



## **TECHNICAL** REPORT

# Social determinants and risk factors in tuberculosis surveillance in the EU/EEA

**ECDC TECHNICAL REPORT**

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## Abbreviations

ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EU	European Union
HIV	Human immunodeficiency virus
ICD	International Classification of Diseases
NA	Not applicable
TESSy	The European Surveillance System
TB	Tuberculosis
WG	Working group
WHO	World Health Organization

## Glossary

Social determinant	The conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries. <sup>1</sup>
Risk factor	A risk factor is any attribute, characteristic or exposure of an individual that increases the likelihood of developing a disease or injury. <sup>2</sup>

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1 [http://www.who.int/social\\_determinants/sdh\\_definition/en/](http://www.who.int/social_determinants/sdh_definition/en/)

2 [http://www.who.int/topics/risk\\_factors/en/](http://www.who.int/topics/risk_factors/en/)

# Executive summary

## Background

Tuberculosis (TB) is more frequent in certain socio-economic groups and the course of the disease can be more rapid or more severe in individuals with specific risk factors. To address the TB epidemic there is therefore a need for information on social determinants and risk factors in TB patients. This information can be collected in TB surveillance systems.

## Objective

The objective of this report is to provide countries with advice on what social determinant and risk factor variables to collect and what definitions to use, and to propose information to be collected at the national and European level.

## Methods

A survey was conducted by the European Centre for Disease Prevention and Control (ECDC) and the World Health Organization (WHO) Regional Office for Europe to better understand the definitions and categories used for collecting information on social determinants and risk factors for TB. The results of the survey were discussed at the European Union (EU)/European Economic Area (EEA) TB Surveillance Network meeting in 2016, and thereafter, an ECDC Working Group (WG) on Social Determinants and Risk Factors for TB was established. The WG discussed and decided which variables to collect and WG members developed definitions for the selected social determinants and risk factors. The proposed variables and definitions were presented at the joint ECDC and WHO Tuberculosis Surveillance Network meeting in 2017 and input of the network members was sought. The WG subsequently developed the final list of variables and definitions and recommended which variables to collect at national level and at EU/EEA level.

## Results

Twenty-seven of 31 (87%) countries responded to the survey and reported collecting information on 21 different social determinants/risk factors. Countries used different definitions and categories for the social determinant and risk factor concepts.

The WG recommended nine variables to be collected at the national level: 'education' (educational status); 'imprisonment'; 'employment status'; 'homelessness'; 'year (date) of entry to the country'; 'in contact with TB case'; 'use of alcohol'; 'use of illicit drugs'; and 'diabetes mellitus' and provided definitions for these variables. One variable 'year (date) of entry to the country' was recommended by the WG for collection at EU level.

## Conclusions

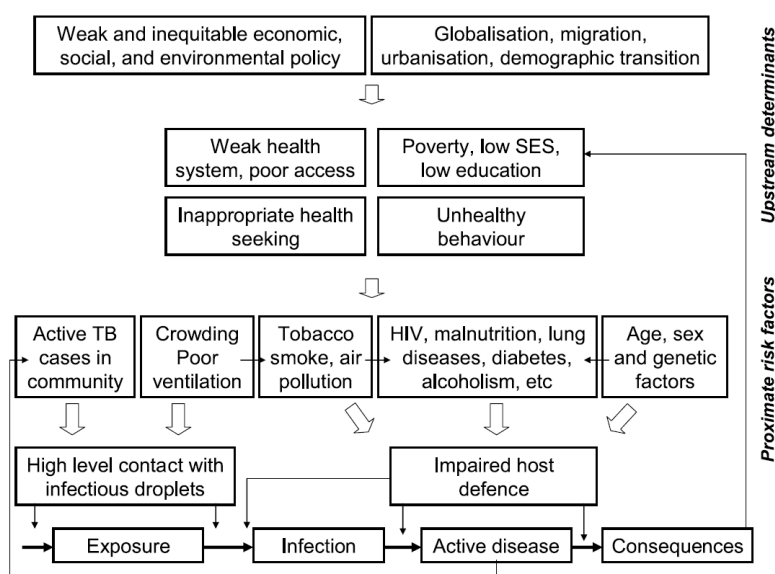
The collection of information on social determinants and risk factors for TB is important to guide prevention and control activities in the EU/EEA. The list of nine variables and the standard definitions are meant to be a guide for Member States. The collection of these variables will provide information for prevention and control of TB and will contribute to ending TB in the EU/EEA.

# 1. Background

Tuberculosis (TB) is an infection which results in disease in approximately 60 000 individuals per year in the European Union and European Economic Area (EU/EEA) [1]. Exposure to the disease is more common in certain socio-economic groups and the course of the disease can be more rapid or more severe in individuals with specific risk factors [2]. To address the TB epidemic there is a need for information on the presence of social determinants and risk factors in TB patients to inform action. This has been acknowledged in the World Health Organization (WHO) End TB Strategy [3].

The WHO Regional Office for Europe (WHO Europe) and the European Centre for Disease Prevention and Control (ECDC) jointly coordinate TB surveillance in Europe. ECDC collects case-based surveillance data in the European Surveillance System (TESSy) and WHO Europe collects aggregated data in the WHO Tuberculosis Monitoring and Evaluation platform. Through these systems, information on a limited number of social determinants and risk factors is collected. Both systems collect information on nationality, age, sex and HIV infection, and the aggregated system also collects information on imprisonment. In addition to the social determinants and risk factors that are included in TB surveillance in Europe, others have also been identified as being associated with TB. These include both proximate risk factors and upstream determinants (Figure 1) [2].

**Figure 1. Framework for proximal risk factors and upstream determinants\*** [2]



\* Reprinted from *Social Science & Medicine*, 68/12, Lonnroth K, Jaramillo E, Williams BG, Dye C, Raviglione M, *Drivers of tuberculosis epidemics: the role of risk factors and social determinants*. 2240-6. Copyright (2009), with permission from Elsevier  
 SES = socio-economic status; TB = tuberculosis; HIV = Human immunodeficiency virus

European countries have national TB surveillance systems that collect information considered relevant for prevention and control of TB in the country. These national systems often collect more information than what is submitted to the joint WHO Europe/ECDC surveillance system. To identify social determinants and risk factors collected and monitored at national level, a survey was conducted by the Wolfheze Working Group on Social Determinants of TB and Drug Resistant TB [4]. According to the survey results, 17 different social determinants were monitored, including occupation, homelessness, and education, and 16 different risk factors, including diabetes mellitus, illicit drug use, and smoking.

In order to provide countries with advice on what social determinant and risk factor variables to collect, what definitions to use, and also to assess what information should be collected at the European level, a follow up survey was conducted and an ECDC Working Group on Social Determinants and Risk Factors for TB (WG) was established. This technical report provides the results of the survey and summarises the deliberations and conclusions of the WG.

## Objectives

### General objective

- To provide countries with advice on what social determinant and risk factor variables to collect and what definitions to use, and to assess what information should be collected at the European level.

### Specific objective of the survey

- Document the definitions of social determinants and risk factors of TB as used by the national surveillance systems.

### Specific objectives of the working group on social determinants and risk factors for TB

- Develop a list of variables on social determinants and risk factors that can be used at the national level, including standard definitions and methods for data collection and analysis;
- Propose the minimum information on social determinants/risk factors to be collected at the European level.



## 2. Methods

### Survey

A survey to better understand the definitions of variables and categories used for collecting information on social determinants and risk factors for TB was conducted in 2015 by ECDC and WHO Regional Office for Europe. The survey consisted of a semi-structured questionnaire which was sent to TB Surveillance Operational Contact Points of each Member State of the EU/EEA (Appendix 1).

The results of this survey were discussed at the European Union (EU)/European Economic Area (EEA) TB Surveillance Network meeting on 21–22 June 2016 in Bratislava. The meeting participants requested ECDC to convene an ECDC working group on social determinants and risk factors for TB.

### ECDC working group on social determinants and risk factors for TB

The WG on social determinants and risk factors for TB was established in November 2016 and consisted of National Focal Points for Tuberculosis and Operational Contact Points for TB surveillance who volunteered for the WG. WG members selected a chair and a co-chair from among the members. The main method of communication was through e-mail. In addition, five teleconferences were organised. ECDC developed the Terms of Reference for the WG and prepared and circulated the agenda for the teleconferences and the draft minutes to all members. Final minutes, proposals and suggestions were based on group consensus.

The WG first decided on the variables that were to be considered for collection and standardisation taking into account feasibility to collect the information, cost and the possibility to standardise variables across countries. The selection was done in two steps. First, WG members indicated whether collection and standardisation should be considered for each variable identified in the survey. The results of this inventory were discussed in a teleconference, and in the second step the members voted on the social determinants and risk factors that needed harmonisation.

After selection of the variables that could be considered for collection and that required standardisation, WG members developed a proposal on the definition, categories, data sources, and the level for collection (national and/or EU/EEA) for the selected social determinants and risk factors. This proposal was further discussed by WG members in a teleconference and consensus was reached on the definitions and categories of the selected variables.

The definitions and categories for social determinant and risk factor variables proposed by the WG were presented at the joint ECDC and WHO Tuberculosis Surveillance Network meeting in 2017. All EU/EEA participants of the meeting were asked to fill in an inventory questionnaire in which they indicated for each variable whether they agreed with the proposed definition (Appendix 2). The results of this inventory and suggestions for the definitions and categories of the meeting participants were provided to the WG. The WG members discussed the results of the inventory and the suggestions made by the meeting participants in a final teleconference and made changes to the definitions and categories taking into account the suggestions from the participants of the joint ECDC and WHO Tuberculosis Surveillance Network meeting.

ECDC drafted a working group report summarising the work of the WG and the final proposed definitions, categories, data sources and level of data collection for social determinants and risk factors. The working group report was reviewed by all WG members and approved and served as input for this technical report.

## 3. Results

### Survey

Twenty-seven of 31 (87%) countries responded to the survey. Information on 21 different social determinants/risk factors for TB was collected by at least one country in 2014 (Appendix 3). The variables 'citizenship'/ 'nationality', and 'place of birth', which are already included in TESSy, were collected by most countries, 16, and 26, respectively. The variable 'HIV infection', also included in TESSy, was collected by 20 countries. Variables currently not included in TESSy but collected by more than half of the responding countries were: 'contact with TB case' (21); 'current imprisonment' (20); 'homelessness' (17); 'employment' (15); 'occupation' (15); 'years since entry in country' (15); 'diabetes mellitus' (15); 'urban'/ 'rural' (14); 'use of alcohol' (14); and 'use of illicit drugs' (14). Countries used different definitions and categories for the social determinant and risk factor concepts.

### List of variables on social determinants and risk factors

The WG decided on a list of variables on social determinants and risk factors that can be used at the national level (Table 1). The working group recommended nine variables to be collected at the national level: 'education' (educational status); 'imprisonment'; 'employment status'; 'homelessness'; 'year (date) of entry to the country'; 'in contact with TB case'; 'use of alcohol'; 'use of illicit drugs'; and 'diabetes mellitus'. One variable 'year (date) of entry to the country' is proposed to be collected at EU level. For the variables 'year (date) of entry to the country' and 'in contact with TB case', linkage with the national population registry might be possible.

**Table 1. List of variables proposed by the ECDC working group on social determinants and risk factors for tuberculosis.**

Concept	Definition	Categories*	Suggested level of data collection for surveillance	Suggested data source national TB registry	Comments
<b>Education (educational status)</b>	A modified International Standard Classification of Education definition based on the three cycles of education (primary, secondary and tertiary) and proposed that the definition be equivalent to 'Highest level of completed formal education'	0 No formal education or incomplete primary education 1 Completed primary school 2 Completed secondary school 3 University or higher 9 Unknown	National	TB notification form rather than linkage and could consist of a single question with a drop down menu/ list of options	Some doubts about usefulness of the variable, particularly for those countries with free universal education, drop out from school and failure to progress to higher education is an indicator of wider social problems and thus potentially useful as one measure of social risk of TB
<b>Imprisonment*</b>	Imprisonment includes incarceration in a prison and/or remand centre, juvenile institution or young offender's institution. It does not include migration detention or removal centres	0 Prisoner 1 Former prisoner 2 Not prisoner 9 Unknown	National	TB notification form – status of patient at the time of diagnosis	Time factor for the imprisonment definition: at the time of notification or diagnosis Former imprisonment is not a TB risk factor for several EU/EEA countries – the category could be optional
<b>Employment status</b>	Employed: 'individual receiving an income from an employer or self-employed'; Unemployed: 'individual without work but available for and seeking work'	0 Unemployed 1 Retired 2 Children (pre-school) 3 Pupils (primary and secondary school) 4 Students (post-secondary school) 5 Employed (or self-employed) 6 Other (or specify in free text) 9 Unknown	National	TB notification form; variable name should be 'Activity' or 'Occupational status'	

Concept	Definition	Categories*	Suggested level of data collection for surveillance	Suggested data source national TB registry	Comments
<b>Homelessness**</b>	Sleeping out doors or staying in homeless institutions/shelters	0 Yes 1 No 9 Unknown	National	TB notification form	Can be collected also as a category in broader concept: 'Living Status', depending on country's specifics. Beyond sleeping outdoors/sleeping rough, homelessness may include situations of living in temporary, insecure or poor-quality housing. Typical causes of homelessness are: - unemployment and poverty - migration - ageing - health problems - relationship breakdowns - lack of affordable housing for rent and for sale Inadequate support for people leaving care facilities, hospitals, prisons or other public institutions <sup>iii</sup> .  Homeless people may face reduced life expectancy, health problems, discrimination, isolation and barriers to access to basic public services and benefits.
<b>Year (date) of entry to the country</b>	Date of entrance	Date format: yyyy, yyyy-Qq, yyyy-mm, yyyy-Www, yyyy-mm-dd, unknown (year and month is preferred)	European	TB notification form with possibility to link it to the national population registry and migrations centre data	Less specific date is simpler and may be sufficient. Possible issues with defining the dates for immigrants, who are periodically returning in the country of birth for longer periods of time or who are returning on a regular basis for a short time. Can be collected as the years since entering.
<b>In contact with TB case**</b>	Known close contact with TB case	0 Yes 1 No 9 Unknown Additional categories: Type of contact – close, regular and casual contacts and the duration from the last contact (e.g. within 2 years, more than 2 years)	National	TB notification form with possibility to link it to the national population registry	References [5, 6]
<b>Use of alcohol**</b>	Having an alcohol use disorder (as recorded in the clinical record, or according to the opinion of the case manager) or current alcohol consumption of over 40 g (4 standard drinks) per day	Does the person have a current or past alcohol use disorder? (either self-reported or recorded in the clinical notes) 0 Never 1 Past alcohol use disorder 2 Current alcohol use disorder 9 Unknown  Would the person drink more than 4 standard drinks in a typical day? 0 Never 1 Occasionally (i.e. once per week) 2 Regularly (i.e. two times or more per week) 9 Unknown	National	TB notification form at the time of notification (diagnosis)	Type of alcohol (beer, wine, spirits), pattern of alcohol consumption and overall context should be taken into consideration when defining the category on daily drinking habits

<sup>iii</sup> <http://ec.europa.eu/social/main.jsp?catId=1061>

Concept	Definition	Categories*	Suggested level of data collection for surveillance	Suggested data source national TB registry	Comments
<b>Use of illicit drugs<sup>†</sup></b>	Problematic drug use of illicit injecting drug(s) or long duration/regular use of illicit drugs	0 Yes 1 No 9 Unknown	National	Reporting by physician on the TB notification form; after interviewing the patient or checking from the patient' medical history	Definitions of the variable of interest are difficult because of deficiencies in the data collected by countries on illicit drug use, and by disagreements over what constitutes 'problematic' illicit drug use. The definition used here was long-term regular injecting use of opioids, amphetamines or cocaine. Data on the prevalence of problematic illicit drug use were derived from a range of sources that used variable methods of deriving estimates.
<b>Diabetes mellitus<sup>†</sup></b>	Presence of fasting plasma glucose: 7.0 mmol/l (126 mg/dl) or 2 h plasma glucose 11.1 mmol/l (200 mg/dl) or recorded in the patient records Optional: International Classification of Diseases-10 codes: E10-E14 <sup>iv</sup>	0 Yes 1 No 9 Unknown	National	TB notification form at the time of notification (diagnosis)	Comorbidities are usually poorly recorded at the national level, however has a great impact to TB epidemiology.

*This table has been adapted taking into account the input from the participants of the joint ECDC and WHO Tuberculosis Surveillance Network meeting in 2017.*

*EEA = European Economic Area; EU = European Union; ICD = International Classification of Diseases; m = month; Qq = quarter; TB = tuberculosis; w = week; WHO = World Health Organization; y = year*

*\* Missing information is considered as 'Unknown'*

*\*\* Currently collected for WHO European Region in WHO Global Database in aggregated format*

Twenty-seven participants of the joint ECDC and WHO Tuberculosis Surveillance Network meeting in 2017 from 24 EU/EEA countries indicated their agreement with the definitions proposed by the WG (Table 2). More than 90% of respondents agreed with the definitions for 'homelessness', 'in contact with TB case', 'year entry to country', and 'diabetes mellitus'.

<sup>iv</sup> International Classification of Diseases, <http://www.who.int/classifications/icd/en/>

**Table 2. Results of the inventory among the participants of joint ECDC and WHO Tuberculosis Surveillance Network meeting in 2017 with the proposed definitions for the social determinant and risk factor variables.**

Do you agree with the proposed definition* for	Agree	Not agree	No opinion	Total	Percentage 'Agree'
Education	23	1	3	27	85%
Imprisonment	24	1	2	27	89%
Employment status	23		4	27	85%
Homelessness	26		1	27	96%
Year (date) entry to the country	25		2	27	93%
In contact with TB case (known TB contact)	26		1	27	96%
Use of alcohol (harmful use of alcohol)	22	1	4	27	81%
Use of illicit drugs	20	2	5	27	74%
Diabetes mellitus	25		2	27	93%

\* See Table 1

Based on the results of the inventory among participants of the joint ECDC and WHO Tuberculosis Surveillance Network meeting in 2017, the WG members made some changes to the definitions and categories (included in Table 1). The following changes were made:

- the term 'Current imprisonment' was renamed to 'Imprisonment'
- in the term 'Employment status' self-employed was added to the categories
- the definition for 'Homelessness' was changed from 'Without permanent appropriate living place or sleeping outdoors or stays in homeless institution/shelters' to 'Sleeping out doors or staying in homeless institutions/shelters'
- the definitions for 'In contact with TB case' was changed from 'Known contact with TB case' to 'Known close contact to TB case'
- from the definition for 'Use of illicit drugs' drug names were removed
- in the definition for 'Diabetes mellitus' the option 'or recorded in the patient records' was added

The members of the WG all agreed on the final list of variables definitions, categories, data sources and level of data collection for social determinants and risk factors that was included in the working group report.

## 4. Discussion

The collection of information on social determinants and risk factors for TB is important to guide prevention and control activities in the EU/EEA. For most of the variables identified by the WG there are no standard definitions, or the standard definitions are considered to be too complicated for TB surveillance, e.g. the definition for education was simplified. Therefore, it is of value that the WG has come up with a proposal for variables to be included in TB surveillance and their definitions.

An advantage of using standard definitions in the EU/EEA is that information from different countries will be comparable. The use of standard definitions will facilitate exchange of information between countries and implementation of studies on social determinants and risk factors.

Only one variable 'Year (date) of entry to the country' was suggested for collection at EU/EEA level. EU/EEA level surveillance already includes variables that can be used for understanding the TB epidemic and for guiding action, i.e. information on nationality, age, sex and HIV infection.

For some countries, it will be challenging to use the proposed definitions and categories, since countries may have country-specific definitions for social determinants and risk factors which need to be used according to national regulations. Also, not all variables may be relevant for all countries. Currently, not all countries report on the social determinant and risk factor variables that are currently collected at EU/EEA level. For example, the variable HIV status was only reported by 20 countries for 69% of the TB cases in these countries in 2016 [1]. We do however observe an increase in the number of countries that report on this variable.

This technical report can contribute to the initiation of the collection of variables and may provide inspiration for experts working on TB surveillance.

## 5. Conclusions

In conclusion, nine variables on social determinants and risk factors are proposed for inclusion in national TB surveillance. The collection of these variables will provide information for prevention and control of TB and will contribute to informing options for interventions to end TB in the EU/EEA.

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# Appendix 1. Survey

## Social determinants and risk factors for tuberculosis

### Definitions and data

#### Background

In most countries of the World Health Organisation (WHO) European Region, including the European Union (EU) and European Economic Area (EU/EEA) countries, tuberculosis (TB) rates are declining. In 2013, 21 countries in the Region (18 in EU/EEA) reported less than 10 new TB cases per 100,000 population, falling under the definition of TB low-incidence country and facing the new challenge to reach TB elimination by 2050.

TB epidemiology is unequally distributed in societies, and is often concentrated in individuals according to a socioeconomic gradient and exposure to risk factors, also in countries with higher TB rates. To successfully prevent and control TB, it is important to identify and monitor those social determinants and risk factors for TB.

In 2014, the Wolfheze Working Group on Social Determinants of TB and Drug Resistant TB has conducted a survey among the national TB surveillance correspondents of all 53 countries of the Region, with the objective of understanding which social determinants and risk factors for TB are collected in countries through surveillance/surveys but not reported to the European Centre for Disease Prevention and Control (ECDC)/WHO Joint Reporting Platform (manuscript submitted for publication). The main conclusions were that some social determinants and risk factors are collected by the majority of countries (and could be considered for expanding the reporting to ECDC/WHO) and that there is a need to develop/standardize epidemiological case definitions to improve surveillance of social determinants and risk factors to properly guide the implementation of the End TB Strategy ('Social protection, poverty alleviation and actions on other determinants of TB' component of the 'Bold policies and supportive systems' pillar II).

Building on the previous survey and aiming at building future consensus across the 53 countries of the WHO European Region on surveillance of social determinants and risk factors of TB based on standard epidemiological case definitions, ECDC and WHO Regional Office for Europe are launching a new study.

ECDC would also like to use the opportunity of this survey to collect available information on vulnerable populations and co-morbidities in the EU/EEA. This information will support the implementation of the ECDC scientific advice 'Interventions for tuberculosis prevention and control in hard to reach and vulnerable populations' that is currently under development. This scientific advice will provide options for interventions for tuberculosis prevention and control in hard to reach and vulnerable populations in the EU/EEA.

#### Objectives of survey

- 1) Document the definitions of social determinants and risk factors of TB as used by the national surveillance systems; and
- 2) Collect existing data on social and health determinants that are currently collected by national surveillance systems

#### Methods

ECDC and WHO European Regional Office developed a simple questionnaire which was tested before wide distribution. The list of concepts of social determinants and risk factors included in the questionnaire builds on the work done by Wolfheze Working Group on Social Determinants of TB and Drug Resistant TB.

The questionnaire is distributed to the TB Surveillance Operational Contact Points (EU/EEA countries) by ECDC and to the National TB Surveillance Correspondents (non EU/EEA European Region countries) by WHO.

The results of the survey will be jointly analysed by ECDC and WHO and documented in a joint ECDC/WHO report and/or scientific paper for publication.

ECDC will analyse the data provided by the EU/EEA countries separately to support the implementation of the scientific advice 'Interventions for tuberculosis prevention and control in hard to reach and vulnerable populations'.



## Output

ECDC/WHO European Regional Office guidance to Member States on standardized epidemiological case definitions of social determinants and risk factors of TB for national surveillance.

ECDC/WHO European Regional Office jointly prepared manuscript for publication in a peer reviewed scientific magazine.

ECDC prepared report or manuscript on the existing data on social and health determinants that are currently collected by national surveillance systems.

## Next steps

The survey results will be used to build consensus on standard epidemiological case definitions of the most common social determinants and risk factors of TB for the 53 countries of the WHO European Region. Such consensus will be built jointly by ECDC and WHO using opportunity events (e.g. ECDC TB Surveillance Meeting in 2016, UNION European Regional Conference in June 2016 in Bratislava, Slovakia, others).

## Instructions

The questionnaire consists of a two parts, one part for collecting information about the person completing the questionnaire and the total number of all TB cases and two tables: (1) on social determinants and (2) on risk factors. The two tables contain a lists of concepts for which surveillance data may be collected in your country. For each concept that is included in your TB surveillance system you are asked to provide the definition of the concept (most likely available in the description of the TB surveillance data or data dictionary used for the national TB surveillance), the categories that are used (e.g. employed, unemployed, not applicable, unknown), and the number of all TB cases that were reported in 2014 for each category (e.g. employed 1 234, unemployed 4 321, not applicable 123, unknown 321). If the concept is not included in you TB surveillance system please indicate by including NA (not available).

Not all concepts in the list are mutually exclusive, e.g. corticosteroid treatment, tumor necrosis factor (TNF $\alpha$ ) treatment and immuno-suppression treatment. If, for example, corticosteroid treatment and tumor necrosis factor (TNF $\alpha$ ) treatment are one concept in your TB surveillance system you are asked to indicate this in the table for risk factors.

At the end of Table 1 social determinants and Table 2 risk factors there is a row 'Other (please specify)'. You can add as many rows as needed to include concepts of social determinants or risk factors that are not listed in the tables.

We provide the questionnaire in 'Word format' to enable you to copy and paste definitions, categories and 'number of all reported TB cases with determinant or risk factor by category in 2014' from other documents.

Below you find an example.

Concept	Definition#	Categories used	Number of all reported TB cases with determinant by category in 2014
<b>Example:</b> Unemployed	<b>Example</b> In accordance with the ILO standards adopted by the 13th and 14th International Conference of Labour Statisticians (ICLS), for the purposes of the Community labour force sample survey, unemployed persons comprise persons aged 15 to 74 who were: (a) without work during the reference week, i.e. neither had a job nor were at work (for one hour or more) in paid employment or self-employment; (b) currently available for work, i.e. were available for paid employment or self-employment before the end of the two weeks following the reference week; (c) actively seeking work, i.e. had taken specific steps in the four week period ending with the reference week to seek paid employment or self-employment or who found a job to start later, i.e. within a period of at most three months.	<b>Example</b> Unemployed Not unemployed Not applicable Unknown	<b>Example</b> Unemployed XX Not unemployed XX Not applicable XX Unknown XX

# NA (not available) if no definition is available in the description of the TB surveillance data or data dictionary used for the national TB surveillance

Any personal data included in the questionnaire will be processed pursuant to Regulation (EC) No 45/2001 on the protection of individuals with regard to the processing of personal data by the Community institutions and bodies and on the free movement of such data.

# Questionnaire

Identification number: 

## 1. Date

## 2. Your country

## 3. Person completing this questionnaire

Name	<input type="text"/>
Functional title	<input type="text"/>
E-mail	<input type="text"/>
Telephone number	<input type="text"/>
Institution of affiliation	<input type="text"/>

## 4. General tuberculosis information

Total number of all tuberculosis cases notified in 2014	<input type="text"/>
---	----------------------

## Social determinants

Concept	Definition#	Categories used	Number of all reported TB cases with determinant by category in 2014
Education			
Employment			
Occupation			
Income			
Current imprisonment			
History of imprisonment			
If ex-prisoner, years after release			
Citizenship			
Place of birth			
Origin (national/foreign)			
Asylum seeker			
Refugee			
Undocumented migrant			
Internally displaced			
Years since entered in country			
Employment abroad			
Ethnic minority			
Homeless			
Orphan			
Slum dweller			
Urban/rural			
Other (please specify)			

# NA (not available) if no definition is available in the description of the TB surveillance data or data dictionary used for the national TB surveillance

## Risk factors

Concept	Definition#	Categories used	Number of all reported TB cases with risk factor by category in 2014
<b>Environmental factors</b>			
In contact with TB case			
Type of housing			
Smoking tobacco			
Use of alcohol			
Use of illicit drugs			
<b>Medical conditions</b>			
HIV infection			
Diabetes mellitus			
Silicosis			
Malignancies			
Corticosteroid treatment			
Immuno-suppression treatment			
Tumor necrosis factor (TNF $\alpha$ ) treatment			
Malnutrition			
Pregnancy			
Other causes of immunodeficiency			
Gastrectomy			
Jejunioileal bypass			
Chronic renal failure			
Haemodialysis			
Solid organ transplantation			
Other (please specify)			

\* NC (not collected) if concept is not collected in national TB surveillance system

# NA (not available) if no definition is available in the description of the TB surveillance data or data dictionary used for the national TB surveillance

## Appendix 2. Inventory questionnaire

### Harmonisation of social determinants and risk factors for tuberculosis surveillance in the EU/EEA

Name: \_\_\_\_\_

#### Questionnaire:

1. Do you agree with the proposed definition for '**Education**'?
  - Yes
  - No
  - No opinion
2. Do you agree with the proposed definition for '**Imprisonment**'?
  - Yes
  - No
  - No opinion
3. Do you agree with the proposed definition for '**Employment status**'?
  - Yes
  - No
  - No opinion
4. Do you agree with the proposed definition for '**Homelessness**'?
  - Yes
  - No
  - No opinion
5. Do you agree with the proposed definition for '**Year (date) entry to the country**'?
  - Yes
  - No
  - No opinion
6. Do you agree with the proposed definition for '**In contact with TB case (known TB contact)**'?
  - Yes
  - No
  - No opinion
7. Do you agree with the proposed definition for '**Use of alcohol (harmful use of alcohol)**'?
  - Yes
  - No
  - No opinion
8. Do you agree with the proposed definition for '**Use of illicit drugs**'?
  - Yes
  - No
  - No opinion
9. Do you agree with the proposed definition for '**Diabetes mellitus**'?
  - Yes
  - No
  - No opinion

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Appendix 3. Results of survey on social determinants and risk factors for tuberculosis

The results presented in the table below were collected using a survey questionnaire (Appendix 1) from European Union and European Economic Area Member States. Twenty-seven of 31 (87%) countries responded to the survey. The answers provided by the survey respondents were interpreted so that they fitted the table format.

Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Education</b> (educational status) Collecting countries: 2 (7%)	<ul style="list-style-type: none"> <li>Modified International Standard Classification of Education (EE, LT)</li> </ul>	<b>Nominal variable:</b> <ol style="list-style-type: none"> <li>Lower or less</li> <li>Basic</li> <li>Secondary/gymnasium</li> <li>Secondary/vocational</li> <li>Higher –vocational education</li> <li>University degree</li> <li>Basic/vocational</li> <li>No data/data missing (EE, LT)</li> </ol>
<b>Employment**</b> (unemployed or not) Collecting countries: 15 (56%)	<ul style="list-style-type: none"> <li>TB patient who is not employed and is not working freelance and has no other source of living (social benefits) at the time of diagnosis. (CZ)</li> <li>Place/type of employment (DK)</li> <li>Current employment status (IE)</li> <li>Working place (NO)</li> <li>Without work in last 24 months (PT)</li> <li>TB patient &gt;14 years old is employed or not at the moment of registration. Patients actively seeking work and receiving social income for that, are registered as 'Unemployed Worker' (RO)</li> <li>Employment status in the last 24 months prior to TB diagnosis (SI)</li> <li>Person employed (SK)</li> <li>All those with an occupation but excluding those that have 'None' as their occupation (UK)</li> <li>No definition available or not reported in six countries (CY, EE, LT, LU, LV, MT)</li> </ul>	<b>Nominal variable:</b> Selected commonly used categories: <ol style="list-style-type: none"> <li>Paid Employment</li> <li>Housewife/husband</li> <li>Unemployed</li> <li>Disabled</li> <li>Retired</li> <li>Student</li> <li>Imprisoned</li> <li>Working irregularly</li> <li>Other/free text</li> </ol> (CY, DK, IE, LT, LU, LV, MT, PT, RO, UK) <ul style="list-style-type: none"> <li>Official Job Classification of Ministry of Social Affairs (EE)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Yes/No (CZ, SK)</li> </ul> <b>Free text</b> (NO, SI)
<b>Employed abroad</b> Collecting countries: 2 (7%)	<ul style="list-style-type: none"> <li>Residence for &gt;3 months in a high incidence country (IE, NO)</li> </ul>	<b>Binary variable:</b> <ul style="list-style-type: none"> <li>Yes/No (IE, NO)</li> </ul>
<b>Occupation</b> (current or most recent) Collecting countries: 15 (56%)	<ul style="list-style-type: none"> <li>Health care worker/Teacher/Other occupational risk of TB infection (CZ)</li> <li>Collected under 'Place/type of employment' (DK)</li> <li>National Classification of Occupation or International Standard Classification of Occupations (EE, LT)</li> <li>Occupation in social or health section (FR)</li> <li>Current or most recent occupation (IE)</li> <li>Some occupations that are considered having an epidemiological risk are registered according to the Occupational Classification of Romania (RO)</li> <li>The current occupation of the patient at the time of notification (UK)</li> <li>No definition available or not reported in seven countries (CY, EL, LV, MT, NO, PT, SI)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>National Classification of Occupation or International Standard Classification of Occupations (EE, LT)</li> <li>Yes, No, Unknown (FR)</li> <li>Worker; farmer; self-employed; medical staff; other employed (LV)</li> <li>National health institution; Other health institution; Prison; Community residency; Other; Unknown (PT)</li> <li>Personnel from the pneumology network; Health workers, other than pneumology network; Teaching personnel; Personnel from penitentiary system; Active militaries on duty; Military personnel from the Ministry of Defence; Civil personnel from the Ministry of Defence; Personnel from the Ministry of Internal Affairs; Agricultural worker; Student; Unemployed worker; Other employments (RO)</li> <li>Agricultural/animal care worker; Education; Health care worker; Laboratory/pathology; Social service/prison worker; Other (UK)</li> </ul> <b>Free text</b> (CY, CZ, DK, EL, IE, MT, NO) <b>Not specified</b> (SI)
<b>Income</b>	Not collected in EU/EEA countries	

Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Current Imprisonment</b> Collecting countries: 20 (74%)	<ul style="list-style-type: none"> <li>Diagnosed in prison at the time of tuberculosis diagnosis/notification (BE, BG, CZ, DK, EE, FR)</li> <li>Collected under 'Current living status' variable (IE)</li> <li>Reported by prison to the register (MT, RO)</li> <li>A prisoner is a person detained at time of diagnosis. Included are persons screened in prison and diagnosed (as a result of further investigation) after release from prison (NL)</li> <li>Imprisonment at the moment of diagnosis (PT)</li> <li>Incarceration including incarceration in a prison and/or remand center, juvenile institution or young offender's institution. (UK)</li> <li>No definition available or not reported (EL, ES, HU, LT, LU, LV, PL, SI)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>Yes, No, Unknown (BE)</li> <li>Collected in variable activity: 1. working; 2. jobless; 3. at military service; 4. prisoner; 5. university student; 6. retired; 7. incapable to work (EE)</li> <li>Registered in penitentiary system as prisoner/ Registered outside penitentiary system; the patient is not prison (RO)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Circle if yes (CZ)</li> <li>Imprisoned/Not imprisoned (EL, LT)</li> <li>Yes/No (ES, LV, MT, PT, UK)</li> <li>Tick a box (FR, HU, IE, NL)</li> </ul> <p><b>Not specified</b> (BG, DK, LU, PL, SI)</p>
<b>History of imprisonment</b> Collecting countries: 4 (15%)	<ul style="list-style-type: none"> <li>History of incarceration (EE)</li> <li>History of incarceration including incarceration in a prison and/or remand center, juvenile institution or young offender's institution (UK)</li> <li>No definition available or not reported (HU, LV)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>Yes/No/No data (EE)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>The risk factor 'former prisoner' marked in the notification (HU, LV)</li> <li>In prison in the last 5 years or more than 5 years ago Yes/No; If yes selected, in prison abroad? Yes/No (UK)</li> </ul>
<b>If ex-prisoner, years after release</b> Collecting countries: 1 (4%)	<ul style="list-style-type: none"> <li>No definition available or not reported (UK)</li> </ul>	<p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>More or less than 5 years ago in prison (Yes/No): If yes, in prison in the last 5 years (Yes/No); In prison more than 5 years ago (Yes/No) (UK)</li> </ul>
<b>Citizenship</b> Collecting countries: 16 (59%)	<ul style="list-style-type: none"> <li>As obtained from population registry registry (BE, LU)</li> <li>Has identification card of country (BG)</li> <li>Has citizenship of Czech Republic (CZ)</li> <li>Citizenship at beginning of treatment (DE)</li> <li>Citizen of country (DK)</li> <li>Nationality of reporting country (EL, FI, SK)</li> <li>Nationality as defined by the National Institute for Statistics and Economic Studies (FR)</li> <li>Foreign country at or before diagnosis (IS)</li> <li>Patients without Polish identification number (PL)</li> <li>Country of citizenship (PT)</li> <li>Identification card/passport available at registration as TB case (Romanian or foreign) (RO)</li> <li>No definition available (HU, LT)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>Yes, No, Unknown (BE, DK, EL, RO, SK)</li> <li>Country list (DE, FI, FR)</li> <li>1. Usually does not have permanent address of stay in Czech Republic; 2. Has permanent address in Czech Republic and Czech birth certificate number; 3. Analogous to 1 and 2. but outside EU/EFTA; 3. Asylum seeker and those who already got the protection; 5. Illegal stay (CZ)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Hungarian or other (HU)</li> <li>Yes/No (IS)</li> <li>Lithuanian/Other (LT)</li> </ul> <p><b>Not specified</b> (BG, LU, PL, PT)</p>
<b>Place of birth</b> Collecting countries: 26 (96%)	<ul style="list-style-type: none"> <li>As obtained from population registry (BE, LU)</li> <li>Country of birth (Country, in which person was born) (BG, CZ, EE, FI, FR, IE, IS, MT, NL, PL, PT, RO, SE, SK, UK)</li> <li>For those with one or two non-Danish parents place of birth of parents (DK)</li> <li>State in which the place of birth is located at beginning of TB treatment – current borders; Place of birth of mother (only for children &lt;15 years); Place of birth of father (only for children &lt;15 years) (DE)</li> <li>Parental birth country (NO)</li> <li>The patient is considered immigrant if they are born outside Slovenia (SI)</li> <li>No definition available or not reported (CY, ES, HU, LT, LV)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>ISO country codes (BE, FR, IE, MT)</li> <li>Country name (BG, CZ, DE, DK, ES, FI, HU, LT, LV, NL, NO, PL, PT, RO, SE, SI, SK, UK)</li> <li>Born in reporting country Yes/No/Unknown (EE)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Yes/No (IS)</li> </ul> <p><b>Not specified</b> (CY, LU)</p>
<b>Origin</b> Collecting countries: 27 (100%)	<ul style="list-style-type: none"> <li>Defined by citizenship (BE, EL, HU, PL)</li> <li>Defined by place of birth (BG, CY, CZ, DE, DK, EE, ES, FI, FR, IE, IS, LT, LU, LV, MT, NL, NO, PT, RO, SE, SI, SK, UK)</li> <li>Parental place of birth or country is used for children under age 15 (DE, DK, NO)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>Foreign/Native/Unknown (BE, BG, CY, CZ, DE, DK, EE, EL, ES, HU, FI, FR, IE, IS, LT, LU, LV, MT, NL, NO, PL, PT, RO, SE, SI, SK, UK)</li> </ul>



Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Asylum seeker</b>  <b>Collecting countries:</b> 11 (41%)	<ul style="list-style-type: none"> <li>• Status documented through contacts with administration in charge of asylum seekers (BE)</li> <li>• General variable including asylum seekers, refugees and undocumented migrants (BG, DE, IE, NO)</li> <li>• Asylum seeker in the reporting country at TB diagnosis/notification (CZ)</li> <li>• In asylum system, no Danish personal identification number (DK)</li> <li>• Persons which are outside their national borders and have legitimate concerns of being persecuted for reasons of race, religion, and ethnic reasons or membership of a particular social group (SI)</li> <li>• An asylum seeker/refugee &lt; 2.5 years in the Netherlands is a person who wants to apply for asylum in the Netherlands or a person who already has a residence permit to stay and stayed less than 2.5 years in the Netherlands at the time of diagnosis (NL)</li> <li>• Under occupation category None, have sub-option 'asylum seeker' (UK)</li> <li>• No definition available or not reported (SK)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>• Yes, No, Unknown (BE, IE, SI)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>• Circle if yes (CZ)</li> <li>• Yes/No (DE, NO)</li> <li>• Tick the box (UK)</li> <li>• Selected/not selected on the list of risk groups (NL)</li> </ul> <b>Not specified</b> (BG, DK, SK)
<b>Refugee</b>  <b>Collecting countries:</b> 9 (33%)	<ul style="list-style-type: none"> <li>• Refugee at time of notification. Refugee refers to a generic term with no strict definition (BE)</li> <li>• General variable including asylum seekers, refugees and undocumented migrants (DE, DK, IE, NL, NO, SI)</li> <li>• Stay in a camp for refugees (IS)</li> <li>• Persons which are outside their national borders and have legitimate concerns being persecuted for reasons of race, religion, ethnic reasons or membership of a particular social group or certain political views, who cannot adopt or, owing to such concerns are rejected protection in their country; or stateless persons without citizenship, who are located outside the country of former habitual residence as a result specific events and who, owing to such fear not or unwilling to return (SK)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>• Yes/No/Unknown (BE, IE, SI)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>• Yes/No (DE, IS, NO)</li> <li>• Tick the box (SK)</li> <li>• Selected/not selected on the list of risk groups (NL)</li> </ul> <b>Not specified</b> (DK)
<b>Undocumented migrant</b>  <b>Collecting countries:</b> 7 (26%)	<ul style="list-style-type: none"> <li>• Absent in population registry and no indication of valid asylum seeker status (BE)</li> <li>• A person without a legal residence permit to stay in the reporting country at the time of diagnosis (CZ)</li> <li>• General variable including asylum seekers, refugees and undocumented migrants (DE)</li> <li>• A person who, owing to unauthorized entry, breach of a condition of entry, or the expiry of his or her visa, lacks legal status in a transit or host country. The definition covers inter alia those persons who have entered a transit or host country lawfully but have stayed for a longer period than authorized or subsequently taken up unauthorized employment (definition from IOM) (MT)</li> <li>• A person without a legal residence permit to stay in the Netherlands at the time of diagnosis, regardless of the duration of stay (NL)</li> <li>• No definition available or not reported (SI, SK)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>• Yes/No/Unknown (BE)</li> <li>• 1. Citizen of CZ; 2. Citizen of EU/EFTA – short term stay; 3. Citizen of EU/EFTA – temporary or permanent stay; 4. Other foreigner - short term stay; 5. Other foreigner - long term stay or permanent stay; 6. Asylum seeker; 7. Illegal stay (CZ)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>• Yes/No (DE)</li> <li>• Selected/not selected on the list of risk groups (NL)</li> </ul> <b>Not specified</b> (SI, SK, MT)
<b>Internally displaced</b>  <b>Collecting countries:</b> 3 (11%)	<ul style="list-style-type: none"> <li>• Patient who has moved their residence and has been transferred to another registration system, and whose treatment results are unknown (ES)</li> <li>• Resident of long-term care-facility (SI)</li> <li>• No definition available or not reported (SK)</li> </ul>	<b>Binary variable:</b> <ul style="list-style-type: none"> <li>• Yes/No (ES)</li> </ul> <b>Not specified</b> (SI, SK)

Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Years since entered in country</b> Collecting countries: 15 (56%)	<ul style="list-style-type: none"> <li>Data on citizenship from the population registry (through local council's administration) (BE)</li> <li>Date of last entry to Germany (DE)</li> <li>Number of years between entry and notification (DK)</li> <li>Year/date of entry in country (FR, NL)</li> <li>Year of immigration (IS)</li> <li>Years residing in country (NO)</li> <li>Date of entrance for foreign born (PT)</li> <li>Date of arrival in Sweden (SE)</li> <li>Years since entry in the UK (UK)</li> <li>No definition available or not reported (CZ, EE, EL, ES, IE)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>Less 1 year, 1-2 years, 2-5 years, &gt; 5 years. (EE)</li> </ul> <p><b>Date variable:</b></p> <ul style="list-style-type: none"> <li>Date as year (BE, DK, ES, FR, IE, IS)</li> <li>mm/yyyy (CZ)</li> <li>Exact date (DE, NL, PT)</li> </ul> <p><b>Discrete numerical variable:</b></p> <ul style="list-style-type: none"> <li>Number of years between entry and notification (NO)</li> </ul> <p><b>Free text (UK)</b></p> <p><b>Not specified (EL, SE)</b></p>
<b>Ethnic minority</b> Collecting countries: 7 (26%)	<ul style="list-style-type: none"> <li>Roma minority: TB patient who is claiming to be Roma or originating from this ethnic minority (CZ, SK)</li> <li>Ethnicity (coding) as by Estonian Vital registry (EE)</li> <li>Minority not collected but 'Race or Ethnic group' (IE, UK)</li> <li>Ethnic group according to 'The Regulations about Ethnic Groups' (LV)</li> <li>Patients with Romanian citizenship, are born in Romania, but with other nationality (ethnicity) than Romanian (RO)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>Estonian; Russian; Etc. other ethnicity (EE)</li> <li>Black; White; Irish traveler; South Asian descent; East / South East Asian descent; Other (IE)</li> <li>Ethnic groups: Latvians, Russians, Ukrainians, Belarussians, Roma, Poles, etc. (LV)</li> <li>White; Black-Caribbean; Black-African; Black-Other; Indian; Pakistani; Bangladeshi; Chinese; Mixed/other (UK)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Circle if Yes (CZ, SK)</li> </ul> <p><b>Free text (RO)</b></p>
<b>Homeless</b> Collecting countries: 17 (63%)	<ul style="list-style-type: none"> <li>A homeless person is someone with no permanent living place or shelter (BE, CZ, HU, LT, NL, PT, SK)</li> <li>Information captured from civil registry (DK, LU)</li> <li>Collected under 'Living status' as one category (EE, IE)</li> <li>No place to stay, verified by TB nurse (RO)</li> <li>One or more of the following criteria in the last 12 months prior to diagnosis of TB: the patient had no home, did not pay their rent, did not own an apartment or did not live with their family or friends on a permanent basis (SI)</li> <li>Homeless and insecure housing as not having permanent or secure accommodation. (UK)</li> <li>No definition available or not reported (ES, FR, LV)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>Yes/No/Not known (BE, FR)</li> <li>Permanent housing; occasional housing; homeless; migrant (EE)</li> <li>Home (Private / Rented); B&amp;B / hotel; Homeless; Hostel; Prison Institution; Other (IE)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Circle if yes (CZ, LU, RO)</li> <li>Yes/No (ES, LV, PT)</li> <li>Selected/not selected on the list of risk groups (NL)</li> <li>Yes, No, Not known: If yes: Current homelessness (Yes/No); Homelessness in the last five years (Yes/No); Homelessness more than 5 years ago (Yes/No) (UK)</li> </ul> <p><b>Not specified (DK, HU, LT, SI, SK)</b></p>
<b>Orphan</b> Collecting countries: 3 (11%)	<ul style="list-style-type: none"> <li>Child whose parents are dead or have abandoned the child permanently. Can be identified, if child (below 15 years) as nursing home inhabitant (EE)</li> <li>Adopted from abroad (NO)</li> <li>Patients under 18 years that have no place to stay or are institutionalized in social facilities at registration of TB case (RO)</li> </ul>	<p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Tick if appropriate (NO)</li> <li>Orphan, Not Orphan (RO)</li> </ul> <p><b>Free text (EE)</b></p>
<b>Slum dweller</b> Collecting countries: 1 (4%)	<ul style="list-style-type: none"> <li>Person who lives in a slum, inhabitant of Roma settlement (SK)</li> </ul>	<b>Not specified (SK)</b>

Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Urban/rural</b>  <b>Collecting countries:</b> 14 (52%)	<ul style="list-style-type: none"> <li>According to place of residence, status can be derived from address of patient (BE, CZ, EE, LT, LV, PL, SK)</li> <li>In accordance to territorial and administrative planning (BG)</li> <li>Defined by county/community of residence (DE, IS)</li> <li>Obtained from postal code (FR, NL)</li> <li>Different definitions, no clear association with TB; urban: people living in towns over 40000 inhabitants (HU)</li> <li>Can be identified from the address at registration as TB case (from the identification documents, or in case of homeless orphans or slum dweller from the statement of the patient, verified by TB nurses) (RO)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>Urban/rural/no data (BG, LV, PL, RO, SK)</li> <li>Postcode used in analysis to assess rural/urban (FR, NL)</li> <li>8 Regions, 9<sup>th</sup> – abroad, 99 – other (IS)</li> <li>County level information (DE)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Density threshold: dwelling in municipalities &gt;100k inhab vs &lt;100k inhab (BE)</li> <li>Yes/No (HU)</li> </ul> <b>Free text</b> code of municipality (CZ, EE, LT)
<b>Other social determinants</b>	<ul style="list-style-type: none"> <li>Homosexual (CZ)</li> <li>Health insurance available (CZ, NL)</li> <li>Marital status (EE)</li> <li>Type of case finding (EE)</li> <li>Place of infection (ES)</li> <li>TB diagnosed in school (LU)</li> <li>Travel to high TB incidence country (NL)</li> </ul>	<b>Nominal variable:</b> Yes, No, Unknown (CZ) <b>Nominal variable:</b> Yes, No, Unknown (CZ, NL) <b>Nominal variable:</b> Married; cohabitant; divorced; widow(er) – tick appropriate (EE) <b>Nominal variable:</b> Active screening; with symptoms; as a contact of TB case; post mortal – tick appropriate (EE) <b>Nominal variable:</b> Country; Autonomous region; Municipality (ES) <b>Binary variable:</b> Selected/not selected on the list of risk groups (NL) <b>Not specified</b> (LU)
<b>In contact with TB case</b>  <b>Collecting countries:</b> 21 (78%)	<ul style="list-style-type: none"> <li>Contact with TB case in the last 2 years (BE)</li> <li>Reported previous contact with tuberculosis (BG)</li> <li>Known contact with active (pulmonary; PL) TB case (CZ, LT, LV, SE)</li> <li>Known contact with active TB case within 3 (4 years in RO) years (DK, EL)</li> <li><b>Close contact:</b> Those contacts who are living in the same household, regular sexual partners or have a relationship that involves continuous and close contact with the case (more than 6 hours a day). Also children under 5 years old and people with compromised immune system, or when the source of infection is part of a microepidemic, although the duration was less than 6 hours.  <b>Regular close contact:</b> Co-worker or who work in the same school where the case works, friends or relatives who maintain regular relationship with them (less than 6 hours a day) without fulfilling the conditions of a close contact. <b>Casual contact:</b> Those people who have only maintained sporadic connection with the case (ES)</li> <li>Contact of an (index) case (HU, IE)</li> <li>Case included in contact tracing (NO)</li> <li>Co-inhabitants and persons with a cumulative exposure over 8 hours in a closed space with a TB patient (PT)</li> <li>No definition available or not reported (DE, EE, IS, LU, NL, SK, SI). Recorded if case is part of the outbreak (DE)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>Yes/no/no data (BE, EL, IE, SE)</li> <li>Family contact, household, workplace, casual contact other, unknown, no information (several or all categories DK, EE, IS)</li> <li>Recent/In the past/No data (PL)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Yes/No (BG, DE, HU, LT, LU, LV, NL)</li> <li>Tick box if 'Yes' (CZ, ES, NO, PT, SK)</li> </ul> <b>Not specified</b> (SI)

Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Type of housing</b>  <b>Collecting countries:</b> 4 (15%)	<ul style="list-style-type: none"> <li>In congregate setting at the time of notification (FR)</li> <li>No definition available or not reported (CZ, EE, IE)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>Yes/no/no data (FR)</li> <li>Home (Private / Rented), Bed &amp; Breakfast / hotel, Homeless, Hostel, Prison, Institution, Other (IE)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Circle if yes: Permanent housing; occasional housing; homeless; migrant housing, mental institution, old peoples home, sanatorium, hospital (for other disease) (all or several categories CZ, EE)</li> </ul>
<b>Smoking tobacco</b>  <b>Collecting countries:</b> 5 (19%)	<ul style="list-style-type: none"> <li>Smoking at the time of diagnosis, irrespective if regular or occasional smoker (CZ)</li> <li>No definition available or not reported (EE, LT, RO, UK)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>Yes/no/no data (EE, UK, LT)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Circle if Yes (CZ)</li> <li>Smoker/non-smoker (RO)</li> </ul>
<b>Use of alcohol</b>  <b>Collecting countries:</b> 14 (52%)	<ul style="list-style-type: none"> <li>According to 10th revision of International Classification of Diseases (ICD), code F10.2, at the time of diagnosis (CZ, SK)</li> <li>Alcohol abuse (ES) or misuse (IE)</li> <li>Dependent on use of alcohol (HU)</li> <li>Excessive use of alcohol (LV)</li> <li>An alcohol dependent is someone familiar with alcohol abuse (according to the standard of the Dutch General Practitioners association 'Problematisch alcoholgebruik', 2005) at the time of diagnosis (NL)</li> <li>Cage score:             <ul style="list-style-type: none"> <li>Have you ever felt you needed to cut down on your drinking?</li> <li>Have people annoyed you by criticizing your drinking?</li> <li>Have you ever felt guilty about drinking?</li> <li>Have you ever felt you needed a drink first thing in the morning (Eye-opener) to steady your nerves or to get rid of a hangover?</li> </ul> </li> <li>Scores of 2 or more would translate alcohol abuse (PT)</li> <li>The patient is considered alcohol abusive or addicted if he/she has been abusing alcohol or has been addicted to alcohol in the last 12 months prior to diagnosis of TB. Alcohol abuse includes psychological addiction to alcohol and occasional excessive alcohol consumption despite social and occupational problems. Alcohol addiction includes increased tolerance to ethanol and alcohol withdrawal symptoms (SI)</li> <li>Using clinical judgement as a case manager, does alcohol misuse or abuse affect the patient's ability to adhere to the prescribed tuberculosis treatment regimen in the absence of Directly Observed Treatment? Is the patient's ability to self-administer treatment affected by alcohol misuse/abuse? (UK)</li> <li>No definition available or not reported (DK, EE, LT, RO)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>Yes; No; Unknown (EE, UK)</li> <li>Yes; No; Unknown, and if Yes, then:             <ul style="list-style-type: none"> <li>up to 11 standard drinks in a week for women</li> <li>up to 17 standard drinks in a week for men</li> </ul> </li> <li>In Ireland a standard drink has about 10 grams of pure alcohol in it (IE)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Circle if Yes (CZ)</li> <li>Yes, all otherwise considered as No (HU, NL, SK)</li> <li>Yes/No (LV, PT)</li> <li>Alcoholic/non-alcoholic (RO)</li> </ul> <b>Not specified</b> (DK, ES, LT, SI)

Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Use of illicit drugs</b>  <b>Collecting countries: 14 (52%)</b>	<ul style="list-style-type: none"> <li>Use of drugs which are under international control and consumed illicitly according to ICD 10 F11.2, F12.2, F13.2, except F17.2. at the time of diagnosis (CZ)</li> <li>Use or previous use of illicit drugs as reported by doctor (EE)</li> <li>Injecting Drug User (ES)</li> <li>Dependent on use of illicit drugs (HU)</li> <li>A substance-dependent / drug addict is someone who regularly uses hard drugs (incl. methadone and cocaine) which has led to some degree of social derailment at the time of diagnosis (NL)</li> <li>Dependence and deprivation symptoms present – occasional use is excluded (PT)</li> <li>The patient is considered drug abusive or addicted if they have been consuming drugs in the last 12 months prior to diagnosis of TB. Alcohol consumption is excluded from the definition. It is also noted if the patient has been using injecting or non-injecting drugs and if there is no information on drug consumption (SI)</li> <li>Morbid relationship with drugs (SK)</li> <li>Does the patient have a history of problem drug use? Problem drug use is defined as injecting drug use or long duration/ regular use of opiates, cocaine and or amphetamines (UK)</li> <li>No definition available or not reported (DK, IE, LT, LV, RO)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>Yes/No/Unknown (EE, IE)</li> <li>Yes/No, Unknown, if Yes: <ul style="list-style-type: none"> <li>Injectable drugs use: yes or no</li> <li>Inhaled drugs use: yes or no</li> </ul> </li> </ul> <p>Current drug use refers to drug use while in the care of the case manager notifying the case; Drug use in the last 5 years refers to drug use before diagnosis/presentation up to 5 years ago; Drug use more than 5 years ago refers to drug use before diagnosis/presentation more than 5 years ago (UK)</p> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Drug use circle if yes, (CZ, SK)</li> <li>Yes or otherwise consider no (HU, NL)</li> <li>Yes/No (LV, PT, RO)</li> </ul> <b>Not specified (DK, ES, LT, SI)</b>
<b>HIV infection</b>  <b>Collecting countries: 20 (74%)</b>	<ul style="list-style-type: none"> <li>According to European Union case definition 2008 (CY, MT)</li> <li>1993 revision of the European AIDS surveillance case definition (EL)</li> <li>Result of the last HIV test (HU, PT)</li> <li>Positive HIV test at the moment of TB diagnosis or before (RO)</li> <li>Patient is considered HIV positive if they have a positive HIV laboratory test result or has been previously diagnosed with HIV infection or AIDS (SI)</li> <li>No definition available or reported (BE, BG, CZ, DK, EE, ES, IE, IS, LT, LV, NL, NO, SK)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>Yes/No/Not known (BE, EL, IE, IS, MT)</li> <li>Positive/negative/not tested/refused (EE)</li> <li>Positive/negative/not tested/no data (CZ, ES, HU, LV, NL, NO, PT, RO, SK)</li> </ul> <b>Not specified (BG, CY, DK, LT, SI)</b>
<b>Diabetes mellitus</b>  <b>Collecting countries: 15 (56%)</b>	<ul style="list-style-type: none"> <li>ICD 10, E10-14 (EE)</li> <li>WHO definition (EL)</li> <li>Medical history of diabetes mellitus (HU)</li> <li>Based on patient information or on diagnostic tests (PT)</li> <li>Diagnosed with diabetes at the time of diagnosis (SI)</li> <li>Persons with diabetes mellitus which are under control of diabetologist (SK)</li> <li>No definition available or reported (CZ, DK, IE, IS, LT, LV, NL, RO, UK)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>ICD code E10-14 (EE)</li> <li>Yes/No/Not known (IE, UK)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Circle if yes (CZ)</li> <li>Yes, all others considered as No (HU)</li> <li>Yes/No (IS, LV, PT)</li> <li>Diabetes Mellitus selected/ not selected (NL)</li> <li>Patient with diagnosed diabetes/without diagnosed diabetes (RO)</li> </ul> <b>Not specified (DK, EL, LT, SI, SK)</b>
<b>Silicosis – Pneumoconiosis</b>  <b>Collecting countries: 7 (26%)</b>	<ul style="list-style-type: none"> <li>ICD 10 J62 (EE)</li> <li>Based on patient information or on diagnostic tests (PT)</li> <li>No definition available or not reported (CY, CZ, RO, SI, SK)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>ICD 10 codes (EE)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>Circle if Yes (CZ)</li> <li>Patient with diagnosed silicosis/without diagnosed silicosis (RO)</li> </ul> <b>Not specified (CY, PT, SI, SK)</b>

Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Malignancies</b> Collecting countries: 11 (41%)	<ul style="list-style-type: none"> <li>ICD 10, C00-D48 (EE, LV)</li> <li>Based on patient information or on diagnostic tests (PT)</li> <li>No definition available or not reported (CZ, EL, IS, LT, NL, RO, SI, SK)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>ICD 10 code (EE)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Circle if yes (CZ)</li> <li>Yes/No (IS, LV, PT)</li> <li>Malignancy selected/ not (NL)</li> <li>Patient with diagnosed cancer/without diagnosed cancer (RO)</li> </ul> <p><b>Not specified</b> (EL, LT, SI, SK)</p>
<b>Corticosteroid treatment</b> Collecting countries: 8 (30%)	<ul style="list-style-type: none"> <li>Persons treated with corticosteroids according to the medication list, only if systematically administered, at the time of diagnosis (CZ)</li> <li>Systematic glucocorticoids &gt;4 weeks (NL)</li> <li>Persons treated with corticosteroids according to medication list (SK)</li> <li>No definition available or not reported (EE, EL, IS, LV, SI)</li> </ul>	<p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Circle if Yes (CZ, EE)</li> <li>Yes/No (IS, LV)</li> <li>Selected/not selected (NL)</li> </ul> <p><b>Not specified</b> (EL, SI, SK)</p>
<b>Immuno-suppression treatment</b> Collecting countries: 10 (37%)	<ul style="list-style-type: none"> <li>Immunosuppressive treatment as cause of immunosuppression (EL)</li> <li>Other immunosuppressive medication (IE)</li> <li>No definition available or not reported (CZ, DK, EE, FR, IS, NL, SI, UK)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>1. biological treatment with (TNF<math>\alpha</math>) inhibitors; 2. chemotherapy; 3. radiation treatment; 4. corticosteroid treatment; 5. previous treatment with BCG-vaccine; 6. other immunosuppressive treatment; 7. autoimmune disease (EE)</li> <li>Yes; No; Not Known (IE, IS)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Circle if Yes (CZ)</li> <li>Yes/No, if Yes, specify (FR)</li> <li>If yes, select from the following: <ul style="list-style-type: none"> <li>Anti-TNF-Alpha-Treatment</li> <li>Transplantation (UK)</li> <li>Selected /not selected (NL)</li> </ul> </li> </ul> <p><b>Not specified</b> (DK, EL, SI)</p>
<b>Anti tumor necrosis factor (TNF) treatment</b> Collecting countries: 10 (37%)	<ul style="list-style-type: none"> <li>TNF alfa treatment as cause of immune suppression (EL)</li> <li>Persons on TNF<math>\alpha</math> treatment (SK)</li> <li>Treatment with a class of drugs that are used to treat inflammatory conditions such as rheumatoid arthritis (UK)</li> <li>No definition available or not reported (CZ, DK, EE, IE, NL, NO, SI)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>Yes; No; Not Known (IE)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Circle, if yes (CZ, EE)</li> <li>Selected /not selected, if selected which drugs (NL)</li> <li>Select immunosuppression and if yes, select from the list: - Anti-TNF-Alpha-Treatment (UK)</li> </ul> <p><b>Not specified</b> (DK, EL, NO, SI, SK)</p>
<b>Pregnancy</b> Collecting countries: 8 (30%)	<ul style="list-style-type: none"> <li>ICD 10, Z34 (EE)</li> <li>Pregnancy as a cause of immune suppression (EL)</li> <li>No definition available or not reported (CZ, IS, RO, SE, SI, SK)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>ICD 10 code (EE)</li> <li>Yes; No; No data; NA (SE)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Circle if Yes (CZ)</li> <li>Yes/No (IS)</li> <li>Pregnant/Not pregnant (RO)</li> </ul> <p><b>Not specified</b> (EL, SI, SK)</p>
<b>Other causes of immunodeficiency</b> Collecting countries: 10 (37%)	<ul style="list-style-type: none"> <li>Other miseries (DK)</li> <li>ICD-10: Gastrectomy ICD 10: Z 70.3; Chronic renal failure ICD-10: N 18-19; Haemodialysis ICD-10: Z 49; Transplantation ICD-10, Z94-95; Any co-morbidity by ICD-10 A00-Z99 other than TB diagnosis (EE)</li> <li>Chronic renal failure; haemodialysis; other (EL)</li> <li>Immuno suppressive illness (IE)</li> <li>No definition available or not reported (IS, NL, NO, RO, SI, UK)</li> </ul>	<p><b>Nominal variable:</b></p> <ul style="list-style-type: none"> <li>ICD codes (EE)</li> <li>Yes; no; unknown (EL, IE)</li> </ul> <p><b>Binary variable:</b></p> <ul style="list-style-type: none"> <li>Yes/No (IS)</li> <li>Select other cause reduced immune status and specify (NL)</li> </ul> <p><b>Free text</b> to allow reporting if the patient has any other immunosuppression (NO, UK)</p> <p><b>Not specified</b> (DK, RO, SI)</p>

Concept Collecting countries: n (%)	Definitions used (country)	Type of variable and response options# (country)
<b>Other medical conditions:</b>  <b>Collecting countries: 5 (19%)</b>	<ul style="list-style-type: none"> <li>• BCG vaccination (CZ)</li> <li>• Other miseries (DK)</li> <li>• Previously treated for LTBI (HU)</li> <li>• Any other risk factors not listed as specific variables can be recorded (IE)</li> <li>• Other co-morbidities collected: Hepatic disease; Sarcoidosis; Interstitial lung disease; Articular inflammatory disease; Cancer; Lymphoma or other lymphoproliferative diseases, COPD (PT)</li> </ul>	<b>Nominal variable:</b> <ul style="list-style-type: none"> <li>• Not vaccinated; Vaccinated; Unknown; Year of vaccination (CZ)</li> </ul> <b>Binary variable:</b> <ul style="list-style-type: none"> <li>• Yes – all others considered as 'No' (HU)</li> </ul> <b>Free text (IE)</b>  <b>Not specified (DK, PT)</b>

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