

Chapter 1

Families created through
donor conception

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Chapter 1: overview

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

Creating a family through donated gametes and embryos

- 1.1 The development of assisted reproduction services, and the willingness of people to donate their sperm, eggs and embryos for the treatment of others, has made it possible for many people who would otherwise have remained childless to create families of their own. While the donation of sperm is not new (children have been born as a result of medically-assisted artificial insemination using donated sperm for over 100 years²), conception using donated eggs or embryos first became possible only after the development of *in vitro* fertilisation (IVF) techniques, with the first reported use of donated eggs and embryos taking place in the early 1980s.³ Medical involvement with surrogacy arrangements, and hence the possibility of such

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

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

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

- 1.2 While the reason that prospective parents consider donor conception may often be because of fertility problems experienced by either or both heterosexual partners, donor conception services (combined where necessary with the use of surrogacy arrangements) are also increasingly used in order to enable the creation of 'non-traditional' family forms: for example families created by same-sex couples, single women, or, less commonly, single men.⁵ Donor conception may also be considered in order to avoid the passing on of a serious heritable condition from parent to child.
- 1.3 The circumstances in which people donate eggs, sperm or embryos to others, or act as surrogates, similarly differ. 'Known' donors and surrogates may be friends or relatives of the prospective parent, as, for example, where one sister donates eggs or acts as a surrogate for another.⁶ In such cases, there is likely to be ongoing contact between the parents of any resulting child and the donor or surrogate, although the nature of this contact will depend on those concerned. 'Unknown' donors, on the other hand, usually have no prior connection with the recipient, and choose to donate through a clinic for the benefit of unknown recipients whom they may never meet. In cases of unknown donation, both the professionals involved in providing treatment services, and the state in its regulatory role (see Chapter 2) potentially have an important part to play in determining and controlling what information is made available between the parties involved.
- 1.4 These two categories of 'known' and 'unknown' donation may, however, become blurred. In some cases potential donors and recipients may identify each other in advance (for example through personal advertising) and present themselves for treatment services as a 'known' donor-recipient pair, even though there is no longstanding connection between them. In such cases, despite the lack of prior friendship or relationship, the possibility of information exchange and contact between donor and recipient after the birth of any resulting child clearly exists. Such open arrangements similarly arise, inevitably, in the case of surrogacy arrangements where the surrogate and prospective parents are initially unknown to each other: the nature of the arrangement is such that they will become known to each other by the time of a child's birth. 'Matching services' also exist that link potential egg donors with recipients, and provide detailed non-identifying information about the donor, without donor and recipient ever meeting.⁷ On the other hand, relationships between recipients and longstanding 'known' donors may break down, or simply fade away over time, with the result that the child born as a result of the donation may have no knowledge of the donor, despite the latter's prior connection with the recipient parents. Thus, from the perspective of the resulting donor-conceived person, the question as to whether a 'known' or 'unknown' donor was involved in their conception may in some cases be of little importance.
- 1.5 Donors may also themselves be undergoing fertility treatment. The possibility of embryo donation, in particular, only arises in the context of fertility treatment, where women or couples

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

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

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

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

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

- 1.6 In the case of sperm donation, medical assistance for donation and insemination is not essential, although it is strongly recommended in order to facilitate screening for infections or significant genetic conditions in the donor (see paragraphs 3.11 to 3.18). Women or couples seeking a sperm donor outside the clinic system may thus make arrangements either with someone known to them, or with a stranger contacted via third parties or the internet. In such cases, the amount of information available later to the donor-conceived person about the donor will depend entirely on the arrangements between donor and recipient at the time.
- 1.7 Initially, clinics offering assisted reproductive treatment, including treatment with donated gametes or embryos, were not subject to any special regulation or oversight by the state, and it is therefore not known how many children were born as a result of these procedures.⁸ However, this changed in 1991, with the enactment of the Human Fertilisation and Embryology Act 1990: this created a new legal framework governing all forms of assisted reproduction services, and established the Human Fertilisation and Embryology Authority (HFEA) as a regulatory oversight body. Since 1991, all clinics offering assisted reproductive services must by law be licensed and inspected by the HFEA, and operate in accordance with the HFEA's *Code of practice*.⁹
- 1.8 In the period between 1992 (the earliest date from which official figures are available) and 2009, over 35,000 children were born of parents who received donated eggs, sperm or embryos in UK-licensed clinics.¹⁰ The actual number of people conceived as a result of donated gametes and living in the UK will be significantly higher: as noted above, there are no official figures for those conceived before 1991, and there are also no records of those conceived as a result of treatment outside the UK or of those conceived through 'informal' donor insemination, where a woman uses donated sperm without assistance from a clinic. These fall outside the regulatory framework created by the 1990 Act, and hence are not included in the figures collected by the HFEA.

Family and kinship

- 1.9 Families formed through the donation of gametes or embryos, which we will call, for present purposes, 'donor-conceived families', can be viewed alongside the emergence of other diverse family forms in the UK. The bigger picture also includes families created through adoption (both national and transnational), single parent families, and 'reconstituted' families that include step-children.¹¹ Despite high divorce rates, the idea of family and marriage remain popular and rates of remarriage are also high.¹²
- 1.10 The 'family' is of central concern to the questions that the Working Party has been addressing. But what do we mean by family? Donated gametes and embryos are used explicitly to create a

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

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

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

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

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

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

- 1.11 Today, in the UK, families come in many shapes and sizes, and there is a rich social vocabulary to describe this diversity of family forms. The term ‘nuclear family’ is often used to refer to two parents and their children; while it can be narrowly defined as a cohabiting, married couple and their children, it can also refer to two adults in civil or common law partnerships and their children. There are also many forms of single-parent families, created by choice or unplanned, or arising after the death of a partner, or after divorce or separation; as well as combined and reformed families that include children from previous marriages or partnerships. In these examples, it is children who make a family, and these children can be conceived naturally or through assisted reproductive technologies, or they can be adopted or brought into families from previous marriages or partnerships. Additionally, married or cohabiting couples in permanent relationships without children may consider themselves a family.¹³ The word family, in English, then, is used for a wide range of relationships. It refers not only to the unit comprising one or more parents and their children (however and wherever conceived), but also to a wider set of relations sometimes referred to as the ‘extended’ family. One’s own family can be confined to a partner and/or offspring or extended to close and distant relatives. In its extended form it can also include in-laws and step-relatives: that is, relatives through marriage or partnerships. Very close friends are sometimes referred to as being ‘part of the family’. In ordinary and everyday parlance the sociological terms for the diversity of family forms are largely irrelevant and all of them are embraced by the term ‘family’. Our notions, then, of what constitutes ‘our family’ are flexible and cover a wide variety of combinations of relationships.
- 1.12 Despite this flexibility of the notion of the family, however, we suggest that the concept of ‘kinship’ might provide better traction than ‘family’ for addressing the complex and contested issues emerging from questions of donor conception and disclosure. The concept of kinship can embrace the ways in which people *know* themselves to be related to each other. It is not universally the same the world over, but is culturally and historically shaped. Across the UK, for example, at different times in history, and in different populations and classes, various conventions of birth, marriage, cohabitation, nurture and inheritance, as well as ideal ways of maintaining appropriate family relationships, have been emphasised. Islamic law, for example, divides kinship into three parts: relations through blood, through marriage, and through milk.¹⁴ In many societies, nurture as well as shared substances, including food, forge enduring kinship connections over time.¹⁵ Starting from kinship rather than family frees us from assuming particular family forms and from knowing in advance what a ‘family’ looks like on the ground.
- 1.13 Kinship not only encompasses relatedness (of different kinds) but also includes different cultural understandings of how both persons and kin are brought into being. It may be true to say that

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

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

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

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

- 1.14 If we turn to what might be considered dominant understandings of kinship in the UK, there has been an emphasis on both biological and social relations. Biological relatedness in this kind of kinship thinking has usually been described in idioms of blood, such as 'blood ties' and 'blood relatives' and, in common parlance, 'blood is thicker than water'. More recently, and perhaps increasingly, idioms of genes and genetics are used to refer to biological kin, with reference, for example, to genetic fathers or genetic families. Some scholars have argued that genetic relatedness is supplanting other ways of understanding kinship and is part and parcel of what they refer to as the 'geneticisation' of social life where genetic explanation is becoming more and more prominent in describing complex social phenomena (see paragraph 1.27).¹⁹
- 1.15 Others have suggested that genetic relatedness connotes something different from earlier versions of biological relatedness. The idea of the 'genetic family', it is argued, marks a shift away from the notion of families "as units of love, solidarity and lasting commitment",²⁰ because genetic connection is self-contained and can exist without the exercise of choice or the activation of family bonds. In the 'genetic family' the knowledge of kinship is carried in the genes themselves, and can exist independently of family relationships.²¹ Another example that underlines a perceived difference between biological and genetic kinship emerges from surrogacy arrangements. Many people consider a fetus to be biologically related to a surrogate mother even where the intended mother's egg has been used. This relatedness is said to be forged, amongst other things, through the role of the surrogate mother in feeding the fetus and is also often imagined in terms of shared blood.²² Similarly, a woman who has successfully used donated eggs to conceive a child, while not genetically related to her child, usually considers herself to be biologically related through gestation and birth.

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

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

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

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

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

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

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

- 1.16 Others again use the language of genetic connection simply as a synonym for ‘biological’ or ‘blood’ connection, without placing any particular significance on the choice of idiom. The implications of the changing language with which understandings of kinship are formulated are relevant to the arguments put to the Working Party both for and against the disclosure of information after donor conception. While it is fair to say that metaphors of blood, biology and genes are nowadays intermingled, and all are deployed to describe an aspect of kinship that is also said to be ‘natural’, *which* of these metaphors is deployed in particular situations may matter. In what follows we use the term ‘biological’ to capture this specifically ‘natural’ aspect of kinship, while recognising that no choice of term can be entirely neutral (see paragraph 1.32 below).
- 1.17 One accepted general understanding of kinship in the UK is that we also create kinship bonds through care and nurture. Thus kinship can be forged through desire, will and intention, and in this way adopted and step-children, for example, are made one’s ‘own’. At the same time the givenness of biological kin (who it is said cannot be chosen) can fade without due care and attention: thus, at times, people who are biologically ‘close’ to us may play no part in our lives and may no longer be reckoned by us as kin. There have been legal cases where parenthood has been disputed by donors and recipients and granted by the courts to non-genetic parents on the basis of their desire and intention to create a family and their existing relationship with the child;²³ in other cases the biological link, rendered visible in the idiom of genetics, has been privileged and deemed unassailable.²⁴ The kinship thinking with which we are concerned in this report relies on an interweaving of biological and social strands. Indeed, the biological aspects of kinship are also deeply social insofar as they are given meaning and made more or less significant in different societies.
- 1.18 Successful assisted reproductive technologies, including donor conception, not only result in the birth of an individual child but also *create* kin and kinship. The individual or couple who have successfully conceived a child using donated gametes become parents, and their parents become grandparents, and their siblings aunts and uncles, whether the biological disconnection is known or not. The English kin terms ‘aunt’ and ‘uncle’ usually refer to people who act in these roles, so that people without a biological link are frequently made into an aunt or an uncle. For many UK families these kin terms are also used as markers of respect between younger and older persons. We could see these examples as a ‘fictive’ kinship, or as persons acting ‘as if’ they were an aunt or an uncle. However that would not do justice to all the ways in which families in the UK appropriate aunts and uncles, as social roles, for various emotional and pragmatic reasons.
- 1.19 This raises a question for the relationship between the donor-conceived person and the donor and his or her family. Are the donor’s siblings automatically aunts or uncles to the donor-

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

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

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

- 1.20 Thus, the notion of kinship is flexible and allows for an emphasis on either its biological or social aspects. Depending on how one looks at it, the link between a donor and a donor-conceived person may be indisputably there, or self-evidently not, or indeed ‘there’ in some subtle way that is in between these two positions. This was highlighted in the Council’s earlier report *Human bodies: donation for medicine and research*, which identified the range of views expressed by consultation respondents on the specialness or otherwise of gametes. Some respondents argued there was no difference between gametes and other bodily materials, while others pointed to a radical difference between them because of the potential of gametes to create new life.²⁵ Ethnographic studies have also shown a variety of views on the status of gametes: as “just” or “merely” bodily fluid and alienable,²⁶ or with the potential for creating unbreakable, albeit diffuse, links between people.²⁷ The *Human bodies* report notes that the consultation responses to this issue “demonstrate vividly the pluralism of opinion with which policymakers in the UK must grapple”.²⁸
- 1.21 This pluralism of opinion was echoed in the consultation exercise and factfinding meetings carried out by this Working Party. In looking at who should be responsible for making decisions about disclosure, one respondent to the online survey put it emphatically: “It is for the birth parents to decide what is best for their child, it is for them to decide what to tell the child, how much to tell them and when. In the end, a donor gives a single cell. It is the birth mother who carries the child, grows it and nourishes it from *her* blood and then gives birth and nurtures and teaches the child. Genetics do not make the parent!” Another respondent equally emphatically took the opposing view: “Some donors of my acquaintance (both egg and sperm) have regretted the act of what they have later come to regard as ‘giving away their own children’ into the hands of unknown strangers.”²⁹
- 1.22 Similarly, variations in how ‘one’s own’ family is defined emerged in factfinding meetings with people with personal experience of donor conception. One parent told us that where a family includes donor-conceived and naturally-conceived children, there is no question of difference: “the donor-conceived child is ‘mine’, from the second they are born”. Similarly, a donor commented that when they meet a child conceived from their gametes they do not feel “they’re mine” or that they are “50 per cent me”.³⁰ However, another donor-conceived person argued that “you can’t just ignore the genetic side of things – that matters too.” This person went on to highlight how often donor-conceived siblings (those conceived as a result of gamete donation by the same donor) find many similarities with each other when they meet for the first time, and

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

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

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

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

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

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

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

Comparisons with other family forms

- 1.23 Families created through donor conception are often compared with families created through adoption: indeed, comparisons with adoption provided a significant spur to the recent change in UK policy regarding access by donor-conceived people to identifiable information about their donor (see paragraph 2.9). There are conflicting views as to how meaningful these comparisons are: for some the fact that donor-conceived families usually have biological links between one parent and offspring demonstrates a self-evident difference from adoptive families; while others point to the absence of that biological link between one parent and offspring as demonstrating an equally self-evident similarity between the two family forms. Others suggest, in this context, that embryo donation is more similar to adoption than egg or sperm donation.³² Clearly adoption does not disaggregate the component parts of kinship in the same way that donor conception does: there is no doubt that children who are later adopted are nonetheless biologically related to the parents who conceived them. Nonetheless, there is also no doubt that the child then becomes, legally, emotionally and socially, the child of the adoptive parents, just as the donor-conceived child is legally, emotionally and socially the child of the 'recipient' parents from conception and birth. Another similarity, from the perspective of the parents, may be that, both in cases of adoption and of donor conception, prospective parents require external assistance in order to build a family.
- 1.24 Significant differences may, however, be found between adoptive and donor-conceived families in that adoption involves the placing of existing children, born into one family (often in the context of adoption referred to as the 'birth family') into a new family, while donor-conceived children are usually born directly, and by design, into the family where they will be brought up. Thus, except in cases involving surrogacy, in donor conception there is no 'relinquishment' on the part of birth parents (either voluntarily or through the involvement of others) and no associated difficulty for children in understanding why their birth parents were unable or unwilling to bring up their own child. Families created through surrogacy arrangements may be perceived as more like adoptive families in that the child is 'relinquished' by the surrogate mother at birth (and legal intervention is required to reassign legal parenthood – see paragraph 2.1); or more like naturally-conceived families in that in some cases of surrogacy both egg and sperm may come from the 'intended' parents.
- 1.25 Research with donor-conceived adolescents and adults indicates that some donor-conceived offspring are interested in obtaining information about their donor, and in understanding their reasons for donation (see paragraph 4.25). Such interest has clear parallels with the interest some adopted adolescents and adults have in finding out about their birth parents, although the *nature* of the information sought (the extent to which value is placed on biological kinship, as opposed to curiosity about biological connection) is likely to vary widely within both groups.³³ It

³¹ Factfinding meeting with Rachel Pepa, 24 April 2012.

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

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

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

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

Current context

- 1.27 The call for disclosure, and for access to information, in connection with donor conception comes at a particular moment when genes, genetic connection, and genetic explanation are prominent in society.³⁵ The promises of developments in genetic medicine are reported and debated extensively in the mass media as well as the specialist press, and experiences, views and information (accurate and inaccurate) circulate about genetic testing and the genetic basis of various diseases and disorders. The potential to provide personalised drug treatments and gear medicines to genotypes (pharmacogenetics) is an avenue of research that solicits and attracts attention. The current availability of 'over-the-counter' or 'via the internet' DNA tests also raises the profile of genetics in social life. The same companies that offer paternity tests also offer DNA test kits to enthusiasts of family history and genealogical research.³⁶ At the same time, television, literature and film (fact and fiction) are saturated with the potential of DNA profiling to aid criminal investigations.³⁷ Many scholars have identified such examples, among others, as part of a wider process of a 'geneticisation' of social life where genetic explanation has become increasingly more prominent in explanation of disease, disorder, identity and relatedness.³⁸
- 1.28 We noted above, however, that a more nuanced analysis of the place of genetics in kinship is necessary (see paragraphs 1.14 to 1.16). It is not given the same value universally, and it appears, at least in the UK context, that as genetic connection has become more prominent (explicit), so too has social connection.³⁹ An emphasis on genetic relatedness thus runs

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

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

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

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

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

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

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

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

- 1.29 The emphasis on disclosure and access to information is also occurring at a time when a high societal value is placed more generally on 'openness' and 'transparency'. The internet and ever-expanding technologies of communication and social networking, such as Facebook and Twitter, have presented us with unprecedented means of 'disclosure' in all spheres of social life, including, potentially, the ready sharing of individuals' genetic information.⁴² This burgeoning of information and communication possibilities is challenging the boundaries of privacy: both in the sense of changing (some) individuals' sense of what is private, and in increasing the likelihood of private information being inadvertently made available to others. The popularity of the television programme *'Who do you think you are?'*, devoted to the family history of celebrities, is enhanced by the growing capacity of interested people to trace their origins, ancestors and heritage.⁴³ These social phenomena, and others, are threads in the cultural fabric of the beginning of the 21st Century and they mutually shape and inform each other. The Working Party has found it helpful to be reminded of the contemporary value placed on 'openness' and 'transparency' in many social domains.
- 1.30 The political lobby for disclosure in the context of donor conception also appears to be stronger in 'Euro-American' societies⁴⁴ than elsewhere, and there is detailed ethnographic evidence from other parts of the world that the issue of disclosure in donor conception is not as high on the agenda of concerns as it is in the UK. Ethnographers highlight, for example, the stigmatisation of infertility in some societies (especially of male infertility) which compels people not only to hide the fact of infertility but also not to reveal the use of assisted conceptive technologies.⁴⁵ In some societies, the mixing of sperm with the egg of a married woman is not only shameful but

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

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

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

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

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

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

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

Choice of language in donor conception

- 1.31 During the factfinding meetings that the Working Party held with a wide range of stakeholders (see Appendix 2), it became apparent that the vocabulary used in donor conception is very influential: particular terms are used in different ways by different people, and it is therefore essential to ‘unpack’ what is meant in particular cases. We have already noted the way that the language of genetics is increasingly being used in the context of family and identity, and that while some will use the language of ‘genetic’ connection to mean something quite specific (see paragraphs 1.14 to 1.16), others will use it synonymously with ‘blood’ or ‘biological’ connection. In a meeting with practitioners and researchers working with donor-conceived families, for example, we were told that when people talk about their ‘genetic origin’, this should not be narrowly understood as concern about their ‘genetic’ inheritance, or that they understand their identity as genetically determined. It should be understood, rather, much more broadly in terms of ‘their own story’, including their biography, background and family connections: how, in other words, information about the circumstances in which they were conceived is integrated into their own narrative.⁴⁹
- 1.32 For the sake of clarity, therefore, in this report we will use the broader term ‘biological’ for this aspect of kinship which includes ‘genetic’, unless our respondents state otherwise. We confine use of the term ‘genetic’ to discussion of medical information that relates specifically to genes and genetic mutations. In our discussions of kinship, we will also distinguish between ‘connections’ where a biological link exists (regardless of what value is placed on that link by any party) and ‘relationships’ where that connection has been ‘activated’ by choice, or has been created through care and attention. In line with the underlying premise of creating donor-conceived families, we will refer to the legal parents of donor-conceived people as ‘parents’ (regardless of the absence of biological connection); to those who provide gametes or embryos as ‘donors’; and to those hoping to create a family using surrogacy arrangements as ‘intended parents’. We include egg, sperm and embryo donation when referring to donor conception unless otherwise specified. Donors’ own biological children are referred to as ‘donors’ children’

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

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

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

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

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