



NIH Office of Research on Women's Health (ORWH)

Enhancing Community Engagement at ORWH

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NIH Office of Research on Women's Health

60th Meeting of the Advisory Committee for Research on
Women's Health

April 9, 2024



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www.nih.gov/women

#ResearchForWomen

Background: Community Engagement in Health Research

- “The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people”
- Ongoing and meaningful community engagement is a widely accepted best practice in health research
- Benefits of community engagement:
 - Increased and expanded recruitment and retention
 - Improved research quality
 - Enhanced research effectiveness
 - Increases trust in research
 - Demonstrates respect for community
 - Increases uptake of research findings

Background: Community Engagement at NIH

Circulation

PERSPECTIVE

Centering Patient Voices Through Community Engagement in Cardiovascular Research

Tiffany M. Powell-Wiley, MD, MPH

We are experiencing converging pandemics. The coronavirus disease 2019 (COVID-19) pandemic has highlighted and exacerbated the cardiometabolic disease pandemics globally. Obesity, diabetes, and cardiovascular disease (CVD) prevalence remains stagnant or is rising across populations and geographic regions. These pandemics intersect in the midst of increasingly glaring social inequities and systemic discrimination that promote health disparities across racial/ethnic and sex/gender groups.¹ Moreover, persistent

care organizations do not traditionally adapt their clinical care models based on feedback from those who are most invested in improving population-level cardiometabolic health: individuals from communities that are most vulnerable to cardiometabolic diseases. Emerging patient care frameworks have started to incorporate SDH in clinical care to address patients' social needs by large ing upstream barriers to cardiometabolic health, such as structural racism that produces differential health access or health literacy.² Professional organizations and

Intramural programs

Open access Communication

BMJ Open Integrating participants as partners in research governance and operations: an approach from the *All of Us* Research Program Engagement Core

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To cite: Hammack-Aviran C, Fair AM, Aldrich M, et al. Integrating participants as partners in research governance and operations: an approach from the *All of Us* Research Program Engagement Core. *BMJ Open* 2023;13:e008100. doi:10.1136/bmjopen-2022-008100

► Publication history and additional supplemental material for this paper are available

ABSTRACT
Objectives During the last two decades, researchers and funders increasingly recognized the value of engaging patients and communities in research. Despite progress, community engagement remains challenging. There are few examples of successful participant engagement in governance of large-scale research programmes. Here we describe efforts to engage participants as partners in new governance roles in the *All of Us* Research Program, a precision medicine research initiative which intends to enroll at least one million participants. Using intentional, participant-centric engagement strategies, the *All of Us* Engagement Core recruited and integrated a

creation of the Patient-Centered Outcomes Research Institute in 2010¹⁰ and the launch of the National Institutes of Health's (NIH) Clinical and Translational Science Awards (CTSA) Program in 2006,¹¹ which required community engagement. Subsequently, the value of engaging non-researchers in science has become widely accepted, and community advocates, patients and research participants are increasingly involved in biomedical research in a myriad of ways.⁹⁻¹¹

Extramural programs

SUPPLEMENT ARTICLE

OPEN

Engaging Transgender People in NIH-Funded HIV/AIDS Clinical Trials Research

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Abstract: In 2009, the National Institutes of Health recognized the need to expand knowledge of lesbian, gay, bisexual, and transgender (LGBT) health and commissioned the Institute of Medicine to report on the health of these populations in the United States. The resulting Institute of Medicine publication called for more knowledge of the health of LGBT populations, as well as improved methodologies to reach them, more LGBT-focused research, and enhanced training programs and cultural competency of physicians and researchers. Several of the National Institutes of Health-funded HIV/AIDS clinical trials networks, including the Adolescent Medicine Trials Network for HIV/AIDS Interventions, HIV Prevention Trials Network, HIV Vaccine Trials Network, and Microbicide Trials Network,

ships to build trust with and seek input from TG individuals on research plans and policies. They have established standing advisory groups and convened consultations for this purpose. To ensure that trial data are reflective of the participants they are seeking to enroll, they have reviewed and revised data collection forms to incorporate the 2-step method of collecting sex at birth and gender identity as 2 independent variables, and some have also revised research protocol templates and policies for concept development to ensure that they are appropriate for the inclusion of TG participants. The networks have also initiated trainings to enhance cultural sensitivity and developed a range of materials and resources for network and clinical research site staff. They continue to identify TG-specific research needs in an effort to be

Community Advisory Boards

Community Forums

About NIEHS Community Forums

NIEHS sponsors Community Forums in cities throughout the United States on the general theme of environmental impacts on human health. The purpose of the community forums is to bring together members of the public who are interested in public health and the environment with NIEHS and other federal, state, and local government health officials; environmental health professionals; and disease and environmental advocacy groups.



The forums provide a platform for an open dialogue to establish better coordination among the public and health professionals working on community exposures, industrial exposures, and other environmental issues. These forums also provide an opportunity to promote local and state media coverage of environmental health issues to broaden public understanding.



Many of these Community Forums are organized in collaboration with NIEHS Environmental Health Sciences Centers and

Community forums

Powell-Wiley TM. *Circulation*. 2023

Hammack-Aviran C, et al. *BMJ Open*. 2023

Siskind RL, et al. *J Acquir Immune Defic Syndr*. 2016

<https://www.niehs.nih.gov/about/community/communityforums>

Background: Community Engagement at ORWH

Updates on OADR-ORWH Session 1: Community Roundtable

Date and Time
February 2, 2024, 12:00 PM – February 2, 2024, 12:45 PM
Virtual Only

Event Information **Agenda Tab** Special Accommodations

Session 1: Community Roundtable Session 1: Community Roundtable Session 1: Community Roundtable
Friday, February 2, 2024, 12:00 p.m.–12:45 p.m. EST

Session 1: Community Roundtable
Intended Audience: Community partners, including advocacy groups, patients, and members of the public

12:00 p.m.–12:20 p.m. EST OADR-ORWH Updates

Listening sessions and Roundtables

Active poll

What are your top research priorities for women & HIV?

HPTN 096 for women

Female hormone and LAI Multi purpose technology Harmful laws & policies

Health communication rese Spheres of influence Trauma and Qual of Life MPT Increasing PrEP/Black wom

Sexual health Visibility Stigma reduction

PrEP awareness and access

Prep use in pregnancy Women's health and aging Spheres of 1649274

PrEP Unnecessary exclusion Menopause

HIV and Aging Prevention in older age Longterm exposure HIV med

Free/reduced cost access Additional Prevention

OAR-ORWH Listening Session at US Conference on HIV and AIDS, Sept. 2023

<https://orwh.od.nih.gov/OADR-ORWH>

NIH Request for Information (RFI) on NIH-Wide Strategic Plan for Research on the Health of Women

Notice Number:
NOT-OD-22-186

Key Dates

Release Date: July 22, 2022

Response Date: September 29, 2022

Request for Information (RFI)s

NIH Request for Information (RFI) on Research Opportunities Related to HIV and Women's Health

Notice Number:
NOT-OD-24-011

Key Dates

Release Date:

Response Date:

Request for Information (RFI): Future Directions in Violence Against Women Research

Notice Number:
NOT-NR-23-008

Key Dates

Release Date: February 10, 2023

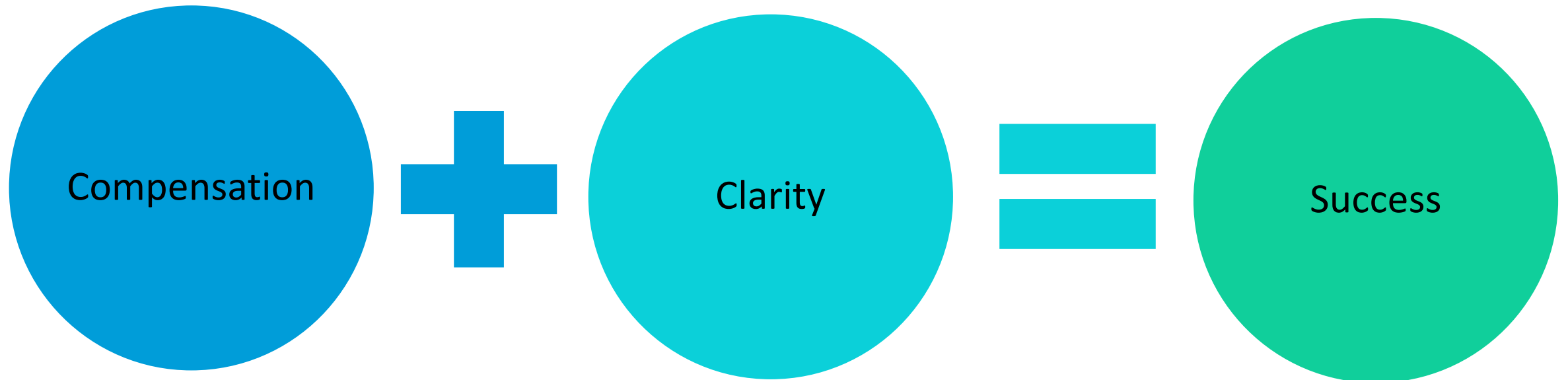
Response Date: March 31, 2023

Objective

- To (1) meet the need for sustained community partnership and (2) ensure responsiveness to and input from the women ORWH serves, ORWH proposes the establishment of a standing ACRWH community engagement subcommittee.
 - Subcommittee to be comprised of patients; community members
- This subcommittee of the ACRWH will elicit regular, ongoing, community- and patient-focused input into ORWH programs and priorities.

Key Considerations

- Information-gathering meetings with existing NIH community engagement efforts to understand best practices and lessons learned (2023).



Approach and Outcomes

- Size: Onboard 8 members/year to serve 3-year terms; optional 4th year
- Membership: Self-nominations to reflect a diversity of perspectives
- Meetings: Quarterly meetings (virtual & hybrid)
- Deliverables: ORWH to produce at least 2 public-facing resources annually, informed by the subcommittee's input

Potential Perspectives to Include

Disease/condition agnostic
Adolescent girls and young women
Disability
Diverse populations
Environmental justice
Non-English language preference
Older women
Rural women
Sexual and gender minority women
Substance use
Violence against women

Disease/condition specific
Autoimmune disease (e.g., Lupus)
Cancers
Chronic obstructive pulmonary disease/Lung disease
Chronic pain
Diabetes
Female-specific conditions (e.g., endometriosis)
Heart disease
HIV
Mental health
Neurologic disorders (e.g., Multiple Sclerosis)
Sexually transmitted infections (STIs)

Planned Next Steps

April 2024	Charge subcommittee (60 th Meeting of the Advisory Committee on Research on Women's Health)
May 2024	Membership solicitation
June 2024	Membership committee (3-5 ORWH, CCRWH members) reviews statements of interest
July 2024	Conversations with nominees
Aug. 2024	Invitations to first round of members
Sept. 2024	Finalize plans for first meeting
Oct. 2024	1 st Meeting of the ORWH community engagement subcommittee 61 st Meeting of the Advisory Committee on Research on Women's Health

Questions?

