Centering Health Equity: Seeking Community Perspectives for Transformative HIV Research
Community Town Hall - May 3, 2024

Summary and Key Findings

Executive Summary

The San Diego Center for AIDS Research (SD CFAR) and the UC San Diego Altman Clinical and Translational Research Institute (ACTRI) co-sponsored the *Centering Health Equity: Seeking Community Perspectives for Transformative HIV* Research Community Town Hall on May 3, 2024. The Planning Committee was led by the SD CFAR Health Equity Sociobehavioral Science Core leadership, Co-Directors Drs. Jamila Stockman and Eileen Pitpitan and Leadership Trainee Dr. Chadwick Campbell, and SD CFAR Health Equity Community Advisory Board Co-Chairs Danielle Campbell and Wanda London. The full-day event was held at Park & Market in Downtown San Diego, a central location in the San Diego region located near public transportation, and parking costs were covered for all attendees. Live, simultaneous Spanish translation was provided, with one invited panelist presenting in Spanish while English translation was broadcast to the room.

The overarching goal of the Community Town Hall was to strengthen partnerships between researchers and the community, ensuring that research efforts are relevant, impactful, and aligned with the local community's values and needs. The program was designed to 1) Facilitate meaningful dialogue between community members, researchers, service providers, and healthcare professionals to identify and prioritize the health issues that matter most to the community; 2) Empower community members to help shape SD CFAR's research agenda by providing a platform for their voices to be heard and valued; 3) Foster new and strengthen existing collaborations between community members and researchers to develop action plans for how to address the identified health priorities; 4) Provide a forum to discuss best practices for establishing and supporting sustainable collaborative partnerships between researchers and community-based organizations (CBOs).

The agenda included a brief presentation on health equity and health disparities to set the stage for the day. That session was followed by a community member panel where panelists discussed their experiences with research as well as gave feedback on priority research topics and best practices for collaboration. Researchers and community partners shared lightning-round presentations on three current SD CFAR research projects and participated in a subsequent panel discussion to share key insights and what work still needs to be done. The day concluded with a 90-minute facilitated Community Wisdom and Vision session which provided an open forum for discussion on priority research topics, sharing ideas for addressing health disparities and promoting and fostering health equity, suggestions for addressing barriers, and recommendations for building meaningful partnerships.

The full-day event brought together 47 attendees (68 registrants) including researchers, service providers, healthcare professionals, and community members from the San Diego and Tijuana region to collaboratively identify priorities and advance a community-driven HIV research agenda. Participants engaged in vibrant, synergistic discussions around best practices for collaboration, identification of unmet needs and strategies to bridge disparities in research, and ideas to support building capacity in communities.

SD CFAR has developed two funding initiatives aimed at translating the community recommendations from the Community Town Hall into action. The first is a Community Research Kick Start grant, built from

a successful model previously established at SD CFAR, which is tailored to support workshops, planning meetings, symposia, or similar endeavors aimed at advancing the scientific recommendations put forth during the Town Hall event. Additionally, a call for larger-scale Developmental grants designed to directly address recommendations from the Town Hall will be issued in Fall 2024.

Key Findings and Recommendations

- **Engagement in HIV research has been a tool of empowerment for many living with or impacted by HIV.** Participation in research can provide key insights into personal health status, access to resources, and education that benefits the individual and the wider community.

- **Approach to HIV research and care should be whole-body focused and address issues such as aging, comorbidities, and the unique needs of the target population.**

- **Many persistent barriers to care and research participation remain unchanged, including childcare, access to transportation, geographic locations of care/research facilities, and the overall time-intensive nature of engaging in care/research.**

- **Fair compensation for participation in research is key.** Partner with the community to determine what compensation is most meaningful and in what form it should come. Compensation should consider more than just the time it takes to engage in the specific research activity.

- **There is a significant need for resources, care, and research access in rural communities and the South Bay and East County areas of San Diego near the border of Mexico.**

- **A Spanish-language centered community forum is essential to engaging the communities in the South Bay, and East County, and border regions of San Diego.**

- **There is enthusiasm for establishing an interdisciplinary network of local HIV research, service, and healthcare-oriented organizations.** A quarterly meeting of this network will improve collaboration and resource sharing with the aim of achieving optimal outcomes for individuals living with and affected by HIV in the San Diego region.

- **Report back to participants/communities engaged in the research in a timely manner.** It was shared that this step is often missed. Permission to follow up with study results should be integrated into the Informed Consent. Share preliminary findings/results with participants at the earliest feasible opportunity. Waiting for the full peer review process can delay meaningful implementation in impacted communities.

- **Researchers should engage community-based organizations (CBOs) early and in the project development stage.** Early engagement is key for success, as needs and methods for a particular community/CBO may not be congruent with what was outlined in the grant. Enlisting a CBO after funding has been awarded is not optimal, as community and organizational needs are often not adequately factored into existing projects.

- **Build capacity for serving migrant communities, particularly for Haitian immigrants and providing resources in Haitian-Creole.**

- **Establish resources to better enable the community and CBOs to approach researchers with ideas and to share opportunities for collaboration.**

- **Employ Language Justice principles by taking care to properly translate materials and not rely on automated internet tools.**

- **Invest resources and create mentorship opportunities to build a diverse pool of investigators, study coordinators, and a new pipeline of leaders.**

- **Researchers and study facilitators should focus on forming relationships and have a consistent, physical presence in recruitment efforts and implementation.**

- **Research opportunities should be expanded outside of central San Diego**. Impacted communities that are geographically distant or rural (e.g., South Bay, Campo, Boulevard) do not have equitable access to participate in research.

- **Research opportunities and care should be offered outside standard business hours to improve access to individuals with work and family commitments.**

Additional Summary Notes

What is Health Equity?

- HIV disparities exist whereby people of different races and ethnicities, age groups, and sexual and gender minority groups experience poorer HIV prevention and treatment outcomes, for example, differential access to HIV testing, treatment, and care.
- Some of the populations that are disproportionately affected by HIV include youth or young people, Black and Latinx women and men, incarcerated people, transgender women, people who inject drugs, and sexual minority men, among others.
- Equity is not the same as equality. Those with the greatest needs and fewest resources require more, not equal, effort and resources to equalize opportunities.
- Health equity:
    - Means that everyone has a fair and just opportunity to be as healthy as possible.
    - Means removing social and economic obstacles to health, such as poverty and discrimination.
    - Is the ethical and human rights principle that motivates people to eliminate disparities in health and in the determinants of health that adversely affect excluded or marginalized groups.

Community Panel: Identifying Health Priorities

- Personal experiences with HIV research / role that research plays in your community:
    - Vital – engaging in research taught participant much more about HIV than they previously knew. Researchers were able to answer questions and the participant took this knowledge back to their family and community.
    - Provides a space for learning and supported self-empowerment.
    - Impression changed over time. At first, research opportunities and new medications only seemed accessible to wealthy white men.
- Research topics needed in your community / related barriers and challenges:
    - The trans community has a lot of access to information about HIV, "we get it!" – but there is a need for research on trans people and family planning. "Plenty of trans people are having families, but where is the research?"
    - Family planning/reproductive health spaces with signs that say "Women's Clinic" are not welcoming to the trans community.
    - Consistent messaging that HIV affects gay men and women – but trans men are often left out of that messaging and conversation.
    - Research opportunities for people 55 and older – in particular, 65 and older.
        - Research engagement provided key insights on personal health and information on how well medications were working. Research opportunities seem few and far between at 55 and non-existent at <65. No longer has the personal health information that was previously available and this has had a significant impact on the discussant.
    - Co-morbidities related to HIV. For example, HIV and stroke.

- o Stigma is a major concern.
  - ▪ Several attendees noted that they are not out to their families or community even though they are otherwise engaged in groups for those living with or impacted by HIV or engage in activism/advocacy.
  - o Discrimination is a significant issue – cultural norms/expectations, race, gender identity, sexuality, sex workers, people who use substances, etc.
  - o Long-term survivors – what is the impact that the medications someone took 20+ years ago have had on their bodies?
  - o Research on the long-term benefits/impact of participating in research. Demonstrate how engaging in studies has a real impact on long-term health and longevity. For example, prove that there are beneficial impacts of peer navigation.
  - o Ask CBOs what they are doing well and how researchers can study it, repeat it, and demonstrate effectiveness through research.
- Best practices for collaborations between researchers and community:
  - o Engage the community before you have the grant in hand. Community should be involved early so they can inform the development of the aims and research plan, not down the line once they are needed for recruitment.
  - o Get input from the community on what recruitment flyers should look like.
  - o Tailor incentives to the community engaged in the research - $25 Amazon gift cards don't effectively incentivize participation anymore. Example: wig giveaway.
  - o Huge bonus if facilitators look like the community they are trying to reach.
  - o Work with community leaders and key opinion leaders who have their fingers on the pulse of their community and what is needed, best ways to engage people in research, etc.
  - o Researchers should focus on forming relationships. The same person should be showing up at community events for recruitment. Form the relationship, establish trust. Seeing the same person bridges barriers to engagement. "I don't want to know a flyer. I want to know people." Be consistent, keep showing up. "Don't hide in the tower. Be consistent. Be personable."
  - o Researchers should have a physical presence to improve engagement. There are many barriers that can impact someone taking action from a flyer. "People do see the flyers but a lot of times decide to not be involved because they have to make a call, don't want to disclose all this information on a website or on the phone."
  - o Research opportunities are too focused in central San Diego – in particular, Hillcrest and La Jolla. Impacted communities that are geographically distant or rural (e.g., South Bay, Campo, Boulevard) do not have equitable access to participate in research. Coming in to central San Diego for an appointment can consume an entire day, and those reliant on public transportation are further impacted.

SD CFAR Science Spotlights – Community Perspectives

- People need to feel connected to their providers to stay engaged in care.
- Mental health and substance use are still major barriers to care.
- Peers are important –evidence-based research about peer impact is needed to further inform research.
- Researcher and CBO working on the project from the start (at grant development stage) was a key to success in the PATH study.
- CBO noted that participating in a research project helped benefit their center from the start. They didn't need to wait for research results to see the impact. The project provided professional development for staff and peers, so everyone had new knowledge and the organization learned important information for future peer programs.
- Trans Health project: Collaboratively learned that more trans leadership and trans voices needed to be there from the very beginning and throughout - not just as a sounding board but fully

integrated.

- Fair compensation is key. Partner with community to determine what compensation is most meaningful and what form should it come. Compensation should consider more than just the time it takes to take the survey, etc. For example, "$50 seemed fair but then in practice, it was not fair. People miss income generating opportunities to engage in a 30-minute survey."
- Important to consider sustainability and scalability when implementing a project with a CBO. For example, if a peer training program takes three weeks, every time there is turnover or a new peer brought on, they have to undergo that three-week training. It is one thing for a research study, but not feasible outside of this context or sustainable for a clinic to maintain this model. Consider the long-term impact that initiatives may have on CBOs.

Community Wisdom and Vision

- Education, resources, and research are needed on those impacted by the criminal justice system. Linkage programs are often programmatic and not necessarily designed to be sustainable.
  - Peter Davidson at UC San Diego is doing a study out of Los Angeles County jails looking at naloxone and how it is being distributed in their communities.
  - The California HIV Research Program (CHRP) has a funding mechanism focused on economic justice to evaluate universal income for people living with HIV.
- Status of research on unintended consequences of exposure to early HIV medications? For example, children exposed to AZT in utero.
  - The UC San Diego Mother, Child, & Adolescent HIV Program (MCAP) has ongoing, long-term (20+ years) research studies looking into this general area.
- Aging and HIV:
  - "One of the challenges about aging with HIV is it's not just about HIV anymore. It's one pill out of 15 a day. It's a whole-body problem."
  - Maile Karris currently has a study focused on women, whole-body approach (WE RISE)
  - Advocacy is needed in this area – keep talking about the need for more research on aging and HIV.
  - The AIDS Clinical Trial Group (ACTG) has a study on mental health associated outcomes of living with HIV (A5402).
- The NIH Office of AIDS Research has sought input on their [Strategic Plan for HIV and HIV-Related Research](#). The window for input closed on March 28, 2024.
- Need for way for local organizations to regularly connect about priority research topics, funding opportunities, programs, etc.
  - Gilead previously coordinated a program with local organizations and providers but can no longer host. Could potentially support in some way but not host.
  - Quarterly? Ideally, structure could be such that it isn't just another thing on the calendar competing with other priorities.
- Transportation is a significant barrier to engagement in care and research. There used to be a van that picked people up for appointments but there is no longer funding.
- There are 20 seats open on the San Diego County HIV Planning Group and they are looking for new members.
- A representative from The LGBT Center offered resources for sharing flyers and potential meeting space.
- Suggestion to send consumers to conferences and meetings by supporting travel and associated costs.
- Childcare and family-oriented spaces are key for research engagement. For example, offer a space away from children for blood draws, etc.
- Evening care and research opportunities are needed. Share this feedback widely.
- There is a need to provide resources and support for migrants, including migrants from Haiti and build capacity for providing care/materials in Haitian-Creole.