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**THE HUMAN FERTILISATION AND EMBRYOLOGY ACT 2008:
A MULTIDISCIPLINARY WORKSHOP**

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1. Background

1.1. The Genomics Forum

The ESRC Genomics Policy and Research Forum (the Forum)¹ is a novel initiative funded by the UK's Economic and Social Research Council (ESRC). The Forum is a knowledge exchange unit that aims to connect social science research on genomics and related areas of the life sciences with policymakers, business, the media and civil society. The Forum also has a capacity-building remit, strengthening UK and international research capacity in this field, and in particular building capacity for interdisciplinary research by enabling dialogue and networking between researchers in different disciplines. The Forum is based at the University of Edinburgh and is part of the ESRC Genomics Network,² a major ESRC investment spanning five UK universities, which researches ethical, legal and social aspects of genomics, biotechnology and the life sciences.

1.2. The Human Fertilisation and Embryology Act 2008

The Human Fertilisation and Embryology Act 2008 (HFE Act)³ was a landmark in national scientific decision-making, covering emotive issues such as the creation of human admixed embryos and 'saviour siblings'. The process of debate and policymaking leading to its passage has remained controversial after the fact, as have its myriad provisions and their impact in practice. The Forum's remit has placed it uniquely to engage with the legislation by bringing into dialogue different stakeholder groups (including scientists, social scientists, policymakers, journalists and patient groups), and ensuring that social scientific perspectives are heard.

1.3. Previous Events

The Forum's ongoing engagement with the HFE Act began in March 2009 with a major "Retrospective" workshop⁴ about the Act, which took place in London. This conference-scale event examined the nature of the public debate leading up to the Act and how this debate influenced the policy-making process, with a wide range of speakers including Phil Willis MP, Fiona Fox (Director of the Science Media Centre), and Dr Stephen Minger (King's College London). The majority of the HFE Act came into force in October 2009, and a second workshop⁵ was planned that month at the Genomics Network Annual Conference, to be topical and timely for regulators and

¹ <http://www.genomicsnetwork.ac.uk/forum/>.

² <http://www.genomicsnetwork.ac.uk/media/Workshop%20Forum.pdf>.

³ http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH_080211.

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<http://www.genomicsnetwork.ac.uk/forum/publications/egneventreportsvideospresentations/title,8496,en.html>.

⁵ <http://www.genomicsnetwork.ac.uk/media/Workshop%20Forum.pdf>.

policymakers, scientists and clinicians, social scientists and the media. Attendance at the Retrospective had identified that cutting-edge research on the HFE Act was being done at postgraduate level. Consequently, for this second workshop three current PhD students and recent graduates from the Genomics Network and beyond were invited to present their findings.

2. Workshop Objectives

At both of these previous events it was evident that scholars across a wide range of different social science and humanities disciplines were researching the legislation. However, these individuals were not being brought together, leaving scope for cross-disciplinary dialogue. Consequently the Forum conceived its next event in the series explicitly as a capacity-building and networking event for academics at all levels working in this area, bearing in mind especially the high proportion of postgraduates working on this topic.

More than two years since the HFE Act passed through Parliament, researchers had now had significant time to analyse the legislation's development, provisions and effects. We wanted to offer scholars from a range of different disciplines working on the Act (sociology, law, media studies, bioethics, and political science, for example) the chance to meet, network, share their findings, and begin discussions across disciplinary boundaries. The event covered the full chronology of the Act, including the policymaking process, legislative provisions themselves, and subsequent impact of the legislation.

Planning of the workshop was undertaken by Dr Christine Knight, Forum Policy Research Fellow, and Dr Malcolm Smith, who had spoken as a PhD student at the second of the Forum's workshops on this topic (looking specifically at the regulation of "saviour siblings"). Dr Smith was based at the Forum during January 2011 (when this event took place) as a Bright Ideas Programme Visiting Fellow,⁶ prior to taking up a lectureship in Law at Queensland University of Technology, Australia.

3. Workshop Presentations and Activities

3.1. Event Welcome and Introductions

The event was opened by the organisers and the Workshop commenced with a session of in-depth self-introductions by all participants. Given the wide scope of the HFE Act, this in-depth session enabled all participants to highlight the work being undertaken in this field and to outline their involvement with the 2008 Act. This proved beneficial in stimulating discussion from the outset and as a result, participants were actively engaged with other researchers throughout the day.

During the introductory session, Sarah Norcross, Commissioning Editor of *BioNews* and Director of Progress Educational Trust (PET), provided an overview of an event which took place two days prior to the Workshop: "The End of the HFEA: Are We Throwing the Baby out with the Bathwater?"⁷ Norcross summarised some of the main themes from the PET event, and given the significant role of the Human Fertilisation

⁶ <http://www.genomicsnetwork.ac.uk/forum/people/brightideasfellowshipsandresidencies/>.

⁷ http://www.bionews.org.uk/page_87217.asp.

and Embryology Authority (HFEA) in administering the statutory framework, this session served as a powerful reminder of how the proposed abolition of the HFEA would severely impact on the current statutory framework.

3.2. Workshop Presentations

Over the course of the day, four papers were presented, each covering very different issues under the scope of the 2008 Act. The first paper entitled “Selling Science: Source Struggles, Public Relations, and the Newspaper Coverage of Hybrid Embryos”⁸ was presented by Dr Andy Williams, RCUK Research Fellow in Risk, Health and Science Communication at Cardiff University. The focus of this fascinating paper was centred on an analysis of the media coverage of the hybrid embryo debate.

As part of his research, Dr Williams had analysed an array of media sources to assess how this specific issue had been portrayed by the UK media. His research was also informed by a number of interviews with key participants in the media debates, such as news sources and behind-the-scenes media managers. The paper considered the influence of the Science Media Centre (SMC) on the coverage of the hybrid embryo issue, a subject which was also intensely debated at the Forum’s HFE Act “Retrospective” event. Dr Williams drew attention to the so-called public relations “war-council”, a coalition which was formed as a media management strategy in favour of the hybrid embryo issue and included members of the SMC, disease charities, learned societies, and UK funding bodies. It was observed that this particular media strategy resulted in a practice of “churnalism” – a form of media coverage heavily influenced by PR, rather than quality science journalism. Dr Williams then considered some of the main implications of this strategy and outlined the recurring themes within the media concerning arguments for, and in opposition to, hybrid embryo research. Dr Williams’ paper provided a fascinating insight concerning the influence of these strategies on the UK media, which led to a lively discussion between participants of how such factors had impacted on the legislative process surrounding the passage of the 2008 Act through Parliament.

The second paper of the day, entitled “Abortion and the HFE Act 2008: The Substantive Representation of Women”,⁹ was presented by Professor Sarah Childs, Professor of Politics and Gender at the University of Bristol. Professor Childs highlighted what she deemed to be an inadequacy of parliamentary time for debating abortion under the realm of the bill as it progressed through Parliament. She then considered a number of specific issues in the context of the abortion debate, such as late-term abortion and the emphasis on parental decision-making in cases of foetal disability. This presentation provided an interesting perspective on the factors influencing debate in the context of this politically sensitive topic.

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http://www.genomicsnetwork.ac.uk/media/Andy%20Williams%20presentation_HFE%20Act%20workshop.pdf.

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http://www.genomicsnetwork.ac.uk/media/Sarah%20Childs%20presentation_HFE%20Act%20workshop.pdf.

Although the main focus of Professor Childs' paper concerned the representation of women during the political process, the paper also charted the input of men on debate. The paper referred to the fact that men had a tendency to rely on the terrain of science to inform contribution to the debate. Women on the other hand (particularly those affiliated with the Labour Party) were more inclined to make reference to the "right to choose" and to consider the impact that any restrictions on access to abortion services may have on the health of women. Professor Childs also reminded participants that the quality of the debate is just as important as the outcome in legislative terms.

The morning session generated lively debate and discussion between participants which continued over lunch. In the afternoon, the Workshop progressed with two further papers, both presented from a legal perspective. Dr Julie McCandless, Lecturer in Medical Law and Family Law at the London School of Economics, presented the third paper of the day entitled "Cinderella and Her ugly Sister: Parenthood and Welfare in the HFE Act 2008". Dr McCandless posed the question as to why, out of the eighty hours of parliamentary debate concerning the 2008 Act, eight of those hours were spent debating the proposal to remove the "need for a father" requirement under the welfare clause, while only one was concerned with the parenthood provisions. This presentation generated discussion between participants concerning the abolition of the "need for a father" requirement which has been replaced with the requirement to consider the potential child's need for "supportive parenting". This same issue had similarly dominated parliamentary debate. Some participants questioned whether the change to the "welfare clause" makes any difference in practice. Thus, it was accepted that the former "need for a father" requirement had not prevented single women or lesbian couples from accessing reproductive services. Why then, was parliamentary debate so focused on an issue which had already been accepted in practice?

Turning to consider the reformed parenthood provisions, Dr McCandless outlined the complexities of the changes to the law and how they impact on differing family units within modern society. To bring the law into line with changes in social attitudes and other legislative developments (such as the Civil Partnership Act 2004), the HFE Act now recognises the legal status of same-sex parents who conceive via assisted conception techniques. Despite these changes however, Dr McCandless highlighted some of the inconsistencies in the reformed law, which in many respects still prioritises bio-genetic links between parent and child for the purposes of establishing legal parentage. This led to the conclusion that the law unjustifiably prioritises bio-genetic links in some cases, but ignores their relevance in others. Participants therefore questioned whether the legislative changes reinforce traditional notions of the family unit in modern society and wondered why these provisions were not considered further by Parliament.

The final paper of the day was presented by Dr Malcolm Smith, co-organiser of the Workshop and resident at the Forum as a Bright Ideas Programme Visiting Fellow in January 2011. Dr Smith's paper, entitled "Restrictions to IVF and Pre-implantation Tissue-typing for the Creation of 'Saviour Siblings': An Examination of the UK Regulatory Approach from a Harm Perspective",¹⁰ sought to analyse the regulatory

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http://www.genomicsnetwork.ac.uk/media/Malcolm%20Smith%20presentation_HFE%20Act%20workshop.pdf.

position concerning IVF when it is used to create a tissue-matched child. This final presentation provided participants with an overview of the UK regulatory developments concerning this contentious issue and considered the impact of the changes imposed under the 2008 Act. Dr Smith outlined the normative factors underpinning the development of regulatory policy in this field and used the harm principle to analyse the restrictions imposed under the reformed HFE Act. The main argument put forward was that the restrictive approach is disproportionate when considered in comparison to the potential harms that may result to any child born as a 'saviour' following IVF. This presentation encouraged participants to question the underlying principles guiding regulatory policy on this issue and the session finished with a discussion concerning future regulation should the HFEA be abolished.

4. Conclusions and Next Steps

4.1. Concluding Session

The final hour of the Workshop took the form of a group discussion and enabled participants and speakers to reflect on the day's events. Dialogue concerning the papers continued into this final session and a number of key themes from the course of the day were noted, ranging from the nature of identity and kinship, to access to assisted reproduction services, and the value of public engagement and consultation. The event proved successful in bringing together a range of researchers and highlighting overlapping research interests between participants. As outlined at the start of this report, participants came from a wide range of disciplines, yet as the day progressed it became evident that research interests overlapped significantly. Positive feedback was provided concerning the potential for future collaboration between participants, and this has been reflected subsequently in new lines of communication amongst the group.

4.2. Future Outcomes

The final session was also used as an opportunity to consider the next steps following the Workshop and establish whether the Forum might facilitate further activities for knowledge exchange concerning research on the 2008 Act. Direct outputs from the event include this report and an event review prepared by Sarah Norcross, which appeared in *BioNews* on 31 January 2011.¹¹ The event organisers and Workshop participants noted that there was no existing literature published in the form of a collection (e.g. an edited book or a special edition journal publication), which addresses the scope of the parliamentary process and debate surrounding the passage of the 2008 Act, together with an analysis of the Act's provisions. We have therefore identified an opportunity to publish a collection of papers as a special edition journal issue (including a range of papers from the speakers and other participants involved with the Workshop). The details concerning this are currently being finalised.

¹¹ http://www.bionews.org.uk/page_87717.asp.