UNAIDS STRATEGY DEVELOPMENT

UNAIDS STRATEGY REVIEW:
Focus Group Synthesis template

Organizers: GNP+, ICW, and Y+ Global
Date: August 21, 2020

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Focus Group Synthesis

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Please use the template to organize your feedback from the session. Please keep responses succinct and as clear as possible to ensure our synthesis is a reflection of the focus groups hosted.

You can enter your report directly into a form on SurveyMonkey:
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Would you accept for UNAIDS to make your report publicly available: Yes / No

SECTION 1: Information about the focus group (to be completed by host of Focus Group)

Organization leading discussion: **GNP+, ICW, and Y+ Global**
Date of discussion: **August 21, 2020**
Theme to be discussed: **People Living with HIV and Health Services**

Participants: **GNP+, ICW, Y+ Global – Including representatives from organizations in Argentina, Cameroon, Canada, Eswatini, Indonesia, Kenya, Lebanon, Malawi, Mexico, Morocco, Nepal, Philippines, Puerto Rico (US), Russian Federation, South Africa, Trinidad and Tobago, Uganda, United States, Zambia**

Country, regional or global focus: **Global**

Introducing the theme

Please enter the main characteristics of the theme being explored in 5 sentences (please share the presentation if possible by email)

People living with HIV have been at the forefront of advocating for and delivering comprehensive, quality health services that are accessible, affordable and acceptable to all. Our communities struggle with high levels of stigma and discrimination in healthcare settings; stockouts of medicines, diagnostics, condoms; poor quality services and poor retention; not enough adequately trained doctors and nurses, poor health infrastructure, and user fees and other expenses. We demand more person-centred and integrated health care (including for sexual and reproductive health and rights, harm reduction, TB, HepC, cervical cancer, mental health and others) – for young people, for men, for women, for key populations. We also demand more systematic inclusion and investment so that community organisations can scale up delivery of peer-led services to those most marginalised and advocate for human rights and gender equality.

SECTION 2: People-centered response to HIV – key emerging messages

Please enter the main messages coming out, up to 5 points maximum per section

REACHING THE PERSON	
How do we see the current situation?	● While there are many people living with HIV who now have access to HIV treatment there are numerous communities of people living with HIV who do not have access to reliable treatment and health services. Drug stockouts are a reality in many communities. ● Gender inequality, racism, classism, age-related, and other forms of discrimination related to key populations create barriers for people living with HIV to access health services including for example sexual and reproductive health and rights services, and treatment for co-infections. ● While people living with HIV have been advocating for quality health services for all - everywhere, it has yet to be realized. The lack of universal health coverage worsens the inequities in health outcomes for people living with HIV who live in poverty. ● The majority of health services for people living with HIV are based in urban areas making it hard to reach people living with HIV in rural contexts. ● Communities of people living with HIV are not systematically consulted and not engaged in the planning and implementation of health services delivery in their communities. This leads to services not reaching the most vulnerable and hard to reach. There is a lack of targeted communication materials to reach everybody including people with disabilities, Indigenous communities and so on.
What concerns us?	● We are deeply concerned about the lack of systematic engagement of all the most vulnerable groups in the technical advisory committees and implementation of health services – most notably, adolescents and young people, women, and key populations living with HIV. Often if there is representation, it is only one spot and the engagement may not be meaningful because while some partners at the meetings are well-resources to deliver programs, others are not. Often people living with HIV representatives are not part of these organizations or networks that are resources to lead programmes. ● Discrimination and stigmatization in society fuelled by discriminatory cultural norms, religious beliefs, and legal barriers prevents many from accessing services in numerous countries. For many people, it is easier to not get tested, access prevention services, treatment or other HIV related services and live in denial.

	- Access to quality health care, and trained professionals is not universal. Many people living with HIV do not have access to viral load testing (and therefore no knowledge of undetectability or if ARVs are working), preventative tests or treatments (example: HPV vaccine for young women to prevent cervical cancer in later years), and quality treatment and programs for co-infections. - Discrimination of people living with HIV in the workplace means that people living with HIV are more likely to be living in poverty and therefore having to make difficult choices between choosing their family, work, and accessing health services. Meaningful employment also means access to insurance and better health services. - Discrimination in health services and hospital settings are a barrier to people living with HIV accessing treatment, especially if they are linked to potential criminalization of one's HIV status and/or "behaviours", the potential for forced/coerced sterilization, or other bodily harm and in some cases death.
What gives us hope?	- Seeing programs and services conceptualized, implemented and coordinated by diverse people living with HIV so that they are reaching not only the masses but also the most marginalized in our societies. This includes programs that reach beyond urban centers and into remote villages and communities. - The decentralization and integration of health services including mental health services. - Health services where young people and women are mentored to take leading roles in educating others about human rights, testing, and their sexual health. - Programs that facilitate interest in health seeking and health promoting behaviors, including testing for HIV in particular for younger generations. Communities are best placed to make these suggestions and deliver health in new ways that fit lifestyles. - Well-coordinated and managed programs for people living with HIV that are resourced with qualified community staff and appropriately funded.
What constrains our ability to achieve our goals?	- There is little support both financially and politically to integrate the various levels of dialogue needed to create a strong, involved and engaged health services for diverse people living with HIV. - At the country level, there is limited funding from governments therefore, limiting the means to implement quality health services that prioritise the long-term health needs of people living with HIV.

	● While networks of people living with HIV have the knowledge and capacity to conceptualize and implement health services that are community-led and reach the most vulnerable, we are under-resourced to do so. This creates a disconnect in communication between national, regional and global level networks and how we work and translate information to the broader public. ● We do not see a commitment to practicing the GIPA principle and the representation and engagement of people living with HIV from diverse experiences in lead roles and paid positions in health services nor in decision making bodies. ● Despite being the leading cause of death for young women globally, not to mention over 60% of new cases are in key populations communities, HIV prioritization has declined over the years. We have seen during the COVID-19 pandemic, how quickly resources can shift away from HIV services and towards another health issue leaving people living with HIV vulnerable.

THE STRUCTURES THAT RESPOND TO HIV	
How do we see the current situation?	● There is a concentration in the HIV response on biomedical solutions for HIV while behavioural and structural components are left out. We see the impacts clearly during country stockouts of treatment and/or gaps in treatment services. ● Sexual and reproductive health and rights are not addressed broadly and gender is not put in focus leaving many women and in particular, young women and girls behind. ● Our networks are weakened as movement building and capacity building of people living with HIV are not included in funded proposals. The repercussions of this creates stress on under-funded organizations working in the field and in a number of cases collapses in local networks in particular of marginalized groups and women. ● In the HIV response, systematic structural barriers and human rights violations create poorer health outcomes for key populations, Indigenous people, incarcerated people, women, you people, and those most marginalized in our communities. Without actual movement forward to dismantle punitive laws and to address human rights violations, the HIV response will not succeed.
What concerns us?	● We are deeply concerned about the lack of resources to fund, support, and adequately equip networks of people living with HIV. More so, we are concerned specifically about the lack of resources for networks led by and for women living with HIV. We see the steady decline in the number of national networks of women linked to a weakened global movement. The result of this is a lack of empowerment of women and girls and a weakened gender response.

	● Mental health is an issue that impacts all people living with HIV but there are limited programs and services that link mental health with general health outcomes. Mental health services including those delivered through peer support need further investment. ● Access to quality treatment and other medications without treatment gaps and stockouts remains of concern. In addition, there is a lack of screening and treatment available for non-communicable diseases and co-infections for people living with HIV. There is also a lack of adequately addressing co-morbidities and side-effects related to HIV medication. ● Governments are not accountable to treaties and conventions signed to end AIDS (including the Abuja declaration - 15% of the budget to health). There is a lack of support for civil society initiatives to hold governments accountable. ● We have to make sure young people, women and key populations are involved in decision making platforms through involvement, backed with resourcing to deliver on programmes and be part of policy development. We are concerned with the lip service of GIPA in structures that respond to HIV.
What gives us hope?	● The push in some countries for health services to also address gendered issues such as gender-based violence, and empower women and girls to advocate for their rights. ● The movement of vibrant young people living with HIV! Their readiness to step up and fight for rights. We are excited that we now have an active and supported global network to do this. ● We welcome the advancements on HIV innovation such as PrEP, self-testing and the vaginal ring. We support greater investment in the HIV cure and vaccine research. ● Even though there are many networks and community groups that are under-funded, we are encouraged that our movement is continuously working for the collective betterment of our communities. During the COVID-19 pandemic, it was our networks that were on the front lines creating innovative solutions to the most pressing needs of people in our communities. ● UNAIDS is ready to listen to the community and want to find solutions to ensure that communities are put first not only in words but in practice. We are excited and welcome the collaboration and joint workings of the three global networks of people living with HIV. We want further support for our joint collaborations to continue in the future.
What constrains our ability to achieve our goals?	● Resources are the biggest structural barriers for person-centred health services that engage communities. Of particular concern is an unwritten lack of trust of donors in networks of young people and women living with HIV. The lack of resources makes it very difficult for our advocates to engage at decision-making spaces and to implement the essential health services at the

	community level. Without resources we do not see GIPA being an actuality in many countries and settings. ● Stigma and discrimination remain huge barriers to accessing health services. It is also a barrier for some advocates to be open about their status in local and global platforms. ● Governmental laws and policies, and the criminalization of HIV, sex work, drug use, gender expression, and same sex relationships, are barriers for many of us to do the important work that we are doing to ensure that people living with HIV from diverse groups have the same access to treatment and other health services. ● Without universal health coverage we will continue to have systems that include high user fees for health services that many cannot pay as well as a dependency on donor subsidies for health services.

CONTEXTUAL ENVIRONMENT	
How do we see the current situation?	● The COVID-19 lockdowns, while necessary to slow the spread of the pandemic, resulted in human rights abuses and the restricted access of treatment and services for people living with HIV. Many people living with HIV outside urban centers and in different regions struggled to access treatment and the health services – including social security that they needed. Stockouts in the last few months were an ongoing reality for many people living with HIV, including children and adolescents. The COVID-19 pandemic showed us the precariousness of the current HIV infrastructure. ● In many communities we are witnessing a reduction in qualified health care providers (including in harm reduction, testing, counciling) and community advocates to fight for our health rights. This is based on the low or non-existent wages in direct services especially in rural areas where the salaries are not competitive. ● People living with HIV, especially adolescent and young people have limited choices on where to access treatment. This can also be linked to the need for parental consent. ● There is a lack of holistic healthcare and supports needs - specifically mental/emotional health services to deal with the impact of HIV.
What concerns us?	● The division between public and private investment in HIV and neither one being an adequate strategy. The insecurity of depending on governments to fully fund the work including health care workers as well as other issues, such as COVID-19, present themselves are risks for the future sustained investment in the HIV response by governments and donors.

	- The problems of data being hacked and/or not being kept confidential and the sharing of personal health information like one’s HIV status which can have grave impacts on our health and lives. In addition, the surveillance and selling of biometric data to the state and countries where HIV is criminalized. We are also concerned that while innovation and new technologies are good there is an over dependence on technology that leaves us open to confidentiality breaches. - During the COVID-19 pandemic, we have witnessed an increase in new infections while clinics are closed, and numerous reasons for people being unable to continue their treatment. Support for prevention of COVID-19 for people living with HIV is limited. There is also a de-prioritisation of HIV services such as viral load monitoring as these machines and other equipment as well as health care staff were shifted to COVID-19 testing. The timelines and frequency of HIV services are not continuous as resources and support is being redirected to COVID-19 response. - People living with HIV should be at the center of the design and implementation of programs and services for people living with HIV. We are concerned that people living with HIV are seen merely as statistics and often there is little contact with on-the-ground peers who can help coordinate. Test-and-Treat protocols remove personal interaction and education. - No meaningful consideration or provision of services for sex workers, people who use drugs, men who have sex with men, transgender people, incarcerated people, migrants, and Indigenous people.
What gives us hope?	- When we are able to collaborate meaningfully with donors and decision makers to address the needs of diverse communities of people living with HIV. - When time and commitment is put into succession planning and mentoring people living with HIV, in particular young people and women to take on new leadership roles in a coordinated and powerful HIV response. - Other intersecting movements such as Black Lives Matter, Defund the Police, the anti-government corruption protests in Beirut, to show the power of activists challenging systems of power around the world. - Peer programs using social media platforms as ways to share our stories and struggles globally. - New research and treatment options give hope for seeing HIV as something of the past.
What constrains our ability to achieve our goals?	- At the core we see the denial, refusal of voices of young people living with HIV, women and other key populations such as sex workers, people who use drugs, people with disabilities, men who have sex with men, transgender people, and others in developing governmental and organizational responses on issues that impact the lives of people living with HIV. This

	includes the exclusion and/or tokenism of people living with HIV in processes including a concentration of consultations with few gatekeepers in urban city centers. ● We see limited investment in long-term sustainable funding of networks and community organisations as a constraint to seeing progress in the HIV response. Most of our time is spent writing grants, reporting, and in administrative red tape when people living with HIV in the movement could be doing the actual work needed. When it comes to the implementation of health services and programs designed by people living with HIV there are little resources for this to happen as they have been developed. ● Funding for treatment in many countries disproportionately comes from donors as there is a lack of domestic funding or resources to sustain these programs (in particular ARV procurement). ● Monitoring of human rights violations in health services depends on external partners to support the documentation as systems of power and control over our bodies in relation to sex work, same sex relationships, gender identity and expression, drug use, and reproductive rights greatly impede advancements made in the HIV response. Human rights defenders living with HIV need protection and support to have a freedom to talk about our HIV status (and other intersecting identities) without fear. ● Capitalism doesn't allow for sharing of resources, and interdependence within communities. It is competitive, pervasive, unrelenting and not kind. We see this as a barrier to accessing quality, unbiased health services and as the root to poverty and injustice.

EMERGING PATTERNS:

- Through the COVID-19 pandemic, we are encouraged that our movement is continuously working for the collective betterment of our communities. During the COVID-19 it was our networks that were on the front lines creating innovative solutions to the most pressing needs of people in our communities. Once again, we saw networks of people living with HIV stepping up on the front lines to respond to a public health crisis. But what our networks noted as a deep concern is that HIV and sexual and reproductive health services have been deprioritized during COVID-19.
- We know the power and success of programs and services that are conceptualized, implemented, and coordinated by diverse people living with HIV. We know that these programs are able to reach not only the broader public but the most marginalized in our societies.
- Networks want meaningful collaboration with each other. The global networks have been actively collaborating through this process, and the support for this joint endeavor has been overwhelmingly positive and "inspiring". We want UNAIDS and our partners to continue to support collaborations and meaningful engagement led by networks of people living with HIV as we continue to work together.

- We want the prioritization and increased investment to deliver on comprehensive integrated health services which are human rights and evidence based and include sexual and reproductive health services and mental health.

SECTION 3: RECOMMENDATIONS World Café

Please enter the main messages coming out, up to 5 points maximum per section

What are the key recommendations back to UNAIDS in terms of the strategy specifically?	
CONTINUE	• *CONTINUE: Involvement of networks for and by young people, women and people living with HIV in policy development and programming at local, regional, and global levels. Continue to reach out and ask (but also listen) to what their priorities are and how they want to implement their activities.* • *CONTINUE: Advocacy for the human rights and inclusion of all vulnerable groups including men who have sex with men (and women who have sex with women too), transgender people, people who use drugs, sex workers, Indigenous people, migrants and refugees, women, young people, people living with HIV and other marginalized communities by ending punitive laws and calling out discriminatory practices.* • *CONTINUE: Building the capacity of civil society and providing technical support to bridge the gaps between community and governments. Continue to help us hold our governments accountable.* • *CONTINUE: Supporting methadone assisted therapy/ harm reduction services in countries as well as promoting the creation of favourable legal working environment for people living with HIV organizations to engage in difficult human rights work.* • *CONTINUE: To ensure that people living with HIV networks get emergency/catalytic funding to support the organizations sustainability through COVID-19. Continue to support HIV in other pandemics and emergency situations.*
STOP	• *STOP: Tokenism of people living with HIV. UNAIDS should stop doing non-ethical engagement of people living with HIV when they are invited to be the part of the meeting for ticking a box.* • *STOP: Non the contextualizing of the UNAIDS strategy to fit different countries to cope with the inequalities in services for people living with HIV, prevention, and sexual and reproductive health and rights services.* • *STOP: Being silent about gender issues and deprioritizing sexual and reproductive health and rights issues. Stop ignoring women and girls living with HIV including their claims about gender inequality and rights violations.* • *STOP: Making ministries of health and government UNAIDS's primary partners in the regions and at country level.*

	- *STOP: Threats to funding withdrawal or stopping funding for networks of people living with HIV when there are issues. Instead find different approaches to disburse the available funding and solutions to improve the situations.*
START	- *START: Engaging with more countries and regions that have been left behind in relation to data collection and/or disconnects between country claims and what activists are saying. (Example: Puerto Rico is not taken as a country, no data, and accountability for the US government.) Starts supporting countries to transition out of Global Fund funds, including funding advocacy.* - *START: Acknowledging that human resources under catalytic funding be considered important. Human resources are not free and should be budgeted for.* - *START: Holistic approach to the HIV response including complex challenges. Advocate to other donors about flexibility in the HIV response.* - *START: Acting as a negotiator for prices of medication between the people and pharma companies. Start working in intellectual property and access to medicine. Intensify advocacy in addressing the research for HIV cure.* - *START: Supporting psychological and mental health. Include this in the work on stigma and discrimination as well as part of universal health coverage.*
What is the one key recommendation you want to reiterate for strong consideration?	*Networks of people living with HIV have decades of experience of improving the health and well-being of their communities - by delivering health services, to all communities, by monitoring the quality of services, and by advocating on issues including stigma, human rights and gender equality. UNAIDS must do more to ensure that governments meet their commitment on social contracting by recognising and adequately resourcing this community leadership and contribution to their national health systems. Community engagement is essential to making universal health coverage deliver on its promise for health for all.*

Please share with us any references you think would be useful for the Strategy Development, such as examples of case studies that illustrate the challenges or recommendations you outlined in the discussion report.

Please also share a list of names and email addresses of participants who would wish to continue to be informed of the Strategy development process. Note names and contacts will not be shared publicly or with any third party.

You can send us additional documents via e-mail ***strategyteam@unaids.org***

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