100%LIFE

TB STIGMA ASSESSMENT IN UKRAINE

PUBLIC
HEALTH
CENTER

TB PEOPLE
UKRAINE

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EUROPEAN INSTITUTE
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POLICY

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The assessment is the joint initiative of the CO 100% LIFE, the research organization European Institute of Public Health Policy LLC implemented within the strategic partnership with the state institution Public Health Centre of the Ministry of Health of Ukraine and CO TB people Ukraine. The assessment was carried out under the financial support of the Global Fund to Fight AIDS, Tuberculosis and Malaria grant to Ukraine.

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Abbreviations

ACSM	– Advocacy, Communication and Socail Mobilization
ART	– Antiretroviral therapy
CG	– Core Group
CO	– Charity Organization
DOT	– Directly observed therapy for treating tuberculosis monitored by a trained medical care provider
Global Fund, GF	– Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV	– Human immunodeficiency viruses
MDR-TB	– Multidrug-resistant tuberculosis
MoH	– Ministry of Health
NGO	– Non-governmental organisation
TB	– Tuberculosis
PC	– Primary care
PHC	– Public Health Center of the MoH of Ukraine
PLHA	– People living with HIV/AIDS
PWTB	– People with TB
UN	– United Nations
WHO	– World Health Organization
XDR-TB	– Extensively drug-resistant tuberculosis

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Introduction

Ukraine is one of the thirty countries in the world with some of the highest prevalence of multidrug-resistant tuberculosis (MDR TB)[1]. The burden of TB epidemic is made worse by the HIV epidemic: one in four patients with TB is living with HIV (PLHA).[2] In 2019 Ukraine's TB morbidity has registered at 60.1 per 100,000[3], with estimated MDR TB morbidity at 29 per 100,000.[4] Both figures are significantly higher compared to the average statistics registered in the European region.[5] The successful treatment rate is lower compared to the WHO global targets (90%) and the statistics available from the European region (85%).[6] According to the 2018 patient cohort studies 77% of patients were successfully treated among the new TB cases and cases of relapsed TB.[7] However, only half of patients with MDR TB and one third of patients diagnosed with extensively drug resistant TB (XDR TB) in the 2017 cohort completed treatment and/or were successfully treated.[8] Ukraine has limited resources to respond to the epidemic, the World Health Organisation (WHO) estimates that in Ukraine the gap between the financing available under the national strategic plan and what is required for impact in relation to TB prevention, testing, and treatment is 73 million USD.[9]

In order to reach the targets set under the State Strategy for Strengthening the National TB Care Provision[10] it is important to eliminate the barriers which prevent the TB patients from accessing medical care services at every level: from screening for TB to provision of care and support. In this respect overcoming stigma and discrimination is vital and without it patient-centred services cannot function successfully[11]. In the process of medical care delivery stigmatisation is of the most significant social factors which hinders equal access to the health care services. There is a global call to fight TB associated stigma. The first-ever UN General Assembly high-level meeting on tuberculosis in 2018 endorsed a political declaration to accelerate progress towards End TB targets in 2022, this includes eliminating stigma and all types of discrimination associated with tuberculosis.[12]

Stigmatisation is a complex process which is shaped by institutional and community norms, interpersonal factors and attitudes. In a wider sense TB associated stigma is a process which begins when a particular trait or characteristic of an individual or a group is identified as undesirable or disvalued, as a result the stigmatised individual adopts a set of self-regarding attitudes which include shame, disgust and guilt which produces a set of behaviours that include hiding the stigmatised trait, withdrawing from inter-personal relations or increasing risky behaviour.[13] Stigmatisation differs from discrimination in a sense that the latter is characterised by socially excluding the person and violating the person's rights as a result of stigma. The stigma associated with tuberculosis has a negative effect not only on the patient but the patient's family, is a source of shame, fear and isolation, which hinders the

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[1] World Health Organization (WHO) (2020) Global tuberculosis report 2020. Geneva.

[2] Centre for Public Health (2020) Tuberculosis in Ukraine. Analytical and statistical reference book for 2019. Kyiv.

[3] https://phc.org.ua/kontrol–zakhvoryuvan/tuberkuloz/statistika–z–tb/analitichno–statistichni–materiali–z–tb

[4] Tuberculosis profile: Ukraine. https://worldhealthorg.shinyapps.io/tb_profiles/?_inputs_&entity_type=%22country%22&lan=%22EN%22&iso2=%22UA%22.

[5] Centre for Public Health (2020) Tuberculosis in Ukraine. Analytical and statistical reference book for 2019. Kyiv.

[6] Ibid.

[7] Ibid.

[8] Ibid.

[9] World Health Organization (WHO) (2020) Global tuberculosis report 2020. Geneva.

[10] https://zakon.rada.gov.ua/laws/show/1414–2019–%D1%80#Text

[11] Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. Am J Public Health. 2013;103(5):813 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3682466/

[12] Resolution A/RES/73/3 adopted by the United Nations General Assembly on 10 October 2018 following approval by the high–level meeting of the General Assembly on the fight against tuberculosis on 26 September 2018. https://www.who.int/publications/m/item/political–declaration–of–the–un–general–assembly–high–level–meeting–on–the–fight–against–tuberculosis

[13] Courtwright, A., & Turner, A. N. (2010). Tuberculosis and stigmatization: pathways and interventions. Public health reports (Washington, D.C. : 1974), 125 Suppl 4(Suppl 4), 34–42. https://doi.org/10.1177/00333549101250S407

treatment.[14-15] Stigmatisation goes beyond individual barriers to medical care and often extends to the structural components which requires both personal interventions involving the patients together with the medical care providers and interventions at the level of medical care facility and the society at large.

Despite the concerted large scale effort applied by the government agencies, NGOs and international organisations and significant progress in strengthening TB testing, prevention and treatment, still there are strategic gaps in raising awareness about TB-associated stigma. Prevalence of stigma and discrimination, types thereof and impact on accessing medical care have not been studied in full in Eastern Europe and Asia, which includes Ukraine. This report is the result of assessment conducted using the methodology developed by The Stop TB Partnership[16]. The study was commissioned by the CO 100% LIFE and carried out by the European Institute of Public Health Policy, LLC in cooperation with the Public Health Centre of the MoH of Ukraine and the CO TB People Ukraine.

The assessment includes important national data on the scale and level of TB associated stigma which could potentially inform interventions aimed at eradicating unequal access to medical services for TB patients and supporting patient-oriented approaches in prevention, testing for TB and treating the disease.

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[14] Juniarti, Neti & Evans, David. (2010). A qualitative review: The stigma of tuberculosis. Journal of clinical nursing. 20. 1961–70. 10.1111/j.1365–2702.2010.03516.x.

[15] Cremers, A. L., de Laat, M. M., Kapata, N., Gerrets, R., Klipstein–Grobusch, K., & Grobusch, M. P. (2015). Assessing the consequences of stigma for tuberculosis patients in urban Zambia. PloS one, 10(3), e0119861. https://doi.org/10.1371/journal.pone.0119861.

[16] Stop TB Partnership (2019) TB stigma assessment implementation handbook; http://www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Implementation%20Handbook.pdf

Methodology

Aim and objectives

The overarching aim of this assessment is to analyse the extent to which TB-associated stigma prevents the patients from accessing TB testing services, treatment and prevention services as well as its impact on the process of service delivery. The study also aims to developing recommendations on eradicating TB-associated stigma in Ukraine.

The study has set the following **objectives**:

- assess the level and scale of the anticipated and experienced stigma as well internalised stigma among people diagnosed with TB;
- assess the level and scale of secondary stigma, i.e., stigma experienced by TB patients and stigma experienced by the family/caregivers of people with TB;
- evaluate the level of anticipated TB stigmatization of people with TB at community level and the level of stigma reported by community representatives;
- analyse the level and scale of anticipated stigma which exists in health care settings towards people with TB and towards health care provides working with TB patients;
- analyse to what extent institutionalised stigma which exists in the framework of current legislation and policies as well as stigma in the mass media could harm or protect people with TB;
- obtain data needed for developing recommendations on eliminating TB-associated stigma with aim to reducing vulnerability to TB infection, scaling up access to the TB services, and improving the treatment success rate.

Study participants and geography

The study has analysed the experiences and views of the five key populations:

- People with TB. The population includes adult patients (≥18 yo) who registered in the 2019 State TB Registry as first time TB patients or patients with relapsed TB infection.
- Family and close contacts of people with TB disease. This key population includes the family members, other close contacts and caregivers of people living with TB who provide support in the process of screening for TB and TB treatment. The survey included both men and women, parents or children of participants with TB. The age cap was set at ≥18 yo.
- Community representatives. This group includes community leaders identified by the research team and the people working in close vicinity to the TB clinic. The survey was conducted exclusively inside the communities located in the oblasts covered by study.
- Medical care providers. The research included the doctors and medical nurses at the Primary Care clinics and specialised clinics which provided TB testing, prevention and/or treatment for TB infected patients.
- Stakeholders. This key population included programme managers coordinating the efforts to fight TB at the global, national and regional level, law experts, politicians, MoH of Ukraine representatives, the media, donors, representatives of medical facilities, NGOs and representatives of communities of people who had experienced TB.

The sample of people who had experienced TB was intended as random and representative of the geography at the level of macro-regions, it is reflective of the share of people living in the cities and rural areas, age and gender and includes representatives of all key populations. The sample population of patients was developed based on the 2019 statistics on TB patients available from the Public Health Centre of he MoH of Ukraine. The sampling for other key populations was uniform. Three family members of a TB patient, 3 community representatives, and 17 medical providers were selected from each specific oblast.

Overall, the study engaged 1,437 participants, representative of 15 Ukrainian oblasts and the city of Kyiv, including 1,101 people who had experienced TB, 45 family members of TB patients, 43 community representatives, and 248 medical care providers. Also 15 stakeholders participated in two focus groups; all of the stakeholders were based in Kyiv.

The process of data collection has slightly deviated from the first intended sampling procedure (Table 1). The study has failed to engage 27% (42 out of 156) of patients with TB in Kyiv, 16% (26 out of 161) in the Odesa oblast and 2 out of 37 people living with TB in the Kherson oblast. In order to compensate for the dropped out TB patients the sample has engaged additional patients from the Poltava and Ivano-Frankivsk oblast. Also the study has engaged more representatives of other key populations than was initially intended.

Table 1. The sampled population as planned and realised

		People with TB		Family/ close contacts		Community representatives		Medical providers	
Region	Oblast	Plan.	Real.	Plan.	Real.	Plan.	Real.	Plan.	Real.
North	Zhytomyrska	33	33	3	2	3	3	17	17
	Kyiv City	156	114	3	3	3	3	17	16
	Kyivska	49	49	3	2	3	3	17	17
	Chernihivska	22	22	–	3	–	1	–	14
East	Donetska	33	62	3	4	3	2	17	17
	Luhanska	156	18	3	3	3	3	17	17
South	Zaporizhska	56	56	3	3	3	3	17	18
	Mykolayivska	21	39	3	3	3	3	17	20
	Odeska	161	135	3	3	3	3	17	17
	Khersonska	37	35	3	3	3	1	17	17
Centre	Dnipropetrovska	161	162	3	6	3	3	17	17
	Kirovihradska	73	73	3	3	3	3	17	25
	Poltavska	–	42	–	–	–	3	–	–
West	Zakarpatska	31	31	3	3	3	3	17	19
	Ivano-Frankivska	–	50	–	–	–	2	–	–
	Lvivska	130	180	3	4	3	4	17	17
	Total	**1100**	**1101**	**39**	**45**	**39**	**43**	**221**	**248**

Plan. – sample as planned; Real. – realised sample.

Methods and procedures

The survey was conducted during the COVID-19 pandemic, the recommendations on social distancing measures were in full force and as a result the data was collected remotely. The four key populations, including people with TB, their family, community representatives, and medical providers were interviewed by phone using a standardised questionnaire as presented in the TB Stigma Assessment Handbook[17], which was adapted for Ukraine. The data collection was conducted by independent interviewers (7 women and 6 men) using the Qualtrics 13 programme, the interviewers underwent special training on the survey methodology, approaches to collecting data by phone, and ethics. The majority of interviewers came from the TBpeopleUkraine and had personally experienced TB. The stakeholders were interviewed during two focus groups (7-8 participants) which were remotely organised in Kyiv.

In the regions recruiting of people with TB disease was organised by the survey's Regional Coordinators (RC), i.e., medical professionals employed by the TB clinics with access to the TB Patients' Registry. In the beginning of the study the RCs have created primary e-lists of patients corresponding to the survey criteria; the encrypted patients' depersonalized lists were forwarded to the study headquarters using a secure system of data transfer. The survey data manager ascribed personal identification numbers to each clinic, randomly selected the patinets' numbers specific to the region and formed a new depersonilzed e-list of randomly selected respondents. The data manager forwarded the list to the RCs from respective regions, the RCs used the patient IDs from the TB Registry to connect with the selected respondents using the approved protocols on collecting data and offered them to participate in the study. If the potential participant has not expressed any interest in the study, the RC would make a note in the e-list of randomly selected respondents and move on to the next candidate.

The patients who participated in the survey were engaged to recruit the family members, in the process the interviewer would suggest the client to engage their family and offered to contact the study team in case they were interested. The medical providers were recruited by the Regional Coordinators, the RCs were used to engage the medical staff at the TB clinics and Primary Care clinics in the cities covered by the survey which engaged the clinic's patients and their families.

The local community representatives were selected using two methodologies:
- independent interviewers engaged into the survey random people whose professional activities placed them in close proximity to the TB clinic;
- community representatives (members of the HIV and TB Coordination Councils, local MPs) were selected by the Head of Team via the civil society representatives located in the regions covered by the survey.

The sample selection of family members, community representatives and medical providers was not random. The study participants were compensated 100 UAH for their time and effort.

The stakeholders were selected based on the recommendations provided by the Core Group established by the National TB and HIV Council's ACSM Working Group.

The Core Group is an ad hoc advisory panel which was created in the project's framework with the aim to engage a wider circle of stakeholders and provide expert support to TB Stigma Assessment in Ukraine. The Group members were government officials and NGO representatives, including international civil society organisations and people affected by TB (ten organisations in total). The Core Group meetings were facilitated by TB Expert under the Public Health Centre of the MoH of Ukraine leadership; the Group has endorsed the study's protocol and provided recommendations used to adapt the study guidelines initially developed by the Stop TB Partnership; the Core Group was fully engaged in discussing the study's milestones. Following the Group's recommendations, the survey methodology initially developed by the Stop TB Partnership was extended to include a larger number of medical care providers – from 40 to 248 participants, the move was intended to reflect the newly implemented changes which came into force in Ukraine as a result of the medical reform and help cover both specialised TB care and the primary care clinics which now find most TB cases and provide outpatient care to the TB patients.

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[17] Stop TB Partnership (2019) TB stigma assessment implementation handbook; http://www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Implementation%20Handbook.pdf

Data analysis

All of the digital data was downloaded from Qualtrics to MS Excel. The data was validated through running a logical test to detect doubles and missing values. The list of indicators selected for analysis reflected the international TB stigma assessment implementation handbook[18]:

- Indicators used to identify the «stigma radar» associated with TB, e.g. comprehensive analysis of self-stigma, secondary stigma within the family, anticipated stigma within the community and in the health care community (see. Attachment 1);
- specific manifestations or dimensions of stigma within each key population;
- indicators of experienced stigma along the TB journey, including the ones which inhibited PWTB from seeking and receiving care;
- stigma indicators observed by the key populations along the TB journey;
- indicators used to assess the legislative and political climate and its impact on stigmatisation and discrimination of PWTB.

The stigma scales are an adapted version of the following tools: Van Rie, et al questionnaire which was used to evaluate stigma faced by PWTB and communities[19]; R. A. Arcêncio, et al questionnaire which was used to assess secondary stigma experienced by the family of PWTB[20]; Corrigan, et al questionnaire which was used to evaluate the nine dimensions of stigma (AQ-9)[21].

The analysis of quantitative data was mostly statistically-descriptive, e.g., calculations of frequencies and percentages, mean values and standard errors in the aggregated scale of stigma. Indicators to assess stigma were analysed in respect to PWTB and health care providers. In respect to the rest of the key populations this type of analysis was not applicable due to the insufficient sample size. In dealing with quantifiable resultative variables, e.g., the total score of self-stigma, the discrepancies between populations were identified by using a multiple linear regression used to simultaneously analyse the impact of several variables. The results are presented as an adjusted mean difference as compared to the reference group, its 95% confidence interval and p values. For the categorical binary resultative variables, e.g., present/absent experience of stigma, the indicator analysis was performed using multiple linear probability models. This helps assess the adjusted percentage discrepancy (prevalence) related to a specific phenomenon in a population, its 95% confidence interval and p values. The confidence interval indicates that if this analysis was repeated many times over, in 95% of studies the actual discrepancy between the means or percentages within a population will stay within the same interval. Confidence intervals which exclude the null value and $p<0.05$ indicate that there are statistically significant discrepancies between populations. The quantitative data analysis was performed in the R programme, ver. 3.5.2 (Copyright (C) 2018 The R Foundation for Statistical Computing).

Qualitative data analysis focused on developing the interview transcripts using MS Word and identifying specific topics as per the developed list of codes. MS Excel was used for coding qualitative data collected in the course of the surveys and focus groups. The interview topics were analysed in respect to the participant's gender and age. For the report the researchers have selected some of the most distinctive quotes which best describe the selected topic. For some of the most disputed subjects conflicting messages were selectee to reflect their controversial nature.

Ethics

The study's protocol and tools went through the ethical assessment procedure and were approved by the Ethics Committee of the Ukrainian Institute on Public Health Policy (IRB # 00007612; FWA # 00029648). All study participants have given verbal consent to participate in the survey.

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[18] Stop TB Partnership (2019) TB stigma assessment implementation handbook; http://www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Implementation%20Handbook.pdf

[19] 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.

[20] Arcêncio, R. A., de Almeida Crispim, J., Touso, 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

[21] 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' profiles

PWTB

The majority of PWTB (64%) were men between the ages of 25 and 44 (50%) or 45-64 (40%). The discrepancy between men and women was particularly visible in the group of patients aged between 45 and 64, where only 28% of respondents were women (Diagram 1). In relation to the other age groups the gender correlation was approximately 40 to 60%. None of the respondents has indicated being transgender or identified as a different gender group.

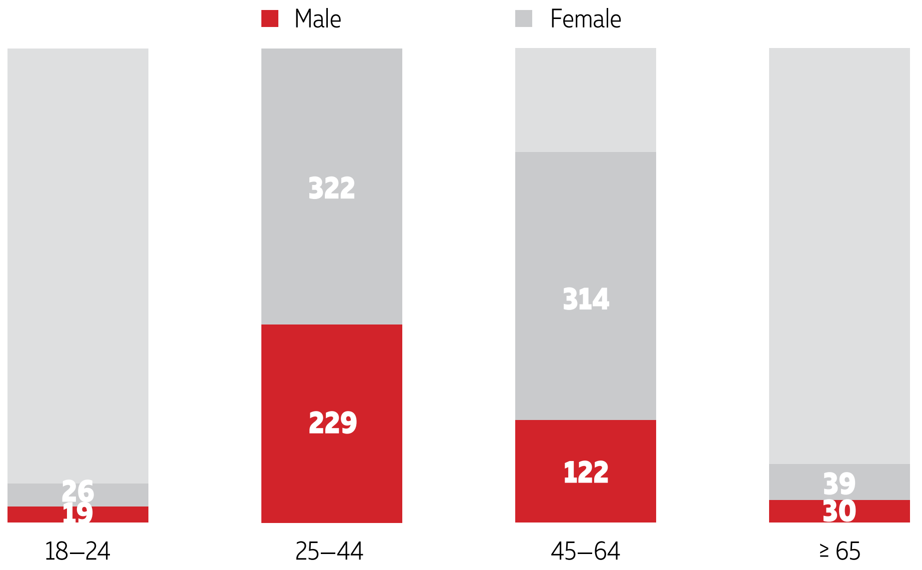


Diagram 1. Distribution of PWTB by gender and age, participants (n=1101)

PWTB are most likely to identify with the following five groups: people with TB related disability, the urban and rural poor; PLHA, and family of people with TB disease (Diagram 2). Only a quarter of respondents (26%) have failed to identify with any key population (Diagram 2). One third (36%) have identified with two or three populations from the list and 11% have identified with five and more groups. For example, TB associated stigma could be exacerbated by HIV stigma and the stigma experienced by the former inmates.

Table 2. Self-identification by PWTB with key populations, participants and % (n=1101)

Key populations (several answer alternatives, the total does not equal 100%)	n	%
Person with a TB related disability	**241**	**22%**
Urban poor	**208**	**19%**
Person living with HIV	**181**	**16%**
Rural poor	**173**	**16%**
Family of PWTB	**167**	**15%**
Former inmate	**131**	**12%**
Person with other disability	**109**	**10%**
Seniors (over 60 yo)	**91**	**8%**
People with alcohol addiction	**89**	**8%**
A person smoking over 40 cigarettes per day	**85**	**8%**
People with mental health issues	**62**	**6%**
People living with diabetes	**51**	**5%**
Health care providers (non TB services)	**45**	**4%**
Non-medical staff who extensively contact with PWTB in the professional field	**40**	**4%**
Internally displaced person	**38**	**3%**
People who inject drugs	**35**	**3%**
ATO veterans	**27**	**2%**
National minorities (Romani)	**23**	**2%**
Coalminer/diagnosed with silicosis	**19**	**2%**
Homeless	**19**	**2%**
Health care provider (TB care)	**12**	**1%**
Refugee	**9**	**1%**

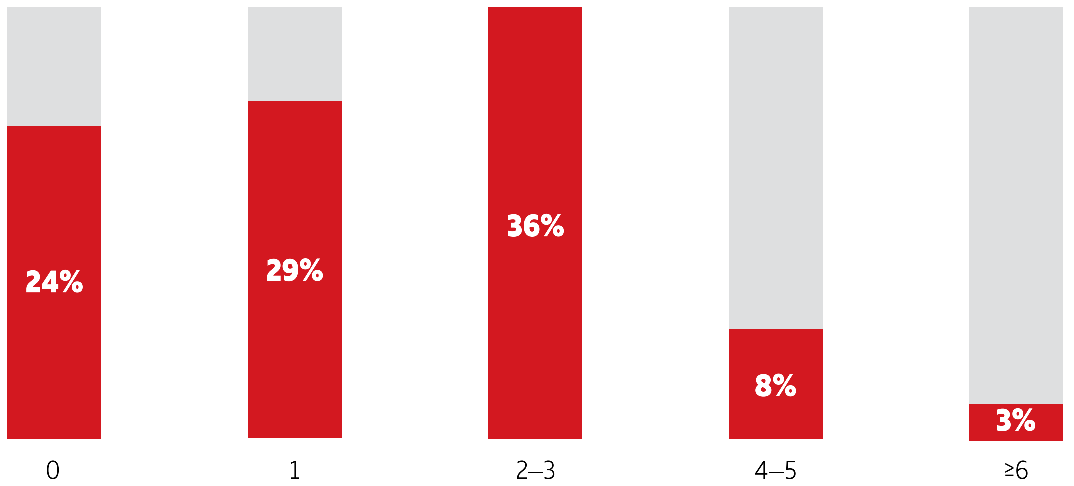


Diagram 2. Distribution of key populations PWTB have self-identified with, % (n=1101)

The majority of the respondents (83%) have completed TB treatment at the time of the interview, including 34% of the respondents who received treatment a year ago. Approximately one in six (17%) was receiving treatment at the time of the survey. Only two respondents diagnosed with TB have not initiated treatment. One patient has refused treatment because he was not willing to take the new anti-TB medication, the other patient was intent on initiating treatment but at the time was in the process of being transferred between facilities.

Overall, only 27% of participants could accurately name the type of TB they were diagnosed with and knew if they have developed any drug resistance to the TB medication (Table 3). The majority of respondents in the group of people who could accurately name their TB diagnosis were diagnosed with drug sensitive lung TB (160 respondents; 53%) and MDR-TB (101 respondents, 33%).

Table 3. Distribution of PWTB by TB type and drug sensitivity to anti-TB medication, respondents and % (n=1101)

	Lung TB		Extra-pulmonary TB/Both		N/A	
	n	%	n	%	n	%
Drug-sensitive TB	160	17%	8	10%	3	4%
MDR-TB	101	11%	7	9%	0	0%
XDR-TB	24	3%	2	3%	1	1%
Unable to name	665	70%	60	78%	70	95%

Almost two thirds of the respondents (64%) received out-patient DOT-based TB treatment provided by a medical clinic, which includes daily visits to a specialised TB clinic or Primary Care clinic to receive the medication and controlled intake of the medication observed by a TB doctor, family doctor or a medical nurse (Diagram 3). Approximately 7% have indicated that their TB treatment was unsupervised and they independently maintained the intake of the medication.

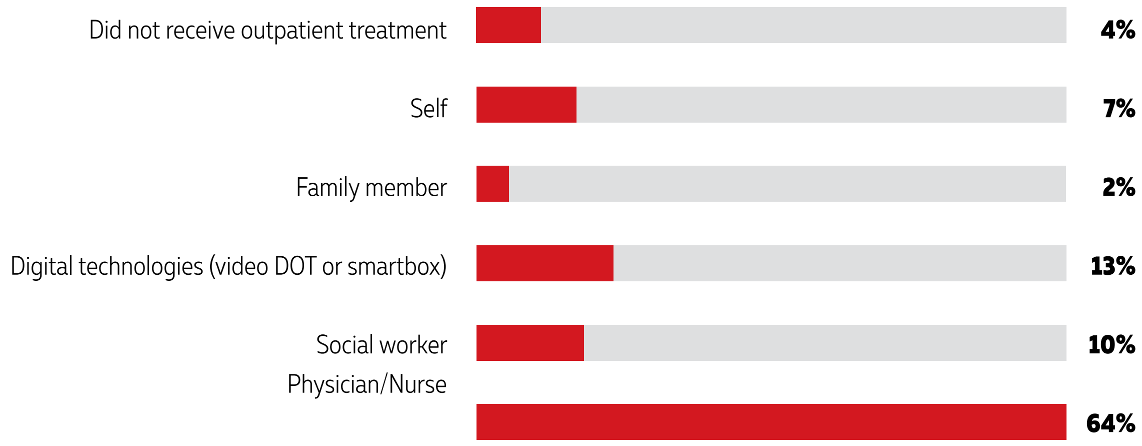


Diagram 3. Distribution of responses to Question: «Name the person responsible for overseeing your outpatient treatment, administering the medication, controlling the medication intake» (n=1101)

Family

The sample of family members of PWTB was represented mostly by women (36 out of 44 respondents, 82%), aged between 25 and 44 (18 out of 44, 41%). The youngest (18-24 yo) and oldest age groups (65 yo and over) were exclusively represented by women (Diagram 4).

The first line family members, e.g., parents, siblings and children constitute only 39% out of the total number of respondents (Diagram 5). The respondents tended to engage into the survey other family members.

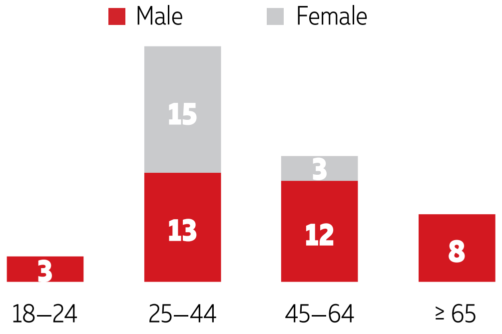


Diagram 4. Distribution of PWTB family members by age and gender, respondents (n=44)

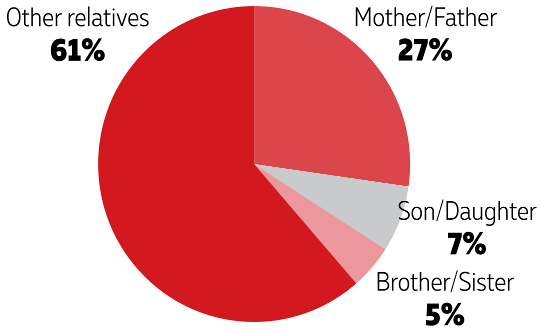


Diagram 5. Distribution of responses to Question: «What is your family relation with a PWTB?», % (n=44)

Community representatives

The group of community representatives is mostly represented by women (27 out of 43 respondents, 63%) (Diagram 6). The majority is aged between 25 and 44 (21 out of 43, 49%) and 45-64 yo (18 out of 43, 42%). Almost all of the community representatives (93%) had a personal connection with the people with TB disease who now or before lived in their community.

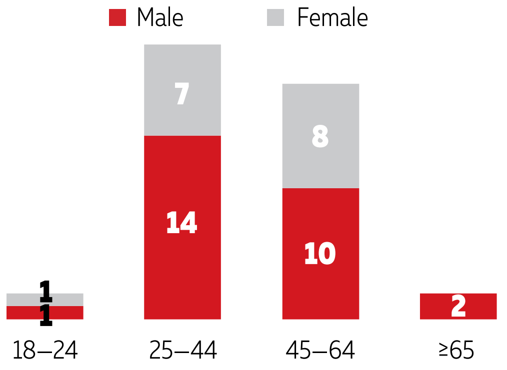


Diagram 6. Distribution of community representatives by age and gender, respondents (n=43)

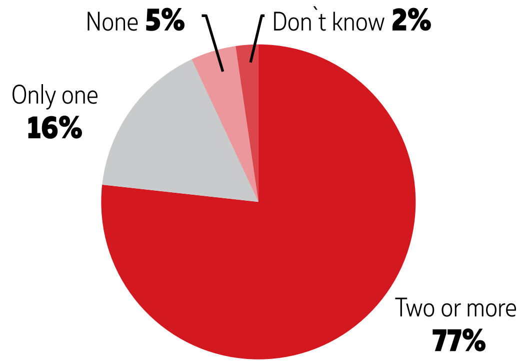


Diagram 7. Distribution of responses to Question: «How many people from your community/neighbours with TB or people who had TB you know personally?» (n=43)

Health care providers

Over 90% of the surveyed medical care providers were women, this reflects the general gender imbalance in Ukrainian health care, including TB care (Diagram 8). Half of the respondents (51%) were aged between 25 and 44, an additional 42% – aged between 45 and 64. Almost two thirds (65%) of the selected medical care providers were employed in TB care, e.g., TB doctors and medical nurses (Diagram 9). Health care providers employed by the Primary Care clinics make up 32% of the respondents. Four of the respondents occupied managerial positions in health care. Only nine out of 248 respondents at the time of the survey lacked any practical experience in TB care provision, for the most part they were family doctors and nurses new to the profession.

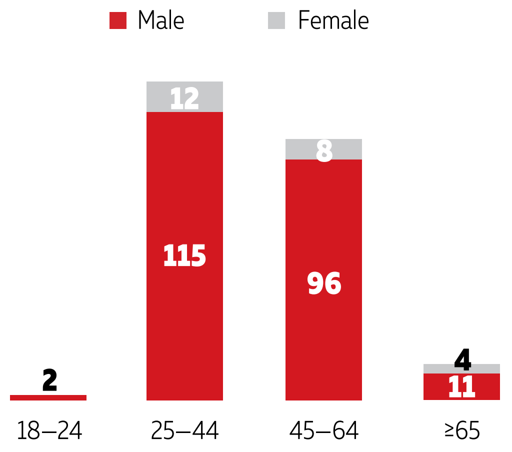


Diagram 8. Distribution of medical care providers by age and gender, respondents (n=248)

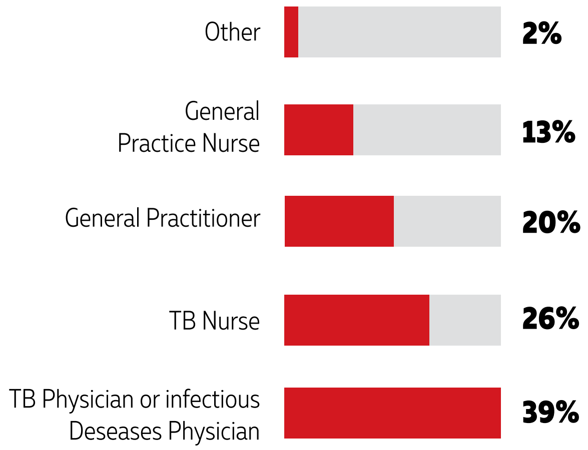


Diagram 9. Distribution of medical care providers by position, % (n=248)

Stakeholders

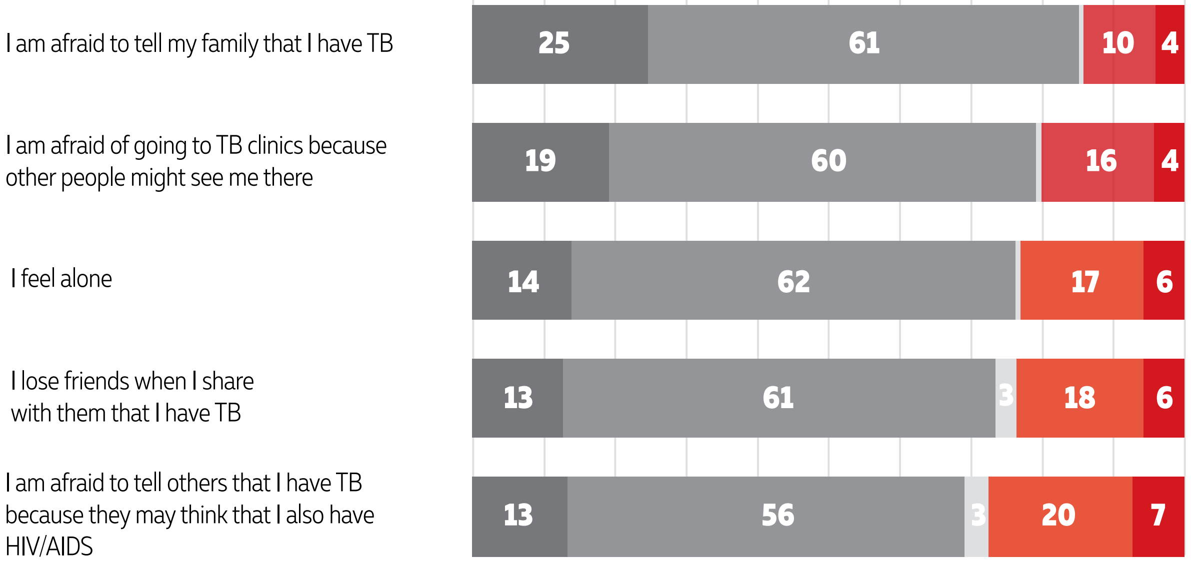
This group has included the national, international, and regional TB programme managers, experts in law, politicians, MoH representatives, journalists, donors, medical clinics, NGOs, as well as representatives of people who have experienced TB and other patient organisations. All of the experts have participated in focus groups which were organised remotely in Kyiv. This group comprised of 15 experts, five men and ten women.

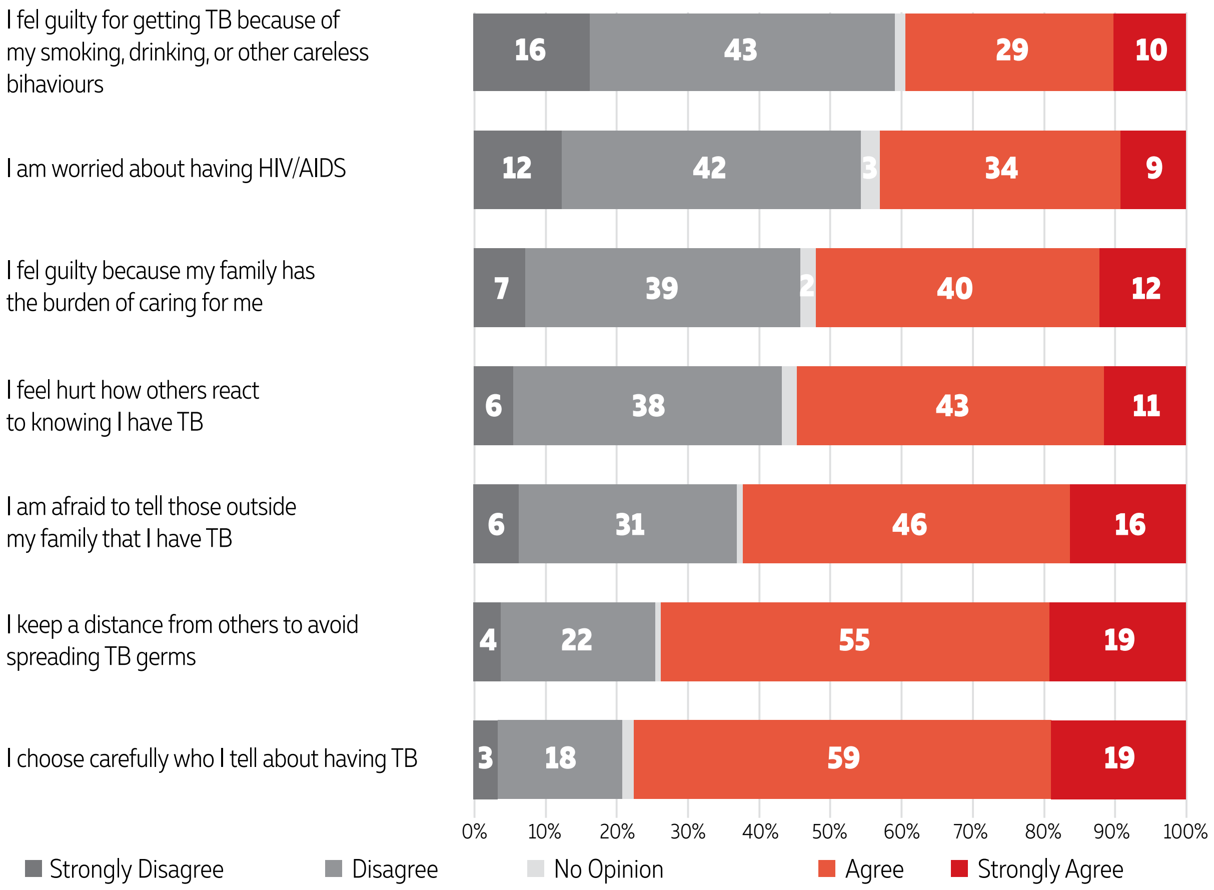
Results

Self-stigma in people with TB

The level of self-stigma in PWTB was measured by using a set of 12 statements describing the attitude towards TB disclosure, feelings of guilt, social isolation and so on. Practically all of the respondents have clearly expressed their views on the statements and under one percent of the respondents have either refused to answer or could not specifically tell. Over half of the respondents have identified with the feelings of guilt for letting down their family; reported being hurt by a negative reaction after a disclosure; fearing disclosure of TB status; and limiting social contacts with aim to preventing spread of TB (Diagram 10). Over one quarter of respondents (27%) have supported statements on associated TB and HIV stigma, saying that after finding out that they have TB the others may think that they are also infected with HIV. The PLHA respondents (54%) also identified with the statement that if the others find out about TB, they may also assume HIV. One in seven respondents (14%) associates disclosing their TB status to the family with the feeling of fear, and every fifth respondent (20%) associates visiting a medical clinic for TB care with the feeling of fear because at the clinic they could be seen by someone they know and who could find out about their TB status. Overall only 3% of respondents have not indicated any self-stigma associated with tuberculosis and contradicted all of the 12 statements.

Based on the responses to the 12 statements the average self-stigma score was 22.4 with a standard error of 7.8 points. Data from half of the respondents indicates that the level of stigma is measured at 18 and 27 points. Compared to the Northern oblasts and the City of Kyiv the level of self-stigma was higher in the West and South of the country (Table 4). In general, the women felt more self-stigma compared to the men. There is a link between self-stigma associated with tuberculosis and age – older respondents felt more self-stigma. Patients with extra-pulmonary TB usually exhibited less self-stigma compared to the people diagnosed with pulmonary TB. This could be explained by the fact that pulmonary TB is more infectious and the patients with pulmonary TB were afraid of spreading the infection further and felt isolated as a result. At the same time there was no discrepancies in the level of self-stigma between the patients diagnosed with drug-sensitive and drug-resistant TB – out of the number of respondents who could accurately name their diagnosis. Also there was no correlation between the directly observed treatment model and the level of self-stigma associated with tuberculosis. The highest levels of self-stigma were registered among such key populations as the PLHA and low-income populations in the cities and rural areas.





The statements are arranged based on the share of participants who responded with «agree» or «totally agree».

Diagram 10. Dimensions of self-stigma in PWTB: level of support for each statement which refers to living with TB, % (n=1101)

Table 4. Factors associated with self-stigma (n=1101)

Factor		Sample size, individuals	Average self-stigma score (standard error)	Adjusted mean discrepancy [95% confidence interval] p value
Region	East	80	21.3 (5.6)	0.1 [–1.9;2.0] p=0.96
	West	261	23.1 (8.0)	**1.6 [0.2;3.0] p=0.03**
	South	265	23.8 (8.9)	**2.1 [0.8;3.5] p=0.00**
	Centre	277	21.6 (7.1)	0.2 [–1.1;1.6] p=0.74
	North	218	21.3 (5.6)	ref.
Gender	Women	400	23.2 (7.8)	**2.0 [1.0;3.0] p=0.00**
	Men	701	21.9 (7.5)	ref.
Age	18–24	45	19.2 (7.4)	ref.
	25–44	551	22.4 (7.5)	**3.3 [1.0;5.5] p=0.00**
	45–64	436	22.6 (7.8)	**3.4 [1.1;5.7] p=0.00**
	65 and over	69	23.8 (8.1)	**3.9 [0.5;7.4] p=0.02**
Time interval	At the time of the survey was in treatment	185	24.8 (8.2)	**2.7 [1.4;3.9] p=0.00**
	Completed treatment at the time of the survey	914	21.9 (7.5)	ref.

Localisation of TB	Pulmonary TB	950	22.5 (7.6)	ref.
	Extra-pulmonary TB/both	70	21.3 (6.8)	**–3.1 [–4.9;–1.2]p=0.00**
	N/A	74	22.7 (8.9)	–0.4 [–2.2;1.4] p=0.65
Type of TB	Drug-sensitive TB	171	20.8 (7.3)	ref.
	MDR-TB/XDR-TB	135	22.9 (7.0)	0.9 [–0.9;2.7] p=0.31
	N/A	795	22.7 (7.8)	**1.3 [0.1;2.6] p=0.04**
Type of DOT	Health care provider	700	22.4 (6.9)	ref.
	Social worker	109	22.3 (6.4)	–0.2 [–1.7;1.4] p=0.85
	Digital technology (video-DOT or SMARTbox)	139	22.5 (9.2)	0.0 [–1.4;1.4] p=0.99
	Self-administered	82	22.4 (10.0)	–0.1 [–1.8;1.6] p=0.92
	Other	68	22.3 (9.8)	0.0 [–1.9;1.8] p=0.97
Populations	PLHA	181	24.8 (8.3)	**2.7 [1.5;4.0] p=0.00**
	Occupational groups at high risk of infection: health care providers; non-medical staff, who extensively contact with PWTB, coalminers, ATO veterans	136	22.4 (6.9)	0.9 [–0.5;2.2] p=0.20
	Refugees; internally displaced persons; national minorities	60	23.3 (7.5)	0.7 [–1.2;2.7] p=0.47
	Low income populations in cities/rural areas	378	24.1 (7.9)	**1.5 [0.5;2.5] p=0.00**
	Groups with at risk behaviour: people who use injecting drugs; smokers; people with alcohol abuse issues; homeless people; former inmates	253	23.3 (7.5)	0.7 [–0.5;1.9] p=0.24
	At risk populations due to underlying health conditions: people with disability; patients with diabetes; people with mental health issues	396	23.6 (7.7)	0.8 [–0.2;1.8] p=0.12
	Seniors (over 60 yo)	91	23.8 (7.2)	1.3 [–1.0;3.7] p=0.25
	Family of PWTB	167	23.0 (7.1)	0.8 [–0.5;2.0] p=0.22

Note: self-stigma is measured as a total score in the 12 item questionnaire, see Diagram 10. Each statement was measured on a scale from 0 (totally disagree) to 4 (totally agree). Respectively the total self-stigma score varies from 0 to 48 – higher scores indicate high levels of stigma. Discrepancies between the groups are reflected as linear regressions which simultaneously include all of the indicated factors. The mean difference reflects the difference in the average level of self-stigma in a population compared to a reference population (ref.) if all of the above factors are taken into consideration. In the key populations people who do not identify with the population were used as a reference group. If the 95% confidence interval excludes the null value and p<0.05, the differences between the populations become statistically significant. Some categories of factors were combined (e.g., key populations) if the sample size within a category was not sufficient for analysis.

When responding to open-ended questions the participants would describe their depressed mental state after diagnosis, they would describe the feelings of shame and guilt associated with having TB and their unwillingness to share the diagnosis with anyone.

> «I am well aware of how the others view the disease, so I am not discussing it with anybody. This is not a disease that you can talk about. I personally know a person with TB who got kicked out of a medical clinic, they would not even let him come close to it, even though at the time he was in treatment. Get lost, just like that. I don't want something like that happening to me, that's for sure.
> **Female (32), East**

> «Sure, it's my fault, I have become burden to my family. Before I was earning money for the family, but now they have to support me. I feel ashamed before the children.»
> **Male (52), South**

> «Naturally there was fear. They would even take me to a clinic's psychologist…Cos frankly speaking I wanted to drown myself just after I found out that I have the disease. I still cannot understand why this had to happen to me.»
> **Male (43), East**

> «There is a general belief that only people with a certain life style can get TB. I am still young and if I meet a girl or get a different circle of friends, I am not going to disclose my status, otherwise the attitude towards me is gonna change, I am 100 percent certain.»
> **Male (27), Centre**

Stigma experienced by PWTB along the TB journey

Over one third of PWTB (39%) have reported personally experiencing stigma along the TB journey which prevented them from accessing medical services (Diagram 11). In the majority of cases the respondents have reported experiencing stigma while visiting medical clinics (18%). In total, 9% of respondents have reported experiencing stigma at a TB clinic; another 9% – at a Primary Care clinics and 2% at other medical facilities.

One in ten respondents has experienced stigma associated with tuberculosis at work (11%) and in the community, in a neighbourhood setting (10%). Only 5% of PWTB reported being stigmatised by the family.

The respondents local to the West of Ukraine reported cases of stigmatisation in medical clinics less frequently compared to the respondents from other regions (Table 5-A). For example, 12% of PWTB living in the West of the country and receiving the treatment locally reported experiencing stigma at a TB clinic or Primary Care clinic. In the North of Ukraine and the South the reported statistics are 24 and 20% respectively. The women and disadvantaged populations experienced more stigma in a health care setting.

PWTB who were in treatment at the time of the survey mostly reported experiencing stigma within their community (Table 5-B). In this population 16% reported being stigmatised by neighbours compared to 8% of respondents who completed treatment. Also the people who identified as low-income tended to have more stigma within the community.

Also the people who identified as low-income tended to have more stigma within the community.

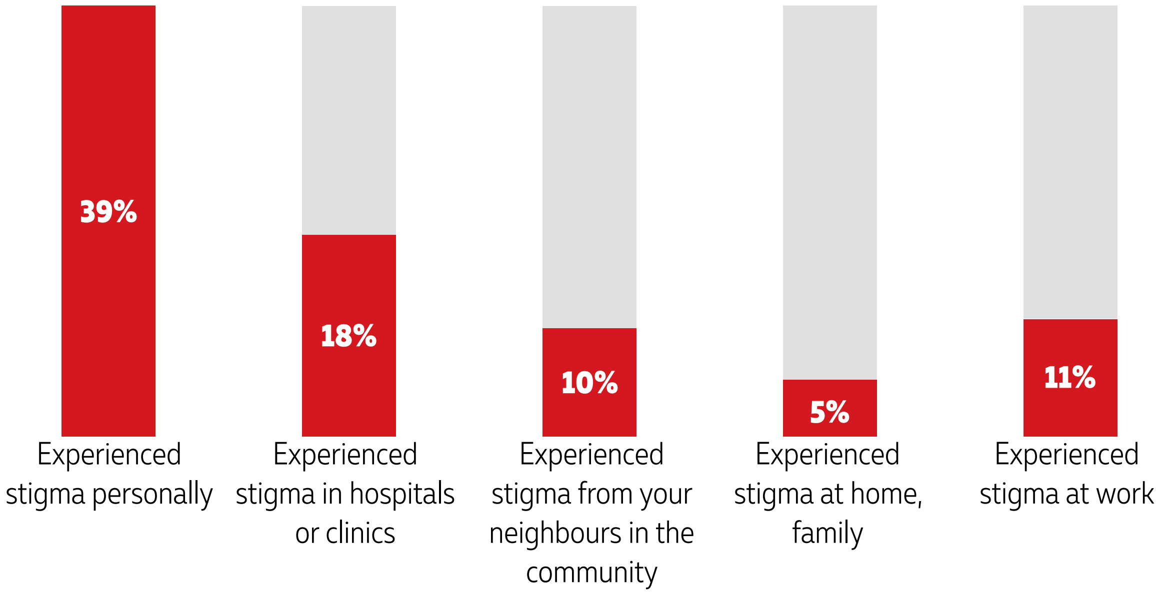


Diagram 11. Personal experience of TB associated stigma and stigma setting, % (n=1101)

The patients who self-administered TB treatment without any outside supervision have reported more stigma in a family setting (Table 5-C). Only 5% of the total number of respondents have experienced stigma in a family setting, but in people who self-administered TB treatment one in every eight respondents (12%) have reported being stigmatised by the family. In key populations people with low-income and at risk populations due to underlying health conditions, including people with disability, patients with diabetes and people with mental health issues had higher levels of stigma compared to the respondents who did not identify with these groups.

Stigmatisation in a work setting is more prevalent in the South of Ukraine compared to other regions (Table 5-D). The patients who were in treatment at the time of the survey reported more stigma in a work setting compared to the respondents who completed their treatment

Table 5. associated with experiencing stigma (n=1101)

A. Stigma in a health care setting

		N	Experienced stigma n (%)	Adjusted mean discrepancy [95% confidence interval] p
Region	East	80	15 (18.8)	–0.3 [–11.5;10.9] 0.96
	West	261	30 (11.5)	**–9.3 [–17.3;–1.3] 0.02**
	South	265	64 (24.2)	4.5 [–3.2;12.2] 0.25
	Centre	277	48 (17.3)	–3.3 [–10.9;4.2] 0.39
	North	218	44 (20.2)	ref.
Gender	Women	400	84 (21.0)	**8.5 [2.8;14.2] 0.00**
	Men	701	117 (16.7)	ref.
Age	18–24	45	7 (15.6)	
	25–44	551	107 (19.4)	6.8 [–6.2;19.7] 0.31
	45–64	436	81 (18.6)	7.7 [–5.6;21.0] 0.26
	65 and over	69	6 (8.7)	–0.4 [–20.6;19.7] 0.97
Time interval	At the time of the survey was in treatment	185	43 (23.2)	5.6 [–1.5;12.7] 0.12
	Completed treatment at the time of the survey	914	158 (17.3)	ref.
Localisation of TB	Pulmonary TB	950	173 (18.2)	ref.
	Extra-pulmonary TB/both	70	13 (18.6)	0.3 [–10.4;11.0] 0.95
	N/A	74	13 (17.6)	0.3 [–10.5;11.1] 0.96
Type of TB	Drug-sensitive TB	171	33 (19.3)	реф.
	MDR-TB/XDR-TB	135	35 (25.9)	1.6 [–8.6;11.7] 0.76
	N/A	795	133 (16.7)	–5.4 [–13.0;2.2] 0.16
Type of DOT	Health care provider	700	117 (16.7)	ref.
	Social worker	109	17 (15.6)	–6.1 [–14.9;2.7] 0.17
	Digital technology (video-DOT or SMARTbox)	139	28 (20.1)	–2.5 [–10.3;5.4] 0.54
	Self-administered	82	18 (22.0)	2.2 [–7.1;11.6] 0.64
	Other	68	20 (29.4)	**11.7 [1.3;22.0] 0.03**
Populations	PLHA	181	43 (23.8)	1.6 [–5.6;8.8] 0.67
	Occupational groups at high risk of infection: health care providers; non-medical staff, who extensively contact with PWTB, coalminers, ATO veterans	136	30 (22.1)	4.8 [–2.8;12.3] 0.22
	Refugees; internally displaced persons; national minorities	60	14 (23.3)	1.9 [–9.3;13.0] 0.74
	Low income populations in cities/rural areas	378	88 (23.3)	**6.0 [0.3;11.7] 0.04**
	Groups with at risk behaviour: people who use injecting drugs; smokers; people with alcohol abuse issues; homeless people; former inmates	253	62 (24.5)	6.5 [–0.1;13.1] 0.05
	At risk populations due to underlying health conditions: people with disability; patients with diabetes; people with mental health issues	396	86 (21.7)	3.3 [–2.3;9.0] 0.24
	Seniors (over 60 yo)	91	11 (12.1)	1.4 [–11.9;14.7] 0.83
	Family of PWTB	167	37 (22.2)	2.0 [–4.9;8.9] 0.57

B. Stigma in a community/neighbourhood setting

		N	Experienced stigma n (%)	Adjusted mean discrepancy [95% confidence interval] p
Region	East	80	5 (6.3)	1.5 [–6.7;9.7] 0.72
	West	261	16 (6.1)	–1.0 [–6.9;4.9] 0.75
	South	265	45 (17.0)	**10.5 [4.9;16.1] 0.00**
	Centre	277	22 (7.9)	1.2 [–4.4;6.7] 0.68
	North	218	18 (8.3)	ref.
Gender	Women	400	37 (9.3)	–0.2 [–4.3;4.0] 0.94
	Men	701	69 (9.8)	ref.
Age	18–24	45	7 (15.6)	ref.
	25–44	551	60 (10.9)	–3.2 [–12.7;6.2] 0.51
	45–64	436	34 (7.8)	–7.0 [–16.7;2.6] 0.15
	65 and over	69	5 (7.2)	–9.4 [–23.9;5.1] 0.20
Time interval	At the time of the survey was in treatment	185	30 (16.2)	**6.5 [1.3;11.6] 0.01**
	Completed treatment at the time of the survey	914	76 (8.3)	
Localisation of TB	Pulmonary TB	950	94 (9.9)	ref.
	Extra-pulmonary TB/both	70	7 (10.0)	1.2 [–6.6;9.1] 0.76
	N/A	74	5 (6.8)	–4.1 [–11.9;3.7] 0.31
Type of TB	Drug-sensitive TB	171	14 (8.2)	ref.
	MDR-TB/XDR-TB	135	19 (14.1)	1.1 [–6.2;8.4] 0.77
	N/A	795	73 (9.2)	0.5 [–4.8;5.8] 0.85
Type of DOT	Health care provider	700	57 (8.1)	ref.
	Social worker	109	13 (11.9)	1.7 [–4.7;8.2] 0.59
	Digital technology (video-DOT or SMARTbox)	139	14 (10.1)	–1.4 [–7.2;4.4] 0.64
	Self-administered	82	11 (13.4)	3.5 [–3.4;10.5] 0.32
	Other	68	11 (16.2)	6.5 [–1.2;14.1] 0.10
Populations	PLHA	181	24 (13.3)	2.2 [–3.1;7.4] 0.42
	Occupational groups at high risk of infection: health care providers; non-medical staff, who extensively contact with PWTB, coalminers, ATO veterans	136	11 (8.1)	–1.6 [–7.1;4.0] 0.58
	Refugees; internally displaced persons; national minorities	60	12 (20.0)	7.5 [–0.7;15.7] 0.07
	Low income populations in cities/rural areas	378	61 (16.1)	8.9 [4.7;13.0] 0.00
	Groups with at risk behaviour: people who use injecting drugs; smokers; people with alcohol abuse issues; homeless people; former inmates	253	34 (13.4)	1.7 [–3.1;6.6] 0.48
	At risk populations due to underlying health conditions: people with disability; patients with diabetes; people with mental health issues	396	41 (10.4)	–1.9 [–6.0;2.1] 0.35
	Seniors (over 60 yo)	91	8 (8.8)	3.5 [–6.1;13.0] 0.48
	Family of PWTB	167	24 (14.4)	4.3 [–0.7;9.4] 0.09

C. Stigma in a family/home setting

		N	Experienced stigma n (%)	Adjusted mean discrepancy [95% confidence interval] p
Region	East	80	2 (2.5)	–2.8 [–9.1;3.4] 0.37
	West	261	**9 (3.4)**	–3.7 [–8.2;0.8] 0.11
	South	265	17 (6.4)	–0.8 [–5.1;3.6] 0.73
	Centre	277	17 (6.1)	0.2 [–4.1;4.4] 0.94
	North	218	12 (5.5)	ref.
Gender	Women	400	**22 (5.5)**	1.6 [–1.6;4.8] 0.32
	Men	701	35 (5.0)	ref.
Age	18–24	45	2 (4.4)	ref.
	25–44	551	25 (4.5)	0.5 [–6.7;7.8] 0.89
	45–64	436	27 (6.2)	2.5 [–4.9;9.9] 0.51
	65 and over	69	3 (4.3)	2.4 [–8.7;13.5] 0.67
Time interval	At the time of the survey was in treatment	185	13 (7.0)	**2.0 [–1.9;6.0] 0.31**
	Completed treatment at the time of the survey	914	44 (4.8)	ref.
Localisation of TB	Pulmonary TB	950	54 (5.7)	ref.
	Extra-pulmonary TB/both	70	1 (1.4)	–5.2 [–11.2;0.8] 0.09
	N/A	74	2 (2.7)	–2.4 [–8.4;3.6] 0.43
Type of TB	Drug-sensitive TB	171	9 (5.3)	реф.
	MDR-TB/XDR-TB	135	9 (6.7)	–0.7 [–6.2;4.9] 0.82
	N/A	795	39 (4.9)	–1.1 [–5.2;3.0] 0.58
Type of DOT	Health care provider	700	27 (3.9)	ref.
	Social worker	109	3 (2.8)	–2.7 [–7.6;2.2] 0.28
	Digital technology (video-DOT or SMARTbox)	139	10 (7.2)	2.8 [–1.7;7.2] 0.22
	Self-administered	82	12 (14.6)	**10.4 [5.1;15.7] 0.00**
	Other	68	5 (7.4)	3.0 [–2.9;8.9] 0.32
Populations	PLHA	181	11 (6.1)	0.1 [–3.9;4.1] 0.97
	Occupational groups at high risk of infection: health care providers; non-medical staff, who extensively contact with PWTB, coalminers, ATO veterans	136	6 (4.4)	–0.9 [–5.1;3.4] 0.69
	Refugees; internally displaced persons; national minorities	60	3 (5.0)	–1.6 [–7.9;4.7] 0.62
	Low income populations in cities/rural areas	378	29 (7.7)	**3.2 [0.1;6.4] 0.05**
	Groups with at risk behaviour: people who use injecting drugs; smokers; people with alcohol abuse issues; homeless people; former inmates	253	16 (6.3)	0.2 [–3.6;3.9] 0.93
	At risk populations due to underlying health conditions: people with disability; patients with diabetes; people with mental health issues	396	29 (7.3)	3.5 [0.4;6.7] 0.03
	Seniors (over 60 yo)	91	4 (4.4)	–0.8 [–8.2;6.5] 0.82
	Family of PWTB	167	10 (6.0)	0.6 [–3.3;4.5] 0.76

D. Stigma in a work setting

		N	Experienced stigma n (%)	Adjusted mean discrepancy [95% confidence interval] p
Region	East	80	9 (11.3)	−4.4 [−4.1;13.0] 0.31
	West	261	11 (4.2)	−4.8 [−11.0;1.3] 0.12
	South	265	43 (16.2)	**6.0 [0.1;11.9] 0.05**
	Centre	277	25 (9.0)	−1.6 [−7.4;4.2] 0.58
	North	218	28 (12.8)	ref.
Gender	Women	400	38 (9.5)	−1.9 [−6.2;2.4] 0.39
	Men	701	78 (11.1)	ref.
Age	18–24	45	4 (8.9)	
	25–44	551	70 (12.7)	5.6 [−4.2;15.5] 0.26
	45–64	436	40 (9.2)	3.0 [−7.1;13.1] 0.56
	65 and over	69	2 (2.9)	0.5 [−14.7;15.6] 0.95
Time interval	At the time of the survey was in treatment	185	28 (15.1)	**5.7 [0.4;11.0] 0.04**
	Completed treatment at the time of the survey	914	88 (9.6)	ref.
Localisation of TB	Pulmonary TB	950	105 (11.1)	ref.
	Extra-pulmonary TB/both	70	6 (8.6)	1.1 [−7.1;9.3] 0.79
	N/A	74	4 (5.4)	−5.1 [−13.3;3.1] 0.22
Type of TB	Drug-sensitive TB	171	24 (14.0)	
	MDR-TB/XDR-TB	135	18 (13.3)	−3.6 [−11.2;4.1] 0.36
	N/A	795	74 (9.3)	−3.9 [−9.5;1.7] 0.17
Type of DOT	Health care provider	700	54 (7.7)	ref.
	Social worker	109	17 (15.6)	6.2 [−0.5;12.9] 0.07
	Digital technology (video-DOT or SMARTbox)	139	9 (6.5)	6.0 [−0.1;12.1] 0.05
	Self-administered	82	23 (28.0)	5.4 [−1.8;12.7] 0.14
	Other	68	13 (19.1)	5.3 [−2.7;13.3] 0.20
Populations	PLHA	181	18 (9.9)	−2.8 [−8.2;2.7] 0.32
	Occupational groups at high risk of infection: health care providers; non-medical staff, who extensively contact with PWTB, coalminers, ATO veterans	136	20 (14.7)	4.7 [−1.1;10.5] 0.11
	Refugees; internally displaced persons; national minorities	60	7 (11.7)	−2.0 [−10.6;6.5] 0.64
	Low income populations in cities/rural areas	378	48 (12.7)	4.2 [−0.1;8.6] 0.06
	Groups with at risk behaviour: people who use injecting drugs; smokers; people with alcohol abuse issues; homeless people; former inmates	253	35 (13.8)	3.5 [−1.6;8.5] 0.18
	At risk populations due to underlying health conditions: people with disability; patients with diabetes; people with mental health issues	396	33 (8.3)	**−4.5 [−8.7;−0.2] 0.04**
	Seniors (over 60 yo)	91	4 (4.4)	−2.5 [−12.5;7.5] 0.62
	Family of PWTB	167	25 (15.0)	4.1 [−1.2;9.5] 0.13

Note: Discrepancies between the groups are reflected as linear probability regressions which simultaneously include all of the indicated factors. The difference percentage reflects the difference in the number of persons who reported their personal experience of stigma in a group compared to a reference population (ref.) if all of the other available factors are taken into consideration. For the key populations people who do not identify with the population were used as a reference group. If the 95% confidence interval excludes the null value and p<0.05, the differences between the populations become statistically significant. Some categories of factors were combined (e.g., key populations) if the sample size within a category was not sufficient for analysis.

Overall, the majority of PWTB did not believe that the stigma they experienced along the TB journey has hindered them from being diagnosed, initiating treatment and remaining in care (Table 6). Almost 8% of patients have reported that stigmatisation by the TB clinics prevented them from receiving services, mostly related to recognising the TB symptoms. Almost the same proportion of respondents (9%) reported stigma in the community acting as a barrier, a smaller proportion of participants reported stigma in a work setting (6%) and stigma experienced in the family (4%). Only two people in a sample have reported that sigma in a teaching facility prevented them from seeking services (i.e., recognising TB symptoms).

The findings were similar when the respondents were asked to describe the stigma experienced by the people they know – the majority did not believe that it prevented them from receiving TB care (Table 7). The respondents reported that the PWTB they know also faced stigma in different settings, the stigma was mostly related to recognising TB suggestive symptoms, but the rest of the patient pathway was not effected as much.

Table 6. Components of the patient pathway and stigma: proportion of PWTB who responded «yes» to Question: «Have you ever experienced stigma in the following settings which was responsible for delays in ...?» (n=1101)

	TB clinic n (%)	Family doctor n (%)	Family n (%)	Work setting n (%)	Teaching facility/ school n (%)	Communi-ty/ neigh-bours n (%)
Recognising TB?	57 (5.2)	42 (3.8)	32 (2.9)	59 (5.4)	2 (0.2)	90 (8.2)
Seeking medical care?	20 (1.8)	9 (0.8)	3 (0.3)	2 (0.2)	–	8 (0.7)
Getting accurate diagnosis?	19 (1.7)	15 (1.4)	3 (0.3)	5 (0.5)	–	5 (0.5)
Beginning treatment?	20 (1.8)	9 (0.8)	4 (0.4)	7 (0.6)	–	9 (0.8)
Getting treatment adherence support?	22 (2.0)	6 (0.5)	8 (0.7)	2 (0.2)	–	11 (1.0)
Completing treatment?	26 (2.4)	7 (0.6)	8 (0.7)	7 (0.6)	–	8 (0.7)
Remaining in medical care post-treatment?	26 (2.4)	10 (0.9)	5 (0.5)	4 (0.4)	–	5 (0.5)
At least one of the above	86 (7.8)	58 (5.3)	42 (3.8)	70 (6.4)	2 (0.2)	100 (9.1)

Table 7. Components of the patient pathway and stigma: proportion of PWTB who responded «yes» to Question: «Are you aware of any cases of stigma in patients with TB or people who had TB in the following setting which was responsible for delays in ...?» (n=1101)

	TB clinic n (%)	Family doctor n (%)	Family n (%)	Work setting n (%)	Teaching facility/ schoo n (%)	Community/ neighbours n (%)
Recognising TB?	35 (3.2)	7 (0.6)	30 (2.7)	29 (2.6)	–	106 (9.6)
Seeking medical care?	19 (1.7)	7 (0.6)	9 (0.8)	7 (0.6)	–	20 (1.8)
Getting accurate diagnosis?	21 (1.9)	5 (0.5)	6 (0.5)	8 (0.7)	1 (0.1)	12 (1.1)
Beginning treatment?	22 (2.0)	4 (0.4)	7 (0.6)	10 (0.9)	1 (0.1)	16 (1.5)
Getting treatment adherence support?	33 (3.0)	2 (0.2)	9 (0.8)	9 (0.8)	1 (0.1)	20 (1.8)
Completing treatment?	37 (3.4)	1 (0.1)	9 (0.8)	11 (1.0)	–	23 (2.1)
Remaining in medical care post-treatment?	21 (1.9)	8 (0.7)	8 (0.7)	9 (0.8)	–	21 (1.9)
At least one of the above	66 (6.0)	18 (1.6)	41 (3.7)	40 (3.6)	1 (0.1)	124 (11.3)

The survey respondents with TB were asked to describe in detail their experience of stigma. Some of the most frequent words and phrases generated as a result of text analysis show that the respondents mostly described stigma at work and coming from friends and neighbours (Table 12).

Note: Words in large print were used most often.

Diagram 12. List of the most frequent words used by the PWTB when describing a personal experience of stigma (n=1101)

The respondents have described severing or significantly limiting their social contacts which resulted in the feelings of loneliness and isolation. PWTB have referred to a change in attitude of friends and family as they found out about the respondents TB status.

> «A nurse spread rumour around the village and all of the neighbours we had good relations with before stopped talking to me; prevented their children from playing with my kids.»
> **Female (45), South**

> «The whole village knew. As I was being discharged from the sanatorium I went grocery shopping; the shop assistants refused to serve me, blocked me from entering the store, so I do not touch anything and breath on them».
> **Male (55), Centre**

> «I was living in a shared accommodation at the time. As I was discharged from the hospital the other residents organised a protest and blocked me from entering the building, placed my personal belongings in the yard, did not even let me stay the night. They were saying that it does not matter how much treatment I get; I am never going to be safe to be around. People with families were the most active, they pressed the housing manager. I had to look for another apartment».
> **Male (46), Centre.**

Stigma and discrimination in a work setting included cases of being fired from employment as a result, breaking off relationships with the colleagues and not being able to find another job.

> «My work colleagues treated me as if I was a leper – would not come close, stopped shaking my hand.»
> **Male, (32), Centre**

> «I wanted to get back to work, but at the time when I got sick and was in treatment a disinfection van came to clean the room I was sitting in and all of the colleagues were like «you what? is she really gonna be back with us? we have young children at home» and the rest. The human resources department has requested me to file for voluntary leave, cos there were gonna be job cuts anyways».
> **Female (32), Centre**

> «In our country getting TB is like getting a sentence. My colleagues at work did not say much, but stopped coming over to talk to me. My boss would communicate with me only by phone. I was completely cured but had to leave that job. Could not bear the attitude and grimaced faces. I am still looking for a job.»
> **Male (52), Centre**

> «I was transferred to light labour and the people there found out the reason why; some wanted me to bring a doctor's note saying that I am safe to be around. I asked my doctor to produce such a document so he did. I framed it and stuck it on the wall over my work station. No more questions followed.»
> **Male (49), South**

> «The Sanitary Services informed my employer about the diagnosis, as a result the college management has chosen not to continue our contract».
> **Female (51), Centre**

Respondents have often referred to the stigma experienced in a health care setting. People who have had TB often mentioned disrespectful attitude exhibited by the medical staff at the TB clinics, as well as Primary Care clinics, including lack of understanding and cases of status disclosure.

Although some respondents spoke fondly of the support they received form their TB doctors, quite often participants expressed dissatisfaction and even outrage at the type of treatment they received while in care. They often referred to the TB doctors as «rude and uncaring», describing them as people who view their patients as «second-rate citizens» with an inherently careless attitude towards treatment and unable to take responsibility for their own health.

«The TB clinic dispenses medication in a baggie with pills wrapped in paper: one paper sachet has Rifampicinum inside and so on...One baggie has four paper sachets. This is their explanation: the patients are different, this is done to prevent diversion. So this is the initial assumption they go by – the patient is not interested in getting the treatment, but he wants to paddle the pills»
Male (52), Centre

Often PWTB emphasised lack of communication between them and the TB care providers, where the patients are not just uninvolved in making decisions about their own health and medical care but are also kept in the dark about their treatment plan and prescribed medication.

«The TB clinic is absolutely ruled by uncaring people, no communication, getting information is like pulling teeth. To get my test results I had to wait in the corridor for the doctor for hours. As the doctor was discharging me, I received no recommendations; wanted to ask something, but the doctor said: «I have a whole bunch of sick people outside my office, you are cured now, what else do you want?»
Female (32), Centre

«The patients are different, but the attitude is the same – heartless, rude and demeaning. Nobody cares if you get well or not».
Female (50), East.

People who have had TB also mentioned being stigmatised at primary care clinics or at other types of specialised medical facilities (non-TB).

«It took me three months of visits to my family doctor to get diagnosed, when my x-ray results came in the doctor started screaming – get away from me, do not come close, put on your mask, take your x-rays and head to a TB clinic, do not come here, you are infectious».
Male (32), East

«My OBGYN has recommended ultrasound. This was not my first visit to this ultrasound office, but just as I have mentioned to the technician my history of pelvic tuberculosis she right off the bat refused to provide services and slammed the door on me in front of everybody. It was two years ago and it still feels like yesterday. I was just refused medical treatment full stop...Now I do not disclose my medical history to the doctors.»
Female (54), Centre

«I fell pregnant right after coming out of treatment for TB and early in pregnancy there was a threat of miscarriage. But I was told right of the bat at my gynaecology office that they cannot be using their facilities, and I need to seek specialised treatment at a different maternity hospital. It was very unpleasant. I refused to go so they prescribed out-patient treatment but refused to hospitalise me».
Female (31), Centre

And finally, quite often PWTB experienced multiple stigma in different settings, e.g., being stigm tised by family and friends, neighbours, in a health care setting and at work. The respondents said that the experience has left them emotionally drawn out.

«None of my family is talking to me. No one would visit me at the clinic, they were scared of being infected. At work I was transferred to light labour, but in time I felt so much emotional pressure I was had no choice but to quit. It is absolutely unbearable to see how people are scared of shaking your hand or coming close to you. My family doctor knew that I completed my TB treatment – atradar the time I had tick-borne encephalitis, but my lungs were clear – still he would not even auscultate me. He wanted me to produce a document supporting the fact that I had competed my treatment. Did not even look at my CT scans or x-rays. I never went back.»
Male (38), Centre

«I stayed at the hospital for about a month, during that time my husband has left me. The neighbours, as they found out that I just came out of the clinic and completed my treatment – they were scared stiff. Stopped coming to my yard, started to keep their distance. When I visited my family doctor – I was wearing a mask, he screamed: «Get away from me!»
Female (43) South

The patients provided a list of suggestions on how to improve TB care and fight stigma associated with tuberculosis in society.

«All of the people in in-patient care have been through so much stress: they are stressed about the diagnosis, because they see people dying around them. They talk about the bogeyman amongst themselves. It is absolutely vital to have a psychologist on call, especially at the start of the TB journey.»
Male (40), Centre

«The information on the Internet is for the experts, there is no reliable information for the ordinary folk. How is it treated, how do you live with it ...»
Male (42), South

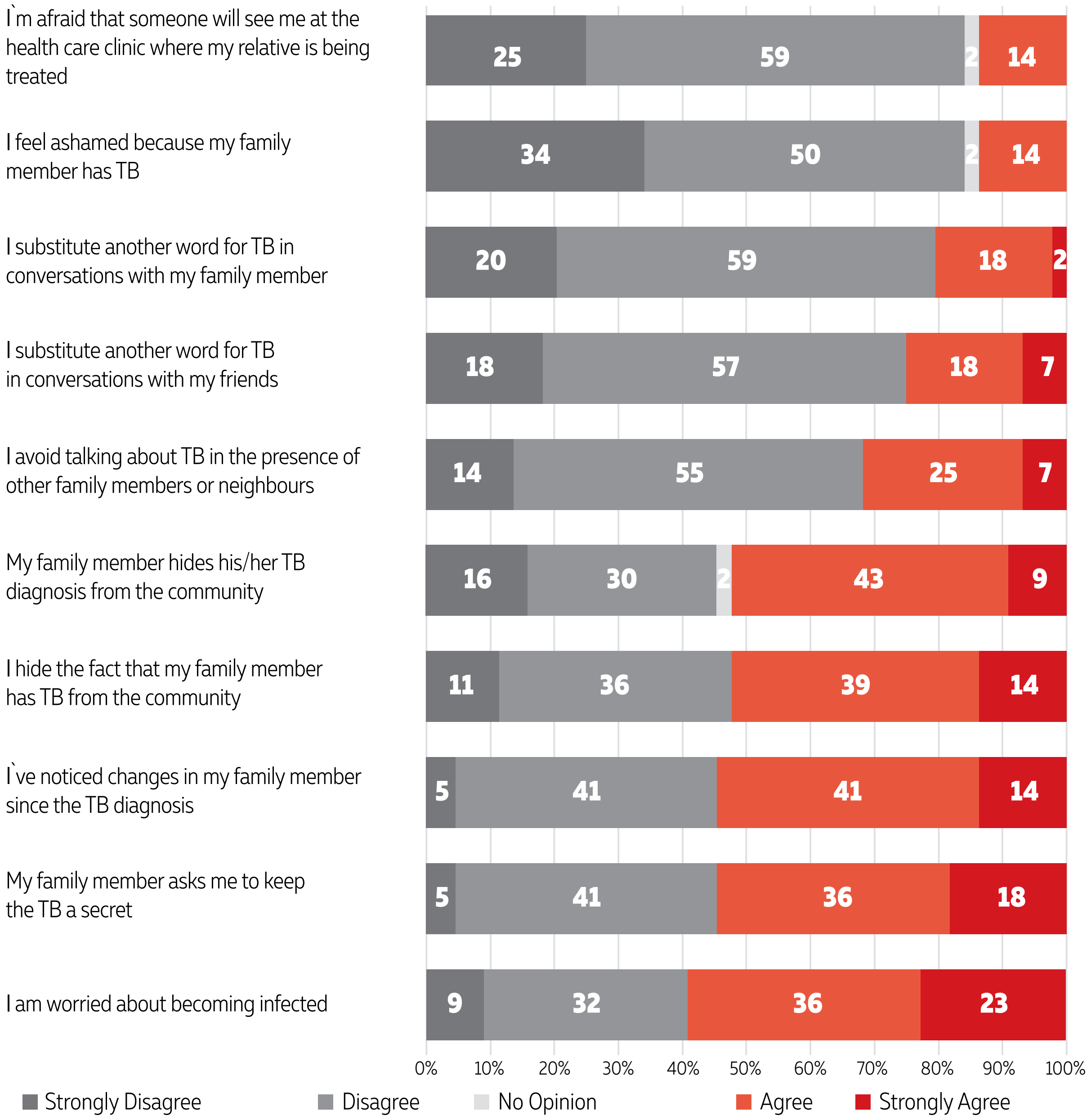
«It is absolutely vital for the people to understand that someone with TB does not become lesser of a person, there is no need to isolate them and stop communication.»
Female (24), Centre

«The media should be producing news stories on the ordinary folk who get TB not just the junkies and winos. They should be saying that it's not a lifetime burden and can be cured. But this information does not get outside the walls of the TB clinics, nobody knows.»
Male (27) Centre.

Secondary stigma in families of PWTB

Secondary stigmatisation is mostly marked by the fear of being infected and status disclosure. Out of the overall number of families surveyed 59% were afraid of getting TB. Over half of the PWTB family members (52%) in the survey chose not to disclose their family member's status (Diagram 13). The feelings of guilt and shame were less prevalent – 20% would use euphemisms when discussing tuberculosis with the infected person, and 14% felt ashamed that their family member was infected with TB. Every seventh respondent (14%) in the PWTB family has reported that that being seen by someone they know at a TB care facility is associated with the fear of status disclosure.

Five respondents (11%) in the group of PWTB family members did not report experiencing any secondary stigma, they supported none of the 10 statements. Just under a half of respondents (18 out of 44) supported 3-4 statements out of 10.



The statements are arranged based on the share of participants who responded with «agree» or «totally agree».
Diagram 13. Dimensions of secondary stigma in families of PWTB: level of support for each statement which refers to living with TB, % (n=44)

The average secondary stigma score among the families was 16.9 points out of 40. The women and first-line relatives, e.g., parents and children scored higher on the secondary stigma scale compared to the rest of the family, however the sample size was not sufficient to assess statistically significant differences (Table 8).

Table 8. The general level of secondary stigma in families of PWTB, per social and demographic populations, (n=44)

		N	Experienced stigma n (%)
	Total	44	16.9 (7.2)
Gender	Women	36	17.5 (7.1)
	Men	8	14.8 (7.5)
Age	18–24	3	15.7 (2.1)
	25–44	18	17.5 (6.0)
	45–64	15	15.5 (8.2)
	65 and over	8	19.1 (9.0)
What is your family relation to a PWTB	Mother/father	12	18.9 (9.3)
	Son/daughter	3	17.3 (5.0)
	Brother/sister	2	13.0 (1.4)
	Other	27	16.4 (6.7)

Note: secondary stigma in the family is measured as a total score in the 10 item questionnaire, see Diagram 13. Each statement was measured on a scale from 0 (totally disagree) to 4 (totally agree). Respectively the total secondary stigma score varies from 0 to 48 – higher scores indicate high levels of stigma. The sample size was not sufficient to test and assess statistically significant differences.

In total, 16% (7 out of 44) family members of PWTB had personally experienced secondary stigma due to having a family member with TB. Almost all of the respondents (6 out of 7) who experienced stigma weren't the first-line relations of PWTB, e.g., grandparents, aunts/uncles, other.

Two out of 44 (5%) respondents reported being stigmatised in specialised TB care and primary care settings which hindered them from providing support to their loved one infected with TB (Table 9). A somewhat larger proportion of respondents (three out of 44, i.e., 7%) experienced secondary stigma within the community which hindered them from supporting their loved throughout their TB journey. None of the respondents reported experiencing secondary stigma at work or teaching facilities, which hindered them from providing support to their relation with TB.

Table 9. Share of families who responded «yes» to Question: «Have you ever experienced stigma which hindered you from supporting your family member with TB when visiting a site which provides direct observed treatment at the start of treatment, during the treatment maintenance stage and at treatment completion?» (n=44)

	TB clinic n (%)	Family doctor n (%)	Family n (%)	Work setting n (%)	Teaching facility/ school n (%)	Community/ neighbours
Recognising TB?	1 (2)	2 (5)	1 (2)	–	–	n (%)
Seeking medical care?	–	1 (2)	–	–	–	–
Getting accurate diagnosis?	1 (2)	–	–	–	–	–
Beginning treatment?	1 (2)	–	–	–	–	–
Getting treatment adherence support?	1 (2)	–	–	–	–	–
Completing treatment?	1 (2)	–	–	–	–	–
Remaining in medical care post-treatment?	1 (2)	–	–	–	–	–
At least one of the above	2 (5)	2 (5)	1 (2)	–	–	3 (7)

When asked about secondary stigma they have witnessed which prevented PWTB from receiving support, majority of the respondents reported being stigmatised by the community (Table 10). Eight family members (18%) reported seeing how other families were stigmatised by the community which hindered them from providing support to PWTB on their TB journey in respect to recognising TB, seeking medical care and completing treatment.

Table 10. Share of families who responded «yes» to Question: «Are you aware of any cases in which other families were stigmatised and which hindered them from supporting their family member with TB when visiting a site which provides direct observed treatment at the start of treatment, during the treatment maintenance stage and at treatment completion?» (n=44)

	TB clinic n (%)	Family doctor n (%)	Family n (%)	Work setting n (%)	Teaching facility/ school n (%)	Community/ neighbours n (%)
Recognising TB?	1 (2)	–	–	–	–	7 (16)
Seeking medical care?	1 (2)	–	–	–	–	1 (2)
Getting accurate diagnosis?	1 (2)	–	–	–	–	–
Beginning treatment?	1 (2)	–	–	–	–	–
Getting treatment adherence support?	1 (2)	–	–	–	–	–
Completing treatment?	1 (2)	–	–	–	–	1 (2)
Remaining in medical care post-treatment?	1 (2)	–	–	–	–	1 (2)
At least one of the above	2 (5)	–	–	–	–	8 (18)

When describing their personal experience of secondary stigma, the families usually referred to the friends and neighbours, i.e., their closest contacts (Diagram 14). The respondents would not usually differentiate between stigma in their family members with TB and secondary stigma in the rest of the family. For example, prejudice towards a family member with TB was perceived as prejudice towards the family as a whole. Only two respondents out of 44 reported being stigmatised at a primary care setting.

Note: Words in large print were used most often.
Diagram 14. List of the most frequents words used by the families of PWTB when describing personal experience of stigma (n=44)

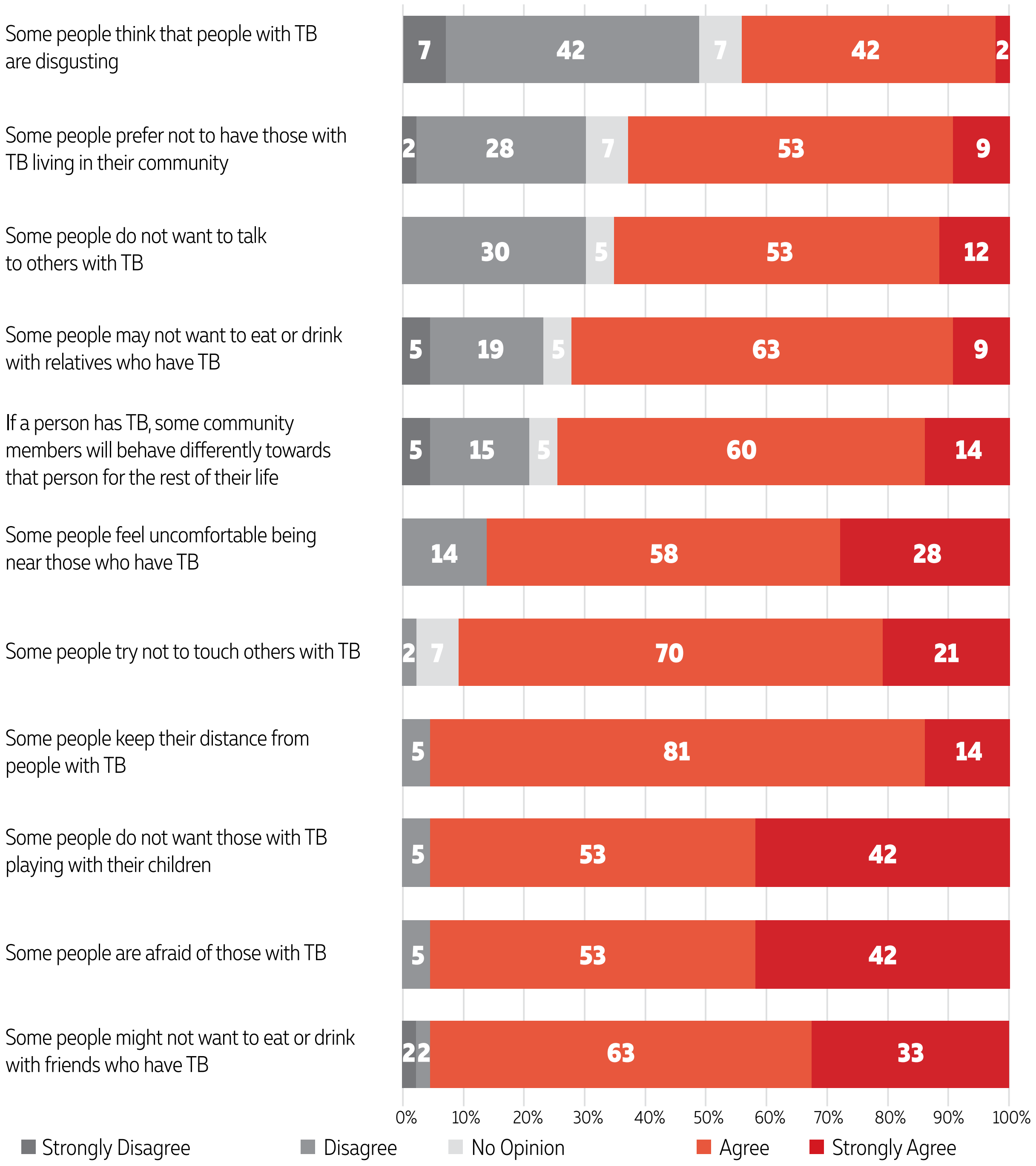
> «When my husband got sick, he was treated very badly by the friends and neighbours; so when I got sick we did not tell anybody».
> **Female (51), East**

> «At school the attitude towards my son has changed. When the sanitary service has arrived to disinfect our house, all of the neighbours were quite shocked as they found out about my disease. Following which the others started avoiding my son at school, he was bullied».
> **Male (41), East**

> «As the family doctor found out that my husband has TB, he started actively avoiding me, saying «I have no time for you». Call me and ask your questions over the phone. Do not come here ever again. It stopped when I got my x-ray done.»
> **Female (21), South**

Anticipated stigma within the community

The registered level of anticipated stigma within the community was quite high, it was mostly manifested as limiting contacts because of the fear of being infected. Over 90% of the responding community representatives have confirmed the statement that people with TB are feared, the other community members try to keep their distance, refuse to share food and drink, do not want their children to have any contact with PWTB (Diagram 15). A large proportion of community representatives believes that the change in the attitude towards people with TB is long term, 74% confirm that if a person has had TB some society members will continue to treat them differently for the rest of their life. Two thirds of community representatives (63%) confirm that some people believe that it is best if people with TB have left their community altogether.



The statements are arranged based on the share of participants who responded with «agree» or «totally agree».

Diagram 15. Dimensions of anticipated stigma in community: level of support for each statement which refers to living with TB, % (n=43)

High levels of anticipated stigma was characteristic of all respondent populations in respect to age and gender (Table 11). At the same time the sample size of community representatives was not sufficient to assess the totality of responses.

Table 11.. The general level of anticipated stigma in community representatives, per social and demographic populations

		N	Experienced stigma
	Total	43	n (%)
Gender	Women	27	31.5 (6.0)
	Men	16	30.1 (7.4)
Age	18–24	2	36.5 (5.0)
	25–44	21	31.3 (6.1)
	45–64	18	29.9 (7.1)
	65 and over	2	32.0 (7.1)
How many PWTB or people who have had TB in the community/ neighbourhood do you know personally?	Two and more	33	31.2 (7.0)
	Just one	7	31.1 (4.6)
	N/A	2	31.0 (2.8)
	None	1	–

Note: the anticipated stigma is measured as a total score in the 11 item questionnaire, see Diagram 15. Each statement was measured on a scale from 0 (totally disagree) to 4 (totally agree). Respectively the total anticipated stigma score varies from 0 to 44 – higher scores indicate high levels of stigma. The sample size was not sufficient to assess statistically significant differences.

Three thirds of the respondents in the communities (72%) have either witnessed or heard about a person from their community who was stigmatised because of TB. Over half of the respondents (58%) knew of someone in the community for whom stigma became a barrier to seeking specialised TB care, including initiation of treatment. A somewhat lesser share of respondents (40%) have either witnessed or heard about cases of stigmatisation associated with tuberculosis in a primary care setting, which hindered PWTB from seeking medical care and getting an accurate diagnosis. Half of the community representatives (51%) recall cases of stigma in the family which happened in their community and confirmed that stigma became a barrier to seeking diagnosis and managing TB.

Table 12. Share of community representatives who responded «yes» to Question: «Do you know any community members with TB who were stigmatised in different settings, e.g., community/neighbourhood, hospitals/clinics, at work which became a barrier to visiting a site which provides direct observed treatment at the start of treatment, during the treatment maintenance stage and at treatment completion?» (n=43)

	TB clinic n (%)	Family doctor n (%)	Family (%
Recognising TB?	21 (49)	9 (21)	12 (28)
Seeking medical care?	19 (44)	16 (37)	15 (35)
Getting accurate diagnosis?	17 (40)	16 (37)	15 (35)
Beginning treatment?	25 (58)	12 (28)	16 (37)
Getting treatment adherence support?	23 (53)	12 (28)	18 (42)
Completing treatment?	23 (53)	14 (33)	16 (37)
Remaining in medical care post-treatment?	25 (58)	12 (28)	15 (35)
At least one of the above	25 (58)	17 (40)	22 (51)

Community representatives have generated a long list of cases of stigma and discrimination that they either witnessed or heard about within their communities. Many respondents cited cases of PWTB being ostracised by their friends and neighbours, being fired and legally mistreated, cases of status disclosure, bullying and secondary stigma in school settings in children who have had TB or whose parents have had TB and stigma in primary care settings (Diagram 16).

Note: words in large print were used the most.
Diagram 16. List of the most frequent words used by the community representatives when describing anticipated stigma (n=43)

> «Sure, there was a case over here when the school found out that a father of one of the boys has had TB; the kid was ordered to sit at a separate desk from the other children, the other kids had been instructed to exercise caution when interacting with him; the other kids' parents event wanted him to be expelled from school, even though his father was out of treatment.»
> **Male (57), West**

> «In our small town we had an incident when a person with TB was dying of hunger; he was up in his flat in an apartment block, he did not have any family close by and even though his door was left ajar none of the neighbours would bring him any food because they were afraid of getting TB. If his family hadn't returned...»
> **Female (32), South**

Community representatives believe that stigma is a significant barrier which results in late referral or unwillingness to seek treatment. They are convinced that PWTB (mostly populations vulnerable to TB) could be subjected to prejudicial treatment anywhere, including in a health care setting.

> «Vulnerable populations are stigmatised the most, especially when the stigma is linked to an HIV status or drug use behaviour. And sometimes the doctors show ignorance, for example, when a surgeon is afraid of being infected he thinks to himself «it's best if I refer the patient to a different clinic». Fear and ignorance — these are the two main causes.»
> **Male (38), West**

> «In my township the medical providers are the ones who usually disclose the status, because there are no legal means of preventing this behaviour. There are no cases of successfully prosecuting the medical providers, because no one wants to enter into a legal battle with a medical establishment and its staff. In general, there is lack of trust in the court system and the people see no sense in filing charges because they believe that they wouldn't be able to prove their case in court but will just create a situation where more people will find out about their status.»
> **Female (30), South**

Community representatives were extremely helpful in developing recommendations on how to fight TB related stigma and what the role the local communities could play in the process. Mostly their recommendations focused on raising awareness in society about TB, e.g., nature of the disease, ways of infection, diagnostic tools, modern means of TB control and so on.

> «There are so many ways keeping the population informed! But [in Ukraine] TB awareness posters can be found only inside the specialised TB clinics. But TB awareness information should be everywhere, first of all, it should be available from the primary care clinics, where the patients are able to see it while waiting for the doctor. Family doctors could be handing out flyers as well, brochures with TB information could be available from pharmacies as advertising material handed out together with the medicines. The people at every level of society need to be informed: from people in the communities to family doctors — TB is not a disease which affects only the homeless and people with alcohol abuse issues, no one is safe.»
> **Male (39), West**

The majority of respondents believe that these efforts should be comprehensive and include raising awareness through the media and the Internet together with pushing the issue to the top of the political agenda of HIV and TB Councils, NGOs and the local MPs.

> «A preacher when giving a sermon also could include a passage on loving thy neighbour with TB, these people live in our community and they are in extreme need of care and support.»
> **Male (57), West**

> «Utilise the capacity of the local programmes, continue cooperation with the health care services supported by the local council. Local MPs are authorised to allocate funds from the local budget to support awareness campaigns.»
> **Female (62), South**

Anticipated and experienced stigma in health care providers

The medical care providers are convinced that the anticipated stigma associated with tuberculosis is widespread within the medical community. An overwhelming majority (90%) have confirmed the fact that there are medical providers who would support quarantining TB patients during the more intense stages of treatment (Diagram 17). Eighty-eight percent of the respondents have expressed support for mandatory TB treatment. Almost three quarters (73%) say that some health care providers try to avoid TB patients.

Only one respondent in the group of the surveyed medical care providers did not agree with any of the statements describing anticipated stigma. Almost every tenth (11%) respondent has supported all of the statements.

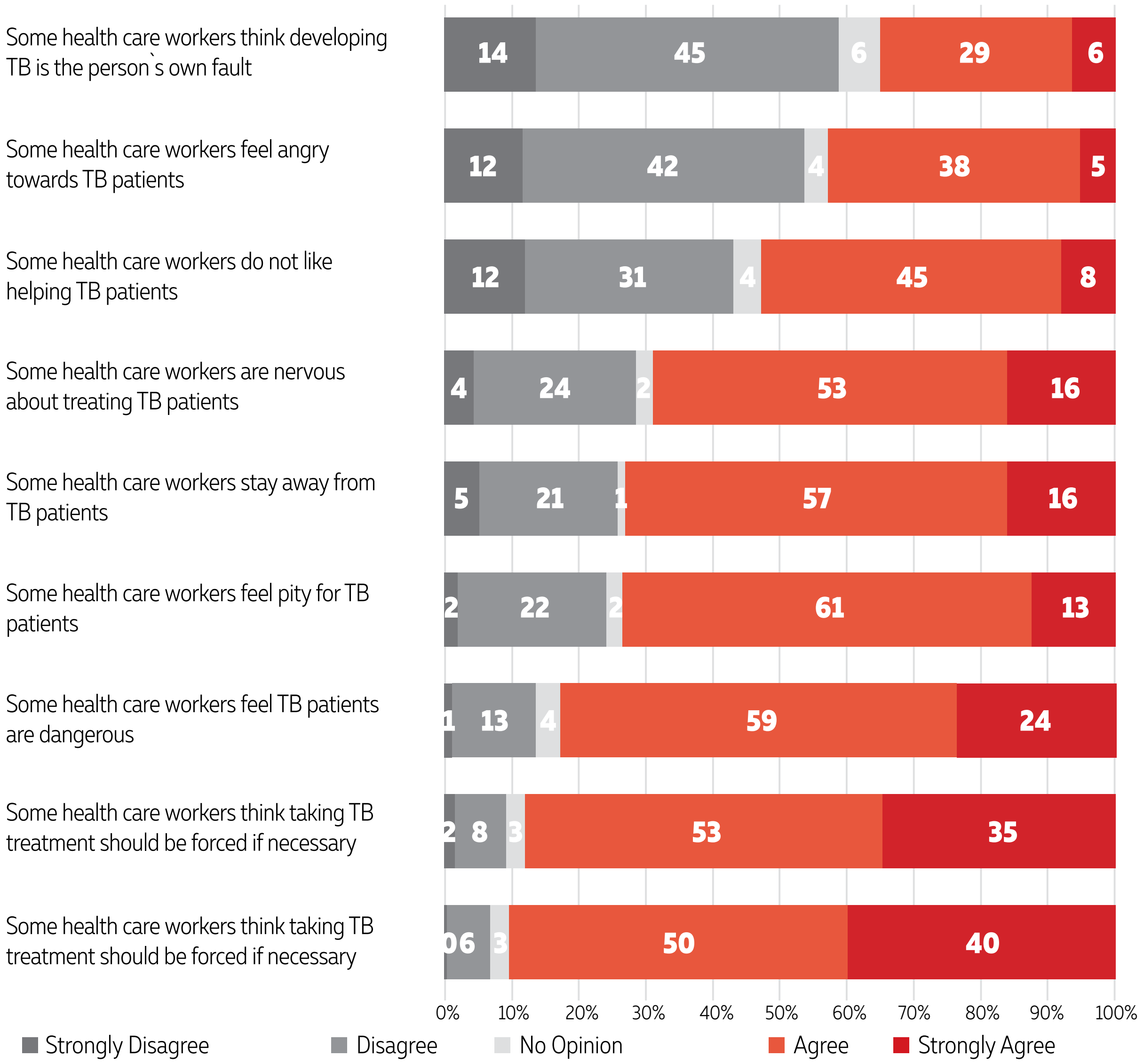


Diagram 17. Dimensions of anticipated stigma in medical care providers: level of support for each statement which refers to living with TB, % (n=248)

Compared to the primary care setting, specialised TB care exhibited higher levels of stigma (Table 13). In the population group a larger proportion of respondents supported the following statement: «Some health care providers believe that patients with TB are a hazard to others», «Some health care providers do not want to be around patients with tuberculosis», «Some health care providers are anxious about providing medical care to PWTB», «Some health care providers dislike providing medical care to PWTB» and «Some health care providers become angry with PWTB».

Table 13. Dimensions of anticipated stigma in health care providers: level of support for each statement which refers to living with TB, per type of TB service, % and number of respondents (n=248)

	Total (N=248)	PC (n=85)	TB care (n=163)	p
Some health care providers believe that it would be best to quarantine TB patients during the more intense stages of treatment.	224 (90.3%)	77 (90.6%)	147 (90.2%)	1
Some health care providers believe that in some cases TB treatment should be mandatory.	218 (87.9%)	76 (89.4%)	142 (87.1%)	0.75
Some health care providers believe that patients with TB are a hazard to others.	205 (82.7%)	62 (72.9%)	143 (87.7%)	0.01
Some health care providers feel pity towards PWTB.	182 (73.4%)	65 (76.5%)	117 (71.8%)	0.52
Some health care providers do not want to be around patients with tuberculosis.	181 (73.0%)	54 (63.5%)	127 (77.9%)	0.02
Some health care providers are anxious about providing medical care to PWTB.	171 (69.0%)	47 (55.3%)	124 (76.1%)	0.00
Some health care providers dislike providing medical care to PWTB.	131 (52.8%)	36 (42.4%)	95 (58.3%)	0.02
Some health care providers become angry with PWTB.	106 (42.7%)	27 (31.8%)	79 (48.5%)	0.02
Some health care providers believe that the TB disease is the patients fault.	87 (35.1%)	23 (27.1%)	64 (39.3%)	0.08

The analysis of distribution of the general level of anticipated stigma as per the employment position has uncovered differences in opinion expressed by the TB care providers and the primary clinics staff in respect to the number of people with TB stigmatised by »some health care providers» (Diagram 18). The TB doctors and infection doctors would often comment on their responses by saying: «Sure, they are not aware of the way TB is transmitted, hence the fear (anxiety, avoiding the patient, and so on)»; the observation mostly referred to the primary care providers. Nonetheless, the nurses at specialised TB clinics have similarly assessed the level of TB associated stigma to the primary care providers, including doctors and nurses. The differences in type of clinic and position remain statistically significant even if the providers' age, gender, and location are controlled (Table 14).

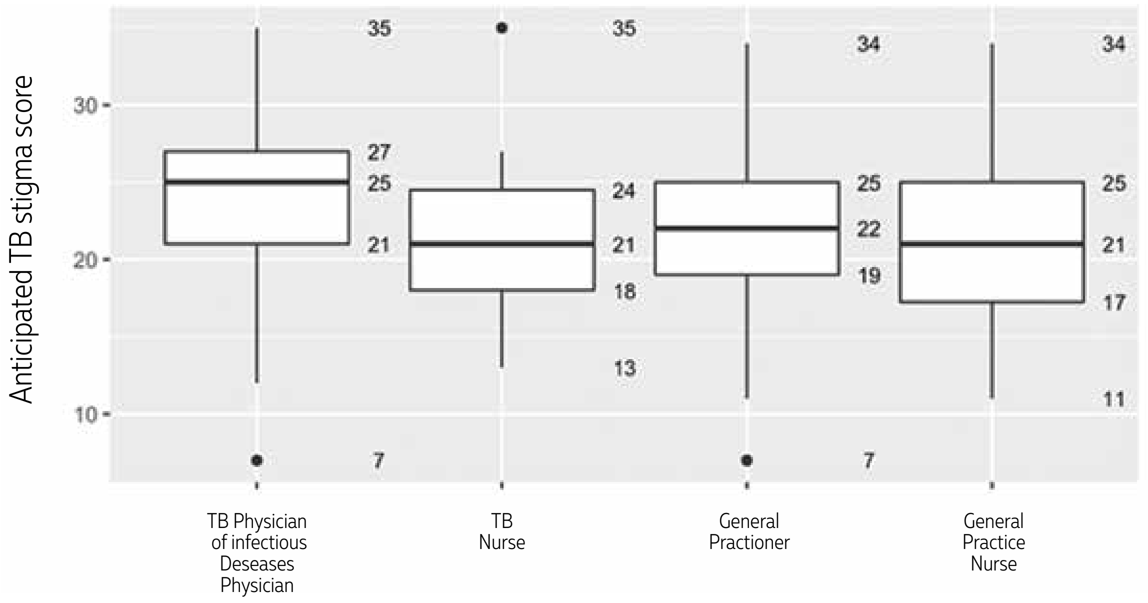


Diagram: The rectangles represent 50% of the most frequent values with the median value indicated by the thick crossline. For example, in the group of primary care nurses a quarter have scored 18 points out of 36, one half scored from 18 to 24 points, and another quarter over 24 points. Mean – 21 points.
Table 18. Level of anticipated stigma in medical care providers, per position, points

Table 14. Factors associated with anticipated stigma in medical care providers (n=248)

Чинник		**Sample size, persons**	**Average anticipated stigma score (standard deviation)**	**Adjusted mean discrepancy [95% confidence interval] p value**
	Total	248	22.5 (5.4)	
Region	East	34	22.4 (5.3)	0.2 [–2.1;2.5] 0.86
	West	36	23.1 (6.4)	0.8 [–1.4;3.0] 0.48
	South	72	22.7 (5.9)	0.5 [–1.4;2.3] 0.63
	Centre	42	22.1 (6.0)	0.2 [–1.1;1.6] p=0.74
	North	64	22.4 (4.0)	ref.
Gender	Women	224	22.5 (5.4)	0.8 [–1.6;3.2] 0.51
	Men	24	22.5 (6.1)	ref.
Age	≤44	129	22.6 (4.9)	ref.
	45–64	104	22.3 (6.0)	–0.4 [–1.8;1.0] 0.55
	65 and over	15	23.3 (6.3)	0.1 [–2.8;3.1] 0.93
Type of TB service	TB care	163	23.2 (5.4)	2.0 [0.6;3.4] 0.01
	PC clinic	85	21.3 (5.3)	ref.
Staff position	MD	152	23.2 (5.5)	1.9 [0.5;3.4] 0.01
	Nurse	96	21.5 (5.2)	ref.

Note: anticipated stigma is measured as a total score in the 9 item questionnaire, see Diagram 17. Each statement was measured on a scale from 0 (totally disagree) to 4 (totally agree). Respectively the total anticipated stigma score varies from 0 to 36 – higher scores indicate high levels of stigma. Discrepancies between the groups are reflected as linear regressions which include all of the indicated factors. The mean difference reflects the difference in the average level of anticipated stigma in a population compared to a reference population (ref.) if all of the above factors are taken into consideration. For the key populations people who do not identify with the population were used as a reference group. If the 95% confidence interval excludes the null value and p<0.05, the differences between the populations become statistically significant. Some categories of factors were combined (e.g., key populations) if the sample size within a category was not sufficient for analysis.

Almost one third (30%) of the health care providers felt the stigma as a result of working with people with TB or people who have had TB. Each fifth respondent (21%) has witnessed or was aware of prejudicial treatment of other health care providers in TB care.

In total, 15% of the providers were stigmatised at work by their colleagues, 12% in the community, and 6% by the family and relations (Diagram 19). A smaller proportion of respondents either witnessed or was made aware of prejudice-related incidents involving other providers and different settings.

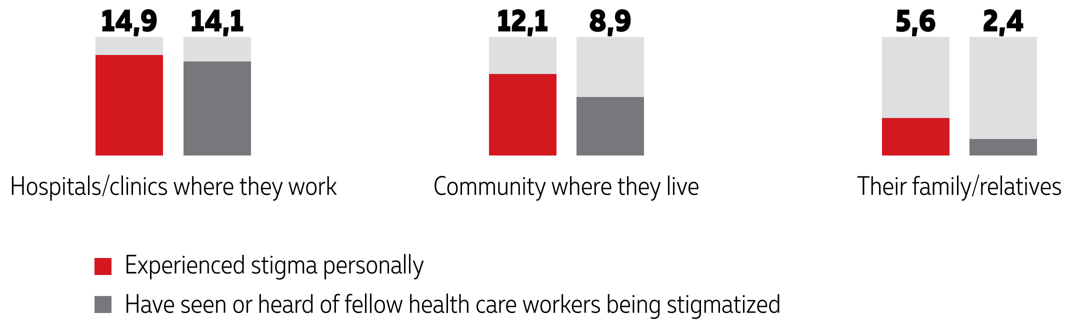


Diagram 19. Share of medical care providers who have personally experienced, witnessed or were aware of prejudice-related incidents due to working with TB patients, %

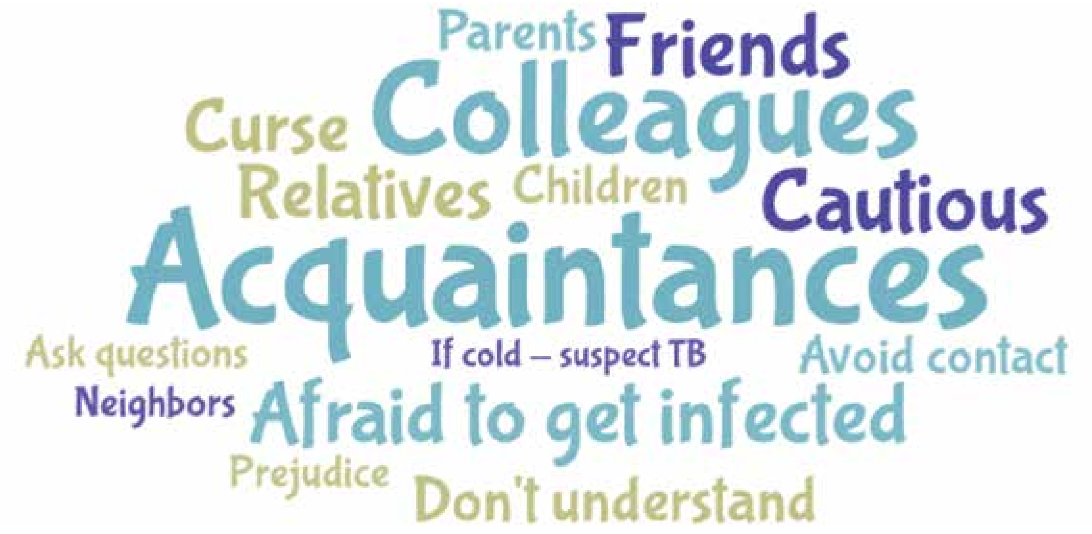
The experienced stigma is much more frequent in TB care providers compared to the providers working in primary care. In specialised TB care 37% were stigmatised by their immediate circle due to working in TB care provision, compared to 17% of respondents employed in primary care (Table 15). Other factors, namely location, age, age, and position bear no significance to their experience of stigma within their immediate circle.

Table 15. Factors relevant to the prejudiced treatment of medical care providers exerted by their close circle because of their interaction with people with TB

		N	**Proportion of medical care providers who have personally experienced prejudicial treatment (n=74)**		**Proportion of medical care providers who have witnessed or were made aware of prejudice-related incidents (n=53)**	
		248	n (%)	Adjusted mean discrepancy [95% confidence interval] p	n (%)	Adjusted mean discrepancy [95% confidence interval] p
Region	East	34	9 (26.5%)	2.1 [–17.1;21.2] 0.83	7 (20.6%)	–6.4 [–23.8;11.0] 0.47
	West	36	10 (27.8%)	2.7 [–15.9;21.4] 0.77	6 (16.7%)	–8.2 [–25.2;8.7] 0.34
	South	72	26 (36.1%)	11.1 [–4.4;26.5] 0.16	14 (19.4%)	–7.6 [–21.7;6.4] 0.29
	North	64	17 (26.6%)	ref.	16 (25.0%)	ref.
	Centre	42	12 (28.6%)	3.6 [–14.4;21.5] 0.69	10 (23.8%)	–2.5 [–18.8;13.9] 0.76
Gender	Women	224	68 (30.4%)	9.1 [–11.1;29.4] 0.37	44 (19.6%)	**–18.6 [–37.0;–0.2] 0.05**
	Men	24	6 (25.0%)	ref.	9 (37.5%)	ref.
Age	≤44	129	36 (27.9%)	ref.	27 (20.9%)	ref.
	45–64	104	33 (31.7%)	2.7 [–9.2;14.7] 0.65	24 (23.1%)	3.0 [–7.9;13.8] 0.59
	65 and over	15	5 (33.3%)	3.6 [–21.4;28.7] 0.78	2 (13.3%)	–12.1 [–34.9;10.7] 0.30
Type of TB service	PC clinics	85	14 (16.5%)	ref.	18 (21.2%)	ref.
	TB care	163	60 (36.8%)	**20.5 [8.5;32.4] 0.00**	35 (21.5%)	0.7 [–10.2;11.6] 0.90
Position	MD	152	49 (32.2%)	8.1 [–4.0;20.2] 0.19	36 (23.7%)	4.0 [–7.1;15.0] 0.48
	Nurse	96	25 (26.0%)	ref.	17 (17.7%)	ref.

Note: Discrepancies between the groups are assessed using a linear probabilistic model which simultaneously includes all of the indicated factors. The difference in percentage reflects the difference in the number of persons who reported on their personal experience of stigma in a group compared to a reference population (ref.) if all of the other available factors are taken into consideration. If the 95% confidence interval excludes the null value and p<0.05, the differences between the populations become statistically significant. Some categories of factors were combined if the sample size within a category was not sufficient for analysis.

Medical care providers, mostly in TB service, believe that the stigma they were experiencing was due to the fear of being infected (Diagram 20). They would illustrate by describing situations when they exhibited symptoms of a common cold their family and relations would immediately assume TB. Several TB doctors have recalled incidents of miscommunication between themselves and the other speciality doctors who were either trying to avoid them or immediately assumed infection. Their neighbours and friends limit contact with them because they believe that working in TB care is associated with a constant risk of infection. Some respondents discussed conflict situations at school when the other parents did not want their children to be in the same classroom with the children of TB care providers. Also, the medical care providers who have had TB experienced more stigma.



Note: Words in large print were used most often.
Diagram 20. List of the most frequent words used by health care providers when describing enacted stigma (n=248)

> «It has been like that a while at our clinic, I have noticed that each time I visit my colleagues at their office, they would try to keep their distance, all of a sudden air the room or switch on the bactericidal lamp...Perhaps, they think I haven't noticed but it is very apparent. So I stopped coming into their office, I would just ask my question without entering the room and be on my way.»
> **TB doctor, South**

> «It does happen, my in-laws avoid communication because I work in TB care».
> **TB care nurse, East.**

> «I never talk about my place of employment and the patients I provide care to; only if I absolutely have to. Because I feel that the attitude will change.»
> **TB doctor, Centre**

> «My boyfriend has broken up with me when he found out that I work at a TB clinic. Kept asking: «How can I be sure that you are not gonna get sick? Do you get like special vaccines or something?» Me being a responsible doctor who follows TB preventive guidelines and keeps herself heathy was not enough for him.»
> **TB doctor, East**

The TB doctors often placed responsibility for perpetuating stigma associated with TB on the other medical care services, mostly the primary care.

> «Here's what I say: the TB service is totally fine with the TB patients, but the primary care providers' attitude is appalling. They are mistreating the other patients as well. Keep their distance, consider dangerous... Fear is the key factor. They are afraid of getting infected.»
> **TB doctor, East**

> «The general care medical system is mistreating its patients, this is true. No one wants to provide care and associate with them in any way. There is a whole history of stigma associated with tuberculosis stemming from the Soviet times where it was strongly associated with the inmate population and drug users... The new generation of doctors are not as prejudiced towards this disease».
> **TB doctor, East**

The primary care doctors also expressed their concerns and emphasised that TB care provision falls within the jurisdiction of TB doctors.

> «Why do some providers avoid providing care to the TB patients? Sure, it's because they are afraid of being infected. Because a sick health care provider is no longer useful. We have no legal protection at all. And some people with TB are intentionally spreading the disease to others...»
> **Family doctor, West**

> «The nurses at my mobile clinic, yeah, they are afraid of bringing something home, infecting their children. Even though the patients in out-patient treatment programmes no longer pose any danger.»
> **Family doctor, Centre**

> «Lack of information and fear. Some are afraid, some do not want to provide care to the patients with TB because these are difficult patients, this is why quite often «this is a TB doctor's job». Make a quick referral to a TB doctor and you are done.»
> **Family doctor, East.**

> «When a patient exhibiting symptoms suggestive of TB comes into the office, the doctor's mind starts racing: is it active TB, can the patient infect me and my nurses? Wish it was possible to speed up the examination process. And at this difficult time of the COVID pandemic the TB doctors could reclaim at least some of their patients from primary care...»
> **Family doctor, West.**

Assessment of the legal and policy environment in TB

According to the Stop TB Partnership recommendations, the assessment of the legal and policy environment in TB focused on the seven TB rights most relevant to living with TB or with the most cases of rights violations. A desk review was conducted to perform the assessment. The review's findings were discussed on two focus groups which aimed to assessing the extent to which the legal and policy environment in Ukraine could harm or protect people diagnosed with TB.

This section focuses on the problems in the legislative environment raised by the focus group participants.

1) Right to Freedom from Discrimination.

Right's essence: All people are equal before the law. There should be legislation in place which prevents prejudicial treatment of people with TB in the public sphere as well as the private sphere, including health care, employment, education, and access to social services.

Assessment of the legislative and policy environment in health care and other fields has not generated any policies which would directly prohibit unequal treatment of PWTB and ensure the rights and liberties of people with TB in education, in work settings and other social aspects.

For example, the policies which regulate legal protection in the workplace offer basic guarantees ensuring equality and freedom from discrimination but allow limiting the rights of people in the workplace due to health. The employment rights are protected by the Ukrainian Criminal Code. However, some employment policies in conjunction with the health care legislation could act as discriminatory in respect to universally limiting access to in paid employment for all PWTB, i.e., being able to retain a source of income.

Health care legislation (Law of Ukraine «On TB Control», Article 21, paragraph 1) limits the rights of people with tuberculosis who are in full-time employment to remain in paid employed as it essentially requires a PWTB to be on medical leave «for the whole duration of the most intense stages of treatment as per the doctor's discretion». Following these employment standards, the employer is essentially required to provide the employee who is in full time employment, with time off work for the duration of TB treatment.

As a result, the List of professions, production companies, and organisations subject to regular preventative health screening which includes restrictions on professional activities as defined by the 208 MoH Decree as of 23.07.2002 is in need of review to ensure the right of people with latent TB to stay in employment and people with active TB to be able to remain in paid employment under conditions which would guarantee their safety and the safety of others, e.g., working from home.

In reference to the policies, the focus group participants and representatives of non-governmental organisations have raised concerns about the growing number of PWTB complaining about discrimination by the employer and prejudicial treatment at work. Stigma and discrimination at work was mostly related to status disclosure and being terminated from employment due to long-term treatment. Also it was mentioned that the law requires PWTB to be on temporary disability leave for the whole duration of treatment which limits the right of people with TB to earn a living. The law also limits the employer's ability to keep PWTB on a payroll in respect to people with TB working full-time compared to PWTB in part-time employment.

Stigma in the family and immediate circle. The focus group participants and NGO representatives have discussed concerns voiced by PWTB in respect to their family life upon establishing/disclosing TB status; as well as relations at work and within their immediate circle, e.g., neighbours, the local residents.

The focus group participants believe that it is possible to eradicate stigma in the immediate circle through comprehensive government supported awareness campaigns on TB, which would focus on the impact of TB on health and community, TB prevention and control, e.g., at clinics, in health care settings, supported by the local council, and so on. These awareness efforts should place a special emphasis on the human dignity and human rights of people with tuberculosis.

Also the medical providers could also become involved in preventing TB associated stigma in the family, in following The Public Health Guidelines and TB Control Guidelines the medical provider is required to (1) conduct investigation of contacts of persons with TB; (2) provide information and raise awareness in patients and their family members on exercising infection control measures at the time of in-patient and out-patient treatment. People exposed to TB are recommended to self-monitor for symptoms.[22]

Language and stigma. The Global Plan to End TB 2016-2020 involves a paradigm shift in ideas, language and communicating about TB which will push tuberculosis up the world political agenda. This change in thinking should start with developing a new language to discuss tuberculosis.

Language can be stigmatising, it shapes behaviour and ideas and could be decisive in initiating treatment or undergoing testing. Similar to the way the HIV/AIDS community tries to avoid such expressions like «the fight against AIDS», the TB community should develop a comprehensive set of people-centred approaches aimed at bringing TB into the spotlight and encouraging people to openly discuss TB in their homes, communities and at work.

The Stop TB Partnership and UNOPS have developed guidelines «Every word counts. Suggested language and usage for TB communications»[23], these guidelines were designed for all engaged in TB control. The developers believe the use of appropriate language has the power to strengthen the global TB response.

The guidelines distinguish between the three types of language used within the TB community and in reference to tuberculosis, namely, the technical language, conversational language, and the language of compassion. In the context of this Assessment it is most relevant to analyse the recommendations on the technical language, which includes methodological, clinical and medical aspects.

For example, the term «case», even though widely used in public health to refer to an instance of a disease, should be used with sensitivity in health to avoid dehumanising people with TB. Patients seeking medical assistance may find it demeaning when a medical provider refers to them as a case; the terms «compliance and non-compliance» which are used to describe treatment adherence unfairly assign blame to the person receiving treatment when many external factors outside of a person's control may be the cause, e.g., systemic health care factors, economic reasons like poverty and so on. Other words like «TB suspects»[24], are stigmatising and harmful, transferring the suspicion of the disease to the person with tuberculosis and suggesting the patient is guilty of a crime or offence. [25]

2) Right to Access Information.

Right's essence: People with TB need to have access to basic information about the disease, ways of transmission, effective preventive measures, treatment options and regimens, including treatment duration, names and types of the medication used, possible side effects and the risks involved in not following the treatment guidelines.

The health care legislation in Ukraine (namely, the Framework legislation of Ukraine on health care, Law of Ukraine «Infection control in general population» and «On TB control») do not follow the in-

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[22] https://phc.org.ua/sites/default/files/users/user90/Nakaz_MOZ_vid_25.02.2020_530_Standarty_medopomogy_pry_TB.pdf;

[23] 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/

[24] e.g., definition of hospitalisation under paragraph 1, Article 1 of the Law of Ukraine «Infection control in general population»;

[25] 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/

ternational guidelines and recommendations and do not include the necessary comprehensive set of information about TB, ways of transmission and risk of infection, effective preventive measures, treatment options and regimens, including treatment duration, names and types of the medication used, possible side effects and the risks involved in not following the treatment guidelines. Moreover, the legislation includes punitive measures for non-compliance.

Policy issues.

The focus group participants have openly criticised the Medical and Social Expert Commission (MSEK) for purposefully withholding information on their procedures and standards of service delivery, terms and requirements for registering a disability. Also the participants have emphasised that many medical providers fail to perform their duties in providing the patients with comprehensive information on the treatment options, including the availability of out-patient care, which essentially prevents the patient from making an informed decision.

The participants have discussed lack of information available to the TB patients, e.g., availability of social support and the existing social services.

3) Right to Access Services.

<u>Right's essence:</u> People with TB have a right to freely and openly access quality services on diagnostic and treatment.

The health care legislation in Ukraine includes legal guarantees on medical care provision to PWTB. However, the by-laws do not include comprehensive guarantees on medical care provision to people with tuberculosis.

Article 49 of the Ukrainian Constitution and health care legislation (namely, the Framework legislation of Ukraine on health care, Laws of Ukraine «On TB control» and «On the state financial guarantees in medical care provision») formally ensure medical care delivery to PWTB by the state, including (1) prevention, diagnostic, treatment and rehabilitation; (2) open access to health care facilities; (3) quality of medical care provision corresponding to the health care standard; (4) financial support to all the citizens and other persons as defined by law in receiving a guaranteed level of medical care services and medicines.

Policy issues:
The focus group participants and civil society representatives have discussed cases of rights infringement of people with tuberculosis in accessing services, namely:
non-provision of medical care and treatment at in-patient facilities;
unavailability of effective MDR-TB treatment;
cases of TB infection while receiving in-patient treatment;
lack of free medication;
TB dispensaries lack the required medication; the patients complain about sub-standard food provision and poor conditions;
discontinued TB treatment due to shortages of Bedaquiline;[26]
lack of medical training and unfriendly doctors;
lack of TB doctors and understaffed medical facilities, e.g., a TB doctor working part-time at 0.25 standard rate, one TB site provides services to the whole borough;

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[26] Some of these issued have been highlighted in the «Legal Environment Assessment for Tuberculosis (TB LEA)» (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);

delays in providing the essential drugs, long delays which sometimes last several months in making medication available;
untimely diagnosis, which results in deteriorated health;
lack of funds in health care together with lacking legislative control over the right to receive free of charge treatment of TB associated diseases;
rights violations of inmates infected with TB;
corruption perpetrated by Medical Commission and other medical care providers refusing to continue disability status for PWTB who refuse to make a «charitable donation»; re-selling anti-TB medication and not providing referrals for medical testing;
delays in medical care delivery at the time the national COVID-19 prevention measures.

4) Right to Privacy.

<u>Right's essence:</u> All of the private information on TB treatment should be kept confidential, stored safely and under no circumstanced should be provided to third parties, except in the following cases (1) when such transfer of data was approved by a qualified medical professional, (2) under strict conditions as stipulated by law, (3) including cases when third parties need to be protected to prevent grievous harm and immediate risk of infection and (4) in cases of exchanging patient data between the medical care providers in the process of delivering TB care.

The health care legislation in Ukraine.

The Law of Ukraine «On TB control» and MoH by-laws on managing TB <u>do not have any explicit references to the right to privacy</u> for people with tuberculosis as reflected in the Framework legislation of Ukraine on health care (Article 39-1, Article 40, Article 78), which requires the medical providers to keep patient data private and confidential.
Policy issues.

The focus group participants voiced concerns over the growing number status disclosures by the medical staff and employers. Notably the procedures for diagnosing and managing TB are not designed to ensure confidentiality of test results and disease management. In Ukraine provision of medical services at the local level has been decentralised which has spawned a strong «corporate culture» within the medical community and resulted in the lack of accountability.

The focus group participants and civil society representatives have discussed at length breach of confidentiality in TB, namely:
the community of people with TB has sought to file claims against medical professionals who disclose private patient information;[27]
MDs fail to keep patient data confidential. They mistakenly believe that sharing sensitive information with the clinic's junior medical staff does not qualify as breach of confidence as they are seemingly not sharing with a third party;[28]
state controlled facilities which house people with TB have failed to ensure proper storage of medical records;[29]

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[27] numerous cases of status disclosure by MDs, mostly in primary care, as well as reckless acts by the junior medical staff which resulted in status disclosure. «Legal Environment Assessment for Tuberculosis (TB LEA)». P.37: https://www.ua.undp.org/content ukraine/uk/home/library/democratic_governance/legal—environment—assessment—for—tuberculosis—in—Ukraine.html;

[28] See «Barriers to TB treatment in Ukraine: Study results. 2020. P.101. https://phc.org.ua/sites/default/files/users/user90/Bariery_likuvannia_TB_report.pdf;

[29] Special report of the Ukrainian Parliament Commissioner On the state of observance of the right to health care and medical assistance in the Pretrial Detention Facilities and penitentiary facilities of the State Penitentiary Service of Ukraine . http://www.ombudsman.gov.ua/ua/page/npm/provisions/reports/.

the patient pathway in TB is not designed to keep the patient data confidential;
correctional facilities unlawfully engage inmates in assisting medical staff in service provision;
difficult to prove in court claims of breaches of confidentiality in TB by the medical workers. Also going to court and engaging in trail proceedings could result in additional breaches of confidentiality;
disclosing a person's TB status often results in rights violations, e.g., being fired from work.

On specific populations:

strong cultural differences between the Romani community and the rest of the population as well as high levels of stigma in people with TB within those communities need to be taken into consideration when managing TB in the Romani people. The national experts point out that status disclosure within the Romani community could often result in physical violence («in a threat of death»);[30]
homeless persons: sensitive health information including test results, diagnostic notes, medical examination notes, HIV test results as per the patient's consent, also including excerpts from the medical record describing medical procedures together with the other medical algorithms are kept in a file which is stored at the facility for the homeless;[31]
people with TB at correctional facilities: disclosure of TB diagnosis during preliminary confinement and at facilities managed by the State Department of Corrections.[32]

5) Right to Informed Consent.

Right's essence: People with TB have a right to informed consent to medical procedures prior to the initiation of TB treatment and right to refuse mandatory treatment under any circumstances.

Policy issues.

The researchers have analysed the direct effect of stigma and discrimination on the right to informed consent to medical procedures in people with TB, as well as on comprehensive provision of information on the treatment options, health risks, availability of social support and so on.

The focus group participants have noted that the existing system of obtaining informed consent to medical procedures is formal in essence, instead they suggested a new system of obtaining informed consent and initiating medical procedures similar to the one which exists in pre- and post-test counselling for HIV.

The participants also discussed methods of informing the patient before signing the medical consent form. The participants have distinguished between passive and active information provision. During passive information provision the patient is given a blank consent form and information brochures available at the clinic at the time. Typically, there is no active information provision when the medical doctor details most relevant aspects of care provision available to a specific patient, treatment options and so on. As a result, the patients are often left uninformed.

6) Right to Freedom from Arbitrary Arrest/Detention and Involuntary Isolation.

Right's essence: People with TB have a right to freedom from arbitrary arrest, including detention and involuntary isolation of individuals with TB disease excluding exceptional instances as stipulated by legislation requisite to what is absolutely necessary and following the application of less restrictive and punitive measures used to fulfil the lawful goals of public health (e.g., to prevent the risk of infection in other people in cases when a person with TB refuses treatment and all other reasonable means of treatment provision have failed.) People with TB should not be detained at non-medical facilities for not following treatment guidelines.

Policy issues.

The group participants have discussed the guidelines regulating the involuntary isolation and mandatory treatment of PWTB and identified the following policy issues:
- the request for mandatory treatment at an in-patient facility or extending the terms of mandatory treatment for patients with active TB is filed by the TB clinic's representative but not directly by the clinic which provides the treatment services (which is also supported by random analysis of court decisions from the 1st of Jan, 2019 till the 1st of Sep 2020[33]). However, some court cases have been filed directly by the clinics[34];
- when reviewing the clinic's request, the courts are not concerned with investigating if all other alternative means of care provision have been applied prior to going to court and filing for mandatory treatment of a person with TB;
- the decision on mandatory treatment at an in-patient facility for people with active TB is made based on the findings made by the supervising medical doctor rather than health care authorities[35];
- a court case on mandatory hospitalisation of a patient with TB with aim to providing in-patient treatment of active TB for the duration of three months is reviewed without the claimant or claimant's representative being present (the court records state that the claimant's representative was duly informed about the time and location of the upcoming court proceedings but failed to appear[36]); also the legislation regulating prompt implementation of court decisions on mandatory hospitalisation of patients with TB or extending the duration of mandatory hospitalisation of patients with active TB is in need of review[37]. There is no follow up of how court decisions on mandatory hospitalisation are implemented by PWTB.

There are no positive changes in respect to the procedure regulating mandatory hospitalisation and prevention of involuntary isolation of people with TB[38].

There is no data published in the open sources on comprehensive monitoring by the state of incidents involving voluntary isolation compared to involuntary isolation of people with TB, duration of isolation, rights infringements of people with TB in the course of implementing court sanctioned hospitalisation of PWTB.

On vulnerable populations: PWTB housed at correctional facilities.

Legislative issues:
The guidelines regulating provision of court sanctioned mandatory treatment for people with TB and HIV-associated TB within the criminal justice system are in need of review. The identified problem areas include limited treatment options; not having access to comprehensive information on associated

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[30] Ibid, p. 78;
[31] Ibid, p. 118;
[32] Special report of the Ukrainian Parliament Commissioner On the state of observance of the right to health care and medical assistance in the Pretrial Detention Facilities and penitentiary facilities of the State Penitentiary Service of Ukraine. http://www.ombudsman.gov.ua/ua/page/npm/provisions/reports/.

[33] http://reyestr.court.gov.ua/Review/84225825;
[34] http://reyestr.court.gov.ua/Review/86525897;
[35] of Ukraine «On TB control», Article 11;
[36] http://reyestr.court.gov.ua/Review/86525897;
[37] of Ukraine «On TB control», Article 11;
[38] Legal Environment Assessment for Tuberculosis (TB LEA)» P. 161. https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_governance/legal–environment–assessment–for–tuberculosis–in–Ukraine.html;

risks, purpose and duration of isolation; gaps in providing social and psychological support; involuntary isolation is exercised regardless of the person's decision to accept/refuse treatment; and no specific time cap on isolation. Involuntary quarantine and isolation should be exercised based on the decision made by a medical facility. In regards to inmates with TB and HIV-associated TB mandatory treatment should be exercised only following a court decision as stipulated by law and only in cases when patients refuse treatment. People with TB and HIV-associated TB in mandatory treatment are currently subject to financial sanctions, i.e., they stop receiving unemployment benefits. Such punitive measures for not following the treatment protocol do not encourage treatment adherence[39].

7) Right to a Safe Workplace

Right's essence: Employees have right to a safe workplace which is reasonably free from health risks and the employer is responsible for implementing measures aimed at reducing the occupational risk of TB.

The health care legislation does not include any special provisions for people with TB who remain in employment. Instead the law encourages social isolation of people with all types of TB. The same principle is stipulated in the by-laws on the extended disability leave (The Ukrainian Labour Code, Article 40) and on preserving continuity of employment (Law of Ukraine «Infection control in general population», Article 25 and «On TB control», Article 21). These two laws need to be harmonised: while one guarantees preserving continuity of employment for people with newly diagnosed TB (regardless of type) or patients with relapsed tuberculosis, the second provides such guarantees only for people with active TB or relapsed TB[40].

Also legislation bans people with TB from working in spheres which involve direct contact with people, e.g., health care, public catering, service industry, and so on).

The legislation continues to limit employment opportunities for people with TB and HIV-associated TB and makes it legal to dismiss PWTB (The Ukrainian Labour Code, Article 40, Law of Ukraine «On TB control», Article 21, «On provision of sanitary and epidemiological control», Article 28, «Infection control in general population», Article 23, List of professions, production companies and organisations subject to periodic preventative screening, approved by the #208 MoH Degree as of 23.07.2002, List of especially hazardous infections and parasitic diseases in humans and carriers of these diseases, approved by the #133 MoH Degree as of 19.07.1995). Safe work conditions are guaranteed by the Ukrainian Labour Code (Article 2, 153–155) but in the context of the existing policies this has no bearing on the creation of a safer working environment for people with TB.

Such policies encourage self-stigma in the commercial sphere when people with TB choose not to disclose their diagnosis or are forced to leave employment. Unregistered workers with TB employed by the shadow economy also present a serious health risk as they are not subject to regular health screening procedures and have no social insurance.

Policy issues.

The focus group participants have concluded that Ukrainian legislation does not allow any employment opportunities for PWTB. However, the experts shared some success stories about people with TB who were able to continue work under the conditions duly organised by the employer.

The key finding based on the analysis of legislative and political environment of TB-related stigma in Ukraine have demonstrated that since the latest assessment of the legal environment and level of stigma in people with TB in Ukraine (2018-2020) no discernible progress has been made in systemically overcoming stigma and discrimination of people with tuberculosis.

For example, the Ukrainian medical reform which claimed as its motto «money follows the patient»[41], has effectively failed at the local level. There is a flood of complaints from patients with TB[42], complaining about the lack of medication, poor conditions at TB clinics, widespread poverty among people with TB who lost their job or are unable to work as a result of disability. The new reform has failed in introducing to health care the new financial principles, that is the financial protection which prevents the patients from incurring massive medical bills and ensures the availability of vital medical care at all times even if there is no available funding at the time of service delivery[43].

Also the patient-oriented approach has not been introduced[44] to legislation and standards of medical care delivery; the legislation on infectious disease control remains punitive in essence – people with infectious diseases and carriers of the disease are warned about the legal consequence of not following the sanitary and epidemiological regulations and spreading the infection.[45]

The health care legislation and by-laws regulating correctional facilities, employment, education, and so on have not been harmonised. The health care legislation and legislation to protect the population from the spread of infectious disease and TB control is largely focused on the medical rights of people with TB. Instead the rights of people with TB like the right to a safe workplace are not protected at all. The Ukrainian labour legislation also does not include such guarantees. This perpetuates systemic stigma in legislation and increases TB-related stigma perpetuated by the «bearers of responsibility.»

The focus group participants made different suggestions as to eliminating stigma and discrimination in legislation; some experts believed that special clauses on the rights of people with TB must be introduced to the health care legislation and respective legislation regulating specific areas, like education and labour laws. Other experts were convinced that the rights of people with TB are part of the human rights and there is no need in developing a special set of regulations for PWTB. Instead the rights of people with tuberculosis should be afforded the same level of protection as the other human rights.

The researchers believe that systemic stigma in legislation will be eradicated as a result of introducing the human rights approach to into the methodology in which legislation is developed and implemented.

The researchers have also emphasised a vital need for extensive government monitoring of rights violations of people with TB. Such monitoring is currently exercised by the National Preventive Mechanism (NPM) with support from the Ukrainian Parliament Commissioner for Human Rights. However, it mostly focuses on specific human right violations relevant to the implementation of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.[46] Regular monitoring reports by the Centre for Public Health essentially present statistical facts but lack deeper analysis in respect to the international human rights context.

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[39] «Legal Environment Assessment for Tuberculosis (TB LEA)» P. 167.» https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_governance/legal–environment–assessment–for–tuberculosis–in–Ukraine.html;

[40] «Legal Environment Assessment for Tuberculosis (TB LEA)». c. 38–44. https://www.ua.undp.org/content/ukraine/uk/home/library/democratic_governance/legal–environment–assessment–for–tuberculosis–in–Ukraine.html;

[41] Draft reform on financing health care in Ukraine. https://zakon.rada.gov.ua/laws/show/1013–2016–%D1%80#Text;

[42] The complaints are presented in Attachments 1-8 to the survey;

[43] Ibid.

[44] Draft of the National target social programme to combat tuberculosis in 2018-2021 https://zakon.rada.gov.ua/laws/show/1011–2017–%D1%80#top;

[45] Law of Ukraine «Infection control on general population»;

[46] For more on the NPM and its functions please visit http://www.ombudsman.gov.ua/ua/page/npm/;

Based on the focus group interviews with the stakeholders the research team has developed a matrix for the assessment of TB-related stigma in the legislative and policy environment (Table 16). The experts have identified gaps in legislation and policies which are sought to protect people with TB, issues in implementation and coverage by the media.

Table 16. Matrix for the assessment of TB-related stigma in the legislative and policy environment, per expert opinion

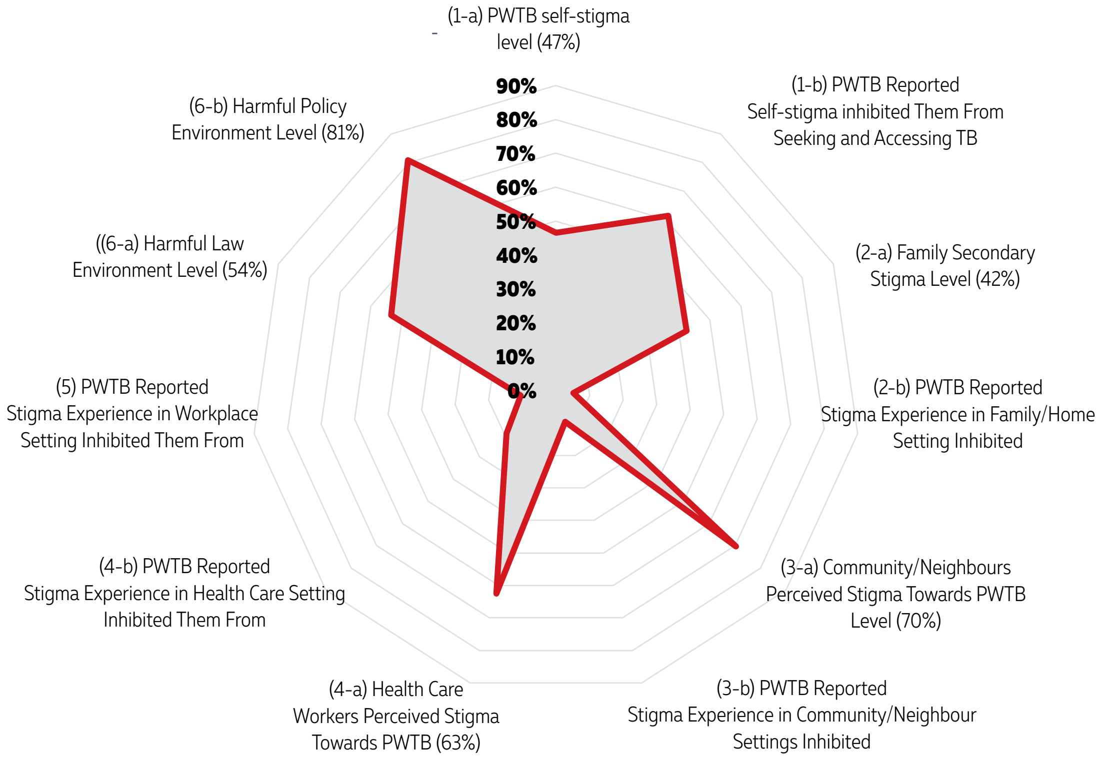
	(1) Introduced		2) Implemented		(3) Covered by the media	
	Legislation	Policies	Legislation	Policies	Legislation	Policies
Right to Freedom from Discrimination	4	0	0	0	2	0
Right to Access Information	2	2	1	2	0	0
Right to Access Services	0	4	1	0	0	0
Right to Privacy	4	1	0	0	2	0
Right to Informed Consent	4	0	0	0	2	2
Right to Freedom from Arbitrary Arrest/ Detention and Involuntary Isolation	4	0	4	0	3	0
Right to a Safe Workplace	2	0	2	3	2	2
Legislation/policies which could harm the rights of people with TB (codes 0-1)	1	5	5	5	2	5

Note: a right is assessed using a following scale:
(1) 0 – national legislation/policies which could harm people with TB; 1 – legislation/policies which could harm people with TB exist at the regional level only, 2 – no existing legislation/policies on people with TB, 3 – legislation/policies which protect people with TB exist at the regional level only, 4 – national legislation/policies which could protect people with TB.
(2) 0 – legislation/policies which could harm people with TB are implemented at the national level; 1 – legislation/policies which could harm people with TB are implemented at the regional level only, 2 – no existing legislation/policies on people with TB, 3 – legislation/policies which protect people with TB are implemented at the regional level only, 4 –legislation/policies which could protect people with TB are implemented at the national level.
(3) 0 – legislation/policies which could harm people with TB are covered by the national media; 1 – legislation/policies which could harm people with TB are covered by the regional media only, 2 – no media coverage of legislation/policies on people with TB, 3 – legislation/policies which protect people with TB are covered by the regional media only, 4 –legislation/policies which could protect people with TB are covered by the national media.

The stigma radar

The stigma radar is a comprehensive standardised assessment of TB-associated stigma which includes internalised stigma, the impact of stigma on accessing services, stigma in the family, community and in health care workers, as well as the stigma's legislative and political environment. The larger the radar web, the bigger the problem.

The assessment results show that the situation is the most dire with anticipated stigma in the community and coming from the health care providers, as well as political barriers which could harm people with TB and perpetuate stigma (Diagram 21).



Note: An indicator is assessed on a scale from 0 to 100%. The larger the radar web, the more likely PWTB will face barriers in seeking and accessing TB services due to stigma and discrimination.
Diagram 21. Stigma radar in Ukraine

Findings

The overwhelming majority of people with TB (97%) show signs of self-stigma. These signs are not always recognised for what they truly are. Often the respondents try to avoid anticipated stigma by not disclosing their TB status to their family or in the community. However, the need for non-disclosure indicates self-stigma and anticipated stigma. Non-disclosure of the status is hardly an effective means of fighting stigma as it increases social isolation and limits opportunities in which PWTB could receive support.

PWTB often identify with several key populations, where each identity can be a source of stigma. Each tenth PWTB has identified with five or more key populations, including people with disability, low-income populations, PLHA, former inmates and so on. Addressing TB-related stigma is not enough, the process requires developing interventions which could address multiple stigma and mitigate its effects on accessing medical care for people with tuberculosis.

TB-related stigma diminishes post-treatment but is never gone completely. In this study PWTB in post-treatment at the time of the interview did not show as many signs of stigma and were more willing to discuss experienced stigma compared to the respondents who remained in treatment at the time of the interview.

Experiencing stigma along the TB journey could prevent PWTB from entering care. In total 39% of PWTB reported that experienced stigma acted as a barrier to accessing TB diagnostic, entering care and receiving support. The reports mostly referred to stigma in a health care setting, in community and at work.

Secondary TB-related stigma in the family was mostly perpetuated by the fear of TB infection and concerns that someone from the community will learn that a family member has TB. At the same time secondary stigma in the family in most cases did not prevent the family from supporting their family members with TB, as they continued to provide support in the family and during hospital visits.

The level of anticipated TB-related stigma in the community is dangerously high. Two out of three community representatives agreed with a statement that some residents do not want people with TB living in their community. It is especially significant when three quarters of respondents believe that having TB has long term consequences regarding how PWTB are viewed in the community. Communities often fail to differentiate between people with TB and people who have had TB, and stigma can continue even post-treatment. Stigma in the community is directly associated with self-stigma in PWTB and secondary stigma in the family when the fear of status disclosure and its possible consequences served as a source for both types of stigma. Addressing stigma in the community would have direct consequences for self-stigma and secondary stigma.

Anticipated stigma is prevalent in the professional community of health care providers, its level measured at 63%. At the same time experienced stigma due to working in TB care is less prevalent: 30% of health care providers were stigmatised in a work setting, in community and family. Usually TB care providers, especially physicians have experienced higher levels of anticipated stigma and enacted stigma compared to primary care providers.

The experts assessed the level of harm in the legislative and policy environment at 54% and 81% respectively, where 0 indicates no harm and 100 – extreme harm to PWTB. The key gaps identified in legislation and policies include lack of laws and policies and/or unwillingness to implement them with aim to protecting the right to freedom from discrimination, right to access information, right to access services, right to privacy, right to informed consent and so on.

Recommendations

The key populations engaged in this study were able to provide recommendations on eliminating TB-related stigma. The following section presents recommendations provided by PWTB, their families, community members and medical care providers; it also includes general recommendations developed by the research team.

Recommendations made by PWTB

People with TB mostly stressed the need for anonymity and their right to non-disclosure of TB status. The second most frequent request was for the medical providers to have a more humane attitude towards patients with TB, including being more attentive, communicating clearly, try to avoid the condescending attitude and meaningfully engage the patients in making decisions in respect to their health. Often PWTB mentioned scaling up access to psychological support, especially while in in-patient treatment and social support. PWTB requested more information in the media about the social impact of TB. Also many respondents have noted the need to improve in-patient living conditions and food provision at TB clinic, including access basic amenities like hot water and working lavatories. Some PWTB have recommended splitting the patient flow at the TB clinics as to more efficiently separate TB patients in different stages of the disease, people with risky behaviours, like alcohol and drug abuse disorders and so on.

Recommendations made by families of people with TB

The recommendations made by the families mostly reflected those provided by the people with TB. The respondents mostly recommended the medical providers to have more training in adopting a more humane and friendly attitude towards the patients. Some family members would like to have psychological support available for the family member with TB as well as the family as a whole. The families also frequently stressed the need to improve the standards for in-patient living condition with regard to the diet.

Recommendations made by community members

Community members stressed the need for large scale awareness campaigns on TB launched at different medical settings, education facilities, on transport networks, social networks and in the media with aim to improving knowledge on TB and busting myths prevalent among the medical community and society as a whole. The respondents in their majority believe that this recommendation should be made a priority. There were some recommendations on establishing a help line on TB which would provide telephone counselling to PWTB and their families. Ukraine already has a TB help line[47], the existing service should be advertised on a larger scale in order to be made available to more people with TB.

Recommendations made by the medical care providers

The medical care providers also have made recommendations on raising TB awareness in society at

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[47] http://helpme.com.ua/ua/tub/info/default.html

large as well as among different groups and levels of medical care providers, namely a) explaining the possible risks posed by the TB patients and b) emphasising that TB acts indiscriminately and the risk of infection goes beyond people of low economic status and people with behavioural disorders due to alcohol abuse and poor living conditions. One medical professional suggested counselling sessions on TB for mothers during vaccinating their children with BCG. The medical community believes that it is absolutely vital to respect confidentiality of a person with TB especially in the rural areas and train the doctors and nurses in TB care and primary care on methods to prevent status disclosure. The medical providers requested training and education on communicating with the patients about TB, especially in primary care and working with at-risk populations to motivate them to get treatment. The medical workers in primary care complained about the lack of clear and concise information materials for the patients and patient success stories which could be used for motivation.

General recommendations

1. Ensure the empowerment and meaningful engagement of people affected by TB in the TB response: Involving people with TB into decision-making regarding their own health and the treatment process. Insufficient communication between the medical provider and patient creates misunderstanding and stigma. The patient should be meaningfully engaged in discussing decisions on treatment, including their treatment options, managing side effects, mental health issues and so on. The doctors should provide this information in a manner which is clear and understandable respective of the patient's age and gender, cultural background and use the terminology understandable to the patient. For best results, the patient's treatment plan should be discussed by a multidisciplinary team which includes the patient, treating physician, psychologist,peer supporter and social worker. This approach ensures the patient's right to be involved in managing their own health otherwise any decision on the patient's health adopted without the patient's approval could be viewed as discriminatory and lead to undesired consequences. Develop and ensure implementation of a detailed algorithm for informing people with TB prior to obtaining informed consent to perform any medical procedures.

2. Create and enabling policy and legal environment

Shaping the political and legislative environment to protect the rights of people with TB. Legislation and policies should include guarantees of continued employment following TB diagnosis, uninterrupted immigration status or qualifying criteria for receiving other benefits or services.

Ukrainian legislation is essentially punitive in respect to people with TB. The current legislation and policies which regulate access to TB care should be analysed in detail to identify discriminatory practices and introduce clauses on preventing discrimination of people with TB and their families at society at large (including but not limited to education and employment) and introduce mechanisms to ensure that these guarantees are implemented in practice based on the human right approach. Ensure due implementation of state financial guarantees in TB care provision. To approve Action plan for 2021-2023 on implementing the State strategy on combating HIV/AIDS, tuberculosis, and viral hepatitis till 2030.

Right to data privacy and confidentiality: In order to ensure the right to privacy MoH of Ukraine should introduce changes to the Law of Ukraine «On TB control» and MoH by-laws on TB management, including MoH Decrees as of 02.09.2009 #657 «Instructions on completing primary reporting documentation #060-1/o «Registration journal of TB cases in _____ region TB 03»; as of 25.02.2020 #530 «On implementing health care standards in TB control»; as of 15.05.2014 #327 «On identifying cases of TB and Mycobacterium infection», joint Decree by MoH Decree and State Committee on Statistics #112/139 as of 25.03.2002 «On introducing primary documentation form N 089/o «Reporting new active TB cases or relapses» and Completion guidelines», including other by-laws developed as per the existing international standards to ensure patient confidentiality for people with TB, and define responsibilities of the medical staff in respect to keeping patient data private and confidential. Add a confidentiality clause to the job descriptions of medical staff with access to private patient information, including the data on TB patients as per guidelines which ensure confidentiality, privacy and security of health information (the obligation of patient-doctor confidentiality). Develop and implement local mechanism for investigating breaches of confidentiality and cases of disclosing protected health information.

To the Ministry of the Interior and Ministry of Justice: prohibit non-medical staff employed by the Department of Corrections and Preliminary Confinement Wards from having access to sensitive health information and ensure security of data.

MoH of Ukraine should ensure the security of health data, including security of digital information (e.g. video-DOT, SMARTBOX, and so on).

The patient should feel safe and confident that private information is not going to be disclosed and confidentiality will be protected. To this end, a state policy on safeguarding patient confidentiality should be developed and implemented as law.

Right to Information: Ensuring the right to information will require introducing changes to the Framework legislation of Ukraine on health care, Laws of Ukraine «On TB control» and «Infection control in general population», Health care standards in TB care, Standards of medical care delivery, and Ukrainian Code of medical ethics with aim to harmonising them with the international standards in legislation and right to information for people with TB. Following introduction of the amendments to the guidelines a system of information delivery and counselling patients with TB should be developed and its implementation should be ensured by the medical providers and providers of social services.

Right to work: Initiate legal amendments to the Ukrainian Labour Code, Laws of Ukraine «On TB control» and «Infection control in general population» in order to create more employment opportunities for PWTB. Introduce amendments to the requirements on completing a temporary disability leave which ensures uninterrupted treatment of TB and rehabilitation as to allow continued employment as per the employee's agreement and if there are no medical contra-indications. Introduce amendments to the Ukrainian Labour Code, Laws of Ukraine «On TB control» and «Infection control in general population» which would create more employment opportunities for people with TB, support implementation of safe working conditions, and preserve continuity of employment for the duration of treatment. Directly ban unlawful denial of employment for people with TB and HIV-associated TB due to health reasons and ensure that the requirement is duly followed by the employers. Prohibit employers from terminating employment with people with TB and HIV-associated TB due to health reasons and prevent them from classifying PWTB unfit to perform certain professional or other types of functions due to the public health reasons associated with their activities.

Right to freedom from arbitrary arrest/detention and involuntary isolation for people with TB. The current legislation regulating involuntary hospitalisation of people with active TB has to be amended in relation to by-laws which govern cooperation between different state services and the courts. More awareness programmes on TB and human rights should involve judges so court decisions on involuntary isolation take into account if any alternative TB control measures were implemented prior to going to court. MoH should exercise control over the execution of court decisions on involuntary isolation by PWTB.

To the Ukrainian Parliament Commissioner for Human Rights: perform regular monitoring of incidences of involuntary isolation compared to voluntary isolation, duration of isolation, and exercise of involuntary isolation for people with TB by the heath care facilities.

To the Supreme Court of Ukraine: make recommendations to harmonise the decision making processes in courts in relation to involuntary isolation of people with active TB and provide courts with respective instructions.
Reports on the regular state monitoring of incidents of involuntary isolation compared to voluntary isolation, duration of isolation, rights violations of people with TB during the implementation of court decisions on involuntary hospitalisation of people with TB should be made available from open sources. Exercise involuntary isolation as the final means following all other available means of motivating the patient.

Introduce amendments to the criminal code with aim to harmonising the criminal law with international standard on mandatory treatment sanctioned by the court for people with TB and HIV-associated TB in the criminal justice system, namely in ensuring access to effective treatment regimens, obtaining informed consent, and providing social and psychological support.

3. Enhance cooperation between the Ministry of Health and the Ministry of Social Policy

Strengthen cooperation and improve exchange of information with respect to confidentiality between agencies which provide health services and social services and/or grass roots civil society organisations which work with people in crisis. Developing and implementing methods of cooperation at the local level has proved to be an effective way of improving assess to TB services in Ukraine, especially for people at risk of tuberculosis due to difficult social circumstances. These joint interventions should the introduced into the national strategy and become part of norms and regulations which ensure their effectiveness, namely governing cooperation between the Ministry of Health and Ministry of Social Policy of Ukraine.

4. Ensure linkages and integration of TB care and support services along the TB journey

Scale up access to effective diagnostic of TB for anyone with symptoms suggestive of tuberculosis and effective and efficient test result communication. Study results show that extended periods of waiting for the TB test results especially when screening for the infectious types of TB and drug-resistant tuberculosis could result in long term stigma and self-stigma. But effective methods of testing for TB are able to detect Mycobacterium in sputum and identify specific types of TB which are resistant to first-line drugs within just several days. When using precise testing methods, a patient is able to initiate treatment in due time, effectively prevent the spread of infection, and return to life as normal without enduring stigma and long term isolation. In order to ensure the state financial guarantees on early TB diagnosis, it is important to harmonise Standards in medical care delivery in Primary Care and Standards of medical care delivery in Diagnosing and managing TB in adults and children, namely the patient pathway in accessing medical and social services for patients with symptoms suggestive of tuberculosis or people with TB.

Addressing TB stigma and raising TB awareness during the contact tracing process. Contact tracing for household contacts following a positive TB test could be a source of stigma. It is important to ensure provision of quality counselling on health literacy in the process of tracing contacts, e.g., provide family counselling and patient support in disclosing TB status to family and friends.

Develop and scale up interventions for PWTB to eliminate self-stigma as component of a comprehensive set of TB care services. It is vitally important to empower patients to successfully counteract stigma and self-stigma by fighting stigmatising language and learning to accept their diagnosis, e.g., by participating in self-help groups for TB patients. In this respect, TB clubs have proven to be one of the most effective programmes with international success.[48] The TB clubs were usually organised on a weekly basis by medical providers or social workers to provide social support, encourage treatment adherence and manage adverse effects of the drugs. The interventions were developed based on the principle of the Acceptance and Commitment Therapy (ACT)[49], which counteract TB-related guilt and the feelings of shame.

Ensure peoples' right to information: Other types of successful interventions could include mandatory provision of comprehensive information on TB, ways of transmission, effective means of prevention, treatment options and regimens, duration of treatment, types of medication, adverse effects of medical drugs, and the risks involved in not following the treatment regimen. This information should be provided to a person with tuberculosis by the medical provider or social worker during the first motivational counselling session and made easily available to the patient by providing information booklets which the patient can study at a convenient time or through information in the patient's personal e-account.

Scale up linkages and access to interventions to ensure access to social, psychosocial and financial support, to ensure social stability and financial independence. It is vital to scale up access to TB-related social services, psychological support and economic rehabilitation of people with TB. Peer-to-peer counselling has been identified as a recommended strategy.

Economic rehabilitation of people who have had TB ensures the right of PWTB to continued employment and education, work in a safe environment and equal opportunities in education. Advocacy efforts should be in place on preventing rights violations and protecting the rights of PWTB and people with HIV-associated TB by introducing changes to collective employment agreements, motivating the employers to develop policies and programmes for TB prevention and providing support to people with TB by adding relevant clauses to the collective employment agreements and so on. To successfully implement policies to prevent stigma and discrimination in people with TB at work, workplace interventions should be developed, including awareness campaigns to combat stigma and discrimination of people with TB, infection control programmes at work, support programmes for people with TB, including setting up DOG sites under the company medical units. Organise awareness campaigns on the right of PWTB to preserve continuity of employment and their right to a safe workplace with support from trade unions and employers' associations.

Launching rehabilitation and support programmes for people who have had TB and are currently in post-treatment, but continue to need medical follow-up and social support. The study has confirmed that TB-associated stigma continues in people who are in post-treatment and pose no risk of infection. TB awareness campaign and documents which shape the policy environment in Ukraine should include clear messages stating that people who have had TB no longer pose an infection risk to others and should be given full access to vital medical services to prevent relapse of TB disease.

5. Enhance health care worker training to eliminate TB stigma

Protection of data privacy and patient confidentiality. The study includes numerous cases of TB

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[48] Demissie M, Getahun H, Lindtjørn B. Community tuberculosis care through «TB clubs» in rural North Ethiopia. SocSci Med. 2003 May;56(10):2009–18. doi: 10.1016/s0277–9536(02)00182–x. PMID: 12697193.

[49] Luoma, J.B. and Platt, M.G., 2015. Shame, self–criticism, self–stigma, and compassion in Acceptance and Commitment Therapy. Current opinion in Psychology, 2, pp.97–101.

status disclosure, including breach of confidentiality by health care providers. The study has confirmed that health care workers, e.g., physicians and nurses, require training on the human rights issues including identifying and managing cases of patient discrimination.

The patient should feel safe and confident that private information is not going to be disclosed and confidentiality will be protected. To this end, a state policy on safeguarding patient confidentiality should be developed and implemented as law. The information on the basic principles of the policy should be visibly displayed at each clinic; and be made available from the patient's personal e-account. The medial staff should be duly informed about the legal consequences of a breach of confidentiality.

6. Enhance public / Community awareness on TB and their rights

Launch awareness campaigns to bust myths which perpetuate TB-related stigma and discrimination. For the most part TB stigma is fuelled by the fear of infection. This fear is stoked by lack of knowledge in the community on the ways TB is transmitted and the level of risk which TB infected patients could pose to others. It is important for the awareness campaigns to focus on the ways of transmission and prevention while stressing the following messages: a) within 2-3 weeks of taking anti-TB medication a person with tuberculosis is no longer infectious to others, b) TB is treatable, c) TB can be treated in out-patient programmes at the time of diagnosis. It is important to introduce human rights awareness as part of these information campaigns and continue raising awareness in communities, in medical providers and other service providers on the rights of people with TB. The campaigns should also be used to inform the public on the new procedures regulating TB care delivery under the medical reform and the available social services for PWTB.

Active campaigning in communities. Launching information and awareness campaigns in the national media may not be sufficient to eradicate stigma at the grass roots level. It is important to support activities in communities by engaging community members. Interventions to eradicate stigma in communities could be implemented with support from specially trained volunteers[50], medical providers and social workers who could distribute information materials, facilitate group sessions and interactive sessions on TB during such events like the local council meetings and church gatherings.

It is absolutely vital for community leaders to engage as part of awareness campaigns. The list of community leaders could include heads of local council, town mayors, representatives of the local authorities, local MPs, major local employers, educators, popular artists and so on.

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[50] Balogun, M., Sekoni, A., Meloni, S. T., Odukoya, O., Onajole, A., Longe-Peters, O., Ogunsola, F., & Kanki, P. J. (2015). Trained community volunteers improve tuberculosis knowledge and attitudes among adults in a periurban community in southwest Nigeria. The American journal of tropical medicine and hygiene, 92(3), 625–632. https://doi.org/10.4269/ajtmh.14-0527

Attachment 1. Description of indicators in the TB stigma radar

Indicator	Description	Method	Result
(1-a) PWTB self-stigma level (0–100%)	12 item questionnaire with a scale from 0 to 4, where the higher score indicate higher stigma; the tool adapted from Van Rie TB Patient Stigma Scale, Tropical Medicine and International Health 2008;13(1):20–30)	numerator: total score in the 12 item questionnaire within the general sample; denominator: number of respondents x 4 (points) x 12 (number of questions)	47%
(1-b) PWTB Reported Self-stigma Inhibited Them From Seeking and Accessing TB Services	Based on response to the following question: «Have you experienced any of these feeling [12 self-stigma questions] when seeking TB treatment services and accessing the services?"	numerator: number of respondents who answered «yes» to a question; denominator: number of respondents	61%
(2-a) Family Secondary Stigma Level (0-100%)	10 item questionnaire with a scale from 0 to 4, where the higher score indicate higher stigma; secondary stigma experienced by the family of PWTB at the time of diagnosis – tool Arcencio TB Stigma Scale, Public Health Action 2014;4(3):195–200)	numerator: total score in the 10 item questionnaire within the general sample; denominator: number of respondents x 4 (points) x 10 (number of questions)	42%
(2-b) % PWTB Reported Stigma Experience in Family / Home Setting Inhibited Them From Seeking and Accessing TB Services	Based on response to the following question: "Have experienced stigma in a home/family setting which has prevented you from seeking and receiving services on diagnosing and managing TB?"	numerator: number of respondents who answered «yes» to a question; denominator: number of respondents	5%
(3-a) Community/ Neighbours Perceived Stigma Towards PWTB (0–100%)	11 item questionnaire with a scale from 0 to 4, where the higher score indicate higher stigma; tool adapted from Van Rie TB Community Stigma Scale, Tropical Medicine and International Health 2008;13(1):20–30	numerator: total score in the 11 item questionnaire within the general sample; denominator: number of respondents x 4 (points) x 11 (number of questions)	70%
((3-b) PWTB Reported Stigma Experience in Community/ Neighbour Settings Inhibited Them From Seeking and Accessing TB Services	Based on response to the following question: "Have you ever experienced stigma (i.e., prejudiced attitude) in a neighbourhood setting which has prevented you from seeking and receiving services on diagnosing and managing TB?"	numerator: number of respondents who answered «yes» to a question; denominator: number of respondents	10%
(4-a) Health Care Workers Perceived Stigma Towards PWTB (0–100%)	9 item questionnaire with a scale from 0 to 4, where the higher score indicate higher stigma; tool adapted from Corrigan 9 Stigma Domains (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: total score in the 9 item questionnaire within the general sample; denominator: number of respondents x 4 (points) x 9 (number of questions)	63%

(4-b) PWTB Reported Stigma Experience in Health Care Setting Inhibited Them From Continuing to Seek and Access TB Services	Based on response to the following question: "Have you ever experienced stigma (i.e., prejudiced attitude) in a health care setting (hospitals/clinics) which has left you feeling uncomfortable and prevented you from seeking and receiving services on diagnosing and managing TB?"	numerator: number of respondents who answered «yes» to a question; denominator: number of respondents	19%
(5) PWTB Reported Stigma Experience in Workplace Setting Inhibited Them From Seeking and Accessing TB Services	Based on response to the following question: " Have you ever experienced stigma in a work setting which has prevented you from seeking and receiving services on diagnosing and managing TB?"	numerator: number of respondents who answered «yes» to a question; denominator: number of respondents	11%
(6-a) Harmful Law Environment Level (0–100%)	The current laws on the 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 assessed on a scale from 0 (extreme harm) to 4 (no harm) based on the following criteria: existing laws/by-laws, execution of laws, coverage of the execution of laws in the media.	numerator: 1 – (total score from 7 (rights) by 3 (parameters) in the matrix; denominator: 7 (rights) x 3 (parameters) x 4 (maximum score))	54%
(6-b) Harmful Policy Environment Level (0–100%)	The current policies on the 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 assessed on a scale from 0 (extreme harm) to 4 (no harm) based on the following criteria: existing policies, execution of policies, coverage of policies in the media.	numerator: 1 – (total score from 7 (rights) by 3 (parameters) in the matrix; denominator: 7 (rights) x 3 (parameters) x 4 (maximum score))	81%