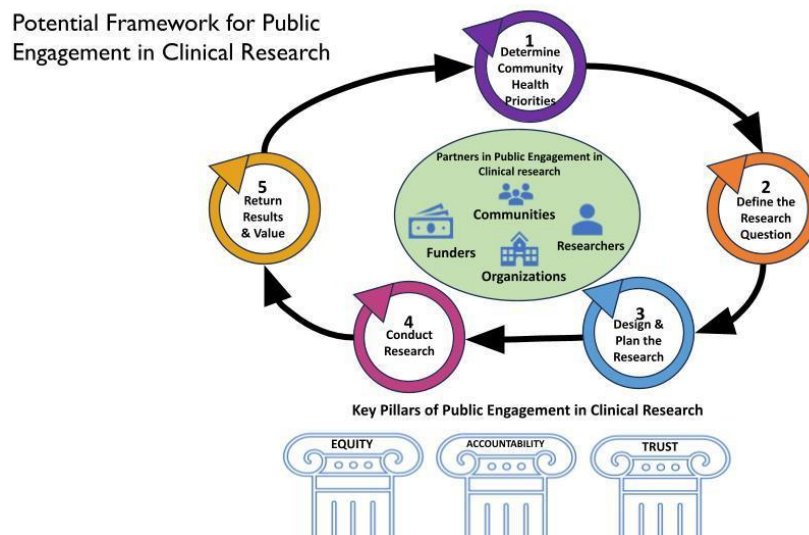


**Summary Report of NIH Community Conversation  
Jan. 9, 2025 – Baton Rouge, LA  
Hosted in Partnership with the Family and Youth Service Center of East Baton  
Rouge (FYSC)**

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: Potential New 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 shared insights on where public input would be most valuable in the clinical research process. Many emphasized the importance of including community voices in the early stages, particularly in determining community health priorities and defining the research question. They expressed belief that starting with community input ensures the research aligns with real-world needs and builds trust.

Some community members voiced concern that the design and planning phase often overlooks marginalized communities, and advocated for clearer communication about how research questions are selected and how findings will be used. Many agreed that ongoing engagement throughout the process is essential to maintain trust and interest in research.

Several community members cited historical mistrust of clinical research, limited access to research opportunities, and logistical challenges such as transportation and time commitments as barriers to engagement with research. They also stressed the need for clear communication, culturally-relevant outreach efforts, and transparency about how research results impact their communities.

Additionally, there was strong support for transparency in returning research findings, and several community members expressed frustration that study results are not always shared with the communities that participated. To remedy this, several community members requested more approachable, user-friendly ways to communicate findings, such as community meetings and collaborations with local healthcare providers.

## **Topic 2 – Clinical Research Framework**

In the discussion about the potential new clinical research framework, community members examined the key players in the research process, and many provided their input on improving engagement strategies. The framework introduced four key players: Communities, Researchers, Organizations, and Funders. While many community members noted that they appreciated this structure of the potential framework and the identification of those four key players, they raised concerns about power dynamics and decision-making within these entities.

**Clarifying the Role of Funders:** Several community members expressed skepticism about funders' motivations and their influence over research priorities. They emphasized the need for increased transparency regarding funding sources and decision-making processes to build trust and ensure accountability.

**Defining the Role of Research Institutions:** A number of community members called for clearer definitions of the responsibilities of research institutions when it comes to engaging with communities. Many also emphasized the importance of ensuring that commitments made to communities are upheld throughout the research process, and that communities do not feel abandoned after a study concludes.

**Broad Definition of Community:** Many community members noted that “community” is a broad term encompassing different populations with unique needs and priorities, and they recommended

incorporating flexibility into the framework to ensure the representation of historically marginalized groups.

**Mechanisms to Uphold Core Principles:** Many community members emphasized the need for clear mechanisms to uphold the framework's core principles in practice. Some suggested establishing community advisory boards or oversight committees to bridge the gap between researchers and the public and ensure that studies align with community priorities and ethical standards.

**Fostering Ongoing Collaboration:** Individual community members emphasized the need for ongoing collaboration rather than one-time engagements. They recommended that researchers build relationships before launching studies, maintain consistent follow-up, and offer meaningful opportunities for community participation in decision-making.

**Accessibility of Research Findings:** Several community members stressed the importance of making research findings accessible through a variety of mediums and communication methods, including community meetings, digital platforms, and printed materials in plain language.

### **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.

**Logistical Support:** Several community members cited transportation, childcare, and financial incentives as critical factors that influence participation in research studies. They suggested that research institutions allocate funds to address these barriers.

**Clear and Consistent Communication:** Many community members expressed a desire for ongoing updates on research projects, and suggested using social media, local newspapers, and community meetings to keep participants informed.

**Educational Initiatives:** Many also emphasized the need for research literacy programs to teach communities about the research process, and they suggested developing educational materials tailored to different audiences.

**Trust and Relationship-Building:** Individual community members highlighted the importance of relationship-building beyond individual studies, and encouraged researchers to work continuously with community organizations, rather than engaging only when they need participants for a research study.

Participants reiterated that sustained engagement, clear communication, and logistical support are essential for fostering lasting relationships between researchers and the communities they seek to serve. They also stressed that research should be aligned with community priorities and lead to tangible benefits for the community, such as improved healthcare services, policy changes, or new community programs. **A heartfelt thank you to all who participated and shared their valuable insights!**