



implementing Patient Research Partner Engagement in Research

Chief investigator: Dr Martin Stevens  
University of Aberdeen Epidemiology Group

## **Participant Information Sheet**

### **Stage 1: Questionnaire**

#### **Introduction:**

You are being invited to complete a questionnaire as part of the iPREPaRe study. Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. Please read the following information carefully and, if you wish, discuss it with others. You can ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

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

Patients should be involved at all stages of research and development of health services as they have expert knowledge of their conditions. Patient research partners (PRP) involvement

with research is an important and expanding consideration for investigators, healthcare practitioners, patients, and research funders alike.

The iPrePaRe study will explore the way in which the work of patient research partners (PRPs) in rheumatic and musculoskeletal disease (RMD) research is perceived by the partners themselves and by RMD researchers. A working group of RMD researchers and PRPs have prepared a questionnaire, designed to look at the perception of PRPs in RMD research.

### **Why have I been invited to complete this questionnaire?**

#### **Patient Research Partners**

We are looking for European based, patient research partners with a rheumatological and or musculoskeletal condition who have worked as part of a rheumatology research study team. You have been invited because you responded to an advertisement about the study, because you previously participated in another study within the Epidemiology group and gave your consent for us to contact you about other studies, or you are a member of a Patient and Public Involvement (PPI) group or PRP group.

**We understand that the work of PRPs is wide ranging and can encompass tasks such as working on research committees, or developing guidelines, and working as part of a research team in scientific studies. In the questionnaire any reference to the work of a PRP or work on a study or project should be interpreted widely encompassing all PRP activities.**

**Note that we do not include being a participant in a research study as PRP work.**

#### **RMD Researchers**

We are also looking for European based, RMD researchers to complete the questionnaire. We would like your perspective whether you have worked with PRPs or not. You have been invited because either you responded to an advertisement about the study, or because you have been contacted through a professional network.

### **Do I have to complete the questionnaire?**

No. It is up to you to decide whether to take part. If you decide to take part, you are still free to withdraw at any time and without giving a reason. During the questionnaire you are able

to skip questions you do not wish to answer. If you decide not to answer any further questions you can shut the browser down and no further information will be collected about you, but previously obtained data will remain part of the study.

### **What will taking part involve?**

Taking part in the study involves completing an anonymous questionnaire online. This questionnaire will ask about your experience of working on research studies. We are interested in how the work of PRPs is perceived by the PRPs themselves and by rheumatology researchers. We are also looking for a small group of participants to complete an online interview within the next year. This is optional and you can indicate within the consent form for the questionnaire whether you would be happy to participate in the interviews. If you choose to take part in the interviews we will use your personal data from the questionnaires to select participants for the interview stage. Even if you provide consent to be contacted about this, you may not necessarily be contacted by the research team depending on the interest we receive.

You can find the link to access the questionnaire on the study invitation letter/advertisement.

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

There are no risks involved in completing this questionnaire. Completing the questionnaire will require you to give approximately 25 minutes of your time to the study.

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

We do not anticipate that there will be any direct benefit to you if you decide to take part. However, we hope that the findings from this study will help us understand more about the work of PRPs in rheumatology research. These findings will help us to identify barriers to, and successes in, patient involvement across RMD research, and differences in perceptions and expectations between PRPs and RMD researchers.

### **How will we use information about you?**

We will need to use information from you for this research project. People will use this information to do the research or to check your records to make sure that the research is being done properly. This information will include your name and contact details if you agree

to be contacted for the interview and/or further studies. 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.

Data is being collected by the University of Aberdeen and we will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data for up to five years, stored on secure computers at the University of Aberdeen. Access will be restricted to the study team and may also be looked at by other individuals within the university to check how the study has been run. 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.

If you agree to take part in this study, you will have the option to be notified about future research studies.

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

You can find out more about how we use your information:

- by contacting the chief investigator by e-mail [martin.stevens@abdn.ac.uk](mailto:martin.stevens@abdn.ac.uk) or telephone number +44 1224 437124
- by contacting Dr LaKrista Morton, a researcher outside of the study team, by e-mail [lakrista.morton@abdn.ac.uk](mailto:lakrista.morton@abdn.ac.uk)

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

Results from the questionnaire will be used to inform the next stage of work in iPrePaRe. They will also be published in academic conferences and journals and in summary format on our website. We also intend to create a video blog summarising the results. Anonymised comments from participants may be used in these publications. When this happens, it will not be possible to identify individuals.

### **Can I take part in other research studies in the future?**

If you are interested to do so, you can provide consent for us to retain your contact details on a secure drive at the University of Aberdeen for a period of five years after the end of the

study, in order to contact you about other ethically reviewed and approved projects in the future. Providing consent for this is optional and is not required for you to complete the questionnaire.

**Who is organising and funding the research?**

The study is sponsored by the University of Aberdeen and the work is supported by a Research Methods Grant from the European Alliance of Associations for Rheumatology (EULAR).

**Who has reviewed the study?**

Research at the University of Aberdeen School of Medicine is looked at by a group of people, called the School of Medicine, Medical Sciences and Nutrition Ethics Review Board (SERB), to protect your interests. This study has been approved by SERB (ref 1395172).

**Who can I talk to about the study?**

You can contact the researchers using the contact details at the end of this information.

**What if there is a problem?**

If you have a concern about any aspect of the questionnaire, please contact the study team via email [iprepare@abdn.ac.uk](mailto:iprepare@abdn.ac.uk) who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance Team at the University of Aberdeen via [researchgovernance@abdn.ac.uk](mailto:researchgovernance@abdn.ac.uk)

**For further information and to contact us, please use these details:**

**E-mail Address:** [martin.stevens@abdn.ac.uk](mailto:martin.stevens@abdn.ac.uk)

**Phone number:** +044 1224 437124