

Participant information sheet
Creative Submissions to Website, *Translating Chronic Pain*

I am a researcher at Lancaster University and I would like to invite you to take part in a research study about short creative writing representations of chronic pain. Please take time to read the following information carefully before you decide whether or not you wish to take part.

What is the website about?

People living with chronic pain often say they feel invisible and unseen. To try to help overcome this, we are collecting short fragments of writing to try to capture and communicate vivid fragments of diverse experience in the lives of people living with chronic pain, and the people who support them, both carers and medical professionals. We are hopeful that we will find benefit in short-form work including poetry, poetry/prose hybrids, 'flash fiction', and visual/text hybrids such as graphic comic panels and photography/text combinations.

Who is participating?

We are advertising the website to the public. There are no restrictions on who can contribute. Contributors can be people living with chronic pain, carers, healthcare practitioners, or anyone else with an interest in the subject.

What will I be asked to do if I take part?

If you wish to submit work to the online database, you can upload a submission via the project website. Contributions will be licensed under Creative Commons BY-NC, and contributors choose to be anonymous, pseudonymous, or named. The submitted work cannot name any other individual, nor can it be extremely violent or highly sexually explicit; where this may be an issue, the PI and CI will jointly assess the submission and offer guidance for a possible re-submission. If you are an NHS employee, please do not describe specific details of your NHS professional practice/location of work, but draw instead on your general personal opinions and views on pain experience, care and medicine.

What are the possible benefits from taking part?

If you take part in this study, your insights will contribute to our understanding of the ways that creative, short literary representations might be helpful to people with chronic pain and to those who support them.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Your participation is voluntary.

What if I change my mind?

Since the website is public, once it is uploaded it will be recorded in webcaches, so we will not be able to entirely remove it from the web if requested. However, to enable authors to have time to reflect, we will delay posting any submission for 30 days after the date it was sent to us. During that thirty day waiting period you can withdraw your writing by emailing s.wasson@lancaster.ac.uk. Please allow five days

for a reply. If I am away due to medical or annual leave, then my out of office message will direct you to an alternative site of support.

What are the possible disadvantages and risks of taking part?

Writing creatively about chronic pain – either your own or another’s - can be distressing, so that is a possible risk. However, the overriding focus of the project is about identifying ways that these fragmented forms of writing may ultimately be enriching and supportive – even distressing writing is being approached as of value - for example, in discussions of how a person living with chronic pain may feel vindicated and recognised. Another aspect of the project to be aware of is that the website will be freely available online.

Will my data be identifiable?

When you submit your writing for inclusion in the website, you can specify whether you wish to be anonymous, pseudonymous, or named.

How will we use the information you have shared with us and what will happen to the results of the research study?

The creative writing on the website will be publicly freely available under Creative Commons BY-NC licensing. We may quote your work in research articles, in papers for academic conferences, and in media outreach. We will follow your preferences with regard to any quotations, making them named, pseudonymous, or anonymous, as you indicate on the questionnaire.

How my data will be stored

Your data will be stored in encrypted files (that is no-one other than me, the researcher will be able to access them) and on password-protected computers. I will keep data that can identify you separately from non-personal information (e.g. your views on a specific topic). In accordance with University guidelines, I will keep the data securely for a minimum of ten years.

What if I have a question or concern?

If you have any queries or if you are unhappy with anything that happens in your participation in the website, please contact myself, Dr Sara Wasson s.wasson@lancaster.ac.uk.

If you have any concerns or complaints that you wish to discuss with a person who is not directly involved in the research, you can also contact: Professor Sally Bushell, head of the Department of English Literature and Creative Writing, s.bushell@lancaster.ac.uk, tel 01524 592249, Department of English Literature and Creative Writing, County Main, Lancaster University, Lancaster LA1 4YD.

Sources of support

The following charities and organisations offer a wide range of advice and support for people living with chronic pain, and for those who care for them.

- The British Pain Society: <https://www.britishpainsociety.org/people-with-pain/>
- Action on Pain <http://www.action-on-pain.co.uk/>

- A Way with Pain <http://www.awaywithpain.co.uk/>
- Pain Concern <http://painconcern.org.uk/>
- Fibromyalgia Action UK <http://www.fmauk.org/>
- Ehlers-Danlos Support UK <https://www.ehlers-danlos.org/>
- Endometriosis UK <https://www.endometriosis-uk.org/>
- Pain Relief Foundation: <http://www.painrelieffoundation.org.uk/about/pain-relief-foundation/>
- Pain Support <http://painsupport.co.uk/>

This study has been reviewed and approved by the Faculty of Arts and Social Sciences and Lancaster Management School's Research Ethics Committee.

Thank you for considering your participation in this project.