

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.