Accepted: 4 June 2018

SPECIAL ARTICLE

WILEY

Participatory research—A modernizing science for primary health care

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Abstract

Participatory research is the science of partnerships underlying research, concerned with research governance, ownership of research products, and relationships behind research objectives and methods. The common strand behind the quite different schools of participatory research is that research should be in respectful partnership with people; it is not about researchers working on, for, or about people. Modern participatory research embraces different philosophies through several applications. The first application addresses research objectives, with participation at different points in the research cycle. Second, modern participatory research is relevant in adaptive management, including management of primary health care. Third, participatory research is a tool for patient engagement and patient-centered outcomes in the clinical context. A fourth application is participatory research as an intervention: Participatory research moves people, and it mobilizes resources and can thus be pivotal to sustainability and for health-promoting intersectoral linkages. As primary health care is a family medicine responsibility, participatory research offers family medicine a valuable toolbox complementing the accepted clinical toolboxes. Through shared identification of problems and decisions about solutions, participatory research increases participant capacity to identify and address their own issues. Among clinicians, it enhances professional practices. In the bigger social picture, all this promotes social justice, self-determination, and knowledge utilization.

KEYWORDS

decision making, family practice, health services research, patient advocacy, patient participation, physician-patient relations, primary health care, program evaluation, qualitative research, quality improvement, translational medical research

1 | THE SCIENCE OF RESEARCH PARTNERSHIPS

If there is uncertainty about quite what participatory research is science, discipline, philosophy, objective, method, or branded research procedure—there should be little doubt about what it is not. Responding to a questionnaire is not participatory research. Taking part in a focus group is not participatory research and nor is serving as a key informant in a semistructured interview. These examples of participation *in* research are methods that can be used in participatory research and that are also useful in highly conventional investigator-led research that treats participants as objects.

Participatory research is more than a method, more than an objective, and much more than a branded research procedure like

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Participatory Action Research or Community-based Participatory Research; it is a science and a discipline of knowledge creation and use. More specifically, participatory research is the science of partnerships underlying research, concerned with research governance, ownership of research products, and relationships *behind* research objectives and methods.¹

As a science, modern participatory research has objectives—and consequently the methods to meet objectives—that vary, just as they do in other sciences like epidemiology or sociology or anthropology.

As a discipline or set of methods, modern participatory research is concerned with systematic cocreation of new knowledge by equitable partnerships between researchers and those affected by the issue under study, or those who will benefit from or act on its results.^{2,3} Related disciplines, methods, branded procedures, and terminology include "Community-Based Participatory Research, Participatory Rural Appraisal, empowerment evaluation, Participatory Action Research, community-partnered participatory research, cooperative inquiry, dialectical inquiry, appreciative inquiry, decolonizing methodologies, participatory or democratic evaluation, social reconnaissance, emancipatory research, and forms of action research embracing a participatory philosophy".⁴

There are several common assertions and preoccupations about participatory research that merit discussion to draw out the essence of the science. Some point out that participant views might challenge or inappropriately controvert accumulated scientific evidence from conventional sources. Some see it as a variant of qualitative research. Some practitioners see participatory research as necessarily small scale. And, in one view, it is not truly participatory research if participants do not set the research question, design and do the research, and own the results and the interpretations.

I do not believe any one of these assertions is true for modern participatory research, and I do believe discussion of the preoccupations can help to characterize the science more accurately and to understand its boundaries.

2 | DOES IT CONTRADICT EVIDENCE-BASED MEDICINE?

In an age of evidence-based medicine and evidence-based public health, what is the role of participatory research?

The weigh-up of local experiential knowledge with existing knowledge from conventional scientific research (perhaps a metaanalysis of published studies) depends on the mindset of the researcher or family doctor. The professional modesty implicit in evidence-based medicine (we do not know because we are superior, we know because we have evidence) could be extended easily to other kinds of evidence generated by interaction with stakeholders. It is possible to take an extreme position, of course, ignoring published evidence in the face of local experience, or vice versa. But treating participatory research as a *science* implies there is a discipline and there are methods to collate and build on accumulating knowledge from different sources. Participatory research proposes an alternative to two-stage knowledge translation where a researcher passes research products to a knowledge user who acts on the evidence. Participatory research *integrates* knowledge translation and exchange by engaging the end users who would ordinarily take up the evidence for action, throughout key stages of the research.⁵ In this integrated knowledge translation, dialogue about evidence is the immediate tool for rational persuasion^{6,7} and thus for motivated evidence-based action. Just as people tend to be more open to evidence when they see its subject as something that affects their lives, their responsiveness increases when they see the consequence of their own actions.

Viewed this way, far from increasing the potential tension between existing scientific evidence and local experience, participatory research provides a framework for collating and contextualizing knowledges.¹⁰ In fact, one participatory method called Weight of Evidence¹¹ uses Bayesian updating to combine existing scientific knowledge from systematic reviews with local lived experience of stakeholders—healthcare providers and patients. The combined knowledges, in effect a highly contextualized and digested appreciation of published evidence, are much more likely to be locally relevant and actionable.

In summary, there is no contradiction between evidence-based medicine and participatory research. Participatory research offers a powerful vehicle for contextualizing evidence from multiple sources, adapting it for local conditions.

3 | THE TRADITIONS INSPIRING PARTICIPATORY RESEARCH

While very different traditions underlie the lexicon of participatory research and branded research procedures that apply to it, most imply the systematic cocreation of new knowledge with people affected or those who will benefit from or act on it.¹² Our understanding builds on four distinct scientific traditions:

The "northern tradition," building on the pioneering work of Lewin¹³ and the Tavistock Institute, is often utilitarian—to achieve something specific, like diabetes prevention—and focussed on objectives set by researchers (though these might be shared by other stakeholders). This approach has received a massive boost in the last decade, through evidence-based management¹⁴ and patient-oriented outcomes.¹⁵ The widely recognized branded research procedures, like Community-Based Participatory Research (CBPR),^{16,17} cooperative inquiry,¹⁸ appreciative inquiry,¹⁹ and Participatory Rural Appraisal,²⁰ are heavily informed by this northern tradition.

A "southern" or conscientizing educational tradition, advanced in Latin America by Freire^{21,22} and Fals Borda,²³ centers on participant authorship with transformative learning. In contrast to the utilitarian motivation of the northern tradition, the southern tradition is about how participating in fact-finding and generating solutions empowers and changes the participants. Branded research procedures like Empowerment Evaluation,²⁴ Participatory Action Research,^{25,26}

Community-Partnered Participatory Research,²⁷ and also dialectical inquiry,²⁸ decolonizing methodologies,^{29,30} participatory or democratic evaluation³¹ have roots in this tradition.

In addition to these prominent traditions, both of which are well recognized in the participatory measurement sciences, two other influences inform my own participatory research practice and teaching.

The Italian labor movement's alternative operaia or workers' model³² has lessons about ownership of research tools and products. In this approach, measurement specialists are political allies who help stakeholders (the trade unions) gain competence in using the tools of measurement and assessment. This has important implications. First, skilled researchers do not come to the table with nothing; they bring much-needed research skills and their own experience. Second, the participant skill level in epidemiological methods might start off at a rudimentary level but it is not fixed at zero forever; participants are alive and interested, and their skill sets can evolve with time and training. Third, the value of experience and the methods for collating it have no assumed primacy over "statistics." If the argument needs numbers and statistics, the task is to provide these through allied researchers skilled in epidemiology and statistics. If the issue calls for narrative and experiential accounts, the task is to provide these with appropriate qualitative techniques. The ownership and governance remain clear, with workers pivoting from being objects of research to research protagonists, and that's what makes it participatory research.

The key message is that method is a function of the research *objective*, not of the ownership and governance of the research. Participatory research can be qualitative and it can be quantitative, depending on the objectives. What makes it participatory research is not the research method, but the ownership and governance framework.

The fourth influence is a set of theories that help to understand how research does not happen in a vacuum, but in social contexts that define and are defined by relationships. Postcolonial theory, critical theory, and intersectional feminist theory all have implications for the texture and detail of partnerships, the power relations between researchers and participants, how researchers see themselves, behave, and grapple with issues of power, and how they in turn are seen and engaged by their partners. Modern participatory research has a special concern for grappling with issues of cultural safety and intercultural dialogue^{33,34} which, in conventional research, are at best a meta-level ethical concern of researchers.

There will undoubtedly be many other influences across the wide community of participatory research practice. The common strand behind nearly all influences is that research should be in respectful partnership with people; it is not about researchers working *on*, *for*, or *about* people.

4 | APPLICATIONS OF PARTICIPATORY RESEARCH IN PRIMARY HEALTH CARE

Participatory research is an umbrella term for a wide range of partnered research.³⁵ Embracing this diverse background, modern participatory research can be small-scale, involving a single patient group or segment of a single community; it can be multicentered, national, or international in scope. It can involve qualitative research, mixed methods, or multinational community-led randomized control trials. It can be utilitarian, a way to push an agenda, and it can be liberating and empowering.

Modern participatory research embraces these different objectives and philosophies through several areas of application.

The first application addresses research objectives. Participatory methods can improve many research questions and thus help to set the research design.³⁶ Meeting contemporary research objectives typically calls for mixed methods (combining qualitative and quantitative techniques), with participation at different points in the research cycle. Much research addresses complex problems, with a high degree of customization of complex interventions. Hawe and colleagues argue that the function and process (the protocol) of a complex intervention should be standardized, rather than the components or steps of the intervention, thus allowing tailoring of the form to local conditions.³⁷ This is the work of participatory research. Modern participatory research does not propose participation as the method, but it offers a partnership and governance framework for appropriately tooled moments-quantitative methods where appropriate and qualitative methods where appropriate-in the research cycle.³⁸ This is especially important in intercultural research, where the way researchers acquire knowledge may be as critical for eliminating health disparities.³⁹

Second, modern participatory research is highly relevant in adaptive management, including management of primary health care. The issue here is that national-level programs and norms are designed to fit the average setting; on either side of that average, adaptation is necessary. There are also very few programs that work equally from their initiation to their conclusion; they need to be fine-tuned to keep fitting. And even when the programs and norms do fit a given setting, there will be outliers and marginal groups in that setting for whom the program must be adapted. Conventionally, these are within the domain of improvement science and quality improvement, but modern participatory research offers an alternative framework and methods for local experience to meet collated scientific experience. This is relevant to the management of primary health care and to provincial and national health programs.

Third, participatory research is a lens for patient engagement and patient-centered outcomes in the clinical context.⁴⁰ A concern here is the replacement of authentic patient engagement by rent-a-patient schemes, token inclusion of patient advocates, and professional patient representatives who add "the patient voice".⁴¹ Viewing patient engagement and patient-centered outcomes through a participatory research lens brings authenticity of the partnership into focus. Participatory research methods make space for genuine patient authorship and contrast with approaches where the patient is co-opted into a conventional executive boardroom. In the context of conventional executive management and the unidirectional and exquisitely unequal doctor-patient relationship, patient representation is only one small step into issues in fully informed patient engagement. Several influential authors have drawn attention to the need for evolution of patient engagement along a spectrum,^{42,43} and modern participatory research offers a scientific framework for that to happen.

A fourth application of participatory research is as an intervention. Whether the objectives are those of research, system management, or clinical, the common denominator is that participatory research moves people. It mobilizes resources for health objectives and can thus be pivotal to program sustainability and for forging health-promoting intersectoral linkages like environment, education, and employment. Management of informed engagement and the mobilizing dynamic of participatory research is the focus of community-led randomized controlled trials⁴⁴; participatory research is part of the modern battery of scientific tools.

If primary health care is a family medicine responsibility, participatory research offers family medicine a valuable science and toolbox complementing the accepted clinical toolboxes.

Primary health care involves a range of complex interventions bridging clinical, psychological, and social dimensions. Some interventions address behavior change, and others address disease processes—but all can be difficult to replicate from setting to setting.⁴⁵ The approach to dealing with this highly local character, improving and expanding primary care, can come from an institutional (system) or participant perspective. Institutional perspectives⁴⁶ assume that improvement can be based on detailed centrally designed manuals or norms for replicating interventions.

In family practice and at the community level, there are gaps between national and provincial norms for program delivery and the local needs or ways of seeing things in everyday primary health care practice. National and provincial programs are designed for "average" people in mainstream settings, and adaptation to other settings requires method and rigor. Participatory research informs managerial strategies to close the gaps, to find the fit between national or provincial programs and the local skill base and local needs. This is relevant across the board, in nearly all primary health care practices, but especially so in rural and remote areas, and in primary health care involving the indigenous peoples and economically marginalized who contribute disproportionately to morbidity and mortality.

Not incidentally, family doctors and their teams are particularly well placed for participatory research because they usually have good local partnerships, trust, and understanding with patients, community organizations in their practice area, and local policy makers.⁴⁷

5 | ETHICS IN PARTICIPATORY RESEARCH

Participatory research approaches can add value to informed consent, community review and approval of research, improve recruitment, disclosure and comprehension.^{48,49} These aspects can only increase the quality of research and increase its impact as end users are brought on board early in the process. Particularly stringent in randomized controlled trials where informed consent is a central concern,⁵⁰ ethical codes play out very differently in conventional researcher-led and in participatory research—where stakeholders essentially choose what they want to do.⁵¹ In participatory research, there are seldom concerns about placebos and issues of withholding interventions in controls⁵² can be settled by randomizing the delay among all eligible participants, as in a stepped wedge design.

There are residual ethical problems. For example, some individuals might disagree with or feel put upon by decisions made by a group in a participatory research context or the subsequent action. The challenge for the outside researcher is to demonstrate respect for participant and community autonomy when, in cases like this, the locus of research shifts from the individual to community or group level.⁵³ Another issue is that of confidentiality, especially in participatory research addressing sensitive themes like mental health or gender violence. In this setting, the external researcher can add value through data stewardship, holding, and anonymizing participants' data.

6 | CONCLUSION

Participatory research has three core dynamics: engagement in governance and co-ownership of the research, the primacy of local evidence or experience, and innovation by participants (Figure 1). As we start to understand the dynamics within this evolving science, participatory and nonparticipatory methods stand out as responses to objectives, which are in turn responses to the ownership and governance of the research. Modern participatory research *can* use quantitative methods, even randomized controlled trials, and qualitative methods are not by definition participatory. So, a first step in modernizing participatory research sets a hierarchy of concepts and processes—what is the science, what are objectives, what are methods, and what is no more than the branding of procedures with participation terminology.

A second and related step in modernization recognizes that *scale* is not at all part of the definition or character of the science. An action research project might address an issue in a single community or segment of a community, but a much larger domain—a district, province, country, or several countries—can also implement a participatory research protocol.



Three components of authentic participatory research

FIGURE 1 Three defining dynamics of authentic participatory research

While participation *is* intensely local, it can happen in more than one place.

How participatory research gets the job done is a third modernization. A conventional research to action dynamic involves knowledge translation from the researchers, who bundle their results for easier understanding, and transmit the bundle to users who interpret and then implement the results. Modern participatory research engages the users from the beginning, largely eliminating the need to "translate" findings for users.

There may be a perceived tension between participatory research and conventional research, or concerns about giving primacy to the views of participants over existing evidence. I believe these are better viewed as terms of reference than as irreconcilable differences. These are the issues that modern participatory research must resolve (and is resolving).

The big-ticket item in modernization is ownership. If participation *in* research leaves people in no greater control of the research or its products, the counterpoint is participatory research—initiatives *with* the users or intended beneficiaries—which should eventually leave people in greater control. The time dimension here (eventually) is not trivial. Participation is not an on/off light switch, but a dimension of and process in governance. And governance is a way of doing things that leads to different results, not a full and final outcome in its own right.

Transformation *through* research is the outcome and modernization that matters. Through shared conceptualization of problems and decision making about solutions, participatory research increases participants' capacity to identify and address their own issues.⁵⁴ It increases decision maker and service provider ability to mobilize resources and to improve policies.⁵⁵ Among clinicians, it enhances professional practices.⁵⁶ In the bigger social picture, all this promotes social justice, self-determination, and knowledge utilization.

ACKNOWLEDGEMENTS

The author is grateful for the comments received on this from the 2016 and 2017 PhD classes in the Department of Family Medicine, McGill University.

CONFLICT OF INTEREST

The authors have stated explicitly that there are no conflicts of interest in connection with this article.

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How to cite this article: Andersson N. Participatory research—A modernizing science for primary health care. *J Gen Fam Med*. 2018;19:154–159. https://doi.org/10.1002/jgf2.187