

Transnational Reproduction: An exploratory study of UK residents who travel abroad for fertility treatment

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 particular very little research exploring the perspectives of those actually undertaking fertility travel.

A survey of 46 clinics (Shenfield et al. 2010) in Belgium, the Czech Republic, Denmark, Switzerland, Slovenia and Spain carried out in 2008-2009 estimated that 25,000 cross-border treatment cycles may be carried out in Europe each year. Extensive travel from Italy has been documented (Bertolucci 2008) and data from Belgian clinics (Pennings et al. 2009) also shows a steady growth in patients travelling to Belgium from France, the Netherlands, Italy and Germany.

The literature suggests a number of reasons why people are crossing borders for fertility treatment: legal restrictions on access to certain forms of treatment such as third party assisted conception or pre-implantation genetic diagnosis (PGD); shortage of gamete donors; long waiting times; exclusion of certain categories of people such as single women or lesbians; a desire for treatments considered too experimental to be provided in the home country; a desire for donor anonymity or a desire for more donor information; a lack of expertise in some forms of ART; sex selection; perceived higher success rates and a desire for culturally sensitive treatment (Blyth & Farrand 2005, Pennings 2004, 2006, Ferraretti et al. 2010, Shenfield et al. 2010, Inhorn & Shrivastav, 2010).

There is limited information about why or how UK patients are accessing overseas treatment. Shenfield et al. (2010) report on data for 53 UK patients collected in their survey. Over 62% of these were seeking egg donation treatment. Thirty-four percent stated their reasons as ‘access difficulties’, 37% gave ‘previous treatment failure’ as a reason for crossing borders, and 28% suggested they were seeking better quality of care. Over 26% of UK patients indicated a ‘wish for anonymous donation’.

A limited number of studies report on patient experiences of cross border treatment in Europe (IN UK 2008, Pennings 2009, Shenfield et al. 2010) and these suggest a broadly positive picture, though some disadvantages are discussed.

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.

Our research study (the ‘Transrep’ project) was designed as an exploratory study with the aim of beginning to fill the gap in our understanding of cross border reproductive travel from the UK perspective. The research team made no assumptions that the availability of cross-border reproductive services should be identified as necessarily ‘problematic’. Rather we sought to explore this under-researched area from the perspective of those who are engaged in the phenomenon as users or potential users, service providers and other interested parties.

2. What did we aim to do?

The study was designed to:

1. Provide an account of the motivations, expectations, experiences and support-needs of people who travel abroad from the UK for infertility treatment;
2. Provide an enhanced knowledge-base and recommendations for user-support and regulatory policy;
3. Make a contribution to the theoretical debates about globalisation and ARTs.

This summary report addresses the first two objectives, and forthcoming academic papers will address objective 3.

3. What methods did we use?

The study began with a review of the international literature on cross border reproductive travel (Hudson et al. 2011). Also in this early phase, the research team interviewed 15 key informants in order to contextualise the study and assist in devising the interviews carried out with those travelling to access fertility treatment in the main part of the study. In this second phase we interviewed 51 people (detailed below), who had been, or were planning to go, overseas for fertility treatment. The interviews were semi-structured in nature, lasting for one to two hours, covering key issues identified from the literature, as well as allowing participants extensive opportunity to express their own perspectives and tell us about their individual experiences. Participants were recruited in a number of ways, including: online fora and websites (44%); patient support group newsletters and mailings (22%); media coverage about the project (17%); word of mouth (7%); overseas clinics (7%); and UK clinics (2%). Data were analysed

thematically, assisted by the computer software package Nvivo. This process involved the initial identification of themes by all team members, followed by the development of a systematic coding framework which was applied to all transcripts in Nvivo (Silverman 2001). In addition, aspects of the interview data were also subjected to ‘quantitative translation’, involving simple counts of experiences and phenomena described in the interviews (Boyatzis 1998, Culley et al. 2011). The quantitative tables presented in this report are based on these counts.

The final part of the project consisted of a stakeholder workshop attended by: people who had travelled abroad for fertility treatment; healthcare providers; counsellors; representatives from overseas clinics; patient support group representatives; academics and regulators. Twenty-two delegates, plus the research team were in attendance. This provided the opportunity for interested parties to explore and debate the findings of the study, and suggest practical recommendations for taking this issue forward in a variety of arenas.

The project was overseen by an expert advisory group consisting of 24 members including: 10 representatives from patient and voluntary sector organisations, 3 clinicians, 2 nurses, 3 counsellors, 3 academics, 2 patient users and 1 representative from the Human Fertilisation and Embryology Authority (HFEA). This group included 6 ‘virtual’ members, a number of whom are based overseas and who commented on the project’s progress by email and telephone. The group met regularly over the course of the project to discuss progress and emergent findings.

4. What did we find?

We have divided the findings reported here into three broad areas: the literature review; interviews with key informants; and data from those travelling to access fertility treatment. For the purpose of this summary, we will be concentrating on the latter, but it is worthwhile briefly commenting on the first two sets of data.

4.1 Literature review

Our literature search revealed a range of commentaries on cross border treatment, but little empirical research. We reviewed papers which discussed various aspects of cross border travel in Europe and elsewhere. The review identified significant limitations and important gaps in the current knowledge-base and indicated some areas for further research. Existing surveys begin to give some indication of the areas of movement relating to access to fertility treatment and some rough estimation is offered of the extent of cross-border travel in some parts of the world. However, more comprehensive and systematic data collection is required before we can arrive at any clear conclusions about the global picture regarding the incidence of cross-border travel. The review also concluded that our understanding of the motivations for, and experiences of, cross-border treatment and its consequences for patients, families, donors, surrogates, healthcare systems and economies is also currently very limited, and merits much

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 heterosexual couples where both partners were interviewed; 6 single, heterosexual women; and one woman in a lesbian relationship but taking part on her own. Most people were interviewed individually, apart from three heterosexual couples who preferred to be interviewed together.

4.3.1 Demographic profile

Age and ethnicity

Since female age is of significance in fertility terms, and is important in allowing a comparison to be made between our sample and British treatment seekers more generally, here we give both the woman’s age at the time of the first cycle of treatment abroad (as reported in the interviews), as well as both the women’s and men’s ages at the time of the interview. Where participants were currently in or about to start treatment abroad, their current age is used in both calculations.

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).

Shortage of donor gametes in the UK

Long UK waiting times

Cost of treatment

Better success rates overseas

Dissatisfaction with care in the UK

Treatment in a less stressful environment

Age of treatment seeker

Choice of donors overseas

For multiple embryo transfer

Convenience

Age of UK donors

Anonymity of donors in other countries

Overseas clinic reputation

As a 'last chance'

To try something new

Treatment not available in the UK

Box 1. Reasons for travel

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 way treatment and associated practices are organised in the UK. It has been argued, for example, that there has long been a shortage of gamete donors in the UK (Hamilton & Pacey 2008) and that changes to the law on donor anonymity, combined with an increase in demand for egg-donation treatment, in particular, have exacerbated this shortage.

A total of 71% of our sample were having treatment with donor gametes, making the shortage of donors and associated waiting times in the UK an important consideration when planning treatment. Forty-six percent (19 cases) of those using donor material were using donor eggs, 12% (5 cases) donor sperm, 10% (4 cases) both donor eggs and donor sperm, and in 1 case (3%), donor embryos. A further 29% (12 cases) were seeking treatment with their own gametes at the time of interview and were therefore not taking into consideration the need for a donor in their reasons to travel. This group were more likely to state 'cost', 'to have treatment in a less stressful environment' and 'overseas success rates' as reasons to cross-borders (Culley et al. 2011).

The cost of treatment in the UK was highlighted as an important factor in the decision to go abroad in 13 cases. Availability of public (NHS) funding for infertility in the UK has been described as a 'postcode lottery' whereby the availability of funded treatment varies from one locality to another (Kennedy et al. 2006) and a range of different social criteria (e.g. age,

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 the anonymity of donors in countries such as Spain and the Czech Republic; others were keen to try treatments not readily available in the UK and some participants were also attracted by perceived higher rates of success in some overseas clinics. A minority of participants reported receiving poor care in the UK (n=7 cases) and directly attributed their decision to travel to this. In just one case (2%) a desire to have multiple embryo transfer was given as a specific reason to travel abroad for treatment, and was also linked to the destination chosen, India, where 4 embryos were transferred, resulting in a singleton pregnancy and live birth.

Contrary to the way this phenomenon has been reported in the press, although wanting to combine treatment with a holiday was a consideration for some, it was certainly not a primary reason to go overseas. Most participants actively resisted the 'fertility tourist' label and felt that this was an unfair and inaccurate representation of their experiences.

'...you don't do this lightly, you really don't... They [the press] belittle it and are kind of making it sound like it's on the spur of the moment kind of thing, "oh by the way lets have IVF treatment while we're here", as if people do that! They don't seem to realise how desperate people are to have a family. To do that, to go to a foreign country, it's even harder than having treatment here.'

(female, Hungary, IVF with donor sperm)

Two important conclusions can be drawn from these data. Firstly, that people are seeking treatment overseas for a range of reasons, and the choice to go abroad in many cases involves more than one factor. A desire for timely treatment with donor gametes was clearly evident in a high percentage of cases, but this was not the only important motivating factor in cross-border travel. Secondly, the study confirms the findings of Shenfield et al. (2010) that on the whole, UK patients are not crossing borders to avoid restrictive legislation. In the UK, whilst the regulation of ARTs is comprehensive, there is relatively liberal access to treatment. In contrast

with several other European countries, UK residents can receive third-party assisted treatment, and there are no formal legal barriers to single women or lesbian women accessing treatment. The UK does not allow potential parents to choose the sex of the embryos other than for certain medical conditions, but no one in our study gave sex selection as a reason for travelling abroad.

4.3.3 Where did they go and how was it organised?

4.3.3.1 Where did they go?

People travelled to a wide range of countries. The bar chart below shows actual and planned destinations (Figure 1). The most popular destinations were Spain and the Czech Republic, a finding that was also reported by Shenfield et al. (2010). However, an additional 11 countries featured in the participants' accounts. The majority of participants had been abroad at the time of the interview (83%, 34 out of 41 cases). In the seven cases where they had not yet travelled, firm plans and preparation for treatment abroad had been made at the time of interview.

The total number of visits, as represented in Figure 1, is more than the number of cases in the study, because some people had visited or were planning to visit more than one country for treatment. In six cases, two different countries had already been visited by participants and in a further three cases, plans to visit a second different country for treatment were being made at the time of interview. In four cases people had children as a result of treatment provided in two different countries.

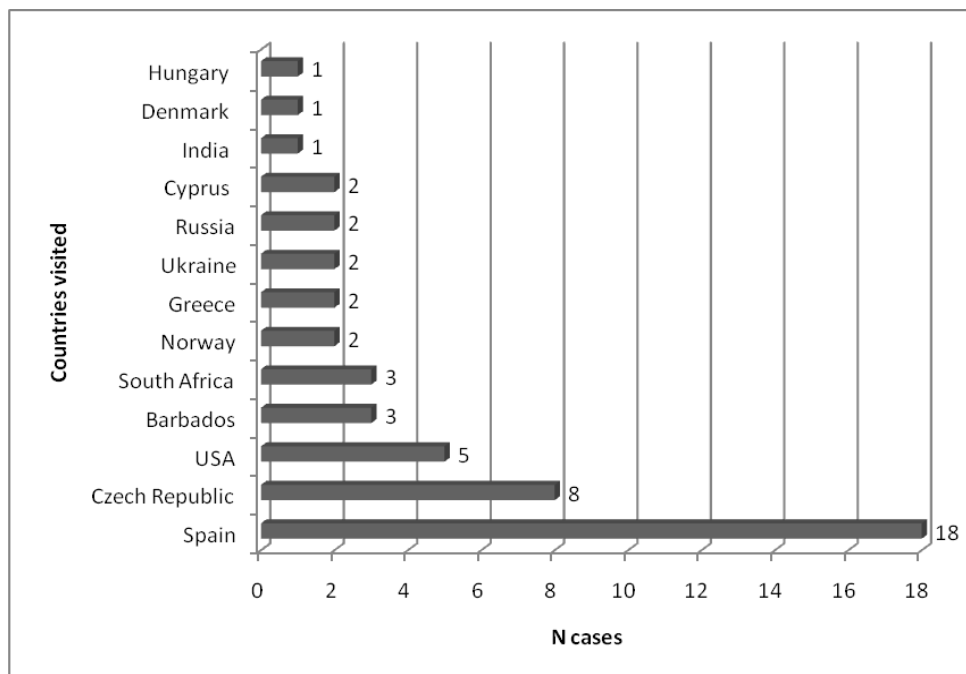


Figure 1. Countries visited/intended.

People chose which countries to travel to in a variety of ways. In some cases this was based on accessibility and transport links: hence the large representation of countries within Europe. An

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.

‘I went on 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 they found good about it and what they didn’t like about it?” So loads of people are really friendly and give you loads of advice on that sort of thing...So that has been really good, it’s a very good support network.’

(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, and whether or not they were successful. The participants' accounts demonstrate that experiences of cross-border treatment can vary considerably according to which country, or even to which clinic, a patient travels. For the purposes of this summary report, we present a brief overview of the positive and challenging elements of the experience, as reported by the participants. Further details will be reported in subsequent publications.

4.3.4.1 Positive aspects of cross-border treatment

One of the main benefits of going overseas was the quality of care people felt they received in overseas clinics. All participants who had been abroad at the time of the study reported general satisfaction with the way they had been treated. Participants reported that on the whole they felt involved in decision-making about their treatment; that their care and treatment protocols were personalised and tailored to them as individuals and that communication with clinics was better than in the UK. Many made favourable comparisons with treatment they had received in the UK. Common complaints about the UK clinics included: long waiting times for and between appointments; a lack of contact with the consultant leading care; feeling they were treated 'like a number' or that they were 'on a conveyor belt'; lack of new options for treatment when a cycle fails; and high costs.

For a number of people, especially those with longer, unsuccessful treatment histories, this allowed them to feel more in control of their care pathway than they had done previously. Many reported having good access to and contact with, the clinician leading their care, though this did vary according to the clinic. Feeling that they were able to ask questions and negotiate their treatment was a positive experience for many people. Few people reported difficulties caused by language differences. Most participants reported that clinics had English speaking doctors and often English speaking staff were specifically employed to liaise with overseas patients.

For some people, having more extensive information about donors than is commonly available in the UK, and/or a wider choice of donor, were important advantages of treatment abroad. In most cases participants reported more opportunity to choose a donor who would 'match' the recipients than is often the case in the UK, although information clinics provided about donors varied between countries. A desire to choose a donor was not about creating 'designer babies' but principally about maximising physical resemblance between parent and child which is something desired by most people using third party assisted conception (Becket et al. 2005).

Other benefits of cross-border treatment were the shorter or non-existent waiting times at overseas clinics, quicker test results and apparently better success rates. For some of those who were using donor gametes, the anonymity of donors in countries such as Spain, the Czech Republic or the Ukraine was important. For others it was access to more extensive information about donors in countries like the US, which was perceived as an advantage.

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		
<i>Countries</i>	<i>Number of embryos transferred per cycle</i>	<i>Number of cycles* (%)</i>
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%)

*(fresh & frozen)

This pattern of embryo transfer is not too dissimilar to that which occurred in the UK in 2007, where most cycles involved the transfer of two embryos and just 4% involved the transfer of three embryos, although the UK figures are likely to change following the introduction of the multiple births policy introduced in the UK in 2008 (HFEA 2010b).

4.3.4.2 Challenging aspects of cross-border treatment

Although experiences were broadly positive, participants highlighted a range of concerns related to the process of going overseas. Some of these were specific to the treatment they were having (for example, the selection of donors) or were particular complaints related to specific countries or clinics. Some expressed broader concerns about feeling that they were viewed negatively for having taken this option. A number of people reported that they had received negative responses from health care professionals in the UK when they had discussed the possibility of having overseas treatment. After returning from treatment abroad, while many people suggested that GPs and other NHS staff had responded professionally and positively to them, some participants reported some negative reactions. These reactions served to highlight

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 Were participants successful?

Twenty six cases were successful: having either a live birth or well established pregnancy from cross border treatment at the time of taking part in the study. Six cases had experienced more than one pregnancy (live births and current pregnancies) from treatment outside the UK. There were 32 pregnancies in total (Table 3).

Table 3. Singleton and multiple rates by country			
<i>Singleton vs. multiple</i>	<i>Countries (n=number of pregnancies)</i>	<i>n</i>	<i>%</i>
twins	US (2), Barbados (1), Spain (1), Czech Rep (1), Ukraine (1)	6	19%
singletons	Spain (9), Czech Rep (3), US (3), Barbados (3), Norway (2), Ukraine (2), Greece (1), India (1), South Africa (1), Denmark (1)	26	81%
Total pregnancies		32	100

There were no higher order multiple pregnancies (triplets or above) among our participants. Most were either singleton (81%) or twin (19%) pregnancies. No one reported foetal reduction. The twin rate is similar to that which the HFEA suggests UK clinics should be working towards (HFEA 2010b). This finding may reflect the specific sample of participants in this study and the fact that the majority were travelling to European destinations where numbers of embryos transferred are generally falling (de Mouzon et al. 2010).

5. Stakeholder Workshop

An important part of the project was the final stakeholder workshop, where data from the project were discussed in an open dialogue between people with knowledge of, and in some cases direct experience of, cross border care as patients, providers, counsellors, patient advocates, professional bodies and those involved in working with families conceived from third party assisted conception. As part of this debate, workshop participants were asked for their specific recommendations to address any problems which cross border travel might present. A wide range of views on cross border care were represented at this event and have been incorporated, along with the participants' suggestions, into the final recommendations from the study (see Section 7).

6. Conclusion

The findings from this study challenge the dominant media image of 'fertility tourism'. Our participants were not significantly older than those having treatment in the UK. The twin pregnancy rate was similar to UK figures. Most had received treatment in the UK prior to seeking out an overseas clinic, often over many years. The people we spoke to were not naive consumers; often they had done extensive research prior to seeking treatment abroad, using the internet and seeking advice and information from fellow travellers. They were, on the whole,

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 (CARE Fertility, 2011), thus eliminating the need to travel. However, such treatment is very expensive and further reproduces existing inequalities in access to fertility treatment.

While a demand for donors was a key reason for many to travel for treatment, almost 30% of those going abroad did not require a donor in their treatment and had a range of other reasons, including the high cost of UK treatment and for some, dissatisfaction with standards of care they had received in UK clinics.

Most people reported a broadly positive experience of cross border treatment, although this varied between clinics. As our report shows, many (though not all) of the perceived difficulties that participants discussed related more to issues in the UK (accessing scans etc.) than to the quality of care they felt they had received overseas. Many of those having third party treatment had considered the potential implications, such as those that may arise from donor anonymity. Some were unconcerned about such issues, others were unsettled by some of the consequences of donor treatment abroad, but felt that they had little choice given the waiting times and costs in the UK.

Some participants would have preferred a closer link with UK clinics in a form of shared care arrangement or at least a recommendation from UK clinicians. Few such formal arrangements existed at the time that many of our participants had treatment. Shared care programmes would now appear to be more commonly available though may not be affordable for many patients. Several participants suggested that their search for a clinic would have been aided by some form of international benchmarking or accreditation system for treatment centres to allow a degree of confidence in the claims clinics make about quality, safety and success rates.

7. Recommendations

The recommendations arising from this project are divided into two sections. First there are suggestions for action to reduce the need or demand for cross border reproductive travel and second, we suggest measures which would help to facilitate good practice in cross border fertility treatment for those who choose to go abroad.

Reducing the demand for cross border reproductive travel

- It is important to know more about why a UK donor shortage exists. Further research on donor motivation and recruitment would be helpful in devising strategies to improve donation rates from UK gamete providers. Such strategies should include specific efforts to recruit donors from minority ethnic communities, where the shortage is particularly acute.
- A properly funded donor recruitment strategy is needed to raise awareness, improve recruitment practice and co-ordinate a donor supply infrastructure. Such an infrastructure should include a central, accessible data-base with up-to-date information on donor availability and waiting times for treatment in UK clinics which would allow patients more informed decision making about the option of having timely treatment in the UK should they wish to access this.
- The NICE guidelines on NHS funding should be implemented in full. The implementation of a robust and fair system of public funding would reduce the need for treatment abroad for those whose main motivation is to find affordable treatment either because NHS treatment is not available in their locality or because they have received less than the 3 funded cycles recommended by NICE.
- Several participants in this study were motivated to travel overseas by a perceived lack of responsiveness of UK clinics to their needs and a desire for more personalised care. UK clinics, professional organisations such as the British Fertility Society and the Royal College of Nursing, and the regulators, the HFEA, need to work to ensure a consistently positive patient experience in UK clinics.

Facilitating good practice and safeguarding patients

- Potential travellers would benefit from accessible, objective information on travelling for treatment. Several organisations (HFEA, I NUK) are already providing useful information for patients and this should be extended, kept up-to-date and clearly signposted.
 - Patients should be informed about how to research clinics, be provided with a list of essential questions to ask clinics prior to deciding on treatment, and with information on how to assess quality of care and professional expertise in the field.

- 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.
- There are significant professional responsibilities involved in cross border treatment if patients are to be treated in a safe and ethical manner. ESHRE have published a 'good practice guide' for centres and physicians treating foreign patients (Shenfield et al. 2011), which should of course apply to UK clinics; several of which treat substantial numbers of patients from outside the UK. The ESHRE guide suggests a series of operational principles relating to patients, donors and families. We recommend that ESHRE and other professional bodies take steps to ensure the full implementation of this guidance, to protect patients, families and donors from potential exploitation and inappropriate treatment. The extension of such a code of conduct to the wider international context would be helpful, since our study suggests that some potentially harmful practices, such as high order multiple embryo transfer, are more likely to occur outside Europe.
- In the longer term, patients would benefit from the development of an independent international system of benchmarking and accreditation for fertility clinics and national and international professional and regulatory bodies could consider developing this. Quality assurance programs are in place for some other forms of medical travel. These could be developed for fertility treatment, to cover a range of issues such as practitioner qualifications and experience, protocols and treatments, donor recruitment and screening, facilities, accessibility, communication, outcomes and complaints procedures.
- Several participants would have welcomed 'shared care' with a UK clinic. It is currently very difficult to find information on which UK clinics have overseas links, what forms these links take and what costs are involved. The HFEA could update their 'Choose a Clinic' function to include information about which UK clinics offer these packages and what arrangements are in place for monitoring safety and quality.
- Participants in our study reported receiving a range of responses from their GPs when requesting assistance and support with overseas treatment. The Royal College of General Practitioners should consider how best to inform general practices about the issue of responding to patients who have had or are seeking overseas fertility treatment, to ensure a consistent response to patients.

- Information on the potential benefits of counselling and how to access a counsellor in the UK either pre or post treatment, should be available on the HFEA, support group and clinic websites. UK fertility counsellors should explore ways in which patients can be most appropriately supported throughout the fertility treatment journey, bearing in mind that this may be once treatment is concluded and after patients return to the UK. The British Infertility Counselling Association and the International Infertility Counselling Organisation have defined quality standards of counselling interventions which should include a consideration of issues specific to cross border travel. The International Federation of Social Workers should ensure maximum publicity for its policy on cross border treatment which extends its ethical standards to overseas treatment.
- Further research on cross border fertility travel is needed. This should be both quantitative and qualitative and should include the contribution of social scientists. In particular there is an urgent need to clarify the recruitment and experiences of gamete providers abroad (especially egg donors). Little is known in many countries about who the egg donors are, how they are recruited to clinics, what screening or counselling they receive and whether they are protected from excessive stimulation or repeat donation cycles. Follow up research with families with children conceived abroad should also be undertaken.

Recommendations links and references:

International Federation of Social Workers (IFSW). Policy paper on cross border reproductive services. Download at: <http://www.ifsw.org/p38001484.html>

IFFS Surveillance 2010. Download at: http://www.iffs-reproduction.org/documents/IFFS_Surveillance_2010.pdf

Shenfield, F, de Mouzon J, Pennings G, Ferraretti AP, Nyboe Andersen A, de Wert G, Goossens V and the ESHRE Taskforce on Cross Border Reproductive Care. Cross border reproductive care in six European countries. *Hum Reprod* 2010: Advance Access published March 26, 2010, doi:10.1093/humrep/deq05

8. Limitations

The project was designed as an exploratory, in-depth study of a sample of British fertility travellers. There are some limitations to the study, mainly relating to the sample. It is impossible to know if our sample is in any way representative of those who travel from the UK for fertility treatment, since no official record-keeping of this activity takes place. However, there are similarities with our sample and UK residents who took part in Shenfield et al.'s European survey (2010). The participants were recruited through a number of routes, but all were self-selecting. However, we did purposively sample in a number of ways, including attempting to cover a range of destinations as well as re-advertising for specific groups (for

example, those using their own gametes and same sex couples). The participants in our study were also relatively homogenous in terms of their educational and employment profile, which may be a reflection of the economic resources required to engage in cross border reproductive travel. There were also fairly high rates of success amongst our participants, which may have influenced both their readiness to take part in the study as well as how they reported their experiences. The team did not have access to medical records and relied on the self-reporting of diagnoses and treatment.

9. Dissemination

The project has a website: www.transrep.co.uk through which we communicate the project's progress and outputs from the work. We also have a newsletter; past issues of which can be obtained from nhudson@dmu.ac.uk or through the website.

We have presented papers about the study at a number of conferences and have published two journal articles with a further one accepted for publication.

The project has also received media coverage on Women's Hour Radio 4, Radio Five Live, BBC Radio Scotland, in the British Medical Journal, BioNews, the Guardian, the Sunday Telegraph, The Observer, the Leicester Mercury, the Western Mail and the Yorkshire Post.

Details of outputs and dissemination activities are given in Appendix 1.

10. Acknowledgments

This project is the result of a successful collaboration between academics, professionals, support groups and most importantly, the individuals who take their quest for a family across borders.

We would particularly like to thank the participants who so generously shared their stories with us.

We acknowledge the significant contribution made to the project by our Advisory Group and the people who attended the stakeholder workshop and thank them for sharing their expertise with us.

We would also like to thank the funding body, the UK Economic and Social Research Council.

The conclusions and recommendations are those of the research team alone.

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:

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Appendix One: Project Outputs

View a podcast on the project at: www.ivfpodcasts.com (see below)

Journal articles:

Culley, L. Hudson, N. Blyth, E. Norton, W. Rapport, F. Pacey, A. (2011) Crossing borders for fertility treatment: motivations and destinations of UK fertility travellers. *Human Reproduction*. Forthcoming.

Hudson, N. Culley, L. Blyth, E. Norton, W. Rapport, F. Pacey, A. (2011) Cross-border reproductive care: a review of the literature, *Reproductive Biomedicine Online*. 22: 673-685.

Culley, L & Hudson, N. (2010) Why do people travel abroad for fertility treatment? What we don't know. *Journal of Fertility Counselling* 17 (1): 64-67.

Hudson, N. & Culley, L. Assisted Reproductive Travel: UK Patient Trajectories. Under review. *Reproductive Biomedicine Online*.

Culley, L & Hudson, N. (2010) Fertility Tourists or Global Consumers? A Sociological Agenda for Exploring Cross-border Reproductive Travel. *International Journal of Interdisciplinary Social Sciences* 4(10) 139-150

Forthcoming talks:

Culley, L. (2011) Women and Medical Tourism: travelling abroad for fertility treatment. RCN Women's Health Forum Politics of Women's Health Conference. November 4th.

Culley, L. (2011) The rise in cross-border reproductive care. Paper to be presented at Reproductive Medicine 2011. London, 15-16th September.

Conference presentations and invited talks:

Culley, L. (2011) Home and Away. Fertility Travel from the UK. Northern Nurses Fertility Forum, All Wales Midwifery and Reproductive Health Research Forum, June 17th, Leeds.

Hudson, N. Culley, L. Norton, W. (2011) On-line communities of hope: biosociality and the negotiation of overseas fertility treatment. Paper presented at BSA Human Reproduction Study Group Conference. Open University, Milton Keynes, 15th June, 2011.

Culley, L. (2011) Plenary Speaker: Making Babies Beyond Borders: assisted conception in the age of globalisation. *Fertility 2011, the 7th biennial conference of the UK Fertility Societies: the Association of Clinical Embryologists, the British Fertility Society and the Society for Reproduction and Fertility*. Also supported by the Irish Clinical Embryologists Association and the Irish Fertility Society. Dublin Convention Centre, 5-7th January 2011.

Culley, L. Hudson, N. Blyth, E. Norton, W. Rapport, F. Pacey, A. (2010) 'Travelling abroad for fertility treatment: an exploratory study of UK residents seeking cross-border care' oral presentation at the *26th Annual Meeting of ESHRE, Rome, Italy, 27 June – 30 June, 2010*.

Culley, L. Hudson, N. Blyth, E. Norton, W. Rapport, F. Pacey, A. (2010) 'Crossing Borders for Reproductive Care: Hearing the Patient Voice', paper presented at *The First International Congress on Global Reproductive Tourism*, Vienna, March 2010.

Culley, L. (2010) Transnational Reproduction: UK patient perspectives. Presentation to *the Progress Educational Trust Annual Public Conference: Passport to Parenthood, the evidence and ethics behind cross-border reproductive care*. Institute of Child Health, London, 24th November.

Culley, L. (2010) 'Cross border ARTS: 'User' perspectives in the Transrep study' invited talk at *Globalization in ART and its Impact on Psychosocial Care, Post Graduate Course of the International Infertility Counselling Organisation*, Munich, September, 2010.

Culley, L. (2010) Fertility treatment abroad: the evidence base. Presented at the *Human Fertilisation and Embryology Authority, Ethics and Law Horizon Scanning Seminar*, 24th February 2010.

Culley, L. (2010) Travelling Overseas for Fertility Treatment. Presentation and discussion at the *Nuffield Council on Bioethics, Human Bodies in Medicine and Research Working Party*, London, 20th May.

Culley, L. (2010) The UK Case. Cross border reproductive care meeting: standards, towards a Code of Practice? *The ESHRE Task Force on Cross Border Reproductive Care*, Paris, 14th May 2010.

Culley, L. Hudson, N. (2010) 'Ethical Issues in Transnational Reproductive Technologies' paper presented at the *Second International Conference on Science in Society*. Madrid, November 2010.

Culley, L. & Hudson, N. (2010) 'Making babies across borders: user perceptions of transnational assisted reproductive technologies' paper presented at *XVII ISA World Congress of Sociology, RC15 session – Sociology of Health*. Sweden, July 2010.

Culley, L. & Hudson, N. (2010) 'Globalizing Biomedicine: creating babies across borders' paper presented at *Negotiating Inclusion and Exclusion of Reproductive Technologies in Local Contexts of Men and Women's Reproduction Session at Society for Applied Anthropology 70th Annual Meeting*, Mexico, March 2010.

Hudson, N. & Culley, L. (2010) "She has what I want and I have perhaps got a little bit of what she wants": Constructing the egg donor in transnational reproduction', paper presented at *XVII ISA World Congress of Sociology, Joint session RC15 RC32 - Women's Health and Health Risks in an Unequal World*. Sweden, July 2010.

Hudson, N. & Culley, L. (2010) *Reproductive Tourists? UK Trajectories of ART travel*. Paper presented at "Reproductive Tourism: Travelling for Conception and the Global ART Market" an international workshop held the University of Cambridge, 3-5th December 2010.

Culley, L. Hudson, N. Pacey, A. Rapport, F. Blyth, E. Norton, W. (2009) 'Fertility Tourism? Discourses of Cross-border Reproductive Care', at the *10th Annual Interdisciplinary Research Conference "Transforming Healthcare through Research & Education"* 4th - 6th November 2009, Trinity College, University of Dublin.

Culley, L. Hudson, N. Blyth, E. Norton, W. Rapport, F. Pacey, A. (2010) 'Cross border reproductive care: The Research Evidence'. Poster presented at the *13th Congress on Controversies in Obstetrics, Gynecology and Infertility (COGI)*, Berlin, November 2010.

Culley, L. & Hudson, N. (2009) 'Crossing Boundaries: exploring professional discourses on 'reproductive tourism'', paper presented at *International Sociological Association Research Committee on Sociology of Health (RC 15) Mid-term Conference "Health for All: Opportunities and Challenges"*, Jaipur, India, September 21-23, 2009.

Culley, L. & Hudson, N. (2009) 'Fertility Tourists or Global Consumers? Constructions of cross border reproductive travel' paper presented to *The Fourth International Conference on Interdisciplinary Social Sciences*, University of Athens, Greece, 8-11 July 2009.

Hudson, N. & Culley, L. (2009) 'Reproductive tourism': exploring experiences, challenging popular discourses. Paper presented at the *BSA Medical Sociology Group Annual Conference*, Thursday, 3rd–Saturday, 5th September 2009, University of Manchester, UK.

Hudson, N. (2009) '“Reproductive tourism”? Presenting a sociological agenda for exploring the use of overseas fertility clinics' invited talk to the *Cambridge Interdisciplinary Reproduction Forum*, 10th November, 2009, University of Cambridge.

Policy:

- Findings from the study informed the development of an international professional Code of Practice for fertility clinicians produced by the European Professional Body: *European Society of Human Reproduction and Embryology*.
- Evidence from the study was presented to the *Nuffield Council on Bioethics Working Party on Human Bodies in Medicine and Research*, May 2010. Report due 2011.
- Findings have been discussed by the Board of the International Society for Cross Border Care, which is considering international clinic accreditation.
- Interim findings discussed by the *Human Fertilisation and Embryology Authority* (UK regulatory body) Ethics and Law Horizon Scanning Seminar, May 2010.
- Findings contributed to Expert Workshop on 'intra-family gamete donation' organised by HFEA who are developing a revised donor policy.

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.