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 key stakeholders sheds light on the contexts and conditions that affect home visiting's effectiveness for different groups of participants; this aids the search for active ingredients and meaningful subgroups of children and families. In particular, stakeholders can improve research that seeks to help home visiting programs address sensitive topics (such as substance use, child abuse, and neglect) and engage hard-to-reach populations (such as families with unstable housing or those who may distrust social services). By respectfully engaging and incorporating multiple perspectives, strong partnerships help prevent implementation challenges and create a more efficient 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 stakeholders 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 stakeholders' technical skills 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 system change[iii]
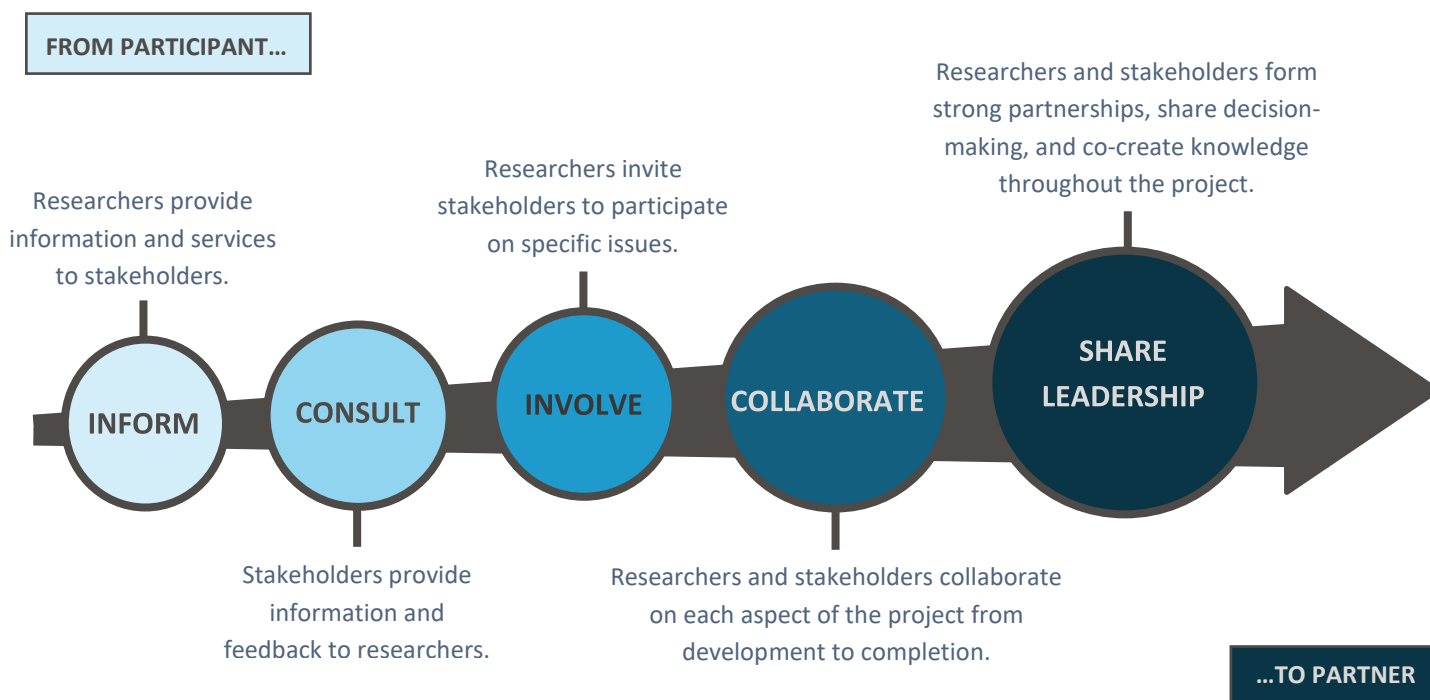
> **Key terms**
>
> **Active ingredient:** The element(s) of a home visiting intervention empirically proven to be responsible for changes in specific outcomes. If an active ingredient is not present, the intervention will not produce the desired outcomes.
>
> **Meaningful subgroup:** A specific group of children or families empirically proven to benefit from an active ingredient.

Stakeholders at multiple levels of the research process—from funders to research teams and frontline staff—must contribute to and buy into using a participatory approach for it to be successful. It takes time to establish and develop strong stakeholder relationships. 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 stakeholder participation

Stakeholder participation in research falls along a continuum, ranging from minimal participation 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, stakeholder 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 stakeholder participation.

Exhibit 1. Continuum of stakeholder participation

FROM PARTICIPANT…

Researchers provide information and services to stakeholders.

Researchers invite stakeholders to participate on specific issues.

Researchers and stakeholders form strong partnerships, share decision-making, and co-create knowledge throughout the project.

INFORM

CONSULT

INVOLVE

COLLABORATE

SHARE LEADERSHIP

Stakeholders provide information and feedback to researchers.

Researchers and stakeholders collaborate on each aspect of the project from development to completion.

…TO PARTNER

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 stakeholders by informing them about the study miss opportunities to build on stakeholders' knowledge. Researchers may focus on topics that aren't important to key stakeholders or that fail to recognize 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 two core principles:

- Individuals affected by an issue identify needs that drive the research.

- Key stakeholder 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 key stakeholders to translate these two principles into practice.

Identification of key stakeholders

To identify potential stakeholders, 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 stakeholder groups when developing home visiting research teams. It includes examples of agencies and individuals within those stakeholder groups.

Exhibit 2. Examples of relevant stakeholder groups for home visiting research teams[v, vi]

Stakeholder 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; 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), private insurance, 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 stakeholders to engage based on a project's goals. Not all stakeholder groups will be relevant for every project. Research teams may also find themselves relying more heavily on certain stakeholder groups at different phases of a project.

Ongoing stakeholder engagement

Stakeholders should be involved in all phases of the study. Study teams can plan for stakeholder engagement in precision home visiting research by asking—[vii]

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

Engagement strategies should align with potential stakeholder partners' specific and diverse needs. Teams should prioritize relationship building early on and revisit it throughout to ensure stakeholders remain engaged. Local or national advisory committees can help facilitate engagement of multiple stakeholder types. Exhibit 3 presents a sample structure for engaging stakeholders during a hypothetical, comparative effectiveness study of a postpartum depression intervention delivered by home visitors and clinicians.

Exhibit 3. Example structure for engaging multiple stakeholder groups[viii]

Project role	Stakeholders	Engagement frequency
Executive committee (key personnel, authors of grant submission)	• **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	Monthly
Operations team	• 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	• **Policy makers:** National advocacy organizations, government officials • **Researchers:** Additional home visiting researchers	Annually

Participatory approaches can add value in all phases of a project:[ix]

- Stakeholders can share knowledge in the **development phase** to strengthen researchers' understanding of an issue, assure that interventions align with current policy and practice, ensure that study questions and measures are relevant, and specify study designs that are feasible, efficient, and rigorous.
- Stakeholder participation in the **implementation phase** promotes faithful study implementation and helps troubleshoot challenges. Key stakeholders can help study teams refine 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.
- Stakeholders 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. Stakeholders 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 stakeholder engagement and value across project phases[x]

Phase	Value
Development	• **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	• 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, as designed, 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 mental health consultation network** refine site and participant recruitment strategies.

Phase	Value
Interpretation and application	• The **national advisory committee** and **operations team** convene to review and interpret results, including unanticipated findings. • Representatives from **each stakeholder 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 multiple stakeholders can also raise many challenges. Research teams can navigate these challenges more effectively if they recognize and address them early on.

Challenges

While diverse groups of stakeholders provide critical insights for research, they can also raise competing priorities and perspectives. In addition, power dynamics can impact the participation of key stakeholders 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 stakeholder 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 stakeholders early and carefully and build in the time and structures needed to sustain engagement. Clearly articulate the benefits and responsibilities of participation to potential stakeholders, 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 stakeholders can contribute to a project and match stakeholders to specific activities based on their strengths. This will help stakeholders 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 stakeholders.

- **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 stakeholders 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.
- **Recognize contributions.** Acknowledge community stakeholders and identify ways to recognize their contributions to the project, such as through formal acknowledgements, co-authorship and joint presentations.

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 stakeholder perspectives 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 stakeholder groups** in research activities.
- To maximize the benefits of a participatory approach, precision home visiting researchers should **engage key stakeholders 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 home visiting stakeholder groups exist, precision home visiting research teams must **determine which stakeholders 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.

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