



- **FACT SHEET No. 6**

Integrating the Patient Voice in Pain Education and Research

Pain is a multidimensional phenomenon that varies with each individual and with each pain challenge. Patients and their families have personal experiences to share that help educators, students, and researchers understand more accurately how pain affects their lives. The assessment of another's pain is not easy, and empathic care can facilitate this by listening to patient stories or narratives (2, 7). As partners in education and research, they can influence the clinical and research decisions involved in their pain care.

The Patient Voice in Education

- Providing students with opportunities to listen to patient and family stories or narratives creates the opportunity for transformative learning beyond the biomedical to a more humanistic, patient-centered approach to health care (6). This can help us understand the process of health care and potential barriers to treatment effectiveness (5).
- Reflective writing exercises that draw on personal or clinical experience can help students explore the subjective experiences of illness, creating greater empathy and self-awareness (2).
- Curriculum development and reviews offer the opportunity for patients to contribute and bring their perspective to health professionals' education.
- People with pain are "stakeholders" who can be involved in curriculum design and the implementation process (e.g., as committee members and/or participants in classroom and clinical sessions) (8).

Including the Patient Voice in Research as Partners and as Research Participants

Pain is a hugely personal and subjective experience. Qualitative research is a research approach that often incorporates individuals' personal stories or narratives. The following are ways to incorporate patients' voices into research as partners in the research team and as research participants.



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- Patient and public involvement in research (sometimes known as “patient engagement”) is often defined as doing research “with” or “by” people who use services, rather than “to,” “about,” or “for” them (6).
 - Patients can be partners in research and take a lead in gathering the patient voice (5) and identifying priorities for research (6).
 - There is a spectrum of patient and public involvement in research from informing, consulting, involving, collaborating, and empowering them (4).
 - Patient engagement in patient-oriented research involves meaningful and active collaboration in governance, priority setting, conducting research, and knowledge translation.
 - Guiding principles for patient engagement in research include inclusiveness, support, mutual respect, and co-building (working as partners from the beginning) (1).
 - Many funding agencies require patient involvement at all levels of grant development.
 - Benefits of engaging patients as partners in research include increased study enrollment, improved grant-funding success, design of study protocols, and selection of relevant outcomes to patients (3).
 - Patient engagement in research is a rapidly growing area with emerging science assessing its potential benefits to patients, researchers, and health care.

- Qualitative research provides opportunities to capture the patients’ voice and often incorporates personal stories or narratives of peoples’ experiences.
 - Qualitative data may be collected through interviews, observation, and documents.
 - Asking people about their experiences using an interview can elicit rich information and understanding about a topic of interest.
 - Open-ended questions, such as “tell me about” or “how did...” provide more detail than closed-ended questions.
 - Storytelling is embedded in many cultures, and this form of qualitative research is called “narrative research.”
 - When the focus of the inquiry is about the “lived experience,” it is known as phenomenology; e.g., “What is it like to live with fibromyalgia pain?”
 - A focus group is where six to 10 people come together with a facilitator to explore a specific question or topic. It is a useful approach for gathering different perspectives.
 - Qualitative approaches are often important starting points to generate patient-centered research questions.

RESOURCES

Patient and Community Engagement Research: <https://pacerinnovates.ca/engage/>

<http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/>: This organization helps identify research questions important to patients and addresses the mismatch between clinician-driven research and gaps in evidence that is important to patients.

<http://www.invo.org.uk>: This organization is part of, and funded by, the National Institute for Health Research to support active public involvement in public health and social research.

<http://www.iap2.org>: This organization provides a guiding framework for conceptualizing the spectrum of the public's role in a public participation process.

<http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx>: This organization has created a resource hub compiling international open-source tools for patient engagement initiatives to improve health and health care.

<https://www.pcori.org>: This organization funds research to help patients choose health-care options that best meet their needs. It provides a number of resources to guide patient engagement in research.

https://painconsortium.nih.gov/nih_pain_programs/coepes.html: Patient interviews may be found here.

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AUTHORS

Eloise C J Carr, BSc (Hons), RN, PGCEA, RNT, MSc, PhD
Professor, Faculty of Nursing
University of Calgary
Calgary, Alberta, Canada

Jennifer Stinson, RN-EC, PhD, CPNP
Mary Jo Haddad Nursing Chair in Child Health
Peter Lougheed CIHR New Investigator
Scientist, Child Health Evaluative Sciences
Nurse Practitioner, Chronic Pain Program
The Hospital for Sick Children
Professor, Lawrence S. Bloomberg, Faculty of Nursing, University of Toronto
Peter Gilgan Centre for Research and Learning
Hospital for Sick Children
Toronto, Ontario, Canada

Kathryn Birnie, PhD, CPsych
Postdoctoral Fellow
University of Toronto and Hospital for Sick Children
Peter Gilgan Centre for Research and Learning
Hospital for Sick Children
Toronto, Ontario, Canada

REVIEWERS

Marit Leegaard RN PhD
Associate Professor
Institute of Nursing and Health Promotion
Oslo and Akershus University College
Oslo, Norway

Fran Toye, MA Cantab MSc (PT) PhD
Qualitative Research Lead
Nuffield Orthopaedic Centre
Oxford University Hospitals NHS Foundation Trust
Oxford, England



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