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## Permanent Forum on Indigenous Issues

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Item 14 of the provisional agenda\*

**Future work of the Permanent Forum, including issues considered by the Economic and Social Council and emerging issues**

## Study on tuberculosis and indigenous peoples\*\*

### Note by the Secretariat

At its seventeenth session, the Permanent Forum on Indigenous Issues appointed Mariam Wallet Aboubakrine, member of the Forum, to conduct a study on tuberculosis and indigenous peoples, to be submitted to the Forum at its eighteenth session (see [E/2018/43-E/C.19/2018/11](#), para. 115).

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\* [E/C.19/2019/1](#).

\*\* The contributions of several individuals and organizations have been crucial to the conduct of this study. I would like to thank Zoé Boirin-Fargues for her involvement in all stages of this project, and Myrna Cunningham and Sandra Del Pino for providing me with data on the Latin America and Caribbean region. I am also grateful to Zaira Taveira and her colleagues at the Ministry of Health of Brazil for the documentation provided. I appreciate the support offered by my colleagues in the Permanent Forum on Indigenous Issues in selecting this topic.



## I. Introduction

1. Based on the most recent censuses, indigenous peoples account for about 360 million people in the world.<sup>1</sup> They often live in isolated territories, which limits their access to basic services, such as education, health and road infrastructure. The challenges presented by natural physical barriers are compounded by other issues such as the outbreak of multiple conflicts, the effects of climate change and other natural disasters. In addition, colonization has marked the history of indigenous peoples and left a negative legacy for indigenous communities.

2. For example, in French West Africa, decolonization has led to the fragmentation of the Tuareg territory across the independent States of Algeria, Burkina Faso, Libya, Mali and the Niger. Artificial borders and new visions and limitations have thus been imposed on the Tuareg people, threatening their entire organization. In terms of political organization, “the Tuareg country is defined by a cultural community which creates links to its identity through language and familial, social and political structures”.<sup>2</sup> The Tuareg were organized in tribes. Several tribes constituted a confederation headed by a chief, the *amenokal*, who was responsible for protecting them from all threats. Today, the Tuareg are identified as ethnic minorities in States with development policies that do not always take their way of life into account, placing them in an extremely precarious situation, which is exacerbated by drought and recurring conflicts. The most recent conflict, which dates back to 2012, is protracted and complex, and has resulted in alarmingly low development indicators, including health indicators. According to the Office of the United Nations High Commissioner for Refugees, the malnutrition rate at the Mbera refugee camp, of which 99 per cent of inhabitants are Tuareg from Mali, was 11.98 per cent.<sup>3</sup>

3. Regrettably, other indigenous communities also have alarming malnutrition rates. For example, according to the Food and Agriculture Organization of the United Nations, in 2014 and 2015, 61 per cent of indigenous children in Guatemala suffered from malnutrition.<sup>4</sup> Similarly, 70 per cent of the Inuit of Nunavut live in a state of food insecurity; that rate is six times higher than the national average.<sup>5</sup> In this regard, as described below, malnutrition is one of the factors contributing to the emergence of tuberculosis. In general, indigenous peoples present the worst health indicators.<sup>6</sup>

### ***What is tuberculosis?***

4. Tuberculosis is an infectious disease caused by a bacterium called *Mycobacterium tuberculosis*. According to the World Health Organization (WHO), one quarter of the world’s population has latent (non-transmissible) tuberculosis. There is a 5 per cent risk that latent tuberculosis will develop into active tuberculosis. The symptoms of active tuberculosis are a cough, a fever, night sweats and weight loss.<sup>7</sup>

<sup>1</sup> Harry Patrinos and Gillette Hall, “Indigenous peoples, poverty and development”, draft manuscript (World Bank, April 2010).

<sup>2</sup> Talkalit Walet Aboubacrine, *Femme touarègue face aux inégalités du système éducatif moderne. Comment concilier la coutume, les réalités d’un mode de vie pastoral et la scolarisation des filles?* (Éditions universitaires européennes, 2014), p. 20.

<sup>3</sup> [www.unhcr.org/publications/fundraising/539809f6b/unhcr-global-report-2013-mauritania.html](http://www.unhcr.org/publications/fundraising/539809f6b/unhcr-global-report-2013-mauritania.html).

<sup>4</sup> [www.fao.org/news/story/en/item/1164256/icode/](http://www.fao.org/news/story/en/item/1164256/icode/).

<sup>5</sup> [www.itk.ca/nuluaq-mapping-project/inuit-food-insecurity-canada-background/](http://www.itk.ca/nuluaq-mapping-project/inuit-food-insecurity-canada-background/).

<sup>6</sup> Marina Smelyanskaya, “Key Populations Brief: Indigenous Peoples”, (Stop TB Partnership, 2017), p. 5; “The right to health and indigenous peoples”, Expert Mechanism on the Rights of Indigenous Peoples, Advice No. 9 (2016), para. 3. World Health Organization, “Health of indigenous peoples”, Fact sheet No. 326, October 2007.

<sup>7</sup> [www.who.int/news-room/fact-sheets/detail/tuberculosis](http://www.who.int/news-room/fact-sheets/detail/tuberculosis).

5. In cases of active tuberculosis, the treatment consists of a sixth-month course of four tuberculosis drugs. The effectiveness of the treatment depends on the support provided to the patient. In cases of multidrug-resistant tuberculosis, two of the medications are not effective, and other, more expensive and longer-term treatment options (lasting two years) are required. This treatment is therefore more restrictive. Lastly, there is not as yet any treatment available for extensively drug-resistant tuberculosis.

6. According to WHO, Africa, Asia, Central and South America, Central and Eastern Europe, and certain European Union countries<sup>8</sup> are areas where tuberculosis has a significant impact.<sup>9</sup> As described below, certain factors that are notably present among indigenous peoples affect the development of the disease.

***Why conduct a study of tuberculosis among indigenous peoples?***

7. For nearly four decades, the demands of indigenous peoples have gone beyond the national and regional levels, reaching and influencing international forums, including the United Nations. However, scant attention has been paid to the health issues of indigenous peoples, and the occasional studies on the subject have focused on mental health and maternal and child health. Tuberculosis has not been the subject of a thorough analysis, although the disease is preventable and continues to disproportionately affect indigenous communities.

8. This study therefore aims to take stock of the disease among indigenous peoples, highlight the urgent need to take action to reverse the current trend, and identify the issues to be taken into account in order to eliminate tuberculosis by 2030, which is one of the Sustainable Development Goals established by the United Nations in 2015.<sup>10</sup> The slogan of the 2030 Agenda for Sustainable Development is “to leave no one behind”,<sup>11</sup> including indigenous peoples. Indigenous peoples are also clearly mentioned in the Moscow Declaration to End TB,<sup>12</sup> as well as in the commitment set out in paragraph 17 of the political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis, held in September 2018.<sup>13</sup>

9. The study is based on various reports, scientific papers and testimonies that we have accessed. It is not intended to be exhaustive, but rather to serve as a wake-up call and raise the awareness needed to produce concrete actions.

10. The report begins by outlining the right to health of indigenous peoples and the resulting State obligations. This is followed by a summary, based on the available data, of the prevalence of tuberculosis in various indigenous sociocultural regions and the contributing factors to such prevalence.

11. Specific reference is made to the situation of indigenous peoples in Canada, as this is a developed country where the tuberculosis rate among indigenous peoples is the highest when compared with rates among non-indigenous peoples. The situation of the tribal/indigenous people of India is also examined, since that country has the highest tuberculosis rate in the world.

<sup>8</sup> Bulgaria, Estonia, Hungary, Latvia, Lithuania, Poland, Portugal and Romania.

<sup>9</sup> Asia (26 per cent) and Africa (26 per cent) are the most affected continents. In 2015, tuberculosis was among the top ten causes of death worldwide, ahead of HIV and malaria. In 2016, 65 per cent of new cases were reported in India, Indonesia, China, the Philippines, Nigeria, Pakistan and South Africa ([www.who.int/news-room/fact-sheets/detail/tuberculosis](http://www.who.int/news-room/fact-sheets/detail/tuberculosis)).

<sup>10</sup> See General Assembly resolution 70/1.

<sup>11</sup> Ibid.

<sup>12</sup> [www.who.int/tb/features\\_archive/Moscow\\_Declaration\\_to\\_End\\_TB\\_final\\_ENGLISH.pdf?ua=1](http://www.who.int/tb/features_archive/Moscow_Declaration_to_End_TB_final_ENGLISH.pdf?ua=1)

<sup>13</sup> General Assembly resolution 73/3.

12. The study concludes with several recommendations that could guide stakeholder efforts to eradicate tuberculosis in indigenous communities. Without considering these communities, the 2030 deadline for the goal established by the international community to end this epidemic and leave no one behind cannot be met.

## **II. The right to health of indigenous peoples, a right to be implemented**

### **A. The right to health**

13. The right to health is enshrined in several international texts,<sup>14</sup> in particular the International Covenant on Economic, Social and Cultural Rights, which, in its article 12, sets out “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.<sup>15</sup>

#### *What are the components of the right to health?*

14. In its general comment No. 14 on the right to health, adopted in 2000, the Committee on Economic, Social and Cultural Rights underscores the close link between the right to health and other human rights. The Committee states that the right to health extends to “underlying determinants of health”, comprised of access to safe and potable water and adequate sanitation, proper food and nutrition, safe and healthy working conditions, a healthy environment, and access to health-related education and information, including on sexual and reproductive health.<sup>16</sup>

15. The right to health contains “the right to control one’s health and body [and] the right to be free from ... non-consensual medical treatment and experimentation” and “the right to a system of health protection that provides equality of opportunity for people to enjoy the highest attainable level of health”.<sup>17</sup>

#### *How is the “highest attainable level of health” defined?*

16. The Committee on Economic, Social and Cultural Rights recognizes that the definition of “highest attainable standard of health” takes into account both the individual’s biological and socioeconomic situation and a State’s resources.<sup>18</sup>

17. Evaluation of the implementation of the right to health requires an analysis of whether health facilities, goods and services meet the following four interrelated criteria: availability; accessibility, which includes physical accessibility, especially for “vulnerable or marginalized groups, such as ethnic minorities and indigenous populations” and economic accessibility “including [for] socially disadvantaged groups”; acceptability; and quality (they are appropriate and of good quality).<sup>19</sup>

<sup>14</sup> The right to health was recognized for the first time in the Constitution of WHO in 1946. It was reaffirmed in the Declaration of Alma-Ata of 1978 and the World Health Declaration, adopted by the World Health Assembly in 1998. It is specifically recognized in article 25 (1) of the Universal Declaration of Human Rights, article 12 (1) of the International Covenant on Economic, Social and Cultural Rights, and by some regional instruments, such as the amended European Social Charter of 1961 and the African Charter on Human and Peoples’ Rights of 1986.

<sup>15</sup> General Assembly resolution 2200 (XXI).

<sup>16</sup> E/2001/22, annex IV, paras. 3, 4 and 11.

<sup>17</sup> Ibid., para. 8.

<sup>18</sup> Ibid., para. 9.

<sup>19</sup> Ibid., para. 12.

***What are the obligations of States by virtue of this right?***

18. The Committee emphasizes in several instances the obligation of States to respect the principles of non-discrimination and people's participation.<sup>20</sup>

19. Within the framework of article 12 of the Covenant, States must “ensure provision of health care, including immunization programmes against the major infectious diseases, and ensure equal access for all to the underlying determinants of health, such as nutritiously safe food and potable drinking water, basic sanitation and adequate housing and living conditions”; and are obligated to “promote the right to health”, including by “ensuring that health services are culturally appropriate and that health-care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups”.<sup>21</sup>

20. States have the obligation to progressively realize the Covenant rights. However, the obligation to guarantee respect for the principle of non-discrimination and the obligation to take steps towards the full realization of article 12 are of immediate effect.<sup>22</sup>

**B. How is the right to health interpreted for indigenous peoples?**

21. The Committee on Economic, Social and Cultural Rights states that indigenous peoples have the right “to specific measures to improve their access to health services and care”. These services should be “culturally appropriate, taking into account traditional preventive care, healing practices and medicines”. To ensure that indigenous peoples enjoy the highest attainable level of health, States “should provide resources for indigenous peoples to design, deliver and control such services”, and should ensure the protection of the vital medicinal plants, animals and minerals necessary to indigenous peoples.<sup>23</sup>

22. The Committee also emphasizes that the health of individuals, in the context of indigenous communities, has a “collective dimension” and that measures that lead to the displacement of indigenous peoples against their will from their traditional territories and environment, “denying them their sources of nutrition and breaking their symbiotic relationship with their lands”, have a deleterious effect on their health.<sup>24</sup>

23. Article 24 of the United Nations Declaration on the Rights of Indigenous Peoples enshrines the right to health of indigenous peoples. As in article 12 of the International Covenant on Economic, Social and Cultural Rights, that right is based on the principle of non-discrimination and the objective of achieving the highest attainable standard of health. Article 24 provides that:

1. Indigenous peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous individuals also have the right to access, without any discrimination, to all social and health services.

2. Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.

<sup>20</sup> Ibid., paras. 11, 54 and 57.

<sup>21</sup> Ibid., paras. 36 and 37.

<sup>22</sup> Ibid., paras. 30–32.

<sup>23</sup> Ibid., para. 27.

<sup>24</sup> Ibid.

24. Article 21 (1) of the Declaration enshrines the right of indigenous peoples, on the basis of the principle of non-discrimination, “to the improvement of their economic and social conditions ... [in the area of] health”.

25. Moreover, by virtue of article 23, the right of indigenous peoples “to be actively involved in developing and determining health ... programmes affecting them and, as far as possible, to administer such programmes through their own institutions” is an integral part of their right to development.

26. In this regard, in 2016, the Expert Mechanism on the Rights of Indigenous Peoples issued advice specifically on the right to health, emphasizing the links that exist between that right and the fundamental rights of indigenous peoples to “self-determination, development, culture, land, territories and resources, language and the natural environment”.<sup>25</sup>

27. The Expert Mechanism explains that colonization and discrimination, which continue to victimize indigenous peoples, have prevented the full realization of their right to health.<sup>26</sup> The following section will illustrate this within the specific context of tuberculosis.

### III. Tuberculosis among indigenous peoples, an alarming situation

28. It is widely acknowledged, even in view of the lack of comprehensive data, that tuberculosis affects indigenous peoples disproportionately. A number of factors contributing to this inequality should be given particular attention when identifying effective responses to eradicate the disease.

#### A. Lack of data, analysis and evaluation

29. A lack of relevant data, not only in respect of the health of indigenous peoples, but also in terms of their social and economic conditions, is the first problem. This has been denounced on many occasions, both at the United Nations<sup>27</sup> and at the national level.<sup>28</sup>

30. The lack of data disaggregated by ethnic origin, coupled with the systemic exclusion of indigenous peoples from decision-making processes that affect them, impedes the understanding of indigenous peoples’ health issues and the development of appropriate and effective policies. This is compounded by a lack of analysis and evaluation of health programmes and services for indigenous peoples.<sup>29</sup>

<sup>25</sup> “The right to health and indigenous peoples”, Expert Mechanism Advice No. 9 (2016), para. 3.

<sup>26</sup> *Ibid.*, para. 2.

<sup>27</sup> Smelyanskaya, “Key Populations Brief”, p. 2; Expert Mechanism Advice No. 9, para. 8; United Nations, *State of the World’s Indigenous Peoples: Indigenous Peoples’ Access to Health Services*, p. 3; Pan American Health Organization (PAHO)-WHO, *Report of the regional meeting of heads of national tuberculosis control programmes, São Paulo, Brazil, 7–10 August 2012*.

<sup>28</sup> Canada ([www.nccah-ccnsa.ca/docs/context/FS-PaucityMetisHealth-MetisCentre-FR.pdf](http://www.nccah-ccnsa.ca/docs/context/FS-PaucityMetisHealth-MetisCentre-FR.pdf)); India, Ministry of Health and Family Welfare and Ministry of Tribal Affairs, “Tribal Health in India: Bridging the Gap and a Roadmap for the Future”, Report of the Expert Committee on Tribal Health, Executive Summary and Recommendations (2018).

<sup>29</sup> Stefania Errico, “The rights of indigenous peoples in Asia” (Geneva, International Labour Organization, 2017), p. 6.

31. With regard to tuberculosis in particular, very few data are available,<sup>30</sup> particularly data on indigenous peoples in South Asia, China, Africa and the former Soviet Union.<sup>31</sup>

## B. A disease primarily affecting indigenous peoples

32. The available data on tuberculosis among indigenous peoples show an alarming situation that requires greater efforts in response.<sup>32</sup>

33. In North America, in 2010, the tuberculosis incidence rates of the two groups of indigenous communities in the United States were 6.8 and 22.9 times higher than that of the rest of the population.<sup>33</sup> As detailed below, the disparity between indigenous and non-indigenous populations is even greater in Canada. A colonial history and the socioeconomic factors relating to the challenges posed by the remoteness of certain communities explain, but do not justify, these disparities.

34. In the Latin America and Caribbean region, 15 members of the Pan American Health Organization incorporated data on ethnicity into their reporting of tuberculosis cases.<sup>34</sup> Indigenous communities are more affected by the disease than the rest of the population. The prevalence of tuberculosis among the Guarani of the Plurinational State of Bolivia, for example, is five to eight times higher than in the rest of the population.<sup>35</sup>

35. In Paraguay, the incidence rate is 427 per 100,000 residents in indigenous communities, as compared with 36.3 per 100,000 residents among the rest of the population. The displacement of communities from their ancestral territories, and their higher rates of diabetes, malnutrition and alcoholism, make indigenous people particularly vulnerable to the disease.<sup>36</sup>

36. The data available on the Russian Federation<sup>37</sup> and other countries of the circumpolar region,<sup>38</sup> also attest to the prevalence of tuberculosis among indigenous peoples. The tuberculosis rate of the Inuit in Greenland is 14.2 times higher than that of the rest of the population.<sup>39</sup>

<sup>30</sup> Smelyanskaya, “Key Populations Brief”.

<sup>31</sup> Ibid, p. 7. D. Tollefson and others. “Burden of tuberculosis in indigenous peoples globally: a systematic review”, *The International Journal of Tuberculosis and Lung Disease*, vol. 17, No. 9 (September 2018).

<sup>32</sup> See, in particular, Smelyanskaya, “Key Populations Brief”.

<sup>33</sup> See Tollefson, “Burden of tuberculosis”, p. 1142; Bruce Chandler, “Alaska’s ongoing journey with tuberculosis”, *State of Alaska Epidemiology Bulletin*, vol. 19, No. 1 (April 2017), p. 3.

<sup>34</sup> Belize, Brazil, Chile, Colombia, Costa Rica, Ecuador, Guatemala, Guyana, Honduras, Mexico, Panama, Paraguay, Peru, Suriname and Venezuela (Bolivarian Republic of). Honduras has no information available; Guatemala has only had data since 2017; and Ecuador has just incorporated this variable. PAHO-WHO, *Situación de la tuberculosis en los pueblos indígenas de la Región* (Washington D.C., 2018).

<sup>35</sup> Fund for the Development of Indigenous Peoples of Latin America and the Caribbean (FILAC), *Status of Tuberculosis in Indigenous Peoples of Latin America and the Caribbean* (2018), p. 4.

<sup>36</sup> Ibid, pp. 4 and 6.

<sup>37</sup> Tatiana E. Burtseva and others, “The health of populations living in the indigenous minority settlements of northern Yakutia”, *International Journal of Circumpolar Health*, vol. 73, No. 1 (October 2014), p. 11.

<sup>38</sup> Leena Soininen, “The health of the Finnish Sami in light of mortality and cancer pattern”, academic dissertation, University of Helsinki, 2015, pp. 93–95; Sámediggi, *Proposal for Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material* (Karasjok, Norway), p. 24; Karen Bjorn-Mortensen and others, “Erythema nodosum and the risk of tuberculosis in a high incidence setting”, *International Journal of Circumpolar Health*, vol. 75 (October 2016).

<sup>39</sup> Smelyanskaya, “Key Populations Brief”, p. 6.

37. In the Pacific region, the WHO Western Pacific regional strategy does not mention indigenous peoples as belonging to groups that are at risk or vulnerable.<sup>40</sup> In New Zealand, the largest proportion of new cases of tuberculosis in 2015 was among the Maori (3.2 per 100,000 people), at a rate that was five times higher than that of the rest of the population.<sup>41</sup> In Australia, in 2014, the tuberculosis rate among Aboriginal and Torres Strait Islander peoples was six times higher than the rate among the non-indigenous population.<sup>42</sup> The tuberculosis rate among Aboriginals in Australia is lower than the rate among New Zealand Maori and Pacific Islanders, but it is still higher than the rate among non-indigenous groups.<sup>43</sup> The national programme of Fiji does not specifically mention indigenous peoples, but underscores the importance of involving traditional healers in the detection of tuberculosis cases.<sup>44</sup>

38. No data could be found on tuberculosis among indigenous peoples in the countries that make up the South-East Asia region<sup>45</sup> and the Africa region.<sup>46</sup> In Africa, the lack of data can be explained in part by the scarcity of health services in areas populated by indigenous peoples, which also attests to the marginalization and political and social exclusion they are subjected to in this region.<sup>47</sup>

39. We note with concern that a number of studies, including in Greenland, Canada, Australia and the Latin America region, show that it is indigenous youth who suffer the most from tuberculosis.<sup>48</sup>

40. HIV is also a significant risk factor for the emergence of tuberculosis. The study conducted by the Global Stop TB Partnership in 2017 demonstrates that indigenous women, who are more exposed to HIV, are more susceptible to contracting tuberculosis. This is owing to the systemic discrimination they experience both as

<sup>40</sup> WHO, *Regional Strategy to Stop Tuberculosis in the Western Pacific 2011–2015* (Geneva, 2011).

<sup>41</sup> Institute of Environmental Science and Research Limited, *Tuberculosis in New Zealand: Annual Report 2015* (Porirua, New Zealand, 2018).

<sup>42</sup> Cindy Toms and others, “Tuberculosis notifications in Australia, 2014”, *Communicable Diseases Intelligence*, vol. 41, No. 3 (September 2017).

<sup>43</sup> Tollefson, “Burden of tuberculosis”.

<sup>44</sup> Fiji, Ministry of Health and Medical Services, *Fiji TB Manual*, 4th edition, 2017.

<sup>45</sup> Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, the Republic of Korea, Sri Lanka, Thailand and Timor-Leste. Half of all tuberculosis cases have been reported in countries in this region (in India and Indonesia, which account for 37 per cent of those cases) as well as 35 per cent of all cases of multi-drug-resistant tuberculosis, while the population of those countries accounts for only 26 per cent of the world population ([www.ncbi.nlm.nih.gov/pmc/articles/PMC5582343](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC5582343)). However, it is estimated that one third of people with tuberculosis go undetected or get treated outside national programmes (<https://www.who.int/bulletin/volumes/88/3/09-073874/en/>).

<sup>46</sup> There are only isolated studies on specific indigenous groups. For example, one study found that the first laboratory dedicated to diagnosing the disease in pastoral settings in Chad had revealed a prevalence rate of 4.5 per cent of human tuberculosis (A. Montavon and others, “Health of mobile pastoralists in the Sahel – assessment of 15 years of research and development”, *Tropical Medicine and International Health*, vol. 18, No. 9 (September 2013). At an internal meeting of the organization Action Damien, held from 22 to 25 August 2018 in Kinshasa, Jacques Gumbaluka stressed the lack of data on tuberculosis among the indigenous persons of Haut-Uele in the Democratic Republic of the Congo. He revealed that in 2016, out of a sample of 13 persons considered to be indigenous to that region, 78 per cent of patients had completed the treatment, as compared with an average rate of 81.3 per cent in the population as a whole.

<sup>47</sup> International Work Group for Indigenous Affairs and the African Commission on Human and Peoples’ Rights, *Indigenous Peoples in Africa: the forgotten peoples? The African Commission’s work on indigenous peoples in Africa* (Copenhagen, 2006).

<sup>48</sup> Lena Faust and others, “Recommendations for the screening of paediatric latent tuberculosis infection in indigenous communities: a systematic review of screening strategies among high-risk groups in low-incidence countries”, *BMC Public Health*, vol. 18, No. 1 (August 2018), p. 2; Noni MacDonald and others, “Tuberculosis in Nunavut: a century of failure”, *CMAJ*, vol. 183, No. 7 (April 2011), p. 741.



women and as indigenous persons, as well as the lack of knowledge about HIV and certain cultural practices, such as polygamy and early marriage.<sup>49</sup> In developed countries, indigenous men are more exposed to HIV than non-indigenous men because of their overrepresentation in prison settings.<sup>50</sup>

### C. Tuberculosis among indigenous peoples – key factors

#### *Addressing the socioeconomic factors conducive to the disease*

41. In all regions, the high rate of tuberculosis among indigenous peoples is intrinsically linked to their specific socioeconomic situations.<sup>51</sup>

42. The socioeconomic factors<sup>52</sup> conducive to the emergence of the disease are inextricable from the factors that constitute an obstacle to its prevention and treatment. These consist of poverty<sup>53</sup> and a lack of resources and education,<sup>54</sup> which also account for the lack of indigenous health professionals and overcrowding. Food insecurity and malnutrition, particularly owing to the effects of climate change and environmental damage; ailments such as diabetes, obesity and other chronic diseases; and tobacco, alcohol and drug use, also increase the risk of tuberculosis outbreaks.<sup>55</sup> In addition, vagrancy, homelessness, mental health problems and the stigmatization of people living with the disease complicate detection and the monitoring of treatment.<sup>56</sup>

43. The eradication of tuberculosis among indigenous communities must therefore involve actions that address these specific factors.<sup>57</sup>

#### *Restoring trust: partnerships and cultural adaptation*

44. A number of studies conducted in various countries emphasize that indigenous communities' lack of trust in health systems impedes the prevention and treatment of tuberculosis. This lack of trust is the result of historical traumatic and discriminatory practices, such as forced sterilization and scientific experimentation, cultural and/or linguistic differences that limit mutual understanding, inequality in the distribution of health services, and even, at times, the animosity of health professionals.<sup>58</sup>

45. This situation is exacerbated by the systemic discrimination experienced by indigenous communities, which manifests as a lack of access to information and ill treatment. These effects are doubly harmful in the case of tuberculosis, where monitoring of treatment is crucial to recovery.<sup>59</sup>

<sup>49</sup> Smelyanskaya, "Key Populations Brief", p. 15.

<sup>50</sup> Ibid.

<sup>51</sup> Burtseva, "The health of populations living in the indigenous minority settlements of northern Yakutia", p. 11. On Norway: Soile Hämäläinen and others, "Sami yoik, Sami history, Sami health: a narrative review", *International Journal of Circumpolar Health*, vol. 77, No. 1 (2018), p. 3.

<sup>52</sup> The social determinants of health are defined by WHO as "the circumstances in which people are born, grow, live, work and age" (Canada, *Canadian Tuberculosis Standards*, 7th edition, chapter 14, p. 379).

<sup>53</sup> Smelyanskaya, "Key Populations Brief", p. 11

<sup>54</sup> This may be due to "geographic isolation, stigma and discrimination, language and cultural barriers", Smelyanskaya, "Key Populations Brief", p. 12.

<sup>55</sup> Chandler, "Alaska's ongoing journey with tuberculosis", pp. 4–6.

<sup>56</sup> Ibid., pp. 5–6.

<sup>57</sup> In accordance with the approach adopted by WHO.

<sup>58</sup> India, "Tribal Health in India", p. 5; Smelyanskaya, "Key Populations Brief", p. 15; Sámediggi, *Proposal for Ethical Guidelines*, p. 21.

<sup>59</sup> Smelyanskaya, "Key Populations Brief", p. 15.

46. No measures can be effective without efforts to restore the trust of indigenous communities in health systems. To that end, States should include indigenous peoples as partners in the design and implementation of health programmes, incorporating indigenous perspectives on health,<sup>60</sup> and train health workers so that they are aware of the historical context, sensitive to the problems experienced by indigenous communities and deliver culturally appropriate care. Involving communities and defining intercultural health strategies have proved to be effective practices.<sup>61</sup>

#### ***Prevention and treatment for isolated and nomadic communities***

47. The isolation of indigenous communities poses unique challenges to monitoring treatment, guaranteeing access to quality health services, training skilled staff and providing sufficient resources.<sup>62</sup> The cases of Canada and India, described below, are illustrative.

48. Furthermore, nomadic communities also require an appropriate response to ensure their access to health services and that such services are adapted to their needs and lifestyles. The case of nomadic pastoralists in Africa offers a good example. Proximity to animals and the impact of the environment (dust, dry and hot air, and high humidity) should also be addressed.<sup>63</sup>

49. It has been demonstrated that the decentralization of detection and treatment of the disease improves the accessibility of services.<sup>64</sup> Some initiatives in this vein have been undertaken, such as the construction of temporary housing alongside health centres to allow family members to accompany patients.<sup>65</sup>

#### **Strengthening inter-State cooperation**

50. There is no single tuberculosis surveillance system at the international level,<sup>66</sup> whereas surveillance of the disease is essential for its prevention and control.<sup>67</sup> In some contexts, inter-State cooperation therefore appears necessary.

#### *Example of the circumpolar region*

51. The circumpolar region is characterized by a difficult environment and a small population scattered over large areas that depends on fishing and hunting. The lack of infrastructure and proper sewage treatment, water supply and health-care systems complicate the prevention and treatment of tuberculosis. Added to this are the many socioeconomic factors already described above, in particular poverty and

<sup>60</sup> Ibid., p. 17; Sámediggi, *Proposal for Ethical Guidelines*, p. 26; FILAC, *Status of Tuberculosis in Indigenous Peoples*, p. 7.

<sup>61</sup> FILAC, *Status of Tuberculosis in Indigenous Peoples*, p. 8.

<sup>62</sup> Smelyanskaya, “Key Populations Brief”, p. 12; Chandler, “Alaska’s ongoing journey with tuberculosis”, pp. 5–6. See also the example of Canada below.

<sup>63</sup> Montavon, “Health of mobile pastoralists in the Sahel”.

<sup>64</sup> FILAC, *Status of Tuberculosis in Indigenous Peoples*, p. 8.

<sup>65</sup> An initiative carried out in Kenya. In Namibia, family members of patients are trained so that they are aware of the importance of treatment and help the patient to continue it during long hunting periods, when treatment is likely to be interrupted (Smelyanskaya, “Key Populations Brief”, pp. 17–18).

<sup>66</sup> WHO does not define a standardized approach to tuberculosis surveillance but provides a list of norms and standards for the evaluation of surveillance systems; Annie-Claude Bourgeois and others, “Descriptive review of tuberculosis monitoring systems across the circumpolar regions”, *International Journal of Circumpolar Health*, vol. 75 (April 2016) p. 2.

<sup>67</sup> Alan J. Parkinson and others, “International Circumpolar Surveillance, an Arctic network for the surveillance of infectious diseases”, *Emerging Infectious Diseases*, vol. 14, No. 1 (2008), p. 20.

malnutrition.<sup>68</sup> The latter are exacerbated by the effects of climate change and the economic changes brought about by greater population movement from South to North (from tourism and the oil and mining industry).<sup>69</sup>

52. In the 1970s, “circumpolar cooperation” facilitated studies on the health of indigenous peoples. Moreover, in 1999 the Arctic Council established the Sustainable Development Working Group and the International Circumpolar Surveillance System for invasive bacterial diseases, a network for the surveillance of infectious diseases in the member countries of the region.<sup>70</sup>

53. A working group on tuberculosis was established in 2006.<sup>71</sup> Its mission is to improve the detection of tuberculosis, analyse developments and impacts of the disease, increase awareness of the disease and improve collaborative research on it.<sup>72</sup>

54. Since no jurisdiction, apart from Norway, is collecting information on the social determinants of health and the risk factors associated with tuberculosis, such as smoking, steroids, HIV or diabetes, the existence of this working group is welcome.<sup>73</sup> This provides an appropriate channel for the different States and territories to work together and define, in partnership with indigenous peoples, responses that are adapted to the specific features of the circumpolar region. Other regions could follow suit.<sup>74</sup>

#### **D. Example of Canada: a country with a low incidence of tuberculosis and the greatest disparity between the indigenous and non-indigenous population**

55. Canada is a developed country with a low incidence of tuberculosis. However, it has a much higher rate of tuberculosis among indigenous peoples than in the rest of the population.<sup>75</sup> This gap is the widest in Nunavut: in 2009, the incidence rate of tuberculosis there was 150 times higher than among the non-indigenous population.<sup>76</sup> Tuberculosis also greatly affects members of First Nations with Indian status in Manitoba and Saskatchewan, where the incident rate is 27.4 times higher for the former and 7.3 times higher for the latter.<sup>77</sup> While the rate of tuberculosis has decreased in the non-indigenous population, it increased from 14.7 per cent to 21.2

<sup>68</sup> Ibid., p. 19; Canada, Canadian Tuberculosis Standards, chapter 14; MacDonald, “Tuberculosis in Nunavut”, p. 741; Soininen, “The health of the Finnish Sami”, p. 57.

<sup>69</sup> Parkinson, “International Circumpolar Surveillance”, p. 22; Soininen, “The health of the Finnish Sami”, p. 60.

<sup>70</sup> Greenland, Iceland, Alaska and the northern regions of Canada, Norway, Sweden, Finland and the Russian Federation.

<sup>71</sup> Bourgeois, “Descriptive review of tuberculosis surveillance systems”, p. 3.

<sup>72</sup> Parkinson, “International Circumpolar Surveillance”, p. 33.

<sup>73</sup> Bourgeois, “Descriptive review of tuberculosis surveillance systems”, pp. 6–7.

<sup>74</sup> It should be noted that in the South-East Asian region, the ministries of health of 11 countries from the region held a meeting in Delhi in 2017. In the declaration emanating from that meeting, the countries recognized the socioeconomic factors influencing the disease and the importance of community involvement, including communities at risk. They also recognized the importance of building their capacities in a holistic manner and of establishing a common fund for the sharing of knowledge and data. The declaration does not, however, mention indigenous peoples ([www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(17\)30817-6.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(17)30817-6.pdf), <https://www.theunion.org/news-centre/news/body/Call-for-Action.pdf>).

<sup>75</sup> Smelyanskaya, “Key Populations Brief”, p. 5.

<sup>76</sup> Tollefson, “Burden of tuberculosis”, p. 1142.

<sup>77</sup> Ibid.

per cent among the indigenous population of Canada between 1970 and 2010.<sup>78</sup> The country also has a higher rate of tuberculosis among indigenous youth.

56. The Canadian Tuberculosis Standards recognize the need to improve tuberculosis prevention in indigenous communities, to establish partnerships with communities and to prioritize contact tracing. Health Canada adopted a tuberculosis control strategy for members of First Nations living on reservations in 2012.<sup>79</sup> The priority identified by the Standards is to no longer treat isolated cases but to improve contact tracing strategies in order to prevent disease transmission, while taking the specificities of indigenous communities into account.<sup>80</sup>

57. The challenges facing Canada are shared by other countries: a failure to detect latent tuberculosis in order to prevent active tuberculosis; and limited access to services, which is related to the isolation of the population in Nunavut but also a lack of personnel (high turnover), a lack of knowledge among casual health workers, limited diagnostics services and cultural barriers. Added to that is the lack of confidence of indigenous communities in the health services, as we have seen, and the mobility of members of First Nations between provinces. This requires a level of communication between the provinces and the establishment of partnerships with the communities.<sup>81</sup> Canada must also ensure coordination between the different levels of government.<sup>82</sup>

58. Several studies underline the importance of the lack of adequate housing and food security as risk factors<sup>83</sup> and the need for Canada to first of all address the social determinants of indigenous health that are intrinsically linked to colonization, globalization and the loss of language, culture and land. Indigenous peoples therefore need to be seen as “full partners in contemporary life” and their “right to self-determination” recognized.<sup>84</sup>

59. We note that the Standards identify the following as effective practices: incorporating indigenous beliefs in health programmes, as guided by patient wishes; ensuring that language concepts are developed in partnership with indigenous peoples; and using creative multimedia methods and effective education by conveying cognitive messages but also affective messages of empathy, openness, concern and respect for the patient. In order to improve the monitoring of patient care, the Standards recommend, in particular: bringing care closer to the patient (e.g. to the home); using incentives (e.g. food) and enablers (e.g. vouchers); and developing reminder and follow-up mechanisms, simplifying protocols, reducing referral times and rigorously tracking migrant patients. They also recommend enhancing health services that are emotionally and culturally accessible and having indigenous community health workers, preferably from the community or region, act as educators, human rights defenders and cultural brokers.<sup>85</sup>

<sup>78</sup> Ibid.

<sup>79</sup> Ibid., p. 381.

<sup>80</sup> Ibid., pp. 382–383; Victoria J. Cook and others, “Modern contact investigation methods for enhancing tuberculosis control in aboriginal communities”, *International Journal of Circumpolar Health*, vol. 71, No. 1 (May 2012), p. 1.

<sup>81</sup> The Canadian Standards contain a set of recommendations (see para. 59 above).

<sup>82</sup> MacDonald, “Tuberculosis in Nunavut”, p. 741.

<sup>83</sup> Faust, “Recommendations for the screening of paediatric latent tuberculosis infection in indigenous communities”, p. 1; Richard Long and others, “Tuberculosis elimination in Canada: Truce or Victory?”, *CMAJ*, vol. 187, No. 16 (November 2015), p. 1192.

<sup>84</sup> Ibid.

<sup>85</sup> Canada, *Canadian Tuberculosis Standards*, 7th edition, chapter 14.

## E. Example of India: an emerging country with the highest incidence rate of tuberculosis

60. A quarter of the cases of tuberculosis in the world are found in India, which has the highest rate of multi-drug-resistant tuberculosis.<sup>86</sup> In 2016, 28 million people had tuberculosis and 4.5 million died from it.<sup>87</sup>

61. India developed a national tuberculosis control programme in 1997 and has been implementing it nationwide since March 2006. Tuberculosis is dealt with by the public services, through the Revised National Tuberculosis Control Programme of 2016, and also by the private sector, which deals with more than half of the cases of tuberculosis. The coexistence of public and private services poses particular challenges, especially in terms of data collection. Moreover, many people are unaware that free public health services are available.<sup>88</sup>

62. The new National Strategic Plan 2017–2025 aims to drastically reduce mortality and morbidity from tuberculosis and to work towards the elimination of tuberculosis by 2025.

63. The strategy comprises four areas: detection, treatment, prevention and building. For people in “high risk” groups, the aim is to prevent the development of active tuberculosis among people with latent tuberculosis and thus to detect cases of latent tuberculosis beforehand, including by addressing the social determinants of the disease.

64. People in tribal areas are among the “key populations” targeted by the plan as being in high risk or vulnerable groups. In order to prioritize interventions, the plan defines the criteria for selecting certain areas. Areas with known high malnutrition or tuberculosis, or areas where the population consumes animal products,<sup>89</sup> for example, are priorities.<sup>90</sup>

65. The Government of India recognizes 104 million indigenous people across 705 tribes (scheduled tribes), accounting for 8.6 per cent of the population.<sup>91</sup> Seventy-five tribal groups are classified as “particularly vulnerable tribal/indigenous groups”.

66. A report of the Government of India on the health of tribal peoples, published in 2018, recognizes the lack of information on the health of these groups.<sup>92</sup> The available information indicates clearly, however, that their level of health is much lower than that enjoyed by the rest of the population and that scheduled tribes suffer disproportionately from communicable diseases. The incidence rate of tuberculosis was reported as 703 per 100,000 among indigenous peoples, as compared with 256

<sup>86</sup> [www.tbfacts.org/tb-india/](http://www.tbfacts.org/tb-india/).

<sup>87</sup> Ibid.

<sup>88</sup> Ibid.

<sup>89</sup> Including to prevent the spread of zoonotic tuberculosis, a problem shared by nomadic pastoralists in Mali (interview with Mr. Aboubacrine ag Ayaya, 30 July 2018, Agadir, Morocco. From 1962 to 2000, he worked as a veterinary nursing and then as a veterinary in Mali. He was also a livestock consultant for nomadic pastoralists in Mali, Mauritania, Burkina Faso and Chad).

<sup>90</sup> [www.tbfacts.org/tb-india-nsp/](http://www.tbfacts.org/tb-india-nsp/).

<sup>91</sup> Article 342 of the Constitution defines “scheduled tribes” as tribes or tribal communities or parts of or groups within tribal communities which the President of India may specify by public notice. According to the Government of India, 40.6 per cent of the tribal population lives below the poverty line, compared to 20.5 per cent of the non-tribal population; and 10.7 per cent of the tribal population has access to tap water, compared with 28.5 per cent of the non-tribal population.

<sup>92</sup> India, Ministry of Health and Family Welfare and Ministry of Tribal Affairs, “Tribal Health in India: Bridging the Gap and a Roadmap for the Future”, Report of the Expert Committee on Tribal Health, Executive Summary and Recommendations (2018).

per 100,000 in the rest of the population. The studies analysed suggest that only 11 per cent of cases of pulmonary tuberculosis in indigenous communities are treated.

67. Factors behind this disparity include the lack of infrastructure in the tribal areas, cost, distance and the lack of transport for communities to care centres, as well as the animosity of health professionals, the language barrier, the gap in understanding and the lack of trust in a foreign system.

68. The limited extent of interactions among health professionals, the sense of social and professional isolation, weak human resources policies, poor working conditions and environments and a lack of nursing staff are all factors contributing to the variances between the health personnel working in tribal areas and those working in the rest of the country. The report also notes that the quality of care is lacking owing to a lack of motivation, understanding and mutual respect. The reluctance of indigenous persons to use the Indian health-care system reflects the lack of emotional content and spiritual security in modern healthcare and the limited understanding of the Indian health-care system.

69. Lastly, the report highlights the damaging absence of indigenous communities in the planning and implementation of health programmes.

70. The principles that should guide the Government's indigenous health policy are identified in the report as follows: autonomy, to ensure that health services are tailored to the needs and culture of indigenous peoples; the accessibility of health services; the coordination of actions, in order to effectively address the social determinants of health; and the provision of adequate financial resources.

71. Priority should moreover be given to establishing an administrative structure that enables participation, planning and management at the local level. Decentralization of diagnosis and treatment is a strategy that can also be found in tuberculosis control programmes in South America.<sup>93</sup>

72. The report of the Indian Government recommends, inter alia: the improvement of public health infrastructure in tribal areas by ensuring that services are managed by qualified and sensitive individuals who treat indigenous peoples with respect; the training of local people to increase the number of health-care personnel in tribal areas in the long term; and the undertaking of certain initiatives to attract specialists in these areas.

73. The report also contains a series of recommendations to integrate traditional tribal/indigenous medicine in primary health-care centres, including by identifying effective traditional medicines and practices and enabling traditional healers to practise in primary health-care centres. We note that traditional practices should be identified in partnership with indigenous peoples and with respect for the rights of indigenous communities, as recognized by the United Nations Declaration on the Rights of Indigenous Peoples.

## **IV. Recommendations**

74. In order to achieve the goal of eradicating tuberculosis by 2030 and to ensure that indigenous peoples, who are particularly vulnerable to this disease, are not left behind, we call upon States, national and international organizations and members of indigenous communities to take the following recommendations into consideration:

1. Member States should collect disaggregated data that enable them, on the one hand, to have a precise description of the disease among indigenous peoples,

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<sup>93</sup> FILAC, Status of Tuberculosis in Indigenous Peoples.

in order to realize their right to health as defined by article 12 of the International Covenant on Economic, Social and Cultural Rights and by article 24 of the United Nations Declaration on the Rights of Indigenous Peoples; and, on the other hand, to report in 2020 on the progress made with respect to indigenous peoples in accordance with para 53 of the political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis, held in September 2018.<sup>94</sup>

2. Member States, international organizations, such as WHO and the Global Fund to Fight AIDS, Tuberculosis and Malaria, and the scientific community should develop research on tuberculosis among indigenous peoples, in partnership with the communities, in order to understand the uniqueness of each community<sup>95</sup> and region, and define appropriate responses to the epidemic.<sup>96</sup>

3. In accordance with the right of indigenous peoples to self-determination and to development, as recognized by articles 3 and 23 of the United Nations Declaration on the Rights of Indigenous Peoples, States should work in partnership with indigenous peoples on the socioeconomic factors conducive to the disease,<sup>97</sup> such as HIV, smoking, alcoholism, food insecurity, diabetes<sup>98</sup> and the housing crisis.

4. By virtue of the right of indigenous peoples to free, prior and informed consent, as recognized by article 19 of the United Nations Declaration on the Rights of Indigenous Peoples, Member States should develop and implement, in partnership with indigenous peoples, policies or programmes for the prevention, detection and treatment of tuberculosis in order to ensure that such policies and programmes are accessible and culturally appropriate, and should incorporate within them indigenous peoples' perspectives on health,<sup>99</sup> in accordance with article 24 of the United Nations Declaration on the Rights of Indigenous Peoples; and should do so while respecting their right to maintain, control, protect and develop their knowledge, as protected by article 31 of the United Nations Declaration on the Rights of Indigenous Peoples.

5. Member States have at their disposal a number of strategies to support monitoring of the treatment of patients with tuberculosis, particularly those belonging to nomadic peoples, including training for community members to attend to the sick while allowing their traditional way of life to continue in accordance with article 20 (1) of the United Nations Declaration on the Rights

<sup>94</sup> General Assembly resolution 73/3.

<sup>95</sup> For example, no programme could be effective unless it takes into account certain elements of the Tuareg culture that facilitate the spread of the disease: the Tuareg live in communities and they eat and talk together in very close proximity, *takshé*. They are uncomfortable with isolating a member of their community because of his or her bacteriological status. These factors are conducive to contamination by air and secretions. With regard to disease prevention, one expert recommended immunization during periods when the communities gather together, namely in the warm season and in the winter.

<sup>96</sup> Sámediggi, *Proposal for Ethical Guideline*, pp. 25–26; see also WHO, “*Indigenous peoples & participatory health research*” ([www.who.int/ethics/indigenous\\_peoples/en/index1.html](http://www.who.int/ethics/indigenous_peoples/en/index1.html)); Assembly of First Nations of Quebec-Labrador, *Research protocol of the First Nations of Quebec and Labrador* (June 2005); Canada, Canadian Institutes of Health Research (*CIHR Guidelines for Health Research Involving Aboriginal People* (2007)).

<sup>97</sup> An approach promoted by WHO ([www.un.org/sg/en/content/sg/statement/2018-09-26/secretary-generals-remarks-high-level-meeting-tuberculosis](http://www.un.org/sg/en/content/sg/statement/2018-09-26/secretary-generals-remarks-high-level-meeting-tuberculosis)).

<sup>98</sup> Maxime Cormier and others, “Proximate determinants of tuberculosis in Indigenous peoples worldwide: a systematic review”, *Lancet Global Health*, vol. 7 (January 2019).

<sup>99</sup> Smelyanskaya, “Key Populations Brief”, p. 10.

of Indigenous Peoples; and the construction of housing close to health centres so that patients can be accompanied by members of their community.

6. Member States have at their disposal a number of strategies to address the lack of health personnel in remote areas, such as basic training for personnel at the local level, financial support for members of indigenous communities to be trained and work in their community, the establishment of mobile clinics and the development of telemedicine.

7. Member States should ensure that particular attention is paid to the detection of tuberculosis among indigenous children and youth, in accordance with article 17 of the United Nations Declaration on the Rights of Indigenous Peoples.

8. International organizations and States should strengthen regional collaboration specifically regarding indigenous peoples, and in partnership with them, in order to establish shared surveillance systems whereby data can be disseminated and effective strategies defined for the prevention and treatment of tuberculosis.

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