

## PARTICIPANT INFORMATION SHEET

**Title of study:** How do women undergoing In Vitro Fertilisation (IVF) in the UK experience the counselling support offered as part of their fertility treatment?

**Name of Researcher:** Ruth Paterson

### **1. Invitation to take part**

You are invited to take part in a research study about how women experience infertility counselling in the UK. The research aims to understand women's personal experiences of the counselling offered as part of their fertility treatment. It will identify themes including what participants felt was significant within the counselling process. The research is interested in counselling which includes emotional support.

Before you decide whether to take part, it is important to understand why the research is being carried out, and what it will involve. Please take time to read the information below and discuss it with others if you wish. If you have any questions at all, or want to clarify anything, please contact me, Ruth Paterson, at [r.paterson@edu.salford.ac.uk](mailto:r.paterson@edu.salford.ac.uk)

### **2. What is the purpose of the study?**

Over 50,000 people go through fertility treatment in the UK every year. The experience can be challenging, and licensed fertility clinics are required by law to offer an opportunity for professional counselling. Less than half of patients take up counselling, and there is little academic research undertaken with those who do request counselling. Current research tells us that generally people find counselling helpful, particularly when it is focused on emotional support. A deeper, more detailed understanding could inform how counsellors work with clients, how clinics offer counselling, or help other women considering counselling as part of their own treatment.

The project is a requirement for the researcher to pass the MSc Counselling and Psychotherapy (Professional Practice) at the University of Salford.

### **3. Who can take part?**

If you have experience of counselling as part of your own fertility treatment, you have useful knowledge which could contribute to the study. To take part in the research, women need:

- a) To have had In Vitro Fertilisation (IVF) or Intracytoplasmic Sperm Injection (ICSI) in the UK
- b) To not be in active IVF/ICSI treatment at the time of the interview
- c) To have completed their latest IVF/ICSI cycle at least 3 months ago
- d) To have chosen to access counselling as part of their treatment
- e) To have had 2 or more sessions of individual or couples counselling
- f) To have concluded infertility counselling at least 3 months ago
- g) To feel they are emotionally safe to reflect on their counselling experience

### **4. Do I have to take part?**

Taking part in the study is your decision and is entirely voluntary. If you agree to take part, but change your mind, you can choose to withdraw from the study at any point. If you withdraw up to two weeks

after your interview then your data will be removed from the research. If you withdraw more than two weeks after your interview, your anonymised data may be included in the research findings.

### **5. What will happen to me if I take part?**

First, the researcher will arrange to talk to you by phone, to answer any questions and make sure the project is right for you. If you fit all the selection criteria and decide you want to take part, you will be asked to confirm your consent.

You will be invited to take part in an individual interview, which should take around 60 minutes to complete and no longer than 90 minutes. You will be able to see the list of questions in advance. The interview will include time at the end to reflect on any issues that have arisen for you.

You can choose to meet face-to-face or have a Skype interview.

If you would prefer a Skype interview, we will arrange a convenient time for the interview to take place. There is further information on page 7 of this document, including some guidance to help the interview run smoothly via Skype.

If you would prefer a face-to-face interview, then you will be invited to meet in a quiet, private room in the University of Salford Counselling & Psychotherapy Centre.

If you are not able to travel to Salford, but would still prefer to meet in person, then we may be able to find an alternative location. A suitable space would be a quiet, private room located in a safe, publicly accessible place. The researcher would look for somewhere mutually convenient. For example, we might use a counselling room in a local facility, or a small meeting room in a community centre.

The interview will be audio recorded. The researcher will transcribe it and remove any details that could identify you such as names, clinics or places. You will be offered the opportunity to receive a copy of the final report if you wish.

### **6. Expenses and payments?**

Participants will be reimbursed for out-of-pocket travel expenses for taking part, up to £30, on production of valid receipts.

### **7. What are the possible disadvantages and risks of taking part?**

Fertility and counselling experiences can both be sensitive subjects, so there is a risk that taking part in the study interview could result in difficult emotions or psychological discomfort.

Please think carefully about how this would feel when you are deciding whether to take part. Consider what support you have in place and whether you want to revisit your counselling experiences. There is a list of support organisations at the end of this document.

### **8. What are the possible benefits of taking part?**

The main benefit is in helping other people going through fertility problems, by identifying significant elements of infertility counselling, from the client point of view. This knowledge could help those providing counselling and emotional support to develop their practice and offer improved support.

Participants in similar studies have reported personal benefits. Sharing your experiences can be therapeutic; helping others can feel good, and you could gain self-awareness by reflecting on past experiences.

### **9. What if there is a problem?**

If you have any concerns about this research, please contact the researcher in the first instance, Ruth Paterson, on [r.paterson@edu.salford.ac.uk](mailto:r.paterson@edu.salford.ac.uk) who will do their best to answer your questions.

Following this, if you have any issues or complaints, you can contact the research supervisor, Dr India Amos, by email at [I.A.Amos@salford.ac.uk](mailto:I.A.Amos@salford.ac.uk) or by telephone 0161 295 3808

If the matter is not resolved, please forward your concerns to either of the Co-Chairs of the Health Taught Ethics Panel at the University of Salford;

Dr Linda Dubrow-Marshall: [L.Dubrow-Marshall@salford.ac.uk](mailto:L.Dubrow-Marshall@salford.ac.uk) or telephone 0161 296 6988  
Room C809, Allerton Building, Frederick Road Campus, University of Salford, Salford, M6 6PU  
Dr Anna Cooper-Ryan: [A.M.Cooper-Ryan@salford.ac.uk](mailto:A.M.Cooper-Ryan@salford.ac.uk) or telephone 0161 295 5094  
Room L812a Allerton Building, Frederick Road Campus, University of Salford, Salford, M6 6PU

### **10. Will my taking part in the study be kept confidential?**

Your personal information will be kept confidential and all data used in the study will be anonymised and given a unique code. Interviews will all be carried out by the same researcher, Ruth Paterson, who will audio record and transcribe the data herself. All identifying details will be removed, including names, locations and clinics. Anonymised data may be reviewed by members of the research team or examiners. Electronic data files (e.g. contact details, selection questionnaire, audio files and transcripts) will be stored on the University's secure F drive and accessed only by the researcher. Hard copy data (e.g. consent forms) will be kept in lockable document storage, accessible only by the researcher. All publications of data will use pseudonyms and be written to disguise the identity of the participants. Data must be archived for a minimum of 3 years after the graduate award has been made, to allow for verification of data. It will be destroyed securely as soon as it is no longer needed.

If during our communication or interview you should reveal information about illegal activity, a risk of serious harm to yourself or others, or something a professional counsellor did that would be considered a serious breach of ethical guidelines, then the researcher may need to break confidentiality. The researcher would always aim to discuss this with you first.

### **11. What will happen if I don't carry on with the study?**

If you decide not to take part after reading this information, you don't need to do anything else.

If you agree to take part, but later change your mind, you can choose to withdraw from the study at any point. You do not have to give a reason and this does not affect your rights in any way. You would do this by contacting the researcher at [r.paterson@edu.salford.ac.uk](mailto:r.paterson@edu.salford.ac.uk) confirming your decision.

If you choose to withdraw at any time **up to two weeks after your interview**, your data would be removed from the study and destroyed. If you withdraw **more than two weeks after your interview**, your anonymised data may be used in the research.

### **12. What will happen to the results of the research study?**

The results of the study will form the researcher's MSc dissertation, which will be submitted for assessment. Results may be published in a peer reviewed academic journal or other publications such as the British Infertility Counselling Association journal. Findings may be shared in presentation at workshops or conferences or discussed publicly via other media such as a blog or podcast. The findings may also be included in future research. In any of these cases, your data will be anonymised, meaning that you will not be identifiable.

### **13. Who is organising or sponsoring the research?**

This project is a dissertation and the final requirement to complete the MSc in Counselling & Psychotherapy (Professional Practice) for the researcher. It is supported by the University of Salford.

### **14. Further information and contact details:**

If you have any queries about the study or if you are interested in taking part then please contact the researcher:

Ruth Paterson  
MSc Counselling & Psychotherapy  
University of Salford  
[r.paterson@edu.salford.ac.uk](mailto:r.paterson@edu.salford.ac.uk)  
07516 980 565

The research supervisor is:  
Dr India Amos  
[I.A.Amos@salford.ac.uk](mailto:I.A.Amos@salford.ac.uk)  
0161 295 3808

### **15. Sources of Support**

#### **Infertility**

**Fertility Network UK:** A national charity for anyone who has ever experienced fertility problems, offering information, advice and support.

Info line: 01424 732361

Website: <https://fertilitynetworkuk.org>

#### **Bereavement & Loss**

**Baby Loss:** Website providing information and support online for anyone affected by the death of a baby during pregnancy, at birth, or shortly afterwards.

Website: [www.babyloss.com](http://www.babyloss.com)

**Miscarriage Association:** UK charity providing information and support for those who have experienced pregnancy loss.

Helpline: 01924 200799

Email: [info@miscarriageassociation.org.uk](mailto:info@miscarriageassociation.org.uk)

Website: [www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)

**Saying Goodbye:** Saying Goodbye provides comprehensive information, advice, support and much more to anyone who has suffered the loss of a baby, at any stage of pregnancy, at birth or in infancy

Website: [www.sayinggoodbye.org](http://www.sayinggoodbye.org)

### Childlessness

**The Dovecote:** Supporting, enabling and inspiring people dealing with involuntary childlessness to reconnect with their daily lives and rediscover a passion and purpose.

Website: [www.thedovecote.org](http://www.thedovecote.org)

**Gateway Women:** The global friendship and support network for childless women

Website: <https://gateway-women.com>

### Counselling

**British Association for Counselling & Psychotherapy:** The BACP offers information about counselling including a directory of registered professionals and advice on how to find a therapist.

Website: [www.bacp.co.uk](http://www.bacp.co.uk)

**British Infertility Counselling Association:** The national organisation for Infertility Counsellors, including a list of specialist therapists.

<https://www.bica.net>

**Counselling Directory: Infertility:** Directory of UK counsellors, this section of their website includes background information about infertility and a search for infertility counsellors.

<https://www.counselling-directory.org.uk/infertility.html>

**University of Salford Counselling & Psychotherapy Centre:** The centre offers general counselling and some specialist services, a range of issues including depression, anxiety, trauma, relationship problems, stress, bereavement and loss. The service is available to residents of Salford and Greater Manchester, it does not charge a fee and clients can self-refer.

<https://www.salford.ac.uk/health-and-society/facilities-and-services/counselling-suites/university-of-salford-counselling-and-psychotherapy-centre>

### Health Support

**Daisy Network:** Daisy Network is dedicated to providing information and support to women diagnosed with Premature Ovarian Insufficiency, also known as Premature Menopause.

Website: [www.daisynetwork.org](http://www.daisynetwork.org)

**Verity:** A national charity and self-help group for women with polycystic ovary syndrome (PCOS).

Website: [www.verity-pcos.org.uk](http://www.verity-pcos.org.uk)

**Women's Health Concern:** The patient arm of the British Menopause Society (BMS). They provide a confidential, independent service to advise, reassure and educate women of all ages about their gynaecological and sexual health, wellbeing and lifestyle concerns.

Website: [www.womens-health-concern.org](http://www.womens-health-concern.org)

### Mental Health

**Mind:** The National Mental Health charity, their website offers information and advice about mental health including details about their local services.

Website: [www.mind.org.uk](http://www.mind.org.uk)

**NHS: Every Mind Matters:** Mental health information provided by the NHS, including advice and support for lots of different mental health problems and how to access urgent support.

Website: [www.nhs.uk/oneyou/every-mind-matters](http://www.nhs.uk/oneyou/every-mind-matters)

**Samaritans:** 24-hour support for anyone experiencing distress, despair or suicidal thoughts.

Website: [www.samaritans.org](http://www.samaritans.org)

Freephone: 116 123

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

### **Guidance for taking part in Skype interviews**

An increasing number of research studies now offer participants the option to take part in an interview by Skype. Video interviews mean people living in different places can take part more easily, and we can be more flexible in terms of when and where interviews can take place.

Subjects like infertility and counselling can feel very personal. Some people prefer face-to-face interviews to talk about these kinds of sensitive subjects. Other people feel more comfortable doing a video interview from their own home or another private, quiet space. It is up to you to choose how you would like to take part.

The researcher will talk you through this guidance if you choose to participate via Skype.

#### **Technology and connection:**

In advance of the interview:

- Check you have the most recent Skype software installed on your computer or device
- Make sure your internet connection is working properly
- Try a test call, to check out the sound quality
- Check your device is charged or plugged in

If the Skype call quality is bad or the connection drops during the interview, the researcher will contact you on an agreed phone number and you can decide together how to proceed.

#### **Comfortable and confidential:**

Before you start:

- Find a place to sit that is comfortable, quiet and private, where you hopefully won't be distracted or interrupted.
- Think about whether anyone else is close by and whether you would be comfortable with them overhearing your conversation.
- Once you have chosen your location and got your screen set up, take a minute to check nothing is visible in the video frame that you do not want the researcher to see.

People often take part in research interviews from their own home, and this usually works well as they feel at ease and secure in their environment.

During the interview, the researcher will be talking to you from a private space, where the interview cannot be overheard by anyone else, so that your information is kept confidential. The researcher will record the video interview, using an additional piece of software and will tell you when this recording begins and ends during the interview.

#### **If you have any questions at all you are welcome to contact the researcher:**

Ruth Paterson [r.paterson@edu.salford.ac.uk](mailto:r.paterson@edu.salford.ac.uk) 07516 980 565