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Summary Report

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1. Introduction

In the United Kingdom (UK) it is estimated that one in six couples will experience difficulty in conceiving a child (Boivin 2007). Over the last 25 years many new procedures have emerged to overcome infertility using Assisted Reproductive Technologies (ART) such as in vitro fertilization (IVF), the most common form of ART in the western world. There are indications that, for a variety of reasons, individuals and couples are increasingly traveling abroad to access ARTs. This process has been variously labeled as 'fertility' or 'procreative tourism'; 'reproductive exile' and 'cross-border reproductive care'.

There has been little in the way of systematic study of the cross border use of ARTs and in

Concern at the possible consequences of cross border reproductive travel has been voiced by clinicians, regulators, policy makers, infertility support groups and social workers (Deech 2003, Blyth & Farrand 2005, Science and Technology Select Committee 2005, HFEA 2006, Leather 2006) who have raised issues about quality, safety requirements and standards of treatment and care in some countries and the consequences for children conceived from overseas treatments involving anonymous donors. The media have also widely reported the issue of 'fertility tourism' and much of this has been negative, suggesting that those seeking treatment abroad are older women who have 'left it too late' to have treatment in the UK and who are returning home pregnant with triplets and putting a huge burden on the NHS.

more detailed research. This piece of work has been published in the journal Reproductive Biomedicine Online (Hudson et al. 2011).

4.2 Key informant interviews

We interviewed 15 'key informants' including clinicians, nurses, counsellors, support group and policy representatives. Participants were invited to give their views on cross border treatment, as well as providing contextual information to aid the development of our user interview schedules. All the key informants felt that treatment overseas was a legitimate 'choice' for patients, especially in the context of limited public funding and limited availability of some treatment options in the UK. At the same time, however, they felt that the choice to go overseas could entail some risks for patients and families. Concerns were expressed about the control of quality and safety standards in some overseas clinics; the need to protect patients against incompetence, negligence and recklessness on the part of some practitioners; the absence of counselling and inadequate information about possible health risks. Some were concerned at the possibility of an increase in multiple pregnancies from overseas treatment and the infertility counsellors expressed concern for donor-conceived children who might not have the opportunity to know the identity of the donor. Most key informants stressed the importance of good public and patient information to assist people in evaluating the potential risks and benefits of foreign treatment and the claims made about success rates in countries with little or no official monitoring of standards or safety. A small number of participants discussed potential risks to donors overseas who might have inadequate information about the physical and emotional risks of donation and might be open to 'exploitation' as a result of being offered higher rates of compensation for egg donation than those available in the UK.

4.3 Travellers seeking fertility treatment abroad

Our study included interviews with 41 women and 10 men, constituting a total of 41 'cases' (a case is defined as either an individual or a couple seeking treatment together). This sample included 24 heterosexual women in a couple but participating in the study alone; 10

Table 1. Female age at time of first treatment abroad	
Mean female age	**38.8 years**
Range	**29-46 years**
Average age UK treatment seekers (HFEA 2010a)	**35.2 Years**

At the time of the first treatment abroad, the women's mean age was 38.8 years (Table 1), which is not substantially older than UK treatment seekers more generally (35.2 years) and reflects the fact that many participants had already had treatment in the UK.

At the time of interview the mean (average) female age was 40.71 years (range 29-48 years) and the mean male age was 41.3 years (range 28-65 years).

The participants were predominantly white (92%), with 4% of participants describing their ethnicity as British Asian, 2% Black British, and 2% mixed ethnicity (Indian and White).

Occupational status

The participants were, broadly speaking, of professional, middle-class background. Their occupational breakdown, derived using NS-SEC classifications (ONS 2008), was as follows: 72% (n= 37) professional and managerial occupations, 18% (n=9) intermediate occupations, 2% (n=1) routine and manual occupations, 6% (n=3) were full time parents, and 1 was a student (2%). This profile is similar to that of other users of private health care services, including fertility treatment (Throsby 2004).

Marital and parental status

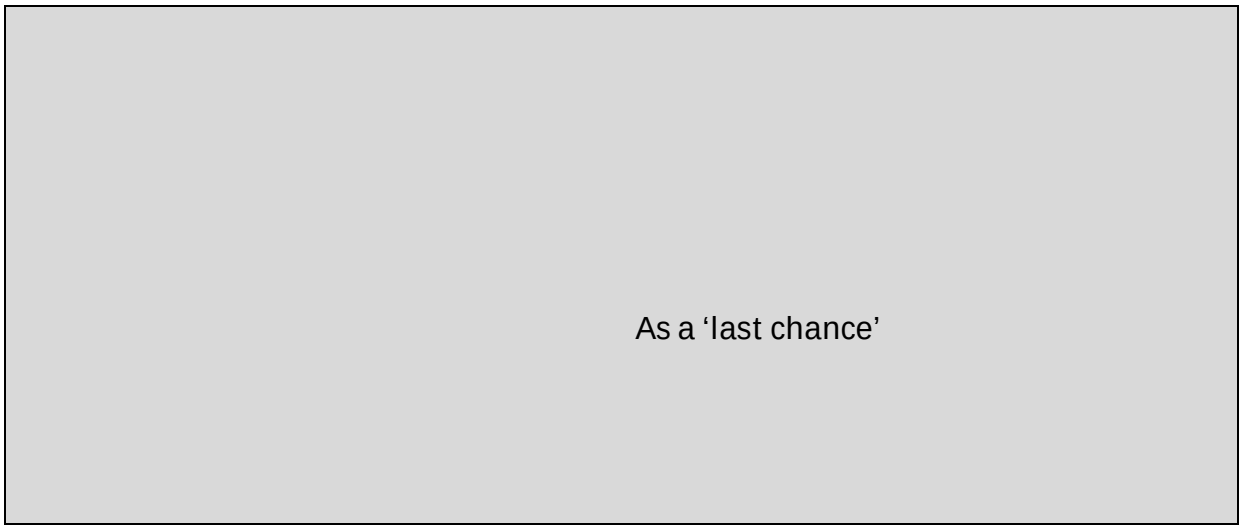
The majority of participants in our study were married (68%, 28 cases, including one same-sex couple in a civil partnership). 17% (7 cases) were co-habiting and 15% (6 cases) were single women. Not all participants were childless. There were already children in the family in 11 cases (27%), though these were not always living with the couple. Five couples already had a child from the current relationship (adopted or naturally conceived) and in 6 cases existing children were from a previous relationship.

UK treatment

The majority of participants had attempted one or more treatment cycles in the UK before considering travelling overseas (32 of 41 cases, 78%). For some, this had included multiple attempts at treatment with no successful outcome.

4.3.2 Why did they go abroad?

The reasons people gave for deciding to travel abroad were varied and complex. No one had a single reason for using a clinic overseas, although for some (such as those needing donor eggs) there was a dominant motivation. A range of motivating factors were described in the interviews (Box 1).



Shortages of donor gametes in the UK; the cost of UK treatment; better success rates overseas, and previous unsatisfactory care in the UK were the four most commonly mentioned reasons for travelling abroad for treatment (for a full breakdown see Culley et al. 2011). These are factors that appear to be closely linked to the (in t6v94.49 Tof)-9eatment

presence of existing children) are commonly applied. The National Institute for Health and Clinical Excellence (NICE) Guideline for fertility treatment (NICE 2004) has recommended that three cycles of IVF should be available to those clinically suitable. However, relatively few NHS commissioners have provided this level of treatment and currently several are reducing the already limited access to public funding (Johnson 2011, Guy 2010). It is estimated that only around 12% of UK citizens have private health insurance (Coulter 2006) and often infertility treatment is not included. Consequently, it has been estimated that around 85% of IVF cycles are paid for directly by patients (HFEA 2008). Given this context, it is perhaps not surprising that the cost of treatment may be a factor in the decision to go overseas. Some overseas clinics offer what have been termed ‘shared risk’ programmes in which they offer several cycles, with a money back guarantee if you do not become pregnant. For a small number of our participants, this was felt to be a way to manage the financial burden of repeat treatment cycles.

Further reasons for travel were raised by individual participants. Some were keen to have more information about donors than currently available in the UK; a small number were attracted by thava

existing familiarity with the country also influenced the choice for some people. For example one couple had relatives in South Africa and so went there; another couple chose the US since they were often in the country for work-related reasons. In other cases, the choice of country was linked to the kind of treatment participants were seeking. For example, those who needed donor eggs were attracted to Spain and the Czech Republic where donors are plentiful and waiting times relatively short. Some participants had a very high regard for particular US clinics, which have a strong international reputation for their medical expertise, and chose to go the US despite the high cost of treatment. Others were seeking low-cost treatment which they found on offer in the Czech Republic, Greece and Norway.

4.3.3.2 How did people organise their treatment overseas?

Participants described a number of ways in which treatment overseas was organised and managed. A substantial proportion of our sample had no involvement or assistance from UK health care professionals when organising their treatment (44% or 18 out of 41 cases). These were more likely (though not exclusively) to be those people who were travelling to longer-haul destinations (for example, US, Barbados, South Africa, Russia, India) and were staying in their destination country for longer periods of time as a result. The other major category of travellers were those who had arranged their own overseas treatment, but were assisted in some way by UK medical professionals (44%, 18 cases). Most often this assistance involved the provision of ultrasound scans (measurement of uterine lining), but in some cases also included help with getting prescriptions raised and dispensed. The remaining cases either had a shared care arrangement with a UK clinic (n=4) or used a medical travel agency to arrange all aspects of the treatment (n=1). An important finding of this study is that peer networks and 'word of mouth' were almost universally used by our participants and were considered invaluable in helping people initiate and manage the process of cross–border treatment. Many people used internet sites such as 'Fertility Friends' and 'IVF World' to get information about treatments, about overseas clinics, and about transport links and hotels. The internet also featured as an important source of peer support for those undertaking cross border travel.

> *to the boards, they have a board for each clinic so I went on the boards for the different clinics, and just said I am thinking about going, can people tell me what So loads of people are really friendly and give you loads of advice on that sort of thing...So that has been really*
>
> (female, Spain, PGD donor egg)

4.3.4 What were people's experiences of cross-border fertility treatment?

The experiences reported in our study were broadly positive. However, being treated abroad was acknowledged by many as not always their ideal or preferred way to undergo fertility treatment, and a number of concerns were expressed around the process. Our interview data highlight complex and nuanced treatment experiences which may be influenced by a number of

factors including: whether this was the participants’ first cycle of treatment; which country or clinic they visited; how much emotional support they felt they received; how well informed they were, 0 0 5icmed

The option of having more than one embryo transferred during a treatment cycle was also mentioned as a positive aspect of treatment abroad. Most people did not desire or indeed actually have more than 3 embryos transferred, but several felt that they certainly did not want to be restricted to single embryo transfer. The majority of participant cycles discussed in the interviews involved the transfer of 2 embryos (see Table 2).

Table 2. Number of embryos transferred per cycle and by country

Countries	***Number of embryos transferred per cycle***	***Number of cycles* (%)***
Spain, Czech Republic	1	4 (6%)
Spain, Czech Republic, Norway, Barbados, US, Greece, Russia	2	48 (70%)
Czech Republic, Russia, Ukraine, US, South Africa, Barbados	3	12 (17%)
Ukraine, India, US	4	4 (6%)
US	5	1 (1%)

feelings of exclusion and marginality and made some feel that they had been placed ‘outside the system’ of care in their own country.

A significant difficulty experienced by those managing their own fertility treatment cycles was accessing the scans, blood tests and drugs they needed whilst in the UK and there were many examples of this creating problems both prior to and especially following treatment abroad.

Some participants were also unsettled by being generally unfamiliar with healthcare systems abroad. This appeared to be particularly acute in relation to countries like Russia or the Ukraine. Others felt uncomfortable that treatment abroad was not always as highly regulated as in the UK and some expressed concern about not being aware of complaints processes in other countries. Some had anxieties about the potential trustworthiness of information provided by clinics, for example information about donor screening and treatment success rates.

As we have seen, communication with clinics was generally described very positively and language differences were not a significant concern. However, in a small number of cases participants reported being concerned by the fact that some of the staff within the clinic did not speak English or that staff spoke between themselves in a language other than English during particular procedures (such as at embryo transfer).

Specific to the experience of treatment-seeking abroad were the associated travel and cost implications. A number of people reported the pressure of having to arrange overseas travel at the last minute and the additional cost that they incurred. The impact of last minute travel on people’s work and family routines was also highlighted by some participants as a negative aspect of the process.

4.3.5

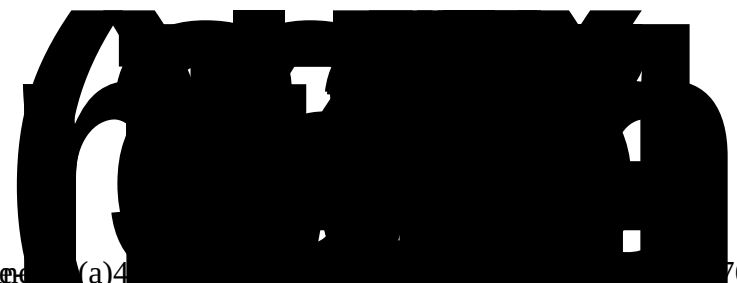
Table 3. Singleton and multiple rates by country	
Singleton vs. multiple	***Countries*** *(n=number of pregnancies)*

knowledgeable about IVF and its potential adverse effects, and most had considered at least some of the additional issues which might arise whilst seeking treatment outside the UK. Nevertheless, despite understanding several of the potential risks many had felt compelled to enter into what they often regarded, at least at the outset, as the more complex venture of overseas treatment. All of them felt that, especially in the absence of timely and affordable treatment being available for them in the UK, the option to go abroad was an important right and that any effort to curtail such travel would be inappropriate.

A need for donor treatment was a significant issue for a majority (71%) of the people we spoke to. There is a shortage of eggs, and increasingly of sperm, for fertility treatment in the UK, although anecdotally it would appear that donor availability varies from clinic to clinic. Increasing the supply of eggs available for patients in the UK therefore is likely to reduce the numbers of people travelling abroad. There is some evidence of treatment using imported vitrified eggs now being available in the UK

- Anonymised personal accounts of patients might also help potential travellers to consider some of the pros and cons of treatment abroad.
- Information on the different regulatory and legal contexts of fertility treatment and surrogacy in different countries is essential. Details of the legal implications in the UK of different forms of overseas treatment and how to seek legal advice should be clearly stated. The importance of specialised medical insurance for fertility travel should also be stressed.
- The HFEA and patient support groups should post links to independent research on cross border treatment and to the most recent version of the International Federation of Fertility Societies' (IFFS) Surveillance survey which provides an overview of current national rules and regulations for assisted reproductive technology worldwide.

example, those using their own gametes and same sex couples). The participants in our A4(n our)477c(n our)



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Please give us your feedback on this report

We are always interested to hear thoughts about our work: especially the impact it may have on individuals or organisations. We would very much welcome your comments on the content of this report, our recommendations, or suggestions about how this research could be continued or built up on. Please contact nhudson@dmu.ac.uk or write to us at:

Dr N Hudson

De Montfort University

Hawthorn Building

The Gateway

Leicester

LE1 9BH

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Media:

- Interviews: BBC Women's Hour (http://www.bbc.co.uk/radio4/womanshour/03/2009_21_fri.shtml), Radio Five Live.

- Press: The Sunday Telegraph, British Medical Journal, The Guardian, Bionews, Leicester Mercury, Yorkshire Post, Swansea Post, Western Mail.

- US based *IVF Podcasts: Educational and historical IVF videos* have recorded a podcast based on the study findings, available at http://www.ivfpodcasts.com/IVF_Podcasts/Podcasts.php?Transnational-Reproduction-47. *IVF Podcasts* is aimed at improving awareness and understanding of patient experiences amongst academics and clinicians.