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**COMPLETE**

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Page 1: Focus Group Discussion report to UNAIDS

**Q1**

Please share with us information about your organization

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**Q2**

What was the theme of your discussion?

Theme discussed:	<b>INDIGNEOUS PEOPLES</b>
Participants (number, composition, anything else you would like to share about participation):	<b>11 Participants; Geographic Breakdown 2 from Canada; 2 from India; 1 from French Polynesia; 2 from Nepal; 1 from Nigeria; 3 from USA</b>
What was the geographical scope of the discussions: Global, regional, national, other?	<b>Indigenous-specific global (and regional)</b>

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**Q3**

What were the main topics shared on the theme of your discussion to introduce the subject?(please share messages and/or data you used to guide your discussion)

- a) **Indigenous Peoples are mostly left behind in the HIV response**
  - b) **Indigenous Peoples are at higher risk for contracting HIV**
  - c) **There is no mention of Indigenous Peoples in the current UNAIDS Strategy nor the UNAIDS Gap Report**
  - d) **In many Indigenous communities, HIV, sex and illness are taboo subjects.**
  - e) **The UN Declaration on the Rights of Indigenous Peoples (UNDRIP) calls for States to consult and cooperate in good faith with the Indigenous peoples concerned through their own representative institutions in order to obtain their free, prior and informed consent before adopting and implementing legislative or administrative measures that may affect them.**
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**Q4**

People-centred response to HIV - key emerging issues Reaching the person

How do we see the current situation?

• **STIGMA AND DISCRIMINATION** o They both greatly hinder the successful dissemination of information and implementation of programming and services o Racism, transphobia and other forms of discrimination serve as additional barriers in reaching Indigenous youth or Indigenous families who may not have access to accurate information • **FINANCING OF INDIGENOUS RESPONSE:** o COVID19 has diverted funding to Indigenous funding that is already scant. • **CULTURAL SAFETY:** o The dominant culture is not considerate or knowledgeable of Indigenous norms o While HIV prevention, treatment and care programs have supported non-indigenous people well, Indigenous peoples require Indigenous-centered HIV prevention, treatment and care programs • **RURAL AND ISOLATED AREA SPECIFIC FOCUS:** o In some rural or isolated areas, there is no dedicated HIV treatment services. There may be some radio awareness or advertisements about STIs in urban areas, but not in the remote or isolated communities o Poverty and lack of awareness are root causes for HIV/AIDS in tribal communities o Poverty eradication programs need to be better integrated to address tribal poverty so members of Indigenous tribes can meet local cost of living.

What concerns us?

• **THE CURRENT HIV RESPONSE IS NOT CENTERED ON INDIGENOUS PEOPLES** o There is a need to Indigenize the HIV response and to raise awareness through culturally appropriate messaging o We require Indigenous-specific funding from the viewpoint of Nothing About Us Without Us and GIPA • **LACK OF CULTURALLY-APPROPRIATE SUPPORT:** o Saving lives of Indigenous Communities □ Tribal members are not going to HIV testing and services due to low awareness of available programs □ There is a need for dedicated, culturally-safe programs for various groups of Indigenous peoples, including: • Indigenous-centered prevention and care • Social and economic protection and Indigenous people who live poverty, in particular Indigenous women who are widows, • Indigenous children and adolescent who are born and infected, or affected by HIV • **LACK OF HOLISTIC CARE:** o We require holistic care that not only provides bio-medical care, but holistic services that provide social, emotional, mental, spiritual and financial support • **INDIGENOUS YOUTH** o The mentorship of youth leaders is a key priority

What gives us hope?

- **INDIGENOUS SOLIDARITY AND RESURGENCE MOVEMENTS**
- **INDIGENOUS-LED RESPONSE & PARTNERSHIPS**
  - o The fact that we can be in control of our well-being
  - o The companionship and support within our communities
  - o Connecting and sharing gives our youth give us hope
  - o Exchange knowledge and wise practices with other Indigenous communities
  - o Working with other Indigenous peoples with HIV and connecting with other service providers, researchers and stakeholders
- **THE ADVANCES IN BIOMEDICAL INTERVENTIONS** give us hope, but they need to reach Indigenous peoples and communities
- To have more opportunities to discuss and share our collective wisdom on what is happening worldwide

What constrains our ability to achieve our goals?

- **COVID-19**
  - o COVID19 has greatly curtailed our programming and services
  - o Finding new ways to work around engage and provide services that are acceptable and appropriate during COVID.
- **LACK OF DEDCIATED FUNDING:**
  - o Lack of dedicated funding and sufficient budget to address the current needs
- **LACK OF INDIGENOUS PROGRAMMING:**
  - o Lack of culturally safe and appropriate programming on HIV, COVID 19, T.B, Malaria and co-morbidities for Indigenous peoples and communities
  - o Lack of sufficient integrated tribal economic development programs for Indigenous families.

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**Q5**

People-centred response to HIV - key emerging issues  
The structures that respond to HIV

How do we see the current situation?

• **INTERSECTIONAL CONSIDERATIONS:** ○ We need to focus on addressing intersectional issues such as mental wellness, injection drug use, housing, lack of access to PrEP and other factors that exacerbate HIV transmission and incidence rates. • **HEALTH EQUITY:** ○ Compared to the general population, Indigenous people require specialized Indigenous programming and the necessary support to carry the work to the next phase ○ A group of white HIV exceptionalism states should no longer be needed in the West. Such push against HIV exceptionalism has hurt the Indigenous response ○ From the viewpoints historically oppressed communities including Indigenous, Black and People of Colour Communities (BIPOC), we require a continuation of HIV exceptionalism as we require dedicated focus to address the health inequity within the HIV response ○ Self-testing needs to be equitably promoted within Indigenous Communities • **COVID-19** ○ Indigenous people are suffering from COVID19 and HIV/AIDS ○ There is a lack of prevention efforts to address HIV/AIDS and COVID19 among Indigenous families and communities ○ HIV is not the pandemic of NOW. There is an apathy towards HIV/AIDS and political will to sustain the response. How can we attract attention and priority? ○ It is a good time to re-introduce HIV as a global health priority and a global pandemic. ○ We need to translate what we have learned and the approaches we have used from the global HIV response to address the dual pandemic of HIV and COVID-19, as well as other pandemics such as TB and Malaria that disproportionately impact people living with HIV

What concerns us?

• **FOCUSING ON THE BASICS:** ○ There exist differences in attitudes towards HIV/AIDS between older and younger generations. ○ Need to focus on comprehensive sexual education and HIV prevention • **ADDRESSING STIGMA:** ○ How to keep confidentiality especially in small communities • **GEOGRAPHIC CONSIDERATIONS:** ○ Having accessible services (urban vs. rural vs. isolated) • **PROVIDER EDUCATION:** there is a lack of understanding on Indigenous worldviews and ways to provide culturally-safe services by doctors and allied health professionals

What gives us hope?

- **SUCCESS IN INDIGENOUS-CENTERED RESPONSE:**
  - o Success of special Indigenous awareness-raising projects or campaigns
  - o Some Indigenous communities are winning the battle against HIV.
  - o Some Indigenous communities are doing well providing care from not just from a western perspective and are integrating traditional Indigenous and western approaches to medicine and holistic well-being
- **ADVOCACY:**
  - o There is now a willingness for Indigenous peoples to be more vocal, to negotiate, and to demand change
  - o Indigenous youth are taking action
- **SOCIAL AND ECONOMIC PROTECTION** for Indigenous people living with HIV
- **THE SCALING UP** of local government supported Indigenous programs

What constrains our ability to achieve our goals?

- **PRESENT-DAY LEGACY OF COLONIZATION:**
  - o The fact that governments still control who is defined as Indigenous
- **STIGMA:**
  - o Community gossip and breach of confidentiality
  - o Communities not acknowledging that HIV/AIDS is an issue, or that believed that it is “witchcraft”
- **UNAIDS-specific:**
  - o portraying that AIDS/HIV people feel HIV is not an issue
- **EDUCATION:**
  - o Based on research studies, we hear that time and time again that some Indigenous communities’ people do not know about HIV, or that HIV has already been taken care of
- **ADDRESSING APATHY AND HIV FATIGUE**
- **TESTING TREATMENT AND CARE**
  - o Lack of culturally-appropriate knowledge and capacity of providers to support rural/On-reserve care:
  - o Lack of health insurance and care in urban communities
- **CAPACITY**
  - o There are not enough Indigenous leaders to work on all the priorities that need to be addressed
  - o For tribal leaders, they already have an array of issues to focus on, yet they must also put HIV/AIDS on the agenda
  - o Amongst the Indigenous leaders, there is not enough leaders who are championing Indigenous HIV issues
- **STRUCTURAL INEQUITIES:**
  - o Lack of specific Indigenous-centered HIV/AIDS programming
  - o Lack of sufficient budget and tribal development programs to support Indigenous families to meet local cost of living and to eradicate poverty, especially for Indigenous women and widows, adolescents, children of Indigenous people living with HIV and orphaned children
  - o Lack of programming to address Indigenous migration needs
- **INCLUSION & ENGAGEMENT:**
  - o Lack of integration of local Indigenous leaders, youth, and spiritual leaders in mainstream HIV testing, treatment and care efforts
  - o Lack of integration of Indigenous traditional Health practitioners with Western health practitioner
- **COVID-19**
  - o Loss of lives to Indigenous people due to COVID19

**Q6**

People-centred response to HIV - key emerging issues Contextual environment

How do we see the current situation?

- **UNDERFUNDING OF THE INDIGENOUS-LED RESPONSE** o Indigenous peoples have the solutions, yet the Indigenous HIV response is underfunded
- **LACK OF INDIGENOUS-FOCUSED RESPONSE:** o Compared to non-Indigenous people, Indigenous people are more likely to receive late diagnosis In some countries, there is lack of proper sensitization on education and awareness among Indigenous communities
- **GEOGRAPHIC & STRUCTURAL CONSIDERATIONS:** o In remote Indigenous villages, there is a lack of medical or health centers. No one is responding to HIV impacting Indigenous peoples and communities. Indigenous people are not reaching or well-supported by government funded programs

What concerns us?

- **STIGMA:** o Stigma, discrimination, ignorance and racism even after all these years, which prevents people from accessing health care o Indigenous people do not feel safe seeking health services from mainstream health centres due to the lack of Indigenous-centered, culturally-safe programming
- **NON-INDIGENOUS CENTERED STRUCTURES AND APPROACHES TO HIV** o There is a disconnection and destruction of the land that is happening around the world o While there are institutions that have been funded to provide testing, treatment, care, and support, Indigenous peoples continue to face barriers in accessing care, even in developed countries. This is especially true for Indigenous people who use drugs o There are service providers that think they are serving Indigenous people, yet they possess a saviour mentality and assume that they know better than us

What gives us hope?

• **INDIGENOUS-LED RESPONSE:** • The Canadian Aboriginal AIDS Network (CAAN) is building foundations to identify solutions in the HIV response • There are similar organizations around the world that are rising to meet these challenges, BY Indigenous people FOR Indigenous people • Indigenous people who have been distanced from their cultures due to the legacy of colonization are gradually gaining back their culture knowledge, and traditions. Such resurgence helps support the future generation of Indigenous youth. • **BUILDING SUPPORTIVE PARTNERSHIPS:** • Indigenous people work in cooperation, not competition. How can mainstream organizations work together with Indigenous peoples this way? • There needs to be dedicated Indigenous staff recruitment for staff working in Indigenous areas in government, NGOs and other institutions • The present structures are giving good benefits for general people, but very less benefits for Indigenous peoples.

What constrains our ability to achieve our goals?

• **LEGACY OF COLONIALISM** ○ Colonial mindset (“we know what’s best for Indigenous people”) • **FUNDING:** ○ Lack of funding for Indigenous organizations • **LACK OF INCLUSION:** ○ Indigenous peoples are not represented and do not have a seat at the table • **STRUCTURAL CONSIDERATIONS** ○ Lack of support for an Indigenous-led response ○ There needs to be a mechanism to address the prevention of AIDS, COVID19, TB and other diseases. This can be accomplished with through collaboration with Indigenous communities and tribal leaders ○ Very few organizations working with Indigenous organizations globally • **CULTURALLY-SAFETY:** ○ Indigenous peoples are not going to community health centers because of lack of confidentiality and cultural safety.

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**Q7**

Emerging patterns - the person, the structures, the context

- a) 

The global HIV pandemic will not end if Indigenous Peoples continue to be left behind. To turn the tide, it is of critical urgency that UNAIDS and member states support a well-funded Indigenous-led HIV response which provides culturally-appropriate, holistic approaches to testing, treatment, and care, as well as with other pandemics such as TB and Malaria. Special attention needs to be paid to address the intersectional needs of Indigenous Peoples, such as mental wellness, social and economic protection, and migration.
- b) 

In addition to the legacy of colonialism, anti-Indigenous racism, stigma and discrimination serve as major barriers within the Indigenous HIV response. Many communities do not have accurate information about HIV/AIDS, while others may be mistaken that HIV/AIDS is no longer a serious health matter. Indigenous and Tribal leaders are often overwhelmed with an array of issues and priorities to address, and must also tackle HIV/AIDS. Support mechanisms are needed to promote comprehensive sexuality education and knowledge exchange of (wise) best practices amongst Indigenous communities. There needs to be greater support of international organizations and bodies to work with Indigenous organizations on the global level.
- c) 

UNAIDS, its cosponsoring agencies and members states, must recognize Indigenous Peoples as a key population, uphold the UN Declaration of Rights of Indigenous Peoples (UNDRIP), especially the duty of Free, Prior and Informed Consent (FPIC) of Indigenous Peoples. They should work with the UN Permanent Forum on Indigenous Issues (UNPFII) to enhance their capacities to engage with Indigenous Peoples, and to establish a coordinated and respectful approach to ensure Indigenous Peoples have a seat at the decision-making tables. The Indigenous HIV response can benefit from UNAIDS' support to coordinate the collection of disaggregated epidemiological data that attests to Indigenous Peoples' existence.

- d) **Structural Inequities, distrust of government-funded programs, and a lack of culturally-safe services serve as barriers of Indigenous Peoples to engage in mainstream services. In some rural or isolated areas, there are no dedicated HIV treatment services. Among the Indigenous and tribal communities, social and economic protection programs can help support Indigenous families to meet local cost of living and to eradicate poverty, especially for Indigenous women and widows, adolescents, children of Indigenous people living with HIV and orphaned children**
- e) **COVID-19 has presented new challenges to the Indigenous HIV, TB, and Malaria response as funding and resources are prioritized to address COVID-19, thus sidelining the response even more than before. It is critical that Indigenous Peoples and Communities are supported to create Indigenous-led solutions to address a multi-pandemic based on an Indigenous-centered holistic care approach.**
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**Q8**

Recommendations from Wolrd Cafe session

CONTINUE(what is working that we must continue to do?)

• **CONTINUE & EXPAND PROGRAMMING & SERVICES:**  
 o ...all existing prevention, treatment, and are activities must continue. This is especially true since many Indigenous youth lack awareness of HIV o ...increase the promoting the biomedical advances and access to Indigenous communities • **Community Engagement:** o ...increase inclusive participation of Indigenous communities in various regions • **MULTI-STAKEHODLER EDUCATION:** o ...continue education on cultural awareness to stakeholders including government officials and UN agencies • **GLOBAL FUNDING** including PEPFAR • **YOUTH PROGRAMMING** in the development sector supported by government allies • Indigenous and tribal led work in the communities • **CAPACITY-BUILDING** o ...building capacities of Indigenous peoples and communities to engage on the high level with member states and key funding mechanisms • **KNOWLEDGE EXCHAGE** o ...facilitating the knowledge exchange on global wise practices across international Indigenous communities • **SOLIDARITY:** o ...standing united as Indigenous communities globally • **UNAIDS-SPECIFIC:** o While UNAIDS adds value by bringing communities/agencies/governments and academics that normally do not work together, the joint programme also need to greatly scale-up their efforts on supporting an Indigenous-led HIV response

STOP(what must we stop doing, that if we don't stop will ensure failure?)

• **STRUCTURAL DISCRIMINATION** o ...stop not treating us as a priority population • **IMPOSITION OF CULTURALLY INAPPROPRIATE INTERVENTIONS** o ... imposing interventions that are not a part of our way of thinking o ...tying funding to non-Indigenous interventions. Our communities must come up with culturally-safe interventions. • **COLLECTION OF INDIGENOUS DATA:** o ...stop relying on government data that does not include disaggregated data on Indigenous peoples. Such data does not represent the story and realities of Indigenous Peoples • **NEO-COLONIALISM** o ...waiting for the government to save us (such action reinforces the colonization of Indigenous peoples) o ...the attempts by government to separate Indigenous communities by triggering competition • **A DIVIDED RESPONSE** o ...putting or placing people in different silos of key population groups while leaving Indigenous peoples out • **Complicated reporting structures and requirements**

START(what are we not doing that we have to start doing?)

- **INCLUSION** • ...demanding a seat at the table, including funding (locally, nationally, regionally and internationally) • ...creating opportunities for Indigenous communities
- **DECOLONIZATION**: • ...decolonizing the data (It's not just about the percentage; it's how it impacts on our communities)
- **ADDRESSING MULTIPLE PANDEMIC**: • ...establishing special Indigenous-focused programs on HIV prevention, COVID-19, TB, Malaria and co-morbidities
- **NOTHING ABOUT US WITHOUT US** • Free, prior and informed consent • Each and every program must have an Indigenous approach when it affects Indigenous people
- There needs to be specific Indigenous HIV programming internationally
- **FUNDING**: • International organizations (eg PEPFAR) and member states must understand ways to interact with Indigenous communities and organizations, including Indigenous-friendly ways of reporting • Need to scale up of Indigenous pilot projects
- **DOCUMENTATION & DISSEMINATION OF GOOD WORK DONE** by Indigenous communities through knowledge translation exchange and communication efforts
- **UNAIDS-SPECIFIC**: • Must adhere to UN Declaration on the Rights of Indigenous Peoples • Coordination of collection of disaggregated data that includes Indigenous people
- **SPECIAL INDIGENOUS FOCUS** • ...prioritizing Indigenous voice • ...partnering with UNPFPII to develop Indigenous-specific strategies and inter-cultural responses to address Indigenous-specific HIV/AIDS issues
- **TRADITIONAL CEREMONY** • ...our gatherings with prayers so we can connect with our ancestors

What is the one key recommendation you want to reiterate for strong consideration?

- **We must be recognized as a key population, have a seat at the table, and have decolonized data and evidence to support Indigenous funding, programming, interventions, and advocacy efforts that can protect Indigenous human rights, health and well-being**
- **Indigenous-led approaches must happen/be implemented at all levels: epidemiology, process development, program development, reporting structures and funding decisions**
- **Support for Indigenous communities to lead this work -- leadership training, demystify processes and motivate groups to get involved**
- **There is a need for dominant actors to engage Indigenous leaders, tribal government chairs, Indigenous agency directors more effectively**
- **UNAIDS and its co-sponsors must work in partnership directly with the UNFPII to develop Indigenous-specific responses**
- **Since it requires Indigenous communities longer time to consult and make collective decisions, we request governments and multilateral entities to provide us with more realistic timelines to engage in community consultations and to provide report back**

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## Q9

A final message to UNAIDS Programme Coordinating Board on the Strategy

- UNAIDS and its co-sponsors must work in partnership directly with the UNFPII to develop Indigenous-specific strategies to address HIV, TB, Malaria and COVID-19, recognizing Indigenous Peoples as a key population, partner with Indigenous entities to coordinate the collection of disaggregated data which includes Indigenous Peoples, and support dedicated funding for Indigenous-led programming, interventions, and advocacy efforts that protect Indigenous human rights, health and well-being

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## Q10

What are some background documents or references you can share with us?

**CAAN IIWHGHA Indigenous Peoples UNAIDS Focus Group Background Documents.pdf (4.2MB)**

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