

Institution: De Montfort University
Unit of Assessment: 3
Title of case study: Social Aspects of Assisted Reproduction
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>This case study draws on social research on endometriosis, infertility and assisted reproduction dating from 2002 to 2011, and encompasses several distinct research projects. This body of work has been directed towards: improving patients' understandings of these conditions (particularly among South Asian communities); facilitating access to appropriate healthcare services; enhancing the awareness of healthcare practitioners and policy makers around key issues affecting patients and communities in the field of reproductive technologies; and facilitating debate to inform policy in the regulation of such technologies.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>A lack of patient information about infertility and problems of access to fertility treatment have been highlighted as persistent concerns, particularly (though not exclusively) in relation to members of culturally and linguistically diverse communities. The awareness of healthcare providers of the impact of living with conditions such as endometriosis and infertility in all communities has also been shown to be limited, with consequent impact on quality of care provided. This case study encompasses several linked research projects which sought to address these and related issues of policy and practice.</p> <p><i>A Study of the Provision of Infertility Services to South Asian Communities: Improving Policy and Practice ('ASFERT')</i> (Trent Region NHS, 2002-2004. Grant-holding institution, DMU) led by Dr Lorraine Culley (then Reader in Health Studies at DMU) with CIs: Prof Mark Johnson (DMU), Dr. F. Rapport (Swansea University), Dr. S. Katbamna (the University of Leicester) and research fellow N. Hudson (DMU). This project explored unique community understandings of infertility and its treatment and identified barriers to services for British South Asian communities. Major outputs included a collaboratively developed patient resource 'Trying for a Baby' (booklet and CD in four South Asian languages) and an educational resource for health professionals giving guidance on culturally sensitive infertility care [1,2].</p> <p>Similar outputs were produced for the condition of endometriosis (one cause of infertility) by the 'ENDOCUL' study: <i>Endometriosis and Cultural Diversity: Improving services for minority ethnic women</i> (NIHR RfPB Programme, 2008-2010. Grant-holding institution BCU), PI Prof Elaine Denny (Birmingham City University), CIs: Prof Lorraine Culley (DMU), Prof Irena Papadopoulou (Middlesex). The findings highlighted specific cultural and religious contexts as significant elements of the experience of endometriosis and infertility. Outputs included DVDs tailored to five minority ethnic communities and an online educational resource for health professionals [3].</p> <p>An issue which arose in both of the above projects was an acute shortage of gametes available to South Asian couples in fertility treatment. The study: <i>Public Perceptions of Gamete Donation in British South Asian Communities</i>, 'GAMDON' (ESRC, RES -160-25-0044, 2005-2006. Grant-holding institution DMU). PI Culley, CIs: Johnson (DMU), Rapport (Swansea), Bharadwaj (Edinburgh) and research fellow Hudson (DMU) addressed this issue. This study (evaluated as 'outstanding' by the ESRC) found a very low public profile of donor treatment and donor shortages. The project had a high degree of stakeholder and public involvement in its design and delivery and impacted upon the work of the National Gamete Donation Trust [4, 5].</p> <p>One key issue which emerged from ASFERT and GAMDON was an apparent movement of people abroad for fertility treatment (fertility tourism). The causes and consequences of this in the UK were investigated for the first time in relation to UK residents in the 'TRANSREP' study: <i>Transnational Reproduction. An exploratory study of UK residents who travel abroad for fertility treatment</i> (ESRC, RES 000-22-3390, 2009-2011). PI Culley (DMU), CIs: Hudson and Wendy Norton (DMU), Rapport (Swansea); Prof E. Blyth, (Huddersfield); Dr. A. Pacey (Sheffield). This project demonstrated that a</p>

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shortage of gamete donors was a major driving force for cross border reproductive travel and made recommendations for a range of stakeholders to both reduce the need for travel and facilitate good practice to safeguard patients who undertake such journeys [6].

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

- *1. **Culley, L. Hudson, N.** Rapport, W. (2013) Assisted Conception and South Asian communities in the UK: public perceptions of the use of assisted conception in the UK: public perceptions of the use of donor gametes in infertility treatment. *Human Fertility*. 16 (1): 48-53.
2. **Culley, L., Hudson, N,** Rapport, F, **Johnson, M,** Katbamna, S (2006) British South Asian Communities and Infertility Services. *Human Fertility* 9(1): 37-45.
3. Denny, E, **Culley L,** Papadopoulos, R. (2011) From womanhood to endometriosis: Findings from focus groups with women from different ethnic groups. *Diversity in Health and Care*, 8 (3): 167-180.
- *4. **Culley, L. and Hudson, N.** (2009) 'Constructing relatedness: Ethnicity, gender and third party assisted conception in the UK', *Current Sociology* vol 57 no 2, Monograph 1 pp.257-275.
5. **Hudson, N. Culley, L.** Rapport, F. **Johnson, M.** Bharadwaj, A. (2009) "Public" perceptions of gamete donation: a research review' *Public Understanding of Science*, 18 (1): 61-77.
- *6. **Culley, L. Hudson, N.** Rapport, Blyth, **Norton, Pacey.** (2011) Crossing Borders for Fertility Treatment: Motivations, Destinations and Outcomes of UK fertility travellers. *Human Reproduction*, 26 (9): 2373-2381.

All publications have been subject to peer review. DMU researchers in bold.

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

This body of research has achieved impact in a number of areas:

1. Improved access to information for patients with a diagnosis of infertility and/or endometriosis, especially in languages other than English. The ASFERT project found no existing information from UK healthcare providers on infertility in any language other than English and this was shown to be a barrier to good communication. Booklets and CDs [*Trying for a Baby*] produced in Punjabi, Gujarati, Bengali, and Urdu were distributed (on request) to 30 infertility clinics for use with South Asian patients. PDFs of these resources are available to the public and health professionals via the DMU website. These remain in use as key resources with over 300 copies distributed to clinics and individuals (2005-present). In 2009, the ENDOCUL study produced DVDs specifically tailored to five minority ethnic communities. These are in use in at least five major hospital sites in: the West Midlands (Birmingham Women's Hospital, City Hospital Birmingham, Sandwell Hospital); Leicester (University Hospitals of Leicester); and London (Whittington), providing information on the condition and its management for patients. This material is also available via YouTube, where it had received ca. 500 views in one year (until 31st July 2013). The DVD material and an educational resource for professionals is also publicly available from www.endocul.co.uk. As of 31st July 2013 248 health professionals have taken the educational training course online.

2. Facilitation of dialogue between infertility professionals, patients, and their support representatives in the voluntary sector. The TRANSREP project held a successful stakeholder event attended by 22 invited delegates including patients, support groups and clinicians (including from overseas clinics), third sector groups, the HFEA and the British Fertility Society (2009). TRANSREP was also the subject of two public lectures attended by 150 people on each occasion (2009, 2010). These activities formed the basis of a series of recommendations about policy on cross-border care, which were used by the HFEA to inform their 2011 review of donation policy.

3. Development of a network of local skilled community based South Asian research facilitators. The ASFERT, GAMDON and ENDOCUL (2002-09) projects recruited, trained and employed a team of bilingual members of South Asian communities to conduct qualitative

fieldwork. The ENDOCUL project was showcased by INVOLVE (2010) as an excellent example of public and patient involvement.

4. An improved understanding of patients' experiences of infertility and use of assisted reproduction amongst healthcare professionals and patient support group representatives.

The studies have been presented and discussed at over 20 national and international meetings of infertility and reproductive medicine specialists between 2008-2012. TRANSREP has generated invitations to speak at three national events specifically aimed at fertility nursing staff, an event organised by the International Infertility Counselling Organisation in Munich and a plenary address at a joint conference of the British and Irish Fertility Societies and the Association of Clinical Embryologists (2010). Combined attendance at these events included 2,500 fertility professionals. Findings and recommendations from the TRANSREP project have also been recorded as an international IVF podcast for fertility professionals and has received 3188 hits by 31st July 2013. Media coverage of the ENDOCUL and TRANSREP projects in particular has been extensive, including radio interviews and features (BBC Asian Network, BBC Women's Hour Radio 4; BBC World Service; BBC World TV and several local and regional stations, see also www.transrep.co.uk).

5. Co-development of strategy for recruitment of minority ethnic donors. Following the GAMDON study in 2006, the findings were used to develop, in collaboration with the National Gamete Donation Trust, a strategy to enhance the recruitment of egg and sperm donors from minority ethnic communities across the UK.

6. Enhanced awareness of key issues in infertility and related conditions for policymakers and regulators nationally and internationally.

The Human Fertilisation and Embryology Authority (HFEA - the licensing authority for all infertility treatment in the UK) and patient support groups (Infertility Network UK, Donor Conception Network, Daisy Network) have been heavily involved in supporting our work. Evidence includes involvement in stakeholder meetings, invitations for team members to speak at HFEA meetings, contributions to HFEA debates and 'Horizon Scanning' events and information gathering exercises. The TRANSREP study was discussed and minuted at a public meeting of the HFEA in the context of the HFEA Donation Review. In addition, Culley was invited to:

- work with the European Society for Human Reproduction and Embryology Task Force on Cross Border Reproductive Care which produced an International Code of Practice, which is now being implemented in European member states
- present evidence to the International Society for Cross Border Care (Clinical group), who are developing international clinic accreditation
- present evidence to the Nuffield Council for Bioethics Working Party on Human Tissue Donation. Reference to GAMDON and TRANSREP projects are included in the Nuffield report
- to discuss the TRANSREP and GAMDON studies with Gareth Johnson MP, Chair of the All Party Parliamentary Committee on Infertility to inform their work: a meeting was held at Westminster in June 2011

In February 2012 Hudson gave evidence at the Nuffield Council on Bioethics Working Party on Donor Conception: ethical aspects of information sharing. Both the GAMDON and TRANSREP findings were used in the report from this consultation, which made a number of recommendations for the regulation of donor treatment in the UK.

In the commercial sector, the team have provided advice to Intuition Communication, a major commercial player in international web-based information for medical travel via the Managing Director. This company are preparing a website specifically targeting infertility travellers with information on overseas providers and how to ensure safe treatment. An extensive interview with Professor Culley was published in the International Medical Travel Journal published by Intuition Communication for healthcare providers in medical travel with a circulation of 8,500 readers.

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

Section 4.1.

- Copies of the booklets and DVDs are available from the research team upon request.
- Material on YouTube can be accessed at <http://www.youtube.com/user/endocul#p/u> (accessed 05/08/13)
- The educational resource can be accessed at <http://breeze.mdx.ac.uk/p24169437/> (accessed 05/08/13)

Section 4.3.

- The evidence for the involvement of stakeholders at the stakeholder event can be obtained upon request by the authors of the case study
- The Head of Policy, Human Fertilisation and Embryology Authority is prepared to verify our claims about the contribution to the 2011 review of donation policy

Section 4.4.

The ENDOCUL project was showcased by INVOLVE in 2010 as an excellent example of public and patient involvement. INVOLVE is a national advisory group that supports greater public involvement in NHS, public health and social care research (www.invo.org.uk) Section 4.4

- Copies of invitations to speak can be made available upon request by the authors of the case study
- IVF Podcasts: Educational and historical IVF videos 'Transnational Reproduction' available at: http://ivfpodcasts.com/IVF_Podcasts/Podcasts.php?Transnational-Reproduction-47 (see above, 4.4)
- Evidence of the media coverage of the projects can be accessed from the DMU Press Office.

Section 4.5.

- The Chair of the National Gamete Donation Trust (who is also a member of the HFEA Donation Strategy Group) is happy to verify our claim that we jointly developed a strategy to enhance the recruitment of donors from ethnic minority communities

Section 4.6.

- In addition to contacts listed previously, the Chief Executive, Infertility Network UK is prepared to describe their support for our work.
- The HFEA (2010) Ethics and Law Horizon Scanning Seminar report is available at: http://www.hfea.gov.uk/docs/2010-03-25_-_Ethics_and_Law_Horizon_Scanning_report.pdf (accessed 05/08/13) – HFEA minutes are available from [http://www.hfea.gov.uk/docs/2010-06-22_-_ELAC_-_minutes\(1\).pdf](http://www.hfea.gov.uk/docs/2010-06-22_-_ELAC_-_minutes(1).pdf)
- The co-ordinator of ESHRE Task force on Cross Border Reproductive Care can verify our contribution to the International Code of Practice, which is being implemented in European member states. The code itself can be accessed here: <http://www.ncbi.nlm.nih.gov/pubmed/21505043> (accessed 05/08/13)
- The Nuffield Bioethics Working Part on Human Tissue Donation can be accessed here (see pp94-95 p133 and p220) http://www.nuffieldbioethics.org/sites/default/files/Donation_full_report.pdf
- Nuffield Council on Bioethics (2013) Donor Conception: ethical aspects of information sharing is available at: <http://www.nuffieldbioethics.org/donor-conception> (accessed 05/08/13)
- The interview with Prof Culley is available at <http://www.imtj.com/articles/2011/why-uk-patients-travel-for-infertility-treatment-abroad-30105> (accessed 05/08/13)
- The Managing Director of Intuition Communication can be contacted to verify advice provided to the company by the team.