

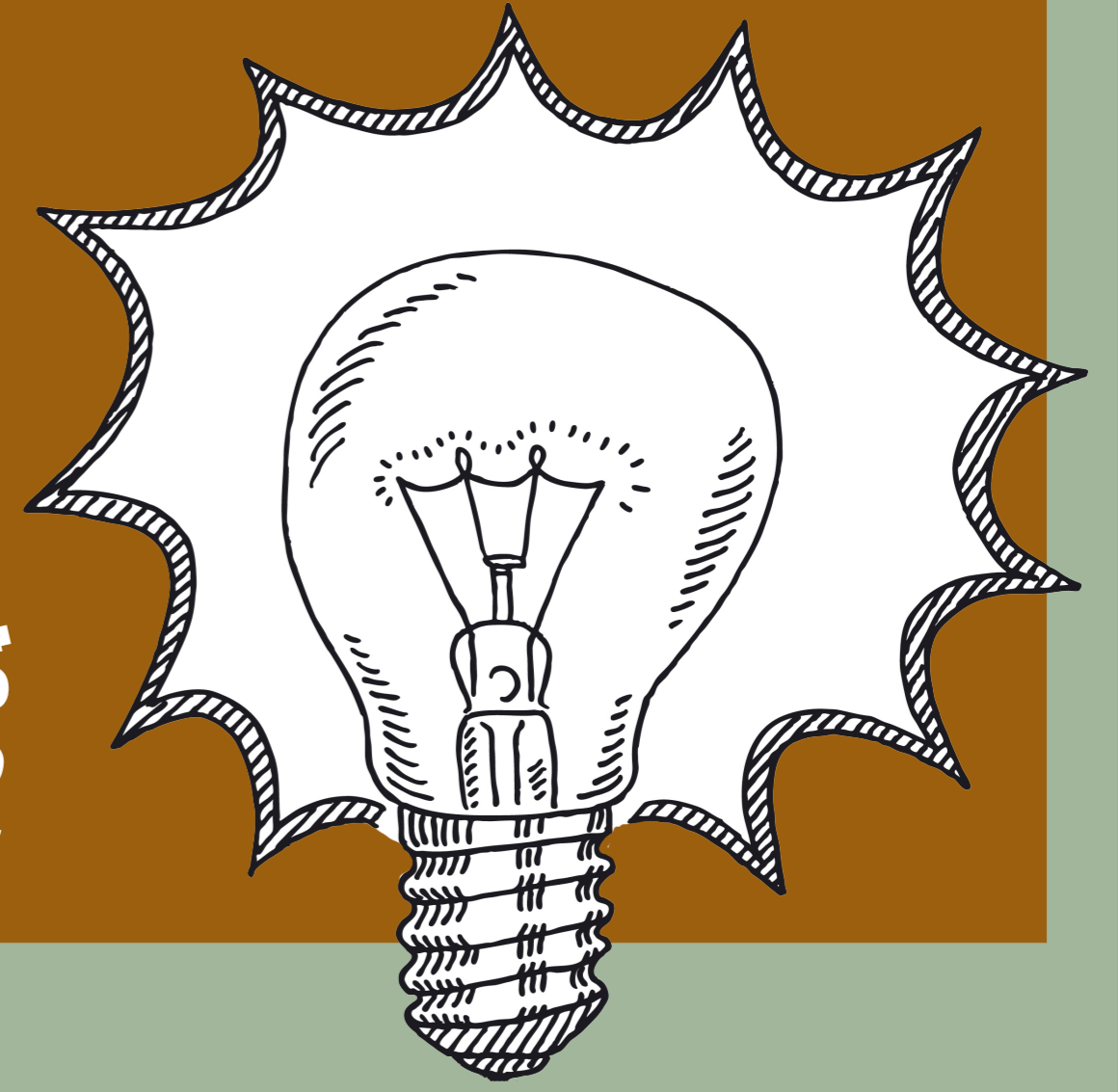
Relative Strangers. Negotiating Non-genetic Kinship in the Context of Assisted Conception

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effectively use research to improve the situation for children or families or to address issues in personal relationships

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centre for research on families and relationships

What research was used? Why was it appropriate?

We used the 'Relative Strangers' study; a qualitative ESRC funded project comprising 74 interviews with parents and grandparents of donor conceived children. Our in-depth semi-structured interviews told us about the experiences of family life in participants' own words. The data offered in-depth, rich and nuanced insights into how donor conception impacts on family life. By interviewing both parents and grandparents we gained insight from different generational perspectives. Through a thematic analysis we discovered that these experiences are socially patterned and linked to wider social discourses and social change.

It was appropriate and important for us to communicate the findings to families because there is little information available. Our data contained unique and important stories that have not been heard previously; it is vital that these voices are heard in order to impact on policymaking, or, equally important, family decision making.

We discovered, for example, that donor conception means different things for men and women, for lesbian and heterosexual couples, and for their parents. We also discovered that openness about genetic origins, which might seem easy enough in theory, is often a complicated process in practice: different generations can hold contrasting moral beliefs which can lead to tensions in families. Thus we've been able to feed into the current policy debate.

How did you get people interested in the research?

We worked closely with user groups and stakeholders throughout the project to understand their needs. We thought of creative ways to disseminate our findings to communities and we shared our unique insights by undertaking a range of activities:

- We published *Relative Strangers: Family Life, Genes and Donor Conception*. Rather than being a traditional research monograph this was written with a dual audience in mind; it is of academic interest, but it is also accessible for a special interest public audience.
- We produced information sheets and leaflets (<http://www.manchester.ac.uk/relative-strangers/families/>) for families and those working with them – such as infertility clinics, representative bodies and lawyers. We made four leaflets targeted at lesbian and heterosexual parents, and grandparents in such families. The leaflets, distributed in print and available online, drew directly on our interview data. They are available at no cost through our website and we also post them out for free.
- The Human Fertilisation and Embryology Authority have recognised the importance of our insights by recommending our leaflets on their website (<http://www.hfea.gov.uk/8350.html>).
- We contributed to debates through writing comment pieces in BioNews and blogs for Discover Society and Policy@Manchester.
- The team produced videos which are available on YouTube; these raise awareness about donor conception and legal issues, and offer support for families.
- We presented at patient/parent DCN and FCSNI conferences.
- We organised three conferences ourselves with significant stakeholder involvement.
- We organised a public debate 'Do Genes Matter?' (with Progress Educational Trust) in London May 2014 which attracted an audience of 200 people.
- We were invited to contribute to the Nuffield Council on Bioethics' 2013 report on donor conception and information sharing, and we presented at their high profile launch.
- Awareness has been raised through featuring in the national press, e.g. The Independent (10.08.15) and BBC Radio4's Woman's Hour (17.04.14).
- Social media has been used to spread the word.

Who benefitted from the research?

Relative Strangers explored heterosexual and lesbian couples' experiences of forming families by egg, sperm and embryo donation, as well as the experiences of grandparents. These families are often isolated, socially invisible and may suffer stigma, and we recognised the potential to enhance support for them and their communities:

- **Families:** We made the experience of donor conception and its impact on family life more visible by creating videos, leaflets, and attending user conferences. This has helped raised awareness so that such families are now better understood and families themselves are better able to feel part of a community.
- **Practitioners** working with families, e.g. infertility counsellors, can now draw on our discoveries to offer better targeted support to couples and families.
- **User groups and stakeholders:** Organisations such the Donor Conception Network (DCN), Fertility Counselling Service Northern Ireland (FCSNI) and Natalie Gamble Associates have been able to develop better targeted support material to use in the work with clients. Our leaflets are also available in clinics.

How did you evaluate the impact?

We used a combination of counting usage statistics for videos and leaflet downloads/requests, feedback sheets for events, and also asking for feedback from collaborating partners. We also collected unsolicited feedback from families and professionals.

Indicators of impact are:

- 2,445 printed **leaflets** have been distributed and 1,918 downloaded in 44 countries since the leaflets were launched in March 2015.
- Our four **videos** have been viewed 7048 times since being uploaded starting 2012.
- Clinics and the FCSNI use our leaflets in meetings with patients.
- The DCN, with over 2000 families as members, include our leaflets in their Welcome Packs and received our book with the highest praise.
- Our leaflets are used as **teaching material** on the BMEdSci in Health and Human Sciences, University of Sheffield.
- Our public debate '**Do Genes Matter?**' was deemed 'stimulating', 'thought-provoking' and 'eye-opening' (audience feedback).

What did the team learn from the project?

We have learnt:

- About the importance of building on and developing good relationships with key stakeholders, such as the DCN.
- To listen to families and professionals about what their concerns are, and see how our expertise can contribute to personal and policy conversations.
- About developing a flexible, responsive approach to working with audiences; to be sensitive to their different needs and requirements and finding ways of adapting to these. We now aim our outputs accordingly; e.g. we write in-depth comment pieces for policy makers, provide shorter

introductions for more generalist press, and attractive leaflets with key insights, brief quotes and discussion for patients and parents.

- About the importance of sharing personal stories – we wrote separate leaflets for parents and grandparents, and lesbian and heterosexual couples. The issues were different, so we extracted the relevant information for each group from our data.
- That producing and printing professional-looking leaflets can be a great way of getting people interested in using the research. Making these 'bite-size' and providing them at no cost is also significant.
- That impact work is time consuming, costly and requires professional assistance. It thus needs to be planned at the inception of grant application and study.