WHO guidance on TB surveillance (2024)

Chapter 5: Core data items to collect

TB Monitoring, Evaluation and Strategic Information Unit
Global Tuberculosis Programme

World Health Organization

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Consolidated guidance on tuberculosis data generation and use. Module 1:

Tuberculosis surveillance

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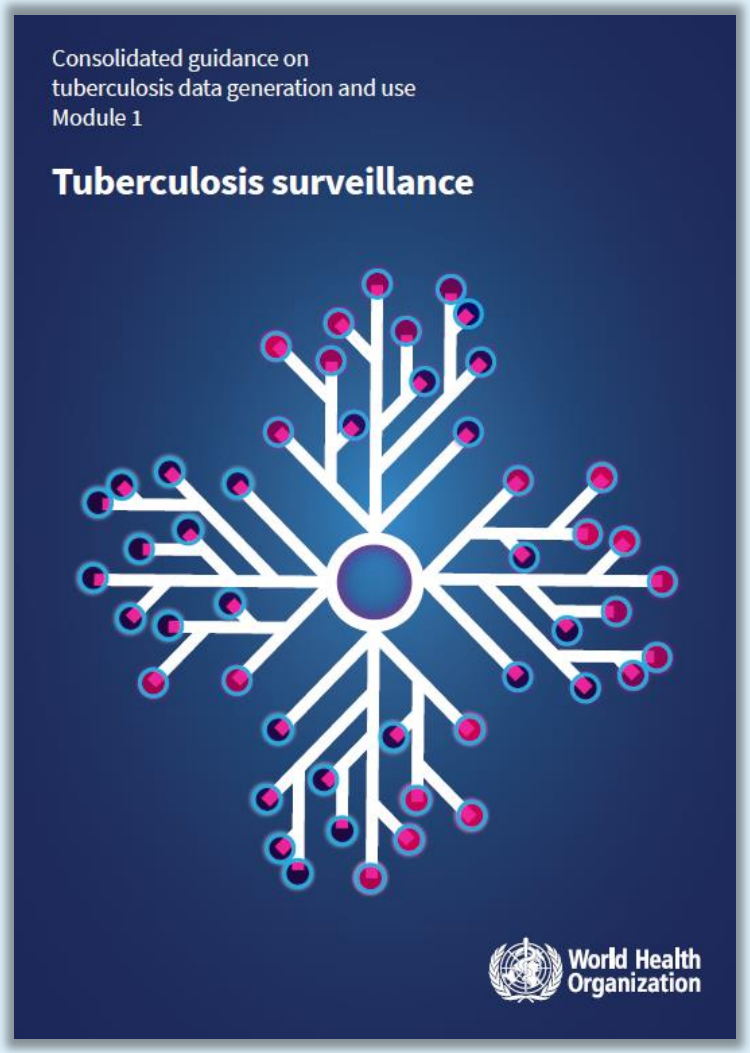

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5.1 Data items to record for every person with TB in all countries, irrespective of whether a case-based digital or paper-based aggregated surveillance system is in place

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Data items to record for every person with TB, all countries

Section 5.1 provides detailed specifications of how each of the data items required for the core set of indicators that are applicable to all countries can be named, categorized, coded and recorded in either a digital or paper-based system.

The data items presented in Section 5.1 relate to the core indicators listed in Table 4.2 (for quarterly reporting) and Table 4.6 (for annual reporting).

Data items to record for every person with TB, all countries

Table 5.1 lists the data items that need to be recorded for every person with TB disease so that the core set of TB indicators can be calculated, including recommended short names, a variable or "code" name, possible valid values and a fuller description of the item.

Data item name	Possible values
Health facility ID	(Unique ID for facility that recorded the notification)
Notification details of the person with TB disease	
Person ID	(Unique ID of the person moving through the health system)
Registration date	(Valid date)
Age	(Years)
Sex	Female | Male | Intersex | Unknown/unspecified
Treatment history	New | Recurrent | Re-registered | Undocumented history of TB treatment
Anatomical site of TB disease	Pulmonary | Extrapulmonary
Method of diagnosis	Bacteriologically confirmed | Clinically diagnosed
HIV status	HIV-positive | HIV-negative | HIV status unknown
Date started on antiretroviral therapy	(Valid date)

Data items to record for every person with TB, all countries

Table 5.1 (continued) lists the data items that need to be recorded for every person with TB disease so that the core set of TB indicators can be calculated, including recommended short names, a variable or "code" name, possible valid values and a fuller description of the item.

Data item name	Possible values
Notification details of the person with TB disease (continued)	
Rifampicin susceptibility test result	Susceptible | Resistant | Unknown
Date rifampicin susceptibility status determined	(Valid date)
Isoniazid susceptibility test result	Susceptible | Resistant | Unknown
Date isoniazid susceptibility status determined	(Valid date)
Fluoroquinolone susceptibility test result	Susceptible | Resistant | Unknown
Date fluoroquinolone susceptibility status determined	(Valid date)
Bedaquiline susceptibility test result	Susceptible | Resistant | Unknown
Date bedaquiline susceptibility status determined	(Valid date)
Linezolid susceptibility test result	Susceptible | Resistant | Unknown
Date linezolid susceptibility status determined	(Valid date)

Data items to record for every person with TB, all countries

Table 5.1 (continued) lists the data items that need to be recorded for every person with TB disease so that the core set of TB indicators can be calculated, including recommended short names, a variable or "code" name, possible valid values and a fuller description of the item.

Data item name	Possible values
Eligibility for TB treatment	
TB treatment regimen type eligibility	Regimen for TB not resistant to rifampicin | Regimen for TB resistant to rifampicin*
Result of TB treatment	
Was treatment started?	Yes | No
Date treatment started	(Valid date)
Treatment duration of chosen regimen	(Number of months)
Reason treatment was not started	Died | Lost to follow-up
Result of TB treatment	
Treatent outcome	Cured | Completed treatment | Failed | Died | Lost to follow-up | Not evaluated
Date outcome assigned	(Valid date)

*There is a need to distinguish between treatment based on fluroquinolone resistance. Regimen for rifampicin-resistant TB should be further split into 1) regimen for TB that is resistant to rifampicin, but not resistant to fluoroquinolones; and 2) regimen for TB that is resistant to rifampicin and also resistant to fluoroquinolones.

5.2 Data items required for five additional indicators recommended for countries with a case-based digital surveillance system

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Data items for five additional indicators for case-based digital systems

Section 5.2 provides detailed specifications of how each of the data items required for the five additional indicators that are recommended in countries with a case-based digital surveillance system can be named, categorized, coded and recorded in either a digital or paper-based system.

The data items presented in Section 5.2 relate to the five additional indicators listed in Table 4.4 (for quarterly reporting) and duplicated for ease of reference in Table 4.7 (for annual reporting).

Data items for five additional indicators for case-based digital systems

Table 5.2 lists the data items that need to be recorded for every person with presumptive TB to calculate two indicators for people with presumptive TB. **Table 5.3** lists the data items that need to be recorded for every person diagnosed with TB to calculate the coverage of rapid testing for initial diagnosis. Both tables include recommended short names, a variable or "code" name, possible valid values and a fuller description of the item.

Data item name	Possible values
Presumptive TB	
WHO recommended rapid diagnostic test result	Test result positive | Test result negative | Test result unknown or not done
Notification details of the person with TB disease	
Use of a WHO-recommended rapid diagnostic as initial test	Yes | No

Data items for five additional indicators for case-based digital systems

Table 5.4 lists the data items that need to be recorded for household contacts to calculate indicators related to contact investigation coverage and provision of TB preventive treatment, including recommended short names, a variable or "code" name, possible valid values and a fuller description of the item.

Data item name	Possible values
Household contacts	
Index case ID	(Unique ID of index case)
Household contact ID	(Unique ID of household contact)
Age	(Years)
Has the person been screened for TB disease?	Yes | No
Date screened for TB	(Valid date)
Is the person eligible for TB preventive treatment according to national guidelines?	Yes | No
TB preventive treatment started?	Yes | No
Date started TB preventive treatment	(Valid date)
Completion of TB preventive treatment	Yes | No

5.3 Examples of data items required for additional disaggregations of the number of people notified with a new episode of TB disease, which can be considered in countries with a case-based digital surveillance system

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Data items for optional disaggregations for case-based digital systems

Section 5.3 provides some examples of the data items that would be required for the additional disaggregations of notification data, which can be considered in countries with a case-based digital surveillance system, and how these example data items can be named, categorized, coded and recorded.

The data items presented in Section 5.3 relate to the additional disaggregations presented in Table 4.5 (for quarterly reporting) and duplicated for ease of reference in table Table 4.8 (for annual reporting). These disaggregations are for a) sector of the health system; b) level of the health system; c) country of origin; d) ethnic group; e) risk factor; f) source of referral.

The collection of these additional data items for additional disaggregations of notification data should only be done if there is capacity to record, analyse and use the additional data, or this capacity can be created.

Data items for optional disaggregations for case-based digital systems

Table 5.5 lists examples of data items that would be required for additional (optional) disaggregations of data for people diagnosed with TB, including recommended short names, a variable or "code" name, possible valid values and a fuller description of the item. The table does not provide an example for ethnic group.

Data item name	Possible values
Sector of the health care facility (health care provider)	Public | Private not-for-profit | Private for-profit
Level of the health care facility	Primary | Secondary | Tertiary
Diabetes screening test result*	Diabetic | Not diabetic | Unknown
Source of referral	Community | Self-referral | Provider
Country of birth/origin	Native | Other

*Diabetes is one example of a risk factor for TB disease for which it may be useful to collect data. Other comorbidities or socioeconomic factors could be relevant (e.g. smoking, undernutrition, alcohol use disorders) depending on the country context.

5.4 Specific issues with patient and data flow that need attention

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Specific issues with patient and data flow that need attention

Section 5.4 provides guidance on how to handle three specific issues that require attention during data collection:

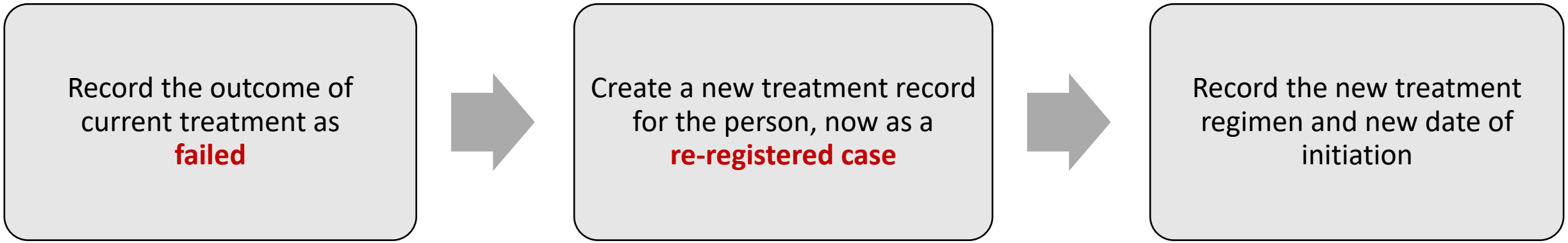
1. How to record and report data for a patient whose treatment regimen changes
2. How to record and report data for a patient who transfers to the care of a different health facility during their TB treatment
3. How to de-notify case of TB

What to do when a treatment regimen is changed

Section 5.4.1 provides guidance of what to do when a patient's TB treatment regimen is changed.

TB surveillance systems need to be able to record and monitor when a person with TB disease changes treatment regimen (e.g., patient is not responding to treatment, drug resistance is uncovered, or patient is experience adverse events).

How to record a change in treatment regimen:



Illustrative scenarios related to the reporting of people diagnosed with TB, when their treatment regimen is changed are provided in Web Annex E.

What to do when a patient transfers to another facility

Section 5.4.2 provides guidance of what to do when a patient transfers to another facility. Data items required for tracking transfers are listed in **Table 5.6** (for the source facility) and **Table 5.7** (for the destination facility), including recommended short names, a variable or "code" name, possible valid values and a fuller description of the item.

Data item name	Possible values
Source facility	
Transfer out	Yes*
Transfer date	(Valid date)
Destination facility ID	(Unique ID of the destination facility)
Destination facility	
Transfer in	Yes*
Transfer date	(Valid date)
Source facility ID	(Unique ID of the source facility)

*The destination facility must confirm with the source facility that the patient has been received. When a national case-based digital system is in place, the treatment record can be re-allocated to the destination facility, along with an audit trail of the re-allocation.

Web Annex D shows how transfers can be accounted for in quarterly and annual reporting forms.

What to do when a patient transfers to another facility

Section 5.4.2 provides guidance of what to do when a patient transfers to another facility.

How to record treatment outcomes when a patient transfers to another facility:

This edition of WHO guidance of TB surveillance recommends that the responsibility for reporting the notification remains with the source facility, but the responsibility for reporting the final treatment outcomes is shifted to the destination facility.

Old:

Treatment outcomes are recorded and reported by the facility where the patient started treatment.

New:

Treatment outcomes are recorded and reported by the facility where the patient last received treatment.

What to do when a case is de-notified

Section 5.4.3 provides guidance of what to do when a case needs to be de-notified. Data items related to case denotification are listed in **Table 5.8**, including recommended short names, a variable or "code" name, possible valid values and a fuller description of the item.

Reasons for needing to de-notify a case:

- Multiple records exist for the same notification
- The person was found not to have TB

Data item name	Possible values
De-notify case record	Yes
Reason de-notified	Duplicate record | Not TB

How to de-notify a case, depending on the type of surveillance system in place:

- Paper-based TB register: cross the record out so that it is not included in any aggregate report. If a report was already sent, then the higher level will need to be informed.
- Case-based digital system: complete the variables "De-notify case record" and "Reason de-notified" so that the record will automatically be excluded from any aggregate report. Recording denotification is more transparent than physically deleting a record.

5.5 Compiling and reporting aggregated data

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Compiling and reporting aggregated data

Section 5.5 provides guidance on how to calculate and report aggregated totals.

All health facilities that provide TB care services, including public and private hospitals or health centres, general practitioners and prisons, should report into the national TB surveillance system.

Totals are used to gauge the level of disease activity, and hence resource needs, in each geographical area.

- In paper-based systems, the numbers are manually aggregated at individual health facilities, then further aggregated up an administrative hierarchy towards the national level.
- In case-based digital systems, the aggregated totals can be calculated automatically from the individual records held in the system.

More details can be found in Web Annex D, which includes templates for manual or paper-based reporting of aggregate data on a quarterly and annual basis, with a detailed explanation and formulae to calculate the aggregate totals.

For further information or in case of any questions, contact:

tbdata@who.int

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Links to the guidance on TB surveillance

Consolidated guidance on tuberculosis data generation and use. Module 1: Tuberculosis surveillance
https://iris.who.int/handle/10665/376612

Web annex A: Commonly observed problems and associated solutions.
https://iris.who.int/handle/10665/376481.

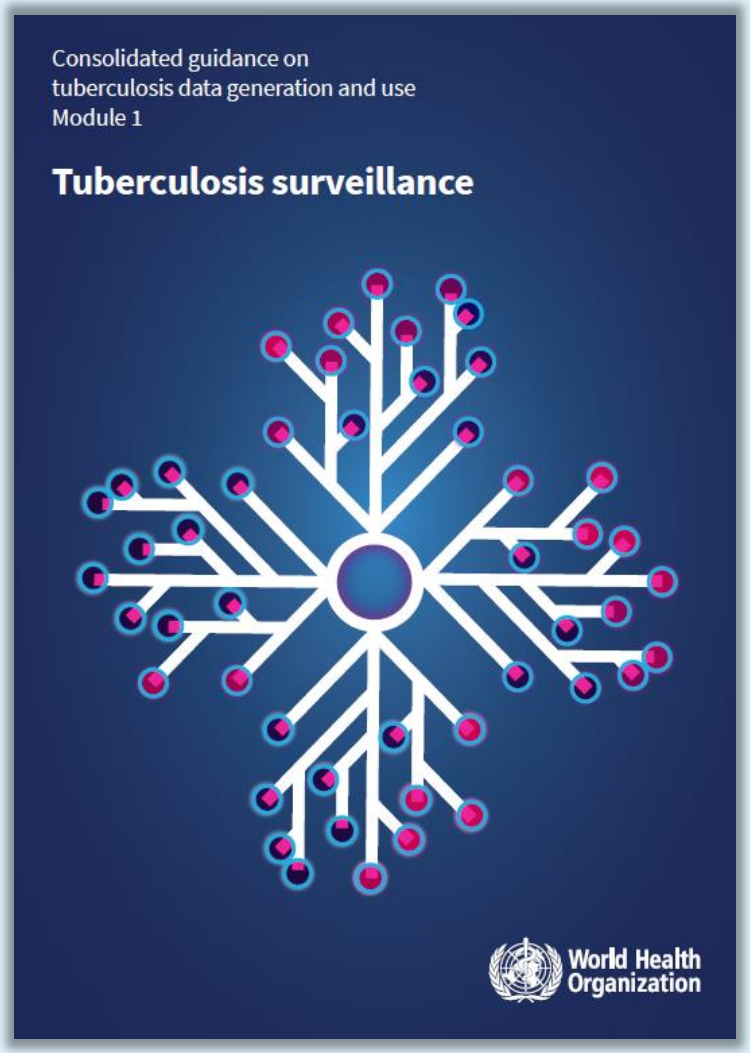
Web annex B: Standards and benchmarks for tuberculosis surveillance and vital registration systems: checklist, 2nd ed.
https://iris.who.int/handle/10665/376483

Web annex C: Record-linkage exercises.
https://iris.who.int/handle/10665/376484

Web annex D: Reporting of aggregated data and calculation of core indicators: templates and formulae.
https://iris.who.int/handle/10665/376486

Web annex E: Examples of how to report diagnosis, start of treatment and treatment outcomes.
https://iris.who.int/handle/10665/376489

Web annex F: Evaluation of the WHO DHIS2 case-based package for tuberculosis surveillance (TB tracker) in five pilot countries: summary of key findings.
https://iris.who.int/handle/10665/376490



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