

ESF Exploratory Workshop on

**NEW PERSPECTIVES ON GAMETE
AND EMBRYO DONATION:
ETHICS, KINSHIP AND CITIZENSHIP
IN A GLOBALISED WORLD**

Essex, UK, September 11-12th, 2012

Convened by:

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SCIENTIFIC REPORT

1. Executive summary

Organisation and Context

The meeting was held at the University of Essex, Colchester, UK over two days, from the 11th to the 12th of September, 2012. The event was hosted by the Department of Sociology, an internationally renowned institution that has consistently achieved the highest ranking in the Research Assessment Exercise (RAE).

Participation numbered 23 people from 14 different countries. The majority of participants were academics, but a number of practitioners from different fields also participated. For example, Dr. Gianaroli is Scientific Director of the Italian Society for the Study of Reproductive Medicine (S.I.S.Me.R). Two psychologists (Riikka Toivanen & Maiju Tokola) travelled from Finland, where they counsel people undergoing assisted conception treatment and are doing research in cooperation with the University of Helsinki. All participants brought valuable practical and theoretical insights to bear, both in their presentations and the discussions that followed.

The campus is a short car/bus journey from the nearest town and the entire event, including accommodation, was self-contained on the campus. There were plenty of facilities for participants' entertainment and this facilitated additional interaction between conference participants. The university campus is set in green parkland, including a lake complete with swans! Participants were able to mingle during the breaks but also enjoy walks on campus before dinner. While coffee breaks took place in the room adjacent to the workshop space, breakfast and evening meals were held at a restaurant on campus. Conference participants had exclusive use of the restaurant during this time. This helped promote camaraderie and mingling among participants, most of whom followed the evening meal with a visit to the campus bar where discussions continued until later in the night. The general atmosphere was extremely friendly and congenial, with many participants resolving to keep in touch following the workshop.

As one of the organisers (Róisín Ryan-Flood) was on maternity leave at the time of the workshop (from June 21st 2012), an administrator (Agnes Skambalis) had been appointed (funded by the University of Essex) to take over organisational duties in the run up to the conference. Agnes did an outstanding job of corresponding with participants and handling their queries, as well as booking the venue, accommodation and meals. Numerous participants commented that they had found her exceptionally helpful and efficient. Some of them even brought gifts for her and the conference organisers to show their appreciation!

Aims and Objectives:

This workshop aimed to explore the theoretical, ethical and policy issues that arise from gamete (eggs and sperm) and embryo donation. The purpose of the workshop was to bring together academics, policy makers, organisations and practitioners working on gamete and embryo donation in order to: identify common interests and themes; encourage interdisciplinary and international discussion of the issues raised; and review existing legislation and regulation in order to inform future research and policy agendas. It was intended from the outset that the workshop would result in an edited book and a report for practitioners.

Specific goals for the workshop included the following:

Create a space for people from different disciplinary and professional contexts to engage in dialogue across traditional boundaries and forge new relationships.

Identify common interests and areas of concern, as well as agendas for future collaborative interdisciplinary research.

Develop an interdisciplinary research network consisting of academics, policymakers and practitioners.

Produce an edited book.

Produce an executive summary written for a practitioner audience.

Conclusions:

The two day workshop constituted a highly productive series of presentations and discussions. Participants presented a wide range of theoretically complex and empirically rich work.

A particular strength of the workshop was the range of geographical expertise presented. Participants drew on fascinating empirical material derived from diverse regions. This allowed commonalities and differences to be explored. It highlighted common areas of interest, as well as providing thought provoking case studies that gave rise to new questions. For example, it was clear that across regions, new reproductive technologies are generating complex ethical concerns yet there is considerable variety in terms of regulation. For example, the rights of donor conceived children to trace their donor has been a high profile issue in recent years. Some countries, such as Sweden and the UK, allow donor conceived children to access their donor's contact information when they turn eighteen. In other countries, such as Spain, discussions about gamete and embryo donation have specifically emphasised the right of donors to privacy. Clearly, cultural and social norms and understandings inform the variety of policy regulation.

It was also very helpful to have clinical practitioners participating in the workshop, as they brought interesting insights to bear on the discussions, raising new questions. For example, psychologists from Finland who counsel people undergoing assisted conception treatments, outlined some of the complexities of using a known donor. In relation to their work with women who receive eggs donated by their sisters, they discussed the complexities of family dynamics that can arise, for instance the possible emotions generated for the donor and recipient when the resulting child resembles the donor. Dr. Gianaroli in a discussion of the

2004 ban on gamete and embryo donation in Italy that results in women travelling to other jurisdictions to access these technologies highlighted the resulting consequences in difficulty in monitoring the healthcare and treatment that these women receive abroad. Dr. Karl-Gösta Nygren gave a presentation on IVF and pointed out the importance of follow up data for exploring later-in-life consequences and epigenetic risks. However, there is currently a considerable dearth of data on this subject. The insights from practitioners proved a valuable resource for generating new research possibilities.

In terms of outputs from the workshop, it was agreed that the workshop would result in an edited book and participants were asked to provide abstracts. Following the workshop, these abstracts have been collected by the co-organisers, who have completed a related book proposal that has been submitted to publishers for consideration. A report for practitioners is also in preparation.

Finally, all participants were enthusiastic about the potential for future research collaborations. The workshop resulted in the creation of an email list consisting of participants from the workshop that will be used to inform one another of research, publications, cases and policies. In addition, the final discussion session generated new ideas for research collaborations. It was agreed that the workshop organisers (Róisín Ryan-Flood and Jenny Gunnarsson Payne) would put together a funding application (as principal investigators), that would bring together a range of different projects involving workshop participants. The proposed research would explore ethics, identity and governance in relation to gamete and embryo donation. Possible funders include the European Research Council.

2. Scientific content of the event

The workshop consisted of six panel sessions over two days (three per day), plus an introduction by the workshop organisers on the first day and a concluding discussion concerning future research and publication plans resulting from the workshop on the second day.

In their **introduction**, Dr. Róisín Ryan-Flood and Dr. Jenny Gunnarsson Payne provided practical information about meals, accommodation and the programme schedule. They also highlighted that key goals of the workshop were to produce an edited book and a research funding proposal. They asked participants to keep this in mind over the two days in order to have some ideas prepared for the final discussion. Dr. Ryan-Flood then gave a presentation of PowerPoint slides provided by the ESF, as their representative was unable to make it. The slides provided a helpful overview of the ESF and their funding schemes.

The first panel session explored '**Patient Perspectives and Public Attitudes**'. The first speaker, Mariana Martins (Portugal), was unfortunately unable to attend due to a last minute illness. However, she provided PowerPoint slides and a voiceover for her presentation on adolescents' views on gamete donation. This was presented in her absence to excellent effect. She also attempted to listen to the other presentations and participate in the end of panel discussion via Skype, however this was less successful due to difficulties with sound quality and the roving microphone. The second presentation in this session, by Susana Silva (Portugal) explored understandings of and attitudes towards the duration of embryo and cryopreservation. She argued that the duration of storage of cryopreserved embryos should be included in the scientific and political agenda. The final presentation in this session by Riika Roivanen and Maiju Tokola (Finland) examined the experiences of Finnish families using a known donor. Drawing on interview material, they provided poignant insights into the complexities involved in donation that is not anonymous. The resulting discussion considered the ethical and practical issues highlighted by the presentations.

After a break for lunch, the second session addressed '**Legal and ethical perspectives on gamete and embryo donation in a Globalised world**'. This was the session with the greatest number of presenters, due to speaker availability and cohesiveness of topics. There were five presenters on this panel. The first, Dr. Luca Gianaroli (Italy) discussed the consequences of the Italian ban on gamete and embryo donation, particularly in relation to the resulting demand for cross-border reproductive care. The second speaker, Professor Judit Sandor (Hungary) discussed the legal implications of gamete and embryo donation, generating fascinating insights regarding the importance of retaining a concern with gender inequality in dealing with cases involving biotechnology and new forms of kinship. The third speaker, Wannes van Hoof (Belgium), presented work on legal and ethical reactions to cross-border movements for donor gametes, arguing that the current situation means that legal diversity will continue to exist and that crossing borders will continue to be the only option for many seeking assisted conception services. The next speaker in this session, Cathy Herbrand (Belgium and London), gave a presentation about openness, disclosure and anonymity in gamete and embryo donations in the UK and Belgium. She argued that numerous factors influence patients' decision to choose known versus unknown donors and the role of resemblance in creating families that incorporate genetic and non-genetic relationships. The final speaker in this session, Guido Pennings (Belgium), outlined a model for gamete donation that provided incentives for partners of donors to be moved up the

waiting list in return for donating. The resulting discussion covered a range of fascinating issues and involved a lively discussion. Some contributors suggested that it was important not to adopt a model of a gender neutral body and that any discussion of ethics and donation should incorporate an acknowledgment of differential experiences of female and male donors. The implications of cross-border care and differences in legislative constraints were also discussed.

After a short coffee break, the final session of the day examined the topic of '**Global Networks and Global Markets**'. The first speaker, Zalka Drglin (Slovenia), examined the implications of the global trade in embryos. The second speaker, Paul Just (Austria) took a novel approach in addressing the governance of foetal tissue across Europe in relation to neural grafting of Parkinson's disease. This presentation provided a welcome addition to the wider context for IVF and the use of foetal material. The next speaker, Joysna Gupta (Netherlands), gave an insightful presentation on gender and embodiment in the globalized bioeconomy, with particular reference to surrogacy. The final speaker in this session, Enikő Demény (Hungary), presented fascinating case studies regarding egg donation in Eastern Europe and implications for kinship. Once again, the panel was followed by an animated discussion about the global context for gamete and embryo donation.

The second day began with a panel session on '**Spaces of exclusion: Reproductive inequalities, rights and citizenship**'. The first speaker, Karl-Gösta Nygren, outlined the implications of IVF and the importance of obtaining long term data that explored health and social consequences for resulting children. The second presentation by Róisín Ryan-Flood outlined the difficulties faced by lesbians excluded by law from access to assisted conception services and considered the concomitant implications for citizenship and care. The final speaker, Jenny Gunnarsson Payne, presented work on donor egg recipients who travel abroad for treatment. The resulting discussion explored questions of equality, gender and care within a transnational perspective.

After a short coffee break, the second session of the day began, entitled '**Cultural Perspectives on Gamete and Embryo Donation**'. The first speaker, Sebastian Mohr (Denmark), presented groundbreaking work on sperm donors in Denmark, outlining their motivations and views on donating. The second speaker, Sven Bergmann (Germany), presented empirical research on gamete donation, drawing on ethnographic fieldwork at assisted reproduction clinics. He provided thoughtful findings concerning questions of openness, secrecy and 'resemblance' that raised interesting questions regarding the wider cultural context for these issues. The final speaker in this session, Andrèa Wiszmeg (Sweden), presented preliminary work on the use of foetal tissue in research on Parkinson's Disease. The three presentations provided the basis for a valuable discussion about ethics, gender and embodiment.

Following a lunch break, the third session of the day was entitled '**Reproducing Relations : Kinship patterns and relationships**'. The first speaker, Catarina Delaunay (Portugal), considered the potential longterm implications of donor insemination for future generations from both an ethical and legal perspective. The next speaker, Tabitha Freeman (UK) gave a fascinating presentation about her research on donor conceived families, including donor conceived children's search for donor siblings and donors. Her work suggests that these families are finding themselves in uncharted territory, exploring new forms of relatedness. The next speaker, Carles Salazar Carrasco (Spain), presented work on gamete donation,

drawing on an evolutionary psychology perspective. The final speaker in this session, Venetia Kantsa (Greece), considered how discussion of gamete and embryo donation are often restricted to a dichotomy of 'restrictive' versus 'permissive' regimes and argued that an approach that extended beyond an emphasis on 'libertarian' or 'restrictive' dichotomies and instead focused on 'local' cultural conceptualizations of kinship, gender, sexuality is potentially more productive. The panel concluded with a productive discussion of the new family forms, situations and ethical dilemmas generated by gamete and embryo donation.

Following a coffee break, the **concluding session on network and publication plans** attempted to outline possible future collaborations generated by the workshop. All discussions across both days acknowledged the complexities in attempting to produce legislation that respected the rights and needs of these families. There were also a number of 'data gaps' identified, where further research was needed. The discussion identified areas of collaborative research within the context of a wider study. It was agreed that the workshop organisers would coordinate a collaborative funding proposal incorporating various case studies and involving workshop participants. In addition, the workshop would result in a mailing list for participants where they would disseminate information about relevant research and publications. An edited book and practitioners' report would also be produced, drawing directly on the presentations and discussions of the workshop.

3. Assessment of the results, contribution to the future direction of the field, outcome

As the previous sections indicate, the two day workshop constituted of stimulating and thought provoking presentations and discussions. Intellectual connections were made across disciplines and geographies, generating useful insights about theoretical concerns, legislative contexts, and productive areas for future research. All participants benefitted from the exposure to a wider array of geographical diversity in terms of learning about assisted reproduction in new cultural and legislative contexts. Listening to presentations from different disciplines and clinical practitioners presented different perspectives, raising interesting questions. In particular, questions of **human rights, gender and embodiment were considered to be of paramount importance** in a context where new and evolving technologies throw into question the nature of personhood and challenge old truisms about what constitutes a parent. The need for **original empirical research to inform new ethical and legal frameworks** in a local and transnational context was identified as an issue of key importance.

The workshop organisers presented a model for a funding proposal for a **collaborative research project**, which drew on ideas presented in discussions over the previous two days. The proposed research consisted of a two pronged approach. The first part attempted to map connections, focusing on services and border crossings, outlining the different legislative contexts and reproductive tourism. Possible empirical studies could include Western heterosexuals and gay men travelling Eastwards for surrogacy services; and the infrastructure for cross border services. The second component would attempt to trace links, focusing on identities and relationships. Possible empirical projects would include research on: donors; donor conceived family relationships; umbilical cord banking (registries and depositories); and mediated intimacies – for example internet technology as a means of tracing donors; popular media/media representation and donation. The proposed funding could potentially be used for new projects, follow on research, postdoctoral fellowships and

PhD studentships. Possible funding sources include the ESF and ERC. All future research would engage closely with governance and policies, with a key aim being to inform policy and practitioners. The workshop organisers have begun work on a funding application.

Finally, it was agreed that the workshop would lead to **an edited book**. This is already underway as a resulting book proposal is currently under review. A short **report for practitioners** presenting insights from the workshop is also in development. An **email list** for participants from the workshop is already being used to disseminate information about research, policies and funding.

4. Final programme

PROGRAMME

Tuesday, 11 September 2012

- 09.00-9.45 **Coffee and registration**
- 9.45-10.00 **Welcome by Convenors**
Róisín Ryan-Flood (Department of Sociology, Colchester, University of Essex), and **Jenny Gunnarsson Payne** (School of Gender, Culture and History, Huddinge, Södertörn University) **General Housekeeping**
- 10.00-10.15 **Presentation of the European Science Foundation (ESF)**

Session 1: Patient perspectives and public attitudes

- 10.15-10.35 **"Adolescents' attitudes towards and willingness to use gamete donation", Mariana Martins** (Faculty of Psychology and Education Sciences, University of Porto Portugal)
- 10.35-10.55 **"Patients' views on the duration of embryo and cryopreservation: Knowledge, expectations and uncertainties", Susana Silva** (Institute of Public Health, University of Porto, Porto, Portugal)
- 10.55-11.15 **"Experiences of Finnish families using a known donor", Riika Toivanen & Maiju Tokola** (Tunnetila, Helsinki, Finland)
- 11.15-12.00 Discussion
- 12.00-13.00 Lunch

Session 2: Legal and ethical perspectives on gamete and embryo donation in a Globalized world.

- 13.00-13.20 **"The Italian ban on gamete and embryo donation and its consequences", Luca Gianaroli** (Società Italiana di Studi di Medicina della Riproduzione, SISMER, Bologna, Italy)
- 13.20-13.40 **"Kinship and gamete donation: How far can courts go?", Judit Sandor** (Center for Ethics and Law in Biomedicine ,CELAB, Central European University, Budapest, Hungary)
- 13.40-14.00 **"Legal and ethical reactions to cross-border movements for donor gametes", Wannes van Hoof** (Bioethics Institute, Ghent University, Ghent, Belgium)
- 14.00-14.20 **"Between openness, disclosure, and anonymity in gamete and embryo donations: a comparative analysis of the British and Belgian legal", Cathy Herband** (Université Libre de Bruxelles & Kings College London)
- 14.20-14.40 **"Gamete donation based on reciprocity rather than altruism", Guido Pennings** (Bioethics Institute, Ghent University, Ghent, Belgium)
- 14.40-15.45 Discussion
- 15.45-16.15 Coffee break

Session 3: Global networks and global markets

- 16.15-16.35 **"Echoes in the semi-darkness: Considerations of possible consequences of the global trade with embryos", Zalka Drglin** (The National Institute of Public Health & Department of Health Studies, University of Ljubljana, Slovenia)
- 16.35-16.55 **"Governing and foetal tissue economies across Europe: The case of neural grafting in Parkinson's Disease", Paul Just** (Department of Political Science, University of Vienna, Austria)
- 16.55-17.15 **"Reproductive labour or reproductive trafficking? Women's reproductive bodies in the globalised bioeconomy", Joytsna Gupta** (University for Humanistics in Utrecht, The Netherlands)
- 17.15-17.35 **"Networks of reproduction in the globalized world"
Enikő Demény** (Center for Ethics and Law in Biomedicine, CELAB, Central European University, Budapest, Hungary)
- 17.35-18.15 Discussion
- 19.00 Dinner

Wednesday, 12 September 2012

Session 4: Spaces of exclusion: Reproductive inequalities, rights and citizenship

- 9.00-9.20 **"Now 5 million born after IVF worldwide, but what about access and safety inequity", Karl-Gösta Nygren** (International Committee Monitoring Assisted Reproductive Technology (ICMART), Stockholm, Sweden)
- 9.20-9.40 **"Negotiating sexual citizenship: Lesbian parenthood and transnational borders", Róisín Ryan-Flood** (University of Essex, Colchester, UK)
- 9.40-10.00 **"Before it is too late: Age, cross-border reproductive care and intimate citizenship", Jenny Gunnarsson Payne** (Södertörn University, Huddinge, Sweden)
- 10.00-10.45 Discussion
- 10.45-11.15 Coffee break

Session 5: Cultural perspectives on gamete and embryo donation

- 11.15-11.35 **"The indeterminacy of sperm: Reflections on the gendering of matter", Sebastian Mohr** (Centre for Medical Science and Technology Studies, University of Copenhagen, Denmark)
- 11.35-11.55 **"What is contained in a donated gamete?: Practices and concerns of classifications in IVF", Sven Bergmann** (Institut für Europäische Ethnologie, Humboldt University, Berlin, Germany)
- 11.55-12.05 **"Performing potentialities and creating realities of the foetal neural cell in therapy for Parkinson's disease" Andrèa Wiszmeg** (Department of Arts and Cultural Sciences, Lund University, Sweden)
- 12.05-12.50 Discussion

12.50-14.00 Lunch

Session 6: Reproducing Relations: Kinship patterns and relationships

- 14.00-14.20 **"Donor insemination and future generations: Implications for parenthood, ethical limits and legal regulation", Catarina Delaunay** (Centro de Estudos de Sociologia, CESNova, Universidade Nova de Lisboa, Lisbon, Portugal)
- 14.20-14.40 **"A web of relationships: Searching for donor siblings and donors", Tabitha Freeman** (Centre for Family Research, University of Cambridge, United Kingdom)
- 14.40-15.00 **"Parental bonding in gamete donation: Imagined relationships and evolutionary riddles", Carles Salazar Carrasco** (Department of Anthropology, University of Lleida, Spain)
- 15.00-15.20 **"Future investments: Law, technology and the order of kinship", Venetia Kantsa** (Department of Social Anthropology and History, University of Aegean)
- 15.20-16.20 Discussion
- 16.20-16.50 Coffee break
- 16.50-18.00 Network and publication plans**
- 19.00 Dinner

Thursday, 13 September 2012

Departure

5. Final list of participants

1. **Mr. Paul Just**, Research Assistant, Department of Political Science, University of Vienna (M) (25-35)
2. **Dr. Cathy Herbrand**, Lecturer in Sociology, Free University of Brussels (F) (25-35)
3. **Dr. Guido Pennings**, Professor of Ethics and Bioethics, Centre for Environmental Philosophy and Bioethics, University of Ghent (M) (45-55)
4. **Mr. Wannes van Hoof**, Research Assistant, Bioethics Institute, Ghent University, Ghent, Belgium (M) (25-35)
5. **Mr. Sebastian Mohr**, PhD Candidate, Centre for Medical Science and Technology Studies, University of Copenhagen (M) (25-35)
6. **Dr. Riikka Toivanen**, Psychologist, The Family Federation of Finland Fertility Clinics, Helsinki (F) (30-40)
7. **Dr. Maiju Tokola**, Psychologist, The Family Federation of Finland Fertility Clinics, Helsinki (F) (30-40)
8. **Mr. Sven Bergmann**, PhD candidate, Department of European Ethnology, Humboldt University, Berlin (M) (25-35)
9. **Dr. Venetia Kantsa**, Assistant Professor, Department of Social Anthropology and History, University of Aegean (F) (30-40)
10. **Dr. Enikő Demény**, Researcher, Centre for Ethics and Law in Biomedicine, Central European University, Budapest (F) (30-40)
11. **Professor Judit Sandor**, Department of Law and Political Science, Central European University, Budapest (F) (35-45)
12. **Dr. Luca Gianaroli**, Scientific Director, Società Italiana di Studi di Medicina della Riproduzione, SISMER, Bologna, Italy (M) (45-55)

