

***Communicating Chronic Pain* Workshop Information Sheet**

Thank you for registering for one of our *Communicating Chronic Pain* workshops. We’re looking forward to meeting you. These workshops are part of a research project undertaken by LSE researchers and funded by the Economic and Social Research Council through the National Centre for Research Methods. Here is some information about the aims of the project and what we will do with the data we collect. Please read through it and let us know if you have any questions.

**Aims:**

Recognising that one of the problems with pain diagnosis and treatment is that pain is difficult to express to others, the *Communicating Chronic Pain* project aims to explore and assess new, non-verbal methods for communicating chronic pain. The goals of the project are to find new ways for chronic pain sufferers to express their pain that do not rely on language, and to investigate what methods from the arts and humanities have to offer in this regard. The research is funded by the Economic and Social Research Council through the National Centre for Research Methods. We hope that the research will benefit people with pain by providing new forms of expression and ways of representing and communicating pain that can be used by people with pain and clinicians.

**Methods:**

We are running a series of five workshops with people with chronic pain and clinicians who work with them. Four workshops will be live while one will be available online. These workshops are our main form of data collection. You can participate in just one workshop, or as many as you wish. Each workshop is devoted to exploring a different method of chronic pain communication, from body mapping, to the sounds of pain, to the way spaces affect experiences of pain, to the use of social networking for expressing pain, to the role of technologies in documenting pain.

Each workshop will be audio and video recorded using an unobtrusive, fixed camera. These recordings are for our records and later analysis and will only be viewed by members of the research team. We will store them securely with file encryption and keep them for as long as we are working on the project and publications resulting from it.

The creative methods used in the workshops will result in outputs by individuals or groups of participants, which may be in the form of models, drawings, sound recordings or digital photographs. These have a central role in our data analysis. We are asking you to share these with us under Creative Commons License ([www.creativecommons.org](http://www.creativecommons.org)). Under Creative Commons you retain ownership of your outputs but allow us to use the material with certain conditions which you can choose, for example around attribution and re-sharing. You can choose who you share these with.

Publications resulting from the research may use your words our outputs. If you so choose, we can do this anonymously. Please indicate this on the consent form below.

The creative outputs of the workshop will be deposited in the UK Data Archive as part of the terms of our research funding. This is to assist future researchers in investigating similar topics. The researchers may give permission to selected individuals to re-use these data for research purposes. Again, these outputs can remain anonymous if you wish.

**About Us:**

We are a team of social scientists with backgrounds in health sociology, community health psychology, anthropology and political science. Two of us also have first hand experience of chronic pain and chronic illness. This is not a medical project and while we hope you will find it useful in your understanding and experience of pain, we are not intending to diagnose or treat you.

**Your Rights as a Participant:**

You have the right to withdraw from the project at any time without penalty and you do not need to give a reason. If you choose to withdraw after you have participated in a workshop your individual data will not form part of our analysis. Any collective data you have created with a group of people, such as a sound recording, may still be included in our analysis.

If you wish, you may participate in the project and contribute your materials while remaining anonymous. Please see the consent form below for more details about this. Consent forms with your signature will be stored securely and will only be seen by the researchers.

If you have any questions or comments about any of the above, please contact us at:

E-mail: [info@communicatingchronicpain.org](mailto:info@communicatingchronicpain.org)

Office Tel: 020 7955 6950

Mobile: 07941 877 775

funded by

 EPS CMYK Large.eps



***Communicating Chronic Pain* Workshop Consent Form: Soundscape of a Body in Pain**

I have read the accompanying information sheet and have been sent a copy to keep. I understand what is being asked of me and have been given the opportunity to ask questions. I understand that I am entitled to withdraw from the research at any time without penalty and without needing to give a reason. I hereby consent to participating in this research.

I wish to have my words remain anonymous in all outputs from the

project: ☐

I wish to have only my creative outputs remain anonymous: ☐

Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Researcher’s Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Creative Commons Outputs**

In most research projects where creative materials are produced, researchers ask participants to sign over their copyright to the research team. Using Creative Commons licensing allows you to retain the copyright of the materials while still allowing us to use your materials as part of our research. It also means that materials can be re-shared and used by others, subject to certain conditions. These conditions include ‘attribution’, ‘no derivatives’, ‘share alike’ and ‘non-commercial’. We hope that this re-use will enable others to find new ways of communicating about pain.

For this workshop, the materials you create will be collaborative and will be developed with other workshop participants. As such, we recommend a ‘share alike’ and ‘non-commercial’ license. Please indicate below whether you agree to these conditions:

* I am willing to share the materials produced in this workshop under Creative Commons License ☐
* I would like my work to be attributed to me (to have my name on it) ☐
  + - Please indicate your preferred name: this can be an alias if you

prefer to remain anonymous \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* I agree to allow others to adapt or modify our work provided they ‘share alike’ with others ☐
* I agree to disallow commercial uses of our work ☐

Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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Every license helps creators — we call them licensors if they use our tools — retain copyright while allowing others to copy, distribute, and make some uses of their work — at least non-commercially. Every Creative Commons license also ensures licensors get the credit for their work they deserve. Every Creative Commons license works around the world and lasts as long as applicable copyright lasts (because they are built on copyright). These common features serve as the baseline, on top of which licensors can choose to grant additional permissions when deciding how they want their work to be used.’