Lancaster University
Doctoral Programme in Clinical Psychology

LANCASTER UNIVERSITY
DIVISION OF HEALTH RESEARCH
Doctorate In Clinical Psychology

Participant Information Sheet

The experience of women who have received a diagnosis of puerperal psychosis and their significant others: Exploring the role of relationships

Thank you for taking the time to look at this information sheet, which I have sent to you because I would like to invite you to take part in my study. Before you decide, I will explain why I am doing the research and what your involvement would be. If you are interested in finding out more, I will be happy to telephone you to discuss the information sheet and answer any questions that you may have. Please feel free to discuss the study with others if you wish.

The information sheet is divided into two sections:

- Part one tells you about the purpose of the study and explains what you will be asked to do, if you wish to take part
- Part two tells you more detailed information about how the study will be carried out.

I will use the term puerperal psychosis throughout this information sheet, although I am aware that some of you may think of this in other ways (for example postnatal psychosis).

PART ONE

What is the purpose of the study?

This study aims to explore the experience of women who have experienced mental distress after the birth of their baby and have received a diagnosis of puerperal psychosis, and people important to them. We are particularly interested in the role of relationships during and after this time. It is hoped that the study will allow services to understand what it is like for the mother experiencing puerperal psychosis, as well as her family and friends. This is important because services often involve family and friends in supporting mothers, particularly after discharge from a mother-and-baby unit. This research is being undertaken as part completion of the lead researcher's Doctorate in Clinical Psychology.

Why have I been invited to take part?

You have been invited to take part because you have experienced emotional distress after the birth of your baby which was diagnosed as an episode of puerperal psychosis. This information sheet has

been sent to you either because medical staff at the mother-and-baby unit where you stayed thought you may be interested or because you have got in touch in response to an advert. I am hoping to interview up to ten pairs of people (a mother and someone close to her) for this study.

Do I have to take part?

No – taking part in the study is entirely voluntary, and if you do not want to be involved, this will not affect your care in any way. If you are interested in taking part, you will be asked to complete a consent form before participating, a copy of which you will keep. If you wish to withdraw your consent at any point, you are free to do so without giving a reason.

What will happen to me if I take part?

If you agree to take part in the study, I will contact you to discuss the information on this sheet. I will try to answer any questions that you may have and will then arrange a convenient time to interview you. This interview would be with both you and somebody close to you, who also wishes to take part in the research. The interview is likely to last for about an hour. It can take place either in your own home or at a local NHS building, depending on your preference. The interview would be audio-recorded and later typed up in full. If you are currently receiving medical or psychological care, this will not need to be altered in any way.

Expenses and payments

You will be reimbursed for any travel expenses up to £10. As I plan to interview you either at your home, in a local community building, I hope to reimburse all of your expenses. Travel expenses will be at public transport rates or 25 pence per mile if travelling by car. Any parking costs will also be reimbursed.

What will the interview involve?

During the interview you will be asked questions related to your experiences of the postnatal period, during which time you were given a diagnosis of puerperal psychosis. The questions will mostly focus on the role which you feel your relationships with significant others played during this time. For example, I may ask about whether these have been affected by the experience. You will not be expected to answer any questions that you do not wish to.

What are the possible risks of taking part?

Whilst we do not anticipate that you will experience any distress, you will be aware that speaking about your experiences of puerperal psychosis can be an emotional process. You will be encouraged to take a break whenever necessary during the interview, and you can decide to stop the interview at any point. When the interview finishes, you will be given a list of resources which you can access, should you feel that this is necessary. I will also provide time at the end of the interview to discuss any concerns.

What are the possible benefits of taking part?

Although this study does not intend to provide any specific benefits to individuals taking part, it is hoped that the information we gain could help improve awareness of puerperal psychosis and a wider understanding of the impact of this experience on mothers and those close to them.

What if there is a problem?

If you experience any problems due to taking part in the study, I would be happy to discuss these with you. However, contact details for other people involved in the research are available in Section Two, and they can also help with any problems or complaints.

Will my participation in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details of these procedures are available in Part Two.

Thank you for reading this far. If you are still interested in taking part in the study, please continue to read Part Two.

PART TWO

What will happen if I don't want to carry on with the study?

You are able to withdraw from the study at any point and you will not be expected to provide a reason. You can contact the lead researcher to discuss withdrawing from the study, at which point any data and personal information relating to you will be destroyed. If your data has already been made anonymous and analysed, it may not be possible for this to be withdrawn. However, the researcher will discuss any concerns with you and will make every effort to withdraw your data

Will my taking part in the study be kept confidential?

Yes. All information about your participation in this study will be kept in accordance with the Data Protection Act (1998).

- Your interview will be audio-recorded and I will later type this up, with all identifying information removed. The audio-recording may be listened to by my clinical research tutor.
- Transcripts (typed copies of your interview) will be kept electronically on a password protected and encrypted computer.
- Your anonymised transcript will be seen by members of the research team, employed by Lancaster University.
- Once the research is completed (this is anticipated to be by May 2014), electronic copies of the transcript will be stored securely on the university network until the point of secure disposal.
- If, during the interview, I am concerned that you or somebody else is at risk of harm, I will have to break confidentiality to inform my supervisors and seek advice. However, I would discuss this fully with you at the time.

What will happen to the results of the research study?

As the study is part of my doctoral course in Clinical Psychology, it will be submitted to the University for marking. I also hope to publish the findings of this study in a relevant journal and perhaps present this at a conference. A brief report of the findings will be sent to interested participants. Participants will not be identified within any of these publications, but anonymous quotes will be included, if you provide your consent for this.

Who is organising and funding the research?

I have organised the researcher as part of my studies, alongside staff at Lancaster University. Expenses are covered by Lancaster University.

Who has reviewed the study?

All research in the NHS is looked at by an individual group of people, called a Research Ethics Committee (REC). This study has been reviewed and approved by the Greater Manchester Central Research and Ethics Committee. It has also been approved by various NHS Foundation Trust Research and Development Committees.

What if there is a problem?

If you have a concern about any aspect of this study, I am happy to discuss this with you and do my best to answer your questions (my contact details are provided at the end of this information sheet). If you remain unhappy and wish to complain formally, you can do so by contacting:

Professor Susan Cartwright (Head of the Division of Health Research)

Email: s.cartwright@lancaster.ac.uk Tel: 01524 592430

Lancaster University

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Contact details

For further information about the following areas, please consult below:

- General information about research – www.nimh.nih.gov – search for 'participants guide to clinical research'
- Specific information about this study:

Caroline Wyatt (trainee psychologist)

Email: c.wyatt@lancaster.ac.uk

Post: Doctorate in Clinical Psychology
C12 Furness College
Lancaster University
LA1 4YG

Tel: 0785 251 6566 or 01524 492730

Dr Craig Murray (academic research supervisor)

Email: c.murray@lancaster.ac.uk

Post: Doctorate in Clinical Psychology
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Dr. Jenny Davies (clinical research supervisor)

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Thank you for taking the time to read this information sheet.