

# Appendices

# Appendix 1: Method of working

## Background

The Nuffield Council on Bioethics established the Working Party on *Donor Conception: ethical aspects of information sharing* in February 2012, and the Working Party subsequently met six times between February and December 2012. In order to inform its deliberations, it launched a 'call for evidence' and online survey in March 2012, and between April and October held a series of 'factfinding' sessions with donor-conceived people, parents of donor-conceived people, donors, health and social care professionals, academic researchers, and those involved in regulation. It also carried out a detailed literature review of the research evidence relating to the experiences of donor-conceived people, parents and donors in relation to information sharing. In November 2012, 15 external reviewers, encompassing a diverse range of experiences and perspectives, were invited to comment on a draft version of the report, which was subsequently reviewed in the light of the comments received.

In total 198 people and organisations, including 11 donor-conceived individuals, 56 parents and 14 donors (where specified), contributed to the Working Party's evidence gathering, and we are enormously grateful to them for the generosity with which they gave their time, their enthusiasm and their expertise.

## Call for evidence

The Working Party's 'call for evidence' (including indicative questions, but also inviting respondents to raise any issues they wished within the remit of the terms of reference) was launched on 21 March 2012 and remained open until 15 May 2012. The call for evidence was accompanied by a briefer online survey with the aim of reaching as many people with personal experience of donor conception as possible. Forty responses to the call for evidence were received (of which 23 came from individuals and 17 from organisations), and 90 people responded to the online survey. Those responding to the call for evidence and online survey included donor-conceived adults, parents, donors, people working with individuals affected by donor conception, representatives from charities or support groups, representatives from professional bodies or government, individuals with an academic or research interest, and those with a legal or regulatory interest, as well as members of the public with a general interest.

Details of the content of the call for evidence, and a full list of respondents, excluding those who asked to remain anonymous, is included in Appendix 2. The online survey did not require respondents to identify themselves; however the organisations who chose to contribute through the online survey and provided organisational details are also listed in Appendix 2. Some respondents to the online survey also indicated a willingness to meet with the Working Party to provide further information, and subsequently two individuals (selected on the basis that the issues they raised had not, as yet, been heard in factfinding sessions) were invited to factfinding meetings on 16 July 2012.

The responses received through these two consultative methods were circulated to all Working Party members and discussed in subsequent meetings. A summary of responses is available on the Council's website, as are copies of individual responses where respondents gave us permission to publish them in this way.<sup>498</sup>

## Factfinding sessions

A series of 'factfinding' sessions with people with personal and/or professional experience of issues arising out of donor conception played a central part in the Working Party's evidence-gathering. A total

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<sup>498</sup> See: 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>.

of ten meetings were held, mainly involving discussion sessions lasting between one and a half and two and a half hours, as follows:

**24 April 2012: meeting with Rachel Pepa, donor-conceived person**

**27 April 2012: full day meeting, encompassing three sessions with people with personal experience of donor conception, as follows:**

Members of UK DonorLink (participants included donor-conceived adults and donors)

- Sylvia Barr
- Freddie Howell
- Jess Pearce
- Andy Waters
- Philippa Wilkinson
- Shirley Brailey (contributed in writing after the meeting)

Members of the Donor Conception Network (participants included donor-conceived adults and parents)

- Danny Charles
- Jane Ellis
- Katherine Litwinczuk
- Walter Merricks
- William Merricks
- Zannah Merricks
- Tamsin Mitchell
- Olivia Montuschi

Members of the National Gamete Donation Trust (participants included parents and donors)

- Sarah Betts
- Shaun Betts
- Eleanor Clapp
- Mark Jackson
- Pip Morris
- Cathy Sidaway

**30 May 2012 (am): meeting with practitioners/researchers**

- Gary Clapton (social worker and academic; currently consultant at Birthlink Scotland)
- Marilyn Crawshaw (social work academic, practitioner and activist; advisor to UKDL and chair of Progar)
- Julia Feast (researcher and practitioner; formerly with the Children's Society and currently based at the British Association for Adoption and Fostering)
- Christine Gunter (social worker; coordinator of UK DonorLink)
- Sharon Pettle (consultant clinical psychologist and psychotherapist with 15 years' experience of donor conception issues; work for DCN includes running groups for donor-conceived children)
- Jennifer Speirs (anthropologist, former medical social worker and activist; volunteer intermediary worker for NorCap, support worker for UK DonorLink, and member of NGDT Advisory Council)

**30 May 2012 (pm): meeting with academics**

- John Appleby, Centre for Family Research, University of Cambridge

- Sarah Franklin, Department of Sociology, University of Cambridge
- Tabitha Freeman, Centre for Family Research, University of Cambridge
- Lucy Frith, Department of Health Service Research, University of Liverpool
- Nicky Hudson, Reproduction Research Group, De Montfort University
- Fiona MacCallum, Department of Psychology, University of Warwick
- Ilke Turkmendag, PEALS, Newcastle University

**22 June 2012 (am): meeting on regulatory aspects of donation**

- Joanne Anton, HFEA
- Natalie Gamble, Natalie Gamble Associates
- Jagbir Jhutti-Johal, University of Birmingham, Department of Theology and Religion
- Caroline Jones, University of Southampton Law School
- David Katz, Board of Deputies of British Jews
- Michal Nahman, UWE, Department of Health and Applied Social Sciences
- Marcelle Palmer, Board of Deputies of British Jews
- Ted Webb, Department of Health
- Morgan Clarke, Institute of Social and Cultural Anthropology, University of Oxford (contributed in writing after the meeting)

**22 June 2012 (pm): meeting with professionals involved at the time of donation**

- Joanne Adams, sperm donor bank manager, Manchester Fertility Services
- Peter Braude, emeritus professor of obstetrics and gynaecology, King's College London
- Jenny Dunlop, senior infertility counsellor, Manchester
- Anil Gudi, consultant, Homerton Fertility Centre
- Yacoub Khalaf, consultant Guy's and St Thomas' NHS Foundation Trust
- Jenny Parker, nurse co-ordinator, CRM London
- Pip Reilly, independent fertility counsellor
- Amit Shah, consultant, Homerton Fertility Centre
- Venessa Smith, donor services co-ordinator, London Women's Clinic

**6 July 2012: presentation on 'why parents choose not to tell'**

- Lucy Blake, research associate, Centre for Family Research, University of Cambridge

**16 July 2012: meeting with Juliet (prospective parent and online survey respondent)**

**16 July 2012: meeting with Christine Whipp (donor-conceived person and online survey respondent)**

**2 October 2012: meeting on the significance of medical information from the donor**

- Tara Clancy, consultant genetic counsellor and lecturer in medical genetics, Central Manchester University Hospital
- Peter Harper, university research professor in human genetics, Cardiff University
- Efun Johnson, designated doctor for looked after children (Lambeth), Guy's & St. Thomas' Community Health Services
- Alastair Sutcliffe, reader in general paediatrics, honorary consultant paediatrician at University College London Hospitals and Great Ormond Street Hospital
- Andrew Wilkie, Nuffield professor of pathology, Weatherall Institute of Molecular Medicine, University of Oxford

- Ron Zimmern, chair of the PHG Foundation, honorary consultant in public health medicine at Addenbrooke's Hospital
- Pascal McKeown, Director of the Centre for Medical Education, Queen's University Belfast (contributed in writing before the meeting)
- Andrew Papanikitas, portfolio GP, London and Buckinghamshire, and sessional tutor/facilitator in ethics, interprofessional education and clinical communication, King's College London (contributed in writing before the meeting)

## Literature review

Kate Harvey of the staff of the Nuffield Council carried out a detailed review of existing published quantitative and qualitative research with donor-conceived people, parents of donor-conceived people, and donors, addressing the issue of the impact on them of disclosure or non-disclosure in connection with donor conception. In preparation for this review, a keyword search of PubMed and Google Scholar was undertaken, and the abstracts of 114 articles were analysed for relevance to the research question.

The Working Party would like to thank John Appleby and Lucy Blake of the Centre for Family Research, University of Cambridge, for their advice and support in connection with this literature review.

## External review

A draft version of the report was circulated at the end of October 2012 to 15 external reviewers with personal and/or professional expertise in the issues arising out of information sharing in donor conception, encompassing a diverse range of perspectives. The 15 reviewers were:

- Shirley Brailey
- Ken Daniels
- Heather Draper
- Jonathan Herring
- Jennifer Hunt
- Walter Merricks
- Petra Nordqvist
- Allen Pacey
- Liz Scott
- Francoise Shenfield
- Marilyn Strathern
- Juliet Tizzard
- Steve Wilkinson
- Andy Waters
- Clare Williams

The Working Party is very grateful to these 15 external reviewers for their detailed and thoughtful comments, which were invaluable in producing the final report.

## Appendix 2: Wider consultation for the report

The aim of the open consultation was to obtain views from as wide a range of individuals and organisations concerned with donor conception as possible. The ‘call for evidence’ was published online on 21 March 2012 and remained open until 15 May 2012. After providing details of the Terms of Reference (reproduced on page xi of this report) and a background paper, the call for evidence set out a series of questions, listed in the box below.

### Call for evidence: questions

In order to inform and support the Working Party’s deliberations, the Council would like to invite anyone with an interest (personal, professional or general) in this field to contribute views, examples and evidence within the scope of the terms of reference. The questions on which the Council is particularly interested in hearing your views are set out below. Please feel free to answer any or all of these questions, or to give your views in any other way on the issues within the scope of the terms of reference. Where possible, it would help us if you could explain the reasoning behind your answers.

1. What ethical concerns arise in the disclosure, or not, of information in connection with donor conception?
2. Is the disclosure of a child’s donor conception essentially a matter for each individual family to decide? What if there is disagreement within the family? Who else should have a role in making this decision?
3. What information, if any, do parents need about a donor in order to enable them to carry out their parenting role? Please explain.
4. What information might a donor-conceived person need about the donor, either during childhood or once they become adult? Please explain.
5. How significant is information about the medical history of the donor and the donor’s family for the health and well-being of donor-conceived offspring? Do you know of any examples or evidence in this area?
6. Where information about inherited medical risk becomes apparent after donation has taken place, who should be told, and by whom?
7. What is the impact on donor-conceived offspring of finding out about their donor conception at different ages: for example medically, psychologically and socially? Do you know of any examples or evidence in this area?
8. What is the impact on donor-conceived offspring of making contact with either the donor or any previously unknown half siblings? Do you know of any examples or evidence in this area?
9. What interests do donors and donors’ families have in receiving any form of information about a child born as a result of the donation?
10. What responsibilities arise in connection with the disclosure of information? Where do these responsibilities lie? (for example with government, fertility clinics, professionals or families?)
11. What support is required in connection with these responsibilities?
12. Do you have any other comments? Please highlight any relevant areas you think we have omitted, or any other views you would like to express about information disclosure in the context of donor conception.

At the same time, the Working Party published an online survey, using the website ‘Survey Monkey’, with the aim of asking a more limited number of questions and hence encouraging as wide a range as possible of people personally affected by donor conception to respond.

### Survey Monkey: questions

1. Should children always be told that they are donor-conceived? If so, why?
2. Who should decide whether, and if so when, to tell a child that they are donor-conceived? Is this a decision only the parents can take – or should anyone else be involved?
3. What information do the parents of donor-conceived children need about the donor to help them look after their child? Why?
4. What information about the donor do donor-conceived children need? Why?

5. What information (if any) might an egg, sperm or embryo donor want about a child born as a result of their donation? Why?
6. If a donor finds out later that they have a genetic condition, should they try to pass on this information to the child conceived with their egg/sperm?
7. What support might donors, donor-conceived children and parents of donor-conceived children need? Who do you think ought to provide it?
8. Do you have any other comments?

The Working Party received 40 responses to the call for evidence (of whom 23 were individuals and 17 were responding on behalf of organisations), and 90 responses to the online survey, three of which came from organisations who provided organisational details (Anscombe Centre, Fiom, and Hindu Council UK). A summary of the responses received from both formats is available on the Council's website, and individual responses will also be published where the Council has received permission from respondents to do so. The responses the Working Party received, in conjunction with the face-to-face factfinding meetings described in Appendix 1, were very important in shaping the deliberations of Working Party members, and the Working Party would like to express its gratitude to all those who responded.

### ***List of respondents to the call for evidence***

#### **Individuals**

Anonymous (4)

Dr John B. Appleby and Dr Lucy Blake, Centre for Family Research, University of Cambridge

Dr Thérèse Callus

Mhairi Cowden, Australian National University

Emily Engel

Group 10, Leicester Medical School (Aneesa Iram Azhar, Helen Frances Brodie, Daniel Downey, Daniel Gibson, Martin Guichard-Wheatley, Jamila Kassam, Elizabeth Frances Kershaw, Michal Konisiewicz, Immanuel Amrita Rhema)

Jennie Hunt, Senior Accredited Member of BICA

The International Donor Offspring Alliance

Dr Maggie Kirkman, The Jean Hailes Research Unit, Monash University, Australia

Maren Klotz, Lecturer, European Ethnology Humboldt University Berlin, and Honorary Fellow at the Egenis Centre, University of Exeter

Mr James Martin

Lynda Mizen

Rachel Pepa

Andrea Powell

Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester

Venessa Smith, Donor Services Coordinator, The London Women's Clinic

Tsuyoshi Sotoya, Graduate School of Social Sciences, Hitotsubashi University

Professor Marilyn Strathern

#### **Organisations** (including those who responded via the online survey)

Anonymous (1)

Anscombe Centre (via the online survey)

Australian and New Zealand Infertility Counsellors Association

Professor David Katz, on behalf of the Board of Deputies of British Jews

British Fertility Society

The British Infertility Counselling Association

British Medical Association

The Christian Medical Fellowship

Church of England: Mission and Public Affairs Council

Trustees and Steering Group of the Donor Conception Network

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Donor Sibling Registry (DSR)  
Fiom (via the online survey)  
Louisa Ghevaert, partner at Porter Dodson Solicitors & Advisors  
Hindu Council UK (via the online survey)  
Human Fertilisation and Embryology Authority  
Pride Angel Ltd.  
PROGAR (Project Group on Assisted Reproduction, British Association of Social Workers)  
Progress Educational Trust  
Department of Reproductive Medicine, St. Mary's Hospital, Manchester  
Royal College of Nursing  
Victorian Assisted Reproductive Treatment Authority

## **Respondents who submitted published material**

Dr Sonia Allan  
British Medical Association  
Mhairi Cowden, Australian National University  
Human Fertilisation and Embryology Authority  
Victorian Assisted Reproductive Treatment Authority

(NB: Some respondents submitted published material and also responded directly to questions listed in the Working Party's call for evidence document. These respondents are listed more than once in the headings above.)

## Appendix 3: The Working Party

**Rhona Knight** (chair) is a portfolio GP based in Leicester. She is a senior clinical educator at Leicester University, and is the clinical lead in the Royal College of General Practitioners' (RCGP) Health for Health care Professionals pilot programme. As a GP she has been involved in teaching practical medical ethics for many years, including the ethics of professionalism, communication and of the consultation. She has an interest in making medical ethics accessible to non-specialist audiences. She is a member of the RCGP ethics committee, a trustee of the Institute of Medical Ethics, and she chairs the Nuffield Council's Education Advisory Group.

**Wybo Dondorp** is Assistant Professor of Biomedical Ethics at Maastricht University, and his main research interests are in the ethics of reproductive medicine and the ethics of genetic screening. He has worked with the Health Council of the Netherlands, both in the past on the scientific staff (contributing to advisory reports on IVF and other forms of assisted reproduction), and currently as a member of the Council's permanent committee on population screening. He chairs the Task Force Ethics & Law of the European Society of Human Reproduction & Embryology. Recently, he was part of a research group that conducted the government-requested evaluation of the 2004 Dutch Act that put an end to anonymous donation of gametes and embryos in the Netherlands.

**Jeanette Edwards** is Professor of Social Anthropology at the University of Manchester, currently Head of Discipline Area and Vice President of the European Association of Social Anthropologists. She has a long-standing research interest in the ethnography of class, kinship and community in the north of England and has published widely on kinship and assisted reproductive technologies. She convened and directed a European, multi-disciplinary and cross-cultural project on 'public understandings' of genetics, and more recently has been developing research into religion and biotechnology in the Middle East.

**Susan Golombok** is Professor of Family Research and Director of the Centre for Family Research at the University of Cambridge, and a Professorial Fellow at Newnham College. Her research examines the impact of new family forms on parent-child relationships and children's social, emotional and identity development, with a particular focus on lesbian mother families, gay father families, single mothers by choice and families created by assisted reproductive technologies including in vitro fertilisation (IVF), donor insemination, egg donation and surrogacy.

**Anneke Lucassen** is Professor of Clinical Genetics at the University of Southampton Faculty of Medicine, and Consultant at the Wessex Clinical Genetics Service. She specialises in cancer and cardiac genetics and has a busy NHS workload. At the University she leads a research group that addresses the social, ethical and legal aspects of genetic medicine. Current research explores the familial aspects of confidentiality in genetics; childhood genetic testing; and incidental findings discovered through genetic tests. She coordinates the teaching of medical ethics and law throughout the medical undergraduate curriculum in Southampton and co-chairs the Southampton University Hospitals NHS Trust Clinical Ethics Committee. She co-founded the UK Genethics Club in 2001 which holds thrice-yearly national meetings.

**Sheila Pike** is Senior Counsellor at the Jessop Fertility HFEA licensed centre in Sheffield. She has a background in psychology and counselling, has been a specialist infertility counsellor for over 20 years and is a past Chair of the British Infertility Counselling Association. She has worked both privately and within HFEA licensed centres, counselling clients with a range of fertility issues including those considering the implications of family creation using donor assisted conception and those considering donation. She also has extensive experience of counselling clients involved in surrogacy arrangements. She is a member of the National Gamete Donation Trust's Advisory Council and an External Advisor for the HFEA.

**Rosamund Scott** is Professor of Medical Law and Ethics at the Centre of Medical Law and Ethics in the Dickson Poon School of Law, King's College London. Her background is in philosophy and law,

and her research and publications have centred on reproductive ethics and law. She has had extensive involvement in interdisciplinary research with others and in 2012 was awarded (together with Professor Stephen Wilkinson, University of Keele) a Senior Investigator Award in Ethics and Society by the Wellcome Trust to support a research programme on 'The Donation and Transfer of Human Reproductive Materials'. Other roles in policy advice and engagement include membership of the MRC Steering Committee for the UK Stem Cell Bank and, previously, the Royal College of Obstetricians and Gynaecologists' Ethics Committee.

**Laura Witjens** is Chief Executive of the National Gamete Donation Trust, having joined the NGDT in 2003 after having been an altruistic egg donor. The NGDT works closely with patients, donors, clinics and other professionals on the issues around gamete donation and since January 2013 has also been responsible for running the voluntary Donor Conceived Register. She was a member of the British Fertility Society Working Group on Sperm Donation Services and a member of HFEA Donation Advisory Group, and is currently a member of the HFEA's National Donation Strategy Group.

# Glossary

(How terms commonly used in donor conception are employed in this report.)

**Anonymous donor:** Unknown donor whose identity will not be released, either to recipients or to the person born as a result of their donation, at any point. (See also **unknown donor**, and **identity-release donor**.)

**Donor:** Provider of sperm, egg or embryo, with the aim of enabling others to create a family.

**Donor-conceived person:** Person born as a result of donated gametes or a donated embryo.

**Donor-conceived siblings:** Donor-conceived people who are born as a result of donation by the same donor, but to different recipient parents.

**Donor conception:** The creation of children through the use of donated egg, sperm or embryo.

**Identity-release donor:** Unknown donor, initially anonymous, whose identity may be made available to donor-conceived offspring when they reach the age of 18.

**Intended parents:** Prospective parents intending to create a family through a surrogacy arrangement.

**Known donor:** Donor who is known to the recipient(s) before treatment with donated gametes begins. Known donors may be longstanding friends or family, or may become acquainted with recipients through third parties such as matching websites.

**Recipients:** Prospective parents intending to create a family through donated gametes or embryos.

**Unknown donor:** Donor whose identity is unknown to recipients at the time of treatment. Unknown donors may be either **anonymous donors** or **identity-release donors**.

## List of abbreviations

<b>BACP</b>	British Association for Counselling and Psychotherapy
<b>BICA</b>	The British Infertility Counselling Association
<b>CJD</b>	Creutzfeldt-Jakob disease
<b>COTS</b>	Childlessness Overcome Through Surrogacy
<b>DCN</b>	Donor Conception Network
<b>DSL</b>	Donor Sibling Link
<b>DSR</b>	Donor Sibling Registry
<b>ECHR</b>	European Convention on Human Rights
<b>ESHRE</b>	European Society of Human Reproduction and Embryology
<b>HFEA</b>	Human Fertilisation and Embryology Authority
<b>HIV</b>	Human immunodeficiency virus
<b>HTLV</b>	Human T-lymphotropic virus
<b>IVF</b>	in vitro fertilisation
<b>JCHR</b>	Joint Committee on Human Rights
<b>NGDT</b>	National Gamete Donation Trust
<b>NHS</b>	National Health Service
<b>PROGAR</b>	BASW's Project Group on Assisted Reproduction
<b>UKDL</b>	UK DonorLink
<b>UNICEF</b>	United Nations Children's Fund
<b>UNCRC</b>	United Nations Convention on the Rights of the Child