

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.