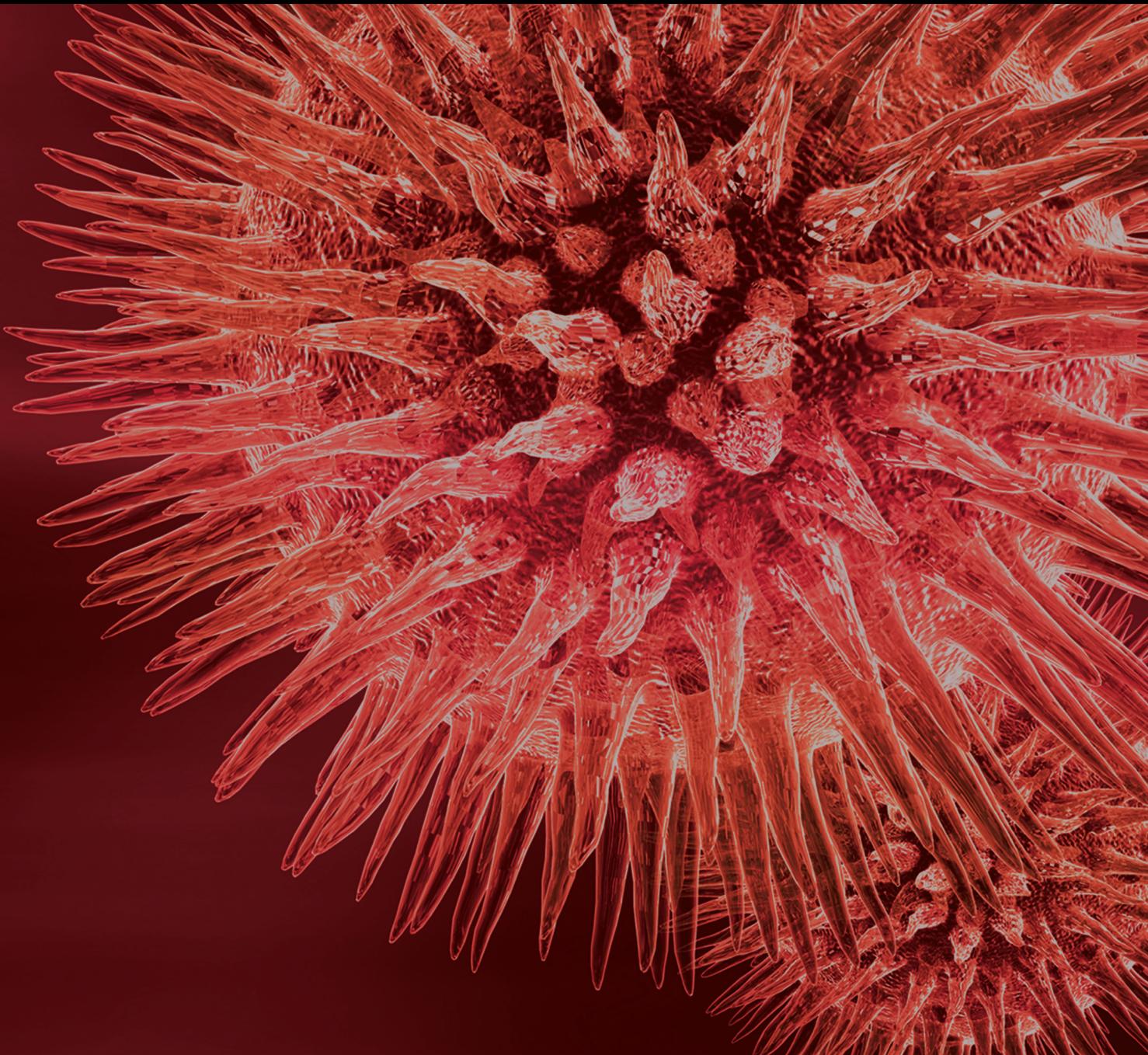


BioMed Research International

Impact in Participatory Health Research

Lead Guest Editor: Michael T. Wright

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Editorial

Impact in Participatory Health Research

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Copyright © 2018 Michael T. Wright et al. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

The idea for this special issue arose from the first *International Scientific Meeting on the Impact of Participatory Health Research* organized by the International Collaboration for Participatory Health Research (ICPHR), the German Network for Participatory Health Research (PartNet), the Institute of Population and Public Health, Canadian Institutes of Health Research (CIHR), and Community-Based Research Canada (CBRC). The conference took place in June 2015 at the Center for Interdisciplinary Research (ZiF) in Bielefeld, Germany. Experts in PHR from eleven countries met to launch an international discussion on what impact means in the participatory research process, how to maximize the impact of the research, and how to observe and document what impact has occurred. Several of the themes discussed at the conference are addressed in this issue.

Participatory health research (PHR) is an approach in which those people whose life or work is the subject of the research influence the research process. PHR enables nonacademic researchers to take part directly in deciding the topic of the research, the research questions, the mode of data collection, the interpretation of the results, and the dissemination of the findings. Through this involvement, PHR seeks not only to describe and explain health problems and their causes, but also to bring about the necessary social change for the benefit of people's health. In PHR learning and research are not considered separate entities. Social learning (learning together and from each other) is a fundamental dimension of the PHR process, and the continual cycle of "look, reflect, act" underpins the dynamics of developing

a connected knowing [1]. This means trying to understand the other person or idea through dialogue from relations of trust and empathy [2]. Everyone learns as a coresearcher to differing degrees. Ideally, the process should engage the participants in transformative learning, i.e., changes in the way they see the world and themselves [3, 4], through interactive processes which address both the personal and the collective. In turn, this generates an intention of being able to act based on the research findings, thus having a wider impact beyond the scientific community. On the whole, how social change is defined is largely determined by whether the approach is pragmatic (that is, focused on issues of practical utilization) or emancipatory (where the focus is on changing the way people think and act in their world)—or an attempted combination of both [5, 6].

The work of Cook et al. [7] has demonstrated the difficulty authors have in recognizing and articulating impact in PHR. This includes recognizing the impact of participation on the research process and capturing the longitudinal aspect of impacts that occur long after a project has been completed. In an extensive review of the English language literature, Jagosh et al. [8] identified, selected, and appraised a large-variety sample of primary studies describing PHR partnerships. They used key realist review concepts to analyze and synthesize the data, employing the PHR partnership as the main unit of analysis (compare Jagosh et al. [9]). The link between the participatory research process and the outcomes in these partnerships was explained using the middle-range theory of *partnership synergy*, which demonstrates how PHR can

(1) ensure culturally and logistically appropriate research; (2) enhance recruitment capacity; (3) generate professional capacity and competence in stakeholder groups; (4) result in productive conflicts followed by useful negotiation; (5) increase the quality of outputs and outcomes over time; (6) increase the sustainability of project goals beyond funded time frames and during gaps in external funding; and (7) create system changes and new unanticipated projects and activities.

A review by Staley [10] describes positive and negative impacts which can result from PHR, based on an extensive review of published and gray literature on the INVOLVE strategy for public involvement in the research of the National Health Service in the UK. This includes impact on the research process (agenda, design, delivery, and ethics), impact on the public involved, impact on academic researchers, impact on other research participants, impact on the wider community, impact on community organizations, and impact on change processes (e.g., improved service delivery).

In this special issue the topic of impact in PHR is examined from several perspectives. Janet Harris and colleagues call attention to the lack of clarity in the literature regarding what participation means and the frequent lack of information on participatory processes. Taking into account these and other challenges, they make recommendations for conducting systematic reviews of impact in PHR, citing recent reviews while providing practical examples for dealing with issues at each stage of the review process. In the article by Erica Di Ruggiero and Nancy Edwards another overarching issue regarding impact in PHR is addressed; namely, the interface between implementation research and PHR. They compare and contrast these two relatively recent developments in research practice, highlighting the ways in which PHR can contribute to the impact of health research, more generally. John G. Oetzel and colleagues present an empirically-tested model for examining the various forms of impact in PHR as an integrated part of research planning and evaluation. Their model is the result of a large-scale study in the United States involving PHR practitioners which has since been applied to many different settings.

The remaining articles in this issue are examples of how three very diverse projects in three different countries have addressed the issue of impact. Lisa Gibbs and colleagues present a case study of *Beyond Bushfires*, a large, multisite, mixed method study of the psychosocial impacts of major bushfires in Victoria, Australia. The challenges of balancing local interests with state-wide implications are explored in the description of the methods of engagement and the study processes and outcomes. A similar tension between local and national interests is described by Michael T. Wright and colleagues in their article on *PartKommPlus—German Research Consortium for Healthy Communities*. The consortium, composed of seven subprojects focused on participation in local strategies of health promotion, has struggled to bring together the knowledge arising from the wide variety of contexts and methods. The contribution of Sónia Dias and colleagues provides a well-documented example of how PHR can impact a specific health issue in a specific community,

with both social and political implications. A participatory HIV research project was conducted with sex workers and men who have sex with men to understand epidemiological HIV dynamics and associated sociobehavioural factors in Portugal. Advantages of the participatory process were encountered but also challenges, evidencing the dynamic and complex nature of each project stage.

The collection of articles in this special issue inspires and challenges us to examine the complex and important issue of impact in the emerging field of participatory approaches to health research.

Conflicts of Interest

The authors hereby declare that we have no conflicts of interest or private agreements with companies related to the publication of the special edition.

Michael T. Wright
Jon Salsberg
Susanne Hartung

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Research Article

Impact and Lessons Learned from a National Consortium for Participatory Health Research: PartKommPlus—German Research Consortium for Healthy Communities (2015–2018)

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Integrated strategies of health promotion at the municipal level are receiving particular attention in public health policy and practice in Germany. These strategies are intended to provide a coordinated approach to health promotion during the entire lifespan, with a particular focus on vulnerable communities. They are also intended to be participatory in both their design and implementation, involving all sectors of the social welfare, educational and healthcare systems, civil society, and the general public. PartKommPlus—German Research Consortium for Healthy Communities is examining such strategies using participatory forms of research. The goal is to determine how participation can best be planned and implemented and what effects this participation has. In this article the work of PartKommPlus from the first funding phase (2015–2018) will be described with particular attention to the lessons learned and the forms of impact which are being considered as part of the participatory research process.

1. Background

Under the coordination of the Federal Center for Health Education in Germany (BZgA) and EuroHealthNet, the European Union initiative “Closing the Gap: Strategies for Tackling Health Inequalities in Europe” was launched in 2004 to bring together the evidence regarding the causes of health inequality and the strategies to address them [1, 2]. A central recommendation for the member states is the development of an appropriate and effective national strategy [3]. A cornerstone of the German response has been the Cooperation Network “Equity In Health” (EIH), a national initiative founded in 2003 by the BZgA. An important goal of EIH is promoting the establishment of integrated municipal strategies (IMS) for health promotion, also known as

“chains of prevention” [4–6]. These strategies are intended to provide a coordinated approach to health promotion during the entire lifespan, with a particular focus on vulnerable communities. The IMS aim to involve all sectors of the social welfare, educational and healthcare systems, civil society, and the general public in designing long-term strategies to improve and maintain the health of the population [7]. Local stakeholders are supported by coordinators located at the regional Association for Health Promotion (AHP) or a similar body found in each of the sixteen states in Germany. The new Law on Prevention requires all states to develop health promotion and prevention strategies while providing new funding mechanisms for these strategies. This includes supporting the AHP as they assist municipalities in setting up and maintaining IMS [8].

The need to establish IMS as an integral part of population-based health promotion strategies was identified more than twenty years ago. The concept was first taken up by the Healthy Cities movement which was formed in Europe to implement the WHO Ottawa Charter on Health Promotion. The Healthy Cities Network now comprises over 1,200 municipalities worldwide with over 70 in Germany. Research on the impact of Healthy Cities has been limited, largely due a lack of consensus on suitable indicators and their measurement [9]. This controversy relates to the current international discussion on the need to develop meaningful ways to evaluate the effects of complex health promotion strategies [10, 11]. An evaluation of the Healthy Cities Network in Germany [12] revealed progress in most cities regarding the goals of the IMS; however, 90% of those responding reported structural and organizational factors which significantly hindered such strategies. These included inadequate resources; inadequate understanding of the Healthy City concept; lack of commitment to the program of action proposed by Healthy Cities; inadequate integration into the national network and into the local political process; and inadequate documentation and evaluation. The latter is often characterized by a lack of clarity regarding the overall strategy and the intended objectives. Positive outcomes were more likely in larger cities with a longer history of involvement in the network and with continuity in local program coordination.

Another body of evidence which can inform the implementation of IMS is the literature regarding the building of local coalitions for the purpose of improving the health of a specific group of people (most commonly in a neighborhood), often focusing on a specific health problem or set of health problems. Largely originating in North America, this body of work investigates the factors supporting and hindering such coalitions, formulating the findings in terms of principles to guide the practice of coalition-building and maintenance [13–19].

There is an emergent, comparable literature in Germany on coalitions, also with a strong focus on specific neighborhoods or districts in a city. In this literature two priority issues have been identified as needing further attention: community engagement, particularly the engagement of vulnerable groups, and governance strategies [20]. A review of the German literature by Bär [21] revealed three emerging approaches for IMS: (1) top down, expert-centered—e.g., led by municipal governments [22]; (2) bottom-up, citizen-led—e.g., as found in broad-based community organizing [23]; and (3) participatory strategies initiated by professionals—e.g., as in the city of Flensburg [24]. According to Bär, the first approach appears to be most common in Germany, the second least common, and the third is receiving increasing attention.

2. The Research Consortium PartKommPlus

The focus of PartKommPlus—German Research Consortium for Healthy Communities is to study the process of building and maintaining IMS in Germany, with a particular focus on the issue of participation. Attention is being given to questions regarding how to establish ongoing, intersectoral

cooperative structures for health promotion and to questions regarding the engagement of vulnerable communities in developing IMS. The knowledge gained will be applied to assist EIH and other interested parties in using participatory methods to establish IMS in more municipalities and to support an ongoing process of mutual learning to strengthen existing IMS.

The consortium was formed by members of the German Network for Participatory Health Research (PartNet) in response to a call of the Federal Ministry for Education and Research (BMBF) in the funding stream “Prevention Research” to build research consortia composed of research institutions, service providers, and local communities in order to answer key questions related to improving the infrastructure for health promotion and prevention, particularly for vulnerable communities. The subprojects of PartKommPlus were chosen based on pragmatic considerations (where could viable partnerships be formed) and the desire to maximize diversity in terms of geographical distribution in the country, the topics and communities to be addressed, and the participatory methods to be employed. PartKommPlus is one of seven research consortia being funded by the Ministry. The funder has exercised no influence in terms of focus or content of the work, explicitly supporting innovation and experimentation regarding participatory process and methods. This has included providing monetary support for various cooperative structures, based on the individual needs of the local projects and allowing the projects and the coordinating institution of the consortium to make changes, based on their emergent needs. This high level of flexibility on the part of the funder and the explicit support for the often unpredictable participatory processes has given the consortium the basis required by participatory research which is often not provided [25].

PartKommPlus is based on the internationally recognized principles of participatory health research (PHR) as formulated by the International Collaboration for Participatory Health Research (ICPHR). PHR is an umbrella term for the various local and regional traditions among the over twenty countries represented in the ICPHR, like *community-based participatory research*, *participatory action research*, *interactive research*, *participatory rural appraisal*, *militant research*, etc. The ICPHR has defined the core, defining principle of PHR as maximizing the participation of those whose life or work is the subject of the research in all stages of the research process, from the formulation of the research question and goal to the dissemination of the findings [26]. By engaging the people who are the subject of the research in the research process itself, data can be generated which have an immediate relevance for understanding local problems and for developing local solutions to the problems identified, in the case of PartKommPlus, integrated local strategies for health promotion. PHR also addresses the ethical imperative of people being directly involved in decisions which affect their health and well-being [27].

PartKommPlus is unique in two ways. It is the largest participatory research project funded in Germany to date, a country in which participatory forms of research have been rare [28, 29]. The size and structure of PartKommPlus also

TABLE 1: The projects in PartKommPlus.

Project Title (with abbreviation)	Focus
Parents Asking Parents: From Model Project to Municipal Roll-Out (ElfE ²)	Parent peer research to promote the participation of vulnerable families in pre-schools
Participatory Evaluation of the Prevention Chain in Braunschweig (PEBS)	A participatory evaluation of the Braunschweig network to prevent poverty among families with children
Development of Municipal Health Promotion Strategies (KEG)	Developing municipal strategies for health promotion through a dialogue between research and practice
Health Promoting Neighborhoods (Age4Health)	Engaging vulnerable older people in developing local health promotion strategies
People with Intellectual Disabilities and Health Promotion Programs (HEALTH!)	Inclusion of people with intellectual disabilities in health promotion strategies
Municipalities and Health Insurance Funds—Cooperating for Healthy Local Environments (K ³)	Governance in municipal health promotion strategies with the focus on the cooperation between health insurers and public authorities
Participatory Epidemiology: From Data to Recommendations (P&E)	Participatory approaches to epidemiology and health monitoring

appears to be a distinguishing characteristic, no comparable consortium having been found in our search of the literature.

This article describes lessons learned and how impact has been conceptualized at the consortium level during the first phase of funding (2015–2018). The article is based on working papers and observations produced over the course of the three years by the consortium members in the context of joint colloquia and coordinating meetings. Various constellations of local and national partners participate in the meetings (see below).

3. Structure and Goals of PartKommPlus

PartKommPlus is providing new knowledge on the role of participation in municipal health promotion strategies. In line with the international discussion, we define participation as not just taking part, but as having influence on central aspects of one's living and work environments [27, 30, 31]. We are focusing specifically on the following issues which are raised by participation in municipal health strategies:

- (i) *Cooperation and coordination (governance)*: local authorities are challenged to provide a form of oversight which is based on cooperation and consensus and which coordinates vertically between levels (administrative level, intermediate level, district level, and project level) as well as horizontally between the various functional departments and disciplines. This presumably requires specific forms of governance which we want to describe.
- (ii) *Forms of participation*: the various stakeholders—local authorities, civil society, social service, and health providers, and local citizens—can influence municipal strategies in different ways. We are looking at the various forms which this influence can take.
- (iii) *Impact of participation*: the various forms of participation on the part of the stakeholders can presumably have different effects on the municipal strategies, for example, in terms of the focus of the strategy, the

measures taken at the local level, and their outcomes. We seek to describe these impacts.

- (iv) *Role of participatory health research*: the consortium is applying various forms of participatory research to support the development and maintenance of municipal strategies. We are looking at how this form of research can contribute to the work at the local level.
- (v) *Participatory epidemiology and health reporting (surveillance and monitoring)*: data on the health of the population is a basis for all public health activities. Here we are looking at how participatory forms of data collection and analysis can support municipal and regional strategies in their work.
- (vi) *Participation within a research consortium*: participatory research projects are commonly local in scope. Within PartKommPlus we seek to bring together the knowledge gained from local studies to contribute to a national strategy. To do this, we are developing ways to work together in a participatory fashion and are reflecting specifically on our own participatory process.

PartKommPlus is composed of seven subprojects (descriptions of the individual projects can be found at www.partkommplus.de). Each project has its own specific questions and goals which are related to the above themes. Five of the projects are based at the local level, with research studies taking place in eight different communities located in six different states (Baden-Württemberg, Berlin, Brandenburg, Hamburg, Hesse, and Lower Saxony (Berlin and Hamburg are so-called city-states in which the city constitutes its own state jurisdiction)). Two of the projects are focused on general issues related to participatory processes in municipal health promotion. One of the projects is focusing on issues of governance in IMS, while the second project is developing participatory forms of health reporting and epidemiology (see Table 1). The consortium is coordinated by the Catholic University of Applied Sciences

Berlin (KHSB). The Berlin-Brandenburg Association for Health Promotion (GBB) is in charge of an important part of the communication strategy for the consortium, which consists largely in interacting with the larger IMS community through a dedicated Internet site called *inforo* (www.inforo-online.de).

4. Participatory Process in PartKommPlus

At the heart of each of the seven subprojects is a participatory research process involving stakeholders at various levels, including local community members. The design of the projects varies widely, however, and each project has changed over time. These changes have included trying out different forms of engagement and adapting the research questions and methods to the differing interests of a growing group of stakeholders. The projects have also focused their work by using different approaches to participatory research, such as Appreciative Inquiry [32], peer research [33], participatory evaluation [34], and participatory epidemiology and health reporting [35]. Each approach has a specific frame of reference which sets a specific focus in terms of the participatory process.

The consortium as a whole has also sought to conduct its work in a participatory way. Given the lack of documented participatory research consortia of this size, it has been a process of experimentation to find forms of working together which not only maximize the participation of each lead institution in decision-making at the consortium level, but which also bring the voices of local people into the work of the consortium as a whole. The latter has proven to be the larger of the two challenges, but also the most rewarding in terms of the mutual learning process.

We began with a relatively conventional structure with a coordinating body in charge of integrating and synthesizing the data from the five projects taking place at the local level. The data collection was intended to take place at colloquia scheduled twice a year, each lasting three days and focusing on a topic related to the overarching research questions and being attended by representatives from each of the five local projects. In addition, interviews were to be conducted with people taking part in the five projects and other local data were to be gathered so as to address questions of governance and monitoring. The idea was to draw together systematic data from each of the five subprojects and to discuss these data at the colloquia so as to answer the overarching research questions of the consortium.

This plan did not work, for two primary reasons. Firstly, the five representatives of these projects felt that they were being made the objects of researchers from outside of the local context. They felt that they were being called to deliver data, but that they did not have sufficient control over what data were collected or how they would be analyzed. Several attempts were made to be more transparent about the central data collecting process and to include the five projects in that process, until we concluded that the problem was a structural one. We recognized a parallel process taking place in the local municipalities. Just as the people at the local level initially felt like they were the objects of research from the lead

institutions, so too did the lead institutions feel like they were the objects of research from the consortium leadership. We were surprised by this dynamic because all the consortium partners were involved in designing the initial structure for the integration and synthesis of the data. It seems that a negotiation of power and control needs to take place at the start of any participatory research project, regardless of the time spent in collaborating on an initial plan. Apparently, this principle does not only apply to community members at the local level without prior research experience, but also to experienced researchers in a consortium structure, if they are not satisfied with the amount of influence they are having on the research process.

Secondly, participatory research is at its heart a local process [26]. In PartKommPlus the research processes at the municipal level are focused on maximizing the participation of the various stakeholders thereby enabling a broad ownership of the local projects. Building trust and ownership at the local level stands in contrast to a central and, for many partners, abstract and geographically remote process of data synthesis.

Over the years of the funding phase we decentralized our data collection and analysis strategy at the consortium level, thus departing from our initial structure. This bottom-up, inductive approach has led to identifying topics in which different constellations of lead institutions and stakeholders from the various projects bring together what they have learned about a topic of common interest. And each of these subgroups is deciding how they will work together and what product they will produce. For example, a group of peer researchers may come together to produce a list of criteria for participating in research. Whereas, a group of academic researchers may write a journal article on how participatory health research differs methodologically from other forms of health promotion research. Or a group of practitioners and academic researchers may design a tool for helping municipalities in setting up local strategies. Thus, not all subprojects are involved in all topics, and the option is also available for a subproject to work on a specific topic which only applies to its focus area. The result will not be a neat data synthesis from which answers to all research questions can be formulated, but rather a diverse assortment of various types of knowledge, products, and forms of reflection and analysis regarding municipal strategies of health promotion and participation.

We have continued meeting twice a year at the colloquia, but the focus has shifted to mutual support and exchange of ideas, for example, by sharing lessons learned at the local level and through peer supervision. The subprojects have also taken on an increasing role in determining the focus and structure of the colloquia, including an increasing involvement of their local partners.

5. Identifying the Types of Impact in PartKommPlus

As our work progresses, we are turning our attention increasingly to issues of data analysis, including that of impact. Here

we present an initial description of the types of impact taking place in our work.

An important emerging issue internationally, regardless of the participatory research approach, is how best to report on research impact. A narrative approach is increasingly promoted as being most valuable in contexts of applied research [36]. A simple listing of impacts, however thorough in the description, fails to address the ways in which the impacts interact and how various factors determine how impacts emerge or are stymied. A narrative makes these connections and is thus instructive for those wanting to apply the findings to their own context. PartKommPlus will be using impact narratives at the project and consortium levels in order to provide a more coherent and comprehensive picture of the evidence.

The impact of health promotion can be described in terms of various outcomes. Bauman and Nutbeam [37] draw a distinction between health promotion outcomes (e.g., social action and influence), intermediate health outcomes (either program impact or short-term outcomes, e.g., an effective preventive health service), and social health outcomes (long-term outcomes, e.g., like quality of life). Thus, from a health promotion perspective, it is important to differentiate between the project level and higher structural levels, with different time scales for the various levels.

A central concern of PHR is impact in a broad sense. As a form of action research, PHR has the explicit intention of bringing about social change. In PHR learning and research are not considered separate entities. Social learning (learning together and from each other) is a fundamental dimension of the PHR process and the continual cycle of “look, reflect, act” underpins the dynamics of developing a connected knowing [38]. This means trying to understand the other person or idea through dialogue from relations of trust and empathy [39]. Everyone learns as a coresearcher to differing degrees. Ideally, the process should engage the participants in transformative learning, i.e., changes in the way they see the world and themselves [40, 41], through interactive processes which address both the personal and the collective. In turn, this generates an intention of being able to act based on the research findings, thus having a wider impact beyond the scientific community in the narrow sense. On the whole, how social change is defined is largely determined by whether the approach is pragmatic (that is, focused on issues of practical utilization) or emancipatory (where the focus is on changing the way people think and act in their world)—or an attempted combination of both [42, 43].

The work of Cook et al. [44] has demonstrated the difficulty authors have in recognizing and articulating impact in PHR. This includes recognizing the impact of participation on the research process and capturing the longitudinal aspect of impacts that occur long after a project has been completed. In an extensive review of the English language literature, Jagosh et al. [45] identified, selected, and appraised a large-variety sample of primary studies describing PHR partnerships. They used key realist review concepts to analyze and synthesize the data, employing the PHR partnership as the main unit of analysis (compare Jagosh et al. [46]). The link between the participatory research process and the outcomes

in these partnerships was explained using the middle-range theory of *partnership synergy*, which demonstrates how PHR can (1) ensure culturally and logistically appropriate research; (2) enhance recruitment capacity; (3) generate professional capacity and competence in stakeholder groups; (4) result in productive conflicts followed by useful negotiation; (5) increase the quality of outputs and outcomes over time; (6) increase the sustainability of project goals beyond funded time frames and during gaps in external funding; and (7) create system changes and new unanticipated projects and activities.

A review by Staley [47] suggests an interesting, preliminary typology describing positive and negative impacts which can result from PHR, based on an extensive review of published and gray literature on the INVOLVE strategy for public involvement in the research of the National Health Service in the UK. This includes impact on the research process (agenda, design, delivery, and ethics), impact on the public involved, impact on academic researchers, impact on other research participants, impact on the wider community, impact on community organizations, and impact on change processes (e.g., improved service delivery). This typology is particularly useful for characterizing the work of PartKommPlus as it takes into account both impacts at the project level and at higher structural levels.

We present here an initial typology to describe the impact of our work which we will begin to apply over the course of the coming year. Following Staley, it will be important to describe both the positive and negative impacts/challenges which PartKommPlus has had.

5.1. Impact on the Participants. Each of the seven research projects is being conducted in a partnership between different constellations of academic institutions, community organizations, professionals in the healthcare, social service and education systems, and engaged citizens. The workings of the consortium as a whole, as organized by the coordinating institution, can be considered an additional level which participants should consider in terms of how PartKommPlus has impacted them.

In order to understand the impact in each project and at the consortium level it will be necessary to describe the specific partner constellation and the degree of participation each partner has in the project. As stated above, participation is defined as the degree of influence a partner has had on the research process. This includes partners at all project levels, from the project leads to those who have provided information about their lives or work over the course of the project, and includes both academic researchers and the members of research teams without formal research training. Expected impacts, based on existing findings in participatory research projects, include insights into the perspectives and needs of other stakeholders, empowerment, learning new forms of research practice, gaining research skills, gaining interpersonal skills regarding facilitation and negotiation, insights into one's own workplace or living situation, new ideas for health promotion in a specific context or for a specific group of people, and a growth in self-confidence.

Impact at the participant level can be assessed using the data gathered through participatory methods (such as photovoice or community mapping) and over the course of conversations, reflection exercises, and other forms of interaction with those who have been involved in the projects.

5.2. Impact on the Municipalities. The intention of PartKommPlus is to have an impact on how local municipal strategies are planned and implemented, with a particular focus on issues of participation, as detailed in the research goals above. This includes improved communication between the various stakeholders; a new awareness of what is necessary in order for participation to take place, in terms of resources, structures, and ways of working; and a new common understanding among the stakeholders for reporting, planning, and action.

The seven subprojects are imbedded in different ways in local, regional, and/or national contexts. It will be important to describe in what way each of the projects is imbedded and what effects were intended by the various stakeholders. This description will provide a basis not only for depicting the specific impacts reached or not reached, but also for explaining how and why such impacts were made possible or were not successful.

Evidence for impact on local municipal strategies can be obtained from the partners involved in the research projects and from those with whom the projects have interacted in order to effect change. Other sources for mapping impact are municipal reports on health or social issues in which public authorities, public health practitioners, activists, and other citizens can be involved.

5.3. Impact on the IMS Community. An explicit goal of the Ministry for Education and Research (BMBF) in funding research consortia is to generate new knowledge which can directly support the development of more effective structures for prevention and health promotion in Germany. As described above, PartKommPlus has positioned itself strategically in order to contribute to the establishment and sustainability of integrated municipal strategies for health promotion by focusing on the issue of participation. To what degree PartKommPlus has a unique and specific impact on the larger discourse and practice regarding IMS in the country will be difficult to assess. Evidence can be gathered through the national website inforo dedicated to IMS (see above) through which the work of PartKommPlus is being disseminated. The site provides several different opportunities for interaction between the consortium and the wider community of practice. Other evidence can be obtained by documenting how the work of the consortium as a whole and that of the subprojects is being discussed in various local, regional, and national contexts, for example, at conferences, in planning forums, in the media, and in professional and academic publications. It can also be observed to what extent the consortium has widened the circle of municipalities taking part in our colloquia and other forums.

5.4. Impact on the Research Community. PartKommPlus is the largest PHR project to date in Germany. We are seeking

specifically to establish PHR within the landscape of health promotion research in a country in which participatory forms of research are relatively uncommon. It will be difficult to ascertain the unique impact of PartKommPlus on the scientific community, given the growing number of projects and initiatives promoting participatory research in Germany, and given the various ways in which the German Network for Participatory Research (PartNet) is involved in addressing issues of research practice and policy. However, evidence for impact can be gathered in terms of how and where the work of PartKommPlus as a whole and the work of the subprojects are being cited in research contexts, including both conferences and publications, and the degree to which we are collaborating with other researchers.

6. Summary of Lessons Learned

- (i) We needed to experiment with different formats and means of communication to achieve a level of participation at the consortium level which meets the expectations of the local partners.
- (ii) In spite of longstanding working relationships between many of the consortium members and the mutual process of writing the grant proposal, we needed to negotiate power and control at the consortium level and build mutual trust.
- (iii) There is a parallel process operating at the local and the consortium levels. At both levels, participation, ownership, and trust are being simultaneously negotiated.
- (iv) Maximizing the participation of each lead institution in the decision-making has been challenging, but not as challenging as bringing the voices of local people to the consortium level.
- (v) The research processes at the municipal level are focused on maximizing the participation of the various stakeholders, thereby enabling a broad ownership of the local projects. Building trust and ownership at the local level stands in contrast to a central and, for many partners, abstract and geographically remote process of data synthesis.
- (vi) A decentralized, bottom-up, inductive approach to data analysis at the consortium level is more appropriate than applying a centralized data collection and analysis strategy. This approach means that we will not have a neat data synthesis from which answers to all research questions can be formulated. However, such an approach allows for a diverse assortment of various types of knowledge, products, and forms of reflection and analysis regarding municipal strategies of health promotion and participation. It also maximizes opportunities for the various stakeholders to take part in the analysis process.
- (vii) The consortium meetings have fulfilled the important function of providing mutual support and a place for sharing ideas and experiences, thus supporting local capacity building.

- (viii) The issue of impact needs to be conceptualized as multileveled, including the impact on the participants, the impact on the municipalities, the impact on the IMS community, and the impact on the research community.

7. Looking Forward

The size and scope of PartKommPlus provide a unique opportunity to observe the impact of PHR at several levels of health promotion research and practice in Germany. Given that a broad impact has been the explicit intention of PartKommPlus from the start, we are seeking to document various forms of change which have been made possible through our work. The strength of the evidence will vary, as commented above; however, the variety of sources, participants, methods, and settings will provide a strong basis for describing what impacts are possible and which factors promote and hinder these impacts. These findings will, in turn, provide a foundation for advancing IMS and PHR in Germany while serving as an example internationally for assessing impact of a national research consortium active in several regions of a country.

Data Availability

The data used to support the findings of this study are available from the corresponding author upon request.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

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Research Article

Ethical Use and Impact of Participatory Approaches to Research in Post-Disaster Environments: An Australian Bushfire Case Study

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This paper presents a case study of Beyond Bushfires, a large, multisite, mixed method study of the psychosocial impacts of major bushfires in Victoria, Australia. A participatory approach was employed throughout the study which was led by a team of academic investigators in partnership with service providers and government representatives and used on-site visits and multiple methods of communication with communities across the state to inform decision-making throughout the study. The ethics and impacts of conducting and adapting the approach within a post-disaster context will be discussed in reference to theories and models of participatory health research. The challenges of balancing local interests with state-wide implications will also be explored in the description of the methods of engagement and the study processes and outcomes. Beyond Bushfires demonstrates the feasibility of incorporating participatory methods in large, post-disaster research studies and achieving rigorous findings and multilevel impacts, while recognising the potential for some of the empowering aspects of the participatory experience to be reduced by the scaled-up approach.

1. Introduction

There are many different forms of participatory health research (PHR) but the shared principle is that “research is not done *on* people as passive subjects providing *data* but *with*

them to provide relevant information for improving their lives. The entire research process is viewed as a partnership between stakeholders...” [1]. This aims to ensure that the people whose lives or work are the subject of the study have a

central role in decision-making. Research activities in PHR create opportunities for cocreation of knowledge, and the different forms of expertise that each person brings to the process are valued [2]. There is also a shared commitment to achieve outcomes from the research that are of direct benefit to those involved.

There is growing evidence of the benefits of PHR in terms of recognition of different forms of expertise, increased relevance and uptake of outcomes, increased empowerment and/or self-efficacy, improved health status and health behaviours, and changes located in the social system [3–6]. However, there is limited evidence about the essential mechanisms to achieve change [7], an issue that a recent study by Lucero et al. begins to address in their evaluation of a conceptual framework for community based participatory research (CBPR) [8].

The uncertainty about mechanisms for change perhaps reflects the nature of PHR as an adaptive research approach incorporating many different forms of expertise, conducted in the complexity of real world situations. The strength of PHR is its contextual relevance [9] but this also offers the greatest challenge; the various forms of PHR defy attempts to define and confine them within structured guidelines [1, 10]. PHR has particular relevance for communities of disadvantage or potentially vulnerable groups because there is scope for their lived experiences to be recognised and to build their capacity and empower them in the process of shaping the research and outcomes [11]. This requires diligence in consideration of the ethics and impacts of research practice to ensure avoidance of the symbolic violence that arises if those involved are misunderstood or misrepresented [12]. Procedural ethics and review committees have been widely established in research institutions in many countries to guide the development and approval of study designs. However, an additional form of ethics in practice, referred to as “ethical reflexivity”, is proposed by Guilleman and Gillam to enable sensitive responses in situ to the complex issues that can emerge unexpectedly in health and social research [13]. Similarly, Banks et al. note the importance of relationship based approaches to ethics in participatory research [14]. The *Guide to Ethical Principles and Practice* has been produced and promoted by the International Collaboration for Participatory Health Research to provide helpful guidance in this field [9].

This paper presents a case study of Beyond Bushfires: Community Resilience and Recovery, a large, multisite post-bushfire research study. The purpose of this paper is to explore the multilevel processes involved for PHR and the importance of reflexive decision-making, particularly in sensitive contexts, and to highlight the subsequent impacts on stakeholders. The terms *impact* and *outcomes* can be used differently in evaluation. In this paper *outcomes* refers to specific changes that have occurred because of the program and *impact* refers to the effect of these changes on the stakeholders over time [1]. This case study is presented according to two core principles of the *Guide to Ethical Principles and Practice* which were found to have particular relevance, the principles of “equality and inclusion” and “making a difference”.

2. Background

In February 2009, intense bushfires raged across the regional areas of Victoria, Australia. The worst of the fires occurred on Saturday 7 February, which became known as “Black Saturday”. The impact on social and physical infrastructure was severe with 173 lives lost, over 2,000 homes destroyed, and entire communities devastated. The Vice-Chancellor of the University of Melbourne sent out a call to staff to see how the university could respond to this terrible event. In one response, a team of investigators with expertise relating to mental health, social connectedness, and wellbeing was formed and engaged in initial discussions with service providers and affected communities. It was agreed there was potential to make a considerable contribution to the evidence base to support the recovery of those affected and to inform ongoing disaster management policy and practice. The subsequent **Beyond Bushfires: Community Resilience and Recovery** mixed method study [15] was conducted from 2010 to 2016 and examined individual and community level resilience and recovery in the 3-5 years following the Black Saturday bushfires in 10 rural regions of Victoria, Australia, and involving 25 communities. A survey was circulated in 2012 to people living in the selected communities and those who had relocated, and 1,056 people participated either by phone interview or online. When the survey was repeated in 2014, 736 (78%) completed the survey again. Semistructured interviews were also conducted with 35 people aged from 4-66 years in 2013 and 2014. These interviews included a participant-guided mobile method where participants took the researchers around their homes, properties, and communities to show what was important to them [16]. There was no significant difference between participants in high, medium, and low impact communities in terms of sex, age, country of birth, or employment status.

3. Equality and Inclusion

The Guide to Ethical Principles and Practice [9] defines the role of equality and inclusion in PHR as follows:

...encouraging and enabling people from a range of backgrounds and identities (e.g., ethnicity, faith, class, education, gender, sexual orientation, (dis)ability, age) to lead, design and take part in the research, including a commitment to:

- (i) *seeking actively to include people whose voices are often ignored.*
- (ii) *challenging discriminatory and oppressive attitudes and behaviours.*
- (iii) *ensuring information, venues and formats for meetings are accessible to all. (p9)*

The initial development of the Beyond Bushfires study proposal involved the formation of a community of scholars [17] in the immediate aftermath of the fires. The term ‘community of scholars’ is used in this paper to refer to a group of people bringing different forms of expertise to the issue being researched, including academic, community, government

and service provider representatives. The University of Melbourne allocated seed funding to make it possible to develop and commit to a program of research on the individual and community level impacts of the bushfires. It was led by Professor Elizabeth Waters, a public health academic who had expertise in and commitment to PHR, ensuring the organisational structures were in place to support participatory processes [18]. The community of scholars cogenerated the research topic and study design to enable preparation and submission of a detailed application for substantial Australian Research Council Linkage funding (LP100200164). Members of the community of scholars included a team of academic investigators with expertise in trauma, grief, public health, social networks, resilience, and community wellbeing. Organisational partners included the following: Victorian Department of Health, Australian Red Cross, Australian Rotary Health, Centrelink, Phoenix Australia: Centre for Posttraumatic Mental Health, and six Primary Care Partnerships. The government and organisational partners all had responsibility for disaster recovery services. The Primary Care Partnerships (PCPs) were regional collectives of health service providers and were the initial representatives for community perspective on bushfire recovery. The University of Melbourne as the academic lead also had overall responsibility for leading Beyond Bushfires, as is often the case in participatory studies involving substantial research funding and associated ethical processes [19]. The funding proposal was for a mixed method 5-year study examining the impact of the bushfires on mental health, wellbeing, and social connectedness in diverse communities across Victoria with different levels of bushfire impact, supported by participatory principles to guide decision-making and research processes throughout the study. Mixed and multimethod research designs can be usefully combined with participatory methods to address health research issues in a way that is meaningful to local communities and stakeholders [20].

There were inevitable time delays in securing major research funding. Major competitive funding grants are not structured to respond quickly to sudden events such as disasters and tend to have low success rates. For this reason, it can be difficult and potentially unethical to invest fully in a participatory process if there are high levels of uncertainty and delays. The university's seed funding enabled us to commit the resources to cogenerated the competitive funding submission that was ultimately successful. When the PCPs were notified eight months later of the success in securing funding they were reluctant to continue to act as community representatives because they were no longer directly involved in the coordination of bushfire recovery services. This had been allocated to specially established bushfire recovery committees which varied in each location but were generally led by community members and had links to local government. In larger, more complex communities, the PCPs advised that there were many established and newly formed community groups and service provider committees that had different and sometimes competing roles in relation to bushfire recovery. This was the reality of the post-disaster environment and reflects the episodic nature of leadership that shifts in response to changed processes and context [21]. So we asked

our PCP partners to direct us to all relevant contacts in their local communities who were involved in the bushfire recovery process or were connected to community information sharing networks. The relevant contacts varied considerably so in each community we asked them "who should we be speaking to?" (Yes, we know this is not good grammar!) and following these instructions we embarked on a series of formal and informal community visits that included meeting with community leaders, walking around town with a local host, and attending meetings of different committees, community groups, and networks to listen to their local issues and talk to them about the research (see Figure 1). In those initial encounters we presented the research concept and asked if they would accept our invitation to engage in a research partnership with their community so that we could work together to develop and conduct the research. This took time and we developed a better sense of the interests and needs of the communities as we went. All but one of the communities responded very positively to this approach. The community that declined was the first one we spoke to. They explained that they felt the research was important and they understood this approach would require an investment from them but in the post-disaster circumstances they did not have the energy or capacity to accept. We always wondered whether they would have accepted if they had been one of the last ones we approached almost a year later, when things were slightly less chaotic. We did not reapproach them out of respect for their considered decision to decline the invitation.

Initially we anticipated that we would invite community members to be part of our bimonthly research investigator and partner meetings because that was where we anticipated most of our decisions would be made but through the early process of community visits and attending community meetings relating to the bushfire recovery, it increasingly became clear that there were many competing voices and tensions over people acting as unelected spokespersons. The community visits were conducted in pairs providing the opportunity to debrief and reflect on the journey back. This ethical reflexivity extended into our combined investigator and partner meetings where the post-disaster political environment, including a Victorian Bushfires Royal Commission conducted from 2009 to 2010 to investigate the causes and responses to the bushfires, was also taken into account in our decision-making [13, 22]. The process of reflexivity in our discussions included consideration of how the research processes and the broader post-disaster environment could have an unintended influence on community members' experience of the research and the research outcomes. These challenges in determining who should be involved and how should public participation be achieved are common in participatory approaches [23, 24]. As a result, we decided to engage in an ongoing process of community visits and communications to enable us to hear the multiple voices and perspectives rather than rely on a small group of community representatives. Taylor et al. [25] in their application of a Scottish participation framework to an Australian rural multisite participatory study identified "having the right people involved" as an essential factor to success (pg. e102). In the post-disaster context, it was unlikely this could be achieved



PROJECT ENGAGEMENT ACTIVITIES

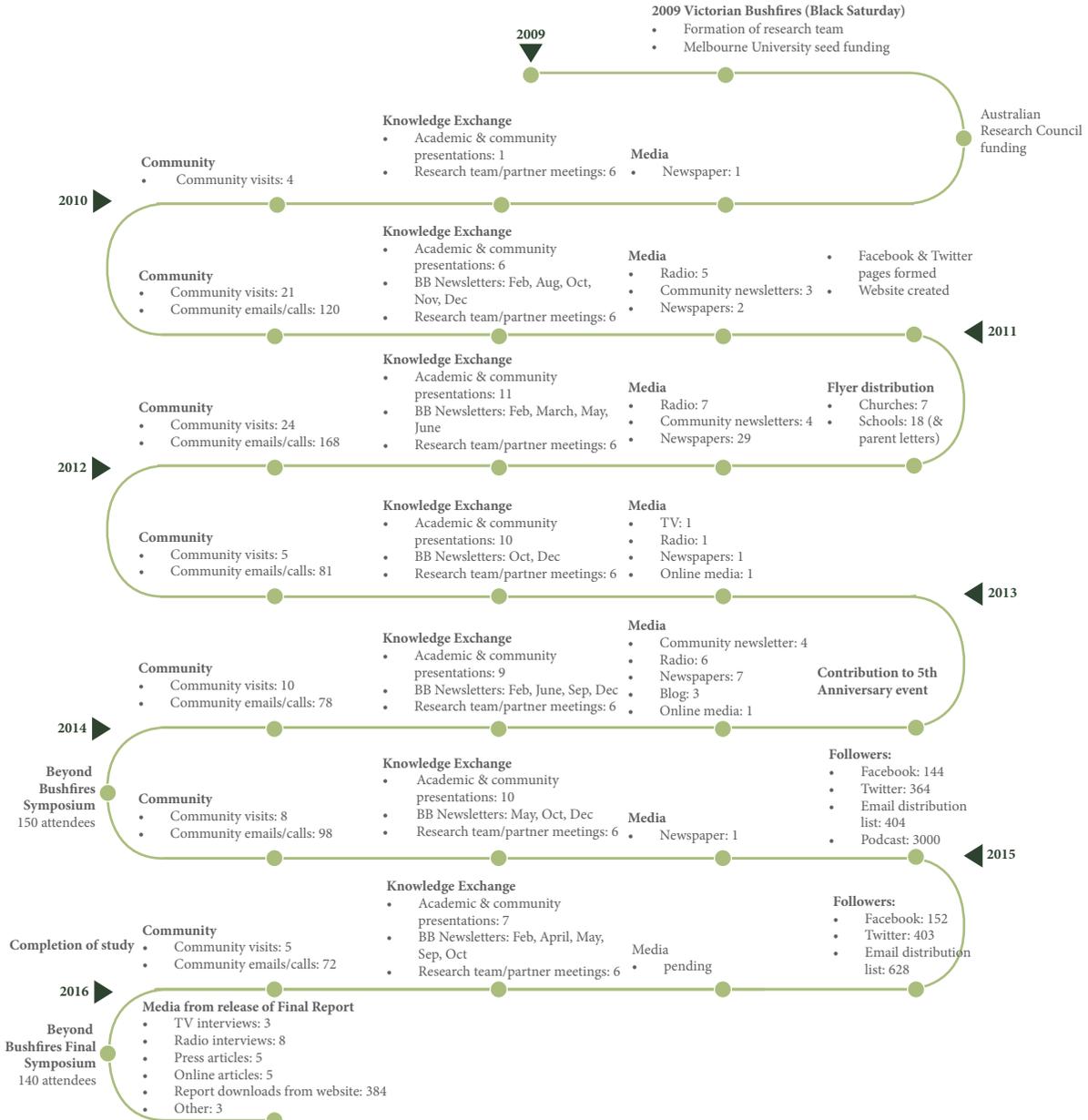


FIGURE 1

with a small number of people so we endeavoured to make as many community connections as possible. This was achieved initially through an extensive process of engagement over 12 months contacting and visiting selected communities to discuss the proposed study, to check if it seemed the right approach and if there was local support for participation in

the study, and to discuss local contextual considerations and sensitivities.

Comments and suggestions were made by each of the participating communities throughout the study which contributed to progressive adjustments to the study design and measures, enacting Freire's praxis in the development and

conduct of the study [26]. Our efforts to operate ethically and sensitively in a highly politicised and emotive environment may have inadvertently undermined community members' right to self-determination in the study, i.e., by visiting multiple sites and collecting multiple perspectives, we reduced the opportunities for a single group of community members to take responsibility for the decision-making and thereby may have limited the capacity for joint critical reflexivity and collective action [1]. However, community members demonstrated that they valued this neutrality by their willingness to include us in neighbourhood and committee meetings and to direct us to speak with other groups with competing views. Sometimes we received long phone calls and emails from community members who felt the research was important and wanted to make a contribution but had decided not to attend community meetings anymore because of previous experiences of hostility in that context. The high level of trust in the researchers was particularly notable given reports of earlier negative experiences with insensitive research practices. Another university had sent a questionnaire and consent form directly to residents in affected areas soon after the fires. Many service providers told us that the community members had been extremely distressed to open an unsolicited letter and be confronted by questions about their bushfire exposure. Instead of this nonparticipatory approach, we used our community visits to guide us. We shared information about our study through local networks before we even began a recruitment process, and we established a sensitive research protocol to minimise any potentially distressing impact of our research processes. The protocol included the community based participatory approach; obtaining informed consent before presenting the survey material about the bushfires; referral material for support services; a participant-guided approach for qualitative interviews; checks and progressive consent embedded within the surveys to alert people to upcoming questions about disaster exposure; closed questions about trauma exposure; and mental health supports [27].

The post-disaster period is generally marked by initial bonding from the shared experience of the incident, followed often by a fracturing of personal and community relationships [28]. Respecting diverse perspectives proved to be an important means of navigating through this constantly shifting social context [14]. It also allowed us to see the common issues arising at different stages of the recovery processes as well as the differences arising from personal circumstances and contextual influences. For example, in the early stages of recovery many community members who were affected by the bushfires were reluctant to access support services and resources in deference to those who were perceived to have lost the most. However, over the next couple of years tensions arose as different forms of support were disseminated and there was a perception that some people who had not really been adversely affected were benefiting unfairly from donated goods and recovery grants. The involvement of partner agencies provided important insights at all stages, including Red Cross advice on a humanitarian response; Phoenix Australia advice on care in a post trauma context; and government advice on current service delivery and uptake.

We also had to manage the differing perspectives and approaches of the team of academic investigators. An initial academic workshop was held so that each of the investigators could present their field of expertise, explain what they brought to the process, what were the required standards of rigour for their methods, and the research gaps they were interested in addressing. This proved to be instrumental in embarking on a transdisciplinary approach throughout. For example, it emerged that our epidemiologists needed to use random sampling for the survey, while our social network analysts needed snowball sampling. As a result we engaged in saturation sampling within selected communities; this satisfied both paradigms.

The insights we gleaned from our community visits, phone calls, emails and social media were always brought back to include in the decision-making processes with the academic and organisational partners. This influenced all aspects of the research including the study name, the study design, the research questions, the terminology (e.g., do not use the word "victim"), the recruitment zones, the questions in the survey, recruitment and information sharing methods, the focus of analyses, and dissemination of findings. For example, we consulted with community members about the recruitment zones for their community and discovered the area maps were not a useful guide for inclusion/exclusion. We expanded the recruitment zones to neighbouring towns when told the map boundaries were meaningless and the residents in the neighbouring areas were so closely connected it would be offensive to exclude them. Information about the study and recruitment processes was disseminated differently in each community, utilising local information networks. Repeatedly hearing emotional discussions about decisions on whether to stay living in the disaster affected community or to move away guided us in our sampling to include people who had relocated and ensured we also addressed this issue in our research questions and analyses [29]. The extensive and ongoing efforts to engage with different stakeholder groups across the state were only feasible because we had substantial research funding for an extended time. It was similar to other participatory studies in terms of consulting with citizens about research topics, priorities, and methods [30, 31] but the process did result in final decisions being made by the researchers and organisational partners, which is counter to the ideals of PHR [32–34]. Consistent with the findings of a systematic review of participatory research studies, participation was lowest regarding financial responsibility for the research funds [35].

In the early stages of Beyond Bushfires we asked community members if it should be presented as a University of Melbourne study or would it be better to be led by Australian Red Cross or community agencies to ensure sensitivity to local experiences. We were repeatedly told that the Black Saturday fires were such a major event that it made sense that a respected academic institution should lead the research process to ensure that we maximise the learnings. Perceived relevance of the findings was reinforced by informal feedback received throughout the study and indicated by over 3,000 downloads by community members of a podcast of one community seminar providing an overview of the study

findings. Social media tweets from the final symposium reached 3,388 stakeholders. The different communication channels also provided opportunities for negative feedback which were valued in guiding the processes. For example, at one symposium we presented findings that after 3 years the majority of respondents were recovering, but a significant minority (approximately twice the levels evident in the general population) were showing signs of poor mental health [36]. Audience members were very unhappy with this finding and suggested that in their experience the levels of poor mental health were far greater. The resultant discussion changed the way we presented the research findings, taking care to note that the levels being presented referred to signs of diagnosable mental health conditions which may require clinical care, were likely to be under-reported and did not include the many people likely to be experiencing lower levels of impact on mental health and wellbeing. It is possible that community members and other stakeholders who were not comfortable with our research approach chose not to engage with the study or related events at all. Indeed, the intention of our initial awareness raising activities (see Figure 1) was to give them the opportunity to make a decision about participation before they were approached.

Repeated turnover of representatives of stakeholder groups, particularly in government departments, did make it difficult to maintain partnerships over the six years of the study. This was offset by the ongoing commitment by the research team and the partner organisations to the collaborative process so that handovers were arranged and briefings held to enable new contacts to come on board quickly. Internal presentations were provided when needed for all government and organisational partner agencies to share and discuss research findings with their staff/membership, to provide an opportunity for them to contribute insights into the data analysis and dissemination strategies, and to guide their own service delivery.

4. Making a Difference

The Guide to Ethical Principles and Practice [9] suggests that “making a difference” in PHR refers to the following:

...promoting research that creates positive change for communities of place, interest or identity... (p10)

One of the primary goals of PHR is to generate positive change for those involved [9, 11]. In a large multisite study it is not possible for all stakeholders to have the direct, empowering experience of cogenerating the research process and outcomes that is a typical feature of PHR [1, 2]. Instead, we used and adapted PHR principles to reflect community issues and achieve outcomes that resonated for community members who were not directly involved, in an effort to conduct research that was experienced as positive, respectful, and relevant. In this sense, the intent was *substantive*, as described by Blackstock et al. [37] in the sense that “encouraging multiple perspectives improves understanding of the issues, and therefore the selection of appropriate solutions” (p727). The approach used was consistent with the model for community based participatory research (CBPR) with significant

contributions from service providers and policy makers in addition to community members [1, 38–40]. There are other examples of large multisite, sometimes international studies using participatory methods to address health issues [41, 42].

Predicting and capturing the long-term benefits of participating in PHR studies are challenging, as shown by a review of 60 community based participatory health research studies by Viswanathan and colleagues [43]. For Beyond Bushfires, the impact of the participatory experience on stakeholders was not systematically assessed other than monitoring and responding to feedback received on the study processes, and participant reported experiences of interviews and questionnaires. Analysis of the questionnaire responses showed that the vast majority of participants were glad they participated even if they felt distress while reflecting on the questions [27]. Many people commented in their interviews about how it aided their own reflection about their experiences or that they felt it made a contribution for others:

Well that's what it's all about isn't it. That's what we've been banging on about, information sharing to save somebody else or to influence something.

One of the community leaders who had been very positive about the study in her own presentations was asked to provide a quote for a University of Melbourne annual report. She reported the following:

The Beyond Bushfires study provides a unique window into recovery from an individual and community perspective. It has helped us to understand what we are seeing in ourselves and others, to know what is to be expected, and conversely, what is not. Most importantly, it has provided a safe, supportive environment for us to explore the lived experience of bushfire recovery...The Beyond Bushfires project and linked research has helped to make sense of the way recovery evolves over time. It has added significantly to our understanding and validated our perceptions and insights...Participating in the research was both empowering and cathartic.

Without agreed measures of impact in terms of the effect of the research processes and outcomes on the stakeholders involved, it is impossible to demonstrate the benefits of the participatory processes with any strength of evidence. Inclusion of a cogenerated framework for evaluating the impact of the participatory elements of Beyond Bushfires would have strengthened the study design [1, 37].

The participatory processes in the Beyond Bushfires study did make it possible to identify evidence gaps that needed to be addressed to guide post-disaster decision-making at individual, community, service provider, and government level. This was reflected in a subsequent mapping of key Beyond Bushfires research findings and recommendations using a socioecological framework to provide clear guidance to stakeholders about opportunities to promote positive impacts at individual, family, community, systems/services, and public policy levels (Figure 2). Additional information about

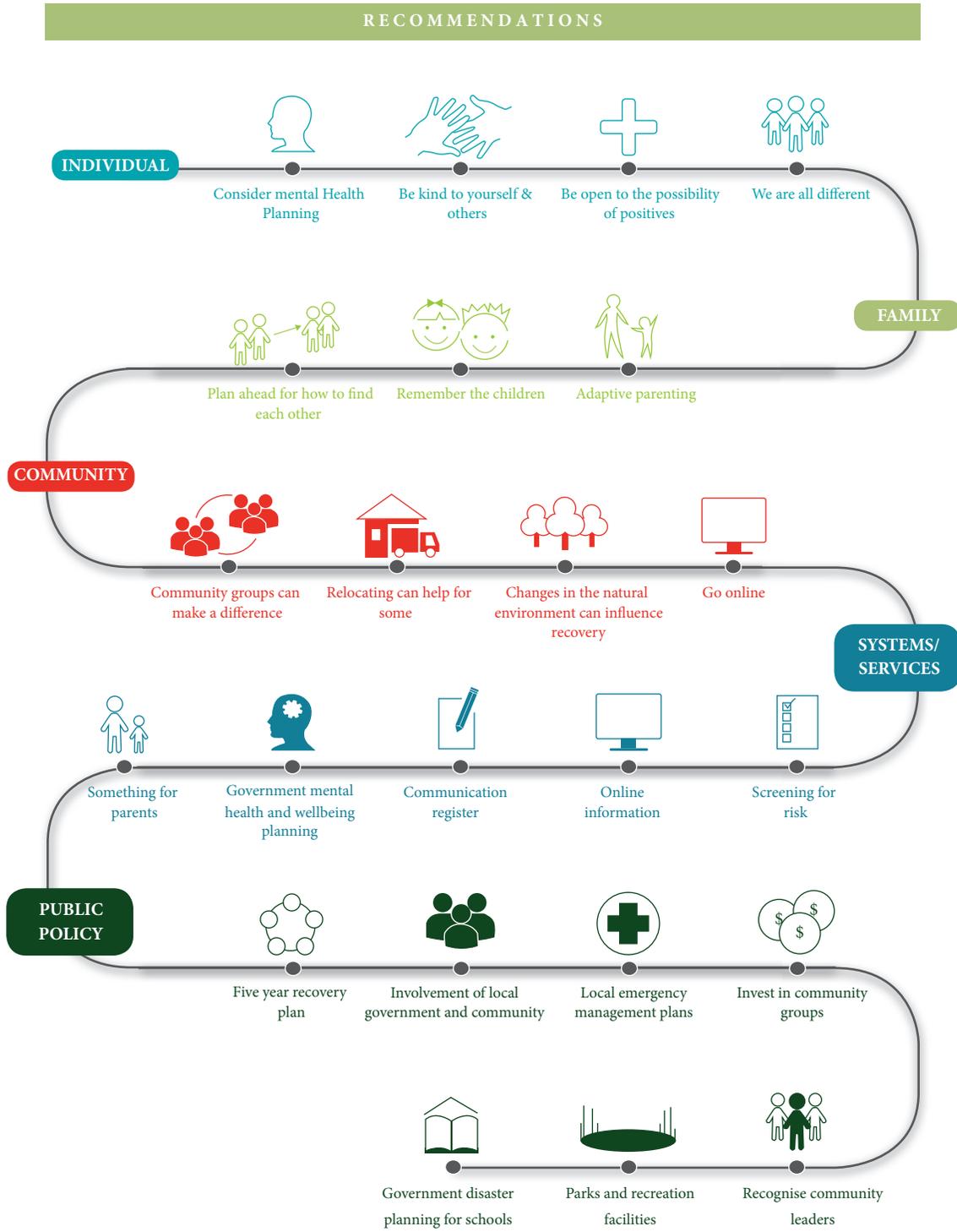


FIGURE 2

these findings and recommendations can be found in the final report [44]. Partner organisation, Australian Red Cross, identified one of their evidence gaps in relation to separation. They are responsible for providing reunification services in emergency events. They requested inclusion of survey questions about the immediate separation of family members during and after the bushfires. This enabled analysis of duration and impact of separation [45], and methods of recontact, which has been used by Red Cross to guide their review of their reunification services, Register Find Reunite [46], and will thus contribute to sustainable change promoting health and wellbeing [1].

This cogeneration of knowledge has resulted in increased relevance and application of the research and researcher understanding of the complexities of disaster recovery and contextual influences on individual and community impact. For example, the Beyond Bushfires research showed that involvement in community groups is a strong protective factor for individual mental health impacts [44], consistent with other disaster related research which has shown the importance of social capital [47, 48]. However, community visits showed that decisions about rebuilding of community facilities sometimes promoted involvement and sometimes deterred it, if it forced different groups who did not get along to now share the same venue.

The involvement of government, service provider and community organisation partners also contributed to research translation into policy and practice. The final Beyond Bushfires symposium, held in October 2016, provided an opportunity for 140 stakeholders (community 30%, academics 30%, and government and service providers 40%) to discuss the findings and potential multilevel recommendations, and to consider next steps. The aim was to create a final communicative space in the research process to encourage shared learning and outputs [49]. It was encouraging to find that issues raised by the panel speakers and the audience, such as the importance of building knowledge about how to strengthen the disaster resilience of school communities, are already being addressed in new collaborative research projects that have emerged from Beyond Bushfires and involve the existing study partners and the Department of Education and Training. This is an example of the unexpected benefits that can emerge from a participatory process and contribute to ongoing changes promoting better health [1]. Additional community seminars were organised by local partners and embedded in local events to share and discuss the findings. A plain language report was also produced and distributed widely through the different stakeholder networks to ensure the accessibility of the findings and recommendations [44]. These different outputs are consistent with one of the goals of participatory research, to allow the different contributors to determine how best to report on and share the findings [50].

Each organisational partner engaged in a different way and had different outcomes, according to their core operations and interests [43]. The academic partners increased their expertise in disaster recovery research, understanding of community, policy and practice issues, and developed an ongoing research program and collaborations with the study

partners. Having Australian Red Cross involved, as a national organisation with a clear organisational goal in supporting people affected by disasters, enabled the knowledge ascertained through the research to be incorporated into their own practice, including the Register Find Reunite service, as well as contributing to their advocacy for sound policy development in the emergency management sector. The Australian Government Department of Human Services funded a PhD scholarship within the study which was undertaken by a senior social worker employed by their Centrelink Service responsible for welfare payments. The Victorian Department of Health and Human Services used the partnership to inform their policy and practice in relation to disaster recovery psychosocial services, including consideration of disaster impact in their 10-year Mental Health Plan for the State of Victoria. Australian Rotary Health was able to share the research findings with service clubs throughout Australia. Phoenix Australia: Centre for Posttraumatic Mental Health are using the research findings to inform their trauma counselling training courses and to progress their research program. The Primary Care Partnerships use the research to inform local service delivery. Community members are using the research findings to inform their personal decisions about recovery and to make sense of their individual and community level experiences. A central goal of PHR is to “give primacy to the local context” to ensure local relevance and impacts [1]. In Beyond Bushfires it was possible to provide differentiated findings relating to level of bushfire affectedness in different areas and to incorporate influencing factors arising from local contexts. This provided outcomes which had local relevance despite the size and spread of the study.

The publication to date of 21 Beyond Bushfires academic articles in high ranking journals (<http://www.beyond-bushfires.org.au/>) demonstrates that academic rigour and contribution to evidence was not compromised by this PHR approach and the subsequent stakeholder influence on study design and research processes. This is supported by the Viswanathan et al. review which showed the capacity of community based participatory research (CBPR) studies to implement high quality research methods, contributing to positive health outcomes [43].

In summary, the multilevel outcomes of the Beyond Bushfires study achieved in the context of ethical and reflexive processes demonstrate a virtuous cycle between the “making a difference” and “equality and inclusion” aspects of the participatory approach (Figure 3) [9].

5. Conclusion

The inclusive research activities and the reflexive processes engaged in by the Beyond Bushfires community of scholars reflected a commitment to ethical and sensitive approaches and meaningful outcomes in a post-disaster environment. The participatory approach was adapted at community level to allow a scaled-up approach while still accommodating local tensions and contextual differences. It became clear in the early stages of the study that making many community connections over multiple sites was more likely to capture the multiple voices and perspectives rather than working closely

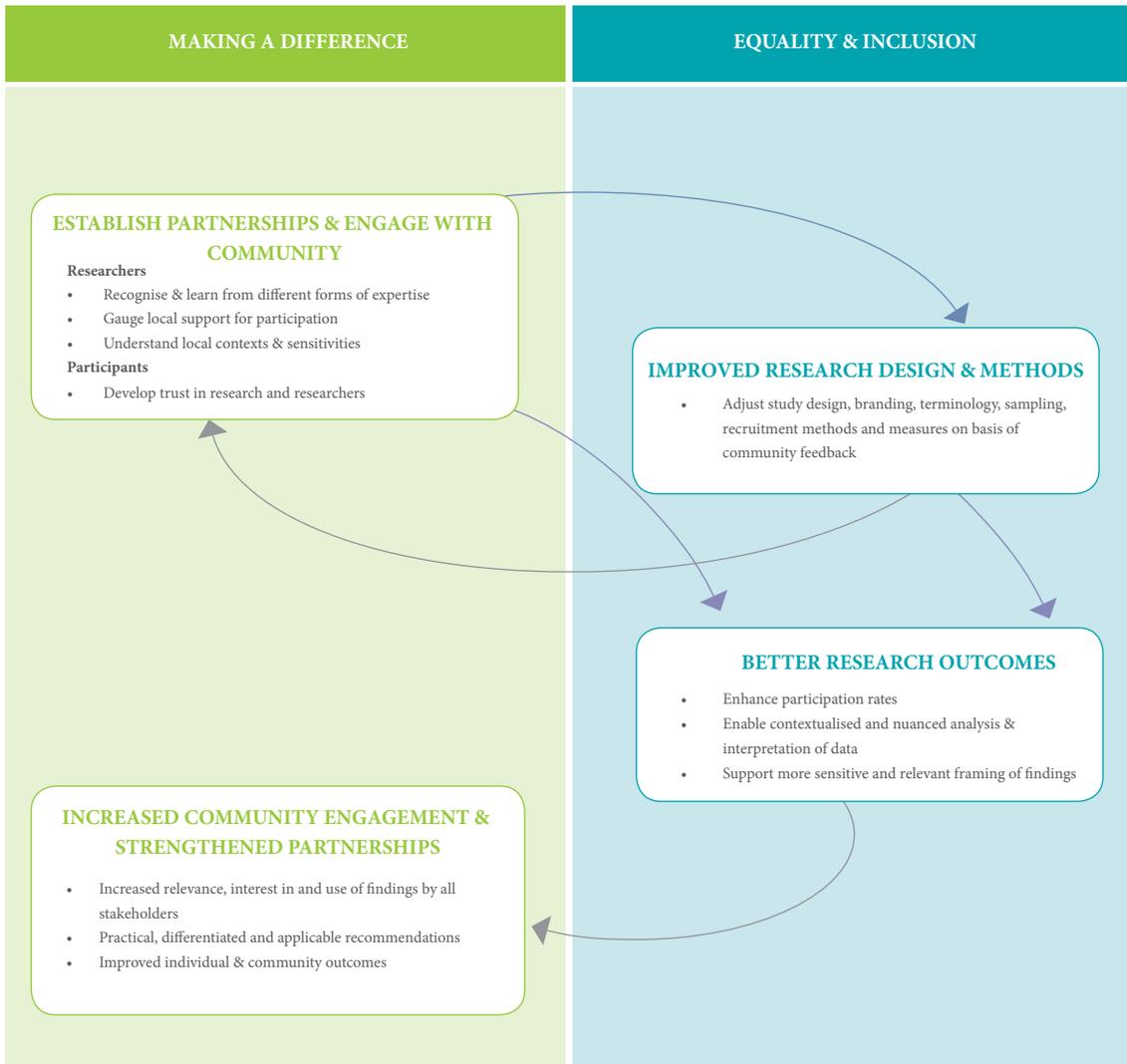


FIGURE 3: Outcomes of PHR: a virtuous cycle.

with a small group of unelected community spokespersons. This made it possible to reflect the wide ranging experiences for the large number of communities and stakeholder groups that were involved and to achieve wider scale outcomes through the government and agency partners, but is likely to have reduced the potential for individual empowerment that would typically be ascribed to a participatory process. The time and funding that was available for this study made it possible to invest in the participatory process in a way that is not always possible in research studies. Ongoing stakeholder engagement and multilevel research outcomes indicate the participatory processes were positive and worthwhile. This demonstrates the value of the investment in relationships, site visits, recognition of different forms of expertise, and an adaptive approach to the development and implementation of the study design and research processes. Other factors which contributed to success were the use of different strategies customised to local contexts to engage with community members and share information; valuing multiple perspectives; and incorporating sensitivity protocols. While the

impacts of the PHR processes in this study were not systematically monitored or measured, this descriptive account is intended to contribute insights into ethical applications of PHR in a large, multisite, mixed methods, post-disaster study.

Ethical Approval

Ethics approval was provided by The University of Melbourne’s Human Research Ethics Committee (EC-1034829).

Consent

All participants provided verbal or written consent informed by a plain language statement.

Conflicts of Interest

The authors declare that there are no conflicts of interest to report other than the relevance of the research to partner

organisations' policy and practice, as is consistent with participatory research approaches.

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Research Article

Implementation Process and Impacts of a Participatory HIV Research Project with Key Populations

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A participatory HIV research project was conducted with sex workers (SW) and men who have sex with men (MSM) to understand epidemiological HIV dynamics and associated sociobehavioural factors among these vulnerable groups. We examine the impact of this project, critically analysing the processes undertaken and focusing on the advantages and the challenges faced. A partnership was built through two Community Advisory Boards (CABs) and a Scientific Commission (SC). Regular meetings, workshops, and focus groups were conducted with CABs, SC, and partners to assess the processes and outcomes of the project implementation. This participatory research produced change processes with impacts at different levels: individuals, community organizations, health professionals, academics, and policy-makers. Advantages of the participatory process were encountered but also challenges, evidencing the dynamic and complex nature of each project's stage. This project showed that participatory research can work as an intervention. Indeed, it triggered a dynamic and interactive process of knowledge coproduction and translation into effective community-oriented health actions and policies. The participatory research reproduced an innovative alliance for HIV prevention and sexual health promotion responsive to local needs and priorities. Further efforts are needed to systematize and evaluate the processes and impacts of participatory health research.

1. Introduction

The production of evidence that informs effective and sustainable health policies and actions is key to improving populations health and obtain health gain [1]. Several authors advocate that such evidence produced through health research should (1) have quality, be focused on the health problem but also be based on its context and the involved actors; (2) be relevant, i.e., meaningful for affected communities as well as beneficial, constructive, and useful; and (3) have applicability, be usable or implementable in order to improve health practices, health outcomes, and conditions affecting health [1, 2]. This is particularly relevant in the context of most vulnerable populations, who are frequently exposed to conditions and spaces of vulnerability that reinforce their vulnerability process and distinguish them from the other populations, which translates into health inequities [3].

This is the case of sex workers (SW) and men who have sex with men (MSM) who are considered most vulnerable in the field of sexual health, namely, sexually transmitted infections as HIV infection [4–6]. Over the last decades, despite HIV infection having evolved into a chronic disease with effective combination of antiretroviral therapy [7–9], HIV infection continues to be a concern in global public health. In the European Region, Portugal had the second highest HIV prevalence—0.7% [0.6–1.0%] (among adults aged 15–49 years old)—according to the most recent available estimates [10]. In low-level and concentrated epidemics as in Portugal, SW and MSM are considered key populations who, due to specific higher-risk behaviours in combination with interpersonal, sociopolitical, and cultural contexts, are at increased risk of HIV [11, 12]. These most vulnerable populations are often subject to social stigma and marginalization which renders them particularly hard to reach [4–6]. Indeed, health research has struggled with the inability

to reach and cover such “hidden” populations who, despite being vulnerable to poor health, are frequently understudied and missed in conventional surveillance efforts [3–6]. Given the frequent inability to reach and recruit participants from these most vulnerable subgroups and obtain their perspective about the problem/phenomenon under study, the gap between knowledge producers and studied populations is often complex to overcome. The challenges in reaching and covering most vulnerable populations in research have called for a different paradigm of doing research, giving special attention to the participatory approach in health research.

In this context, based on a joint partnership between an academic institution and an HIV/AIDS nongovernmental organization with years of community work experience, a participatory HIV research project called PREVIH-*HIV/AIDS infection in Sex Workers and Men who have Sex with Men: Prevalence, determinants, prevention interventions and access to health* was developed in Portugal. The general aim of the project was to produce knowledge that contributed to the promotion of sexual health, to reduce the transmission of HIV infection and to improve access to healthcare among SW and MSM. Simultaneously, it intended to promote capacity building of stakeholders for advocacy and policy-making and to empower communities to develop skills for sexual health promotion. With an intersectoral nature, this project involved all the stakeholders interested in and affected by the HIV problematic: research/education institutions, policy-making institutions, health services, nongovernmental organizations (NGOs), community-based organizations (CBOs), and civil society. In a global perspective, the evidence produced informed the design and implementation of HIV prevention interventions in a subsequent component of the project.

In literature, participatory research is defined as a collaborative approach that involves equitably community members, representatives of governmental and nongovernmental organizations, and researchers in the process of knowledge production, incorporating the different perspectives and experiences of these stakeholders [13, 14]. Each partner contributes with unique resources and shared responsibilities to the understanding of the phenomenon being studied and its sociocultural dynamic [13, 14]. This approach combines research with capacity building strategies in order to reduce the gap between the produced knowledge through research and the translation of that knowledge into interventions and policies that improve populations health [13, 15].

Conducting research in collaboration with the communities increases the study population's adherence to the studies, which allows reaching the most vulnerable populations and obtaining spontaneous and reliable information from participants. This advantage is even more relevant given the fact that HIV and sexual risk behaviours, being strongly shaped by culturally based factors as social norms and values related to gender and taboos, are particularly sensitive topics for some communities [16, 17]. Additionally, using the participatory approach in sexual health research with most vulnerable populations has the potential for producing greater knowledge, incorporated with the perspective of communities and translatable into effective sexual health promotion policies

and strategies, more adapted to the communities' needs [13, 18–21]. Indeed, the collaborative nature of participatory research, in which communities act as active partners in the identification of the key problems, in the implementation of the methods and in the utilization of research results, has contributed to the collection of relevant and useful information from communities for improving their health [22].

In a dynamic, ecological-systems perspective, the participatory approach in health research is valuable to address the complexity, multifactoriality, and multidimensionality of health problems, framed in population-setting systems [23]. This draws attention, not only to the system context, but also to the linkages and interactions among the system's parts, especially the networks of social relationships that make up the system, the variety of roles that exist or can be created within those networks, the status conferred on those roles, the symbolism, and the meaning that different actors draw from the intervention event [23]. In this sense, alliances and coalitions that are inclusive of a diversity of actors are essential features of public health research and intervention [24].

Health research with a participatory approach can be considered as a time limited new activity setting with the potential to produce changes in the system [23]. In this sense, participatory approach can impact evolving networks of person-time-place interaction, changing relationships, displacing existing activities, creating new roles and redistributing, and transforming resources across the network [23]. The result of this collaborative and action-oriented process is the enhancement of capacity building and empowerment of communities to address and meet their health priorities [25].

Despite the increasing attention to this approach, the changes that occur when participatory research is placed into action are not fully understood. Additionally, comprehending what happens during participatory research implementation contributes to effectively linking research events to outcomes [26].

In this article we examine the impact of a participatory HIV research project with SW and MSM. We critically analyse the processes undertaken during its implementation, focusing on the advantages, the challenges encountered, and the extent of the results of this participatory research.

2. Methods

In order to ensure a strong involvement of key stakeholders in the project and considering the diversity of the study groups, at the start both initial promoters conducted an exhaustive mapping of NGOs and CBOs that worked with SW and MSM nationwide in an attempt to embrace a high and diverse number of potential partners to collaborate in the project. Each organization filled in a questionnaire providing information on the actions they undertook and the areas being reached. Organizations also indicated focal points of linkage with PREVIH team. Two Community Advisory Boards (CABs) were formed comprising social intervention workers, NGOs representatives, and members of the communities: one CAB with the Civil Society and

SW Community and one CAB with the Civil Society and MSM Community. The SW CAB initially involved social intervention workers who worked in the field with SW and had expertise and knowledge on strategies of intervention. Starting from the outreach structures, the project team described the principles, objectives, and importance of SW to participate in the CAB and asked these structures to invite their users to integrate it. This way a group of elements from the SW community was integrated into the SW CAB, which comprised 7 SW and several organizational representatives. The MSM CAB comprised representatives of organizations and LGBT associations, community leaders, and 14 MSM. For validation and monitoring of the project, a Scientific Commission (SC) was constituted with several specialists and experts with long experience in research and intervention, such as academics in the areas of epidemiology, public health, and social sciences, professionals from diverse health institutions and NGOs working with SW and MSM populations, and representatives of policy-making institutions.

The formation of both these structures (the CABs and the SC) was the base for building a partnership with all stakeholders. After establishing the partnership, CABs meetings were held for deep discussions between partners on the overall purpose and strategies of the project, in order to achieve meaningful consensus of the project's focus and boundaries.

At the start, formative research was carried out in close collaboration with partners, focusing on SW and MSM communities, to assess the feasibility and acceptability of research activities, the accessibility of health services, and prevention needs. This included a mapping of MSM socialization venues/sex work venues and networks; an assessment of implemented intervention activities and coverage; an assessment of information, education, and communication (IEC) materials followed by a revision of its content; an assessment of information lacking and strategies to reach those who need information; a mapping of the HIV services/organizations working with SW and MSM; and an assessment of accessibility, services provided, and social attitudes towards SW/MSM.

The participatory research was conducted through a biobehavioural survey to assess HIV prevalence, understand its social and behavioural correlates, and characterize the access to HIV health services. All partners—governmental and nongovernmental organizations, community members, and health services—participated in defining the objectives of the studies, outlining the methodological procedures, designing the questionnaires, implementing the field work, and interpreting the results. Methodological procedures are described elsewhere [27, 28]. In brief, a snowball sampling method was used in an attempt to reach hidden subgroups of SW and MSM. Data were collected by interviewers (members of NGOs, CBOs, and SW/MSM civil society) who participated in interviewer training sessions and were coached in collecting quality data. The data collection instrument consisted of a closed-ended questionnaire with items on sociodemographics, sexual health, risk behaviours, and access to health services. After completing the questionnaire, an HIV rapid test was provided to respondents. Facing the possibility of dealing with HIV-positive cases, a referral system for appropriate healthcare was ensured based on

an effective cooperation with the health services. Finally, all participants and SW/MSM approached were given a prevention kit containing condoms, lube, and informative leaflets on HIV prevention and testing. This participatory research was approved by the Ethics Committee for Health of the North Regional Health Administration. Regular meetings with the CABs and the SC were conducted throughout the project in order to discuss and establish the appropriate methodology for the SW and MSM populations and settings ensuring the quality and rigor of the project.

The findings obtained provided useful information and tools to develop a subsequent component of HIV prevention interventions. Therefore, after the survey, two workshops with key actors (some of them were members of the CABs and the SC) were conducted to ultimately debate upon the questions “How to understand and use the results in the communities' own settings?” and “How to put the results into practice and translate them into effective interventions?”

The following component of PREVIH involved the design and implementation of innovative evidence-based interventions for sexual health promotion, HIV prevention, and promotion of access to healthcare. These interventions covered HIV services/organizations mapping, IEC activities, peer education, and HIV testing initiatives in community-based settings.

A critical analysis of all processes was produced through focus groups with key informants who were members of the partnership and represented diverse stakeholders. Focus groups were chosen as the most appropriate method to explore the impact of new practices on roles, activities, processes, and perceptions and examine interactions among participants [29, 30]. The organization of the focus groups was decided in collaboration with the community partner. The six group discussions occurred throughout the project in key moments before, during, and after the project's implementation. In each phase, two focus groups were conducted with 8–10 participants each: one group with community members and representatives of community organizations and one group with policy-makers, health professionals, and academics. The organization of focus groups based on relative homogenous backgrounds was key to facilitating communication within the group. The group discussions focused on the assessment of the processes of the project implementation, the innovative practices taking place within the network, and the advantages and challenges encountered throughout the project.

3. Results

Throughout time, the development of this participatory project produced change processes with impacts at different levels. Along the way, clear advantages were found but also several challenges were encountered, evidencing the dynamic and complex nature of each stage of this HIV project.

3.1. Establishing the Partnership. From the start, an effort was made to embrace a high and diverse number of partners to collaborate on the project, ensuring that the principles of active participation, ownership, and empowerment were

transversal and constant throughout the project. However, this initial process occurred differentially with the SW group and the MSM group. On the one hand, the context of organized MSM social movements and community organizations made an easy task for the PREVIH team to identify community partners and later to conduct the formative research. In contrast, the SW civil society was not organized nor was easily recognizable, and therefore greater efforts were demanded to reach and involve this community in the project. From the beginning, the NGO promoter of the project acted as mediator between the project and the SW community until the “trust point” was achieved. This articulation was less complex with the MSM community. Additionally, based on the professional links with policy-makers and health professionals, the initial promoters of the project invited representatives of these stakeholders to the partnership. Building this comprehensive partnership helped create a setting conducive to making new links, connections, and exchanges between partners, especially reducing the gap between policy-makers and communities.

Overall, this first phase was essential to render the context more favourable and open to the project. At the end, the project partnership embraced diverse and numerous partners: 22 NGOs/CBOs spread nationwide, the regional health administrations of the entire country (governmental institutions), 10 public early HIV detection centres, 6 hospitals and other public health structures (specialized HIV/STI care services), over 20 different experts from key scientific fields (Epidemiology, Public Health and Social Sciences), and over 50 MSM and SW community members.

From the start of the project some challenges were foreseen, namely, the difficulty of starting research with little knowledge on such understudied populations and the fact that relevant NGOs were poorly organized (often fragmented or isolated) and had implemented sporadic actions oriented to SW and MSM. Pertinent questions arising during this stage and requiring critical analysis included the following: which organizations best represented the communities and which ones should be included in the partnership? How would the previous relationship between the different organizations have an influence? How to deal with noninterested/opponent organizations? The level of community participation varied from situations in which partners were actively involved in most stages of the research to ones in which, according to their will, partners were only consulted and kept informed about issues of interest to the research. Most partners lacked experience and preparedness to work in participatory research projects and some partners expected to have a more passive participation as top-down models are common. This demanded partners' adaptation to a new system of collaborative working, more time, and dialogue to increase participation. These background circumstances paved the way to establishing from the starting point a synergistic partnership between academic and community partners to design the project and take on shared governance.

Also, having numerous stakeholders to consider delayed some of the project's components. Some partner organizations were understaffed, which required an effort from them to stay involved. Overall, to maintain an active partnership

(with different competencies, degrees of commitment, interests, motivations, expectations of the project outcomes, and the need of continued adjustments to the project) required time, dialogue, resources, and increased workload.

3.2. Conducting the Participatory HIV Research. In the first meetings in partnership, the debates on the research overall purposes and strategies allowed all partners to rethink and redefine the substantive issues underlying the project and address specific SW and MSM concerns. This enhanced the relevance of the main health questions of the project to the community and communities' awareness of the importance of knowledge production to improve health. Yet, achieving a full commitment of community partners on the project's relevance and ensuring that they acknowledged the project as a priority were challenging. The integration of stakeholders as partners led them to act as negotiators between the project's objectives and their own objectives. Multiple preconceptions/prejudice from communities, NGOs/CBOs, academics, health professionals/services, and policy-makers/state had to be addressed. It demanded a continuing effort to build and maintain mutual trust and respect and to achieve agreement between academic scientific methods and civil society commitment with advocacy for SW and MSM rights. One example of this effort was an initial discussion within the MSM CAB on the term used to designate the study population—MSM. Though in the academic context “MSM” has been broadly adopted in research, for the community this was considered a reductive expression to characterize a heterogeneous group based on the single feature of sexual partners' sex. These discussions allowed reducing defensive stances from partners, addressing myths and misconceptions, and reaching a consensual definition of the target population that could be operationalized to respond to the research questions.

Globally, the discussions in partnership about the procedures and implementation of the research led to developing a more appropriate study design, methodology, methods, and measures for the SW and MSM populations and settings. More specifically, through CABs auscultation, all partners participated in the definition and revision of the items to be included in the questionnaire. During this process misinterpretation of several questions was detected. For example, while discussing the instrument within the SW CAB disparate definitions of “occasional” and “regular” sexual partner emerged. Debating these issues with partners was valuable to bridge differences, ending up having contextually congruent concepts and measures. Ultimately, this process helped adapt the instrument to the study populations' characteristics and context.

The meetings with both CABs enabled consulting members about obstacles and strategies to best reach and involve SW and MSM hidden subgroups in the survey assuring scientific rigor. For example, in a pilot phase a high rate of noncompliance with the study was observed among SW and MSM and the discussions with the CABs allowed bringing up some strategies to alter this trend. An agreed upon strategy was to include elements of the study populations (MSM and ex-SW) in the interviewers' team, and this helped enhance

the acceptance of the study and reach hidden subgroups that were out of range of the existing structures.

In the field, the implementation of the snowball sampling method was possible through the social networks of community partners and their expertise in the field. The interviewer training sessions for data collection were dynamic, with feedback being collected from all participants and taken into account. This increased capacity of trainees as they actively participated in the debate about, for example, dubious questions/answers and terminology used in the questionnaire, the approach to invite potential participants, and procedures to obtain the informed consent and to administer the questionnaire.

Overall, the collaboration of community partners in advertising the project, recruiting participants, and collecting data as interviewers enhanced the communities' acceptance of the study, the recruitment and retention rates of participants, and the diversity of participants by including hard-to-reach subgroups. The meetings with the SC conducted throughout the project to discuss and validate the methodological options and the monitoring and evaluation of its implementation ensured the quality and scientific rigor of the project, as well as its relevance and responsiveness. At the end of this phase, 60 SW peers/representatives of NGOs and CBOs working with SW and 31 MSM (peers and NGO/CBO members) had been enrolled as interviewers. Total samples of 1040 SW and 1046 MSM respondents were reached, over 1100 HIV rapid tests were performed, and about 3400 people received HIV information and prevention material.

This kind of research that focuses on sensitive topics like HIV among most vulnerable populations raises relevant ethical issues related to human rights, social inequities, potential harm and impact in terms of social stigma/discrimination, and protection of participants' anonymity and data confidentiality. In this context, using a participatory approach also allowed addressing and discussing these crucial aspects within partnership.

3.3. *Analysing, Interpreting, and Disseminating the Results.*

After collecting the data, the presentation of the preliminary results to the CABs and the SC stimulated the discussion on the relevant analyses and the interpretation of the findings. Although the members of the partnership had different backgrounds and competencies, acknowledging and respecting each other's contribution allowed creating new synergies and discovering possibilities for knowledge and action. Members outside the academic institutions had a meaningful role, providing important insights into additional analyses to further explore the complex links between variables that were not initially foreseen. Indeed, discussing the findings within the partnership allowed the integration of multiple perspectives that enriched the interpretation and contextualization of the results and enhanced a process of exchange between community stakeholders and researchers. The dissemination of the results was another aspect discussed in partnership. Controversy arose during this period, especially with an ethical "dilemma" in the centre of the discussion: while the evidence on HIV prevalence and associated factors among SW and MSM would be crucial to inform health

policies and prevention strategies, the risk of consequent social prejudice and stigma towards SW and MSM populations was real and this required serious debate within the partnership. Discussing the dissemination strategy with partners enabled the presentation of the results to diverse and wide audiences beyond the scientific community (policy-makers, health professionals, SW/MSM communities, and civil society). Some examples included a public conference coorganized by academic and community partners with visibility in social media, as well as "Community Reports" presented and distributed by the community partners. In addition, the main findings were presented in scientific conferences and were published in peer-review scientific journals where community partners were included as co-authors [27, 28]. In addition, the project constituted a data source for response to specific health and HIV indicators by international institutions like UNAIDS, ECDC, and WHO and national institutions like the General Directorate of Health and the National Institute of Statistics.

3.4. *Designing and Implementing HIV Prevention Interventions.*

The interventions developed in a subsequent component of the project attempted to adequately respond to communities' specific needs identified through the participatory research. The planning and implementation of the different interventions in close partnership with the NGOs, CBOs, and civil society partners enabled promotion of institutional capacity building on advocacy for sexual health promotion and rights. It also enhanced the empowerment and the capacity of SW/MSM communities to understand their health needs and redirect their efforts in addressing them. The developed interventions comprised HIV services/organizations mapping, IEC activities, peer education, and HIV testing initiatives in community-based settings.

The systematic mapping of HIV services and organizations nationwide working in the HIV field, particularly with SW and MSM, provided a knowledge base that contributed to promoting the creation of collaborative partnerships for the development of multisectoral interventions as effective responses to complex problems such as HIV, in the future.

The elaboration of IEC materials was based on the partners' contribution to the revision and assessment of existing IEC materials, which helped improve the appropriateness and effectiveness of IEC materials. This intervention also covered the promotion of campaigns for HIV information and prevention through the distribution of IEC and prevention materials within SW and MSM communities, using innovative and creative methodologies. The IEC materials were made available to NGOs/CBOs and institutions working with SW and MSM. This approach helped prevent duplication of efforts across the NGOs and CBOs that implement IEC activities in their daily activities and allowed developing more targeted and effective initiatives by providing the information that is really needed.

The peer education initiatives contributed to promote changes in knowledge, skills and competencies, reduction of risk behaviours, and access to healthcare. Those initiatives were implemented by members of the SW and MSM peer group who were influential in eliciting behavioural change

among their peers. A total of 25 MSM peer educators trained other peers to disseminate risk reduction information within their social networks. Among SW, six peer educators were trained and were integrated in a semiprofessionalized fashion on NGOs outreach teams in which individual goals and evaluation plans were designed collaboratively. Moreover, based on the connections built between these SW, a network of SW was established with the aim of recognition and valorisation of sex work in the country.

Also, new HIV testing strategies were collaboratively designed and developed by community partners aimed to improve access to HIV health services to subgroups that often did not access formal healthcare due to stigma and discrimination-related barriers. HIV testing was traditionally only available at formal healthcare services, but the knowledge produced from this project raised stakeholders' awareness, especially policy-makers, towards the urgency of developing HIV testing strategies that would cover those most vulnerable and out of reach of existing health structures. Examples of such initiatives were the establishment of new proximity responses such as mobile units and community-based centres for HIV testing and counselling targeting those most vulnerable (including sex workers and injection-drug users).

In this interventional phase, adjustments to activities were required according to each area and population and often to organization/community partner. Several "subprojects" with specific implementation procedures and processes were created, which increased the project workload. Overall, the involvement and participation of community partners in designing and implementing the interventions favoured the creation of a context to promote sexual health and advocate for changes in public policies that have an adverse impact in their communities.

4. Discussion

The experience of implementing this HIV research project within a participatory approach reinforced its potential for producing relevant knowledge that contributes to effectively improving populations' health, as documented elsewhere [31]. Through the active participation of key stakeholders in this HIV research project it was possible to reach and gather large and heterogeneous samples of SW and MSM, including hard-to-reach subgroups at increased risk of HIV infection, in a context where many of these populations have a feeling of mistrust and disinterest towards research. Indeed, the obtained sample of 1040 SW was comprised of outdoor and indoor SW and nationals and nonnationals, with poor socioeconomic status and reported HIV/other STIs. This research also reached a subsample of transgender SW, a subgroup who is frequently missed in research initiatives and is particularly at increased risk of HIV infection [32]. Moreover, the 1046 MSM enrolled in this research included men with diverse sexual identities and orientations, a feature that has been described as an individual-level factor associated with HIV risk behaviours. Overall, through this HIV research project it was possible, for the first time, to obtain information on the HIV prevalence and associated

factors among key populations in the country that were not being covered in traditional surveillance efforts and therefore reliable information had not existed thus far.

The integration of the perspectives and experiences of communities enabled deeper understanding of the complex processes underlying the multiple interdependent sociocultural and contextual factors associated with HIV infection. For instance, it allowed better comprehension at what extent contextual factors, such as poverty, drug use, and sex work settings, are linked and increase SW vulnerability to HIV infection and what contexts increase MSM exposure to HIV risk, especially considering cruising venues and other locations where MSM seek sexual partners [27, 28]. Ultimately, this process of collaborative knowledge production enabled generation of more relevant knowledge translatable into practices that effectively responded to these populations' needs. In this sense, the recommendations driven from this project were contextually and culturally grounded and relevant, enhancing the applicability of the research findings into more effective community-oriented health actions and policies. Taking shared decisions contributed to strengthening the partners' sense of ownership, regulation, and coresponsibility, while enhancing trust, legitimization, and credibility of the project by nonacademic partners.

This participatory research worked in and of itself as an intervention as it increased all actors' capacity to deal with the HIV issue. At individual and civil society level, there are now more people aware and committed to HIV issues, with access to HIV prevention information, tested for HIV and aware of their serostatus, and informed about where to get tested and treated. Community-based organizations have developed a more reflexive practice, increased capacity for monitoring their activities, and are better informed to address communities' health needs and advocate for sexual health rights. Health professionals are more aware of further steps to improve the adequateness of healthcare delivery. Academics are now more knowledgeable of the epidemiological HIV dynamics; the best strategies do reach most vulnerable populations and are better prepared to produce evidence to inform sexual health rights-based policies and HIV prevention interventions. Researchers with different backgrounds worked together to synthesize existing evidence on this theme. By drawing on evidence across different contexts, disciplines, and actors, academics could make stronger arguments for policy change, along with increasing their expertise and being seen as credible by policy-makers. In their turn, policy-makers have better understanding on the contexts of vulnerability, what policies and strategies work, and what does not work and why.

Nevertheless, several challenges in adopting the participatory approach in this HIV research were experienced and should be considered in the future. Sharing power and ensuring an equitable involvement of the different partners in decision-making were lengthy and demanding processes [33]. Maintaining an effective partnership, which is a fluid, evolving process, required continuing effort and negotiation skills. These challenges were experienced by the research team. Academics are generally used to having the control of the research process. To share power and negotiate with

partners and be available to make adjustments along the way in this participatory project implied flexibility. In fact, the focus groups conducted to assess the project's implementation served also as a tool and an opportunity for the research team to exercise their self-reflexivity on the effects of the participatory processes undertaken and the adaptations needed throughout the project. Another common challenge was related to the different partners' priorities. For example, the academics were committed to more traditional methods that ensured the scientific rigor of research, were pressured by the need to quickly publish the evidence in high-impact scientific journals, and prioritized research topics that they considered more interesting and appealing to investigate and publish. On the other hand, some community partners were resistant to research that challenged their values, attitudes, and practices, were not sensitized to the methodological procedures required, and were committed to respond to their specific real concerns. Divergence and controversy arose while achieving a compromise to meaningful consensus that implied negotiation between conflicting interests. Globally, the process forced actors to reorient and expand the problematization, considering their multiple perspectives of analysis of the project and different interpretations of its successes/failures.

PREVIH operated in a singular context of different actors (academics, community representatives, NGOs/CBOs, health professionals, and policy-makers) reconfigured in terms of their identities, interests, and practices, confirming that participatory research has the potential to intervene and transform the system by its interaction with the context and the capability created from that interaction [23, 26]. Through a reflexive dynamic, this participatory research reproduced an innovative alliance for HIV prevention and sexual health promotion responsive to local needs and priorities [24]. The creation of new connections between partners changed social positions, some people becoming more central, others less central, and others connected for the first time. These connections created new opportunities for the exchange of information, material resources, and support. In other words, the created network facilitated the exchange of diverse forms of knowledge and knowing and enabled the development of shared understanding and insight between initially foreign universes, which, in turn, gradually reconfigured themselves through their interactions, as described by other authors [23, 24].

This experience confirmed that rather than the conventional view of research as a "program package" standardised and replicable across settings, research should be understood as a dynamic process [23]. In fact, innovative practices took place throughout the project and were crucial to the coconstruction of knowledge among the actors at different levels, as theorized by other authors [29] as practices at cognitive level: circulating partners' knowledge which helped to frame research questions, knowledge production processes, and translation into the various partners' networks; strategic level: all activities, tools, and competences mobilised to raise and maintain the different partners' interest in participatory research; and logistic level: the coordination tasks that create the actual conditions for the partnership.

Indeed, the discussions promoted within the CABs and the SC at key stages of the project were a major mechanism to enhance partners' capacity building. The interaction that was created between the different elements of the CABs generated mechanisms of ownership and empowerment among these groups, in which each other's experiences and knowledge were valuable resources for the partnership performance. Additionally, having CABs enabled the proximity to the study populations, increasing communities' adherence and the appropriateness of activities, which ultimately helped ensure that the project would permanently respond to the communities' needs and concerns.

The emergence of this new structure for action aimed to jointly promote sexual health, reduce the transmission of HIV infection, and improve access to healthcare among SW and MSM, which represented a system-level impact of the participatory approach. Besides the individual units of change within the system, the knowledge and skill sets changed in the partners. The new structure potentially represents a particular new capability and its outcome is other vital new connections made both within the original network and outside of it, which continually place the actors in the network in a position to access resources and opportunities for adaptation and growth, as described elsewhere [23].

This experience also triggered a dynamic and interactive process of knowledge translation, i.e., of knowledge production and application into effective actions aimed to improve populations' health. The PREVIH experience led to identifying specific community needs and opportunities to intervene. In this sense, outcomes not foreseen initially emerged such as the development of new HIV testing policies, networks, and initiatives that continued after the project's timeline ended.

5. Conclusions

This experience enabled the construction of innovative alliances for coproduction of knowledge adapted to the needs of involved actors and translatable into effective sexual health promotion and HIV prevention interventions. This participatory health research enhanced partners' capacity for conceiving actions more relevant, coherent, responsive, and sustainable overtime.

This project reinforced the relevance of the participatory research as an alternative approach to address the current challenges in health research and tackle health inequities. Indeed, the complex nature of health problems, the diversity of settings, and the disparate levels of vulnerability across populations highlight the need of innovative ways to conduct research collaboratively, which calls all stakeholders to "step outside of the box."

Though some challenges remain, how to move forward to better systematize and evaluate the processes and impacts of participatory health research in its different complex dimensions, measure the dynamic changes, underlying shared values and principles, and assess capacity building in network, among others, is still challenging. This implies that stakeholders are skilled to undertake new practices and funders are aware of the need for further resources allocation.

Overall, in the face of the innumerable strengths and potentialities of participatory health research, to scale up this approach while tackling its challenges is key to maximizing its impact in improving populations health and promoting health equity.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

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Review Article

The Interplay between Participatory Health Research and Implementation Research: Canadian Research Funding Perspectives

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Objectives. The objective of this paper is to investigate what participatory health research (PHR) can offer implementation research (IR) and vice versa and discuss what health research funders can do to foster the intersection of both fields. *Methods.* We contrast points of divergence and convergence between IR and PHR. We reflect on whether community engagement is necessary and on the unintended consequences of participation in IR. We describe how a research funder can incentivize PHR in IR. *Results.* Participation is encouraged in IR but the nuances of who is involved merit greater attention in IR. PHR and IR differ in emphasis placed on the scale-up of the intervention. However, they share a common interest in generating real-world contextually relevant evidence. *Conclusions.* We need to assess whether and how funding practices influence researchers in how they undertake PHR. Researchers need to better account for participatory approaches to ensure that any potentially harmful consequences are described (and better understood so they can be mitigated in the future) and elucidate the ways in which these processes do or do not enable implementation and scale-up of interventions in IR.

1. Introduction

Increasingly, researchers and research funders around the globe are turning their attention to funding and conducting implementation research (or science). This growing trend is in response to a need for real-world and contextually sensitive evidence to respond to and solve implementation problems facing policy-makers, practitioners, communities, and other social actors working in sectors such as health [1, 2]. Lack of community readiness or engagement and a poor understanding of the sociopolitical and cultural contexts in which interventions are implemented are among the reasons cited for this limited progress in using evidence in policy and practice settings [3, 4].

“Implementation science examines what works, for whom, under what contextual circumstances, and whether interventions are scalable in equitable ways. The intervention

includes the “what”—[for instance, a policy or community program]—as well as the “how”—the implementation activities that are required to achieve full (equitable) coverage of . . . the intervention” [2]. Like with any emerging field, a plurality of research methods and theories are expected to contribute to the further conceptualization, design, and conduct of implementation research studies. In recent decades, interest in participatory health research (PHR) has been steadily rising, in part due to increased funding incentives for academics to cocreate knowledge and align research with the real-world needs and interests of different actors with the promise of greater applicability and impact of the research for communities, policy-makers, and practitioners [5–7].

In light of such trends, research funders are responding. The Canadian Institutes of Health Research (CIHR), Canada’s premier health research funding agency, supports research that is either investigator-led or priority-driven across the

four health research pillars/themes (biomedical, clinical, and health services and social, cultural, environmental, and population health) [8]. While PHR is generally applicable to three of the four pillars of health research at CIHR, this article focuses on research funding initiatives addressing two of the four (health services and social, cultural, environmental, and population health). CIHR has, over the last five years, stepped up its contributions to implementation research (IR) through its investments in global health research (e.g., maternal and child health, chronic diseases) [9], Pathways to Health Equity for Aboriginal Peoples [10], HIV/AIDs [11], and various health systems and patient-oriented research initiatives to name but a few [12]. CIHR has also declared its commitment to citizen engagement in health research, which it defines as the meaningful involvement of individual citizens in activities such as research priority-setting, planning, governance, and peer review to enhance the relevance and application of research into practice and policy [13].

2. Methods

In this commentary-style article, we pose the following central questions: what does participatory health research (PHR) have to offer implementation research (IR) and what does IR have to offer PHR? We start by looking at how PHR and IR diverge and how they intersect or converge with respect to participatory approaches. Then, we briefly consider the following questions in relation to implementation research: Who are the “participants” in IR studies and is community engagement always necessary in IR? What are the possible unintended consequences of participatory processes in the context of IR studies? Using illustrative examples from recently funded research initiatives, we also discuss what roles health research funders can play in fostering the intersection of participatory health research and implementation research and consider how this would advance research in both fields.

3. Results

3.1. What Does Participatory Health Research (PHR) Have to Offer Implementation Research (IR), and What Does IR Have to Offer PHR? How Do They Intersect and Diverge from Each Other? While it is well beyond the scope of this paper to review all possible theoretical and methodological approaches that underpin PHR (refer to other papers in this supplement), suffice it to say that PHR approaches hold some common core principles. These include meaningful community engagement and cocreation of knowledge that accounts for different ways of knowing, commitment to social change extending beyond the generation of knowledge, grounding in participants’ lived experiences in the local context, and reflexivity [14, 15]. PHR has been defined as a “transformative research paradigm that bridges the gap between science and practice through community engagement and social action to increase health equity” [16, p.40]. It is also a field of research that goes by different names (community-based research, action research, community-based participatory research, participatory methods, etc.), reflecting different country and ideological and disciplinary traditions [17].

3.2. Points of Divergence between PHR and IR. Implementation researchers are encouraged to be more explicit about the “nature” of the intervention (which should also include who defines what “it” is), what underlying sociostructural determinants are at play, and how these need to be considered in planning for both horizontal and vertical scale-up of the intervention [2]. The starting point in IR is usually innovations or interventions with some level of demonstrated effectiveness. While participation is certainly encouraged in IR, we argue that the nuances of participatory engagement processes and related measures have not received sufficient attention in IR [18]. This matters because participant characteristics and their structural influences can affect implementation effectiveness [19]. The focus is generally on the participation of those responsible for delivering or implementing the innovation or intervention. This tendency reflects some of the roots of implementation research (science), which stem from quality assurance initiatives and their related focus on those formally responsible for health services delivery [1, 2]. The quality assurance approach involves the plan-do-study-act cycle but PHR and IR diverge with respect to who is primarily involved in this cycle of reflexivity [20].

A second point of divergence concerns scale-up of the intervention. While PHR is mainly focused on the codesign of research questions, participation in implementation, and analysis processes, implementation research (or science) is usually concerned with approaches that will enhance scale-up of effective interventions. A key difference between PHR and IR is therefore the extent of emphasis on scale-up, stemming in part from the “who” is participating in IR (i.e., usually actors delivering the intervention). There are in fact many examples of PHR where the potential scalability of the innovation or intervention and the scalable unit are simply not considered throughout the research process [21].

3.3. Points of Intersection between PHR and IR. Where IR and PHR fundamentally intersect is in a seemingly shared desire to generate “real-world” evidence—with many social realities unfolding. Both can be viewed as a response to the limitations of the one-way pipeline model of transferring evidence-based knowledge from researcher to end-users such as community members. Without an understanding of community needs, the uptake of such knowledge can fall short. If the ultimate goal is therefore to understand and characterize these real-world and dynamic (as opposed to linear) contextual conditions under which different social actors operate and to improve knowledge use, then PHR is necessary for all implementation research efforts. Shirk et al. [22] argue that outcomes are affected by the degree and quality of public participation as negotiated at the outset. The research question or implementation problem is the starting point for implementation research and related methods. For example, the degree of intervention acceptability and appropriateness during implementation are key topics for interrogation in IR, requiring a robust account of the intervention embedded in its context and the use of participatory approaches [1, 23].

PHR and IR also intersect given the increasing imperative of better accounting for context to improve understanding of how and for whom an intervention works and to explain

variations in implementation [24]. Researchers are being encouraged to better theorize about and measure context rather than treating it as something that is static and must be controlled for or as rationale for an intervention's implementation failure [25–27]. The ways in which PHR can best inform IR therefore concern who is involved and engaged in identifying salient dimensions of context and how these may drive inequities or create barriers to or enablers of change [3, 28]. The notion of adaptation of the intervention to context is also noteworthy. This is a feature of IR, although preoccupations with questions of fidelity also present in IR may limit the extent to which consideration is given to adaptive designs [2, 28]. To date, there has been a tendency for the salient dimensions of context and the nuanced characteristics of that context to be defined by researchers, sometimes in a way that is bereft of any authentic community engagement processes [29]. PHR approaches have also been promoted as a strategy to reduce health inequities [30], given some evidence that these approaches can improve social capital and cohesion [30]. The use of PHR approaches could help in better elucidating how an intervention adapts to its context throughout implementation and with what health and health equity impacts. These approaches can inform what the intervention actually entails, how it interacts with context in compatible and incompatible ways, how and why it changes over time, and “who” is affected disproportionately by social and health inequities potentially arising from the intervention's implementation [31]; they can also help better characterize and contextualize changes in coverage and benefits for intended participants [1]. Another area for further exploration might be how PHR can contribute knowledge about why the “fidelity” of an intervention is not retained or how and why interventions are adapted when implemented in a different setting.

3.4. Who Are the “Participants” in IR Studies and Is Community Engagement Always Necessary in IR or Not? At its core, PHR requires the democratic participation of different actors (which vary depending on the intervention and the context)—researchers, policy-makers, health system practitioners, community members, citizens, and so on. “Who” participates, the extent to which they participate, and how and when they participate are all clearly pertinent to the operationalization of PHR approaches. This leads us to also ask whether or not community engagement (and also what is meant by community) is always necessary in IR. As described above, who is engaged and the nature and the extent of community engagement are points of divergence between PHR and IR. While considered an essential element of PHR, in IR studies, community engagement is not always considered essential and how community engagement is operationalized varies considerably. With PHR, we are most often referring to the main beneficiary of the intervention (e.g., community members, target population), while, in IR, the engagement may be policy stakeholders and those responsible for delivering the intervention. Second, the timing and frequency of that engagement also vary considerably between PHR and IR.

3.5. What Are the Possible Unintended Consequences of Participatory Processes in the Context of IR Studies? Negotiating community and research perspectives and interests present ongoing conundrums in the application of participatory approaches in research, including but not limited to IR studies. Different career and cultural imperatives between academic and community partners require open debate and transparent discussion throughout the research process [32, p. 300]. “Involving people in decisions that affect them is justified both by ethical and political arguments and by instrumental arguments asserting that involvement will lead to decisions more relevant to the people being served” [33, p. 6]. While encouraging community engagement through the use of participatory processes comes with certain advantages, it can also present risks of potential harm and unintended consequences. Authentic engagement of communities does not always transpire in all research endeavours, let alone in implementation research. Engagement in research can make communities more vulnerable. Without the necessary safeguards, such as mechanisms of co-governance that ensure transparency and accountability in decision-making, communities can inadvertently become the objects of research agendas to the benefit of others. Katz et al. [34] documented harms related to, for example, delegated control (e.g., participatory process perpetuates status quo of neoliberalism, colonialism, and/or racism), demobilization (e.g., participant burn-out), or sanctions (e.g., participant resistance results in loss of paid work). These authors concluded that participation was often discontinued at implementation, making it challenging for communities to hold the conveners accountable, further underscoring differences in power relations [34]. If “communities” do know best and are well-positioned to contextualize an intervention by “integrating cultural values and practices to enhance sustainability when grant funding ends,” they also need to be valued as equal contributors in the production of knowledge [15]. This implies that, throughout the research, all partners be engaged in how the process is governed, recognizing the unique strengths that each can contribute while mitigating any potential harms from participation. Let us take the example of North-South partnerships in global health research.

3.5.1. Power Relations between the “Participants” in the Research Process. The development and sustainability of Canada and low- and middle-income country (LMIC) partnerships that are egalitarian have been an objective of research funding in global health such as Canada's former Global Health Research Initiative [35]. It is, however, no easy feat and may in fact not be fully realized in practice given preexisting power asymmetries within teams, including those between researchers from different disciplines and decision-makers and communities, and across country contexts. Not only are preexisting power differences challenging to overcome in North-South partnerships, but they can also inadvertently undermine the ability to achieve an equitable orientation in research programming [36]. In an analysis of a Canadian-led global health research funding program, the authors argued that “the donor's finance and grant administration systems favored lower-risk Canadian

TABLE 1: *Eligibility and review criteria respecting who needs to be engaged in selected CIHR-funded initiatives on implementation research (IR). Table 1 outlines excerpts from IR-focused initiatives led by/involving CIHR that favour the use of participatory health research (PHR). It focuses on the “who” needs to be engaged in IR. The eligibility criteria relate to who can lead the research, who must be involved in the research, and who can hold the funds. Eligibility is assessed first and if these criteria are not met, the application does not advance through peer review. The peer review criteria are used by reviewers to assess the proposals.*

Funding initiative	Eligibility (who <i>must</i> lead and be involved in research)	Peer review criteria (how the research proposal is assessed)
CIHR Pathways to Health Equity for Aboriginal Peoples—Implementation Research Teams (component 2)	Independent researcher (Nominated Principal Applicant (PA)) At least one community member must be listed as a principal knowledge user Community-based policy/decision-maker expected to play key role in ensuring sound engagement strategies with communities.	Composition of team: “demonstrated experience working with Aboriginal communities in different contexts” Research and Community Engagement plan is culturally appropriate, gender sensitive, ethical, and methodologically sound Evidence of equitable and ethical partnerships with communities
Innovating for Maternal and Child Health—Implementation Research Teams (no longer publicly available) (CIHR, International Development Research Centre (lead) & Global Affairs Canada)	African researcher based in a targeted country (PA) Canadian researcher as a co-PA National level decision-maker as a co-PA (from same country as PA)	Team demonstrates a strong track record relevant to IR
HIV Implementation Science—Component 1	One knowledge user must be a community member with lived experience One knowledge user must be a decision-maker from service/policy-oriented organization.	Multidisciplinary, multisectoral team with expertise <i>relevant to involved communities/settings</i> ; policy environments; disciplines relevant to IR

institutions over generally higher-risk LMIC grantees and placed less restrictions on Canadian institutions than it did on LMIC ones” [36, p8]. Although inequitable fiscal relationships may adversely affect partnerships, other features of international partnerships can thrive. For example, an analysis across several case studies of North-South partnerships found that the global health partnered research could result in thriving and impactful partnerships. These partnerships were characterized as follows: (1) long-term and sustainable North-South partnerships; (2) interdisciplinary responses to complex issues; (3) participatory action research that grounds the research in its context; and (4) research with a policy or practice impact orientation [37]. Bearing the above intersections between IR and PHR in mind, we now explore the role and selected practices of research funders, and in particular CIHR.

3.6. Role and Practices of Research Funders. Research funders such as CIHR can incentivize different types of research such as implementation research through priority-driven funding calls. They can also encourage the ways research should be conducted through the use of specific eligibility and peer review criteria. Funders can build incentives to help make participation more feasible and equitable through a policy of release time allowance for knowledge users such as community members and decision-makers [38].

Tables 1 and 2 feature illustrative examples from priority-driven CIHR initiatives where deliberate efforts were taken to create funding initiatives and related criteria that support specific aspects of implementation research/science. They do not reflect the full range of IR funding calls at CIHR. The Pathways example emphasizes authentic engagements with Aboriginal communities, guided in part by OCAP® (Ownership, Control, Access, and Possession) principles [39]. In contrast, the HIV example is focused on implementation science across settings such as communities, prisons, and so on. The global health funding opportunities reflect an example to support IR on different health issues (e.g., maternal and child health, chronic diseases), across different disciplines, countries/regions (e.g., Sub-Saharan Africa), and sectors (e.g., health systems strengthening orientation). Through the use of criteria, funders such as CIHR are stipulating who should be involved in setting the overall priorities for the research and governing its implementation and thus implicitly encouraging the use of PHR methods without actually dictating which methods should be applied. Nevertheless, for some initiatives, a wide range of appropriate research designs and disciplines that may be considered are encouraged to pave the way for applying PHR approaches. In the context of research with vulnerable populations in Canada (e.g., Aboriginal communities) and in low- and middle-income countries where there is a history of misconduct in research

TABLE 2: *Evaluation criteria pertaining to the intervention and engagement approaches in CIHR-funding initiatives on implementation research.* Table 2 features excerpts from implementation research-focused initiatives led by/involving CIHR. The evaluation criteria relate to the what (intervention) and related context(s) and how (research and community engagement approach), and they are used to assess the proposals. Criteria related to the research and community engagement approach signal how the funding opportunity was designed to ensure relevance and to try to mitigate harm or unintended consequences (i.e., culturally appropriate, collaboratively developed, and acceptable to communities; community-informed interventions; gender and equity considerations).

Funding initiative	Description of the intervention and related context(s)	Evaluation criteria
		Research and community engagement approach
CIHR Pathways to Health Equity for Aboriginal Peoples Implementation Research Teams (component 2)	Addresses contextual factors (e.g., social, political, physical, and cultural), community engagement, and partnership processes thought to affect intervention implementation and scalability.	Governance plan for community engagement is well described, collaboratively developed with communities, culturally appropriate, and feasible Evidence that the proposed intervention is adaptable to different contexts, developed by and/or acceptable to communities, and potentially scalable Adaptation plans include <i>community-informed</i> intervention enhancements critical to improving effectiveness and scalability
Global Alliance for Chronic Diseases (lung disease call) (multiple funders)	Intervention relevant to the sociopolitical, cultural, legislative, and economic contexts of the study settings.	Inequities and equity gaps including gender taken into account in implementation strategy design (GACD, lung diseases)
Innovating for Maternal and Child Health (MCH)—Implementation Research Teams (no longer publicly available) (CIHR, International Development Research Centre (lead) & Global Affairs Canada)	Research relevant to countries' priorities. Interventions to be studied demonstrate consideration for potential for scale-up to improve MCH.	Research driven by needs of communities, health care providers, program implementers, and policymakers Gender equality and equity considerations embedded throughout IR process Buy-in from decision-makers and other relevant stakeholders within/outside health sector
HIV Implementation Science—Component 1	Research questions, design, and methods are appropriate to assess interventions and heterogeneity of communities.	Feasible and appropriate plan for developing/extending relationships with communities Plan to collaborate with decision-makers and community partners to identify interventions and assess adaptation and contextual factors with relevance to implementation and scale-up

perpetuating colonial practices, specific criteria may be even more essential. These need to be complemented by other mechanisms (e.g., guidelines, community ethics boards) to help ensure the ethical conduct of research.

4. Discussion

What remains an open question is the extent to which these funding incentives are having the intended impact—in terms of the degree and quality of participatory research processes and achieving meaningful results for communities and other participants in IR such as policy-makers and practitioners. The above featured examples raise important considerations for the monitoring and evaluation of participatory research processes in the context of research investments. Research

fundors such as CIHR use explicit eligibility and evaluation criteria to “steer” who ought to be involved in the research process, the approach to engagement, and how and the extent to which both the context and the intervention are described and are shaped by the engagement of different participants (e.g., communities, practitioners), while encouraging adequate documentation and reflexivity about ethical and equity considerations, including the ethical foundations for the interventions and the community engagement, extending what is typically considered in research ethics reviews [40]. These requirements can help set the stage for reporting requirements for researchers after funding and for assessing the impact of funders’ practices.

There are of course limits to what funders can and cannot do to encourage researchers to use more participatory

approaches in their research. Said funders could include grant writing proposal meetings where those most affected by the health inequities are brought into the discussions with researchers. They can then consider the option of engaging lay reviewers and asking them to specifically comment on the robustness of participant engagement approaches. For some grant reviews in the UK such as with the National Institute for Health Research (NIHR), funders are requiring a public engagement plan as part of the application for funding [41]. For such NIHR reviews, someone on the peer review committee (a lay person) is asked to review all grants to assess them and comment on their public engagement approaches.

5. Conclusion

In this paper, we describe the intersecting relationship between IR and PHR, identifying points of convergence and divergence and also highlighting how health research funders can advance both fields using illustrative examples from CIHR led/co-led funding initiatives. We conclude with a few areas requiring further exploration in implementation research and participatory health research and in the assessment of research funding agency practices.

Going forward, there is first a need to evaluate the science of funding to determine whether peer review criteria and other requirements influence researchers to expand relevant expertise on their team, to engage communities differently and use a wider range of appropriate and relevant participatory approaches. Relatedly, deliberate comparisons of participatory approaches across IR initiatives of various research funders are needed.

Second, researchers need to better describe the breadth and scope of participatory health approaches in reporting to funders and in the literature to enhance the evidence base of PHR in the context of IR. Jagosh et al. [42] conducted a systematic realist review to capture evidence about the benefits of participation and, in particular, which mechanisms and contextual features influence outcomes. They found that participatory research supports health by improving “research quality, empowerment, capacity building, sustainability, program extension, and unanticipated new activities” [42, p. 337]. Other scholars have shown through a meta-analysis that there is robust evidence that community engagement interventions positively impact health but perhaps not surprisingly no one model was found to be more effective than another [43]. Researchers need to be further encouraged to explicitly document the participatory health research approaches so the repertoire of methods that can be used is expanded and critiqued, any potentially harmful consequences are described (and better understood so they can be mitigated in the future), and the ways in which these processes do or do not enable implementation and scale-up of interventions are further elucidated.

Disclosure

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with the Canadian Institutes of Health Research-Institute of Population and Public Health. The views expressed herein are those of the authors and do not reflect those of CIHR and its institutes.

Conflicts of Interest

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Research Article

Searching for the Impact of Participation in Health and Health Research: Challenges and Methods

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Internationally, the interest in involving patients and the public in designing and delivering health interventions and researching their effectiveness is increasing. Several systematic reviews of participation in health research have recently been completed, which note a number of challenges in documenting the impact of participation. Challenges include working across stakeholders with different understandings of participation and levels of experience in reviewing; comparing heterogeneous populations and contexts; configuring findings from often thin descriptions of participation in academic papers; and dealing with different definitions of impact. This paper aims to advance methods for systematically reviewing the impact of participation in health research, drawing on recent systematic review guidance. Practical examples for dealing with issues at each stage of a review are provided based on recent experience. Recommendations for improving primary research on participation in health are offered and key points to consider during the review are summarised.

1. Introduction

Participation in developing and delivering health interventions is increasing as more health care is shifted to communities. Aging populations and the rise in chronic and long term conditions in resource-constrained health systems are triggering a shift from reactive, acute care to health promotion and illness prevention, with the aim of reducing health care costs [1, 2]. There have been calls for direct involvement of citizens in the development, implementation, and evaluation of health equity in policy, program, and service structure changes. As a result, the impact of participation

in relation to health and community development is now being researched in a number of ways ranging from action research to randomised trials of effectiveness.

Participating in designing, delivering, and evaluating health interventions can potentially produce more relevant and appropriate interventions for different groups and communities [3]. Benefits include opportunities to contribute to setting research priorities, develop more user-focused research objectives, improve trajectories to impact, and develop research skills, while benefits to the people receiving the intervention range from user-friendly information, more appropriate strategies for recruitment, and user

interpretations of findings [4]. Despite the many claims of benefit, systematic reviews of effectiveness to date have encountered challenges in relating participation to health impact [5–10]. A review assessing effectiveness of interventions driven by coalitions of governmental and non-governmental organisations, for example, found they may improve health and reduce inequities among racial and ethnic minorities [8]. The effectiveness review was unable, however, to “provide a definitive answer” on the added value of such coalitions. Similarly O’Mara-Eves et al. [7] found that relating participation to health outcomes was difficult because experimental, quasi-experimental, and process evaluations provided only partial descriptions of structure and process. Without information on organisational contexts, political environments, and prevailing priorities, it becomes impossible to identify what influences the process and outcomes of interventions and initiatives using participatory approaches. These issues are compounded when attempting to synthesize evidence across countries, given the marked differences regarding public health and health care systems and the histories, understanding and practices of participation in health interventions and health research.

This paper takes a critical view toward systematic reviews of effectiveness that use health outcomes as the sole vehicle for defining the impact of participation. Participation in the process of designing and delivering health interventions can be a key factor in effectiveness. It is a complex phenomenon, leading to a wide range of short-term, intermediate, and longer term changes in health and well-being. The many dimensions of participation include building relationships; interacting with social and organisational networks; accessing and communicating with service providers; dealing with changes in the physical, social, and political environment in which people live and the structures of the system providing services. Further, effects of participation can be conceptualised at different levels and over various periods of time. For example, factors impacting health can occur at the level of individuals, relationships, community, and society [11]. Impact is also relative, dependent upon the stage of project development, and may increase over time when relationships lead to increasing involvement, trust, and communication [3].

The challenges of conducting reviews that explore the roles and impact of participation [9–15] include the following:

- (i) Assembling teams that include people with experience of participation.
- (ii) Variation in descriptions of participation in health:
 - (a) Inadequate reports of how and why context, relationships, group dynamics, or partnership synergy can influence outcomes.
 - (b) Thin description of the structures and cultural understandings of participation in the country in which the study is taking place.
- (iii) Documenting the extent to which participation is reported and recognized as a possible factor influencing implementation and effect.

- (iv) Managing issues of quality, comparability, and synthesis when there is heterogeneity in terms of
 - (a) different definitions of impact
 - (b) different views on the importance of proximal and intermediate outcomes
 - (c) different views on reporting unexpected and emergent end products.

Given the above challenges, this paper presents strategies that can be used when conducting systematic reviews examining the impact of participation. Our strategies are based on practical experiences reviewing and developing methods for qualitative and mixed methods synthesis, and experiences conducting studies looking at the impact of participation. The aim of the paper is to advance methods for systematically reviewing the wide-ranging impact of participation in health research. The paper is aimed at reviewers who need suggestions for dealing with a range of issues while conducting this type of reviews.

2. Methods

Methods for reviewing the impact of participation can follow the standard systematic review stages which include defining the intervention and outcomes, setting inclusion criteria, developing a preliminary theory for how the intervention ought to work, and judging quality and relevance of studies, data extraction, and synthesis [16]. This article is structured to show how at each stage these methods need to be adapted in order to address the challenges of conceptualising participation, identifying papers that include information on impact, extracting the information, and synthesizing the findings.

2.1. Assembling a Review Team. While review teams are traditionally comprised of people with expertise in systematic review methods and the topic, reviews of participation impact also need people who are experienced in using participatory approaches in research and knowledgeable about conceptualisation of impact. This would include nonacademic social actors who are participating as coresearchers in guiding the participatory research projects. For example, people with lived experience of the health issue who have participated in designing, delivering, and receiving health interventions are key to integrating experiential knowledge with theories of what works [17]. The different perspectives help to identify important elements of intervention and context. The process of facilitating the group needs to take into account the fact that people from academic backgrounds may be challenged to work with people that have a nonresearch background [4]. While local people with little experience of research may devalue their own contributions, seeing them to be less useful than academic knowledge, in other situations local people who are on research teams may have grown to see their own value. Facilitating the process needs to focus on drawing out different perspectives and reinforcing that all types of knowledge and experience are equally valued [18]. Practically, a diverse review team will view different

TABLE 1: Questions for reviews of the process of participation.

Type of inquiry	Types of review questions
Implementation inquiry: How do participatory approaches contribute to the process for designing and delivering the intervention or programme?	(i) How were people involved in deciding the components of the intervention? (ii) Were local people consulted or engaged in developing recruitment strategies? Did they do the recruiting? Were there barriers to recruitment that can be attributed to lack of engagement? (iii) Who participated? How many over time? Did the programme attract the target audience? (iv) What was the frequency, duration, and intensity of the intervention? Did it reflect the levels of participation that the target group would consider realistic or appropriate? (v) Did participants actually engage with the intervention? How did participants experience the intervention and did their experiences affect engagement? (vi) What were provider experiences of delivering the intervention? (vii) Was the intervention implemented as planned? Why or why not?
Appropriateness inquiry: To what extent does the approach to participation fit (or is it likely to fit) with the cultural, ethical or equity context?	(i) Is the approach appropriate, acceptable and accessible to people within their local context? (ii) How does the participatory intervention (potentially) impact on equity from both a positive and negative perspective for different population groups? (iii) Do the outcomes match the desired outcomes that are valued by the population? (iv) Are the desired outcomes consistent with people's priorities and/or beliefs? (v) What is the population's perception/experience of negative consequences of the intervention?
Effectiveness inquiry: Do participatory approaches work?	(i) What is the effectiveness of a community-based (intervention) compared to (interventions that do not use participatory approaches) for the population? (ii) Do the effects vary in relation to subgroups within the population? (iii) Do effects vary in relation to the country context and history of using participatory approaches in health?

Adapted from [37–39].

elements of participation in research articles and be able to use their experience to interpret these elements when space restrictions in journal articles limit how much participation can be discussed. The diversity of the review team also ensures that a limited definition of participation and impact is not used for the review.

2.2. Describing the Intervention and Outcomes. Describing the intervention, which is the first stage of a systematic review, requires authors to sift through diverse definitions of participation [8, 19–21]. For the purposes of this paper, we are defining participation as the extent to which a person or a group of people exert influence on health research, health structures, practices, services, or policies that have an effect on their health and well-being. It has been described alternatively as patient and public involvement and community engagement, with a range of influence possible, from minimal to being an equal partner in the research decision-making. Searches from existing reviews can be used as a starting point, using preliminary searches to refine the key terms and clarify the concepts (see, e.g., [6, 7, 22]). Three questions can be used as a frame for guiding conceptualisation of impact, which can focus on the process of implementation, appropriateness, and effectiveness (see Table 1):

- (i) Implementation: how do participatory approaches contribute to the process of designing and delivering the intervention?

- (ii) Appropriateness: to what extent does the approach to participation fit with the cultural, ethical or equity context?

- (iii) Effectiveness: do participatory approaches work?

Existing frameworks can also be used to decide upon “cut off” level for participation. The classic Arnstein [23] ladder of participation defines a continuum, from citizen control through cooptation, which followed Cornwall's parallel continuum [24] of six levels (Box 1). Research participation may also be coopted, yet continua in this arena focus more on the different types or extent of contribution of community stakeholders to the research process [3]. This can range from community members being involved at the first stage of defining the problem to being actively involved at all stages of the research including data interpretation and dissemination of findings for community action and benefit [25, 26]. In many research traditions, authors do not use this terminology to describe or classify participation. The description of participation therefore needs to be anchored in descriptions of *whether* different people are engaged, *who* is included in development of the research, and *how* different people contribute to designing and conducting the research. These descriptions can be organised by how people participate at each stage of designing, delivering, and evaluating interventions [29], or the processes that affect participation [27, 30].

The description needs to acknowledge that different types of participation may occur at different stages of a

- (1) *co-option* – where token representatives are chosen but have no real input or power in the research process
- (2) *compliance* – where outsiders decide the research agenda and direct the process, with tasks assigned to participants and incentives being provided by the researchers
- (3) *consultation* – where local opinions are asked for, but outside researchers conduct the work and decide on a course of action
- (4) *co-operation* – where local people work together with outside researchers to determine priorities, with responsibility remaining with outsiders for directing the process
- (5) *co-learning* – where local people and outsiders share their knowledge in order to create new understanding and work together to form action plans, with outsiders providing facilitation
- (6) *collective action* – where local people set their own agenda and mobilize to carry out research in the absence of outside initiators and facilitators

Box 1: Levels of participation [24].

- (i) Changes in the design or conduct of an intervention or research project, incorporating local experiential knowledge and culture, norms and practices
- (ii) Transformative learning e.g. generation of new knowledge, evidence or theory as a result of learning together, which leads to a shift in perspectives with new possibilities for action
- (iii) Building capacity to make decisions about lifestyle, environment, health and wellbeing
- (iv) Changing relationships and group dynamics e.g. changes in traditional hierarchies or historical relationships, formation of new or expanded partnerships, creation of more equitable collaborations, coalitions
- (v) Improving the lives of those involved in the design, conduct, analysis, dissemination of the research, and/or evaluation of the research process
- (vi) Empowerment, defined as a social action process of individuals, organizations, and communities to transform life conditions for greater health and equity.
- (vii) Sustainability of projects beyond initial research funding
- (viii) Structural impacts e.g. changes in traditional structures, practices, cultures, power relations, policies
- (ix) Improved health, reduced disparities, and increased social justice [15, 27, 28]

Box 2: Different definitions of impact.

project [31]. Community engagement, for example, can range from outreach, through consultation, to collaboration and shared leadership [3]. Participation may be initiated from the bottom up in communities where there is a large stock of social capital, or it may be induced by policymakers and implemented by bureaucracies [32]. The aim for participation can be utilitarian, being primarily “a *means* (to accomplish the aims of a project more efficiently, effectively or cheaply)”. Conversely, it can aim to promote empowerment, being used as an *end*, “where the community or group sets up a process to control its own development” [33, 34]. Using this lens, participation can be conceptualised if research or programmes are done “on” communities, “in” community settings, or “with” community partners [35]. These heterogeneous different approaches need to be identified in order to make decisions on whether to include different approaches.

Most studies have defined impact as improvement in individual health outcomes [7]. In projects using participatory approaches, however, impact can also be experienced at group, organisational and/or systems level. Further, impact can be experienced at any stage of the project (Box 2).

The period of time for impact to occur needs to be considered, as changes in partnership processes can over time lead to longer term transformation of systems [10, 35, 36]. Impact therefore needs to be considered as a continuum where different effects are achieved at various levels over different lengths of time. This is quite different from an effectiveness review, which usually defines impact as the achievement of health outcomes at the end of an intervention.

2.3. Formulating a Review Question. Questions can focus on impact within projects or beyond projects. Within projects,

TABLE 2: Questions for reviews of the impact of participation.

Impact questions
(i) Did sharing of local experiential knowledge and culture, norms and practices instigate a change in the design or conduct of the intervention or research project?
(ii) Did participation improve the lives of those involved in the design, conduct, analysis, evaluation and/or dissemination of the research?
(iii) Did participation change historical relationships, group dynamics and traditional hierarchies or lead to more equitable partnerships and collaborations?
(iv) Did participation lead to the formation of new or expanded partnerships, collaborations or coalitions?
(v) Did participation create transformative learning, e.g., generation of new knowledge, evidence or theory, as a result of learning together?
(vi) Did participation increase capacity on individual and/or collective levels to make decisions about lifestyle, environment, health and wellbeing?
(vii) Did participation promote a social action process across individuals, organizations, and communities to transform life conditions for greater health and equity?
(viii) Did participation have structural impacts, where changes occurred in traditional structures, practices, cultures, power relations, and policies?
(ix) Did participation lead to improved health and wellbeing, reduced disparities, and increased social justice?

If there is adequate information, then the impact question would be included in the review and relevant data from papers would be used to answer it.

the relative contribution of participation at various stages can be the focus of the review, or the review question can ask whether participation “works” in terms of achieving the desired health outcomes. Examples of possible questions are presented in Table 1. The examples are informed by existing theory and evidence of implementing systematic reviews [37–39].

There is also a “beyond project” set of review questions, assessing impact in terms of broader and more far reaching changes, often occurring after the original study has been completed. Table 2 presents possible review questions to assess whether impact has been reported on social, economic, environmental, and health benefits for individuals, groups, communities, and systems. During the project, it is likely that researchers and local participants will be the main beneficiaries, while policymakers and nonacademics are the main beneficiaries after the study is completed [40].

2.4. Setting Inclusion Criteria. For reviews of participation, we would suggest that the focus of the review needs to be clarified using a scoping review. Scoping reviews are a way of mapping the territory of participation for a particular health topic. They not only serve develop definitions for participation and impact, but also help in making decisions about the boundaries of the review [41]. Four important questions to ask when scoping the literature are as follows:

- (1) What is the context in which participation takes place?
- (2) What is the aim of the participation?
- (3) What is the length of time over which the impact of participation is assessed?
- (4) What is the range of impacts therefore which are possible based on these three questions (i.e., short-term through long term, and individual through system/policy/structural changes).

Boundaries for what to include in the review should be set by assessing whether the aims for participation are similar across studies and whether diversity of context is an issue.

2.5. Dealing with Issues of Diverse Contexts. Context is important because participation can be very different across different localities and countries. For example, the US population is largely immigrant (whether recent or generations before) and includes the African-American legacy of the slave trade and American Indian tribes. This has spawned a specific understanding of “community” as sociocultural or political identity, often geographic or based in ethnic/minority group, but also including other shared identities such as disability or LGBTQ communities. These identities have promulgated specific forms of community organising and activism, strongly influenced by the early labour and later civil rights movements [42]. In the United States, a particular form of partnership is the academic-community research partnership (often labelled community-based participatory research or community-engaged research) that forms around the development of health interventions and policy initiatives, and research on their effectiveness. These collaborative partnerships typically involve academic researchers working with a diversity of community-based organisations or NGOs, community members and grassroots associations, policy makers, service providers, and other public and private agencies through all stages of the research process [14, 35]. In Australia, participation of stakeholders in health research is promoted through specific grants administered by the Australian government major research funding bodies to ensure the relevance of the research and translation into policy and practice. The model is most consistent with community-based participatory research with academics typically forming partnerships with government, industry, community, and health organisations.

In other countries, social participation is embedded within structures, for example, in Germany where municipal health promotion is being integrated via government

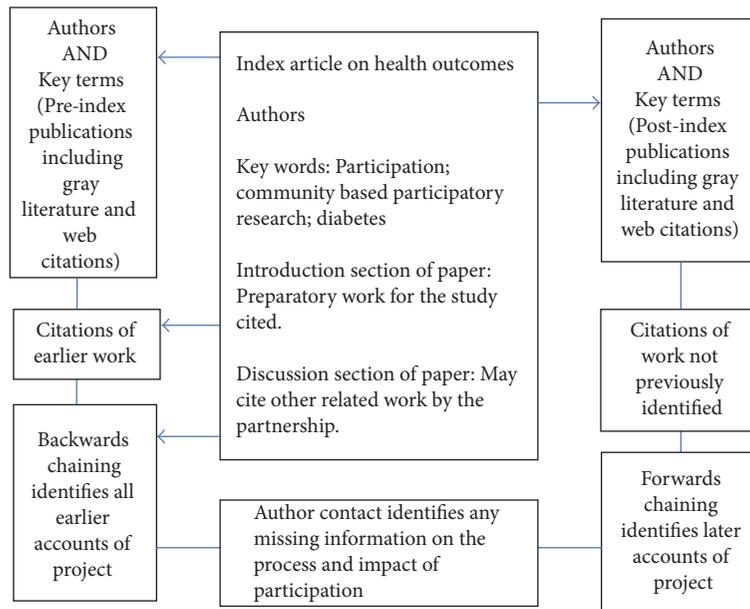


FIGURE 1: Cluster searching: a worked example.

sectors, nongovernmental organisations (NGOs), and citizen action groups working together to set priorities and define strategies for addressing health inequities. These efforts are supported by coordinating centers for health promotion in each state which obtain funding and guidance through structures created by the new Law on Prevention. In Brazil, though participatory precepts were well articulated in the 1960s with writings and activism inspired by Freire [43], social participation was codified in the 1988 constitution and in further redemocratization policies after dictatorship, including community councils for clinics and social determinant initiatives [44].

In contrast, while action research approaches are found within health research in the UK, there is little tradition of CBPR. INVOLVE, an organisation funded by the National Institute of Health Research (NIHR), was originally established mainly to recruit more people into research studies. It now supports active public involvement, defining public involvement as “research being carried out *with* or *by* members of the public rather than *to*,” *“about,”* or *“for”* them” [45]. In addition the UK has established Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) their role being to bring together Universities, local health and social care organisations, the National Health Service, and citizens. If an international review is proposed, then these very different histories need to be taken into account as they may reflect different forms and understandings of participation.

In each of these contexts, the aims of participation may be similar or different. Tables 1 and 2 can be used to categorise aims for the various studies and make decisions about which aims to include in the review.

The period of time covered by the project is important because it is related to different types of impact. During the

project, impact directly related to the research may be created by those who are on the research team. Other activities may also be triggered, causing an indirect ripple effect. “Beyond project” impact is created by nonacademic partners such as policy makers and community members who use the learning to inform decisions and programme development. It is rare to find short-term and longer term impact in one publication, unless a journal is devoted to reporting a single project [46, 47].

Journals often require authors to publish methodology and results for intervention studies separately. If included articles are limited to those that report only health outcomes, reviewers will be working with articles where “years of partnership development and collaboration must be distilled to few words in a small number of journals willing to publish this more descriptive science” [6]. Articles reporting on longer term impact, as well as those describing process, may not be indexed to the original study because they are seen as separate. This has implications for searching, as a straightforward search on outcomes will rarely produce citations for process or longer term participation impact.

A method called cluster searching can be used to identify all documents related to a particular project in order to trace pathways to impact [48]. Cluster searching is an iterative process. As shown in Figure 1, forwards and backwards chaining is done using the relevant article, the index paper, to identify all related materials. If it is possible to cluster papers on process, outcomes, and impact, a rich picture can be produced tracing the pathway from participation to impact [22].

Mapping what exists in terms of participation aims and contexts and periods of time to achieve various impacts will lead to being able to answer the question what is the range of impacts which is possible based on these three questions

TABLE 3: An a priori theoretical framework for participation in diabetes research.

Propositions about involvement by stage of research
<i>Priority setting:</i> Getting people to identify the most important issues and participate in setting priorities for research will increase interest in participating in codesign of the intervention. Deciding priorities without involvement leads to questions on the relevance of the research.
<i>Proposal writing:</i> Involving people in writing proposals for funding increases collective ownership for research projects. Involving people after proposals are written risks less ownership and may make people feel that they are not equal partners in the project.
<i>Intervention design:</i> Asking people to help with the design of the intervention produces more culturally acceptable interventions, more appropriate approaches to recruitment, and more user-friendly information and tools. Excluding people from the design process may lead to project information that is difficult to understand, less cultural acceptance, and lower recruitment rates.
<i>Implementation:</i> Involving people in (a) recruitment produces high recruitment rates because they are able to help participants understand the relevance and benefits of the research. (b) delivering the intervention may increase trust and communication, and foster relationships which lead to high retention rates and good levels of active participation. (c) data collection and analysis may produce additional insight into how and why an intervention works (or does not work).
<i>Dissemination:</i> Involvement at any stage (a) promotes understanding of the aims and benefits of the research, creates local ownership and likelihood that a local network is created to share what is learned, and (b) helps to ensure that findings is relevant and understandable.

(i.e., short-term through long term, and individual through system/policy/structural changes).

The scoping review will produce information on the types of studies that have been published on participation, which can be used to decide upon the type of systematic review that can be conducted. As of 2009, 14 different systematic review types had been identified [49] and the number continues to rise. As studies exploring participation in health research are relatively new, it is likely that the most appropriate review types will involve (a) mapping, where an overview is presented and research gaps are identified; (b) qualitative reviewing where constructs and themes are identified illustrating the contribution of participation to health research; or (c) mixed methods reviews that combine learning from both process and outcomes studies to relate participation and intervention.

3. Developing a Preliminary Theory for Impact

As yet, there are no guiding conceptual frameworks for the relationship between participation and impact in health research. In both primary studies and systematic reviews, a preliminary conceptual map of how participation works can be developed using existing research and stakeholder experiences. A theoretical or conceptual framework can be developed that proposes general relationships between participation and impact (see, e.g., [50]). Alternatively, a logic model can be developed which illustrates the relationships between participation, research design, implementation, and outcomes for specific populations in a given context [51–53]. Reviewers can develop their own model or use or adapt a preexisting framework such as the CBPR conceptual model, which suggests that context influences participatory processes, which then influence the interventions and research undertaken, to ultimately contribute to a range of outcomes [27, 35].

For example, in our review of patient and wider community involvement in diabetes [54] we proposed that participation at different stages of the project could enhance

the processes of clarifying problems related to diabetes, setting priorities for the research, designing the intervention, recruiting participants, collecting and analysing data, and disseminating learning (Table 3).

Frameworks and models can be used a priori to ensure that the search strategy explicitly looks for key concepts. They can also be used during the review to iteratively develop explanations for how participation works [55, 56].

4. Judging Quality and Relevance

When deciding which studies ought to be included in a review, concerns related to the quality of the primary research need to be addressed. Appraisal of quality generally asks whether the research was conducted in an ethical manner, whether it is relevant to practice or policy, the clarity of reporting, the coherence of the findings, and the appropriateness and rigour of the methods [57]. Filtering removes poor quality studies that may not enable decisions about the effectiveness of participatory research. Reviews that include studies with experimental or quasi-experimental research designs assessing the effectiveness of participation may use critical appraisal tools that are appropriate for the specific study design to assess methodological rigour.

Where the review question wants to know how and why something works, however, qualitative studies or studies with descriptive elements may be included on the grounds of relevance because they contribute to developing the explanation. In this instance, the appraisal process is used to make judgments about relevance. Studies containing “nuggets” of relevant explanation are included, rather than just including studies based on assessment of overall methodological quality [58].

5. Synthesizing Information on Participation

Participation adds to the complexity of an intervention, because it can mediate or moderate the effects of an intervention. Participation at one stage can create both positive

and negative feedback loops, influencing the relative success of later stages. Where the components of an intervention are a poor fit with local contexts, participation can create a more receptive setting for the intervention. For all of these reasons, the approach to synthesis needs to be appropriate for complex interventions [59]. As noted in the section on review types, most of the research to date on participation is descriptive, mainly qualitative in nature with some studies on process and others focusing on outcomes. This type of research asks open-ended questions about participation. The approach is configurative aiming to generate theory and explore relationships. The recommended approaches to synthesis are outlined by Hannes [58] and include meta ethnography, thematic synthesis, critical interpretive synthesis, framework synthesis, realist synthesis, and narrative synthesis. The choice of approach is usually based on the material available and the skills of the review team. While it is beyond the scope of this article to explore synthesis in detail, there are several issues that will arise regardless of approach. These include selecting a framework for organising data, dealing with thin description of participation, establishing relationships between participation and outcomes, and mapping longer term impact.

At the synthesis stage, the original a priori logic model or theoretical framework can be used to organise data. Data extractors need to be trained in using an expanded and unconventional lens, as review authors have noted that information on the characteristics of partnerships and coalitions is often missing or inadequate, making it difficult to explain underlying mechanisms that promote health [9]. People may be motivated to participate when space is created for relationship building, where deliberation and dialogue is facilitated, and knowledge cocreation is promoted. Few primary studies, however, describe how the process fosters inclusivity and involvement. The important components of the project and descriptions of process may be scattered across documents. The challenge becomes one of configurations, where reviewers “read across” articles and report to piece together the story of how participation was promoted and how it contributed to impact. Further, where participation is an underlying storyline rather than the phenomenon being researched, reviewers will need to “read within” different sections of each paper. Data may be found in descriptions of the research problem, which are often outlined in the introduction section of a paper; accounts of getting people to participate; and reflections on the process found in Methods and Discussion. This process is referred to as “bricolage,” where the reviewers use the information “at-hand” to construct an explanation for participation that is based on information derived from different epistemologies [60].

Documenting the pathways to health impact/outcomes remains an important arena of inquiry, with challenges still in primary studies and reviews of participation and community engagement. For example, although O’Mara-Eves et al. [7] found solid evidence that community engagement was effective; their review was unable to explain why due to the lack of information in process studies. Further, they were challenged to explain the causal pathway “between community engagement, improvements in social capital/cohesion, and

improvements in health outcomes (mortality, morbidity, and health behaviours).” [7, page 75].

We suggest that there are several reasons why causal pathways to health outcome are difficult to establish. First, health research interventions are usually conceived as consistently delivered, distinct and bounded activities that improve health outcomes for individuals independent of context. Recently there has been acknowledgement that the success of an intervention may depend on how well it is tailored to the individual [61] and the quality of the relationship between professional and client [22]. Where this “relational research” is missing, researchers are challenged to establish how social participation influences the trajectory of health interventions [62]. In community interventions, it is also difficult to draw boundaries around an intervention because they are events that both affect a wider community system and are affected by it [34, 63]. Instead of referring to interventions as linear pathways, we should be visualizing them as streams which are fed by events and relationships, which contribute in turn to larger changes in groups and networks. These collaborations have been described as the “steady process of mutual enlightenment born of longstanding exposure to each other’s ideas” [22] but it is important to also search for instances where participation has led to unintended and potentially harmful consequences. What emerges may “have little or nothing to do with those targeted in the initial study” [6] and may include emergent outcomes which have very little to do with “health.” For example, reductions in crime and improvements in housing and social capital may occur at community and system levels [6, 15, 50, 64].

People who form partnerships and coalitions, combining their perspectives, knowledge, and skills can create a synergy where the whole becomes greater than the individual contributions [10]. This partnership synergy can contribute to intervention “blurring,” where interventions that were originally conceptualised as distinct and formal may over time become generic and embedded in informal networks of support, particularly when those that are delivering the intervention are part of the local community. This process raises the question of when to assess impact in terms of individual health outcomes, and the importance of tracking interventions over time.

Capturing the ripple effect at community and system-level is difficult and may require methods that go beyond traditional data extraction from journal articles. Explanations of impact can be obtained via participatory reviews, where stakeholders are involved throughout the review process in interpreting findings based on experience and knowledge [22]. Author interviews can be conducted, to explain relationships between participation, outcomes, and longer term impact that were not reported in primary studies [10]. Collaborative reflection across researchers on different projects has also recently been used to capture “between the lines” knowledge that may not be reflected in the main objectives or published studies [65].

These examples of the evolution of individual interventions, emergent individual outcomes, and synergy and ripple effects at community and systems level illustrate several key points about impact. First, impact is time-dependent in the

sense that single studies usually report on a distinct point in the intervention. Whenever possible, this point needs to be documented to reduce the risk of synthesizing data that actually represents very different stages in the process. Second, impact occurs at all stages of a project, from its inception to completion, as well as leading to further spinoff projects [10]. When defining impact in a review, these key points need to be explicitly considered with statements about whether the review covers one or more levels, whether data will be synthesized for a specific stage of participation or as an evolutionary stream, and whether nonhealth outcomes are included.

A variety of issues need to be considered when determining the impact of a participatory intervention [35, 66, 67]. For example, historical issues of trust among the participating parties shape the nature of the participatory dynamics [27]. A poor fit between the proposed intervention and the context may lead to detrimental or ineffective processes and outcomes [68] and influence effectiveness of participatory interventions [66]. Readiness for change in organisations can influence the process of implementation [67]. One approach that integrates many of these issues and challenges is the CBPR conceptual model, <https://cpr.unm.edu/research-projects/cpbr-project/cbpr-model.html> [35]. This model suggests paths from context to participation to intervention design to intermediate and distal outcomes. An empirical test of the model, using data from 200 CBPR US partnerships, illustrates two predominant paths: (a) where values/principles influences participation leading to synergy and then outcomes; and (b) where resources and shared control lead to increase community involvement in research leading to outcomes.

6. Recommendations

This article has introduced a range of methods that can be used or adapted to synthesize evidence on the impact of participation in health research. As methods continue to be developed, however, it is likely that this article will need to be updated within the next few years. For the present, we can conclude based on our experiences that researchers need to consider whether and how participation could affect the research. Ideally, this starts when framing the problem to be researched, but when that is not possible then participation issues need consideration at the design stage. More description is needed of how the participatory process contributes to the design of studies, their implementation, and the process of generating research knowledge. Primary research often contains inadequate descriptions of participation. Researchers could develop a priori logic models or theories that conceptualise how participation may affect the intervention and include evaluation of the process alongside findings. Authors could consider ways to provide more information about context, relationships, and participatory processes, by (a) integrating the information within the article, (b) publishing as a separate methods article, or (c) providing material supplementary to the publication.

We offer the following recommendations in the hope that systematic reviews of the impact of participation can address

some of the limitations that have been encountered thus far.

Reviews of effectiveness should be open to recognizing that different forms of impact can be realized at various points in time during an intervention and that interventions can be greatly influenced by participation.

Reviews should consider the contextual issues (e.g., SES, salience of the health issue to the community, history of collaboration among stakeholders) and how these shape participation, relationships, research design, and intervention choices.

Reviews should consider the theoretical and conceptual mechanisms through which participation impacts interventions and outcomes, presenting these as a theoretical framework or logic model where possible.

Reviews should start with an explicit definition of participation. While this is good practice for all reviews, the definition needs to describe whether

- (i) different levels and types of participation will be considered
- (ii) nonhealth outcomes will be included
- (iii) outcomes will include proximal, intermediate, and distal outcomes
- (iv) projects at different stages will be included
- (v) how different cultural and system contexts will be dealt with
- (vi) how degree of alignment between the intervention and the context will be assessed
- (vii) the length and process of collaboration can be included as a criterion for selecting and extracting data from primary studies

When deciding what studies to include in the review, reviewers need to ask the following:

- (i) Does the primary research actually meet the definition for engaged participation (conceptual security)?
- (ii) Is the amount of information on context, development of partnerships, and relationships between partnership processes and context adequately reported?
- (iii) Can strategies that compensate for thin description be used, such as
 - (a) identifying all papers related to a specific project (cluster searching)?
 - (b) contacting authors and/or conducting interviews with participants?
 - (c) including participants in the process of systematic review (participatory review)?
- (iv) Should primary research that is of poor quality be included when it meets criteria for relevance, for example, including important information contributing to explanations of impact?

Reviewers need to ask whether differences between studies by cultural context, health or political system, partnership processes, type of population, intervention, or outcome warrant the analysis of impact by splitting papers into subgroups and conducting subgroup analysis. Further, when considering subgroup analysis decisions need to be made about whether to split papers by their participatory stance, with the assumption that projects with utilitarian aims may actually represent very different forms of participation than those that have aims of empowerment.

The use of a framework to categorise and judge the quality of participation could be considered, although none of the current frameworks have been used for a systematic review.

Last but not least, studies need to be viewed using a relational lens, examining processes of participation, how these processes foster relationships, and how relationships may lead to positive outcomes that reflect changes in community conditions, policies, and services, as well as those that are health.

7. Conclusions

Participation is an underlying but critical process which can affect health interventions. Methods are therefore needed to assess the potential impact of participation in health research beyond that of simply health outcomes. Reviews of the impact of participation are challenged by primary studies that focus on health outcomes with limited exploration of other outcomes and processes such as empowerment and capacity building. Social processes of participation that may have a major influence on impact of the interventions are rarely described in detail. Because the context and process of promoting participation are poorly reported, we recommend that review authors take a configurational approach to synthesizing evidence.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

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Research Article

Impact of Participatory Health Research: A Test of the Community-Based Participatory Research Conceptual Model

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Objectives. A key challenge in evaluating the impact of community-based participatory research (CBPR) is identifying what mechanisms and pathways are critical for health equity outcomes. Our purpose is to provide an empirical test of the CBPR conceptual model to address this challenge. **Methods.** A three-stage quantitative survey was completed: (1) 294 US CBPR projects with US federal funding were identified; (2) 200 principal investigators completed a questionnaire about project-level details; and (3) 450 community or academic partners and principal investigators completed a questionnaire about perceived contextual, process, and outcome variables. Seven in-depth qualitative case studies were conducted to explore elements of the model not captured in the survey; one is presented due to space limitations. **Results.** We demonstrated support for multiple mechanisms illustrated by the conceptual model using a latent structural equation model. Significant pathways were identified, showing the positive association of context with partnership structures and dynamics. Partnership structures and dynamics showed similar associations with partnership synergy and community involvement in research; both of these had positive associations with intermediate community changes and distal health outcomes. The case study complemented and extended understandings of the mechanisms of how partnerships can improve community conditions. **Conclusions.** The CBPR conceptual model is well suited to explain key relational and structural pathways for impact on health equity outcomes.

1. Introduction

Community-based participatory research (CBPR) and other forms of community engaged (CEnR) and participatory health research (PHR) are viewed as critical approaches for improving health and health inequity in ethnic/racial minority, underserved, and otherwise vulnerable communities

[1–3]. While there is a continuum of community engagement, this paper will use “CBPR” to encompass PHR (used more internationally) and CEnR projects that espouse collaborative practices and values. Further, CBPR promotes implementation of innovative, culturally appropriate, and evidence-based interventions that enhance translation of research findings for community and policy change [4, 5]. As a collaborative

research approach, CBPR equitably involves community and academic partners, recognizes the unique strengths of each, shares leadership and resources, addresses health problems important to the community, and uses information gained for community benefit [1, 2]. Supported by communities, CBPR seeks to collaboratively develop research knowledge, mutual trust, culturally centered research methods, sustainable interventions, and community capacity and change power relations among academics, policy makers, community members, and other stakeholders [6–8].

While there is evidence of CBPR promoting positive outcomes, the science and understanding of why it works is in its nascency [9–11]. The main challenge in evaluating and theorizing CBPR is identifying what aspects are critical for interventions and health improvement. Jagosh and colleagues [3] noted that this involves understanding whether context (e.g., cultural nuances), partnership (e.g., degree of cooperation), and research interventions, separately or together, are responsible for contributing to intermediate and distal health outcomes. Given the claim that CBPR brings together individuals and organizations to address unequal distribution of social determinants that contribute to health inequities [12–14], examining how these dynamics work together is critical to understand the added value of CBPR in achieving social justice.

Three recent sets of studies advance the science of CBPR. First, Wallerstein and colleagues [15] introduced a CBPR conceptual model with four domains: context, partnership dynamics, research/intervention, and outcomes. The model drew upon prior research [16], extensive literature reviews, a survey of CBPR practitioners, and consultation with a national advisory board of academic and community CBPR experts [15]. It represents visually a flow of domains and attributes that play a role in research and health outcomes. Context includes socioeconomic-cultural characteristics, governance and policy trends, historical collaborations, university and community capacities, and the health issue being researched. Contextual factors provide a backdrop for partnership dynamics, that is, on partnership structures and members and on relationships, including how they are managed and strengthened. If partnering practices are effective, then they shape both intervention and research design, which reflect mutual learning and partner synergy or ability to work together effectively. Finally, the model indicates that CPBR intervention/research processes produce intermediate outcomes such as systems or capacity changes and distal outcomes such as improved community health equity. The original model has undergone community consultations to assess face validity [17], and iterative updates based on our team's research are also used in this article [18] in addition to international translations and applications. Figure 1 provides the latest iteration of the model.

Second, Khodyakov and colleagues [19, 20] explained how partnership characteristics result in several outcomes among projects focused on mental health and substance abuse issues. The authors surveyed 62 community and academic leaders from 21 federally funded research centers focusing on mental health and completed full-length interviews for 23 projects. They found that community

engagement in research and partnership size affect partnership functioning; partnership functioning influences partnership synergy; and partnership synergy positively affects outcomes such as capacity building and community outcomes.

Third, Jagosh and colleagues [3, 10] examined how pathways of trust and commitment to power-sharing in CBPR support sustained collaboration towards health improvement and community transformations. Based on a realist review of literature and interviews with 24 CBPR investigators, they argued that partnership synergy is developed through trust, which has ripple impacts on culturally appropriate research, project sustainability, capacity development, system-changes, and population health outcomes.

While all three sets of studies contribute to the science of CBPR, the CBPR conceptual model is more comprehensive in its coverage by including multiple domains of context, intervention/research, partnership practices, and outcomes [15]. Conceptually, this model embeds health outcomes in local conditions and histories and in broader sociopolitical systems, which shape relationships between partners, and place CBPR/PHR strategies within social justice goals [13, 17, 21]. It further provides a concrete framework for understanding CBPR contexts and dynamics and their impact on research processes and outcomes. This model, therefore, is well-suited for addressing a key gap in CPBR/PHR literature; that is, to theoretically and empirically explain how contexts, partnership practices, and research/intervention engagement factors contribute to broad-based CBPR and health outcomes.

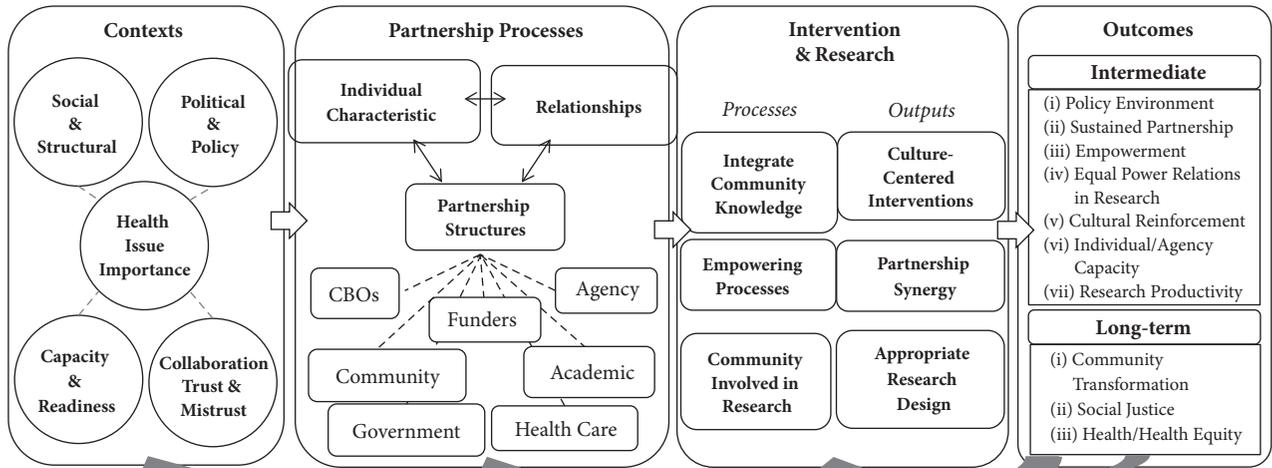
The purpose of this study is to provide an empirical test of the CBPR conceptual model to better understand the mechanisms for impact on research results, community conditions, and health equity. We could not include every variable from Figure 1 and we derived a model for testing (see Figure 2). We hypothesized that the exogenous contextual variables would shape the partnership structures and dynamics. Further, we hypothesized that the partnership dynamics would be associated with synergy, which in turn is associated with intermediate and then distal outcomes. We also hypothesized that partnership structures and dynamics would be associated with community involvement in research, which in turn is associated with intermediate and then distal outcomes.

2. Methods

To test the model, we used data from our Research for Improved Health (RIH) study of 200 US CBPR projects [22]. As a mixed-method design, the sample was drawn from the National Institutes of Health RePORTER database of federally funded CBPR projects. Selected projects completed a cross-sectional Internet survey, paired concurrently with seven diverse qualitative case studies [18]. In this analysis, we examine the fit of the survey data to the conceptual model using structural equation modelling. We also use one of the case studies to illustrate mechanisms of CBPR that complement and extend understanding of the model. IRB approval was provided by two universities and supported by the Indian Health Service review board.

CBPR Conceptual Model

Adapted from Wallerstein et al., 2008 [15] & Wallerstein et al., 2018 [11], <https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html>



Visual from amoshealth.org 2017

Contexts	Partnership Processes	Intervention & Research	Outcomes
(i) Social-Structural: Social-Economic Status, Place, History, Environment, Community Safety, Institutional Racism, Culture (ii) Role of Education and Research Institutions (iii) Political & Policy: National/Local Governance/Stewardship Approvals of Research; Policy & Funding Trends (iv) Health Issue: Perceived Severity (v) Collaboration: Historic Trust/Mistrust between Partners (vi) Capacity: Community History of Organizing/Academic Capacity/Partnership Capacity	Partnership Structures: (i) Diversity: Who is involved (ii) Complexity (iii) Formal Agreements (iv) Control of Resources (v) % Dollars to Community (vi) CBPR Principles (vii) Partnership Values (viii) Bridging Social Capital (ix) Time in Partnership Individual Characteristics: (i) Motivation to Participate (ii) Cultural Identities/Humility (iii) Personal Beliefs/Values (iv) Spirituality (v) Reputation of P.I.	Relationships: (i) Safety/Respect/Trust (ii) Influence/Voice (iii) Flexibility (iv) Dialogue and Listening/Mutual Learning (v) Conflict Management (vi) Leadership (vii) Self & Collective Reflection/Reflexivity (viii) Resource Management (ix) Participatory Decision-Making (x) Task Roles Recognized Commitment to Collective Empowerment	Intermediate System & Capacity (i) Policy Environment: University & Community Changes (ii) Sustainable Partnerships and Projects (iii) Empowerment – Multi-Level (iv) Shared Power Relations in Research/Knowledge Democracy (v) Cultural Reinforcement/Revitalization (vi) Growth in Individual Partner & Agency Capacities (vii) Research Productivity: Research Outcomes, Papers, Grant Applications & Awards Long-Term Outcomes: Social Justice (i) Community/Social Transformation: Policies & Conditions (ii) Improved Health/Health Equity

FIGURE 1: CBPR conceptual model.

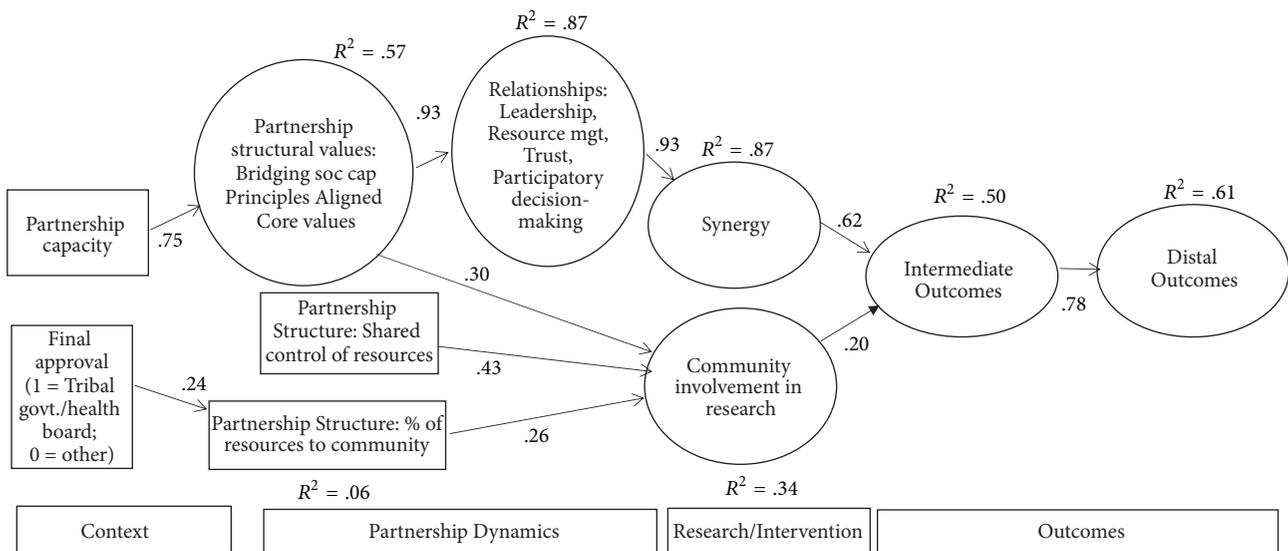


FIGURE 2: Empirical test of CBPR conceptual model. Note. Only significant paths ($p < \text{or} = .01$) are displayed.

2.1. Internet Survey

2.1.1. Research Design and Sampling. The research design included three stages of a cross-sectional survey of federally funded CBPR partnered projects in 2009. Methods are described briefly here, and in depth elsewhere [18, 23, 24]. Phase one involved selecting 294 CPBR projects in 2009 from US databases through an extensive search strategy. Secondly, we sent out a key informant Internet survey (KIS) to principal investigators or project directors (PI) in 2011, with 200 (68.0%) respondents, who also identified up to four partners (three community and one academic) to participate in the community engagement survey (CES).

Thirdly, the CES was sent to 404 partners and 200 PIs in 2012; 450 in total participated: 312 partners (77.2%) and 138 PIs (69.0%). The CES sample included 272 White, non-Hispanic, 37 American Indian/Alaska Native, 37 African American, 32 Hispanic, 28 Asian/Pacific Islander, and 23 mixed race or other; 73 male and 205 female; and 194 community partners and 118 academic partners.

2.1.2. Measures. Table 1 presents descriptive information of measures used in this study including relationship to each domain and construct in the model. Table 2 presents the original items, scaling, and Cronbach alphas of the measures. Prior studies provide evidence of validity and psychometric properties of the measures including internal consistency and factorial and construct validity [24, 25].

For context, we included in the CES a measure of *partnership capacity* based on a prior measure [26]. The governance context measure in the KIS was *final approval* created by the research team, who provided approval of participation in this research project on behalf of the community, with six response items recoded to tribal government/health board or other. Two other KIS items were *percentage of resources* provided to the community and *shared control of resources* (in-kind, financial, personnel) [23].

Partnership dynamics, measured by the CES, included three broad categories: partnership structures, relationships, and community engagement in research. *Partnership structures* included a prior measure of partner values [27] and two measures created by the research team: principles of CPBR (partner focus) and bridging social capital [24]. *Relationships* included leadership, resource management, participatory decision-making [20], trust [28], and (dis)respect, participation, and cooperation [29]. *Community engagement in research* (CER) was measured from a prior scale [20] with three subscales: background research, data collection, and analysis and dissemination.

Perceived outcomes, measured in the CES, included the *proximal outcome* of partnership synergy from a previous scale [20]; *intermediate outcomes* of three prior scales—personal and agency capacity building [20] and sustainability [24]; and *distal outcomes* of a community transformation scale [20] and a single item measuring improvement in community health [24].

2.1.3. Data Analysis. Data analysis was based on project-level data. Specifically, the CES responses were averaged across

the project to create a single score because there was a high level of agreement among the partners within any given partnership about the outcomes ranging from .75 to .88 on a measure of consensus of responses [30]. Analysis of the latent structural model was completed using SPSS AMOS 23.0. The analysis was completed with means and intercepts estimated for missing values using maximum likelihood. There was a small amount of missing data determined to be missing at random. The model was assessed using four fit indices: χ^2 to df ratio (χ^2/df), comparative fit index (CFI), Tucker-Lewis index (TLI), and root mean square error of approximation (RMSEA): CFI and TLI $\geq .90$, RMSEA $\leq .08$, and $\chi^2/df \leq 2.0$.

2.2. Case Study Methods and Analysis Design. The RIH qualitative arm sought complementary and distinct knowledge on CBPR pathways in the model, specifically asking how contexts *interact* with partner perceptions and how partnership practices over time contribute to the range of outcomes in the model. Concurrent with the survey, we implemented an iterative parallel methodology [31], especially during analysis, using the transformational lens of advancing equity [32]. We chose a purposefully diverse sample of seven case studies, by being urban/rural, geography, health issue, and racial/ethnic or other social identities, for example, the deaf community. Methods (fully described elsewhere [18]) included document review; on-site visits, with individual academic and community interviews, focus groups, meeting observations, and partnership historical timelines; and a brief survey (instruments at [<https://cpr.unm.edu/research-projects/cbpr-project/research-for-improved-health.html>]). Using ATLAS.ti, we coded transcripts following the model constructs and first triangulated themes with the SEM scales, confirming the importance of context partnership capacity, resource sharing, relational dynamics, CER, synergy, and agency capacity and health outcomes. Secondly, we coded on themes not included in the survey, such as sociocultural historical contexts, trajectories of time and impact, and motivation and actions of partners towards outcomes, which allowed us to add developmental theorizing.

Due to space constraints, this paper reports on one illustrative case study to illuminate pathways and mechanisms in the model. This project was National Institute of Cancer (NCI-) funded research to test the effectiveness of lay health workers (LHW) to increase colorectal cancer screening among Chinatown immigrants, given inequity in this cancer [33, 34]. The primary partnership was between the University of California San Francisco (UCSF), San Francisco State University, and NICOS Chinese Health Coalition, a community organization; partners also included the Chinatown Health office and AANCART, an NCI-network to address Bay Area Asian-American cancer inequities. Specific data collection included a 2.5-day visit, 11 stakeholder interviews, partnership focus group, historical timeline, and brief partner surveys. Transcripts were transcribed, coded, and consolidated into narratives, which were returned to the partnership for verification, editing, and cointerpretation.

TABLE 1: Descriptive information for constructs.

Latent variable	Definition	M	SD	1	2	3	4	5	6	7	8	9
(1) Partnership capacity	Project has resources to achieve its aim	4.34	.38	1.0								
(2) Final approval	Who approved the project on behalf of the community	.24	.43	.02	1.0							
(3) Control of resources	Whether resources were controlled by community, academic, or both	2.02	1.00	.11	-.12	1.0						
(4) % of resources to community	The percentage of overall financial resources that went to the community	36.08	25.67	-.08	.24*	.03	1.0					
(5) Partnership structural values	Principles, values, and people for organizing the partnership	13.05	1.24	.73*	-.07	.10	-.16	1.0				
(6) Relationships	Nature and quality of the interaction among the partners	24.11	2.60	.59*	-.09	.15	-.12	.78*	1.0			
(7) Community involvement in research	Extent to which community members are involved in research	6.57	1.24	.14	-.07	.41*	.22*	.21*	.22*	1.0		
(8) Synergy	Ability to work effectively	4.45	.49	.61*	.04	.15	-.01	.75*	.82*	.29*	1.0	
(9) Intermediate	Intermediate outcomes	10.83	1.74	.52*	-.05	.24*	.05	.61*	.56*	.34*	.59*	1.0
(10) Distal	Long-range outcomes	6.41	1.41	.42*	.01	.24*	.09	.47*	.38*	.20*	.43*	.59*

* $p < .01$.

TABLE 2: Scale items and Cronbach's alphas for measures.

Category	Scale	Items	Response scale	Cronbach's alpha
Context	Partnership capacity	(1) Skills and expertise (2) Diverse membership (3) Legitimacy and credibility (4) Ability to bring people together for meetings and activities (5) Connections to political decision-makers, government agencies, and other organizations/groups (6) Connections to relevant stakeholders	1 (not at all) to 5 (to a great extent)	0.78
	Final approval	(1) Who made the final decision to approve participation in this research projects on behalf of the community? Choose all that apply	(1) Agency leader, representative, board, or staff, (2) tribal/local government or health board/public health office, (3) individual community member(s), (4) project advisory board, (5) no community decision; individual research participants give consent	N/A
Partnership structures	Shared control of resources	(1) Which partner (academic, community, or both) hires personnel on the project? By community partners we mean agencies, organizations, tribal communities, health departments, individuals, or other entities representing communities By academic partners we mean university or research institutions (2) Who decides how the financial resources are shared? (3) Who decides how the in-kind resources are shared?	(1) Community; (2) academic; (3) both	N/A
	Percentage of resources to the community	(1) Thinking of the overall budget, how are the project's financial resources divided among community partners and academic partners?	% to community	N/A
	Bridging social capital	(1) Does the <i>community</i> research team have the knowledge, skills, and confidence to interact effectively with the academic researcher team? (2) Does the <i>academic</i> research team have members who are from a similar cultural background as the community research team? (3) Overall, does the <i>academic</i> research team have the knowledge, skills, and confidence to interact effectively with the community research team? (1) This project builds on resources and strengths in the community (2) This project emphasizes what is important to the community (environmental and social factors) that affect well-being (3) This project views community-engaged research as a long term process and a long term commitment (4) This project fits local/cultural beliefs, norms, and practices	1 (not at all) to 5 (to a great extent)	0.69
Partnership structural values	Alignment with CBPR principles: partner focus	(1) Members of our partnership have a clear and shared understanding of the problems we are trying to address (2) There is a general agreement with respect to the mission of the partnership (3) There is general agreement with respect to the priorities of the partnership (4) Members agree on the strategies the partnership should use in pursuing its priorities	1 (not at all) to 5 (to a great extent)	0.82
	Core values		1 (strongly disagree) to 5 (strongly agree)	0.89

TABLE 2: Continued.

Category	Scale	Items	Response scale	Cronbach's alpha
Relationships	Participation	(1) We showed positive attitudes towards one another (2) Everyone in our partnership participated in our meetings (3) We listened to each other	1 (strongly disagree) to 5 (strongly agree)	0.78
	Cooperation	(1) Arguments that occurred during our meetings were constructive (2) When disagreements occurred, we worked together to resolve them (3) Even though we did not have total agreement, we did reach a kind of consensus that we all accept	1 (strongly disagree) to 5 (strongly agree)	0.83
	Respect	(1) There were disrespectful remarks made during the conversation (2) There was hidden or open conflict and hostility among the members (3) The way the other members said some of their remarks was inappropriate	1 (strongly disagree) to 5 (strongly agree)	0.83
	Trust	(1) I trust the decisions others to make about issues that are important to our projects (2) I am comfortable asking other people to take responsibility for project tasks even when I am not present to oversee what they do (3) I can rely on the people that I work with on this project (4) People in this group/community have confidence in one another	1 (strongly disagree) to 5 (strongly agree)	0.86
Participatory decision-making		(1) Feel comfortable with the way decisions are made in the project (2) Support the decisions made by the project team members (3) Feel that your opinion is taken into consideration by other project team members (4) Feel that you have been left out of the decision making process	1 (never) to 5 (always)	0.83
		(1) Taking responsibility for moving the project forward (2) Encouraging active participation of academic and community partners in the decision-making (3) Communicating the goals of the project (4) Working to develop a common language (5) Fostering respect between partners (6) Creating an environment where differences of opinion can be voiced (7) Resolving conflict among partners (8) Helping the partners be creative and look at things differently (9) Recruiting diverse people and organizations into the project (10) Providing orientation to new partners as they join the project	1 (very ineffective) to 5 (very effective)	0.94
Resource management		(1) The team's financial resources (2) The team's in-kind resources (3) The team's time	1 (makes poor use) to 5 (makes excellent use)	0.86

TABLE 2: Continued.

Category	Scale	Items	Response scale	Cronbach's alpha
	Community involvement in research: background research	(1) Developing community-based theories of the problem or intervention (2) Grant proposal writing (3) Background research (4) Choosing research methods (5) Developing sampling procedures	1 (community partners did not participate in this activity) to 3 (community partners were actively engaged in this activity)	0.81
	Community involvement in research: data collection	(1) Recruiting study participants (2) Implementing the intervention (3) Designing interview and/or survey questions (4) Collecting primary data	1 (community partners did not participate in this activity) to 3 (community partners were actively engaged in this activity)	0.69
Research/intervention	Community involvement in research: analysis & dissemination	(1) Interpreting study findings (2) Writing reports and journal articles (3) Giving presentations at meetings and conferences	1 (community partners did not participate in this activity) to 3 (community partners were actively engaged in this activity)	0.82
	Partnership synergy	(1) Develop goals that are widely understood and supported in this partnership (2) Develop strategies that are most likely to work for your community or stakeholders as a whole (3) Recognize challenges and come up with good solutions (4) Respond to the needs and problems of your stakeholders or community as a whole (5) Work together as a team	1 (not at all) to 5 (to a great extent)	0.90
	Personal capacity building	(1) Enhanced my own reputation (2) Increased utilization of my expertise or services (3) Increased my ability to acquire additional financial support	1 (not at all) to 5 (to a great extent)	0.80
Intermediate outcomes	Agency capacity building	(1) Enhanced the agencies' reputation (2) Enhanced the agencies' ability to affect public policy (3) Increased utilization of agencies' expertise or services	1 (not at all) to 5 (to a great extent)	0.87
	Sustainability of partnership/project	(1) I am committed to sustaining the community-academic relationship with no or low funding (2) This project is likely to continue forward after this funding is over (3) Our partnership carefully evaluates funding opportunities to make sure they meet both community and academic partners' needs	1 (strongly disagree) to 5 (strongly agree)	0.71
Distal outcomes	Community transformation	(1) Resulted in policy changes (2) Improved the overall health status of individuals in the community (3) Resulted in acquisition of additional financial support (4) Improved the overall environment in the community	1 (strongly disagree) to 5 (strongly agree)	0.79
	Health outcomes: community health improvement	(1) Overall, how much did or will your research project (insert name) improve the health of the community?	1 (not at all) to 5 (a lot)	N/A

3. Results

3.1. Latent Structural Model. Prior to testing the latent structural model, the measurement model was examined. The overall measurement model provided a good fit to the data; χ^2 (236, $N = 161$) = 438.97, $p < .001$, CFI = .93, TLI = .91, and RMSEA = .07. To achieve this fit, we had to remove three scales: change in power relations, principles (community focus), and influence as these scales had significant overlap with other scales in the model. We chose to remove these scales rather than try to include items in the retained scales as we had established distinctness of the scales in prior testing.

Figure 2 illustrates the model and the significant paths among latent variables to include the effect sizes (e.g., variance accounted for). The model achieved reasonable fit. χ^2 (315, $N = 161$) = 542.95, $p < .001$, CFI = .92, TLI = .90, and RMSEA = .07. Table 1 includes the description of, and relationships among, the constructs in the model. The contextual variables were associated with partnership structures and dynamics although in unique ways. Partnership capacity was positively associated with partnership structural values. Partnership structural values were then positively associated with relationships and CER. Governance, as final approval given by a health board/tribal government, was associated with a greater percentage of resources to the community. Greater percentage of resources and shared control of resources were associated with CER.

Relationships were strongly and positively associated with synergy. Both CER and synergy were positively associated with intermediate outcomes, which were strongly and positively associated with distal outcomes.

3.2. Case Study. The qualitative data below offers support for quantitative findings, as well as new findings of the relationships between CBPR model domains. Given space limitations, single exemplary quotes are provided even though multiple community and academic partners supported each theme.

Qualitative context data provided distinct information about community inequities and consequent effect on research participation.

40% of Chinese households are linguistically isolated... no one over the age of 14 speaks English well or at all. [As] new immigrants, they have a lower standard of living... If they are people who recently came to the country, especially from mainland China, they're really sceptical about research... They might think that the government is trying to get something from them.

Yet understanding cultural foundations as assets was also important.

To understand why we run things certain ways, a person would need to understand Chinese culture... Nutrition is of great interest... they go to herbalists to make soup to get better.

These elements exemplify the need to focus on the broader context of the community that the partnership needs to

understand and operate within. These broader contexts of community, including how the role of nutritional health could add to research messaging, were not captured in the surveys.

The understanding of a survey context variable, partnership capacity, was strengthened with information about the existing capacity of NICOS, as a highly regarded community organization and key community partner, to provide proxy trust for the academics. With a subcontract from UCSF, as an important structural construct in the model of sharing resources, NICOS became the de facto implementer and bridge, hiring LHWs and a research coordinator, who worked closely with the UCSF coordinator. Having an influential community partner facilitated successful implementation of the grant, especially through collaborative structures (i.e., the second domain of the model).

The roles of subcommittees of both academic and community members, not included in the surveys, were noted as important bridging mechanisms to good relationships and effective collaborative work.

One of the things that makes us have such a good working relationship is the sub-teams; the translation sub-team, because we're all Chinese speakers. We have a lot of fun, because sometimes things can be translated in a really funny way... And we have a lot of laughs... just trying to figure out what's the right way... After meetings we go eat lunch together. That really helps in developing a good working relationship.

Since many academic team members were multilingual/multicultural, they used this culturally centered bridging capacity to cocreate the intervention and research materials, seen as cultural fit in the third domain of the model.

... all the materials, I would say it's scrutinized by a group of Chinese people. Like we spend so much time on translation and just reviewing whether the pictures are culturally appropriate, the wordings, everything... It's unbelievable how much time we spend"... "Like they would say a common belief among the Chinese about colon cancer; and then instead of saying 'don't do that; that doesn't work,'... in our flip chart, they don't approach it that way. They say, 'It's good you are doing something to promote your health.' The best way... is to combine the Chinese and the western... This is something I've never seen before.

Respect for different expertise of the partners was also apparent in how partners talked about CBPR and on their working together well, defined in the model and literature as synergy.

CBPR really opens up the communication channels... not everyone is a trained researcher, but we all have the same goal... and that really influences how we work together. We all have different expertise... We look to UCSF for all their research-related questions we have; and NICOS

is more the community expert... And San Francisco State, their specialty is... traditional Chinese medicine... For different issues, we go to different people. And most of the time we respect the other party's expertise, and we accept what they suggest.

The use of structural features of subcommittees and shared resources helped in creating synergy and cultural centeredness and enable intermediate and distal outcomes.

Outcomes of the trial confirmed intervention effectiveness on knowledge and screening [35]. In addition to research outcomes, the strength of synergy meant that social outcomes were also embraced by the academics, facilitated by a new favourable political environment.

I think the community is also highly activated... You know the mayor now is Chinese... There's a very powerful awakening in the Chinese community politically.

This meant for NICOS that not only did they gain agency capacity in research, but there was a window of opportunity for their broader LHW workforce development agenda. This illustrates how intervention outcomes can foster political opportunities for partnerships to promote health equity.

It won't affect the project directly, except if we decide to take this workforce issue as far as we want, there might be more sympathetic ears at certain places. We just found obviously that when you go into a Chinese-American leader and say, "Well, this a need for the community," they tend to grasp it a little bit quicker than having to explain to someone who's not from the community.

In sum, qualitative data deepened an understanding of temporal pathways of how community and partnership capacity and the structures of subcommittees and shared resources interacted with CBPR-driven mutual relationships and culture-centered interventions to strengthen synergy and promote health and social equity outcomes, including potential feedback loops to change contexts.

4. Discussion

The purpose of this study was to provide a mixed-method assessment of the domains and pathways linking components of the CBPR conceptual model to demonstrate the transformational impact of participatory health research on health and social equity. The model was validated by a robust mixed-method data set from a large US sample of CBPR projects across different communities and health conditions. It is the first attempt at using a latent variable structural model to examine components of CBPR.

There are two key parts to the contextual and relational dynamics domains and their respective impacts demonstrated by the structural equation model. One is the shared governance structure of the projects in terms of approvals, resource sharing, and resource control (i.e., structural pathway). These factors ensure community engagement and

representation in the research, facilitating community stewardship, and making sure that the community benefits [25]. The other factor is the partnership having capacity and high quality partnership practices, having resources and skills to interact with principles of mutual learning and respect (i.e., relational pathway) [16, 36, 37]. These elements collectively shape partnership synergy given the significant paths in the model, as synergy is associated with effective relational dynamics [10, 20, 38, 39]. Further, synergy and CER mediate context and partnership dynamics with the intermediate and distal outcomes, consistent with other research [10, 20].

The qualitative results reinforce this model and provide distinct findings of how relationships are strengthened and how the model moves across time towards outcomes, beyond specific grant aims. Qualitative findings demonstrate depth and specificity in the conceptual relationships and extend the model particularly in terms of context and feedback loops. For example, case study data provide a deeper understanding of context, especially identifying the sociohistorical risks and assets in which the partnership is situated. Community contexts then shape the development of trust and navigating structural and relational dynamics [18]. These findings also provide more depth to understanding how partnership structures and relationships interact in order to create synergy. In this particular case, the respected community organization was widely credited as strengthening synergy by bridging academic and community members. Finally, the case study was able to illustrate how various outcomes of the project provide feedback to context and relational dynamics. This dynamism is reflective of CBPR and helps to overcome limitations of the cross-sectional survey.

A major implication of this study is the impact that CBPR context and dynamics has on intermediate and distal outcomes. This study demonstrates with mixed-method data that the nature of partnership dynamics within a particular context has effects on a variety of capacity building, community transformation, and community health outcomes through partnership synergy as demonstrated by the positive and significant paths in structural equation model from context and partnering processes to outcomes. A key goal of many using CBPR, and other forms of PHR, is to contribute to social justice and public health and this study provides strong evidence that partnering processes matter for health and social equity outcomes [13, 14, 21].

The study also has some limitations. The survey is cross-sectional, with perceptual measures of dynamics and outcomes. The case study helps address this limitation as it is from a different sample and is avoiding same sample bias. While also based on people's perceptions, community and academic stakeholders were deeply engaged with strong awareness of their practices and impact of their work on the community. However, future research should also examine longitudinal and actual outcomes resulting from CBPR processes to assess the extent to which perceived and observed indicators work in similar or distinct ways, and whether one may be more predictive of outcomes than the other, and, if so, under what conditions.

5. Conclusion

This study sought to provide an empirical test of the CBPR conceptual model to advance the science of CBPR and other forms of PHR. The mixed-methods findings from a robust data set provide some empirical support for specific domains of the model, with pathways identified through both quantitative modelling and qualitative data. Qualitative data additionally offered insights into how context and partnering practices influence each other across time towards partnership effectiveness. The model can be used as a theoretical and evaluation tool to help enhance the practice of the many forms of participatory health research and holds much promise for achieving health equity and improving the health of communities. These approaches provide the opportunities for communities to codevelop and thus allow for holistic self-determined interventions that reflect the life experiences, values, and goals of the community. The current study helps to illustrate key contextual and partnering processes to enable this type of impact.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

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