

Review Article

Participatory Research and Family Medicine

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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. By integrating knowledge translation into the research, participatory research proposes an alternative to the view of knowledge translation as a multi-stage process where a researcher might pass on research products to a different entity that shares the information for action, and from there to a third entity that acts on it. 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 objectives and philosophies through several areas of application. The first application addresses research objectives, typically calling for mixed methods (combining qualitative and quantitative techniques), with participation at different points in the research cycle. Second, modern participatory research is highly relevant in adaptive management, including management of primary health care. Third, participatory research is a lens for patient engagement and patient-centered outcomes in the clinical context. A fourth application of participatory research is as an intervention: participatory research moves people. It mobilizes resources for health objectives, and can thus be pivotal to program sustainability and for forging health-promoting inter-sectoral linkages like environment, education and employment.

If primary health care is a family medicine responsibility, participatory research offers family medicine a valuable science and toolbox complementing the accepted clinical toolboxes. Through shared conceptualization of problems and decision making about solutions, participatory research increases participants' capacity to identify and address their own issues. It increases decision-maker and service provider ability to mobilize resources and to improve policies. 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; Program Evaluation; Primary Health Care; Patient Participation; Physician-Patient Relations; Quality Improvement; Qualitative Research; Translational Medical Research

Is it a Bird, is it a Plane?

Participatory research is more than an objective, more than a method and much more than a branded research procedure like Participatory Action 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 co-creation 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, emancipator research, and

forms of action research embracing a participatory philosophy” [4]. If there is uncertainty about quite what participatory research is - science, discipline, philosophy, objective, method or branded research procedure –there is 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 semi structured interview. These examples of participation in research are methods that can be used in participatory research, but that are also useful in highly conventional investigator-led research that treats participants as objects.

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

Controvertaccumulatedscientificevidencefromconventional 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 don’t 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 and to understand its boundaries.

Participatory Research and Evidence-Based Medicine

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

The weigh-up of local experiential knowledge with existing knowledge from conventional scientific research (perhaps a meta-analysis of published studies) depends on the mindset of the researcher or family medicine practitioner. Extremes are possible-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 methods to collate and to make more of the accumulating knowledge from both sources. A new approach known as Weight of Evidence, for example, takes systematic and formal account of stakeholder views of the issues dealt with in a meta-analysis [5].

Participatory research proposes an alternative to the view of knowledge translation as a multi-stage process where a researcher might pass on research products to a different entity that shares the information for action, and from there to a third entity that acts on it. Participatory research integrates knowledge Translation and Exchange (iKTE) by implicating appropriate end-user partners, those who would ordinarily share the evidence for action, or act on it themselves, throughout key stages of the research [6]. In integrated knowledge translation, co-creation of evidence is the immediate

tool for rational persuasion [7,8], and thus for motivated 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 experience this evidence as actionable [9,10], and more so when they see the consequence of their action. Viewed this way, far from increasing the potential tension between existing scientific evidence and local experience, participatory research provides a framework for collating knowledge’s: through participatory methods like Weight of Evidence [3], it is possible to combine existing scientific knowledge with local experience. The combined knowledge, in effect a highly contextualized and digested appreciation of published evidence, is much more likely to be locally relevant and actionable.

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 co-creation of new knowledge with people affected or those who will benefit from or act on it [11]. Our understanding builds on four distinct scientific traditions: The “northern tradition”, building on the pioneering work of Kurt Lewin [12]. 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 management [13]. and patient-oriented outcomes [14]. The widely recognized branded research procedures, like Community-Based Participatory Research (CBPR) [15,16], cooperative inquiry [17], appreciative inquiry [18], and Participatory Rural Appraisal [19] are heavily informed by this northern tradition.

A “southern” or conscientizing educational tradition, advanced in Latin America by Paulo Freire [20,21] and Orlando Fals Board [22], centres 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 [23], Participatory Action Research [24,25], Community-Partnered Participatory Research [26], and also dialectical inquiry [27], decolonizing methodologies [28,29], participatoryordemocratievaluation[30]haverootsinthistradition.

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 labour movement’s alternative operaia or workers’ model [31] 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 has 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 key lesson is that method is a function of the research objective, not of the ownership and governance of the research – which is the domain of participatory 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. Post-colonial 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 [32,33] which, in conventional research, are at best a meta-level ethical concern of researchers. The common strand behind all four influences is that research should be in respectful partnership with people; it is not about researchers working on, for or about people.

Applications of Participatory Research in Family Medicine

Participatory research is an umbrella term for a wide range of partnered research [34]. 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 multi-centred, national or international in scope. It can involve qualitative research, mixed methods or multi-national community-led randomised 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 (Table 1).

	Dynamic involved	Methods
Research objectives	Participatory research is a governance framework	Range of mixed methods research
Adaptive management	Local contextualisation and adaptation especially for marginalised groups	Participatory quality improvement and implementation research
Patient engagement	Spectrum from token consultation to co-management	Deliberative dialogue based on clinical records; patient groups
As an intervention	People get involved and convinced; engagement is transformational	Typically starts off with deliberative process, discussing evidence; action planning

Table 1: Applications of participatory research in family medicine and primary health care.

The first application addresses research objectives. 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 [35]. This is the work of participatory research. Modern participatory research does not propose participation as the only 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. 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 family medicine and to

provincial and national health programs.

Third, participatory research is a lens for patient engagement and patient-centred outcomes in the clinical context [36]. 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” [37]. 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 [38,39], 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 inter-sectoral linkages like environment, education and employment. Management of informed engagement and the mobilising dynamic of participatory research is the focus of community-led randomised controlled trials [40]; 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 changes and others address disease processes - but all can be difficult to replicate from setting to setting [41]. The approach to dealing with this highly local character, improving and expanding primary care, can come from an institutional (system) or participant perspective. Institutional perspectives [42] 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 family medicine 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 family medicine 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 [43].

Conclusion

As we start to understand the dynamics within this evolving science, participatory and non-participatory 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 objectives are, what methods are, 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 implement a participatory research protocol. 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. The perceived tension between participatory research and conventional research, concerns about giving primacy to the views of participants over existing evidence are, I believe, 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 [44]. It increases decision-maker and service provider ability to mobilize resources and to improve policies [45]. Among clinicians it enhances professional practices [46]. In the bigger social picture; all this promotes social justice, self-determination and knowledge utilisation.

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