Division of AIDS Directory for HIV Research Community Advisory Boards & Community Working Groups July 2025

Background

The Division of AIDS (DAIDS) at the National Institute of Allergy and Infectious Diseases (NIAID) has long recognized that community members play a vital role in the clinical research process. Community Advisory Boards (CABs) and Community Working Groups (CWGs) are an effective way to solicit information about community priorities, concerns, and ideas as they relate to the research agenda, protocol design and conduct, messaging and outreach, and the dissemination of research results. Therefore, all the NIAID-funded networks and programs have established CABs or CWGs to provide ongoing input and guidance throughout the research process and ensure that community voices are heard. These CABs and CWGs support NIAID-funded HIV research that encompasses the spectrum of HIV research underway in the HIV research programs listed below. For more information on the scope of research within each network or program, please visit the following websites:

- HIV/AIDS Clinical Trials Networks:
 - o Advancing Clinical Therapeutics Globally for HIV/AIDS and Other Infections (ACTG)
 - o International, Maternal, Pediatric, Adolescent AIDS Clinical Trials Group (IMPAACT)
 - <u>HIV Prevention Trials Network (HPTN)</u>
 - HIV Vaccine Trials Network (HVTN)
- The Centers for AIDS Research (CFARs)
- The Martin Delaney Collaboratories (MDC)
- MACS/WIHS Combined Cohort Study (MWCCS)

CAB/CWG Overview

CABs/CWGs can be at both the local site level and network/program level.

- Each of the four HIV/AIDS Clinical Trials Research Networks has network-level/global CAB or CWG as does each clinical research site. The <u>Office of HIV/AIDS Network Coordination (HANC)</u> also coordinates Community Partners, an overarching body of community representatives from each of the global CABs that provides guidance across all the networks and helps promote effective representation of the many communities within which the research is conducted. HANC also coordinates the Legacy Project, which focuses on promoting the representation of underrepresented populations in HIV research conducted in the United States (US); the Legacy Project has a variety of working groups focused on different communities (more information at the end of this document).
- In the CFARs, in addition to CABs at each research sites, there is a National CFAR CAB Coalition (N3C) that represents all the CFAR CABs. The N3C serves as a resource for community engagement and involvement in national CFAR initiatives and as a resource for the creation, development, and sustainability of CFAR CABs.

- Each of the Martin Delaney Collaboratories has a CAB that advises the research staff on various aspects of the research agenda. The Community Engagement Coordinator (CEC) at each Collaboratory also works with organizations and/or individuals who are identified as "Community Partners" to help carry out community engagement activities.
- Each MACS and WIHS site has a CAB, and a representative from each forms the National CAB (NCAB). The NCAB is active in all levels of the study, including participation on working group conference calls and the biannual scientific Executive Committee (EC) meeting, and provides feedback on the practicality and validity of all proposed studies.

Each CAB/CWG is comprised of a diverse group of individuals with a mix of scientific knowledge and lived experience. Some members may have participated in a research study, work in the field, or be directly affected by HIV through family or friends. CABs provide a community perspective on the research, study design, and local issues. They help researchers understand and connect with community needs and concerns. Typically, CAB/CWG members attend regularly scheduled meetings with the Principal Investigator and/or staff from the clinical research site to discuss ongoing or proposed research; review protocols, including informed consent materials; and provide input on outreach activities and messaging.

Trainings are provided to help CAB/CWG members be more effective in their role. Supplemental training resources to support CAB/CWG members and staff that work with them are available on the <u>DAIDS Learning Portal</u>. The resources are available to anyone, although an account is needed to access the e-learning modules. While a site ID is typically required for an account, if you are not site affiliated you can use 99999 as your site ID when requesting an account.

Learn More and Volunteer to Join a CAB/CWG

If you are interested in learning more about becoming a CAB/CWG member for an HIV research program, you can visit the websites listed below to determine if there is a site located in your community and/or a staff person to contact. Each program has its own process for selecting CAB/CWG members. You can reach out to the points of contact listed to learn more about joining.

HIV/AIDS Clinical Trials Networks

Network	Site Listing	Community Page & Community Contact
Actracting Clinical Therapeutics Olibelity for HVXADS and Other infections	https://actgnetwork.org/clinical-trial/	<u>https://actgnetwork.org/global-</u> <u>community-advisory-board/</u> <u>lcsg@dlhcorp.com</u>
International Maternal Pediatric Adolescent AIDS Clinical Trials Network	https://www.impaactnetwork.org/about /sites	<u>https://www.impaactnetwork.org/co</u> <u>mmunity</u>
HIV Prevention Trials Network	https://www.hptn.org/research/sites	https://www.hptn.org/community
HIV VACCINE TRIALS NETWORK	https://www.hvtn.org/participate/study -clinics.html	<u>https://www.hvtn.org/community/co</u> <u>mmunity-overview.html</u>

Martin Delaney Collaboratories

MDC	Institution	Community Engagement Coordinator	Email
REACH : Research Enterprise to Advance a Cure for HIV	Weill Cornell Medicine, New York, NY	Jessica Salzwedel	jessica@avac.org
BEAT-HIV : Delaney Collaboratory to Cure HIV-1 Infection by Combination Immunotherapy	Wistar Institute, Philadelphia, PA	Amy Onorato	aonorato@pennmedicin e.upenn.edu
Delaney AIDS Research Enterprise to Cure HIV (DARE)	University of California, San Francisco	Lynda Dee	lyndamdee@aol.com
I4C 2.0 : Immunotherapy for Cure	Beth Israel Deaconess Medical Center, Boston, MA	Jessica Salzwedel	jessica@avac.org
Enterprise for Research and Advocacy to Stop and Eradicate HIV (ERASE-HIV)	Emory University, Atlanta, GA	Amanda Van Buren	avanburen@sisterlove. org
Collaboratory of AIDS Researchers for Eradication (CARE)	University of North Carolina at Chapel Hill	Allison Mathews	<u>mathewsallison@gmail.co</u> <u>m</u>
CRISPR for Cure	Temple University of the Commonwealth, Philadelphia, PA	Kate Goldston	Kate.Goldston@Pennme dicine.upenn.edu
Reversing Immune Dysfunction for HIV-1 Eradication (RID)	The Scripps Research Institute, San Diego, California	Jeff Taylor	jeff.taylor@harp-ps.org
HOPE - HIV Obstruction by Programmed Epigenetics	J. David Gladstone Institutes, San Francisco, CA	Patricia Defechereux	patricia.defechereux@gl adstone.ucsf.edu
Pediatric Adolescent Virus Elimination (PAVE) Martin Delaney Collaboratory	Johns Hopkins University, Baltimore, MD	Jessica Salzwedel	jessica@avac.org

Centers for AIDS Research

Program	Point of Contact for all CFAR CABs	Email
Centers for AIDS Research	Amy M. Onorato	aonorato@pennmedicine.upenn.edu

MACS/WIHS Combined Cohort Study

Program	NCAB Point of Contact	Email
MWCCS	Alicia Diggs, NCAB Chair	alicia_diggs@med.unc.edu

Office of HIV/AIDS Network Coordination (HANC)

In addition to CABs/CWGs, there are other mechanisms for community-focused engagement and outreach, including through HANC. Information about each of the HANC working groups listed below can be found on the HANC <u>Community Page</u>.

Working Group	Coordinator	Email
Legacy Project Working Group (focused on all underrepresented populations)	Cat Banobi	<u>cbanobi@fredhutch.org</u>
American Indian & Alaska Native Working Group	Gabriella Olague	golague@fredhutch.org
Community Partners	Greg Davis	gpdavis@fredhutch.org
Destigmatizing Substance Use	Gabriella Olague	golague@fredhutch.org
Be the Generation www.bethegeneration.org	Cat Banobi	<u>cbanobi@fredhutch.org</u>
The Latinx Caucus	Gabriella Olague	golague@fredhutch.org
Minority-Serving Institutions Working Group	Cat Banobi	<u>cbanobi@fredhutch.org</u>
New Investigators Working Group	Cat Banobi	<u>cbanobi@fredhutch.org</u>
Women's HIV Research Collaborative (WHRC)	Gabriela Olague	golague@fredhutch.org