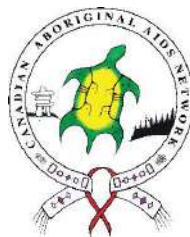




# A qualitative study on stigma and discrimination experienced by indigenous peoples living with HIV or having TB at work



Undertaken by:  
The Canadian Aboriginal AIDS Network



Secretariat of the International Indigenous HIV & AIDS Working Group



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*A qualitative study on stigma and discrimination experienced by indigenous peoples living with HIV or having TB at work*

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## Preface

The HIV and TB response have made important strides over the past decades and have witnessed an additional push with the 2030 Agenda on Sustainable Development that pledges to leave no one behind. While indigenous peoples are resilient and diverse in their experiences, traditions, aspirations and ways of life, they continue to face stigma and discrimination leaving many indigenous women and men economically and socially marginalized. Indigenous peoples constitute over six per cent of the global population and are about three times more likely to be in extreme poverty than their non-indigenous counterparts. Data gaps however remain in understanding the situation of indigenous peoples regarding HIV and TB, and in particular about intersecting forms of discrimination based on indigenous identity, gender and HIV or TB status.

The ILO collaborated with the Canadian Aboriginal AIDS Network (CAAN), the secretariat of the International Indigenous HIV & AIDS Working Group (IIWGHA), to undertake a qualitative study on stigma and discrimination experienced by indigenous peoples living with HIV and/or having TB at work and make recommendations. The study contributes to marking the 30th anniversary of the ILO's Indigenous and Tribal Peoples Convention (No. 169). It captures experiences of indigenous peoples living with HIV and/or having TB from four regions.

While the first part of the report, based on a rapid literature review, shows there is a lack of published data, the second part narrates stories of inequalities from individual interviews and follow up focus groups conducted around the world. Indigenous peoples living with HIV and/or having TB, shared their own experiences and recounted multiple experiences of advocating for those who had been fired from work or been denied proper medical care.

The report shows that indigenous peoples face double discrimination – because they are indigenous as well as living with HIV and/or having TB. Being an LGBT indigenous person adds another layer to this. Barriers to accessing health services, denial of the right to work and discrimination in employment settings are highlighted.

The report makes important recommendations to address the situation, emphasizing the meaningful participation of indigenous peoples, especially those living with HIV and/or having TB. A priority is the production of reliable data about indigenous peoples; HIV and TB, increasing the focus on enforcement of laws and policies, and efforts to reduce stigma and discrimination faced by indigenous peoples in health care as well as workplace settings. Multiple layers of discrimination need multi-sectorial policies and interventions. Promoting and protecting the rights of indigenous peoples, engaging them in policy dialogue, ensuring economic empowerment particularly for indigenous women, and creating decent work opportunities will be critical. It is also important to make health services culturally safe and sensitive including having communication materials in indigenous languages and changing the attitudes of health providers.

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- Evince Mugumbate (Zimbabwe) **interviews** in Anglophone Africa
- Fabiola Pérez (Guatemala) **focus group** in Guatemala
- Jasmine Cotnam (Canada) **focus group** in Canada
- Kayitare Marshal (Rwanda) **interviews** in Francophone Africa
- Phylesha Brown-Acton (New Zealand) **interviews** in Asia and the Pacific
- Pilar Montalvo (Peru) **interviews** in Chile, Bolivia and Peru and **focus group** with people living with HIV and working in the field of HIV and TB from Chile, Bolivia, Peru and Mexico
- Sekagya Yahaya (Uganda) **focus group** in Uganda (Africa region)
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Photo credit page 7 and back cover: Renée Masching

## List of acronyms and abbreviations

AIDS:	Acquired Immunodeficiency Syndrome
CAAN:	Canadian Aboriginal AIDS Network
FJN+:	Fiji Network for People Living with HIV
GIPA:	Greater Involvement of People Living with HIV/AIDS
GNP+:	Global Network of People Living with HIV
HIV:	Human Immunodeficiency Virus
ICW:	International Community of Women Living with HIV
IIWGHA:	International Indigenous Working Group on HIV & AIDS
ILO:	International Labour Organization
IPPF:	International Planned Parenthood Federation
LGBT:	Lesbian, Gay, Bisexual, and Transgender
TB:	Tuberculosis
UNAIDS:	Joint United Nations Programme on HIV/AIDS
WHO:	World Health Organization



## Executive summary

The International Labour Organization (ILO) Geneva engaged the Canadian Aboriginal AIDS Network (CAAN) and the secretariat of the International Indigenous HIV & AIDS Working Group (IIWGHA) to undertake a qualitative study on stigma and discrimination experienced by indigenous peoples living with human immunodeficiency virus (HIV) and/or having tuberculosis (TB) at work.

The development of this report began with a targeted literature review of seminal articles, grey literature, ILO and UNAIDS reports and citation mining for key references. CAAN then mobilized with indigenous contacts in four of the five ILO global regions to undertake one-on-one interviews and follow-up regional focus groups. In total, 21 interviews with indigenous peoples living with HIV and/or having TB, and five focus groups with leaders and representatives of indigenous peoples living with HIV and/or having TB were completed over three months. This engagement was aimed at exploring indigenous peoples' perceptions and experiences of stigma and discrimination in the context of work. The interviews and focus groups were translated in English (as necessary), transcribed and thematically analysed by the writing team. This report offers a 'snapshot' of issues faced by indigenous peoples living with HIV and/or having TB, focusing centrally on the experiences of stigma and discrimination at work. Findings are limited by low numbers of individual contributors in each region.

### **Background literature**

There is plenty of literature on the topic of discrimination and racism against indigenous peoples globally, as well as on stigma and discrimination against people living with HIV or having TB. Numerous studies and reports demonstrate that HIV- and TB-related stigma and discrimination are significant barriers in accessing and retaining employment and can result in difficulties in being promoted or receiving other work benefits. There is also abundant literature on discrimination and exclusion against indigenous peoples in general, showing the impact of decades of marginalization and abuse against indigenous peoples in multiple contexts, including in education, housing, healthcare and economic opportunities. That being said, specific literature on stigma and discrimination of indigenous peoples living with HIV and/or having TB in the workplace is scarce.

The main source of information on stigma and discrimination of people living with HIV in the workplace is provided by reports from the Global Network of People living with HIV (GNP+), based on the analyses from the People Living with HIV Stigma Index. It is clear that research on stigma and discrimination among indigenous peoples living with HIV or having TB is still insufficient to provide a full picture of their experiences in the workplace.

### **Knowledge of HIV and TB and health services**

According to most participants, the level of knowledge about HIV and TB is still low among indigenous peoples in many countries, in spite of some progress through educational programmes and health campaigns in reaching their communities with health messages on these infections. In many countries there is a lack of culturally adapted information on HIV and TB, no materials in indigenous languages or presentation that is culturally relevant. This leaves indigenous peoples to rely on messages and documents developed for the general population. The main sources of information are peer groups living with HIV and/or having TB, social media, traditional media platforms (radio, TV), online websites, community-based



organizations and health services. A less common source was direct person to person communication with friends and colleagues.

Overall, health services for indigenous peoples living with HIV and/or having TB are available, but barriers to access are a major problem in most countries. The main barriers are lack of culturally appropriate information and discrimination by health care providers; lack of health professionals able to speak indigenous languages, affordability of some services including the costs of long travel distances to the health services; discriminatory attitude of service providers, drug-supply shortages (stock-outs), stigma and concerns regarding confidentiality (both related to disclosure and also being seen accessing the service).

### **Experiences of discrimination at work**

Generally, participants reported that they face a double burden of stigma and discrimination: first as indigenous peoples and second for living with HIV and/or having TB. Most of the participants were aware of multiple examples of stigma and discrimination in the workplace, which continue to occur despite existing national legislation and human rights policies, regulations and laws that should protect people from any kind of discrimination when looking for employment or in the context of work.

As suggested by many of the views and experiences shared by the participants, in spite of employment regulations and rights, the chances of getting a job or, once employed, having the same opportunities as other employees to be promoted or to be treated fairly in the workplace is not equal for indigenous peoples living with HIV and/or having TB. Participants shared several cases of indigenous peoples with HIV who experienced changes to their job description, to the nature of their work, or were refused the opportunity for promotion. Numerous experiences were shared about indigenous peoples who lost their jobs or were fired because of their HIV status and/or for having TB. There were multiple examples of discrimination by employers and co-workers.

Another recurrent theme that emerged consistently was gender discrimination. For many participants, women were recognized as experiencing more forms and frequency of discrimination than men. Confidentiality was another important issue for many participants. There were reported cases of disclosure of their status by employers or colleagues without the person's consent.

### **Laws and regulations**

Most of the participants live in countries with legal protection and human rights policies, regulations and laws in place against multiple forms of discrimination. There are national legislation and norms in most countries that protect the rights of workers. However, in many countries, the implementation and enforcement of those legal mechanisms are weak.

Overall, the knowledge of the ILO Indigenous and Tribal Peoples Convention, 1989 (No. 169) is low. Only a few participants acknowledged their awareness about this international convention and were able to properly explain its purpose. The best knowledge was shown among participants whose countries have ratified the Convention. However, the message has reached some countries that have not ratified Convention No. 169, which suggests that there is some communication of this important instrument, and that there is a need for improving its dissemination among indigenous peoples more broadly.

As revealed by several participants, in spite of employment regulations, the work environment in many countries is not inclusive of indigenous peoples living with HIV and/or having TB. Regardless of laws and human rights norms that are in place against discrimination

in the workplace, in many countries indigenous peoples and those living with HIV and/or having TB are unaware of the regulations. Some people did highlight successfully upholding their right to work but ongoing stigma and discrimination continued to impact day to day access and safety in the workplace.

### **Recommendations**

The development of strategies to reduce workplace discrimination and all other responses should include indigenous stakeholders living with HIV and/or having TB to reflect GIPA.

Continued promotion of the ILO Convention No. 169 and the ILO Recommendation on HIV and AIDS and the world of work (No. 200) needs to be made and advocacy efforts must be strengthened to implement and enforce legal solutions and mechanisms to support legal claims against discrimination. Enforcement of laws assuring non-discrimination at workplaces must be expedited.

Considering the gaps in data and evidence, there is need to undertake more research with full participation of indigenous peoples living with HIV and/or having TB. One of the ways could be to expand the GNP+ stigma index to explicitly look at the stigma and discrimination faced by indigenous peoples.

Stigma and discrimination faced by indigenous peoples in health care settings must end. Training of service providers must be taken up on respecting confidentiality and learning about indigenous cultures to address stereotypes and judgment when indigenous peoples reach out to them. Communication and training materials need to be provided in indigenous languages and must be culturally-sensitive.

## Introduction

Indigenous peoples living with HIV or having tuberculosis (TB) bring unique perspectives and needs to the workplace. The recognition of human rights, including the rights to health and security, interact with the day-to-day realities of workplace engagement. Exploring the complexities of how indigenous identity, health status and stigma and discrimination intersect in the workplace highlights the ILO Indigenous and Tribal Peoples Convention, 1989 (No. 169)<sup>1</sup> as an international tool for protecting rights.

HIV and tuberculosis (TB) both affect people in the most productive age groups. According to estimates from UNAIDS and WHO, over 36 million of people over 15 years of age are living with HIV<sup>2</sup> and in 2018 there were an estimated 8,9 million new cases of TB in this age category<sup>3</sup>. There is also a need to address the impact of coinfection of HIV and TB; in 2017 there were an estimated 920,000 people living with HIV who fell ill with TB and TB remains the leading cause of death among people living with HIV, accounting for around one in three AIDS-related deaths.<sup>4</sup>

history of these social inequities has been widely documented.<sup>5-7</sup> This colonial context has also deeply contributed to shaping indigenous peoples' experiences with HIV- and TB-related stigma and discrimination.

Stigma and discrimination are well-documented social aspects of the health-disease process in medical and public health literature.<sup>8,9</sup> Stigma in relation to disease refers to exclusion, rejection or devaluation by others against patients and their families based on beliefs of social unacceptability or inferiority.<sup>10</sup> Disease-related stigma can be an expression of negative assumptions and rejection coming from other people; but it may also manifest as internalized stigma, where people who are living with HIV and/or having TB have a generalized fear of discrimination and modify their behaviours accordingly. In the context of the workplace, discrimination often manifests itself in the form of discriminatory practices by employers, co-workers, clients and customers.

Discrimination and stigma are bound up in the histories of HIV and TB transmission and care.<sup>11,12</sup> People living with HIV often experience discrimination and bias from others and may restrict their own employment and educational activities and goals to protect their dignity and safety.<sup>9</sup> People that have TB and their families can also experience discrimination and negative attitudes, such as shame, blame and a sense of being judged.<sup>12</sup> The stigma associated with HIV and TB has deep historical precedents rooted in government inaction, denial of the severity of rates of infection and moralistic framings of worth. Perceived TB stigma refers to patient and family anticipation of an adverse judgment, this itself is grounded in a history of government and medical violence against indigenous and other marginalized groups.<sup>14</sup>

Discrimination and stigmatization in the context of work undermines the capacity of people living with HIV and/or having TB to secure and keep employment, to better their

employment prospects, “to claim freely and on the basis of equality of opportunity, their fair share of the wealth which they have helped to generate, and to achieve fully their human potential”.<sup>15</sup> There is ample literature that has documented the problem of stigma and discrimination in health and healthcare more generally.<sup>16-18</sup> However, the situation of workplace discrimination and stigmatization against indigenous peoples living with HIV and/or having TB is insufficiently documented.

This report presents the results of a literature review examining stigma and discrimination against indigenous peoples living with HIV and/or having TB at work; it presents the main findings of a number of semi-structured interviews with indigenous peoples living with HIV and/or having TB; and it deepens this analysis by engaging with HIV experts and leaders from the participating regions through a number of focus groups. Concluding with recommendations for future research and intervention, it is clear that more work in this area would be beneficial.

## Methodology

This report unites and maximizes the perspective of indigenous peoples living with HIV, CAAN’s research expertise and IIWGHA’s network, while also benefiting from ILO’s expertise at a time when the ILO Convention No. 169 is marking its 30<sup>th</sup> anniversary. The Greater Involvement of People living with HIV/AIDS principles (GIPA Principles) have been entrenched in our approach to every stage of this process. Our data gathering methodology builds on this foundation.

### 1. Literature review

A broad literature review approach was used to rapidly scan the academic and grey literature and summarize the information regarding stigma and discrimination against indigenous peoples living with HIV or having TB in the workplace. The search aimed at identifying literature specifically related to “stigma and discrimination of indigenous peoples living with HIV or having TB in the workplace”.

A document search was performed in two main medical and health sciences bibliographic databases, EMBASE and PUBMED, to retrieve peer-reviewed and academic references on the topic. The search strategy was comprised of searching key terms individually and in combination. The search terms used were: “indigenous peoples”, “HIV” “tuberculosis” “discrimination” and “employment or workplace”. Only 43 articles, 38 in EMBASE and 5 in PUBMED, were located for the combined search and a review of the titles and abstracts of these academic records, indicated that none of the articles were specific to the review’s purpose.

Grey literature relevant to this topic was manually and purposively searched based on an expert consultation as well as through a direct search in specialized organizations’ websites i.e. ILO, UNAIDS, GNP+, WHO. Further reference mining assisted in identifying additional academic publications of relevance to this study. The relevant selected documents/articles from both sources were grouped thematically to summarize their content (see detailed list of references in appendix 1).

## 2. Individual interviews and focus groups

Semi-structured interviews were conducted to collect qualitative data from indigenous peoples living with HIV and/or having TB about their experiences of workplace stigma and discrimination. Interviewers were recruited by the IIWGHA project coordinator based in Canada. He reached out to HIV activists to serve as project consultants in Latin America, North America, Eastern Europe, Asia and the Pacific and Africa. African-Canadian activists were additional supports to connect with HIV activists in Africa.

The consultants used their own contacts and were instructed to purposely seek out a balance between indigenous peoples living with HIV with little contact with services and those who were HIV and/or TB activists. All consultants were provided with a list of specific items to be addressed in data collection – introduction to the project, explaining the process, recording the interview, field notes, saving and sending the file(s) to CAAN. Each consultant was also provided with the interview and/or focus group discussion guides created to consistently guide the data gathering (appendix 2 and 3). Consultants were paid for their work. Interviewees received a small honorarium. Focus group expenses were compensated for catering, transportation and participant honorariums.

A total of 21 individual interviews were conducted with participants from Africa, Asia and the Pacific, Europe and Central Asia, and the Americas. In addition, five focus groups of regional leaders and representatives of indigenous peoples living with HIV and/or having TB were conducted to gather additional information about discrimination in the context of the workplace. The recordings of the interviews and focus groups were sent to Canada, transcribed to English as necessary, thematically coded and analysed by the writing team.

The countries included were Australia, Bolivia, Burundi, Canada, Chile, Democratic Republic of the Congo, Fiji, India, Mexico, New Zealand, Nigeria, Norway, Peru, the Russian Federation, Rwanda, Uganda, Ukraine, United States and Zimbabwe. The sessions were recorded in English, French, Russian, and Spanish reflecting the diversity of the indigenous populations engaged in the study and the reach of colonial powers.

Findings are limited by low numbers of individual contributors in each region.

## Findings from the literature review

There is abundant literature on stigma and discrimination in general, as well as on HIV-related stigma and discrimination. Racial discrimination has been established as an important determinant of health and a key driver of racial/ethnic health inequities.<sup>9, 19, 20</sup> Numerous studies and reports worldwide have found significant relationships between self-reported experiences of racial discrimination and impoverished health status among indigenous peoples.<sup>16-18, 21, 22</sup> However, there is little literature that deals with HIV- or TB-related discrimination and stigma in the context of work. This section briefly describes the existing evidence.

### 1. Current evidence on stigma and discrimination against people living with HIV and/or having TB

HIV-related stigma and discrimination exist worldwide, and are manifested differently across countries, communities, religious groups and individuals.<sup>26</sup> HIV-related stigma and

discrimination refer to prejudice, negative attitudes and abuse directed at people living with HIV. This stigma negatively affects the health and well-being of people living with HIV, with deleterious effects on their care, treatment and quality of life.<sup>23, 24</sup> According to UNAIDS, over 50% of people worldwide report having discriminatory attitudes towards people living with HIV.<sup>25</sup>

Stigma and discrimination against people living with HIV have been identified, measured and documented in numerous studies.<sup>26-35</sup> Much literature reveals the significant social impact that stigma and discrimination has on people living with HIV. For example, there is significant evidence of HIV-related stigma within healthcare globally, both in wealthy countries like Canada,<sup>24, 27, 29</sup> and in developing regions.<sup>33, 36</sup> In addition to affecting access to and quality of healthcare, stigma and discrimination against indigenous peoples living with HIV can negatively impact their lives, constraining their access to social support services as well as affecting the wellbeing of family, peers, and community.<sup>37</sup>

To address HIV-related stigma and discrimination, the *People Living with HIV Stigma Index* was developed in 2008 by the Global Network of People living with HIV (GNP+), the International Community of Women living with HIV (ICW), the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS).<sup>38</sup> The Stigma Index is a research tool that uses a standardized questionnaire to gather evidence on stigma and discrimination experienced by people living with HIV. Since the beginning of the project, this instrument has been applied in more than 100 countries, and was updated in 2016 (version 2.0). This new version focuses more directly on the experiences and needs of subpopulations often missed within larger analytical groupings. Both the initial and current version of the Stigma Index measure the magnitude of factors associated with stigma and discrimination such as self-stigma and access to care, to better understand experiences of stigma and discrimination in different contexts and provide evidence that can be used to advocate for the rights of people living with HIV to shape programmatic interventions and policies.

Several studies and reports have documented discriminatory practices against indigenous peoples connected to the disproportionately high prevalence of TB in indigenous populations.<sup>12, 39-41</sup> Research has consistently described the socio-political effects of colonization and provided ample examples of discrimination within and outside the healthcare system for Inuit (indigenous people in the circumpolar North) having TB for example. While discussing treatment with healthcare professionals, Inuit patients said they felt patronized, not respected, controlled, not informed, and neither listened to nor taken seriously.<sup>40</sup> These discriminatory practices have contributed to the increase of health inequalities between indigenous and non-indigenous groups worldwide.<sup>42-44</sup>

## 2. Stigma and discrimination towards indigenous peoples at work

According to the ILO's Recommendation concerning HIV/AIDS and the World of Work, 2010, No. 200, "*there should be no discrimination against or stigmatization of workers, in particular jobseekers and job applicants, on the grounds of real or perceived HIV status or the fact that they belong to regions of the world or segments of the population perceived to be at greater risk of or more vulnerable to HIV infection*".<sup>15</sup> Several reports and analyses have revealed that many people living with HIV worldwide lose their jobs or cannot find one because of discrimination against them for living with HIV.<sup>45 - 46</sup>

The evidence on experiences of discrimination by indigenous peoples living with HIV and/or having TB in the workplace is scarce. Taking into consideration the history and the overwhelming volume of research on the occurrence of discrimination against indigenous populations, as well as on the extent of HIV-related stigma and discrimination more broadly, it can safely be presumed that discrimination against indigenous peoples living with HIV and/or having TB is also a significant problem in many countries, but is not well documented.

The literature captured in this rapid review describes discrimination against indigenous peoples by co-workers and in attaining suitable employment.<sup>47-49</sup> Indigenous peoples experience higher unemployment rates, lower occupational status, industry segregation and lower income levels than non-indigenous people.<sup>49,50</sup> Among the main factors driving these inequalities are institutionalized barriers connected to accessing land and resources derived from the land, inequitable funding for health, education and social services, less employment opportunities on traditional lands, inadequate housing, lower education, poorer socioeconomic conditions, stigma, racism and discrimination.<sup>50</sup>

## Findings from the interviews and focus group discussions

### 3. Levels of knowledge on HIV and TB

Levels of knowledge on HIV and TB varied considerably across individual participants and regions, generally there were higher levels in relation to HIV and lower for TB. Participants from all regions: Asia and the Pacific, Africa, the Americas and Europe and Central Asia showed an overall medium to high level of knowledge about HIV.

The levels of knowledge on TB averaged higher among participants from the Asia and the Pacific region. Overall, participants from the Americas showed low TB knowledge, but the knowledge of this disease was higher in South American countries (medium-high) compared to North America (low-medium). Among African participants, TB knowledge was variable with understandings of TB as carried by fumes, bad air or transmissible in the way that HIV is transmissible. Participants from the Europe and Central Asia region reported lower knowledge of TB than of HIV. In one context, TB seemed to be associated largely with refugees.

### 4. Sources of information on HIV and TB

The most common sources of information about HIV and TB for indigenous peoples were groups living with HIV or having TB, social media, traditional media platforms (radio, TV), online websites, community-based organizations and health services. A less common source was direct person to person communication with friends and colleagues.

Overall, participants from Asia and the Pacific region obtained much of their first-hand knowledge about HIV from indigenous peoples' groups living with HIV, from radio and from word of mouth. In New Zealand and Australia particularly, respondents identified epidemiological groups, the Global Fund to Fight AIDS, Tuberculosis and Malaria, and community organizations as a source of knowledge; while in India, community-based organizations and health services were frequent sources of information.

Participants from North America indicated that indigenous peoples living with HIV and/or having TB obtained much of their information from indigenous organizations, as well

as from social media, but there is little culturally specific information readily available. In Chile, indigenous peoples visit Peruvian and Bolivian websites to obtain information on TB but, otherwise they cannot access indigenous-specific information on HIV or TB. In Peru, most of the information is shared by or obtained from health professionals, but these same health professionals are often unable to speak indigenous languages. This is a significant barrier to a large proportion of the indigenous populations for whom they provide care.

According to participants from the African region sources of knowledge vary quite significantly. In some countries, many indigenous peoples living with HIV and/or having TB get their official information from health services, while others get their information from the media and community organizations. In Burundi, indigenous peoples living with HIV and/or having TB tend to get informed through community members, a participant from the Democratic Republic of the Congo identified the main sources of information as being radio and newspapers or TV if people have one. In Rwanda and Zimbabwe, they usually get information from community organizations, and specialized agencies such as the WHO, as well as from radio and TV.

Respondents from Europe and Central Asia indicated that there is no HIV and TB information specifically for indigenous peoples. For participants from the Russian Federation, the internet is the main source of knowledge, as well as direct personal transmission and other media platforms. In the European region, health workers are also sources of information about HIV/TB. Some participants noted the lack of regular sources of information on HIV/TB for indigenous peoples in this region, but there are campaigns targeting refugees and new immigrants.

## 5. Availability and access to health care services

Participants from Australia and New Zealand indicated that HIV drugs and treatment are available for free for indigenous peoples with HIV through health clinics, but they are often not easily accessible. TB testing is only available in hospitals. According to the participants from Asia and the Pacific region there are available services (testing and treatment) that are free for indigenous peoples. However, those services are often quite far and travel is expensive. In India, access to free TB and HIV treatment is available through Directly Observed Treatment Short-course centres spread throughout the country.

Health services are available for many indigenous peoples in the Americas, but stigma represents a major barrier to use the services. Participants from North America indicated that healthcare for indigenous peoples is provided by local health units, larger centres, through mobile clinics that go to reserves, or through indigenous-specific agencies in large reserves. In many of these contexts, care is not really anonymous, so it can be a barrier. In South America, participants indicate that healthcare is provided by hospitals, local health centres and peer educators but often not in indigenous languages, so communication barriers are a significant issue.

HIV testing and care services are available but there are significant barriers to access them across Africa. According to the participants, in many countries treatment and testing are generally provided in local health centres and by community health workers, but there is significant discrimination against indigenous peoples by doctors and health workers. Several participants reported that stigma and lack of information represent significant barriers to testing and treatment. Other obstacles include shortages of medicine (stock-outs), cost, corruption, and distance.



Participants from Europe and Central Asia indicated that they can receive healthcare services for HIV and TB. However, availability of health services seems to vary in Eastern Europe. One participant from the Russian Federation reported that HIV testing and treatment are available at work or at medical centres. However, only some of these centres offer free medication, so access to treatment can be difficult. People can get testing and treatment at special health and rehabilitation centres but discrimination and stigma are major obstacles. According to a participant from Norway, indigenous peoples can receive HIV testing and treatment throughout the country, using the same services as the general population, but in small communities, fear of disclosure is a major concern.

## 6. Multiple layers of stigma and discrimination against indigenous peoples

Most of the participants recognized the existence of stigma and discrimination against indigenous peoples as well as against those living with HIV or having TB, although it is less frequently acknowledged for TB. For some participants, there has been progress, but stigma and discrimination still exist in all regions. The reflections of the focus group leaders in this study reiterated interview findings on the multiple layers of stigma and discrimination faced by indigenous peoples living with HIV and/or having TB. Although there was considerable overlap, there were also varying views regarding how discrimination was experienced differently from one region to another.

In the Asia and the Pacific region, there is a general perception of the existence of multiple levels of discrimination. Participants from Australia and New Zealand, particularly, recognized that systemic, familial, individual and social discrimination is present against those who are indigenous, and more strongly against indigenous women and transwomen. They recognized that indigenous peoples living with HIV and/or having TB are discriminated against in multiple ways. For example, racial discrimination is frequent against Maori people in New Zealand and Aboriginal Australians. Indigenous peoples in Australia and New Zealand are underrepresented in political office, overrepresented in prisons and are often subject to stereotypes connected to laziness, poverty and drug use.

For participants from the Asia and Pacific region, the overall levels of discrimination seem to be lower, but there is a clear sense of discrimination in workplaces against people living with HIV and those having TB. A

*“Most of our members or our friends who are living with HIV, they've encountered it, some kind of stigma and discrimination at every level”*

Participant from Asia and the Pacific, employed in the formal sector

participant from India expressed that discrimination against indigenous peoples is tied to the caste system, with the worst cases of discrimination occurring against women.

Participants from the Americas revealed that multiple layers of discrimination against indigenous peoples are still evident. In North America, discrimination against indigenous peoples is evident in housing, child welfare, education, and other social and health services. Discrimination is also expressed against those who are assumed to use substances and those who do so. According to the participants, stigma and discrimination is often expressed against indigenous peoples living with HIV and is revealed in healthcare and social networks. For some participants, stigmatization and discrimination against indigenous peoples living with HIV comes both from within and outside of the community. For participants from South America, discrimination against people for being indigenous is mostly based on stereotypes and is experienced differently for men and women. For indigenous peoples living with HIV,

discrimination can be especially harsh, to the point where indigenous women with HIV have been forcibly sterilized.

Discrimination connected to HIV or having TB only further exacerbated the violence experienced by indigenous peoples living with HIV or having TB in some African countries. Leaders from the IIWGHA – which include representatives from North America, Australia and New Zealand - and

*“And in [the country], regardless of whether there are laws or even if the native people have been recognized through a law, there is still discrimination against the indigenous peoples. And double discrimination, also for being a person living with HIV.”*

Participant from Latin America, employed in the formal sector

representatives from South America reiterated that indigenous peoples often face a doubling of discrimination for being indigenous and for living with HIV and/or having TB. The layers of discrimination were shown to compound. Canada, where forced sterilizations continue to occur, demonstrates the ways in which violence continues to be used as an underlying precursor for further discrimination against indigenous peoples living with HIV. In Latin America, both family and religious institutions played a key role in acts of discrimination and resistance. These institutions mediated indigenous peoples’ knowledge and experience of living with HIV and/or having TB, their relation to society and to the workplace.

In Africa, participants reported numerous expressions of discrimination against indigenous peoples. For some participants, discrimination based on indigeneity is

*“Discrimination is still there. (...) Stigma is even there, in workplaces. Stigma is there in schools. Stigma is there in churches. Stigma is there in families. Stigma is still there, as well as discrimination. It's too common.”*

Participant from Africa, employed in the informal sector

frequent and is evident in healthcare, as well as in the context of employment and other social contexts. One African participant discussed that much discrimination is experienced by indigenous peoples because they are visibly distinctive from non-indigenous people and thereby become easy objects of discrimination. Another participant considers that discrimination against people living with HIV is less than before, yet many people still do not socialize, eat with, hug, or have other forms of relationships with people living with HIV due to fear of exposure. Although in some African countries, discrimination against people living with HIV is illegal, participants perceive that it is still present and puts people on the margins of society. African leaders endorsed their fellow nationals from Sub-Saharan Africa. Discrimination against indigenous peoples in this region was described as extraordinarily high in many countries. This discrimination was systematically reflected in unequal access to employment, to fair wages, to medicine and to effective legal recourse. Some African representatives reaffirmed the fact that indigenous peoples in some countries generally live at a level of poverty below the majority of the population and are systematically exploited for their labour because they are visibly identifiable as indigenous. In some cases, the levels of abuse were so high that physical assaults against indigenous peoples were common.

In Europe and Central Asia, participants also reported the presence of discrimination against people living with HIV, but not always for being of indigenous origin.

## 7. Experiences of discrimination against indigenous peoples and people living with HIV and/or having TB

Numerous experiences and types of discrimination have been reported, either by the participants themselves or by other members of their community. Self-stigma or self-discrimination, internalizing the negative judgment and imposing it on oneself, has been identified as an important factor contributing to discrimination by participants from several regions. These experiences can be encountered in different social contexts, including in the workplace.

Participants from Asia and the Pacific region shared multiple experiences of discrimination. Many declared that some people have been discriminated against by younger community members for living with HIV and/or having TB or

*"I do not know if, due to having an indigenous surname, it's the people themselves who feel self-discrimination or feel that the process of their work environment is less valued than other people who do not have the indigenous name"*

Participant from Latin America, employed in the formal sector

for being of indigenous origin in gay bars. There were also examples of women experiencing more discrimination than men in the context of education and access to social services. In India specifically, there are experiences of indigenous peoples outed by community members for their HIV status, and cases of disclosure without consent by medical staff. In Fiji and New Zealand, participants reported numerous experiences of discrimination in the form of joking or mocking within the community, and reported that some groups such as women and members of the LGBT community (especially transwomen) often suffer more violent forms of discrimination than other members of the community.

In the Americas, despite contextual, cultural and development differences between North America and South America, experiences of stigma and discrimination are common in both contexts, often under assumptions that indigenous peoples are poor or less capable. Examples of people ostracized from the community, from health services or from public spaces for living with HIV or having TB and being indigenous were discussed by North American participants. Examples include a woman being left to bleed on the street because of rumours that she had HIV; a son being left out in the cold in winter with his tongue stuck to a pole because the school administrators thought he had HIV; or a man not being able to buy a bottle of wine because he was assumed to be drunk because he was indigenous.

*"I know that health professionals, due to ignorance of the native people's culture, have discriminated in the sense that [they think] indigenous peoples do not follow the treatment correctly because they have [the opinion that] the culture .... , is messy, it is irresponsible. And they have told this directly to a man, that he will not be able to go ahead with the treatment because he is irresponsible."*

Participant from Latin America, employed in the formal sector

Similarly, discrimination against indigenous peoples in South America is related to stereotypes. Indigenous peoples living with HIV face a significant extra layer of discrimination. Experiences of discrimination from health providers were often reported. Much of this discrimination is systemic, with numerous governments failing to develop adequate outreach programmes for many who are marginalized. In general, women suffered more discrimination by healthcare practitioners because they access health services more often.

African participants described numerous experiences of discrimination that were common in the region, with indigenous peoples often being treated as lesser than non-indigenous people. One participant described the strong and multiple forms of discrimination against Pygmies in Burundi. The experiences of discrimination are evident in education, in healthcare, in government services and more widely in the society. In addition to their indigenous origin, people tend to be discriminated against due to their HIV and/or TB status, even in relation to non-indigenous people with these infections. One participant described how community members start talking (gossiping) when they saw someone getting help from caregivers, and cases of people rejecting people living with HIV, or stopping to buy goods from women who were suspected of being infected. In the experience of many participants, women generally face more forms and frequency of discrimination than men.

*"I just know of one person - this lady who used to sell things, so she would move around with a basket, but one day she got sick. We don't even know if it was HIV or not, but people were saying it's HIV, because she got really, really sick. Now, when she got back to her selling, it was very difficult for her to continue with her business, because now people were scared to buy her things."*

Participant from Africa, employed in the informal sector

Participants from Europe also shared experiences of discrimination, mainly in the context of health care and related to disclosure of their HIV or TB status. There are examples of health professionals who had disclosed people's HIV status. In addition, health professionals themselves described being forced to take mandatory HIV and/or TB tests in order to keep their jobs. In Norway, there were experiences reported of parents not wanting people with HIV to work with their kids. There continues to be discrimination against indigenous peoples based on stereotypes. The Sami, for example, are often still regarded as dirty, and there continues to be workplace discrimination against them and discrimination in accessing health services.

## 8. Discrimination against indigenous peoples living with HIV and/or having TB at work

Most participants had experienced discrimination in the workplace or were aware of these experiences, despite legislation and human rights policies, regulations and norms that should protect people from any kind of discrimination when looking for employment or in the workplace. Many declared having knowledge of friends or members of their community that have been subject to discrimination due to their indigenous origin and/or their HIV status.

*"I ended up getting basically seven months leave with pay, and a settlement to leave the job. Basically, they didn't want me back on the job."*

Participant from Asia and the Pacific, employed in the formal sector

According to the participants, discrimination is revealed in different contexts and forms in the world of work. Multiple experiences were reported of being unable to get a job, of losing jobs or being denied a promotion because of their HIV and/or TB status and/or being indigenous. Numerous experiences of not getting work or being fired because of indigenous origin or living with HIV or having TB were reported by participants from all regions. There were also numerous experiences of discrimination by employers and co-workers.

*"I've been denied promotions and employment for being indigenous and for having HIV, so both ways. (...) I was working at an organization and there was no reason that I could not have been promoted, but I was looked over. I was passed over, and it could have been because of HIV. It could have been because of being indigenous or being a woman too. Basically, the person that did get the promotion could barely speak English, so that was even harder to swallow."*

Participant from Asia and the Pacific, employed in the formal sector

Participants from Asia and the Pacific region described experiences of workplace discrimination on multiple grounds, for being indigenous and also for living with HIV. In Australia, New Zealand, Fiji and India – despite laws and human rights policies, regulations and norms, – there are many known cases of discrimination against indigenous peoples in the workplace. Although there are laws against workplace discrimination, they are rarely

enforced. Participants from this region related that many people stop looking for work after being diagnosed with HIV and/or TB. They also reported that there were significant cases of job losses because of their HIV status, or not getting paid full wages because of the assumption that the person does not need to invest in their retirement. In addition, there are reported cases of disclosure of their status without consent by colleagues.

*"In work situations, once my status had been found out, I've been discriminated and stigmatized, and gone from being a productive member of that work team, to being shut out and left out of a lot of what I used to be involved with. I've lost jobs. I've been looked over because of my HIV status and passed over for promotions."*

Participant from Asia and the Pacific, employed in the formal sector

Similarly, participants from Asia and the Pacific region described cases of discrimination against people living with HIV in the workplace and gave numerous examples of people losing their jobs, even though there is legislation to protect against it. Sometimes, the recruitment process required HIV tests prior to being hired, so people who were living with HIV refrained from applying to jobs for fear of discrimination. This happened even when people in recruiting organizations knew that there were strict rules against discrimination.

In the Americas, although there are several laws, and civil and human rights regulations and laws currently in place to protect people against workplace discrimination, there are numerous examples of discrimination related to work. In general, there is less stigma related to TB than HIV. In North America, several examples of this type of discrimination were described. Participants gave examples of an indigenous person being turned away from giving a presentation on HIV because of their HIV status, and of people avoiding engaging with people living with HIV out of fear that they will be suspected of having HIV as well.

*"I was heading up to [an indigenous] community to do some education around HIV. (...) The person I was travelling with took the call, asked why, and they said they did not realize that somebody living with HIV was actually coming up to (work), and we got turned back as a result of that."*

Participant from North America, employed in the formal sector

In South America, there are also several laws prohibiting discrimination against indigenous peoples with HIV, yet discrimination is frequent. According to participants, many

*“Rather than discriminating there is something that [...] we call the bullying line where you can make a joke to an indigenous person, telling them that they are Indians or ‘cholos’. For instance, this person might receive the joke in a conversation or in a meeting... But yes, in the workplace, there is bullying towards people who have a different last name.”*

Participant from Latin America, employed in the formal sector

people may not disclose their status so to avoid being publicly outed. There were many examples of people who had difficulties applying for or getting a job when they live with HIV and/or have TB due to fear of discrimination. Participants also described cases of women who were tested for HIV without their consent and others that were fired for living with HIV.

In many African countries, in spite of workplace policy and legislation aiming at preventing discriminatory practices, there are frequent cases of discrimination in the workplace against indigenous peoples living with HIV. Some participants described the situation as a generalized discrimination against indigenous peoples and those living with HIV and/or having TB, when looking for employment or in the workplace. According to participants the laws are not enforced in most countries and discrimination is rampant. For one participant, indigenous peoples are not aware of their rights and so not able to fight to have them protected. This situation seems to be related to deficient mechanisms about communicating the laws. Employers sometimes pretend not to discriminate but they talk and make public comments about people living with HIV and/or having TB. There are anti-disclosure regulations or laws in place, yet there are ample cases of disclosure without consent. Several participants shared examples of people not getting a job because of their HIV status, or people being treated differently for living with HIV.

*“Yeah, a lot of discrimination in the workplace. Most people, they don't want to associate with you. Maybe they fear that if they associate with you, they can get HIV through you. Even if you go to lunch together with people, people will sit aside. They will leave you alone eating. They don't want to eat together with you.”*

Participant from Africa, employed part-time

*“I have experienced stigma and discrimination. There was a time when I was sick, and my juniors at work were promoted, but I was left out. There was a rumour that they suspected that my sickness was HIV related, and, therefore, they could not risk promoting me.”*

Participant from Africa, employed in the formal sector

In Europe and Central Asia, there are also labour laws that prohibit discrimination against people with HIV. In the Russian Federation, there is reportedly a high level of stigma and numerous examples of discrimination against those living with HIV and/or having TB in the workplace. For some jobs, HIV testing is required, so people sometimes quit rather than be found out. Sometimes people are fired with spurious reasons, but it is believed that is actually because of their HIV status.

Leaders and representatives across all regions tended to agree that there was significant work to be done in terms of protecting the workplace rights of indigenous peoples living with HIV and/or having TB. It was largely recognized that workplace protection had to occur in two ways; institutionally at the policy and enforcement levels and socially within

*“There were situations in the [company], when managers find out that an employee had a diagnosis of HIV infection, they simply fired him. They use any excuse in this case.”*

Participant from Europe and Central Asia, not employed

communities and families. This would help to ensure that indigenous peoples living with HIV and/or having TB gain employment in the first place and are able to keep their employment regardless of their HIV or TB status.

Participating countries have regulations and laws that are supposed to protect the rights of workers living with HIV and/or having TB but there is little enforcement of those legal instruments. Because of the unequal enforcement of these regulations and laws, many people with a positive HIV and/or TB status choose instead not to disclose their status for fear of negative and ongoing repercussions of forced disclosure.

## 9. Laws and regulations against discrimination in the world of work

As revealed by several participants, in spite of employment regulations and laws, the work environment in many countries is not inclusive for indigenous peoples living with HIV and/or having TB. The chances of getting a job or, once employed, to have the same opportunities as non-indigenous employees to be promoted or be treated fairly in the workplace are lower for indigenous peoples in general and even more so for those living with HIV and/or having TB.

Most countries of origin of the participants have workplace legislation and policy and human rights regulations and laws in place against multiple forms of discrimination. In addition to this, there is national legislation and jurisprudence in most countries that protect the rights of workers. In many countries though, the implementation and enforcement of those legal mechanisms are weak or absent.

According to one participant in Chile, Law No. 19779 prohibits discrimination against employees with HIV, and yet there continues to be ongoing discrimination against indigenous peoples in the workforce. This suggests that the workplace rights of indigenous peoples with HIV are circumvented or simply ignored. Another participant said that in Peru, the Law No. 26626/Amendment No. 28243 offers protection against discrimination based on HIV status in the workplace, however discrimination against indigenous peoples and against those living with HIV is common. In Rwanda and Zimbabwe, participants indicated knowledge of laws that protect people against discrimination (Rwanda) and sexual harassment (Zimbabwe) in the workplace, but they were not able to identify specific laws protecting indigenous peoples living with HIV and/or having TB from discrimination. In some countries the protection against discrimination is provided through general labour codes or human rights legislation (e.g. Norway, Canada).

## 10. Awareness of Indigenous and Tribal Peoples Convention, 1989 (No. 169)

The Indigenous and Tribal Peoples Convention, 1989 (No. 169) (see box below) was approved in 1989 and entered into force in 1991. So far, it has been ratified by 23 states, though it has influenced laws and policies in many more countries. Overall, the knowledge of Convention No. 169 amongst the indigenous peoples interviewed is low, with only a few participants being fully aware of this international Convention. The best knowledge of the Convention No. 169 was, perhaps not surprisingly, of participants in countries where the Convention had been ratified. It is notable that in some countries that have not ratified Convention No. 169 there is good or some knowledge of the Convention (e.g. Australia, Rwanda).

There was low knowledge of Convention No. 169 among African participants and also few ratifications from this region. However, it seems that the message has reached some African communities, and some participants were aware of the benefits of the Convention for indigenous peoples.

One experience related to the implementation of Convention No. 169 was shared by one of the participants that considered it as a positive step for indigenous communities, but there was a sentiment of politization of the Convention and that it is used to benefit certain economic interests rather than actually protecting the rights of people.

*“With ILO Convention 169, we are taught protection of indigenous peoples, to enable them to continue to live in harmony with their customs and respect for their culture, and to give them a developmental pace, to give them access to work.”*

Participant from Africa, not employed

*“I remember that I once heard on the radio that the workers are defended by these laws of 169. But for us, given we are unemployed and poor and unhappy, how to know all that?”*

Participant from Africa, employed in the formal sector

### **Indigenous and Tribal Peoples Convention, 1989 (No. 169)**

ILO Convention No. 169 on indigenous and tribal peoples is an international treaty, adopted by the International Labour Conference of the ILO in 1989. The Convention represents a consensus reached by ILO tripartite constituents on the rights of indigenous and tribal peoples within the member-States where they live and the responsibilities of governments to protect these rights. It is based on respect for the cultures and ways of life of indigenous peoples and recognizes their right to land and natural resources and to define their own priorities for development. The Convention aims at overcoming discriminatory practices affecting these peoples and enabling them to participate in decision-making that affects their lives. Therefore, the fundamental principles of consultation and participation constitute the cornerstone of the Convention. Further, the Convention covers a wide range of issues pertaining to indigenous peoples, including regarding employment and vocational training, education, health and social security, customary law, traditional institutions, languages, religious beliefs and cross-border cooperation.

Source: ILO, 2013, Understanding the Indigenous and Tribal People Convention, 1989 (No. 169): Handbook for ILO Tripartite Constituents (Geneva).



## Recommendations

Many participants consider that colonial history is a key factor in indigenous peoples' experiences of stigma and discrimination. This must be considered as a constant reality in

*"Of course, we need to recognize that some work is being done. I think we still have much to do. There is so much to do regarding the people's education. There is a lack of strategies that originate from indigenous peoples, lack of leaders who represent their native peoples for them to know more about how the subject is addressed and how they want to deal with HIV in the indigenous communities, how they want to handle the prevention strategies in indigenous peoples."*

Participant from Latin America, employed in the formal sector

the lives in indigenous peoples which impacts every aspect of life in a constant process of protecting traditional worldviews and identity as a unique culture within a dominant colonial society. At the same time, participants emphasize the importance of the knowledge and capacities of indigenous peoples as the essential strengths to address and overcome these problems. Some participants acknowledged that some progress

has been made, but that there is still a lot to do.

There were numerous reflections and recommendations by the participants on how to improve the situation of indigenous peoples. Among the most common recommendations were to improve mechanisms for legal recourse for discrimination; to improve knowledge and education about their rights; and, to encourage and enable the deeper involvement of indigenous peoples living with HIV and/or having TB in the monitoring of workplace rights.

*"In the workplace itself, there are specific cases that demonstrate the existence of a certain degree of discrimination against people living with HIV because they see them as an impairment, like a cost or a problem".*

Participant from Latin America, employed in the formal sector

*"Indigenous peoples living with HIV or TB have very limited knowledge of their human rights related to stigma and discrimination in the world of work. I would say, more work needs to be done in order to make both the employer and the indigenous employee aware."*

Participant from Africa, employed in the formal sector

*"Create teaching institutions that encourage everyone to learn. Push people to form community associations, what we call grassroots association."*

Participant from Africa, not employed

Education and information on the socioeconomic conditions and rights of indigenous peoples are necessary in order to better support indigenous peoples living with HIV and/or having TB in the workplace. Many participants pointed out that education on workplace rights should target not only indigenous peoples and people living with HIV and/or having TB, but also employers and co-workers.

**Recommendations include:**

**Involve people with living experience:**

1. Include indigenous stakeholders living with HIV and/or having TB in the development of strategies to reduce workplace discrimination and all other responses to reflect GIPA;
2. With representation from indigenous peoples living with HIV and/or having TB, review disclosure and confidentiality policy and workplace protections related to stigma and discrimination;

**Provide information and education:**

3. Design culturally-sensitive outreach efforts and materials in the languages of indigenous communities as well as in official languages;
4. Develop training packages for service providers focussing on stigma and discrimination, respecting confidentiality and learning about indigenous cultures to address stereotypes and judgment when indigenous peoples reach out to them;
5. Design and implement campaigns against stigma and discrimination directed to the general public;

**Engage and enforce legal solutions:**

6. Ratification and implementation of ILO Convention No. 169 for promoting and protecting the rights of indigenous peoples, including with regard to participation and consultation, employment, education and health care;
7. Improve mechanisms to support legal claims against discrimination;
8. Implement and enforce the legal mechanisms that are in place to protect indigenous peoples living with HIV and/or having TB in the workplace;

**Respond in the workplace:**

9. Continued promotion of the ILO Convention No. 169 and the ILO Recommendation on HIV and AIDS and the world of work (No. 200);
10. Target employers, co-workers, trade unions and indigenous peoples living with HIV and/or having TB in the development and execution of interventions;
11. Increase the effectiveness of strategies to improve broad-based education on the rights of indigenous peoples living with HIV and/or having TB in the workplace by engaging employers and employees in training about country specific legislation and policy and international conventions and covenants;

**Pursue research to improve the availability of data by and for indigenous peoples:**

12. Conduct and support further research on the experiences of stigma and discrimination against indigenous peoples living with HIV and/or having TB by engaging in more in-depth research on country-specific studies (this may include partnering to extract indigenous data from in-country Stigma Index studies);
13. Research effective responses and interventions to improve worker's conditions in the workplace and generally in the world of work;
14. Ensure that research offers benefits to indigenous communities that participate in the study, through ongoing engagement with policy development, nation-specific program development, and support for community-specific goals.

This report and its recommendations contribute to increasing the availability of evidence on indigenous peoples' experiences, individually and collectively, of stigma and discrimination specifically related to HIV and TB in the world of work. This will contribute towards further, hopefully more in-depth examination of stigma and discrimination toward indigenous peoples living with HIV and/or having TB in the workplace. By initiating this investigation and pursuing further work, we will better understand the factors influencing stigma and discrimination in the world of work and thereby inform policies and effective interventions.

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## Appendices

### Appendix 1: Literature search and list of relevant documents

#### List of references in academic literature

#### Academic search: Ovid (EMBASE, from 1974 to June 2019)

Search history sorted by search number ascending				
#	Searches	Results	Type	Actions
1	Indigenous peoples.mp. or ethnic group/ or Aborigine/ or indigenous people/ or American Indian/	91702	Advanced	<a href="#">Display Results</a> <a href="#">More</a>
2	HIV.mp. or Human immunodeficiency virus/	400737	Advanced	<a href="#">Display Results</a> <a href="#">More</a>
3	discrimination.mp.	174244	Advanced	<a href="#">Display Results</a> <a href="#">More</a>
4	employment/ or employment discrimination/ or workplace/ or workplace discrimination.mp.	94422	Advanced	<a href="#">Display Results</a> <a href="#">More</a>
5	tuberculosis/ or Tuberculosis.mp.	222376	Advanced	<a href="#">Display Results</a> <a href="#">More</a>
6	1 and 2 and 4 and 5	0	Advanced	<a href="#">Save</a> <a href="#">More</a>
7	1 and 2 and 4	38	Advanced	<a href="#">Display Results</a> <a href="#">More</a>
8	1 and 2 and 3 and 4 and 5	0	Advanced	<a href="#">Save</a> <a href="#">More</a>
9	1 and 4 and 5	2	Advanced	<a href="#">Display Results</a> <a href="#">More</a>

The 7<sup>th</sup> search list includes the references of publications related to HIV stigma and discrimination in the workplace, but none was specific to indigenous peoples. From the 38 references returned from the bibliographic search, 18 were excluded due to duplicates and/or clearly irrelevant by reviewing the title and abstract.

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#### **List of relevant documents in complementary search**

The selected documents/articles were grouped into four categories:

#### **Stigma and discrimination of indigenous peoples**

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**Stigma and discrimination of people living with Tuberculosis**

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**Stigma and discrimination and HIV in the workplace**

1. Nwanna, C.R. 2005. *Social consequences of HIV/AIDS: Stigma and discrimination in the workplace in Nigeria*. Lagos, Nigeria.
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## **Appendix 2: Interview guide**

### **Preamble**

The Canadian Aboriginal AIDS Network (CAAN), the International Indigenous Working Group on HIV & AIDS (IIWGHA) and the International Labour Organization (ILO) have partnered to conduct a qualitative study to explore the issue of stigma and discrimination faced by indigenous peoples living with HIV and tuberculosis in the world of work.

CAAN (<https://caan.ca>) is a Canadian organization that provides a national forum for Aboriginal Peoples to holistically address HIV and AIDS, and other health issues, to promote a social determinants of health framework through advocacy; and to provide accurate and up to date resources on these issues in a culturally relevant manner for Aboriginal Peoples wherever they reside. IIWGHA (<http://www.iiwgha.org>) is an international organization with the mission of creating a global voice and structure that links indigenous peoples with their indigenous leadership, all levels of governments, AIDS service organizations, cooperatives, and others in a global collective action to lower the disproportionate impact of HIV and AIDS experienced by indigenous peoples. ILO (<https://www.ilo.org>) is the only tripartite UN agency that brings together governments, employers, and workers of 187 member States to set labour standards, develop policies and devise programmes promoting decent work for all women and men.

This questionnaire has been developed for conducting in-depth interviews to collect information and perspectives of people and representatives of indigenous peoples with or without HIV or TB, in different regions of the world, and to publish and disseminate a report on this issue globally. The study will contribute to the activities of the 30<sup>th</sup> anniversary of ILO Convention 169 and incorporate the perspectives from indigenous peoples working in the formal and informal economy, self-employment well as those seeking employment. The study report will inform the work of ILO, IIWGHA, CAAN and other relevant partners as well as being available as a web-based publication to illustrate and raise awareness about stigma and discrimination faced by indigenous peoples living with HIV in the world of work and contribute to addressing this issue.

We very much appreciate your help to produce a collective snapshot of indigenous people's living with HIV experiences in the world of work including a special focus on the recognition of rights of indigenous peoples living with HIV, where possible. The interview will take about 30 to 45 minutes. We would like your permission to audiotape the interview and to write notes as we do not want to forget any important points. All the information you share with us will be used only for the purposes of this study and will be kept confidential and stored under the protection of the three organizations supporting this study.

### **A. Awareness of ILO Convention No. 169, formally known as the Indigenous and Tribal Peoples Convention, 1989 (No. 169)**

Convention No. 169 is the major binding international Convention concerning indigenous peoples adopted in June 1989, and a forerunner of the Declaration on the Rights of Indigenous Peoples. Protection is still the main objective, but it is based on respect for indigenous and tribal peoples' cultures, their distinct ways of life, and their traditions and customs. It is also based on the belief that indigenous and tribal peoples have the right to continue to exist with their own identities and the right to determine their own way and pace of development.

1. What is your level of awareness or knowledge about ILO Convention No. 169?  
*Note to Interviewer:* Open response. But a suggestion of a 5-levels of awareness/knowledge can be asked to the participant (0 – None/No knowledge; 1 - Very limited; 2 - Some knowledge; 3 - Good knowledge; 4 – Expert/advanced knowledge)
2. Are you aware of any work to implement Convention No. 169? If yes, can you please provide specific examples:
  - a. In your country
  - b. In the community
  - c. In the world of work

**B. Knowledge of HIV and tuberculosis amongst indigenous peoples**

1. What is your level of knowledge about the situation of HIV and TB amongst indigenous peoples?  
*Note to Interviewer:* Open response. But a suggestion of a 5-levels of awareness/knowledge can be asked to the participant (0 – None/No knowledge; 1 - Very limited; 2 - Some knowledge; 3 - Good knowledge; 4 – Expert/advanced knowledge)
2. Can you please provide examples of sources of information about HIV and TB amongst indigenous peoples?
3. Are you aware of HIV testing and treatment services available to indigenous peoples living with HIV and/or having TB? If yes, can you please provide specific examples of those services?
4. In your view, what could be helpful and what are the main obstacles for accessing HIV and/or TB services for indigenous peoples, either in your community, country or anywhere?

**C. The multiple layers of stigma and discrimination faced by indigenous peoples due to being indigenous as well as living with HIV.**

1. Do you feel or have knowledge about the existence of discrimination against indigenous peoples living with HIV, a) in any context, b) in the context of work?
2. Have you or someone you know experienced racism due to your indigenous identity? If you do, can you please provide examples of those experiences?
3. Have you or someone you know experienced racism due to your indigenous identity and living with HIV? Please describe any example of experiences with other people living with HIV.

**D. Experiences of upholding or violating rights in the workplace/work context because of HIV and/or TB status:**

1. Have you ever been discriminated against or have knowledge of someone being discriminated while in seeking employment because of HIV and/or TB status? Please provide examples.
2. Have you ever been left out or felt purposively excluded in seeking employment or in recruitment because of HIV and/or TB status? If so, please provide examples.

3. Have you or someone you know experienced stigma and discrimination from colleagues in your workplace due to your indigenous identity and or your HIV and/or TB status? Also, in your experience, are there examples of where someone with indigenous background with HIV and/or TB was not discriminated against at work? Can you please provide examples of any of those situations?
4. Have you or someone you know had their HIV and/or TB status disclosed to an employer without their consent? Please provide examples, without disclosing any personal information.
5. Have you or someone you know lost their job or source of income because of HIV status? Please provide examples, without disclosing any personal information.
6. Have you or someone you know been refused employment or a work opportunity because of HIV and/or TB status? Please provide examples, without disclosing any personal information.
7. Have you or someone you know experienced discrimination due to HIV and TB status?
8. Can you describe what you know about the attitudes of employers and co-workers regarding people living with HIV and/or having TB?
9. Do you have any other comment or opinion regarding stigma and discrimination of indigenous peoples living with HIV and/or having TB in the workplace?

**E. Experiences of engagement in the world of work**

1. Have you or someone you know experienced changes to their job description, to the nature of their work and/or were refused the opportunity for promotion for a range of reasons including ill health, discrimination and/or other factors related to their HIV and TB status?
2. In your view, what are the key aspects that should be taken into account at social and community levels to address this issue?
3. How the employers should be prepared to properly face/tackle this problem? What are the most important elements to reduce or prevent stigma and discrimination of indigenous peoples living with HIV and/or having TB in the workplace?
4. Is there anything else that you would like to add regarding experiences of engagement in the world of work for indigenous peoples living with HIV and/or having TB?

**Socio-Demographic information**

Next, to conclude this interview we want to ask you some personal questions. These questions have simply the purpose of describing the characteristics of the participants in this study. Remember, no personal information will be disclosed, but please feel free to not respond if you're not comfortable.

1. What is your sex/gender?
  - a. Male
  - b. Female
2. In which age group are you?
  - a. 20-44 years of age
  - b. 45-64 years of age

- c. 65 or more years of age
- 3. What indigenous peoples' community or group you are member or identify with?
  - a. Describe: \_\_\_\_\_
  - b. Not indigenous community
- 4. Are you a member of an indigenous peoples' organization? Yes: \_\_\_\_ No: \_\_\_\_
- 5. What is your sexual orientation or gender identity?
  - a. Heterosexual
  - b. Gay
  - c. Lesbian
  - d. Bisexual
  - e. Transgender
  - f. Other. Describe: \_\_\_\_\_
- 6. Where were you born (city, community)? Describe: \_\_\_\_\_
- 7. Where do you live?
  - a. City: \_\_\_\_\_
  - b. Country: \_\_\_\_\_
- 8. Are you married? Yes: \_\_\_\_ No: \_\_\_\_
- 9. Are you currently employed? Yes: \_\_\_\_ No: \_\_\_\_
  - a. If yes, for how long? \_\_\_\_\_
- 10. Are you living with HIV? Yes: \_\_\_\_ No: \_\_\_\_
- 11. Have you been diagnosed with TB? Yes: \_\_\_\_ No: \_\_\_\_

**Thanking the interviewees**

Thank you very much for participating in this interview.

### Appendix 3: Focus Group Dialogue Guide

#### Preamble

The Canadian Aboriginal AIDS Network (CAAN), the International Indigenous Working Group on HIV & AIDS (IIWGHA) and the International Labour Organization (ILO) have partnered to conduct a qualitative study to explore the issue of stigma and discrimination faced by indigenous peoples living with HIV and/or having TB in the world of work.

CAAN (<https://caan.ca>) is a Canadian organization that provides a national forum for indigenous peoples to holistically address HIV and AIDS, and other health issues, to promote understanding of health in the context of the natural and social environments that surround indigenous peoples; and to provide culturally relevant resources for indigenous peoples.

IIWGHA (<http://www.iiwgha.org>) is an international organization with the mission of creating a global voice and structure that links indigenous peoples with their indigenous leadership, all levels of governments, AIDS service organizations, cooperatives, and others in a global collective action to lower the impact of HIV and AIDS experienced by indigenous peoples.

ILO (<https://www.ilo.org>) is the only tripartite U.N. agency (involving 3 parties) that brings together governments, employers and workers of 187 member States to set labour standards, develop policies and devise programmes promoting decent work for all women and men.

This Focus Group has been planned to discuss information and perspectives of indigenous peoples who are living with HIV and/or TB related to the world of work. We have completed over 20 interviews with indigenous peoples in different regions of the world. We have begun to summarize the information from the interviews and we would like to talk about what we are learning with you. We will bring together what we heard in the interviews and what we learn from our focus group to produce and distribute a global report on the issues of stigma and discrimination faced by indigenous peoples living with HIV in the world of work.

The study will contribute to the activities of the 30<sup>th</sup> anniversary of ILO Convention 169 and incorporate the perspectives from indigenous peoples working in the formal and informal economy, self-employment as well as those seeking employment. The study report will inform the work of ILO, IIWGHA, CAAN and other relevant partners as well as be available as a web-based publication to illustrate and raise awareness about stigma and discrimination faced by indigenous peoples living with HIV in the world of work and contribute to addressing this issue.

We very much appreciate your help to produce a collective report of the experiences of indigenous peoples living with HIV in the world of work including a special focus on the recognition of rights of indigenous peoples living with HIV, where possible. The Focus Group will take about one hour (60 minutes). **We would like your permission to record the dialogue and to write notes as we do not want to forget any important points. All the information you share with us will be used only for the purposes of this study and will be kept confidential and stored under protection of the three organizations supporting this study.**  
**(Wait for agreement)**

#### **(Start recording dialogue)**

Optional – open the Focus Group following local protocol when people gather together (note: this may or may not be recorded. Please ask every time).



Note: Socio Demographic details are also useful for the Focus Group participants. Please ask them to fill out the questionnaire before leaving the Focus Group.

## **Discussion Guide**

### **Part 1: Knowledge of HIV and TB**

1. We conducted a series of interviews among indigenous peoples living with HIV and TB and we found the following key themes: (present a list/summary of the findings).
  - Based on your knowledge and experience on this matter, what is your view/opinion about these results?
2. Now, can you tell us more about the general levels of knowledge of HIV and tuberculosis amongst indigenous peoples?

Prompts for areas to listen for and/or further explore:

- What are your own views/perspectives on the levels of knowledge among indigenous peoples?
- Is there enough or insufficient knowledge or awareness?
- Provide examples of sources of information about HIV and/or TB amongst indigenous peoples?
- Discuss options identified for HIV and/or TB testing and treatment services available to indigenous peoples?
- Review specific examples of those services

### **Part 2: Multiple layers of Stigma and Discrimination**

3. In the interviews conducted, these are the themes that emerged regarding the issue of stigma and discrimination: (present a list/summary of the findings).
  - Again, based on your knowledge and experience on this matter, what is your view/opinion about these results?
4. Now, what else you think is important about the existence of discrimination against indigenous peoples living with HIV and/or having TB?

*Prompts for areas to listen for and/or further explore:*

- How do you think discrimination occurs due to HIV and/or TB status and/or indigenous identity?
  - Are indigenous men more at risk of facing racism than indigenous women?
- a. What do you think about stigma and discrimination **in workplaces based on indigenous identity**?
  - b. Are there different experiences with indigenous and non-indigenous employers and co-workers?
    - Are there differences with male and female employers and co-workers?

**Part 3: Rights in the workplace/work context regarding HIV and/or TB status:**

5. In the interviews conducted, these are the themes that emerged regarding the rights in the workplace: (present a list/summary of the findings).
    - Again, based on your knowledge and experience on this matter, what is your view/opinion about these results?
  6. Now, can you tell us more about the knowledge and experience of indigenous peoples living with HIV or having tuberculosis regarding their rights in the workplace?
- c. Can you describe what you know about the **attitudes of employers and co-workers** regarding people living with HIV and/or having TB?

*Prompts for areas to listen for and/or further explore:*

- Do you think attitudes are different between male and female employers and co-workers?
- Are people left out or felt purposively excluded in seeking employment or in recruitment or denied a promotion at work because of HIV and/or TB status?

**Part 4: Engagement in the world of work**

7. In the interviews conducted, these are the main themes that emerged regarding this topic: (present a list/summary of the findings).
  - Again, based on your knowledge and experience on this matter, what is your view/ opinion about these results?
8. Now, can you tell us more about the main problems faced by indigenous peoples with HIV and TB while engaging in the world of work?
  - Generally, what steps could be taken to create Stigma and Discrimination-free workplaces?
  - What are the key aspects that should be taken into account at national, workplace and community levels to address engagement in work for an indigenous person living with HIV or with TB?
  - Are you aware of any national legislation / laws that protect rights in workplaces?

**Part 5: Awareness of Indigenous and Tribal Peoples Convention, 1989 (No. 169)**

ILO Convention No. 169 is the major binding international convention concerning indigenous peoples adopted in June 1989, and a forerunner of the Declaration on the Rights of Indigenous Peoples. Protection is still the main objective, but it is based on respect for indigenous and tribal peoples' cultures, their distinct ways of life, and their traditions and customs. It is also based on the belief that indigenous and tribal peoples have the right to continue to exist with their own identities and the right to determine their own way and pace of development.

9. In the interviews conducted, these are the issues that emerged regarding the knowledge of Convention No. 169: (present a list/summary of the findings).
  - Again, based on your knowledge and experience on this matter, what is your view/opinion about these results?

10. Now, can you tell us more about the general levels of knowledge of HIV and tuberculosis amongst indigenous peoples?
- d. What is the level of knowledge or awareness about the Convention No. 169 among indigenous peoples in your country or community? Is it good or there is a lack of knowledge?
  - e. Are you aware of any work to Implement Convention No. 169?
    - a) In your country
    - b) In the community
    - c) In the world of work

**Closing**

If time permits, suggest an open ‘round’ where everyone present is invited to share any closing comments regarding engagement in the world of work for indigenous peoples living with HIV and/or having TB in general or related to stigma and discrimination specifically?

If an hour is already over, or after a final open ‘round’, thank all of the participants for sharing their time.

**Participants**

	<b>Sex/ Gender</b>	<b>Age</b>	<b>City/ Country</b>	<b>Indigenous peoples’ group/ community</b>	<b>Living with HIV and/or having TB (yes/no)</b>	<b>Currently employed (yes/no)</b>



#### Appendix 4. Summary of results by country

Region	Country	Awareness of Convention No. 169	Convention No. 169 Ratification	Awareness and experience of workplace discrimination
<b>Africa</b>	Burundi	Little knowledge	No	Disclosure of HIV status; frequent assumptions that indigenous peoples are less than human because of distinctive difference in size; being fired from work; not getting jobs because being indigenous and living with HIV and/or having TB; discrimination by co-workers
	Democratic Republic of the Congo	Little knowledge	No	Frequent discrimination based on difference in size; gender discrimination in work; employers pretending they don't discriminate against indigenous peoples living with HIV but publicly disclosing status; discrimination by co-workers
	Nigeria	No knowledge	No	HIV discrimination seems to be decreasing but still experienced through shunning; not getting jobs; being fired for living with HIV; discrimination by co-workers; alternate account of people getting jobs specifically because they are living with HIV
	Rwanda	Good knowledge	No	Recognition that people living with HIV are put on the margins of society; marginalization by co-workers; broader discrimination connected to increased rates of poverty of indigenous peoples living with HIV
	Zimbabwe	No knowledge	No	Disclosure of HIV status by community members; significant discrimination against indigenous peoples resulting in less access to work, to fair wages, to medicine or to effective legal recourse; shunning of infected people; loss of clients; gender differences with women suffering more discrimination; mandatory testing; not being hired if suspected that people are living with HIV and/or having TB
<b>Asia and the Pacific</b>	Australia	Good knowledge	No	Systematic discrimination (institutionalized, familial, community) against indigenous peoples living with HIV is echoed in the workplace; increased discrimination against women; stopping to look for work after getting

Region	Country	Awareness of Convention No. 169	Convention No. 169 Ratification	Awareness and experience of workplace discrimination
				diagnosed with HIV or TB for fear of disclosure or discrimination; disclosure by community members
	Fiji	No knowledge	No	High levels of self-stigma resulting in stopping to look for work after getting diagnosed with HIV or TB; lower levels of discrimination against people living with HIV but it is present; disclosure by community members; mandatory testing for some jobs; women tend to suffer more discrimination than men
	New Zealand	Good knowledge	Yes	Discrimination against indigenous peoples quite high; assumptions about lack of education, poverty; cases of people living with HIV not being paid full wages and denied promotions based on assumption that they don't need to save for future; being fired from work
	India	Some knowledge	No	Discrimination against indigenous peoples intertwined with caste system; women tend to be discriminated against significantly more than men; cases of being fired or demoted for living with HIV less common than previously; until recently there were more cases of compulsory testing
<b>Europe and Central Asia</b>	Norway	No knowledge	Yes	Discrimination against indigenous peoples tends to depend on geography; in some instances, suggest genetic testing as proof of indigenous status; shunning by customers and co-workers due to HIV status; some fields ban practitioners who are living with HIV (surgeons and military officers)
	The Russian Federation	No knowledge	No	Discrimination largely connected to health care with disclosure occurring by health workers; mandatory testing of health workers; discrimination against women connected to pregnancy because of HIV and TB status; being fired, especially for having TB; people feeling they have to hide their status
<b>The Americas</b>	Canada	Little knowledge	No	Significant discrimination against indigenous peoples; shunning by community members for living with HIV and/or having TB; discomfort

Region	Country	Awareness of Convention No. 169	Convention No. 169 Ratification	Awareness and experience of workplace discrimination
				about disclosing status; denial of work opportunities; discrimination by co-workers
	USA	No knowledge	No	Significant institutionalized discrimination against indigenous peoples; disclosure by community members; self-stigma due to HIV status; denied opportunities, no recruitment, mandatory testing
	Chile	Some knowledge	Yes	High levels of discrimination for being indigenous; less evident discrimination for people living with HIV; people living with HIV may not disclose status for fear of negative repercussions, including being fired or discriminated against by co-workers
	Peru	No knowledge	Yes	High levels of discrimination against indigenous peoples based on stereotypes that indigenous peoples are poorer, less educated and less capable than non-indigenous people; difficult to get a job if it is suspected that one is living with HIV; mandatory testing; being fired; discrimination by co-workers



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