

Chapter 6

Implications for regulation
in the UK

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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 information form 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: scenarios⁴⁵⁸

- 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

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

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:

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

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 wholesale 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

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 1*, 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 1*, 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,

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

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

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 born⁴⁷⁶) 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

⁴⁷³ House of Commons Science and Technology Committee (2005) *Human reproductive technologies and the law: fifth report of session 2004-5 - volume 1*, 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: scenarios⁴⁷⁸

- 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

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

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

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

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

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 politicians, 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,**

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

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: scenarios⁴⁹⁴

- 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

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**

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: scenarios⁴⁹⁶

- 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

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

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.