UNAIDS STRATEGY DEVELOPMENT

UNAIDS STRATEGY REVIEW:
Focus Group Synthesis template

Country: Latin America and the Caribbean

Organizer: **RST LAC - Renpo**

Date: August 27, 2020

UNAIDS STRATEGY REVIEW: Focus Group Synthesis template

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:
https://www.surveymonkey.com/r/3HC9Q6M

If you are not able to enter it on line you can send us a copy via e-mail ***strategyteam@unaids.org***

Would you accept for UNAIDS to make your report publicly available: Yes

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

Organization leading discussion: RENPO

Date of discussion: August 27, 2020, from 3:30 p.m. to 7:00 p.m.

Theme to be discussed:

- Social determinants - Reduction of inequalities - stigma and discrimination - SDG 10
- Integration of the two medicines - allopathic and traditional – SDG 3 adherence and retention in ARV treatment

Participants (types of organizations participating):

- Country networks of indigenous people of Aymaras (Chile) Mapuches (Chile), Guaranies (Paraguay), Muxes (México), Maya Kaqchike (Guetemala), Waraos (Venezuela)

Country, regional or global focus: Regional (LAC)

Introducing the theme

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

- Indigenous peoples: the appropriation of prevention and learning.
- ARV medicines and traditional medicine. How to promote complementarity - the cohabitation of two models
- How we create strategies together to have specialized programs that respond to the needs of indigenous peoples

- How to achieve specialized programs in health centres that translates and explains the services to indigenous people
- Multiple inequalities faced by indigenous peoples - reduce them

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

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

REACHING PEOPLE	
How do we see the current situation?	• In some Central American countries, health services are centralized in the capital. The response in the interior of the country is weak – in reality, there is no response. Furthermore, with each change of government, there is no will to implement strategies to respond to HIV. Indigenous peoples and young people perceive a lack of access to information – especially information on prevention. Prevention efforts should be prioritized. There are public policies that are not aimed towards educating young people on sexual and reproductive health and rights, specifically HIV: we are not educated in schools. • In Panama, HIV is only talked about concerning homosexual subjects – straight, young people have no way of knowing about HIV and even less about aids. There's a lack of education in the communities in general, mostly among indigenous populations and young people. In my country, the approach is not prevention and information-based. • In Chile, thanks to the work of RENPO, there is some progress. As indigenous populations, we are always focused on education, because there's a lack of it. The governments never consider us, and they ignore the Mapuche people. The state is racist against us. • In Chile, the government does not carry out campaigns that are relevant within indigenous communities. We are always waiting for someone to take us into account; HIV is rarely talked about, but it is a massive pandemic in our country. • In Paraguay, culturally conscious information in indigenous languages is missing. There are also no campaigns directed at indigenous peoples; this is a very significant limitation. Moreover, access to information is minimal. The isolation of indigenous peoples does not favour acquiring inputs for HIV prevention. • The importance of cultural relevance for indigenous peoples: the infographics and campaigns directed towards us are designed and developed by people who do not know the indigenous population or our reality. For example, the issues that NJUVE works on in Mexico are not contextualized to the communities they are targeting, let alone the indigenous population, who have different needs from those who live in cities. Those in charge do not consider cultural or indigenous medicine. Moreover, they do not include contextualized information. I have not seen data on HIV and indigenous peoples; there is a lack of linkage between these points. • In Venezuela, the response of solidarity groups is not focused on indigenous communities, and their campaigns/information are not in indigenous languages. The response should be focused on them, since they are our roots. • In all the countries in LAC, we have been divided and separated by territories. This has hampered working jointly to make governments aware of our needs.

	• A strategy to strengthen the networks of indigenous peoples in each country should be developed. Indigenous groups could strengthen each other by sharing information between themselves. It's important for these issues to be on the table when national programmes are being discussed and developed.
What concerns us?	• In our countries, HIV is not a topic of conversation. We need to talk and learn about HIV to address our fears and face our disease. • Lack of alliances between countries and territories. Each territory has its own strategies they can share with other communities. I am concerned that there is no strategy to share information and knowledge on HIV and aids. If it exists, it is not well known and/or it does not have the scope it should have. • The information does not reach everyone, and there is no culturally relevant information. If it exists, I am concerned that it is not reaching the people it is meant to reach. The low number of local campaigns is worrying. • Not all people have access to the internet or the other communication methods (television, for example). This situation makes it difficult to transmit culturally relevant information to these people. • We are concerned that traditional medicine elements are not being considered when developing the response to HIV in indigenous communities.
What gives us hope?	• The organizations that have reached indigenous peoples give me hope. • The access to information has empowered me, this gives me hope. Moreover, the prioritization of indigenous communities also gives me hope. • Give focus to the rites, and rhythms that give tranquillity, so that the immune system is strengthened. Don't focus only on ARV treatment, but on indigenous spirituality as well. • It gives me hope that, as part of the response, the rituals and rhythms that provide tranquillity are included, so that the immune system is strengthened—both on ARV treatment and indigenous spirituality. We, as indigenous people, have a rich knowledge of spirituality. We keep our medicine alive. • The most important thing is that we are joining forces to move our communities forward. This gives me hope. • We must develop a document that is widely recognized and that addresses indigenous issues.
What constrains our ability to achieve our goals?	• The spreading of our populations in the countries in LAC. There is a lack of monitoring and support: health promoters in indigenous communities do not do adequate monitoring and support. • The lack of information available in indigenous languages. The lack of education greatly limits access to medication or prevention efforts. • Indigenous populations' access to health services. People die because journeys to acquire ARVs can last up to three days. In Paraguay, ARVs are freely distributed, but people must travel many kilometres to reach them, and there is no monitoring to ensure everyone has access to treatment.

	• Monthly dispensing of ARVs - the indigenous population should be given multi-month dispensations, especially because of the distances they must travel to acquire their medications. In the case of indigenous peoples, we cannot keep up with the pace in clinics. If there are no changes, the death toll of this pandemic will keep rising. • Health agents lack awareness regarding indigenous people and their rights. We have been told that indigenous people cannot contract HIV, and this is simply NOT the case. Health workers' lack of awareness could continue to limit and weaken us. • The lack of campaigns that consider indigenous health forms. We have knowledge in many areas, especially mental health. There are very few campaigns directed towards indigenous populations and they have no cultural identity. By law, these campaigns must be translated into indigenous languages.

THE STRUCTURES THAT RESPOND TO HIV: QUALITY, FREE AND TIMELY PUBLIC HEALTH SYSTEMS. HEALTH EDUCATION, HEALTH CAMPAIGNS IN INDIGENOUS LANGUAGES, STATISTICAL DATA, SUPPLIES AND PROTECTION OF INDIGENOUS HEALTH. NATIVE METHODS IN HEALTH. (INDIGENOUS MEDICINE). MEDICATION AVAILABILITY. AVAILABILITY OF INFORMATION IN INDIGENOUS LANGUAGES, PREVENTION, TREATMENT AND INTERCULTURAL DIALOGUE. INCLUSION OF INDIGENOUS YOUNG PEOPLE'S LEADERSHIP AND DECENTRALIZATION OF NATIONAL HIV AND HEALTH ACTIONS. PUBLIC HEALTH INSTITUTIONS' COVERAGE. HEALTH SERVICES WITH CULTURAL RELEVANCE AND TECHNICAL TRAINING TO STAFF.	
How do we see the current situation?	• The health structures in our countries are designed for urban populations and are not suitable for indigenous communities. • The few programmes that focus exclusively on indigenous communities have enormous language limitations that make it difficult for indigenous peoples to have proper access to care systems. It also makes it difficult for doctors and health personnel to provide care. • In addition to the gaps or language barriers, there is also no consideration or respect for people's needs, customs, and traditions regarding public health issues. • The few States that have included programmes that adapt to the realities of indigenous communities in their public policies are not sensitive enough towards the different indigenous communities that have settled in the country. States tend to group all indigenous communities as one, making their individual needs invisible. • There are substantial regional gaps within our countries, which are worsened by the politization and electoral manipulation of HIV and other sensitive issues. • Indigenous populations' traditional health practices are not respected by national health systems. Our sages must be heard and allowed to contribute to health efforts and public policy as well.
What concerns us?	• Human rights cannot be guaranteed until public policies are modified to be more inclusive and sensitive towards indigenous peoples' needs.

	• The lack of information, support, and access to medicines greatly increases the impacts HIV has on our lives. We will never achieve our goals with a system that excludes us from the responses. • There is no curriculum sensitive to indigenous issues within educational systems. • There can be no effective decision-making processes, or inclusive or effective public policies if there is no data or technical statistics.
What gives us hope?	• Spaces, like this one, that allow us to reflect, propose ideas, and improve mechanisms give us hope.
What constrains our ability to achieve our goals?	• The Public Policies on Health, specifically those related to HIV, are not sensitive to indigenous peoples.

CONTEXTUAL ENVIRONMENT: ELIMINATION OF STIGMA AND DISCRIMINATION	
How do we see the current situation?	• The current environment is adapted to the pandemic, with home delivery systems of ARVs for indigenous people. When ARVs are not collected, people are called to pick them up, or they're delivered to their homes. Favourable environment for access to ARV during the pandemic. • The health services never reached indigenous populations. The governing authorities committed to reaching the 90-90-90 goals; however, they did not take action to achieve them. • HIV programmes are free to everyone, including indigenous populations. The health systems of each country limit the inclusive participation of indigenous populations. • The public health policies are *flat* and don't consider the needs and realities of indigenous populations. The health system is aggressive - it thinks more about business than about people's health. In health services, people are not treated humanely. The counselling and diagnoses protocols are not respected. • Indigenous populations aren't educated on HIV. There is a lack of support and public policies focused on people living with HIV and indigenous populations.
What concerns us?	• We are concerned about the social part of indigenous population's health. We are worried about the abuses that lead to the death of indigenous people without HIV treatment. Scheduled surgeries are being postponed due to the COVID-19 pandemic. • UNAIDS never truly considered indigenous populations and their needs. We are concerned that both UNAIDS, and the rest of the world, will neglect indigenous populations. • We are concerned about the effects the pandemic will have on indigenous populations. Furthermore, many indigenous communities are significantly affected by HIV. • We have many limitations, but we must work autonomously within our communities.

	• There is no intercultural public policy and many HIV cases are not reported. Moreover, indigenous populations who don't know what HIV is don't have access to treatment and prevention services.
What gives us hope?	• This platform gives us hope – to be listened to and taken into account. It gives us hope that there are spaces like these and indigenous population organizations that ensure that this population's voices are not heard. UNAIDS must come together with the *children of the earth* to validate this new strategy. • The possibility to create a new strategy that significantly includes indigenous populations and their rights. Prevention is a global solution to all diseases; we must work on prevention efforts. There are rural indigenous populations that need education and information on prevention. • Re-establish trust between indigenous populations and governments. The education and health sector should work closer together protection spaces for indigenous populations. • It gives us hope that one day our communities will be able to autonomously respond to HIV and improve this disease's situation. • Continuing to educate young people gives us hope. Moreover, comprehensive sex education for young indigenous people gives us hope. Young indigenous people must know how to care for themselves.
What constrains our ability to achieve our goals?	• The combination of both medicines (mainstream and indigenous) limits us: two treatments that do not integrate. UNAIDS and PAHO don't recognize the existence of different cultures, languages and autonomous systems. • The UN doesn't respect cultural diversity, this limits us. There is no respect for interculturality. We will not move forward until governments understand and recognize what interculturality is. • Cultural coexistence and the lack of access to information and communications technologies limit us.

EMERGING PATTERNS:

- In some Central American countries, health services are centralized in the capital. The response in the interior of the country is weak – in reality, there is no response. Furthermore, with each change of government, there is no will to implement strategies to respond to HIV. Indigenous peoples and young people perceive a lack of access to information – especially information on prevention. Prevention efforts should be prioritized. There are public policies that are not aimed towards educating young people on sexual and reproductive health and rights, specifically HIV: we are not educated in schools.
- A strategy to strengthen the networks of indigenous peoples in each country should be developed. Indigenous groups could strengthen each other by sharing information between themselves. It's important for these issues to be on the table when national programmes are being discussed and developed.
- The information does not reach everyone, and there is no culturally relevant information. If it exists, I am concerned that it is not reaching the people it is meant to reach. The low number of local campaigns is worrying.

- The health structures in our countries are designed for urban populations and are not suitable for indigenous communities.
- The few programmes that focus exclusively on indigenous communities have enormous language limitations that make it difficult for indigenous peoples to have proper access to care systems. It also makes it difficult for doctors and health personnel to provide care.
- Indigenous populations aren’t educated on HIV. There is a lack of support and public policies focused on people living with HIV and indigenous communities.

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 precisely?	
CONTINUE	• Continue bringing the information to the communities. Also, continue working towards expanding capabilities. • Continue supporting people living with HIV. Ensure that the information is in their native languages. Develop strategies for the distribution of information through the spoken word, because some people cannot read or write. Videos and other audio-visual educational materials are required for distribution to audiences lacking adequate reading skills. • Continue with the UN-led volunteering programmes that reach the indigenous communities who are isolated and assess their needs regarding HIV. As for volunteering, who better than us indigenous people to contribute to the response to HIV. We know the realities of indigenous populations, and we know our resources. We must develop strategies that make use of our knowledge. • Keep listening to us. Open spaces, like this one, for communities, indigenous communities, and the rest of the diverse population that responds to this issue. Open spaces for youth, women. • We are currently working with counselling services. We need the UN to identify us as a key population and to recognize indigenous medicine and its influence on adherence to ARV. • Indigenous populations are not included in the health policies established by UNAIDS. Empathy towards indigenous populations is essential. • We have not reached the MDGs, and we created the SDGs. With the pandemic, achieving the SDGs becomes more difficult as well.
STOP	• The "message" is not reaching indigenous populations; it should not be assumed that all people have access the internet or social media. Access to information must be guaranteed. Stop excluding indigenous peoples from HIV prevention and treatment programmes and other responses. • Stop the belief that people who don't belong to indigenous communities are more knowledgeable than the communities themselves, this has very negative effects on indigenous populations. • Integration at a country level is needed. In the case of land and water, we should not stop building structures as indigenous communities. We cannot allow the isolation the states have subjected us to, and their efforts to establish reservations. We must develop inter-ethnic ties to rebuild our networks and keep insisting to states that indigenous populations deserve to be recognized and treated as a social group in each country. We must not stop making this effort to build inter-ethnic structures. • DO NOT stop fighting for our health and HIV, so that we may achieve the goals we have as a population. We are fighting, and we will continue to fight for our brothers and siters who need us. We must reach every corner and continue fighting towards ending the HIV epidemic. We must join efforts to continue making our demands and ensure we are

	heard. Discrimination must be eradicated. Rather than empty words, let's take action. • Not enough effort has been made to make indigenous peoples visible as key populations. • There has been a lack of sensitivity towards indigenous traditions, customs, and values. We are human, we live different realities, and we must be heard. • UNAIDS must focus more. • Stop putting us on a par with other populations - we have special needs, and there isn't a specific response directed solely towards indigenous communities. Most calls are generic and general. • Embrace our cultural idiosyncrasies and stop trying to erase them. Be more empathetic and respectful of different cultures. We must start working jointly, in all sectors, to address the issues indigenous populations face.
START	*What are we not doing that we have to start doing?* • We have neglected the statistical and historical components of our communities. We must celebrate those leaders who fought from extreme poverty and crossed borders using their own resources – this must be made visible in large countries like Brazil. Leaders must be celebrated. • We do not have hard and disaggregated data on how many indigenous people have died from HIV. We need this data. We also need a database that is accessible to all of LAC. • More advocacy is needed regarding our issues, needs, and realities. UNAIDS must empathize with our indigenous communities. No one knows what indigenous people, or people living with HIV, feel or suffer. People in the city and those in the interior of the country do not share the same feelings. We need empathy towards indigenous people. We also need specialized communication messages that take into account the realities and needs of indigenous peoples. We must continue the conversation about interculturality. • We are leaving aside the issue of grief. When someone finds out they are HIV positive, they go through a period of mourning. These mental health issues must be addressed. • We do not know if young people living with HIV are receiving support – they will be on life-long medication. Sexual and reproductive health education is needed. It must also be managed according to the different developmental stages young people go through. If we educate them, we will create knowledgeable and empowered young women. • The context in which young women live - patriarchy is deeply rooted in the communities. We are aware of what men are told – don't use condoms because you'll lose virility. They are experiences that we, as young women, live. We must begin to sensitize, inform, educate, and understand the entire indigenous population's context and knowledge, including that of indigenous women and youth. Once we understand how they live, we can develop strategies that are directed specifically towards indigenous women. • Health systems are strengthened with traditional knowledge and medicine. This neglects the fact that there is a wealth of knowledge

	available to all humanity when it comes to the spiritual component of the response. There is a lack of awareness among medical personnel. Moreover, the role or function of traditional healers and doctors, and how ancestral ceremonies and rituals can be helpful in times of crisis, are not recognized. We are not working together to respond to address the mental health of key populations. The programmes UNAIDS supports should promote access, and, from and allopathic standpoint, recognize the value of our traditional healers and rituals. Start integrating the two medicines and increase prevention for indigenous populations. Treatments must be appropriately marketed towards indigenous populations for them to work. • Indigenous people are not included in health policies at both national and international levels. Efforts to guarantee confidentiality and privacy are needed. UNAIDS must promote and respect free, prior and informed consent and demand that states respect this right. Comprehensive actions in the response for indigenous populations are needed. • Open specific financing windows for indigenous populations. • The new UNAIDS strategy should have a differentiated approach towards indigenous peoples. We need specialized protocols to treat HIV in indigenous populations, based on our unique needs. These protocols must also be taught by indigenous health personnel or other health personnel who are sensitive to us and our worldview. You must decentralize and work as a team. Moreover, food supplements are needed for indigenous populations. • You must reach indigenous populations in rural areas. Our autonomy is essential, and we need resources from the State to respond to HIV within our communities. • UNAIDS must become more involved with young indigenous people. Many of them migrate to cities and aren't prepared for the situations they will encounter. There should be a focus on prevention campaigns that target young people living in rural communities, so that when they migrate to the cities, they aren't caught off guard and their risk for contracting HIV or other STIs isn't increased.
What is the one key recommendation you want to reiterate for strong consideration?	• Disaggregated data is needed for indigenous people living with HIV. • Funds should be allocated to specific programmes for indigenous populations. • Our healing ceremonies should be included in the response to HIV. No documents or informational instruments that include indigenous healing ceremonies or other practices that will strengthen individuals' mental health have been developed. Manuals that are useful for managing the process of mourning, healing, and accepting the status of living with HIV, with the relevance of ancestral rites and values, and considering the peace and spirituality that each nation experiences, should be developed. This educational instrument must be developed by indigenous people, for indigenous people. • Work more with mothers. There is stigma surrounding women's use of contraception and protection methods – this is frowned upon by indigenous people.

	• Data disaggregated by sex, age, gender, LGBTQ+, indigenous population, language, is required. If we are going to make something visible, we must think carefully about how we want to disaggregate it. • Peer-training for young people, with a specific focus on indigenous populations, is needed. • In the new UNAIDS strategy, there must be a specific approach towards indigenous populations. Under the vulnerability concept, UNAIDS must recognize indigenous communities as key populations, allocating programmes and resources towards their response. • More efforts to sponsor and promote specialized networks of indigenous peoples are needed. • We could transform the word AIDS into something positive: Acceptance, Integration, Diversity, Solidarity. • UNAIDS should focus on working towards decentralization, empathy, and the intersectionality of interculturality. We must include every person and their diversities. • Work with young people, who are the present and the future. They're also the most vulnerable on social media. • It is necessary to discuss more in depth how we can be a part of the response.

Please share with us any references you think would be useful for 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 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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