





# COMMUNITIES, RIGHTS AND GENDER TB TOOLS ASSESSMENTS IN UKRAINE

# **REPORT**

ON THE PROJECT RESULTS

data as of October-December 2017

# REPORT ON THE PROJECT RESULTS "COMMUNITIES, RIGHTS AND GENDER TB TOOLS ASSESSMENTS IN UKRAINE"

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Report on the project results "Communities, Rights and Gender TB Tools Assessments in Ukraine" — (data as of October — December 2017), «Alliance for Public Health»., Kyiv 2018. — 112 pages.

The study was made possible due to the support of the Stop TB Partnership. The information outlined in this publication does not necessarily reflect the views of the Stop TB Partnership.

The authors of this report appreciate the unique input of Dr. Yana Terleeva, (State Institution «Public Health Center of the Ministry of Health of Ukraine"), whose expertise significantly contributed to this research study.

We would like to acknowledge the expert contribution of U.Galustyan, O.Klimenko, K.Maksimenko, U.Pylypas, V.Pylypenko, V.Rudenko, and O.Smetanina.

Special thanks to all the stakeholders, activists and TB survivors, people who never give up in their efforts to end TB epidemic in Ukraine.



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# **ABBREVIATIONS**

AIDS	Acquired Immunodeficiency Syndrome		
ART	Antiretroviral therapy		
ATO	Armed conflict zone in the East of Ukraine		
BCG	Bacillus Calmette-Guerin		
CEDAW	Committee on the Elimination of Discrimination against Women		
СО	Community Organization		
DOT	Directly observed therapy		
GF	Global Fund to Fight AIDS, Tuberculosis and Malaria		
HIV	Human Immunodeficiency Virus		
ICF	International Charity Foundation		
IDP	Internally displaced person		
LGBT	Lesbian, gay, bisexual and transgender		
MDRTB	Multidrug-resistant TB		
МОН	Ministry of Health of Ukraine		
MSM	Men who have sex with men		
M&E	Monitoring and evaluation		
NGO	Non-governmental organization		
PHC MOH Ukraine	Public Health Center of the MOH of Ukraine		
PHR	Populations at high risk of TB		
PLWH	People living with HIV		
PWID	People who inject drugs		
RHP	Rural health post		
SIDA	Swedish International Development Cooperation Agency		
SMT	Substitution maintenance therapy		
ST	Sexually transmitted infection		
SW	Sex worker		
ТВ	Tuberculosis		
UNAIDS	Joint United Nations Programme on HIV/AIDS		
UNODC	United Nations Office on Drugs and Crime		
WHO	World Health Organization		
XDR TB	Extensively drug-resistant TB		

# INTRODUCTION

The Global Plan to Stop Tuberculosis (TB) calls for change in the paradigm of TB service provision by switching to active search for patients, integrated services, optimization of financial investment, and focus on the gender-oriented needs of people facing TB. As in many countries, for a number of reasons a disproportionate share of people in Ukraine go unnoticed by the health system, face limited access and specific barriers to receiving TB diagnostics and treatment, and are subject to higher risks caused by biological and/or behavioral factors, stigma and discrimination, and systematic violations of their rights. Globally there are 1.5 million people with tuberculosis that are currently missed by health systems.

Stop TB Partnership, in accordance with the paradigm shift demanded in the Global Plan to End TB, has developed several tools to help in this process. These tools include a legal environment assessment, gender assessment, key populations data action framework and a community monitoring tool. Stop TB has also supported training in the implementation of these tools. This gender and key populations data action assessment are part of this work.

In November and December 2017 the International Charitable Foundation "Alliance for Public Health" in collaboration with the Stop TB Partnership implemented the project "Tools for Evaluation of Communities, Rights and Gender Aspects in the TB Context in Ukraine". The project included a study based on the tool developed by the Stop TB Partnership Gender assessment tool for national HIV and TB responses and Data for Action Framework on Key, Vulnerable and Underserved Populations<sup>1</sup> (in Ukrainian legislation — "populations at high risk of TB"<sup>2</sup> or PHR).

Using a gender-based approach to assess TB programs helped to identify barriers and risks for men, women and transgender people within TB programs. This in turn will aid service planning and development of interventions considering human rights and gender specifics.

Application of the second tool focused attention on PHR that, in the existing epidemiologic and socio-economic conditions in Ukraine, are at high risk of TB infection and suffer the most from the negative consequences of TB. Thorough analysis involving expert opinion and public consultation allowed formation of an exhaustive list of PHR, intended to be updated annually on national and regional levels. The analysis' results and recommendations are to ensure that the health system of Ukraine takes into consideration populations vulnerable to TB that are usually underserved in terms of TB care. The tool may also be used by NGOs as a strong advocacy tool.

A specific feature of the study was involvement of a broad range of stakeholders in desktop review and public consultations, and a qualitative element that included two focus group discussions with women and men who had survived TB, as well as in-depth interviews in four regions of Ukraine with 22 experts (medical specialists, representatives of public bodies and civic leaders) and people who had

Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations Working Document. September 2017. http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key, %20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf

<sup>2</sup> Order of the Ministry of Health of Ukraine of May 15, 2014 № 327 http://zakon3.rada.gov.ua/laws/show/z0577-14

faced the problem of TB (30 patients and their relatives). An opportunity to hear from people who had personally suffered from TB provided important information about their needs in the context of the TB care system.

Among the qualitative data collection key findings were the specific needs of women, men and transgender people with regard to TB diagnostics and treatment. In particular, members of the focus groups emphasized the need to separate "gender flows" during diagnostics procedures, ensure acceptable conditions in inpatient facilities taking gender aspects into account, provide social and psychological support for TB patients and their families at all stages of TB treatment, and switch to outpatient treatment as the form that most satisfies the many needs of patients without placing a significant financial and organizational burden on the healthcare system.

Triangulation of information provided by the study enabled identification of numerous barriers encountered by people accessing TB services and other social health determinants, discussion of effective mechanisms to overcome such barriers through policy change at national and regional level based on equal and fair access to services, and preparation of recommendations on strengthening the national TB and TB/HIV response.

As the result of working meetings and consultations with the wide group of national experts and stakeholders based on the use of updated Instrument *Prioritizing Populations of High Risk for TB*<sup>3</sup>, recommendations were provided that prioritised key populations (Roma and Internally Replaced Persons) should be included in the next phase of the study for: 1) qualitative study (focus groups and/or in-depth interviews) with representatives of these specified KPs to explore cultural factors, all types of risks and barriers regarding TB; 2) quantitative data collection to study prevalence of cultural factors, risks and barriers identified for these prioritised KPs in the qualitative study, as well as using TB screening questionnaire. We will see for opportunity to link the follow up on the person screened and referred to TB services through available programmatic support interventions to ensure the TB prevalence estimates. The received data will be used to further advocate and secure the Government buy-in for launching TB programs/interventions for the prioritised KPs in several strategic regions of Ukraine, to test the feasbility of the CBO-public-private collaboration in delivering person-centered patient-friendly TB services to the prioritised KPs.

<sup>3</sup> Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations Working Document. September 2017. http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf

# SECTION I.

# Problem Description and Goals of the Study. Study Methods and Tools.

#### Problem description

Fighting tuberculosis in Ukraine is a state health policy priority and one of the country's international commitments. According to estimates provided by WHO experts, TB incidence and mortality rates have been decreasing over the last five years<sup>4</sup>; new modern methods of TB diagnostics (including of multidrug-resistant (MDR) TB) and standards of treatment for patients with all forms of TB are being implemented and collaboration between HIV and TB services has been established; a TB patients' registry has been created. At the same time, the WHO considers Ukraine a country with a high burden of TB and MDR-TB. The TB epidemic is characterized by the significant spread of multidrug-resistant and extensively drug-resistant (XDR) TB, relatively high MDR-TB-related mortality, and growing prevalence of TB/HIV co-infection. In 2014, Ukraine was among the world's top five countries with the heaviest burden of multidrug-resistant tuberculosis<sup>5</sup>. Current TB prevalence is 82.1 per 100,000 population<sup>6</sup>, which is almost three times higher than the target set by the Global Plan to Stop TB. In this situation, especially dangerous factors include: late presenting of TB patients for medical aid; delayed detection of TB or HIV/TB co-infection resulting in high TB mortality, and insufficient coverage of vulnerable populations (so-called populations at high risk (PHR) of TB)<sup>7</sup>.

To shape a sustainable response to the problem of TB and comply with international obligations to fight TB, the government has developed and approved the Concept of the National Targeted Social TB Program for 2018–2021<sup>8</sup>. Following a Europe-wide approach, Ukraine will continue implementing patient-centered models of care, reforming TB services as a part of general health reform, and minimizing costs following contemporary epidemic and socio-economic trends and WHO recommendations.

<sup>4</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017. — 216 p.

<sup>5</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K.: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017. — 216 p.

<sup>6</sup> Tables with statistics for 2016, Table 41 https://phc.org.ua/pages/diseases/tuberculosis/surveillance/statistical-information

<sup>7</sup> Order of the Ministry of Health of Ukraine of May 15, 2014 № 327 http://zakon3.rada.gov.ua/laws/show/z0577-14

 $<sup>8 \</sup>quad http://zakon3.rada.gov.ua/laws/show/1011-2017-\%D1\%80$ 

A comprehensive patient-centered approach to TB prevention, diagnostics and treatment is the basic element of the WHO's End TB Strategy for 2016–20359. It involves systematic study of populations at high risk of TB and their existing barriers to accessing TB services; directing efforts and resources with focus on the gender-based needs of patients<sup>10</sup>; reducing stigma and discrimination of TB patients and PHR; involving associations representing PHR of TB and HIV into TB program planning and implementation. By focusing on people affected by TB and the experiences of TB survivors, a people centered response to TB can be achieved. However, gender assessment of the national TB response, and development and budgeting of gender-sensitive programs, are new to Ukraine. There are significant gaps in understanding the barriers PHR of TB face to accessing TB diagnostics and treatment and forming treatment adherence, including barriers caused by human rights violations and gender inequality. Definition of TB-vulnerable groups in Ukraine also requires revision, taking into account the current difficult epidemic and socio-economic situation that has changed significantly since 2014, when the list of populations at high risk of TB was last updated<sup>11</sup>.

This study is based on approaches recommended by Stop TB Partnership. It aims to use the *Gender Assessment Tool for National HIV and TB Responses* and the *Action Framework for TB Key Populations* developed by Stop TB partnership and UNAIDS to plan measures targeting populations at high risk of TB, identify existing gender-specific barriers to accessing TB diagnostics and treatment, determine key TB-vulnerable groups and gaps in understanding specific risk factors within those groups, and identify what studies need to be conducted and interventions developed to enhance the efficiency of national and local TB measures. We have an obligation to identify barriers to effective TB services that these people face. Therefore, the study ensured any possibility to document the lived experiences of people affected by TB as well as to review the legislation and policy at the country level barriers to TB services and identify solutions to overcome these barriers.

Through adding qualitative methods to the study (focus groups and in-depth interviews with key stakeholders and community members in four regions of Ukraine) the project was expanded to national and regional levels. It collected new information on existing needs and gender barriers to PHR participation in TB programs, and ensured completeness of the study through triangulation of information sources. Recommendations based on analysis of study data will enhance TB diagnostics and treatment services in Ukraine, thus strengthening the national TB and HIV response.

#### Study goals

#### The main goals set by the researchers were:

- Use the Gender Assessment Tool for National HIV and TB Responses<sup>12</sup> (hereafter gender assessment tool) from Stop TB Partnership and UNAIDS to assess existing gender barriers and the influence of gender norms and practices on seeking and receiving TB services in Ukraine.
- Identify any manifestations of inequality between women, men, and transgender people in terms of accessing and receiving TB care, that need to be removed by changing policies.

<sup>9</sup> http://www.who.int/tb/post2015\_strategy/en/

<sup>10</sup> A people-centred model of tuberculosis care A blueprint for eastern European and central Asian countries, 1st edition. WHO, 2017.

<sup>11</sup> Order of the Ministry of Health of Ukraine of May 15, 2014 № 327 http://zakon3.rada.gov.ua/laws/show/z0577-14

<sup>12</sup> Gender assessment tool for national HIV and TB responses. — Stop TB Partnership and UNAIDS, 2017.

- Identify the national/regional TB policy and program changes required to eliminate gender-based risks and barriers that men, women and transgender people face.
- Hold consultations with experts to determine populations at high risk of TB in Ukraine based on evidence data and using the tool *Prioritizing Populations of High Risk for TB* developed by Stop TB Partnership<sup>13</sup>, to optimize TB response planning and budgeting at national and local level.
- Based on the results of PHR determination, conduct a quality study among key informants (experts, TB patients and their relatives) in four oblasts of Ukraine to identify current needs and barriers (gender-based and other) to accessing TB services.
- Develop recommendations for action for the healthcare system of Ukraine based on a patient-centered approach in TB services.

#### Methodology Project phases:

#### Preparation.

 Development of a protocol and questionnaires for qualitative interviews and focus group discussions; receiving approval from the Ethics Committee of UIPHP — 1–10 November 2017.

#### Data collection and analysis.

- Conducting 22 interviews with key decision makers (managers of government and non-government organizations, donors, representatives of international TB organizations) — 20–30 November 2017.
- Conducting 20 interviews and 2 focus group discussions with representatives
  of the community of people who have faced TB (TB patients and their families) —
  20–30 November 2017.
- Transcribing interviews 1–20 December 2017.
- Data analysis and preparation of the report and recommendations — 21–31 December 2017.

#### **Preparation**

- Development of a protocol for the STOP TB study, to assess gender barriers and data in order to select activities concerning PHR of TB;
- preparation of the package of documents and receiving approval of the study by the Ethics Committee of the UIPHP;
- adapting and piloting the gender assessment tool;

<sup>13</sup> Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations Working Document. September 2017. http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20 Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf

- adapting and piloting the tool Prioritizing Populations at High Risk of TB, based on the data collection tool for planning measures targeting vulnerable or underserved populations (Stop TB Partnership)<sup>14</sup>;
- development of guidelines for conducting interviews with key stakeholders on gender barriers and data for selection of activities.

#### **Data collection and analysis**

- Conducting consultations with national stakeholders/experts; desktop analysis of legislation.
- Completing the gender assessment tool by national experts.
- Holding consultations with national and international experts and groups for evidence-based identification of populations at high risk of TB in Ukraine.
- Conducting qualitative semi-structured interviews with key informants:
  - 7 national experts;
  - 15 experts/decision-makers in 4 oblasts of Ukraine (Kyiv, Mykolaiv, Odesa, Lviv);
  - 30 interviews with community representatives (patients who have completed TB treatment and their family members) in 4 oblasts of Ukraine (Kyiv, Mykolaiv, Odesa, Lviv).
- Holding 2 focus-group discussions (separate male and female discussions) with people who have received TB treatment.
- Triangulation of data received in the course of desktop review/consultations with experts; data received during interviews and focus-group discussions with key informers; data received using the gender assessment tool and the tool *Prioritizing Populations at High Risk of TB*, in order to determine gaps in policies and programs concerning gender-specific barriers and needs of men, women, and transgender people.
- A meeting with stakeholders: 1) to develop recommendations on policy and program change considering gender-specific barriers and the needs of people who require TB care; 2) to discuss and agree upon the updated list of populations at high risk (PHR) of TB, as well as fine-tuning definitions of these PHRs based on the expertise of stakeholders and key informant interviews findings on risks for individual KPs. Among the participating stakeholders, there were representatives of the Verkhovna Rada of Ukraine, of the Government of Ukraine (Ministries and their departments), of the international organisations (UNDP, PATH, Health Right International, Project Hope etc.) and national NGOs, as well as representatives of the communities of key populations for TB and HIV and of TB patients (such as All-Ukrainian Association of People Who Overcame Tuberculosis "Stronger Than TB", International Charitable organization "Roma women fund Chiricli" etc.)(see Anex 2).
- Preparation of the final report providing recommendations on national planning and budgeting of TB measures considering gender aspects. The provided recommendations should specify several prioritised key populations

<sup>14</sup> Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations Working Document. September 2017. http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20 Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf

(KPs, or PHRs, according to the Ukrainian legislation) that should be included in the next phase of the study for: 1) focus groups with representatives of 1-2 prioritised KPs; 2) quantitative data collection of the prioritised KPs. The received data will be used to further advocate and secure the Government buy-in for launching TB programs/interventions for the prioritised KPs in several strategic regions of Ukraine, to test the feasibility of the CBO-public-private collaboration in delivering person-centered patient-friendly TB services to the prioritised KPs.

#### **Study tools**

According to the gender assessment tool from Stop TB Partnership and UNAIDS<sup>15</sup>, **the process of gender evaluation of the national HIV/TB response should include the following stages:** 

- collecting data on the TB and HIV epidemiological situation in the country, considering gender aspects;
- gender-centered review of Ukrainian legislation on HIV and TB;
- development of a shortened version of the gender assessment tool from Stop TB Partnership and UNAIDS, to be applied in work with an expert group;
- polling key informants using the gender assessment tool;
- using the gender assessment results to take inventory of existing and development of new gender-sensitive TB and HIV interventions.

The **gender assessment tool** was developed to systematize information on gender inequality and other problems with regard to accessing TB services. This tool helps identify the specific needs of women, men, transgender people and other vulnerable populations in the context of TB or HIV/TB. The gender assessment tool helps not only to create a national epidemic response protocol, but also to assess weaknesses and strengths and detect gaps in national policies.

At the initial stage, a group of experts was established to develop and assess the national TB policy to be presented to a wide circle of key people. A number of working meetings and expert consultations were held to identify problems and opportunities for obtaining support at the upper echelons of power.

The next stage of the gender assessment was forming a team of experts to participate directly in the assessment. The team included experts in HIV and TB, gender policies and services, and human rights; representatives of civil society working in TB and HIV, including people from populations at high risk of TB and representatives of the All-Ukrainian Association of TB Sufferers "Stronger than TB". The team of experts developed a strategy for the study, including analyzing the TB epidemiological situation in Ukraine and the legislative and legal framework concerning TB and gender issues, as well as conducting a qualitative study (in-depth interviews with key TB responders, TB patients and their relatives).

information for individual sections of the gender assessment tool from Stop TB Partnership and UNAIDS was collected both through interviewing experts and using expert reports. These sections include: gender equality in TB policies; involvement of PHR organizations in TB-related decision making and the political and legal conditions of such involvement; gender-based violence; sexual and reproductive health and human rights. These and other issues were also highlighted in in-depth interviews with key informants, and interviews with former TB patients and their family members.

<sup>15</sup> Gender assessment tool for national HIV and TB responses. — Stop TB Partnership and UNAIDS, 2017.

The data allow identification of existing barriers (such as cases of inequality between female, male, and transgender people) in TB prevention and treatment services, and formation of an algorithm to overcome these barriers through changes to national and regional policies.

The **tool** *Prioritizing Populations at High Risk of TB*, adapted using the tool National-level Key Population Prioritization<sup>16</sup> (Stop TB Partnership) focused attention on underserved populations at high risk of TB because of biological and behavioral factors. The tool was adapted to the needs of Ukraine according to national expert recommendations, and considering the current epidemic and socio-economic trends in the country.

#### The PHR prioritization assessment used the following criteria:

- 1A: Estimated contribution to the country's TB burden (intensive indicator: population's TB incidence)
- 1B: Estimated contribution to the country's TB burden (extensive indicator: individual population's share in the structure of TB incidence)
- 2: Environmental risks
- 3: Biological risks
- 4: Behavioral risks
- Legal and economic barriers to accessing services
- 6: Human rights and gender-related barriers to accessing services

The total score for each key population was obtained by adding the above seven scores.

Using the tool **Prioritizing Populations at High Risk of TB** allowed preparation of an exhaustive list of such populations. Focusing the healthcare system on populations at high risk of TB will enable enhancement of state TB response policy against a background of scarce resources and a difficult epidemic and socio-economic situation.

<sup>16</sup> Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations Working Document. September 2017. http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key, %20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf

# SECTION II.

Overview of the TB Response in Ukraine. TB epidemic situation in Ukraine. Review of the applicable regulatory framework concerning populations at high risk of TB and gender aspects

TB epidemic situation in Ukraine.
TB prevalence, incidence and behavioral aspects

As of 01.01.2017, 34,966 patients with active TB of all forms were under observation<sup>17</sup> by TB institutions of the MoH of Ukraine and healthcare institutions.

In the last five years, the main indicators of TB (prevalence, incidence, mortality) in Ukraine have been decreasing<sup>18</sup> (Fig. 1).

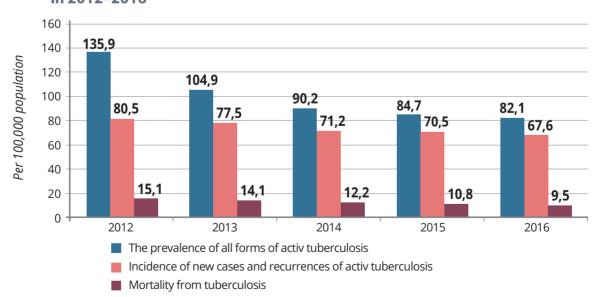


Figure 1. Dynamics of the main indicators of TB (prevalence, incidence, mortality) in 2012–2016

<sup>17</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017.

<sup>18</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017.

# TB prevalence and its distribution by sex and age at national level and in the regions

TB prevalence was 82.1 per 100,000 population, as compared to 84.7 in 2015, i.e., it has decreased by 3.1%. In general, TB prevalence in Ukraine in 2012–2016 shows a clear declining trend (from 135.9 per 100,000 population in 2012 to 82 per 100,000 in 2016)<sup>19</sup> (**Fig. 1**). At the same time, TB prevalence is distributed unevenly among Ukrainian regions (oblasts). For example, in 2016, while the overall average TB prevalence was 82.1 per 100,000 population, the highest rates were registered in Odesa (157.5), Mykolaiv (130.3), Kherson (115) and Dnipro (114.3 per 100,000 population) oblasts; the lowest TB prevalence was in the city of Kyiv (57), and in Ternopil (58.3) and Chernivtsi (60.3 per 100,000 population) oblasts (**Fig. 2**). Compared to 2015, the fastest growth of TB prevalence was observed in Odesa (15.2%) and Luhansk (11.8%) oblasts.

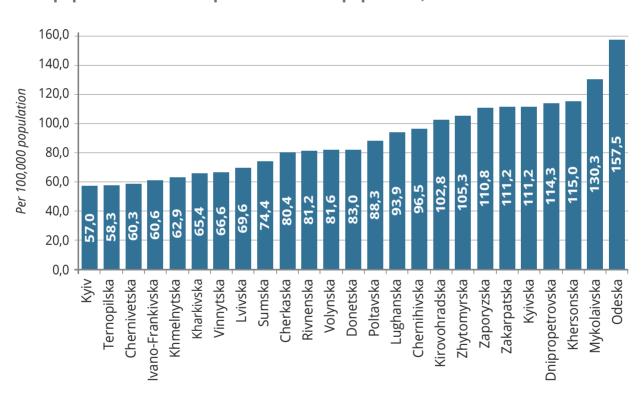


Figure 2. The prevalence of all forms of active tuberculosis among the total population of Ukraine per 100 thousand population, 2016

#### TB prevalence broken down by age and sex

Three out of four TB patients in Ukraine are people aged between 25 and 54 (25–34 — 23%, 35–44 — 28.8%, 45–54 — 20.1%). Children aged under 17 comprise 2.4% of TB cases. TB in children is not gender-differentiated, but after 18 TB prevails in men, with the most prominent difference in the 25–34 age group (67.3% of patients are men, 32.7% are women), 35–44 (76% vs. 24%), 45–54 (78.5% vs. 21.5%), 55–64 (79.9% vs. 20.1%) (**Fig. 3, 4**). On average, men comprise 72% of the total number of TB patients in Ukraine. The share of men is higher in all age groups (**Fig. 4**).

<sup>19</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine", 2016.

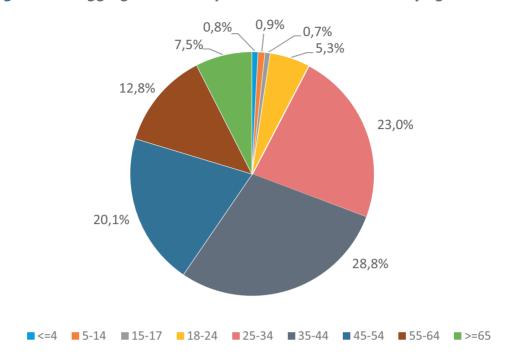
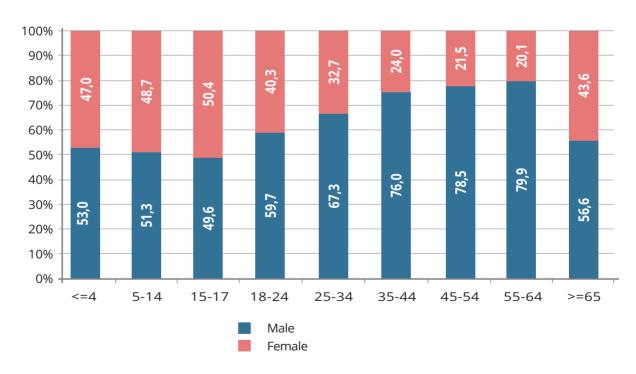


Figure 3. Disaggregation of the prevalence of tuberculosis by age, 2016 %

Figure 4. Disaggregation of the prevalence of tuberculosis by sex, 2016 %



# HIV/TB prevalence and its distribution by sex and age at national level and in the regions

Among patients under observation of healthcare institutions as of the end of 2016, the highest rates were registered in Odesa (48.4 per 100,000 population), Mykolaiv (32.8), Kyiv (27.4), and Dnipro (33) oblasts. The lowest TB/HIV prevalence was registered in Zakarpattia (2.9), Ternopil and Chernivtsi (both 3.7), and Ivano-Frankivsk (3.5 per 100,000 population) oblasts (**Fig. 5**).

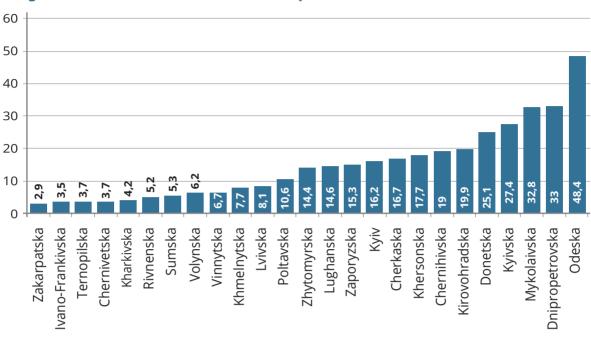


Figure 5. Prevalence of TB/HIV, Ukraine, per 100.000.,

In 2012–2016, the share of TB/HIV co-infection among the total number of TB patients grew from 15.1 per 100,000 population in 2012 to 19.5 per 100,000 in 2016<sup>20</sup>.

In children, prevalence of TB/HIV is basically not gender-differentiated. Women prevail in terms of TB/HIV prevalence in the 18 –24 age category (35.5% male vs. 64.5% female). In all other age categories TB/HIV is more prevalent in men, with the most prominent difference in the 15–17 (80% male vs. 20% female) and 35–44 age groups (73.6% vs. 26.4%) (**Fig. 6**). The overall ratio of TB/HIV prevalence in men and women is 2:1.

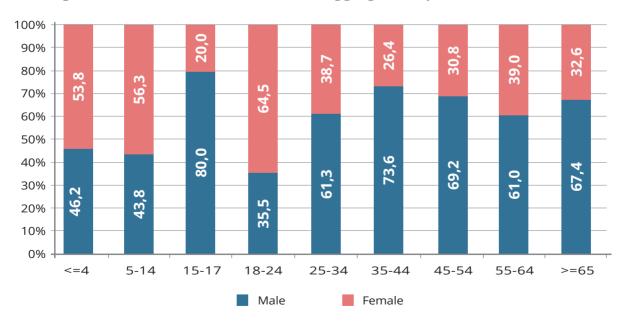


Figure 6. The Prevalence of TB / HIV, disaggregation by sex, 2016, %

A total 92.9% of TB/HIV prevalence falls within the 25–54 age group (25–34 — 28.2%, 35–44 — 46.2%, 45–54 — 18.5%) (**Fig. 7**).

<sup>20</sup> Tuberculosis in Ukraine. Analytical and statistical guide, 2016., p.47.

Figure 7. Disaggregation prevalence of TB/HIV by age, 2016, %

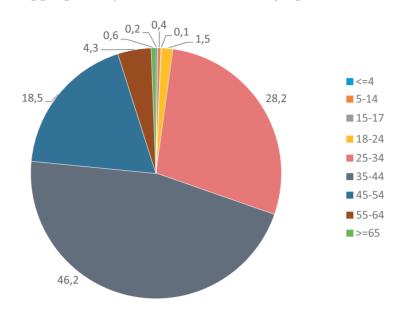
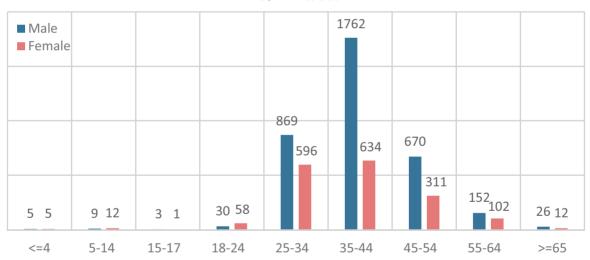
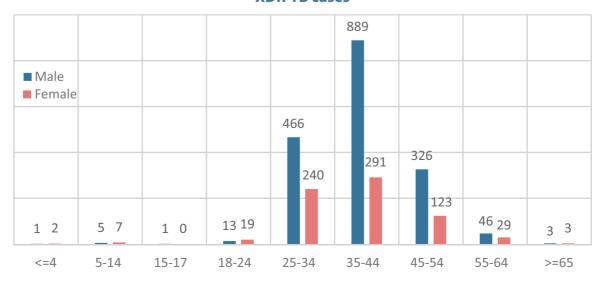


Figure 8. TB/HIV co-infection broken down by age and sex, 2016, %

#### **TB/HIV** cases



#### **XDR-TB** cases

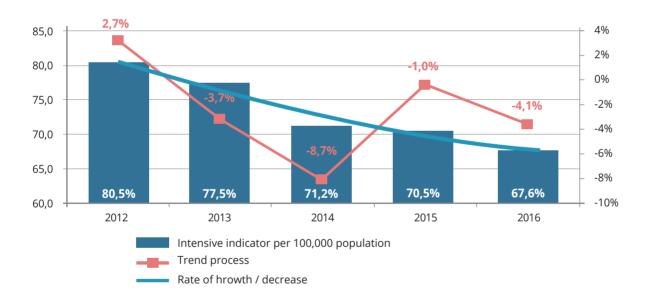


In the structure of new TB/HIV cases in 2016 broken down by age and sex, the number of new co-infection cases was higher among women compared to men in the 18–24 age group, both for drug-susceptible and XDR-TB. In all other age groups, the share of men is larger (**Fig. 8**).

# New TB cases in Ukraine broken down by sex and age at national level and in the regions

TB incidence (new cases and relapsing TB) in 2012–2016 tended to decrease (from 80.5 per 100,000 in 2012 to 67.6 per 100,000 in 2016) **(Fig. 9)**. In 2016, a total of 28,800 cases of TB (new cases + relapses) were registered in Ukraine. At the same time, TB incidence in Ukraine in 2016 as estimated by the WHO (87 per 100,000 population) differs significantly from that reported by routine surveillance data (67.6 per 100,000 population). This means that 22.2% of TB patients were not detected and correspondingly placed under medical observation.





TB incidence significantly varies between regions of Ukraine (from 39.8 to 130.6 per 100,000 population) **(Fig. 10)**. As of 2016, with an average incidence of 67.6 per 100,000 population, the highest rates of TB incidence were registered in Odesa (130.6), Kherson (99.1) and Kyiv (85.7) oblasts; the lowest in Kharkiv (52.5) and Chernivtsi (39.8) oblasts and the city of Kyiv (52.6)<sup>21</sup>.

Overall, in the last five years TB incidence in men exceeded that in women 2–2.5 times. This trend is observed in all age groups<sup>22</sup>. Men make up 70.1% of all people who developed TB in 2016.

<sup>21</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017.

<sup>22</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017.p.33.

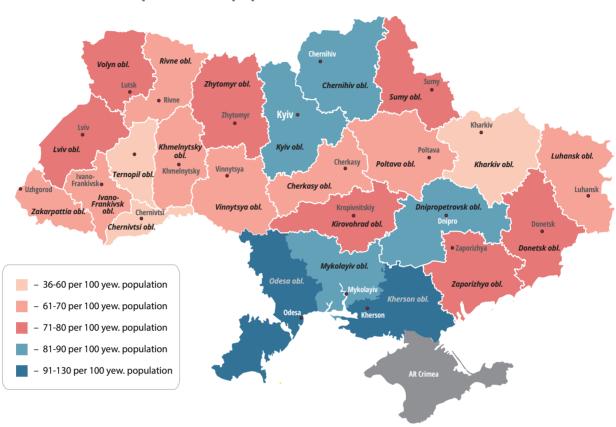


Figure 10. TB incidence including new cases and relapses, Ukraine 2016, per 100,000 population

One important epidemiological indicator of successful elimination of TB in the country is the trend of age composition of TB incidence. Age-based analysis shows that the shares of male and female populations who have developed TB are equal only in the 15–17 age group. In the general structure in all age groups, TB incidence among men prevails, with the most prominent difference in the 35–64 age group (35–44 — 73.9% men vs. 26.1% women, 45–54 — 76.6% vs. 23.4%, 55–64 — 79.1% vs. 20.9%) (Fig. 11).

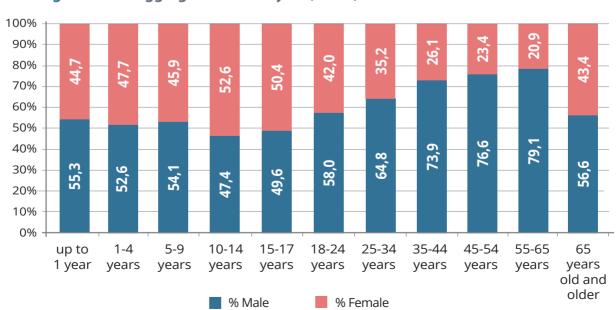


Figure 11. Disaggregation of TB by sex, 2016,%

In the overall structure of all new TB cases in 2016, half were adults aged 25–44 (**Fig. 12**). A total 76% of people who developed TB were of working age (18–54); the 25–44 age group comprised 50.7% of all patients. These values are evidence of the high social importance of TB incidence, and the economic burden the disease places on the state. In addition to the cost of treatment, TB involves long-term exclusion of working-age patients from productive activities. However, the increasing average age of people developing TB is an indicator of positive changes in the epidemic process. Analysis of the age composition of TB incidence over the last five years demonstrates a trend of slowly decreasing incidence in the 25–44 age group, attesting to a switch to positive dynamics in development of the TB epidemic in the country.

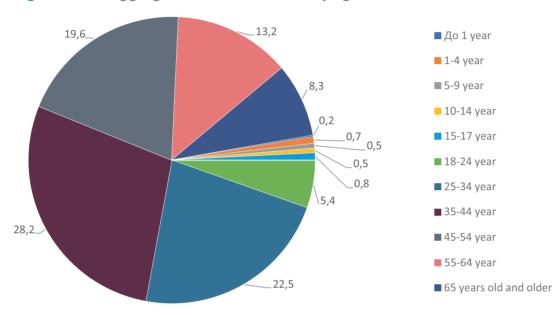


Figure 12. Disaggregation of TB incidence by age, 2016,%

It is worth noting that in virtually all oblasts of Ukraine, TB incidence (new cases + relapses) among the rural population is 20–30% higher than among urban residents (38% higher in Chernihiv oblast). Exceptions are Dnipro, Zakarpattia and Kherson oblasts (**Fig. 13**).

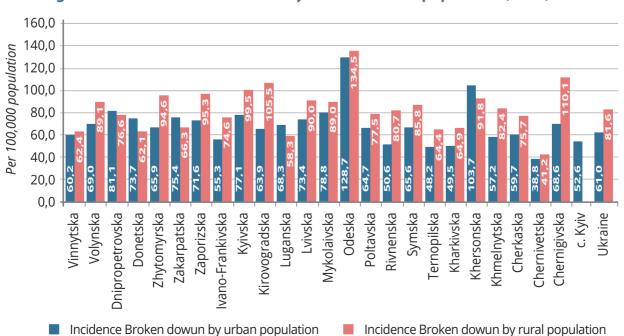


Figure 13. Incidence broken down by urban and rural population (2016)

The rate of decline of TB incidence among the urban population is also higher than among the rural population. All of the above indicates lower accessibility of TB diagnostic and treatment services for rural residents (Fig. 14).

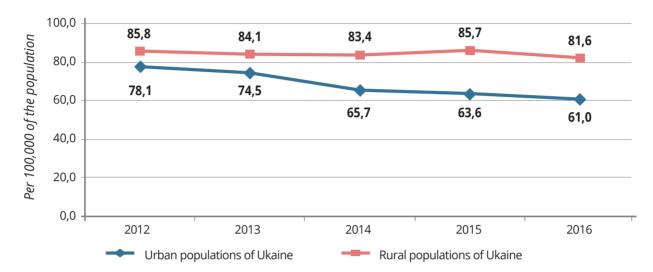


Figure 14. Dynamics of TB incidence among urban and rural populations of Ukraine

Concerning the social composition of new TB cases in 2016, the most-at-risk social group was the unemployed working-age population — 57.2% (**Fig. 15**). The highest share of unemployed among people who developed TB is noted in Rivne oblast —  $60.4\%^{23}$ . A significant share in the overall social composition of new TB cases consists of retired (12.6%) and employed (10.6%) people. Medical workers comprise 1.6% of all new TB cases. According to the WHO, high TB incidence rates in Ukraine clearly correlate with the country's economic development. This fact is confirmed by the steadily high share of unemployed among persons who developed TB (52–59%); this population is consistently the largest in the composition of TB patients.

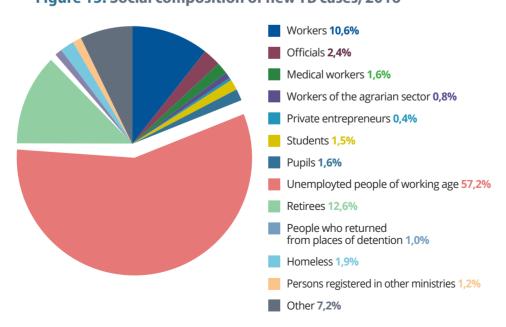


Figure 15. Social composition of new TB cases, 2016

<sup>23</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017.. P.36.

#### New TB cases among PHR of TB

Analysis of the structure of TB cases among PHR of TB according to profiles of the regions shows the highest TB incidence in 2016 among unemployed and poor, as well as HIV-positive people (Fig. 16).

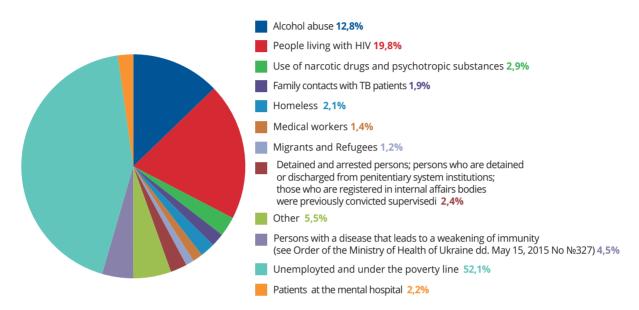


Figure 16. Structure of TB cases among PHR according to profiles of the regions, 2016

Finally, analysis of TB incidence among all healthcare workers in the system of the MoH of Ukraine and personnel of TB facilities, in intensive indicators (per 100,000 of the corresponding population), proves that the risk of developing TB is much higher for personnel from TB services (Fig. 17).

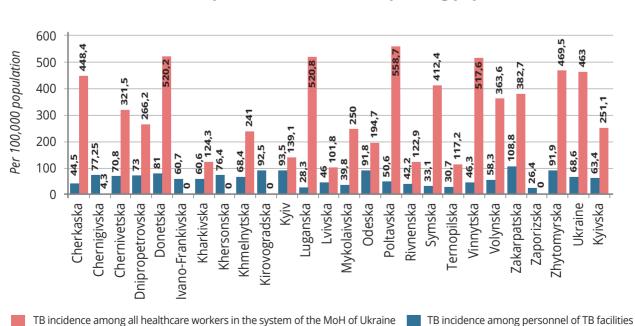


Figure 17. TB incidence among all personnel of healthcare institutions in Ukraine and personnel of TB facilities, in intensive indicators (per 100,000 of the corresponding population)

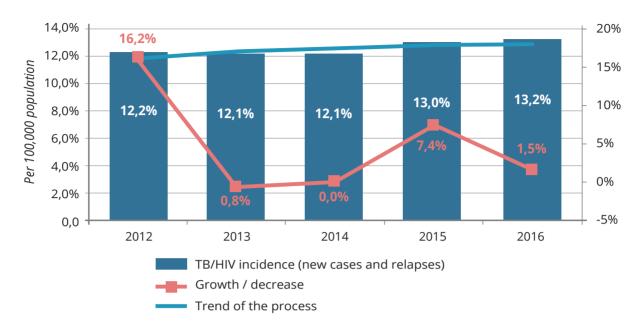


Figure 18. TB/HIV incidence dynamics (per 100,000 population)

TB/HIV incidence remains a real driving force behind development of the TB epidemic in Ukraine. In 2012–2016, TB/HIV incidence in the country kept growing (from 12.2 per 100,000 in 2012 to 13.2 per 100,000 in 2016). In 2016, 5,622 cases of TB/HIV (new cases and relapses) were registered, as opposed to 5,572 in 2015, i.e., incidence grew by 1.5% (**Fig. 18**). The share of TB/HIV co-infection in the structure of incidence has also been growing steadily<sup>24</sup>.

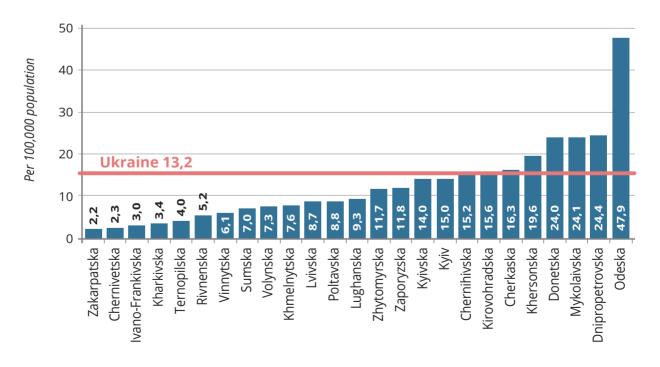


Figure 19. TB/HIV incidence in 2016 broken down by regions of Ukraine (intensive indicators per 100,000 population)

<sup>24</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017.p.47.

The highest TB/HIV incidence in the country is observed in Odesa oblast — 47.9 per 100,000 population. High levels of new co-infection cases are also noted in Kyiv, Dnipro, Mykolaiv and onetsk oblasts, while the lowest incidence (2.2) is in Zakarpattia oblast (**Fig. 19**). Odesa oblast also has the highest share of TB/HIV in the structure of TB incidence (36.7%)<sup>25</sup>.

# TB-related mortality broken down by sex and age at national level and in the regions

In Ukraine there has been a trend of declining TB mortality, with an 8.1% average annual rate of decrease over the last 10 years. In 2016, compared with 2015, the level of TB mortality decreased by 12.0% (to 9.5 from 10.8 per 100,000 population) (**Fig. 20**).

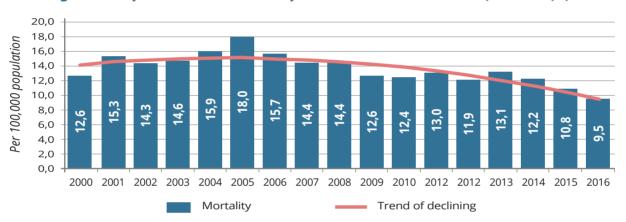


Figure 20. Dynamics of TB mortality in Ukraine (intensive indicators per 100,000 population).

The highest level of TB mortality was registered in Luhansk oblast, where it exceeds the average Ukrainian level 1.87 times and equals 17.8. The lowest mortality was registered in the city of Kyiv - 5.8 per 100,000 population (**Fig. 21**).

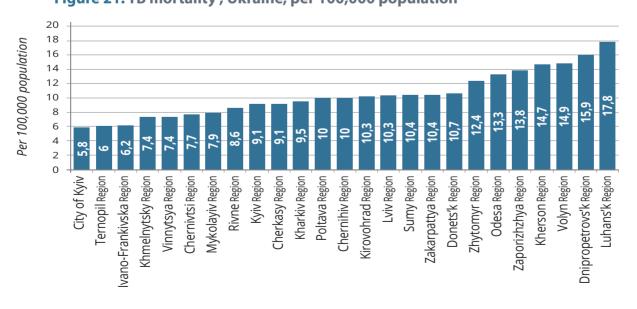


Figure 21. TB mortality, Ukraine, per 100,000 population

<sup>25</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017.. P.49.

Analysis of TB mortality in 2016 broken down by age and sex shows that 90% of the deceased who had active TB were people aged 25–64 (25–34 — 12.8%, 35–44 — 27.5%, 45–54 — 29%, 55–64 — 21.2%). Children under 17 accounted for 0.3% of TB mortality (Fig. 22).

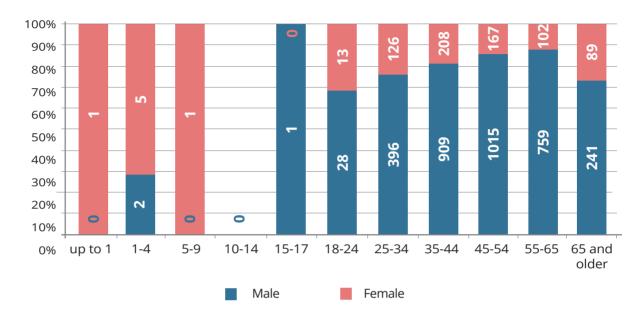


Figure 22. Ratio of TB mortality between male and female populations, 2016, abc.

The ratio of TB mortality between male and female populations is 4:1. Mortality among women with HIV/TB co-infection is higher only in the 25–29 age category. It must be noted that, although the large majority of TB incidence and mortality is observed in men, TB remains one of the main causes of mortality among women in Ukraine, especially those with the double problem of HIV/TB.

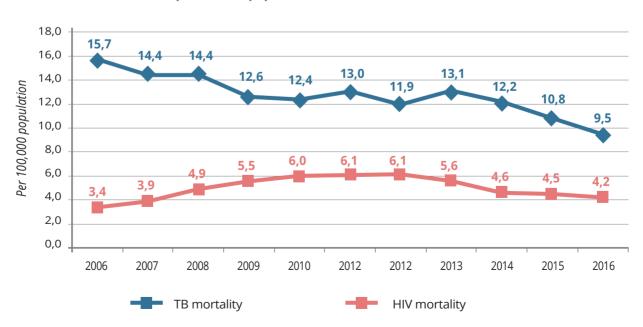


Figure 24. Dynamics of TB and TB/HIV mortality in Ukraine (intensive indicators per 100,000 population)

The dynamics of HIV/TB mortality compared with TB mortality show a somewhat slower rate of decrease of mortality among people with co-infection (**Fig. 24**). The highest level of TB mortality was registered in Luhansk oblast, where it exceeded the average Ukrainian level 1.87 times and equaled 17.8; the lowest mortality was registered in the city of Kyiv — 5.8 per 100,000 population. In Mykolaiv oblast, TB/HIV mortality per 100,000 exceeds TB mortality.

#### **HIV prevalence among key populations**

No overall assessment of the numbers of PHR of TB has been conducted in Ukraine.

In 2015, HIV prevalence among key populations was: 7.0% among sex workers (SWs)<sup>26</sup> (p. 103); 8.5% among men who have sex with men (MSM)<sup>27</sup> (p. 65); 21.9% among people who inject drugs (PWID)<sup>28</sup> (p. 68). There are no data on estimated numbers of new HIV cases in key populations broken down by sex and age, except for PWID (**Fig. 25**).

Figure 25. Prevalence of HIV, hepatitis C and syphilis among PWID, % 29

Ratio	HIV prevalence (№ %)	HBV prevalence (№ %)	HCV prevalence (№ %)
To all	2073 (21,9)	522 (5,4)	5105 (55,9)
Sex of the respondents	p<0,001	p<0,05	p=0,074
Male	1538 (20,5)	426 (5,5)	4075 (56,1)
Female	509 (27,6)	91 (5,1)	965 (55,2)
Age of the respondents	p<0,001	p<0,001	p<0,001
14–19	4 (2,7)	2 (1,2)	17 (13,5)
20-24	37 (4,5)	25 (3,6)	212 (29,2)
25–34	689 (16,9)	230 (5,4)	2176 (53,7)
35 and odher	1343 (31,3)	265 (6,0)	2700 (65,2)

HIV prevalence in female PWID is somewhat higher than in males (**Fig. 25**). With the increase of age, the share of HIV-positive PWID also increases.

<sup>26</sup> Monitoring the behavior and spread of HIV infection among sexually transmitted infections reward / Sereda Yu.V., Sazonova Ya.O. — K.: ICF "Alliance of Public Health", 2017. — 142 p. http://aph.org.ua/wp-content/uploads/2017/06/Monitoryng-povedinky-ta-poshyrennya-VIL-infektsiyi-sered-RKS\_22.06.2017\_Natsyonalnaya-chast.pdf

<sup>27</sup> Monitoring behavior and spread of HIV among sexually active males with men / M. Kasyanchuk, O. Trofimenko, E. Bilous, Y. Sazonova — K .: ICF "Alliance of Public Health", 2017. — 80 p. http://aph.org.ua/wp-content/uploads/2017/06/Analituchnuy\_zvit\_Nacionalna-chastyna\_28.06.2017\_com.pdf

<sup>28</sup> Monitoring the behavior and prevalence of HIV among people who inject drugs, and their sexual partners / Barskaya Yu.G., Sazonova Ya.O. — K.: ICF "Alliance of Public Health", 2016. — 130 p. http://aph.org.ua/wp-content/uploads/2015/09/monsin.pdf

<sup>29</sup> Monitoring the behavior and prevalence of HIV among people who inject drugs, and their sexual partners / Barskaya Yu.G., Sazonova Ya.O. — K.: ICF "Alliance of Public Health", 2016. — 130 p. http://aph.org.ua/wp-content/uploads/2015/09/monsin.pdf

#### Comprehensive HIV and TB response.

#### Free HIV and TB prevention and care services

The expert group considers the following prevention services to be freely available to patients:

- Access to information on HIV and TB
- BCG vaccination
- Isoniazid preventive therapy for people living with HIV and people with latent TB30
- Monitoring contacts of TB carriers and prevention of the disease
- Prevention of mother-to-child transmission of HIV
- Voluntary counseling and testing services for HIV

Services that are not always available include: communication about behavior change; peer-to-peer awareness building; provision of condoms (male and female); drug use harm reduction, and preventive antiretroviral treatment.

The average percentage of TB patients tested for HIV in Ukraine is 96.7. The highest rate (100%) is in Zakarpattia, Lviv, Rivne, and Ternopil oblasts; the lowest is in Chernihiv oblast (84.6%).

Most TB/HIV cases are caused by HIV infection. This trend indicates gaps in preventive measures among HIV-positive people. According to WHO recommendations, the main measures of TB prevention among PLWH are active TB detection, isoniazid preventive therapy, early prescription of ART, and implementation of infection control programs at facilities attended by HIV positive people<sup>31</sup>.

#### Current indicator of success of TB and MDR-TB treatment in Ukraine (broken down by age and sex)

Treatment success rates of new cases of sputum smear-positive pulmonary TB in the cohort of 2015 in Ukraine remain low compared with WHO-recommended targets: 72.9% as opposed to 85%. The highest success rates were registered in the age groups of 5-14 (96.4%), 15-17 (94.5%), and 18-24 (87%). The lowest effectiveness of TB treatment was registered in the age categories of 45-54 (68.5%) and 35-44 (69.5%). Effectiveness of treatment is higher in women (79%) than men (70%)<sup>32</sup>.

<sup>30</sup> WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders. World Health Organization, 2004.

<sup>31</sup> WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders. World Health Organization, 2004.

<sup>32</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017.



Figure 26. Results of TB treatment according to Registry, cohort 2015

At the same time, the treatment success rate of patients with XDR-TB of the cohort of 2014 is 42.2%. The highest success rates were observed in children aged 5–14 (100%, 21 persons), 0–4 (93.9%, 31 persons), and 15–17 (85.7%). The lowest success rates of treatment of XDR-TB were registered in people over 65 (35.9%), 55–64 (36.3%) and 45–54 (38.4%). Effectiveness of treatment was also higher in women (51%) than in men (38%).

According to data from the Registry of TB Patients, the following factors have a positive effect on treatment results:

- TB detected during screening
- First TB diagnosis
- Susceptible TB
- Female patient
- Age under 18
- The patient is a medical worker

#### On the other hand, factors leading to poorer results of treatment include:

- TB detected at inpatient facilities
- Treatment following failed or interrupted treatment
- Sputum smear-positive TB
- MDR-TB
- Male patient
- Age over 18
- Alcohol abuse
- Using injected drugs
- Homeless status
- Prison experience
- Status of a displaced person
- Co-infection with HIV

Thus, belonging to most of the social risk groups (alcohol abuse, injecting drugs, homelessness, prison experience, and status of a displaced person) decreases the probability of successful treatment several times over, and increases the likelihood of death without completing treatment.

#### Ukrainians' awareness of TB

### The share of people capable of correctly identifying TB symptoms and knowing where they need to go to get help with TB

Results of the sociological survey *TB-related knowledge, attitude, practices and behaviors of the population of Ukraine in 2011*<sup>33</sup> conducted as a part of the Program "Stop TB in Ukraine" show levels of TB-awareness in all regions of Ukraine.

Generally, respondents rate their awareness of TB as quite high: 6% — excellent, 29% — good, 42% — satisfactory. A total 16% of respondents consider their knowledge poor, and 5% said they knew nothing about the disease. Totally unaware respondents equally include men and women, residents of different types of areas, people of different ages and educational levels.

With regard to awareness among PHR, about 90% of respondents representing such categories as homeless, PWID and ex-prisoners name the main signs of TB correctly. General knowledge among Roma was lower than that among other PHR — 50% as opposed to 59-66% in other groups. At the same time, Roma are the only vulnerable population among whom the main path of TB infection (airborne) was correctly identified by all 30 respondents. Generally, PHR's knowledge of TB is low (overall indicator of knowledge varies from 59-66%) and requires correction with regard to widespread stereotypes about the possibility of getting TB in the course of household activities.

Only 57% of PWID and 39% of homeless expressed willingness to immediately seek medical care upon finding symptoms of TB. The main barrier for PWID is stigmatization by medical personnel and perception of the treatment as expensive, while for homeless the barriers to accessing treatment are poverty and lack of funds, including funds to pay for treatment. The main reasons for failure to go to healthcare institutions for former prisoners and detainees diagnosed with TB are a neglectful attitude towards their health, alcohol and drug abuse, and social exclusion.

<sup>33 &</sup>quot;Level of knowledge, attitude, practice and behavior of the population of Ukraine and certain social groups on tuberculosis as of 2011". — Kyiv, 2013. — 139 p.

Most of the general population (79%), upon encountering the main symptom of TB (prolonged coughing), would go to public healthcare institutions: polyclinics, rural health posts (RHPs) (74%) or TB clinics (11%). Every fourth respondent tended to put off going with TB symptoms to a doctor; 11% of respondents would go to a healthcare institution if self-treatment fails, 10% would go if they are seriously ill and feel sick. This situation needs to be changed through effectively informing the population, as better awareness of TB issues strengthens the intent to see a doctor in good time. Informing people about the affordability of TB diagnostics and treatment also has a positive effect on respondents' intent regarding hypothetically seeking TB services.

#### The level of stigma and discrimination of people living with TB, HIV/TB or MDR-TB

At present there are no data on levels of stigma and discrimination in the health system of people living with TB, HIV/TB or MDR-TB. These questions were therefore included in the questionnaires that make up the qualitative component of the study (conducting interviews and focus groups with key informers). However, results of a study of stigma of TB patients among the general population are available<sup>34</sup>.

The prevalence of stigmatizing attitudes towards TB patients was determined based on results of the sociological study *TB-related knowledge, attitude, practices and behaviors of the population of Ukraine in 2011* conducted as part of the "Stop TB in Ukraine" program implemented by Rinat Akhmetov's Foundation "Development of Ukraine" with support from the Global Fund to Fight AIDS, TB and Malaria.

While 92% of respondents believe TB patients should receive support and a positive attitude from others, the share of those supporting specific displays of tolerance was much lower. Fewer people also claimed willingness to behave in a tolerant manner in hypothetical situations: not to avoid people who have had TB (39%), to work together with such a person (45%) or to eat at a restaurant knowing that a cook or waiter there has had TB and is completely cured (33%). Thus, most respondents perceive TB as a life-long sentence and do not understand that TB can be completely cured. Eighty-five percent of respondents believe that TB patients should be forcibly isolated, and 48% spoke in favor of terminating employment of TB patients.

The study showed that a generally stigmatizing attitude towards TB patients is more prevalent in people with a low awareness of TB, and in residents of rural areas. Most respondents do not see a difference between TB patients and people who have been successfully treated for TB. Most respondents prefer to keep away from both actual and former TB patients.

During another study of stigma and discrimination of TB patients in Ukraine, the authors learnt that only a small segment of the population can be considered tolerant towards TB patients<sup>35</sup>. While almost 80% of people would agree to take care of a family member with TB, only 60% were willing to share a dining table with such a person, and only 28% would feel comfortable near a colleague who has latent TB. The authors emphasize that the stigmatizing attitude towards TB patients forces the latter to conceal their diagnosis, which often leads to reduced adherence to treatment.

All these data speak of a high level of stigma of TB patients and lack of awareness about the curability of tuberculosis. Tolerant attitudes, social support and case management of TB patients are not yet common in Ukrainian society.

<sup>34 &</sup>quot;Level of knowledge, attitude, practice and behavior of the population of Ukraine and certain social groups on tuberculosis as of 2011". — Kyiv, 2013. — 140 p.

<sup>35</sup> Potaichuk V.I, Galan I.O, Varchenko Y.A. Some aspects of the formation of stigma and discrimination of patients with tuberculosis. — Tuberculosis, pulmonary diseases, HIV-infection, 2014, No. 3 (18), p. 110-111.

#### **Conclusions**

- In the last five years the main indicators of TB (prevalence, incidence, mortality) in Ukraine have been decreasing. At the same time, TB prevalence is distributed unevenly among Ukraine regions: in some oblasts it is almost twice as high as the country average. On average, 72% of all TB patients in all age groups are male.
- TB incidence has been steadily decreasing over recent years; however there is evidence that about 22% of TB patients in 2016 went undetected. TB prevalence varies significantly in different regions of Ukraine, from 39.8 per 100,000 population in Chernivtsi oblast to 130.6 in Odesa oblast. In almost all oblasts of Ukraine, TB is more common in rural residents than urban residents. In all age groups, TB is more prevalent in men.
- Most new TB cases are in unemployed people of working age; a large portion of
  patients are retired or employed. Among PHR, the highest TB incidence in 2016
  was seen in unemployed, people living below the poverty line, and PLWH. Of all
  medical workers, personnel of TB institutions are at highest risk of getting infected.
- In recent years, the share of TB/HIV in the structure of TB incidence has been growing. The highest TB/HIV incidence rate is observed in Odesa oblast: 47.9 per 100,000 population.
- While there is a national decrease in TB mortality, it is four times higher in men than in women. Nevertheless, TB remains one of the main causes of mortality among women in Ukraine, especially among people with HIV/TB co-infection.
- Concerning TB treatment success rates, women show better results in treatment
  of all types of TB compared to men. Among age groups, the best results are seen
  in children up to 18. Belonging to most of the PHR (alcohol and drug abuse,
  homelessness, unemployment, prison experience, status of a displaced person)
  substantially reduces the likelihood of successful treatment completion.
- Despite quite high levels of awareness of TB among PHR, there are major barriers
  to their seeking TB-related medical services. One barrier is the high level of
  stigmatization of TB patients in society, as confirmed by several studies. It turns
  out that most people perceive TB as a life-long sentence. They do not realize the
  disease is curable, and tend to be intolerant and stigmatizing towards actual and
  former TB patients.
- Availability of free medicines; acceptable treatment conditions; social support
  and case management; information about treatment opportunities; acceptance
  of responsibility for one's own health, and reduction of stigma and discrimination
  of PHR and TB patients are the main factors capable of motivating PHR to receive
  TB treatment.

# SECTION III.

Assessing gender barriers and data to determine activities concerning key populations in the TB context. Studying gender barriers and their influence on access to tuberculosis treatment services.

Review of the applicable regulatory framework concerning populations at high risk of TB, and gender policies Legislative regulation of phthisiatric care in Ukraine (with a focus on PHR of TB and gender-related barriers)

Generally the existing laws of Ukraine, orders of the MoH of Ukraine and other documents regulating provision of TB care in Ukraine do not cover gender aspects. A number of documents pay more attention to key populations (in Ukrainian legislation — populations at high risk of tuberculosis).

The main law regulating provision of TB care in Ukraine is the Law of Ukraine "On Fighting Tuberculosis" 36. The law does not mention gender-sensitive services, but provides a list of people to be subject to mandatory prophylactic TB examinations. It also says that the criteria for categorizing people as populations at high risk of TB are determined by the executive authority shaping and implementing state health policy.

Decree of the Cabinet of Ministers of Ukraine (CMU) dd. 27.12.2017 no. 1101-p approved the Concept of the National Targeted Social TB Program for 2018–2021<sup>37</sup>. The program's goals are stabilization of the incidence rate, reduction of mortality, and improvement of effective treatment of

<sup>36</sup> http://zakon4.rada.gov.ua/laws/show/2586-14

<sup>37</sup> https://www.kmu.gov.ua/ua/npas/pro-shvalennya-koncepciyi-zagalnoderzhavnoyi-cilovoyi-socialnoyi-programi-protidiyi-zahvoryuvannyu-na-tuberkuloz-na-20182021-roki

patients with drug-susceptible tuberculosis, drug-resistant tuberculosis, and TB/HIV co-infection. Approval of the program will help achieve the goals of the Tuberculosis Action Plan for the WHO European Region for 2016–2020<sup>38</sup> and ensure free access to uninterrupted TB diagnostics, treatment access for all TB patients through implementation of a patient-centered approach, access to counseling and HIV testing, etc. The problem of the TB epidemic in Ukraine demands rapid reform of approaches to provision of TB care through development of a system of outpatient care for TB patients in compliance with modern principles of infection control, providing case management of patients, and using innovative evidence-based methods of TB diagnostics and treatment. This involves, in particular, differentiated definition of PHR of TB for the purpose of active detection of TB depending on regional specifics, and ensuring full coverage of PHR with TB diagnostics involving civil society organizations.

Some activities envisaged by the program concern populations vulnerable to TB:

- implementation of a patient-centered approach with a focus on socially maladjusted groups;
- providing social support to TB and MDR-TB patients focusing on the needs of patients and their families, to ensure adherence to treatment and completion of the full treatment course, with the assistance of civil society;
- ensuring continuity of services to internally displaced people, migrants, and stateless persons through implementation of a mechanism of cross-border control.

As the program has not yet been approved, the activities it envisages for the most vulnerable populations are not being implemented. The program does not mention a gender-oriented approach to provision of TB services.

"Unified Clinical Protocol for Primary, Secondary (specialized) and Tertiary (highly-specialized) Care for Adults" (approved by order of the Ministry of Health dd. 04.09.2014 no. 620) contains no information about gender barriers. This protocol introduces principal changes in organization of TB patients' treatment with the emphasis on outpatient treatment, optimization of inpatient treatment practices and controlled therapy for TB patients involving not only TB service medical personnel but also personnel from primary healthcare facilities, social workers, NGO volunteers, etc. It was determined that during treatment, TB services need to consider possible measures to improve patients' adherence to TB treatment, including support or advice on getting social support, and incentives such as transport vouchers, meal tickets, etc. They should employ methods to mitigate financial and psychosocial factors that may affect treatment adherence, such as spending on medicines and transport. Treatment should be organized so as to be of maximum convenience for TB patients.

The protocol also lists populations at high risk of TB (see more detail in section IV).

Order of the MoH of Ukraine dd. 30.04.2009 no. 287 "On Referral to Sanatorium Therapy for TB Patients and Persons from Risk Groups" lists indications and contraindications to sanatorium therapy for TB patients and persons from risk groups. They include groups in contact with TB patients, such as medical or other staff of TB institutions.

Order of the MoH of Ukraine no. 483 dd. 11.06.2010 "On Approval of Sample Provision of a Hospice Hospital (Department, Ward for Palliative Care) for TB Patients" includes among the hospital's objectives organization of socio-psychological assistance for TB patients and their families during the period of illness and after the loss of a relative.

Order of the MoH of Ukraine no. 657 dd. 02.09.2009 "Form of Primary Reporting Documentation no. 081-2/o" determines factors influencing the course of the disease and the result of TB treatment,

<sup>38</sup> https://phc.org.ua/news/show/plan-dii-po-borotbi-z-tuberkulozom-dlya-jevropeiskogo-regionu-vooz-na-2016-2020rr

including HIV diagnosis, alcohol abuse, injection drug use, and belonging to certain groups: homeless, unemployed, medical staff (TB and general healthcare network), migrant, refugee/immigrant, former prisoner or detainee (in the last two years).

Order of the MoH of Ukraine dd. 15.05.2014 no. 327 "On Detection of Persons with TB or Infected with TB Mycobacteria" determines:

- procedure for conducting mandatory preventive medical examinations for TB;
- list of persons included in populations at high risk of TB;
- criteria for including a population category into the list of populations at high risk of TB (for more detail see section IV).

#### The last update of PHR of TB was in 2014.

Order of the MoH of Ukraine, Ministry of Interior of Ukraine and Ministry of Social Policy of Ukraine no. 41/119/95 dd. 02.02.2015 "On Approval of the Procedure for Interaction of Health Care Facilities, Territorial Bodies and Institutions of the State Migration Service, State Border Guard Service and State Employment Service for Organization of Provision of Medical Aid Regarding TB to Foreigners or Stateless Persons Staying in Ukraine" sets forth a procedure for interaction between institutions to ensure timely detection and provision of medical aid to TB patients among categories included in PHR:

- foreigners or stateless persons staying in Ukraine legally or illegally;
- persons applying for the status of refugee or requiring extra protection;
- persons requiring interim protection.

Order of the Ministry of Interior, MoH, Administration of the State Border Guard Service of Ukraine dd. 17.04.2012 no. 336/268/254 "Procedure for Provision of Medical Aid to Foreigners and Stateless Persons Kept at Accommodation Centers for Foreigners or Stateless Persons Illegally Staying in Ukraine of the State Migration Service of Ukraine and Accommodation Centers and Specially Equipped Premises of the State Border Guard Service of Ukraine" guarantees provision of free medical aid, including emergency care, to such persons: "...persons with a suspected infectious disease shall be referred for treatment to specialized healthcare facilities."

Order of the MoH of Ukraine dd. 15.05.2014 no. 326 "On the Department of Monitoring and Evaluation of TB Response Measures at TB Institutions" names the following among the main functions of an M&E department:

- ensuring keeping an electronic registry of TB patients;
- systematic analysis of information on the TB epidemic situation, including using data from the electronic registry of TB patients, etc.
   It is important that the M&E system allows collection of information for analysis, including information broken down by age, sex, PHR status, etc.

#### Documents regulating the issue of providing aid to families and persons affected by TB

A number of documents regulate the issue of providing aid to families and persons affected by TB. None of these documents defines the gender specifics of receiving TB care.

The Law of Ukraine "On Social Services" defines the term "difficult life situation", which includes circumstances caused by disability, age, health condition, social standing, life skills and way of life that deprive the person, in full or in part, of the ability or possibility to take care of their personal (family) life and participate in society.

In the Procedure for Detection of Families (Persons) in a Difficult Life Situation and Provision of Social and Case Management Services approved by Decree of the CMU on 21.11.2013 no. 896, possible reasons for difficult life situations include **prolonged illness**, poverty, etc; a way of life rendering a family member unable or incapable, fully or in part, of taking care of his/her personal life and participating in society; discrimination of a person and/or groups of persons. The above circumstances may concern families or persons affected by TB.

Case management is conducted according to the *State Standard for Case Management of Families* (*Persons*) in *Difficult Life Situations* (approved by Order of the Ministry of Social Policy dd. 31.03.2016 no. 318). This state standard defines content, scope, conditions and procedures of providing case management for families (persons) in a difficult life situation. The standard does not provide for any specific types of work with a family/person affected by TB (the algorithm for provision of case management services is the same for different categories of difficult life situations).

According to the Law of Ukraine "On Protection of Childhood", if, because of a difficult life situation, a child temporarily cannot stay with his/her parents or other legal representatives, he/she may be supported and raised by relatives, a foster family, centers of socio-psychological rehabilitation for children, shelters for children run by children's affairs services, or other facilities for children (regardless of their form of ownership or subordination) which have adequate conditions for accommodation, care, education and rehabilitation of children according to their needs (article 23).

Decree of the Cabinet of Ministers of Ukraine of 06.11.2016 no. 834 "On Approval of Sample Provision of a Center for Case Management of Children and Families" envisages creation of such centers — institutions of social protection of children and families with children in difficult life situations. The main objectives of the centers include provision of a complex of social services for children in difficult life situations, as well as their families, based on day-care or long-term accommodation facilities. Currently there are two institutions of this type, in Dnipro and Kyiv oblasts.

Article 4 of the *Law of Ukraine "On TB Response"* determines state guarantees in the sphere of prevention of TB. The state guarantees free provision of medical aid, tuberculin diagnostics, chemical prophylaxis of TB and sanatorium treatment of TB patients at state and communal healthcare institutions (HCIs). During treatment, TB patients shall receive TB drugs free of charge. During inpatient or sanatorium treatment at TB institutions, patients shall receive free meals.

Article 20 of the same law sets forth the rights and obligations of TB patients, including the **right to social and psychological support**, in particular, to free medical aid and adequate conditions of stay during treatment at TB institutions; receiving information from the medical worker conducting treatment about specifics of the disease, treatment method, diet, existing health risks, consequences of refusing treatment; provision of psychological support, etc.

Article 21 defines social protection measures for TB patients. In particular, the sickness certificate given to TB patients shall cover the whole period of the main course of treatment as determined by the doctor, and may not be extended beyond 10 months after the start of the main treatment course. TB patients shall retain their job for the whole duration of treatment. An employee may not be fired because of his/her TB status, except in cases where this disease is a contraindication for this occupation.

Article 64 of the Law of Ukraine "Foundations of Health Legislation of Ukraine" ("Benefits for mothers in case of disease in children") does not cover phthisiatric care specifically, but stipulates that in cases where hospitalization of the ill child is impossible or not indicated, the mother or another family member caring for the child may be relieved from work and receive financial support from social insurance funds. In the event of inpatient treatment of children under six years of age, as well as seriously ill older children who require maternal care as confirmed by doctors, the mother or other family members shall be provided with the opportunity to stay at the HCI with the child and receive free meals and accommodation, as well as financial support from social insurance funds.

The Order of the Ministry of Social Policy of 10.09.2015 no. 912 "On Approval of the State Standard of the Social Service of Prophylaxis" includes forming adherence to completing a full course of TB treatment in the scope of services of tertiary prophylaxis.

At the same time, Orders of the Ministry of Social Policy no. 760 dd. 13.11.2013 "On Approval of the State Standard of Home Care" and no. 452 dd. 30.07.2013 "On Approval of the State Standard of Day Care" do not list TB patients specifically as recipients of services within the scope of these two standards; information about possible practice of their application requires additional review.

## Social, cultural and economic factors influencing the risk of TB infection

Social and cultural norms and practices that may increase the risk of transmission of HIV or TB among women and girls, men and boys, and/or transgender people

Social and cultural norms and practices in society that may increase the risk of transmission of HIV or TB among women/girls, men/boys and/or transgender people include:

- gender inequality that includes women's increased economic vulnerability, dependence on husband's decisions, lower mobility, burden of unpaid care work;
- masculine norms that encourage men's risk behaviors (consumption of alcohol, tobacco, drugs) and neglect of medical services and health needs;
- feminine norms that deprive women and girls of the right to self-defense, reactive aggression, assertiveness and upholding their boundaries, and encourage submission to men;
- traditional gender roles according to which a man earns money outside (men are involved in labor migration and work in hazardous industries), while a woman stays at home looking after children and the ill (worse access to treatment, economic dependence);
- gender-based violence that includes:
  - sexual violence (most often, violence by a sexual partner, including ignoring the requirement of consent, unsafe sex, sexual contacts with minors);
  - sexual violence related to the conflict in the east of Ukraine aggravated by poor access to post-exposure prophylaxis and services for victims of violence;
  - domestic violence;
  - violence based on hatred towards transgender and MSM.

Outdated patriarchal views of gender roles in Ukraine have been changing, though somewhat slowly. Social and political opportunities for women and men remain unequal. For example, according to the report on the **Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)**, the share of women in top elected or appointed offices is insignificant. A gender-discriminatory attitude is promoted in mass media, advertising, recruitment ads and even school education. State policies do not pay enough attention to the gap between salaries of women and men and do not focus on reducing women's load of unpaid work. This increases women's dependence on men and their social vulnerability. According to official statistics, the average women's salary is 25% below that of men. The index of economic inequality GGGR-2015 estimates the ratio of women's salaries compared to men's as 0.66%.

"And yet men hold most managerial positions. That is, we generally understand that a managerial position means a higher income, right? There is this thing, yes." (Representative of an international organization)

Common gender stereotypes about sexual consent, or condom use being not mandatory, increase the risk of transmission of HIV and STIs, and undesired pregnancies. Legislation on protection of sexual rights is imperfect: only articles on the sexual integrity of minors exist. Such issues as sexual harassment, sexual contacts without the woman's consent and unsafe sex demanded by the man are often not seen by communities as violence. At the same time, there is no systematic sex education in society. In the context of misinformation on gender roles and sexual contacts, youth may practice behaviors that are risky in terms of HIV and STIs.

The scale of gender-based violence increases the risk of HIV infection. According to studies included in the UN Report on Human Development (2016), 13% of women have experienced violence from their sexual partners, and 1% from other men. These values may be understated, as the topic of violence is taboo; besides, not all types of violence are seen as such: 3% of women and 9% of men aged 15 to 49 consider it lawful for a husband to beat his wife<sup>39</sup>.

Following the norms of masculinity and male gender socialization, men are heavier smokers and drinkers and engage in risky practices; they face higher risk of imprisonment in places of confinement where there are high prevalence rates of infectious diseases and inadequate sanitary conditions. Men's occupational activities are also related to higher health risks: there are more men among miners with silicosis, ATO military conflict participants in hard field conditions, and labor migrants who often work in inadequate conditions and do not have access to health services. All these factors contribute to increased risk of TB or other diseases causing premature mortality. The average expected lifespan at birth in Ukraine is 66.2 years for men and 76 years for women<sup>40</sup>.

## Social and cultural norms and practices among PHR increasing the risk of HIV and TB transmission and strengthening gender inequality and gender-based violence

Existing gender inequality and its negative effects on health only intensify in the disadvantaged marginalized groups that PHR of TB and HIV belong to. Discrimination complicates access to social services and mechanisms of protection and justice for representatives of these groups. As a result, women become more dependent on men, and the scope of gender-based violence grows. Women from PHR have less access to services and may encounter stigma and discrimination at health institutions, and know less about disease prevention and their rights. Health risks for men from PHR, in turn, increase because of greater involvement in risky practices.

"A pregnant woman, an injection drug user in the 32<sup>nd</sup> week of pregnancy, came from Borodianka. She used 'shirka'. Beside HIV infection, they diagnosed, regretfully — but hers was at an advanced stage already — they diagnosed tuberculosis. They simply kicked her out of the family." (**Representative of a state agency**)

For example, in communities of **people who inject drugs**, the risk of women getting infected with HIV and STIs is increased by gender-based factors such as using syringes after men, vulnerability to sexual violence, involvement in sex work in exchange for drugs, and difficulty of participating in harm reduction programs if the partner is against it<sup>41</sup>. The estimated number of people who inject drugs (PWID) in Ukraine is 346,900<sup>42</sup>. A total 27.5% of them are women; 82,266 women who use drugs are of reproductive age<sup>43</sup>.

<sup>39</sup> UN HUMAN DEVELOPMENT REPORT 2016. http://hdr.undp.org/sites/default/files/hdr\_2016\_statistical\_annex.pdf

<sup>40</sup> UN HUMAN DEVELOPMENTREPORT 2016. http://hdr.undp.org/sites/default/files/hdr\_2016\_statistical\_annex.pdf

<sup>41</sup> A short summary of the results of a formative study of gender-based harm reduction projects and services. Basics / L. Shulga, M. Warban, E. Yaremenko — K .: ICF "Alliance for Public Health" LLC "Agency Ukraine", 2015. — 36 p. // http://aph.org.ua/wp-content/uploads/2016/08/Resume.pdf

<sup>42</sup> Report on the results of the survey "Estimation of the number of representatives of key groups in Ukraine" / Berleva G., Sazonova Y. — K.: ICF "Alliance for Public Health" LLC "Agency" Ukraine "2017. — 64 p.

<sup>43</sup> O. Balakireva, T. Bondar, T. Tarasova, Ya. Sazonova. Estimation of the Number of Addicted Women of Reproductive Age and Addicted Pregnant Women in Ukraine, -2013.-2013. https://www.unicef.org/ukraine/ukr/UA\_Population\_Booklet\_Helios.pdf

"If a drug user comes to you, be happy he has made it, because he may not come to you ever again. And do your best to make him start treatment and continue it, because if you just say something wrong or somehow show disregard, he won't come back. And it is quite likely he will then die." (TB doctor)

There were an estimated 237,500 **people living with HIV** in Ukraine as of the beginning of 2017. According to results of a community-based study<sup>44</sup>, positive HIV status significantly increases likelihood of violence in all spheres, and the most (by factor 15.5) in healthcare. 1.5% of women do not know where to go for help if their rights are violated at medical institutions.

**Roma communities** are marginalized and discriminated against in Ukraine. In their communities, men dominate over women<sup>45</sup>. Without their husband's consent, women cannot seek medical care or receive it from a male doctor. Their access to health, social services or justice is limited because of society's general discriminatory attitude, as well as because of dependence on husband and community.

"Speaking about culture, I think of Roma. These people basically have no habit of seeing a doctor, and they don't value their health. They have other values. Besides, Roma are such families or communities where being ill is not accepted. There are diseases that may lead to a patient being banished." (Ombudsperson)

In groups of *vulnerable youth*, gender-based factors lead to unsafe sex, early pregnancy, and growing STI incidence<sup>46</sup>. Boys may experiment with drug use and engage in criminal activities, be placed in juvenile prisons, and experience physical violence from their peers. Girls are vulnerable to sexual violence. Lack of sex education and the taboo nature of this topic lead to unawareness and shyness in discussing topics related to youth sexuality. The estimate of numbers of teenagers in risk groups in Ukraine includes young PWID, girls involved in provision of sex services, and young MSM. The total estimated number of people in these groups is 85,000, or 1.6% of all adolescents<sup>47</sup>.

#### Social determinants increasing vulnerability to TB

The economic vulnerability of Ukrainians increases their vulnerability to TB. According to the UN Human Development Report<sup>48</sup>, about 60% of Ukrainians live below the poverty line. In 2017, Ukraine held 7th position in the world in Bloomberg's Misery Index because of high inflation and unemployment rates<sup>49</sup>. The occupation of Crimea and armed hostilities in the east of Ukraine created a lot of *internally displaced persons (IDPs)* who are a socially vulnerable population, including with regard to TB infection. As of 2015, there were 1,679,000 IDPs<sup>50</sup>.

In Ukraine, *prisoners* are a population at high risk of TB. As of September 2016, there were 167 prisoners per 100,000 population (excluding occupied and uncontrolled territories); of them, women com-

<sup>44</sup> Community-based research: "Sexual and Reproductive Health, Gender Equality and Human Rights, Gender Violence, Economic and Political Opportunities of Women Living with HIV in Ukraine" Kyiv, 2016 https://goo.gl/92XGGd

<sup>45</sup> Alternative report on the implementation by Ukraine of the Convention on the Elimination of All Forms of Discrimination against Women: VIII Periodic Report / Ed. M. M. Skoryk. — Kyiv: CO BT "Kyiv Institute of Gender Studies", 2017 — 60 p.

<sup>46</sup> Annual report on the health of the population, 2015 http://www.uiph.kiev.ua/dawnload/Vidavnictvo/Shchorichna%20dopovid/% D0%A9%D0%BE%D1%80%D1%96%D1%87%D0%BD%D0%B0%20%D0%B4%D0%BE%D0%BF%D0%BE%D0%B2%D1%96% D0%B4%D1%8C.2016.pdf

<sup>47</sup> Estimation of the number of children and young people of the age group of 10–19 years belonging to risk groups / UNICEF;
O. Yaremenko Ukr. institute of social research — K., 2011. — 48 p https://www.unicef.org/ukraine/Ocinka\_chiselnosti\_ditey\_ukr.pdf

<sup>48</sup> UN HUMAN DEVELOPMENT REPORT 2016. http://hdr.undp.org/sites/default/files/hdr\_2016\_statistical\_annex.pdf

<sup>49</sup> Bloomberg's Misery Index

<sup>50</sup> UN HUMAN DEVELOPMENT REPORT 2016. http://hdr.undp.org/sites/default/files/hdr\_2016\_statistical\_annex.pdf

prised 4.6%<sup>51</sup>. A large number of prisoners are people with drug dependence, and vulnerable to HIV and TB. Their access to quality healthcare is limited; infection control is inadequate.

"If a person had TB while in prison, and then is released without having completed treatment, we lose track of him. Such people go into the civilian sector with different problems: they look for a job, they need to adapt and resocialize, and TB is not always their priority. And if the health system proves unfriendly because they are a special category... Even if such a man accesses TB services, he might not get proper conditions for successful treatment. And so he stops it. His doctor and nurse are glad he doesn't come to them anymore. Less headache for them..." (MoH expert)

**Alcohol abuse** is a TB risk factor. According to the WHO, 35% of men and 12% of women over 15 years of age in Ukraine have had episodes of heavy drinking. Prevalence of alcohol use disorders and alcohol dependence is 9% in males and 1% in females (2010)<sup>52</sup>.

## Results of gender assessment of the national TB/HIV response in Ukraine

The gender assessment process involved all stakeholders and national TB experts. Interviewing key informers — national-level experts using the gender assessment tool, as well as discussions with a broad circle of experts and representatives of civil society during working meetings — allowed the identification of gender-based barriers to accessing services. The information enabled us to identify the specific needs of women, men, transgender people and other vulnerable populations in the context of TB or HIV/TB. A number of issues were detected; in particular, all the experts noted that TB policy is not gender-sensitive and does not meet the needs of different populations.

Currently, the issues of gender-based stigmatization and discrimination are not covered in TB policies. More studies need to be conducted to determine the levels of stigmatization and discrimination, violence, and rights awareness, as well as access to diagnostics, treatment and care in populations at high risk of TB.

### National gender policy in Ukraine. Key documents on ensuring equal rights and opportunities for women and men

Legal and political factors affecting men/boys, women/girls, transgender people and populations at high risk of TB and HIV/TB co-infection

Experts noted the following aspects in the lives of women/girls, men/boys, transgender people and PHR most affected by TB, HIV/TB or MDR-TB:

criminalization of drug use; criminalization of HIV transmission or exposure to HIV (including HIV transmission from mother to child); criminalization of sexual activities for financial gain (commercial sex); lack of comprehensive sex education for youth under 18 years of age; prisoners' rights to health services.

<sup>51 (</sup>http://prisonstudies.org/country/ukraine)

<sup>52</sup> http://www.who.int/substance\_abuse/publications/global\_alcohol\_report/profiles/ukr.pdf?ua=1

At the same time, there are some legal frameworks protecting people living with TB, HIV/TB and MDR-TB, and women, girls and other key populations, such as criminalization of early or forced marriage; criminalization of partner violence; Ukrainian legislation on family and property (laws on marriage, cohabiting couples, divorce, child custody, succession to property, etc.); universal access to medications; labor relations and legislation on social support; laws ensuring complete sex education free from stigma and discrimination (though they do not work in fact); legislation on free provision of TB and MDR-TB testing and treatment; legal provisions for free HIV counseling and testing services on a voluntary and confidential basis; legal framework for sexual and reproductive rights; rights of migrants; rights ensuring access to health services, information on health problems and necessary care and treatment, receiving ART, condoms, cotrimoxazol and isoniazid prevention, isoniazid preventive therapy for children residing with a TB-infected person, and post-exposure prevention services.

With regard to protection of the main key populations (PHR), it was noted that Order of the MoH no. 327 of 15.05.2014 identifying populations at high risk of TB is outdated and not responsive to current circumstances. In particular, it does not account for current social and economic factors of development of the country and risk factors related to internal displacement of people from the east of Ukraine or Crimea. That is why the *list of populations at high risk of TB requires updating and regulatory definition*.

Access to many services remains unequal for women, girls, men, boys, transgender people and people from PHR. These services include counseling on existing health services; employment; services for victims of sexual violence including post-exposure prophylaxis of HIV and STIs; psychosocial support of PLWH and communities affected by TB; sexual and reproductive health services; social protection.

"About transgenders — there is a 100% stigma, so I think it should be a better-paid doctor who knows they will be coming to him, as he will not force transgenders to go to the general health clinic. This is not because I want to have them separated, I just understand where they will not go. They are not protected from people's reactions." (Coordinator of NGO projects)

The main international documents on ensuring equal rights and opportunities for women and men ratified by Ukraine are:

- UN Convention on the Elimination of All Forms of Discrimination against Women<sup>53</sup>
- Beijing Declaration adopted at the Fourth World Conference on Women on 15.09.1995<sup>54</sup>
- Resolution 1325 of the UN Security Council<sup>55</sup>

#### **National documents**

- The Law of Ukraine "On Ensuring Equal Rights and Opportunities for Women and Men"56
   of 08.09.2005, last revised on 13.05.2014 (basic regulatory legal act in the sphere of
   gender policy in Ukraine);
- The Law of Ukraine "On Foundations of Prevention and Countering Discrimination in Ukraine dd. 06.09.2012 no. 5207-VI (in part gender-based discrimination);
- Decree of the President of Ukraine "On Improvement of Work of Central and Local Executive Authorities on Ensuring Equal Rights and Opportunities of Women and Men" of 26.07.2005 no. 1135/2005;

<sup>53</sup> http://zakon2.rada.gov.ua/laws/show/995\_207

<sup>54</sup> http://zakon2.rada.gov.ua/laws/show/995\_507

<sup>55</sup> http://zakon3.rada.gov.ua/laws/show/995\_669)

<sup>56</sup> http://zakon3.rada.gov.ua/laws/show/2866-15

- Decree of the Cabinet of Ministers of Ukraine of 05.09.2007 no. 1087 (revised)
   "On Consultative Advisory Bodies on the Issues of Family, Gender Equality, Demographic Development, Prevention of Domestic Violence and Human Trafficking";
- Order of the Cabinet of Ministers of Ukraine "On Approval of the National Action Plan to Implement Resolution 1325 of the UN Security Council 'Women, Peace, Security' for the Period until 2020" dd. 24.02.2016 no. 113-p;
- Order of the Cabinet of Ministers of Ukraine "On Approval of the Concept of the State Social Program for Ensuring Equal Rights and Opportunities of Women and Men for the Period until 2021" dd. 05.04.2017 no. 229-p;
- Order of the Ministry of Social Policy "On the Expert Council for Consideration of Complaints about Instances of Gender-based Discrimination" dd. 11.04.2016 no. 376.

The government has adopted a resolution introducing the position of Government Commissioner on Gender Policy<sup>57</sup>. The main tasks of the government commissioner are: facilitating implementation of the unified state policy aimed at achieving equal rights and opportunities for women and men in all spheres of society; participation in coordinating work of ministries and other central and local executive authorities on the above issue; monitoring inclusion of gender equality principles in legal acts adopted by the Cabinet of Ministers of Ukraine; cooperation and interaction with civil society, etc. This will improve coordination of executive authorities working on practical implementation of the principle of gender equality in all spheres of life.

The central executive body authorized to shape state gender policy is the Ministry of Social Policy of Ukraine. The corresponding unit within its structure is the Department of Gender Development and Countering Human Trafficking.

## Ukraine's implementation of international agreements and declarations on elimination of discrimination against women

Ukraine signed the UN Convention on the Elimination of All Forms of Discrimination against Women on 17.07.1980 and ratified it on 12.03.1981<sup>58</sup>. Ukraine has also signed the Beijing Convention. At the same time, the Alternative Report on Ukraine's Implementation of the UN Convention prepared by a network of women's and human rights organizations, on the initiative of the Gender Strategic Platform, concluded that the equal rights of women and men are insufficiently ensured. Transgender people are not mentioned. According to the report, Article 12 on taking all appropriate measures to eliminate discrimination against women in the field of healthcare in order to ensure access to healthcare services on the basis of equality of men and women is not enforced. The report concludes that access to healthcare is most limited for women from ethnic minorities; women who have been subjected to gender-based violence; elderly women; women in difficult situations caused by armed conflict; female refugees; women at high risk of HIV or other STIs. The state report does not contain this information; there are no statistics about access of women from these categories to healthcare services.

It notes low usage of effective contraception methods, lack of sex education for children, and lack of knowledge about healthy lifestyles and family planning. The report's authors recommend developing standards of sex education for youth; organizing free women's health consultations with girl-friendly gynecologists; making a list of gender-disaggregated indicators; improving collection of statistical information and access thereto.

<sup>57</sup> https://www.kmu.gov.ua/ua/npas/250049925

<sup>58</sup> http://dhrp.org.ua/uk/publikatsii1/1623-20161219-ua-publication

The specific problems of **women living in rural areas** are not adequately highlighted and explored, and so they are not considered in state policies and programs. Available data point to low access of women living in rural areas to paid jobs; there is no social protection of the labor rights of rural women who have limited access to other social services, quality education and medical aid. Because of limited access to employment they are vulnerable to such violence as human trafficking. It is recommended to pay more attention to enforcing the rights of women living in rural areas and female representatives of ethnic minorities:

"...and there's a special difference between the village and the city. Because women are so immersed in housekeeping that they don't have time for themselves... They need to manage the household and look after the kids and husband. As a rule, their elderly parents live with them, and they also need care. And very often the women come for treatment with a more advanced stage of tuberculosis, with major complications." (Head of a NGO)

Experts believe that, despite acceding to international agreements and adopting national legislation on equal rights and opportunities for women and men, there is a lack of political will to implement gender-related transformations. The state has not yet been able to ensure real equality between women and men in society. At the same time, women are virtually not considered a target audience in socio-economic development programs, including poverty eradication. Vulnerable women are not paid proper attention in government programs and activities.

Analyzing discrimination at healthcare institutions that may affect access to TB and HIV/TB services for women living with HIV, including those from key or marginalized populations, experts agree that types of discrimination include: forced family planning; restricted access to contraception; sexual orientation-based discrimination; discrimination of transgender people; stigma of people living with HIV or affected by TB; stigma and discrimination of people who use drugs; loss of job because of TB or HIV-related stigma, and denial of support during treatment.

Finally, an indicator of the equal rights of men and women is the percentage of women in parliament and the Cabinet of Ministers. In Ukraine, out of 422 Members of Parliament, there are 48 women (11.47%); out of 24 members of the Cabinet of Ministers, there are three women (12.5%).

#### Gender equality and inclusion of PHR needs in TB policies and programs

The national response to tuberculosis and HIV/TB does not take the needs of physically disabled people or people with special needs into consideration; nor does it contain any differences in methods oriented to the needs of men/boys and women/girls. *The national targeted program "National Action Plan to Realize Conventions on the Rights of Persons with Disabilities"* for the period up to 2020 approved by Order of the Cabinet of Ministers dated 01.08.2012 Nº706<sup>59</sup> does not take into account a gender-sensitive approach either.

The national response to tuberculosis and HIV/TB doesn't take the needs of elderly people and especially women into consideration. Overall, there are no programs targeted at addressing the needs of elderly people related to TB (for instance, provision with food, fares to places of treatment, cervical cancer screening, etc.).

#### Financing of the national response to HIV and TB by means of internal and external sources.

Planned financing capacity and sources of the State Targeted Social Program of Fighting HIV-infection/AIDS 2014–2018 are as follows:

<sup>59</sup> Cabinet of Ministers Act dd. 01.08.2012 № 706 "Adoption of the State Targeted Program "National Action Plan to Realize Conventions on Rights of Persons with Disabilities" by 2020 "http://zakon3.rada.gov.ua/laws/show/706-2012-%D0%BF

Courses of financing	Funding Capacity, thousand. UAH 2014	Year					
Sources of financing		2015	2016	2017	2018		
State budget	4820060,21	785763,56	857157,26	920780,8	1122393,88	1133964,71	
Local budgets	331377,58	11385,34	11382,63	11380,75	147135,09	150093,77	
The Global Fund to Fight AIDS, Tuberculosis and Malaria	1224342,84	375305,09	419700	429337,76			
Other sources	4367,79	4367,79					
Total	6380148,42	1176821,78	1288239,9	1361499,3	1269528,97	1284058,48	

Therefore the state is gradually fulfilling its obligations in terms of funding of the national response to fight epidemics of HIV and TB at the expense of the state budget.

#### Interventions aimed at gender equality as part of the existing national response to HIV and TB.

Funding interventions aimed at gender equality in the country accounted for by the State Targeted Social Program to Fight HIV-infection/AIDS during 2014–2018							
External							
Financing	Internal	GF, different fu bi-lateral don	ınds, iors	UN		Civil Society	Private Sector
Total in USD, \$	151 thousand	1373,95 thousand					
100%	9,9%	90,1%					

The formal reporting system related to HIV/TB response, and allowing civil society, UN agencies and citizens to monitor expenses on gender equality in the process of fighting HIV and tuberculosis, is implemented in compliance with CMU Act "Collaboration in Realizing Public Expertise of Executive Department Governance" dated 05.11.2008 № 976 as well as CMU Act "To Ensure Participation of Civil Society in Constituting and Implementing State Policy" dated 03.11.2010 № 996.

## Official mechanisms conveying the thoughts, needs and rights of key populations and attracting attention towards them in the decision-making process of the response to HIV and tuberculosis.

In Ukraine a significant number of networks and organizations lobbying the interests and rights of people living with HIV, women, youth, key populations, etc. are involved in decision-making on different levels and in different areas providing a response to TB and HIV (including program development and implementation): the All-Ukrainian Network of PLWH, "Positive Women", the All-Ukrainian Association of People who struggled with TB "Stronger than TB", and other civil societies and associations. The National Council to Fight Tuberculosis and HIV/AIDS in the Cabinet of Ministers of Ukraine includes representatives of key groups representing the thoughts, needs and rights of the corresponding groups including representatives of civil society uniting former TB patients, people living with TB and HIV, and people belonging to groups at increased risk of TB or HIV. For instance, the head of "Stronger than TB", V. Pylypenko, is a member of the National Council to Fight Tuberculosis and HIV/AIDS in the Cabinet of Ministers as well as a member of working groups in the Ministry of Health of Ukraine. The targeted social program to fight TB includes fulfillment of the following indicator: "The number of regions where NGOs are collaborating with anti-tuberculosis clinics" the aim of which is collaboration with civil society to improve access to hidden and vulnerable groups. Within the GF grant, active TB detection/screening among highly vulnerable groups, case management and

work on adherence to treatment are realized by grant sub-recipients such as the All-Ukrainian Charitable Fund "Coalition of HIV service organizations", ICF "Alliance for Public Health", Red Cross Society of Ukraine, CO "All-Ukrainian Network of PLWH" ("100% Life") and other non-government organizations.

On 13–14 February 2017 during the CEDAW meeting in Geneva, the government report on overcoming violence, as well as alternative reports from the non-government sector placing emphasis on necessary legal changes and elimination of punitive actions towards women, were presented. A representative of the All-Ukrainian Charitable Organization "Positive Women" presented to the UN a report on critically high levels of harassment/violence towards four groups of marginalized women: women living with HIV; female sex workers; women who use drugs; lesbians and transgenders.

There are no key groups that would be excluded by Ukrainian legislation from the process of responding to HIV/TB, or would not have access to services.

## Gender Equality Coordination in the Process of Providing a Response to HIV and HIV/TB

#### The issue of gender equality in the national coordination mechanism on HIV and TB

The system of coordinating the process of fighting HIV/AIDS and tuberculosis includes the following:

Collegiate body taking decisions on the national level — The National Council to Fight Tuberculosis and HIV-infection/AIDS is founded in compliance with Resolution of the Cabinet of Ministers (CMU) dated 11.07.2007 № 926, functioning as an advisory and consultative body in the CMU. The national council addresses issues of Ukrainian policy in relation to HIV and tuberculosis and, in particular, issues of implementing state programs on HIV/AIDS, TB and GF grants.

The State Targeted Social Program to Fight HIV/AIDS 2014–2018 addresses tolerant attitude formation towards people living with HIV to overcome discrimination and ensure implementation of a gender-oriented approach in the process of planning and implementing actions to fight HIV/AIDS. The program reflects a gender-sensitive approach in the process of planning and implementing actions to fight HIV/AIDS; there is also a suggestion to include a gender constituent into the topic of reproductive health in the context of HIV prevention: "To promote development and implementation of gender sensitive programs of sex education for youth as well as skills promoting reproductive health". Another point aims "To introduce gender-oriented approaches to providing medico-social and preventive services to people living with HIV (including adolescents)".

The work of the "Stop TB Ukraine" partnership founded within the Global Partnership to Stop TB to provide a proper and effective response to the TB epidemic in Ukraine should also be noted. Among the tasks and aims of the partnership are development and implementation of effective mechanisms of social protection for people with TB, patients' rights protection, introducing gender equality based on existing legislation and the patients' rights charter.

It should be noted that in the "Harmonized Report of Ukraine on the progress achieved in implementing national measures to respond to AIDS" (the reporting period is 2015)<sup>60</sup> in the context of analyzing the problem of gender equality, the "Gender" indicator ("The proportion of women aged 15–49 who have ever been married or had a partner and have experienced physical violence or sexual harassment on the part of the man within the last 12 months") was announced to be irrelevant for Ukraine. The indicator "Percentage of men and women aged 15–49 who reported a discriminatory attitude towards people living with HIV" was not reported at all. The reason for this may be the absence of relevant information on the exact problem, rather than the absence of discrimination.

At present the Concept of the State Targeted Social Program to fight Tuberculosis during the period of 2018–2022<sup>61</sup> has been developed. Analysis of the concept shows a lack of attention to issues of gender equality. Some experts are pretty sure that the concept can be expanded in the following way: "Comprehensive coverage with high quality free of charge services on prevention, screening, treatment and social support for the general population and patients suffering from TB adhering to principles of social justice and *gender equality (expanded by the authors)*" (Chapter II. Resolute Political Measures and Support Systems. Political Commitment).

### Additional coordinating mechanisms in different government sectors and levels to achieve joint actions towards gender equality in the sphere of TB and HIV

Collegiate working bodies to develop joint resolutions on the national level include:

- thirty temporary and permanent working groups of technical experts on different aspects of fighting TB and HIV. The working groups are formed within ministries represented in the national council; they contain experts, government representatives and local and international NGOs;
- national council committees on program issues and regional policy, aimed at improving
  the quality of preparation of national council draft resolutions; more extensive
  involvement of interested parties into work, and harmonization of the working groups'
  activity. National council committees are led by members of the national council.

Collegiate bodies on taking decisions at *regional level* are regional councils to fight TB and HIV/AIDS, formed to perform the role of consultative and advisory bodies.

The Verkhovna Rada (parliament) structure for human rights includes a designated representative for issues related to respecting the rights of children, non-discrimination and gender equality<sup>62</sup>. There is also a special department on gender equality. Gender working groups and coordinating mechanisms have been formed in central executive branch authorities and regional public administrations. A multi-agency council on issues of family, gender equality, demographic development, violence prevention in the family and counter-trafficking was created within the CMU; counselors of ministers and governors on gender issues have been appointed; an advisory council dealing with cases of gender discrimination has been formed.

Based on the Law of Ukraine "On Providing Equal Rights and Opportunities for Females and Males" and the resolution of the CMU dated 12.04.2006, gender expertise on legislation has been introduced. Expert testimony must be an integral constituent of the package of documents provided alongside the regulatory draft act.

In total, 113 indicators constitute gender-sensitive statistics. Every two years the statistical collection "Women and Men in Ukraine" is published.

#### Budgeting to realize gender-adapted and transformational initiatives. Expenditure assessment.

The project "Gender Budgeting in Ukraine" is realized at national level with financial support from the Swedish International Development Cooperation Agency (SIDA), initiated by the Ministry of Finance of Ukraine<sup>63</sup>.

<sup>61</sup> http://www.moz.gov.ua/ua/portal/Pro\_20160309\_1.html#2

<sup>62</sup> http://www1.ombudsman.gov.ua/index.php?option=com\_content&view=article&id=2822

<sup>63</sup> Gender-oriented budgeting: analysis of programs funded by the budget on the basis of gender equality. The guide is for representatives of the executive branch and local self-government. http://www.fes.kiev.ua/new/wb/media/genderresponsivebugeting2015ukr.pdf

#### Factors influencing budget decisions related to gender and HIV

Experts name the following core factors having a negative impact on budget decisions related to gender and HIV:

- Absence of an efficient normative system aimed at regulating gender issues;
- Limited budget financing;
- Complicated procedures of acquiring international support;
- Stigma and discrimination from stakeholders;
- Absence of an accessible system of information documenting national and external expenditures on gender issues in the sphere of TB in Ukraine.

Advocacy in the sphere of state political commitments to gender equality on the national and regional levels is crucial. In the sphere of budgeting for gender projects as well as projects to fight TB, possible problems can be the absence of political commitment and insufficient executive capacity. The budget for the national response to HIV does not fully account for the specific needs of women, girls, men, boys and transgender.

#### UNAIDS program for women and girls in the national response to HIV

The national response to HIV is realized within UNAIDS' program for women and girls. UNAIDS strategy for 2016–2021 fully corresponds to UN Sustainable Development Goals, among which are overcoming AIDS by 2030. The aim of UNAIDS' program for women and girls is volume increase and increase in efficiency in using donor support and national resources to fulfill national commitments on gender equality and scaling up the rights and potential of women. The program also aims to influence the process of taking financial decisions, and the practices of donors and national partners through collaboration and partnership with a wide range of interested parties on national and international levels.

## Awareness and Competence in the Sphere of Gender equality

## Inclusion of gender sensitivity, human rights, stigma and discrimination topics into curricula for medical personnel

The following topics "Stigma and Discrimination" and "Voluntary HIV counseling and testing" are included in the HIV thematic advanced training course for family practitioners. The curriculum includes patients' rights and fighting stigma and discrimination, as well as thematic advanced training on reproductive health.

The one-week thematic advanced training on issues of HIV infection is organized for family practitioners once a year for 12–15 doctors. Outcomes assessment is organized with the help of pre and post questionnaires.

To reduce HIV-related stigma and discrimination among healthcare workers against the most at-risk populations (MARPs), including people living with HIV (PLHIV) and people who inject drugs (PWID), and involve patients in HIV testing and treatment the Network has implemented the USAID RESPECT Project with the financial support of the United States Agency for International Development (USAID) in the framework of the US President's Emergency Plan for AIDS Relief (PEPFAR) in 2013-2017.

A manual for the one-day training on issues of tolerant attitude towards PLHIV and MARPs was developed for health workers. The trainers' teams conducted 330 training sessions for 7647 practicing doctors and nurses from the pilot regions.

The training programs of the following institutions of pre- and postgraduate training of doctors and nurses were supplemented with approved working programs consisting of the component *Reducing Stigma and Discrimination*:

- National Medical University named after O.O.Bogomolets;
- The higher educational institution "Kyiv City Medical College";
- The higher educational institution "Kyiv Medical College named after P.I.Gavrosya";
- Donetsk National Medical University named after M. Gorky;
- Donetsk College of Advanced Training and Retraining of Medical and Pharmaceutical Personnel:
- National Medical Academy of Postgraduate Education named after P.L.Shupyk.

Seven non-governmental organizations received sub-grants to carry out project tasks related to the reduction of stigma and discrimination in medical institutions in Ukraine. These are the Kyiv and Kryvy Rih municipal districts of the Network, Lviv, Cherkasy, Mykolaiv, Kirovograd Oblast Branches of the Network and the Ukrainian Association of Family Medicine.

Gender aspects, human rights, stigma and discrimination, and the specifics of providing medical services to transgender people do not constitute an integral part of curricula, post graduate studies or thematic advanced trainings for other doctors. Nor are these questions a focus of the organizing process of training courses involving international technical support funding.

There is no information as to whether people involved in the process of providing the HV and TB response in Ukraine realize the consequences and outcomes of gender inequality between men and women and/or marginalization of particular groups in the context of TB and HIV.

### Policy to overcome gender violence related to TB and HIV in discipline-specific programs, initiatives and services

Ukraine signed the Council of Europe Convention on preventing and fighting violence among women and domestic violence (the Istanbul convention) in 2011. The convention lays out a comprehensive approach to fighting violence against women and domestic violence and essentially adds to existing tools, suggests new definitions of the concepts, and strengthens protection against gender discrimination. The main targets of the Istanbul Convention are protection of women from all forms of violence; prevention, prosecution and elimination of violence against women and domestic violence; assisting in elimination of all forms of discrimination against women, and achieving equality between men and women.

A crucial step towards overcoming domestic violence, including compliance with the Istanbul Convention, was adoption on 06.12.2017 of the Act of Ukraine "On Introducing Changes to Some Acts of Ukraine Related to Council of Europe Convention Ratification to Prevent Violence against Women and Domestic Violence as well as Overcoming all the Above-mentioned" and, to be exact, changes introduced to the Criminal Code and Code of Criminal Procedure allowing creation of preventative, protective and punitive mechanisms to fight violence against women including domestic violence. The Act of Ukraine dated 07.12.2017 "To Prevent Domestic Violence" (which implies cancellation of the existing Act of Ukraine "To Prevent Violence within Families") indicates a procedural and institutional basis of prevention and opposition to domestic violence and the main directions of implementing state policy in this particular sphere targeted at protecting the human rights and interests of people who have suffered from this kind of violence.

The introduced legislation implies a wide range of entities acting in the sphere of preventing domestic violence, among which are children's services, competent departments within the National Police of Ukraine, educational authorities, healthcare institutions, courts and prosecutors' offices, competent departments and services to support people suffering from violence among which are Centers of Social Services for Family, Children and Youth and institutions providing people and children suffering from vi-

olence with the possibility of twenty-four-hour accommodation. Local and international NGOs can also be involved in implementing activities directed towards prevention of domestic violence.

The act states that all activities targeted at preventing domestic violence are implemented without gender discrimination, which can also apply to people living with HIV and suffering from TB. The act states that in the process of providing support to people suffering from violence, their age, gender, health, religion, ethnic background and special needs (with needs assessment), including HIV and TB status, are taken into consideration.

The Concept of the State Social Program for Equal Rights and Capabilities of Women and Men for the period up to 2021 adopted by the Cabinet of Ministers of Ukraine on 05.04.2017 № 229-p<sup>64</sup> states the following: "Discrimination is one of the main obstacles to achieving gender equality in economic, political and other spheres. Separate groups of women (elderly women, women and girls with disabilities especially in rural areas, HIV-positive and/or drug addicted women and women from ethnic groups) suffer from several discriminatory factors at once." Among the expected outcomes are: "scaling up the access of women and men to goods and services by means of using principles of gender equality in all spheres of social activity taking into account the regulatory legal acts' gender component and special needs of different groups of women and men related to such key characteristics as age, place of living, disability, socio-economic status."

The Ministry of Social Policy is designated by the state entity ordering the program. Together with other central executive authorities, the ministry is responsible, within six months of adoption of the program concept, for developing and presenting to the CMU the project of the State Social Program of Providing Equal Rights for Women and Men by 2021.

As far as considering HIV and TB status while providing services to prevent violence is concerned, the main structural and legal principles of providing social services are identified by the Act of Ukraine "On Social Services", where social services are identified as an action plan to provide support to people and separate social groups in difficult life circumstances. "Difficult" circumstance are those associated with disability, age, health, social conditions, living habits and mode of life, as a result of which a person is not able or capable of taking care of their personal (family) life or participating in society. The act does not consider people suffering from violence as separate subjects for receiving services. **Special social services related to gender violence due to HIV or TB status are not available.** Social services to families and people in difficult life circumstances are provided in compliance with state standards (adopted by Act of the Ministry of Social Policy 03.09.2012 Nº 537).

In the corresponding chapter related to gender violence, including HIV and TB status, the state standards of social services do not make reference to relevant target groups. The scope of services within tertiary social prevention includes formation and support of adherence to a comprehensive treatment course with anti-TB medicines. This is the only standard in the scope of social services which directly refers to recipients of services going through TB treatment (excluding a gender approach).

Among the fundamental principles of preventing domestic violence is attention to the disproportionate effect of domestic violence on women and men, children and adolescents, and observance of the principle of providing equal rights for women and men in the process of implementing activities directed at preventing domestic violence.

Legislation on the issues of preventing domestic violence implies providing support and protection to people suffering from violence, including information in plain language on their rights and possibilities to implement their rights, access to support services for people suffering from violence to receive medical, social and psychological support; temporary shelter if necessary; access to justice and other mechanisms of legal protection; a 24-hour call center on preventing gender and domestic violence as well as violence against children to urgently respond to cases. It is essential that the above mentioned services do not depend on initiation of legal action by people suffering from violence. This is vital especially for target groups who are often faced with discrimination and do not bring cases to court.

At present the problems and obstacles preventing people suffering from violence from receiving effective support include: insufficient National Police staffing capacity; heavy workload of specialists from Centers of Social Services for Family, Children and Youth; insufficient levels of awareness and knowledge among experts involved in support provision (the regulatory system doesn't imply special vocational training on gender issues); absence of clear collaboration mechanisms in the process of providing support in cases of violence; absence of accessible social services on the level of society, etc. There is no government order mechanism for providing social services by civil society or the developed market of social service providers. The "admissibility" of violence in partner relationships, especially among vulnerable groups, constitutes a serious problem.

One way of implementing the State Targeted Program to Fight HIV-infection/AIDS for 2014–2108 is a gender-oriented approach during planning and implementing activities to fight HIV/AIDS. A gender-oriented approach in the process of providing services to PLWH and PHR can be realized by means of training experts.

#### Relation between gender violence and HIV/TB in the national policy to fight HIV and HIV/TB

Ukrainian legislation in the sphere of fighting HIV and HIV/TB doesn't identify a relation between gender violence and these illnesses. At the same time there is an understanding of this relation and the need for a comprehensive approach to service provision on the level of the expert community and central executive bodies.

There is partner collaboration between the government of Ukraine and organizations lobbying the rights of women, patients, communities suffering from TB, women living with HIV and other vulnerable groups, aimed at developing and implementing initiatives to fight HIV, TB and gender violence. In the sphere of preventing violence against women, the government of Ukraine is collaborating with the following organizations: UN Women Ukraine, UNFPA Ukraine, Civil organization "La Strada-Ukraine", ICF "Ukrainian Foundation for Public Health" and the representative of Health Rights International in Ukraine, The Global Fund, USAID, USAID RESPOND, UNAIDS, All-Ukrainian Network of People Living with HIV, Deutsche Gesellschaftfur Internationale Zusammenarbeit (GIZ) GmbH, ICF "Alliance for Public Health", All-Ukrainian Coalition of organizations "Stop TB Together" (this list is not comprehensive).

In 2011–2014 ICF "Ukrainian Foundation for Public Health" with financial support from the UN Agency on gender quality and scaling up rights and possibilities for women (UN WOMEN) implemented the project "Freedom from violence; scaling up rights and possibilities of women and girls in difficult living circumstances". At the very beginning of the project, a survey was organized. The results showed that 100% of HIV-positive women correspondents had suffered from violence related to their HIV-positive status. Within the project, provision of integrated services for HIV-positive women to prevent violence, as well as inclusion of this component into the work of service-providing organizations, was piloted; a rehabilitation program for girls and women who have suffered from violence and an intervention program for men committing violent acts were developed. In 2013 in Kyiv ICF "Ukrainian Foundation for Public Health" in collaboration with the representative of Health Rights International in Ukraine piloted "social apartments" as a form of rehabilitation for mothers and children who have suffered from violence.

### Sexual and Reproductive Health and Human Rights

#### Policy in the sphere of sexual and reproductive health and human rights

The Ministry of Health of Ukraine initiated discussion of a CMU order "On Concept Validation of the State Program "Reproductive and Sexual Health of the Nation by 2021". The aim of the concept is to preserve reproductive and sexual health, adhering to reproductive rights, to achieve individual well-being as well as productivity and stable development of Ukraine.

The program implies developing and implementing modern communicative strategies and programs of sex education for children, adolescents and youth on the issues of STI/HIV prevention, prevention of teen pregnancy, and violence prevention using approaches targeted at developing life skills.

Development of the legal framework of Ukraine related to reproductive and sexual health is done with the involvement of experts from civil society and in compliance with key international documents, particularly the Millennium Development Goals, Sustainable Development Goals 2030, WHO recommendations and WHO European Regional strategy in the sphere of reproductive health.

Services in the sphere of sexual and reproductive health and human rights in Ukraine are equally accessible for women and men and transgender people. However, transgenders rarely consult doctors especially in relation to their sexual and reproductive health. The main reason is fear of discrimination and disrespect from medical workers.

### Discrimination in the process of providing medical services to women, girls, transgender, men, boys and vulnerable groups with HIV-positive status or TB

In Ukrainian medical establishments there are cases of stigma and discrimination of HIV-positive patients, patients ill with TB or representatives of groups vulnerable to HIV and TB. They can be illustrated by the following examples:

"The general physical state worsened of a four-year-old HIV-positive child suffering from viral hepatitis, The parents went to consult a doctor in an infectious diseases hospital. After they informed the doctor about their child's HIV-positive status, they were refused hospitalization. In despair, the parents decided not to leave the hospital and insisted on urgent hospitalization. Only after five hours, when the child's state further deteriorated, was the child hospitalized."

Since the start of the armed conflict in eastern Ukraine and the situation in Crimea (2014), large-scale population migration has been observed in Ukraine. The UN High Commission on Human Rights reports more than 2 million displaced people, including 1.2 million internally displaced. Observation shows that about 70% of internally displaced people are women. This mass migration has resulted in a shortfall of basic service provision, which particularly affects vulnerable groups.

"Nelya was faced with a number of refusals from hospitals in Kharkiv, that refused to operate on her for different reasons, and she needed that operation badly: she risked losing her sight due to a head injury she received during bombing. They explained that they weren't able to operate on an HIV-positive woman."

According to data of the Center for Public Health of the Ministry of Health of Ukraine, as of 01.01.2017, 1,614 HIV-positive internally displaced people are registered, including 784 women who received referrals for medical care<sup>66</sup>.

#### Situation in providing medical services to transgender people

According to results of a survey by <sup>67</sup> CO "Insight", a large number of transgender people face the following human rights violations when consulting doctors: incorrect and offensive comments, and the necessity to teach the specialist. Most cases of violation of the human rights of transgenders

<sup>65</sup> http://www.ua.undp.org/content/ukraine/uk/home/presscenter/articles/2017/08/07/living-with-hiv-as-an-internally-displaced-woman-in-ukraine.html

<sup>66</sup> Read more on UNIAN: https://health.unian.ua/country/144878-yak-porushuyutsya-prava-vil-infikovanih-v-ukrajini.html

<sup>67</sup> http://www.insight-ukraine.org/wp-content/uploads/2014/10/%D0%94%D0%BE%D1%81%D0%BB%D1%96%D0%B4%D0 %B6%D0%B5%D0%BD%D0%BD%D1%8F.pdf

in the sphere of medical services in Ukraine are observed and reported during the preparation process for sex identity correction. Formally this procedure is aimed at improving medical support for people in need of sex identity correction, but in reality it often serves as an obstacle. The actual needs of transgender people in the process of preparing for sex identity correction (endocrinological therapy, psychological support) are not comprehensively met. This data is supported by the results of qualitative interviews with experts held within the survey.

"As far as transgenders are concerned today, it's terra incognita in medicine as this needs separate research in this sphere." (NGO head)

"You can often meet transgenders in inpatient departments. They are faced with stigma from other patients and they need a separate approach. Cases of violence are also reported, which serves as a reason for changing their treatment to outpatient. The inpatient system is not thought-out. More often they are in departments for multidrug-resistant TB. They often tell their doctors about their gender identity and ask for a separate patient room." (Lung health doctor)

#### Youth policy in relation to TB and HIV

In compliance with Ukrainian legislation, youth are citizens of Ukraine aged from 14 to 3568. The main directions of state youth policy in Ukraine in terms of social genesis and youth development are identified in the Act of Ukraine "On Assistance to Social Genesis and Development of Youth in Ukraine" <sup>69</sup>. Part of the Ukrainian Ministry of Youth and Sports' responsibilities are forming and realizing state policy in this sphere.

The main directions of state policy in the sphere of social work with families, children and youth ascertained by Act of Ukraine "On Social Work with Families, Children and Youth" imply social support for HIV-infected children, youth and their family members. Clause 7 of the Act of Ukraine "On Social Services" indicates the right to receive social services free of charge for children and youth in difficult living circumstances due to disability or illness. Therefore children and young people living with HIV have a guaranteed right to receive social services.

In compliance with Attachment 2 to Act of Ukraine "On Adoption of the State Targeted Program to Fight HIV-infection/AIDS for the period of 2014–2018" the strategy of providing access for PHR representatives to HIV prevention services 2014–2018 was adopted. The strategy contains a component of state policy for adolescents from risk groups and particularly children from families in difficult living circumstances, homeless and street children, and implies the following:

- Counseling and information on issues of HIV, STI, TB and viral hepatitis (B and C) (starting from the age of 14);
- Dissemination and exchange of syringes (starting from the age of 14);
- Dissemination of condoms and lubricants (starting from the age of 14);
- Counseling and testing on HIV (starting from the age of 14);
- STI testing (starting from the age of 14);
- STI treatment (starting from the age of 14);
- Social care (starting from the age of 14).

<sup>68</sup> http://zakon2.rada.gov.ua/laws/show/2998-12

<sup>69</sup> http://zakon3.rada.gov.ua/laws/show/2998-12

<sup>70</sup> Order of the State Service of Ukraine on the response to HIV / AIDS and other socially dangerous diseases dated January 22, 2015 No. 6. https://www.zakon-i-normativ.info/index.php/component/lica/?href=0&view=text&base=1&id=1452653&menu=1

#### National policy for elderly people/pensioners

The national policy for elderly people/pensioners is regulated by the Act of Ukraine "On Obligatory Statutory Pension Insurance" dated from 09.07.2003 № 1058-IV.

From the experts' point of view, this policy is not effective and does not solve problems related to vulnerability to HIV and TB, or obstacles to access to HIV and/or TB treatment and prevention services.

Specific risks of HIV and/or TB and the vulnerabilities of elderly people are not identified in national gender strategies or national policies on HIV and/or TB.

## CONCLUSIONS to Section III. Review of the applicable regulatory framework concerning populations at high risk of TB and gender policies

- Existing laws of Ukraine, orders of the MoH of Ukraine and other documents regulating provision of TB care in Ukraine do not cover gender aspects. A number of documents pay some attention to populations at high risk (PHR) of TB.
- The list of people included in PHR of TB is determined by Order of the MoH of Ukraine dd. 15.05.2014 no. 327. The list of PHR of TB was last updated in 2014 and does not account for socio-economic changes in the country.
- The Concept of the 2018-2021 National Targeted Social Program for TB Control, that has been approved in December 2017, includes measures concerning PHR, in particular:; differentiated formation of groups of high-risk for tuberculosis for the active detection of TB depending on the regional features (social, epidemiological, and TB and HIV morbidity) and ensuring their full coverage with TB diagnostics with the involvement of civil society organizations;ensuring continuous service provision to internally displaced people, migrants, etc. However, the 2018-2021 TB Program has not yet been approved, and does not envisage gender-oriented provision of TB services.
- A number of documents regulate the issue of providing aid to families and persons affected by TB. None of those documents defines gender specifics of receiving TB care.
- Socio-cultural norms and practices in Ukrainian society may promote increased risk of TB and HIV transmission among women/girls, men/boys, and transgender. They include gender inequality, traditional gender roles, and gender-based violence, including sexual or domestic violence.
- Social and political opportunities for women and men remain unequal.
   A gender-discriminatory attitude is promoted in mass media, advertising and even school education.
- Access to many health and social services remains unequal for women, girls, men, boys, transgender people and people from PHR. Existing gender inequality and its negative effects on health only intensify in the disadvantaged groups to which PHR of TB partially belong. As a result of discrimination, accessing medical and social services for members of such groups is getting more difficult; women from PHR are especially vulnerable.
- Despite acceding to international agreements and adopting national legislation on equal rights and opportunities for women and men, there is a lack of political will to implement gender-related transformations. Women are not seen as a target group in

socio-economic development programs; vulnerable women (elderly, especially in rural areas, HIV-positive and/or drug-dependent women, as well as women belonging to ethnic minorities) suffer from discrimination on several grounds at once.

- At the same time, there are many organizations in Ukraine representing PLWH, women, youth, key populations, etc. who are involved in decision-making on TB and HIV response at different levels.
- The National Targeted Social Program to Fight HIV/AIDS in 2014–2018 declares application of a gender-oriented approach during planning and implementation of activities related to the HIV/AIDS response. However, review of the Concept of the National Targeted Social TB Program for 2018–2021 reveals a lack of attention to the issue of gender equality.
- Among the main factors affecting gender-related budget decision-making are:
  - lack of an advanced normative system which would regulate gender issues;
  - limited budget funding;
  - decision-makers' lack of political will and understanding of the importance of gender equality in society; etc.

Advocacy is needed in the sphere of state political commitments concerning gender equality at national and regional levels.

- The Concept Paper of the State Social Program on Equal Rights of Women and Men for the period until 2021 envisages application of the principle of gender equality in all spheres of social life. However, despite approval of the concept in April 2017, the program has not yet been adopted.
- The state has undertaken commitments to overcome gender-based violence, and ratified a number of international documents on fighting violence against women and domestic violence. At the end of 2017 the Law of Ukraine "On Preventing and Counteracting Domestic Violence" was adopted, and determines the main activities to implement state policy in this sphere, including those aimed at protecting the rights and interests of people suffering from violence. The law identifies a wide range of subjects which should take action to prevent and counteract domestic violence.
- Ukrainian legislation on HIV and HIV/TB does not indicate a link between gender-based violence and these diseases. However within the expert community there is an understanding that such a connection exists and a comprehensive approach to service provision is required.
- Sexual and reproductive health services and human rights-related services in Ukraine
  are equally accessible to women, men and transgender people. But in general
  transgender people rarely seek medical aid, especially in regard to their sexual
  and reproductive health, as they fear discrimination from medical personnel.
- Inclusion of questions of gender sensitivity, human rights, stigma and discrimination into medical training curricula especially on TB issues is extremely insufficient.
- Training, post-graduate or advanced training plans for other medical specialists do not include topics of gender, human rights, TB stigma and discrimination, or specifics of medical service provision to transgender people.
- There is no information available on whether people involved in the HIV and TB response in Ukraine are aware of the consequences of gender inequality between men and women, or the marginalization of certain population groups in the TB and HIV context.

## SECTION IV.

## **Prioritization of Populations** at High Risk of TB

According to the WHO, prevalence and incidence of TB since 2007 have been decreasing, on average, by 4.4% and 3.3% a year respectively<sup>71</sup>. Estimated TB incidence in 2016 was 87 per 100,000 population<sup>72</sup>; however, national statistical data puts it at 67.6 per 100,000 population (according to the official TB statustics by 01.01.2017 by MoH)<sup>73</sup>. Thus, about 22.2% of new TB cases annually go undetected in Ukraine, contributing to further spread of the disease among the population. Current TB prevalence is 82.1 per 100,000 population<sup>74</sup>, which is almost three times higher than the target set by the Global Plan to Stop TB.

Because tuberculosis is currently a nationwide problem, a comprehensive approach is needed to formation and implementation of a state TB policy<sup>75</sup> with an emphasis on populations at high risk (PHR) of TB. The first step in national planning for PHR of TB is systematic study of all possible PHR, their prioritization as per their contribution to TB incidence, and the risks and barriers they encounter to accessing TB services<sup>76</sup>. This will enable reviewing existing gaps in the national healthcare system's capacities and resources, mobilizing scarce resources in a targeted manner for the purpose of prevention and timely detection of TB patients and people infected with TB mycobacteria, and ensuring TB services reach priority PHR in order to prevent spread of the disease.

'Risk population' is a term used mostly in medicine and sociology, denominating members of the general population most vulnerable to certain social or medical factors, or to the influence of the environment. The term 'risk population' or 'key population' is used in the legislation of Ukraine to refer to people at risk of HIV infection. Key populations at risk of HIV are populations that, considering the specifics of their behaviors and the behaviors of their environment, are at high risk of contact with sources of HIV. According to WHO's definition, five key populations at risk of HIV include: men who have sex with men; people who inject drugs; people in prisons and other closed settings; sex

<sup>71</sup> Tuberculosis in Ukraine. Analytical and statistical guide. — K .: DU "Center for Public Health of the Ministry of Health of Ukraine", LLC "Agency Ukraine" 2017. — 216 p. https://phc.org.ua/pages/diseases/tuberculosis/surveillance/statistical-information

<sup>72</sup> Tuberculosis profile, Ukraine. https://extranet.who.int/sree/Reports?op=Replet&name=%2FWHO\_HQ\_Reports%2FG2%2FPR OD%2FEXT%2FTBCountryProfile&ISO2=UA&LAN=EN&outtype=html

<sup>73</sup> Tables with statistics for 2016, table 14. https://phc.org.ua/pages/diseases/tuberculosis/surveillance/statistical-information

 $<sup>74 \</sup>quad Tables \ with \ statistics for \ 2016, \ table \ 14. \ https://phc.org.ua/pages/diseases/tuberculosis/surveillance/statistical-information$ 

<sup>75</sup> Cabinet of Ministers of Ukraine, Order of 27 December 2017 p. Number 1011-p Kyiv On approval of the Concept of the National Targeted Social Program TB for 2018-2021 years http://zakon2.rada.gov.ua/laws/show/1011-2017-%D1%80#n9

<sup>76</sup> Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations Working Document. September 2017. http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf

workers; transgender people<sup>77</sup>. Definition and revision of the list of such groups is performed by the authorized central executive healthcare agency, considering criteria and recommendations provided by WHO.

Legislation regulating provision of phthisiatric care in Ukraine uses the term 'populations at high risk of tuberculosis (PHR)'. These key populations in the TB context should be defined by their level of risk of developing tuberculosis, and type of vulnerability (according to international recommendations concerning the TB program for 2007–2011)<sup>78</sup>. Order of the MoH of Ukraine dd. 15.05.2014 no. 327 "On Detection of People with Tuberculosis or Infected with Tuberculosis Mycobacteria" approves the **List of Populations at High Risk of Tuberculosis** as follows:

- 1. People living with HIV.
- 2. People having contacts with TB patients (family or professional).
- 3. Immunocompromised people.
- 4. Smokers; alcohol or drug dependent people.
- 5. Migrants or refugees from regions with high TB incidence.
- 6. Persons below the poverty line; unemployed.
- 7. Homeless.
- 8. Patients of mental health institutions.
- 9. Detained and arrested persons sent to temporary detention facilities; persons in prison or released from prison, and persons registered with internal affairs authorities as previously convicted and placed under surveillance.
- 10. Personnel of penitentiary, mental health and healthcare institutions in frequent contact with TB patients and performing corresponding examinations and tests.

The list of populations at high risk of tuberculosis in Ukraine was last updated in 2014. However, in recent years changes in the country have adversely affected the TB situation. The main aggravating factors are a socio-economic crisis, lower living standards and increased migration of large population groups (internally displaced people, seasonal workers) who go virtually unaccounted for by healthcare facilities and are not reached by TB-related measures. All these factors, as well as the above-mentioned data indicating that every fifth new case of TB annually goes unnoticed, suggest that the list of populations at high risk of TB in Ukraine needs to be updated according to relevant regional specifics<sup>80</sup> and the current economic and political situation in the country.

The wide group of experts and stakeholders worked on the updating of the list of populations at high risk of TB in Ukraine, including representatives of Verkhovna Rada of Ukraine, of the Government of Ukraine (Ministries and their departments), of the international organisations (UNDP, PATH, Health Right International, Project Hope etc.) and national NGOs, as well as representatives of the communities of TB patients and of KPs for TB and HIV (such as All-Ukrainian Association of People Who Overcame Tuberculosis "Stronger Than TB", International Charitable organization "Roma women fund Chiricli" etc.)(see Annex 2).

<sup>77</sup> Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. World Health Organization 2014, reprinted in 2016 with changes. http://www.who.int/hiv/pub/guidelines/keypopulations/en/

<sup>78</sup> http://stoptb.in.ua/uk/vsi-rekomendacii

<sup>79</sup> Order of the Ministry of Health of Ukraine dated May 15, 2014 № 327 "On the identification of persons with tuberculosis and infected with mycobacterium tuberculosis". http://zakon3.rada.gov.ua/laws/show/z0576-14

<sup>80</sup> Tuberculosis profile, Ukraine. https://extranet.who.int/sree/Reports?op=Replet&name=%2FWHO\_HQ\_Reports%2FG2%2FPR OD%2FEXT%2FTBCountryProfile&ISO2=UA&LAN=EN&outtype=html

During the expert's working meeting 21.11.2017 were presented the goals and methodology of the study as well as it was agreed to use Tool "Prioritizing Key Populations At National Level". A list of highrisk groups for TB was added to the instrument in accordance with the Order of the Ministry of Health of Ukraine dated May 15, 2014, No. 327.

The assessment of prioritization was carried out according to the criteria of the estimated impact of TB incidence on the country's burden in the area of TB (extensively), environmental risks, biological, behavioral risks, legal and economic barriers to access the services, and barriers to access the services in the area of human rights and gender, according to the Tool. As the extensive indicator shows only the specific weight of these groups in relation to the overall morbidity, the expert group recommended the introduction of an intensive TB incidence rate, which shows the incidence of TB in a particular risk group, on the assessment scale.

The tool *Prioritizing Key Populations At National Level* (Stop TB Partnership)<sup>81</sup>, used in this study, focused attention on the underserved populations at high risk of TB because of biological and behavioral factors. The mentioned tool was adapted to the needs of Ukraine according to national expert recommendations, and taking into account modern trends concerning the epidemiological and economic situation in Ukraine. Therefore, the following groups were included in the list of high risk groups: internally displaced persons (IDPs) who suffered as a result of armed conflict in the East of Ukraine; Roma population; ATO (Armed conflict zone in the East of Ukraine) participants; persons who have professional contacts with TB patients.

The miners did not stand out in a separate group, but were included in a group of people who suffer from silicosis, as the incidence of TB in miners with silicosis is 26 times higher than that of miners without silicosis. In addition, taking the lack of influence of the number of smoked cigarettes on the development of TB disease into account, an assessment of prioritization was carried out among people who smoke more than 40 cigarettes a day.

The final list of populations at high risk of TB, to determine their contribution to new TB cases and further prioritization, was formed considering expert recommendations and all the above factors. It includes:

- 1. People living with HIV
- 2. People with silicosis
- 3. Migrants; refugees; internally displaced people
- 4. Prisoners and detainees
- 5. People who inject drugs
- 6. People with alcohol dependency
- 7. Smokers of more than 40 cigarettes a day
- 8. Ethnic minorities (Roma)
- 9. Homeless
- 10. People with mental disorders
- 11. Urban poor
- 12. Rural poor

<sup>81</sup> Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations Working Document. September 2017. http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf

- 13. People with diabetes
- 14. Children
- 15. Elderly (over 60)
- 16. People professionally in contact with TB patients (personnel of social care facilities of all forms of ownership and subordination, who are frequently in contact with TB patients and conduct examinations and tests)
- 17. Medical workers (non-TB related)
- 18. Family contacts of TB patients
- 19. Armed conflict zone in the East of Ukraine participants
- 20. Miners
- 21. Commercial sex workers (CSWs)
- 22. LGBT and community
- 23. Prison workers
- 24. Refugee camp workers
- 25. Community health workers/outreach workers
- 26. Hospital visitors
- 27. Prison visitors
- 28. Communities around prisons
- 29. Mining communities
- 30. Sex worker clients
- 31. Family members of people who use drugs
- 32. Miners' family members
- 33. People at risk of zoonotic TB

A number of groups were included in the tool "Prioritizing Key Populations At National Level", a number of groups were assigned to the groups with High Risk in accordance with the MoH Order No. 327 of 2014, and the overall list was completed in agreement with a panel of experts and stakeholders based on the results of the study.

Data for Action for TB Key, Vulnerable and Underserved Populations Working Document, September 2017	Order of the MoH of Ukraine of 15.05.2014 No. 327, List of the Groups with High Risk for TB	Experts' recommendations based on the current epidemiological, economical and social trends in Ukraine	Final list of the GHR for TB
People Living with HIV	People living with HIV		People living with HIV
People with Silicosis		People with silicosis	People with silicosis
Miners		T copie with sincosis	'
Migrants	Migrants or refugees		Migrants;
Refugees	from regions with high TB incidence		Refugees
Internally Displaced People	18 incluence		Internally displaced persons
Nomadic Populations			
Prisoners & Detainees	Detained and arrested persons sent to temporary detention facilities; persons in prison or released from prison, and persons registered with internal affairs authorities as previously convicted and placed under surveillance.		Prisoners and detainees
People who Use Drugs			People who inject drugs
People with Alcohol Dependency	Smokers; alcohol or drug dependent people		People with alcohol dependency
Smokers	acpendent people		Smokers of more than 40 cigarettes a day
Urban poor	Persons below the poverty		Urban poor
Rural poor	line; unemployed.		Rural poor
		Ethnic minorities (Roma)	Ethnic minorities (Roma)
People with Mental or Physical Disabilities	Patients of mental health institutions.		People with mental disorders
Homeless	Homeless.		Homeless
People with Diabetes	Immunocompromised people.		People with diabetes
Indigenous Populations			
Hospital Workers	People having contacts with TB patients	Medical workers (non-TB related)	Medical workers (non-TB related)
'	(family or professional).	Family contacts of TB patients	Family contacts of TB patients
Prison Workers	Personnel of penitentiary, mental health and healthcare institutions in frequent contact with TB patients and performing corresponding examinations and tests.		People professionally in contact with TB patients (personnel of social care facilities of all forms of ownership and subordination, who are frequently in contact with TB patients and conduct examinations and tests)
		Armed conflict zone in the East of Ukraine participants	Armed conflict zone in the East of Ukraine participants
Elderly			Elderly
Children			Children

Data for Action for TB Key, Vulnerable and Underserved Populations Working Document, September 2017	Order of the MoH of Ukraine of 15.05.2014 No. 327, List of the Groups with High Risk for TB	Experts' recommendations based on the current epidemiological, economical and social trends in Ukraine	Final list of the GHR for TB
Sex Workers			Persons providing sexual services for a fee
Lesbian, Gay, Bisexual & Transgender			LGBT and community
Refugee Camp Workers			Refugee camp workers
Community Health/ Outreach Workers			Community health workers/ outreach workers
Hospital Visitors			Hospital visitors
Prison Visitors			Prison visitors
Peri-prison Communities			Communities around prisons
Peri-mining Communities			Peri-mining communities
Sex Worker Clients			Sex worker clients
Family Members People who Use Drug			Family members of people who use drugs
Miners' family members			Miners' family members
People at risk of zoonotic TB			People at risk of zoonotic TB

As national studies to determine the impact of TB risk factors (behavioral risks, legal and economic barriers to access services, human rights or gender-related barriers to access services) are limited and out-of-date, risk assessment was based on available local and international data, aligned with the expert opinion of the experts and stakeholders involved in the study (see Annex 2) during the stakeholders meeting, 24.11.2017.

During the stakeholders meeting, of 13.12.2017, the results of the expert group were presented to the stakeholders. Results of discussion and group work among stakeholders on the definition of barriers to access TB services were made to the finalized research tool; the results of the tool filled in the groups were presented and approved by a wide range of attendees at the meeting (see Annex 2).

According to the tool *Prioritizing Key Populations at National Level*<sup>82</sup>, **prioritization followed seven criteria:** 

- Score 1A: Estimated contribution to the country's TB burden (intensive indicator: population's TB incidence). This indicator allows comparison of incidence in different populations. Scoring method: 1 low (equal to/not exceeding average incidence in the total population), 2 medium (exceeding the average rate, but below 100 cases per 100,000 in this population), 3 high (100 or more per 100,000 in this population). Source of information: state statistics and estimates.
- **Score 1B:** Estimated contribution to the country's TB burden (extensive indicator: individual population's share in the structure of TB incidence). Scoring method: 1 Very low (0–1%), 2 Low (1–3%), 3 Medium (3–5%), 4 High (5–10%), 5 Very high (>10%). Source of information: state statistics and estimates.

<sup>82</sup> Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations Working Document. September 2017. http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf

- **Score 2:** Environmental risks (whether the key population is exposed to any environmental risks such as overcrowding or poor ventilation (0 No, 1 Yes)). Source of information: scientific data, publications, expert consensus.
- **Score 3:** Biological risks (whether the key population is exposed to any biological risks such as reduced immunity or poor nutrition (0 No, 1 Yes)). Source of information: scientific data, publications, expert consensus.
- **Score 4:** Behavioral risks (whether the key population is exposed to any behavioral risks (0 No, 1 Yes)). Source of information: scientific data, publications, expert consensus.
- **Score 5:** Legal and economic barriers to accessing services (whether the key population faces any legal and/or economic barriers to accessing services, such as criminalization or poverty (0 No, 1 Yes)). Source of information: scientific data, publications, expert consensus.
- **Score 6:** Human rights and gender barriers to accessing services (whether the key population faces any violations of human rights or gender barriers such as stigma or discrimination (0 No, 1 Yes)). Source of information: scientific data, publications, expert consensus.

**The total score** for each key population was obtained by adding the above seven scores (max. 13).

We took the combined impact of intensive and extensive statistics on the impact of environmental, behavioral risks and legal, economic and social barriers to accessing services related to human rights and gender, on a scale (low priority level 1-4 points, average — 5-8, high — 9-13 points) into account.

Based on the results reached through the prioritizing tool, **priority populations at high risk of TB are** (Annex 1. Prioritizing Populations of High Risk for TB):

- 1. People living with HIV
- 2. Prisoners and detainees
- 3. People who inject drugs
- 4. People with alcohol dependency
- 5. Smokers of more than 40 cigarettes a day
- 6. Ethnic minorities (Roma)
- 7. Homeless
- 8. People with mental disorders
- 9. Urban poor
- 10. Rural poor
- 11. People with diabetes
- 12. Children
- 13. Elderly (over 60)
- 14. People professionally in contact with TB patients (personnel of social care facilities of all forms of ownership and subordination, who are frequently in contact with TB patients and conduct examinations and tests)

- 15. Medical workers (non-TB specialists)
- 16. Family contacts of TB patients
- 17. Armed conflict zone in the East of Ukraine participants

High barriers to access had Prisoners and detainees, People with alcohol dependency, People who inject drugs, Ethnic minorities (roma), CSWs, and ATO (Armed conflict zone in the East of Ukraine) participants. At the same time, the study discovered a lack of regional and national statistical data on intensive and extensive indicators of TB incidence in the following populations:

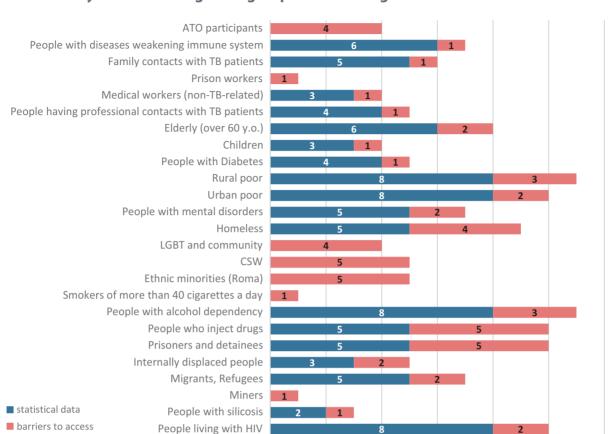
- Miners
- Commercial sex workers (CSWs)
- LGBT
- Prison workers
- Refugee camp workers
- Community health workers/outreach workers
- Hospital visitors
- Prison visitors
- Communities around prisons
- Mining communities
- Sex worker clients
- Family members of people who use drugs
- Miners' family members
- People at risk of zoonotic TB
- Smokers of more than 40 cigarettes a day
- Ethnic minorities (Roma)
- Anti-Terrorist Operation participants

A combined impact of epidemiological data, environmental risks, behavioral risks, and legal, economic and social barriers to accessing TB services that are related to human rights and gender and significantly increase the risk of TB was determined for the following PHRs:

- People living with HIV
- Prisoners and detainees
- People who inject drugs
- People with alcohol dependency
- Homeless
- Urban and rural poor

The risk of TB is lower, although still the case, in people with silicosis, children, medical workers (non-TB-related).

Taking into account the above, the risks of TB in these groups need further study. At the same time, in groups such as Ethnic minorities (Roma), CSW, LGBT ATO (Armed Conflict in the East of Ukraine) participants revealed high barriers to accessing TB services, which may be a factor influencing the statistics or determining a lack of official statistics on TB incidence among these groups.



#### Priority schedule of high-risk groups for TB taking into account all defined barriers.

The results of the study on prioritizing populations at high risk of TB and the recommendations of the final stakeholders meeting on 13.12.2017 emphasized the necessity of the following steps to form an adequate response to the TB epi Yulia demic in Ukraine:

• To include recommendations on the update for the TB vulnerable, underserved and key populations into the draft of the National TB Program;

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- To advocate inclusion of the Roma population data, and IDPs in the National TB register;
- To ensure follow up with the qualitative/quantative data collection for two key high
  risk groups (Roma national minority and Internally Displaced Persons (IDP)) as well
  as to ensure the mapping of the available programmatic services;
- Recommend annual implementation of the questionnaire for prioritizing populations at high risk of TB, at national and regional levels, for further shaping TB policy;
- Update the list of PHR of TB considering the determined priority groups.
   Ensure collection of statistical data on intensive and extensive indicators of TB incidence among priority populations at high risk of TB;
- At-risk populations having professional contacts with TB patients should include personnel of social care facilities of all forms of ownership and subordination who are frequently in contact with TB patients and conduct examinations and tests;
- At the level of legislation, strengthen tobacco control to reduce prevalence of smoking according to WHO recommendations;

- Implement self-testing for detection of alcohol dependence among TB patients. In order to determine the level of poverty among TB patients, conduct questionnaire-based polls concerning monetary and non-monetary poverty;
- Consider conducting studies to determine the typical characteristics of migrants, and specific mental disorders and diseases associated with increased risk of TB;
- Consider conducting a study to determine the impact of the quantity of smoked cigarettes on TB risk;
- According to the recommendations of the final stakeholders meeting on 13.12.2017, consider conducting a qualitative study with representatives of LGBT and CSW identified as groups at high risk of TB, to explore their TB-related environmental, biological and behavioral risks, social and cultural norms and practices, and individual, institutional and system barriers to access TB services, including legal and economic barriers, and barriers related to the human rights, stigma and discrimination;
- Conduct national studies of behavioral risks, legal and economic barriers to accessing TB services, and barriers related to human rights and gender, among the determined priority populations at high risk for TB in Ukraine, specifically Roma population and IDPs.
- According to the recommendations of the final stakeholders meeting, the prioritised key populations (Roma and Internally Replaced Persons) should be included in the next phase of the study for: 1) qualitative study (focus groups and/or in-depth interviews) with representatives of these specified KPs to explore cultural factors, all types of risks and barriers to accessing TB services; 2) quantitative data collection to study prevalence of cultural factors, risks and barriers identified for these KPs in the qualitative study, as well as using TB screening questionnaire. The received data might be used to secure the launching TB programs for the prioritised KPs in several strategic regions of Ukraine, to test the feasbility of the CBO-public-private collaboration in delivering person-centered patient-friendly TB services to the prioritised KPs.

## SECTION V.

# Analysis of in-depth interviews with national and regional experts and decision makers

The study involved conducting in-depth, semi-structured interviews with seven national experts and 15 regional experts in Ukraine.

Among them were 9 men and 13 women. The age range was 31 to 65 years old.

The interviewees included:

Three medical directors of tuberculosis clinics and one oblast phthisiologist;

One head and one coordinator of programs of Oblast Centers for Social Services for Family and Youth;

- Five heads of NGOs;
- One ombudsman;
- One head of the Oblast State Administration Department of Social Protection;
- One program coordinator of an LGBT NGO;
- Two experts from the All-Ukrainian Network of People Living with HIV;
- One expert from the Ukrainian Red Cross Society;
- One expert from an international organization;
- · One coordinator of programs fighting human trafficking;
- One coordinator of the "Life without TB" project;
- Two experts from the MoH of Ukraine.

Eight of the 22 experts reported dealing with prevention, diagnostics and treatment of TB as phthisiologists or medical directors. The remaining experts work in organization and provision of legal, psychosocial or social services to TB patients or populations at high risk (PHR) of TB.

"Currently I am a project manager. My main task is to improve the quality of care for patients with multidrug-resistant TB in Ukraine. And the sub-task is implementation of new TB drugs, short treatment regimens, and new diagnostic methods." (Expert from an international organization)

"The Red Cross Society in Ukraine is involved in TB treatment at the outpatient stage. Mostly we start managing patients after they leave inpatient facilities, and these are the people at risk of terminating treatment." (Expert from an international organization)

All the experts said they understood what gender is and noted **inequality between males and females** in Ukrainian society in the following spheres: employment; unpaid work load; income; access to different kinds of services (legal services, sexual education, family planning services, etc.):

- Men tend to have higher incomes than women do. Women usually depend on men financially.
- Men enjoy priority in matters of employment. Because a young woman may take maternity leave, employers may refuse to hire her.
- Managerial positions are mostly occupied by men.
- Women have a higher load of (unpaid) housework. They take care of children and elderly parents.
- Women are more interested in family planning matters than men.

"Generally, women think about such things, you know, like harvesting the crops or planting vegetables in the garden if they live in a village. Or their children are taking exams and need help preparing, or this, or that, finishing house repairs, and so on. And somewhere far down the list is 'me and my health'. Women, by the way, are often admitted to the TB hospital in a comatose condition. That is, when it is too late. And often they are mothers... But then again, socially adapted men with good jobs find it hard to believe they may encounter disability." (Ombudsman)

#### **Gender-specific barriers to access to TB services**

Responding to the question on availability of gender-sensitive TB services, the respondents noted that both men and women encounter problems when coming for TB medical services:

- TB services in Ukraine are not gender-sensitive;
- access to prevention, diagnostics, and treatment is equal for all, i.e. equally inadequate;
- no personalized approach to patients' needs;
- barriers to receiving services are purely social and geographic (patients live far from health care facilities);
- financial inequality persists: doctors tend to do more for those willing to pay a bribe.

"The concept of gender is, first of all, about equal access regardless of the patient's sex or individual features. I wouldn't say there are major gender-related problems with access to TB services in Ukraine. I believe we do have barriers to access to services regardless of gender; they are barriers for all — men and women and transgender people." (Expert from an international organization)

"In the current situation with tuberculosis treatment, doctors do not even think about a personalized approach to needs. And that's the problem — they all use the same standard approach to all patients." (NGO representative)

At the same time, the respondents said there was somewhat **different access to TB information**, **prevention and diagnostics for men and women**. Some of the experts believe that:

- men have better access to information and diagnostics because they are more socially active;
- women enjoy less access to information and diagnostics because they are more occupied with family matters and are less mobile.

#### **Barriers for rural populations**

Experts believe that urban and rural residents have substantially different levels of access to TB services. Villagers come for medical aid very late, mostly at an advanced stage of TB (because of remoteness of TB facilities and lack of funds for travel) — that is, because of geographic and economic barriers.

"There are also serious problems with diagnostics, because a lot depends on who the breadwinner is in the household. There are also single women with a house in a village. Talking about gender, there are also differences between the situation of men and women. Or between urban and rural populations. Rural people have problems with TB treatment, it's not always prescribed to them. When doctors detect a pathology, they tell the person 'you need treatment, we will treat you.' But he says 'I can't, I have a house, a smallholding, I won't take further tests, I won't take the treatment.' These are big problems. You need to look into the context. Is there a significant other, a family? And single people too; different policies are needed for single women and men and for people with families — that needs to be taken into account." (Phthisiologist)

#### Financial barriers to diagnostics and treatment

Some experts believe that access to services depends not on gender, but rather on the financial standing of the person in question. If the person is poor, access to services is low.

"Accessibility of services is related to their paid nature. Because, after stigma or discrimination, another barrier I see is fear to come and hear the amount. An overwhelming amount. They keep hearing: 'Please pay for the x-ray film, and make a donation to the hospital, and something else too, we've run out of cleaning detergents,' and so on. In a country with a TB epidemic, this is unacceptable." (NGO representative)

"Actually, I think the biggest barrier is poverty. It is not even poverty, it is penury. If people were not so poor, always thinking, 'if I can't work, I won't be able to pay for my room, and if I don't pay I will end up on the street.' Very often people — mostly men —will keep working even with a temperature and feeling sick, just to keep their status quo..." (Ombudsman)

"A man and a woman may get different kinds of care from the same doctor... Well, we doctors do have our favorites. There are people who can pay; I can tell you for sure that those who pay will get more information; that is 100%." (NGO representative)

#### Gender-specific barriers at the stage of TB diagnosis

Most of the experts expressed the opinion that there are barriers at the stage of TB diagnosis that may affect receiving TB treatment. Barriers include:

- lack of privacy during diagnostic procedures;
  - common queues and shared rooms for sputum sampling (feeling uncomfortable; women cannot produce sufficient amounts of sputum);
  - shared rooms for CT, X-ray (transgender people may delay treatment because they are forced to come out; discomfort for women).

"About privacy — how do they actually do these diagnostics? 'Go and undress' — and there is some room anyone can walk through or look into, and so on." (**NGO representative**)

#### **Gender-specific barriers during TB treatment**

The hygiene needs of men, women, and transgender people are not taken into account in the course of inpatient treatment, namely:

- different sanitary-hygienic kits for men and women considering their physiological differences and specific needs;
- separate sanitary facilities;

- hot water supply in hospital departments;
- separation of hospital departments based on gender, and not just on forms of tuberculosis.

"Talking about treatment itself — I think there is this problem of non-separation of men and women in health-care facilities; that is, there are no proper conditions. Hygiene... come on! No hot water, a shared toilet because the second toilet, for ladies, is broken and no-one is going to repair it, the doors don't close — the usual story. Clearly, some clinics separate patients based only on the drug-resistance of their TB..." (NGO representative)

"Even social support — sometimes some projects provide sanitary-hygienic kits. They must be different for men and women: some need shaving foam and razors, and some need laundry powder for the whole family. And sanitary towels that they can't afford. It should all be taken into account, to retain people in treatment... I think these issues of social support and help with groceries are important to ensure people proceed with treatment." (Medical director of TB clinic)

#### Lack of awareness of the needs of transgender people

It was found that most experts are not aware of the needs or interests of transgender people because this issue is poorly explored.

- Transgender people are an extremely stigmatized group who do not tell doctors much about their needs during diagnostics or treatment.
- The main need of transgender people, experts believe, is to be accepted in the gender they feel they belong to.
- The best model of service provision would be peer-to-peer, or forming a network of friendly doctors.

"Yes, of course, some basic needs are the same, but there are some specifics for men, women and transgender people. They are very important to take into account. One of the main needs of transgender people is to be accepted in the gender they identify with. What do I mean? In a perfect world, the ideal model of service provision would be peer-to-peer. Or, at least, prevention services should be provided by a person who knows what transgender is, who is aware of the issue, knows how to address such people, and so on." (NGO representative)

"We have been speaking for years about the need to form a network of friendly doctors. There should be a wide range of specialists, but this is absent. And that's why we don't provide case management for transgender people who would gladly come for services at healthcare institutions. What treatment do they get? None. Self-treatment — at best, they go to a pharmacy, avoiding all doctors, because there they find a medic who has studied the same six years at a medical institution. The Internet means self-treatment, very often." (NGO representative)

#### Gender specifics of adherence to treatment and possible reasons for termination of treatment

Experts believe that adherence to treatment is higher in women than in men because, again, gender roles enter into the picture:

- women want to return sooner to their children, husband, or parents, and continue to keep house and look after the children;
- men terminate their treatment more often because they need to earn money; they have more dependencies that also affect their adherence to treatment.
   Access and adherence to treatment is complicated for seasonal workers, labor migrants, and internally displaced people.

"I think that, however strange it may sound, men who have more time tend to be less adherent to treatment, while women who have multiple responsibilities and have children — I am speaking specifically about women with children — they would sooner... They would manage somehow, take the children with them, do something... They are better motivated." (Expert from an international organization)

"I used to think that people who are unemployed or drink are less adherent... It appears this is not so. Treatment is also terminated by people with families, who go off to earn money. There is more than one case of this. They might go to Poland or Russia, still ill. And they terminate treatment. And when problems start, they come and ask 'Why? Who will support my family?' That is, a lot of factors need to be considered." (Phthisiologist)

Some respondents believe that adherence to treatment also depends on inpatient treatment conditions. They mentioned the need to turn away from inpatient treatment if proper hospital conditions cannot be ensured.

"We are turning away from using inpatient treatment. In the long 17 years I have been working as a medical director, I have tried to avoid inpatient treatment. For me, it has always been desirable to retain patients on treatment. Because a TB patient's emotional state is very important. If a person finds herself at an inpatient facility where she feels uncomfortable, you would hardly expect her treatment to go well and result in a cure." (Medical director of TB clinic)

#### The needs of patients during TB treatment

Talking about extra needs during TB treatment, experts believe that relevant and desirable services for both women and men include consultation with a gynecologist, endocrinologist, and sexual and reproductive health specialist.

- Young women are interested in issues of future pregnancy, sexual life (when possible), and methods of contraception during TB treatment.
- Women during the menopause want to learn more about combining TB drugs with drugs to relieve climacteric syndrome.
- Men want to know about their sexual health during treatment, but are sometimes too embarrassed to ask the doctor, and doctors do not raise this topic.
- Transgender people would benefit from an endocrinologist's consultation during TB treatment, especially when they are in the transition period of gender reassignment.

"Especially for younger women, consultation with a gynecologist is a must. When pulmonary tuberculosis is diagnosed, it's necessary to understand the condition of the reproductive organs, because they can also be affected by tuberculosis..." (Phthisiologist)

"They need an endocrinologist. Treatment regimens might be somehow revised, because if a woman is going through the menopause and taking medications, she is on hormonal or substitution therapy, or she takes medications to manage osteoporosis and so on, then how will all those drugs... And she will keep on taking them, it's vitally important, because otherwise she will encounter other problems..." (Phthisiologist)

#### Available and necessary support for family members caring for a TB patient

Experts believe that the government does not pay sufficient attention to supporting family members caring for TB patients (the maximum support is 18 hryvnias per month, medical examination of family members, and disinfecting personal belongings). Families are most often supported by charitable organizations or funds (food packages, discounts for medical services, medications).

"NGOs provide services and help such as food packages, help to get free or cheaper diagnostics, MRI, CT." (**NGO representative**)

"I haven't heard about that. At least, nowhere in our legislation is provision for any benefits or preferences for women with a relative with tuberculosis. The only thing provided for families is medical examination of contacts." (**Medical director of TB clinic**)

"We have this concept of care for serious patients; it is paid, and I think they even give you sick leave. Those who look after a seriously ill patient are entitled to 18 hryvnias a month. They are just examined for TB, and recommended to clean the floor with disinfectant; cups and pillows are taken for disinfection, and sometimes outer clothing is disinfected in cases of open tuberculosis. They are also recommended to eat more meat." (NGO representative)

Experts noted that families require material, psychological, and information support, as well as a guarantee of confidentiality regarding a TB diagnosis. For women raising children alone, it is important to ensure that children are housed in comfortable conditions during their mother's treatment.

"If there were some help for a mother, to be sure that they will not take her child away and her parental rights will not be forfeited, so she can go on with treatment while her child eats and sleeps and is not beaten by anyone... And not kept in some terrible conditions, and she's constantly in touch with him, she can call him at any time — that would really encourage women." (Ombudsman)

"I think comprehensive support is needed. Both social and psychological. And financial support too, because treatment is very expensive, I know that very well." (NGO representative)

## Social and cultural norms and practices that may increase the risk of spread of TB among men, women, and transgender people

Respondents noted that in Ukraine in general, certain social and cultural norms and practices promote increased risk of spread of TB, namely:

- people's lack of knowledge about tuberculosis and responsibility for their own health;
- asocial lifestyle;
- welcoming hugs, non-compliance with hygienic norms (washing hands, etc.), sharing cups and cigarettes;
- high level of stress in society;
- myths about vaccination, refusal to vaccinate children.

"This is caused by the fact that many people do not vaccinate their children. They don't do tuberculin tests in younger children for many reasons — they don't have medications, there is a lot of hype that it's harmful and you shouldn't do it. All these hugs and kisses... Lack of hygiene. Lack of timely diagnosis, detection and treatment. Lack of knowledge about tuberculosis, lack of understanding that all TB patients need to be detected and treated; they can all be cured, tuberculosis is curable." (NGO representative)

"Asocial lifestyle, crowding... And I would also add stressful situations that is also important." (Expert from an international organization)

#### Legislative provision of equal access to TB services

When asked "To what extent do existing laws and policies ensure equal access to TB services for women, men, transgender people and people from populations at high risk for TB?" respondents answered:

- national TB programs pay insufficient attention to the issue of gender sensitivity and overcoming stigma, discrimination, punitive approaches, practices and regulatory policies;
- the same methods of diagnostics, prevention, and treatment are used for all genders.

"Based on what I've seen about how it actually happens, we can draw two conclusions: either the program does not work as intended, or it was gender-neutral, gender-blind from the very beginning." (NGO representative)

"All regulations describe 'equal access' to TB services. In building a system, one must consider the specific needs of the patients, including gender-related ones. Our inpatient facilities usually take no account at all of patients' gender specifics." (Expert from an international organization)

Among the authorities influencing decision-making concerning regional provision of TB services, experts distinguished the following main agents of change:

- Public Health Center of the MoH of Ukraine;
- Oblast State Administration Departments of Health;
- deputies;
- territorial medical phthisiatry associations;
- oblast TB clinics.

Respondents noted that there is a **dialogue between state institutions and non-government organizations** representing women, men, transgender people, and PHR concerning planning and implementation of TB programs. Such associations or civil society organizations can deliver information to public decision-makers.

"The authorities now are totally open to it. If there is the desire, there are definitely opportunities to influence decisions. But it should all be properly explained and reasoned. Good reasons are accepted and heard." (Expert from the All-Ukrainian Network of People Living with HIV)

"We cooperate with NGOs in implementing the Global Fund grant. This is a project for early detection of tuberculosis and psychosocial support on the regional level." (NGO representative)

#### Education of medical workers on gender issues, human rights, fighting stigma and discrimination

Respondents' answers to the question "Do training or retraining programs for medical workers include learning about gender-sensitivity, human rights, fighting stigma and discrimination?" were almost unanimous: inclusion is insufficient. Some experts have not even heard about such programs, though they often attend advanced training courses. Some experts noted that such training courses are conducted as part of NGO projects and are not regular. In general, gender issues are given little or no attention in training or retraining programs for medical workers.

"Regarding training programs for social workers that are now conducted more and more by non-government organizations... The training programs often cover this matter. They may discuss it when they talk about counseling — of course, they raise such questions here. But I don't think it is a systemic approach, they just have a project and do something for certain populations... But it is not a training system." (Expert from an international organization)

"I think this is needed. Because phthisiologists actually know it, but it's not called 'gender specifics' or whatever. We talk about the specifics of TB in men, in women, the specifics of diagnostics... It takes... about 40 minutes during the whole course [laughs]." (Medical director of TB clinic)

#### Populations at high risk of TB

Experts identified the following PHR of TB. The results are very similar to those we received using the Tool for Prioritization of Populations at High Risk of TB:

- people with depressed immune system function;
- people under constant stress;
- alcohol and drug-dependent;
- homeless;
- prisoners;
- rural population, especially women;
- unvaccinated children;
- elderly;
- Roma;
- migrants;
- people in constant contact with a large number of people;
- poor.

"For me they are people looking for wages, i.e. labor migrants, especially inside our country, and those travelling to the east, to the RF, Kazakhstan and Asian countries. Also people dependent on psychoactive substances. Also, prisoners or ex-prisoners. And women living in rural areas with no direct access to medical services who are burdened with family duties in addition to occupational responsibilities, and young mothers... Also, people working in poor conditions, e. g. on construction sites, those who cannot protect their lives and health, including because they live in unacceptable conditions and are unable to get adequate nutrition and rest. I would also name transgender people in difficult life situations who are stigmatized. Chronically unemployed people with irregular income, who cannot provide themselves with adequate accommodation and nutrition..." (Coordinator of programs fighting human trafficking)

"... There's a particular difference between the village and the city. Because women are so immersed in housekeeping, they don't have time for themselves... They need to manage the household and look after the kids and husband. As a rule, their elderly parents live with them, and they also need care. Very often women come for treatment with a more advanced stage of tuberculosis, with major complications." (NGO representative)

Most experts pointed out Roma as a PHR of TB:

• Roma are a closed group who only trust their kin, so getting information to them or working with them is only possible through intermediates;

- Roma women are very dependent on their men in all aspects of life. It is the
  husband who decides about treatment for his wife (allowing or forbidding it);
- in most cases, women's needs are neglected.

"Speaking about culture, I think of Roma. These people basically have no habit of seeing a doctor, and they don't value their health. They have different values. Besides, Roma are such families or communities where being ill is not accepted. Some diseases may lead to patients being banished." (Ombudsman)

"If, according to epidemiologic surveillance data, there are 67 cases of TB per 100,000 general population, for Roma it is 400 cases..." (**MoH expert**)

## Stigma of certain populations as a barrier to receiving TB treatment

The respondents believe that a diagnosis of tuberculosis is a stigma in itself. This is especially true in regard to ex-prisoners, transgender people, homeless and drug users.

"Talking about the stigma of TB patients, it is quite high. I believe it is one of the highest, it is higher than that of HIV/AIDS at the moment, this stigma a TB patient bears." (Expert from an international organization)

"Stigma of ex-prisoners, as well as HIV-positive people, as well as transgender people, as well as homeless... It's good if the person has enough desire to return to normal life. Why do setbacks happen, why do people stop fighting the disease? Because, what's the point? What's the point if society has already done with you... society does not accept you." (NGO representative)

"If a drug user comes to you, be happy he has made it, because he may not come to you ever again. And do your best to make him start treatment and continue it, because if you say something wrong or somehow show disregard, he won't come back. And it's quite likely that he will then die." (NGO representative)

"Transgender people come to the doctor in cases of extreme emergency, when they can't avoid it. This is because they fear a bad attitude. They don't know competent doctors who would take transgender specifics into account. Some prefer dealing with their health themselves. That is, they self-medicate." (NGO representative)

Most people who develop TB tend towards self-stigmatization. This self-stigmatization is more common among women. Women are afraid of being separated from society, from their neighbors or family; communication is more important to them.

"There is also such a thing as self-stigmatization. I think women are more susceptible to it than men, because they tend to reflect more on why this happened to them, and so on. I would say that in this aspect women are more at risk of self-stigmatization than men." (Expert from an international organization)

# TB diagnosis as a cause of violence in families or society

All the respondents believe that a TB diagnosis can be a cause of different forms of violence:

- first of all, psychological or financial abuse. Women are more likely to be abused.
- Men more often leave a woman on learning that she has TB. Women consider they are obliged to take care of a man and stay close.
- Stigma in the workplace is typical, affecting even fully recovered individuals.

"It [violence] is definitely present, because even domestic violence is often gender-based. It is violence against women. Women are basically weaker, at least in physical terms, than men. They are abused more." (Coordinator of programs fighting human trafficking)

"I have seen it many times in my practice. I have seen divorces quite often when women were diagnosed with tuberculosis. Yet I have never seen a wife leave her husband because he was diagnosed with tuberculosis, while I keep seeing that situation with female patients. All too often..." (Medical director of TB clinic)

# Recommendations for improving access to TB prevention, diagnostics and treatment services

The experts gave the following recommendations:

- TB services need to be decentralized;
- TB services need to be reformed: there is a need for specialized institutions capable of providing quality inpatient treatment to patients with severe forms of TB, compliant with all infection requirements;
- change the model of TB treatment to make funding follow patients and their needs;
- a broad awareness-raising campaign on tuberculosis (diagnostics, treatment, prevention) is required to increase Ukrainians' level of awareness;
- develop an algorithm to support mothers with TB. Long-term separation from children, and keeping children in specialized institutions for contact children affects adherence to treatment and the psycho-emotional state of both women and children.

"...If it's a woman with children, everything must be done to prevent her from feeling like a bad mother neglecting her kids, and to provide maximum support. If separation from the children is required, it must be as short as possible, and psychotherapists or psychologists, anybody, should be engaged to help her feel she is not to blame for her illness and the way it affects her children or husband, her family... And somehow people should be prepared to keep on living, to return to society, neighbors and friends after having had TB, because returning is very difficult..." (NGO representative)

"For mothers with kids it is extremely important to arrange a way to receive treatment." (Medical director of TB clinic)

"What we call a patient-centered model of TB treatment is primarily changing the funding model, where the money follows the patient and all services are available, where 90% of patients must be cured, and they must adhere to treatment; finally, doctors must be motivated." (NGO representative)

"... A broad information campaign to explain that tuberculosis is curable, that there are medications available in Ukraine, that treatment is free of charge, you just need to come and get cured, you are awaited. This set of actions would yield results." (NGO representative)

"Reform should include decentralization of services — it is the right, important step to improve accessibility of care, including for TB." (Expert from an international organization)

# Analysis of focus group discussions with men and women who have faced TB, and in-depth interviews with former TB patients and their families

# Sample

We conducted two focus groups (one for men and one for women who had completed TB treatment) and semi-structured interviews with 30 patients and their relatives in four oblasts of Ukraine (Dnipro, Lviv, Mykolaiv, Odesa).

Eight persons took part in the **male focus group.** Their sociodemographic characteristics were very diverse: age from 30 to 60, five married, two single, one has a partner. Five participants have secondary education, three have university degrees; at the time of the interview, four participants had full-time jobs, two had part-time jobs, one was retired, and one was a person with disability.

The **female focus group** included five former TB patients. Their age is 26 to 50; one said she was single, two are married, one is a widow, and one lives with a partner. Four participants have children. One lives in the suburbs, the rest live in Kyiv. One woman has a full-time job, two are unemployed, the other two are women with disability. Three participants have incomplete higher education, the other two have secondary education.

The sociodemographics of the **interviewees** is as follows: of 30 participants, 17 were male and 13 female; age 24 to 77, median age being 40. Nine interviewees described their marital status as single, eight are married, one divorced, seven are widowed, 5 live with partners. Ten have underage children (in most cases, one child), 14 have adult children.

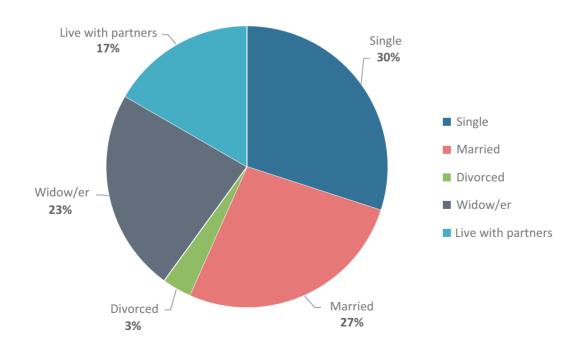


Figure 27. Marital status of participants of in-depth interviews

Thirteen interviewees said they had completed secondary education or less, seven have graduated from a vocational school or secondary technical school, two have incomplete higher education, and seven have a university degree. Eight interviewees said they were unemployed, three have full-time jobs, three have part-time jobs, and seven are people with disabilities. Relatives (four interviewees) provided care to their husband, wife, son, or cousin while they were treated.

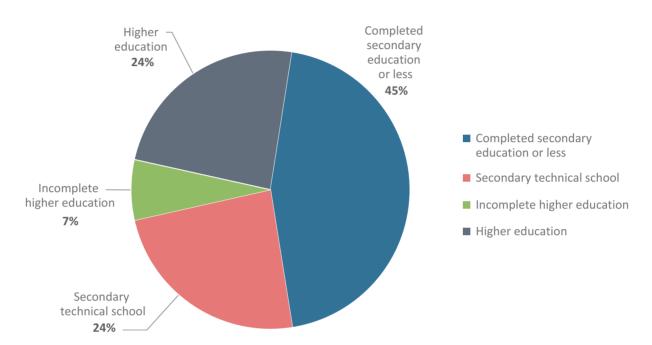


Figure 28. Education level of participants of in-depth interviews

# Participants' perception of the diagnosis of TB

In talking about their thoughts and feelings upon hearing their diagnosis, the respondents mention having felt "shock, stupor, a blow". The TB diagnosis caused self-stigmatization as a result of socially-imposed stereotypes and the patient's separation from society.

"When I came to do a routine fluorography at the polyclinic, I was speechless. They found this, and it was a psychological blow for me. Of course everyone's different, but for me it was a psychological... I probably needed a psychologist right then. First of all, I needed a psychologist. I was ashamed and felt guilty, I thought that only a hobo could have TB. I was very ashamed. I was ashamed even before my children." (Female patient, 57 y.o.)

"When I heard I had tuberculosis, I was stupefied. You may know what it is, and yet you can't be prepared. You may try to prepare yourself, you understand everything, yet when they say that, let's be frank, that verdict... I don't know about the others, but I fell into a stupor. It was carved in my brain — 'tuberculosis', like a court sentence." (Male patient, 40 y.o.)

# Gender-specific barriers at the stage of TB diagnostics

When asked: "How much more comfortable would it be for you to deal with a medical worker of your gender?" the patients said unanimously that the doctor's sex does not matter, what's important is that the doctor is a good professional.

"Competence. And professionalism. Professionalism. It absolutely does not matter whether it's a woman or a man." (Male patient, 41 y.o.)

Regarding the opportunity to receive services separately for women and men, most women would like to undergo diagnostic procedures separately from men, especially if they involve undressing (X-ray, fluorography). Some men said the same.

Women said they felt shame and discomfort when submitting sputum samples and felt stigmatized by medical workers during other examinations.

"Regarding sorting, that is, separation — ... Usually, when people come to have an X-ray, CT, or to submit a sputum sample, both men and women stand in the same queue, and they are embarrassed by each other. I've felt it myself..."" (Male patient, 37 y.o.)

"Well, actually it should be... At least... concerning our bodies, and undressing... I think that there must be women for that [laughs], and not men. Because every person reacts to that in their own way. I am kind of not like that, I can be rude, but if we're talking about such things, I am very shy. And my body isn't perfect, and I'm embarrassed, for instance. And I wouldn't have been able to give a jar with sputum... to a man... Ew!.. All this spitting, this is gross. Even when I brought it together with my husband, I was uncomfortable that he saw it." (Female patient, 30 y.o.)

# Gender-specific barriers at the stage of making a decision about the start of TB treatment

When asked about problems that men/women/transgender may encounter when they first learn their TB diagnosis, or start TB treatment, interviewees said that it is harder for women to seek help and ask for treatment:

- A woman has a lot of household responsibilities; her responsibility for her family comes before her own life.
- Women usually depend on men financially. The fear of being left alone and without money, medications or food makes it difficult to approach a doctor with symptoms or ensure adherence to treatment.
- The need to treat TB left many men (especially those with a family with small children) with a difficult choice: to get treatment and lose their job, which would affect the family budget, or keep working and jeopardize their health. This is why some participants had not completed their treatment course.

Most respondents were set to complete treatment in full, and did so, but many men felt very anxious because they could not provide material support — on the contrary, they themselves became a burden for their families.

"I did worry, because I learnt about it purely by chance. My wife was on bed rest [for pregnancy]. And yes, an X-ray. And then I learnt I had TB. Sure, I was shocked. Panic, tears, hysterics. I was anxious — I understood it would take a long time — and the children, I had a child coming... And, because of it, although I was admitted to hospital I didn't complete the course, I left because I took two jobs unofficially, because the child was going to be born soon. Tuberculosis, on top of everything else. I didn't finish treatment..." (Male focus group participant, 31 y.o.)

"It's probably harder for a woman who has to keep house. Because she depends on the man who brings her money and who can provide her with medications and groceries..." (Female patient, 40 y.o.)

## Participants' needs at the beginning and during the course of TB treatment

### Receiving information about TB

• When asked: "What did they tell you about the disease (methods of diagnosis, treatment scheme and duration, place of treatment, free-of-charge services)?" many participants complained that doctors had not given them sufficient information on TB at the start of treatment, while they especially needed information about the process of TB treatment, its side effects, etc. Exhaustive information is especially required while a patient is coming to terms with the diagnosis and making a decision about treatment. Doctors do not engage patients in making decisions concerning their health; usually no information is provided about possible options of receiving treatment depending on the individual situation of the patient.

"They removed a lung, and after surgery they suggested I go for a consultation to Boyarka. I went there, and what I want to say is that it is bad they don't tell you from the start. Like, you have the sense that you will have to spit for a couple of weeks, do a blood test, and go home. Okay, I spat, I did the blood test — and no going home. Six months. Eight months. Nine months. No information. You keep taking pills, you ask: 'What is it? What for? Why should I take them?' Sixteen pills a day, yeah. 'Oh, come on, the doctor tells you, 'take them." (Male focus group participant, 43 y.o.)

"I asked doctors about everything I wanted to know. I approached them and asked. They told me absolutely nothing. For two weeks they could not even tell me what drugs I was taking. I asked medical personnel about it, to look it up on the Internet — it was very, very hard at the beginning, I was going crazy. Five antibiotics... No-one told me anything. However, I had an epileptic fit caused by Coxerine... I understand that they had only two doctors for the whole department. They have a lot of paperwork, severe cases, someone is dying all the time — every day while you are in hospital one person dies. Every day. And you can kind of understand them..."" (Female patient, 40 y.o.)

# The need for gender-specific services

With regard to opportunities to receive gender-specific information or support from medical workers, the respondents (both male and female) claimed they were never told about sexual and reproductive health and received no other necessary information they might require as a man/woman/transgender person. Even their questions were never clearly answered, although long-term stay in inpatient facilities affected their morale and psychological state. Some participants would like to have had a psychologist's consultation, and women would like to have had consultation with a gynecologist and other specialist doctors.

"...When the doctor was discharging me, she said: 'You must not try to have children. With your diagnoses—no!' That was the whole discussion we two women had about reproductive health." (Female patient, 32 y.o.)

"And about sexual health, yes, those vital issues for a man... There was no talk. The doctor told me nothing." (Male patient, 53 y.o.)

# Psychological support

Many participants mentioned the need for psychological support, especially right after the diagnosis was determined and during lengthy inpatient treatment, but none had received it. In hospitals that had a staff psychologist, this position was perfunctory.

"...There were fears — how should I make contact with my husband. How should I live a sexual life. Who can I ask to get psychological counseling... Yes, I wish I could have got it." (Female patient, 32 y.o.)

# **Barriers during TB treatment**

When asked: "What was most difficult in TB treatment for you?" the participants named two main types of barriers: financial problems related to TB treatment, and poor conditions at inpatient facilities.

### **Financial barriers**

Patients and their families had to spend significant amounts of money on medical drugs (in addition to free TB drugs), travel to receive drugs, etc. They all had to buy auxiliary drugs themselves, which was difficult in terms of funds. Additionally, very poor meals forced people to spend resources on food for the ill family member.

"A lot, a lot of money. A bowl for water, bedclothes — everything, you need to buy absolutely everything... From a mask to everything else, everything. Not a single auxiliary pill. I had to buy all those liver pills. Very expensive, they warned me. I was just given the prescription and told: 'Go to the pharmacy!" (Female patient, 32 y.o.)

"I keep spending money on travelling there and back. I have nowhere to get this money from all the time... Every time — three hryvnias one way, three hryvnias back. Sometimes it's 10, sometimes 15. it's depressing. I don't know where I'm supposed to get this money from." (Female patient, 36 y.o.)

# Unacceptable conditions at inpatient facilities

Describing the healthcare facilities (clinic, hospital) where they received TB treatment and talking about how comfortable treatment there is for men, women or transgender people, the participants were emotional in their complaints about conditions at inpatient facilities:

- crowded wards;
- women and men share hospital departments;
- limited access to toilet and shower rooms: one toilet for both women and men, no hot water, showers available only once a week;
- poor meals;
- bad sanitary conditions: cockroaches in the wards, shabby furniture;
- the practice of placing severely ill patients in wards with other patients is common, to make the latter perform some of the functions of medical personnel. This affects the psychological state of convalescing patients.

"At that time there was no hot water, they had turned it off. And cockroaches were running around..."
(Male patient, 40 y.o.)

"Let's start with saying that in our ward we could take a shower once a week. One shower cubicle and... a crowd of people. Water was available at a scheduled time. Whether you made it or not within that time was your personal problem." (Male patient, 42 y.o.)

"...And they cooked some watery porridge. I wondered, because it was summer, but they couldn't even buy some cabbage to make a simple salad. In short, we were always hungry. And we had just one toilet for the whole floor!" (Female patient, 32 y.o.)

# Violation of the rights of patients

During TB treatment, both women and men encountered violation of privacy, confidentiality, rights, disclosure of status — especially people with co-infection (HIV and TB).

"Sometimes there are situations when they come out into the corridor and give you something or explain something — how many pills you need to take, what additional tests are required. For example, a nurse may come out and tell a person in the queue 'You need to go there, to the urologist or psychologist'. I think this is unacceptable. Why should people sitting nearby be aware of all his problems? I would be embarrassed if they told me right in the corridor that I need to see a gynecologist." (Female participant, family member, 42 y.o.)

"No, there is no confidentiality there as such. Because I have HIV, and literally all the personnel, all the nurses knew who had AIDS, who had HIV. 'Don't go there!' they shouted at me. 'Don't go there, we've cleaned that area!" (Male patient, 53 y.o.)

# Available and desirable support for family members caring for a TB patient

The participants were unanimous in saying that family members who had supported them throughout TB treatment had received no services or support. Participants believe that family members need financial and psychological support, as well as information about TB treatment.

"Nothing. They came and said they would come and clean the house with bleach. He said: 'I can do that myself'. And that was it." (Female patient, 32 y.o.)

"Of course, I would like — and it's not just me, other patients would also like the state to do something about the period when the breadwinner in the family is in a severe condition. There should be some financial support for the wife during the treatment period. Of course, we'd like the government to support us. Because the children suffer, since a lot of money is needed..." (Male patient, 42 y.o.)

"Well, first of all, some money, at least a bit. Second, as you say, information. If I were doing social work, I would conduct a training for parents of such ill people. So that they could know more, and could be more aware." (Female patient, 47 y.o.)

"I believe that some psychological support should definitely be provided, and it was not — obviously, this socio-psychological service doesn't work properly. Not in TB dispensaries, or in hospitals in general. In our hospital there is no position of psychologist. Although there should be one, there are seriously ill patients... Both patients and their families need support. I believe that my wife badly needed conversation and psychological support." (Male patient, 37 y.o.)

## Desirable changes to the process of treatment and support of TB patients

When asked: "What could be changed in diagnostics and treatment of TB, and support of patients and their families, to make men, women, and transgender people feel more comfortable?" many respondents regardless of their sex spoke in favor of placing men and women in separate wards during inpatient treatment, and for separation of procedure rooms.

"To this I can also add having separation of inpatient facilities for men and women, they can do it internally. It all depends on the department head or head of the hospital. They could separate attendance and procedures, yes, it should be done, because I've seen procedure rooms attended simultaneously by men and women, by young girls. I would like them to be separated, to have

two procedure rooms... Because men were just standing on one side and women on the other." (Male patient, 47 y.o.)

The patients also spoke in favor of improving conditions in the wards: renovation, TV, two people per room; more sanitary facilities (preferably one bathroom per hospital ward).

"I would like the wards to be different — at least no more than two beds each... Cozy wards... And a TV... And a bathtub with water, so that people could have a wash. Because there are people who come from far away... And the water is always cold. You can't have a wash there, you have to go home for that." (Female patient, 47 y.o.)

While women were more concerned with sanitary and hygienic conditions in inpatient facilities, men noted that a long period of idleness combined with poor conditions in inpatient facilities affected their psychological state. During the group discussion they spoke about providing opportunities for various recreational activities (recreation ground, library) and said they would like to do some light work during treatment, take exercise, they also wanted to have a TV set available.

Participants (both female and male) complained about the lack of adequate psychological and moral support. They believe that it is needed primarily at the beginning of treatment.

Women would like to have some support groups for women at inpatient departments, and the services of a case manager, to avoid facing the problem alone.

"...I wish there was a psychologist to provide counseling who knows what tuberculosis is and what a person new to this situation may feel. Of course I wanted to talk to somebody... Only now, four months later, I've found myself a psychologist to support me. I'm seeing him privately, I pay for these services to somehow get out of this unstable emotional state. Help is absolutely needed." (Female focus group participant, 30 y.o.)

"There should be psychologists in the hospital, and a psychological relief room... For patients with open forms of TB not to feel like prisoners." (Male patient, 41 y.o.)

"I wanted to say about women. I wish there were some self-help groups specifically for women at inpatient facilities. It would be even better to have peer counseling. Because a person who has already completed this journey, who has survived it and become stronger mentally, can support you..." (Female focus group participant, 50 y.o.)

Absolutely all former patients and their families complained about running out of money during TB treatment. Both at inpatient facilities and after switching to outpatient treatment, people need to spend money on medicines, a nourishing diet, and travel. Interviewees and participants of the focus groups spoke in favor of providing financial support, food packages, vitamins, and payment of fares during treatment.

"It would be good if international organizations and our Ukrainian philanthropists could provide at least something, some vitamins, fruit, vegetables... Because without proper support of the body, the disease won't go." (Male patient, 53 y.o.)

"I wish we could get some support, to pay fares and other things. Because, since it's the lungs, we are already disabled in any case. We don't need much — just for someone to think about our finances, our situation. We are dying now because... My husband returned to work nine months after hospital, and his friends are shocked because he's in so much debt. I have found a job now to pay off the debts. I borrowed money to buy vitamins, apples..." (Female patient, 36 y.o.)

Support from social services would be important for people not to feel rejected, to feel they are still a part of society.

"Sometimes you want to find some care and understanding not just in your family, but in other people too... But we had this thing in Soviet times: if you got a disease of this kind, you were an outcast. And it remains that way... Because not everyone can understand it. You know, most people, when they know about it — tuberculosis, HIV — they kind of label you... For me it was important not to feel like an outcast. Support from my family is one thing, but I also want understanding from outsiders..." (Male patient, 40 y.o.)

During the discussion most of the participants (both female and male) spoke in favor of broader use of **outpatient treatment**. At the same time, respondents with HIV/TB co-infection believe that **integration and decentralization of services** would make TB care more accessible.

"If I had been told about tuberculosis and living with TB, I would have stayed at home. It was doctors who impressed in me this fear that I'm dirty, I'm a 'tuberculosnik'. And it's only later, when you're walking out of the office with this stamp, that you start to really notice how people react, and you internalize this perception of yourself as a 'tuberculosnik'." (Female focus group participant, 31 y.o.)

"When I was at that hospital I kept asking — why isn't everything in one place? Take a trip there, submit samples for tests, then go somewhere else, and give more samples. Why isn't it all in one place? Like, this is here, and this too... I think there should be a cascade of hospitals. It should all be in one place. Now you travel 10 kilometers to one hospital, and then you travel to another one. Why don't they make it all at one institution? When it's about HIV therapy — go to Kryva Balka. And it's actually difficult to get there, you need to go by car or take a taxi. And there are people who simply don't have a car and don't have money for a taxi... I say, why can't you combine it if tuberculosis is connected with HIV? Why don't they have one place, a hospital with an inpatient unit?" (Male patient, 56 y.o.)

"Well, maybe it would be good to have more accessible TB specialists, to have them at normal health clinics. Because in health clinics they have a nurse who issues TB drugs, but no doctor." (Male patient, 39 y.o.)

# Traditional roles and responsibilities of men and women; social norms affecting access of men, women, and transgender people to TB services

The participants voiced different opinions on who finds it harder to start TB treatment, men or women:

- it is harder for a man to start treatment because he needs to work and support his family, while a woman has a more responsible attitude towards her health and understands the consequences;
- a woman is burdened more with unpaid work without leave, she tends to look at her health as the last priority, and it is easier for a man to find an opportunity to attend to his health.

Thus, both women and men face certain socially induced barriers to start complex, uncomfortable and lengthy TB treatment.

"A woman does all the housekeeping. She needs to feed her husband, wash his clothes, other things, and who will do it during these two months? And the woman starts panicking — if I go to hospital, who will take care of him?" (Male patient, 40 y.o.)

"Everyone realizes: if I am going to have year-long treatment, I will lose my job. That is, I will not return to my old job. God forbid to tell the employer I have TB... Every man starts concealing it, not saying a word..." (Male patient, 37 y.o.)

# Tuberculosis' impact on the financial standing of a family with a TB patient

When asked: "What changed in your life and the life of your family after you were diagnosed with tuberculosis?" almost everyone mentioned the financial impact of the disease.

• A lot of participants (mostly men) were very anxious because their families had to spend money on their treatment and they were a burden for relatives.

"Well, talking about money... You see, my wife works every second week. When her shift was over, she'd come to me every Tuesday. And then I just said: don't visit me. Because she wouldn't come empty-handed. And the money she would spend on me — what for? I'd rather she spent it on the children." (Male patient, 42 y.o.)

"The main need of a man who's got TB and is taking treatment is support for his family, because he loses his job, his income, he needs financial support. If the man doesn't have support, instead of taking treatment peacefully he will have to go to work, and it's very hard — to work and take medications. Many terminate their treatment because of it, and may infect someone afterwards... It would be good to have some agency or government help for such men, at least during the treatment period, to allow them to support themselves and their families." (Male focus group participant, 31 y.o.)

"Well, I was anxious because I was used to it all being alright at home, I'm the breadwinner. And now it's not. I'm in hospital, and for such a long time... I thought, 'I am a disabled man. What good am I to my family?' I felt totally useless... There was no pressure, but I still felt it, like, that was how we used to live, and now it's different. They were used to me making all the decisions, they didn't have to think about anything, and now it was different, they had to do everything." (Male patient, 41 y.o.)

Women, in turn, found it hard to accept that they would not be able to do their
duties as a wife and mother. They were also concerned with the thought that
because of their disease the family had to spend a lot of money.

"It was difficult for me, because I had to put the burden of looking after my daughter onto my parents, and it's difficult for them. At the time, I was worried about how it would be, how the child would be looked after, whether grandma would be able to take care of both granddaughter and grandfather. Would she manage? She is in her late 60s already. I was worried, thinking that more money had to be earned to spend on me. What would my husband eat at home without me..." (Female patient, 33 y.o.)

# Changes in attitude from partner, family or other people related to the diagnosis of tuberculosis. Stigma, discrimination, violence as barriers to TB treatment

Family members were the first people to learn about the participants' diagnosis. Most of them did not disclose their status to other people because of fear of condemnation and embarrassment.

"We don't share this subject. At all. We... have a sort of taboo. The thing is, many people are not ready and they don't understand the issue and don't know how dangerous or not this disease is. And they draw their own conclusions. I wouldn't want them to... So, we don't discuss this topic. We are trying to keep it strictly within our family." (Male patient, 56 y.o.)

"I am fighting by myself for my life. \*Did you tell the neighbors?\* God forbid! They shrink away from such things. And, come on, they will treat me like a leper... They don't understand it. Everybody's afraid, and very afraid at that." (Female patient, 36 y.o.)

 The negative expectations of some participants proved correct — they encountered stigma (including at other healthcare institutions) and colleagues or friends turning away from them upon learning they had TB. Most of the men believe that women are more often subjected to stigma and discrimination and suffer more from TB-related violence. People with TB/HIV co-infection, especially drug users or MSM, face double/ triple stigma and discrimination, including physical violence.

"A pregnant woman, an injecting drug user, in the 32nd week of pregnancy, came from Borodianka. She was using 'shirka'. Beside HIV, unfortunately she was diagnosed — at an advanced stage already —she was diagnosed with tuberculosis. They just kicked her out of the family." (Female patient, 36 y.o.)

"For instance, when they called me to the local police precinct, they were afraid to come near me. What a negative attitude. As if I were an animal, not a person: 'Stay near the door! Don't cough! Put your mask on over there!' Like that." (Male patient, 53 y.o.)

After being diagnosed with TB, some participants (mostly women, but some men too) were afraid that their spouse would leave them when he/she learned about their diagnosis. Female respondents mentioned the fear of rejection, and separation from their children or family.

"My husband, of course, was shocked. There was a period when he did not believe it was tuberculosis. Like, it's impossible. And then he was just very concerned about me and supported me as best as he could. I had this moment when I asked, 'What, you aren't going to abandon me?' Of course, he said he wasn't... I was afraid, most of all, of uncertainty, and I feared my social standing could change: I was afraid I would lose my job and my man, I was afraid of being a danger to my child... I had those fears and they were natural, I think." (Female patient, 33 y.o.)

Some respondents said that tuberculosis had changed their life for the better: they began living their lives in a more meaningful way, appreciating life more (they gave up unhealthy habits and started paying more attention to themselves, their families and health). Some participants described the great support they received from their families throughout the lengthy treatment and how family relations improved thanks to the hardships they had overcome together.

"I had this feeling I really am a 'Tuberculosnik', yes. And I felt I could lose my family. I could lose my wife, they would drift away from me... And yet, you know, maybe our love and relationship has moved us closer together. Of course we can not tell our family about this disease that we've overcome — not just me, we've done it together. And our relations have become much better." (Male patient, 37 y.o.)

"... I would also like to say that I now value my life much more than before. That is, in this period of three years I've given up unhealthy habits. Knowing what you just survived, you don't want to go through it again." (Male patient, 42 y.o.)

# Stories of patients and their relatives who faced the problem of tuberculosis

# **Story 1**

A man who was receiving inpatient treatment at a TB clinic complained that doctors had provided him with no information about his sexual health. As a family man, he wanted to complete treatment and return to his wife and society as a healthy person.

While taking TB drugs he noticed deterioration in his libido, erectile function, sight and hearing. When he returned home to continue with outpatient treatment, his sexual contacts with his wife were not very successful. He stopped feeling like a man and fell into despair. He turned to his doctor with this problem, hoping he would help.

The doctor only laughed and said everything would be alright later on. The man considers that the doctor's attitude was dismissive. He did not raise the question again with any doctors, because he was embarrassed.

He thinks doctors must discuss the issue of sexual health with their patients, especially with men taking such serious medications.

# Story 2

A dramatic story of a young man who went to Russia to earn money. He lived and worked in poor conditions: we lived in construction trailers, 20 people in each, absolutely overcrowded.

The foreman and his wife were always coughing, but no one paid attention.

The salary was low, so the young man decided to return home. Later he found a job in the Czech Republic. There he met a young woman, they got married and she became pregnant. They earned some money in the Czech Republic and decided to return to Ukraine. They bought a small house in his native village, and even bought a car. The wife gave birth to a child, and then was diagnosed with tuberculosis. The young man was diagnosed with tuberculosis in advanced form.

When they were questioned about the source of the disease, the couple said they had worked in the Czech Republic, but there was no TB epidemic there. The man believes he was infected while living in unhygienic conditions during his stay in Russia. The couple are now on treatment, and their child is also ill. The man is upset and blames himself, saying he saw that the foreman and his wife were ill, but he did not go to doctor to get examined when he came home. That is, as he himself now understands, one of the problems is that people are not aware of the symptoms and lack sufficient information about tuberculosis.

# Story 3

In Yenakiyevo, during the ongoing conflict on territory controlled by illegal armed formations, an HIV-positive woman and single mother of three was receiving TB treatment at the TB clinic. She was not in the inpatient unit but going to receive drugs daily at the dispensary. Since she had no-one to leave her children with, she left them alone at home. Her neighbors complained to members of armed formations and they took her children to an orphanage. Only through support provided by an AIDS-service NGO were the children returned to their mother, and they were all taken to territory under the control of the Ukrainian government.

# Story 4

A relative (father) said he had spent a lot of money to pay for his son's treatment that he had been saving to build a house.

The father noted that the main thing in TB treatment is care and good nutrition. If he had not provided these, his son would have died long ago. His son had spent 14 weeks in hospital. According to the father, during that period most other patients whose relatives did not visit or help with food died. Their villages were 100-120 km away from the hospital, which is why relatives brought them food once a month (it was expensive).

This man brought fresh food to his son daily. After his working hours were over, he would go to the market to buy whatever was needed, his wife cooked it, and then he took food to his son every day. When the bus service was suspended in winter due to bad weather, the man spent 300 hryvnias a day on taxis to visit his son. He took all the costs on himself, but he has no regrets because he thinks that the main thing in TB treatment is material support. If it is not available, it is hard to leave a TB hospital in good health.

# Conclusions based on findings of the study's qualitative component among experts and former TB patients and their families

# At the level of legislation and regulation:

- The existing national TB program is generally not gender-sensitive and pays insufficient attention to the issues of stigmatization, discrimination, countering punitive practices, and regulatory policies.
- The state does not pay sufficient attention to providing aid to family members taking care of TB patients. Families are most often supported by charitable organizations or foundations (food packages, discounts for medical services, free medications).

# Access to prevention, diagnostics, and treatment is equal for all, i.e. equally inadequate.

- The same diagnostic, prevention, and treatment methods are used for all genders.
- Accessibility of services is substantially different for urban and rural residents.
   Villagers seek medical aid very late, mostly at an advanced stage of TB,
   because of the distance to TB facilities and lack of funds for transport that is,
   because of geographic and economic barriers.
- Single mothers face high risk of treatment termination because of lack of opportunity to ensure their children stay in comfortable conditions during the mothers' treatment.

Gender-insensitive infrastructure in TB institutions, inadequate conditions in inpatient facilities, and no individual approach to patients' needs have a negative effect on patients' psychological state and treatment adherence.

- At the beginning of treatment, doctors rarely provide patients with the necessary information about the whole process of TB treatment, even though possession of full information about the disease is especially important when a patient receives the diagnosis and makes a decision about treatment. Usually, no information on possible treatment options depending on the individual's situation is provided.
- During treatment, the doctor's gender is of no importance to patients, who pay more attention to his/her professional qualities.

- Adherence to treatment is higher in women than in men because of prevailing gender roles.
- Consultation with a gynecologist, endocrinologist, and sexual and reproductive health specialist are desirable and relevant for women, men and transgender people receiving TB treatment.
- Medical workers are poorly aware of the needs or interests of transgender people, because this issue is little studied. It is important for transgender people to be accepted in the gender they identify with.
- Long-term stay at inpatient facilities, and TB treatment in general, affects the morale and psychological state of patients, meaning there is a need for the quality services of a psychologist and case manager, and for provision of basic recreational opportunities in inpatient facilities (library, TV, recreation ground).

# TB-related stigma, discrimination and self-stigmatization

- Stigma and discrimination towards people with TB are a barrier at the stage of seeking medical aid. They also negatively affect people's lives during and after treatment.
- Women and transgender people are most vulnerable to TB-related stigma.
- Most people who develop TB tend towards self-stigmatization.
   Self-stigmatization is more characteristic of women.

# The gender-specific barriers and needs of people from PHRs need to be considered during informing about, diagnosing and treating TB.

 The method of passive detection of TB cases can be ineffective for vulnerable populations; in particular for women from such populations, who constitute the least mobile and financially independent category.

**Poverty and social exclusion** are barriers to accessing TB services. People diagnosed with TB and members of their families require material and psychosocial support at all stages of TB treatment.

**Training or retraining curricula for medical workers** do not cover gender and TB-related stigma and discrimination.

There is a **dialogue in Ukraine between public and non-government organizations** representing women, men, transgender people and PHR concerning planning and implementation of TB programs.

# SECTION VI.

# Overcoming gender-specific barriers; best practices in provision of TB services

To overcome gender-specific barriers and provide key populations with full access to TB programs, existing international and domestic experience compliant with the principles of evidence-based medicine and involving modification of funding models should be considered.

# **Examples of successful international practices**

- 1. Active search for TB cases has improved detection of women with TB in rural areas in Nepal<sup>83</sup>.
  - This practice may be useful for women from vulnerable populations, including ethnic minorities and rural residents, with limited access to services.
- 2. In many countries, various **incentives** are used to encourage patients to come for TB diagnostics and treatment<sup>84</sup>:
  - material incentives for completing a treatment course;
  - food packages or vouchers;
  - transport subsidies (reimbursement, tokens, passes or vouchers);
  - packages of personal hygiene products.

# Examples of domestic best practices of informing, diagnosing and treating tuberculosis in Ukraine

- 1. In a TB epidemic context, when the disease has become a national problem, it is important and necessary to educate not only people from populations at high risk, and TB patients and their relatives, but also the general population of Ukraine.
  - Under the program "Stop TB in Ukraine", Rinat Akhmetov's Foundation "Development of Ukraine" produces and disseminates information materials covering TB-related issues.
    - Some of the foundation's information materials are aimed at the general public and contain information about the main symptoms of TB, the phone number of a national free TB hotline (0 800 50 30 80) and the web-site www.stoptb.in.ua. The key message is "See a doctor! Tuberculosis is curable!"

<sup>83</sup> Gender difference in delays to diagnosis and health care seeking behaviour in a rural area of Nepal. Yamasaki-Nakagawa M, et al. Int J Tuberc Lung Dis. 2001.

<sup>84</sup> Worldwide: Incentives for Tuberculosis Diagnosis and Treatment. Alexandra Beith, Rena Eichler, and Diana Weil.

- A leaflet questionnaire for the general public has been developed containing questions for self-monitoring for TB symptoms and advice to see a doctor to have a check-up for TB (USAID's "Ukrainian Tuberculosis Control Partnership Project" implemented by PATH in Ukraine).
- ICF "Alliance for Public Health" has developed a brochure for patients and their families containing basic information about TB symptoms, diagnostics and treatment, and specific aspects of TB treatment for people who use drugs and HIV-positive people.
- Rinat Akhmetov's Foundation and the USAID project "Strengthening Tuberculosis Control in Ukraine" has produced wall posters explaining the procedure for sputum collection for examination as a piece of visual information to educate patients.
- 2. The USAID project "Strengthening Tuberculosis Control in Ukraine" (implementing a TB patients' outpatient treatment model in the city of Kryvyi Rih; patient training by nurses from the Ukrainian Red Cross Society). This project includes counseling patients and providing them with information materials to educate themselves on TB.
- 3. UNODC project "Practices of Provision of Gender-sensitive Services for Vulnerable Women" (from the experience of implementing the "Women for Women" initiative in Ukraine).
  Under this project, a number of practices were introduced to reduce the barriers preventing women from vulnerable groups from visiting healthcare institutions and receiving consultative, information or diagnostic services.
- 4. As a response to instances of homophobia and stigma towards LGBT from medical personnel in state healthcare institutions and social workers from non-government organizations, the All-Ukrainian Charitable Organization "FULCRUM" implemented the "Friendly Doctor" project (https://friendlydoctor.org/aboutcourse/).
  Friendly Doctor is an innovative platform to search for friendly and tolerant health services for LGBT citizens. Through it, people from the LGBT community can access a number of free services, such as free testing for HIV.
- 5. Under the program "Investing for Impact Against Tuberculosis and HIV" of the Global Fund to Fight AIDS, TB and Malaria, ICF "Alliance for Public Health" is implementing a **project for early detection of TB in high-risk groups**: homeless, ex-prisoners, Roma, and injection drug users. These populations suffer the most from the TB epidemic and have limited access to health services. The goal of this initiative is to find people with symptoms of TB and help them to be examined at healthcare facilities.
- 6. ICF "Alliance for Public Health", in partnership with the Ukrainian Red Cross Society and with support from the Public Health Center of the MoH of Ukraine, implemented a program of support for patients with multidrug-resistant tuberculosis at the stage of outpatient treatment.
  In order to improve their adherence to treatment, patients with MDR-TB receiving outpatient treatment with second-line medications were provided with directly observed treatment (DOT) by nurses from the Ukrainian Red Cross Society. The package of services included organization of quality patient-focused DOT services aimed at maximum preservation of the patients' normal lifestyle. Among such services were delivery of medications and observation of their administration at

home or at another place convenient for the patient, and twice-monthly provision of food packages to all patients adherent to treatment. All patients received ongoing medical, psychological and social support throughout the treatment period, which raised the treatment success rate to 85.6% as opposed to 37% in patients who were not receiving such support.

- 7. USAID RESPOND project in cooperation with CO "All-Ukrainian Network of PLWH" developed the **behavioral intervention "TB is Curable"** based on the most successful experience of Ukrainian NGOs. The goal of the intervention is to form adherence to outpatient TB treatment in PLWH with TB, so that they complete treatment successfully. The intervention involves conducting five structured sessions (45–60 minutes each) covering in detail organization of the treatment process, the patient's regimen, infection control, using one's own resources for examinations, etc. Patients receive comprehensive information about their treatment, and support from social workers.
- 8. The NGO "Infection Control in Ukraine" in partnership with CO "All-Ukrainian Network of PLWH" implemented their **pilot project developing and implementing a new model of funding of a "patient-centered" TB treatment system.** Under the project, from April to December 2017 69 patients were engaged in Chernihiv oblast and 25 in the city of Zhytomyr. The organizational model of treatment involved cooperation between phthisiatrician and medical social teams who managed outpatient treatment of TB patients and received bonuses for successful outcomes. The doctor's bonus for each successfully treated patient was UAH 3000. The project showed good results, with the treatment success rate reaching 96.8%.

After the launch of medical reform in Ukraine, the results of this pilot project on implementing a new funding model of a "patient-centered" TB treatment system can be expanded to the whole country.

# SECTION VII.

# Recommendations for further steps to overcome gender barriers and enhance provision of services to key populations at risk of TB in Ukraine

Triangulation of data received from desktop review, expert polling using the gender assessment tool, and analysis of the findings of the study's qualitative component resulted in the following recommendations:

National level (MoH, Public Health Center, Ministry of Social Policy, Ministry of Justice, Ministry of Education and Science).

- 1. Improve the regulatory framework on gender policy in general, and specifically in the sphere of TB. Provide legal definitions of the concepts of "gender", "gender identity" and "gender stereotypes".
- 2. Make changes to legislation enabling patients to receive key medical services not only at their place of registration.
- 3. When developing programs, consider a gender-based approach and introduce gender-based budgeting.
- 4. Conduct systematic analysis of epidemiological data broken down by sex and age (prevalence, incidence, adherence, accessibility of services, treatment success rate) to identify gender-specific risks and vulnerabilities related to TB.
- 1. Improve coordination between the medical service of the penitentiary system and the TB service of Ukraine. Ensure access to quality ART, TB and SMT services in prison environments and at the stage of social integration of men, women and transgender people.
- 2. Include topics of tuberculosis, HIV, stigma and discrimination into advanced training curricula for personnel from the penitentiary system, Ministry of Interior and National Police.
- 3. Actively involve civic associations of representatives of PHR of TB and HIV into planning, implementation and monitoring of TB and HIV/AIDS programs.

- 4. Ensure legislative establishment of a patient-centered approach to the needs of TB patients (material, social and psychological support; palliative care).
- 5. Conduct information campaigns on TB and TB/HIV aimed at raising awareness and reducing stigma and discrimination in the general population through mass media, outdoor advertising, Internet and social media. Involve opinion leaders and celebrities in information campaigns.
- 6. Advocate for policies and practices aimed at reducing stigma in society, the health system, and the workplace.
- 7. Update the list of PHR of TB taking into consideration the defined priority groups. Ensure collection of statistical data on intensive and extensive indicators of TB incidence among priority populations at high risk of TB.
- 8. Recommend annual implementation of the questionnaire for prioritizing populations at high risk of TB at national and regional levels, for further shaping TB policy.
- It is recommended that at-risk populations having professional contacts with TB
  patients should include personnel of social care facilities of all forms of ownership
  and subordination, who are frequently in contact with TB patients and conduct
  examinations and tests.
- 10. Conduct national studies of behavior risks, legal and economic barriers to accessing TB services, and barriers related to human rights and gender among the defined PHR of TB in Ukraine. Conduct research to measure stigma and discrimination of people with TB and former TB patients. Consider conducting a study to determine whether sex workers or LGBT are PHR of TB.
- 11. Consider recommendations to the draft objectives and actions of the National Targeted Social TB Program for 2018–2022.

  In order to implement activities for raising awareness and resolving the problem of stigma and discrimination of TB and TB/HIV patients and populations at high risk of TB, with due consideration of a gender-based approach, add the following to Objective 6 "Involvement of civil society in the TB response" of section II "Resolute political actions and support systems (systemic support and reform of services provision)":
  - 11.1. Introduce changes to reporting documentation on TB prevention, diagnostics and treatment, including the concept "transgender" in the item of disaggregation by sex.
  - 11.2. Develop information support aimed at promoting healthy lifestyles (including anti-smoking), sexual and reproductive health, tolerant attitudes towards TB and TB/HIV patients and populations at high risk of TB, considering a gender-based approach.
  - 11.3. Ensure that specialist educational programs, advanced training courses and pre-certification training for all medical personnel cover the legal aspects of quality of health services provision to the population considering a gender-based approach and human rights, and overcoming stigma and discrimination.
  - 11.4. Provide access to legal assistance for TB and TB/HIV patients and populations at high risk of TB considering gender aspects.
  - 11.5. Assess stigmatization and discrimination of PHR of TB considering a gender-based approach among the general population and specialists implementing TB diagnostics and treatment services; develop an action plan to reduce the level of stigma and discrimination.

# Regional level (oblast and rayon structures, oblast and city health administrations, education departments and oblast social services).

- 1. In regional social targeted programs, ensure funding to conduct social procurement bidding to provide case management services for TB patients.
- 2. Introduce information campaigns (social advertising, training courses) on TB for the general public. Gain local authority support to ensure social advertising on TB in transport and public places.
- 3. Improve interagency coordination of TB prevention, diagnostics and treatment services between agencies, regardless of their form of ownership and subordination, which perform TB diagnostics and provide preventive and therapeutic care to patients with TB and TB/HIV.
- 4. Form a network of friendly lawyers and other specialists to provide necessary services for PHR (questions concerning employment, obtaining a disability pension).
- 5. Recommend that NGOs providing HIV/TB services include internally displaced persons and migrants as their clients, and conduct "Know your rights" training on legal literacy for PHR.

# Recommendations at the level of healthcare institutions (TB clinics, hospitals, DOT premises), facilities of the penitentiary system and social services.

- 1. Expand the practice of outpatient treatment, considering the specific needs of each patient that would help patients to complete full treatment courses and reduce the load on existing infrastructure; create more comfortable, gender-sensitive conditions for TB patients' inpatient stay, such as separate departments for men, women, and transgender.
- 2. Provide patients with access to necessary services considering their gender-related needs:
  - consultation on reproductive health, family planning and sexual life related to TB, including for pregnant or breast-feeding women who may terminate treatment because of misconceptions about the harm of therapy to the child;
  - provision of psychosocial support during inpatient or outpatient treatment based on determination of the individual needs of patients, in order to improve adherence to treatment;
  - peer counseling; patient self-help groups similar to the experience common in HIV services;
  - refer patients to social services providers, such as centers of social services for family, children and youth, social services institutions and NGOs, to receive aid for both patients and their families.
- 3. In collaboration with NGOs, introduce questionnaires for patients to determine populations at high risk of TB.

- 4. Ensure patients' privacy during diagnostics and treatment:
  - if it is impossible to provide separate rooms for sputum sample submission and fluorography examination, set up a schedule of examinations with separate hours for men and women;
  - during inpatient treatment, provide men and women with the opportunity to stay on different floors or in different wings of the department.
- 5. Integrate gender-sensitive TB services (screening, case management, motivational counseling) with the services of outreach programs for HIV prevention, care and support and peer support programs.
- 6. Introduce provision of integrated services for patients with dual or triple diagnosis (tuberculosis, HIV, drug dependence) to achieve simultaneous removal of gender-related and legal barriers to accessing both ART and TB services.
- 7. Provide TB patients with legal support and protection from instances of discrimination.
- 8. Ensure provision of social services to women and men (patients with small children):
  - create proper conditions of stay at facilities taking care of contact children;
  - consultation for men in order to change their attitude to health and form adherence to treatment; peer counseling;
  - fare reimbursement, provision of food packages (including as an additional motivation to continue DOT).
- 9. Ensure access to quality ART, TB and SMT services in prison environments and at the stage of social integration of men and women.
- 10. Establish systematic collaboration between women's health clinics and TB and HIV-service institutions to improve women's access to information and TB services.

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# ANNEX

# Anex 1. Prioritization of Populations of High Risk for TB

Combined score	Загальний бал (сума оцінок 1-5, макс. 13 балів)			
Score 6	Human rights and gender barriers to accessing services	(stigma, discrimination)	0 — No	1 — Yes
Score 5	Legal and economic barriers to accessing services	(criminalization, poverty) (stigma, discrimination)	0 — No	1 — Yes
Score 4	Beheviour risks	(in/exhaling from/into other's mouth, sharing smoking equipment)	0 — No	1 — Yes
Score 3	Biology risks	(reduced immunity, poor nutrition)	0 — No	1 — Yes
Score 2	Environment risks	(overcrowded, poorly ventilated space, reside in zoonotic TB areas)	0 — No	1 — Yes
Score 1 B	Estimated contribution to the country's TB burden (extensive indicator: individual population's share in the structure of TB incidence)	(active TB cases of all forms)	1 — Very low (0-1%)	2—Low (1- 3%)
Score 1A	Estimated contribution to the country's TB burden (intensive indicator: population's TB incidence)	(active TB cases of all forms)	1 — low (equal to/ not exceeding average inci- dence in total population)	2 — medium (exceeding the average rate, but below 100 cases per 100 thousand in this popula-
			STATISTICS	
		Populations	of high risk for TB	

Combined score					10			co			<del>-</del>	
Score 6				1	Manifested in the form of social (external) and internal stigmatization and discrimination [33], Violation of confidentiality of HIV-infected people [41]		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 5				0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 4				0	The risk is not higher than that of the general population	2	0	The risk is not higher than that of the general population	1	0	The risk is not higher than that of the general population	_
Score 3				1	reduces capacity of immune system to prevent reactivation or dissemination of TB [4,35]		1	Inhaling SiO2 impairs protective function of the immune system is violated [34] TB development is related to endogenic reactivation of TB		1	Inhaling coal dust impairs protective function the immune system is violated [4]. TB development is related to endogenic reactivation of TB, exogenic superinfection is much less important.	
Score 2				0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 1 B	3 — Medium (3-5%)	4 — High (5-10%)	5 — Very high (>10%)		5	~		<b>—</b>	2		Notrated	Not rated
Score 1A	3 — high (100 or more per 100 thou- sand in this population)				m			<b>—</b>			Not rated	Not
					4384.5 per 100 th. people (19.8% in the structure of TB cases) [1]			3 total number (2016) or 0.01 % according to State Statistics Service			no data available	
					People living with HIV			People with silicosis			Miners	

Combined		nigher general 36]						nigher general 5 n			ne form al) and ization 10 ation,			ne form al) and ization on [32]	
Score 6	0	The risk is not higher than that of the general population [36]		0	·		0	The risk is not higher than that of the general population		<u></u>	Manifested in the form of social (external) and internal stigmatization and discrimination, n [37], social deprivation f		_	Manifested in the form of social (external) and internal stigmatization and discrimination [32]	
Score 5	_	In the absence of a legal status, a MIGRANT has limited access to health services		_	In the absence of a legal status, has limited access to health services		_	In the absence of a legal status, has limited access to health services [42]		<u></u>	the functioning of a "prison hierarchy", where "senior" convicts can act as interme- diaries in access to medical care and have an impact on access, trade, exchange of medicines [31]		_	Punitive drug policy [28]	
Score 4	_	Harrassment by the police, criminalization of illegal migration	2		Harrassment by the police, criminalization of illegal migration	2	0	The risk is not higher than that of the general population	2		the risk of self- infections [39]	5	_	People with drug dependency usually do not care about their health and rarely see a doctor	
Score 3	0	The risk is not higher than that of the general population [36]		0	The risk is not higher than that of the general population		_	hronic stress [46] weakens immune system. Lack of prop- er and balanced nutrition.		_	hronic stress [38] weakens immune system. Lack of proper and balanced nutrition.		_	drug intoxication leads to metabolic disorders, degenerative and destructive changes of internal organs and increases person's susceptibility to active TB infection, as well as reactivation of a latent disease [15]	
Score 2	0	The risk is not higher than that of the general population [36]		0	The risk is not high- er than that of the general population		0	The risk is not higher than that of the general population		_	overcrowding, violation of sanitary and hygienic and infection control in places of detention and during prison transfer [39]		_	cramped, poorly ventilated places where PWID take drugs. High home- lessness rates	
Score 1 B		,	7			5		2	3		2	5		2	
Score 1A		,	~					<b>—</b>			m			m	
		111.3 per 100	(1.2 % in the	structure of TB	[1](حجد)			2016 — 263 persons 22.2 per 100 thousand			1030.9 per 100 thousand people prisoners (including previously convicted and persons under trial) 2.4% in the structure of TB cases	Ξ		587.7 per 100 thousand people (2.9% in the structure of TB cases) [1]	
		Migrants			Refugees	, ,		Internally displaced people			Prisoners and detainees			People who inject drugs	

Combined		orm and 11 In			eral 1			orm d d 440] ci-			unity ola- ola- sale 5 gh na- cess-	
Score 6	<b>—</b>	Manifested in the form of social (external) and internal stigmatization and discrimination		0	The risk is not higher than that of the general population [45]		<u></u>	Manifested in the form of social (external) stigmatization and discrimination, [26,40] dependency on decisions of a rom baro		<u></u>	Marginalized community vulnerable to violence and human rights violations (especially female CSWs) [55, 56]; High stigma and discrimination is a barrier to accessing medical services.	
Score 5	0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population [45]		<u></u>	Low education level [26]		<u></u>	Administrative measures for prostitution are foreseen [55, 56, 67]. Often migrating persons (from rural or small towns), without official registration. Lack of stable source of income.	
Score 4	<b>←</b>	Alcohol-dependent people usually do not care about their health and rarely see a doctor	3	0	The risk is not higher than that of the general population [45]	<b>—</b>	<u></u>	Health is not a priority for Roma women [26]	5	<b>—</b>	Provide sex services to clients with signs of illness [67], Health is not a priority [64,66]	5
Score 3	<u></u>	Alcohol leading to suppression of local anti-infection response, leads to metabolic disorders, degenerative and destructive changes of internal organs and increases the person's susceptibility to active TB infection, as well as reactivation of a latent disease [4,42,44,49-53]		<b>—</b>	Consumption of cocaine leads to significant reduction impaired coordination of actions of all types of cells of the immune system. [45]		<u></u>	Lack of funds disables proper balanced nutrition [26]		_	Chronic stress [66], malnutrition [65.67] hypothermia weaken the immune system.	
Score 2	0	The risk is not higher than that of the general population [43,44]		0	The risk is not higher than that of the general population [45]		<b>—</b>	Overcrowding [26]		<b>—</b>	Overcrowding of a large number of people in small areas (in case of joint residence female CSWS)[66]; risk of hypothermia (when working on the street	
Score 1 B		5	∞		Not rated	Not rated		Not rated	Not rated		Not rated	Not rated
Score 1A		m			Not rated	Not		Not rated	Not		Not rated	Not
		654.3 per 100 thousand people (12.8% in the structure of TB cases) [1]			no data available			no data available			2016 — 20 per 100 thousand CSW [68]	
		People with alcohol depen- dency			Smokers of more than 40 cigarettes a day			Ethnic minorities (roma)			Commercial sex workers (CSW)	

Combined score		4			6			7	
Score 6	<b>—</b>	Marginalized community vulnerable to violence and human rights violations [59, 60, 62]; systematically face violence, high level of stigma and discrimination on the grounds of sexual orientation or gender Identities [61] and selfstigma as a barrier to care. For TG there is a negative experience of interaction with the medical staff. Closed group. The priority is a change of gender (operation, access to hormone therapy), not other kinds of treatment.		<b>—</b>	Manifested in the form of social (external) and internal stigmatization and discrimination, social deprivation		<b>—</b>	Manifested in the form of social (external) and internal stigmatization and discrimination [29], social deprivation [30].	
Score 5	_	The problem of spreading hate crimes against LGBT in Ukrainian society is growing, Impunity for intolerance on the grounds of sexual orientation or gender identity [61].		<b>←</b>	Limited access to healthcare services		<b>←</b>	They may have limited access to healthcare services	
Score 4	_	Among MSM, often – non-injecting drug use.  TRANSGENDERS: The extreme poverty levels (80% of TG live below the poverty line). Often without work; rarely higher education. Involvement in criminal activities that leads to incarceration. Lack of identity documents, in accordance with the gender.	4	_	Health is not a priority for homeless people	4	0	The risk is not higher than that of the general population	2
Score 3	_	The elevated risk for HIV that may lead to the immune suppression. For transgender persons (TGs): Chronic stress; unknown influence of hormone therapy on immune status; some drugs cause depression, depression.		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 2	0	The risk is not higher than that of the general population.		<u></u>	lack of any dwelling that has a purpose of and is fit for residence		0	The risk is not higher than that of the general population	
Score 1 B		Not rated	Not rated		2	5		2	5
Score 1A		Not rated	Not		3			3	
		2016 – 3.9 per 100 thousand MSM [68]			1713.9 per 100 thousand people (2.1% in the structure of TB cases) [1]			118.6 per 100 thousand people (patients of psychiatric facilities) 2.2% in the structure of TR cases (11	
		LGBT and community			Homeless			People with mental disorders	

Combined score		10			=			50			4	
Score 6	_	Manifested in the form of social (external) and internal stigmatization and discrimination, social deprivation [23].		1	Manifested in the form of social (external) and internal stigmatization and discrimination, social deprivation [23].		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 5	0	The risk is not higher than that of the general population		1	Limited access to healthcare services 22]		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 4	0	The risk is not higher than that of the general population	2	0	The risk is not higher than that of the general population	3	0	The risk is not higher than that of the general population	_	0	The risk is not higher than that of the general population	1
Score 3	<u></u>	Lack of funds [23 disables proper balanced nutrition		1	Lack of funds [23 disables proper balanced nutrition		_	The deterioration of the immune system, the body's reaction, carbohydrate [27,48], fatty, protein, and mineral metabolism, acidosis weakens the protective properties of the body [24]		<b>—</b>	Physiologic specifics related to hormonal transformation and acceleration phenomenon, the age of 12 to 16 is considered a risk group. [4, 24].	
Score 2	0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 1 B			2			8		m	4		2	3
Score 1A			3					<del>-</del>			<del>-</del>	
		870 per 100 thousand people (unemployed and below the poverty line) 52.1% in the	cases [1] (the data	urban and rural	poort; segregated data not available. According to the National statistics, the groups refers as "unemployed")	(5)(0.4)		759 abs. number, 60.9 per 100 thousand patients with DM (3,2%) among cases of upper lobe TB		The age structure of	people 18 incoence: up to 1 year — 0.16%, 1-4 — 0.75%, 5-9 — 0.55%, 10-14 — 0.53%, 15-17 — 0.79%. Incidence in children: 10.5 per 100 thousand children (2.75% in	TB cases) [1]
		Urban poor			Rural poor			People with Diabetes			Children	

Combined score		∞			S			4	
Score 6	0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 5	1	They may have limited access to healthcare services		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population	
Score 4	0	The risk is not higher than that of the general population	2	0	The risk is not higher than that of the general population	1	0	The risk is not higher than that of the general population	_
Score 3	1	dystrophic changes in muscle, cartilage, mucous membranes, bronchial tree violate the evacuation of secretion and create a ground for inflammatory processes; concomitant diseases that reduce immunity [4, 25]		0	The risk is not higher than that of the general population		0	The risk is not higher than that of the general population [12,13]	
Score 2	0	The risk is not higher than that of the general population		<b>—</b>	non-compliance with infection control at healthcare facilities; [1,17-21]; established contact with active TB		_	non-compliance with infection control at healthcare facilitie [16 ] contact with active TB patients	
Score 1 B		5	9		<del>-</del>	4		2	3
Score 1A		<del>-</del>						<del>-</del>	
		The age structure of people who TB incidence: 55-64 — 13.2%, over 65 — 8.3%, 15.4 per 100 thousand of people aged 60 or more. [1]			265. 6 per 100 thousand people (0.2% in the structure of TB cases) [1]			1.5% in the structure of TB cases 60,2 per 100 thousand medical workers [1]	
		Elderly (over 60 y.o.)		People having	contacts with TB patients (personnel of social care facilities of all forms of ownership and subordination, who frequently contact TB patients,	studies and make tests)		Medical workers (non-TB- related)	

	Score 1A	Score 1 B	Score 2	Score 3	Score 4	Score 5	Score 6	Combined score
			-	0	0	0	0	
no data available	Not rated	Not rated	non-compliance with infection control at facilities of State Service for Enforcement of Criminal Sanctions; possible contacat with TB patients [14,21]	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	<b>—</b>
	Not	Not rated			<b>←</b>			
			0	0	0	0	0	
no data available	Not rated	Not rated	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	0
	Not	Not rated			0			
			0	0	0	0	0	
no data available	Not rated	Not rated	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	0
	Not	Not rated			0			
			0	0	0	0	0	
Hospital visitors DELETE	Not rated	Not rated	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	0
	Not	Not rated			0			

		Score 1A	Score 1 B	Score 2	Score 3	Score 4	Score 5	Score 6	Combined score
				0	0	0	0	0	
Prison visitors	no data available	Not rated	Not rated	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	0
		Not	Not rated			0			
				0	0	0	0	0	
Peri-prison communities	no data available	Not rated	Not rated	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	0
		Not	Not rated			0			
				0	0	0	0	0	
Peri-mining communities	no data available	Not rated	Not rated	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	0
		Not	Not rated			0			
				0	0	0	0	0	
Sex worker clients	no data available	Not rated	Not rated	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	0
		Not	Not rated			0			
				0	0	0	0	0	
People who use drugs family members	no data available	Not rated	Not rated	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	The risk is not higher than that of the general population	0
		Not	Notrated			0			

**Itense indicators** make it possible to compare the incidence of different areas at different times, in different groups or groups of people because they associate the number with the disease population, among whom were registered.

To quantify the epidemiological process, the following intrinsic indicators are used:

**morbidity** = absolute number of patients with  $I / in TB \times 100$  thousand / total population

**Indicator of morbidity in one of the population groups** = absolute number of patients with TB in / in the given population group x 100 thousand / the population of this group.

As a result of the analysis of morbidity in groups of the population, there are groups of risk, that is, groups of people with high rates of morbidity.

(Intranet.tdmu.edu.ua/data/kafedra/internal/infect\_desease/classes\_stud/uk/med/lik/ptn/ Епідеміологія/5/02.%20Епідеміологічний%20метод%20дослідження.htm)

"The risk group for tuberculosis is considered to be contingents, the incidence among which is more than 100 per 100 thousand population"

**Source:** Broekman, J.F. European framework for tuberculosis control and elimination in countries with a low incidence: Recommendations of the World Health Organization (WHO), International Union Against Tuberculosis and Lung Disease (IUATLD) and Royal Netherlands Tuberculosis Association (KNCV) Working Group / JF Broekmans [et al] // Eur. Respir J. — 2002. — Vol. 19. — P. 765-775.

**Extensive indicators characterize part of the whole** and are expressed in percentages. In terms of expressing roz¬podil extensive disease in individual patients by month, the factors of transmission of pathogens terms of diagnosis vyyavlen¬nya patients after their hospitalization, and more.

Structure of morbidity

Number of diseases in this nosology X

Number of diseases 100

Specific gravity shows the impact on the overall rate of morbidity <a href="https://studfiles.net/preview/5344249/">https://studfiles.net/preview/5344249/</a>

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# Annex 2. Organizations which participated in stakeholders meetings

1	Charitable Organization "All-Ukrainian League" LEGALIFE"
2	Public Health Capital
3	PATH
4	HealthRight International
5	Project HOPE
6	UNDP
7	Charitable Organization "All-Ukrainian League" LEGALIFE — Ukraine"
8	Charitable Organization "Light of hope"
9	Charitable Organisation "The Public Movement — Ukrainians Against Tuberculosis Foundation"
10	Charitable Organisation "TB Hope"
11	Charitable Organisation "Positive Women"
12	Verkhovna Rada of Ukraine
13	All-Ukrainian Association of People Who Overcame Tuberculosis "Stronger Than TB"
14	NGO "Infection-control in Ukraine"
15	NGO "Club Eney"
16	NGO "HPLGBT"
17	NGO "Alliance.Global"
18	Kyiv City Center for Social Services for Family, Children and Youth
19	International Charitable Organisation "Eurasian Women's Network on AIDS"
20	International Charitable organization "Roma women fund Chiricli"
21	International Charitable organization "East Europe & Central Asia Union of People Living with HIV (ECUO"
22	International Charitable organization "Alliance for Public Health"
23	International NGO "Labor and Health Social Initiatives" (LHSI)
24	Ministry of Health of Ukraine
25	The National Committee of Ukrainian Red Cross Society
26	BOGOMOLETS NATIONAL MEDICAL UNIVERSITY
27	Trade Union of Health Care Workers of Ukraine
28	International association of journalists 'Health Without Borders'
29	Territorial-medical association "Ftyzyatriya"
30	LLC "Alliance Consultancy"
31	Charitable Organization "Ukrainian Institute on Public Health Policy" (UIPHP)
32	State Institution "Public Health Center of the Ministry of Health of Ukraine"

# Report on the project results "Communities, Rights and Gender TB Tools Assessments in Ukraine"

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