

BUILDING THE INFRASTRUCTURE

CLINICAL RESEARCH ENGAGEMENT AND ACTIVITIES TEAM (CREATE)

Lyric Jorgenson, PhD

NIH Associate Director for Science Policy

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Director

National Center for Advancing Translational Sciences

*NExTRAC Meeting
June 17th, 2024*



CREATING A RUNWAY TO IMPLEMENTATION

CHARGE

CLINICAL RESEARCH ENGAGEMENT AND ACTIVITIES TEAM (CREATE)

- Provide a collaborative forum to share best practices and develop an NIH-wide Community of Practice
- Support ENGAGE workgroup with data or information needs
- Identify resource and infrastructure needs to address NExTRAC recommendations
- Serve as stewards for public engagement across NIH

MEMBERS

CLINICAL RESEARCH ENGAGEMENT AND ACTIVITIES TEAM (CREATE)



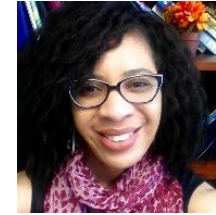
Lyric Jorgenson
(Co-Chair), NIH Office of Science
Policy



Joni Rutter
(Co-Chair), National Center for
Advancing Translational Sciences



Rebecca Baker,
Office of the NIH Director



Shalanda Bynum,
National Institute of Nursing
Research



Sheila Caldwell,
Tribal Health Research Office



Rebekah Corlew,
National Institute of Neurological
Disorders and Stroke



Sarah Dunsmore,
National Center for Advancing
Translational Sciences



Nancy Jones,
National Institute on Minority
Health and Health Disparities



Jenna Norton,
National Institute of Diabetes and
Digestive and Kidney Diseases



Felicia Qashu,
Office of Strategic Coordination



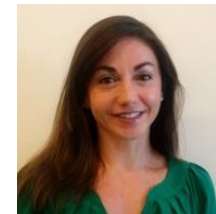
Sarah Read,
National Institute of Allergy and
Infectious Diseases



Carolina Solis Sanabria, National
Institute on Minority Health and
Health Disparities



Karriem Watson,
All of Us Research Program

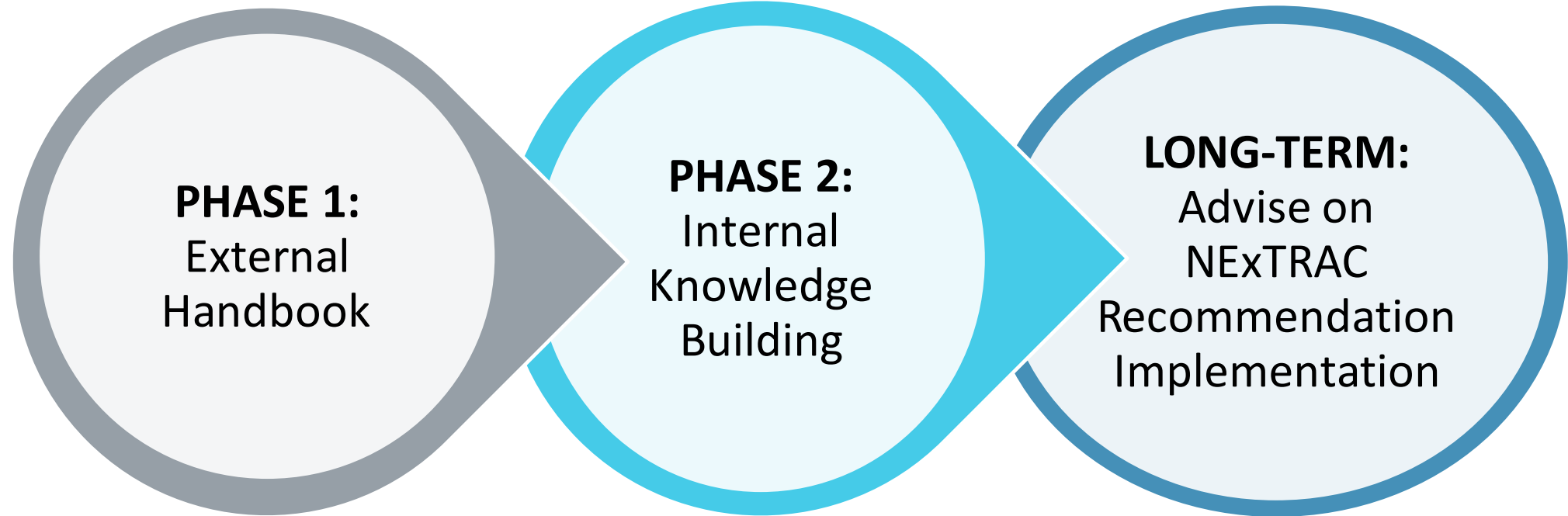


Amy Williams,
National Cancer Institute

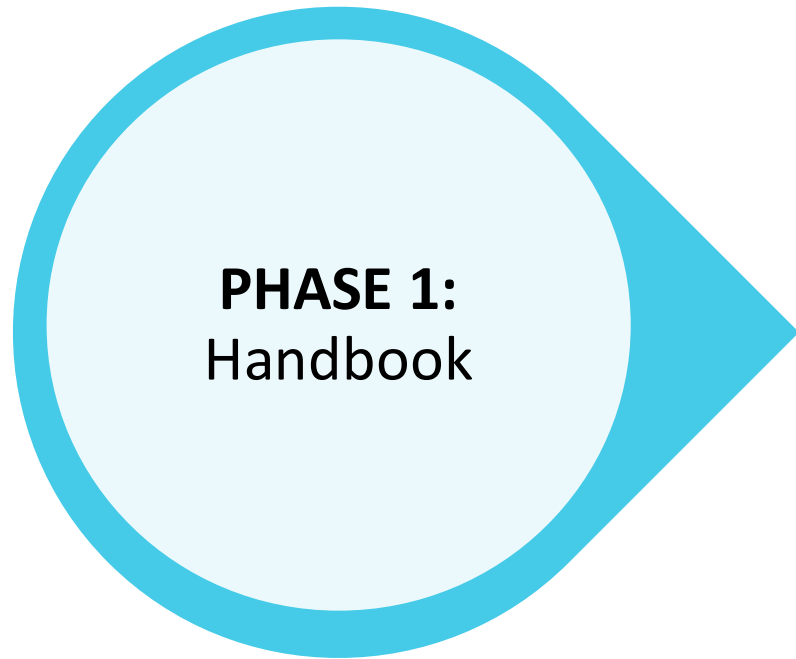


Shondelle Wilson-Frederick,
National Heart, Lung, and Blood
Institute

WORKPLAN



EXTERNAL HANDBOOK



- **Goal:** Highlight strategies for clinical research engagement
- **Resources for**
 - Patients, Caregivers, and Patient Advocacy Groups
 - Communities
 - Researchers
- A **'living'** document

Launching this week on PartnersInResearch.nih.gov!

External Handbook

Engagement Objective	Collaborative Decision-Making	Equitable Engagement	Methods of Engagement	Sustainable Engagement & Capacity Building	Return of Research Value
Engaging Patients and Caregivers	Case study(ies)	Case study(ies)	Case study(ies)	Case study(ies)	Case study(ies)
Engaging Communities	Case study(ies)	Case study(ies)	Case study(ies)	Case study(ies)	Case study(ies)
Engaging Researchers	Case study(ies)	Case study(ies)	Case study(ies)	Case study(ies)	Case study(ies)
Resources (Templates, Frameworks, additional guidance, etc.)					

Lay Audience Definitions

Collaborative Decision-Making

Patients, community members, and research teams working together to make decisions and design research

Equitable Engagement

Enabling patients and community members with diverse viewpoints and experiences to partner with research teams

Methods of Engagement

Practical ways to include the ideas and opinions and patients and community members in research

Sustainable Engagement & Capacity Building

Ensuring research partnerships have the resources and support to continue long-term

Return of Research Value

Making sure that research and its results are useful for patients and communities

Case Studies

Community Convenings with Faith-Based and Community Partners

Community Convenings are in-person conversations between community members and researchers. They are held at churches or other faith institutions, and the conversation is led by a faith leader...

[Learn More](#)

NINDS Nonprofit Forum: Progress Through Partnership

The Nonprofit Forum happens once a year and brings together diverse voices in the neurological disorder community. The Nonprofit Forum is attended by people with lived experience of neurological disorders, leaders of nonprofit organizations...

[Learn More](#)

Community Partnerships to Advance Science for Society (COMPASS)

The COMPASS program aims to empower community organizations to take ownership over their own health challenges and solutions. COMPASS is an innovative model that directly funds community organizations rather than...

Building Research for Academic and Community Equity (BRACE) Toolkit

The BRACE Toolkit is a set of materials to help community organizations and researchers build equitable partnerships. The toolkit provides information for both community organizations and researchers on...

HOMEPAGE

CASE STUDY FORMAT

Community Convenings with Faith-Based and Community Partners

Posted on June 13, 2024

Share:    

Community Convenings are in-person conversations between community members and researchers. They are held at churches or other faith institutions, and the conversation is led by a faith leader, such as a pastor. Community members attend the Community Convening and learn about *All of Us* research from leaders of community organizations, people who participated in *All of Us* research, and researchers themselves.

Community members can also ask questions and talk about their thoughts and opinions. Researchers, community organization leaders, and *All of Us* research participants talk directly with community members and answer their questions.

Research teams that want to host their own Community Convenings should think about some details. They should create a planning team that includes community members, researchers, and participants from their study. They need to choose a venue, think about offering food, and make decisions about using technology. Research teams should make sure they have enough money to pay for these items, and work with community organizations to make the best choices. The advertising and other types of communication should be provided to people in ways they prefer, such as on the radio, social media, or in newspapers.

Links to Relevant Resources:

- [Example of a Flyer Advertising a Faith-Based Community Convening](#)
- [Example of an Event Page for a Faith-Based Community Convening](#)
- [Video of Session 1 of Macon County Community Convening: Moving Us Forward!](#)
- [Video of Session 2 of Macon County Community Convening: Lessons Learned from the Past](#)
- [Video of Session 3 of Macon County Community Convening: Opportunities to Collaborate](#)
- [Publication Describing How All of Us Participants Define Return of Value in Research](#)
- [News Article Describing Macon County Community Convening: Discussing Medical Wrongs](#)
- [News Video Describing Macon County Community Convening: Medical Research Transparency](#)
- [2022 All of Us Engagement and Outreach Annual Report](#)
- [2023 All of Us Engagement and Outreach Annual Report](#)

RESOURCE LINKS

Case Studies

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**BE SURE TO CHECK OUT THE
CASE STUDIES ON
[PARTNERSINRESEARCH.NIH.GOV](https://partnersinresearch.nih.gov)**