerations again, given the extent to which donation is intertwined with their own treatment decisions, and the particular consideration (in the case of embryo donation) that any resulting person will be a full sibling to the donors' own children.

6.63 We took the view above that counselling sessions in which prospective parents would be able to receive information and think through the implications of donation for their particular situation, as well as receiving therapeutic support where this was needed, should not be made statutorily mandatory but should be offered by clinics as part of a routine series of appointments (see paragraphs 6.16 and 6.17). We take the same view with regard to the role of the counsellor for prospective donors. While some prospective donors may be very well informed about the practical and legal implications of donation, it is only responsible for clinics to ensure that they have been prompted to think through these implications for others. We return below to the important question of the implications for recipients and offspring, but highlight here, in particular, the implications for the donor's current or future partner and children who, in 18 years' time, may also be affected by the question of contact with donor-conceived offspring. Indeed the situation of the donor's own children is potentially inequitable in that they have no way of initiating contact with their 'donor half-sibling' if they wish to do so in adulthood (see paragraph 5.20): such contact will only be possible if the donor-conceived person actively seeks contact first with the donor. This imbalance in access to identifying information may be inevitable, given the problems inherent in providing identifying information about donor-conceived people to the donor's family where the donor-conceived person might not know of the existence of the donor, or wish for contact if they do. However, it draws further attention to the need to help donors think through how they will manage sharing information and expectations within their own family. **We recommend that clinics should ensure that sessions with a counsellor are scheduled as part of the routine series of appointments that donors attend before deciding whether or not to go ahead with donation. We further recommend that, where donors have partners, clinics should strongly encourage partners to attend these sessions**. **Such an approach to the counselling support available to donors should be required of clinics as a matter of good professional practice by the relevant professional bodies, including the British Fertility Society and the British Infertility Counselling Association**.

6.64 We have already emphasised that a key implication of being a donor (with some exceptions for known donors) is the recognition that they will have no role in the upbringing of any resulting

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[497] De Wert G, Dondorp W, Pennings G *et al.* (2011) Intrafamilial medically assisted reproduction *Human Reproduction* **26(3)**: 504-9.

child. However, we have also highlighted throughout this report that some parents, and some donor-conceived people, will have a significant interest in information about the donor, in particular information that gives some indication as to the kind of person the donor is. Some prospective parents may find such information very reassuring when deciding to go ahead with donation; some parents may find it easier talking to their children about the donor if they have some brief biographical details that makes him or her ‘real’; some donor-conceived people may find such information very important in assimilating the notion of being donor-conceived into their sense of identity. Others may feel no need of such information, either because they actively prefer to know as little as possible about the donor, or because they just do not find it interesting (see Boxes 4.1 and 4.2). While it would be possible to match donors and recipients on the basis of their informational wishes, clearly it is impossible to predict in advance whether a particular donor-conceived person is likely to find it important to know about their donor or not. **We therefore conclude that, in deciding to donate, donors have a responsibility to think seriously about how they provide information about themselves, in the knowledge that for some recipients, and in particular for some donor-conceived people, this information will be very important. We further conclude that clinics have a responsibility not only to encourage donors to engage seriously with the provision of information about themselves, but also to provide appropriate support in doing so where required. Filling in the donor form should not be perceived as a brief administrative task**.

6.65 However, the question still remains as to how ‘much’ information is an acceptable minimum, or the right amount, or even too much. We note that, in the case of unknown donation, the information provided on the donor information form will be the only information available to the parents and children, until the possibility of direct contact at 18 (with some rare exceptions – see paragraph 6.67). This ‘one-off’ opportunity to provide information both emphasises the importance of giving it serious attention, but also demonstrates the limitations of such information: it can only try to present the donor at one moment in time which will gradually become more and more out-of-date. Moreover, it is important for all concerned to understand that ‘narrative’ information, apart from specific factual details, is never a straightforward ‘truth’: how a person tries to describe themselves in a few paragraphs, or the reasons given for donation which may well be complex and multi-faceted, will always be a form of ‘story’, a selected narrative about themselves. It is impossible to know how much that ‘story’ will resemble the donor ten, 20, or 30 years after donation. It is also the case that what a donor might see as a honest account of himself or herself, and their motivations for donating, might be a potential source of distress for a donor-conceived person: an example of where less, rather than more ‘openness’ might be ethically preferable.

6.66 Taking these factors into account, the Working Party did not feel that it had sufficient evidence to recommend a particular ‘information set’ that all donors should provide. Nevertheless, we conclude that it *is* the role of a stewardship state to collect sufficient information about donors, including ‘narrative’ information about why they donated, so that those who do desire and value this information are able to access it, while recognising its limitations. At the same time, we consider it very important that the state’s role in this sphere should not be seen as sending a message that donor-conceived people and their families ‘ought’ to want or need information. It will remain the case that some will, and some will not. **We recommend that the HFEA’s National Donation Strategy Group should consider further the question of how much and what kind of information should be expected on the donor information form, drawing on the expertise of a range of interested parties**.

6.67 We have highlighted above a number of issues that clinics should ensure that donors have the opportunity to consider before they go ahead with donation, including the impact on donors themselves and their families, and the need to consider carefully how the information provided at the time of donation may be understood and used by parents and donor-conceived people. Clinics should further ensure that donors have been encouraged to think through the circumstances in which there may be later contact, direct or indirect, with the donor-conceived person and their family. We have recommended above that, in the exceptional cases where a donor receives a medical diagnosis that could have a significant effect on the health and health care of their donor-conceived offspring, there should be an easily-accessible route for passing on this information (see paragraph 6.49). Donors should be made aware (for example during counselling sessions) of the importance of passing on such information where it arises, and should also understand that, similarly, recipient families will be encouraged to pass back information if a donor-conceived person is diagnosed with a condition with implications for their donor or the donor's own family. More routinely, donors may, of course, be contacted in 18 years' or more time by those born as a result of their donation. Before making a final decision to donate, prospective donors should be encouraged to think carefully about how they might respond to such initial contact: while future circumstances clearly cannot be predicted, and contact certainly cannot be mandated, clinics should, as a minimum, encourage donors to consider the importance to donor-conceived people of a sensitive initial response from their donor. We reiterate again, here, the importance of intermediary services being available to support both donors and donor-conceived people in making such initial contact (see paragraph 6.38).

### *Valuing donors*

6.68 Much of this report has considered the responsibilities of those concerned with donor conception, and in this concluding section on the role of donors we have highlighted a number of areas where donors have responsibilities to the people they help create, to recipient families, and to their own families. We conclude this report by recalling our discussion earlier in this chapter of the wider role of the state in encouraging an environment where donor conception would be seen as one way among a number of others of creating a family of one's own, and where donor-conceived families would feel 'ordinary' and included (see paragraphs 6.43 and 6.44). Such a society would also have a high value for donors, and their generosity in making donor-conceived families a reality.

# Appendices

# Appendix 1: Method of working

## Background

The Nuffield Council on Bioethics established the Working Party on *Donor Conception: ethical aspects of information sharing* in February 2012, and the Working Party subsequently met six times between February and December 2012. In order to inform its deliberations, it launched a 'call for evidence' and online survey in March 2012, and between April and October held a series of 'factfinding' sessions with donor-conceived people, parents of donor-conceived people, donors, health and social care professionals, academic researchers, and those involved in regulation. It also carried out a detailed literature review of the research evidence relating to the experiences of donor-conceived people, parents and donors in relation to information sharing. In November 2012, 15 external reviewers, encompassing a diverse range of experiences and perspectives, were invited to comment on a draft version of the report, which was subsequently reviewed in the light of the comments received.

In total 198 people and organisations, including 11 donor-conceived individuals, 56 parents and 14 donors (where specified), contributed to the Working Party's evidence gathering, and we are enormously grateful to them for the generosity with which they gave their time, their enthusiasm and their expertise.

## Call for evidence

The Working Party's 'call for evidence' (including indicative questions, but also inviting respondents to raise any issues they wished within the remit of the terms of reference) was launched on 21 March 2012 and remained open until 15 May 2012. The call for evidence was accompanied by a briefer online survey with the aim of reaching as many people with personal experience of donor conception as possible. Forty responses to the call for evidence were received (of which 23 came from individuals and 17 from organisations), and 90 people responded to the online survey. Those responding to the call for evidence and online survey included donor-conceived adults, parents, donors, people working with individuals affected by donor conception, representatives from charities or support groups, representatives from professional bodies or government, individuals with an academic or research interest, and those with a legal or regulatory interest, as well as members of the public with a general interest.

Details of the content of the call for evidence, and a full list of respondents, excluding those who asked to remain anonymous, is included in Appendix 2. The online survey did not require respondents to identify themselves; however the organisations who chose to contribute through the online survey and provided organisational details are also listed in Appendix 2. Some respondents to the online survey also indicated a willingness to meet with the Working Party to provide further information, and subsequently two individuals (selected on the basis that the issues they raised had not, as yet, been heard in factfinding sessions) were invited to factfinding meetings on 16 July 2012.

The responses received through these two consultative methods were circulated to all Working Party members and discussed in subsequent meetings. A summary of responses is available on the Council's website, as are copies of individual responses where respondents gave us permission to publish them in this way.[498]

## Factfinding sessions

A series of 'factfinding' sessions with people with personal and/or professional experience of issues arising out of donor conception played a central part in the Working Party's evidence-gathering. A total

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[498] See: Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering.

of ten meetings were held, mainly involving discussion sessions lasting between one and a half and two and a half hours, as follows:

### *24 April 2012: meeting with Rachel Pepa, donor-conceived person*

### *27 April 2012: full day meeting, encompassing three sessions with people with personal experience of donor conception, as follows:*

Members of UK DonorLink (participants included donor-conceived adults and donors)

- Sylvia Barr
- Freddie Howell
- Jess Pearce
- Andy Waters
- Philippa Wilkinson
- Shirley Brailey (contributed in writing after the meeting)

Members of the Donor Conception Network (participants included donor-conceived adults and parents)

- Danny Charles
- Jane Ellis
- Katherine Litwinczuk
- Walter Merricks
- William Merricks
- Zannah Merricks
- Tamsin Mitchell
- Olivia Montuschi

Members of the National Gamete Donation Trust (participants included parents and donors)

- Sarah Betts
- Shaun Betts
- Eleanor Clapp
- Mark Jackson
- Pip Morris
- Cathy Sidaway

### *30 May 2012 (am): meeting with practitioners/researchers*

- Gary Clapton (social worker and academic; currently consultant at Birthlink Scotland)
- Marilyn Crawshaw (social work academic, practitioner and activist; advisor to UKDL and chair of Progar)
- Julia Feast (researcher and practitioner; formerly with the Children's Society and currently based at the British Association for Adoption and Fostering)
- Christine Gunter (social worker; coordinator of UK DonorLink)
- Sharon Pettle (consultant clinical psychologist and psychotherapist with 15 years' experience of donor conception issues; work for DCN includes running groups for donor-conceived children)
- Jennifer Speirs (anthropologist, former medical social worker and activist; volunteer intermediary worker for NorCap, support worker for UK DonorLink, and member of NGDT Advisory Council)

### *30 May 2012 (pm): meeting with academics*

- John Appleby, Centre for Family Research, University of Cambridge

- Sarah Franklin, Department of Sociology, University of Cambridge
- Tabitha Freeman, Centre for Family Research, University of Cambridge
- Lucy Frith, Department of Health Service Research, University of Liverpool
- Nicky Hudson, Reproduction Research Group, De Montfort University
- Fiona MacCallum, Department of Psychology, University of Warwick
- Ilke Turkmendag, PEALS, Newcastle University

### *22 June 2012 (am): meeting on regulatory aspects of donation*

- Joanne Anton, HFEA
- Natalie Gamble, Natalie Gamble Associates
- Jagbir Jhutti-Johal, University of Birmingham, Department of Theology and Religion
- Caroline Jones, University of Southampton Law School
- David Katz, Board of Deputies of British Jews
- Michal Nahman, UWE, Department of Health and Applied Social Sciences
- Marcelle Palmer, Board of Deputies of British Jews
- Ted Webb, Department of Health
- Morgan Clarke, Institute of Social and Cultural Anthropology, University of Oxford (contributed in writing after the meeting)

### *22 June 2012 (pm): meeting with professionals involved at the time of donation*

- Joanne Adams, sperm donor bank manager, Manchester Fertility Services
- Peter Braude, emeritus professor of obstetrics and gynaecology, King's College London
- Jenny Dunlop, senior infertility counsellor, Manchester
- Anil Gudi, consultant, Homerton Fertility Centre
- Yacoub Khalaf, consultant Guy's and St Thomas' NHS Foundation Trust
- Jenny Parker, nurse co-ordinator, CRM London
- Pip Reilly, independent fertility counsellor
- Amit Shah, consultant, Homerton Fertility Centre
- Venessa Smith, donor services co-ordinator, London Women's Clinic

### *6 July 2012: presentation on 'why parents choose not to tell'*

- Lucy Blake, research associate, Centre for Family Research, University of Cambridge

### *16 July 2012: meeting with Juliet (prospective parent and online survey respondent)*

### *16 July 2012: meeting with Christine Whipp (donor-conceived person and online survey respondent)*

### *2 October 2012: meeting on the significance of medical information from the donor*

- Tara Clancy, consultant genetic counsellor and lecturer in medical genetics, Central Manchester University Hospital
- Peter Harper, university research professor in human genetics, Cardiff University
- Efun Johnson, designated doctor for looked after children (Lambeth), Guy's & St. Thomas' Community Health Services
- Alastair Sutcliffe, reader in general paediatrics, honorary consultant paediatrician at University College London Hospitals and Great Ormond Street Hospital
- Andrew Wilkie, Nuffield professor of pathology, Weatherall Institute of Molecular Medicine, University of Oxford

- Ron Zimmern, chair of the PHG Foundation, honorary consultant in public health medicine at Addenbrooke's Hospital
- Pascal McKeown, Director of the Centre for Medical Education, Queen's University Belfast (contributed in writing before the meeting)
- Andrew Papanikitas, portfolio GP, London and Buckinghamshire, and sessional tutor/facilitator in ethics, interprofessional education and clinical communication, King's College London (contributed in writing before the meeting)

## Literature review

Kate Harvey of the staff of the Nuffield Council carried out a detailed review of existing published quantitative and qualitative research with donor-conceived people, parents of donor-conceived people, and donors, addressing the issue of the impact on them of disclosure or non-disclosure in connection with donor conception. In preparation for this review, a keyword search of PubMed and Google Scholar was undertaken, and the abstracts of 114 articles were analysed for relevance to the research question.

The Working Party would like to thank John Appleby and Lucy Blake of the Centre for Family Research, University of Cambridge, for their advice and support in connection with this literature review.

## External review

A draft version of the report was circulated at the end of October 2012 to 15 external reviewers with personal and/or professional expertise in the issues arising out of information sharing in donor conception, encompassing a diverse range of perspectives. The 15 reviewers were:

- Shirley Brailey
- Ken Daniels
- Heather Draper
- Jonathan Herring
- Jennifer Hunt
- Walter Merricks
- Petra Nordqvist
- Allan Pacey
- Liz Scott
- Francoise Shenfield
- Marilyn Strathern
- Juliet Tizzard
- Steve Wilkinson
- Andy Waters
- Clare Williams

The Working Party is very grateful to these 15 external reviewers for their detailed and throughful comments, which were invaluable in producing the final report.

# Appendix 2: Wider consultation for the report

The aim of the open consultation was to obtain views from as wide a range of individuals and organisations concerned with donor conception as possible. The 'call for evidence' was published online on 21 March 2012 and remained open until 15 May 2012. After providing details of the Terms of Reference (reproduced on page xi of this report) and a background paper, the call for evidence set out a series of questions, listed in the box below.

### Call for evidence: questions

In order to inform and support the Working Party's deliberations, the Council would like to invite anyone with an interest (personal, professional or general) in this field to contribute views, examples and evidence within the scope of the terms of reference. The questions on which the Council is particularly interested in hearing your views are set out below. Please feel free to answer any or all of these questions, or to give your views in any other way on the issues within the scope of the terms of reference. Where possible, it would help us if you could explain the reasoning behind your answers.

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 family 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 well-being 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.

At the same time, the Working Party published an online survey, using the website 'Survey Monkey', with the aim of asking a more limited number of questions and hence encouraging as wide a range as possible of people personally affected by donor conception to respond.

### Survey Monkey: questions

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 their 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 born 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?

The Working Party received 40 responses to the call for evidence (of whom 23 were individuals and 17 were responding on behalf of organisations), and 90 responses to the online survey, three of which came from organisations who provided organisational details (Anscome Centre, Fiom, and Hindu Council UK). A summary of the responses received from both formats is available on the Council's website, and individual responses will also be published where the Council has received permission from respondents to do so. The responses the Working Party received, in conjunction with the face-to-face factfinding meetings described in Appendix 1, were very important in shaping the deliberations of Working Party members, and the Working Party would like to express its gratitude to all those who responded.

## *List of respondents to the call for evidence*

**Individuals**

Anonymous (4)
Dr John B. Appleby and Dr Lucy Blake, Centre for Family Research, University of Cambridge
Dr Thérèse Callus
Mhairi Cowden, Australian National University
Emily Engel
Group 10, Leicester Medical School (Aneesa Iram Azhar, Helen Frances Brodie, Daniel Downey, Daniel Gibson, Martin Guichard-Wheatley, Jamila Kassam, Elizabeth Frances Kershaw, Michal Konisiewicz, Immanuel Amrita Rhema)
Jennie Hunt, Senior Accredited Member of BICA
The International Donor Offspring Alliance
Dr Maggie Kirkman, The Jean Hailes Research Unit, Monash University, Australia
Maren Klotz, Lecturer, European Ethnology Humboldt University Berlin, and Honorary Fellow at the Egenis Centre, University of Exeter
Mr James Martin
Lynda Mizen
Rachel Pepa
Andrea Powell
Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester
Venessa Smith, Donor Services Coordinator, The London Women's Clinic
Tsuyoshi Sotoya, Graduate School of Social Sciences, Hitotsubashi University
Professor Marilyn Strathern

**Organisations** (including those who responded via the online survey)

Anonymous (1)
Anscombe Centre (via the online survey)
Australian and New Zealand Infertility Counsellors Association
Professor David Katz, on behalf of the Board of Deputies of British Jews
British Fertility Society
The British Infertility Counselling Association
British Medical Association
The Christian Medical Fellowship
Church of England: Mission and Public Affairs Council
Trustees and Steering Group of the Donor Conception Network

Donor Sibling Registry (DSR)
Fiom (via the online survey)
Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors
Hindu Council UK (via the online survey)
Human Fertilisation and Embryology Authority
Pride Angel Ltd.
PROGAR (Project Group on Assisted Reproduction, British Association of Social Workers)
Progress Educational Trust
Department of Reproductive Medicine, St. Mary's Hospital, Manchester
Royal College of Nursing
Victorian Assisted Reproductive Treatment Authority

**Respondents who submitted published material**

Dr Sonia Allan
British Medical Association
Mhairi Cowden, Australian National University
Human Fertilisation and Embryology Authority
Victorian Assisted Reproductive Treatment Authority

(NB: Some respondents submitted published material and also responded directly to questions listed in the Working Party's call for evidence document. These respondents are listed more than once in the headings above.)

# Appendix 3: The Working Party

**Rhona Knight** (chair) is a portfolio GP based in Leicester. She is a senior clinical educator at Leicester University, and is the clinical lead in the Royal College of General Practitioners' (RCGP) Health for Health care Professionals pilot programme. As a GP she has been involved in teaching practical medical ethics for many years, including the ethics of professionalism, communication and of the consultation. She has an interest in making medical ethics accessible to non-specialist audiences. She is a member of the RCGP ethics committee, a trustee of the Institute of Medical Ethics, and she chairs the Nuffield Council's Education Advisory Group.

**Wybo Dondorp** is Assistant Professor of Biomedical Ethics at Maastricht University, and his main research interests are in the ethics of reproductive medicine and the ethics of genetic screening. He has worked with the Health Council of the Netherlands, both in the past on the scientific staff (contributing to advisory reports on IVF and other forms of assisted reproduction), and currently as a member of the Council's permanent committee on population screening. He chairs the Task Force Ethics & Law of the European Society of Human Reproduction & Embryology. Recently, he was part of a research group that conducted the government-requested evaluation of the 2004 Dutch Act that put an end to anonymous donation of gametes and embryos in the Netherlands.

**Jeanette Edwards** is Professor of Social Anthropology at the University of Manchester, currently Head of Discipline Area and Vice President of the European Association of Social Anthropologists. She has a long-standing research interest in the ethnography of class, kinship and community in the north of England and has published widely on kinship and assisted reproductive technologies. She convened and directed a European, multi-disciplinary and cross-cultural project on 'public understandings' of genetics, and more recently has been developing research into religion and biotechnology in the Middle East.

**Susan Golombok** is Professor of Family Research and Director of the Centre for Family Research at the University of Cambridge, and a Professorial Fellow at Newnham College. Her research examines the impact of new family forms on parent-child relationships and children's social, emotional and identity development, with a particular focus on lesbian mother families, gay father families, single mothers by choice and families created by assisted reproductive technologies including in vitro fertilisation (IVF), donor insemination, egg donation and surrogacy.

**Anneke Lucassen** is Professor of Clinical Genetics at the University of Southampton Faculty of Medicine, and Consultant at the Wessex Clinical Genetics Service. She specialises in cancer and cardiac genetics and has a busy NHS workload. At the University she leads a research group that addresses the social, ethical and legal aspects of genetic medicine. Current research explores the familial aspects of confidentiality in genetics; childhood genetic testing; and incidental findings discovered through genetic tests. She coordinates the teaching of medical ethics and law throughout the medical undergraduate curriculum in Southampton and co-chairs the Southampton University Hospitals NHS Trust Clinical Ethics Committee. She co-founded the UK Genethics Club in 2001 which holds thrice-yearly national meetings.

**Sheila Pike** is Senior Counsellor at the Jessop Fertility HFEA licensed centre in Sheffield. She has a background in psychology and counselling, has been a specialist infertility counsellor for over 20 years and is a past Chair of the British Infertility Counselling Association. She has worked both privately and within HFEA licensed centres, counselling clients with a range of fertility issues including those considering the implications of family creation using donor assisted conception and those considering donation. She also has extensive experience of counselling clients involved in surrogacy arrangements. She is a member of the National Gamete Donation Trust's Advisory Council and an External Advisor for the HFEA.

**Rosamund Scott** is Professor of Medical Law and Ethics at the Centre of Medical Law and Ethics in the Dickson Poon School of Law, King's College London. Her background is in philosophy and law, and her research and publications have centred on reproductive ethics and law. She has had extensive involvement in interdisciplinary research with others and in 2012 was awarded (together with Professor Stephen Wilkinson, University of Keele) a Senior Investigator Award in Ethics and Society by the Wellcome Trust to support a research programme on ‘The Donation and Transfer of Human Reproductive Materials’. Other roles in policy advice and engagement include membership of the MRC Steering Committee for the UK Stem Cell Bank and, previously, the Royal College of Obstetricians and Gynaecologists’ Ethics Committee.

**Laura Witjens** is Chief Executive of the National Gamete Donation Trust, having joined the NGDT in 2003 after having been an altruistic egg donor. The NGDT works closely with patients, donors, clinics and other professionals on the issues around gamete donation and since January 2013 has also been responsible for running the voluntary Donor Conceived Register. She was a member of the British Fertility Society Working Group on Sperm Donation Services and a member of HFEA Donation Advisory Group, and is currently a member of the HFEA’s National Donation Strategy Group.

# Glossary

(How terms commonly used in donor conception are employed in this report.)

**Anonymous donor**: Unknown donor whose identity will not be released, either to recipients or to the person born as a result of their donation, at any point. (See also **unknown donor**, and **identity-release donor**.)

**Donor**: Provider of sperm, egg or embryo, with the aim of enabling others to create a family.

**Donor-conceived person**: Person born as a result of donated gametes or a donated embryo.

**Donor-conceived siblings**: Donor-conceived people who are born as a result of donation by the same donor, but to different recipient parents.

**Donor conception**: The creation of children through the use of donated egg, sperm or embryo.

**Identity-release donor**: Unknown donor, initially anonymous, whose identity may be made available to donor-conceived offspring when they reach the age of 18.

**Intended parents**: Prospective parents intending to create a family through a surrogacy arrangement.

**Known donor**: Donor who is known to the recipient(s) before treatment with donated gametes begins. Known donors may be longstanding friends or family, or may become acquainted with recipients through third parties such as matching websites.

**Recipients**: Prospective parents intending to create a family through donated gametes or embryos.

**Unknown donor**: Donor whose identity is unknown to recipients at the time of treatment. Unknown donors may be either **anonymous donors** or **identity-release donors**.

# List of abbreviations

| | |
|---|---|
| **BACP** | British Association for Counselling and Psychotherapy |
| **BICA** | The British Infertility Counselling Association |
| **CJD** | Creutzfeldt-Jakob disease |
| **COTS** | Childlessness Overcome Through Surrogacy |
| **DCN** | Donor Conception Network |
| **DSL** | Donor Sibling Link |
| **DSR** | Donor Sibling Registry |
| **ECHR** | European Convention on Human Rights |
| **ESHRE** | European Society of Human Reproduction and Embryology |
| **HFEA** | Human Fertilisation and Embryology Authority |
| **HIV** | Human immunodeficiency virus |
| **HTLV** | Human T-lymphotropic virus |
| **IVF** | in vitro fertilisation |
| **JCHR** | Joint Committee on Human Rights |
| **NGDT** | National Gamete Donation Trust |
| **NHS** | National Health Service |
| **PROGAR** | BASW’s Project Group on Assisted Reproduction |
| **UKDL** | UK DonorLink |
| **UNICEF** | United Nations Children’s Fund |
| **UNCRC** | United Nations Convention on the Rights of the Child |

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*['n' denotes footnote locators; 't' denotes table locators; 'b' denotes box locators]*

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Published by
Nuffield Council on Bioethics
28 Bedford Square
London WC1B 3JS

Printed in the UK

ISBN 978-1-904384-28-1