

## **Title Page**

Title: Participatory implementation science to increase the impact of evidence-based cancer prevention and control

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## Abstract

It is critical to accelerate the integration of evidence-based programs, practices, and strategies for cancer prevention and control into clinical, community, and public health settings. While it is clear that effective translation of existing knowledge into practice can reduce cancer burden, it is less clear how best to achieve this. This gap is addressed by the rapidly growing field of implementation science. Given that context influences and is influenced by implementation efforts, engaging stakeholders in the co-production of knowledge and solutions offers an opportunity to increase the likelihood that implementation efforts are useful, scalable, and sustainable in real-world settings. We argue that a participatory implementation science approach is critical, as it supports iterative, ongoing engagement between stakeholders and researchers to improve the pathway between research and practice, create system change, and address health disparities and health equity. This article highlights the utility of participatory implementation science for cancer prevention and control research and addresses: a) the spectrum of participatory research approaches that may be of use, b) benefits of participatory implementation science, and c) key considerations for researchers embarking on such projects.

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## Keywords

Implementation science; Community-based participatory research; Participatory implementation science; Cancer prevention and control; Evidence-based practice

## 1. Introduction

Accelerating the integration of evidence-based programs, practices, and strategies for cancer prevention and control into practice settings is critical to improve cancer morbidity and mortality. About half of cancer cases occurring today could be prevented by incorporating existing scientific knowledge into clinical, community and public health settings [1]. In reality, the path from creating evidence to implementing evidence in routine practice is long and arduous [2, 3]. Dissemination and implementation science offers frameworks, theories, and methods to influence the pathway from evidence to practice, through an explicit focus on the factors that impact the spread, adoption, and implementation of evidence-based practices in the context of the organization, community, or other stakeholders that will be impacted [2-4]. Hereafter in this paper, we use the term “implementation science” to cover both dissemination research and implementation research. We also use the term “evidence-based practice” to include programs, practices, and strategies supported by research findings and the term “stakeholder” to refer to a broad spectrum of potential partners (e.g., patient, practitioners, organizational leaders, engaged citizens) that may design, deliver, and/or receive an evidence-based practice.

The risk factors for cancer are complex, and multifaceted thinking needs to be applied to address our most vexing cancer prevention and control challenges [5]. Targets for cancer prevention and control (e.g., tobacco use or obesity) have complex upstream causes that are multifactorial, interrelated, and often closely linked with the social determinants of health [6]. Accordingly, implementation science theories and frameworks emphasize context as a critical factor in determining which interventions are adopted, how these interventions are adapted, and what factors serve as barriers and facilitators to implementation within a specific setting [7]. Through stakeholder engagement and co-learning (in which researchers, communities, institutions, and other partners learn from each other), research efforts can more effectively assess and address contextual influences [2-4].

Initiatives such as the Cancer Moonshot [8] and Cancer Prevention and Control Research Networks (<http://cpcrn.org/>) are increasingly challenging scientists to speed the translation of evidence-based practices for cancer prevention and control. We have a rich, but underutilized, evidence base for cancer prevention and control that affords opportunities to improve the utilization and impact of research evidence, from the individual to policy levels and from primary prevention to survivorship [8]. At the same time, the rich literature on participatory approaches emphasizes stakeholder engagement to increase the impact of research evidence in practice settings, address health disparities, and advance health equity [9]. Increasing the utilization of cancer prevention and control evidence requires coordinated and effective action by a wide range of stakeholders; we propose that those goals can best be achieved through “participatory implementation science.” Building on a rich literature (see [10, 11]), we argue that stakeholders and researchers can engage in an iterative, ongoing manner to leverage diverse expertise, co-produce knowledge and solutions, and create system-level change for the integration of research evidence into practice and community settings, with the explicit goals of improving cancer outcomes and addressing cancer disparities.

This paper highlights the potential of participatory implementation science for cancer prevention and control and: a) presents a spectrum of participatory research approaches that may be of use, (b) describes the benefits of participatory implementation science, and (c) identifies key considerations for researchers embarking on such projects.

## 2. A spectrum of participatory research approaches

Participatory research is notable for its focus on research, action, and education to address health disparities [12]. The level of stakeholder engagement in participatory research can span a wide spectrum, from community-based participatory research (CBPR) (full engagement) to contractual (minimal engagement). CBPR is a collaborative approach that seeks to equitably involve partners in all phases of the research process – from topic selection through research design, conduct, and analysis, to dissemination of results, with the goal of supporting research and action to address health disparities [13, 14]. CBPR is often identified by key principles that focus on capacity building, long-term relationships, and local relevance/application of solutions generated [9]. Less engaged approaches to research include: a) collaborative styles, in which stakeholders and researchers work together, with researchers controlling decisions and resources; b) consultative styles, in which stakeholders are consulted initially or in an ongoing manner for specific goals, e.g., to facilitate recruitment; and c) contractual styles, in which the stakeholders provide a site or setting for the research [15, 16]. As engagement increases, the quality and utility of research activities and outcomes are expected to increase as well [15].

Despite the potential for participatory approaches to bridge the divide between research and practice, they are not yet the norm. In a recent assessment, researchers identified 103,250 externally-funded projects funded in the United States in 2009 and found that 333 used participatory approaches (0.33%) [17]. Of the 333 participatory projects, 64 focused on cancer and the research team highlighted the utility of participatory approaches to adapt cancer-focused interventions, leverage local knowledge related to culture, and build research capacity in communities experiencing cancer disparities [18]. These benefits are echoed by the work of the Metropolitan Chicago Breast Cancer Taskforce, which highlights the importance of participatory approaches to ensure that research activities and products (e.g., interventions and policies) consider the culture, resources, and constraints of vulnerable communities, thereby increasing their likely utility and impact [19].

### **3. Advantages of participatory implementation science for cancer prevention and control**

Participatory approaches offer a range of benefits for implementation science, as stakeholders and researchers collaborate to influence the pathway from evidence to action. Here we describe the benefits in relation to six areas: selection of the issue or evidence-based practice, study execution, data interpretation, dissemination, building the evidence base, and capacity-building. Illustrative examples from the authors' work are provided.

1) Selection of the issue or evidence-based practice: An engaged approach to issue or evidence-based practice selection can increase the relevance and impact of implementation science efforts. For example, a collaborative effort might assess the viability of a given evidence-based practice proposed for implementation within a community or setting within which it has not been tested [11]. Alternatively, stakeholders can work with researchers to determine which evidence-based practice to implement. For example, one research team used CBPR approaches to work with four rural community coalitions to address childhood obesity, a priority identified by the community and embraced by the research partners. Coalition focus areas varied widely based on local context, priorities, and the expertise and interests of coalition members. Accordingly, the coalitions leveraged diverse evidence-based practices, ranging from increasing utilization of parks and recreation programs to removing chocolate milk from school lunches [20, 21].

2) Study execution: Collaboration with stakeholders can improve study design by developing recruitment and retention strategies that are acceptable to the community and

informing intervention and instrument development [15]. For example, a recent CBPR project funded by the National Cancer Institute (NCI) to build capacity in community-based organizations for the use of evidence-based practices was facing challenges with recruitment and retention of trainees. Community Advisory Board members suggested marketing the training as professional development subsidized by the NCI, rather than emphasizing the need for evidence-based practices in local communities. Although this only required a minor change in the recruitment materials, the impact was substantial. Trainees saw the program as an opportunity for career advancement and organizational leaders saw it as a way to achieve employee development goals without incurring additional costs [22].

3) Data analysis and interpretation: Depending on their capacity and interest, stakeholders may engage with data analysis, but it is typical for the research team to drive this effort [23]. For the interpretation phase, stakeholders play a critical role in providing insight into what findings mean within their contexts and identifying potential implications [15]. In this way, participatory approaches provide opportunities to leverage knowledge from a diverse set of experts to ensure that a wide range of evidence is brought to bear [24]. As an example, researchers partnered with local government members to examine the feasibility, utility, and outcomes of an intervention to increase the use of research evidence in local government. The researchers and a subset of government practitioners jointly interpreted the findings to propose a set of recommendations for capacity-building and change of organizational culture so that local governments could more effectively use research evidence for health promotion [25].

4) Dissemination (including designing for dissemination): Sharing results from a participatory implementation study is a critical obligation. Planning for dissemination (sometimes called designing for dissemination) should begin early in the life cycle of a study. We need to better understand how to design cancer interventions with the elements most critical for external validity in mind, addressing these issues during early developmental phases, not near the end of a project. To support this process, designing for dissemination is defined as: “an active process that helps to ensure that public health interventions, often evaluated by researchers, are developed in ways that match well with adopters’ needs, assets, and time frames” [26]. A study of public health researchers in the United States found considerable room for improvement in designing for dissemination as only one-third of respondents (34%) always or usually involved stakeholders in the research process [26].

5) Building the evidence base: Implementation science offers the reminder that if we want more evidence-based practice, we need to improve the quality and quantity of practice-based evidence [27]. Participatory approaches offer opportunities to integrate knowledge held by stakeholders into the formal scientific literature and influence the evidence base that follows. This is important for deepening the knowledge base about contextual drivers of implementation and which implementation strategies might be most effective in the target setting. Given that the outcomes of cancer prevention efforts are a function of the characteristics and activities of researchers, implementers, and recipients, engagement of these key players in design, delivery, and evaluation is expected to increase the utility of implementation science findings [28].

6) Capacity-building: The benefits of participatory approaches for implementation science also accrue at a higher level, with impacts far beyond a given research study. A hallmark of engaged approaches is the emphasis on capacity-building among partners, so that at the end of the effort, partners are better equipped to handle current and future health challenges [29]. This can translate into an increased ability of stakeholders to engage with data and research evidence as they create change in their communities, organizations, or systems going forward [30]. The

focus on capacity to support future efforts is critical as stakeholders must be equipped to react to the dynamic cancer prevention and control evidence base, whether implementing new evidence-based practices or deimplementing those that are no longer the standard of care [31].

#### **4. Key considerations for designing participatory implementation science efforts**

Researchers interested in using participatory approaches for implementation science have several useful resources at their disposal [10, 11]. Three core questions can support initial forays into using this approach: 1) Which stakeholders should be engaged? 2) What level of engagement is appropriate? and 3) How should stakeholders be engaged?

**Which Stakeholders Should be Engaged?** Given that implementation of research evidence for cancer prevention and control has a range of influences at multiple levels, the range of relevant stakeholders is likely to be quite broad, from community members, patients, and caregivers to agency and organization leaders and policy makers. Partnership composition provides an opportunity to reflect on the roots of many participatory research traditions as methods to address disparities based on race, ethnicity, rurality and social class by empowering marginalized communities and individuals [23]. In the context of implementation science for cancer prevention and control, engaging stakeholders can offer an important opportunity to ensure that the benefits of research evidence accrue to underserved communities and to prevent differential implementation from creating or exacerbating cancer disparities. Identifying stakeholders and building long-term relationships and commitments to the community are challenging, but achievable, goals. Exemplar resources for identifying potential partners are available through the Community Tool Box (<http://ctb.ku.edu/en>) and Campus Community Partnerships for Health (<https://ccph.memberclicks.net/>).

Determining which stakeholders to engage may vary based on the stage of research, the research setting, and stakeholder interest. For example, if working in a clinical setting, the research team may initially wish to engage decision-makers to ensure the topic is relevant and that resources are available to sustain key learnings beyond the funded research period. As study planning progresses, practitioners and administrative champions might become part of the team. Additionally, patients may also be engaged to ensure that the evidence-based practice is acceptable and appropriate. In studies based in the community, the spectrum of potential stakeholders is just as broad and may vary based on the topic and setting of interest (e.g., community members; faculty, staff, or parents at a given school; faith-based institutions; or YMCA members). The broad range of potential partners reflects the complexity of the systems into which cancer prevention and control innovations must be integrated.

As participatory approaches have become more common, including through inclusion in Clinical and Translational Science Award (CTSA) programs and the Patient-Centered Outcomes Research Institute (PCORI), a broad spectrum of stakeholders is now engaged in participatory research. For example, the CTSA program enables the inclusion of patient advocacy organizations and community members within research teams to address “system-wide scientific and operational problems in clinical and translational research that no one team can overcome” [32]. PCORI promotes the engagement of patients, caregivers, clinicians, and other healthcare stakeholders in research activities [13]. An example of a robust research infrastructure with support from CTSA and PCORI is the OneFlorida Clinical Research Consortium and its OneFlorida Cancer Control Alliance (<http://onefloridaconsortium.org>). This statewide network includes researchers, clinicians, patients, and other stakeholders and hosts the Citizen Scientist Program, which engages patients and other stakeholders as collaborators throughout the research

process. The program also provides training and support to ensure productive interactions between researchers and stakeholders, and supports a platform for the sustainable, responsive stakeholder engagement.

**What Level of Engagement is Appropriate?** As described above, there is a wide spectrum of engagement for participatory research. Conducting research in this manner requires investments of time and active engagement by partners, which can be a challenge given resource constraints and institutional demands for both researchers and partners [33]. This can be a particular challenge for implementation science projects as there may be a greater diversity of partners (e.g., community members, leaders from a health center, etc.) in the partnership team than for other projects. Researchers and stakeholders can determine which model of engagement is appropriate based on stakeholder roles, research objectives, philosophical orientation of partners, available resources/infrastructure, and the context for collaboration. Researchers must consider power differentials amongst those to be engaged. As highlighted in the work of the Community Health Advocacy Research Alliance (CHARA, see [www.communityresearchalliance.org](http://www.communityresearchalliance.org)), it can be useful to discuss the full spectrum of research approaches with stakeholders. CHARA educates stakeholders about what to expect when engaging in collaborative research, the trade-offs and benefits of these various models, and how to ensure they benefit from participation. Rather than judge CBPR as the “ideal” level of engagement for participatory research, researchers and stakeholders must assess the goals and objectives for a given collaboration.

Along the same lines, partnerships that include a wide range of stakeholders may need to build in flexibility for participation. After all, not all phases of the study design may be of interest or relevance to all partners. Thus, a flexible structure will allow for relationship maintenance, while still allowing for fluctuations in the intensity of engagement. Again, this likely has particular relevance for participatory implementation science as stakeholders across levels of the system (e.g., community members to policy makers) may be engaged and the participation requirements must be manageable.

**How Should Stakeholders be Engaged?** Researchers must assess partners’ stage of readiness and invest time in building relationships and capacity for research, rather than focusing solely on executing research activities. For marginalized and disenfranchised populations, the burdens on this population may be higher and resources to engage in research may be lower. Excellent curricula exist to facilitate training for stakeholders and researchers interested in engaging in participatory research [14, 20]. Moreover, researchers must recognize that stakeholders are often interested in action – and methods are needed to balance the short-term wins feasible through community health development and the longer-term discoveries that can emerge through research [34].

Investigators who align their research with existing practice-based research networks, prevention research centers, CTSAs, or other existing infrastructures may benefit from building on existing collaborations rather than creating new collaborations [20]. Developing academic-community partnerships over time has the added benefit that the capacity and learnings that occur from the first study can benefit and transfer to future research opportunities. Moreover, leveraging these existing partnerships ensures that academic-stakeholder collaborations extend beyond individual, funded projects and sustains ongoing collaboration and capacity-building for all partners, a hallmark of participatory research models.

**Additional considerations:** In addition to the questions highlighted above, researchers considering use of a participatory implementation science approach may wish to consider a few



more details. First, researchers are increasingly prompted to collect implementation data across a range of study designs and at various stages of building the evidence base [35, 36]. This ensures that opportunities are not missed to collect data that can inform subsequent translation of the evidence base. In the same way, stakeholder engagement along the path of evidence development also affords opportunities to gather data to inform later utilization in practice. Second, dissemination of findings to stakeholders is a core issue for implementation science. Although participatory approaches emphasize the importance of dissemination, the question of what to disseminate for participatory implementation science projects (e.g., manuals for implementation) and how best to accomplish this (e.g., through selection of relevant strategies) must still be understood and elaborated. Third, participatory approaches will require additional funding and extended timelines. Information about the costs of these approaches should be considered and the alignment with learning health system structures explored. Finally, creating a platform for ongoing, sustainable engagement, beyond individually funded projects, is a central challenge for researchers using participatory implementation science approaches.

## **5. Conclusions**

Participatory implementation science for cancer prevention and control may support increased adoption, adaptation, implementation, and sustainability of evidence-based practices in real-world practice and community settings. By considering the types of stakeholders, the level of engagement, and the ways in which stakeholders will be engaged, researchers and stakeholders can customize an engagement approach that meets the needs of the population and goals of research efforts. A participatory implementation science approach can leverage complementary expertise and allow researchers and stakeholders to learn and create knowledge together, making the pathway from research to practice more efficient and effective. Engagement with stakeholders experiencing and / or addressing cancer disparities will increase the utility and relevance of implementation science for vulnerable populations. Implementation scientists are already working with a broad range of stakeholders and doing this in a partnership model represents an important shift from the top-down or traditional research approach and may increase the likelihood of creating sustainable, system change to address complex cancer control challenges.

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