NIH National Institutes of Health
Office of Science Policy

Summary Report of NIH Community Conversation
Nov. 12, 2024 – Bangor, Maine
Hosted in Partnership with Dignity First

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.

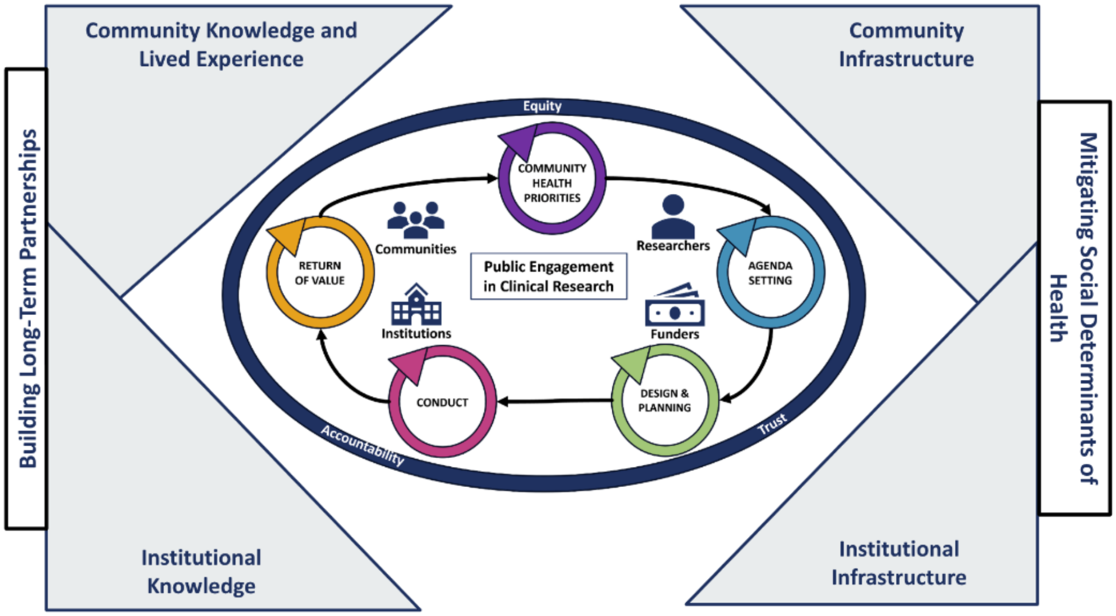

Figure 1: Framework for Public Engagement in Clinical Research

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

Individual community members gave feedback on where community input would be most useful in the clinical research process and where they would like to participate. Individual community members generally indicated that public input was most needed on Community Health Priorities, followed by Design & Planning. Many agreed that researchers should understand what matters to people who will be affected by a study before designing it.

In the Design & Planning phase, individual community members worried that some groups would be left out without public input and that people may care more about a research study's results if they were involved earlier.

Many community members wanted to be involved in all aspects of the Lifecycle. However, not everyone agreed on the public's role in clinical research. Individual community members proposed a collaborative role for the public. They want the public to work with researchers and experts who have unique information that should be respected. There was also interest in trainings for the public to help people understand their role in the process.

Several community members wanted more transparency in the research. They linked this to their experiences in Maine and nearby rural areas where people are often skeptical that researchers understand the community's intricacies. Individual community members also wanted to elevate different voices. They sought fair representation of the whole community, not just a single socioeconomic group or health condition.

Individual community members identified several barriers to participating in clinical research, including fear and skepticism about experimental research, not knowing about opportunities to provide input, financial issues, general mistrust of the medical system, lack of transportation, the study information's accessibility and reading level, and uncertainty about how much say they have as participants.

Finally, individual community members wanted a clearer explanation of the lifecycle after a study ends. They cited a need for ongoing communication with study participants as the study progresses and concludes. They also wanted to know about backup plans for potential research obstacles. Lastly, they wanted to know what happens after the Return of Value phase.

Topic 2 - Clinical Research Framework

In the discussion about the framework for clinical research, community members gave feedback on the key players, the Equity-Trust-Accountability oval, and other design elements of the Framework.

The meanings of the key players: Many community members equated “Researchers” with people in white lab coats and “Funders” with pharmacies, drug companies, large corporations, and “Big Pharma" rather than NIH. The term “Institutions” was seen as confusing.

The term “Mitigating Social Determinants of Health”: Some individual community members wanted a simpler term that more people could understand. Multiple individuals questioned if all Social Determinants of Health need to be “mitigated”, pointing out that some may be positive.

Framework design and content: A few community members felt the lifecycle “flows well” but found it unclear where it starts and ends. The words were seen as confusing and should be simplified. The design, colors, shapes, and text were described as “too complicated” and that there was not enough focus on “community,” with the word included only twice. Individual community members suggested emphasizing community input and tailoring the design for different audiences, such as researchers, the community, and community-based organizations.

Topic 3 - Sustaining Partnerships

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

Need for logistical support: Lack of transportation, food, time off, and pay could hinder a community's engagement in clinical research. Individual community members were eager to engage, but reminded facilitators of their other obligations, like family and work. If NIH or other research sponsors could help address these logistical issues, it might boost participation.

Publicly available information about ongoing studies: Individual community members want to join the research process but can only contribute to studies and discussions they know about. Publicizing the start of a research study is key. Also, using accessible locations for future events was key for individual community members' continued participation.

Returning research results to the community: Individual community members appreciated the inclusion of Return of Value in the research process and sought clear, accessible results shared with the community. They requested actionable feedback on key takeaways to understand the research's impact and emphasized sharing study results with family doctors and service providers to bridge gaps between individuals and institutions.

Follow-up from organizations conducting research: Individual community members want updates on ongoing studies and results. They wish to stay engaged with the research, but information must be accessible and understandable. Community members suggested using libraries, universities, and schools to share information through seminars, posters, and other outreach methods.

In summary, sustaining partnerships with communities in clinical research requires ongoing support, clear communication, cultural sensitivity, and trust. These efforts must ensure everyone feels involved and valued. **A heartfelt thank you to all who participated and shared their valuable insights!**