



## **Participant Information sheet**

You are invited to participate in a research project. In this document, you will receive information about the project and about what it means to participate.

### **What is the purpose of the study and why do you want me to participate?**

We will invite you to participate in a study to find out how usable and acceptable you find an online education resource. This resource aims to provide you with education to help manage persistent back pain, that is back pain with a duration of greater than 3 months.

We would like you to participate because you are older than 55 years of age and are living and working with back pain. Often as we age, we may face more barriers to managing our back pain at work. We want to understand if the online resource we have developed helps you to better manage your back pain at work, and in your daily life outside of work.

The results of the project are expected to contribute to increased knowledge of how to assist people like you to self-manage their low back pain. Additionally, we hope the findings will improve and expand the range of high-quality learning opportunities tailored to the needs of older workers.

The overall responsibility for the MyRelief project is held by Lund University in Sweden. However, Ulster University is responsible for the work carried out on the study in Northern Ireland. This is led by Professor Suzanne McDonough and Dr Joanne Marley.

### **What will the study involve?**

**Online registration:** We will invite you to register for the study via our Study Website. If you agree to participate via the website, you will be directed to a consent form and asked to complete it. Alternatively, we can email you a copy of the consent form which you can complete and return to us. We will ask you to retain one copy and the other copy will be retained by the researchers. Once you are registered you will have access to the online resources.

**Online resource:** We have developed an online resource, also known as a Massive Open Online Course or MOOC, which contains eight units of educational material about how to manage your back pain using text, short videos with people like you (workers aged 55+ years with low back pain) and professional experts, and quizzes to test your knowledge. Each unit should take no more than 20 minutes to complete. We recommend completing two units a week over a month period. You will also be able to access a mobile phone app to track your health.

In addition, at the start of the study we will ask you to complete questionnaires that will measure your ability to function in your day to day life with your back pain and your general quality of life. We will ask you to complete these again at the end. Additionally, at the end of the study we will ask you to complete another short questionnaire on your ability to cope with your back pain following using the online program (MOOC).

**Interviews or Focus Groups at the end of the study**

You will also be invited to participate in a focus group interview with 4-8 other people or a one-to-one interview. During the interview, we will ask your opinion of the MOOC, what you liked, what you disliked and what we could change or add to the MOOC.

The focus group will be conducted by specially trained researchers. It will take approximately one hour and will be audio-recorded. If you participate in a one-to-one interview it will take 30

minutes. The focus group/interview will take place in person or over the phone/video call. If you are interested in participating, we can answer any questions that you may have about the study.

### **What are the potential benefits/risks of participating in the study?**

The MOOC and the mobile phone app have been designed by an international team of experts in the management of low back pain, as well as experts in the design of MOOCs. The content of the MOOC is based on best research evidence and national clinical guidelines. We expect that following the advice and education will assist you in the management of your back pain.

Our experience has shown us that when people start to become active their back pain can increase for a couple of days, sometimes called a flare up, or they may experience muscle soreness especially in their legs. These flares or muscle pain is completely normal and expected and are explained by the fact that your muscles are getting used to activity. This will settle over a couple of days if you keep moving. If, however, you experience an increase in your back pain or related symptoms does not settle within a few days, you should seek advice from a healthcare professional and/or contact a member of the research team.

### **What if something goes wrong when I'm taking part in this study?**

There is a very low risk of any harm associated with taking part in this research; however, the University has procedures in place for reporting, investigating, recording, and handling what are called adverse events.

### **What will happen to my information?**

The project will collect and record information about you. The results of the study will help us understand if using social media and a website is a good way to recruit people into a study; and the acceptability and usability of the MOOC content and structure. The results will be presented in reports and scientific articles.

Only the research team will have access to your data, and your data will be stored securely in a locked filing cabinet in the School of Health Science at Ulster University and on a password protected computer. Your data will be stored by the research group for ten years and then destroyed. All processing and all presentation of results will take place in an unidentified form and the results will be reported at group level, so that no individual person can be identified. The group results will be shared with the wider team of researchers, user organizations and private companies in Italy, Sweden, United Kingdom, Lithuania and Portugal.

The study will comply with the 2018 data protection act and all GDPR regulation. According to GDPR, you have the right, free of charge, to receive information about you that is handled within the study and, if necessary, get any errors corrected. You can also request that information about you be deleted and that the processing of your personal data is limited.

If you would like to find out about the information about you, please contact Dr Sarah Howes email: [s.howes@ulster.ac.uk](mailto:s.howes@ulster.ac.uk). If you are dissatisfied with how your personal data is processed, or any other aspect of the study you have the right to complain. Any complaints will be taken seriously and should be made, in the first place, to the Chief Investigator, contact details are below. Following this, the research office can also provide additional guidance, contact details below. A link to the complaints procedure is at <https://internal.ulster.ac.uk/research/rq/0208ResearchVolunteerComplaintsProcedure.pdf>.

### **How about insurance and compensation?**



The University is insured for its staff to carry out research involving people. The University knows about this research project and has given permission for it to proceed. Further details can be found in the University's research indemnity statement which is available on request.

**Do I have to take part?**

Your participation is voluntary and you can choose to withdraw your participation at any time. If you choose not to participate or want to withdraw your participation, you do not need to state why, and it will not affect your future care or treatment. If you want to withdraw your participation, you should contact the researchers responsible for the study (Dr Sarah Howes).

**Who is responsible for the study?**

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