

Global Indigenous

STOP TB
Expert Meeting



Global Indigenous STOP-TB Context Paper

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**Assembly of First Nations
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Overview

One third of the world's population is infected with tuberculosis and up to 50 million may be infected with multi-drug resistant tuberculosis.¹ Tuberculosis is a leading killer of women and the leading infectious killer of youth and people living with HIV/AIDS. Tuberculosis claims a life *every 15 seconds*. This global epidemic is more than a health problem, it attacks the body and assaults the spirit, it hinders economic development, it holds the poor in the grip of poverty and disease, and none of our nations are immune to its threat.²

We cannot afford to delay in addressing the epidemic of tuberculosis. We all share in the problem and the solution.³ At the turn of the century extensive public health systems were created to improve living conditions and hygiene in order to combat the spread of tuberculosis. When effective medication became available the number of tuberculosis cases dropped dramatically. As the numbers dropped, officials and the public became complacent. Despite high rates of tuberculosis that persisted in the poorest communities and countries, there was a belief that modern medicine had defeated this ancient enemy. Funding was slashed and tuberculosis control declined. Clinics were disbanded and hospital beds for tuberculosis patients were eliminated.⁴ After decades of decline, tuberculosis rates have sky rocked due to increasing homelessness, greater poverty, over-crowding and the emergence of HIV-AIDS.⁵

Background

Tuberculosis continues to affect at least 2 billion people in the world, according to 2008 statistics.⁶ Labeled as a disease that affects those primarily living in poverty, the *WHO Stop TB Partnership's* goal is to halve the incidence of tuberculosis by 2015. The following outlines the epidemic situation:

- Globally tuberculosis (TB) deaths numbered around 1.6 million in 2006, with an average of 9.6 million new cases.
- Globally, Indigenous populations are at an increased risk of suffering from tuberculosis
- While programs have been designed to combat tuberculosis they often do not reach indigenous populations because of issues related to poverty, such as poor housing and a lack of access to medical care and drugs, cultural barriers, language differences and geographic remoteness.
- 1.7 million people died from tuberculosis in 2006, including 231,000 people with HIV.

¹ WHO International Tuberculosis conference, Amsterdam, the Netherlands, March 23, 2000 www.hhs.govnews/speechs/000323.html Page 1 of 4

² WHO International Tuberculosis conference, Amsterdam, the Netherlands, March 23, 2000 www.hhs.govnews/speechs/000323.html Page 1 of 4

³ *ibid*

⁴ *ibid*

⁵ *ibid*

⁶ Tuberculosis Facts, © WHO April 2008 Page 1 of 2 www.who.int/tb



- Tuberculosis is a disease of poverty, accounting for the majority of deaths occurring in the developing world.
- The total number of deaths and cases is rising due to population growth.⁷
- Globally, nearly 4 out of 10 tuberculosis cases are not being properly detected and treated.
- Every year about 490,000 new Multi-Drug Resistant (MDR)-TB cases occur causing more than 130,000 deaths.
- The former Soviet Union and China have the highest rates of tuberculosis.
- 5% of all tuberculosis cases have MDR-TB.
- 52 out of 53 people infected with XDR-TB died within 3 weeks of diagnosis. Most were HIV positive and many were on ARV's (Anti-Retrovirals).
- The highest rates of MDR-TB ever recorded were reported by WHO in 2008⁸

Tuberculosis and Indigenous People

In New Zealand, Pacific Islanders and Maoris have a 22.3 and 10.5 risk rate of contracting tuberculosis. In Kalaallit Nunaat, residents have a risk rate of 45 times, and rising, that of Danish born. As a result of poverty, tuberculosis continues to affect indigenous communities around the globe. Indigenous peoples⁹ remain on the margins of society: they are poorer, less educated, die at a younger age, are much more likely to commit suicide, and are generally in worse health than the rest of the population.¹⁰ The statistics surrounding indigenous people in the context of tuberculosis indicate that:

- There are 370 million indigenous people worldwide spanning more than 70 countries. For indigenous peoples tuberculosis is a disease of poverty; and poverty exacerbates tuberculosis in most areas.
- The true magnitude of tuberculosis in indigenous populations is not known and access to tuberculosis care is not guaranteed across countries.
- Low socio-economic disadvantages, geographic remoteness, and language barriers all complicate tuberculosis prevention efforts.
- Strengthened efforts are required to address indigenous population's needs, as well as, to continue to Stop TB globally.
- The latest estimates indicate: the number of cases for all forms of TB accounts for 9.2 million cases and 1.7 million deaths; the greatest number of cases are in Asia and the greatest rates per capita in Africa. For multidrug resistant TB (MDR-TB) the estimated number of cases are 490 000 and deaths 116 000.¹¹

The Stop-TB Partnership

⁷ Tuberculosis Facts, © WHO April 2008 Page 1 of 2 www.who.int/tb

⁸ Tuberculosis Facts, © WHO April 2008 Page 1 of 2 www.who.int/tb

⁹ For the purposes of this paper indigenous people are defined as: those who identify themselves and are recognized and accepted by their community as indigenous; demonstrate historical continuity with pre-colonial and or presettler societies, have strong links to territories and surrounding natural resources, have distinct social, economic or political systems, maintain distinct languages, cultures and beliefs, form non-dominant groups of society, resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.

¹⁰ WHO Fact Sheet.

¹¹ WHO Fact Sheet.



The Stop-TB partnership is a world-wide movement that was established in the year 2000 to solicit the political will to support treatment and eradicate tuberculosis. It is a network that includes 400 international organizations, countries, various donors from the public and private sectors, NGO organizations and individuals, all committed to the goal of the permanent elimination of tuberculosis.

The Stop-TB partnership consists of 3 phases. The first part of the plan (2001-05) was to rally new partnerships and move forward in terms of research and development to directly impact those areas suffering from the epidemic. The second phase of the plan is to attain the target for the Millennium development goals for 2015 to reduce poverty and begin to halt the growth of tuberculosis. The third phase goals for the Stop TB plan includes the treatment of 50 million cases of tuberculosis, the formation of new diagnostic tests, new drugs, increased community care, and to garner support for the political agendas to invest in tuberculosis control for stronger health systems and poverty reduction in developing areas of the world.

The Stop TB partnership is a global social movement with a vision to eradicate tuberculosis from the world. The mission of this partnership is four-fold:

1. To ensure that every tuberculosis patient has access to effective diagnosis, treatment and full recovery from tuberculosis.
2. To halt the transmission of tuberculosis.
3. To reduce the inequitable social and economic tolls of tuberculosis.
4. To develop and implement new preventive, diagnostic and therapeutic tools and strategies to Stop TB.¹²

The United Nations Permanent Forum on Indigenous Issues (UNPFII)

The United Nations Permanent Forum on Indigenous Issues was created by the United Nations Economic and Social Council (ECOSOC) in July 2000), through resolution 2000/22 with the mandate to provide expertise and recommendations on indigenous issues to the United Nations through ECOSOC. The forum's role includes promotion and coordination of activities, as well as, the preparation and dissemination of information specific to indigenous issues.

The United Nations Permanent Forum on Indigenous Issues mandate is to:

- Discuss indigenous issues within the Council's mandate, including economic and social development, culture, environment, education, health and human rights.

¹² PowerPoint Presentation Slide 15. Tuberculosis: A Call for Action, Stop TB Partnership, April, 2008.



- Provide expert advice and recommendations to the Council and to programmes, funds and agencies of the United Nations.
- Raise awareness about indigenous issues, and help to integrate and coordinate activities in the UN system.

The UNPFII consists of 16 independent experts who function in their personal capacity and serve for 3 years as members, with the option of being reappointed for up to one additional term. Eight of these members are nominated by governments while the other eight are nominated by the indigenous organizations in their regions. In addition, there are seven socio-cultural regions represented which are: Africa; Asia; Central and South America and the Caribbean; the Arctic; Eastern Europe; the Russian Federation and Central Asia and Transcaucasia; North America and the Pacific.¹³

This high-level body in the UN's hierarchy demonstrates the increasing political engagement of states in cooperation with indigenous peoples to address a multiplicity of issues. The Permanent Forums' holds annual sessions for 10 days (usually in April or May) which take place at the United Nations Headquarters in New York. More than 1,200 indigenous participants from all parts of the world attend the annual sessions of the UNPFII, in addition to some 70 countries and about 35 inter-governmental entities.¹⁴

The Stop-TB Partnership and Indigenous Populations

At the UNPFII in April 2008 several key actions arose from the discussions at that meeting. These included the need for:

- The development of a specific indigenous led initiative that will work in partnership with the Stop TB partnership, along with its relevant subgroups.
- An analysis of the unique social determinants of health that contribute to the increased burden of tuberculosis within indigenous populations, including self-determination and the uneven distribution of wealth and resources.
- Enablement of reliable disaggregated data into reliable, quality data to better ascertain the infection rate within indigenous populations globally.

It was further identified that several next steps were required in order to establish an Indigenous working group on tuberculosis. This working group would involve:

1. The bringing together of Indigenous health leaders, political leadership, global tuberculosis expertise, and government officials, as well as, prominent non-governmental organizations to consider the burden of tuberculosis.

¹³ McDonald, RJ (2008). Report to the AFN CEO on the UN Permanent Forum on Indigenous Issues. AFN : 4.

¹⁴ Indigenous Peoples and the United Nations : Prepared by the Secretariat of the United Nations Permanent Forum on Indigenous Issues : 4-5



2. The development of an action plan that will describe next steps in addressing the issues identified.
3. The presentation of this action plan to the UNPFII 9th session and the Stop TB Partnership meeting in Brazil, 2009.

Purpose of Meeting

The purpose of this meeting is to bring tuberculosis and indigenous experts together to develop a strategic plan to reduce the burden of TB within Indigenous populations globally. This strategic plan will be utilized as a key tool to secure funding support from donor agencies and to create a new “partner” within the Global Stop TB Partnership. This plan would have the unique function of supporting indigenous specific actions designed to permanently eradicate tuberculosis and the burden of tuberculosis in an indigenous context

The essential elements of this meeting will include the following:

1. Create an Action Plan that is funded, sustainable and will address the burden of tuberculosis in Indigenous Communities globally with appropriate interventions to develop this Action Plan.
 - This Action Plan will be submitted to the United Nations Permanent Forum on Indigenous Issues 9th Session and Stop TB Partnership meeting in Brazil, March 2009.
 - This action plan will guide the long-term strategy of identifying and treating indigenous peoples with tuberculosis globally including the principles and objectives that will guide this work.
2. To raise awareness of the unique burden of TB within Indigenous populations :
 - Increase the understanding about the global issue of tuberculosis and its impact on indigenous populations at the global level.
 - To promote new projects that are designed to fight tuberculosis through traditional and multimedia reaching Canada and country delegates.
 - To raise awareness about the Global Expert meeting on Indigenous Tuberculosis and its objectives.¹⁵
 - Promotion and funding of pilot projects to implement culturally appropriate TB control interventions in partnership with Indigenous communities.

The overall purpose of the meeting is to draw attention to the issue of tuberculosis and to discuss how indigenous communities globally need to proceed in light of the Stop TB

¹⁵ Communications Plan for Global Expert Meeting on Indigenous Tuberculosis – draft paper.



plan. In other words, adapt the Stop TB plan to reflect the real needs surrounding indigenous communities.

The STOP TB Strategy¹⁶

THE VISION

A world free of tuberculosis

GOAL

To dramatically reduce the global burden of tuberculosis by 2015 in line with the Millennium Development Goals and the STOP TB Partnership Targets

OBJECTIVES

<i>Achieve universal access to high quality diagnosis and patient centered treatment.</i>	<i>Protect poor and vulnerable populations from TB, TB/HIV and multidrug-resistant TB.</i>
<i>Reduce the human suffering and socio-economic burden associated with multidrug-resistant TB.</i>	<i>Support development of new tools and enable their timely and effective use.</i>

TARGETS

By 2015 reduce prevalence of and deaths due to TB by halving the burden of disease and mortality

GUIDING PRINCIPLES – KEY ACTIONS

ACT: *mobilize resources to implement the tasks set out in the global plan.*

TREAT: *access to quality diagnosis and treatment is a human right to those who have tuberculosis.*

REACH: *to ensure that all tuberculosis patients have access to quality care.*

ACHIEVE: *full funding and following the global plan will result in achievements to attain the goals of the Partnership's 2015 target.*

COLLABORATE: *efforts of over 400 Partners that comprise the Stop TB Partnership. This partnership is crucial to the success of the implementation of the global plan.*

COMMIT: *implement the commitment to mobilize resources, expand our efforts and sustain activities long-term.*

ADVOCATE: *advocate for change in terms of the global political and health agenda.*

INVEST: *investing time and effort and financial resources to stop tuberculosis.*

INNOVATE: *expanding the access to quality tuberculosis care.*

HOPE: *provide hope to the countless millions who are suffering and dying from tuberculosis.¹⁷*

GOVERNANCE

STRATEGIC DIRECTIONS: *strengthening health systems, addressing TB and poverty, TB and gender and TB in children. This also includes the planned achievements, resource needs and their impact.*

GLOBAL AND REGIONAL SCENARIOS FOR TB CONTROL TO 2015: *Analysis of the impact and cost of planned activities.*

¹⁶ WHO 2006 Stop TB Partnership The Global Plan to STOP TB 2006-2015

¹⁷ STOP TB IP brochure. Actions for Life: Towards a World Free of Tuberculosis. Stop TB Partnership.



PARTNERSHIP ACTIONS: *strategic vision, objectives, planned activities, expected impacts and costs. Establish a baseline and milestones for monitoring progress in implementation of the strategic plan.*¹⁸

Potential Next Steps

In order to support the initiative, several key steps should be undertaken to ensure:

1. Funding applications to donor organizations to support the recommendations from the expert group meeting, including the implementation of an indigenous secretariat that could be a partner within the Stop TB Partnership and in implementing the objectives and goals identified during the meeting Nov 13-14, 2008.
2. A global recognition of the need for in-country programs to build relationships with their respective Indigenous groups.
3. The need to develop a methodology to identify indigenous rates of tuberculosis within country level data.
4. The need to develop unique tools and strategies to address the control and treatment of tuberculosis, as well as, the broader issues of poverty within indigenous populations globally.

Based on the Stop TB action plan a model for an indigenous governance and partnership would be characterized as follows:

To maximize the benefit from proactive rather than passive involvement of partners, an Indigenous Secretariat could engage and coordinate with working groups, non-traditional partners and NGOs, as well as, strengthen the constituency of indigenous patient-TB experts.

An Indigenous Secretariat could support national and regional partnerships and strengthen TB control at the local level. These partnerships could become self-sustaining, independently operating entities answerable to their own constituent partners under the umbrella of the Global Stop TB Partnership and the Global Plan to Stop TB (2006–2015).

Advocacy and country communication of an Indigenous Secretariat would need to ensure that TB control remains a critical priority for governments and the general public worldwide. It would have to catalyze TB advocacy, communication and social mobilization activities at all levels, and promote the Stop TB Partnership as an effective mechanism for innovation and progress.¹⁹

¹⁸ STOP TB IP brochure. Actions for Life: Towards a World Free of Tuberculosis. Stop TB Partnership.

¹⁹ WHO. (2006). Global STOP TB Plan paper “The Global Plan to STOP TB: Actions for Life: Towards a World Free of Tuberculosis” 2006-2015. STOP TB: 154



Summary and Conclusion

The Global Stop TB Plan to halve the rates of tuberculosis infection needs to include the 370 million indigenous peoples globally if it is to successfully achieve its goal. To date, the identification of indigenous groups as unique and requiring special attention in all aspects of TB control and treatment has been inadequate.

Indigenous groups must be part of the design of strategies to address tuberculosis control within an indigenous context. This means solutions designed *for* indigenous people *by* indigenous people. Key actions are required to ensure the indigenous voice is heard and priorities made to address the unique needs of the indigenous population world wide.

Indigenous communities, leaders, experts and nations must act immediately to:

- Advocate among indigenous authorities, governments, community leaders, councils, etc. to prioritize tuberculosis control.
- Strengthen and develop consensus-building processes between western and traditional (indigenous community) medicine.
- Ensure long-term sustainability of tuberculosis prevention, surveillance and control activities for indigenous people within the health system.
- Link Indigenous communities' patient's expatriates and family members and their leaders to the STOP TB movement thorough their National Stop TB partnerships.
- Identify social and cultural factors that affect compliance with the treatment on the part of indigenous communities.²⁰
- Develop the materials and resources to increase the awareness of tuberculosis in an indigenous context.
- Share information globally on best practices in tuberculosis control in an indigenous context.
- Identify and involve appropriate stakeholders at all levels.

²⁰ PowerPoint presentation. (2008). Tuberculosis: A Call for Action, Stop TB Partnership. Slide 20.



- Assess and build capacity and resources.
- Assign roles and responsibilities.
- Manage partnerships, and,
- Create and manage budgets²¹
- Conduct situation assessments and stress the importance of tuberculosis in indigenous populations.

To ensure success at all levels there must be:

- Collaboration between all partners.
- Inclusiveness in order to ensure that everyone is included: NGOs, foundations, government, academia, private and public sectors, indigenous populations, etc.²²

It is essential to invest in tuberculosis control because it is the biggest preventable cause of death from a single infection. There must be equal access to the cure for TB and a reduction in the inequity of vulnerable groups to infection. Investment addresses the major economic burden on patients and families. Treatment is cost-effective, even for TB-HIV and MDR-TB. Most importantly, the global plan to Stop TB is a clear and widely supported plan of action to meet defined targets (including indigenous), based on record of achievement.²³

²¹ WHO. (2007). ACSM for Tuberculosis Control: A Handbook for Country Programmes. WHO and Stop TB partnership : 9.

²² PowerPoint presentation. (2008). Tuberculosis: A Call for Action, Stop TB Partnership. Slide 17.

²³ PowerPoint presentation. (2008). Tuberculosis: A Call for Action. Stop TB Partnership: 22.



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