

Report

Assessment of Tuberculosis Stigma in Ukraine

Kyiv 2024

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List of abbreviations

BCG - a vaccine designed to protect infants and young children against the most severe forms of TB

HIV - human immunodeficiency virus

WHO - World Health Organization

VRU - Verkhovna Rada of Ukraine

SCES - State Criminal Executive Service

DOT - direct supervision of medical workers over the intake of anti-TB drugs

USRCD - Unified State Register of Court Decisions

ECPHRFF - European Convention for the Protection of Human Rights and Fundamental Freedoms

ECHR - European Convention on Human Rights

ECtHR - European Court of Human Rights

ESC - European Social Charter

Media - mass media

HCF - Health care facilities

LU - Law of Ukraine

IRP - individual rehabilitation program

TDF - Temporary detention facility

LC - Code of Labor Laws

CC - Criminal Code

PCELLB - Program Classification of Expenditures and Lending of Local Budgets

CEAFDAW - Convention on the Elimination of All Forms of Discrimination Against Women

CMU - Cabinet of Ministers of Ukraine

CRC - Convention on the Rights of the Child

CRPD - Convention on the Rights of Persons with Disabilities

CUAO - Code of Ukraine on Administrative Offenses

PLHIV - person living with HIV

MAC - medical advisory commission

DR-TB - drug-resistant tuberculosis

LTBI - latent tuberculosis infection

MIA - Ministry of Internal Affairs

ICEAFRD - International Convention on the Elimination of All Forms of Racial Discrimination

ISCD - International Statistical Classification of Diseases and Related Health Problems

MDR-TB - multidrug-resistant tuberculosis (previously used the term XDR-TB)

ICCPR - International Covenant on Civil and Political Rights
ICESCR - International Covenant on Economic, Social, and Cultural Rights
MOH - Ministry of Health of Ukraine
MES - Ministry of Education and Science of Ukraine
MSEC - Medical and Social Expert Commission
ILO - International Labor Organization
NPM - National Preventive Mechanism
NHSU - National Health Service of Ukraine
NGOs - non-governmental organizations
UN - United Nations Organization
PHC - primary health care
Vocational school - vocational educational institution
RNTAC - registration number of the taxpayer's account card
PTDC - pre-trial detention center
AIDS-acquired immunodeficiency syndrome
TB - tuberculosis
PI of the SCES - Penitentiary institutions of the State Criminal Execution Service of Ukraine
FGD - focus group discussions
PHC - Public Health Center
XDR-TB - extensively drug-resistant tuberculosis
HRBA-approach - Human rights-based approach
UNESCO (United Nations Educational, Scientific and Cultural Organization) - United Nations Educational, Scientific and Cultural Organization
UNAIDS (Joint United Nations Program on HIV/AIDS) - Joint United Nations Program on HIV/AIDS

Research Methodology

The purpose of the research

The main objective of the research is to assess the extent to which TB-related stigma is a barrier to access and delivery of TB diagnostic, treatment, and prevention services, and to develop recommendations for overcoming TB stigma in the country.

Research objectives

The research aims to solve the following tasks:

- 1) to assess the level and extent of perceived and experienced stigma, as well as self-stigma ("inner stigma") among people diagnosed with TB;
- 2) assess the level and extent of secondary stigma, i.e. stigma experienced by people diagnosed with TB and stigma experienced by family members/caregivers of people diagnosed with TB;
- 3) assess the level of stigma of people diagnosed with TB in the community and the stigma observed by the community;
- 4) to understand the level and extent of perceived stigma in health care facilities (HCFs) towards people diagnosed with TB and towards health care workers working with people with TB;
- 5) to understand the extent to which stigma at structural levels - within existing laws and policies and in the media - can harm or protect people with TB;
- 6) to obtain information to develop recommendations for overcoming TB stigma to reduce people's vulnerability to TB infection, increase access to TB services, and improve treatment outcomes.

Research design

The fieldwork stage was conducted in December 2023-March 2024. The following components of the research were conducted:

- 1) Quantitative survey of patients with tuberculosis (new cases of tuberculosis and cases of repeated treatment of tuberculosis that were registered during 2021-2022 (in the state TB register)); survey method: telephone interviews (computer-assisted telephone interviews). Sample size: 669 respondents.
- 2) Quantitative survey of family members of TB patients or their relatives who are direct caregivers; survey method: computer-assisted telephone interviews. Sample size: 44 respondents.
- 3) Quantitative survey of representatives of the community where people with TB live; survey method: personal interviews (computer-assisted personal interviews). Sample size: 39 respondents.

4) Quantitative survey of healthcare workers involved in the diagnosis/treatment of TB patients; survey method: computer-assisted telephone interviews. Sample size: 114 respondents.

5) Qualitative survey (focus group discussions (FGD)) with stakeholders (TB program managers at the national and regional level, lawyers, politicians, media representatives, donors, NGOs, etc.); method of survey: online via Zoom. Two online FGDs were conducted (6-7 people each).

The inclusion of this particular configuration of target groups in the research is explained by the need to compare data with the previous wave, which was conducted in 2021 and used a similar data collection methodology.

The distribution of the quantitative survey sample by region is shown in the table below. The comparison of the sample by the regions is not provided, as the population of the regions has changed compared to the previous survey (in particular, due to the full-scale war).

Table 1. Distribution of the quantitative survey respondents by region

Area	Region	People with TB	Family members/relatives	Community representatives	Health care workers
Center	Kirovograd	76	5	8	13
	Poltava	28	2	5	20
	Cherkasy	111	6	5	10
North	Kyiv	86	7	5	15
	Kyiv city	68	18	6	12
West	Volyn	77	5	5	18
	Lviv	67	1	5	17
East	Dnipropetrovsk	110	-	-	1
South	Odesa	46	-	-	8
Total (2024)		669	44	39	114
<i>Total (2021)</i>		<i>1101</i>	<i>45</i>	<i>43</i>	<i>248</i>

Methods and procedures

As the research took place during the full-scale russian aggression against Ukraine, remote data collection methods were chosen for most target groups. Four target groups - people with TB, their family members, community representatives, and healthcare workers - were interviewed

by phone using a standardized questionnaire "TB Stigma Assessment" that was adapted to the Ukrainian context.

Data was collected using Info Sapiens in-house software by Info Sapiens interviewers who are experienced in surveying vulnerable groups and have received special training on the specifics of the project. Stakeholders participated in two online focus group discussions.

Recruitment of people with TB and health care workers in the regions was carried out by the regional coordinators (RCs) of the study, who were health care workers at TB facilities and had access to the TB registry. The selection of people with TB for the survey was done randomly with a specified step. If a candidate was interested in participating in the survey, the RC passed his/her contact phone number to the interviewers.

Family members were recruited through respondents who completed the survey: interviewers asked people with TB to provide the interviewers with the phone number of relatives living with the person with TB.

The recruitment of local community representatives for the study was carried out in the following way: Info Sapiens interviewers invited random people who live near the TB clinic or regularly visit the area because of their occupation. Community representatives were interviewed in person.

Survey participants received monetary compensation for their time.

Data analysis

Analysis of the qualitative component was based on the focus group data. FGD records were transcribed and transcripts were created for further analysis.

Quantitative survey data were analyzed using specialized software (SPSS). Based on these data, the key research objectives were solved through hypothesis testing and descriptive analysis, including the following:

- analysis of key variable distributions;
- analysis of subgroups;
- analysis of indicators according to the global TB stigma assessment guidelines;
- comparison of the study results with the results of the first TB stigma survey conducted in 2020-2021 (<https://network.org.ua/doslidzhennya-otsinyuvannya-stygmy-shhodo-tuberkulozu-v-ukrayini/>);
- comparison of mean values and proportions between subgroups;

The list of indicators for the analysis complied with the global TB stigma assessment guidelines:

- indicators for determining the "TB stigma radar" - a comprehensive assessment of self-stigmatization (see Appendix 1 for details);
- secondary stigma in the family, perceived stigma in the community and among health care workers;
- separate stigma measurements within each target group;
- indicators of experienced stigma in TB diagnosis and treatment, including the extent to which it interfered with service seeking and service utilization;
- indicators of stigma that target groups have observed in other people while receiving TB diagnosis and treatment;
- indicators to evaluate the legislative and policy context in terms of its impact on TB-related stigma and discrimination.

The stigma scales are adapted versions of the following instruments: the Van Rie et al. Stigma Assessment Questionnaire for People with TB and the Community¹; the R. A. Arcêncio et al. to assess secondary stigma faced by family members of people with TB²; Corrigan et al. nine-dimensional stigma questionnaire (AQ-9)³.

The data on respondents with TB were weighted by age and gender in accordance with the age and gender structure of people with TB.

In the graphs and tables of the report, statistically significant differences between 2024 and 2021, as well as statistically significant differences between subgroups of respondents and the sample mean, are highlighted in color: green indicates significantly higher values, and red indicates statistically significantly lower values.

Ethical aspects

The study protocol and instruments were ethically approved by the Ethics Committee of the Public Health Center. All study participants provided verbal informed consent to participate in the study.

¹ Van Rie A, Sengupta S, Pungrassami P, Balthip Q, Choonuan S, Kasetjaroen Y, Strauss RP, Chongsuvivatwong V. Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales. *Trop Med Int Health*. 2008 Jan;13(1):21—30. doi: 10.1111/j.1365—3156.2007.01971.x. PMID: 18290998.

² Arcêncio, R. A., de Almeida Crispim, J., Touse, M. M., Popolin, M. P., Rodrigues, L. B., de Freitas, I. M., Yamamura, M., & Neto, M. S. (2014). Preliminary validation of an instrument to assess social support and tuberculosis stigma in patients' families. *Public health action*, 4(3), 195—200. <https://doi.org/10.5588/pha.13.0095>

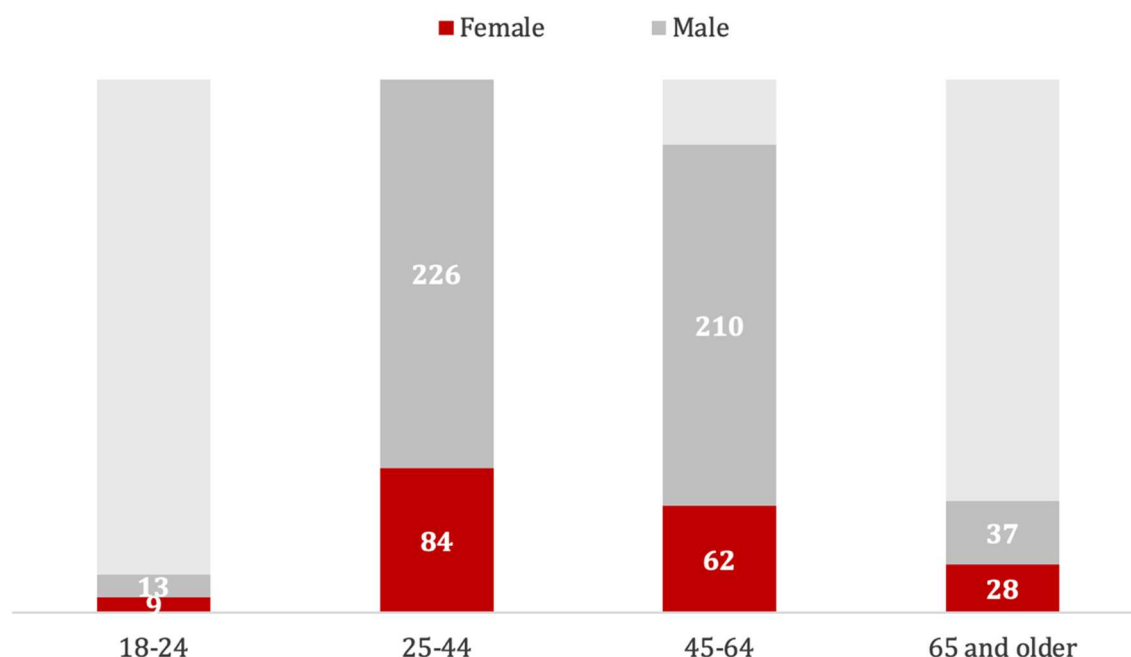
³ Corrigan, Patrick W.; Watson, Amy C.; Warpinski, Amy C.; Gracia, Gabriela (1 August 2004). "Stigmatizing Attitudes About Mental Illness and Allocation of Resources to Mental Health Services". *Community Mental Health Journal*. 40 (4): 297—307.

Participants' Profile

People with TB

The majority (73%) of people with TB were men and belonged to the age group 25-44 years (47%) or 45-64 years (41%). None of the respondents reported being transgender or having other gender identities.

Figure 1. Distribution of participants with TB by age and gender, persons (n=669)

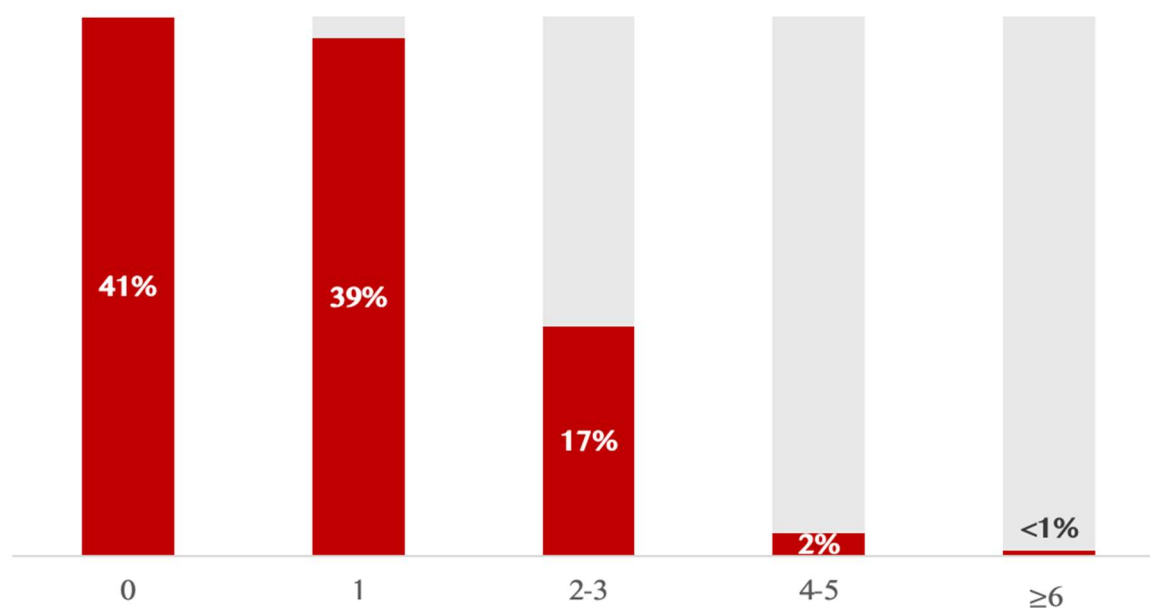


The top 5 most common groups people with TB identified themselves with were: elderly people; people with HIV; people with TB-related disabilities; former prisoners; and low-income urban residents (Table 2). More than a third (39%) identified themselves with one group from the list, 17% chose two or three groups, and 2% chose four or more groups (Fig. 2). 41% did not identify themselves with any of the key groups.

Table 2. Self-identification of participants with TB to different key populations, persons, and % (n=669)

Key groups ("multiple choices" were possible, the total does not equal 100%)	n	%
Elderly people (over 60 years old)	98	15%
A person with HIV	83	12%
A person with a TB-related disability	83	12%
Former prisoners	44	7%
Low-income urban residents	39	6%
A person with a disability caused by other diseases	33	5%
Internally displaced person	31	5%
Participants of the anti-terrorist operation	30	4%
Low-income residents of villages	28	4%
Smokers who smoke more than 40 cigarettes a day	24	4%
People with diabetes	21	3%
Relatives of people with TB	13	2%
Health care worker (not TB care worker)	12	2%
People who inject drugs	11	2%
People with alcohol addiction	11	2%
People with mental disorders	10	1%
Homeless people	7	1%
Non-healthcare workers who have frequent professional contact with people with TB	7	1%
Refugee	6	1%
Health care worker (TB care worker)	4	1%
Miner/person diagnosed with silicosis	4	1%
Do not belong to any of the groups	275	41%
Total	669	100%

Figure 2. Distribution of the number of key groups people with TB identified themselves with, % (n=669)



The majority of respondents (72%) had already completed TB treatment at the time of the interview, including 44% of respondents who received treatment more than a year ago. 28% of respondents were receiving treatment at the time of the survey. Only two respondents diagnosed with TB had not started treatment because they were diagnosed before the survey.

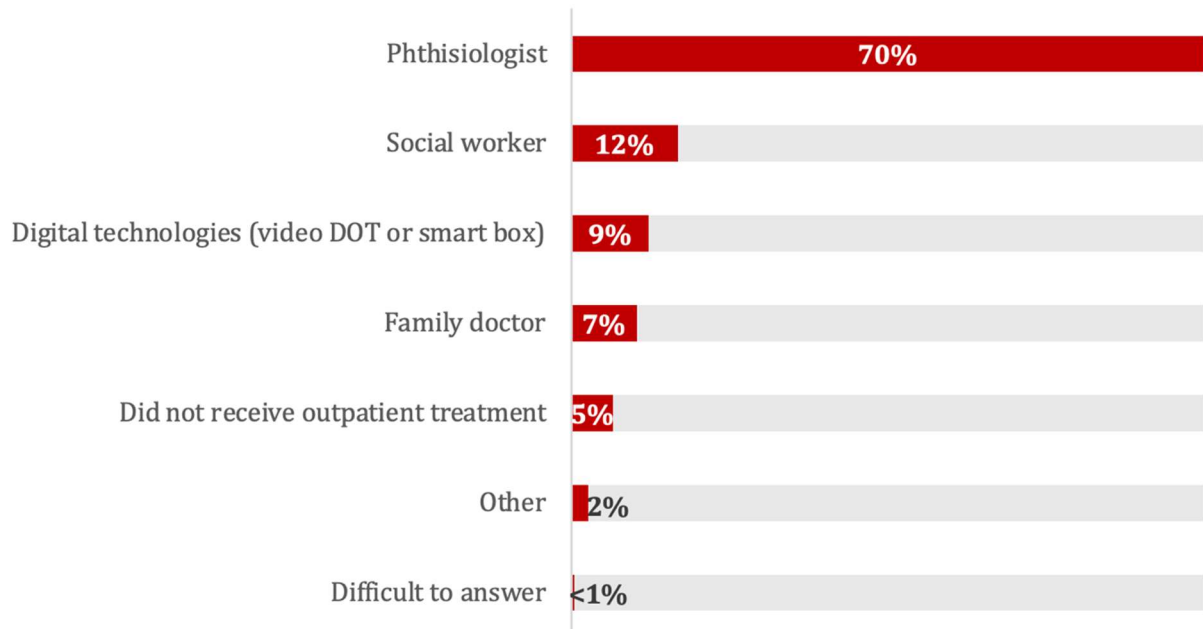
In general, only 17% of participants knew what form of TB they had and whether they had drug resistance to anti-TB drugs (Table 3). Among those who knew their form of TB, there were mostly respondents with pulmonary-sensitive TB (9%).

Table 3. Distribution of participants with TB by TB location and presence of drug resistance to anti-TB drugs, persons, and %. (n=669)

	Pulmonary TB		Extrapulmonary TB / Both forms		Does not know		Total	
	n	%	n	%	n	%	n	%
Sensitive TB	46	9%	9	11%	6	6%	61	9%
MDR-TB	22	5%	5	7%	1	1%	29	4%
XDR-TB	23	5%	2	2%	1	1%	25	4%
Does not know	398	81%	63	80%	94	92%	554	83%
Total	489	100%	79	100%	102	100%	669	100%

The majority of respondents (70%) received outpatient TB treatment according to the DOT model in a health care facility - visits to a TB hospital or primary care facility to receive medications and monitoring of drug intake by a phthisiologist (Figure 3).

Figure 3. Distribution of answers to the question: "Who supervised your outpatient (not inpatient) TB treatment, gave you pills, monitored your medication intake?" (n=669)



Family members

The sample of family members of people with TB consisted mainly of women (33 out of 44 respondents, 75%) and people aged 45-64 years (19 out of 44, 43%). The oldest group (65 years and older) was represented exclusively by women (Figure 4).

Relatives of the first level of kinship - parents/mothers, brothers/sisters, or children - accounted for only 38% of the total number of respondents (Figure 5). Mostly people with TB involved other relatives in the interview.

Figure 4. Distribution of family members of TB patients by age and gender, persons (n=44)

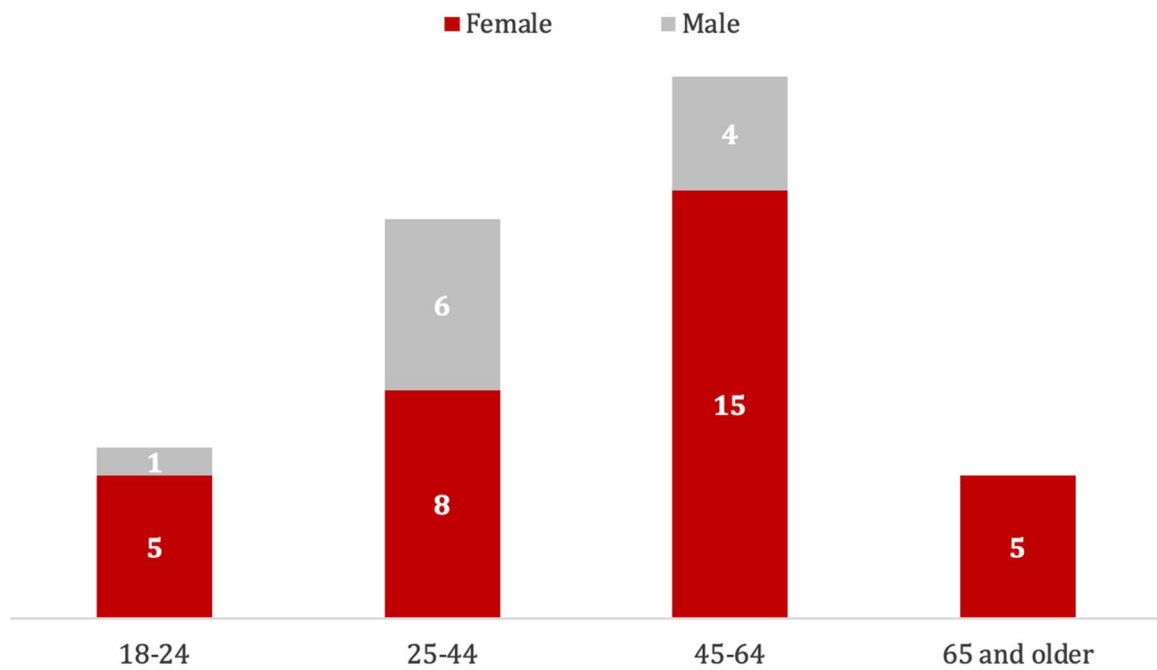
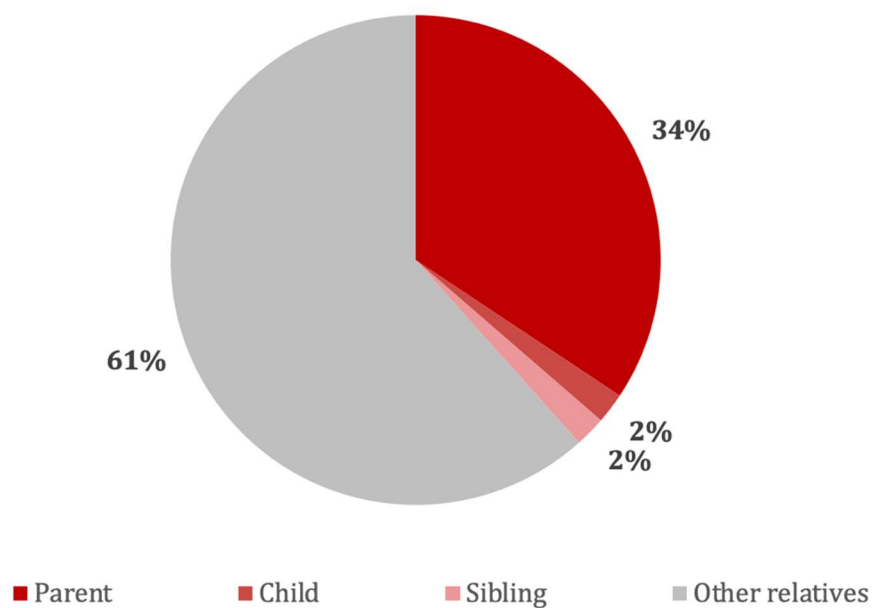


Figure 5. Distribution of answers to the question: "Who are you for a person with TB in your family?", % (n=44)



Community representatives

Among the respondents from the communities where people with TB lived, the majority were women (23 out of 39 respondents, 59%) (Fig. 6). Most were aged 45-64 years (17 out of 39,

44%). Almost half (46%) of community representatives were personally acquainted with people diagnosed with TB who live or have lived in their community.

Figure 6. *Distribution of community representatives by age and gender, persons (n=39)*

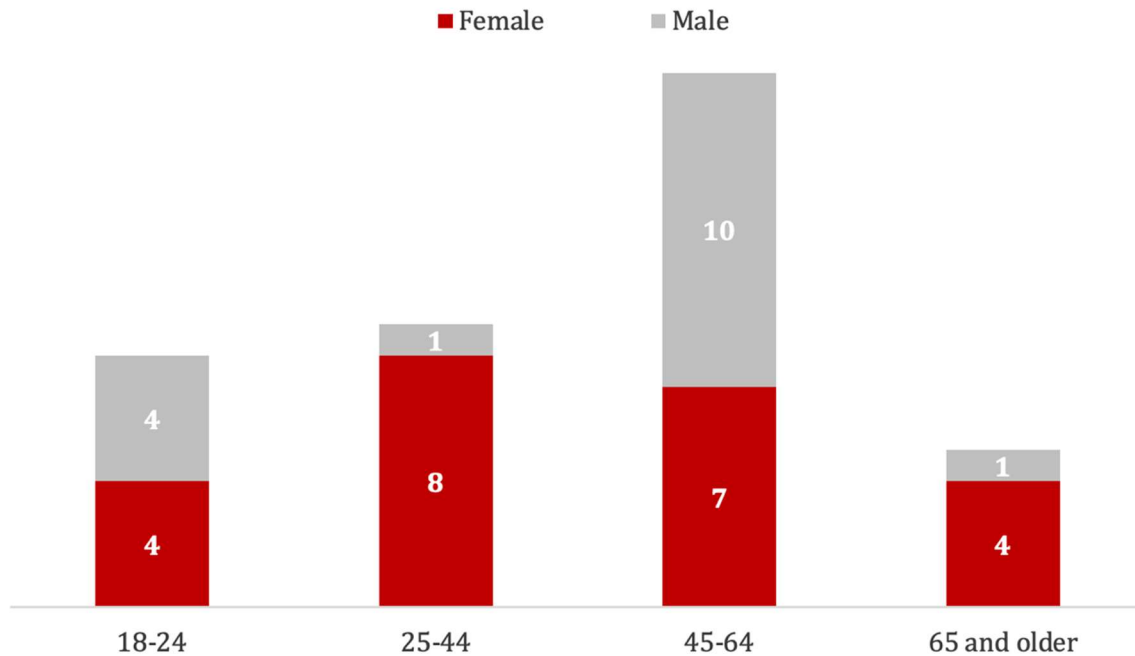
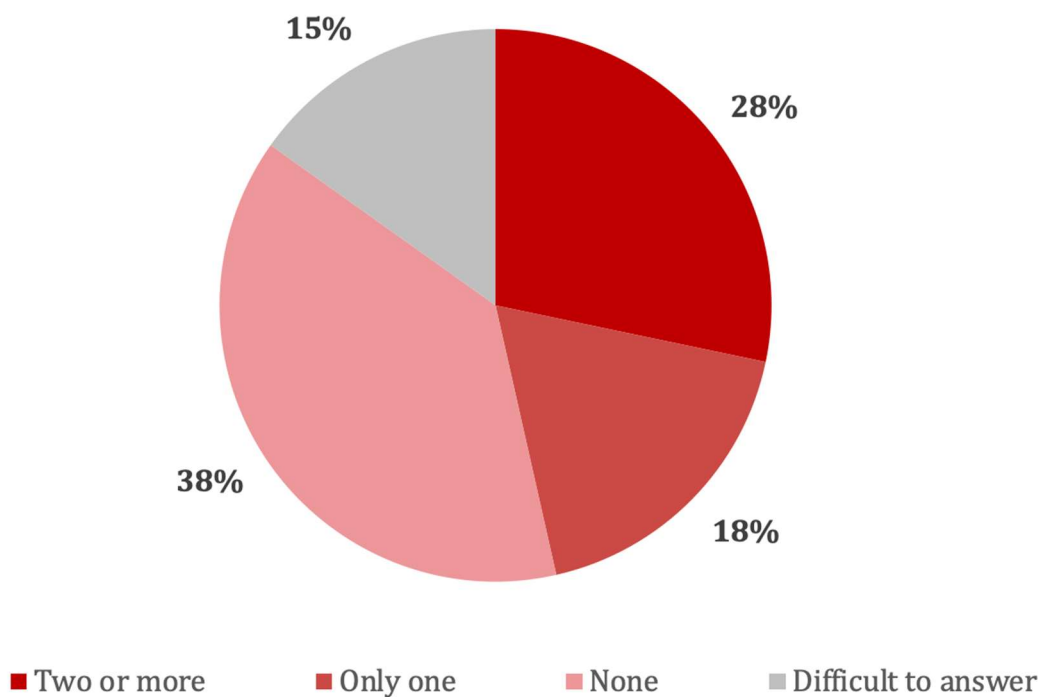


Figure 7. *Distribution of answers to the question: "How many people with TB or people who have had TB who live in your neighborhood/ your community do you know personally?" (n=39)*



Healthcare workers

97% of the involved healthcare workers were women, which reflects the general trend of gender imbalance among healthcare workers, in particular in the TB sector (Fig. 8). Half (49%) of the surveyed healthcare workers were aged 45-64 years. The overwhelming majority (94%) of the healthcare worker sample were TB service workers - nurses and phthisiologists (Fig. 9). All 114 people had experience in providing TB-related services at the time of the study (this was a criterion for respondent selection).

Figure 8. *Distribution of healthcare workers by age and gender, persons (n=114)*

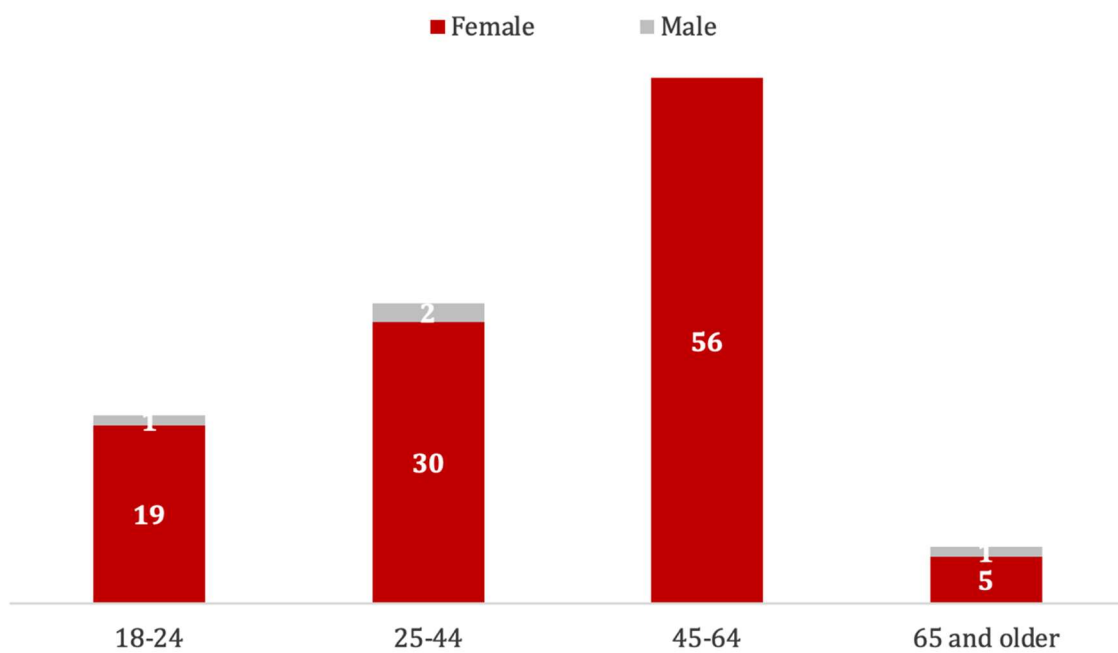
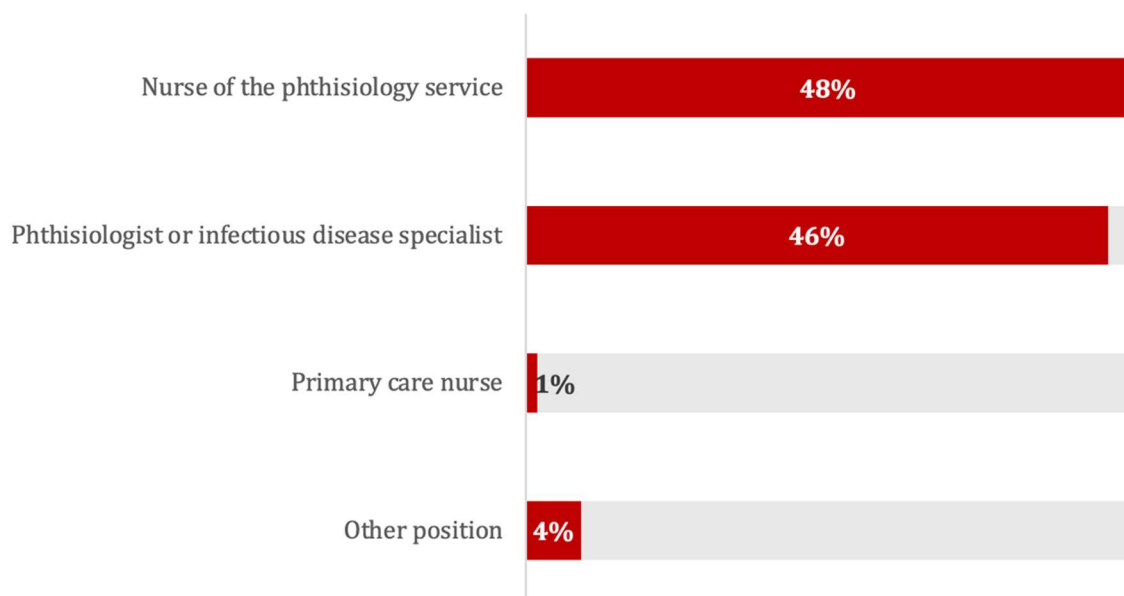


Figure 9. *Distribution of healthcare workers by their positions, % (n=114)*



Stakeholders

This group of participants included international, national, and regional TB program managers, legal experts, representatives of the Public Health Center (PHC), donors, health care facilities (HCF), the Shupyk National University of Healthcare of Ukraine, NGOs, and patient organizations. All of them participated in online focus groups. Among the 13 focus group participants, there were three men and 10 women.

Representatives of the following organizations took part in the FGDs:

- 1) Alliance for Public Health
- 2) CO "100 PERCENT OF LIFE"
- 3) CO "100 PERCENT OF LIFE CHERKASY"
- 4) CO "TB People Ukraine"
- 5) AUCO "Convictus Ukraine"
- 6) Volyn Regional Phthisiopulmonary Medical Center
- 7) Shupyk National University of Health of Ukraine, Department of Phthisiology and Pulmonology
- 8) Ukrainian Institute for Public Health Policy
- 9) Partnership STOP TB Ukraine.
- 10) Public Health Center
- 11) Cherkasy Regional Tuberculosis Dispensary

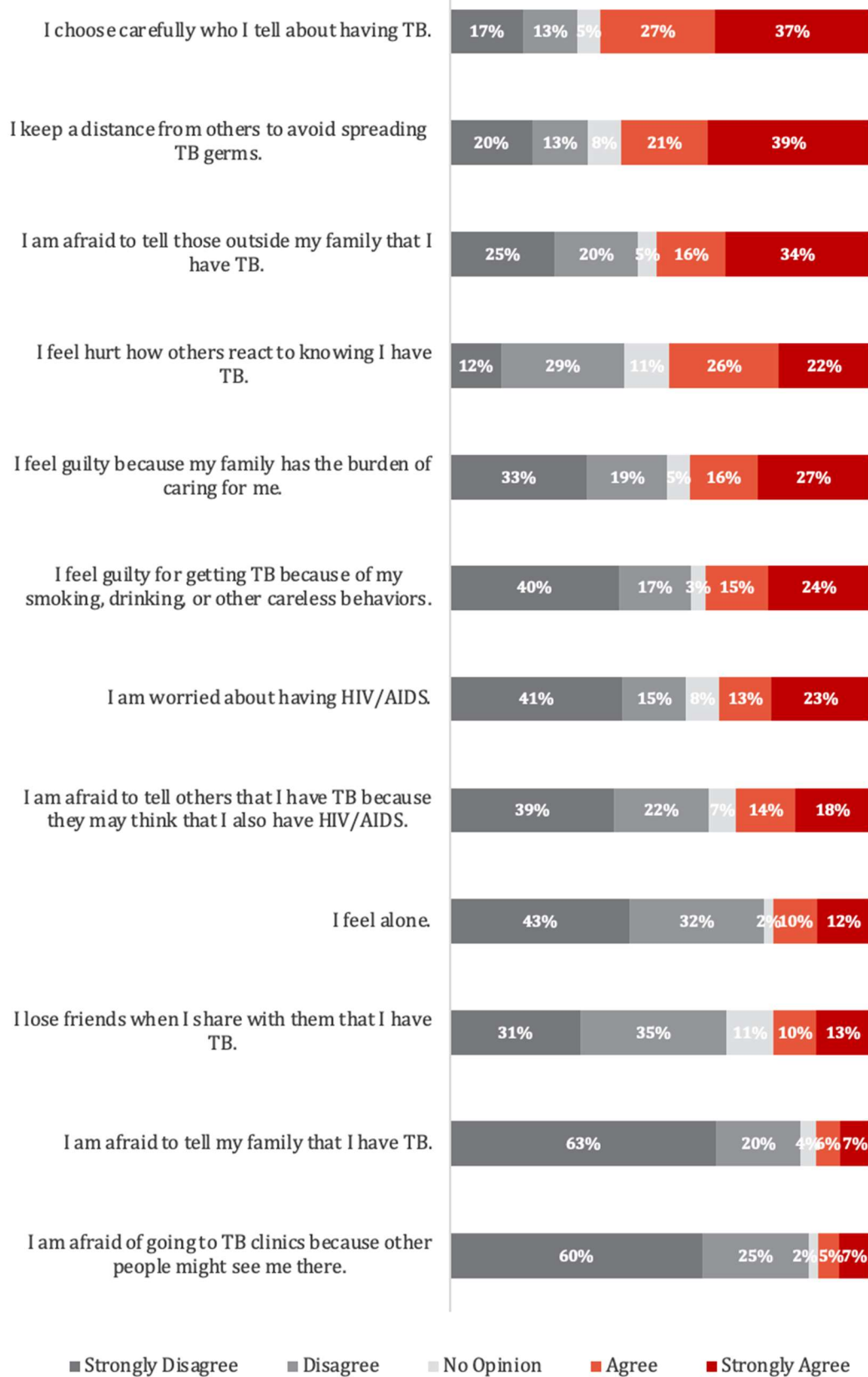
Survey Results

Self-stigmatization of people with TB

The level of self-stigmatization of people with TB was measured by using 12 statements about attitudes toward disclosing information about the disease, guilt, social isolation, etc. The statements agreed with by almost half of the respondents were related to fear of disclosing information about their disease; limiting social contacts to prevent the spread of TB; and suffering from the reaction of others to the fact that they have TB (Fig. 10). 43% of respondents feel guilty about their loved ones, and 39% of respondents feel guilty that they got sick because of bad habits or negligent actions. 32% of participants agreed with the statement about the stigma associated with TB and HIV, particularly that other people may think they have HIV if they learn about their TB diagnosis.

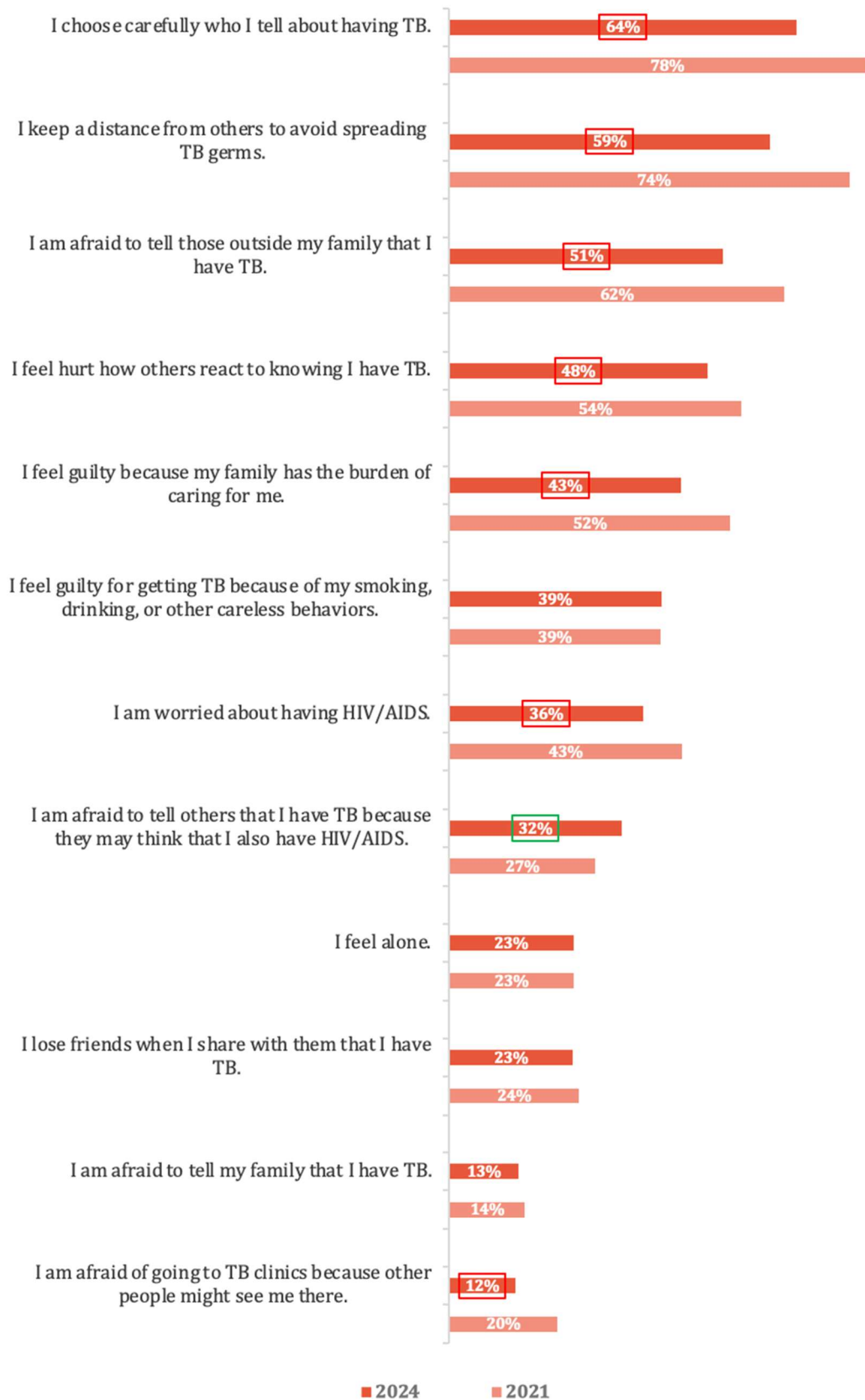
Almost one in seven respondents (13%) said they were afraid to tell their family about TB, and 12% said that visiting a healthcare facility to receive TB treatment services was scary because they might meet people they know and they might learn about their disease. In total, only 4% of respondents did not show any self-stigmatization of TB and denied all 12 statements.

Figure 10. Measurement of self-stigmatization among people with TB: rate of agreement with selected statements describing attitudes toward TB, % (n=669)⁴



⁴ The statements are ranked by the share of people who answered "agree" or "strongly agree".

Figure 10. Measurements of self-stigmatization among people with TB: % of those who agree or strongly agree with the statement (2024: n=669; 2021: n=1101⁵)



The average score of self-stigmatization based on 12 statements was 19.9 with a standard deviation of 10.1 points (in 2021 - 22.4 with a standard deviation of 7.8 points). Thus, there was a statistically significant decrease in the indicator.

In 2024, the level of self-stigmatization was statistically significantly higher in the South (Odesa Oblast) and lower in the North, due to a lower rate in the capital (Table 4).

There was a change in the trend in the perception of stigma among people with TB: according to 2021 data, people with pulmonary tuberculosis showed a higher level of self-stigma, but in 2024 there was no significant difference. There were also no differences in the level of self-stigmatization of respondents who knew they had sensitive and resistant TB (such results were recorded in the previous wave of the survey).

At the same time, people with TB who were receiving treatment at the time of the survey demonstrated a relatively higher level of self-stigmatization than those who had completed treatment.

Among various key populations, the highest levels of self-stigmatization regarding TB were recorded, as in the previous wave of the study, among PLHIV. At the same time, a statistically significantly lower level of self-stigmatization was observed in the group of people with professional TB risks.

Table 4. Average score of self-stigmatization (2024: n=669; 2021: n=1101)

Factor		Sample size, people		Average self-stigma score (standard deviation)	
		2024	2021	2024	2021
Region⁶	South	46	-	25.7 (10.9)	-
	East	110	-	22.0 (10.1)	-
	West	143	-	20.6 (10.5)	-
	Center	215	-	18.5 (9.7)	-
	North	155	-	18.1 (9.0)	-
Gender	Female	183	400	21.2 (10.1)	23.2 (7.8)
	Male	486	701	19.5 (10.0)	21.9 (7.5)
Age	18-24	23	45	18.6 (9.5)	19.2 (7.4)

⁵ A green/red mark hereinafter in the charts means that the 2024 figures are statistically significantly higher/lower than the figures for 2021.

⁶ Comparison by region is not possible, as the population of regions has changed compared to the previous survey.

	25-44	309	551	20.1 (10.2)	22.4 (7.5)
	45-64	272	436	20.1 (10.0)	22.6 (7.8)
	65 and older	65	69	19.3 (9.7)	23.8 (8.1)
Period	Undergoing treatment at the time of the study	188	185	22.3 (10.4)	24.8 (8.2)
	Treatment was completed by the time of the study	480	914	19.0 (9.8)	21.9 (7.5)
Localization of TB	Pulmonary TB	489	950	19.5 (9.9)	22.5 (7.6)
	Extrapulmonary TB / Both forms	79	70	22.2 (9.9)	21.3 (6.8)
	Does not know	102	74	20.3 (10.9)	22.7 (8.9)
Type of TB	Sensitive TB	61	171	22.0 (10.7)	20.8 (7.3)
	MDR-TB/XDR-TB	54	135	21.2 (9.0)	22.9 (7.0)
	Does not know	554	795	19.6 (10.1)	22.7 (7.8)
Type of DOT	Health care worker	490	700	19.7 (9.7)	22.4 (6.9)
	Social worker	76	109	22.1 (11.5)	22.3 (6.4)
	Digital technologies (video DOT or smart box)	57	139	17.4 (10.3)	22.5 (9.2)
	By myself	-	82	-	22.4 (10.0)
	Other	46	68	22.2 (10.9)	22.3 (9.8)
Groups	PEOPLE WITH HIV	83	181	23.9 (9.7)	24.8 (8.3)
	Groups with occupational risks	54	136	18.0 (8.5)	22.4 (6.9)
	Low-income residents of villages/towns	66	378	20.4 (10.3)	24.1 (7.9)
	Groups with behavioral risks	79	253	23.0 (10.5)	23.3 (7.5)
	Risk groups based on medical indicators	132	396	20.7 (9.9)	23.6 (7.7)
<i>Total</i>		<i>669</i>	<i>1101</i>	<i>19.9 (10.1)</i>	<i>22.4 (7.8)</i>

* Indicators that are statistically significantly higher/lower than the sample as a whole are highlighted in green/red font.

** Green/red shading of the cell means that the 2024 figures are statistically significantly higher/lower than the 2021 figures.

Comments: Self-stigmatization was evaluated as a total score from 12 statements shown in Fig. 10. Each statement was rated on a scale from 0 (strongly disagree) to 4 (strongly agree). Accordingly, the total score of self-stigmatization could range from 0 to 48; the higher the score, the higher the level of stigma.

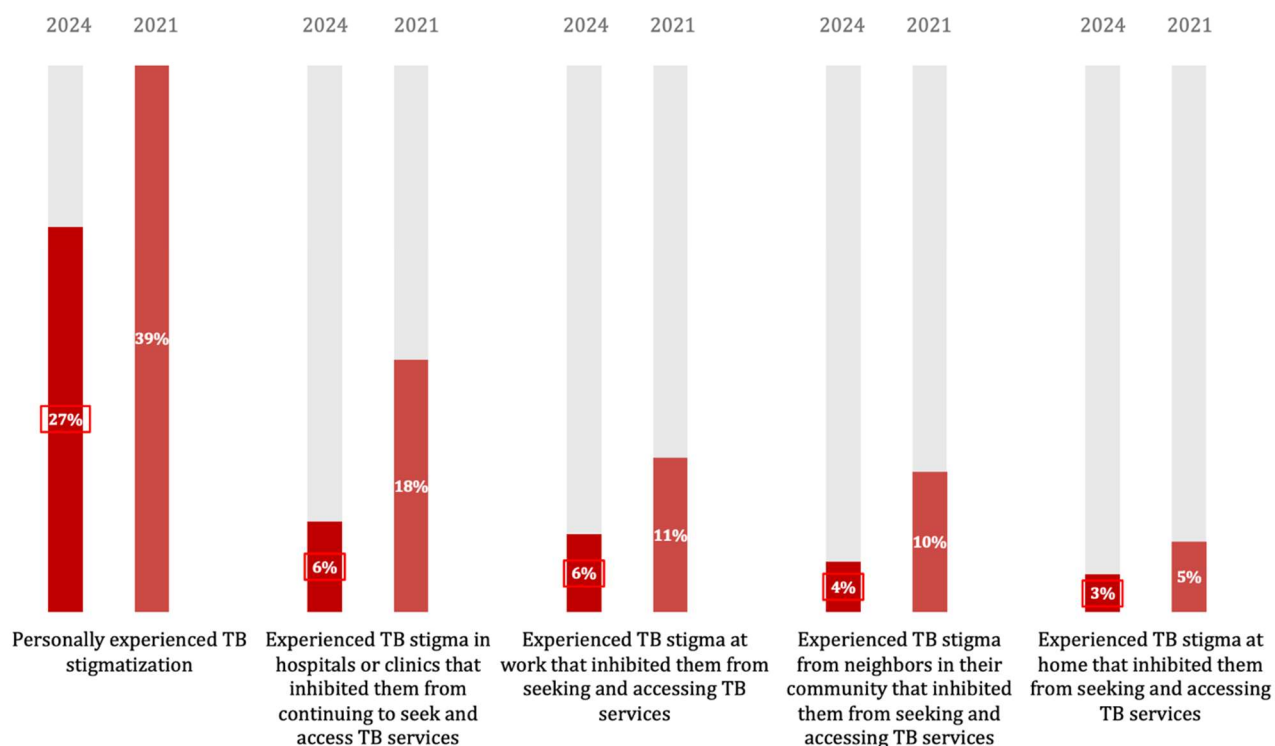
Experiencing stigma during diagnosis and treatment among people with TB

27% of people with TB reported feeling stigmatized because of having TB, compared to 39% of respondents in 2021. The decrease in this figure may indicate a certain improvement in the situation, in particular, due to efforts to inform the population about the disease (Fig. 11). The proportion of those who felt stigmatized because of having TB was significantly higher among those diagnosed with XDR-TB/ MDR-TB (42% of people with TB reported compared to 27% on average in the sample), and significantly lower among the group of people with TB with occupational risks (16% vs. 27%) and among people with TB aged 65 years and older (14% vs. 27%). In particular:

- 6% of the surveyed respondents mentioned stigmatization during visits to healthcare facilities or at work, which prevented them from seeking medical care for TB diagnosis and treatment.
- 4% of respondents had experienced stigmatization by neighbors, which prevented them from being treated for TB and receiving medical care, 3% of respondents reported such stigmatization in their families.

Among those who encountered stigma in hospitals or clinics, 30% of respondents reported that they faced stigma in primary care facilities; 20% - in TB facilities; the rest - in other health care facilities or did not remember.

Figure II. Personal experience of stigmatization through TV and the context of stigma, %
(2024: n=669; 2021: n=1101)



As in the previous wave of the survey, the majority of people with TB did not believe that stigma prevented them from getting a diagnosis, starting treatment, or remaining on medical care. In general, the situation has improved for almost all indicators of this type (see Table 5):

- 4.2% of people with TB reported that stigmatization at work was an obstacle to receiving services, mostly for diagnosing TB (vs. 6.4% in 2021).
- A share of respondents (3%) identified stigma from their family doctor as an obstacle (vs. 5.3% in 2021);
- Slightly fewer people reported stigma in the community (1.9% vs. 9.1%) and in TB hospitals (1.5% vs. 7.8%).
- 1% of respondents reported that stigma in educational institutions was an obstacle for them to receive health care services (vs. 0.2% in 2021).

Table 5. Route stages and stigma: proportion of people with TB who answered yes to the question "Have you encountered stigma in the following conditions that prevented you from...?" (2024: n=669; 2021: n=1101)

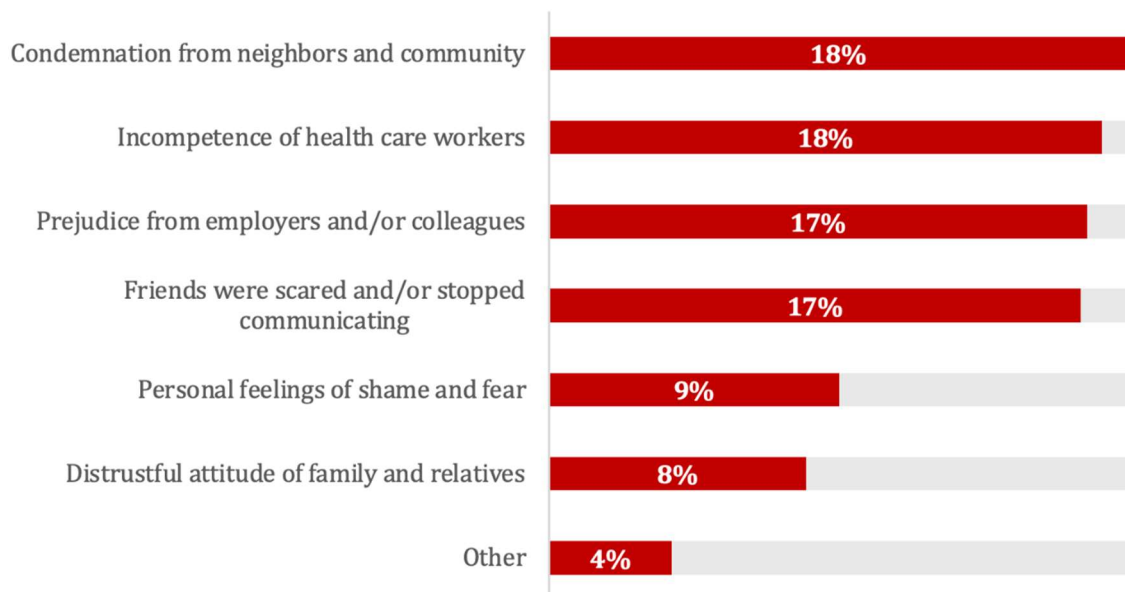
	TB Hospital, %		General Practitioner, %		Family, %		Workplace, %		Institute/school, %		Community/Neighbors, %	
	2024	2021	2024	2021	2024	2021	2024	2021	2024	2021	2024	2021
Suspect tuberculosis?	0.4	5.2	2.2	3.8	0.4	2.9	2.7	5.4	0.3	0.2	1.5	8.2
Seek medical care?	0.3	1.8	1.3	0.8	0.1	0.3	1.5	0.2	0.1	-	0.9	0.7
Get an accurate diagnosis?	0.4	1.7	1.9	1.4	0.3	0.3	1.0	0.5	0.1	-	0.7	0.5
Start treatment?	0.3	1.8	1.6	0.8	0.1	0.4	1.2	0.6	0.1	-	0.3	0.8
Develop treatment commitment?	-	2.0	1.3	0.5	0.1	0.7	1.3	0.2	0.3	-	0.3	1.0
Complete treatment?	0.4	2.4	0.4	0.6	0.3	0.7	0.6	0.6	-	-	0.6	0.7
Be under medical supervision after treatment?	0.7	2.4	0.9	0.9	0.7	0.5	1.5	0.4	0.6	-	0.6	0.5
At least one of the following	1.5	7.8	3.0	5.3	1.3	3.8	4.2	6.4	1.0	0.2	1.9	9.1

* Green/red shading of the cell means that the 2024 figures are statistically significantly higher/lower than the 2021 figures.

In their answers to open-ended questions, research participants most often mentioned the following experiences of stigma:

- Condemnation from neighbors and community (18%);
- Incompetence of health care workers (18%);
- Prejudice from employers and/or colleagues (17%);
- Friends and acquaintances were afraid and/or stopped communicating (17%);
- Distrustful attitude of family and relatives (8%)

Figure 12. Personal experience of stigma due to TB and context of stigmatization, % (among those who have experienced stigma, n=184)



"No one wants to communicate because of TB, no friends and acquaintances. The family doctor told me not to visit the health care facility."
(Male, 29, West)

"People in the society don't understand, they are afraid, horrified by the word tuberculosis"
(Male, 37, Center)

"My boss at the workplace had a negative attitude - he didn't even want to greet me, he was biased, he was afraid of getting infected from me"
(Male, 37, Center)

"I felt biased attitude at work from colleagues who expressed fears and made inappropriate jokes about my illness"
(Female, 53, North)

"The staff of the health care facility spread confidential information about my TB diagnosis. My acquaintances didn't want to talk to me, they stayed at a distance, afraid. People at the post office or in the store did not want to be near me."

(Female, 40, Center)

"Neighbors, acquaintances, people at school and in public transport stayed at a distance and didn't want to communicate (even on the phone). I tried not to work or communicate with anyone because of my TB diagnosis. Employers refused to hire me because of my TB diagnosis. Some friends stopped communicating with me, and relatives - only by phone".

(Female, 37, Center)

When respondents were asked about the stigma experienced by other people they knew, the results were similar: most did not believe that it was an obstacle to receiving TB healthcare services (Table 6). Respondents said that among their acquaintances who also had TB and faced stigma in different contexts, stigma mostly prevented them from diagnosing TB, starting treatment, and staying under medical supervision after treatment.

In general, the impact of stigma on aspects of receiving services by acquaintances was somewhat higher than people with TB reported about their self-stigmatization. About 6% of respondents reported that stigma in the community was an obstacle for other people, and almost 5% mentioned stigma in hospitals, in the family, or at work.

Table 6. Route stages and stigma: share of people with TB who answered positively to the question "Do you know of any cases of stigma towards people with TB or people who had TB in the following environments that hindered...?" (2024: n=669; 2021: n=1101)

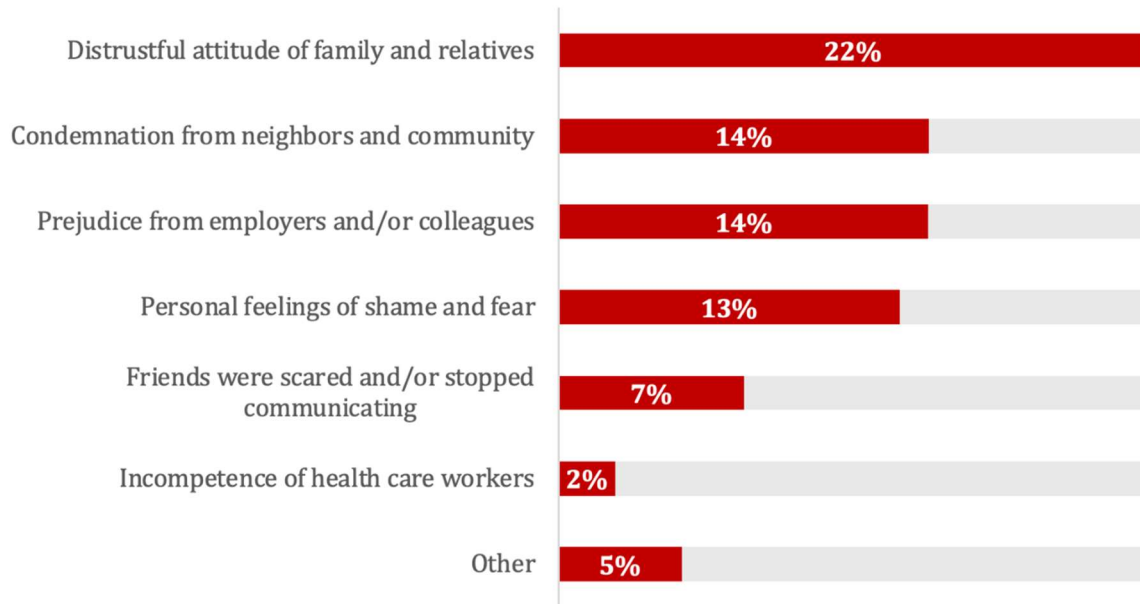
	TB Hospital, %		General Practitioner, %		Family, %		Workplace, %		Institute/school, %		Community/Neighbors, %	
	2024	2021	2024	2021	2024	2021	2024	2021	2024	2021	2024	2021
Suspect tuberculosis?	1.8	3.2	0.4	0.6	1.9	2.7	1.9	2.6	0.6	-	2.5	9.6
Seek medical care?	1.5	1.7	0.9	0.6	2.1	0.8	1.3	0.6	0.6	-	1.6	1.8
Get an accurate diagnosis?	1.3	1.9	0.7	0.5	1.6	0.5	2.2	0.7	0.3	0.1	2.4	1.1

Start treatment?	1.5	2.0	0.6	0.4	1.9	0.6	2.2	0.9	0.6	0.1	2.2	1.5
Build commitment to treatment?	1.3	3.0	-	0.2	2.2	0.8	1.8	0.8	0.3	0.1	1.9	1.8
Complete treatment?	1.3	3.4	0.3	0.1	1.2	0.8	2.2	1.0	0.3	-	1.9	2.1
Receive follow-up care after treatment?	1.8	1.9	1.8	0.7	1.5	0.7	1.2	0.8	0.6	-	2.1	1.9
At least one of the things listed above	4.9	6.0	2.8	1.6	4.8	3.7	4.6	3.6	1.6	0.1	5.5	11.3

* Green/red shading of the cell means that the 2024 figures are statistically significantly higher/lower than the 2021 figures.

When talking about examples of stigma experienced by other people, respondents most often mentioned distrustful attitudes of family and relatives (22%). Respondents also mentioned judgment from the community and prejudice at work (14% each), and personal feelings of shame and fear (13%).

Figure 13. *Reported experience of stigmatizing other people because of TB and context of stigmatization, % (among those who have experienced stigmatization of other people with TB, n=78)*



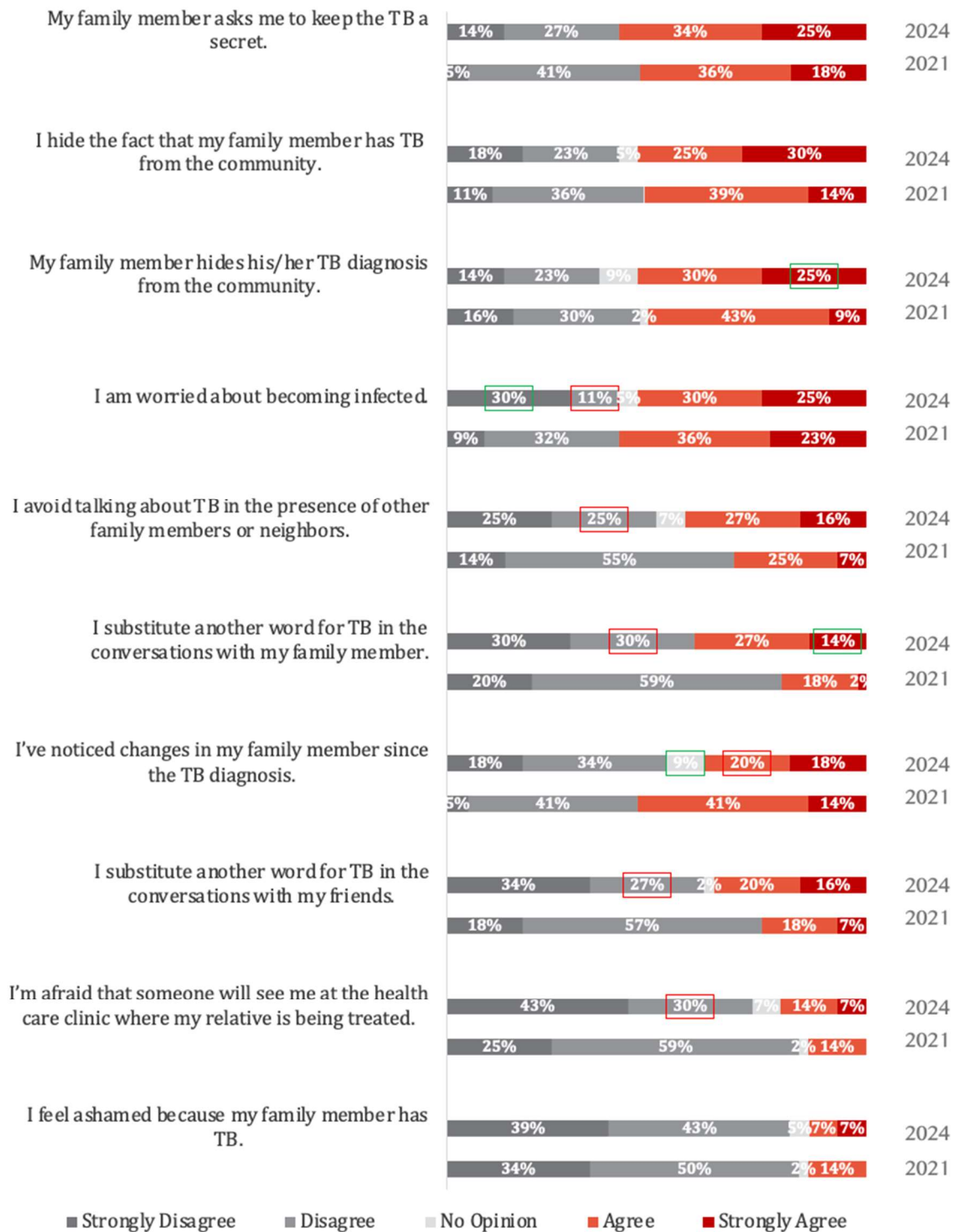
Secondary stigma in families of people with TB

The main aspect of secondary stigma was the fear of spreading information about the fact that a family member has TB. Out of the total number of surveyed family members, 59% said that a relative with TB had asked them to keep his/her TB disease a secret (Fig. 15). More than half (55%) of respondents hide the diagnosis of a relative from others, the same number said that the TB patient hides his/her diagnosis from society. In addition, 55% of the surveyed relatives are afraid of contracting TB.

Only some situations were more widespread than in the previous wave: 43% of respondents avoided talking about TB in general (32% in 2021), 41% replaced the word "TB" with another word in conversations with a family member or neighbor (20% in 2021), 36% replace the word "TB" with another word in conversations with friends (25% in 2021).

7% in the group of families of people with TB did not have secondary stigma; they didn't agree with any of the ten statements.

Figure 15. Measures of secondary stigma among family members of people with TB: rate of approval of selected statements describing attitudes toward TB, % (2024 n=44; 2021 n=45)⁷



⁷ The statements are ranked by the proportion of people who answered "agree" or "strongly agree".

The average score of secondary stigma among families was 18.0 points out of 408; this indicator remained statistically unchanged compared to the previous wave (16.9 points in 2021).

9% of family members of people with TB had personal experience of secondary stigma because their family member had TB. At the same time, 23% of respondents said that they had observed or heard about cases of stigmatization of other families because their family members had TB.

Speaking about the examples of TB-related stigma that respondents have observed or heard about, they mentioned the following situations: friends and neighbors avoid people with TB; relatives refuse to provide psychological and financial support; and prejudice against a child at school.

Perceived stigma in communities

Compared to 2021, the level of perceived stigma in the community has decreased. Similar to the results of the previous wave, it mainly appeared as a desire to limit contacts due to fear of infection. In particular, more than 70% of community representatives agreed that people try to stay at a distance and object to TB patients having contact with their children - in the previous wave, more than 90% of respondents felt this way (Fig. 15). In 2021, many community representatives believed that changes in attitudes toward people with TB were long-lasting: 74% agreed that if a person has TB, some members of society will behave differently towards that person for the rest of their lives, while in 2024 less than half of respondents (46%) agreed with this statement. 23% of community representatives agreed that some people would prefer that people with TB do not live in their community at all (62% in 2021), and 18% said that people with TB might be perceived as disgusting (44% in 2021).

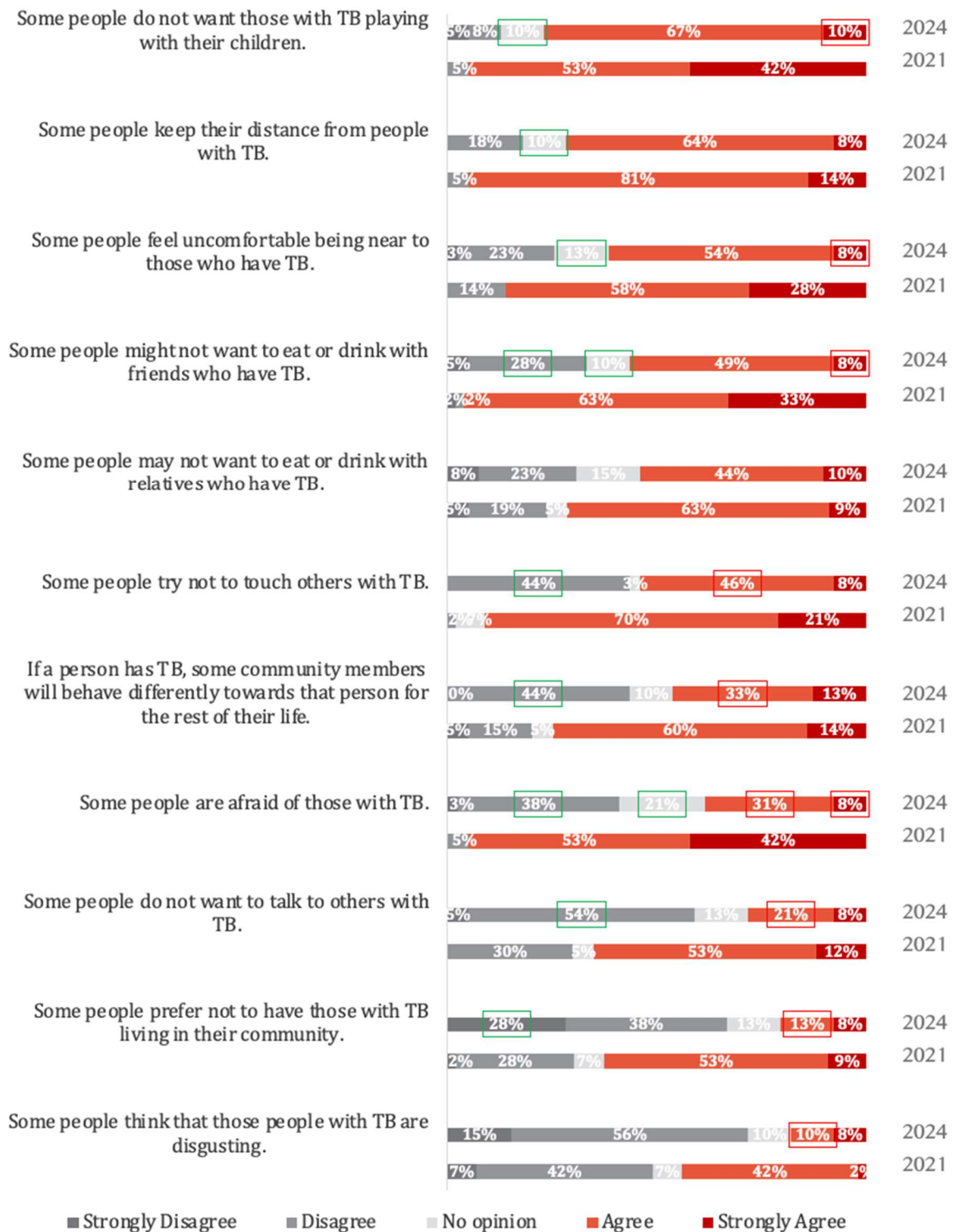
The average score of perceived stigma based on 11 statements was 23.0 with a standard deviation of 9.3 points; thus, the indicator decreased significantly compared to the previous wave (31.0 with a standard deviation of 6.5 points in 2021).

5% did not agree with any statement about stigma.

15% of respondents witnessed or heard about a person from their community who was stigmatized because of TB. Respondents who had observed or heard about the stigmatization of people with TB in the community gave the following examples of stigma: a person with TB was fired from work or refused to work; friends and relatives stopped communicating; a person with TB refused to disclose his/her disease.

⁸ Secondary stigma in the family was assessed as the sum of scores from 10 statements shown in Fig. 12. Each statement was rated on a scale from 0 (strongly disagree) to 4 (strongly agree). Accordingly, the total score of self-stigmatization could range from 0 to 40; the higher the score, the higher the level of stigma. Given the small sample size, no statistical differences between the groups were tested.

Figure 16. Measuring perceived stigma in the community: level of agreement with selected statements that describe attitudes toward TB, % (2024 n=39; 2021 n=43)⁹



⁹ The statements are ranked by the proportion of people who answered "agree" or "strongly agree".

Perceived and experienced stigma among healthcare workers

Healthcare workers consider perceived stigma towards TB in their professional community to be quite widespread. 87% agreed that some healthcare workers consider TB patients to be dangerous. 80% of surveyed healthcare workers agreed that there are healthcare workers who support the isolation of TB patients during the intensive phase of treatment. 81% of respondents agreed with the statement that they support compulsory TB treatment if necessary.

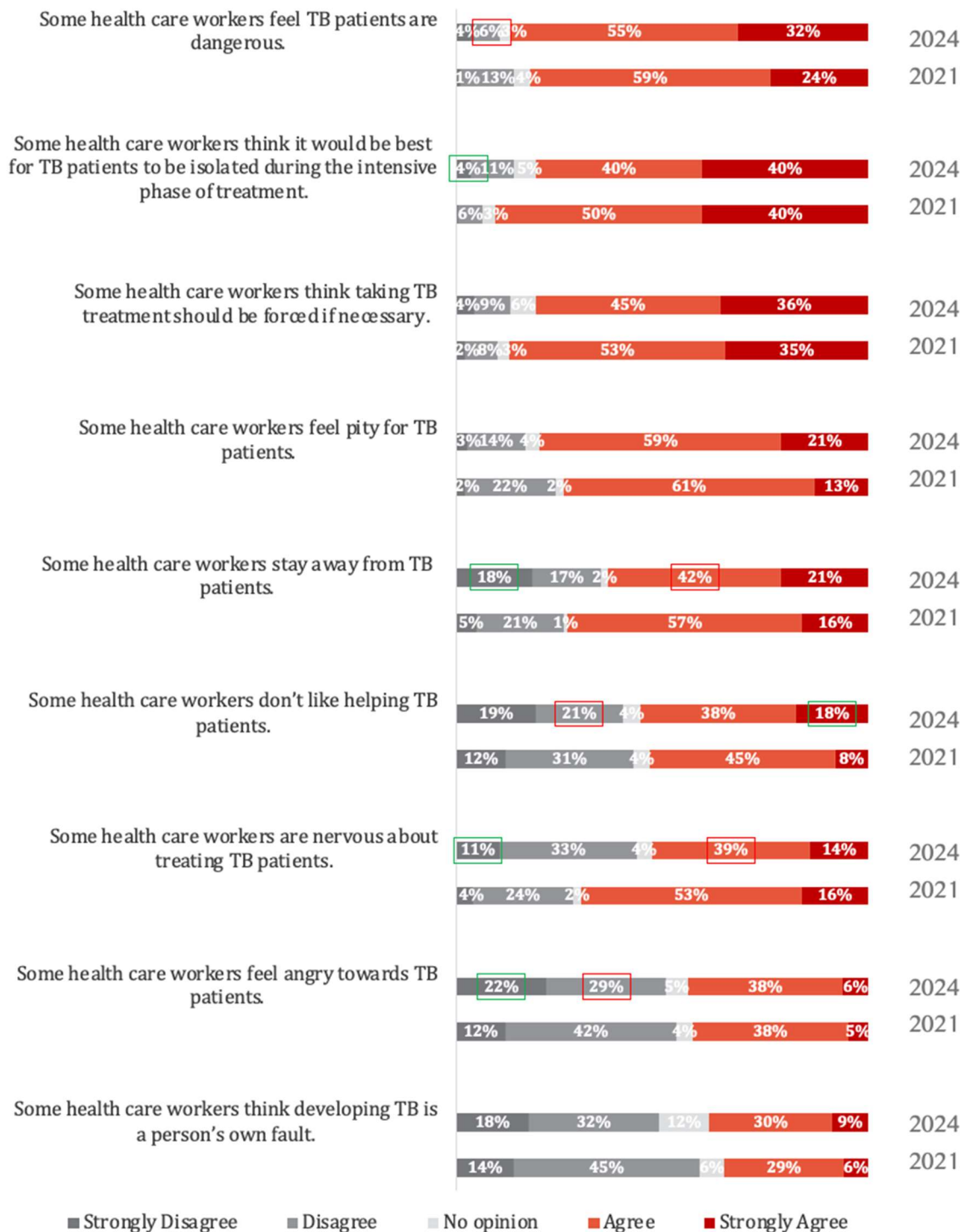
In comparison with the previous wave, there were different changes, for example:

- The proportion of those who agreed with the statements decreased:
 - Some healthcare workers believe that it would be better to isolate TB patients during the intensive phase of treatment
 - Some healthcare workers are nervous about providing treatment to TB patients
- The proportion of those who agreed with the statements increased:
 - Some healthcare workers don't like helping TB patients.

As a result, the mean score of perceived stigma based on 9 statements did not change significantly compared to the previous wave, amounting to 22.0 with a standard deviation of 6.6 points (22.5 with a standard deviation of 5.4 points in 2021).

As in the previous wave, only one respondent from the total number of surveyed healthcare professionals did not agree with any statement about perceived TB stigma. At the same time, 12% of surveyed healthcare workers agreed with all statements (11% in 2021).

Figure 17. Measuring perceived stigma among healthcare workers: agreement rates with selected statements describing attitudes toward TB, % (2024 n=114; 2021 n=248)



Phthisiologists or infectious disease specialists had a higher level of perceived stigma, with a score of 24.1 points compared to 22.0 in average (Table 8). In particular, more respondents among them than among TB nurses agreed with the statements "Some health care workers stay away from TB patients" and "Some health care workers do not like helping TB patients".

Table 8. Measuring of perceived stigma among healthcare workers: proportion of those who agreed with the statement, according to position, % (n=114)

	Total (n=114)	TB doctor / infectious disease specialist (n=53)	Nurse of the tuberculosis service (n=55)
Some healthcare workers consider TB patients to be dangerous	87%	96%	84%
Some healthcare workers believe that it would be better to isolate TB patients during the intensive phase of treatment	81%	85%	78%
Some healthcare workers believe that TB treatment should be compulsory if necessary	81%	81%	80%
Some healthcare workers feel pity for TB patients	80%	72%	89%
Some healthcare workers stay away from TB patients	63%	81%	49%
Some healthcare workers do not like helping TB patients	55%	74%	42%
Some healthcare workers are nervous about treating TB patients	53%	64%	45%

Some health workers are angry with TB patients	44%	58%	31%
Some healthcare workers believe that the patient is to blame for having TB	39%	49%	33%

* Green shading of the cell means that the rate among TB doctors/infectious disease specialists is statistically significantly higher than the rate among nurses.

Half of the surveyed healthcare workers believe that some doctors avoid providing medical care to people with TB primarily because of the fear of being infected. 45% of respondents stated that this is due to low awareness of the disease, and 11% believe that this is due to existing stereotypes about people with TB.

As in the previous wave, 30% of healthcare workers felt that they were stigmatized because their work involves interaction with people with TB or people who have had TB. Speaking about the stigma they faced, healthcare workers most often described the following situations: relatives, friends, and/or the community try to avoid them; other healthcare workers are biased against them.

"People in public transport got scared and tried to keep their distance after learning about my place of work."
(TB nurse, Western Ukraine)

"Medical workers in other facilities don't consider it prestigious to work in the TB service."
(TB doctor, West)

"At a consultation in another health facility, doctors wore masks, stayed at a distance from me, and were afraid. One of the doctors believed that all the staff in the TB dispensary had TB."
(TB doctor, Center)

"I experienced a biased attitude towards me in another healthcare facility (healthcare workers were terrified, kept their distance, asked me to wear a mask, asked if I had been tested, and were surprised by my choice of workplace). Because of this attitude, I went to another medical facility."
(TB service nurse, Center)

"When I talk about my place of work, people in some companies are afraid that I may be a carrier of the disease."

When I order a taxi to the TB dispensary, the drivers are afraid, they open the window, ask me to put on a mask, and ask if I am sick."

(TB doctor, Center)

Every fifth respondent (22%) has observed or heard about cases of stigmatization of other healthcare workers related to the delivery of services for people with TB.

11% of healthcare workers personally felt that they were stigmatized in the workplace, 15% - by the community, and 8% - in the family or among relatives (Fig. 18). Respondents reported almost the same level of stigmatization of other healthcare workers in the specified contexts. At the same time, respondents reported stigmatization of other healthcare workers by family members relatively more often than in the previous wave.

"My colleague was treated with prejudice and suspicion by the employer during the hiring process because of her previous job (pediatric TB specialist)."

(TB doctor, West)

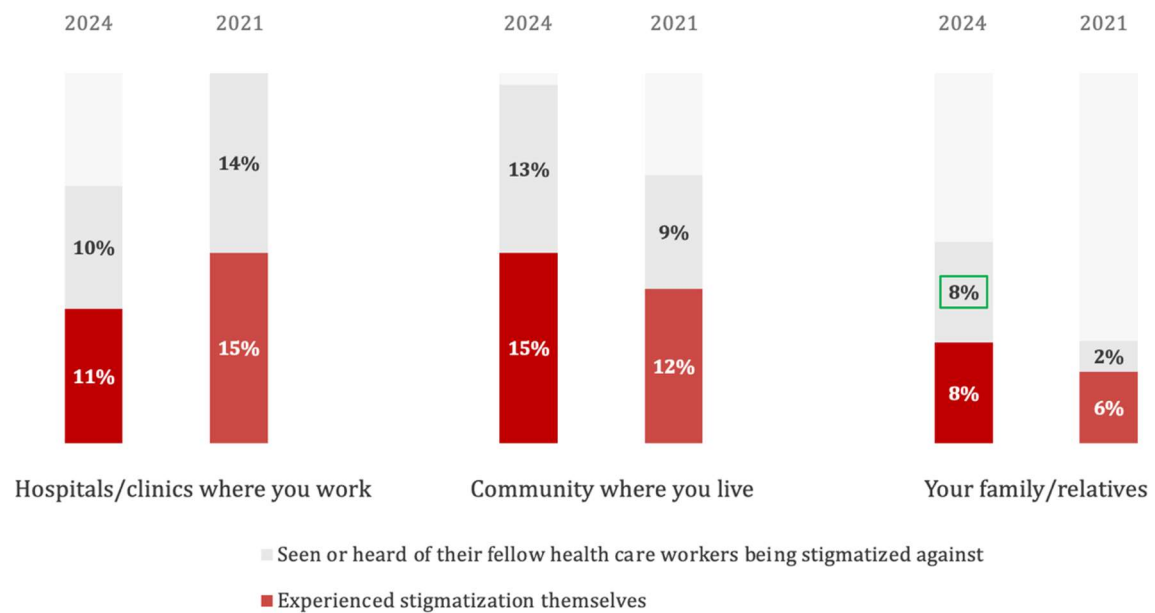
"Lack of understanding from other people. They often ask the question "How is it possible to work here?". It is believed that this work is dangerous for health, there is a stereotype about working only with anti-social patients."

(Nurse, TB service, Center)

"Neighbors were afraid and kept their distance. Distant relatives were afraid that we could transmit the disease through our clothes, hair, and personal items."

(TB doctor, Center)

Figure 18. Percentage of healthcare workers who have personally experienced, observed, or heard about intolerance from others because their work is related to contact with people with TB, % (2024 n=114; 2021 n=248)



Legal and political context of stigmatization

The legislative and policy context of stigma was assessed according to the methodology, focusing on seven areas of rights (areas) that are either the most relevant or most frequently violated in relation to people with TB. This assessment was conducted as a desk study (Annex 2). The legislative and policy context of stigma was also discussed with representatives of the non-governmental sector and key TB community to find out to what extent it protects or, contrarily, contributes to the violation of the rights and freedoms of people with TB.

This chapter summarizes the problematic aspects of the legal and regulatory setting that were highlighted by the participants of the focus group discussions. A broad description of the existing legal framework for each right is provided in Appendix 2.

1. The right of freedom from discrimination

Content of the right: All people are equal before the law. There should be a legal framework that prohibits unequal treatment of people with TB in both private and public settings, including in health care, employment, education, and access to social services.

The analysis of laws and policies has shown that there are no legal regulations in healthcare and other areas that explicitly prohibit unequal treatment of people with TB, as well as no regulations that establish rights and guarantees for the realization of the rights and freedoms of people with TB in education, employment and other areas of public life.

This does not mean that nothing should be done if there are no regulations, but it means that we cannot focus only on regulations without working with society.

The information strategy for fighting tuberculosis was approved. Unfortunately, we don't see in what way and how actively it is being implemented.

The Law of Ukraine "About Overcoming Tuberculosis in Ukraine" of July 14, 2023, No. 3269-IX¹⁰ is quite progressive: in particular, it establishes the status of regional TB centers that diagnose and treat tuberculosis under the medical guarantee program; the Law also clearly defines the mechanism for providing preventive treatment drugs.

The main legislative changes include the development of a diagnostic network. It is a three-level system of microbiological laboratories for TB diagnostics, headed by a central laboratory that will provide external quality control of lower-level laboratories.

The law also strengthens social protection for employees of regional TB centers. The document provides the right to an annual additional paid vacation. This law is not perfect, but it is significantly more powerful and better than the previous one, particularly because there are changes ranging from the use of tolerant vocabulary to the introduction of labor law articles. This means that there are slightly stronger tools to protect people's rights at the legislative level. In general, despite the difficulties in implementing the reform, we cannot say that the legislation in Ukraine harms people with TB, as we practice modern treatment approaches, all innovative medicines are registered, outpatient treatment is available, and there are mechanisms to prevent discrimination. Most services are funded by the state, including public procurement of support services.

The main principles of the state policy in the field of TB control include multidisciplinary and multisectoral cooperation of national ministries and agencies with relevant local executive authorities not only in the medical sector but also in the spheres of social protection, education, etc.

However, this law does not provide for compulsory treatment of people who evade treatment and repeatedly interrupt it. The current regulation on compulsory hospitalization of people with infectious forms of TB in Ukraine needs to be regulated in terms of by-laws that ensure the interaction of various services and the judicial system, and the issue of compulsory treatment should be coordinated between the two services: the medical and the police services. It is important to keep in mind that there is a big difference between compulsory treatment and compulsory isolation.

Employment legislation establishes general guarantees of equality and non-discrimination and allows restrictions on people's employment rights based on health status. The Criminal Code protects the established guarantees for employees. However, several norms of the employment legislation, in combination with the healthcare legislation, are considered discriminatory in terms of unconditional restrictions for all people with TB to work (i.e., receive a salary).

The list of contraindications for working in the professions defined in the List of professions, industries, and organizations whose employees are subject to mandatory preventive medical examinations, approved by the Order of the Ministry of Health of 23.07.2002 No. 280, needs to be revised to remove restrictions on work for people with non-contagious forms of TB, and for people with contagious forms of TB to guarantee the right for paid work in conditions acceptable to them and others (e.g., remote work).

The Global Plan to End TB 2023-2030¹¹, developed by the Stop TB Partnership, includes recommendations for crucial policy interventions to address TB, including scaling up active case-finding strategies, including contact tracing, which in turn requires additional investment, and improving the quality of existing activities in latent TB testing and preventive TB treatment.

Global targets to be achieved by 2030:

- Ensure 100% coverage of TB preventive treatment for relevant TB contacts.

¹⁰ <https://zakon.rada.gov.ua/laws/show/3269-20#Text>

¹¹ <https://www.stoptb.org/global-plan-to-end-tb/global-plan-to-end-tb-2023-2030>

- Ensure 100% coverage of preventive TB treatment among PLHIV.
- At least 90% of the world's countries should identify key and vulnerable populations.

These goals also align with the priorities set out in the WHO TB Action Plan for the European Region for 2023-2030 (scaling up comprehensive preventive TB treatment, prioritizing targeted TB screening among key populations and vulnerable groups, etc.)¹².

Under the coordination of the PHC and with the technical support of the Global Fund, the TB Information Strategy for 2022-2025¹³; was developed in Ukraine; it describes the general area of use of information resources and provides a holistic vision of TB communication tools, identifies key categories of target audiences, including people with TB, their close environment, presumably healthy people, people from risk groups, primary and secondary health care personnel and physicians. Tasks and key messages were developed for each of the key categories and suggested distribution channels and sources of information were identified. In addition, due to the introduction of martial law in Ukraine, the Center for Public Health, together with partners, has developed additional recommendations for specific target audiences with whom communication in crisis conditions and messaging for working with key groups under martial law should be continued. One of the expected outcomes of the TB Information Strategy implementation is an increase in TB case detection, including among the most vulnerable populations, and, as a result, the promotion of effective treatment of all forms of TB. These tools allow to increase the spread of materials on access to TB care in Ukraine, in particular during the war.

The Strategic Action Plan for Improving TB Detection and Preventive Treatment was developed by the PHC in collaboration with partners to ensure a systematic approach in the country to achieve the common goal of implementing TB contact investigation as one of the strategic components of TB detection and prevention within the WHO Global Strategy to End TB.

Ukraine can achieve the WHO Strategy's goal of reducing morbidity if the following measures are increased linearly from 2022 to 2025 and are maintained in the future: improvement of TB diagnosis; improvement of MDR/XDR-TB treatment outcomes; active TB case finding (active case finding as well as creating demand for existing TB services); detection of TB at the subclinical stage; preventive therapy focused on key and vulnerable populations.

The implementation of international technical assistance projects under the Global Fund and USAID grant "Support to TB Control in Ukraine" provides technical, organizational, and methodological assistance to the regions in the field of systematic TB screening among the identified risk groups.

The war in Ukraine has caused an escalation of the humanitarian crisis, which can seriously affect the progress towards achieving regional TB goals. The war has a devastating impact (both direct and indirect) on people's lives and health and the health care system. Interruptions in treatment and care caused by disruptions in health services and shortages of medicines and medical supplies create a serious risk of increased mortality and morbidity from infectious diseases such as HIV and TB due to the conflict's negative impact on the provision of long-term treatment and care services. Addressing the urgent healthcare challenges in Ukraine, and ensuring the continuous treatment of TB and drug-resistant TB is among the most urgent priorities.

¹² https://phc.org.ua/sites/default/files/users/user90/Strateghichni_naprijamky_realizaciji_zakhodiv_TB.pdf

¹³

<https://phc.org.ua/sites/default/files/users/user92/%D0%86%D0%BD%D1%84%D0%BE%D1%80%D0%BC%D0% B0%D1%86%D1%96%D0%B9%D0%BD%D0%B0%20%D1%81%D1%82%D1%80%D0%B0%D1%82%D0%B5%D0% B3%D1%96%D1%8F.pdf>;

The problem of law enforcement (policy). Focus group participants reported a small number of complaints from people with TB about discriminatory actions of employers and stigma in the workplace. Stigma and discrimination in the workplace were related to the disclosure of diagnosis and dismissal due to too long treatment. Restrictions of the legislation on sick leave were also mentioned: the maximum duration of sick leave for TB is 10 months, i.e. sick leave is paid until the group is determined (until recovery or until a new MSEC is conducted), in case of TB, a person is referred to the MSEC within 10 months from the date of disability. The legislation also restricts the possibility of employers to pay wages to such employees if the person is assigned to a position in accordance with the staff list and does not work under a civil law contract.

Stigma in the family and in the community. The focus group participants described the appeals of people with TB related to problems in family life after TB diagnosis/disclosure, as well as at work and in the immediate environment (neighbors, residents of the community).

According to the focus group participants, stigma in the environment can be overcome through proper information by state agents (doctors, health care facilities, local governments, etc.) about TB, the consequences of the disease for people and their environment, and the means of prevention and control of the spread of TB. Such information should be based on humane treatment of people with TB and respect for their dignity and rights.

In addition, a situation of stigma in the family of a person with TB can be prevented by a physician, who, according to the Public Health Standard and the TB Treatment Standard, is obliged to: (1) identify contacts of people with TB; (2) educate and counsel people with TB and their family members on how to implement infection control measures by a person with TB both in the inpatient and outpatient stages of treatment. Contact persons are advised to self-observe TB symptoms.

The impact of language on stigma. A key paradigm shift in the WHO Regional TB Action Plan for the European Region 2023-2030 is to change the way we think, speak, and talk about TB, putting people with TB at the center of the global TB response. It starts with acknowledging the fact that the vocabulary commonly used to talk about TB needs to evolve. The Center for Public Health has developed national guidelines on destigmatizing terminology to shape and develop gender-sensitive, rights-based language around TB¹⁴.

Language influences stigma, beliefs, and behaviors and can determine how comfortable a person is with the process of being tested or treated. Just as the HIV/AIDS community avoids using terms such as "AIDS control," the community must move toward more empowering, people-centered language to help bring TB out of the dark and encourage people to talk about TB in their homes, communities, and workplaces.

All efforts to address stigma and discrimination and build tolerant attitudes start with the language of communication. We need to change the way we think, speak, and dialogue about TB in everyday and professional life. We need to focus on people, not on their characteristics or disease, and respect people's rights. Person-centered language encourages people to speak openly about their experiences and fosters a tolerant attitude towards people with TB in society. Tolerant vocabulary is a way to overcome tuberculosis globally.

According to the Medical Guarantee Programs for 2023 and 2024 for the diagnosis and treatment of tuberculosis, one of the requirements for the organization of service provision is to maintain a tolerant attitude towards people with TB.

To improve the quality and effectiveness of investigation and examination of contacts, Ukraine has introduced the systematization of modern approaches to regular TB screening and

¹⁴ https://www.phc.org.ua/sites/default/files/users/user90/Rekomendaciji_destygmacyzacija_TB_2023.pdf

unification of appropriate treatment and diagnostic procedures according to the principles of evidence-based medicine and best international practices:

- 1) The Order of the Ministry of Health of Ukraine dated 09.03.2021 No. 406, registered with the Ministry of Justice of Ukraine on 11.05.2021 under No. 622/36244, approved the Procedure for TB Epidemiological Surveillance (hereinafter - the Procedure for TB Epidemiological Surveillance).¹⁵ The TB surveillance procedure regulates the requirements for surveillance of contact persons with TB cases, including the algorithm of actions of PHC specialists/epidemiologists/TB doctors for contact tracing and examination of contacts, key stages and algorithm of contact examination, and duration of contact surveillance by PHC specialists, defines approaches to prioritization of contacts (determination of the risk of contact infection, priority contacts by risk categories), agreed standardized definitions and indicators of contact investigation components in accordance with WHO recommendations. In addition, to assess the surveillance of contact persons, the Procedure for TB epidemiological surveillance stipulates that the average number of contact persons per index TB case should not be lower than the average household size (calculated by the State Statistics Service by region and in Ukraine as a whole).
- 2) The Order of the Ministry of Health of Ukraine No. 102 of January 19, 2023, approved the Standards of Medical Care "Tuberculosis" (hereinafter referred to as the TB Standards)¹⁶. Among other things, the TB Standards define priority risk groups for the development of TB/XDR-TB, regulate algorithms for systematic screening for TB among identified risk groups, and define mandatory quality criteria for the examination, observation, and treatment of persons with focal or close contacts with people with active TB and TB with bacterial excretion, regulate the introduction of modern short-term preventive treatment regimens for TB, as well as approaches to the preventive treatment of contacts with drug-resistant TB, etc.
- 3) The Order of the Ministry of Health of Ukraine No. 302 dated 16.02.2022, registered with the Ministry of Justice of Ukraine on 30.03.2022 under No. 366/37702, approved the Procedure for Organizing the Detection of TB and Latent TB Infection (hereinafter - the Procedure for Detection of TB and LTBI)¹⁷. The Procedure for Detection of TB and LTBI defines the organizational framework for effective detection of TB and LTBI among TB risk groups and the general population, as defined in the industry standards in the field of health care. The organization of the necessary measures to detect TB at the level of HCFs and private entrepreneurs providing primary health care services, among other things, includes the participation of physicians of the primary health care center in the examination/investigation of TB infection foci, investigation, and tracing of contacts under the supervision of a physician and/or epidemiologist in accordance with the Procedure for TB epidemiological surveillance; provision of medical services for the diagnosis and treatment of LTBI among certain target groups, etc.
- 4) In 2023, the evidence-based clinical guideline "Tuberculosis" was updated in accordance with the new modules of the WHO Consolidated TB Guidelines 2022 (Module 4: Treatment. Treatment of drug-susceptible TB; Module 4: Treatment. Care and support for TB; Module 4: Treatment. Treatment of drug-resistant TB;

¹⁵ <https://zakon.rada.gov.ua/laws/show/z0622-21#Text>

¹⁶ <https://moz.gov.ua/article/ministry-mandates/nakaz-moz-ukraini-vid-19012023--102-pro-zatverdzhennja-standartiv--medichnoi-dopomogi-tuberkuloz>

¹⁷ <https://zakon.rada.gov.ua/laws/show/z0366-22#Text>

Module 5: Treatment of TB in children and adolescents), which enables rapid implementation of all modern approaches to TB prevention, diagnosis, care, and support in Ukraine¹⁸.

2. The right to access information

Content of the right: People with TB should have access to information about the nature of the disease, its transmission, effective preventive measures, treatment options and possibilities, including the duration of treatment, names and types of medicines used, the nature of side effects and risks of non-compliance with treatment.

Healthcare legislation, contrary to international standards and recommended sources of international standards, does not contain the full scope of mandatory information on the nature of the disease, its transmission and infectious danger, effective preventive measures, treatment options and possibilities, including the duration of treatment, names and types of medications used, the nature of side effects and risks of non-compliance with the treatment regimen.

For 2022-2025, the Public Health Center of the Ministry of Health of Ukraine has developed an information strategy that describes the general area of use of information resources and provides a holistic vision of communication tools aimed at:

- ensuring a shift in public attitudes towards the TB problem, including overcoming stigma and discrimination against people with TB;
- introduction of effective means of communication in the professional environment (among medical and social workers) to promote positive behavior change in people with TB, ensure adherence to TB treatment, create a positive psychological climate during treatment, create conditions and provide opportunities for people and communities affected by TB to participate and influence decision-making¹⁹.

The problem of law enforcement (policy). Focus group participants noted the unscrupulous work of MSECs, which deliberately concealed the procedure for obtaining consultations for assistance, the timing, and the procedure for obtaining disability status. There was also a lack of information for people with TB, for example, about social security and available social services. Also, it is not uncommon for doctors to be inactive and not provide full information about treatment options and opportunities to receive outpatient care, which in fact deprives people with TB of a conscious choice of treatment. Sometimes the level of trust is higher in social workers, so the concept of a "patient-centered approach" implies that a doctor should be a social worker, psychologist, and lawyer. This comprehensive approach ensures that the patient gets what he or she needs, and this approach works.

As for the quality of counseling by medical professionals, it is generally getting better. Healthcare professionals are constantly improving, undergoing training, and training on stigma/discrimination.

Therefore, **there are trends for improvement**, and according to the survey of people with TB, there is an increase in awareness, which also allows us to state that access to information has improved.

3. The right to access services

¹⁸ <https://www.dec.gov.ua/wp-content/uploads/2023/01/klinichna-nastanova-tuberkuloz-sichen-2023.pdf>

¹⁹

<https://www.phc.org.ua/sites/default/files/users/user92/%D0%86%D0%BD%D1%84%D0%BE%D1%80%D0%BC%D0%B0%D1%86%D1%96%D0%B9%D0%BD%D0%B0%20%D1%81%D1%82%D1%80%D0%B0%D1%82%D0%B5%D0%B3%D1%96%D1%8F.pdf>

Content of the right: People with TB have the right to accessible, free, and quality diagnosis and treatment without discrimination.

The healthcare legislation at the level of legislative acts establishes guarantees for the provision of medical care to people with TB. However, by-laws and other legal acts do not contain the full scope of guarantees for the provision of medical care to people with TB: all support services for people with TB are not taken into account, there is no mechanism for implementing the right to free treatment of comorbidities, etc.

According to the provisions of Article 49 of the Constitution of Ukraine and laws in the field of health care (Fundamentals of Health Care Legislation of Ukraine, Laws of Ukraine "On Overcoming Tuberculosis in Ukraine", "On State Financial Guarantees of Medical Care for the Population"), it can be stated that the state guarantees medical care to people with TB, which includes: (1) prevention, diagnostics, treatment, and rehabilitation; (2) an accessible network of health care facilities; (3) quality of medical care in accordance with the system of health care standards; (4) financing of the provision of a guaranteed amount of medical services and medicines to all citizens and other persons specified by law.

According to the Program of Medical Guarantees for 2023 on Diagnosis and Treatment of Tuberculosis (Resolution of the Cabinet of Ministers of Ukraine No. 1464 of December 27, 2022)²⁰, one of the requirements for the organization of service provision is to maintain a tolerant attitude towards people with TB according to the program of counteracting discrimination and stigmatization of TB patients approved by the healthcare provider and ensuring the confidentiality of relevant medical data.

The problem of law enforcement (policy). The focus group participants provided common examples of violations of the right of people with TB to access services, namely:

- failure to provide inpatient treatment and care;
- lack of effective treatment of resistant forms of TB;
- failure to provide free medicines;
- incompetence and unfriendly attitude of doctors;
- absence or insufficient staffing of TB specialists (e.g., a TB specialist works part-time at 0.25 rate; one TB cabinet is available for the entire district);
- some institutions are left without doctors and preventive check-ups;
- untimely diagnosis of TB, which leads to health complications;
- service of extrapulmonary tuberculosis was eliminated and now does not exist;
- lack of a mechanism for implementing the right (due to lack of funds in health care facilities) to free treatment of concomitant diseases caused by TB, including free consultations;
- violation of the rights of people with TB in prisons;
- corrupt actions of the MSEC and other health care workers: refusal to extend the disability status of a person with TB who has not paid a "charitable contribution";
- resale of anti-TB drugs and refusal to provide referrals for examination;
- there is a certain category of people (without documents, lost for one reason or another) who are entitled to diagnostic and treatment services under state guarantees, but they fall out of this system. As a temporary solution to this problem, we can consider the involvement of local governments: when the relevant territorial community should allocate funds in its budget for people who will need such services in the community. This would require legislative changes. A comprehensive solution to this problem will

²⁰ <https://zakon.rada.gov.ua/laws/show/1464-2022-%D0%BF#Text>

require more time and political action, including a solution as to how local authorities can finance the restoration of documents and these services.

So, the above-mentioned violations can be attributed to structural barriers: discrimination, or restrictions, or failure to fulfill certain obligations at a certain government level and in the process of realization of these rights.

4. The right to confidentiality

Content of the right: Information relating to a person with TB and TB treatment must be kept confidential and may not be disclosed to any party except: (1) when authorized by the relevant health care professionals; (2) in strictly defined circumstances listed in the law; (3) including for the protection of third parties who are at serious and imminent risk of infection; (4) to share necessary health information with health care providers who provide care to TB patients.

Healthcare legislation. The Law of Ukraine "On Overcoming Tuberculosis in Ukraine" and the MOH regulations on TB do not contain the right of people with TB to confidentiality, which is consistent with the obligation of health care workers to keep patient health status and medical confidentiality as defined by the Fundamentals of Health Care Legislation (Art. 39-1, Art. 40, Art. 78).

The problem of law enforcement (policy). Focus group participants noted the widespread practice of disclosure of TB status by healthcare workers and employers.

It is now almost impossible to keep information about a person's TB status secret in Ukraine. The issue is not even in the imperfection of the legal framework but in the spiritual state of society. It is the disclosure of the diagnosis that is a very big problem in both the medical and social spheres. This violation occurs at different levels but is more typical not for big cities, but for more remote small towns and small communities, where people know each other better. This problem is especially acute in those regions where there have been no projects of international assistance and where outdated approaches are still practiced. There is a higher level of stigma and discrimination. People from such settlements try not to go to the counseling office even at their place of residence but try to go to a big city to avoid giving rise to conversations and fears of people they communicate with, relatives and friends. This is especially true now with a large number of internally displaced persons with TB who need to continue treatment at their new place of residence, but even in this case, their diagnosis is not always kept confidential. The diagnosis is disclosed, and this leads to the stigmatization of TB patients. The legislation stipulates liability, even criminal liability, for violation of the rights of TB patients, but the question is how well this legislation is enforced (for example, who should sue, how to prove that there was indeed a disclosure). It is necessary to involve Centers for Control and Prevention of Diseases, which are responsible for investigating such cases. At the same time, both the person with TB and the doctor should have their own mechanism for protecting their rights (in particular, to avoid the "automatic" guilt of the doctor).

The situation is gradually improving, and many efforts are being made to ensure the right to confidentiality of people with TB, but in general, the problem of confidentiality remains relevant.

Some focus group participants noted low awareness and tolerance among doctors and educators, as well as among the population. There is a wide range of prejudices among the population, from "if a person has TB, it's forever and they will definitely die" to "it's nothing, you just need to take one pill and then there is nothing to be afraid of."

Another problem is that the Procedure for Organizing TB Diagnosis and Treatment does not ensure the anonymity of diagnosis and treatment. Due to the decentralization of medical

services at the local level, the strong "corporate solidarity" of doctors makes it possible for them to act irresponsibly.

The focus group participants provided common examples of violations of the TB patients' right to confidentiality, including:

- there is a request from the community of people with TB to hold medical staff accountable for disseminating information about a person's TB status;
- doctors often do not understand what medical confidentiality is. They believe that if they tell their junior staff, it is not a violation of medical confidentiality, which only applies to disclosing the diagnosis to outsiders;
- in facilities where people with TB are under state control, proper storage of medical records is not ensured confidentially;
- the "patient route" to TB facilities often discloses information about a person's TB status;
- in penitentiary institutions, convicts are illegally used to help medical staff;
- it is difficult to prove in court that a healthcare worker has disclosed TB status (breach of confidentiality). In addition, the very fact of going to court and the court proceedings already carries a risk of confidentiality violation;
- disclosure of medical confidentiality (TB status) leads to violation of other rights (e.g., dismissal of a person with TB).

5. The right to informed consent

Content of the right: People with TB have the right to provide informed consent to medical interventions before starting TB treatment and the right not to be subjected to forced treatment without consent under any circumstances.

The problem of law enforcement (policy). The authors studied the direct impact of stigma and discrimination on the realization of the right to consent to medical intervention for people with TB, as well as on the procedure for properly informing people with TB about treatment options, health consequences, opportunities to receive social services, etc.

Focus group participants noted the mainly formal approach to providing informed voluntary consent to medical intervention and suggested introducing a procedure for informing people and preparing them for medical intervention similar to the procedure for pre-and post-test counseling in connection with HIV testing. The barriers they describe are very rare. If there has been a violation of such rights, it is an individual case of a certain person in a certain place. These are isolated incidents that should be viewed in the context of a particular healthcare facility and a particular doctor or someone who violated human rights in TB. There is no compulsory treatment in Ukraine.

They also discussed the practice of informing a person with TB before they sign a consent for medical intervention. The participants expressed opinions on the existence of passive and active informing. In the case of passive informing, a person is provided with a form, information, and booklets from those available in the health care facility. Often, there is no active informing, when a doctor explains in detail the possible forms of hospitalization, treatment options, etc. that are acceptable for a person, so a person often does not understand what they are signing.

6. The right to freedom from arbitrary arrest/detention and forced isolation

Content of the right: People with TB have the right to be free from arbitrary detention, including involuntary detention or isolation of infected persons, except in extraordinary circumstances

listed in the law and in proportion to what is strictly necessary, using the least restrictive and intrusive means available to achieve legitimate public health objectives (e.g., when a person is known to be likely to infect others but refuses treatment and all reasonable measures to ensure treatment compliance have been taken but have failed). People with TB should not be detained in custody or in non-medical facilities for non-compliance with treatment.

The problem of law enforcement (policy). Focus group participants discussed the practice of isolation and compulsory treatment and identified certain problems in policies.

In Ukraine, it is almost impossible to forcibly isolate a person, except for those who are imprisoned. This means that a person can only be taken to an emergency room, and the responsibility of the legal authorities ends there. Doctors also cannot force a person to undergo treatment. As for equipped wards, these wards are designed for people who are under arrest by court order (people with tuberculosis); such wards are equipped in multidisciplinary hospitals. In case people with tuberculosis with bacterial excretion, including during outpatient or inpatient treatment, violate the anti-epidemic regime, which puts other people at risk of contracting tuberculosis, to prevent the spread of tuberculosis, they may be compulsorily hospitalized by court order to regional TB centers (TB facilities) that have appropriate wards (departments) to accommodate such patients (Article 12 of the Law of Ukraine "On Overcoming Tuberculosis in Ukraine").

If a person is not convicted, he or she belongs to the civilian service sector. And all services that are guaranteed by medical guarantees are available to them. If a person is serving a sentence according to a court decision, they are sent to a specialized institution, which is a medical facility for a particular nosology (this also raises the question of whether TB will be diagnosed in time if a person is serving a sentence).

The legislation provides that an application for compulsory hospitalization or extension of the term of compulsory hospitalization of a patient with an infectious form of TB is submitted to the court by a representative of the TB facility that provides the appropriate treatment for this patient, and not by the facility itself (as confirmed by a selective analysis of court practice for the period from 01.01.2019 to 01.12.2023). The application is filed with the court at the location of the TB facility that provides medical (dispensary) supervision of the patient, or with the court at the place of detection of the patient (Article 343 of the Civil Procedure Code of Ukraine).

Deadline for filing an application: the application must be filed within 24 hours from the time of detection of a violation of the anti-epidemic regime by a patient with a contagious form of tuberculosis (Article 344 of the Civil Procedure Code of Ukraine).

The decision to satisfy the application is subject to immediate execution and is the basis for compulsory hospitalization or extension of the period of compulsory hospitalization of a person in a TB facility for the period stipulated by law.

Compulsory hospitalization of persons subject to a court decision shall be carried out taking into account the doctor's opinion for a period of up to 3 months.

Once the court decision on compulsory hospitalization to a TB facility or extension of the term of compulsory hospitalization enters into force, the court shall send the decision to the relevant local government body to take measures to protect the property of the person subject to the court decision.

Local police authorities, at the request of the head of a regional phthisiopulmonological center (TB facility), provide assistance in enforcing a court decision within their authority (Article 12(5) of the Law of Ukraine "On Overcoming Tuberculosis in Ukraine").

Court practice: Decision of the Dobropillya City Court of Donetsk Region of 29.11.2023 in case No. 227/3359/23²¹; Decision of the Novomoskovsk City Court of Dnipropetrovsk Region of 12.04.2019 in case No. 183/2275/19²².

There have been no changes in the procedure for applying compulsory hospitalization and implementing other guarantees against the arbitrary restriction of freedom of people with TB. There is no information in open sources about the state's systematic monitoring of the ratio of voluntary and involuntary isolation, the duration of isolation, and the observance of the rights of people with TB when implementing the court procedure for their involuntary hospitalization.

Legislative problems for certain groups, including people with TB in prisons. The rules on compulsory treatment by court order for people with TB and HIV-associated TB who have committed crimes remain unchanged. The possibility of alternative treatment is not checked; the person is not informed about the risks, significance, and reasons for isolation, is not provided with social and psychological support, is not taken into account if he or she refuses to undergo treatment, and there is no set time for isolation. The use of involuntary physical isolation requires a statement from a healthcare facility. For convicts with TB and HIV-associated TB, compulsory treatment is allowed only based on a court decision according to the above-described procedure, if these people refuse to receive treatment.

7. The right to work in safe conditions

Content of the right: Employees have the right to work in an environment that does not present an excessive health hazard, and employers are responsible for implementing measures to reduce the work-related risk of TB.

The healthcare legislation does not contain any special regulations on working conditions for people with TB. Moreover, the legislation is aimed at the social isolation of people with TB, regardless of its form. This is confirmed by the regulations on long days of sick leave (Labor Code, Article 40), and preservation of the job (Law of Ukraine "On Protection of the Population from Infectious Diseases", Article 25, "On Overcoming Tuberculosis in Ukraine").

In addition, the legislation forbids people with TB to work in areas that involve contact with people (health care, catering, services, etc.). The legal grounds for not hiring people with TB and HIV-associated TB or suspending them from work are still in place (Labor Code, Article 40; Law of Ukraine "On Overcoming Tuberculosis in Ukraine": "On Ensuring Sanitary and Epidemiological Welfare of the Population", Article 28, "On Protection of the Population from Infectious Diseases", Article 23; List of Contraindications for Work in Professions Defined in the List of Professions, Industries and Organizations, Employees of Which Are Subject to Mandatory Preventive Medical Examinations, approved by the Order of the Ministry of Health of Ukraine of 23. 07.2002, No. 280; List of Particularly Dangerous, Dangerous Infectious and Parasitic Diseases of Human and Carriers of Pathogens of These Diseases, approved by the Order of the Ministry of Health of Ukraine No. 133 of 19.07.1995).

Safe working conditions are guaranteed by the Labor Code (Articles 2, 153-155), but in terms of general policy, they do not take into account the creation of working conditions for people with TB.

This situation leads to self-stigma in the economic environment when people with TB do not disclose their diagnosis or quit their jobs. The "shadow" economy also poses a threat, when people without official employment are carriers of the disease, avoid medical examinations, and are not insured in the system of compulsory state social insurance.

²¹ <https://reyestr.court.gov.ua/Review/115287597>

²² <https://reyestr.court.gov.ua/Review/81823388>

The problem of law enforcement (policy). Focus group participants stated that the legislation doesn't provide any job opportunities for people with TB. Some positive examples were given of employers providing employment opportunities for people with TB within the terms of internal regulations. The general conclusions of the research on the legislative and policy context of TB-related stigma in Ukraine show that since the last assessment of the legal environment and the level of stigma against people with TB in Ukraine (from 2021 to March 2024), there have been no systemic changes in overcoming the preconditions for stigma and discrimination against people with TB. For example, the health care reform, which was supposed to introduce the "money follows the patient" approach²³, approach, has not really worked at the local level. This is confirmed by the huge number of appeals from people with TB, complaints about the long absence of medicines, and the terrible financial and technical condition of inpatient TB facilities. As a result, due to insufficient political commitment to implementing a comprehensive response to the state strategy for reforming the TB service and insufficient cross-departmental cooperation, the principle of a new healthcare financing model has been only partially implemented. This also applies to the financial protection of citizens, i.e. the prevention of huge expenses in case of illness or refusal to receive necessary medical care due to the inability to pay for it.

The principle of a patient-centered approach²⁴ has not been implemented in the legislation and standards of medical care; the legislation on combating infectious diseases retains a punitive approach: people with infectious diseases and bacteria carriers should be warned of liability for non-compliance with sanitary and epidemiological rules and regulations and infecting others²⁵.

There is no connection between the norms of healthcare legislation and special legislation on detention facilities, labor legislation, education, etc. In particular, the legislation related to health care, protection of the population from infectious diseases and tuberculosis focuses on the medical rights of people with TB. However, other rights of people with TB, such as the right to work in safe conditions, are not guaranteed at all. Labor legislation also lacks such guarantees. This fact demonstrates the existence of prerequisites for structural stigma in the legislation and gives impetus to the stigmatization of people with TB by "duty-bearers".

Participants in the focus groups expressed different positions on how to eliminate stigma and discrimination in the legislation. Some participants believe that special rules on the rights of people with TB should be included in health care legislation and in corresponding "industry-specific" legislation, for example, in the field of employment, and education. Others argue that the rights of people with TB are part of general human rights, and there is no need for special rules for people with TB. Instead, the rights of people with TB should be protected on the same level as the rights of other people.

Focus group participants also noted that Ukraine has approved a strategy and the concept of infection control standards, but many institutions do not comply with infection control because many healthcare facilities are outdated and need to be reconstructed, modernized, and have ventilation systems repaired. This situation is gradually improving: each facility is trying to organize its activities to comply with infection control to the extent that funds allow. These issues were brought up at high levels, including in local governments, but changes take time.

²³ Concept of healthcare financing reform in Ukraine. <https://zakon.rada.gov.ua/laws/show/1013-2016-%D1%80#Text>;

²⁴ Concepts of the National Targeted Social Program to Combat Tuberculosis for 2018-2021. <https://zakon.rada.gov.ua/laws/show/1011—2017—%D1%80#top>

²⁵ Law of Ukraine "On Protection of the Population from Infectious Diseases" of April 6, 2000 № 1645-III. / <https://zakon.rada.gov.ua/laws/show/1645-14#Text>

According to the authors of the research, structural stigma in legislation will be eliminated as a result of the implementation of a human rights-based approach to policy making and policy enforcement. Another problem is the lack of a systematic state monitoring of the fulfillment of obligations regarding people with TB. The only monitoring that exists is conducted by the NPM (Ukrainian Parliament Commissioner for Human Rights), which covers only one aspect of human rights: the state's implementation of the Convention against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment²⁶.

8. Specifics of realization of rights during martial law. Rights of access to public information under martial law

The most important tool to combat the spread of tuberculosis in wartime, amid the coronavirus infection, is information work. The majority of the Ukrainian population is still unaware of the causes/factors that increase the risk of TB infection.

In regions of active hostilities, people suffer from food shortages, chronic stress, and lack of access to basic medical services. During the fighting, people are forced to stay in often overcrowded shelters. When leaving the combat areas, particularly at the beginning of the invasion, people stayed at train stations, buses, trains, and temporary shelters that were overcrowded and poorly ventilated. A significant number of people with TB were unable to continue their treatment due to difficulties in visiting a treatment facility, changing their place of residence, or restrictions on the work of the TB service. Interruption of treatment for these people with TB led to disease progression and re-infection. Unfortunately, all these conditions, in which our citizens were living, led to a worsening of the incidence rate.

Under martial law, access to public information is an extremely valuable legal tool that can save lives and preserve human health. It is important to inform citizens in advance about the threat of attack/occupation, which ensures timely evacuation of the population.

The problem of law enforcement (policy). Focus group participants stated that under martial law, many public services have suspended their work or operate with restrictions due to the threat to national security and the lack of a real possibility of proper functioning.

At the same time, it is important to have high-quality and timely access to public information under martial law to ensure the proper functioning of the legal system.

Some restrictions exist because medical facilities focus the efforts of their specialists on providing emergency life-saving measures for victims and wounded from the aggressor's illegal actions. At the same time, all TB facilities provided assistance to TB patients and were working according to their intended purpose, except for security-related situations and the fact that many doctors left due to the danger while laboratories were not working. However, even during martial law, people with TB can receive treatment in any part of the country to which they have evacuated from dangerous regions, and if a person suspects that they have TB symptoms, they can get a consultation at the nearest TB facility or see a family doctor.

Based on the results of the focus group interviews with stakeholders, a Matrix of the legislative and policy context of TB stigma was compiled (Table C). Experts identified gaps in the laws and policies that protect people with TB, their implementation, and media coverage.

²⁶ https://zakon.rada.gov.ua/laws/show/995_085#Text

Table 4. Matrix of the legal and policy context for TB-related stigma, as assessed by stakeholders

	(1) Availability		(2) Performance		(3) Media coverage	
	Laws	Policy	Laws	Policy	Laws	Policy
The right to equality and freedom from discrimination	4	4	2	3	2	3
The right to access information	4	4	3	3	3	3
The right to access services	4	4	3	3	4	3
The right to confidentiality	4	4	2	3	3	3
The right to informed consent	4	4	4	4	3	2
The right to freedom from arbitrary arrest/detention and forced isolation	4	3	3	4	2	2
The right to work in safe conditions	4	3	2	3	2	2
Specifics of the rights implementation during martial law. The right to access public information under martial law.	3	4	4	4	2	3
The number of rights harmed by laws/policies (codes 0-1).	0	0	0	0	0	0

Note: Each right is scored on the following scale:

(1) 0 - There are laws/policies at the national level that harm people with TB; 1 - Laws/policies that harm people with TB exist only at the regional level; 2 - There are no laws/policies related to people with TB; 3 - Laws/policies that protect people with TB exist only at the regional level; 4 - There are laws/policies at the national level that protect people with TB.

(2) 0 - Laws/policies that harm people with TB are implemented at the national level; 1 - Laws/policies that harm people with TB are implemented only at the regional level; 2 - There are no laws/policies related to people with TB, 3 - Laws/policies that protect people with TB are implemented only at the regional level; 4 - Laws/policies that protect people with TB are implemented at the national level

(3) 0 - Laws/policies that are harmful to people with TB are covered by national media; 1- Laws/policies that are harmful to people with TB are covered only by regional media; 2 - No media coverage of laws/policies; 3 - Laws/policies that protect people with TB are covered only by regional media; 4 - Laws that protect people with TB are covered by national media.

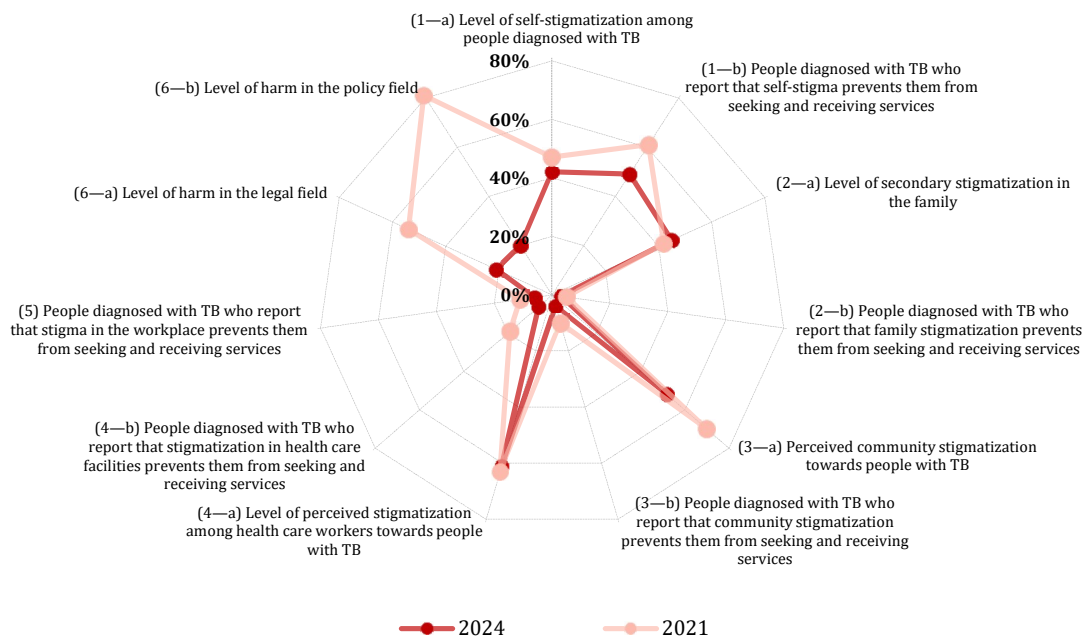
TB stigma radar

The TB Stigma Radar is a comprehensive, standardized assessment of TB-related stigma, including self-stigma, its impact on service use, family, community, and health worker stigma, and the legal and policy context of stigma. The wider the "wings" of the radar, the bigger the problem.

The study results show that the most problematic is the situation with perceived stigma in the community and from health care workers and self-stigmatization of TB patients (Fig. C).

Explanation: Each indicator can have a value from 0 to 100%. The larger the "wing" of the radar, the more likely people with TB are to face TB diagnosis and treatment barriers due to stigma and discrimination.

Figure 21. TB Stigma Radar in Ukraine



Findings

Almost all (96%) respondents with TB have signs of self-stigmatization. Respondents often try to avoid possible stigmatization by keeping their TB diagnosis confidential outside the family. At the same time, the desire to hide the status already indicates the presence of self-stigmatization and anticipated stigma.

In general, **the indicators in the research focus remained the same or improved compared to 2021.** In particular, the level of self-stigmatization of people with TB and the level of perceived stigma in the community decreased, which may indicate some improvement, in particular thanks to efforts to inform the population about the disease.

People with TB often identify themselves with several key groups, and each of these identities can be a source of stigma. 59% of respondents identify themselves with at least one vulnerable group, including elderly people; people living with HIV; people with disabilities; former prisoners; low-income urban residents, etc.

The level of stigma associated with TB decreases after treatment, but does not disappear completely. According to the survey results, people diagnosed with TB who had already completed treatment at the time of the interview had a lower level of self-stigma compared to those who had not yet completed treatment at the time of the survey.

Overall, 27% of people with TB (compared to 39% in 2021) reported experiencing stigma because they had TB. Most often, it was stigmatization during visits to healthcare facilities, at work, or in the community, which kept them from accessing medical care for TB diagnosis and treatment.

As in the previous wave, the main source of secondary TB stigma in the family was the fear of spreading information that a family member had TB and the fear of getting infected. The level of secondary stigma in the family has not changed statistically (18.0 points vs. 16.9 points in 2021).

The level of perceived stigma in the community has decreased: the average score was 23.0 points compared to 31.0 in 2021. Similar to the results of the previous wave, this was mainly expressed as a desire to limit contacts due to fear of infection. Community stigma is directly related to the self-stigmatization of people with TB and secondary stigma in the family, as the fear of status disclosure in the community and its potential consequences is one of the main components of both stigmas. Accordingly, reducing perceived stigma in the community will help to address self-stigma and secondary stigma.

The average score of perceived stigma among healthcare workers remained the same (22.0 points vs. 22.5 points in 2021). TB doctors or infectious disease specialists had a higher level of perceived stigma compared to TB nurses. Similarly to the previous wave, 30% of healthcare workers felt that they were stigmatized because their work involved interaction with people who had TB.

Experts assessed the level of harm of the legal and policy environment at 20% and 21%, respectively, where 0% means no harm and 100% means maximum harm to people with TB. Key gaps in the legal and policy context include the lack of enforcement of laws protecting the rights to freedom from discrimination, privacy, and a safe workplace, as well as media coverage of laws and policies related to a range of rights.

Recommendations

As part of the study, all target groups had the opportunity to provide recommendations to counteract TB-related stigma and discrimination. This section describes the recommendations provided by people with TB, their families, community members, and healthcare providers, and summarizes the recommendations developed by the authors of the report.

Recommendations from people with TB

As for the desired changes in TB facilities, laws, and policies to combat TB stigma, people with TB most often mentioned more public awareness about all aspects of TB and prevention. Some respondents would like to improve the attitude of doctors towards people with TB, talked about insufficient funding for TB facilities, and suggested improving the conditions of stay in

healthcare facilities. Occasionally, respondents also recommended combating fear and shame among people with TB, as well as psychological and financial support for people with TB.

Recommendations of TB patients' family members

The recommendations of relatives were similar to those expressed by people with TB: they mainly recommended educational activities for the general public, funding, and modernization of TB health facilities.

Recommendations of community members

Most often, respondents mentioned the need for educational and preventive measures. Less frequently were recommendations to treat people with TB with understanding and support.

Recommendations of health care workers

Healthcare workers also recommended awareness-raising and prevention activities for society, as well as awareness-raising activities and training for healthcare workers. There were occasional calls to treat all people with TB with understanding; to increase funding for TB services and to encourage medical specialists to work in this area.

General recommendations

Holding information and educational campaigns

- One of the main reasons for stigma is the fear of transmission. This fear is intensified by a low level of awareness of the ways TB is transmitted and to what extent people with TB can put others at risk. Therefore, it is critical to conduct extensive TB information campaigns in healthcare facilities at various levels, educational institutions, transportation, social media, and the media to improve knowledge and debunk myths among healthcare professionals and the general population.
- In information campaigns and materials about TB, it is important not only to spread information about the ways of transmission and prevention, but also to emphasize the following messages
 - After taking anti-TB drugs for 2-3 weeks, people with TB are not a source of infection for others;
 - TB is curable; people with TB do not pose a danger to others;
 - TB can be treated in outpatient facilities starting from the moment of diagnosis;
- An important component of educational campaigns should also include:
 - Informing people with TB about their rights, as well as informing community members, health care workers, and other service providers about the rights of people with TB.
 - Informing the population about the procedures for receiving anti-TB care in terms of health care system reform and about available social services for people with TB;
 - Explaining the extent to which people with TB can pose a risk to others;
 - Explaining that TB can be contracted not only by people with low social status or behavioral risks;

- Eliminating stigmatizing and discriminatory language in both professional and everyday communication.
- The most promising approach to reducing TB stigma and self-stigma is to strengthen the ability of people with TB to counteract external stigmatizing judgments and accept the diagnosis, for example, through self-help groups. Another effective approach would be to provide complete information about the nature of the disease, how it is transmitted, effective preventive measures, treatment options, duration of treatment, types of medications, side effects, and risks of non-compliance with treatment. Such information should be provided to a person with TB by a health or social worker during the first motivational counseling in the form most convenient for the person, for example, in a brochure that can be taken home and read at any time, or through the information in the patient's electronic cabinet. To that end, amendments to the Fundamental Laws of Ukraine on Health Care, the Laws of Ukraine "On Overcoming Tuberculosis in Ukraine", "On Protection of the Population from Infectious Diseases", the Standards of Health Care for Tuberculosis, the Specification for the Provision of Medical Services, and the Ethical Code of Physicians of Ukraine should be developed to align the right to information of people with TB with international standards. After introducing amendments to the legal acts, develop an algorithm for informing/counseling on TB and ensure its implementation by all health and social service providers.
- Specifics to be taken into account when informing and training healthcare workers:
 - Improve the level of teaching skills of the teaching staff of medical educational institutions.
 - To use ECHO sessions for training doctors more widely²⁷.
 - Training in simulation centers in medical schools (for example, as part of the Ukrainian-Swiss project "Medical Education Development") should take into account TB specifics.
 - As part of undergraduate and postgraduate medical education, special attention should be paid to the topic of humanity and empathy in health care.
 - Particular attention should be paid to raising awareness and training of primary healthcare workers.
- Raising awareness in communities, spreading information materials and media campaigns at the national level may be insufficient to counteract stigma at the community level. It is important to work actively in the communities involving members of the community. Stigma reduction interventions can be used in communities with the participation of trained volunteers, health and social workers who can provide information materials, facilitate group sessions and interactive lectures on TB during community meetings, in religious centers, etc. It is essential to involve opinion leaders within specific communities in information campaigns. These can be leaders of communities, mayors, representatives of the executive branch, deputies, business leaders, school staff, prominent cultural figures, etc.

²⁷ ECHO (Extension for Community Health Outcomes) is a distance learning program that combines the format of lectures and multilateral discussion of specific clinical cases, and is one of the methods of continuous medical development. For example; phthisiologists can act as experts in video conferences, and primary care physicians can act as listeners).

Improving the legislation on equality and freedom from discrimination

- Create a legal and political context that protects the rights of people with TB. Legislation and policies should include mechanisms to ensure that a TB diagnosis does not affect employment status or qualifications for other benefits or services.
- It is necessary to ensure anti-discrimination expertise of legislation and policies that regulate access to health care services for people with TB, to supplement the norms prohibiting discrimination against people with TB and their family members in all spheres of public life (including, but not limited to, education, labor relations) and to provide tools to ensure compliance with these guarantees, introducing a human rights-based approach. Implement state financial guarantees to ensure access to anti-TB services in full.

Ensuring access to services

- Involve people with TB in decision-making during treatment. Insufficient communication between healthcare workers and people with TB is a source of misunderstanding and stigmatization. It is important to engage people with TB as much as possible in discussing their treatment decisions, including the choice of treatment model, side effect management, mental health, etc. Physicians should provide this information in an accessible and appropriate form relevant to age and gender, taking into account cultural specifics, and provided in a language that the person receiving the information understands. It is recommended to discuss the treatment plan and needs of a person with TB involving a multidisciplinary team that includes the person with TB, a doctor, a psychologist, and a social worker. This practice is part of the realization of a person with TB's right to participate in decision-making, and any decisions regarding the treatment process of a person with TB made without their participation may be considered a manifestation of discrimination with consequences for the offender.
- It is recommended to separate the flows of people with TB in TB facilities, including people with different diseases and people with behavioral risks (alcohol or drug addiction), and gender separation. When organizing the treatment process, take into account the interests of vulnerable groups, including single mothers and transgender people.
- Social support services should be person-oriented and funded from the budget.
- Ensure the provision of social services to TB patients, as very often the obstacle to treatment is not the lack of access to therapy, but the inability to meet other urgent needs (in particular in the case of comorbidities).
- It is necessary to ensure that people with TB have access to social, psychological, and economic rehabilitation services after treatment, taking into account their needs, as well as access to psychological assistance for the relatives of a TB patient;
- Ensure a friendlier attitude of healthcare workers towards people with TB, including more attention, clear communication, lack of "superior" attitude, and involvement in decision-making regarding their health; in this context, peer-to-peer counseling can be a good strategy.

- It is important to conduct information and logistics interventions to improve access to modern TB diagnostic methods for all people with suspected TB and to inform them of the results of the diagnosis. If diagnosed correctly, a person will be able to quickly start treatment with the best possible drug regimen, to stop bacterial excretion and return to their normal life, avoiding long-term isolation and stigmatization. To ensure state financial guarantees for early TB diagnosis, it is advisable to align the Primary Health Care Service Specification with the Diagnosis and Treatment of Adults and Children with Tuberculosis Service Specification.

Protecting the confidentiality of people with TB by healthcare workers

- It is essential to ensure the confidence of TB diagnosis information, especially in rural areas, and to train doctors and nurses in TB and primary care facilities to prevent disclosure of diagnosis.
 - Solving the problem seems to be a long-term task: starting with educating students of relevant medical professions and changing their attitudes, ending with training of doctors and nurses in the workplace.
- Provide necessary counseling as part of contact investigation - provide family counseling and support people with TB in disclosing their diagnosis to their loved ones.
- People with TB need to feel safe and confident knowing that their personal medical information will not be disclosed and that their right to confidentiality will be respected. To achieve this, an official mechanism for responding to violations of the rights of people with TB should be established and legislated. Information about this mechanism should be posted in a noticeable place in every healthcare facility and be available in the personal electronic account of every person with TB. Medical staff should be informed about the consequences of violating the right to confidentiality.
- Promote collaboration, and sharing of information between health services and social services and/or NGOs that provide community-based services for people in difficult life circumstances, in compliance with confidentiality rules (development and implementation of algorithms for collaboration at the local level is an important intervention that has proven effective in Ukraine to improve access to TB services for people at high risk of contracting socially caused TB). It is necessary to include such interaction not only in national strategies, but also in the regulations that shape policy and ensure the organization of such work, especially between the Ministry of Health and the Ministry of Social Policy of Ukraine.
- To realize the right to confidentiality, the MOH should develop amendments to the MOH regulations on tuberculosis, in particular, the MOH Orders: No. 657 of 02.09.2009 "On Approval of Primary Medical Records and Reporting Forms for Tuberculosis"; No. 530 of 25.02.2020 "On Approval of Health Care Standards for Tuberculosis" (as amended by the Order of the Ministry of Health of Ukraine of October 6, 2021 No. 2161); Order of the Ministry of Health and the State Statistics Committee No. 112/139 of 25. 03.2002 "On Approval of the Primary Medical Record Form N 089/o "Report of a Patient with a First-time Diagnosis of Active Tuberculosis or Relapse" and Instructions for its Filling" and others, which should provide for the following international standards: the right of people with TB to confidentiality about

their health status; the obligation of health care workers to keep confidential the health status of a person with TB and medical confidentiality. Amend the job descriptions of health care workers who have access to confidential information, including on people with TB, with requirements for personal data protection and confidentiality (the obligation of health care workers to keep confidentiality about the health status of a person with TB and medical secrecy); develop and implement a mechanism at the local level to investigate cases of violation of medical secrecy and the right of people with TB to confidentiality.

- Ministry of Internal Affairs, Ministry of Justice: prohibit access to medical records for non-medical staff of pre-trial detention centers and penal institutions of the State Criminal Executive Service, and ensure its confidentiality. The MOH should ensure the confidentiality of personal data of people with TB, including those obtained using modern digital technologies (video DOT, smart box, etc.).

Ensuring the realization of the rights of people with TB to freedom from arbitrary arrest/detention and forced isolation

- The current regulation on compulsory hospitalization of people with infectious forms of TB needs to be regulated in terms of bylaws that ensure the collaboration of different services and the judicial system. The issue of compulsory treatment should be coordinated between the two services: the medical and the internal affairs services, and the differences between compulsory treatment and compulsory isolation should be taken into account. Judges' awareness of TB and human rights should be raised so that when deciding on involuntary isolation, they take into account whether all necessary preliminary measures have been taken before the case is brought to court.
- The Ministry of Health should introduce control over the implementation of a court decision on compulsory hospitalization by a person with TB. To the Parliamentary Commissioner for Human Rights: to systematically monitor the ratio of voluntary and involuntary isolation, the duration of isolation, and the use of the procedure for involuntary hospitalization of people with TB by health care facilities.
- To the Supreme Court: to recommend to summarize the court practice in cases of involuntary hospitalization of patients with infectious forms of TB and provide the courts with relevant explanations. Publish information in open sources on the state's systematic monitoring of the ratio of voluntary and involuntary isolation, the duration of isolation, and the observance of the rights of people with TB when applying the court procedure for involuntary hospitalization of people with TB. Use forced isolation as a last measure.
- Amend the criminal executive legislation to bring the norms on compulsory treatment of people with TB and HIV-associated TB who have committed crimes in line with international standards, in particular, to ensure access to modern treatment regimens, obtain informed consent for treatment, provide social and psychological support, etc.

Interventions aimed at reintegrating people with TB into social and professional networks to ensure social well-being and financial independence

- The economic (re)integration of people with TB should ensure the right of people with TB to continue working and studying, to proper working conditions, and equal access

to educational institutions. For this purpose, it is necessary to advocate for the settlement of issues of prevention and protection of the rights of people with TB and HIV-associated TB at the level of collective agreements, to motivate employers to develop policies and programs for TB prevention and support for people with TB, to include appropriate clauses in collective/ labor agreements, etc. To implement the policy of combating stigma and discrimination against people with TB in the workplace, it is necessary to develop and implement workplace programs, which may include information campaigns to combat stigma and discrimination against workers with TB, infection control and protection measures for workers, support programs for people with TB, including the organization of DOT sites at health centers of enterprises. Engage employers' associations and trade unions in information campaigns on job security for people with TB and ensuring proper working conditions.

- At the legislative level, it is necessary to initiate changes to the Labor Code, the Laws of Ukraine "On Protection of the Population from Infectious Diseases" and "On Overcoming Tuberculosis in Ukraine" to eliminate restrictions on access to work for people with TB; to change the rules on the compulsory sick leave for continuous treatment and rehabilitation to enable the person with TB to continue working with the consent as long as there are no medical contraindications; remove restrictions on access to work for people with TB, provide for proper working conditions and guarantee job security for the entire period of TB treatment in the Labor Code, the Laws of Ukraine "On Protection of the Population from Infectious Diseases" and "On Overcoming Tuberculosis in Ukraine". Establish a direct ban on unjustified refusal to hire people with TB and HIV-associated TB, based on their health status, and ensure proper control over employers' compliance with these norms; eliminate the possibility of dismissing people with TB based on their health status, as well as recognizing them medically unsuitable for professional or other activities related to a high risk to others, as well as for performing certain functions.

Changes in legislation related to martial law

- To regulate the issue of declarations at the legislative level so that the medical facility from the city where people with TB left receives reimbursement for the services provided (this issue became more urgent during martial law).

Appendix 1

Description of indicators for assessing the TB stigma radar

Indicator	Description	Calculation	2024	2021
(1a) Level of self-stigmatization among people diagnosed with TB (0-100%)	12 questions with a scale from 0 to 4, where a higher level means higher stigma; adapted from VanRie TB Patient Stigma Scale, Tropical Medicine and International Health 2008; 13(1):20-30)	Numerator: sum of scores of 12 questions among the total sample; denominator: number of respondents x 4 (scale) x 12 (number of questions)	42%	47%
(1-b) People diagnosed with TB who report that self-stigma prevents them from seeking and receiving TB treatment services (0-100%)	Based on the question: "Have you experienced any of these feelings [12 self-stigma questions] when seeking and accessing TB treatment services?"	Numerator: number of people who answered the question in the affirmative; denominator: number of respondents	49%	61%
(2a) Level of secondary stigma in the family (0-100%)	10 questions with a scale from 0 to 4, where a higher level means higher stigma; secondary stigma experienced by family members of patients with TB at the time of diagnosis - Arcencio TB Stigma Scale tool, Public Health Action w2014;4(3):195-200)	Numerator: sum of scores of 10 questions among the total sample; denominator: number of respondents x4 (scale) x10 (number of questions)	45%	42%

(2-b) People diagnosed with TB reporting that family stigma prevents them from seeking and receiving TB-related services (0-100%)	Based on the question: "Have you faced stigma at home, within your family, that made it difficult for you to seek and get TB diagnosis and treatment services?"	Numerator: number of people who answered the question in the affirmative; denominator: number of respondents	3%	5%
(3-a) Level of perceived stigma in the community towards people with TB (0-100%)	11 questions with a scale from 0 to 4, where a higher level means higher stigma; tool adapted from VanRie TB Community Stigma Scale, Tropical Medicine and International Health 2008;13(1):20-30	Numerator: sum of scores of 11 questions among the total sample; denominator: number of respondents x 4 (scale) x 11 (number of questions)	52%	70%
(3-b) People diagnosed with TB reporting that community stigma prevents them from seeking and receiving TB-related treatment services (0-100%)	Based on the question: "Have you experienced any stigma (negative attitudes towards you) from your neighbors that would prevent you from seeking and getting TB diagnosis and treatment services?"	Numerator: number of people who answered the question in the affirmative; denominator: number of respondents	4%	10%
(4-a) Perceived stigma of health care workers towards people with TB (0-100%)	9 questions with a scale from 0 to 4, where a higher level means higher stigma; the tool was adapted from Corrigan 9 StigmaDomains (AQ-9), KNCV Stigma Measurement Guidance Chapter 5 Table 3 (2018), Psychiatry Research 2014; 215:466-70), Community Mental Health Journal 2004;40(4): 297-307, Journal of Family Psychology 2006; 20(2):239-46	Numerator: sum of the scores of 9 questions among the total sample; denominator: number of respondents x 4 (scale) x 9 (number of questions)	61%	63%

<p>(4-b) People diagnosed with TB reporting that stigma in health care facilities prevents them from seeking and receiving TB-related services (0-100%)</p>	<p>Based on the question: "Have you experienced stigma (i.e., prejudice against you) in hospitals or clinics that made you unable or uncomfortable to get TB diagnosis and treatment services?"</p>	<p>Numerator: number of people who answered the question in the affirmative; denominator: number of respondents</p>	<p>6%</p>	<p>19%</p>
<p>(5) People diagnosed with TB who report that stigma in the workplace prevents them from seeking and receiving TB-related treatment (0-100%)</p>	<p>Based on the question: "Have you experienced stigma at work in a way that it prevented you from seeking and receiving TB diagnostic and treatment services and access to such services?"</p>	<p>Numerator: number of people who answered the question in the affirmative; denominator: number of respondents</p>	<p>6%</p>	<p>11%</p>
<p>(6a) Level of harm in the legal environment (0-100%)</p>	<p>Current legislation on seven rights related to TB: the right to freedom from discrimination; the right to access information; the right to access services; the right to privacy; the right to informed consent; the right to freedom from arbitrary arrest detention and involuntary isolation; and the right to a safe workplace. Each right is assessed on a scale from 0 (maximum harm) to 4 (no harm) according to the following parameters: availability of laws/regulations; enforcement of laws; media coverage of law implementation.</p>	<p>Numerator: 1 - (the sum of the scores in the 7 (rights) by 3 (parameters) matrix; denominator: 7 (rights) x 3 (parameters) x 4 (maximum score))</p>	<p>21%</p>	<p>54%</p>

<p>(6-b) Level of harm in the policy environment (0-100%)</p>	<p>Current policy on seven TB-related rights: right to freedom from discrimination; right to access information; right to access services; right to privacy; right to informed consent; right to freedom from arbitrary arrest detention and involuntary isolation; right to a safe workplace. Each right is evaluated on a scale from 0 (maximum harm) to 4 (no harm) according to the following parameters: availability of policies; implementation of policies; media coverage of policies.</p>	<p>numerator: 1 - (sum of points in 7 (rights) by 3 (parameters) of the matrix; denominator: 7 (rights) x 3 (parameters) x 4 (maximum score))</p>	<p>20%</p>	<p>81%</p>
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Appendix 2

Assessment of the level of stigma in legislation and policy on the example of the rights/freedoms of people with TB.

1. THE RIGHT TO EQUALITY AND FREEDOM FROM DISCRIMINATION

1.1. The content of the right to equality and freedom from discrimination for people with TB: all people are equal before the law. Human rights and freedoms are inalienable and inviolable. There should be a legislative framework that prohibits unequal treatment of people with TB in private, public, and state settings, including health care, employment, education, and access to social services. Medical care should be provided to patients regardless of age, gender, race, nationality, religion, social status, political views, place of residence, citizenship, and other non-medical characteristics, including financial status.

Focus group participants, as well as non-governmental organizations, provided examples of discrimination against people with TB in employment, health care, education, family, and community relations. The combination of stigma and discrimination, as well as violations of several rights of people with TB in one situation, is common.

A selective analysis of legislation and policies, as well as **focus group assessments**, revealed the following:

The right to equality and freedom from discrimination:

1. Availability: Laws - 4 Policies - 4
2. Implementation: Laws - 2 Policies - 3
3. Media coverage: Laws - 2 Policies - 3
4. Number of rights that are harmed by laws/policies – 0

1.2. International standards that define the right to equality and freedom from discrimination

1. Universal Declaration of Human Rights (1948)²⁸: All human beings are born free and equal in dignity and rights. Everyone is entitled to all the rights and freedoms outlined in this Declaration, regardless of race, color, sex, language, religion, political or other opinions, national or social origin, property, birth, or other status.

2. The European Social Charter (ESC) (1996)²⁹ (Part I, paragraph 20; Part V, Article E): all workers have the right to equal opportunity and equal attitude in employment and occupation without discrimination based on sex. The exercise of the rights under this Charter shall be ensured without any discrimination based on race, color, sex, language, religion, political or other beliefs, national or social origin, health status, membership in a national minority, birth, or other circumstances.

3. The European Convention on Human Rights (ECHR) (1950) (Article 14): the use of the rights and freedoms recognized in the present Convention shall be ensured without discrimination on any ground such as sex, race, color, language, religion, political or other opinion, national or social origin, membership in a national minority, property, birth or other

²⁸ https://zakon.rada.gov.ua/laws/show/995_015#Text

²⁹ https://zakon.rada.gov.ua/laws/show/994_062#Text

status.

4. The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) (1979) (Article 12): States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care.

5. The International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966)³⁰: The States Parties to the present Covenant undertake to ensure that the rights outlined in the present Covenant, in particular the right of everyone to achieve the highest attainable standard of physical and mental health, are exercised without any discrimination as to race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

6. The International Covenant on Civil and Political Rights (ICCPR) (1965)³¹: All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, all discrimination of any kind shall be prohibited by law and the law shall guarantee to all persons equal and effective protection against discrimination on any basis such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

7. The Convention on the Rights of Persons with Disabilities (CRPD) (2006)³²: States Parties recognize that all persons are equal before the law and are entitled to equal protection and enjoyment of the law without discrimination of any kind. States Parties shall prohibit all discrimination on the basis of disability and shall guarantee equal and effective legal protection to persons with disabilities against discrimination on any grounds. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate measures to ensure reasonable accommodation. Specific measures necessary to promote or achieve de facto equality for persons with disabilities shall not be considered discrimination within the meaning of this Convention.

9. The Convention on the Rights of the Child (CRC) (1989)³³: States Parties shall respect the rights of the child.): States Parties shall respect and ensure all the rights outlined in the present Convention to every child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, color, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status; and shall take all appropriate measures to ensure that the child is protected from all forms of discrimination or punishment on the basis of the child's or his or her parent's or legal guardian's status.

10. Convention on the Elimination of Discrimination in Education (1960)³⁴: The right to universal access to education and to equal conditions in education.

11. The Salamanca Declaration on Principles, Policies, and Practices in Special Needs Education (1994)³⁵ is the first international document that emphasized the need for educational reforms towards inclusive education. The appeal to all governments emphasizes that the priority in terms of policy and budgetary allocations should be "reforming the education system to enable all children to learn, regardless of individual differences and difficulties."

12. The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) (1965)³⁶: States Parties undertake to prohibit and eliminate racial discrimination in all its forms and to ensure the equality of all persons before the law, without distinction as to

³⁰ https://zakon.rada.gov.ua/laws/show/995_042#Text

³¹ https://zakon.rada.gov.ua/laws/show/995_043#Text

³² https://zakon.rada.gov.ua/laws/show/995_g71#Text

³³ https://zakon.rada.gov.ua/laws/show/995_021#Text

³⁴ https://zakon.rada.gov.ua/laws/show/995_174#Text

³⁵ https://zakon.rada.gov.ua/laws/show/995_001-94#Text

³⁶ https://zakon.rada.gov.ua/laws/show/995_105#Text

race, color, national or ethnic origin, particularly with regard to the realization of the following rights: the right to security of person and protection by the State against violence or bodily harm, the right to health, medical care, social security and social services; and to encourage understanding between all races.

1.3. Stigma and discrimination in legislation

Healthcare laws contain discriminatory rules that restrict the right of people with TB to work (and, accordingly, to receive wages), illegal dismissal of employees based solely on their illness, and disclosure of health information. The acts of the Cabinet of Ministers of Ukraine in the field of health care contain provisions that may lead to discrimination against people with TB based on race and ethnicity. At the same time, there are no legal provisions in health care and other areas that explicitly prohibit unequal treatment of people with TB.

There are signs of discrimination in the legislation related to access to the medical guarantees program for persons who do not have the documents required to choose a doctor (registration number of the taxpayer's account card (hereinafter - RNOCP), identity document: passport of a citizen of Ukraine / temporary certificate of a citizen of Ukraine / birth certificate for persons under the age of 14 / a certificate of permanent residency in Ukraine / refugee certificate/certificate of a person who needs additional protection). The submission of copies of these documents is stipulated by the Procedure for choosing a doctor who provides primary health care, the form of the declaration on choosing a doctor who provides primary health care, Order of the Ministry of Health of Ukraine dated 19.03.2018 No. 503³⁷ (registered with the Ministry of Justice of Ukraine on March 21, 2018 under No. 347/31799).

Such persons are Roma women and men who do not have identity documents and/or registration of permanent residence, and for this reason cannot sign a formal agreement with family doctors³⁸ (discrimination based on race and ethnicity).

According to the researchers, these norms also limit the rights of citizens to choose a doctor at the second and third levels of health care service.³⁹ Due to the fear of TB stigma and discrimination, people are usually afraid to learn about their status, tell others about it, seek medical care and adhere to treatment. This increases their vulnerability, suffering and leads to a loss of human rights.

1.4. Researched Legal Acts of Ukraine

Constitution of Ukraine:

Art. 21 stipulates that all people are free and equal in their dignity and rights; Article 24: citizens have equal constitutional rights and freedoms and are equal before the law. There shall be no privileges or restrictions based on race, skin color, political, religious or other beliefs, gender, ethnic or social origin, property status, place of residence, language or other characteristics.

1.4.1. Healthcare Legislation

³⁷ <https://zakon.rada.gov.ua/laws/show/z0347-18#Text>

³⁸ Factsheet "Impact of the COVID-19 pandemic on the rights of Roma people in Ukraine. June 3, 2020. OHCHR / Human Rights Monitoring Mission in Ukraine (HRMMU). <http://www.un.org.ua/images/documents/4933/BN%20C19%20Roma%20UKR.pdf>; Роми в Україні – Time for action: Priorities and ways of effective integration policy. Analytical report 2019. p.12. https://minorityrights.org/wp-content/uploads/2019/05/MRG_Rep_Ukraine_UKR_Apr19.pdf

³⁹ https://aph.org.ua/wp-content/uploads/2021/02/Analiz-normativno-pravovih-aktiv__Zvit__final.pdf

Ensuring TB treatment and prevention is a state obligation, which should be based on an equal approach, ensuring free access to TB health care services, and preventing human rights violations, as well as stigma and discrimination against people living with TB.

The Association Agreement between Ukraine, on the one hand, and the European Union, the European Atomic Energy Community, and their Member States, on the other hand⁴⁰ (hereinafter - the Association Agreement), has consolidated the vector chosen by Ukraine for integration into the European Union, including in the healthcare sector. Section 22 "Public Health" of the Association Agreement states that the parties shall develop cooperation in the field of health care to improve its safety and protect human health as a prerequisite for sustainable development and economic growth. Article 427 of the Association Agreement defines the prevention and control of infectious diseases, such as HIV/AIDS and tuberculosis, as one of the areas for cooperation (Part 1, paragraph b).

In May 2014, the World Health Assembly (Geneva, Switzerland) approved the Global Strategy to End TB for 2016-2035, which aims to remove obstacles in the fight against tuberculosis, multidrug-resistant tuberculosis, and HIV/TB co-infection, and to summarize the implementation of the Global Plan to Stop TB, which was developed by the WHO Strategic Working Group on TB and agreed by all WHO member states. The main objective of the new WHO Global Strategy to Stop TB by 2035 is to free the world from TB, achieving zero morbidity, mortality, and suffering from this disease. The issue of TB control in Ukraine is one of the priority areas of state policy in the field of health care and social development and is the subject of international obligations.

1. The Law of Ukraine "Fundamentals of the Legislation of Ukraine on Health Care":

Article 4: the basic principles of health care in Ukraine include, in particular, the observance of human and civil rights and freedoms in the field of health care and the ensuring of related state guarantees; equality of citizens in the health care sector;

Article 6: among the rights of every citizen of Ukraine to health care is legal protection against any illegal forms of discrimination related to health status;

Article 9: restrictions on the rights of citizens related to their health condition are allowed, particularly: on the basis and in accordance with the procedure provided by the laws of Ukraine, citizens may be recognized as temporarily or permanently unfit for professional or other activities related to increased danger to others, as well as for the performance of certain state functions.

2. The Law of Ukraine "On Protection of the Population from Infectious Diseases" (Article 19) contains only medical rights, namely the rights of persons suffering from infectious diseases or being bacterial carriers.

3. The Law of Ukraine "On Overcoming Tuberculosis in Ukraine" of July 14, 2023, No. 3269-IX⁴¹ establishes the status of regional phthisiopulmonary centers that will diagnose and treat tuberculosis under the medical guarantee program. The Law also clearly defines the mechanism for providing medicines for preventive treatment. The Law attributes to the task of central and local executive authorities, and local self-government bodies the implementation of equal opportunities to receive appropriate medical care; defines the medical rights of people with TB and infected with mycobacterium tuberculosis.

4. The Law of Ukraine "On Ensuring Sanitary and Epidemic Welfare of the Population" does not contain any rights of citizens at all.

⁴⁰ https://zakon.rada.gov.ua/laws/show/984_011#Text

⁴¹ <https://zakon.rada.gov.ua/laws/show/3269-20#Text>

5. The Law of Ukraine "On State Financial Guarantees of Medical Care for the Population":

Article 5 defines the provision of equal state guarantees for the realization of the right to health care by patients regardless of age, race, skin color, political, religious, and other beliefs, gender, ethnic and social origin, property status, registered place of residence, language or other characteristics as one of the principles of the program of medical guarantees;

Article 9: medical service providers are prohibited from refusing to accept a declaration of choice of a primary care physician and to manage a patient, in particular, based on the patient's chronic disease, age, gender, social status, financial situation, registered place of residence, etc., except as provided by law.

6. The Law of Ukraine "On Rehabilitation in the Field of Health Care" of 03.12.2020 No. 1053-IX⁴² (effective from 19.08.2022) describes rehabilitation assistance until the onset of a permanent disability, i.e. until a medical and social examination is conducted and a person with a disability status is obtained. The law defines the legal, organizational and economic principles of rehabilitation of persons with disabilities in the healthcare sector. The Law creates conditions for the formation of a modern healthcare rehabilitation system in Ukraine, which will function and develop in accordance with the principles and standards of the European Union.

7. The Law of Ukraine "On the Public Health System" of 06.09.2022 No. 2573-IX⁴³ (entered into force on 01.10.2023). This Law defines the legal, organizational, economic, and social principles of the public health system in Ukraine in order to promote public health, prevent diseases, improve the quality and increase life expectancy, regulate public relations in the field of public health and sanitary and epidemiological well-being of the population, defines the relevant rights and obligations of state and local governments, legal entities and individuals in this area, establishes the legal and organizational principles of state supervision (control) in the areas of economic activity that may pose a risk to the sanitary and epidemiological well-being of the population. It assigns a long list of public health functions to the Ministry of Health, changing the idea of the 2015 reform, which envisaged a decentralized model with distributed functions under the coordination of the newly created Public Health Center (PHC).

8. The Law of Ukraine "About Overcoming Tuberculosis in Ukraine" of 14.07.2023, No. 3269-IX⁴⁴ changes the conceptual approach and provides for a transition from the policy of combating tuberculosis to its elimination in accordance with the guidelines of the World Health Organization. The law stipulates more accessible and better services for people with TB

:

- diagnosis, prevention and treatment of tuberculosis;
- defines the status of regional TB centers that diagnose and treat tuberculosis under the medical guarantees program;
- clearly defines the mechanism of providing medicines for preventive treatment.

Among the main legislative changes is the strengthening of the diagnostic network: a three-level system of microbiological laboratories for the diagnosis of tuberculosis, headed by the Central Laboratory, which will provide external quality control of lower-level laboratories.

⁴² <https://zakon.rada.gov.ua/laws/show/1053-20#Text>

⁴³ <https://zakon.rada.gov.ua/laws/show/2573-20#Text>

⁴⁴ <https://zakon.rada.gov.ua/laws/show/3269-20#Text>

Currently, Ukraine is in 4th place in terms of the spread of the disease in the WHO European Region. Over the past year, 18,510 people were diagnosed with tuberculosis, which is 2.5% more than last year.

Since the beginning of the full-scale war, a system of early detection of tuberculosis, in particular among internally displaced persons (IDPs), has been established at the regional level. For this purpose, 23 regional teams for detecting and combating tuberculosis have been established in the regions.

Tuberculosis screening covered 395 thousand Ukrainians who were forced to leave their homes and were at risk of the disease or had symptoms of the disease. This work will continue. This was discussed during a joint meeting of the committees on programmatic issues and regional policy of the National Council on Combating Tuberculosis and HIV/AIDS.

These comprehensive steps will improve the situation with overcoming the disease in Ukraine and improve TB treatment in accordance with WHO global standards.

The document envisages a change in the conceptual approach enshrined in Ukrainian legislation, namely a shift from a policy of combating tuberculosis to overcoming it.

The new law, in particular, updates the terminology, as well as organizes and clarifies the powers of the Ministry of Health to develop and approve bylaws in the field of TB control.

The law defines regional TB centers as the only municipal institutions in each region that provide TB diagnosis and treatment services under the medical guarantees program.

It also defines the mechanism for providing medicines for the preventive treatment of tuberculosis (latent tuberculosis infection). Such medicines will be procured centrally and distributed in the regions between providers (primary healthcare facilities and regional centers) of healthcare packages from the National Health Service that include this type of treatment.

The law regulates active and passive TB detection, with an emphasis on the obligation of primary care providers to continuously identify people with TB who are at risk and conduct annual examinations.

TB diagnostics is provided by a three-level network of laboratories that are established and operated in health care facilities. External quality control of lower-level laboratories will be provided by the Central Reference Laboratory.

The law stipulates that preventive vaccinations against tuberculosis are free of charge, as well as the need to ensure conditions for education of students, including children with tuberculosis, in healthcare facilities.

9. The Law of Ukraine "On Amendments to the Law of Ukraine "On Prevention of Diseases Caused by the Human Immunodeficiency Virus (HIV) and Legal and Social Protection of People Living with HIV" on the Application of Modern Approaches to HIV Prevention, Testing and Treatment in accordance with WHO Guidelines" of 12.01.2023 No. 2869-IX⁴⁵, which systematically revised the main provisions of the basic law in the field of HIV/AIDS, which had not been amended for 12 years.

10. The Law of Ukraine "On Amendments to Article 70 of the Fundamentals of the Legislation of Ukraine on Health Care regarding the Peculiarities of the Establishment and Operation of Military Medical Commissions" of 02.05. 2023, No. 3079-IX⁴⁶, which granted the right to establish military medical commissions (MMCs) to all military formations and special bodies of the security and defense sector, as well as to "civilian" healthcare institutions of state and municipal ownership, which allowed to involve more than 500 hospitals for the

⁴⁵ <https://zakon.rada.gov.ua/laws/show/2869-20#Text>

⁴⁶ <https://zakon.rada.gov.ua/laws/show/3079-20#Text>

examination of persons subject to military service and significantly reduce the time of examination and queues for passing the military medical commission.

11. The State Strategy for Combating HIV/AIDS, TB, and Viral Hepatitis for the period up to 2030, approved by the Cabinet of Ministers of Ukraine on November 27, 2019. No. 1415-p (hereinafter referred to as the 2030 Strategy), establishes that the goals and tools for implementing the Strategy are based on the following key principles and foundations, including, in particular, respect for human rights and non-discrimination based on health, age, social status, sexual orientation, gender identity, occupation, and other grounds, and ensuring equality, including gender equality, and the exercise of human rights and freedoms regardless of these grounds. Strategic goal 3 "Reduce morbidity and mortality from tuberculosis" is based on the WHO Global Strategy to End Tuberculosis by 2035 and contains one of the objectives - to ensure respect for the rights of people with tuberculosis by overcoming stigma and discrimination, ensuring equal rights and freedoms at the legislative level during and after tuberculosis treatment.

To achieve strategic objective 3, it is expected that a comprehensive review of legislation will be carried out not only in the healthcare sector, but also in other areas (education, labor, social security, etc.), which should ensure that legislation, and on its basis - in policy, a human rights-based, gender-responsive approach to tuberculosis, as stipulated by WHO and StopTBP Partnership, based on international and regional human rights documents.

12. The State Strategy for the Development of the Tuberculosis Medical Care System for the Population, approved by the Order of the Cabinet of Ministers of Ukraine No. 1463-p⁴⁷ dated November 18, 2020.

The purpose of this Strategy is to create a new model of prevention, early detection of tuberculosis and medical care for patients with tuberculosis, aimed to meet the needs of the population for medical and public health services. One of the main ways to ensure the development of the TB medical care system for the population is "implementation of effective preventive TB measures", which means, among other things, that the key task for the outpatient TB treatment model is to involve socially vulnerable groups of the population with difficulties in accessing medical services and an increased risk of developing TB (unemployed, IDPs, migrants, homeless, people with alcohol and drug addiction, low-income and isolated ethnic and/or religious communities), by providing free medical services in accordance with the medical guarantee program and implementing regional / national / international TB control programs. The introduction of new approaches to the organization of TB medical care for the population involves: amendments to the regulatory framework to ensure prevention, detection, diagnosis and outpatient treatment of tuberculosis, support of TB patients at the level of primary health care providers with informing the public health facility about the case/suspected TB, controlled treatment, treatment monitoring, pharmacological surveillance, psychosocial support for people with TB, in coordination with the regional TB service, involving various health care and public health service providers who can carry out such activities.

The amount of material, technical and labor resources required for the implementation of this Strategy is determined annually, taking into account funding opportunities.

13. The Order of the Ministry of Health of 01.02.2019 No. 287⁴⁸ approved the new Standard of Infection Control for Healthcare Facilities Providing Care to Patients with

⁴⁷ <https://zakon.rada.gov.ua/laws/show/1463-2020-%D1%80#Text>

⁴⁸ <https://zakon.rada.gov.ua/laws/show/z0408-19#Text>

Tuberculosis (Standard No. 287). The document entered into force on July 1, 2020. On July 01, 2020, the Order of the Ministry of Health "On Approval of the Standard of Infection Control for Tuberculosis in Healthcare Facilities, Places of Long-Term Stay and Residence of Patients with Tuberculosis" No. 684 of August 18, 2010, became invalid. Therefore, TB healthcare facilities should review the relevant local documents. Unlike infection control measures for other infectious diseases, infection control of tuberculosis (IC TB) should take into account the ultra-easy (aerogenous) route of transmission and long-term treatment.

14. The Global Plan to End Tuberculosis 2023-2030⁴⁹, developed by the Global Stop Tuberculosis Partnership, includes recommendations for critical programmatic interventions to address TB, including expanding active case finding strategies, including contact tracing, which in turn requires additional investment, and improving the quality of existing interventions in XDR-TB testing and preventive TB treatment.

The Global Plan to End TB 2023-2030 also proposes to:

- Expanding access to early TB diagnosis, including at subclinical stages, including active TB detection among key, vulnerable and hard-to-reach populations,
- regular contact tracing and screening, implementation of radiological computer-aided detection (CAD) systems based on artificial intelligence for TB screening, etc;
- Integration of TB screening and testing programs into other public health services, with a focus on services targeting common comorbidities or risk groups, depending on the local epidemiological context;
- support decentralized patient-centered models of TB prevention and treatment at the community and home level;
- expanding testing for LTBI in accordance with the "test and treat" strategy, with priority given to key and vulnerable populations and communities that will benefit most from preventive TB treatment;
- ensuring universal access to prevention and treatment of TB for children and adult TB contacts, PLHIV, key and vulnerable populations depending on the local epidemiological context, etc;
- expanding the use of digital real-time TB surveillance systems, etc.

Global targets to be achieved by 2030:

- Ensure 100% coverage of TB preventive treatment of eligible TB contacts.
- Ensure 100% coverage of preventive TB treatment among PLHIV.
- At least 90% of countries have identified key and vulnerable populations in their national TB plans, proposed specific actions and have appropriate budget lines and monitoring mechanisms, etc.

These goals are aligned with the priorities set out in the WHO TB Action Plan for the European Region for 2023-2030 (scaling up comprehensive preventive TB treatment, prioritizing targeted TB screening among key populations and vulnerable groups, etc.)

Main proposals:

- 1) to change the legislatively defined conceptual approach, moving from the policy of TB control to the policy of TB elimination;
- 2) to establish the status of regional TB centers as providers of medical services for the diagnosis and treatment of tuberculosis under the program of medical guarantees;
- 3) to clearly define the mechanism of providing medicines for TB treatment;
- 4) to oblige primary health care providers to actively identify people with TB who are at

⁴⁹ <https://www.stoptb.org/global-plan-to-end-tb/global-plan-to-end-tb-2023-2030>

risk and to conduct annual examinations;

5) to define a three-level system of microbiological laboratories for TB diagnosis under the direction of the Central Reference Laboratory;

6) ensure the creation of conditions for education of students, including children with tuberculosis;

7) strengthen social protection of employees of TB facilities.

1.4.2. Anti-discrimination legislation

The Law of Ukraine "On Principles of Preventing and Combating Discrimination in Ukraine" (2012) distinguishes the following forms of discrimination: direct discrimination; indirect discrimination; incitement to discrimination; aiding and abetting discrimination; and harassment.

In Article 1, the definition of "discrimination" does not include "health status" as a protected ground, but leaves open the list of grounds for recognizing a situation as limiting a person's recognition, realization, or enjoyment of rights and freedoms. Instead, Article 4 of the law covers a wide range of social relations, including labor relations, health care, education, social protection, housing relations, access to goods and services, etc.

Taking into account Article 8 of this law and the 2030 Strategy, which is focused on ensuring human rights and overcoming stigma and discrimination, an important step in overcoming structural stigma and discrimination will be to conduct an anti-discrimination review of draft regulations to be developed to implement the above-mentioned strategic goal 3.

One of the legal mechanisms for preventing the adoption of discriminatory norms is the "Procedure for Conducting Anti-Discrimination Expert Evaluation of Draft Regulatory Acts by Executive Authorities" of January 30, 2013, approved by the Cabinet of Ministers of Ukraine, No. 61⁵⁰.

At the international level, anti-discrimination norms were formulated in Article 1 of the Universal Declaration of Human Rights (1948), which states that "all human beings are born free and equal in dignity and rights."

The Declaration of Human and Civil Rights (*Déclaration des Droits de l'Homme et du Citoyen* is a historical French document⁵¹ adopted by the French National Assembly on August 26, 1789, a significant documentary monument of the French Revolution) stated that people are born and remain free and equal in rights; no one shall be oppressed for his or her views, including religious views, if their expression does not violate public order established by law; the free communication of ideas and opinions is one of the most valuable human rights. As a result, every citizen may freely speak, write and print, but is liable for abuse of this freedom in cases stipulated by law.

In the second half of the twentieth century, the following anti-discrimination international acts were adopted:

- UN Declarations "On the Elimination of Discrimination against Women" (1967), "On the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief" (1981);

- UN Conventions "On the Elimination of All Forms of Racial Discrimination" (1965), "On the Suppression and Punishment of the Crime of Apartheid" (1976), "On the Elimination of All Forms of Discrimination against Women" (1979);

⁵⁰ <https://zakon.rada.gov.ua/laws/show/61-2013-%D0%BF#Text>

⁵¹ https://uk.wikipedia.org/wiki/Declaration_of_Human_and_Civil_Rights

- ILO Conventions: ILO Conventions: No. 100 " On Equal Remuneration" (1951), No. 111 "On Discrimination in Respect of Employment and Occupation" (1958), No. 122 "On Employment Policy" (1964);

- UNESCO Convention "Against Discrimination in Education" (1960).

Anti-discrimination legislation also includes the International Covenant on Civil and Political Rights (1966) and the International Covenant on Economic, Social and Cultural Rights (1966).

The Convention for the Protection of Human Rights and Fundamental Freedoms (1950) is an important piece of anti-discrimination legislation, which allows for the protection of rights and freedoms in the European Court of Human Rights.

Anti-discrimination legislation in the EU includes: The Charter of Fundamental Rights of the European Union (2000), directives: on the establishment of common standards to support equality in employment and occupation (2000), on the principle of equal treatment of persons irrespective of their racial or ethnic origin (2000), etc.

The Political Declaration on Tuberculosis Control was adopted by UN General Assembly Resolution 73/3 (2018)⁵². The document declares a commitment to meet the 2030 targets for ending the tuberculosis epidemic worldwide in accordance with the Millennium Development Goals, to ensure the implementation of joint efforts to intensify global collective action at the national level to overcome the epidemic, as well as investments and innovations for the speedy elimination of the disease.

1.4.3. Legislation in the field of education

Legislation in the field of education provides for general norms that create opportunities for the realization of the right to education for people with TB, although it does not contain specific norms for people with TB.

1. The Law of Ukraine "On Education" establishes the principles of equality and non-discrimination of citizens in the educational process on the basis of health status and defines the duty-bearers authorized to monitor compliance with these guarantees:

Article 1, paragraph 12: inclusive education is a system of educational services guaranteed by the state, based on the principles of non-discrimination, taking into account human diversity, effective involvement and inclusion of all participants in the educational process;

Article 3: Ukraine creates equal conditions for access to education. No one shall be restricted in the right to education. The right to education is guaranteed regardless of age, gender, race, health status, disability, as well as other circumstances and characteristics. The state shall provide social protection to students in cases determined by law, as well as ensure equal access to education for persons from socially vulnerable groups. The right to education may not be restricted by law. The law may establish special conditions for access to a certain level of education, specialty (profession);

Article 6: The principles of the state policy in the field of education and the principles of educational activity include, among other things, ensuring equal access to education without discrimination on any grounds, including disability; developing respect for human rights and freedoms, intolerance to humiliation of honor and dignity, physical or psychological violence, as well as discrimination on any grounds;

Article 53: Students have the right, in particular, to protection during the educational process from humiliation of honor and dignity, any form of violence and exploitation, bullying

⁵²https://www.uiphp.org.ua/media/k2/attachments/Case_Law_Related_HIVAIDS_TB_Ukraine_2021.pdf

(harassment), discrimination on any grounds, propaganda and agitation that harm the health of the student;

Article 54: The protection of these guarantees for students is entrusted to pedagogical, research, and scientific staff.

2. The Law of Ukraine "On Complete General Secondary Education":

Article 1: Accessibility of complete general secondary education is a set of conditions that contribute to meeting the educational needs of individuals and provide each person with the opportunity to obtain complete general secondary education in accordance with state standards, including non-discrimination on any grounds or circumstances, and providing students with support in the educational process.

A safe educational environment is a set of conditions in an educational institution that make it impossible to cause physical, property and/or moral harm to participants in the educational process, in particular as a result of non-compliance with the requirements of sanitary, fire and/or building norms and regulations, legislation on personal data protection, by physical and/or psychological violence, exploitation, discrimination on any grounds, humiliation of honor, dignity, business reputation (bullying, dissemination of false information, etc.), propaganda and/or agitation, including through the use of cyberspace;

Article 4: complete general secondary education may be obtained in full-time, distance, network, external, family (home), or pedagogical patronage forms, etc;

Article 7: prohibition of discrimination in general secondary education stipulates that there can be no restrictions on access to complete general secondary education. The right to complete general secondary education is guaranteed regardless of health status, disability, social and property status, difficult life circumstances, as well as other circumstances and characteristics. No participant in the educational process shall be subject to any form of discrimination, in particular, to any restrictions in the educational process or in the right to participate in activities held in an educational institution;

Article 37: control over the prevention of privileges or restrictions (discrimination) is exercised by the founder of a general secondary education institution or an authorized body (official).

3. The Law of Ukraine "On Higher Education":

Article 49: a person has the right to receive higher education in various forms or to combine them. The main forms of higher education are: institutional (full-time (day, evening), part-time, distance, network), etc.; distance education is an individualized process of education, which takes place mainly through the indirect interaction of remote participants in the educational process in a specialized environment that operates based on modern psychological, pedagogical, information and communication technologies.

4. Regulations on the distance form of completing general secondary education, approved by the order of the Ministry of Education and Science of September 08, 2020, №1115 (registered with the Ministry of Justice on September 28, 2020, under №941/35224):

- Distance learning is the organization of the educational process (through distance education or through the use of distance learning technologies in various forms of education) in conditions of the remoteness of its participants from each other and their indirect interaction in the educational environment, which operates based on modern educational, information and communication (digital) technologies;

- the organization of distance learning provides an opportunity to fulfill the right of individuals to quality and accessible education regardless of health status, disability, or other signs and circumstances, including those that objectively make it impossible to attend

educational institutions;

- if necessary, distance learning can be organized according to an individual curriculum;
- to ensure unified approaches to the creation of an electronic educational environment in an educational institution, the pedagogical council approves the use of specific information and telecommunication systems (electronic educational platforms), online communication services, and tools that organize the educational process in distance learning. Within the framework of such unified approaches, teachers, using academic freedom, can choose forms, methods, and means of distance learning. Educational institutions can use the state information and telecommunication system (electronic educational platform), which has the technical capabilities to provide distance learning.

5. Regulation on Distance Learning, approved by the Order of the Ministry of Education and Science of Ukraine No. 466 dated 25.04.2013 (registered with the Ministry of Justice on April 30, 2013, under No. 703/23235):

(1.3) this Regulation applies to distance learning in: vocational education and training institutions (hereinafter referred to as VETIs); higher education institutions (hereinafter referred to as HEIs); postgraduate education institutions or structural subdivisions of higher education institutions, scientific and educational institutions providing postgraduate education (hereinafter referred to as PEIs);

(1.5) the task of distance learning is to provide citizens with the opportunity to exercise the constitutional right to obtain education and professional qualifications, and advanced training, regardless of health status, in accordance with their abilities;

(2.2) the introduction of distance learning in higher education institutions and PEIs is possible in agreement with the Ministry of Education and Science of Ukraine;

(2.5) the number of students, trainees, pupils of higher education institutions, PEIs, VETIs enrolled in distance learning shall be determined in accordance with the resolution of the academic council of the higher education institution (post-graduate institution), pedagogical council of the vocational education and training institution within the licensed scope of training (retraining, advanced training, specialization) in distance learning and/or within the licensed scope of preparation for admission to a higher education institution;

(2.8) distance learning technologies may be used in higher education institutions, VETIs, and PEIs in the organization and provision of full-time, evening, part-time, individual, and external forms of education, provided they have the appropriate personnel and system support;

(2.9) the decision to use distance learning technologies in the educational process of VETIs, higher education institutions, and PEIs shall be made by the academic (pedagogical) council of the educational institution.

1.4.4. Legislation in the field of employment

Legislation in the field of employment provides for general guarantees of equality and non-discrimination and allows for restrictions on people's employment rights based on their health status. The Criminal Code protects the established guarantees for employees. However, several norms of the employment legislation, in combination with the healthcare legislation, contain signs of discrimination due to the introduction of unconditional restrictions for all people with TB on the ability to work (and, accordingly, to receive a salary).

1. The Labor Code:

Article 2-1: prohibits any discrimination in the field of labor, including direct or indirect restriction of employees' rights based on their health status;

Article 24: It is prohibited to conclude an employment contract with a citizen who, according to a medical report, is offered a job that is contraindicated for health reasons;

Article 22: unjustified refusal to hire is prohibited. Requirements to the employee's health status may be established by the legislation of Ukraine;

Article 40: an employment contract concluded for an indefinite period of time, as well as a fixed-term employment contract before its expiration, may be terminated by the owner or his authorized body only in the event of, inter alia, the employee's incompatibility with the position held or work performed due to health conditions that prevent the continuation of such work. Dismissal on this basis is allowed if it is impossible to transfer the employee, with his/her consent, to another job;

Article 169: the list of professions whose employees are subject to medical examination, the terms and procedure for its conduct are established by the central executive body responsible for formulating the state policy in the field of healthcare, in agreement with the central executive body responsible for establishing the state policy in the field of labor protection. The list of contraindications for work in professions defined in the List of professions, industries, and organizations whose employees are subject to mandatory preventive medical examinations, approved by the Order of the Ministry of Health of Ukraine No. 280 of 23.07.2002;

Article 170: the owner or his authorized body must transfer employees who need lighter work for health reasons, with their consent, to easier work in accordance with a medical report, temporarily or without any time limits. When transferred for health reasons to an easier lower-paid job, employees keep their previous average earnings for two weeks from the date of transfer, and in cases provided for by the legislation of Ukraine, the previous average earnings are kept for the entire period of lower-paid work or financial support is provided under the compulsory state social insurance.

2. The Criminal Code of Ukraine establishes criminal liability for:

Article 161: violation of the equality of citizens based on their race, nationality, religious beliefs, disability, and other grounds, which consists of intentional actions, such as direct or indirect restriction of rights or establishment of direct or indirect privileges of citizens on other grounds;

Article 172: gross violation of labor legislation, namely unlawful dismissal of an employee for personal reasons, as well as other gross violation of labor legislation;

Article 173: gross violation of a labor agreement, namely gross violation of a labor agreement by an official of an enterprise, institution, or organization regardless of ownership, as well as by an individual citizen or a person authorized by them through deception or abuse of trust or coercion to perform work not stipulated by the agreement;

Article 175: non-payment of wages, scholarships, pensions or other statutory payments, namely unjustified non-payment of wages, scholarships, pensions or other payments to citizens for more than one month, committed intentionally by the head of an enterprise, institution or organization regardless of ownership or by a citizen acting as a private entrepreneur.

3. The Law of Ukraine "On Protection of the Population from Infectious Diseases":

Article 25: Persons of working age who are newly diagnosed with TB or have a relapse may be issued a sick leave certificate for a continuous course of treatment and rehabilitation for up to 10 months. Such persons shall retain their jobs during this period.

4. The Law of Ukraine "On Overcoming Tuberculosis in Ukraine" of 14.07.2023, No. 3269-IX, which changed the conceptual approach and provides for the transition from a policy of combating tuberculosis to overcoming it, provides for more accessible and better services for people with TB. The document stipulates the right to an annual additional paid vacation. Changes have been made, ranging from the use of tolerant vocabulary to the inclusion of

articles on labor law. In other words, stronger tools have emerged to protect people's rights at the legislative level.

The owner or an authorized body of an enterprise, institution, or organization of all forms of ownership has no right to dismiss an employee due to his or her tuberculosis unless tuberculosis is a contraindication to work in the profession specified in the List of professions, industries, and organizations whose employees are subject to mandatory preventive medical examinations, and it is impossible to transfer the employee to another job with his or her consent. The list of such contraindications is established by the central executive body that ensures the development and implementation of state policy in the field of health care.

This norm restricts the rights of working people with TB to work and receive wages, as it actually obliges a person to stay on sick leave "for the entire period of the main course of treatment determined by the doctor". For employers who have hired an employee who has been diagnosed with TB, according to the staff list, this means that the person is actually suspended from work for the period of the main course of treatment.

The list of contraindications for working in the professions defined in the List of professions, industries, and organizations whose employees are subject to mandatory preventive medical examinations, approved by the Order of the Ministry of Health of 23.07.2002 No. 280, needs to be revised to remove restrictions on work for people with non-contagious forms of TB and to guarantee the right for paid work under conditions acceptable to them and others (e.g. remote work).

1.5. Law enforcement (policy) problem

Focus group participants and non-governmental organizations provided information and examples of discrimination against people with TB. In particular, they noted the lack of cooperation between higher education institutions and healthcare facilities to ensure the right to higher education for people with TB. According to the focus group participants, an algorithm for interaction between educational and healthcare institutions should exist to address such situations.

The USRCD for the period of 2021-2023 contains about 200⁵³ decisions of Ukrainian courts in civil and administrative cases related to the refusal of parents to provide preventive vaccinations (without medical contraindications) to their children and violation of children's right to education in this regard. As a rule, the rights of young children to education in a preschool or general education institution were temporarily restricted taking into account the public interest (until vaccination, improvement of the epidemiological situation, obtaining a positive opinion of the medical advisory commission) because parents failed to comply with the mandatory vaccination calendar and refusal to vaccinate their child.

The Supreme Court put an end to this issue in its Resolution of April 17, 2019 (case No. 682/1692/17, First Judicial Chamber of the Civil Court of Cassation), namely: referring to the case law of the European Court of Human Rights, the Supreme Court found that the requirement for mandatory vaccination of the population against particularly dangerous diseases, given the need to protect public health, as well as the health of the persons involved, is justified. This means that the principle of the importance of public interests over personal interests prevails in this matter, but only if such intervention has objective grounds, i.e., is justified.

In our opinion, given the impact of COVID-19 on human rights and changes in public life, the State can ensure the right to education for children whose parents refuse to vaccinate them by improving distance education procedures. The authors believe that preventive vaccinations

⁵³ <https://reyestr.court.gov.ua>

are an important component of ensuring the right to health, and therefore the public interest should be prioritized in this matter.

A review of open sources (official websites of the Ministry of Education and Science and the Ministry of Health) suggests that there is no monitoring of the fulfillment of the rights of people with TB to guaranteed education.

Focus group participants and NGOs reported a significant number of complaints from people with TB about discriminatory actions by employers and stigma in the workplace. Stigma and discrimination in the workplace were associated with the disclosure of diagnosis and dismissal on the grounds of long-term treatment. Restrictions of the legislation on sick leave were also mentioned: the maximum duration of sick leave for TB is 10 months, i.e. sick leave is paid until the disability status is established (until recovery or until a new MSEC is conducted), and in case of TB, a person is referred to the MSEC within 10 months from the date of disability.

Stigma and discrimination continue to be serious barriers to HIV and TB prevention and treatment.

Human rights violations (including stigma and discrimination, inequality, lack of human rights mechanisms, and legal restrictions), in addition to causing health harm to the key risk groups, impede the effectiveness of national HIV and TB prevention and treatment efforts, the country's progress in meeting its commitments under the Political Declaration on HIV/AIDS (2016), and the achievement of global goals.), as well as achieving the global goals of ending AIDS by 2030 and the UN Sustainable Development Goals⁵⁴.

According to a study of the Unified State Register of Court Decisions for the period 2018-2023, there is practically no court practice on discrimination in the dismissal of people with TB based on health status. Only one decision was found in an administrative case on the dismissal of a civil servant who considered his TB disease to be the reason for his dismissal. The court dismissed the claim of the plaintiff (a person with TB) because it did not find any discriminatory actions in the actions of the public authority based on the health status of the dismissed employee⁵⁵.

In our opinion, the court did not investigate the actual circumstances of the dismissal of the person with TB and limited itself to a formal assessment of the public authority's orders.

According to the practice of non-governmental organizations, the actual absence of judicial practice on the protection of the rights of people with TB is explained by the fear of people with TB disclosing their diagnosis.

According to the Unified State Register of Court Decisions for the period from 01.01.2020 to 01.07.2023, the courts of first instance received 14 applications for compulsory hospitalization to a tuberculosis facility or to extend the term of compulsory hospitalization of a patient with a contagious form of tuberculosis (the courts of Kherson region received 5 applications, Vinnytsia region - 3, Sumy region - 2, Kyiv region - 1, the city of Kyiv - 2, Kharkiv - 1), of which 12 were satisfied, 1 was partially satisfied, 1 was sent to another court jurisdiction.

1.6. Family and social environment stigma

Focus group participants and non-governmental organizations described the appeals of people with TB related to family problems after TB diagnosis/disclosure, as well as at work and in the immediate environment (neighbors, residents of the settlement).

According to the focus group participants, stigma in the environment can be overcome by

⁵⁴ <https://ips.ligazakon.net/document/MU15167>

⁵⁵ <https://reyestr.court.gov.ua/Review/90233265>

proper informing by state agents (doctors, health care facilities, local governments, etc.) about TB, the consequences of this disease for a person and his/her environment, and the means of prevention and control of the TB spread. Such information should be based on humane treatment of people with TB and respect for their dignity and rights.

Long-term treatment of TB often leads to loss of work, and lower financial and social status (after recovery, one cannot return to specific professions, such as teacher, educator, lawyer, hairdresser, etc., i.e. those that require close contact with people). Unlike other diseases, disability status for tuberculosis is given not only on clinical but also on social grounds. The way of life changes significantly, affecting not only the patient but also his or her family members.

A situation of stigma in the family of a person with TB can be prevented by a doctor⁵⁶, who, according to the Public Health Standard and the TB Treatment Standard, is obliged to: identify contacts with TB patients; train and counsel people with TB and their family members on how to implement infection control measures (both inpatient and outpatient). Contact persons are advised to conduct self-monitoring for symptoms that may indicate TB⁵⁷.

It is also recommended to use the mechanisms of the legislation on preventing and combating domestic and gender-based violence. For example, in the described cases of stigma of women with TB, the Procedure for Interaction of Entities Implementing Measures to Prevent and Combat Domestic and Gender-based Violence, approved by the Cabinet of Ministers of Ukraine on August 22, 2018, No. 658⁵⁸, should be applied.

On the territory of the relevant administrative-territorial unit, the interaction of entities is coordinated by district, regional state administrations in Kyiv and Sevastopol and executive bodies of village, settlement, city, and district councils in cities (if established), including amalgamated territorial communities (clause 7).

Coordination of measures to prevent and combat domestic and gender-based violence and monitoring of their implementation at the local level is carried out by authorized persons (coordinators) in executive authorities and local self-government bodies that are responsible for ensuring equal rights and opportunities for women and men, preventing and combating gender-based violence (clause 8).

Public organizations, foreign non-governmental organizations, international organizations, and other stakeholders may participate in measures to prevent and combat domestic and gender-based violence on their own initiative and/or be involved as entities (clause 9).

1.7. The impact of language on stigma

The TB stigma index research conducted in the country not only identified the extent of stigma in specific settings or target groups but also developed proposals for new forms of work to ensure effective healthcare delivery in Ukraine. The verbal constructs that are commonly used to talk about TB need to be constantly evolving. The words that a person with TB hears influence stigma, stereotypes, and behavior and can play a decisive role in a person's comfort

⁵⁶ The Ethical Code of Physicians of Ukraine, adopted and signed at the All-Ukrainian Congress of Medical Organizations and the X Congress of the All-Ukrainian Medical Society of 27.09.2009. [cl. 2.4, 4.5]: "Doctors - heads of health care institutions... are obliged to take care of... creating appropriate conditions..."

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https://phc.org.ua/sites/default/files/users/user90/Nakaz_MOZ_vid_25.02.2020_530_Standarty_medo_pomogy_pry_TB.pdf

⁵⁸ <https://zakon.rada.gov.ua/laws/show/658-2018-%D0%BF#Text>

level during TB testing or treatment. The words used by researchers and health care providers in scientific or medical terminology have a huge impact on building adherence to TB treatment, as well as on how people talk and think about TB.

Language can empower and encourage people with TB to take control of their condition and become partners in treatment or create stigma, dependency, and fear.

In the context of Ukraine's European integration, it is necessary to avoid words that have stigmatizing and discriminatory aspects in both professional and everyday communication. It is important to draw attention to the impact of language and encourage everyone to think about the power of their words. All measures to combat stigma and discrimination and to build tolerant attitudes start with the language of communication. It is necessary to change the way we think, speak, and dialogue about TB in everyday and professional life, to focus on people rather than their characteristics or disease, and to respect people's rights. Person-centered language allows us to respect people, encourage them to speak openly about their experiences and build tolerant attitudes toward people living with TB in society.

TB treatment can cause several serious challenges for a person, such as disability, loss of income, new expenses during treatment, side effects of medications, etc. Showing empathy and understanding of the problems people with TB face starts with language. By using words that empower people with TB, we can move together towards global TB elimination. The introduction of person-centered approaches is necessary not only in treatment but also in the way we treat others and the language we use.

A key paradigm shift in the Global Plan to End TB 2016-2035 is "a shift in thinking, language, and dialogue about TB that puts people living with TB at the center of the global TB response." This change must begin with recognizing that the language commonly used to talk about TB needs to evolve.

Language influences stigma, beliefs, behaviors, and a person's comfort level about undergoing testing or treatment. Just as the HIV/AIDS community avoids using terms such as "AIDS control," the community must move toward more empowering, people-centered language to help bring TB out of the shadows and encourage people to talk about TB at home, in their communities, and in their workplaces.

StopTBPartnership and UNOPS have developed the "Every Word Counts: A Guide to Tuberculosis Communication"⁵⁹ to be used by all those involved in the TB response. The developers believe that the use of appropriate language should strengthen the global response to the TB epidemic.

For example, the manual distinguishes between different types of language used in the TB community or about TB: technical language, colloquial language, and compassionate language. For the purpose of this research, the recommendations on scientific and technical language, which includes terms used in clinical and medical settings, are relevant.

1.8. Recommendations

1. Recommendations on legislation for the Cabinet of Ministers and Verkhovna Rada:
 - Amend the Law of Ukraine "On Protection of the Population from Infectious Diseases" to remove the requirement to present a document confirming the absence of HIV infection or active TB for issuing visas to foreigners and stateless persons to enter Ukraine.
 - Supplement the laws with norms prohibiting discrimination against people with TB and their family members in all areas of public life (including education and labor relations) and

⁵⁹ Every word counts.suggested language and usage for tuberculosis communications. first edition. Stop TB Partnership. UNOPS. <https://eecaplatform.org/en/every-word-counts-tb-language-guide-issued-developed-by-stop-tb-partnership-unopc/>

provide tools to ensure compliance with these guarantees.

- Amend the norms on the mandatory sick leave for continuous treatment and rehabilitation to provide for the possibility to continue working with the consent of a person with TB and in the absence of medical contraindications.

- In the Labor Code, the Laws of Ukraine "On Protection of the Population from Infectious Diseases" and "On Overcoming Tuberculosis in Ukraine" of 14.07.2023, No. 3269-IX, remove restrictions on access to work for people with TB⁶⁰.

- Introduce a policy of access to palliative and hospice care for people living with HIV or TB (including children) by amending the Order of the Ministry of Health of Ukraine of 21.01.2013 No. 41 "On the Organization of Palliative Care in Ukraine", namely to remove from the mentioned Order the norm that prohibits people with TB and HIV/AIDS from receiving palliative care.

- Introduce a new funding mechanism for anti-TB efforts aimed at encouraging healthcare workers to identify and achieve successful TB treatment, as well as encouraging people with TB to develop treatment adherence.

- Reorganize the network of TB facilities in accordance with current epidemiological trends, optimize the use of existing resources, regional characteristics, and hospitalization and discharge criteria.

2. Policy recommendations (enforcement):

- for the Ministry of Health, Ministry of Education and Science:

- To develop recommended algorithms of interaction between healthcare facilities and educational institutions, healthcare facilities, and employers to eliminate stigma and discrimination against people with TB in employment and education settings⁶¹.

- for the Ministry of Health, Ministry of Economy:

- Ensure that target groups (territorial communities, employers, etc.) are properly informed about the nature of the disease, its transmission, and contagion, effective preventive measures, as well as about the human rights of TB people and guarantees of their observance.

- Ensure (involving the non-governmental sector) systematic screening and active detection of TB cases and people in contact with TB patients, including key population groups.

- Ensure that all newborns are vaccinated against tuberculosis; stop the practice of over-the-counter sales of anti-tuberculosis drugs.

- For the Ministry of Health:

- Ensure anti-discrimination expertise of legislative drafts, as well as the HRBA approach in the development of draft legislation and policy implementation.

- Start implementing the recommendations on language contained in the manual "Every Word Matters: A Guide to Tuberculosis" prepared by StopTBPartnership and UNOPS.

- Ensure that physicians monitor the implementation of the Public Health Standard and the TB Treatment Standard, in particular in terms of the physician's obligation to: (1) identify contacts with TB patients; (2) train and counsel people living with TB and their family members on how to implement infection control measures (both at the inpatient and outpatient stages of treatment). Contact persons are advised to self-observe for symptoms that may indicate TB.

- for the Ministry of Health in cooperation with local governments:

⁶⁰ It is advisable to consider it together with the researchers' proposals outlined in the document "Analysis of Regulatory Legal Acts in the Field of Health Care. Under the provisions of the political declaration on universal health coverage". 2020. ICF "Alliance for Public Health". p.60-61.

⁶¹ It is advisable to consider this along with the researchers' proposals to ensure the right of children with TB to study in general education institutions.. p.79-80.

- Promote the use of legislative mechanisms to prevent and combat domestic and gender-based violence.

- For successful TB control in Ukraine, it is necessary to ensure compliance with one of the basic principles of infectious disease control, as defined in Article 10 of the Law of Ukraine "On Protection of the Population from Infectious Diseases," namely: "the complexity of preventive, anti-epidemic, social and educational measures, the obligation to finance them".

- for the Ministry of Health and the Verkhovna Rada:

- To develop and approve a new relevant nationwide targeted social program to combat TB⁶².

3. THE RIGHT TO ACCESS INFORMATION⁶³

2.1. Content of the right to access information: This right is a constitutional human right. The right to information enshrined in the Constitution of Ukraine is primarily provided by the laws of Ukraine "On Citizens' Appeals", "On Information", "On Access to Public Information" and other legal and regulatory acts.

People with tuberculosis should have access to information about the nature of the disease, its transmission and risk of infection, effective preventive measures, treatment opportunities and options, including the duration of treatment, names and types of medications used, the nature of side effects and the risks of non-compliance with treatment.

Tuberculosis is still highly stigmatized, associated with poverty, social marginalization, and the risk of transmission. It is worth noting that dismissive or stigmatizing attitudes persist even after successful treatment of TB. Stigma is most prevalent in general medical facilities, non-medical facilities, small towns, and rural areas. The main method of combating stigma among the general population is to develop and implement information campaigns aimed at raising awareness about TB and overcoming myths about the transmission of the disease.

Focus group participants and non-governmental organizations provided examples of violations of the right to access to information for people with TB by healthcare facilities, doctors, and MSEC. They also mentioned the lack of information for people with TB, such as social security and available social services. Doctors often don't provide complete information about treatment options, or opportunities to receive medical care on an outpatient basis, which actually deprives people with TB of a conscious choice of treatment. Sometimes the level of trust is higher in social workers, so the concept of a patient-centered approach implies that a doctor should be a social worker, psychologist, and lawyer. Thanks to this integrated approach, the patient gets what he or she needs, and this principle really works.

The quality of counseling provided by medical professionals is generally improving. Healthcare professionals are constantly learning, undergoing training, and training on stigma/discrimination.

So, there are **trends for improvement**, and we see an overall improvement in TB awareness among people with TB. This actually makes it possible to say that access to information has improved.

A selective analysis of legislation and policies, as well as **focus group** assessments, revealed the following:

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<https://www.undp.org/sites/g/files/zskgke326/files/migration/ua/7747b21f564c2890b321a54ea1efdc0f333c7b5d1d61c5ca4713a96adabd50cc.pdf>

⁶³ In this section, information means publicly available information about diseases, medical services and treatments. It does not include personal health information, which will be discussed in the section on the right to privacy.

The right to access information:

1. Availability: Laws - 4 Policies - 4
2. Implementation: Laws - 3 Policies - 3
3. Media coverage: Laws - 3 Policies - 3
4. Number of rights that are harmed by laws/policies – 0

2.2. International standards defining the right to access information

1. 1. ICCPR (International Covenant on Civil and Political Rights) Article 19 (2): Everyone has the right to freedom of expression; this right includes freedom to seek, receive, and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.

3. General Comment No. 14 (2000) of the Committee on Economic, Social and Cultural Rights "The right to the highest attainable standard of health" (Article 12 of the ICESCR):

- the right to health includes not only the right to timely and adequate health services but also to the fundamental prerequisites for health, such as access to health education and information;

- the right to health includes, among other things, access to information: accessibility includes the right to seek, receive, and impart information and ideas relating to health. However, the accessibility of information should not prejudice the right to confidentiality of personal health data;

- the right to health includes the creation of conditions that would ensure medical care and treatment for all in case of physical or mental illness;

- the right to prevention and treatment of diseases: prevention and treatment of epidemic, endemic, occupational, and other diseases involves the preparation of information and prevention programs on diseases associated with certain forms of behavior (such as sexually transmitted diseases) and diseases harmful to sexual and reproductive health, as well as the improvement of social conditions that contribute to health, such as environmental safety, education, economic development, and gender equality.

The Committee emphasizes that many measures, for example, most policies and programs to eliminate discrimination in health, can be implemented with minimal resources through the adoption, amendment or abolition of legislation or the dissemination of information.

The Committee also reaffirms that such obligations are comparable in terms of their degree of priority:

- educating and providing access to information on major health problems in the community, including information on how to prevent and combat such problems;

- ensuring adequate training of health care workers, including information on health and human rights issues.

2.3. Recommended sources of international standards

1. Patients' Charter for the Treatment of Tuberculosis (World Medical Council, 2006)⁶⁴:

- the right to information about available medical services for TB treatment, responsibilities,

⁶⁴ 1 Health and human rights: a resource guide. © 2015 François-Xavier Center for Health and Human Rights. Chapter 3. Tuberculosis and human rights.

http://medicallaw.org.ua/fileadmin/user_upload/PDF/%D1%80%D0%B5%D1%81%D0%BE%D1%80%D1%81%D0%A0%

activities, and related direct and indirect costs;

- the right to receive a timely, concise, and clearly stated history, diagnosis, prognosis (an opinion on the likely future course of the disease), and recommended treatment, including the overall risks and appropriate alternatives;
- the right to know the names of medicines and dosages or methods of treatment, their effects, and possible side effects, as well as possible effects on other medical conditions or treatments;
- the right to access medical information regarding the patient's health status and treatment process;
- the right to free and equal access to medical care for TB patients: from diagnosis to treatment, regardless of financial status, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or other diseases;
- the right to respect and dignity, including the provision of services without stigma or discrimination by healthcare professionals and authorities;
- the right to quality health care in a dignified environment, with moral support from family, friends and community;
- the right to work after diagnosis or to appropriate rehabilitation after treatment.

2. WHO (World Health Organization) Ethical Guidelines for the Prevention, Care and Control of TB (WHO, 2010): Information, counseling and the role of consent. Persons undergoing TB testing should receive basic information about TB and an explanation of why they are being tested. Persons who are offered TB treatment should be informed about the risks and benefits of the suggested interventions (both for the person with TB and other community members), the importance of completing a full course of treatment and taking infection control measures, and the support available to people with TB to complete the full course of treatment.

3. Declaration of the Rights of People with TB, section 14, article 11. Right to information. Everyone affected by TB has the right to seek, receive and share information.

This means that information about TB infection and disease, including symptoms of the disease, medical research on TB and developments in health technologies, services for its prevention, diagnosis, and treatment, and possible side effects during treatment, should be fully available, of good quality, age- and gender-relevant, culturally appropriate, and in a language that the person receiving the information can understand.

It also means that every person affected by TB has the right to

- request and receive official copies of medical records;
- receive timely, accurate, and understandable explanations of their health status and diagnosis, especially for key and vulnerable populations
- have access to counseling at any time from the moment of diagnosis to the end of treatment;
- receive an explanation of the benefits, risks and financial costs of treatment, if any, of the proposed treatment, including preventive treatment, as well as possible treatment options, with full information about the specific drugs prescribed, such as their names, doses, potential side effects and ways to prevent or reduce their likelihood, as well as possible effects of interaction with other drugs, such as antiretroviral drugs for the treatment of HIV in the presence of co-morbidities or co-infection

2.4. Researched legal acts and regulations

The Constitution of Ukraine enshrines the following rights:

Article 34: Everyone shall have the right to freely collect, store, use, and disseminate

information orally, in writing, or in any other way of his or her choice. The exercise of these rights may be restricted by law in the interests of national security, territorial integrity or public order, for the prevention of disorder or crime, for the protection of public health, for the protection of the reputation or rights of others, for the prevention of disclosure of information received in confidence, or for the maintenance of the authority and impartiality of justice;

Article 32: No one shall be subjected to interference with his or her private and family life, except in cases provided for by the Constitution of Ukraine. It is not allowed to collect, store, use and disseminate confidential information about a person without his or her consent, except in cases determined by law, and only in the interests of national security, economic well-being, and human rights;

Article 15 establishes the political and ideological diversity of public life and prohibits censorship;

Article 21 enshrines the inalienability and inviolability of human rights and freedoms;

Article 28 enshrines the right of a person to respect for his or her dignity, prohibits subjecting a person to torture, cruel, inhuman or degrading treatment or punishment; subjecting a person to medical, scientific or other experiments without his or her free consent.

Information legislation and civil law contain general guarantees for all people to receive information, including on their health status, the general epidemic, and environmental situation that may affect human health.

2.4.1. Legislation of Ukraine on information

1. The Law of Ukraine "On Information" (hereinafter - the "Law") stipulates that everyone has the right to free receipt, use, dissemination, storage, and protection of information necessary for the exercise of their rights, freedoms, and legitimate interests. The Law defines information as any information and/or data that can be stored on physical media or displayed electronically.

The exercise of the right to information should not violate public, political, economic, social, spiritual, environmental, and other rights, freedoms, and legitimate interests of other citizens, as well as the rights and interests of legal entities.

The Law establishes the basic principles of information relations, namely: guarantee of the right to information; transparency, accessibility of information, freedom of information exchange; accuracy and completeness of information; freedom of expression of views and beliefs; legitimacy of obtaining, using, spreading, storing and protecting information; protection of a person from interference in his or her private and family life.

According to the Law, the right to information is protected by law, and the state guarantees equal rights and opportunities for access to information to all subjects of information relations.

Also, no one may restrict the rights of a person to choose the forms and sources of information, except in cases provided for by law.

A subject of information relations may demand the elimination of any violations of his/her right to information.

Article 11 deals with information about an individual and defines this information (personal data) as information or a set of information about an individual who is identified or can be specifically identified. It is not allowed to collect, store, use, and spread confidential information about a person without his or her consent, except in cases determined by law, and only in the interests of national security, economic well-being, and protection of human rights.

Confidential information about an individual includes, in particular, information about his or her nationality, education, marital status, religious beliefs, health status, as well as address, date, and place of birth.

Article 20: according to the access procedure, information is divided into open information and information with limited access. Any information is open, except for that which is classified by law as information of limited access.

Article 21: Confidential information is information with limited access. Confidential information is information about an individual. Confidential information may be disseminated at the request (consent) of the relevant person in the manner determined by him/her in accordance with the conditions stipulated by him/her, as well as in other cases determined by law.

When considering the issue of exercising the right of access to information, the Law of Ukraine "On Citizens' Appeals" and the Law of Ukraine "On Access to Public Information" cannot be ignored.

2. The Law of Ukraine "On Citizens' Appeals" stipulates that citizens of Ukraine have the right to apply to state authorities, local self-government bodies, associations of citizens, enterprises, institutions, organizations regardless of ownership, mass media, officials in accordance with their functional duties with comments, complaints, and proposals related to their statutory activities, applications or petitions for the realization of their socio-economic, political and personal rights and legitimate interests and complaints about their violation.

3. The Law of Ukraine "On Access to Public Information" defines the procedure for exercising and ensuring the right of everyone to access information held by public authorities, other public information managers defined by this Law, and information of public interest.

Article 10 obliges the administrator of information about a person to use it only for the purpose and in the manner specified by law.

2.4.2. Civil law

1. Civil Code:

Article 302: an individual has the right to collect, store, use, and spread information freely;

Article 285: an adult individual has the right to reliable and complete information about his/her health status, including the right to familiarize himself/herself with relevant medical documents concerning his/her health.

2. The right to receive information on health status is also regulated by the Law of Ukraine "On Information" and Article 39 of the Law of Ukraine "Fundamentals of the Legislation of Ukraine on Health Care".

If information about an individual's illness may worsen the state of his/her health or the state of health of individuals specified in part two of this Article, or impair the treatment process, medical professionals have the right to provide incomplete information about the state of health of an individual or to limit the possibility of their familiarization with certain medical documents.

Laws on liability for violation of legislation on information and in the field of health care (which may be applied in terms of violation of the right to access information):

3. Criminal Code of Ukraine:

Article 238 establishes criminal liability for concealment or misrepresentation of information on the environmental status or morbidity of the population (concealment or intentional misrepresentation by an official person of information on the state of morbidity of the population in areas with high environmental hazards);

Article 140 establishes criminal liability for failure to perform or improper performance of

professional duties by a medical or pharmaceutical worker due to negligence or dishonesty, if this has caused serious consequences for the patient;

Article 137 establishes criminal liability for non-performance or improper performance of professional or official duties to protect the life and health of minors as a result of negligence or dishonesty, if this caused significant damage to the victim's health.

4. Code of Ukraine on Administrative Violations:

Article 44-2 establishes administrative liability for violation of restrictions imposed on medical and pharmaceutical workers in the course of their professional activities.

2.4.3. Legislation in the field of healthcare

Ukrainian healthcare legislation, contrary to the above-mentioned international standards and recommended sources of international standards, does not contain the full scope of mandatory information on the nature of the disease, its transmission and contagion, effective preventive measures, treatment options and options, including the duration of treatment, names and types of drugs used, the nature of side effects, and the risks of non-adherence to treatment. In addition, the legislation has a certain punitive nature in relation to people with TB.

1. The Law of Ukraine "Fundamentals of the Legislation of Ukraine on Health Care":

Article 6 enshrines the right to health care for every citizen of Ukraine, which includes, among other things, reliable and timely information about the state of one's health and the health of the population, including existing and possible risk factors and their degree;

Article 39 clarifies the obligation to provide medical information:

- A patient who has reached the age of majority has the right to receive reliable and complete information about his or her health status, including the right to familiarize himself or herself with relevant medical documents concerning his or her health.

- Parents (adoptive parents), guardians, and custodians have the right to receive information about the health status of a child or ward.

- A health care professional is obliged to provide the patient with information in an accessible form about the patient's health status, the purpose of the suggested tests and treatment measures, and a prognosis of the possible development of the disease, including the risk to life and health.

If information about a disease of a person with TB may worsen the health status of the person or worsen the health status of individuals, or harm the treatment process, healthcare workers have the right to provide incomplete information about the health status of a person with TB, to limit the possibility of their familiarization with certain medical documents.

2. The Law of Ukraine "On Protection of the Population from Infectious Diseases":

Article 19 establishes the rights of persons suffering from infectious diseases or who are bacterial carriers; they have the right to: receive reliable information about the results of medical examination, examination, and treatment, as well as to receive recommendations on preventing the spread of infectious diseases;

Article 38 clarifies the responsibilities of healthcare officials and healthcare workers in case of detection of a patient with an infectious disease: healthcare workers are obliged to provide patients with infectious diseases and bacterial carriers and/or their legal representatives with information about the risk of infection of others and the requirements of sanitary and epidemiological rules and regulations that should be followed to prevent the spread of the disease. Patients with especially dangerous and dangerous infectious diseases and bacterial carriers of pathogens of these diseases should also be warned of the responsibility for non-compliance with sanitary and anti-epidemic rules and regulations and infection of

other persons, which is recorded in the medical records of these patients and bacterial carriers, signed by the attending physician, the patient or bacterial carrier and (or) his legal representative.

3. The Law of Ukraine "On Overcoming Tuberculosis in Ukraine" of 14.07.2023, No. 3269-IX:

- establishes the rights of patients with tuberculosis and those infected with mycobacterium tuberculosis, which includes, among other things, obtaining information from a medical professional providing treatment about the characteristics of the disease, treatment methods, diet, existing health risks, consequences of refusal to receive treatment, the threat of creating a real danger of infection to others, and responsibility for violation of the anti-epidemic regime;

- explains the powers of the Council of Ministers of the Autonomous Republic of Crimea, and local executive authorities in the field of tuberculosis control, which should inform the population through the media about the epidemic situation with tuberculosis in the region and measures taken to improve it.

4. Ukraine was the first country in the European region to bring its national health care standards for tuberculosis in line with the WHO 2022 recommendations. On January 19, 2023, the Ministry of Health of Ukraine approved the standards of medical care "Tuberculosis" by Order No. 102.

The updated version of the medical care standards "Tuberculosis" includes the following areas:

- Public health protection and tuberculosis prevention.
- Systematic screening for tuberculosis among high-risk groups.
- Diagnosis and treatment of tuberculosis, including drug-resistant tuberculosis.
- Management of HIV and other comorbidities in people with tuberculosis.
- Management of tuberculosis in children and adolescents.

What's new in the medical care standards "Tuberculosis":

- The standards for the management of tuberculosis in children and adolescents have been updated to include BCG vaccination among HIV-infected children, modern approaches to TB diagnosis in children and adolescents, an integrated algorithm for making decisions about treatment of children under 10 years of age with suspected pulmonary tuberculosis, and modern approaches to the development of pediatric TB treatment regimens.
- The standards for treatment of susceptible TB have been updated by age and severity of the disease. Shortened 4-month treatment regimens for susceptible TB were introduced instead of the traditional 6-month regimens.
- The standards for the treatment of drug-resistant tuberculosis (DR-TB) have been updated: The standard provides for the regulation of the choice of modern treatment regimens with a priority for fully oral treatment regimens. Ukraine is the first in the European region to introduce innovative BPaLM / BPaL treatment regimens as part of routine use.

Thanks to the BPaL regimen, the total treatment duration for people with MDR-TB is reduced by almost three times: 6-9 months versus 18-24 months, and there is no need to receive painful injections for many months. According to clinical trials, this regimen increases the chances of cure by up to 90%.

The overall goal of the new TB treatment standards is not only to achieve a relapse-free cure for all people with TB but also to stop transmission and prevent the development or expansion of additional drug resistance.

5. Ethical Code of Physicians of Ukraine (2009) (clauses 3.3, 71):

The actions of a physician should be aimed at achieving maximum benefit for life and health, and social protection. Throughout the treatment, when providing information to the patient about his or her condition and recommended treatment, the physician must take into account the patient's personal characteristics, monitoring the patient's assessment of his or her situation.

A physician is obliged to constantly improve his/her qualifications, be informed about the latest achievements in the field of professional activity, and actively oppose any false information in scientific publications and mass media.

2.5. The problem of law enforcement (policy)

Focus group participants noted the unscrupulous work of MSEC employees who deliberately conceal the procedure for obtaining consultations for assistance, the timing, and the procedure for obtaining disability status.

Another widespread problem is the inaction of doctors who do not provide full information about treatment options, the possibility of receiving medical care on an outpatient basis, and in this way actually deprive people with TB of a conscious choice of treatment.

The issue of spreading myths about "folk remedies" for treating TB was raised. As a result of the lack of complete and accessible information about TB, there have been situations of refusal to provide medical care to children in families where parents do not trust conventional medicine.

There was also a lack of information for people with TB about social security and social services.

2.6. Recommendations

1. Recommendations on legislation for the Ministry of Health:

The Law of Ukraine "Fundamentals of the Legislation of Ukraine on Health Care", "On Protection of the Population from Infectious Diseases", TB health care standards, the Specification for the provision of medical services, and the Ethical Code of Physicians of Ukraine should be aligned with international standards on the right of people with TB to information, in particular, to provide (in addition to the current legal norms) for people with TB to receive information on:

- the nature of the disease;
- its transmission and infectious danger;
- effective preventive measures;
- risks and benefits of the proposed interventions (both for the person with TB and others in the community);
- how to get support;
- possible comorbidities;
- direct and indirect costs associated with treatment;
- names of medicines and dosages or methods of treatment, its usual and possible side effects and ways to prevent or reduce them, possible effects on other medical conditions or treatments, possible effects of interaction with other medicines, such as antiretroviral drugs for HIV treatment in the presence of co-morbidities or co-infection;
- types and mechanisms of social support for people with TB, the procedure for obtaining disability status.

After making amendments to the legal acts, an algorithm for informing/counseling about TB should be developed. Oblige health care facilities and doctors to provide the information in

an accessible age- and gender-relevant form, taking into account cultural differences and in a language that is understandable to the person receiving the information;

2. Policy (enforcement) recommendations for the Ministry of Health:

- Raise awareness of physicians, including primary care physicians, about TB, medical ethics, and rights.

3. THE RIGHT TO ACCESS SERVICES

3.1. The content of the right to access services: people with TB have the right to affordable, free, and quality diagnosis and treatment without discrimination. Limited access to healthcare services creates gaps in TB diagnosis and treatment, leading to high levels of active TB, poor clinical outcomes, and the development of resistant forms.

According to clause 1, paragraph 2 of the Decree of the President of Ukraine "On the Oath of a Doctor" of 15.06.1992 №349, a doctor undertakes to provide medical care to all who need it, to be selfless and sensitive to patients⁶⁵.

Focus group participants and non-governmental organizations provided common examples of violations of the right of people with TB to access services, including:

- lack of treatment and care in the hospital;
- lack of effective treatment of resistant forms of TB;
- lack of free medicines;
- incompetence and unfriendly attitude of doctors;
- - absence or insufficient staffing of TB specialists (e.g., a TB specialist works part-time at 0.25 rate; there is only one TB room for the entire district);
- some institutions were left without doctors and preventive examinations;
- untimely diagnosis of TB, which leads to health complications;
- the service of extrapulmonary tuberculosis was destroyed;
- lack of a mechanism for realization of the right (due to lack of funds in health care facilities) to free treatment of concomitant diseases caused by TB, including free consultations;
- violation of the rights of people with TB in prisons;
- corrupt actions of the MSEC and other health care workers: refusal to extend the disability status of a person with TB who has not paid a "charitable contribution";
- resale of anti-TB drugs and refusal to provide referrals for examination;
- there is a certain category of people (without documents, lost for one reason or another) who are entitled to diagnosis and treatment services under state guarantees, but they fall out of this system. The involvement of local governments can be considered a temporary solution to this problem, i.e., the territorial community should allocate some funds in its budget for such people who will need such services on the territory of the community. The legislation needs to be amended accordingly. A systemic solution to this problem requires more time and political action, including resolving the issue of how local authorities can finance the renewal of documents and these services.

In general, the participants of the focus groups as part of the study noted that there are almost no violations in this category of rights. Even in the penitentiary system, there are no violations, and assistance is provided, sometimes even better than in the civilian sector.

Therefore, the above-mentioned violations can be attributed to systemic barriers: discrimination, or restrictions, or failure to fulfill certain obligations on a certain level of the governmental authorities and in the process of realization of these rights.

⁶⁵ <https://zakon.rada.gov.ua/laws/show/349/92#Text>

A selective analysis of legislation and policies, as well as focus group assessments, revealed the following:

The right to access services:

1. Availability: Laws - 4 Policies - 4
2. Implementation: Laws - 3 Policies - 3
3. Media coverage: Laws - 4 Policies - 3
4. Number of rights that are harmed by laws/policies – 0

3.2. International standards defining the right to access services

1. European Convention on Human Rights (Article 2): everyone's right to life is protected by law.

2. The European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1987).

3. International Convention on the Elimination of All Forms of Racial Discrimination (Article 2): States Parties undertake to prohibit and eliminate racial discrimination in all its forms and to ensure the equality of everyone before the law, without distinction as to race, color, national or ethnic origin, especially about the enjoyment of the following rights; the right to health, medical care, social security, and social services.

4. The Convention on the Elimination of All Forms of Discrimination against Women (Article 11): States Parties shall take all appropriate measures to eliminate discrimination against women in employment to ensure, on a basis of equality of men and women, equal rights, in particular the right to health.

5. The International Labor Organization Convention concerning Social Security (Minimum Standards), adopted in Geneva on June 28, 1952 (Article 10): care shall include at least: a) in the case of sickness: b) attendance by a general practitioner, including home visits; c) attendance by a specialized physician for inpatients or outpatients in hospitals and the same attendance as may be provided outside hospitals; d) provision of essential pharmaceuticals prescribed by a physician or other qualified practitioner; e) hospitalization if necessary⁶⁶.

6. International Labor Organization Convention concerning Medical and Sickness Benefits, adopted in Geneva on June 25, 1969⁶⁷:

Article 7: the covered insured events include the following: a) the need for medical care of a curative nature and, under established conditions, the need for medical care of a preventive nature; b) disability due to sickness resulting in the suspension of earnings as defined by national law;

Art. 8: Each Member of the Organization shall guarantee to the persons subject to medical coverage, according to the specified conditions, the provision of medical care of a curative or preventive nature in the case stipulated in paragraph a) of Article 7;

Article 9: medical care stipulated in Article 8 shall be provided to maintain, restore, or improve the health of the person subject to the provision of medical care, as well as his or her ability to work and meet his or her personal needs;

Art. 10: the persons subject to providing support in case of the event stipulated in paragraph a) of Article 7 include: a) all employees, including students, as well as their spouses and children; b) the specified categories of economically active population, which constitute in total not less than 75 percent of the total economically active population, as well as the spouses and children of persons belonging to the above categories; c) the specified categories

⁶⁶ https://zakon.rada.gov.ua/laws/show/993_011#Text

⁶⁷ https://zakon.rada.gov.ua/laws/show/993_184#Text

of residents, which constitute in total not less than 75 percent of all residents⁶⁸.

6. Convention on the Rights of the Child (Article 24): States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health care and to the treatment and rehabilitation of illness and disease. States Parties shall ensure that no child shall be deprived of his or her right to access to such health services.

7. International Covenant on Economic, Social and Cultural Rights: Article 12(1): The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; Article 12(2): The measures which States Parties to the present Covenant shall take for the full realization of this right shall include those necessary to: [...] (c) Prevent, treat and control epidemic, endemic, professional and other diseases.

3.3. Recommended sources of international standards

1. European penitentiary (prison) rules⁶⁹.
2. Standard Minimum Rules for the Treatment of Prisoners (Nelson Mandela Rules)⁷⁰.
3. United Nations policy summary on "HIV prevention, treatment and care in prisons and other closed settings: a comprehensive package of intervention", June 2013;⁷¹

3.4. Researched legal and regulatory acts

The Constitution of Ukraine (Article 49) stipulates the right of everyone to health care, medical assistance, and medical insurance. Health care is ensured by state funding of relevant socio-economic, medical, health, and preventive programs. The state creates conditions for effective and accessible medical care for all citizens. In state and municipal healthcare institutions, medical care is provided free of charge; the existing network of such institutions cannot be reduced. The state promotes the development of medical institutions of all forms of ownership.

3.4.1. Legislation in the healthcare field

The healthcare legislation provides guarantees of medical care for people with TB at the level of legislative acts. However, bylaws and regulations do not contain the full scope of guarantees for the provision of medical care to people with TB: all support services for people with TB are not taken into account, there is no mechanism for exercising the right to free treatment of comorbidities, etc.

1. Guided by the provisions of Article 49 of the Constitution of Ukraine and healthcare laws (which will be cited below), it can be stated that the state guarantees medical care to people with TB, which includes: (1) prevention, diagnosis, treatment and rehabilitation; (2) an accessible network of healthcare facilities; (3) quality of medical care in accordance with the system of healthcare standards; (4) financing of the provision of a guaranteed amount of

⁶⁸ Some of these problems were highlighted in the study "Assessment of the legal environment for tuberculosis in Ukraine" (c.103). https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_governance/legal-environment-assessment-for-tuberculosis-in-Ukraine.html (c. 69-73)

⁶⁹ https://zakon.rada.gov.ua/laws/show/994_032#Text

⁷⁰ https://zakon.rada.gov.ua/laws/show/995_212#top

⁷¹ https://www.unodc.org/documents/hiv-aids/HIV_comprehensive_package_prison_2013_eBook.pdf

medical services and medicines to all citizens and other persons specified by law.

The decision of the Constitutional Court of Ukraine in the case on free medical care (May 29, 2002, case № 10-пн/2002)⁷² in the official interpretation of the provisions of part three of Article 49 of the Constitution of Ukraine, in particular, stated (para. 5) that Article 49 of the Constitution of Ukraine, along with the guarantee of free medical care in state and municipal health care institutions, contains other provisions, in particular, the right of everyone to health care, medical insurance, the obligation of the state to create conditions for effective and accessible public health care, promote the development of medical institutions of all forms of ownership, etc.

Articles of the Constitution of Ukraine and laws of Ukraine define the rights and obligations of people with TB and doctors. The Basic Law of Ukraine contains Articles 27, 29, 32, 40, 49, 55, 56, and 28 (part 3), which define the right of people with TB to life, medical care, personal integrity, medical information, full information and voluntary consent to a biomedical experiment, and to appeal against unlawful decisions and actions of health care workers and health care institutions.

The rights of medical workers are defined by Articles 32, 34, 35, 43, and other articles of the Constitution of Ukraine, including the right to proper conditions of professional activity, to establish scientific medical societies, trade unions, and other public organizations, etc.

2. The rights and obligations of people with TB and doctors are also defined by the articles of the Law "Fundamentals of the Legislation of Ukraine on Health Care".

3. Ukraine was the first country in the European region to bring its national health care standards for tuberculosis in line with the WHO recommendations of 2022⁷³. On January 19, 2023, the Order of the Ministry of Health of Ukraine No. 102⁷⁴ approved the standards of medical care "Tuberculosis" aimed at improving the regulatory framework based on evidence-based medicine and WHO recommendations. They will improve the quality of treatment, reduce morbidity, disability, and mortality, as well as reduce costs and risks for people with TB.

3.4.2. Laws of Ukraine on prevention, diagnosis, treatment and rehabilitation

1. The Law of Ukraine "Fundamentals of the Legislation of Ukraine on Health Care":

Article 3: medical care is the activity of professionally trained medical workers aimed at prevention, diagnosis, treatment, and rehabilitation in connection with diseases, injuries, poisoning, and pathological conditions, as well as in connection with pregnancy and childbirth;

Article 7: The state, in accordance with the Constitution of Ukraine, guarantees to all citizens the realization of their rights in the field of health care by financing the provision of a guaranteed amount of medical services and medicines to all citizens and other persons determined by law in accordance with the procedure established by law; establishing liability for violation of the rights and legitimate interests of citizens in the field of health care.

Article 8: The state recognizes the right of every citizen of Ukraine to health care and ensures its protection. Every citizen has the right to receive free emergency, primary, secondary (specialized), tertiary (highly specialized) medical care, and palliative care in state and municipal healthcare institutions.

The state guarantees

- Free provision of medical care in state and municipal health care facilities for epidemic

⁷² <https://zakon.rada.gov.ua/laws/show/v010p710-02#Text>

⁷³ <https://moz.gov.ua/article/news/ukraina-onovila-standarti-medichnoi-dopomogi-pri-tuberkulozi>

⁷⁴ https://www.dec.gov.ua/wp-content/uploads/2023/01/43243-dn_102_19012023_dod.pdf

indications;

- free medical and social examination, forensic medical and forensic psychiatric examination, pathological autopsies, and related studies under the procedure established by law

- Provision of necessary medical services and medicines at the expense of the State Budget of Ukraine under the conditions and in the manner prescribed by law.

In case of violation of the legitimate rights and interests of citizens in the field of health care, the relevant state, public or other bodies, enterprises, institutions, and organizations, their officials, and citizens are obliged to take measures to restore the violated rights, protect the legitimate interests and compensate for the damage caused.

Judicial protection of the right to health care is carried out under the procedure established by law;

Article 12: the state healthcare policy shall be provided with budgetary allocations in the amount corresponding to its scientifically substantiated needs, but not less than ten percent of the national income;

Article 14: the implementation of the state health care policy is entrusted to the executive authorities, namely:

The Cabinet of Ministers of Ukraine organizes the development and implementation of state-targeted programs, ensures the development of the network of healthcare institutions, and also exercises other powers vested in executive authorities in the field of healthcare within its competence; central executive authorities develop programs and forecasts in the field of healthcare, determine unified scientifically based state standards, criteria, and requirements that should contribute to the protection of public health, exercise state control and supervision and other executive and administrative activities

The Council of Ministers of the Autonomous Republic of Crimea, local state administrations, as well as local self-government bodies implement the state policy in the field of health care within the limits of their powers provided by law;

Article 14-1: the system of health care standards consists of state social norms and industry standards. Compliance with the standards of medical care (medical standards), clinical protocols, and material and technical equipment lists is mandatory for all healthcare institutions, as well as for individual entrepreneurs engaged in medical practice.

2. The Law of Ukraine "On Overcoming Tuberculosis in Ukraine" of July 14, 2023, No. 3269-IX:

Article 8. Powers of local self-government bodies in the field of tuberculosis control.

1. Local self-government bodies in the field of tuberculosis control:

- 1) approve local programs of tuberculosis control, social support for people with tuberculosis, as well as programs of local incentives for medical personnel involved in tuberculosis control, provide their logistical and financial support and control over their implementation;

- 2) ensure the implementation of social protection measures for people with tuberculosis provided for by law;

- 3) exercise other powers defined by law;

Article 9. Identifying people with tuberculosis and people with latent tuberculosis infection.

1. Passive detection of people with tuberculosis is carried out through mandatory prescription and diagnostic tests for tuberculosis in case of typical complaints or symptoms when a patient seeks medical care for any reason at any health care facility, regardless of ownership or departmental subordination, or at an individual entrepreneur who has obtained a license to carry out business activities in medical practice.

Active detection of people with tuberculosis and people with latent tuberculosis infection (systematic screening for tuberculosis) is mandatory for primary health care providers among persons who have submitted a declaration on the choice of a primary health care provider by continuously identifying people with TB who are at risk of developing tuberculosis, including latent tuberculosis, and organizing and conducting their annual examination for the detection of tuberculosis.

Active and passive detection of tuberculosis and detection of latent tuberculosis infection is carried out under the standards of health care for tuberculosis and the procedure for organizing the detection of tuberculosis and latent tuberculosis infection established by the central executive body that ensures the formation and implementation of state of the health care policy.

Services for active and passive detection of people with tuberculosis and people with latent tuberculosis infection are included in the relevant packages of medical services subject to payment under the medical guarantee program.

Services for active and passive detection of tuberculosis and latent tuberculosis infection are provided to citizens of Ukraine, as well as foreigners and stateless persons, regardless of the grounds for their stay in Ukraine and the availability of identity documents, under the procedure established by the central executive body that ensures the development and implementation of state policy in the field of health care.

2. To timely identify people with tuberculosis and people with latent tuberculosis infection and prevent the spread of this disease, mandatory preventive medical examinations for tuberculosis are carried out. Mandatory preventive medical examinations for tuberculosis in state and municipal health care institutions are carried out at the expense of state and local budgets and other sources not prohibited by law. The procedure for conducting mandatory preventive medical examinations for tuberculosis is established by the central executive body responsible for the development and implementation of state policy in the field of health care.

The list of persons subject to mandatory preventive medical examinations for tuberculosis is established by the central executive body that ensures the development and implementation of state policy in the field of health care.

3. In case of deterioration of the epidemic situation with tuberculosis, at the request of the chief state sanitary doctor of the administrative territory where the incidence of tuberculosis significantly exceeds the established level for this territory, executive authorities and local self-government bodies decide to conduct extraordinary mandatory preventive medical examinations for tuberculosis of persons subject to mandatory preventive medical examinations or other groups of the population, among which the incidence rate is higher than that on the respective territory.

4. The criteria for classifying a certain category of persons as key populations and high-risk groups for tuberculosis are established by the central executive body that ensures the development and implementation of state policy in the field of health care.

5. Persons who refused to undergo a mandatory preventive medical examination for tuberculosis or failed to undergo it within the period specified by law shall be suspended from work, students - from attending educational institutions and children's institutions, and students of vocational (vocational-technical education), professional pre-university, higher education - from undergoing practical training for the period until they undergo such examination.

6. To ensure registration of a case of tuberculosis, organization of proper medical examination of a person with tuberculosis, his/her treatment, and implementation of appropriate anti-epidemic measures, a healthcare worker who has detected tuberculosis shall notify the regional center for disease control and prevention and the regional phthysiopulmonological center in accordance with the procedure for epidemiological surveillance of tuberculosis;

Article 10. Laboratories for diagnostics of tuberculosis in the system of anti-tuberculosis medical care for the population.

1. Diagnostics of tuberculosis is provided by a three-level network of laboratories, which are created and function in health care institutions.

2. Microbiological laboratories for the diagnosis of tuberculosis of the first level operate in general health care facilities and/or cluster health care facilities in hospital clusters and in health care facilities providing medical care to convicts and persons in custody. These laboratories provide primary microbiological diagnosis of tuberculosis.

3. Microbiological laboratories for the diagnosis of tuberculosis of the second level function within the structure of regional phthisiopulmonological centers and provide a complete microbiological diagnosis of tuberculosis. These laboratories are obliged to organize and carry out external quality control of tests performed in the first-level laboratories.

4. The third level microbiological laboratory for tuberculosis diagnostics is a laboratory that performs the functions of a reference laboratory in the public health system.

This laboratory provides organizational and methodological guidance and ensures the functioning of the system of external quality control of laboratories for microbiological diagnosis of tuberculosis of the first and second levels, control over the work of laboratories of the second level, provides organizational and methodological assistance in optimizing the laboratory network for microbiological diagnosis of tuberculosis in Ukraine.

The laboratory for microbiological diagnosis of tuberculosis, which performs the functions of a reference laboratory, is also responsible for the development of regulatory acts on the microbiological diagnosis of tuberculosis and standards for microbiological diagnosis of tuberculosis under international requirements and the introduction of modern methods of tuberculosis diagnosis.

The laboratory performing the functions of a reference laboratory ensures cooperation with the World Health Organization reference laboratory to participate in international programs for external quality control of microbiological research.

5. Standard regulations on microbiological laboratories for tuberculosis diagnostics, as well as instructions for microbiological diagnostics of tuberculosis are approved by the central executive body that ensures the formation and implementation of state policy in the healthcare sector;

Article 20. Rights and obligations of people with tuberculosis and people with latent tuberculosis infection:

1. People with tuberculosis and people with latent tuberculosis infection have the right, in particular, to:

1) free medical care and appropriate conditions of stay in health care facilities according to sanitary standards

2) to receive information from a medical professional who provides treatment about the specifics of the disease, treatment methods, diet, existing health risks, consequences of refusal to receive treatment, the threat of infecting others, and responsibility for violating the anti-epidemic regime;

3) rehabilitation according to medical conditions and within the budget allocated;

4) receiving psychological assistance and social services;

5) receiving palliative and hospice care;

6) communication with family members and other persons in compliance with the anti-epidemic regime;

7) participation in worship and religious services in compliance with the anti-epidemic regime.

2. People with tuberculosis have the right to free meals during inpatient treatment in regional TB centers, rehabilitation centers, and palliative and hospice care centers according to

the standards established by the Cabinet of Ministers of Ukraine.

3. People with tuberculosis and people with latent tuberculosis infection are obliged to comply with:

1) the treatment regimen prescribed to them in accordance with health care standards and the standard of infection control for tuberculosis

2) internal regulations of the healthcare facility during inpatient treatment;

3) established deadlines for mandatory medical examinations and tuberculosis testing, as defined by the relevant industry standards in the field of health care;

4) requirements of the anti-epidemic regime;

5) requirements of healthcare professionals to provide information necessary to identify contact persons.

4. People with tuberculosis released from penitentiary establishments are obliged to report to the relevant regional phthisiopulmonary center within three days after release from prison for further treatment and medical monitoring.

3. The Law of Ukraine "On State Financial Guarantees of Medical Care for the Population":

Article 2: the program of state guarantees of medical care for the population (medical guarantees program) determines the list and scope of medical services (including medical devices) and medicines, the full payment for the provision of which to patients is guaranteed by the state at the expense of the State Budget of Ukraine according to the tariff for prevention, diagnosis, treatment, and rehabilitation in connection with diseases, injuries, poisoning, and pathological conditions, as well as in connection with pregnancy and childbirth.

Article 4: the program of medical guarantees determines the list and scope of medical services and medicines, payment for which is guaranteed at the expense of the State Budget of Ukraine; the program of medical guarantees is developed taking into account the requirements of industry standards in the healthcare sector in accordance with the procedure determined by the central executive body responsible for the development of state policy in the healthcare sector, in agreement with the central executive body responsible for the development of state financial and budgetary policy; the program of medical guarantees is approved by the Verkhovna Rada of Ukraine as part of the Law of Ukraine "On the State Budget of Ukraine for 2024"⁷⁵. The first paragraph of the fifth part of Article 4 of the Law of Ukraine "On State Financial Guarantees of Medical Care for the Population" was suspended for 2023 under Law No. 2710-IX dated 03.11.2022⁷⁶; the program of medical guarantees is not allowed to be reduced, except in cases stipulated by law.

Therefore, state financial guarantees have not yet been fully implemented.

4. Procedure for the organization of TB and LTBI detection. Healthcare providers ensure the organization and provision of TB and LTBI detection services under the Procedure for the organization of TB and latent tuberculosis detection, approved by the Order of the Ministry of Health of February 16, 2022 No. 302⁷⁷, registered with the Ministry of Justice of Ukraine on March 30, 2022, under No. 366/37702.

5. According to the decision of the Program Committee of the National Council on Combating Tuberculosis and HIV/AIDS, the Strategy for Comprehensive Response to Human Rights Barriers to Access to HIV and Tuberculosis Prevention and Treatment Services until

⁷⁵ <https://zakon.rada.gov.ua/laws/show/3460-20#Text>

⁷⁶ <https://zakon.rada.gov.ua/laws/show/2710-20#Text>

⁷⁷ <https://zakon.rada.gov.ua/laws/show/z0366-22#Text>

2030 (hereinafter - the Strategy) and the Strategic Plan for comprehensive response to human rights barriers to access to HIV and tuberculosis prevention and treatment services for 2019-2022 (hereinafter - the Strategic Plan), which is an appendix to this Strategy, were developed. This Strategy is developed to implement the basic principles of the state policy in combating HIV/AIDS, tuberculosis, and viral hepatitis for up to 2030 and following the Action Plan for the implementation of the National Human Rights Strategy for up to 2020, approved by the Cabinet of Ministers of Ukraine on February 23, 2015, №1393- p. The Strategic Plan contains a detailed description of the measures of a comprehensive response to human rights barriers to access to HIV and TB prevention and treatment services for 2019-2022 and their estimated total cost. The comprehensive response includes all necessary measures to sufficiently reduce or eliminate human rights barriers to access to HIV and TB services. In addition, the Strategic Plan contains a mapping of planned activities from various funding sources that correspond to the program areas of the comprehensive response, as well as their responsible executors and planned costs. The Strategic Plan is approved every 3-4 years. The State Strategy for the Development of the TB Medical Care System was approved by the Cabinet of Ministers of Ukraine on November 27, 2019, No. 1414-p⁷⁸ (the Strategy was supposed to be implemented in 2020-2023).

The main ways and means of ensuring the development of the system of TB medical care for the population, in particular, are as follows:

- 1) introduction of new approaches to the organization of TB medical care to the population, which includes:
 - introduction of standards of medical care for patients with tuberculosis and criteria for signing contracts between the NHSU and health care facilities providing TB medical care to the population, with the definition of a medical service package (diagnosis, inpatient treatment, coordination of TB activities, counseling) and requirements for the provision of such services within the framework of the medical guarantee program;
 - Amendments to the legislative and regulatory base to ensure prevention, detection, diagnosis, and outpatient treatment of tuberculosis, follow-up of patients with tuberculosis at the level of primary health care providers with informing the public health facility about the case/suspected tuberculosis, controlled treatment, treatment monitoring, pharmacological supervision, psychosocial support for people with TB in coordination with the regional TB service with the involvement of various health care and public health service providers that can carry out such services
 - Ensure legal and regulatory framework for the creation of a unified system of TB medical care for the population, including the inclusion of TB medical care services provided by TB health care facilities of departmental subordination into regional TB medical care systems;
 - creation of a system of rehabilitation of TB patients, including both social and medical rehabilitation, the ultimate goal of which is the reintegration of TB patients into society, with the development of the relevant legislative and regulatory framework;
- 2) implementation of new approaches to tuberculosis treatment, which includes
 - regulation of the provision of supervised treatment (including using interactive methods) and monitoring of treatment, and side effects at all stages of health care for patients with tuberculosis, including the necessary laboratory and instrumental studies, consultations, and physical examination required in the process of monitoring treatment at the outpatient stage, in general health care facilities with reimbursement for such services using new funding mechanisms;
 - ensuring the possibility of outpatient TB treatment from the first days after diagnosis;
 - approval of a guaranteed list of supervised treatment services for tuberculosis patients

⁷⁸ <https://zakon.rada.gov.ua/laws/show/1414-2019-%D1%80#Text>

receiving outpatient services, including: motivational counseling of tuberculosis patients to develop adherence to treatment; motivational counseling of the close environment of tuberculosis patients to undergo tuberculosis screening; training on the prevention and treatment of tuberculosis of patients and their close environment; support to ensure monitoring of treatment; ensuring controlled intake of anti-tuberculosis drugs; prevention of adverse reactions and support to eliminate adverse reactions caused by anti-TB drugs;

- ensuring the possibility of treating clinical forms of tuberculosis that require secondary (specialized) medical care and tertiary (highly specialized) medical care, including extrapulmonary tuberculosis, as well as treatment of comorbidities in people with TB based on health care facilities of various profiles;

- integration of services for detection, diagnosis, and treatment of comorbidities in people with TB with the possibility of treatment, including inpatient treatment if necessary, in healthcare facilities of different profiles in compliance with infection control requirements;

- taking measures to create comfortable and safe conditions for inpatient and outpatient TB treatment following individual needs, providing appropriate care, social and psychological support, and medication monitoring, including interactive methods, by engaging various service providers who can carry out such activities;

- taking measures to create a system of physical rehabilitation services for TB patients.

However, the implementation of the Strategy has not been started, as stated in the Report on the audit of the effectiveness of measures to combat tuberculosis, conducted by the Accounting Chamber in 2019.⁷⁹

6. The Specification for the provision of healthcare services in the field of "Primary Healthcare" (clause 6) does not include laboratory and instrumental tests in the list of laboratory tests.

Instead, such tests are stipulated in the Specification for the provision of medical services in the area of "Diagnosis and treatment of adults and children with tuberculosis" (clause 1: in the course of establishing the diagnosis of tuberculosis, microbiological diagnosis of TB, determination of sensitivity to anti-tuberculosis drugs using bacteriological and molecular genetic methods, radiological diagnostic methods, ultrasound, bronchoscopy, biopsy, pleural puncture to verify the diagnosis of TB).

In our opinion, to ensure state financial guarantees for early TB diagnosis, it is necessary to harmonize the Specification for the provision of medical services in the field of "Primary health care" with the Specification for the provision of medical services in the field of "Diagnosis and treatment of adults and children with tuberculosis".

3.4.3. Ensuring an accessible network of healthcare facilities

The Fundamentals of Healthcare Legislation of Ukraine define the guarantees for the formation and development of healthcare institutions of all forms of ownership (Articles 14 and 16), the powers of state authorities and local self-government bodies to manage and develop healthcare institutions, organize their logistical, personnel and financial support under the law, and guarantee that the existing network of such institutions cannot be reduced.

The network of state and municipal healthcare institutions is formed taking into account the development plans of hospital districts, the needs of the population for medical care, the need to ensure the proper quality of such care, timeliness, accessibility to citizens, and the

⁷⁹ The report on the results of the audit of the effectiveness of measures to combat tuberculosis was approved by the decision of the Accounting Chamber dated 18.08.2020 No. 22–2. https://rp.gov.ua/upload-files/Activity/Collegium/2020/22-2_2020/Zvit_22-2_2020.pdf

efficient use of material, labor, and financial resources.

A hospital district is created to ensure territorial accessibility of quality medical care to the population and includes a set of healthcare facilities and individual entrepreneurs registered following the procedure established by law and licensed to carry out business activities in medical practice and provide medical care to the population of the respective territory.

Within the hospital district, basic healthcare institutions are determined.

The World Health Organization's Guidelines on the Ethics of Tuberculosis Treatment, Prevention, Care and Control (WHO, 2010) state the following general goals and objectives: all people with TB should receive the same treatment. People with TB have the right to receive counseling and treatment that meets international quality standards, to be free from stigma and discrimination, and to form and join support groups.

The TB control program should take into account the needs of all people with TB and, in particular, the special needs of socially vulnerable groups, for which specific measures should be actively developed. These groups include but are not limited to, people living in extreme poverty, refugees, asylum seekers, migrants, miners, prisoners, drug users (including alcohol abusers), and people who are homeless. In addition, the needs of women, children, and people living with HIV require special attention.

The World Health Assembly Resolution 62.15 "Prevention and control of resistant forms of TB" (WHO, 2009) calls for "effective mobilization, advocacy, communication, and social policy measures to eliminate stigma and discrimination, including measures to raise public awareness of policies and plans for the prevention and control of tuberculosis, including resistant forms of TB".⁸⁰

3.4.4. Quality of medical care in accordance with the system of healthcare standards

1. Law of Ukraine "On State Financial Guarantees of Medical Care for the Population":

Article 5: the program of medical guarantees is based, in particular, on the principle of ensuring the preservation and restoration of public health through the providing of medical services and medicines of appropriate quality;

Article 6: people with TB have the right to receive the necessary medical services and medicines of appropriate quality at the expense of the State Budget of Ukraine allocated for the implementation of the medical guarantees program from medical service providers;

Article 12: control of the quality of medical services provided by medical service providers and systematic analysis of the results and effectiveness of medical services and medicines is carried out by the central executive body responsible for the development of state policy in the field of health care.

2. The Ministry of Health of Ukraine approved an action plan for the implementation of the State Strategy for the Development of the TB Medical Care System for 2020-2023⁸¹. The implementation of the measures allowed us to achieve the targets for improving the effectiveness of tuberculosis treatment, reducing mortality, and overcoming the tuberculosis epidemic in Ukraine.

⁸⁰ Health care and human rights: a resource guide. F.-C. Banyu Center for Health and Human Rights and the Open Society Foundations, 2015. http://medicallaw.org.ua/fileadmin/user_upload/PDF/%D1%80%D0%B5%D1%81%D0%BE%D1%80%D1%81%D0%A0%D0%B5%D1%81%D0%BE%D1%80%D1%81_%D0%B2%D1%81%D1%82%D1%83%D0%BF__introduction_.pdf

⁸¹ <https://zakon.rada.gov.ua/laws/show/1414-2019-%D1%80#Text>

The Ministry of Health of Ukraine has published for public discussion the draft order of the Cabinet of Ministers of Ukraine "On Approval of the Strategy for the Development of the TB Medical Care System in Ukraine for 2024-2026"⁸².

3.5. State financial guarantees

Demanding "charitable contributions" from the MSEC or other actions of health care facilities and doctors to "sell medicines" violates the Constitution of Ukraine (the above-mentioned decision of the Constitutional Court of Ukraine in the case of free medical care of May 29, 2002, case №10-rp/2002: in the phrase "medical care is provided free of charge" the last word in the context of the whole Article 49 of the Constitution of Ukraine means that a person receiving such care in state and municipal health care institutions should not be reimbursed for its cost either in the form of any payments or in any form, regardless of the time of provision of medical care).

1. The Law of Ukraine "On State Financial Guarantees of Medical Care for the Population":

Article 3: according to this Law, the state guarantees full payment according to the tariff at the expense of the State Budget of Ukraine for the provision of medical services and medicines to citizens that they need, as provided for by the program of medical guarantees;

Article 4: the amount of funds from the State Budget of Ukraine allocated for the implementation of the medical guarantees program is annually determined in the Law of Ukraine on the State Budget of Ukraine as a share of the gross domestic product (in percentage terms) in the amount of not less than 5 percent of the gross domestic product of Ukraine. Expenditures on the medical guarantees program are protected budget items;

Article 10: health care providers, which are state and municipal healthcare institutions, are forbidden to demand any form of remuneration from people with TB for medical services and medicines provided under the medical guarantee program. Such actions are grounds for bringing to liability under the contract for medical services, including unilateral termination of the contract at the initiative of the authorized body.

2. The Law of Ukraine "On Prevention of Corruption":

Article 54: state bodies and local self-government bodies are prohibited from receiving free of charge money or other property, intangible assets, property benefits, privileges, or services from individuals or legal entities, except in cases provided for by laws or applicable international treaties ratified by the Verkhovna Rada of Ukraine. Unlawful receipt of money or other property, intangible assets, property benefits, privileges, or services from individuals or legal entities free of charge, if there are grounds, entails liability of the relevant officials of state bodies, authorities of the Autonomous Republic of Crimea, local self-government bodies.

3. The Procedure for Implementation of the Program of State Guarantees of Medical Care for the Population in 2023, approved by the Resolution of the Cabinet of Ministers of Ukraine No. 1464 of 27.12.2022 "Some Issues of Implementation of the Program of State Guarantees of Medical Care for the Population in 2023"⁸³ (clause 7):

The NHSU pays for the medical services provided in accordance with the tariffs and adjustment coefficients specified in this Procedure, based on reports on medical services drawn up in accordance with the procedure provided for by the Standard Form of the Agreement on Medical Services for the Population under the Medical Guarantees Program, approved by the

⁸² www.umj.com.ua/uk/novyna-252882-rozrobleno-strategiyu-rozvitku-sistemi-protituberkuloznoyi-medichnoyi-dopomogi

⁸³ <https://zakon.rada.gov.ua/laws/show/1464-2022-%D0%BF#Text>

Resolution of the Cabinet of Ministers of Ukraine No. 410 "On Agreements on Medical Services for the Population under the Medical Guarantees Program" dated April 25, 2018, in accordance with the concluded agreement within the budget allocations provided for 2023 for the relevant package of medical services. It is prohibited to demand and receive payment from people with TB or their representatives for such medical services.

4. The Criminal Code of Ukraine:

Article 364. Abuse of power or position;

Article 365-2. Abuse of power by persons providing public services;

Article 368. Acceptance of an offer, promise, or receipt of undue advantage by an official.

5. Order of the Ministry of Health of Ukraine of January 19, 2023 No. 102 "On Approval of Medical Care Standards "Tuberculosis"". The revision of the standards of medical care "Tuberculosis" includes the following areas:

- Public health and tuberculosis prevention.
- Systematic screening for tuberculosis among high-risk groups.
- Diagnosis and treatment of tuberculosis, including drug-resistant tuberculosis.
- Management of HIV and other comorbidities in people with tuberculosis.
- Management of tuberculosis in children and adolescents.

6. Order of the Ministry of Health of Ukraine dated 09.03.2021 No. 406 "On Approval of the Procedure for Epidemiological Surveillance of Tuberculosis and Amendments to the Criteria for Determining Cases of Infectious and Parasitic Diseases Subject to Registration⁸⁴".

All measures are funded according to the financial and economic calculations for the draft plan. Namely: financial support is determined within the budget programs CPCELC 2301040 "Public Health and Epidemic Control Measures", CPCELC 2308060 "Programs of State Guarantees of Medical Care for the Population", CPCELC 2311500 "Subvention from the State Budget to Local Budgets for Support of Certain Institutions and Measures in the Health Care System" (in terms of expenditures for the first quarter of 2020), local budgets for the relevant years, international financial assistance (as agreed by Ukraine's request to the Global Fund to Fight AIDS, Tuberculosis and Malaria for the financing of tuberculosis and HIV/AIDS programs in 2021-2023, developed by the Ministry of Health of Ukraine and approved by the National Council on Tuberculosis and HIV/AIDS on June 30, 2020).

Budgetary funding for the public health system is limited, in particular for measures for harm reduction, prevention, care and support, and other services for key populations, which also include TB services; there is low priority given to TB services by local governments when setting funding priorities.

Existing guarantees of job security for the entire period of treatment are often not implemented in practice by employers.

3.6. Recommendations

1. Recommendations for legislation:

- For the Verkhovna Rada of Ukraine:
 - Amend the Law of Ukraine "On State Financial Guarantees of Medical Care for the Population" to create favorable conditions for asylum seekers (citizens of Ukraine from the temporarily occupied territories) to receive medical care in state healthcare

⁸⁴ <https://zakon.rada.gov.ua/laws/show/z0623-21#Text>

facilities. Allow asylum seekers to sign a declaration with a doctor. Such changes are possible as part of the work on the draft law "On Granting Protection to Foreigners and Stateless Persons."

- Conduct advocacy work with the Ministry of Health, the State Health Service, and local governments to develop estimates of the cost of medical services for asylum seekers in Ukraine. The development of such calculations is possible within the framework of the current legislation.
 - For the Ministry of Health:
- Harmonize the Specification for the provision of medical services in the area of "Primary health care" with the Specification for the provision of medical services in the area of "Diagnosis and treatment of adults and children with tuberculosis" to ensure state financial guarantees for early TB diagnosis;

2. Policy recommendations for the Ministry of Health:

- Ensure implementation of the recommendations of the Accounting Chamber

3.7. Legislative and law enforcement issues about specific groups: people with TB in places of detention

3.7.1. The problem of legislation

1. Due to the separation of penitentiary medicine from the general health care system, there is no proper basis for the delivery of complex services for the prevention and treatment of HIV and tuberculosis in penitentiary institutions and pre-trial detention centers⁸⁵;

2. The basic normative act regulating in Ukraine the procedure and conditions for the execution and detention of criminal sentences, legal status, and the provision of medical care, including treatment for HIV/AIDS, drug addiction, and tuberculosis, as well as the prevention of torture or inhuman or degrading treatment of prisoners, is the Criminal Executive Code⁸⁶. Thus, Article 8 of the said Code stipulates the right of convicts to health care, which is ensured by a system of medical sanitary and health improvement measures, as well as a combination of free and paid forms of medical care. The convicted person is guaranteed the right to free choice and access to a doctor to receive medical care, including at his/her own expense. Convicts who have mental and behavioral disorders due to the use of alcohol, narcotic drugs, psychotropic substances, or their analogs or other intoxicants may, with their written consent, undergo treatment for these diseases. At the same time, reports of human rights organizations in Ukraine based on the results of monitoring visits⁸⁷ to penitentiary institutions within the framework of the National Preventive Mechanism (NPM) indicate that penitentiary institutions are understaffed with doctors and that medical care in penitentiary institutions is critically unsatisfactory. For example, during the monitoring visits, the following problems were identified regarding the right of prisoners to receive medical treatment:

- Insufficiency or absence of medicines. Often, prisoners have to buy them at their own expense (or that of their relatives).

⁸⁵ Strategy for a Comprehensive Response to Human Rights Barriers to Access to HIV and Tuberculosis Prevention and Treatment Services until 2030 and Strategic Plan (Annex to paragraph 7.2. of the minutes of the meeting of the National Council on Tuberculosis and HIV/AIDS of May 23, 2019). <https://cutt.ly/lfxp2FQ>;

⁸⁶ The Criminal Executive Code of Ukraine dated 11.07.2003 №1129-IV. available at: <https://zakon.rada.gov.ua/laws/show/1129-15#Text>

⁸⁷ Review of publications on NPM visits regarding violations of prisoners' rights. available at: <http://pk.khpg.org/index.php?r=2.6>

- Doctors do not monitor the health status of their TB patients, do not make daily rounds, and do not even come to visit the prisoners at their request.

Article 116 of the Criminal Executive Code states that a convicted person has the right to seek consultation and treatment at healthcare facilities licensed by the Ministry of Health of Ukraine that provide paid medical services and are not under the jurisdiction of the central executive body that implements state policy in the field of execution of criminal sentences. Thus, it is possible for persons held in places of detention to receive medical services from the following sources: in the medical unit or special hospital of the penitentiary institution; if the institution is unable to provide the necessary medical care, the convicted person has the opportunity to apply to civilian health care institutions. However, a prerequisite is that such institutions are included in the relevant lists approved by the Ministry of Justice of Ukraine and the central executive body responsible for the formation of state policy in the field of health care. Currently, such a list has not been approved, which makes it difficult for a convict to choose a medical institution.

It is unacceptable to oblige convicts and prisoners to stay in places where they cannot receive proper treatment due to the lack of appropriate facilities or if such facilities refuse to accept them. The European Court of Human Rights has recognized a violation of Article 3 of the European Convention on Human Rights (ECHR) in such situations.

There is no legal basis for providing palliative care in prisons.

Because of the separation of penitentiary medicine from the general health care system in the context of ongoing reforms, several institutional, organizational, and law enforcement problems, and insufficient legal and regulatory framework, there is no proper basis for providing comprehensive services for the prevention and treatment of HIV and tuberculosis in penitentiary institutions and pre-trial detention centers.

3.7.2. The problem of law enforcement

People with TB in prison do not have access to medical care and medicines. Prisoners are at a higher risk of contracting TB, other diseases, or death. Risk factors include overcrowding in prisons, inadequate nutrition, poor access to health care, sexual activity (including sexual violence), inability to find safe injection equipment, and lack of access to treatment and opioid substitution therapy.

People with tuberculosis do not have access to quality treatment and care in prisons. People with resistant TB are denied second-line therapy. The government is unable to use donor resources to build isolation rooms.

At the same time, the provisions of the International Covenant on Economic, Social and Cultural Rights⁸⁸ (ICESCR) provide for the following: Article 12: The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; Article 12(2): The measures to be taken by the States Parties to the present Covenant for the full realization of this right shall include such measures that are necessary for: (c) prevention, treatment and control of epidemic, endemic, occupational and other diseases.

Also, Article 19 of the Law of Ukraine "On Overcoming Tuberculosis in Ukraine" provides for:

Article 19. Medical care for people with tuberculosis among persons taken into custody and sentenced to imprisonment, restriction of liberty, or arrest.

1. The procedure for providing medical care to people suffering from tuberculosis from among persons taken into custody or held in penal institutions is established by the Cabinet of

⁸⁸ https://zakon.rada.gov.ua/laws/show/995_042#Text

Ministers of Ukraine.

2. In case of release of a person suffering from tuberculosis from a penitentiary (arrest house), the penitentiary institution where such a person served his/her sentence informs him/her about the state of health and the need to continue treatment at the chosen place of residence or stay, and provides medical information about his/her disease to the relevant regional phthisiopulmonological center.

3. In case of release of a person suffering from tuberculosis with bacterial excretion, the relevant penitentiary institution shall warn him/her about the need to comply with the anti-epidemic regime, which shall be certified in writing, and deliver such a person (with his/her consent) by transport of the penitentiary institution to the nearest regional phthisiopulmonary center for hospitalization and continuation of treatment. In case the person does not give his/her consent, the issue of his/her compulsory hospitalization is resolved under the procedure stipulated by Article 12 of this Law.

3.8. Recommendations

1. Recommendations on legislation for the Ministry of Health and the Ministry of Justice⁸⁹:

- Ensure the integration of the penitentiary healthcare system into the system of the MOH⁹⁰.
- Consider establishing a joint commission to ensure control over the provision of medical care to persons held in penitentiary institutions.

- It is necessary to define in the legislation specific terms for medical examination and assistance to persons held in places of detention. This is especially important for those who suffer from tuberculosis or other serious illnesses.

2. Policy recommendations for the Ministry of Justice, State Criminal Executive Service:

- Provide TB screening for newly arrived prisoners and convicts.
- Conduct preventive medical examinations of all convicts twice a year, in particular with the use of mobile fluoroscopic rooms.
- Ensure regular and systematic supervision and the availability of a therapeutic plan to treat prisoners' illnesses or prevent their complications, rather than eliminate symptoms (if caused by a medical condition).

4. RIGHT TO CONFIDENTIALITY (as part of the right to privacy)

4.1. Content of the right to confidentiality: Information relating to a person with TB and TB treatment should be kept confidential and should not be disclosed to any party except a) when approved by the relevant healthcare professionals; b) under strictly defined circumstances listed in the legislation; c) to protect third parties who are at serious and imminent risk of infection; d) to share necessary health information with healthcare professionals who provide care to TB patients.

⁸⁹ Strategy for a Comprehensive Response to Human Rights Barriers to Access to HIV and Tuberculosis Prevention and Treatment Services until 2030 and Strategic Plan (Annex to paragraph 7.2. of the minutes of the meeting of the National Council on Tuberculosis and HIV/AIDS of May 23, 2019). <https://cutt.ly/lfxp2FQ>;

⁹⁰ "Assessment of the legal environment for tuberculosis in Ukraine" (p.103) [https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_gov-ernance/legal-environment-assessment-for-tuberculosis-in-Ukraine.html\(c.102-103\)](https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_gov-ernance/legal-environment-assessment-for-tuberculosis-in-Ukraine.html(c.102-103)); Special Report of the Ukrainian Parliament Commissioner for Human Rights on the state of implementation of the National Preventive Mechanism in 2018. <http://www.ombudsman.gov.ua/ru/page/npm/provisions/reports/>; Annual report of the Ukrainian Parliament Commissioner for Human Rights in 2019: "On the state of observance of human and civil rights and freedoms". <http://www.ombudsman.gov.ua/ua/page/secretariat/docs/presentations/&page=4>;

The issue of confidentiality of TB status of people with TB or those who have had TB is not sufficiently regulated in Ukraine, which leads to potential disclosure of information about the diagnosis unnecessarily from the public health point of view. There are numerous cases of disclosure of status when notifying contact persons without proper measures to maintain confidentiality, in particular when notifying kindergartens and schools. Anti-epidemic measures at the center of TB infection also led to disclosures.

Most stigmas were observed in general medical institutions, non-medical institutions, small towns, and rural areas. There are cases of refusal to provide medical care due to fear of TB infection. Dismissive or stigmatizing attitudes persist even after successful treatment of TB. Close relatives and friends mostly support the patient when they learn about the disease, while people with TB try to keep their status secret from more distant people (neighbors, colleagues).

Focus group participants and non-governmental organizations provided examples of common violations of the right to confidentiality of people with TB, namely

- There is a request from the community of people with TB to hold medical staff accountable for disseminating information about a person's TB status⁹¹;
- doctors do not understand what medical confidentiality is. They believe that if they tell junior staff of health care facilities, it is not a violation of medical confidentiality, which only applies to disclosure of information to outsiders⁹²;
- in institutions where people with TB are under state control, there is no storage of medical records⁹³;
- the "patient route" to TB facilities already reveals information about a person's TB status;
- in penitentiary institutions, prisoners are illegally used to help medical staff;
- it is difficult to prove in court that a health care worker disclosed TB status (breach of confidentiality). In addition, the very fact of going to court and the court proceedings is already a risk of confidentiality violation;
- disclosure of medical confidentiality (TB status) leads to violation of other rights (e.g., dismissal of a person with TB from work).

A selective analysis of legislation and policies, as well as focus group assessments, revealed the following:

The right to confidentiality:

1. Availability: Laws - 4 Policies - 4
2. Implementation: Laws - 2 Policies - 3
3. Media coverage: Laws - 3 Policies - 3
4. Number of rights that are harmed by laws/policies – 0

⁹¹ There are numerous cases of disclosure of diagnosis by doctors, mostly at the primary health care level, as well as careless actions that led to disclosure of status by junior medical staff. "Assessment of the legal environment for tuberculosis in Ukraine".C.37: https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_governance/legal-environment-assessment-for-tuberculosis-in-Ukraine.html

⁹² See also: Barriers to TB treatment in Ukraine: survey results.. 2020. C.101. https://phc.org.ua/sites/default/files/users/user90/Bariery_likuvannia_TB_report.pdf;

⁹³ Special report of the Ukrainian Parliament Commissioner for Human Rights "On the state of observance of the right to health care and medical assistance in pre-trial detention centers and penitentiary institutions of the State Criminal Executive Service of Ukraine". <http://www.ombudsman.gov.ua/ua/page/npm/provisions/reports/>.

4.2. International standards defining the right to confidentiality (part of the right to privacy)

1. The Universal Declaration of Human Rights of 1948 (Article 12): No one shall be subjected to arbitrary interference with his privacy, family, home, correspondence, or honor and reputation. Everyone has the right to the protection of the law against such interference or attacks.

2. The Convention for the Protection of Human Rights and Fundamental Freedoms of 1950 (Article 18) stipulates that everyone has the right to respect for his private and family life, home, and correspondence; public authorities may not interfere with this right except insofar as such interference is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

3. European Convention on Human Rights (1950) (Article 8): Everyone has the right to respect his or her private and family life. The public authorities may not interfere with the exercise of this right except insofar as such interference is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety, or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

4. The International Covenant on Civil and Political Rights of 1966 (Article 17): No one shall suffer arbitrary or unlawful interference with his privacy, family, home, or correspondence, nor unlawful attacks on his honor, reputation, or privacy.

5. International Covenant on Economic, Social and Cultural Rights of 1966 (Article 12). General Comment No. 14 (2000) on the right to the highest attainable standard of health: accessibility as a component of this right includes access to information. However, accessibility of information should not prejudice the right to confidentiality of personal health data. Acceptability as a component of this right includes the obligation of all healthcare institutions to comply with the principles of medical ethics and cultural criteria and to be committed to maintaining confidentiality.

6. UN Convention on the Rights of the Child 1989 (Article 16): No child shall be subjected to arbitrary or unlawful interference with his or her right to privacy, family, home, correspondence, or to unlawful attacks on his or her honor and dignity.

4.3. Recommended sources of international standards

1. WHO ethical guidelines for TB prevention, care, and control (WHO, 2010): Information, Consultation and the Role of Consent. In exceptional cases, this obligation applies to third parties, where disclosure of TB status without consent can be justified. Disclosing a person's TB status without consent should be considered a measure of last resort if they have not been persuaded to take treatment. In addition, non-consensual disclosure of a person's TB status is only possible to those close to the person who is at risk of infection if they do not know the person's TB status. Health authorities and TB control programs should have a clear policy on non-consensual disclosure of TB status, which should include standards and procedures that must be followed before non-consensual disclosure is authorized. These standards and procedures should be designed to protect people with TB and their loved ones from stigma and other TB-related social harms in many healthcare settings. People with TB should be notified before any inappropriate disclosure of their status is made.

2. The Patients' Charter for the Treatment of Tuberculosis (World Health Council, 2006),

proclaimed the following rights:

- Confidentiality. The right to respect for privacy, dignity, religious beliefs and culture;
- The right to confidentiality of medical information; the transfer of this information to other institutions should be done with the consent of the person with TB⁹⁴.

3. Council of Europe Convention No. 108 for the Protection of Individuals about Automatic Processing of Personal Data, adopted on January 28, 1981. This document sets out for the first time the key principles of personal data processing, the rights of an individual in connection with the processing of his or her personal data, and the basic rules for cross-border data transfer⁹⁵.

4. Declaration of rights of people with TB⁹⁶:

Article 10. The right to confidentiality. Every person affected by tuberculosis has the right to confidentiality of personal medical information and data.

This means that disclosure, transfer, or transmission in electronic or other form of personal health information or data about a person affected by tuberculosis, including in the context of employment, is allowed only with his/her informed consent and in cases where it is done to protect his/her health or public health. To protect public health, including in connection with epidemiological surveillance or health care programs, such information may be transmitted without the informed consent of a person only if it is done anonymously without specifying the name or other information that can be used to identify the person.

The right to privacy should also be respected and taken into account in the design and implementation of contact tracing and other related public health activities. This right includes, but is not limited to, providing people exposed to TB with access to counseling about disclosure of diagnosis, the opportunity to make joint decisions about how and when to disclose possible infection to contacts, and access to qualified health and social workers to provide support and answer questions that might emerge in the process.

4.4. The right of a TB patient to medical confidentiality

An individual may be obliged to undergo a medical examination in cases established by law (Article 286 of the Civil Code of Ukraine).

The Law of Ukraine "On Overcoming Tuberculosis in Ukraine" of July 14, 2023, No. 3269-IX, Article 5, provides for the powers of the Cabinet of Ministers of Ukraine in the field of tuberculosis control:

- 1) develops, approves, and ensures the implementation of relevant state-targeted programs in accordance with the law;
- 2) directs and coordinates the work of ministries and other executive authorities;
- 3) takes measures to create and improve the material and technical base of health care institutions, public health institutions, enterprises, institutions, and organizations involved in

⁹⁴ Health and human rights: a resource guide. © 2015 François-Xavier Center for Health and Human Rights. Chapter 3. TUBERCULOSIS AND HUMAN RIGHTS. http://medicallaw.org.ua/fileadmin/user_upload/PDF/%D1%80%D0%B5%D1%81%D0%BE%D1%80%D1%81%D0%A0%D0%B5%D1%81%D0%BE%D1%80%D1%81_%D1%80%D0%BE%D0%B7%D0%B4%D1%96%D0%BB_3.pdf

⁹⁵ Convention for the Protection of Individuals Regarding Automatic Processing of Personal Data of 28.01.1981. – Ofitsijnyi Visnyk Ukrainy. 2011. January 14. 2011. January 14. (№58). p. 701.

⁹⁶ <http://www.stoptb.org/assets/documents/communities/russian%20declaration%20of%20rights%20of%20people%20affected%20by%20TB.pdf>

anti-tuberculosis activities in terms of their implementation of such activities;

4) ensure control over the implementation of anti-tuberculosis measures by executive authorities;

5) approves nutritional standards in regional phthisiopulmonological centers, rehabilitation, palliative, and hospice departments that provide inpatient medical services for people with tuberculosis;

6) approves the list of professions, industries, and organizations whose employees are subject to mandatory preventive medical examinations, the procedure for conducting these examinations, and issuing personal medical books;

7) approves the state strategy for overcoming tuberculosis in Ukraine;

8) exercises other powers defined by law.

According to Subpara. 4 of clause 3.6 of the Ethical Code of Physicians of Ukraine, medical information about a patient may be disclosed

- if keeping the secret significantly threatens the health and life of the patient and/or other persons (dangerous infectious diseases);

- in the case of involvement of other specialists in the treatment for whom this information is professionally necessary.

Ukrainian legislation provides for cases **of disclosure of medical secrets**.

Under part two of Article 39 of the Law of Ukraine "Fundamentals of Healthcare Legislation", part 2 of Article 285 of the Civil Code of Ukraine, parents (adoptive parents), guardians, and trustees have the right to receive information about the health status of a child (under 18 years of age) or ward (incapacitated person).

Also, medical secrets may be disclosed without the patient's consent in the following cases:

- If the patient consents to the dissemination of such information (Article 21, part 2 of the Law "On Information")⁹⁷;
- Medical records about a person may be obtained only directly by the person to whom it concerns (Article 285(1) of the Civil Code of Ukraine), or by his/her representative under a power of attorney or a legal aid agreement (provided that copies of the said documents are attached to the request), as well as by parents (adoptive parents, guardian or trustee) as legal representatives of a child (under 18 years of age) or ward (incapacitated person).
- Temporary access to documents containing medical secrecy may be granted by an investigator, judge, or court in criminal proceedings if it is established that there are no other ways to obtain the information necessary for the investigation (part 6 of Article 163 of the Criminal Procedure Code of Ukraine).
- Newlyweds have the right to be mutually informed about their health status (Article 30 of the Family Code of Ukraine).
- Information about HIV test results, the presence or absence of HIV infection in a person is allowed to be provided only to: the person who was tested; parents or other legal representatives of such a person; other medical workers and health care institutions - exclusively in connection with the treatment of this person; other third parties - only by court decision in cases established by law (part. 4 of Article 13 of the Law "On Prevention of Diseases Caused by Human Immunodeficiency Virus (HIV) and Legal and Social Protection of People Living with HIV"). Disclosure of information about a person's positive HIV status to a partner(s) by a healthcare professional is permitted if the person living with HIV requests it in writing, or if the person living with HIV has died, lost consciousness, or there is a possibility that he or she will not recover and will

⁹⁷ <https://zakon.rada.gov.ua/laws/show/2657-12#Text>

not regain the ability to provide informed consent.

- It is allowed to transfer information about the state of mental health of a person and provide him/her with psychiatric care without the consent of the person or without the consent of his/her legal representative to organize the providing of psychiatric care to a person suffering from a severe mental disorder and to conduct a pre-trial investigation, drafting a pre-trial report on the accused or a trial at the written request of the investigator, prosecutor, court and representative of the authorized probation body (Article 6 of the Law "On Psychiatric Care").
- Information about treatment in a drug treatment facility may be disclosed to law enforcement agencies in case of criminal or administrative liability (Article 14, part 5 of the Law "On Measures to Counteract Illegal Trafficking in Narcotic Drugs, Psychotropic Substances and Precursors and Their Abuse").

According to Article 7 of the Law of Ukraine "On Personal Data Protection"⁹⁸, special requirements are imposed on the processing of personal data on human health. Personal data of this nature may be subject to collection and processing only in case of health care needs, medical diagnosis, care or treatment, or provision of medical services, provided that such data is processed by a health care worker or other person of a health care institution who is responsible for ensuring the protection of personal data and who is subject to the law on medical secrecy.

A healthcare worker who has detected a case of tuberculosis is obliged to report it to the chief state sanitary doctor of the relevant administrative territory and to the district/city phthisiologist at the place of detection of the case.

The form of the notification and the procedure for its submission are approved by the Order of the Ministry of Health of Ukraine and the State Statistics Committee of Ukraine "On Approval of the Primary Record Form No. 089/o "Report on a Patient with a First-time Diagnosis of Active Tuberculosis or its Relapse and Instructions for its Completion" of 25.03.2002 No. 112/139⁹⁹. According to this order, the notification is to be filled in by a doctor who has diagnosed tuberculosis or its relapse, regardless of his/her specialty.

The notification is to be filled out for all patients who are diagnosed with active tuberculosis or its relapse for the first time in their lives (i.e., activation of tuberculosis in persons who previously had tuberculosis and were considered cured), regardless of the circumstances of the disease detection - during a visit for the disease, preventive examination or examination in a hospital, etc.

Under the provision of paragraph 3.2 of the Instruction on the procedure for filling out a sick leave certificate, approved by the Order of the Ministry of Health of Ukraine, the Ministry of Labor and Social Policy of Ukraine, the Social Insurance Fund for Temporary Disability, the Social Insurance Fund for Accidents at Work and Occupational Diseases of Ukraine No. 532/274/136-oc/1406 dated November 3, 2004, in the column "Primary diagnosis" the doctor indicates the primary diagnosis on the first day of issuing the sick leave certificate ЖН(за454-04). In the "Final diagnosis" column, the physician indicates the final diagnosis, and in the "ICSD-10 code" column, the diagnosis code under the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, adopted by the World Health Assembly on January 1, 1993 (hereinafter - ISCD-10). The primary diagnosis, final diagnosis, and ISCD-10 code are indicated only with the written consent of the patient. Otherwise, the primary and final diagnoses and the ISCD-10 code are not indicated.

In the case of registration of a case of tuberculosis, information about patients with tuberculosis may be included in the relevant register. The collection, use, and dissemination of

⁹⁸ <https://zakon.rada.gov.ua/laws/show/2297-17#Text>

⁹⁹ <https://zakon.rada.gov.ua/laws/show/z0405-02#Text>

such information shall be carried out in compliance with the requirements of the law on the protection of information about an individual (personal data) under the procedure established by the central executive body that ensures the formation and implementation of state policy in the field of health care. Other records of tuberculosis patients are kept in compliance with the requirements of the Law "On Personal Data Protection" (part 2 of Article 16 of this Law).

4.5. Legal and regulatory acts that have been studied

The Constitution of Ukraine:

Article 3: A person, his or her life, and health are recognized in Ukraine as the highest social value. Human rights and freedoms and their guarantees determine the content and direction of the state's activities.

Article 32: No one shall be subjected to interference with his or her private and family life, except in cases provided for by the Constitution of Ukraine. It is not allowed to collect, store, use, and disseminate confidential information about a person without his/her consent, except in cases determined by law, and only in the interests of national security, economic welfare, and human rights. Thus, only an individual who is the subject of confidential information, in accordance with the constitutional and legislative regulation of the right of a person to collect, store, use, and distribute confidential information, has the right to freely, at his/her own discretion, determine the procedure for familiarizing other persons, the state and public authorities with it.

The provisions of this Article are clarified in the decision of the Constitutional Court of Ukraine dated January 20, 2012, No. 2-рп/2012 in the case on the constitutional petition of the Zhashkiv District Council of Cherkasy Region regarding the official interpretation of the provisions of parts one and two of Article 32, parts two and three of Article 34 of the Constitution of Ukraine dated January 20, 2012.

In addition, the decision of the Constitutional Court of Ukraine in the case concerning the official interpretation of Articles 3, 23, 31, 47, 48 of the Law of Ukraine "On Information" and Article 12 of the Law of Ukraine " On Prosecution" (the so-called "K. Ustymenko case") is of some interest from the point of view of personal data protection.

Article 15 establishes the political and ideological diversity of public life and prohibits censorship;

Article 21 enshrines the inalienability and inviolability of human rights and freedoms;

Article 28 enshrines the right of a person to respect for his or her dignity, prohibits subjecting a person to torture, cruel, inhuman, or degrading treatment or punishment; subjecting a person to medical, scientific, or other experiments without his or her free consent.

3. The Law of Ukraine " On Personal Data Protection":

Article 7 establishes special requirements for the processing of personal data and prohibits their processing if they relate, in particular, to health. This provision does not apply if health information is necessary for healthcare purposes for: establishing a medical diagnosis, providing care or treatment or provision of medical services, functioning of the electronic healthcare system, provided that such data is processed by a medical professional or other person of a healthcare institution or an individual entrepreneur who has obtained a license to conduct economic activity in medical practice and its employees who are responsible for ensuring the protection of personal data and are subject to the legislation on medical secrecy, employees of the central executive body that implements the state policy in the field of state financial guarantees of medical care for the population, who are responsible for ensuring the protection of personal data

The Civil Code:

Article 286: An individual has the right to secrecy about his/her health status, the fact of seeking medical care, diagnosis, as well as information obtained during his/her medical examination.

It is prohibited to demand and provide information about the diagnosis and methods of treatment of an individual at the place of work or study.

An individual shall refrain from spreading the information referred to in part one of this Article, which became known to him/her in connection with the fulfillment of official duties or from other sources.

4.5.1. Laws on liability for violation of information and healthcare legislation (which may be applied in case of violation of the right to access information)

1. Criminal Code:

Article 132: establishes criminal liability for disclosure of information about medical examination for detection of infection with human immunodeficiency virus or other incurable infectious disease (disclosure by an official of a medical institution, an auxiliary worker who obtained information without authorization, or a medical worker of information about medical examination of a person for detection of infection with HIV or other incurable infectious disease that is dangerous to human life, or acquired immunodeficiency syndrome (AIDS) and its results, which became known to them as a result of their official or professional duties).

Article 140: establishes criminal liability for improper performance of professional duties by a medical or pharmaceutical worker (failure to perform or improper performance of professional duties by a medical or pharmaceutical worker due to negligence or dishonesty, if this caused serious consequences for the patient);

Article 145: establishes criminal liability for unlawful disclosure of medical secrets (intentional disclosure of medical secrets by a person who learned about them while performing professional or official duties, if such action caused serious consequences).

2. Code of Ukraine on Administrative Violations:

Article 44-2: establishes administrative liability for violation of restrictions imposed on medical and pharmaceutical workers during the performance of their professional activities.

4.5.2. Healthcare legislation

1. The Law "Fundamentals of Legislation of Ukraine on Health Care":

Article 39-1: A patient has the right to confidentiality of his/her health status, the fact of seeking medical care, diagnosis, as well as information obtained during his/her medical examination. It is prohibited to demand and provide information about the patient's diagnosis and treatment methods at the place of work or study;

Article 40: medical workers and other persons who, in connection with the performance of their professional or official duties, have become aware of an illness, medical examination, examination, and its results, intimate and family life of a citizen, have no right to disclose this information, except in cases provided for by law.

When using information constituting a medical secret in the educational process, research work, including in cases of its publication in special literature, the anonymity of the patient must be ensured;

Article 78: the professional duties of medical and pharmaceutical workers include compliance with the requirements of professional ethics and deontology and preservation of medical secrecy.

2. The Law of Ukraine "On State Financial Guarantees of Medical Care for the Population":

Article 6: the rights of people with TB in the area of state financial guarantees include, in particular, ensuring that doctors and third parties comply with the requirements of the Law of Ukraine "On Personal Data Protection" when providing the right of access to personal data and other information contained in the electronic healthcare system, including information about their health status, diagnosis, information obtained during medical examination.

3. Ethical Code of Doctor of Ukraine:

3.6. A doctor shall respect the honor and dignity of the patient, and his/her right to privacy, treat him/her kindly, and understand the concerns of relatives and friends about the patient's condition.

Every patient has the right to keep personal secrets. A doctor, as well as other persons involved in the provision of medical care, is obliged to keep medical confidentiality even after the patient's death, as well as the fact of seeking medical care, unless otherwise ordered by the patient, or if the disease does not threaten his or her family and society.

The secrecy applies to all information obtained in the course of the patient's treatment (including diagnosis, treatment methods, prognosis, etc.).

Medical information about a patient may be disclosed

- in case of written consent of the patient;
- in case of a reasoned request of the inquiry, investigation, prosecution, and court authorities, sanitary and epidemiological service;
- if keeping the secret significantly threatens the health and life of the patient and/or other persons (dangerous infectious diseases);
- in case of involvement of other specialists in the treatment for whom this information is professionally necessary.

Persons other than the physician who have the right of access to medical information are obliged to keep all information received about the patient confidential and must be informed by the physician of the liability associated with its disclosure.

In the course of scientific research, training of students, and advanced training of doctors, medical confidentiality must be observed. Demonstration of the patient is possible only with the consent of the patient, his/her parents or guardians.

4.6. The problem of law enforcement (policy)

Focus group participants noted the widespread practice of disclosure of TB status by healthcare workers and employers. Another problem is that the very procedure for organizing TB diagnosis and treatment does not ensure the anonymity of diagnosis and treatment. Due to the decentralization of medical services, the "corporate solidarity" of doctors at the local level makes it possible for them to be irresponsible. The level of disclosure of positive HIV status and information about being a participant in a substitution maintenance therapy program remains high.

There are isolated cases of disciplinary proceedings (see below) or internal investigations into the disclosure of medical confidentiality in open sources (on the official website of the Ministry of Health).

The court practice of bringing healthcare professionals and/or other officials (e.g., employers) to liability is also not very extensive, but there are court decisions:

- a) Decision of the Shevchenkivskyi District Court of Chernivtsi dated April 12, 2018, in

case No. 727/8977/17¹⁰⁰ on the recognition of actions where the rights of a person to protection of confidential information were violated as illegal and compensation for moral damages by the chief doctor of the city polyclinic. The decision was made in favor of the patient;

b) Ruling of the Kyiv Court of Appeal dated 11.04.2019 in case No. 761/29995/17¹⁰¹ on compensation for non-pecuniary damage caused by the disclosure of medical secrets: the decision was not in favor of the patient due to insufficient evidence of disclosure of medical secrets;

c) Decision of the Zavodskiy District Court of Mykolaiv dated 28.03.2018 in case No. 487/1982/17¹⁰² on the cancellation of the order imposing a disciplinary sanction in the form of a reprimand on a nurse of the medical department of general surgery of the Mykolaiv Regional Clinical Hospital for disclosure of medical secrets and disclosure of patient information. The court decision canceled the order to impose a disciplinary sanction, but the decision of the Court of Appeal of Mykolaiv Oblast of May 23, 2018, reversed the decision of the court of first instance and issued a new decision dismissing the applicant's claim, i.e., recognizing the fact that she had disclosed medical secrets and that the disciplinary sanction in the form of a reprimand was lawful;

d) Decision of the Constitutional Court of Ukraine in the case on the constitutional petition of Zhashkiv District Council of Cherkasy region regarding the official interpretation of the provisions of parts one and two of Article 32, parts two and three of Article 34 of the Constitution of Ukraine¹⁰³ dated January 20, 2012, №2-пп/2012. The Constitutional Court of Ukraine, giving official interpretation of parts one and two of Article 32 of the Constitution of Ukraine, considers that information about personal and family life of a person (personal data about him/her) is any information or set of information about an individual who is identified or can be specifically identified, namely: nationality, education, marital status, religious beliefs, health, financial status, address, date and place of birth, place of residence and stay, etc., data on personal property and non-property relations of this person with other persons, including by family members, as well as information about events and occurrences that have happened or are happening in the domestic, intimate, social, professional, business and other spheres of a person's life, except for data on the exercise of powers by a person occupying a position related to the exercise of functions of the state or local self-government bodies. Such information about an individual and his/her family members is confidential and may be disclosed only with their consent, except in cases specified by law, and only in the interests of national security, economic well-being and human rights. According to Article 8 of the 1950 Convention for the Protection of Human Rights and Fundamental Freedoms, everyone has the right to respect for his or her private and family life, home, and correspondence. Public authorities may not interfere with the exercise of this right except where such interference complies with the law and is necessary in a democratic society in the interests of national security, public safety, or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

e) Decision of the Constitutional Court of Ukraine in the case on the constitutional complaint of Pleskach Vyacheslav Yuriyovych on the compliance of the provisions of the second sentence of part four of Article 42 of the Law of Ukraine "On the Constitutional Court of Ukraine" of January 22, 2020 No. 1-p(I)2020¹⁰⁴. The right of a person to access information guaranteed by Article 34 of the Constitution of Ukraine is not absolute and may be subject to restrictions. Such restrictions must be exceptions provided for by law, serve one or more

¹⁰⁰ <https://reyestr.court.gov.ua/Review/73544783>

¹⁰¹ <https://reyestr.court.gov.ua/Review/81170220>

¹⁰² <https://reyestr.court.gov.ua/Review/73131097>

¹⁰³ <https://zakon.rada.gov.ua/laws/show/v002p710-12#Text>

¹⁰⁴ <https://zakon.rada.gov.ua/laws/show/va01p710-20#Text>

legitimate purposes, and be necessary in a democratic society. In case of restriction of the right to access to information, the legislator is obliged to introduce a legal regulation that will allow to achieve the legitimate goal with minimal interference in the realization of this right and not violate the essential content of such a right. (*paragraph eight of subparagraph 2.2 of paragraph 2 of the motivational part*).

Persons may not be interrogated as witnesses about information constituting medical secrets. Exemption from the above professional obligation may be granted only by a person who has entrusted the above-mentioned persons with information constituting medical secrets. The scope of information that may be legally disclosed is also determined by the person who provided it, i.e. the patient or his/her legal representative. It is important to emphasize that the law also establishes an algorithm of actions for such release from the obligation, namely a written form of expression of the will signed by the person who entrusted the specified information. The ECtHR judgment in the case of *Z. v. Finland* (application no. 22009/93 [1997] ECtHR 10)¹⁰⁵ (Strasbourg, January 25, 1997), in particular, states that on September 23, 1992, senior doctor L. filed a complaint with the Parliamentary Commissioner for Human Rights against a court decision obliging him to testify. In his opinion of 05.02.1993, the Parliamentary Commissioner for Human Rights expressed the opinion that national legislation had not been violated and the city court, investigating the crime, had properly balanced the public interest and the applicant's right to medical confidentiality. The ECtHR takes into account that the protection of personal information, not only medical information, is extremely important for the exercise of the right to respect for private and family life guaranteed by Article 8 of the Convention. Respect for the confidentiality of health information is an integral principle of the legal systems of the countries party to the Convention. It is crucial not only to respect the patient's medical confidentiality but also to ensure his or her trust in the medical profession and medical services in general. Therefore, domestic legislation must provide guarantees sufficient to prevent the transfer or disclosure of medical secrets that may contravene the provisions of Article 8 of the Convention (see paragraph (c) of Articles 3, 5, 6, and 9 of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data, 1981).

4.7. The problem of legislation and the problem of law enforcement in relation to certain groups of the population

Communication with the Roma community does not take into account socio-cultural factors and the strong stigma of TB in this group. National experts noted that in the Roma community, TB patients may face physical violence if their diagnosis is disclosed ("they can be killed")¹⁰⁶.

People with TB in places of detention: violation of the confidentiality of people with TB in places of detention (in detention centers and penitentiary institutions of the State Criminal Executive Service)¹⁰⁷.

In 2017, amendments were made to the Order of 15.08.2014 №1348/5/572 "On approval of the Procedure for organizing the medical care of persons sentenced to imprisonment", according to which medical examinations (examinations) of convicts are conducted out of earshot and (unless the medical worker wishes otherwise in each case) out of sight of non-medical personnel. The introduction of such a provision in the Order is an important step that

¹⁰⁵ http://medicallaw.org.ua/fileadmin/user_upload/pdf/Z_against_Finland.pdf

¹⁰⁶ 100% life. Assessment of tuberculosis stigma in Ukraine, Kyiv, 2021.

¹⁰⁷ Special report of the Ukrainian Parliament Commissioner for Human Rights on the observance of the right to health care and medical assistance in pre-trial detention centers and penitentiary institutions of the State Criminal Investigation Service of Ukraine. <http://www.ombudsman.gov.ua/ua/page/npm/provisions/reports/>.

ensures confidentiality when providing medical care to convicts and, ultimately, may contribute to the better quality of treatment. Paragraph 24 of the Order requires that documents containing information about the health status of a convicted person and the provision of necessary medical care to him/her should be kept in compliance with the conditions guaranteeing the confidentiality of this information¹⁰⁸.

4.8. Recommendations

1. Recommendations on legislation:

- For the Ministry of Health:
 - To amend the legislation to provide detailed regulation of the issues of maintaining the secrecy of TB diagnosis during medical care, notification of contact persons, epidemiological investigations, social support, etc;
 - To develop amendments to the MOH regulations on tuberculosis, in particular, to the MOH Orders: No. 657 of 02.09.2009 "Instruction on filling in the form of primary accounting documentation No. 060-1/o "Journal of registration of tuberculosis cases, TB 03"; Order of the MOH and the State Committee of Statistics No. 112/139 of 25.03.2002 (registered with the Ministry of Justice on April 29, 2002, under No. 405-6693). No. 405/6693) "On Approval of the Primary Registration Form No. 089/o "Report on a Patient with a First Time Diagnosis of Active Tuberculosis or Relapse" and Instructions for Filling It Out" and others, which provide for the following in accordance with international standards
 - a) the right of people with TB to keep their health status confidential
 - b) the obligation of health care workers to keep patient health information and medical confidentiality secret;
 - c) supplement the job descriptions of health care workers who have access to confidential information, including about people with TB, with requirements for personal data protection and confidentiality (establish the obligation of health care workers to keep patient health status and medical information confidential) ¹⁰⁹;
 - d) develop and implement at the local level a mechanism for investigating cases of violation of medical confidentiality and the right to confidentiality of people with TB.
 - для МВС, Мін'юсту:
 - заборонити доступ до медичної документації немедичному персоналу СІЗО та УВП ДКВС, забезпечити її конфіденційність¹¹⁰;
 - for the Ministry of Internal Affairs, the Ministry of Justice:
 - to prohibit access to medical records for non-medical personnel of pre-trial detention centers and penal institutions of the State Criminal Executive Service, to ensure its confidentiality;

¹⁰⁸ Interim alternative report of the Ukrainian Helsinki Human Rights Union on the implementation of the recommendations made by the UN Committee against Torture based on the results of consideration of the sixth periodic report of Ukraine (CAT/C/UKR/6) / A. Blaga, O. Martynenko, I. Telychkin, V. Chovgan; edited by A. Bushchenko: Scientific and Practical Edition / Ukrainian Helsinki Human Rights Union - K., KIT, 2015. 34 p. with illus.– p. 29

¹⁰⁹ Strategy for a Comprehensive Response to Human Rights Barriers to Access to HIV and Tuberculosis Prevention and Treatment Services by 2030 (Annex to paragraph 7.2. of the minutes of the meeting of the National Council on Tuberculosis and HIV/AIDS of May 23, 2019 Strategy for a Comprehensive Response to Human Rights Barriers for Access to HIV and Tuberculosis Prevention and Treatment Services by 2030). <https://cutt.ly/mfcSIJo>

¹¹⁰ Assessment of the legal environment regarding tuberculosis in Ukraine. p.119. https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_gov-ernance/legal-environment-assessment-for-tuberculosis-in-Ukraine.html.

2. Policy (enforcement) recommendations for the MOH:

- Provide a mechanism for exercising the right to an anonymous medical examination of a person who has applied to a health care facility (use the experience of applying the Law of Ukraine "On Prevention of Acquired Immunodeficiency Syndrome (AIDS) and Social Protection of the Population"), as well as the possibility of remote (without a personal visit to a health care facility by a person with TB) support for people with TB.

- To ensure the confidentiality of data on HIV or TB status¹¹¹:

a) Develop and implement unified registries of HIV-positive and TB patients (or improve the module of the E-TB manager to personalize patient data and personal code for each patient) with appropriate data protection and confidentiality systems.

b) Supplement the job descriptions of healthcare workers who have access to confidential information, including on HIV-infected persons and people with TB, with requirements for personal data protection and confidentiality.

c) Include the requirement for protection of confidential information about patients in the Licensing conditions for carrying out business in medical practice to prevent violation of confidentiality by health care providers.

d) To supplement the accreditation standards for healthcare facilities with a requirement to comply with the principle of confidentiality of information about HIV-infected persons and people with TB (section on the rights, responsibilities and safety of people with TB).

e) Amend Ukrainian legislation to provide for detailed regulation of TB diagnosis confidentiality;

f) Measure the level of status disclosure as part of the TB and HIV stigma index.

5. THE RIGHT TO INFORMED CONSENT ON MEDICAL INTERVENTION

5.1. Content of the right to informed consent to medical care: The legislation does not contain a clear definition of the term "informed consent to medical care". However, based on the content of Article 28 of the Constitution of Ukraine, Articles 43, 39 of the Law of Ukraine " Fundamentals of Legislation in Ukraine on Health Care" (hereinafter - the Fundamentals), Article 284 of the Civil Code of Ukraine, we conclude that: informed consent for medical care is a free, informed decision of a person seeking medical care and/or his/her legal representatives regarding the choice and application of diagnostic, preventive and treatment methods, based on receiving information from a doctor in an accessible form about the state of his/her health, the purpose of the proposed research and treatment measures, the forecast of possible development of the disease, including the risk to life and health.

The decision to give consent to medical care must be free. It cannot be the result of external coercion (coercion by threats, psychological pressure from other people, official dependence) or active persuasion of anyone, including a doctor (psychological pressure from other people, pressure from medical staff who claim that it is possible to refuse to undergo this medical intervention in the future).

The decision should only be the result of a personal choice based on full information about the situation (health status). The doctor/healthcare professional is obliged to provide the patient with information in an accessible form about the patient's health status, the purpose of the proposed research and treatment measures, the forecast of possible disease development, including the risk to life and health (part three of Article 39 of the Fundamentals).

¹¹¹ Strategy for a comprehensive response to human rights barriers to access to HIV and TB prevention and treatment services until 2030.

People with TB have the right to provide informed consent to medical interventions before starting TB treatment and the right not to be subjected to compulsory treatment without consent under any circumstances.

According to the Law of Ukraine "On Overcoming Tuberculosis in Ukraine" (Article 11),

1. Medical care for people with tuberculosis is provided taking into account the needs of people and gender aspects on an outpatient basis, including through telemedicine, or in the inpatient setting of a regional phthisiopulmonary center in accordance with industry standards for the provision of medical care and the standard of infection control for tuberculosis and the procedure for providing outpatient treatment services for people with tuberculosis in primary health care facilities. Organizational, anti-epidemic and preventive measures to prevent the spread of tuberculosis in tuberculosis institutions and institutions for permanent stay of people are carried out in accordance with the standard of infection control, which is approved by the central executive body that ensures the formation and implementation of state policy in the field of health care.

2. Mandatory requirements for TB treatment are written informed consent of the patient or his/her legal representative or guardian for treatment and written warning about the need and conditions for compliance with the anti-epidemic regime.

3. Control over patients' compliance with the treatment regimen and anti-epidemic regimen prescribed by a doctor, including detection of their violations, is carried out by healthcare workers who respectively provide or should provide treatment to a person with tuberculosis.

4. People with tuberculosis with bacterial excretion, if there are indications for hospitalization established by the central executive body that ensures the formation and implementation of state policy in the field of health care, are provided with hospitalization in the regional phthisiopulmonary center.

5. In case a person affected by tuberculosis with bacterial excretion refuses to be hospitalized, his/her treatment may be carried out on an outpatient basis, if it is possible to isolate such a person at home.

6. Medical care for people with tuberculosis - citizens of Ukraine, as well as foreigners and stateless persons - is provided regardless of the grounds for their stay in Ukraine and the availability of identity documents, in accordance with the procedure established by the central executive body that ensures the formation and implementation of state policy in the health care sector.

Focus group participants noted the largely formal nature of informed voluntary consent to medical interventions, and suggested introducing a procedure for informing a person and preparing for medical interventions similar to the procedure for pre- and post-test counseling in connection with HIV testing.

A selective analysis of legislation and policies, as well as focus group assessments, revealed the following:

The right to informed consent:

1. Availability: Laws - 4 Policies - 4
2. Implementation: Laws - 4 Policies - 4
3. Media coverage: Laws - 3 Policies - 2
4. Number of rights that are harmed by laws/policies - 0

**5.2. International standards defining the right to medical intervention
(informed consent)**

In international law, the issue of "informed consent to medical intervention" is covered in the following documents:

- The Lisbon Declaration of the Rights of the Patient (1981): a mentally competent adult patient has the right to give or withhold consent to any diagnostic procedure or treatment. The patient has the right to information necessary to make his or her decision;
- Declaration on the Development of Patients' Rights in Europe (1994);
- Declaration of Policy on Patients' Rights in Europe (1994);
- The Universal Declaration on Bioethics and Human Rights (2005): any preventive, diagnostic or curative measures should be carried out with the prior informed and free consent of a person who has adequate information;
- Convention for the Protection of Human Rights and Human Dignity with regard to the Application of Biology and Medicine (1997): any medical procedure may be performed only after the patient has freely given informed consent;
- The European Charter of Patients' Rights (2002): everyone has the right to access full information to help them actively participate in decisions about their health; this information may serve as a prerequisite for a medical procedure or treatment¹¹².

Informed consent to medical intervention is a voluntary, competent acceptance by a person with TB of a proposed treatment option based on receiving complete, objective, and comprehensive information about the upcoming treatment, possible complications, and alternative treatment methods¹¹³.

"Everyone has the right to receive any type of information that will help him/her to actively participate in decision-making regarding his/her health; this information is a prerequisite for any procedure and treatment, including participation in scientific research¹¹⁴".

The right to medical intervention (informed consent) is viewed through the content of the concept of "patient autonomy - the right of the patient to make decisions regarding medical care; healthcare professionals can influence the patient's awareness, but cannot make decisions for him/her", as well as through the human right to physical integrity.

Although the human right to physical integrity is not directly enshrined in fundamental international documents, such as the ICCPR, the ICESCR, and the ECHR, it is interpreted as part of the human right to physical integrity (ICCPR, Art. 9; ECHR, Art. 5); the right to freedom from torture, cruel, inhuman or degrading treatment (ICCPR, Art. 7; ECPHRFF, Art. 3), the right to privacy (ICCPR, Art. 17; ECPHRFF, Art. 8), the right to the highest attainable standard of physical and mental health (ICESCR, Art. 12; ESC, Art. 11).

General Comment No. 14 (2000) of the Committee on Economic, Social and Cultural Rights on the Right to the Highest Attainable Standard of Health (Article 12 of the ICESCR) states that the right to health includes both freedoms and related rights. The freedoms include the right to control one's health and body and the right to be free from any interference, such as the right to be free from torture and not to be subjected to medical or scientific experimentation without free consent.

Convention on the Rights of the Child (1995) (Article 19): States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical and mental violence, injury or abuse.

¹¹² Sakalo V.O. Informed consent to medical intervention: bioethical aspect / V.O. Sakalo // Forum of Law. - 2012. - №2. – p. 609–613.

¹¹³ Lashkul Z. V. Informed consent: concept, purpose and significance in the process of realization of the rights and obligations of health care workers and patients: a textbook / Z. V. Lashkul, Y. Y. Sizintsova, Y. Y. Fershal - Zaporizhzhia: Keramist.. – 2013. – p.189

¹¹⁴ <http://medicallaw.org.ua/vydavnytstvo/praktychnyi-posibnyk-prava-liudyny-u-sferi-okhorony-zdorovia/3-regionalni-standarti-prav-ljudini-v-sferi-okhoroni-zdorovja>

5.3. Recommended sources of international standards

1. WHO Ethical Guidelines for TB Prevention, Care and Control (WHO, 2010)¹: General goals and objectives.

Autonomy can be defined in different ways, but is generally seen as a guarantee of citizens' right to make decisions about their lives, including health care. For example, respect for autonomy means that people with TB should usually have the right to choose their treatment options.

Information, consultation and the role of consent. There are several reasons why people should be tested and treated for TB and receive full and accurate information about the risks, benefits, and alternatives available. At a basic level, people have a right to know what is being done to their bodies and why it is being done.

People who are tested for TB should receive basic information about TB and an explanation of why they are being tested. Persons who are offered TB treatment should be informed about the risks and benefits of the proposed interventions (both by people with TB and other community members), the importance of completing a full course of treatment and infection control measures, and information about available support for people with TB during the full course of treatment.

Support of the desire to be treated for TB. Direct therapy should be seen as a process that includes providing support, motivation and understanding to people with TB. It is a necessary part of TB treatment, but in no case is it aimed at treatment against the patient's will. In rare cases, if all reasonable efforts have failed and the patient remains infected, involuntary isolation or detention should be considered.

2. Declaration of the rights of people with TB¹¹⁵:

Article 12. Right to informed consent.

Everyone affected by tuberculosis has the right to informed consent.

The right to informed consent, i.e. voluntary consent to receive health care services, means respect for a person's autonomy, self-determination and dignity. Informed consent - verbal or written, as appropriate - includes consent to all forms of TB-related diagnosis, treatment and medical research; the right to receive age- and gender-appropriate, culturally relevant information in a language that is understandable to the person receiving the information.

Children affected by tuberculosis are not able to give informed consent, so all decisions made by their parents or legal guardians regarding diagnosis, treatment or medical research related to tuberculosis should be made in the best interests of the child, based on accurate medical evidence.

5.4. Legal and regulatory acts that have been studied

The Constitution of Ukraine:

Article 28 establishes the right of everyone to respect for his or her dignity and sets out the following constitutional guarantees:

- No one shall be subjected to torture, cruel, inhuman or degrading treatment or punishment;
- No person shall be subjected to medical, scientific or other experiments without his or her free consent;

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<http://www.stoptb.org/assets/documents/communities/russian%20declaration%20of%20rights%20of%20people%20affected%20by%20TB.pdf>

Article 28(1): Everyone has the right to personal inviolability.

Civil Code of Ukraine

Article 289 of the CCU defines the human right to respect for dignity, including the right of an individual to bodily integrity. An individual may not be subjected to torture, cruel, inhuman or degrading treatment or punishment.

Criminal Code of Ukraine

Article 140 establishes criminal liability for improper performance of professional duties by a medical or pharmaceutical worker (failure to perform or improper performance of professional duties by a medical or pharmaceutical worker due to negligence or dishonesty, if this caused serious consequences for the patient);

Article 137 establishes criminal liability for improper performance of duties to protect the life and health of children (failure to perform or improper performance of professional or official duties to protect the life and health of minors as a result of negligent or dishonest attitude to them, if this caused significant damage to the victim's health);

Article 144 establishes criminal liability for the forcible or fraudulent removal of blood from a person for the purpose of using it as a donor.

Code of Ukraine on Administrative Offenses:

Article 44-2 establishes administrative liability for violation of restrictions imposed on medical and pharmaceutical workers in the course of their professional activities.

5.4.1. Healthcare legislation

Healthcare legislation generally complies with international standards and recommended sources of international standards that define the right to medical intervention (with informed consent). A common problem in the implementation of legislation, when systemic violations of the rights of people with TB to medical intervention (the right to informed consent combined with violations of the right to access information) are committed, is the inconsistency of health care legislation with the patient-centered approach.

1. The Law of Ukraine "Fundamentals of the Legislation of Ukraine on Health Care":

Article 43: according to Article 39 of these Fundamentals, informed consent of the patient is required for the implementation of diagnostic, prevention and treatment methods. In the case of a patient under the age of 14 (a minor patient), as well as a patient who is recognized as incapacitated under the procedure established by law, medical intervention is carried out with the consent of his or her legal representatives.

The consent of the patient or his/her legal representative to medical intervention is not required only if there are signs of a direct threat to the patient's life, provided that it is impossible to obtain consent to such intervention from the patient or his/her legal representatives for objective reasons.

If the absence of consent may lead to serious consequences for the patient, the physician is obliged to explain this to the patient. If the patient still refuses treatment, the physician has the right to take a written confirmation from the patient, and if it is impossible to obtain it, to certify the refusal by a relevant act in the presence of witnesses;

Article 44: new methods of prevention, diagnostics, treatment, rehabilitation and medicines that are reviewed under the established procedure but not yet approved for use, as well as unregistered medicines may be used in the interests of the person's treatment only after obtaining his or her written consent. In the case of a person under the age of 14 (minor), these methods and means may be used with the written consent of his/her parents or other legal representatives, and in the case of a person aged 14 to 18 - with his/her written consent and the written consent of his/her parents or other legal representatives; in the case of a person whose civil capacity is limited - with his/her written consent and the written consent of his/her

guardians; in the case of a person recognized as incapacitated under the procedure established by law - with the written consent of his/her legal representative.

When obtaining consent for the use of new methods of prevention, diagnosis, treatment, rehabilitation and medicinal products that are under consideration in accordance with the established procedure but not yet approved for use, as well as unregistered medicinal products, the person and/or his/her legal representative shall be provided with information about the goals, methods, side effects, possible risks and expected results;

Article 45: the use of medical and biological experiments on humans is allowed with full information and free consent of an adult capable individual subject to the experiment.

2. Ethical Code of Ukrainian Doctor, adopted and signed at the All-Ukrainian Congress of Medical Organizations and the X Congress of the All-Ukrainian Medical Society of 27.09.2009 [para. 3.5], states: "A physician must obtain a patient's voluntary consent to an examination, treatment or research in a personal conversation with him/her. This consent must be conscious... If the patient is unable to consciously express his/her consent, it is given by the patient's legal representative or permanent guardian. Treatment and diagnostic measures without the patient's consent are permitted only in cases of threat to the patient's life and health in case of inability to adequately assess the situation. Decisions in such cases must be made collectively and with the participation of the patient's relatives. During the treatment of a child or a patient under guardianship, the physician is obliged to provide full information to his/her parents or guardians, to obtain their consent to the use of a particular treatment method or drug."

3. The Order of the Ministry of Health of Ukraine No. 549 dated 08.08.2014 (registered with the Ministry of Justice on 29.08.2014 under No. 1049/25826) "On Amendments to Certain Orders of the Ministry of Health of Ukraine" approved the form of primary accounting documentation No. 003-6/o "Informed voluntary consent of the patient for diagnostics, treatment, surgery and anesthesia" and the Instructions for its completion.

It is important to note that the Order provides for obtaining the patient's informed voluntary consent at the stage of diagnosis, and then for treatment, surgery and anesthesia. In our opinion, the content of the document contains the basic scope of guarantees for a person with TB, as defined by international standards and laws in the healthcare sector.

4. Specifications of medical service packages in 2020 (approved by the Ministry of Health on January 21, 2020), namely: Specification for the provision of medical services in the area of "Primary Health Care" (hereinafter - the Primary Health Care Specification) and Specification for the provision of medical services in the area of "Diagnosis and Treatment of Adults and Children with Tuberculosis" (hereinafter - the TB Specification) do not contain direct instructions for doctors to obtain, in accordance with Article 39 of the Fundamentals, the patient's informed consent for the use of diagnostic, prevention and treatment methods.

At the same time, clause 21 of the PHC Specification (21. Keeping primary records) and clause 7 of the TB Specification (Organizational and methodological work on TB: keeping records) refers, among other things, to the implementation of the above-mentioned Order of the Ministry of Health of Ukraine of 08.08.2014 No. 549 "On Amendments to Certain Orders of the Ministry of Health of Ukraine", which approves the form of primary record documentation No. 003-6/o "Informed voluntary consent of the patient for diagnosis, treatment, surgery and anesthesia" and the Instructions for its filing.

It can be assumed that such a terminological "substitution" of the doctor's obligation to ensure human rights for a person with TB, i.e. the right to consent to medical intervention (informed consent), with the obligation to perform organizational and methodological work does not meet the objectives of implementing a patient-centered approach and socially maladjusted populations, introducing short-term treatment regimens and new drugs under WHO recommendations, defined in the Concept of the National Targeted Program for

Combating Tuberculosis for 2018-202, approved by the Cabinet of Ministers of Ukraine on December 27, 2017, No. P. 1011 ¹¹⁶

Thus, informational consent for medical care is a free, informed decision of a person seeking medical care and/or his/her legal representatives regarding the choice and use of diagnostic, preventive and treatment methods, which is based on receiving information from a doctor in an accessible form about the health condition, the purpose of the proposed research and treatment measures, the prognosis of possible development of the disease, including the risk to life and health.

The decision to give consent to medical care must be free. It cannot be the result of external coercion (coercion by threats, psychological pressure from other people, official dependence) or active persuasion of anyone, including a doctor (psychological pressure from other people, pressure from medical staff who assure that there is a possibility to refuse to perform this medical intervention in the future).

The decision should only be the result of a personal choice based on full information about the situation (health condition). The doctor/healthcare professional is obliged to provide the patient with information in an accessible form about the patient's health condition, the purpose of the proposed research and treatment measures, the forecast of possible disease development, including the risk to life and health (part 3 of Article 39 of the Fundamentals).

If information about the patient's illness may worsen the patient's health or the health of his or her representatives, or harm the treatment process, healthcare professionals have the right to provide incomplete information about the patient's health status, and to restrict the possibility of their familiarization with certain medical documents (part 4 of Article 39 of the Fundamentals).

5.5. The problem of law enforcement (policy)

Focus group participants discussed the practice of informing people with TB before they sign a consent for medical intervention. In particular, opinions were expressed about the existence of passive and active informing. Passive informing occurs when a person is given a form or booklets from those available at the health care facility. However, there is no active information, in which the doctor explains in detail the possible forms of hospitalization, treatment options, etc.

No case law has been found in Ukraine in 2021-2023 on violations of the human rights of TB patients regarding consent to medical intervention (informed consent).

There is a decision of the European Court of Human Rights of April 13, 2023 in the case of Mayboroda v. Ukraine (application No. 14709/07) ¹¹⁷ on the removal of a patient's kidney without her consent. The European Court of Human Rights unanimously ruled that there had been a violation of Article 8 (right to respect for private and family life) of the European Convention on Human Rights in terms of the failure to ensure Ms. Mayboroda's right to informed consent.

5.6. Recommendations

1. Recommendations on legislation¹¹⁸ for the Ministry of Health:

¹¹⁶ <https://zakon.rada.gov.ua/laws/show/1011-2017-%D1%80#Text>

¹¹⁷ <https://www.hsa.org.ua/blog/nezabezpecennia-prava-pacijenta-na-informovanu-zgodu-suddia-jespl-vid-ukrayini-mikola-gnatovskii>

¹¹⁸ Analysis of health care regulations in accordance with the terms of the political declaration on universal health coverage. International Charitable Foundation "Alliance for Public Health". 2020. p. 52-53.

Ensure the revision of healthcare legislation to implement a patient-centered approach, in particular, to amend the laws of Ukraine "Fundamentals of the Legislation of Ukraine on Healthcare", "On Protection of the Population from Infectious Diseases", healthcare standards for tuberculosis, and specifications for the provision of medical services.

2. Policy recommendations for the Ministry of Health:

Develop and implement a detailed algorithm for informing people with TB to obtain consent for medical intervention.

6. THE RIGHT TO FREEDOM FROM ARBITRARY ARREST/DETENTION AND FORCED ISOLATION

6.1. The content of the right to freedom from arbitrary arrest/detention and involuntary isolation: People with TB have the right to be free from arbitrary detention, including involuntary detention or isolation of infected persons, except in extraordinary circumstances listed in the law and proportionate to what is strictly necessary, using the least restrictive and intrusive means available to achieve legitimate public health objectives (e.g., when a person is known to be contagious and likely to infect others but refuses treatment and all reasonable efforts to secure treatment have been made but have failed). People with TB should not be detained in custody or in non-medical settings for non-compliance with treatment.

A selective analysis of legislation and policies, as well as focus group assessments, revealed the following:

The right to freedom from arbitrary arrest/detention and forced isolation:

1. Availability: Laws - 4 Policies - 3
2. Implementation: Laws - 3 Policies - 4
3. Media coverage: Laws - 2 Policies - 2
4. Number of rights that are harmed by laws/policies - 0

In Ukraine, it is almost impossible to simply forcibly isolate a person, except for persons deprived of their freedom. That is, a person can only be taken to an emergency room, and the responsibility of the legal authorities ends there. And doctors cannot force it either. As for the equipped wards, these wards are equipped for those who are under arrest by court order (people with tuberculosis), and such wards are also equipped in multidisciplinary hospitals for all nosologies.

Also, you cannot force a person to come to the hospital, because nowadays Ukraine is fully covered by social support services, and psychologists are available.

If a person is not convicted, he or she belongs to the civilian service sector. And all the services guaranteed by medical guarantees are available to them. If a person is serving a sentence by a court decision, they are sent to a specialized institution, which is a medical facility for a particular nosology (here the question also arises whether TB will be diagnosed in time if a person is serving a sentence).

Prisoners with TB and HIV-associated TB are allowed to receive compulsory treatment only based on a court decision under the procedure described below, if people refuse treatment. This practice of punishing non-compliance with treatment does not promote treatment adherence in any way.

The legislation provides that an application for compulsory hospitalization or extension of the term of compulsory hospitalization of a patient with an infectious form of TB is submitted to the court by a representative of the TB facility that provides the relevant treatment to the patient, and not by the facility itself (as confirmed by a selective analysis of court practice for

the period from 01.01.2019 to 01.12.2023). The application is filed with the court at the location of the TB facility that provides medical (dispensary) supervision of the patient, or with the court at the place of detection of the patient (Article 343 of the Civil Procedure Code of Ukraine).

Deadline for filing an application: the application is filed within 24 hours from the moment the patient with a contagious form of tuberculosis violates the anti-epidemic regime (Article 344 of the Civil Procedure Code of Ukraine).

The issue of compulsory hospitalization of people with tuberculosis is also stipulated in the Law of Ukraine "On Overcoming Tuberculosis in Ukraine":

Article 12. Involuntary hospitalization of people suffering from tuberculosis with bacterial excretion (patients with contagious forms of tuberculosis) by court decision

1. If people suffering from tuberculosis with bacterial excretion, including during outpatient or inpatient treatment, violate the anti-epidemic regime, which puts other people at risk of tuberculosis infection, to prevent the spread of tuberculosis, they may be compulsorily hospitalized by court decision to regional phthisiopulmonological centers (anti-tuberculosis institutions) that have appropriate departments (wards) for the accommodation of such patients.

2. An application for compulsory hospitalization or extension of the term of compulsory hospitalization of a person suffering from tuberculosis with bacterial excretion shall be submitted to the court by a representative of the regional phthisiopulmonary center (anti-tuberculosis institution) that provides appropriate treatment to such a patient within 24 hours from the moment the patient's violation of the anti-epidemic regime is detected. The application shall be accompanied by a reasoned opinion of the physician who treats or is to treat such a patient on the need for compulsory hospitalization to a regional phthisiopulmonological center (anti-tuberculosis institution) or the extension of the term of compulsory hospitalization.

3. Compulsory hospitalization of persons in respect of whom a court has made a relevant decision shall be carried out taking into account the doctor's opinion for a period of up to three months.

4. The term of involuntary hospitalization of such persons shall be extended by a court decision for a period specified by the court, taking into account the opinion of the doctor treating such patient.

5. A decision on compulsory hospitalization to a regional phthisiopulmonological center (anti-tuberculosis institution) or extension of the term of compulsory hospitalization of people suffering from tuberculosis with bacterial excretion shall be made by a court at the place of detection of such patients or at the location of the regional phthisiopulmonological center (anti-tuberculosis institution) and is subject to immediate execution. Territorial police authorities, upon request of the head of the regional phthisiopulmonological center (anti-tuberculosis institution), shall provide assistance within their powers to ensure the enforcement of the court decision.

6. Compulsory hospitalization of people suffering from tuberculosis with bacterial excretion and suffering from mental disorders shall be carried out in accordance with the procedure established by this Law, taking into account the legislation on psychiatric care.

7. Failure to comply with a court decision on compulsory hospitalization to a regional phthisiopulmonological center (TB facility) or on extension of the term of compulsory hospitalization entails liability in accordance with the law.

Court practice: Decision of the Dobropole City District Court of Donetsk Region of 29.11.2023 in case No. 227/3359/23¹¹⁹, Decision of the Novomoskovsk City District Court of Dnipropetrovs'k Region of 12.04.2019 in case No. 183/2275/19¹²⁰.

¹¹⁹<https://reyestr.court.gov.ua/Review/115287597>

¹²⁰ <https://reyestr.court.gov.ua/Review/81823388>

There have been no changes in the procedure of involuntary hospitalization and implementation of other guarantees against the arbitrary restriction of freedom of people with TB¹²¹.

There is no information in open sources about systematic monitoring by the state of the ratio of cases of voluntary and compulsory isolation, the duration of isolation, and observance of the rights of people with TB when applying the court procedure for their compulsory hospitalization.

6.2. International standards that define the right to freedom from arbitrary arrest/detention and forced isolation

1. Universal Declaration of Human Rights (Article 3): Everyone has the right to liberty and security of person.

2. European Convention on Human Rights (Article 5): everyone has the right to liberty and security of person. No one shall be deprived of his liberty except in such cases and in accordance with the procedure established by law: b) lawful arrest or detention of a person for failure to comply with a lawful court order or to ensure the fulfillment of any obligation established by law; e) lawful detention of persons to prevent the spread of infectious diseases.

3. International Covenant on Civil and Political Rights (Article 9): Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his or her liberty except on the grounds and in accordance with the procedure established by law.

4. The right to physical integrity is not defined in the ICESCR and should be interpreted as part of the right to personal integrity, to freedom from torture and cruel, inhuman and degrading treatment, and to the right to the highest attainable standard of health.

5. Similarly, the right to physical integrity is not specifically recognized under the CEAFDAW, although it has a broader interpretation that includes the right to protection from violence against women¹²².

6. Provisions in two major international human rights treaties: The ICCPR (4) and the ICESCR (5) allow for limitations on individual rights in certain cases, provided that they are in accordance with the law necessary to achieve the aim.

7. The Siracusa Principles on the Interpretation of Limitations and Exceptions to the Provisions of the ICCPR (UN Document E/CN.4/1985/4, Annex (1985))¹²³:

These principles state that limitations on human rights must:

- be provided and enforced in accordance with the law;
- be aimed at achieving legitimate goals of public interest;
- be necessary in a democratic society to achieve the goal;
- be based on scientific evidence and not be considered arbitrary or discriminatory;
- not be limited in time, respect human dignity and be protected by applicable law.

Deviations from the rights defined in the ICCPR in the interests of "public health" are interpreted as follows: the desire to protect public health may serve as a basis for limiting certain rights if the state needs to take measures to eliminate a serious threat to the health of the population or individuals. These measures may be aimed directly at preventing disease, or

¹²¹ "Assessment of the legal environment for tuberculosis in Ukraine". p. 161. https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_governance/legal—environment—assessment—for—tuberculosis—in—Ukraine.html

¹²² Health care and human rights: a resource guide. Chapter 3. Tuberculosis and human rights. François-Xavier Banquo Center for Health and Human Rights and the Open Society Foundations.. 2015.

¹²³ <http://www.legislationline.org/ru/documents/action/popup/id/14624>

at providing care for the sick or injured, or threatening physical health. International health standards adopted by the WHO should be given due consideration.

8. Convention on the Rights of the Child (Article 19): States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical and psychological violence and abuse.

9. The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and Other Cruel, Inhuman or Degrading Treatment or Punishment (Article 16, part 1): Each State Party undertakes to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment not falling within the definition of torture laid down in Article 1, when such acts are committed by public officials or other persons¹²⁴.

6.3. Recommendations for sources of international standards

1. The WHO states that it is unethical to force TB patients to undergo treatment if they refuse it, and furthermore, it is unlikely to achieve any public health goal.

The WHO Guidelines for the Ethical Treatment, Prevention, Care and Control of Tuberculosis (WHO, 2010) state that:

- In general, tuberculosis treatment should be provided on a voluntary basis, with the patient's informed consent and willingness. Involving the patient in treatment decisions demonstrates respect for the patient, thus promoting autonomy and increasing the likelihood of adherence.

- Infectious TB patients who refuse treatment and/or infection control measures may be isolated to prevent the spread of the disease. While in isolation, if a patient expresses a reasonable refusal to receive treatment, their decision should be respected. Forcing people with TB to undergo treatment against their will only violate their right to physical integrity and may jeopardize the safety of health care workers. In addition, from a practical point of view, it is impossible to provide effective treatment without interaction with the person with TB¹²⁵.

Forced isolation and detention should be considered as a last resort. People with TB who do not adhere to treatment or are unable or unwilling to comply with infection control measures pose a significant risk to the public, and these risks can be eliminated by isolating the patient. People with TB who are isolated should be offered the opportunity to receive treatment, but if they do not accept it, their informed refusal should be accepted because the isolated patient does not pose a threat to public health. Forcing these people with TB to receive treatment despite their refusal would violate the right to physical integrity.

2. The Declaration of the Rights of People with TB¹²⁶:

Article 7. Right to liberty and physical integrity.

Everyone affected by tuberculosis has the right to freedom and security of person.

No person with tuberculosis shall be deprived of freedom except on the grounds and in accordance with the procedure established by law. Everyone affected by tuberculosis and deprived of their freedom has the right to humane treatment and respect for the inherent dignity of the human person.

3. The World Health Assembly has adopted the Global Strategy to End TB for the period

¹²⁴ https://zakon.rada.gov.ua/laws/show/995_085#Text

¹²⁵ Health care and human rights: a resource guide. Chapter 3. Tuberculosis and human rights. François-Xavier Banyu Center for Health and Human Rights and the Open Society Foundations. 2015. p. 28. http://medicallaw.org.ua/fileadmin/user_upload/PDF/%D1%80%D0%B5%D1%81

¹²⁶ <http://www.stoptb.org/assets/documents/communities/russian%20declaration%20of%20rights%20of%20people%20affected%20by%20TB.pdf>

2016-2035. The main objective of the Strategy is to free the world from tuberculosis with zero morbidity and mortality, and no family affected should have to bear the catastrophic costs of TB.

6.4. Legal and regulatory acts that have been studied

6.4.1. Ukrainian legislation on the right of freedom and personal integrity

1. The Constitution of Ukraine:

Article 29 stipulates that everyone has the right to freedom and personal integrity. No one may be arrested or detained except by a reasoned court decision and only on the grounds and in the manner prescribed by law.

2. Civil Code of Ukraine:

Article 270: an individual has the right to freedom and personal integrity.

6.4.2. Healthcare legislation

The healthcare legislation generally complies with international standards and recommended sources of international standards that define the right to freedom from arbitrary arrest/detention and forced isolation, which is not the case with the penal legislation.

1. The Law of Ukraine "Fundamentals of the Healthcare Legislation of Ukraine":

Article 9: restrictions on the rights of citizens related to their health status:

On the grounds and in the manner stipulated by the laws of Ukraine, citizens may be recognized as temporarily or permanently unfit for professional or other activities related to increased danger to others, as well as for the performance of certain state functions.

The use of compulsory treatment for persons who have committed criminal offenses and have a disease that poses a danger to the health of other persons, restriction of the rights of other citizens in the form of compulsory treatment, compulsory hospitalization or in connection with the establishment of quarantine are allowed only on the grounds and in the manner specified by law.

Decisions on restriction of the rights of citizens related to their health may be appealed in court;

Article 53: in order to protect the health of the population, healthcare bodies and institutions are obliged to implement special measures for the prevention and treatment of socially dangerous diseases (in particular, tuberculosis), as well as quarantine diseases.

The procedure for hospitalization and treatment of such patients, including compulsory hospitalization, shall be established by legislative acts of Ukraine;

Article 6: every citizen of Ukraine has the right to healthcare, which provides, in particular, for the possibility of conducting an independent medical examination of the relevant type in case of a citizen's disagreement with the conclusion of a state medical examination, the involuntary treatment, involuntary hospitalization and in other cases where the actions of healthcare workers violate the healthcare rights of a Ukrainian citizen.

Every person with TB has the right to the highest attainable standard of physical and mental health.¹²⁷

2. The Law of Ukraine "On Protection of the Population from Infectious Diseases":

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<http://www.stoptb.org/assets/documents/communities/russian%20declaration%20of%20rights%20of%20people%20affected%20by%20TB.pdf>

Article 38: officials of health care facilities regardless of ownership and health care workers in case of detection of a patient with an infectious disease are obliged to take measures for his/her temporary isolation, provide emergency medical care, if necessary, organize ongoing disinfection measures, urgently notify the relevant body of the state sanitary and epidemiological service and organize hospitalization of the patient to the relevant health care facility.

2. The Law of Ukraine "On Overcoming Tuberculosis in Ukraine":

This Law defines the legal, organizational and financial principles of activities aimed at overcoming tuberculosis, ensuring medical care for people with tuberculosis and equal access to it, and establishes the rights, duties and responsibilities of legal entities and individuals in the field of tuberculosis control, taking into account the provisions of the Global Strategy and Targets for Tuberculosis Prevention, Treatment and Control beyond 2015, approved by the 67th World Health Assembly in May 2014.

Article 1:

1) hospitalization - placement of a person with tuberculosis in an inpatient department of a regional phthisiopulmonological center for diagnosis, treatment or isolation;

2) diagnosis of latent tuberculosis infection - conducting diagnostic tests to identify people with latent tuberculosis infection by specially trained medical professionals in accordance with the procedure established by the central executive body that ensures the formation and implementation of state policy in the healthcare sector;

3) isolation - separation of a person suffering from tuberculosis with bacterial excretion from others to provide medical care, prevent transmission of infection to other persons and monitor compliance with the anti-epidemic regime;

4) infection control of tuberculosis - a system of organizational, anti-epidemic and preventive measures established by the central executive body that ensures the formation and implementation of state policy in the field of health care, in the standard of infection control of tuberculosis, aimed at preventing the occurrence of tuberculosis and reducing the probability of transmission of tuberculosis mycobacteria to healthy people, superinfection of people with tuberculosis in health care facilities, places of long-term stay and residence of people with tuberculosis;

Article 11. In case a person suffering from tuberculosis with bacterial excretion refuses from hospitalization, his/her treatment may be carried out on an outpatient basis, if it is possible to isolate such a person at home.

Article 12 defines the procedure for compulsory hospitalization of people suffering from tuberculosis with bacterial excretion (patients with infectious forms of tuberculosis) by a court decision: if people suffering from tuberculosis with bacterial excretion, during outpatient or inpatient treatment, violate the anti-epidemic regime, which puts other people at risk of contracting tuberculosis, to prevent the spread of tuberculosis, they may be involuntarily hospitalized by court order to regional phthisiopulmonary centers (anti-tuberculosis institutions) that have appropriate wards (rooms) to accommodate such patients.

An application for involuntary hospitalization or extension of the period of involuntary hospitalization of a person suffering from tuberculosis with bacterial excretion shall be submitted to the court by a representative of the regional phthisiopulmonary center (anti-tuberculosis institution) that provides appropriate treatment to such a patient within 24 hours from the moment the patient's violation of the anti-epidemic regime is detected. The application shall be accompanied by a reasoned opinion of the doctor who treats or is to treat such a patient regarding the necessity of compulsory hospitalization to a regional phthisiopulmonological center (TB facility) or extension of the term of compulsory hospitalization.

Compulsory hospitalization of persons in respect of whom the court has made a relevant

decision is carried out taking into account the doctor's opinion for a period of up to three months.

Extension of the term of involuntary hospitalization of such persons is carried out by a court decision for a period specified by the court, taking into account the medical report of the doctor treating such patient.

The decision on compulsory hospitalization to the regional phthisiopulmonological center (anti-tuberculosis institution) or on extension of the term of compulsory hospitalization of people suffering from tuberculosis with bacterial excretion is made by the court at the place of detection of such patients or at the location of the regional phthisiopulmonological center (anti-tuberculosis institution) and is subject to immediate execution. Territorial police authorities, upon request of the head of the regional phthisiopulmonological center (TB institution), shall provide assistance within their powers to ensure the enforcement of the court decision.

Involuntary hospitalization of people with bacterial tuberculosis who suffer from mental disorders shall be carried out in accordance with the procedure established by this Law, taking into account the legislation on psychiatric care.

Failure to comply with a court decision on compulsory hospitalization to a regional phthisiopulmonological center (anti-tuberculosis institution) or on the extension of the term of compulsory hospitalization entails liability in accordance with the law.

Article 19. Medical care for people with tuberculosis among persons taken into custody and sentenced to imprisonment, restriction of liberty or arrest.

The procedure for providing medical care to people with tuberculosis from among persons taken into custody or held in penitentiary institutions is established by the Cabinet of Ministers of Ukraine.

In case of release of a person with tuberculosis from a penitentiary ("detention center"), the penitentiary institution where such a person served his or her sentence informs him or her about the state of health and the need to continue treatment at the chosen place of residence or stay, and provides medical information about his or her disease to the relevant regional phthisiopulmonary center.

In case of release of a person suffering from tuberculosis with bacterial excretion, the relevant penitentiary institution warns him/her about the need to comply with the anti-epidemic regime, which is confirmed in writing, and transports such a person (with his/her consent) by the penitentiary institution's transport to the nearest regional phthisiopulmonary center for hospitalization and continuation of treatment. In case the person does not give his/her consent, the issue of his/her compulsory hospitalization is resolved in accordance with the procedure established by Article 12 of this Law.

4. The Order of the Ministry of Health of Ukraine No. 504 of March 19, 2018 approved the Procedure for providing primary health care¹²⁸. As stated in this Procedure, the main task of a primary healthcare provider is, in particular, to prevent the development of diseases, reduce the need for hospitalization, and improve the quality of life. The list of medical interventions within primary health care for groups at high risk of developing tuberculosis includes only contacts with patients with active tuberculosis; HIV; and staying in the institutions of the SCES of Ukraine.

5. The Criminal Executive Code of Ukraine:

Article 21: In relation to convicts who have a disease that poses a danger to the health of other persons and have not completed a full course of treatment, the penitentiary authorities and institutions shall provide treatment.

¹²⁸ <https://zakon.rada.gov.ua/laws/show/z0348-18#Text>

Persons with TB are held in separate premises from other prisoners. If during the serving of a sentence, it is established that a convicted person has contracted the diseases referred to in part one of this Article and refuses treatment, the penal body or institution shall submit to the court a request for the application of appropriate compulsory treatment to such a person;

Article 117: for persons sentenced to imprisonment who have a disease that poses a danger to the health of other persons and who have not completed the full course of treatment and refuse to undergo it, the colony administration shall apply compulsory medical measures or compulsory treatment imposed by a court.

6. 6. Procedure No. 205¹²⁹ regulates the conduct of mandatory preventive medical examinations to detect tuberculosis among persons taken into custody or held in penitentiary institutions. The procedure for conducting such medical examinations for foreigners and stateless persons staying in Ukraine is defined by the Procedure for Interaction between Healthcare Institutions, Territorial Bodies, and Institutions of the State Migration Service, the State Border Guard Service, and the State Employment Service¹³⁰, registered with the Ministry of Justice of Ukraine on February 19, 2015, under No. 194/26639.

6.5. The problem of law enforcement (policy)

Discussing the practice of isolation and compulsory treatment, focus group participants identified the following problems with the policies:

- an application for compulsory hospitalization or extension of the term of compulsory hospitalization of a patient with an infectious form of TB is submitted to the court by a representative of the TB facility that provides the relevant treatment to the patient, and not by the facility itself (which is confirmed by a selective analysis of court practice for the period 01.01.2020 to 01.06.2023)¹³¹. Although in some court decisions, the case is considered at the request of the health care facility;

- in court practice, while considering the application of a healthcare facility, the court does not investigate whether preliminary measures or conversations with a person were conducted before deciding to go to court to apply coercion;

- consideration of an application for compulsory hospitalization of a person with TB for inpatient treatment of a threatening form of tuberculosis for 3 months is carried out without the participation of the applicant and his/her representative (who, as stated in the court decision, did not appear at the court hearing, although he/she was duly notified of the time and place of the hearing); This is despite the fact that the rule on the immediate execution of a court decision on involuntary hospitalization in a TB facility or on extension of the term of involuntary hospitalization of patients with contagious forms of TB has not been changed¹³².

There is also no control over the implementation of a court decision on compulsory hospitalization by a person with TB.

There have been no changes in the procedure for applying compulsory hospitalization and implementation of other guarantees against the arbitrary restriction of liberty of people with TB¹³³.

There is no information in open sources about the systematic monitoring by the state of the ratio of voluntary and involuntary isolation, the duration of isolation, and the observance of the rights of people with TB when applying the court order for involuntary hospitalization

¹²⁹ <https://zakon.rada.gov.ua/laws/show/205-2014-%D0%BF#Text>

¹³⁰ <https://zakon.rada.gov.ua/laws/show/z0194-15#Text>

¹³¹ <https://reyestr.court.gov.ua>

¹³² The Law of Ukraine "On Combating Tuberculosis", p.11;

¹³³ "Assessment of the legal environment regarding tuberculosis in Ukraine".;

for people with TB.

Under the Order of the Ministry of Health of Ukraine No. 110 dated 14.02.2012, the primary accounting form No. 003-6/o "Informed voluntary consent of the patient for diagnosis, treatment, surgery and anesthesia" or the form "Informed voluntary consent of the patient for diagnosis, treatment according to the new clinical protocol" approved by the Order of the Ministry of Health of Ukraine "On creation and implementation of medical and technological documents for standardization of medical care in the system of the Ministry of Health of Ukraine" No. 751 dated 28.09.2012 is used. The latter applies if TB treatment is based on a new clinical protocol.

The decision of the Transcarpathian Court of Appeal of the panel of judges of the Judicial Chamber on Civil Cases (case No. 308/10493/14-a of 06.11.2018)¹³⁴ is notable. The case concerned the issue of compulsory hospitalization of a person to a medical institution without his or her consent and without the consent of any of his or her relatives on the grounds of suspected pulmonary tuberculosis.

The court's decision, among other regulatory documents, refers to Article 10 of the Law of Ukraine "On Combating Tuberculosis", which specifies the mandatory conditions for anti-tuberculosis treatment, including the provision of written informed consent of the patient or his legal representative or guardian for treatment. It appears that the case in question does not involve compliance with this requirement, as there is only a mention of informed consent to psychiatric care. There was also no court decision on compulsory hospitalization. In the absence of such informed consent and a decision on compulsory hospitalization, there can be no question of the legality of medical care in a tuberculosis healthcare facility.

6.6. The problem of legislation and the problem of law enforcement about specific groups: people with TB in places of detention

The rules on forced isolation by court order of people with TB and HIV-associated TB who have committed crimes remain unchanged. In particular, the possibility of alternative treatment is not checked, the person is not informed about the risks, significance, and reasons for isolation, social and psychological support is not provided, it is not taken into account whether the person refused to undergo treatment, and a clear period of isolation is not set.

It should be noted that there are insufficient procedural safeguards when applying compulsory isolation to people with TB as a measure that should be applied only in exceptional cases, given the awareness of the consequences and compliance with the principle of transparency.

To apply compulsory physical isolation, a conclusion of a healthcare facility must be issued.

6.7. Tuberculosis and Human Rights in the Case Law of the European Court of Human Rights

Regarding the rights of people with tuberculosis, the ECtHR notes the lack of proper conditions of detention and medical care for people with tuberculosis in penitentiary institutions. Therefore, when considering cases of violation of the rights of persons with TB, the ECtHR found violations of Articles 2, 3, 13 of the Convention for the Protection of Human Rights and Fundamental Freedoms (1950). Article 3 of the Convention, the violation of which was found by the ECtHR and which guarantees the prohibition of torture, inhuman or degrading treatment or punishment, is absolute and cannot be subject to any restrictions by the state.

Legal positions of the ECtHR in cases concerning persons suffering from tuberculosis:

¹³⁴ <https://reyestr.court.gov.ua/Review/77904482>

Melnyk v. Ukraine (Application no. 72286/01)¹³⁵, date of approval and entry into final status 28.03.2006. The Court concluded that there had been a violation of Article 13 of the Convention for the Protection of Human Rights and Fundamental Freedoms (1950) in respect of the lack of an effective and available remedy under domestic law for the applicant's complaints about his treatment and conditions of detention. The applicant was not provided with adequate or timely medical care, taking into account the seriousness of the disease and its consequences for his health. The court awarded the applicant EUR 10,000 in damages.

Yakovenko v. Ukraine (Application no. 15825/06)¹³⁶, date of approval and entry into final status 25.01.2008. The applicant was not provided with timely and proper medical care, which amounted to inhuman and degrading conduct within the meaning of Article 3 of the Convention. There was a violation of Article 3 of the Convention due to the failure of the authorities to provide timely and adequate medical care to the applicant as an HIV-positive person and a patient with tuberculosis. The court awarded the applicant EUR 10,000 in damages.

Pokhlebin v. Ukraine (Application no. 35581/06)¹³⁷, date of approval and entry into final status 20.08.2010. Violation of Article 3 of the Convention due to inadequate material and living conditions of the applicant's detention in a temporary detention center and inadequate treatment of the applicant during his detention. The court awarded the applicant EUR 7000 in compensation for moral damages.

Ivanov and Kashuba v. Ukraine (applications no. 12258/09 and 54754/10)¹³⁸, date of approval and entry into final status 29.01.2019. Violation of Art. 3 of the Convention for the Protection of Human Rights and Fundamental Freedoms (1950) regarding the lack of proper medical treatment during the applicants' detention. Violation of Art. 3 of the Convention for the Protection of Human Rights and Fundamental Freedoms (1950) regarding the use of handcuffs on the second applicant. Violation of Article 13 of the Convention for the Protection of Human Rights and Fundamental Freedoms (1950). The court awarded compensation: EUR 7,500 to the first applicant, EUR 9,800 to the second applicant's son, EUR 650 to the first applicant as reimbursement of court and other costs.

Petukhov v. Ukraine (no. 2) (Application no. 41216/13)¹³⁹, date of approval and entry into final status 09.09.2019. The applicant was sentenced to life imprisonment. Among other things, he complained about inadequate medical care in prison and suffered an irreversible deterioration in his health: a relapse of pulmonary TB. The court found a violation of Article 3 of the Convention due to the lack of adequate medical care available to the applicant during his detention and since the applicant's sentence of life imprisonment was such that it could not be reduced. The court awarded 20,770 euros in compensation.

6.8. Recommendations

1. Recommendations on legislation for the Ministry of Health and the Ministry of Justice:
 - Consider amending the current regulations to include data about cases of late detection

¹³⁵ https://zakon.rada.gov.ua/laws/show/974_049#Text

¹³⁶ https://zakon.rada.gov.ua/laws/show/974_049#Text

¹³⁷ https://zakon.rada.gov.ua/laws/show/974_438#Text

¹³⁸ https://zakon.rada.gov.ua/laws/show/974_834#Text

¹³⁹ https://zakon.rada.gov.ua/laws/show/974_d98#Text

of tuberculosis patients and cases of diagnosis of tuberculosis after death among citizens who have signed declarations while determining the amount of remuneration for doctors providing primary health care;

- take effective measures to improve the efficiency of treatment of drug-sensitive pulmonary tuberculosis, multidrug-resistant tuberculosis, and extensively drug-resistant tuberculosis;

- to develop specific measures to reform TB institutions, taking into account the specifics of the epidemic situation in administrative-territorial units and the financial base of institutions, the qualifications of medical staff, and ensuring access to medical care for the population;

- Ensure revision of the criminal executive legislation to ensure that prisoners with TB and HIV-associated TB are guaranteed their human rights with TB, namely

- a) the right to use alternative treatment¹⁴⁰;

- b) the establishment of a clearly defined period of isolation;

- c) the use of forced physical isolation solely based on a conclusion of a health care facility¹⁴¹.

2. Policy recommendations:

- For the CMU¹⁴²:

- to instruct the MOH to revise the state policy in the field of combating tuberculosis to ensure early detection of patients, including those from vulnerable groups, to increase the level of TB treatment efficiency;

- for the Ministry of Health:

- to ensure control over the submission of applications for compulsory hospitalization or extension of the term of compulsory hospitalization of a patient with a contagious form of tuberculosis to the court by a health care facility, and not by an individual doctor, and on behalf of this health care facility (and not a doctor);

- consider introducing control over the implementation of a court decision on compulsory hospitalization by a person living with TB;

- for the Ukrainian Parliament Commissioner for Human Rights:

- to conduct systematic monitoring of the ratio of voluntary and involuntary isolation, the duration of isolation, and the use of the procedure for involuntary hospitalization of people with TB by healthcare facilities.

- For the Supreme Court:

- to recommend summarizing the court practice on cases of involuntary hospitalization of patients with infectious forms of TB and provide the courts with relevant explanations.

7. THE RIGHT TO WORK IN A SAFE ENVIRONMENT

¹⁴⁰ It is advisable to take into account the recommendations of the Ukrainian Parliament Commissioner for Human Rights (Special Report of the Ukrainian Parliament Commissioner for Human Rights on the state of observance of the right to health care and medical assistance in pre-trial detention centers and penitentiary institutions of the State Criminal Executive Service of Ukraine). 2018. <http://www.ombudsman.gov.ua/ua/page/npm/provisions/reports/>;

¹⁴¹ It is also advisable to consider the recommendations of the researchers in the publication "Assessment of the Legal Environment for Tuberculosis in Ukraine". p. 161. https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_governance/legal-environment-assessment-for-tuberculosis-in-Ukraine.html

¹⁴² It is also advisable to consider the researchers' proposals to amend the legal acts to expand the range of cases when a person will be provided with medical care without his or her consent; "Analysis of health care regulations under the provisions of the political declaration on universal health coverage". ICF "Alliance for Public Health". 2020.

7.1. The meaning of the right to work in a safe environment: employees have the right to work in an environment that does not pose an excessive health hazard, and employers are responsible for implementing measures to reduce the work-related risk of contracting TB. Unfavorable living and working conditions increase the risk of TB infection. Risk factors include frequent exposure to people with active TB, including in crowded and poorly ventilated areas, workplaces, healthcare facilities, public transportation, and prisons. In fact, prisons are one of the most prominent examples of how substandard environments can increase vulnerability to TB.

A selective analysis of legislation and policies, as well as focus group assessments, revealed the following:

The right to work in safe conditions:

1. Availability: Laws - 4 Policies - 3
2. Implementation: Laws - 2 Policies - 3
3. Media coverage: Laws - 2 Policies - 2
4. Number of rights that are harmed by laws/policies – 0

7.2. Standards that define the right of people with TB to work in safe conditions

The meaning of the right of people with TB to work in a safe environment (conditionally) includes two components:

1) the right of people with TB to work without discrimination (unless there are medical reasons). It is about reducing the risk of impoverishment of people with TB, as TB adds to the permanent cycle of poverty. Treatment can make a person a debtor or force them to sell property assets, leading to "catastrophic expenditures" that make families poor. People with TB may lose income because they are sick or undergoing treatment. They may lose their jobs completely or not find work because of the stigma associated with the disease. Consequently, children whose caregivers lose income due to TB may not receive education, adequate nutrition, or access to social services¹⁴³.

The State Strategy for the Development of the TB Medical Care System for 2020-2023, approved by the CMU Resolution No. 1463-r of November 18, 2020, states that households may suffer from catastrophic TB-related costs, although in most cases TB medical care is free of charge for people with TB.

2) the right of people with TB who contracted TB while performing work related to the risk of TB to continue working without discrimination (unless medically indicated).

This includes people who work in prisons, hospitals, and other healthcare facilities and are at great risk of contracting TB. According to the WHO, healthcare workers have an ethical obligation to visit people with TB, even if this entails a risk of TB infection, and at the same time, they do not have the right to adequate protection against TB infection. Therefore, the government and the health care system have a responsibility to provide the necessary goods and services for a safe working environment. The WHO has established the Ethical Guidelines for the Prevention, Treatment, and Control of Tuberculosis, which provides in-depth information on the rights of healthcare workers and their obligations regarding the treatment of TB infection (CMU Order of November 18, 2020, No. 1463-p).¹⁴⁴

The right of people with TB to work in safe conditions is realized under the condition that

¹⁴³ Health care and human rights: a resource guide. François-Xavier Center for Health and Human Rights. 2015. Chapter 3. Tuberculosis and human rights.

¹⁴⁴ <https://zakon.rada.gov.ua/laws/show/1463-2020-%D1%80#Text>

other rights and freedoms of people with TB are ensured, in particular, the right to equality and freedom from discrimination (see Section 1), access to information (see Section 2), access to services (see Section 3), and confidentiality (see Section 4).

In addition to the international standards already mentioned in the study, the right to work in safe conditions is also defined in the content of the right to an adequate standard of living and the right to employment without discrimination (Universal Declaration of Human Rights, CRC, ICESCR). General Comment No. 14 (2000) of the Committee on Economic, Social and Cultural Rights on the Right to the Highest Attainable Standard of Health (Article 12 of the ICESCR) states that the right to health, as defined in Article 12, paragraph 1, includes safe working conditions.

7.3. Legal and regulatory acts that have been studied

Article 43 of the Constitution of Ukraine establishes the right of everyone to work, which includes the opportunity to earn a living by work that they freely choose or agree to. The state creates conditions for the citizens to fully realize the right to work, guarantees equal opportunities to choose a profession and type of work, and implements programs of vocational education, training, and retraining of personnel following social needs.

Everyone has the right to proper, safe, and healthy working conditions and to a salary not lower than the one established by law.

Legislation does not contain special norms on working conditions for people with TB. Moreover, the legislation is aimed at social isolation of people with TB, even those with non-contagious forms.

This is confirmed by the norms on long days of incapacity for work (Labor Code, Article 40), keeping the job (Law of Ukraine "On Protection of the Population from Infectious Diseases", Article 25).

1. Law of Ukraine "On Overcoming Tuberculosis in Ukraine" of 14.07.2023, No. 3269-IX:

Article 21: People with a diagnosis of tuberculosis who are insured persons under the compulsory state social insurance shall be issued a sick leave certificate for the period of treatment determined by the attending physician in accordance with the treatment period and the criteria for admission to work as defined by the industry standards for medical care approved by the central executive body that ensures the development and implementation of state policy in the healthcare sector, but not more than 10 months from the date of the start of the main course of treatment. For the entire period of disability, a person with tuberculosis shall keep his or her job, except in cases of complete disability.

The owner of an enterprise, institution, organization of all forms of ownership or an authorized body has no right to dismiss an employee due to his/her disease with tuberculosis unless tuberculosis is a contraindication to work in the profession specified in the List of professions, industries and organizations whose employees are subject to mandatory preventive medical examinations, and it is impossible to transfer him/her to another job with his/her consent. The list of such contraindications is established by the central executive body responsible for the development and implementation of state policy in the field of healthcare.

Local executive authorities, local self-government bodies, enterprises, institutions, and organizations regardless of their form of ownership, type of activity, and business, public and charitable organizations may assist people with tuberculosis or people with latent tuberculosis infection in providing treatment and providing food according to higher standards than those determined by law.

2. Law of Ukraine of 19.11.1992 " On the Fundamentals of Ukrainian Legislation on Health Care" (Articles 5, 6 (d), 77 (b)). Article 6 enshrines the right to health care, which includes, among other things, the right to safe and healthy working conditions. Article 77(b) states that "Medical workers shall have the right to proper conditions for their professional activity".

3. Law of Ukraine of 14.10.1992 "On Labor Protection", Article 1, Article 4. According to Art. 1 of the Law, the right to proper, safe, and healthy working conditions is realized through labor protection as a system of legal, socio-economic, organizational, technical, sanitary, hygienic, and medical preventive measures and means aimed at preserving human life, health and working capacity in the process of labor activity.

4. The right of healthcare workers and other employees whose working conditions have certain health risks, defined by labor legislation: The Labor Code (Articles 2, 153-155), the Criminal Code (Articles 172, 173), the Code of Administrative Offenses (Article 41), the Law of Ukraine "Fundamentals of the Legislation of Ukraine on Health Care" (Articles 5, 6, 77), the Law of Ukraine "On Labor Protection" (Articles 1, 4), the Law of Ukraine of 22.02.2000 "On Psychiatric Care", Article 29, para. 9 ("The owner of a psychiatric institution or its authorized body is obliged to ensure proper working conditions for specialists and other employees involved in providing psychiatric care, including caring for persons receiving psychiatric care"), the Law of Ukraine of 14. 07.2023 "On Overcoming Tuberculosis in Ukraine", Art. 23 ("Owners or their authorized managers of health care facilities that provide medical care to people with tuberculosis are obliged to provide employees of these facilities with the necessary means of protection and conduct mandatory preventive medical examinations of these employees for tuberculosis").

5. The Labor Code of Ukraine of 10.12.1971 [Articles 2 (part 2), 153-155] guarantees safe working conditions:

Article 2(2): "Workers have... the right to healthy and safe working conditions...";

Article 153: "Safe and harmless working conditions should be created at all enterprises, institutions, and organizations. Ensuring safe and harmless working conditions shall be the responsibility of the owner or his authorized body."

An employee also has the right to refuse to perform the assigned work if the production situation is dangerous to his or her life or health or to the people around him or her and the environment. The existence of such a situation is confirmed by the healthcare facility's health and safety specialists with the participation of a trade union representative and an authorized labor representative, while the employee retains his or her average salary for this period.

The employee has the right to terminate the employment agreement at his/her own request if the employer does not comply with the labor protection legislation or the terms of the collective agreement on these issues. In this case, the employee is paid severance pay in the amount stipulated by the collective agreement, but not less than three months' salary (Article 38(3) and Article 44 of the Labor Code of Ukraine).

The grounds for the company's liability to the employee, as well as the employee's right to terminate a fixed-term employment contract early or resign at his or her own request without giving two weeks' notice, are non-compliance with the requirements outlined in the labor protection legislation.

Such conditions include:

- a) working conditions at any given workplace;
- b) safety of technological processes, machines, mechanisms, equipment, and other

facilities;

- c) the condition of collective and individual protective equipment;
- d) sanitary and living conditions.

When compensating for damage caused to an employee due to a health injury, the amount of compensation includes

- payment of lost earnings (or the corresponding part of it) depending on the degree of loss of professional ability to work;
- payment of a one-time allowance to the victim (family members and dependents of the deceased) in specified cases;
- compensation for medical and social care expenses (enhanced nutrition, prosthetics, third-party care, etc.).

6. The requirements of labor and labor protection legislation are also outlined in the following laws:

- Criminal Code of Ukraine of April 05, 2001 [Article 172].
- Code of Ukraine on Administrative Offenses of 07.12.1984 [Article 41].

7. However, there are still legal grounds for not hiring people with TB and HIV-associated TB or suspending them from work (Labor Code, Article 40; Law on Ensuring Sanitary and Epidemic Welfare of the Population, Article 28; Law on Protection of the Population from Infectious Diseases, Article 23; List of Contraindications to Work in Occupations Specified in the List of Occupations, Production Facilities and Organizations Subject to Mandatory Preventive Medical Examinations, approved by the Order of the Cabinet of Ministers of Ukraine No. 23; List of contraindications for work in professions defined in the List of professions, industries and organizations whose employees are subject to mandatory preventive medical examinations, approved by the Order of the Ministry of Health of Ukraine of 23.07.2002, No. 280; List of particularly dangerous, dangerous infectious and parasitic human diseases and carriers of pathogens of these diseases, approved by the Order of the Ministry of Health of Ukraine of 19.07.1995, No. 133). Safe working conditions are guaranteed by the Labor Code (Articles 2, 153-155), but, given the general policy, do not take into account the creation of working conditions for people with TB.

This situation leads to self-stigma in the economic environment, when people with TB either do not disclose their diagnosis or quit their jobs. The "shadow" economy is also a threat when people without official employment are carriers of the disease, avoid medical examinations, and are not insured in the system of compulsory state social insurance.

8. Other regulatory legal acts in this area:

1). On Approval of the List of Industries, Workshops, Professions, and Positions with Hazardous Working Conditions, Employment in Which Entitles to a Reduced Working Week: Resolution of the Cabinet of Ministers of Ukraine of February 21, 2001, No. 163¹⁴⁵, section "Health Care, Education, and Social Assistance".

2). On Approval of Working Time Standards for Employees of Health Care Institutions and Facilities: Order of the Ministry of Health of Ukraine of 25.05.2006 No. 319¹⁴⁶.

3). Order of the Ministry of Health of Ukraine of February 1, 2019, No. 287 "On Approval of the Standard of Infection Control for Health Care Facilities Providing Care to Patients with Tuberculosis".

4). Concept of the National Program for Improvement of Safety, Occupational Health and

¹⁴⁵ <https://zakon.rada.gov.ua/laws/show/163-2001-%D0%BF#Text>

¹⁴⁶ <https://zakon.rada.gov.ua/laws/show/z0696-06#Text>

Production Environment for 2011-2016 (Order of the Cabinet of Ministers of Ukraine of 31.08.2011 No. 889-p). The purpose of the Program is to develop and ensure the implementation of the latest safe technologies and achievements of science and technology in the field of occupational health and safety, review and adaptation of legislation on occupational health and safety to EU legislation to reduce the level of occupational injuries and occupational morbidity, preserve the labor potential of Ukraine and create a legal basis for Ukraine's accession to the EU.

5). The Code of Ethics for Physicians of Ukraine, adopted and signed at the All-Ukrainian Congress of Medical Organizations and the X Congress of the All-Ukrainian Medical Society of 27.09.2009 (clauses 2.4, 4.): "Doctors - heads of health care institutions... are obliged to take care of... creating appropriate conditions for professional activity...".

Penal institutions and pre-trial detention centers are guided by the Regulation on the Procedure for Investigating and Keeping Records of Accidents and Incidents Occurred to Persons Detained in Penal Institutions and Pre-trial Detention Centers (hereinafter - the Regulation), approved by Order of the State Department of Corrections No. 44 of 11.03.2009, registered with the Ministry of Justice on April 3, 2009, under No. 305/16321¹⁴⁷.

Regarding the investigation and recording of incidents and accidents that occurred to members of the rank and file and senior staff of the State Penitentiary Service of Ukraine during the period of service in the performance of their duties, the investigation of accidents that occurred to these employees, who, according to labor legislation, work under employment contracts, is guided by the Procedure for Investigation and Recording of Accidents and Incidents that Occurred in the Bodies and Institutions of the State Penitentiary Service, Order of the Ministry of Justice of Ukraine No. 1166/5 of August 06, 2012¹⁴⁸.

7.4. The problem of law enforcement (policy)

Focus group participants stated that the legislation does not provide employment opportunities for people living with TB at all. Only a few positive examples of employers providing employment opportunities for people with TB under internal regulations were mentioned.

The analysis of the current legislation of Ukraine confirms the lack of adequate legislative guarantees for job retention of people with TB and HIV-associated TB during treatment due to the inconsistency of the norms with the principle of legal certainty. In particular, due to inconsistencies in legislation, courts may limit the guarantee of job retention for the entire period of treatment of a TB patient to only contagious forms of TB or for up to 10 months, etc. The existing guarantees of job retention for the entire period of treatment are often not fulfilled by employers in practice.

Focus group participants in the research noted another very important problem: there is not a single TB facility in Ukraine that meets the requirements of infection control, this issue is more about administrative control and should be addressed at the top governmental levels, as it involves the rebuilding and repair of TB facilities. The need to improve living conditions and food in inpatient TB facilities, including access to basic amenities (hot water, proper toilets), was often emphasized.

Focus group participants emphasized the lack of legislation that ensures the right of people with TB to work. In practice, due to the stigmatization of people with TB, employers simply dismiss them in different ways.

¹⁴⁷ <https://ips.ligazakon.net/document/RE16321>

¹⁴⁸ <https://zakon.rada.gov.ua/laws/show/z1345-12#Text>

Another problem was also voiced - violation of the rights of healthcare workers who, after contracting a work-related disease, then apply to the court for protection of their violated rights.

7.5. Recommendations

1. Recommendations on legislation for the Ministry of Health, Ministry of Economy:

- To review healthcare and labor legislation from a human rights-based approach to establish and ensure the human rights of people with TB to work in safe conditions, in particular, to provide for

a) the right of people with TB with non-contagious forms to continue working and to have proper working conditions;

b) to eliminate discrepancies in the Law of Ukraine "On Protection of the Population from Infectious Diseases" and the Law of Ukraine "On Overcoming Tuberculosis in Ukraine" to ensure that people with TB and HIV-associated TB, regardless of its form, can keep their jobs while undergoing a full course of treatment in both inpatient and outpatient facilities, as well as for concomitant diseases caused by TB in inpatient facilities;

- Establish an explicit ban on unjustified refusal to hire people with TB and HIV-associated TB based on their health status and ensure proper control over employers' compliance with these norms;

- Eliminate the possibility of dismissing people with TB and HIV-associated TB for health reasons, as well as recognizing them as permanently unfit for professional or other activities related to increased danger to others, as well as for the performance of certain public functions;

- Introduce access to palliative and hospice care for people living with HIV or TB (including children).

2. Policy recommendations for the Ministry of Economy:

- Advocate for the resolution of issues related to the prevention and protection of the rights of people with TB and HIV-associated TB at the level of collective agreements;

- Organize information campaigns among employers with the involvement of trade unions and employers' associations on job retention guarantees for people with TB.

8. SPECIFIC FEATURES OF RIGHTS REALIZATION DURING MARTIAL LAW. THE RIGHT TO ACCESS PUBLIC INFORMATION UNDER MARTIAL LAW

8.1. Tuberculosis during the war and its prevention

Despite the full-scale invasion, Ukraine continues to implement international standards for the diagnosis and treatment of tuberculosis, and innovative methods of diagnosis and treatment of tuberculosis are available.

Currently, one of the significant achievements is the new standard for TB control - the Order of the Ministry of Health No. 102 of January 19, 2023¹⁴⁹, which abolished sputum microscopy as an insufficiently effective method, and switched to TB diagnosis using molecular genetic systems. Currently, there are more than 327 of them in Ukraine: any patient can find a facility with such a system nearby and get diagnosed for free. The detection of

¹⁴⁹ https://www.dec.gov.ua/wp-content/uploads/2023/01/43242-dn_102_19012023.pdf

tuberculosis among children has improved, and biomaterial is now being tested using GeneXpert systems, a non-invasive, fast, and painless method.

Since the beginning of 2023, the National Health Service of Ukraine has paid almost UAH 56 million to provide inpatient care for people with tuberculosis¹⁵⁰. For two years now, Ukraine has been offering a package of outpatient TB treatment at the primary care level. This means that when a patient has already undergone inpatient treatment and stops excreting bacteria, he or she can apply to the family doctor to continue their treatment receive medications, and monitor the treatment process. According to the National Health Service of Ukraine, 511 institutions currently have a contract for this service. The total amount of contracts is almost UAH 6 million. The facilities are operating evenly throughout Ukraine, even in the areas with intense fighting.

However, due to the war and survival priorities, about 20% of the population does not seek treatment for possible TB symptoms from family doctors. According to the Center for Public Health, in Ukraine in 2022, the number of newly registered cases of tuberculosis was 18,510, or 45.1 per 100,000 people, which is 2.5% more than in 2021.

Information work remains the most important tool for counteracting the spread of tuberculosis in wartime against the backdrop of coronavirus infection. After all, the majority of the Ukrainian population is still unaware of the risks of infection. In the regions with active hostilities, people suffer from food shortages, chronic stress, and lack of access to basic medical services. During the fighting, residents are forced to stay in shelters, often overcrowded. Leaving the combat areas, in particular at the beginning of the invasion, was accompanied by people remaining at train stations, buses, trains, and temporary shelters, which were also overcrowded and poorly ventilated. A significant number of people with TB were unable to continue their treatment due to problems with attending a healthcare facility, changing their place of residence, or restrictions in the work of the anti-TB service. Interrupting treatment for these people with TB led to disease progression and renewed contagiousness. Unfortunately, all these conditions, in which our citizens were living, led to increased rates of tuberculosis.

The Center for Public Health believes that the actual prevalence of tuberculosis in Ukraine already exceeds 0.5% of the population¹⁵¹ and, according to epidemiological surveillance data after World Wars I and II, will increase in the coming years. That is why, due to this possible development, it is proposed to introduce systematic screening of the general population for tuberculosis in Ukraine within two years, namely:

- conduct X-ray screening of all persons over 15 years old at least once a year;
- conduct screening for symptoms that may indicate tuberculosis among children and adults who seek medical care at all levels of healthcare facilities, regardless of the reason for their treatment, according to the screening questionnaire approved by the industry standards for healthcare related to tuberculosis;
- organize mandatory TB screening in healthcare facilities for IDPs who are registered or receiving assistance in social protection institutions;
- introduce self-screening using an anonymous online questionnaire and spread information about this questionnaire in social networks.

¹⁵⁰ According to the press conference "Tuberculosis in the context of war: risks of spread, successes and prospects" / <https://phc.org.ua/news/preskonferenciya-do-vsesvitnogo-dnya-borotbi-z-tuberkulozom-osnovni-tezi>.

¹⁵¹ Recommendations of the Center for Public Health of the Ministry of Health of Ukraine on the implementation of measures for the prevention, detection, and management of tuberculosis cases under martial law to overcome the consequences of the military aggression of the Russian Federation in Ukraine.

Systematic screening for tuberculosis and fluoroscopic examination is recommended primarily for representatives of key populations (people who have had long-term household contact with a person with TB; people living with HIV, diabetes mellitus; smokers; people with chronic respiratory diseases; internally displaced persons; people with immunodeficiency diseases; people who use psychoactive substances; people aged 60+ years, etc.).

A selective analysis of legislation and policies, as well as focus group assessments, revealed the following:

Specifics of the realization of rights during martial law. The right to access public information under martial law:

1. Availability: Laws - 3 Policies - 4
2. Implementation: Laws - 4 Policies - 4
3. Media coverage: Laws - 2 Policies - 3
4. Number of rights that are harmed by laws/policies – 0

8.2. Rights of people with TB during martial law ¹⁵²

The Ministry of Healthcare of Ukraine (MoH) has taken the necessary measures to facilitate access to medical care for all those in need throughout Ukraine, where medical facilities and doctors can operate, regardless of the place of registration and the available declaration of medical services.

Under the orders of the Ministry of Health and the Government of Ukraine, the following opportunities are provided for the unchecked exercise of the citizens' right to medical care during the martial law period:

1. Medical institutions will provide emergency medical care around the clock to anyone who needs it, regardless of the presence or absence of a declaration signed by citizens, the presence or absence of documents to prove their identity, regardless of the place of registration or residence of the person who sought medical care or was taken to the nearest medical institution.

2. If a physician does not have the technical ability to issue an electronic prescription for medicinal products of the "Available Medicines" category, he or she may issue a paper prescription. Medicines are dispensed according to the type of prescription submitted. If a patient presents a paper prescription, the pharmacy shall record it in paper form.

Primary healthcare doctors issue prescriptions for medicines regardless of whether a person with TB has a declaration. Prescriptions for "affordable medicines" are no exception.

3. If the doctor or the area does not have the technical capability to issue electronic prescriptions to the patient, they are issued in paper form and have the same validity as electronic prescriptions.

8.3. The work of the MSEC under martial law

The disability status of a person with tuberculosis may be granted to a patient if the treatment lasted more than 10 months from the date of disability. The decision to grant disability status is made exclusively by a medical and social expert commission after a full medical examination, conducting the necessary research, assessing the person's social needs, etc. in accordance with the Regulation on the Procedure, Conditions, and Criteria for Granting

¹⁵² <https://jurfem.com.ua/pravo-na-medychnu-dopomogu-voennyi-stan>

Disability Status, approved by the Cabinet of Ministers of Ukraine on December 3, 2009, No. 1317¹⁵³.

In accordance with the Resolution of the Cabinet of Ministers of Ukraine No. 225 of March 8, 2022 "Some Issues of the Procedure for Conducting Medical and Social Expertise for the Period of Martial Law in Ukraine"¹⁵⁴, the procedure for establishing and prolonging disability status for the period of martial law has been significantly simplified:

1) if a person applying to establish disability status is unable to come to the MSEC for examination, such a commission may decide on disability status in absentia based on a referral from the MAC;

2) MSEC exercises its functions on the principle of extraterritoriality and ensures medical and social examination upon referral of the MAC, regardless of the place of registration, residence, or stay of the person applying for establishing disability status.

Specifics of the MSEC procedure under martial law, particularly for internally displaced persons

- a doctor who issues a referral to the MSEC cannot require an IDP patient to sign a declaration;

- doctors do not have the right to require people with TB to come for a second examination during martial law to confirm the persistent impairment of body functions caused by the disease, which causes restrictions on a person's life;

- medical and social examination upon the referral of the MAC is carried out regardless of the place of registration, residence, or stay of the person applying for disability determination;

- during martial law, the requirements for examination of applicants residing in remote areas (at home) and for elderly applicants and persons with disabilities undergoing inpatient treatment do not apply.

If a person suffering from tuberculosis is assigned a disability group, he or she may be eligible for one of two types of state benefits

1) based on the Law of Ukraine "On Compulsory State Pension Insurance" of July 09, 2003, No. 1058-IV, disability pensions are paid. If a person has the required work experience provided for by law, he or she may apply to the territorial office of the Pension Fund of Ukraine for a disability pension. This pension is higher than social assistance;

2) based on the Law of Ukraine "On State Social Assistance to Persons Not entitled to Pensions and Persons with Disabilities" dated May 18, 2004 No. 1727-IV, if a person does not have the required work record and income exceeding the subsistence minimum, state social assistance may be granted to a person with disabilities upon his/her application to the territorial Department of Social Protection of the Population or other authorized body.

Each case of disability payments is considered individually.

For the period of martial law, persons with disabilities do not need to undergo re-examination to confirm their disability to receive social benefits, as according to the Resolution of the Cabinet of Ministers of Ukraine No. 390 dated 30 March 2022¹⁵⁵, the period of disability and individual rehabilitation program (IRP) is extended for the period of martial law. The period of re-examination that occurred during the period of martial law in Ukraine is postponed for a period not later than six months after its termination/cancellation. At the same time, the disability status and the degree of loss of professional ability to work (in percent) shall be extended until the last day of the sixth month after the termination or cancellation of the martial law period, unless a re-examination is conducted earlier.

¹⁵³ <https://zakon.rada.gov.ua/laws/show/1317-2009-%D0%BF#Text>

¹⁵⁴ <https://zakon.rada.gov.ua/laws/show/225-2022-%D0%BF#Text>

¹⁵⁵ <https://zakon.rada.gov.ua/laws/show/390-2022-%D0%BF#Text>

The only temporary restriction on the exercise of the right to medical care is due to the need to ensure that all medical institutions and their specialists are able to promptly save the lives of victims and wounded from the aggressor's illegal actions, is the temporary suspension of planned hospitalization and operations until a separate order of the Government and the Ministry of Health.

8.4. Specifics of realization of the right to access to public information under martial law¹⁵⁶

Information work remains the most important tool for counteracting the spread of tuberculosis in wartime against the backdrop of coronavirus infection. The majority of the Ukrainian population is still unaware of the risks of infection.

In the regions affected by military hostilities, people suffer from food shortages, chronic stress, and lack of access to basic medical services. During the fighting, residents are forced to stay in shelters, often overcrowded. When leaving the combat areas, particularly at the beginning of the invasion, people stayed at train stations, buses, trains, and temporary shelters, which were also overcrowded and poorly ventilated. A significant number of people with TB were unable to continue their treatment due to difficulties in visiting a healthcare facility, changing their place of residence, or restrictions on the work of the anti-TB services. Interruption of treatment for these people with TB led to the progression of the disease and renewed contagiousness. Unfortunately, all these conditions, in which our citizens were living, led to an increase in tuberculosis rates.

Under martial law, access to public information is an extremely important legal tool that can save lives and preserve human health. Informing citizens in advance about the threat of attack or occupation can facilitate the timely evacuation of the population, prevent humanitarian disasters, and save them from the crimes of the Russian military.

Under martial law, many public services have suspended their work or operate with restrictions due to both the threat to national security and the lack of a realistic possibility of proper functioning.

At the same time, under martial law, it is important to have high-quality and prompt access to public information to ensure the proper functioning of the legal system.

The right of access to public information is guaranteed by Articles 34 and 50 of the Constitution of Ukraine, the Council of Europe Convention on Access to Official Documents, the Law of Ukraine "On Access to Public Information" and other laws.

According to part two of Article 34 of the Constitution of Ukraine, everyone has the right to collect, store, use, and spread information freely orally, in writing, or in any other way of their choice. At the same time, under the terms of part three of Article 34 of the Constitution of Ukraine, the exercise of the rights to free collection, storage, use, and dissemination of information may be restricted by law in the interests of national security, territorial integrity or public order to prevent riots or crimes, to protect public health, to protect the reputation or rights of others, to prevent the disclosure of information confidentially received, or to maintain the authority and impartiality of justice.

In the conditions of total disinformation warfare by the special services, as well as aggressive and inhumanly cruel actions of the military forces of the Russian Federation on the territory of Ukraine, it is vital to maintain a balance between the ability to freely express one's views and receive reliable information about the course of the war, on the one hand, and the

¹⁵⁶ The explanations were prepared with the assistance of an expert on access to information O. Kabanov (Center for Access to Information).

protection of life and health of people who may suffer from the implementation of such a right, on the other.

According to paragraph 3 of the Decree of the President of Ukraine "On the Introduction of Martial Law in Ukraine" No. 64/2022¹⁵⁷ (approved by the Law of Ukraine "On Approval of the Decree of the President of Ukraine "On the Introduction of Martial Law in Ukraine" No. 2102-IX of 24.02. 2022), in connection with the introduction of martial law in Ukraine, the constitutional rights and freedoms of man and citizen provided for in Articles 30-34, 38, 39, 41-44, 53 of the Constitution of Ukraine may be temporarily restricted for the period of martial law, as well as temporary restrictions on the rights and legitimate interests of legal entities may be introduced within the limits and to the extent necessary to ensure the possibility of introducing and implementing measures of the martial law regime provided for in part one of Article 8 of the Law of Ukraine "On the Legal Regime of Martial Law".

The constitutional restriction of the right of a person to collect, store, use, and spread information complies with the provisions of Article 29(2) of the Universal Declaration of Human Rights of 1948, which states that everyone is subject only to such limitations in the exercising of his or her rights and freedoms as are determined by law exclusively to secure proper recognition and respect for the rights and freedoms of others and ensure the fair requirements of morality, public order and the general welfare in a democratic society (Decision of the Constitutional Court of Ukraine of January 20, 2012, No. 2-пп/2012). Taking into account the full-scale invasion of the territory of Ukraine by the Russian Federation, the main grounds for limiting this right should be considered "protection of national security interests and territorial integrity or public order to prevent riots or crimes".

The Law of Ukraine "On Access to Public Information" defines the main ways of exercising the right to access public information as follows:

- familiarization with information published by its managers in official sources;
- attendance of meetings of a collegial body;
- familiarization with documents in a place provided by the information manager;
- sending a request and, accordingly, receiving a response to it;
- familiarization with information in the information services based on open data.

At the same time, under martial law, the exercise of these opportunities by citizens may be complicated because of

- introduction of control over the content and spreading of information;
- temporary suspension of the work of state registers and databases;
- introduction of a special mode of operation and increased security of objects of national importance;
- introduction of a curfew;
- postponement of processing information requests, etc.

Also, under martial law, the state may introduce the following information security measures

- introduction of control over the content and spreading of information to limit or prevent false information or information the disclosure of which may harm human life and health, national security of the state
- restriction of access to enemy information and propaganda resources on the territory of Ukraine by Internet providers;
- regulation of the work of electronic communication networks and/or services providers, printing companies, publishing houses, broadcasting organizations, television and radio centers, and other enterprises, institutions, organizations, and cultural and mass media

¹⁵⁷ <https://zakon.rada.gov.ua/laws/show/2102-20#Text>

institutions, as well as the use of local radio stations, television centers, and printing houses for military purposes and carrying out explanatory work among the troops and the population;

- prohibition of the operation of receiving and transmitting radio stations for personal and collective use and the transmission of information through computer networks.

This list of restrictions is not complete and may be supplemented by separate laws of Ukraine.

These and other restrictions may significantly impede and affect the ability of citizens to exercise their right to access public information.

There are certain restrictions related to the fact that medical institutions focus the efforts of their specialists on ensuring quick response to save the lives of victims and wounded from the illegal actions of the aggressor. However, all TB facilities provided care to TB patients and worked directly for their intended purpose, except for situations related to security and the fact that many doctors left immediately after the invasion, and laboratories did not work.

But even during martial law, people with TB can receive treatment in any part of the country to which they have evacuated from dangerous regions, and if a person suspects that they have TB symptoms, they can get a consultation at the nearest TB facility.

Particular attention should be paid to the draft Law of Ukraine No. 5488 "On Amendments to the Code of Ukraine on Administrative Offenses and the Criminal Code of Ukraine on Combating Discrimination"¹⁵⁸, submitted on May 13, 2021, by the Cabinet of Ministers of Ukraine to the Verkhovna Rada of Ukraine, which stands out among other legislative initiatives in recent years for its comprehensive approach and focus on systematically addressing several legislative gaps.

Draft Law No. 5488 is a powerful response to several contemporary challenges, such as crimes motivated by intolerance; unacceptable infringement of the rights of our fellow citizens based on various grounds; insufficient powers of the authorities to respond to discrimination and violence; intentional spread of particularly dangerous infectious diseases and hate speech.

Draft law No. 5488 is currently still pending consideration. This document is a follow-up to many years of constructive cooperation between the government and civil society to improve the social climate in Ukraine and introduce liability for violations of human rights and infectious disease legislation.

Draft Law No. 5488 is aimed at implementing several fundamental national and international documents, including the National Human Rights Strategy, the Association Agreement between Ukraine and the European Union, the European Atomic Energy Community and their Member States, and the Strategy for a Comprehensive Response to Human Rights Barriers to Access to HIV and Tuberculosis Prevention and Treatment Services by 2030. Despite the goal of the Strategy, due to the existing barriers, Ukraine remains a country with a high prevalence of human immunodeficiency virus (HIV) infection and high rates of late treatment seeking by HIV-positive people in healthcare facilities and one of the five countries with the highest incidence of multidrug-resistant tuberculosis in Eastern Europe and Central Asia. Despite considerable experience in implementing the best international approaches and services in response to the TB and HIV/AIDS epidemics, the analysis of the situation shows that there are shortcomings in this area.

The main reasons for the tense TB situation in Ukraine are low TB detection rates and inadequate TB treatment for people with multidrug-resistant TB. Particularly threatening is the untimely seeking of medical care by patients, late detection of the disease, and patients with co-infection (TB/HIV), which leads to high mortality rates from TB and is the result of the lack of an integrated approach to combining prevention and treatment programs into a single

¹⁵⁸ https://w1.c1.rada.gov.ua/pls/zweb2/webproc4_1?pf3511=71891

effective system of combating epidemics. As part of the efforts of technical partners and donors to assess the existing structural barriers to overcoming the HIV and TB epidemics in Ukraine, several assessments of existing legal and human rights barriers to access to HIV and TB prevention, treatment and social support services in Ukraine were conducted. In addition, the draft law No. 5488 is aligned with the goals of the Global Partnership to End All Forms of HIV Stigma and Discrimination, which Ukraine officially expressed its intention to join in 2020.

This draft law contains many areas for improvement, for developing more accurate wording to achieve greater legal certainty, to prevent possible abuses in the balance between freedom of speech and belief and responsibility for inappropriate public statements. This legislative initiative is equally aimed at protecting the rights, freedoms, and safety of the majority of our fellow citizens and at ensuring the observance of the legitimate rights and interests of certain social groups that are still persecuted in Ukraine, including people living with HIV, various religious communities, people with disabilities, LGBT communities, other groups and communities distinguished by race, color, political beliefs, gender, age, ethnic and social origin, citizenship, marital and property status, language and place of residence, etc.