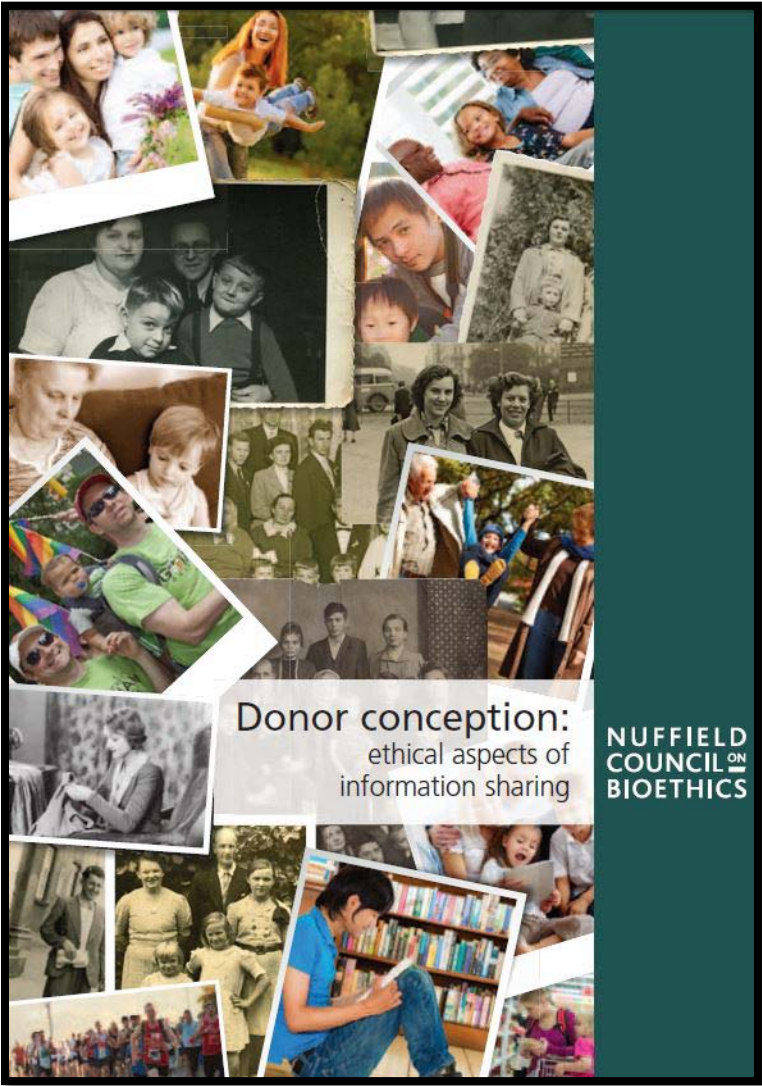


NUFFIELD COUNCIL ON BIOETHICS

Donor conception: ethical aspects of information sharing

Report developments

June 2014



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Introduction

The Nuffield Council's report *Donor conception: ethical aspects of information sharing* was published on 17 April 2013.¹ This paper notes key developments reported in the year since the report's publication.

Reaction

Most of the report's recommendations were targeted at a few key organisations including the HFEA, the Department of Health, and professional fertility organisations such as British Infertility Counselling Association (BICA) and the British Fertility Society.

Some of the organisations campaigning in this area (such as the Project Group on Assisted Reproduction and the leadership of the Donor Conception Network (DCN)) have been somewhat critical of the Working Party's approach. However, there has been positive feedback from individual parent members of the DCN after a presentation at their annual conference; from academics; and from professionals both in the UK and beyond.

The report therefore drew a wide range of opinion on its recommendations and conclusions, ranging from very positive to wholly negative reactions, a snapshot of which is provided below.

Positive reactions

"... the report acknowledges that genetic relatedness matters to people but rejects arguments based upon one-dimensional genetic determinism. This thinking is behind the Working Party's hope that donor conception will eventually become 'no big deal'."²

"The HFEA welcomes this report about donor conception published by the Nuffield Council on Bioethics today. Their recommendations balancing the 'interests' and 'responsibilities' of all those involved in the fertility treatment process very much mirror the work we have already undertaken."³

"The report was criticised for not doing enough for donor-conceived adults. However, the report did clearly illustrate the complexity of information

¹ Nuffield Council on Bioethics (17 April 2013) *New ethics report addresses if, when and how people conceived using donor sperm or eggs should be told of their origins*, available at: <http://nuffieldbioethics.org/news/new-ethics-report-addresses-if-when-and-how-people-conceived-using-donor-sperm-or-eggs-should-b>.

² BioNews (29 April 2013) *Why we should welcome the conclusions of the Nuffield report on donor conception*, available at: http://www.bionews.org.uk/page.asp?obj_id=290058.

³ Human Fertilisation and Embryology Authority (17 April 2013) *HFEA welcomes the Nuffield Council in Bioethics report on information in donor conception*, available at: <http://www.hfea.gov.uk/7825.html>.

sharing and that societies and cultures have different perspectives and individual values.”⁴

Negative reactions

“The recent Nuffield report makes two disappointing recommendations. First, that anonymous donation should not be reintroduced. Second, that the state should encourage those who donated pre-2005 to come forward. Both positions are obstructive to donors, past and present.”⁵

“... the report provides a catalogue of missed opportunities. Take, for example, the situation of around 30,000 children and young adults following donor conception in the UK between 1992 and 2006. The Human Fertilisation and Embryology Authority holds records of the donor procedures that resulted in their births, including the identity of their donor. However, as the law stands, donor-identifying information will not be disclosed to donor-conceived persons.”⁶

General media coverage

The report also received significant coverage in the general press,⁷ especially following a news release from the Press Association.⁸

Dissemination, presentations and events

A coordinated effort was made to make copies of the report available to those with a personal or professional interest in the issues addressed by the report. Approximately 200 printed copies of the report were posted upon its publication, and further dissemination has been initiated at conferences, presentation, and other meetings. An email notification detailing the report’s main recommendations, and with a link to the full report, was sent to around 500 relevant stakeholders (both individual and organisational recipients).

⁴ Western Australian Reproductive Technology Council (2013) *Annual report* (Perth: Western Australian Reproductive Technology Council), at page 20.

⁵ BioNews (13 May 2013) *Enough of Nuffield – let’s stop sidelining donors*, available at: http://www.bionews.org.uk/page_296916.asp.

⁶ BioNews (29 April 2013) *Little for donor-conceived people in the Nuffield Council’s report*, available at: http://www.bionews.org.uk/page_290373.asp.

⁷ See, for example, The Independent (17 April 2013) *Sperm and egg donors urged to reveal identity*, available at: <http://www.independent.co.uk/news/science/sperm-and-egg-donors-urged-to-reveal-identity-8575692.html>.

⁸ See, for example, The London Evening Standard (17 April 2013) *Parents back in donor conception*, available at: <http://www.standard.co.uk/panewsfeeds/parents-backed-in-donor-conception-8575803.html>.

Short versions of the report have also been distributed to delegates at a number of conferences. Members of the Working Party and Secretariat have presented at or attended several events since publication of the report, including:

- Working Party member Sheila Pike gave a talk about the report at a regional meeting of the BICA on 19 April 2013.
- Katharine Wright presented at the DCN's annual conference in London which Kate Harvey also attended on 21 April 2013.
- Katharine Wright and Sarah Walker-Robson ran a small stand at the annual conference of BICA on 10 May 2013.
- Laura Witjens took part in a panel discussion at the Cheltenham Science Festival in an NCOB-sponsored event '*Donor conception: a private family matter?*' on 5 June 2013.
- Rhona Knight presented at the University of Manchester conference *New families and genetic identities* on 20 June 2013.
- Jeanette Edwards highlighted the report in a paper on '*Revisiting genetic relatedness with donor siblings*' at a Wellcome Trust workshop on '*Motherhood: all change*' at the University of Manchester in September 2013. In the same month, Professor Edwards also highlighted the conclusions of the report at a conference on '*Contesting fertilities, families and sexualities*' at the University of Zurich, when giving a paper on '*Donor conception: (dis)closure, openness and privacy*'.
- Rhona Knight discussed the report in a parallel workshop session at the Institute of Medical Ethics Student Ethics Conference in Norwich on 7 December 2013.⁹
- Jeanette Edwards discussed the report as an invited discussant to Marilyn Strathern on '*Anthropological reasoning: some thoughts*', at symposium titled '*Anthropological knots*' at the University of Helsinki in January 2014.
- Jeanette Edwards highlighted the evidence and findings of the report in February 2014 when presenting a paper on '*The politics of see-through kinship*' at a conference on '*Doing politics - making kinship*' at Humboldt University, Berlin.
- Katharine Wright contributed to a two-day seminar at the University of Cambridge in April 2014 to discuss draft chapters of a book on reproductive donation (see below) produced by researchers from King's College London and Lancaster University.

Policy developments

⁹ Institute of Medical Ethics (2013) *Go forth, increase and moralise; student ethics conference*, available at: http://www.instituteofmedicalethics.org/website/index.php?option=com_content&view=article&id=358:go-forth-increase-and-moralise&catid=22:current-events&Itemid=4.

HFEA reaction

The HFEA noted in its initial press release following the publication of the Nuffield Council report that “the importance of information to people affected by donation and one of our tasks is to help donors provide better information about themselves for future families.”¹⁰ Following this declaration, the HFEA discussed its donation work programme for 2013-5 at an Authority meeting in July 2013. The Nuffield Council’s report was discussed extensively, and the Authority agreed to adopt a number of its recommendations.¹¹

Summary of policy-makers’ reaction to the Nuffield Council’s report

The next section of this report summarises each recommendation that has been addressed by policy-makers thus far, and their reaction to each.

Donors’ responsibility to think seriously when providing information about themselves in pen portraits and good will messages

Nuffield Council recommendation

“... in deciding to donate, donors have a responsibility to think seriously about how they provide information about themselves, in the knowledge that for some recipients, and in particular for some donor-conceived people, this information will be very important. We further conclude that clinics have a responsibility not only to encourage donors to engage seriously with the provision of information about themselves, but also to provide appropriate support in doing so where required. Filling in the donor form should not be perceived as a brief administrative task.”

In October 2013, the HFEA updated its guidance to clinics on encouraging donors to provide additional personal information – or a ‘pen portrait’. The guidance states that “this information is of great value to donor-conceived people” and that “it is important that the donor knows that this information can be shared with patients considering treatment with the donor’s gametes, parents of any children born as a result of treatment with their gametes and donor-conceived people themselves.”¹² At the HFEA’s annual conference, the results of its donation patient survey (via the DCN and the Infertility Network UK) were also drawn upon to highlight the significance of the pen portrait. The survey, which received over 200 responses, found that 83 per cent of

¹⁰ HFEA (17 April 2013) *HFEA welcomes the Nuffield Council on Bioethics report on information in donor conception*, available at: <http://www.hfea.gov.uk/7825.html>.

¹¹ HFEA (3 July 2013) *Authority meeting: donation work programme for 2013/15* <http://www.hfea.gov.uk/Authority-meeting-July-2013.html>.

¹² HFEA (2013) *HFEA donor information form (form v2012): completion guidance notes*, available at: <http://www.hfea.gov.uk/2505.html>, at page 9.

respondents felt that the pen portrait was important tool for informing donor-conceived children of their origins; 81 per cent thought it important to help parents choose a donor. In the same survey, 75 per cent of respondents noted that a goodwill message was important to inform children of their origins, and 50 per cent stated that it would help parents to choose a donor.¹³

Reassuring parents about screening for serious conditions

Nuffield Council recommendation

“... details of the major conditions that have been ‘screened out’ before donors are allowed to donate should be provided to the parents in an easily accessible and comprehensible format that they can retain for later reference.”

The HFEA has stated that the issue of providing parents with clear and comprehensible information about significant heritable diseases that are screened out during the process of donation will be considered for its update of the *Code of practice* in October 2014.¹⁴

Guidance on disclosure: pre-1991

Nuffield Council recommendation

“We recommend that the HFEA should issue guidance to clinics setting out what is expected of them with respect to making information from pre-1991 records available to applicants.”

The HFEA responded to this recommendation by noting that, when updating its *Code of practice* in October 2014, it would consider the issue of how clinics might be guided in what they can and cannot do with respect to making pre-1991 records available.¹⁵

The HFEA has also observed that “although the first cohort of donor-conceived people conceived following the removal of anonymity (in 2005) will not reach the age of 18 until 2023-4, at the time of writing, approximately 130 pre-2005 donors have re-registered as identifiable with the HFEA and this figure is expected to increase over time. This means that their contact information will be available to anyone conceived using their donation, once they reach the age of 18. Some of the children conceived from these re-registered

¹³ Watkin J (26 February 2014) *Presentation: improving the sharing and quality of donor information* (London: HFEA Conference 2014).

¹⁴ HFEA (3 July 2013) *Authority agenda: donation work programme for 2013/15*, available at: <http://www.hfea.gov.uk/Authority-meeting-July-2013.html>, at 4.31.

¹⁵ Ibid.

donors have now reached that age and the HFEA has already received a small number of enquiries.”¹⁶

Counselling

Nuffield Council recommendation

“We recommend that, as a matter of good professional practice, clinics should present counselling sessions as a routine part of the series of consultations undertaken before treatment with donated gametes or embryos begins. Clinics can thus be confident that their patients have had access to the information and support that they may need in order to make a properly informed decision to go ahead with treatment. Prospective parents should clearly understand that such sessions will be treated as confidential and that their counsellor is not involved in making any judgments about their suitability as parents. Given the importance of a trusting relationship between counsellors and their clients, prospective parents should also be able to see an alternative counsellor if, for whatever reason, they do not feel comfortable with the counsellor whom they first see. We recommend that these requirements should be professionally mandated by the relevant professional bodies, including the British Fertility Society and the British Infertility Counselling Association.”

The HFEA will consider this issue as part of its review of the *Code of practice* in October 2014. The review will take into consideration the recommendation of the Nuffield Council in addition to comments made about counselling provision at the HFEA’s stakeholder meeting.¹⁷

The role of counselling was also raised in the final report of the New South Wales (NSW) Legislative Assembly on managing donor conception information. The report stated:

“The Committee notes that while NSW Health [which manages the State’s central and voluntary donor registers) does not currently offer counselling or support services, it does have experience in public education and public awareness campaigns, and it could be an administratively straightforward task to expand their function to include provision of counselling, intermediary and other support services.”¹⁸

¹⁶ HFEA (5 March 2014) *HFEA Authority meeting March 2014*, available at:

<http://www.hfea.gov.uk/8782.html>, agenda item 8, at paragraph 1.4.

¹⁷ HFEA (3 July 2013) *Authority agenda: donation work programme for 2013/15*, available at:

<http://www.hfea.gov.uk/Authority-meeting-July-2013.html>, at 4.31.

¹⁸ Legislative Assembly of New South Wales Committee on Law and Safety (2013) *Managing donor conception information*, available at:

<http://www.parliament.nsw.gov.au/Prod/Parlment/committee.nsf/0/089181807C549768CA257CC7008251CB>, at paragraph 5.12.

Making donor conception ‘unremarkable’

Nuffield Council recommendation

“...encouraging a social environment where the creation of families through donor conception is seen as unremarkable: as just one way among a number of others of building a family.”

The HFEA acknowledged this recommendation, and the additional provision that the state has a ‘stewardship’ role in promoting an inclusive and accepting environment for individuals becoming parents in different ways. In its Authority paper, it stated that these goals cut “across many of the [HFEA] work strands, particularly the donation information website.”¹⁹

Sharing medical information

Nuffield Council recommendation

“We recommend that the HFEA should take responsibility for ensuring that a clear, well-publicised, route for sharing significant medical information is established, either via fertility clinics or via the HFEA’s own Register, to make it as easy as possible for donors, or donor-conceived people and their families, to pass on such information where it arises. We further recommend that the UK’s NHS clinical genetics services are involved in such communications.”

The HFEA will consider the question of establishing a clear mechanism to share serious medical information about the donor with donor-conceived people when it reviews its *Code of practice* in October 2014.

Dedicated donor conception website

Nuffield Council recommendation

“We recommend that the HFEA, as the public body with the most expertise in this field, should expand and make more easily available the information it provides to all those directly affected by donor conception, for example through the creation of a dedicated donor conception website, distinct from the main HFEA website.”

¹⁹ HFEA (3 July 2013) *Authority agenda: donation work programme for 2013/15*, available at: <http://www.hfea.gov.uk/Authority-meeting-July-2013.html>, at 4.31.

In its July Authority paper, the HFEA notes that “At the end of the donation review, the Authority suggested developing a stand-alone website for donors, recipients and donor-conceived people. Using the model of the *One at a Time* website, it would reach a broad audience, including those considering going abroad for treatment and having unlicensed treatment with donor sperm. The website could also raise awareness of donor re-registration (recommended by the Nuffield Council on Bioethics) and help to make donor conception an ‘unremarkable’ route to parenthood (also a Nuffield recommendation).”²⁰

The HFEA has therefore stated its intention to “continue to plan a dedicated donation website through the National Donation Strategy Group”.

The provision of intermediary services

Nuffield Council recommendation

“The Working Party takes the view that the state, in legislating for a system where identifiable information about donors is seen as desirable, has a responsibility to make sure that those affected are appropriately supported. This means that the state should take an active role in ensuring that an appropriate intermediary and counselling service (that is, one whose role is to support both the donor-conceived person and the donor in possible contact) should be made available. Such a service could also potentially incorporate the service currently available to facilitate contact between donor-conceived siblings.”

One of the areas identified as needing further work by the HFEA in its July Authority paper was that of “improving information about donation”.²¹ One particular area that falls under this heading is that of the provision of intermediary services, and the Authority paper notes that “suggestions have also been made – by professional organisations and the NCOB – that an intermediary service of some kind be established to support donor-conceived people and donors in situations where identifying information about a donor has been released and both parties wish to meet. There are a number of models for an intermediary service and each would obviously have cost implications for the HFEA (or whichever organisation provided it).”²² In a later Authority paper, the HFEA states that “there is no established, professional practice for providing support to those

²⁰ HFEA (3 July 2013) *Authority meeting: donation work programme for 2013/15* <http://www.hfea.gov.uk/Authority-meeting-July-2013.html>, agenda item 10, at paragraph 4.27.

²¹ *Ibid.*, at paragraphs 4.26-9.

²² *Ibid.*, at paragraph 4.4.

accessing donor identifying information from the HFEA Register and potentially making contact with a donor.”²³

The need to establish coordinated intermediary services was also highlighted by the McCracken review, which was published in the same month as the Nuffield Council’s report. Recommendation seven of the review stated that the HFEA should “identify the best means of providing information from the register, together with appropriate support, to people born as a result of ART.”²⁴

The number of donor-conceived people who have approached the HFEA whose donor has re-registered as identifiable is, to date, very small: it has had three enquiries, all of which have been addressed on an *ad hoc* basis. The HFEA therefore agreed to initiate a three-year pilot where it would draw up a contract with one or more post-adoption agencies that have the capacity to deliver the service nationwide. Payment will be on a ‘per case’ basis, and would include up to five contact sessions between the donor and the donor-conceived person, and support workers’ supervisory sessions with their clinical and managerial supervisors. Other forms of support – such as for a spouse or parent of a child seeking information about the donor – would require funding by individuals.

The HFEA has noted further that “professional bodies and the NCOB have also argued for support to be made available for people affected by donation who do not necessarily request information from the Register. These might be parents who need further support after their child is born or donor-conceived people who need support but aren’t seeking information from the Register.”²⁵

Retrospective removal of donor anonymity

Nuffield Council recommendations

“... we suggest that the state, rather than regulating retrospectively the removal of anonymity, should instead take action to increase awareness among past donors that a willingness on their part to become identifiable would be highly valued by some donor-conceived adults.”

“We recommend that the HFEA, in conjunction with the Donor Conceived Register, should initiate a public information campaign about donor conception and the possibility for past donors to make themselves identifiable if they wish.”

²³ HFEA (5 March 2014) *HFEA Authority meeting March 2014*, available at: <http://www.hfea.gov.uk/8782.html>, agenda item 8, at paragraph 1.2.

²⁴ Department of Health (2013) *Review of the Human Fertilisation & Embryology Authority and the Human Tissue Authority*, available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216947/Justin_McCracken_report_of_review_of_HFEA_and_HTA.pdf.

²⁵ HFEA (3 July 2013) *Authority meeting: donation work programme for 2013/15* <http://www.hfea.gov.uk/Authority-meeting-July-2013.html>, agenda item 10, at paragraph 4.5.

The most recent debates that have addressed the retrospective removal of donor anonymity have occurred in Australian States.

Developments in New South Wales

During the course of the Nuffield Council's project, the Legislative Assembly Committee on Law and Safety in New South Wales (NSW) undertook its own review of the laws pertaining to donor conception information. In October 2013, the Committee published a report which drew together its findings. In a press release made on the publication of the report, the Chair of the Committee drew particular attention to the retrospective removal of donor anonymity:

“The Committee considers that access to identifying donor conception information should always be made possible where all parties to donor conception consent. We believe that the recommendations we have made around access to information being dependent on consent by all parties strike a balance between fulfilling the wishes of donor-conceived people to know their genetic heritage and respecting the wishes of those who donated anonymously to maintain their privacy if they wish.”²⁶

The Committee further recommended that “the Ministry of Health conduct an advertising campaign to raise awareness of the Voluntary Register.”²⁷

Developments in the State of Victoria

Following an extensive public consultation exercise, and its own research review, the Australian State of Victoria also responded to the issue of the retrospective removal of donor anonymity:

“Based on the consultation findings, and further detailed consideration of research into all stakeholder interests and human rights impacts, the Government supports the introduction of legislation to allow all donor-conceived people to obtain identifying information about their donors. However, the Government considers that identifying information should only be released with the consent of donors; seeking consent would increase the likelihood that donor-conceived individuals could gain access

²⁶ Legislative Assembly of New South Wales: Committee on Law and safety (17 October 2013) *Parliamentary Committee recommends comprehensive change to the management of donor conception information in New South Wales*, available at: <http://www.parliament.nsw.gov.au/Prod/Parlment/committee.nsf/0/70C93C3EB27A658ECA257C070017A0DA>.

²⁷ Legislative Assembly of New South Wales: Committee on Law and Safety (2013) *Managing donor conception information*, available at: <http://www.parliament.nsw.gov.au/Prod/Parlment/committee.nsf/0/EE71C90F0F8B8713CA257ABC001A28AA?open&refnavid=x>, at page 62.

to relevant contemporaneous information about their donors. To this end, the Government intends to introduce legislation to extend the 1988-1997 legislative arrangements to all donor-conceived people conceived using gametes donated prior to 1988.” It further adds that “under the Government’s proposal information will only be given to donor-conceived individuals seeking it, in the case of non-identifying information if this available from the records, and in the case of identifying information where the donor consents to its release.”²⁸

Prior to the Victorian response, the Nuffield Council shared its own report (prior to the date of publication, in confidence).

Access to specialist support

Nuffield Council recommendation

“... we take the view that the state, which has chosen through regulatory action both to promote donor conception as a legitimate means of creating a family, and actively to encourage early disclosure to resulting children, retains an ultimate responsibility for ensuring that donor-conceived families continue to be able to access specialist support where this is needed.”

The Legislative Assembly of NSW has similarly underscored the argument that the state retains ultimate responsibility for providing specialist support through its recommendation that “the Attorney General establish a new agency to manage a Register of donor conception information and that this agency also assume responsibility for providing support to those involved in donor conception.”²⁹

Literature

The Nuffield Council’s report has been the subject of a number of publications since its launch. This section of the report summarises the contents of some of those citations.

Articles that focus primarily on the Council’s report

Norwegian coverage

²⁸ Parliament of Victoria Law Reform Committee (2013) *Inquiry into access by donor-conceived people to information about donors*, available at: http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/donor-conceived/Response_to_Donor-conceived.pdf.

²⁹ Legislative Assembly of New South Wales: Committee on Law and Safety (2013) *Managing donor conception information*, available at: <http://www.parliament.nsw.gov.au/Prod/Parlment/committee.nsf/0/EE71C90F0F8B8713CA257ABC001A28AA?open&refnavid=x>, at paragraph 5.35.

In June 2013, the Nuffield Council's report featured as the top story in the *Journal of the Norwegian Medical Association*.³⁰ The feature provided a summary of the main recommendations and the ethical framework of the report. In particular, it focused on the conclusion that parents should be the party who undertakes to tell the donor-conceived person about the mode of their conception. It also explores the reason that this was held, and provides a discussion of values, family history, weighing of interests, autonomy and privacy of the family and the fear or possibility of stigma.

The Norwegian article also highlights the Council's use of the conception of 'kinship', and the changing nature of family relationships. It concludes that "The Nuffield Council on Bioethics is an international authority within bioethics and has delivered a comprehensive and thorough report which many can learn from. The report brings together important knowledge and moral assessments that are significant for all those who have an interest in modern reproductive technologies".

The article concludes by noting that not enough is known about the impact of disclosure on donor-conceived children – which the article refers to as 'the weak party' – but that this does not justify not telling them. Further, it notes that, in a society where openness and honesty are ideals and where genetic information and relations are becoming more and more important, it is essential that people have the opportunity to know about their genetic origins.

Medical Law Review article

Like the Norwegian article, kinship was also the focus of a paper written by UK-based academics. The authors noted that "kinning and de-kinning are complex and contested, and questions concerning them tend to be complex and contested too." This article summarised the Nuffield Council's report, and complimented its "emphasis on kinship to the strong support for parents as decision-makers, and the characterisation of donor conception information as both personal and 'interpersonal'. There is also an adroit handling of personal identity, in that the genetic dimension is acknowledged but not allowed to squeeze out other identity-crafting forces."³¹

Articles that cite the Council's report

The disclosure decisions of parents, rather than the identification of donors, was the issue addressed by a Finnish study that considered the question: "what are the disclosure intentions and experiences of heterosexual parents with children born after assisted DI or IVF with donor sperm?" It found that, of all parents, 16.5 per cent reported that they had already told their child of his/her conception. The children had been between the ages of three and 14 years of age when they were told. Parents of older children were significantly more unwilling to tell their child than parents of younger

³⁰ Hofmann B (2013) *Trenger donorbarn å vite?*, available at: <http://tidsskriftet.no/article/3026905>.

³¹ Murphy T and Turkmendag I (2013) Kinship: born and bred (but also facilitated)? A commentary on 'Donor conception: ethical aspects of information sharing' (Nuffield Council on Bioethics, London 2013) *Medical Law Review* 0: 1-14.

children. There was no difference in disclosure between DI and IVF with donor sperm families. Less than 42 per cent of parents had been satisfied with the psychological support offered to them (parents of older children were the most dissatisfied).³²

A further small-scale study that asked 79 participants of the DCN's *Preparation for parenthood* workshop found that using such workshops was felt to be useful for people considering donor conception.³³ The use of such workshops echoes the spirit of the Council's recommendation which highlights the importance of maintaining voluntary organisations.

Short films have also been released that focus on donor conception. One film, which references the Council's report directly, explores the process of sperm donation, and the benefits of donation. It also highlights the importance of treating donors well, for example by making the clinic environment appealing, and offering refreshments.³⁴

The report has been cited in a number of journal articles and texts, including:

Crawshaw M and Montuschi O (2014) It 'did what it said on the tin' – participants' views of the content and process of donor conception parenthood preparation workshops *Human Fertility* **17(1)**: 11-20

Edwards J (2013) Donor siblings: participating in each other's conception *HAU: Journal of Ethnographic Theory* **3(2)**: 285-92

Hammarberg K, Johnson L, Bourne K, Fisher J and Kirkman M (2013) Proposed legislative change mandating retrospective release of identifying information: consultation with donors and Government response *Human Reproduction* **29(2)**: 286-92

Millbank J (2014) Numerical limits in donor conception regimes: genetic links and 'extended family' in the era of identity disclosure *Medical Law Review* (advance access publication, 28 January 2014): 1-32

Nordqvist P and Smart C (2013) *Relative strangers: family life, genes and donor conception* (Basingstoke: Palgrave Macmillan)

Ravelingien A, Provoost V and Pennings G (2013) Donor-conceived children looking for their sperm donor: what do they want to know? *Facts, Views and Visions in ObGyn* **5(4)**: 257-64

³² Salevaara M, Suikkari A-M and Soderstrom-Anttila V (2013) Attitudes and disclosure decisions of Finnish parents with children conceived using donor sperm *Human Reproduction* **28(10)**: 2746-54.

³³ Crawshaw M and Montuschi O (2014) It 'did what it said on the tin' – participants' views of the content and process of donor conception parenthood preparation workshops *Human Fertility* **17(1)**: 11-20.

³⁴ Pettit AL (20 May 2013) *Sperm donors*, available at: <https://www.youtube.com/watch?v=mXX5b7QemMc>.

Zubai S, Mustafa AS, Badir AA *et al.* (2013) A revisit of assisted reproduction technology and the humanization paradigm *Perintis E-journal* **3(1)**: 1-16

Articles of general interest

ESHRE study on egg donors' altruistic motivation

A study from the European Society of Human Reproduction and Embryology (ESHRE) published the results of a survey of 1,423 egg donors at 60 clinics in 11 European countries, concluding that the majority of donors are keen to donate for altruistic reasons. The study found that 'pure' altruism motivated 46 per cent of egg donors. However, a significant percentage (32%) was motivated jointly by altruism and financial compensation. It also found that ten per cent were motivated by financial considerations alone; and five per cent were motivated by altruism and their own treatment.

Observations were also made about the age of the donors, and their respective motivations. For example, younger donors were found to be less likely to donate eggs for altruistic reasons alone, with just under half of donors under 25 citing altruism as their motive compared to 79 per cent of those over 35. Professor Guido Pennings, who led the research, concluded "the older you are, the more altruistic you are."³⁵

Secrecy

The issue of secrecy has also been discussed in the literature published in the last year. One commentator, for example, argues that in the context of donor conception, it is not clear that secrets are wrong, or that all secrets need to be justified. The same author argued that overemphasising genetic connections might not be the best way to ensure well-being in non-genetic families; in reducing the significance of genetic information, parents' reluctance to disclose might be similarly lessened.³⁶

Other articles

Several other academic articles have been published which relate to the Council's report, with several citing the report directly (see also the list of citations above).

News stories

The media have reported on several developments in the past year that are relevant to the conclusions made by the Council's report.

³⁵ ESHRE (2013) *Egg donation in European clinics: why do women do it?*, available at: http://www.eurekalert.org/pub_releases/2013-07/esoh-edi070213.php.

³⁶ De Melo-Martin I (2014) The ethics of anonymous gamete donation: is there a right to know one's genetic origins? *Hastings Center Report* **44(2)**: 28-35.

In May 2013, the BBC reported on the comments of employees from Birmingham Women's Hospital who suggested that a shortage of Asian egg donors meant that UK couples increasingly travel abroad for fertility treatment.³⁷

Other relevant UK news includes the report of a court case where a widow fought to extend the period for which her husband's sperm could be frozen. Warren Brewer, Mrs Warren's husband, had frozen his sperm before dying of a brain tumour and given his consent for his wife to use the sperm to conceive following his death. Regulations enforced by the HFEA state that a person's sperm can be stored for decades as long as they *regularly* renew their consent for this to happen, but following Mr Brewer's death, his consent could no longer be renewed. Mrs Warren sought permission from the court to extend the period for which her husband's sperm could be stored, in the absence of his written consent to do so.

The High Court decided that Mrs Warren could keep her husband's sperm beyond the period for which he had consented to its storage. In her ruling, Mrs Justice Hogg held that "the evidence indicates that both Mr Brewer and his wife were in agreement. He wanted her to have the opportunity to have his child, if she wanted, after his death... [But] written consents provided by Mr Brewer did not specify that his gametes should be stored beyond the statutory period required by the HFEA." She ruled that it was "right and proper, and proportionate" to allow the sperm to be kept until at least April 2023.

In a press release following the court's decision, the HFEA announced that it would not challenge the decision, stating that "after carefully considering not just the legal issues, but also the moral ones, we have come to the conclusion that an appeal is not the right approach." The HFEA statement continued: "... given that the judgment acknowledges that there is no written consent to store Mr Brewer's sperm beyond 2015, we needed properly to consider the wider consequences for other patients, in particular those cases where there may be no consent to extended storage, and where the sperm provider's wishes are less clear than Mr Brewer's."

Online developments

There have been several website launches in the past year that focus on donor conception and information provision.

For example, Natalie Gamble Associates, a firm of solicitors specialising in fertility law, launched a website that hosts a non-profit surrogacy and egg donation agency. The website provides practical advice and support for families created through surrogacy and/or egg donation, and to surrogates/donors. The website also offers a service whereby surrogates and egg donors in the UK are matched, subject to screening.³⁸

A website with another aim in mind has also been launched recently in the USA by Genepeeks. This website aims to allow parents to check for potential disease in 'virtual'

³⁷ BBC News (15 May 2013) *Asian egg donor shortage in UK 'forcing couples abroad'*, available at:

³⁸ Brilliant Beginnings (2014) *Homepage*, available at: <http://www.brilliantbeginnings.co.uk/>.

babies. According to its website, the company “designed our flagship Matchright technology around a simple truth: when it comes to genetics, the definition of ‘safe’ is personal. For example, a healthy sperm donor for one person might be a risky match for another. That’s why GenePeeks developed a breakthrough approach to donor selection that identifies high-risk matches based on your own genetic signatures.”³⁹ Genepeeks therefore offers a service where “we simulate the process of reproduction, forming virtual sperm and virtual eggs. We put them together to form a hypothetical child genome.”

Conclusion

The Nuffield Council will continue to monitor policy, legal and academic developments in relation to the report on *Donor conception: ethical aspects of information sharing*. In summer 2014, the Council will also discuss the report’s recommendations with the Department of Health.

³⁹ Genepeeks (2014) *About us: helping you protect your future family*, available at: http://www.genepeeks.com/about_us/genepeeks_mission/. See also: BBC News (4 October 2013) *Genepeeks firm to offer ‘digital baby’ screen for sperm donors*, available at: <http://www.bbc.co.uk/news/science-environment-24398312>.