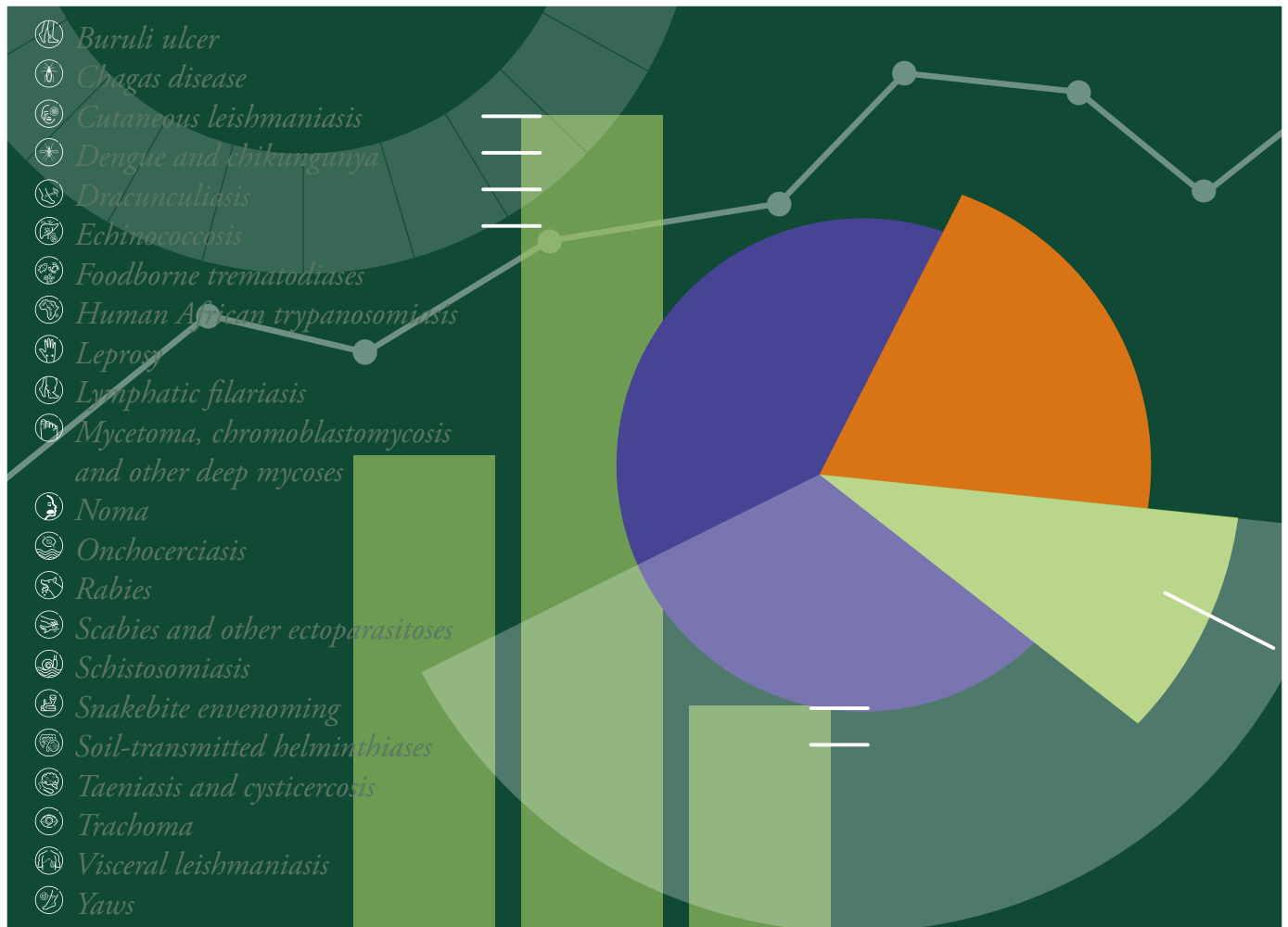




Routine health information system and health facility data for neglected tropical diseases

General guidance for national programme managers and data clerks

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neglected tropical diseases

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Main contributors

Preparation of the guidance was supported by a steering committee comprising members from the WHO African (Dorothy Achu, Elizabeth Juma), Americas (Luis Gerardo Castellanos, Ana Luciañez, Santiago Nicholls), South-East Asia (Aya Yajima), European (Stela Bivol), Eastern Mediterranean (Mona Osman, Supriya Warusavithana) and Western Pacific (Kazim Sanikullah) regions.

Technical input was provided by focal points from the WHO Global Neglected Tropical Diseases Programme: Bernadette Abela, Pedro Albajar Viñas, Kingsley Asiedu, Daniel Argaw Dagne, José Ramon Franco-Minguell, Albis Francesco Gabrielli, Amadou Garba Djirmay, Xiaoxian Huang, Saurabh Jain, Jonathan King, Antonio Montresor, Denise Mupfasoni, Gerardo Priotto, Maria Rebollo Polo, José Ruiz-Postigo, Dieudonné Sankara, Anthony Solomon, Afework Tekle, Raman Velayudhan, David Williams and Rajpal Yadav. Junerlyn Farah Virrey Agua, Gautam Biswas, Claire Cotton, Pamela Sabina Mbabazi and Alexei Mikhailov consolidated and validated technical inputs.

External reviewers

Programme managers from the health ministries of the following countries (listed alphabetically) reviewed the guidance for consistency with disease-specific frameworks: Earnest Njih Tabah (Cameroon), Aboa Paul Koffi (Côte d'Ivoire), Souad Bouhout (Morocco), Naseem Salahuddin (Pakistan), Lydia R. Leonardo, (Philippines), Khadime Sylla (Senegal), Lucille Blumberg (South Africa), Yawovi Agbenyigan Gadah and Piham Gnossike (Togo), Ndellejong Cosmas (United Kingdom of Great Britain and Northern Ireland), Kaushi Kanankege (United States of America) and Veronica Kabona (United Republic of Tanzania).

Abbreviations

GNARF	Global NTD Annual Reporting Form
NTD	neglected tropical disease
RHIS	routine health information systems
WASH	water, sanitation and hygiene
WHO	World Health Organization

1. Introduction

National health programmes continuously generate data as part of their service delivery activities. These data are collected and reported regularly through routine health information systems (RHIS) and are analysed and used at all levels of the health system to improve access and quality of care. The wide array of datasets in health information systems includes community data; health facility data; health surveys; measurement of quality of care; logistics management and information systems; disease surveillance; population data sources; household surveys; and civil registration and vital statistics. Countries need information in these datasets to be reliable and readily accessible for use at various levels to assess the performance of their health services as they work towards achieving the targets set in *Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021–2030* (“the road map”) (1), universal health coverage, primary health care and the Sustainable Development Goals.

1.1 The WHO routine health information system toolkit

In 2018, the World Health Organization (WHO) and the Health Data Collaborative (2) launched an initiative to develop a set of resources for capacity-building to optimize the analysis of routine facility data, commonly known as the RHIS toolkit (3). The toolkit, depicted in Fig. 1, comprises three broad categories of technical resources for use in health facility settings:

- 1 Standards for measurement and analysis of RHIS, including general principles, core indicators and metadata, and data quality review toolkit; technical specifications for data quality (4) considerations and high-level descriptions of analyses as applicable to all health programmes are provided in this component of the RHIS toolkit.
- 2 Guidance for planners and managers of national health information systems, including for integrated health service analysis at the facility, district and national levels.
- 3 Programme-specific guidance documents (e.g. immunization, HIV, tuberculosis, malaria, maternal and child health).

1.2 Approach to development of this guidance

This guidance was developed based on a template provided to health programmes by the WHO Division of Data, Analytics and Delivery for Impact. WHO regional advisers and disease focal points in the Global Neglected Tropical Diseases Programme provided technical content in alignment with the strategic priorities presented in the road map (1). A steering committee comprising members of the Working Group on Monitoring, Evaluation and Research of the WHO Strategic and Technical Advisory Group for Neglected Tropical Diseases with expertise in developing information systems contributed to the writing and review of initial drafts of this document. Disease experts external to WHO and national programme managers at country level reviewed the document for technical accuracy and relevance.

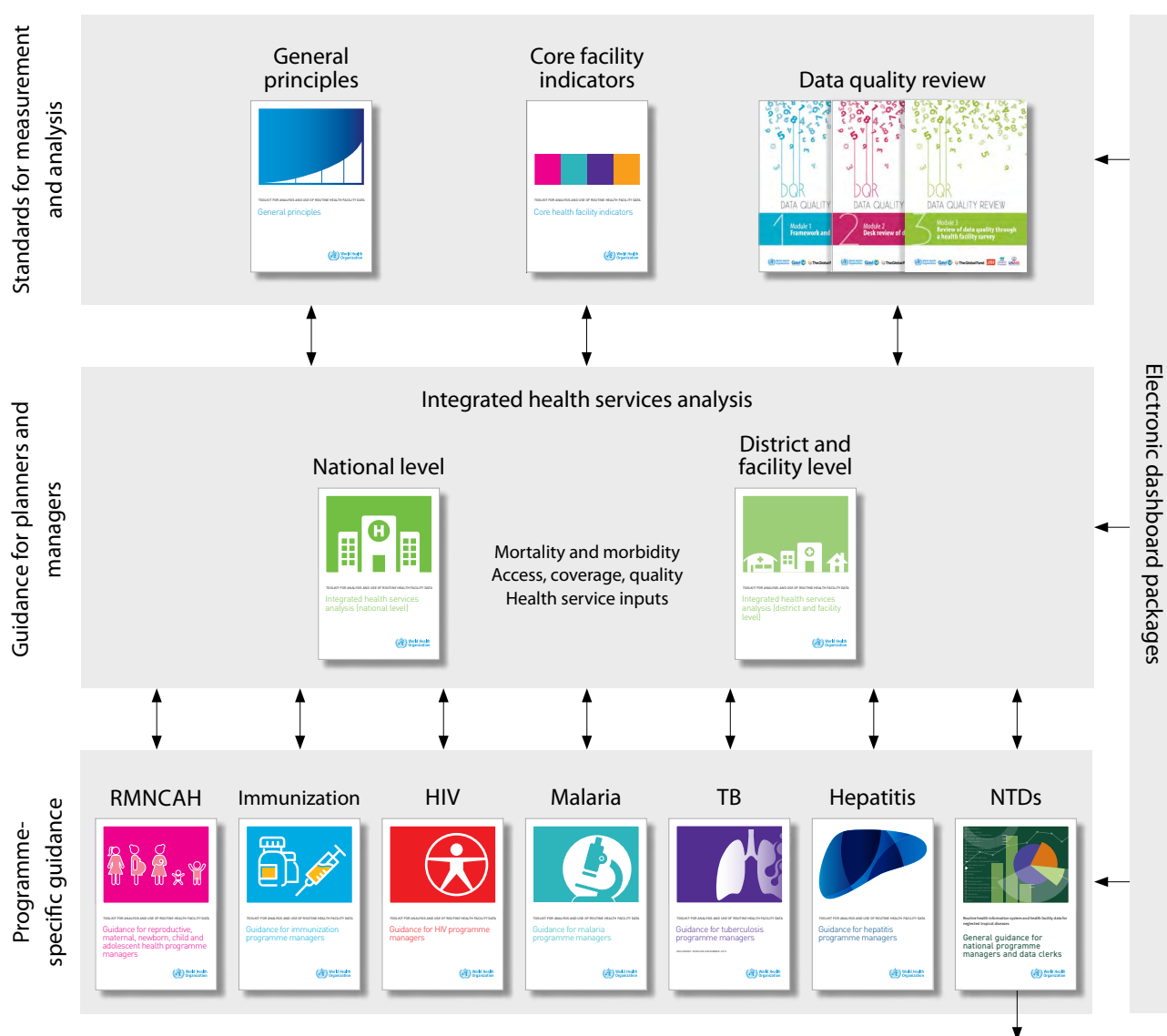
1.3 Declarations of interest

Contributing members of the Working Group on Monitoring, Evaluation and Research submitted signed disclosures of declarations of competing interests with details of academic or scientific activities for review by the secretariat. No conflicts of interest were identified.

1.4 Endorsement

This programme-specific guidance on NTDs comprises part of the corporate WHO RHIS toolkit (3). Its development was led by WHO and the Collaborating Centre on Innovation and Implementation Research for Health Information System Strengthening (University of Oslo, Norway), with support from Health Data Collaborative partners, including the United Nations Children's Fund (UNICEF), the Global Fund, GAVI, the Vaccine Alliance and the United States President's Emergency Plan for AIDS Relief (PEPFAR). The aforementioned agencies developed the initial framework which guides engagement of the Health Data Collaborative partners. This document supports the WHO secretariat's work in responding to resolution WHA60.27 on strengthening of health information systems (23 May 2007).

Fig. 1. Components of the WHO RHIS toolkit



Source: WHO toolkit for routine health information systems data (3).

- Buruli ulcer
- Chagas disease
- Cutaneous leishmaniasis
- Dengue and chikungunya
- Dracunculiasis
- Echinococcosis
- Foodborne trematodiasis
- Human African trypanosomiasis
- Leprosy
- Lymphatic filariasis
- Mycetoma, chromoblastomycosis and other deep mycoses
- Noma
- Onchocerciasis
- Rabies
- Scabies and other ectoparasitoses
- Schistosomiasis
- Snakebite envenoming
- Soil-transmitted helminthiasis
- Taeniasis and cysticercosis
- Trachoma
- Visceral leishmaniasis
- Yaws

Technical resources for community-based health interventions developed through the Health Data Collaborative (2), which includes WHO, have the following objectives:

- to enhance alignment, coordination and collaboration across global and country stakeholders dedicated to improved generation and use of community data and systems for health;
- to optimize, harmonize, and/or promote standards, guidance and tools that support integration of routine community data and data systems into broader health information system and information ecosystems; and
- to learn from and build on country community data and systems efforts aimed at supporting frontline community health worker service delivery and enhancing population health.

1.5 Purpose and scope of this document

Given the heterogeneity of NTDs, information pathways and data management practices supporting programmes to eradicate, eliminate and control these diseases have tended to be equally diverse. This situation has created an uneven, complex information pathway beset by duplication and dispersion of effort, inefficiencies and missed opportunities. The WHO-led development of the RHIS provides a unique opportunity to address several of these challenges and harness investments in systems by several stakeholders to strengthen national health information systems. In response, the Global NTD Programme has collaborated with the corporate WHO RHIS toolkit initiative by developing programme-specific guidance. The NTD component of the RHIS toolkit comprises this general guidance document, several disease-specific documents, and an area-specific document on logistics information management systems for medicines and health products.

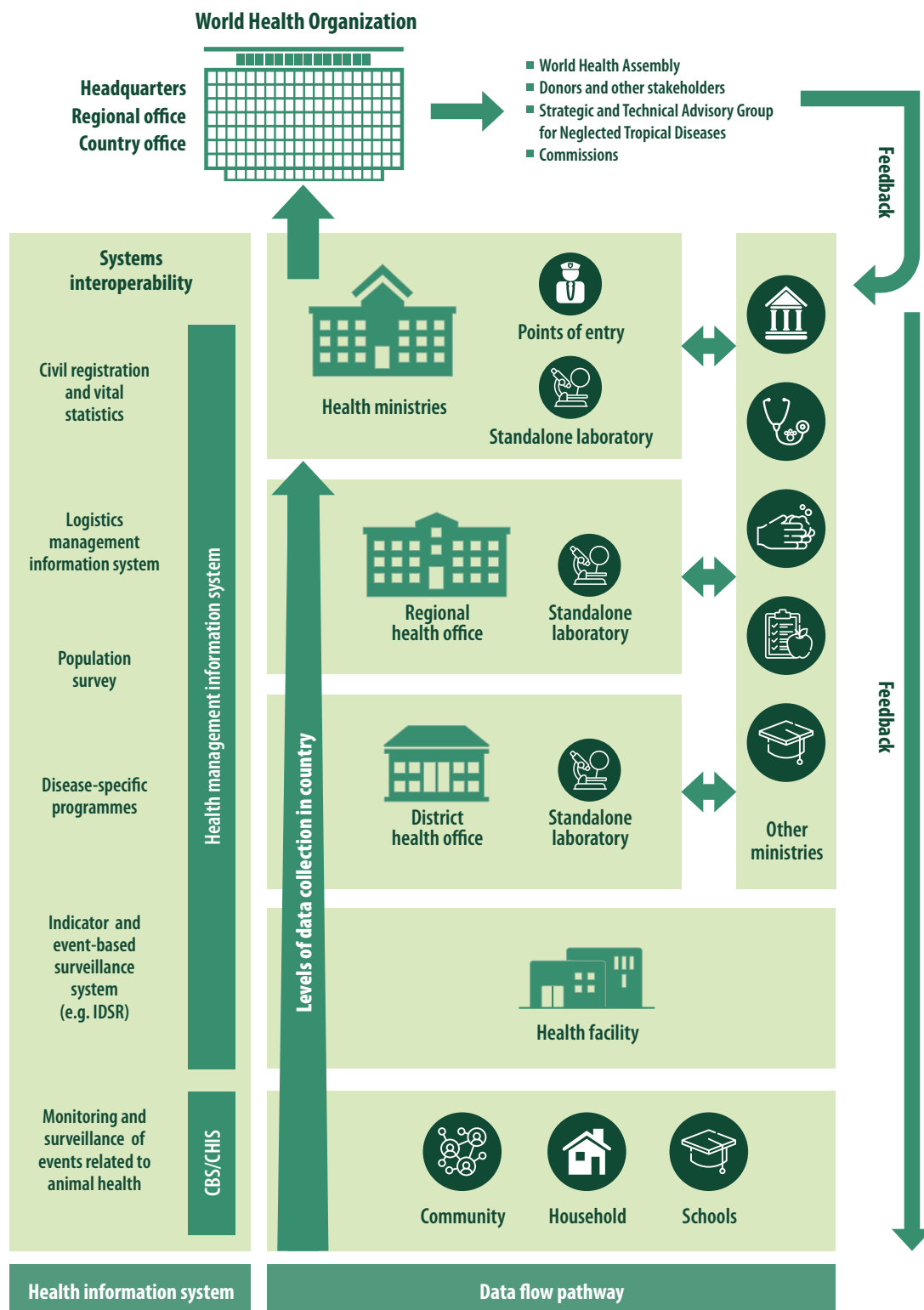
This general guidance document provides an overarching description of the NTD indicators required to monitor programme progress in alignment with the road map (1) and its related strategic companion documents including the monitoring and evaluation framework (“the M&E Framework”) (5). Its main purpose is to provide high-level concepts for NTD programme design for data management and use for health information system managers wherever NTD data are aggregated, through the hierarchy of administrative levels.

The disease-specific guidance documents provide recommendations for the basic minimum set of disease-specific indicators to be included in national routine health information systems starting at the health facility level. The development of these documents has been led by the disease focal points of the WHO Global NTD Programme in close collaboration with the respective NTD community of experts. The purpose of each document is to inform basic primary data collection of the minimum set of indicators, especially at health facilities. These documents should be used to conduct data management training that covers indicators relevant to the endemic diseases in the district. Annex 3 of the M&E framework describes the disease-specific indicators used for tracking progress of programmes towards meeting established targets (5).

NTD data are collected through a variety of means including population-based surveys, data routinely reported through health facilities and data reported routinely after community-based interventions (Fig. 2). This document emphasizes the key NTD data that are generated during clinical interactions with patients and community-based interventions within the catchment areas of the corresponding health facilities. NTD data should flow through data health information systems where they will be validated, compiled, analysed and used for decision-making at each supervisory level. Use of the national health information system facilitates mainstreaming of NTD data and enables systemic data strengthening and sustainability. NTD data should flow through established data pathways throughout the different levels of the health system within countries, as shown in Fig. 2.

This document does not include guidance on data collection from sectors beyond health (such as indicators on water, sanitation and hygiene (WASH), veterinary public health/One Health and education) and summary data collected through Civil Registration and Vital Statistics systems. Consequently, it does not include detailed information on these complementary aspects. These additional data should be obtained by the NTD programme and data managers from the relevant primary databases at country level for consideration during decision-making to inform how best to use complementary interventions in support of the NTD programme.

Fig. 2. Recommended pathway for data flow from national NTD programmes



CBS: community-based surveillance; CHIS: community health information system; IDSR: integrated disease surveillance and response.

NTD programmes are strongly encouraged to mainstream NTD data collection, storage, analysis and reporting into national health information systems (5). Mainstreaming increases the likelihood that management of NTD programme data benefits from broader health information system investments within the health sector, and is sustainable even with shifts in disease epidemiology, the donor landscape or country priorities. Mainstreaming will also allow NTD programmes to leverage administrative processes, technological advances, best practices and lessons learnt within the health information system that benefit other public health programmes. Some countries already include a few NTD-related indicators to a limited extent in their health information systems; however, in several more instances, data are not reported through the health information system but through disease-specific parallel systems, often leading to increased administrative burden and poor data quality in one or both systems. Decision-makers within the health ministry should assess NTD programmes and promote efficient integration and mainstreaming of NTD indicators into the national health information system, and vice versa.

NTD programmes should undertake a service delivery and systems readiness assessment approach to their current data management practices in order to chart how best to optimize the transition of NTD indicators into the broader national health information system (6). This transitioning and mainstreaming may be done in incremental phases if necessary. The process includes pinpointing which NTD indicators will be managed through the routine health information system, identifying at which level data entry will occur, determining the number of indicators to update, timing of transition, training individuals now responsible for data management, and training decision-makers on how to access data to be used to make decisions.

1.6 Digitization of data

The technical resources developed for health facility-based and community-based interventions have been designed to be software agnostic to facilitate digitization into any data management software for use in planning, monitoring and evaluation, budgeting, operational decision-making and patient follow up. As an example, through collaboration with the University of Oslo, technical resources for health facilities have been digitized into DHIS2 configuration packages, which some countries are adopting to support the data management needs of their health programmes. Similarly, through the global Health Data Collaborative, technical resources for community-based interventions have been digitized into DHIS2 configuration packages and implemented where needed (7). WHO Member States should choose whichever software is most suitable for use in mainstreaming and managing NTD data sustainably in the context of their national health information system.

1.7 Objectives

By the end of this document, readers should be able to:

- describe the core NTD indicators that support the national programme to monitor progress towards attaining established public health goals;
- report on trends in NTD incidence, prevalence, morbidity and mortality, at national and subnational levels;
- monitor the performance of key interventions against NTDs administered at health facilities and/or through community-based interventions;
- implement basic data quality checks and understand their implications when interpreting data; and
- use NTD data to make decisions at their corresponding administrative level.

1.8 Target audience

This document is relevant for different members of the health workforce working with NTD data, including:

- health workers and data clerks involved in first-line data collection and reporting at peripheral-level health facilities diagnosing and treating cases and/or performing outreach activities in endemic communities to fight against NTDs;
- district-level health management information officers, data clerks and teams;
- health information officers, health information system managers at district and higher administrative levels;
- ministry of health decision-makers, programme managers, epidemiologists and data managers working with the national NTD programme and on health systems strengthening;
- staff of partner organizations supporting the implementation of NTD programmes at country level, including those involved with complementary interventions such as WASH, One Health and vector control; and
- consultants and technical personnel working at research institutes involved with non-routine assessments and improvement of NTD control activities and, specifically, with the analysis of NTD data.

2. Data for neglected tropical diseases

2.1 Basic concepts and general information

NTDs are a diverse group of currently 21 diseases or conditions.¹ WHO recommends five core interventions to control, eliminate or eradicate NTDs, namely:

- Preventive chemotherapy: the large-scale delivery of safe, single-administration, quality-assured medicines, either alone or in combination, at regular intervals, to entire population groups. The intention is to reach a minimum target threshold for treatment, which must be attained to achieve the desired public health goals and outcomes.
- Case management: health-facility based individual case management through detection and (sometimes prolonged) treatment because the disease is complex to manage or because effective diagnostic tools and medicines are unavailable.
- Veterinary public health: a component of public health that focuses on the application of veterinary science as a contribution to the protection and improvement of human well-being. It is applied to neglected zoonotic diseases, which are a subset of NTDs. Zoonoses are naturally transmitted from vertebrate animals to humans and vice versa.
- Vector control: an important cross-cutting activity that aims to enhance the impact of other strategic interventions, with specific focus on prevention of selected NTDs whose transmission cycle relies on vectors or intermediate hosts. Proven, cost-effective vector control tools and interventions include long-lasting insecticidal nets, indoor residual spraying, space sprays, larvicides, molluscicides and environmental management for specific target vectors.
- WASH: a key component of the global NTD strategy. As well as supporting the achievement of Sustainable Development Goal (SDG) 6 on clean water and sanitation, WASH contributes to the achievement of SDG 3.3 to “end the epidemics of ... neglected tropical diseases”, among others. A set of core indicators define “basic” service levels for water, sanitation, hand hygiene, health care waste management and environmental cleaning in health-care facilities and at population level in the associated catchment area.

These interventions are the basis for action against NTDs. As they target diseases of inequity, NTD programmes can provide a gateway to and act as an indicator for equitable progress towards achieving universal health coverage and contribute to the achievement of the Sustainable Development Goals. Public health targets have been established for each NTD to guide the implementation of programme activities at country and community level, as defined in the *Generic framework for control, elimination and eradication of neglected tropical diseases* (8) (Table 1).

¹ Buruli ulcer; Chagas disease; dengue and chikungunya; dracunculiasis; echinococcosis; foodborne trematodiasis; human African trypanosomiasis; leishmaniasis; leprosy; lymphatic filariasis; mycetoma, chromoblastomycosis and other deep mycoses; noma; onchocerciasis; rabies; scabies and other ectoparasitoses; schistosomiasis; soil-transmitted helminthiasis; snakebite envenoming; taeniasis/cysticercosis; trachoma; and yaws.

Table 1. Public health targets for NTD programmes

Programme target	Definition ^a	Disease
Control	Reduction of disease incidence, prevalence, morbidity, and/or mortality to a locally acceptable level as a result of deliberate efforts; continued intervention measures are required to maintain the reduction. Control may or may not be related to global targets set by WHO.	Buruli ulcer Chikungunya Dengue Echinococcosis Foodborne trematodiasis Leishmaniasis (cutaneous) Mycetoma, chromoblastomycosis and other deep mycoses Noma Scabies and other ectoparasitoses Snakebite envenoming Taeniasis and cysticercosis
Elimination as a public health problem	A term related to both infection and disease. It is defined by achievement of measurable global targets set by WHO in relation to a specific disease. When reached, continued actions are required to maintain the targets and/or to advance the interruption of transmission. The process of documenting elimination as a public health problem is called validation.	Chagas disease Human African trypanosomiasis (rhodesiense) Leishmaniasis (visceral) Lymphatic filariasis
Elimination of transmission (also referred to as interruption of transmission)	Reduction to zero of the incidence of infection caused by a specific pathogen in a defined geographical area, with minimal risk of reintroduction, as a result of deliberate efforts; continued actions to prevent re-establishment of transmission may be required. The process of documenting elimination of transmission is called verification.	Human African trypanosomiasis (gambiense) Leprosy Onchocerciasis
Eradication	Permanent reduction to zero of a specific pathogen, as a result of deliberate efforts, with no more risk of reintroduction. The process of documenting eradication is called certification.	Dracunculiasis Yaws

^a Source: *Generic framework for control, elimination and eradication of neglected tropical diseases (8)*.

2.2 Administrative processes

For several NTDs, related technical guidance provides details on disease-specific indicators and describes established data processes, but mostly in a siloed manner. National NTD programmes are encouraged to transition data collection from such vertical processes to mainstreaming into existing platforms for national health information systems in alignment with strategic efforts to facilitate country ownership and sustainability. This can be achieved using an incremental, phased approach that allows for iterative learning, cyber confidence-building measures, and technical updates that improve efficiencies and strengthen the health information system.

WHO receives NTD data through formal reports submitted by its Member States that are used to monitor indicators and track progress towards the road map targets (1). Progress towards global targets depends on regular monitoring at national and subnational levels. Subnational data on several indicators need to be reported through the formal administrative pathways to the national level. The NTD data from these levels are aggregated and computed at national level for onward reporting to global levels. National health authorities are required to submit their annual country reports to WHO using the Global NTD Annual Reporting Form (GNARF) (9). Quantitative data collected across Member States are then aggregated to

measure overarching, cross-cutting and diseases-specific indicators at the global level. These data are then made publicly available through interactive dashboards in the NTD road map tracker (10) and country and disease profiles (11). Information from the GNARF is used as a core component of the annual Global report on NTDs.

2.3 Compendium of indicators

This document is complemented by a compendium of indicators for NTD data containing a standardized listing of recommended indicators relevant to countries (12). The compendium uniformly collects and interprets data, enabling comparisons over time and among different disease-specific programmes. The indicators are standardized and describe the basic terminology used for each indicator. Key terms are presented on reference sheets that specify the definition, numerator, denominator, method of measurement, method of estimation, frequency of data collection, preferred data source and key technical reference documents. These definitions enable anyone using NTD data to derive the same indicator values in a harmonized manner and allow data users to compare performance. Wherever available, the reference sheets also provide information on procedures for analysis and information for responsible entities who may be contacted to provide further clarification when needed.

3. Key programme indicators

The recommended key indicators, definitions, disaggregation levels and data sources for NTDs are summarized in Table 2. They are presented in the context of integration within NTD programmes and mainstreaming in the broader health information architecture within and beyond the health sector. Indicators for specific diseases are presented separately in the disease-specific guidance documents.

Table 2. Key indicators for tracking progress of NTD programmes

Disease	Key indicator	Measurement	Disaggregation	Data source
NTD burden				
NTD morbidity, incidence, prevalence				
All endemic NTDs	Number of cases reported, by NTD	= Number of cases reported, by NTD	• By NTD • By case classification (suspected or probable; clinically confirmed or laboratory confirmed) • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By type (new, relapse, recurrent) • By residency status (autochthonous, imported): diseases target for elimination or eradication • By potential transmission route (oral–faecal, nasal, blood, bites/skin penetration) • By administrative unit(s)	Health facility
Dracunculiasis, yaws	Number of rumours reported	= Number of rumours reported	• By diseases targeted for eradication • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By administrative unit(s)	Health facility, community-based surveys
Dracunculiasis	Number of rumours investigated within 24 hours	= Number of rumours investigated within 24 hours	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By administrative unit(s)	Health facility, community-based surveys

Disease	Key indicator	Measurement	Disaggregation	Data source
All endemic NTDs for which incidence is a key performance indicator	Annual reported incidence, by NTD	= Number of new cases of NTDs reported in a year/population living in the area x unit population	• By NTD • By case classification (suspected or probable; clinically confirmed or laboratory confirmed) • By type (new, relapse, recurrent) • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By administrative unit(s)	Health facility
All endemic NTDs for which community-based surveys are recommended	Estimated NTD prevalence, by NTD	= Number of cases of NTDs detected during the survey/ population living in the area x unit population	• By NTD • By sex • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By administrative unit(s)	Community-based surveys
NTD mortality				
Any NTD that causes death (Chagas disease, dengue, HAT, rabies, snakebite envenoming, VL and others)	Number of deaths reported attributable to NTDs	= Number of deaths reported attributable to NTDs	• By NTD • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By administrative unit(s)	Health facility or civil registration and vital statistics
Any NTD that causes death (Chagas disease, dengue, HAT, rabies, snakebite envenoming, VL and others)	NTD case-fatality rate	= Number of reported deaths associated to NTDs/number of reported cases × 100	• By NTD • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male or female) • By administrative unit(s)	Health facility or civil registration and vital statistics
Any NTD that causes death (Chagas disease, dengue, HAT, rabies, snakebite envenoming, VL and others)	NTD reported mortality rate	= Number of reported deaths associated to NTDs/population living in the area × unit population	• By NTD • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By administrative unit(s)	Health facility or civil registration and vital statistics
NTD requiring intervention				
All NTDs	Total number of people requiring interventions against NTDs	= Number of people requiring interventions by NTD	• By NTD • By intervention (clinical treatment including surgery and morbidity management, preventive chemotherapy) • By administrative unit(s)	Population-based surveys, district health office

Disease	Key indicator	Measurement	Disaggregation	Data source
NTD key interventions				
Primary care interventions (health facility based)				
All NTDs confirmed with a diagnostic test	Proportion of suspected cases confirmed by any diagnostic test	= Number of diagnostic or laboratory-confirmed cases/number of suspected cases × 100	• By NTD • By administrative unit(s)	Health facility, laboratories
All relevant NTDs	Proportion of NTD cases receiving clinical treatment	= Number of NTD cases treated/number of NTD cases reported × 100	• By NTD • By case classification (suspected, probable, clinically confirmed or laboratory confirmed) • By treatment or interventions • By administrative unit(s)	Health facility
All relevant NTDs	Proportion of NTD cases having completed a full course of treatment	= Number of cases who have completed a full course of treatment/number of cases detected × 100	• By NTD • By case classification (suspected, probable, clinically confirmed or laboratory confirmed) • By administrative unit(s)	Health facility
Community-based interventions				
All NTDs targeted for active case detection	Proportion of cases detected during active case searches (dracunculiasis, Buruli ulcer, HAT, VL, yaws)	= Number of cases detected/number of people screened during active case search × 100	• By NTD • By administrative unit(s) • By assessment method	Community-based surveys, administrative unit
Schistosomiasis	Proportion of people presenting haematuria (either visible haematuria reported by the patient or micro-haematuria detected by a positive dipstick)	= Number of individuals reporting visible haematuria or with positive dipstick for micro-haematuria/number of individuals screened × 100	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male or female) • By administrative unit(s)	Community-based interventions
Implementation units requiring PC^a	Geographical coverage of mass drug administration	= Number of endemic geographical areas treated/number of endemic geographical areas requiring treatment × 100	• By NTD • By drug • By administrative unit(s)	Community-based intervention: MDA registers or tally sheets
NTDs requiring PC^a	Geographical coverage of PC ^a for targeted NTDs	= Number of communities/villages/localities receiving PC against NTDs according to national policy	• By NTD • By type of PC • By administrative unit(s)	Community-based intervention: MDA registers or tally sheets

Disease	Key indicator	Measurement	Disaggregation	Data source
NTDs requiring PC^a	Minimum effective coverage	= Number of administrative units with effective coverage for PC interventions	• By NTD • By drug/drug package • By administrative unit(s)	Community-based intervention: MDA registers or tally sheets Targets: • SCH, STH = 75% • LF = 65% • Oncho = 65%, 80% • Trachoma = 80% • Yaws = 90% • FBTs = 75% • Taeniasis = 70%
NTDs requiring PC^a	Proportion of people receiving PC ^a for deworming	= Number of people receiving a dose of PC for deworming according to national policy/number of people targeted for PC for deworming according to national policy $\times 100$	• By NTD • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By administrative unit(s)	Community-based intervention, administrative unit
All NTDs	Number of people referred to health facility for diagnosis or treatment	= Number of people referred to health facility for diagnosis or treatment	• By NTD • By administrative unit(s)	Community-based intervention, administrative unit
NTDs requiring PC^a	Population coverage of PC for targeted NTDs	= Number of people receiving a dose of PC against NTDs according to national policy/number of people targeted for PC against NTDs according to national policy $\times 100$	• By NTD • By type of PC • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By administrative unit(s)	Community-based intervention, administrative unit
All NTDs	Proportion of households in the targeted communities that received social mobilization/awareness campaigns	= Number of households in the targeted communities that received social mobilization/awareness campaigns on NTDs/number of households in the communities targeted for social mobilization/awareness campaigns on NTDs $\times 100$	• By NTD • By NTD intervention (case management, One Health approach, PC, vector control) • By administrative unit(s)	Community-based intervention, administrative unit
Skin NTDs	Proportion of people screened for skin lesions consistent with NTDs (and population coverage)	= Number of people screened for skin NTDs/population targeted for skin NTD screening $\times 100$	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By administrative unit(s)	Community-based intervention, district/subdistrict

Disease	Key indicator	Measurement	Disaggregation	Data source
All relevant NTDs	Proportion of people suffering from physical disability related to NTDs who receive rehabilitation support	= Number of people suffering from physical disability related to NTDs who receive rehabilitation support/ number of people suffering from physical disability related to NTDs $\times 100$	• By sex • By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By residential status (resident/migrant) • By administrative unit(s)	Health facility, community-based intervention, administrative unit
All relevant NTDs	Proportion of cases who received instructions for self-care for relevant NTDs	= Number of NTD cases who received instructions for self-care for relevant NTDs/ number of NTD cases relevant for self-care $\times 100$	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By residential status (autochthonous, imported) • By administrative unit(s)	Health facility, community-based intervention, administrative unit
All NTDs	Proportion of people assessed for mental, neurological and substance use (MNS) disorders	= (Number of people with an NTD assessed for MNS disorders or mental health conditions/number of people with a possible MNS symptom) $\times 100$	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By pregnancy/postpartum • By type of MNS disorder (depression, psychoses, epilepsy, child and adolescent mental and behavioural conditions, dementia, substance use conditions, suicide/self-harm) • By sub-population with comorbid conditions (e.g. HIV, TB, NCD) • By administrative unit(s)	Health facility, community-based intervention, administrative unit
All NTDs	Proportion of people with mental, neurological and substance use (MNS) disorders referred	= (Number of people with an NTD assessed for MNS disorders or mental health conditions who have been referred to specialist services/ total number of people assessed for MNS disorders or mental health conditions) $\times 100$	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By pregnancy/postpartum • By type of MNS disorder (depression, psychoses, epilepsy, child and adolescent mental and behavioural conditions, dementia, substance use conditions, suicide/self-harm) • By sub-population with comorbid conditions (HIV, TB, NCD) • By administrative unit(s)	Health facility, community-based intervention, administrative unit

Disease	Key indicator	Measurement	Disaggregation	Data source
All NTDs	Proportion of people with mental, neurological and substance use (MNS) disorders receiving services	= (Number of people with an NTD assessed for MNS disorders or mental health conditions receiving services/total number of people assessed for MNS disorders or mental health conditions) × 100	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By pregnancy/postpartum • By type of MNS disorder (depression, psychoses, epilepsy, child and adolescent mental and behavioural conditions, dementia, substance use conditions, suicide/self-harm) • By sub-population with comorbid conditions (e.g. HIV, TB, NCD) • By administrative unit(s)	Health facility, community-based intervention, administrative unit
Integrated vector control				
Vector-borne NTDs requiring integrated vector control^b	Proportion of households covered by IVM activities for NTDs	= Number of households covered by IVM activities for NTDs/ number of households targeted by IVM activities for NTDs × 100	• By NTD • By relevant IVM interventions (spraying, source reduction, insecticide-treated net use) • By administrative unit(s)	Integrated vector management team (includes district, health facility and community) and/ or vector control activity reports
Vector-borne NTDs requiring integrated vector control^b	Proportion of targeted houses/structures covered by domiciliary vector reduction measures	= Number of houses/ structures where some domiciliary vector reduction measures were implemented/number of houses targeted for domiciliary vector reduction measures × 100	• By targeted vector • By administrative unit(s)	Integrated vector management team (includes district, health facility and community) and/ or vector control activity reports
Vector-borne NTDs requiring integrated vector control^b	Proportion of population at risk covered by IVM activities for NTDs	= Number of people protected by IVM activities for NTDs annually/population at risk of vector-borne NTDs × 100	• By relevant interventions (spraying, source reduction, infrastructure improvement, mollusciciding, etc.) • By NTD • By administrative unit(s)	Integrated vector management team (includes district, health facility and community) and/ or vector control activity reports
Vector-borne NTDs requiring integrated vector control^b	Vector abundance (surveillance)	= Periodic assessments of vectors transmitting NTDs	• By vector species • By stage (adult/immature stage) • By administrative unit(s)	Entomological survey by integrated vector management team (includes district, health facility and community) or routine sentinel surveillance

Disease	Key indicator	Measurement	Disaggregation	Data source
Vector-borne NTDs requiring integrated vector control^b	Insecticide resistance monitoring	= Proportion of sites with confirmed/possible insecticide resistance = Proportion of resistant vectors, i.e. number of vectors resistant or susceptible/total number of vectors	• By vector species • By insecticide used • By administrative unit(s)	Entomological survey by integrated vector management team (includes district, health facility and community) or routine monitoring of resistance
All relevant NTDs	Proportion of eligible water sources where vector control activities were conducted	= Number of eligible water sources where vector control activities are conducted/total number of eligible water sources targeted for treatment × 100	• By administrative unit(s)	Integrated vector management team (includes district, health facility and community) and/or vector control activity reports
All relevant NTDs	Proportion of households with all water storage containers covered and protected (safe water storage practices)	= Number of households with all water storage containers covered and protected/number of households visited in the catchment area × 100	• By targeted vector • By administrative unit(s)	Integrated vector management team (includes district, health facility and community) and/or vector control activity reports
One Health^c				
Rabies and snakebite envenoming	Number of people bitten by animals	= Number of people bitten by an animal	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By animal (dog, snake or other) • By administrative unit(s)	Health facility, community-based interventions
Rabies and snakebite envenoming	Number of deaths in the community occurring within 3 months after a snakebite or a dog bite	= Number of deaths in the community occurring within 3 months after a snakebite or a dog bite	• By age group (years): < 1 year, 1–4 years, 5–14 years, 15–24 years, 25–49 years, 50–64 years, 65 and older • By sex (male/female) • By animal (dog, snake or other) • By administrative unit(s) • By residential status (autochthonous, imported) • By administrative unit(s)	Health facility
Rabies and snakebite envenoming	Number of people receiving prophylactic treatment for animal bites	= Number of people receiving antivenom = Number of people receiving post-exposure prophylaxis = Number of people receiving appropriate bite wound care	• By animal • By administrative unit(s)	Health facility (including specialized animal bite treatment centres)

Disease	Key indicator	Measurement	Disaggregation	Data source
Logistics				
All endemic NTDs	Opening stock	= Number of medical products available at the health facility at the beginning of the month	• By NTD medical product by type • By administrative unit(s)	Health facility, pharmacy records, warehouse (logistics team)
	Medical products received	= Number of medical products received by the health facility during the month	• By NTD medical product by type • By administrative unit(s)	Health facility, pharmacy records, warehouse (logistics team)
	Medical products used/ consumed	= Number of medical products used by the health facility during the month	• By NTD medical product by type • By administrative unit(s)	Health facility, pharmacy records, warehouse (logistics team)
	Days stocked out	= Number of days during which an item is out of stock at any time	• By NTD medical product • By administrative unit(s)	Health facility, pharmacy records, warehouse (logistics team)
	Medical products expired	= Number of medical products expired during the month	• By NTD medical product • By administrative unit(s)	Health facility, pharmacy records, warehouse (logistics team)
Human resources				
All endemic NTDs	Number of health workers trained on the relevant endemic NTDs	= Number of health workers receiving integrated in-service training on NTDs at least once a year	• By NTD • By administrative unit(s)	Health facility, district management team records

FBT: foodborne trematodiasis; HAT: human African trypanosomiasis; IVM: integrated vector management; MDA: mass drug administration; MNS: mental, neurological and substance use; NDC: noncommunicable disease; NTD: neglected tropical disease; PC: preventive chemotherapy; SCH: schistosomiasis; STH: soil-transmitted helminthiasis; TB: tuberculosis; VL: visceral leishmaniasis.

^a NTDs requiring PC: FBTs, LF, onchocerciasis, schistosomiasis, STH, taeniasis, trachoma and yaws.

^b Vector-borne NTDs requiring integrated vector control: Chagas disease, chikungunya, dengue, dracunculiasis, HAT, leishmaniasis and SCH.

^c This table presents only the One Health indicator, which can be captured at the health facility. Other One Health and WASH indicators are measured by their respective programmes and sectors. The NTD programme should obtain data from the relevant programmes and use it as secondary data to inform activities and decision-making.

4. Data quality considerations

Correct interpretation of data relies on the quality of the data that are collected, analysed and reported. There are multiple reasons why data quality may be low, such as inconsistent data entry, cleaning and management practices across individuals, or limited resources available for entering and cleaning data. Establishing systems and protocols to enhance high-quality data collection and reporting can facilitate data analysis and use. However, as for all data sources, any analysis must consider whether the results are affected by data quality issues.

NTD data should be considered during these regular data audits and reviews that are routinely conducted for the health information system. WHO has developed data quality review toolkits which provide guidance for defining measures of data quality, conducting a desk review to assess data quality and conducting data verification of routine facility data systems (13, 14). The standard metrics for periodic assessments of data quality are summarized in Table 3 and should be used when assessing the quality of routinely reported NTD data. The data quality of recommended core indicators is examined against these standard metrics. The benchmarks and cut-offs for measuring quality are also shown. These recommended benchmarks should be tailored to the country context, in consultation with the national health information management system unit.

Table 3. Standard metrics for periodic assessment of data quality for NTD programmes

Data quality metric	National level	Subnational level
Completeness of health facility reporting	% of expected facility monthly reports for previous one year that are actually received	Number and % of districts with at least 90% of monthly facility reports received
Timeliness of health facility	% of submitted facility monthly reports for the previous one year that are received on time	Number and % of districts with at least 75% of monthly facility reports received
Completeness of district reporting	% of expected district monthly reports that actually received	Number and % of districts that submitted 100% of expected monthly reports
Timeliness of district reporting	% of submitted district monthly reports for previous one year that are received on time	Number and % of districts that submitted on time at least 75% of monthly reports received at national level from district
Completeness of indicator data	% of data elements that are non-zero values, % of data elements that are non-missing values	Number and % of districts with <90% non-zero values; non-missing values
Consistency of reporting of completeness	Evaluate the trend in completeness of reporting from district to national over the past 3 years.	Evaluate the trend in completeness of reporting from health facility to district over the past 3 years.

4.1 Standard metrics for periodic assessment of data quality for NTD programmes

4.1.1 Completeness and timeliness of reporting

Completeness measures the extent to which priority data elements are included in each report. It can be calculated by reviewing the number of reports that were submitted over the number of reports expected and should also examine completeness of the indicators within the forms themselves.

Timeliness refers to whether reporting units submit their data according to the timeline set by national NTD programme and HMIS guidelines. It can be calculated by the number of reports received on or before the specified deadline divided by the number of reports expected. If timeliness is poor, caution should be taken when interpreting the data immediately after the deadline, and efforts should be put in place to address the issues for late reporting.

4.1.2 Internal consistency

Internal consistency relates to the coherence of data being evaluated. It examines whether data are coherent when collected over time and across locations. It checks for presence of outliers, consistency over time, consistency between indicators, and compares reported data and original records. Data that are not internally consistent may not be inaccurate, and such inconsistencies should be followed up and addressed through training and supervision. The data quality check should consider a select set of questions to assess the internal consistency of the reported data.

Sample questions

- Are there any outliers or reported values which are unusually high or low compared to other reporting units or compared to historical performance? These outliers may be the result of changes in the programme—for example, increased coverage resulting from a mop-up campaign—but may alternatively be an issue with data quality.
- Do the reported data have the same values over time or locations?
- Do the values show an unexpected pattern, such as always ending in 5, or always 100%?
- Are the values of related indicators aligned? For example, the number of persons treated is related to the number of doses administered.

4.1.3 External consistency

External consistency assesses the level of agreement between two different sources of data measuring the same health indicator. The two sources of data that are usually compared are data flowing through the routine health information system or the programme-specific information system and data from periodic population-based surveys.

It is valuable to check for external consistency as part of validation of routinely collected data against such other data sources which may be more rigorous but are collected less frequently due to the high resource requirements for that type of data collection such as health facility assessments, specialized studies or population-based coverage evaluation surveys. Such comparisons should be made as and when updated external data become available, e.g. annually or less frequently.

Examples of external sources of NTD data which may be used to check for external consistency to determine whether two sources of information fall within a similar range include:

- disease prevalence surveys;
- burden of disease estimates by scientific research and centres of excellence institutions;
- specially commissioned studies;
- pharmacy records;
- logistics management information system; and
- integrated diseases surveillance and response information systems.

4.1.4 Consistency of population data

Consistency of population data relates to the evaluation of adequacy of denominators used for calculating performance indicators. The desired observation is that as the denominator value in the data set increases, the outcome of the computation procedure should approach the correct anticipated outcome.

- Examine the consistency of denominator data with different sources of the same information, at corresponding administrative levels.
- Conduct reviews of denominator data during regular data review activities.
- Possible sources of denominator data include: national bureau of statistics census data, health programme census data, other sector census data.

5. Use of key indicators

5.1 Measurement and basic analysis of disease burden

NTDs have complex epidemiologies with diverse life cycles that typically involve the environment, vectors, zoonotic reservoirs, and intermediate and definitive hosts. As a result, measurement of progress towards established programme goals is challenging. The overall performance of national NTD programmes is monitored using composite indicators that track progress towards the road map targets at macro levels and through disease-specific indicators that track programme process nationally and subnationally. This enables monitoring of NTD disease burden within the context of national health systems and facilitates synergistic intersectoral actions.

The main objectives of measuring NTD burden are to:

- determine the geographical distribution of cases, by administrative level;
- monitor disease incidence, prevalence, morbidity and mortality trends over time;
- track patient case load, particularly at each major treatment facilities; and
- assess progress towards disease control, elimination and/or eradication targets.

The burden of disease for NTDs is presented in numerical values based on commonly used health metrics which measure three categories.

5.1.1 Number of cases

The number of cases reports a numerical value that provides a count for cases of disease, which are described as follows:

- Suspected case: a patient who meets set clinical criteria and does not have presumptive or supportive laboratory results.
- Probable case: a patient who meets set clinical criteria, and has presumptive laboratory results or is epidemiologically linked to a cluster of cases.
- Confirmed case: a patient with a clinically compatible illness that is laboratory confirmed.
- Imported case: a patient with a clinically compatible illness that is laboratory confirmed, whose residence is external to the national borders of where the patient presents.
- Relapse case: a person with a disease who has previously completed a full treatment course for the disease, was declared cured or treatment completed at the end of their treatment and then afterwards was diagnosed with the same disease.
- Recurrent case: a person with repeated clinical presentation of a disease, who having received treatment and was cured, then presents again with a separate episode of illness for the same disease.

The majority of NTD programmes most commonly use the categorization of suspected, probable and confirmed. The Annex presents a summary case definition and description of what constitutes a case for NTDs, and its related code from the *International classification of diseases*, 11th edition (ICD-11) (15).

5.1.2 Disease frequency

Measures of disease frequency describe how often a disease occurs in a population and aim to identify how disease may differ over time or among subgroups. Two key measures are important for investigating the potential causes of a disease and determining effective methods for prevention and care: prevalence and incidence.

Prevalence represents existing cases of a disease and can be seen as a measure of disease status. It is the proportion of people in a population having a disease. The prevalence is often useful as it reflects the burden of a disease in a certain population and is not limited to burden in terms of socioeconomic status and costs related to access to interventions. Knowledge of prevalence of disease can help decision-makers to determine where investments in health care should be targeted.

$$\text{Prevalence} = \frac{\text{Number of individuals having the disease at a point in time}}{\text{Total number of individuals in the population}}$$

Incidence reflects the number of new cases of disease within a certain period and can be expressed as a risk or an incidence rate. The incidence rate is the more commonly used measure for NTD programmes. It is calculated by dividing the number of individuals developing a disease by the total period of time during which all people in the set area are at risk of the disease. The denominator includes a measure of time instead of a number of individuals. The incidence rate is therefore interpreted as an instantaneous concept, like speed. For NTD programmes, incidence rates are usually considered for a reporting period of 12 months (calendar year).

$$\text{Incidence rate} = \frac{\text{Number of individuals developing the disease}}{\text{Total time at risk for the disease for all subjects followed}}$$

Generally, NTD programmes do not routinely measure risk, which is a measure that determines the probability that individuals within a population will develop a given disease, or other health outcome, over a specified follow-up period. This requires that individuals who are without a disease and living in an endemic area are followed up over time. Where required, other methods such as periodic surveys, sentinel surveillance and analysis of secondary data from other sectors (WASH, environment, One Health, etc.) can be applied to determine a measure of risk.

5.1.3 Disease outcomes

The following measures of disease outcomes are used:

- Cure is when an individual is without illness as a result of the successful treatment of a disease.
- Relapse is when an individual has completed a full course of treatment for a disease and experiences a return of the disease after weeks or months after its apparent cessation.
- Morbidity is the state of being symptomatic or unhealthy for a disease or condition. It is usually represented or estimated using prevalence or incidence.
- Mortality is the number of deaths caused by the disease under investigation. It can be communicated as an absolute numeric number or as a rate. Mortality usually gets represented as a rate per 1000 individuals, also called the death rate.

$$\text{Mortality} = \frac{\text{Number of deaths caused by the disease}}{\text{Total population affected by the disease}}$$

$$\text{Mortality rate} = \frac{\text{Number of deaths caused by the disease}}{\text{Total population affected by the disease in a given time period}}$$

Note: To keep the mortality rate value concise and for ease of comparison to other health events, this number can be multiplied by 1000 to reflect the “per 1000” rate of the target population.

Morbidity and mortality are two types of retrospective information that allow for continuous evaluation of the effectiveness of either a specific health care system or an implemented public health intervention. Both measures are most commonly used for epidemiological surveillance to describe the progression and severity of a given health event. They are useful tools for learning about risk factors of diseases, comparing and contrasting health events between different populations, and enabling further epidemiological study of the disease burden NTDs place on a population. These metrics also allow stakeholders to more effectively prioritize which health events to tackle and allocate resources towards and more proactively manage the potential onset of significant health events and risks associated with NTDs. Additionally, mortality caused by NTDs should also be linked to the national civil registry for vital statistics and routinely reported along with programme data on deaths documented by other health programmes.

The above measures of NTD disease burden can be further analysed and calculated to compare baseline and benchmark values against established programme targets and across administrative units. These measures are also typically disaggregated by various factors by NTD (Table 4).

Table 4. Types of data disaggregation of data for NTD programmes

Data element	Disaggregation
Sex	Male, female
Age group	Preschool-aged children (< 1 year, 1–4 years), school-aged children (5–14 years), adults (15–24 years, 25–49 years, 50–64 years, 65 and older)
Young adults	19–24 years
Women of child bearing age	15–49 years
Geo-location	Rural, urban
Disease status	Suspected, probable, confirmed
Case type	New case, relapse, chronic
Administrative level	National, subnational (region, state, district, village)
Residence	Autochthonous/indigenous, imported/non-indigenous
Intervention type	Routine health facility-based treatment Community-based periodic mass treatment

Note: Some of these disaggregation types may be more relevant for some NTDs than others. Details on the preferred data aggregation type are provided in the relevant disease-specific documents which complement this general guidance.

5.2 Interpretation and use of data

NTD data provide valuable insights for decision-making at individual and population levels. When analysing NTD data over time, national programme managers and data clerks should observe changes that depict increases or decreases in values, how these values compare with the targeted values, whether such changes are heterogenous or not, and how the observed values compare against baseline or annual benchmark values. NTD data should also be analysed to determine whether certain subpopulations are experiencing higher disease burden than others, especially for vulnerable populations such as those of

lower socioeconomic status, rural areas, indigenous populations, women, children and older people. This information should be used to inform how interventions are carried out. In practice, community data and health facility-based data should be used to inform inventory management and provide personalized health care to patients. Additionally, analysis of core indicators for NTD programmes that is obtained from health facilities should be supplemented by analysing data on community-based interventions, which can help stakeholders understand why targeted results are or are not being realized against set targets.

The most commonly applied analytics to NTD data consider age groups, spatial parameters and disease outcome measures over a time series, often displayed as charts or in summary tables, which are sufficient for simple reporting from a disease-specific perspective and detecting outbreak-prone NTDs. However, consideration of these few aspects of NTD data in analytics limits their potential. This is further compounded by the weak or limited mainstreaming of NTD data pathways into existing national health information systems and institutional planning mechanisms. Consequently, most NTD programmes are not harnessing the full potential of medical data analytics, clinical data analytics and hospital data analytics to enable health-care professionals at various levels of national health systems to make well-informed decisions that can lead to significant improvements in service delivery, patient care and health-care management.

6. Conclusion

Health service data play a crucial role in patient management, facility administration, disease surveillance, and monitoring service delivery and resource utilization. These data are indispensable for countries as they strive to evaluate the effectiveness of their health-care systems, and subsequently achieve universal health coverage and the Sustainable Development Goals. NTD data must therefore be incorporated and included in national health information systems and reflected in computations measuring progress towards universal health coverage and the Sustainable Development Goals.

The road map calls for three strategic shifts in approaches to tackling NTDs: (i) increase accountability for impact by using impact; (ii) move away from siloed, disease-specific programmes by mainstreaming programmes into national health systems and intensifying cross-cutting approaches centred on the needs of people and communities; and (iii) change operating models and culture to facilitate greater ownership of programmes by countries. Tracking and guiding country progress through these fundamental shifts requires the generation and use reliable NTD data.

This general guidance document presents the minimum standards and harmonized core indicators that should be implemented within existing national health information systems using a systems-based approach to strengthening information at country level. National programme managers and data clerks are encouraged to use the guidance to facilitate mainstreaming of NTD data into national health information systems and sustainably strengthen the evidence-base for guiding programme implementation at all levels.

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Annex. Case definitions for neglected tropical diseases

Disease (reference)	Case definition	Description
Buruli ulcer (1) ICD-11: 1B21.20	Suspected	Any person with painless nodule, papule, plaque or oedema evolving into a painless ulcer with undermined edges, often leading to invalidating sequelae in an endemic area.
	Probable	Not applicable
	Confirmed	A suspected case confirmed by direct microscopy, histopathology, culture, mycolactone test or PCR.
Chagas disease (2) ICD-11: 1F53	Suspected	Not applicable
	Probable	Acute case in endemic areas: person with unexplained fever, hepatosplenomegaly and a chagoma (inflammation at site of infection).
	Confirmed	A clinically compatible case that is laboratory-confirmed with positive parasitology or serology with two positive patterned reactions.
Chikungunya (3) ICD-11: 1D40	Suspected	Any person with acute onset of fever > 38.5 °C and severe arthralgia/arthritis not explained by other medical conditions.
	Probable	A patient meeting both the clinical and epidemiological criteria.
	Confirmed	A suspected case with laboratory confirmation.
Chromoblastomycosis (4) ICD-11: 1F24	Suspected	Presence of a skin lesion clinically consistent with chromoblastomycosis, i.e.: - a lesion that begins as an erythematous macular skin lesion and progresses to a pink and smooth papular lesion. With time, the lesion might manifest as a papulosquamous lesion and evolve with polymorphic aspects. or - a nodule or plaque or verrucous or tumoral lesion on the skin with visible black dots (pepper-like appearance) on the surface.
	Probable	Suspected chromoblastomycosis based on clinical examination and Fungal culture from a clinical specimen with growth of a melanized fungus consistent with <i>Fonsecaea</i> spp., <i>C. carrionii</i> , or <i>R. aquaspersa</i> from a clinical sample with no molecular confirmation available.
	Confirmed	Suspected chromoblastomycosis based on clinical examination AND Skin lesion with direct mycological examination and/or histopathology showing pigmented thick-walled cross-septate fungal cells (muriform, sclerotic, Medlar, fumagoid cells/bodies).

Disease (reference)	Case definition	Description
Dengue (5) ICD-11: 1D20 Dengue without warning signs 1D21 Dengue with warning signs 1D22 Severe dengue	Suspected	Dengue: A person who lives in or has travelled to areas with dengue transmission in the last 14 days and presents acute fever, usually from 2 to 7 days duration, and two or more of the following manifestations: nausea/vomiting, rash, headache/retro-orbital pain, myalgia and arthralgia, petechiae or positive tourniquet test (+), leukopenia, with or without any warning sign or sign of severity. Any child who resides or has travelled in the last 14 days to an area with dengue transmission that presents acute fever, usually from 2 to 7 days duration, with signs of a neurological focus is also considered a suspected case. Severe dengue: Every dengue case that has one or more of the following manifestations: • shock or respiratory distress due to severe plasma leakage • shock evident from tachycardia, cold extremities, and capillary refill time equal to or greater than three seconds, weak or undetectable pulse, convergent/ differential blood pressure ≤ 20 mmHg; arterial hypotension in late phase. Severe bleeding, based on evaluation by the attending physician (e.g. hematemesis, melena, ample metrorrhagia, and central nervous system bleeding). Severe organ involvement, such as major liver impairment (AST or ALT > 1000 IU), central nervous system (change in mental state), heart (myocarditis), or other organs. <i>Note:</i> Every severe case should be confirmed by laboratory tests specific for dengue.
	Probable	Every suspected dengue case that has a positive IgM or NS1 result or clinical-epidemiological link. <i>Note:</i> During outbreaks, reported cases that could not be investigated are also considered probable dengue cases, since it is considered that all have a clinical-epidemiological link.
	Confirmed	Every laboratory-confirmed dengue case (molecular techniques, such as conventional RT-PCR, real-time RT-PCR, or others; viral isolation, IgM or IgG seroconversion in paired sera or a fourfold IgG titer increase). <i>Note:</i> Laboratory diagnosis should include differential diagnosis for other diseases, according to the epidemiological characteristics of each country. Serological diagnosis should include an evaluation of cross-reactivity with other flaviviruses.
Dracunculiasis (6) ICD-11: 1F64	Suspected/ rumours	Information about an alleged case/infection of dracunculiasis (Guinea-worm) obtained from any source (informants).
	Probable	Not applicable
	Confirmed	A person exhibiting a skin lesion with emergence of a Guinea worm, and in which the worm is confirmed in laboratory tests to be <i>Dracunculus medinensis</i>. That person is counted as a case only once during the calendar year (i.e. when the first worm emerges from that person). All worm specimens should be obtained from each case patient for laboratory confirmation and sent to the United States Centers for Disease Control and Prevention (CDC). All cases should be monitored at least twice per month during the remainder of the calendar year for prompt detection of possible emergence of additional guinea worms.
Echinococcosis (7) ICD-11: 1F73	Suspected	Cystic echinococcosis: person living in an endemic area showing clinical signs compatible with hydatid disease.
	Probable	Cystic echinococcosis: person living in an endemic area with positive serology or imaging.
	Confirmed	Cystic echinococcosis: a probable case confirmed by both imaging and serology.

Disease (reference)	Case definition	Description
Foodborne trematodiasis (8) ICD-11: 1F80 Clonorchiasis 1F82 Fascioliasis 1F84 Opisthorchiasis 1F85 Paragonimiasis	Suspected	- Clonorchiasis, opisthorchiasis: person living in an endemic area with signs compatible with gall bladder obstruction or cholangiocarcinoma. - Fascioliasis: person living in an endemic area with extreme abdominal pain or signs compatible with liver inflammation, jaundice or anaemia. - Paragonimiasis: person living in an endemic area showing symptoms and signs similar to those of tuberculosis or lung cancer.
	Probable	Not applicable
	Confirmed	Suspected case confirmed by parasitological and or immunological methods.
Human African trypanosomiasis (HAT) (9) ICD-11:1F51 1F51.0 Gambiense trypanosomiasis 1F51.1 Rhodesiense trypanosomiasis	Suspected	Not applicable
	Probable	Serological unconfirmed case: individual with an epidemiological risk for HAT in whom anti-trypanosomal antibodies have been detected with a validated serological test with high positive predictive value, in whom trypanosomes are not observed microscopically in body fluids. Molecular unconfirmed case: individual with an epidemiological risk for HAT in whom specific DNA or RNA has been detected in body fluids but in whom trypanosomes are not observed microscopically in body fluids.
	Confirmed	Individual with an epidemiological risk for HAT infection in whom trypanosomes have been observed microscopically in one or more body fluids.
Leishmaniasis (cutaneous) (10) ICD-11: 1F54.1	Suspected	Not applicable
	Probable	A person showing clinical signs (skin or mucosal lesions) without parasitological confirmation of the diagnosis (positive smear or culture).
	Confirmed	A person showing clinical signs (skin or mucosal lesions) with parasitological confirmation of the diagnosis (positive smear or culture) and/or, for mucocutaneous leishmaniasis only, serological diagnosis.
Leishmaniasis (post kala-azar dermal leishmaniasis) (11) ICD-11: 1F54.0	Suspected	Not applicable
	Probable	A patient from an area endemic for kala-azar with multiple hypopigmented macules, papules or plaques or nodules with no sensitivity loss.
	Confirmed	A patient from an area endemic for kala-azar with multiple hypopigmented macules, papules, plaques or nodules who is parasite- or PCR-positive in a slit skin smear or biopsy.
Leishmaniasis (visceral) (VL) (11) ICD-11: 1F54.0	Suspected	Not applicable
	Probable	A person living in or having travelled to VL endemic areas showing clinical signs and symptoms of VL (mainly irregular fever lasting more than two weeks and splenomegaly and/or weight loss).
	Confirmed	A person showing clinical signs (mainly prolonged irregular fever, splenomegaly and weight loss) with serological and/or parasitological confirmation.

Disease (reference)	Case definition	Description
Leprosy (12) ICD-11: 1B20	Suspected	A person who shows the following signs and symptoms: dark-skinned people might have light patches on the skin, while pale-skinned people have darker or reddish patches; loss or decrease of sensation in the skin patch; numbness or tingling of the hand or feet; weakness of the hands, feet or eyelids; painful or tender nerves; swelling or lumps in the face or earlobes; painless wounds or burns on the hands or feet.
	Probable	Not applicable
	Confirmed	Leprosy is diagnosed by finding at least one of the following cardinal signs: definite loss of sensation in a pale (hypopigmented) or reddish skin patch; thickened or enlarged peripheral nerve, with loss of sensation and/or weakness of the muscles supplied by that nerve; presence of acid-fast bacilli in a slit-skin smear.
Lymphatic filariasis (13) ICD-11: 1F66.3	Suspected	Not applicable
	Probable	A case that meets clinical case definition.
	Confirmed	A person with positive laboratory criteria even if he/she does not meet the clinical case definition (hydrocoele or lymphoedema in a resident of an endemic area for which other causes of these findings have been excluded).
Mycetoma (14) ICD-11: 1G60.0	Suspected	A patient suspected of having mycetoma if: I. The patient presents with the triad of: • A painless subcutaneous mass • Multiple sinuses formation • Purulent or sero-purulent discharge that contains grains. II. The patient presenting with mass only but, from high endemic areas and/or with history of local trauma III. The patient presents with mass is having a relevant occupational history (farmer or shepherd). IV. The patient presents with mass is resident or with a history of visiting animal corral area.
	Probable	Ultrasound examination of the suspected lesion, cytological examination showed inflammatory cells, but no grains were seen.
	Confirmed	Diagnosis is confirmed by the lesion ultrasound examination, Aspiration cytology, surgical biopsy and histopathological examination confirm, grains culture and PCR examinations.
Noma (15, 16) ICD-11: DA0C.31	Suspected	A necrotizing orofacial disease affecting mostly children aged 2–6 years who suffer from malnutrition and live in extreme poverty, often with a notable medical history of antecedent illness such as gastroenteritis, measles, malaria, bronchopneumonia, tuberculosis or HIV infection.
	Probable	Localized gingival ulceration spreading rapidly through orofacial tissues. Acute phase is characterized by chronic malnutrition, halitosis, mouth soreness, excessive salivation, facial swelling, difficulty in swallowing and often with fever.
	Confirmed	There is currently no point of care diagnostic test. Diagnosis is predicated on clinical manifestations. WHO classifies noma into five clinical stages: Stage 0 – simple gingivitis (gum inflammation) Stage 1 – acute necrotizing gingivitis Stage 2 – oedema Stage 3 – gangrene Stage 4 – scarring Stage 5 – sequelae

Disease (reference)	Case definition	Description
Onchocerciasis (17) ICD-11: 1F6A	Suspected	In an endemic area, a person with fibrous nodules in subcutaneous tissues and/or patchy loss of skin pigmentation
	Probable	Not applicable
	Confirmed	A suspected case that is confirmed by one or more of the criteria: Presence of microfilariae in skin snips. Presence of adult worms in excised nodules. <i>and</i> Presence of typical ocular manifestations, such as punctate keratitis and/or positive identification of microfilariae (e.g. slit-lamp observations of microfilariae in the cornea) in the eye.
Rabies (18) ICD-11: 1C82	Suspected	A case that is compatible with a clinical case definition of human rabies. (A suspected clinical case of rabies in humans is defined as: an acute neurological syndrome (i.e. encephalitis) dominated by forms of hyperactivity (furious rabies) or paralytic syndromes (paralytic rabies) progressing towards coma and death, usually by cardiac or respiratory failure, typically within 7–10 days of the first signs if no intensive care is instituted.)
	Probable	A suspected case plus a reliable history of contact with a suspected, probable or confirmed rabid animal.
	Confirmed	A suspected or probable case that is confirmed in a laboratory.
Scabies (19) ICD-11: 1G04	Suspected	A person with intense itching and a pimple-like skin rash papules or burrows in typical locations, including the web spaces of the fingers and toes, wrists, buttocks, breasts in females, and genitals.
	Probable	Not applicable
	Confirmed	A person that is confirmed by identification of the mite or mite eggs or faecal matter (scybala).
Schistosomiasis (20) ICD-11: 1F86	Suspected	• Urinary schistosomiasis in endemic areas: not applicable • Urinary schistosomiasis in non-endemic areas: A person with visible haematuria, or with positive reagent strip for haematuria, and possibly infective water-contact • Intestinal schistosomiasis in endemic areas: A person with non-specific abdominal symptoms, blood in stool, hepato(spleno)megaly • Intestinal schistosomiasis in non-endemic areas: A person with non-specific abdominal symptoms, blood in stool, hepato(spleno)megaly and possibly infective water-contact
	Probable	Not applicable
	Confirmed	• Urinary schistosomiasis in endemic areas: A person with visible haematuria, or with positive reagent strip for haematuria, or with eggs of <i>Schistosoma haematobium</i> in urine (microscope). • Urinary schistosomiasis in non-endemic areas: A person with eggs of <i>S. haematobium</i> in urine (microscope). • Intestinal schistosomiasis in endemic areas: A person with eggs of <i>S. mansoni</i>, <i>S. japonicum</i>, <i>S. mekongi</i> or <i>S. intercalatum</i> in stools (microscope). • Intestinal schistosomiasis in non-endemic areas: A person with eggs of <i>S. mansoni</i>, <i>S. japonicum</i>, <i>S. mekongi</i> or (possibly) <i>S. intercalatum</i> in stools (microscope); a person with a positive reaction to immunoblot test.

Disease (reference)	Case definition	Description
Snakebite envenoming (SBE) (21) ICD-11: XM4KN1	Suspected	A reported history of snakebite, whether the snake was seen or not (as in many cases at night or in undergrowth), where SBE is the most likely diagnosis based on the presenting history of the circumstances of the event and subsequent evolution of symptoms.
	Probable	
	Confirmed	History of snakebite, whether the snake was seen or not (as in many cases at night or in undergrowth), where a diagnosis of SBE is confirmed by a combination of (i) the presenting history of the circumstances of the event, (ii) subsequent evolution of symptoms reported by the patient, (iii) physical signs of SBE, and, when possible, (iv) results of laboratory investigations (even basic ones like 20-minute WBCT, blood count, urine examination, etc.).
Soil-transmitted helminthiases (STH) (22) ICD-11: Ascariasis: 1F62 Hookworm infection: 1F68 Trichuriasis: 1F6G	Suspected	• Ascariasis: Abdominal or respiratory symptoms, and/or history of passing worms. • Hookworm infection: Abdominal pain, diarrhoea, loss of appetite, weight loss, fatigue and anaemia. • Trichuriasis: Bloody, mucoid stools.
	Probable	Living in an area of high STH endemicity
	Confirmed	• Ascariasis: Presence of <i>Ascaris lumbricoides</i> eggs in stools (microscope examination) or passage of <i>Ascaris lumbricoides</i> (anus, mouth, nose). • Hookworm infection: presence of hookworm ova in stools (microscope examination). • Trichuriasis: presence of <i>Trichuris trichiura</i> eggs in stools.
Sporotrichosis (23) ICD-11: 1F2J	Suspected	Presence on clinical examination of one of the following: • Skin or subcutaneous nodular abscesses with proximal spread along the lymphatic circulation. • Erythematous-scaly, papulopustular, nodular, vegetative, infiltrative, or crusty lesions.
	Probable	Suspected sporotrichosis based on clinical examination <i>and</i> Known lifestyle factor or occupation (e.g. gardener, landscaper, forester, veterinarian, cat owner) with trauma <i>or</i> Trauma caused by domestic cats or contact with their cutaneous or mucosal exudates or respiratory droplets with known or suspected sporotrichosis infections.
	Confirmed	Suspected sporotrichosis based on clinical examination <i>and</i> Culture of <i>Sporothrix</i> species from skin or mucosal scrapings, swabs, biopsy, cerebrospinal fluid, sputum, or synovial fluid <i>or</i> Histopathologic findings (densely eosinophilic yeast forms with a surrounding ray of eosinophilic material) consistent with asteroid bodies <i>or</i> Identification of <i>Sporothrix</i> species using molecular DNA sequencing methods.
Taeniasis and cysticercosis (24) ICD-11: Taeniasis: 1F76 Cysticercosis: 1F70	Suspected	Neurocysticercosis: A person living in a <i>Taenia solium</i> endemic area with neurological symptoms compatible with neurocysticercosis.
	Probable	Neurocysticercosis: A person living in a <i>Taenia solium</i> endemic area with positive serology and clinical signs compatible with neurocysticercosis.
	Confirmed	Neurocysticercosis: A case confirmed by imaging.

Disease (reference)	Case definition	Description
Trachoma (25) ICD-11: 1C23	Suspected trachomatous trichiasis	Any patient from a trachoma-endemic population, with likelihood increasing with increasing age, particularly if they complain of pain in the eye that is exacerbated by blinking.
	Probable trachomatous trichiasis	At least one eyelash from the upper eyelid touches the eyeball, or evidence of recent epilation of in-turned eyelashes from the upper eyelid.
	Confirmed trachomatous trichiasis	Diagnosis confirmed by an ophthalmologist, ophthalmic clinical officer, or eye nurse with experience of trachoma.
Tungiasis (26) ICD-11: 1G05	Suspected	Not applicable
	Probable	Not applicable
	Confirmed	A person of any age living in or having visited an endemic area having a painful, extremely itchy area of the skin. At onset, no spot is visible but develops in a few days to a nodule, circular in shape, cream colour with a dark spot in the centre. Usually on the feet but can be any body part.
Yaws (27) ICD-11: 1C1D	Suspected	A person of any age who is or was living in a previously or currently endemic area, presenting with clinical signs consistent with yaws.
	Probable	A suspected case with RDT + (SD Bioline™ syphilis test).
	Confirmed	A clinically suspected infectious case who is confirmed with dual positive serology (either DPP-dually positive or TPHA/TPPA+RPR positive). PCR may be used during the implementation phase to monitor azithromycin resistance but is not an essential part of the case definition.

DPP: dual path platform; PCR: polymerase chain reaction; RDT: rapid diagnostic test; RPR: rapid plasma regain; RT-PCR: reverse transcription PCR; SBE: snakebite envenoming; STH: soil-transmitted helminthiasis; TPHA: *Treponema pallidum* hemagglutination assay; TPPA: *Treponema pallidum* particle agglutination assay; WBCT: whole blood clotting test; WHO: World Health Organization.

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Global Neglected Tropical Diseases Programme

World Health Organization

20 avenue Appia

1211 Geneva 27

Switzerland

neglected.diseases@who.int

<https://www.who.int/teams/control-of-neglected-tropical-diseases>