Focus Group Information Sheet

This PIS should be read in conjunction with The University privacy notice,

We invite you to take part in a research study

- You are being invited to participate in a focus group that will advise researchers working on building a forecast of pain.
- Before you decide whether you want to take part, it is important for you to understand why the research is being done and what it will involve.
- Please take time to read the following information carefully. Discuss it with friends and relatives if you wish.
- Ask us if there is anything that is not clear or if you would like more information.

Important things that you need to know

- This study is being conducted by Claire Little, a PhD researcher at the Centre for Epidemiology, University of Manchester. The focus group will be co-facilitated by Prof John McBeth who is the supervisor of Claire Little's work, and Dr Katie Druce.
- We are asking people to attend a focus group meeting lasting up to 1.5 hours, at a date to be decided.
- To take part in this study you will need to be at least 18 years old, have a chronic pain condition, have good use of spoken English and be willing and able to consent to participate.
- The meeting will be recorded and analysed by the study researchers to help them understand the outcomes preferred by participants.
- This Project Has Been Approved by the University of Manchester Proportionate Ethic Committee, [UREC reference number 2021-11862-19751].

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How to contact us

If you have any questions about this study, please contact Claire Little by emailing: claire.little@postgrad.manchester.ac.uk

If you would rather discuss your questions on the phone, please email the above address with your phone number, and we will call you back.

MANCHESTER 1824
The University of Manchester

Who will conduct the research?

- This study is being conducted by Claire Little, a PhD researcher at the Centre for Epidemiology, University of Manchester. The focus group will be co-facilitated by Prof John McBeth who is the supervisor of Claire Little's work, and Dr Katie Druce.

What is the purpose of the research?

- In 2016, we conducted a study to investigate the effects of weather on pain. The study, called Cloudy with a Chance of Pain, successfully recruited 13,000 participants, many of whom provided daily symptom data for up to a year. More information can be found at cloudywithachanceofpain.com

- We think it would be useful to use these data to develop a way of predicting pain events, a bit like a weather forecast, and making these available to patients with chronic pain through an app. However, we are not yet sure what events should be predicted.

- We would like your help to understand what information you would like to receive from such an app. We would also like you to help us build a questionnaire which can be sent to other people to learn about their views.

What would I need to do to take part?

- We would ask you to complete the study's online screening questionnaire. This will include a brief demographics questionnaire which will collect information such as your age, diagnosis and disease duration.
- During this screening questionnaire, we will also ask for you to provide us with your postal address. This will allow us to send you a consent form and (optional) refreshments.
- If you meet the study inclusion criteria we will contact you by email to discuss available meeting dates and any accessibility requirements.
- If you agree to participate we will you will be asked to attend a 90 minute focus group meeting held online using the platform Zoom. Instructions and assistance in using Zoom will be provided. Reimbursement for broadband costs of £5 will also be provided.
- At the meeting we will ask you to discuss your previous experience of managing your pain by predicting how your pain will be in the coming days.
- We will then provide you with a brief introduction to some research that we are planning to conduct. In smaller groups, we will ask you to discuss your views of this research and the outcomes that you would like to see.
- After a break, we collect our thoughts in the larger group. We will then ask you to help us to build a questionnaire which we will send out to learn other people's views on this topic.
- In addition to your broadband expenses, you will be reimbursed £37.50 for your active participation at the focus group. It is important for you to know that these payments may have considerations for your financial status. As benefit conditions are complex we strongly urge you to contact the necessary organisations.

Who can take part?

We wish to recruit people who:

- Have a chronic pain condition
- Are willing and able to provide consent and participate
- Have a good use of spoken English

What will happen to my personal information?

- In order to undertake the research project we will need to collect the following personal information about you:
  - Name
  - Gender
  - Age
  - Email address
  - Postal address
- We will also ask you to complete a brief demographic questionnaire to tell us about you and your chronic pain condition, including information about your ethnicity and the duration of your disease.
- You will optionally provide us with your dietary requirements. If you choose to do so, we will send you some refreshments.
- We will then ask you to participate in a focus group. We will record the meeting. Within 30 days of the meeting, an anonymised transcription of the meeting will be made, and the recording will be deleted.
- The information from the transcription will be used to inform changes to the questionnaire and subsequent work on pain forecasts. Anonymous written quotations from the transcription may be used in the future.
- We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is "public interest task" and "for research purposes" if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our Privacy Notice for Research Participants.
- In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:
- Your personal details and demographic data will be kept separately from the recording and transcriptions on secure databases within the Centre for Epidemiology Versus Arthritis. Your name, or any details that could identify you will not be used in any publications resulting from this study. While the researchers will keep information confidential, due to the nature of a focus group confidentiality cannot be assured from fellow group members.
- A member of the research team will transcribe the audio recording, but no identifiable information about you will be included. For administrative purposes, a written copy of the recording will be stored securely for 5 years. Recordings will be deleted within 30 days of the focus group taking place.

What will happen to my personal information?

- Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this project to make sure it is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the project will have a strict duty of confidentiality to you.
- You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our Privacy Notice for Research Participants and if you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL. at the University and we will guide you through the process of exercising your rights. You also have a right to complain to the Information Commissioner's Office, about complaints relating to your personal identifiable information. Tel 0303 123 1113

Can I change my mind?

- It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.
- If you do decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, once you have attended the focus group, it will not be possible to remove your anonymised quotes from the data set.

What if I want to make a complaint?

- It is important that you know who to contact if you wish to report any problems or to make a complaint. The details you need to do this are below:

Minor complaints

If you have a minor complaint then you need to contact the supervisor of the researcher in the first instance. Please contact:

John McBeth (john.mcbeth@manchester.ac.uk)

Formal complaints

If you wish to make a formal complaint related to this activity or if you are not satisfied with the response you have gained in the first instance then please contact :

The Research Ethics Manager Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL

Email: research.complaints@manchester.ac.uk,Telephone: 0161 306 8089

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- **You can contact Claire Little at claire.little@postgrad.manchester.ac.uk**