

The Impact of Chronic Pain on Daily Life Survey

Research Participation Information Sheet

This survey is organised by Dr Luke Pattison and Prof. Ewan St. John Smith from the Department of Pharmacology at the University of Cambridge. Ethical approval for the study has been granted by the University of Cambridge Psychology Research Ethics Committee (PREC). Beyond their usual salaries the researchers are not receiving any extra pay to undertake this study.

Before you decide whether 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 and discuss it with others, or us, if you wish. Contact details are provided at the top of this sheet, **if you would like further information on any aspects of this information or the study, please do not hesitate to get in contact.**

Purpose of the Study

Chronic pain affects ~25% of the adult population in the UK and there is an urgent need to develop safer and more effective medications to help those living with pain. A major hurdle in the development of new painkillers is poor translation of pain when tested in laboratory animals and human patients. We believe focussing on how pain affects the natural behaviour of mice may hold better value when testing novel medications. Measuring changes in natural behaviours, such as digging activity, also represent a refinement in the assessment of pain in lab animals. To determine how well such changes correlate with how humans experience pain we are running this study to better understand how chronic pain impacts the daily lives of adults (18 years of age or older).

Deciding whether, or not, to participate and withdrawal processes

The choice to participate in this research is completely yours. If you do decide to take part, you will be asked to confirm that you have read and understand this information and complete the Consent Form. In order to participate you should have a medical diagnosis of a condition which causes you chronic pain (defined here as regular occurrence of pain experienced for at least 3 months), e.g. endometriosis, fibromyalgia, inflammatory bowel disease, arthritis, migraine etc. Participation in the survey is completely voluntary (i.e. we are unable to remunerate you for your participation). However, your engagement will help shape research into pain. If you decide to take part, you are free to withdraw (without providing a reason) at any time before submitting your response – simply close the survey without submitting it. Please note though, if you submit a response to the survey, it will not be possible to later withdraw your participation. This is because all data is collected anonymously, so it will not be possible to identify your response to remove it.

What to expect

You will be asked questions about health conditions which may cause you chronic pain, how you manage your pain and how the pain that you experience impacts your day-to-day life. All data gathered will remain anonymous to the researchers, although some basic demographic information will also be collected to assess how representative responders are of the general population. **The survey should take no longer than 10 minutes to complete.**

Confidentiality, anonymity and data storage

Data collected will be stored anonymously on a secure University of Cambridge server, only the research team will have access to responses. Analysed summary data will however, be made available in one or more of the following sources: scientific papers in peer reviewed academic journals – for example, comparing how the experience of humans living with chronic pain is similar to / different from the experience of animals; presentations at a scientific conferences and/or public forums. Upon reasonable request summary data (i.e. not individual responses) may also be shared with other researchers.