Treatment Action Group

Introduction

1. This submission focuses on Mexico's obligations to address tuberculosis (TB) prevention, diagnosis, and care analyzed from the perspective of the human right to enjoy the benefits of scientific progress and its applications (i.e., the Right to Science or RtS).
2. TAG's analysis was developed in consultation with local healthcare providers in Mexico and is based on testimony and desk research.
3. TAG notes that the research for this submission was hindered by fear of reprisals, including violence, among affected communities. The pervasive intimidation, disappearance, and murder of activists working on economic, social, and cultural rights in Mexico is well documented.
4. TAG stipulates that Mexico must integrate the RtS framework into its TB response in order to meet the global goal of ending the TB epidemic by 2030 (Sustainable Development Goal 3.3); fully achieve its national health targets; and fulfill its obligations under the Universal Declaration of Human Rights (UDHR) and International Covenant on Economic, Social, and Cultural Rights (ICESCR).

Background on the Right to Science

5. The right of all people to share in the benefits of scientific progress is enshrined in Article 27 of the UDHR.
6. ICESCR Article 15 asserts the right of everyone "to enjoy the benefits of scientific progress and its applications."
7. ICESCR Article 15 lays out States parties' responsibilities to include "the conservation, the development and the diffusion of science […]" (Art. 15.2); and to "recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields" (Art. 15.4).
8. The dimensions of RtS, its intersection with other human rights, and its application to health include participation in science and science-based policy-making, and the importance of science for human rights-based policy-making.[1]
9. In a May 2012 report, the Special Rapporteur (SR) in the field of cultural rights noted the strong interdependence of RtS and other human rights, including the obvious linkage with the Right to Health.[2] The SR points in particular to non-discriminatory access to scientific knowledge and its advances. The concept of access includes access not only to the results, but also to the means and processes of scientific inquiry, as part of the right's benefits.[3]
10. ICESCR Article 15 speaks of "development and diffusion of science […]" as State obligations. Together with the SR's reading of access, development must be understood as a State's obligation to support scientific research and innovation; and diffusion as making the benefits thereof available and accessible in a non-discriminatory manner.[4]
11. Thus, States must take measures to guarantee not only availability, but also affordability of tangible health technologies, including medicines or diagnostics.
12. The above analysis clarifies that RtS is inseparable from several other human rights, including the Right to Life, Right to Health, Right to Participation, and Right to Non-

Discrimination, among others. This submission will describe shortcomings in Mexico's TB response with respect to its obligations under RtS and interrelated rights.

Right to Science in Regional and Domestic Law

13. The American Convention on Human Rights (ACHR) Art. 26 obligates States to "the full realization of the rights implicit in the economic, social, educational, scientific, and cultural standards set forth in the Charter of the Organization of American States (Charter) as amended by the Protocol of Buenos Aires."

14. Charter Article 34 highlights equality of opportunity, elimination of extreme poverty, and participation as integral to development. States agreed to "i) Protection of man's potential through the *extension and application of modern medical science"* [emphasis added].

15. Charter Articles 38 and 47 respectively recognize the importance of diffusion of science and promotion of science.

16. The Protocol of San Salvador (Protocol) Article 10.2 includes provision of universal healthcare; prevention and treatment of diseases; health education; and specifically mentions communities at high risk of ill health due to poverty.

17. Closely echoing RtS according to ICESCR Article 15, the Protocol Article 14.1 provides for availability and access, i.e. the right of everyone: "[…] b. To enjoy the benefits of scientific and technological progress"; and Article 14.2 explicitly mentions States' obligation for development and dissemination of scientific progress.

Prior UPR Recommendations

18. In the Second Cycle UPR, Mexico accepted recommendations A-148.149/Nigeria, A-148.154/Uruguay, and A-148.156/Australia to expand access to universal healthcare and poverty alleviation, and to protect in particular health rights of vulnerable communities.

19. Mexico publicly reinforced its own commitment to health, including equitable access, the needs of vulnerable communities, and the links between poverty, education, social services, and health, in Second Cycle UPR recommendations to Georgia, Mali, and Morocco.

20. While Mexico has made progress in the realm of health and TB, Mexico still falls short of its obligations under several human rights conventions, in particular concerning RtS obligations.

21. TAG's research shows Mexico must act on its RtS obligations in its TB response to achieve SDG 3.3 (end the TB epidemic by 2030), comply with international human rights standards, and protect the lives of its citizens.

TB and Right to Science in Mexico

22. As one of the world's 20 largest economies, Mexico has increased access to healthcare and tackled social determinants of health through the 2013–2018 PROSEA health program, based on Mexico's 2013-2018 National Development Plan.[5]

23. However, TAG's research indicates that a large gap to accessing medical services persists, as exemplified by challenges relating to the availability, accessibility, acceptability, and quality of TB services.

24. In its 2017 report to the CESCR review of Mexico in 2018, the Federal District Human Rights Commission (CDHDF) of Mexico City states that of the 11,858 complaints on Right to Health violations it received from 2011–2016, "the most frequent violation was the hindering, restriction or refusal of medical care."[6]

25. Mexico had 28,000 new TB cases in 2016 and nearly 3,000 deaths.[7] World Health Organization (WHO) data show large differences in TB incidence across Mexico's regions, i.e. "3 cases/100,000 inhabitants in Jalisco to 58.5/100,000 in Baja California." Tijuana reported the highest (and increasing) rates.[8]

26. About 60% of TB cases are clustered in five of Mexico's 32 states, prompting local assessment that the national government may consider TB a local problem, thus not giving it sufficient attention.[9]

27. Poverty drives the spread of TB. Recent data suggest progress in reducing poverty has stalled: the percentage of the population living in poverty rose from 45.5% in 2012 to 46.2% in 2014; extreme poverty dropped only slightly from 9.8% to 9.5% in the same period.[10]

28. TAG expresses grave concern about limited, inequitable access to the highest available standard of TB prevention, diagnosis, and treatment in Mexico, combined with the stalled state of poverty alleviation. To address the continued burden of TB on vulnerable poor and indigenous communities, Mexico must embrace a RtS framework to ensure nondiscrimination in innovation and access to health technologies.

<u>Violations of Right to Science within the National TB Program</u>

29. Mexico's national TB guidelines were last modified in 2013 and do not reflect current international standards as defined by WHO. Though an addendum was announced, it was never published or shared with health providers. Mexico's national TB guidelines are updated only five years; 2018 should see a new national plan.

30. However, the national TB program has had no director since the beginning of 2018. Though a new director was supposed to assume the post mid-March 2018, by end of March the post remains vacant.

Participation:

31. Public health responses that disregard the participation of communities can contribute to stigma, and therefore discrimination and other human rights violations.

32. From a RtS perspective, community health workers and community-based organizations assist in the diffusion of medical advancement by bringing health services into the community. This is a critical enabler of patient-centered care, which is a central pillar of the WHO End TB Strategy.[11]

33. Community engagement in Mexico's TB is negligible.[12] Where civil society-organized efforts exist, they suffer from government inaction and non-existent structural support. Mexico has not created an enabling environment for community involvement in the TB response.

34. TAG's research suggests a lack of information and knowledge transfer from providers to patients, and no community organizations to support TB health education.

Nondiscrimination and Equitable Access:

35. Mexico clearly fails its obligations to diffuse scientific benefits in an equitable manner. TAG notes that shortcomings pertain not only to the material lack of health products, but also to the lack of policies on their use, the disarray of procurement systems, and the lack of investment in research to ensure the availability of better innovations required to end TB.

36. Diagnostics: Mexico reported progress on availability of diagnostic methods, and the national TB program began a pilot to expand use of the rapid Xpert MTB/ RIF Ultra diagnostic across Mexico starting with the highest incidence regions in mid-2018.[13]

    a. In reality, Mexico does not use rapid diagnostics as the first test for all people, including children, with signs of TB. Although Xpert MTB/ RIF Ultra is available, government labs often do not stock cartridges necessary to analyze patient samples due to high cartridge prices.[14] TAG's research shows local skepticism that the above pilot will be successfully expanded nationally without additional financial investments.

    b. Lack of resources means even smear tests (an inexpensive TB test developed over 100 years ago) are often unavailable. In one state laboratory, necessary reagents for smear testing were unavailable for over two months in 2018.[15]

    c. For latent TB infection diagnosis, the same laboratory reported unavailability of latest generation tests (e.g., the Quantiferon blood test).

    d. TAG's research revealed that people with TB often die undiagnosed because of unavailable or inaccessible testing services. Similarly, people diagnosed with TB often die before receiving treatment.

    e. Drug-susceptibility testing—critical for identifying and guiding treatment for drug resistant TB (DR-TB)—reportedly became available in 23 laboratories by 2016.[16] Insufficient access to DST means doctors have to rely on a trial-and-error method to define effective treatment regimens.

37. Treatment: TB treatment is often delayed because of unavailability of medication. This includes medication that should be available according to the National TB Program, and medication generally unavailable in Mexico.

    a. Among first line medications, at least two essential drugs (rifampicin and pyrazinamide) suffer stock-outs. For adults with DR-TB, moxifloxacin, bedaquiline, and delamanid are not available. Mexico does not offer the new, shorter 9-month treatment regimen for DR-TB. Bedaquiline, registered with the Mexican regulatory authority in October 2015, has yet to receive approval.

    b. One barrier to medication accessibility is that Mexico's national government has awarded the contract to source TB drugs to a single company, creating supply vulnerabilities. To stabilize supply, Mexico should procure drugs through international mechanisms such as the Global Drug Facility.

38. Prevention: According to national TB guidelines, Mexico provides TB preventive therapy for children five years or younger and adults living with HIV or diabetes. However, Mexico does not offer preventive therapy for all people at risk, including people of all ages who share the same household as someone with TB.

    a. The lack of TB preventive therapy can have grave consequences for the right to life. Based on provided testimony, in one family, one family member was cured of TB, while her father, sister and daughter died and her brother has been waiting to receive

TB treatment for three months.[17] These stark differences in outcome within a single family demonstrate the poor quality of care and grave weaknesses in TB education and linking people to testing and treatment.

39. TB/HIV: People with HIV face a much higher risk of developing active TB, and TB is the leading cause of death among people living with HIV. However, Mexico does not use the WHO-recommended TB-LAM test to diagnose TB in PLHIV with CD4 ≤ 100 µL or who are seriously ill.
    a. Only 2% of PLHIV in Mexico receive TB preventive therapy.[18] Mexico does not provide access to shorter, safer, and more effective preventive therapies, for example 3HP.
40. Drug-Resistant TB: Mexico's reporting to WHO shows a large gap between the estimated number of people who newly develop DR-TB each year and the number notified and put on treatment, indicating many people with DR-TB are not being linked to health services.[19]
    a. One civil society-run TB testing and treatment site in Baja California reported 40 people with DR-TB; only some received treatment and only 5 survived. The site reported toxic treatment side effects, and patients commonly do not receive necessary follow up e.g. monthly liver function tests in local hospitals.[20]
    b. Mexican providers have tried to work with the government to invoke compassionate use (i.e., pre-approval access) to provide DR-TB patients access to newer drugs still under development. However, specific attempts have failed due to administrative obstacles and government inaction.[21]
41. Infection control: Data on TB infections among health-care workers (HCWs), used as an indicator of infection control in healthcare settings, show Mexico is failing. In 2016, Mexico was one of only seven countries with infection among HCWs double that of general adult notification rates.[22]
    a. Testimony from one HCW revealed inadequate occupational safety standards for HCWs and inpatient facilities. This individual stated they were not provided appropriate respiratory protection as an emergency room staff, and said "isolation areas for TB patients are not properly equipped."[23]

Respect for Right to Privacy

42. TAG's research revealed scarring violations of the Right to Privacy. In one instance, written notices were posted to migrant farm workers' dormitory rooms revealing they had tested positive for TB. These cramped living spaces, which farm workers share with their families, increase the risk of TB spreading among a community of workers beyond the immediate family. Farm workers found to have TB lost their salary, exacerbating the economic hardship their families face in a time of financial need.[24]
43. In another instance, in March 2018, a school sent a letter to a health-care provider listing personal information (names, age, and medical status) of three students, one living with HIV and all three on TB preventive therapy.[25] The inquiry compromised the students' Right to Privacy and put them at risk of stigma and discrimination.

Rights of Indigenous People

44. TAG's research revealed a dire situation among indigenous people with respect to TB. Provided testimony showed that many indigenous people die before ever receiving a TB diagnosis.[26]

45. Indigenous communities face higher risk of TB attributable to poverty, compromised access to healthcare, and the fact that indigenous people often migrate for work in settings where they live in close quarters.[27]

46. A study in Chiapas, the poorest state in Mexico, which has a large indigenous population, showed that discrimination in healthcare settings kept indigenous people from seeking care. The study revealed stark structural weaknesses in Mexico's TB response beyond the unavailability of medicines and diagnostics. Research uncovered TB cases exceeding official numbers threefold and lack of patient medical records, explaining in part the underreporting.[28]

Recommendations

47. As science progresses, the understanding of what constitutes "the highest attainable standard of health" must equally evolve [29] The Right to Science ensures that with the advancement of science, new health technologies become available. Therefore, the benchmark for State obligations is always progressing alongside new discoveries.

48. Based on this understanding of the RtS in relation to health, TAG makes the following recommendations to the State of Mexico:

    A. Immediately update and align national TB program policies with international standards to ensure that all people with and at risk of TB have access to the highest available standards of care**.** In particular:

        a) **Diagnosis**: Provide universal access to GeneXpert MTB/RIF Ultra as the first diagnostic test for all. Use TB LAM in addition to GeneXpert in people with HIV with low CDC counts or who are seriously ill.

        b) **Treatment**: Provide full access to DR-TB medications, in particular newer drugs bedaquiline and delamanid (including requesting registration and assuring timely approval). Increase state and national resources to end drug stock outs and ensure a stable supply of all medicines.

        c) **Prevention**: Provide TB preventive therapy to all people living with HIV; expand preventive therapy eligibility to include close contacts; and strengthen infection control in high transmission settings, in particular hospitals and workplaces.

    B. Promote the participation of civil society and communities affected by TB in the TB response.

        a) Include people affected by TB in all regulatory and public health decision-making processes that affect access to interventions.

        b) Meaningfully integrate local communities and their organizations into the TB response; coordinate structural and financial support for local TB services.

    C. Implement specific legislation to protect the rights of people with TB, in particular the Right to Privacy and the Right to Nondiscrimination.

    D. Restructure the administration of TB services to enable more efficient collaboration between local and central health authorities.

E. Strengthen operations of the National Human Rights Commission so it can play a meaningful role in protecting the health rights of Mexico's people. In particular, increase the Commission's budget to enable actual operations and the implementation of recourse mechanisms for rights petitioners.

END NOTES:

[1] Mikel Mancisidor. Is There Such a Thing as a Human Right to Science in International Law? In: ESIL Reflections Volume 4, Issue 1. April 7, 2015 (available at http://www.esil-sedi.eu/sites/default/files/Mancisidor%20Reflection%20%28Word%29.pdf)

[2] Shaheed F. Report of the Special Rapporteur in the field of cultural rights, Farida Shaheed: the right to enjoy the benefits of scientific progress and its applications (UN Doc No. A/HRC/20/26). Human Rights Council 20th Session. 14 May 2002. P. 8. http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-26_en.pdf

[3] ibid.

[4] Frick M, et al. Falling Short of the Rights to Health and Scientific Progress: Inadequate TB Research and Access. In: Health and Human Rights Journal. June 21, 2016. (https://www.hhrjournal.org/2016/06/falling-short-of-the-rights-to-health-and-scientific-progress-inadequate-tb-drug-research-and-access/).

[5] WHO Mexico Country Report. In: Health in the Americas + 2017. (http://www.paho.org/salud-en-las-americas-2017/?p=4283)

[6] Human Rights Commission of the Federal District NHRI report on Mexico to CESCR 63rd Session (https://bit.ly/2GSTKW1)

[7] World Health Organization. Mexico Tuberculosis Profile 2016. (https://bit.ly/2ISjp1F)

[8] World Health Organization. Mexico Country Report. In: Health in the Americas + 2017. (http://www.paho.org/salud-en-las-americas-2017/?p=4283)

[9] TAG interview with healthcare provider. 26 March 2018

[10] World Health Organization. Mexico Country Report. In: Health in the Americas + 2017. (http://www.paho.org/salud-en-las-americas-2017/?p=4283)

[11] By 2030, 80% reduction in new cases; 90% reduction in mortality; 100% protection of catastrophic costs.

[12] World Health Organization. 2017 Global TB Report data set (http://www.who.int/tb/country/data/download/en/)

[13] The number of laboratories providing smear microscopy diagnosis increased from 1299 in 2014 to 1416 in 2016. Availability of Gene Xpert MTB/RIF increased from 39 machines in 2014 to 85 in 2016. World Health Organization. 2017 Global TB Report data set (http://www.who.int/tb/country/data/download/en/)

[14] TAG interview with healthcare provider. 26 March 2018.

[15] TAG written correspondence with healthcare provider. 22 March 2018.

[16] World Health Organization. 2017 Global TB Report data set (http://www.who.int/tb/country/data/download/en/)

[17] Testimony collected in Baja California, March 2018 [on file with TAG].

[18] World Health Organizations. Mexico Tuberculosis Profile 2016 (https://bit.ly/2ISjp1F)

[19] Ibid.

[20] TAG interview with healthcare provider. 26 March 26 2018.

[21] TAG interview with healthcare provider. 9 March 2018.

[22] World Health Organization. 2017 Global TB Report. Geneva: World Health Organization; 2017. (http://www.who.int/tb/publications/global_report/en/)

[23] Testimony collected in Baja California, March 2018 [on file with TAG].

[24] TAG interviews with healthcare providers. 26 February and 7 March 2018.

[25] TAG interview with healthcare provider. 9 March 2018.

[26] TAG interview with healthcare provider. 26 March 2018.

[27] TAG interviews with healthcare providers. 26 February and 8 March 2018.

[28] Sánchez-Pérez et al. Tuberculosis (TB) and Human Rights in Chiapas, Mexico. In: H.J. Sánchez-Pérez,

Anaximandro Gómez-Velasco, G. Leal, A. Bencomo-Alerm, N. Romero-Sandoval and M. Martín-Mateo (2015). Tuberculosis (TB) and Human Rights in Chiapas, Mexico, Tuberculosis - Expanding Knowledge, Dr. Wellman Ribón (Ed.), InTech, DOI: 10.5772/59670. (https://mts.intechopen.com/books/tuberculosis-expanding-knowledge/tuberculosis-tb-and-human-rights-in-chiapas-mexico)

[29] For a discussion on the minimum core, human rights and scientific advancement see, for example, https://www.hhrjournal.org/2015/06/evolving-human-rights-and-the-science-of-antiretroviral-medicine/.