

Division of AIDS
Directory for HIV Research
Community Advisory Boards & Community Working Groups
December 2021

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. As a result, all of the NIAID-funded networks and programs have established Community Advisory Boards (CAB) or Community Working Groups (CWGs) to provide ongoing input and guidance throughout the research process and ensure that that community voices are heard.

CABs and CWGs have been 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 results.

CABs/CWGs support NIAID-funded HIV research that encompasses HIV treatment and treatment of HIV-related co-infections (ACTG, IMPAACT, HVTN), prevention (HPTN, IMPAACT), vaccines (HVTN), broadly neutralizing antibodies for HIV prevention (HPTN, HVTN), cure research (ACTG, MDCs), and multidisciplinary research to End the Epidemic (CFARs). For more information on the scope of research within each network or program, please visit the websites listed below.

- **HIV/AIDS Clinical Trials Networks**
 - [AIDS Clinical Trials Group \(ACTG\)](#)
 - [International Maternal, Pediatric, Adolescent AIDS Clinical Trials \(IMPAACT\)](#)
 - [HIV Prevention Trials Network \(HPTN\)](#)
 - [HIV Vaccine Trials Network \(HVTN\)](#)
- **[The Centers for AIDS Research \(CFARs\)](#)**
- **[The Martin Delaney Collaboratories \(MDC\)](#)**

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 HIV/AIDS Office of Network Coordination (HANC) 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.
- In the CFARs, in addition to strong community engagement or a CAB at each research site, there is a National CFAR CAB Coalition (N3C) that represents all of 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 CAB/CWG is comprised of a diverse group of individuals; some have extensive knowledge of HIV research while others have less scientific or research 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 typically 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 DAIDS Learning Portal at <https://www.niaid.nih.gov/daids-ctu/community-engagement>. (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 one of the HIV/AIDS clinical trials research sites, you can visit the network website listed below to determine if there is a site located in your community and/or if provided, staff person listed below. CAB/CWG membership would be at the local site level as each network has its own process for selecting local CAB/CWG members to participate in the network-level (global) CAB. This is true for the CFARs as well. For both the CFARs and MDCs, points of contact are listed below. You can reach out to them directly to learn more about joining one of their CABs. The website and point of contact for other DAIDS and HANC-supported working groups are also provided below.

HIV/AIDS Clinical Trials Networks

Network	Site Listing	Community Page & Community Contact
AIDS Clinical Trials Group (ACTG)	https://actgnetwork.org/sites-list/	https://actgnetwork.org/committees/ Allegra Cermak, Community Coordinator allegra.cermak@dlhcorp.com
International Pediatric Maternal Adolescent AIDS Clinical Trials (IMPAACT)	https://www.impaactnetwork.org/about/sites	https://www.impaactnetwork.org/community
HIV Prevention Trials Network (HPTN)	https://www.hptn.org/research/sites	https://www.hptn.org/community
HIV Vaccine Trials Network (HVTN)	https://www.hvtn.org/en/hvtn-international-sites/hvtn-north-america-sites.html	https://www.hvtn.org/en/community.html

Centers for Martin Delaney Collaboratories (MDC)

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	anonorato@penncmedicine.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	Nea Richards	nrichard@sisterlove.org
Collaboratory of AIDS Researchers for Eradication (CARE)	University of North Carolina at Chapel Hill	Meredith Blumberg	meredith_blumberg@med.unc.edu
CRISPR for Cure	Temple University of the Commonwealth, Philadelphia, PA	Kate Goldston	Kate.Goldston@Penncmedicine.upenn.edu
Reversing Immune Dysfunction for HIV-1 Eradication (RID)	Sanford Burnham Prebys Medical Discovery Institute, La Jolla, CA	Jeff Taylor	jeff.taylor@harp-ps.org
HOPE - HIV Obstruction by Programmed Epigenetics	J. David Gladstone Institutes, San Francisco, CA	Patricia Defechereux	patricia.defechereux@gladstone.ucsf.edu
Pediatric Adolescent Virus Elimination (PAVE) Martin Delaney Collaboratory	Johns Hopkins University, Baltimore, MD	Jessica Salzwedel	jessica@avac.org

Centers for AIDS Research (CFAR)

Program	Point of Contact for all CFAR CABs	Email
Centers for AIDS Research	Amy M. Onorato	aaonorato@penntestbed.org

Community Engagement

In addition to CABs/CWGs, there are other mechanisms for specific types of community-focused engagement and outreach through DAIDS and the Office of HIV/AIDS Network Coordination (HANC). The DAIDS Cross-Network Transgender Working Group, for example, supports efforts to increase the inclusion of transgender and gender nonbinary individuals in research across all of the NIAID-funded networks. While the focus is reaching out to research staff to ensure cultural awareness and understanding, the group works to stay abreast of critical issues relevant to transgender participants. HANC supports the Legacy Project and several Working Groups as well as the Women's HIV Research Collaborative, all of which are intended to increase knowledge and awareness of HIV research among key populations and facilitate research participation within communities that have historically been underrepresented in clinical research. Participation in these groups generally comes from within the HIV research arena; membership is welcome based on interest and experience.

Office of HIV/AIDS Network Coordination (HANC)

Information about each of the working groups and projects listed below can be found on the HANC [Community Page](#)

Working Group	Coordinator	Email
Legacy Project Working Group	Russell Campbell	rcampbel@fredhutch.org
The Latinx Caucus	Pedro Goicochea	pgoicoch@fredhutch.org
American Indian/Alaska Native Working Group (AI/AN WG)	Pedro Goicochea	pgoicoch@fredhutch.org
Women's HIV Research Collaborative (WHRC)	Brian Minalga	bminalga@fredhutch.org
Be the Generation (BTG)	Brian Minalga	bminalga@fredhutch.org
Division of AIDS Cross-Network Transgender Working Group (CNTWG)	Rona Siskind	rsiskind@niaid.nih.gov