**Institution:** University of Liverpool

**Unit of Assessment:** UoA 30 Philosophy

**Title of case study**: Providing information about gamete and embryo donor relatives: improving practice

**Period when the underpinning research was undertaken:** 2000 – present

**Details of staff conducting the underpinning research from the submitting unit:**

| **Name(s):** | **Role(s) (e.g. job title):** | **Period(s) employed by submitting HEI:** |
|---|---|---|
| Dr Lucy Frith | Reader in bioethics | Dr Lucy Frith, 1995- present |

**Period when the claimed impact occurred:** 2014- present

**Is this case study continued from a case study submitted in 2014?** N

## 1. Summary of the impact (indicative maximum 100 words)

Gamete (eggs and sperm) and embryo donor conception is an international practice. There are no precise figures on the numbers of donor-conceived people born world-wide. In the UK is it estimated that 81,000 people have been born since 1991 and approximately 60,000 born a year in the US.

Frith's research has considered the rights to information (both identifying and non-identifying) about one's donor relatives (the donor and donor-siblings) and includes empirical ethics studies on donor-conceived peoples' experiences of searching for their donor relatives. This work has been influential in changing regulations (Australia, Victoria, Germany); been used in professional guidelines (ASRM, BICA, German cross-professional Guidelines); and in recommendations for how to support those searching for donor-relatives (BFS). These changes have had a significant impact on members of the donor-conception community who are, depending on the jurisdiction, able to either access information about their donor relations for the first time or have opportunities to access a greater amount of information about these relatives.

## 2. Underpinning research (indicative maximum 500 words)

It is now widely recognised that openness in donor conception, telling people they were donor-conceived and allowing access to information about their donor relatives, is optimal. The research carried out by Frith and her collaborators has challenged conventional wisdom, that secrecy was best, and encouraged debate amongst stakeholders. Frith's research on what information should be provided and how, combines rigorous ethical analysis of policy and practice, using a combination of philosophical and empirical ethics methods. Her work has focused on three areas:

### 1. Ethical arguments for non-anonymous donors.

Frith began researching this area in 2000, when, in the UK, donor conception operated under conditions of anonymity and recipients of treatment were generally counselled not to tell their prospective children that they were donor-conceived. There was a growing feeling amongst some of the donor-conceived community that donor anonymity should be removed. Frith's work (3.1, 3.2) examined the ethical arguments for and against anonymity: do donor people have a right to information about their donor? What kind of right is this? Should donor-conceived people have a right to be told they are donor-conceived? Whose interests should take precedence in policy decisions – the donors, the parents or donor-conceived people? Her work also considered what duties and obligations are owed to donor-conceived people and how the duty to provide information can form the basis of policies to enable them to find information about their donor. The research put forward the case for the removal of donor anonymity and for greater openness and information sharing in donor conception – this work proved highly influential (widely cited in policy documents).

Foregrounding theoretical debates over donor-offspring's' rights and the nuanced consideration of what these rights might be based on and how they could be translated into policy, helped pave the way for the change in the law on donor anonymity in the UK in 2005, when gamete donors became non-anonymous to future offspring. The minister responsible argued that the decision was taken on the grounds that the interests and rights of the child are paramount. In the UK. The importance of telling children they are donor-conceived is now widely recognised and was enshrined in the revised Human Fertilisation and Embryology Act (2008), and all subsequent Codes of Practice (HFEA, 2019).

**2. Donor-conceived peoples' experiences of managing information about their donor and donor relatives.**

Frith published a highly-cited synthesis of the evidence on donor-conceived peoples' views on what they wanted to know about their donor and donor-siblings and how either knowing or not knowing they were donor-conceived affected them (3.3). She has conducted empirical ethics studies on donor-conceived adults' experiences, concluding that there are good ethical arguments for openness in families about donor-conceived origins and that secrecy in families can have negative repercussions (3.4).

**3. Rethinking regulations and policies on donor conception information - donor registers.**

Frith's research has analysed policies on information giving to donor-conceived people (3.5), and how donor registries should be organized (3.6). This work emphasised the importance of support mechanisms for those seeking donor relations and established a need for more bespoke counselling and intermediary services for this group of people. It also concluded that with the rise in direct-to-consumer genetic testing (home ancestry DNA testing), searching for and finding donor relations is likely to become even more common.

## 3. References to the research (indicative maximum of six references)

1. Frith, L. (2001) Gamete donation and anonymity: the ethical and legal debate, *Human Reproduction*, 16 (5) pp 818-824.
2. Frith, L. (2001) Beneath the rhetoric: the role of rights in the practice of non-anonymous gamete donation, *Bioethics*, 15 (5/6), pp 473-484.
3. Blyth, E. Crawshaw, M. Jones, C & Frith, L (2012) Donor conceived peoples' views and experiences of their genetic origins: a critical review of the literature, *Journal of Law & Medicine*, 19 (4) 769-789.
4. Frith, L. Blyth, E. Crawshaw, M. van den Akker, O. (2017) Secrets and disclosure in donor conception. *Sociology, Health & Illness*, online 16 November 2017 doi: 10.1111/1467-9566.12633.
5. Frith, L. (2015) The Limits of Evidence: Evidence based policy and the removal of gamete donor anonymity in the UK. *Monash Bioethics Review*. 33 (1) 29-44.
6. Frith, L. Blyth, E. Crawshaw, M. van den Akker, O. (2017) Searching for 'relations' using a DNA linking register by adults conceived following sperm donation, *BioSocieties*, doi: 10.1057/s41292-017-0063-2

(All available from the Institution on request)

This underpinning research has been published in peer-reviewed journals and widely cited in the academic debates and regulatory and practitioner literature.

## 4. Details of the impact (indicative maximum 750 words)

There are a number of beneficiaries of Frith's research and this case study focuses on benefits to: fertility professionals (clinic staff, counsellors); legislators and regulators; people planning and receiving treatment with donated material, parents of donor-conceived people; and donor-conceived people and donors.

### BENEFITS FOR PROFESSIONALS

### Evidence-based professional guidance

Frith's work has been influential in professional debates on the issue of telling children they were donor-conceived.

The American Society of Reproductive Medicine (ASRM) issues guidance for fertility practitioners in the United States, and in the absence of overarching regulation, these guidelines have a significant impact on the practice of fertility treatment in the US. Frith's research has been used in the ASRM's Ethics Committee Opinion 'Informing offspring of their conception by gamete or embryo donation'. Its latest iteration, published in 2018 (5.1), references two of Frith's papers (3.1, 3.3), and states, 'disclosure to donor-conceived persons of the use of donor gametes or embryos in their conception is strongly encouraged' (5.1).They use Frith's arguments that it is a human right to know one's donor in support of their advice to tell children that they were donor-conceived, and their recommendation to provide recipients of treatment with more information about the donor.

This represents a shift away from their previous advocacy of donor anonymity and not telling. In the ASRM's 2014 guidance it explicitly recognised that, 'Traditional practices of anonymity in gamete donation are slowly changing as views about the interests and rights of children to know the identity of their genetic parents evolve.' Frith's research (3.1 and 3.3) has been used to justify this change and cited in successive versions of the Guidance.

Frith's research has also been published in the British Infertility Counselling Association (BICA) professional journal, widely read by both infertility counsellors and others in the multi-disciplinary teams in fertility clinics. Frith's work has also been adopted and referenced in UK professional guidelines: British Infertility Counselling Association (5.2) and UK Guidelines for the Medical and Laboratory Procurement and Use of Sperm, Oocyte and Embryo Donors (2019) (pages 71,95,96 in 5.2). Both guidelines encourage openness in donor conception.

The trend towards more openness in donor conception has also occurred in Germany. Frith's work (3.3) was referenced in the German guidelines (2014) (5.3) published by a consortium of professional groups involved in fertility treatment and donor conception (infertility counsellors, medical practitioners and family therapists) that advocated for more openness in donor conception.

## BENEFITS FOR REGULATORS

### International legislative change

*Australia*

Frith's work has had impact in other international contexts: the Australian state of Victoria (that passed one of the first laws on reproductive technologies in 1984) has debated the issue of anonymity and telling extensively over the last 10 years. Frith's work has been used in a number of ways in this context: contributing to the amendments to the Assisted Reproductive Treatment Amendment Act in 2014 that allowed access to identifying information about donors for those born before 1988, with the donor's consent and the subsequent legislation in 2016, Assisted Reproductive Treatment Amendment Act, which removed the donor consent provision (5.4). These changes in the law arose out work by the Victorian parliament in 2010, who began an 'Inquiry into Access by Donor-Conceived People to Information about Donors.' Frith's work was cited in a number of submissions to this. This Inquiry formed the basis for an ongoing programme of work and Frith's research was drawn on in the recommendations arising from the Victorian Assisted Reproductive Treatment Authority's consultation with donors in May 2013. These inquiries and reports resulted in the Assisted Reproductive Treatment Amendment Acts 2014 and 2016.

Two other Australian states have reviewed their laws on gamete donation, South Australia and Western Australia. Frith's research on the ethical arguments for non-anonymity and the importance of openness and the need for the provision of facilities to enable donor-conceived people to find their donor relatives, influenced these legislative reviews.

South Australia's review reported in 2017 and recommended that a donor-conception register should be established. In 2019 an amendment to existing legislation was passed to mandate the creation of a donor register.

In Western Australian the review of the Human Reproductive Technology Act 1991 and the Surrogacy Act 2008 published in 2019 makes the following key recommendation: 'A donor conception register [should be kept] to enable all donor-conceived people to access identifying information about their donor' (5.5 https://bit.ly/2Le7Zv5). The recommendations to establish a register of donors has been implemented in both South and Western Australia. Professor

Sonia Allan, (Professor of Law, Western Sydney University) who was the Chair of both reviews, stated: ‘Dr Frith’s work undoubtedly has had a great impact on informing my knowledge, and on the recommendations made in both reviews.’ (5.5).

*Germany*

In Germany, the culmination of debates in both the public arena and research literature, and professional guidance was the Sperm Donor Register Act (SaRegG - Samenspenderregistergesetz) 2018. This Act will allow access to donor information for donor offspring. Part of the pressure for change was an open letter to the Minister of Justice written by the German Society for Fertility Counselling in 2014, arguing for the implementation of a working group on new family structures. This letter made suggestions for legal changes and Frith’s research (3.3) formed part of the underpinning evidence for these suggestions. As one of the lead authors of this letter, Dr Petra Thorn states, ‘The work of Frith and her colleagues has been very influential in the debates over removing donor anonymity’ (5.6).

**Current developments in the UK**

Now openness and non-anonymity have become more generally accepted, new issues become relevant. A key question is how to organise registers of information held about gamete donors and donor-conceived offspring. Professional organizations have debated what good practice in this area should look like and Frith’s work (5.3) has been cited in recommendations (5.7) that contributed to the decision by the UK regulator, the Human Fertilization and Embryology Authority (HFEA) to fund a 3-year pilot specialist intermediary and support service for those approaching its statutory register (HFEA, 2014, https://bit.ly/35OE6bR) and subsequent policies on support mechanisms.

**BENEFITS FOR PARENTS/POTENTIAL PARENTS**

The Donor Conception Network (founded in 1993) is the largest group in the UK that represents users of donor conception services and their families. Frith’s work (3.3) was quoted as part of the guidance (2018) on their website to give people advice on the issues raised by travelling abroad for donor conception and different countries’ policies on anonymity (5.8). The Victorian Assisted Reproductive Technology Authority’s guidance on what to tell children about donor conception has drawn on Frith’s research (5.9).

**BENEFITS FOR DONOR-CONCEIVED PEOPLE AND DONORS**

Frith’s work on the arguments for non-anonymity (3.1) has contributed to professional and public debates about openness in donor conception and has been part of the gradual shift away from donor anonymity towards non-anonymous donors and greater openness about donor conception origins (3.6). There is growing evidence that more parents now tell their children they are donor-conceived and that this is largely beneficial for children (https://pubmed.ncbi.nlm.nih.gov/28758779/).

Frith has worked with the Donor Conceived Register members (gamete donors and donor-conceived people) on supporting them in their representations to the HFEA when the pre-1990 voluntary register was being retendered, drawing on her research (3.4, 3.5) to argue for adequate funding for the provision of support services. Her research was used by the Chair of British Association of Social Worker's Project Group on Assisted Reproduction in arguing for such support to the HFEA (5.10). This support from Frith and the ability to draw on evidence to support the Registrants’ claims made a significant impact on ensuring the future of the Register and associated support mechanisms, and this has produced significant benefit for the Registrants. The Donor Conception Register is now based at the Hewitt Centre, Liverpool Women’s Hospital and Frith’s research has been used by their team to inform their approach to offering support to the donor community. The Senior counsellor at the Hewitt Centre said, ‘Our team at the Hewitt Centre have drawn on Frith’s research to help us in our work in supporting the members of the DCR.’ (Testimonial 5.10)

## **5. Sources to corroborate the impact** (indicative maximum of 10 references)

**5.1** Frith's work (R1) has been cited by the America Society for Reproductive Medicine (the US professional organisation for fertility specialists) guidelines on good practice in gamete donation, first being citied in 2004, and subsequent iterations 2009 and 2014, and in the most recent guidance published 2018.

**5.2** Frith's work has been cited in the British Infertility Counselling Association (BICA). Implications counselling for people considering donor-assisted treatment. Gerry McCluskey and Patricia Gilbert. BICA Practice Guides Series. 2015, BICA Publications.
UK Guidelines for the Medical and Laboratory Procurement and Use of Sperm, Oocyte and Embryo Donors (2019) - Helen Clarke, Shona Harrison, Marta Jansa Perez & Jackson Kirkman Brown on behalf of the Association of Clinical Embryologists, the Association of Biomedical Andrologists, the British Fertility Society. Human Fertility, DOI: 10.1080/14647273.2019.1622040

**5.3** Guidelines on Psychosomatically oriented diagnosis and treatment of fertility disorders' 2014 citing Frith's research as underpinning their work. Advisory Network for Children's Desire Germany; German Society for Analytical Psychology; German Society for Medical Psychology; German Society for Psychosomatic Obstetrics and Gynecology; German Society for Medical Sociology; German Society for Psychosomatic Medicine and Medical Psychotherapy; German Society for Sexual Research; German College of Psychosomatic Medicine.

**5.4** Frith was cited in reports that led to the Assisted Reproductive Treatment Amendment Act 2014 and 2016, Victoria Australia https://www.varta.org.au/regulation/regulation-art-victoria/legislation-about-right-information-about-donors

**5.5** Review of the Western Australian Human Reproductive Technology Act 1991 and the Surrogacy Act 2008, March 2019. Testimonial Professor Allan.

**5.6** Letter to the minister of justice from the German Society for Fertility Counselling, 2014, pdf. And Testimonial Dr Petra Thorn.

**5.7** Family building using donated gametes and embryos in the UK: Recommendations for policy and practice on behalf of the British Infertility Counselling Association and the British Fertility Society in collaboration with the Association of Clinical Embryologists and the Royal College of Nurses Fertility Nurses Forum Wilde et al (2014) Human Fertility, 7:1, 1-10, DOI: 10.3109/14647273.2013.862041.

**5.8** Frith's research (3.3) is quoted in Donor Conception Network's (a patient and user organisation) advice to prospective parents on issues they should think about when choosing where to access donor treatment, 'Home or Overseas? Donor Conception Outside the UK' (2018).

**5.9** Victorian Assisted Reproductive Treatment Authority 2014, Why, when and how to tell children about donor conception.

**5.10** Email exchange from the Chair of BASW's Project Group on Assisted Reproduction (PROGAR) with the HFEA.
Testimonial of Patricia Lambert from the Hewitt Centre who are now managing the Donor Conceived Register.