

**Research Involvement PPIE Case Studies form**

**Name: Stephanie Smith (academic), Stevie Vanhegan (PPAG member) and David Walsh (academic), on behalf of Pain Centre Versus Arthritis**

**Name of research project: A questionnaire to assess central nervous system aspects of pain**

**What stage(s) did you involve PwA in your research?**

Identifying and Prioritising Research [x]

Project design and application [x]

Monitoring and conducting [x]

Dissemination [x]

**What area is your research in?**

Clinical [x]

Pre-clinical [ ]

Discovery/Fundamental [ ]

Health services [ ]

Translational [x]

Other (please state):

**How did PwA get involved?**

Please let us know in as much detail as possible how PwA contributed to your research.

Tell us about your project (main aims etc):

What people feel as pain is not simply a question of what is happening in their joints. The brain and spinal cord (central nervous system) decides how we feel pain. Sometimes, it can make pain feel worse, and sometimes it can reduce pain. How the central nervous system is involved in pain can be measured using special tests such as quantitative sensory testing (QST) and magnetic resonance imaging of the brain (MRI). In QST, heat, cold or mechanical pressure is applied to the individual who is asked to describe whether or how painful it is. Brain MRI can make some people feel anxious or claustrophobic. These tests can be time-consuming, require specialist equipment, and are sometimes unpleasant. Pain Centre Versus Arthritis is a partnership between people with lived experience of pain and researchers with expertise in how the brain and spinal cord work. This partnership has enabled us **to develop a simple questionnaire to detect and measure these central nervous system aspects of pain: the Central Aspects of Pain (CAP) Questionnaire.**

**How did you involve people?**

People with lived experience of pain, the Centre’s Patient and Public Advisory Group (PPAG), are essential to the work of Pain Centre Versus Arthritis. Their valuable insights contributed to the Centre’s successful application to Versus Arthritis in 2015 to fund a 5-year programme of research exploring the mechanisms of arthritis pain and develop improved treatments. They contributed through focus groups, sharing and reviewing ideas and ensuring that what we put in writing was meaningful. Pivotal to that research, we established a (Knee Pain In the Community: KPIC) of approximately 9,500 people who completed annual 20-page questionnaires about their arthritis and pain over the 5 year period.

People from the KPIC cohort attended the University of Nottingham for a detailed assessment of their pain. Kehinde Akin-Akinyosoye, a PhD student within the Centre, worked with individuals with knee pain to refine the 20-page questionnaire booklet. They produced a simple 8-question questionnaire that contained only the best questions to detect and measure central aspects of pain. Kehinde interviewed 30 people experiencing knee pain to make sure that the questionnaire made sense to them. We then changed some questions in response to their difficulties and comments. By doing this, we could ensure that people answered the questionnaire in a way that matched the scientific intentions behind each question. For example, we adapted the question about pain experienced in response to heat or cold to clarify that it meant contact with a hot or cold object or water, rather than the ambient temperature in the winter or summer.

The modifications resulted in the Central Aspects of Pain (CAP) questionnaire, a user-friendly and practical tool. It brings together many different aspects of the pain experience, such as anxiety, depression, catastrophizing, fatigue, sleep disturbance, and difficulty thinking straight. CAP is a simpler method to assess an individual’s pain experience than tests such as QST or MRI. It has many other advantages. It opens the way in the NHS for more routine assessment of important brain and spinal cord contributions to arthritis pain.

Positive feedback from the Pain Centre’s Patient and Public Advisory Group (PPAG) resulted in CAP’s inclusion in the questionnaire booklet for a second large group of people with musculoskeletal pain (the Investigating Musculoskeletal Health and Wellbeing Survey: IMH&W). Some of these people had knee pain. Others had pain elsewhere. Inclusion in IMH&W enabled further refinement of the questionnaire so that people with pain at sites other than the knee could now use it. Through discussions with people with lived experience of pain, we now know that the CAP questionnaire validly measures central aspects of pain in people with low back pain, rheumatoid arthritis or fibromyalgia, as well as in people with osteoarthritis. A satisfaction survey showed that a large majority (92%) of people in one study found CAP easy to follow, and almost all (99%) would be happy to complete the questionnaire again. Very few (4%) questionnaires could not be scored because of questions having been left unanswered. This information tells us that CAP is easy to use and acceptable to people with arthritis pain.

We then looked at applying the CAP questionnaire to those with an even broader range of musculoskeletal conditions. People with rheumatoid arthritis contributed to a focus group, highlighting the importance of pain that does not get better despite the optimal use of anti-inflammatory treatments. Two members of this group contributed as co-applicants to successful funding applications to Versus Arthritis and Pfizer Ltd. Research studies often need to have a Steering Committee, to make sure that everything goes as planned, or to find ways to work around any difficulties that are encountered. The 2 study co-applicants with lived experience of arthritis were key members of the Central Aspects of Pain in Rheumatoid Arthritis (CAP-RA) Steering Committee. In the CAP-RA study, we used the CAP questionnaire to understand interactions between inflammation and central nervous system mechanisms in people with painful rheumatoid arthritis. People with lived experience undertook a walk-through of the study visit (the study visit required people to come to the hospital and undertake several assessments of their pain). Together, we refined and streamlined these visits, thinking about the order in which we undertake assessments and what participants could complete more conveniently at home. The Steering Committee members with rheumatoid arthritis enabled us to think about recruitment from a patient perspective during the many COVID-19 spikes. The Steering Committee members and other members of the Pain Centre’s PPAG have worked with researchers to prepare scientific reports and summaries that are accessible to patients and the public, explaining what we have found and the importance of the findings. The CAP questionnaire can now detect central aspects of pain in people with a wide range of musculoskeletal conditions.

We are currently exploring how the CAP questionnaire can identify people who could benefit from specific treatments in clinical practice and research trials. By better understanding the precise mechanisms underlying the central aspects of pain, we can develop new and better treatments to relieve the burden of arthritis pain. Specifically, people with lived experience of pain and researchers have co-produced two new and successful research funding applications building on our work with the CAP questionnaire:

1. The Assessing Central Nervous Systems Contributions to Accelerate Musculoskeletal Pain Diagnosis and Treatment (AsCent) project explores combining the CAP questionnaire with a simplified version of QST to help manage arthritis pain. Versus Arthritis and EULAR now fund this study.
2. An NIHR-funded project is investigating pain in people living with dementia (CAPPPeD) using CAP and QST.

In each project, people with lived experience of pain contribute as equal partners as members of the study Steering Committees, providing valuable input and insight into the study's management and running. Together with people with lived experience of pain, we summarise all articles accepted for publication in scientific journals so that they can be understood by a non-specialist audience. Members of the Centre’s PPAG (all of whom have lived experience of pain) review these summaries to ensure that they are understandable and adequately address concerns of people with lived experience of pain before being posted on the Centre’s website at https://www.nottingham.ac.uk/paincentre/publications/lay-summaries.aspx .

**How did you find people to involve in your project?**

Pain Centre Versus Arthritis established at its outset a Patient and Public Advisory Group (PPAG), comprising people with lived experience of arthritis pain. Over the years, while some people have left PPAG, new people have joined, bringing new ideas and perspectives. Members of the group have approached the Pain Centre seeking to become more involved through email contact and other research and clinical activities in which they have participated. We have also involved people from our research studies who have had a range of experiences of pain and arthritis. We circulate invitations to become involved in our PPAG through the Pain Centre’s newsletters and website (<https://www.nottingham.ac.uk/paincentre/ppi/index.aspx>). Involvement has also cascaded from PPAG members to their friends and relatives, including carers who have contributed valuable insights into the Centre’s research. Members of the Pain Centre PPAG have also joined other PPI groups, for example in local NHS Trusts. We offer PPI opportunities to PPAG members, who may opt to contribute to any specific activity or project.

**How did you support people in your project?**

Pain Centre Versus Arthritis has benefited from infrastructure funding through Versus Arthritis and other sources. With this funding we have supported the Patient and Public Advisory Group (PPAG) with efficient administration and communications. Working closely with Nottingham University Hospitals NHS Trust’s Biomedical Research Centre and the University of Nottingham School of Medicine, we have developed efficient processes, including payments for PPI activities. We support individuals through the complex tax and benefits considerations for suitably reimbursed PPI payment. All PPI activities are financially supported for necessary expenses and payment according to NIHR guidelines, while we recognise that not all PPAG members choose to receive such money.

PPAG members contribute in many different ways to the Centre’s activities, including helping to develop the CAP questionnaire. Co-applicants with lived experience on grants need expertise and understanding of the research process to be able to comfortably contribute to projects. For this, academics who are also involved in the projects and peers from the PPAG, support our lived experience co-applicants. We signpost people to publicly accessible resources to help them to be involved in research.

**Can you give more examples of how you worked with them?**

People with lived experience have also contributed to the training and development of generations of our researchers, from PhD students and postdoctoral scientists to senior academics. They have made presentations locally to researchers about what PPI has meant to them, and why it is important, and presented and co-chaired workshops in national scientific meetings. Insights from people's lived experiences are crucial for understanding their needs and concerns and enabling better communication with members of the public. Through these discussions, researchers discover exactly what people with lived experience do and do not find helpful, and the questions they want answered. People with lived experience make researchers think about things they have never considered and in different ways. Reciprocally, they can gain a new understanding of pain and research. Together, we achieve much more than we could ever do alone.

**What impact did it have?**

Some detailed changes to research studies resulting from PPI are given above, but this risks diminishing the true impact of PPI. We integrate PPI into our research to the extent that we cannot easily distinguish the contributions of people with lived experience of arthritis pain from those of academics, since the final outputs and impact result from discussions and collaboration between the two, as equal parties. In our opinion, the CAP questionnaire and its implementation would undoubtably have gone in entirely different directions were it not for PPI. CAP might not have progressed at all beyond the initial simple idea, and certainly not in directions that can most benefit people with arthritis pain without the input and direction from people with lived experience of pain. Feedback from PPAG members highlights how also they feel they have benefited from their involvement, as individuals. PPI has sometimes given them a better understanding of their own condition, and satisfaction at knowing that they have contributed to worthwhile research. The appreciate being taken seriously, as equal partners, with expertise that is different, but no less valuable than that of researchers.

**What would you change if you could do it again?**

* It would be of value to increase diversity further within our PPAG,
* Over the next few years, we want to better understand how PPI can best lead to research outputs that are most useful for people with arthritis pain.
* We would like to develop more reliable and valid ways to measure the value of PPI

**What tips would you give another researcher?**

Involve people with lived experience within your research programme so they can contribute to the project’s conception (right from the initial idea). This requires a commitment to developing infrastructure that is in place before a project starts and continues long after it has ended.

Find out early who are the key people to ask for help/support/training and talk with other researchers and people with lived experience of arthritis who have worked with PPI.

**What challenges did you face and how did you overcome them?**

Managing expectations from researchers and people with lived experience of arthritis pain can be a challenge. It requires clarity from the start about what each party hopes to gain from the collaboration and we must identify shared objectives towards which we can work.

