

# UNAIDS STRATEGY DEVELOPMENT

## REVIEW OF THE UNAIDS STRATEGY:

### Focus Group Synthesis Template

**An alternative proposal for consultations via WhatsApp with migrants and refugees in Latin America**



Countries	Colombia, Ecuador, Peru
Organizers	Red Somos (Colombia), Diálogo Diverso (Ecuador) and Aid for Aids (Peru)
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## Introduction to the report

In the process of convening the Focus Groups through non-governmental organizations that have programs for migrants and refugees living with HIV in Latin America, we were informed of methodology limitations in carrying out the Focus Groups as foreseen due to the following aspects:

- **Low connectivity:** lack of internet access by refugees and migrants for a long time, which would prevent them from staying connected to the Zoom session for more than an hour.
- **Privacy:** given that they are migrants or refugees, most of them live in shared accommodations, so they do not have a physical space in their residence to have a private conversation. Some believe that disclosing their HIV status could affect their relationships with roommates, neighbors and even leaseholders, many of whom do not know they are HIV-positive.
- **Confidentiality:** to a lesser extent, some of the migrants or refugees stated that they felt restrained from participating in consultation sessions where they could be identified as a person living with HIV by their voice or by comments made to others,

In response to these limitations, and with the desire to keep listening to the voices of refugees and migrants living with HIV in the countries that have received the greatest number of Venezuelan nationals in recent years (Colombia, Ecuador and Peru), the UNAIDS Regional Office proposed a consultation methodology via WhatsApp, since this application is used by those consulted on an ongoing basis to maintain contact with their families and for work purposes.

The UNAIDS Regional Office designed this methodology using two tools:

- 1) **A WhatsApp group created per country**, with those who express their interest in participating through this channel, which would allow the exchange of views and opinions; and
- 2) **A broadcast list** through which messages could be sent to several people at once, without them seeing each other's phone numbers. Using these lists, you can re-broadcast a message to the same recipients without having to select them again one by one.

Accordingly, the questions were distributed employing both tools so that the participants could send their answers through texts or voice messages, which were then transcribed and recorded in this format.

## SECTION 1: Focus Group Information (to be completed by the NGO that will support the offline invitation)

### Identify the host organization:

- **Host organizations of the discussions:** Red Somos (Colombia), Diálogo Diverso (Ecuador) and Aid for Aids (Peru).
- **Number of migrants and refugees summoned for consultation:** 21 people were invited (18 men and 3 women), out of which 12 people finally participated (10 men and 2 women).
- **Topic of the discussion:** Migration and Access to HIV related services.
- **Participants (types of organizations involved):** Venezuelan refugees and migrants living with HIV in Colombia, Ecuador and Peru.

Sex	Sexual orientation	Country	Status
Man	Gay	Colombia	Asylum seeker
Man	Gay	Colombia	Regular migrant
Man	Gay	Colombia	Asylum seeker
Man	Gay	Colombia	Asylum seeker
Man	Gay	Ecuador	Regular migrant
Man	Gay	Peru	Regular migrant
Man	Heterosexual	Peru	Regular migrant
Female	Heterosexual	Peru	Regular migrant
Female	Heterosexual	Peru	Regular migrant
Man	Gay	Peru	Regular migrant
Man	Gay	Peru	Regular migrant
Man	Gay	Peru	Regular migrant

### National, regional or global focus:

National:

Regional:

Global:

## Introduction to the topic

- The flow of refugees and migrants from the Bolivarian Republic of Venezuela is the largest mobilization of people in the history of Latin America and the second largest worldwide, after Syria. By July 2020, because of the economic, institutional and political crisis affecting that country, more than 5 million people of Venezuelan origin had left their homes, betting on a better life and access to basic services. Out of these, almost 4 million people have gone to countries in Latin America and the Caribbean.

- One of the key motivations for this mobilization is addressing health care issues, including living with HIV/AIDS. People seek access to antiretroviral treatment and health services that guarantee their survival. Many of the refugees and migrants living with HIV are part of the LGBTI+ community and because they suffer greater stigma and discrimination, they become one of the most vulnerable groups in contexts of human mobility, facing xenophobia, trafficking and smuggling of people, abuse, labor and sexual exploitation, among other risks.
- This flow of people has challenged national capacities in the destination countries and, in many cases, it has prevented timely and efficient responses. As a result, a large proportion of refugees and migrants do not have access to health services, a situation that has been exacerbated by the COVID-19 pandemic<sup>1</sup>.
- People in mobility situations are being directly affected because policies that restrict free movement, quarantine and social distancing have limited their opportunities to engage in economic activities - which in many cases were already precarious - thus impacting their access to health systems, food, housing, medicines and other essential consumer goods, and preventing them, in many cases, from continuing their transit routes to their destination countries.
- Through this Focus Group, the consultation centered on access to health services for refugees and migrants living with HIV in the three countries that have received the largest number of refugees and migrants from Venezuela (Colombia, Ecuador and Peru), using a specific methodology described below.

## **SECTION 2: A people-centered response to HIV - key emerging messages**

### **Methodology used to conduct the consultation with refugees and migrants**

**Step 1:** to invite the people who were to be consulted, the host organization in each country issued invitations with the following information. Standard messages were suggested and requested to be adapted in terms of language according to the local slang. The initial messages were sent through WhatsApp texts and audios.

#### ***MESSAGE 1 (text form is suggested)***

***We invite you to participate in the Consultation that UNAIDS has designed for the review of its 2016-2021 strategy.***

***UNAIDS is reviewing its Strategy to make it relevant to the real needs of people living with HIV.***

<sup>1</sup> More on COVID-19 and HIV: <http://onusidalac.org/1/index.php/internas/item/2555-covid-19>

We want your voice to be heard. The results of this consultation will be presented in a report to the UNAIDS headquarters and will be considered in the update of the 2016-2021 Strategy.

**Your opinion matters.**

If you want to participate, answer YES to this message and we will send you more information.

**MESSAGE 2 (a voice message is suggested due to its length)**

**What is UNAIDS?**

The Joint United Nations Programme on HIV/AIDS was created in 1994 to respond to the HIV/AIDS pandemic.

**What are we doing and why are we asking you to participate?**

UNAIDS is reviewing its [Strategy 2016-2021: On the Fast-Track to end AIDS](#) to take a look at what has been achieved and to assess the areas where work is still needed to reach the goals, especially for the most vulnerable groups in society.

**What is our purpose?**

The COVID-19 pandemic has exposed the weaknesses in global health structures and our economic, social and health vulnerabilities. It has also highlighted the need to continue providing HIV services to ensure positive health outcomes for people living with HIV who may become infected with COVID-19, and it has magnified those same vulnerabilities in populations such as migrants who have additional limitations in accessing health and HIV services.

Reviewing the strategy means listening to the voices of those affected to learn how we can better respond to their needs in the future.

**Why is it important for you to participate?**

- We believe that the experiences of people living with HIV must be shared for strategies to respond to their needs.
- This process is inclusive, participatory, interactive, and cross-sectional, so your voice must be heard.
- We want to include all people living with HIV and especially groups that have different needs, such as migrants, refugees and asylum seekers.

**What do we need?**

- Your phone number (it is important that you are familiar with the data protection policy that we follow for this consultation).
- That you tell us how you wish to participate. You have two options:
  - **Through a WhatsApp Group:** you will receive the questions and all group members will see your answers as well as everyone else's. Everyone who selects this option will be able to see your phone number.
  - **Through a broadcast list:** you will receive the questions and only the admin will be able to read your answers, which in this case is a person from the UNAIDS Regional Office.
- Availability of at least one hour to answer the questions that will be sent to you through the **WhatsApp Group or Broadcast List** in which the consultation will be extended to all the persons who agreed to participate. The questions will be sent beginning on Friday, August 7 in the afternoon and the answers will be received until Sunday.

August 9 at midnight, according to a schedule that will be sent in advance.

**MESSAGE 3 (a voice message is suggested due to its length)**

We want to explain to you the data protection principles that govern this consultation, and that you should know before participating:

**Data quality principle:**

- All personal data collected (including your phone number) shall not be used for purposes other than this consultation.
- The organization responsible for the event in each country must expressly communicate to the persons invited the purpose and use of the personal data provided. If you feel that you do not have enough information about this, please ask as many times as needed.

**Duty of secrecy:**

- The duty of secrecy refers to the fact that both the organization responsible for collecting the data and the recipient (in this case UNAIDS), and all persons involved in any phase of the data processing are obliged to keep professional secrecy and respect the principle of confidentiality, even when the relationship between them has ended.
- This basic principle is related to the confidentiality of personal data and the right of individuals to maintain their privacy. Therefore, the duty of secrecy implies that personal data cannot be disclosed to third parties who are not involved in this consultation process.
- Therefore, those who are invited to this consultation should be informed that, if they provide their phone number and choose to participate through a WhatsApp Group, their phone number will be visible to the rest of the participants in that group (since this is allowed by the instant messaging application).
- Similarly, those who are invited to this consultation should be explicitly informed that, if they provide their telephone number and choose the option to participate through the Broadcast List, their telephone number will not be visible to the rest of the participants on that list and that the answers to the questions will only be received by UNAIDS, who will disseminate them in a technical report, safeguarding people's identity whenever explicitly required.

**MESSAGE 4 (text + image suggested)**

***This is the schedule for sending the answers to the questions made:***

**Friday, August 7th (in the afternoon)**

Questions, doubts  
and round of introductions.



**Saturday, August 8th (in the morning):**  
reception of the answers to the 4 questions  
related to personal matters:  
How do we see the current situation?  
What concerns us?  
What gives us hope?  
What constrains our ability to reach our goals?

**Sunday, August 9th (in the morning):**  
reception of the answers to the 3 questions  
related to future measures:  
**CONTINUE:** What is working that we must  
continue to do?  
**STOP:** What must we stop doing, if not  
stopped it will ensure failure?  
**START:** What are we not doing that we  
must start doing?

**Saturday, August 8th (in the afternoon):**  
reception of the answers to the 4 questions  
related to institutional responses and the  
contextual environment  
How do we see the current situation?  
What concerns us?  
What gives us hope?  
What constrains our ability to reach our goals?

**Sunday, August 9th (in the afternoon):**  
What are the key recommendations you  
would make for the new UNAIDS Strategy  
and specifically for the situation of  
migrants living with HIV?  
What is the one key recommendation that  
you want to reiterate for strong  
consideration?  
Further questions or comments

**MESSAGE 5 (text form is suggested)**

*If you wish to participate in this consultation, please send us a text stating the following :*

**I agree to participate in the consultation on the UNAIDS Strategy and commit to answering the fifteen (15) questions that will be sent from Friday, August 07th to August 09th, 2020.**

*After having this information, the person should be asked if they want to participate in the process through **1) A WhatsApp Group or 2) A Broadcast List.***

**Each organization was advised to invite between 5 and 10 people to this consultation.**

**Step 2:** after agreeing to participate in the process, people were asked the following information:

- Phone number (linked to WhatsApp)
- Age
- Sex
- Gender
- Sexual orientation
- Nationality
- Current immigration status (regular, irregular, in progress, asylum seeker, others).

Those who indicated that they wished to protect their identity were assigned a code in order to maintain the principle of confidentiality. This option was communicated to the persons invited. Those who expressed the willingness to provide their name and surname were also free to do so.

The contact form is presented below and it was sent in an Excel file:



Phone number linked to WhatsApp:	Assigned code <sup>2</sup> : CO-01
Age:	Nationality:
Sex:	Gender:
Sexual orientation:	Migration status:
WhatsApp group: <input type="checkbox"/>	Broadcast list: <input type="checkbox"/>
Name (in case the person decides disclose it):	
E-mail: (in case the person decides to share it in order to receive information about the process):	

**Step 3:** with the completed forms, the country host organizations provided the UNAIDS Regional Office with all the contacts so they could create the **WhatsApp Groups** (one for each country) and the **Broadcast Lists**. The completed forms were sent to UNAIDS on Thursday, August 6, 2020.

The questions were sent from the UNAIDS Regional Office on Friday, August 7 to all the people who accepted to be included in the **Groups** or **Broadcast Lists**, and who sent all the required data.

**Step 4:** all the questions were sent with a schedule for answers. People could decide whether to answer the entire consultation at once or to stick to the timeline.

According to the established schedule, each time a response cycle started, the **WhatsApp Group** and **Broadcast List** admin reminded people of the instructions to respond to the consultation. Participations are considered valid when the person responds to all the questions during the period established for this purpose (until Sunday, August 9, at midnight in their country).

### SECTION 3: Reporting template to summarize focus group discussions conducted through WhatsApp

Type the main messages that emerge, up to a maximum of five items per section.

<b>Date:</b> from Friday, 07th to Sunday, 09th August 2020	
<b>Organization:</b> Red Somos, Dialogo Diverso and Aid for Aids.	<b>Country:</b> Colombia, Ecuador, Peru.
<b>PERSONAL MATTERS</b>	
How do we see the current situation?	<ul style="list-style-type: none"> <li>- The COVID-19 situation has affected livelihoods and, especially, the possibility of earning an income, which keeps people from having adequate housing and food.</li> <li>- Loss of employment creates uncertainty and is perceived as an additional constraint to re-entering the labor market due to the condition of living with HIV.</li> <li>- The situation is more difficult than usual, taking into account that</li> </ul>

<sup>2</sup> The code will be assigned according to the following: CO for Colombia; PE for Peru; and EC for Ecuador; followed by a number based on the confirmation. For example: CO-01 for the first participant from Colombia and so on.

	<p>migrants are mostly alone in their countries of origin.</p> <ul style="list-style-type: none"> <li>- They feel that they will suffer more discrimination and stigma for being migrants, for having no income (being poor) and for living with HIV.</li> </ul>
What concerns us?	<ul style="list-style-type: none"> <li>- That the situation of quarantine and isolation lasts for a long time and affects us at such a level that we have to return to Venezuela.</li> <li>- To be left without medicines, to reach the AIDS stage and die even though I left Venezuela with much sacrifice to save my life.</li> <li>- To die far away from my family and children because I have no job, food or treatment.</li> <li>- The emotional cost of leaving Venezuela to save our lives because we are HIV positive affects mental health and emotional stability.</li> <li>- There is stigma and discrimination against Venezuelan immigrants, but host countries must understand that we are where we are because we have no options left in Venezuela.</li> </ul>
What gives us hope?	<ul style="list-style-type: none"> <li>- That economic activities resume so we can have an income again.</li> <li>- That some foundations and organizations care for refugees and immigrants living with HIV even if governments do not.</li> <li>- The organizations that inform us about immigration procedures and access to medicines, in addition to the support they give us in different areas.</li> </ul>
What constrains our ability to achieve our goals?	<ul style="list-style-type: none"> <li>- Not having a regular migration status is a limitation to make progress on our goals.</li> <li>- The emergency status imposed by the pandemic is keeping us from getting jobs, food, and even medicines in a timely manner.</li> <li>- The discrimination that still exists because of being an HIV-positive person.</li> </ul>
<b>INSTITUTIONAL RESPONSES AND CONTEXTUAL ENVIRONMENT</b>	
How do we see the current situation?	<ul style="list-style-type: none"> <li>- There is a fear that health care systems could potentially collapse due to the COVID-19 pandemic and that the supply of medicines could be affected.</li> <li>- The impact on the economy, logistical systems and availability of medicines may result in a wave of deaths of PLHIV who are not in their home countries or are poor and unprotected.</li> <li>- The situation is very difficult, especially for NGOs that maintain programs for people living with HIV who will be affected by the pandemic (sustainability).</li> </ul>
What concerns us?	<ul style="list-style-type: none"> <li>- The institutional inactivity makes it difficult for us to carry out immigration procedures and to stop being irregular immigrants.</li> <li>- There is stigma and discrimination against Venezuelan immigrants because there are many of us, but we have no possibilities to back in Venezuela.</li> <li>- The institutional limitations to provide timely attention to people living with HIV who are outside their countries.</li> <li>- The likelihood that we will not be able to move to countries that have a better response to HIV and that include refugees and migrants in care programs.</li> </ul>
What gives us hope?	<ul style="list-style-type: none"> <li>- That there is a vaccine universally accessible that includes people in</li> </ul>

	<p>mobility situations.</p> <ul style="list-style-type: none"> <li>- That there are organizations other than States that provide support in a timely and efficient manner.</li> <li>- That consultations be held that take into account the voice of the people, especially of those who are not in their countries of origin and live different realities.</li> </ul>
<p>What constrains our ability to achieve our goals?</p>	<ul style="list-style-type: none"> <li>-Associating migration and migrants with pandemics, diseases and death.</li> <li>-That institutions do not take into account the needs of migrants and refugees, and see them as troublemakers.</li> <li>-The lack of social, cultural and economic integration of refugees and migrants, and feeling persecuted and harassed just for wanting a better life.</li> <li>- Xenophobia, the lack of documentation and access to health services prevent us from being healthy and integrating effectively into society.</li> </ul>
<b>FUTURE MEASURES</b>	
<p><b>CONTINUE:</b> <i>What is working that we must continue to do?</i></p>	<ul style="list-style-type: none"> <li>- Promoting education more strongly to demystify negative imaginaries about HIV, as this contributes to the integration of PLHIV into environments favorable to their productivity and health.</li> <li>- Continuing to progress on scientific research that point to better antiretroviral drugs, a definitive cure, and other treatment options.</li> <li>- Using social networks to disseminate information about prevention, treatment options, and expected behavior changes in PLHIV.</li> <li>- Training health personnel to treat migrants and refugees with respect and to enable them to adapt.</li> <li>- Strengthening NGOs and communities so that they can assist States in their responses to HIV and serve directly those populations that are reached by National AIDS Programs, such as migrants and refugees.</li> <li>- Promoting the interaction of NGOs and the health services of the ministries of health.</li> </ul>
<p><b>STOP:</b> <i>What must we stop doing, if not stopped it will ensure failure?</i></p>	<ul style="list-style-type: none"> <li>- Neglecting people and their needs to respond to bureaucratic and institutional procedures.</li> <li>- Establishing limitations and not insisting on breaking down barriers between people and UN agencies.</li> <li>- Focusing HIV attention only on medicines, as more comprehensive care is needed for people, especially refugees and migrants living with HIV who require support to integrate economically into host countries.</li> </ul>
<p><b>START:</b> <i>What are we not doing that we must start doing?</i></p>	<ul style="list-style-type: none"> <li>- Taking into account the relationship between mobility (migrants and refugees) and HIV/AIDS, and acting accordingly.</li> <li>- Creating universal policies that set standards of care for PLHIV regardless of the country where they are located.</li> <li>- Using social networks and digital media more strongly to educate</li> </ul>

	<p>against stigma, discrimination and xenophobia, especially against people living with HIV and belonging to LGBTI+ communities.</p> <ul style="list-style-type: none"> <li>- Involving the private sector (companies) in the response to HIV, especially so that they are open to including people living with HIV in their businesses, especially if they are migrants, but also so they provide services and invest in research for better treatments.</li> </ul>
<b>Key recommendations</b>	
<p>What are the key recommendations you would make for the new UNAIDS Strategy and specifically for the situation of migrants living with HIV?</p>	<ul style="list-style-type: none"> <li>- Promoting universal care and protection policies for PLHIV regardless of the country where they are located. This way, the continuity of treatment and care can be ensured.</li> <li>- Giving visibility to the UNAIDS policies that focus on refugees and migrants, and the recommendations for their care and protection in all countries.</li> <li>- Investing more in research to improve HIV medicines so that more people can be included in the care and protection of their rights.</li> <li>- Strengthening AIDS programs so that they are managed with clear and consistent standards in all countries, thereby ensuring equality and equity in care.</li> </ul>
<p>What is the one key recommendation that you want to reiterate for strong consideration?</p>	<ul style="list-style-type: none"> <li>- Training of health personnel to assist refugees and migrants living with HIV without discrimination.</li> <li>- More and better research to improve the effectiveness and cost of treatment.</li> <li>- That there be a global standard of care for HIV and people living with HIV.</li> <li>- Strengthening NGOs which do a job that is sometimes better than that of the States in assisting people who are discriminated, such as those who live with HIV, are part of the LGBTI community and are also migrants.</li> </ul>
<p>Further questions or comments</p>	<ul style="list-style-type: none"> <li>-More support for NGOs and their work is needed, as they are the ones who have prevented the deaths of migrants living with HIV and other diseases.</li> <li>-"Health should be promoted as a human right and not as a business, which is the case in Colombia".</li> <li>-"I would like that, after the pandemic is over, we can share among positive people to cheer us up and share experiences as migrants living with HIV".</li> </ul>

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

*Also, please provide a list of the names and email addresses of participants who wish to continue to receive information about the Strategy Development process. Names and contacts will not be shared publicly or with third parties.*

You can send us additional documents via e-mail at [pontead@unaids.org](mailto:pontead@unaids.org)

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