



# Improving the estimates of childhood TB disease burden and assessing childhood TB activities at country level

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## Introduction

Global estimates of disease burden (incidence, prevalence, mortality) on childhood tuberculosis (TB) remain weak, despite their importance in disease surveillance and the keen international public health interest. TB is increasingly recognized as a major contributor to global child morbidity and mortality. The burden of tuberculous infection and TB disease in children is an important marker of recent ongoing transmission, and therefore of TB control. Children infected with *M.tuberculosis* today are an important source of future TB disease.

The expanded WHO Stop TB strategy now aims to increase case-finding including vulnerable groups such as children. In order to achieve this, much better data of the burden of disease in children are required by National TB Control Programmes (NTPs). Existing TB case notification data do not allow for a complete assessment of the situation. In 2010, out of the 22 TB high burden countries (HBCs) that account for approximately 80% of all new TB cases arising each year, 21 reported data disaggregated by age (0-14 years) for smear positive TB, and only 10 did so for smear negative and extrapulmonary TB.

Key barriers that prevent the improvement of childhood TB estimates include: (i) weak surveillance systems which fail to record and report all childhood TB cases that are registered with the NTP, and (ii) challenges in case ascertainment and diagnosis.

The project aimed to: (i) assess the availability of surveillance childhood TB data, other than what is routinely collected by WHO, (ii) collect these data to feed into the newly produced global estimates of childhood TB that feature in the Global Tuberculosis Report 2012, and (iii) produce a snapshot of the structure for the management of childhood TB at country level, stakeholders involved and challenges faced regarding implementation of childhood TB activities at country level.

## Methods

A survey questionnaire was developed that aimed to collect responses addressing the following areas:

1. Management of childhood TB
2. Childhood TB guidelines
3. Implementation of childhood TB activities
4. Childhood TB notification data
  - a. Data routinely collected through the WHO global TB data collection system but not reported for 2010
  - b. Data not routinely collected by WHO but provide important information on the burden of childhood TB
5. Reported practice of diagnosis of childhood TB at country level



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6. Treatment of childhood TB
7. Implementation of contact tracing and isoniazid preventive therapy (IPT)
8. Collaborative activities in the management of childhood TB (PPM and integration of other stakeholders)

Two versions of the questionnaire were developed (see Appendices 1 and 2): A short version, containing Sections 1-4, aimed to collect information on the management structure and implementation of childhood TB activities as well as to collect missing childhood TB surveillance data. A longer version, containing Sections 1-8, aimed to provide more comprehensive data on implementation of policies and practices for managing childhood TB at national level.

Countries were selected to participate in the survey based on the following criteria:

- a) TB HBCs that submitted incomplete childhood TB surveillance data to WHO in 2010 (e.g. data not disaggregated by age on smear negative or extrapulmonary TB), and/or
- b) Countries in various WHO regions where project partners had good contacts.

## Results

The survey was conducted in June-July 2012 and those invited to participate included NTP staff, WHO staff at country level, and other contacts with strong links to the NTP. The survey was sent out with a deadline for initial response, and a reminder was sent to those that had not responded by the initial deadline. Queries and clarifications were addressed via email during data entry and analysis.

In total, 25 countries were included in the survey. Only 13 responses were received, representing four WHO Regions and ten TB high burden countries: The short questionnaire was sent to ten country contacts and five responded. The long questionnaire was sent to 15 country contacts, of which eight responded. Those that responded are listed in **Table 1**.

**Table 1:** Countries participating in the survey represented four different WHO regions

Survey	Country	WHO Region	TB high burden country
Short	Belarus	EURO	
	Cambodia	SEARO	x
	Tanzania	AFRO	x
	Thailand	SEARO	x
	Viet Nam	SEARO	x
Long	Brazil	AMRO	x
	Kenya	AFRO	x
	Namibia	AFRO	
	Nigeria	AFRO	x
	Pakistan	SEARO	x
	Philippines	SEARO	x
	Russian Federation	EURO	x
	Swaziland	AFRO	

In the following, the responses to the survey are described in detail.

## Sections 1 to 4: responses from 13 countries

### 1. General management of childhood TB

NTPs were asked to indicate providers and organizations managing childhood TB within their country. Five countries provided information of either local and/or international NGOs involved in childhood TB activities. In addition, specialist infectious diseases or pulmonology pediatricians (9 countries), government hospitals (13 countries), and TB hospitals (8 countries) were named as managing childhood TB. Ten countries indicated involvement of private care providers.

When asked whether care providers regularly notify TB cases to the NTP most countries indicated this to be a challenge, whereas one country (Tanzania) was confident that all health care providers in the country manage and report childhood TB according to NTP guidelines.

**Table 2** lists challenges with regard to childhood TB that respondents identified as important from a list of potential issues. In addition, countries mentioned challenges with the implementation of contact tracing and preventive therapy (including for MDR contacts), the lack of appropriate diagnostic tools, the management of complicated cases (including side effects of BCG vaccination), the lack of availability of child-friendly medicines, and the management of adherence. The need for better and sustainable public-private partnerships was highlighted as well as the challenge to report childhood TB data disaggregated by age-groups when reporting tools provided by the NTP to not provide this option.

**Table 2:** Challenges in the management of childhood TB at country level

Potential challenges	Number of countries seeing this as a challenge
Under-diagnosis of childhood TB	10/13
Lack of training of NTP staff	7/13
Childhood TB cases are not reported	7/13
Children not accessing TB services	8/13
Over-diagnosis of childhood TB	3/13
No childhood TB expert in the country	1/13

#### **Example Tanzania: Reporting forms need to be up-to-date**

The electronic NTP database in Tanzania currently only gives the option to capture data for children 0-14 years. Reporting of disaggregated data by age-bands is not possible. Recent National guidelines for childhood TB have incorporated the need to report all children 0-4, 5-14 and 0-14, and there are plans to update the register to do this.

### 2. Childhood TB guidelines

All 13 countries have childhood TB guidelines in place (in the case of the Russian Federation they are different 'orders' by the Ministry of Health regulating childhood TB) and all were updated since 2008. In 9 countries the guidelines also include sections on the management of MDR TB in children.



When asked whether other care providers generally manage childhood TB according to the official NTP guidelines, 5 countries emphasized this would need improvement and better communication between the NTP and these providers, beyond just wide distribution of the guidelines.

### 3. Implementation of childhood TB activities

The need of a focal point for childhood TB as well as the formation of a childhood TB working group to help coordinate activities have been identified by NTPs as priority strategies, for example at the USAID-supported Regional Centre for Quality Health Care on “Best practices in TB control” in Kigali, Rwanda in 2010. Of the 13 countries responding to the survey, 11 have a childhood TB focal point and 7 a working group within the NTP.

NTPs undertake various efforts to implement childhood TB activities. These range from broad distribution of guidelines (8 countries), the existence of NTP training modules (5), training of Regional/District NTP managers (6) as well as NTP staff at clinics (4) to training of other care providers (1).

Funding of these activities is an issue for some countries.

#### **Example Viet Nam: Building a structure and enhancing local capacity for childhood TB at country level**

Funded by TB CARE through the Vietnam KNCV project and with support of WHO Vietnam country office, a 3-day childhood TB workshop was held in 2011 with representatives from 4 provinces. The workshop included discussions around issues arising while trying to implement childhood TB guidelines, a review of the current evidence-base in child TB management, a presentation of training modules that had been developed, feedback on the approach to evaluate training at different levels of care, as well as next steps and future plans. Training has since been translated into Vietnamese and child TB activities are being piloted in 3 of the 4 provinces.

Most countries report that childhood TB guidelines seem better implemented in urban rather than rural areas, and in tertiary care facilities or facilities with expert pediatricians.

MDR TB, if implemented at all, is mainly managed by tertiary care facilities and expert pediatricians. The lack of diagnostics for MDR TB in children is emphasized as a major challenge.

The Russian Federation and Belarus, where childhood TB management is primarily managed by state organizations, report good implementation of guidelines, including MDR-TB, throughout the country.

### 4. Childhood TB notification data

#### *a) Data that are routinely collected through WHO's global TB data collection system but were not reported for 2010*

The WHO global TB data collection system requests all countries to submit routine surveillance data annually, which are used for WHO's Global Tuberculosis Reports. The following data are requested among children (age groups: 0-4, 5-14, 0-14): new cases (separately for smear positive, smear negative, extra-pulmonary), as well as total MDR cases. We targeted countries that had submitted incomplete data in 2010 to report the missing information, if available, for both 2010 and 2011. Any data reported were used for the analyses presented in the 2012 WHO Global TB Report.

6 out of 13 countries that responded did not submit data on newly notified childhood TB cases, disaggregated by age group and case type. The summary of responses from countries can be seen in **Table 3**. Data reported from the remaining seven countries were used for the analyses presented in **Box 2.2 – The burden of TB disease among children** (see Appendix 3).<sup>1</sup>

**Table 3:** Summary of responses to availability of surveillance data for new TB cases collected routinely by WHO (Appendix 1: Tables 1 & 2)

	Total notifications by age and year	Notifications by case type, age and year
<b>Belarus</b>	Data reported	Data reported
<b>Brazil</b>	Data reported	Data reported
<b>Cambodia</b>	Data reported	Data reported
<b>Kenya</b>	No data reported	No data reported
<b>Namibia</b>	No data reported	No data reported
<b>Nigeria</b>	No data reported	No data reported
<b>Pakistan</b>	Data reported	Data reported
<b>Philippines</b>	No data reported	No data reported
<b>Russian Federation</b>	Data reported	No data reported
<b>Swaziland</b>	Data reported	Data reported
<b>Tanzania</b>	No data reported	No data is reported
<b>Thailand</b>	Data reported	Data is reported
<b>Viet Nam</b>	Data reported	Data reported

*b) Data that are not routinely collected by WHO but provide important information on the burden of childhood TB*

WHO does not routinely collect data on treatment outcomes in children, despite the recommendation to countries to collect these published in the childhood TB guidance in 2006.<sup>2</sup> The guidance suggests that treatment outcomes for children should be monitored and reported in the categories completion, death, default and unknown.

In 4 of the 13 countries responding to this survey, the recording and reporting of treatment outcomes in children is available and one country, Brazil, provided these data for the 0-14 age group. Pakistan is planning to add this option to the official reporting forms. For a summary of country responses see **Table 4**.

**Table 4:** Summary of responses to availability of surveillance data on TB outcomes and HIV, not collected routinely by WHO (Appendix 1: Questions 17 & 18)

<b>Question</b>	Do district reporting forms allow reporting of treatment outcomes (17a)	Data on treatment outcomes new cases provided (17b)	Are treatment outcomes for MDR-TB routinely collected by the NTP? (17c)	Are data on MDR-TB treatment outcomes for age group 0-14 reported? (17d)	Are data on MDR-TB treatment outcomes available? (17e)	Are TB/HIV surveillance data reported? (18)
<b>Belarus</b>	No	No	Yes, nearly all settings	No	No	Yes
<b>Brazil</b>	Yes, 0-4, 5-14,	Yes	Yes, most	No	No	Yes

	0-14		settings			
<b>Cambodia</b>	No	No	No	No	No	No
<b>Kenya<sup>7</sup></b>	-	-	-	-	-	-
<b>Namibia</b>	No	No	No	No	No	No
<b>Nigeria</b>	Yes, 0-14	No	Unsure	No	No	No
<b>Pakistan</b>	No	No	No	No	No	No
<b>Philippines<sup>1</sup></b>	-	-	-	-	-	-
<b>Russian Federation</b>	No	No	Yes, few settings	No	No	No
<b>Swaziland</b>	No	No	Yes, few settings	No	No	Yes
<b>Tanzania</b>	Yes, 0-14	No	Yes, all settings	No	Yes	No
<b>Thailand</b>	No	No	No	No	No	No
<b>Viet Nam</b>	Yes, few settings	No	No	No	No	No

<sup>1</sup>No response was provided.

In addition, 3 countries indicated that data on treatment outcomes, among the 0-14 age group, for MDR- and/or XDR-TB cases are routinely collected by the NTP, but none of the countries provided these data. Brazil and Swaziland were the only countries that reported TB/HIV surveillance data among children. This included numbers of HIV tests recorded as well as those receiving ART and CPT for years 2010 and 2011.

## Sections 5 to 8: responses from 8 countries

This section was aimed as a pilot to assess what kind of information about actual implementation of childhood TB activities could be gained by means of an online survey.

### 5. Practice of diagnosis of childhood TB at country level

Countries generally use standard case definitions for the diagnosis of sputum smear positive pulmonary, sputum smear negative pulmonary or extrapulmonary TB in children, recognizing that the final diagnosis is usually made at the discretion of the managing health professional. Six countries are using some kind of clinical algorithms, flow charts or scoring systems to support diagnosis of childhood TB, sometimes in combination with TST and/or chest X-rays.

#### **Example Brazil: Implementation of a clinical scoring system**

In Brazil, a scoring system has been recommended for the diagnosis of TB in children <10 years since 2002. This system was tested in several states and has been validated in HIV-infected and uninfected children in Brazil.<sup>3,4</sup> Given the low sensitivity of microscopy and culture in children and the difficulty to perform gastric aspirates outside of a hospital setting, it is recommended that all investigations for childhood TB (<10 years) start with the scoring system. If the results are inconclusive, children should be further evaluated.



The availability of diagnostic tools depends very much on the setting. Five out of eight countries indicated availability of bacteriology in almost all settings, which includes the option of good mechanisms for sample transport. Xpert MTB/RIF as a new diagnostic tool is being rolled-out in a few settings in four countries. DST seems only available in few countries in very limited settings. For TST, three countries indicated good availability in nearly all settings, whereas it is mainly available in a few settings such as secondary or tertiary care hospitals or private facilities in the other five countries. Similarly for chest X-rays, which seem to be widely available in four countries but restricted to higher levels of care with experts to read them in the other three countries. Fine Needle Aspirations are mainly restricted to higher levels of care.

Six countries indicate that samples (both, gastric aspirates and/or expectorated sputum) for both smear microscopy and culture are routinely collected in most settings. Three countries have an age cut-off for routine sample collection in children (<4, <5 and <10 years).

## 6. Treatment of childhood TB

In all eight countries daily therapy is provided, using the revised dosage recommendations by WHO (2010) with slight adaptations to individual medicines in two countries.<sup>5</sup> Standard regimens with dosage recommendations for different weight bands are available in seven countries. However, two countries note that the implementation of the new dosage recommendations at national level is still impacted by lack of training and availability of better, child friendly formulations. Stock-out of medicines for childhood TB was not reported as being an issue in the eight participating countries.

Main challenges faced by countries with regard to the management of medicines for childhood TB are related to the unavailability of new FDCs and child-friendly medicines and resulting problems in matching the current dosage recommendations with existing medicines, which are sometimes difficult to administer to children, particularly young children with low weight (e.g. non-dispersible tablets). In addition, long timelines for global procurement systems lead to reduced shelf-life of medicines, complicating the planning process for procurement.

## 7. Implementation of contact tracing and isoniazid preventive therapy (IPT)

Implementation and uptake of IPT are poor and, if happening at all, restricted to either NGO-funded programmes or selected settings, as is the use of IPT registers. Exceptions are Nigeria and the Russian Federation, where preventive therapy seems to be widely implemented (using isoniazid for either three or six months depending on the region).

TST is not necessarily recommended for contact screening (depending on availability) but is used in six of the eight countries. Testing for LTBI is mainly done in the context of contact tracing, except for Russia where annual TST testing is routinely performed in children between the age of 1 and 17 years of age. In Brazil, annual TST testing is recommended for HIV-infected children. However, contact tracing seems to generally be poorly implemented.

Preventive therapy for MDR contacts is usually not recommended.



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## 8. Collaborative activities in the management of childhood TB

When asked about linkages of the NTP with other childcare providers, such as mother and childcare services, vaccination services, community child health programmes, private providers it became clear that this is an area that needs improvement. Few linkages exist, mainly with vaccination services providing BCG and, sometimes, mother and child care services.

### Discussion

The survey aimed to: (i) assess the availability of surveillance childhood TB data, other than what is routinely collected by WHO, (ii) collect these data to feed into the newly produced global estimates of childhood TB that feature in the Global Tuberculosis Report 2012, and (iii) produce a snapshot of the organization and implementation of childhood TB activities at country level.

There were a limited number of responses and this poses a major limitation to the quality and interpretation of the information received. This was despite targeting countries where the study team had personal contacts. Ten country contacts approached were participants from a recently-conducted pilot course for training of trainers on childhood TB in Cape Town. These colleagues were sensitized to the issue and play key roles in their countries and yet only three responded. Reporting bias throughout the survey cannot be excluded. With regard to the submission of surveillance data, countries had just completed their submissions to the WHO global TB database and might have felt overburdened by this additional task. In addition, we did not always contact the NTP directly and the respondents did not necessarily have direct access to the requested information.

All information on childhood TB activities received through this survey establishes reported rather than actual practice. The project did not include actual observations through field assessments. Due to the limited number of responses we are unable to draw firm conclusions. However, there are similarities in many of the responses which highlight common challenges that NTPs confront and that might be prioritized and addressed through technical assistance and/or training. These should be further assessed and verified in the field, e.g. through programme reviews.

Surveillance data reported to WHO is sometimes incomplete and contributes to the uncertainty around the true burden of childhood TB along with inadequate case detection and registration of child TB cases with NTPs. In 2010, 13 of the 22 TB high burden countries submitted no or incomplete case notification data for childhood TB. With the increased international focus on childhood TB the situation improved for the reporting year 2011, with all 22 countries reporting age-disaggregated data for smear-positive notifications, and among those 15 countries which also reported data for smear-negative and extra-pulmonary TB. However, there are still major gaps in routinely reported surveillance data for children, such as data on treatment outcomes (both for children with susceptible and drug-resistant TB), and TB/HIV collaborative activities. A recent survey showed that countries are often collecting more data than they submit to WHO.<sup>6</sup> The promotion of case-based electronic recording and reporting systems would facilitate compilation and analysis of age-disaggregated data avoiding all limitations of paper forms.

This survey found that recently updated childhood TB guidelines are in place in most countries.<sup>6</sup> National treatment guidelines for childhood TB are generally incorporating



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the 2010 Rapid Advice dosage guidelines but implementation is hindered by the unavailability of child-friendly formulations. The implementation of contact tracing and preventive therapy remain challenging and require increased attention. We believe this should include the exploration of alternative ways to improve access to care for and control of TB disease.

Childhood TB is managed at different levels of the health care sector but also by different providers. According to feedback received through this survey, communication between NTPs and other providers needs to be improved in both directions: guidelines and training for childhood TB needs to reach all stakeholders, and providers outside the NTP need to implement the guidelines and report childhood TB cases to the programme. This crucial need is also highlighted in a study from Java, Indonesia, where only 2% of childhood TB cases recorded in hospital were reported to the NTP.<sup>7</sup>

The main challenges noted by the respondents are all inter-related. Under-diagnosis of childhood TB is partly due to the lack of adequate diagnostic tools, but also lack of training and capacity (e.g. in the application of the WHO-recommended symptoms-based screening and diagnosis). This is particularly true at the peripheral level. The same issues around lack of precise diagnostic tools and adequate training potentially lead to over-diagnosis of childhood TB, the level of which is difficult to assess. Nationwide data on the level of misdiagnosis of childhood TB are sparse. The same holds for the level of under-reporting of childhood TB. These are shortcomings that must be rectified (e.g. through nationwide inventory studies to measure the level of under-reporting). The current assumption used for the childhood TB estimates published in the 2012 Global TB Report is that the level of under-reporting for children is the same as that for adults (Appendix 3) but there needs to be data to help inform assumptions and ultimately improve estimates.

A recurrent issue reported is the structure of health systems, where capacity, training efforts and access to diagnostic tools are often concentrated at and limited to higher levels of care. Efforts have to be made to reach all levels of the system through training and capacity building, the use of mobile technologies should be explored as a way to improve communication and support. WHO recently developed training tools for childhood TB that address many of these challenges and aim to train trainers at country level. These will become available in 2013 to be consistent with the WHO childhood TB Guidance that is currently being revised. The Union is also supporting through initiatives such as the recently developed Desk guide which aims to support health workers at the secondary and primary levels of care, training on chest X-ray reading and through a child TB working group. It will be critical that childhood TB training is incorporated within ongoing training activities, either within the NTP structure or within the maternal and child health sectors such as for HIV, IMCI or PMTCT.

## Conclusions and future steps

Despite its limitations, this survey provides information on some of the major challenges faced in childhood TB at country level, such as limited access to care, and the lack of training and human resources capacity. In addition to challenges in the implementation of activities on the ground, further hindrance is the unavailability of point-of-care precise diagnostics and child-friendly medicines.

There is a clear advantage of field monitoring visits over reported practice: different stakeholders can be interviewed and actual practice observed. TB programme reviews should always include childhood TB, and there is a clear need for trained experts as well as standardized monitoring tools. Future TB programme reviews should pay special attention to some of the challenges raised in this survey to verify and address them.

The need for improved recording and reporting of surveillance data, as well as the generation of new nationwide level data (e.g. to measure the level of under-reporting), need to be emphasized at country and global level. Only then will we be in a position to improve epidemiological estimates and be able to accurately measure the true burden of childhood TB disease. This is important for the management, provision of resources and planning processes at country level, but also for improved international advocacy for childhood TB.

The following activities are proposed as next steps to continue this work:

- **To improve childhood TB estimates**  
Hold a global consultation on childhood TB estimates, inviting representatives from HBCs, paediatricians, epidemiologists, and statisticians. This consultation will aim to reach agreement into, and ensure buy-in by the international TB community of, the epidemiological estimates of childhood TB. The consultation would include discussions on: (i) the assessment of existing data and identification of gaps, (ii) what is the best new data to generate, and (iii) what is the best approach to compiling existing and new data to improve global estimates (e.g. set up sentinel sites and extrapolate, inventory surveys to measure the level of under-reporting).
- **To support childhood TB activities at country level**  
The childhood TB subgroup is working with partners to develop a standardized monitoring tool for childhood TB, which can be implemented into a larger framework for programme reviews currently developed through TB team. This will enable assessment and problem solving for childhood TB activities in collaboration with NTPs.



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## Acknowledgements

The project is a collaboration between WHO and The Union, with input provided from experts from the childhood TB subgroup of the DOTS Expansion Working Group (DEWG) of the Stop TB Partnership (in particular Robert Gie and Heather Menzies).

The Global Health Bureau, Office of Health, Infectious Disease and Nutrition (HIDN), US Agency for International Development, financially supports this publication through TB CARE I under the terms of Agreement No. AID-OAA-A-10-00020. This publication is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of TB CARE I and do not necessarily reflect the views of USAID or the United States Government.

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## Appendices

### Appendix 1. Short version of the survey

### Appendix 2. Long version of the survey

### Appendix 3. Box 2.2 – The burden of TB disease among children

### Appendix 4. Systematic assessment of routine surveillance and monitoring and evaluation (M&E) capacity linked to the development of M&E investment plans: childhood TB component (WHO, Stop TB Department, TB Monitoring & Evaluation Unit)





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**whom we should contact to fill out this questionnaire? (e.g. NGO representatives, Pediatricians)**

- Yes
- No

If yes, please provide name/s, affiliation and contact details (email)

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

- Yes, most of them
- No, not well
- Unsure/don't know

**Additional comments/clarifications:**

## Section 1 – General Management of Childhood TB

*This section aims to get an overview of all stakeholders involved in the management of childhood TB at country level*

### 5. Who is managing and treating childhood TB in your country?

*(check all that apply)*

- NTP-staff
- NGOs

specify which and provide contact emails, if possible

\_\_\_\_\_

- Infectious disease/pulmonology pediatricians
- Government Hospitals
  - Secondary level       Tertiary level
- TB hospitals (n = \_\_\_\_)
- Private care providers
- Others, please specify \_\_\_\_\_

### 6. If there are other care providers who manage childhood TB, outside the network of the NTP, do they notify childhood TB cases to the NTP on a regular basis?

- Yes, generally well

### 7. In your opinion, what are the main programmatic challenges regarding childhood TB in your country

- Children not accessing TB services
- Lack of training of NTP staff
- No childhood TB expert in the country
- Under-diagnosis of childhood TB
- Over-diagnosis of childhood TB
- Childhood TB cases are not reported
- Other, please specify \_\_\_\_\_

### 8. Please take a few minutes and describe in your own words how childhood TB is managed in your country and what challenges you face (by whom, how is the distribution of services, of knowledge/experience, access for children, referral systems, are there centers for the management of complicated cases etc.)



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## Section 2 – Childhood TB Guidelines

*This section assesses the existence of childhood TB guidelines*

**9. Does your country have childhood TB guidelines (either individual or as part of general TB guidelines)?**

Yes

No

**a.** If yes, what year were they last updated? \_\_\_\_\_

*(would you mind sending a version of these guidelines to [adetjen@theunion.org](mailto:adetjen@theunion.org)?)*

**b.** If yes, do the guidelines include a section on the management of MDR TB in children?

Yes

No

Additional comments/clarifications:

**10. Do other care providers manage childhood TB according to national guidelines (e.g. diagnosis, treatment)?**

Yes, generally well

Yes, most of them

No, not well, needs improvement/better communication

Unsure/don't know

Additional comments/clarifications:

**General comments to this section:**

## Section 3 – Implementation of childhood TB activities

*This section aims to get an overview of **how, where and by whom** childhood TB activities are implemented*

**11. Is there a childhood TB focal point appointed by the NTP?**

Yes

No

Unsure/Don't know

**a.** If yes, please provide name and contact details:

\_\_\_\_\_ Name

\_\_\_\_\_ email

**12. Is there a childhood TB working group within the NTP?**

Yes

No



Unsure/Don't know

a. If yes, please provide name and contact details of the chair of that WG:

\_\_\_\_\_ Name \_\_\_\_\_ email

**13. How well would you say are the childhood TB guidelines implemented at country level? If you don't have childhood TB guidelines: how well are childhood TB activities implemented at country level? (tick all that apply)**

Well in nearly all settings

Well in most settings

Please specify in what kind of settings

- In certain districts of the country
- In urban rather than rural areas
- Generally in Tertiary Care facilities/university hospitals
- Settings managed by certain NGOs

Which \_\_\_\_\_

Settings where expert pediatricians are available

Well in very few settings

Please specify in what kind of settings

- In certain districts of the country
- In urban rather than rural areas
- Generally in Tertiary Care facilities
- Settings managed by certain NGOs.

Which \_\_\_\_\_

Settings where expert pediatricians are available

Not well

Unsure/Don't know

Additional comments/clarifications:

**14. What efforts have been undertaken by the NTP to implement the childhood TB activities as per guidelines? (tick all that apply)**

- Broad distribution of guidelines
- NTP training modules in place
- Training of Regional/District NTP managers
- Training of NTP staff at clinics
- Training of other care providers

Please specify

NGOs, which \_\_\_\_\_

Private care providers

Other, specify \_\_\_\_\_

Other activities, specify \_\_\_\_\_

Additional comments/clarifications:

**15. Is MDR TB in children routinely diagnosed and managed in your country?**

Yes

Well in nearly all settings

Well in most settings

Please specify in what kind of settings

In certain districts of the country



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- In urban rather than rural areas
- Generally in Tertiary Care facilities/university hospitals
- Settings managed by certain NGOs  
Which \_\_\_\_\_
- Settings where expert pediatricians are available
- Well in very few settings  
Please specify in what kind of settings
  - In certain districts of the country
  - In urban rather than rural areas
- Generally in Tertiary Care facilities
- Settings managed by certain NGOs.  
Which \_\_\_\_\_  
pediatricians are available
- Not well
- No
- Unsure/Don't know

Additional comments/clarifications:

General comments to this section:

## Section 4 – Notification data beyond Global TB questionnaire

The WHO global TB data collection system requests all countries to submit routine surveillance data annually, which are used for WHO's Global TB Reports. The following data are requested on childhood (age groups: 0-4, 5-14, 0-14) TB: new cases (separately for smear positive, smear negative, extra-pulmonary), as well as total MDR cases. In this section, we would like to collect some additional data, if these are available at the national level in your country.

### 16. New TB cases

Your country did not submit all requested data on new TB cases in children through the WHO global TB data collection system.

If you have these data at the national level, please fill out Tables 1 and 2 below after reading the footnotes to the tables. **Please note: we give the option to enter data for the last 5 years. Most important are the data for 2010 and 2011, but if you have access to the previous years we'd appreciate the information.**

TABLE 1. Total <sup>1</sup> number of newly notified TB patients to the National TB Control Programme: <b>all case types</b>					
Year	All ages	0-14 years	0-4 years	5-14 years	Comments
2007					
2008					
2009					
2010					



2011					
------	--	--	--	--	--

<sup>1</sup> Smear-positive AND smear-negative AND extra-pulmonary  
 NB: Please complete as much of this table as possible. If data are not available for some years, complete "NA" in the appropriate cell. If data on children are collected for different age groups, make a note in the comments column and complete as much of the table as possible. For example, if data are collected for children ages 0 to 10 years, then make a note of this in the table.

TABLE 2. Number of newly notified TB patients to the National TB Control Programme <b>by case type</b>													Comments
Year	0-14 years				0-4 years				5-14 years				
	S <sup>1</sup>	S <sup>2</sup>	EP <sup>3</sup>	Other <sup>4</sup>	S <sup>1</sup>	S <sup>2</sup>	EP <sup>3</sup>	Other <sup>4</sup>	S <sup>1</sup>	S <sup>2</sup>	EP <sup>3</sup>	Other <sup>4</sup>	
2007													
2008													
2009													
2010													
2011													

<sup>1</sup> Smear positive; <sup>2</sup> smear negative (culture positive); <sup>3</sup> extra-pulmonary clinical diagnosis; <sup>4</sup> all other case types  
 NB: Please complete as much of this table as possible. If data are not available, complete "NA" in the appropriate cell. If known, complete information in the comments column about how cases were identified (e.g. smear positive, culture positive, clinical diagnosis, other). Many young children are not smear positive (or a sputum smear is not done), but we would appreciate any available information. If "other", please describe (e.g. contact investigation).

Additional comments/clarifications:

**17. Treatment outcomes: completion, death, default, unknown**  
*These data are not requested routinely through the WHO global TB data collection system. However, we would like to assess if these data are collected and available in order to inform revisions of the data collection system in subsequent years, if appropriate. According to the 2006 WHO childhood TB guidelines treatment outcomes in children should be reported as for adults.*

- a. **Do the aggregated district reporting paper forms used by the NTP allow for recording of treatment outcomes for children?**  
 Yes If yes, tick all age groups that apply  0-4  5-14  0-14  
 No  
 Unsure/don't know

Additional comments/clarifications:

- b. **If you have data on treatment outcomes for new cases, please enter them in the table below**

TABLE 5a. Treatment outcomes for <b>all newly notified TB patients: 0-14 years</b>					
Year	Total	Completion	Death	Default	Unknown
2010					
2011					

NB: Please complete as much of this table as possible. If data are not available, complete "NA" in the appropriate cells.

TABLE 5b. Treatment outcomes for <b>all newly notified TB patients: 0-4 years</b>					
---	--	--	--	--	--



Year	Total	Completion	Death	Default	Unknown
2010					
2011					

NB: Please complete as much of this table as possible. If data are not available, complete "NA" in the appropriate cells.

TABLE 5c. Treatment outcomes for all newly notified TB patients: 5-14 years					
Year	Total	Completion	Death	Default	Unknown
2010					
2011					

NB: Please complete as much of this table as possible. If data are not available, complete "NA" in the appropriate cells.

**c. Treatment outcomes for MDR/XDR-TB cases (completion, death, default, unknown)**

Are these data routinely collected by the NTP?

- Yes, from nearly all settings
- Yes, from most settings
- Yes, from few settings
- No
- Unsure/Don't know

**d. If you have data on treatment outcomes for MDR-TB cases, please enter them in the table below for all years possible**

TABLE 6a. Treatment outcomes for MDR cases: 0-14 years					
Year	Total	Completion	Death	Default	Unknown
2010					
2011					

NB: Please complete as much of this table as possible. If data are not available, complete "NA" in the appropriate cells.

**e. Do you have available data on treatment outcomes for MDR-TB cases disaggregated by age ?**

- Yes If yes, tick all age groups that apply  0-4  5-14  0-14
- No
- Unsure/Don't know

**18. HIV results among children diagnosed for TB (disaggregated by age)**

*These data are not requested routinely through the WHO global TB data collection system. However, we would like to assess if these data are collected and available in order to inform revisions of the data collection system in subsequent years, if appropriate.*

TABLE 4. TB/HIV surveillance in children									
Year	0-14 years			0-4 years			5-14 years		
	N <sup>1</sup> (% <sup>2</sup> )	ART <sup>3</sup>	CPT <sup>4</sup>	N <sup>1</sup> (% <sup>2</sup> )	ART <sup>3</sup>	CPT <sup>4</sup>	N <sup>1</sup> (% <sup>2</sup> )	ART <sup>3</sup>	CPT <sup>4</sup>
2010									
2011									

<sup>1</sup> Number of HIV test results recorded; <sup>2</sup> percentage positive over results recorded; <sup>3</sup> number of children receiving ART; <sup>4</sup> number of children receiving CPT

NB: Please complete as much of this table as possible. If data are not available, complete "NA" in the appropriate cells.



**Appendix 2. Long version of the survey (Sections 5-8, in addition to sections 1-4 shown in Appendix 1)**

**Section 5 – Diagnosis of childhood TB**

*This section aims to assess how the diagnosis of childhood TB is made, what kind of and how broadly throughout the country diagnostics are available, whether algorithms are used etc.*

**19. How is the diagnosis of childhood TB generally made in your country?**

- Using existing case definitions
- Using clinical algorithms/scoring systems
- On an individual basis
- Unsure/Don't know

**a. If case definitions exist, please describe them for the different forms of TB (e.g. age-cut-off, what criteria are used if the child does not have bacteriologic diagnosis)**

- i. Pulmonary TB, smear or culture positive:  
\_\_\_\_\_
- ii. Pulmonary TB, smear negative:  
\_\_\_\_\_
- iii. Extrapulmonary TB:  
\_\_\_\_\_

**b. If scoring systems are used: what kind of an algorithm do you use?**

- A certain number of the elements ticked above need to be present for a diagnosis (e.g. at least 3)?  
How many? \_\_\_\_\_
- A point system

*(Would you mind sending a copy of the algorithm to [adetjen@theunion.org](mailto:adetjen@theunion.org))*

**20. Please describe how consistent the diagnosis of childhood TB is approached in your country? (Are there big differences in the diagnostic approaches between settings/districts etc., are the approaches and results comparable, are you confident about the diagnostic certainty in different settings??)**

Additional comments/clarifications:

**21. Which diagnostic elements are generally available and used for the diagnosis of tuberculosis, and where are they available? (tick all that apply)**

- Bacteriology/histology showing *M. tb*
  - Available in nearly all settings (this includes: good sample transport mechanisms available to culture labs)
  - Available in most settings (please specify which kind of settings) \_\_\_\_\_
  - Available in very few settings (please specify which kind of settings) \_\_\_\_\_
  - Unsure about coverage



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- Xpert MTB/RIF
  - Available in nearly all settings (this includes: good sample transport mechanisms available to culture labs)
  - Available in most settings (please specify which kind of settings) \_\_\_\_\_
  - Available in very few settings (please specify which kind of settings) \_\_\_\_\_
  - Unsure about coverage
- Tuberculin skin testing (TST)
  - Available in nearly all settings
  - Available in most settings (please specify which kind of settings) \_\_\_\_\_
  - Available in very few settings (please specify which kind of settings) \_\_\_\_\_
  - Unsure about coverage
- Chest radiography
  - Available in nearly all settings
  - Available in most settings (please specify which kind of settings) \_\_\_\_\_
  - Available in very few settings (please specify which kind of settings) \_\_\_\_\_
  - Unsure about coverage
- Fine Needle Aspiration for detection of Lymph node TB
  - Available in nearly all settings
  - Available in most settings (please specify which kind of settings) \_\_\_\_\_
  - Available in very few settings (please specify which kind of settings) \_\_\_\_\_
  - Unsure about coverage
- Clinical symptoms
- Contact history
- Response to therapy
- Other (please describe) \_\_\_\_\_

Additional comments/clarifications:

**22. Are smears and cultures routinely collected on children?**

- Yes, in nearly all settings
  - Yes, in most settings
  - Unsure/Don't know
- a.** If yes, what specimens are collected? *(check all that apply)*
- Gastric aspirate
  - Expecterated sputum (e.g. coughed-up sputum)
  - Induced sputum
  - Other (please describe) \_\_\_\_\_
- b.** Is there an age cut-off when sputum specimens are **not** collected?
- Yes, under the age of \_\_\_\_\_
  - No

Additional comments/clarifications:

**23. Is drug-susceptibility testing routinely available for children?**

- Available in nearly all settings (this includes: good sample transport mechanisms available to culture labs)
- Available in most settings (please specify which kind of settings) \_\_\_\_\_



Available in very few settings (please specify which kind of settings) \_\_\_\_\_

Unsure about coverage

Additional comments/clarifications:

**General comments to this section:**

### Section 6 – Treatment of childhood TB

*This section seeks some basic information on treatment and medicines available for childhood TB. (The WHO Global data collection system already covers whether pediatric formulations of anti TB drugs were procured specifically for children)*

**24.** What are the recommended dosages for first-line anti-tuberculosis drugs in children?

- Daily Therapy
- Intermittent therapy

Please tick dosage recommendations that apply

	WHO 2006 <sup>1</sup> mg/kg	WHO 2010 <sup>2</sup> Mg/kg	Other
<b>INH</b>	5 (4-6)	10 (10-15)	
<b>RMP</b>	10 (8-12)	15 (10-20)	
<b>PZA</b>	25 (20-30)	35 (30-40)	
<b>EMB</b>	20 (15-25)	20 (15-25)	

<sup>1</sup> According to WHO childhood TB guidance 2006 [World Health Organization. Guidance for national tuberculosis programmes on the management of tuberculosis in children; 2006.]

<sup>2</sup> According to updated WHO recommendations [World Health Organization. Rapid Advice: Treatment of tuberculosis in children.; 2010]

**25.** Do you have standard regimens for children available, with the dosages listed by weight bands?

- Yes
- No
- Unsure/don't know

Additional comments/clarifications:

**26.** Do you have problems with stock-outs, expired drugs?

- Yes
- No
- Unsure/don't know

Additional comments/clarifications:



27. Please outline the main challenges you experience regarding drug management in children (e.g. procurement, stock-outs, correct dosing or anything else that comes to your mind):

### Section 7 – Contact tracing and preventive therapy

*Some information regarding preventive therapy is collected through the WHO global TB data collection system, such as the number of contacts screened, number of contacts started on IPT (disaggregated by age). In addition, we would like to know:*

28. How well would you say is IPT implemented at country level?

- Well in nearly all settings
- Well in most settings
  - Please specify in what kind of settings
    - In certain districts of the country
    - In urban rather than rural areas
- Generally in Tertiary Care facilities/university hospitals
- Settings managed by certain NGOs
  - Which \_\_\_\_\_
- Settings where expert pediatricians are available
- Well in very few settings
  - Please specify in what kind of settings
    - In certain districts of the country
    - In urban rather than rural areas
- Generally in Tertiary Care facilities
- Settings managed by certain NGOs.
  - Which \_\_\_\_\_
- Settings where expert pediatricians are available
- Not well
- Unsure/Don't know

Additional comments/clarifications:

29. Are there issues with the availability of INH for preventive therapy in children?

- Yes

Please describe:

- No



Unsure/Don't know

**30. Are IPT registers being used/implemented?**

Well in nearly all settings

Well in most settings

Please specify in what kind of settings

In certain districts of the country

In urban rather than rural areas

Generally in Tertiary Care facilities/university hospitals

Settings managed by certain NGOs

Which \_\_\_\_\_

Settings where expert pediatricians are available

Well in very few settings

Please specify in what kind of settings

In certain districts of the country

In urban rather than rural areas

Generally in Tertiary Care facilities

Settings managed by certain NGOs.

Which \_\_\_\_\_

Settings where expert pediatricians are available

Not well

Unsure/Don't know

Additional comments/clarifications:

**31. Despite not being recommended in the 2006 WHO childhood TB guidance: Is there any testing done for LTBI?**

Yes

TST

Other, specify \_\_\_\_\_

Is provision of IPT based on a positive test?

Yes

No

Other, specify \_\_\_\_\_

No

Unknown

a. If TST or other test is performed for LTBI: at what time points is it done in children?

annually

at age \_\_\_\_\_(please indicate)

for contact tracing only

Other, specify \_\_\_\_\_

Additional comments/clarifications:

**32. Who is included in routine contact investigations?**

*(please check all that apply)*

Children < 5 years of age

Children < 15 years of age

All household contacts

Persons with HIV infection

Other (please describe) \_\_\_\_\_

Contact investigations are not routinely implemented

Additional comments/clarifications:



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**33. Is preventive therapy routinely provided to MDR child contacts?**

- Yes
  - In nearly all settings
  - In most settings
  - In few settings
- No, not recommended
- No, not done
- Unknown

If yes, what kind of treatment

- INH
- Other, specify \_\_\_\_\_

Additional comments/clarifications:

**General comments to this section:**

**Section 8 – PPM/Collaboration with other child care providers**

**34. How well is the NTP generally linked with other child-care providers?**

- Well with
  - Mother and child care services
  - Vaccinations services
  - Community child health programmes
  - Private providers
  - Other, please specify \_\_\_\_\_
- Not well
- Unknown

Additional comments/clarifications:

**35. If linkages exist, what are the roles of these other providers?**

- (tick all that apply)*
- Contact tracing
  - Provision of IPT
  - Referral of TB suspects
  - Diagnosis
  - Treatment
  - Treatment support
  - Reporting of data

Additional comments/clarifications:

**General comments to this section:**

## Appendix 3. Box 2.2 The burden of TB disease among children

### BOX 2.2

#### The burden of TB disease among children

For many years, the prevention, diagnosis and treatment of TB among children have been relatively neglected. Greatest attention has been given to the detection and treatment of infectious cases, most of which occur in adults. The Stop TB Strategy launched by WHO in 2006 includes case-finding in high-risk or vulnerable groups such as children and prevention of TB in children who live in the same household as newly detected TB cases. To help to address the burden of TB in children (defined as those aged <15 years) and monitor progress, robust data on childhood TB are necessary. This is the first WHO report on global TB care and control to include estimates of the burden of TB disease among children, with best estimates of 490 000 cases and 64 000 deaths per year.<sup>1</sup> The reasons why it remains difficult to estimate the burden of TB disease in children, the methods used to produce this first set of estimates and the next steps needed to improve them are discussed below.

#### Challenges in assessing the number of TB cases and deaths among children

There is no easy-to-use and accurate diagnostic test for TB in children. Most children have paucibacillary TB that is harder to diagnose with sputum smear microscopy and culture. Many children, especially younger children, are also not able to expectorate sputum. Diagnosis is usually made using a combination of clinical (as opposed to laboratory) criteria and a non-specific test for tuberculous infection, but there is no universally applied diagnostic algorithm. The definitive diagnosis of extrapulmonary TB requires specialised services that are usually available only in referral hospitals, and thus often not accessible to those in need. Besides diagnostic challenges, children diagnosed with TB are not always reported to national surveillance systems because of the lack of linkages among individual paediatricians, paediatric hospitals and national TB programmes, and data from national surveys including children are limited. Many countries lack VR systems in which deaths from TB are disaggregated and reported by age.

#### Estimates of TB notifications and TB incidence in children in 2011 – methods and results

The global number of new TB case notifications among children (aged <15 years) is estimated at 327 000 in 2011 (Table B2.2.1). This includes cases reported among children and an estimate of the number of cases among children in countries that did not report notifications disaggregated by age. For countries that did not report age-disaggregated data (Figure B2.2.1), it was assumed that the child:adult ratio among notified cases was the same (for each case type) as the ratio in countries that did report notifications disaggregated by age (an alternative method using the assumption that the child:adult ratio of notification rates was the same gave

similar results). WHO does not request age-disaggregated data for relapse cases or those reported as of unknown treatment history; the number of children in these categories was assumed to be zero.

To estimate TB incidence among children, it was assumed that the ratio of notified to incident cases at the global level in 2011 (best estimate 66%, range 64%–69%) was the same for adults and children. On this basis, TB incidence among children was estimated at 490 000 (range, 470 000–510 000) in 2011, equivalent to about 6% of the total number of 8.7 million incident cases.

Limitations of the methods used include:

- The assumption that the ratio of notified to incident cases is the same for adults and children, in the absence of any data on levels of under-reporting of diagnosed cases for children and adults separately;
- The assumption that reported cases were true cases of TB. Misdiagnosis is possible, especially given the difficulties of diagnosing TB in children; and
- The proportion of cases among children may be different in countries for which age-disaggregated data are not available.

#### Estimates of TB mortality in children in 2011 – methods and results

Mortality data disaggregated by age from VR systems that have been reported to WHO were analysed. TB death rates per 100 000 population were calculated for children and adults, after adjustment for incomplete coverage and ill-defined causes (see Annex 1 for further details). For countries without VR data, an ecological statistical model was used to predict the ratio of childhood to adult TB mortality rates. The model included a set of risk factors known to be associated with TB mortality (for example, GDP per capita, the percentage of new cases with MDR-TB, HIV prevalence in the general population and the treatment success rate). The total number of deaths from TB among HIV-negative children was estimated at 64 000 (range, 58 000–71 000) in 2011, equivalent to 6% of the 990 000 TB deaths among HIV-negative TB cases in 2011. The main limitation in the methods is that the countries reporting usable VR data were all middle or high-income countries. Predictions for low-income countries had to be extrapolated from these countries.

Besides the direct impact of TB on children themselves, parental deaths from TB have created large numbers of orphans. In 2009, there were almost 10 million children who were orphans as a consequence of losing at least one of their parents to TB.

#### Estimates of TB prevalence in children

Data on the prevalence of TB in children are limited to a few nationwide surveys conducted before 2001. Examples include a survey in India in 1956, and surveys in China in 1980, 1990, and 2000. The 2007 survey in the Philippines included children aged 10–14 years. These surveys consistently found a low burden of bacteriologically-confirmed TB in children compared with adults.

There has been impressive progress in the implementation of nationwide prevalence surveys to measure bacteriologically-confirmed TB since 2008 (see Section 2.5.2). These surveys are focusing on adults (aged ≥15 years) and the typical sample size is 50 000–

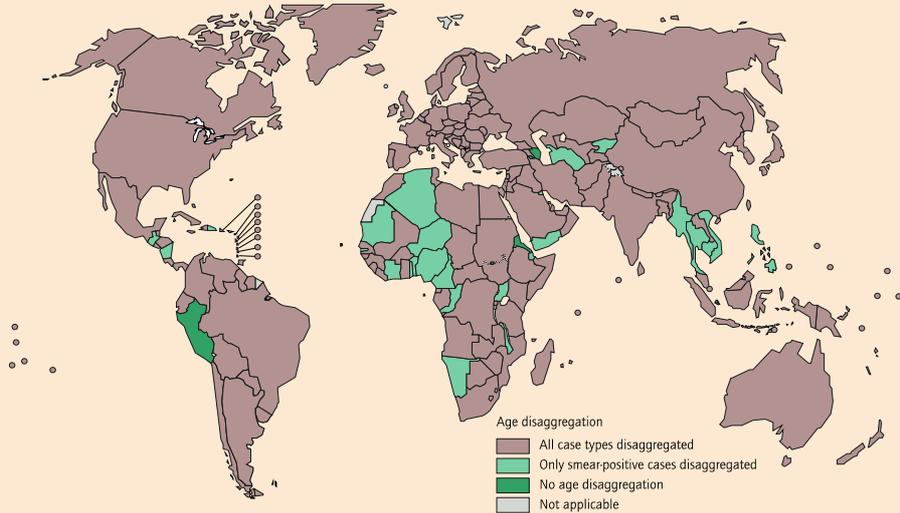
**TABLE B2.2.1 Reporting of TB case notifications disaggregated by age, 2011**

	SMEAR-POSITIVE	SMEAR-NEGATIVE <sup>a</sup>	EXTRAPULMONARY
<i>Total notifications</i>	2 621 049	1 872 745	813 636
Countries disaggregating by age	2 601 032	1 582 235	684 233
Countries not disaggregating by age	20 017	290 510	129 403
(% total notifications disaggregated)	(99%)	(84%)	(84%)
<i>Number of countries that reported notifications disaggregated by age (number of HBCs)<sup>b</sup></i>	197 (22)	171 (15)	171 (15)
<b>Total estimated childhood notifications</b>			<b>327 000</b>

<sup>a</sup> This includes reported cases for whom smear results were unknown or smears were not done.

<sup>b</sup> An additional 9 countries reported zero TB cases in 2011 and two countries had not reported data to WHO by July 2012.

**FIGURE B2.2.1**  
**Reporting of notification data disaggregated by age, 2011**



70 000 people. The screening strategy includes chest X-rays and a symptom-based questionnaire for the entire survey population, followed by collection of sputum samples from all those with TB signs and symptoms for subsequent smear and culture examination.

After careful weighing of the advantages and disadvantages by WHO's Global Task Force on TB Impact Measurement (see [Section 2.5](#)), the inclusion of children in national prevalence surveys has not been recommended. Major reasons are:

- Inclusion of children in a survey would not lead to a precise estimate of TB prevalence among children, since only a few bacteriologically-confirmed cases would be found. Even existing surveys of adults are not able to provide precise estimates for different age groups.
- There are ethical considerations associated with the mass screening of all children, most of whom are healthy. While evidence exists that chest X-ray screening is safe for adults, similar evidence does not exist for children. Furthermore, there is no simple and reliable tool that could be used to restrict the number of children screened by X-ray: for example, there is no reliable test for tuberculous infection.
- Among adults, use of broad criteria for considering an X-ray "abnormal" is encouraged to minimize the number of cases that are missed during screening. Among children, use of tests for tuberculous infection and broad criteria for considering an X-ray "abnormal" would lead to unnecessary efforts to obtain specimens, which among young children requires invasive and uncomfortable gastric aspiration.
- Referral hospitals are needed for the follow-up and diagnostic confirmation of TB in children. These are often not available in the rural areas that account for a large share of the clusters included in national prevalence surveys.

- Inclusion of children would approximately double the sample size and associated costs. The additional logistical complications of including children could also jeopardise the survey as a whole.

**Next steps to improve existing estimates of TB cases and deaths among children**

Next steps to improve the measurement and estimation of TB incidence among children include:

- Systematic literature reviews of existing data on incident childhood TB, under-reporting of TB in children and misdiagnosis;
- A global consultation to further develop analytical methods and to define and prioritize actions needed to obtain new data;
- Promotion of case-based electronic recording and reporting systems that would facilitate compilation and analysis of age-disaggregated data (among other advantages – see [Section 2.5.1](#)); and
- Nationwide inventory surveys to measure under-reporting of childhood TB.

More contact-tracing and the integration of TB activities in maternal, newborn and child health services would also help to find children with TB that might otherwise not be diagnosed.

To improve estimates of TB mortality among children, the main actions required are:

- Collection of age-specific data from sample VR systems and mortality surveys in high-burden countries including China, India and Indonesia;
- Advocacy for further development of and continued investment in VR systems.

<sup>1</sup> This estimate is for TB deaths among HIV-negative children. TB deaths among HIV-positive children are classified as HIV deaths in ICD-10.



#### **Appendix 4. Systematic assessment of routine surveillance and monitoring and evaluation (M&E) capacity linked to the development of M&E investment plans: childhood TB component**

(for a full version of the tool please contact the TB Monitoring and Evaluation Unit, Stop TB Department, WHO)

##### **STANDARD C3:**

Surveillance data for children reported with TB (defined as ages 0-14 years) are reliable and accurate or all diagnosed childhood TB cases are reported

##### **BENCHMARKS:**

both benchmarks should be satisfied to meet this standard:

- Ratio of age groups 0-4 to 5-14 years is in the range 1.5-3.0
- $\geq 90\%$  of childhood TB cases are reported to national health authorities, as determined by a national-level investigation (e.g. inventory study) conducted in last 10 years

##### **RATIONALE FOR STANDARD AND BENCHMARKS**

Registration of TB cases is completed on standardized recording and reporting forms, involving the collection of patient demographic, clinical, diagnosis, and treatment outcome data. The improvement of diagnosis continues to be the greatest challenge of TB in children (defined as between the ages 0-14 years), where obtaining a sputum specimen is often not even attempted. Diagnosis depends on the level of health care services, availability of standard TB diagnostic tests and human resources. It is based on a composite set of clinical criteria and diagnostic test results ranging between the "three or more criteria"<sup>1</sup> WHO-recommended algorithm for the straight-forward pulmonary cases, to the more complicated tertiary care diagnosis of different disease manifestations, which are seen more often in children compared to adults. These diagnostic challenges, combined with the lack of routine recording and reporting of childhood TB, make it difficult to know the true burden of TB disease in children which is most likely under-estimated from the TB surveillance data.

##### **METHOD TO ASSESS BENCHMARK**

**Data sources and data collection methods:** Case data from national routine surveillance systems disaggregated by case type, age and sex. Routine checks on national and first administrative level sub-national data. The assessment should be done annually.

**Main limitations:** The ranges of values used for the benchmarks have been based on data from a limited number of countries.

**Interpretation of results:** Accurate benchmark values within the suggested ranges compared with what is known about childhood TB epidemiology<sup>2,3</sup> as well as within the same country over time, provide some reassurance of a well-functioning surveillance system. Meeting both benchmarks is required in order for this standard.

**Recommended actions:** Unmet benchmarks should be investigated further and potential reasons for these discrepancies should be hypothesized.

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<sup>1</sup> Guidance for national tuberculosis programmes on the management of tuberculosis in children. Geneva, World Health Organization, 2006 (WHO/HTM/TB/2006.371).

<sup>2</sup> BJ Marais et al. The clinical epidemiology of childhood pulmonary tuberculosis: a critical review of literature from the pre-chemotherapy era. *IJTLD*, 2004. 8(3):278-285

<sup>3</sup> AD Harries et al. childhood tuberculosis in Malawi: nationwide case-finding and treatment outcomes. *IJTLD*, 2002. 6(5):424-431



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## EXAMPLE

Review of child TB data in a high-burden country with incidence of all forms TB disease of over 200/100,000, and 30% of the population are children (0-14 years). Available data report that child TB accounts for 1.7% of all TB cases recorded, the majority (70%) of the child TB cases is aged between 5 and 14 years of age, and common types of TB in this older age group are sputum smear positive PTB and TB adenitis.

Young children (0-4 years) are at far higher risk of TB disease after infection than older children, and TB disease will usually present within 1 year after infection. Therefore in a high TB endemic setting, the majority of child TB cases will be in young children, and the commonest type will be PTB (smear not done or smear negative). The emphasis of NTP reporting has traditionally been on sputum smear-positive disease, and this is not uncommon in school-aged children and adolescents, and diagnosis and registration is as per adult suspect TB cases. TB adenitis is also relatively common in older children and often a straightforward clinical diagnosis due to the common presentation being visibly enlarged neck glands.

Therefore, the data above strongly suggest a marked under-representation of child TB cases, especially those in 0-4 year age group which cannot provide sputum, require a clinical diagnosis, and present with features that overlap with other common disease in children such as pneumonia and malnutrition. Therefore the benchmark is not met.