**Information Sheet**

**Project title**: Impact of the COVID-19 pandemic on self-care: Perspectives of people with rheumatoid arthritis

**Staff members**: Professor Jo Adams, Dr Rachel Dadswell, Dr James Gavin

You are being invited to take part as a consultee for the above project. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this project. If you are happy to participate you will be asked to sign a consent form.

1. **What is the research project about?**

The purpose of this project is to look at the impacts that the coronavirus (COVID-19) and it’s response strategy have had on people living with rheumatoid arthritis in the UK.

The response to COVID-19 has been worldwide and informed by the World Health Organisation. However, each country has adopted its own regional responses to managing the disease. We are working with partners in Canada to see what similarities and differences there are between a Canadian and a UK lived experience of rheumatoid arthritis.

The pandemic and its response strategy have unique impact on people with rheumatoid arthritis. Our Canadian partner, the University British Columbia, have two ongoing research projects looking at the impact of the COVID-19 home isolation on the self-management of care for people with rheumatoid arthritis. This work involves interviewing people who have rheumatoid arthritis to understand their experiences of the self-care during the pandemic.

1. **Why have I been asked to participate?**

You have been invited because you are over 18 years old and have said that you are living with rheumatoid arthritis and are interested to hear more about this public consultation project

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

If you decide to take part, you will be given the opportunity to ask questions, and then you will be invited to attend an online consultation (i.e. a one-on-one discussion) on a date and time that are convenient to you.

The discussion will last for around 30 minutes and be led by Rachel Dadswell supported by James Gavin. Your responses will be confidential, and the online consultation will not be audio or video recorded.

**4. Are there any benefits in my taking part?**

There is no direct benefit in taking part, but you will gain insights into how we develop health sciences research with public partners. If you are interested we will send you a summary of the findings from this project.

1. **Are there any risks involved?**

No, the consultation will be a one-to-one online discussion

1. **What will be collected?**

If you decide to take part in the consultation, then you will be invited to consider:

1. The similarities and differences of Canadian people’s experiences and your own
2. Whether you agree with the ‘barriers and facilitators’ mentioned by Canadian people’s experiences of using online resources for a self-care programme for rheumatoid arthritis
3. Whether you recognise and agree with the some topics identified by Canadian’s living with rheumatoid arthritis on the impact of COVID-19 on self-care.

No information will be recorded, nor held in digital format by the University of Southampton. Instead, each consultation will finish with an information sheet to identify the top 5 issues that you think are similar, and top 5 issues that you think may be different to the Canadian experiences.

We will then ask you to list your own priorities (any number and no limit) for how the research can be further developed to consider a more global context.

1. **Will my participation be confidential?**

Yes. The staff will preserve the confidentiality of you as the consultee in the discussion and consultation. We will only ask for your age and gender.

1. **Do I have to take part?**

No, there is no obligation to take part and you can withdraw from the consultation at any stage, without giving any reason.

1. **What happens if I change my mind?**

You have the right to change your mind and withdraw at any time.

1. **What will happen to the results of the project?**

We will use your feedback to help us develop further research that matters to people living with rheumatoid arthritis.

1. **Where can I get more information?**

If you want to know more about the project, please contact James Gavin (023 8059 5311, J.P.Gavin@soton.ac.uk), who can tell you about the project and answer any questions you may have.

1. **What happens if there is a problem?**

If you have a concern about any aspect of this project, you should speak to the researchers who will do their best to answer your questions. These are:

James Gavin Rachel Dadwsell

Email: J.P.Gavin@soton.ac.uk Email: R.Dadswell@soton.ac.uk

Telephone: 023 8059 5311 Telephone: 02380 595302

1. **Data Protection Privacy Notice**

No personal data will be collected from you in the project.

1. **Thank you**

Thank you for having taken the time to read this information sheet and your interest in the project. If you do decide to take part in the project, you will be given a copy of this information sheet and a signed consent form for you to keep.