

Department of Clinical Research (DCR)
Patient and public involvement (PPI)

sitem-insel, first floor
Freiburgstrasse 3
3010 Bern, Switzerland

ppi.dcr@unibe.ch
www.dcr.unibe.ch

Call for Proposals for Edited Volume: *Implementing Patient and Public Involvement (PPI): Engaging Patients and the Public in Clinical Research*

Background: Involving People in Clinical Research

Involving patients and the public in health care—although not a new phenomenon—is an area of increasing importance in the field of clinical, patient-centered research. From the early days of modern medicine, people outside health care systems influenced patient care.¹ For example, as AIDS raged in epidemic proportions in 1980s United States, associations fought the Food & Drug Administration (FDA) to speed up approval processes and access to new treatments.^{2–5} Facing protests and pressure from associations, the FDA finally conceded in 1987.⁵ It marked a step forward in the fight against AIDS and an important turning point in the history of medicine—patients were no longer mere spectators; they were now players in the healthcare system. As WHO later noted in 2013, “It [was] time to pay more attention to the demand side—patients, families, communities and society at large.”

In 1996, the United Kingdom’s National Institute for Health Care Research (NIHRS) launched project INVOLVE—a pioneering project promoting and supporting patient and public involvement (PPI) in research.^{6,7} Leading the way, NIHRS inspired many countries by involving patients and the public more and more in research.^{8–12} For example, the U.S. Patient-Centered Outcomes Research Institute¹³ or more recently, the Swiss National Science Foundation mandated PPI for clinical trials.¹⁴

It is only from the development of medicine and specialization that healthcare staff have positioned themselves as connoisseurs, imposing their decisions and giving patients and the public a more passive role.¹ As a result, healthcare systems then became “overly biomedical oriented, disease focused, technology driven and doctor dominated” according to the World Health Organisation (WHO)¹⁵—a transformation visible in healthcare systems, that also impacts the way clinical research is conducted. Today, strong authority gradients on all levels of healthcare exist. Counterbalancing such healthcare systems requires patient voices and the public to achieve better informed, patient-engaged health care.

Volume Scope

In *Implementing Patient and Public Involvement: Engaging Patients and the Public in Clinical Research*, we aim to provide meaningful definitions and overviews of the current state of PPI across the world, including disentangling and defining aspects of PPI occurring before, during, and after PPI activities commence and how they influence clinical research. For example, clinical trials requiring PPI rely on members of the public and individuals with experiences with a disease or condition to provide their feedback on trial endpoints, enrollment, or recruitment materials before studies are funded or commence.

Yet, research involving patients, such as advisements from patient advocates who are members of patient organizations or patient experts, differs from other commonly conflated terms, such as public engagement or involvement and participatory research or community-based participatory research. While the terrain of involving patients and members of the public in clinical research continues to expand and diversify in important ways, definitional and conceptual work help to better understand how these terms conceptually intersect, diverge, and relate.

Volume Questions

Although by now it is becoming clear that patients and the public have important roles to play in clinical research, questions and uncertainties remain. Our volume plans to explore the following questions (and more).

- At what clinical research stages is involvement from patients and the public needed and why?
- What does it mean to involve patients and the public in research before it commences? During? After?
- Who are patients? The public?
- How can we reach patients and public?
- What communication practices best suit patients and the public?
- Should we train patients and public? If so, how?
- What are the limitations of PPI?
- When can PPI be implemented?
- How can PPI be implemented in clinical research?
- What are the benefits and pitfalls of involving patients and the public?
- How does PPI play out in various fields and intersections, such as artificial intelligence and basic research or medical oncology?
- What are the challenges of PPI in low- and middle-income countries?
- What methodological and systems resources can be used to study PPI and its impact?
- What problems can be encountered when involving patients and the public in clinical research?
- What distinguishes PPI from other approaches and methodologies involving people in research generally and/or clinical research, specifically?

We invite scholars to reframe PPI: what it is and what it is not in clinical research by providing clear definitional and conceptual work and distinctions about terms related to it. Whether writers are interested in the design, the recruitment and/or the implementation of PPI in clinical research, the collection is a unique opportunity to explore the boundaries of PPI in clinical research when engaging and involving the public in research in general.

In keeping with the theme of the collection—although academic—it is aimed at a wider audience wishing to understand, implement, or participate in public involvement and engagement in clinical research.

Volume Interest

A major UK-based academic publisher requested a full proposal for the entire volume. However, prior to submitting the full volume proposal, we must bring together other authors—such as yourself—to contribute chapters to the edited volume.

We plan to seek funding for publishing the edited collection as gold open access, which makes it immediately available for all.

Planned Timeline

March 19, 2024	Submit 250-word proposals and 50-word bios (with ORCID) in 1 docx attachment to ppi.dcr@unibe.ch
April 5, 2024	Share decisions with authors about proposals and invite full chapters
July 3, 2024	Submit full chapters for internal review by volume editors and external review
September 1, 2024	Return full chapters with revision guidance from volume editors and external review
October 14, 2024	Submit revised chapters to volume editors
November 1, 2024	Finalize volume; apply for gold open access funding

Our planned timeline anticipates a complete volume ready for production in early 2025 and available ideally via gold open access in spring 2025. Timeline dates are local with submissions no later than 11:59 pm on the same day.

Proposal Content

In your 250-word proposal, please include the following information.

- context/background and outline of the proposed chapter
- question or questions the planned chapter addresses
- 2–3 planned takeaways for readers

Full chapters include about 3,000 words, excluding no more than 15 References, and 2–3 take aways for readers, 3–5 keywords, and 100-word summaries.

We encourage accessible, evocative, rich writing, which uses person-first and identity-first language as appropriate and active voice. We plan to provide more writing guidance later for accepted proposals.

Research staff from the volume's editing team could potentially assist writing chapters as co-authors—kindly advise if you would like to discuss the option, which is available upon proposal acceptance.

Feel free to reach out to the volume editors (ppi.dcr@unibe.ch) with questions or ideas before submitting your proposal. **Volume Editors:** Dr. Kristin Marie Bivens, Dr. David Schwappach, and Dr. Eva Segelov (alphabetical order)



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