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## Participatory Qualitative Research Methodologies in Health: A Review

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## Participatory Qualitative Research Methodologies in Health: A Review

### Abstract

*Participatory Qualitative Research Methodologies in Health* is an edited collection of essays on the methodologies, challenges, and opportunities of participatory research. It provides guidance in designing and executing participatory studies, and thoughtful examinations of the ethical and practical issues of research partnerships, with particular attention to marginalized or vulnerable people.

### Keywords

Participatory Research Methods, Health Research, Research Design

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## ***Participatory Qualitative Research Methodologies in Health: A Review***

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*Participatory Qualitative Research Methodologies in Health is an edited collection of essays on the methodologies, challenges, and opportunities of participatory research. It provides guidance in designing and executing participatory studies, and thoughtful examinations of the ethical and practical issues of research partnerships, with particular attention to marginalized or vulnerable people. Keywords: Participatory Research Methods, Health Research, Research Design*

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*Participatory Qualitative Research Methodologies in Health* (Higgenbottom & Liamputtong, 2015) sounds like a textbook, but delightfully is instead a collection of topical essays with the unifying aim of exploring ways to engage marginalized people in health research. The editors used this approach to create a text in which the reader finds both basic guidance in designing and executing participatory studies, and thoughtful examinations of the ethical and practical issues of research partnerships with marginalized or vulnerable people. Each chapter provides a concise guide to the conceptual, ethical, and logistical realities of executing participatory research methods by study stage or within specific health-related contexts, and provides a bibliography of further reading for those wishing to delve further. Chapters were written by experts hailing primarily from Canada and thus many of the illustrative examples used in the text reflect Canadian populations or health issues. As an American researcher, this turned out to be quite helpful in an unexpected way: the inclusion of examples quite foreign to me only served to underscore the value of methods specifically intended to help outsiders comprehend the perspectives of a group to which they do not belong.

Higgenbottom and Liamputtong co-wrote the introductory chapter outlining the history of participatory research (PR), providing an overview of the principal methodologies, and discussing the most important question: why do it? This question becomes a refrain throughout the book, and is an important consideration in light of the editors' critical observation that PR requires the researcher establish "credible and trusting relationships." Building these relationships can be difficult and time-consuming when people's health or access to health care is at stake. These realities are often at odds with the priorities of health research sponsors who typically want quick results. The authors of other chapters pick up and explore these themes, offering both conceptual guidance and practical advice for addressing and resolving these issues.

The first half of the book is organized essentially as a text book, with chapters addressing the theoretical underpinnings of PR, study design, managing and analyzing data, and drawing conclusions. The remaining chapters focus on a variety of specialized topics, such as PR with youth or older people, or the use of communication technologies in PR. There is also a chapter exploring the relationships between PR, engaged scholarship, and knowledge transfer. These chapters are particularly useful for their explication of how concepts like "respect" and "trust" can encompass quite different territory depending on the people with whom you are engaging. Similarly, researcher bias can be influenced differently by different participant groups. For example, a researcher may exhibit bias when working with youth by changing their natural language into words that are more familiar or palatable

to funders or stakeholder audiences. Most chapters include illustrative case studies that help the reader see how methods play out “in the real world” and provide a set of practical tips for executing PR. In fact, many tips are actually new information not reflected in the text itself.

The chapter devoted to exploring the ethical considerations of PR is particularly near and dear to my heart. It is a topic of critical importance that often receives little attention in health research publications. Institutional Review Board (IRB) approval, the authors note, can be both difficult to obtain and also insufficient for purpose: IRB oversight is based on the assumption that research questions and designs can be fully articulated in advance and that informed consent is best managed through a legal form. In PR, research is co-constructed and emerges from the relationships that are built over time. Obtaining and, more importantly, maintaining informed consent is of paramount importance because it serves as the foundation of the trusting relationship that permits high quality research. The ethics chapter may be of particular value to those who need to educate their IRB about how informed consent works in PR, but also serves as an important reminder of the key considerations to maintaining meaningful consent throughout a research project.

For me, the weak link in the book is the chapter on drawing conclusions from your work. This chapter wanders from giving rather broad and vague advice—for example, that researchers should have a clear audit trail, without clarifying what that might actually look like—to oddly specific information about dissemination channels for particular audiences. This weakness may result from the fact that drawing conclusions in PR is not inherently all that different from drawing conclusions from any other research. But, it might have been helpful if the authors had focused on the specific challenges of working within participatory partnerships to develop conclusions and implications, rather than on the mundane aspects of documentation and dissemination.

I do not often get to do true participatory research and, funnily enough, found this book helpful in understanding why the people for whom I do research generally resist the idea. Not only is PR time-consuming and challenging, it carries a high burden of risk that the research will go in directions that suit the participants but not the funder. Health research is typically aimed at finding out “what works,” usually so that you can make actionable recommendations about what health care providers or patients, and sometimes policy makers, should or should not do. Its focus is the production of *evidence*. PR steps beyond evidence production and is fundamentally a *knowledge* construction paradigm. As the examples throughout the book tend to illustrate, PR may be better suited to exploring why and how different groups of people adopt or resist medical evidence, how they navigate the health system, and how they form or avoid relationships with each other during the health decision making process. These topics are not unheard of in health, but they are still unusual. During the last ten years, however, health care researchers and providers alike have placed increased emphasis on engaging patients, family members, and other stakeholders in both research and care itself. For example, the Patient Centered Outcomes Research Institute (PCORI), established in 2010, requires that its awardees collaborate with patients and other stakeholders in the development and execution of studies. PCORI does not, however, provide a tremendous amount of practical advice on how to go about successfully achieving that goal. With its well-balanced overview of the major issues in PR and its practical guidance, this book could also serve as a useful guide for figuring out effective ways to engage meaningfully with various partners within the context of more traditional research methodologies.

### References

Higgenbottom, G., & Liamputtong, P. (Eds.). (2016). *Participatory qualitative research methodologies in health*. Los Angeles, CA: Sage.

### Author Note

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