

# Community Advisory Boards: Introduction & Overview

The HIV Vaccine Trials Network is supported through a cooperative agreement with the National Institute of Allergy and Infectious Diseases



HIV VACCINE  
TRIALS NETWORK

# Topics

- What is a Community Advisory Board (CAB) and why do they exist ?
- How does the HVTN involve CABs?
- Getting started, forming a CAB
- Ongoing CAB education, roles and responsibilities.
- Site support for CABS

# What is a Community Advisory Board?

- A formal advisory group that is coordinated by the research site.
- Made up of diverse community members varying in age, race, gender, education, religion and sexual orientation.
- Meets regularly to provide feedback to the site on research and its relevance to the local community.
- Provides 2-way communication channel for information between the research site and the broader community.

# Before CABs...

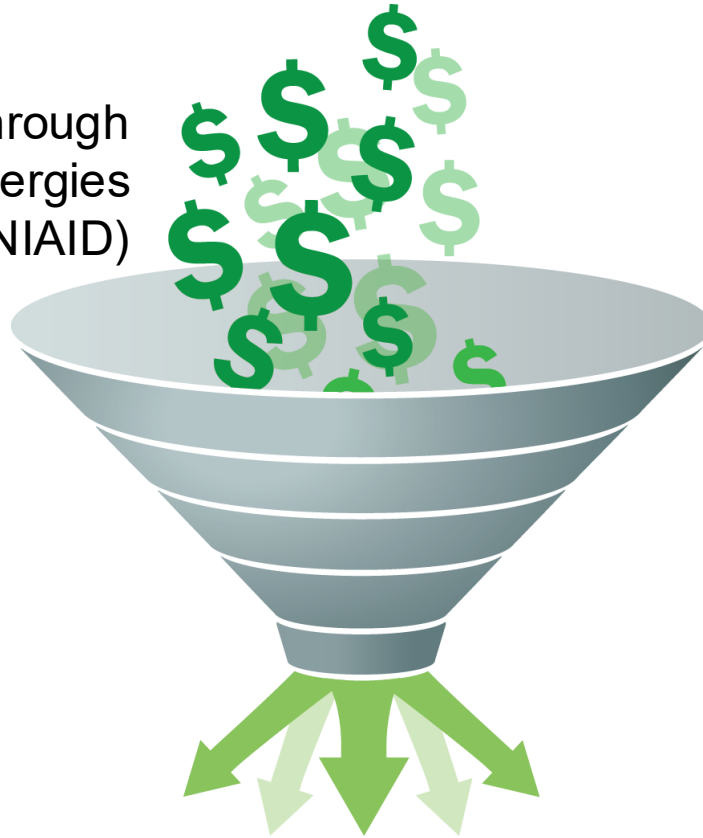


**GAY RAGE:** Demonstrators mass outside Health Dept. offices in lower Manhattan yesterday to protest a city decision to cut in half its estimate of the number of AIDS-infected New Yorkers. Four were arrested as protest leaders called the city decision a maneuver to cut health services to AIDS victims.

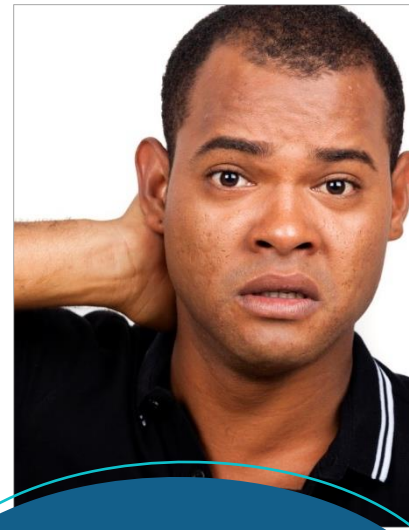
- AIDS activists were concerned about the slow response of the US government and private pharmaceutical companies to respond to the AIDS epidemic.

# With research Networks came CABs

US government funding through the National Institute of Allergies and Infectious Diseases (NIAID)



# Common communities perceptions about research:



... "Eek this is terrifying!"

# Challenges of HIV vaccine research

- Community support and knowledge level generally low
  - Anti-Vaccine movement
  - Research raises complex issues
  - Distrust of government, medicine and research
  - Concern about HIV infections during the trial
  - Fear of getting AIDS from the vaccine
  - Recruitment strategies
- 
- Relationship of vaccine development to HIV prevention
  - Relationship of vaccine development to HIV treatment



*CABs can serve as a bridge*

# Who makes up a CAB?

- Study participants, or individuals with similar characteristics
- Prominent community members & key opinion leaders
- Family members of study participants
- Representatives of local community-based organizations and/or AIDS service organizations
- Religious leaders
- Individuals affected by or living with HIV



# Role of CABs

- Serve as a link between the research site and the community, providing a conduit for bi-directional communication.
- Participate in CAB meetings and activities, including skill building and training opportunities.
- Help dispel myths about HIV vaccine research and provide accurate information to peers.
- Help educate the community about the site's research activities.
- Help recruit, train, and retain new CAB members.
- Provide insight into the “real lives” of the populations prioritized for trial participation.

# Role of CABs - continued

- Help ensure community concerns are adequately addressed in informed consent documents & the overall consent process, including language & cultural sensitivity
- Represent the diversity of individuals that are living with HIV/affected and the concerns of those communities.
- Help to identify emerging research needs and identify gaps
- Advise on the site's community education programs
- Advise on site recruitment and retention activities
- Advise on strategies for dissemination of research results to the community.
- Ask questions! (and respond to questions asked of you)

# Advise/Advocate vs. Activism

- The “A” in CAB stands for advisory.
- CAB members may be advocates for their communities, their CAB, and study participants. However, the site PI is ultimately responsible for the conduct of the study and for the study participants’ wellbeing.
- *Activism*, which can easily become confrontational, is not the goal.



# When are CAB members involved?

- ALL stages of the research process
  - Planning
  - Development
  - Implementation
  - Dissemination of results
- Providing input on
  - Local relevance and acceptance
  - Ethical and scientific quality of research
  - Anticipated concerns by study volunteers



# How is a CAB structured?

- **Some CABs:**
  - Have by-laws and constitutions. Some don't.
  - Have officers with term limits. Some don't.
  - Meet monthly, bi-monthly or quarterly.
  - Have subcommittees. Some don't.
  - Provide input to multiple DAIDS networks. Some don't.
- **All CABs:**
  - Have a Global CAB representative who participates on bi-monthly conference calls
  - Send a member to the HVTN conferences

# Examples of CAB projects



**World AIDS Day- December 1st**

"Vacuman," a vaccine superhero played by model and law student Alex Vega Gonzales, gets ready for his dance act at a World AIDS Day party honoring AMP Study participants at a gay disco in Lima.  
Photo by Katie Jennings / New Canoe Media



PHRU- Soweto



Aurum Institute- Klerksdorp

# More projects!!



Birmingham, AL- Gay Pride.  
CAB members (with a few site staff) came together to build this float for the Gay Pride Parade, which took first place!

Iquitos, Peru.  
This CAB developed its own brochure to share what the CAB does and invite other community members to join.



**Actividades en las que intervenimos:**

- Participación en la creación, revisión, evaluación, validación y aprobación del material para la población objetivo.
- Sensibilización y Capacitación en Vacunas contra el VIH, temas actualizados de VIH/SIDA, Hepatitis.
- Participación en el Día Mundial de la Vacuna contra el VIH.
- Participación en Día Mundial de la Lucha Contra el SIDA.
- Participación en diversas capacitaciones en Ética y Confidencialidad.
- Derechos Humanos, Estrategias y formas de enfrentar crisis frente a los medios de comunicación, etc.

**Miembros Activos**

- Sr. Pablo David Oueda Herrera - Presidente
- Sra. Silvia Barbarán Mafaldo - Miembro
- Sra. Angélica Valcarlos Hernández - Miembro
- Sr. Erick Murayari Macayo - Miembro
- Sr. Luis Chinama Orbe - Miembro
- Sr. Alejandro Barrios Alves Wilho - Miembro
- Sr. Juan Sandro Monsalvo Ruiz - Vocal
- Sra. Deyce Gómez Cruz - Miembro
- Sr. Luis León Pinedo (Rita) - Secretaria
- Sra. Silvia Torres Canayo - Miembro

Si tienes alguna duda o inquietud, no dudes en comunicarte:

**Línea Gratuita : 0800 - 1 - 3231**

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# The Global CAB (GCAB)

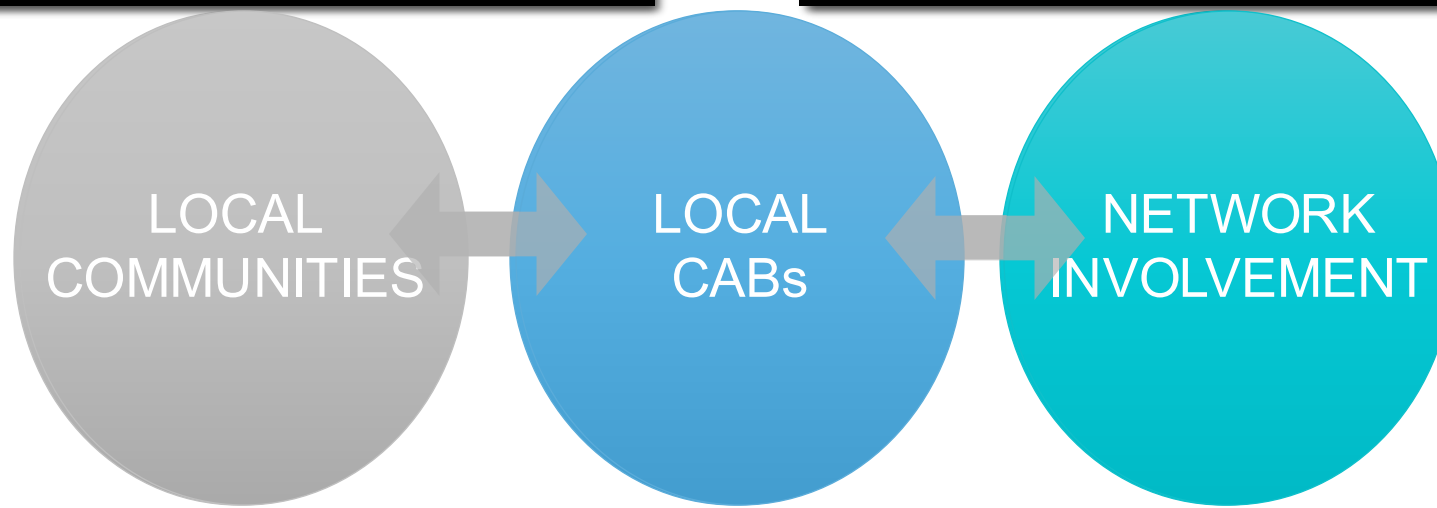
- 2 co-chairs elected to 3-year term
- Co-chairs are from 1 U.S. and 1 non-U.S. site
- Each site has a representative and gets one vote
- Holds bi-monthly conference calls
- GCAB representatives have a bidirectional responsibility- liaising between site and network, sharing concerns and info both ways.

# CAB connections to the Network & each other

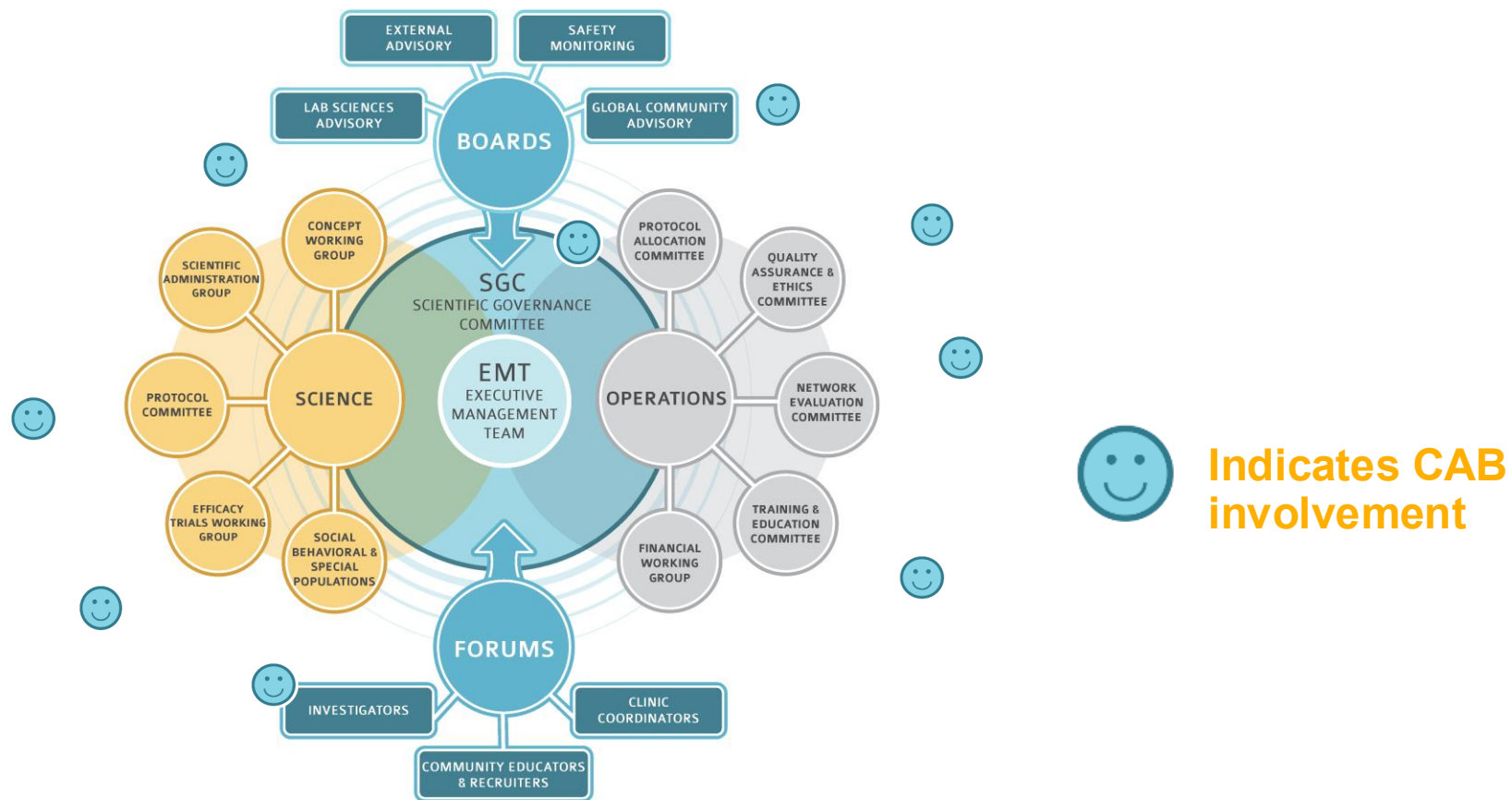
HVTN Conference-  
Community Session, October



Regional CAB Retreat,  
April 2010



# HVTN organizational structure



# CAB input at a Network level

- Participant's Bill of Rights and Responsibilities (PBORR)
- Transgender Working Group



One of several HVTN conference workshops focusing on better understanding how to better welcome and serve transgender participants in HVTN studies

Global effort. Global hope. Global network.

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## Participants' Bill of Rights and Responsibilities

[Print this page](#)

Revised April 20, 2007  
This document provides a short list of the rights and responsibilities you have while you participate in an HIV Vaccine Trials Network (HVTN) trial. See the study informed consent form for more information.

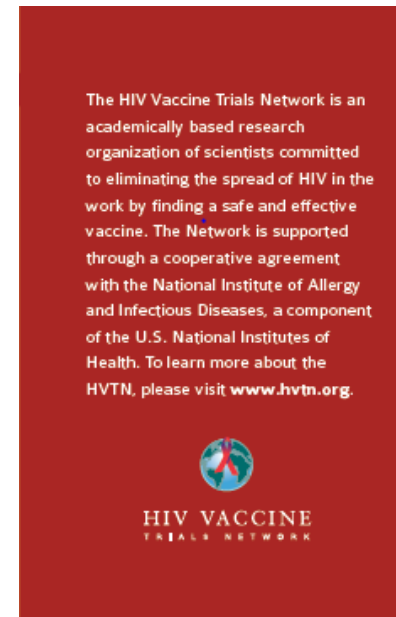
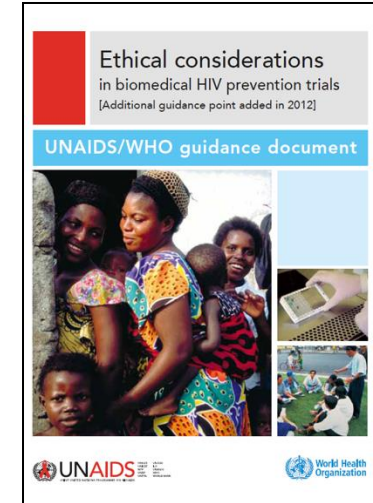
### Rights

As a participant in an HIV Vaccine Trials Network study, you have the right to:

- **Have all known information, including potential risks and benefits of trial participation, presented to you in a way in which you can understand.** You will be told about any new information learned during the course of the study.
- **Refuse to join the study or decide to leave the study at any time.** You can also refuse to join any follow-up studies you are told about. You will not lose any of the rights referred to in this document if you refuse to join the study or leave the study.
- **A discrimination-free study environment.** Your personal choices, values, beliefs, and cultural context will be respected by the people running the study.
- **Referral to available counseling and support services for issues related to the study and HIV prevention.**
- **Referral to available counseling, support, medical, and treatment services for illnesses you suffer during the study, including HIV.**
- **Assistance resolving study-related social problems and/or discrimination.** With

# CAB input (continued)

- Ethical Considerations in Biomedical HIV Prevention Trials- network improvements based on guidance document
- How/who to educate and inform about Vaccine-Induced Seropositivity (VISP).



## GETTING THE RIGHT TEST FOR HIV

What HIV vaccine study participants and former participants need to know

# Staff support for CABs



# Role of the CAB liaison

- Provide direct support to CAB members
- Be a resource so CAB members can access technical expertise
- Coordinate orientations and trainings for CAB members
- Serve as a point of contact for both CAB and staff, channeling communications and questions as appropriate
- Seek CAB input regarding materials and work plans and any planned events



Community liaison staff from the Aurum site in Klerksdorp (left), and the University of Cape Town site in Nyanga/Crossroads (right). Both work to facilitate CAB participation at their sites.

# Role of the clinic staff

- Serve as a resource for information regarding ongoing and planned studies, including new procedures
- Translate science into lay language
- Seek community input on clinic activities, such as the informed consent process
- Seek community input regarding understandable language, local dialects/slang, and cultural sensitivity

# Role of the Investigator of Principal Investigator

- Build trust and share information with communities
- Be willing to LISTEN
- Hire staff from key communities
- Translate science into lay language
- Work with community media
- Trust that community can contribute and add value
- See community input on proposed research or grant applications, plans for results dissemination and sharing of new information
- Provide meeting space and appropriate resources so that CAB members convene comfortably

# Conclusion

- CABs play an important role in community engagement.
- Without community engagement we would not have participants.
- Without participants we will not be able to find a safe and effective vaccine



# Science + Community = better research



# THANK YOU



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