NCATS Day 2018: Engaging Patients and Communities for Smarter Science
National Institutes of Health • William H. Natcher Building (Bldg. 45) • Natcher Conference Center (Rooms E1/E2)
45 Center Drive • Bethesda, Maryland

Final Agenda

Sept. 28, 2018

8:00 a.m. Registration and Poster Setup

8:30 a.m. Welcome
Christopher P. Austin, M.D., Director, National Center for Advancing Translational Sciences (NCATS), National Institutes of Health (NIH)

8:45 a.m. Setting the Stage for the Day’s Activities
Penny Burgoon, Ph.D., Director, Office of Policy, Communications and Education, NCATS, NIH

9:00 a.m. Panel Session 1: Getting Started on Developing Relationships*
Moderator: Megan O’Boyle, Principal Investigator, Phelan-McDermid Syndrome (PMS) Data Network and the PMS International Registry
Panel Members:
- Kristi D. Graves, Ph.D., Associate Professor of Oncology and Director of Cancer Survivorship Research, Cancer Prevention and Control Program, Georgetown University
- Laura A. Logie, Ph.D., M.A., Director of Research, Nueva Vida, Support Network for Latinas with Cancer
- Cynthia Grossman, Ph.D., Director, FasterCures
- Paul Harris, Ph.D., Professor of Biomedical Informatics and Research Professor of Biomedical Engineering, Vanderbilt University Medical Center

10:00 a.m. Break

10:15 a.m. Panel Session 2: Valuing Partner Perspectives*
Moderator: Elaine Collier, M.D., Senior Advisor to the Director, NCATS, NIH
Panel Members:
- Karen L. Erickson, Associate Executive Director of Community Engagement, Alpha-1 Foundation
- Karen Baldi, Volunteer Participant Advisory Board Member, Georgetown-Howard Universities Center for Clinical and Translational Science
- Peter C. Grayson, M.D., M.Sc., Head, Vasculitis Translational Research Program, National Institute of Arthritis and Musculoskeletal Diseases, NIH

11:15 a.m. Panel Session 3: Sharing Research Results*
Moderator: Patricia Jones, Dr.P.H., M.P.H., Program Director, Division of Clinical Innovation, NCATS, NIH
Panel Members:
- Consuelo H. Wilkins, M.D., M.S.C.I., Executive Director, Meharry-Vanderbilt Alliance; Associate Professor of Medicine, Vanderbilt University Medical Center and Meharry Medical College
- Cheryl Jernigan, CPA, FACHE, Lead Advocate, Patient Investigator Voices Organizing Together, University of Kansas Cancer Center; and Clinical Data Research Network, University of Kansas Medical Center
- Jennifer Gordon, Ph.D., Patient Partner on Vasculitis Patient-Powered Research Network; Associate Dean of Research, Lewis Katz School of Medicine, Temple University
- Finie Hunter-Richardson, M.P.H., Practice-Based Research Network Coordinator, Community Engagement and Research, Georgetown-Howard Universities Center for Clinical and Translational Science
12:15 p.m.  Lunch (on your own) and Poster Session

1:30 p.m.  **Patient and Community Engagement Studio Demonstration**

Consuelo H. Wilkins, M.D., M.S.C.I., Executive Director, Meharry-Vanderbilt Alliance; Associate Professor of Medicine, Vanderbilt University Medical Center and Meharry Medical College

Yvonne Joosten, M.P.H., Executive Director, Office for Community Engagement, Institute for Medicine and Public Health, Vanderbilt University; Associate Director, Community Engaged Research Core, Meharry-Vanderbilt Alliance; and Assistant Professor of Medical Education and Administration, Vanderbilt University School of Medicine

Tiffany Israel, M.S.S.W., Community Navigator, Institute for Medicine and Public Health, Vanderbilt University Medical Center

*Community Engagement Studios are consultative sessions for researchers to get input on their project from key stakeholders, such as patients, caregivers and providers. A panel of stakeholders will provide feedback to enhance the planning, design, implementation, translation or dissemination of the research. The one-hour demonstration will be followed by a 30-minute question-and-answer session.*

3:00 p.m.  **Breakout Group Discussions**
Small group discussions during which participants will reflect on the event sessions and share their own experiences.

4:00 p.m.  **Group Report-Back**
Representatives from each breakout group will share highlights from their discussions.

4:45 p.m.  **Closing Remarks**
Christopher P. Austin, M.D., Director, NCATS, NIH

5:00 p.m.  **Adjourn**

*Each session will focus on lessons learned that could be generalizable to other individuals, organizations, research or initiatives.*