Global STOP-TB Indigenous Experts Meeting
Summary of Proceedings Toronto, Ontario, Canada

November 12-14, 2008

Global Indigenous Health: A Framework for Action on TB Control

Assembly of First Nations
Health Secretariat

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Preface

This document summarizes the proceedings of the *Global Indigenous Stop TB Experts Meeting* held November 12-14, 2008 in Toronto, Ontario, Canada. Herein lies the valuable insights and contributions of the 29 presenters and 130 international indigenous experts from over 50 countries. The summary contained herein is based on the verbatim presentations and input of the presenters and delegates regarding the issues of TB control within an indigenous context.

"For today, the community and health care system needs to continue to collaborate and work together with all TB partners and to continue to support patients and assist them with completion of their therapy. This alone will not eradicate the disease, so for tomorrow, we need to change the health, social and economic landscape of our local and global indigenous communities." ***Chief Alex James Robinson 2008***

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Acknowledgements

Appreciation is extended to the sponsoring government agencies (Health Canada, the Canadian International Development Agency (CIDA), the Public Health Agency of Canada) and the Global Stop TB Partnership of the World Health Organization for their funding support for this meeting. Also, to the planning committee members for their personal commitment and contribution to this first ever global meeting of indigenous TB experts. We gratefully acknowledge the hard work and dedication of our indigenous brothers and sisters who traveled from all over the world to walk with us where there was no path and to leave a trail for future generations to follow.

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Executive Summary

"Nothing About Us Without Us"

The purpose of this meeting was to bring tuberculosis and indigenous experts together to provide a framework for the development of 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 meeting was conducted over three days and was structured to maximize the sharing of knowledge and experience among the global indigenous participants and TB experts which included Indigenous health leaders, political leadership, global tuberculosis experts, government officials and prominent non-governmental organizations, as well as, indigenous Elders.

The meeting was designed to integrate knowledge and experience around central themes regarding TB control, within a framework of plenary sessions. The themes were:

- Global indigenous populations – who are they, where are they and the importance of social determinants of health.
- Targets, trends, challenges and impediments in TB control.
- Tuberculosis control best practices and success stories.
- The right to health in an indigenous context.

Day One of the meeting illustrated that the indigenous peoples of the world are most vulnerable to poverty, overcrowding, lack of access to health care, lack of economic security, poor and inadequate housing and chronic employment. As a result indigenous peoples globally are predisposed to the risk of TB. The burden of TB is most notable in

Africa and Asia, although TB impacts more than one third of the world population globally.

The realities of indigenous health indicate that life expectancies are lower, mortality rates are higher and there is a lack of adequate health care facilities. There are acute shortages of health professionals and health care resources tend to be urban based. Challenges for indigenous health care include geographical barriers, discrimination, language, culture, lack of respect for indigenous peoples and limited capacity. Involvement of indigenous peoples in problem solving and designing solutions is limited and lack of access to facilities and resources is a major problem along with the need for the acknowledgement of health as a *human right.*

Actions are required that ensure care, maximizes scarce resources and increases awareness and knowledge of health personnel. Actions are required that empower indigenous peoples and reduces the cost of the patient and caregiver. Actions are also required to address remoteness and transportation issues, as well as, overcoming geographical barriers.

Strategies are required that target the poor and the most vulnerable. They must ensure easy and equitable access to quality care and that every patient has access to effective diagnosis treatment and cure as a *basic human right*. Strategies are further required that reduce the inequitable social and economic toll of tuberculosis on indigenous peoples of the world and that pro-poor policies are implemented that monitor progress over time. Finally, surveillance must be a key component of any indigenous tuberculosis control strategy in order to ensure that there are measures for success and indicators to account for investment from a cost-benefit perspective.

Poverty is a major determinant that must be addressed in terms of security and vulnerability of indigenous peoples globally. Economic status and unemployment, along with health, education and nutrition also must be addressed. Political rights, freedoms, status, dignity and self-esteem are critical elements in addressing the multi-dimensional issues of poverty within an indigenous context. Key risk factors for tuberculosis are direct results of poverty. They include HIV infection, malnutrition, diabetes, alcohol use, indoor air pollution and active smoking.

Presenters and delegates together concluded that the challenges and *issues facing indigenous peoples globally are bigger than the disease itself.* Poverty, high unemployment rates, poor nutrition, limited food choices, housing shortages, overcrowding, homelessness and overburdened health facilities are the biggest challenges before, *and in addition to*, tuberculosis.

Day Two of the meeting breakout groups were formulated to enable maximum input from the delegates. These sessions facilitated wider discussion and consensus forming on the meeting outcomes. A strategic framework was then developed based on the breakout group input. The framework acknowledges and highlights the global

characteristics of a strategic plan and action items required to control tuberculosis within an indigenous context. The framework is based on the need to address the health, social, economic, educational and political global indigenous realities within the context of the basic *human right to health.*

Meeting delegates also passed two resolutions on *Day Two* of the *Global Indigenous Expert Stop TB Expert meeting.* They were as follows:

Resolution 1

It is hereby resolved that an action plan will be submitted to the UNPFII on health at the next forum meeting and that a side event be planned on the topic of Indigenous TB control as part of the Stop TB partnership.

Resolution 2

It is hereby resolved that the Stop TB Partnership Meeting scheduled for March 2009 in Brazil recommend a specific reference to the Global Indigenous Stop TB Experts meeting report and outcomes on the Brazil agenda.

In terms of next steps, delegates felt that further action required as an outcome of the meeting, was the development of an *Indigenous Declaration on Health* to address tuberculosis control, and that, the human right to health be addressed within this context.

The final outcomes of this meeting were an *Indigenous Stop TB Strategic Plan* and a *Global Indigenous Stop TB Action Plan*.

Overview

One third of the world's population is infected with tuberculosis and up to half a million people develop multi-drug resistant tuberculosis,[1] a form of TB that does not respond to standard treatment. 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]

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 900 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* 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.[3]

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.
- Provide expert advice and recommendations to the Council and to programmers, funds and agencies of the United Nations.

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

- 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.[4]

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 Forum 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.[5]

During the 8th Session of 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.
- Research 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 and TB expert 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.
2. The development of an action plan that will describe next steps in addressing the issues identified.

[4] UN Permanent Forum on Indigenous Issues. AFN : 4.

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

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 was to bring tuberculosis and indigenous experts together to develop the framework for 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 expected outcomes of this meeting included the following:

1. Create an Action Plan that will address the burden of tuberculosis in Indigenous Communities globally.

    - This Action Plan will be submitted to the United Nations Permanent Forum on Indigenous Issues 9th Session and the 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.[6]

The overall purpose of the meeting was to draw attention to the issue of tuberculosis and to discuss how indigenous communities globally need to proceed in light of the Stop TB plan. In other words, to inform the Stop TB Partnership on the need to engage them in solution development.

[6] Communications Plan for Global Expert Meeting on Indigenous Tuberculosis – draft paper.

Meeting Framework

The meeting was conducted over three days and was structured to maximize the sharing of knowledge and experience among the global indigenous participants which included Indigenous health leaders, political leadership, global tuberculosis experts, government officials and prominent non-governmental organizations, as well as, indigenous Elders. The meeting was opened with traditional prayers from indigenous Elders representing the Assembly of First Nations and Inuit Tapirrit Kanatami. The Elders also provided guidance and advice throughout the three days of the meeting.

The meeting was designed to integrate knowledge and experience around central themes regarding TB control, within a framework of plenary sessions. Speakers from key countries provided brief overviews of the current situation regarding TB control in their respective country, emerging issues for that theme and key focuses on strategic actions that are required to address TB control within an indigenous context.

The meeting themes were:

- Global indigenous populations – who are they, where are they and the importance of social determinants of health.
- Targets, trends, challenges and impediments in TB control.
- Tuberculosis control best practices and success stories.
- The right to health in an indigenous context.

The meeting was also designed to construct reflective input from the delegates on eight key questions for the purpose of developing the essential components of a framework for a strategic plan to address TB control in an indigenous context.

Breakout groups were formulated to enable maximum input from the delegates who brought with them unique experiences integral to their particular countries. These sessions facilitated wider discussion on the meeting outcomes. The breakout session discussions were reported back to the larger meeting in plenary format to facilitate input from the wider group on the questions discussed. A small team of facilitators and note takers oversaw the small group discussions and provided summaries of the small group sessions to the wider group via appointed indigenous spokespersons for each group. A summary of the proceedings was provided to the meeting participants by the lead facilitator for day one and again at the end of day two in the form of a roll up of next steps, resolutions and action items.

This report is based on the individual country presentations and plenary sessions, the summary team breakout session notes and is structured to reflect the meeting framework and outcomes.

Framework

Day One

- **Showcased the problem of tuberculosis control within an indigenous context highlighting global indigenous populations.**
- **Highlighted TB partnerships for TB control related to targets, trends, challenges and impediments.**
- **Presented models of tuberculosis control in Latin America, the USA, Asia, the Pacific, Iran, Nepal, India, Canada, China, Bolivia, Kenya, Brazil, Russia and Australia.**
- **Provided examples of tuberculosis control success stories, best practices and challenges to TB control in an indigenous context.**
- **Discussed the right to health and social determinants of health in an indigenous context.**
- **Encompassed traditional evening reception and dinner activities to highlight and celebrate the cultural and linguistic richness of the global indigenous participants.**

Day Two

- **Plenary overview of the previous day sessson highlighting the key issues that were discussed and presented consistent with the themes of the meeting.**
- **Breakout and plenary sessions on eight key questions designed to construct the framework for a indigenous TB control strategic plan.**
- **Key questions discussed by the delegates related to what is required to promote indigenous specific approaches and methodologies to TB control, linkaging of partners to control TB, the culturally appropriate factors needed to be taken into consideration to raise awareness regarding TB control and additional themes that need to be considered.**
- **Additional key questions discussed by the delegates were what the governance structure might look like for an indigenous secretariat, the key roles a secretariat should perform, how the UNPFII can provide support and what is required to enhance the focus on socioeconomic determinants of TB on global non-health agendas.**

Day One

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- **Provided examples of tuberculosis control success stories, best practices and challenges to TB control in an indigenous context.**
- **Discussed the right to health and social determinants of health in an indigenous context.**

Global Indigenous Populations – Who are they and where are they? And The Importance of Social Determinates in Their Health
Dr. Manuel Carballo – Executive Director, International Centre for Migration and Health

The WHO Stop TB Partnership: Targets, Trends, Challenges and Impediments.
Dr. Marcos Espinal – Executive Secretary of the Stop TB Partnership - WHO

Examples of Tuberculosis Control in Latin America
Dr. Mirtha Del Granado – Pan America Health Organization

The Importance of TB Surveillance
Dr. Eugene McCray – National Centre for Disease Control and Prevention, Atlanta, Georgia,
Dr. Marcos Espinal - The Stop TB Partnership - World Health Organization

Luncheon Speaker: Dr. David Butler-Jones, Chief Public Health Officer of Canada

PANEL: Asia/Pacific and African Indigenous Stories
Chairperson – Ms. Paimaneh Hasteh – (Iran) UNPFII Member
Mr. Tshering Lama – (Nepal)
Dr. Nandakumar Menon –Ashwini (India)

PANEL: Tuberculosis Control Success Stories
Chairperson – Ms. Margaret Lokawua (Uganda) UNPFII Member
Dr. André Corriveau - (Canada)
Dr. Jiang Shiwen - (China)

PANEL: Tuberculosis and Poverty – A Right to Health?
Chairperson - Ms. Soipan Tuya, Maasai tribe, Kenya, Global Indigenous Women Caucus
Members of the Stop TB Partnership's TB and Poverty Sub-group – World Health Organization,
Dr. Gillian Mann, Dr. Pervaiz Tufail and Ms. Delia Boccia

The FIDELIS Experience – An Example of an Approach to Community-Based Interventions In Controlling TB
Dr. Don Enarson, International Union Against Tuberculosis and Lung Disease

PANEL: Best Practices and Challenges for TB Control
Chairperson – Ms. Elisa Canqui Mollo (Bolivia), UNPFII Member
Ms. Roxana Linares Cáseres - (Bolivia)
Chief Alex James Robinson – (Canada)
Dr. Larisa Abryutina – (Russia)

Evening Keynote Address
Professor Ian Anderson, University of Melbourne (Australia)

The following is a summary of the presentations by theme:

Global Overview of TB Control

Tuberculosis is an ancient and deadly poverty related disease caused by the air-borne bacillus mycobacterim tuberculosis. It affects primarily the lungs, but can develop in most organs. *One third of the world's population is infected with TB,* although only 5%-10% of those infected will eventually develop active diseases. If adequately treated, drug sensitive TB is virtually always curable. If left untreated, two thirds of those afflicted with TB will die after infecting others.

Rates of TB are higher among indigenous than non-indigenous peoples across several countries. There are 370 million indigenous peoples in the world representing 70 countries. Indigenous peoples are most vulnerable to poverty, overcrowding, lack of access to health care, social determinants of health that predispose and increase the risk of TB, lack of economic security, poor and inadequate housing and chronic unemployment.

The global response to the TB crisis was the *Stop TB Partnership.* It was established in 2000. It was a global movement to accelerate social and political action to stop the spread of TB. It consists of a network of international organizations, countries, donors (public and private sector), governmental and non-governmental organizations and individuals. The *Stop TB Partnership* Secretariat is housed within the World Health Organization (WHO) in Geneva.

The vision of the Partnership is a *TB free world*. The Global Plan 2006-2015 is that the Partnerships' targets halve the prevalence and mortality of TB and treat 50 million people with TB, three million with TB/HIV co-infection and who are on ARV (anti-retro virals) and 1.6 million with MDR (multi-drug resistant) TB. The goal is to save 1.4 million lives and introduce new diagnostics, drugs and vaccines against TB.

Some potential roles of indigenous peoples in the *Stop TB Partnership* are to create bottom-up approaches at the country level; establish in alliance with other stakeholders and populations in order to demand accountability and access from country level governments for TB control; suggest local efforts on TB surveillance that includes indigenous peoples; offer help to country level governments to expand TB control in

indigenous communities; educate, advocate and inform indigenous communities about their rights to TB control; and to generate resources for TB control. Also, to ensure indigenous cultural values are taken into account in TB control strategies and to identify indigenous champions to advocate for TB control in an indigenous context.

Models of TB Control

Tuberculosis control at the country level requires political momentum, economic growth, government social programs, more employment to decrease the number of people living below the poverty line and political commitment for financial support. For example, the fifth top health priority for **Brazil** is TB. The *Brazilian Public Health Care System* is unified and universal, provides treatment free of charge for all populations (as a constitutional right) and is provided at the primary, secondary and tertiary levels. There are 221 indigenous groups in Brazil that add up to around 500 thousand peoples (2% of the country's total population). The greatest distribution of indigenous peoples in Brazil's five Macro Regions are in the *Northern Region* at 45%, *Northeast Region* at 24% and *Central Western Region* at 20% respectively. The majority of the indigenous lands are concentrated in the Amazonian region (98%) where 60% of the indigenous populations live.

In **the USA** there are an estimated 4.3 million indigenous peoples (self-identified as American Indians and Alaska Natives). The American Indian and Alaska Native TB mortality rate is 3-5 times greater than the national rate. Surveillance is important to define the magnitude of the problem and allows for better understanding of the epidemiology of TB in indigenous peoples. Surveillance also enhances the ability to examine trends and detect changes over time for the purpose of improving TB program quality and performance. It further allows for targeting of resources, advocacy and mobilization of resources.

Samples of data collected by state and local health departments on all newly reported TB cases since the 1950's include geographic location, demographics (age, sex, race/ethnicity, birth country, etc.), as well as, clinical characteristics (disease site, smear and culture results). Since the 1990's the USA has started collecting data on socio-demographics (homelessness, illicit drug use, excess alcohol use, and occupation and employment status), drug resistance, directly observed treatment and treatment outcome.

The highlights from TB surveillance in the USA indicate that TB rates remain elevated among American Indians and Alaska Natives possibly due to poor access to care, lower socioeconomic status, missed opportunities for latent TB infection screening and case finding, and more frequent progression to disease from latent infection. Factors related to progression from latent infection to TB disease are clinical conditions and risk factors commonly reported among American Indian and Alaska Natives. These include diabetes mellitus, use of immunosuppressive drugs, homelessness, excess alcohol use and unemployment. As a result characteristics common to many indigenous communities

(poverty, rural location, sovereign status, co-existing medical conditions, etc.) pose unique challenges for TB control.

In **Nepal,** the population is estimated at 27.6 million and it is one of the poorest countries in the world. It consists of mainly mountainous country with 86% of its population living in rural areas. It is an agro-based country with limited modern transportation and communication services. The life expectancy is 60 years. Infant and maternal mortality rates are high along with birth rates. There is an acute shortage of health professionals and most health care resources are urban based making them inaccessible for the majority of the population. Sixty-nine percent of the total population of Nepal consists of minority groups with indigenous nationalities representing the highest percentage at 36.31%.

There are 59 different indigenous nationalities in Nepal. The biggest challenge for the indigenous nationalities of Nepal are lack of access to facilities and resources, geographical barriers, poverty, discrimination, lack of opportunities and cultural barriers. In addition, they have the lowest life expectancy, highest maternal and infant mortality rates and are the main contributors to all disease statistics (skin, acute respiratory infections (ARI) and diarrhea).

Immediate actions are required to improve access to health care, education and facilities by overcoming geographical barriers and reducing the distance due to lack of transportation and poor roads. Reducing the cost for patient care along with access to quality health care (specialists, referrals to hospital and primary case management) is also required. In addition, increasing the knowledge and qualifications for health care local personnel and maximization of scarce resources is essential. Action is required that is characterized by *trust and respect, indigenous involvement, empowerment* and *capacity building.*

In the Northwest Territories of northern **Canada,** there are 34 communities representing 41,795 people (consisting of 51% Aboriginal people). There are 10 official languages in the NWT and the government is a consensus style public governance system. In the 1950's and 60's tuberculosis was a medical tragedy for northern residents. Thousands of residents were sent south for treatment and some were never seen again. In 1998 TB programming became the responsibility of the territorial government. An external review of the NWT TB control activities was conducted in the fall of 2000 and 26 recommendations were made to improve the NWT program.

The goal of the program was to reduce the incidence rate of active TB in NWT to less than 5/100,000 per year. Reporting is centralized and TB registry uses a database tool called iPHIS. There are annual progress reports and TB summaries reported in EpiNorth. Two areas of focus are key – increased active case findings and adding emphasis on the identification and treatment of latent infection. The key messages are, although TB rates are decreasing, there is a need to keep resources dedicated to TB control because "one

case can become an outbreak." There is a need to develop and keep TB/public health expertise in the NWT and to enhance public health capacity at the health authority level. Social issues contributing to the incidences of TB in the NWT were found to be high frequency of alcohol use, non-adherence to scheduled appointments, patients not bringing children to the health center for screening, over-crowding in houses and people going out on the land without notifying health care workers, along with 92% *unemployment* and *under employment* rates.

To address the problem community interventions were undertaken. They consisted of an intervention plan that was coordinated with Chief and Council, training of CHR's to deliver TB programs, regular physician visits, public education on TB (using plain language) and temporary community bans of alcohol and alcohol based solvents (one month to one year) including notification of surrounding communities and airlines of temporary bans.

Positive spin offs have been children are now being brought in for their medications, increased employment, improved school attendance for children and community satisfaction of having worked on an issue together.

In Ashwini Gudalur, **India** there is one health program for 15,000 indigenous people (Adivasis) spread over 200 hamlets. The Gudalur Valley is home to 25,000 primitive tribes who make up 10% of the population. Their history started from a life of plenty in the forest as hunter-gatherers. Over time, however, with deforestation by British tea plantations and nationalization of forests people, Adivasis became displaced and ignored.

Tuberculosis is high in India because of emaciation, extreme malnutrition, poor housing, inadequate ventilation (due to open fires in homes and other such dwellings), overcrowding and issues related to treatment. Many patients are unable to take their medication due to gastritis and not enough food at home to provide nourishment during treatment. Villages are distant from health care facilities and often patients are too sick to walk to the place where treatment is administered twice a week. Tuberculosis can be controlled if housing is addressed and there are changes to the mode of administration of drugs to increase compliance. DOT providers need to become motivators and health educators and they need to be compensated for their efforts. Food also needs to be provided during the period of treatment.

Human Rights and TB Control

Human rights are *entitlements inherent to all human beings without discrimination*. All humans are *born free and equal in dignity and rights*. *Universality* is the cornerstone to International Human Rights law. Human rights *are inalienable* and should not be taken away.[7]

Human rights are *expressed and guaranteed by law* via declarations and treaties. International Human Right law lays down obligations of Governments to *act on* or *refrain from* certain acts. This includes the obligation to *respect the right of others*. States have ratified at least one, and 80% of States ratified four or more, of Human Rights treaties. This reflects the *consent to be bound by legal obligations* and a concrete expression of universality.

Globally indigenous people have a consistent pattern of health inequality across a variety of jurisdictional contexts from the *resource poor* to the *resource rich*. Indigenous health inequalities are multi-faceted and produced within diverse social contexts characterized by social inequalities and political marginalization.

In Kenya life expectancy, per capita income and school enrolment among indigenous peoples has been on the decrease. Poverty has increased in the country and inequality is on the rise. Regional, rural-urban, gender and social class inequalities have also been on the rise. Historical marginalization and social exclusion consistently subjects the county's indigenous population to inequalities. Social and human development is lower than the country's average levels. Indigenous peoples consistently experience lack of access to primary health care, transportation, as well as, high costs for essential supplies. Deliberate affirmative action is required to address the special needs of indigenous peoples to ensure equitable access.

The *International Convention on Economic Social and Cultural Rights* entered into force in 1976. It recognizes the right to the highest attainable standard of health. The *International Convention on the Elimination of all Forms of Racial Discrimination* (ICERD) evaluates reports, makes observations and recommendations. General recommendation XXIII of the fifty-first session in 1997 noted the situation of indigenous peoples *as a matter of close attention and concern*. It consistently affirmed that discrimination against indigenous peoples falls under the scope of the ICERD and that all *appropriate means must be taken to combat and eliminate such discrimination*. It further recognizes that in many regions of the world indigenous peoples have been, and are still, being discriminated against.

[7] TB is a Human Rights Concern, GlobaL Indigenous Stop TB Experts Meeting Presentation, Soipan Tuya, Kenya November 2008

The International *Convention on the Elimination of all Forms of Racial Discrimination* calls upon States parties with indigenous peoples to include in their periodic reports full information on the situation of such peoples, taking into account all relevant provisions of the Convention. Many countries have no concise data on indigenous peoples present within their territories; therefore, some indigenous peoples are forced to "belong" to other "bigger" ethnic groups. The consequence is a lack of national planning for indigenous peoples. This is the situation in Kenya, for example, where the full extent of TB is not known in indigenous territories.

> *Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity. The realization of the right to health may be pursued through numerous, complementary approaches, such as the formulation of health policies, or the implementation of health programmes … or the adoption of specific legal instruments."* [8]

In his presentation Professor Ian Anderson (**Australia)** stated that the rights to health are:

- Integrally linked to the recognition of *other rights*, such as rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement[9]

- The right to health is not to be understood as a right to be *healthy*. The right to health contains both freedoms and entitlements. For example, the freedoms include the right to control one's health and body. The entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health[10]

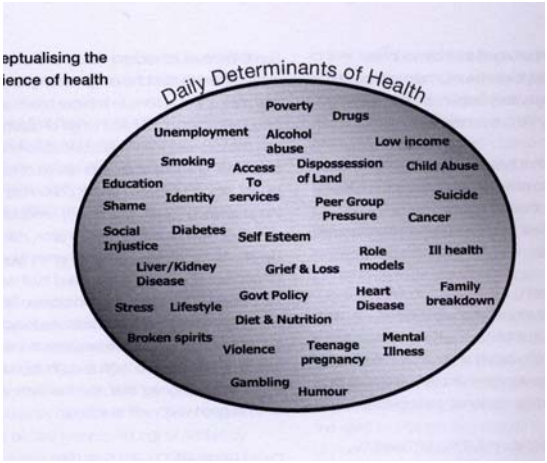
The relationship between *rights and health outcomes* is complex. The recognition of rights is not in itself sufficient to guarantee the eradication of health inequalities but neither should it be assumed that there is a fundamental disconnect between policy outcomes and the rights agenda. Indigenous rights and rights in an Indigenous context include Native title, treaty rights and self-determination.

Social context is important in the development of strategies to address Indigenous health inequalities due to several important factors that include the:

[8] United Nations Economic and Social Council (11/08/2000) "Substantive issues arising in the implementation of the international covenant on economic, social and cultural rights" *General Comment* No. 14 (2000)
[9] ibid
[10] ibid

- Historical processes of colonization and the social processes which have underlain the social and political marginalization of Indigenous people;
- Distinct forms of social and cultural organization in Indigenous societies;
- Political economies of Indigenous people and their relations with *settler society* and its institutions; and
- Indigenous explanatory frameworks for health inequalities.

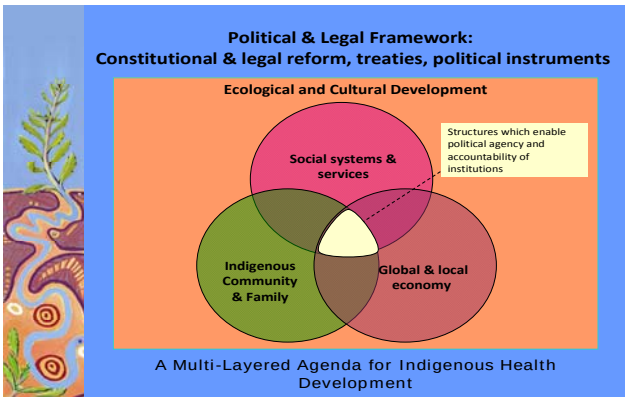
For example, the Koori (Aboriginal people in south-east Australia) concepts of health emphasize a holistic approach to health that emphasizes social, political and spiritual dimensions but with some reference to specific issues such as health knowledge, youth, drugs and alcohol. The significance of identify formation in regards to self-esteem and lack of self-confidence is key, as well as, the relationship with mainstream in terms of dispossession, colonization, intergenerational processes and racism. The following diagram illustrates the determinants of health within this context.



Poverty for indigenous people needs to be contextualized within the broader social domain which constitutes the *lived experience* of Indigenous peoples. That is indigenous poverty = low income + low education levels + limited work skills + relatively higher imprisonment + racism and social indifference, etc. *Indigenous health and human rights* must recognize the potential relationship between indigenous self-determination and health.

It is critical to strategies that are developed in partnership which enable indigenous self-determination to be expressed. This includes partnerships in policy, facilitating indigenous civil engagement in policy and service responses, partnerships with indigenous civil society organizations which include service providers, and advocacy and awareness raising. Capacity building and empowerment strategies are also essential.

The following diagram illustrates the essential relationships for a multi-layered agenda for indigenous health development.



As this diagram illustrates, mechanisms are required to address indigenous tuberculosis which must take into account inequalities within Indigenous communities and integrate TB strategies with indigenous primary health care development programs and other health, social and cultural strategies. It must also minimize cost barriers for health, social systems, services and indigenous community and family development.

Tuberculosis is *the poor man's disease*. It is a disease of neglect, and the poor and neglected person *is the* indigenous person. There is a responsibility to respond not only to demands of human decency but also legally in terms of *binding international human rights obligations.*

The **TB and Poverty Subgroup of the Stop TB Partnership** is a network of individuals and organizations interested in the needs of the poor and vulnerable populations with respect to TB. The subgroup was officially endorsed in 2005. The subgroup exists because case detection in many countries is low and the poor cannot access TB services. Poor and vulnerable people face significant costs and delays in accessing care. As a result the subgroup's purpose is to enable the Stop TB Partnership to achieve its goal and targets and contribute to its poverty related mission statements. That is to ensure that every TB suspect/patient has easy and equitable access to effective diagnosis, treatment and care and to reduce the inequitable social and economic toll of TB.

The vision of the subgroup is for a world where the poor and the most vulnerable are protected from TB and have easy and equitable access to quality care. The subgroup monitors progress in a number of countries by measuring socio-economic status to document equitable access to care and by having an official pro-poor policy that includes TB. The subgroup also implements key strategies for improving access to TB care. The subgroup can help by identifying the poor and vulnerable groups in the community/region served by the national TB control program. It can also help to identify the barriers to accessing TB services faced by the poor and vulnerable groups in

the country/region. Harnessing resources for pro poor TB services, assessing pro-poor performance of the national TB control program and the impact of pro-poor measures is another function of the sub-group. Finally, identification of potential actions to overcome the barriers to access is a task of the subgroup.

Best Practices and Challenges to TB Control

Poverty is multidimensional. It consists of economic, protective, political, social-cultural, and human and gender issues. There are several risk factors experienced by indigenous peoples due to poverty that predispose them to TB infection. Those risk factors include HIV infection, malnutrition, diabetes, smoking, alcohol use and indoor air pollution. Continuous efforts are required to reach the poor and the vulnerable. Stronger preventative efforts are required along with better collaboration and coordination between agencies and partners.

The **Fidelis Experience** is an example of a best practice that is based on small projects of one-year duration consisting of funding between $150-250,000. The projects are based on local solutions to local problems and the encouraging of innovative ideas within existing programs. The projects also focus on populations with limited access. Systemic monitoring and evaluation are integral components of the projects. There have been 49 contracts approved to date in sixteen countries. Twenty-four of the projects are in the six highest burden countries.

Project results have included enhanced diagnostic services in urban slums in **Africa** and mobilizing junior high school students in Anhui, **China** to screen family members for TB. In addition results have included strengthening referrals from country hospitals to country TB dispensaries in Hunan, China and training and utilizing community volunteers to increase community awareness in North Sumatra.

Fidelis has been a good example for TB control best practices by illustrating *that local ideas do lead to local solutions*. This is ideal since local solutions work best and can be implemented promptly thereby leading to social mobilization and political commitment.

In **Canada** in the Cross Lake First Nation community in Manitoba there are 6,700 First Nation members living in the reserve community. There are a total 808 housing units for that community and at least 200 are in need of repairs and many homes have indications of mould. Eight to nine-hundred new homes are needed to eliminate overcrowding. There is no local hospital and all primary care services are provided by the nursing station. Residents have to leave the community to receive secondary and tertiary services from Thompson or Winnipeg.

To address the recent outbreak of TB the community has undertaken community education and awareness programs along with DOT training, orientation and support. Incentive items are also being provided in the form of food programs and promotional

items to increase awareness of TB control. Intervention successes have included immediate referral to hospitals outside the community, isolation of patients and administration of medications. After discharge medications are provided at the nursing station by DOTS (direct and observed therapy). The challenges while on treatment are while people feel better they still suffer from fatigue. People with substance abuse problems have difficulty meeting their medication commitments and poverty related social conditions remain (poor or lack of housing, unaffordable food, unemployment, etc.).

The issues of TB control, therefore, are bigger than the disease itself. Poverty, high unemployment rates, poor nutrition, limited food choices, high rates of addictions and solvent/drug misuse, housing shortages, overcrowding, homelessness, overburdened community based clinics and nursing stations, and service delivery outside the community makes interventions difficult, if not impossible, in some cases. For today, the community and health care system needs to continue to collaborate and work together with all TB partners and to continue to support patients and assist them with completion of their therapy. This alone will not eradicate the disease, so for tomorrow, we need to change the health, social and economic landscape of our local and global indigenous communities.

SUMMARY OF DAY ONE

In summary, the opening themes of *Day One* illustrated that the indigenous peoples of the world are most vulnerable to poverty, overcrowding, lack of access to health care, lack of economic security, poor and inadequate housing and chronic employment. As a result indigenous peoples globally are predisposed to the risk of TB.

The burden of TB is most notable in Africa and Asia, although TB impacts more than one third of the world population globally. Tuberculosis claims a life *every 15 seconds*. The *Stop TB Partnership* was created in response to the global TB crisis with the vision of a TB free world. It is a social movement with the mandate to halt the transmission of tuberculosis and reduce the inequitable social and economic tolls of tuberculosis.

TB control must be part of the human rights agenda. It is also critical to ensure that cultural values are considered in any partnership actions. As a result, surveillance is essential to facilitate decision making and policy development. It also documents the burden of the disease at multiple levels. It further provides a profile for intervention to better understand the socio-economic issues that impact TB control along with indigenous specific policy making.

The impacts of colonization on indigenous peoples of the world must be acknowledged and governments must take responsibility for the impacts of colonization on indigenous peoples of the world at multiple levels. At the same time, although the global economic crisis is a further barrier to addressing the social determinants of TB in many countries, investment in infrastructure as a means to strengthening international economies may turn into an opportunity for indigenous regions globally.

The realities of indigenous health indicate that life expectancies are lower, mortality rates are higher and there is a lack of adequate health care facilities. There are acute shortages of health professionals, and health care resources tend to be urban based. For indigenous communities, which tend to be remote, rural and poor; the lack of transportation for health care is a major barrier.

Challenges for indigenous health care include geographical barriers, discrimination, language, culture, lack of respect for indigenous peoples and limited capacity. Involvement of indigenous peoples in problem solving and designing solutions is limited and lack of access to facilities and resources is a major problem along with the need for the acknowledgement of health as a *human right.*

Actions are required that ensure care, maximizes scarce resources and increases awareness and knowledge of health personnel. Actions are required that empower indigenous peoples and reduces the cost of the patient and caregiver. Actions are also required to address remoteness and transportation issues, as well as, overcoming geographical barriers.

Strategies are required that target the poor and the most vulnerable. They must ensure easy and equitable access to quality care and that every patient has access to effective diagnosis treatment and cure as a *basic human right*. Strategies are further required that reduce the inequitable social and economic toll of TB on indigenous peoples of the world and that pro-poor policies are implemented that monitor progress over time. Finally, surveillance must be a key component of any indigenous TB control strategy in order to ensure that there are measures for success and indicators to account for investment from a cost-benefit perspective.

Poverty is a major determinant that must be addressed in terms of security and vulnerability of indigenous peoples globally. Economic status and unemployment, along with health, education and nutrition also must be addressed. Political rights, freedoms, status, dignity and self-esteem are critical elements in addressing the multi-dimensional issues of poverty within an indigenous context. Key risk factors for TB are direct results of poverty. They include HIV infection, malnutrition, diabetes, alcohol use, indoor air pollution and active smoking.

Success stories in TB control were described during *Day One* and they where characterized by *local solutions* to *local problems*. Encouraging innovative ideas within existing programs. Focusing on populations with limited access, incorporating monitoring and evaluation, enhancing diagnostics and *strengthening referrals*. Most importantly success stories emphasized *capacity building, training, social mobilization* and political *commitment.*

Presenters and delegates together concluded that the challenges and issues facing indigenous peoples globally are bigger than the disease itself. Poverty, high unemployment rates, poor nutrition, limited food choices, housing shortages, overcrowding, homelessness and overburdened health facilities are the biggest challenges before, and in addition to, TB. Immediate action is required to improve access to health and care facilities. TB can be better controlled if housing is addressed.

Changes are required to the mode of administration of drugs to increase compliance. Quality care is required with specialists and quick referral to primary care. Maximization of scarce resources is required and the cost of care and transportation needs to be reduced. Communities need to be *empowered* and solutions must be *indigenous driven.* Capacity building and training is essential. There must be *ownership for solutions* by indigenous peoples and their communities.

In conclusion, *the right to health is a human right*. Political momentum and commitment is required along with sustainable resources long term. Targeted health and social programs are required to address the social determinants of health in an indigenous context. Surveillance is essential to establish baselines and milestones for policy making, resource investment and targeted action.

The future of our children (the little child) is in our hands. It is our responsibility to look out to ensure their needs are met at every basic level. We must think generations ahead for our children. They are our future.

We must address the health, social, economic, educational and political realities within the context of the basic human right to health. We must act and make governments responsible. Our child – our future – means security, a good home, love and health.

We are partners in the problems and solutions. Let us work together to make this world a better place. A place free of TB and where our indigenous peoples can flourish individually, as families, communities and nations.

We are truly brothers and sisters in this global effort to eradicate TB and we must walk hand and hand together so that our children will have a brighter future.

Day Two

- **Plenary overview of the previous day sessson highlighting the key issues that were discussed and presented consistent with the themes of the meeting.**
- **Breakout and plenary sessions on eight key questions designed to construct the framework for a indigenous TB control strategic plan.**
- **Key questions discussed by the delegates related to what is required to promote indigenous specific approaches and methodologies to TB control, linkaging of partners to control TB, the culturally appropriate factors needed to be taken into consideration to raise awareness regarding TB control and additional themes that need to be considered.**
- **Additional key questions discussed by the delegates were what the governance structure might look like for an indigenous secretariat, the key roles a secretariat should perform, how the UNPFII can provide support and what is required to enhance the focus on socioeconomic determinants of TB on global non-health agendas.**

RECAP OF DAY ONE AND OVERVIEW OF CONTEXT PAPER

BREAKOUT SESSION ONE – Questions # 1-4

1. In order to make the case for a unique strategy for indigenous populations globally, what is required to promote indigenous specific approaches and methodologies for tuberculosis control? Why is an indigenous specific approach required?
2. In order to develop strong partnerships to control TB in an indigenous context who do we need to include in the development of stronger relationships at the in-country, regional and global level? How could these linkages be facilitated and strengthened between indigenous groups and in-country TB programs?
3. What culturally appropriate factors need to be taken into consideration when developing strategies to raise awareness and reduce stigma regarding TB control in an indigenous context?
4. Of the key messages we have heard during these two days is there anything else we need to consider within an indigenous context regarding TB control? For example, in terms of indigenous social determinants, the importance of being identified in country level TB surveillance data, etc.

Breakout Session Facilitators Report Back on First Four Questions

BREAKOUT SESSION TWO Questions # 5

5. Thinking ahead to next steps how might an Indigenous secretariat serve the interest of the Indigenous populations globally? What type of governance structure might it have? What should its objectives and functions be?

6. In the formation of an indigenous secretariat what key role should it perform in terms of advocacy and communications? Which types of individual(s) should be considered the spokesperson? What should the key messaging be in an indigenous context?
7. How can the UN Permanent Forum on Indigenous Issues provide support with respect to the outcomes of this meeting? What should the roles and activities be of the STOP TB Partnership with respect to the outcomes of this meeting?
8. How do we use the information we heard during this meeting to better inform and address the socioeconomic determinants of tuberculosis and enhance the focus on TB in an Indigenous context on global non-health agendas e.g. human rights, poverty, housing, etc.

Breakout sessions - Report back – next four questions

WRAP UP AND NEXT STEPS
Dr. Rose-Alma J. McDonald

CLOSING REMARKS
Alberta - Regional Chief Willie Littlechild (Canada)
Gail Turner on behalf of President Mary Simon, ITK

The following is a summary of the break out session notes to the eight questions posed to the meeting delegates:

Question 1

(a) In order to make the case for a unique strategy for indigenous populations globally, what is required to promote indigenous specific approaches and methodologies for tuberculosis control? (b) Why is an indigenous specific approach required?

The unique challenge is that Indigenous people must be able to create the solution themselves from their own world view and cultural perspective. A strategy has to start from an indigenous perspective.
There must be engagement with the people. An indigenous specific approach must include indigenous language, concepts, world views, traditional values, practices, knowledge and medicine. The right to health for indigenous people must acknowledge and recognize geography and funding.

The indigenous population needs to *trust the system*. This may take some time to achieve. The messenger *must b*e from the people.

An Indigenous specific approach is required because:

- It must be accepted that Indigenous peoples are different and that we have the *right to be different.*

- There is a need to decrease the disparities between the indigenous population and other populations. It is necessary to address factors that pre-dispose Indigenous populations to TB.

- The campaign must include a communication strategy. There needs to be different messages for different countries depending on the situation. There are huge impacts by virtue of the Stop TB partnership. The voices of indigenous peoples need to be added to the TB strategy in order to enrich the strategy and for it to be more effective in its goal.

- A cultural focus is important. Indigenous representation at the policy making level would have a positive impact. Policy needs to be informed and reflective of the cultural characteristics of the target population. There must be a cultural match for policy to be effective. It needs to fit the culture of the people. Socio-economic policy must be aligned with cultural needs. This is the challenge.

Question 2

(a) In order to develop strong partnerships to control TB in an indigenous context who do we need to include in the development of stronger relationships at the in-country, regional and global level? (b) How could these linkages be facilitated and strengthened between indigenous groups and in-country TB programs?

- Indigenous leadership needs to be engaged. There is an opportunity to work with the WHO and UN agencies. Countries included in the Stop TB partnership are required to report (by providing data) to the WHO. If we put indigenous issues on the agenda, it will change the picture.

- Local indigenous organizations in each region should be engaged in identifying appropriate indigenous processes and engagement strategies.

- We should have a **global accord** that includes a number of seats for indigenous people and voices in decision making. We have socio–economic disparities in government as well that need to be addressed.

How :

- The professional associations, nurses, and community organizations and media include all levels of providers. We need to ask the question, *what about TB*?

- A small change starts with raising the awareness. Concrete examples of TB needs to be on the leaderships' agenda.

- Annual government report backs at the UNPFII would enable accountability on the TB rates of indigenous populations in their Region/County.

Question 3

What culturally appropriate factors need to be taken into consideration when developing strategies to raise awareness and reduce stigma regarding TB control in an indigenous context?

- "Indigenous Peoples' concepts of health and wellbeing are both a collective and individual continuum, encompassing a holistic perspective incorporating four distinct shared dimensions of life. These dimensions are the *spiritual, intellectual, physical and emotional*. Linking these four fundamental dimensions, health and wellbeing manifests itself on multiple levels where the past, present, and future co-exist simultaneously. For indigenous peoples, health and wellbeing is a dynamic equilibrium, encompassing interaction with life processes and the natural laws that govern the planet, all life forms, and spiritual understanding."

- "Expressions of cultural relevance to the health and wellbeing of indigenous peoples includes, but is not limited to, individual and collective relationships, family, and kinship systems, social institutions, traditional justice, music, dances, ceremonies, ritual performance and practices, games, sports, language, narratives, mythology, stories, names, land, sea and air and their resources, designs, writings, visual compositions, permanently documented aspects and forms of Indigenous culture including scientific and ethnographic research reports, papers, and books, photographs, digital images, film, and sound recording, burial and sacred sites, human genetic material, ancestral remains, and artifacts" (*the Geneva Declaration*).

- There are still colonial remnants left in many countries, there is much distrust regarding priests, doctors, etc. We need to talk about, and rebuild, trust. The stigma is caused by western doctors (by them wanting to isolate people); they cause the stigma, not the communities themselves. *We need to rebuild trust.*

- Diverse cultures and practices need to be considered to create awareness and TB control strategies. Because of these differences, all actors in the process need to appreciate these differences in cultures and practices. Also, there is a need for communities to come up with practices themselves in order to deal with stigma. There needs to be ownership by indigenous communities. Also, research should address that some cultural practices carry risk for these diseases.

- Recognition of identity and practices is key. We need to get people to recognize and apply the UN Declaration on the Rights of Indigenous Peoples. Use of indigenous languages is also important.

- Currently, TB control strategies work better when we take into account each group of Indigenous peoples. There are different ways to organize and we need to consider the existing way that people/communities are organized. There is no dynamic communication and there is lack of respect of communities' organizations. We need to talk to the leaders of indigenous communities as they would be the ones to promote the strategies in their respective areas.

- There is a need to consider personal relationships in terms of the ways communities/individuals interact with each other. Also, we need to consider expectations within Indigenous communities. Any successful response needs to take that into account.

- Health seeking behavior when individuals are ill needs to be examined. Medical versus traditional knowledge and practices also needs to be acknowledged. Cultural styles of learning (visual, graphics, print, written and oral) need to be incorporated into policies and strategies to control TB. A holistic perspective of indigenous health is required. Inclusion of the whole family, across generations and cultures is required. Improvement of sociocultural, economic, and social conditions of our lives, and maintaining our customs is required. Self-governance must be an integral component of planning.

Question 4

(a) Of the key messages we have heard during these two days is there anything else we need to consider within an indigenous context regarding TB control? (b) For example, in terms of indigenous social determinants, the importance of being identified in country level TB surveillance data, etc.

- Discussion of social determinants should incorporate the perspective of the specific indigenous populations. It is important that there is recognition of indigenous peoples in all aspects of society. Some countries do collect data, but they do not use the standard definition of indigenous peoples. Perhaps census data can be better used to get this information (as long as it is used appropriately).

- Make information accessible to Indigenous peoples. Don't just do research *on* indigenous peoples, do research *with* indigenous peoples. Restitution is also important. Indigenous peoples have been robbed since colonial times. Land has been taken away. Indigenous peoples have suffered by the theft/robbery of their resources.

- It is important to get the perception of the population so there is a community approach. It needs to come *from the people*; we cannot impose something

(especially when TB is not always their biggest priority). Capacity building is key especially in terms of training and volunteers. Identification of local leaders and health officials is also required.

- Messaging needs to be framed positively so that it is urgent and constructive. Respecting indigenous peoples' customs and values is important. Determinants (health and social) are known from the scientific perspective but we don't know about the perception of indigenous peoples regarding determinants (they must be taken into account). Not all regions are affected equally by TB. Surveillance and regular analysis to understand critical factors and affected locations is required. We need to be proactive actors and reach out to indigenous peoples.

- Where feasible, collecting information is important regarding co-morbid conditions (e.g. diabetes, end-stage renal disease and HIV). We must learn about the knowledge and cultural values of the indigenous populations, and we must incorporate these into health models.

Question 5

(a) Thinking ahead to next steps how might an Indigenous secretariat serve the interest of the Indigenous populations globally? (b) What type of governance structure might it have? (c) What should its objectives and functions be?

How might an indigenous secretariat serve the interests of the Indigenous population globally?

- Advocacy, communication and social mobilization.
- Resource mobilization.
- As an information coordination function.
- Relationship facilitation between indigenous groups and national TB programs.

What type of governance structure might it have?

- A small group of people who carry out the wishes/requests of a broader steering group who might be formed from people at this current forum.
- There should be some type of selection process.

Objectives and functions

- Information collection and dissemination functions (reports, documents, issues of indigenous peoples worldwide).
- Resource mobilization function.

- Identify appropriate national groups to work with.

Generally a secretariat needs to:

- Provide technical support to country level forums (to link to resource mobilization as well) and help national indigenous groups have a strong voice.

- Three roles could consist of: 1) organization of highlights, conferences, discussion; 2) coordination; 3) and a technical role. Also, advocacy and communication at all levels, especially since in some areas indigenous peoples are not recognized by their government. Therefore, this needs to happen at the national level but also at a more global level.

- Linking local indigenous leaders to national organizations, and then global organizations is required. A Secretariat should address policy change at the global level (e.g. include an indigenous component), and, at the local level, work with governments to create/make sure there are health programs available. A Secretariat should have a balanced approach; top-down and bottom-up (such as lobbying to the WHO level and also working with regional groups).

- *WHO did not participate in the UN process on indigenous peoples so it didn't clearly recognize indigenous peoples. Therefore, the secretariat should recommend this working group to WHO and that they work together.*

- A Secretariat should have a political and a technical role; however, this secretariat must be accountable to other organizations who would attend worldwide meetings. It is necessary to make a distinction between the technical role and those who create policy. These would be representatives from around the world. A Secretariat would work based on input from indigenous peoples. It should be a small group, in order to focus on day to day business and links with other organizations, and work on behalf of indigenous communities.

- Leaders of the secretariat should be someone from the indigenous community. Identifying best practices is also important. Coordination of the implementation of the strategies, collecting and disseminating information, such as a resource center, and extending research strategies is required.

Question 6

(a) In the formation of an indigenous secretariat what key role should it perform in terms of advocacy and communications? (b) Which types of individual(s) should be

considered the spokesperson? (c) What should the key messaging be in an indigenous context?

The types of individuals that should be in the secretariat include indigenous persons who have: political and cultural awareness, resource mobilization abilities and excellent communication skills. Key messaging must encompass:

- Use of existing structures, including regional Stop TB partnerships, is important. Senior leadership should be someone from the indigenous community. There should be a process to select such a leader. We need to be able to identify people from around the world who can speak on behalf of their communities and indigenous peoples overall. There should be not just one spokesperson but several should be involved. There should be a call for these positions.

- A collective approach is important. We need to look at this meeting to see how many different people/groups participated. The role of the secretariat should be to identify these people and then ensure capacity building happens.

- Different skills may be needed depending on the different tasks at hand. Political representatives from indigenous communities should be solicited. They may be health experts as well. There needs to be a cascade effect with someone at the national level that represents indigenous groups, that links to the working group and which links to the secretariat. There needs to be a focal point for international TB networks. It will be important to create linkages for all TB indigenous stakeholders.

- The goals of the secretariat should be to function as a focal point to exchange share/information on best practices, to conduct advocacy activities and to engage donors and finance projects. Also, to unite the global cause of TB control and engage governments to assist the indigenous TB cause and facilitate evidence based interventions and policy.

- The Secretariat could also function as a parallel and integrated structure, integrated with the Stop TB partnership but with a parallel indigenous stream and with ***separate governance.***

Objectives and functions of the Secretariat should:

- To get the world thinking about TB as a global pandemic and about how indigenous communities are most vulnerable. A strategy is required to address this. The Secretariat needs to be careful not to focus on just medicalization. TB is a social issue and it is critical to keep that as one of the main goals for the Secretariat.

- Disaggregation of indigenous data is required. We need to ensure an indigenous social determinants focus. As a body it could be coordinated to get at men, women, children issues and look at gender pieces. It is a good argument for having at the UN Permanent Forum on Indigenous Issues.

- The Secretariat will need to monitor and show change over time. This is another important function. Communities are looking for interventions. Report carding is a key advocacy and monitoring function that the Secretariat could undertake.

Communications

- Tuberculosis has always been there. A global pandemic paradigm needs to be emphasized. We are all collectively a part of this. If TB is left untreated indigenous peoples will become even more vulnerable. We need to consider social conditions which render them more vulnerable. It is a threat to the greater community.

General Discussion Points:

- Taking the TB issue to get a broader discussion on indigenous issues is important, as well as, linking the secretariat to other covenants or treaties. Looking at other partnerships, for example the Gates Foundation, Global Fund, GAVI, etc. is essential. It is important to engage donors. Advocacy could be a goal. Creating a global network parallel with a Global TB strategy is also required.

Final Summary Recommendation

- Start with a body within the UN Permanent Forum on Indigenous Issues and utilize that to strengthen a global indigenous health network. For example, TB control can be the conduit to start the global health indigenous network.

Question 7

(a) How can the UN Permanent Forum on Indigenous Issues provide support with respect to the outcomes of this meeting? (b) What should the roles and activities be of the STOP TB Partnership with respect to the outcomes of this meeting?

The supports of the UNPFII are envisioned as:

- Communication is important. We need to know who they (the UNPFII) are and how they can help us move forward. We need to encourage member states to create a platform for engagement with indigenous peoples and enable the expression of a political voice and implement national mechanisms for engagement with the Stop TB Partnership.

The UNPFII proposed roles and how the UNPFII can provide support:

- Encourage it's (the UNPFII) member organizations to work with the Stop TB Partnership. Demand that social determinants be addressed in order to make indigenous people less vulnerable to TB. Track the UNPFII Indigenous TB trends annually.

- The UNPFII Forum should recommend that UN agency funds and programs engage more actively with the Stop TB partnership to address TB among indigenous peoples especially at the country level. The UNPFII should come up with policies governing /protecting indigenous peoples.

The STOP TB Partnership role:

- Must include an indigenous specific strategy which has been driven and arisen from the community level. It is recommended that the indigenous burden of TB be acknowledged (and adhered to) and that Indigenous groups be encouraged to join the stop TB partnership globally and nationally. Also, that the partnership support the establishment of a secretariat to develop messages, interventions and track trends.

- There is a disconnect between groups that have the mandate to help, and what is happening at the community level. This needs to be addressed. We should set up a process to ensure indigenous peoples input and to encourage member organizations to work with the Stop TB partnership.

- The Partnership needs to demand social determinants be addressed to make indigenous people less vulnerable and to encourage members states to create a platform (to implement the national mechanisms) for engagement with Indigenous peoples on TB control and enable the expression of the Indigenous political voice. The Stop TB partnership (Secretariat based in the WHO) needs to ensure proposals are required to include the indigenous component.

Question 8

How do we use the information we heard during this meeting to better inform and address the socioeconomic determinants of tuberculosis and enhance the focus on TB

in an Indigenous context on global non-health agendas e.g. human rights, poverty, housing, etc?

- Poverty and housing must be linked to TB control. There is no funding for social determinants programs. We need to join the partnership to bring the issue of TB control forward. There needs to be more political attention and inclusion of key decision makers. There is a need for a call for action. We need to have governments that can be held accountable.

- Inter-sectoral action is required to address social determinants. "Local action *without national action* will succeed. National action *without local action* won't."

- That the Stop TB partnership should take an early opportunity to reflect on its engagement with, and contribution to, the eradication of TB in Indigenous communities. The partnership should undertake a review of its operation and acknowledge this meeting with a commitment to funding and to empower its contribution to the important objectives of TB control in an indigenous context.

- The UNPFII, UN agencies including the WHO and the Global Stop TB partnership need to demand that social determinants be addressed to make indigenous peoples less vulnerable to TB. Discussion is required on the lack of, and urgent

- Need, for political will and politicization of the issue of TB control.

In summary, the following framework has been developed based on the breakout group input outlined herein. Where possible the framework acknowledges and highlights the global characteristics of the undertaking. This document is the expression of the ideas, experiences, wisdom and inspiration of the indigenous experts in attendance. This framework is proposed as follows:

Next Steps

Meeting delegates passed two resolutions on day two of the *Global Indigenous Expert Stop TB Expert meeting.*

Resolution 1
Moved by Regional Chief Wilton Littlechild.
Seconded by Dr. Ann Fanning.
And approved by consensus.

It is hereby resolved that an action plan will be submitted to the UNPFII on health at the next forum meeting and that a side event be planned on the topic of Indigenous TB control as part of the Stop TB partnership.

Resolution 2
Moved by Regional Chief Wilton Littlechild.
Seconded by Hassan Idbalkassm.
And approved by consensus.

It is hereby resolved that the Stop TB Partnership Meeting scheduled for March 2009 in Brazil recommend a specific reference to the Global Indigenous Stop TB Experts meeting report and outcomes on the Brazil agenda.

Further action required as an outcome of this meeting is the development of an Indigenous Declaration on Health to address tuberculosis control and that the human right to health be addressed within this context.

We are partners in the problems and solutions. It is our responsibility to work together to make this world a better place. A place free of TB and where our indigenous peoples can flourish individually, as families, communities and nations. We are truly brothers and sisters in this global effort to eradicate TB and we must walk hand and hand together so that our children will have a brighter healthier future.

Appendix A Summary Program

NOVEMBER 12TH EVENING WELCOMING RECEPTION
Opening Ceremonies: Remarks by Regional Chief Angus Toulouse, Canada, Traditional Opening Ceremonies

DAY ONE: Thursday November 13, 2008
WELCOME AND OPENING REMARKS
National Chief Phil Fontaine – Assembly of First Nations
Ms. Gail Turner for President Mary Simon – Inuit Tapiriit Kanatami
President Clément Chartier, Métis National Council
Ms. Anne Marie Robinson - Assistant Deputy Minister, Health Canada

Global Indigenous Populations – Who are They and Where are they? And The Importance of Social Determinates in Their Health
Dr. Manuel Carballo – Executive Director, International Centre for Migration and Health

The WHO Stop TB Partnership: Targets, Trends, Challenges and Impediments.
Dr. Marcos Espinal Fuentes – Executive Secretary of the Stop TB Partnership - WHO

Examples of Tuberculosis Control in Latin America
Dr. Mirtha Del Granado – Pan America Health Organization

The Importance of TB Surveillance
Dr. Eugene McCray – National Centre for Disease Control and Prevention, Atlanta, Georgia,
Dr. Marcos Espinal - The Stop TB Partnership - World Health Organization

Luncheon Speaker: Dr. David Butler-Jones, Chief Public Health Officer of Canada

PANEL: Asia/Pacific and African Indigenous Stories
Chairperson – Ms. Paimaneh Hasteh – (Iran) UNPFII Member
Mr. Tshering Lama – (Nepal)
Dr. Nandakumar Menon –Ashwini (India)

PANEL: Tuberculosis Control Success Stories
Chairperson – Ms. Margaret Lokawua (Uganda) UNPFII Member
Dr. André Corriveau, (Canada)
Dr. Jiang Shiwen, (China)

PANEL: Tuberculosis and Poverty – A Right to Health?
Chairperson - Ms. Soipan Tuya, Maasai tribe, Kenya, Global Indigenous Women's Caucus
Members of the Stop TB Partnership's TB and Poverty Sub-group – World Health Organization,
Dr. Gillian Mann, Dr. Pervaiz Tufail and Dr. Delia Boccia

The FIDELIS Experience – An Example of an Approach to Community-Based Interventions In Controlling TB
Dr. Don Enarson, International Union Against Tuberculosis and Lung Disease

PANEL: Best Practices and Challenges for TB Control
Chairperson – Ms. Elisa Canqui Mollo (Bolivia), UNPFII Member
Ms. Roxana Linares Cáseres - (Bolivia)
Chief Alex James Robinson – (Canada)

Dr. Larisa Abryutina – (Russia)

WRAP UP AND SUMMARY OF DAY ONE:

TRADITIONAL EVENING DINNER AND RECEPTION

Hosted by AFN Regional Chief Wilton Littlechild (Canada)
Keynote address by Professor Ian Anderson, University of Melbourne, (Australia)
Cultural Performers

DAY TWO Friday November 14, 2008
RECAP OF DAY ONE AND OVERVIEW OF CONTEXT PAPER

BREAKOUT SESSION ONE – Questions # 1-4

1. In order to make the case for a unique strategy for indigenous populations globally, what is required to promote indigenous specific approaches and methodologies for tuberculosis control? Why is an indigenous specific approach required?
2. In order to develop strong partnerships to control TB in an indigenous context who do we need to include in the development of stronger relationships at the in-country, regional and global level? How could these linkages be facilitated and strengthened between indigenous groups and in-country TB programs?
3. What culturally appropriate factors need to be taken into consideration when developing strategies to raise awareness and reduce stigma regarding TB control in an indigenous context?
4. Of the key messages we have heard during these two days is there anything else we need to consider within an indigenous context regarding TB control? For example, in terms of indigenous social determinants, the importance of being identified in country level TB surveillance data, etc.

Breakout Session Facilitators Report Back on First Four Questions

BREAKOUT SESSION TWO Questions # 5

5. Thinking ahead to next steps how might an Indigenous secretariat serve the interest of the Indigenous populations globally? What type of governance structure might it have? What should its objectives and functions be?
6. In the formation of an indigenous secretariat what key role should it perform in terms of advocacy and communications? Which types of individual(s) should be considered the spokesperson? What should the key messaging be in an indigenous context?
7. How can the UN Permanent Forum on Indigenous Issues provide support with respect to the outcomes of this meeting? What should the roles and activities be of the STOP TB Partnership with respect to the outcomes of this meeting?
8. How do we use the information we heard during this meeting to better inform and address the socioeconomic determinants of tuberculosis and enhance the focus on TB in an Indigenous context on global non-health agendas e.g. human rights, poverty, housing, etc..

Breakout sessions - Report back – next four questions

WRAP UP AND NEXT STEPS

CLOSING REMARKS

Alberta - Regional Chief Willie Littlechild (Canada)
President, Gail Turner, ITK

CLOSING PRAYER

Appendix B Evaluation Summary

#	Question	Rating 1 Poor	Rating 2	Rating 3	Rating 4	Rating 5 Excellent
1	The overall organization and structure of this meeting was	0	0	3	14	23
2	Contributions of the presenters were	0	0	6	17	15
3	The information and ideas presented in the presentations were	0	0	7	19	12
4	The materials provided in your meeting kits were:	0	0	8	22	9
5	All things considered the information presented and format for discussion on the global action plan to stop TB was	0	0	4	15	20

#	Question	Just right	Too short	Too long
6	The length of this meeting was	17	21	0

#	Question	Summary of responses
7	What did you like the BEST about this meeting?	Indigenous peoples participation; presentations from other countries; very good organization; organizational skills of the lead facilitator; the opportunity to experience the diversity of thoughts and beliefs; experts' presentations; the cultural events on Thursday evening; the experiences and ideas from indigenous presenters; the breakout discussions were particularly interesting; the excellent discussions during the breakout sessions due to active engagement with indigenous people during the discussions; the goal of developing a framework for indigenous populations TB control and action plan; to get to know other realities around the globe; the diversity of participants; the open environment in the group discussions for us to express our feelings; the exchange of views and experiences from different people from different places; information sharing and talking about a plan of action; the quality of the people; the elders; the diversity of expertise (medical and technical).
8	What did you like the LEAST about this meeting?	Too much discussion about things already known and not on solutions; too Canada focused in break-outs; the exclusion of many indigenous groups (e.g. Pacific Island Nations); not enough time for discussions following presentations; the pace; the terminology.
9	If you end up remembering only one thing about this meeting what will it probably be?	The prayers on the first day and the talk by Chief Robinson (he is quiet and great); the presentation from Nepal; excellent organization; the only major initiative to address TB among the disadvantage people of the world; the fact that indigenous TB has been part of the global agenda; the meeting was informative; the focus on the child and family; commitment of participants to address social determinants of health*; local* solutions for *local* problems; the relation between TB and social determinants among indigenous populations; the personal connections and building of an international team; diversity of participation and similarity of spirit; most of the indigenous people of the world have the same problems with TB as a disease and in terms of soci-economics; the fact that poverty has been identified as a contributing factor to TB among indigenous communities; the different aboriginal groups that spoke out in *one voice*; that indigenous populations exist - that TB exists and we should consider both when making decisions; "*yes we can*"; exchanging experiences/lessons/challenges with colleagues and friends from around the world; that TB is curable and fairly inexpensive to treat – this is very empowering information; social determinants and how we should address them; social

#	Question	Summary of responses
		determinants need to be addressed – especially housing and food security – in order to address TB; to be grateful; the results that will come; many people making sure that indigenous voices were heard; that there is a global indigenous peoples' unity; poverty has many faces; indigenous people need a special set of initiatives.
10	Additional comments and suggestions	This should not be just another meeting but one which will be actioned to the benefit of the intended purpose; for the secretariat to be meaningful it should strive to be evidence based in order to be respected by governments and communities; resolutions for actions should come out of this meeting; the action plan; the most important thing about the meeting is that indigenous people were present and related their experiences and feelings; let the people determine their own path; the goals to stop TB can be achieved only if indigenous people are engaged from the outset.

Appendix C Breakout Group Allocation

Group 1	Group 2	Group 3	Group 4
Gillian Mann	Jonathan Thompson	Shannon McDonald	Gail Turner
Michael Riggs	Jan Hatchet Roberts	Rosemary Ramsingh	Tracy O'Hearn
Mirtha Del Granado	Peter Steenkamp	Don Enarson	Solonka Nomback
Willie Littlechild	Ida Lamaigne	Kim Barker	Sharon Peake
Hassan Id Balkassm	Gary Aslanyan	Christine Dendys	Anne Fanning
Jean Marie Caron	Andre Corriveau	Jeremiah Shikulu	Onalee Randell
Tshering Lama	April McNaughton	Manual Carballo	Lorne Clearsky
Spoipan Tuya	Meghan McKenna	Elis Canqui Mollo	James Cheek
Miriam Nogeles	Ian Anderson	John Redd	Isaac Sobol
Winston Zulu	Karin Lagefoged	Alan Parkinson	Paulin Tuya
Jian Schwen	Julius Tome	Delia Boccia	Juan Nunes
Teresa Mersereau	Elsa Zerbini	Nandakumar Menon	Bang Wang
Larisa Abryutina	Pam Orr	Dawn Walker	Paimaneh Hastaie
Rima Platnonova	Elizabeth Ford	Boothran Shreetharan	Olga Heinrich
Julio Ramos	Regi George	Selma Ford	Miriam Angain
Joselo Durbano Tayo	John O'Neil	Nora Sobolov	Shane Houston
Goreto Pianissolla	Achmat Jacobs	Richard Sitonik	Anne Kaciulis
Eugene McCray	Maria Roxos	Healther Gilford	Alex Robinson
Anastasios Konstantinos	Nadine Girouard	Malcom King	Anne Marie Ramanye
David Tunubala	Lori Murphy	Jeremiah Shikulo	Matewiki Karechana
Carolos Condori	Eric Martel	Elain Minoose	
Roxana Caseres	Andrea Saunderson		
Flavio Nunes			

APPENDIX D PRESS RELEASES

Indigenous leaders call for action to reduce illness and death from tuberculosis

November 13, 2008 – Toronto, Canada – During the 5 year period 2002-2006, the First Nations tuberculosis rate (on and off reserve) was 29 times higher than among the non-aboriginal population born in Canada. For the Inuit, it was 90 times higher. Pacific Islanders and Maoris are at least 10 times more likely to contract tuberculosis (TB) than other people living in New Zealand. The Indigenous people of Kalaallit Nunaat (Greenland) are 45 times more likely to get active tuberculosis than Danish-born residents.

Across the globe Indigenous peoples are at exceptionally high risk of becoming ill with tuberculosis and dying from the disease. Today, for the first time, public health experts and Indigenous leaders from 60 countries began to carve out a plan to reduce the incidence of tuberculosis among Indigenous peoples by 2015, at a meeting co-hosted by the Assembly of First Nations and the Inuit Tapiriit Kanatami.

"Indigenous peoples are at special risk of TB because of the conditions under which many live – in poor housing and with lack of access to health services. They also face cultural barriers and language differences that limit their access to TB prevention and treatment," said Dr Marcos Espinal, Executive Secretary of the Stop TB Partnership. "Without reaching these disadvantaged groups, we will not attain the targets of the Global Plan to Stop TB."

"Many of the factors that allow tuberculosis to persist among Indigenous peoples around the world are similar to the challenges First Nations face in Canada. For example, one in five First Nations adults cannot access a doctor or nurse. Clearly, we need to improve access to healthcare," said National Chief Phil Fontaine. "However, lasting solutions must also address the social determinants of health such as housing and nutrition. In turn, employment opportunities and wealth are created which are key to creating healthy people and sustainable communities."

"The fact that the tuberculosis rates in Inuit communities are 90 times higher than for all Canadians is unacceptable. A lack of adequate housing, and overcrowding are contributing to this rate, and until we have addressed these and other determinants of health, the situation will not improve. We have a tragic history when it comes to tuberculosis, and unfortunately for many Inuit communities, it continues to be today's reality," said national Inuit leader Mary Simon.

There were more than 9 million new cases of tuberculosis worldwide in 2006, and some 1.7 million people around the world died from the disease—even though it is curable and the drugs needed to treat it are inexpensive and widely available. The vast majority of tuberculosis cases and deaths occur in low and medium-income countries and among disadvantaged people.

There are 370 million Indigenous people worldwide living in more than 70 countries. There are no firm global estimates for tuberculosis incidence in these populations, but evidence from targeted studies, such as among the Maori of New Zealand and aboriginal peoples in Canada, strongly suggest a high rate of tuberculosis among Indigenous groups living under similar conditions.

The meeting today was the follow-up to a session at the United Nations Permanent Forum on Indigenous Issues in April, which called for the development of a specific Indigenous-led initiative on TB to collaborate with the Stop TB Partnership.

***Note to Editors**

The Stop TB Partnership, which is hosted by the World Health Organization in Geneva, Switzerland, consists of more then 700 international organizations, countries, donors from the public and private sectors, and nongovernmental and governmental organizations that are working together to eliminate TB. The Partnership's Global Plan to Stop TB (2006-2015) sets forth a roadmap for halving TB prevalence and deaths compared with 1990 levels by 2015.

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