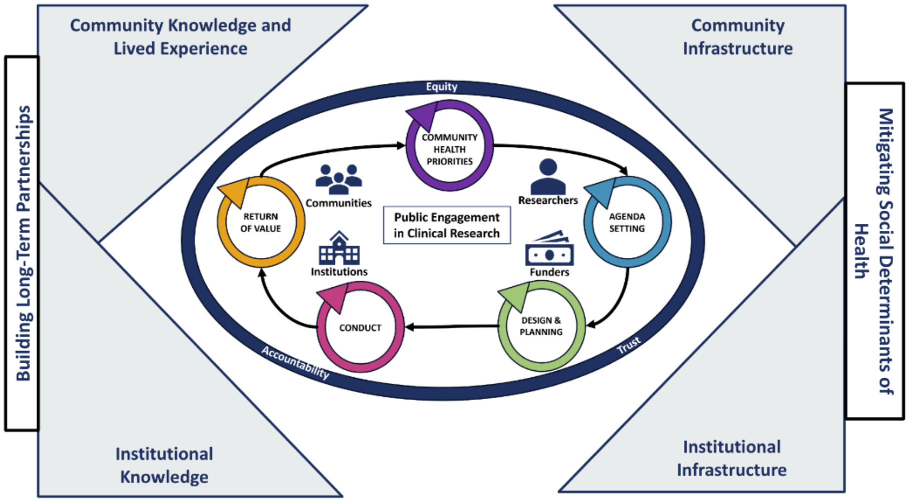
NIH National Institutes of Health
Office of Science Policy

Summary Report of NIH Community Conversation
October 30, 2024 – Idaho Falls, ID
Hosted in Partnership with Eastern Idaho Community Action Partnership

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, several important ideas emerged, especially surrounding the role of community involvement in the stages of Community Health Priorities, Agenda Setting, and Design & Planning.

Individual community members wanted to be involved early, especially in the Community Health Priorities and Design & Planning stages, to make sure research addresses issues that matter to them. They felt their input could keep research on track and relevant as well as make sure the research is based on the community's needs.

Individual community members noted challenges like lack of education, awareness, and clear communication when it comes to fully understanding the purpose and process of a research study. They suggested better outreach through social media and promotion to encourage participation. To encourage public involvement, incentives like community service hours or small payments were recommended. Clearer communication about why input is needed was also seen as important.

Overall, the discussions showed a strong desire for greater community involvement in clinical research to make sure the research is based on their needs and a desire to provide input at all stages, especially in the early stages.

Topic 2 – Clinical Research Framework

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

Understanding Key Players: Individual community members felt the framework made communities look disconnected from the research process, especially in later stages. They suggested communities be involved throughout the whole process, and that the framework design should clearly illustrate this.
Confusion Around Key Terms: Terms like “Mitigating Social Determinants of Health” and “Agenda Setting” were hard to understand. Simpler language like “navigating how social issues affect health” and “identifying a research topic” was suggested. The term "Return of Value" was seen as confusing. Individual community members suggested replacing it with simpler terms like "impact on community" or "how does this affect you?" to make the concept easier to understand.
Design and Layout Concerns: Several individual community members pointed out that the triangles (representing key factors like Community Knowledge and Institutional Infrastructure) should be moved to the outside of the framework to improve clarity and show better connections between elements. There was a desire to make the framework more interconnected, possibly using a circular design to visually represent the relationships between components.
Clarity and Accessibility: Suggestions included adding definitions and examples for key terms, possibly with a QR code for easy access. Accessibility for people with disabilities, like audio descriptions for the visually impaired, was also emphasized.

Visual and Aesthetic Suggestions: Individual community members mentioned that the gray color in the triangles was unappealing and that using more vibrant colors would make the framework more engaging. They also suggested the icons representing institutions looked too formal, which may not resonate with the community.
Public Input and Participation: Individual community members wanted the framework to show how the public can guide and influence the research process, especially early on.

Overall, individual community members had thoughtful feedback on both the design and content of the framework. They highlighted the need for clearer language, better visual connections, and clearer terminology. There was a shared desire for a more accessible, engaging, and community-focused framework that reflects the important role of the public in shaping clinical research.

Topic 3- Sustaining Partnerships

In discussions on sustaining long-term partnerships with communities, the focus was on supporting community involvement, maintaining relationships, and sharing research findings in meaningful ways.

Support Needed for Community Involvement: Individual community members recommended clear communication to make the process relatable to the community members, such as holding City Hall or school board meetings to explain how research could impact the community. Other suggestions for encouraging participation included offering incentives, such as money or gift cards.
Sustaining Long-Term Engagement: To keep the public engaged, individual community members suggested simplifying research updates to make them more approachable and avoiding complicated scientific terms. Using audio newsletters or videos could also help reach different learning styles. Regular updates through email, social media, and other channels were seen as effective for maintaining involvement.
Building Long-Term Partnerships: A key theme was creating sustainable systems for engagement, like the Little League model, meaning engagement is consistent over time with little disruption. The goal is to develop systems that keep communities involved in research without restarting efforts.

In summary, the discussion stressed the importance of ongoing community engagement in research. Key strategies included making research more approachable, offering incentives, and using various communication methods to maintain involvement. Individual community members also highlighted the need for sustainable systems that support long-term engagement. These insights will help strengthen future partnerships between researchers and communities. **A big thank you to everyone who participated and shared their valuable thoughts!**