

PRE-CONGRESS COURSE 5

# The ethics of gamete donation and information sharing

Special Interest Group Ethics and Law  
Munich - Germany, 29 June 2014







# **The ethics of gamete donation and information sharing**

**Munich, Germany  
29 June 2014**

**Organised by  
The ESHRE Special Interest Group Ethics and Law**



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# **Course coordinators**

Wybo Dondorp (The Netherlands), Guido Pennings (Belgium) and Guido de Wert (The Netherlands)

## **Aim**

The aim of the course is to present an update of the current debate about the ethics of gamete donation and information sharing between donors, parents and donor conceived children/persons. The course will provide background information (state of the art in relevant psychosocial research and expert knowledge about the importance of sharing genetic information), as well as balanced overviews of the arguments at stake in relevant parts of the ethical debate. There will be ample opportunity for discussion among the audience.

## **Background**

There is a fierce debate among policy makers, professionals and interested scholars about the ethics of gamete donation and information sharing between the parties involved. Is having children through donor conception a morally acceptable way of parenting, given that they will not grow up with their biological parents? Whereas a number of countries have in past decades decided to only allow open-identity donation, other countries continue to allow (or even require) anonymous donation. What about the ethics of these opposite policies? Is anonymous donation acceptable or should it be regarded as an infringement on the child's right to know his or her genetic roots? In countries where information about the identity of the donor is available to donor-offspring, they can only make use of this right if their parents have told them how they were conceived in the first place. But many parents decide to not tell their children. How to think about this from a moral point of view: ought parents to tell or should it be left to them to decide about the morality of disclosure? And what about the responsibility of counsellors and other professionals: should they try to convince (prospective) parents that openness is better? Finally: as the lifting of anonymity in several countries has led to a different type of donor, many of whom have a positive attitude towards possible contact, how to think about claims from donors who find that the right to information should run both ways?

## **Target audience**

The course is meant for congress participants who as professionals (gynaecologists, psychologists, counsellors) or policy makers/advisors have an interest in the debate about the ethics of the practice and policy of gamete donation.

## **Course type**

Advanced





# Scientific programme

Chairman: Wybo J. Dondorp - The Netherlands

- 09:00 - 09:30 Psychosocial aspects of gamete donation. Overview of empirical data  
**Tabitha Freeman - United Kingdom**
- 09:30 - 09:45 Discussion
- 09:45 - 10:15 Gamete donation and the sharing of medical information  
**Anneke Lucassen - United Kingdom**
- 10:15 - 10:30 Discussion
- 10:30 - 11:00 Coffee break
- 11:00 - 11:30 Gamete donation: can parental rights and duties be transferred?  
**Tom Bayne – United Kingdom**
- 11:30 - 11:45 Discussion
- 11:45 - 12:15 Is donor anonymity morally acceptable?  
**Heather Draper - United Kingdom**
- 12:15 - 12:30 Discussion
- 12:30 - 13:30 Lunch

Chairman: Veerle Provoost (Belgium)

- 13:30 - 14:00 Is not-telling the child morally reprehensible?  
**Theo Boer - The Netherlands**
- 14:00 - 14:15 Discussion
- 14:15 - 14:45 Telling or not-telling: should counsellors be directive?  
**Wybo J. Dondorp - The Netherlands**
- 14:45 - 15:00 Discussion
- 15:00 - 15:30 Coffee break
- 15:30 - 16:00 Do donors have a right to information about their offspring?  
**Guido Pennings - Belgium**
- 16:00 - 16:15 Discussion
- 16:15 - 17:00 Concluding debate session  
**Moderators: Wybo J. Dondorp - The Netherlands and Veerle Provoost – Belgium**



## Psychosocial aspects of gamete donation: Overview of empirical data

Dr Tabitha Freeman PhD  
Research Associate  
Centre for Family Research  
University of Cambridge  
UK  
trf23@cam.ac.uk



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## Conflicts of interest

None

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## Learning objectives

- (i) To outline key empirical findings concerning psychosocial aspects of gamete donation and information sharing
  - Primary focus on child wellbeing in gamete donation families based on assessment of children's psychological development and parent-child relationships
- (ii) To highlight key issues raised by using empirical data as 'evidence' in ethical debates
  - Caveats and complexities of research findings
  - Changing cultural (regulatory and ethical) context

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### Gamete donation and information sharing: Three main research areas

1. Psychosocial impact of gamete donation
2. Psychosocial impact of disclosure - and non-disclosure - of donor conception
3. Psychosocial implications of disclosure - and non-disclosure - of donor's identity

>> centrality of meaning of 'genetic relatedness'

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### 1. Gamete donation families Key findings

- Does gamete donation in itself have a negative impact on child wellbeing?
  - Does the absence of 'genetic relatedness' between a child and their parent(s) negatively affect their psychological development and family relationships?
- No. Children in gamete donation families are faring as well as (or better than) their counterparts in other family forms
  - Longitudinal comparative studies of sperm donation, egg donation, natural conception, IVF, surrogacy and adoptive families (Golombok et al. 1995 – present)

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### 1. Impact of gamete donation Example: European study

- European Study of Assisted Reproduction Families
  - 111 sperm donation, 116 IVF, 115 early adoptive, 120 natural conception
  - UK, Spain, Italy and the Netherlands from mid-1980s
  - Age 6, 12, 18
- Child development
  - No differences in emotional or behavioural problems in children conceived by sperm donation c.f. IVF, natural conception and adoption
- Parent-child relationships
  - Quality of parenting more positive in sperm donation families c.f. natural conception and adoptive families
- Similar findings for egg and embryo donation families

Golombok et al. 1995, 1996, 1999, 2002, 2002; MacCallum et al. 2007, Murray et al. 2006

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## 1. Impact of gamete donation

### Conclusions

- No evidence of absence of genetic relatedness to parent(s) having a negative impact on child wellbeing in gamete donation families
  - Gamete donation 'kids are alright'
  - Provides an important benchmark for future debates
- Quality of parenting and family environment more significant to child wellbeing than family structure
  - See also comparative studies of gamete donation families headed by heterosexual couples c.f. lesbian couples (Bos et al. 2007; Gartrell et al. 2012) and single mothers (Murray et al. 2005); ongoing work on single mother and gay father gamete donation families (Golombok, Blake, Freeman, Zadeh)

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## 1. Impact of gamete donation

### Caveats and context

- Children in early studies generally unaware of their donor origins
  - e.g. In the European Study, no sperm donation family disclosed at age 6, <10% disclosed at 12 years and, in UK follow-up, <10% disclosed at 18 years (Golombok et al. 2002; Owen et al. 2009)
  - Early studies therefore suggest that non-disclosure does not interfere with child psychological development and parent-child relationships.
- Cultural context
  - Low rates of disclosure (non-disclosure as the norm), heterosexual couples, anonymous donors, professional advice not to tell, taboos around sperm donation etc.

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## 2. Disclosing families

### Key findings

- Does parental disclosure of gamete donation have a negative impact on child wellbeing?
  - Does a child's awareness of the absence of genetic relatedness with their parent(s) negatively affect their psychological development and family relationships?
- No. Children in families where there is openness about gamete donation are faring as well as (or better/differently than) their counterparts in 'non-disclosing' families
  - Post-2000 longitudinal studies of gamete donation families (Golombok et al. 2004-present)
  - Comparative studies of disclosing and non-disclosing gamete donation families (Chan et al. 1998; Lycett et al. 2004, 2005; Freeman et al. 2012)

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## 2. Impact of disclosure

### Example: UK longitudinal study

- UK longitudinal study
  - 50 sperm donation, 51 egg donation, 42 surrogacy, 80 natural conception
  - 2000 onwards, age 1, 2, 3, 7, 10

#### Preschool years

- Child development
  - No differences in emotional and cognitive development between children conceived by sperm and egg donation c.f. natural conception
- Parent-child relationships
  - More positive parent-child relationships in sperm and egg donation c.f. natural conception families

Golombok et al., 2004, 2005, 2006

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## 2. Impact of disclosure

### UK longitudinal study

#### Middle childhood

- Rates of disclosure
  - 46% of sperm donation parents and 56% egg donation parents *intended* to tell child. At age 7, only 28% of sperm donation parents and 41% of egg donation parents had disclosed
- Parent-child relationships
  - More positive relationships in disclosing than non-disclosing families: non-disclosing gamete donation families showed less positive mother-child interaction and higher levels of mothers' emotional distress
- Child development
  - Children continued to function well in early school years. Children who were aware of their donor conception *and whose mothers were distressed* showed higher levels of emotional problems at age 7 but not at age 10

Golombok et al. 2011, 2013; Readings et al. 2011

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## 2. Impact of disclosure

### Example: Adolescence study

- Small UK study
  - 46 sperm donation families

#### Aged 4-8 years

- Rate of disclosure
  - 13% of parents had disclosed
- Parent-child relationships
  - More positive relationships in disclosing than non-disclosing families: less mother-child conflict
- Child development
  - No differences in psychological development between disclosing and non-disclosing families

Lycett et al. 2004, 2005

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## 2. Impact of disclosure

### Adolescence study

Aged 10-14 years

- Rate of disclosure
  - 33% of parents had disclosed
- Parent-child relationships
  - Disclosure continued to be associated with more positive family relationships : less mother-son conflict. Adolescents who were aware of their donor origins reported less warmth in their relationship with their father but they also reported the relative unimportance of the lack of genetic relatedness with him
- Child development
  - Continued to be no differences in psychological adjustment between disclosing and non-disclosing groups

Freeman et al. 2012. See also Casey et al. 2013

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## 2. Impact of disclosure

### Caveats and complexities

When interpreting differences between disclosing and non-disclosing families, it is essential to bear in mind that ....

- Differences are not indicative of dysfunction
  - Variation all within normal range
- Differences cannot necessarily be attributed to parents' disclosure decisions
  - May reflect other differences in families (e.g. disclosing families may be more open generally) rather than being directly caused by disclosure/non-disclosure
- Differences are not great
  - Differences in parent-child relationships not reflected in children's psychological wellbeing
  - Differences may change over time (e.g. identity issues and tensions in parent-child relationships more salient during adolescence)
- Limitations of studies
  - Sample size (esp. low numbers of disclosing families) and measures

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## 2. Impact of disclosure

### Caveats and complexities

- Most research has focused on children's response to first disclosure in early childhood
  - Varying impact of disclosure over time – a process not an event
  - Children's level of understanding of - and interest in - donor conception changes
  - At early age, children have limited understanding of process and implications of egg and sperm donation (Blake et al. 2010)
  - Impact at gamete donation at adolescence and beyond?
- Limitations of categories 'disclosed' c.f. 'non-disclosed'
  - Fluctuations towards both secrecy and openness (Freeman in press)
  - High levels of 'partial' disclosure (Readings et al. 2011; Freeman et al. 2012)

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## 2. Impact of disclosure

### Caveats and complexities

- Age, manner and circumstances of disclosure are significant
  - Early disclosure associated with more positive outcomes (ideal to have 'always known')
  - Experiences of those who are told, or find out about, their donor conception in adolescence or adulthood is strikingly different: more likely to feel upset, angry, shocked and confused than those told in childhood (Jadva et al. 2009)
  - Some donor-conceived individuals report that secrecy about the nature of their conception caused them severe psychological harm and felt angry and deceived by their parents (Turner et al. 2000)

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## 2. Impact of non-disclosure

### Cultural shifts in UK

- Shift in concern about impact of telling children to impact of not telling children
  - Concern about secrecy arising from adoption research
    - open communication about adoption between adoptive parents and child is important for positive parent-child relationships and child wellbeing (Brodzinsky 2006; Grotevant et al. 2005)
  - Family therapy perspective
    - child's awareness and negative impact of family secrets (Imber-Black 1998)
- Increased openness around donor conception
  - Professional advice from parental secrecy to encouraging openness
  - Emerging consensus that disclosure is in child's best interests
  - Removal of donor anonymity from 2005
- Emphasis on 'genetic identity'
  - Right to knowledge of 'genetic origins' (Appleby et al. 2012; Freeman et al. in press)

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## 2. Impact of non-disclosure

### Conclusions and caveats

Comparative studies between disclosing and non-disclosing families do not provide evidence that parents' disclosure decisions in themselves have a detrimental impact on child wellbeing

- HOWEVER.... non-disclosure carries risk of 'accidental' disclosure which may have negative outcomes
  - Discovery through telling by other family member or friend, argument/divorce/death, genetic testing etc.
  - Discovery of donor conception at later age, esp. under adverse circumstances, can have negative outcomes
  - No disclosing parents report regretting telling their child; some non-disclosing parents report regretting not telling when their child was younger (Freeman in press)
- Whether or not parents disclose remains an ethical question
  - Empirical research is concerned with what 'is' c.f. ethical debate is concerned with what 'ought' to be
  - Limitations of empirical data

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### 3. Impact of disclosure of donor's identity

Two areas of research re. psychosocial implications of gamete donation concerning donor identification:

- Children's response to disclosure of donor conception
  - Are children interested in the identity of their donor?
- One potential outcome: contact between 'donor relations'
  - What happens if donor-conceived individuals make contact with their donor?
  - What happens if there is contact between families who share the same donor?

>> Increasing research focus on network of relationships created through gamete donation, incl. donors' perspectives

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### 3. Children's perspectives - during childhood UK longitudinal study

- Children told about their donor conception in preschool years responded neutrally or with curiosity rather than distress
- However, they appeared to have little understanding of egg or sperm donation by age 7. By age 10, most could give a clear account of the nature of their conception

*'My dad couldn't really make the seed so had a seed from a special man who gave one up.'* (child age 10, sperm donor-conceived)

*'[My mum] had the eggs put into her and then my dad's sperm mixed it up and then I got created, and then she said like, about all the particles and stuff that like, run about and make stuff.'* (child age 10, egg donor-conceived)

- At age 10, most children had positive feelings about their donor conception, but tended not to discuss this with friends and family, with some reporting feeling embarrassed about this

Blake et al. 2010, Readings et al. 2011

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### 3. Children's perspectives - during adolescence Adolescence study

- Most adolescents expressed neutral or positive feelings about their donor conception

*'I just felt the same. It doesn't make a difference how I got here. I was just made.'* (child age 12, sperm donor-conceived)

*'When you're young everything's new to you so it's just one more thing that you just accept.'* (child age 14, sperm donor-conceived)

- All understood and minimised the significance of their lack of 'genetic relatedness' with father

*'He is always going to be my dad.'* (child age 11, sperm donor-conceived)

Blake et al. in press; Freeman in press

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### 3. Children's perspectives - during adolescence

#### Adolescence study

- Feelings about donor: little interest or some curiosity  
*'I was quite surprised when my mum told me. But then I thought, hang on, my dad's not my physical dad, but ... he is the one who has looked after me over the years and he has like comforted me, played with me and brought me up... I don't really think about who the donor is, I think more that my dad's my dad now because he's looked after me and that's all that really matters.'* (child age 12, sperm donor-conceived)
- 'I'm curious but on the other hand I don't really want to know about him [the donor] because it doesn't really affect me at all.'* (child age 12, sperm donor-conceived)

Blake et al. in press; Freeman in press

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### 3. Children's perspectives on the donor

#### Conclusions and caveats

- Children appear to be able to assimilate information about their donor conception if told from a young age
- Some, but not all, sperm-donor conceived individuals may be interested in their donor
  - Often motivated by curiosity about resemblances (e.g. physical appearance, personality) and identity issues rather than relationships
  - Parallels with adoption: increased interest in origins at adolescence but variation in extent to which being adopted is central to an adolescent's identity; searching for birth relatives is important to some but viewed as irrelevant by other
- Much research focuses on children in heterosexual couple families conceived by anonymous sperm donation
  - Influence of family type (heterosexual couple, lesbian couple, solo mother) on likelihood of disclosure and perception of donor
  - Some recent studies on children with identifiable donors (formerly anonymous donors or identity-release donors)
  - NB. Identity-release donation does not necessarily lead to parental disclosure

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### 3. Contact between offspring and donor

#### Example: Donor Sibling Registry (DSR) studies

- 165 sperm donor-conceived offspring age 13-61 years
- 58% heterosexual couple, 23% solo mother, 15% lesbian couple families
- Main reason for searching for donor was curiosity. Although many wished to meet their donor, not one gave the wish to form a relationship with him as their main reason for searching

Jadva et al. 2010

See also Scheib et al. 2005. Small study of adolescents with identity-release sperm donors: most were curious about the donor and planned to request identifying information and pursue contact, but only 10% reported that he was an important person in their life and only 7% wanted a father-child relationship

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### 3. Contact between offspring and donor

- Mostly positive experiences of making contact with sperm donor

*'She always wanted to meet her biological father... When he sent his picture my daughter was so happy to see that she looked exactly like him.... She likes the fact that he has made her feel welcome with his family and now we have larger extended family. She can complete the other side of her family tree.'* (mother of sperm donor-conceived child)

*'I used to think of the donor as sort of a super-human... perfect in a lot of ways (based on knowing he was chosen out of a catalogue). Now I know he's just a normal guy.'* (age 19, from lesbian couple family).

Jadva et al. 2010, Freeman et al. 2009, in press

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### 3. Contact between offspring and donor

- Some negative outcomes

*'I did not meet my biological father. I only exchanged a few letters with him. His responses were clear that although he's glad that I was born, he is not proud to have participated in donor conception... It is a pretty bad feeling that my life has been such a source of shame and embarrassment, through no fault of my own, by the people who brought me into the world.'* (age 40, from heterosexual couple family)

See also work on donor-linking (mediated contact) in Victoria, Australia

- Variation in experience: negative outcomes attributed to factors including:
  - No discussion of expectations
  - Boundary confusion (esp. sexual)
  - Not involving/communicating with other family members

Jadva et al. 2010, Freeman et al. 2009, in press

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### 3. Contact between families who share the same donor: DSR studies

- Again, overwhelmingly positive findings reported
  - 85% of offspring reported positive experiences of meeting 'donor siblings'

- Exceeding expectations

*'I was actually just curious about what the sibs might be like... After connecting with the other moms it turned out to be a more wonderful experience than I'd imagined... We've become a family of sorts of our own and share a special bond.'* (mother of sperm donor-conceived child)

- Close kinship attachments

*'we are all now one big family', 'a family of close friends', 'a very large extended family'.*

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### 3. Contact between donor relations

- Complexities of information sharing: new issues re secrecy and disclosure
  - Disclosure and sharing of information amongst different families
  - Mismatch of expectations
  - Limiting numbers of donor relations known

- Problem of terminology – what to call each other?

*'I am not sure what you call the relationship. It doesn't really have a name...being called a 'sperm donor' is dreadful! I think it's even worse for the biological offspring of sperm donors. They can be called biological children or biological offspring. I don't know what to call them either.... Words for relations and friends are deeply embedded in our language and psyche so with something odd like this it's really hard to know how to describe it.'* (sperm donor)

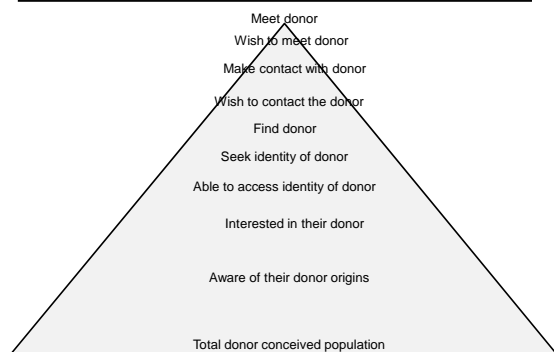
*'My sons are still so young that they don't quite register the meaning of sharing a donor with this other little boy they sometimes play with. My oldest knows this other boy has the same donor and that it is important, but he has not attached the word "brother" to him yet.'* (mother of sperm donor-conceived children)

### 3. Contact between donor relations Conclusions and caveats

Although contact between donor relations can be positive, very little is currently known about the outcomes

- Most research to date has focused on
  - *Motivations* for searching rather than *process* of making contact
  - Contact between *donor siblings* rather than *donor* and *offspring*Blyth 2012; Jadva et al. 2010; Freeman et al. 2009; Scheib et al. 2008; Hertz et al. 2011
- Limitations of research
  - Self-selected samples, snapshots of experiences
  - Lack of qualitative research
    - need for in-depth interviews following up development of relationships over time
    - meanings from perspectives of those involved
- Very few studies report on face-to-face meetings between donor relations
  - Current research: in-depth interviewing about experiences of contact

### Caveat: The tip of the iceberg



## Conclusions

- Impact of gamete donation
  - Absence of genetic relatedness between parents and children does not have an adverse affect on quality of parent-child relationships and child development in childhood
  - Little known about adolescence and beyond
- Impact of disclosure – and non-disclosure – of gamete donation
  - Child's awareness - or lack of awareness - of absence of genetic relatedness with parent(s) does not have an adverse affect on child wellbeing. However, donor-conceived people's feelings about their origins may change over the life course and non-disclosure always carries the risk of accidental discovery
  - Early disclosure is associated with positive outcomes: donor-conceived children whose parents talk to them about their donor conception from an early age seem to integrate this information into their developing sense of identity
  - Donor offspring who find out about their donor conception in adolescence or adulthood are more likely to react negatively

## Conclusions

- Implications of disclosure - and non-disclosure - of donor's identity
  - Some evidence that rates of disclosure are rising but many parents still do not disclose to their children
  - For those children who are aware of their origins, some may be interested in finding out about their donor
  - The significance placed on knowing the donor's identity is shaped by complex and sometimes contradictory individual and cultural meanings attributed to 'genetic relatedness'
- Gamete donation children and families are functioning well
  - >> genetic relatedness is less important than quality of parent-child relationship
- However, searching for the donor and other 'donor relations' does seem to be important for some
  - >> insignificance of genetic relatedness re parent-child relationships c.f. significance of genetic relatedness re donor and 'donor siblings'

## Conclusions: cautious and critical approach to empirical data

- Wary when asked for 'the evidence'
  - Example: debates around limits on donor offspring numbers
  - Arguments for (e.g. Sawyer 2010) and against (e.g. Janssens et al. 2011) lowering limits post-donor identification
- Difficulties of presenting interests/perspective of 'the child'
  - Variation re. individual and cultural circumstance
- Differences and similarities of egg and sperm donation
  - Most evidence is concerned with sperm donation but discussion often of 'gamete donation'
- Significance of language of policy/ethical/regulatory debates
  - E.g. meaning of 'genetic half sibling'
- Importance of qualitative research on parents', children's and donors' perspectives to understand meaning ascribed to relatedness

## Acknowledgements

Thank you

Empirical data presented from studies headed by Prof Susan Golombok, Centre for Family Research, UK. Funders include the Wellcome Trust and the Nuffield Foundation.

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## Gamete donation and the sharing medical information

Prof Anneke Lucassen DPhil FRCP  
Southampton UK

**ESRE 29 June 2014**

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## Conflicts of interest

I am not aware of any conflicts of interest but for information I note my membership of committees (which are non-renumerated) that have an interest in this topic:

1. UK's Nuffield Council of Bioethics and member of its working party on donor conception (report published April 2013)
2. Human Fertilisation and Embryology Authority panel on mitochondrial treatments
3. Genomics England Ethics advisory committee
4. British Society of Genetic Medicine policy and ethics committee
5. Wellcome Trust Ethics and Society panel Expert review group

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## Learning Objectives

- Develop knowledge and understanding of the ethical and legal issues involved in the sharing of medical information with gamete donors and recipients
- Explore how rhetoric of genetic determinism influences perceptions around information sharing
- Explore the language of 'right to know' or 'not to know' in this setting
- Explore how conflicts/tensions between different parties may be resolved in practice
- Justify the actions that you would take after exploring ethical and legal dilemmas in clinical practice

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What do my genes say about me?



“Everything”  
“my identity”  
“predict the future”

↕

“not very much”  
“don’t think they  
really know yet”

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The Telegraph

HOME > SCIENCE > SCIENCE NEWS

Life of crime is in the genes, study claims

Lifelong criminals could be genetically programmed to break the law, a study claims.

HOME NEWS WORLD SPORT FINANCE COMMI

Politics

Obitu

Education

Earth

Science

Defence

Science News

Space

Night Sky

Roger Highfield

HOME > SCIENCE > SCIENCE NEWS

Studying Adam Lanza: is evil in ou

Studying the DNA of gunman Adam Lanza could revv

spree killers. Why are so many scientists against it?




• Genes and

• behaviour

Southampton: [www.soton.ac.uk/cels](http://www.soton.ac.uk/cels)

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Genes and science



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Direct to consumer genetic testing

this is my

Health Screening & Ultrasound Centres

Baby

DNK

Fertility

Body

this is my: Gene 100+ UK L

New all inherited

Counsyl

One Test for 10

Each year, millions of unsuspecting people are diagnosed with genetic diseases, such as cystic fibrosis. While these diseases cannot be cured, early diagnosis is recommended to be offered to at-risk groups for maximum safety. Learn more about each of the diseases.

GENOME SCAN

One Test for 10

Register

Medical Professionals

Register Now

Register

Medical Professionals

Register Now

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Language of genetics

Personalised: Tailoring interventions and treatments for the individual based on their genetic code.

Familial: genetic code to some extent shared with others. When/ how to alert relatives; give them ability to make informed decisions?

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Genes and Medicine

Her mother died of cancer


NEWS

Gene test spares mother surgery

By Cella Hail Medical Editor

WOMAN who decided to have her breasts removed rather than risk developing cancer has avoided surgery thanks to the discovery of a gene.

Healthy and happily married with a baby and a two-year-old, Annmarie Blomfield was within weeks of surgery when she was advised that the discovery of a BRCA2 gene would lead to a test to establish her risk of developing breast cancer.



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Page 26 of 84

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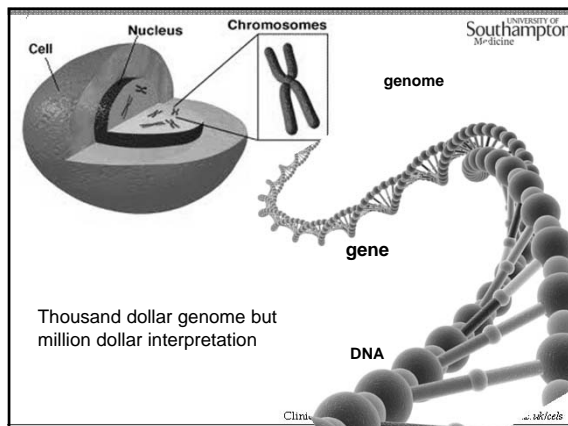
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### Common diseases

- Complex combination of gen variation
- Each alone small effect

17

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High risk gene faults  
Clear test results

Many different genetic  
-and other- factors

One test result gives  
limited information

18

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Case 1: Rare form of inherited bowel cancer

- John diagnosed with bowel cancer aged 30
- Gene test shows he has a faulty gene
- John has 5 siblings, 11 nephews and nieces, 10 aunts and uncles; 23 cousins....
- When he was a medical student he donated sperm...
- Should they be told?

19

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Should John's family be told that they could have a gene test?

Members of the public n=121

81%	1. Yes
0%	2. No
19%	3. Unsure

Health professionals n=108

54%	1. Yes
12%	2. No
34%	3. Unsure

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Should John be responsible for telling his relatives?

Members of the public n=121

36%	1. Yes
52%	2. No
12%	3. Unsure

Health professionals n=108

76%	1. Yes
6%	2. No
20%	3. Unsure

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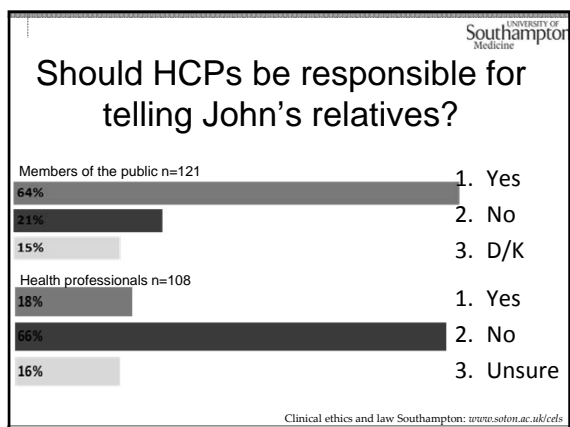
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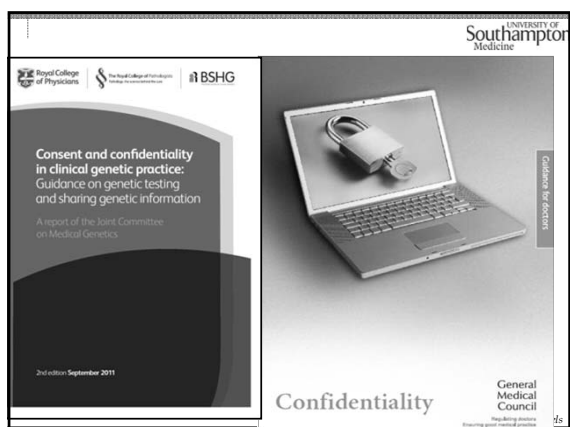
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General Medical Council Regulating doctors, ensuring good medical practice

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News centre  
News archive

You are here: Home > News centre > News archive > Doctors told to warn patients of genetic risks

Doctors told to warn patients of their genetic risks

Press Release

From The Times  
September 26, 2011

Genetic disease patients may lose privacy rights to protect families

**Urgent Changes Needed To Patient Confidentiality Laws To Prevent Breast Cancer Deaths JAMA 2009**

Special  
Should patient confidentiality come second to the prevention of disease in others?

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### Case 2: Unexpected information?

- Kylie (3) has learning difficulties and some ‘features’ suggesting she might have a genetic problem
- Genetic testing finds no explanation for her problems but does find a gene that means she is likely to develop breast cancer as an adult.
- No early checks for another 20+ years. The chance of cancer in the next 20 years is 0

25

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### Should Kylie’s parents be told now about her adult risks?

Members of the public n=121

66%	1. Yes
23%	2. No
11%	3. Unsure

Health professionals n=108

61%	1. Yes
27%	2. No
12%	3. Unsure

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### Case 3: complex information



- Mark, sperm donor to 3 families
- No known family history of disease at time of donation
- Subsequently discovers several family members have heart disease
- Should families be told?

Donor conception: ethical aspects of information sharing

NUFFIELD COUNCIL ON BIOETHICS

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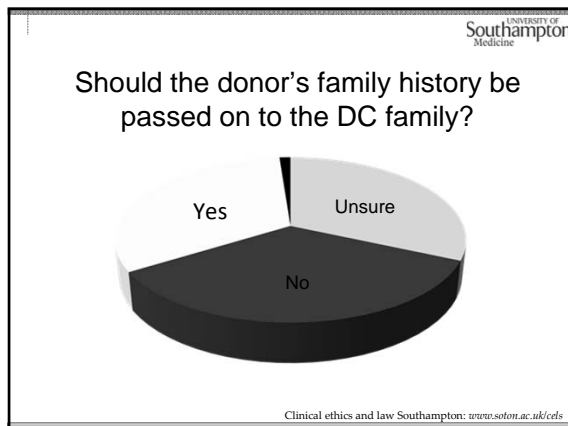
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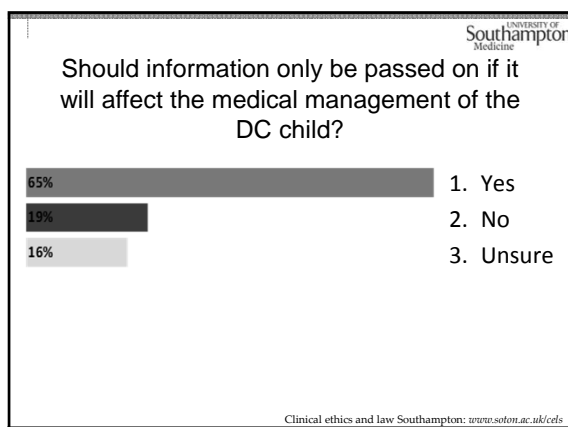
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Case 4: mismatched expectations

- Sperm donor
- CF screen at time donation negative
- Subsequently discovers has 'rare' mutation
- ACU tell donor family (children aged 4 and 6) to 'get children tested'
- Fact of donation has not [yet] been disclosed to children. Parents request secret testing
- Guidance on genetic testing of children suggests defer testing since results give information about reproductive risks

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## Case 5: communication back to donor

- 5 year old girl conceived through use of egg donor
- Developmental delay investigated with aCGH
- Deletion encompassing large portion of the Duchenne muscular dystrophy gene on chromosome X
- Girls carriers; boys affected
- Possible relevance for donor if has sons
- Donor contacted and tested. Deletion was de novo

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## Genomes are “inferentially fecund”

O'Neill and Manson 2005

(capable of producing an abundance of offspring or new growth; highly fertile)

The meaning of information is critically dependent on context and on the understanding of the person to whom the information is conveyed.

Many different types of information, varying certainties, unclear how interact

Yet popular representations of genetic ‘blueprint’; clear answers; knowledge is power; “information contained within” DNA

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## Joint account model

- Information should be available to account holders unless good reasons to do otherwise
- Emphasis reversed: Will disclosure cause harm to relatives? not whether they would be harmed by non-disclosure
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*Parker and Lucassen BMJ 2004*  
*Lucassen et al E J Hum Genet 2005*  
*Lucassen and Parker Lancet 2010*

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Clinical ethics and law Southampton: [www.soton.ac.uk/cels](http://www.soton.ac.uk/cels)

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SWF seeks sperm donor with genetic code:

TTG CTA AGC TGA GGT ATG CTT  
TAA CCG GCA TGT AAC GAG GAC  
ATA CCC CAG ACG TGC CAA ACT  
TGG TAT AGT AGA TGA CTA GAG

Must have no FH heart disease, diabetes, cancer, mental illness

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## Conclusions

- Sharing of medical information between gamete donor and recipients very important in some cases/ Not at all important in others!
- Considered clinical judgement important +/- MDT discussions such as genetics
- Some of these decisions will not be amenable to clear up-front consent, nor vetoes
- Consider whether disclosure of genetic information is utilising confidential information about one person or is informing an at-risk group about their risk.
- Clinical genetics community can and should deliver helpful guidance for communication of medical information in donor conception

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Page 34 of 84

## **Gamete donation: can parental rights and duties be transferred?**

Tim Bayne, Ph.D (2002)

Professor of Philosophy  
Department of Philosophy  
University of Manchester  
tim.bayne@manchester.ac.uk

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I have no commercial or financial relationships with any manufacturers of pharmaceuticals, laboratory supplies and/or medical devices.

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### **Learning objectives**

- To understand the main arguments that have been given for thinking that Gamete Donation (GD) is morally problematic
- To understand some of the main responses that have been made to those arguments, with particular emphasis on questions relating to the grounding of parental rights and duties.

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I will focus on *moral* objections to gamete donation rather than *legal* objections to it.

"Gamete donation is almost always morally wrong" - David Benatar (1999)

"Sperm donation poses a serious moral problem" - Rivka Weinberg (2008)

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### The structure of the objection

(1) Gamete donors have parental responsibilities towards the offspring that result from their act of gamete donation. ("responsibility principle")

(2) Gamete donors behave immorally or recklessly in transferring their parental responsibilities. ("transfer principle")

(C) Gamete donors behave immorally or recklessly ("without moral seriousness" - Benatar).

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(1) Do GD have presumptive parental responsibilities w/r/t 'their' offspring?

(2) If so, do they behave immorally/recklessly in transferring those responsibilities to others?

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## the responsibility principle

In order to evaluate the responsibility principle, we need to ask what grounds *parental responsibility* (PR).

It is tempting to assume that parental rights and responsibilities have a shared ground, although that claim has been contested (see Archard 2010).

There are a number of accounts of parental responsibility (PR), and the literature on the topic is complex and often confusing.

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The legal determination of parenthood is complex:

- In the US, a pregnant woman's husband is generally presumed to be her child's legal father.
- But US courts have removed children from their adoptive families and returned them to their genetic fathers (Hubin 2003).
- The Ontario Court of Appeal has recognized three legal parents (*A.A. v. B.B.*, 2007 ONCA 2)—a lesbian couple and sperm donor.
- Hereditary titles in the UK are determined by genetic parentage.

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## Parental Responsibility (PR)

*Genetic account* (Hall): PR accrues to the genetic parents.

*Gestational account* (Rothman): PR accrues to the gestational mother (and those appropriately related to her).

*Voluntaristic account* (Brake): PR accrues to those who (intend to) take on the parental role.

*Causal account* (Archard): PR accrues to the cause(s) of the child.

*Autonomy account* (Benatar): PR accrues to those who have reproductive autonomy w/r/t the relevant gametes.

*Control account* (Weinberg): PR accrues to those who have rightful control over the relevant gametes.

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On the genetic account gamete donors **clearly have** parental responsibilities  
On the gestational and voluntaristic accounts gamete donors **clearly lack** parental responsibilities  
And it is **unclear** whether gamete donors have parental responsibilities on the causal, autonomy, or control accounts.

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The genetic, gestational and intentional relations can dissociate from each other.  
*Case Study:* Andrew & Bridget intend to start a family. With this in mind, they acquire gametes from Charlotte and Dinesh, and hire gestational surrogate Eve in order to carry the resulting embryo to term. To whom should parental responsibilities be assigned?

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## Geneticism

The self-ownership argument (Hall): the genetic parents provide the constitutive material, and this grounds their claim to parenthood rights and responsibilities.

Replies:

- Even if one has property-rights in one's gametes, doesn't follow that one has property-rights in what one's gametes compose.
- Doesn't the child's self-ownership defeat any ownership claims the parents might have?
- Parental claims are not property claims.

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## Geneticism

"By upholding a system of involuntary (genetic) ties of obligation among people, even when the adults among them prefer to divide their right and obligations in other ways, we help to secure children's interests in having an assured place in the world. The genetic principle also places children in a far wider network of associations and obligations than the consent-intent rule sanctions. It supports the roles of grandparents and other relatives in the nurturing of children, and provides children with a possible focus of stability and an additional source of claims to care if the parents cannot sustain a well-functioning household."

Anderson 1990

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## Geneticism

I find Anderson's line of thought rather persuasive, but those who defend a voluntaristic approach to the grounding of special moral relations (see below) would reject it.

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## Gestationalism

*The relationship argument:* "Any pregnant woman is the mother of the child she bears. Her gestational relationship establishes her motherhood . . . [Children] enter the world in a relationship, a physical and social and emotional relationship with the woman in whose body they have been nurtured." (Barbara Katz Rothman)

*An objection:* "Special rights have a habit of being accompanied by special responsibilities" – Purdy.

Rothman's argument might have implications for abortion that many would not welcome

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## Gestationalism

The 'Sweat equity' argument: pregnancy – not to mention childbirth – is hard work. The gestatory mother has a right to 'the fruits of her labour'.

*Reply:* This argument concerns parental rights not responsibilities.

The 'identifiability argument: The gestational mother is guaranteed to be identifiable at birth

*Reply:* True, but it's not clear that we should base an entire account of parental responsibility on this consideration

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## Gestationalism

The problem of paternity: "If men want to have children, they will have to either develop the technology that enables them to become pregnant (and so be 'legal' mothers of children they gestate themselves) or have children through their relationships with women."

Barbara Katz Rothman 1989

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## Voluntarism

"voluntary acceptance of moral parental obligations is necessary, but not sufficient, for those obligations" (Brake 2010).

Brake defends voluntarism by appeal to the idea that parental obligations are a species of special obligations, and that special obligations are acquired only through voluntary undertaking or as compensation for some harm

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## Voluntarism

One response to Brake's argument rejects her claim about how special obligations are acquired on the grounds that it fails to do justice to the special obligations we have to family members (grandparents, siblings). (Cf. Anderson's defence of the genetic approach)

Another response would be to claim that the special obligations of parenthood are acquired as compensation for the harm of bringing individuals into existence.

Brake responds by claiming the parental responsibilities far outweigh compensatory responsibilities.

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## Causalism

Parental rights and responsibilities ought to be ascribed to ascribed to the individual(s) who are causally responsible for the child's existence:

But who is causally responsible for the child?

- The commissioning couple?
- The gamete donors?
- The gestational mother?

Causalism invites a *pluralistic* approach to parenthood, although one might argue that the commissioning couple are the primary cause of the child's existence.

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## Reproductive Autonomy

Parental Responsibility accrues to those who have reproductive autonomy w/r/t the relevant gametes.

But why think that reproductive autonomy generates parental responsibility? (Consider someone who becomes pregnant despite using contraception.)

The key question concerns who has reproductive autonomy over the gametes in question—should we be allowed to transfer legitimate control over our gametes to other individuals?

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## The Control account

"...parental responsibility is derived from our possession and high degree of control over hazardous material, namely, our own gametes. Our gametes are dangerous because they can join with the gametes of others and grow into extremely needy persons with full moral status. ... gamete owners are comparable to owners of pet lions or enriched uranium. Dangerous possessions under our voluntary control—e.g. enriched uranium, viable sperm—generate an extremely high standard of care. When we choose to engage in activities that put our gametes at risk of joining with others and growing into persons we assume the costs of that risky activity." (Weinberg)

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## Responsibility Principle

But the question is whether control over one's gametes can be legitimately transferred to another without generating even presumptive parental responsibilities.

From parental responsibility to its transfer: when might parental responsibilities be permissibly transferred?

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## the transfer principle

"Some responsibilities—including some that pertain to child-rearing—are such that even if others are as competent as oneself to perform them, one manifests a lack of seriousness about the responsibilities if one is happy to transfer them to others." (Benatar)

Example: Taking one's sick child to the hospital.

Objection: Such cases typically occur in the context of a close interpersonal relationship, which is missing in gamete donation.

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### the transfer principle

"If a child's basic needs include the need to be loved, it is unclear to me that a responsibility of this kind—a responsibility to relate with a particular feeling towards another person—can be coherently transferred. When we promise to love our spouses in sickness and in health, can we fulfil this promise by transferring it to someone else?" (Weinberg)

Response: It seems implausible to claim that GD make a *promise* to the child in question – even an implicit one.

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### the transfer principle

"Even if parental responsibility could be fulfilled by seeing to it that one's child is adequately raised, most sperm donors do not meet that standard."

This is plausible, although a lot depends on one's conception of what it for a child to be 'adequately raised'.

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### the objection from adoption

If parental responsibilities can be transferred in cases of adoption why not in cases of gamete donation?

Weinberg and Benatar argue that there are important disanalogies between the cases:

1. "Adoption is usually a *post facto* solution to the problem of a child whose parents cannot or will not care for it."
2. "Parents who relinquish their children for adoption may do so as an expression of their love for the child, it is hard to see how sperm donation could be an expression of love."

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## The objection from adoption

"Parents who relinquish their children for adoption may do so as an expression of their love for the child, it is hard to see how sperm donation could be an expression of love. 'I loved you so much that I released you to a family more capable of caring for you' a parent who has relinquished a child for adoption may say to her biological child. But what comparable statement can a sperm donor make? 'I loved you so much that I donated (or sold) the gamete from which you grew to someone else?'" (Weinberg)

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## Conclusion

There is no consensus regarding the force of the moral objection to gamete donation.

It is debatable whether gamete donors have presumptive parental responsibilities, and also whether gamete donors act immorally ("without moral seriousness") in transferring those responsibilities to other individuals.

Finally, note that even if it is successful on its own terms, it is unclear what the *legal* implications of the moral objection to gamete donation would be.

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## **Is donor anonymity morally acceptable?**

Professor Heather Draper PhD  
University of Birmingham  
h.draper@bham.ac.uk

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## **Conflicts of interest**

None to declare

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## **Learning outcome**

- To gain a working understanding of some of the ethical arguments for and against donor anonymity

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## Structure of session

Conclusion towards which I will be arguing is  
'Yes, but...'

- Look at some of the arguments against donor anonymity and their weaknesses
- Look at what 'morally acceptable' means in the light of these weaknesses
- Outline the 'but...' aspects

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### I. Arguments against donor anonymity 1. Interests of donor conceived individuals

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- Should break this group down into two:
  - Minors
  - Adults
- This is useful to avoid the temptation to see this as solely as an issue tied to the welfare of a child – where child means a vulnerable minor
- Minors occupy a special place in ethics and law
  - For instance in the UK the interests of children are considered paramount in any judicial decision-making

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- So we might distinguish between arguments that object to donor anonymity with respect to donor conceived individuals (DCIs) when they are minors and claims made by DCIs as adults
- For instance, in UK law, DCIs are only entitled to access to identifiable information once they are adults

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- Yet we might suppose that if there is a strong arguments based on the interests of minors against donor anonymity, it would be DCI minors who were entitled to access this information rather than DCI adults
- So what interests might minors have that speak against donor anonymity?

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- Interest in being protected from any harmful consequences of being donor conceived – for example:
- 1. Medical interests
  - Investigation and treatment (if possible) of genetic conditions & tissue transplantation
- 2. Being raised well to adulthood
  - In loving relationship with parents and other family members

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## 1. Medical interests

- Need for genetic information
  - But does this need to be identifiable information?
  - To whom does it need to be identifiable?
  - When does it need to be made available?
- Tissue transplantation
  - Is there a reasonable expectation that, if identifiable, the gamete donor (or further member of his/her family) would also be a willing donor of other tissue ?
  - Issues of identifiable to whom and when also apply in this case

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## 2. Being raised well to adulthood

- Minors can be damaged by information about donor conception
  - E.g. When told in anger or out of spite
- But should separate openness, timing and manner of openness in relation to circumstances of conception from issue from donor anonymity
- Minors are best raised by their parents
  - This begs question about who or what a parent is
  - (Previous session discussed transfer of responsibility)
  - General argument against use of donor gametes rather than argument in favour of identifiable donors
  - Not obvious that identifiable donors are expected to raise the resulting child – counter-productive?

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- Harmful consequences of being donor conceived may actually result from openness
  - E.g. Undermine relationships with wider family
  - Undermine parental authority
- But (again) it is openness (and manner of openness) about donor conception rather than the identity of the donor which is the issue here
  - It could be possible to conceive of circumstances where the identity could itself exacerbate these kinds of problems, however.

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DCI as adults – do they have interests that speak against donor anonymity?

- NB adult/adult weighing of interests now
- Medical interests – as for minors
  - (see above)
  - 1. Some DCI really want to know
  - 2. Equal treatment with people who have been adopted
  - 3. Genetic information matters sufficiently to create an interest

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1. Really want to know

“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.” (Nuffield Council on Bioethics 2013)

Are these reasons sufficient to create an *interest* in knowing?

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2. Equal treatment with adopted people

- Seems to have been at least in part a driver for UK change of policy
- But was this a fair comparison?

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3. Genetic information matters sufficiently to create an interest

- Genetic-relatedness and parental responsibility
  - Adult/minor distinction again here
  - Transfer of responsibility issue again
- Genetic-relatedness and family beyond parents
  - Genetic v social family (again)
  - Being deprived of a family v having the family one has (whatever its size)
    - Do we have a over-riding interest in having siblings/grandchildren/ nephews or nieces etc?

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Summary

4 important points

1. Paramountcy of welfare of child (minor) doesn't really come into play
2. Distinction between openness and identity
3. Being clear about what gives someone an interest
4. Being clear about whether/why genetic information is important

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**1. Arguments against donor anonymity**

**2. Donors' responsibilities**

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Gamete donors retain (some) (parental) responsibility?

– See previous session on transferring parental responsibility

1. Parental responsibilities and genetic-relatedness
2. Responsibilities and genetic-relatedness
3. Responsibilities related to donation
4. Exercising responsibilities anonymously

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### 1. Parental responsibility and genetic relatedness

- Once a parent always a parent?
  - Some distinctly parental responsibilities retained even if legal responsibilities transferred
  - Unclear what the content of such would be – e.g. 'being' a parent? Willingness form a relationship? Donation of tissue?
- Thin notion of parenting?
- Potentially undermines purpose of act of donation?

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### 2. Responsibilities and genetic-relatedness

- Perhaps not parental but (close) genetic relatedness counts for something (morally)
- Content?
  - Wider family? Greater incentive for duty of rescue? Weightier obligations under duty of rescue?
- OR (see above) is it social family ties that bind us morally to others?
  - Need to fully absorb implications of changing family structures

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### 3. Responsibilities related to donation

- Obligations to avoid harms?
  - Analogy with communicable disease re genetics?
- Suggests willingness to be tested and pass on information that arises later
- But this doesn't require donor to be identified (see medical interests above)

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### 4. Exercising responsibilities anonymously

- IF (and its a big IF) responsibilities flow from being genetically related disclosure of identity seems inevitable
- But at least some of the reasons provided – even non-medical information – could be done anonymously
- Is identifiable information really another way of stating that there are, in fact, legitimate expectations in relation to (future) contact?
- Means of ensuring responsibilities are fulfilled – more accountable if identifiable?

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### Summary

1. Donors have some responsibility
2. Genetic relatedness seems to play at least some part in this, the basis is at least questionable
3. At least some (possibly all of the better justified) responsibilities can be exercised anonymously
4. Changing policy in relation to anonymity may itself generate expectations that in their own turn generate responsibilities

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## II. Anonymity is morally acceptable

- That anonymity is acceptable does not mean that it should be compulsory
  - Known donation and identifiable stranger donation could remain options for those who want it
- Some donor responsibilities are compatible with donor anonymity
- Schemes for putting donors & DCI adults in touch can run alongside anonymity

- Anonymity should also not be confused with openness about the circumstances of conception
  - Some of the potential harms that identifiable donation are meant to create could be addressed by openness with a minor
  - Compulsory openness may undermine parental authority (see later sessions)



- It is not clear why the desires of DCI adults are thought to weigh more heavily than the desires of donors or recipients
  - Be this at the time of donation or later
- Privacy concerns in relation to donors and recipients also need to be taken into account
  - Intrusion must be both legitimate and proportionate
- Being identifiable can leave donor (and his/her other family members) open to unfair and unsolicited pressures/demands from DCIs

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- Donors may make it possible for recipients to conceive but responsibility for the parental project (conception and therefore the DCI) rests with the gamete recipients

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### III. Recapping on the 'but...'

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- Donation is not responsibility free
  - Question is whether exercising responsibility requires identifiable donors
- Exchange of medical information through a third party is a reasonable expectation
  - Recipients and possibly even DCIs share this responsibility, however.
- Voluntary identification also acceptable
- Donors and DCIs should behave reasonably
  - Some useful suggestions in this regard from Nuffield Council on Bioethics.

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Nuffield Council on Bioethics. *Donor conception: ethical aspects of information sharing* (April 2013)

Available online

<http://www.nuffieldbioethics.org/donor-conception>

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## Is Not-Telling the Child Morally Reprehensible?

ESHRE - The Ethics Of Gamete Donation And  
Information Sharing  
Munich, June 29, 2014

Theo A. Boer, PhD, Associate professor of ethics.  
Protestant Theological University (Groningen);  
Utrecht University, Ethics Institute

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## Is Not-Telling the Child Morally Reprehensible?

Dr. Theo Boer  
No commercial relationships or any other activities that  
may be perceived as a potential conflict of interest. No  
commercial and/or financial relationships with  
manufacturers of pharmaceuticals, laboratory supplies  
and/or medical devices.

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## Learning Objectives

- Understanding why the telling-not telling issue in case of gamete donation is morally complex
- Identifying the good reasons for not telling the truth
- Identifying the better reasons for telling the truth
- This presentation intends to provide policymakers and health care professionals an awareness of all the different interests and perspectives involved.

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### Telling what?

- The fact of gamete donation?
- The most important genetic and biographical data of the donors?
- The identity of the donor?
- Opening the possibility of (mutual) (incidental/ long term) personal involvement?
- We will not discuss here the different arguments for and against gamete donation

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### Cultural and medical shift from not telling to telling

- End of life: telling the bad news
- Consumer's rights: knowing what one buys, knowing what one eats
- Autonomy presupposes being informed
- Beginning of life: one's origins

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### Why telling/ not telling is ethically complex

- Procreation belongs to the private sphere
- Not one but two autonomies (parent[s]) and child collide
- Unresolved legal issues
  - How to define 'parent'
  - How to deal legally with matters that belong to the private sphere
- Debated empirical questions: the positive and negative effects of (not/) disclosing,

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### Differentiation between situations

- ...in which the child will find out anyway (single parenthood, same-sex couples)
- ... in which gamete donation can be concealed (heterosexual couples)

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### The parents as autonomous actors

- Acting from a deep desire to be parent
- As any parent, they will try to do what's best for their offspring
- Privacy & personal values
  - they may see social parenthood as one and only
  - they may feel inhibitions or shame to tell
  - they may want to tell later, if at all, and in their own way
- They themselves have not had a say in what *their* parents did
  - but normally, they will have known the identity of their biological parents

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### The child as autonomous actor

- The right to have essential knowledge about oneself
  - genetic identity as an essential part of one's identity
  - biographical, ethnographical, etc. knowledge
  - insight in motivations on the side of the donor
- Person has a right to decide himself whether or not this knowledge is to be known
- Autonomous choices presuppose knowledge
- Some children may desire the knowledge
- Other children may feel embarrassed by being presented a choice

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### Advancing the interests of the child (1)

- Positive: genetic, biographical, historical, social, and characterological knowledge of oneself and one's potential offspring; In an age of genetic research, knowledge of origins of great instrumental value
- Self-understanding/ identity
- Openness may reinforce bonds to social parent(s); Not-disclosing will inhibit the transparency, confidence, and trust of the child-parent relationship

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### Advancing the interests of the child (2)

- Early telling may be less traumatic
- The child will find out anyway
- Not-telling may create very painful incidents
- "What if I fall in love with my half-sibling?"
  - That will also be possible in normal life
  - "Take a test"
- Getting to know one's biological parent(s) may become a blessing

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### Negative sides of openness

- Burdening knowledge of health risks, liabilities
- Search for biological parent may inhibit bonding to social parents
- Child and/ or parents may feel shame for fact of donation
- Finding biological parent may turn out disappointing
- Some children will regret to having been informed
- Decreasing donor availability

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### Other arguments

- In ordinary life, a substantial percentage of children are not informed about their origins
  - <-> That is no reason to create such situations
  - <-> Once involved, fertility centers do have a responsibility to advance the child's best interests
- advances in genetic science and technology make it easy to discover the identity of a one's genetic parents ('Family Finder test')

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### The donor (1)

- has feelings too: may wish to have children/ pass on their genes
- may have applied to be a donor for this reason (in Sweden, the switch from not-informing to informing led to a remarkable shift in the donor population)
- may have a wish to know more about his/ her child(ren)
  - the fact of having child(ren)
  - general information
  - disclosure of identity
- personal involvement for longer or shorter period of time

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### The donor (2)

- is a grown up person who will be asked to sign the conditions
- eligible are only those who agree with the conditions
- Still, they may change their minds:
  - deciding to not cooperate (own family protection, etc.)
  - developing a deep wish to be in contact
- The donor's well-being and autonomy need to be taken into consideration

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## Legal / institutional options

- (1) No legal regulations whatsoever: institutions are free
- (2) Two counters: one anonymous, one not anonymous
- (3) Forcing donor data to be stored but no obligation to tell
- (4) Full obligation to tell
  - Subject only to emergency exceptions
- (5) Storing genetic data and/ or medical record donor

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## Conclusions

- The rule: the child is the primary owner of information about its genetic and biological origins
- Parents will have to act in the child's best interests and will have to respect their child's autonomy. This includes a moral duty to tell their child
- A moral duty to tell the child is plausible but a legal duty is problematic
- Health care and fertility institutions have a responsibility to make ethically solid policies with regard to donor anonymity
- Individual health care professionals need to be trained to explain institutional policies to patients/ clients
- There is no duty to know but a right to know

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## Telling or not-telling: should counsellors be directive?

Wybo Dondorp PhD  
Dept Health, Ethics & Society  
GROW & CAPHRI  
Maastricht University  
the Netherlands

ESHRE München 2014 – PCC5

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## Interests

- No conflicting interests
- But:
  - was member of research group evaluating the Dutch Donor Conception Data Act (report 2012)
  - idem of Nuffield Council Working Party that drew up the report: Donor conception ethical aspects of information sharing (2013)

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## Learning objectives

- Insight in ethical considerations with regard to whether or not counsellors working in the practice of medically assisted reproduction (MAR) must tell (future) parents – or try to convince them – that they should disclose to their children how they were conceived.

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## Set-up

- Background
- Should parents disclose?
- Co-responsibility for the welfare of the child in MAR
- Implications for counselling
- Discussion of different views
- Conclusion: yes counsellors should be directive – but not in the sense of telling parents what to do.

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## Many parents don't tell

- “It has become obvious that there is a wide divergence between the intentions of the legislation and how parents act in relation to them regarding telling children about their DI conception” (Lalos, 2007)
- “Although there is some indication that an increasing proportion of parents of donor-conceived children may be disclosing (....), it is questionable whether relying on time alone will bring about a sufficiently rapid change in parental disclosure levels” (Blyth & Frith, 2009).

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## Should they?

- [Obligation not to frustrate the law?]
- Parental responsibility
  - No evidence of harm to children as a result of parents telling or not telling
  - Finding out inadvertently at a later age may have adverse impact on well being
  - *Lebenslüge* (even if not harmed, still ‘wronged’)?
- → Parents have a *prima facie* responsibility to disclose and to do so at an early age (Evaluation report of Dutch Act: Winter, 2012)

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## MAR only for those willing to tell?

- Professionals/ clinics causally & intentionally involved in the creation of a child >> co-responsible for welfare of the child
- Standards (Pennings 1999)
  - Maximum welfare
  - Minimum welfare ('non-identity argument': child cannot be harmed unless life is so miserable that any reasonable person would prefer non-existence)
  - Reasonable welfare (no medically assisted reproduction if high risk of serious harm) eg. ESHRE, HFEA, NCoB, KNMG
- Telling or not-telling: no 'high risk of serious harm'
  - No reason for making MAR a 'coercive offer' (NCoB 2013)

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## Beyond the threshold

- Reasonable welfare standard defines a lower limit threshold for providing MAR.
- Beyond this threshold: even when fertility treatment is morally acceptable (...), professionals involved in providing MAR are still under a prima facie obligation to reduce reproductive risks (including risks affecting the welfare of the future child) to the extent that doing so is reasonably possible and proportional" (ESHRE Task Force Ethics & Law, 2010).
- Should the pre-treatment information & counselling offered by MAR-professionals/centers be just 'factual', or aimed at getting the message across that 'it is really best to tell'?

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## Counselling

In medical settings, counselling has two forms (Adler et al. 2009):

- supporting people facing unusually difficult circumstances or decisions, e.g. whether or not to undergo complex, risky or arduous procedures such as HIV testing, genetic screening, organ transplant or similar.
- to promote psychological adjustment (...) when clients seem likely to benefit from help or support when facing challenging life changes. [Eg ..] when receiving a cancer diagnosis, [some people.....] might benefit from receiving counselling to facilitate their psychological adjustment if they react to the diagnosis with unusual levels of, for example, denial (...), suppressed distress (...), or depression (...).

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## Infertility counselling

BICA:

- enable people to reflect upon and understand the implications of a proposed course of action for that person, their family, children born as a result and anyone else affected by the treatment or donation of gametes and embryos.
- to provide emotional support before, during and after treatment or donation of gametes and embryos, particularly if the person is experiencing stress, ambivalence or distress
- to assist people in developing successful coping strategies for dealing with both the short and longer term consequences of infertility and treatment
- to help people to try to adjust and to accommodate to their particular situation.

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### Counselling potential recipients or commissioning couples

In addition to providing emotional support and therapy, counselling can make a significant contribution to a person's preparation for parenthood through donation or surrogacy. The purpose of this counselling should be to encourage the client(s) to reflect upon and understand:

- their feelings about the medical diagnosis and cause of infertility
- their initial reactions to the option of using donation / surrogacy and changes to attitudes and feelings over time
- their acceptance, emotional preparedness and expectations of parenthood through donation / surrogacy
- the implications of differences and similarities between their feelings and those of their partner (if they have one) to the option of donation / surrogacy
- the personal implications of donation / surrogacy for them in the short and longer term including cultural issues
- the impact on their wider family and social relationships
- their attitudes to and preparation for sharing biographical and genetic origins information with children conceived by donation / surrogacy
- the welfare of children and families in relation to the manner and timing of sharing information on genetic origins.

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## HFE Act/ HFEA CoP#8

Human Fertilisation and Embryology (HFE) Act 1990 (as amended)

Conditions of licences for treatment

13 (6C) In the case of treatment services falling within paragraph 1 of Schedule 3ZA (use of gametes of a person not receiving those services) or paragraph 3 of that Schedule (use of embryo taken from a woman not receiving those services), the information provided by virtue of subsection (6) or (6A) must include such information as is proper about—

- (a) the importance of informing any resulting child at an early age that the child results from the gametes of a person who is not a parent of the child, and
- (b) suitable methods of informing such a child of that fact.



HFEA guidance (cont)

The importance of informing children of their donor origins

- 20.7 The centre should tell people who seek treatment with donated gametes or embryos that it is best for any resulting child to be told about their origin early in childhood. There is evidence that finding out suddenly, later in life, about donor origins can be emotionally damaging to children and to family relations.
- 20.8 The centre should encourage and prepare patients to be open with their children from an early age about how they were conceived. The centre should give patients information about how counselling may allow them to explore the implications of treatment, in particular how information may be shared with any resultant children.

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## Role of the counsellor

- Independent professional
- Part of a team that shares a co-responsibility also for the welfare of the future child  
(I assume that this is the case and will consider the implications)

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## Models for morally laden choices

- Adapted from Emanuel & Emanuel (4 models of the professional relationship):
  1. Just provide factual information that people may need in order to decide about (non-) disclosure
  2. Help people make well-informed choices about (non-) disclosure that are really their own
  3. 'Shared decision making' – as a deliberative process in which professionals try to convince people that it is always best to disclose
  4. Tell people they ought to disclose

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## Which model is most adequate?

- #4 is inconsistent with the notion that not telling does not expose the child to a high risk of serious harm (if it did, MAR should only be offered to those willing to disclose)
- #3 is still too strong given that parents only have a *prima facie* duty to disclose. If parents have what on reflection they regard as good moral reasons for not telling (in the interest of their family, including the future child), what would be the justification for trying to convince them to do otherwise? As there is no reason for thinking that they are necessarily mistaken in choosing as they do, trying to win them over to a different view is disrespectful of parental autonomy.

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### Which model is most adequate?

- #1 seems best to respect parental autonomy, but that is an illusion insofar as it in fact leaves parents in the cold when facing a difficult choice with far reaching implications
- In #2 the counsellor helps parents to make a well considered choice that they can really identify with in the light of their values and ideals. (NCoB recommends HFEA to revise its guidance to make it reflect the 'non-judgmental ethos' of this model).
- However, a qualification may be needed in order to avoid that 'non judgmental' is taken to mean that parents may not be confronted with the need to consider the responsibilities that go with their role.

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### Autonomy & responsibility

- Persons cannot be held responsible without allowing them the space to make their own decisions: no responsibility without autonomy (seems to be forgotten in models #3&4)
- Respect for autonomy as an ethical principle refers to the right of persons to be respected as the authors of their own life. But we cannot be such authors in isolation from others. To the extent that our choices affect the lives of others, there is no autonomy without responsibility (important qualification of #1&2)

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### Conclusion

- Directivity in the sense of telling parents what they need to do is morally problematic
- Non-directivity in the sense of: 'it does not matter what you choose as long as it is your choice', fails to address applicants in their role of parents. This failure is especially problematic in the context of counselling as provided in MAR-practice.
- Directivity in the sense of telling parents what they should consider (prima facie duty to disclose) is not at odds with (non-judgmentally) respecting their autonomy in how they eventually decide.
- Counsellors working in MAR practice should be directive, but only in this sense.

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Do donors have a right to information about their donor offspring?

Guido Pennings  
Ghent University

ESHRE 30th Annual meeting, München, 29 June – 2 July 2014



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Obligatory

I have no conflict of interest



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Learning objectives

- to realise that information sharing is a general question for all parties involved.
- to realise that the fact that someone wants some information or expresses an interest means nothing in itself: we need a theoretical framework to determine whether this should be expressed as a right.



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### Information sharing

The debate is almost exclusively focused on the right of offspring to get information on the donor.  
However, information sharing may be a concern of all parties involved: the would-be parent(s), the donor, the surrogate etc.

We need to distinguish between various types of information:

- basic information,
- medical information,
- general information,
- extended donor child profile, and
- identifying information.

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### Consistency

The first point worth mentioning is that known donors do have most, if not all, the information on the child they want. Donors who find it important to know and follow their donor offspring will only enter into the arrangement if this condition is fulfilled.

Baetens et al., 2000; Laruelle et al., 2011: in Belgium, donors and recipients of eggs negotiate on their position in the family.

Still, the situation is not necessarily comparable with unknown donors given differences in motivation, relationship with the recipient etc.

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### I. Basic information

Basic information: whether and how many children were born from the donation (including possibly the sex)

When the donation is a real gift, should we not thank / reward the donor for this?

A person who donates to charity receives feedback on what has been achieved with his money.

Participants in scientific research are informed about the results.

*Basic information is a way to reward the donor and recognize his/her contribution.*

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### I. Basic information

Other possible reasons in case of identifiable donors:

- 1) it can offer psychological closure,
- 2) it can caution the donor that later contact may occur, and
- 3) it can give donors who already have children the opportunity to consider the impact of future contacts on their children and/or partner (Ethics Committee of the ASRM, 2009)

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### II. Medical information

Medical information: mainly the presence of a genetic disease in the offspring

1. for the donor's own health (earlier tests, better and faster treatment, ...)
2. for the donor's reproduction: make informed reproductive decisions (have or not have a child of his own, need for prenatal testing of PGD)
3. for the donor's own children: health information, treatment if possible and reproductive decisions.

The same rules should apply here as in other cases of genetic information in the family. This information can be passed on anonymously through the doctor.

*Medical information about the offspring may benefit the donor and his or her own possible future children.*

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### III. General information

General information: the well-being of the children, how they are doing

Some egg and sperm donors worry about the well-being of offspring. This information can be provided anonymously and updated every 5 years. Problem: how to find out? Life satisfaction questionnaire?

Problem: what in case of negative information (familial problems, learning difficulties ...)?

*General information about the offspring's wellbeing may reduce the donor's concerns.*

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#### IV. Extended offspring profile

Extended donor child profile: phenotypic information, personality traits, photos, letters addressed to the donor, hobbies etc.

If donor offspring have an interest in knowing more about the donor, is the reverse also true? They could also discover differences and similarities and use this information for a more complete construction of their identity.

Problem: how to do this? Periodically update?

However, the donor does not need the information on the offspring in the same way as the donor offspring. It does not tell him where he came from. Moreover, donors can obtain this information by having children of their own.

Problem: violation of the child's right to privacy: information about the child is given to another person without the child's consent.

#### Extended offspring profile

Asymmetry but there is one point where information about offspring may be important for the donor's identity: knowing that he/she is a 'mother' or 'father' (in the strict biological sense) and that he/she lives on. For this, however, only basic information is needed.

*An extended donor child profile (phenotype, hobbies etc.) may enrich the donor's identity but the desire is not such that he/she has a right to this information.*

#### V. Identifying information

Open identity system attracts donors who are interested in future contact with the offspring.

Identifiability = contactability

Problem: contact may harm the interests of the other parties. E.g., social parents, donor offspring who were not informed ...

No right but no principled objection to information sharing, just like for donor offspring. Exchange with mutual agreement can be made possible through registries.

Danger: incompatible expectations

Identifying information enables contact and this may fulfill the donor's wish for parenthood.

### Information sharing

What are the ethical principles concerning information sharing?

Different positions:

- deontological theories: it is wrong to lie  
certain information belongs to a person  
it is a violation of a person's right to privacy
- consequentialist theories: the consequences of sharing or not sharing  
Crucial point: many consequences are knowledge-dependent.  
Crucial point: information sharing always concerns at least 2 persons  
whose interests should be taken into account.

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### Consequentialist theories

For consequentialist theories, there are two problems:

- how to determine the effects of information sharing on people.
- how to distinguish between needs and desires.

From the donor offspring debate, we learn that without a theory to frame questions from donor offspring, there is no limit to what the children can ask for.

The studies all indicate that the wish of donor offspring for information about their donor is based on curiosity.

Curiosity is not a basis to attribute rights.

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### Need for information?

Without a theoretical framework, every wish of a person can be transformed into a need and every need is transformed into a right.

WISH  $\Rightarrow$  NEED  $\Rightarrow$  RIGHT

In general, one has to show that the information is necessary to avoid suffering or to obtain something that leads to well-being.

Even when we accept that there is a right, no right is absolute; even if the person has a right to certain information, this right may be overridden by a stronger right of someone else.

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### Conclusion

Based on the previous analysis, we can only retain a right of the donor to medical information about his/her donor offspring. We assume here that this information will in some way benefit the donor's or the donor's children health or reproduction.

All other types of information can be given tot the donor in specific circumstances:

- when no harm is caused to other people,
  - when no rights are violated,
  - when there is a mutual agreement among all parties to share
  - when no disproportional costs are incurred
- but there is no right to this information.

# UPCOMING ESHRE EVENTS

## // ESHRE CAMPUS EVENTS

### ESHRE's 30<sup>th</sup> Annual Meeting

🏠 [www.eshre2014.eu](http://www.eshre2014.eu)

Munich, Germany  
29 June - 2 July 2014



### Epigenetics in reproduction

🏠 [www.eshre.eu/lisbon](http://www.eshre.eu/lisbon)

Lisbon, Portugal  
26-27 September 2014



### Endoscopy in reproductive medicine

🏠 [www.eshre.eu/endoscopyoct](http://www.eshre.eu/endoscopyoct)

Leuven, Belgium  
15-17 October 2014



### Making OHSS a complication of the past: State-of-the-art use of GnRH agonist triggering

🏠 [www.eshre.eu/thessaloniki](http://www.eshre.eu/thessaloniki)

Thessaloniki, Greece  
31 October-1 November 2014



### From gametes to blastocysts – a continuous dialogue

🏠 [www.eshre.eu/dundee](http://www.eshre.eu/dundee)

Dundee, United Kingdom  
7-8 November 2014



### Controversies in endometriosis and adenomyosis

🏠 [www.eshre.eu/liege](http://www.eshre.eu/liege)

Liège, Belgium  
4-6 December 2014



### Bringing evidence based early pregnancy care to your clinic

🏠 [www.eshre.eu/copenhagen](http://www.eshre.eu/copenhagen)

Copenhagen, Denmark  
11-12 December 2014



### An update on preimplantation genetic screening (PGS)

🏠 [www.eshre.eu/rome](http://www.eshre.eu/rome)

Rome, Italy  
12-13 March 2014



For information and registration: [www.eshre.eu/calendar](http://www.eshre.eu/calendar)  
or contact us at [info@eshre.eu](mailto:info@eshre.eu)



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