

**Summary Report of NIH Community Conversation
October 2, 2024 – Washington, DC
Hosted in Partnership with Community of Hope**

On behalf of NIH, Pyxis Partners facilitated a community conversation to gather feedback on how to better include community voices in all phases of clinical research. Community members were compensated for their time and engaged in a three-hour session that included discussions on the clinical research process, a potential framework for public engagement, and strategies for sustaining partnerships with the community.

Clinical research is medical research that involves people to better understand diseases and improve health. The typical process of clinical research includes researchers choosing a medical question to study, designing a study to answer that question, collecting data from the people participating in the study, and then analyzing and sharing the results. The NIH wants to better include community voices in this process, so community members were asked to discuss a new potential framework for public engagement in clinical research (see Figure 1). The framework includes a revised clinical research process and considerations for how to build lasting partnerships between organizations, researchers, funders, and communities.

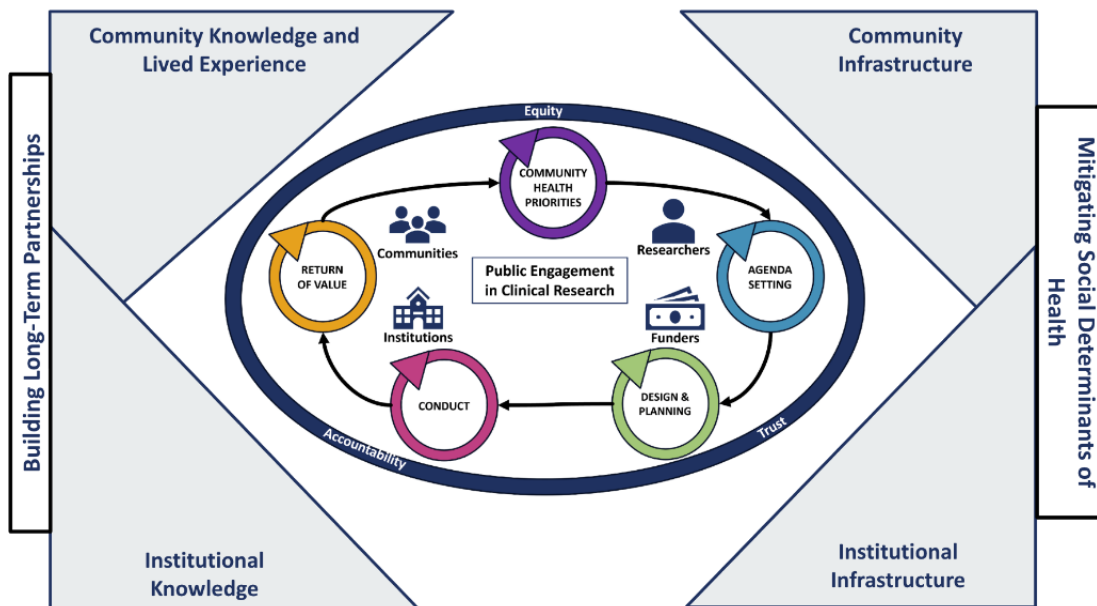


Figure 1: Framework for Public Engagement in Clinical Research

The session was structured around several key topics, allowing community members to share their thoughts and ideas on improving public involvement in research. Community members worked in small groups to discuss what support communities need to engage in research and how to maintain their involvement over time. The individual insights gathered during this event are intended to inform the ENGAGE initiative's efforts to foster bi-directional engagement, transparency, and trust in clinical research. This report provides a summary of the individual perspectives voiced during the event.

Topic 1 - Clinical Research Process

In discussing the clinical research process, key themes emerged about the importance of community input, especially during the Community Health Priorities, Agenda Setting, and Design & Planning phases of the process. Many community members emphasized that understanding a community's history and priorities is vital for meaningful research. These individuals expressed frustration about a disconnect between what healthcare professionals see as priorities and what community members care about, using personal examples to illustrate this gap.

Individual community members called for more involvement from the community in research decisions, stating that they should have a say in what is studied and how. They suggested that researchers show genuine care for community members by engaging with them regularly and providing practical benefits, not just monetary incentives, which could help build trust and encourage participation.

Another important discussion point was about the "Return of Value." Individual community members highlighted the need for researchers to align their definition of "value" with that of the community. They believed that everyone should be included in the feedback process to ensure all voices are heard and that research addresses real community needs.

Overall, there was a strong desire for greater community participation in clinical research, with individual community members advocating for a more balanced approach that recognizes and values the lived experiences of community members.

Topic 2- Clinical Research Framework

In the discussion about the framework for clinical research, several key themes emerged regarding the four main players: Communities, Researchers, Institutions, and Funders.

Language Matters: Many community members felt the term "institutions" sounded negative, comparing it to being in jail. These individuals suggested using "organizations" instead to create a more positive connection. There were concerns about how "funders" should be more transparent about their roles and the source of funding behind research, as this lack of openness can lead to mistrust.

Trust and Accountability: Trust is an issue that affects community involvement in research. Individual community members discussed how researchers can build trust by hiring community members to share their experiences and successes with researchers. Clear communication and accountability from funders and institutions are vital for gaining public trust.

Simplifying Language: Individual community members stressed the need for simpler language and visuals to help people understand complex research concepts. They suggested using clear graphics, larger text, and providing definitions or examples to improve accessibility. Many individuals found terms like "Social Determinants of Health" and "agenda setting" to be too technical.

Community Input: Individual community members emphasized the importance of being actively involved in the design and planning stages of research, highlighting that everyone should have a voice and that community knowledge is vital to effective outcomes. Individual community members stressed the need to consider cultural differences and individual needs in research design and planning,

suggesting that involving community members early in the process would ensure their voices are heard and their concerns are addressed.

Visual Aids: Individual community members recommended using diagrams and visual aids to explain the research process better. They felt that visuals could help people grasp ideas more easily and that a key or legend should be included to clarify symbols used in diagrams. These individuals also highlighted the need for visuals to reflect the communities being engaged with.

Overall, the discussions highlighted the importance of using positive language, building trust, ensuring community involvement, and making information accessible and understandable.

Topic 3- Sustaining Partnerships

In the discussion about sustaining partnerships with communities in clinical research, several key themes were highlighted:

Building Long-Term Relationships: To maintain public involvement over time, continuous communication and feedback are essential. Individual community members expressed the importance of knowing how participation benefits them and the community. They suggested that researchers provide clear timelines and updates on how data will be used and shared.

Incentives and Engagement: Individual community members noted that incentives for the community to engage with research do not always need to be monetary; fostering a sense of community through gatherings that bring people together can motivate participation.

Education and Empowerment: There was a call by individual participants for education around the research process, so community members understand what to expect and how they can contribute. This education includes training for community members on how to conduct research, as well as clear explanations of research goals and outcomes.

Transparency and Trust: Building trust between researchers and communities was a recurring theme. Individual community members highlighted the need for transparency in communication and decision-making, which is crucial for fostering loyalty and respect.

Effective Communication: The need for clear and accessible communication was discussed, including using easily understood terms and visual aids to explain complex concepts. Individual community members suggested that researchers should show up in community spaces, rather than relying solely on emails or online communication.

Feedback and Adaptation: Continuous feedback from the community was viewed as vital. Individual community members suggested regular surveys and community meetings to assess how well research initiatives are meeting community needs and expectations.

In summary, individual community members conveyed that sustaining partnerships with communities in clinical research requires ongoing support, clear communication, cultural sensitivity, and trust-building efforts to ensure that everyone feels involved and valued in the process. **A heartfelt thank you to all who participated and shared their valuable insights!**