MAKING CHRONIC PAIN MATTER—HOW CAN QUALITATIVE RESEARCH SHAPE THE CONVERSATION?

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This paper reflects on our experience of designing, running and evaluating participatory qualitative research methods to better understand pain communication. It emerges from Communicating Chronic Pain: Interdisciplinary methods for non-verbal data, a research project funded by the National Centre for Research Methods, which aimed to bridge the gap between experiencing and communicating about pain. Focusing on non-verbal forms of communication instead of personal illness narratives, this project explored pain communication in non-clinical contexts, analysing non-verbal forms of pain expression across multiple social media platforms and by using arts methods as experimental and participatory methodologies to explore pain communication.

Involving a mixed group of people living with different forms of chronic pain, clinicians and pain researchers, we set up a series of four workshops which were designed as a context in which participants could collectively explore dimensions of pain communication beyond individual pain narratives. Each of these workshops was collaboratively led by two arts practitioners and attended by our team of three researchers as full participants. Workshops were structured around a process of making or working with objects (drawings, photographs, soundscapes and spaces). We analysed both the content of participants’ communication about pain, and the processes enabling that communication. Regarding content, the methods yielded evocative and relational versions of pain that encompassed tensions (such as immediate/chronic; owned/disowned; internal/external), rather than repeating traditional linguistic distinctions. Regarding process, we argue that the combination of practical arts methods and inclusive, anti-hierarchical social relations fostered a context which allowed for ambiguity and multiple meanings, in ways that are not traditionally enabled in the context of clinical communication.

**In this paper we ask** Did this type of experimental/participatory workshops succeed at reframing pain in ways that could improve clinical communication? What practices worked best in terms of participant engagement? Could this format be taken forward as a form of collaborative, open-ended, participatory research practice?