

Summary Report of NIH Community Conversation

Dec. 13, 2024 – Flint, Mich.

Hosted in Partnership with the Charles Stewart Mott Department of Public Health at Michigan State University and the Community Based Organizations Partners (CBOP)

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 participated in a three-hour session that included discussions of the clinical research process, a draft framework for public engagement, and strategies for sustaining partnerships with the community. Community members were also compensated for their time.

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 draft 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.

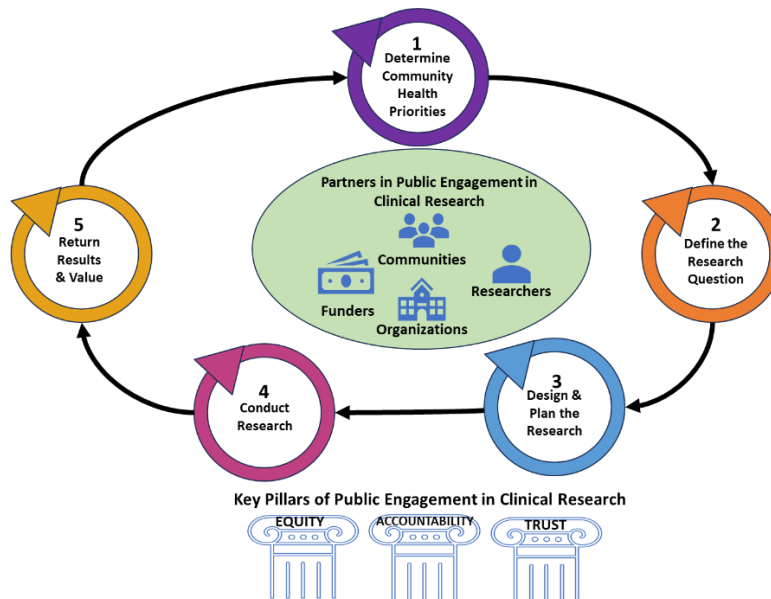


Figure 1: Potential New Framework for Public Engagement in Clinical Research

The session was structured around several key topics, allowing individual 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 participation 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 importance of early community involvement, particularly during the stages of Determining Community Health Priorities and Designing & Planning the Research. Early engagement ensures that research focuses on the real needs, values, and concerns of the community it aims to serve. Several community members noted that they believed their contributions help make research designs culturally relevant by drawing from their lived experiences. By tailoring research to reflect the community's unique needs, researchers can foster stronger connections and more meaningful outcomes.

However, several community members also highlighted challenges to public participation in clinical research, including a lack of awareness and education about the research process, difficulties in understanding technical language and unclear messaging, and a lack of trust due to prior experiences with researchers not following through on their commitments. Issues such as language barriers, lack of transportation, and limited time or childcare options further complicate participation. To address these barriers, individual community members proposed increasing outreach efforts through social media and community organizations, providing incentives like monetary payments or community service credits, and hiring community facilitators to serve as trusted liaisons between researchers and the public. Additionally, they stressed the need for simple, visually appealing materials that clearly explain the research process, its goals, and the potential benefits for the community.

Overall, the discussions during this section of the community conversation highlighted the community's collective desire for increased opportunities to participate in the early stages of the clinical research process, ensuring that more community members feel like their needs and priorities are reflected in the research topics that researchers and institutions identify. Individual community members also noted that, in addition to these increased opportunities for engagement, they would like to see research funders and drivers make stronger efforts to help communities navigate potential obstacles to participation, such as lack of transportation, language and understanding gaps, and lack of trust that researchers will follow through on their promises.

Topic 2 – Clinical Research Framework

Community members reviewed a draft framework designed to guide public engagement in clinical research. Several key insights emerged on how to make the framework more effective:

Make it Clearer: Some of the framework language was too technical, and individual community members suggested providing clear definitions and practical examples. Visual aids would also be a helpful tool, and several people recommended diagrams or charts that show how community input directly influences research decisions and outcomes.

Incorporate Interactions into Design: A few community members suggested redesigning the framework to use a circular layout that visually represents how different groups interact and work together. Individual community members also emphasized the need to address social challenges directly, provide ongoing education, and build community capacity for sustained engagement.

Prioritize Trust and Tailoring: Individual community members stressed the importance of transparency about funding priorities, research goals, and decision-making processes in building trust. They also

highlighted the importance of customizing engagement strategies to the unique needs of each community.

Foster Long-Term Partnerships: Citing the need for ongoing communication and collaboration, individual community members recommended creating community ethics review boards to ensure research aligns with community needs and values. They also suggested regular feedback loops, quarterly check-ins, and annual events to keep lines of communication open.

Overall, individual community members emphasized the need for clearer language with definitions, examples, and visual aids to show how their input shapes research. They suggested a circular framework design to highlight collaboration, along with efforts to address social challenges and build community capacity. Transparency in funding, research goals, and decision-making was seen as key to building trust. Individual community members also supported the co-ownership of projects, which could ensure mutual accountability and shared responsibility.

Topic 3 – Sustaining Partnerships with Community

The final section focused on discussing strategies to maintain long-term relationships between researchers and the community. The final section also introduced a proposed online toolbox of engagement resources for researchers and community members.

Support for Engagement: Transparent communication and regular updates are essential, and community suggestions included hosting town halls and providing updates through multiple formats like videos, audio newsletters, and interactive online tools. They also emphasized the need for a clear and consistent timeline of research activities so that participants know what to expect.

Overcoming Barriers: Many people believed that financial and logistical challenges often prevent people from participating in research, and individual community members proposed offering financial compensation, childcare, and transportation support to reduce these barriers. They also recommended creating a designated space where community members can access trainings and other resources.

Building Long-Term Systems: To sustain partnerships, individual community members advocated for regular dialogue and trust-building activities. These efforts would ensure that a study's purpose and progress stays aligned with community needs and expectations.

Make the Toolbox More User-Friendly: Individual community members expressed enthusiasm for the proposed toolbox but emphasized the need for it to include user-friendly features such as a table of contents, definitions, and practical examples. Many community members also wanted researchers to ensure user-friendliness for users with varying needs, including those with limited digital literacy.

In summary, individual community members emphasized that they want to be involved at every stage of the clinical research process, from identifying health priorities to sharing results. They stressed the need for clear communication, transparency, and mutual trust to ensure meaningful partnerships.

Suggestions included user-friendly tools, ongoing dialogue, and strategies to overcome barriers like access to transportation and language proficiency. Sustaining these partnerships will require researchers to value and include community voices consistently throughout the clinical research process. **A heartfelt thank you to all who participated and shared their valuable insights!**