

# Neglected tropical diseases

Now is the time to say goodbye to NTDs





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#### Opposite and cover image

Peace, 11, sings a song that helps her remember how to wash her hands and face, a part of the Sightsavers water, sanitation and hygiene project in Meru, Kenya.

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## Acronyms

**ESPEN** Expanded Special Project for Elimination of NTDs

LF Lymphatic filariasis

**MDA** Mass drug administration

NTD Neglected tropical disease

**SDGs** Sustainability development goals

Water, sanitation and hygiene **WASH** 

**WHO** World Health Organization



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#### **Foreword**

This is our second Sightsavers neglected tropical diseases (NTD) strategy. The first set ambitious themes for Sightsavers. This strategy builds on those original themes but now takes us, along with the international NTD community, to the elimination objectives set out in the World Health Organization (WHO) NTD roadmap to 2021-2030. This strategy is our response to the opportunities and challenges raised in that roadmap. This is our contribution to the global NTD elimination agenda.

Our work, with many other partners, on the development and scale-up of the community directed approaches for mass drug administration (MDA) in the 1980s and 1990s has provided the basis for the reach of NTD programmes in Africa. Our work on the Global Trachoma Mapping Project, which started in 2012, has been acknowledged as one of the key events in the elimination programme for that disease. Our investments, as part of our first NTD plan, on digital health and linking NTD programmes to water, sanitation and hygiene programmes have shown that we are innovative in our approaches and not shy of showing global leadership.

I know the path towards disease elimination will not be straightforward. There will be all sorts of obstacles thrown in our way, and while this document captures the confidence and optimism that countries will be able to achieve elimination goals and milestones, I know that it will only be possible if we collectively recognise and respond to the challenges that programmes operate under (identified in this strategy).

We need to embrace the cross-cutting principles outlined in the strategy and ensure that while pursuing our strategic objectives and goals, we remain adaptive, creative and inclusive in how we address these obstacles.

The strategy is issued as our planet is coming to terms with and developing responses to the global pandemic of COVID-19. NTD programmes reach one sixth of the world's population through their activities. Our own supported programmes have flexed to

behaviour change programmes aimed at suppressing the pandemic. The roll-out of a global vaccination programme will start in 2021. I would not be surprised if our NTD programmes were utilised to support this work through the community-directed approaches we have developed and worked on for many years, which reach the most hard-to-reach populations, and tell people about the disease and vaccination programmes via mass behaviour change messaging.

As Professor Stephen Hawking said in December 2017 when he was celebrating our billionth-supported NTD treatment: "No single organisation can hope to eliminate neglected tropical diseases on its own. The effort requires cooperation among a diverse team of players, taking advantage of the strengths each member of the team brings with it." This document represents our team effort to eliminate NTDs and also Sightsavers' part in this global partnership.



NTD programmes reach one sixth of the world's population



Simon Bush
Director neglected tropical diseases
Sightsavers



## **Executive summary**

The road towards elimination of NTDs is long and challenging. Sightsavers is proud to continue our journey along this road with our new NTD strategy for 2021-2030 which works towards Sightsavers' vision: to create a world where no one is blind from avoidable causes, and where people with disabilities participate equally in society.

This document highlights Sightsavers' new goals in our NTD work and provides a map of the roads to get there during our new strategic period. Our approach is fully in line with what NTD endemic countries have identified as a priority within their NTD master plans. We focus on and will continue to focus our efforts on five NTDs: intestinal worms (soil-transmitted helminths), lymphatic filariasis (LF), river blindness (onchocerciasis), schistosomiasis and trachoma.

While only two of these diseases affect the eyes specifically, all five are preventive chemotherapy NTDs. This means that interventions for the diseases use largely the same platforms, including those used for mass drug administration (MDA). Therefore we increase our impact and provide value for money by working on all five of these NTDs.

To ensure we are travelling forward together with the broader NTD community, we have developed our NTD theory of change using key international documents of importance to our work: the WHO NTD Roadmap 2021-2030, the WHO NTD Sustainability Framework and the UN Sustainable Development Goals. These documents are ambitious, and so we have upped our ambition in our strategy and theory of change.

## We identify our two overarching goals through which our NTD work will be framed as:

- contribution to health systems strengthening
- progress towards universal health coverage

## Three key objectives will then guide us in achieving our overarching goals:

- **1.** Address health system gaps and weaknesses to enable equitable patient care and effective surveillance
- **2.** Facilitate opportunities for evidence-based decision making by supporting data standardisation and data ownership
- **3.** Support universal health coverage through ensuring equitable access to NTD and inclusion services

## We have identified six cross-cutting NTD principles, which underpin all our work:

- Integration
- Innovation and learning
- Research and evidence uptake
- Advocacy
- Equity
- Environmental responsibility

We place a specific emphasis on how our NTD work links with the rest of Sightsavers' work and explore opportunities for further coordination. We will learn from the many experiences across our organisation to ensure effective, innovative and impactful programming.

Sightsavers has adapted to the political and social challenges of the last decade, most recently COVID-19, and we will continue to operate resiliently over the coming 10 years.

This document addresses some of the critical challenges we foresee along the road towards elimination. These challenges include operating in complex environments, and breaking silos to work collaboratively and in partnerships. We outline how we plan to resolve such challenges to help us support the elimination of NTDs in all countries in which we operate.

The NTD environment is fluid and everchanging and the content of this document is based on information as of October 2020. This document is not an operational work plan. To best guide and track our progress over this 10-year period we will develop an annual work plan, linking to annual country and project work plans, and based on the cross-cutting approaches we have identified.

Each year we will report against the previous annual work plan before we develop the next, incorporating any new areas of work and issues which we come across along our journey.

Improving the health of the poorest and most disadvantaged people in a cost-effective way remains at the heart of our work.



Background on Sightsavers' NTD work can be found in our briefing documents: www.sightsavers.org/protecting-sight/ntds/ntd-briefs



Rosa Mustar drying her farm produce at home in Namila Village, Nacaroa district, Mozambique. Rosa is now healed of trichiasis after surgery.

## Our NTD theory of change

Our NTD theory of change emphasises how our investments to break down siloed disease approaches will help address longer-term sustainability issues and ultimately lead to advancing our health systems strengthening and universal health coverage goals. It revolves around Sightsavers' approach to partnering with governments in their NTD interventions. Sightsavers helps to equip communities, health facilities, and sub-national and national governments with the skills and tools they need (our 'inputs'), to ultimately support 'stronger, integrated government-owned health systems with the resources and capacity to provide universal health coverage for NTDs' (the overall 'impact').

#### **Impact** Stronger, integrated government-owned health systems with the resources and capacity to provide universal health coverage for NTDs Communities are... **Outcomes** Achieving inclusive MDA with adequate coverage Providing health education for disease prevention Increasing uptake of water, sanitation and hygiene measures Health facilities Sub-national **National** governments are... governments are... are... Tracking MDA Supervising Managing and coverage and programme coordinating partners inclusion performance Collaborating with and inclusion Managing surgical other ministry outcomes directorates Conducting data quality assessments Ensuring WHO Monitoring disease burden guidelines for Using data and elimination and research evidence Generating and control are met to prioritise using data to report resources and challenges, identify Using data and interventions knowledge gaps research evidence and prioritise to prioritise resources resources and guide decisionmaking **Outputs** Governments and local partners are accountable for quality and inclusion standards Government and local partners have capacity to manage health information systems Government and local partners have the opportunity to implement comprehensive, cost-effective disease control and prevention programmes **Inputs** Sightsavers is... Engaging with governments and partners to plan and develop integrated NTD platforms, tools and processes that support disease elimination and sustainability of health systems Supporting operational research to address programmatic challenges and knowledge gaps Coordinating through existing systems and processes to limit fragmentation and promote national programme governance and evidence-based decision making

Figure 1: Sightsavers NTD theory of change



Andrea Malimi works as a case finder in Tanzania. He is tasked with seeking out potential sufferers of trachoma, and enabling them to access health care facilities.

## Our roadmap

Sightsavers' vision is a world where no one is blind from avoidable causes, and where people with disabilities participate equally in society. Sightsavers recognises that the root cause of certain disabilities can be prevented through the elimination of NTDs and that only when there is equitable access to strong health care services will it be possible to sustain the elimination of NTDs. Based on our theory of change, overleaf we outline two overarching goals, and Sightsavers' objectives and cross-cutting principles that will support the achievement of these goals.

#### Vision

A world where no one is blind from avoidable causes, and where people with disabilities participate equally in society.

#### Mission

We are an international organisation working with partners in developing countries to eliminate avoidable blindness and promote equality for people with disabilities.

#### **NTD** goals

Contribution to health systems strengthening

Progress towards universal health coverage

#### **NTD** objectives

Address health system gaps and weaknesses to enable equitable patient care and effective surveillance Facilitate
opportunities for
evidence-based
decision making
by supporting data
standardisation and
data ownership

Support universal health coverage through ensuring equitable access to NTD and inclusion services

#### NTD cross-cutting principles

Integration, innovation and learning, research and evidence uptake, advocacy, equity, environmental responsibility

#### **External factors: enablers and challenges**

Global policy frameworks, WHO framework for disease elimination, collaboration and partnerships, challenging environments

Figure 2: Sightsavers' vision and mission, and NTD goals and objectives

# Goal 1: Contribution to health systems strengthening

The term 'neglect' in neglected tropical diseases is partly rooted in the inability of weak health systems to manage NTDs. Health systems, often already overburdened, are challenged with scaling up preventative services while managing existing NTD cases. As we reduce the number of cases and prevent further cases of NTDs, stronger health systems will help ensure that work can be successfully managed through routine primary health services.

As per the WHO health system building blocks, our approach to NTD programming places governments in the driver's seat by ensuring the following items form part of a country's health systems strengthening approach. We outline below the six building blocks and how our approach supports each of them.

- Service delivery: NTD programmes and interventions are delivered within and by government-owned health systems, thereby increasing capacity for and access to essential NTD services.
- Health workforce: health systems are well equipped with staff who have the skills and tools to manage NTDs; there is national support given for different cadres of the health workforce.
- Health management information systems: national NTD programmes are fully represented within the national health management information system and NTD data is integrated with other databases, including water, sanitation and hygiene.

- Supply: NTD elimination programmes help strengthen the chains of medical products, vaccines and technologies; communities are empowered to deliver treatments, support access to surgeries and strengthen referral pathways.
- Finance: advocacy for domestic financing builds local, well-costed delivery models for NTDs, strengthening overall health systems financing.
- Leadership and governance: high-level leadership is engaged in advocating for the mainstreaming of health systems strengthening within the NTD control and elimination agenda; Sightsavers is responsive to local needs and supports local leadership.

Here, we define Sightsavers' two objectives and their sub-objectives that will help us to support this goal. We will use the sub-objectives to set performance indicators and monitor our progress.

View the World Health Organization (2017) fourth report on integrating neglected tropical diseases here: www.apps.who.int/iris/bitstream/handle/10665/255011/9789241565448-eng.pdf

## **Objective 1:** Address health system gaps and weaknesses to enable equitable patient care and effective surveillance

Weaknesses in health systems are often a result of resource (physical and financial) and capacity gaps. These gaps need to be filled ahead of disease elimination so that health systems are ready to manage NTDs as part of business as usual post-elimination. This includes providing long-term support to patients and preventing future resurgence of infection through surveillance services.

To work toward achieving this objective, Sightsavers will lead and provide support in the following areas:

## a. Strengthen in-country capacity of health workforces

Current state: Knowledgeable health workforces at the primary health and managerial levels are crucial. NTD-endemic areas often have insufficient capacity to deliver patient care for morbidity management and disability prevention and implement disease assessments and surveillance.

Moving forward: Sightsavers will continue to support training of health workforces in coordination with governments in four areas. First, we will support hiring and training more health staff to assess, diagnose, and provide quality case management for patients with morbidity. Second, we will advocate for national curriculums to include female genital schistosomiasis, trachoma and LF treatment and management practices for doctors, nurses, and community health workers. Third, we will help equip and train local teams to use standardised protocols and digital platforms so countries can estimate the disease prevalence needed for impact assessments and pre- and post-elimination surveillance. Finally, community-based surveillance, volunteers, teachers and other groups at the primary health level will be trained to have a high level of awareness and sensitivity for trachomatous trichiasis, hydrocele and other morbidities associated with NTDs.

## **b.** Improve infrastructure of existing facilities

Current state: Some countries have inadequate facilities and tools to reach and sustain elimination. Surgical facilities are not all at the standard they need to be. Hardware needed to facilitate the collection, distribution, storage, and use of data may be lacking or of poor quality. Access to safe water, sanitation and hygiene services may not be in place.

Moving forward: Sightsavers will conduct health care facility assessments at the primary health level to identify where there are inadequacies and gaps, which can then be addressed in coordination with governments and partners. We will focus on improving existing facilities for hydrocele and trichiasis surgeries. which will include ensuring that the procurement and distribution systems for surgical instruments are integrated into national systems. If there are availability gaps found in hardware, such as mobile phones and computers, we can work with governments, non-governmental organisations and technology partners to ensure they are filled. We will partner with the water, sanitation and hygiene sector to ensure that facilities have safe access to these services.

#### c. Improve quality and availability of fieldbased and lab-based diagnostics

Current state: Access to diagnostics for programme monitoring, NTD elimination verification, and post-elimination surveillance is limited and must be expanded. Local capacity is often a challenge. Linkages within country laboratory networks are lacking, and protocols and standardised reporting need to be put in place.

Moving forward: We will strengthen national diagnostic capacity for NTDs so that quality starts at a national level and ripples out to sub-national and local areas, producing quality data from all levels. Work will be done to accelerate the movement of the global community away from outdated diagnostic techniques. Sightsavers will support laboratory capacity strengthening, local laboratory and surveillance networks, and the instigation and maintenance of regional and national quality assurance protocols. Work will be done to align with existing global quality improvement programmes, strengthen supply chains, and standardise national reporting.

#### d. Advocate for domestic funding

Current state: Governments generally provide the workforce and infrastructure for NTD programme delivery. However in many situations financial resourcing for NTD programmes is dependent on external donor support. There is a critical need for countries to provide domestic funding, especially as they reach elimination and need to manage post-elimination surveillance and response activities.

Moving forward: Sightsavers will support country programmes to generate and raise funds by advocating the success and cost-effectiveness of interventions. We will make a case to governments and domestic donors to encourage sustained commitment to surveillance and response once diseases have been validated as eliminated.



A Sightsavers team performs trichiasis surgery in a makeshift operating theatre in the Turkana region of Kenya.

## **Objective 2:** Facilitate opportunities for evidence-based decision making by supporting data standardisation and data ownership

Our expertise in data and systems means that we are well-placed to facilitate the evidence-based decision making needed for governments to reach and sustain NTD elimination. This will help countries in planning, resource allocation, programme efficiency, advocacy, tracking progress towards elimination and achieving the Sustainable Development Goals (SDGs).

## e. To improve health care infrastructure, logistics and technology

Current state: National NTD programmes are often not fully represented within national and sub-national health management information systems, leading to a lack of understanding of the disease burden by governments and making surveillance and post-elimination surveillance activities onerous.

Moving forward: Sightsavers will work with governments to ensure that the routine NTD indicators needed for disease surveillance are well-integrated into disease surveillance and response systems and health management information systems. However, simply including indicators is not enough to guarantee data quality and completeness, so we will also work to ensure that those who collect and make inputs into these systems are adequately trained to do so, and that the right supervision is in place at all levels.

## f. Support government ownership of data through nationally managed systems

Current state: There are often disjointed data systems for NTD programmes and other critical related data. This creates parallel reporting streams, questions of data governance, and an inability to easily use data for decision making and planning.

Moving forward: Sightsavers will assist ministries of health to identify and incorporate critical information (disease prevalence; programmatic activities; drug stock; water, sanitation and hygiene data, etc.) into nationally owned, appropriate data systems. We will do so fully aware that each country has very specific needs, challenges and possibilities, and that in order for governments to take ownership of their data we need to support solutions that are practical and in line with existing systems. We must also ensure that sufficient training is given so that ministries of health can gather, store and analyse as much data as is useful for decision making and planning.

## g. Support standardisation on disease elimination and other measures

Current state: Not all countries we work in are using globally standardised processes, indicators and systems. In some instances, standardisation does not exist.

Moving forward: Sightsavers will facilitate the creation and/or application of globally accepted standards for use across all levels. This includes indicators (such as NTD disease measures, WASH, inclusion, etc.), survey processes, reporting (such as Joint Application Protocols, Trachoma Elimination Monitoring Form, Expanded Special Project for Elimination of NTDs [ESPEN]), national post-validation surveillance guidance, diagnostics, and quality assurance.

# Goal 2: progress towards universal health coverage

Through our NTD work we have an opportunity to advance a vision of universal health coverage. We define universal health coverage as ensuring that all people have access to health services of sufficient quality, and the users of these services are not exposed to financial hardship.

Universal heath coverage is included in SDG 3.8 and is a cornerstone of the WHO's 13th General Programme of Work. In September 2019, world leaders adopted a high-level United Nations Political Declaration on universal health coverage. Paragraph 34 of the declaration pledges to: "...strengthen efforts to address eye health conditions and oral health, as well as rare diseases and neglected tropical diseases, as part of universal health coverage". This declaration is a significant political commitment in the fight against NTDs. As well as committing to strengthening efforts to address NTDs, the declaration recognises (among other items) the need for member states to:

- Strengthen primary health care.
- Strengthen health information systems.
- Provide necessary funding to support the capacity of their health programmes (including the NTD department) to achieve universal health coverage goals.

Objective 3 will guide our way in supporting universal health coverage, and three sub-objectives will set performance indicators and monitor our progress.

See the Resolution adopted by the UN General Assembly on 10 October 2019 here: www.undocs.org/en/A/RES/74/2



Abana Kumah, who lives in Asubende, Nigeria, became blind from onchocerciasis at a young age. She sits in front of her house with her daughter Efia Kruwah.

## **Objective 3:** Support universal health coverage through ensuring equitable access to NTD and inclusion services

To truly support universal health coverage, we will adopt a multi-faceted approach, particularly prioritising the following elements where NTDs can make a significant contribution towards universal health coverage and strengthening health systems.

a. Attain coverage thresholds and sustain access to preventative chemotherapy

Current state: When we support governments to carry out MDA, we work to ensure that disease-specific coverage thresholds recommended by the WHO (table 1 overleaf) are achieved and sustained. We do this through community-based distributions that are supported through paid and unpaid health workers, as well as through school-based platforms that leverage teachers and school health programmes to treat school-age children. While we continue with this approach moving forward, there are areas we must strengthen.

Moving forward: We will target our efforts to strengthen universal health coverage by promoting NTD programme ownership from the community level up. This will mean delivering high-quality training, and prioritising coverage appraisal to provide evidence that we are attaining and sustaining coverage. To help achieve 2030 elimination goals for NTDs, geographic expansion of MDA into currently untreated areas will be required. With governments and partners, we will utilise existing epidemiological data and prioritise support for mapping and disease-specific assessments to identify the need, then advocate for necessary

programming. Cross-sector collaboration and communication will be essential to ensure that programme adaptation into new areas is culturally appropriate.

 Support provision of inclusive services to manage long-term NTD-associated morbidity

Current state: As stated under Objective 1, skills, facilities and services for the management of NTD-associated morbidity are patchy and of variable quality. This means that many people who require care, services and support are not currently able to receive it.

Moving forward: We will put greater emphasis on community-based initiatives for patient care such as peer support groups, shared learning days, and selfadvocacy for rights. We will work to ensure that people who are impacted by disabling NTD-related conditions can access the information and support they need, such as through organisations for people with disabilities. Acknowledging the mental health burden carried by those with chronic NTD symptoms, we will continue work to reduce the stigma around NTDs and explore ways to address mental health as part of our wider disability programme.

Table 1: WHO coverage thresholds by disease

Disease	Target
Lymphatic filariasis	≥65% epidemiological coverage
River blindness	≥65% epidemiological coverage
Trachoma	≥80% epidemiological coverage
Schistosomiasis	≥75% programme coverage of school-age children
Intestinal worms	≥75% programme coverage of school-age children

## c. Lead on building partnerships at global and country level

Current state: Many people and sectors are required to work together for successful NTD programming and post-elimination work. Strong leadership is currently lacking in some cases and is needed to bring these sectors together.

Moving forward: Sightsavers will strengthen multi-sectoral partnerships, bringing sectors and personnel together at various levels – international, national, sub-national – as needed. This includes the water, sanitation and hygiene sector,

organisations for people with disabilities, the education sector, national health management information system teams, NTD partners, the WHO, technology partners, and veterinary public health. It is important to recognise that all sectors and organisations have specific goals and objectives, and that not all priorities will align. Knowing this, Sightsavers will take the lead in identifying where priorities do align and communicating how efforts are mutually beneficial. At the national and sub-national level, we will work with governments to do the same.



Surajo Khadi, a health worker from Town Clinic, Jega, Kebbi state, Nigeria.



### Our cross-cutting approach

#### Six key cross-cutting principles

Six key principles form the foundation of our strategy: integration, innovation and learning, research and evidence uptake, equity, advocacy, and environmental responsibility. They will enable us to achieve our objectives and ensure that disease elimination is sustained long after our work has concluded in endemic countries. Each principle will be led by a member of the Sightsavers NTD directorate who will help promote organisation-wide ownership and help us achieve our objectives.

#### Integration

Integration is fundamental to our way of working in three main ways.

First we help governments to integrate work on the different NTDs. This means that they can use the same interventions, platforms and databases for tackling multiple NTDs. Aligning government disease programmes in this way improves their efficiency, resulting in stronger health systems that can better handle NTD care, control and prevention.

Second, we support the integration of NTD work with other sectors. This includes working together with ministries and partners focusing on areas such as education; water, sanitation and hygiene; academia; agriculture and animal health. We can only successfully eliminate NTDs when we work together with these sectors to, for example, improve access to water, enhance sanitation and hygiene behaviours, increase knowledge and understanding of NTDs and associated areas, and improve vector control.

The third way integration is key to our work is 'mainstreaming' NTDs into the wider health system. One important reason for mainstreaming is to ensure that governments are better equipped to manage NTDs as part of their 'business as usual' after the diseases are eliminated.

#### Innovation and learning

The goal in innovation, as with everything we do, is to improve the effectiveness and efficiency of our programming consistently. Innovation for us means being user-driven in our design, developing and testing creative solutions to known challenges, learning from what we test, and scaling up solutions that are proven to work. At the heart of this approach is a commitment to listen to what NTD programmes, ministries of health and communities need and innovating to address gaps.

Two areas where Sightsavers will lead in innovation over the coming decade are our social behaviour change communication work, and our novel uses of data for planning, implementation, monitoring, and evaluation.

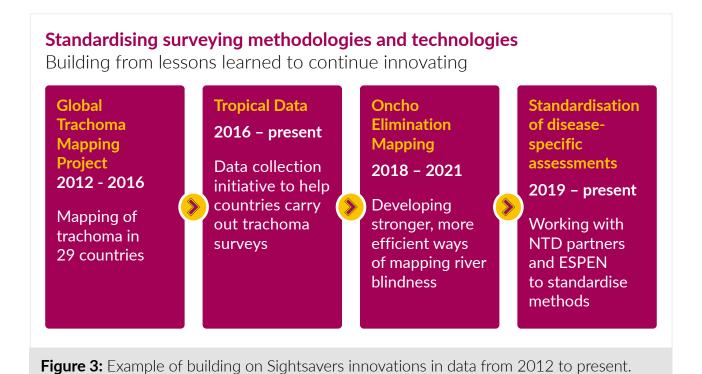
In the coming decade, innovations in social behaviour change communication work will play a pivotal role in ensuring the sustainability of elimination. This is because the risk for recrudescence is often closely correlated to community behaviours and practices.

As the world shifts towards the digital space, the innovative use of data will help governments and our partners better plan their resource allocations, predict disease trends and ultimately enhance disease

surveillance and response. We will draw lessons learned from our programmes, the broader development space and the private sector to innovate in these areas.

As an organisation, Sightsavers encourages innovation in programmes, and our experienced staff and our flexible

approach to programme design make this possible. We will, however, continue to improve on our processes to generate and capture creative solutions and work to ensure that we are not so engrossed in our 'business as usual' work that we don't have time to innovate.



Sightsavers

#### Research and evidence uptake

For Sightsavers, research is a core activity, which contributes to organisational learning, improved quality of programmes, and effective advocacy. By contributing to global partner NTD research and programmatic support, we are generating new evidence to address key knowledge gaps. Under the previous strategic framework, Sightsavers made significant investments in research and our internal research capacity. At present, our in-house research expertise includes epidemiology. statistics, economics, social science, participatory research methods, systematic reviews and geographic information systems. In 2017, Sightsavers was awarded Independent Research Organisation status by Research Councils UK.

Our research in NTDs in the next strategic period will be driven by programmatic needs and questions around NTD diagnostics, control, elimination, surveillance, morbidity management, adaptability to global disruptors and disability prevention. Our disease focus will continue to be on trachoma, river blindness, lymphatic filariasis, schistosomiasis and intestinal worms.

We will specifically prioritise questions of integration, equity and endgame challenges, with an increasing entomological component as lymphatic filariasis, river blindness, trachoma and schistosomiasis are dependent for transmission on insects or snails. In line with our commitments to equity and inclusion in our programming, we will focus on learning questions that will enhance the knowledge base on what works to ensure inclusion of women, people with disabilities, transient populations and other groups at risk of exclusion. Our links to communities allow for the generation and application of new ideas through research. We will be

looking to build stronger links with both disability research and surveillance and expanding the use of both participatory and systems research methodologies.

We will align our research priorities with the content of the WHO NTD roadmap research companion document and research priorities of the WHO NTD collaborating centres. Through our partnership with the Coalition for Operational Research on NTDs, we will continue to support global efforts to identify and prioritise essential NTD programme research needs and contribute to scalable and cost-effective programmes and related advocacy.

In this strategic period, we will work further to build closer relationships between research and programmes through a recently established function, research evidence uptake and learning. The global advisers, who support this function, will work closely with technical leads and programme teams to facilitate evidencebased adaptive programming and promote a continuous learning culture across the organisation. We will specifically focus on two related goals: 1) ensure that research evidence is captured from internal and external sources, made accessible and easy to use; and 2) support the use of research evidence in decision making and ensure that research is responsive to and informed by programme needs. We will also continue to work closely with other teams across the organisation to triangulate research findings with other sources of evidence and to coordinate our evidence uptake and learning approaches and tools.

For more information on our research, visit: **research.sightsavers.org** 

#### **Advocacy**

Advocacy cuts across everything from funding, planning, implementation, monitoring, and surveillance – all while focusing on strengthening national health systems. Sightsavers has invested in key advocacy partners, including Uniting to Combat NTDs, to drive forward advocacy agendas at all levels of engagement from community-based advocacy to global stakeholder and multilateral partnership advocacy.

Sightsavers' approach to advocacy in NTDs is broadly defined in three parts:

**1.** Engaging necessary resources

At the global level, we engage resources where they are lacking, specifically focusing on work with global funders to fill gaps where needed, so no country or area is left behind in their fight against NTDs.

2. Reaching and sustaining elimination

To help reach and sustain elimination, Sightsavers passionately supports and helps shape global policies. Key advocacy components at national level include strengthening eye care services, focusing on data management, and working towards universal health coverage.

Sightsavers is an advocate for stronger integrated data platforms, and we will continue to work with our global and national partners to achieve integrated data platforms, including the integration of NTD and water, sanitation and hygiene data into national health information systems.

We also support countries to secure domestic financing for their own programmes by sharing opportunities, methods and messaging. **3.** Supporting the use of best practices at all levels of our programmes

We help in the creation and application of standardised best practices for the five preventive chemotherapy NTDs. These best practices play an essential role in unifying the global approach to eliminate these diseases. We also work directly with governments and ministries of health to incorporate best practices that support and sustain elimination through ownership of processes, systems and services at the national and sub-national levels.



Bopta Jean conducts research as part of a river blindness research project in Cameroon.

#### **Equity**

We recognise the importance of equity in all of our work. Reaching some population sub-groups is more challenging, and the benefits and impacts of our work are not automatically equitable. Therefore, critical to the success of our approach is monitoring equity and advocating that all people have equal access to NTD interventions and other health services.

Population sub-groups include vulnerable groups such as children, youth, women, people with disabilities, people with chronic diseases, people from poorer households, people from minority groups, older people, indigenous peoples, refugees, prisoners, internally displaced people and migrants.

We aspire to adopt leave no one behind strategies within all our programmes to ensure such sub-groups are included in interventions. To advance this, we are testing different approaches and mechanisms, in particular within MDA; surgeries; water, sanitation and hygiene; and social behaviour change communication.

Understanding what leaving no one behind means in different country contexts helps us work more effectively. The



Patients wait to have their bandages removed after their operations at a mobile trachoma clinic in Bahi Makulu, Tanzania.

inequitable distribution of disease burden in countries requires our programmes to be able to monitor differences between sub-populations in meeting targets. We will build in-country capacity to support ongoing monitoring and evaluation and to standardise the collection and analysis of additional quantitative and qualitative data from research and population-based surveys.

Regarding gender, recommendations put forward by the Countdown project in a discussion paper exploring the gender dimensions of NTDs are helpful to ensure inequalities are not exacerbated. Rapidly changing environmental and political contexts due to conflict, climate change, urbanisation and migration affect levels of infection for people of different genders. The intersection of gender with other social determinants of health shapes peoples' vulnerability to and experience of NTDs, as well as their ability to access care and treatment.

Working with vulnerable groups requires us to follow rigorous safeguarding guidance. More information can be found in our safeguarding policy below.

For more information on our safeguarding policy visit: www. sightsavers.org/how-were-run/accountability-and-transparency/

To view the Countdown project paper visit: www.adphealth.org/upload/resource/2523\_ADP\_Discussion\_Paper\_NTDs\_211119\_web.pdf



The road from Zwerdu to Greenville in Liberia during rainy season is difficult. Heavy trucks often block the road. Local villages charge drivers to divert through their villages, but often the truck drivers, who are paid very little, do not want to pay.

#### **Environmental responsibility**

In this strategic period we will examine global and local environmental aspects of our work. This means continuing to make changes to reduce our environmental impact. To date, we have taken the following actions:

- Minimised travel by running workshops regionally or virtually and flying only when absolutely necessary.
- Limited the amount of paper we use by ensuring that this strategy and other key documents are made available digitally.
- Discouraged the use of single-use plastic bottles.

Going forward, we plan to:

- Identify the most environmentally friendly means of disposing our medical packaging.
- Find ways to reduce the impact of the increased use of masks as a result of COVID-19.
- Assess how we can minimise the environmental impact of vector control.

To see our environmental impact report visit: www.sightsavers.org/how-were-run/accountability-and-transparency/



## Shaping elimination: the NTD landscape

We have shaped our goals and objectives around key global policy frameworks, including the WHO road map for neglected tropical diseases 2021–2030, the WHO sustainability framework and the SDGs.

Sightsavers' modus operandi is consistent with the operating model and culture described by these documents. Investment in health systems strengthening and intersectoral collaboration is critical to realise the elimination of NTDs and to improve health and other outcomes, especially those related to poverty alleviation and moving countries towards universal health coverage.



Zithromax® is dispensed to patients after receiving trachoma operations in Turkana, Kenya.

#### WHO NTD road map for neglected tropical diseases 2021–2030

The WHO NTD road map for neglected tropical diseases 2021-2030 sets global targets and milestones to prevent, control, eliminate or eradicate 20 diseases and disease groups.

To support attainment of the 2030 NTD targets, Sightsavers is committed to concerted action in the three pillars defined in the WHO road map:

Pillar 1: Accelerate programmatic action

Pillar 2: Intensify cross-cutting approaches

Pillar 3: Change operating models and culture to facilitate country ownership

In addition, we will support country governments to achieve the NTD-specific elimination targets outlined in the road map (as per table 2). Our approach will be guided by the WHO's 13th General Programme of Work and the Sustainable Development Goals.

In the same way that we contributed to this edition of the WHO road map, we will offer our contributions for any future updates. In turn, we see it as a priority to adapt our own strategy to work with those updates.

In addition to the road map, a suite of materials will be provided by the WHO. One of those important documents will be the WHO's investment case for NTDs. This will be published in 2021 and will highlight global gaps in programming which we will need to assess carefully and aim to work, with others, to ensure that the gaps, be they disease or country coverage, are addressed.



To view the WHO NTD Road Map to Elimination visit: www.who.int/publications/i/item/WHO-UCN-NTD-2020.01

Disease	Indicator	2020	2023	2025	2030	
Targeted for elimination (interruption of transmission)						
River blindness	No. of countries verified for interruption of transmission	4 (12%)	5 (13%)	8 (21%)	12 (31%)	
Targeted for elimination as a public health problem						
Lymphatic filariasis	No. of countries validated for elimination as a public health problem	19 (26%)	23 (32%)	34 (47%)	58 (81%)	
Schistosomiasis		26 (33%)	49 (63%)	69 (88%)	78 (100%)	
Intestinal worms		7 (7%)	60 (60%)	70 (70%)	96 (96%)	
Trachoma		8 (13%)	28 (44%)	43 (68%)	64 (100%)	

**Table 2:** 2030 WHO NTD Road Map to Elimination 2030 Disease-specific targets (for the preventive chemotherapy NTDs)

#### WHO NTD Road Map Sustainability Framework

The WHO NTD Sustainability Framework is a supplement to the 2030 NTD road map referenced above. The framework operates at three levels: context, health system, and service delivery, with components within each of these levels highlighting different aspects of programme sustainability.

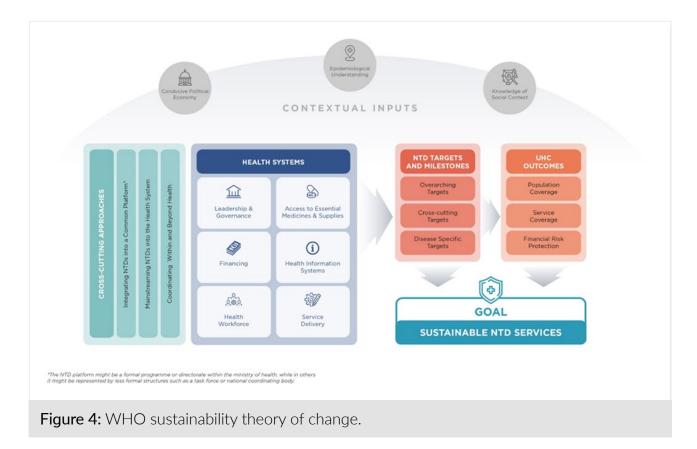
The objective of this framework is to help national governments prioritise and sequence actions that:

- 1. strengthen political and financial commitment and technical capacity to achieve global NTD targets and milestones, aligned with the SDGs and universal health coverage objectives;
- 2. create country-specific platforms that plan, manage, implement, and evaluate NTD services and mainstream NTD programmes into the health system; and

3. enhance coordination and collaboration across sectors in support of NTD programmes.

Sightsavers has used the WHO sustainability theory of change (figure 4) as the foundation of our own NTD theory of change. We have built upon and expanded the WHO model to suit our unique Sightsavers approach to NTD elimination and community health support. Sightsavers is committed to supporting national governments to use these frameworks to develop their own NTD sustainability action plans.

To view the WHO Sustainability Framework visit: www.who.int/publications/i/item/9789240019027





Sia Tamba sits with her children after her son, Solomo, was screened for river blindness during a survey in River Cess county, Liberia.

## Sustainable Development Goals (SDGs)

Adopted by all United Nations Member States in 2015, the SDGs marked a new agenda for inclusive, equitable and sustainable development, including universal access to essential services. The commitment embodied in the SDGs to leave no one behind recognises the need for cross-sectoral action to build strong systems and ensure equitable access across health and other sectors to sustain programme efforts to control, eliminate and eradicate NTDs.

NTDs are formally recognised as a target for global action through SDG target 3.3 to "end the epidemics of... neglected tropical diseases", which sits under the goal to "ensure healthy lives and ensure well-being for all at all ages" (SDG 3). Progress against other SDGs can also accelerate the achievement of NTD goals, for example, eliminating NTDs can support poverty reduction, as discussed in Bangert et al 2017.

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To view Bangert et al visit: www. idpjournal.biomedcentral.com/articles/10.1186/s40249-017-0288-0

## Framework for disease elimination

Our framework for disease elimination (figure 5 overleaf) summarises the WHO Generic framework for control, elimination and eradication of neglected tropical diseases and its purpose is to guide our planning processes at a high level.

The ultimate goal in the framework is to verify elimination of disease as a public health problem or verify the elimination of transmission where possible. Therefore, while public health measures such as MDA can be stopped, monitoring and surveillance still need to continue, including the management of individual cases. Targeted public health responses where disease recrudescence occurs may also need to be implemented.

The framework captures the necessity of government-led NTD programmes to be able to transition from initial scale-up of integrated MDA to post-treatment surveillance, and then to mainstream activities into general health services during post-elimination.

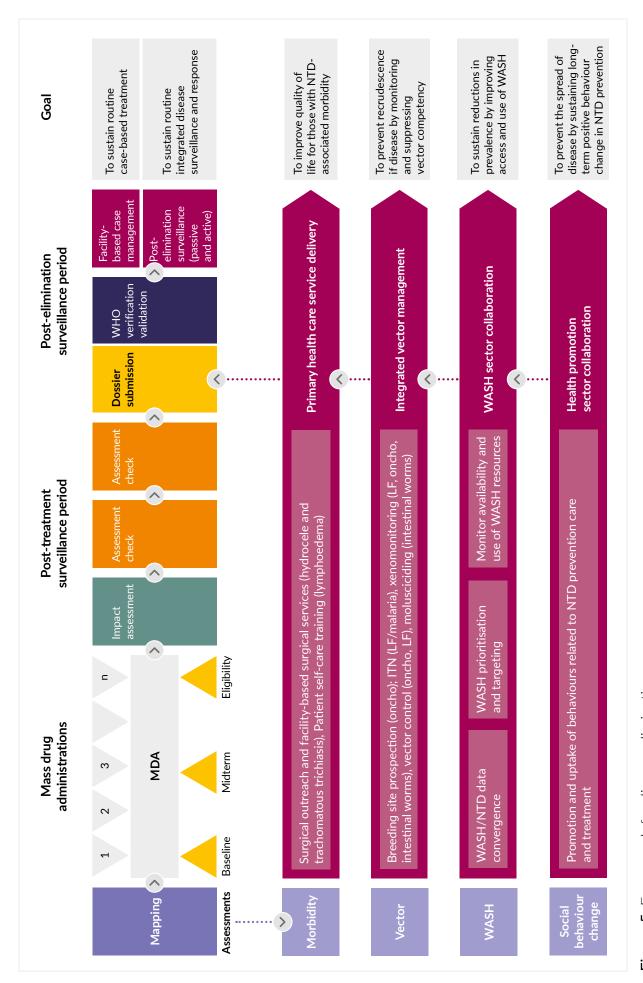


Figure 5: Framework for disease elimination

Sightsavers extends the WHO generic framework further by incorporating six additional activities that will help us reach and sustain our ultimate goal of verified elimination:



Routine case-based treatment



Integrated vector control



Routine integrated disease surveillance and response



Improved access to and use of water and sanitation



Improved quality of life for those with NTD-associated morbidities



Long-term, positive behaviour change in hygiene and other preventative behaviours



**Graduation of countries to low-middle income status** 



Reduced funding commitments from donors.

**5** Co-morbidity of disease



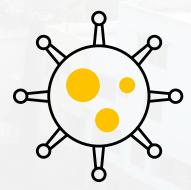
Weak health systems burdened with multiple diseases.

Poverty and population trends



Strained domestic resources.

6 Infectious diseases (e.g. Ebola, COVID-19)



Interruption of routine health work by unanticipated outbreaks.

For more details on how Sightsavers addresses each of the above, see our Plan for Operating in Challenging Environments.



## **Collaboration and partnerships**

#### Travelling the long road together: external partnerships

At Sightsavers, partnerships and collaborations are instrumental for the successful delivery and implementation of our interventions and greatly influence the outcomes of our programmes. The very fact that we play a supporting role to governments means that collaboration is key in everything that we do. Our partnerships and collaborations enable us to create sustainable change and longlasting impacts on the health conditions of the people we serve. To date, we have proven agile at maintaining relationships despite politics, existing and emerging challenges, and conflicting priorities.

As part of our NTD strategy for this new phase of our work, Sightsavers will continue to build on our already strong network of partners and collaborations to strengthen the work that we do. We will draw on lessons learnt from our long and rich history of improving and empowering the lives of the most vulnerable so that we can reach many more and bring an end to preventable morbidity and mortality due to NTDs.

We will review the ever-changing landscape and map our current and future potential partnerships. To achieve this, we will seek out a diverse network of partners, including multiple sectors within governments, donors, multilateral organisations, research institutions, non-governmental organisations, community-based organisations and the private sector. Such mapping will allow us to better track changing dynamics among partners and identify opportunities for collaboration.

We will draw on three fundamental principles for enhanced partnerships and collaborations: strategic partnerships, public-private partnerships with industry leaders and south-south collaborations.

Strategic partnerships: we will continue to be the global coalition leader in NTDs, forging strategic partnerships with industry leaders to reach our collective goals of disease elimination. We need to develop links with the water, sanitation and hygiene sector further and identify a clear set of partners beyond the current and small group we have identified. We will also strengthen our engagement with grassroots and local organisations to ensure that in our work, we leave no one behind.

Public-private partnerships: we will engage in public-private partnerships with innovative industries from a variety of sectors, drawing on their strengths and experiences to help solve complex public health problems. We need to build stronger private sector links such as the relationship we have with Unilever on the School of Five projects in East Africa. Our digital health work will allow us to engage with Africa's mobile phone companies and other technology firms.

South-south collaborations: we will work across our network of partners and countries to establish a network of south-south collaborations, in which countries and organisations can draw on their shared experiences and lessons learned to advise and guide others who are experiencing similar challenges. Country and between country-level partnerships with national non-governmental organisations, the private sector, universities and others require attention and a more defined approach to communications/meetings, knowledge sharing, scale-up and advocacy.

#### Internal collaboration with other Sightsavers thematic areas

Sightsavers works across the domains of health and inclusion. Our health work focuses on strengthening systems to ensure access to eye and NTD services and integrated services as aligned with our mission. Our work in inclusion promotes equal opportunities for people with disabilities across education, health, livelihoods, and political participation.

Sightsavers' work centres on four thematic areas in health and inclusion: NTDs, eye health, social inclusion and education. To best respond to the needs of communities in which Sightsavers works, linkages between the thematic areas need to be strengthened to achieve more. By creating

synergies between thematic areas, we can increase our impact. For example, social inclusion, which covers disability inclusion and gender mainstreaming, is both a crosscutting approach as well as a specific programmatic area. Because of societal stigma, people with disabilities are often marginalised, which means they are less likely to engage in community interventions such as MDA.

In the next decade, the NTD team intends to collaborate even more strongly with the other Sightsavers thematic areas. Figure 6 below shows the crossover themes between these thematic areas.

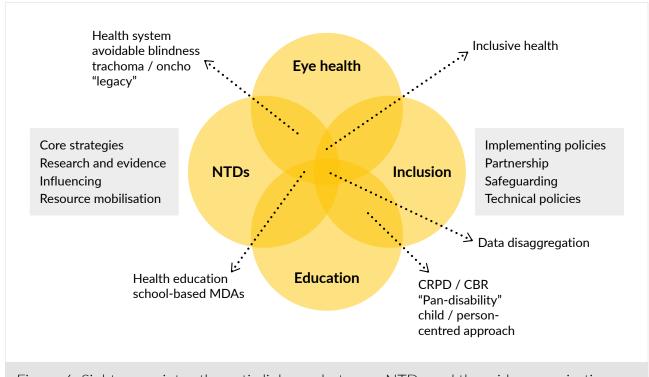


Figure 6: Sightsavers inter-thematic linkages between NTDs and the wider organisation.

## Working with the social inclusion thematic area

Designing NTD programmes through an inclusion lens (the leave no one behind approach) enables us to contribute to the greater involvement and inclusion of people with disabilities in NTD programmes, whether on MDA; water, sanitation and hygiene components; or surgery (i.e. trichiasis or hydrocele surgery).

We aim for everyone with disabilities to participate in and benefit from all parts of NTD programmes. A large proportion of Sightsavers' country offices already have close relationships with disability movements and social affairs ministries through our social inclusion work. A few, but a growing proportion, of community-based organisations have social inclusion projects. Engagement with these institutions and teams enables a transfer of knowledge, partnerships and approaches that can be mutually beneficial to achieve greater inclusion for women and people with disabilities, including those caused by NTDs.

## Working with the eye health thematic area

Collaboration between eye health and NTDs continues to be further strengthened as we move towards the elimination of potentially blinding conditions, like trachoma and river blindness. As the number of people affected by these diseases continues to reduce, ongoing prevention, detection, and treatment will rely on the existing eye health system, especially on the health workforce, infrastructure and health financing. The fact that eye health systems, surgical and refractive services, and other basic public health services are essentially non-existent

in many NTD-endemic areas means a substantial level of strategising, advocacy and investment will be required to address this challenge.

While significant progress has been made in reducing the prevalence and impact of NTDs, global gains in reducing overall visual impairment over the last few decades continue to erode, and the actual burden of eye health conditions continues to increase. This suggests that more than ever, the synergies between eye health and NTDs needs to be strengthened. It is, therefore, important to find synergies. For example, the requirement to meet the needs of postelimination trachoma management is not dissimilar to the requirements for increasing coverage for eye health in general. Schools in rural areas find it hard to obtain an eye test for a child suspected to have a visual impairment or get a pair of spectacles, particularly in the same very low-income areas where trachoma is so prevalent. The same basic service is what will provide the support to the trachoma patient and the child with visual impairment – except with some differences in supply chains. Reliance on the existing eye health resources will result in short-term positive effects with little assured sustainability or maintenance of results despite large investments in posttrachoma elimination services in the places that need it most.

In addition, there are opportunities to support digital solutions and strengthen management information systems that ministries of health and education are using, which will support the collection and utilisation of eye health and NTD data. This is particularly the case where we explore data flow and identify needs to strengthen health management information system teams.

## Working with the education thematic area

In Sightsavers' education work, our NTD behaviour change communications already help to engage with communities more effectively. The team does this by reinforcing desired prevention and uptake of various services behaviours.

Conversely, NTD programmes can provide a platform for delivering inclusive education messages and for advocating to key stakeholders for the inclusion of children with special educational needs and disabilities in school.

We always design education, communication and other forms of behaviour interventions in an inclusive manner, for example, ensuring any printed materials on MDA or other activities are in accessible fonts for people with low vision or dyslexia.

Children with poor health are unable to reach their full educational potential. Given that poor health may be due to schistosomiasis or intestinal worm infections, and/or vision impairment, there are potential linkages between our NTD deworming programmes and education and school-based eve health programmes. In the deworming and school eye health programmes, teachers are trained to dispense medications, carry out vision screening, and communicate key health messages to children and school staff. Joint health messaging can be a powerful tool to influence positive behaviour change. Further linkages need to be considered while designing the behaviour change and health promotion interventions to ensure that teachers, parents and children are aware of the occurrence, reasons, benefits, risk factors and safety of school-based deworming and eye health programmes. Sightsavers'

new refractive error strategy will also be focusing on identifying the strategic interventions and synergies to effectively reach out of school children, particularly girls, children with disabilities and children on the move by engaging with local organisations working in these areas – this can be another opportunity to strengthen interlinkages between NTD and refractive error programmes.

By strengthening links between these programmes, we can support a model of integrated school health delivery that will improve inclusive access, costeffectiveness, and continuum of care. This model will also reduce the burden on the health system and promote government ownership.



Lamik gives a demonstration of Super School of 5, which encourages children to wash their hands and faces, at his school in Chikinakata, Zambia.



People fetch water from the river in Asubende, Ghana.

# Keeping track of the road ahead: measurement, learning and accountability

#### Measurement, learning and accountability framework

Sightsavers is committed to robust and effective monitoring, evaluation and learning in all work we undertake, grounded in WHO best practices, national data ownership and a culture of learning.

Through the strengthening of national systems and the implementation of supportive organisational tools and practices, we will work to ensure effective data capture, collation, analysis, assimilation and reporting.

We will ensure that our programme data is captured by sex, age and geography where relevant. We will also strengthen the capture of disability data, partnering with other projects or using appropriately designed surveys to do so.

#### Supporting the adoption and use of standardised indicators at the national and regional level

We support governments to use standardised indicators when measuring their NTD programmes. This includes three aspects:

# 1. WHO indicators (demographic, endemicity, treatment, morbidity management and disability prevention and impact)

Sightsavers, together with other stakeholders, has worked with the WHO to improve the quality of surveillance, monitoring and evaluation through the standardisation of demographic, endemicity, treatment, morbidity management and disability prevention, and impact indicators. We will continue to work on this.

# 2. National health systems integration (figure 8 on page 46)

Sightsavers will continue to support national programmes to collect data against indicators to manage programmes effectively, populate the national database and complete WHO NTD drug donation request and reporting forms (Joint Request for Select Medicines, Joint Reporting Form, Epidemiological Reporting Form, and the Trachoma Elimination Monitoring Form).

To promote sustainability and integration of vertical disease programmes with the national health management information systems, Sightsavers has supported and will continue to support the integration of routine indicators into national health information systems. This integration replaces the manual disease reporting process. It allows for all disease programmes to use the same administrative units (district and sub-district levels) and populations across all health programmes.

#### 3. NTD roadmap

Sightsavers will commit to using nationally reported data for ongoing oversight and analysis of progress to elimination across supported countries.



Ophthalmic clinical officer and trichiasis surgeon Jerome Mbewe examines patients' eyes at the Kasungu district hospital in Malawi.

# Ensuring the quality of our programmatic interventions – Quality Standards Assessment Tool

Sightsavers has a responsibility to ensure that the projects we support are aligned to recognised international best practices for NTD interventions. The Quality Standards Assessment Tool is Sightsavers' principal way of checking that NTD country programmes meet defined minimum standards. These standards cover all stages of the NTD framework for disease elimination and were developed through a process of comprehensive consultation. We update them regularly to make sure that they align with the latest international policy developments and recommendations.

# 1. Commitment to conduct standards in partnerships with ministries

We use the tool to assess the capacity of national and state NTD programmes to deliver quality interventions. These are done in collaboration with national ministries of health.

Assessments are an opportunity to reflect on programme performance, and, where needed, to define and trigger strengthening measures through carefully monitored quality improvement action plans.

#### 2. Actively supporting action plans

We will continue working with ministries to prepare, execute and monitor action plans. This is done collaboratively between ministries of health and Sightsavers over a defined period.

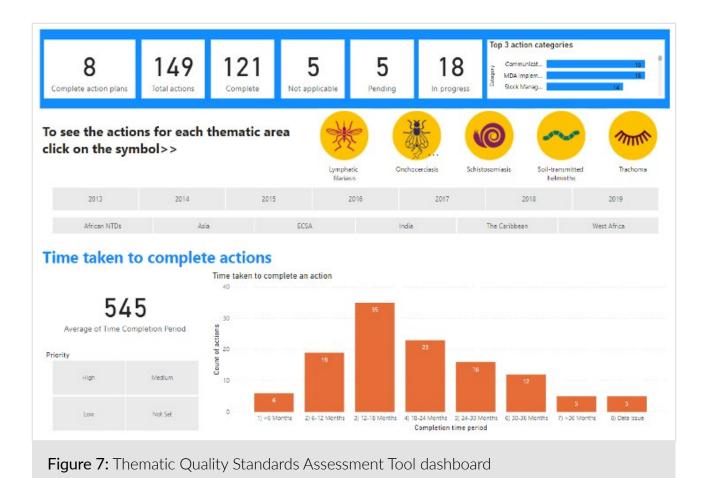
# 3. Improved analysis of granular components

As the tool assesses the capacity of a national programme to deliver a quality programme, it underpins the measurement of our NTD strategy. It is a direct source of data for indicators within our public-facing Strategy, Implementation and Monitoring Card. We commit to collectively analysing scores from all assessments to better understand and react to cross-cutting organisational successes and challenges using interactive visual tools. See an example dashboard monitoring the time to completion of defined quality improvement actions in figure 7 opposite.



See our Strategy Implementation and Monitoring card here:

www.sightsavers.org/wp-content/ uploads/2017/09/Sightsavers-SIMcard-2017.pdf



## Standardisation of monitoring and evaluation activities

To ensure consistency in the measurement of programmatic indicators at any level within this strategic period, Sightsavers commits to the use of an organisationally approved NTD monitoring and evaluation framework. This framework comprises standardised NTD log frames, and an accompanying reference guide to clearly define the purpose and calculation behind each indicator. Our approved indicators will be aligned to those recommended by the WHO, with additional content specific to Sightsavers organisational tools and processes, e.g. the Thematic Quality Standards Assessment Tool.

Approved indicators will be outlined to measure interventions across the NTD monitoring and evaluation framework for disease control and elimination, from treatment and surveillance activities to patient care; vector control; and water, sanitation and hygiene.

We will work to make sure the right standardised digital tools and visual platforms are in place and functional to ensure effective data demand and use in our country offices.

#### Data and evidence-based programming

As outlined in the theory of change, Sightsavers supports the integration of NTD platforms, tools and processes that support NTD control and elimination. Our approach to data and evidence is to evolve the enabling environment to give national and sub-national stakeholders the opportunity, accountability, and capability to use data to increase coverage, inclusion, and equity in their communities and improve efficiencies concerning drug use and wastage.

The diagram below represents a fully integrated ideal state, in which i) routine NTD treatment and morbidity indicators are reported through health management information systems, ii) donated medicines are tracked by the logistics management and information system from central warehouses to communities, iii) high-quality data is produced by prevalence surveys, and iv) all routine, event, and management data is aggregated into one national NTD database, serving as a data warehouse.

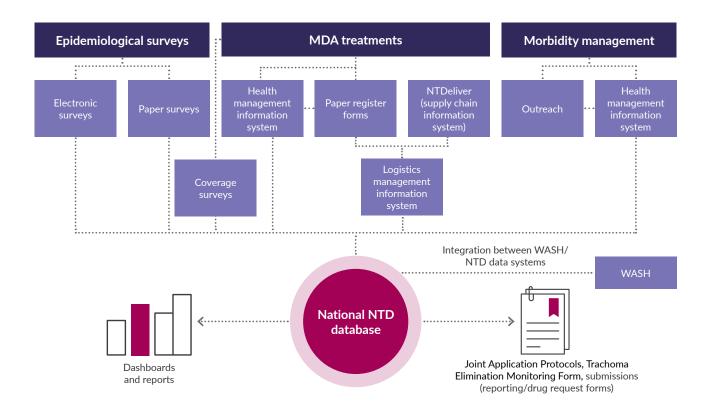


Figure 8: Ideal integrated data health information system

#### Collaboration, learning and adaptation framework

A continuous cycle of learning and adaptation is considered a regular component of NTD programme reviews, evaluations, and other meetings. Through the collaboration, learning and adaptation framework and its associated tools, we encourage decisions and adjustments to be made in response to new information, which is often identified through our existing monitoring and evaluation activities.

One key component of the framework is pause and reflect sessions: dedicated time to reflect on whether a programme or activity is reaching its intended outcomes, examine what is working and what is not working, and decide what level of adaptation is required.

Adopting the collaboration, learning and adaptation framework in our programmes and fostering adaptive leadership and data-driven practices by our national counterparts will continue to benefit our NTD work in multiple ways:

- Improvement in the use of evidence generated through project implementation and monitoring and evaluation.
- Amendments in project/programme action plans and decisions based on learning.
- Improvement in organisational performance because of our strategic collaboration.
- Monitoring and evaluation positively and significantly associated with achieving development outcomes.

- Increased country ownership of programmes.
- Improved programmes that attract additional external investment.
- Strengthened management and performance indicators.
- Improved skill sets at the country level to analyse data and programme performance.
- More opportunities to promote a learning culture.



We work with partners in developing countries to eliminate avoidable blindness and promote equal opportunities for people with disabilities.

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