

GUIDE FOR CIVIL SOCIETY ORGANISATIONS
AND ORGANISATIONS OF THE COMMUNITIES
AFFECTED BY TUBERCULOSIS



COLLECTING DATA FOR CALCULATION OF THE FOUR INDICATORS OF THE WHO REGIONAL OFFICE FOR EUROPE

ON CONSISTENT MEANINGFUL ENGAGEMENT
OF THE COMMUNITIES AND CIVIL SOCIETIES
IN THE PROGRAMMES UNDER
THE NEW TUBERCULOSIS ACTION PLAN
FOR THE WHO EUROPEAN REGION
2023-2030



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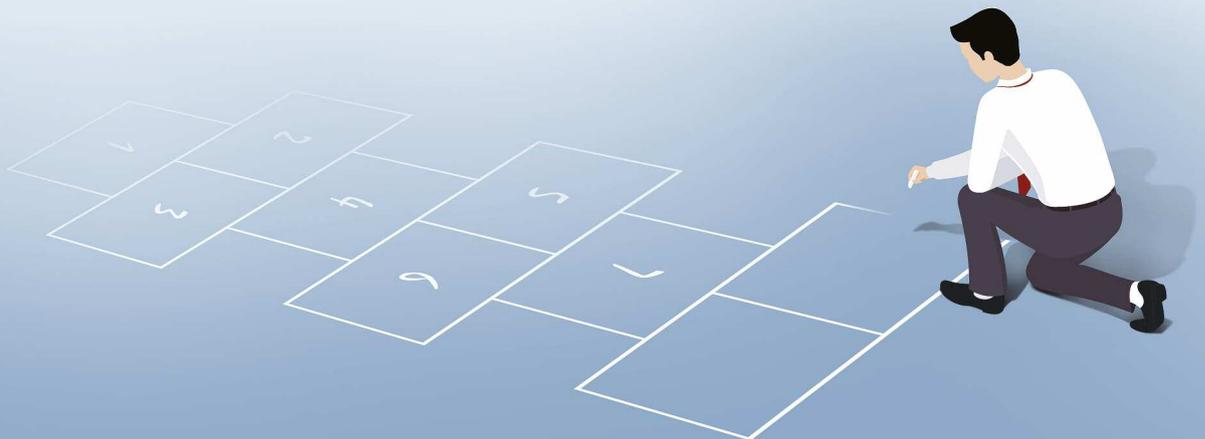
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Acronyms

CMM	Country Coordination Mechanism
CSO	Civil society organisation
ETBR	Electronic TB Registry
GF	Global Fund
NTP	National TB Control Programme
TB	Tuberculosis
WHO	World Health Organisation



ABOUT THIS DOCUMENT

Every year, World Health Organisation (WHO) collects data from different countries in order to track the progress in fighting tuberculosis (TB). For this purpose, they use WHO-provided the global TB database that has a standard format for all countries. The global data collection form includes a chapter on indicators representing meaningful involvement of civil society organisations and TB-affected communities (hereafter - CSOs and the communities respectively) in the fight against TB.

The monitoring and evaluation framework of the Tuberculosis Action Plan for the WHO European Region 2023–2030 includes four new indicators reflecting consistent meaningful engagement of the communities and civil society organisations in the fight against TB in the region. The WHO Regional Office for Europe plans reporting on the progress on the new indicators in the next regional report to be published in March 2024.

This Guide is based on the [Algorithm of data collection for the four WHO Europe indicators, to measure the level of engagement of communities and civil society organisations in the National TB response included in the new TB Action Plan for the WHO European Region 2023–2030](#) (hereafter referred to as the Algorithm). The Algorithm was developed in 2022 by the TB Europe Coalition together with the WHO Regional Office for Europe.

Purpose: A simplified presentation of the data collection process with more detailed explanation of all stages, and process visualisation. Besides, the Guide offers practical recommendations and advice on implementation of the Algorithm based on the results of the pilot data collection in Kazakhstan, Kyrgyzstan and Ukraine in 2021 and 2022. Thus, the Guide aims at improving understanding and helps CSOs/ community and other stakeholders to collect data on the new indicators for WHO Regional Office for Europe in a more effective manner.

THE INDICATORS OF THE WHO REGIONAL OFFICE FOR EUROPE REFLECTING MEANINGFUL ENGAGEMENT OF CSOS IN TB PROGRAMMES:



1

Number of Member States with adopted standards and operational procedures for CSOs in the provision of psychosocial support services to ensure treatment adherence for people with TB

2

Number of Member States with adopted procedures of subcontracting mechanisms under the state funds or other relevant funding mechanisms for CSOs in the provision of psychosocial support and active case-finding services for people with TB

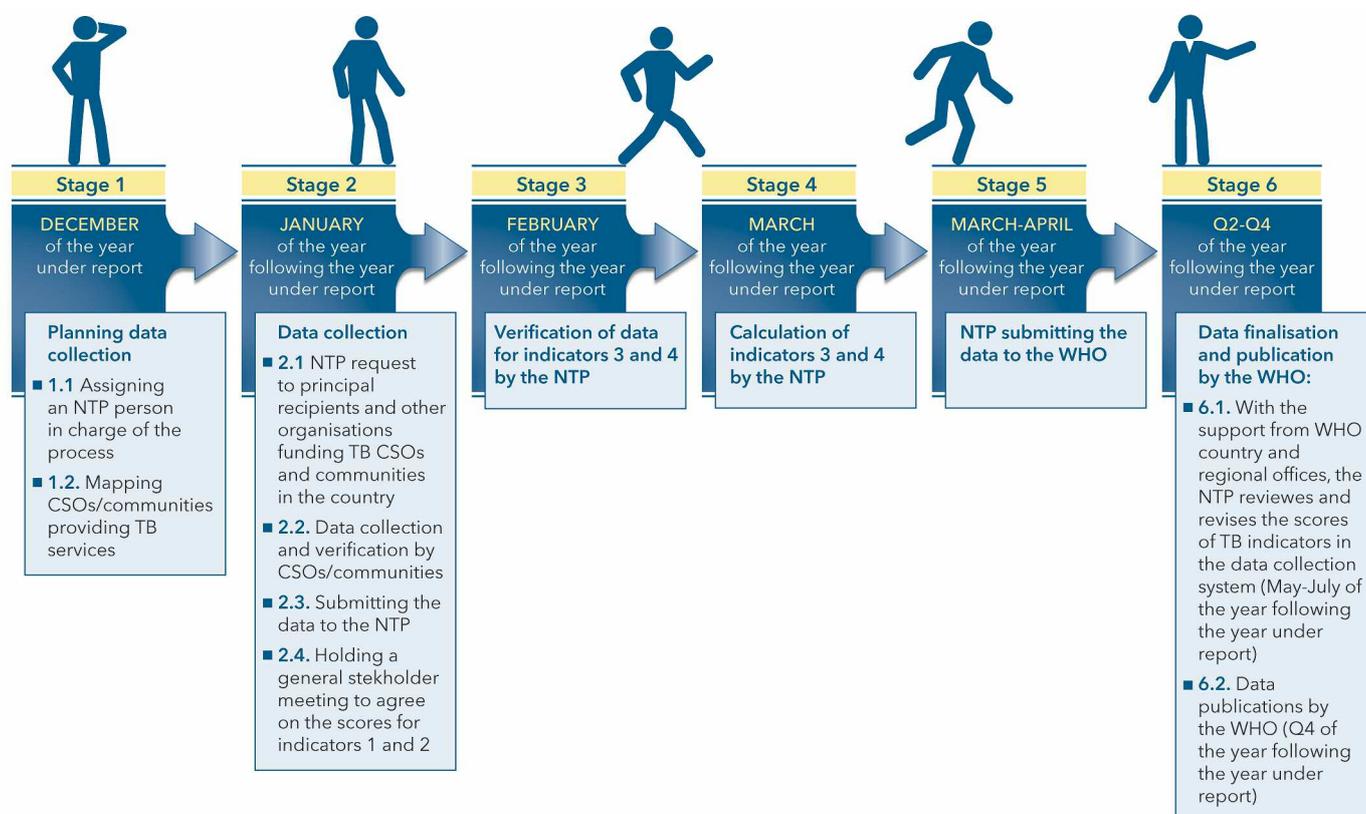
3

Proportion of people with TB found through active case-finding activities implemented through CSOs

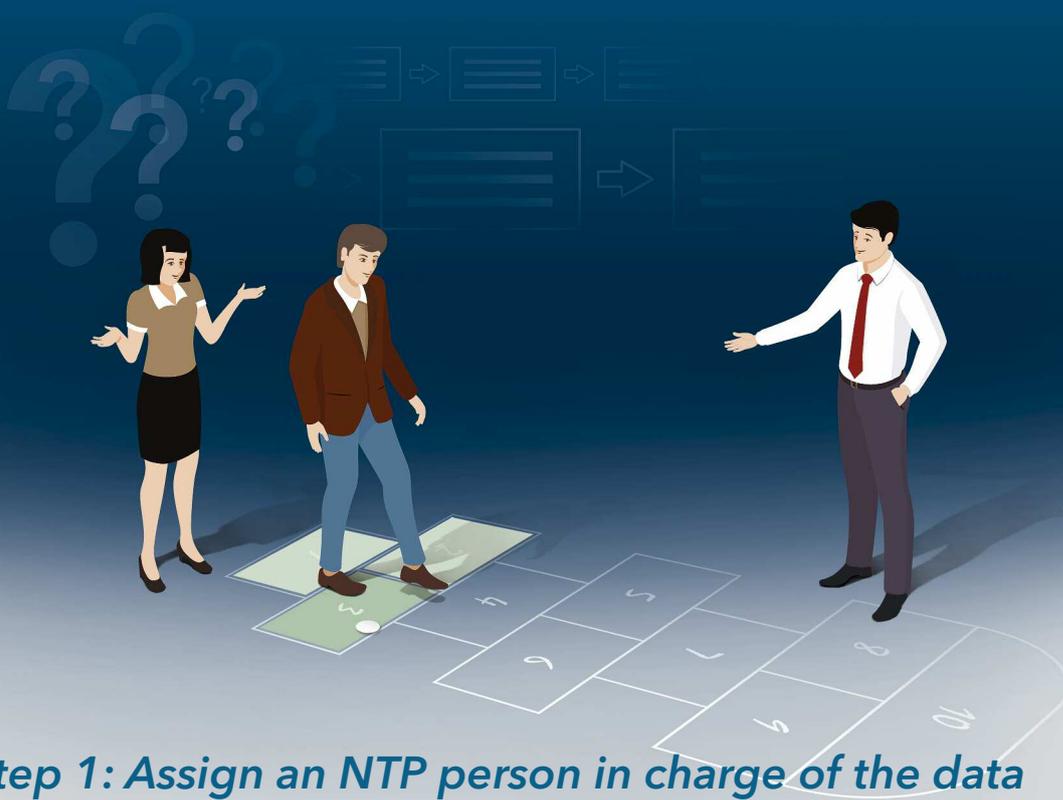
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Proportion of people with TB who started TB treatment and who received any form of treatment adherence support from CSOs (including psychosocial support)

DATA COLLECTION PROCESS DIAGRAM



STAGE 1: PLANNING NATIONAL DATA COLLECTION FOR THE FOUR INDICATORS



Step 1: Assign an NTP person in charge of the data collection for the four indicators and of communications with the CSOs/community

The National TB Programme Coordinator is the key manager of the data on the four indicators. They ensure national data collection, verification, analysis and aggregation for the indicators and annually submit a summary on the indicators to the WHO.

Step 2: Mapping the CSOs/community providing TB services in the country in the period under report

The data will be complete and of good quality if all the CSOs/community providing TB services, regardless of the sources of their funding, are meaningfully involved in the process. That is why at the stage of *Planning* the most important task is to map all the CSOs/communities providing TB services in the country and to determine their interactions and accountabilities.

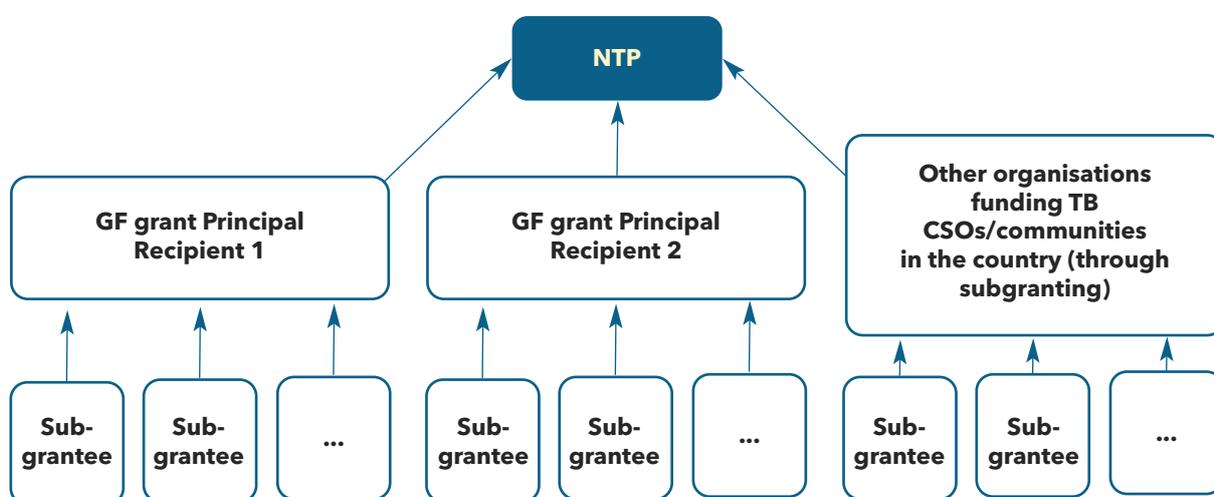
Mapping timeframe: December of the year under report

Responsible persons: The mapping needs to be initiated by the NTP by sending requests to the CCM, principal recipients of GF grant and other organisations funding CSOs/communities implementing TB-related projects (through subgranting).

The mapping needs to:

- create a full list of CSOs/communities having conducted active TB case finding or provided any treatment adherence support (including psychosocial support) to people with TB in the period under report;
- identify the schemes of their vertical interaction and accountability to ensure correct data collection for indicators 3 and 4 and verification thereof.

Example:



STAGE 2. DATA COLLECTION

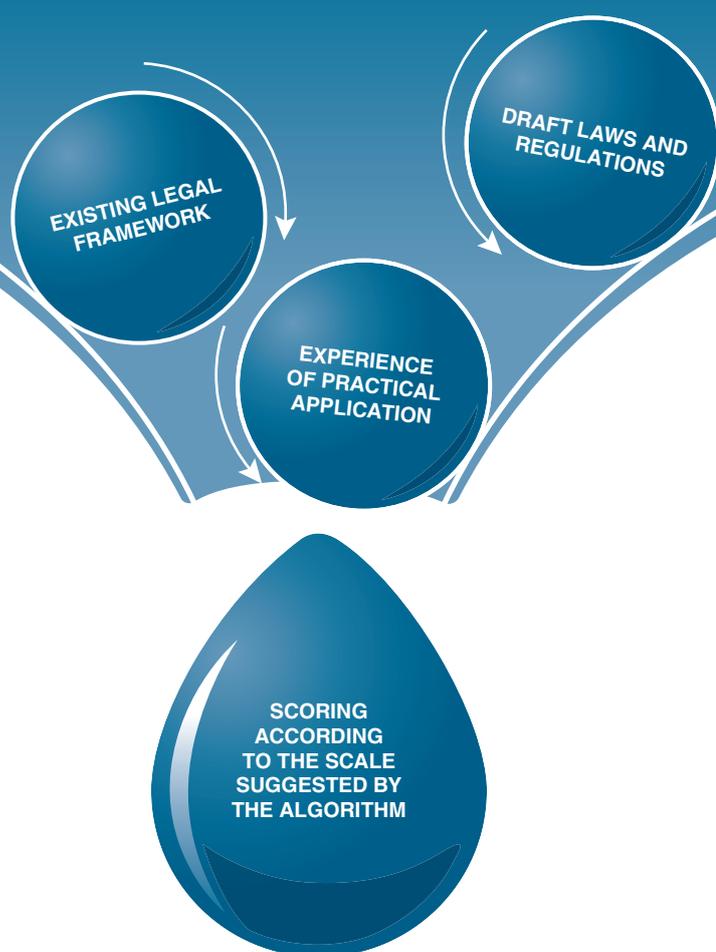
Collecting data for indicators 1 and 2

Indicators 1 and 2 are quality ones. NTP and CSOs/communities collect data on these indicators by analysing the existing national legal framework concerning engagement of CSOs/communities, draft laws and regulations and the practice of their actual application.

E.g., to produce a score for indicator 2, i.e. to determine whether the country has adopted legal procedures of subcontracting mechanisms under the state funds or other relevant funding mechanisms for CSOs in the provision of psychosocial support and active case finding services for people with TB, it is recommended to review the provisions of laws, orders and decrees of respective ministries and agencies concerning mechanisms of operation, standards, rules of forming, monitoring and evaluation of social contracting.

It is recommended to provide a list of existing or draft laws and regulations and their provisions and to describe the experience of their actual application in the country: implementation of pilot projects, scope of funding already provided or to be provided by the state to implement the social contracting in the country, etc. as a justification of the particular score.

The score for the indicators is determined through a collective decision of a broad circle of stakeholders, including NTP and CSOs/communities, following discussions and consultations.



It is desirable that such a collective decision about the score was noted in the Minutes of a general meeting involving all the stakeholders. The agreed score needs a justification, i.e. a list of laws and regulations adopted (or drafted) on the national level and analysis of their implementation and practical application: there needs to be a description of which of these documents are already applied in the country and to what extent, and which not, with a list of present barriers and planned activities to eliminate those, if any.

Responsible persons: The meeting and joint decision may be initiated (offline or online) by the NTP or by the principal recipients of the GF grant or other organisations funding TB CSOs/communities in the country (through subgranting).

Timeframe: The Minutes with a joint decision about scores for Indicators 1 and 2 and their justifications need to be approved by all the stakeholders, including NTP, by 31 January of the year following the year under report.

Collecting data for indicators 3 and 4

Step 1: In the first ten days of January of the year following the year under report, the, **NTP shall submit a request to the principal recipients of the GF grant and other organisations funding TB CSOs/communities in the country (through subgranting), as well as to respective healthcare facilities**, to provide the data required to calculate the numerators for indicator 3 (the number of people with TB from key affected populations referred by community volunteers/NGOs for TB diagnosis and treatment in the period under report) and indicator 4 (the number of people with TB who started TB treatment and who received any form of treatment adherence support from CSOs in the period under report).

Step 2: GF grant PRs and other organisations funding TB CSOs/communities in the country (through subgranting), **shall collect the data to calculate numerators for indicators 3 and 4** from their subgrantees as per the previously identified scheme of their vertical interaction and accountability used to ensure that an organisation that receives subgrants from several PRs does not submit the data to them all so they are included in the calculation multiple times.

No new reporting forms need to be specially produced for collecting these data. CSOs collect the data using any of the existing systems for accounting the progress under programme indicators they have.

Step 3: GF grant PRs and other organisations funding projects of TB CSOs and communities, **shall verify the data received** from their respective subgrantees.

Step 4: GF grant PRs and other organisations funding TB CSOs/communities in the country (through subgranting) as well as applicable healthcare facilities **shall submit the data to the NTP by 31 January of the year following the year under report.**

Collecting the data for denominators of indicator 3 (total number of people diagnosed with TB in the country in the same period under report) and indicator 4 (total number of people with TB having started treatment during the same period in the country) is done by the NTP as a part of routine monitoring.

Depending on the needs of the country, the NTP may collect data for calculation of indicators 3 and 4 from the CSOs/communities twice a year:

- midterm report as of July 1 for the first six months (it needs to be submitted by July 31) used to evaluate progress towards the indicators and timely respond to actual and potential risks;
- annual report as of December 31 (to be submitted by January 31) used by the NTP to form consolidated information on progress towards the indicators for the WHO.

STAGE 3: DATA VERIFICATION BY THE NTP

The NTP shall verify the data received from healthcare facilities and CSOs/communities to ensure there are no duplications in reporting on people with TB in the aggregated national data if the same person with TB received services from multiple CSOs/communities within one period under report.

STAGE 4: CALCULATING INDICATORS 3 AND 4

NTP shall calculate indicators 3 and 4 based on the verified data received from CSOs/communities and healthcare facilities to evaluate the progress towards the indicators achieved by the country and to timely respond to actual and potential risks.

Let us consider for example calculation of indicator 3 for 2022:

Numerator: 620 people with TB from key populations were diagnosed with TB thanks to CSO activities in the country in 2022

Denominator: 7032 is the total number of people diagnosed with TB in the country in 2022

Calculation of indicator 3:

$$\frac{(620 \times 100)}{7032} = 8,8\%$$

Therefore, the proportion of people with TB found through active case finding activities implemented through CSOs in 2022 was 8.8%



STAGE 5: SUBMITTING THE DATA TO THE WHO

As of the time of writing of this Guide, the WHO Regional Office for Europe had not yet produced special reporting forms for submitting the data under the four indicators used to measure the level of engagement of communities and civil society organisations in the National TB response included in the new TB Action Plan for the WHO European Region 2023-2030.

In 2023, the WHO used the global TB database with the standard format for all countries to collect the data on quantitative indicators 3 and 4. The global TB database includes a chapter on indicators reflecting meaningful engagement of CSOs/communities in TB response.

- ◆ Numerator of indicator 3 in the form of the WHO global TB database corresponds to indicator CE.6 'Number of new and relapse cases referred by community health workers / community volunteers* among the cases in CE.5').

Referrals by community health workers / community volunteers in 2022

(if yes to CE.3)

CE.4	Number of BMUs with data on referrals by community health workers / community volunteers in 2022	bmu_ref_data
CE.5	Total number of new and relapse TB cases notified in the BMUs of CE.4 in 2022	notified_ref
CE.6	Number of new and relapse cases referred by community health workers / community volunteers* among the cases in CE.5	notified_ref_community

- ◆ Numerator of indicator 4 corresponds to indicator CE.9 'Total number of patients who started TB treatment in 2021 and who received any form of treatment adherence support from community health workers / community volunteers* in the BMUs of CE.7'.

Treatment adherence support from community health workers / community volunteers for patients who started TB treatment in 2021

(if yes to CE.3)

CE.7	Number of BMUs with data on community treatment adherence support	bmu_rxsupport_data
CE.8	Total number of patients who started TB treatment in the BMUs of CE.7 in 2021	bmu_rxsupport_data_coh
CE.9	Total number of patients who started TB treatment in 2021 and who received any form of treatment adherence support from community health workers / community volunteers* in the BMUs of CE.7	rxsupport_community_coh
CE.10	Number of TB cases who were cured or who completed treatment among the cases in CE.9	rxsupport_community_succ

* Include contributions from all community health workers / community volunteers including those supervised by the government, non-governmental organizations, community-based organizations, faith-based organizations and patient-based organizations.

National NTPs submit the data for calculation of indicators 3 and 4 **in April of the year following the year under report** by completing the respective chapter in the forms of the WHO global TB database the WHO grants NTPs access to normally in March of the year following the year under report.

As of the time of writing of this Guide, the WHO global TB database contained no chapter for submitting the data on indicators 1 and 2. However, the WHO plans adding indicators 1 and 2 to the global data collection system in 2024 in the form for the WHO Europe Region. The WHO Regional Office for Europe plans reporting on the progress towards the new indicators in its next regional report to be published in March 2024. Therefore, it is recommended for NTPs of the countries of the region to submit the scores on indicators 1 and 2 to the WHO Regional Office for Europe with justification to be later considered by the Office to calculate indicators 1 and 2 and used for the Regional Report.

STAGE 6: DATA FINALISATION AND PUBLICATION BY THE WHO

Following the analysis of the received data, the WHO may ask the NTP for clarifications. As a rule, in the May of a year following the year under report, the NTP should provide the WHO with exhaustive answers and comments.

Then the WHO shall produce draft country profiles and, in June and July, the NTP with the support of country and regional offices of the WHO can check the scores of TB indicators in the data collection system before they are included in the Global TB Report that is normally published in the last quarter of the year following the year under report.

At this stage, the country profiles in the Global TB Report may not include the data on the four indicators of the WHO Regional Office for Europe measuring consistent involvement of CSOs and communities. The WHO Regional Office for Europe plans reporting on the progress regarding these four indicators included in the regional Action Plan 2023-2030 in the next Regional Report to be published in March 2024.

LESSONS LEARNT AND SUGGESTED SOLUTIONS



❓ During the pilot data collection not all the CSOs/communities were willing to share with the NTP the information about TB cases they had found or about the people receiving treatment adherence support services referring to directives for non-disclosure of client information. They submitted coded data, and the lack of personal data (or a unified coding system) makes NTP verification impossible.

✅ Transfer of verifiable data to the NTP became possible in some cases after signing confidentiality agreements. To simplify data verification by the NTP, a national unified coding for people with TB need to be used by all TB-service CSOs/communities regardless of their sources of funding, as well as the NTP and corresponding healthcare facilities.

❓ Most healthcare facilities do not register information that a particular person with TB was found by or receives services from a CSO/community, which also makes NTP verification of the data impossible. At the same time, even if a CSO submits information about a TB case to the NTP and the NTP can find this person in the e-health system, there is no way to check whether this person was brought in for diagnosis by the CSO because healthcare facilities do not register that fact.

✅ The country e-health system should include the data about the CSOs finding TB cases or providing any forms of treatment adherence support. This information may be entered in the electronic record of the patient provided the country has a system of e-health record storage and management.

✅ The new WHO indicators should be included in the national monitoring and evaluation plans, and the process of collecting the data for these indicators should be included in routine monitoring.

*** In the context of the suggested solution, it is important to present the experience and achievements of Kyrgyzstan with regard to expanding the functionality of the Electronic TB Registry (ETBR) following a successful pilot data collection. Kyrgyzstan State Healthcare Social Contracting Programme enabled adding a new element in the ETBR structure following the pilot data collection project: 'Interaction with CSOs/NGOs' subsection was added to the existing 'Records' section. This innovative approach allows furnishing the registry with information about the work of CSOs/communities actively involved in TB response, the services they provide and the modality of services provision (one-off or regular) indicating the date for accounting of the activities. This change facilitates both improvement of mechanisms of monitoring and evaluation of CSO/community activities in the context of the four indicators suggested by the WHO Regional Office for Europe and strengthening cooperation between healthcare institutions and civil society, thus increasing the effect of joint efforts in TB response.

? During calculation of the indicator 4 during the pilot collection of data for 2021 and 2022 it was unclear what period the people who started treatment in 2021 but began receiving treatment adherence support only in 2022 should be assigned to.

✓ While this report was being written, the WHO Regional Office for Europe explained that if a person started treatment in 2021 but did not receive any adherence support services until 2022, they should be included in the reporting for 2022. It is important that the new WHO reporting forms account for such situations to avoid missing people who started treatment in one period under report but began receiving treatment adherence support services in another period.

? The definitions of the numerator for indicator 3 in the M&E Framework of the WHO TB Action Plan for the European Region for 2023-2030 and in the Global Data Collection Form (CE.6) are somewhat different. During the pilot data collection, it was unclear whether the numerator of indicator 3 should include only people with TB from the key populations or all TB cases found by CSOs in the period under report.

✓ Representatives of the WHO Regional Office for Europe explained that the numerator of indicator 3 should include all people CSOs/communities interact with presuming that they mostly work with the key populations regardless of what national definitions of the key populations are applied.

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