



PARTICIPANT INFORMATION SHEET

TITLE OF STUDY: IMPACT OF ARTHRITIS ON PLANNING TO HAVE A FAMILY, PREGNANCY AND THE PERIOD AFTER HAVING A BABY

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

We would like to know more about the impact having inflammatory arthritis has on your decision and experience of planning to have a family, pregnancy and the period after you have had your baby. There has been very little research in this area and we would therefore like to interview women who have inflammatory arthritis and have had a baby in the last year, about their experience.

We hope that this research will help us to provide a clearer understanding of your pregnancy experience, so that research in this area can expand. The research is being conducted by researchers from City, University of London.

Why have I been invited?

We will be interviewing between 12 and 15 women about their experiences. Women need to be over the age of 18 years, have had a baby within the last year within the UK and been diagnosed with either rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis or systemic lupus erythematosus.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate. You can also withdraw at any stage of the project without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

If you agree to take part you will be asked to participate in one semi-structured interview lasting approximately 1 hour, at a time and place convenient for you. If you live in central or greater London this could be at City, University of London, at your home or work location or over the phone. If you live outside of this area or if you need your children to be with you, then telephone interviews can be arranged. With your permission, the interview will be audio recorded and we also collect some



personal information about you such as your age, your children's ages, number of children, diagnosis and how long you have had your rheumatic condition.

What do I have to do?

If you are interested in taking part in the study or have any questions about participating please contact the researcher Hannah Rowlands by emailing her at Hannah.rowlands.1@city.ac.uk or her supervisor Dr Hayley McBain by telephone 0207 040 0870 or email Hayley.mcbain.1@city.ac.uk. Alternatively, you can send us your contact details online via this link https://cityunilondon.eu.qualtrics.com/jfe/form/SV_72PNs2kmB9upmFD.

What are the possible disadvantages and risks of taking part?

We are always required to tell you about any risks to you, should you agree to take part in research. This study does not involve any change to your medical treatment. It consists only of participating in one interview. Although it is unlikely, due to the nature of the study, some questions in the interview may raise emotions that could be distressing. If this does occur the researcher can stop the interview, if necessary and can provide contact details for organisations that can offer support and advice. If you feel you need to discuss anything further after the study then please contact the safeguarding team at City, University of London.

What are the possible benefits of taking part?

Although we do not expect there to be any personal benefits from you taking part this research may be of interest to you and will attempt to identify gaps in care to help us expand the research around women with inflammatory arthritis who are planning to have a family.

What will happen when the research study stops?

Once you have participated in the interview, the audio recordings will be transcribed by the research team and subsequently destroyed. The responses from the interviews and other paperwork will be stored anonymously on a password-protected computer and in locked cabinets. All the information collected during the study will only be used for research purposes.

Will my taking part in this study be kept confidential?

All the information collected during the study will be held securely in the strictest confidence at City, University of London. Only members of the research team will see these files. Your name and other recognisable information will be changed to maximise anonymity.



What will happen to the results of the research study?

This study is being conducted as part of a Master's in Health Psychology at City, University of London. The results will form part of the student's dissertation thesis, and will be published in peer reviewed academic journals and at professional conferences. Anonymity will be maintained throughout. If you would like a copy of the publication or a summary of the results, please let the researcher know at the interview.

What will happen if I do not want to carry on with the study?

Participation in the study only requires one interview which will last approximately 1 hour. However, if you decide at any point during your participation in the study that you wish to withdraw, you can speak the research team to discuss this. It would be useful for us to use the information you have given us up until that point in the study; however, if you wish for us to destroy this data, this can also be arranged.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through City's complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: A Qualitative Exploration of the Impact of Inflammatory Arthritis on Family Planning, Pregnancy and the Post-Natal Period.

You could also write to the Secretary at:

Anna Ramberg
Research Governance & Integrity Manager
Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

City holds insurance policies that apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?

This study has been approved by the School of Health Sciences, City University of London, Research Ethics Committee.



Further information and contact details

If you have any questions about the research please contact Hannah Rowlands via email Hannah.rowlands@city.ac.uk or her supervisor Dr Hayley McBain by telephone 0207 040 0870 or email Hayley.mcbain.1@city.ac.uk.

For further information and support about your arthritis please contact the relevant support organisation:

National Childbirth Trust (NCT)

Helpline: 0300 330 0700

Arthritis Research UK

Helpline: 0800 5200 520

Psoriasis and Psoriatic Arthritis Alliance (PAPAA)

Website: <http://www.papaa.org/resources/about-psoriasis>

Lupus UK

Website: <https://www.lupusuk.org.uk/#>

National Ankylosing Spondylitis Society (NASS)

Support Website: <https://nass.co.uk/nass/en/get-in-touch/helpline/>

Helpline: 020 8741 1515

National Rheumatoid Arthritis Society (NRAS)

Support Website: <https://www.nras.org.uk/helpline>

Helpline: 0800 298 7650

Email: helpline@nras.org.uk