Understanding the Lived Experience of Neuropathic Pain and Improving its Assessment (WP2 PAINSTORM)

Participant Information Sheet

Introduction

You are being invited to take part in an interview and two focus groups as part of the PAINSTORM research 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?

Neuropathic Pain is caused by damage to the nerves from, for example, diabetes, cancer treatments, viruses or accident/trauma injury. Nerves transmit signals within the brain and spinal cord (the central nervous system or CNS) and extend from the CNS to the muscles, skin, and organs. In neuropathy, this nerve damage can cause long persistent pain that lasts for more than three months, described as chronic pain. We would like to understand what it's like for you living with Neuropathic Pain. We would also like to know if the healthcare professionals looking after you have asked about or measured your pain, and the ways in which they did this.

Why have I been chosen?

We are looking to hold a series of interviews and focus groups made up of people living with Neuropathic Pain from across the UK. You have been invited because you volunteered to take part, or you have let people know in the past that you would be willing for researchers to contact you about this topic.

Do I have to take part?

You do not have to take part unless you want to. If you decide to take part, you are free to change your mind at any time without giving a reason.

What will taking part involve?

After reading this, if you are still interested in taking part, we would need you to complete the short online questionnaire we have sent to you. This will be in the invitation email or letter which was sent by post. The short questionnaire asks some basic questions about you and your condition. This will help the research team decide who we would like to invite to take part, based on your condition, age, gender, ethnicity and socio-economic criteria. Using this information will ensure we speak to a wide variety of people. We will let you know if you have been chosen to take part.

If you do not meet the criteria to participate, we will let you know.

If you are chosen to take part in the study, we will send you a consent form to review and return. This will let us know that you wish to take part and understand what you need to do. Once we have received your consent form a member of our team will be in touch to arrange a time for your interview that suits you. The interview will take place either online or by telephone and last for approximately one hour.

If you meet the criteria but the research is oversubscribed, we will let you know that you have been placed on a waiting list. If a place becomes available, we will contact you and invite you to take part in an interview and or one or more online focus groups. In any event we will inform individuals on the waiting list when the research has closed recruitment.

What will I be asked?

Before we start the interview, we will ask for your verbal consent by going through the consent form with you to check that you still want to take part. Your verbal consent will be recorded and stored separately from the interview recording on a secure server.

The interviews will focus on what it's like for you living with Neuropathic Pain. We would like to understand more about your experiences of living with Neuropathic Pain and how it impacts on your everyday activities.

After the interview we will let you know of the dates and times of the two online focus groups. They will each last for approximately one hour, will discuss different topics, they are:

1) We want to understand your views and opinions on the ways and tools that are used to assess Neuropathic Pain. Do these describe your experience of living with Neuropathic Pain?
2) We would like to discuss devices that can be worn to measure Neuropathic Pain. Questions will include – would you use these devices?

Participants who have indicated they have recent experience of Quantitative Sensory Testing (QST) may be invited to take part in an additional focus group to discuss their experience of QST.

At the end of the interview, participants will be asked if they would like to provide additional information by thinking about the prompt, 'Living with Neuropathic Pain is like….' and answering in any way they choose, for example, creative writing, drawing/painting, or sending in a photograph, or title/lyrics of a song.

What will happen to the information I give you?

Researchers at the University of Aberdeen will look at what has been said in the interviews and Focus Groups to help understand people's experiences of

Neuropathic pain and how it is assessed. We will anonymise what you have said so that the researchers won't be able to identify you.

The findings from the interviews and focus groups will be presented at workshops with key stakeholders. Information from the study will also be used to create innovative patient and public engagement activities as part of PAINSTORM research which you can find more about by visiting the website: PAINSTORM — Nuffield Department of Clinical Neurosciences (ox.ac.uk). This will include a summary of the findings from the interviews and focus groups and will be available to participants if they wish and disseminated on the study websites, social media and newsletters. We will also produce conference abstracts/presentations and submission of manuscripts to scientific peer-reviewed journals. The findings will also be published in medical journals. Nobody will be able to identify you from the anonymous data or from any publications.

What are the possible disadvantages and risks of taking part?

The one-to-one interview and two focus groups will each take about one hour of your time for a total of three hours. 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. Confidentiality cannot be guaranteed when taking part in focus groups however we will ask group members to keep discussions confidential.

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 how living with Neuropathic Pain impacts people's lives and the suitability of assessment tools and acceptability of wearable devices for people who suffer from Neuropathic Pain.

What if I have a complaint?

If you have any concerns with any aspect of this study, please ask to speak to the study team who will do their best to answer your questions – contact details are at the end of this Participant Information Sheet.
If you remain unhappy and wish to make a formal complaint, you can do this by contacting the Research Governance Team at the University of Aberdeen, by telephoning 01224 437220 or by email to researchgovernance@abdn.ac.uk

Will my taking part in this study be kept confidential?

Yes, all information that is collected about you during the research will be kept strictly confidential.

Who is organising and funding the research?

This study is organised by The University of Aberdeen and is part of the PAINSTORM project which is part of the Advanced Pain Discovery Platform (APDP) which is funded by the Medical Research Council, supported by Biotechnology and Biological Sciences Research Council and Economic and Social Research Council and partners with Versus Arthritis, Health Data Research UK (HDR UK) and Eli Lilly.

Who has reviewed the study?

This study has been reviewed and approved by University of Aberdeen School Ethics Research Board SERB (2022-3-2322)

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.

We need to manage your records in specific ways for the research to be reliable. This means that we will not 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?

The University of Aberdeen is the sponsor for this study based in the United Kingdom. We will be using information from you to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Aberdeen will keep identifiable information about you until the study is finished. Your rights to access, change or move your information are limited as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible. You can find out more about how we use your information at http://www.abdn.ac.uk/privacy and/or by contacting the University Data Protection Officer by email at dpa@abdn.ac.uk.

Where can I get further information about this study?

If you have any questions about this study, you can contact Dr Kathryn R Martin Principal Investigator (PAINSTORM WP2) by email, painstorm@abdn.ac.uk