



Partnering with People with Lived Experience in Pain Research

Pain research has created a wealth of knowledge about pain and pain management, yet much of that knowledge has not been communicated to the public or made an impact on clinical practice in a meaningful way. Some of these challenges can be overcome by partnering with people with lived experience of pain along the knowledge translation spectrum – including in research, education, practice (see Global Year Fact Sheet on Clinical Practice Guidelines), and policymaking.

People with lived experience bring more than just their pain experiences to these projects, they also bring their lifetime of education, work, life experiences and their unique talents, skills, and creativity. Partnering with people with lived experience helps ensure the relevance of research, improve the quality and delivery of health care services for people living with pain, and improves patient and public health outcomes, all of which lead to more meaningful and wider-reaching impacts^[2,3,24,25]. Plus, including people with lived experience in pain in research is just the right thing to do^[1].

Terminology

Many terms are used to describe people with lived experience partnering in research and within healthcare systems^[24], including patient and/or public involvement, patient engagement, public participation, or patient partnerships. In some regions, other terms may be used in place of patient or public, such as stakeholder, consumer, citizen, and/or community. Such research collaborations may also be referred to as participatory [action] research, citizen science, patient-oriented research, or community- or practice-based research networks.

The process of partnering with people with lived experience in research is referred to in a variety of ways, including co-creation^[14], co-production^[8], co-design^[16], and co-development. Such collaborative practices may also be reflected in initiatives around inclusivity, diversity, representation, health equity, and social justice^[10].

‘Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge^[12].’

In co-produced research, people with lived experience are often referred to as ‘patient partners’ (can also refer to carers, family members, and patient advocates), yet they are not patients in these roles. Rather, people with lived experience are members of the research team who bring their lived expertise, knowledge, and insights to inform the design, execution, and mobilization of projects.

How to Include People with Lived Experience with Pain in Research

There is a rich and growing practice of involving people with lived experience in research, and many research funders now require meaningful patient engagement in the research process^[21]. People with lived experience can be [involved throughout the research process](#)^[15], including setting priorities; establishing research agendas; applying for funding; developing research questions; designing and overseeing of studies^[7]; recruiting participants; collecting,

analyzing and interpreting data; co-authoring and publishing peer-reviewed papers^[19]; and sharing research findings to patients, clinicians, and the general public. An interactive roadmap that includes information and resources at each stage can be found here: [A Journey Through Public & Patient Engagement in Health Research: A Road Map](#).

The International Association for Public Participation (IAP2) has identified five levels of engagement with each level along the continuum reflecting greater patient and public involvement. The stages are: inform, consult, involve, collaborate, and empower:

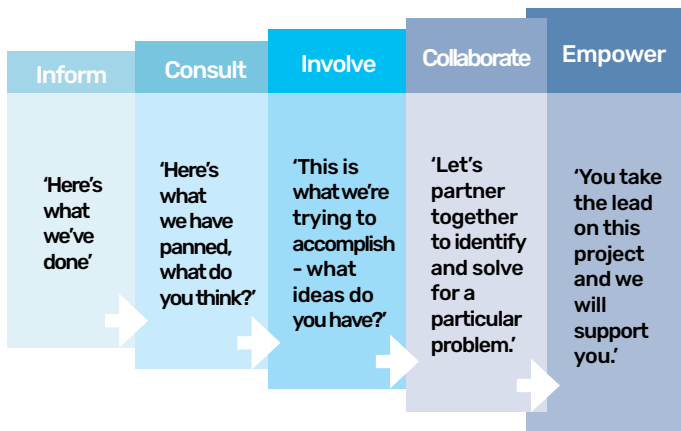


Figure 1. Adapted from [IAP2 Spectrum of Public Participation](#)

People with lived experience of pain can be involved at all levels of the translational science spectrum as well, including in basic, preclinical^[9], and clinical research^[22]; clinical implementation; and public health initiatives^[6]. There are a number of frameworks and resources available, including,

- [NIHR Training and Resources for Public Involvement in Research](#)^[13]
- [Strategy for Patient-Oriented Research - Patient Engagement Framework from Canadian Institutes of Health Research](#)^[5]
- [How-to Guide for Patient Engagement in the Early Discovery and Preclinical Phases](#)^[16] from [Patient Focused Medicines Development](#).

How to Involve People with Lived Experience in Knowledge Mobilization and Dissemination

People with lived experience can also help share and mobilize the knowledge about pain that we have gained through pain research in recent decades. They can co-produce public information campaigns, programs in schools and communities, plain language summaries of current and existing research, and help share this knowledge through videos, social media, popular media formats, blogs/vlogs, infographics, and other means of communicating information. Co-design and delivery of such materials can increase relevance, accessibility, representation, and practicality – how to put knowledge into action for clinicians, patients and the public. (For more, see the [Translating Knowledge into Practice Fact Sheet](#)).

Best Practices for Research Engagement

Equity, diversity, inclusion, and representation

To have the greatest impact, it is important to ensure the people with lived experience of the conditions being studied are included. It is also important that all members of the communities for whom services are being co-designed are represented, including those from racialized, minoritized, marginalized, and historically excluded populations^[4,16,17]. (See [Addressing Inequities fact sheet](#) for more on this topic.)

Recognition and compensation

It is important to recognize and value the time, expertise, and contributions that people with lived experience provide^[21]. Reimbursement or upfront payment of expenses patient partners incur as a result of their contributions should always be included. It is also best practice to offer compensation. Other ways to recognize and value the contributions of patient partners include acknowledgements in research articles and other public forums, co-authorship on manuscripts, invitations to speak at conferences or in classrooms (with expenses paid), and access to knowledge, training, and resources^[23]. Here is a handy guide on [talking with patient partners about compensation](#)^[20].

How to Evaluate It

Evaluation approaches should also be co-created with research partners who have lived experience^[15]. There are a number of approaches to evaluation, which can be qualitative or quantitative^[15]. There are also multiple themes that can be evaluated, such as the structure of how people with lived experience were involved in the project, the processes employed, or the outcomes of various stages of the project^[11].

Available Online Resources:

- [National Institute for Health Research \(NIHR\) Learning for involvement](#)
- [A Journey through Public & Patient Engagement in Health Research: A Road Map](#)
- [Canadian Institutes of Health Research \(CIHR\). Strategy for Patient-Oriented Research – Patient Engagement Framework](#)
- [International Association for Public Participation](#)
- [Ontario SPOR Support Unit Patient Engagement Resources](#)

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