

# How to make health research more relevant to patients and veterans? Make them partners in the research process

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There is growing evidence that involving patients and other health care stakeholders in all aspects of the clinical research process can make

studies and the results they produce more relevant and useful to those who need the evidence to make important care decisions, articles in a new special supplemental issue of the *Journal of General Internal Medicine (JGIM)* suggest.

Papers in the supplement, which was a joint effort by the Patient-Centered Outcomes Research Institute (PCORI) and the Veterans Affairs Health Services Research and Development Service (VA HSR&D), make several things clear about engagement in research. First, they indicate that this approach can help ensure that studies address questions important to patients and stakeholders.

But perhaps more importantly, they suggest engagement is feasible at all stages of the [research process](#), that participants and researchers both see and value the benefits of this approach to themselves and the studies in which they are involved, and that engagement helps to improve the studies' feasibility, relevance and quality.

A critical goal of engaging patients and [veterans](#) in designing, conducting, analyzing and disseminating the results of studies designed to improve their care and outcomes is to see that the findings will be trustworthy and used in day-to-day practice, helping to improve [patient care](#) and outcomes over time. Most recently, the COVID 19 pandemic has emphasized the importance of relevance and trust in [health research](#).

The supplement includes some two dozen research papers, commentaries and editorials, and a series of first-person patient- and patient/researcher-authored narratives—a rarity in any major scientific journal.

"PCORI and the VA HSR&D are committed to the engagement of patients and other stakeholders throughout the research process for the studies they fund," said PCORI Executive Director Nakela L. Cook, M.D., MPH. "We were pleased to work with the VA on this collection of

articles designed to advance our mutual goal of providing health care decision makers—especially patients and caregivers—reliable evidence they can use to make important health and health care decisions."

There is increased academic interest in engagement in health research given how robust, diverse and extensive this approach is becoming, and that research teams are increasingly interested in and motivated to share what they are learning.

[One paper in the supplement](#), by Maureen Maurer, MPH, of the American Institutes for Research and colleagues, deepens our understanding of the benefits of patient and stakeholder engagement in research and the dynamic influence research partnerships can have on key aspects of studies, including their feasibility and acceptability. It also offers some new insights into how this influence happens. And it notes that based on a PubMed review, patient engagement literature citations grew more than 900% from 2000 to 2020. This stems partly from PCORI's establishment and its commitment to engagement as fundamental to all of its work.

In line with these efforts, VA HSR&D in 2015 established a national workgroup to outline an approach to local veteran engagement initiatives and to develop goals for promoting veteran research engagement nationally. That work, described in [an article](#) by Sara J. Knight, Ph.D., of the VA Salt Lake City Healthcare System, led to the development of a unique model for engaging veterans in research to address their concerns and challenges.

Hundreds of research teams have implemented patient and stakeholder engagement as part of PCORI and VA HSR&D funding requirements. The shared emphasis on engagement has also helped fuel the integration of engagement approaches in research funded by others, including the Department of Defense (DOD) and the National Institutes

of Health (NIH).

Several of the narratives included in the supplement are accounts from patients and veterans describing their experiences partnering with researchers, including one by [a veteran with a spinal cord injury](#). Others are [collaborative efforts](#) by patients, veterans and researchers describing shared experiences and lessons learned about how to work together most effectively.

Together, these articles provide a rich overview of how partnering with patients and veterans in health research has evolved over the past decade in terms of both the practice of engagement—what researchers, patients and other stakeholder partners are doing—and the science of engagement—what we know about the real differences that engagement is making in research.

The perspectives and original research articles focus on the lived experience of the participants of engagement and explore barriers and facilitators that can affect how groups not used to partnering can work together.

"We have learned that engagement affects both the conduct of research and the people involved for the better," Cook said. "This is particularly true when seeking to build trust; [engagement](#) can strengthen trust in the research process and increase patients' willingness to participate in research."

**More information:** Susan L. Zickmund et al, Patient and Veteran Engagement in Health Research: the Emergence of a Field of Study, *Journal of General Internal Medicine* (2022). [DOI: 10.1007/s11606-022-07393-9](#)

Articles in the supplement can be accessed free of charge via [this](#)

[collection page](#) on PCORI's website and directly on the [JGIM website](#).

Provided by Patient-Centered Outcomes Research Institute

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