Theorizing Participatory Research

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Abstract

A wide variety of scientific research projects include public participation in roles going beyond the classic use of subjects in human subjects research. "Participatory research" is an umbrella term for such projects. In this chapter, we begin by surveying the variety of participatory research approaches across fields. We examine what goals participatory research projects seek to achieve, both of social and scientific value. Next, we apply this theoretical framework to challenges that participatory research faces. We then survey three typologies of participatory research projects, each of which can illuminate and guide decisions in project development. We end with a look at participatory research approaches in health contexts, applying the theoretical resources we introduced earlier in the chapter.

1. Introduction

Scientific research involving public participation is nothing new. Participatory research about the environment and living world was conducted as early as the 1880s. These projects mostly consisted of the public collecting data on birds and the weather (Bonney et al. 2009). In the 1960s and 1970s, participatory research on butterflies was conducted in the UK, and on spiderwort flowers near nuclear reactors in Japan (Kimura and Kinchy 2019). Another early example of participatory research of this form is the long-running work of the Cornell Lab of Ornithology, in which members of the public help to collect data on bird breeding habits, courtship behaviors, habitats, color morphs, and more (Bonney et al. 2009; Eitzel et al. 2017). Kimura and Kinchy (2019) highlight several more recent projects, ranging from studies on the impact of fracking on communities in Pennsylvania and New York to the detection of radiation in Japan to the monitoring of genetically engineered crops in Mexico.

Some trace the beginning of participatory research back to Kurt Lewin's "action research" and the associated "participatory action research." This early version of participatory research was connected to social activism and "undertaken with or by—not *on* or *for*—society's marginalized peoples" (Macaulay 2017, 256). This tradition is also tied to Paulo Freire's theories and his influential work, *Pedagogy of the Oppressed* (1970). Other terms for participatory research include citizen science, community-based participatory research, community science, and critical participatory action research. Different terminology is associated with different scientific disciplines and, often, different forms of public participation. Participatory research ranges from large-scale ecology monitoring programs, to localized studies of health outcomes carried out with community leadership, to research designed from the ground up with community-identified social change as the outcome. See Vaughn et al. (2020) for a fuller discussion of the

variety of terminology and participatory practices. We follow Dunlap et al. (2021) and use the term "participatory research," or PR, as an umbrella term for any scientific research involving public participation.

The purpose of this chapter is to survey theoretical resources for conceptualizing and designing participatory research projects. In section 2, we introduce two competing formulations of the goal of PR: *social change* and *knowledge gathering*. We then consider subtler questions about why scientists conduct participatory research and why community members participate, as well as the value of such research. In section 3, we apply this theoretical framework to challenges that participatory research faces and provide some guiding questions for the development, implementation, and analysis of participatory research projects. In section 4, we consider different typologies of participatory research. One typology categorizes projects by level of community member involvement (Shirk et al. 2012), while others take virtues of participation into account (Kimura and Kinchy 2016; Dunlap et al. 2021). In section 5, we explore how these theoretical resources apply to participatory research occurring in health contexts. PR approaches are perhaps particularly promising in health research, given the research focus on human subjects and the relevance of the research to stakeholder concerns.

2. What's the Point of Participatory Research?

One helpful approach to gaining perspective on participatory research emerges from the question of what goal or goals are furthered by including the public in the research process. Because PR occurs in a variety of research contexts, focused on different phenomena with different aims of prediction, explanation, or action, there is reason to think its goals may vary with some of these differences.

Cooper and Lewenstein (2016) and Eitzel et al. (2017) introduce a helpful way to characterize two distinct strands of participatory research: one focused on *social change* and the other focused on *knowledge gathering*. The first strand primarily comes from the work of Alan Irwin (1995). This approach sees participatory research as a form of democratic participation and an effort towards systemic change. As Irwin (1995) puts it, "We now have 'science for the people'; in other words, the various attempts (both practical and theoretical) to place technical expertise at the direct service of people" (5).

The PR examples mentioned above on fracking, radiation, and genetically engineered crops, drawn from Kimura and Kinchy (2019) were all spurred by concerned community members and designed to serve the interests of the community. Therefore, these are examples of PR as social change. For example, in 2012 communities in Pennsylvania and New York began monitoring their own water quality in response to fracking in the area. Water monitoring groups were created that forged partnerships with academic researchers and professional scientists. This research had an impact, spurring agencies to take action on water quality (Kimura and Kinchy 2019). The purpose of this effort was not only to gather knowledge but also to protect the health and safety of community members. We can also understand action research and

participatory action research to be in the tradition of PR as social change. These forms of research put primary emphasis on the role of the community members pushing for reform.

The second strand characterizes the value of participatory research as consisting in the ability to collect large swathes of data. This is exemplified by the approach of Rick Bonney and colleagues at the Cornell Lab of Ornithology (2009). For years, the lab has recruited public participants to assist scientists in answering research questions about birds resulting in data about bird distribution patterns, how the environment impacts breeding, how infectious diseases spread in animal populations, and how acid rain affects birds. In addition to data collection, the lab aims to educate the public on birds—pursing both "scientific and educational outcomes" (Bonney et al. 2019, 978). Despite this commitment to educating the public, a major goal of the lab is clearly to harness the power of public participation to gather more data than would be possible in a traditional study:

> Studying large-scale patterns in nature requires a vast amount of data to be collected across an array of locations and habitations over spans of years or even decades. One way to obtain such data is through citizen science, a research technique that enlists the public in gathering scientific information. (Bonney et al. 2009, 977)

These two different orientations to public participation in scientific research—social change vs. knowledge gathering—result in different features and standards for success. Ottinger (2017) also emphasizes the distinction between these two orientations and points out how the locus of authority differs between them. Whereas the goal of knowledge gathering motivates the preservation of authority for scientists, the goal of social change motivates disrupting traditional authority structures and empowers the included members of the public to lead, in a way that generates both social and scientific change. Ottinger stresses the risk that the more conservative knowledge gathering approach will divert resources and attention from the more radical approach that can change both science and society.

We also see a difference between the two strands of PR in which perspectives they emphasize. Members of the public participating in PR can be expected to have different intentions, aims, and agendas than the scientists pursuing PR (cf. Dunlap et al. 2021). Projects that pursue social change will benefit from taking on board perspectives of the participating public in order to achieve community goals. PR projects aimed at knowledge gathering, in contrast, are more often scientist-driven, since knowledge gathering is central to the aim of traditional scientific research. That said, it is possible for PR with the goal of social change to nonetheless preserve scientists' authority and prioritize their perspectives and, conversely, PR with the goal of knowledge gathering to take seriously the participating public's priorities.

Finally, note that these two PR goals of social change and knowledge gathering are not mutually exclusive and may not be at odds. It is possible for projects to both further the scientific aim of generating knowledge and contribute to social change—indeed, sometimes pursuing certain types of scientific knowledge furthers a social agenda. As mentioned above, the efforts in New York and Pennsylvania to study the impact of fracking were both to obtain data about water

quality and pressure the government to improve water quality. Nonetheless, in our view, it is helpful to think of participatory research in terms of these two strands of social change and knowledge gathering identified by Cooper and Lewenstein (2016) and Eitzel et al. (2017). As we have discussed, these strands relate to distinct traditions of PR, are associated with different priorities, and may impact the power dynamics of the collaboration between researchers and participants.

Let's now take a closer look at participatory research's specific purposes and how those might relate to one another. As one might imagine, the recognized purposes of participatory research vary across disciplines and research traditions, as reflected in the terminological variety we've already noted. Citizen science expands scientific projects by leveraging the power of citizens; community-based participatory research leverages the participation of community members for the good of those communities; action research aims at practical, often sociopolitical, goals. Finer delineations of types of purposes within these traditions can help identify different kinds of values produced by participatory approaches, as well as challenges posed by conflicting agendas among researchers, participants, or the combination of the two.

Returning to PR as social change and PR as knowledge gathering, we can see that the former is *sociopolitical* in nature, while the latter is *epistemic*. Dunlap et al. (2021) similarly distinguish between epistemic, practical, and ethical goals of participatory research. Their category of ethical goals is similar to what we have termed sociopolitical goals, while practical goals is a helpful third category. Dunlap et al. also point out that the same features of PR might satisfy multiple different goals. Increasing scientific data, for example, is a way that PR serves a common epistemic goal but might also promote the practical goal of increasing the chance of publication, and this increase in data might also serve the ethical or sociopolitical goal of, say, improving health outcomes.

We think it is useful to further break down the category of sociopolitical or ethical goals, as this lumps together types of goals that are importantly different. These goals can be *political* in nature, that is, goals that are politically valanced given current societal norms. These might be perceived as politically partisan and be controversial, such as the goal of ending fracking. *Societal* goals, in contrast, are broad social goals that are widely shared, such as improving health or educational outcomes. Finally, *communal* goals are sociopolitical or ethical goals that benefit some particular, often local, community. An example of a communal goal for PR is improving the water quality in Flint, Michigan. We summarize these categories of potential goals participatory research might aim to advance in Table 1.

Categories of PR Goals	Description of Goals
Epistemic	Goals that further knowledge, such as improving research questions, increasing data, and improving accuracy of findings.

Practical	Goals that improve an individual's life, or practice of life. For example, publication success, educational enrichment, or being a part of a research community.
Communal	Goals of a specific (often local) community as defined by community stakeholders, such as improved water quality in a particular city or improved healthcare access for transgender adults.
Societal	Broad social goals that are widely shared, such as improving health or educational outcomes.
Political	Goals that are politically valanced or the priority of which is disputed, such as ending fracking or decreasing reliance on coal and oil.

Table 1: Based in part on the discussions of Cooper and Lewenstein (2016), Eitzel et al. (2017), and Dunlap et al. (2021), we propose these five categories of goals participatory research may aim to advance.

We have suggested that a given participatory research project can simultaneously pursue different types of goals, and the same features of PR projects might advance multiple goals of different types. It's also possible, or even likely, that different stakeholders in a PR project—especially researchers and participants—will prioritize different types of goals (Dunlap et al. 2021). The setting of goals and prioritization among them reflects one's perspective—the values possessed by an individual or community. Dunlap et al. (2021) call this the "perspectival nature of values" (286). We have already encountered the significance of perspective for goal setting when discussing how the influence of the participating public can improve participatory research's ability to promote social change. Members of the public motivated to participate in scientific research are often motivated by communal, societal, or political goals. We can also see divergence in terms of practical goals. Scientists involved in PR are likely to have, as a practical goal, publication of their research. In contrast, public participants are more likely to value other forms of recognition, such as their contribution publicized on the project website, practical impacts of the research, or their own personal enrichment by contributing to the scientific process. There can be divergence within or between any category of goals, and different stakeholders often have different goals.

Nonetheless, we can't draw sweeping conclusions about types of goals pursued by scientists vs. public participants. While it may be that scientists often have epistemic and practical goals for their research, this need not be the case. A scientist may aim to affect social change with their research, and a public participant may genuinely want to contribute to knowledge gathering. Researchers and public participants may share a goal that benefits society at large. The point is simply that the goals of any PR project depend on who is involved—not just researchers, but public participants as well. As Dunlap et al. (2021) put the point, "What counts as a virtue and how important it is compared to other virtues depends on who is evaluating it and what their larger goals and values are" (287).

3. Addressing the Challenges of Participatory Research

Articulating categories of PR goals and how these can vary with perspective clarifies concerns that have been raised about PR. A standard objection is that PR is too tainted by advocacy (Elliott and Rosenberg 2019; Kimura and Kinchy 2019). This criticism expresses skepticism about the political goals of PR from a perspective that privileges epistemic goals. The categorization of PR goals we've introduced makes it possible to replace this objection with more helpful specific questions about individual PR projects: What, if any, is the project's political goal, and does pursuit of that goal improperly impinge on the epistemic attributes of the research? For example, a project on the impacts of climate change run by activists clearly has a political goal and may be criticized for being epistemically biased. Would a different goal (say, societal or practical) lead to a different research approach, and if so, what benefits and drawbacks would there be to that alternative approach? Another criticism of PR is that it results in volunteers doing research that should be the government's responsibility, shifting responsibility for health and safety onto the community itself (Kimura and Kinchy, 2019). This challenge indicates that two societal goals can be at odds: government accountability vs. public knowledge of water quality.

A related but distinct concern sometimes raised about PR, especially when the inclusion of the participating public is limited to data collection, is that the quality of data is lower than it would have been if professional scientists had collected it. Kovaka (2021) points out that, in a survey by Burgess et al. (2017), many scientists cited this as a concern with PR—that the data wouldn't be of high enough quality for their research projects. Kovaka compellingly argues that attending to the specific goals of any given research project enables us to appreciate the compensatory advantages of participatory approaches—such as breadth of data and variety of circumstances for data collection, investment in the research, and more—that offset any limitations in data quality. Of course, sometimes data accuracy is of the upmost importance; in those cases, a PR approach with a large number of participants may not be well suited to the project. In many other cases, research projects stand to further their goals by including the public. This response to the concern with data quality also speaks to our emphasis on attending to the particular goals of PR projects. It should also be noted that, in certain contexts, efforts are made to understand the specific impact that scientist and community participant involvement has on data. For example, one qualitative study on mental healthcare experiences involved both university researchers and service-user researchers collecting and interpreting data and then analysis was conducted to understand the differences in the way each group interpreted the data (Gillard et al. 2010).

Attending to the perspectival nature of goals also offers a helpful interpretation of concerns that have been raised about the power dynamics of PR. In some projects, despite public involvement, scientists remain in charge:

> Scientists primarily value volunteers' contributions to the extent that the information collect can be compiled into large data sets. Conceptualizing citizen scientists as

"volunteers" seems to put them in a role that is perpetually subordinated to "real" scientists. (Kimura and Kinchy 2019, 64)

This potential power imbalance between scientists and public participants can be articulated in terms of which goals—or more to the point, whose goals—a PR project serves. Scientists and the participating public may well have divergent goals for the project, and if the scientists have more power than the participating public, their goals may be advanced to the detriment of the public participants' goals.

We cannot fully address these challenges here. Rather, our point is that attending to the types of goals furthered by PR, how those goals relate to one another, and who possesses those goals, can be used to productively engage with such challenges—and thus to ascertain when participatory approaches are called for, and what variety of participation is appropriate. Inspired by this promise, here is a goal-based series of questions that may be useful to consider and perhaps even explicitly discuss when designing, implementing, and analyzing a PR project:

1. What are the primary goals of the research project from the scientists' perspective(s)?

2. What are the primary goals of the research project from the participants' perspective(s)?

3. From the scientists' perspective(s) what is the main reason for including the public in the project?

4. From the public participants' perspective(s), what is the main reason for working with scientists to pursue their goals?

5. What is the relationship between public participants' goals and the scientists' goals? To what extend can both be achieved, and how can this be maximized? What methods are in place to achieve this?

6. What is the relationship between public participants and scientists in the project? Are matters of power and privilege adequately addressed? How is that done?

Questions 1 and 2 concern the motivation of the project from the perspective of all participants. More explicitly attending to both questions can help ensure that details of project design, especially the extent and form of public participation, further the goals of both scientists and the public. Questions 3 and 4 explore why public participation is appropriate for the project and what motivates scientists and public participants to be part of the project. Finally, questions 5 and 6 explicitly interrogate the interactions between scientists and public participants such that power dynamics are addressed.

4. Types of Participatory Research

The previous two sections' discussions of the goals of participatory research suggests that participatory methods can be useful in different regards (epistemic, practical, political, societal, communal) and that the goals of a participatory research project may vary with perspectives, especially of scientists vs. participating public. In this section, we draw from three typologies for participatory research approaches developed by Shirk et al. (2012), Kimura and Kinchy (2016), and Dunlap et al. (2021) to articulate a perspective-driven approach to categorizing types of PR projects. Such a categorization can be helpful in clarifying the similarities and differences among PR projects. This can also highlight decision points in the development of a participatory research project by making more explicit how the project could have developed differently along some dimension(s). When designing a PR project, we suggest using all three typologies in the following order: start by using the Dunlap et al. (2021) typology to identify divergence in goals, then use the Kimura and Kinchy (2016) typology to determine the intended virtues or payoffs of the project, and end with the Shirk et al. (2012) typology to determine the level of public participation. We end by extending our list of questions to consider when developing and implementing a project.

As discussed above, Dunlap et al. (2021) highlights the perspectival nature of PR goals. This is the starting point Dunlap and colleagues suggest for PR categorization: What are the goals of the participating public and scientists, and to what extent do these diverge? When the goals of the participating public and scientists are well aligned, then either party can guide the research design and execution, with the other party included as expertise, ability, and interests dictate. Often, this scenario plays out with the professional scientists conceiving of, planning, and designing the research, with public participation in data gathering and/or data analysis. This arrangement works well for the Cornell Lab of Ornithology, where scientists and interested public share goals of protecting birds and educating the public about birds. Professional scientists are well positioned to structure the research, while the participating public has strength in numbers and geographic distribution to support data collection and outreach efforts.

However, as we have noted, the goals of public participants often deviate from those of professional scientists. In such cases, we concluded in the prior section that it is essential to ascertain the goals of the participating public and ensure these are met by research design, with any issues caused by power differentials addressed. In the present context, note that when goals diverge, ensuring public participants' goals are met by the research design also tends to require the inclusion of public participation earlier in research design, often at the stages of determining the specific research questions and methods used. This approach is common in some traditions of PR, including community-based participatory research and action research, but less common in citizen science traditions. We should also note that in some cases of participatory research as social change, public participants initiate and lead the research process, as in the example of water monitoring in New York and Pennsylvania discussed above (Kimura and Kinchy 2019). In situations like this, public participant goals will take precedence over the goals of scientists (if scientists are involved in the research at all).

Once the goals of the participating public and scientists are identified and alignment or divergence among them ascertained, this information can be used to specify the particular aims of the research. Different specific aims of explanation, prediction, or action motivate different features of the methods and design of scientific research (Potochnik 2015). This is where the categorization put forward by Kimura and Kinchy (2016) comes in. Their typology of PR is in terms of the *virtues* of the project. Kimura and Kinchy emphasize that there are some widely recognized virtues to participatory research, such as increasing scientific data and improving the participating public's scientific literacy and engagement, which we mentioned above, as well as building community capacity for action, improving the relationships between scientists and the public, driving policy change, and more. These are five of the seven virtues that Kimura and Kinchy list, and they note that their list is not exhaustive. Notice that these virtues range across the types of goals we identified in the previous section: epistemic, practical, communal, societal, and political. The participating public's and scientists' specific goals for a PR project will help to determine which of these virtues are prioritized, which in turn shapes other aspects of the project.

One important consideration of any PR project is the nature of public participation: To what parts of the project does the public contribute, and to what extent? This aspect of PR projects is—or should be—influenced by the virtues the project aims towards, which we have suggested are shaped in turn by the professional scientists' and participating public's goals. One might think of this chain of considerations as moving from a question of participants' possibly divergent goals for the research project, to the question of the virtues or payoffs of the project and approach, to—finally—the question of what form of participation is warranted.

Shirk et al. (2012) categorize participatory approaches according to the extent of public participation, which is helpful at this juncture. Here we've ordered Shirk et al.'s categories in increasing degree of influence by the participating public. *Contributory* projects are fully designed by scientists and members of the public contribute to carrying out the research, often in data collection. *Collaborative* projects are also designed by scientists but allow the public to have some control of research questions. In *co-created* projects, at least some members of the public participate in all aspects of the research, including design and management. *Contractual* projects occur when communities contract scientists to conduct research on their behalf. Finally, in *collegial* contributions, members of the public conduct independent research with varying degrees of recognition by the scientific establishment. This categorization provides a neat separation of PR projects into types, ordered by degree of public participants' control of the project. Used on its own, it might tempt us into thinking that this alone is the important variable in PR approaches. But as part of the broader analysis we've developed here, we hope it's clear that goals and virtues should also be considered. When designing PR projects, we suggest proceeding from a consideration of goals—taking into account a possible divergence in goals, to a consideration of payoffs or virtues, and only then to a consideration of the necessary degree of participation.

Continuing with the approach we adopted in the previous section, we'll end this section with some questions focused on what type of involvement public participants and scientists should have in a PR project, based on aims considerations:

7. In what ways should the relationship between scientists' goals and public participants' goals each shape the research agenda?

8. Whose expertise is relevant, and in what ways, to the pursuit of these goals?

9. What are the ultimate virtues or payoffs for the project, and are these reflected in the shared goals between scientists and public participants?

10. At what PR project stage(s) should scientists be involved? At what PR project stage(s) should public participants be involved? How does this set up further the ultimate goals of the project?

Question 7 stems from Question 5 at the conclusion of the previous section, regarding the relationship between public participants' goals and scientists' goals, but this time the question is posed to identify how the various goals influence the specifics of the research design. Question 8 encourages reflection about how the expertise of the scientists and public participants is important for pursuing the specific constellation of goals for the PR project. Question 9 connects goals to payoffs, making sure that the goals for the project actually align with expected outcomes. Finally, Question 10 prompts project designers to reflect on what role scientists and public participants should play in the project, given the considerations of previous questions.

5. Participatory Research in Health Contexts

In this section, we apply the theoretical resources we have introduced above to health contexts, including a discussion of the unique ethical challenges of participatory health research. Often, PR in health contexts is referred to as 'biomedical,' as with, 'biomedical citizen science.' But this term is linked to specific medical contexts like research hospitals and associated with the reductionist 'medical model' of health. In this section, we adapt our umbrella term 'participatory research' and speak of 'participatory health research,' including not only traditional biomedical research that involves public participation but also research done by individuals in their own homes or by groups of non-professionals in the community.

There are a variety of approaches under the umbrella of participatory health research. 'Community-based participatory research' (CBPR), an approach we discussed above, is often conducted in public health contexts. The orientation of CBPR is to treat the community as a partner rather than the subject of research (Shore 2007). CBPR falls under the umbrella of PR as social change since its goals are often social, communal, or political in nature. In contrast, 'research as coproduction' is a term used by Gillard et al. (2012) for health research in which service users and university researchers work together, not with the goal of social change, but

instead with the goal of knowledge gathering. 'Biohacking,' in turn, is the practice of do-it-yourself biology. This involves, for example, people tinkering with biotechnology in their home or at a community laboratory (Trejo et al. 2021). 'Grinders' are people who experiment on their own bodies, via body modification, often with the goal of enhancement (Trejo et al. 2021). In 'self-tracking studies,' people track their daily health data either individually or in collaboration with others, usually using an internet-based platform (Wiggins and Wilbanks 2019). The last version of participatory health research we discuss is 'survivor research.' This approach stands in contrast to both CBPR, which is a collaboration between scientists and public participants, and biomedical citizen science, which is primarily individual-driven. 'Survivor research' is conducted by mental health service users who often reject the way that psychiatry operates and are seeking out an alternative (Survivor Researcher Network 2018).

An example of CBPR is the LU-Salud project conducted by researchers in psychology, education, and medicine at the University of Cincinnati. This study sought to better understand health issues in the local Latino community. Academic researchers recruited Latino community members, who were conceived of as "co-researchers" and collaborated at each stage of the research (Vaughn et al. 2017). The co-researchers helped design surveys and then led efforts to disseminate the surveys in the targeted community. There were regular meetings between the academic researchers and community co-researchers as data were collected so that all parties stayed informed throughout the process. At the end of the study the co-researchers contributed to the interpretation of data as well (Vaugh et al. 2017). Considering the resources for analysis of approaches introduced above, this PR project involved shared researcher and public participant goals of improved health outcomes in the targeted community that are communal in nature, alongside perhaps other subsidiary epistemic and practical goals. These communal goals were best served by including significant community involvement.

In contrast, an example of 'research as coproduction' is found in Gillard et al. (2010), in which university researchers and service-user researchers conducted a qualitative study on the experience of being psychiatrically detained. In this study, all parties took part in the development, implementation, and interpretation of the interviews. Though this study is similar in structure to the LU-Salud study, its goals were not necessarily social change but instead the coproduction of knowledge.

Unlike both CBPR and 'research as production', biohacking, grinders, and self-tracking studies are typically driven by individual goals rather than shared goals. These practices are sometimes referred to collectively as 'biomedical citizen science' and are characterized by their autonomous and individualized nature (Trejo et al. 2021). Interestingly, citizen science traditions discussed above are typically driven by professional researchers, while biomedical citizen science of this form is driven by public participants, with professional researchers only involved in the margins if at all. That is not to say that there is no community aspect to these practices. Biohacking and grinder groups gather to promote and collaborate on projects, but even then, research is still primarily individual-driven.

One example of this approach is the self-tracking of health data. People who engage in these activities are sometimes called "lifehackers" (Trejo et al. 2021). Wiggins and Wilbanks (2019) distinguish between forms of lifehacking—with varying levels of social collaboration. In 'N-of-1' studies, individuals track their "diets, environments, sleep, medicines, bathroom habits, and more…" independently without collaborating with others. In contrast, 'N-of-we' communities exist for lifehackers to share results and tips with each other. These communities employ N-of-1 methods, but exchange information with each other. A third model is 'N-of-many-1s' studies, which are top-down operations in which professional institutions standardize and aggregate self-tracking data. This is the least autonomous of the three types of self-tracking studies (Wiggins and Wilbanks 2019); this accordingly bears the most resemblance to researcher-driven citizen science in other fields.

The final type of participatory health research we discuss is 'survivor research.' This tradition exists in opposition to the power structures of establishment psychiatry, and so bears resemblance to the antipsychiatry and Mad Pride movements. The "Survivors Researcher Network Manifesto Summary," explicitly describes this movement as having roots in "survivor activism" that "seeks to challenge the psychiatric system" (Ormerod et al. 2018). The purpose of the Survivor Researcher Network is to connect service users who want to conduct mental health research that is independent, and often critical of, academic psychiatric research. Despite the fact that both survivor research and CBPR push for social change, survivor research is distinct in that it exists outside the mainstream of healthcare and has a particular focus on mental health issues.

The challenges that PR in general faces also arise in participatory health research. For example, power dynamics can also be an issue in health contexts. Institutional Review Boards, administrative bodies required for any institutionally sponsored research to protect the rights of human subjects, are often viewed with suspicion in biohacking and grinder communities (Trejo et al. 2021). And just like PR in non-health contexts, participatory health research is sometimes criticized as biased or tainted by advocacy. This is especially the case in CBPR and forms of action research, since goals are often framed in terms of community improvement and social change. Recall from above that attending to the specific goals of a PR project can reveal the particular advantages and limitations of participatory methods, as well as the most advantageous degree of involvement of public participants—and professional researchers, for that matter. All of this applies to participatory health research as well.

There are also challenges specific to participatory health research. In health contexts, the line can be blurred between public participant and human subject. In forms of PR that target non-human subjects, this is not an issue: when PR projects test food for radiation, it is clear that the food is the subject of research, and the public participants are engaging as scientists. However, in health contexts, the bodies and/or viewpoints of participants can do double duty as the subject of scientific inquiry while also participating in the process of inquiry. In the LU-Salud study, for example, data consisted of survey results from community members. Even though community members played an active role in the development and implementation of the research, the data being collected was ultimately the beliefs, needs, and behaviors of other

community members. So, while some community members played the role of co-researcher, others played the role of human subject. Similarly, even though grinders have autonomy over what is done to their body, it is still their body that is being experimented on. In this way, grinders are both scientist and human subject. We should note that being involved in participatory health research can be empowering as well. As one interviewee in the Shore's (2007) study put it in reference to CBPR, "participants [become] actors in the process rather than just objects, and by giving them some control over the process, it potentially creates the kind of knowledge that will be more useful to them" (34).

Since participatory health research can involve intervening on human bodies, safety concerns also arise. As noted above, health research in institutional settings is regulated by IRBs which review all proposed human subjects research and decide what is allowable according to ethical standards. With practices like biohacking and body modification conducted without institutional backing, no such ethical oversight exists. Trejo et al. (2021) conducted a qualitative study that observed attitudes about ethical oversight in biomedical citizen science communities. They found that these communities highly value their bodily autonomy and consider practices like body modification their right. Options like obtaining IRB approval were generally unpopular not just because of the value these groups place on autonomy, but also because it is expensive and time consuming to acquire IRB approval. Instead, community members tended to prefer ethical oversight that occurred from within their community or ethical self-reflection completed by individuals (Trejo et al. 2021). In this context too, it is helpful to consider the specific goals motivating the PR projects. Any initiatives of professional researchers and their institutions to constrain, shape, or regulate projects will be most likely to succeed if those initiatives meaningfully further the goals public participants have for their research. This might consist in institutional recognition, financial resources for the research, access to intellectual or practical resources from the institution, or something else. The key consideration here, as in many other questions about PR projects, is to consider the specific goals for the research and the public participation in, or leadership of, that research.

Another challenge that participatory health research faces is the risk of data mining. This is particularly the case for lifehackers who track their daily health data. Most of these studies require the use of large data-sharing networks like Facebook, Fitbit, or 23andme. These options run the risk of data breaches and the misuse of data by corporations (Wiggins and Wilbanks 2019). This raises the ethical question: Who benefits from these studies? Even though much of this research is driven by individuals' interests, their reliance on corporations and institutions for data tracking puts participants at risk of exploitation (Wiggins and Wilbanks 2019).

We have already suggested some ways in which the theoretical resources introduced earlier in the chapter can be applied to these health-specific challenges. More generally, a goal-based consideration of PR projects such as we have introduced provides resources for understanding the array of participatory health research approaches and the distinctive contributions and challenges of each. We have suggested that PR goals can be divided into five categories: epistemic, practical, political, societal, and communal. Because goals are perspectival in nature, it is important to identify when goals diverge between stakeholders. CBPR projects often aim

towards communal and political goals—they seek to benefit the local community and push for social change. Biohackers and grinders, on the other hand, usually have more practical goals (e.g., learning about science, body enhancement, expressing bodily autonomy) and so the projects benefit the individuals that implement them. When more than one stakeholder is involved, goals can diverge. For instance, scientists conducting participatory health research may have primarily epistemic goals that conflict with the primarily practical, communal, or political goals of participants. Determining what the goals are, whose goals they are, and where goals diverge is thus enlightening for participatory health research.

We can also use the typologies introduced above to better understand participatory health research in all its variety. Using Shirk et al.'s (2012) typology, for example, we can identify biohacking and body modification projects as collegial contributions—since they involve community members doing science independent of institutional influence. CBPR, on the other hand, tends towards the production of collaborative or co-created research depending on the level of community involvement. LU-Salud is co-created because community members participated in setting the research questions and the designing of surveys. Survivor research may be seen as a form of collegial contribution, but even that might be a stretch given that this tradition formed in opposition to establishment psychiatry.

Finally, as this discussion suggests, the questions that we introduced at the end of sections 3 and 4 are useful for participatory health research. It is important to understand how and why public participants and academic researchers alike are involved in the research, how they benefit, and what the shared goals of the project are. Further it is important to determine how goals result in outcomes and what role scientists and public participants each play in that process. In fact, these questions become even more urgent in health contexts. Because the line can be blurry between public participant and human subjects, and because some participatory health research occurs fully outside the governance of institutional structures, the risk of exploitation is higher. A study that appears or even intends to be working with a community towards common goals may actually exploit participants for labor and data collection. Indeed, this pitfall has been all too common in the history of participatory research. Therefore, it is vital for the goals and interests of public participants to be explicitly identified and protected, which requires significant attention to power structures, thoughtful research design, and more.

6. Conclusion

Participatory research is a big tent—so it is at once important and challenging to describe the relevant terminology, concepts, and theoretical resources. In this chapter, we began by introducing a handful of examples of PR and varieties in its execution. We discussed two strands of participatory research that have been identified by Cooper and Lewenstein (2016) and Eitzel et al. (2017): *social change* and *knowledge gathering*. We highlighted the perspectival nature of goals and the importance of considering the divergence of goals between stakeholders. We also introduced three typologies that exist for categorizing participatory research projects and suggested a method of applying all three, working from attending to the goals of professional researchers and public participants, to identifying the virtue(s) of the PR

project, to finally identifying the extent of public participation that can further the specific goals at hand. Sections 3 and 4 resulted in a list of questions that might be used to guide the development, implementation, and analysis of PR projects. We ended by applying these concepts to participatory health research and identifying specific challenges that this form of PR faces. We hope that the theoretical resources introduced in this chapter prove helpful to the design, implementation, and theorizing of participatory research.

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