Chronic Pain Study: Chronic Pain Sufferer Information Sheet

Introduction and study purpose
You have been identified by your General Practice as an eligible pain sufferer to participate in a study about pain in Glasgow. The aim of the study is to examine what pain sufferers think is just or fair and unjust or unfair about their pain, and how these beliefs are related to pain. The research is being conducted by Dr Joanna McParland and Mr Stephen Wallace, at Glasgow Caledonian University, and Professor Christopher Eccleston, from the University of Bath. The researchers are looking to recruit patients who can speak English, are aged between 18-65 years, have suffered from pain for at least six months, are currently taking medication to relieve their pain, and, as determined by a General Practitioner, have non-malignant (non life-threatening) pain and are not suffering from a recorded serious and enduring mental health condition.

Your valuable contribution to the study will be used to help inform interventions to improve the quality of life of chronic pain sufferers, and will help these researchers to take their work forward in this important area. Before you decide whether or not to participate, it is important for you to understand what participation in the study will involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please contact Stephen at the address below, for more information.

What will I have to do if I take part?
There are two phases to the study. A selection of participants will take part in the first phase and all participants will take part in the second phase. In phase 1, participants will be invited to Glasgow Caledonian University in Glasgow’s city centre, to participate in an anonymous audio-recorded group discussion with around 7 other chronic pain sufferers. The Project Leader, Joanna, will provide questions to be discussed, and Stephen, the study researcher will take notes. Participants will also be asked to complete a short questionnaire and to sign a study consent form. The discussion will last for between 2.5 – 3 hours, with a break, and will be held sometime between April and June 2008. Everyone will be posted a summary of the discussion results and will be invited to take part in the second study phase along with all of the other participants. In this phase postal questionnaire materials will be anonymously completed (taking 1-2 hours to complete) sometime between August and October 2008.

Do I have to take part?
No. It is up to you to decide whether or not to take part. You can stop participating in the study at any time, without giving a reason. This will not affect your medical care. However it may not be possible to destroy your existing data because all participation will be anonymous.

Will I receive expenses or payment?
Participants will receive £20 travel and out-of-pocket expenses. Withdrawing from the study will not affect receipt of these expenses.

What are the possible disadvantages and risks of taking part?
One possible disadvantage of being part of study phase 1 is that the things people say during the group discussion could upset other participants. However, in the unlikely event of this the discussion will be redirected. Participants in study phase 2 might also find some of the questionnaire items to be personal. However, all questions are anonymously completed and are relevant to the study.
What are the possible benefits of taking part?
We can’t promise that the study will help you personally. Nevertheless, the results should increase our understanding of the experience of chronic pain and this, in turn, is expected to be beneficial to future chronic pain sufferers.

What happens when the research study stops?
You will be posted a written report of the results of the completed study.

What if there is a problem?
If you are concerned about your participation in the study and this cannot be resolved by the project team, please contact the University Secretary, Peter Finch at: Glasgow Caledonian University, 70 Cowcaddens Road, Glasgow G4 OBA. Telephone: 0141 331 3440, Email: Peter.Finch@gcal.ac.uk

Will my taking part in this study be kept confidential?
Yes. Ethical and legal practice will be followed, and all of your information will be handled in confidence.

Who is organising and funding the research?
This research is being funded by the Economic and Social Research Council (ESRC), and is sponsored by Glasgow Caledonian University. Your data will be stored securely at Glasgow Caledonian University for 5 years before questionnaires are shredded, and group discussion audio-recordings are destroyed.

What will happen to the results of the research study?
Study phase 1 group discussions will be used to develop a set of justice statements that will form a task for the second, questionnaire study phase. Additionally, anonymised quotes from the group discussions and anonymous questionnaire results will be made available to a range of people including other chronic pain sufferers, their spouses or partners, health professionals, relevant Government agencies and researchers through specially written reports, established website reports, the media, presentations and journal publications. Your data, in the form of numeric machine-readable questionnaire results, transcripts of group discussions, audio-recordings of group discussions, observational notes from the discussions and justice statements developed from group discussions will be offered to the ESRC funding body for possible selective archiving (storage) for an unlimited time for use by registered bonafide researchers. All of these data will be checked to make sure that they are completely anonymous first and we will sign a licence agreement stating the conditions under which other researchers are able to use them. Archiving will help to preserve, secure and control access to anonymous data.

Who has reviewed the study?
All research in the National Health Service (NHS) is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been given ethical approval by NHS Greater Glasgow and Clyde Research Ethics Committee. The Division of Psychology at Glasgow Caledonian University has also granted ethical approval for the study. Consent to participate in the study will be obtained following British Psychological Society guidelines by Joanna, the Project Leader, who is experienced in obtaining written consent. You will receive a copy of all signed consent materials.

Further information and contact details
Further information about public involvement in NHS research can be found at the following web address: http://www.invo.org.uk/. More study information can be obtained from Stephen Wallace at: Division of Psychology, Glasgow Caledonian University, 70 Cowcaddens Road, Glasgow, G4 OBA. Telephone: 0141 331 3831. Email: painstudy@gcal.ac.uk
What happens next?
If you decide you are interested in participating in or finding out more about the study after reading this information sheet, please either complete and return the attached contact details sheet using the enclosed stamped addressed envelope or telephone/email Stephen within two weeks of receiving this study invitation. Thank you for taking the time to read this study information sheet.