

People-Centered, Rights-Based TB Legislation

In Eastern Europe and Central Asia

A Global TB Caucus Study

MARCH 2022

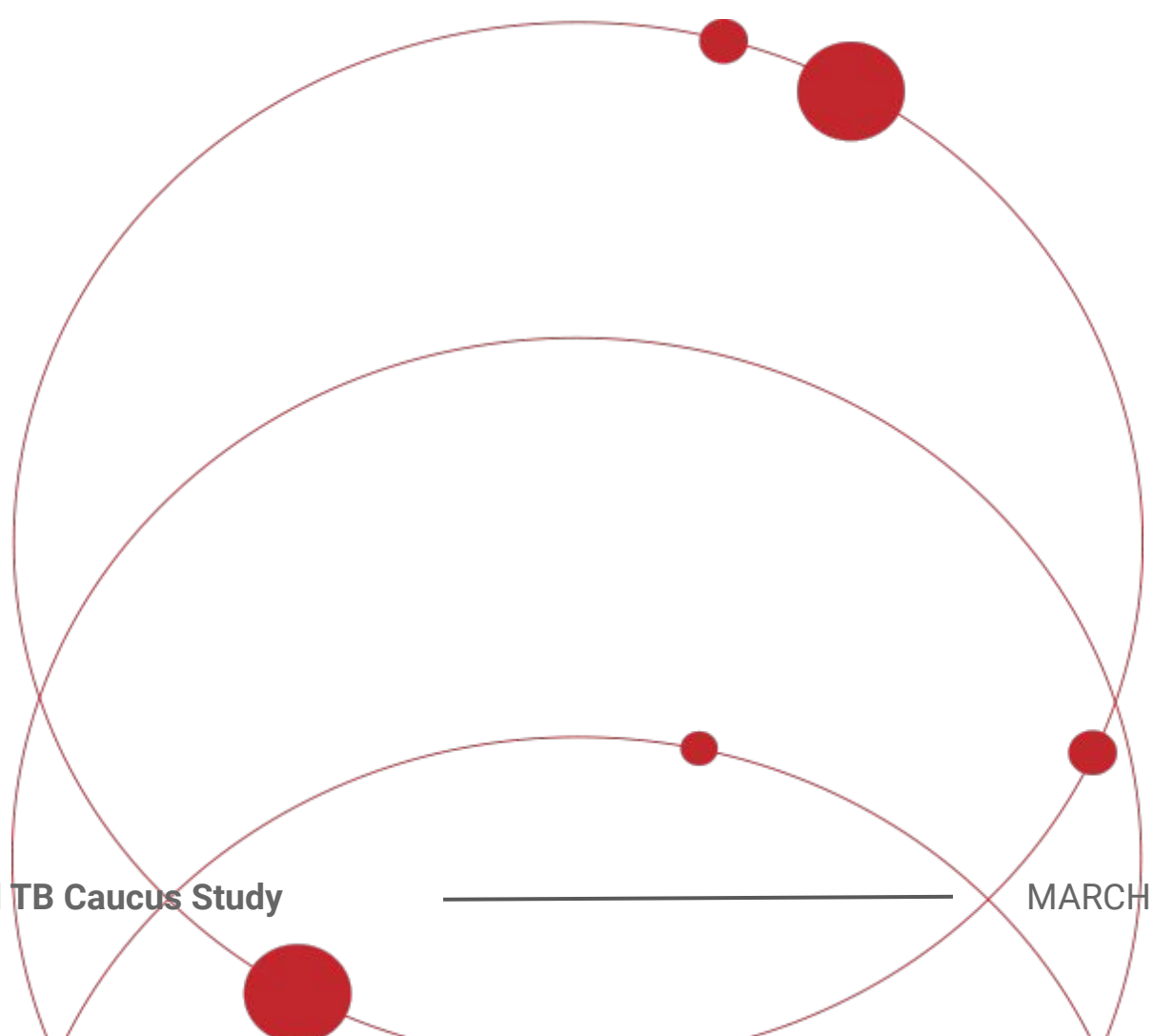


Table of Contents

01	Acknowledgments
02	Introduction
03	Background
05	Methodology & Limitations
06	Research Framework
08	10 Key Results & Takeaways
09	Full Results & Analysis
09	Tuberculosis Laws
10	Infectious Disease Laws
11	Public Health and Health Care Laws
12	Labor Laws
13	15 Essential Recommendations

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Introduction

The Global TB Caucus is a unique international network of more than 2,500 parliamentarians with a presence in more than 150 countries. The Caucus works collectively and individually through its members to end TB.

This Global TB Caucus study is part of an initiative to promote people-centered, rights-based TB legislation in Eastern Europe and Central Asia. The study is part of the Tuberculosis Regional Eastern European and Central Asian 2.0 Project (TB-REP 2.0) administered by the Center for Health Policies and Studies (PAS Center) to advance quality, people-centered TB care in the region with support from the Global Fund Strategic Initiatives program.

This study comprises **11 countries** in Eastern Europe and Central Asia:

Republic of Armenia, Republic of Azerbaijan, Republic of Belarus, Georgia, Republic of Kazakhstan, Kyrgyz Republic, Republic of Moldova, Republic of Tajikistan, Republic of Turkmenistan, Ukraine, and Republic of Uzbekistan

This study's **objectives** are to:

- Complete a legislative landscape survey to identify and analyze laws related to TB in the study countries; and
- Develop recommendations for people-centered, rights-based TB legislation in the region.

Background

In 2018, the United Nations (UN) General Assembly held the first-ever High-Level Meeting on the Fight against Tuberculosis (UNHLM). In a Political Declaration produced at the meeting, Heads of State committed to a series of ambitious targets to end TB by 2030. In addition to successfully treating 40 million people with TB by 2022, countries made many other pioneering commitments. These include increasing financing for TB, enabling a multisectoral disease response, meaningfully engaging civil society and affected communities, ensuring social protection for vulnerable groups, providing treatment support and people-centered, community-based care, reforming discriminatory laws, and protecting and promoting the human rights of people affected by TB.¹

In 2020, delegations to the Board of the Stop TB Partnership representing civil society organizations and communities affected by TB around the world published *A Deadly Divide: TB Commitments vs. TB Realities*. Based on consultations with members of civil society and people affected by TB in more than 60 countries, the report highlights progress made towards fulfilling the UNHLM Political Declaration and draws attention to the deadly divide between countries' commitments and the reality of what has been delivered on the ground. To close this gap, the report makes six calls for action: (1) reach all people through TB prevention, diagnosis, treatment, and care through ambitious and time-bound national targets; (2) make the TB response rights-based, equitable, and stigma-free, with communities at the center; (3) accelerate the development of, and access to, essential new tools to end TB; (4) invest the funds necessary to end TB; (5) commit to accountability, multisectoral cooperation, and leadership on TB; and (6) leverage COVID-19 as a strategic opportunity to end TB.

In line with the UNHLM Political Declaration and these urgent calls for action, this study builds on the Global TB Caucus's **legislative work in the Americas** and its *Key Considerations for Tuberculosis Legislation*. This study is also predicated on the recent technical brief on TB and human rights, *Activating a Human Rights-Based Tuberculosis Response*, written by Brian Citro in partnership with the Global Coalition of TB Activists, Stop TB Partnership, and Northwestern Pritzker School of Law Bluhm Legal Clinic. Brian Citro's fieldwork in **Azerbaijan** and **Tajikistan** as a Senior Research Officer for the United Nations Special Rapporteur on the Right to Health and the Stop TB Partnership's

¹United Nations General Assembly, *Political Declaration of the High-Level Meeting of the General Assembly on the Fight against Tuberculosis*, UN Doc. A/RES/73/3 (Oct. 18, 2018). Available at <https://digitallibrary.un.org/record/1649568?ln=en>.

Community, Rights and Gender (CRG) Assessments in Eastern Europe and Central Asia also informed this study.

In 2021, the Stop TB Partnership Country and Community Support for Impact Team, people affected by TB in the Democratic Republic of the Congo, Indonesia, and Ukraine, and Brian Citro published a technical analysis of the findings from CRG Assessments conducted in 20 countries, including Georgia, Kazakhstan, Kyrgyzstan, Tajikistan, and Ukraine. The research and analysis in the article, entitled ***Building the Evidence for a Rights-Based, People-Centered, Gender-Transformative Tuberculosis Response: An Analysis of the Stop TB Partnership Community, Rights, and Gender Tuberculosis Assessment***, further laid the groundwork for this study.²

This study is also based on discussions, debates, and information shared during three regional workshops the Caucus conducted from September to December 2021. These workshops involved the study's researchers and project manager, the TB-REP 2.0 national focal points, Dr. Jennifer Furin of Harvard Medical School, honorable Members of Parliament from Armenia, Belarus, Kazakhstan, Tajikistan, and Ukraine, and members of civil society and groups of people affected by TB from around the region.

² Brian Citro et al., *Building the Evidence for a Rights-Based, People-Centered, Gender-Transformative Tuberculosis Response: An Analysis of the Stop TB Partnership Community, Rights, and Gender Tuberculosis Assessment*, 23 Health and Human Rights Journal 2, 253-267 (Dec. 2021).

Methodology & Limitations

The researchers conducted online legal research to identify the legislation in this study using the following websites, databases, and search engine:

- Official government websites of the study countries.
- **CIS Legislation** (a database of legislation in members of the Commonwealth of Independent States).
- **International Labour Organization NATLEX** (a database of national labor, social security, and related human rights legislation).
- Google Search.

The researchers read and used keyword searches to analyze the legislation following the research framework detailed below. They then invited external reviewers to review and provide feedback on the research findings, report, and recommendations. The researchers received and incorporated feedback from five external reviewers, including a TB doctor, a TB survivor, and other experts.

This study was subject to two main limitations. First, the researchers could not travel to the study countries due to the ongoing COVID-19 pandemic. They relied on desk-based research, email communications, and video conferencing. Second, the researchers are native English speakers. They used Google Translate and other machine translations provided by the Commonwealth of Independent States (CIS) Legislation database and official government websites to translate legislation into English. In addition, to reviewing the translated legislation, the researchers conducted keyword searches in the original language of each law. The three workshops associated with this study involved simultaneous English and Russian translation.

Research Framework

This study's research framework has five main aspects.

First, this study involved 11 countries in Eastern Europe and Central Asia, as listed above.

Second, this study reviewed enacted legislation in the study countries as the primary source of law.³

Third, this study focused on 5 types of legislation:

1. TB laws
2. Infectious disease laws
3. Public health, health care, and health system laws
4. Sanitation and epidemiology laws
5. Labor laws

Fourth, this study relied on a variety of normative sources to analyze the legislation:

Global TB Plans and Commitments	Normative Legislative and Legal Sources	Global TB Standards
<ul style="list-style-type: none"> ✓ <i>Political Declaration of the UN General Assembly High-Level Meeting on Tuberculosis</i>, UN General Assembly ✓ <i>End TB Strategy</i>, WHO ✓ <i>Global Plan to End TB</i>, Stop TB Partnership 	<ul style="list-style-type: none"> ✓ <i>Good Practice in Legislation and Regulations for TB Control: An Indicator of Political Will</i>, WHO ✓ <i>Key Considerations for Tuberculosis Legislation</i>, Global Fund, Stop TB Partnership, Global TB Caucus ✓ <i>General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12)</i>, UN Committee on Economic, Social and Cultural Rights ✓ <i>Declaration of the Rights of People Affected by TB</i>, Stop TB Partnership, TBpeopleE ✓ <i>Activating a Human Rights-Based TB Response: A Technical Brief for Policymakers and Program Implementers</i>, Stop TB Partnership, Global Coalition of TB Activists, Northwestern Pritzker School of Law Bluhm Legal Clinic 	<ul style="list-style-type: none"> ✓ <i>International Standards for Tuberculosis Care (3rd ed)</i> ✓ <i>Ethics Guidance for the Implementation of the End TB Strategy</i>, WHO

³ Exception: the study reviewed a ministerial order on TB in Armenia in the absence of TB legislation in the country.

Fifth, the researchers developed a series of questions based on these normative sources with which to analyze legislation in the study countries:

TB Laws	<ol style="list-style-type: none"> 1. Is there is a list of patient obligations or responsibilities? 2. Is there a list of rights? 3. Is the right to nondiscrimination based on health status protected? 4. Are the rights to privacy or confidentiality protected? 5. Are employment rights provided? 6. Is the right to information provided? 	<ol style="list-style-type: none"> 7. Is judicial protection of rights or access to legal remedies provided? 8. Is social protection provided? 9. Is treatment support, such as counseling, food, or travel expenses, provided? 10. Is disability status recognized? 11. Is TB recognized as an occupational disease (not limited to health workers)? 	<ol style="list-style-type: none"> 12. Are TB key or vulnerable populations recognized? 13. Is a role for civil society organizations provided? 14. Is compulsory hospitalization or treatment permitted? 15. Are court procedures or the right to appeal for compulsory hospitalization, treatment, or isolation provided?
Infectious Disease, Public Health, Health Care, Health System, and Sanitation & Epidemiology Laws	<ol style="list-style-type: none"> 1. Is TB explicitly addressed? 2. Is there is a list of patient obligations or responsibilities? 3. Is there a list of rights? 4. Is the right to nondiscrimination based on health status protected? 5. Are the rights to privacy or confidentiality protected? 6. Is the right to information provided? 	<ol style="list-style-type: none"> 7. Are employment rights provided? 8. Is judicial protection of rights or access to legal remedies provided? 9. Is social protection provided? 10. Is disability status recognized? 11. Is a role for civil society organizations provided? 	<ol style="list-style-type: none"> 12. Is compulsory hospitalization or treatment <i>required</i>? 13. Is compulsory hospitalization or treatment <i>permitted</i>? 14. Are court procedures or the right to appeal for compulsory hospitalization, treatment, or isolation provided?
Labor Laws	<ol style="list-style-type: none"> 1. Is TB explicitly addressed? 2. If TB is addressed, is it recognized as an occupational disease (not limited to health workers)? 3. Are infectious diseases explicitly addressed? 4. Is worker's health recognized and protected? 	<ol style="list-style-type: none"> 5. Is the right to nondiscrimination protected? 6. Is discrimination based on TB prohibited? 7. Is discrimination based on HIV prohibited? 8. Is discrimination based on infectious disease prohibited? 	<ol style="list-style-type: none"> 9. Is discrimination based on health status prohibited? 10. Is discrimination based on disability prohibited? 11. Is discrimination based on "other" status prohibited?

10 Key Results & Takeaways

- 1. None of the laws in this study prohibit discrimination against people affected by TB.**
- 2. All the TB and infectious disease laws allow compulsory hospitalization or treatment, but 25% of the TB laws and 67% of the infectious disease laws do not provide court procedures or the right to appeal.**
- 3. None of the TB laws provide a role for civil society or community groups in the disease response, but all the infectious disease laws and 70% of the public health and health care laws do.**
- 4. Only one TB law and none of the infectious disease laws protect the rights to privacy or confidentiality, but 80% of the public health and health care laws do.**
- 5. None of the labor laws and only one TB law recognize TB as an occupational disease for all workers (not limited to health workers).**
- 6. Only one TB law provides judicial protection of rights or access to legal remedies.**
- 7. Only 25% of the TB laws recognize TB key or vulnerable populations.**
- 8. 75% of the TB laws include lists of both patient obligations and rights.**
- 9. Approximately 40% of the TB laws do not provide employment rights for people affected by TB.**
- 10. All the infectious disease, public health, and health care laws, and 75% of the TB laws provide the right to information.**

Full Results & Analysis

Tuberculosis Laws

7 of 11 countries in the study, or 64%, have laws on TB—i.e., legislation that is specific to TB:

1. Azerbaijan (No. 875-IQ, 2000)
2. Georgia (No. 4629-Il, 2015)⁴
3. Kyrgyzstan (No. 65, 1998)
4. Moldova (No.153-XVI, 2008)

5. Tajikistan* (No. 1413, 2017)
6. Ukraine (No. 2586-III, 2001)
7. Uzbekistan (No. 215-II-son, 2001)
- Armenia** (No. 21-N, 2008)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	Patient obligs	List of rights	Non-discrim	Privacy Confid	Empl rights	Right to info	Jud protect	Social protect	Treat supp	Disabl	Occup disease	Key vuln groups	Civil society	Comp hosp treat	Appeal court proc
Azerbaijan (2000)	Yes	Yes	No	No	Yes	Yes	No	Yes	Yes	Yes	Yes	No	No	Yes	No
Georgia (2016)	No	No	No	No	No	No	No	Yes	Yes	No	No	No	No	Yes	Yes
Kyrgyzstan (1998)	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes
Moldova (2008)	Yes	Yes	No	No	No	Yes	No	Yes	No	Yes	No	No	No	Yes	Yes
Tajikistan* (2017)	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	No	Yes	Yes
Ukraine (2001)	Yes	Yes	No	No	Yes	Yes	No	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Uzbekistan (2001)	Yes	Yes	No	No	Yes	Yes	No	Yes	Yes	Yes	No	No	No	Yes	Yes
Armenia** (2008)	No	No	No	No	No	No	No	No	No	No	No	Yes	No	Yes	No
	75% Y 25% N	75% Y 25% N	0% Y 100% N	13% Y 88% N	63% Y 38% N	75% Y 25% N	13% Y 88% N	88% Y 13% N	75% Y 25% N	75% Y 25% N	13% Y 88% N	25% Y 75% N	0% Y 100% N	100% Y 0% N	75% Y 25% N

⁴ Entered into force January 1, 2016.

*TB chapter in a larger health law

**Ministry of Health order on TB, not legislation

Infectious Disease Laws

3 of 11 countries in the study, or 27%, have infectious disease laws:

1. Belarus (No. 345-3, 2012)
2. Turkmenistan (No. 2506, 2021)
3. Ukraine (No. 1645-III, 2000)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
	TB	Patient obligs	List of rights	Non-discrim	Privacy confid	Empl rights	Right to info	Judicial protect	Social protect	Disabl	Civil society	Comp hosp treat req	Comp hosp treat perm	Appeal court proc
Belarus (2012)	No	Yes	Yes	No	No	No	Yes	No	No	No	Yes	No	Yes	Yes
Turkmenistan (2021)	Yes	Yes	Yes	No	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No
Ukraine (2000)	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
	67% Y 33% N	100% Y 0% N	100% Y 0% N	0% Y 100% N	0% Y 100% N	33% Y 67% N	100% Y 0% N	33% Y 67% N	67% Y 33% N	67% Y 33% N	100% Y 0% N	67% Y 33% N	100% Y 0% N	33% Y 67% N

Public Health and Health Care Laws

10 of 11 countries in the study, or 91%, have public health or health care laws:

1. Azerbaijan

(No. 360-IQ, 1997, public health)

2. Belarus

(No. 2435-XII, 1993, health care)

3. Georgia

(No. 5069-ES, 2015, public health)

4. Kazakhstan

(No. 360-VI 3PK, 2020, public health & health system)

5. Kyrgyzstan

(No. 6, 2005, public health)

6. Moldova*

(No. 411-XIII, 1995, health protection & health care; No. 263-XVI, 2005, patient rights & obligations; No. 10-XVI, 2009, public health)

7. Tajikistan

(No. 1413, 2017, health care)

8. Turkmenistan

(No. 223-V, 2015, public health)

9. Ukraine

(No. 2801-XII, 1992, health care)

10. Uzbekistan

(No. 265-I-son, 1996, public health)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
	TB	Patient obligs	List of rights	Non-discrim	Privacy confid	Empl rights	Right to info	Judicial protect	Social protect	Disabl	Civil society	Comp hosp treat req	Comp hosp treat perm	Appeal court proc
Azerbaijan (1997, public health)	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	Yes	No	No	Yes	No
Belarus (1993, health care)	Yes	Yes	Yes	No	Yes	No	Yes	No	No	Yes	Yes	No	Yes	No
Georgia (2015, public health)	Yes	Yes	Yes	No	No	No	Yes	No	No	No	No	No	Yes	No
Kazakhstan (2020, public health & health system)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Kyrgyzstan (2005, public health)	No	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	No	No	No	n/a
Moldova* (1995, health protection & health care; 2005, patient rights & obligations; 2009, public health)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Tajikistan (2017, health care)	Yes	Yes	Yes	No	No	No	Yes	No	Yes	Yes	Yes	No	Yes	Yes
Turkmenistan (2015, public health)	No	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	n/a
Ukraine (1992, health care)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Uzbekistan (1996, public health)	No	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	n/a
	70% Y 30% N	80% Y 20% N	100% Y 0% N	30% Y 70% N	80% Y 20% N	20% Y 80% N	100% Y 0% N	70% Y 30% N	80% Y 20% N	90% Y 10% N	70% Y 30% N	0% Y 100% N	80% Y 20% N	50% Y 50% N

*Moldova's assessment includes multiple laws because public health, health care, and patient's rights and obligations are addressed across several pieces of legislation.

Labor Laws

All the countries in the study, or **100%**, have labor laws:

- 1. Armenia** (No. ZR-124, 2004)
- 5. Kazakhstan** (No. 414-V ZRK, 2015)
- 9. Turkmenistan** (No. 30-IV, 2009)
- 2. Azerbaijan** (No. 618-IQ, 1999)
- 6. Kyrgyzstan** (No. 106, 2004)
- 10. Ukraine** (No. 322-VIII, 1971)
- 3. Belarus** (No. 296-Z, 1999)
- 7. Moldova** (No. 154-XV, 2003)
- 11. Uzbekistan** (No. 161, 1995)
- 4. Georgia** (No. 4113-რს, 2010)
- 8. Tajikistan** (No. 1329, 2016)

	1	2	3	4	5	6	7	8	9	10	11
	TB	TB occup disease	Infectious disease	Workers' health	Non-discrim	TB discrim	HIV discrim	Infect disease discrim	Health status discrim	Disability discrim	Other status discrim
Armenia (2004)	No	n/a	No	Yes	Yes	No	No	No	No	Yes	Yes
Azerbaijan (1999)	Yes	No	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes
Belarus (1999)	No	n/a	No	Yes	Yes	No	No	No	No	Yes	Yes
Georgia (2010)	No	n/a	No	Yes	Yes	No	No	No	Yes	Yes	Yes
Kazakhstan (2015)	No	n/a	No	Yes	Yes	No	No	No	No	Yes	No
Kyrgyzstan (2004)	No	n/a	No	Yes	Yes	No	No	No	No	No	No
Moldova (2003)	No	n/a	No	Yes	Yes	No	Yes	No	No	Yes	Yes
Tajikistan (2016)	No	n/a	No	Yes	Yes	No	No	No	No	No	No
Turkmenistan (2009)	No	n/a	No	Yes	Yes	No	No	No	No	Yes	Yes
Ukraine (1971)	No	n/a	No	Yes	Yes	No	Yes	No	Yes	Yes	Yes
Uzbekistan (1995)	Yes	No	Yes	Yes	Yes	No	No	No	No	No	Yes
	18% Y 82% N	0% Y 100% N	18% Y 82% N	100% Y 0% N	100% Y 0% N	0% Y 100% N	27% Y 73% N	0% Y 100% N	18% Y 82% N	73% Y 27% N	73% Y 27% N

15 Essential Recommendations

Based on the results of this study and in line with the UNHLM Political Declaration, the *Deadly Divide* report calls to action, and the Global TB Caucus's prior legislative work, the Caucus sets forth 15 essential recommendations to promote people-centered, rights-based TB legislation in Eastern Europe and Central Asia:

1. **Prohibit all forms of discrimination of people affected by TB**, including, but not limited to, in employment, health care, education, and housing.
2. **Eliminate mandatory, compulsory, or forced treatment of people with TB** in all circumstances in line with the WHO *Ethics Guidance on the Implementation of the End TB Strategy*.
3. **Eliminate mandatory or compulsory hospitalization and isolation of people with TB except in extremely rare cases**, only as a last resort after all other approaches have been tried and failed, based on a court decision with the right to appeal, and only when a person presents a high risk of transmission of TB to others because of treatment non-initiation or lack of infection control measures.
4. **Establish as the national standard people-centered TB care**, including outpatient and community-based treatment and preventive therapy with individualized treatment support in line with the *International Standards for Tuberculosis Care*.
5. **Designate roles and provide technical and financial support for civil society and community groups to participate in the TB response**, including during the formulation of regulations and programmatic and policy decision-making and implementation.
6. **Protect the rights to privacy and confidentiality of people affected by TB**, including, but not limited to, in employment, health care, and education, and during public health interventions, such as screening, contact tracing, and active case finding.
7. **Designate TB as an occupational disease**, including, but not limited to, people who work in health care settings and miners, for which sufficient benefits are provided by law in an accessible manner, sensitive to the needs of people affected by TB.

8. **Ensure rights created in TB legislation are judicially enforceable with appropriate remedies**, providing people affected by TB the right to bring claims under the law in court and, where feasible, other adjudicatory bodies in the executive branch.
9. **Recognize and afford special attention to TB key and vulnerable populations** based on national and local circumstances.
10. **Remove patient "obligations," "responsibilities," and "duties" from TB legislation** to be included, if at all, in non-legislative guidelines or recommendations for patients.
11. **Provide employment rights for people affected by TB**, such as paid sick leave, flexible working hours, protection against termination and dismissal, light-duty, if necessary, and other temporary or permanent arrangements.
12. **Ensure access to social protection and temporary disability benefits for people with TB** as a legal right during treatment and afterward for individuals with long-term medical needs by linking TB legislation with existing social protection and disability legislation and programs.
13. **Provide treatment support for people with TB**, such as psychosocial counseling, food and nutrition support, and compensation for transportation and other expenses associated with their treatment.
14. **Ensure sufficient and sustainable financing for TB programs**, including for human resources, and to purchase and integrate new TB drugs, diagnostics, and vaccines, including preventive therapies, when they become available and recommended for use by WHO.
15. **Acknowledge and grant institutional authority and responsibility in a multisectoral manner** including relevant ministries and agencies, such as health, labor, justice, education, social protection, family, and the environment.

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