



World Health
Organization

21

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

Ending the neglect to
attain the Sustainable
Development Goals

A framework for monitoring
and evaluating progress of
the road map for neglected
tropical diseases 2021–2030

30

Ending the neglect to attain the Sustainable Development Goals: a framework for monitoring and evaluating progress of the road map for neglected tropical diseases 2021–2030

ISBN 978-92-4-002368-0 (electronic version)
ISBN 978-92-4-002369-7 (print version)

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FOREWORD

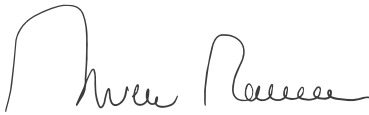
Ending the neglect to attain the Sustainable Development Goals: a framework for monitoring and evaluating progress of the road map for neglected tropical diseases 2021–2030 is a companion document to the road map for neglected tropical diseases 2021–2030.

The road map was endorsed by the Seventy-third World Health Assembly in November 2020, calling on Member States to work towards the targets for 2030. The need for such a companion document had emerged during the consultative process for the new road map. Monitoring and evaluation are recognized as one of the four commonest programmatic gaps across the diseases, warranting accelerated programmatic action to reach the goals set in the road map. This companion document was also developed through an extensive consultative process under the guidance of the Strategic and Technical Advisory Group for Neglected Tropical Disease’s Working Group on Monitoring, Evaluation and Research. It embodies the same shifts and principles of focus on impact, integration and country ownership in monitoring and evaluating progress against neglected tropical diseases.

This framework is a call to action to countries and implementing partners with fully defined operational impact indicators for greater accountability and action, starting at the country level. It aims to provide guidance on mainstreaming the monitoring and evaluation of neglected tropical diseases within health information systems and emphasizes that monitoring and evaluation are integral components of interventions against neglected tropical diseases. The framework highlights the importance of standardization of indicators and defines the core set and the additional indicators to ensure comparability across the different implementational levels as well as across countries.

The framework aligns with WHO’s vision of strengthening national information systems and contributes to building a world health data hub at the global level. It concludes with a section on looking forward, identifying gaps and research needs for strengthening monitoring and evaluation further.

“What gets measured gets done” reiterates that for the successful implementation of interventions against neglected tropical diseases, monitoring and evaluation will remain important components. Accordingly, this framework will remain a living document to support national programmes and be updated periodically with new evidence and experience.



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ACKNOWLEDGEMENTS

The road map team – Bernadette Abela-Ridder, Gautam Biswas and Pamela Sabina Mbabazi – was assisted in the development of this framework by a drafting group comprising Junerlyn Farah Agua, Lise Grout and Alexei Mikhailov (WHO Department of Control of Neglected Tropical Diseases). The group was supported by Katie Zoerhoff (RTI International) and Patrick Lammie and Joanna Pritchard (Task Force for Global Health), who participated in the conceptual development and consolidation of inputs from consultations. Additional topical technical inputs were provided by Pedro Albajar Viñas, Kingsley Asiedu, Daniel Argaw Dagne, Jose Ramon Franco-Minguell, Amadou Garba Djirmay, Xiaoxian Huang, Saurabh Jain, Jonathan King, Antonio Montresor, Denise Mupfasoni, Gerardo Priotto, Vaidyanathan Ramakrishnan, Jose Antonio Ruiz Postigo, Dieudonné Sankara, Anthony Solomon, Afework Tekle, Raman Velayudhan and Rajpal Yadav (WHO Department of Control of Neglected Tropical Diseases), Erwin Cooreman and Rao Pemmaraju (WHO Global Leprosy Programme), Sophie Boisson (WHO Department of Environment, Climate Change and Health) and Navneet Bahl and Somnath Chatterji (WHO Division of Data, Analytics and Delivery for Impact).

The Steering Committee was chaired by Mwelecele Ntuli Malecela, Director, WHO Department of Control of Neglected Tropical Diseases, with members from the WHO regional offices for Africa (Maria Rebollo Polo and Alexandre Tiendrebeogo), the Americas (Santiago Nicholls), South-East Asia (Mohammed Jamsheed and Zaw Lin), Europe (Elkhan Gasimov), the Eastern Mediterranean (Mona Osman and Supriya Warusavithana) and the Western Pacific (Aya Yajima), who provided inputs from country perspectives and reviewed the concepts and drafts.

The Working Group on Monitoring, Evaluation and Research of the WHO Strategic and Technical Advisory Group for Neglected Tropical Diseases was chaired by Julie Jacobson (United States of America) and cochaired by Sung-Tae Hong (Republic of Korea) and Sanjay Madhav Mehendale (India). The group comprised Um Boock Alphonse (Cameroon), Edwin Ampadu (Ghana), Iwan Ariawan (Indonesia), Sanaa Botros (Egypt), Mark Bradley (United Kingdom), Meritxell Donadeu (Australia), Monique Dorkenoo (Togo), Maciej Grzybek (Poland), Juan Pablo Gutierrez (Mexico), Theresa Gyorkos (Canada), Eliane Ignotti (Brazil), Olaf Horstick (Germany), Ulrich-Dietmar Madeja (Germany), Mourad Mokni (Tunisia), Khin Mon Mon (Myanmar), Upendo John Mwingira (United Republic of Tanzania), Jordan Tappero (United States of America), Hasitha Tissera (Sri Lanka), Violetta Yevstigneyeva (United States of America) and Jing Xu (China), who provided technical guidance and reviewed all of the drafts for the final publication¹.

Peer review was conducted by Steven Ault (United States of America), Ahmed Be-Nazir (Bangladesh), Fiona Fleming (United Kingdom), Leda Hernandez (Philippines), Alain Javel (Haiti), Naresh Kumar Gill (India), Tsedeke Mathewos (Ethiopia), Mohammad Naeem Habib (Afghanistan) and Fasihah Taleo (Vanautu).

Funding was contributed by the United States Agency for International Development and the Bill & Melinda Gates Foundation.

¹ For profiles of the members of the Working Group on Monitoring, Evaluation and Research, 2020–2022, see: [https://cdn.who.int/media/docs/default-source/ntds/strategic-and-advisory-group-on-neglected-tropical-diseases-\(stag-ntds\)/members-stag-wg-mer.pdf?sfvrsn=665ccaf7_19](https://cdn.who.int/media/docs/default-source/ntds/strategic-and-advisory-group-on-neglected-tropical-diseases-(stag-ntds)/members-stag-wg-mer.pdf?sfvrsn=665ccaf7_19)

The definitions given below apply to the terms used in this document. They may have different meanings in other contexts.

Control: Reduction of disease incidence, prevalence, morbidity and/or mortality to a locally acceptable level as a result of deliberate efforts; continued interventions are required to maintain the reduction. Control may or may not be related to global targets set by WHO.

Coordination: Collaboration among adjacent sectors and programmes, within and beyond health, in the broader NTD network. Sectors such as vector control, animal health and WASH make critical contributions to progress against NTDs, and working together more effectively will accelerate and sustain progress towards elimination and control of NTDs. In the context of monitoring and evaluation, coordination refers to the organization of the different stakeholders involved in NTD-related data processes, and collaboration (e.g. data sharing and joint evaluation) among adjacent health programmes (such as mental health) or non-health sectors (such as WASH) to enable them to work together effectively.

Disability-adjusted life year (DALY): A measure of overall disease burden, expressed as the number of years lost due to ill health, disability or early death; introduced in the 1990s to compare overall health and life expectancy in different countries. DALYs for a disease or health condition are calculated as the sum of the years of life lost due to premature mortality in the population and the years lost due to disability resulting from the health condition or its consequences.

Disability: Inability to adequately or independently perform routine daily activities; the negative aspects of the interaction between a person with a health condition and his or her context (environmental and personal factors).

Effectiveness: Degree to which an intervention is successful in producing the desired public health result.

Efficiency: A measurable level of peak performance by which waste is minimized by using the least amount of inputs and harnessing synergies to attain the highest output and desired impact of neglected tropical disease programmes.

Elimination (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 action to prevent re-establishment of transmission may be required. Documentation of elimination of transmission is called verification.

Elimination as a public health problem: A term related to both infection and disease, defined by achievement of measurable targets set by WHO in relation to a specific disease. When reached, continued action is required to maintain the targets and/or to advance interruption of transmission. Documentation of elimination as a public health problem is called validation.

Equity: The absence of avoidable or remediable differences among groups of people defined socially, economically, demographically, geographically or by sex.

Eradication: Permanent reduction to zero of the worldwide incidence of infection caused by a specific pathogen, as a result of deliberate efforts, with no risk of reintroduction. Documentation of eradication is termed certification.

Evaluation: Periodic, rigorous and independent assessment of information about programme activities, processes and outcomes to make judgements about programme effectiveness and inform decisions about future programme development. It requires consideration of inter-programmatic and intersectoral engagement.

Financing: Raising adequate funds for health in ways that ensure people can use needed services and are protected from financial catastrophe or impoverishment associated with having to pay for them.

Impact indicators: A measure of the extent to which the overall objectives of the programme are being achieved in terms of health status and financial risk protection.

Implementation indicators: Indicators that measure programme inputs, processes, outputs and outcomes, rather than programme impact.

Input indicators: A measure of the resources needed to implement the intervention; they include trained personnel, finance, standards and guidelines, communication facilities, forms for surveillance, computers, medicines, diagnostics, stockpiles for emergency response and any other logistics as deemed necessary.

Integrated vector management: A rational decision-making process to optimize the use of resources for vector control.

Integration: Grouping or “packaging” of several diseases, depending on their burden in countries, to facilitate joint delivery of interventions through a common platform such as preventive chemotherapy and use of multiplex diagnostics, and integrated monitoring, evaluation and reporting for all relevant endemic NTDs.

Mainstreaming: Planning and delivery of interventions against NTDs through the national health system infrastructure to build capacity and contribute to sustainable, efficient disease prevention and control. In the context of monitoring and evaluation, the term is used more specifically as planning and implementing monitoring and evaluation activities against NTDs through the national health information system infrastructure to build capacity and contribute to sustainable, efficient monitoring and evaluation systems.

Mass drug administration: Distribution of medicines to the entire population of a given administrative setting (for instance, state, region, province, district, subdistrict or village). In this document, the terms mass drug administration and preventive chemotherapy are used interchangeably.

Monitoring: Regular collection, analysis and use of data on programme implementation (weekly, monthly, quarterly or annually) to measure progress towards programme/project objectives through tracking activities conducted, resource utilization and the outputs generated; programme outcomes and impacts may also be included.

Morbidity: Detectable, measurable clinical consequences of infection and disease that adversely affect the health of individuals. Evidence of morbidity may be overt (such as the presence of blood in the urine, anaemia, lymphoedema, blindness, chronic pain or fatigue) or subtle (such as stunted growth, impeded school or work performance or increased susceptibility to other diseases).

One Health: Recognizing the fundamental interconnectedness among human populations, animal populations and the environment, One Health represents an integrated approach to designing and implementing programmes, policies, legislation and research in which multiple sectors communicate and work together to achieve better public health outcomes. The areas of work in which a One Health approach is particularly relevant for neglected tropical disease programmes include food safety, control of zoonoses and combatting antibiotic resistance, among others.

Outcome indicators: Indicators that measure the effect of interventions on programme-enabling factors, disease risk factors and behaviours, among others.

Output indicators: Indicators that measure whether planned NTD programme activities and operations are actually occurring as intended; these are indicative of service availability, accessibility and quality, among others.

Preventive chemotherapy: Large-scale use of medicines, either alone or in combination, in public health interventions. Mass drug administration is one form of preventive chemotherapy; other forms could be limited to specific population groups such as school-aged children and women of childbearing age. In this document, the terms preventive chemotherapy and mass drug administration are used interchangeably.

Process indicators: Indicators that measure procedural and administrative aspects of a programme that relate to the rate of implementation of planned health interventions which are critical for attaining programme goals.

Results-based monitoring and evaluation: A systematic approach to tracking programme performance based on reflective logic to inform managerial action by policy-makers and decision-makers.

Surveillance: Ongoing systematic collection, collation, analysis, interpretation and prompt dissemination of data for use in planning and implementation of public health programmes. A communicable disease surveillance system serves two key functions; early warning of potential threats to public health and programme monitoring functions which may be disease-specific or multi-disease in nature.

Theory of change: Comprehensive description, usually represented pictorially, of how intended goals are expected to be realized as a result of a programme or initiative in a particular context. It often begins with the desired impact of the programme and works backwards to identify the required outcomes, outputs, activities, inputs and assumptions and how they relate to each other causally for the intended changes to occur.

Universal health coverage: All people have access to needed health services (including prevention, promotion, treatment, rehabilitation and palliation) of sufficient quality to be effective while at the same time ensuring that the use of these services does not expose the user to financial hardship.

EXECUTIVE SUMMARY

The road map for neglected tropical diseases for 2021–2030 (“the road map”) sets global targets and milestones to control, eliminate or eradicate 20 diseases and disease groups. It also sets cross-cutting targets aligned with both WHO’s Thirteenth General Programme of Work and the Sustainable Development Goals, with strategies for achieving the targets during the next decade.

Providing a framework to track progress towards the road map targets

This framework for monitoring and evaluating progress against the road map targets (“the M&E framework”) is a companion document to the road map that aims to facilitate tracking of progress against set goals while enabling course corrections to be made where necessary. It is a call to action to provide countries with fully defined operational impact indicators so that the burden of all neglected tropical diseases (NTDs) is reported for greater accountability and action starting at the country level. The M&E framework presents a theory of change which shows how the shifts described in the road map will come about, and what needs to be done in order to reach the road map goals and targets.

The three pillars outlined in the road map – accelerating programmatic action, intensifying cross-cutting approaches, and changing operating models and culture to facilitate country ownership – represent key inputs, processes and outputs for achieving the intended long-term outcomes and impact by 2030. Echoing the strategic shifts of the road map, the M&E framework shifts the approach to monitoring and evaluation towards: (i) impact orientation, (ii) holistic, cross-cutting approaches and (iii) monitoring and information systems defined and established by the country to primarily meet the needs for evidence-based decision-making and reporting, aligned with national policies.

The set of indicators and tools to track progress towards the 2030 targets presented in the road map is described in more detail in this M&E framework: 36 core quantitative indicators (four overarching, 10 cross-cutting and 22 disease specific) and 34 additional disease-specific indicators; and a qualitative gap assessment conducted for each NTD independently and analysed in a cross-cutting manner through a heat map.

Monitoring impact

The quantitative indicators are focused primarily on assessing impact. The metadata are described in detail in the compendium of indicators for monitoring and evaluating progress of the road map (“the NTD indicator compendium”) published by WHO.

Data on the road map, and additional implementation data at country level, should be collected and stored on integrated data platforms and mainstreamed into national health information systems. WHO will provide guidance and technical support over the next decade to facilitate these processes, which will also promote the capture and use of data from other sectors.

Assessing bottlenecks

The road map targets are ambitious and will continue to require considerable work by countries and stakeholders to ensure that all programmatic inputs are in place. Scientific understanding to develop new tools and improve interventions; strategies, guidance, governance and capacity to deliver services; and enablers such as advocacy, funding and collaboration, all require the concerted actions of numerous stakeholders at all levels. Building on previous experience, with evidence generated through data science, the main hindrances to achieving the 2030 targets and the corrective actions required will be assessed periodically.

| Evaluating progress

The evaluation of progress towards the road map targets requires the structured engagement of all relevant stakeholders in an operating model that facilitates country ownership and fosters a culture of equity, putting people and communities at the centre. At country level, evaluations should encompass a set of principles that support country-owned processes from which findings should help in improving programme effectiveness and reaching targeted goals. Periodic and objective evaluation of global progress against the 2030 road map targets shall be conducted in milestone years. The reviews by the World Health Assembly in reporting years (2022, 2024, 2026 and 2029) may result in updated targets in line with changing contexts, and a final one in 2031.

| Looking forward

In the years leading up to 2030, NTD programmes and the tools used to monitor them and to measure their impact are expected to evolve. Several indicators will emerge while others still require better definition, tools and methods of how they will be measured and monitored, necessitating systematic update. Training and implementation research are required to improve collection and use of good-quality data at all levels of the health system. New intervention strategies, diagnostic tools and survey methodologies need to be translated from the research realm into routine programme use. Identification of opportunities to integrate and mainstream disease-specific activities within existing surveillance, monitoring and evaluation activities at national and subnational levels is pivotal and requires additional work.

Consequently, countries should be prepared to work to strengthen their monitoring and evaluation portfolios to accommodate changes which enable tracking of progress towards attaining their respective NTD programme goals. Investing in robust monitoring and evaluation and focusing on the integrity of such systems will pay dividends by precisely and proactively informing the health system on the interventions and status of NTDs, thereby ensuring the 2030 targets are achieved and ultimately benefit affected or at-risk communities. Such renewed efforts on NTDs will have an important overall impact on global health.

Introduction

Introduction

1.1 Background

The neglected tropical diseases (NTDs) prioritized by the World Health Organization (WHO) are a diverse set of 20 diseases and disease groups with a singular commonality: their devastating impact on impoverished communities. Interventions against NTDs contribute to achievement of the Sustainable Development Goals.

NTDs are formally recognized as targets for global action in target 3.3, which calls to “end the epidemics of ... neglected tropical diseases” by 2030, as part of Goal 3 (Ensure healthy lives and promote well-being for all at all ages). Successful interventions against NTDs also contribute to meeting the other Goals, such as alleviating poverty (Goal 1) and hunger (Goal 2), among others. Conversely, progress towards other Goals can accelerate the achievement of NTD goals.

Monitoring and evaluation are essential to ensure that the priority health actions outlined in Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021–2030 (“the road map” (1)) are implemented as planned against stated objectives and desired results.

Effective monitoring and evaluation is essential for policy dialogue and evidence-based decision-making. High-quality monitoring and evaluation at the country level sets the foundation for assessing progress nationally, regionally and globally against the road map targets and milestones, as well as the health-related Sustainable Development Goals and health equity. Yet despite progress in the past decade, monitoring and evaluation remain weak for most NTD programmes and have been identified as a dimension where gaps exist and action is required to achieve the road map targets (Fig. 1). A current assessment of gaps in monitoring and evaluation and actions required for each disease are presented in more detail in Annex 1 and specify a broad range of challenges from M&E frameworks to information systems.

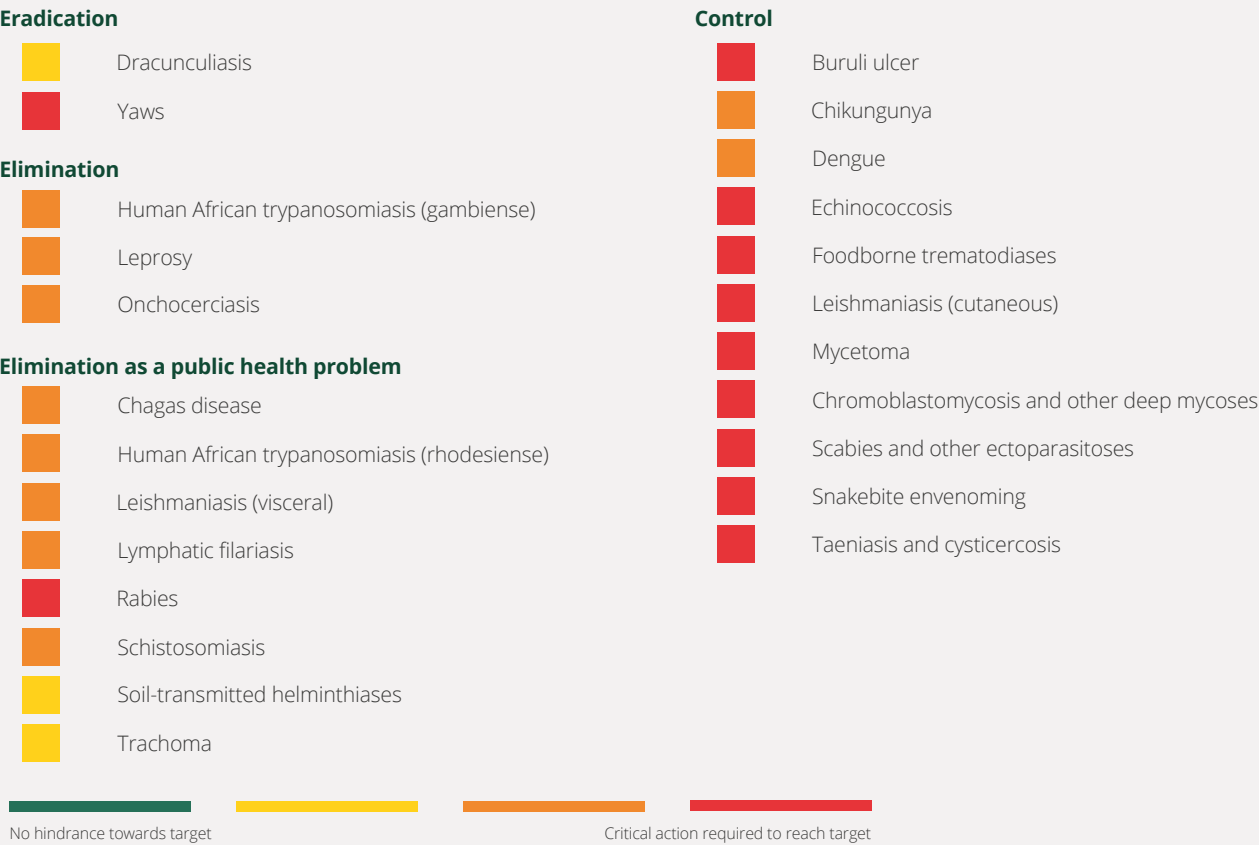
This framework for monitoring and evaluating progress of the road map (“the M&E framework”) issues a call to action to provide countries with defined indicators so that the burden of all NTDs is reported with greater accountability and responsive action starting at the country level.

Many NTD-specific information systems were established in disease-specific silos, often in parallel with one another and to existing national health information systems. Although NTD data-sharing and management practices have improved, for some disease programmes this has not been sufficient to achieve high data quality and efficient data use across all the NTDs. Importantly, notable variations existed in the use of terminology on monitoring and evaluation and on methods of evaluation across NTDs, with consequent inconsistent interpretation of data. This M&E framework aims to address these inconsistencies.

There is also a need to strengthen, integrate and mainstream monitoring and evaluation within national health information systems and strengthen coordination with all relevant sectors, both within and beyond health.

The strength of disease-specific guidance on monitoring and evaluation and its implementation varies substantially across the NTDs. Additionally, since 2017, new NTDs have been included in the expanded list of 20 NTDs for which systematized and integrated monitoring and evaluation need to be established and mainstreamed into national health information systems. Information about synergistic actions, such as for water, sanitation and hygiene (WASH) interventions, vector control interventions and One Health, is generally either under-collected or under-utilized at country level. There is limited use of qualitative methods to support structured dialogue on accessing assessments of barriers to progress and enablers for strengthening NTD programme performance.

Fig. 1. Assessment of gaps in monitoring and evaluation for each NTD



Source: Fig. 7 of the road map (1); analysis obtained through technical consultations, WHO 2019

Despite these challenges, impressive public health gains have been reliably validated, verified or certified through independent committees. Important lessons and best practices have been learned and developed, which provide an important foundation to inform future approaches to monitoring and evaluating progress against NTDs for further integration and mainstreaming into national systems.

The road map encourages all actors to evaluate the effectiveness and efficiency of their approaches. This requires an optimal M&E framework to facilitate accountability and greater collaboration within and beyond the health sector.

This M&E framework should guide activities involving the development of standards, tools and methods for generating, collecting, compiling, analysing, using and disseminating data on NTDs. Although these efforts are generally linked to disease-specific initiatives, there is also a need to track the overall performance of national NTD programmes within national health systems, and synergetic intersectoral actions, all of which are pivotal to the sustainable achievement of the overarching, cross-cutting and disease-specific

road map goals. This, in turn, will enable governments and organizations to respond to internal and external pressures and thereby to demonstrate accountability, transparency and results.

A series of technical consultations was held in 2019 with content experts to select goals for the road map that was endorsed by Member States in 2020 at the Seventy-third World Health Assembly. The recommendations from these consultations were discussed further for consensus-building with the reconstituted Working Group on Monitoring, Evaluation and Research of the WHO Strategic and Technical Advisory Group for Neglected Tropical Diseases and a steering committee with representation from all WHO regional offices, with inputs from Member States. This provided the foundational information for developing the M&E framework.

Box 1. Key components of an M&E system

The four components of a strong M&E system include:

- sound **policy and institutional environment**;
- well-functioning **data sources**;
- strong institutional **capacity for data collection, management, analysis, use and dissemination**; and
- effective country **mechanisms for review and action**.

Although guidance on strengthening monitoring and evaluation systems has been developed for several NTDs, this is the first attempt to provide a comprehensive M&E framework across all NTDs.

This M&E framework has been built in the context of general guidance published by WHO (2–4) (Box 1), disease-specific documents on monitoring and evaluating NTD programmes (Annex 2) and similar frameworks for major infectious diseases (e.g. malaria (5), tuberculosis and HIV/AIDS (6)).

The M&E framework aligns with WHO's vision of integrating data on health into a single platform to strengthen mechanisms for evidence-based decision-making.

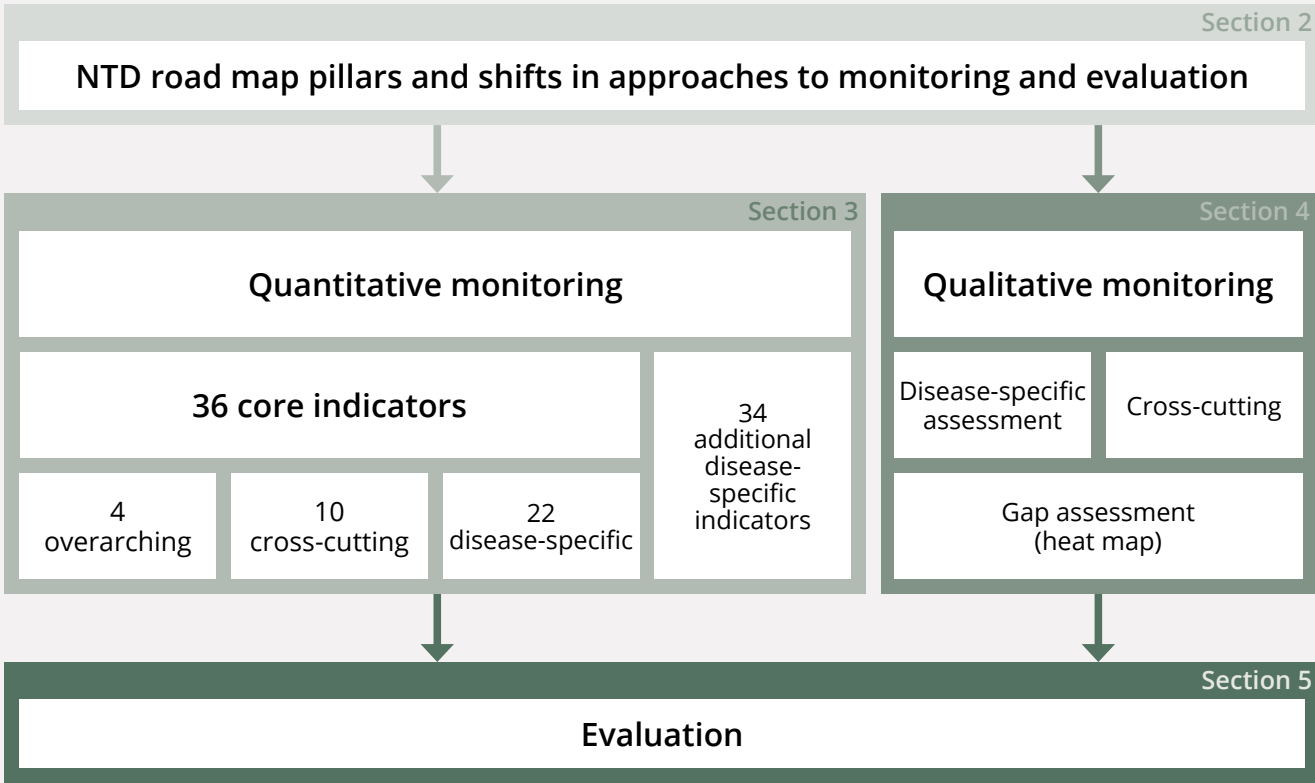
Comprehensive, timely and reliable health and health-related metrics are fundamental for assessing the health of populations and how it is measurably impacted by interventions. WHO will build a world health data hub to serve as a single repository of health data in WHO and establish a data governance mechanism for Member States, partners and the public. Accordingly, WHO strongly encourages countries and partners to build comprehensive and mainstreamed country-owned platforms for monitoring and evaluation. Such efforts ideally bring

1.2 The M&E framework: purpose, target audience and scope

This M&E framework aims to facilitate tracking of progress against set goals while enabling course corrections to be made where necessary. This will require shifts in approaches to monitoring and evaluating progress against NTDs nationally, regionally and globally.

The M&E framework is focused on measuring impact. It moves beyond an emphasis on inputs, process and outputs to a greater focus on outcomes and impacts to inform operational and strategic decision-making and measure progress towards 2030 goals at national and global levels. This aligns with the road map's first fundamental shift in approach to tackling NTDs: increased accountability through a focus on impact indicators instead of process indicators. This M&E framework is built on the set of outcome and impact indicators presented in the road map to support strategic thinking, operational tracking, evidence-based decision-making and performance feedback mechanisms and to support advocacy and transparency in the implementation of NTD programmes.

Fig. 2. Key components of the M&E framework



- section 2 describes the guiding conceptual framework and strategic shifts of the M&E framework;
- section 3 focuses on quantitative monitoring; that is, how to collect, analyse, report and use the quantitative indicators set forth in the road map;
- section 4 focuses on qualitative monitoring and presents the gap assessment tool;
- section 5 highlights the evaluation of progress towards 2030 road map targets; and
- section 6 looks forward and highlights gaps and calls for solutions.

The **36 core quantitative indicators** (four overarching, 10 cross-cutting and 22 disease-specific) and 34 additional disease-specific indicators (annexed as the disease summaries to the road map (1)) are described in more detail in **section 3**.

The primary target audience for the M&E framework is professionals working in the areas of NTD services planning, implementation, health systems and health information systems at both national and international levels.

Policy-makers, managers and researchers working within and beyond the health sector in other sectors are also among the intended key users.

The scope of this M&E framework includes key concepts, indicators, data management processes and pathways, and gaps that need to be addressed to support the attainment of the 2030 road map targets.

The M&E framework presents the linkages between existing tracking of NTD indicators, which will continue under the new road map, and tracking the new road map targets, many of which are built upon the existing indicators. It does not provide an exhaustive list of all NTD-specific indicators, as these can be found in published WHO guidelines (Annex 2). Countries will continue to monitor existing programmatic indicators at the country level. Additional country-level indicators, some of which are new, introduced by the road map and described in the compendium of indicators for monitoring and evaluating progress of the road map ("the NTD indicator compendium" (7)), support monitoring and evaluating of progress towards the road map targets globally.

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