Building Trusted Networks



The second workshop in our series focused on the benefits of and best approaches for partnering with clinicians, community-based organizations, and patient advocates to assist in promoting messaging about clinical trial participation. The workshop started with a panel presentation "Meeting Patients Where They Are: Making the Case for Clinical Trials" moderated by Mia Keeys Director of the American Medical Association's Center for Health Equity. She was joined by panelists: Paul Conway, Dr. Faluso Fakorede, and Dr. Diane Barber to discuss the challenges and opportunities to promote engagement in clinical research to a more diverse population of patients. The panel discussion highlighted many of the factors that present challenges to participation including historical breaches of trust; the need for sincerity and credibility in interacting with potential participants, lack of proactive outreach, and problematic eligibility criteria. The panel presentation was followed by stakeholder breakout discussions which covered the following issues and questions:

Building Community Partnerships

Why should the community be interested in clinical research?

How do we educate patients about the value of clinical research?

What are some practices for engaging community partners to share messaging about participating in clinical trials?

Developing/Gaining Trust

Who are trusted sources in patient communities? How do we use these sources to assist with trust concerns?

What are the major considerations that need to be addressed in gaining/building trust with clinicians (e.g., nurses, physician assistants, physicians) and their patients?

What tools and best practices should be utilized to build trust between the research team, clinical team, and prospective patients?

Research Community

Who are the key players in building networks that foster greater clinical research diversity?

What considerations, tools, and resources are needed to build diverse research communities/ ecosystems?

How do we ensure the sustainability of diverse research communities/ ecosystems?



The breakout discussions resulted in the identification of approaches and strategies that the attendees view as critical in building networks of community-based leaders, members, and organizations, along with non-research affiliated health professionals. The following approaches, associated with the thematic areas guiding the various discussions, were identified:

Building Community Partnerships

Build sustainable relationships that start at the beginning of the process and are preserved through the end

Promote health literacy and engagement by being transparent and using layman's terms

Listen to the community to understand their needs

Answer the community's questions

Acknowledge/recognize the value of patient data

Recognize the role of social determinants of health in making these decisions and address those needs for participants

Ensure access to technologies coming out of trials to participants and people like them

Developing/Gaining Trust

Identify trusted care institutions and providers

Focus on building lasting relationships with communities

Resist the tendency to be transactional in setting up trials

Use nurses as a trusted source in reaching community members

Align research goals with those of the community

Utilize non-traditional sources to build trust (community leader, patients, families, primary care providers)

Learn from the patients including their expectations

Include patients in the trial design process

Research Community

Involve the full spectrum of stakeholders (patients, caregivers, health care providers, regulators, societies, sponsors/developers)

Incorporate local groups and stakeholders; use a combination of outreach tools including low tech and social media/community centers

Continuously diversifying the research pipeline with personnel, resources, and funding

Value patients as coresearchers