

The Importance of Participatory Approaches in Precision Home Visiting Research

Benefits of participatory approaches

Participatory approaches strengthen precision home visiting research by promoting authentic, trusting, and sustainable partnerships to identify the unique needs of individuals and communities. Input from individuals and communities served by home visiting programs, as well as other groups involved in the home visiting field, can shed light on the contexts and conditions that affect home visiting's effectiveness for different groups of participants. In particular, engaging people from these key interest groups can improve research that seeks to help home visiting programs address sensitive topics (such as substance use, child abuse, and neglect) and connect with populations that home visiting programs have not historically been successful at reaching (such as families with unstable housing or those who distrust social service systems due to past experiences of discrimination). By respectfully engaging and incorporating multiple perspectives, strong partnerships help prevent implementation challenges and create a more efficient and effective path to tailored home visiting services.

Some home visiting research teams already use components of participatory approaches for specific research or evaluation activities. Authentically engaging people from key interest groups across the full life of a project, however, can harness additional benefits and strengthen a project's relevance, efficiency, and effectiveness. For example, participatory approaches have been shown to—

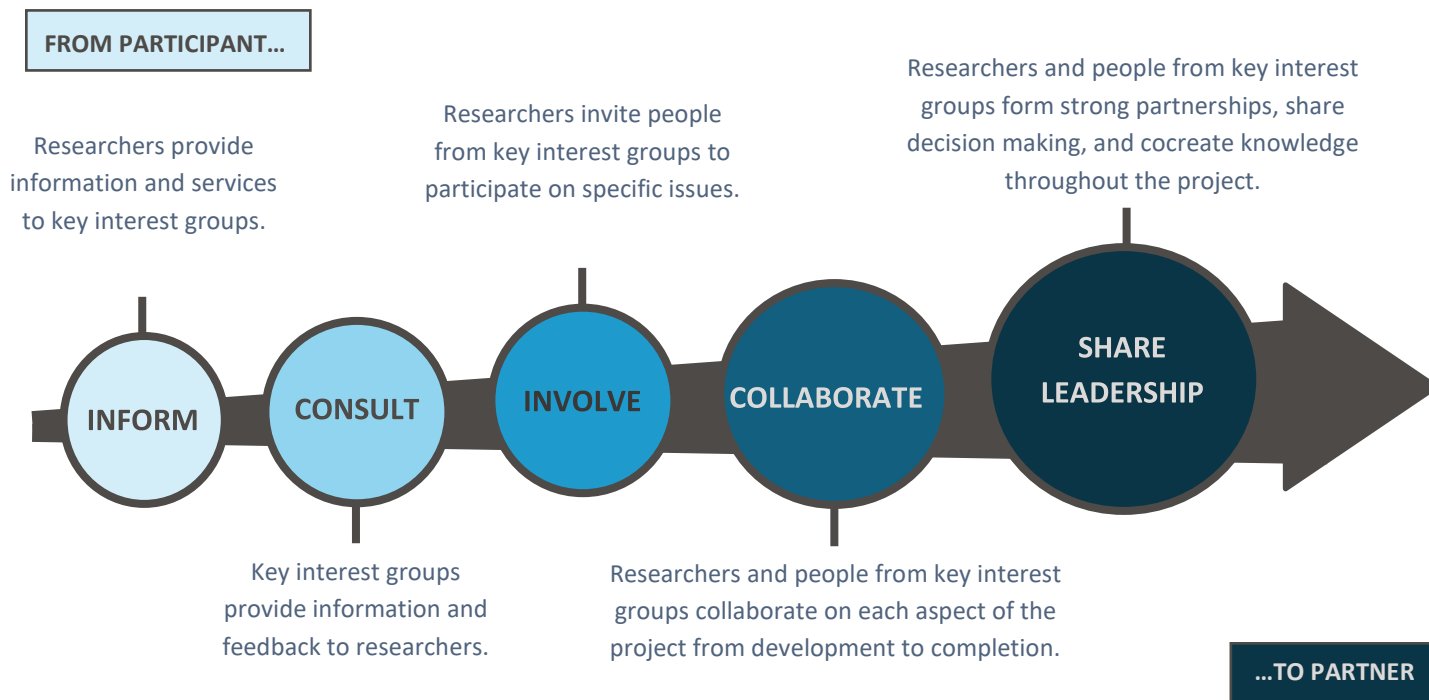
- Ensure projects are culturally and logistically appropriate, which can boost study participation and minimize implementation challenges.ⁱ
- Improve the technical skills of people from key interest groups who are involved in the project and enable diverse teams to navigate conflict.ⁱⁱ
- Strengthen the quality of project outputs and outcomes, thereby promoting sustainability beyond initial funding periods and helping generate new projects and systems change.ⁱⁱⁱ

People from key interest groups involved at multiple levels of the home visiting research process—from funders to research teams to frontline staff—must contribute to and buy into the use of participatory approaches for them to be successful. It takes time to establish and develop strong relationships between research teams and these individuals. However, early investments of time and money in a participatory approach will boost the overall efficiency of the research and ultimately lead to stronger impacts on practice.

Continuum of engagement in research

Engaging people from key interest groups in research occurs along a continuum, ranging from people from key interest groups participating minimally in distinct project activities to highly collaborative short- and long-term partnerships marked by bidirectional learning and shared leadership (exhibit 1). A project or partnership’s place on the continuum varies by factors such as study longevity, key interest group preferences, and the orientation of the research team. It is also dynamic, often advancing along the continuum as research teams incorporate best practices to strengthen participation.

Exhibit 1. Continuum of engagement in research



Adapted from:

Balazs, C. L., & Morello-Frosch, R. (2013). The three R's: How community based participatory research strengthens the rigor, relevance and reach of science. *Environmental Justice*, 6(1).

National Institutes of Health. (2011). *Principles of community engagement second edition*. (NIH Publication No. 11-7782).

Projects that don’t use a participatory approach or that only engage key interest groups by informing them about the study miss opportunities to build on the knowledge of people from key interest groups. Researchers may focus on topics that aren’t important to these interest groups or fail to account for an issue’s complexity. Research teams should aim to conduct studies further along the continuum to maximize the benefits of a participatory approach.

Core principles of participatory approaches

Researchers can use a range of participatory approaches. Common examples include community-based participatory research, participatory action research, utilization-focused evaluation, and empowerment evaluation. Each participatory approach has a slightly different emphasis, but all share the same core principles:

- Individuals affected by an issue identify needs that drive the research.
- Key interest groups—often the individuals affected by an issue and those responsible for taking action—participate in research activities and co-create knowledge.

Research teams must identify and engage people from key interest groups to translate these principles into practice.

Identification of key interest groups

To identify people from key interest groups, precision home visiting research teams should consider—^{iv}

- Who will be affected by the project, either positively or negatively?
- Who can influence the project, either positively or negatively?

Exhibit 2 provides a framework that researchers can use to identify key interest groups when developing home visiting research teams. It includes examples of agencies and individuals within those interest groups.

Exhibit 2. Examples of key interest groups in precision home visiting research^{v, vi}

Key interest group	Examples in home visiting research
Participants	Families eligible for home visiting and current or past home visiting participants
Providers	Home visitors, home visiting supervisors, educators, and managers, and other service providers
Funders	City, state, tribal, federal, and private sources of funding for home visiting services
Payers	Medicaid (e.g., reimbursement for depression screening, developmental screening) and federal and state funders
Policy makers	City, state, tribal, and federal government officials, federal government agencies (e.g., Administration for Children and Families), and advocacy organizations
Developers	Home visiting model developers and assessment or measurement developers
Researchers	Home visiting researchers and evaluators

Research teams should decide which key interest groups to engage based on a project's goals. Not all groups will be relevant for every project. Research teams may also find themselves relying more heavily on certain groups at different phases of a project.

Ongoing engagement with people from key interest groups

People from key interest groups who become research partners should be involved in all phases of the study. Research teams can plan for their engagement in precision home visiting by asking—^{vii}

- Who can serve as a liaison to facilitate engagement?
- Whose skills need to be built to support or enhance participation?
- What structures must be in place to facilitate participation?

Engagement strategies should align with key interest group partners' specific and diverse needs. Teams should prioritize relationship building early in the project and revisit throughout to ensure partners remain engaged. Local or national advisory committees can help facilitate engagement of multiple key interest groups. Exhibit 3 presents a sample structure for engaging partners during a hypothetical, 3-year comparative effectiveness study of a postpartum depression intervention delivered by home visitors and clinicians.

Exhibit 3. Example structure for engaging multiple key interest groups^{viii}

Project role	Key interest groups and partners	Engagement frequency
Executive committee (key personnel, authors of grant submission)	<ul style="list-style-type: none"> • Providers: Home visiting program manager, coordinator of state infant mental health consultation network • Funders: Head of state home visiting agency • Researchers: Home visiting principal investigator 	1-2 times per month
Operations team	<ul style="list-style-type: none"> • Executive committee members • Participants: Current and former home visiting families who struggle or have struggled with postpartum depression • Providers: Home visitors, home visiting managers, clinicians working on postpartum depression, depression content experts • Policy makers: Local advocacy organizations 	Quarterly
National advisory committee	<ul style="list-style-type: none"> • Policy makers: National advocacy organizations, city government officials • Researchers: Additional home visiting researchers 	Annually

Participatory approaches can add value in all phases of a project:^{ix}

- Key interest group partners can share knowledge in the **development phase** that enhances researchers' understanding of an issue, builds on innovations already occurring in practice, ensures that research questions and outcomes are relevant to key interest groups, and encourages use of efficient and rigorous study designs.
- Participation of key interest group partners during the **implementation phase** promotes efficient implementation and helps troubleshoot challenges. Key interest groups can help research teams develop effective recruitment and retention strategies, shape intervention activities that are contextually and culturally relevant, and identify factors that help elements of an intervention have real-world impact.
- Key interest group partners play a critical role in the **interpretation and application phase** by helping to identify and interpret findings that resonate for different audiences and support the scale-up of effective practices. These partners can also guide the development of dissemination plans to communicate findings and promote sustainability beyond the initial grant or project period.

Exhibit 4. Examples of key interest group engagement and value across project phases*

Phase	Value
Development	<ul style="list-style-type: none"> • Former home visiting families share the barriers and facilitators they experienced while seeking treatment for postpartum depression (such as not recognizing early symptoms and logistical challenges in carrying out treatment plans). • Home visitors express concern that families may avoid some topics due to fears that their children could be removed from their care. • Executive committee members outline a plan to compare the effectiveness of a postpartum depression intervention delivered by home visitors to one delivered by clinicians outside the home.
Implementation	<ul style="list-style-type: none"> • Members of the operations team develop incentives and recruitment materials for engaging families in the study. • They also collaborate with home visiting researchers to ensure the intervention design addresses barriers mentioned by former home visiting families in the development phase and strategies used in similar home visiting interventions. • Home visiting managers and representatives from the state home visiting agency and state infant mental health consultation network define recruitment activities.
Interpretation and application	<ul style="list-style-type: none"> • The national advisory committee and operations team convene to review and interpret results, including unanticipated findings. • Representatives from each key interest group identify the findings they consider most striking to inform dissemination products and tailor products by audience (such as practitioners, policy makers, home visiting programs, families). • Members of the executive committee and national advisory committee discuss opportunities for funding the home visiting-based intervention statewide.

Translation from theory to practice

Participatory approaches add value to precision home visiting research without compromising a project's rigor or limiting a research team's study methods and design options. In fact, participatory approaches can enhance rigor by ensuring that researchers use methodologies that consider the full context in which a home visiting intervention takes place. Authentically engaging people from multiple key interest groups can also raise challenges. Research teams can navigate these challenges more effectively if they recognize and address them early on.

Challenges

While diverse key interest groups provide critical insights for research, they can also raise competing priorities and perspectives. In addition, power dynamics can impact the participation of people from specific groups like families and home visitors. The culture of research itself, which often privileges ideas of objectivity and scientific expertise, adds to these dynamics. Addressing differences can be time consuming, especially toward the beginning of the project; researchers must take care not to place additional burdens, particularly time burdens, on families or the systems tasked with delivering home visiting services.

At a broader level, funding and policy contexts present their own challenges. Priorities identified by home visiting families, for example, may not align with funders' interests. Similarly, funding timelines may not allow for the time needed to implement a strong participatory approach. Other potential roadblocks include—

- Policy changes that impact home visiting reimbursement structures.
- Shifting regulations that guide home visiting program and service delivery.
- Decisions about who represents a particular key interest group, such as an agency or organization.

Strategies for success

Precision home visiting research teams can implement several strategies to prevent and overcome challenges to using participatory approaches:

- **Commit to using a participatory approach.** Recruit key interest group partners early and carefully and build in the time and structures needed to sustain engagement. Clearly articulate the benefits and responsibilities of participation to potential partners, allow them to identify their preferred level of involvement, and gauge their readiness for partnership.
- **Define roles and responsibilities.** Identify a variety of ways that key interest group partners can contribute to a project and match these individuals to specific activities based on their strengths. This will help partners see the value their perspective adds to the project.
- **Create skill-building opportunities.** Make sure orientation activities address the research team's soft skills and technical skills. Examples of soft skills include conflict resolution and listening; examples of technical skills include knowledge of program operations, state policy, research methods, and theories of human behavior. Reinforce skills throughout the project to foster trust and promote continued contributions from all key interest groups.
- **Minimize potential barriers to participation.** Potential barriers to authentic engagement include institutional processes, confidentiality concerns, travel costs, use of technical/research jargon, language barriers, and meeting times and locations. Foster open dialogue to identify barriers and create feasible solutions (such as travel stipends, diverse formats for project updates, meetings in community settings to promote comfort and transparency).
- **Evaluate partnerships regularly.** Evaluate partnerships throughout a project to ensure key interest group partners remain engaged and existing structures facilitate meaningful contributions. Use a range of evaluation methods, including satisfaction surveys, conversations, and exit interviews, to adjust and sustain relationships as needed.
- **Recognize contributions.** Acknowledge partners involved in the research process and identify ways to recognize their contributions to the project (such as co-authorship, involvement in presentations and other dissemination activities).

Participatory approaches: A theoretical example

State infant mortality data indicate that preventable risk factors in the sleep environment cause many American Indian/Alaska Native (AI/AN) infant deaths. Yet, home visitors in the state's largest city are concerned that they don't have the cultural knowledge, materials, or skills to encourage safer infant sleep practices with AI/AN families. Recognizing limited internal capacity to address these challenges, the city's home visiting program director reaches out to a researcher who has worked with area tribes on infant health topics. Together, they outline a plan to engage a large, nearby tribe in participatory research. With appropriate research approvals in place, they form a community advisory board (CAB) of tribal elders and parents, health care providers, and home visitors from the city and tribe. The CAB helps to—

- Refine the research questions and design a mixed methods study to create and test a culturally based infant safe sleep curriculum in home visiting programs serving the city and tribe
- Navigate perceived tensions in cultural and mainstream infant sleep practices
- Determine what is culturally acceptable to include in a curriculum to be delivered by tribal and nontribal home visitors
- Establish control group procedures that address tribal concerns about using a randomized controlled trial design in their low-resource setting
- Define study outcomes and create measures that respectfully assess the role of culture
- Interpret the results and carry out the dissemination plan they co-developed

Evidence from the study inspires city policy makers to fund distribution of the curriculum to local home visiting programs. Several CAB members agree to serve in a similar role on a new project that will evaluate the curriculum in additional tribal home visiting programs across the state.

Note: This example is based on a real scenario adapted to apply to precision home visiting.

Take-home messages

- Participatory approaches incorporate diverse perspectives from people across key interest groups to make precision home visiting research more relevant, efficient, and effective.
- There are many participatory approaches; all share a commitment to allowing research to be driven by the needs of individuals affected by an issue and engaging key interest groups in research activities.
- To maximize the benefits of a participatory approach, precision home visiting researchers should engage people from key interest groups in the development, implementation, and interpretation and application phases of a project.
- Participatory approaches do not limit research teams to specific methods or designs, or compromise project rigor.
- Although many key interest groups exist in home visiting, precision home visiting research teams must determine which partners are most important for meeting a project's stated goals and provide opportunities to participate.
- Challenges can arise when using participatory approaches; however, precision home visiting research teams can mitigate obstacles with preparation and committed investment in relationships.

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ⁱⁱ Jagosh et al., 2012

ⁱⁱⁱ Jagosh et al., 2012

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^{vii} Center for Community Health and Development (2018).

^{viii} Tandon, D. (2018, April).

^{ix} Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. *Annual Review of Public Health*, 29(3), 325–350.

^x Tandon, D. (2018, April).

