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INFERTILITY PATIENTS' MOTIVATIONS FOR, AND EXPERIENCES OF, CROSS-BORDER
REPRODUCTIVE SERVICES (CBRS): AN ASYNCHRONOUS ONLINE INVESTIGATION

STEVE SUN CHONG LUI

A thesis submitted to the University of Huddersfield

In partial fulfilment of the requirements for
the degree of Doctor of Philosophy

The University of Huddersfield

05/08/2015

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Abstract

The desire for, and provision of, cross border reproductive services (CBRS) (i.e. gamete donation and surrogacy) is a growing international phenomenon. CBRS describes the travel by infertile patients from one country or jurisdiction where access to treatment is limited or unavailable to another country or jurisdiction to seek infertility treatment. There are numerous reasons for CBRS and it is an under-researched and under-theorised area of health research. The aim of this thesis was to explore patients' motivations for and experiences of CBRS. This study provided themes on the decision-making process of CBRS patients and contextualised them within a partial trans-Theoretical Model.

Data regarding CBRS were collected from 26 international participants by means of asynchronous email in-depth semi-structured interviews via two international infertility networks. SPSS was used to analyse the quantitative data whereas NVivo 10 software aided the systematic thematic coding method within an Interpretative Grounded Theory.

Participants' motivations for and experiences of CBRS are complex. Seven stages of patients' infertility journeys emerged: 1. Pre-contemplation: participants had no awareness of their own infertility; 2. Contemplation: participants became aware of their infertility and treatment at home and / or CBRS; 3. Preparation: participants researched CBRS using internet/infertility networks; 4. Action: participants took specific steps to initiate CBRS; 5: Maintenance: participants' expectations and experiences were important to whether or not they would continue with CBRS; 6: Exit: some participants successfully built their family. Others' overall experience was negative, their expectations were not met and they decided to quit treatment; 7: Re-engagement: some participants re-engaged with infertility treatment; some participants re-considered their decision regarding infertility treatment either at home or CBRS.

A partial Trans-Theoretical Model could explain some of the decision-making process in seeking CBRS. Future research is needed to explore the implications of CBRS for patients, donors, offspring and healthcare systems.

Abbreviations

ART	Assisted Reproduction Technology(ies)
ASRM	American Society for Reproductive Medicine
*CBRS/CBIT	Cross Border Reproductive Services /Cross Border Infertility Treatment
D+C	Dilation (or dilatation) and curettage
DI	Donor Insemination or sperm donation
ED	Egg Donation
ERPC	Evacuation of Retained Products of Conception
ESHRE	European Society of Human Reproduction and Embryology
ET	Embryo(s) Transfer
FET	Frozen Embryo(s) Transfer
HFEA	Human Fertilisation and Embryology Authority
ICMART	International Committee Monitoring Assisted Reproductive Technologies
ICSI	Intra-cytoplasmic sperm injection
IFFS	International Federation of Fertility Societies
IUI	Intra-uterine insemination
IVF	In vitro fertilization
MRKH	Mayer-Rokitansky-Küster-Hauser syndrome
MTESE	Micro-dissection testicular sperm extraction
PGD	Pre-implantation Genetic Diagnosis
PGS	Pre-implantation genetic screening
SIM	A subscriber identity module or subscriber identification module

*CBRS/CBIT was used in this thesis as a short hand version for cross border travel for reproductive services.

Assisted Reproduction Technology (ART) Glossary

This glossary is adapted from the HFEA (2015a) glossary.

Assisted Reproductive Technology (ART): all treatments that include in vitro handling of human gametes (eggs or sperm) and embryos to establish a pregnancy – often called medically assisted reproduction (MAR).

Blastocyst: 5-6 days old embryo

Clinical pregnancy: a pregnancy diagnosed by ultrasound of definite sign of pregnancy.

Cryopreservation: frozen storage of sperm, eggs, embryos or ovarian and testicular tissues.

Dilation (or dilatation) and curettage: this refers to the dilation (widening/opening) of the cervix and surgical removal of part of the lining of the uterus and/or contents of the uterus by scraping and scooping (curettage). It is a therapeutic gynaecological procedure as well as most often used method of first trimester abortion.

Ectopic pregnancy: implantation of embryos outside the uterus.

Embryo: the product up to eight weeks after fertilisation, later it is called a foetus.

Embryo donation: transfer of an embryo that did not originate from the recipient and her partner.

Evacuation of Retained Products of Conception: removing any parts of the pregnancy that may remain in the womb following a miscarriage.

Fertilisation: a sperm penetrates the egg leading to a combination of genetic materials resulting in a fertilised egg.

Gamete: a reproductive cell, egg in the females and sperm in males.

Infertility: a disease of the reproductive system defined by the failure to conceive after 12 months of regular unprotected sexual intercourse.

Intra-cytoplasmic sperm injection (ICSI): process by which egg is fertilised by injecting a single sperm into the egg.

In vitro fertilisation: fertilisation of an egg by sperm in a laboratory dish.

Micro-epididymal sperm aspiration: surgical collection of sperm direct from the epididymis (tube that carries sperm out of the testis). Used when a blockage in the epididymis leads to absence of sperm in the semen.

Miscarriage/preclinical spontaneous abortion: pregnancy diagnosed by the detection of HCG in serum or urine that does not develop into clinical pregnancy.

Mayer-Rokitansky-Küster-Hauser syndrome: this is a congenital malformation characterised by a failure of the Müllerian duct to develop, resulting in a missing uterus and variable malformations of the upper portion of the vagina.

Percutaneous epididymal sperm aspiration (PESA): collection of sperm under local anaesthesia by needle aspiration of the epididymis.

Pre-implantation genetic diagnosis: diagnostic technique involving genetic tests on the embryo or a polar body (a cell structure inside the egg). Usually this is done when the embryo is at the 6-8 cell stage. One cell is removed for analysis of its DNA or chromosomes to determine if the embryo is likely to develop a genetic disease.

Pre-implantation genetic screening: technique to check if an embryo has the correct number of chromosomes. Used particularly for older women (increased risk of chromosomal abnormalities) and for women who have recurrent miscarriages (often due to chromosomal abnormalities).

Still birth/foetal death: death of foetus before it is born at, or after, 20 weeks of pregnancy.

Testicular sperm aspiration (TESA): needle aspiration of the testis to collect sperm, usually carried out in case of PESA had been unsuccessfully.

Testicular sperm extraction (TESE): done when other extraction method were unsuccessful.

Vitrification: an ultra-rapid freezing method for eggs and embryos. It avoids the damage usually caused in freezing from ice crystals.

Publications

Parts of this thesis have been reported in the following publications:

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Table of Contents

Copyright Statement	2
Acknowledgements	3
Abstract	4
Abbreviations	5
Assisted Reproduction Technology (ART) Glossary	6
Publications	8
List of Tables	17
List of Figures	18
Chapter 1 Introduction	19
1.1 Infertility and involuntary childlessness	19
1.2 Infertility treatment options	20
1.2.1 Donor insemination	21
1.2.2 Egg Donation.....	22
1.2.3 IVF surrogacy.....	22
1.2.4 Pre-implantation genetic diagnosis (PGD) and pre-implantation genetic screening (PGS).....	22
1.2.5 Multiple embryo transfer and Selective foetal reduction	23
1.2.6 Posthumous conception	23
1.3 Variations regarding ART in different countries/jurisdictions	23
1.3.1 Funding of ART services.....	24
1.3.2 Variations in permitted ART procedures	24
1.3.2.1 Gamete and embryo donation and surrogacy.....	25
1.3.2.2 Preimplantation genetic diagnosis and sex selection	27
1.3.2.3 Number of embryos for transfer in IVF/ART cycles and Selective foetal reduction	27
1.3.2.4 Posthumous conception	27
1.3.3 Eligibility for ART services	28
1.4 Factors influencing cross border travel to access reproductive services .	28
1.5 Medical Tourism	29
1.6 Cross Border Reproductive Services - the need for further study	30
1.7 The rationale for this study	31

1.8 Biography	31
1.10 The structure of the thesis	33
Chapter 2 Literature Review.....	35
2.1 Review of literature published between 2011 and 2013	38
2.1.1 Methodology.....	39
2.1.2 Search strategy	39
2.1.3 Critical Analysis	40
2.1.4 Ethical considerations	40
2.1.5 Results	41
2.2 Terminology and definition of CBRS	48
2.3 Prevalence of CBRS	48
2.4 Experience of CBRS	49
2.4.1 Patients' perspectives	49
2.4.2 Law evasion	50
2.4.3 Patients' safety	50
2.4.4 Religious circumvention	50
2.4.5 Returning 'home' for treatment.....	51
2.4.6 Changing CBRS clinics	51
2.4.7 CBRS communities and activism	51
2.4.8 Health care providers' perspectives	51
2.5 Review from the commentary papers.....	52
2.6 Discussion.....	53
2.7 The differences between CBRS and infertility treatment at home	55
2.8 Chapter Summary	55
Chapter 3 Methodology and Research Design.....	56
3.1 Philosophical Viewpoint	56
3.2 Theory and Research	59
3.3 Rationale for asynchronous email interview	60
3.4 Rationale for the Voice Centred Relational Method (VCRM)	61
3.4.1 The first read: Relational and reflexively constituted narratives.....	61

3.4.2	<i>The second read: Tracing narrated subjects</i>	61
3.4.3	<i>The third read: Reading for relational narrated subjects.....</i>	62
3.4.4	<i>The fourth read: Reading for structured subjects</i>	62
3.5	Grounded Theory	63
3.6	Grounded Theory data analysis.....	66
3.7	Ethical approval	67
3.7.1	<i>Respect for Autonomy</i>	68
3.7.1.1	<i>Informed consent</i>	68
3.7.1.2	<i>Confidentiality</i>	69
3.7.1.3	<i>Anonymity</i>	69
3.7.2	<i>Non-maleficence</i>	69
3.7.2.1	<i>Participants' safety.....</i>	69
3.7.2.2	<i>Researcher safety</i>	70
3.7.3	<i>Beneficence.....</i>	70
3.7.4	<i>Justice.....</i>	71
3.7.5	<i>Professional-Patient Relationships</i>	72
3.8	Internet research.....	73
3.9	Survey research on the internet.....	73
3.10	Synchronous online interviews using Instant Messenger (IM).....	74
3.11	Asynchronous online interviews using electronic mail (email).....	75
3.12	Ethical issues relating to internet research	80
3.12.1	<i>Blurring of public and private spaces</i>	81
3.12.2	<i>Netiquette.....</i>	81
3.13	Computer assisted qualitative data analysis software (CAQDAS).....	83
3.13.1	<i>NVivo</i>	83
3.13.2	<i>Using asynchronous email interviewing methodology.....</i>	84
3.14	Researcher's reflection on the methodology and research design.....	89
3.15	Chapter Summary	89
Chapter 4	Socio-demographic profile of participants.....	91
4.1	Demographic information of participants.....	92
4.1.1	<i>Age, gender and sexual orientation</i>	92
4.1.2	<i>Geographical location and ethnicity</i>	93

4.1.3	<i>Education level and employment status</i>	94
4.1.4	<i>Language spoken</i>	95
4.1.5	<i>Length of relationship</i>	95
4.1.6	<i>Number of children</i>	96
4.2	Experience of treatment at home	97
4.2.1	<i>Treatment cycles at home</i>	97
4.2.2	<i>Cost of treatment at home</i>	98
4.3	Reason for cross border infertility treatment	98
4.4	Organisation and management for CBRS.....	100
4.4.1	<i>Planning for CBRS treatment</i>	100
4.4.2	<i>Support for CBRS treatment.....</i>	101
4.5	Cross Border Reproductive Services.....	102
4.5.1	<i>Destination countries for CBRS</i>	102
4.5.2	<i>Cost of CBRS.....</i>	103
4.5.3	<i>Number of embryos transferred in a single IVF treatment cycle</i>	104
4.5.4	<i>Issues raised during and after CBRS.....</i>	104
4.5.5	<i>Experience of CBRS.....</i>	106
4.6	Commentary on these findings.....	106
4.7	Chapter Summary	107
	Chapter 5 CBRS adapted “I” poems findings	108
5.1	Case studies selection.....	108
5.2	Construction of ‘I’ poems.....	110
5.3	Participant 1	110
5.4	Participant 3	111
5.5	Participant 10	113
5.6	Participant 14	116
5.7	Participant 17	117
5.8	Participant 20	119
5.9	Participant 23	121
5.10	Participant 24	122

5.11 Participant 25	124
5.12 CBRS: the emerging words from 'I' poems.....	125
5.12.1 Cost	126
5.12.2 Wait.....	127
5.12.3 Time	128
5.12.4 Process.....	128
5.12.5 Recommendations.....	129
5.13 Chapter Summary	129
Chapter 6 Qualitative narratives and themes from participants	130
6.1 Coding and mental mapping of data.....	130
6.2 Stage 1: Before Infertility Treatment at Home	132
6.2.1 Early personal concerns	132
6.2.2 Single Women	133
6.2.3 Previous pregnancy.....	133
6.2.4 Costs and time	133
6.3 Stage 2: Perspectives of infertility treatment at home	134
6.3.1 Age starting infertility treatment at home	134
6.3.2 Costs of infertility treatment at home	135
6.3.3 Emotional responses	136
6.3.4 Relationship breakdown	137
6.3.5 Experiences of Infertility treatment at home.....	138
6.3.5.1 Availability of treatment	138
6.3.5.2 Clinical support.....	139
6.3.5.3 Decision on third party treatment	141
6.3.5.4 Logistic arrangements	141
6.3.5.5 Complementary therapy	142
6.3.5.6 Adoption.....	142
6.3.5.7 Restrictions and regulations	142
6.4 Stage 3: Reasons for and journey towards CBRS	142
6.4.1 Emotional response to their CBRS selection.....	144
6.4.2 Participants' CBRS Research Strategy.....	144
6.4.3 CBRS Logistic Arrangements	146
6.4.4 Support for CBRS.....	147
6.5 Stage 4: Expectation and experience of CBRS	148
6.5.1 Financial Cost.....	149

6.5.2	<i>Emotional responses during their CBRS</i>	150
6.5.2.1	Autonomy	150
6.5.2.2	Stress and anxiety	151
6.5.3	<i>Language barriers</i>	152
6.5.4	<i>Law and regulations</i>	153
6.5.5	<i>The clinical environment</i>	154
6.5.6	<i>Patient Characteristics</i>	155
6.5.7	<i>Risks</i>	155
6.5.8	<i>Treatment protocol</i>	156
6.5.9	<i>Staff</i>	158
6.5.9.1	Staff Attitudes	158
6.5.9.2	Staff communication	159
6.5.10	<i>Successful attempt</i>	161
6.5.11	<i>Recommending CBRS to others or returning to CBRS themselves</i>	162
6.5.12	<i>Support</i>	162
6.6	Stage 5: Returning home after CBRS	163
6.6.1	<i>Cross border reproductive clinics response</i>	164
6.6.1.1	Medical complications	164
6.6.1.2	Non-medical or legal and regulation issues	165
6.6.1.3	Staff attitudes	165
6.6.2	<i>Home clinics' response</i>	166
6.6.3	<i>Decision for CBRS</i>	166
6.6.4	<i>Emotional response to CBRS</i>	167
6.6.5	<i>Support</i>	168
6.6.5.1	Partner Support	168
6.6.5.2	Family and Friends	169
6.6.5.3	CBRS clinic and home clinic support	169
6.6.5.4	Infertility networks and counselling	170
6.7	Chapter Summary	170
	Chapter 7CBRS model	172
7.1	Push and Pull	172
7.2	Seriality or Serial Collectivity	173
7.3	Risk perception and unrealistic optimism	174
7.4	Health Belief Model (HBM)	175
7.5	Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB)	176

7.6	Trans-Theoretical Model.....	180
7.7	The proposed partial model for CBRS.....	183
7.7.1	<i>Stage 1: Pre-contemplation.....</i>	<i>183</i>
7.7.2	<i>Stage 2: Contemplation.....</i>	<i>183</i>
7.7.3	<i>Stage 3: Preparation.....</i>	<i>184</i>
7.7.4	<i>Stage 4: Action.....</i>	<i>186</i>
7.7.5	<i>Stage 5: Maintenance.....</i>	<i>187</i>
7.7.6	<i>Stage 6: Exit.....</i>	<i>187</i>
7.7.7	<i>Stage 7: Re-engagement.....</i>	<i>187</i>
7.9	Limitations of the study	188
7.10	Chapter Summary	189
Chapter 8	Participants' Recommendations for CBRS	190
8.1	Participants' recommendations for other CBRS patients	190
8.1.1	<i>Trusting their own judgement.....</i>	<i>191</i>
8.1.2	<i>CBRS protocol</i>	<i>191</i>
8.1.3	<i>Communication with CBRS.....</i>	<i>192</i>
8.1.4	<i>Undertaking research before utilising CBRS.....</i>	<i>192</i>
8.1.5	<i>Financial issues.....</i>	<i>193</i>
8.1.6	<i>Accommodation, travel and local communications.....</i>	<i>193</i>
8.1.7	<i>Emotional Responses</i>	<i>194</i>
8.1.7.1	<i>Avoiding stress</i>	<i>194</i>
8.1.7.2	<i>Counselling</i>	<i>195</i>
8.1.8	<i>Support</i>	<i>196</i>
8.1.8.1	<i>Support from infertility networks</i>	<i>196</i>
8.1.8.2	<i>Support of family and friends</i>	<i>197</i>
8.1.8.3	<i>Support from doctors</i>	<i>197</i>
8.1.8.4	<i>Support from work.....</i>	<i>198</i>
8.2	Participants' Recommendations for CBRS Providers	198
8.2.1	<i>Communication.....</i>	<i>198</i>
8.2.2	<i>Language barriers.....</i>	<i>198</i>
8.2.3	<i>Person-centred care</i>	<i>199</i>
8.2.4	<i>Links between home and overseas clinics.....</i>	<i>199</i>
8.3	Participants' Recommendation for National and/or Supra-national Bodies	200
8.3.1	<i>Information on cross border reproductive services</i>	<i>200</i>

8.3.2 Educational material.....	201
8.3.3 Legal Perspectives around CBRS	202
8.3.4 CBRS and socioeconomic disparities	202
8.3.5 CBRS and the Media	203
8.5 Chapter Summary	204
Chapter 9 Discussion.....	205
9.1 Reflection upon the appropriateness of the chosen methodology	209
9.2 How this study has contributed to existing theoretical knowledge.	210
Chapter 10 Conclusion	215
References	219
Appendices.....	240
Appendix 1	241
Appendix 2	243
Appendix 3	244
Appendix 4	245
Appendix 5	247
Appendix 6	251

List of Tables

TABLE 1: EXCLUDED STUDIES	41
TABLE 2: SUMMARY OF FINDINGS FROM INCLUDED PAPERS	42
TABLE 3: EPISTEMOLOGICAL DIFFERENCES BETWEEN QUALITATIVE AND QUANTITATIVE RESEARCH STRATEGIES	58
TABLE 4: COMPARISON OF CLASSIC GROUNDED THEORY AND STRAUSSIAN GROUNDED THEORY	64
TABLE 5: VALIDITY CRITERIA FOR QUALITATIVE DATA.....	65
TABLE 6: ADVANTAGES AND DISADVANTAGES OF EMAIL INTERVIEWS	76
TABLE 7: THE 'TEN COMMANDMENTS' OF COMPUTER ETHICS.....	81
TABLE 8: NETIQUETTE GUIDELINES FOR INTERNET RESEARCHERS.....	82
TABLE 9: STRENGTHS AND WEAKNESSES OF USING NVIVO SOFTWARE.....	84
TABLE 10: RESPONSE RATE FOR ADVANTAGES OF EMAIL INTERVIEW METHODOLOGY	84
TABLE 11: RESPONSE RATE FOR DISADVANTAGES OF EMAIL INTERVIEW METHODOLOGY	85
TABLE 12: REASONS FOR EXCLUSION FROM THE ANALYSIS	91
TABLE 13: TYPES OF CBRS SOUGHT BY THE PARTICIPANTS	93
TABLE 14: COUNTRY OF RESIDENCE AND ETHNICITY	94
TABLE 15: EDUCATION ATTAINMENT AND EMPLOYMENT STATUS	95
TABLE 16: NUMBER OF CHILDREN AND THEIR AGE	96
TABLE 17: NUMBER OF INFERTILITY TREATMENT CYCLES IN HOME COUNTRY	97
TABLE 18: REASONS FOR CROSS BORDER REPRODUCTIVE SERVICES.....	98
TABLE 19: PLANNING FOR CROSS BORDER REPRODUCTIVE SERVICE.....	101
TABLE 20: PROVISION OF SUPPORT DURING CBRS.....	101
TABLE 21: PROBLEMS FACED BY PARTICIPANTS DURING AND AFTER THEIR CBRS ...	105
TABLE 22: GENERAL EXPERIENCES OF CBRS	106
TABLE 23: THE PARTICIPANTS' CHARACTERISTICS INCLUDING OUTCOMES FOR THE 'I' POEM	109
TABLE 24: THE PARTICIPANTS' CHARACTERISTICS EXCLUDED FROM THE 'I' POEM...	109
TABLE 25: FIVE MOST FREQUENT WORDS USED IN 'I' POEM	126
TABLE 26: RESPONSES ON "BEFORE INFERTILITY TREATMENT AT HOME".....	132
TABLE 27: COST OF TREATMENT AT HOME.....	135
TABLE 28: EXPERIENCES OF INFERTILITY TREATMENT AT HOME	138

List of Figures

FIGURE 1: FLOW CHART SHOWING RESULTS OF CRITICAL ANALYSIS OF DATABASE RESULTS	40
FIGURE 2: MODEL FOR THE ADVANTAGES OF EMAIL INTERVIEW METHODOLOGY.....	85
FIGURE 3: MODEL FOR THE DISADVANTAGES OF EMAIL INTERVIEW METHODOLOGY..	86
FIGURE 4: DESTINATION COUNTRIES FOR CBRS	102
FIGURE 5: PARTICIPANT'S BRUISING AFTER USING HIGH DOSE ASPIRIN *	113
FIGURE 6: GRAPHICAL REPRESENTATION OF GROUNDED THEORY APPROACH UTILISED IN THIS STUDY	130
FIGURE 7: PERSPECTIVES OF INFERTILITY TREATMENT AT HOME.....	134
FIGURE 8: JOURNEY TOWARDS CBRS	143
FIGURE 9: EXPECTATIONS AND EXPERIENCES DURING CBRS	149
FIGURE 10: RETURNING HOME AFTER CBRS	164
FIGURE 11: HEALTH BELIEF MODEL	175
FIGURE 12: THEORIES OF REASONED ACTION AND PLANNED BEHAVIOUR	177
FIGURE 13: THE TRANS-THEORETICAL MODEL (STAGES OF CHANGE).....	182
FIGURE 14: CBRS PARTIAL TRANS-THEORETICAL MODEL	185

Chapter 1 Introduction

In this chapter, I will set out the context for this study, first by discussing the phenomenon of infertility and involuntary childlessness, followed by an overview of traditional and more recent responses to infertility and involuntary childlessness and a review of the range of ways in which different countries/jurisdiction have sought (or not) to regulate assisted reproductive services. I then identify factors that influence travel across national or state borders to access reproductive services within the context of 'medical tourism'. The need for research into, and greater knowledge and understanding of, cross border travel to access reproductive services is then identified together with the rationale for this study. I follow this with a brief biography, which accounts for my personal journey of twenty seven years transformation from an embryologist providing reproductive services to a social scientist investigating reproductive services. During these twenty seven years, much has changed in the medical treatment of infertility including scientific development, regulation and legislation of assisted reproduction. The availability of assisted reproduction has expanded worldwide, increasing the family-building options for individuals who are infertile or involuntarily childless. Finally, I will outline the structure of the thesis, and briefly describe the content of each chapter.

1.1 Infertility and involuntary childlessness

Infertility and its treatment have increasingly attracted attention from a diverse community including behavioural, biological and social scientists, ethicists, theologians, lawyers, legislators, social activists, cultural critics and social media (Sandelowski and De Lacey, 2002).

Boivin et al. (2007) estimated that 72.4 million women aged between 20–44 years in married and consensual unions are affected by infertility worldwide, of whom 40.5 million are currently seeking infertility treatment. Cahill and Wardle (2002) estimate 1 in 6 couples require referral for investigation for infertility treatment. In addition to individuals experiencing clinical fertility difficulties, there are women for whom carrying a pregnancy may pose high risks, men or women who may be at risk of transferring an adverse genetic condition to any genetically-related child, and a potentially large - but currently not quantified - population of people who may not be medically/clinically infertile, but who are involuntarily childless as a consequence of social or lifestyle reasons.

Infertility brings together both medical and social perspectives, in which the infertile person drifts between reproductive incapacity and capacity. Greil (1991) described this

as “not yet pregnant state” but ever hopeful of achieving pregnancy and having a baby to take home. Sandelowski and De Lacey (2002) suggested that this be-twixt-and-between condition of infertility emerged when infertile couples and their doctors could expect their infertility to be overcome by reproductive technological advances. “Infertility triggers grave anxieties about how far human beings can and should go to circumvent nature, fate and divine will in the pursuit of health and happiness” (Sandelowski and De Lacey, 2002, p.35). Infertile couples were often viewed as white, married and socially economically advantaged, whereas poor and minority groups were often viewed as hyper-fertile. Single persons or gay and lesbian couples were viewed to be “dis-fertile”, that is as unsuitable for parenthood no matter what their fertility state (De Lacey, 1998; Ikemoto, 1996). Debate continues with current international interest in the differing views of same sex parenthood and children born as a result of reproductive technologies; for example, Italian fashion designers Domenico Dolce and Stefano Gabbana were publicly condemned by Sir John Elton, the father of two IVF-surrogacy children, when they referred to IVF babies as “synthetic children” (ABC News, 2015).

An extensive body of literature which describes the infertility experience in great detail and depth now exists. Dominant themes identified by infertile couples includes negative identity, a sense of worthlessness and inadequacy, a feeling of lack of personal control, anger and resentment, grief and depression, anxiety and stress, lower life satisfaction, envy of other mothers, loss of the dream of co-creating, the emotional roller coaster and a sense of isolation (Greil, 2009).

1.2 Infertility treatment options

Historically, humankind has devised a range of responses to infertility and involuntary childlessness. Biblical sources, for example, highlight the impregnation of female household servants as a response to the infertility experienced by Jewish matriarchs (see Genesis chapters 16 and 30); in other cultures, the “gifting” of a child for childless members from within the extended family (Douthett and Bennett, 1999), arranging for a male family member or from the wider community to impregnate the female partner of an infertile man (Tabong and Adongo, 2013), and providing a new sexual partner for a man whose female partner has been unable to conceive, such as the sister of the woman, or allowing the man to have more than one wife (Tabong and Adongo, 2013) have been reported.

Over time, such “traditional” interventions have been augmented by medicalised responses that are conventionally referred to collectively as Assisted Reproductive Technology (ART). Initially medical professionals’ response to infertility

took the form of 'artificial' impregnation of the fertile female partner of an infertile man ("artificial insemination by donor", subsequently re-designated as "donor insemination" or simply "DI"). While there was no essential medical reason for DI to fall within the remit of the medical profession, it nevertheless successfully established itself as the appropriate profession to administer DI services (Snowden, 1993; Novaes, 1998).

By the final quarter of the 20th century, an extensive range of ART options had become available alongside DI. Most of these developed from the discovery and application of in vitro fertilisation (IVF) - a procedure devised by obstetrician Patrick Steptoe and biologist Robert Edwards that enables human embryos to be fertilised outside a woman's uterus and in so doing makes possible the creation of an embryo using the sperm of any man and the egg of any woman, including using the gametes (sperm or eggs) of deceased persons (Landau and Blyth, 2004). The first baby conceived by IVF, Louise Brown, was born in Oldham in July 1978 and by 2012 it was estimated that more than 5 million children had been born worldwide as a result of IVF and variant procedures, such as intra-cytoplasmic sperm injection (ICSI), egg (oocyte) donation (ED), embryo donation and in vitro maturation (IVM). ART currently accounts for a sizeable – and generally increasing – percentage of all births in many countries, up to 5.9% of all births in Denmark in 2010 – the corresponding figure for the UK reported as 2.2% (Kupka et al., 2014).

1.2.1 Donor insemination

Donor insemination has been provided as a means of circumventing male infertility for many years (Snowden, 1993; Novaes, 1998). As a reproductive technique, DI is relatively straightforward; sperm is produced by means of masturbation and placed in the woman's vagina. From DI's early beginnings as a medical procedure, practitioners endorsed anonymity between donor and recipient (Barton, Walker and Wiesner, 1945; Snowden, 1993; Novaes, 1998), as well as non-disclosure of recourse to DI, in particular to any child conceived as a result of its use (Royal College of Obstetricians and Gynaecologists, 1987). Despite DI's initial utilisation for couples in a heterosexual relationship who experience male factor infertility/sub-fertility, it has subsequently become a significant family-building option for women who do not have a male sexual partner (Zadeh, 2014), while ICSI, which enables an egg to be fertilised by means of injecting a single sperm, has become the preferred treatment option for many heterosexual couples where the male partner has poor quality sperm (HFEA, undated).

1.2.2 Egg Donation

Egg donation is the giving of eggs (oocytes) by a female donor to another woman (Bryan and Higgins, 1995). Egg donation became available as a family-building option only in the 1980s as IVF became more routinely available. The first birth resulting from egg donation was reported in Australia in 1984 (Lutjen et al., 1984). The use of egg donation has expanded in recent years with the development of more successful procedures to cryopreserve and thaw eggs (IFFS, 2013). Unlike DI, egg donation is a complex process, the donor needs to complete an invasive course of IVF treatment, which requires a daily injection of hormones to stimulate the ovary, ultra-sound scans and ultra-sound egg collection. Egg donation poses some risks to donors and they may experience adverse conditions such as ovarian hyperstimulation syndrome (OHSS), which in some rare instances may be fatal (ASRM, 2014).

1.2.3 IVF surrogacy

IVF surrogacy combines traditional practices of surrogacy as described above with IVF. It is an arrangement where a woman carries and delivers a child for another couple when the commissioning couple is unable to do so. The commissioning couple, generally, cannot carry a child mostly for health reasons (e.g. congenital or acquired uterine abnormality or serious medical contraindication to pregnancy) (Milliez, 2008, IFFS; 2013). While IVF surrogacy is mostly used by heterosexual couples, the growing use of surrogacy services by same sex couples, involving both a surrogate and an egg donor, has been reported (Riggs and Due, 2010). IVF surrogacy has received extensive publicity in popular media especially following its use by celebrities such as Elton John and Nicole Kidman.

1.2.4 Pre-implantation genetic diagnosis (PGD) and pre-implantation genetic screening (PGS)

The ability to examine embryos outside the body prior to implantation in the uterus has enabled an increasing number of embryo characteristics to be identified by means of pre-implantation genetic diagnosis (PGD) and pre-implantation genetic screening (PGS) (ESHRE, 2012). Many of these identifiable characteristics relate to genetic conditions with significant adverse health-related outcomes. PGD and PGS can thus be used to prevent the transmission of some inherited genetic disorders; they can also be used to determine the sex of embryo. This may be especially beneficial in providing treatment for individuals at risk of passing a serious sex-related genetic condition to any child. However, the potential of these same procedures to ensure or prevent the conception of children on the basis of the embryo's sex alone (i.e. for "social" reasons, mostly for parents wishing for children of a specific sex only or wishing both to limit the size of their

family and to ensure that it comprises children of both sexes) poses significant ethical dilemmas and potentially substantial demographic implications (IFFS, 2013).

1.2.5 Multiple embryo transfer and Selective foetal reduction

In the early days of IVF it was common practice to transfer multiple embryos during a single IVF cycle in order to maximise the chance of a successful pregnancy – and in many countries/jurisdictions multiple embryo transfer remains commonplace (IFFS, 2013). However, multiple embryo transfer contributes to significant increases in the rates of multiple pregnancy (including twin, triplet, quadruplet and higher order multiple births) with consequent risks of adverse health, psychological and social outcomes for both mothers and children (IFFS, 2013). ‘Selective foetal reduction’, a procedure in which one or more embryos in a multiple pregnancy is aborted so as to increase the chances of survival and healthy development of the remaining embryos has been developed as a pragmatic response to multiple pregnancy following multiple embryo transfer. Whilst selective foetal reduction is considered a relatively straightforward procedure technically, it is fraught with controversial social, psychological, religious and ethical implications (IFFS, 2013).

1.2.6 Posthumous conception

While in most instances ART procedures involve the use of gametes provided by living adults, there are situations in which the gametes of a deceased person may be used to conceive a child; either where the individual has died following the collection and storage of her/his gametes or where gametes may be retrieved following the individual’s death (IFFS, 2013).

1.3 Variations regarding ART in different countries/jurisdictions

It is evident that treatments for infertility and involuntary childlessness go to the heart of what makes up human society and its regeneration. How children are conceived, by whom they are conceived, to whom they are born, and how families are built, can be seen to exert an intrinsic impact on the nature of society itself. “Rules” regarding what is considered “normal” or acceptable permeate customs, traditions, laws and religious doctrines. Variant cultural, religious, ethical and political influences in different communities have impacted on the ways in which different countries/jurisdictions have responded to the perceived opportunities and threats posed by ART. In addition, the prosperity and economic status of different countries generally impact on the availability of the necessary resources (such as facilities, expertise, and funding) to provide sophisticated technological services, which is largely restricted to high income countries.

In a recent surveillance report, the International Federation of Fertility Societies (IFFS, 2013) examined the regulatory and legislative contexts of ART provision in 60 countries/jurisdictions, highlighting significant differences between different countries/jurisdictions regarding the provision and funding of ART services, which ART procedures may or may not be permitted, and who may or may not be permitted to access them. These are discussed in more detail below, drawing primarily on data from the IFFS study.

1.3.1 Funding of ART services

The IFFS surveillance reported considerable variation between different countries/jurisdictions regarding the extent to which provision for ART was made by national health programmes or insurance plans. Where cover existed, it largely reflected prevailing domestic arrangements for health care. Rarely was ART provision complete; more usually cover was partial, and subject to eligibility criteria, chief amongst which were marital status, parity, age, existing of children in the family, and household income. IFFS found that high-income countries - with the principal exception of the United States, where funding for ART services is largely reliant of private insurance - were more likely than middle- and low-income countries, to include at least some provision for ART care within their national health programmes. For example, many European countries, and in particular the Nordic countries, have comparatively generous publicly-funded infertility services (Nyboe Andersen et al., 2009) and in Australia, almost all patients receive IVF treatment via the public health care system.

Even where they exist, national health and insurance plans frequently restrict both the type and number of funded treatment cycles to eligible persons. In many countries/jurisdictions, patients are personally responsible for funding all or a significant element of their ART treatment. Almost invariably the costs of ART cycles are high in comparison to income levels. In the USA, the average cost per IVF cycle in 2006 was £8,000. The cost per live birth in the USA and the UK was estimated at £25,000 and lowest in Scandinavia and Japan £15,000 (Adamson, 2009). The average IVF cost per cycle in the Czech Republic is £4,000, in Hungary £1,225.80, in Thailand £1,838, while in India the cost per IVF could be as low as £900 (IVFcost.net. 2011).

1.3.2 Variations in permitted ART procedures

There are considerable variations between countries/jurisdictions regarding their approaches to different ART procedures. In countries/ jurisdictions with a longer history in ART, there are often more developed guidelines and Codes of Practice to inform and regulate ART practice.

1.3.2.1 Gamete and embryo donation and surrogacy

While most countries/jurisdictions permit sperm and egg donation, somewhat fewer allow embryo donation and even fewer permit surrogacy. According to the IFFS, sperm donation for IVF and non-IVF procedures, and egg donation for IVF was used by 70% of the countries/jurisdictions surveyed, whereas embryo donation was used by 43% and IVF surrogacy was used by 31% of the same countries/jurisdictions.

Gamete and embryo donation and surrogacy are less likely to be permitted or practiced in countries/jurisdictions where strong religious views maintain an impact on behaviour and legislation. Most Muslim countries, for example, prohibit all forms of donation and surrogacy, although Iran permits egg donation. Surrogacy is prohibited in countries such as China, Finland, France, Italy, Japan, Norway and Sweden. However, Israel, uniquely has introduced a state regulatory scheme for surrogacy.

Furthermore, where gamete and embryo donation and surrogacy are permitted, variations between countries/jurisdictions exist regarding age limits for donors and surrogates; protection of the identity of donors and surrogates, financial compensation for donors and surrogates, limits on the number of offspring (or families) that may be born from the gametes/ embryos of any single donor and the legal status of children born as a result of these procedures.

In a small number of countries/jurisdictions donors are permitted to donate only if they register their personal details with a central registry and agree to the disclosure of their identity to any offspring at some future time, usually when the offspring reach the age of maturity. (At the time of writing this was the pattern of donation in Austria, Finland, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the UK and the Australian states of New South Wales, Victoria and Western Australia). However, in most other countries/jurisdictions where gamete/embryo donation is practiced donors may be identifiable or anonymous as they wish, while in others, such as Spain and France, donor anonymity is mandated.

In many countries/jurisdictions, donors and surrogates are required to offer their services altruistically, where the donor or surrogate may be compensated for expenses only. The rationale for this is that gametes, embryos or reproductive services should not be considered as a commodity, and some countries/jurisdictions explicitly prohibit commercial surrogacy (e.g. Australia, Brazil, Canada, Greece, New Zealand and the UK).

As regards compensation for donors the UK's regulatory body, the Human Fertilisation and Embryology Authority (HFEA, 2015c) permits sperm donors to claim up to £35 per clinic visit or 'reasonable expenses' to cover any financial losses incurred in connection with the donation, with the provision to claim an excess to cover higher expenses (such as travel, accommodation or childcare). In comparison, Danish sperm donors receive £44 for each donation and £130 for examination and tests, whilst in Spain sperm donors are compensated with £40 for loss of earnings and inconvenience. Canada's Assisted Human Reproductive Act (AHR Act, 2004) makes it illegal to pay sperm donors (Daniels et al., 2006).

In the UK, payment to egg donors is similar to the package offered to sperm donors, although providing higher levels of compensation in recognition of the greater inconvenience and risks associated with egg donation (loss of earnings of up to £750 per cycles of egg donation, compared to £900 per donation paid to egg donors in Spain (Berkley et al., 2005). In France, Canada and Australia, egg donors do not receive compensation payment.

In other countries, both gamete procurement and surrogacy operate on an explicitly commercial basis (e.g. India and some US states).

Galbraith et al. (2005) collected information on costs from 20 California surrogacy agencies. They estimated the total cost per surrogate transaction could be between US\$38,000 and \$57,000 (£24,000 to £36,000). More recently Pande (2009) reported the surrogate transaction cost is between US\$50,000 to \$80,000 (£31,000 to £50,000) with surrogates receiving between US\$14,000 to \$30,000.

In contrast, in India, the cost of a surrogacy arrangement is much lower, between US\$5,000 to \$12,000 (£3,200 to £7,500), with surrogates usually receiving between \$3000 and \$5000 (£2,000 to £3,200) (Pande, 2009). The advent of legalised commercial surrogacy in India in 2002 has facilitated India becoming an important centre of commercial surrogacy (Whittaker, 2011a). Similarly, Ukraine offers commercial surrogacy, with one Ukraine IVF clinic website promoting its surrogacy programme as 60-70% cheaper than in the USA (Surrogacy in Ukraine, 2014).

In some countries/jurisdictions formal limits may be placed on the number of offspring that may be conceived from the gametes/embryos of any single donor

For example, the offspring limits for sperm donation in Australia and the UK is 10 families. However in other countries/jurisdictions no similar restrictions exist; as a result

gametes from a single donor could be used to conceive an unlimited number of offspring (Mroz, 2011).

1.3.2.2 Preimplantation genetic diagnosis and sex selection

IFFS report wide variations in different countries'/jurisdictions' approach to PGD. In some, e.g. Denmark, Latvia, Libya, Senegal, Slovenia, South Korea, Sweden and Venezuela, its use is restricted to specific hereditary disorders. In other countries/jurisdictions (e.g. Kazakhstan, Norway, Sweden, Libya, Philippines, Singapore, and Slovenia) PGD is not permitted under any circumstances.

Sex selection is specifically prohibited in many countries/jurisdictions, especially sex selection for "social" reasons only. However, sex selection is permitted by law in Belgium, Czech Republic, Greece, Hong Kong, Israel, Libya, Russia, Saudi Arabia, and the United States, while another 20 countries/jurisdictions reported that it is practiced (IFFS, 2013).

1.3.2.3 Number of embryos for transfer in IVF/ART cycles and Selective foetal reduction

As the risks of adverse outcomes resulting from multiple embryo transfer have become more widely acknowledged, professional body guidance and in some cases, regulation and legislation have introduced restrictions on the number of embryos that may be transferred in a single IVF cycle. IFFS (2013) reports that an increasing number of clinics worldwide are restricting to one or a maximum of two the number of embryos transferred in order to give effect to what is being seen as current 'best practice': "Transfer as many embryos as you like, but one at a time." (IFFS, 2013: 37). However, despite the overall trend, the IFFS reports that multiple embryo transfer, advocated in pursuit of higher success rates, is still common in many countries. As a consequence of these practices combined with increases in the number of IVF cycles performed over time worldwide IFFS (2013) reports an increase in the rate of selective foetal reduction and anticipates that any reduction in selective foetal reduction levels will be achieved only as a consequence of reductions in the number of multiple embryo transfers performed (IFFS, 2013).

1.3.2.4 Posthumous conception

Although the IFFS reports on posthumous insemination only, variations between different countries/jurisdictions are evident. A quarter of respondent countries/jurisdictions indicated that posthumous insemination was allowed, almost half

(45%) reported that it was not allowed, and another quarter reported that it was not mentioned in national legislation.

1.3.3 Eligibility for ART services

Regardless of the availability of particular services in different countries/jurisdictions, many reflect conservative family values in their public policies towards ART, restricting eligibility to ART services to married heterosexual couples only or to heterosexual couples in a "stable relationship." This is especially the case in countries/jurisdictions where traditional religious views, such as Islam and Roman Catholicism, that proscribe extramarital sexual relationships and homosexual relationships, continue to exert an impact on behaviour and/or legal systems. Other countries/jurisdictions with more liberal social mores extend eligibility to ART to single people and individuals in male and female same sex relationships.

1.4 Factors influencing cross border travel to access reproductive services

The IFFS review illustrates that the ways in which different countries/jurisdictions have chosen to regulate ART services (or not) and the economic status of different countries/jurisdictions have impacted on the availability and accessibility of ARTs.

Specifically:

- The cost of broadly similar services may vary between different countries/ jurisdictions (Pennings, 2004). The cost of IVF treatment in many developed countries is more expensive than in developing countries, thus leading to patients deciding to obtain ART treatment in developing countries. Madsen, the founder of the American Fertility Society, for example, suggested that despite the fact that there are 355 IVF clinics in the USA, the main reason for patients travelling abroad for IVF treatment is due to cost (Lee, 2005).
- More successful outcomes may be reported by specific clinics and/or in other countries/jurisdictions more generally.
- Services may be available but not accessible by certain groups, e.g. where there are eligibility restrictions on the grounds of age, marital status, sexual orientation (Pennings, 2002; Pennings et al., 2008). Ethnic minorities in the USA, UK and the Netherlands are reported to have less ready access to infertility treatment at home than do the white majority (Becker et al. 2005; Culley and Hudson 2006, 2007).
- Services may not be available or waiting lists may be lengthy because of a shortage of resources (Pennings, 2002), e.g. a lack of availability of altruistic donors or surrogates – and especially in countries/ jurisdictions that also require donors and surrogates to be willing to disclose their identity to offspring. In Canada, the ban on commercial sperm donation is reported to have resulted in a

significant reduction in the number of sperm banks operating in the country (from 40 down to 1) (Collier, 2010). The introduction of altruistic and non-anonymous sperm donation in Sweden is reported to have created a shortage of sperm donors (Ekerhovd et al., 2008).

- In countries/jurisdictions with fewer regulatory controls, the decision to provide specific services (e.g. higher order embryo transfer, PGD or PGS) and whether to offer a service to certain types of patients (e.g. gay couples seeking surrogacy, older women seeking egg donation) rests more on the discretion of individual clinics and doctors.

These variations between different countries/jurisdictions provide the context in which individuals are able and might be willing to travel to access reproductive services, and which may be seen as part of the global phenomenon of medical tourism.

1.5 Medical Tourism

Medical tourism is portrayed in the 21st century as a means by which “citizens from highly developed countries choose to by-pass care offered in their own communities and travel to less developed areas of the world to receive a wide variety of medical services” (Horowitz, Rosenweig and Jones, 2007, p.33). However, “medical tourism” is not a new phenomenon. By the eighteenth century, numerous seaside resorts and towns in the countryside became famous for harnessing the powers of nature and for their curative powers to which people flocked (Connell, 2006). In Thomas Mann’s book ‘Death in Venice’ (1912) an author, Gustav von Aschenbach, travelled to the Grand Hotel des Bains on the Lido Island to recuperate from his illness. Non-coastal spa towns enjoyed popularity for example; the Royal Pump Room in Harrogate is famous for its “curing” sulphur water, which was visited by the Tsarina Alexandra of Russia in 1911. Medical tourism is often linked with relaxation, pleasure and an increase of health and well-being.

Globalisation of health care is a growing phenomenon. Many people are travelling to another country each year to obtain medical treatment (e.g. dental treatment, hip replacement, plastic surgery), primarily because services are cheaper, or of better quality, in the ‘destination’ country compared to the ‘home’ country. As health care costs increase and waiting lists lengthen in home countries (Hopkins et al., 2010), many patients in the developed world are looking for cheaper and quicker medical treatment overseas.

Currently there are no verifiable statistics on the magnitude of medical tourism; a 2007 estimate suggested that 100 million patients travel to developing countries for health

care treatment annually (Jones and Keith, 2007). Medical tourism is a burgeoning industry; it has been estimated that global medical tourism could generate annual income valued at £37 billion with a 20% annual increase (Arnold, 2006). Medical tourism to India was estimated to be worth £2.7 billion by 2012 (Horowitz et al., 2007).

1.6 Cross Border Reproductive Services - the need for further study

Crossing national or state borders to access reproductive services as a specific form of medical tourism has generated increasing professional and media interest in recent years. The first high profile case of a UK citizen undergoing fertility treatment abroad was that of Diane Blood (2015). Diane's husband Stephen became ill with meningitis in 1996 from which he never recovered. Prior to Stephen's death, doctors extracted sperm that was subsequently cryopreserved. Several years after the death of her husband, Mrs Blood sought to use her late husband's sperm to have his child but she was prevented from doing so by the HFEA. Mrs Blood challenged this decision in court and on 6th February 1997 (HFEA, 2003), the UK Court of Appeal ruled that under European Law she had the right to use her former husband's sperm posthumously, even though the HFEA had proscribed its use in the UK. Mrs. Blood received her treatment in Belgium and gave birth to her son in 1998. The most recent high profile case of UK citizens seeking IVF abroad was that of Elton John and David Furnish who had a contract with a Californian surrogate and a separate egg donor, resulting in the birth of baby boys, Zachary in 2010 and Elijah in 2013.

There are an increasing number of qualitative research papers on the motivation of and experience of individuals crossing borders for reproductive services, mainly from developed countries (e.g. European countries). Seminal research has also been undertaken by Pande (2011), Inhorn (2012) and Whittaker (2011) focusing on patients' experiences of cross border reproductive services in India, Middle Eastern and the Far Eastern countries.

However, as the literature review undertaken for this study (Chapter 2) indicates, interest in the phenomenon is of relatively recent origin and current knowledge and understanding remain rudimentary. In a previous review of the research literature (see also Chapter 2) Hudson et al. (2011) argue there is a need for more research to advance understanding and assess the many complex questions (i.e. ethical, socio-economic and political impact) of cross border travel for reproductive services:

"commodification, commercialization and the potential exploitation of patients, donors and surrogates, concerns about 'stratified reproduction' and social justice, ethical issues for clinicians involved in sending and receiving [travellers for cross border reproductive

services] and the potentially harmful impact of fertility tourism on access of local populations to reproductive healthcare systems” (Hudson et al., 2011, p.683).

1.7 The rationale for this study

As has been established, cross border travel to access reproductive services is a growing phenomenon at the intersection of medicine, law, business and travel (Gürtin and Inhorn, 2011). Much existing literature and research concentrates on the legal and ethical aspects of cross border reproductive travel. Little research has been conducted on the decision-making processes and experiences of individuals undertaking international travel for reproductive services. This study aims to explore the motivations for, and experiences of, a group of individuals who have used cross border reproductive services (CBRS). This study aims to provide a better understanding in how individuals negotiate their CBRS journey between their needs for reproductive services and legal and other restrictions on services in their home country.

The research questions are:

1. What is the current literature reporting on CBRS?
2. What is the socio-demographic profile of individuals engaging in CBRS?
3. What are the experiences of individuals who have undertaken CBRS?
4. What is the decision-making process /model of individuals who have undertaken CBRS?
5. What are the recommendations from individuals who have undertaken CBRS?

1.8 Biography

Having set out the context of and rationale for this study I now outline my personal motivation for undertaking this research.

I gained an undergraduate degree in Chemistry and Biology and went on to gain my Masters in Medicinal Chemistry at Loughborough University in the mid-1980s. Biological cell line research was still in its infancy and I was fortunate to work on a tissue culture project for my Masters dissertation. After working as an organic chemist in Hong Kong, I returned to the UK in 1988. My first job was as a trainee embryologist in a private infertility clinic. Infertility treatment was then developing at a rapid pace. It was a very exciting time working as an embryologist; techniques such as cryopreservation, pre-implantation genetic diagnosis (PGD) and intra-cytoplasmic sperm injection (ICSI) were all in their infancy of development. The treatment of infertility was, and continues to be, a very competitive field of medicine; clinics were focusing on the publication of their success rates and the implementation of newly developed techniques. However, the

sharing of knowledge is always at the forefront of many clinics. I visited Bourn Hall clinic in Cambridge, the first infertility clinic, which was set up by Prof. Robert Edwards and Mr. Patrick Steptoe in 1980, and Hammersmith Hospital in London, the first infertility clinic to provide PGD in 1989. At this time, I met many of the scientific and clinical pioneers in reproductive medicine. In collaboration with clinical colleagues, I wrote a paper on genetic screening (Findlay et al., 1995), and follicular fluid and oocytes maturation (Salha et al., 1998).

As an embryologist, part of my role was to establish and manage the sperm bank and the recruitment of sperm donors. In the early 1990s, sperm donors were paid £10 for their travel expenses. Whilst chatting with the donors, I was not convinced that they understood the full implications of their donation. In collaboration with several psychologists and infertility clinicians, I contributed to a number of papers (Fielding et al., 1998; Lui and Weaver, 1996; Lui et al., 1995) on the attitudes and motivations of sperm and egg donors and the implications for the recruitment of altruistic donors. These papers represented initial research on sperm and egg donation and even after 20 years they are still widely cited in peer reviewed journals (Google citations search on 22 January, 2015 with the following results: Fielding et al., 1998 – 52 citations; Lui and Weaver, 1996 – 25 citations; Lui et al., 1995 – 50 citations).

Subsequently, I progressed onto health psychology research focusing upon addiction research and specialised in systematic review methodology. I took up my Senior Lecturer post at the University of Huddersfield in October 2009 where I met Professor Eric Blyth. We discovered our mutual interest in infertility, which inspired me to resume my research interest into psychosocial aspects of infertility for my doctoral studies. Professor Blyth had recently concluded an online survey on cross border reproduction for the Canadian government (Blyth, 2010) and was also a member of a multi-professional and multi-institutional research team on transnational reproduction, based at De Montfort University that focused on UK residents who travelled abroad for reproductive treatment (Culley et al., 2011, 2013; Hudson et al., 2011).

At the same time, I was also aware of the work carried out by the European Society of Human Reproduction and Embryology (ESHRE) Task Force on Ethics and Law on cross border reproductive care (Pennings et al., 2008). Their initial work focused on ethics and law, although a subsequent paper (Shenfield et al., 2010) reported on empirical work regarding cross border reproductive travel within Europe. However, there still appeared to be scope for further research to examine in more detail than had been possible in any previous research, individuals' and couples' motivation for, and

experience of, cross border reproductive services in a global context, since to my knowledge, none had been undertaken to date.

As my study progressed I had the opportunity to present this study's initial findings at the annual meeting of ESHRE (Lui and Blyth, 2011) and more recently at the annual meeting of the American Society for Reproductive Medicine (ASRM) (Lui, Blyth and Chirema, 2014). Attendance at these meetings enabled me to re-engage with colleagues from a variety of professions involved in reproductive services and infertility treatment. Upon reflection, I found little change over the years relating to the standard infertility treatment provided; however some advances have occurred in relation to vitrification of oocytes and stem cell research. The focus of these meetings remained medically orientated and little focus was placed upon the needs and the experiences of those seeking assisted reproduction.

1.10 The structure of the thesis

This thesis is organised into 9 chapters. Chapter 2 provides a systematic literature review updating the systematic review carried out by Hudson et al. (2011). This chapter provides current literature and research knowledge on CBRS. Chapter 3 seeks to present the ontological and epistemological assumptions underpinning the research. The research is located within Interpretative Grounded Theory (GT) methodology and the use of Voice Centred Relational Method (VCRM) position to analyse qualitative interview data, emphasising the individual experience of CBRS. This chapter also presents the asynchronous online interview methodological approach used in this study, including the advantages and disadvantages of such an approach, illustrated by asynchronous online feedback from participants. Chapter 4 presents the empirical socio-demographic profile provided by the 26 participants. Chapters 5 to 8 present the main findings and themes that emerged from the study. Chapter 5 recounts the individual narrations of nine participants regarding their CBRS journey and provides a rationale for inclusion in/exclusion from this process. Voice Centred Relational Method (VCRM) or 'I' poem approach (Brown and Gilligan, 1992b; Mauthner and Doucet, 1998; Gilligan et al., 2003) was used to analyse the participants' individual perspectives. Chapter 6 presents the full NVivo analysis of the 26 participants' email interview transcripts and the emerging themes from the participants. In this chapter, I re-visited the Grounded Theory methodology and introduced symbolic interactionism (Blumer, 1969). All the substantive themes are described in detail in this chapter. In chapter 7, I offer the reader different theoretical perspectives such as the 'push and pull' theory used by Inhorn (2011), which is taken from an anthropological perspective and seriality and communality (Young, 1994; Hudson and Culley, 2011), which was from a sociological perspective. I introduce

the readers to a number of social cognition theories (i.e. risk perception and optimistic bias (Weinstein, 1980); the Health Belief Model (Rosenstock, 1966); Theories of Reasoned and Action and Planned Behaviour (Fishbein and Ajzen, 1975; Ajzen, 1991); the Trans-Theoretical Model (TTM) (Prochaska and DiClemente, 1982) and contextualise them within the CBRS scenario. In chapter 8, I focus upon the recommendations derived from the participants. The participants' recommendations were divided into three main areas: recommendations for their CBRS fellow travellers, recommendations for clinics and recommendations for National and/or Supra-national Bodies. In the final chapter, I reflect upon the appropriateness of the chosen methodology and how this may be improved if the study was to be replicated. I provide research and policy recommendations and how this may enhance the potential delivery for CBRS.

Chapter 2 Literature Review

In chapter one, I have discussed infertility treatment, medical tourism, cross border reproductive services and the rationale for this study.

This chapter draws on a comprehensive review of literature pertaining to cross border reproductive services (CBRS) published before 2011 undertaken by Hudson et al. (2011) and a systematic review of literature undertaken specifically for this study relating to CBRS literature published between 2011 and 2013.

Hudson et al. identified 54 papers including 36 commentary and debate papers and 18 empirical research studies. CBRS were the central focus in only nine of these studies (Blyth, 2010; Hughes and DeJean, 2010; Inhorn and Shrivastav, 2010; Nygren et al., 2010; Pennings, 2010; Pennings et al., 2009; Shenfield et al., 2010; Smith et al., 2009; Whittaker and Speier, 2010). CBRS were a secondary focus in three studies (McKelvey et al., 2009; Pande, 2009; Whittaker, 2009) and six were either unpublished or focussed only partially on CBRS (Bartolucci, 2008; Bergmann, 2007; Infertility Network UK, 2008; Inhorn, 2009a; Inhorn and Patrizio, 2009). Little empirical research had been carried out before 2010 and a number of authors suggested that CBRS is an under-researched and under-theorised health phenomenon (Inhorn and Gürtin, 2011; Hudson et al., 2011).

Hudson et al. (2011) identified the following key themes discussed in the literature: (1) terminology; (2) prevalence; (3) patients' experiences.

1. Terminology

Hudson et al's (2011) review identified a variety of terminology and definitions had that emerged to describe the phenomenon of travelling from one country/jurisdiction to another for fertility treatment. When it was first documented, Knoppers and LeBris (1991) drew on the analogy with medical tourism by referring to 'procreative tourism'.

Many scholars subsequently used the term 'reproductive tourism' (Blyth and Farrand, 2005; Blyth, 2006; Chung, 2006; Ciocchi et al., 2006; Cohen, 2006; Culley and Hudson, 2009; Deech, 2003; Heng, 2006; Heng, 2007; Ikemoto, 2009; Martin, 2009; McKelvey et al., 2009; Mladovsky, 2006; Pennings, 2004; Pennings, 2002; Spar, 2005; Storrow, 2005). Storrow (2005) suggested "clinics that cater to reproductive tourists appear to welcome the development of new markets and have undertaken to market their services so as to create a fantasy of conceiving a child during a romantic holiday" (pp.326-327).

Despite its extensive use, the term 'reproductive tourism' has generated controversy largely due to the potentially negative, and inappropriate, connotations of the term 'tourism' with 'leisure' and 'enjoyment' that devalues the personal motivation for IVF treatment, trivialises infertility problems (Matorras, 2005) and implies even less acceptable connotations with 'sex tourism' (Storrow, 2005; Inhorn and Patrizio, 2009). Some critics of the cosy image associated with 'reproductive tourism', highlighted its failure to acknowledge the potentially exploitative nature of trading in human eggs involving socio-economically deprived and vulnerable young women, a practice that Pfeffer (2010) termed 'rotten trade'. Patients in Inhorn and Patrizio's (2009) study reported that the term 'reproductive tourism' sounds like a 'gimmick' and made a mockery of the potentially devastating physical and emotional pain and effort they experienced. They made the point that their preference is not to travel abroad if legal, trustworthy and economical IVF treatment were available in their home country. Inhorn and Patrizio (2009) preferred the term 'reproductive exile' (previously used by Matorras, 2005), a much more emotive term that highlights the duress experienced by patients. Inhorn and Patrizio (2009) argued that restrictive legislation relating to fertility treatment in patients' home countries created barriers and constraints 'forcing' them to travel abroad for treatment. However, Pennings (2005) argued against use of the term 'reproductive exile' since neither 'punishment' nor 'compulsion' is evident in the majority of instances of reproductive travel. Pennings (2005) conceived what he suggested was a more neutral term, 'cross border reproductive care' (hereafter CBRC) that avoids the negative connotation of 'tourism', which holds no value judgement regarding the movements and links with the general term 'cross border health care' which is commonly used when describing movements of health services. CBRC was subsequently adopted in several academic studies (e.g. Bartolucci, 2008; Ferraretti et al., 2010; Nygren et al., 2010; Pennings et al., 2009). At the 24th Annual Meeting of the European Society for Human Reproduction (ESHRE) in 2008 some patient groups advocated similar terms to CBRC as 'Cross border assisted reproductive technology' (cross border ART) (ESHRE, 2008).

Hudson and her colleagues themselves proposed 'transnational reproduction' as an alternative term (Culley and Hudson, 2009; Whittaker, 2009; Culley et al., 2011; Hudson et al., 2011). Culley and Hudson (2009) suggested this term links the process of fertility travel and more general processes of globalisation, which are occurring across all economic, social, cultural and political structures. Hudson et al. (2011) subsequently acknowledged the limitation of the term as it does not account for travel within countries for reproductive treatment, such as Australia or the USA where there are inter-state

differences in legislation. For example, in Australia women from Victoria have travelled to New South Wales to benefit from less restrictive law and regulation.

2. Prevalence

While CBRS seemed to be of increasing interest globally, the evidence of prevalence was based upon a few surveys reporting only estimations of incidence. Available data on CBRS are mainly based on retrospective survey questionnaires, which are either conducted with patients (Infertility Network UK, 2008; Blyth, 2010; Shenfield et al., 2010), IVF clinics and health professionals (Hughes and DeJean, 2010; Pennings et al., 2009) or via an international monitoring centre (Nygren et al., 2010).

For example, Shenfield et al. (2010) surveyed 46 clinics in Belgium, the Czech Republic, Denmark, Switzerland, Slovenia and Spain. They found the proximity and cultural similarity between the countries affected patients' decisions regarding specific treatments and destinations (e.g. Italians were most likely to seek treatment in Switzerland and Spain). Pennings et al. (2009) presented CBRS data from 16 Belgian IVF clinics, showing that the majority of non-Belgian patients travelled from France, the Netherlands, Italy and Germany and were most likely to seek DI and ICSI. Pennings et al. suggested that CBRS travel was most likely to be motivated by legal restriction or the availability of appropriate technology. Hughes and DeJean (2010) found patients entering Canada were most likely seeking IVF (73%), and Canadians seeking CBRS treatment elsewhere were most likely seeking egg donation (ED) (80%). CBRS patients entering the USA for IVF treatment were mostly from Europe (25%) and Latin America (39%). American patients sought treatment abroad for ED (52%) or IVF (41%) and they travelled to either India or Asia. The perceived safety and success rates are important for CBRS patients. Communication between CBRS patients and CBRS clinics is critical when determining whether the CBRS clinics could deliver safe and effective care. Nygren et al. (2010) utilised internationally collected data. They found few countries were able to accurately quantify the number of CBRS patients they had treated and that patients who had used CBRS are not required to disclose their treatment in their home country. They suggested that CBRS data are easier to accumulate by clinics providing treatment in destination countries because there is a clinic registration procedure. Nygren et al. (2010) advocated the creation of national databases to collect quantitative information to help regulatory bodies to provide support and accurate information to CBRS patients.

Studies also contained missing data, which make extrapolation problematic (InfertilityNetworkUK, 2008; Pennings et al., 2009).

In other studies the sample size was too small to enable firm conclusions to be drawn from the data (Blyth, 2010). Collins and Cook (2010) proposed this data collection process could be facilitated via the International Committee Monitoring Assisted Reproductive Technologies (ICMART). However, the 2006 ICMART world report on assisted reproductive technology was not published until 2014 (Mansour et al., 2014) suggesting that ICMART would have great difficulty in producing useful up-to-date data.

3. Patients' experiences

Hudson et al. (2011) reported that only 10 papers had made reference to patients' experiences of CBRS, the majority of whom made their own arrangements via the internet independently of clinics or other services in their home country (Blyth, 2010; Infertility Network UK, 2008) and were mostly satisfied with their experience of CBRS. Numerous commentaries (as opposed to the research on patients' experiences) primarily discussed the negative implications of CBRS, focusing on patients, donors and surrogates, children conceived via CBRS and the CBRS clinics. Different policy responses to CBRS, including prohibition, regulatory harmonisation and harm minimisation, were also extensively discussed by many commentators. Following this review, Hudson et al. (2011) identified a gap in the research i.e., limited CBRS research with patients or users, CBRS information on patients' socio-economic status and perspectives of infertility professionals on CBRS.

2.1 Review of literature published between 2011 and 2013

Following the review by Hudson et al. (2011), a special issue of the journal *Reproductive Biomedicine Online* (Volume 23, issue 5) was published in August 2011 devoted to CBRS. Global medical tourism is part of the new millennial interest by medical anthropologists and bioethicists. Seven special issues (*Global Social Policy*; *Signs: Journal of Women in Culture and Society*; *Anthropology and Medicine*; *Medical Anthropology*; *Gender, Place and Culture*; *Developing World Bioethics* and *International Journal of Feminist Approaches to Bioethics*) have been published since 2010 and some have touched upon CBRS.

In the following section I will describe the methodology, search strategy, additional searches, critical analysis, ethical considerations, results of the literature review and discussion of the review findings.

2.1.1 Methodology

The literature review undertaken specifically for this study utilised systematic review methodology (Aveyard, 2010; Centre for Reviews and Dissemination, 2009) that would enable the capture and analysis of all relevant empirical research and commentaries. Based on my prior analysis of Hudson et al.'s (2011) literature review, I anticipated that the heterogeneity of CBRS research and the variation in research methodology quality would mean that a traditional systematic assessment of the papers (as undertaken, for example, through a Cochrane systematic review focussing on findings from randomised controlled trials) would neither be appropriate nor possible (Centre for Reviews and Dissemination, 2009).

2.1.2 Search strategy

A pre-defined systematic search strategy (see Appendix 1) adapted from Hudson et al. (2011) was undertaken. This strategy incorporated the use of Boolean Logic – 'and/or' to ensure results generated were applicable to the current study, as recognised in the Cochrane Handbook (Higgins and Green, 2011). So as not to overlap with Hudson et al.'s (2011) review, the search date for this review encompasses the period between January 2011 and October 2013.

The principal sources of data were the electronic databases Medline (Medical Literature Analysis and Retrieval System Online), and CINAHL (Cumulative Index to Nursing and Allied Health Literature), via an Athens login at NHS Evidence online. This approach was promoted by Higgins and Green (2011) and Bettany-Saltikov (2012) to facilitate the identification of relevant research evidence from both medical and nursing databases on the topic of CBRS thus reducing the risk of bias.

The reference lists of all articles obtained as full reports were reviewed to identify any further studies not retrieved by the electronic search. Conference abstracts (ESHRE and ASRM) and unpublished information was sought from authors' websites. In addition, I checked the websites of the Human Fertilisation and Embryology Authority (HFEA), Progress Educational Trust and Economic and Social Research Council (ESRC) to identify additional CBRS reports. I scanned a number of internet web sites including the Infertility Network UK, Fertility Friends and performed a hand search in a number of leading infertility journals i.e., Human Reproduction, Fertility and Sterility to strengthen the review approach. I applied an English language restriction to this review and acknowledged this as a potential source of bias. Figure 1 (p.40) illustrates the process of the database search.

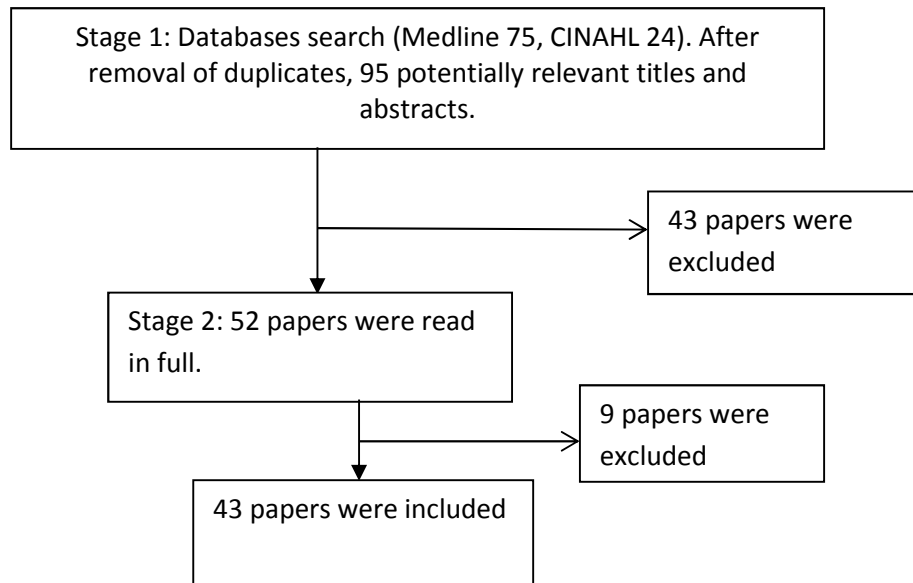


Figure 1: Flow chart showing results of critical analysis of database results

Exclusions were applied to the systematic search to make certain only relevant studies were identified, ensuring results were applicable to the aim of this study. For inclusion the papers needed to focus on CBRS and not medical tourism in general or gametes/embryos being transported internationally. An integral aspect of this review therefore is the 'patient travel' across a border in order to access CBRS (see Table 1, p.41 – Excluded Studies).

2.1.3 Critical Analysis

When analysing the studies, a number of tools were utilised to critique the research and to assess validity, reliability and transferability of the results (Aveyard, 2010). This review utilised an adaptation of the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2014) tools to evaluate each of the included papers (Ousey et al., 2010). A summary of the critical analysis is included in Table 3 (Included Studies, See Table 2, p. 42).

2.1.4 Ethical considerations

Although this literature review did not require ethical approval by an ethics committee, as it did not involve patients or health professionals (Aveyard, 2010), it is vital to ensure the five principles of biomedical ethics (respect for autonomy, non-maleficence, beneficence, justice, and professional-patient relationships) (Beauchamp and Childress, 2013) are recognised. With empirical studies where participants circumvent legal restrictions at home it is important to safeguard participants' confidentiality and anonymity. All primary studies identified in this review maintained privacy via pseudonyms and have ethical approval for the studies.

2.1.5 Results

After removal of duplicates, the search described above generated 95 potential papers. After reading the titles and abstract, 43 papers were excluded and 52 papers were read in full. Following this reading nine papers were excluded as they were not related to CBRS patients (see Table 1 below).

Table 1: Excluded Studies

Reference	Reason for exclusion
Downie and Baylis (2013)	Canada's law and policy regarding the prohibition of transnational trade in human eggs.
Madanamoothoo (2011)	Ethical and legal framework regarding 'saviour siblings' in the UK and France.
Markens (2012)	Online readers' comments. Focused mainly on surrogacy arrangements. Touched on globalization of the surrogacy industry especially in India.
Nahman (2011)	25 interviews with egg donors and 21 interviews with health professionals in Israel. Author examined 'reverse egg donation' traffic between Israeli and Romania; Israel's new laws to forbid cross-religious donation, further hardening the borders of the Jewish State. Repro-migration was highlighted.
Purewal et al. (2012)	33 Parental Order Reporters (PORs) in England and Wales completed questionnaires. Focused on surrogacy and child's needs.
Shenfield (2012)	Commentary that reiterates the main points of Shenfield et al's (2011) more substantive paper, which is included in the review.
Siva (2011)	Reiteration of Whittaker's (2011a) paper, which is included in the review.
Snyder and Crooks (2012)	Editorial introduction to medical tourism.
Wu et al. (2013)	Time cost for fertility care. Not CBRS.

This left 43 papers from the two database searches for inclusion in this review. To assist presentation of the results, I categorised the papers according to year of publication, sample and location of study, nature of publication and whether or not they are primary research, commentary or review papers (see Table 2, p. 42).

There were 26 commentary papers, 2 quantitative (questionnaires or secondary data analysis) studies, 14 qualitative studies (interviews or ethnographical or anthropological study, or internet forums) and 1 reviews.

The results from the papers were summarised in a narrative thematic approach to conform to the themes as proposed by Hudson et al. (2011) and identify any others themes emerging from the papers.

Table 2: Summary of findings from included papers

Authors	Sample and Location	Nature of publication	Findings relating to CBRS
Berg Brigham et al. (2013)	13 of the 15 EU countries that affirmatively regulate and publicly finance IVF	ESHRE (2009) data regarding regulatory frameworks	Countries with the most generous public financing schemes are more restrictive. Regulations related to public financing were not linked with utilization of IVF treatment. Whether CBRS was driven by cost and legal restriction is still unknown.
Culley et al. (2013)	20 interviews with UK health care professionals	Qualitative study	Three concepts are: 1. Autonomous patients, 2. Cross border travel as risk and 3. Professional responsibilities in harm minimisation. Professional narrative of the CBRS patients as vulnerable and knowledgeable; as engaged in risky behaviour and its active minimisation. Little support for government to legislate CBRS, however an argument for safeguarding patients' interests was raised.
Rozée Gomez and de La Rochebrochard (2013)	6 CBRS patients' organisations, 8 health professionals and 26 French patients	Cross sectional study (2010-2012) with questionnaire	Accessing egg donation is difficult in France. In France same sex couples and single women are prohibited from accessing infertility treatment. Many patients travelled for CBRS to Greece, Spain and Belgium. CBRS among French patients reflects both law evasion and limited access to egg donation in France.
Hunt (2013)	N/A	Commentary	In the UK, many patients choose CBRS independently; however some are referred under shared care arrangements between UK and foreign clinics. The involvement of counsellors appears to be limited even though counselling could support and prepare patients for the additional challenges which could arise for them in undertaking CBRS. Recommends that UK clinics routinely refer patients for counselling prior to cross border travel.
Ramskold and Posner (2013)	N/A	Commentary	Argues the need for international laws and regulations to protect all parties involved in commercial surrogacy via the Hague Conference on Private International Law (HCCH).
Thorn and Wischmann (2013)	N/A	Commentary	The German Society for Fertility Counselling Guideline for psychosocial counselling on CBRS.
Van Hoof et al. (2013)	8 Dutch internet forums.	Inductive thematic analysis between 10.2010-12.2011.	8 themes identified: medical expertise and testing, feelings and experiences, costs, trying out different clinics, travel and waiting times, treatment in the Netherlands, cooperation between clinics and laws and regulations. Forums analysis suggested that quality of care is higher

			in Belgium than in the Netherlands and patients feel more respected as a person in Belgium.
Cohen (2012)	N/A	Commentary: Legal	Travel to circumvent domestic prohibition. Four examples: female genital cutting (FGC), abortion, assisted suicide and CBRS. Cohen shows that, in most instances, home countries seek extended extraterritorial criminal prohibitions on FGC, abortion and assisted suicide, and, to a less extent for CBRS.
Crozier and Martin (2012)	N/A	Commentary: Bioethics	Exploration of two models (national self-sufficiency model and regulatory market model). Pros and cons of both models were discussed. Common values were identified: importance of regulations to safeguard egg donors and surrogates, international accreditation of clinics and partial harmonisation of legislation on CBRS.
Deonandan et al. (2012)	N/A	Commentary	CBRS is an international and multi-billion dollar industry. Eight challenges were discussed: robustness of informed consent, custody rights, quality and limits of surrogate care, remuneration, multiple embryo transfer and selective abortion, medical advocacy, exploitation of the poor.
Inhorn and Patrizio (2012)	N/A	Review	CBRS is a growing international industry. Review findings: debates of terminologies and the lack of international monitoring. Religious bans and legal restrictions create a patchwork of 'restrictive' and 'permissive' countries, with legal evasion being a driver for CBRS.
Inhorn et al. (2012)	Ethnographic research with 300 CBRS patients in 2 fertility centres (Dubai and Yale University)	Qualitative – 2 exemplar interviews.	Argues that CBRS terminology should encompass the concept of 'exile'. Identified barriers for CBRS.
Ross-Sheriff (2012)	N/A	Commentary	Author explores issues and concerns with Asian surrogacy. Feminists have criticized transnational surrogacy as a form of prostitution and slavery. Paper argued that Asian women are coerced by family into surrogacy.
Thorn et al. (2012)	N/A	Commentary	Major challenges associated with CBRS are the lack of information regarding the number of patients travelling abroad for treatment and transparency regarding the quality and safety of treatment procedures, especially in countries without legislation or binding professional guidelines. This could give rise to malpractices.

			Given international legislation or guidelines are unlikely to appear in the near future, the authors suggest the implementation of ethically based minimum standards of care to safeguard patients' safety.
Van Hoof and Pennings (2012a)	N/A	Commentary	Paper reviews the statement of European Convention of Human Rights (ECHR) Legal diversity within EU on CBRS. There are difficulties in the EU harmonisation project for CBRS due to conflict of national identity.
Van Hoof and Pennings (2012b)	N/A	Commentary	Turkey and several Australian states have enacted extraterritorial laws to stop citizens from accessing treatments abroad that are prohibited domestically. Within EU, ECHR would normally remove the needs for extraterritorial laws. EU's interests in harmonisation are at odds with member states' right to national identity especially in the areas of contested morality.
Ahmad (2011)	N/A	Commentary: legal	Comparative analysis of the Malaysian (Malaysian Parliament, 2012), Indian (ART bill 2010), USA and UK positions on assisted reproductive technology.
Bergmann (2011a)	4 empirical vignettes (Europe)	Ethnographic study	Patients' reasons for CBRS in Europe are diverse, in part due to different regulations between amongst countries. In Spain, Denmark and the Czech Republic, gamete donation is strictly anonymous. Close phenotypical matching served to install social legitimacy through the unborn child having similar physical resemblance with the recipient couple. CBRS intertwined with new form of kinship. Secrecy and concealment could create a potential problem when CBRS children wish to find their genetic parents.
Bergmann (2011b)	36 patients interviewed in Barcelona and Prague	Qualitative study	German patients circumventing legal prohibition of egg donation (Embryo Protection Act, 1990) utilising CBRS in Spain and the Czech Republic. The concepts of 'reproductive agency' and 'reproductive projects' are used to describe the way in which patients search for information about CBRS. How patients embed, deal with and position themselves within the CBRS process.
Blyth et al. (2011)	N/A	Commentary	Infertility treatment is immensely stressful and could impact upon both patients' and their partners' psychological and emotional health. Counselling by skilled professionals therefore may be beneficial. Authors mapped out the practice issues within an ethical framework for

			counsellors where CBRS is considered or undertaken.
Connolly (2011)	N/A	Commentary	CBRS reflects a global market bringing the needs of patients and the medical skills in treating infertile couple. Provides economic arguments for the benefits of CBRS within a population which is both ageing and has a low birth rate.
Crockin (2011)	N/A	Commentary	Discusses CBRS and accompanying legal challenges and concerns: including exploitation, abandonment of children born following surrogacy new born (genetic anomaly or divorce) and legal scandals.
Culley et al. (2011b)	51 UK residents	Qualitative study	Patient motivations for CBRS are complex. Patients seeking CBRS do not conform to media stereotypes. Further research needed to explore implications of CBRS for donors, offspring and healthcare systems.
De Sutter (2011)	N/A	Commentary	CBRS experience from Gent University Hospital Fertility Centre, Belgium. CBRS demand a major investment in treating clinics as patients often have a more complex history. CBRS clinics should not abandon or discriminate against their local patients for more profitable CBRS patients. Quality of care should be exactly the same for both the local and CBRS patients.
Donchin (2011)	N/A	Commentary	Compares the British (HFEA) and USA (Market Model) approach to legislation and regulation of infertility treatment. She argued that regulatory bodies are seldom neutral arbiters. The author considered initiatives by activist groups to build a transnational reproductive justice movement.
Forman (2011)	N/A	Commentary	CBRS from a doctor's perspective. CBRS is likely to increase and doctors must be encouraged to improve the quality and standards of care for these patients.
Franklin (2011)	N/A	Commentary	CBRS raises new global issues for both medicine and social science. Transparency is crucial to facilitate best practice in CBRS.
Gürtin (2011)	50 IVF patients and 33 experts were interviewed between 2005 and 2010 in Turkey	Empirical study	Turkey's assisted reproduction law was introduced in March 2010, particularly relating to third party reproductive assistance. The author explores the legal, ethical and practical implications of this legislation which restricts freedom of movement to curtail reproductive autonomy. Turkish government insisting that all citizens should follow the majority opinion.
Hudson and Culley	41 cases including	Qualitative study –	Existing media conceptualisations of CBRS

(2011)	10 heterosexual couples, 6 single women, 24 heterosexual women and 1 lesbian woman	3 cases	patients are simplistic and do not account for the diversity and often ambiguous motivation for CBRS. Authors use concept of seriality to formulate commonality (i.e. agency, goals and resources) and difference for CBRS. Authors argued against 'knee jerk' policy responses to CBRS.
Inhorn (2011a)	Author's four studies on Middle Eastern infertile couples 'returning home' for infertility treatments	Ethnographic studies	Research sites include four different Middle Eastern locales (Egypt, Lebanon, United Arab Emirates and Arab America). Identifies infertile couples' wish to have IVF 'back home' for various reasons, including medical, patriotism, language, co-religion and moral trustworthiness, donor phenotype, the comforts of home and discrimination.
Inhorn (2011b)	N/A	Ethnographic study	Islamic 'local moral worlds' (e.g. between Sunni and Shia) informing the movements of Middle Eastern infertile couples. Iran is leading the way into this 'brave new world' of third party assisted reproduction. This paper provides key insights into the understanding of techno-science, religious morality and modernity, which have deep implications for CBRS.
Inhorn and Gürtin (2011)	N/A	Commentary: Research	The research agenda for CBRS is a prime example of contemporary 'technological transnationalism' with infertile couples and other would-be parents pursuing international IVF treatments in the quest for conception.
Mancini et al. (2011)	1 Italian woman	Case study	Case study of 41 year old Italian woman following CBRS in Spain. Two embryos transferred and heterotrophic pregnancy following return home - a potentially fatal complication. Authors argue that patients' safety is paramount when seeking CBRS.
Pande (2011)	42 surrogates, their husbands and in laws, 8 intending parents, 2 doctors and 2 brokers between 2006 and 2008 in India	Ethnographic study	Women negotiate pathways to international surrogacy in India. Both surrogates and commissioning mothers used the language of 'gift', 'sisterhood' and 'mission' to describe the surrogacy arrangement, downplaying the economic aspects and contractual nature of the surrogacy process.
Pfeffer (2011)	N/A	Commentary	Highlights inconsistencies in different governments' regulations related to human kidney and egg donation. Neo-liberalism supports the growth of CBRS and is responsible for the exploitation of relatively poor and powerless

			women in destination countries.
Shenfield (2011)	N/A	Commentary	Comment on ESHRE's Good Practice Guide (GPG) for CBRS for clinics and health professionals. This voluntary guidance is to ensure appropriate quality of care and safety for all concerned, including patients, gamete donors, surrogates as well as future offspring. Six principles underpin the GPG: equity, quality, safety, evidence based care, patients' involvement and redress. If GPG is not followed by practitioners voluntarily, external regulation may be imposed on IVF clinics.
Shenfield et al. (2011)	N/A	Commentary	ESHRE's good practice guide for CBRS for clinics and practitioners. This guide focused upon: equity, quality, safety and evidence based care in CBRS, timeliness and patients' involvement.
Speier (2011)	30 surveys and 28 interviews conducted with patients, brokers, coordinators and IVF specialists In USA and Czech Republic	Ethnographic study	North American patients' journey to the Czech Republic for CBRS. Since distance is extensive, reproductive travel could be arranged by clinical staff, travel brokers and patients. Patients' choices often determine the success of brokers and clinics thus could influence the structure of the Czech Republic CBRS.
Storrow (2011)	N/A	Commentary: Legal	Examination of four legal regimes for CBRS 1. Prohibition limiting access to ART; 2. Criminalisation of CBRS; 3. Refusal of citizenship to CBRS offspring; 4. Prosecution of CBRS facilitators. Paper explores the legal doctrines of proportionality, extraterritoriality, and comity to assess the legality and normative validity of government efforts to curb or limit infertility treatment.
Whittaker (2011a)	N/A	Commentary	Discusses specific concerns regarding access and inequality, potential commercial exploitation and needs for protection via regulations in CBRS in low resource countries in Asia. CBRS challenges global health care services to meet the needs of vulnerable groups in circumstances of economic inequality.
Whittaker (2011b)	Three private and two public IVF clinics in Thailand, interviewing 31 (6 overseas patients / couples) patients and staff over 6 months	Qualitative study: case study	Non-medical sex selection is a lucrative global trade as a mean of "family balancing". Paper calls for ethical consideration of the role of political economy and commodification in peoples' reproductive decision-making.

	between 2007-2008		
Van Hoof and Pennings (2011)	N/A	Commentary	National legislation can no longer determine citizens' actions. Some countries react to people evading restrictions by implementing even more restrictive laws (i.e. Turkey and New South Wales, Australia). Authors concluded that CBRS legislation should be modest, tolerant and nuanced.
Zanini (2011)	22 cases in a private clinic	Ethnographic study	CBRS was undertaken by Italians reacting to the restrictive Italian law 40 issued in 2004, which provoked individual feelings of abandonment and betrayal. It transformed CBRS into a form of resistance against the government. Patients undertaking CBRS became involved and performed dissent act against the state.

2.2 Terminology and definition of CBRS

As Hudson et al's (2011) review indicated, the term 'cross border reproductive care' (CBRC) had begun to enjoy considerable currency amongst academic scholars. This trend was also evident among the reviewed studies published after 2011 (e.g. Inhorn and Grtin, 2011; Inhorn and Patrizio, 2012; Roze Gomez and De La Rochebrochard, 2013; Shenfield et al., 2011, Van Hoof and Pennings, 2012b; Van Hoof et al., 2013; Whittaker, 2011a; Zanini, 2011). CBRC was subsequently accepted by ESHRE (Pennings et al., 2008; Shenfield et al., 2010; 2011), and other professional bodies, such as the American Society for Reproductive Medicine (ASRM, 2013). However, a number of authors felt that 'care' has not been the experience of many of the patients and that CBRC does not encapsulate the exploitation (Pfeffer, 2011) or the exile concepts suffered by the cross border patients (Inhorn et al., 2012). Forman (2011) argued that in gamete donation, sperm donors were also being taken advantage of, expanding on the concept of 'eggsploitation' that had highlighted the plight of some egg donors. Blyth et al. (2011) and Nahman (2011) both suggested the term CBRC may be less value laden than its advocates and users assumed and that 'care' is noticeably absent in some accounts of experiences of patients, donors and surrogates. They proposed 'cross border reproductive services' (CBRS) as a more objective term. This is the term that has been adopted for this thesis.

2.3 Prevalence of CBRS

Eighteen primary research papers provided varying coverage of cross border reproductive travel. However, none could provide the actual prevalence for CBRS. Qualitative studies may give some suggestions regarding the pattern of travel (e.g.

French travelled to Greece, Spain and Belgium for IVF treatment (Rozée Gomez and de La Rochebrochard, 2013), Turkish travelled to Cyprus (Gürtin, 2011), Australians went to Thailand (Whittaker, 2011), Germans went to Spain and the Czech Republic (Bergmann, 2011), British to Spain (Hudson and Culley, 2011), Italian to various EU countries (Zanini, 2011), Israeli to Romania (Nahman, 2011), Sunni Muslim travelled to Shia Muslim areas for gamete donation (Inhorn, Shrivastav and Patrizo, 2012) and many patients from the USA and EU travelled to India for gestational surrogacy (Pande, 2011). Brigham et al. (2013) is the only paper that reported the infertility treatments rates in 13 European countries using the ESHRE 2009 data, however the actual level of cross border IVF treatment in Europe is still unknown. Many authors (Donchin, 2011; Inhorn and Gürtin, 2011; Whittaker, 2011a) expressed frustration with the lack of data, thus hampering the debate and policy development of CBRS. Without accurate information it is difficult to ascertain the power imbalance between the commercial interests and those of patients, and the potential difficulties faced by both the patients and health care services.

2.4 Experience of CBRS

Fifteen papers (Culley et al., 2013; Rozee Gormez and La Rochebrochard, 2013; Van Hoof et al., 2013; Inhorn, Shrivastav and Patrizio, 2012; Bergmann, 2011a; Bergmann, 2011b; Culley et al., 2011; Hudson and Culley, 2011; Inhorn, 2011b; Mancini et al., 2011; Nahman, 2011; Pande, 2011; Whittaker, 2011b; Speier, 2011; Zanini, 2011) mentioned the experiences of patients' experiences, focussing on patients' perspectives, law evasion, patient safety, circumvention for religious reasons, returning 'home' for treatment, changing CBRS clinics, CBRS communities and activism, and health care providers' perspectives.

2.4.1 Patients' perspectives

Rozee Gomez and La Rochebrochard (2013) utilised a pre-defined questionnaire to elicit CBRS patients' experiences, Van Hoof et al. (2013) utilised an internet forum to ascertain CBRS patients' experiences and Mancini et al. (2011) reported a case study regarding complications post-CBRS treatment. Twelve papers are qualitative studies reporting the direct experiences of CBRS patients and many key issues have been identified (Hudson et al., 2011): language and communication (Inhorn, 2011; Speier, 2011), availability of gamete donors (Gomez et al., 2013; Culley et al., 2011) and the associated waiting times (Hudson and Culley, 2011; Inhorn, Shrivastav and Patrizo, 2012) and cost (Brigham et al., 2011; Culley et al., 2011; Speier, 2011; Inhorn, Shrivastav and Patrizo, 2012) and feeling comfortable with the CBRS clinic and the country of destination (Hudson and Culley, 2011; Inhorn, Shrivastav and Patrizo, 2012).

Additional themes identified by this review were:

2.4.2 Law evasion

Many CBRS patients felt they were being abandoned and discriminated by the national institutions (Zanini, 2011) and felt 'constrained by the state' (Bergmann, 2011). Egg donation is prohibited in Germany while sperm donation is legal (Bergmann, 2011). Same sex couples or single women were not legally eligible for IVF in France therefore, many French patients travelled to Belgium to circumvent domestic legal restrictions (Roze Gomez and La Rochebrochard, 2013). In March 2010, Turkey became the first country to legislate against CBRS (Official Gazette no. 27513, Gürtin's translation). Even with this legislation, Gürtin (2011) reported Turkish couples still travelled to Cyprus for egg donation and many patients were matched with Turkish egg donors. Turkish egg donors often had their ovarian stimulation in Turkish IVF clinics and usually would be sent to Cyprus on the day of egg retrieval. Whittaker (2011) recounted Australian couples travelled to Thailand for PGD. The law changed in Thailand on May 2010, after which sex selection was no longer offered there. Pande (2011) described the Indian CBRS structure as more aligned to a liberal market model where clinics operate not only without state interference but often benefit from government support.

2.4.3 Patients' safety

Mancini et al. (2013) also raised patients' safety concerns and complications arising from post-CBRS and when patients return to their home countries. Inhorn (2011) described an infertile couple (Hatem and Huda) who had CBRS in Beirut via egg donation. After returning home due to complications the twin babies died and the hospital became suspicious with the blood groups of the babies; 'their blood group was AB, and it did not match ours'.

2.4.4 Religious circumvention

Inhorn (2012) explores the CBRC movement among Middle Eastern infertile couples. Due to the difference between Sunni and Shia Islamic beliefs, there was a 'secret egg quest' for Sunni Muslim patients to slip across neighbouring Shiite countries for donor gametes in order to 'save their marriage' (Inhorn, 2006). Sunni majority Middle Eastern countries (i.e. the United Arab Emirates) do not permit any form of third party reproductive technology, multifoetal pregnancy reduction or cryopreservation, therefore many patients travel out of Sunni majority Middle Eastern countries in their quest for treatment. For example, patients requiring egg donations would travel to India or Cyprus and those needing multifoetal pregnancy reductions would travel to London or India (Inhorn, Shrivastav and Patrizio, 2013).

2.4.5 Returning 'home' for treatment

Inhorn (2011) identified six factors pulling infertile couples 'back home' for CBRS: medical expatriotism (believing that better medical professional qualifications and experience are to be found at home), language of medicine, co-religion and moral trustworthiness, donor phenotypes, comforts of 'home' and perceived cultural discriminations. Inhorn, Shrivastav and Patrizio (2013) reported on a Sunni Syrian couple who resided in Lebanon. After failed cycles, they sought IVF treatment in Dubai (Sunni Muslim region) and even though the couple were treated by an Indian doctor, the wife felt good about her decision to 'give up on Lebanon'.

2.4.6 Changing CBRS clinics

Changing CBRS clinics is not unique as CBRS patients are highly mobile and are able to move around to seek the 'best' treatment. CBRS patients do move between different countries for treatment e.g. from Germany to Poland or Spain (Bergmann, 2011); from Italy to Spain or the USA (Inhorn, Shrivastav and Patrizio, 2013); from Germany to Slovakia or South Africa or the Czech Republic (Bergmann, 2011).

2.4.7 CBRS communities and activism

The internet continues to be the most important platform for CBRS information. Speier (2011) described the process of CBRS patients 'doing the research' and 'stumbling upon' CBRS websites or infertility support groups. Bergman (2011) commented how patients embed CBRS research and social networking within their daily routine. For patients who lived in countries with legal restrictions on ART, "the internet is the only possibility to gain access to information about IVF treatment abroad" (Bergmann, 2011, p.604).

CBRS patients use internet forums to access information. Many successful infertility patients would stay on the forum or launch websites to help other couples achieve their goal (Bergmann, 2011a). This demonstrated the altruistic nature of CBRS patients. Speier (2011) reported an active online community which was reminiscent of self-help groups. Activists want to help others by sharing information and as more patients blog about their journeys; there might be a point where future patients could create a 'do-it-yourself' guide for their own CBRS journey without the aid of a broker.

2.4.8 Health care providers' perspectives

Four studies provided accounts of the experience of health care providers involved in CBRS and one paper provided the view of health care professionals in home health care systems.

Speier (2011) found the CBRS brokers could be lay experts in infertility and are 'travel savvy' about getting around in the Czech Republic. Brokers advertise their business mainly online; however 'word of mouth' and blogs could have a significant effect on the brokers' business. CBRS doctors in the Czech Republic are becoming entrepreneurs with their private practice and hoping that their country's legislation will remain liberal. Some brokers have commercial links with specific clinics offering CBRS and could arrange all-inclusive packages including travel accommodation and infertility treatment (Whittaker, 2011). Pande (2011) found that surrogates view the process of surrogacy in India as providing a 'gift' to the needy, bonds of global sisterhood, whereas altruism and the gift narrative was emphasised by the surrogates in the Western countries.

Culley et al. (2013) found three concepts identified by 20 UK IVF professionals: patients' autonomy, CBRS risk and professional responsibilities for harm minimisation. Very little is known about how infertility professionals negotiate the implications of CBRS on their clinical practice and the potential implications for the health care systems after patients returned to their home country following CBRS treatment.

2.5 Review from the commentary papers

Twenty six commentary papers tend to explain the regulatory, ethical or legal concerns relating to the restrictions of infertility treatments (Gormez et al., 2013; Ramskold and Posner, 2013; Cohen, 2012; Crozier and Martin, 2012; Van Hoof and Pennings, 2012a; Van Hoof and Pennings, 2012b; Ahmad, 2011; Crocklin, 2011; Gürtin, 2011; Storrow, 2011; Van Hoof and Pennings, 2011). Hudson et al. (2011) identified factors for CBRS - patients' safety concerns (Thorn, Wischman and Blyth, 2012; Shenfield, 2011; Shenfield et al., 2011), reasons for patients' travel (i.e. lack of expertise in patients' home country (Connolly, 2011), cost of treatment, lack of publicly funded treatment, excessive waiting times and shortage of donors), increased availability of low cost travel, the growth of the internet enabling international marketing and the inequality and uneven process of CBRS (Gürtin, 2011; Shenfield, 2011; Shenfield et al., 2011).

This review identified similar findings to Hudson's et al review. Additional to Hudson's et al findings, this review found a number of authors focused on the potential exploitation of the donors (Deonandan, 2013; Forman, 2011; Pfeffer, 2011; Whittaker, 2011a) and coercion by the family into surrogacy (Ross-Sheriff, 2012). Two papers by IVF doctors (De Sutter, 2011; Forman, 2011) both advocate quality of CBRS care, whereas Shenfield et al. (2011) focused upon the ESHRE Good Practice Guide for IVF clinics and health professionals. Franklin (2011) went further by suggesting that transparency is crucial to

facilitate CBRS best practice. Three papers emphasised the need of psychological care for CBRS patients to have counselling in their home country to avoid language barriers (Hunt, 2013; Thorn and Wischman, 2013; Blyth, Thorn and Wischman, 2011).

2.6 Discussion

This chapter reviewed 1 literature reviews, 26 commentary papers and 16 empirical studies from January 2011 until October 2013 (see Figure 1, p.38). This illustrates that there is a growing interest in CBRS empirical research and an increasing range of research disciplines i.e., social scientists and anthropologists generating new and diverse perspective on the CBRS phenomena. The key points reported by Hudson et al. (2011) are still central to many CBRS patients. The debate relating to the terminology and definition is still on-going (e.g. exile or the exploitation concepts). Within this thesis, I used the terminology CBRS (Blyth et al., 2011; Naham, 2011) instead of the term proposed by the ESHRE, which is cross border reproductive care as the term 'care' is not always present during overseas infertility treatments. The lack of CBRS primary data continues to hamper knowledge and frustrates many authors regarding impact and implications of CBRS for both overseas and home clinics. Much of the CBRS current evidence is still based upon European data (Brigham et al., 2013) and even with these data, the actual level of CBRS in Europe is still unknown. There is some indication relating to the pattern of worldwide CBRS travel, which was derived mainly from a number of qualitative studies.

Language problems and communication could be an issue for many CBRS patients. Inhorn (2011) suggested the importance of the use of medical language in one's native tongue, thus compelling many expatriates to return 'home' for infertility treatment. In some Eastern European CBRS clinics, clinics will hire English speaking coordinators to overcome language barriers (Speier, 2011). Availability of gamete donors, the associated waiting time in the home countries along with the perception for low treatment cost overseas facilitated by low cost travel continues to induce infertility patients to travel overseas (Hudson and Culley, 2011). With more patients' journeying to the Czech Republic, Speier (2011) suggested the price for CBRS at these clinics will inevitably increase. Some CBRS patients explicitly rule out certain countries as being too 'foreign' (Hudson and Culley, 2011). However, some expatriates believe that their 'home' countries offer higher quality medical care than their country of residence (Inhorn, 2011).

The internet is the most important platform for patients to access CBRS information and many embed this practice within their daily routine (Bergman, 2011). CBRS patients are

also highly mobile and are willing to move around to seek the 'best' treatment (Bergmann, 2011; Inhorn, Shivastav and Patrozio, 2013). With no clear professional guidelines, many infertility patients depend on each other for information. Some CBRS patients have even launched their own website to help others to achieve their infertility quest (Bergmann, 2011). These activisms could affect patients' choice in both clinics and the destination for CBRS. CBRS promote their business via websites; however the key to this promotion is still via 'word of mouth' by patients. Negative blogs by patients could have detrimental effects on a CBRS business (Speier, 2011). My concern for such activities would be the potential infiltration by bogus individuals as one could not tell if individuals are genuine with their overseas infertility journey or paid to tell their stories. Whilst some infertility health professionals appear to favour the end to CBRS, few have advocated an outright prohibition due to the impracticality for such response (Hudson et al., 2011). There are a small number of countries prohibiting all, or part of, CBRS for example, Turkey and three states in Australia have outlawed domestic commercial surrogacy and have also criminalised the use of foreign commercial surrogacy by their citizens (Van Hoof and Pennings, 2011). Patients, therefore, may seek CBRS in another country. For example, patients from Turkey travelled to Cyprus for CBRS. Infertility health professionals support the increase of the quality and standard of care for both local and CBRS patients (De Sutter, 2011; Forman, 2011) however, they fall short in suggesting how such safeguards could be implemented. The ESHRE's Good Practice Guide (GPG) for CBRS (Shenfield et al., 2011) consisted of 4 factors: equity in CBRS; quality, safety and evidence based care in CBRS; patient involvement and redress. This voluntary GPG adhesion is a good start to improve the CBRS medical practice. However, there is still no information published relating to which clinics are 'in the club' and, when patients have concerns, who are the ombudsman or the people to whom a complaint should be made (Shenfield, 2011). Whilst some authors (Culley et al., 2011; Pennings, 2006) proposed a system of international accreditation of infertility clinics to ensure minimum safety standards, implementation of such a system has not been initiated. Counselling support is also advocated by a number of authors (Hunt, 2013; Blyth et al., 2011; Thorn and Wischmann, 2011), nevertheless many CBRS patients did not have counselling to prepare them for the additional challenges for their cross border reproductive journey. The ESHRE guidelines recommend counselling be provided by the overseas clinics (Shenfield et al., 2011), whereas Hunt (2013) proposed a good reason, i.e., language barriers, for counselling to be provided in the home country. With some home countries prohibiting CBRS, home countries' clinics would be prohibited by law and would not be able to support the CBRS patients' endeavours.

Within the past three years, there have been a considerable number of commentaries on the law and regulatory position in relation to CBRS and the potential harmonisation and the extra-territorial laws required for such harmonisation. However, many infertility health professionals took the view that there is little chance of any international harmonisation of regulations materialising soon (Culley et al., 2013). Many authors have discussed the change in legal restrictions in Turkey and Thailand (e.g. Grtin, 2011; Whittaker, 2011a).

2.7 The differences between CBRS and infertility treatment at home

Childlessness is a major public health concern. In the United States, particularly among educated women who turned 45 in 2006, one fifth had no children. Although attitudes toward childlessness have become more positive over time, most childless women at any age still want a baby sometime in the future (Craig et al., 2014; Lee and Zvonkovic, 2014). Individuals seeking to complete their family naturally would prefer to obtain care near their home or even have the choice of not seeking to complete their family. However, the individual desire for family building is strong at overcoming hurdles (i.e. law evasion when difficulty of access because of either restrictive legislation or long waiting lists and expected quality of care), these individuals are willing to sacrifice everything including their house or disregard their religious belief in order to complete their family unit.

2.8 Chapter Summary

This chapter and the previous chapter portray the current evidence relating to CBRS. This identifies CBRS as a complex phenomenon, which interests multi-disciplinary health professionals, patients groups and research scholars. Once again, this reiterates the need of this study to investigate international individuals who have had CBRS and their motivation for, and experiences of, CBRS

In chapter 3, I seek to present the ontological and epistemological assumptions underpinning the research. The research is located within Interpretative Grounded Theory (GT) methodology and the use of Voice Centred Relational Method (VCRM) to analyse qualitative interview data, emphasising the individual experience of CBRS. I also present the asynchronous online interview methodological approach used in this study including the advantages and disadvantages of such an approach illustrated by asynchronous online feedback from participants.

Chapter 3 Methodology and Research Design

I locate this thesis within a Straussian Grounded Theory methodological approach and will explore the underpinning and philosophical stance of this particular methodological position. I begin this chapter by describing the epistemological issues and ontological considerations. I outline how these assumptions have influenced my choice and use of the Straussian Grounded Theory methodology within my research process. Subsequently, I explain my position in the use of the Voice Centred Relational Method (VCRM) to analyse the qualitative interview data.

In this chapter, I also provide a rationale for the utilisation of asynchronous email interviewing methodology in gathering data from the participants who had used CBRS. I describe the process in gaining ethical approval from the University of Huddersfield for the study and an overview of the principles of biomedical ethics (Beauchamp and Childress, 2013). This chapter will also discuss the use of NVivo for data analysis in this study. Participants' perspectives on the advantages and disadvantages of using asynchronous email interviewing methodology are themed together, allowing the researcher to reflect upon the utilisation of asynchronous email interviewing in this particular study.

3.1 Philosophical Viewpoint

Descartes' view of science was long held as the only approach to new knowledge and his ideas were grounded in an objective reality; this position supported the idea that cause and effect could explain all things. However, Kant (1952) proposed that perception was more than the act of observation. Not all reality could be explained by cause and effect, thus what was observed was not the only reality. This philosophy further developed and expanded the idea about self, self-consciousness, reality and freedom (Streubert, 2011).

The basic ontological and epistemological position that underlines this thesis can be summarised by the following questions (Guba and Lincoln, 1994):

1. What is the nature of reality and therefore what can be known about it? (Ontological question)
2. What is the relationship between the 'knower' and 'would be knower'? What can be known? (Epistemological question)
3. How can I go about finding out what I believe can be known? (Methodological question)
4. What are the means by which I can collect the knowledge? How can I construct the knowledge? (Methods question)

I address the first three questions in the first part of this chapter and the final part of this chapter relates to question four, the collection of knowledge (i.e. asynchronous email interview) and the construction of knowledge using both Voice Centred Relational Method and Grounded Theory.

Ontology is concerned with an explanation regarding the structure and the nature of social entities (Guba and Lincoln, 1989; Crotty, 1996; Bryman, 2008). Social entities can and should be considered objective entities and have a reality which can be socially constructed from the perceptions and actions of social actors. This thesis describes participants' perception of factors that help or hinder their cross border reproductive journey. Reality here is viewed from the participants' perspective and gives primacy to their individual experiences. The research approach is required to acknowledge the existence and value of the participants' interpretation and their lived reality (Bryman, 2008).

Objectivism is an ontological position which suggests that social phenomena confront us as external factors that are beyond our influence (Bryman, 2008). As regards CBRS, participants are confronted by rules and regulations which vary between different countries. All these rules and regulations are reality and are external to the CBRS participants' control. Countries utilise these rules and regulations to preserve social order and constrain their residents' choice of fertility treatments (Van Hoof and Pennings, 2011; Gürtin, 2011).

Epistemology is the 'theory of knowledge' and concerns the means of knowledge production. It deals with questions concerning the nature, scope and sources of knowledge (Bryman, 2008). The epistemology position affirms positivism, an application of natural sciences to the study of social reality, which advocates the study of social reality and is concerned with 'what it means to know' (Gray, 2009).

Positivism and objectivism have been discussed above as part of an overview of research methods. However, Grounded Theory, a research method that seeks to develop a theory, was the approach utilised in this study to explore the CBRS participants' decision making process. Below I provide further information about Grounded Theory and the reason for its use in this study. Straussian Grounded Theory allows for prior knowledge. In this thesis, I began by drawing upon my prior experience as an embryologist. I also performed a literature review in order to understand the complexity of the CBRS phenomenon. With this combined knowledge and experience, I hope to develop a broad understanding of the main research paradigms and the underlying theoretical assumptions within the CBRS setting. My epistemological stance is that the participants

are the experts in their own lives and that my role was to investigate the participants' meanings and behaviour which constitute their realities.

Table 3 shows the epistemological differences between qualitative and quantitative research. Qualitative research emphasises the words used by the participants whereas quantitative research emphasises quantification in the collection and analysis of data (Bryman, 2008).

Table 3: Epistemological differences between qualitative and quantitative research strategies

	Qualitative	Quantitative
Principal orientation of the role of theory in relation to research	Inductive; generation of theory	Deductive; Testing of theory
Epistemology orientation	Interpretivism	Natural science model, in particular positivism
Ontological orientation	Constructivism	Objectivism

(Source: Bryman, 2008).

Qualitative research offers the opportunity to focus on finding answers to questions centred on social experience (Denzin and Lincoln, 2000). In conducting a qualitative inquiry, I am obliged to indicate my philosophical viewpoint underpinning the methodology selected for this research. Carper's (1978) seminal framework on ways of knowing (empirical knowing, aesthetic knowing, personal knowing and moral knowing) provides a starting point to understand my commitment to understanding the phenomenon relating to the participants' motivation and their experience of CBRs. Empirical knowing is to provide an explanation for CBRs and attempt to ensure that the participant's voice is heard. Aesthetic knowing is to understand and interpret the participant's subjective experiences. Personal knowing is my personal knowledge and my own beliefs and understanding to aid a participant's journey. Finally, moral knowing reflects on my own ethical paradigm so I will not make judgement upon what is right and just for participants undertaking CBRs.

Knowledge is generated from either a deductive or an inductive approach (Bryman, 2008). Deductive reasoning moves from general to specific. In this thesis, I have chosen inductive reasoning as this process starts with the details of participants' experience and moves to a more general picture of the CBRs phenomenon.

Qualitative research methods are accepted as legitimate approaches to the discovery of knowledge, especially to the investigation of people's life experience. The main philosophical approaches within qualitative research methodology are Phenomenology, Ethnography and Grounded Theory. Phenomenology is concerned with the question of how individuals make sense of the world around them and how in particular the researcher should bracket out their own preconceptions concerning their grasp of the

world (Bryman, 2008). As I have prior knowledge, previous experience working as an Embryologist and performed a literature review of the CBRS phenomenon, as a researcher it will not be possible for me to perform the study utilising the phenomenological approach. Ethnography is concerned with the way in which social order is accomplished through talk and interaction, which is the intellectual foundation of conversation analysis, a fine grained analysis of talk as it occurs in naturally occurring situations. Ethnography researchers immerse themselves into the social setting for a period of time observing behaviour, listening to what it said in conversations between the participants and the field researchers and asking questions (Bryman, 2008). As I am not interviewing the participants directly within their natural settings this theoretical approach was also not selected as appropriate for this study. Grounded Theory aims to generate theory from the research data by achieving a close fit between the data and the theory (Bryman, 2008). In the following section, I will provide a rationale for my ultimate choice of the use of the Straussian Grounded Theory approach.

3.2 Theory and Research

This study focuses on the participants' motivations for, and experiences of, CBRS. With my previous working experience as an Embryologist, I developed an interest in why participants seek fertility treatments abroad. I felt that the combination of my experience and interest would enable me to provide insight and to formulate a theory to enhance participants' experiences of CBRS.

This thesis therefore does not begin with an existing theory but uses an inductive approach in order to generate theory about the decision-making process experienced by participants seeking CBRS. The primary purpose of this thesis is to utilise the interview data to generate or discover theory that could be used to explain the phenomenon of CBRS, thus Grounded Theory as outlined by (Glaser and Strauss, 1967) is the approach I used in this thesis.

Rather than take for granted and assume understanding of the word 'theory', I use the Oxford English Dictionary (2014) definition

A supposition or a system of ideas intended to explain something, especially one based on general principles independent of the thing to be explained.

A formal theory is developed following critical investigation of the CBRS phenomenon and its theoretical perspective of other cross border health care services and acknowledges that similarities and differences may be present in other cross border health care situations. The conclusions of the thesis thus might be transferable to a wider cross border treatment context. The main application of the theory still remains

within the CBRS context and should not transfer the whole theory into other cross border treatment context.

3.3 Rationale for asynchronous email interview

I needed to decide how I would make contact with the potential participants who have travelled internationally for reproductive services. During the planning stage of this study, Culley et al. (2011a) embarked upon a seminal study with UK residents who had travelled abroad to seek infertility treatments. My supervisor was a member of this research team and great care was taken to ensure that the two studies did not encroach upon each other. With this consideration, it was decided that I would recruit participants outside the UK. In the event, while I was still recruiting participants, Culley et al. stopped recruiting new participants, so I was able to recruit from the UK as well. I decided to advertise and recruit participants via two international infertility networks (Infertility Network (2015) which is based in Canada and the International Consumer Support for Infertility (2015) (iCSi), which is based in Australia (this is an 'umbrella' organisation for a number of national fertility participant support groups)). These two organisations have a global internet presence offering information and support regarding infertility treatment.

Due to the nature of the participants' location, which could be anywhere in the world, and the cost implication of performing face-to-face interviews, an alternative data collection procedure was required. During the planning of my study, I became aware of the relatively innovative idea for data collection via synchronous online interviews with students' using Instant Messenger (IM) (Hinchcliffe, 2010). This was a 'cutting edge' medium used frequently by many people as part of their everyday life. As a research tool, IM was considered by participants and researchers alike to be convenient, easy, comfortable and a very enjoyable experience for research interviewing. Due to the international nature of my study, with potential participants living in different time zones, synchronous interviewing was not practical. At the same time, I came across books by Jones (1999) 'Doing Internet Research' and James and Busher (2009) 'Online Interviewing' on the impact of internet technology as a medium for collecting qualitative research data and in which the researcher could 'infiltrate other space and times of participants'. I quickly realised that an asynchronous email research design could offer me an exciting opportunity to interview CBRS participants. It provided me with the chance to engage with participants who are geographically dispersed and this method also enabled the participants to express their intimate knowledge to me, the researcher, whom they have never met (Zhao, 2006).

3.4 Rationale for the Voice Centred Relational Method (VCRM)

In addition to the Grounded Theory, I have chosen the Voice Centred Relational Method (VCRM) for my data analysis, as this allows me to actively hear the participants' individual autobiographical account for their CBRS journey. My own and Doucet and Mauthner's (2008) approach is the basic Grounded Theory question, which is 'what is happening here?' (Charmaz, 2006). This enables me to be explicit in the analysis of the data (Paliadelis and Cruickshank, 2008).

VCRM advocates four reading/listening approaches to the transcripts. Each reading/listening serves a distinct purpose to explain the meaning of the read text and focuses on certain elements of the participants' stories.

3.4.1 The first read: Relational and reflexively constituted narratives

In the first reading/listening, I reflected on the whole narration (Mauthner and Doucet, 1998) and made notes of the participants' actions to formulate a story for each of the participants. I considered the recurring words, themes, events, protagonists and all the key characters within the transcripts (Mishler, 1986; Elliot, 2005). I also paid particular attention to the 'plots' (i.e. the social construction of the participants' CBRS journey) and the participants' emotions as elicited in their individual stories. This enhances the credibility of the interview data (Hewitt, 2007).

I utilise a 'worksheet' technique advocated by Brown and Gilligan (1992b), comprising two columns, whereby the participants' words are laid out in one column and my reactions and interpretations in the adjacent column. This enables me to reflect upon some of my assumptions and views, which might affect my interpretation of participants' 'words'.

Mauthner and Doucet (2003) suggested that some influences could be identified with ease, whilst others may emerge only after completing the whole study. It is through this constant reflexivity of narrations process that I came to know the participants' motivation and experiences.

3.4.2 The second read: Tracing narrated subjects

The second reading/listening involves the active listening of the participants as narrator in the interview transcripts, how the participant speaks about him/herself and the parameters within their social world. The words, 'I' ('me' or 'my' or 'you' or 'them'), will elicit the participants' sense of self, thus gaining the 'heart and mind of another body' (Brown and Gilligan, 1992a). The word 'I' highlights participants' emotional or intellectual struggle with their infertility. Within this context, I gain insight into the participants' perspectives. I also focus upon the shifts from 'I' to 'me' and 'you' to 'them'

when re-telling their CBRS story. This shift indicates not only how the participants perceived themselves but also how they think others perceive them (Mauthner, 2002; Letvak, 2003). An 'I' poem was generated for each of the participants. These poems are designed to allow the participants' voice to be heard in a distinctive rhythm (Gilligan et al., 2003). These 'I' poems help me to identify the 'voice of the participants' by creating a space for them to speak for themselves (Paliadelis and Cruickshank, 2008). Somers (1994) refers to this as ontological narrative and reading for the 'I' gives me access to the participants' 'self' and allows them to narrate about 'who they believe they are' (Doucet and Mauthner, 2008).

3.4.3 The third read: Reading for relational narrated subjects

The third reading/listening is a reading for social networks, close and intimate relationships. This is the notion of 'analytic rationality', where participants narrate their understanding of other people's reaction to their decisions/actions (Somers, 1994).

I paid particular attention to the participants' interpersonal relationships/tensions with others (i.e. their partners, their relatives and friends) (Mauthner and Doucet, 1998) and how they locate themselves within their wider inter-personal relationships (Brown and Gilligan, 1992a; Gilligan et al., 2003). I was particularly interested to uncover how others interact with participants to discover the power dynamics at play.

3.4.4 The fourth read: Reading for structured subjects

The fourth reading/listening focuses on the structured power relations and dominant ideologies which frame the narrative (Doucet and Mauthner, 2008). This 'conceptual narrative' is to seek to "reconstruct and plot over time and space the ontological narrative and relationships of historical actors, the public and cultural narratives that inform their lives and the crucial interaction of these narratives with other relevant social forces" (Somers, 1994, p.604-605). This, read along with the previous three, aligns closely with Benhabib's (1995) position on subjectivity in which the participants are individuals but are related to one another. Their individual experiences are interlinked with one another providing a macro-narrative construct.

I have positioned the participants' collective accounts into a wider social, cultural and political context (Brown and Gilligan, 1992a; Mauthner and Doucet, 1998; Gilligan et al., 2003). The final read/listening sets the context as a whole. I acknowledge my own values, beliefs and emotions as I re-tell, remember and re-configure the central coherent plot of the final process.

The four readings provided the participants' self-experience with CBRS, their feelings with others, and the social, political and cultural context of CBRS. The sub-themes and

themes are conceptualised from the data, thus enabling me (incorporating my own feelings and reactions to the participants' stories) to formulate the underlying pattern to develop theories and diagrams for the participants' decision-making process.

VCRM is a feminist approach used to express women's feeling in the first person. As a male researcher and as some participants were also male, I sought advice from Professor Ruth Deery (formerly employed at the University of Huddersfield and currently at the University of West of Scotland, an expert of VCRM). Professor Deery suggested the use of third person narrative could be more appropriate for this study. As this study was carried out using asynchronous email interviews, it was not possible for me as the researcher to ascertain nuances in the voices of participants that would have been apparent in an oral interview. Consequently, a general narrative in the spirit of "I" poem was considered appropriate when reporting the individual's perspective of their CBRS journey.

3.5 Grounded Theory

Grounded Theory is a research method used to discover new dimensions of social process at play in people's lives. Barney Glaser was influenced by theorists, such as Paul Lazarfield, Paul Merton and Herbert Hyman. Anselm Strauss was a critical qualitative methodologist from the Chicago School of Sociology (Goulding, 2005). Glaser and Strauss developed the Grounded Theory approach in 1967 to promote qualitative research and to offer a way forward in sociological research based on systematic data analysis and construction of conceptual ideas to formulate credible scientific theory.

Grounded Theory is rooted in the precepts of symbolic interactionism focused on the individual within society. This is an alternative to theory verification. In contrast to other interpretive approaches (i.e. phenomenology), Grounded Theory goes beyond conjectures and hypotheses. The primary purpose of Grounded Theory is to develop a theory to make sense of human behaviour in which there is an interactional element to it. Therefore, Grounded Theory is ideal for this thesis when studying participants' CBRS journey. The theories discovered through Grounded Theory are derived directly from the data; thus the theory is 'grounded' in the experiences of the participants. It is essential to acknowledge the role of subjectivity whilst using Grounded Theory in this study. Therefore caution is necessary in suggesting that its findings may be generalised beyond the population of study participants.

Glaser and Strauss jointly promoted and developed Grounded Theory for 30 years until a split occurred with the publication of 'Basics of qualitative research: Grounded theory procedures and techniques' (Strauss and Corbin, 1990). The book offered practical advice to novices as an easy-to-read, step-by-step guide, to implement Grounded

Theory research. Glaser reacted strongly to its publication as he felt the guide minimised the importance of comparative methods, which forces both data and analysis into superficially conceived categories. Glaser demanded Strauss and Corbin to withdraw the book, which did not happen, thus establishing the two approaches to Grounded Theory (Glaserian or Classic Grounded Theory and Straussian Grounded Theory). Heath and Cowley (2004) and Hernandez (2008) discussed thoroughly the difference between the Classic Grounded Theory and Straussian Grounded Theory.

Table 4 below compares the differences between the Classic Grounded Theory and Straussian Grounded Theory. I have chosen to use Straussian Grounded Theory in this thesis.

Table 4: Comparison of Classic Grounded Theory and Straussian Grounded Theory

	Glaserian /Classic Grounded Theory	Straussian Grounded Theory
Epistemology	No preconceived ideas about the area of study. No literature review is to be conducted. The researcher begins from a position of naivety and learns from the experts (those who lived it)	Researcher can gain insight into data through literature review. Theories are considered as a lens through which the researcher approaches the data and should be named, if used.
Research question	The researcher studies an area of interest; a specific research question is not needed. The researcher trusts that participants will reveal their main concern	A research question is stated
Ethical considerations	Grounded Theory is about concepts, not people. Transcription of interviews is not necessary, but information about specific individuals should be confidential	Interviews can be transcribed and this is recommended for novices. Data should be stored securely. Confidentiality should be ensured
Data gathering	No interview guide is needed because these are based on preconceptions. The participants are considered the experts and will reveal their main concerns. Field notes can be used, as well as photos, news articles, historical documents and other information that clarifies the concepts	Unstructured interviews are recommended however semi-structured interviews could be used. Observations of participants are also part of the data but are subject to interpretation and should be clarified with the participants. Themes are identified and supported with data
Data analysis	The researcher sorts and re-sorts memos until major concepts become clear. Then, the theoretical connections among the concepts should be stated	Computer programmes can be used to aid data analysis
Results	The results of the study should be written up from the memos. The study will result in a substantive theory that explains what is going on in the area of interest. Numerous theories can be discovered from one study	Data analysis, at a minimum, results in themes and concepts. Theories can also be developed from the data, but this is not the necessary outcome
Evaluation	Fit for purpose, work, relevance and modifiable	Fit for purpose, applicability, concepts, contextualisation of concepts, logic, depth, variation, creativity, sensitivity and evidence of memos

(Source: adapted from Hernandez, 2008)

Corbin and Strauss (2008) noted that not everyone wants to develop theory, however, theory development seemed to have fallen out of fashion, being replaced by descriptions of 'lived experience' and 'narrative stories' (Corbin and Strauss, 2008, p.55). In this thesis, my aim is not just to provide a narrative description of the participants' motivation for, and experience of, CBRS, I also wish to understand their decision process in undertaking CBRS.

The validity of qualitative data has been conceptualised by many authors. Whittemore et al. (2001) summarise the major validity criteria in the following table (see Table 5 below).

Table 5: Validity criteria for qualitative data

Authors	Validity Criteria
Lincoln and Guba (1985); Guba and Lincoln (1989)	Truth, value, applicability, consistency, neutrality
Marshall (1990)	Goodness, canons of evidence
Smith (1990)	Moral and ethical component
Eisenhart and Howe (1992)	Completeness, appropriateness, comprehensiveness, credibility, significance
Sandelowski (1986); (Sandelowski, 1993)	Credibility, fittingness, auditability, confirmability, creativity, artfulness
Altheide and Johnson (1994)	Plausibility, relevance, credibility, importance of topic
Leininger (1994)	Credibility, confirmation, meaning in text, recurrent patterning, saturation, transferability
Lincoln (1995)	Positionality, community as arbiter, voice, critical subjectivity, reciprocity, sacredness, sharing prerequisites of privilege
Maxwell (1992), (Maxwell, 1996)	Descriptive validity, interpretive validity, theoretical validity, evaluate validity, generalizability
Thorne (1997)	Methodological integrity, representative credibility, analytical logic, interpretive authority

(Source: adapted from Whittemore et al., 2001)

I used Leininger's (1994) research criteria (i.e. 1. credibility, 2. confirmation, 3. meaning in text, 4. recurrent patterning, 5. saturation, 6. transferability) in this study. I have found these criteria allow the creativity of the researcher, whilst retaining academic integrity, which was particularly suited to this study.

1. **Credibility:** this refers to the truthfulness of the findings which is established by my immersion in the CBRS phenomenon and by engagement with the (emic (insider)) view of participants who have lived through the CBRS experience
2. **Confirmation:** this relates to the interview data obtained from the participants. There was a mechanism for the participants' feedback and verification on their CBRS experience. I provided follow up questions and verification statements during the eight email interview questions and also provide a final 'pros and cons' question to the participants to provide their feedback relating to the email interview research process
3. **Meaning-in-text:** this refers to the holistic comprehensiveness of the interview data where the participants reflect upon the whole CBRS experience. The theme enables that main decision process of participants to be identified
4. **Recurrent patterning:** this means the repetition of themes, sequences of events or experience
5. **Saturation:** this is the point in the research when all concepts are well defined and explained (Corbin and Strauss, 2008, p.145). Themes have all been accounted for; this is the stage when data analysis reveals no new themes. Some researchers (Hutchinson, 2001; Guest et al., 2006) suggest that saturation can

occur after as few as 12 interviews. In this study, no new themes emerged following analysis of the response of the 20th participant, thus saturation was reached at this point. However, 26 potential participants indicated a willingness to take part in the study. In line with the original ethical approval for this study, it was decided to complete all 26 interviews. The experiences and views of all 26 participants are included in this thesis

6. Transferability: this is when the general findings can be related to other associated situations. The aim for qualitative research is not to produce generalisability of the findings, however the knowledge synthesised from CBRS might be translated into other cross border health care situations (e.g. transgender reassignment surgery or selective dorsal rhizotomy operation for children with cerebral palsy).

Glaser (1998) advocates the researcher must enter the research topic as one who is naive and willing to learn from those who are experts. As I have not encountered the phenomenon of cross border travel for reproductive services during either my clinical work or personal life and I am willing to learn from the participants who have undertaken such travel, I feel Grounded Theory will suit the theoretical approach of this thesis. Strauss and Corbin (1998) identified the researcher's need to be able "to step back and critically analyse situations, to recognise and avoid bias, to obtain valid and reliable data, and to think abstractly" (Strauss and Corbin, 1998, p.18). I feel I am able to maintain analytical distance, while at the same time, drawing upon my past clinical experience to interpret what is being said and observed by utilising my interactional skills to formulate a theoretical framework for CBRS. In Chapter 7, I offer a combined perspective of the findings and potential theoretical perspectives. Grounded Theory helps me to stay focused on the research process. This enables me to increase my analytical awareness of the data and the emerging findings.

3.6 Grounded Theory data analysis

Open coding utilised line-by-line close examination of the interview data to identify the concepts and conceptual patterns. The code could be words or phrases taken directly from transcripts. This is known as 'in vivo' coding (Glaser, 1978).

Continuous reflecting and reviewing of the codes and comparing other codes with similar concepts are grouped together by the technique of constant comparison. Major themes emerging generate hypotheses about how themes relate to each other. Memos help the researcher to discover the core categories which occur frequently and aid the researcher's conceptualisation and theory building (Glaser, 1992; Glaser, 1978).

In this thesis, I used NVivo 10 (2015) to perform coding, and memoing functions to conceptualise the emerging themes. Mind map diagrams were used to summarise the emerging themes. This process is flexible and multiple reflections can be made to ensure comprehensive consideration of the data.

Glaser explained, "the researcher undertakes the quest for this essential element of theory, which illuminates the main themes of the actors in the setting, and explicates what is going on in the data" (Glaser, 1978, p.94). Strauss also reiterates that "the core recurs frequently in the data, links various data, is central, and explains much of the variation in all data, has implications for more general or formal theory, moves theory forward, and permits maximum variation and analyses" (Strauss, 1987, p.36).

When no new themes and concerns emerged from the transcripts, I began to develop these into a psychosocial model about the participants' CBRS journey (i.e. motivation and experiences). This helps to understand the barriers or facilitators from the CBRS participants' perspective during their decision-making process.

In this study, I used asynchronous email interviews to collect my data. The Voice Centred Relational Method was used to analyse nine individuals' CBRS journey by unfolding the series of events in chronological order. Grounded theory was used to analyse the accounts of all 26 participants and generate the themes that emerged from the data.

3.7 Ethical approval

This research required ethical approval from the School of Human and Health Sciences Research Ethics Panel (2015) (SREP) at the University of Huddersfield. The framework for research ethics and the code of practice as set out by the British Psychological Society (BPS, 2009) and the Economic and Social Research Council (ESRC, 2012) provided the ethical groundwork for this study. As this study utilises internet research, the recommendations from the Association of Internet Researchers (AOIR, 2012) were also observed to ensure ethical decision making whilst performing this internet research study. This study gained ethical approval from SREP in January 2010.

My position when undertaking research was to apply the five key ethical principles developed by Beauchamp and Childress (2013), which include respect for autonomy, non-maleficence, beneficence, justice and professional-participant relationships. They are presented below in a conventional sequence; therefore each principle should be afforded equal weight.

3.7.1 Respect for Autonomy

The word autonomy is derived from the Greek 'autos' ('self') and nomos ('rules', 'governance' or 'law') (Beauchamp and Childress, 2013, p.99). This is the minimal standard for ethical conduct. Autonomy is an assertion that individuals have a right to determine their own fate, to make decisions and to control what happens in their lives and to their bodies. Participants therefore have the personal capacity to decide and deliberate whether to participate in this study. They are also given the opportunity to make informed choices as to whether or not to be involved in this study. Respect for autonomy requires them to act with the intention to participate, understanding the purpose of the study and without undue influence towards their decisions (Beauchamp and Childress, 2013).

I addressed participants' autonomy through seeking their informed consent. I had to ensure confidentiality and anonymity of the participants was protected. I advertised and recruited participants via the Infertility Network (2015) and the International Consumer Support for Infertility (2015) (iCSi) websites. In this advertisement, I stated clearly the aim of the study to all potential participants and the ways in which potential participants could contact me, which was via a confidential University of Huddersfield email address (cbit@hud.ac.uk). All potential participants were provided the opportunity to discuss the study with me via the secure email address before deciding upon their participation. Thus I ensured that all the potential participants possess the autonomy to elect to participate.

3.7.1.1 Informed consent

Informed consent was sought from all those who expressed an initial interest in taking part in the study following publication of preliminary information via the two collaborating networks. The voluntary nature of the research is stated clearly in the information sheet, in that the participants are free to withdraw from the study at any time without giving a reason.

Traditionally, informed consent is obtained via face-to-face interaction between the participants and the researcher. Obtaining informed consent via email is not as straight forward, even though Sharf (1999) suggested that by the mere action of participation in an online interview, participants have made a conscious choice to participate in the study.

In this study, I had the option of mailing out the information sheet and the consent form to all potential participants' postal address via postal service. However, Houston (1996) pointed out there is no guarantee of a postal return from the participants. After

consultation with my supervisors, and following a precedent set by Golding (2011), participants were offered several choices in order to indicate their consent: email consent and/or electronic signature on the consent form. Participants who were unable to provide an electronic signature on the consent form were offered the alternative option of scanning the consent form to me as a Portable Document Format (pdf) or replying with an email statement giving their informed consent (AOIR, 2012). I, therefore, safeguarded the participants' autonomy during the whole email interviewing procedure.

3.7.1.2 Confidentiality

Once informed consent was obtained, the emails were saved in a secure email account provided by the University of Huddersfield. All identifiable information was removed from data (i.e. names of participants and their email address). A unique identifying code (Participant 1, Participant 2 etc.) was given to each participant and hard copies of the forms were printed and stored in a secure locked office at the University. This study therefore complied with the conditions as set out by the University of Huddersfield and the UK Data Protection Act (1998) to ensure confidentiality of the participants' data.

3.7.1.3 Anonymity

Participants' anonymity is paramount when conducting traditional health and social care research. Performing email interviews should be no different and participants' anonymity should be at the forefront when conducting the study. In this study, participants' identities were protected via the use of a unique identifying code. I confirmed that the participants gave explicit permission to be quoted and that no information could lead to the identification of the participants in this thesis or any report or publication resulting from the study.

3.7.2 Non-maleficence

The non-maleficence principle is an obligation in which no harm is inflicted on participants (Beauchamp and Childress, 2013). This follows a course of action that carries the least harm and risks to both the participants and the researcher.

3.7.2.1 Participants' safety

The Hippocratic Oath states that doctors should cause no harm (directly or indirectly) to their participants. This principle has also been extended to health and social care research. This biomedical principle is complex and the researcher may inadvertently provoke a participants' previous or current painful experience whilst engaging with them in research. I have a track record of successful research with sensitive issues (both for my clinic work and academic research) (Lui et al., 1995; Edward et al., 2013). In the event that psychological support is required for the participants, options for counselling

referrals were explored (see Appendix 6). Support could also be gained for the participants via the Infertility Network (2015) and the International Consumer Support for Infertility (2015) (iCSi). During the email interviewing sessions, I paid particular notice to ascertain if the participant's response indicated a need for counselling support. In fact, none did so and none withdrew from the study. Indeed, a number of participants expressed that talking about their cross border fertility treatment was cathartic. This will be explored further in the section on the advantages and disadvantages of asynchronous email interviewing.

3.7.2.2 Researcher safety

The School of Human and Health Sciences Research Ethics Panel (SREP) at the University of Huddersfield adheres to the British Sociological Society framework to safeguard the researcher's safety. Robley (1995) suggested that the nature of health and social research requires the researcher to be immersed in the lived experience of the participants, thus the researcher requires an inner strength that can be enhanced by the researcher's own resilience.

I left my clinical embryology post in late 1998 due to family commitments. I am aware that re-engagement in infertility research could evoke my own psychological history affecting my emotional well-being. After discussion with my supervisors, I decided to utilise the counselling facilities provided by the University of Huddersfield if such need arose. Knowing the availability of this counselling service provided me with a safety net to carry on with this study. Despite twelve years of absence from infertility practice and research, it was interesting and enlightening to discover that my paper on a survey of semen donor attitudes (Lui et al., 1995) had received 47 citations by current infertility researchers. I presented the preliminary findings on my CBRS study at the 27th Annual General meeting of the European Society of Human Reproduction and Embryology (Lui et al., 2011); I had a warm and respectful reunion with my previous infertility colleagues and was encouraged by the interest my poster presentation received.

My personal safety as a researcher was also made more secure by the use of the University email address. This ensured no personal contact could be made by the participants. Interestingly, a number of participants queried my intentions and my motivation for this study; this will be addressed in a later section of this chapter.

3.7.3 Beneficence

Researchers are required to show respect for autonomy and refrain from harming the participants. In addition to this, the researcher needs to promote the health and well-being of the participants. Beneficence implies acts of mercy, kindness and charity.

There are two principal aspects of beneficence: positive beneficence and utility (Beauchamp and Childress, 2013).

Positive beneficence requires the researcher to provide benefit to the participants; in this study I engaged with the participants by allowing them to vocalise their experiences.

One of the aims of the study was to raise awareness of the potential barriers encountered by the participants throughout their cross border reproductive journey by sharing with others in a similar situation their experiences and the knowledge they gained. The participants in this study demonstrated beneficence to others by their willingness to share their experience with me, an unknown researcher, in the hope of helping and benefiting others.

Utility is sometimes known as 'proportionality', it requires the researcher to weigh up the possible good against potential costs and harm, in order to gain the highest net benefits for participants. Costs are generally expressed in monetary terms, however in health and social research the term costs is synonymous with the term risk. Potential risks refer to the possible future harm or setbacks, which could be faced by the participants.

Minimisation of risks in this study utilised an experienced researcher who has a track record of research of sensitive issues and the provision of psychological support for the participants when the need for it is identified (see Appendix 6).

3.7.4 Justice

Justice as considered in this chapter is neither criminal justice (just infliction of punishment) nor rectificatory justice (compensation for breach of contract) (Beauchamp and Childress, 2013). In this study, the justice concept explicates fairness and entitlement when distributing health care services to participants. The scarcity of resources combined with the escalating costs of healthcare leads to inequalities in access to fertility treatments by individuals (e.g. participants' inability to gain health insurance or other funding for fertility treatments) (ASRM, 2013). This has also fuelled debate concerning the comparative justice, which entails decisions about who or which population are more deserving of limited healthcare resources (Daily Mail, 2014).

Distributive justice is based on the distribution of health resources according to economic or social principles. In this instance, fertility treatment is no longer a 'healthcare' scenario; it is now almost a case of how resources are distributed according to need. The principle of distributive justice has the following characteristics:

- To each person equal share
- To each person according to need
- To each person according to effort
- To each person according to contribution

- To each person according to merit
- To each person according to free market exchange.

A free market has led to participants having a choice to have infertility treatment in their home location or travel to a more 'successful' clinic in the participants' home country and the freedom to embark on CBRS. However, in reality, many participants felt that they had very little choice when selecting the CBRS route either for legal or financial reasons, which will be discussed in more detail in Chapter 6 of this thesis. I will highlight other considerations when embarking on this free market journey for example, safety and clinical governance. I also question the distributive justice anecdote that participants want to have the freedom to choose their infertility treatment if there are no barriers for example, egg donors' availabilities and no legislative restrictions in their home countries. Why travel abroad and is there a need to travel abroad for CBRS?

3.7.5 Professional-Patient Relationships

This relates to four moral rules: veracity, privacy, confidentiality and fidelity (Beauchamp and Childress, 2013). Veracity refers to the comprehensive, accurate and objective transmission of information, as well as to the way the professional fosters the participants' understanding of the research. Veracity is closely related to respect for autonomy however, it has three main differences. Veracity is based upon respect owed to others, obligations of fidelity (promise keeping and contract) and finally the relationships of health professional and patients depending on trust. There are five forms of privacy: informational privacy (biomedical medical information about the person), physical privacy (persons and personal space), decisional privacy (personal choice), propriety privacy (personal property interest) and relational or associational privacy (individuals making decisions in conjunction with their family or intimate relations). Confidentiality is central to the Hippocratic Oath and the World Medical Association's Declaration of Geneva (The World Medical Association's Declaration of Geneva, 2015). Within the context of this study, participants consented for their CBRS medical experiences to be shared with third parties (i.e. research supervisors, examiners, readers of the thesis and any other publications based on the study) with the agreement that their anonymity would be observed. Obligation of fidelity arises when professionals and patients form a significant relationship and trust is established. In relation to this study, I wish to uphold the virtues of fidelity by involving participants and representing their experiences truthfully and honestly. I have no conflict of interest in relation to this study (i.e. this study has not received funding from any external bodies).

3.8 Internet research

Since the early 1990s, internet and online communication has proliferated in many households. In 2012, 21 million British households had internet access, representing 80% of all households (Office of National Statistics, 2015), compared with 19 million (77%) in 2011 and 13.9 million (57%) in 2006. Globally, by the end of 2012, 678 million households could have internet connection, which is an increase of 8.5% from 2011. This is equal to a quarter of global households now having internet access. By 2016, it is estimated that 800 million households globally (42% of all households) could have internet access (Strategy Analytics, 2015).

Researchers traditionally are more open to technology, accessing and retrieving information utilising a range of media including online materials (i.e. books, journals). Researchers already gain numerous secondary data (i.e. censuses, Millennium Cohort Study, British Household Panel Survey (Economic and Social Data Service, 2015). from the internet to perform quantitative research. It is therefore not surprising that researchers may be drawn to the internet environment when conducting health and social care research (Bryman, 2008).

3.9 Survey research on the internet

Researchers recognise the strengths of survey research and its ability to reach and describe a large population (Babbie, 2007). Most people who use the internet are also aware of online surveys. Respondents have to indicate their replies using simple check boxes, radio buttons or delete items that do not apply. If questions are open, they are asked to type the answer in text boxes. Once completed, the respondents click a reply button to complete the process or via email. There are many online survey providers (i.e. Survey Monkey, 2015; Bristol Online Survey, 2015) to enable researchers to conduct surveys. Individuals who have filled in online surveys are mindful that many questions in the questionnaires are too broad, thus one may not be able to articulate a meaningful answer. Babbie (2007) suggested that "surveys cannot measure social action; they can only collect self-reports of recalled past action or of prospective hypothetical action" (p.287). In this study, the participants might not have formulated an opinion until the particular topic is presented to them through the research instrument; therefore a survey was not appropriate for this study.

Issues when considering whether or not to perform a survey were:

1. I would like to enable the participants to express their feelings employing their own 'words'
2. I would like to mimic face-to-face interviews and the conversation experience for the participants

3. Utilisation of the survey provider will incur costs to the institution (e.g. a standard Bristol Online Survey (BOS) account costs £500 plus VAT per annum).

From the above considerations, I therefore decided not to choose an online survey methodology for this study.

3.10 Synchronous online interviews using Instant Messenger (IM)

Instant Messenger (IM) originated in the 1960s as a multi-users timesharing computer facility. When computer networks became more common, in the 1980s, these facilities were extended to allow messaging to be passed between different computers (Gaiser and Schreiner, 2009). IM is a synchronous online interviewing communication method and when used in a research study enables communication to go directly from the researcher to one or more participants' computers. IM messages are not stored on a server nonetheless they may be logged onto a system to enable participants to receive messages whilst online. This archiving capacity enables researchers to save, store and retrieve IM messages. Flynn described this as 'turbo charged email' which produces a "rapid real time chat at lightning speed" (Flynn, 2004, p.8). IM is cheap and is delivered by many service providers (e.g. America Online (AOL) Instant Messenger (AIM), Window Live Messenger (was MSN messenger), Yahoo! Messenger, Google Talk or Apple iChat).

IM interviews are very attractive for participants who do not like face-to-face interviews (Hinchcliffe, 2010), discussing sensitive and confidential issues verbally (Davis et al., 2004) or cannot physically converse in an interview setting (e.g. people with verbal communication impairments, learning disabilities or acquired brain injuries) (Ison, 2009). IM exchanges between researcher and participants tend to involve a dynamic form of dialogue, which leads to immediate responses and engagement with the topic being discussed (O'Connor and Madge, 2003). This could be an advantage if the aim of the research is to create a spontaneous response from the participants.

Another advantage offered by IM relates to recording of interviews. Traditionally, qualitative research yielded taped conversations between researcher and participants and time consuming transcription was required to convert taped conversations into text words. IM could overcome this labour intensive task as IM messages are in text format and words are provided exactly by the participants. IM avoids the conventional constraints of spatial and temporal proximity between the researchers and participants (see Table 7) (Bryman, 2008; James and Busher, 2009).

Whilst IM interviews provide many advantages for the researcher, they also have a number of disadvantages for example, fewer opportunities to develop rapport with the

participants even though James and Busher (2009) suggest that this could be overcome by meeting participants 'offline' prior to IM interviews. IM interviews may be slow, depending on the online traffic, and follow up probing could inhibit the 'conversation' between participants and researcher. Social and conversational cues are absent in IM interviews, and there are frequent break downs in turn taking; for this reason, the text generated from IM interviews could be brief (James and Busher, 2009) and ambiguous (Davis et al., 2004) due to the loss of participants' intonation (Gaiser and Schrenier, 2009). Hinchcliffe (2010) also highlighted computer security concerns (i.e. hackers, eavesdroppers, viruses and spam) and Flynn (2004) advised IT department control over the identity and passwords should enable authentication of the end user's safety. Davis et al. (2004) concluded that IM interviews do not readily lend themselves to explore meaning; Davis et al. raised the question as to whether IM interviews may contribute to an in-depth description of the social experience. IM interviews therefore appear to have a number of limitations and they could be overcome by conducting asynchronous online interviews (e.g. email). Despite these limitations, IM has proved itself a useful tool for research purposes. In this study, because of the participants were located in different time zones to myself, IM was not feasible. I therefore chose to use asynchronous online email interviews.

3.11 Asynchronous online interviews using electronic mail (email)

There is a rapid penetration of information technologies throughout our society. Electronic mail (email) is perhaps the oldest form of computer based communication and has been integrated into many businesses, homes and academic institutions. Email is relatively easy to use for one-to-one, one-to-many and many-to-many communications (Bryman, 2008). Email is a 'store and forward' technology. Messages are written by the sender and transmitted to a mail server and, after perhaps several transmissions, received by the recipient's mail service provider server. Using a unique account code, the recipients then may retrieve the mail from his/her own computer (Gaiser and Schrenier, 2009). Email messages can be managed by the recipients on their local computer or via a web browser. Once email messages are copied to a local storage facility, the recipient may access the message offline whereas web-based email recipients could allow access to messages anywhere via the web browser. The email message remains on the server until the recipient deletes it. Once again, email is delivered by many service providers (e.g. Microsoft Outlook Express, Apple Mail, Yahoo! Mail, Google Gmail).

Email as an academic research tool is increasing and there is a plethora of discussion papers (Selwyn and Robson, 1998; Bampton and Cowton, 2002; McAuliffe, 2003; McCoyd and Kerson, 2006; Bryman, 2008; Ison, 2009) on the advantages and disadvantages of such a method. Here I will concentrate on the 'qualitative research

interview' (semi-structured or unstructured interview) as described by Bryman (2008) as opposed to the structured interview used in many research studies.

Table 6: Advantages and Disadvantages of email interviews

Author (Year)	Advantages	Disadvantages
Selwyn and Robson (1998)	<ol style="list-style-type: none"> 1. Easy access to worldwide sample thus overcoming geographical and time zone constraints 2. Low administration cost 3. Ease of distribution 4. Unobtrusive 5. 'Friendliness' to respondents 6. 'Ready-transcribed' interview data 	<ol style="list-style-type: none"> 1. Difficulties in ensuring anonymity 2. Requires tactful communication 3. Biased population (in terms of age, income, gender and race) 4. Difficulties in controlling response rate and response time 5. Information overload and research via email runs the risks of becoming 'junk mail' 6. No visual and verbal cues between the interviewee and interviewer
Bampton and Cowton (2002)	<p>Email interviews could transform the interview on the time and space issues.</p> <ol style="list-style-type: none"> 1. Convenient time for researcher and participants to talk to each other (overcoming time and travel constraints) 2. Permitting delay between communications 3. Enables interviewee to reflect and then supply considered reply 4. Reduce pressure felt by interviewees 5. Interviewer has the time to develop dialogue 6. Protect participants from embarrassment, such as when discussing sensitive issues 7. Protect researcher by offering a degree of anonymity 8. No time consuming and costly transcription 	<ol style="list-style-type: none"> 1. Loss of spontaneity 2. Typographical errors 3. Uncertainty about the reasons for a delay in reply from participants 4. Risks in sending too many questions at once (this could be daunting and discouraging), particular closely related questions 5. Interview 'fatigue' because of too many email interview episodes 6. Lack of body language and other non-verbal (e.g. voice inflexions) communication
McAuliffe (2003)	<ol style="list-style-type: none"> 1. Overcoming time constraints and geographical limitations (broaden sample population to national level, to include participants from rural and isolated areas and international participants) 2. Cost of the study 3. Possibility of developing rapport 4. Reflective dialogue process as 'cathartic therapeutic experience' 5. More honest due to participants' anonymity 6. No need for transcription (time and cost saving) 	<ol style="list-style-type: none"> 1. Lack of personal cue, voice tone and body language 2. Uncertainty regarding the trustworthiness of the data 3. Assurance of confidentiality and privacy
McCoyd and Kerson (2006)	<ol style="list-style-type: none"> 1. Interview data to be collected from geographically dispersed and socially silenced group (e.g. women experiencing grief after termination of pregnancy due to the diagnosis of foetal abnormality) 2. Extensive, longitudinal communication 3. Allow respondents to complete the 	<ol style="list-style-type: none"> 1. No direct observation of emotion, only reports 2. Technical problems – disappearing text and email address changes

	<p>interview at their convenience</p> <ol style="list-style-type: none"> Written text response – no transcription Less social pressure; few visual cues to create judgment Geographical differences in experience are revealed 	
Bryman (2008)	<ol style="list-style-type: none"> Extremely cheap to conduct Participants who would otherwise normally be inaccessible or hard to involve in research can more easily be involved Participants could reflect on their answer and give a more considered response Participants are able to re-read what they have previously written Participants could fit the interviews into their own time Do not need to make additional allowance for time spent on travelling Interviews do not need audio recording thus eliminating participants' apprehension about speaking and being recorded No need for transcription saving time and cost involved in the recorded interview / transcription Transcripts could be entered directly to qualitative data analysis package (e.g. NVivo) Transcripts are more likely to be accurate avoiding problems, such as mishearing or misinterpretation Email interviews make it easier to discuss sensitive issues Anonymous, secure and non-threatening environment encourage email interview process especially for vulnerable groups Researchers are not confronted by potentially discomfoting experiences of having invaded participants' home or workplace which could be sometimes unsafe environments 	<ol style="list-style-type: none"> Difficulties to establish rapport and to engage with the participants Difficulties in retaining rapport over a long period of time Researcher could not capitalise upon body language that might suggest puzzlement Probing is more difficult though not impossible Email interview may take longer time to complete depending on cooperativeness There may be a greater tendency for participants to discontinue their involvement prematurely compared to face to face interviews Non-response rate is higher in email interview compared to face to face interviews Researcher could not be certain that participants are who they say they are Software incompatibility between participants and researcher and online usage cost. Online connection may be lost, this might be unknown by the researcher Researcher might not be aware of other distractions within the participants' circumstances
Ison (2009)	<ol style="list-style-type: none"> Interview could be undertaken with people with verbal communication impairment (e.g. cerebral palsy) Interviews could be undertaken with people who are geographically apart from the researcher Participants could find email interviews to be more relaxed in their home environment Cathartic for the participants Transcription is simultaneous No need to travel Participants could clean up their response before they send them Time to reflect on their answers, 	<ol style="list-style-type: none"> Participants' selection bias includes participants' capacity and skill to use computers and access to computer or email account. The desire to participate could be influenced by economic status, culture, age, gender and language Participants' physical disability e.g. inability to operate computer keyboard Email is 'faceless' and 'body-less': lack of voice qualities, body language and facial expression

	<p>often leading to more detailed, thoughtful and richer responses</p> <p>9. Longitudinal aspects give interviewer 'second chance' to ask follow up questions and clarify information gathered from emails</p>	
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In the past, I have undertaken traditional qualitative interviews with two tape recorders in position (to ensure a backup in case of mechanical failure or other misadventure that could sabotage effective and comprehensive recording). I considered both synchronous (IM) and asynchronous (email) interviews for my research methodology. Undertaking my interviews in real time did not present itself as a viable option when I aimed to recruit research participants worldwide due to the constraints imposed by the location of different parties in different time zones. My remaining option would be to perform asynchronous email interviews.

Email interviews definitely provide an attractive and manageable means for me to conduct interviews with participants. As illustrated by the above authors, email interview methodology may be an advantageous way (i.e. overcoming geographical and time zone constraints) of recruiting an international pool of participants to undertake qualitative interviews. The administration cost is relatively low and email interviews could be distributed with ease (Selwyn and Robson, 1998). Email interviews enable the researcher and participants to communicate at a time which is convenient to both parties (e.g. allowing a delay between communications (Bampton and Cowton, 2002) and this dialogue could take place in the comfort of the home environment (Mann and Stewart, 2000). The key benefit of participating in email interviews is the unobtrusive nature of such methodology (Selwyn and Robson, 1998). This reduces the 'social pressure' felt by participants (McCoyd and Kerson, 2006), thus promoting a sense of anonymity and reducing apprehension when discussing sensitive issues (Bampton and Cowton, 2002; McAuliffe, 2003; Bryman, 2008). In this study, the participants and I discussed sensitive issues concerning their infertility treatment and their reasons for engaging in CBRs. Email interviews also gave the participants an opportunity to reflect upon their answers, which often leads to a richer and a more considered reply (Bryman, 2008). McAuliffe (2003) and Ison (2009) suggested this could be a 'cathartic therapeutic experience' sensed by the participants. Participants are able to edit the email prior to sending it to the researcher and the researcher is able to ask follow up questions (Ison, 2009), therefore increasing the accuracy, clarity and comprehensiveness of the responses provided by the participants. I decided to interview my participants using eight episodes of asynchronous email interviews (see Appendix 5 – semi-structured questionnaire), thus enabling me to develop a 'friendly' and dialogue approach (Bampton and Cowton, 2002),

similar to face-to-face interviews and promote rapport (McAuliffe, 2003) with my research participants. All the above authors (Selwyn and Robson, 1998; Bampton and Cowton, 2002; McAuliffe, 2003; McCoyd and Kerson, 2006; Ison, 2009; Bryman, 2008) highlighted that the benefits of email interviews from the researcher's perspective are that data collection and transcription are simultaneous therefore, avoiding the time consuming and the substantial cost of transcription. The interview data can be directly transferred to a qualitative data analysis package such as NVivo (Bryman, 2008); this will be discussed in the latter part of this chapter.

Despite the many advantages of email interviews, I am mindful of the limitations when considering this research methodology and the ways in which I have tried to acknowledge and overcome these issues. When formulating the study, I sought guidance from the computer technician to set up a private and confidential email account. This will ensure that any technical problems, software compatibility (Bryman, 2008) and access issues (McCoyd and Kerson, 2006) are resolved and in place prior to the participants being recruited for the study, thus safeguarding their 'anonymity' (Selwyn and Robson, 1998). One of the key limitations of the study is that it requires the participants to have computer and literacy skills; this could introduce recruitment bias for the study (Selwyn and Robson, 1998; Ison, 2009). Culley et al. (2011a) and Culley et al. (2011b) established that participants who journeyed overseas for infertility treatments are predominantly (72%) from professional or managerial backgrounds. They also highlighted that internet access is essential in order to engage in CBRs. One, therefore, could presume that the intended participants were able to use and have access to a computer with an email account. On a different note, the lack of non-verbal communication (i.e. voice tone, body language and facial expression) in email interviews is widely acknowledged (Selwyn and Robson, 1998; Bampton and Cowton, 2002; McAuliffe, 2003; McCoyd and Kerson, 2006; Bryman, 2008; Ison, 2009). In this study, I used expressive open/conversation-like questions (e.g. 'could you tell me'), participants use multiple vowels to indicate rising intonation (e.g. 'sooooo') and emoticons (e.g. ☺ (happy) and ☹ (sad)) to aid the lack of non-verbal cues. Response time (Selwyn and Robson, 1998) and attrition rates (Bryman, 2008) are difficult to control; this could be due to too many questions posed to participants or interview 'fatigue' because of too many email exchanges (Bampton and Cowton, 2002). I tried to strike a balance by using the eight episodes to develop rapport with the participants whilst not using complex questions. Participants were requested to reply to each email within three days, if possible (see Appendix 3 - Information sheet). Life events or distractions may be unknown to the researcher (Bryman, 2008), I therefore sent out a weekly email reminder to those participants who had not responded. This was to avoid email overload and the risk of the research email being treated as 'junk' mail by the

participants, with a reply date to encourage participants' response, thus avoiding the premature discontinuation of their participation. As noted above, once they had engaged with the study, none of the participants discontinued. Researchers must assume good faith that the responses are authored by the participants even though they might not be absolutely certain of this (McAuliffe, 2003; Bryman, 2008). In this study, participants' partners could be involved to provide a comprehensive picture of their treatment whilst abroad. Seymour (2001) argued despite the 'invisibility' of the 'body' in an email interview, the human body is still central to the email interview transaction. She suggested that researchers sometimes underestimate the presence of the body in online interviews whilst they overestimate the power of the body in face-to-face interviews, therefore there is no more or less about the 'truth' and veracity in email interviews compared with face-to-face interviews.

The emerging research that exploits email interview methodology tends to be in education and social sciences (Selwyn and Robson, 1998; Bampton and Cowton, 2002; McAuliffe, 2003; McCoyd and Kerson, 2006; Bryman, 2008; Ison, 2009). I performed a search on the MEDLINE database from 1950 to the present using the terms 'email interview' and 'qualitative' as title and abstract (accessed in January 2014); only 23 articles were obtained from the search. One could conclude that email interview methodology is still in its infancy within health research. The potential for email interviews in health research is growing. This study therefore provides a new platform to 'give a voice', using email interviews, to the participants who have used CBRS.

3.12 Ethical issues relating to internet research

Bio-ethical principles have been discussed previously, this section is to address the specific ethical issues when performing internet research e.g., asynchronous interview. The term 'internet' could be defined as the decentralised communication of information whilst using a network of computers, which could encompass numerous technologies, devices and social media (Mann and Stewart, 2000). Many new ethical and methodological issues could be raised when carrying out internet research by the emergence of new technologies within internet research (AOIR, 2012). James and Busher (2009) offer the 'ten commandments' of computer ethics (see Table 7, P.81) in which items 1, 4, 5, 8 and 9 have relevance to internet research.

Table 7: The 'ten commandments' of Computer ethics

1. You shall not use a computer to harm other people
2. You shall not interfere with other people's computer work
3. You shall not snoop around in other people's computer files
4. You shall not use a computer to steal
5. You shall not use a computer to bear false witness
6. You shall not copy or use proprietary software for which you have not paid
7. You shall not use other people's computer resources without authorisation
8. You shall not use other people's computer resources without proper compensation
9. You shall not appropriate people's intellectual property
10. You shall think about social consequences of the programme you are writing.

(Source: adapted from James and Busher, 2009)

The ability to obtain participants' email addresses and access to their views on sensitive subjects places the researcher in a very powerful position. In this study, I need to consider carefully the responsibilities that this access placed upon me and try to observe the fidelity principle (Beauchamp and Childress, 2013), whilst protecting their privacy and anonymity.

3.12.1 Blurring of public and private spaces

There is much debate and discussion regarding what is private and public conversation in internet research (James and Busher, 2009). In this study, careful consideration was given to choosing the one-to-one asynchronous email interview methodology so as to ensure email communication stayed as a 'private' communication between the participants and the researcher. AOIR (2002) argued that participants are more likely to take part in research when personal information and communication are secure in a safe online environment. The University computer technician set up a unique confidential email account for this study to safeguard the security of the email conversations between the participants and the researcher.

This study was advertised on two specialist support group websites (<https://www.infertilitynetwork.org> and <http://www.icsicommunity.org>), which are accessible to the general public and, as a result, I received a number of unsolicited emails e.g., requesting financial assistance, medical/infertility advice and personal relationships. After consultation with my supervisors, I have disregarded these emails. In this instance, the researcher's privacy has also been protected by the utilisation of a secure email account procedure.

3.12.2 Netiquette

Netiquette is a new form of communication which encourages politeness, civility and enhancing understanding between participants and researchers. Internet researchers will still have interpersonal contact with participants, albeit in the absence of non-verbal

communication (Sharf, 1999). For example, CAPITAL LETTERS could be used to express accentuation; common symbols (i.e. ☺, ☹) could be used to convey feelings. Netiquette is important to help prevent aggressive and insulting behaviour whilst undertaking internet research (James and Busher, 2009). I observed all of these netiquette guidelines as identified by Hall et al. (2004) (see Table 8). In this study, I provided a comprehensive information sheet to the participants. As I have a clinical background in infertility, I have good knowledge of the terminology used by the participants and the treatment options faced by infertile participants.

Table 8: Netiquette guidelines for internet researchers

<ol style="list-style-type: none"> 1. The subject header used in any posting must not misinform the participant and not create misunderstanding between the researcher and participants 2. Self-identification and self-presentation of the researcher are critical, as participants of the research will form their evaluation about credibility of the research and the researcher 3. To ensure respect for those being researched, the researcher must be familiar with the common language used by the participants, including jargon, abbreviations, acronyms, emoticons and common grammatical rules 4. Researchers should always ask appropriate questions and to do this they must acquaint themselves with the subject matter before asking for help 5. Prior understanding of the specific culture of the group should be attained by observing the group for a period of time 6. The researcher has an obligation to inform the participants about the purpose, nature, procedure and risks of the research.

(Source: Hall et al., 2004, 244-247)

All documentation for the project has been subjected to peer-review by the University of Huddersfield's School Research Ethics Panel (SREP) to ensure clarity of the questions and ethical nature of the study. The identification of the researcher, institution, aims and objectives of the study are clearly stated in the information sheet for the participants (see Appendix 3). Both myself and my main supervisor have previously performed infertility research, thus were able to understand the terminology (i.e. medical and lay) used by the participants. Mann and Stewart (2000) and Crystal (2001) advocated that email interviews should be succinct. Participants should be able to view all the text in a single page, eliminating the need to scroll up and down, which can be exasperating for the participant and, in addition, there is the risk of the participant not scrolling down far enough, thus missing requested information. A decision was therefore made to break the email interviews into eight discrete 'episodes' to be sent sequentially to the participants, thus making the study more interactive. This allowed the participants to clarify their responses and permitted the researcher to incorporate supplementary questions in subsequent emails to participants (Bampton and Cowton, 2002), thus constructing credible and authentic information on cross border reproductive services.

3.13 Computer assisted qualitative data analysis software (CAQDAS)

In the last twenty years, one of the most important developments in qualitative research has been the development of computer software to assist the analysis of qualitative data (Bryman, 2008). Qualitative data in this study included email text or pictures obtained from the participants that could be coded into themes, concepts, processes or contexts to build explanations or theories (Lewins and Silver, 2014). CAQDAS removes most of the routine administrative tasks associated with the manual coding and retrieval of data. There are a number of CAQDAS packages on the market (e.g. ATLAS. Ti, MAXqda and NVivo). All the packages have their own advantages and disadvantages.

3.13.1 NVivo

NVivo (earlier version known as NUD*IST) was developed by Tom and Lyn Richard in 1981 (Bazeley, 2007). It contains tools to help qualitative researchers to work with text-based data and more recently NVivo version 10 also supports multimedia data (i.e. audio and video files, digital photos, PDF, spread-sheets, web and social media). NVivo software allows researchers to manage data, manage ideas, query data, conceptualise ideas via a graphical model and report the outcomes of qualitative data. The decision to use NVivo was both a personal preference as I intended to take this opportunity to learn the ways to manage a large set of qualitative data and in part due to the IT support for NVivo provided by the University.

All the email interviews were converted into Word format and imported into NVivo. As outlined in Chapter 2, Grounded Theory was used in this study therefore no a priori themes were set for analysing the data. Initial findings from email interviews were used to generate preliminary themes, which were explored further to generate subsequent concepts. The process continued until no new themes came to light. Memos were written, in no order of preference, as they emerged from perusal of the data. The transcripts were read and re-read several times line-by-line to enable the researcher to become familiar with the data and to identify initial codes. The collated codes were gathered into potential themes and were constantly re-examined. Diagrams or schematic models were developed to depict the links between various concepts. The themes are defined and refined to provide an overall story voiced by the participants and finally producing a concise, coherent and logical report (Braun and Clarke, 2006). Coding stripes in NVivo could highlight these codes, which are similar to the use of highlighter pens.

The main issue in using NVivo was the time taken to learn how to use the software (Walsh, 2003). Even after attending a data analysis module at the University in 2010, the skills required to fully utilise the software remained problematic. After discussion

with my supervisors in 2012, I attended a workshop run by the NVivo (2015) publisher QSR International; this clarified some of the difficulties; however the data analysis process took longer than anticipated.

Thurgood (2008) offered the strengths and weakness of using NVivo software for qualitative data analysis (see Table 9) and I echo these viewpoints based on my first-hand experience.

Table 9: Strengths and weaknesses of using NVivo Software

Strengths	Weaknesses
1. Quick search facility	1. Time consuming and difficult to learn to use
2. Node function allows easy production of codes and themes.	2. Complex facilities, such as memo query and report
3. Large capacity for data	3. Cannot help with conceptual aspects of analysis
4. Easy colour facility to code text	4. Needs technical support if problems occur with the software.
5. Good for mechanical analysis of large amounts of data.	

(Source: Thurgood, 2008)

3.13.2 Using asynchronous email interviewing methodology

In order to ascertain participants' views on their experiences of taking part in this type of research, a final question posed to the 26 participants was "Could you tell me the pros and cons of asynchronous email interviews?" It was hoped the participants' responses to this question would inform future researchers considering using the asynchronous email interview methodology.

I illustrated the use of NVivo when coding these interview transcripts. The rationale for performing these tasks here is to illustrate that using a relatively small amount of data with NVivo could produce a model.

The response rates and models for both aspects are illustrated in the following tables (Tables 10 and 11) and figures (Figures 2 and Figure 3).

Table 10: Response rate for advantages of email interview methodology

Advantages	Number of responses
1. Allows delay	6
2. Autonomy	2
3. Cost	2
4. Geographical dispersal	2
5. Interest in the study	10
a. Interested in the format of the study	3
b. Interested in helping others	5
6. Not attempt to please	1
7. Positive rapport	13
8. Sense of autonomy	3
9. Works well	9
a. Interactive	2
b. Time to suit participants	6

c. Convenient	4
d. Clarity of questions	4
e. Reflective answers	9
f. Share experience	1
g. Not time consuming	3
h. Easy to follow	2
i. Cathartic process	3

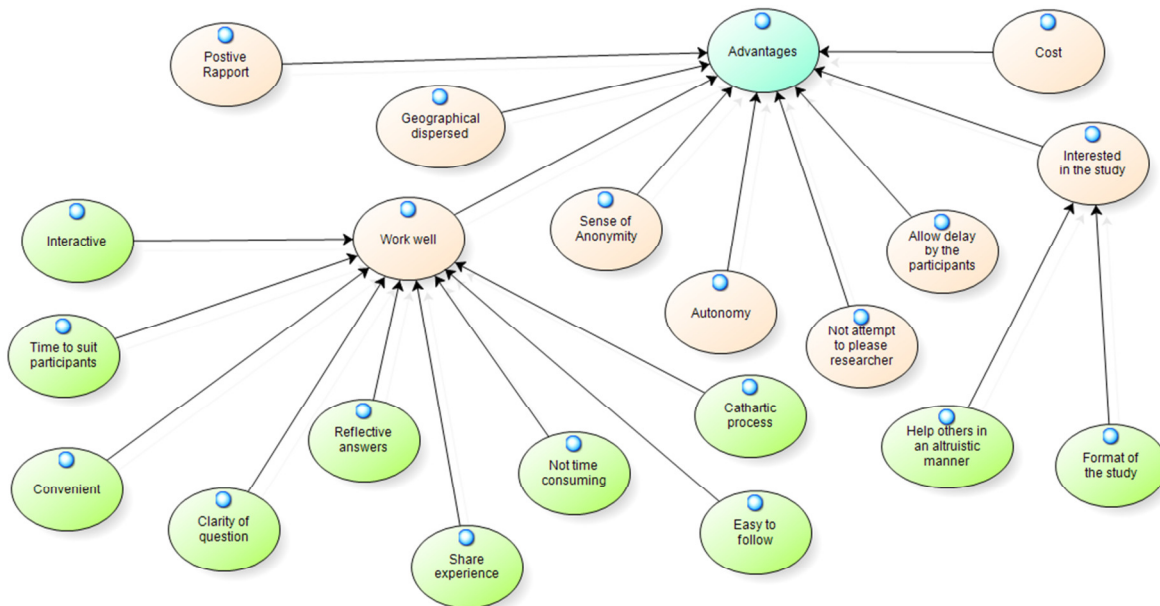


Figure 2: Model for the advantages of email interview methodology

Table 11: Response rate for disadvantages of email interview methodology

Disadvantages	Number of responses
1. Lack of non-verbal communication	4
a. More direction requested	5
b. Unsure about depth of answer	4
c. Participants' uncertainty with research expectation	3
d. Question researcher's motive	2
2. Negative rapport	
a. Less rapport	1
b. Literacy	1
3. Not truly conversational	1
4. Not noticed email	1
5. Personal preference	2
6. Time consuming	5
a. Complex questions	2
b. Lack of time	2
c. Repetition	10
d. Slow pace	4

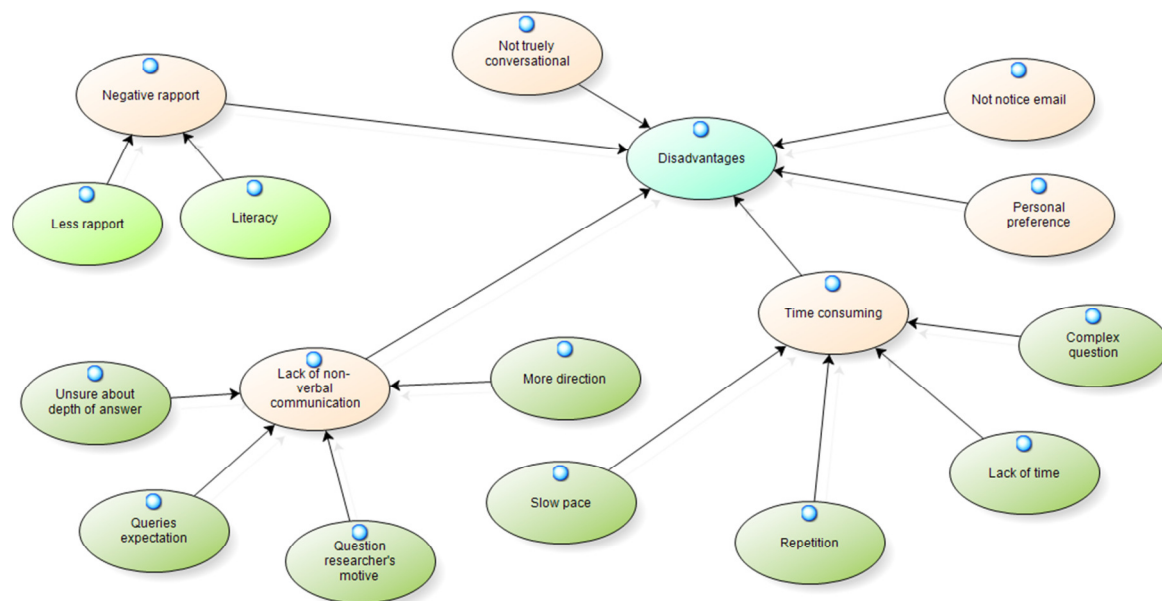


Figure 3: Model for the disadvantages of email interview methodology

Once codes were created and on reflection, themes could develop from the qualitative data. NVivo enables the researcher to have some awareness of the number of responses for each code. One needs to treat these response rates with caution as qualitative research places importance on the 'words' used by the participants. However, the response rates could still add to the information regarding the importance of each code.

McAuliffe (2003) suggested that it is possible to develop good rapport with participants. Positive rapport was obtained from participants and is illustrated by Participant 8's statement:

"Sharing my experience ... with a friend rather than an academic".

The findings of previous studies that many participants find the email interview method 'works well' because they are able to provide a more reflective answer (Bampton and Cowton, 2002; McAuliffe, 2003; Bryman, 2008 and Ison, 2009) were reflected in comments from participants in this study:

Participant 1: "There is time to think and formulate an answer"

Participant 12: "A thoughtful approach Ability to review what I thought at each stage and reflect on our experiences".

Some participants had successfully conceived after their fertility treatment and had young children. The use of asynchronous email interviews provided the flexibility of enabling participants to fit in responding to my questions with their child-care responsibilities (Bampton and Cowton, 2002), enabling them to respond in their own time (Bryman, 2008) and at a time convenient to them (Bampton and Cowton, 2002; McCoyd and Kerson, 2006; Bryman, 2008):

Participant 11: "Sorry for the delay... I don't have a moment to myself"

Participant 19: "I could do it at home in my own time" and

Participant 10: "Flexibility to answer questions when you have time So it is good for busy people".

Participants in this study were all able to source information from the internet and were interested in the development of reproductive technology. Several expressed interest in the results of the study:

Participant 3: "Interested to read the finished document".

Participant 5: "I look forward to seeing the summary"

Participant 12: "Would be interested to see the result".

In particular, participants demonstrated altruism in their wish to help others:

Participant 11: "I hope this may help someone else in the future".

Participant 15: "I am happy to share my experience as that is what was most helpful to me in considering IVF overseas and wish to help others doing the same".

Ison (2009) commented that email interviews can be cathartic for participants, as was evident in this study:

Participant 8: "participating in the study helped me put some closure to an unpleasant experience".

Participant 24: "I enjoyed answering the questions – it was quite cathartic for me".

Participants were aware of the cost and geographical constraints (Selwyn and Robson, 1998; McAuliffe, 2003; McCoyd and Kerson, 2006; Ison, 2009), thus making email interviews an attractive option:

Participant 1: "Email gives you an easy, inexpensive way to reach a broad number of participants" and "I suppose you are working with participants all over the world".

A sense of autonomy and anonymity (Bampton and Cowton, 2002; McAuliffe, 2003) was felt by the participants, consequently making it easier for them to discuss sensitive issues (Bryman, 2008) and reduce any social pressure for participants to please the researcher:

Participant 8: "This is the first study... that I truly felt I could disengage/withdraw consent".

Participant 10: "I think you also feel more likely to be open via email and say things that you might not be comfortable saying face to face.... I am personally quite open and honest about my IVF treatment but it's a sensitive area.... Whereas writing it down is much easier and I guess you feel more anonymous".

Participant 16: "I was not tempted to please".

More importantly, participants found the email interactive, questions were clear, easy to follow and not too time consuming:

Participant 1: "The back and forth of email is good for follow up questions and makes the process more interactive".

Participant 22: "I felt questions were all highly relevant and can't think of any issue that was omitted".

Participant 5: "I found email very easy to follow".

Participant 7: "Didn't take long".

The problem of lack of non-verbal communication between researcher and participants, identified in the previous literature (Selwyn and Robson, 1998; Bampton and Cowton, 2002; McAuliffe, 2003; McCoyd and Kerson, 2006; Bryman, 2008; Ison, 2009), was also noted by participants in this study. Some participants felt that they were uncertain of what was expected of their response to a question:

Participant 12: "The lack of verbal cues and feedback you would have in a normal interview to try to understand what is required".

Participant 22: "I found questions too open ended and would have found it more helpful to have had prompts as to what issues I was expected to cover".

Participant 11: "I did not know what information you needed and how much depth to go to".

The use of follow up questions to clarify participants' answers introduced a risk of repetition. Some participants noted this, although acknowledged that this could be hard to avoid:

Participant 4: "There was some element of repetition which I suppose is hard to avoid but so long as you don't mind reading the same response a couple of times that isn't really a problem!"

I have employed Grounded Theory in this study and the themes are required to be elicited from the participants and repetition in participants' answers sometimes provides confirmation for the researcher. Nevertheless, careful thought must be paid to avoid prompting the same responses by asking different questions (Bryman, 2008).

With email bombarding our daily life, the researcher's emails could run the risk of being treated as 'junk mail' and being ignored by participants (Selwyn and Robson, 1998):

Participant 16: "I found it hard to notice in my many emails Sometimes anonymous is too anonymous!".

Literacy skills for participants to articulate their view in writing is important as well as the skill to use a computer (Ison, 2009):

Participant 10: "For those people who are less articulate/strong in writing especially on some abstract or emotional element e.g. humour, sarcasm etc. are difficult to put in writing".

Of course one could never expect that all participants would prefer email interviews and the personal choice of the participants must be accepted by the researcher. Finally, some participants were particularly interested in the motives behind my research and this required tactful communication whilst protecting my own researcher's privacy.

3.14 Researcher's reflection on the methodology and research design

When embarking on asynchronous email interviews, it is necessary to ensure that participants had the IT abilities and skills required. There are numerous clinics worldwide with their own websites advertising infertility services. Participants who embarked on CBRS are required to be computer literate in order to research and make contact with their chosen clinic. I concur with the literature that asynchronous email interview is an unobtrusive method that enables the researcher to engage with participants across time zones and without geographical constraints (McAuliffe, 2003). Asynchronous email interviews are not time consuming and avoid costly transcription (Selwyn and Ronson, 1998; Bampton and Cowton, 2002; McCoyd and Kerson, 2006; Bryman, 2008; Ison, 2009). Participants' text responses avoid problems of inaccuracy (i.e. mishearing or misinterpretation the audio tapes) (Bryman, 2008). As a researcher, I could send, read and reply to emails in the comfort of my own home or office at a time that was convenient to me and could accommodate other commitments. Asynchronous email interviews also enable toleration of any delay on the part of either the researcher or participant. This was evidenced to good effect when, during a period of international travel, I was caught up in the chaos which ensued following the Icelandic volcanic ash cloud in May 2011. This resulted in me being unable to access a computer for some time. However, I apologised to the participants on my return and did not lose any of them from the study as a consequence.

When considering the asynchronous email interviews, University computer technicians were consulted to avoid technical problems (McCoyd and Kerson, 2006) and the creation of a unique University email address (cbit@hud.ac.uk). This ensures anonymity, confidentiality and privacy of the participants and the researcher. I was surprised with the time and dedication required for email interviews; this required true collaboration with the participants (Bryman, 2008).

3.15 Chapter Summary

In this chapter I have explored how my research is underpinned and located within the Straussian Grounded Theory approach. I provided an overview of Glaserian/Classic Grounded Theory and Straussian Grounded Theory. I presented Hernandez's (2008)

comparison of the Glaserian Classic Grounded Theory and Straussian Grounded Theory (see Table 5); I provided my rationale and my inductive orientation in choosing the Straussian Grounded Theory approach. I have used Leininger's (1994) framework for ensuring the validity of qualitative data and detailed how each stage linked within the aims and objectives of the study. Grounded Theory data analysis was briefly described and the Voice Centred Relational Method was comprehensively examined.

This thesis focused on the role of participants who have undertaken CBRS and their associated decision-making process. The Grounded Theory approach was chosen because little is known about the experience of CBRS and participants' perspectives of the role played by clinics in this process. I am also aware that the CBRS journey may be accompanied by pitfalls and unsafe practices. This study highlighted the participants' concern and this study finding may be helpful for those embarking on the CBRS journey in the future.

This chapter provides an overview of the principles of biomedical ethics (Beauchamp and Childress, 2013) and discussed issues relating to internet research ethics. An understanding of asynchronous email interviewing data collection methodology and analysis is fundamental to critical scrutiny of conclusions drawn from the data (Silverman, 2000, Denzin and Lincoln, 2000). Research should be explicit and the process of analysis required transparency. Grounded Theory continues to guide the procedures used to collect data and the theory development is grounded in the data collected from participants. I offered the view as a researcher and made sense of the advantages and disadvantages from the participants' perspectives.

Chapters 4 to 8 of the thesis include a description of the activities involved in my 'data construction', which was the gathering of data and reflects upon the ways the participants narrate their cross border infertility treatment, which contributed to the construction of their decision-making process. Finally, chapter 9 will provide discussion and conclusion of the whole thesis.

Chapter 4 Socio-demographic profile of participants

This chapter reports the findings from the quantitative analysis of 26 participants who completed the CBRS asynchronous email interview between 1st April 2010 and 1st November 2010. The sample size was small and participants self-selected to take part in the study, thus any observations gained from this study must be treated with caution. The aim of the chapter is to highlight the demographic characteristics of the participants, their experience of treatment in their home country, their planning for cross border infertility treatment and their experiences of cross border reproductive services. The information gained will formulate the plan for the in-depth qualitative data analysis in Chapters 5 and 6.

Thirty three email responses to the initial email announcing the study were excluded from the analysis (see Table 12 below). Responses were excluded either because the response was inappropriate or indicated eligibility but the participant did not engage in this study.

Table 12: Reasons for exclusion from the analysis

Reasons for exclusion	Number (%)
Inappropriate responses	12 (36%)
Fertility service providers	3 (9%)
Soliciting/inappropriate email	2 (6%)
Seeking fertility advice	1 (3%)
Participated in the Transrep (Culley et al., 2011a) study	1 (3%)
Passed recruitment period	1(3%)
Did not have CBRS	4 (12%)
Eligible but did not engage	21 (63%)
Cannot participate due to child birth issue	1 (3%)
Found computer difficult	1 (3%)
Did not provide consent	3 (9%)
Did not reply to email interviews	16 (48%)
Total	33

Three responses were from fertility service providers. Participants were recruited via two international fertility networks' websites; I obtained two soliciting and inappropriate emails during the study period. Other reasons for exclusion included: a request for fertility advice, an inability to participate due to imminent child birth, finding email interview difficult to complete, having already participated in the 'Transnational Reproduction: An exploratory study of UK residents who travel abroad for fertility

treatment' (Transrep) study (Culley et al., 2011a), and having passed the recruitment period. Four responses were from patients who did not have CBRS and three potential participants were sent the consent form, but they failed to respond. Sixteen participants (27%) who originally expressed interest to take part did not complete all eight asynchronous email interview questions, even with numerous email requests to re-engage with the study. None of the responses from these sixteen participants were included in this study.

4.1 Demographic information of participants

Participants were asked to provide basic information relating to age, gender, sexual orientation, geographical location, ethnicity, education level, employment status, language spoken, length of relationship and number of children.

4.1.1 Age, gender and sexual orientation

The mean age of the participants was 43.35 ($SD \pm 5.549$) and age range was 32-57 years.

As there are no robust international demographic data to draw upon as a comparison to this study's demographic data, I decided to use the UK data to form a comparison. The mean age of patients seeking infertility treatment in the UK in 2008 was 35.2 years (HFEA, 2010), whereas in the survey undertaken by the ESHRE Task force (Shenfield et al., 2010), the mean age of 53 UK participants was 40.8 years ($SD \pm 5.4$). In the UK Trans-national reproduction study (Culley et al., 2011a; Culley et al., 2011b), the mean age of female participants when they received CBRS was 38.8 (range 29-46) years.

In this study, the mean age was the age when they completed the demographic questionnaire and not their age when they had CBRS. For example, two participants were 52 and 57 at the time of interview and started their CBRS 15 and 14 years previously respectively, whereas another participant who was 51 at the time of interview had started her CBRS when she was 49. This could be the reason why the mean age reported here was higher than other studies (Shenfield et al., 2010; HFEA, 2011b). Accounting for the time of interview, as in Culley et al. (2011b), this study still found a higher mean age by three years. This age profile indicated that most (81%) of the participants in this study had already had infertility treatment(s) in their home country as CBRS is not usually considered as the first treatment option unless they have very specific reasons for doing so for example, legal restriction in their home country.

In this study, the majority of participants were seeking specialised infertility treatment and only 2 participants sought standard IVF procedures (see Table 13). Most participants

(75%, N=20) were seeking third party assisted conception with egg donation (46.2%, N=12), sperm donation (11.5%, N=3) and both egg and sperm donation (19.2%, N=5).

Table 13: Types of CBRS sought by the participants

Types of CBRS		Frequency	%
	Sperm donation	3	11.5
	Egg donation	12	46.2
	Surrogacy	1	3.8
	Embryo donation	1	3.8
	Egg donation and sperm donation	5	19.2
	Other- autoimmune IVF	1	3.8
	Other -M-TESE	1	3.8
	IVF	2	7.7
	Total	26	100.0

Twenty-three participants were female and three were male. Participants were asked about their sexual orientation. The majority (69.2%, N=18) declared themselves as in a heterosexual relationship, 26.9% (N=7) declared themselves as single heterosexual and one participant declared herself as single bisexual. This finding was similar to the participants in Culley et al's. (2011b) study in which 98% (N=50) participants declared their sexual orientation as heterosexual and only one person as bisexual. Neither Culley et al. (2011b), nor this study, included homosexual participants, thus they both differed from Shenfield et al's. (2010) study, which found the combined homosexual and bisexual rate (mean rate = 9.7%) in patients seeking cross border infertility treatment was between 1.5% (Italy) to 39.2% (France). In this study, 15 female participants were in a heterosexual relationship and their mean age was 42.87 (SD±6.57) years and the age range was 32-51 years. Seven female participants were of single heterosexual orientation and their mean age was 43.57 (SD±2.99) years and the age range was 40-48 years. The mean age of the three male participants was 42.33 (SD±3.78) years and the age range was 38-45 years. Once again this was similar to the male mean age in Culley et al. (2011b), which was 41.3 (range 28-65) years. One female participant declared her sexual orientation as single bisexual and her age was 52 years.

4.1.2 Geographical location and ethnicity

In this study, 14 (53.8%) participants resided in the UK, 3 (11.5%) resided in Ireland, 1 (3.8%) resided in France, 4 (15.4%) resided in USA, 2 (7.7%) resided in Canada and one participant each from Hong Kong and Tanzania (see Table 14). Whilst this study is drawn from seven countries, the majority (92%) of the participants were White, which is similar to the Culley et al. (2011b) UK CBRS study, in which 82% of participants were White. One UK participant was of mixed race origin (Asian and White) and the participant

from Tanzania was of African origin. The participant who resided in Hong Kong was White British.

Table 14: Country of residence and ethnicity

Country of residence	Ethnic group			Total
	White	Mixed	African	
UK	13	1	0	14
USA	4	0	0	4
Canada	2	0	0	2
France	1	0	0	1
Hong Kong	1	0	0	1
Ireland	3	0	0	3
Tanzania	0	0	1	1
Total	24	1	1	26

4.1.3 Education level and employment status

In this study, the participants' education level and employment were used as proxy measures of their social economic status instead of utilising the UK NS-SEC occupational classification (i.e. Professional managerial occupations, intermediate occupations and routine and manual occupations) (ONS, 2008). The rationale for not using the UK NS-SEC classification was due to the fact that international participants were recruited in this study. Countries such as the USA and Canada tend to use income, education and ethnicity as proxy measures for socioeconomic status (Williams and Collins, 1995) and most occupation classifications were developed and validated on working men (Shavers, 2007). Additionally, since most of the participants in this study were female, UK NS-SEC occupational classifications might not be a valid measure for these participants.

Regarding the education levels of the participants (see Table 15), the majority (65.4%, N=17) held a postgraduate qualification and most of these (94%, N=16) were in employment, 26.9% (N=7) had an undergraduate degree and once again most of these (71%, N=5) were in employment. Only two participants were at home to look after their family. Two (7.7%) participants had post-sixteen qualifications and both of these were in employment.

Table 15: Education attainment and employment status

Education Level		Employment status				Total
		Employed or self-employed	Looking after home and family	Other	Part time employment	
	Post 16 education	2	0	0	0	2
	Degree	4	2	0	1	7
	Postgraduate qualification	14	0	1	2	17
Total		20	2	1	3	26

Culley et al. (2011b) found that 38% (N=19) participants had a postgraduate qualification, 31% (N=16) had an undergraduate degree and 31% (N=16) had a post-16 qualification. This might indicate that the education attainment of participants in this study was higher than those in Culley et al. (2011b). Interestingly, the numbers of participants who look after home and family were similar; in the study by Culley et al. (2011b) three participants were full-time parents compared to two in this study. In Culley et al. (2011b) and this study it was found that infertility patients who undertake CBRS tend to be very well educated; more so than their peers in the general population.

4.1.4 Language spoken

All participants could communicate in English since this was an eligibility criterion for participation in the study. The majority (76.9%) of the participants could utilise at least two languages, including French (54%, N=14), Spanish (23%, N=6), German (12%, N=3), Russian (12%, N=3), Italian (8%, N=2), Irish (8%, N=2), Chinese (4%, N=1), Swahili (4%, N=1) and Polish (4%, N=1). One participant could utilise five languages, four participants could speak four languages; two participants could speak three languages. In this study, none of the participants who could speak Spanish sought CBRS in Spain. Interestingly, of the three participants who could speak Russian, one attended a clinic in the Czech Republic and the other attended a clinic in Ukraine. There was no correlation between the language spoken and the participants' CBRS destination, this could be accounted for by the small sample size of this study. Due to the universality of English, CBRS services in destination countries are probably reasonably proficient in English (or claim to be) and the use of English language is used as a marketing strategy to attract overseas patients.

4.1.5 Length of relationship

Participants were asked about the length of their relationship. The mean duration of the relationship declared by the majority (94%, N=17) who stated that they were in a heterosexual relationship was 11.82 years (SD±6.2) and ranged from 2-30 years, thus suggesting that most of the participants were in a long term relationship with their partner. One female participant who was currently single and who declared her sexual

orientation as heterosexual reported a previous partnership of thirteen years' duration, although it had ended at the time of her participation in the study.

4.1.6 Number of children

When asked if participants had children, 57.7% (N=15) (see Table 16) did have children and 42% (N=11) did not have children although of the latter one was expecting her child (38 weeks pregnant) during the time of the interview. This indicated that 16 participants were successful in having either a live birth or well established pregnancy at the time of taking part in the study. This finding is similar to the patients' pregnancy rate in Culley et al. (2011b)'s study, which was 51% (N=26). HFEA (2011b) reported the overall live birth rate per cycle between 2009 and 2010 was 24.5%. In the current study, almost two-thirds of participants sought third party infertility treatment with egg donation (65%, N=17), I therefore compared the egg donation live birth rate as reported by the UK HFEA, which was 26.8% (512/1908). This suggested that cross border infertility treatment could result in a higher live birth rate for third party assisted conception treatment.

Table 16: Number of children and their age

Participant number	Number of children	Age of child
Participant 1	1	Under 12 months
Participant 2	Twins	Under 12 months
Participant 4	1	1 year
Participant 7	3 (including twins)	4, 4, 2
Participant 9	1	Under 12 months
Participant 11	3 (including twins)	9, under 12 months, under 12 months
Participant 12	2	9,2
Participant 16	2	ages not provided
Participant 17	1	6
Participant 19	1	age not provided
Participant 20	Twins	9
Participant 21	2	2,4
Participant 22	1	Under 12 months
Participant 25	1	12
Participant 26	1	age not provided

For those who had children, eight participants had one child, five participants had two children and two participants had three children (see Table 16, see above). Participants provided information about the ages of 20 children. Five participants had children under 1 year old and there were four set of twins (multiple birth rate = 15.4%). The HFEA (2011b) reported multiple birth rates for women of all ages as 20.6% and aged 40-42

was 16%. This indicated that cross border fertility treatment undertaken by these participants has not necessarily had a higher multiple rates when compared to treatment at home. Most of the participants (55%) who participated in the study had recent cross border reproductive treatment. Six (23%) participants had experienced more than one pregnancy from treatment abroad.

4.2 Experience of treatment at home

4.2.1 Treatment cycles at home

Before embarking upon CBRS, 21(81%) participants had treatment in their home country. Five participants did not have any treatment in their home country. Of these five participants, one had Mayer Rokitansky Kuster Hauser Syndrome (MRKH), where the vagina and uterus might be underdeveloped or absent, therefore surrogacy is the participant's only option. Unfortunately, surrogacy is illegal in the participant's home country (France); therefore the participant could only enter into a surrogacy arrangement by travelling abroad. Another participant, a single woman, travelled abroad for infertility treatment because the country in which she lived, Hong Kong, forbids infertility treatment for single women. Two participants required third party assisted conception and long waiting times encouraged them to seek CBRS. The participant from Tanzania had investigation for infertility at home; however she was not confident to have infertility treatment in her home country and thus embarked on CBRS.

Of the twenty one participants who had previous treatment in their home country (see Table 18 below), the mean number of infertility treatment cycles was 3.71 (SD±2.28), ranging from 1 to 10 treatment cycles. Seven participants had three cycles in their home country prior to seeking CBRS.

Table 17 Number of infertility treatment cycles in home country

No. of cycles	No. of participants	%
0	5	19.2
1	3	11.5
2	3	11.5
3	7	26.9
4	1	3.8
5	4	15.4
6	1	3.8
8	1	3.8
10	1	3.8
Total	26	100.0

Of the fourteen UK participants, twelve provided information about the number of treatment cycles they had had in the UK; the mean number of treatment cycles prior to embarking on CBRS was 3.167 (SD ±1.58) (ranging from 1 to 6 cycles). The mean number of treatment cycles for the four participants from the USA was 4.25 (SD±2.5)

(ranging from three to eight cycles) before undertaking treatment in a different country. Two participants from Ireland reported that they had each undergone five treatment cycles at home prior to CBRS, while the third participant from Ireland did not indicate how many treatment cycles she had at home. For the Canadian participants, one had ten cycles and the other had two cycles before embarking on CBRS. As these results indicate, the majority of participants had undergone a considerable number of treatment cycles at home before seeking CBRS.

4.2.2 Cost of treatment at home

This study asked the participants to recall the cost of treatment at home. One needs to acknowledge that some of the participants had been trying for a family for a long period of time; therefore the cost for infertility treatment might not correlate with the current cost of infertility treatment in their home country. Fourteen participants were from the UK and twelve participants provided the cost of infertility treatment that ranged from £2,000 to £9,500 per treatment cycle. On average they spent £16,833 (SD \pm 12,624) prior to contemplating CBRS. Four participants were from the USA, where the cost per infertility treatment ranged from \$12,000 to \$50,000. On average, the USA participants' expenditure on infertility treatment at home was \$16,833 (SD \pm 12,624). Three participants were from Ireland, the average cost for their infertility at home was €3,100 (SD \pm 1272.7922). A number of participants had spent a considerable amount of money whilst seeking infertility treatment in their home country.

4.3 Reason for cross border infertility treatment

This study found the participants' decision for international travel for reproductive services were diverse and complex, as also evidenced by Bergmann (2011a) and Culley et al. (2011b). Most (77%, N=20) participants provided more than one reason for travelling abroad for infertility treatment. The full range of reasons described by participants is detailed in Table 18 below.

Table 18: Reasons for cross border reproductive services

Reasons	Number
Shortage of egg donors	12
Failed treatment at home	10
Long waiting list for donated gametes	9
Cost	8
Dissatisfaction with treatment at home	6
Donor choice / donor identity	3
Genetic issues	3
Success rate abroad	3
Illegal at home	2
Participants' age	2
Single women	2
Enjoy travel	2

Shortage of donor gametes (in particular donor eggs) causing longer waiting lists, treatment failure at home, cost of treatment and dissatisfaction with treatment at home were the most frequently mentioned reasons for seeking cross border reproductive services. Culley et al. (2011b) suggested that these reasons could be associated with the way clinics organise patients' treatment requests by putting them on a waiting list. Hamilton and Pacey (2008) argued that there has been a long term shortage of gamete donors. Since 1990, donors in the UK have been required to register with the Human Fertilisation and Embryology Authority; subsequently many clinics have reported a shortage of donors. This could be due to potential donors' concerns about the removal of their anonymity (Lui et al., 1995). There has also been an increase in a shortage of gamete donors due to an increase in the demand for egg donation treatment.

Participants' desire for timely treatment using third partner donation (e.g. egg donation) was evident in this study; however, this was not the only reason for seeking CBRS. Multiple failed cycles, which might have triggered some dissatisfaction with clinics in the participants' home country, could have driven the participants to seek infertility treatment elsewhere. Participants, therefore, reported that success rates overseas were also an important consideration when deciding for CBRS.

Cost of treatment at home was highlighted as an important reason for the participants when deciding on CBRS. In the USA, some participants were able to obtain health insurance to offset part of the cost of investigation of their fertility difficulties; however, in most cases the cost of infertility treatment was not covered by health insurance. Participants did not mention the specific cost of medications, although these could be additional to the cost of the treatment.

Other reasons highlighted by the participants were donor choice, participants' age and marital status, treatment availabilities for example, participants' personal genetic issues that required specific treatment, which was not available at home (i.e. surrogacy and egg donation were not available in Canada). In this study, two participants travelled abroad for reproductive services to avoid restrictive legislation at home; this was not found in Culley et al.'s (2011b) study. However, Shenfield et al.'s (2010) study found the majority of Italian patients seeking treatment in Switzerland or Spain did so to overcome home country restrictions. Two participants felt CBRS could be combined with their enjoyment for travelling overseas. One participant from the USA considered international adoption and adoption at home; however due her age, this was not a viable option for her.

4.4 Organisation and management for CBRS

4.4.1 Planning for CBRS treatment

Participants described a number of ways in which they planned for their cross border reproductive treatment (see Table 19). A substantial number of participants explored the internet and websites to seek out overseas infertility information (i.e. health professional qualifications and success rates). Internet and clinics' support groups (both in their home country or international infertility networks) were also able to provide specific information on clinics. Advice from health professionals (e.g. doctors and nurses) was also highlighted by participants in the planning stage of their CBRS even though they might not have direct involvement with the overseas infertility clinic (e.g. in the case of the participant from Hong Kong, her doctor in Hong Kong could not be directly involved in her treatment overseas due to legal reasons). Culley et al. (2011b) identified forms of assistance offered by fertility services in the home country for patients undergoing CBRS that included ultrasound scans and in some cases also included provision of medication. Two participants from the UK embarked on 'shared care' with clinics at home and overseas. In these cases, the clinics in the UK participated fully in the cross border reproductive process (including travel arrangements). For those participants who were in a heterosexual relationship (n=18), five participants mentioned they jointly organised and planned for CBRS journeys. The male partner may be not required for treatment purposes however, most opted to accompany their partner in order to provide emotional and practical support.

Other channels to help the participants in planning for their cross border infertility treatment were agencies/brokers, personal friends and friends with fertility problems. Travel access and logistics were also considered carefully by the participants. Only one participant could plan their cross border infertility treatment event with her family (sister and parent) and one participant attended an infertility trade fair in London. Infertility shows are an emerging phenomenon, which provide a forum for infertility patients to learn more about overseas clinics (Routes to Parenthood, 2015). The UK Fertility Show started in 2009 and is held annually in London by an established UK exhibition company. Exhibitors include UK and international infertility clinics, online pharmaceutical companies, alternative therapies and adoption agencies.

Table 19: Planning for cross border reproductive service

Organisation for CBRS	Number
Websites	16
Support group	9
Doctor	8
Clinics	7
Partner	5
Agency	4
Friends with fertility problems	4
Personal friends	3
Travel access / logistic	2
Family	1
Trade show	1

4.4.2 Support for CBRS treatment

Support during participants' infertility treatment is of vital importance no matter whether they had treatment at home or overseas (see Table 20). The sources of support were predominantly from an infertility support group, which could be accessed from clinics or internet websites. Of those participants who were in a heterosexual relationship (N=18), 11 mentioned their partners played a supportive role during their CBRS journey. Friends and family, including friends with fertility problems, were also important in supporting the participants. However, neither of the two single heterosexual participants said that their family provided support during their cross border infertility treatment.

Even though they might not be directly involved with the participants' treatment, doctors and clinics were still mentioned by some participants as a source of support. As mentioned above, these could be in the form of ultrasound scans or provision of medication (Culley et al., 2011b). A number of participants had medical problems when returning home (e.g. ectopic pregnancy, evacuation of retained products of conception (ERPC) and miscarriages); their doctor would therefore support the participants by making a speedy referral in an effort to resolve these issues.

Table 20: Provision of Support during CBRS

Support	Number
Support group	13
Partner	11
Website	11
Family	10
Friend	10
Doctor	6
Friends with fertility problems	5
Clinic	4
Agency	1

4.5 Cross Border Reproductive Services

4.5.1 Destination countries for CBRS

Participants travelled to a wide range of countries. The bar chart below shows the actual CBRS destinations. In this study, the most popular destinations were Spain (N=8), USA (N=7) and the Czech Republic (N=3) (see Figure 4), this finding is similar to those of Culley et al. (2011b) and Shenfield et al. (2010).

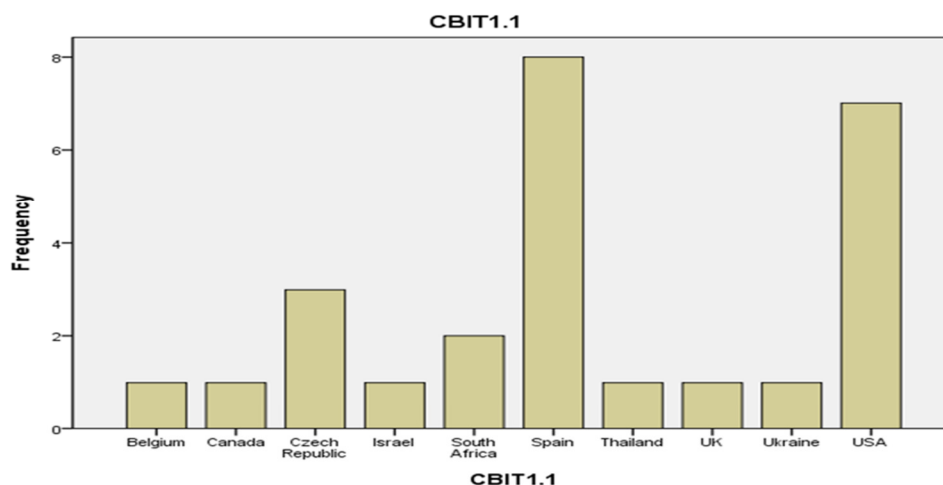


Figure 4: Destination countries for CBRS

Of the 14 UK participants, four travelled to the USA, five to Spain, two to the Czech Republic and one each travelled to Israel, Canada and Belgium for their CBRS. Of the four USA participants, one travelled to each of the Ukraine, Spain, South Africa and the Czech Republic for their overseas treatments. One participant from Ireland travelled to the UK and two travelled to Spain. The participant from France and both Canadian participants travelled to the USA. The participant from Hong Kong travelled to Thailand and the participant from Tanzania travelled to South Africa.

There is no single pattern one could deduce from the participants' home countries to the participants' destinations for cross border infertility treatment. Proximity to the cross border infertility service could have some influence on the participants' choice of their overseas destination (e.g. two Canadians travelled to the USA for their treatment, the Irish participants went to the UK and Spain, the participant from Tanzania went to South Africa and the participant who lived in Hong Kong went to Thailand), this will be explored further in Chapters 5 and 6. Due to the small sample size of this study, this could not be conclusive. However, this could be considered alongside similar findings from studies conducted by Shenfield et al. (2010), Culley et al. (2011b) and Blyth (2010).

Other factors could also affect the participants' decision regarding their choice of destination country:

1. The participants' ethnic origin or family connection to the destination country could have an influence on the CBRS destination. The sole Jewish participant travelled to Israel for treatment, whereas one participant living in the USA whose parents were from Ukraine chose Ukraine for her treatment
2. Advanced treatments: Seven participants (4 UK, 2 Canada and 1 France) travelled to the USA. The participants who chose the USA for treatments mainly related to specific advanced treatment (e.g. micro-dissection testicular sperm extraction (MTESE)), egg donation (e.g. more information relating to donors' identity) or surrogacy.

These will be examined further in the qualitative data analysis in Chapters 5 and 6.

Four participants had repeated cycles of cross border infertility treatments. One participant had three cycles of treatment in the Czech Republic and one participant had two cycles in South Africa. One participant had two failed cycles in Spain (Barcelona and Madrid) and then switched to having treatment in the Czech Republic. One participant had one cycle in Spain and also changed to having treatment in the Czech Republic. This suggests some participants might change their destination for their overseas treatments. In Chapters 5 and 6, I will discuss in more detail the reasons behind the participants' decisions to identify an alternative destination for their treatment.

4.5.2 Cost of CBRS

This study asked participants to recall the cost of their cross border infertility treatment. A cautionary note should be placed upon the limitations of this cost information as the participants were recalling treatment cost over a wide time scale, therefore time alone could have had an impact upon the absolute cost and cost differentials. Most participants were unsure of the actual amount they had spent on their CBRS and did not report the miscellaneous costs separately (i.e. drug cost, travel cost, accommodation cost whilst abroad). Twenty one participants provided an estimate of the cost of their cross border infertility treatments; however, they did not report their treatment cost per cycle.

Eleven UK participants reported total expenditure for their cross border infertility treatments, four went to the USA and their average total spend was £26,750; five went to Spain and four participants reported average total costs of £6,245. Two went to the Czech Republic; one was unsure about her expenditure, however the other participants who went to the Czech Republic said the cost for infertility treatment was £1,000.

Four participants from the USA estimated their average total cross border infertility treatment expenditure was \$15,200. Three participants from Ireland reported their total average spending as €7,667. The participant from Tanzania spent US\$7,000 for her treatment in South Africa, whereas the Hong Kong participant spent £3,000 in Thailand.

The costs above, once again, indicate that the participants had spent a considerable amount of money for their cross border infertility treatments.

4.5.3 Number of embryos transferred in a single IVF treatment cycle

Twelve participants reported the number of embryos transferred during their treatment cycles. Ten (77%) of these had two embryos transferred in a single cycle. One participant, who had three treatment cycles in the Ukraine, had two embryos transferred in her first two unsuccessful cycles and requested that three embryos be transferred in her third cycle. The clinic agreed to this after requesting that the participant sign a waiver, as this is contrary to the normal clinic practice of transferring no more than 2 embryos per cycle. One participant travelled from France to the USA and another participant travelled from the USA to South Africa, both had three embryos transferred. One participant from the UK travelled to the Czech Republic and requested that four embryos be transferred, although this request was declined by the clinician.

This pattern of embryo transfer was comparable to that reported in the UK (HFEA, 2011b), where two embryos (60.2%) was still the most likely number to be transferred in each IVF cycle and only 4.3% involved the transfer of three embryos.

4.5.4 Issues raised during and after CBRS

A variety of issues were described by the participants either during, or after, their cross border infertility treatment (see Table 21). Eleven participants clearly stated that they had no communication issues whilst seeking CBRS. However, two participants from the USA and Ireland reported language problems; both of these had treatment in Barcelona, Spain. One UK participant had treatment in the USA and she reported jargon used by her clinic. This study, therefore found communication and language differences were a significant concern for some participants, as also observed by Culley et al. (2011b).

Three participants were frustrated by the service provided by their overseas clinics. Participants reported their frustration relating to clinic closure, staff availability over holiday periods and staff changes, dignity and respect due to cultural differences (i.e. open doors during embryo transfer or embryo transfer undertaken on a public ward) and general unfamiliarity with the overseas healthcare system. Two participants were requested to drink water in order to achieve a full bladder during the embryo transfer procedure, which caused them pain and distress, a procedure which is not always

required or recommended for clinical reasons. Unexplained delays in undergoing embryo transfer were also reported by one participant. Some participants had difficulties in finding their overseas clinic and turned up at an incorrect address. Identifiable post was sent to a participant's home address even though (s)he had given instructions to mail communications to an alternative address.

Participants also faced logistical problems during their overseas treatment. Two participants had to abandon their travel due to cancellation of their treatment cycles, whereas another participant had to organise travel at very short notice to an overseas clinic when eggs became available for them at the last minute. One participant had her credit card stolen whilst overseas and another participant left cash behind in her overseas accommodation.

One participant developed fibroids and polyps and another developed an ovarian cyst during their treatment cycles. Three participants required urgent medical treatment after their treatment abroad (i.e. Evacuation of Retained Products of Conception (ERPC), miscarriage and ectopic pregnancy). As suggested by Sher et al. (1994), aspirin treatment was found to encourage the growth of the endometrial lining. One participant who travelled to Spain for her infertility treatment was prescribed aspirin to encourage the growth of her endometrium, although this caused her to suffer severe bruising.

Finally, one French participant had surrogacy in the USA and at the time of interview was still attempting to resolve the child's legal status in France.

Table 21: Problems faced by participants during and after their CBRS

Issues	Number
Language	
No communication problem	11
Language problem	2
USA Jargon	1
CBRS services	
Poor service	3
Clinic closure and staff availability	2
Difficulty finding clinic or turning up at the wrong clinic	2
ET delay	1
Full bladder	2
Public ward (i.e. lack of privacy)	1
Postal issues	1
CBRS logistics	
Flight cancellation or last minute booking	3
Monetary issue (stolen credit card/cash left behind)	2

Medical problems	
Fibroids + polyps+ Cyst	2
ERPC	1
Miscarriage and ectopic pregnancy	2
Aspirin treatment	1
Legal status of offspring	1

4.5.5 Experience of CBRS

The experiences reported by the participants were broadly positive as in Culley et al. (2011b) (see Table 22 below). Nine participants rated their cross border infertility as excellent, 14 rated it as good. Only two participants rated their cross border infertility treatment as poor; one of these attended a clinic in the USA and the other attended a clinic in Spain.

Table 22: General experiences of CBRS

		Number	%
	Excellent	9	34.6
	Good	14	53.8
	Satisfactory	1	3.8
	Poor	2	7.7
	Total	26	100.0

4.6 Commentary on these findings

The outcomes illustrated in this chapter highlight the participants' demographic characteristics, their infertility experiences in their home country, planning strategies and finally their experiences of CBRS. Due to the sample size and the self-selected nature of participants, it cannot be assumed that the findings generated from this study can be generalised to all people who had CBRS and should be treated with caution. However, the knowledge gained from the above findings could contribute to contemporary understanding of CBRS.

As detailed previously, a number of limitations must be noted regarding the data highlighted in this chapter. Firstly, when questioning the age of the participants, it might be better to ask for the age of the participants when they first embarked on their CBRS journey. Secondly, when enquiring about treatment in the participants' home country, one might want to question if they had health insurance to cover their infertility treatment and in the case of UK participants if they had NHS paid infertility treatment cycles. I have chosen length of relationship as an indicator of relationship stability rather than marital status. Future studies might benefit by including the above variables as this would be able to obtain a more comprehensive picture and understanding of the CBRS phenomenon.

4.7 Chapter Summary

This chapter presented findings challenging some of the media portrayals of those seeking cross border infertility treatments (e.g. older women seeking infertility treatment in India, homosexuals/celebrities seeking surrogacy). The ages of participants in this study are similar to those seeking treatment in the UK and the multiple live birth rate was similar to the findings by Culley et al. (2011b). Most participants received treatment in their home country prior to their CBRS journey, often after many unsuccessful treatment cycles and having spent a considerable amount of money in their home country. Most participants reported broadly positive experiences of their cross border infertility treatment; however, there were some related issues (i.e. language barrier and embryo transfer delay) during, and after, their cross border infertility journey. This chapter illustrated that the cross border reproductive treatment process is complex. In the next chapter, qualitative data from the study are analysed utilising the Voice Centre Relational Method and 'I' poems are generated to illustrate the individual participants' motivation for, and experiences of, CBRS.

Chapter 5 CBRS adapted “I” poems findings

In this chapter, I will present the individual narrative account of the participants’ experiences prior to, during, and after, their CBRS utilising an adapted version of the VCRM/‘I’ poem approach (Brown and Gilligan, 1992b; Mauthner and Doucet, 1998; Gilligan et al., 2003) as discussed previously in Chapter 3. VCRM allows the researcher to actively hear the participants’ individual autobiographical account for their CBRS journey. This involves four stages (Stage 1: relational and reflexively constituted narratives; Stage 2: tracing narrative subjects; Stage 3: reading for relational narrated subjects and Stage 4: Reading for structured subjects) of reading the transcripts. VCRM is a feminist approach used to express women’s feeling in the first person. As a male researcher and as some of the participants were also male, I sought advice from Prof. Ruth Deery, University of West of Scotland, an expert in the use of VCRM; she suggested the use of third person narrative and this could highlight the rich textual narrative from the interviews.

Nine participants’ ‘I’ poems were selected as their journeys were individual yet intricately linked by their motivation to seek CBRS. This chapter offers the individual voice of the participants and charts their individual story as their journeys unfold.

5.1 Case studies selection

Twenty six participants’ chronicles are worth including in the case studies, however logistically I could not include all of these. I have used the participants’ own words wherever possible and appropriate, indicated by the use of quotation marks, in the attempt to remain close to the narration provided by the participants.

The criteria for selecting participants’ included in the ‘I’ poems were (see Table 23):

- 1) Country of destination: this enabled me to highlight the difference in the location (e.g. Ukraine, the Czech Republic, South Africa, Spain, Israel, Thailand and the USA) and their provision of CBRS
- 2) Types of treatments: this captured the different sorts of treatment types (i.e. standard IVF treatment, donor insemination (DI), egg donation (ED), both sperm and egg donation and surrogacy) sought by the participants
- 3) Complexity of the CBRS experience: the nine stories were selected for their complex stories for example, participant 3 had multiple treatments both in Spain and the Czech Republic and participant 20 experienced legal issues resulting from an international surrogacy arrangement that remained unresolved at the completion of the study.

Table 23: The participants' characteristics including outcomes for the 'I' poem

Participant	Rationale for selection	Outcome
1	Participant is a single woman and travelled from the USA to Ukraine for DI	1 child
3	Participant is a single woman who travelled from the Republic of Ireland to Spain and the Czech Republic for egg and DI	No children
10	Participant is a single woman who travelled from the UK to the Czech Republic for egg and sperm donation	No children
14	Participant is from Tanzania and sought IVF in South Africa	No children
17	Participant resided in the USA and travelled to Spain for egg donation	1 child
20	Participant's wife had Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome. The couple travelled from France to the USA for surrogacy	Twin daughters
23	Participant is a single woman, lives in Hong Kong and sought DI in Thailand	No children
24	Participant travelled from the UK to a shared care clinic in the USA for egg donation	Pregnant
25	Participant travelled from the UK to Israel for egg donation.	1 child

The decision not to include the remaining seventeen participants in the 'I' poem analysis was made where treatment destinations and treatment types were duplicated (see Table 24 below).

Table 24: The participants' characteristics excluded from the 'I' poem

Participant	Rationale for exclusion
2	Participant resided in Canada and sought egg donation in the USA
4	Participant travelled from the Republic of Ireland to the UK for treatment
5	Participant lived in the UK and travelled to Belgium for donor insemination
6	Participant lived in the UK and travelled to Canada for egg donation
7	Participant resided in the UK and his wife had egg donation in the USA
8	Participant resided in Canada and his wife went to the USA for egg donation
9	Participant from the Republic of Ireland travelled to Spain for egg donation
11	Participant resided in the UK and travelled to Spain for egg donation
12	Participant from the UK travelled to the USA for m-TESE
13	UK participant travelled to the Czech Republic for egg and sperm donation
15	Participant from the USA had IVF in the Czech Republic
16	Single participant from the UK had sperm donation from the USA
18	Single participant from the UK sought egg and sperm donation from Spain
19	Participant travelled from the UK to Spain for egg donation

21	Participant travelled from the UK to Spain for egg donation
22	Participant travelled from the UK to Spain for egg donation
26	Participant from the USA had egg and sperm donation from South Africa.

5.2 Construction of 'I' poems

As described in Chapter 2, VCRM or 'I' poem was adapted as a method of data analysis as this would enable the participants to narrate their own individual CBRS story/journey. I read the whole transcripts for each participant and reflected on their recounted journey. I found their experience both enlightening and, at the same time, distressing to read. I isolated all the active words relating to the participants ('I') or the participants as a couple ('We'). As each participant's story unfolded, the series of events could be placed in chronological order. The following stories of each participant are presented below and the actual email texts sent by the participants are encapsulated in quotation marks, all punctuation (e.g.!) including some grammatical errors (to demonstrate authenticity of the participant's text) and the use of capital letters is as they appear in the original emails.

5.3 Participant 1

Participant 1 was in a heterosexual relationship and had numerous cycles in her home country (USA). She had a good relationship with her endocrinologist; however, she did not have confidence in her local infertility doctor. After failed cycles with her partner their relationship ceased. She continued to seek infertility treatment as a single woman despite not having insurance cover for any treatment. As participant 1 "ha[d] to travel ANYWAY" because there were "no providers of donor eggtreatment where I live" she decided to look at CBRS. Participant 1 considered many potential countries: "Cyprus, Spain, the Czech Republic, Ukraine, South Africa or Argentina". She chose: "Ukraine as my father's family is originally from Eastern Europe".

Participant 1 knows what she wants from the clinic: "Very good success rate" and ethical treatment of egg donors. She researched the clinic and spoke with other women who had had treatment from the clinic and checked "affiliations, the education, publications" of the staff from the clinic. Participant 1 planned her treatment around "work holiday and flight schedule....".

She found L "a beautiful city" and communicated with the staff in the clinic. Participant 1 was surprised to realise that she was "the only foreigner at the clinic", "the uniform" (clinical nursing uniform wore by staff) and the need to bring her "own nightgown for the procedure". Participant 1's taxi was delayed, which made her late for her appointment. Participant 1 praised the embryologist performing her embryo transfer procedure

reporting that the staff in the clinic acted professionally toward her needs: "She did not tell me to relax or just breathe and continue to try with the standard size (speculum). She went and got a different size and the rest of the transfer was completed without a hitch".

Participant 1 left cash at the accommodation where she stayed while she was having treatment, the owner arranged prompt transfer of the money back to her.

Participant 1 had three attempts (1st attempt: failed, 2nd attempt: ectopic pregnancy, 3rd attempt: successful) with the clinic in Ukraine. She felt supported by the clinic following the failed cycles "staff were very compassionate and emailed me their condolences". When the cycle was successful, participant 1 had constant worry during her pregnancy: "I keep waiting to miscarry, to have something bad to happen".

She found counselling particularly helpful for her "struggle with infertility" and "I would recommend it".

Participant 1 would like to see the introduction of "best practice guidance for standard of care" both for her home country (USA) and overseas clinics. Participant 1's decision to have CBRS was "largely an economic decision" and felt CBRS "is still expensive" for her.

5.4 Participant 3

Participant 3 is a single woman living in Ireland with a "very supportive" family. She was diagnosed with an early "menopause" when she was "34/35". The doctor in Ireland offered no assistance towards her infertility treatment and also questioned her motives to have a child as a single woman, asking her: "What do you want to do that for?" As a result of this attitude, participant 3 knew that she would need to travel overseas to gain treatment "due to the fact that there are no donor embryos available in Ireland".

She researched via the internet, attended a donor network conference and visited a number of countries including: "Moscow, Czech Republic, Spain (M and B)". Participant 3 did not provide reasons for not having treatment in Moscow. She "learned a lot of information regarding overseas clinics and their reputation" at the donor network conference and "selected the clinics based on the recommendations of" infertility network members. Participant 3 had counselling in Ireland, which was "a great help in making the whole process 'normal'" for her whilst acknowledging counselling by overseas clinics might not be practical: "If you are using cross border treatment you would not be able to attend regularly for a counsellor to get a handle on the concerns of the patient." She felt the record keeping in Spain "would be more comprehensive and secure" and has "more confidence in a European country". She felt that the cost for CBRS "is considerably lower abroad", she will "eventually conceive" and "had a choice!" for her

treatments.

Participant 3 went through numerous treatment cycles in various European clinics and felt like she “was just a cash machine”. She independently planned for her numerous unsuccessful attempts. Her current attempt was set up by a clinic in Ireland and a clinic in a large Spanish city, M.

Participant 3 had treatment in a large city B in Spain. This “took two visits lasting in total no more than one hour...you were out of the street heading for a taxi”. The clinic “gave donor information to” the participant’s “travelling companion” whilst the participant was having the embryo transfer procedure, which angered the participant. When the “English speaking liaison person left”, the participant’s treatment “fell apart” with “no follow up”; “you were very much on your own”. Participant 3 “had reason to phone the clinic over the Christmas holiday to check her medication post-embryo transfer” however “there was nobody” who could speak English and “the answering machine message was only in Spanish as well”. Participant 3 felt “very frustrated” and “alone”. Participant 3 “asked the clinic “not to send identifiable post” to her home address” and “on three occasions” they sent identifiable post to her home. She sensed that “the clinic had the money and it was not in their interest to contact you – conveyor belt”. The participant heard from others that “the clinic has got too busy to care, it’s all about money and their statistics on successful outcomes are skewed as they do not record a lot of unsuccessful treatments”.

The participant had a similar experience in a clinic in the Czech Republic:

“Communication was limited to one online email that could be ambiguous at times”. Once again, “visits took less than one hour”, participant 3 “expected to meet the doctor” however, she “was brought into a room and the procedure was done without actually seeing people’s faces as they were gowned up”, which was “a bit scary” for the participant. There was some confusion from the clinic regarding her pregnancy test result, which was “devastating” and she “never heard from clinic again”. Participant’s experiences of the “staff are efficient but not the warmest personalities”.

Participant 3 also had treatment in a clinic in a large city M in Spain. The cost for her treatment “was exactly double” compared to treatment at home, however she decided she “needed to have someone monitoring” her preparation as she had a number of failed cycles. The clinic “has been very much in contact with the participant in every aspect” of her treatment, which reassured her and the clinic had met her expectations. “The doctor is from the USA” thus “there were no issues and emails are answered directly by the doctor on a daily basis”. “Clinic website was mainly in English however, the success rate and costs page were only in Spanish”.

Participant 3 took on board that “the donors are screened” by clinics and did not have concerns regarding HIV.

Participant 3 “instinctively knew” if she was pregnant or not, however she “always braced herself with a negative result”. After negative results the participant had uncontrollable sadness and guilt whilst having “to go to work and behave as normal”. Participant 3 believes that she “got pregnant twice” from her numerous attempts. She had Pneumonia and a miscarriage following one attempt. A doctor prescribed “a very high dose of aspirin...10mg of aspirin daily”, which caused severe bruising.



Figure 5: Participant's bruising after using high dose aspirin *

*Participant 3 sent this photograph showing her bruising following treatment in Spain and gave permission to use it in this thesis. She said the actual bruising was “worse in reality”.

Participant 3 accepts “whatever service is available” to overcome her childlessness. The decisions to undertake CBRS “were never based on cost”; however, she found herself “becoming increasing Financially Challenged!!!”.

Even with numerous failed cycles and a number of concerns, Participant 3 still regards her CBRS experience as “very positive” and if she had known “how easy the process was, I would have done it 4 years ago”.

5.5 Participant 10

Participant 10 is a single woman living in the UK and had investigations with her doctor. Participant’s doctor directed her to the HFEA and provided her with a list of fertility clinics.

The nearest clinic to her “does not treat single women”, so she was “forced” to seek treatment from a London clinic, which had “a large donor bank”, short waiting list and “seemed very experienced in treating single women”. Participant 10 felt that she was

naive in thinking her "only problem was lack of sperm and that she would fairly quickly become pregnant". After three failed donor insemination treatments, her consultant recommended IVF. Participant 10 considered her own age, success rate and was "keen to give herself the best possible chance of pregnancy" and, therefore, agreed to IVF. Participant 10 had two IVF cycles, both of which bled early after embryo transfer. She had one cycle of frozen embryo transfer, "based on her own research via Fertility Forum"; she requested injectable progesterone, which resulted in a positive pregnancy for a number of weeks. Unfortunately at eight weeks "the pregnancy was declared unviable" and Participant 10 required a procedure for evacuation of retained products of her pregnancy. Participant 10 had follow up appointments with her consultant each time and the advice was "bad luck", which she found "very frustrating to keep being told it was simply bad luck". At this point, Participant 10 felt "treatment in the UK is extremely expensive and questioned the value for money" and the "clinic seemed to offer a one size fits all standard protocol with little attempt to tailor to specific patients".

Participant 10 also had egg donation and donor insemination in her home country. She put herself on the waiting list in two London clinics. She had previously had treatment in Clinic L, whereas Clinic C was "recommended by other women in a similar position". In Clinic C, she was required to see a counsellor and went through the ethics committee, both "at significant cost to" her. Participant 10 felt "very angry" and judged by the whole process. Clinic L "found the donor first and the whole cycle was a disaster from start to finish"; she experienced very poor communication, felt "no one seemed to know the full story" and "spent in the region of £7-8000". Participant 10 "raised concerns with her consultant" and was promised better communication for her next cycle. She went ahead with another shared egg donation and donor insemination cycle, "the cycle was negative". Once again, the consultant told her it was just 'bad luck'. By now, she was beginning to "wonder just how much bad luck one person can have". She expressed concerns about "egg share cycles in the UK" with the "age of the donor tending to be older" and the potential for cancelled or poor responsive cycle is higher. The Consultant in Clinic L shared her sentiment and said she "would probably" pursue egg donation abroad if she was in the participant's position.

By this time, Participant 10 "was fed up" with her UK clinics and decided to explore her options for clinics abroad. The UK clinic "played no role in helping" her identify a suitable clinic abroad; however it "did offer help on an ad hoc basis...in terms of scans...at a cost". Participant 10 also saw a consultant immunologist and he supported her with her medication needs when she sought CBRS.

Participant 10 found some infertility networks are "less positive about overseas treatment and try to sway you towards UK treatment", nonetheless she had read "very good reports and recommendations for a clinic in the Czech Republic on a Fertility Forum" and met women who had treatment from the clinic in the Czech Republic. She felt meeting with these women "was more than just virtual recommendations... benefitted hugely from their experience and recommendations" and "the costs of treatment were so competitive compared to the UK". Participant 10 has "lots of Air Miles" to offset her travel costs as she "travels regularly for work".

Participant 10 arranged her treatment abroad independently and attempted two cycles with her own eggs, requiring stays of 8-10 days. On her second cycle, "all embryos were found to be chromosomally abnormal", so she was "naturally very upset". However, with the understanding of risk and supportive doctors no embryos were transferred. Participant 10 had a further cycle utilising donor eggs requiring a shorter stay for 1-2 days. Participant 10 "always had two embryos transferred"; however, for future treatment she intended to have three embryos transferred and "believes that there are no legal limits for embryos transferred in the Czech Republic". Treatments received were similar to the UK, although distinctive differences are: "own room", saw doctor in each appointment, "modern, very clean and very well organised" environment. Participant 10 "trusted the clinic to do a thorough job" thus did not express concern regarding risks. However, she "would like more information about the donor" even though she "accepted that is simply not possible".

Participant 10 had to "conserve holiday from work" and "keep the cost down" for her treatments. Even though she travelled to city B in the Czech Republic several times, she did not spend extra time sightseeing because "it's not really a holiday". Whilst away, she kept "in touch with her family by text", however she "preferred not to talk about" her treatment as she found this stressful. Participant 10 was "happy to rely on virtual online support" from her infertility network friends.

Participant 10 could not provide the actual cost for her treatment either in the UK or in the Czech Republic; although she believed it could be "easily around £45-50,000". She attempted to keep "a meticulous spread sheet of expenditure"; however she gave up keeping a record "as it's too depressing to see how much I am spending with nothing to show for it" and "prefer not to think about it too much".

Participant 10 would return to the clinic in the Czech Republic to use her frozen embryos and would recommend it to others. However, if the next cycle "is not successful" she "will try" other clinics in the Czech Republic.

Participant 10 would recommend people embarking on CBRS to “research thoroughly” and appreciates “that this could be quite a substantial project” due to the difficulties in establishing the differences in various settings. For a “comfortable” traveller, like herself, she does not see “the need to pay” for agents as she feels “it does not deliver value for money”.

She found the IVF clinic counsellor “a complete waste of time” and would recommend an independent counsellor from the fertility networks whose support she “found to be valuable”.

5.6 Participant 14

Participant 14 was in heterosexual relationship and lived in Tanzania. She was 37 years old and her journey started with an appointment with her gynaecologist in her home country. She had investigation at home and conceived four years later with a tubal pregnancy following which one of her fallopian tubes was removed. Three years later, she had further investigation for her blocked tube and once again she had a tubal pregnancy following treatment.

Participant 14 felt it was difficult to access infertility treatment in Tanzania “because of limited specialists and only one referral hospital where tests are done”.

She felt “DISAPPOINTED” with her home infertility treatment as she suspected tubal pregnancy due to severe abdominal pain. When she went to hospital, her home doctor told her that she was “OK” and told her to return to the clinic if she did not have a period by Monday. Participant 10 was in great pain and had to travel to a nearby country (Kenya) to have treatment.

She started researching on the internet and found infertility clinic information in South Africa, although South Africans were given priority treatment. In 2001, after ten years of investigation and treatment at home, she convinced her partner about CBRS and went through IVF treatment in city J. Participant 10 stayed three weeks in a boarding house managed by one of nurses at the clinic and spent approximately US\$7,000.

She was “optimistic” and expected the treatment “to go smoothly”. She expected “high quality service” and the “use of latest technology” even though she had some scepticism regarding the “history of South Africa”. She received a standard IVF treatment protocol but none of the three eggs retrieved fertilised. Her CBRS fell short of her expectations as she did not get pregnant however, she would “probably” recommend the clinic to others.

Returning home, Participant 14 had to “deal with the stress of IVF failure” and “losing” her “long term partner”.

Participant 14’s recommendations to others are: “research more”, “have a plan B, C, Dchances of failure with infertility are high”, “money..... make sure you have enough”, “for older women.... plan....to go for egg donation”, “make sure that your partner is IN IT” and “learn from others”.

Participant 14 acknowledged “infertility is not life threatening”; however, in African culture “not having children is treated very negatively”. She advocated that “if.... drug can be waived so the prices are bearable for all who need such treatment would be very helpful”. She hoped that “there are standards in place” to ensure transparency of clinics and countries providing CBRS should not prioritise local residents, thus restricting foreigners in accessing treatment.

5.7 Participant 17

Participant 17 is married and lived in the USA. When she was 35, her doctor suggested that she “should not wait any longer to have children”. Participant 17 reported “trying on our own” but was unsuccessful in getting pregnant after a number of years. They did not embark upon infertility treatment due to job commitments and relocation. After reading about “how fertility levels decrease for women in their late thirties”, Participant 17 sought fertility advice.

Participant 17’s insurance plan did not cover IVF; however it “did cover artificial insemination”. She had two DI cycles “which were unsuccessful”. With low success rate using her own eggs, she and her partner decided to move forward with egg donation. The couple “couldn’t see paying \$10,000-\$15,000 for each IVF cycle” when the “clinical outcomes” were so low. This governed the couple’s decision to go down the egg donation route. Participant 17 implied this “did not bother” her, even though she could “trace her family history back to 1249” and admitted this is “the toughest issue” for her to let go of her own “genetic connection”.

Clinics in the participant’s locality “were charging between \$25,000 and \$50,000 for DE-IVF cycle”. The cost of treatment galvanised the couple’s decision for CBRS and “international adoption”. Participant 17 came “upon IVF website”, “joined infertility board” and saw a list of countries offering IVF treatments. Participant 17’s doctor in the USA, “who was very open”, monitored her cycle, whilst she “handled all the correspondence and the purchase” of her medication. They also discussed the countries for CBRS and the doctor thought: “Spain as opposed to Poland or Ukraine...would be more advanced medically”.

Participant 17 received support "on the internet" and felt she had "very little help" from her friends and family at home. Participant 17 expressed her gratitude to her doctor in the USA, she envisaged that "it would have been difficult to complete the whole cycle without having a doctor to work with locally".

Prior to her first cycle Participant 17 had reservations about the facility and "was pleasantly surprised at the excellent treatment" the couple received. The clinic "was very clean and seemed more advanced than some hospitals in the USA". The couple "felt confident in the doctor...he was very professional" and the clinic staff communicated with the couple "to the best of their abilities". The couple felt the staff were "professional and caring" and they "kept in touch" with the clinic "even after" their son was born. The couple did have issues when they returned home, after their anxious wait, they were expecting twins. The participant's doctor was concerned with the twins' "impacted by the scar tissue" and wanted "to do a slightly risky procedure to take one of the twins". In the event, "nature took its course" and she had a singleton birth from the cycle.

During her second cycle, Participant 17 "had a very different experience with the new staff at the clinic and a longer waiting time". The couple contacted the clinic when their son was about a year old requesting the same egg donor. "After a long wait" the couple were told they "could not have the same donor" and that the egg donor "would never be available again". The couple decided to proceed with a new egg donor but felt that the clinic had "changed". The cycle was delayed by an ovarian cyst "the strange thing was that" Participant 17 "had a small cyst during her first cycle" therefore; she could not understand why the new doctor "wouldn't go through with the cycle". When Participant 17 started her treatment, she received "an email from the clinic to say the original donor was now available" and asked if the couple "wanted to cancel" the planned cycle with the new donor. Participant 17 read online that the particular clinic, which used to have a "good reputation", "could not keep up with demand" and "was also importing donors from Eastern Europe". She was, therefore, perplexed with the "conflicting information" from the clinic and felt it was "a stalling process because they could not keep up with demand". Before the trip, she developed a dermatological problem and was prescribed topical medication and even though the doctor said it was safe, Participant 17 still worried about it. Unfortunately, all arrangements had been made and "it was too late in the cycle to cancel the trip". The couple found the "new staff to be less caring and more disorganised" and the new doctor "was less experienced". The doctor told the couple to buy an international cell phone to enable the clinic to contact them when the donor was ready. They did so and they "contacted the clinic so that they'd have our cell phone number". On the day of embryo transfer, the clinic "called the hotel", the participant and her husband "went out thinking the clinic would call the new phone" thus "did not get

the message" until the evening. On embryo transfer day, Participant 17 "found the process to be more hurried" with "a long line of ladies on trolleys in the hallway" reminiscent of "a production line". Participant 17 sensed "the process was less humanistic" unlike her first cycle, which was "more private and personalised". Returning from their second trip, the couple were "a little upset because of chemical pregnancy" and realised due to the currency "exchange rate...the cost/benefit ratio of doing CBRS was no longer advantageous" for them.

Participant 17 and her husband "made the decision together" and participant 17 would not have done CBRS if her husband was not in full agreement.

Participant 17 trusted that she had made the right decision and is "proud of her son" and "wouldn't change the experience for the world".

Participant 17 advocated for home clinics to be "more flexible" to aid patients requiring infertility treatment abroad. She advocated that clinics in destination countries should ensure "English language and/or cultural training" for the "administrative personnel" and better follow up of patients. She "didn't expect any risk" or "any legal implications", however she acknowledged "there could be complications" especially regarding donor information "if there is a health problem with the child".

Participant 17 advises others to "have fun!...don't stress out", whilst having infertility treatment as she "believes that the universe has a way of letting the right thing happen".

5.8 Participant 20

Participant 20 and his wife were from France. Participant 20's wife was diagnosed with MRKH syndrome in her twenties and was told that "it will be difficult to have babies". Twenty years later, the participant's wife went to see her gynaecologist and received a report "by fax" informing her that she has no uterus. This "was a hard time" for the couple. However, the gynaecologist informed them that they could overcome their childlessness via surrogacy but the procedure "was not allowed in France".

The couple researched "hard on the internet" and "found absolutely no information in France" but eventually found information from Canada regarding surrogacy. The couple sought support from an infertility specialist in France to gain treatment in the USA, one doctor "needs to speak to the clinic ethics staff" another doctor "was very silent" and told the participant "you are not going to have babies with this woman". This was "very violent to hear", especially for the participant's wife, who "was thinking about leaving [him]...because she doesn't want to be responsible for [his] potential unhappiness".

The couple decided that surrogacy "was the only option for us to become parents". They considered both the USA and Belgium for surrogacy; however, they sensed that Belgium had a "lack of regulations regarding civil status and a poor social acceptance of surrogacy". Despite Belgium being closer to home, the couple "escaped from France and went to California in order to look at surrogacy". The couple visited two agencies to gain "a better understanding of the actual meaning of gestational surrogacy" and met both clinical and legal staff. After careful deliberation, the couple decided on an agency which was "managed by a former surrogate who was very good at explaining all the psychological aspects of surrogacy" and the clinic doctor was "experienced in surrogacy for MRKH patients".

The couple had one failed cycle utilising their own gametes; "following doctor's advice", they "added egg donation" to their surrogacy treatment, "from two different women". In the first (failed) cycle three embryos were transferred to the surrogate. In this cycle, the couple suffered both emotional and financial setback; however they received "very strong support" from their surrogate. In the subsequent cycle, three embryos were transferred to the surrogate, from which the surrogate became pregnant with twins and nine good quality embryos were frozen. The couple were "very happy" and had "very strong support" and a strong relationship with their surrogate. The couple attended "each ultrasound" scan with their surrogate and felt "the medical staff were very kind to the three of us". The delivery "went smoothly" resulting in two healthy daughters and their surrogate "had a good recovery". The couple are still in contact with their surrogate and "often visit each other". Returning home, the couple received "strong support" from their friends and family. However, they were refused "French papers" for their daughters as surrogacy "is illegal in France". The couple have faced "police investigation, interrogation and trials" for the past ten years and the matter is still unresolved.

The couple found the book: "A Matter of Trust: The Guide to Gestational Surrogacy" (Dutton, 1997), which describes "all the surrogacy process" particularly useful. They found the information regarding clinics is problematic, "it is like Chinese language!" Nevertheless, patients' organisation "is a good starting point" when choosing a clinic.

The couple "did not expect any legal trouble based on the past experiences of other couples who travelled to surrogacy countries"; thus they were surprised by their own experience. They found the information about the legal aspects of surrogacy "messy...most of the time the laws are not clear or well defined". Therefore, the couple advocate "infertile couples to avoid tricky countries such as Ukraine or India" to avoid

legal limbo. The couple believe that "media sensationalism" about CBRS has a "bad impact" upon infertile couples.

5.9 Participant 23

Participant 23 is a 41 year old, single Caucasian woman living in Hong Kong and did not know if she had "any infertility problems other than the lack of a male partner". Doctors "are allowed to advise, perform basic ultrasound checks and administer medication", however "infertility treatment for single women in Hong Kong is illegal". Participant 23 felt she "had no choice" but to travel overseas for her infertility treatment. This "is frustrating and emotionally draining" for her and she felt that she "should have the right to decide whether or not to become a parent". "Travel and time off work" added to the stressful experience that she already experienced with regard to her infertility treatment.

Participant 23 had considered CBRS both in India and Thailand. Having been to India and heard from others, she did "not feel confident in the medical standards there". With her "own research", a friend's research, "recommendations" from a Hong Kong doctor and "a friend who had treatment from Thailand", she decided on a clinic in Thailand for their "reputation", "ease of commute" and cost of travel from Hong Kong. Participant 23 is "familiar" with the cultural environment of Thailand, where she feels "comfortable", thus reducing the stress levels around her treatment.

Participant 23 coordinates between the doctors in Hong Kong and Thailand; she felt her Hong Kong doctor was detached as he "cannot be seen to be aiding" an "illegal quest!!" Currently, she thought she had spent about £3,000 on her treatment. "Language can sometimes be a barrier" and "cross cultural differences" could be "a little frustrating"; however this was resolved by "my contact lady". She found the "liaison person invaluable in cutting through local communication" even with logistic issues such as, last minute hotel and pick up from the airport. Participant 23 was "unnerved" by her treatment; nevertheless she reasoned that "things in Asia rarely go to plan!"

Participant 23 did "not expect any risks"; however she felt the whole process felt like "I was jumping off a cliff a little, trusting people I'd never met who were on the other side of the world!" Neither did she anticipate any "legal complications"; however she realised she "hadn't thought deeply enough about the actual process" and was "double checking" her treatment including the use, and disposal of, sterile needles. She expected the clinic staff to be "qualified and could speak English!" and the environment to be "clean, hygienic and well run". These expectations were met. Participant 23 mentioned "doors left open" as she waited for her clinical examination. Although she "was covered with a towel", she felt "a little exposed!!!". "After the scan, the doctor started discussing the result before...[she]even managed to get changed". Participant 23 felt this raised her

anxiety and stress as she could not fully understand the implication of her treatment. She therefore, has concerns regarding her dignity and privacy during her treatment, which she labelled as a "cross cultural difference". She had DI and was advised to have "a double shot" to increase her "chances of success". She had to drink enough water to ensure a full bladder and she found the procedure "easier and completely pain free". She had "some cramping" after the procedure; however, she was able to discuss this with nursing staff to gain assurance. Returning home, Participant 23 waited for her period date. Unfortunately the treatment was unsuccessful: "No luck this time!" and she informed the clinic of the outcome.

Participant 23 had "strong support from" her friends and family and "conversed" with others via "blog sites". A "close friend" physically accompanied her to Thailand, which "was great". Participant 23 urged others when seeking CBRS to "have fun" and view the journey as a "girl shopping/pampering weekend!"

Participant 23 would consider CBRS again but would use "another clinic" and also "will be using injectables" depending on "how many eggs I produce and then either do IVF or IUI depending on the number". Finally, participant 23 would like to change the reluctant doctor in Hong Kong. She took time out to have a psychological and financial break from her treatment.

Near the end of the e-mail interview, participant 23 embarked on an IVF cycle with the same clinic in Thailand and had a "much more positive experience". She changed her doctor in Hong Kong and considered the second doctor in Hong Kong was "much more on her wavelength...with her best interests at heart...[and] happy to communicate" with her doctor in Thailand. At the concluding of the study, Participant 23 was waiting to learn the outcome of her treatment cycle and was hoping for a positive result.

5.10 Participant 24

Participant 24 is married and was diagnosed as a carrier for "a genetic problem which could manifest in her children", thus she does not see herself as having an "infertility problem". Her "genetic consultant suggested egg donation", therefore she researched and contacted a number of clinics in the UK. Her doctor performed a number of initial blood tests under the NHS. Participant 24 "wanted to try the UK first" as "the child could have information about donor", which she perceived "was kinder for the child".

Participant 24 registered on five private clinic waiting lists to "maximise" her "opportunities of being offered an egg donor" and "underwent three treatments through two clinics"; two clinics "didn't contact" her, however one clinic did offer treatment but it "clashed" with her egg donation treatment cycle with another clinic.

In the first cycle, the egg donor did not have sufficient eggs ("cost approximately £2,000"). The second and third "egg sharing...[cycles] resulted in the eggs not being suitable for IVF" ("cost approximately £4,000"). Participant 24 had three failed egg donation cycles and paid "for part of the cost"; she could not "remember the exact total cost" and had "tried to put cost to the back of her mind". She "started to feel more anxious and stressed" regarding the cost of treatment and quality of tests done, such as sperm analysis and breast scans by "inflexible" clinics. She suspected "that the ongoing tests were a money making exercise" which required her "to take time off work" to attend for tests. She found the clinic staff were "very courteous, professional, supportive and sensitive" when offering egg donors.

One clinic suggested treatment abroad because the participant is "more likely to receive viable eggs...[as] there are more donors" abroad and donors "tend to be younger". She and her partner "deliberated" and finally decided upon a clinic in the USA despite a cheaper European option. Because even though "the donor isn't contactable; the child can have much more detailed information about the genetic donor, including a photograph".

The UK clinic helped the couple through "the process" by setting up a "webcam interview with the USA clinic coordinator...[and] telephone consultation" with a doctor. The USA clinic environment was "clean and comfortable", provided "a very efficient information service" including the "local areas" and staff were "approachable".

Participant 24 felt "stressed" during her "wait" for her egg donation and despite receiving "regular updates" from the coordinator, she was afraid that "it may not work". Her "original plan" was to have the "eggs fertilise naturally...not to use ICSI", due to "desperation" ("never had this opportunity"), clinic rules and "improved chances", participant "went along with this" decision to use ICSI. Waiting 5 days for blastocyst stage transfer was hard for the participant as she "worried that" the embryos could "have all died away". With the aid of her consultant, the couple decided to transfer two embryos, albeit three viable embryos were obtained from the egg donor. Participant 24 felt "the safest place" for her embryos' "survival" was "my womb" and had "a sense of relief" and "excitement", as she had "never gone this far before". "The whole process was a good experience" for the couple and they were "made to feel very individual" throughout their treatment cycle. Participant 24's partner was "much more positive" and was supportive. The couple tried to treat her treatment "like a holiday and went sightseeing to distract" themselves from the treatment.

On the journey home, and at home, Participant 24 remained worried about compromising her treatment and was much more anxious about her health. After a

"pregnancy test at the UK clinic", the outcome was positive, the couple were "over the moon and so happy" and the coordinator from the USA clinic "emailed" the couple with "congratulations".

Participant 24 remained "cautious and anxious" during her gestation period, she did not tell "friends or work until I was at least 20 weeks". Her doctor monitored her carefully as "IVF babies are precious babies", a sentiment appreciated by the participant. At the conclusion of the study, Participant 24 was 38 weeks into her pregnancy and still has concerns relating to "whether the child would be upset by genetic origin" and how to "tell family members" regarding the use of egg donor.

The couple's "friends and family were supportive" by listening and gave "advice when they could". "Family members have been pleased about the pregnancy" however, the participant felt "guilty" and was still "trying to work out" ways to inform them that "the baby is from a donor".

Participant 24 would "recommend CBRS" and would have "done it sooner" mainly because of the shortage of egg donors in the UK, nonetheless CBRS "would not have been her first choice". She found having the UK clinic get in touch with the USA clinic was a help by making the whole process "much smoother...[and] more efficient". Participant 24 reported "a lot of bad press" for CBRS, she believed that the "majority of people in this situation" had gone "through a lot of emotional heartache, stress and money" and had "weighed up" the treatment options and CBRS "for me wasn't an easy decision to make". Participant 24 had considered "adoption" however, this was hindered by "restrictive and judgmental adoption rules" (e.g. age and required "2 years post IVF treatment"). Participant 24 realised that openness is "better" for the child. Unfortunately this "had stopped a lot of donors coming forward" and she advocates that donors "should be compensated properly" as donation is "a personal choice".

5.11 Participant 25

Participant 25 started fertility treatment with her doctor in her late thirties and was subsequently referred to a specialist for further investigations. Participant 25 and her husband "embarked on three IVF attempts" with their own gametes and had multiple "miscarriages" due to "chromosomal abnormality"; Participant 25 "was nearly 43 by this time". Due to age and egg quality, she came round to the idea of egg donation and persuaded her husband ("my husband was reluctant but eventually the statistics convinced him") to "go down this route" of treatment. The couple "changed clinic to one that had a substantial donor programme" and envisaged waiting for "about two years" unless they "could find a donor" themselves. After spending "6 months" of marketing and advertising campaigns to "no effect" the couple had "the idea of going abroad" for

treatment. By now the couple had spent “around £10-11,000” for their treatment. Although they had had a good experience (“small clinic” and “did not feel that they were on a conveyor belt”) they nevertheless sensed that “medical staff were not skilled in handling emotional fall out” (“tiny room to cry” fearing the couple might upset other patients”). Prior to her CBRS treatment, Participant 25 had an agreement with her UK clinic to “look after” her on her return, which boosted her confidence with her CBRS endeavour.

Participant 25 considered treatment in the USA but found the cost prohibitive and the choice overwhelming. She was particularly “interested in a Jewish donor” and “met someone” who recommended an “IVF specialist in Israel...[with] virtually no waiting list”. She felt travelling to Israel for treatment was “much more feasible” (i.e. “closer”, “more manageable”, “closely matched to donor”, “non-identifying information would be shared...and] able to talk directly with specialist”).

Participant 25 expected her “treatment to go smoothly” and was unaware of any risk or legal implications of her treatment. She had no communication issues with clinic staff and the standard of care was similar to the one used in England “with the exception of waiting time and cost, which were both lower than the UK”. The actual treatment instruction from the doctor “was very clear”; nonetheless she acknowledged that “the doctor was not used to answering questions” (e.g. when “asking in relation to the donor” as there is “no donor registration”, the doctor could provide “very little in the way of non-identifying information” as there were “possibly no records” regarding the donors). Participant 25 “was not prepared for” being placed in a “public ward”, where she could be potentially placed next to her “donor”. On returning home, she was referred back as “normal pregnant patient” and had a positive outcome.

5.12 CBRS: the emerging words from ‘I’ poems

In this chapter, after reading the participants’ email text, I reflected on their whole story (Mauthner and Doucet, 1998). I made notes of the participants’ actions, I came to know the participants’ motivation and experience whilst receiving infertility treatments abroad. Here, I acknowledge my own values, beliefs and emotions as I re-tell, remember and re-configure the central coherent plot of the final process; therefore, after discussion with my supervisor and Professor Ruth Deery; I decided to write these adapted ‘I’ poems in the third person.

These nine stories also included the social network (e.g. friends from infertility networks), close (e.g. friends and family) and intimate relations (i.e. husband or partner) of the participants and their interpersonal relationships/tensions with others (i.e. their partners, their relatives and friends) (Mauthner and Doucet, 1998). I am

particularly interested in how participants locate themselves within the wider network of inter-personal relationships (Brown and Gilligan, 1992a, Gilligan et al., 2003) and the power dynamics at play within each story. I also include these participants' accounts of the social, political and cultural context of CBRS (Brown and Gilligan, 1992a; Mauthner and Doucet, 1998; Gilligan et al., 2003).

As indicated in Chapter 3, I utilised Nvivo, a software programme, which enables the researcher to analyse qualitative data (i.e. the text themes from the email interviews). Nvivo queries provided a flexible way to gather and explore themes, events, protagonist and key characters (Mishler, 1986; Elliot, 2005) within the nine stories as told by the participants. By creating queries to ask questions and find patterns based on the coding themes, word frequency queries were used to list the top five most frequently occurring words in my data (i.e. cost, wait, time, process and recommendation). These five themes/words (see Table 25 below) provided insight into the participants' CBRS journey, which enhances the credibility of the interview data (Hewitt, 2007) and they are discussed in turn in more detail below.

Table 25: Five most frequent words used in 'I' poem

Words	Frequency
Cost	19
Wait	15
Time	14
Process	12
Recommendation (to and from)	12

5.12.1 Cost

Cost was mentioned nineteen times within the adapted 'I' poem and this concurred with the findings of studies by Van Hoof et al. (2013) and Culley et al. (2011b). Cost was related to both the multiple failed treatments cost at home and also the cost of CBRS:

Participant 1: "CBRS is still expensive"

Participant 3: "was like a cash machine"

"CBRS were never based on cost...becoming increasing financially challenged!!"

Participant 10: "Spent in the region of £7- 8,000" at home

"the costs of treatment were so competitive to the UK"

"too depressing...how much...prefer not to think about it...easily around £45-50,000 including both home and CBRS"

Participant 14: "spent approximately US\$7,000"

"drug can be waived so the prices are bearable..."

Participant 17: "could see paying US\$10-15,000"

Clinics "were charging between US\$25-50,000".

Participant 23: "spent about \$3,000" Thailand

Participant 24: "cost approximately £2,000...cost approximately £4,000"
Participant 25: "spent £10-11,000" at home. "Considered USA...prohibited by cost".

From the above statements, participants could only record the estimated costs for both their treatment at home and abroad for example, participant 10 intended to keep a spreadsheet of expenditure however, she found this too depressing and preferred not to think about the cost. Similar to Culley et al. (2011b), many participants had already spent a considerable amount (£45-50,000) in their wish for a child at home. The cost implication seemed to have both positive and negative elements to CBRS. CBRS was seen to reduce the cost of infertility treatment, however participants 1 and 3 still found the cost of CBRS expensive and increasingly challenging.

5.12.2 Wait

The concept of "wait" included both positive and negative expressions from the participants. Part of the "wait" concept was related to the waiting time for treatment, which concurred with the findings by Van Hoof et al. (2013) and Culley et al. (2011b) in which participants were required to wait for fertility treatment at home whereas there was a perception that the waiting time for CBRS was shorter:

Participant 1: "I keep waiting to miscarry..."
Participant 17: "after a long wait"
 "after anxious wait"
 "...Long waiting time..."
Participant 23: "a waiting for period..."
Participant 24: "registered on five"...clinics waiting lists to "maximise opportunities of being offered an egg donor"
 "Felt stress during her wait for egg donor...despite regular update..."
Participant 25: "with virtually no waiting list".

Participant 24 registered on five egg donation waiting lists to increase her chances of being offered treatment at home. Participant 25 had the perception that overseas egg donation treatment had virtually no waiting list, whereas in reality patients were still required to wait for their treatment, which was an anxious and stressful time period for them. The waiting also applies to the period following treatment, many participants had previous failures and were naturally worried and had negative thoughts about their current treatment.

5.12.3 Time

The concept of time could be related to the sequence of events that occur during infertility treatment or actual time required to attend CBRS. Time is a difficult concept, which participants used for several different meanings. Time was used by participants to recollect a specific event during their infertility treatment both at home (i.e. denying treatment and discourse with clinic at home) or abroad:

Participant 10: "her consultant each time..."bad luck"

By this time, participant "was fed up with the UK clinic"

Participant 20: "This was a hard time for the couple...not allowed in France"

Participant 23: "Travel and time off work"

"Took time out to have mental and financial break..."

Participant 24: "take time off work".

Similar to the findings here, Van Hoof et al. (2013) found taking time off to travel abroad for CBRS was a burden for some patients. In particular, participant 23 required a break to recuperate from her overseas infertility treatment.

5.12.4 Process

Process related to the treatment both at home and CBRS. The counselling process helps to normalise the participant's feelings, whereas the infertility clinic ethics process (i.e. single women) confronting a participant's 'right' to a child could be challenging for participants:

Participant 3: Counselling..."was a great help in making the whole process normal...CBRS experience was positive and process was easy"

Participant 10: "felt angry and judged by the whole process"

Participant 17: "conflicting information" from clinic "as a stalling process as they could not keep up with demand"

"found the process to be more hurried...sense the process was less humanistic"

Participant 23: felt the whole process was like "jumping off a cliff and trusting people who participant had never met before..."

Participant 24: "the whole process was a good experience".

Participant 17 sensed her clinic had changed (i.e. "less humanistic") as a result of the clinic having increased patient numbers, while participant 23 described the whole process like "jumping off a cliff" and "trusting people who she had never met before". Overall, participants seemed to have positive experience of their CBRS.

5.12.5 Recommendations

The word recommendation occurred 12 times in the nine case studies. This concept had two broad themes, which could either be recommendation "from" or recommendation "to" others:

- Participant 1: Counselling..."would recommend it"
- Participant 3: "based on recommendations of infertility network members"
- Participant 10: Consultant recommended for IVF abroad
 - "recommended by other women in a similar position"
 - "very good reports and recommendations..."
 - "was more than just virtual recommendations" met the people
 - "benefit hugely from their experience and recommendations"
 - "recommend independent counsellor from infertility network" found the support valuable
- Participant 23: recommendation from doctor
- Participant 25:"met someone" "recommending IVF specialist in..."

The recommendation "to" concept related to the participant recommending counselling for those intending to have CBRS. The recommendation "from" concept could either be from their doctor, via infertility network, virtually or in person. Van Hoof et al. (2013) also reported patients receiving valuable advice from 'seasoned patients' and those infertility forum users help each other along their CBRS journey.

5.13 Chapter Summary

This chapter has presented my analysis of findings from the nine email interviews. Nine personal stories adapted 'I' poems were used to illustrate the features employed by the analysis process. I have located some of the emerging themes within the context of CBRS. These will be discussed in both Chapters 6 and 7.

Chapter 6 Qualitative narratives and themes from participants

This chapter addresses the motivations for, and experiences of, the CBRS journey and its consequences from the perspective of 23 female and 3 male participants. The chapter concludes by summarising and reflecting upon the recurrent themes emerging from participants' accounts of their international travel to access reproductive services.

Currently, there is limited evidence and theoretical knowledge relating to cross border travel for reproductive services. I felt it was essential to explore and interpret the relevant phenomena by not imposing preconceptions or existing theoretical frameworks. However, if a particular theoretical framework could elucidate some, or part of, the participants' motivations for, and experiences of, their "CBRS journey"; I will encompass the theoretical framework in order to provide a more comprehensive view. This pragmatic approach is outlined in Figure 6 below (Taylor and Bogdan, 1998, 138).

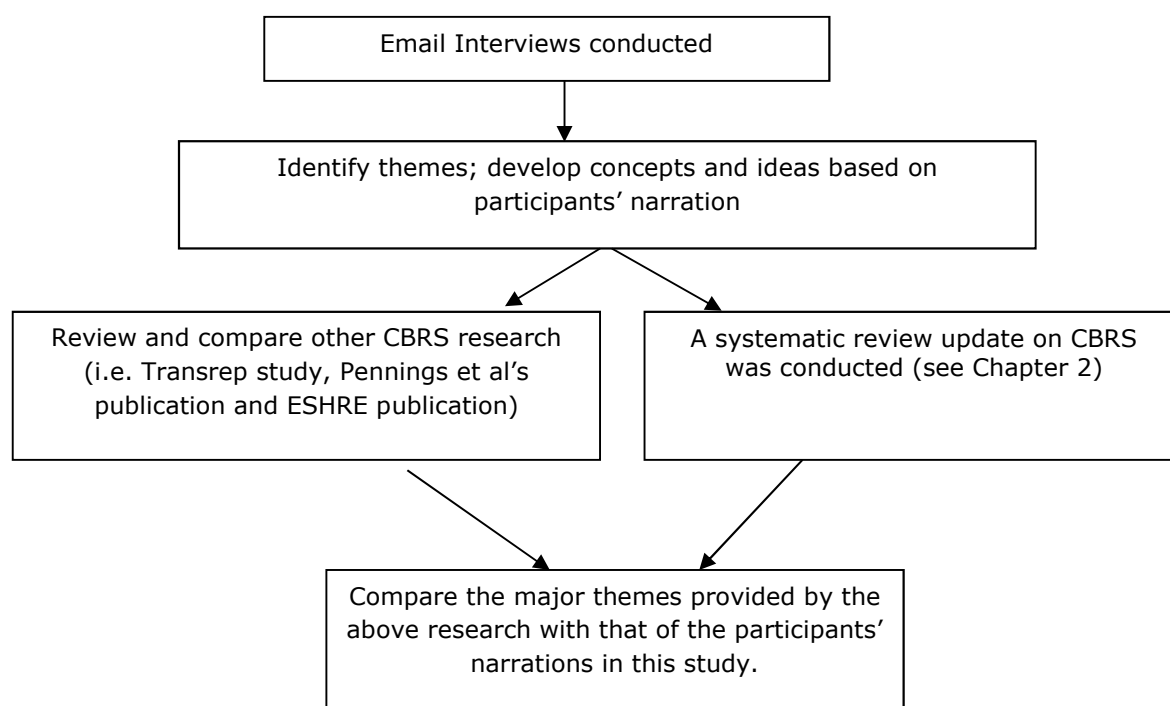


Figure 6: Graphical representation of Grounded Theory approach utilised in this study

6.1 Coding and mental mapping of data

The interviews with participants were via email. The email interview was comprised of eight questions (See Appendix 5). All participants were able to respond in written English, thus translation and transcription were not necessary for this study. I recognised at times participants' narrations might include typographical errors and some phrases used by the participants might have grammatical errors, these were not corrected and were reported as verbatim so as not to change the contextual meaning

provided by the participants. My original intention was to perform manual coding and attempt to immerse myself with the data. However, this intention was abandoned due to the number of participants and the volume of rich data each participant provided in their emails as explained in Chapter 3. I used NVivo 10 to help analyse the data generated from the email interviews with the study participants.

Similar to Doucet and Mauthner's (2008) 'I' poem reading, the interview transcripts were read and re-read several times and examined line-by-line to identify common themes or issues. Folders were created for each theme and the participants' exact quotations were placed within each relevant folder.

Here, I follow the systematic steps for coding and mapping analysis outlined by Denscombe (2007):

1. Preparation of data: transcript preparation, which involves anonymising participants
2. Familiarisation with data/open codes: transcripts were read and re-read for meanings and themes, focussing upon participants' motivation for, and experience of, cross border travel for reproductive services to generate the open codes. Open coding involved examining the words and phrases used by the participants and any additional ideas and concepts expressed by them
3. Generating axial codes: open coding was organised into themes/categories. Diagrams and schematic models were developed to depict the linkage between various concepts
4. Searching for themes: once initial coding and themes/categories were identified, I was able to collate them into overall concepts. In this way, preliminary complex interpretation of data was achieved
5. Reviewing emerging themes: reviewing other data sources and examining current literature could yield affirmation themes (e.g. cost was a concept investigated by both Inhorn et al. (2012) and Van Hoof et al. (2013)). These themes will be highlighted and compared across the interview transcripts with current evidence on the topic.

The following section is sub-divided into the five stages of the participants' CBRS journey. In this chapter, I report on the participants' response to the first six questions. Questions 7 and 8 were asking the participants for their recommendations and additional comments; their responses to these two questions will be presented in Chapter 8.

Surprisingly, even without asking, participants provided information about their infertility prior to a medical diagnosis or infertility treatment at home (see Table 26).

6.2 Stage 1: Before Infertility Treatment at Home

Thirteen participants articulated their concerns in seeking help for fertility difficulties; themes identified were early personal concern for why they did not get pregnant, single women (who had no sexual partner and therefore required infertility treatment in order to conceive), previous pregnancy, waiting to start a family, costs and other forms of cross border treatment.

Table 26: Responses on "Before infertility treatment at home"

Before Infertility Treatment	No of participants
Early personal concern for why they did not getting pregnant	6
Genetic issues	1
Early illness	1
Waited to start family (work)	1
Single women	4
Previous pregnancy	2
Ectopic pregnancy	1
Cost of Investigation	1
Not wanting to waste time and money in home country	1

6.2.1 Early personal concerns

Six participants indicated that they had early concerns about not getting pregnant:

Participant 1: "wondering why I had not gotten pregnant after a year of trying"

Participant 11: "After a year had gone by with no success we went to my GP who told us to try for another year"

Participant 12: "All the women in my family had conceived very easily within 1-2 months and I had always assumed that I was fertile with regular cycles and could not understand why after 6 months we had not managed to conceive"

Participant 17: "After a few years of trying on our own to have a child and being unsuccessful, I read an article about how fertility levels decrease for women in their late thirties. At the age of 37.5 years..."

For Participant 17, even with this information, the couple decided to delay starting a family due to the husband's work and moving to new a residence:

Participant 17: "We waited to start a family because we moved to the...for my husband's job. It took a while to get comfortable with a new area".

One participant had a diagnosis of Hodgkin's disease:

Participant 9: "I was diagnosed with stage 2 Hodgkin's disease...[and] had ovarian tissue re-implantation in Brussels".

Another participant knew that she was a carrier of a genetic condition:

Participant 24: "Approximately 8 years ago I was informed that I carried a genetic problem that could manifest in my children, should I have any. The risk was 50:50".

Apart from those participants who were aware of their individual reason (i.e. Hodgkin's disease, genetic condition) for their infertility, some participants struggled to rationalise their childlessness.

6.2.2 Single Women

Four participants (two sample quotes below) indicated that their status as single women with no sexual partner meant that they required infertility treatment in order to conceive. They do not see themselves as having infertility problems and being a single mother was their choice:

Participant 23: "Actually I don't know if I really have any infertility problems other than the lack of a male partner to test the theory!!"

Participant 26: "...to begin the process of becoming a single mother by choice using donor sperm".

6.2.3 Previous pregnancy

For two participants their infertility followed a previous pregnancy, thus leaving them perplexed by their predicament:

Participant 11: "My son H was conceived naturally after 6 months of 'trying', an easy pregnancy and born by elective c-section when I was 35"

Participant 13: "We already had a daughter together in 2000 but had failed to have another child".

In addition, Participant 14 had multiple ectopic pregnancies and could not comprehend the reasons for her infertility:

Participant 14: "I conceived again and it was another ectopic".

6.2.4 Costs and time

After comparing costs for private infertility treatment at home and abroad, one participant/couple decided not to have treatment at home:

Participant 5: "We went for an initial appointment in London about private treatment and realised that it was going to be very expensive and found out

about treatment abroad and decided to go for that as there was a huge difference in cost”.

Another participant decided not to have treatment at home as she concluded that this would be a waste of time and money:

Participant 3: “My Fertility Treatment in Ireland is limited as I did not want to waste time and money when I knew ultimately I would have to go overseas anyway”.

6.3 Stage 2: Perspectives of infertility treatment at home

Participants provided their perspective of infertility treatment at home (see Figure 7 below). The themes are the age at which they started infertility treatment, costs of infertility treatment, emotional response during their treatment, relationship breakdown, experiences of infertility treatment and restrictions and regulations.

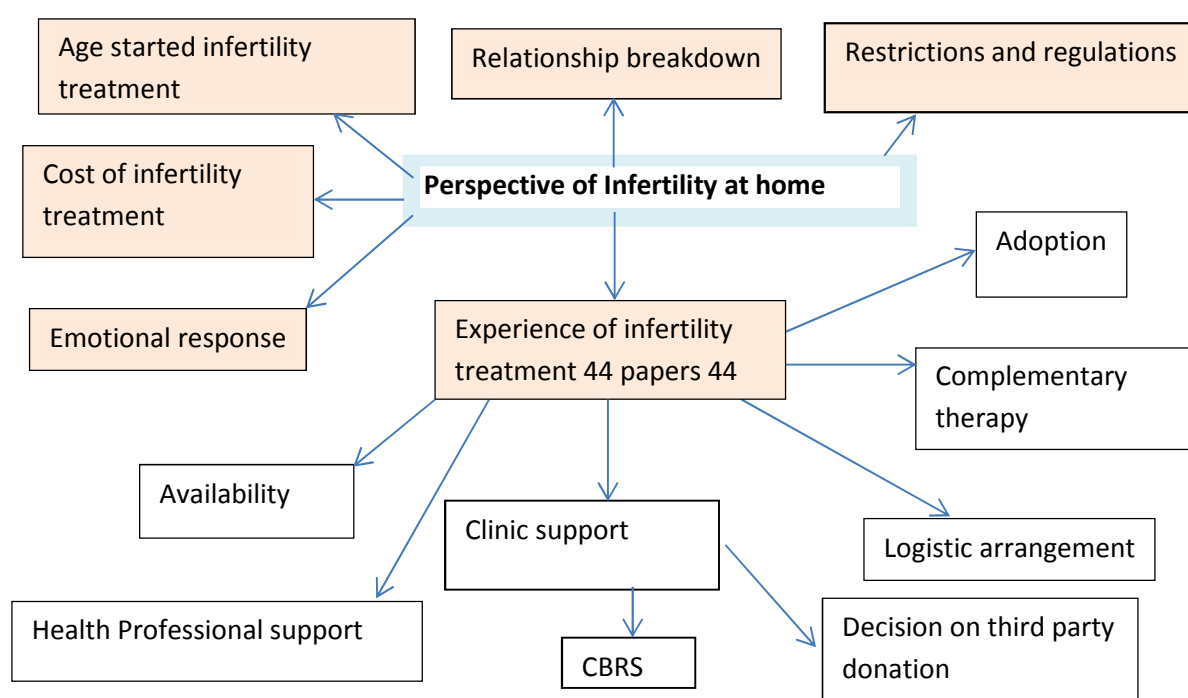


Figure 7: Perspectives of infertility treatment at home

6.3.1 Age starting infertility treatment at home

Thirteen participants disclosed their age when they started their infertility treatments (3 sample quotes below):

Participant 1: “I went to my reproductive endocrinologist when I was 38, wondering why I had not gotten pregnant after a year of trying”

Participant 14: “My journey started in 1991 when I visited a gynaecology clinic, by then I was 37 years old”

Participant 22: “We were advised to try IVF early in 2008. At the time, I was 44”

6.3.2 Costs of infertility treatment at home

Participants provide statements relating to the costs of treatment at home (see Table 27 below).

Table 27: Cost of treatment at home

Cost of infertility treatment at home	No of participants
Vague cost	21
Self-funded	15
Health insurance	6
Covered by public health services	6
Feeling poorer	2

Twenty one participants recalled the costs of their treatment, although their recollections of these were vague (2 sample quotes below):

Participant 2: "I spent approximately \$12,000 on the 3 IVF attempts"

Participant 7: "It was quite a long time ago now, we did about 3 IUI and 2 failed IVF, so maybe £5000 at a guess"

The words and phrases used by participants are "about", "approximately", "estimate", "in the region of", "at a guess", "around" and "I don't remember the cost". This seemed to suggest that participants did not pay attention to costs whilst receiving infertility treatment.

Fifteen participants reported their treatment was self-funded because infertility treatment was not covered by health insurance, even when the treatment is in their home country. One participant self-funded her infertility treatment due to her age. The means of funding treatment were from savings, loans and gifts from parents (3 sample quotes below):

Participant 3: "NO IVF treatment is covered by health insurance in Ireland so it has to be funded by oneself for all people in Ireland"

Participant 6: "It had to be completely self-funded because I was already 40"

Participant 12: "It was self-funded in a private clinic through a combination of our savings, credit cards and parental gifts".

Five participants mentioned that infertility tests and diagnosis were also not covered by their health insurance scheme as private insurance does not offer comprehensive cover for all tests, investigations and treatment for infertility (3 sample quotes below):

Participant 1: "I have no insurance coverage for any infertility related testing or treatment".

Two participants did have insurance cover for their treatment at home:

Participant 19: "This was covered by our private health insurance..."

Participant 26: "I have insurance through my employer that would cover infertility treatment for anyone with a diagnosis of infertility (which I had, given that my fallopian tubes were blocked), up to three IVFs with own eggs...And I had various surgical procedures, such as a D&C to remove something in my uterus and a laparoscopy. My insurance didn't cover all of it; I had various co-pays and deductibles..."

However, when she required removing early pregnancy products her insurance company did not cover all the cost.

Six participants made reference to public health funding in relation to their infertility treatment. Three of these did not receive any public funding, whilst three received some funding:

Participant 1: "Medical procedures can be claimed back from the Revenue Commissioners at the rate of 20% if you are a PAYE worker..."

Participant 8: "Only the lab tests and ultrasounds were covered with the famous 'Universal Canadian Health Care'...Some medications and all diagnostic exams (blood tests and ultrasounds) were publicly funded"

Participant 12: "We discovered the NHS would only fund one cycle of IVF through our PCT..."

Two participants mentioned they are significantly poorer as a result of having to fund their infertility treatment:

Participant 6: "I reduced my working hours from full-time to part-time after the first IVF cycle and stopped working completely after the second cycle".

Participant 6 reduced her workload to give up work completely in order to increase her chances of getting pregnant.

6.3.3 Emotional responses

Participants experienced frustration, stress, anger, loss and disappointment during their quest for a child at home. Five (three sample quotes below) participants expressed frustration regarding their treatment at home:

Participant 10: "It was very frustrating to keep being told it was simply bad luck"

Participant 12: "We could not handle the prolonged wait to know if we would be able to conceive..."

Participant 23: "The fact that this is illegal in country X is frustrating and emotionally draining".

Four (three sample quotes below) participants experienced stress during their treatment, which could be induced by travel to a clinic for treatment, finding somewhere to stay, even for treatment undertaken in their home country and time off from work:

Participant 8: "...travel and accommodation which certainly adds to the stress of trying to achieve pregnancy"

Participant 23: "...all the travel and time off work obviously adds its own burden to an already stressful experience!"

Participant 12: "This was unbelievably stressful as we struggled to cope with the expectations, loss of control and unpredictability of the whole situation".

Three participants articulated that they were angry with their own situation and participants 12 and 26 blamed others for their infertility problems. Participant 12's partner had an inherited infertility problem. Participant 20 felt violated in the way information was communicated to his wife (via Fax), which he felt was inappropriate:

Participant 12: "I spent a lot of time being angry about the situation, especially at the sperm from his dad that had made him this way"

Participant 20: "When my wife read this report she received by fax, she discovers she has no uterus. It was a hard time for her, and later for me...It has been very violent to hear that. And double violence for my wife"

Participant 26: Surgical error...was a significant part of my long and difficult journey toward parenthood".

The loss and disappointment suffered by these participants are immense. As many of them have experienced multiple failed infertility treatment cycles, they have endured multiple grieving processes and felt lonely and isolated recovering from each failed cycle:

Participant 12: "This period was very complicated emotionally, as we were both grieving for the loss of the ability to conceive naturally"

Participant 13: "Each and every one was a loss as I had already imagined them as my children. Being in IVF treatment was a very sad and lonely place to be".

6.3.4 Relationship breakdown

Three (2 sample quotes below) participants reported marital strain during their treatment for infertility:

Participant 13: "Looking back...problems within our relationship...my desire for another child was so very strong...My partner was not at all open to the idea of using donor eggs...around this time we split up...I think this would have

happened regardless of the fertility issues, although of course they did not help. Anyway by this time I no longer had a partner either so now I had double the problems!”

Participant 20: “My wife was thinking about leaving me because she doesn’t want to be responsible of my potential unhappiness”.

In the case of participant 13, the discord between the couple eventually led to their separation. Participant 20 reported that his wife wished to protect him by thinking of leaving him. The emotional impact of infertility is of utmost importance and counsellors could play a vital role in resolving couples’ discourse and feelings.

6.3.5 Experiences of Infertility treatment at home

Participants were asked about their experience of infertility treatment at home (see Table 28). The themes highlighted by participants are: availability of treatment, clinic support, decisions on treatment, complementary therapy, working arrangements and adoption.

Table 28: Experiences of infertility treatment at home

Experience of infertility treatment at home	No of participants
Availability of treatment	
1. Access	6
2. Waiting list	13
Clinic support	
1. Health professional staff support (Negative and positive)	13/8
2. CBRs Suggestion	7
Decisions on third party treatment	
Donated gametes	15
Working arrangements	4
Complementary therapy	4
Adoption	3

6.3.5.1 Availability of treatment

Six participants provided information relating to accessing infertility treatment at home. Four (two sample quotes below) participants reported that they did not have issues accessing infertility services at home:

Participant 18: “I found it easy to access treatment in London”.

Conversely, another participant acknowledged that if it wasn’t for her professional status, she might have difficulties in accessing treatment:

Participant 8: “Fortunately I am a nurse so we did not have any difficulty

accessing service. However, had I not been a nurse, I would have had difficulty finding a family doctor to start the investigation and referral...”.

Two participants had difficulty in accessing treatment at home. Participant 21 had to convince her clinic that she would be able to find more than one egg donor in order to have earlier treatment:

Participant 21: “We had to find our own donor in order to ‘queue’ jump due to my age – I was 43 at the time...at our first consultation we were nearly given an outright no to treatment...only by some persuasion (i.e. we would try and find more than one donor for the clinic) that we were allowed on.

Participant 14 is from Tanzania, a developing country, and experienced great difficulty in accessing infertility services at home as there are limited infertility specialists and clinics in her home country:

Participant 14: “It was difficult because of limited specialists and only one referral hospital where the tests were done”.

Waiting lists were mentioned by thirteen participants, mainly relating to third party reproduction (i.e. egg and/or sperm donation or surrogacy) treatments.

Participant 8 reported their wait for IVF was about five months and for sperm donation, participant 10, had to wait for 6 months prior to receiving treatment.

The waiting time for egg donation reported by the participants ranged from nine months to between 2-5 years, unless the patient could find a donor for their treatment:

Participant 13: “My consultant offered to put my on the waiting list for donor eggs in this country but the waiting list was 9 months...– timescales which were just not acceptable to me” (sic)

Participant 22: “We were also informed that there was a waiting time of between 2-5 years for egg donors in the UK”.

6.3.5.2 Clinical support

The clinical support provided to participants was mixed. Some experienced good and positive support from clinics, regardless of an unsuccessful treatment outcome:

Participant 6: “The staff were generally approachable, all were kind and caring”

Participant 8: “The fertility clinic in C did a very good job despite being unable to assist us with achieving pregnancy”.

Many found clinics provided “excellent pastoral care” (Participant 11). Participant 22 felt staff were “given the utmost care” towards her and “felt very looked after throughout”

her treatment and Participant 19 felt staff were "sensitive and wanting to do the best" for their patients. Participant 25 attended a small clinic therefore, she did not feel too much that the couple were on a "conveyor belt".

However, some participants have some issues relating to clinical care. Participants found some clinics were very busy with their clinical work:

Participant 8: "The clinic was very busy – standing room only on most mornings..."

Participant 18: "I found that the clinic was very busy and the staff were always pushed for time and often kept you waiting long periods before seeing to you due to the number of patients they had".

Therefore, some participants did not feel supported by the clinic and the whole process was becoming "impersonal" (Participant 4).

Participant 11 reported throughout her treatment she did not feel that she knew any doctors in the clinic and they "were just going through the motion...treating us like numbers", the counsellors "were asking questions by rota...[and she] did not see the same doctor twice" throughout the course of her treatment.

Participant 10 sought egg donation and had to go through a clinical ethics committee. Being "judged/evaluated" by others made the participant "angry" with the process. At times participants felt the clinical staff "did not have enough knowledge" (Participant 18) or expertise to deal with failed treatment cycles:

Participant 25: "...staff were not well skilled in handling the emotional fall-out. We were shown to a tiny room to cry in private for fear that we might upset the other patients".

Clinic staff utilised words such as "bad luck" (Participant 4) or "just bad luck" (Participant 10), although participants did not find these words constructive to their problem.

Seven (three sample quotes below) participants recounted that their home infertility clinics suggested they could go abroad for their infertility treatment:

Participant 4: "She seemed to suggest that we should consider travelling to E..."

Participant 6: "We joined the waiting list for donor eggs at the clinic but were advised to try going abroad as it was likely to be a wait of over a year"

Participant 24: "One of the clinics then suggested that I was more likely to receive viable eggs by going through a clinic abroad i.e. because there are more donors and they tend to be younger".

Four participants (Participants 3, 9, 11 and 22) reported that they were referred to overseas clinics (Spain and Portugal). Participant 22 felt that this proposal from the clinic left them "with no alternative but to go abroad".

6.3.5.3 Decision on third party treatment

The decision to use third party treatment was a struggle for many participants. The reasons for third party usage were husband's sperm issues (poor sperm count/quality or azoospermia) (Participant 2) or poor egg quality (High FSH level) (Participant 7). Two participants (Participants 1 and 10) decided to use both egg and sperm donation to increase their likelihood of achieving a pregnancy.

Participant 8 felt that egg donation would be their "only remaining option...the most sensible decision" (Participant 17) and "the best way forward" (Participant 18) to achieve their quest for a child. Participant 13 reported "at the time...[this] was a very hard decision to accept".

Husbands/male partners of infertile couples could find third party reproductive treatment difficult to accept at times and required assurance from partners before embarking on such treatment:

Participant 25: "My husband was reluctant, but eventually the statistics convinced him, and he was willing to go down this route".

With the introduction of third party reproduction within treatment, emotions of the participants are heightened. With the accessibility and waiting for egg donors, many participants decide to discontinue their treatment programme at home and enter into CBRS.

6.3.5.4 Logistic arrangements

Four (2 sample quotes below) participants reported the effort of juggling both work and infertility treatment at home:

Participant 6: "Things did not always run to time and appointments were rarely at convenient times if one was working"

Participant 12: "I continued to work full time throughout the treatment; taking annual leave for the egg collection and transfer (this included injecting myself in the toilet at work)...".

Travelling for treatment at home also posed logistical issues. Two participants reported their travel time was approximately four hours (Participants 1 and 11). Patients are

willing to travel for “better clinics rather than the nearest clinic” (Participant 13). Participant 11 explained their choice of a specific home clinic for treatment “because it was close to” her parent.

6.3.5.5 Complementary therapy

Four participants (Participant 4, 6, 11 and 23) used complementary therapy (i.e. acupuncture, herbal medicine, nutritional supplements and naturopathy) to enhance their fertility treatment. The amount spent by these participants was significant (€4,000 on acupuncture (Participant 4)). Participant 6 tried a “controversial Chinese herbal supplement” and Participant 11 went to Harley Street, London, for specific Chinese herbal treatment “to lower her FSH level” prior to undergoing infertility treatment.

6.3.5.6 Adoption

Participant 16 was “recommended by her consultant” to adopt a child from China as a single woman to complete her family. She adopted a child with “special needs”. Participant 17 considered “international adoption”; however the cost (\$30 -50,000) was a prohibitive factor and the cost of domestic adoption was similar, thus “there’s no way I could afford that”. Participant 17 also stressed the importance of gestational kinship with her potential child:
Participant 17: “... I wanted the experience of carrying and giving birth to a baby...”.

6.3.5.7 Restrictions and regulations

Some countries had regulations relating to third party treatment for single women (Participant 3), age of infertile women (Participant 6) and anonymity and confidentiality of gamete donors (Participant 8).

Participant 8 recounted the experience in his country C, where “only known donors are permitted to participate in egg donation. With no female relatives of child bearing age on my wife’s side this option was not really an option for us at all”.

For Participants 23 and 20, any third party reproductive procedures are illegal in their home country.

6.4 Stage 3: Reasons for and journey towards CBRS

A number of participants reported multiple failure treatments. Waiting lists or legal restrictions and regulations at home left some feeling that they had no choice (Participant 23) and are “forced to look at” (Participant 8) treatment abroad . They reiterated that they “did not want to be too old” (Participant 7) to become parents and

that was “the main reason for going abroad” (Participant 11) for fertility treatment. The cost of treatment at home was an increasing burden for many participants and Participant 26 reported that she “had exhausted all her available insurance coverage for treatment at home”.

The following section relates to the participants’ journey in undertaking treatment abroad. Figure 8 summarises all the substantial themes that emerged from the participants’ responses.

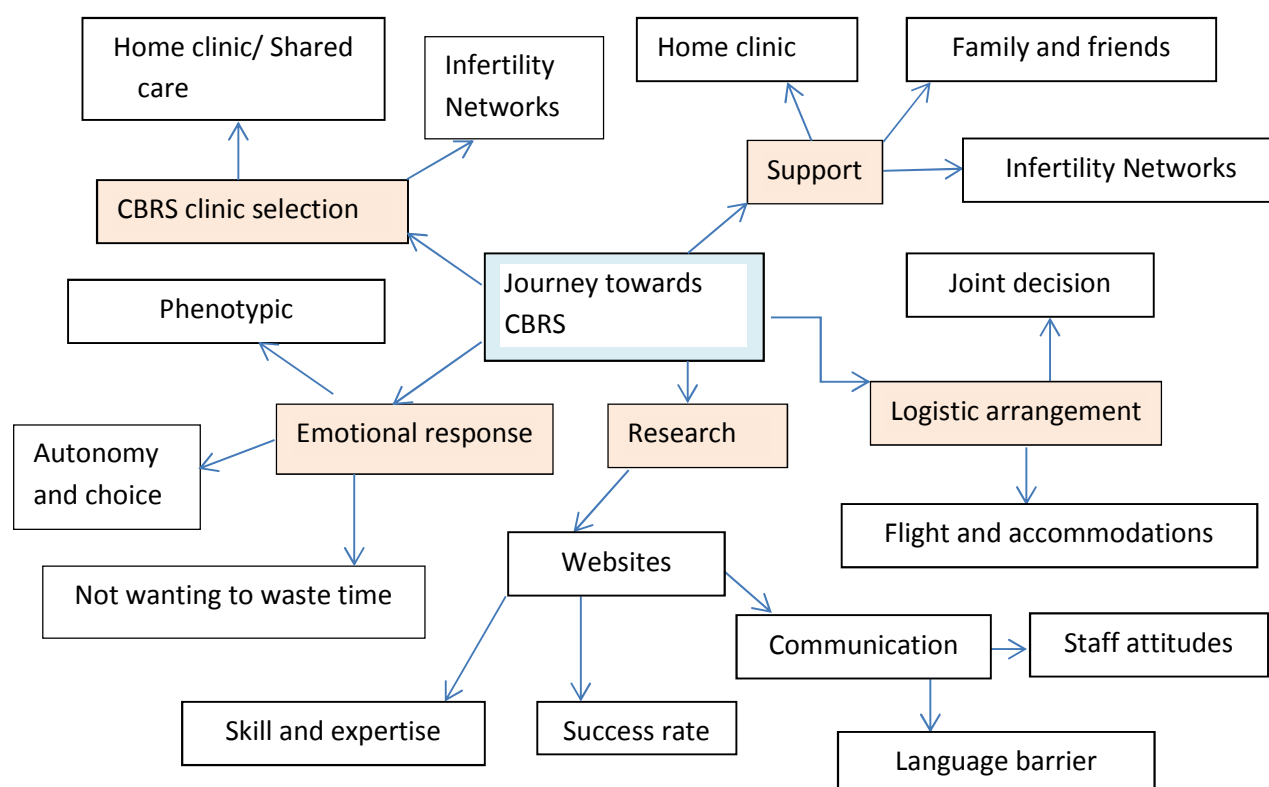


Figure 8: Journey towards CBRS

Six participants (Participants 6, 11, 19, 21, 22 and 24 - two sample quotes below) reported that whilst undertaking research for treatment abroad, their home clinic suggested treatment in another country as a potential option for them:

Participant 11: “Clinic...told us they had shared care with the IVI in Barcelona, Spain....remember being advised it was a better option for us...”

Participant 19: “Our consultant told us...they had a link with clinics in Spain and in the USA, where we could go...We trusted...our consultant ...”.

Four participants (Participants 11, 19, 21 and 24) embarked on shared care with their home clinic during their cross border infertility treatments.

Some participants received recommendations from networks (i.e. infertility support

groups (Participants 11, 21) or internet online support networks (Participant 18)).

Personal recommendations either via the internet (Participant 26), telephone conversations (Participant 4) or a face-to-face meeting (Participant 25) were deemed to be important to participants considering treatment abroad:

Participant 10: "Personal recommendation from other women having treatment abroad was what first encouraged me to look at overseas options..."

Participant 12: "Through FF I talked to women who had had successful...pregnancies through a clinic...They were very encouraging about their experiences and the pictures of their children and their description of the happiness of having a baby and 'beating'...encouraged me a lot. It was clear from talking to them that the set-up...was second to none"

Participant 18: "I met some people who had used this clinic before and had a good experience..."

6.4.1 Emotional response to their CBRS selection

Participants started to express personal autonomy and choice (Participants 16, 18, 22, 23, 24 and 26) and felt that they had control over their infertility journey:

Participant 16: "I was at the mercy of a system...[would decide] what was good for me".

Participants are "keen to move as fast as possible" (Participant 11) with their cross border infertility treatment and "not wanting to waste any more time" (Participant 19).

Five participants (Participants 1, 3, 13, 20, 25 - two sample quotes below) expressed that donors' phenotypic choice is also important for them whilst selecting the CBRS (Bergmann, 2011):

Participant 1: "I thought about Cyprus, Spain, the Czech Republic, Ukraine, South Africa or Argentina. After some research I chose Ukraine as my father's family is originally from Eastern Europe and I thought there might be a good donor match there"

Participant 25: "Going abroad to Israel presented itself as an opportunity during my quest...ticked my preference for a Jewish donor".

6.4.2 Participants' CBRS Research Strategy

Twenty participants reported trawling through the internet for information ranging from location of clinics, cost, waiting list, treatment types (i.e. egg donation), donors information and legal aspects of CBRS. Several participants reported that they had no difficulties in their hunt for information. However, three participants found internet research overwhelming:

Participant 6: "I found the initial research daunting and clinic websites based abroad are not always...comprehensive as those here (at home)...I often had to email them to gain more specific info re success rates/cost etc. But it wasn't difficult to get basic information, just time-consuming..."

Participant 8: "There was a lot of information on the internet but you must remain sceptical of everything you read from positive review to success rates to financial costs"

Participant 23: "It was relatively easy to obtain initial information about CBIT. To gain access to the finer details was a little harder as language can sometimes be a barrier".

With the lack of availability of reliable cross border clinical outcomes, participants found it difficult to compare different clinics' success rates. Participant 8 expressed that positive information about clinics should be treated with caution and Participant 23 found it difficult to ascertain in-depth information from overseas websites due to a language barrier.

Eleven participants (Participants 1, 5, 7, 9, 10, 11, 12, 21, 22, 24, 26) investigated the success rates provided by foreign infertility clinics and three (Participants 4, 12, 15) clinical skills and expertise of the medical staff. Twelve participants (Participants 1, 4, 6, 11, 12, 14, 15, 17, 18, 20, 23, 26) cited the reputation of the staff's specialist expertise as one of the reasons for selecting a specific clinic (sample quotes below):

Participant 4: "...worldwide expert practising in C...N... and so we decided to request a consultation with him..."

Participant 12: "Dr S has published...mTESE and pregnancy data relating to NOA, and particularly to y gene deleted men, with much higher success rates than reported from other clinics"

Participant 20: "We chose...Clinic in SD because the main Doctor had already experienced surrogacy for MRKH patients".

Participants began to communicate with their chosen clinic either online or via telephone conversation to ascertain staff attitudes:

Participant 10: "...they are more flexible, you feel more like an individual"

Participant 24: "...clinics were supportive and sensitive when offering egg donors"

Participant 26: "...staff provided me with travel information and support to plan my trip...I met wonderful people on every step of the journey, who were very professional, caring, and supportive".

Thirteen participants contacted the foreign clinic directly either via internet or telephone

conversation to ascertain potential communication issues (i.e. language barriers) prior to starting their CBRS journey. Other participants sought an infertility agency or shared care with their home infertility clinics:

Participant 15: "Their communication is terrific, the main doctors speak English"

Participant 21: "...good communication/ease of communication with clinic"

Participant 25: "I was able to talk directly to the specialist and set up the appointment at quite short notice..."

6.4.3 CBRS Logistic Arrangements

Fourteen participants were in a relationship whilst undertaking CBRS and reported making joint decisions for their CBRS project (three sample quotes below):

Participant 4: "C (Female) worked out the logistics of the cycle"

Participant 6: "I would say it was a joint effort between me and my husband, the agency and the clinic. Between me and my husband, it was a joint decision – I started the research, narrowed things down and brought choices to my husband. We made the final decision together - In terms of logistical planning we split the jobs between us"

Participant 8: "My wife decided things like donors to use, when to begin, when to stop, which clinic to use - but the logistics...was left to me".

Although some participants reported that the logistic arrangements for CBRS were shared with their partner, for others the majority of the decisions were made by the female participant.

Twenty-two participants also recounted the logistics relating to accommodation. Eighteen participants chose to stay in a hotel, guest house or bed and breakfast accommodation near to the clinic in the destination country. Three participants' organised apartments or home swapping via a travel agency and one participant had her accommodation organised by the clinic in the destination country.

They tend to choose clinics that were easy to get to (Participants 18, 21, 23), in locations that were accessible via low-cost airlines (Participants 18, 21).

The duration of stay by participants varied from only one night (Participant 18) up to three weeks (Participants 12, 14). Participants had to plan all the clinical visits around their employment:

Participant 1: "I planned around work holidays, flight schedules and appropriate intervals between treatment, medicated cycles and availability of clinic"

Participant 18: "I flew from L to B on Friday and returned Saturday for the initial consultation. Therefore I only had to take one day off work. The appointment was late Friday afternoon".

6.4.4 Support for CBRS

Support for CBRS could be derived from a number of sources (i.e. family, friends, support groups and clinics in home country). Four participants reported that they did not receive any support from their family and friends. Two participants articulated that family and friends cannot "really help with advice as they have not been in" (Participant 10) the participant's situation as one could not "just drop it into conversation" (Participant 13).

Thirteen participants reported that they had support from family and friends (three sample quotes below). Family support was received by a number of participating couples (Participants 5, 6, 8, 9 and 12):

Participant 8: "We shared our decision to pursue CBRS with our parents. Our parents supported us with positive thoughts. My father had a friend who had used CBRS and shared his story with us"

Participant 9: "My sister was a great support. Both our parents knew our plans and were very supportive and encouraging"

Participant 12: "Financial support from family, emotional support from both".

Participants were grateful for the help and assistance from their family. Participants also reported practical help they had received from friends:

Participant 13: "...2 good friends who I confided in about what I was doing - one looked after my other child whilst I was away and the other one came with me when I had my treatment"

Participant 23: "...she had done a lot of research...so I was able to go straight to the information required...".

These friends tended to have infertility issues themselves so they could relate to the participant's dilemma:

Participant 18: "I have a very close friend who is also infertile and has used donor eggs to have a child so I am able to talk to her about things. Also I have another close friend whom I share with but is less of a support".

Three participants (Participants 7, 8, 24) did not gain support from infertility networks and fourteen participants obtained support from various infertility networks (i.e. Donor Conception Network, Fertility Friends and IVF connections). This support varied from local support groups, infertility internet chat/forums, workshops to conferences. Many

participants found these networks helpful and useful in preparing them for undertaking international travel:

Participant 3: "The Donor Network Workshops have been a great help in making the whole process 'normal'"

Participant 4: "We met one couple in...support group who had travelled abroad. We heard from them how they planned and implemented their cycle"

Participant 9: "I used the DC network website for information (they were the most informative)"

Participant 10: "The best source of information and support for me has been Fertility Friends website/forum and in particular the Single Women Group. We have regular face to face meetings as well as interacting regularly online and I have benefitted hugely from their experience and recommendations"

Participant 16: "I joined the Single Mothers...email group based in the US, who were very helpful".

Once again, these informal and at time face-to-face meetings enabled the participants to acquire useful information about treatment and practice abroad prior to travelling.

Out of fourteen participants who reported their relationship with their home clinics, only four participants' remained in contact with the clinics:

Participant 10: "My UK clinic played no role in helping me identify the right clinic abroad but was supportive in terms of offering to provide scans etc (at a cost of course!)"

Participant 13: "I linked with my old clinic here in UK who were very happy to help with scans and some meds"

Participant 24: "Once we had decided to use CBRS, a co-ordinator from the UK clinic helped us through the process" (This is a share care CBRS).

Participant 12 reported their home clinic's scepticism about their decision to travel abroad for treatment as they were not convinced that "we would be successful".

Of the 26 participants, only four reported receiving counselling prior to travelling abroad for treatment.

6.5 Stage 4: Expectation and experience of CBRS

The following section presents the participants' responses around their expectations and experience of undergoing CBRS (see Figure 9, p.149). The substantive themes in this

stage were financial cost; emotional responses; language barriers; law and regulations, clinical environment; patients' characteristics; risks; treatment protocol; staff; successful attempt, recommending or returning to CBRS; support (i.e. family and friends).

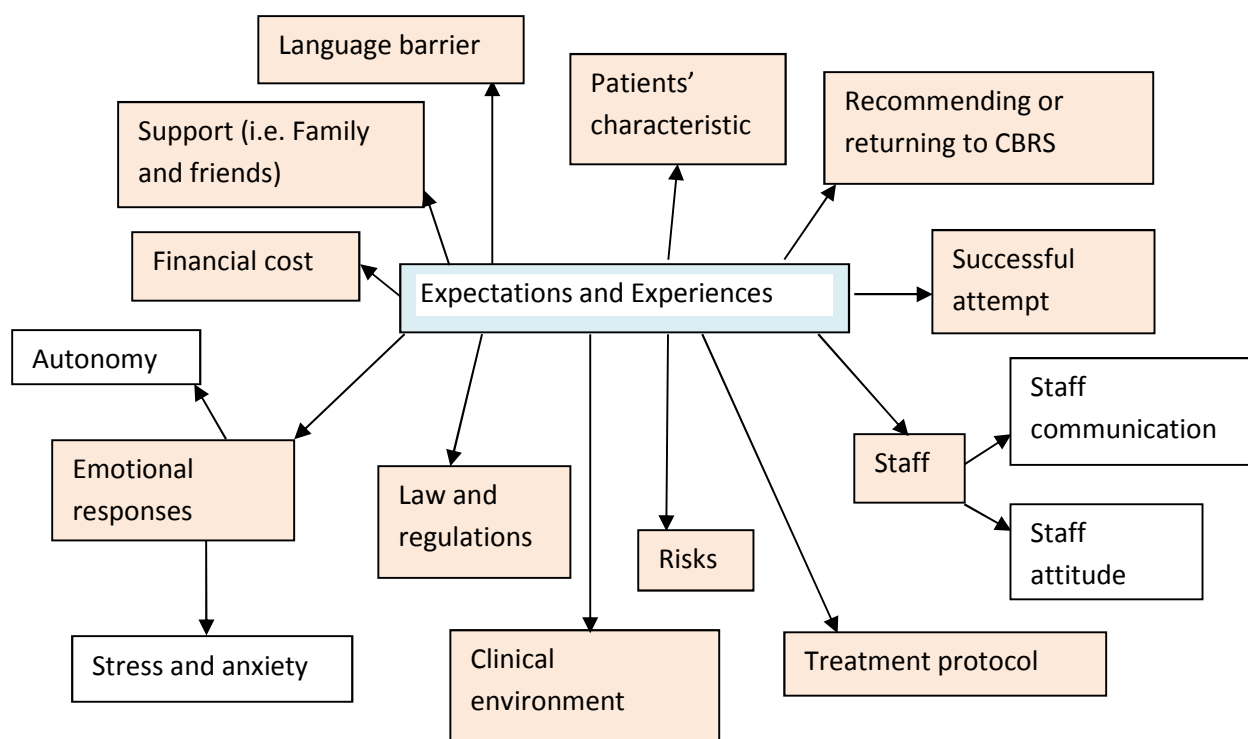


Figure 9: Expectations and experiences during CBRS

6.5.1 Financial Cost

Participants reported they knew the cost of cross border reproductive treatment:

Participant 16: "I had found out what I needed to from the...I had no unpleasant surprises regarding costs etc"

Participant 17: "We had a good idea of what the costs would be..."

Some participants thought the cost was lower than (Participants 5, 11, 13, 14, 15 and 25), or similar to (Participants 8, 23), their treatment at home and some participants (Participants 2, 6, 12, 24) expected treatment costs to be higher as they were accessing specialist treatment:

Participant 2: "I was aware that the cost of treatment out of country would be much higher"

Participant 12: "We knew we were having very expensive treatment ...".

A number of participants (Participants 1, 2, 6, 10, 11, 19, 24) mentioned that they had to pay for their treatment prior to their CBRS. This could be in the form

of a “deposit” (Participants 8, 11) or full cost of the treatment prior to their travel. Participants might not be happy with this arrangement; however, they felt powerless to argue with the clinic’s demands:

Participant 1: “I knew the cost and paid most of it before I left”

Participant 2: “We paid the fees to begin treatment...”

Participant 6: “We had to pay the full cost of the treatment up front which we weren’t happy with but felt we weren’t in any position to argue”

Participant 24: “Like a lot of people, we only paid for half as we couldn’t afford the full amount”.

Participant 11 had her credit card stolen whilst she was abroad having treatment. Her clinic “insisted on payment...[she] had to make a tearful international phone call” to her bank and “arrange an international transfer over the phone to the clinic”.

Most participants had a good understanding of the costs of their treatment in the foreign clinic. However, some reported unexpected costs as a result of increase in drug costs, subsistence and the fluctuation of the exchange rate and cancellation of travel arrangements:

Participant 6: “...the donor required more meds than thought...”

Participant 12: “... ended up ordering too many drugs and spending more money as I was worried about running out and delivery issues...cost us money as we had to cancel our original flights home and buy new ones in the run up to Christmas”

Participant 17: “We also knew the cost of the cycle, airfare and hotel costs, as all was planned beforehand. The only unknown was the cost of food/entertainment ...We realised the cost/benefit ratio of doing a transfer in Spain was no longer advantageous for us”

Participant 22: “...£ and Euro had parity at the time...we were undergoing treatment...”.

6.5.2 Emotional responses during their CBRS

6.5.2.1 Autonomy

Some participants stated that they could “choose” (Participants 1, 2, 6, 7, 8) their gamete donors and expressed a sense of autonomy during their CBRS, although one participant “didn’t have any choice” (Participant 5). Participants 1, 8, 9 had a larger selection of donors to choose from:

Participant 8: “We were given a choice of 150 – 200 donors (which was significantly limited based upon our major request that the donor have Latin ancestry) so our choice was between 10 -12 donors”

Participant 9: "We specified that we would put more importance on matching the blood group rather than the physical attributes when selecting a donor".

Participants could also have some say on the embryo transfer process:

Participant 11: "... how many eggs had fertilised and were told that we could take them to blastocyst stage if we wanted..."

Participant 24: "We were told that we had 3 viable embryos and we chose to have 2 put back".

This autonomy "empowered" (Participant 11) during the CBRS journey with less medicalisation and the participant was able to adopt a business model approach:

Participant 16: "I was treated more as a client. Someone who sought expert, professional advice but could, if I wished, take my business elsewhere...I felt like a customer paying for the services I needed, not someone at the mercy of a medical system".

6.5.2.2 Stress and anxiety

Five participants (Participants 4, 6, 9, 12 and 23) expressed stressful experiences associated with their CBRS (three sample quotes below):

Participant 4: "We expected that doing a cycle abroad would be more stressful than at home because of the additional travel involved and staying away from home for a stretch of time"

Participant 6: "My husband and I have both developed colds which I blame partly...on...the added stress of organising to be abroad..."

Participant 23: "I didn't expect that it would be as stressful as it was".

Ten participants (Participants 6, 8, 10, 11, 12, 17, 18, 22, 23, and 24) reported that their stress invoked either past or current experiences (i.e. previous miscarriages (Participant 6); low stimulation (Participant 12)) or was caused by the CBRS itself (i.e. the "lack of communication from the embryologist/physician during the incubation time created a lot of anxiety of us" (Participant 8); "stress of dealing with the clinic" (Participant 17)) or the logistical arrangements when undertaking CBRS:

Participant 6: "...home swaps so had quite a bit to do to get our apartment ready and to prepare to be away for nearly 3 months"

Participant 11: "We were told we would have 48 hour notice to fly to city B for egg collection/fertilisation which was a stressful situation to undertake as we also have a 9 yr old son at school"(sic).

Participants were worried that uncontrollable events could occur after their embryo transfer (i.e. embryos "fall out if I go to the Loo" (Participant 1)).

Strong emotions were reported by some participants whilst undergoing CBRS (four sample quotes below):

Participant 3: "I would cry uncontrollably for days..."

Participant 11: "I was in tears again (it's a very emotional thing to do!)"

Participant 12: "I cried with happiness after the transfer..."

Participant 24: "...during the periods of waiting, we had more time to think and worry. At these times this caused me a lot of anxiety...Overall it was both exciting and a stressful experience".

Some participants found these sensations (i.e. "lonely and scared") unpleasant (Participant 11), especially when their partner could not be there during the CBRS due to "work reasons" (Participant 12). Participants did not "want the experience to be" (Participant 23) stressful and found these emotions "very hard and quite draining" (Participant 18).

Some participants attempt to get "through it without getting too stress or depressed" (Participant 18); however, some participants found they "were permanently anxious" (Participant 12) and found "it very difficult to relax" as "it was always in the back of my mind" (Participant 24).

The overall feeling from participants were that they had a positive CBRS experience (Participants 1, 8, 11) and were confident with their CBRS clinics (Participants 12, 16, 17). Two stated that they were comfortable throughout their treatment (Participants 13, 18).

6.5.3 Language barriers

Twenty one participants reported that they did not expect to have any language issues with their CBRS. Many participants had contacted their clinic directly either via email or telephone:

Participant 1: "I had emailed and phoned them quite a bit from the USA so I knew their level of language ability"

Participant 25: "I had had several telephone conversations prior to arriving in the foreign 'clinic', so knew to some extent what to expect".

Many participants had a positive experience with their doctors in overseas clinics and reported that they could communicate very well in English with them (four sample quotes below):

Participant 1: "My Drs all spoke OK English..."

Participant 13: "I wondered if the other clinic staff would be able to speak English and most of them couldn't but this was OK as my doctor English was perfect and one or two of the other staff spoke some English too"

Participant 17: "Some of the people at the clinic spoke English well. Our Spanish doctors were educated in the United States"

Participant 19: "The staff were helpful, when I phoned I would ask for the English speaking member of staff (her job as I understand was solely to liaise with non-Spanish patients so she was fluent in English) and be put straight through".

However, some participants experienced language barriers (two sample quotes below):

Participant 3: "...after an English speaking patient liaison person left, it fell apart ...communication was a problem if the English liaison staff were off duty...you are placed on hold while the non-English speaking receptionist tries to get someone to talk to you. This was a lengthy call..."

Participant 11: "We didn't expect to have communication problems with...clinic but we did have communication problems with B - there seemed to be only a few dedicated administrators who could speak English. The receptionists could not speak English and on telephoning the clinic it was impossible to talk to someone immediately - you had to leave a message in English. The language barrier was difficult particularly when things did go wrong".

The issues seemed to be related to the administrative staff's ability to communicate in English and the speed with which participants' concerns regarding their treatment were resolved.

6.5.4 Law and regulations

Sixteen participants (Participants 2, 4, 5, 7, 9, 11, 12, 13, 14, 15, 19, 20, 21, 22, 23 and 25) did not expect any legal implications as a result of undertaking treatment abroad although, most had investigated the legal situation in advance by either contacting a CBRS agency, or sought advice from the foreign clinic itself or from their home clinic (five sample quotes):

Participant 6: "We have contracts with the agency and the clinic, as does the donor and the law in Canada is pretty clear about who is the legal mother with this treatment"

Participant 8: "Prior to considering CBRS we sought specific knowledge about legalities. For example we wanted to know about 'ownership' of embryos, record

retention policy and what the donor's role would be post donation"

Participant 16: "The USA clinic had legal agreements with its donors and clients similar to those in the UK in that the donor would have no legal responsibility for any offspring. The difference was that he undertook to be known to the child when the child was 18. I accepted, however, that many things might make this impossible, including his earlier death, imprisonment, disappearance etc"

Participant 17: "After we thoroughly researched Spain and laws related to donor egg cycles and the fact that the donor and recipient are anonymous, we didn't feel there would be any legal implications"

Participant 19: "...it was explained to me by my consultant here that whoever gives birth to a child is the legal mother".

Many participants seemed to have some legal knowledge; however, some participants still might not fully understand the legal position:

Participant 20: "To be counselled regarding the legal aspects of gestational surrogacy...We did not expect any legal trouble based on the past experiences of other infertile couples who travelled to surrogacy countries. We have been very surprised by reality thereafter".

A number of participants undertook treatment in countries that imposed fewer restrictions than their home country regarding the number of embryos transferred. Some CBRS offered one or two embryos transfer (Participants 1, 2, 7, 8, 9, 10, 12, and 18). Some clinics appeared to place no limits on the number of embryos they were willing to transfer, while others agreed to transfer more than two embryos if the patient signed a "waiver":

Participant 1: "...I had to sign a waiver as their policy was to only transfer 2. The clinic director had to sign off"

Participant 10: "I believe there are no legal limits to no of embryos transferred in Czech Republic...".

6.5.5 The clinical environment

Many participants (Participants 2, 6, 8, 11, 12, 14, 17, 18, 21, 22 and 23) expected the CBRS clinic environment to be of the same level of hygiene and care compared to their home clinics:

Participant 2: "I expected the same levels of treatment in the clinic with respects to staff and hygiene as my home clinic"

Participant 6: "Once I'd researched our clinic pretty carefully I thought the surroundings would be more spacious and comfortable"

Participant 8: "We expected to see a clean environment (offices, treatment room,

etc.)”.

All participants indicated their expectations were met and some found the clinics’ at times exceeded their expectation:

Participant 11: “We expected a clean hygienic modern clinic and we were not disappointed”

Participant 12: “We had very high expectations of hygiene and these were also met - the clinic could not be faulted for cleanliness”

Participant 18: “...state of the art”

Participant 21: “We expected facilities and procedures similar to what we had experienced here but in fact they were far superior”.

6.5.6 Patient Characteristics

Two participants were surprised by the characteristics of other patients in their CBRS clinics:

Participant 1: “Each time I went I was the only foreigner at the clinic. I did not expect that the overwhelming majority of their patients would be Ukrainians. They were”

Participant 12: “We had not expected the number of TESEs that were done in a cycle and the number of couples there having treatment for severe MF infertility”.

Participant 1 did not expect her CBRS clinic to be treating more local patients than foreign patients. Participant 12 received TESEs treatment from a specialist clinic, even with that knowledge, the couple expressed a normalisation feeling as now they know there are many patients with the same “rare” diagnosis and going through the same treatments. This was raised by only two participants; therefore, this observation might not be a significant issue for CBRS.

6.5.7 Risks

Five participants (Participants 5, 7, 9, 19 and 23) did not anticipate the risks of CBRS:

Participant 23: “...When I got to the clinic and started going through the procedure I realised I hadn't thought deeply enough about the actual process and the possible risks involved...”.

Eight participants (Participants 2, 13, 14, 15, 16, 17, 18 and 21) believed that their CBRS treatment would have a similar level of risk (i.e. medical complications) when compared to the treatment they had received in their home country and felt they were prepared and knew the risk involved with their CBRS:

Participant 2: "I did not believe the risks of treatment out of the country to be any higher than in my home country"

Participant 14: "I knew there must be risks with any treatment but I was ready to face any challenge"

Participant 21: "I had already been through treatment in the UK and felt well prepared in terms of my health and knew what risks there might be".

Six participants (Participants 3, 4, 8, 12, 22, and 25) described the potential risks involved in their CBRS: accidental embryo switch, risk of hyperstimulation, egg donors withdrawing from treatment or egg donors becoming ill during their cycle. The participants' biggest fear was that of failed treatment cycles and miscarriages (four sample quotes below):

Participant 3: "...there is always the fear you will be given the wrong embryo – you read of the horror stories...and mix ups and in...donor been given embryos of a different race"

Participant 4: "There is always a risk of hyperstimulation (and I have had borderline OHSS previously) so there was a slight concern there..."

Participant 8: "...we expected a risk that the donor would decide to back out of the process once we started. We expected a risk that the donor would become ill during the stimulation..."

Participant 25: "... the possible risks were that the treatment would not be successful; or I might miscarry again..."

Their experience of risk altered after the participants (Participants 1, 3, 5, 6, 7, 8, 9, 10, 12, 16, 18, 19 and 23) had CBRS; they mainly mentioned the screening process for infectious diseases and genetic conditions. They seemed to place their trust upon the CBRS to provide a safe treatment (four sample quotes below):

Participant 3: "No concerns regarding HIV etc as was informed those donors are screened, which I took on board as fact"

Participant 6: "...who was screened for all infectious diseases...We also had the option to screen for various genetic conditions. So we were happy with the screening process"

Participant 10: "I had no concerns re the screening; I trust the clinic to do a thorough job with this"

Participant 12: "I always felt safe and that they knew what they were doing..."

6.5.8 Treatment protocol

Participants (Participants 1, 2, 3, 4, 7 and 9) felt fairly confident and expected their

treatment to "go smoothly as per plan" (Participants 2 and 6) and one participant was given "a very detailed outline of what to expect" (Participant 9) during their CBRS.

Two participants did not know what to expect from their CBRS infertility treatment:

Participant 16: "I didn't know whether my treatment would go smoothly or not"

Participant 18: "I did not really know what to expect with the treatment".

Participant 23 expressed her "hope" for her treatment to "go smoothly"; however she acknowledged "things in Asia rarely go to plan!!!".

Some participants experienced unexpected complexities in their treatment, such as medications, re-testing for their infertility diagnosis for their CBRS, their own health (i.e. bad cold (Participant 4), premature bleeding (Participant 11), fibroids and polyps (Participant 14), breast lump (Participant 16) or ovarian cyst and dermatological problems (Participant 17)) and the impact of problems with egg donors (i.e. cyst found or sub-optimal response in egg donors (Participants 6 and 8)) upon their treatment cycles:

Participant 6: "The planning was more complex than I'd anticipated and I really had to keep my wits about me dealing with all the different parties and time zones involved (agency - USA/South Africa; clinic - Canada; pharmacist/GP/test centres - UK...I had problems ordering the medication...the nurse phones the pharmacy with the prescription...you phone to pay for it and arrange home delivery. My drugs ended up being delivered and sitting by a radiator in the doorman's office"

Participant 8: "We did not expect to need to take the prescription from the CBRS clinic, give it to our GP, take the GP prescription to the pharmacy and explain the reason why the dosing was not common. We definitely did not expect to have to complete release of records forms to get lab test results so that we could fax them to the CBRS clinic with very tight turnaround times. We expected that tests that were already completed would not have to be repeated".

When participants did not know their treatment protocol or found that it differed from what they had previously experienced in their home country, some voiced concerns:

Participant 3: "I was brought into a room informed...what was going to happen and the procedure was done and I was back in the hotel within 40 mins without actually seeing people's faces as they were gowned up - a bit scary...I was angry and concerned that...donor information to my travelling companion rather than me while I was in having the transfer done..."

Participant 6: "My only slightly negative surprise is that the clinic seemed to be keener on a day 3 transfer than a day 5 one which is not what I'm used to"

Participant 18: "I did get an angry red and painful rash at the site of the patches but only when I put them on certain parts of my body. I was concerned that I would forget to change the patches when I was supposed to"

Participant 23: "I felt like I was not in control of the process the whole time which unnerved me..."

Three participants (Participants 11, 17 and 25) voiced their unease relating to compromises to their privacy and dignity during their treatment:

Participant 11: "Once in the transfer operating room I had to lie with my legs apart and a speculum inserted into me for over 20 minutes while the embryos reached optimum temperature"

Participant 17: "A long line of ladies on gurneys (trolleys) in a queue was in the hallway"

Participant 25: "What I was not prepared for was lying in a public ward, after treatment, next to someone who could potentially have been my donor".

6.5.9 Staff

Eleven participants anticipated a sense of excitement because they could at last "meet" (Participants 1 and 3) the staff with whom they had been communicating prior to their CBRS journey. Many found their CBRS staff were professional (Participants 4, 5, 13 and 25) and "nice, warm and friendly" (Participant 21).

Participants experienced a variation in staff practice. On the one hand, Participant 3 did not even know what the staff looked like, whereas Participant 9 had a detailed explanation of her treatment:

Participant 3: "...without actually seeing people's faces as they were gowned up - a bit scary..."

Participant 9: "Our initial consultation with the clinic gave us a very detailed outline of what to expect".

Participant 14 was from Tanzania and was worried with the history of South Africa and anticipated that she may experience racial discrimination however, she still expected to receive individual consultation with CBRS staff:

Participant 14: "Staff - I was a bit sceptical because of the history of S. Africa of apartheid but I expected flexible one-on-one consultation with the doctors and other staff".

6.5.9.1 Staff Attitudes

Many participants commented upon the supportive and approachable (Participants 1, 2, 8, 15, 16, 20, 21, 23, 24 and 26); professional (Participants 17 and 18); friendly and

competent staff (Participants 4, 7 12, and 13) whom they had met during their CBRS (three sample quotes below):

Participant 1: "At one point before a transfer the embryologist was having difficulty putting in the speculum and she just said hmm, I'll have to go get the other size. She did not tell me to relax or just breathe and continue to try with the standard size. She went and got a different size and the rest of the transfer was completed without a hitch"

Participant 16: "Staff at the clinic knew I had travelled a long way to be treated there and were very kind, including meeting me socially outside the clinic"

Participant 24: "We accidentally bumped into one of the technicians who was very kind and sweet...The co-ordinator came and spoke with us and she was very positive and excited for us".

Contrarily, some participants recalled negative experiences of their contact with staff in the overseas clinic:

Participant 3: "...felt very much like a number being processed most times..."

Participant 11: "The clinic refused to take the eggs to the blastocyst stage...While we all waited the Spanish nurses were chatting to each other and laughing in Spanish...Once the transfer had been done I was specifically told to lie still for 20 minutes before moving. There was no one around and no clock in the room where I was and I was in tremendous pain from my bladder. When I thought 20 minutes was up I got dressed and left the room...I had tears pouring down my face and they didn't notice. It was not a nice experience...There was no one around and no one said good bye to me when I walked back out through reception"

Participant 17: "We felt the original staff were more professional and caring and had a bond with the people through email...this time we had a different experience with the new staff...we found the new staff to be less caring and more disorganised..."

6.5.9.2 Staff communication

Seventeen participants reported on their experiences of communication with staff in the clinic, ranging from clear instructions (Participants 1, 3, 4, 12, 13 and 21), communication by either email (Participants 2, 6, 11, 15, 16 and 24) or telephone conversation (Participants 6, 9, 11, 16 and 18).

Some participants had encountered some good communication practice (Participants 6, 8 and 10); others however, felt they had to chase the clinic for information due to none response or slow response time from their overseas infertility services (Participant 6, 8, 11 and 17):

Participant 6: "After some frantic long-distance calls and a helpful conversation with the Consultant (on a Saturday which impressed me)...I had to chase a little

for information...they hadn't called back because there was a problem and they needed to speak to the doctor...They didn't apologise on the phone and I didn't get a reply to my email..."

Participant 8: "The liaison returned calls very promptly and provided us with information...After we did not hear anything for 2 weeks we called the clinic to find out our next step". Participant 8 also experienced repeated requests for some information during her CBRS as the CBRS "had coordinated 4 appointments (with different professionals) into one day and they...asking the same questions over and over"

Participant 11: "The clinic was very poor in their response to emails and I waited up to 2 weeks for a response to an email question...We received a phone call on a Saturday morning, advising us that our own donor's cycle had failed. However, they told us that they had another donor whose recipient's cycle had failed and her characteristics matched our requirements. If we wanted to accept, we needed to be in Barcelona within 24 hours"

Participant 17: "After waiting a few months for an answer, we were told we could not have the same donor".

Participant 17 bought a local cell phone to facilitate communication with her clinic, although the clinic failed to communicate with her effectively:

Participant 17: "...so we went to the store and bought a cell phone (which wasn't cheap and it took a lot of our time and energy to figure out which one to buy). We contacted the clinic so that they'd have our cell phone number...the day that they wanted us to be at the clinic for transfer, they never called us on the cell phone. The person at the clinic called the hotel. The hotel did not get the message to us that morning. We went out for the day thinking they'd call us on the new phone. We received an urgent message that evening when we returned to the hotel".

With mis-communication, participant 19 arrived at the wrong CBRS clinic and

Participants 22 and 25 did not feel supported during their CBRS treatment:

Participant 19: "...we actually turned up at the wrong clinic, as they had opened a new building and we hadn't been told! However there was a staff member at the place we went to who helped us get a taxi to the correct place..."

Participant 22: "I was told that my embryo transfer was to take place at 12.30 pm and that I needed to have a full bladder. I hung on until 1.00 pm but no-one came for me. I then had to wait while I drank another litre of water so the process could start again"

Participant 25: "I felt that the Doctor was not used to answering questions of the kind and level I was asking in relation to the donor".

Overall, most participants experienced good staff communication from CBRS clinics;

however, some experienced mixed or poor communication from CBRS. CBRS staff communication was found to be vital to the participants' CBRS experience.

6.5.10 Successful attempt

Twenty participants anticipated a positive outcome from their CBRS even though, previously, most of them had had multiple failed treatments at home (two sample quotes below). Participants were in some way looking for answers as to why previous treatments had not worked. With their own personal research, they provided rationales, such as CBRS had a higher "published" success rate (Participants 6, 7, 11 and 20) and used younger donors (Participant 24). Many felt confident that they would achieve their quest "to get pregnant" (Participants 1 and 23), "to hold a baby" (Participant 14) and "becoming parents" (Participant 20):

Participant 4: "We hoped that testing and treatment with the clinic we had found in E would finally provide answers as to why fertility treatment had not been working for us and we hoped that it might result in a successful cycle"

Participant 6: "With success rates of over 70% I was feeling fairly confident that we would go home pregnant ultimately".

In this study, seven participants reported their treatment as excellent, 14 had good and two had satisfactory experiences of their treatment. Four participants reported excellent experience and had a positive outcome; however, three participants (Participants 5, 12 and 18) reported that they had excellent experience with their CBRS clinics despite not getting pregnant. Those who had a positive outcome reported a good experience from their clinics and once again, despite negative outcomes, Participants 3, 6, 10 and 24 reported they had a good experience from their CBRS. Neither of the participants (Participants 8 and 23) who reported satisfactory experiences were successful in their treatment.

The positive responses from participants with negative outcomes derived from the staff attitudes and the way in which the clinic communicated with them.

Nine participants reported their CBRS had met their expectations; however, four participants (Participants 6, 8, 14 and 18) felt their needs were not fully met (two sample quotes below):

Participant 8: "The experience met our expectations or slightly fell short in terms of how much coordination was left to me"

Participant 14: "Fell short".

6.5.11 Recommending CBRS to others or returning to CBRS themselves

Eleven participants (Participants 1, 4, 5, 6, 7, 9, 10, 12, 13, 16, and 18) said they would recommend their CBRS to others. Four participants (Participants 1, 4, 5 and 19) reported that they intended to return to their CBRS, whereas Participants 6 and 23 would like to try CBRS in another country and Participants 12 and 14 were not sure if they would go back to their CBRS. Finally, Participant 16 decided to stop because of her age ("I'm 52 now, so I won't be going back to this clinic again").

Participant 6, even with her unsatisfactory experience of needing to chase information from her clinic, would still recommend her clinic to others and the main reason for her not returning to her CBRS was for financial reasons ("We can't afford to return").

Interestingly, Participant 3 would not recommend her CBRS clinic in City B, in Spain whereas she would recommend her CBRS in City M, Spain and City B, in the Czech Republic. She favours the CBRS in City B in Spain mainly because it is a cheaper clinic.

Participant 8 chose not to return to her CBRS and would place a "caveat" when recommending her CBRS to others that the person "be aware that the clinic expects you to" have access to a fertility clinic close by at home in order for the home clinic to perform all the diagnostic tests and scanning prior to travelling to their overseas clinic.

6.5.12 Support

During participants' cross border reproductive treatment, 11 participants (Participants 1, 3, 5, 6, 8, 10, 11, 12, 14, 19 and 23) received support from family and friends either in the form of email (Participants 1, 6, 12 and 14) and/or phone calls (Participants 3, 5, 6, 8, and 14) .

Participant 10 preferred to receive text messages from her family and friends as she would rather "not talk about the treatment too much..." Similarly, Participant 12 also utilised text and email to receive support from family and friends. She felt they (family and friends) "did not know what to say or what to ask about but when given information they were always very happy and supportive".

Participant 11 received practical help from her parents ("My parents agreed to come down at short notice to look after our son whenever we got the call"), whereas Participant 23's friend accompanied her on her CBRS journey ("it was great to have her there to talk to").

One participant (Participant 4) did not inform her family about her CBRS.

Six participants (Participants 4, 6, 5, 10, 12, and 16) expressed that infertility friends and networks were a good source of support during their CBRS (three sample quotes below):

Participant 4: "...day to day support came mainly from friends we have made through infertility groups ..."

Participant 10: "I also got a lot of 'virtual'/online support from my network of single women...on Fertility Friends"

Participant 12: "Amazing support from internet buddies...".

Three participants had contact with their home infertility clinics (Participants 4 and 11) or family physician (Participant 8). Apart from Participant 6 who had support from her CBRS liaison nurse, four participants (Participants 7, 8, 11 and 14) reported that their clinic was professional in sorting out their infertility treatment needs. However, they did not feel that they were supported emotionally by the clinic:

Participant 7: "...support from clinic in sourcing some drugs..."

Participant 11: "The clinic was very professional but didn't offer much emotional support to me".

Six participants (Participants 5, 7, 9, 10, 14 and 19) reported they had counselling either before (Participants 5 and 19) or during their treatment overseas (Participant 10). However, Participants 7, 9 and 14 did not report when they had their counselling. Participant 9 had fertility counselling and discussed her "thoughts" and found the counsellor advice was "very informed, open and positive".

6.6 Stage 5: Returning home after CBRS

The following section presents the participants' responses around their experience after their CBRS once they returned to their home country (see Figure 10). Five major themes (CBRS clinic responses, emotional responses after CBRS, home clinic responses, decision for CBRS and support) were identified and they will be discussed in turn.

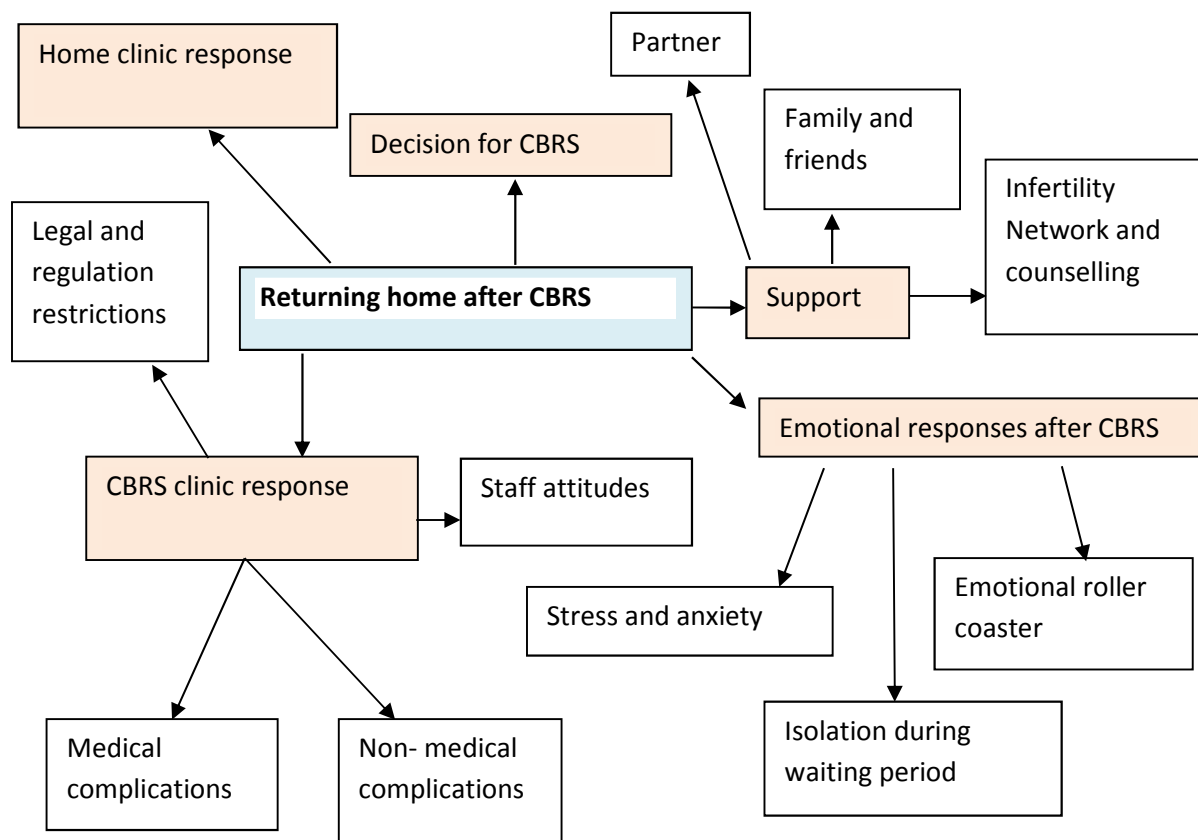


Figure 10: Returning home after CBRS

6.6.1 Cross border reproductive clinics response

6.6.1.1 Medical complications

Thirteen participants reported some form of medical complication after their CBRS ranging from pneumonia, bruising due to high dose of aspirin injection (Participant 3), bad cold, placenta deficiency (Participant 4), abscess around progesterone injection site (Participant 6), arrhythmia (Participant 8), infection (Streptococcus) (Participant 11), miscarriage (Participant 12) and emergency removal of early embryonic tissues (Participants 12 and 16), multiple pregnancy (Participants 7, 15 and 17), bleeding during first trimester of pregnancy (Participants 21 and 22). Only two participants (Participants 19 and 20) reported that they did not have any complication after their CBRS. Assuming the remaining 11 participants did not have any post CBRS medical complication that they considered merited reporting, this indicated 13 out of 26 (50%) participants experienced some form of medical complication after their CBRS treatment.

Eight participants (Participants 4, 6, 8, 15, 17, 19, 21 and 22) communicated with their CBRS regarding their concerns and received advice from clinics to resolve these (four sample quotes):

Participant 4: "...positive pregnancy test, staff were available to talk through medication queries and to discuss results of scans done in Ireland, i.e. the follow

up was also good...My Consultant contacted my GP in Ireland who referred me to an obstetrician"

Participant 6: "It turned out we weren't injecting in quite the right place which may have had something to do with it. Anyway, it resolved by itself without the need for antibiotics"

Participant 8: "The clinic called us the next week asking if we could fax the result for their records and to advise us that we could have a telephone follow up call with the physician if we wished"

Participant 22: "...a doctor from the hospital in Spain rang me immediately (at 10pm – 11pm in Spain) and said not to worry it was probably implantation bleeding and to increase the doses of hormones I was taking".

Participant 3 who had a negative pregnancy test "did not" see "the need to communicate" with her CBRS clinic and the overseas clinic "did not refer" her or never made any reference to medical follow up in her home country (Participant 3).

6.6.1.2 Non-medical or legal and regulation issues

Nine participants reported that they have not had any non-medical problems (i.e. chased up for money) after their CBRS as the participant had "to pay up front" (Participant 18) for their CBRS. Participant 6 felt that the "industry as a whole is fairly money-driven" and Participant 14 expressed that after her failed CBRS she is now "in debt".

Participant 16 was contacted by her CBRS regarding her sperm donor as he "had reached his limit (10) of successful pregnancies and would be "retired"." The clinic suggested if she "wanted to buy more sperm for a sibling...[she] would need to do so now". She "did hope to have another child who was a full sibling...[so she] imported" the sperm to use in her home country.

Participant 20's wife had surrogacy in the USA. On returning with their daughters, the French government refused to issue papers for the children because surrogacy is illegal in France. These participants "faced a police investigation, interrogation, trials...[and] still working on the civil...trials (we won two)".

6.6.1.3 Staff attitudes

Participants who experienced a positive outcome of their treatment (Participants 11, 20, 22 and 24) were more likely than participants who failed to achieve a pregnancy (Participants 8 and 10) to express positive opinions about clinic staff:

Participant 20: "The medical staff were very kind with the three of us (the

surrogate, my wife and I)”

Participant 24: “The USA coordinator also emailed to say congratulations...they made you feel like you were important in the process”

Participant 8: “...follow up call the physician reviewed the treatment plan and determined that the failure was just bad luck...”

Participant 10: “The doctors were very sympathetic but there is little they can do if it does not work so it’s not that I would be expecting anything other than a brief email back from them”.

6.6.2 Home clinics’ response

Thirteen participants reported their experience once they returned from their CBRS. Apart from Participants 4 and 22, most of them did not have any referral pathway back to the home health or maternity system. Participant 13 “did not show” the paperwork from her cross border infertility clinic to her midwife, as she viewed it as “private” to her.

Some participants (Participants 2, 16, 19, 24 and 25) returned to their home infertility consultants for maternity care and some (Participants 5, 7, 9 and 15) went straight to their local doctor (i.e. family doctor or obstetrician) to be referred to maternity services.

6.6.3 Decision for CBRS

Sixteen participants (Participants 3, 4, 5, 6, 7, 8, 9, 10, 11, 13, 14, 15, 17, 18, 19, and 22) articulated that their decision for CBRS had been the correct one. Some participants would like to change certain aspects of their CBRS (five sample quotes below):

Participant 8: “...we would have delayed treatment to wait for our preferred donor”

Participant 10: “I don't think I would have changed anything (apart from the outcome of course!)”

Participant 11: “On reflection, we would have gone straight to...[R clinic] in the Czech Republic because of the cost instead of going to the...[I clinic] in Spain.” Participant thought the I clinic in Spain was “more expensive, that we would receive better treatment and be more successful”

Participant 13: “Of course I would rather have had treatment in my own country ...”

Participant 14: “I would do more research beforehand to decide on clinic...”.

Overall, the sixteen participants did not express any regret about their CBRS, as Participant 13 conveyed the message, which is CBRS “is not about making the right

decisions – it is about achieving ones dream of having a child”.

6.6.4 Emotional response to CBRS

Sixteen participants (Participants 1, 3, 4, 6, 8, 9, 12, 14, 16, 17, 18, 20, 21, 22, 23 and 24) reported they experienced stress and anxiety after their CBRS (three sample quotes below). During the two week post embryo transfer period waiting for their pregnancy test, participants were generally left “very much on your own” (Participant 3) and this was the “hardest” (Participant 9) period which caused stress and anxiety for the participants:

Participant 4: “We had just under two weeks to wait before testing and that period of time is, of course, one of great stress and uncertainty...”

Participant 17: “When we returned home we anxiously awaited the first pregnancy test”

Participant 21: “In terms of emotions the first two weeks waiting for the pregnancy test to be done is still nerve-racking...”.

Participant 8 went to see her doctor with stress problems and the doctor concluded that “the anxiety/stress of the infertility treatment was likely the cause”. Participant 22 had panic attacks “believing that the ones inside...would not survive...”.

During this waiting period, participants expressed that they were worried about “IVF failure” (Participants 14 and 18) and “waiting to miscarry” (Participant 1). Participant 12 worried about the potential need for ERPC.

Participants “occupied” (Participant 9) and “distracted” themselves (Participant 18) to deter intrusion of thoughts. Generally, participants were more cautious and anxious (Participant 24) and do not want to become “over-tired” in order to protect “the embryos inside”.

Participant 18 did “not tell anyone” that she “was having treatment”; Participant 22 avoided attending a “friend’s wedding” and Participant 24 “had to lie to some family and friends when they asked about the holiday”. This period of isolation and sense of feeling “guilty” for not being open with family and friends created additional stress (Participant 24).

This “stress and emotional roller coaster” (Participant 22) could become too much for some participants. At this point, the participant might decide this could be the last “attempt” (Participant 22) for infertility treatment.

The mixed emotional responses during the waiting period at home are immense. Five participants were confident (Participants 1, 8, 9, 12 and 16) that they would get pregnant, whereas four participants were "happy" (Participants 17, 20, 22 and 24) but "remained anxious" (Participant 24) with their CBRS treatment.

Participant 12: "We returned home very optimistic that we had had successful treatment and that we had a good chance of success..."

Seven participants had negative pregnancy outcomes after their CBRS; these outcomes were "devastating" (Participant 8) for the participants (three sample quotes below):

Participant 8: "The result was more devastating than previous treatment in our home country..."

Participant 16: "I felt...disempowered"

Participant 23: "It was still a disappointment and also frustrating".

Four participants (Participants 1, 6, 8 and 12) had miscarriages. The emotions surrounding this failure included "sadness" (Participant 1) and "grief" (Participants 8 and 12) and this loss was overwhelming. Participant 8 "needed to take a day off of work" to grieve with his wife who he said she "was very disappointed and felt that she had failed" him.

The emotional responses to CBRS indicate the need for, and importance of, support for patients from partners, family and friends, overseas clinics in which they had treatment and home clinics, infertility networks and counselling. Participants' experiences of each of these varied, as indicated below.

6.6.5 Support

6.6.5.1 Partner Support

For those participants who had partners, 11 participants (Participants 4, 5, 6, 7, 8, 9, 11, 15, 17, 19 and 22) considered they had undertaken their CBRS journey as a couple sharing all the ups and down that their journey presented to them (three sample quotes below):

Participant 7: "...we were both committed and agreed, it would have been more difficult without that"

Participant 8: "Yes she has similar feelings about CBIT but that could be that we talked about our treatment a lot during its course"

Participant 17: "My husband shares similar feelings. We both discussed everything in depth before we made decisions. I would not have done it if we were not both in agreement".

The three themes to emerge from this study were: "going along with it", "being a rock" and "doing their bit". When this feeling was not shared, relationships could break down after the CBRS (Participant 14).

6.6.5.2 Family and Friends

Family and friends were a source of support for patients who received CBRS. Five participants received a great deal of support from their family (Participants 8, 20 and 24) and friends (Participants 8, 18, 20, 23 and 24) after their CBRS journey (two sample quotes below):

Participant 20: "Back home, we were very busy taking care of our daughters and a lot of people of our family and a lot of friends visited us"

Participant 24: "Family and friends who knew the full circumstances have been very supportive of both of us".

Some participants (Participants 8 and 12) felt that even though their family and friends were supportive "it is still difficult to gain" emotional support from them for their "failed cycle" (Participant 8). Participant 12 felt it was "very difficult" and had to make "a huge effort" to tell family and friends that she was "not pregnant" even after CBRS.

6.6.5.3 CBRS clinic and home clinic support

Three participants (Participants 7, 9 and 15) reported some continued support or advice from their CBRS. However, Participant 8 articulated that he and his partner did not receive "any support or communication from the CBRS".

Eight participants iterated their home doctors' support after their CBRS journey. Participants felt that they had a good relationship and co-operation with their home country doctor (two sample quotes below):

Participant 8: "Our family physician wished us luck when he saw that we were back in town"

Participant 17: "My doctor in the U.S. was concerned about me...I think it would have been difficult to complete the whole cycle without having a doctor to work with locally".

Participant 22 was reassured by her doctor at home and Participant 24 reported her doctor "wanted to ensure that my blood pressure was monitored carefully...as IVF babies

are precious babies". Participants felt their home doctors "understood the efforts" they had to go through to achieve their quest for their child.

6.6.5.4 Infertility networks and counselling

Infertility networks and friends were a great source of CBRS information for participants. Only one participant (Participant 18) mentioned attending an infertility network meeting but she did not find it useful for her. Once again, only the same participant mentioned counselling after her CBRS however, she did not state if counselling was beneficial following her CBRS journey:

Participant 18: "I also joined a support group for infertile people. I only went once though as it was a lot of couples who were talking about how sad they were and I didn't find it helpful. Also I felt uncomfortable as I was the only single person".

6.7 Chapter Summary

This chapter provide an in-depth description of each stage of the participants' CBRS journey. I have identified five stages of participants' journey (i.e. Stage 1: Before infertility treatment at home; Stage 2: Perspective of infertility treatment at home; Stage 3: Reasons for journey towards CBRS; Stage 4: Expectation and experience of CBRS and Stage 5: Returning home after CBRS).

The four substantive themes identified in stage one were "early personal concern/why not getting pregnant"; involuntary childlessness (i.e. single women); previous pregnancy thus perplexed why they are not able to get pregnant again; cost and waiting time of treatment in home country.

Six substantive themes were identified for the second stage. They were the age they started their infertility journey, costs of infertility treatment, emotional response during their treatment, relationship breakdown, experiences of infertility treatment and restrictions and regulations.

Stage three was in respect of the participants' reasons for their CBRS and their journey toward their cross border infertility treatment. Five substantive themes emerged from the participants' responses. They included CBRS clinic selection; emotional response to their CBRS selection; participants' CBRS research strategy; CBRS travel and logistic arrangements and CBRS support.

Stage four considered the participants' expectations and their experiences during their CBRS treatment. The substantive themes for stage four were financial cost; emotional responses; language barriers; law and regulations, clinical environment; patients' characteristics; risks; treatment protocol; staff; successful attempt, recommending or

returning to CBRS; support (i.e. family and friends).

Stage five focused upon the participants' experiences post CBRS treatment when they arrived back in their home country. Five major themes were CBRS clinic responses, emotional responses after CBRS, home clinic responses, decision for CBRS and support.

In Chapter 7, I will elicit these substantive themes into theoretical themes to formulate a partial Trans-Theoretical Model of CBRS journey. I will outline different theoretical perspectives, such as the 'Push and Pull' theory used by (Inhorn, 2011a); seriality (Hudson and Culley, 2011). I will also use social cognition theories (i.e. risk perception and optimistic bias (Weinstein, 1980); the Health Belief Model (Rosenstock, 1966); Theories of Reasoned and Action and Planned Behaviour (Ajzen, 1991, Fishbein and Ajzen, 1975) and Stages model (i.e. Trans-Theoretical Model (TTM) (Prochaska and DiClemente, 1982)) to explain the CBRS phenomenon.

Chapter 7 CBRS model

This chapter aims to generate a theoretical model to explain the CBRS phenomenon and to produce new understandings of participants' motivations and experiences in relation to their cross border reproductive travel within the sociological and health belief context. After searching for a theoretical perspective or model on cross border reproductive services, I have found two models, which were relevant to my study. Inhorn (2011a) provided an anthropological perspective that explores the 'Push and Pull' effects. Hudson and Culley (2011) described a sociological perspective that applies the concept of seriality to cross border travel to obtain reproductive services. A further four health belief/social psychological models were also considered, which had not been applied previously within the CBRS setting. These were "risk perception and optimistic bias" (Weinstein, 1980), the Health Belief Model (Rosenstock, 1966), Theories of Reasoned and Action and Planned Behaviour (Fishbein and Ajzen, 1975; Ajzen, 1991) and the Trans-Theoretical Model (TTM). I will describe these theoretical models and I will attempt to contextualise them within CBRS setting.

Finally, I pulled these theoretical standpoints together to propose a partial working model, incorporating three of the six theoretical models investigated, to describe the initial findings from my study. I will discuss some of the limitations whilst executing this partial model within the CBRS context. I will propose further research be undertaken, which is required to refine the partial model.

7.1 Push and Pull

Glaser (2005) reported the balancing concept, which was used by Han Thulesius (2003). The balancing concept refers to how we handle complex decisions and dichotomise decision making (i.e. to do or not to do something). However, sometimes these decisions are difficult to dichotomise in reality or it could be a continuum. Balancing requires the individual to handle many factors or variables at once in order to start an action, keep an action going or achieve a resolution. One could obtain equilibrium/symmetry between all factors or variables in which it would appear impossible to reach a decision (motionless or in stasis). Alternatively, a decision will be made possible when action or motion occurs as imbalance/asymmetry of factors become apparent.

Inhorn (2011a) suggested five major "pulling" factors (i.e. (1) medical expatriotism, (2) the language of medicine, (3) co-religion and moral trustworthiness, (4) donor phenotype and (5) the comforts of home and discrimination) for those expatriates returning 'home' for their infertility treatment. She also offered a list of standard

“pushing” factors (i.e. couples feel forced out of their home countries by various restrictions, constraints and pragmatic reasons, such as comparative costs) for CBRS.

In the research reported in this thesis, apart from Participant 23, a UK expatriate living in Hong Kong who utilised CBRS in Thailand, the remaining participants were all resident in their country of birth and travelled abroad to undertake CBRS.

Although Inhorn’s (2011a) ‘Push and Pull’ model for explaining CBRS was developed specifically for expatriates returning ‘home’ for fertility treatment, some of the factors identified by her appear to be relevant to my study (i.e. donor phenotypes, legal restrictions and constraints and pragmatic reasons, such as comparative costs). In the section covering social psychological models in this chapter, I will attempt to explore this “Push and Pull”/balancing concept and offer a potential model to explain infertility patients’ motivation for, and experiences, of CBRS.

7.2 Seriality or Serial Collectivity

In an essay entitled “Gender as Seriality”, Iris Marion Young (1994) described a re-conceptualisation of the category of woman. This was derived from Sartre’s ‘Critique of Dialectical Reason’ (1976), in which he originally proposed the concept of the relationship of an individual to social class and capitalism. Serialities are either imposed or adopted labels, which an individual might use.

Hudson and Culley’s (2011) paper discusses the first UK study of individuals’ fertility travel trajectories. They introduce the concept of seriality for CBRS and argue that those who travel overseas for infertility treatment could form part of a wider series that is “fertility treatment seekers” (Hudson and Culley, 2011, p.578).

For the purposes of addressing participants’ decision-making process regarding cross border reproductive travel, I utilised Young’s (1994, p.723) “women as a social collective” concept. The social collective within the CBRS phenomenon is when a group of people identify themselves as a unified group requiring infertility treatment overseas. Members of this group mutually acknowledge that together they would undertake cross border reproductive services. The members felt that travel abroad for treatment offered choice they otherwise did not have. However, they remain powerless and constrained by external factors (i.e. legal restrictions, waiting lists and the availability of suitable donated gametes). CBRS members are united “in flight” (Sartre, 1976) like migratory birds, by the action that they undertake together - some are at the core of the group (those activists within CBRS networks, such as former patients who set up ancillary

services (e.g. travel advice, accommodation) (Speier, 2011)) and some are at the periphery, those who may investigate CBRS and undergo a number of attempts and then decide not to continue with CBRS.

Speier (2011) reported "Do-It-Yourself" agencies were set up by infertility patients who had used CBRS themselves. The agencies offered logistical arrangements (i.e. flights and accommodation near to specific CBRS facilities) to facilitate CBRS for other people. The agencies' business in attracting CBRS patients was aided by their first positive testimonial. However, a negative blog posted by a CBRS patient had a detrimental effect upon their business. The agencies stopped advertising online because they felt that "word of mouth" is a more effective means to attract CBRS patients. Speier (2011) suggested this is a form of infertility community and activism enabling patients to regain their power and influence upon CBRS. This could be a seriality phenomenon displayed amongst those individuals accessing specialist CBRS travel agencies.

7.3 Risk perception and unrealistic optimism

This model proposes that there is popular belief that people tend to think that they are less likely than average to experience misfortunes in life and are more likely than average to experience good things. This bias holds true for a wide range of health beliefs and outcomes, thus people tend to think they are less vulnerable than others (Rutter and Quine, 2002). Weinstein (1980) coined this as "unrealistic optimism. This bias originated from the person's motives and cognitions and the ways in which these were mediated by the person's experiences.

In this study, participants expressed a view that there is a greater hope and a greater probability for them to get pregnant after CBRS overseas than in their home country.

They entrust their fate to their home consultant or are encouraged by others whom they met either via infertility networks online or face-to-face in meetings:

Participant 19: "Our consultant told us...they had a link with clinics in Spain and in the USA, where we could go...We trusted...our consultant..."

Participant 10: "Personal recommendation from other women having treatment abroad was what first encouraged me to look at overseas options..."

Participant 18: "I met some people who had used this clinic before and had a good experience..."

Otten and Van der Plight (1992) suggested that prior experience has more predictive power than just mere "unrealistic expectation". Most participants in this study had infertility treatment in their home country; therefore, their previous experiences mediate

the perception of risks and that home clinics would have undertaken all the blood tests required on donors; therefore they felt CBRS would not pose any greater risk to them:

Participant 2: "I did not believe the risks of treatment out of the country to be any higher than in my home country"

Participant 21: "I had already been through treatment in the UK and felt well prepared in terms of my health and knew what risks there might be".

The experiences of some participants in this study upheld the "unrealistic optimism" concept, which could be a driving force pushing the participants towards CBRS and away from treatment in their home country.

7.4 Health Belief Model (HBM)

The Health Belief Model (Rosenstock, 1966; Rutter and Quine, 2002) proposes that people's health behaviours are motivated by the perceived personal benefits of action, barriers to action and self-efficacy, providing an explanation for the individual's engagement or lack of engagement in this behaviour (see Figure 11 below).

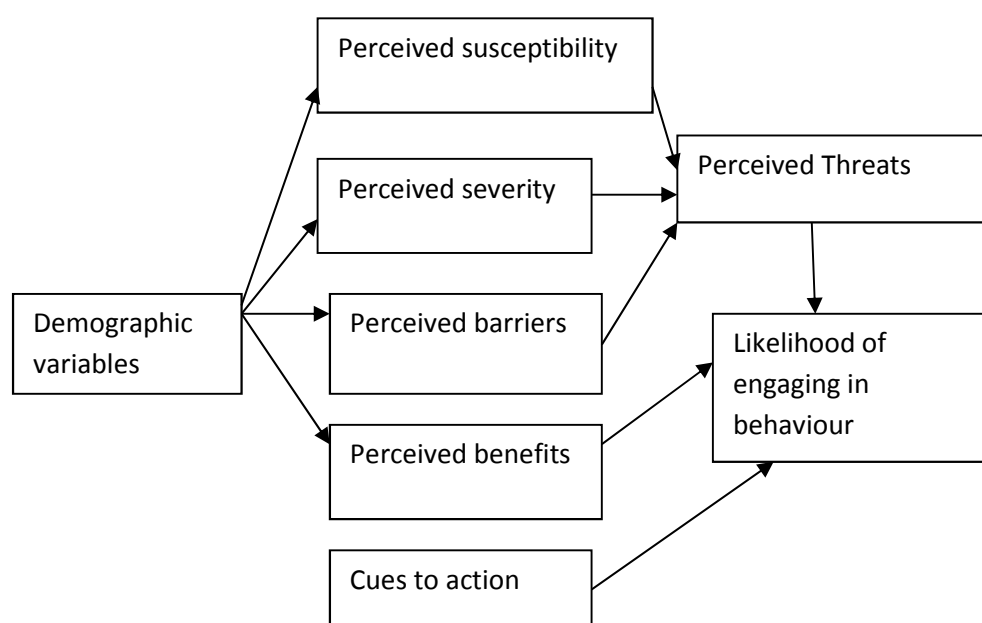


Figure 11: Health Belief Model

(Adapted from Rutter and Quine, 2002)

This model has two important classes of variables: 1. the psychological state of readiness to engage in the behaviour and 2. the personal perception of engagement that is required to satisfy the individual's health needs.

Demographic variables have a significant impact upon the person's perceived action of health engagement. In this study, the older participants (mean age=43.35; SD±5.549),

had higher levels of education (65.4%, N=17 held postgraduate qualification) when compared to those who had treatment at home (HFEA, 2011b; IFFS, 2013) and 81% (N=21) had infertility treatment at home, thus there will be a higher likelihood for them to consider CBRS.

The state of readiness to act is determined by the perceived susceptibility or vulnerability to the health threat and the perceived severity that the threats might have to their life. The person will also be required to weigh the perceived beneficial outcomes against their costs or the barriers for their engagement (Rutter and Quine, 2002). Rosenstock (1966) suggested the level of readiness for a person is when the perceived benefit (i.e. having a child) outweighs the perceived cost of disengagement (i.e. childlessness). Participants in this study looked ahead for positive outcomes. Some participants felt confident that they would achieve their quest "to get pregnant" (Participants 1, 23), "to hold a baby" (Participant 14) and "become parents" (Participant 20). For these participants, the desire to have a child is intense and their positive hope outweighs the perceived barriers, thus triggering their engagement with CBRS.

Within this model, "cues to action" is the decision process made by the individual to accept recommendations by others (e.g. advice from others and media) for their health action. In the context of this scenario, the pain of involuntary childlessness is immense; many have taken advice from health professionals or infertility networks, whilst positive media coverage promoting CBRS also drives the participants along the CBRS pathway.

The key limitations of the health belief model are that it could not specify how different beliefs (i.e. acceptance, habitual effect, social acceptability, environmental and economic factors and access to information) influence one another and it did not offer operational definitions of the variables (Champion, 1984). Despite these conceptual problems, as I am not using the health belief model to predict the CBRS behaviour, I felt this model could, in part, elucidate the CBRS "push" effects, which many participants faced. I attempted to integrate other models to account for the whole CBRS journey undergone by the participants.

7.5 Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB)

The Theory of Reasoned Action (TRA) (Ajzen and Fishbein, 1980; Fishbein and Ajzen, 1975) is the parent theory for the Theory of Planned Behaviour (TPB) (Ajzen, 1991; Ajzen, 1988). Both theories are expectancy-value models and have attracted much attention within the field of social psychology (Rutter and Quine, 2002) (see Figure 12).

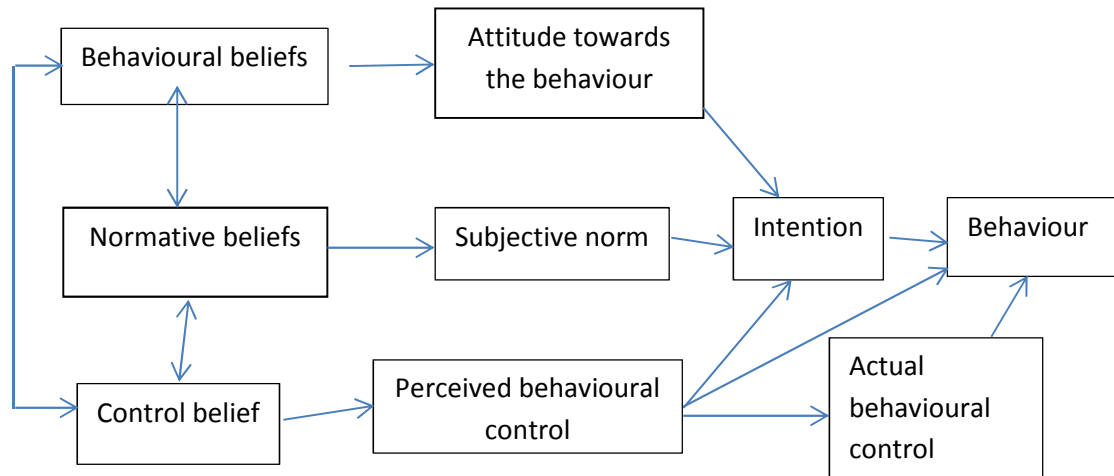


Figure 12: Theories of Reasoned Action and Planned Behaviour

(Adapted from Rutter and Quine, 2002)

The Theory of Reasoned Action suggested the best predictor of behaviour is the person's intention to perform the behaviour, which is in turn, governed by the attitude towards the behaviour and the subjective norm or the perceived social pressure to perform (or not to perform) the behaviour.

Attitude is the first set of salient beliefs in which the person is confident of the consequences of performing the behaviour. In this study, the participants are confident of a successful outcome:

Participant 6: "With success rates of over 70%. I was feeling fairly confident that we would go home pregnant ultimately"

Participant 9: "I always knew there would be a baby in our lives"

Participant 11: "I expected the clinics to be excellent and to achieve a pregnancy for me"

Participant 12: "I thought that we would be successful and my expectations were high".

These positive beliefs trigger the participants' engagement with CBRS.

Subjective norm is determined by the person's normative belief about the social pressure from significant others. For example, Inhorn (2011b) reported the predicament faced by a couple, Hatem and Huda, who saw no other way to achieve parenthood than to travel to another country for their infertility treatment. Hatem and Huda held a belief that parenthood is a social norm; conversely childlessness was an unacceptable norm for them. Even with the restriction placed by many countries (IFFS, 2013) (e.g. the illegality of egg donation and surrogacy in many countries), many infertile patients believe parenthood is the social norm and that their government's policy is wrong in stipulating

legal restrictions regarding access to, and availability of, reproductive services. Many patients, therefore, feel that they have been left with no option but to engage in cross border reproductive services thereby circumventing their home country's legal restrictions in order to realise commonly accepted social norms of having children (Bergmann, 2011a). A number of authors (Ferraretti et al., 2010; Pennings, 2010; Pennings et al., 2009; Pennings et al., 2008; Shenfield et al., 2011; Van Hoof and Pennings, 2011; Van Hoof and Pennings, 2012b) suggested that cross border reproductive services could be viewed as a "safety valve", albeit CBRS is often associated with a higher health risk, frustration for infertile couples and disparities in accessing ART abroad. CBRS, therefore, fitted the prediction of volitional behaviour as intended by the TRA.

The subjective norm within the TPB could also be encouraged by others. Many participants are involved with infertility networks and have gained support from someone in a similar situation to themselves. This communality (Hudson and Culley, 2011) promotes normality, which was explicitly expressed by Participant 3 during her e-interview:

Participant 3: "The Donor Network Workshops have been a great help in making the whole process 'normal'".

CBRS was recommended to some participants by their home clinics, which reinforced the subjective norm perceived by participants:

Participant 11: "Clinic...told us they had shared care with the IVI in Barcelona, Spain...remember being advised it was a better option for us..."

Participant 19: "Our consultant told us...they had a link with clinics in Spain and in the USA, where we could go...We trusted...our consultant..."

All these subjective norms added to the participants' personal belief of the appropriateness of CBRS as the path for their quest for a child.

The Theory of Planned Behaviour (Ajzen, 1988; Ajzen 1991) retains much of the TRA concepts by adding the perceived behavioural control (PBC) concept to encompass the non-volitional behaviour control. PBC refers to people's appraisals of their ability to perform the behaviour and is intended to predict personal behavioural intention, personal perception of control and the actual performance of the behaviour. Control belief underpinned PBC in which the personal perception of barriers, personal skills and resources enable the person to overcome or facilitate the behaviour. These barriers could be external (e.g. availability of time and money) or internal (e.g. ability and skills) influences.

External influences, such as cost and time had been considered by many participants during their CBRS. For example, Participant 3 suggested that she did not embark upon home infertility treatment as she did not want to waste time and money:

Participant 3: "My Fertility Treatment in Ireland is limited as I did not want to waste time and money when I knew ultimately I would have to go overseas anyway".

Participants' perception of their infertility treatments at home is that there are numerous external barriers (e.g. waiting time, negative clinic support, donor availability and legal restriction and regulations), which "forced" (Participant 8) them to seek CBRS. In this study, participants expressed personal autonomy and choice (perceived control) that they could gain from undertaking CBRS:

Participant 16: "I was at the mercy of a system...[that would decide] what was good for me".

They also have skills in organising cross border reproductive travel (i.e. low cost flights and accommodation) and have the skills and ability to undertake research to identify an appropriate clinic.

Participants in this study all had the ability to embark on their CBRS travel. They have personal perceptions of autonomy and control that gave them confidence for their CBRS journey.

A limitation in using these models is that I am not aiming to standardise or predict the participant's individual decision-making process for their CBRS. I am using the email interviews to put forward a potential model to explore the participant's individual narration of their CBRS journey.

The risk perception and optimistic bias (Weinstein, 1980), the Health Belief Model (Rosenstock, 1966) and the Theories of Reasoned and Action and Planned Behaviour (Ajzen, 1991; Ajzen and Fishbein, 1980) could all be seen to provide an account of behaviour that operates as a continuum. They all tried to take a set of perceptions or beliefs, attempting to predict the combined effects where the person will lie on an outcome continuum of behaviour. By knowing the strength/power of the variables (i.e. unrealistic optimism, demographic variables, perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, attitude, subjective norm and perceived behavioural control), these models will have the potential to predict whether or not an individual will engage in a behaviour, in this case, CBRS. The aim of this study is to identify a potential model that could be used to understand the CBRS behaviour. Future research is required to use standardised psychological measurements (i.e. Theory

of Planned Behaviour questionnaire (Ajzen, 1991)) on a larger sample to see if one could predict CBRS behaviour.

For example, if a country would like to 'discourage'/reduce CBRS, the intervention could be to promote egg donation, donor payment, permit mitochondrial replacement technology (MRT) and oocyte vitrification. As an example of reducing the "push" factors, in the UK, the HFEA (2011a) increased permitted remuneration of sperm donors to £35 per visit and to £750 per cycle for egg donors including expenses; levels that were considered would not attract those who are merely donating for financial motivation. This move was an attempt to remedy the shortage of donors and reduce the number of infertile women travelling abroad for IVF treatment (Dyer, 2011). Anecdotal evidence from UK infertility clinics' website (<http://www.carefertility.com>) (e.g. CARE Fertility Manchester, Sheffield) suggests that the waiting list for egg donation is no longer at a crisis situation. Mitochondrial replacement technology (MRT) leading to "three-parent babies" is only for women who have mitochondrial disease and advocates claim that it has an acceptable success rate when compared with normal infertility treatment (Griggs, 2013). The HFEA (2014) published the consultation report from experts on this technique, which suggested that MRT is not an unsafe procedure and further research is required to establish more evidence (i.e. to improve efficiency of the procedure). Following a consultation period, the House of Lords approved regulations that permit MRT to proceed from 29 October 2015. Few women would actually require MRT however, as the UK is the first country to allow such practice this may attract overseas travellers seeking this reproductive technology. Recently, UK fertility clinics received permission from the HFEA to import vitrified donated eggs from Russia to the UK (Hyder, 2010). This could reduce the waiting list for egg donation in the UK, thus avoiding the need for travelling abroad for infertility treatment using egg donation. Careful ethical consideration is required to review the safety and efficacy of these two technologies and their implications for patients.

7.6 Trans-Theoretical Model

The Trans-Theoretical Model was developed in an attempt to understand and collate a range of existing perspectives on smoking behaviour change (Prochaska and DiClemente, 1983) and has had a profound impact upon health promotion (i.e. addiction behaviour). It has become one of the most popular conceptual frameworks in the field of social psychology and the cyclical 'staged' process has struck a chord with many health professionals (Whitelaw et al., 2000). This model proposes individual behavioural change as a reflective set of processes; these processes occur over a period of time, which entails a movement/gradient of commitment to change by the individual through stages of change towards their health belief (Cooper, 2012).

The Trans-Theoretical Model encompasses seven stages of behavioural change (Cooper, 2012; Rutter and Quine, 2002; Prochaska and Norcross, 2007):

Stage 1: Pre-contemplation – the new behaviour is not considered and therefore the individual has no intention of changing behaviour in the near future

Stage 2: Contemplation – the individual recognises and is aware of a problem; new behaviour is considered but not acted upon; the individual might act at some stage in the future although (s)he has no defined timescale. The individual has not yet made a commitment to act upon their concerns

Stage 3: Preparation – the individual is getting ready to change, intends to take action in the near future and makes efforts to prepare for changes, which are involved in adopting the new behaviour. For this stage, the individual might attempt to resolve their situation by themselves or seek professional advice and support; the individual may be more receptive to suggestions than at stages one or two. Such suggestions would help the individual to formulate objectives, which would drive them towards their intended goal

Stage 4: Action – the individual takes specific steps toward their goal. At this stage the individual will invest both time and effort to focus upon their desired goal. The individual is responsive to support and reinforcement therefore, social networks or significant others could help them achieve their goal. When an individual is faced with criticisms or punishment for their adapted behaviour in this instance, the individual travelled abroad for fertility treatment, others might view this as dysfunctional behaviour. However, the individual would actually disregard these criticisms or punishment (Cooper, 2012) and seek to establish their own balance towards their own desired goal

Stage 5: Maintenance – the new behaviour is maintained over a period of time and successful behavioural change will further reinforce the individual belief for their action (i.e. a positive pregnancy test and subsequent miscarriage might maintain the patient to re-engage with the CBRs)

Stage 6: Termination/exit: the individual has completed the change process and is no longer focussed on their goal. The individual has completed their family or had decided not to pursue any more fertility treatment; however, some individuals could relapse and recycle within the stages again

Stage 7: Recycling/relapse – the individual does not necessarily succeed in achieving their goal at their first attempt. The individual might revert to their previous status and return to their desired goal at a later stage:

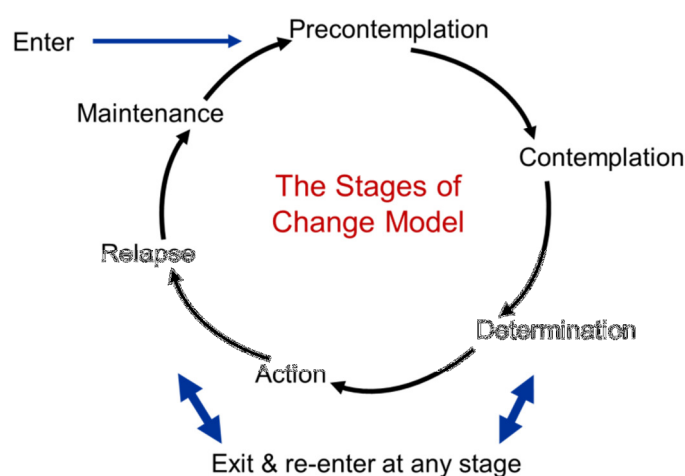


Figure 13: The Trans-Theoretical Model (Stages of Change)

(Adapted from Prochaska and DiClemente's (1982) model)

The above stages of change outlined three main ideas (Prochaska and DiClemente, 1983; Prochaska and DiClemente, 1982). Firstly, behaviour change is seen as a dynamic process, which occurs in a sequenced and cyclical order. Secondly, it suggests these stages are driven by a series of processes including 'consciousness raising' (seeking information regarding the problem), 'counter conditioning' (substituting new behaviour for problem behaviour) and 'stimulus control' (controlling situations that could trigger relapse). Thirdly, the notion of level of change recognises that individuals can experience multiple problems, which exist at different levels. The Trans-theoretical model attempts to accommodate and encompass a range of psychological frameworks, thus I feel it is best suited to the potential model I am proposing to describe the CBRS phenomenon.

In contrast to the other models, this sees individuals as not located on a continuum but located in a discrete stage, in which there is a staged progression towards the intended behaviour. When I embarked upon this study, I was contemplating the use of TPB to explain the CBRS phenomenon. Glaser (2005) proposed that researchers should be prepared for a 'serendipitous moment' in order to integrate concepts into theory. Occasionally there is one dominant concept, although usually there is never just a single theoretical concept that emerges from the substantive coding; therefore, the researcher may need to use multiple theoretical concepts to develop Grounded Theory. True to the Grounded Theory perspective, I aimed to be open and sensitive (Glaser, 2005) by letting the theoretical concepts emerge 'naturally' (Strauss and Corbin, 1998). As my familiarity

with the data from my study grew, I experienced a 'Eureka!' moment that convinced me that the Trans-Theoretical Model could provide a better model to describe the decision-making process of individuals seeking CBRS.

7.7 The proposed partial model for CBRS

This partial model is adapted from the Trans-Theoretical Model and incorporates ideas from other models (i.e. "Push and Pull" model and Seriality) in an attempt to explain the CBRS phenomenon (see Figure 14).

7.7.1 Stage 1: Pre-contemplation

The entry point for this model would be prior to participants becoming aware of their need for fertility treatment and where they have no desire to travel for fertility treatment. Once participants experience concerns about their fertility they will undergo diagnostic tests and infertility investigations at home; most of them will be pushed towards infertility treatment in a clinic in their home country. In this study, four single women did not consider themselves to have a fertility problem; some of them would also have sought treatment (i.e. donor insemination or egg donation) at home. For these patients, if infertility treatment is available in their home country (e.g. not subject to legal restrictions or supply shortages) they would not consider CBRS at this stage.

7.7.2 Stage 2: Contemplation

Some single women or same sex couples might face legal restrictions in their home country (IFFS, 2013) therefore, they would be pushed to consider cross border reproductive services. CBRS could act as a "safety valve" to overcome the legal restrictions in some countries (Ferraretti et al., 2010; Pennings et al., 2008; Storrow, 2010) when participants are contemplating CBRS. France prohibits surrogacy, therefore the French participants in this study felt "pushed" to seek CBRS in another country - in this case the USA. One participant from Tanzania regarded provision for infertility treatment in her home country as limited, therefore she travelled to South Africa for treatment because she considered it provided more specialist and advanced technological infertility treatments:

Participant 14: "It was difficult because of limited specialists and only one referral hospital where the tests were done".

The majority of the participants (81%, N=21) had infertility treatment at home before embarking on CBRS and the mean number of treatments they underwent was 3.71 (SD±2.28). Consequently, their experience of home treatment had an important influence upon their decision to seek CBRS. The cost and experiences of treatment at home, waiting time, the age and emotional responses of the patients and restrictions

placed upon home treatments, all served to push participants towards CBRS. At this stage, the participants recognised the problem when seeking infertility treatment in their home country:

Participant 13: "My consultant offered to put me on the waiting list for donor eggs...but waiting list was 9 months...timescales which were just not acceptable to me".

Furthermore, they were aware of the alternative choice of CBRS. Participants would now consider and investigate the possibility for CBRS and some might decide to have this however, they might not yet have made a commitment to embark upon CBRS.

7.7.3 Stage 3: Preparation

When participants are ready to seek and intend to have CBRS, they would actively select and research CBRS options, gathering information via the internet, home infertility clinics or infertility networks. Seriality and communality (Hudson and Culley, 2011) occurred at this stage and participants are responsive to support and reinforcement from their social networks:

Participant 10: "Personal recommendation from other women having treatment abroad was what first encouraged me to look at overseas options..."

Participant 12: "Through Fertility Fiends I talked to women who had had successful...pregnancies through a clinic...They were very encouraging about their experiences and the pictures of their children and their description of the happiness of having a baby and 'beating'...encouraged me a lot. It was clear from talking to them that the set-up...was second to none".

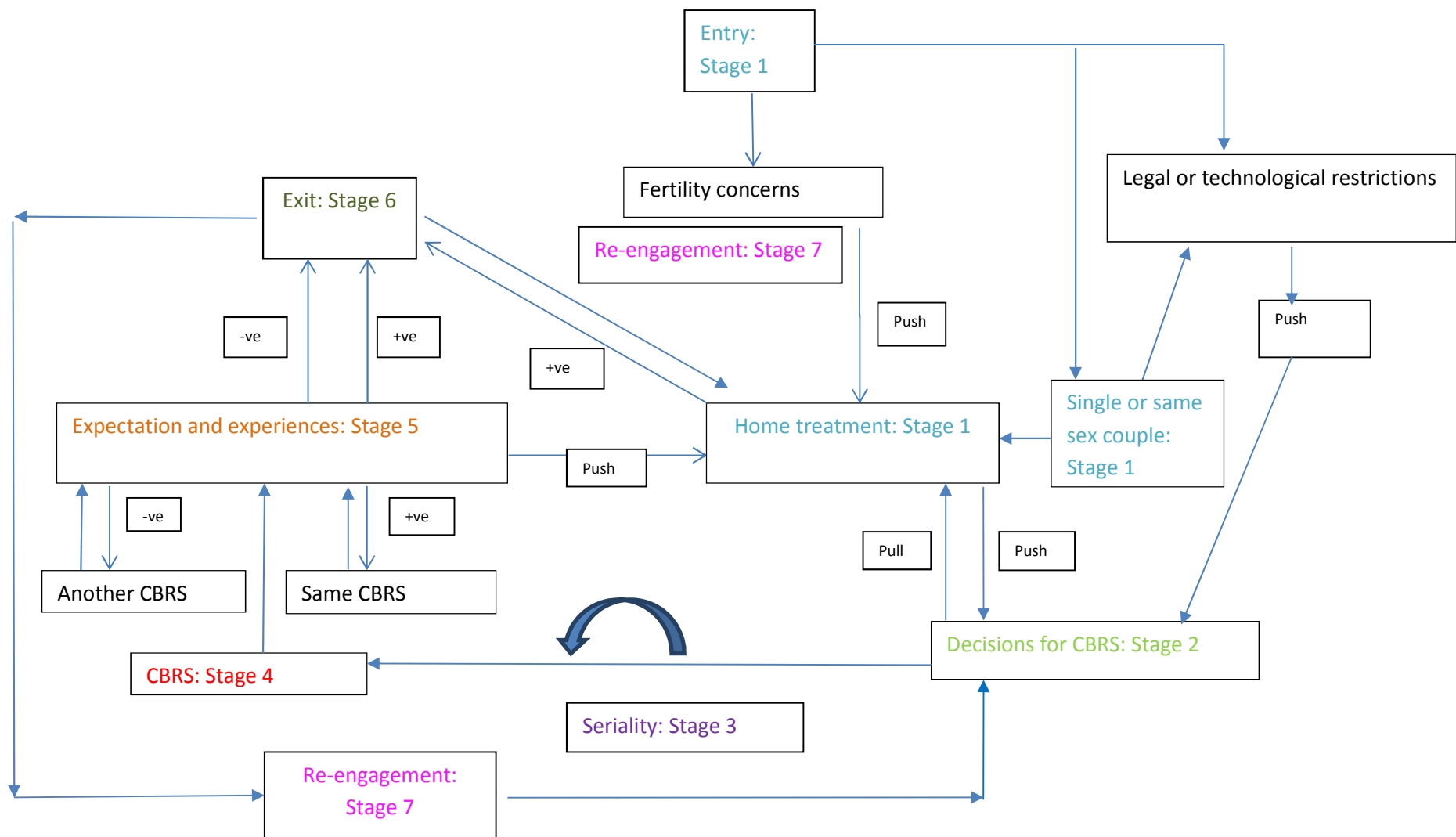


Figure 14: CBRS Partial Trans-theoretical model

Participants would try to resolve their family-building aspirations actively and are receptive to suggestions either from their doctors or infertility friends (whom they have met either online or face-to-face). Their emotional responses changed by expressing that they now have autonomy and choice and felt that they have control over their fertility treatment options. The participants took the time and made the effort to prepare for treatment abroad by making necessary travel and logistic arrangements (i.e. flights and booking accommodation):

Participant 1: "I planned around work holidays, flight schedules appropriate intervals between treatment, medicated cycles and availability of clinics".

These preparations will also act as a drive towards treatment abroad.

7.7.4 Stage 4: Action

Participants took specific steps and actions towards their CBRS by selecting clinics either in conjunction with their home clinic or independently. Some participants have faced criticism for travelling abroad for fertility treatment, for example:

Participant 3: "'What would you want to do that for?' was my GPs response".

This participant actually disregarded these criticisms and sought to make her own arrangements to achieve her desired goal for family-building. Fourteen participants obtained support from various infertility networks. Seriality and communality (Hudson and Culley, 2011) also occurred here as participants are also responsive to support and reinforcement from social networks. Some selected low cost flights and accommodation near to the clinic in the destination country. At this stage, the participants had all the information they needed (e.g. costs and had read reviews on infertility networks) and, therefore, they understood the CBRS process. Participants expressed autonomy and choice; consequently they felt they were no longer a victim within the infertility system:

Participant 24: "we were told we had 3 viable embryos and we chose to have 2 put back"

Participant 16: "I was treated more as a client...".

In many couples undertaking fertility treatment abroad, a majority of the decisions were initiated by the woman but endorsed by their partner so that the couple had a jointly-agreed course of action. Family and friends support the participants via emails and texts. Emotions are heightened during the action stage. Participants found most CBRS staff treated them with politeness and respect; however some participants had experienced negative practice and communication barriers from professional staff:

Participant 3: "...felt very much like a number being processed most times..."

Participant 11: "...There was no one around...I had tears pouring down my face and they didn't notice..."

Participant 17: "...we...brought a cell phone...they never called us on the cell phone. The person at the clinic called the hotel. We received an urgent message that evening when we returned to the hotel"

Participant 19: "We actually turned up at the wrong clinic, as they had opened a new building and we hadn't been told..."

The consequence of the above experiences could have an effect if the participants remained in the same clinic or sought treatment from another clinic either in the same country, an alternative country or returned to their home clinics.

7.7.5 Stage 5: Maintenance

Participants' expectations and experiences of fertility treatment abroad could play an important role in whether or not patients would continue with their CBRS journey. Participants who had an overall positive experience and whose expectations were met with successful outcomes tend to remain in the same clinic. In this study, four participants (Participants 1, 4, 5 and 19) reported that they would return to their clinics for any future treatment. However, some participants who had an overall negative experiences or whose expectations were unmet might consider a different clinic either in the same, or another, country or would rather have infertility treatment at home (Participant 13). With the increasing viability/successful outcomes of oocyte vitrification, there might be a reduction in the number of patients waiting for egg donation in some home countries (e.g. in the UK) (Nahman, 2011), thus some patients might decide to return to their home country for future infertility treatment. This development might push some patients to abandon fertility treatment abroad and pull them back to their home country for future treatment.

7.7.6 Stage 6: Exit

If patients had successful treatment abroad and completed their family, they could exit from their infertility treatment. In this study, 15 patients were successful with fertility treatment abroad and some of them (n=7) who had completed their family (i.e. with older children age ≥ 4 or have more than two children) had exited from their CBRS journey. Those who had not completed their family may choose to exit and wait until their existing child(ren) are older before re-engaging for further treatment either at home or abroad. Some patients who had an overall negative experience and whose expectations were not met, might also decide they had had enough of infertility treatment, whether at home or abroad and will have no desire to undertake any more infertility treatment (Brick, 2013).

7.7.7 Stage 7: Re-engagement

At this stage, patients who had not completed their family might temporarily exit from fertility treatment. However, due to a strong desire to have a family, some may reconsider their decision in the future and seek infertility treatment either at home or abroad. Therefore, they

will re-engage in order to seek further fertility treatment in the hope of completing their family.

7.8 Critiques of the Trans-theoretical Model

The value of the Trans-theoretical Model within the addiction field has been subject to debate. West (2005) argued that there were serious problems. The concept of stages is based on arbitrary distinctions and the stages at times do not fit together coherently. The model assumes the ability of people to make stable and logical plans. Finally, West suggested that the Trans-theoretical model fails to encompass human motivation and neglects the concepts of reward and punishment associated with learning in the development of hard-to-break habits. However, Sutton (2005) has responded to West's (2005) critique by observing that the model has proved remarkably resilient to criticism as clinicians have found the model continues to be useful in explaining many health related behaviours (e.g. smoking cessation, substance misuse, healthy eating and exercise programme). In addition, while acknowledging West's comments, DiClemente (2005) pointed out that there is clearly much more to understand about the process of change and how individuals go about creating and stabilising new behaviour. By challenging the model, we could promote more critical understanding of behavioural change.

Since 2005, there appears to have been no further debate regarding the merits or limitations of the Trans-theoretical model, which continues to have a place within the psycho-social perspective of health related behaviours.

7.9 Limitations of the study

This is a qualitative study on the motivation for, and experiences of, 26 participants engaged in seeking fertility treatment in a country other than the one in which they lived. The sample size is a limitation for this study. However, with no reliable data on the extent of CBRS, this study found similarities with previous research conducted by Shenfield et al. (2010) and Culley et al. (2011b) therefore, some confidence may be placed in the findings of this study. All participants were self-selecting and the information provided relied on their accurate retrospective recall of their experiences. It was not possible to access independent verification of any information given by participants. This could influence both their readiness to take part in this study and the way in which their experiences were expressed. In this study, I did not investigate those participants who did not travel abroad for treatment despite multiple unsuccessful treatments in their home country. I did not investigate those who exited their CBRS and subsequently re-engage back to CBRS again. Their decision process could play an important role in the above partial model. A future study could investigate both of these populations to enhance our understanding of their decision processes within this partial CBRS model.

7.10 Chapter Summary

This chapter presented a partial model for CBRS derived from the 26 participants' email interviews. I have utilised the Trans-Theoretical Model (Prochaska and DiClemente, 1983, Prochaska and Norcross, 2007) to illustrate the different stages and contextualised the theoretical themes/codings within this partial CBRS model. I have also identified a number of limitations when using this partial model and suggested future study to enhance the understanding of this model.

In the next chapter of this thesis, I will draw upon the participants' recommendations to fellow CBRS travellers, fertility clinics both at home and abroad and national and supra-national bodies.

Chapter 8 Participants' Recommendations for CBRS

In Chapter 7, I offered different theoretical perspectives resulting from previous research, such as the "Push and Pull" theory proposed by Inhorn (2011a) from an anthropological perspective and Seriality and Communality (Young, 1994; Hudson and Culley, 2011) from a sociological perspective. I also introduced a number of social cognition theories, i.e. risk perception and optimistic bias (Weinstein, 1980); the Health Belief Model (Rosenstock, 1966); Theories of Reasoned and Action and Planned Behaviour (Ajzen, 1991; Fishbein and Ajzen, 1975) and the Trans-Theoretical Model (TTM) (Prochaska and Norcross, 2007; Prochaska and DiClemente, 1982) and contextualised them within the CBRS scenario. A partial model was proposed in Chapter 7 to explain the motivations for, and experiences of, participants' CBRS journey, which was based upon the Trans-Theoretical Model.

This chapter presents the 26 participants' recommendations for CBRS. The two questions used to seek these recommendations were:

1. Following your experiences of CBRS, what recommendations would you make to improve another person's experience of CBRS?
2. This is the final question for this CBRS study. Please share with us any additional comments you would like to make about your experience of CBRS?

Five participants (Participants 5, 9, 11, 13, and 26) reported that their decision to use CBRS was the correct one for them and four participants (Participants 2, 3, 4 and 19) felt that CBRS was an "easy" process and regretted not having pursued this earlier. Two participants (Participants 1 and 10) suggested that "fertile people" (Participant 1) do not understand why people seek CBRS and should not "be put off" (Participant 10) by others (i.e. doctors or IVF clinics in the home country). Participants suggested that usually most CBRS patients "have exhausted the possibilities for treatment at home...[and] it is not something anyone does lightly" (Participant 1).

Participants' recommendations fell into three main areas: recommendations for their "fellow travellers", recommendations for clinics and recommendations for national and/or supra-national bodies.

8.1 Participants' recommendations for other CBRS patients

Participants' recommendations to other CBRS patients emphasised the need for making their own judgement and being confident with their decisions. Patients seeking CBRS should investigate the protocols of individual infertility clinics and potential communication issues prior to their travel. Participants felt that it was vitally important to undertake thorough research in advance and consider the financial implications. They offered practical advice (regarding

accommodation, travel and local communication) based on their own experiences of CBRS. Participants suggested that their fellow CBRS travellers could prepare for its emotional challenges by avoiding stress, seeking counselling and support from infertility networks, family and friends, doctors and employers.

8.1.1 Trusting their own judgement

Twelve participants (Participants 1, 4, 5, 6, 7, 8, 9, 12, 16, 23, 24 and 25) (three sample quotes below) suggested that when seeking CBRS, patients should decide for themselves which clinic to use by considering the merits of each option. This will require them to conduct relevant research (e.g. regarding success rates, waiting list) about each clinic and be confident with their decision:

Participant 4: "We were right to follow the research and our gut feeling..."

Participant 16: "The best thing is to work out for yourself what is right for you...inform yourself as much as possible and to feel comfortable with your choices"

Participant 23: "Most of all be confident in your decision..."

CBRS travellers need to set their own personal priorities (Participant 24) and equip themselves with "enough knowledge to make an informed decision" (Participant 25). Participant 12 suggested that CBRS travellers needed to "check out" information themselves and "...don't rely on websites or word of mouth". Be assured that "absolutely everything possible" had been done "to achieve success, then, if it did not work". One, therefore, would be able to accept the eventual CBRS outcome "not as necessary evils" but as part of the CBRS travellers' family-building project:

Participant 1: "...that they and I had done absolutely everything possible to achieve success. THEN, if it did not work I could know that we all did everything we could"

Participant 16: "I feel that we are able to live bravely and hopefully, meeting the advantages and difficulties of CBRS not as necessary evils but as interesting parts of full lives".

8.1.2 CBRS protocol

Thirteen participants emphasised that CBRS patients need to familiarise themselves with the risks of undertaking fertility treatment abroad (Participants 4, 12, 14 and 25), timeline (Participant 11), protocol and procedures (Participants 1, 10, 14 and 25). CBRS protocol could relate to medication (i.e. access to drugs, side effects) (Participants 4, 8, 11, 14 and 21), partners' frozen sperm sample (Participant 21), egg sharing information (Participant 22) and donors' information (Participant 9). Participant 12 advocated CBRS patients "...don't be pressurised by the clinic for extra treatment unless they are clinically indicated and have been fully justified...If you are using a donor do everything you can to make sure that the donor has been tested for blood borne infections and you have been given enough information to make

an informed decision in choosing that donor”.

Participant 25 advised others “...do not assume anything: every clinic operates differently” therefore, it is important to know as much information as possible from clinics before embarking upon a treatment cycle.

8.1.3 Communication with CBRS

Six participants (Participants 4, 6, 9, 21, 12 and 23) acknowledged the importance of communication for successful treatment. They suggested their fellow travellers should “think carefully” (Participant 6) and prepare the questions to which they want answers prior to their email or telephone conversations with their chosen clinic:

Participant 4: “I would suggest that the person tries to make contact, probably online”

Participant 9: “Sometimes I would fax my queries or information in advance to the clinic so that our consultant would have an opportunity to look over our queries before we rang”

Participant 21: “Write a list of all the questions you want to ask the clinic – and some more may arise after your visit so find out how best to communicate with the clinic in order to get replies to your questions”.

Participant 12 emphasised the importance of effective communication with the clinic staff with emails and messages before an appointment to ensure “information” patients need is provided in a “timely manner”. Participant 23 also suggested “...if there are any points that...[patients] do not fully understand either due to language barriers or just because you are being bombarded with information in a potentially stressful situation, make sure...[patients take] time to absorb what you have been told and ask if there is ANYTHING that is not clear”.

8.1.4 Undertaking research before utilising CBRS

Fourteen participants (Participants 1, 4, 6, 10, 11, 12, 14, 17, 18, 21, 23, 24, 25, and 26) urged their fellow CBRS travellers to perform research relating to the clinics’ websites and “take time to read about other people’s” (Participant 10) experiences/opinions and speak directly with “as many people as possible” (Participant 12), who have been to their intended clinic prior to going there themselves. This research would enable CBRS travellers “to learn the pros and cons” (Participant 17) of their proposed plans and give the travellers “peace of mind” regarding the intended clinic’s reputation:

Participant 1: “Talk to more than 2 people who have actually been to this clinic”

Participant 4: “...probably online, with other people who have attended the same clinic/doctor, to compare experiences...”

Participant 18: “Do your research carefully and ask people to recommend a clinic if at all possible. A personal recommendation is the best”

Participant 21: “Try to speak with someone who has recently visited the clinic you are

thinking of using or who has gone to a clinic in the same country”.

8.1.5 Financial issues

Six participants (Participants 12, 14, 17, 18, 20, and 21) provided recommendations relating to financial issues. Participant 14 believed having “enough” financial resources was essential for CBRS and CBRS travellers should check if the cost of drugs was included (Participant 21). Participant 12 suggested CBRS travellers should inform their credit card company about their use of their credit card abroad and check their credit card statement to avoid fraudulent use. Participants advocated fellow CBRS travellers to check exchange rates (Participant 17) and health insurance coverage (Participant 20).

8.1.6 Accommodation, travel and local communications

Many participants (Participants 1, 6, 11, 12, 18, 21, 23 and 24) offered practical recommendations for their fellow CBRS travellers. Some participants recommended self-catering accommodation (Participants 6 and 24), whereas others have used hotels (Participant 18) or accommodation booked (Participant 23) or information provided by the clinic (Participant 24):

Participant 6: “We also chose self-catering accommodation which suited us and made us feel much more “at home”

Participant 18: “Book a comfortable hotel that is close to the clinic”

Participant 24: “The US clinic gave us information about where to stay and what we could do while we were there...Looking back we may have been better off in an apartment rather than a hotel as it's easier if you need to rest in your room and eat and cook when you want and it would have been more flexible and cheaper”.

A key recommendation by several participants concerning accommodation was that the accommodation must be near to the clinic. As illustrated by Participant 12: “Try to book accommodation as close to the clinic as you can to avoid travelling in a strange city and ideally use somewhere recommended that has been checked out beforehand”.

Participant 6 recommended if possible “arrive several days before” treatment, especially for long-distance air travel when time might be needed to recover from “jet lag”. Careful planning is helpful (Participant 24) for CBRS therefore, some participants (Participants 1, 18, 21, and 24) advised others to consider the logistics of travelling to the CBRS:

Participant 1: “Get comfortable with all the aspects of travel to the clinic...”

Participant 18: “If you are going to travel overseas find a clinic that is not too far away from home that is easy to get to”

Participant 21: “Think about logistics of travelling there – how can you make the travel easier...”

Participant 24: "...if a couple, you may both need to travel at the same time or in some situations you can go at different times. It is possible to reduce trips, cost and time off from work if careful".

Two participants suggested their fellow CBRS travellers obtain a local mobile telephone (Participant 6) or SIM card (Participant 12) for their mobile phone upon arrival to facilitate telephone communication with the clinic. Participant 12 also suggested their fellow CBRS travellers ensured the accommodation had a "secure wireless network" to enable the travellers to communicate with friends and family at home without excessive cost:

Participant 12: "Make sure your accommodation has secure wireless that you don't have to pay for and can access easily".

8.1.7 Emotional Responses

Five participants (Participants 12, 14, 15, 17 and 18) offered the view that future CBRS travellers should be emotionally prepared for the possible outcomes of treatment as one would have invested "time, money, energy and emotions" in seeking CBRS and without a "100% guarantee of success" (Participant 12). Participants believed future CBRS travellers "must be prepared for the ups and downs" (Participant 17) of the CBRS process by anticipating "chances of failure" (Participant 14) and "find ways to cope with sadness and stress" (Participant 18).

8.1.7.1 Avoiding stress

Infertility treatment is "a stressful experience...wherever you do it" (Participant 23) and for many patients going abroad for treatment would add to this stress. Seven participants (Participants 8, 17, 18, 21, 22, 23 and 26) suggested CBRS travellers should try to relax, keep calm and have fun by treating their CBRS experience as a "shopping/pampering weekend" (Participant 23) or "to be a tourist" (Participant 8). Participant 21 advocated the CBRS traveller to arrange someone who has a calming effect to accompany them for their appointments:

Participant 8: "Take the opportunity to be a tourist while receiving CBRS. It helps keep your mind off things that can't be controlled"

Participant 17: "...enjoy the trip to a different country... Have fun! Don't stress out...Be relaxed"

Participant 18: "Have ways to relax and keep planning things...that keep you happy... and to find ways to take the pressure off and... have some relaxation"

Participant 21: "...you might find another form of support if better for the transfer or just that he can't be there so do arrange for someone to travel with you who will be calming!"

Participant 22: "...was following a holiday...This meant that by the time I had the embryo transfer at the end of the holiday I was rested and relaxed"

Participant 23: "...cuts down on the stress of travelling and arriving on time for appointments and procedures".

8.1.7.2 Counselling

Twelve participants (Participants 3, 4, 5, 6, 8, 9, 10, 11, 12, 17, 18 and 19) recommended counselling as “essential” (Participant 11), “important” (Participant 18) “useful” (Participant 19) for them and other CBRS patients as “it is easy to underestimate the emotional impact” (Participant 18) of the infertility journey. Many participants (Participants 1, 5, 10, 11, 14, 17, 18 and 19) promoted face-to-face counselling; however Participant 15 said she did not need counselling. Participant 14 suggested face-to-face counselling could be expensive and CBRS patients could explore internet options; Participant 18 had tried telephone counselling but did not personally find it useful.

Many participants (Participants 3, 4, 6, 8, 9, 10, 11 and 17) promoted counselling at home prior to their travel especially for those who intended to use donated eggs (Participants 8, 9, 11 and 17), had a failed infertility treatment cycle (Participants 4 and 10) or felt that there is a need for counselling (Participant 6). Participant 3 had organised independent counselling for herself during her CBRS, which she had found useful. Participants 3 and 4 did not expect the CBRS clinics to provide counselling for them because they thought it would not be practical to attend face-to-face counselling in another country with possible language barriers:

Participant 4: “Had the cycle failed, it would perhaps have been beneficial to have a listening ear at the end of a phone – it being impractical to attend for counselling in another country”

Participant 10: “However, after repeated failed cycles/miscarriage, I sought out an independent counsellor recommended by someone at DCN (Donor Conception Network) and have found her support to be invaluable”

Participant 3: “I made independent arrangements and attended 5 face to face sessions of counselling with an IVF counsellor specialising in Donor conception”.

Four participants drew their fellow CBRS travellers’ attention to the balance between “getting pregnant” and “rush” (Participant 6) in the use of anonymously donated eggs. They felt by not “knowing anything about the donor”, they were unable “to tell their child anything” in the future about the gamete donor’s identity. They forewarned that future CBRS patients could “regret” their “action”. Some CBRS patients, after a failed IVF cycle using their own eggs, would decide to use anonymous egg donation “without any counselling” (Participant 11). Participants recommended others to think carefully about the psychosocial implications for themselves and their child. Participants (Participants 11 and 16) promoted openness “is vitally important” when considering the use of donated eggs as it would have future impact upon the child if the parents decided to keep the treatment a “secret”:

Participant 6: “People who just focus on getting pregnant...without thinking about how they may feel not knowing anything about their donor or being able to tell their child anything about the donor later on, may wish they’d done things differently. I’ve read

testimonials of women who have such regrets...Don't rush in thinking that the end goal is to get pregnant. You really need to think about the psychosocial implications for you and the baby you hope to have, especially as it grows up into a child/adult and has to deal with your actions"

Participant 9: "Any support or counselling that we would have been interested in and may seek would be in relation to telling our baby that he was conceived through egg donation, obviously there will be different stages in telling as our baby grows up...Be certain whether or not you are going to tell your baby as it will have major implications for the future"

Participant 11: "A lot of women who I met abroad using donor eggs went straight into it after their last failed IVF without any counselling at all...I don't think a lot of people have understood the full social, moral and ethical implications of the anonymity laws regarding donor conception in Europe and this may be difficult for the child conceived later on in life if the parent keeps the treatment as a 'secret'"

Participant 16: "I feel that being open with any children that result from CBRS is vitally important".

8.1.8 Support

Relating to CBRS support, participants suggested there were four different types of support, which could be sought by CBRS patients: support from infertility networks, support from family and friends, support from doctors and support from work.

8.1.8.1 Support from infertility networks

Many participants' (Participants 3, 5, 6, 10, 11, 15, 16, 19, 20, 25 and 26) found the support of infertility networks (e.g. UK Donor Conception Network or Fertility Friends) "very beneficial" (Participant 6). Many participants attended workshops or forums (Participants 3, 6, 9, 19 and 25) run by the infertility networks:

Participant 3: "...through the UK Donor Conception Network workshops. Here you get the opportunity to raise your concerns and fears"

Participant 6: "The preparation workshop run by the Donor Conception Network was also very beneficial..."

Participant 11: "Join the FertilityFriends.co.uk forums and ask questions".

Participants found infertility networks "were a good starting point" (Participant 20) before embarking upon their CBRS journey. Participants felt they could raise their "concerns and fears" (Participant 3), "take advantage of all the advice" (Participant 10) or "trodden path" (Participant 25) and "hear about other people's experiences" (Participant 16) in the workshops or on the forum. This was particularly valuable when planning their CBRS journey.

8.1.8.2 Support of family and friends

Participants who were in a relationship said it was vital to have their partner's involvement with the CBRS as this will have important implications for future relationships. For those without a partner, the support of friends was endorsed:

Participant 12: "Ensure that you have a partner/friend/cycle buddy with you to hold your hand"

Participant 14: "Make sure that your partner is IN IT, otherwise you are in for frustration/disappointment".

Telling family and friends about their CBRS journey is more challenging. Some participants found they could talk with their family and friends and sought support from them, especially those friends who had gone through a similar experience to themselves. Participant 24 found it difficult to lie to family and friends about her CBRS journey:

Participant 8: "Talk to your family about your treatment as you will need their support (emotional and physical)"

Participant 10: "...essentially I found talking things through with family, friends and other women going through similar experiences was sufficient for me"

Participant 24: "...it's useful to think about what you plan to tell family and friends i.e. I have found it difficult to lie to people when they asked how our holiday was?".

Participant 16 found it "wasn't helpful to ask friends and family" for their advice in what to do; however, she did propose CBRS patients should "tell their friends and family" what they are going to do and "ask" them for support if they are able to do so:

Participant 16: "In my experience, it isn't helpful to ask friends and family what you should do...tell...friends and family what you are going to do and ask them to support you as much as they feel able".

8.1.8.3 Support from doctors

Seven participants (Participants 12, 19, 21, 22, 23, 24 and 25) offered their views on the support from doctors and other health professionals in their home country. The support by the doctors in the home countries ranged from referral to CBRS, blood test, ultrasound scans, medication requirement, communication between clinics and follow up appointments after the CBRS. They felt the cooperation with the home country medical professionals and the CBRS could reduce the stress of the cross border reproductive treatment. Participant 21 suggested that this "tie-in" or shared care with CBRS occurred more and more in the UK clinics:

Participant 12: "Try to ensure your doctor here (GP or fertility doc) is supportive of your decision to seek CBRS and can support you if you have a positive or negative result when you get home (blood tests/scans/drugs/referrals etc)"

Participant 19: "I would recommend that they kept in touch with their local clinic if possible, before and during, as it's helpful to have a consultant locally who can answer

questions about the process. However this may only work if you've been referred abroad by your local clinic, and if they have a link with the overseas clinic"

Participant 23: "Make sure that your doctor in your home country and abroad are willing to communicate with each other. This means that you can be sure of the thorough care which in turn again helps to reduce stress".

8.1.8.4 Support from work

Four participants mentioned their work commitments and getting time off work for their treatment. Participant 8 suggested others share their CBRS requirements with their employer to help in getting time off for their treatment as some companies would allow time off for infertility treatment:

Participant 8: "Also, sharing your treatment requirements with your employer can reduce expectations during your absence"

Participant 21: "...how you are going to get time off work"

Participant 22: "I'm sure this helped. Previously we travelled for a day or two to Valencia and it was more rushed because of work commitments, etc."

Participant 24: "...it may be possible to get time off work for IVF - some companies allow this and I didn't realise until afterwards. It helps if you are not using all your annual leave to travel in one go, in case the treatment doesn't work and you need to travel again for a second treatment".

8.2 Participants' Recommendations for CBRS Providers

Participants' recommendations to CBRS providers focused upon communication with patients and highlighted potential language barriers and promoted the need for patient-centred care and improved linkage between home and overseas infertility services.

8.2.1 Communication

Nine participants (Participants 1, 6, 8, 9, 10, 11, 12, 21 and 23) highlighted communication and that the overseas clinic should respond to email and messages promptly/timely (Participant 1 and 11) to the patients within 24 hours (Participant 3):

Participant 1: "If I could advise my overseas clinic it would be to try and answer emails promptly and tell people to call if they don't understand"

Participant 11: "I would advise the clinic I in city B to answer their emails promptly and with a certain amount of sensitivity".

8.2.2 Language barriers

Six participants (Participants 3, 6, 11, 18, 23 and 25) advocated that overseas clinics should "make sure the clinic staff speak good English so there is no language difficulties" (Participant 18). Participant 23 found her "liaison person invaluable in cutting through local communication both while" she was in country B and "via email before arriving". Participant 11 would like the

overseas clinic to give out “business cards in English to patients” to reduce language barriers with local people. Many CBRS patients do not speak the local language and travel to clinics by taxi, a simple business card could “be an enormous step forward” to reduce the potential stress faced by CBRS patients.

Participant 3 further suggested the “answering machine in the clinic” should “have some of the message in English” to enable CBRS patients to “know what they are saying...[or] a separate phone line for English speaking patients”.

Most doctors in foreign clinics could communicate well in English; however, some nursing or administrative staff in the overseas clinics were not able to converse with patients. They are the frontline staff and were dealing with initial problems and concerns raised by the patients; therefore, participants thought that they should be better trained to facilitate their dealings with concerns raised by patients.

8.2.3 Person-centred care

Four participants stated that they would not like to be “just another name or number on a sheet” (Participant 5) or “on a conveyor belt” (Participant 6). Two participants (Participants 9 and 11) recounted their overseas consultant gave them his “private mobile number and said” they “could call him at any time”. This personal advice made the participants feel “cared for”. In several instances, the women travelled alone without their partner (Participant 11), so the patient is “even more sensitive to her emotion”; consequently, making the patients feel comfortable and secure could enhance their satisfaction with their clinic.

8.2.4 Links between home and overseas clinics

Participant 15 reported her home clinic was using “scare tactics to prevent patients from going abroad” for infertility treatment and felt many patients were discouraged from seeking fertility treatment abroad. Three participants felt that “...it would also be helpful if” their home clinic could have “stronger links” (Participant 13) with clinics abroad and have “less resistance” in aiding the monitoring of cycles following treatment abroad. Participant 17 had difficulties in finding large USA clinics that would monitor her cycle following treatment out-of-country. She “...would advise the American clinics to be more flexible” in facilitating the cycles of patients undergoing treatment abroad. Participant 21 suggested that this “tie-in” or shared care between UK and overseas fertility clinics occurred more:

Participant 21: “...do they have a centre in the UK for the initial consultation, tests etc. (more and more UK clinics are ‘tie-in’ with clinics overseas in order to provide this and only the actual treatment is done abroad)...”.

Anecdotal evidence (personal communication with medical professionals) suggested many providers of fertility treatment for foreign patients promote their services informally at

meetings of professional societies that attract international participants and “wine and dine” infertility doctors in order to gain contracts/referrals. Infertility doctors, therefore would have a duty of care/professional integrity to make sound judgements when embarking on shared care arrangements with CBRS or referring patients for CBRS. McKelvey et al. (2009) pointed out the high multiple pregnancy rates by CBRS, which could pose a challenge for obstetricians and have financial implications for local health services, in addition to the impact on the patients themselves and their families. Forman (2011) and De Sutter (2011) advise CBRS to provide good quality standards of care as prescribed by the ESHRE (2011) ‘Good Practice Guide’ to CBRS patients.

8.3 Participants’ Recommendation for National and/or Supra-national Bodies

Participants would like national and/or supra-national bodies (i.e. Infertility Networks, HFEA, ESHRE, ASRM) to be “objective and supportive of women/couples who choose to go abroad” (Participant 10) for infertility treatment and were conscious of the negative portrayal of CBRS in the media. They would like more information and data regarding CBRS. Participant 7 went further by suggesting that CBRS stakeholders should “be enforcing minimum safety/professional standards” relating to CBRS. Participants found there is a huge amount of information regarding cross border reproductive clinics; however, they would value more information on risks, legislation and psychosocial aspects of CBRS. This study was conducted before the implementation of ESHRE ‘Good Practice Guide’ (Shenfield et al., 2011) therefore; the findings from this study may not be a true reflection of current practice by cross border reproductive clinics.

8.3.1 Information on cross border reproductive services

Seventeen participants commented on regulations regarding cross border infertility treatment (e.g. USA (Participant 1) and Ireland (Participant 4) with no regulatory body) and the UK with HFEA as a regulatory body.

Participants (Participant 14) found it “hard to know what information is correct” and hoped there “could be a standard in place” to ensure that information provided by overseas clinics is genuine. Currently, patients are relying on “internet marketing information to assess their chosen clinic” or “word of mouth” (Participant 11). Participants (Participants 8, 10 and 15) would like infertility clinics to “adopt an international standard for measuring” (Participant 8) treatment outcomes “similar to the HFEA Clinic Finder/review/stats service” (Participant 10). HFEA Clinic Finder reports on individual clinics’ success rate or “similar to the CDC reporting” (Participant 15), which reports on USA clinics’ success rates - although they appreciate “...this would be quite a substantial project and very difficult to establish given the differences in different markets and regulations etc” (Participant 10). Participant 20 felt “it is difficult to have robust information regarding the cost involved in medical procedures”.

Participants would like to know more information regarding staff qualifications to ensure good professional practice (Participants 7 and 11) and minimum safety standards (Participant 7):

Participant 7: "...main activity should be enforcing minimum safety/professional standards and providing information..."

Participant 11: "Definitely information regarding the specialists at the clinic, their background, training, years of experience, membership of professional bodies and also years in their current position. I would like to know what Code of Conduct they follow (i.e., in the UK it's the HFEA) to ensure good practice".

Participants (Participants 8 and 10) believed CBRS stakeholders should "adopt an international standard for measuring" treatment outcomes, collate and publish this information. Participant 11 also advocated that stakeholders should "visit" clinics and "make reports on them" or perhaps "ask" patients to rate their CBRS clinics and publish the information online.

With the implementation of the ESHRE's 'Good Practice Guide', perhaps stakeholders could ensure adherence of the guide by inspection process with fertility clinics. Stakeholders could also implement accreditation, publish the list of accredited clinics to facilitate patients' choice and ensure submission of success rates from clinics (i.e. the yellow form system adopted by the HFEA) to ensure transparency of information. A form of patients' satisfaction score, like those used in the UK University National Students' Survey (2015) or ratings like those developed by TripAdvisor, would assist CBRS patients' decision-making process.

8.3.2 Educational material

Nine participants (Participants 1, 5, 8, 9, 11, 15, 18, 19 and 20) suggested there was a "huge amount" (participant 20) of CBRS information (i.e. medical, psychological and legal information) explaining the treatment options and their implications. However, some participants advocated the availability of more information regarding the risks associated with overseas treatment (Participants 8 and 18):

Participant 8: "Safety education would include: prevention of blood/body fluid infections, genetic transmission of disease, thorough explanation of procedures and medications and who can we contact if we feel something is unsafe (within the organisation or the profession - which ones are regulated). Professional services education: who is involved in care - who should be involved in care in the CBRS, what you can expect from each care provider (who will coordinate care, who will answer technical questions, who will support us with emotional/stress issues)"

Participant 18: "You need to be aware of the risks are of having donor sperm and eggs i.e. health issues such as HIV and other transmittable diseases if there is not proper screening. You need to make sure that there is proper screening of the donors before you receive donor sperm or eggs".

8.3.3 Legal Perspectives around CBRS

Legal perspectives were mentioned by four participants (Participants 8, 17, 20 and 22). They felt the legal situation regarding fertility treatment abroad remains unclear and some raised the issue of anonymous vs. identifiable donors that distinguished policy and practice between different countries. They felt this could be a future issue especially for those who had donor treatments and later on found out there is a health issues with their child. Without open information relating to gamete donors it would be impossible for the recipients or the child to resolve the potential health issues that might arise in the future:

Participant 20: "For the legal aspect, it's a mess! Most of time the laws are not clear or well defined... for French people who are used to coping with a single national health system, it is like Chinese language!"

Participant 22: "...the laws regarding what information is provided about donors"

Participant 17: "In Spain, little information about the donor is known. I think that can get tricky if there is a health problem with the child conceived via CBRS".

8.3.4 CBRS and socioeconomic disparities

Five participants (Participants 1, 14, 15, 21 and 26) stated their awareness of the socioeconomic disparities for CBRS. They sensed CBRS is good and open access for those who could pay for infertility treatment and they also acknowledged that CBRS is an "uneven and unfair playing field" for those who could not afford infertility treatment abroad. Participants suggested the high cost for infertility treatment at home is the reason for CBRS:

Participant 1: "If you are fantastically wealthy then of course you will never need to travel abroad to access medical care so it is really only an issue for middle/working class people. Poor people can't afford to travel for medical care, period and working/middle class people can if they are careful"

Participant 14: "It is good that infertility treatment is open for anyone provided they can pay for it. i.e. there are no restrictions to residents only"

Participant 15: "I think it offers a great solution for family building that is very accessible to everyone"

Participant 21: "However the down side is that only those who can afford to go abroad are able to do this so it's an uneven and unfair playing field"

Participant 26: "...I'll just say that CBRS was the best decision I ever made...I'm so grateful this option is available for those of us living in countries where infertility treatment is very expensive".

Chambers et al. (2013) found that women of higher socioeconomic status utilised fertility treatment more than women of lower socioeconomic status, which is more likely to reflect a greater ability to pay for treatment than a greater needs for treatment. Financial barriers are therefore an important obstacle to ensuring equitable access to infertility treatment.

Participants in this study had high educational qualifications and were in employment, thus would be from a higher socioeconomic status and were able to utilise CBRS. Participants recommended that the stakeholders would need to address the needs of people from lower socioeconomic status and facilitate their access for CBRS.

Participant 14 from Tanzania suggested “it was difficult” to have treatment in Tanzania as there is “only one referral hospital and limited specialists” to perform infertility tests and treatment. Eventually she had tests done in Kenya and treatment in South Africa:

Participant 14: “If there is any way the drugs can be waived so that the prices are bearable for all who need such treatment it would be very helpful”.

Stakeholders in developing countries, therefore, would need to address this technological shortage. She also found drug costs an issue for people from developing countries and advocated that, if possible, developing country stakeholders control the pharmaceutical cost to make it more “bearable” for people requiring infertility treatment in a developing country.

8.3.5 CBRS and the Media

Participants reported the media position on CBRS as “very limited, inaccurate”, sensationalised and negative towards people undergoing CBRS:

Participant 15: “I found the general information in the media to be very limited, inaccurate and often biased against CBRS”

Participant 20: “Media sensationalism about reproductive tourism has a bad impact on public opinion or on political leaders”

Participant 22: “I find the term used in the media “fertility tourism” deeply offensive”

Participant 24: “I think that CBRS has had a lot of bad press recently”

Participant 14: “I know infertility is not life threatening, therefore, there is little financial support but it is a problem which not only affects those who cannot have children but also poses a lot of stigma especially in the African setting where not having children is treated very negatively”.

Budds (2013) found the media portray older mothers as selfish and that they choose to delay motherhood, thus putting themselves and their babies at risk. In this study, the participants had experienced the ‘double whammy’ of being older and had multiple infertility treatment failures; therefore, they felt the media portrayal of them as “deeply offensive” (Participant 22). Participant 14 also expressed that although infertility is not a life threatening disease, culturally it could have a significant negative impact on the individual, especially in an African setting.

Participants suggested that “fertile people” (Participant 1) do not understand why people seek CBRS and are not “put off” (Participant 10) by others (i.e. home doctors or home IVF clinics). Participants argued that most CBRS patients have usually “exhausted the possibilities for treatment at home...[and] it is not something anyone does lightly” (Participant 1). In some way, the stakeholders would have a place to play in promoting the CBRS and demystifying this phenomenon by explaining it to the public in a constructive and helpful manner.

8.5 Chapter Summary

In this chapter, I have elicited themes to formulate the recommendations for CBRS from the participants. These recommendations are divided into three main themes: recommendations for other CBRS travellers, CBRS clinics providers and National and/or Supra-national Bodies. In the final chapter, I will discuss this study and reflect upon the chosen methodology, future research and implications when delivery CBRS.

Chapter 9 Discussion

Cross border reproductive services are a multi-billion dollar industry that is accelerating in many countries (e. g. Eastern Europe, Latin America and Southeast Asia) (IFFS, 2013). Many patients travel to India for surrogacy, which is thought to be the world's greatest provider of surrogacy (Deonandan et al., 2012). Travel for cross border reproductive services raises legal and ethical dilemmas. Recently, two of the major professional associations in this field, the European Society for Human Reproduction and Embryology (ESHRE) and the American Society for Reproductive Medicine (ASRM) have turned their attention to these issues. The ESHRE Task Force in Ethics and Law provided twenty guidelines on specific ethical issues in the practice for infertility treatments (Pennings et al., 2008) and a newly formed ESHRE Task Force on Cross Border Reproductive Care produced a practice guide (Shenfield, 2011), specifically to increase the safety of cross border fertility treatment for patients. The ASRM Ethics Committee also produced a report dedicated to the ethical challenges posed by cross border reproductive travel (ASRM, 2013).

Hudson et al. (2011) and Inhorn and Patrizio (2012) undertook a systematic review on CBRS and found little empirical research had been carried out up to that time, concluding that it was an under-researched and under-theorised health phenomenon. Most empirical studies that have been undertaken are clustered in Europe and North America (Bergmann, 2007; Blyth, 2010; Culley et al., 2011b; Hughes and DeJean, 2010; Pennings et al., 2009; Shenfield et al., 2010) with few recent studies from the Middle East (Inhorn, 2011a; Inhorn and Gürtin, 2011), Asian countries and Australasia (Pande, 2011; Whittaker, 2009; Whittaker and Speier, 2010; Rudrappa, 2010; Palattiyil et al., 2010).

This thesis explored patients' motivations for, and experiences of, cross border reproductive travel and to contextualise the findings of the study within a partial Trans-Theoretical Model (Prochaska and Norcross, 2007; Prochaska and DiClemente, 1982). This thesis comprises nine chapters; I have endeavoured to ensure that these provide a coherent trajectory so as to illustrate the decision-making processes in which participants engaged in relation to their international journeys for fertility services.

Chapters one and two provide an overview of cross border travel for reproductive services and include the literature review undertaken for this study using a systematic review methodology. Two literature reviews, 26 commentary papers and 17 empirical studies were identified that had been published between January 2011 and October 2013. This, alongside the recent ESHRE and ASRM reports on cross border reproductive services mentioned above, indicates a growing professional and academic interest in this field, the latter including a range of research disciplines (i.e. social scientists and anthropologists), thus generating new and diverse

perspectives on this phenomenon. Since submission of this thesis, a special issue of the International Journal of Feminist Approaches to Bioethics on Transnational Reproductive Travel (Fall 2014, Vol. 7, No. 2) has been published that extends both empirical data and theoretical perspectives on the CBRS phenomenon, however this special issue was published too late to be considered in this thesis. From the limited empirical data, consistent features have nevertheless emerged from patients' decisions to embark on, and their experiences of, international travel for reproductive services - excessive waiting time for treatment in their home country; cost of treatment in their home country and increased availability of low cost travel facilitating the feasibility of more distant destinations.

Language and communication barriers also appear to be an issue for many patients undertaking treatment in a foreign country. Expatriates would return "home" for infertility treatment (Inhorn, 2011a) or some patients would hire English speaking coordinators to overcome language barriers (Speier, 2011). With no clear guidance from health professionals, the internet is the most important resource for acquiring information about services, facilitating exchange of information and experiences between patients and for establishing communications with service providers for many CBRS patients. This infertility network (i.e. Seriality and Communitarity) effect (Young, 1994; Hudson and Culley, 2011) could influence patients' choice in their destination clinic and country. For patients who live in countries that impose significant restrictions on infertility treatment (e.g. egg donation or surrogacy) (IFFS, 2013), CBRS could be viewed as a 'safety valve' (Ferraretti et al., 2010; Pennings, 2004; Pennings et al., 2008; Van Hoof and Pennings, 2011; Storrow, 2011; Storrow, 2012; Lui et al., 2011).

ESHRE's 'Good Practice Guide' (GPG) (Shenfield, 2011) and the ASRM Ethics Committee on CBRS (ASRM, 2013) are a starting point in promoting CBRS patients' safety. Thorn, Wischmann and Blyth (2012) have recently proposed ten minimum standards of care:

1. National and supra-national bodies should oversee voluntary commitments to the standards especially for those countries which have not yet established legalisation for CBRS
2. A commitment to altruistic donation and surrogacy and a ban on commercial infertility procedures
3. Gametes donors and surrogates should have the same level of care as the recipients
4. Unbiased and higher levels of informed consent (i.e. medical procedure, psychosocial implications and legal information on their status) should be provided for donors and surrogates
5. All parties should have access to psychosocial counselling prior to, during and post infertility treatment

6. Multi-disciplinary ethics committee should be involved in complex/innovative infertility treatment
7. The recruitment of donors and surrogates should be carried out independently from those institutions that are responsible for informed consent procedures, psychosocial counselling and legal advice to avoid conflict of interest
8. CBRS clinics should archive their clinical records for a minimum of 80 years. Donor-conceived individuals should be entitled to have access to this information, if they wish to do so. Donors should be able to know if their donation was successful and the number of offspring conceived with their gametes
9. All countries should strive towards self-sufficiency for infertility treatment to reduce the need for CBRS
10. Existing international regulations and conventions on human rights (i.e. the Convention of Human Rights and Biomedicine of the Council of Europe) could be used as a framework for CBRS

These minimum standards could be implemented on a voluntary basis by CBRS clinics, professionals and research institutions to provide a degree of transparency to patients, donors, surrogates and other infertility health professionals. The authors hope that these will form a benchmark and promote discussions to provide better CBRS to reduce risks for all affected parties.

Chapter three outlines the ontological and epistemological assumptions underpinning the study. Rationales for the use of Grounded Theory method and Voice Centred Relational Method (VCRM) in the analysis of the participants' email interviews were detailed. The rationale for applying asynchronous email interview methodology, the ethical approval process for the study and the choice of NVivo software utilisation in the analysis of the email interviews were detailed here. I also report on participants' experiences of taking part in the email interviews.

Chapter four provides demographic information about the 26 participants. Most participants were well educated, in a heterosexual relationship and had received multiple failed treatments in their home country prior to undertaking infertility treatment in another country. They had spent a considerable amount of money in their home country. The participants' mean age was 43.35. Some of the reasons identified by the participants for seeking CBRS were the excessive waiting time for gamete donor and/or surrogate and the cost of infertility treatment at home versus cost of treatment overseas. The small sample size prevented the identification of any clear pattern for CBRS destinations. Most participants could not recall the actual cost of their treatment and reported broadly positive experiences of their cross border infertility treatment, although some concerns relating to their treatment and its aftermath were raised by participants. Findings reported in this chapter are similar to the findings reported by Culley et

al. (2011b) and Shenfield et al. (2010), thus providing some confidence in the reliability of the study's findings.

Chapter five recounts nine participants' narrations of their CBRS journey; they were selected because of the country of destination, types of treatments and complexity of CBRS. The Voice Centred Relational Method (VCRM) or "I" poem approach (Brown and Gilligan, 1992b; Gilligan et al., 2003; Doucet and Mauthner, 2008; Mauthner and Doucet, 1998) was adapted to analyse participants' interviews. As this is an account of the individual's motivations for, and experiences of, CBRS, I paid particular attention to the personal narration of their CBRS journey.

Chapter six presents the analysis of the 26 participants' email interview transcripts using NVivo. In this chapter, five stages of participants' CBRS journey are identified. Stage one was before participants became aware of their need for infertility treatment; stage two was participants' perspectives of infertility treatment at home; stage three was reasons for, and journey towards, CBRS; stage four was the participants' expectations, and experiences of, their CBRS and finally stage five, participants' experiences when returning home after their CBRS. All the substantive codes are described in detail in this chapter.

In Chapter seven I offered different theoretical perspectives based on previous research, such as the "Push and Pull" theory used by Inhorn (2011a) from an anthropological perspective and Seriality and Communitarity (Young, 1994; Hudson and Culley, 2011) from a sociological perspective. I also introduced four additional theories, i.e. risk perception and optimistic bias (Weinstein, 1980); the Health Belief Model (Rosenstock, 1966); Theories of Reasoned and Action and Planned Behaviour (Ajzen, 1991; Fishbein and Ajzen, 1975); and the Trans-Theoretical Model (TTM) (Prochaska and Norcross, 2007; Prochaska and DiClemente, 1982) and related these to CBRS. A partial model, based upon the Trans-Theoretical Model utilising the substantive codes from Chapter six to articulate the theoretical codes, was proposed in this chapter to explain the motivations for, and experiences of, participants' CBRS journeys.

Chapter eight outlined 26 participants' recommendations for CBRS. These comprise three substantive areas: recommendations to other CBRS travellers, CBRS clinics providers and National and/or Supra-national Bodies.

In this chapter, I will reflect upon the chosen methodology and how I might have undertaken things differently if I were to conduct this study again. This will then be followed by a discussion of how this study has contributed to existing theoretical knowledge. In Chapter 10, I will discuss the research implications, which could enhance the future development and practice of CBRS.

9.1 Reflection upon the appropriateness of the chosen methodology

In this section, I will provide a reflective account of the methodological aspect of this study. This study employed a Straussian Grounded Theory approach (Symbolic interactionism), whilst acknowledging the Glaser's Grounded Theory standpoint. In Chapter three, I provided the rationale for my research design (asynchronous email interview). I decided a qualitative study was appropriate for this study as it would allow flexibility in providing a holistic exploration of the sensitive nature of the emergent themes. Email interviews, utilising a semi-structured interview schedule, enabled me to establish trust and rapport with the participants in a confidential manner, which facilitated participants to engage in open communication regarding their personal experiences. This semi-structured interview schedule, further allowed a focussed sequential exploration of the participants' journeys, beginning with their treatment at home, their treatment abroad and their experiences following their return home.

In Chapter five, I used the VCRM to facilitate individual voices of the participants. VCRM is a feminist approach for data analysis; therefore, as a male researcher with no personal experience of fertility difficulties, undertaking this study was particularly challenging for me. Upon self-reflection and by including some male participants' individual voices in this study, I feel I have added a male perspective within the CBRS context.

As this is a retrospective study, the accuracy of the participants' recall may have an important impact on the findings. Taking account of the sensitive and stressful period of the participants' CBRS journey, the time-limited nature of a PhD research project and the resources available to me, it would not be logistically possible to follow participants in 'real time' whilst they are undertaking their CBRS journeys. On reflection, the retrospective study was a sufficient approach. However, any future study might benefit from limiting the time period following completion of treatment to six months or one year, so as to facilitate increased accuracy in participants' recall. Another method that could be employed to increase the accuracy of recall would be by means of a contemporaneously completed diary enabling participants to record their journey as it happens (Pope et al., 2000), although the highly emotive nature of the activity could add extra stress (i.e. time spent on the diary) on participants, which may not be desirable.

The participants in this study appeared to be socio-economical stable as they were all well-educated and in employment. It would be premature to generalise the findings of the study to other groups. In particular, future research might usefully include a more diverse population (i.e. more inclusive of participants from minority ethnic backgrounds and/or lower socio-economical groups) to indicate any differences with this study's participants' motivations for, and experiences, of CBRS. This highlights the need for reasonable financial wealth in order to undertake CBRS. Since socio-economically disadvantaged groups are unlikely to be cross

border reproductive travellers, it is unlikely that their exclusion from this study is disproportionate.

Armed with the information generated from this study, future studies might usefully utilise a larger sample size, incorporating both quantitative and qualitative research methodology, to enhance understanding through providing more in-depth knowledge of the 'Push and Pull' factors fundamental to CBRS.

A future study could incorporate a broader cohort of infertility patients (i.e. those who did not choose to engage with CBRS, who had exited from CBRS and who had re-engaged with infertility treatment either at home or abroad). The reasoning behind their CBRS decisions would be of interest to national and supra-national bodies as they are responsible for the legislation and regulation of infertility treatment and services.

In this study, I also did not interview any participants who had exited from CBRS and re-engaged with infertility treatment either at home or abroad. Future studies may be interested in investigating the above groups in order to determine if their decision was to select either infertility treatment at home or abroad.

I have learned many valuable lessons including the generosity of the participants and how best to ask sensitive questions and maintain a professional researcher's position, whilst retaining my natural empathy towards them. I have learned to deal with my own emotions when presented by participants' openness in recounting sometimes harrowing stories. I hope these lessons will enable me to develop both as a researcher, and a teacher, and enhance the ways in which I undertake future studies in the area of human reproduction.

9.2 How this study has contributed to existing theoretical knowledge.

The aim of this thesis was to explore patients' motivation for, and experiences of, CBRS as many authors (Hudson et al., 2011; Inhorn and Gürtin, 2011) suggested this is an under-researched and under-theorised health phenomenon. Although subsequent research has been published in the special issue of *Reproductive BioMedicine Online* (2011) and other journals (i.e. *Human Reproduction* or *Sterility and Fertility*, *International Journal of Feminist Approaches to Bioethics*) using either anthropological or sociological approaches, this study has supported, complemented and made original contributions to the current understandings of the decision processes of CBRS patients. This thesis offered both the individual narrative and substantive themes of the CBRS patients' journey. In addition, this thesis presented a partial Trans-Theoretical Model encompassing the anthropological (Push and Pull) and sociological (Seriality and Communitality) viewpoints to present the decision-making process underlying CBRS patients' journeys. Participants in this study also proposed recommendations for fellow CBRS travellers, clinics offering treatment to foreign patients and national and/or supra-national bodies. Most previous studies have focussed on participants from a single country or

region (Rozée Gomez and de La Rochebrochard, 2013). For example, all British participants in Culley et al. (2011b), all Middle Eastern participants in Inhorn's (2011a) and Inhorn et al. (2012) studies, all European participants in Shenfield et al. (2010) and North American participants in Speier (2011). In contrast, this study recruited a wide range of participants from many different countries. This study also offered unique insight into reproductive travel between Tanzania and South Africa and between Hong Kong and Thailand, even into African and Far Eastern patients' perspective for CBRS. By performing a literature review, utilising a systematic review methodology and semi-structured email interview, this study has made a contribution to knowledge as follows:

- Motivation for and potential barriers to CBRS - there is increasing information regarding CBRS via infertility networks or CBRS websites. Due to the age of patients, many had multiple failures of infertility treatment at home and many required third party infertility treatment; therefore, the lengthy waiting time for treatment at home becomes unacceptable for many patients. The perceived high cost of infertility treatment at home and increased availability of low cost travel contributed to patients' desire to consider CBRS as an option. Language and communication barriers were highlighted by many patients as potential issues for CBRS. CBRS acts as a safety valve in those countries with legal restrictions for infertility treatment
- Experiences of CBRS - participants know the financial cost of CBRS as they are required to pay up front for their treatment. Participants acknowledged that they were able to exercise autonomy as regards their fertility treatment; however, they experienced stress and anxiety during CBRS. Many participants reported language barriers and did not fully comprehend the legal position and regulations around CBRS. Participants had positive experiences relating to the clinical environment however, they found the treatment protocol at times was different from the one at home and staff attitudes and communications were mixed, especially when participants encountered problems. Support from family and friends, including infertility network friends, were important to participants and most found counselling an invaluable support for their journey. Many participants did not declare their cross border infertility treatment at home and they slotted back into their home maternity/healthcare system. Half of the participants had encountered some form of medical complications after their CBRS. This can have major implications for the home country's health care system (McKelvey et al., 2009; Forman, 2011). Finally, most participants articulated their decision for CBRS and indicated it was the correct one for them and would have undertaken CBRS earlier
- Partial theoretical model: Anthropological (Push and Pull), sociological (Seriality and Communitarity) and social psychological (unrealistic optimism, Health Belief Model and Theory of Planned Behaviour) perspectives were considered in this thesis. A partial Trans-Theoretical Model (see Chapter 7) was formulated including the Stage 1: pre-contemplation (before awareness of their needs for infertility treatment), Stage 2: contemplation (recognising their

needs for infertility treatment, most participants had infertility treatment at home however, due to legal or technological restrictions, some might consider CBRS immediately), Stage 3: preparation (researching, either via CBRS websites or infertility networks, for the best CBRS clinics for themselves), Stage 4: action (take action to obtain CBRS), Stage 5: maintenance (expectations and experiences would enhance perseverance towards their family-building quest, participants could either continue their treatment in the same clinic or choose another clinic either in the same country or in a different country), Stage 6: exit (completion of their family-building aspirations from successful infertility treatment or decided they had “had enough” with their infertility treatment) and Stage 7: re-engagement (those who had exited CBRS but re-thought their infertility treatment decision and re-embarked on their infertility treatment either at home or abroad). This thesis provided empirical evidence in unfolding some of the decision-making processes from participants embarking upon cross border reproductive treatments

- Recommendations for CBRS - these are divided into three main areas: (1) other CBRS travellers, (2) clinics providing treatment for foreign patients and (3) national and/or supra-national bodies. Participants encouraged CBRS patients to make their own judgement and investigate protocol and potential communication issues with potential clinics; thus research is vitally important. Patients need to consider financial implications and other practical (i.e. accommodation, travel and local communication) issues surrounding CBRS travel. They need to prepare for emotional responses by avoiding stress, seek counselling and support from infertility networks, family and friends, doctors and employers. The importance of communication, including combating language barriers and promoting person-centred care were highlighted as recommendations to CBRS. Participants offered simple and practical solutions (e.g. business cards) to improve the CBRS experience. Participants would like to see more ‘joined up’ CBRS and less antagonism from home infertility clinics towards cross border travel to provide essential medical care for patients embarking on CBRS. National and/or supra-national bodies should increase the focus on a culture of compassion and care for those who seek CBRS. Participants suggested there was an overwhelming volume of information on CBRS, although it was difficult to ensure the veracity and accuracy of this information. Participants welcomed relevant educational material (relating to risks associated with CBRS, legislation and psychosocial impacts) and efforts by stakeholders to safeguard minimum safety and professionals standards in CBRS. The impact of socioeconomic disparities on availability of, and access to, fertility services was emphasised by participants and they felt more needs to be done for patients living in developing countries whose access to infertility treatment was limited because of financial reasons.

This study has identified gaps in research knowledge, which necessitate further research considerations. Inhorn and Gürtin (2011) suggested empirical work to provide evidence about CBRS; however, this remains partial and fragmented, beginning with a lack of quantitative

research and primary data pertaining to the incidence of CBRS and the estimates for the frequency, and direction of, international reproductive travel.

This research found that some studies have investigated the CBRS experience from healthcare provider perspectives (Culley et al., 2013; Hughes and DeJean, 2010; Pennings et al., 2009; De Sutter, 2011; Forman, 2011) and increasing exploration of international gestational surrogacy in India (Pande, 2009; Pande, 2011; Rudrappa, 2010; Palattiyil et al., 2010). However, almost few study has investigated the views, and experiences of, sperm or egg donors within CBRS (Inhorn and Gürtin, 2011). International gamete donation poses particular ethical concerns, which have been raised by other authors (i.e. Pfeffer, 2011) relating to the potential exploitation of these donors. CBRS is a global phenomenon and research output has tended to focus upon Europe and North America (Shenfield et al., 2010; Culley et al., 2011b; Speier, 2011), Inhorn's and Pande's studies have added to the geographical understanding of CBRS in Middle Eastern countries and India. There are still other major regions of the world (e.g. Latin America, Sub-Saharan Africa and post-socialist Europe and Asia) where CBRS is known to take place, although very little is known about its practice. With the recent political instability in Thailand, Egypt and Ukraine, it might have an impact upon the decision-making process for many infertile patients.

In this study, one participant was from Tanzania, who confirmed that access to fertility treatment is severely limited or simply non-existent (Nachtigall, 2006) and only the elite (i.e. the socio-economically advantaged) have the opportunity to try to resolve their fertility difficulties by seeking treatment abroad (Inhorn, 2009b).

Although there is increasing evidence about the psychological development of children in families built using ARTs, including those using donated gametes and embryos (for a recent overview see, Freeman et al., 2014), there is no information regarding the longer term outcomes for families created via CBRS (Inhorn and Gürtin, 2011). This is an important research gap, especially in the case of cross border reproductive treatment utilising gamete donation, as the donor is likely to be unknown to the recipient, unknown to any resultant offspring and may be of a different cultural and ethnic group to the recipient. Furthermore, there is no current legislation to enforce record keeping or disclosure for the future child in many countries (IFFS, 2013).

Future research would require access to a wider spectrum of ART patient groups. This could be achieved by researchers investigating a wider pool of recruitment sites, such as guest houses, hotels, tourist companies, CBRS agencies, or lawyers handling CBRS cases, as well as clinics in home countries that formally refer patients for treatment abroad and clinics in destination countries serving foreign patients. Gaining access and trust from these sites may generate new perspectives from patients when they negotiate their CBRS journey (Speier, 2011).

The internet is an important space for many cross border reproductive clinics to advertise their services and a key source of information for CBRS patients when planning their CBRS journey. This virtual space enables CBRS patients to seek guidance from, offer support to and exchange personal stories with each other (Bergmann, 2011b; Gürtin, 2011; Van Hoof et al., 2013). In countries with legal restrictions, this form of anonymous communication enables CBRS patients to gain information which is, otherwise, impossible to obtain. In this study, I gained information from Hong Kong where infertility treatment is illegal for single women and from a couple in France where surrogacy is illegal.

From the partial Trans-Theoretical Model, I have identified that some patients might not consider CBRS and some patients might exit from CBRS and later re-engage with fertility treatment; their rationale for not seeking or re-engaging with CBRS would be important for future research.

CBRS is a multi-disciplinary research area involving a range of professional and academic researchers. There is a need for more researchers to undertake CBRS research especially relating to the economic and financial contours of this global market. Further areas of CBRS research could include the psychological and emotional impact of CBRS upon families and the wellbeing of all patients and/or their partners and the children born as a result of CBRS. Finally, the legal perspectives and the legal burden placed upon the individual who resides in countries who have regulations and legislation restricting access to ART at home and overseas (Inhorn and Gürtin, 2011) requires further research.

Chapter 10 Conclusion

In this study I have had the privilege of sharing the personal cross border reproductive journeys of 26 participants seeking infertility treatment in their desire to build a family. I am grateful to the participants for their honesty and willingness to tell me about their journeys. I acknowledge that at time this would have evoked many difficult emotions. I hope that the participants feel this is an accurate reflection of their CBRS journeys.

This chapter aims to inform the future development and practice of CBRS. It was my intention to generate knowledge and evidence that would assist CBRS patients, health professionals providing fertility care and other stakeholders to overcome some of the barriers faced by CBRS patients in their family-building endeavours. Although the data for this study were collected in 2010-2011, the experiences narrated by the participants are still relevant today. There has been little progress in the harmonisation of international regulations and legislation in the provision and the access to ART. CBRS continues to attract considerable international media attention (e.g. the recent case of “baby Gammy”, born to a Thai surrogate and allegedly abandoned by Australian commissioning parents because of his disabilities, generated worldwide media attention and influenced the newly formed national assembly in Thailand to place a draft law to prohibit commercial surrogacy in Thailand (ABC News, 2014). The ESHRE’s ‘Good Practice Guide’ was implemented in 2011 to provide a practical guide for CBRS to address issues relating to the equity, safety, efficiency, effectiveness, timeliness and patient-centred care of cross border fertility treatments (Shenfield, 2011). However, a recent study by Rozée Gomez and de La Rochebrochard (2013) still found CBRS, in reality, is much more complex, especially for those living in countries where fertility treatment is subject to stringent restrictions and where it may be difficult for them to ensure that their fertility needs are addressed.

The rich descriptions and interpretations from the participants in this study may help other CBRS patients to recognise the current CBRS landscapes, their reasons, expectations and experiences and finally the pitfalls when returning home after their CBRS journey. I hope the partial Trans-Theoretical Model offered in this thesis will help patients to negotiate their CBRS journey. The findings from this study may also have implications for the delivery of CBRS and stakeholders, which are considered in turn below.

A number of barriers when engaging in CBRS were reiterated by participants in this study including cost, excessive waiting time for third party reproduction and the lack of trustworthy information. Infertility health professionals and clinics should take action to address these barriers as negative patient experiences might eventually lead to an adverse impact on the reputation and the business prospects of the clinic.

ESHRE's 'Good Practice Guide' clearly states that CBRS should "participate in the collection of national or international data" (Shenfield, 2011, p.1626). However, while some countries have established rigorous recording systems (see for example the regular reports produced by the European IVF-monitoring (EIM), Consortium for ESHRE; Kupka et al., 2014), this is not the norm. In contrast to the efforts of ESHRE, the International Committee for Monitoring Assisted Reproductive Technology (ICMART) continues to publish out-dated figures for infertility treatments (i.e. data for 2004 were not published until nearly a decade later (Sullivan et al., 2013) – a delay that calls into question the value of the data and IFFS persistently exclude CBRS data in their periodic surveillance reports (IFFS, 2013). I do not share many eminent authors' (Nygren et al., 2010; Collins and Cook, 2010; Rozée Gomez and de La Rochebrochard, 2013) views regarding CBRS data gathering as complicated. The IFFS surveillance already collaborates with 60 countries in providing infertility data. I would suggest IFFS implement a simple reporting system in their survey (i.e. a box to identify if the patient is or is not a resident of the country, thus when identified as 'is not' they are not seeking infertility treatments in their home country i.e. CBRS patients) and this data could be reported in the overall outcomes and also separately as CBRS infertility outcomes. I acknowledge there will be instances where patients could be returning 'home' (Inhorn, 2011) for fertility treatment; however, as they are not residing in the particular country (i.e. they had travelled for infertility treatment) consequently, they should be classified as CBRS patients).

Safety and patient-centred care (Shenfield, 2011) were identified as key targets in ESHRE's 'Good Practice Guide'. Participants found many CBRS medical staff had higher qualifications /standard of training than was the case in their home country; however many of the support staff, especially the administrative staff, show a lack of care, compassion and commitment towards the CBRS patients. Dealing with complex and emerging issues, the administrative staff were often the first point of contact with CBRS patients; therefore if they were unable to communicate with the patient or know what to do or say, 'miscommunication' could have serious consequences. CBRS clinics, therefore, requires having a training programme to be in place to facilitate their staff to deal with adverse events experienced by their foreign patients (i.e., if CBRS clinics see patients from Germany, the clinic should have staff who are proficient German speakers), thus better ensuring patient safety and well-being.

The importance of the welfare of the child was also identified in ESHRE's 'Good Practice Guide' (Shenfield et al., 2011, p.1626), which stated "it is essential firstly to establish national registers of gametes donors". Many CBRS clinics offered the use of anonymous donors; although this may be attractive to many patients, anonymity poses potential problems (i.e. broken family secrecy /the use of donated gametes; future health problems for the child – inherited genetic disorders – treatment was not able to be provided by non-biological parent), as articulated by the participants. CBRS clinics should follow the lead by the ESHRE's 'Good Practice Guide' and that the legislators should be responsible for a national registers of donors

to enable future openness of information by donors and their offspring. In the absence of such a register, the responsibility for keeping this information should fall upon the overseas infertility clinics. Psychosocial counselling may have a key role in raising awareness of the complexity of CBRS and exploring the psychological and social implications of using either anonymous or identifiable gamete donors or a surrogate. CBRS clinics should also provide free counselling to gametes donors (Blyth et al., 2011), thus enabling donors to understand the full implications of their actions. Counselling should also be made available for gamete donation offspring when they reach adulthood to explore their genetic identity. Participants suggested receiving counselling in overseas clinics might not be practical and suggested people seek counselling at home before going abroad for fertility treatment. Many participants did not share their cross border infertility treatments with others (i.e., family, friends and healthcare professionals) when returning home and half had encountered some form of medical complications following infertility treatment abroad. Cooperation between clinics in home and destination countries would facilitate patient safety.

For those infertility patients living in some countries with legal restrictions, disclosure of their intended action could be detrimental; Van Hoof and Pennings (2011) urge countries to be modest, tolerant and nuanced when considering CBRS legislation.

Infertility health professionals and stakeholders (i.e., HFEA) should be required to provide educational materials on CBRS clinical risks, access to competent legal advice and psychosocial implications for those patients intending to seek CBRS. This would assist infertility patients to make an informed choice when considering whether or not they would embark upon CBRS. These educational materials need to be blame free and culturally sensitive to those countries for which CBRS is illegal, so as not to disenfranchise the countries. In collaboration with infertility networks and support groups, these educational materials could be developed to cater for CBRS patients' needs and be translated into different languages and accessed online.

Future policy makers should be mindful of the level of interest the international media and public opinion has upon CBRS and to develop a congruent strategy for CBRS regulations and legislations. It is essential that appropriate monitoring and evaluation frameworks are put in place to enable a lay person to understand the CBRS phenomenon in order to make informed decisions when embarking upon cross border reproductive treatments.

By building on the lessons and gaps within literature reviews (Hudson et al., 2011; Inhorn and Gurtin, 2011) and in the undertaking of this qualitative study, I have explored the patients' motivations for, and experiences of, CBRS, contextualised the findings within a health related behaviour change model (partial Trans-Theoretical Model) and shed light on the decision process for CBRS patients; which is a complex process. Patients not only are required to manage their own infertility treatments but are actively engaging with CBRS and other people

who had CBRS in their quest for a child. This study provided unique insights into the CBRS phenomenon required by the CBRS patients. The challenge from this study is how the infertility health professionals and stakeholders could incorporate their support to facilitate an informed CBRS choice to the infertile patients who may, or may not, have decided to have infertility treatment abroad.

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Appendices

Appendix 1

Search Strategy:

1. INFERTILITY/ OR INFERTILITY, FEMALE/ OR INFERTILITY, MALE/
2. REPRODUCTIVE TECHNIQUES, ASSISTED/ OR FERTILISATION IN VITRO/ OR EMBRYO TRANSFER/ OR GAMETE INTRAFALLOPIAN TRANSFER/ OR INSEMINATION, ARTIFICIAL/ OR OOCYTE DONATION/ OR OOCYTE RETRIEVAL/ OR OVULATION INDUCTION/ OR POSTHUMOUS CONCEPTION/ OR SPERM RETRIEVAL/ OR ZYGOTE INTRAFALLOPIAN TRANSFER/ OR REPRODUCTIVE TECHNIQUES/
3. SURROGATE MOTHERS
4. FERTILITY AGENTS/ OR FERTILITY AGENTS, FEMALE/ OR FERTILITY AGENTS, MALE/
5. SPERM BANKS/
6. CRYOPRESERVATION/
7. FREEZING/
8. PREIMPLANTATION DIAGNOSIS/ OR PRENATAL DIAGNOSIS/
9. MICROINJECTIONS/ OR SPERM INJECTIONS, INTRACYTOPLASMIC/
10. subfertilit*.ti,ab
11. IVF.ti,ab
12. (In AND vitro AND fertili*).ti,ab
13. icsi.ti,ab
14. (intracytoplasmic AND sperm AND injection).ti,ab
15. (intra-cytoplasmic AND sperm AND injection).ti,ab
16. cryopreservation.ti,ab
17. cryo-preservation.ti,ab
18. sperm.ti,ab
19. embryo*.ti,ab
20. (intrauterine AND insemination).ti,ab
21. inseminat*.ti,ab
22. insemination.ti,ab
23. (sperm AND donation).ti,ab
24. ((egg* OR embryo*) AND donation).ti,ab
25. (gamete AND donation).ti,ab
26. ((preimplantation OR pre-implantation) AND diagnosis).ti,ab
27. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26
28. (cross AND border).ti,ab
29. (travel OR tourism OR exile).ti,ab
30. (trans-national OR transnational).ti,ab

31. (over-sea* OR oversea*).ti,ab
32. 28 OR 29 OR 30 OR 31
33. 27 AND 32
34. 33 [Limit to: Humans]
35. 34 [Limit to: Publication Year 2011-Current and Humans]

Appendix 2

Initial study title submitted to the School Research Ethics Panel, University of Huddersfield, was "Infertility Patients' Motivations for and Experiences of Cross Border Infertility Treatment (CBIT): An Online Investigation". After discussion with my supervisors, in the light of the paper by Thorn, P., Wischmann, T. and Blyth, E. (2012) entitled Cross-border reproductive services – suggestions for ethically based minimum standards of care in Europe, the title of this study changed to "Infertility Patients' Motivations for and Experiences of Cross Border Reproductive Services (CBRS): An Online Investigation".

Dear Steve,

Prof Nigel King (Co-Chair of SREP) has asked me to confirm to you that your SREP application, "Infertility Patients' Motivations for and Experiences of Cross Border Infertility Treatment (CBIT): An Online Investigation", has now received full ethical approval from the School of Human and Health Sciences Research Ethics Panel, University of Huddersfield.

With best wishes for the success of your research.

Regards,

Kirsty

(on behalf of Prof Nigel King, Co-Chair of SREP)

Kirsty Thomson
School Research Office (HHRG/01)
School of Human and Health Sciences
The University of Huddersfield
Queensgate
Huddersfield HD1 3DH
Tel: +44 (0) 1484 471156
Email: k.thomson@hud.ac.uk

Appendix 3 Information Sheet

Title: Infertility Patients' Motivations for and Experiences of Cross-Border Infertility Treatment (CBIT): An Online Investigation

Researcher: Mr. Steve Lui, Senior Lecturer, HW 3-09, Harold Wilson Building, University of Huddersfield, Queensgate, Huddersfield. England HD1 3DH

This study forms part of Steve Lui's doctoral programme.

Supervisor: Professor Eric Blyth

The purpose of this study is to explore what motivates infertility patients to access cross border infertility treatment and their experiences during the process of their treatment. This study wishes to identify specific decision-making processes for patients who have had cross border infertility treatment.

The findings of the study will make recommendations on the improvement of cross border infertility treatment; the results will be disseminated to relevant stakeholders and regulatory bodies.

This study has gained approval from the Research Ethics Panel of the School of Human and Health Sciences, University of Huddersfield.

The information for the study will be collected via an individual email interview. Please note the following procedure if you wish to participate in this study.

1. If you are willing to take part, please reply to the study's confidential email address (cbit@hud.ac.uk).
2. The interviews will be conducted in the strictest confidence and your anonymity will be assured throughout this study.
3. As well as a few demographic questions, you will be asked eight questions. These questions will be sent to you one at a time. Please respond to the question by email. Each question may be followed by supplementary questions. This process simulates a face-to-face semi-structured interview.
4. Please do not create a new email. You simply type your answer above the question which I emailed to you (not at the bottom of it!) and then press "reply". This is to ensure the correct sequence of the question and answer in our discussion.
5. Please do not delete any part of the email dialogue as it develops – it is your (and my) record of our conversation.
6. If possible, please reply to each email within three days.
7. The whole email discussion is expected to be completed within three weeks.

Your participation is entirely voluntary. You are free to withdraw from the study at any time. If you agree to participate, please read and sign the attached consent form and email it to cbit@hud.ac.uk.

Many thanks for your help and time with this study.

Appendix 4

UNIVERSITY OF HUDDERSFIELD
Harold Wilson Building,
Queensgate,
Huddersfield.
West Yorkshire.
England.
HD1 3DH

PROJECT TITLE: Infertility Patients' Motivations for and Experiences of Cross Border
Infertility Treatment (CBIT): an Online Investigation.
NAME OF RESEARCHER: Steve Lui
Interviewing consent form

Please tick the appropriate
response

	Yes	No
I have been fully informed of the nature and aims of this research and consent to taking part in it.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I have the right to withdraw from the interview at any time without giving a reason, and a right to withdraw my data if I wish.	<input type="checkbox"/>	<input type="checkbox"/>
I give my permission to take part in an email interview.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the emails will be kept in secure conditions at the University of Huddersfield.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that no person other than the interviewer will have access to the email.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my identity will be protected by the use of pseudonym in the research report and that no information that could lead to my being identified will be included in any report or publication resulting from this research.	<input type="checkbox"/>	<input type="checkbox"/>
I give my permission to be quoted (by use of pseudonym).	<input type="checkbox"/>	<input type="checkbox"/>

Name of participant:
Lui

Name of researcher: Steve

*Name:

*Name:

Date

Date

Two copies of this consent form should be completed: One copy to be retained by the participant and one copy to be retained by the researcher.

*Return of the completed Interviewing consent form indicating consent to participate in the study.

Please email this to cbit@hud.ac.uk

Appendix 5

Cross Border Infertility Treatment (CBIT)

SEMI-STRUCTURED INTERVIEW

Open ended questions

Thank you for agreeing to take part in this study. This study is to help us understand the reasons for and experiences of people seeking CBIT. I am going to ask you a number of questions. I will be very interested to hear your story, feelings and opinions. I appreciate that some of the questions will be about personal and sensitive issues. I do not wish to upset you, so please tell me if you are uncomfortable at anytime during the interview or feel free not to answer any specific question.

Demographic information

Did you take part in an online survey for the Assisted Human Reproduction Canada? Yes / No

1. Age	How old are you?
2. Gender	Are you male or female?
	Are you the patient or the patient's partner?
3. Country	Where you do currently reside? What was your place of birth?
4. Ethnicity	How would you describe your ethnic group?
5. Education level	How would you describe your educational attainment? <ul style="list-style-type: none">• Schooling not completed• Completed education up until 16 years• Completed post 16 education• Degree• Postgraduate qualification
6. Language	What languages can you speak?
7. Relationship status	How would you describe your relationship status? Are you: Single: heterosexual / homosexual; In a relationship: heterosexual / homosexual
8. Length of relationship	If in a relationship currently, how long have you and your partner been together?
9. Number of children	Have you got any children? Yes/NO. If Yes, How many children have you got with any previous relationship _____ and how old are they? _____ How many children have you got with your currently relationship _____ and how old are they? _____

	If No, go to question 10.
10. Employment	<p>What is your employment status?</p> <ul style="list-style-type: none"> • in employment or self-employment • not in employment or self-employment • retired • looking after home and family • Other (please specify)
11. Religion	Do you have a particular religious faith? If yes, please provide brief details.

1. Could you tell me about your infertility treatment in your home country?

Prompts:

Type of treatment (DI (single sex couple), ED (single sex couple), OD (single sex couple), surrogacy, IVF, ICSI, PGD (saviour sibling),IVM)

1. Accessing treatment
2. Length of treatment
3. Cost incurred for treatment in your home country – Who funded the treatment (self / health insurance/ public funded treatment/ or combination). How much did you spend?
4. Experience of your treatment in your home country

2. Could you tell me your reasons for using CBIT?

Prompts:

1. Unsuccessful treatment / success rate in your home country
2. Lack of treatment in your home country
3. Delay in accessing treatment in your home country
4. Exclusions in your home country
5. Shortage of donors
6. Cost in your home country

3. Tell me how you chose CBIT?

Prompt:

1. Is this the first time you chose CBIT?
 - a. If yes, please provide treatment date. Continue with 3.2.
 - b. If No. Could you tell me how many times you have had CBIT, please provide treatment dates. Continue with 3.2.
2. How did you find out about CBIT?
3. How did plan your CBIT?
 - a. Independently or link with a clinic in your home country
4. Who took responsibility for planning your CBIT?
 - a. You, partner or joint decision
5. How did you gather the information?
6. How long did you spend planning and researching your CBIT?
7. Did you get any support (advice and help) from others?
 - a. Friends and family
 - b. Patient groups
 - c. Websites
 - d. Media

- e. Clinics in your home country
 8. How did others share their CBIT experiences with you?
 9. How difficult did you find gaining information about CBIT?
 10. Where did you go for your CBIT? Why did you choose this clinic for your CBIT? What treatment were you seeking?
 11. What were your travel arrangements?
 12. Where did you stay (accommodation)?
 13. How long did you stay for?
 14. How much money do you estimate that you have spent on your CBIT?
4. What were your expectations of your CBIT?
- Prompt:
1. Did you expect your treatment to go smoothly?
 2. Did you expect any risks involved with your treatment?
 3. Did you expect any legal implications?
 4. Did you expect to have any communication problems (language)?
 5. What were your expectations (i.e. clinics including staff, hygiene, availability of treatment, waiting time and costs involved)?
5. Describe your experiences of the treatment you received (we know their destination Q3.10)
- Prompt:
1. What treatment did you receive?
 - a. IVF: How many embryos were transferred? Who decided on the number? (legal regulation)
 - b. Donation: what kind of information were you given about the donor? How much choice did you have in your selection? Did you have any concerns (screening HIV)?
 2. Describe a typical day.
 3. What were your experiences (Would you describe your experiences as positive, if not what were the negative experiences)?
 4. Did you encounter any difficulties during your stay? Were these resolved?
 5. What kind of support did you receive whilst having treatment (phone call from family / friends/ network / clinic (counsellor))?
 6. How would rate your CBIT experience (excellent, good, satisfactory or poor)?
 7. Did your experience meet your expectations (exceeded, met, fell short)?
 8. Would you go to this clinic again or recommend the clinic to another couple?
 9. Would you seek CBIT again (how would you do it differently)?
6. What were your experiences following your return to your home country?
- Prompt:
1. Did you have any medical problems (if yes, what were the problems... e.g. hyperstimulation, infections, multiple pregnancy etc)?
 2. Following your CBIT, did the CBIT clinic refer you to the health care system in your home country?
 3. Did you have any non-medical problems (e.g. chase you for money that you have already paid)?
 4. Did you have any other problems during your pregnancy and delivery (e.g. wrong PGD etc.) which may have been caused by CBIT?
 5. Did the clinic live up to their published materials (websites and leaflets)?
 6. On reflection, would you have changed any aspect of your treatment and how?
 7. Does your partner share similar feelings to you about CBIT? If not, how do they differ from you?

8. On reflection, do you feel that you have made the right decisions about your CBIT?
7. Following your experiences of CBIT, what recommendations would you make to improve another person's experience of CBIT?
Prompt:
1. Could you tell me what kind of educational information (safety and professional services) you would like to receive before your CBIT?
 2. Could you tell me what kind of support (counselling) you would like to receive before your CBIT?
 3. How would you like to receive it?
 - a. Face to face
 - b. Internet
 - c. Network
 - d. Media
 4. If you could give advice to anyone else considering CBIT, what would it be?
 5. If you could advise clinics (both in your home country and overseas), what would it be?
 6. If you could advise regulatory bodies (both in your home country and overseas), what would it be?
8. This is the final question for this CBIT study. Please share with us any additional comments you would like to make about your experience of CBIT?
Prompt: Thank the participants for their time and their willingness in sharing their experiences and the findings of the study will be published on the Infertility Network and iCSI websites.

Appendix 6

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

ACTIVITY: PhD Research			Name: Steve Lui	
LOCATION: University of Huddersfield			Date:	Review Date:
Hazard(s) Identified	Details of Risk(s)	People at Risk	Risk management measures	Other comments
Personal safety	Sensitive issues	Researcher/Participants	This study will be conducted using asynchronous online email interview method. Netiquette will be observed throughout the study.	
Psychological safety		Participants	The researcher has a track record of successful work in sensitive issues. In the unlikely event that psychological support is identified for participants, options for counseling referral would be explored.	
Internet technology		Researcher/Participants	This study will use a dedicated email address (cbit@hud.ac.uk) to ensure secure data gathering, processing and storage of the study.	

Theft of data and/or recording equipment	and to storage. During data gathering, sensitive information will be shared by the participant via email. The researcher needs to respond to confidential e-mail. Data will be accumulated and stored over the years, in a designed security email account.	Researcher/Participants	<p>The study will collect sensitive issues from the participants. The researcher will ensure all research related information including field notes will be stored and locked away in a secure office.</p> <p>Transcribed data will be saved under a password protected laptop which will also be kept in a safe place at all time.</p>	
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