

# Chapter 2

Law and practice in the  
UK

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### Chapter 2: overview

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

### Collecting and accessing information about donors

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

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

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

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

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

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

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

<sup>52</sup> The 2008 Act amended and extended the original provisions in the 1990 Act of the same name.

<sup>53</sup> Section 33 of the 2008 Act.

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

<sup>55</sup> Sections 36-7 and 43-4 of the 2008 Act.

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

<sup>57</sup> For potential financial and inheritance implications arising out of pre-Act conceptions, see: UK DonorLink (2011) *Guidance on financial implications for those who may wish to trace family members through the UK DonorLink Register*, available at: [http://www.ukdonorlink.org.uk/UKDL\\_Financial\\_Implications\\_Leaflet\\_June\\_2011.pdf](http://www.ukdonorlink.org.uk/UKDL_Financial_Implications_Leaflet_June_2011.pdf). This reproduces legal advice given to UK DonorLink in 2011, indicating that under Scots law a person has an automatic entitlement to inherit from their biological father, regardless of the lack of any social relationship. No such cases have, however, been reported.

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

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

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

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

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

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

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

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

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

## The HFEA's Register

- 2.5 We noted in Chapter 1 (see paragraph 1.3) that in the case of 'unknown' donors, professionals and regulatory authorities act as intermediaries between donors and recipients, not only in connection with the initial donation and treatment with donated gametes, but also in connection with the collection and management of information: information about the donor and, in cases where donation leads to a successful pregnancy, information about the resulting child. Unlike known donors and recipients who have the potential to make their own arrangements as to how much information they share with each other and with any resulting children, unknown donors, recipient parents and any people born as a result of donation are entirely reliant on third parties (clinics and the HFEA) both for how much information is collected, and on the extent to which they may access that information.<sup>65</sup> Access to information for donor-conceived people, whether from known or unknown donors, will further depend on whether or not their parents tell them that they are donor-conceived: while the HFEA holds and makes available information as described below, and actively encourages parents to disclose to their children (see paragraphs 2.20 and 2.21) it does not itself act to contact donor-conceived people in connection with the information it holds.
- 2.6 Since 1991, the HFE Act has required the HFEA to maintain a 'Register of information' which records all notified births resulting from treatment services, including those where donated gametes and embryos were used, and also holds information about gamete donors.<sup>66</sup> While information about donors' physical characteristics (eye and hair colour, height, weight and ethnic group) has been collected from the beginning, the emphasis on the potential significance of personal and biographical information about donors has changed over time. In 1991, the donor information form included an optional section inviting donors "to give a brief description of yourself as a person",<sup>67</sup> and the HFEA's *Code of practice* emphasised the optional nature of this section, stating that donors should be encouraged to provide as much other non-identifying biographical information about themselves "as they wish[ed]".<sup>68</sup> The approach of clinics in encouraging donors to provide biographical information in this way also varied considerably.<sup>69</sup> Since 2003, however, the emphasis in the HFEA's *Code of practice* has changed to include the expectation that clinics would encourage donors to provide as much information "as possible".<sup>70</sup> Information that must now be collected by clinics about donors and transmitted to the HFEA includes the physical characteristics cited above, donors' medical background, information about any screening tests carried out, and donors' contact details.<sup>71</sup> The latest version of the standard donor information form invites donors to provide optional additional information in the form of biographical information about themselves such as details of their occupation, interests and religion, and their reason for donating, as well as providing the opportunity to write a goodwill message to their future offspring and a pen portrait providing a fuller description of themselves.

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

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

<sup>67</sup> Human Fertilisation and Embryology Authority (1991) *Donor information form 91(4)* (London: Human Fertilisation and Embryology Authority).

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

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

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

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

- 2.7 While the form makes clear that these later biographical sections are optional, it recommends that donors should fill them in, commenting that: “the information you provide can help parents tell children about their origins and answer some questions a donor-conceived person may have.”<sup>72</sup> However, the Working Party was told that these sections are not consistently filled in, or filled in only sketchily;<sup>73</sup> one respondent to the call for evidence also noted that, in her research, she had observed how donors sometimes intended to fill these parts of the form in at home, precisely because they were seen as being more important or complicated, but then never returned them.<sup>74</sup> Clinics may also edit information if they are concerned that it is in some way inappropriate,<sup>75</sup> while the HFEA will redact any information that it deems potentially identifiable.<sup>76</sup> At the time of writing, the HFEA’s National Donation Strategy Group is in the process of developing a leaflet for donors, offering guidance on what information they might provide.<sup>77</sup>
- 2.8 Initially, the intention behind collecting such donor information was to enable limited *non-identifying* details about donors to be released to donor-conceived people, on request, when they reached the age of 18. Donor-conceived people aged 16 or over would also be able to contact the HFEA to ensure that they were not biologically connected to the person they intended to marry.<sup>78</sup> It was not envisaged that any identifying information would be released at any stage: potential donors were encouraged to come forward and donate gametes under assurances of anonymity, and their donation was conceptualised as a one-off gift with no future implications of any kind. However, this approach to the collection, and future sharing, of information was not unchallenged, with the British Association of Social Workers’ Project Group on Assisted Reproduction (Progar) drawing on comparisons with adoption to argue from the beginning that the regulation of donor conception services should include access by donor-conceived people to identifying information about their donor.<sup>79</sup>
- 2.9 Following extended campaigning by Progar and the Children’s Society, the Department of Health announced in December 2000 that it would be undertaking a consultation on the amount of information that should be made available to donor-conceived people, and to their parents during their childhood.<sup>80</sup> Before the promised consultation document was published, a case was brought by a donor-conceived adult (Joanna Rose) and a donor-conceived child (EM) under the *Human Rights Act 1998*, in which it was argued that under Article 8 of the European Convention on Human Rights, states had an obligation to ensure that “certain vital non-identifying information about donors is collected and made available to [donor-conceived] offspring both on maturity and to parents such as those of EM who wish to bring up their child in openness about the circumstances of its conception.”<sup>81</sup> By the time that the case was heard, in May 2002, it was agreed that it would be appropriate to defer consideration of many of the issues raised, until

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

<sup>73</sup> Factfinding meeting with professionals involved at the time of donation, 22 June 2012.

<sup>74</sup> Maren Klotz, Lecturer, European Ethnology Humboldt University Berlin, and Honorary Fellow at the Egenis Centre, University of Exeter, responding to the Working Party’s call for evidence.

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

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

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

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

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

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

<sup>81</sup> *R v Secretary of State for Health* (2002) EWHC 1593, at paragraph 15.

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

- 2.10 Following the consultation and the *Rose* case, the Department of Health announced a policy change in order to enable future donor-conceived adults to access identifying information, if they wished, about their donor. As a result of the *Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004*, anonymous donation was abolished, and any person conceived as a result of gametes donated after 1 April 2005 will be entitled, at the age of 18, to obtain identifying information about their donor.<sup>83</sup> The age for accessing *non-identifying* information about the donor was reduced from 18 to 16 in 2009, for all donor-conceived people conceived since 1991.<sup>84</sup> Those born between 1991 and 2005, however, will not be able to access identifying information about their donor unless the latter has chosen to ‘re-register’ with the HFEA as an identifiable donor: that is, unless they actively choose to waive their right under the legislation to remain anonymous.<sup>85</sup> At present, any donor-conceived person in this group who wants to find out if their donor has re-registered in this way will have to resubmit their request for information on a regular basis, as no mechanism exists to alert people whose donor re-registers *after* the initial request for information was made; however, the HFEA told us that it was in the process of developing a means whereby donor-conceived people would be able to check more easily, on a quarterly basis.<sup>86</sup> The lack of retrospectivity with regard to access to information similarly meant that those born before 1991 were not affected by this policy change relating to anonymity (see paragraphs 2.15 and 2.16).
- 2.11 Changes have also taken place with respect to how the non-identifying information provided on donor information forms, and subsequently held by the HFEA, may be made available to others affected by donor conception. Following the introduction of the 2004 Regulations, the HFEA broadened its approach more generally to the disclosure of information: the parents of donor-conceived children were given access to non-identifying information from the Register, in recognition of the importance attached by some parents to sharing information about the donor with their child as they grew up; and donors were able to find out the number, sex, and year of birth of any people born as a result of their donation. The HFEA told us that, in making policy in

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

<sup>83</sup> Note that clinics were given until 1 April 2006 to make use of their existing stocks of donated gametes, so that some people born as a result of treatment with donor gametes between 1 April 2005 and 1 April 2006 will not be able to access identifying information about their donors. See: Human Fertilisation and Embryology Authority (2005) *Information for centres on transitional period for use of gametes from anonymous donors: CH(05)01*, available at: [http://www.hfea.gov.uk/docs/transitional\\_period\\_for\\_gametes\\_embryos\\_version1.pdf](http://www.hfea.gov.uk/docs/transitional_period_for_gametes_embryos_version1.pdf).

<sup>84</sup> Section 31ZA Human Fertilisation and Embryology Act 1990, as amended.

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

<sup>86</sup> HFEA (Juliet Tizzard), personal communication, 18 January 2013.

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

- 2.12 In 2009, the HFEA developed its *Opening the Register* policy, setting out a broad framework for processing requests for donor information, determining who can receive what information, and identifying the core principles (described as “protection of the right of applicants to access information”; “duty of care”; “treating all applicants sensitively”; and “statutory compliance”) that should underpin the release of such information.<sup>88</sup> This reaffirmed the existing policy of giving parents non-identifying information so that they could share it with their child, and also further extended access rights to allow *prospective* parents (that is, those considering treatment with donor gametes) to receive non-identifying information about available donors from the clinic where they were receiving treatment.<sup>89</sup> The 2008 Act (coming into force in 2009) further enshrined in law the existing policy of giving donors access to information about the number, sex and year of birth of children born as a result of their donation.<sup>90</sup>
- 2.13 While UK regulation and HFEA policy have thus gradually changed over the years to encourage greater information provision by donors and greater access to that information by prospective and actual parents, the time-lag inevitable in prospective regulatory change in such an area means that there is little experience to date of donor-conceived people themselves accessing information direct from the HFEA. Only in 2008 would the first donor-conceived young people, born as a result of treatment regulated by the 1991 Act, have reached 16 and be able to access (non-identifying) information from the HFEA Register. Only in 2024 will those born since the abolition of anonymous donation in 2005 be entitled to receive identifying information from the Register, although, as noted above, it is possible that such information may in the meantime be obtained by those born under the original regulatory regime whose donors have chosen to re-register as identifiable. However, as we discussed in Chapter 1 (see paragraph 1.29), technological and social developments, in particular the research capabilities provided by the internet and the use of social networking, are increasingly enabling people to obtain information about donors, donor offspring and donor-conceived siblings *outside* regulated channels.
- 2.14 We describe later the role of voluntary-sector databases, such as the US-based Donor Sibling Registry (DSR), that exist to facilitate such connections (see paragraph 4.25), but examples have also been reported of individuals ‘tracking down’ their donor through the use of online DNA testing, combined with further research based on little more than their knowledge of the location of their parents’ treatment clinic.<sup>91</sup> Moreover, easy access to personal information through the internet may increasingly challenge the distinction between ‘identifying’ and ‘non-identifying’ information: apparently mundane information provided by a donor about the university where they studied, followed by the city in which they now practise law, for example, may quickly lead to the possibility of identification. Social networking may similarly enable donors potentially to be identified from apparently anonymised biographical information. The current role of the HFEA as the ‘gatekeeper’ of identifiable information about donors may thus gradually be forced to evolve in recognition of the extent to which such information may be obtainable in other ways.

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<sup>87</sup> Factfinding meeting on regulatory aspects of donation, 22 June 2012.

<sup>88</sup> Human Fertilisation and Embryology Authority, responding to the Working Party’s call for evidence. For more information, see: Human Fertilisation and Embryology Authority (2009) *Information access for donor-conceived people [and] donors*, available at: <http://www.hfea.gov.uk/535.html> and Human Fertilisation and Embryology Authority (2009) *Authority paper: opening the Register policy – a principled approach*, available at: [http://www.hfea.gov.uk/docs/AM\\_Item\\_9\\_Jan09.pdf](http://www.hfea.gov.uk/docs/AM_Item_9_Jan09.pdf).

<sup>89</sup> Human Fertilisation and Embryology Authority, responding to the Working Party’s call for evidence.

<sup>90</sup> Section 24 of the HFE Act 2008, inserting new section 31ZD into the 1990 Act.

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



**People conceived through donated gametes before 1991**

- 2.15 The HFEA Register does not hold information about people conceived before 1991, and hence the primary source of information for this group of donor-conceived adults is the clinic where their mother’s treatment took place. The Working Party was told that clinics varied considerably in their attitude to requests, with some going to considerable trouble to try to locate any information they still held (with the consent of the patient to whom the files related, as necessary), while others appeared to the donor-conceived adults approaching them to be unhelpful or even obstructive.<sup>92</sup> In some cases, the original files may no longer exist, because clinics have closed, or lead clinicians have retired. In others, documents may still exist but may be stored or filed in a way that makes accessing them difficult. In the Working Party’s factfinding meeting with professionals involved in providing donor conception services, it was clear that, where files are still accessible, clinics do indeed take different stances on how to respond to information requests: while, for example, one clinic was happy to contact past donors and ask them to consider providing further information and/or contact details, another clinic felt that such contact was unfair to past donors who had donated under assurances of anonymity, and also to past patients who had received treatment with the same expectations.<sup>93</sup>
- 2.16 Recognising that some donor-conceived people born as a result of treatment before the implementation of the 1991 Act have a strong desire to find out about their donor, the Department of Health has, since 2004, funded a voluntary register to facilitate contact, where desired, between donor-conceived adults, donors and donors’ own (adult) children. Given the lack of a clear ‘paper-trail’ linking donors and donor-conceived people, ‘matches’ between donor-conceived people and donors, or between donor-conceived siblings, can only be made through DNA testing. This brings additional challenges, given that such testing cannot provide absolute certainty of biological connections, especially those between donor-conceived siblings. Matches can also clearly be made only if both parties have chosen to join the voluntary register. By the end of June 2012, 174 donor-conceived adults, 82 donors, and four adult children of donors were fully registered on the database, with a further 183 donor-conceived adults, 85 donors, and seven adult children of donors who had started, but not as yet completed, the process of registration. Six links had been made between donor and donor-conceived adults, and 35 probable sibling links (including groups of 11, five and three siblings).<sup>94</sup>
- 2.17 Between 2004 and 2012, the voluntary register, known as UK DonorLink (UKDL), was run by After Adoption Yorkshire.<sup>95</sup> Since 1 January 2013, following a decision by the Department of Health to amalgamate its financial support for the promotion of gamete donation with its support for the voluntary register into a single contract,<sup>96</sup> the register has been provided by the National

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

<sup>93</sup> Factfinding meeting with professionals involved at the time of donation, 22 June 2012.

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

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

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

Gamete Donation Trust as part of a 'national gamete donation service' and renamed the Donor Conceived Register.<sup>97</sup>

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

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

### **Early disclosure to donor-conceived people**

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

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

<sup>98</sup> US sperm banks, for example, often collect very detailed personal and biographical information about donors. Whether or not identity-release or anonymous donors are used, however, varies. See: The President's Council on Bioethics (2004) *Reproduction and responsibility: the regulation of new biotechnologies*, available at: [http://bioethics.georgetown.edu/pcbe/reports/reproductionandresponsibility/\\_pcbe\\_final\\_reproduction\\_and\\_responsibility.pdf](http://bioethics.georgetown.edu/pcbe/reports/reproductionandresponsibility/_pcbe_final_reproduction_and_responsibility.pdf), at page 148. See also: ASRM forty-fifth annual postgraduate program (21 October 2012) *Examining the genetic link: course 16*, available at: [http://www.asrm.org/2012\\_PG16\\_Examining\\_The\\_Genetic\\_Link/](http://www.asrm.org/2012_PG16_Examining_The_Genetic_Link/), where it was noted that over half of US sperm banks have open-identity donation.

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

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

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

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

“The centre should tell people who seek treatment with donated gametes or embryos that it is best for any resulting child to be told about their origin early in childhood. There is evidence that finding out suddenly, later in life, about donor origins can be emotionally damaging to children and to family relations.

The centre should encourage and prepare patients to be open with their children from an early age about how they were conceived. The centre should give patients information about how counselling may allow them to explore the implications of treatment, in particular how information may be shared with any resultant children.”<sup>104</sup>

## Legal challenges to the law on disclosure

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

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

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

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

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

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

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

### Birth certification

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

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

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

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

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

<sup>108</sup> Factfinding meeting with people with personal experience of donor conception, 27 April 2012.

<sup>109</sup> Factfinding meetings with: Rachel Pepa, 24 April 2012; people with personal experience of donor conception, 27 April 2012; practitioners/researchers, 30 May 2012; and Christine Whipp, 16 July 2012. See also: Allan S (2012) Donor identification 'kills gamete donation'? A response *Human Reproduction* **27(12)**: 3380-4; Parliament of Victoria Law Reform Committee (2012) *Inquiry into access by donor-conceived people to information about donors: final report*, available at: [http://www.parliament.vic.gov.au/images/stories/committees/lawreform/iadcpiad/DCP\\_Final\\_Report.pdf](http://www.parliament.vic.gov.au/images/stories/committees/lawreform/iadcpiad/DCP_Final_Report.pdf); BioNews (2 April 2012) *Victoria's secret (or 'V' for victory)*, available at: [http://www.bionews.org.uk/page\\_137523.asp](http://www.bionews.org.uk/page_137523.asp).

<sup>110</sup> Department of Health and Social Security (1984) *Report to the Committee of Inquiry into Human Fertilisation and Embryology [The Warnock Report]*, available at: [http://www.hfea.gov.uk/docs/Warnock\\_Report\\_of\\_the\\_Committee\\_of\\_Inquiry\\_into\\_Human\\_Fertilisation\\_and\\_Embryology\\_1984.pdf](http://www.hfea.gov.uk/docs/Warnock_Report_of_the_Committee_of_Inquiry_into_Human_Fertilisation_and_Embryology_1984.pdf), at paragraph 4.25.

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

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

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

### Retrospective access to identifying information about donors

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

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

<sup>113</sup> House of Lords and House of Commons Joint Committee on the Human Tissue and Embryos (Draft) Bill (2007) *Human tissue and embryos (draft) bill: volume 1 - report*, available at: <http://www.publications.parliament.uk/pa/jt200607/jtselect/jtembryos/169/169.pdf>, at paragraph 276. Concerns about state 'collusion' in parental deception were raised directly with the Working Party by The International Donor Offspring Alliance, who argued in response to the Working Party's call for evidence that, while individuals are not bound by human rights conventions (which apply to the states which sign them), and that states cannot prevent people from circumventing legal requirements (for example, by going abroad for treatment), states do have a duty not to "collude" with parents who do not wish to disclose.

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

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

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

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

### Human rights arguments

- 2.28 As the summary above indicates, much of the discussion around possible further legislative change in this area is based on human rights arguments, in particular on the relevance of Article 8 of the European Convention on Human Rights which protects an individual’s right to respect for their private and family life. We noted above (see paragraph 2.9) that the judge in the *Rose* case held that Article 8 was ‘engaged’ by the desire of donor-conceived people to have information (identifying or non-identifying) about their donor, but, given the policy announcement from the Department of Health that was pending at the time, made no finding as to whether or not a failure on the part of the state to provide that information would ‘breach’ Article 8. In determining in any case whether interference with an Article 8 right constitutes a ‘breach’, courts are required to consider whether the interference can be justified on the basis that it constitutes a ‘proportionate’ means of protecting the rights and freedoms of others.
- 2.29 While those advocating the recognition of a moral and ethical ‘right to information’ emphasise the significant part such information may potentially play in the private and family lives of some donor-conceived people, those resisting further legislative change point to the potential impact on others (for example on parents who feel threatened by mandatory disclosure, or past donors who donated on the clear understanding that they would remain anonymous), and to alternative more ‘proportionate’ ways forward involving the encouragement, rather than the imposition, of information sharing. The Government’s current view on these human rights arguments – in brief that neither the European Convention nor other human rights treaties establish a clear right to information – is summarised in Box 2.1 below. There has been no further case-law on this point in the English courts since the *Rose* case, and no case in the European Court of Human Rights has considered the specific question of access by donor-conceived people to information about their donor.

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

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

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

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

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

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

The Joint Committee on Human Rights concluded:

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

### Legal provisions regarding disclosure in other jurisdictions

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

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

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

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

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

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

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

- 2.31 In Belgium, Bulgaria, the Czech Republic, Denmark, France, Greece, Portugal and Spain, by contrast, the anonymity of donors is protected by law, with exemptions in some countries, but not others, for known gamete donation.<sup>123</sup> In Belgium, for example, fertility professionals are required to make identifiable information about donors 'inaccessible' and all those working within the clinic are bound by professional secrecy. The exceptions to this rule cover information about the physical characteristics of the donor which may be shared by recipients when choosing a donor; medical information which may be shared with a GP at the donor-conceived person's request; and circumstances where donor and recipient mutually request non-anonymity (i.e. in known donation).<sup>124</sup> In France, a strict application of the requirement of anonymity means that those who bring their own donor may only be helped through a cross-donation programme in which donors are exchanged between recipient couples.<sup>125</sup> Some European countries prohibit or restrict donation: egg donation, for example, is prohibited in Austria (although, as noted above, identity-release sperm donation is permitted), Germany and Norway, while Italy does not permit any form of gamete donation and France only permits treatment for married couples.<sup>126</sup> A wide range of approaches to the acceptability of anonymous, identity-release, or indeed donation in any circumstances, is thus found within countries, many of which are subject to the same European Directives on the donation and use of tissues and cells,<sup>127</sup> and between whom there is sufficient professional consensus on other aspects of reproductive care for there to be shared professional guidelines.<sup>128</sup>
- 2.32 Outside Europe, there are similar disparities of legal approach between a number of 'Western' or 'Euro-American' jurisdictions (see paragraph 1.30). In both the USA and Canada, donors may choose whether they wish to donate on an anonymous or identity-release basis;<sup>129</sup> and a high profile court decision in British Columbia in the *Pratten* case, that would have outlawed anonymous donation within this Canadian province, has recently been overturned by the British Columbia Court of Appeal, thus restoring the status quo.<sup>130</sup> New Zealand, on the other hand, has, since 2005, required donors to be potentially identifiable once their donor offspring reach

<sup>122</sup> Overheid (2004) *Wet donorgegevens kunstmatige bevruchting (The Artificial Insemination (Donor Information) Act)*, available at: [http://wetten.overheid.nl/BWBR0013642/geldigheidsdatum\\_04-02-2013](http://wetten.overheid.nl/BWBR0013642/geldigheidsdatum_04-02-2013); Winter HB, Dondorp W, Ploem MC *et al.* (2012) *Evaluatie embryowet en wet donorgegevens kunstmatige bevruchting*, available at: [http://www.zonmw.nl/uploads/tx\\_vipublicaties/embryowet-wdkb\\_webversie.pdf](http://www.zonmw.nl/uploads/tx_vipublicaties/embryowet-wdkb_webversie.pdf).

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

<sup>124</sup> Ejustice.just.fgov.be (2007) *Loi relative à la procréation médicalement assistée et à la destination des embryons surnuméraires et des gamètes*, available at:

[http://www.ejustice.just.fgov.be/cgi\\_loi/change\\_lg.pl?language=fr&la=F&cn=2007070632&table\\_name=loi](http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&cn=2007070632&table_name=loi).

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

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

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

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

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

<sup>130</sup> See: BioNews (3 December 2012) *British Columbia Court of Appeal reverses decision on sperm donor anonymity*, available at: [http://www.bionews.org.uk/page\\_221579.asp?dinfo=k4xM7kuEjsxulJs3htzUEUTk&PPID=221859](http://www.bionews.org.uk/page_221579.asp?dinfo=k4xM7kuEjsxulJs3htzUEUTk&PPID=221859).



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

## Support for people affected by donor conception

- 2.33 One common theme that emerged throughout the Working Party's factfinding meetings and in the responses to the call for evidence and online survey, was the need for greater support for people affected by donor conception: whether as donor-conceived people assimilating information about their conception or considering contacting those with whom they are biologically connected, parents considering whether, and how, to talk to their children about donor conception, prospective parents contemplating treatment with donor gametes, or donors and their own families. Below we summarise the support currently available in the UK: we note here, as elsewhere, that the support available via licensed clinics by its nature only applies to prospective parents who seek UK-licensed treatment, and that, for those seeking overseas treatment, the arrangements and requirements for pre-treatment support will inevitably differ from country to country.
- 2.34 With the exception of the support provided by clinics to prospective parents and donors at the point when they are considering treatment/donation, and information provided on the HFEA's website,<sup>135</sup> the primary sources of support for people affected by donor conception come from the voluntary sector, albeit, in some cases, with public funding. The main source of family support is the Donor Conception Network (DCN), established in 1993 by a number of families with donor-conceived children committed to openness within families about donor conception,<sup>136</sup>

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

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

<sup>133</sup> For further details of the Victorian system, see: Parliament of Victoria Law Reform Committee (2012) *Inquiry into access by donor-conceived people to information about donors: final report*, available at:

[http://www.parliament.vic.gov.au/images/stories/committees/lawreform/iadcpiad/DCP\\_Final\\_Report.pdf](http://www.parliament.vic.gov.au/images/stories/committees/lawreform/iadcpiad/DCP_Final_Report.pdf).

<sup>134</sup> 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/lawreform/iadcpiad/DCP\\_Final\\_Report.pdf](http://www.parliament.vic.gov.au/images/stories/committees/lawreform/iadcpiad/DCP_Final_Report.pdf).

<sup>135</sup> See: Human Fertilisation and Embryology Authority (2012) *For donor-conceived people and their parents*, available at:

<http://www.hfea.gov.uk/23.html>; Human Fertilisation and Embryology Authority (2013) *For donors*, available at:

<http://www.hfea.gov.uk/egg-and-sperm-donors.html>.

<sup>136</sup> Donor Conception Network (2013) *Donor Conception Network homepage*, available at: <http://www.dcnetwork.org>.

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

### Information provision

- 2.35 The HFEA *Code of practice* spells out in some detail the information that patients and donors should be offered before they are asked for their consent to proceed, and makes very clear that “the provision of information should be clearly distinguished from the offer of counselling”.<sup>143</sup> ‘Information’ for prospective parents is used in this context to refer both to knowledge about the regulatory framework and requirements, and to the descriptive and biographical information provided by the donor. Thus prospective parents should be provided with the non-identifying information given by the donor, should be advised of the likelihood of a resulting child inheriting physical characteristics, and should receive an explanation of the screening tests that donors undergo, and of the limitations of such tests. On the ‘regulatory’ side, they should be advised of the legal provisions governing parenthood, and the legal entitlements of any resulting children with respect to access to information about their donor. They should also be advised that “it is best for any resulting child to be told about their origin early in childhood”; be encouraged to “be open with their children from an early age about how they were conceived”; and be given “information about how counselling may allow them to explore the implications of treatment, in particular how information may be shared with any resultant children”.<sup>144</sup> Similar requirements covering information relating to the legal and practical implications of donation or surrogacy are set out in the *Code of practice* as a prerequisite before donation or surrogacy arrangements may proceed.<sup>145</sup>
- 2.36 As professionals working in fertility services highlighted to the Working Party in a factfinding meeting, prospective parents, donors and surrogates approach clinics with very differing degrees of initial knowledge: some may simply have skimmed the clinic’s homepage before

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

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

<sup>139</sup> Surrogacy UK (2013) *Surrogacy UK homepage*, available at: <http://www.surrogacyuk.org/>.

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

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

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

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

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

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

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

- 2.37 The emphasis of clinics and the HFEA’s *Code of practice* relates naturally to the information required for prospective parents and potential donors and surrogates to make their initial decisions regarding treatment or donation. However, there is also a need for information further down the line, as parents think through whether and, if so how, they should approach talking to their children about the way they were conceived; donors similarly think about whether or how to tell their partner (particularly in a new relationship) about their past donation; or donors consider whether or how to share information with their own children about the existence of donor-conceived siblings. The DCN provides a number of support services for families encouraging openness: these include *Telling and talking* workshops for parents of children aged 0-7,<sup>149</sup> *Telling and talking* leaflets for parents of children of different ages, and *My story* and *Our story* children’s books to support talking to very young children.<sup>150</sup> The DCN is currently also developing materials aimed at older children.<sup>151</sup> It was clear from responses to the Working Party’s call for evidence that these materials are highly valued by parents who have decided to tell their children that they are donor-conceived, but who do not necessarily find it easy (see also paragraph 4.11).
- 2.38 Donor-conceived people, parents and donors may of course also choose to make use of both public and private web-based forums, and these may provide opportunities to share information and seek advice from others in a similar situation. The DCN’s annual meetings, and the networking opportunities offered through membership of the Donor Conceived Register (formerly UKDL) for people born before 1991, provide further such opportunities for mutual support, especially for those who have, in the past, felt isolated as a donor-conceived person.<sup>152</sup>

### **Counselling before treatment or donation**

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

<sup>146</sup> Factfinding session with professionals involved at the time of donation, 22 June 2012.

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

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

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

<sup>150</sup> See: <http://www.dcnetwork.org/catalog/books-and-pdfs> for details of DCN publications.

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

<sup>152</sup> Factfinding meeting with Rachel Pepa, 24 April 2012, and with people with personal experience of donation, 27 April 2012.

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

- 2.40 Counselling provided in the context of treatment or donation at an HFEA-licensed clinic is often described as ‘implications counselling’, because of this legal requirement. However, counselling in the context of donor conception may encompass considerably more than the consideration of the implications of treatment or donation. The British Infertility Counselling Association (BICA) describes infertility counselling as offering prospective parents “an opportunity to explore their thoughts, feelings, beliefs and their relationships in order to reach a better understanding of the meaning and implications of any choice of action they may make; counselling may also offer support to them as they undergo treatment and may help them to accommodate feelings about the outcome of any treatment.”<sup>156</sup> Thus, the aim of counselling for prospective parents in the context of donor conception is not solely to provide an opportunity for them to think through the implications of various courses of action with the support of an informed professional, but also, where necessary, to provide therapeutic support in handling the difficult emotions that infertility may generate. Those who consider treatment with donated gametes for reasons other than medical infertility, including single women, same-sex couples and those seeking to avoid passing on a serious genetic condition, may have different support needs, as will those contemplating ‘egg-share’ arrangements.<sup>157</sup>
- 2.41 Counsellors working in HFEA-licensed centres are required to be accredited members, or working towards accredited membership, of their professional body (BICA) or be able to demonstrate equivalent, accredited specialist training and experience, and to abide by the BICA *Guidelines for good practice in infertility counselling* and the HFEA *Code of practice*. Within these requirements there is considerable flexibility, allowing the counsellor to work according to their own philosophy. The BICA guidelines emphasise that while “counselling can increase a client’s ability to make choices and change aspects of their situation... [it] does not involve giving advice or directing a client to take a particular course of action.”<sup>158</sup> Counselling in licensed clinics should thus be predominantly ‘client-centred’ with a focus on the well-being and needs of the individuals engaging with the counsellor. An important aspect of counselling sessions is their confidentiality: the BICA guidelines emphasise the importance of maintaining client consent and

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

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

<sup>155</sup> Section 13(6) of the HFEA Act 1990, as amended.

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

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

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

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

- 2.42 Prospective heterosexual parents who have already spent time trying to conceive naturally, and who have undergone fertility investigations and – in some cases – treatments, may find it difficult to engage with what is termed ‘preparation for parenthood’: their fears around never having a baby are likely to outweigh concerns they may have about the reality of parenting a donor-conceived child. One of the aims of counselling in such cases is to provide a forum in which they can express their feelings without fear of criticism or judgment, and to allow an exploration of the possibility of creating a different family and future from the one they had originally envisaged for themselves. Counsellors may also find that some prospective parents referred for counselling present initially with mental health issues, such as depression associated with infertility, shock and trauma at diagnosis, multiple loss (past, current and anticipated), and grief.<sup>161</sup> Considerable time may be needed to work through issues relating to prospective parents’ inability to have a child who is genetically related to both of them. Prospective parents in this position may benefit from exploring these feelings before considering the ways in which the complicated issues associated with donor conception treatments may affect their future and that of any child conceived.<sup>162</sup>
- 2.43 While the circumstances bringing prospective parents to counselling at this point may thus vary significantly, the BICA guidelines to counsellors provide a helpful summary of the main issues that are likely to be covered in counselling sessions. These suggest that counselling sessions may explore factors such as:
- “[the clients’] feelings about the medical diagnosis and cause of infertility
  - their initial reactions to the option of using donation and/or surrogacy and changes to attitudes and feelings over time
  - their acceptance, emotional preparedness and expectations of parenthood through donation and/or surrogacy
  - the implications of differences and similarities between their feelings and those of their partner (if they have one) to the option of donation and/or surrogacy
  - the personal implications of donation and/or surrogacy for them in the short and longer term including cultural issues
  - the impact on their wider family and social relationships
  - their attitudes to and preparation for sharing biographical and genetic origins information with children conceived by donation and/or surrogacy

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

<sup>169</sup> Sheila Pike, personal communication, 21 January 2013.

<sup>170</sup> Section 31ZA3(b) of the HFE Act 1990, as amended.

<sup>171</sup> Human Fertilisation and Embryology Authority, responding to the Working Party's call for evidence.

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

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

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

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

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

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

### **Contacting siblings**

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

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

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

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

<sup>178</sup> Factfinding meeting with practitioners/researchers, 30 May 2012.

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

<sup>180</sup> HFEA (Juliet Tizzard), personal communication, 18 January 2013.