The Office of HIV/AIDS Network Coordination (HANC)

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Why we are here today

• Invited
• Listen and learn
• Share
• HIV & other health disparities
• Support Cure agenda
Dedication
HANC Team
HANC Introduction

Founded in 2004, the mission of the Office of HIV/AIDS Network Coordination is to support the science and operations of the NIAID HIV/AIDS Clinical Trials Networks by increasing efficiency and resource-sharing through coordination of critical activities across networks and with other research and advocacy partners.
HANC & the NIH-funded HIV Research Networks
Resources for Inclusive Community Involvement

Featured on this page are a list of resources covering various aspects of community engagement in clinical research.

On This Page:

- Bill of Rights and Responsibilities for HEV Research
- Community Engagement Resource Highlights
- CRADDS CAB and CWG Directory
- Guidance for Gender-Inclusive HIV Research Practices
- How to Critically (and Quickly) Read a Protocol
- Long-Acting Antiretroviral Injectable Info Sheet
- NIAID HEV Language Guide
- PHOENIX Study Community Engagement
- Recommendations for Community Engagement
- Representative Studies Rubric
- TB Resources for Communities
- National Women and Girls HEV/AIDS Awareness

Community Resources

www.hanc.info
Cure-Specific Resources: the WHRC
The Representative Studies Rubric (RSR)

Addressing Inclusion:

• Age
• Drug use
• Ethnicity
• Gender
• Pregnancy
• Race
• Sex assigned at birth
Recommendations for Community Engagement in HIV/AIDS Research

A guide for communities and researchers

November 2020

Division of AIDS, National Institute of Allergy and Infectious Diseases, National Institutes of Health
How to Critically (and Quickly) Read a Protocol

• Outlines and explains the most important components of a study protocol
• Empowers CABs and community members to advocate
• Available in English, Portuguese, and Spanish
Community Resources

Bill of Rights and Responsibilities for HIV Research

- Outlines the rights and responsibilities for participants in a clinical trial
- Empowers research participants act on their own behalf and in partnership with study staff
- For use by clinical research sites along with informed consent forms
Mentorship Program

• To support site staff and CABs in an effort to rebuild and reenergize CABs.

• In addition to the Recommendations for Community Engagement document, CP can offer more specific and/or hands-on orientation, consultation, or training.

• Pool of experienced CAB liaisons that sites across the networks can reach out to for mentorship (ex. how to run a CAB meeting, develop your program, schedule trainings, identify critical training needs, prepare bylaws, organize a CAB).

• These individuals who agree to volunteer as mentors would be valuable resource.
Red Ribbon Registry (R3)

www.redribbonregistry.org

A database that connects potential study participants (volunteers) with local clinical studies to strengthen the connection between the community and the doctors and scientists working on clinical research studies.

HANC’s role:
• Facilitate expansion of the R3 to additional network studies.
• Maintain the R3 Resources page on the HANC website to support ACTG, HPTN, and IMPAACT sites.
• Develop processes and workflows to facilitate various communications between external stakeholders and R3 internal team, including processes for regulatory approval of site-developed advertising materials and requests for communications to volunteers.
• Conduct training sessions for site administrators and users.
HANC Webinar Library

• Behavioral Science (4)
• Community Engagement (6)
• Outreach & Marketing (3)
• Health Disparities (6)
• HIV & Substance Use (3)
• HIV Genetic Sequencing (4)
• Lab (6)

• COVID-19 (9)
• MPV (1)
• TB (5)
• Zika (1)
• National HIV Awareness Days (6)
• Women (4)
• Hot Topics (7)
NATIONAL WOMEN & GIRLS HIV/AIDS AWARENESS DAY
March 10, 2023

The Women’s HIV Research Collaborative celebrates these recent advancements in research focused on cis and trans women. Follow us on Facebook for more!

A SHOT FOR PREVENTION

Now is the time to get vaccinated. The latest HIV prevention tool is the HIV vaccine, a vaccine that is under research and development. The more that we test, the more we learn. The more we learn, the more we can protect ourselves.

HOPE FOR A CURE

Diagnosed with HIV in 2013, a multiracial American woman has been treated with a cure for HIV. She is the first woman to go on world tour as a result of her recovery. She and other women are giving scientific clues that may someday lead to widespread cure for HIV.

TRANSGENDER WOMEN

Two major research networks are focused on treating the very rare and complex HIV infections found in transgender women. This is the first time that research is being directed toward transgender women.

HIV VACCINE RESEARCH

Thousands of women have participated in studies testing new vaccines for HIV. The search continues for a vaccine that is safe, effective, and affordable. The search continues for a vaccine that is safe, effective, and affordable.

PREGNANCY & BREASTFEEDING

Women and breastfeeding people are too often excluded from research, leaving them without options and without knowledge. Thankfully, new research is changing the landscape of these women.

REPRESENTATION MATTERS

By Pedro Goldcochea, MSC, MA and Tasia Baldwin, MSC, MA on behalf of the Latinx Caucus*

Lessons Learned from Community Engagement Regarding Phylodynamic Research with Molecular HIV Surveillance Data

AUTHORS
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BE THE GENERATION
TO END THE AIDS EPIDEMIC
Thank you!
Conversation
Background

• As a whole HIV clinical research is not representative of the HIV epidemic.

• Cisgender White men make up 6% of the global epidemic but 51% of participants in RCTs for new ARVs.*

• Underrepresented populations suffer the consequences of exclusion:
  - Cisgender women, transgender people, pregnant people, and PWID globally
  - Black, Indigenous, and Latinx people in the US and territories

The RSR: 12-Item Questionnaire

1-7: Eligibility
1. Age
2. Cisgender women
3. Gender non-binary individuals
4. Persons who inject drugs
5. Transgender men
6. Transgender women
7. Pregnancy

8-12: Processes to Support Representation
8. Enrollment Goals (incl. ethnicity & race)
9. Community Engagement
10. Statistical Analysis: Gender & Sex
11. Defining Gender & Sex
12. Language (stigma)
Protocol Analysis (47)

• AIDS Clinical Trials Group (21)
• International, Maternal, Pediatric, Adolescent AIDS Clinical Trials Network (10)
• HIV Prevention Trials Network (5)
• HIV Vaccine Trials Network (5)
• HPTN/HVTN (3)
• Microbicide Trials Network (2)
• COVID-19 Prevention Network (1)
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Application of CNTWG Guidance: Defining Study Populations by Gender Identity and Sex Assigned at Birth

- Correctly Applied
- Incorrectly Applied

18
12
NIAID HIV Language Guide

• All 47 protocols included at least one instance of stigmatizing language

- HIV-infected / HIV-uninfected
- Infection / infect
- Risk / low-risk / high-risk / at-risk (referring to participants)
- Subjects (referring to participants)
- Target (referring to participants)
Conclusions & Next Steps

• Institutionalized barriers are ongoing and may perpetuate the underrepresentation of certain populations

• Proactive implementation of the RSR for all future protocols
  • RSR Working Group
  • RSR pilots
  • Revise protocol templates
  • Publish findings and promote the RSR for use in all clinical trials