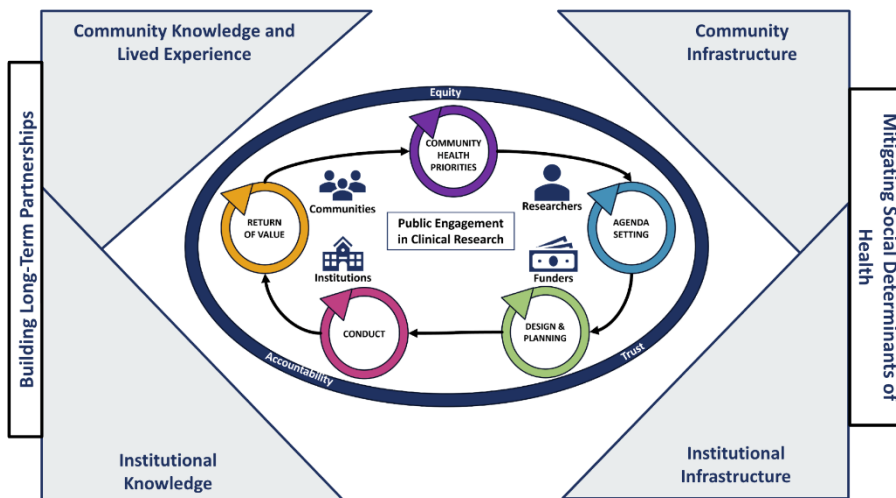


**Summary Report of NIH Community Conversation
Oct. 7, 2024 – Chicago, IL
Hosted in Partnership with Pilsen Arts & Community House**

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, individual community members emphasized the need for increased opportunities for community participation throughout the entire research process. Many people expressed interest in understanding and contributing to research, particularly in the Community Health Priorities and Agenda Setting stages. Concerns were raised about access to information, especially for older generations, and the need for clearer communication and outreach, especially in areas with different ethnic groups.

Key themes included the importance of making research relevant to the community's needs and being transparent in sharing research results. Many individual community members believed the community should be involved in all stages of research, from planning and design to carrying out the study and sharing results. Individuals also stressed the importance of fair compensation for research study participants and community members, and making sure the research addresses "real health issues."

Individual community members also discussed the need for education to help communities better understand the process and results of research studies. Individuals suggested that involving the community earlier in the process could help make studies more successful and lead to findings that benefit everyone. Individual community members showed strong interest in participating in the Design & Planning, Conduct, and Return of Value stages, where they felt they could provide more input on how research is done and how results are shared with the public.

Topic 2 – Clinical Research Framework

When discussing the draft framework for clinical research, several themes emerged on the key players and values framing the Lifecycle:

Central Role of the Community: The community should be at the center of the research process and have power to influence decisions. Individual community members stressed that communities should be involved throughout the entire process, especially in setting research priorities.

Fair Compensation and Trust: Some individual community members shared concerns about past experiences where promised rewards or support were not delivered, which contributed to distrust of clinical research. They emphasized that researchers must be transparent, fair and keep their promises.

Education and Clear Communication: Individuals identified that communities need better education about research. Clear, easy-to-understand language and visual aids were suggested to make sure everyone can engage with the research process. Researchers should explain the purpose of the research, how it benefits the community, and what participating means.

Accountability and Transparency: Individual community members emphasized the importance of accountability, and said that researchers, funders, and institutions should be held responsible for their promises and actions. They wanted clear communication about when study results will be shared and how research funds are used.

Work with the Community to Bridge Gaps: Individual community members suggested that community representatives, especially community health workers, should be part of the research process to help bridge gaps and build trust.

Long-Term Partnerships: There was a shared belief that building long-lasting, trustworthy relationships between researchers and communities is important for successful research.

Flexibility and Adaptability: Individual community members suggested that the research framework should be flexible, especially when it comes to shifting community health priorities. The framework should allow for ongoing input from the community at all stages of the research process.

Overall, individual community members emphasized the importance of fairness, transparency, clear communication, and trust in clinical research. Individuals also called for community involvement at every stage of the research process to ensure research is done *with* the community, not just *on* it.

Topic 3 – Sustaining Partnerships

Several key themes came up during discussions about how to sustain long-term partnerships between communities and researchers:

Financial Support & Incentives: Individual community members stressed the need for financial security and incentives to encourage continued involvement in research.

Trust & Communication: Individuals recommended building trust by being honest about the long-term benefits of the research, using simple and approachable language, focusing on the community's needs, and using communication methods like community meetings and education programs.

Ongoing Education & Capacity Building: Workshops and educational programs are important tools to keep communities involved, and individual community members mentioned the importance of inviting younger generations to participate.

Accessibility: Individuals raised concerns about transportation and other barriers to participation.

Collaboration with Community Organizations: Individuals felt that community organizations should work with researchers to align research with the community's needs and that their voice is heard.

Inclusion of Local Researchers: Involving researchers from the community was seen by individual participants as a way to build stronger, more relevant partnerships.

Accessible Communication: Individual community members noted that it is important to share research results in a way that everyone can understand, using different platforms such as social media, town halls, and workshops.

Inclusion of Vulnerable Groups: Some community members raised concerns about making sure marginalized groups, like people experiencing homelessness, are included in the research process.

In conclusion, the key ideas raised by individuals participating in the community conversation emphasized the importance of trust, respect, financial incentives, clear communication, and collaboration. Individual community members also highlighted the need for education, accessibility, and transparency to keep everyone involved and informed throughout the research process. **A big thank you to everyone who participated and shared their valuable thoughts!**