Participant Information Sheet (staff)

We'd like to invite you to take part in our research study, led by Cardiff University. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve for you. Our researcher will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

The first part of the Participant Information Sheet tells you the purpose of the study and what will happen to you if you take part.

Then we give you more detailed information about the conduct of the study. Do ask if anything is unclear.

What's involved?

The "FAMILIAR Study: Interviews" project is looking to understand how women of child bearing age are supported to make decisions about family planning, when they live with an autoimmune inflammatory arthritis (Rheumatoid Arthritis, Psoriatic Arthritis, Ankylosing Spondylitis, Juvenile Idiopathic Arthritis). Understanding how you and your team deliver family planning will help us identify if anything needs to be improved, and what that might be. Staff in all parts of the rheumatology (secondary care) and primary care healthcare teams may be in the position to provide information and support about preconception choices.

Research conducted in 2018 (the STAR Family Project) has shown there is a lot more which can be done to help women of child-bearing age, with an inflammatory arthritis. We hope to be able to support healthcare teams and their patients to better share information, understand patient priorities, and together identify the best choices for each individual patient ("co-production"). Being able to make more informed decisions about family planning with the right information and support will mean better health for your patients, and potentially, any children they may chose to have.

To do this we are inviting healthcare professionals who provide care to women with inflammatory arthritis to be interviewed and give their experiences and opinions on this subject. Your responses will be reviewed in conjunction with the interview responses from patients and their partners, to see where and how we can support the process of preconception care delivery.

Why have I been invited?

We are interested in hearing the views of healthcare professionals (including, but not limited to consultant rheumatologists, clinical nurse specialists, primary care doctors (GPs), primary care nurses and allied health professionals) who are involved in providing care for women of

childbearing age (18-50 years inclusive) with inflammatory arthritis (including Rheumatoid Arthritis, Psoriatic Arthritis, Ankylosing Spondylitis, Juvenile Idiopathic Arthritis).

What would taking part involve?

Taking part will involve having one interview, which will last approximately one hour. The interview will be arranged at a time which suits you best. The interview will be conducted over the telephone, online (e.g. Zoom) or in person (in your home, place of work or Cardiff University), depending on your availability and what best suits you. The interview will be audio-recorded and then typed up into a written transcript by an independent party, under a Non-disclosure agreement and confidentiality contract. The transcript will be anonymised and will not contain any information which could identify you. With your permission, we would like to use your anonymised word-for-word quotes in the final publications.

Neither your medical nor staff records will be accessed for the purpose of this study. There are no follow-up interviews, though you may wish to stop the interview at any point and continue it at a later time. Your answers will be used to inform the larger FAMILIAR Study, to create a system which we hope will improve patient information and involvement, in their family planning care.

The interview will cover topics relating to identifying decision needs with your patients around their family planning choices and decisions about contraception and pregnancy. We will also ask about your training, confidence, and suitability of appointments for discussing these subjects in relation to each patient's needs, preferences, medication, and other factors they or you deem relevant.

The study has been approved by your employing NHS Trust/Health Board but we will not inform them that you are taking part in the study.

You can choose to be contacted at the end of the FAMILIAR Study to learn the results of the study, if you wish.

What are the possible benefits of taking part?

It is likely that there will be no direct benefits to you for taking part. We do however hope that this study (including answers you provide) may improve how women with inflammatory arthritis understand how their condition affects their family planning choices, and better support them in making the right choices for each of them as individuals, in the future.

What are the possible disadvantages and risks of taking part?

It is not believed that this study carries any risks to taking part. The interview will include questions which you may find personal or emotional, but you may choose not to answer any questions which you find difficult.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name, initials, contact details and information that you provide about your health and condition. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the research team
- by viewing the Cardiff University Data Protection Policy: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection
- by contacting the Cardiff University Data Protection Officer by email: inforequest@cardiff.ac.uk or in writing to: Data Protection Officer, Compliance and Risk, University Secretary's Office, Cardiff University, McKenzie House, 30-36 Newport Road, Cardiff CF24 0DE.

What will happen to the results of the study?

The results from the study will be written up and published as part of a PhD thesis authored by Zoë Abbott. They will also be published in academic journals and presented at conferences. Only anonymised information will be made public, and the researchers will take care to ensure that no one will be able to identify you in any publications or presentations. If you would like a copy of the study results, please indicate this on the consent form.

What if I change my mind about taking part?

If you choose to take part and then change your mind, you are free to withdraw from the study at any point and can stop the interview if you wish to. If you do choose to leave the study, we will ask for your permission to keep any data (e.g. interview and questionnaire responses) you have provided up until the point you leave the study.

Further supporting information

To discuss this study further you can contact the Lead Researcher Zoë Abbott on 02920 687782, or at AbbottZK@Cardiff.ac.uk. To discuss involvement in research with someone independent of the study, or if you have any complaints about the study or its conduct, you can contact Dr Denitza Williams, Cardiff University, on 02922 514040 or at WilliamsD74@Cardiff.ac.uk.

Who has approved and funded the study?

This study is part of a Health and Care Research Wales funded, Cardiff University sponsored PhD studentship. Ethical approval has been given by an NHS Research Ethics Committee REC 6. It has been approved by Cardiff and Vale University Health Board.