

<p>Institution: Middlesex University</p>
<p>Unit of Assessment: 4 (Psychology, Psychiatry and Neuroscience)</p>
<p>Title of case study: Psychosocial impacts of Medically Assisted Reproduction (MAR)</p>
<p>1. Summary of the impact (indicative maximum 100 words) Middlesex University's Applied Health Psychology research on Medically Assisted Reproduction (MAR) has impacted in three areas. First, all Parental Order Reporters and accredited Infertility Counsellors in the UK are exposed to the research through standard professional training and practice materials. Secondly, research has informed Human Fertility and Embryology Authority (HFEA) policy on surrogacy and gamete donation. Thirdly, HFEA-commissioned research on elective Single Embryo Transfer (eSET) and stakeholder group membership has contributed to national guidelines, resulting in decreased numbers of embryos transferred in UK clinical practice, dramatically reducing multiple births and associated maternal and infant morbidity and mortality.</p>
<p>2. Underpinning research (indicative maximum 500 words) <u>Context:</u> MAR is universally used to treat infertility, but gamete donation, surrogacy and multiple embryo transfers pose challenges to the individual and society, and are under-studied. A distinctive element of the research carried out by Professor Olga van den Akker and Dr Sati Purewal (both of whom work within the Department of Psychology and are submitted in this Unit) is the application of a psychosocial approach and insights to a field which is often seen as purely medical. Some of our research derives directly from problems identified as a result of technological interventions in family building, and we investigate these using a variety of research methods, including RCTs.</p> <p><u>Informing Policy:</u> There is a shortfall of gametes from ethnically diverse UK populations. Purewal and van den Akker explained the perceived costs and benefits of gamete donation (3.4), and predicted direct and mediating variables in decisions to become a donor (3.3). The value of a genetic link was seen as being of key importance. A quasi experimental framing study using structural equation modelling confirmed the importance of genetics in people's willingness to donate. We found that offspring links predicted intention to donate in the 'gain' framed condition in White but not South Asian populations, with behavioural control mediating these ethnic differences (3.5). White women were less likely to see a genetic link as an important reason not to donate if they could help infertile women, whereas for South Asian women the importance of a genetic link was a deterrent to donating their oocytes, regardless of the way the question was framed. For South Asian women, low levels of behavioural control over decisions to donate mediated their unwillingness to donate their gametes. This research (3.3 – 3.5) and a SRIP-funded workshop led to a clearer understanding of the cultural barriers in (inter)national gamete donor recruitment, and the research on surrogacy has contributed to policy discussion documents as outlined in Section 4.</p> <p><u>National guidelines:</u> van den Akker and Purewal were commissioned by the Human Fertilisation and Embryology Authority (HFEA) to continue research into the reasons why patients and clinicians were unwilling to opt for single embryo transfer. Evidence that multiple births are the single biggest risk to the health and welfare of children born after IVF is irrefutable. The resulting RCT used a fear appeal and framing conditions, and showed that the use of complex (fearful) persuasive communication techniques to promote eSET is more successful than education. This research has been made available on the HFEA website for practitioners and patient information (3.2) and such research and stakeholder participation led to reductions in multiple births in the UK.</p> <p><u>Professional training:</u> Poote (Warwick) and van den Akker have shown that attitudes to surrogate motherhood remain negative, with consequent implications for disclosure, stigma and attachment to the surrogate baby (3.6). Despite negative attitudes, numbers of Parental Orders granted in the UK following (inter)national surrogacy arrangements have increased by 186% since 1995, and eligibility criteria have been extended to unmarried and same-sex couples (3.1). Using data from UK General Register Offices, Child and Family Court Advisory and Support Services for England and the UK surrogacy agencies, Crawshaw (York), Blyth (Hull) and van den Akker charted the decline in involvement of surrogacy agencies (3.1). The potential for exploitation of internationally</p>

brokered unregulated surrogacy arrangements is a threat to the welfare of children, surrogates and intended parents. Recommendations reviewing national and international policy and practice are made through this research (3.6 and 3.1). A second SRIP-funded workshop was successfully applied for, and which included policy and charity representatives, clinicians and social scientists, to ensure that new policy and practice to MAR family building was informed by research.

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

Key Publications

- 3.1 Crawshaw M., Blyth, E. & van den Akker, O. (2012) The changing profile of surrogacy in the UK – Implications for policy and practice. *Journal of Social Welfare and Family Law*, 1–11. doi: 10.1080/09649069.2012.750478 (citation count: 0)
- 3.2 van den Akker, O. & Purewal, S. (2011) Elective single-embryo transfer: persuasive communication strategies can affect choice in a young British population. *Reproductive Biomedicine Online. Ethics Bioscience and Life*, 23,7, 838-850. doi: 10.1016/j.rbmo.2011.07.022 (citation count: 3)
- 3.3 Purewal, S., & van den Akker, O.B.A. (2010). Attitudes and Intentions to Donate Oocytes for Research. *Fertility and Sterility*. 93,4, 1080-7. doi: 10.1016/j.fertnstert.2008.11.021 (citation count: 8)
- 3.4 Purewal, S., & van den Akker, O. B. A. (2009). Systematic review of oocyte donation: investigating attitudes, motivations and experiences. *Human Reproduction Update*. 15 (5):499-515. doi: 10.1093/humupd/dmp018 (citation count: 32).
- 3.5 Purewal, S., & van den Akker, O.B.A. (2009) A study of the effect of message framing on oocyte donation. *Human Reproduction*. 24(12):3136-3143. doi: 10.1093/humrep/dep342 (citation count: 7).
- 3.6 Poote, A. & van den Akker, O.B.A. (2009) British women’s attitudes to surrogacy. *Human Reproduction*, 24,1, 139-145. doi: 10.1093/humrep/den338 (citation count: 18).

Evidence of excellence:

Citation counts for all references are provided above. All journals are high quality and peer reviewed.

Funding for research includes:

- van den Akker, Baluch and Purewal £1000 ‘Future directions in infertility research and practice’: An international interdisciplinary SRIP-funded workshop, awarded to Middlesex University (2008).
- van den Akker and Purewal £5000. ‘An RCT assessing attitudes to Single Embryo Transfer.’ Human Fertilization and Embryology Authority, awarded to Middlesex University (2010).
- Purewal and van den Akker £7,400. A meta analysis on the psychological and behavioural variables predicting In Vitro Fertilization treatment outcome: A path analytic investigation. British Academy, awarded to Middlesex University (2010).
- van den Akker and Crawshaw (PROGAR/BASW) £1500 ‘A research- and practice- informed approach to family building using donor conception’ An international interdisciplinary SRIP-funded workshop at the Nuffield Foundation and BMA offices, London, awarded to Middlesex University (2012).

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

The WHO estimates that in 2010, 48.5 million couples worldwide were unable to have a child. Many of these seek MAR treatment, some using third party gametes and/or surrogacy. The psycho-socio-cultural consequences of MAR can be enhancing or devastating to quality of life. Our research impacts on the prevention of devastating consequences of MAR through practitioners, policy, and guidelines. Professor van den Akker’s research and membership of Project Group on Assisted Reproduction (PROGAR) ensures evidence based practice informs consultations (5.7) to shape future policy and practice.

Informing policy: Research has informed HFEA policy, through its Ethics and Law Advisory Committee, and has been included in two decision papers, one on Intergenerational donation (5.3), and a second on sperm, egg and embryo donation (5.4). Publication 3.4 supported the HFEA Ethics and Law Advisory Committee (2009) and the Sperm, Egg and Embryo donation Policies (2009). The research review systematically assessed the type, quality and implications of

Impact case study (REF3b)

the psycho-socio-cultural research carried out on gamete donations and led to thorough evidence based conclusions on how future policy should be shaped. The research syntheses revealed distinct differences between patient and non patient (known, commercial, volunteer and potential) donors on demographic characteristics, motives for donation, and issues relating to disclosure and attitudes towards the resultant offspring. Importantly, a significant proportion of oocyte donors and women from the general population were prepared to donate their oocytes as identifiable donors, contrary to previously held (but generally unsubstantiated) beliefs. Donor group differences highlight the need for tailored psychosocial evaluation and counselling. The systematic review also highlighted the important findings that donors are primarily motivated to donate gametes because of their personal views relating to benefits of having a family, and the importance of cultural differences in willingness to donate, which is currently leading to shortages in gametes from non-white populations. The wider donation context was recognised by the HFEA and a tailored approach to recruitment campaigns was advocated and implemented (see 5.4), following a public consultation, and a new policy document which used our research.

National guidelines: van den Akker was appointed to the HFEA's 'one at a time' stakeholder group which aimed to reduce the risks of multiple pregnancies from MAR via guidelines covering every aspect of practice: patient education and selection, embryo selection and freezing, and costs and funding issues. She has contributed to the development of these professional guidelines for elective single embryo transfer (eSET) and the provision of essential information to help clinics introduce eSET policies. This has played a key role in reducing the multiple birth rate by introducing realistic, research based, and achievable targets (5.5), 24% in 2009/10, 20% in 2010/11 and 15% in 2011/12. The HFEA also commissioned research to help design effective mechanisms for single embryo transfer communication in clinical practice, and this is currently listed on the 'One at a Time' stakeholder website.

In the absence of official sources of information for some groups of donor-conceived people, voluntary linking services such as the Donor Sibling Registry (DSR) and UK DonorLink (UKDL) have emerged, enabling donor-conceived offspring, donors and donor siblings to try and identify each other either through anonymous donor numbers, or DNA testing, respectively. Currently, 38,000 members are registered; 1,800 are egg or sperm donors, the vast majority are donor conceived offspring. Since the DSR was established in 2000, more than 9,700 matches have been made between donor offspring and their donor connections. Our research addressing genetic origins and anonymous donations showed that the latter were detrimental to family building, whereas type of family (single, heterosexual or homosexual couples) seeking donation has no differential impact on children's emotional and intellectual development or on their family relationships (3.1), and informed The Nuffield report on the Ethical aspects of information sharing (5.6).

Professional training: Two Society for Reproductive and Infant Psychology (SRIP) funded workshops (2008 and 2012) addressed future directions of embryo transfers, surrogacy and family building using gamete donation. Interdisciplinary (inter)national participant representatives from Government, patient groups, academics and professionals worked together to acknowledge the problems and to improve future third party MAR outcomes. The representatives' active involvement with our research (3.1, 3.3-3.5 and 3.6) led to the development of new practice-based research, involving Middlesex University and patient support groups (INUK, UK DonorLink). This impacts on tailored services (tracing donor links/genetic testing) for donor-conceived offspring seeking a more complete identity (5.1), and highlights the importance of attachments in non-genetic/non-gestational parenting (5.2).

The Children and Family Court Advisory and Support Service (CAFCASS) cites our research on surrogacy in its Research and Resources Bulletin 10 (5.1) which has been sent to around 400 staff, members of the Judiciary and HM Courts Service who sign up to it, and placed on the CAFCASS intranet, to which all staff (over 1000 Family Court Advisors) have access. It has informed professional understanding of the processes involved, and impacted upon Parental Order Reporters' practice in preparing their case studies for court. Evidence for this comes from relevant stakeholders (CAFCASS, lawyers and immigration officials) requests for involvement at our planned round table workshop (November 2013) to discuss improvements in registrations, for UK and overseas surrogate babies and 5.1.

Impact case study (REF3b)

Finally, the British Infertility Counselling Association (BICA) confers accreditation on all UK-based specialist infertility counsellors. BICA has used our research (3.6) in their professional training materials, which are available to all accredited infertility counsellors, thereby informing practice (5.2). BICA has developed the first accredited scheme for infertility counsellors in the World.

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

- 5.1 The CAF/CASS guide link 'Key Messages from research' in their Research and Resources Bulletin 10 and cites our research on Surrogacy (Denis Jones Research Officer CAF/CASS, 2012)
- 5.2 BICA training materials and details on infertility counsellors. Approximately 70 currently listed accredited infertility counsellors (see http://www.bica.net/accredited_members).
- 5.3 HFEA Ethics & Law Advisory Committee (2009) Intergenerational family donation of gametes and embryos. http://www.hfea.gov.uk/docs/2009-07-07_-_Intergenerational_donation_-_ELAC.PDF
- 5.4 HFEA Ethics and Law Advisory Committee Decision paper (2009): Sperm Egg and Embryo Donation Policies. http://www.hfea.gov.uk/docs/2009-12-09_Authority_papers_-_528_SEED_Evaluation.pdf
- 5.5 One at a time National Strategy Multiple Births Stakeholder Group. Membership at <http://www.oneatatime.org.uk/145.htm> Summary of research impact at <http://www.oneatatime.org.uk/498.htm> (see section 5 of report).
- 5.6 The Nuffield Council's report '*Donor conception: ethical aspects of information sharing*'. www.nuffieldbioethics.org/sites/default/files/Donor_conception_report_2013.pdf (see p. 82)
- 5.7 British Association of Social Workers, Project Group on Assisted Reproduction (PROGAR). See <http://www.basw.co.uk/progar/>, under publications and resources.