FUTURE OF AIDS MOVEMENT

COMMUNITY
CONSULTATIONS REPORT
DECEMBER 2023

















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INTRODUCTION

AS A GLOBAL COMMUNITY, AMBI-TIOUS GOALS HAVE BEEN SET TO END AIDS AS A PUBLIC HEALTH THREAT BY 20301. The 2021 Political Declaration on AIDS stated in order to achieve the goals, a strong community leadership and engagement is key and further set targets to ensure adequate resources are available for community engagement including 30 percent of testing and treatment services, with a focus on HIV testing, linkage to treatment, adherence and retention support, and treatment literacy; 80 percent of HIV prevention services for populations at high risk of HIV infection, including for women within those populations; and 60 percent of programmes to support the achievement of societal enablers². As we approach this time, it becomes less likely that this overarching goal will be met - at least not universally. This report highlights insights gathered through a series of community consultations that were led by the global key populations networks. United, GATE, GNP+, ICW Global, INPUD, MPACT, NSWP and Y+ Global wanted to envision the future of the HIV response beyond 2030 with our communities who are at the centre of the HIV movement.

This work was led by the Future of AIDS Movement (FAM). It is an initiative that is aiming to bring together the AIDS sector to reflect on and strategize what the future of our movement could be, by and beyond 2030, in the world where AIDS is deprioritized. As the global key populations networks we want to reflect on our place within the broader global health and development arenas. This report is part of that larger ongoing collaboration.

Our collective approach to this research

has focused on being participatory and community-led, which meant that the work was slow and intentional, spanning over six months. Together we engaged 150³ community members to reflect on the future of the HIV movement.

Each of the networks conducted their own separate focus groups, prioritizing their own constituents. Overwhelmingly, the insights from participants were consistent and shared similar themes across the key populations networks and across regions. While there were many overlapping similarities, the ones that were most prominent was that decriminalization was essential in order to make long lasting progress in the HIV response, and that communities must lead. Another theme that was interwoven throughout the focus groups was that despite challenges within our movement, the HIV movement is stronger and able to accomplish more when we are united as key populations. These are the areas that we as the FAM should reflect on and our partners, in particular donors, need to take notice of.

The remainder of this report walks you through the key themes highlighted by our community, prioritizing the use of our own words and voices during the community consultations. The rising themes section in this report reflect the 4 overarching questions that were across each focus group. We see this report as the beginning of a larger continued body of work that the FAM will do together to strengthen our collective global movement as we re envision our role in the global health sector beyond 2030. A big thank you to all of the advocates who participated in our community consultations. We hope that this report does your words justice.

COMMUNITY CONSULTATIONS OVERVIEW

The Community Consultation was a series of small group discussions (focus groups) led by the FAM partners. The purpose of the Community Consultations was to create a mechanism for civil society members specifically representing people living with HIV, sex workers, people who use drugs, gay, bisexual and queer men, and trans and gender diverse people to inform the FAM's role of the movement in the global health architecture by and beyond 2030.

The FAM was intentional in creating a decentralized global consultation that reached diverse participants that were representative of the key population identities as well as others that are often on the margins of our movement such as prisoners, Indigenous people, migrants and people born with HIV. In order to do this, each network selected a focal point person to support the development of the methodology in which each network would implement in a standardized way with their constituencies.



METHODOLOGY

TO ENSURE DIVERSE REPRESEN-TATION OF THE HIV COMMUNITY DURING THE CONSULTATIONS.

each FAM partner conducted two focus groups with members of their constituencies, using a collaboratively developed toolkit and timeline. Each network selected participants based on a set of predefined criteria using the purposeful sampling⁴.

Demographic data was collected using a short user friendly Google Forms template and translated as needed into other languages⁵. Consent for participation was asked both in written form as part of the demographic survey and confirmed verbally at the beginning of each focus group.

Each focus group was between approxi-

mately 2 hours. Participants were asked a set of 4 questions each with a series of prompts. Participants were encouraged to to share both verbally and using the chat function.

Following the completion of the focus groups by all partners, each network focal point coded the information and did an analysis of the information looking for themes using a reporting template. The reports and demographic information were shared in a verbal report back session with all focal points for collective sense making. The final report is an analysis of the 14 focus groups and analysis by each of the networks.

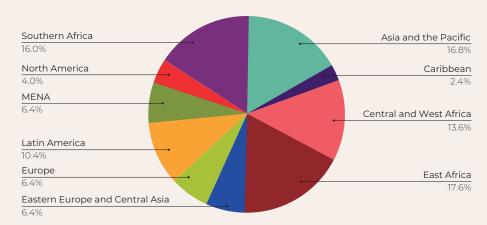
See <u>Virtual Annex</u> I for the full document



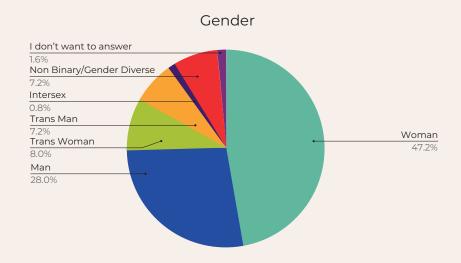
DEMOGRAPHICS

IN TOTAL, THERE WERE 125 PARTICIPANTS FROM 53 COUNTRIES⁶ DISTRIBUTED FROM ACROSS REGIONS GLOBALLY ENGAGED IN THE FOCUS GROUP DISCUSSIONS AND COMPLETED THE DEMOGRAPHIC SURVEY (SEE CHART BELOW).

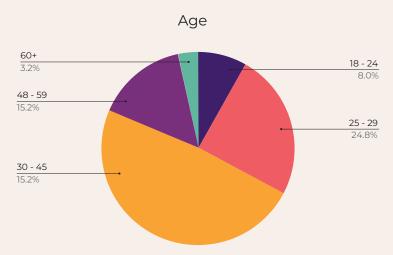




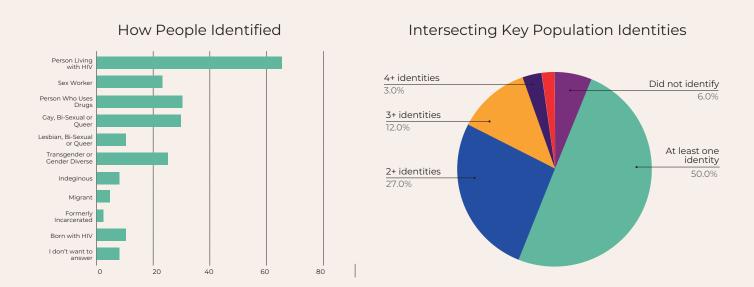
Close to half of the participants identified as cis gender women, with the remaining participants identifying as cis gender men and either trans or gender diverse⁷.



The age range included participants between 18 - over 60 years old. The largest group falling between 30 - 45, followed by 25 - 298. Approximately one third of the participants were young people under 30.



In terms of identity, nearly all the participants (95%) identified as being either a person living with HIV, sex worker, person who uses drugs, trans or gender diverse, and/or as gay, bisexual or queer⁹. Of this number almost half (47%) had at least 2 intersecting identities with 38% of those having 3 or more intersecting key population identities¹⁰. Other identities that participants identified as were born with HIV, migrant, formerly incarcerated, Indigenous, heterosexual and living with a disability.



The demographic survey had limitations. It was in a short survey form only collecting data on country, gender, age and some predefined identities¹¹. Limitations include a lack of information on race, ethnic group, religion and/or other intersecting identities¹².

RISING THEMES

THE ROLE FOR THE HIV MOVEMENT IN THE GLOBAL HEALTH SECTOR

We need to focus on other things, funders are also changing their focus. We are looking at HIV and climate change, and we cannot remain static in where we were 20 years ago. We can't forget our core areas - SRHR (sexual and reproductive health and rights), GBV (gender based violence), stigma, they are not yet solved. In our countries, where we are seeing there are issues coming up, the criminalization is increasing."

Woman living with HIV, Uganda

I hope that we can make a better partnership with the health sector. And then also we need to monitor the w ork of the health sector and government itself. And I think we can identify the actors as a fellow civil society movement such as women, youth and under marginalized groups and underrepresented groups."

Trans man, Indonesia

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Looking beyond 2030, HIV will gradually shift to the periphery of public concerns as it becomes a disease like any other. While stigma and discrimination may persist, maintaining the progress we've achieved, and scientific advancements will be key....As community-based organizations, we'll remain vital in shaping drug policy, particularly at the governmental level."

Person who uses drugs, Senegal

Realizing Decriminalization and Ending Punitive Laws

One persistent problem is that even though advocacy for decriminalization is incredibly important to our access to health and other human rights, existing funding is not in advocacy work but in HIV-related service provision. Despite this, the reality is that criminalization is the main barrier to the HIV response. If we could achieve decriminalization then we could really make a difference."

Sex Worker, Hungary



I think about criminalizing laws. [such as] Uganda's law and Kenya's incoming bill. Criminalizing laws cause key populations to not have access to services. With these laws out of the picture, the services will be more accessible"

Gay man, Kenya

CRIMINALIZATIONAND PUNITIVE LAWS are the main barrier derailing advancements for the HIV response. This is reflected in the 10-10-10 social enabler 2025 targets set by UNAIDS¹³. When communities are criminalized they avoid seeking out health services or treatment thereby driving HIV epidemics underground. It is important that our health is seen beyond access to only health services to also include safe drug supplies, safer working environments, access to abortion services, body autonomy and other essential rights which lessen mortality rates and improve health outcomes. The HIV movement must continue to prioritize and lead decriminalization efforts. These efforts must also be inclusive to challenge the age of consent for young key populations to have access and autonomy. Movements also need to engage in the countering and monitoring of anti-rights actors and ally itself with other movements that are doing this work.

Advocating for Healthcare for All

I think it's only prudent now that the movement should evolve to address a broader range of global health challenges, recognizing that the diseases and the health issues are interconnected. So I think the diversification should include maybe an emphasis on the health equity and then maybe the diseases which are non-communicable, and the emerging health threats. When we bring in other diseases in this, it will help us push the agenda forward because very many diseases are interconnected."

Non-binary, gender diverse participant, Uganda

While we are discussing PreP - last week a woman died from AIDS in Jordan because she couldn't access the health care system. I invite you all to unpack this pain."

Young gay man, Jordan

We need to integrate into the broader UHC movement - this is where our work needs to move. Our movement should be a watchdog for health as it has been and look at lessons we can share with others."

Sex worker living with HIV, Viet Nam

THE HIV MOVEMENT'S MAIN ROLE SHOULD BE TO ENSURE ACCESS TO COMPREHENSIVE HEALTH SERVICES FOR ALL.

The HIV response should align specifically with the movement for universal health coverage (UHC), ensuring that even the most marginalized and vulnerable have equal access to the full range of health services. Included in this would be health services for all key populations¹⁴ additionally highlighting migrants and informal workers who often do not have access. In the future there will most likely be continued conflict and war, environmental disaster and pandemics. Therefore strengthening our health systems to become resilient and integrated is essential. Safeguarding our healthcare systems and making them available and accessible to all should be a priority for the HIV movement. A key part of future resilient health systems will be linked to community system strengthening and direct links to community-led services. Included in this work we can look at how insurance schemes can be leveraged in the future to be inclusive and support national health programs. Health services need to be integrated but not at the risk of minimizing services specific to key populations. In terms of health access, the movement should maintain a continued focus on sexual and reproductive health (SRHR) and rights and harm reduction.

Championing Community-led Services and Advocacy

- We should be able to remind other movements that whatever is done without our communities is done against them."

 Young trans woman, Tanzania
- The HIV response has shown the power of community-led initiatives and the importance of support groups rooted in communities. Sharing this model of community involvement and decision-making can be valuable for other movements looking to build resilience and empower affected individuals."

 Young woman living with HIV, eSwatini
- The more you know about your rights the stronger you are to make decisions. It removes the sense of entitlement and AIDS exceptionalism. We know our rights then we don't expect handouts or charity we demand our rights".

 Gay man living with HIV, Nigeria

THE HIV MOVEMENT IS A LEADER IN BEST PRACTICES FOR COMMUNITY-LED¹⁵ SERVICES AND ADVOCACY. Its power has helped shape and guide community-based programing and service provision. In the future there will be a need to develop and monitor the implementation of integrated community-led practices that are envisioned, monitored and implemented by members of the key populations. The HIV movement must continue to strongly advocate that funding sources go directly to communities and not to intermediaries. While we know that community-led services are ideal, we must realize that they don't always have as far as reach as national programs. It is therefore essential to have communities work with health systems and influence national health programs. Community-led services cater to the specific needs of communities often in settings that dismantle biases¹⁶. It is imperative that the HIV movement continue to play an important role in pushing for community leadership in our health.

Diversification of the Health Movement



HIV has not been a priority issue for sex workers... mainly because we face numerous other more urgent challenges. The priority issues have always been violence, human rights, poverty, etc., and then HIV. If we set aside [these] human rights violations, when we talk about health the main issue is access to basic healthcare. People don't even have the documents they need to access basic healthcare, so HIV ends up at the bottom of the list. We are exhausted by dominant discourses about HIV because they occur in a vacuum that is not in touch with people's lived realities... A more holistic approach... is what is needed." Sex worker living with HIV, Ukraine

"HIV can align itself with other chronic disease management areas within public health. Linking to other chronic diseases can create a comprehensive approach to public health, particularly as HIV is considered a chronic disease"

> Woman living with HIV, Trinidad and Tobago



For the next ten years, if we talk about the clinic, it's not only HIV testing and STI screening, and not only counselling, but we will use the HIV platform for other services. Like hormone therapy. Gender affirming care is very important for transgender people. But this service should be free to everyone."

Young trans woman, Thailand

THERE IS A NEED TO DIVERSIFY THE MOVEMENT AND TAKE OTHER HEALTH FACTORS INTO CONSIDERATION, such as non and see health as interconnected. Often the HIV response fails to realize the diverse needs of people in the movement to not only where they are at. Mental health and psychosocial support should be streamlined in our advocacy and increasingly prioritized in the work of the movement for those who desire them.

FUTURE PARTNERSHIPS FOR THE HIV MOVEMENT



I think that by 2030, we can see that in many countries, funding is going to become very small. Many current organizations that are working with us - they will disappear. The civil society organizations and networks, especially by people living with HIV, and key populations and other marginalized groups, will still be there. HIV is affected directly. We need to strengthen our work with them."

Gay man living with HIV, Viet Nam



"Our political advocacy actions must be formulated from an intersectional perspective, taking into account basic needs. Still, we need to try to include everything without leaving anyone out. Collaborative work is essential, but how to achieve the sustainability of this collaborative work and political advocacy, which has been distorted throughout history."

Young trans women living with HIV, Honduras

Key Populations Movements



"What is envisioned right now is unity.
This is the time we have been one."

Young woman living with HIV, Nigeria



One of the things that is important is the collaboration across the women's movement. When you speak with one voice, it is always stronger. Speaking with one voice has been strong for us in moving policy forward. Together we support sex workers, trans people, drug users - they are all OUR issues.",

Woman living with HIV, Trinidad and Tobago

THERE WAS A CONSENSUS ACROSS ALL THE FOCUS GROUPS that the key populations networks need to continue working together and build stronger organic coalitions amongst ourselves beyond 2030. As we move forward, the movement must continue to strengthen its internal collaborations between key populations, and try to engage more broadly with other movements of LGBTQ, migrants and prisoners. Specific emphasis needs to be on young key populations creating pathways for new leadership and sustainability through intergenerational learning.

Governments, UN Agencies and Other Multilaterals

[We need to organize with national governments because] UNAIDS is a Titanic that is sinking, with less funding than other organizations. It will become part of the WHO program, and perhaps by 2030, UNAIDS as a partner will be gone and the Global Fund always updates its framework" Women living with HIV who uses drugs, Argentina

"National governments because they are responsible for developing health policies, mobilizing resources, providing health care and protecting the rights of people living with HIV CSOs from KPs, PLHIV, DH play a crucial role in mobilization. awareness raising" Intersex person, Algeria

WE PREDICT THAT THERE WILL BE A CONSIDERABLE SHIFT IN THE INTERNATIONAL FUNDING LANDSCAPE IN THE FUTURE, creating landscape we do still see partnerships with UN agencies, the Global Fund and other multilaterals as important to maintain.

Other Movements

The biggest lesson learned is that criminalization is the beginning and end of it all, and if we don't end policing and criminalization there is no effective HIV response... If we go back to the roots of what the sex worker movement has been demanding for the last 50 years, we have been saying end criminalization and end policing. Policing is a public health crisis and should be addressed as such. Ending policing, defunding the police, and decriminalizing sex work would end HIV faster than an injection."

Trans sex worker, Spain



"We need to look at the intersections of health and feminism and how we can bring that into our future work. We have historically played a strong role in research and patient advocacy and need to continue to play that role."

Young woman living with HIV,
Nigeria



We can draw inspiration from other movements that prioritize intersectionality and shared agendas, including gender, nondiscrimination, non-racism, and non-xenophobia."

Man who uses drugs, Ecuador

THEHIVMOVEMENTCLEARLYHASSTRONGINTERSECTIONS WITH OTHER SOCIAL JUSTICE ISSUES THAT WE DO NOT ALWAYS PARTNER WITH. In the future we should nurture relationships and strengthen partnerships with labour rights, defunding the police, anti-poverty, anti- racist, prisoner rights, digital rights, anti-capitalist and sexual and reproductive health and rights, women's rights and feminist movements.

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I was just thinking that this is a conversation that I've been having here and there with other activists, that there is also something around the climate justice movement, whether we like it or not, whether we think it's a priority or not. I do believe it is a priority. And I believe that because any political, social, economic catastrophe hits first the most marginalized, and of course trans people first."

Young trans man, France

"We need to anticipate the impacts of climate change on poverty, health issues, and access to treatment and adherence. We also need to look beyond 2023 and consider issues like climate change, food security, and housing. We must continue to engage and address the impacts these issues will have on HIV prevention and treatment."

Young woman living with HIV, Trinidad and Tabago

CLIMATE JUSTICE WAS CONTINUOUSLY MENTIONED AS A SPECIFIC MOVEMENT THAT THE HIV MOVEMENT MUST FIGURE OUT A WAY TO ALLY ITSELF WITH AND PREPARE TO INTEGRATE THIS WORK INTO THE HIV RESPONSE. Climate change will drive war and conflicts over resources (example fossil fuels and lithium), environmental disaster (example drought and flooding) and birth new pandemics. As a result there will be mass migration, displacement and strains on healthcare systems which we are already seeing and will need to prepare and plan to navigate as a movement. Key populations and other marginalized communities already are and will bear the brunt of climate change, especially in the Global South.

Research and Innovation Partners

We should be able to understand as a network what the financial projections are for drug prices in the next ten years. We should be consulting with partners who are drug manufacturers."

Young, queer person born with HIV who uses drugs, Zimbabwe

We need to be careful when working with pharmaceuticals. They will be one of the new funders in the space. Every pharma has some special funding to support communities. We also know that they are the ones who run the game. It's good to work with them, to support the community on the needs of the community. But it is not good when we have dependence on them for advocacy on treatment. They are running the game and patenting the game all over the world. That narrows down the opportunities for affordable medicines."

Young man living with HIV, Viet Nam

Pharmaceutical companies can play a significant role in the development of innovative HIV treatments, prevention methods and possible cures. Collaborative efforts with pharmaceutical companies are essential to ensure access to effective and affordable medicines. However, this partnership must be balanced with the defense of fair prices and equitable access."

Young gay man, Morocco

THE HIV MOVEMENT NEEDS TO POSITION ITSELF AS A LEADER PUSHING THE RESEARCH AGENDA and to do this we need to partner with researchers and academics to ensure that they are championing the research that is most important to the community. Another partner that is perhaps more contentious is pharma. While the movement needs to be cautious, there needs to be strong collaboration in the future to drive technological advancements such as new affordable treatments and a cure, and ensure that pharmaceutical companies are accountable making certain that treatment is accessible and available without discrimination to the people who need them. This includes mitigating stock outs and treatment provisions for people who use drugs. In order to work with pharma we will also need to warrant that a percentage of the resources generated go directly back into community-led research, programs and services. The HIV movement can play a strong role in keeping pharma in check and creating a more harmonious partnership, especially as it is likely that current funding will continue to decrease.

Religious Leaders and Organizations



On religious partners: last year in Ecuador, the catholic church said it aligned itself with sex workers, but it's important that they respect our decisions. The church is very strong and has a lot of money, also often funds abolitionists. This means that while the church is a good partner, we have to be really careful how we work with it because they have also been homophobic, transphobic, etc." Trans, sex worker, Ecuador



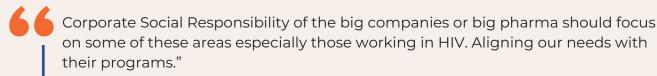
"I think when we relate back to Uganda, our biggest barrier is the religious and faith based organizations. So probably we could strengthen our linkage, our partnership with organizations like that? We need to build relationships with religious and faith based organizations."

Queer, non-binary person, Uganda

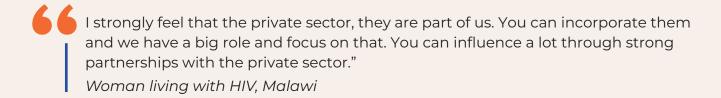
THROUGHOUT HISTORY, WE HAVE SEEN RELIGIOUS SECTORS PLAY BOTH HARMFUL AND HELPFUL ROLES FOR KEY POPULATIONS. In

with little separation between church¹⁷ and state. Developing stronger partnerships with religious leaders and organizations could be a key While influencing religious leaders is seen as necessary by some, the

Private Sector



Gay man, Mozambique



How to kind of leverage that aspect of making sure that HIV itself is also being talked about within the whole diversity equity inclusion, whether it's being sensitizing the employees or in terms of hiring people? Because that kind of helps corporates make it an agenda and invest back in the communities"

Trans man, India

WITH A RISE IN CORPORATE SOCIAL RESPONSIBILITY MODELS AND IMPACT INVESTING, the private sector could be a potential new partner in the future especially as a source of funding. The HIV movement should explore partnerships that would uphold the ethos of the entire movement and not as a way for washing other harm done to people and the environment¹⁹.

WHAT THE HIV MOVEMENT CAN SHARE WITH OTHER MOVEMENTS



The HIV response has shown the power of community-led initiatives and the importance of support groups rooted in communities. Sharing this model of community involvement and decision-making can be valuable for other movements looking to build resilience and empower affected individuals."

Woman living with HIV, Botswana



"The HIV response is one of the best examples of a strong working partnership between affected communities, researchers, and the government, and other movements have a lot to learn from that."

Sex Worker, Ecuador

Community-Led Solutions

The Global Fund only funds HIV prevention, yet as a sex worker movement we have also responded to and addressed other needs beyond the projects we are funded to undertake. We have developed responses that weren't supported by funding streams, and this resilience and adaptability are lessons we can share. We are also an incredible movement for our ability to come together behind a cause. That unity is something we need to maintain."

Sex worker, Kenya



"In the movement, with the HIV movement itself, along with partnering with any kind of organizations or communities, that will eventually have to work with the grassroots communities. Right? Because that's where the buck stops and that's where you want those voices to come up (...) And that is where the actual solutions to the problems will come from and we can only design solutions in consultations with the community."

Trans man, India



Our experience in program implementation and science has yielded valuable lessons. We can share best practices on mobilizing communities, decentralizing services, amplifying voices, and advocating effectively. For example, during the COVID-19 pandemic, we ensured that services were not interrupted. Additionally, we advised and guided donors to better understand the needs of implementation. Our resilience, innovations, and the ability to adapt to challenges are lessons that can benefit other movements."

Man living with HIV, Nigeria

AT THE HEART OF THE HIV MOVEMENT ARE THE PEOPLE MOST IMPACTED.

It has been people living with HIV, sex workers, people who use drugs, trans and gender diverse people and gay men and our closest allies that have led the most impactful advocacy, research and programming. The HIV movement has crafted proven solutions that have been central to informing broader HIV strategy and policy²⁰. This is arguably the biggest lesson that the HIV movement can share with other movements and what we need to keep central to our work beyond 2030.

Intersectionality in Practice



"The humanitarian movement is one that we shared. The HIV movement. we are not. A lot of movements talk about intersectionality. There are a lot of great things about working with criminalized communities." Young gay man living with HIV, Viet Nam



One key lesson we can share is the practice of intersectionality. The HIV response has been effective in recognizing and addressing the complex, intersecting factors that impact individuals and communities, such as race, gender, sexuality, and socio-economic status. This approach should be continued and shared with other movements."

Non-binary sex worker, living with HIV who uses drugs, Canada

WHILE OTHER MOVEMENTS MIGHT TALK ABOUT THE IMPORTANCE OF USING AN INTERSECTIONAL APPROACH, the HIV movement uses intersectional approaches as common practice. While this has between key populations broadly is one of inspiration for other intersectional lens to better include other marginalized groups such as migrants, Indigenous people, people with disabilities and

Advocacy



We advocated for access to treatment when UNAIDS had mentioned that we need to have 3 million to be on treatment by 2005, we recommended Free treatment by 2005. PLHIV are volunteering at health facilities as patient experts.... These helped on stigma reduction and adhere to treatment too. Putting a human face on HIV has shown great results on adherence and service utilization."

Woman living with HIV, Zimbabwe



"The HIV movement re-established a way of doing activism and implemented practices for political advocacy for other movements, like the transgender and diversity agenda"

Woman living with HIV who uses drugs, Argentina



We need to share our activism and how we've successfully fought discrimination and stigma for a decade. We have also been pillars in the search for solutions adapted to the needs of our communities. Sharing these experiences can inspire and guide other movements."

Young man living with HIV, Burundi

FROM OUR MOVEMENT CAME STRONG UNITED GLOBAL ADVOCACY

that has inspired other movements²¹. One of the most important contributions has been the GIPA²² principles. The GIPA principle, a very unique and groundbreaking document taken up by communities, organizations, and governments, has shifted the way that communities more broadly work with various decision makers paving the way for the acknowledgement of the value of community-led practices and lived experience seen as expertise. The HIV movement will need to draw from this historical power and learn new tactics from young people to revive and refresh advocacy efforts.

Peers as Experts



What we do best is peer to peer support. I see the results that it brings. We need to look into psycho-social support groups. It has helped us to reach viral suppression, it helps mental health, and psycho-social support is important, and trying to eradicate things like GBV...you know more about health and what facilities are at your disposal. When you are informed, it is better for you. It also brings in legal support and it is really helping in the country. The more you know about your rights the stronger you are to make decisions. It removes the sense of entitlement and AIDS exceptionalism. We know our rights then we don't expect handouts or charity we demand our rights"

Gay man living with HIV, Nigeria



We can increase our expertise and we can develop regional expert communities who can provide support to other communities.... using (existing) tools like IDUIT, SWIT, MSMIT, we have very good guidelines already [on] how to achieve meaningful participation in the implementation, monitoring, advocacy, and how to develop community and in partnership with other stakeholders."

Man who uses drugs, Moldova

THE MOVEMENT SUCCESSES HAVE COME FROM THE REALIZATION THAT PEOPLE FROM KEY POPULATIONS ARE THE EXPERTS IN THE FIELD. We have produced tools and strategies to solve issues in relation to our communities. What has also been incredibly important in building the movement has specifically been fostering channels for peer to peer exchanges and knowledge sharing amongst groups with similar lived experience. Together this important peer to peer model has been essential to the development of both knowledge generation allowing for the movement to respond effectively.

Community Support Centers

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I think that for the Sisters Foundation or for Thailand, about what we learned from the past - I think the first one is KP-led health services. I think it is successful for running HIV or AIDS programs and ending AIDS. Because it is community. So they feel like it is their second home and are comfortable to get services from the community. And yeah, I think the feeling is different from when we go to a hospital or healthcare provider like a nurse or doctor."

Trans woman, Thailand



"That is why these areas should be funded. Communicable diseases will also still be an issue. What we showed during COVID is that no matter what the health issue is, we have effective community systems."

Sex worker. Ecuador

ANOTHER IMPORTANT LESSON THAT HAS BEEN IMPERATIVE TO SUCCESS IS THE CREATION OF COMMUNITY SUPPORT CENTERS.

These spaces have been important ecosystems for communities from the HIV movement to cater to specific needs of key populations. These centers have been an integral part of people living with HIV and those most affected being linked to resources, treatment, psycho social support and legal aid. They are a powerful example of the power of our community-led solution.

Redefining Research

As a community of women living with HIV, we do our own research. It is important to know that the quality of our research is appreciated by the academic and scientific community. Women can actually do our own research."

Woman living with HIV, Kazakhstan

Community-generated data has played a significant role in the HIV response. Other movements can learn how to utilize community-generated data to inform and improve their programs, policies, and advocacy efforts.....but to access funding, we need data, but acquiring the data requires resources and funding. It's a cycle where we need data for funding, but we also need funding to gather the necessary data. This cycle is perpetuating our struggles"

Young woman living with HIV, Trinidad and Tobego

The HIV response has been very important for advancing decriminalization. The Lancet series on sex work was critical, for example. Sex workers have been saying since the 80s that access to justice, decriminalization, and not having police run our industry would reduce our vulnerability to HIV transmission in the workplace. The fact that the Lancet series made more of a difference says that sex workers' voices weren't enough, but scientific voices were."

Sex worker, Australia

THE HIV MOVEMENT HAS PAVED THE WAY FOR NEW WAYS OF CREATING KNOWLEDGE both within academic frameworks but also outside. The successes around advocacy for people living with HIV to be engaged in and lead their own research has been an important advancement in a world that tends to prioritize knowledge produced within academic institutions. As a movement, there were considerable gains in shifting the perception of what constitutes knowledge and who can create it. The PLHIV Stigma Index is one such example²³ and another is the Peer and Community-Led Responses to HIV: Scoping Review²⁴. While this is something to celebrate the HIV movement must continue to push for this to be universally realized and push back against governments and other partners that dismiss our data. In the future, the movement should continue to push limitations of research and knowledge creation, promoting community ownership.

WHAT LESSONS THE HIV MOVEMENT NEEDS TO LEARN

"That question is difficult because, from the outset, we differ from many other groups due to the issue of stigma and discrimination that makes it difficult for us to be as visible and massive as others."

Young gay man, living with HIV who uses drugs, Mexico

Anti-Rights Monitoring and Tactics

So it might be a bit strange to say, but I think where we have a lot to learn from and depending on how it translates in your national, local, national or regional context, it's to learn from the anti-rights or antigender or to learn from our opponents basically."

Young queer trans man, France



"One question for us to figure out is how can we tap into the general public's moral outrage about injustice?" Sex Worker, Australia

IN HISTORY THERE HAVE BEEN VARIOUS WAVES OF ANTI-RIGHTS

ACTORS and at current times, there is a concerning polarization and concerted efforts by anti-rights actors in the world at large. The HIV movement should learn from feminist, LGBTQI+, sex worker and other movements who have been tracking anti-rights actors. The movement needs to get ahead of these alarming trends in order to prepare for future struggles and not lose any of the grounds that were won in the recent past. By studying the tactics of anti-rights actors and opponents, the HIV movement could learn how to defend and disarm anti-rights agendas.

Retribution and Decolonization

If we have to professionalize the movement, then the community won't be able to lead it. Civil society has to reflect on these questions, and needs to reflect on power and decolonization within our movement."

Trangender sex worker who uses drugs, Spain

Decolonizing the funders is vital; we shouldn't adopt the demands of the global North. We shouldn't respond to their indicators but instead, the needs of our reality."

Young non binary person living with HIV, Chile

The two questions are, what does the future of treatment look like and how does that reach the global south? And I think those are two interlinked issues in terms of, first of all, where are the biomedical developments going? And then secondly, how do we ensure equity in terms of access to the new health interventions?"

Trans man, Uganda

GLOBALLY THERE IS A HEIGHTENED AWARENESS OF THE ONGO-ING AND LONG TERM DAMAGES CAUSED BY COLONIZATION. The HIV movement must incorporate this understanding of the historic and current unequal distribution of power and wealth to its understanding of how resources actually flow to the Global South and the most marginalized communities. These learnings can come from Indigenous and Global South movements, feminists and others using decolonizing methodologies.

Diversified Funding



Legendence on a single, large source of funding, how HIV has been, like the largest ones being Global Fund and so on, becomes too risky for the whole movement to depend on these few. So how do we integrate with climate justice, with the feminist movement, with the human rights movement, et cetera, to ensure that the work continues in whatever manner it needs to be continued?" Trans man. India



Cone movement space we might have overlooked is the labor movement. They are the oldest and largest movement in the world and partnering with the labor movement can help address economic disparities, which is crucial for health equity. Could we learn about autonomous resourcing through them?" Non-binary sex worker living with HIV who uses drugs, Canada

AS FUNDING CONTINUES TO DECREASE, IT WILL BE IMPERATIVE TO EXPAND SOURCES OF FUNDING TO SUSTAIN AND ADVANCE THE AGENDAS OF THE HIV MOVEMENT. Learning how key populations can build other partnerships with progressive donors, and movements will be important to future successes and to mitigate any potential losses. One movement that could be interesting to learn from is how the labour movement and in particular unions, organize and build collective voice and membership. We could look into successful autonomous resourcing practice as well to add to our toolkit.

WHAT ARE CHALLENGES WITHIN THE HIV MOVEMENT

Our work is so important because it is also about the people that we love and care about and have seen die and are seeing lack access to care and are seeing dehumanized. And there has to be something that we take from it. And that has to feed our egos. It has to do that. And when we let too much of our ego be the driver for our work, then it's really hard.... How do we create a distance where we're able to hear criticism of our organizational strategy or our organizational capacities as individuals and not have a response that comes from a place of fear or trauma or all of the things and that's a hard one.."

Non binary sex worker living with HIV who uses drugs, Canada

We don't have one identity, and we need to really understand that experiences are different and unique. We need to have social justice even within us. We don't hold ourselves accountable for our movement shortcomings. We always think about the large number. For example, women's issues are different from transgender issues, or gay men's issues and we need to acknowledge each person's issues holding both the sameness and the difference. In the region - there is a great stigma when we talk up about this. We need to come together but also to create space for each community."

Woman living with HIV, India



"Others see our faultlines and exploit them. At regional, national and global levels they make us fight so we need to be strong - to talk in one voice. That way when we need help we have each other." Woman living with HIV who uses drugs, Ukraine

Meddling Funders



It would be nice if donors would support decriminalization and invest in something that has long-term impact. Stop empty sloganisms: if you don't invest in structural change then you won't achieve real change, it's just empty commitments. What are donors doing to change laws that are getting key populations arrested and killed?"

Sex worker living with HIV, Kenya



Because of the lack of resources, unfortunately, we are put into a competition with other networks...It is the funders that have pushed the women in the HIV movement to war."

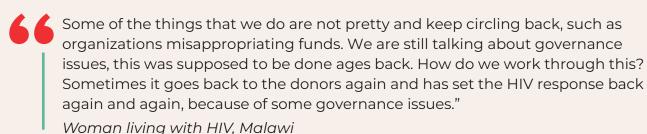
Woman living with HIV who uses drugs, Lebanon

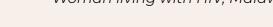
ONE OF THE BIGGEST CHALLENGES FOR THE HIV MOVEMENT IS CAUSED BY DONORS. Donors historically have caused deep tensions in the movement by causing unnecessary competition over resources and often forcing partnerships. As funding priorities shift over the years, some in the HIV movement, such as women and trans men feel invisibilized and discarded, despite funder rhetoric about championing gender. In some cases, funders create new networks to replace others that are struggling rather than investing in capacity building to strengthen the existing networks. Funders spout hollow statements about prioritizing communities but often there is not direct funding to key populations networks and community-led organizations. More often than not the funding is awarded to larger organizations or government institutions who do not always align with our values. Funders need to be held accountable for their actions and harms communities. The power imbalance of the funder and recipient relationship needs to be equalized and transparent.

Need to Support Community Expertise

We believe in community leadership and sex worker-led organizations, but they also come with serious capacity-building needs and this means we need allies to support us without taking money and power away from us. However, we can't do this and be led by the most marginalized community members if funders keep asking us to be as professionalized as cis white gay professionals who don't have the same obstacles."

Trans sex worker who uses drugs, Spain







Youth and women's networks have a difficult time being financed by donors because they think that we do not have enough capacity to manage, execute and make financial decisions with a grant."

Young woman living with HIV, Trinidad

INCREASINGLY THERE IS PRESSURE FROM FUNDERS on community-led organizations to strengthen their administrative capacity. This often translates into bureaucratic and administrative overload that small community-led organizations do not have the capacity or resources to always do to the communities to larger INGOs most of which are not community-led or driven. and undermines community expertise. Our partners, including funders and allied partners, need to understand that strengthened internal capacity cannot happen in funding ecosystems that discriminates resource allocation or investments towards community-led response institutional strengthening. Creative solutions need to be developed to navigate the tensions between led initiatives.

Intermovement Power Struggles and Conflict

People living with HIV have an HIV agenda as part of the collective. It's very heterogeneous because the only thing that unites us is the HIV diagnosis. The space is violent because every organization defends its agenda. There is a constant delegitimization of different identities. Are we HIV or are we gay? Collaborative work is essential, but how to achieve the sustainability of this collaborative work and political advocacy, which has been distorted throughout history. Nowadays, we, in some cases, act like small islands, and governments prefer to dismiss or not pay attention to our requests because internally, within the movements, we are not capable of formulating and/or articulating those inclusive requests with a genuine focus on human rights. I believe we need to formulate and strengthen young leadership."

Gay man living with HIV, Paraguay

"We always include and support key populations in our work because women living with HIV are key populations - sex workers, people who use drugs, LGBTQ - we support gay men in our country when there are harmful bills targeting them but unfortunately key populations networks don't stand up for women in the same way. It is not reciprocal." Woman living with HIV, Uganda



We must recognize that we are in a situation of growing conservatism, globally. We can't just fall into the trap of identity politics and fighting each other for funding, when the real issue is solidarity between movements and the inequalities facing us broadly."

Gay sex worker, United Kingdom

POWER STRUGGLES AND CONFLICT BETWEEN COMMUNITY MEMBERS across key populations plagues the HIV movement. Limited resources for community-led responses foster unhealthy competition and drive the majority of inter movement conflicts, creating interpersonal strife. Interpersonal issues generally impact the ways that networks collaborate and the ability for movements to work together. It depletes much needed human resources and drives distrust and siloing of communities. When the HIV movement is in disagreement and not aligned, anti-rights actors and opponents are able to reverse any gains that have been made. Working in unity and remembering that the HIV movement is stronger together will serve it well. If decriminalization, gender inclusive health services or universal access to treatment were to be realized it will take all of our collective power.

Gender Disparities

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There is patriarchy and misogyny that other movements don't experience in the same way as women in the HIV space. We face different issues, and our lived reality is very different. There are layers of inequality we experience that for example gay men may not experience. Funders take women's issues so lightly, we need to face this patriarchy together. Women are put in leadership roles but expected to do it for less. Our movement is like a pyramid, and the people at the bottom are women, holding it up with less power."

Young woman living with HIV, Nigeria



The money and the funding and stuff still goes to those who are assigned male at birth. And it's really wrecking a lot of people. Not just trans men, but it's also wrecking a lot of CIS women in their health care as well."

Trans sex worker living with HIV, United States



Positive mothers, they are going through a lot and we rarely talk about them or give space broadly in the HIV movement...There are so many stigmas associated with young women - there is a lot of burden. This set of people needs to be looked into, and we need to channel the funds to these people."

Gay man living with HIV, Nigeria

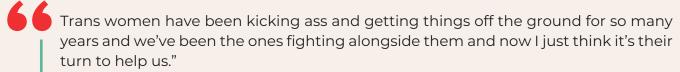
RESOURCES AND POWER IN THE HIV MOVEMENT ARE SUBJECT TO GENDER BIAS AND DISCRIMINATION. There is a particular frustration coming from networks of women living with HIV about the lack of visibility and support from the broader movement. This tension is seen as provoked competition between women and key populations specifically by funders and UN agencies. By creating these false silos, the movement fails to acknowledge intersectionality. Gender disparities are often side-stepped in the HIV movement and need to be addressed in ways that feel inclusive along the gender spectrum and also address particular issues that are experienced by those assigned female at birth, in particular around children and caregiving, access to treatment and body autonomy.

Stigma and Discrimination

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As a HIV+ gay man, I am stigmatized by other gay men....It is harder to see the inner-movement stigma but it still is there."

Gay man living with HIV, Viet Nam



Trans man, United States

I think of the challenges to working with different populations in the HIV response is stigma even among other marginalised populations against people who use drugs and drug use... and one of the ways to move towards overcoming this in future is by pushing back on the disease narrative (seeing drug use as a disease and the pathologisation of drug use)."

Woman who use drugs, Australia

IN THE HIV RESPONSE THERE IS STILL A LOT OF INTERNAL STIGMA AMONGST KEY POPULATIONS that needs to be addressed. Broad terms like "in all our diversity" are hollow if key populations continue to stigmatize and discriminate against each other. The HIV movement must not assume that communities have a shared understanding of gender, sexual orientation, harm reduction, decriminalization and the science of HIV transmission. Key populations networks need to focus on intentional knowledge building about different intersections to mitigate these knowledge gaps.

Intergenerational Divide



One of the biggest challenges is attaining decriminalization for young people. Even where decriminalization is achieved, young people are completely left behind."

Sex Worker, South Africa



Engaging young people in HIV programs and ensuring their active participation is a challenge. Strategies should involve youth-friendly services, education, and the meaningful involvement of youth in policy and program development."

Young gay man living with HIV, Viet Nam



"We should talk about growing old with HIV, historical memory, we are still living life experiences, unity between young and older activists."

Gay man living with HIV, Paraguay

AS THE HIV MOVEMENT IS APPROACHING ITS FIFTH DECADE it will need to find a way to foster new young leadership while also making space for older advocates who have been in the movement since the beginning. How the HIV movement can build meaningful collaborations between young key populations and current movement leaders will be key to future success. The HIV movement also needs to be intentional about creating safe spaces for younger participants such as children and adolescents who rarely have a voice or decision making power. This might mean looking at different tools such as technology and social media which was highlighted in particular from young participants in the focus groups.

Realization of Collective Trauma

I think that first we need to recognize and to acknowledge that there is a collective trauma. I would even say an ancestral trauma that most of our populations are actually going through. So how do we address that to be more radical in the asks that we have? And to actually see our Northern Star in the future, we do need to address that trauma."

Non binary person living with HIV who used drugs, Mexico



Working in the long term, toxic environments discourage involvement and can lead to feelings of being ostracized."

Woman living with HIV, Trinidad and Tobago

AS A MOVEMENT WE HAVE COLLECTIVE TRAUMA that on personal or local levels, groups rarely have the tools to unpack and heal. Instead the HIV movement continues to replicate many societal oppressions thereby adding to the ongoing trauma. Without the tools or space to have complex discussions, individuals work in toxic environments, and commonly experience burnt out, depression and in some cases are ostracized from the movement. The HIV movement will need to address these realities with both sensitivity and urgency for the future.

QUESTIONS RAISED AND NEW DIRECTIONS

- 1. Working with pharma. The HIV movement has historically had a strained relationship with the pharmaceutical industry, and rightfully so based corporate greed putting profits over people. Many of the key population networks have internal policies that currently prevent them from working with pharma, but it was very clear in the consultations that communities see pharma as an important partner beyond 2030. How will the HIV movement navigate the strong anti-pharma stance that many networks historically have had and explore new pathways in the future?
- **2. Language.** In one focus group there was a pointed comment made about the term key populations being outdated. As a term, it is not used in other movements and can be stigmatizing. In the past the HIV movement has used different terminology to understand those most affected by HIV. Is this something that the key population networks want to review?
- **3. Children and adolescents.** The issues of children were raised in the focus groups but were limited to women living with HIV and young people. How will issues pertaining to children and adolescents, especially those who are and/or the children of key populations be represented in our work beyond 2030?
- **4. Climate change.** The HIV response has not been equipped in climate justice framing. As more donors will be looking for us to talk about the important overlaps between climate change and health, the HIV movement needs to learn more about how to successfully advocate in both environmental and human rights spaces about the linkages. How will we adapt our work to be able to successfully advocate for both people and the environment? Is there a role that we can demand from our funders?

CONCLUSION AND RECOMMENDATIONS

THE HIV MOVEMENT HAS BEEN A POW-ERFUL FORCE OVER THE LAST 40 YEARS,

breaking ground in terms of advocacy and collaborative endeavors. It is beyond a doubt that our movement has strong adaptable lessons to share with other movements and that our unique practices should be central to our work in the global health architecture by and beyond 2030. Our role in the global health spaces should prioritize realizing discrimination and ending punitive laws, advocating alongside the UHC movement for health for all, diversification of health movements and most importantly using our community-led expertise to showcase tested best practices for bettering community health.

Our future work will need to continue to engage all current partners and continue to build on our historic relationships with governments, UN agencies, the Global Fund and other multi-laterals, but most importantly with each other as key populations networks. Our partnerships will need to expand to include movements that we have worked less with such as SRHR, feminist and migration movements, and in some cases barely at all, such as climate justice movements. We must examine the benefits and risks of previously contentious partners who have historically taken advantage of members in our movements such as pharma and research institutions; we could also add the private sector here as well. And as we continue to push for deep social change we will need to build bridges

with partners that may have even harmed us, like religious leaders and institutions because we know that we need as many allies on our side.

During the consultations we reflected on the many valuable lessons that we can take with us and share with movements in the future. These include championing community-led solutions, upholding peers as expertise, community-led research and our powerful and proven advocacy strategies. We are experts at not only talking about intersectionality but practicing it as well, working together in multi stakeholder and collaborative approaches. While we have many amazing practices to share, the HIV movement will need to learn from other movements to strengthen our anti-rights HIV specific funding is decreasing rapidly strategies to diversify funding outside of the historic HIV funding pool.

Finally, our journey towards 2030 and beyond will be brighter if we are united and together as key populations. We can only do this if we are intentional about creating processes to reflect on the challenges that we face both externally and internally. First, we need to be conscious about internal competition that is driven primarily by funders. We must be conscious of the pattern of funders dismantling networks

instead of long term capacity building or through burnout through placing increasing burden of administrative expectations on community-led organizations. When we are divided we are weaker and less effective. That is also why we need to reflect on how we treat each other and look for new avenues to address grievances in ways that do not further fragment our movement. We must understand that our movement is plagued with internal power struggles, gender disparities, racism and stigma and discrimination - often replicating some of the same oppression that we experience

from general society. One of the most powerful things that we could do is investigate how to do this work using intergenerational approaches that can mitigate our collective trauma.

This work beyond 2030 will carry many of the same challenges that we have now. As a community we need to ensure that the lessons we have learned both good and bad are used effectively to locate us strongly into the global health infrastructure beyond 2030.

Endnotes

- 1 Global AIDS Strategy 2021 2026. End Inequalities. End AIDS. UNAIDS website: https://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026_en.pdf
- 2 https://www.unaids.org/sites/default/files/media_asset/2021_political-declaration-on-hiv-and-aids_en.pdf
- 3 This number includes 125 participants in the community consultations, 15 participants in the in person pilot during the IAS 2023 Conference in Brisbane, and 10 focal points and facilitators.
- 4 In short this sampling method means that partners will select participants based on predetermined characteristics. To learn more read: https://www.statisticssolutions.com/qualitative-sampling-techniques/
- 5 Interpretation was available in French, Spanish, Portuguese, Russian, Arabic and Vietnamese.
- 6 Actual numbers and breakdown of countries in numbers: Algeria (1), Argentina (1), Australia (4), Bahrain (1), Benin (2), Burkina Faso (1), Burundi (3), Cambodia (1), Cameroon (4), Canada (1), Chile (1), Colombia (1), Congo (1), Ecuador (3), Egypt (1), Eswatini (3), France (1), Georgia (1), Ghana (3), Honduras (2), Hungaria (1), India (3), Indonesia (4), Jordan (2), Kazakhstan (1), Kenya (11), Lebanon (3), Malawi (2), Mexico (2), Morocco (1), Mozambique (4), Nepal (3), Nicaragua (1), Nigeria (5), North Macidonia (1), Paraguay (1), Peru (1), Philippines (1), Portugal (1), Senegal (1), Slovania (2), South Africa (3), Spain (1), Tanzania (4), Thailand (2), Trinidad and Tabego (2), Uganda (4), Ukraine (4), United Kingdom (1), United States (4), Viet Nam (3), Zambia (3), Zimbabwe (4).
- 7 Actual numbers and breakdown of gender in numbers: women (59), men (35), trans women (10), trans men (9), intersex (1), non-binary and gender diverse (9), did not disclose (2).
- 8 Actual numbers and breakdown of age in numbers: 18 24 (10), 25 29 (31), 30 45 (61), 46 59 (19), 60+ (4).
- 9 Of those who selected "I do not want to answer" in the demographic survey, there is a high likelihood/it was known by the facilitators that they also identified as at least one of the key population groups.
- 10 We do know that some participants represented multiple identities and listed only the correlated identity of the majority of the focus group participants. Therefore these numbers are likely higher.
- 11 These also included a space for people to self define
- 12 The survey did ask about a few identities outside of the commonly known key populations which included lesbian, bi-sexual and/or queer, migrant, Indigenous, formerly incarcerated and born with HIV and allowed for people to self identify using a comment section. This list was limited in scope.
- 13 https://www.unaids.org/sites/default/files/2025-AIDS-Targets_en.pdf
- 14 It is essential to remember that this includes people living with HIV, trans, intersex and non-binary people, sex workers, people who use drugs, and gay, bisexual and queer people. Also for this vision we must expand all gender and sexual representation with specific additional advocacy support to both younger and older members of our communities.
- 15 Community-led refers to services and/or programs that are directly led by communities. This means that there is community ownership and funding goes directly to communities. Community-based means that the services and/or programs are based in the community. Often there is a partnership with the community but it does not necessarily mean that the community is engaged in the leadership or ownership and/or a beneficiary of the funding. While both community-led and community-based are important practices in our movement, the HIV movement must advocate for community-led service where possible so the ownership and resources goes directly to communities.
- 16 Trans-led Sisters Foundation and Tangerine Clinic in Thailand were shared as examples during the consultations "Sisters and Tangerine as the only two sites to provide transgender services 100%. Now as the Sisters, we have two sites, in Pattaya and Rayong. We have the transitional health center clinic that provides for free everything for trans people, for HIV testing, for hormone, for counseling. I think we should have more programs for transgender people for HIV testing and clinics in Thailand for the next ten years. Now we will educate the government on this issue. And in the Thailand context we saw it's really successful if we provide trans-specific health services by the community. Because we talk the same language, it's like a relationship. It's very flexible and we can provide it at the right time for our community. We can open in the evening and at night."
- 17 Or mosque, temple, madre, synagogue et cetera.
- 18 An example shared in one focus group was rights groups focusing on affirming gay rights in their country but leaving sex workers behind
- 19 Many participants pointed to pharmaceutical companies but another example could be big oil companies and their HIV support including high profile branding at the International AIDS conference (2018 and 2020). At the same time they have been criticized for their environmental policies and health impacts on communities in the Global South.
- 20 Other examples can be found here: Let Communities Lead. World AIDS Day report 2023. Geneva: Joint United Nations Programme on HIV/AIDS; 2023. License: CC BY-NC-SA 3.0 IGO.
- 21 A recent example being the Jewish Voice for Peace's action in Grand Central Station (2023) was directly inspired by ACT UP's Day of Desperation (1991) thirty years prior in New York City.
- $22\,$ GIPA stands for the Greater Involvement of People Living with AIDS (HIV).
- 23 https://www.stigmaindex.org/
- 24 Ayala G, Sprague L, van der Merwe LL-A, Thomas RM, Chang J, Arreola S, et al. (2021) Peer- and community-led responses to HIV: A scoping review. PLoS ONE 16(12): e0260555. https://doi.org/10.1371/journal.pone.0260555

LEAD

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NETWORK FOCAL POINTS

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