

Chapter 4

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

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Chapter 4: overview

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

- 4.1 This chapter summarises the evidence regarding the impact of disclosure, or non-disclosure, of information in the context of donor conception, drawing on the academic research literature, material submitted in response to the Working Party's call for evidence, and information presented in the Working Party's factfinding meetings (see Appendix 2). We note here that the research literature currently available presents only a partial picture, and there is much that is not known: some qualitative studies are based on small samples such as members of support groups whose experiences and views may not generalise to those who do not join such groups; most studies provide 'snapshots' in time and hence may reflect experiences influenced by past attitudes and cultures; almost all studies of donor-conceived adults relate to those conceived via sperm donation rather than egg or embryo donation; some studies rely on reporting from third

parties, such as parents reporting on their children; some people affected by donor conception are less likely to participate in research than others; there are no longitudinal studies of the impact of donation on donors and their own families;²⁰⁸ and so forth. Where appropriate, this report highlights where further research would be beneficial in adding to our understanding of this area. However, it is inevitably the case that we cannot have any data relating to the views of one group of those affected by donor conception, namely donor-conceived people who do not know they are donor-conceived, and hence a ‘full picture’ of the impact of non-disclosure cannot be achieved.

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

Box 4.1: Views from donor-conceived people

“I would say please, please, please be honest with your child about their origins from day one... I can’t tell you how big a shock it was to discover at the age of 25 that the man I think of as my dad isn’t my biological father.” – *Donor-conceived adult, cited in a response to the Working Party’s call for evidence by the Donor Sibling Registry.*

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

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

“It is a basic human condition to want to know where we come from and who we are, which is derived from our progenitors.” – *Respondent to Working Party’s online questionnaire*

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

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

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

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

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

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

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

Box 4.2: Views from parents

"I think this [information a donor-conceived person needs] varies from child to child and from situation to situation. Many children just need a back story to explain why they are as they are. My son is very sporty but there is no history of sport in our family so it looks like it came from the donor." – Respondent to Working Party's online questionnaire

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

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

"There may be cultural, financial, emotional or social reasons why it is not in the child's best interest for them to be told. There might not be any information available about anonymous donors from abroad and this could be more damaging to the child." – Respondent to the Working Party's online questionnaire

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

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

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

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

Box 4.3: Views from donors

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

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

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

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

"As a sperm donor, I would like to know how many children have been conceived from my donations. Just to know the numbers and if all was ok. I would want to know if any child had serious medical issues." – Respondent to the Working Party's online questionnaire

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

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

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

²¹¹ Jadva V, Freeman T, Kramer W, and Golombok S (2010) Sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor offspring *Human Reproduction* **26**(3): 638-45.

Disclosure decisions: overview

How many people know they are donor-conceived?

- 4.3 Until recently, parents tended not to tell their children they were donor-conceived. In a study of four systematic samples of children born in the late 1980s through donor insemination in Spain, Italy, the Netherlands and the UK, none of the 111 parents who participated had disclosed the donor insemination to their child by early school age;²¹² less than ten per cent of parents had done so by early adolescence;²¹³ and a follow up of the UK sample showed that no further children had been told by age 18.²¹⁴ A similar pattern was found for egg donation families²¹⁵ and for families created through embryo donation.²¹⁶ Investigations in the US produced comparable findings.²¹⁷ In Sweden, where legislation giving donor offspring the right to obtain information about the donor's identity came into force in 1985, levels of disclosure were still low more than a decade later.²¹⁸
- 4.4 In recent years there has been a significant rise in the number of parents who intend to tell their children about their donor conception, with the most recent figures (again from Sweden) showing that 78 per cent of parents of children conceived through sperm or egg donation intend to tell their child.²¹⁹ Intentions to tell, however, do not inevitably translate into actual disclosure. In a longitudinal study of children born in the UK in 2000 as a result of sperm or egg donation, for example, only around half of those who said when their child was age one that they intended to disclose, had in fact done so by the time their child was seven.²²⁰ Moreover, some of the parents who reported that they had 'disclosed' to their children had discussed the use of fertility treatment but not the use of donated eggs or sperm.²²¹ Similar partial disclosure arises in surrogacy: children may be told about the surrogacy arrangement, but not about the use of a donor egg.²²² However, the Working Party was also told of the reverse experience of the Donor

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- ²¹² Golombok S, Brewaeys A, Cook R *et al.* (1996) The European study of assisted reproduction families: family functioning and child development *Human Reproduction* **11**(10): 2324-31.
- ²¹³ Golombok S, Brewaeys A, Giavazzi MT *et al.* (2002) The European study of assisted reproduction families: the transition to adolescence *Human Reproduction* **17**(3): 830-40.
- ²¹⁴ Owen L, and Golombok S (2009) Families created by assisted reproduction: parent-child relationships in late adolescence *Journal of Adolescence* **32**(4): 835-48.
- ²¹⁵ Murray C, and Golombok S (2003) To tell or not to tell: the decision-making process of egg-donation parents *Human Fertility* **6**(2): 89-95; Murray C, MacCallum F, and Golombok S (2006) Egg donation parents and their children: follow-up at age 12 years *Fertility and Sterility* **85**(3): 610-8.
- ²¹⁶ MacCallum F, and Golombok S (2007) Embryo donation families: mothers' decisions regarding disclosure of donor conception *Human Reproduction* **22**(11): 2888-95; MacCallum F, and Keeley S (2008) Embryo donation families: a follow-up in middle childhood *Journal of Family Psychology* **22**(6): 799-808; MacCallum F, and Keeley S (2012) Disclosure patterns of embryo donation mothers compared with adoption and IVF *Reproductive BioMedicine Online* **24**(7): 745-8.
- ²¹⁷ Nachtigall RD, Becker G, Quiroga SS, and Tschann JM (1998) The disclosure decision: concerns and issues of parents of children conceived through donor insemination *American Journal of Obstetrics and Gynecology* **178**(6): 1165-70.
- ²¹⁸ Lindblad F, Gottlieb C, and Lalos O (2000) To tell or not to tell-what parents think about telling their children that they were born following donor insemination *Journal of Psychosomatic Obstetrics & Gynecology* **21**(4): 193-203. Eleven per cent of parents of donor-conceived children born between 1985 and 1997 had disclosed to their child that they were donor-conceived.
- ²¹⁹ Isaksson S, Sydsjö G, Skoog Svanberg A, and Lampic C (2012) Disclosure behaviour and intentions among 111 couples following treatment with oocytes or sperm from identity-release donors: follow-up at offspring age 1-4 years *Human Reproduction* **27**(10): 2998-3007 (part of the Swedish Study on Gamete Donation). Sixteen per cent of parents had begun this process by the age of four.
- ²²⁰ Readings J, Blake L, Casey P, Jadva V, and Golombok S (2011) Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy *Reproductive BioMedicine Online* **22**(5): 485-95. Seventeen out of 36 sperm donor parents intended to tell and nine had done so by age seven; 20 out of 32 egg donor parents intended to tell and 11 had done so by age seven. Follow-up interviews with these parents when their children were ten showed hardly any change: Lucy Blake, personal communication, 6 July 2012.
- ²²¹ Readings J, Blake L, Casey P, Jadva V, and Golombok S (2011) Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy *Reproductive BioMedicine Online* **22**(5): 485-95, at page 491.
- ²²² Jadva V, Blake L, Casey P, and Golombok S (2012) Surrogacy families 10 years on: relationship with the surrogate, decisions over disclosure and children's understanding of their surrogacy origins *Human Reproduction* **27**(10): 3008-14. All the families who had used genetic surrogacy were found to have disclosed about the use of a surrogate, but only 58 per cent had told the child that a donor egg had been used.

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

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

Reasons underpinning parents' disclosure decisions

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

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

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

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

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

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

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

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

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

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

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

Why parents decide to disclose

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

Why parents decide not to disclose

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

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

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

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

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

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

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

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

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

Timing of disclosure

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

²⁵² Ibid.

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

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

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

Impact of disclosure on donor-conceived people

Emotions associated with disclosure

- 4.13 How donor-conceived people are affected by disclosure depends to an extent on their age when the process of disclosure begins. Children who are told in their preschool years about the use of donor eggs or sperm in their conception have been found to respond neutrally, with curiosity, or even sometimes with pleasure, rather than with distress.²⁵⁶
- 4.14 In contrast, some of those who were told (or found out) that they were conceived using donor sperm as adolescents or adults, speak of 'shock', 'anger' or 'confusion' in response to their discovery.²⁵⁷ Larger-scale studies of adolescents and adults conceived through sperm donation, recruited via the US-based Donor Sibling Registry (DSR), have also found significant associations between feeling shocked, angry or confused and an older age of disclosure,²⁵⁸ although one smaller study of adults born through sperm donation recruited through support groups found no association between age of disclosure and the participant's general attitude towards their means of conception.²⁵⁹ People conceived through sperm donation may be more likely to feel shocked or confused if they have been brought up in two-parent heterosexual households where they had no reason to think they were not biologically connected to both their parents, rather than in same-sex or solo mother households.²⁶⁰ While studies of DSR registrants suggest that both shock and confusion may fade considerably over time,²⁶¹ anger appears to be more persistent, with 13 per cent of people conceived through sperm donation reporting that that they still felt angry at the time the research took place (down from 19% at point of disclosure).²⁶² People conceived through sperm donation also report feeling 'relieved' as a

²⁵⁶ Rumball A, and Adair V (1999) Telling the story: parents' scripts for donor offspring *Human Reproduction* **14**(5): 1392-9; Lycett E, Daniels K, Curson R, and Golombok S (2005) School-aged children of donor insemination: a study of parents' disclosure patterns *Human Reproduction* **20**(3): 810-9; Leeb-Lundberg S, Kjellberg S, and Sydsjö G (2006) Helping parents to tell their children about the use of donor insemination (DI) and determining their opinions about open-identity sperm donors *Acta Obstetrica et Gynecologica Scandinavica* **85**: 78-81; Blake L, Casey P, Readings J, Jadva V, and Golombok S (2010) 'Daddy ran out of tadpoles': how parents tell their children that they are donor conceived, and what their 7-year-olds understand *Human Reproduction* **25**(10): 2527-34. See also: MacDougall K, Becker G, Scheib JE, and Nachtigall RD (2007) Strategies for disclosure: how parents approach telling their children that they were conceived with donor gametes *Fertility and Sterility* **87**(3): 524-33, where parents of children conceived through donated eggs or sperm who use 'seed planting' strategies for disclosure at a young age report that children take the information in their stride.

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

²⁵⁸ Jadva V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24**(8): 1909-19 (165 participants aged between 13 and 61, of whom 114 were told after the age of three and the remainder had 'always known'.); Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26**(9): 2415-24 (741 participants aged between nine and over 40). In this study, 45.7 per cent of offspring of heterosexual parents compared with 79.3 per cent of offspring of lesbian parents reported that they have always been aware that they were donor-conceived.

²⁵⁹ Mahlstedt PP, LaBounty K, and Kennedy WT (2010) The views of adult offspring of sperm donation: essential feedback for the development of ethical guidelines within the practice of assisted reproductive technology in the United States *Fertility and Sterility* **93**(7): 2236-46, which included 85 adult offspring of sperm donation recruited through internet-based support networks. The authors note that this finding was unexpected and contrasts with that of other studies with donor-conceived people. Almost half (47%) of respondents learned about their donor conception when they were over 18 years old; 19 per cent learned between ages ten and 18 years; and 34 per cent learned before the age of ten years. The majority were told by their mothers (69%) during a planned conversation (64%), while 37 per cent learned after an argument with a parent, from someone other than their parents, or worked it out themselves.

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

²⁶¹ Jadva V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24**(8): 1909-19; Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26**(9): 2415-24.

²⁶² Jadva V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24**(8): 1909-19.

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

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

Longer term impact of disclosure

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

²⁶³ Jadva V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24(8)**: 1909-19.

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

²⁶⁵ Response to the Working Party's call for evidence from Venessa Smith, Donor Services Coordinator, The London Women's Clinic: "... [O]ne young adult had found out about his conception through discovery of some early medical records. This was devastating for him. Not because he was donor-conceived but because he felt lied to. Interestingly, he found the fact that his brother was from a different donor a great relief because he felt that this explained the physical and emotional differences between them that they had both always found very confusing."

²⁶⁶ Jadva V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24(8)**: 1909-19. Eleven per cent of donor-conceived adults in this study said that they felt indifferent at the point of disclosure. See also: Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24, where it was found that 16 per cent of offspring with two heterosexual parents, and 34 per cent of offspring with two lesbian parents indicated that finding out about their donor conception made 'no difference' to them.

²⁶⁷ Jadva V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24(8)**: 1909-19. See also: Cushing AL (2010) "I just want more information about who I am": the search experience of sperm-donor offspring, searching for information about their donors and genetic heritage *Information Research* **15(2)**: 1.

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

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

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

- 4.17 Issues relating to trust arise in the context both of disclosure and non-disclosure: one reason why parents may decide to disclose is to avoid the risk of their child finding out inadvertently and subsequently feeling that they were deceived (see paragraph 4.7); but parents may also find it hard to make a disclosure when their child is past early childhood because they fear that this disclosure itself may lead to a loss of trust.²⁷¹ Research evidence on how disclosure may in practice affect relationships of trust within families is very limited, as this question has not been explored in the larger quantitative studies of donor-conceived adolescents and adults. The limited evidence available does point again to the relevance of the timing of disclosure: concerns about compromised trust emerged in a qualitative study with 16 donor-conceived adults who found out in adolescence or adulthood,²⁷² while a study of 45 mothers of donor-conceived children concluded that the most common outcome of disclosure was that “telling had created a sense of trust in the child, because s/he knew his or her mother would always inform him or her of reality.”²⁷³
- 4.18 While there is similarly little empirical research that focuses on how disclosure affects a donor-conceived person’s ‘sense of identity’, that which does exist suggests that disclosure may have an impact on how donor-conceived people understand themselves and how they now ‘fit in’ with those around them. Again the age of disclosure appears to be relevant. One donor-conceived person taking part in a qualitative study commented: “I would say that being told at a young age and being raised in openness has contributed to me having a stable sense of self, and feeling secure in my familial relationships”; by contrast, the author of this study also notes that “those who learn as adults that they were donor-conceived may experience disruption to their identity and a sense of not being the person they thought they were. This is readily comprehensible in narrative terms: the story of where I came from and who I am, constructed, developed, and amended on the assumption of consistent social and genetic parentage, has been shown to be based on a false premise.”²⁷⁴ Similar concerns about ‘disruptions’ to one’s sense of identity emerge in other qualitative studies with people who found out they were donor-conceived in adolescence or later;²⁷⁵ and a survey of 47 people conceived through sperm donation, carried out by a donor-conceived person for a high school project, found that 27 of her respondents

²⁷⁰ Factfinding meetings with people with personal experience of donor conception, 24 April and 16 July 2012; factfinding meeting with practitioners/researchers, 30 May 2012. See also responses to the Working Party’s call for evidence, including the response from a person with personal experience of donor conception: “[we] know that a strong and steady sense of identity is an important feature in becoming a stable adult. People benefit from having a sense of belonging and being accepted and respected, in their family and community. Finding out that your true biological origins have been kept secret will undermine confidence and self-esteem”: Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: <http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering>.

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

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

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

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

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

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

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

Indifferent or positive attitudes to donor conception

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

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

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

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

²⁷⁹ Jadva V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24(8)**: 1909-19. The authors of the report also provided a breakdown of these feelings toward being donor-conceived according to the age at which disclosure had occurred. For offspring who were under the age of 18 when disclosure had occurred, 24 per cent felt ‘indifferent’, 27 per cent felt content, and 23 per cent felt happy. For offspring who were over the age of 18 when disclosure occurred, nine per cent felt indifferent, 13 per cent felt content, and 19 per cent felt happy. See also: Beeson DR, Jennings PK, and Kramer W (2011) Offspring searching for their sperm donors: how family type shapes the process *Human Reproduction* **26(9)**: 2415-24, where it was found that 16 per cent of offspring with two heterosexual parents, and 34 per cent of offspring with two lesbian parents indicated that finding out about their donor conception made ‘no difference’ to them.

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

What kind of information is sought?

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

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

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

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

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

²⁸¹ Jadva V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24(8)**: 1909-19.

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

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

- 4.23 As the quotation above suggests, while the information collected on the donor information form may now provide more biographical information for donor-conceived people than was available for those conceived in the 1990s and earlier, some people will, in addition, strongly desire identifying information about their donor, with the associated possibilities for contact, or at least further information sharing. Another reason raised on a number of occasions with the Working Party for desiring identifying information is the fear on the part of donor-conceived people of embarking involuntarily on an incestuous relationship. The Working Party was told that, while the actual risks of such a relationship might be very small, the fear among donor-conceived people, particularly those conceived before the introduction of regulations limiting the number of families that may be created with the assistance of one donor, is very real.²⁸⁷
- 4.24 Donor-conceived people are likely to have different attitudes to information about their means of conception at various points in their lives: the information needs and desires of a young child, for example, will be very different from those of an adult who has children of their own. Despite this speculation, however, most evidence about the informational needs of donor-conceived people represents a 'snapshot in time', as this question has not been addressed in longitudinal studies. It may also be the case that, for some donor-conceived people, a key issue is not so much what information may potentially be available, but rather that they do not have any choice about whether or not to access it because it is being withheld by third parties.²⁸⁸ One donor-conceived person who spoke to the Working Party, for example, commented that they did not know what they would do with information about their donor if they were able to obtain it, but that it was immensely frustrating knowing that others were controlling access to whatever little

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

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

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

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

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

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

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

- 4.25 In the absence of ‘official’ sources of information for some groups of donor-conceived people, voluntary linking services have emerged, enabling donor-conceived offspring, donors and donor siblings to try to identify each other either through anonymous ‘donor numbers’ where available, or potentially through DNA testing (see paragraph 2.16 for information about the UK-based voluntary register for those conceived before 1991). The DSR, based in the US but open for anyone to join, provides a forum for donor-conceived people to search for their donor and/or any donor-conceived siblings, and, in January 2013, had 38,000 registered members, of whom 1,800 are egg or sperm donors.²⁹¹ Since the DSR was established in 2000, more than 9,700 matches have been made between donor offspring and their donor connections: most of these matches are between donor-conceived siblings, with around 700 instances of matches between donors and offspring.²⁹² Approximately 400 registrants are from the UK, almost 100 of whom have matched with half siblings either in the UK or in other countries such as Denmark and the US.²⁹³
- 4.26 Recent surveys of DSR members provide an insight into the nature of donor-conceived people’s interests in knowing about their donor relations, although it should be noted that the experiences of those who join a contact register cannot necessarily be extrapolated to the wider group of people conceived through donor gametes. Donor-conceived participants in the studies have also, to date, all been conceived through sperm donation, rather than egg or embryo donation (see paragraph 4.28 below with reference to family registrants). More than 80 per cent of DSR members conceived via sperm donation who participated in a recent (2011) survey indicated a desire to have contact with their donor at an unspecified time in the future, with the main reasons cited as being curiosity about the donor’s looks, learning about ancestry and learning about medical history.²⁹⁴ Similar findings emerged from an earlier (2010) survey of 165 DSR members: 77 per cent were searching for their donor, with the reasons most commonly cited as being curiosity about the donor’s characteristics, a better understanding of ancestral history, family background and genetic make-up, a better understanding “of why I am who I am”, and a desire to meet the donor.²⁹⁵ Despite the interest in meeting, it appears that few donor-conceived people envisage such contact with their donor as leading to a ‘parental’ relationship with him: none of those responding to the 2010 survey cited “desire to form a relationship” as being their main reason for searching, although 38 per cent included it as one of their

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

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

²⁹¹ The Donor Sibling Registry (2012) *The Donor Sibling Registry: homepage*, available at:

<https://www.donorsiblingregistry.com/>; Wendy Kramer, personal communication, 17 January 2013.

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

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

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

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

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

- 4.27 Seventy-eight per cent of those participating in the 2010 DSR survey were also searching for their donor-conceived siblings. One third of these were successful, and almost all had subsequently been in contact.²⁹⁸ The main reasons given for searching for siblings were curiosity (for example about similarities in appearance and personality) and “to know and understand a ‘missing’ part of me”, and as with the contact with donors, the majority describe their experience of contact with siblings as positive.
- 4.28 Membership of the DSR is also open to parents who wish to make contact either with their child’s donor or with their donor-conceived siblings before their child reaches adulthood, and indeed a majority of DSR members fall into this category, including 750 egg donation families and 80 embryo donation families.²⁹⁹ A survey of 791 parent registrants found that a high proportion of those searching for both donors and siblings were solo mothers, followed by lesbian couple parents, and then a much smaller proportion of heterosexual couple parents.³⁰⁰ The survey found that parents’ main motivation for searching for their child’s donor was for their child to have a “better understanding of who she/she is”, to give their child “a more secure sense of identity”, curiosity about the donor’s characteristics, or to thank the donor. The main reasons for searching for their child’s donor-conceived siblings similarly included curiosity, providing the child with a better understanding of themselves and to give the child a more secure sense of identity.³⁰¹ Nearly twice as many parents were interested in finding the child’s donor-conceived siblings than their donor, and while it appeared to be the case that many parents valued knowing ‘about’ the donor more than actually knowing the donor, contact with donor siblings was rated very highly. Relationships between the families of donor-conceived siblings were commonly described in terms of family or friendship, such as “extended family”, “one big family” or “connected to a larger community”.³⁰²

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

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

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

²⁹⁹ Wendy Kramer, personal communication, 31 January 2013.

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

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

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

Impact of non-disclosure and disclosure on family functioning

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

Non-disclosing families

4.30 The European Study of Assisted Reproduction Families, a longitudinal study that used in-depth interview assessments with mothers and fathers, and standardised questionnaires administered to parents and teachers, found no differences in emotional or behavioural problems between children conceived by either sperm or egg donation (very few of whom had been told that they were donor-conceived) and comparison groups of IVF, naturally conceived, and early-adopted children at early school age³⁰³ and again at age 12.³⁰⁴ The children generally showed high levels of psychological adjustment. More positive parenting was shown in assisted reproduction than natural conception families when the child was aged six. Although differences in parenting quality were no longer apparent by age 12, the families continued to function well. Similarly, studies of children born through embryo donation found that the families were characterised by positive parent-child relationships and that children were faring well.³⁰⁵ In a further study that used parent questionnaires to compare sperm donation, egg donation, embryo donation and surrogacy families (most of whom were likely to be non-disclosing families) with families created by assisted reproductive procedures using the parents' own gametes, no differences in the psychological adjustment of five to nine-year old children were found.³⁰⁶ Similar results emerged from an Australian study of children aged five to 13 conceived through sperm donation (65% of whom were unaware that they were donor-conceived) included within a large-scale family study of natural conception couple families, solo mother families and step-father families.³⁰⁷ These studies indicate that donor-conceived children who are unaware of the nature of their conception do not appear to be at increased risk of developing psychological problems or difficulties in parent-child relationships despite concerns by some to the contrary. However, the conclusions that may be drawn are limited, as, with the exception of the UK sample from the European Study who were followed up at age 18,³⁰⁸ little is known about the psychological well-being of these children in later adolescence or adulthood. Moreover, the possibility can never be

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

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

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

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

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

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

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

Disclosing families

- 4.31 In the first study to compare the functioning of families where parents had told or intended to tell their children that they had been conceived by donor insemination with those who had not disclosed this information, the differences that were identified reflected more positive outcomes for the disclosing families when the children were aged between four and eight years old.³⁰⁹ However, only six out of 46 of the children had actually been told about their donor conception at the time of study. In a follow up of the families when the children were aged ten to 14 years, ten out of 30 had been told about their donor conception.³¹⁰ The disclosing families continued to function well in terms of parent-child relationships and child adjustment, and in-depth interviews with the adolescents revealed the relative unimportance attributed to the non-genetic link with the father.
- 4.32 A longitudinal study initiated in the year 2000³¹¹ provided an opportunity to compare children born through donor insemination and egg donation who were aware of their biological origins by age seven, the age at which most adopted children understand the meaning and implications of being adopted, with those who were not.³¹² As in the earlier European study (see paragraph 4.30), the families showed positive parent-child relationships, with no differences between those formed through egg donation and donor insemination. However, the donor conception mothers who had kept their child's origins secret showed higher levels of emotional distress than those who had been open with their child about their origins (see paragraph 4.44). In addition, interview and observational assessments of mother-child interaction revealed less positive interaction in the families in which parents had not disclosed the donor conception to the child.³¹³ However, it should be noted that the differences identified were not indicative of maternal psychiatric disorder or dysfunctional family relationships in the non-disclosing families, but instead reflected variation within the normal range. Moreover, there was no evidence of elevated levels of psychological problems among the children in non-disclosing families. Although the findings suggest that disclosure may be associated with more positive outcomes for family relationships it is not clear whether this resulted from openness about the donor conception in particular or open communication in the family more generally. It should also be noted that these families have not yet been followed into the children's adolescence.

Fears of stigmatisation by third parties

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

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

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

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

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

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

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

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

- 4.34 While stigma is clearly feared by some parents, both in relation to themselves and their child, the current evidence base relating to actual experiences of stigma is very small. Concerns about stigma are particularly likely to be dependent on the environment and community in which prospective parents live, and the extent to which donor conception is seen as an acceptable way of building a family (see also paragraphs 4.6 and 4.12). The Working Party heard of concerns about donor conception from a number of cultural and religious perspectives, including Muslim,³²¹ Sikh,³²² Jewish,³²³ Hindu,³²⁴ and Christian³²⁵ that could potentially affect parents' decisions with regard to openness, both because of concerns as to the impact of such disclosure on themselves and/or their child.
- 4.35 The strongest concerns expressed to the Working Party came from those with knowledge of Sikh and Muslim communities in the UK, where notions of honour and shame are important, and where it was considered highly unlikely that parents would want to reveal to their extended

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

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

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

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

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

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

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

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

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

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

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

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

- 4.36 Similarly, from Muslim perspectives, the Working Party was told that matters of assisted conception are often sensitive and meant to be kept private. In some cases, analogies are made between the use of donated sperm and adultery. It should be noted, however, that there are differences between Sunni and Shia principles on this issue, and between different religious leaders within the main branches of Islam. There are examples of how Shia ethical reckoning accommodates the use of donated gametes and surrogacy.³²⁷ It was suggested to the Working Party that the importance placed by Muslim communities (and South Asian communities more generally), on ‘lineage’, as traced through the paternal line, raised particular concerns for people conceived through sperm donation, and that non-disclosure in such cases protects the child in the eyes of the outside world. It was also pointed out that ‘openness’ could lead to stigma and ostracism for the family, and would damage the child’s future marriage prospects.³²⁸ Yet it is clear that, despite the views of some religious scholars, some people from communities that overtly reject donor conception do, nevertheless, seek treatment with donated gametes in order to have a family.³²⁹
- 4.37 Recent research on attitudes to gamete donation conducted in three UK cities with focus groups involving 100 men and women of Indian, Pakistani and Bangladeshi origin (including Muslim, Sikh and Hindu participants) similarly found some widely-held perspectives and concerns among participants, although the authors emphasised that it was misguided to assume that there could be a single generalisable ‘South Asian’ viewpoint on gamete donation.³³⁰

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

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

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

³²⁹ For example, the Working Party was told that in Punjab, from where many British Sikhs originate, billboards advertise egg and sperm donation, and other fertility services: Factfinding meeting on regulatory aspects of donation, 22 June 2012. See also: BioNews (21 January 2013) *Donor conception in the UK: the seldom-heard voices of minority ethnic communities*, available at: http://www.bionews.org.uk/page_243313.asp?dinfo=k4xM7kuEjsxulJs3htzUEUTk&PPID=243263.

³³⁰ Culley L, and Hudson N (2009) Constructing relatedness *Current Sociology* **57**(2): 249-67. See also: Hudson N, Culley L, Rapport F, Johnson M, and Bharadwaj A (2009) “Public” perceptions of gamete donation: a research review *Public Understanding of Science* **18**(1): 61-77; Hampshire KR, Blell MT, and Simpson B (2012) ‘Everybody is moving on’: infertility, relationality and the aesthetics of family among British-Pakistani Muslims *Social Science & Medicine* **74**(7): 1045-52; BioNews (21 January 2013) *Donor conception in the UK: the seldom-heard voices of minority ethnic communities*, available at: http://www.bionews.org.uk/page_243313.asp?dinfo=k4xM7kuEjsxulJs3htzUEUTk&PPID=243263.

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

- 4.38 While Muslim participants in these focus groups expressed their concerns primarily with reference to religious acceptability, no Hindu and Sikh participants discussed specifically religious objections, and indeed the Hindu Council UK responded to the Working Party's online survey by emphasising the importance of disclosure and access to information about the donor, because of the need in Hinduism for there to be no 'family' connection between married couples going back at least seven generations.³³² The Board of Deputies of British Jews similarly emphasised to the Working Party the importance of being aware of how 'religious' and 'cultural' concerns within a community may pull in different directions: while interpretation of Jewish law leads to a clear conclusion that transparency is important and that the identity of sperm donors, in particular, should be known to offspring (because of the Talmudic prohibition on keeping a father's identity secret), concerns about stigma for the child and their family lead to a preference for non-disclosure.³³³ We were told that, given anxieties about stigma, most people in the UK's Jewish community would be surprised to hear that Jewish religious law would lean towards disclosure. A parallel disjunction between religious law and culture in Israeli regulation in this area was described to the Working Party: we were told that attempts to establish a formal registry to record information about donors had been abandoned because of an understanding that both patients and professionals would not comply.³³⁴
- 4.39 The responses the Working Party received from those associated with Christian churches in the UK demonstrated further the complex ways in which people may be influenced by their religion. Both the Christian Medical Fellowship (which holds to an evangelical basis of faith) and the Anscombe Bioethics Centre (a Catholic institution) argued for openness about donor conception in their responses to the Working Party's call for evidence – but did not agree that the use of donor gametes was an acceptable way of creating a family at all.³³⁵ Thus, it seems likely that some members associated with Catholic or evangelical Protestant churches who wish to create a family through donor conception may hesitate to reveal their decision to do so. The Church of England: Mission and Public Affairs Council, by contrast, made no comment on the acceptability of donor conception in its response, but advocated encouragement to openness and emphasised the importance of counselling for prospective parents of the longer-term implications of their decisions.³³⁶ It was also suggested to the Working Party that members of the Orthodox Christian churches are unlikely to wish to tell others that they have used donor

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

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

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

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

³³⁵ The Anscombe Centre, for example, set out their view that it is "morally wrong to conceive a child deliberately, even with the most generous of motives, whom one has no intention of parenting oneself", while the Christian Medical Fellowship stated that "we... do not support gamete donation in principle". The catechism of the Catholic Church, approved in 1992, posits donor conception as "gravely immoral": see Vatican (1992) *Catechism of the Catholic Church*, available at: http://www.vatican.va/archive/ENG0015/_P86.HTM, at paragraph 2376.

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

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

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

Impact on parents and prospective parents of donor-conceived people

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

Disclosing families

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

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

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

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

³⁴⁰ MacDougall K, Becker G, Scheib JE, and Nachtigall RD (2007) Strategies for disclosure: how parents approach telling their children that they were conceived with donor gametes *Fertility and Sterility* **87(3)**: 524-33 (study which included 38 families who had disclosed, where it was concluded that "although parents reported a variety of feelings after disclosing that ranged from neutral to a profound sense of relief, no parents expressed regret or reported a negative outcome after having initiated disclosure"); Blyth E, Langridge D, and Harris R (2010) Family building in donor conception: parents' experiences of sharing information *Journal of Reproductive and Infant Psychology* **28(2)**: 116-27 (study of 15 families who disclosed by the age of five, where it was reported that "no parent in our study regretted their decision to tell their child").

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

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

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

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

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

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

Non-disclosing families

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

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

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

³⁴⁷ Jadvá V, Freeman T, Kramer W, and Golombok S (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type *Human Reproduction* **24(8)**: 1909-19.

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

³⁴⁹ Factfinding meeting with practitioners, 30 May 2012.

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

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

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

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

The option of treatment overseas for prospective parents

- 4.45 Where prospective parents experience difficulties in accessing treatment with donor gametes in the UK, in some cases they may consider travel abroad for treatment. As the HFEA does not collect data on the number of UK residents who seek fertility treatment abroad, the total number of those doing so is unknown, although during the course of a factfinding meeting with clinicians, the Working Party were told that difficulties in recruiting black and minority ethnic donors in particular, coupled with discomfort with the idea of asking family or friends to be known donors, meant that many potential patients are likely to go abroad.³⁵⁴
- 4.46 A snapshot of the reasons why prospective parents may go abroad for treatment is provided by a recent study by the European Society of Human Reproduction and Embryology (ESHRE) of the 'cross-border reproductive care' provided by 46 clinics in Belgium, the Czech Republic, Denmark, Slovenia, Spain, and Switzerland.³⁵⁵ Of the 1,230 patients participating in the survey, 53 travelled from the UK to one of these clinics for treatment, citing reasons of: previous treatment failures (20 patients); access difficulty at home (18 patients); the perception that treatment abroad would be "better quality" (15 patients); and "legal reasons" (five patients).³⁵⁶ Most of those travelling from the UK were seeking treatment with donated gametes, and of these over a quarter stated that they wished to access an anonymous donor.³⁵⁷ Detailed interviews with a different group of 29 women from the UK who had been, or were planning to go, overseas in the near future for treatment found that by far the most common reason cited for travelling abroad was donor shortage, with 27 participants citing this reason. Seven participants cited reasons of cost, and the same number indicated that success rates overseas were a reason for travelling for treatment.³⁵⁸ While few reported that their main reason for choosing overseas treatment was to obtain an anonymous donor, some were content that the regulatory regime governing their chosen clinic meant that their future child would have no prospect of access to their donor's identity, while others would have preferred treatment in the UK, with the associated access to identifying information, if this had been feasible for them. For three participants in the study, on the other hand, the prospect of obtaining detailed information about the donor played an important part in determining their choice of country.³⁵⁹ We return to the question of the number of donors available in the UK in paragraph 4.48.
- 4.47 HealthTalkOnline, a website which enables patients to share their experiences of health-related conditions and illnesses illustrates the positive reasons why people may choose to travel abroad for treatment in its recording of the experiences of a couple who chose to travel to Spain for treatment with donor gametes. The woman in the couple noted that "the waiting lists were a lot shorter and the success rates are a lot, lot higher as well." These reasons for travelling abroad were reiterated by her husband who also noted that "people talk about overseas as if it's one

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

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

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

³⁵⁶ More than one reason could be cited per patient.

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

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

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

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

Impact on donors and potential donors

Potential donors

4.48 The removal of donor anonymity in 2005 (see paragraph 2.10) has led to debate about how the supply of gametes from donors has been affected, with considerable concern expressed that the removal of anonymity would discourage potential donors from coming forward.³⁶² However the statistics available present a rather more complicated picture. The number of treatment cycles involving insemination with donor sperm has reduced by more than half over the past ten years, with 3,878 cycles performed in 2010, falling from 6,892 in 2004 and 8,328 in 2000,³⁶³ although it is difficult to separate out the effect of donor shortage from the fact that the development of intra-cytoplasmic sperm injection (ICSI) has resulted in significant decrease in demand for insemination with donor sperm from heterosexual couples.³⁶⁴ The number of IVF treatments using donor sperm, by contrast, has risen in recent years, with 1,200 cycles in 2010, compared with 998 in 2004 and 1,093 in 2000.³⁶⁵ Figures from the past ten years published by the HFEA show that there has been a steady *increase* in the number of people who register as sperm donors (see Table 4.1 below).³⁶⁶ However, the correlation between the number of new donors coming forward and the number of cycles of treatment using donor sperm is made more complex by the fact that some donors (in particular 'known' donors) may choose to limit their donations to one particular family.³⁶⁷

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

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

³⁶² See, for example, Fortescue E (2003) Gamete donation – where is the evidence that there are benefits in removing the anonymity of donors? A patient's viewpoint *Reproductive BioMedicine Online* 7(2): 139-44. See also an Australian study of sperm donors which found that over half said that they would not donate if donor anonymity were to be removed: Godman KM, Sanders K, Rosenberg M, and Burton P (2006) Potential sperm donors', recipients' and their partners' opinions towards the release of identifying information in Western Australia *Human Reproduction* 21(11): 3022-6.

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

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

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

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

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

4.49 Reductions can also be observed in the number of treatment cycles with donor eggs: in 2010, 1,506 cycles were carried out, compared with 1,915 in 2004 and 2,067 in 2000. Embryo donation, by contrast, is higher than it has ever been, with 325 cycles with donor embryos in 2010, compared with 244 in 2004, and 266 in 2000.³⁶⁸ In terms of new donor registrations, Table 4.1 illustrates that, for the past ten years, the number of new egg donors have remained relatively steady. However, the division between ‘egg share’ donors and ‘non-patient’ donors has changed during the same period: in 2000, for example, 601 egg share donors were used in HFEA clinics, compared with 791 non-patient donors. However, ten years later, the balance between the two has shifted, with clinics relying increasingly on ‘egg share’ arrangements.

Table 4.1: Donor registrations: 2000-10³⁶⁹

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

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

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

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

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

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

with donor eggs have halved to an average of less than seven months since the rate of compensation for egg donors rose to £750 in October 2012.³⁷² It appears, therefore, that the issue is not now so much about the removal of anonymity – although the dip in 2004-5 demonstrates that it certainly had an initial effect on some possible donors³⁷³ – but on the extent to which clinics are willing, and have the resources, to put considerable effort into donor recruitment.³⁷⁴ It was suggested to the Working Party that the position of private clinics is thus likely to be rather different from that of NHS and mixed NHS/private clinics.³⁷⁵

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

Donors and their families

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

Donors' families and relationships

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

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

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

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

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

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

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

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

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

- 4.54 This experience in one clinic is not, of course, necessarily representative of wider donor experience; clinics that actively encourage potential sperm donors with partners to involve those partners in their decision-making may prompt very different experiences.³⁸⁰ The experience of egg donors may also potentially differ considerably from that of sperm donors at the time of donation, given the very different kind of procedures involved. In one clinic-based study of egg donation, all but one of 31 donors had told someone that they had donated; almost all partners were described as “very supportive”, and more than half of the donors’ mothers and fathers were also “very supportive.”³⁸¹ However, some participants did report more negative reactions, with one lesbian donor, for example, noting that “all were supportive, except that mother took a long time to accept that if any children were conceived they would not be anything to do with me.” Another donor’s mother felt that the donor had ‘given away’ her grandchildren, and three (two of whom were known donors) felt that donation had had a negative impact on their relationships.
- 4.55 By contrast with the experience of sperm donors described above of a London clinic, over 90 per cent of partnered respondents in a 2012 survey of sperm donors (predominantly members of the US-based DSR) had told their partner that they were a donor.³⁸² While most of the wives/partners of donors in this survey were open to the idea of their partner connecting with donor-conceived offspring, 15 out of 103 donors said that their partners were not open to such contact, and a further 17 made additional comments noting partners’ reservations. Examples of concerns that were feared by, or actually experienced by, partners included the anxiety that “my desire to contact or meet my offspring is a sign that they (my wife and my daughter) are not enough” and “my wife had feelings of jealousy when I would spend time online chatting with my donor child’s mother”.³⁸³ The issue of boundaries, both in terms of online and face-to-face contact, was clearly important in cases where contact had been made, and the authors of the survey suggest that “for a donor with his own family, it may be helpful to think of two families engaging with each other, rather than a donor and his offspring”.³⁸⁴

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

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

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

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

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

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

- 4.56 As the quotations above highlight, the impact of contact with donor offspring may extend beyond the sperm donor and his partner to other members of their family: in particular to their own children. Thirty-three donors participating in the study (out of the 95 donors with children) had, at the time, told their own children about the existence of donor-conceived siblings; 38 others said that their children were too young to tell, and most of these intended to tell them later. Of the 33 families where the children had been told, 23 were interested in meeting donor-conceived siblings, while ten were not. An earlier (2010) survey of DSR registrants, in which 63 sperm donors and 11 egg donors participated, also made brief reference to the reactions of donors' parents: two of the qualitative responses cited referred to the donor's mother or parents being "thrilled" with "these additions to the family" or "their new granddaughter".³⁸⁵
- 4.57 By definition, donors who join contact registers indicate a willingness to engage in some form of contact with, or provide further information for, people born as a result of their donation. By contrast, the image that donor-conceived people may "knock on the door" or "turn up on the doorstep" 18 years or more after donation is widely deployed to suggest that such contact may be experienced as unwanted or disruptive.³⁸⁶ Such a scenario was strongly resisted by one donor-conceived person who contributed to the Working Party's factfinding meetings and who emphasised that there was no reason to think that donor-conceived people would 'force themselves' on to a donor who did not wish to meet them.³⁸⁷ The fact that some donors who donated anonymously in the past have since joined contact registers (see paragraphs 2.16 and 4.25) demonstrates the willingness on the part of some to facilitate contact even where this was never envisaged when they first donated, although these numbers remain very small compared with the total number of past donors. A survey of past donors from one London clinic in the context of the development of the UK voluntary register (see paragraph 2.16) reported that more than three quarters of those willing to be interviewed were in favour of the creation of a voluntary register, and most of these would consider joining it if their partner agreed.³⁸⁸ The proportion of these donors who in fact went on to register is not known. Some respondents to this survey also suggested that they might be willing to be contacted for information even if they had not chosen to register,³⁸⁹ although the anecdotal experience of clinics cited to the Working Party in factfinding meetings suggested that past donors who donated anonymously are not necessarily responsive to such requests.³⁹⁰
- 4.58 Where the creation of a family through donor conception also involves surrogacy arrangements, the further question arises as to the impact of that arrangement on the surrogate's own family. A survey in 2012 of 'parental order reporters' (social workers who write court reports in connection with intended parents' applications for parental orders) reported concerns that insufficient attention was given to the effect on surrogates' children of their mother having a baby and then "giving it away".³⁹¹ Research conducted with 34 surrogate mothers one year after the birth of the surrogate child, however, found that, of the 32 surrogates who had their own child at the time, 26 reported that their child felt positively about the surrogacy arrangement during the

³⁸⁵ Jadva V, Freeman T, Kramer W, and Golombok S (2010) Sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor offspring *Human Reproduction* **26**: 638-4, at 643.

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

³⁸⁷ Factfinding meeting with Rachel Pepa, 24 April 2012.

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

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

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

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

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

Curiosity or concern about the outcome of the donation

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

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

Conclusions about evidence

4.61 The evidence available to the Working Party regarding the impact of disclosure or non-disclosure derives primarily from empirical studies of donor-conceived families; qualitative studies of the experiences of donor-conceived adolescents and adults; surveys of donor-conceived people, parents and (to a lesser extent) donors; and the experience of those working with donor-conceived people, their families and donors, in particular the DCN. This evidence points towards the conclusion that children whose parents begin to talk to them about their donor conception from an early age generally seem to integrate this information into their

³⁹² Jadva V, Murray C, Lycett E, MacCallum F, and Golombok S (2003) Surrogacy: the experiences of surrogate mothers *Human Reproduction* **18(10)**: 2196-204. The remaining mother felt that her child was too young to understand during the pregnancy, but subsequently explained to him.

³⁹³ Imrie S, Jadva V, and Golombok S (2012) The long-term psychological health of surrogate mothers and their families *Fertility and Sterility* **98(3)**, supplement: S46.

³⁹⁴ Fielding D, Handley S, Duqueno L, Weaver S, and Lui S (1998) Motivation, attitudes and experience of donation: a follow-up of women donating eggs in assisted conception treatment *Journal of Community & Applied Social Psychology* **8(4)**: 273-87.

³⁹⁵ Grtin ZB, Ahuja KK, and Golombok S (2012) Emotional and relational aspects of egg-sharing: egg-share donors’ and recipients’ feelings about each other, each others’ treatment outcome and any resulting children *Human Reproduction* **27(6)**: 1690-701.

³⁹⁶ Jadva V, Freeman T, Kramer W, and Golombok S (2010) Sperm and oocyte donors’ experiences of anonymous donation and subsequent contact with their donor offspring *Human Reproduction* **26(3)**: 638-45. Twenty-nine of the 63 sperm donors and seven of the 11 egg donors expressed no concerns.

developing sense of self, whereas donor-conceived people who discover their origins in adolescence or adulthood are more likely to be distressed, and this may impact detrimentally on the relationship with their parents. Thus it appears that, where parents aim to disclose to their children the facts of their conception, the optimal time is in their preschool years. Such early disclosure also avoids any risk of later harm arising as a result of unplanned disclosure or inadvertent discovery by the donor-conceived person of the means of their conception. However, while some parents who choose not to tell their children at an early age that they are donor-conceived later come to regret this decision, studies following the welfare of donor-conceived families have found that such families nevertheless function well up to early adolescence. There is little evidence at present from systematic longitudinal studies on how donor-conceived families function in later adolescence and into adulthood; and the qualitative studies of donor-conceived adolescents and adults relate almost entirely to those who have joined support networks or contact registries (primarily US-based), and who were conceived via sperm donation. Little is known of the attitudes and experiences of donor-conceived people who are not involved in such networks, or of those conceived through egg or embryo donation. The personal experiences of those who do not know they are donor-conceived remain, of course, unknowable.