Title: Helping Community Members Claim Their Power: Building Capacity to Partner with Research Institutions

Presenters:

- Tiffany Israel MSSW. Community Navigator, Meharry-Vanderbilt Community Engaged Research Core
- Alexis Gorden MBA. Sickle Cell Foundation of Tennessee
- Yvonne Joosten MPH. Executive Director, Office for Community Engagement, Vanderbilt Institute for Medicine and Public Health

Learning Objectives:

- 1. Identify potential roles for patients and other community stakeholders as active partners with research institutions.
- 2. Develop knowledge of essential elements for increasing community capacity to take on meaningful roles with research institutions.
- 3. Identify strategies to address institutional barriers to meaningful community engagement.

Engaging community members in research and healthcare improvement activities is becoming more common because of the potential to make research results more relevant and healthcare more effective. Funders are increasingly requiring community input, creating opportunities to organize and better prepare community stakeholders. Expanded research roles and training for community members can enable them to positively impact research design, implementation and dissemination. Expert community feedback can also influence priorities that are culturally balanced in their approach with an increased emphasis on health equity and patient-centeredness. These expanded research roles include proposal preparation, proposal review, short and long term consulting, community advisory board, research team member, and community principle investigator. Furthermore, healthcare regulatory and governing bodies increasingly expect patient and other community stakeholder engagement in healthcare improvement activities such as patient advisory councils and community health needs assessments. In this interactive learning lab we will examine these expanded roles for patients and other community stakeholders. Based on their lived experience and firsthand knowledge of a community or condition, community stakeholders bring a wealth of expertise to the research enterprise. Basic training in research methods and principles, guidance on how to work with researchers, and the priorities of research institutions can help them claim their power in these expanded research roles. Presenters will build on their own experience and draw on the experiences of workshop participants as they discuss 1) how to identify and recruit community members for these roles – particularly groups traditionally underrepresented in research and underserved by healthcare institutions; 2) best practices to adequately prepare community members to serve as consultants, advisors and team members for research and healthcare improvement activities; and 3) effective strategies to address barriers to meaningful community engagement within the institution.

Agenda:

- 1. Identifying and recruiting candidates for research roles. (20 minutes)
- 2. Learning lab participants sharing their experiences. (15 minutes)
- 3. Preparing community stakeholders for expanded research roles. (20 minutes)
- 4. Institutional barriers to expanding community research roles and strategies to overcome them.

- 5. Small group exercise: participants will complete a worksheet to list specific roles for community stakeholders at their academic institution or the institution they work with; organizations in their community they can reach out to help with recruitment; and key institutional leaders that can facilitate the integration of community stakeholders into these roles. (20 minutes)
- 6. Small groups report out. (15 minutes)