



## REPORT

### Ethnicity and Reproductive Technologies

**A Two day colloquium to explore multi-disciplinary approaches to researching new reproductive technologies in the context of multi-ethnic societies.**

Organisers: Lorraine Culley, De Montfort University, Leicester  
Floor van Rooij, University of Amsterdam

#### **1. Background**

Research on ethnic differences in understandings of and responses to reproductive technologies is limited. There are however, a small number of researchers from within anthropology, sociology and psychology who are working on this issue in relatively isolated, often small scale projects in the UK and other European countries. Research in this area is not only of substantive interest but also has much to contribute to the wider research agenda addressing methodological issues in research within discourses of ethnic and cultural difference.

This colloquium was designed to bring together leading researchers and young researchers in the field of new reproductive technologies (NRTs) and minority ethnic and migrant communities in the UK and European countries to present current research and debate methodological, ethical and political questions around NRTs and cultural diversity.

#### **2. Participants**

Mustaq Ahmed	University Hospital Leeds
Theda Borde	University of Applied Science, Berlin
Ada Borkenhagen	Fertility Center, Berlin
Noelle Cotter	Trinity College, Dublin
Marilyn Crawshaw	York University
Lorraine Culley	De Montfort University
Dorothy Fielding	St. James Hospital, Leeds
Sigal Gooldin	Haifa University, Israel
Zeynep Grtin-Broadbent	Cambridge University
Kate Hampshire	University of Durham
Katherine Hooper	De Montfort University
Nicky Hudson	De Montfort University

Naz Iqbal	University of Durham
Mark Johnson	De Montfort University
Saffron Karlsen	University College, London
Dineke Korfker	TNO Leiden, Netherlands
Tina Lavender	University of Central Lancashire
Evelyn Mahon	Trinity College Dublin
Wendy Norton	DMU, Leicester
Sarah Parry	Edinburgh University
Satvinder Purewal	Aston University
Frances Rapport	Swansea University
Bob Simpson	University of Durham
Olga van den Akker	Aston University
Frank van Balen	University of Amsterdam
Floor van Rooij	University of Amsterdam

### 3. Presentations

#### 3.1. Saffron Karlsen from University College, London, *“What ‘Indian’ ought to be in England.” Improving awareness of the shortcomings of simple assessment of ethnicity.*

This paper argued that static measures of ethnicity present an over-simplistic approach. While people’s understanding of ‘ethnicity’, in an abstract way, conforms to traditional ideas regarding cultural and biological inheritances; their appreciation of their own ethnicity and the lived experience of being a member of a, particularly, ethnic minority group in the UK in the ‘noughties’ presents a much greater influence for other people – including those both within and outside one’s ‘own’ ethnic group – on your opportunities for ethnic awareness and mobilisation. As such, ethnic affiliation may not always coincide with the sense of solidarity, community or groupness discussed in the literature and on which much policy is based. The meeting discussed the issues around multiple identities and the bureaucratic and often meaningless categories which were used in official data collection and in many research projects and the implications for health researchers in applying and adapting concepts of ethnicity and specific ethnic categorisations.

#### 3.2 Lorraine Culley, De Montfort University, Leicester, *Exploring Researcher Identity.*

This paper explored some of the ways in which we need to think about our identities as researchers and the impact of these on what we produce. Following an outline of debates on commonality and difference in the research process, the paper challenged those who propose ‘ethnic matching’ as a generalised strategy for researching ethnicity. This theoretical challenge was developed using illustrations from a research project on infertility and South Asian communities. It was argued that many statuses impinge on the research context in complex ways and the intersection of these leads to a dynamic situation of shifting similarities and differences between researcher and participant. Difference makes a difference, but not in any unitary or predictable way. Discussion ranged around examples of similarity and difference (age, gender, class

and ethnicity) in other projects and the potential impact of translation issues and the use of interpreters on diversity research in infertility.

**3.3 Theda Borde, Alice Salomon Fachhochschule, University of Applied Science, Berlin. *Representation of ethnic minorities in research – necessity, chances and adverse effects.***

This presentation highlighted the major challenge for researchers posed by the inadequate representation and inclusion of ethnic minority populations in studies, especially in the European context. The impact of definition problems, marginalization, monocultural research methods and instruments as well as access to “hard to reach” groups were discussed, based on examples from comparative studies on reproduction and infertility focussing on migrants from Turkey resident in Germany. The discussion in the group focussed on the impact of a lack of interpreters on informed consent and quality of care; the ethnicisation of issues and the need for researchers to avoid processes of ‘othering’.

**3.4. Sarah Parry, University of Edinburgh. *Public engagement research: Methodological innovations and limitations with hard-to-reach communities***

Drawing on a current project ‘The Social Dynamics of Public Engagement in Stem Cell Research’, this paper outlined how we can utilise and extend existing methodological tools to encourage participation of communities in public engagement research, focusing in particular, on experiences of engaging typically ‘hard-to-reach’ groups in a research project that attempts to both access their views and involve them in later dialogic events that brings different communities together. The discussion explored the limits to public engagement research and the impact of particular framings of the subject.

**3.5. Dineke Korfker, TNO Prevention and Health, Leiden, the Netherlands *Migrant outreach workers as interviewers: Experiences from the field.***

This paper discussed the researcher’s experience of working with migrant outreach workers in a qualitative study of the infertility treatment of Turkish and Moroccan couples in the Netherlands. It highlighted the success of outreach workers in recruiting participants and in providing a cultural brokerage between researcher and participant. It also demonstrated the many problems which those who do not speak Dutch well, experience in accessing and understanding fertility treatment.

The discussion ranged around the benefits and disadvantages of using community members as researchers, as well as highlighting similar gaps in fertility provision and patient understanding across several countries.

**3.6. Satvinder Purewal and Olga van den Akker. *Cultural and gender differences in reasons for parenthood.***

This paper reported on a small scale study exploring cultural and gender differences in reasons for and against parenthood in a sample of South Asian and ‘white’ British communities. The paper generated an extended discussion of the importance of children and the stigma of infertility in many of the minority ethnic populations in the

UK and Europe. Also important were the incidence of resistance to such dominate pro-natalist ideologies, especially among younger men and women.

**3.7. Nicky Hudson and Lorraine Culley, Mary Seacole Research Centre, De Montfort University: *'Matching' relations: biology, ethnicity and culture in public and professional discourses of gamete donation.***

This paper focussed on the ways in which South Asian participants in a study of gamete donation in the UK envisaged the religious, 'ethnic' and cultural identities of donors and recipients and how they saw the transmission of such identities, via gametes, to the donor-conceived child. The importance of 'matching' donors and recipients has long been a clinical concern in the use of donated gametes, especially in the case of non-disclosure. The ways in which the participants considered the meaning of the 'matching' process in terms of ethnic and religious subjecthood were complex and diverse; with notions of 'biological' and 'cultural' relatedness being deployed simultaneously in the narratives. A range of possibilities were offered in the discussions for the ways in which donated gametes could be considered as acceptable to a South Asian couple and the risks associated with using donor gametes from 'other' contexts. The paper generated an extensive discussion of the different regulatory, social and political contexts of egg and sperm donation in the countries represented at the meeting, with a wide variety of systems in place. The impact of the removal of donor anonymity and the phenomenon of fertility 'tourism' were also debated by participants.

**3.8. Evelyn Mahon, Trinity College, Dublin *IVF in Ireland: Practice and regulation in a Constitutional state: Italian or British?***

Day Two of the meeting began with a contribution from the Republic of Ireland. This paper discussed debates around the regulation of fertility treatment in Ireland following the report of the Commission on Assisted Reproduction published in 2005. This report recommended that a regulatory body be established by an Act of the Oireachtas to regulate Assisted Human Reproduction in Ireland. The Committee's report and recommendations were not unanimous however. The legal protection accorded to the embryo and the precise time at which legal protection should be afforded is a central pervasive issue in the Irish context. It raises a Constitutional issue about when life begins, and how this might be legally interpreted given the "right to life" amendment contained in the Constitution which has prohibited the legalisation of abortion in Ireland. The use of surplus embryos, regenerative medicine and pre-implantation genetic diagnosis were also unresolved among the committee as was surrogacy which may not be legally permissible either. The possible political consequences of re-opening the abortion debate were discussed. National, religious and cultural differences in the timing of the 'start of life' were discussed by participants.

**3.9. Sigal Gooldin, Department of Sociology & Anthropology, University of Haifa, Israel *IVF in a Jewish-Palestinian context: Politics, emotions, hope***

This paper looked at the moral discourses created by reproductive technologies, showing how technology and society shape each other, with examples from the Israeli context, where there is a high level of public provision of IVF treatment. It was

argued that in the Israeli context, the regulative practice of IVF actively creates 'unexpected worlds' of co-operations and alliances between Israeli-Jews (comprising 80% of the Israeli population) and Israeli-Palestinians (comprising 20% of the Israeli population). One example is the co-operation, for many years, between Israeli-Palestinian MPs and Nationalist Jewish Israeli MPs on matters concerning legislation of IVF. These co-operations are anchored in inclusionary moral worlds (of emotional discourses) that go beyond the exclusionary moral worlds (of nationalist discourses). Participants discussed the idea of alliances formed through vulnerabilities and the differing national/legal/ethical contexts of IVF treatment.

**3.10. Mushtaq Ahmed, Department of Clinical Genetics, St James' Hospital, Leeds** *Experience of Pakistani and white men with infertility and its treatment*

This paper discussed qualitative interviews undertaken with 10 Pakistani and 10 white men, following on from a quantitative study of men's experiences of infertility. The paper argued that there were greater similarities than differences between Pakistani and white men's experiences of infertility and its treatment, though there were some socio-cultural differences, such as the perceived degree of social pressure and the influence of religion on decisions. The discussion explored the differences between researching infertility by quantitative and qualitative methodologies and the importance of cultural understandings to make sense of participant accounts. The paper also stimulated a discussion of the 'universals' in the experience of infertility, as a useful alternative to the consideration of difference.

**3.11. Ada Borkenhagen, Fertility Center Berlin.** *Impact of cultural features on counselling and informed consent of ART by Turkish migrants in Germany*

This paper looked at Turkish migrants in Germany and the use of assisted reproduction technologies. The paper emphasized the importance of knowledge about cultural features and specific attitudes towards infertility for ensuring suitable infertility treatment of migrants. Physicians have to take into consideration different level of information and ways to cope with infertility to avoid undesirable side effects. Turkish migrants have a higher preference for invasive treatment and a higher risk of multiple births. The discussion included further examples of the impact of Turkish culture on infertility treatment and the fact that many Turkish couples prefer to visit Turkey for assisted conception treatment.

**3.12 Floor Van Rooij, Frank Van Balen University of Amsterdam.** *Migration and the experience of Infertile Turkish couples in the Netherlands.*

This paper explored the influence of migration on the experience of infertility among Turkish couples in The Netherlands. Several key themes related to migration influencing the infertility experience were discussed: confrontation with two different health care systems; communication problems between practitioners and patients; communication problems between partners as a consequence of deficiencies in communal language; minority stress; homesickness; illegality; visa problems and incorrect older ages in passports. The discussion focused on recommendations to minimize the negative effects of experiencing infertility and the ways in which racism may be present in the system, but difficult to uncover.

**3.13. Zeynep Gürtin-Broadbent, Centre for Family Research, University of Cambridge. *The seed, the soil and a little fertiliser: Turkish patients' experiences of fertility treatments.***

This paper focussed on Turkish patients' experiences of fertility treatments in Turkey explored through qualitative interviews. Turkey is a strongly pro-natalist country and voluntary childlessness is virtually unheard of. Therefore if a couple is childless, they must be infertile and as such it is a very public experience. But there are also high levels of communication about infertility. The use of informal and (rarely) formal adoption were discussed. The importance of Islam was highlighted. Infertility treatment has been 'normalised' in Turkey. The relative openness of debate around NRTs may be related to the fact that gamete donation is not permitted or practiced in Turkey, but also because NRTs are part of a 'modern' agenda and there have been many well publicised cases involving local celebrities.

#### **4. Conclusion**

The meeting ended with a discussion of some of the key themes which emerged during the two days of the colloquium. Clearly the significance of cultural issues was a major finding in most studies, but the need to avoid both essentialism and stereotyping also came across strongly in the debates. Some of the conceptual and methodological issues raised in the discussion around theorising and investigating ethnicity were considered to be very important and worthy of more detailed consideration. The practical and policy implications of research were also felt to be important. Participants discussed the possibilities and necessity of looking at the wider context of assisted conception, in the constitutional and political agenda of several countries.

Exploratory discussions about proposals for new joint projects were an important outcome of the meeting for several participants. Participants spoke highly of the value of the event and written evaluations have been highly positive. There was a 77% response rate to a short questionnaire, with an overwhelmingly positive evaluation of the quality of the papers, the size of the group, the time allowed for discussion within the sessions and the opportunities for networking.

One output from the event has been the creation of a distribution list. One member (Nicky Hudson) has also set up a new jiscmail list, which everyone attending the event signed up to. This has also attracted many additional members, which now stand at around 80. Communication between participants working in this small but growing field has been enhanced considerably by this meeting. Joint research bids are being prepared among participants, and it is hoped that several contributions will be published in an edited volume in 2007. Plans for a similar meeting in 2008 are underway.

Lorraine Culley  
October 2006.

