

UNIQUE Study

Understanding the impact of non-inflammatory musculoskeletal conditions on work:
a qualitative investigation

Participant Information Sheet

Introduction:

You are being invited to take part in a research interview as part of the UNIQUE study. Before you decide whether you would like to take part, it is important for you 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?

Researchers at the University of Aberdeen are conducting a study to understand the different ways that having a non-inflammatory musculoskeletal condition (e.g. osteoarthritis, fibromyalgia, joint hypermobility, lower back pain) impacts on people's work. We plan to use the findings of this study to develop a programme to support people with musculoskeletal conditions in the UK who are struggling with their work. We aim to recruit around 15-25 people for interview.

Why have I been invited for an interview?

We are looking to interview people who are in paid employment (either employed or self-employed) with osteoarthritis or a non-inflammatory musculoskeletal condition (e.g. fibromyalgia). You have been invited because you either indicated to a clinician that you would be interested to learn more, responded to an advertisement about the study, or were identified within the SHARE network.

Do I have to take part in the interview?

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. Deciding to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will taking part involve?

If you are interested in taking part, we would first ask that you complete the screening questionnaire which can be accessed online using the web address on your invitation letter (or which may have been included with your invitation letter if this was sent to you by post). This screening questionnaire will ask some basic questions about you, your work, and your musculoskeletal condition. After you complete this, a member of the study team may contact you to discuss whether you would like to participate in an interview and answer any questions you may have, if you are eligible for the study based on your responses. If you decide to take part, we will ask to arrange an interview at a time that is convenient for you, which will take place over the phone. At the start of the telephone interview, we will review the consent form with you (which has also been included with this information) and check whether you are still happy to participate. If you are, this verbal consent to participate will be audio recorded.

The interview will involve asking you questions about how your musculoskeletal condition has affected your working life. We anticipate that the interview will last between 30-60 minutes.

The interview will be audio recorded. The audio recording will be sent electronically via a secure link to an external company approved by the University of Aberdeen to be transcribed with your permission.

Depending on the interest we receive, not everyone who is eligible for the study may be contacted for participation. If you are not selected, we will contact you by letter (email or by post, depending on the details we hold for you) to notify you of this.

What are the possible disadvantages and risks of taking part in the interview?

Taking part in the interview will take up to approximately 60 minutes of your time. Some people may find talking about their condition to be upsetting or stressful. If this happens, the interviewer will ask you if you would like to pause or discontinue the interview.

What are the possible benefits of taking part in the interview?

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 how musculoskeletal conditions impact people at work and these findings will ultimately inform the design of programmes which can support people who face challenges at work due to their musculoskeletal condition.

We greatly appreciate the time that individuals give to this study and as a small 'thank you' we will be offering participants a £20 shopping voucher.

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 and contact details. 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.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

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

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

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to dpa@abdn.ac.uk
- by ringing us on 01224 272596

What will happen to the results of the research study?

Results from the interviews will be published in academic conferences and journals and in summary format on our website. Anonymised quotations from the interviews may be used in these publications. When this happens, it will not be possible to identify individuals. We will send you a summary of our findings after the study has been completed if you would like to receive this.

Who is organising and funding the research?

The study is organised by the University of Aberdeen and funded by the Wellcome Trust Institutional Strategic Support Fund.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by the Proportionate Review Sub-committee of the London - South East Research Ethics Committee.

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 interviews, please contact the study team 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 or by calling 01224 277220.

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

unique@abdn.ac.uk

01224 437863