

KEY POPULATIONS BRIEF



INDIGENOUS PEOPLES



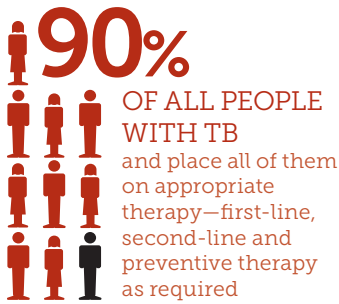
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he world's 370 million indigenous peoples face a plethora of issues caused by displacement, dispossession, loss of livelihood, systematic racism and abuse, and lack of recognition (1–4). Further hindering an adequate response to these challenges, there is a pervasive lack of data about indigenous peoples concerning health and other key development indicators. Data that are available show a prevalence of extreme poverty and severe health disparities that include tuberculosis (TB). Data further indicate that indigenous peoples universally experience higher TB burdens than their non-indigenous counterparts and struggle with access to services due to remote location, severe discrimination, and lack of health programming that can accommodate their non-Western views of health and well-being (4–7). Multiple structural barriers must be eliminated, and TB programmes should include indigenous peoples at all stages of design and implementation in order to be effective.

Global Plan to End TB and key populations

The Global Plan to End TB outlines the following targets to be achieved by 2020, or 2025 at the latest. The Plan refers to people who are vulnerable, underserved or at risk as TB “key populations” and provides models for investment packages that will enable different countries to achieve the 90-(90)-90 targets. The Plan also suggests that all countries:

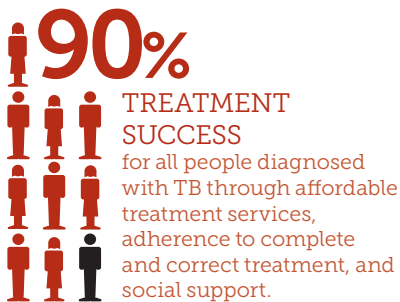
Reach at least



As a part of this approach, reach at least



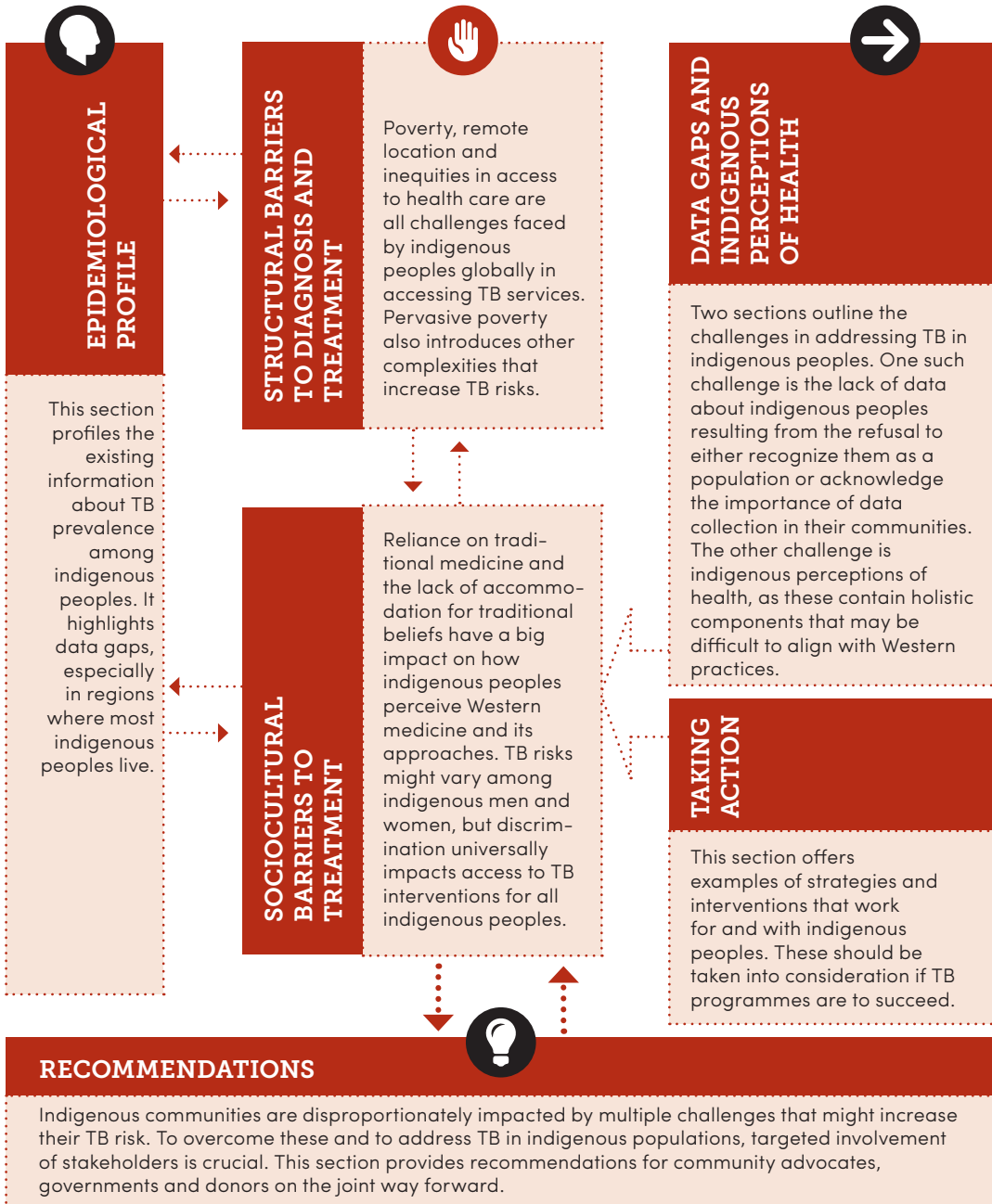
Achieve at least



- Identify their key populations at national and subnational levels according to estimates of the risks faced, population size, and particular barriers, including human rights and gender-related barriers, to accessing TB care;
- Set an operational target of reaching at least 90% of people in key populations through improved access to services, rights-based systematic screening where required, and new case finding methods, and providing effective and affordable treatment to all people in need;
- Report on their progress with respect to TB using data that are disaggregated by key population;
- Ensure the active participation of key populations in the development and delivery of services and the provision of TB care in safe and respectful environments.

This Guide utilizes the above recommendations to discuss data gaps and structural and sociocultural barriers to access as well as reviews local-level solutions for indigenous peoples with TB.

What's in this guide?





Epidemiological profile

According to estimates, the world's 370 million indigenous peoples reside in 90 countries (1). These populations are among the world's most marginalized, and they are further isolated politically and socially by the geographical location of their communities, their culture, language and traditions (4). Indigenous peoples are also among the world's poorest (4). This extreme poverty stems from multiple factors, including lack of access to education (8), forced displacement, loss of lands and resources, armed conflict, and the degradation of indigenous sociopolitical structures (1,3). Poverty and marginalization have served to establish a substantial gap in the achievement of multiple rights, including the right to health. Indigenous peoples across the world present with some of the worst health indicators: high rates of diabetes, dire rates of infant mortality, dramatically lower life expectancy and growing rates of chronic disease, among others (9).

Tuberculosis is no exception. A comprehensive review of the literature conducted in 2013 indicated that there is a significantly higher TB burden among indigenous peoples in settings where information about them is available (5). The majority of articles included in the review were from Australia, Canada, New Zealand and the United States. In these developed settings, the highest TB incidence has been identified among indigenous peoples in Canada, where TB incidence in one group was found to be 150 times that of non-aboriginals born in Canada – a finding also confirmed by recent surveillance (10).

Lack of data is characteristic of indigenous populations everywhere, as is evident in the scarcity of studies on TB among indigenous groups from the rest of the world (3–5). The literature review revealed a particular dearth of information from Africa, where an estimated 14.2 million indigenous peoples reside, and from

Asia, where more than three quarters of the world's indigenous peoples live (2,5). Available research from India has shown a higher TB burden among tribal than among non-tribal populations. Evidence from the two available studies in Africa indicates that the TB prevalence might be significantly higher among the continent's indigenous peoples (5). About 8% of the population of Latin America and the Caribbean is indigenous. Available information from this region suggests that the situation with TB among indigenous peoples is dire. TB incidence among Brazilian Amazonian groups is at least 20 times higher than among the general population in Brazil (11,12). In Paraguay, an indigenous group has reported TB incidence 75 times greater than the national incidence (13).





Figs. 1 and 2. Select comparative prevalence and incidence rates demonstrating the significantly higher prevalence and incidence of TB among indigenous populations in all settings (Numbers taken from: Tollefson D, Bloss E, Fanning A, Redd JT, Barker K, McCray E. Burden of tuberculosis in indigenous peoples globally: a systematic review. *Int J Tuberc Lung Dis.* 2013;17(9):1139–50)

Fig. 1 Prevalence Ratio (indigenous/comparative)

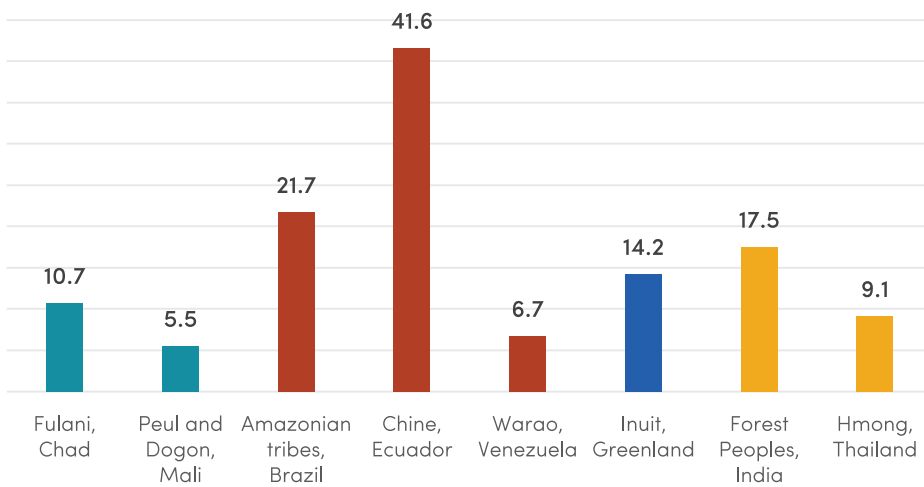
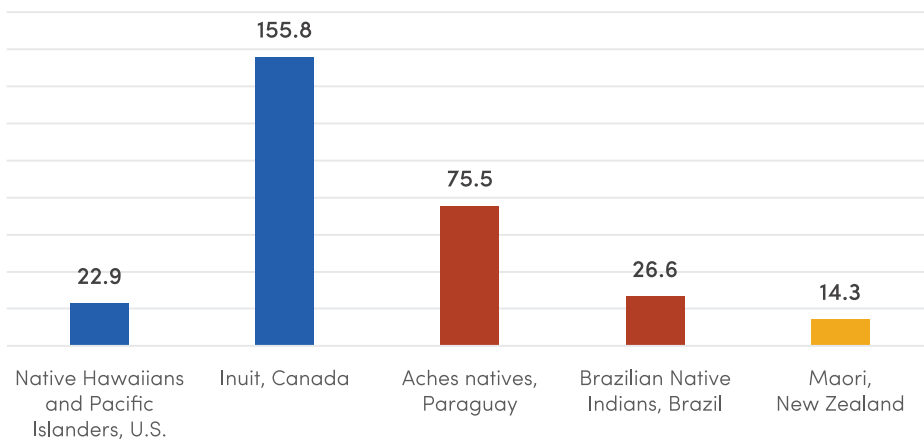


Fig. 2 Incidence Ratio (indigenous/comparative)





The numbers presented in Figs. 1 and 2 reflect the systematic neglect indigenous peoples have experienced globally in terms of their health. To bridge the existing gaps, radical changes must be made. These changes could begin by accounting for indigenous peoples and addressing the need for a shift in how the concept of health is defined, so as to better accommodate the indigenous worldviews. However, these changes must be focused enough to account for remoteness, language barriers and social determinants of health, such as poverty and human rights violations that include discrimination and denial of care (14). Relationships between indigenous groups and governments should also be built and re-built, as tensions stemming from years of neglect and oppression may have resulted in indigenous people's lack of trust in the governments and systems of the dominant culture.

Lastly, it is crucial to recognize and respect the resilience that indigenous peoples have demonstrated in the face of severe adversity – a resilience that has allowed them to preserve their indigenous identity (15). Building on this resilience requires the targeted involvement of indigenous peoples and capacity building for indigenous organizations to design and promote health and other interventions.





Identifying and recognizing indigenous peoples and bridging the data gap

Considering the extensive diversity of indigenous peoples, the United Nations (UN) has not adopted an official definition of “indigenous.” Instead, the UN system has developed the following criteria to provide for an inclusive and modern understanding of indigenous peoples (16,17). According to these criteria, indigenous peoples:

- Self-identify as indigenous at the individual level and are accepted by the community as indigenous;
- Demonstrate historical continuity with pre-colonial and/or pre-settler societies;
- Have a strong link to territories and surrounding natural resources;
- Have distinct social, economic or political systems;
- Have a distinct language, culture and beliefs;
- Form a non-dominant group of society;
- Resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.





The UN Permanent Forum on Indigenous Issues also promotes the idea of “identifying” over the idea of “defining” indigenous peoples. This approach is related to the principle of self-identification that is outlined in multiple human rights documents. Focusing on identity is able to account for the diversity of indigenous peoples, how they are identified and how they identify themselves across the globe.

Despite efforts to respect indigenous identities at the global level, the systematic marginalization and isolation of indigenous peoples continues at the local level. Furthermore, at the national level, indigenous groups might not be recognized as such by national governments (3,18). In some settings, this lack of recognition is the result of disputes over land and natural resources, wherein the recognition of peoples would imply the need to recognize land ownership (3,18). In other settings, political processes such as post-conflict reconciliation have resulted in the refusal to recognize indigenous or other minority groups (3). Almost universally, however, ignoring the need to recognize or refusing to recognize indigenous peoples is the result of a long-standing conflict between governments and indigenous groups, whose rights have been continuously violated as they have been displaced, mistreated and variously disenfranchised from mainstream sociopolitical processes (3,18). In some settings, indigenous peoples might lack citizenship due to conflict around displacement or for other sociopolitical reasons; in others, indigenous children lack access to formal registration processes at birth (3,19).

This absence of recognition and registration, combined with systematic marginalization, racism and isolation, has resulted in a lack of data. Even in settings where indigenous groups are recognized, these groups’ remote location and the fact that their needs might not be prioritized

has led to meager data collection efforts (4). Least is known about regions where estimates of indigenous populations are the largest: Africa, China, South Asia and the former Soviet Union (7). Along with exclusion, competing priorities, lack of infrastructure and other factors are to blame for this lack of data. Solutions do exist, but these are a matter of advocacy and political will. For example, at present, the Demographic Health Survey programme – one of the largest globally collecting health data in Africa and Asia – does not collect data on respondents’ self-reported ethnicity in all of the countries in which it operates. In some countries, surveys might skip certain hard-to-reach areas where indigenous peoples live, thereby excluding crucial information about their health status (4). Decision-making on how to conduct these surveys is made at the national level with guidance from international stakeholders; the need for data on indigenous populations must be considered in designing the surveys. The lack of data not only limits the knowledge on the health of indigenous peoples, but also makes them invisible and excluded from national priority setting and policy making (7).



Indigenous perceptions of health

While it is crucial to address the social determinants of health (e.g., poverty, access to education, racism and discrimination) in order to ensure equitable access to health services, it is also essential to understand the indigenous concept of health in order to design effective interventions that address health disparities such as with TB. Indigenous peoples perceive health and healing in ways that differ from Western perceptions. As such, Western diagnostic modalities, germ-based theory and treatment regimens may not apply. Instead, indigenous peoples connect health and illness to a collective well-being of body and mind, behaviour, relationship with ancestors, community, land and nature. For example, Maori people in New Zealand view health as something that extends beyond physical well-being and depends on a balance between four elements: the spiritual realm, the realm of thoughts and feelings, the body or physical realm, and family (20). First Nations peoples in Canada similarly believe in multiple dimensions of health: physical, emotional, mental and spiritual (21). Only when all of these are in balance is the individual considered “healthy.” In addition, this balance must be maintained with others, the community and the world of spirits (21). Land and connectedness to the land often plays an important part in indigenous perceptions of health (21,22). In some indigenous cultures, the concept of health encompasses the values of balance, doing the right thing, and working without expecting reward (23). As these values serve to protect the health of entire families and communities, health becomes a collective endeavour (23). Similar understanding exists among indigenous African groups, where the concepts of living according to norms and not violating certain taboos maintain the health of communities (24). This holistic view of health makes certain Western interventions incompatible with the needs of indigenous communities,

and further strides must be made in designing health programmes guided by input from indigenous peoples. Such input must be community-specific. While holistic views are common to all indigenous groups, understanding the nuances can be crucial to the effectiveness of the intervention. In approaching indigenous groups, it is also important to recognize that the holistic worldview that is common among them is what has largely contributed to their resilience and survival in the face of severe adversity (15). Thus, understanding this worldview is crucial to engaging with indigenous peoples in order to develop effective programming.





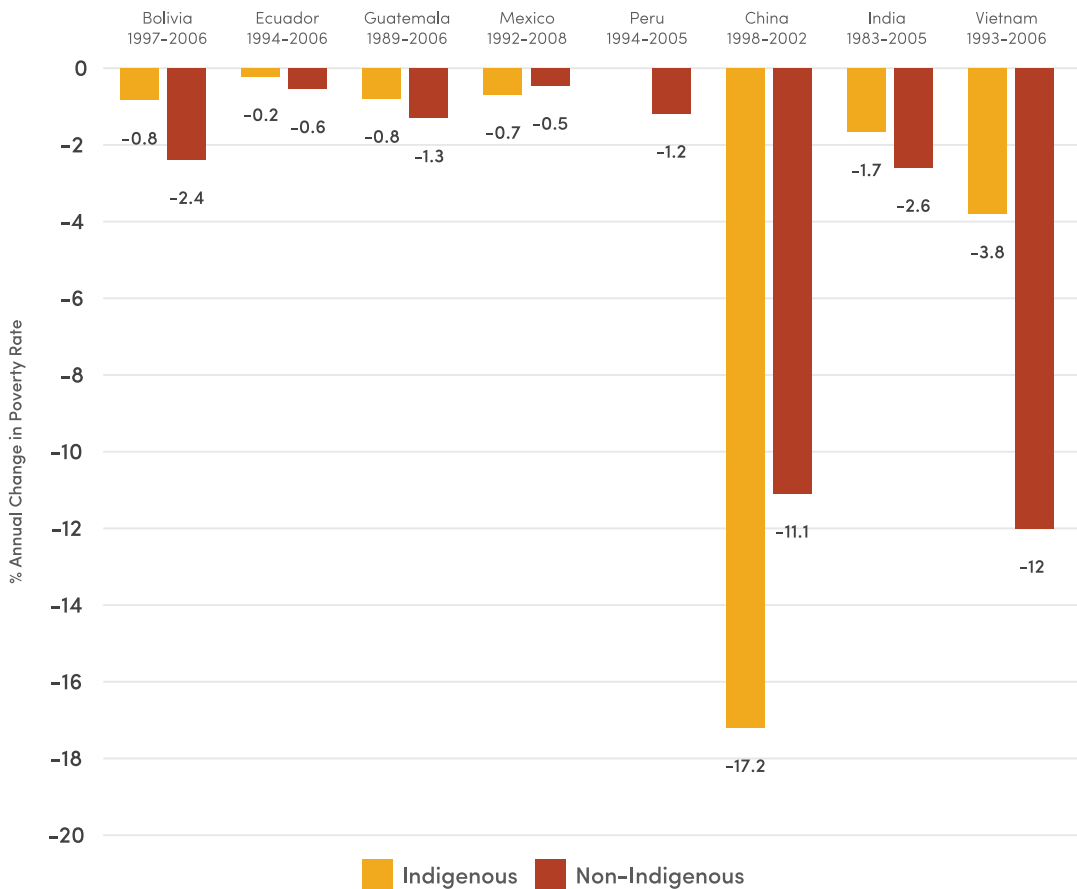
Structural barriers to diagnosis and treatment

Poverty and socioeconomic disparity

Indigenous peoples represent 5% of the world's population, but 15% of the world's poor and about one third of the world's 900 million extremely poor rural people (25). In India, the poverty rate for indigenous groups is twice that

of non-indigenous populations (26). In Mexico, poverty among indigenous groups is twice as high as in the main population (27), and similar rates have been observed in other Latin American settings (28).

Fig. 3 Annual Rate of Change in Poverty: Indigenous vs. Non-Indigenous (29)



Despite progress in many developing countries in terms of education and health, indigenous peoples are far worse off than non-indigenous populations in these settings with respect to all important socioeconomic and human development indicators (28). In most countries, poverty rates are far higher among indigenous peoples than among non-indigenous populations; even in developed nations, indigenous peoples lag far behind in most indicators of well-being (28). This poverty is deeply rooted in displacement, loss of lands, loss of livelihood, marginalization and lack of access to opportunity (3,28). Education attainment is still universally lower among indigenous peoples compared to mainstream populations (8,30). Education enrolment, retention, completion and performance all suffer for a variety of reasons, including geographic isolation, stigma and discrimination, language and cultural barriers (8). Poverty, lack of resources and lack of access to education all have a significant impact on access to health care, including access to TB management. This is reflected, on the one hand, in the inability to access diagnostics and treatment, and on the other in the lack of indigenous health workers who can help connect Western medicine paradigms to indigenous concepts (7). Poverty among indigenous groups also leads to other TB risks, such as malnutrition, crowded living conditions, and other comorbidities (4,31,32). Malnutrition has been relatively well studied in indigenous peoples. The research has shown that malnutrition is as much a result of poverty as it is of environmental degradation and loss of access to the ecosystems and lands where indigenous peoples have traditionally lived and procured food. Malnutrition manifests differently across settings: In some, it impacts maternal and infant health and child development; in others, it causes diabetes, obesity and other non-communicable diseases (4,14). All are factors that constitute a TB risk.

Remote location and inability to access health facilities

Indigenous peoples may be a minority in a national population, but often comprise the majority of people residing in rural regions and remote areas. In Latin America, 40–60% of indigenous peoples reside in rural and remote locations (28). In Australia, 25% of indigenous peoples live in remote areas, and only 32% live in urban centres, as compared to 2% and 70% of non-indigenous populations, respectively (33). Rural and remote locations pose serious challenges in access to TB diagnosis and treatment services. As outlined in the Stop TB Rural Populations Brief (34), these challenges include distance to health facilities, cost of travel, and understaffing at rural clinics. These challenges might be even more extreme for indigenous peoples. In a study among Ashaninka people in the Peruvian Amazon, sputum samples collected from indigenous patients in the underserved Amazon region were only transported to the reference laboratory once a month. This rendered some of the collected samples useless, as they had to wait several weeks to a month for analysis (35). Another study, also in the Peruvian Amazon, noted that prior to attending the mobile clinic used in the study intervention, 38.5% of the surveyed indigenous population had never consulted a doctor and 57% had been unable to seek medical care because of lack of money and the need to travel long distances to a facility (36). In a Canadian study, remote and semi-isolated First Nations communities had 3–4 times the TB incidence rate of non-isolated communities (31); this finding clearly demonstrates the impact of remote location on TB spread.



Inequities in accessing health care

Systematic racism and discrimination, lack of registration/citizenship, and the inability to access health insurance or receive key primary care services all impact how indigenous peoples view the same health care system that can deliver more complex interventions for TB and other diseases (37–39). Together these factors comprise a complex problem of inequity in health care access that must be resolved if interventions addressing TB among indigenous groups are to be effective.



Sociocultural barriers to treatment

Alternative health care and culturally sensitive services

The right of indigenous peoples to “traditional medicines and [maintaining] their health practices, including the conservation of their vital medicinal plants, animals and minerals” is clearly outlined in Article 24 of the UN Declaration on the Rights of Indigenous Peoples (40). This right, along with the contribution of traditional medicine to the well-being of indigenous peoples, cannot be undermined. Traditional healers might be more accessible in areas where indigenous peoples live and more affordable in terms of cost of travel, costs of interventions, and the use of traditional herbs that are free (4,41). Some studies have shown that the involvement of traditional healers or herbalists delays access to formal TB diagnosis and treatment initiation (42–45); however, others have found no impact on diagnostic delay and TB treatment in populations relying on traditional healers (46). Additional evidence has shown that indigenous peoples can successfully balance traditional interventions and formal TB treatment (35); furthermore, supportive TB treatment delivered by traditional healers can positively influence both treatment outcomes and other aspects of the treatment experience (47,48). Moreover, traditional healers are notably knowledgeable about their limitations, able to recognize TB symptoms, and agreeable to collaborating with national TB programmes (47–49). Collaboration between traditional healers and national TB programmes should be encouraged in order to boost diagnosis and treatment among indigenous populations. This is particularly important as the formal health systems are ill-equipped to serve indigenous peoples. Although efforts have been expanded to bring mobile clinics to remote locations where indigenous peoples reside, staff at these clinics may not speak the language of the people they are serving. Such a limitation makes these inter-

ventions costly and futile (4). A study analysing factors that improve access to primary health care among indigenous populations highlighted the need for culturally sensitive programming that includes collaboration with traditional healers and a staff that is respectful of community values and knowledgeable in its traditions and language (37). Thus, indigenous-run and indigenous-staffed care, or at minimum care informed by the indigenous communities themselves, is necessary to overcome the current disparities in TB diagnosis and treatment.

Discrimination and lack of trust in formal health systems

Discrimination against indigenous populations is widespread, blocking access to health and TB treatment services on multiple levels. In some settings, the remote areas where indigenous peoples live do not have health facilities. This forces them to seek care in other communities, where they might face discrimination (50). Fear of this discrimination that begins outside the doors of health facilities might be preventing indigenous peoples from seeking care. Once within health facilities, discrimination is widespread and well documented. Health practitioners may ignore or display indifference to indigenous patients; lie to them about the costs of medications or needed prescriptions; misdiagnose them or provide ambiguous information about their diagnosis; or abuse them by yelling, acting aggressively or performing procedures that are painful (51–53). In addition, systematic discrimination is evident in health information being provided in the dominant language only; as a result, indigenous peoples cannot communicate effectively about their health problems or understand what is required of them to pursue treatment (4). In some settings, health facilities purposely do not allow relatives who would be able to translate into the exam-



ination room (51). Discrimination has been linked to poor physical and mental health outcomes, negative health behaviours and an increase in mortality (54). Studies among indigenous groups have also demonstrated that perceived discrimination is an emerging risk factor for negative health outcomes (4). While these examples are not specific to accessing TB diagnosis and treatment, these experiences are common for indigenous peoples, from Canada to Guatemala to New Zealand. With a condition like TB, where the support and involvement of health care providers is critical, discrimination may have a dire impact on outcomes.

In addition to discrimination, the history of scientific experimentation (55), forced sterilization (56–58) and unequal distribution of power in the delivery of health services (59) makes many indigenous communities wary and untrusting of formal health care systems. This trust can only be re-established by involving indigenous authorities and communities in all stages of programme planning.

Gender

Both indigenous women and men face gender-specific challenges when accessing health services and additional factors that make them susceptible to TB. Indigenous women have been most affected by colonization and discrimination; the unprecedented scope of violence against and exploitation of indigenous women has been well documented (3,22). Almost universally, indigenous women's health indicators lag far behind those of their non-indigenous counterparts or even men in their communities (4). HIV comprises a key risk for TB. There are statistics indicating that the incidence of HIV among indigenous populations in some settings is on the increase and that risks for HIV are

universally heightened for indigenous peoples everywhere (4,60,61). Indigenous women are at increased risk for HIV in some settings where female genital mutilation, polygamy and early marriages are common (4). In other settings, this increased exposure might be amplified by involvement in sex work or the exchange of sex for goods and a lack of knowledge about HIV (4,6). For example, in India, 60.9% of the mainstream population has heard of HIV compared to 38.6% of tribal women; the situation is similar in Bangladesh and Nepal (4). The health of indigenous men is impacted by isolation from family and traditional society, and incarceration (62). Incarceration increases TB risk (63) and is disproportionately experienced by indigenous males in developed nations; this could also be a global phenomenon (22). Programming for indigenous men and women needs to not only take into account culture and tradition, but also involve communities. Such an approach can help to overcome some of the more harmful practices and capitalize on the more positive ones in order to ensure that gender-specific interventions are available.

Genetics and other comorbidities

Loss of land and being distanced from traditional activities have resulted in a multitude of sociopolitical issues for indigenous communities. In terms of health indicators, non-traditional, sedentary lifestyles, change of diet and dependence on foods that might be of poor nutritional value have led to a number of additional health issues, such as malnutrition, obesity, diabetes and cardiovascular disease. Evidence indicates that there is an increased incidence of chronic diseases among indigenous peoples across a variety of settings, including countries in Africa, North America, Asia and the Pacific, and Europe's North. This

could also contribute to a heightened risk for TB (4,6,7,22). For example, in the United States, Native Americans have a greater chance of developing diabetes than any other racial/ethnic group. Furthermore, Native Americans and Alaskan Natives die of diabetes at a rate 3 times that of non-indigenous Americans (64,65). Similarly, indigenous peoples in Asia experience higher rates of diabetes and other chronic diseases than non-indigenous populations in the region (4). Some studies have also pointed to genetic mutations and an atypical immune response that may be responsible

for the increased susceptibility of indigenous populations to TB infection, its progression and activation (66,67). A review of studies focused on indigenous peoples in Latin America found a lack of reaction to the tuberculin skin test and immune system response that could contribute to the faster progression of latent TB infection (67). Another study in a Canadian Aboriginal family revealed the presence of a gene that could potentially be responsible for TB susceptibility (66).





Taking action

Indigenous health with indigenous peoples

A 2012 review of evidence sought to identify what works in indigenous primary care. The review clearly demonstrated that those interventions that involve and solicit buy-in from indigenous communities, are planned locally, and have community ownership tend to deliver more successful results (68). Considering the reliance on traditional medicine and the effectiveness of collaborating with traditional healers to address TB in some settings, the involvement of indigenous communities in the design and implementation of TB interventions cannot be undermined (47–49). In addition, community input must be considered when developing solutions for addressing issues of early diagnosis, medication adherence and other common issues in the successful treatment of TB; otherwise, such solutions risk being unsuccessful.

Ensuring access to information

Informational campaigns about TB and interventions addressing it must be conducted and delivered in a language that indigenous peoples can understand. The mode of communication could also be key in indigenous communities where literacy rates are low (3). Thus, providing information in a visual form that is appropriately understood by communities or engaging storytelling in communities could be cheap and effective solutions in settings where translators are unavailable and/or where the language of the dominant culture can be spoken but not read. The modes of communicating and all materials must be decided on and designed with community input.

Training indigenous health workers

Although the dramatic shortages of health workers in rural and remote areas are prevalent universally, indigenous peoples may be especially affected by such shortages, since the majority of indigenous populations reside in these remote and rural locations (14,69). Several strategies exist to overcome these shortages. These include basing medical and nursing schools in rural areas where more indigenous students can access them and continue to serve their communities; providing tuition support for indigenous students who are eager to serve the communities from which they originated; and offering incentives for nurses and doctors to stay in rural communities, for example, continued education and satisfactory accommodation (4). In New Zealand, a special admissions scheme operates for students of indigenous descent who are enrolling in health programmes. While overall, Maori remain a disproportionate minority in health professions, New Zealand has made laudable strides in supporting the development of Maori health providers. Existing research has demonstrated that Maori health providers serve to increase Maori communities' access to care (70–72).

Other approaches that work

Several interventions have been designed specifically for and with indigenous peoples to address the high burden of TB in these populations.

- In Kenya, temporary lodgings next to health facilities – or TB manyattas – where Kenyan pastoralists can receive TB treatment for 4 months with the help of a family member were established to accommodate the needs of this indigenous groups. The success of the treatment program led to establishing TB manyattas in other remote locations in Kenya (73).



- In Namibia, TB control programmes among the San people saw increased success when family members were educated about TB treatment. The lifestyle of the San often requires long hunting expeditions that frequently interrupt TB treatment, causing drug-resistant TB to emerge in communities. Family members were trained about the importance of administering the medication regularly, and learned how to make notes on treatment cards and collect medical samples. These steps improved adherence, while accommodating the San lifestyle (6).
- In Indonesia, an NGO-run clinic specializing in HIV, TB and other conditions that might be stigmatized services indigenous peoples exclusively; it also trains indigenous nurses and hires indigenous staff and volunteers who can do health promotion and deliver services to their communities (6).
- In Mexico, extended health insurance coverage among indigenous populations has boosted their usage of health care (74).





Recommendations

While these recommendations provide an outline for action for a range of key stakeholders, others, including UN Agencies and local and global health worker collectives, should take note and assess their potential for use in improving TB prevention, treatment and care for indigenous peoples.

Civil Society	Groups of Rural People with TB	National Governments and Health Systems	Donors
<p>Ensure that indigenous communities are involved in every step of identifying, designing and implementing health programming that affects them, and promote health interventions sourced from indigenous communities that could be applied to TB;</p>	<p>Engage with government and NGO bodies that design health- and TB-focused interventions to ensure community buy-in and participation in programming;</p> <p>Promote traditional healer engagement in programmes;</p>	<p>Ensure that indigenous groups are consulted at all levels of policy and intervention design for TB and that buy-in is acquired from communities and indigenous authorities prior to programme implementation;</p> <p>Engage traditional healers in programming, including TB treatment, by encouraging collaboration between traditional healers and mainstream health institutions;</p>	<p>Invest in health and TB programmes that involve indigenous peoples in all stages of planning and implementation;</p> <p>Particularly focus investment on programmes that consider the indigenous concept of health and involve traditional healers in programming;</p> <p>Support capacity building for indigenous-led organizations through grants and technical assistance;</p>
<p>Allow room for capacity building of indigenous organizations and encourage organizing among indigenous researchers and indigenous peoples with TB;</p>	<p>Organize and form alliances between indigenous researchers and advocates;</p> <p>Seek support to build capacity among indigenous organizations;</p>	<p>Promote involvement of indigenous researchers at the national level;</p> <p>Create opportunities to collect input from indigenous peoples with TB, community advocates and researchers;</p>	<p>Support indigenous organizations through funding, technical assistance and capacity building;</p>



Civil Society	Groups of Rural People with TB	National Governments and Health Systems	Donors
<p>Demand equity in health data collection efforts and the participation of indigenous peoples in the design and implementation of research studies and data collection efforts such as the DHS;</p>	<p>Advocate for community-based and community-led research on TB and other conditions among indigenous peoples, and the participation of indigenous communities in broader social and health indicator data collection efforts;</p>	<p>Devise ways to account for indigenous peoples in national health data collection efforts;</p> <p>Support national research institutions that focus on indigenous health;</p>	<p>Fund research and data collection among indigenous populations, especially where health data among them are lacking;</p>
<p>Develop and promote indigenous-specific social determinants of health frameworks to highlight the need for addressing the overlapping vulnerabilities that make indigenous peoples more susceptible to TB;</p>	<p>Insist that data collection account for the impact of TB and HIV on the well-being of indigenous communities in order to prioritize interventions;</p> <p>Utilize existing international instruments to advocate for indigenous access to data about their health;</p>	<p>Ensure a transparent exchange of information that provides indigenous community leaders with access to data on health outcomes and the impact of health disparities;</p>	<p>Fund and support the development of indigenous-specific social determinants of health frameworks;</p>
<p>Advocate with national health leaders for access to low-literacy materials, visual materials, and materials in indigenous languages that can be easily interpreted by indigenous peoples;</p>	<p>Make decisions as to the best strategies with which to educate peers about TB and the importance of medication adherence, using materials, story-telling and other tools that are most accepted in indigenous communities;</p>	<p>With input from indigenous peoples, produce easy-to-understand health communication materials on TB symptoms, risk, and treatment adherence that align with the needs, traditions and lifestyles of indigenous groups;</p>	<p>Promote and invest in materials and interventions that support indigenous health education;</p>



Civil Society	Groups of Rural People with TB	National Governments and Health Systems	Donors
<p>Organize to form and obtain funding for community-based clinics that serve indigenous communities and educate indigenous health workers and health promoters;</p>	<p>Engage with NGOs and government institutions to encourage the establishment of indigenous clinics and training for indigenous health workers;</p>	<p>Support indigenous clinics and clinics that serve indigenous communities;</p> <p>Make educational opportunities available for indigenous peoples to engage in the health system;</p> <p>Fast-track rural and indigenous positions, and provide incentives for indigenous health workers to stay and serve their communities;</p> <p>Create national programmes to accelerate education for indigenous peoples interested in health professions;</p>	<p>Fund educational opportunities for indigenous peoples interested in health and medicine;</p> <p>Promote successful models for engaging health workers in rural and indigenous clinics;</p>
<p>Seek out innovative approaches to indigenous health and TB programming specifically, and ensure their broad adoption and implementation.</p>	<p>Collaborate within the indigenous community to produce models and interventions that can best serve indigenous peoples in expanding their access to TB diagnosis and treatment;</p> <p>Develop reports of cultural protocols and cultural relevance for the main authorities dealing with indigenous communities and health facilitators.</p>	<p>Promote and seek innovative approaches in indigenous health care that have the potential to improve TB treatment outcomes for indigenous populations;</p> <p>Review and promote cultural protocols that can accelerate health care delivery in indigenous communities.</p>	<p>Provide funding for innovative programmes that have the potential to effectively address TB in indigenous communities.</p>

References

- Hall GH, Patrinos HA. Indigenous peoples, poverty, and development. Cambridge: Cambridge University Press; 2012.
- Bartlett JG, Madariaga-Vignudo L, O'Neil JD, Kuhnlein HV. Identifying indigenous peoples for health research in a global context: a review of perspectives and challenges. *Int J Circumpolar Health*. 2007;66(4):287–307.
- State of the world's indigenous peoples, Vol 1. New York: United Nations; 2009 (ST/ESA/328; http://www.un.org/esa/socdev/unpfii/documents/SOWIP/en/SOWIP_web.pdf, accessed 24 February 2017).
- State of the world's indigenous peoples: indigenous peoples' access to health services. New York: United Nations; 2015 (<https://www.un.org/development/desa/indigenouspeoples/publications/2015/09/state-of-the-worlds-indigenous-peoples-2nd-volume-health/>, accessed 24 February 2017).
- Tollefson D, Bloss E, Fanning A, Redd JT, Barker K, McCray E. Burden of tuberculosis in indigenous peoples globally: a systematic review. *Int J Tuberc Lung Dis*. 2013;17(9):1139–50.
- State of the world's minorities and indigenous peoples 2013: events of 2012. London: Minority Rights Group International; 2013 (<http://minorityrights.org/publications/state-of-the-worlds-minorities-and-indigenous-peoples-2013-september-2013/>, accessed 5 March 2017).
- Stephens C, Nettleton C, Porter J, Willis R, Clark S. Indigenous peoples' health—why are they behind everywhere, everywhere? *The Lancet*. 2005;366(9479):10–3.
- Indigenous peoples and education [website]. Copenhagen: International Work Group for Indigenous Affairs (<http://www.iwgia.org/culture-and-identity/indigenous-peoples-and-education>, accessed 25 February 2017).
- Health of indigenous peoples. Geneva: World Health Organization; 2007 (<http://www.who.int/mediacentre/factsheets/fs326/en/>, accessed 25 February 2017).
- Tuberculosis—past and present. In: The Chief Public Health Officer's report on the state of public health in Canada, 2013: infectious disease—the never-ending threat [website]. Ottawa: Public Health Agency of Canada; 2013 (<http://www.phac-aspc.gc.ca/cphorsphc-resp-cacsp/2013/tuber-eng.php>, accessed 27 February 2017).
- Basta PC, Coimbra Junior CE, Escobar AL, Santos RV. Epidemiologic aspects of tuberculosis in the Suruí Indians, Brazilian Amazon. *Rev Soc Bras Med Trop*. 2004;37(4):338–42.
- Sousa AO, Salem JJ, Lee FK, Verçosa MC, Cruaud P, Bloom BR, et al. An epidemic of tuberculosis with a high rate of tuberculin anergy among a population previously unexposed to tuberculosis, the Yanomami Indians of the Brazilian Amazon. *Proc Natl Acad Sci U S A*. 1997;94(24):13227–32.
- Hurtado AM, Hill KR, Rosenblatt W, Bender J, Scharmen T. Longitudinal study of tuberculosis outcomes among immunologically naive Aché natives of Paraguay. *Am J Phys Anthropol*. 2003;121(2):134–50.
- The health of indigenous peoples. New York: United Nations Inter-Agency Support Group (IASG) on Indigenous Issues; 2014 (<http://www.un.org/en/ga/president/68/pdf/wcip/IASG%20Thematic%20Paper%20-%20Health%20-%20rev1.pdf>, accessed 27 February 2017).
- Kirmayer LJ, Dandeneau S, Marshall E, Phillips MK, Williamson KJ. Rethinking resilience from indigenous perspectives. *Can J Psychiatry*. 2011;56(2):84–91.
- Who are indigenous peoples? [website]. New York: UN Permanent Forum on Indigenous Issues (http://www.un.org/esa/socdev/unpfii/documents/5session_factsheet1.pdf, accessed 3 March 2017).
- UN Economic and Social Council. Working paper by Mrs. Erica-Irene A. Daes, on the concept of "indigenous people." New York: OHCHR; 1996 (E/CN.4/Sub.2/AC.4/1996/2; http://ap.ohchr.org/documents/alldocs.aspx?doc_id=7620, accessed 27 February 2017).
- Concept note—indigenous peoples: conflict, peace and resolution. New York: UN Permanent Forum on Indigenous Issues; 2016 (<http://www.un.org/esa/socdev/unpfii/documents/2016/Docs-updates/Concept-note-Conflict-discussion-FINAL.pdf>, accessed 3 March 2017).
- A name, a nationality, an identity: registering indigenous peoples in Panama [website]. New York: OHCHR; 2015 (<http://www.ohchr.org/EN/NewsEvents/Pages/RegisteringIndigenousPeoplesPanama.aspx>, accessed 3 March 2017).
- Durie M. Whaiora: Māori health development. Auckland, New Zealand: Oxford University Press; 1994.
- Wilson K. Therapeutic landscapes and First Nations peoples: an exploration of culture, health and place. *Health Place*. 2003;9(2):83–93.
- King M, Smith A, Gracey M. Indigenous health part 2: the underlying causes of the health gap. *The Lancet*. 2009;374(9683):76–85.
- Casken J. Improved health status for Native Hawaiians: not just what the doctor ordered. *Wicazo Sa Rev*. 2001;16(1):75–89.
- White P. The concept of diseases and health care in African traditional religion in Ghana. *HvTSt*. 2015;71(3).

25. Engagement with indigenous peoples. Rome: International Fund for Agricultural Development; 2009.
26. Still among the poorest of the poor. Washington, DC: World Bank; 2011 (Report No. 64760; <http://documents.worldbank.org/curated/en/144831468330276370/Still-among-the-poorest-of-the-poor>, accessed 2 March 2017).
27. La pobreza en la población indígena de México, 2012. México, DF: Consejo Nacional de Evaluación de la Política de Desarrollo Social; 2014 (http://www.coneval.org.mx/Informes/Coordinacion/INFORMES_Y_PUBLICACIONES_PDF/POBREZA_POBLACION_INDIGENA_2012.pdf, accessed 3 March 2017).
28. Rural development report 2016: fostering inclusive rural transformation. Rome: International Fund for Agricultural Development; 2016 (<https://www.ifad.org/pub/rdr>, accessed 1 March 2017).
29. Hall G. Poverty and exclusion among indigenous peoples: the global evidence. In: *Voices: perspectives on development* [website]. Washington, DC: World Bank; 2016 (<https://blogs.worldbank.org/voices/poverty-and-exclusion-among-indigenous-peoples-global-evidence>, accessed 11 May 2017).
30. Education and indigenous peoples: priorities for inclusive education [website]. New York: United Nations Inter-Agency Support Group (IASG) on Indigenous Issues; 2014 (<http://www.un.org/en/events/indigenous-day/Backgrounder%20Indigenous%20Day%202016.pdf>, accessed 1 March 2017).
31. Clark M, Riben P, Nowgesic E. The association of housing density, isolation and tuberculosis in Canadian First Nations communities. *Int J Epidemiol*. 2002;31(5):940–5.
32. VanSteelandt A, Hurtado AM, Rolón M, Rojas de Arias A, Jara JC. High tuberculosis disease burden among indigenous people of the Paraguayan Chaco and associated community characteristics, 2002–2004: an ecological study. *Epidemiol Res Int*. 2015;2015:e841289.
33. Steering Committee for the Review of Government Service Provision. *Overcoming Indigenous disadvantage: key indicators 2011*. Canberra, Australia: Productivity Commission; 2011 (<http://www.pc.gov.au/research/ongoing/overcoming-indigenous-disadvantage/key-indicators-2011>, accessed 2 March 2017).
34. Key populations brief: rural populations. Geneva: STOP TB Partnership; 2016 (http://www.stoptb.org/assets/documents/resources/publications/acsm/KP_Rural_Spreads.pdf, accessed 2 March 2017).
35. Gianella C, Ugarte-Gil C, Caro G, Aylas R, Castro C, Lema C. TB in vulnerable populations: the case of an indigenous community in the Peruvian Amazon. *Health and Human Rights Journal*. 2016;18(1) (<https://www.hhrjournal.org/2016/06/tuberculosis-in-vulnerable-populations-the-case-of-an-indigenous-community-in-the-peruvian-amazon/>, accessed 22 February 2017).
36. Brierley CK, Suarez N, Arora G, Graham D. Healthcare access and health beliefs of the indigenous peoples in remote Amazonian Peru. *Am J Trop Med Hyg*. 2014;90(1):180–3.
37. Davy C, Harfield S, McArthur A, Munn Z, Brown A. Access to primary health care services for indigenous peoples: a framework synthesis. *Int J Equity Health*. 2016;15:163.
38. Peiris D, Brown A, Cass A. Addressing inequities in access to quality health care for indigenous people. *Can Med Assoc J*. 2008;179(10):985–6.
39. Hall G, Patrinos H. *Indigenous peoples, poverty and human development in Latin America*. New York: Springer; 2005.
40. United Nations Declaration on the Rights of Indigenous Peoples. New York: United Nations Division for Social Policy and Development Indigenous Peoples; 2007 (A/RES/61/295; <https://www.un.org/development/desa/indigenouseoples/declaration-on-the-rights-of-indigenous-peoples.html>, accessed, 3 March 2017).
41. Yamasaki-Nakagawa M, Ozasa K, Yamada N, Osuga K, Shimouchi A, Ishikawa N, et al. Gender difference in delays to diagnosis and health care seeking behaviour in a rural area of Nepal. *Int J Tuberc Lung Dis*. 2001;5(1):24–31.
42. Lienhardt C, Rowley J, Manneh K, Lahai G, Needham D, Milligan P, et al. Factors affecting time delay to treatment in a tuberculosis control programme in a sub-Saharan African country: the experience of The Gambia. *Int J Tuberc Lung Dis*. 2001;5(3):233–9.
43. Eastwood SV, Hill PC. A gender-focused qualitative study of barriers to accessing tuberculosis treatment in The Gambia, West Africa. *Int J Tuberc Lung Dis*. 2004;8(1):70–5.
44. Kassaye KD, Amberbir A, Getachew B, Mussema Y. A historical overview of traditional medicine practices and policy in Ethiopia. *Ethiop J Health Dev*. 2006;20(2):127–34.
45. Needham DM, Foster SD, Tomlinson G, Godfrey-Faussett P. Socio-economic, gender and health services factors affecting diagnostic delay for tuberculosis patients in urban Zambia. *Trop Med Int Health*. 2001;6(4):256–9.
46. Oeser CC, Escombe AR, Gilman RH, Friedland JS, Evans CAW, Moore DAJ. Does traditional medicine use hamper efforts at tuberculosis control in urban Peru? *Am J Trop Med Hyg*. 2005;73(3):571–5.

47. Colvin M, Gumedde L, Grimwade K, Maher D, Wilkinson D. Contribution of traditional healers to a rural tuberculosis control programme in Hlabisa, South Africa. *Int J Tuberc Lung Dis.* 2003;7(9 Suppl 1):S86–91.
48. Madamombe I. Traditional healers boost primary health care: reaching patients missed by modern medicine. *Africa Renewal Online.* January 2006 (<http://www.un.org/africarenewal/magazine/january-2006/traditional-healers-boost-primary-health-care>, accessed 3 March 2017).
49. Viney K, Johnson P, Tagaro M, Fanai S, Linh NN, Kelly P, et al. Traditional healers and the potential for collaboration with the national tuberculosis programme in Vanuatu: results from a mixed methods study. *BMC Public Health.* 2014;14:393.
50. Report of the Special Rapporteur on the Rights of Indigenous Peoples, James Anaya: the situation of indigenous peoples in the Republic of the Congo. New York: United Nations Human Rights Council; 2011 (A/HRC/18/35/Add.5; <http://www.ohchr.org/EN/Issues/IPeoples/SRIIndigenousPeoples/Pages/SRIPeoplesIndex.aspx>, accessed 2 March 2017).
51. Cerón A, Ruano AL, Sánchez S, Chew AS, Díaz D, Hernández A, et al. Abuse and discrimination towards indigenous people in public health care facilities: experiences from rural Guatemala. *Int J Equity Health.* 2016;15:77.
52. Harris R, Tobias M, Jeffreys M, Waldegrave K, Karlens S, Nazroo J. Racism and health: the relationship between experience of racial discrimination and health in New Zealand. *Soc Sci Med.* 2006;63(6):1428–41.
53. Allan B, Smylie J. First Peoples, second class treatment: the role of racism in the health and well-being of Indigenous Peoples in Canada. Toronto: Wellesley Institute; 2015 (<http://www.wellesleyinstitute.com/publications/first-peoples-second-class-treatment/>, accessed 4 March 2017).
54. Williams DR, Mohammed SA. Discrimination and racial disparities in health: evidence and needed research. *J Behav Med.* 2009;32:20–47.
55. Mosby I. Administering colonial science: nutrition research and human biomedical experimentation in Aboriginal communities and residential schools, 1942–1952. *Histoire Soc.* 2013;46(1):145–72.
56. Carpio MV. The lost generation: American Indian women and sterilization abuse. *Soc Justice.* 2004;31(4 (98)):40–53.
57. Ralstin-Lewis DM. The continuing struggle against genocide: indigenous women's reproductive rights. *Wicazo Sa Rev.* 2005;20(1):71–95.
58. Stote K. The coercive sterilization of Aboriginal women in Canada. *Am Indian Cult Res J.* 2012;36(3):117–50.
59. Smith-Oka V. Unintended consequences: exploring the tensions between development programs and indigenous women in Mexico in the context of reproductive health. *Soc Sci Med.* 2009;68(11):2069–77.
60. Narasimhan P, Wood J, Macintyre CR, Mathai D. Risk factors for tuberculosis. *Pulm Med.* 2013;2013:828939.
61. Negin J, Aspin C, Gadsden T, Reading C. HIV among indigenous peoples: a review of the literature on HIV-related behaviour since the beginning of the epidemic. *AIDS Behav.* 2015;19(9):1720–34.
62. Adams M. Establishing a national framework for improving the health and well-being of Aboriginal and Torres Strait Islander males. *Aborig Isl Health Work J.* 2002;26(1):11.
63. Baussano I, Williams BG, Nunn P, Beggiano M, Fedeli U, Scano F. Tuberculosis incidence in prisons: a systematic review. *PLoS Med.* 2010;7(12):e1000381.
64. Native Americans with diabetes: kidney disease in Native Americans with diabetes [website]. Atlanta: Centers for Disease Control and Prevention; 2017 (<http://www.cdc.gov/media/dpk/diseases-and-conditions/native-americans-diabetes/native-americans-diabetes.html>, accessed 11 May 2017).
65. Indian health disparities [website]. Rockville, MD: Indian Health Service; 2017 (<https://www.ihs.gov/newsroom/factsheets/disparities/>, accessed 11 May 2017).
66. Greenwood CMT, Fujiwara TM, Boothroyd LJ, Miller MA, Frappier D, Fanning EA, et al. Linkage of tuberculosis to chromosome 2q35 loci, including NRAMP1, in a large Aboriginal Canadian family. *Am J Hum Genet.* 2000;67(2):405–16.
67. Longhi RMP, Zembrzuski VM, Basta PC, Croda J. Genetic polymorphism and immune response to tuberculosis in indigenous populations: a brief review. *Braz J Infect Dis.* 2013;17(3):363–8.
68. Halliday D, Segal L. What works in indigenous primary health care health reform? a review of evidence. Adelaide: Health Economics & Social Policy Group, University of South Australia; 2012 (<https://www.unisa.edu.au/Global/Health/Sansom/Documents/HESPG/What%20works%20in%20Indigenous%20PHC%20reform.pdf>, accessed 3 March 2017).
69. Increasing access to health workers in remote and rural areas through improved retention: global policy recommendations. Geneva: World Health Organization; 2010 (<http://www.who.int/hrh/retention/guidelines/en/>, accessed 2 March 2017).

70. McMillan V. Maori doctors a growing force – but don't take them for granted. NZ Doctor. 24 September 2015 (<https://www.nzdoctor.co.nz/news/2015/september-2015/24/maori-doctors-a-growing-force-%E2%80%93-but-don%E2%80%99t-take-them-for-granted.aspx>, accessed 15 April 2017).
71. Medical Council. Cultural competence, partnership and health equity: professional obligations towards Maori health improvement. NZ Doctor. 23 September 2015 (<https://www.nzdoctor.co.nz/un-doctored/2015/september-2015/23/Cultural-competence,-partnership-and-health-equity-Professional-obligations-towards-Maori-health-improvement.aspx>, accessed 15 April 2017).
72. Māori providers: primary health care delivered by doctors and nurses. Wellington: Ministry of Health, New Zealand; 2004 (<http://www.health.govt.nz/publication/maori-providers-primary-health-care-delivered-doctors-and-nurses>, accessed 15 April 2017).
73. A brief history of tuberculosis control in Kenya. Geneva: World Health Organization; 2009 (http://apps.who.int/iris/bitstream/10665/43934/1/9789241596923_eng.pdf, accessed 15 April 2017).
74. Leyva-Flores R, Servan-Mori E, Infante-Xibille C, Pelcastre-Villafuerte BE, Gonzalez T. Primary health care utilization by the Mexican indigenous population: the role of the Seguro Popular in socially inequitable contexts. PLOS ONE. 2014;9(8):e102781.

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