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Assembling the Will and Heart of Communities

Are You A SexPro?

Maputo HIV Vaccine Awareness Day 2019 Event
Welcome to the newest edition of the HIV Vaccine Trials Network (HVTN) Community Compass.

In this issue, we showcase some of the amazing and committed members of our family who work hard to support community engagement, administrative operations, and clinical trial operations. We also introduce a groundbreaking new phase 3 HIV vaccine study that will test a candidate HIV vaccine regimen in several countries on multiple continents around the world.

Please help us ensure that this publication is representative of our entire global HVTN community! HVTN members (who have access to the HVTN member’s website) can use our submission page that offers the ability to submit content and articles for inclusion in future issues. More information about this follows on page 04 under the “Meet the Community Compass Team” section.

Thank you for your continued support of the HVTN wherever you are in the world, for the work that you do in whatever role you have in the HVTN community, and for the impact we have been able to make in our collective history and communities, together. Though we have come very far in response to the HIV epidemic, we have so much further to go to achieve an effective global HIV vaccine. The HVTN Community Compass team wants to be everywhere you are, so please share with us what’s happening at your research sites, institutions, and in your communities, so that we can share it with the world.

Be well,

Stephaun E. Wallace
Stephaun E. Wallace, Ph.D.
Editor-in-Chief, HVTN Community Compass
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Our vision is an informed HVTN community that is aware of current events and activities relating to the HVTN network and its sites, advances in the field of HIV prevention and vaccination, as well as community priorities. We work to accomplish this by providing relevant information and updates to promote awareness, understanding, and support for HIV prevention and HIV vaccines, reaching global communities invested in the response to the HIV epidemic.

We welcome submissions of articles on any topic for publication that is relevant to the HVTN community. Submissions must be exclusive to us, and not appear in any other publication. Submissions must be 500 words or less to comply with our layout and design requirements. Due to space limitations, we may need to hold publishing your article for a future issue.

To submit articles for Community Compass, please go to the HVTN Members Site homepage, click on “About”, then click “Community Compass”, then click on “Submit to Community Compass”.
Spotlight

By: Aziel Gangerdine, HVTN Core, Seattle, WA, USA

Walking into Dr. Stephaun Wallace’s office I am greeted by the clatter of his computer’s keyboard. The air is cool and complements his personality. This all too familiar experience has become the introduction to our often-unscheduled meetings to talk about Mosaico, also known as HVTN 706/HPX3002.

Mosaico, he explains, is currently the only Phase 3 HIV vaccine efficacy clinical trial happening in the world. It will test an investigational vaccine regimen at more than 50 trial sites in the U.S., Mexico, Peru, Brazil, Argentina, Poland, Italy, and Spain. Wallace, the Social and Behavioral Sciences Junior Investigator Liaison at the HIV Vaccine Trials Network (HVTN), then delves into why the success of Mosaico pivots on steadfast community engagement. Our discussion is focused and structured by an informal question and answer dialogue.

“In the HVTN, meaningfully engaging and involving communities is not a theoretical concept, but a routine practice”, says Wallace. “We center the voices and perspectives of communities in our studies.” The HVTN, since its inception in 1999, has conducted over 80 clinical trials involving over 22,000 study participants in 13 countries. The network currently coordinates two large-scale HIV vaccine efficacy clinical trials in sub-Saharan Africa (HVTN 702 and HVTN 705/HPX2008), and the two Antibody Mediated Prevention (AMP) studies to test whether a broadly neutralizing antibody (bnAb) called VRC01 can prevent HIV infection. Mosaico, now the fifth efficacy trial, will bolster the HVTN’s relentless scientific pursuit for a safe and globally effective preventive HIV vaccine.

The epidemic has surpassed its third decade unabated, and continues to impact global communities. Despite major breakthroughs in HIV prevention and treatment, there are an estimated 5,000 new HIV transmissions around the world every day. Gay men and other men who have sex with men accounted for an estimated 17% of new HIV infections globally in 2018. The statistics are astounding, yet not nearly as sobering as the awareness that each number represents a personal story and an account of how HIV impacts individuals, their families and communities.

Our dialogue warms the cool office air when brassy-voiced Wallace describes what makes the HVTN’s community engagement program (CEP) an “elixir” to keeping global communities engaged, involved in, and committed to the scientific pursuit. The network has a global footprint evaluating investigational HIV vaccines in key populations ranging from young heterosexual women in southern Africa to transgender persons and MSM in the Americas. Through its Social and Behavioral Sciences and Community Engagement Unit (SBS/CEU), the team implements its CEP to adequately prepare each site for a trial such as Mosaico. The legacy of the HVTN’s CEP transcends nearly two decades of conducting clinical trials.

Mosaico study teams will recruit, screen and, if study participants are eligible and willing to participate, enroll 3,800 HIV-negative at-risk cisgender men and transgender people who have sex with cisgender men and/or transgender people. An awareness...
of the social, behavioral, economic and political drivers of HIV transmission in each local community helps study teams to understand why transgender women in the US may have up to a 49 times greater burden of HIV than the general population, for example. Being mindful of those drivers engenders robust engagement between the local study teams and potential study participants in their communities.

The Mosaico protocol team includes three Community Educator/Recruiter representatives and two Community Advisory Board members, which is a standard practice in the HVTN. “Community members serve in key roles to inform our scientific agenda, support protocol development and implementation, and are involved in dissemination of results activities,” Wallace elaborates.

The SBS/CEU conducts training with participating sites on community education and recruitment to enhance the skills and tactics study teams employ to encourage community involvement in the study. Teams at trial sites educate communities about the study, the broader HIV prevention landscape, and HIV vaccine science, paving the way for study participants and communities to be involved and meaningfully participate in Mosaico. Community engagement and outreach activities are critical, and underscore how the local study teams gain an intimate understanding of the structural and social drivers of HIV in their communities.

Throughout the day I find myself pondering the meaning and value of what Wallace shared. Mosaico will evaluate an investigational vaccine based on “mosaic” immunogens—vaccine components made from elements from multiple strains of HIV—that aim to induce immune responses against the wide variety of global HIV strains, resulting in a globally effective vaccine.

The trial is itself a mosaic, an assembly of science coupled with the heart and will of the diverse communities from around the world who will make Mosaico possible. To safeguard future generations from the transmission of HIV: therein lies the promise of such an assembly.

Aziel Gangerdine is the Director of Communications for the HVTN based in Seattle, WA.

Mosaico is a clinical trial supported by a public-private partnership that includes the HVTN, Janssen Vaccines and Prevention BV, part of the Janssen Pharmaceutical Companies of Johnson & Johnson; the National Institutes of Allergy and Infectious Diseases (NIAID), a division of the National Institute of Health (NIH); and The US Army Medical Research and Development Command (USAMRDC).
On May 18th, we celebrated HIV Vaccine Awareness Day, and our site, Centro de Investigação e Treino em Saúde da Polana Caniço (CISPOC), organized a health fair. This event took place in a peripheral neighborhood in Maputo Province and disseminated education information and encouraged good health practices in the community. We promoted our research site CISPOC to the communities in that region of the Maputo province. During this event, lectures on HIV Vaccine research and HIV testing took place. CISPOC and invited stakeholders also performed aerobic exercises, blood glucose tests, blood pressure measurements, body mass index, breast cancer tests, and blood donations. Award-winning games and quizzes were held where participants were asked to answer questions about HIV vaccine research topics. Information leaflets, t-shirts, and other gifts branded with HIV vaccine research were distributed.

Khelvon Leonel Jose De Araujo is a Community Educator with the CISPOC CRS in Maputo, Mozambique.
Salomão Bila (CAB Member) enjoying the health fair activities, May 2019

Joaquim Macucua (CISPOC Interviewer) (right, standing); Odete Bule (CISPOC Clinical Coordinator) (right, seated); a local reporter from a national broadcast television (left, standing); a community participant getting a blood pressure test (left, seated), May 2019

Joana Macucule (CAB Member) (left, middle), along with community members attending the health fair enjoying the activities, May 2019

Blood Bank of Maputo City Staff (left seated, and standing); a community member donating blood (right, seated), May 2019

Dr. Edna Viegas (CISPOC CRS Director) being interviewed by local reporters, May 2019

Salomão Bila (CAB Member) enjoying the health fair activities, May 2019
Are you a “SexPro”? AT YOUR FINGERTIPS – INFORMED SEXUAL HEALTH PRACTICES

By: Aziel Gangerdine, HVTN Core, Seattle, WA, USA

The Personalized Sexual Health Promotion HIV Risk Prediction Model, known as SexPro, is a first of its kind and when used by physicians and men who have sex with men (MSM), predicts a person’s risk of HIV infection based on answering a few questions about sexual behavior and substance use. SexPro is a valuable tool to help MSM and providers target HIV prevention interventions such as Pre-Exposure Prophylaxis (PrEP).

To create SexPro, the creators used data from four large studies of MSM to develop and validate the tool, with the most recent study ending in 2013. SexPro was developed for use in clinical and non-clinical settings to determine HIV risk in MSM via a study called EXPLORE.

“We set out to develop an easy to use, data-driven tool that supported more accurate risk assessment,” said Dr. Hyman Scott, Bridge HIV (San Francisco) site investigator and HVTN RAMP Scholar Mentor. Via the EXPLORE study, the researchers “…developed and validated an HIV risk assessment tool for MSM, which showed good predictive ability, including among the largest cohort of HIV-uninfected Black MSM in the US.” (Scott et al., 2018)

Current HIV risk assessment tools historically used data from White MSM, without representation of Black and Latino MSM. Because of this, there was concern that the current tools may underestimate risk for Black and Latino MSM, and thus people from these racial and ethnic groups are less likely to receive recommendations for HIV prevention interventions.

“The increased HIV risk among Black and Latino MSM occurs despite similar or lower HIV risk behaviors compared with other groups. This is likely driven by social, structural, and sexual network factors experienced by Black and Latino MSM”, says Dr. Scott.

A granular examination by the study (Scott et al, 2018) revealed that social (higher prevalence among sexual networks) and structural (incarceration policies, poverty, etc.) factors that affect Black and Latino MSM in the US disproportionately impact their risk of HIV. The need to develop a model for risk assessment that accounts for race and ethnicity cannot be overstated given the racial and ethnic disparities in HIV risk in the United States. The lifetime risk for acquiring HIV among Black and Latino MSM in the US is 1 in 2 and 1 in 4, respectively.

“EXPLORE showed underserved populations wanted a self-directed tool”, said Wakefield, HVTN Director of External Relations and EXPLORE study team member.

A CDC survey approximated that one-third of MSM who had never been tested for HIV reported low perceived HIV risk as the reason for not being tested for HIV. On the contrary, 56% of the men reported having more than two male sex partners in the past 12 months, and 37% reported condomless anal intercourse. The CDC’s observation of low perceived risk for HIV acquisition was reinforced by the Young Men’s Study showing that nearly 75% of participants perceived themselves at low risk for HIV, despite 32% reporting four or more partners in the prior 6 months, and 21% having been diagnosed with a recent sexually transmitted infection.

SexPro is easily accessible via www.mysexpro.org and takes into account the recent findings about U=U (undetectable=untransmittable). It adjusts the risk associated with having sex with a virally suppressed HIV-positive partner to be equal to that of having an HIV-negative partner, the only risk tool to currently do so.

Aziel Gangerdine is the Director of Communications for the HVTN and is based in Seattle, Washington, USA.
Hyman Scott (left) and Nicole Walker (right) from Bridge HIV discuss the benefits of using SexPro as a screening tool in a health care setting. Scott and Walker are clinic staff members at Bridge HIV where they screen potential study participants for HIV prevention clinical trials.

More information:
- Development and validation of the Personalized Sexual Health Promotion (SexPro) HIV Risk Prediction Model for Men Who Have Sex with Men in the United States
New SBS-CEU Staff at HVTN Core

The HIV Vaccine Trials Network Social and Behavioral Sciences and Community Engagement Unit would like to welcome two new amazing team members who have joined in order to support the MOSAICO Study globally. Both of these dedicated professionals bring a wealth of experience, resources, and connections to various stakeholders, and we are fortunate to have them with us.

Patricia Segura

Patricia Segura has officially joined the HVTN SBS/CEU team and her first official day was August 1. She is a Community Engagement Project Manager who will be focused on the Mosaico Study. Patricia is based in Lima, Peru and will manage the HVTN Community Engagement Program for sites in Mexico and Peru.

Patricia joins our team with a wealth of experience in community engagement, health education, and nursing that spans about 30 years. She was previously at the IMPACTA CTU in Lima, Peru as the Head of Community Involvement (a role currently occupied by Rosario Leon), and just recently served as the Director of the HIV/STD National Program with the Peruvian Ministry of Health. She earned a Bachelor of Nursing degree from Universidad Nacional del Callao in 1988, and an MPH from University of Washington in 2004. She is excited to join the team in this capacity and looks forward to meeting those she has not met, and reconnecting with those she has.

Patricia can be reached via email at: psegura@fredhutch.org.

Patricia Segura, RN, MPH, HVTN Community Engagement Project Manager
Please give an HVTN welcome to Giulio Corbelli who is the newest Community Engagement Project Manager who will be based in Roma, Italy, who started on September 1st. As the newest member of the Social and Behavioral Sciences/Community Engagement Unit, Giulio will be primarily focused on implementing the HVTN Community Engagement program in Italy, Poland, and Spain for the MOSAICO Study.

Giulio also joins our team with a wealth of experience. He has more than a decade of experience in HIV work, and has additional professional experiences in journalism, theater/film-making, and has been involved with the European AIDS Treatment Group (EATG) as a project advisor and member of their clinical trial management committee, among other roles. Giulio has strong community and research roots in Italy, and established relationships with key stakeholders in other areas of Europe. He earned a Masters Degree in Civil Engineering from the University of Pisa.

Giulio can be reached via email at: gcorbelli@fredhutch.org.

For more information about the MOSAICO Study’s community engagement efforts, please reach out to Stephau Wallace, PhD, HVTN Social and Behavioral Sciences Junior Investigator Liaison via email at: sewallac@fredhutch.org.
UPCOMING EVENTS/CONFERENCES/MEETINGS

1 DECEMBER 2019
World AIDS Day

16-19 JANUARY 2020
16th Annual National African American MSM Leadership Conference
Atlanta, GA, USA
www.naesm.org

24-25 FEBRUARY 2020
13th World Congress on Virology and Infectious Diseases
Tokyo, Japan
https://virology.conferenceseries.com/asiapacific/

26-28, FEBRUARY 2020
2020 HVTN Sub-Saharan Africa Regional Meeting
Cape Town, South Africa
http://www.HVTN.org/

8-11 MARCH 2020
27th Conference on Retroviruses and Opportunistic Infections (CROI)
Boston, MA, USA
http://www.croiconference.org/

27-29 MAY 2020
2020 HVTN Full Group Meeting
Washington, DC, USA
http://www.HVTN.org/

30 MAY – 3 JUNE 2020
2020 HPTN Annual Meeting
Washington, DC, USA
http://www.HPTN.org/

8-12 JUNE 2020
2020 IMPAACT Annual Meeting
Washington, DC, USA
https://impaactnetwork.org/

15-21 JUNE 2020
2020 ACTG Annual Meeting
Washington, DC, USA
https://actgnetwork.org/

5-7 JULY 2020
HIV2020
Mexico City, Mexico
https://www.hiv2020.org/

6-10 JULY 2020
23rd International AIDS Conference (AIDS2020)
San Francisco/Oakland, CA, USA
https://www.aids2020.org/

10-13 OCTOBER 2020
2020 US Conference on AIDS
San Juan, Puerto Rico

11-15 OCTOBER 2020
4th HIV Research for Prevention (HIVR4P)
Cape Town, South Africa
http://hivr4p.org/
JOIN US IN THE FIGHT AGAINST HIV

MOSAICO
A JOURNEY TOWARDS A GLOBAL HIV VACCINE
Dr. Thompson is an Assistant Professor of Pediatric Infectious Diseases at Duke University School of Medicine and a member of the Duke Human Vaccine Institute. She received her BA from Colgate University, followed by an MD and MPH in Global Health from Mount Sinai School of Medicine. She then completed her Pediatrics residency and Pediatric Infectious Diseases fellowship at Emory University School of Medicine/Children’s Healthcare of Atlanta.

She first developed an interest in HIV during university when she completed a course entitled “Critical Analysis of Health Issues: AIDS,” which afforded her the opportunity to explore not only the science of HIV, but the social, political and economic impacts of HIV/ AIDS in her home country, Jamaica. She currently practices as a Pediatric Infectious Diseases specialist. In this role, she diagnoses and manages infectious diseases in children, adolescents and young adults with a particular focus on HIV and co-infections, such as human papillomavirus.

She is a protocol co-chair for HVTN 135, and part of the product development team representing the Duke Human Vaccine Institute on various protocols and concepts including HVTN 115. She is also a member of the HVTN Social Behavior Working Group and is currently mentoring a RAMP scholar in a project entitled “Adolescent HIV vaccine clinical trial acceptability and feasibility in North Carolina”. Since she became involved with the HVTN as a junior investigator, she has been most energized and excited by the collaborative nature of the network’s members in the shared mission of finding a safe and effective HIV vaccine. She also loves that she always has good company on the dance floor at the annual Full Group meetings!

I entered the field of HIV prevention research though a non-conventional route. As Vice President of a for-profit Employees Assistant Program (EAP) and managed care company, I had the unique opportunity to consult with senior executives and Human Resource staff to develop policies and procedures regarding employees living with HIV. Beginning in 1994, I joined the University of Pennsylvania HIV Prevention Research Division and served as Project Director for HIVNET (HIV Network). I was tasked to focus on injection drug users and women at risk for HIV due to their drug use and sexual practices. We soon became a HPTN site, and as Project Director I oversaw a High Risk Injection Drug User trial, Women Fighting HIV Intervention trial, and the HPTN 037 Injection Drug Users Network trial conducted in Philadelphia and Chiang Mai, Thailand. We subsequently became an HVTN site.

Since 2007, it has been my privilege to serve as the Coordinator for Community Engagement: Recruitment & Community Education for the UPenn HIV CTU. I have worked with our computer programmer to design databases to track recruitment and enrollment, resulting in the development of innovative tools to match recruitment venues to enrollment success in trials (Phase I and efficacy trials).

As a member of the HANC Legacy Project and the Women’s HIV Research Collaborative, the HVTN Efficacy Trials Working Group and the HVTN Social Behavioral Working Group, I am an innovative voice and bridge between the CER Working Group and these committees.
When I began in 1998, discrimination was very high, and the HIV/AIDS pandemic had a great impact on our community. Many friends, and acquaintances died, abandoned, without treatment. Many of them went to the shelter “Something Beautiful for God” for medical and human service attention, but the needs could not be covered, so this was motivation to help friends and get involved. Erick, affectionately known as “Guada” (Erick goes by he/him or she/her) began to work in different efforts, as a small and visible representative within the community.

In 2003, Erick along with others decided to form an alternate organization called, “Homosexual Community Esperanza Region Loreto” (CHERL), and, “...during these times, you could not dress as a woman because of discrimination and hatred, including thrown stones and homophobia and stigmatization. It was believed that we (LGBT people) were all carriers of AIDS. Before that we armed ourselves with courage to defend our rights, defend human rights, and have a political and social impact on our community,” says Erick. This commitment led her to volunteer for the research work carried out in Iquitos by the Asociación Civil Selva Amazónica y HVTN. Erick adds, “We won spaces at the cost of effort and courage; some media even invited us to introduce ourselves as weird beings or mocked us, but with perseverance and good arguments we won little by little the respect of the community”. The work and perseverance has resulted in progress however, “...now we are invited to universities, we are interviewed, including the Technical School of Police. Those who chased us before now invite us to give conferences with the police students. Erick Murayari, with his experience and perseverance, is now a member of the Community Advisory Committee of the ACSA CRS, where his contributions are valued and appreciated. “We follow the efforts into a vaccine for HIV prevention, this is very important. Unfortunately the pandemic is maintained and the face of HIV is getting younger. Now the population in general is involved and we will continue in the effort because I am convinced that with the organization and work we will overcome barriers, overcome difficulties and work for a better world and future for all.”

Dr. Fatima Laher is a medical doctor, director of the Soweto-Bara Vaccines Research Centre, and co-chair of HVTN 100, 702, 120, the HVTN Protocol Committee, and the HVTN Training and Education Committee. Dr. Laher, the recipient of a Young Physician Leader award from the Inter Academy Medical Panel in 2012, recently spoke at a Young Women in Science event. With a focus on advising young people how to map their scientific careers, Dr. Laher asked attendees to consider how to address the current systemic imbalances in South African communities affecting women in the workplace. These disparities include leadership roles (more than two-thirds of leaders in South Africa are male), pay gaps (on average men earn more than women despite working fewer hours), and unpaid work (in which women bear the brunt of family/home duties and so-called office housework). Speaking out against the discrimination that young women experience in the health sector, she said, “The health sector needs men and also women: women as healers; women as advocates to speak for our own bodies; women to innovate solutions for health issues; women to lead. Science shows that gender roles are conditioned into us; they are not natural. Be strategic and infuse your life with action. Make your way in the scientific world; change the ground around you, and it will continue to change things for the next wave of women. We are the daughters of thunder.”
Meet D’Jamel Young, Army Veteran, Trans* Community Leader/Activist/Advocate, founder of Trans8tion, The TMSM View, and #iamMSM2 movement. D’Jamel is a driven and outspoken “man of Trans* experience,” also known as a transman, who has deep compassion and passion for serving his under-represented Trans* and gender non-conforming (GNC) community.

D’Jamel’s mission is to reach, educate, empower and assist his underserved community, which is a population at high risk for HIV/AIDS and other health disparities, as well as high numbers of people living with HIV. By providing and/or referring people to comprehensive support services, D’Jamel strives to assist people in taking control of their lives and making sound health decisions. His goal is to contribute to the ultimate eradication of the HIV virus.

For over 10 years as a peer educator, D’Jamel has built his list of community affiliations and community engagements. He is currently a Member Leader for Trans(forming), an intergenerational membership-based organization in metropolitan Atlanta, led by and for trans*, intersex, and gender non-conforming people of color, who were assigned female at birth (AFAB). He assists with providing services like providing assistance with and payment for name changes and document change projects, passport assistance, facilitation of support groups, connections to doctors and other medical professionals, the prison project, as well connecting people with leadership and volunteer opportunities. In addition, D’Jamel is an Atlanta Community Advisory Board (CAB) member at an HVTN site, and has numerous affiliations with allied community-based organizations along the east coast of the US. He has also teamed up with agencies, such as Fulton County Health Department, in efforts to initiate conversations around the sexual health risks and needs of men of trans* experience.

D’Jamel’s work as a committed advocate has expanded and ventured off into a more social approach to support. In 2015, he launched www.Trans8tion.us, a social-mingle, online community for trans*-identified individuals to search, meet and engage other trans* individuals, and also their Lesbian, Gay, Bisexual & Straight Identified (cisgender) Admirers. Trans8tion’s mission is to provide the LGBT community a judgement-free space, and freedom to express, explore and redefine self-identified sexualities and attractions with a sex-positive attitude. Trans8tion promotes the message of embracing gender identity and sexual identity as two completely separate expressions, and that both can be quite fluid. (Gender identity is how one perceives and presents themselves, while sexuality is one’s sexual preferences). Trans8tion is currently in preparation for phase 2, as D’Jamel is planning and raising money to launch a new and revamped Trans8tion program.

In addition to promoting understanding of sexual fluidity, D’Jamel expresses the significance of addressing and stressing the importance of good health and wellness, sexual risk factors, health needs, and available services within the LGBT community. While the trans* community is continuously and disproportionately affected by the HIV epidemic, AFAB individuals in particular tend to be dismissed and are excluded from most conversations, services and care pertaining to HIV prevention and treatment. As an openly bisexual transman, D’Jamel aspires to lead the conversations to build understanding that sexual identity, desire, and behavior among transmen who have sex with men (TMSM) have the same risk factors as MSM (Men who have Sex with Men). Birthed from the acronym MSM, #iamMSM2 is a hashtag movement that D’Jamel has created to promote inclusion of gay and bisexual transmen’s sexual and health needs. This hashtag describes the large number of transmen (also including those individuals who identify as gender non-conforming) who have sex with men. These men have the same sexual and health risk factors as cisgender MSM, but are often left out of the HIV care and prevention conversation. The MSM demographic continues to be the risk group most severely affected by HIV in the United States. D’Jamel says, “If transmen are a part of the
gay and bisexual community, then there is no question why there is an urgent need to expand access to comprehensive HIV care and proven prevention programs for gay and bisexual transmen.” #iamMSM2’s mission is to raise awareness among the CDC, state and federal agencies, CBOs and LGBTQ communities in efforts to educate, support, encourage, and expand access to HIV prevention programs for gay and bisexual transmen. As a continuing effort to support and raise awareness of the sexual and health needs of gay and bisexual transmen, D’Jamel has also created a support group called “The TMSM View”, where gay and bisexual transmen, and other gender non-conforming individuals, are celebrated and offered a safe, judgement-free space to share, confide, and consult with other guys of similar gay and/or bisexual experiences.

All of D’Jamel’s work is inspired by the community he lives in. He has a strong passion to scream for the voiceless and illuminate for the invisible. The trans* and gender non-conforming communities are sadly under-represented and underserved. D’Jamel states, “As fluid as sexuality is, so is the rapid spread of diseases that everyone is equally prone to.” These challenges and disparities are very prominent in his world and in his community. D’Jamel is a firm believer that you should “Be the change you want to see!”

Editors note: The use of an asterisk with the word trans (trans*) comes from the world of computers, where an asterisk is used to indicate “all.” Trans* can be used to refer to people of all transgender and gender non-conforming identities.

Felipe Vilcachagua
Retention Coordinator/Health Navigator, IMPACTA Barranco CRS, Lima, Peru

Since my second year as psychology student, I became involved in educational projects on HIV prevention with adolescents. In 2017, as soon as I finished my studies, I started working with one of the NGOs that was responsible for the implementation of Global Fund projects.

Working in clinical trials was not my first choice, but I was aware of the importance of new HIV prevention and treatment strategies, and that brought me back to IMPACTA Salud y Educación. Years before I had been a voluntary participant in an innovative needle-free vaccination project (CUTHIVAC) and in the PUMA study (Prevention Umbrella for MSM in the Americas) for HIV testing at home.

Since 2018, I have been part of the Community Involvement Unit at Impacta, as a tutor (health navigator) and Retention Coordinator responsible for prevention studies (including the AMP study) at the IMPACTA Barranco site.

What I like most is to facilitate the attention of our participants, and my biggest challenge is to see them satisfied in their participation. One thing I appreciate most about working with HVTN is the use of community education for the positive impact on the study populations. The fact that people can understand and practice HIV prevention in their life is very important. With their commitment, prevention has no limits.

In my free time I usually watch psychological animes, like Psycho Pass, where I like to analyze the tension between the individual’s decision and the social norm. A quote from Akane, the main character in Psycho Pass, that I always remember is, “It is not society which determines the future of people, it is the people who determine the future of society.”
My work on HIV began in the mid-90s. It was a time when HIV had reached the gay/trans community of Peru in a devastating and cruel way, taking the lives of dozens of friends in horrible ways. The life expectancy for a person with HIV was a few years because there was no antiretroviral treatment, there was not much information, and there was a lot of discrimination. This, together with the violence existing in the country toward our community, made it a period of dark and sad years. In ’96 I decided that I wanted to learn more about HIV because I was sure there should be something to tell people that could give them hope and faith. That’s how I discovered the world of scientific research. When I finished my degree in psychology, I decided to look for ways to transmit wellbeing to people. I worked for many years as a coordinator of recruitment, retention and community development, as well as counseling in HIV prevention and giving support to people living with HIV. I currently have my own organization called EPICENTRO, which is aimed at preventing HIV through culture, and I am a community educator at UNIDEC where we work in clinical trials. What moves and enthuses me to participate in the HVTN is the careful manner that its representatives have about what is related to the wellbeing of our community. From the use of a photo that makes everyone feel included, to the minute detail with which they review each clinical procedure, all this gives me hope that we can soon make a big change in the world.

Outside of my HVTN role, I spend my free time working to build LGBTQ+ community at Fred Hutch in partnership with our Office of Diversity and Inclusion. I also network with local scientists to encourage the development of new research focused on transgender health disparities. I hope to one day be a part of a research team that builds on the accomplishments of the HVTN to work with the trans community in authentic partnership, creating health outcomes FOR us and not about us.
I was introduced to HIV and the surrounding prevention work at an early age as a peer youth advocate for the MOCHA center, an organization focused on supporting LGBT youth of color in Rochester, NY. I learned about the devastating impact the disease was having on my community, and how community engagement activities are critical to providing education and tools to those who need it most.

When I first learned of my own HIV diagnosis in 2015, it lit a fire within me. I wanted to turn my diagnosis into something positive. In 2016, I joined the Community Education & Recruitment team, where it has been my mission to not only recruit new study volunteers but also educate people from all backgrounds about HIV prevention research.

Recently, I played an integral role in the University of Rochester Artist in Residence Project. This project aims to break the cycle of stigma surrounding HIV and to foster awareness through a series of watercolor portraits (of folks within our local HIV community), painted by our Artist in Residence. As part of the project, a short documentary was created about the process entitled, “Don’t Define Me”, where I shared my story of being an African American trans woman living with HIV.

Being a part of the HVTN feels like belonging to a big family of superheroes from different walks of life all around the world. From Africa to South America to cities all over the USA, we are all doing the hard work of engaging our communities toward a common goal. I’m proud to be a part of that.
In 1980, when I was 10, living in East New York, Brooklyn, the streets were riddled with heroin injection drug users and soon followed by the crack epidemic. My neighbors also included gay men. Some owned it, however many more preferred to keep their sexuality private. At that time, I witnessed the deterioration of people’s physiques, having fallen ill at the hands of what scientists discovered to be HIV years later. My neighbors were dropping like flies. No one knew why and few cared. There wasn’t much empathy toward drug users and “gays.”

Fast forward 20 years. I made a transition from corporate design to concentrating my studies in biology, phlebotomy, and medical assisting. A friend pointed me to an open position with a research project that was right up my alley, in that it focused on testing a risk-reduction tool among non-injection drug users and their sexual and drug-using networks whose sexual orientations were diverse. In summary, we learned that risk-behavior is challenging to decrease, especially over time, and that the MSM in the study were at higher risk than their heterosexual counterparts.

HIV vaccine research, to me, was a chance to contribute to my communities who were most at risk of getting HIV by exposing them to an intervention that could potentially prevent new infections with an injection (or 4). This is my driving force. The fact that the first drug, Truvada, used for PrEP to prevent HIV was discovered, along with HPV vaccines, gives me much hope that we will one day find an effective vaccine against HIV.

I would be remiss not to acknowledge that together, my family at the Columbia Research Unit, from the PI to me, all bust our butts to do the best we can while keeping ourselves in good spirits. This makes going to work a pleasure as we push forward with our scientific agenda.

Communication ideas and motivating others are two of my passions. After completing a Masters of Arts in Education at Tennessee State University, I immersed myself in Nashville’s health and fitness network. Building on this experience, I then joined the HIV Vaccine Trials Network (HVTN) team at Vanderbilt University Medical Center, bringing my joy and devotion to wellness education with a service-oriented outlook to this new opportunity I enjoy.

Education and empowerment are more than just words. These are critical tools essential to ending the HIV epidemic. Community conversations around sexual health have led to progress; however, there is still so much more work that needs to be done to address health disparities, HIV stigma and health literacy in the general population. Seeing advances in HIV research, specifically through the HVTN, is why I love working with the Network! It’s the people behind the research I find most inspiring. Everyone makes the work done at the HVTN possible and gives hope to those affected by HIV/AIDS.

The community educator role encompasses a wide range of educational topics on HIV/AIDS. Instead of contributing to the stigma, we assist in being part of the solution. Jim Watkins once said, “A river cuts through rock, not because of power, but because of its persistence.” Continued research is critical because it helps to resolve global inconsistencies in the health care system. Leaving an imprint on humanity is the greatest gift of all, and it’s why I look forward to many more years with the HVTN.
I grew up in Nairobi, Kenya, surrounded by medical researchers and academics, and at the age of 18 got my first experience working in clinical research. Coming into my own, fueled by my love for chemistry, and wanting to make a difference in people’s lives, I decided to study pharmacy. It was during my ‘gig’ doing data entry at 18 and later working as a hospital pharmacist that I first encountered the devastation caused by HIV; it was heart-breaking. I couldn’t believe that one day I’d be chatting with one of my patients, and the next day they’d be gone.

I knew from early on that I wanted to go the clinical research route after obtaining my B. Pharm. degree. I also quickly came to learn that my niche was in quality management of clinical research. I left pharmacy practice and was soon involved in numerous trials for TB (treatment studies), malaria (vaccine studies) and HIV (treatment, prevention, and vaccine studies) as a quality monitor (ah yes, I’ll admit that perhaps I have Obsessive Compulsive Disorder!). It was the exposure to monitoring NIH-funded HIV studies that brought me to the HVTN, where I support the Africa Programmes Director (Dr. Glenda Gray) in matters of clinical operations, particularly on 2 large trials - HVTN 702 and HVTN 705/HPX2008. It is humbling that I’m now involved in projects that could help prevent the devastation that HIV brings with it.

I love the fact that I work with very supportive colleagues (especially since my role is ever-evolving), whose common goal is to see the success of our vaccine trials.

Jackline Odhiambo
Project Manager, HVTN Core, Cape Town, South Africa

Around 2016 when I was working in corporate America doing logistics for a shipping company, I found myself working and living without a purpose. I would go to work and do my 9 to 5 but come home miserable and repeat the same patterns every day. HIV research became an area of interest to me when I attended my first Nashville AIDS Walk and met former Community Educator Vic Sorrell. We had a deep conversation that day about all the work that goes on in the community and throughout the world regarding HIV/AIDS. I became involved the following year and started working for the Vanderbilt HIV Vaccine Program, where I met a wonderful community of CAB members, nurses, physicians, activists, researchers, PLWHA and most importantly our study participants. I knew that my role would be more than just working in an office sitting and talking to patients, but getting to know these individuals and their stories. This work is not about me but for the greater good of humanity and finding resources to help end the epidemic. We must start educating and having more uncomfortable conversations with our peers as well as ourselves. What I love about working with the HVTN community is that you get to meet so many people who are willing to sacrifice their time and energy for a noble cause; these participants and community leaders genuinely care about the work and it shows. I truly feel that all of us have a mission while we are here on Earth. This mission can be identified as a charge and responsibility to pull the next generation up behind you.

Keith Richardson
Community Engagement Coordinator, Vanderbilt University CRS, Nashville, TN, USA
José Luis Castro Chuquillanqui
Community Educator, VIA LIBRE CRS, Lima, Perú

In the decade of the 90’s and the beginning of 2000, my life changed significantly, but I didn’t understand why. Little by little I was losing friends from my very close environment, victims of AIDS. An epidemic arrived in Peru without warning in 1983.

My life, and those of many of our generation, were dying or in mourning at every moment. We began to schedule constant visits to hospitals, homes, to see friends who were consumed by the terrible evil, which at that time was impossible to think of a treatment that could calm the anguish and pain that invaded us.

I remember clearly the constant meetings of friends, where the issue of AIDS was entering our conversations, but we were unable to do anything. I also remember the unexpected telephone calls announcing the death of a friend or acquaintance. I remember the wakes, funerals, masses and visits to cemeteries. I remember our cries, our helplessness, our anger, our despair, our life planning. I always remember Leo, Ronald, Carlos, Víctor, Raiza, Pedro, Paco, Jesús, Juan, and many other friends who died of AIDS complications.

In the face of such impotence, I felt the need to be able to do something that could make me feel good. I inquired, I searched, I asked; and that’s how I came to VIA LIBRE. In 2002 I joined the volunteer program that VIA LIBRE had. I had the opportunity to learn more about AIDS. I participated in various information campaigns. VIA LIBRE became my second home. It was the space from which I could feel relief, and be able to do something in the face of so much disinformation that existed at that time about AIDS.

Later, I was invited to participate in projects of political advocacy, prevention and human rights that VIA LIBRE implemented. I felt good, grateful, and satisfied to work on a topic that impacted me. I felt welcomed, and a feeling of being able to always help friends and the community about the new advances that had been taking place regarding HIV infection.

I went through other institutions, also working on HIV. It was the issue I had decided to work on, with no doubt. In 2015, VIA LIBRE summoned me and proposed I be part of the research center, in the position of Community Educator for the AMP study. A new challenge came into my life, which I assumed with a lot of commitment. Being in research allows me to have a more comprehensive view of the epidemic. Being involved means I can be a part of new alternatives in the prevention of HIV, I can contribute to science, I can have hope, and in some way, I can repay what I could not do at the time with the friends I lost.

In parallel, in 2014 I formed a community group in my area. Casa Diversa, an organization that brings together volunteers from LGTBI communities, works to make our sexual orientations and identities visible, and works with civil society and state organizations to expand access to social services and integral health care, with a focus on respect, inclusion and human rights.
After matriculation at age 18, I joined a community policing forum we call a "youth desk" at the local Moroka Police station. Then we were invited to attend a workshop by PHRU on education about HIV Research. It was in 2007 when we established the first Adolescent CAB for PHRU and that was the start of my passion for HIV research. From then on, we were educated on vaccines and a whole lot of other things about HIV research. That is how I learned about the HVTN and the work that it does and funds. Since then we have been going into our local communities and educating them about the HIV research, and I work as a recruiter for the pre-teen study introducing adolescents and teens to HIV research.

Dr. Kathy Mngadi qualified as a medical practitioner at the Nelson Mandela School of Medicine in 1987. While working in a communicable diseases outpatient clinic in Durban, following a personal bout of Tuberculosis, she first encountered HIV and referred confirmed TB cases for HIV testing through an NGO, in the days when only venous blood samples were drawn and results took two weeks to get back. At that time no treatment was available for HIV, and the havoc wreaked by the disease in those co-infected with TB prompted her to take on the role of Medical Director at a local hospice where she was pivotal in opening admissions to HIV-infected patients for respite, end-of-life care, and treatment of opportunistic infections. She worked in the first ART programme in South Africa at the Anglogold Orkney Hospital clinic, where she was first exposed to HIV treatment research through the Aurum Institute. She later joined in their own PEPFAR-funded ART programme and eventually in HIV and TB prevention and treatment research at the Klerksdorp site, working on HVTN 503 among other protocols. She joined CAPRISA in Durban 7 years later, implementing HVTN 100, 107, 108, 702, and 703, and also serves as co-chair of HVTN 107 and HVTN 705/HPX2008. She sits on the Scientific Governance Committee, Protocol Committee, and Efficacy Trials Working Group. She recently re-joined the Aurum team in May 2018 as a CRS leader and PI for HVTN 705/HPX2008 at the Tembisa-Clinic 4 site. She enjoys the sense of community in the HVTN, the effort to build capacity among local investigators, and the strong Community Engagement programme promoted within the HVTN. She is determined to contribute to the collaborative efforts to find a safe and effective HIV vaccine.

Though I studied for a diploma in journalism, I continued to work with PHRU and was later hired full time as a recruiter for HVTN vaccine studies in 2016. I have been working directly with HVTN since then, and I have to say I have learned a lot. I totally look forward to many more years with HVTN for the work that we do is incredible and very important. Meeting so many different people who teach you new and interesting things has been amazing, and the participants we recruit and build research relationships with has been bliss. Something personal that people may not know about me, is that I am strict and disciplined, and I was raised that way.

Khanyisile Khumalo
Recruiter/Counsellor,
PHRU, Soweto-Bara CRS,
Johannesburg, South Africa

Dr. Kathy Mngadi
Principal Investigator, Tembisa CRS,
Johannesburg, South Africa
I have been working in HIV prevention in the Gay & Trans communities for more than 20 years. I was trained in practice, in years where face to face communication was the most used method to do health education with my peers in different venues. Now the ways have evolved and social media is the way, generating key messages that are understandable and acceptable. Social networks and smart phone applications are “our new best friends” in prevention education; communication is spontaneous and direct, without detours.

When I was young, I worked at Germinal, a local NGO which promoted HIV prevention with educational-entertainment strategies in remote areas of the city. Years later I worked as a peer educator in the HIV/AIDS program of the Ministry of Health of Peru, where I met Dr. Jorge Sánchez.

Since 2001, I have been a member of the Impacta Community Involvement Unit - a versatile, creative, entertaining and intense area in all its processes – as recruiter, developing strategies for the information, education and involvement of potential participants for the various HIV prevention trials.

In 2016, we became very motivated to promote participation in the AMP study, exploring a new topic (antibodies and infusions), refining key concepts, and educating about HIV prevention strategies. One of the things I like the most about the network is that HVTN allows us to try strategies that have already proved to be effective in recruitment and retention, and also encourages us to try new ones. It’s all about Education and Entertainment to Prevent HIV.

“For any recruitment process to be successful, instilling the spirit of community ownership amongst the participants is an integral element”, says M’modzi as he prepares for one of his daily errands of engaging potential participants and communities in general. Pearson M’modzi, himself a recruiter, believes community engagement is central to any study. M’modzi has been working with the Lilongwe, Malawi CRS for the past 12 years, primarily focusing on engaging communities and stakeholders, and notes that increasing research literacy in the communities he works with is a passion of his. M’modzi notes that engaging communities should not only be during the time of recruitment – it should be in preparation, throughout the period of study and after. HVTN is very helpful whenever there is a study; the educational and giveaway materials make his work easier and exciting, especially with so many youth interested in HIV vaccine research in the region.

M’modzi holds a Bachelor of Science in Public Health as well as a Diploma in Community Development, and looks forward to start pursuing a Master’s degree. M’modzi first started working with HVTN in 2014 as the site was beginning HVTN 111, and is now involved in the AMP Study and HVTN 705. M’modzi states, “I enjoy doing this work with HVTN, learning so much from the team and my colleagues from the sites all over the world, especially knowing that we are doing all this for a common cause.”
As an undergraduate, I was a Minority Health and Health Disparities International Research Training fellow, working in South Africa to examine the potential effects of diseases spreading between wildlife, livestock and people. I also worked as a volunteer for the sex worker outreach program in Nairobi, Kenya, providing health education and medical services to sex workers. As a graduate student, I worked with Dr. Anna Wald at the University of Washington Virology Research Clinic where we designed and conducted a mixed methods study to assess the interest of persons with genital herpes in finding a herpes cure and their willingness to take on the risks associated with experimental therapy to completely clear or inactivate their infection. I also worked with Dr. Michele Andrasik at the HVTN, where I coordinated the development of animated educational videos for the AMP study.

I was a collegiate and post-collegiate track and field athlete (Hammer Throw). I was encouraged to do track and field by a friend I played basketball with in high school. As a post-collegiate athlete, I competed for Kenya at two Commonwealth Games (India and Scotland), 3 African Championships (Kenya, Benin and Morocco), and the World University Games (China). I was voted co-captain of four of these teams. I am currently the Kenyan record holder in the Women’s Hammer.

As a young child in Kenya, my dream was to find the cure for HIV. I imagined myself as a lead scientist of a lab that would discover a cure. Every paper I wrote in middle school, high school and university was in one way or another linked to HIV. Working at the HVTN is a dream come true! I am proud to be a member of an organization that is conducting cutting edge research to fully characterize the safety, immunogenicity, and efficacy of HIV vaccine candidates. I appreciate working in an environment with like-minded people who are collaborative, passionate and committed to working toward an HIV/AIDS-free generation. Thank you for the opportunity to make my small contribution to our mission of finding a safe and effective vaccine for HIV prevention globally.

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Seventeen years ago there were many cases of HIV in Iquitos, Peru, and very little information on prevention and treatment. Although the HIV incidence has not changed much in Iquitos, there is hope that prevention and research will yield concrete results.

Association Civil Selva Amazónica (ACSA) wanted to contribute to the health of the population of the Loreto region, specifically with infectious diseases and particularly HIV infection control and prevention. For that reason, Dr. Martin Casapia Morales, Principal Investigator of ACSA, developed a local research site to implement studies that contribute information to prevent HIV infection. The site also supports the efforts of Dr. Jorge Sanchez, who leads a research center in Lima.

The first study they conducted was preparatory to assess the incidence of HIV locally, given the high number of cases reported in Iquitos which represented a significant public health problem. In this preparatory study, they demonstrated that they were able to meet people and enroll them in a research study. This was important because Iquitos has the third largest number of new HIV cases in Peru, following Lima and Callao.

With formal training as a specialist in infectious and tropical diseases, Dr. Martin Casapia Morales has held the roles of Investigator of Record and Principal Investigator, and is now the Clinical Research Site Leader.

The ACSA site started by conducting basic studies with small numbers of participants, but today it manages studies with 300 to 600 participants in different clinical trials.

Dr. Martin Casapia Morales started working as a general practitioner in Iquitos, initially seeing patients with HIV at the Hospital Cayetano Heredia in Lima. From there, he gained experience in the management of these patients and then ventured into HIV prevention. Dr. Casapia Morales believes, “Patients should not die, because we have the tools to detect and treat HIV early.”

Working with the HVTN is a great experience because it is an organized, systematic way to develop and implement clinical trials. “The Network has given me a number of opportunities to learn a lot in the clinical trial field. In addition, I recognize that we have the opportunity to interact and learn about new research experiences with diverse researchers, including those who direct the Network, and receive permanent contributions from them, which gives us security for good development in our work,” he emphasized.
Mark Hubbard has lived with HIV/AIDS for over 30 years and has served on Vanderbilt community advisory boards since 2001. He is currently an alternate global community advisory board representative for Vanderbilt for both the HVTN and the ACTG networks.

Mark works with local and regional groups as well as international organizations, including the AIDS Treatment Advocacy Coalition Drug Development Committee, the biomedical HIV prevention research advocacy agency AVAC, and the International Rectal Microbicides Advocates.

Mark has participated in community consultations with the Tennessee Department of Health, the US Centers for Disease Control (CDC), the NIH’s National Institute of Allergies and Infectious Disease (NIAID), and the Microbicides Trials Network. He currently serves on the State of Tennessee Department of Health’s HIV Center of Excellence (Ryan White Clinic Oversight), and the AIDS Drug Assistance Program (ADAP) formulary and medical fee schedule committees.

Mark was awarded 6 consecutive community educator scholarships to the Conference on Retroviruses and Opportunistic Infections and is serving in his third year on the CROI Planning Committee Community Liaison Subcommittee.

Mark is a community representative to the HIV Vaccine Trial Network’s Efficacy Trials Working Group and its Scientific Governance Committee. He is a member of the HVTN/HPTN AMP protocol teams (HVTN 704/HPTN 085 and HVTN 703/HPTN 081). In May of 2016, the HVTN honored him with the Octavio Valente Junior Volunteer Service Award.

One thing he loves about working with the HVTN is the commitment to excellence in every aspect of what the HVTN does – from start to finish, from top to bottom, and across disciplines.

Rosemary Hottinger
Clinical Site Coordinator and CER, CHUV CRS, Lausanne, Switzerland

In 1995, with a degree in biochemistry in my pocket from Trinity College Dublin, I jumped at the opportunity to spread my wings and took up a position in pre-clinical research in one of the ‘big-pharma’ in Switzerland. I quickly realized that (a) there is more to Switzerland than chocolate, watches, and mountains, and (b) life in the lab really was not for me. Soon after I found my first position in clinical operations and can truly say that I found my niche. My first encounter with HIV was circa 1997 when I started working on numerous clinical trials many of which ultimately gave rise to some of the antiretroviral therapies in use today. Following a period working mainly on oncology trials for a bio-pharmaceutical company, I decided a change was in order and in April 2018, I had the opportunity to come to work at the university hospital in Lausanne (CHUV) and take up the position of Study Manager at the Vaccine and Immunotherapy Center. This was my first experience working with the HVTN. In terms of HVTN studies, my role is Clinical Site Coordinator and also the Community Educator-Recruiter. Being a relatively recent addition to the Lausanne site, I am progressively getting to know the CAB and gaining a better understanding of my role vis-à-vis the community. The Lausanne CAB is composed of individuals with diverse backgrounds, all deeply committed to the prevention of HIV and who have been instrumental in educating me on the current culture and public opinion in Switzerland and the challenges we face.

From a clinical operations perspective, working with the HVTN, I cannot help but be impressed by the commitment to quality and excellence; all the systems, processes and procedures have been shaped and guided by GCP and every operational aspect of a protocol has a corresponding well thought through practical application.
Working with the organization’s community and site teams, Ntando ensures that communities are central to the efforts of the search for effective, affordable and accessible HIV vaccines, as well as research for other tools for HIV prevention. Ntando’s work of community engagement is guided by principles of informing, consulting, involving, collaborating, and mutual empowerment, to ensure meaningful roles of communities in the research process. In his role as a lead, he ensures the use of standard development and implementation of community education programmes, advisory mechanisms, partnerships with health service providers, and other community-based stakeholders. Ntando’s work is motivated by an interest in effectively engaging and involving communities, working and being attentive to interests and needs, such that they take ownership in the efforts that seek to achieve control of the AIDS epidemic, especially in sub-Saharan Africa.

As Co-Chair of the HPTN Community Working Group, Ntando has been involved in the establishment of a South African framework for stakeholder engagement which came about as a result of his AVAC fellowship work in 2013. This work bridges the gap between civil society groups that are within the country’s National AIDS Council (SANAC) through to the provincial and local levels where communities are involved in HIV vaccine research and other ARV-based prevention trials of microbicides and pre-exposure prophylaxis.

Ntando feels honoured and excited to have been part of HVTN’s journey as early as the days of Phambili (HVTN 503) through to the current era of Uhambo (HVTN 702) and Imbokodo (HVTN 705/HPX2008). One of the most exciting aspects about this journey is having experienced and knowing what it means to be very hopeful yet humbled by an era of disappointing outcomes of large scale trials in the late 2000s. Those experiences have taught us to appreciate the contribution of communities who, when the field was reeling from futility results, were the ones who reminded us what we had told them when introducing research to them, that it is only a trial. Therefore, the field, led by scientists, with all teams, communities and advocates, cannot stop but has to press on in unison until one of the ultimate hopes to defeat HIV is realized, finding an HIV vaccine.

Looking back and seeing the present, where two large scale vaccine trials are in the field with communities putting themselves forward to advance the discovery, brings cautious hope that whatever the outcome, one thing is for sure: the discovery of an HIV vaccine is more near than far. In fact, if for whatever reason vaccines are delayed, the world is not denied because of the growing body of knowledge about antibody mediated prevention. The future therefore continues to be one that is filled by hope, and the products we have currently in oral and possibly topical PrEP should be maximized. That way HIV has no option but to surrender in the near future!

Ntando Yola
Community Engagement Lead, Emavundleni CRS, Cape Town, South Africa
My work in HIV started in college when I took a course on anthropological biology as a pre-requisite for my degree in Psychology, and I wrote a paper where I drew a comparison between the finches on the Galapagos Islands to HIV and human cells. HIV was like the finches who would evolve based on their unique environment: the island or the human cell. Later that year, I applied to an internship through San Francisco Department of Public Health (SFDPH) called SHARP (Summer HIV AIDS Research Program). I was 1 of 5 students selected from across the nation to go through a summer of intensive learning within the extremely intersectional field of HIV. I was placed at Bridge HIV within SFDPH, and my research project that summer was to analyze a survey we had sent out to Bay Area-based Primary Care Providers about their knowledge of PrEP (Pre Exposure Prophylaxis) and willingness to prescribe it, as it had just been approved by the FDA.

Midway through my internship experience, I identified an open part-time Clinical Studies Recruiter position at Bridge HIV. I applied, got it, and the rest is history. While at Bridge HIV, I have been an intern, a recruiter, an educator, a research associate, and now Community Programs Manager. I have worked on a variety of studies from many different angles.

Not only do I feel exhilarated and humbled by what I get to contribute to my community on a local scale, I get to make an impact on a global scale by being a part of the HVTN. Specifically, my favorite thing about being a part of the HVTN are all the mentors it has provided me. You are all so inspiring!!

Rafael Gonzalez
Community Programs Manager,
Bridge HIV CRS,
San Francisco, CA, USA

I have worked in the field of HIV for more than fifteen years. I graduated from Universidad de Lima, where I received a Bachelor of Social Communication degree and later completed a Master in Social Investment from Universidad del Pacífico (Peru). I worked in the National HIV Program of Peru as Head of the Information, Education and Communication unit in the implementation of behavioral interventions. My goal: people should be educated about HIV prevention.

However, it was clear that condom use was not enough and we need to work on new prevention strategies. In 2005, I worked as Community Educator at Impacta, on my first HIV vaccine trial, and also served as HVTN CER Co-Chair for the North and South America sites. Since 2007, I was the Community Educator for the Lima sites in the iPrEx trial on pre-exposure prophylaxis, where I designed the branding for the Andean sites, as well as community involvement, recruitment and retention strategies that contributed to the trial achievements. Since 2016, I am working on the AMP study.

One of the things that I appreciate the most about working with the HVTN is the permanent respect about education and community involvement efforts. These include: putting in action the Community Advisory Board recommendations, implementation of new strategies on recruitment of participants, as well as educational materials customization. Now, we continue contributing to the generation of science evidence in health and “the force is with us” (Yes! I am a Star Wars groupie. Alias: MaR Leia or Vader)

Maria del Rosario Leon Rhandomy
Head of Community Involvement,
IMPACTA CRSs, Lima, Peru
When the HIV/AIDS crisis emerged in the early 1980s, there was little education available about the disease except that death was certain and imminent if you acquired the virus. In the early 1990s, that’s exactly what started happening to the guys in my circle of friends. It really hit home for me when my good friend Emmett, seemingly out of nowhere, died from AIDS-related complications. Stigma and shame prevented Emmett from telling any of us he was sick or letting us support him. A few years after his death, I attended a conference where I learned about HIV treatment. This motivated me to become an HIV treatment advocate. Unfortunately, by then Tweety had died, Kevin and Derrick were very sick, and my other gay friends remained at risk. That was the impetus for my work in HIV treatment and prevention. Throughout my career I’ve worked with people affected by and living with HIV in various capacities.

As a Bachelor of Public Health student at Monash South Africa, I learned a lot about issues affecting the world and this led me to become interested in research, particularly inequalities affecting women which includes HIV. I have always felt that women need to be given more power to make their own sexual and reproductive health decisions. Therefore, building on my experience as a student, a volunteer for Lovelife Mpinchi, and a fieldworker at Community AIDS Response (CARe) and the Medical Research Council of South Africa, I applied for a job at the Aurum Institute where I work with the recruitment team for the HIV Vaccine Trials Network (HVTN). Being part of a team working toward lessening the HIV disparities among women, with a goal of finding an HIV vaccine, is aligned with my goals of giving women the power to make their own sexual decisions.

In 2017, I was recruited to join the Bridge HIV Community Advisory Group (CAG). As a Black trans man and a public health professional, I know the importance of including the voices of marginalized communities in research. Transgender people are grossly underrepresented in research across illnesses, and it’s important to me that this change. Sharing my expertise in trans health and community organizing to inform HVTN research studies is one way toward that end. I believe the first step to inclusion of trans people in research is education. As a CAG member, I’ve had the opportunity to participate on panels, present at community forums, and provide technical assistance to research scientists about the HIV prevention needs of transgender people. But my absolute favorite thing about being a CAG member is being able to share accurate up-to-date information about things like PrEP and U=U (Undetectable = Untransmittable) with ordinary people in everyday situations.

My job as a research assistant is quiet fulfilling as I get to work with young people, especially women, and educating them on ways in which they can protect themselves against HIV. Targeting young people is a great way to ensure that in the future we can have an HIV-free generation. I have recently completed my Postgraduate Diploma in HIV/AIDS Management (cum laude) and hope I can continue to contribute to the well-being of others through innovation and research. I am grateful to be part of a global initiative to reduce the burden of HIV.

Shawn Demmons, MPH
Bridge HIV (CRS) CAG Member, San Francisco, CA, USA
HVTN Global Community Advisory Board Representative to the Transgender Working Group; Capacity Building and Assistance Provider, UCSF Center of Excellence for Transgender Health

Tshiamo Mmotsa
Research Assistant, Klerksdorp CRS, Klerksdorp, South Africa

Spotlight on the People of the HVTN
I started working on HIV programs in 2014 at Matlosana Youth Centre. In 2007, I joined Aurum as a Counsellor/Recruiter/Research Assistant and started to be more involved in community education. From 2008 I commenced working on HIV vaccine studies, and then community education became intense. It is exciting to educate people on HIV vaccines, which is something new to most of the people. When you give examples like the mothers taking their children for immunizations, people start getting the idea.

I feel honored to be part of the journey working toward and HIV-free society through clinical trials, and I have been part of several HVTN studies (HVTN 100, HVTN 108, HVTN 086, HVTN111, HVTN 503, HVTN702, and HVTN 705). I get an opportunity to work together with different people. I get exposed to different cultures and religions. I learned how different people from different cultures and religions perceive vaccines, HIV, and the drawing of blood samples.

Educating and empowering our communities about HIV and vaccines has given me great pleasure and a purpose in life, as we need informed communities to participate in our clinical trials. I have come to realize that there is no research without our communities. That is why it is vital to educate and empower our communities.

Thandiwe Papalagae
Recruitment and Retention Team Leader, Aurum Institute CRS, Klerksdorp, South Africa

Janie Vinson studied graphic design at the Academy of Art University in San Francisco. She has a BA in Peace Studies: Human Relations from the Johnston Center for Integrative Studies at the University of Redlands, and did graduate work at the European Peace University in Austria, Denmark, and Spain. She was a Guest Suite Artist at Risley Residential College for the Creative and Performing Arts at Cornell University.

I followed the HIV epidemic very closely as a high school student in the late 1980s, however I came to HIV work quite by accident. Returning from graduate studies in Europe, I accepted a position at the NAMES Project Foundation/AIDS Memorial Quilt managing their national chapters. When the AIDS Quilt moved from its longtime home in San Francisco to Atlanta, I moved to a position at Bridge HIV and started just a few days after the events of 9/11 in 2001. My work in HIV now spans two decades and I’m thankful to have been able to forge my education with design to really help people. Many years ago, a participant revealed that he saw a recruitment campaign I designed in a BART transit station back in 2011. The tagline, “What will it take to find an HIV Vaccine? People like you.” affected him so much he was moved to call us and he thanked me. I then thanked him for volunteering for a study and we laughed at all our mutual hand shaking and hugs. These are the moments that make me glad to have “accidentally” stumbled into HIV work.

When I started my tenure at Bridge HIV we had recently joined the new HVTN network and were full swing into working on an HIV vaccine study called AIDSVAX! Today, we have a proven intervention that prevents HIV infection (PrEP) and are on the road to discovering more. Being involved with the HVTN these last two decades has been an invigorating and humbling experience. I have witnessed so many growth moments that others may see as failures; reveled in the hard-fought successes that moved us forward; and have had personal connections to some of the thousands of study participants who are the heart and soul of this movement towards eradicating HIV. I couldn’t be prouder to work with the HVTN.

Janie Vinson
Senior Designer, Bridge HIV CRS, San Francisco, CA, USA
Getting the Right Test for HIV

Antibodies help to prevent infection. Most vaccines cause the body to make antibodies. If you get an HIV vaccine, your body may make antibodies to HIV. However, standard HIV tests search for HIV antibodies, a sign of HIV infection for people who have not previously received an HIV vaccine. If you get a standard HIV test after receiving an HIV vaccine, your HIV test results could come back positive even if you are not infected with HIV. This is called a VISp (Vaccine-Induced Seropositive) test result. To avoid this confusion, our study sites use different kinds of HIV tests that look for the virus itself, not antibodies.

FREQUENTLY ASKED QUESTIONS ABOUT VISp

Where can I get the right test for HIV?

You can get the right HIV test at the study site for free. After you leave the study you can continue to go to your study site to request HIV testing. If you are no longer located near your study site, the HVTN VISp Testing Service can help you get HIV testing in your area. The testing is free.

Getting the right test will prevent an incorrect diagnosis of HIV. Your study site or the VISp Testing Service can provide the right test.

What is “opt-out” testing for HIV?

“Opt-out” testing for HIV means that HIV tests may be done routinely unless a patient refuses to have the testing done. For more information on the Center for Disease Control’s (CDC) recommendations for HIV testing in the U.S., please visit: http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm.

For (U.S.) state-specific information, please visit: http://www.nccc.ucsf.edu/consultation_library/state_hiv_testing_laws/.

For other information about HIV testing guidelines in your country, please visit: http://www.who.int/hiv/pub/national_guidelines/en/

How can I explain this situation to my healthcare provider?

No one can force you to have an HIV test for any reason.

• If anyone asks to test you for HIV or to draw your blood, tell them you are in (or have been in) an HIV vaccine study and that you need to get all your HIV tests at the study site.

• Explain that being tested outside of your study site or the HVTN VISp Testing Service could result in an incorrect diagnosis of HIV infection.

• Give the provider your study coordinator’s contact information. Ask the provider to call the study site or the HVTN VISp Testing Service directly (U.S. toll free: 1-800-327-2932).

• If you have to, simply say “no” to the HIV test, and then ask the study site or the HIV Vaccine Trials Network to help. We are happy to work with you to resolve your situation.

Why don’t standard HIV tests look for actual HIV?

Standard HIV tests that look for antibodies are quick, reliable and affordable. Tests that look for the virus are expensive and not commonly used for an initial diagnosis.

What does “opt-out” testing mean for me?

You should tell your healthcare provider about your HIV vaccine study participation and refuse HIV testing. Even if your healthcare provider does not mention the HIV test, be sure to tell them that you do not want an HIV test because you are (or were) an HIV vaccine study participant.

How long does VISp last?

If you have tested VISp, the antibodies may fade quickly or they may last for several years. In some cases, participants continue to test VISp for more than 20 years.
Can VISP be passed from one person to another?

- In most cases, no. If you have tested VISP you cannot pass the antibodies to another person by kissing or through sexual contact.
- If you are pregnant, we think there may be a chance that you could pass the vaccine antibodies to your baby. Although this has not been shown to happen with HIV study vaccines, we know that this happens with other vaccines, like the tetanus vaccine. Vaccine antibodies that mothers pass to their babies are temporary and go away over time, and they are not harmful to the baby. The HVTN can arrange for you and your baby to have accurate HIV testing for free for as long as it is needed.

In order to donate blood or organs, the donation site will screen you using an HIV antibody test. If you test positive for HIV antibodies you may be unable to donate an organ. You may also be permanently banned from blood donation even though you are not infected with HIV.

How will a VISP test result affect me?

- If someone believes you are infected with HIV, you could face discrimination and/or other problems. For example, you could have problems with medical or dental care, employment, insurance, a visa for traveling, or entry into the military. You might not be allowed to donate blood or other organs. If you are pregnant, you may have to explain your situation to avoid receiving any HIV treatment during your pregnancy or labor/delivery.
- If you are planning to apply for insurance, employment, or the military, please inform your study site right away. The insurance company, employer, or military agency may not accept HIV test results from the HVTN. However, the HVTN can work with them to ensure the right test is done that will show your true HIV status.

What happens if I move far away from the study site where I participated in an HIV vaccine study?

For U.S. participants, call the HVTN VISP Testing Service at 1-800-327-2932 during business hours, Pacific Time. For participants outside the U.S., call your study site and they can assist you with testing for HIV. If you are unable to reach someone at your study site, send an email to vtn.core.vispcounselor@hvtn.org to request testing.

The HVTN VISP Testing Service provides HIV testing for participants who have received a study HIV vaccine in a National Institutes of Allergy and Infectious Diseases (NIAID) Division of AIDS (DAIDS)-funded HIV preventive vaccine trial and who are no longer able to be tested at their study site.

Will my information be confidential?

Yes. All of your information will be stored in a limited-access, password-protected, secure computer database. Access to your information will be limited to the HVTN VISP counselors. No identifying information concerning the testing will be released to any third party without your written approval, except when required by law.

How long does the HVTN VISP Testing Service take to provide test results?

Approximately 2 weeks.

Am I eligible for the HVTN VISP Testing Service?

YES:

- If you participated in an HIV Vaccine Trials Network (HVTN), AIDS Vaccine Evaluation Group (AVEG), or HIV Network for Prevention Trials (HIVNET) HIV preventive vaccine study, AND
- If you received an HIV vaccine*, AND
- You are willing to provide consent to have your blood drawn and for HIV testing.

NO:

- If you have a confirmed HIV infection, OR
- If you are currently enrolled in an HIV Vaccine Trial,** OR
- As a former study participant, you received a placebo.

* If you are not sure if you received an HIV vaccine, call the HVTN VISP Testing Service (1-800-327-2932).

**If you are currently enrolled in an HIV vaccine trial, your testing is provided by your trial site. If for some reason you are unable to be tested at your site, you can contact your study site or the HVTN VISP Testing Service (US toll free: 1-800-327-2932).

What if I live outside the U.S.?

Will I have access to the HVTN VISP Testing Service?

The HVTN VISP Testing Service is open in the United States. Expansion of the testing service in southern Africa is underway. For locations outside of the U.S., please contact your study site or email vtn.core.vispcounselor@hvtn.org to request testing.

For more information about getting the right test for HIV

Contact your study coordinator at the HIV vaccine study site or the HVTN VISP Testing Service at (US toll free) 1-800-327-2932.
The HIV Vaccine Trials Network is an international multi-disciplinary collaboration. Support for the HVTN comes from the National Institute of Allergy and Infectious Diseases (NIAID) of the U.S. National Institutes of Health, an agency of the U.S. Department of Health and Human Services. The Network and NIAID have a close, cooperative working relationship, with shared attention to intellectual and scientific issues.

ABOUT COMMUNITY COMPASS
The Community Compass aims to keep the HVTN community informed about the Network's research, site activities, and advances in the field of HIV prevention and vaccination. We encourage community members to submit news and event reports to this magazine and make this a true community sharing platform.

Translations in Spanish, Portuguese and French provided by Northwest Translations, Inc. www.nwtranslations.com

SEND INQUIRIES ABOUT THIS ISSUE OF COMMUNITY COMPASS TO:
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