

Now is the time
to say goodbye
to neglected
tropical diseases



Sightsavers and NTDs: priority areas of work

2016-2020



Sightsavers



Community Directed Distributor
Dayyaba Abubakar in Sokoto, Nigeria.

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Cover image: Ophthalmic nurse and lead surgeon, Aliyu A-Umar, dances with children in Kware, Nigeria.



A young girl is measured before receiving her Mectizan® treatment in Hore Felo, Guinea-Conakry.

A word from the Director

This document marks a first for neglected tropical diseases (NTDs) at Sightsavers. Instead of the NTD team just talking about elimination, we now have an outline to achieve our ambitious but achievable goals.

Our flagship trachoma and onchocerciasis programmes have their own programme documents, but this document brings all of our NTD work together and runs through our high-level strategy.

Highlights and key tasks ahead include:

- Mapping out relationships between NTDs and other Sightsavers programmes to maximise synergies and coordinate implementation.
- Supporting integration and coordination of NTD treatments to meet the scale up in countries in which we are active to reach elimination goals.
- Ensuring that we support health systems strengthening and get better at explaining how we do that.
- Enabling in-country ownership by working with and assisting in the development of robust national NTD master plans.
- Maintaining and developing partnerships, including across development sectors (WASH, malaria, behaviour change, etc) as well as the private sector.
- Moving ahead rapidly in our niche areas – behaviour change, mHealth, and research.
- Engaging with the external NTD environment for the benefit of our own programmes and the global elimination agenda.
- Improving internal organisational learning across our programmes and promoting sharing of internal and external best practices.
- Reinforcing our leadership in managing consortium grants by extending the ‘trachoma model’ to other NTDs.
- Ensuring that all NTD projects are inclusive of people with disabilities.

The work we do to combat NTDs brings many teams, departments and individuals together – this is when Sightsavers achieves the most. Together we can and will eliminate NTDs by 2025.

This plan has been put together by many people. I hope through this engagement it becomes ‘our plan’ and not ‘their plan’ as it will be the whole organisation that will collectively achieve our place in the success story that is elimination of NTDs.



Simon Bush
Director, Neglected Tropical Diseases



Women dance and sing a song about the dangers of river blindness at a community meeting in Nigeria.

Introduction

This document provides a common understanding of what Sightsavers wants to achieve in our NTD work (and how it fits with the rest of Sightsavers' work) by the years 2020 and 2025.

It defines our neglected tropical disease scope of work and addresses issues identified that need to be worked on, resolved and prioritised as we reach our goal of elimination of NTDs in Africa.

The NTD environment is fluid and ever-changing. The content of this document is based on information as of June 2016. Each year we will report against the strategic plan, but also update it with new areas of work and issues. It is a working document and will change over the life of our disease elimination programmes.

This document is not an operational work plan – the annual team work plan, linking to annual personal work plans, will be based on the priority areas we have identified here.

This document is mainly for internal use although extracts can be used externally when describing our work. A summary will be prepared that can be widely shared externally.

Our elimination agenda and indicators

Disease	Target for elimination
1 Onchocerciasis	2025 – with the majority of Sightsavers projects entering into post-treatment surveillance by 2020
2 Lymphatic filariasis	2020
3 Trachoma	2020
4 Soil transmitted helminths	2020 – control: 75% of all pre-school and school aged children in need of treatment are regularly treated
5 Schistosomiasis (Bilharzia)	Schistosomiasis (in particular <i>Schistosoma mansoni</i>) is not scheduled for elimination in sub-Saharan Africa even by 2020. But steps should be taken towards elimination in countries/areas with appropriate conditions



Our programmes are working towards the achievement of the World Health Organization's (WHO) Road Map for NTDs as outlined in 'Accelerating Work to Overcome the Global Impact of NTDs – A Roadmap for Implementation,' available to read at: po.st/ntd_roadmap

This in turn links up with various World Health Assembly resolutions on the specific diseases.

We also work within the WHO technical guidelines for disease elimination – for example, the 'Guidelines for the Stopping of Mass Drug Administration and Verifying Elimination of Human Onchocerciasis,' available to read at: po.st/guidelinesstoppingMDA

We are committed to working towards the London Declaration available to read at: po.st/londondeclaration

Our work in WASH and behaviour change will be framed by the WHO strategy in 'Water sanitation and hygiene for accelerating and sustaining progress on neglected tropical diseases – A global strategy 2015-2020', available to read at: po.st/WASH

The NTD objectives in Sightsavers' Strategy, Implementation and Monitoring (SIM) card are:

Deliver integrated neglected tropical disease programmes in support of agreed global targets

Lag: % of countries, where Sightsavers supports specific NTD disease projects, that are meeting national milestones to eliminate or control these specific NTDs

Annual

Lead: % of projects which meet or exceed their MDA targets for therapeutic and geographical coverage

Annual

Lead: % of NTD projects with clearly defined strategies to improve access by people with disabilities

Annual

Our experience and aspirations

Experience

Though we were undertaking small-scale lymphatic filariasis (LF) work as early as 2007, it was only in 2010 that we recorded our first LF treatment, followed by schistosomiasis and soil transmitted helminths (STH) in 2011.

In 2011 we responded to the international call to scale up NTD treatments by developing 'fast track initiative' disease-specific programmes (now called our 'flagship programmes') covering onchocerciasis and trachoma. In 2016 we ensured the integration of LF into our onchocerciasis plans.

In 2015 we supported 143 million NTD treatments – the second year in a row that we supported over 100 million treatments.

We are an NTD leader globally in terms of treatments provided and project management of large grants/contracts from donors. We are recognised for our strengths in advocacy, policy, influencing, resource mobilisation, programme delivery and coalition management.

Aspirations

At present we bat above our weight influence-wise, but there are others who are developing comprehensive approaches to NTDs too and we may lose the competitive advantage we have, both in terms of implementation and influence, if we fail to continue to grow and improve.

We want to become better known for:

- Behaviour change (related to prevention and sustaining elimination of NTDs along with encouraging uptake of morbidity management services/surgeries)
- mHealth (for information/data management, increased efficiency and behaviour change)
- Successfully integrated NTD programme models
- Operational research which enhances programme delivery

Hawau Aliyu (right) and Nura Rufai (left) CDDs in Tsafe, Nigeria.



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The GTMP: an example of our leadership

The Global Trachoma Mapping Project (GTMP) ended on 31 December 2015. In total 1,627 districts were mapped in a three-year period. 95% of districts were mapped using the same GTMP standardised methodology and system in 29 countries. Sightsavers brought together dozens of partners – academic institutions, NGOs and ministries of health – to make this idea a reality.

A total of 2.6 million people were examined during the surveys for active trachoma and trichiasis (TT) and in addition to the patient details, information regarding household location (via GPS) and access to water and sanitation was also collected.

The GTMP team worked with ministries of health and NGO partners to: develop sampling protocols and plans/budgets; provide training materials, processes and expert resource to support 'training of trainers' and 'training of grader and recorder' workshops; process, clean and provide technical oversight (supported by WHO) and provide troubleshooting and support during the mapping and collection of over 60 million data items. The GTMP team also developed automated systems to support the ministries of health to review and approve their data and results.



A doctor and grader examine a woman's eyes for trachoma in a village near Khartoum, Sudan during the GTMP.

Although the GTMP project has come to an end (and will go down in history as the largest infectious disease mapping exercise in history, until now) the systems and partnerships will continue to support trachoma baseline mapping, impact surveys and surveillance surveys in the form of the new service Tropical Data. The Tropical Data team intends to expand to other NTDs over the coming years as well.

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Our strategic choices and principles

Strategic choices

- We will confine our **geographic spread in NTD work to Africa**. There are three exceptions to this strategic choice: if funding is available to support trachoma and onchocerciasis in Yemen we will expand there; if we are invited or we choose to bid for contract management work globally we will undertake work outside Africa; and, if NTD work is linked to a programme covering other work (eg the World Bank contract for deworming and vision screening in schools in Cambodia) we would seize this as an opportunity.
- We will reinforce our **leadership in managing consortium grants** by extending the 'trachoma model' to other NTDs.
- We will utilise the **lessons of the NTD projects more widely**. Sightsavers NTDs has been set up as a separate directorate within Sightsavers, recognising that the drive to elimination and the increased level of collaboration requires a new focus and approach. But we need to work better with colleagues across the organisation to review and assess these new processes and solutions to determine if they could be used more widely to reinforce our leadership in other areas. Our team's engagement with and learning from other teams in Sightsavers on research, advocacy, data, systems and policy will be essential.
- We will put in place an **agile and responsive NTD team** that is able to 1) respond to opportunities and provide excellence in project management and technical advice and 2) support integration into Sightsavers' wider work that ensures and enables cohesion, efficiency and effectiveness via processes, systems and structures for success. Given the fast pace of change in the NTD sector we will need to review capacity and specialisms on an annual basis.

Principles

- We support **integration and coordination** of NTD programmes in countries in which we are active to reach elimination goals within NTD national master plans.
- We ensure that NTD projects **promote gender equity and are inclusive of people with disabilities**.
- We support **health systems strengthening** (eg ensuring surveillance systems are in place).
- We work to **develop new NTD partnerships** including partnerships across development sectors between NTDs and WASH, malaria (especially on LF programmes and bed nets) and behaviour change.
- We fully engage with the **external NTD environment** for the benefit of our own programmes and the global elimination agenda.
- We constantly **work to improve internal organisational learning** across our programmes and promote sharing of internal and external best practices (eg the preferred practice documents used in our grant funded work must be used in all NTD country programmes without fail).
- We **coordinate between all Sightsavers health programmes** when they are co-located, to ensure efficiency and to coordinate demands on and sustainable benefits to the health system.
- We **deliver value for money**, endeavouring to maximise the impact of each pound spent to improve people's lives.
- We **strive to reach the poorest people** who live in places that have little or no access to medical care.

The means: how we will reach our elimination goals

Where disease mapping and national plans indicate co-endemicity, vertical approaches to disease control and elimination need to change to coordinated and integrated approaches with other NTDs.

Coordination

Coordination is not about providing medicines at the same time, but rather putting the individual who is to receive the tablets at the centre of our programmes and developing a plan of implementation that ensures they receive the tablets they need along with non-drug based interventions that will sustain elimination.

Coordination with other sectors needs to happen – there are advantages to broader coordination with malaria (vector control and use of ivermectin), immunisation programmes, WASH, behaviour change programmes, etc.

We have no intent to get involved with the Innovative and Intensified Disease Management (IDM) diseases, focusing on diseases for which cost-effective control tools do not exist and where large-scale use of existing tools is limited. Those diseases include buruli ulcer, chagas disease, human African trypanosomiasis and leishmaniasis. However, we will coordinate with others who work in this area if we note that these diseases are endemic and underserved in our operational target areas.

Integration

Integration means putting in place systems and mechanisms that will provide sustained healthy behaviours where drug distribution goals have been achieved. Where coordination would help avoid redundancy, contradiction, and conflicts in timing/scheduling, integration will attain alignment, efficiencies, and leveraging of approaches, resources, and delivery capacity.

The key to this integration is supporting in-country ownership by working with national NTD master plans. NTD master plans need to be of good quality and based on recent robust prevalence data both for planning and for progress tracking – hence initiatives like Tropical Data. We have a role to play in supporting the development of these quality, comprehensive and budgeted master plans, including involvement in the renewal of existing plans and need to support capacity to deliver this crucial area of work. National NTD task forces need to own these plans and be vibrant and supported to deliver. Where required we can support these task forces financially – the country, however, must remain in the leadership position.

To achieve and sustain elimination we must promote multi-sectorial integration and proactively develop strategic partnerships in all areas of work. For example, soil transmitted helminths (STH) programmes need to go beyond schools if national control targets are to be met. STH is more problematic as it has the potential to be an indefinite control programme (until current treatment strategy changes; this will be a long way off) and we would only continue with STH support as part of school health programmes which also include eye health. Onchocerciasis, lymphatic filariasis (LF) and trachoma elimination programmes, which are traditionally community focused, should also look towards school programming to achieve their elimination targets.

There needs to be careful balance in what we try to integrate. Not all programmes lend themselves to integration, but we should always be able to coordinate. Therefore we will integrate where it makes sense and coordinate otherwise (or rather jointly work, eg with WASH or social inclusion).

Control vs elimination

This is a critical area and there is a choice to be made here: either continue with control or work towards elimination. This plan assumes that elimination is the goal and Sightsavers wants to become one of the premiere NGOs in elimination programmes.

Control programmes are those where a reduction of the incidence, prevalence, intensity, morbidity and/or mortality of disease occurs as a result of deliberate efforts. Continued interventions may be required to maintain this reduction.

Elimination programmes result in a reduction to zero (or as defined by the intervention) caused by a specific pathogen in a defined geographical area, with minimal risk of reintroduction. Continued actions to prevent re-establishment of transmission may be required. When elimination of the disease or parasite is confirmed, the endemic area enters into a phase of post-treatment surveillance.

The key differences in shifting from control to elimination programmes are the higher required funding, differing technical and operational inputs, and increased political and system strengthening interventions needed to achieve the end game of NTD elimination. We need to work in all programmes to the various disease elimination definitions and report progress against those criteria.

How to get there

- We must have flexible and adaptable programmes that acknowledge and respond to elimination challenges.
- We must have strong technical support and monitoring and evaluation in order to ensure that adaptation happens – monitoring and evaluation activities (impact assessments, coverage surveys, surveillance activities, etc) must be adequately planned for and resourced.
- We must not continue with the same strategy if we know it will not lead to elimination. We must change our activities or, if need be, try innovative approaches.
- We must continually monitor, promote and advocate for new research and technologies, eg diagnostics, medication, disease surveillance, etc, that can assist in achieving elimination faster. Funds need to be raised for these interventions as they must not be funded at the expense of implementation.
- We must design relevant operational research questions to be able to address programmatic challenges and allow for tailored interventions to improve programme activities.
- We must ensure we learn from our programmes in order to adapt our own approaches to implementation as well as share the knowledge of what works and what doesn't with others.
- We must continue so that our NTD global portfolio works to agreed WHO criteria for disease elimination, WASH and behaviour change and aligns to health system strengthening mechanisms, equity and universal health coverage.
- We must ensure that specific in-country work fit within the approved WHO NTD master plans.

Challenges for oncho/LF

There are some issues that are specific to onchocerciasis and LF elimination that will impact on our supported programmes in the run up to 2025. Elimination of onchocerciasis is by transmission foci/zones. These foci/zones sometimes cut across projects; they also need to be defined to include hypo-endemic communities which were not initially under mass drug administration. Delays in defining the transmission foci/zones could result in recrudescence in areas where transmission has been interrupted. We are currently working with WHO AFRO and national programmes to facilitate defining of these transmission foci/zones.

The LF elimination strategy requires both morbidity management and disability inclusion services. Mapping of the disability for morbidity management has not been carried out and service delivery is yet to commence in many projects – without the provision of services to the individuals, they remain a source of infection and interruption of transmission will be delayed. We are working with Liverpool School of Tropical Medicine and the working group of the NTD NGDO Network for technical support and to develop tools for addressing disability treatment. Pilot projects in Democratic Republic of Congo, Guinea Bissau, Nigeria and Uganda will provide learning for scale up of disease management and disability inclusion for other countries.

Geographic spread

For the use of our unrestricted spend on NTDs our geographic focus will be Africa. In developing our restricted portfolio, however, we will work globally. The exceptions to this are noted in the strategic choices and principles section above.

We realise that we may have to prioritise new funded work in more difficult environments of the Central African Republic, Chad and Angola (less likely given the difficulty to engage) if we are to contribute to the elimination effort in Africa.

As an organisation we do not have the experience or infrastructure that enables us to work safely in conflict areas. However, NTDs are endemic in some of these countries so we need to partner with those such as Médecins Sans Frontières and/or Mentor Initiative who have the expertise needed for working in such environments. Different approaches are needed to deliver against the elimination agenda we have set ourselves and these need to be looked at on a case-by-case basis.

Surveillance

Surveillance is a fundamental part of an NTD programme from the start of planning to implementation and review to the final verification of elimination. We will advocate with funders to ensure that surveillance is seen as an integral part of MDA programmes.

We will invest in, source funding for, and develop partnerships to achieve disease surveillance to internationally agreed methods in all our programmes. This will be integrated, covering multiple NTDs where possible, using the Tropical Data platform.

Improved diagnostics are also coming on board for NTDs. All of our programmes need to be using these improved diagnostic tools as standard.

Funding implications

If we want to deliver elimination across Africa we will need more money and staff.

We have better knowledge of the funding gap implied by differing scenarios of control versus elimination as identified in the NTD strategic alignment process from 2015. We need to develop a more detailed funding plan that has the objective of elimination, not control, at the centre.

As unrestricted fundraising for all UK NGOs is currently facing many challenges and there is ever-growing competition to access these funds, established activities and programmes like NTDs need to continue to develop their relationships with institutional/trust/corporate donors and build the case for more restricted funding to support NTD programmes.

We have had success in restricted some work on onchocerciasis (eg the End Fund). The short-term aim is to reduce unrestricted funding of the onchocerciasis programmes while increasing grant funding.

There is however strategic value in having an agreed amount of Sightsavers' unrestricted funding invested in NTDs in order to leverage and maximise funding from other donors and to ensure consistent treatments to reach elimination. Use of unrestricted funding will also allow us to develop areas such as mHealth and behaviour change.

We have decided to expand our work to fund and support surveillance to support, for example, the ex-OCP countries to achieve elimination after 42 years of funding. Current budgets allocated to countries will not achieve elimination for non-restricted funded projects. Our situation analysis on elimination of onchocerciasis and LF has identified what activities are needed to achieve elimination. Our country briefs outline what additional activities are required to achieve elimination with estimated costs.



Aminata Kâ, nine months old, gets her dose of Zithromax® to prevent trachoma for a year.

Working to the elimination agenda in countries with complex security issues will require a different approach and partners – these new approaches/relationships are likely to be more expensive to implement.

The NTD team needs to work more closely with the fundraising teams to support the NTD portfolio. There is an inherent conflict that needs managing though – that of responding to donor opportunities and preferences versus seeking donors to help fill perceived funding gaps. The areas that require funding are moving away from traditional mass drug administration (MDA) but to surveillance, diagnostics, mHealth, WASH, and behaviour change promotion.

We need to communicate differently with donors to show that these areas are part of a comprehensive NTD elimination projects and not just the MDA component.

We need to have a clearer understanding of how domestic financing can be stimulated and how this links to wider agendas such as system strengthening and universal health coverage. We have considerable skills inhouse on influencing, policy and advocacy to work systematically on this. We will advocate for the establishment of resource mobilisation sub-committees of national NTD task forces to enable countries to raise funds for NTD programmes.

NTDs and other Sightsavers programmes

The overlap between NTD work and other programmatic/advocacy work is increasing, and the same donors often fund them. This is an opportunity for us to exploit.

Within the first six months of this strategic plan, we will have mapped out the relationships between NTDs and other programmes and highlighted plans maximising synergies, implementation, etc. Areas like NTD programmes and their contribution to health systems strengthening and universal health coverage have only recently been talked about. The opportunities for disability inclusion, development of case management programmes and an approach to expanding school-based NTD treatment programmes to cover all in the community will increase during this plan. All will ensure that NTD programmes offer more comprehensive coverage outside of mass drug administration activities. Our NTD portfolio will need to have a clear articulation in response to these major issues. We will then ensure a joined strategy between our NTD programme portfolio and the larger organisation. The annual review of the NTD strategic alignment process will help with this process.

We will also continue to develop horizontal learning initiatives to ensure that countries gain synergies between the programmes to ensure that the portfolio learns, benefits and is strengthened by NTD and non-NTD work alike.

We will work to leverage existing tools to add value to other Sightsavers programmes. Our bespoke tools developed for programme management of the large grants (eg CLAIMS, project management tool for the UNITED programme in Nigeria, etc) and tools developed for the consortia programmes could be cross-purposed to support other programmes, particularly when matched to tools such as Quality Standards Assessment Tool (QSAT). These systems should create efficiencies and not more work for country staff.

At risk of neglect: people with disabilities and NTDs

People with disabilities are a group acknowledged to be at significant risk of being excluded from many development programmes and interventions, including in health. The reality is that the evidence is patchy and weak – as is the case with many development issues, particularly those focused on marginalised groups. But evidence from extremely credible sources such as the WHO and World Bank points to systematic exclusion. To build the evidence base, Sightsavers is currently undertaking some work in this area on our health programmes.

There is no reason to assume efforts to control or eliminate NTDs are immune from this general reality. So it is strongly welcomed that the NTD community is looking to address the exclusion issue as a whole.

As a health intervention group, we believe the NTD community needs to be particularly clear on how to address exclusion. The disability movement is understandably sensitive to suggestions that people can be ‘cured’ or ‘healed’ by health interventions. Often the answer to inclusion lies with shifts in society, specific adaptations to interventions and so on. So, statements around ‘eliminating disability’ or ‘curing the disabled’ are not positive.

What is not controversial is the idea that people with disabilities have the same right to health, without discrimination, as their peers. This is enshrined in the 1948 Universal Declaration of Human Rights and more recently in the UN Convention on the Rights of Persons with Disabilities. So a focus on ‘disability inclusion’ is very welcome if that means removing systemic barriers, and ensuring that people using wheelchairs can access drug distributions, that people with intellectual disabilities can undergo surgery for trachoma or LF, that deaf people can also access spoken health messages, etc.

It is also uncontroversial to manage the painful and debilitating symptoms of diseases such as LF and buruli ulcer, to conduct surgeries where necessary (and where patients elect to undergo) and to provide preventive chemotherapy for trachoma, onchocerciasis and schistosomiasis.



A student at the Dawn Centre, an early childhood development facility in Malawi.

But the conflation of ‘Disease Management and Disability Inclusion’ or DMDI, currently proposed by the NTD community, risks being ineffective as well as not conforming to the CRPD’s rights-based approach. It suggests that we will prevent and cure where possible but where not, we will deal with the medical issues of those we can’t ‘cure’. The reality is we won’t be reaching most people with disabilities in the first place, because we haven’t set up our programmes to be inclusive of anyone except those with the specific symptoms coming from ‘our’ disease.

We recommend that we split DMDI into two groups. One group on Disease Management, which looks at how to most effectively provide for the long-term health care needs of individuals and communities, and one on Disability Inclusion which looks to ensure that people with disabilities are included in the thinking of all the work of the NTD community – MDA, WASH, surgery, case management, etc. Each group needs strong leadership to ensure we are delivering services to ‘neglected people’ not prioritising ‘neglected diseases’.

External partnerships

This is a very complex area of our work. To date we have proved agile at maintaining relationships despite the politics. We need a review of the key players and strategy for how we work with them. The landscape is constantly shifting with our role becoming increasingly prominent. A map of the partnerships, both within the UK and in endemic countries, must be completed and maintained. This would allow us to better track changing dynamics among partners and visualise opportunities for collaboration.

Sightsavers has entered into relationships with Schistosomiasis Control Initiative (SCI), Liverpool School of Tropical Medicine, London School of Hygiene and Tropical Medicine, and the Kilimanjaro Centre for Community Ophthalmology, to provide technical advice and operational research to improve our programmes. With SCI and Liverpool we have arrangements where we also support them with implementation and financial management.

We have active engagement with WHO at headquarters and African regional office levels. We have official relations with headquarters and have a memorandum of understanding with AFRO.

We need to develop links with the Centers for Disease Control (CDC), Tulane University and other US-based research institutions.

We need to further develop links with the WASH sector and identify a clear set of partners beyond the current and small group we have identified.

We need to build stronger private sector links. The relationship we have with Unilever on the School of Five project in East Africa needs to be expanded. This may bring other potential to engage with Unilever. Our mHealth work should allow us to engage with Africa's mobile phone companies.

Managing consortia is the right approach at the moment as DFID, for example, attempts to work out how the next NTD grants will be managed. We believe DFID will encourage one lead agency to work with a wide coalition to deliver on large multi-disease projects.

We will expand the scope of the current UNITED partnership in Nigeria to cover the potential to bid for new DFID NTD work, expected to be one large multi-country and multiple disease NTD project with one contract manager working with multiple partners.

Once the global partnerships are in place and partners have been identified, we need to work diligently to ensure that partnerships in country are also strengthened. Country level partnerships with national NGOs, the private sector, universities and others require attention and a more defined approach to communications/meetings, knowledge sharing, scale-up and advocacy.

Legacy/leverage

Implications of the closure of the African Programme for Onchocerciasis Control (APOC) in 2015 are becoming better known. It is clear the new entity will not support all countries.

2016 will be a critical year for onchocerciasis and Sightsavers as we must maintain and increase treatments to reach elimination status and start to verify this in as many projects as possible using the guidelines from WHO (issued in January 2016).

Another implication is in technical support for impact assessment. The role of the Multi Disease Surveillance Centre has been confirmed for another year from April 2016 but national capacities need to be built too. The Liverpool School is building capacity of national laboratories, as well as working with existing laboratories in the regions to develop a network of laboratories.

We are using the Global Trachoma Mapping Project in the development of the cross-NTD platform Tropical Data with WHO and RTI as key partners.

Sightsavers heads the Uniting to Combat NTDs consortium as part of a grant from the Bill and Melinda Gates Foundation. This showcases our ability to prioritise the overall elimination mission over our own brand. This project provides us with an opportunity to build a strong relationship with the Foundation and the Uniting to Combat NTDs Strategic Working Group.

Two niche areas that we believe will have legacy and impact at a global scale will be our work in mHealth and behaviour change. These are areas we need to develop and fundraise for.

mHealth

Sightsavers is poised to lead the way in using mobile phone-based tools for data collection and the surveillance of NTDs. To quote the Economist: “Out went pens and paper. In came smartphones” (February 2016). The success of the GTMP sets the precedent in both our country and grant-funded programs to collect data electronically on impact assessments, prevalence/coverage/compliance surveys, TT surgery tracking and MDA tracking. Implemented smartly, these tools will transform our field activities – increasing efficiencies, cost savings and impact.

To be successful, Sightsavers programmes will share mHealth experiences; the lessons learned during the 2014 pilots in three countries are already influencing programme design in other countries. And as leaders in the field, we will be able to share lessons with and guide other organisations on how to best transition to mobile – a switch that is viewed as an inevitability despite its complexities. All of this work will take the support and commitment of country offices and funders, as despite the cost savings over time the transition to mobile systems requires both monetary and human resources.

By 2017, pilot programs will have scaled, grant-funded countries set up for standardised data collection, and all other country programmes should have a plan in place to incorporate electronic data collection into their work. As these mHealth programmes grow, the mobile data collection systems used in the field will be integrated directly into Sightsavers’ databases, also transforming how annual output statistics are reported and shared.



Data reporting by mobile phone in Mali.

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Behaviour change

While NTDs continue to gain international attention and recognition, approaches to behavioural change and shifting of the social norms that will ultimately eliminate these diseases have been left out of many of the conversations dominated by drug coverage and clinical interventions. Currently many of the Sightsavers NTD programmes are dominated by a traditional ‘Information, Education and Communication’ approach to behavioural change. But Sightsavers has begun to lead the way in innovative approaches to behavioural change in the prevention and elimination of NTDs through WASH-related interventions (specifically promotion of healthy hygiene practices).

In 2014, Sightsavers partnered with Unilever in Kenya on a school programme called School of Five. An already established hand washing programme for children, School of Five was adapted with trachoma elimination in mind by adding face washing lessons and activities. The intervention resulted in a significant increase of face washing events: in school, observed events went from 22 per cent before the intervention to over 75 per cent, and in the household, observed events went from 17 per cent to 40 per cent. The successful partnership is now expanding in Kenya and to other countries.

As we grow, Sightsavers will continue to draw on insights from modern behavioural and social sciences. We will expand upon existing approaches and generate new ideas that are cost effective and impactful, including social marketing and use of mass media strategies such as entertainment education.



Antou Mbaye, 12, has been taught to wash his face, to prevent the spread of trachoma infection.

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Adam (left), from Ajenejo, Nigeria, weaving a basket.

External developments and our roles within them

We are a key informant and player as the plans for a structure for NTDs in Africa post-APOC are developed and this needs to continue. Our role on the Regional Programme Review Group (WHO – Africa Regional Office) is essential and will be maintained. We are also involved with the transition committee around the future structures for NTDs in Africa. When we have clarity on what this structure will look like and what it will do we will need to decide whether to support the structure through The Queen Elizabeth Diamond Jubilee Trust fund or route funding direct to countries (for surveillance work for example).

We need to contribute to and influence the international debate on NTDs by being active members of the various forums at country, regional and international levels. There are many forums (some proposed and developed by us, like the NGDO NTD Network and the UK Coalition Against NTDs), alliances (NGDO Coordination Group for Onchocerciasis Elimination, International Coalition for

Trachoma Control, etc) and WHO groups (eg GET2020 Alliance), etc. We need to decide how we should engage with each, which are important and where we should devote our energies. A regular review of these networks and our participation is needed. We need to prioritise this area of work and ensure that more people are involved so we are seen as an organisation with many expert voices.

Communicating about our work

Communications activity has a key role to play in raising awareness of Sightsavers' NTD work to external audiences including international and local media, donor organisations, and development partners. Alongside programme management there is an expectation by donors and partners for Sightsavers to provide communications materials such as case studies and images for annual reviews, reports, newsletters and social media, as well as proactive media coverage.

As we move towards elimination a new NTD key message document and/or communications toolkit needs to be developed to reflect this strategy and include key priority areas such as advocacy (SDGs) and strengthening health systems. Communications materials such as the collection of images and case studies, film footage and digital graphics to support social media need to be included in new project proposals and have an allocated budget.

Proactive communications opportunities to generate positive media coverage for priority areas, as well cutting edge and innovative projects such as Tropical Data, mHealth work and WASH will be part of an NTD communications calendar that will ensure a steady stream of communication outputs to reflect and raise awareness of Sightsavers' role as a leading NTD player.

Organisational development

Our approach in terms of structure of the team has been to set up a technical team and a contract management team that unify under the post of Director of NTDs. The full team has only been in place since 2014. Flexibility, agility and the ability to respond to the ever-changing NTD space are essential.

Technical advice

If we want to be leaders in the elimination of NTDs, we will need to add technical expertise and leadership to our team.

These are critical years for our team growth. STH and the cross-cutting issues we have identified, like mHealth and behavior change work, will become increasingly important to programmes along with Sightsavers issues such as equity, health systems, etc. We at Sightsavers have a lot of this expertise and experience but having this as a dedicated part of our NTD team may be a strategy to consider. We can't be an expert in everything – we may choose to have technical advice built into our staffing structure, or to partner with some organisations that do have the specific expertise we are looking for or contract it out.

Sightsavers was at the cutting edge of the early work on community-based and community-directed work around MDA. We need to regain that cutting edge in our technical advice. Technical advisers should be able to draw from their knowledge across Sightsavers' programmes and facilitate learning. For example, we need to be show

how the CDTI programmes have evolved and to discuss how to move forward in the face of integrated programmes and competition for volunteer time while retaining and expanding the principle of working with communities effectively. In other words, our advisors must not just acknowledge our leading role in the development of CDTI, but also expand on it.

We need our technical resources to support and work alongside the programmes and be jointly accountable for the success and failure of the programmes.

We need to make sure our technical advisors, researchers and global technical leads work together to develop a community of practice for NTDs. This should include preferred practices, toolkits, case studies and more to help countries reach their elimination targets. This will strengthen the development of programmes that are more than just MDA (ie ensuring that WASH, behaviour change, mHealth, and operational research all link up to achieve the goal of elimination) and ensure that our technical advice meets the requirements of elimination programmes and the objectives laid out in this document.

Integration

We need to build our expertise in integrated NTD programmes and provide technical advice on how to integrate – this needs to be at the forefront of our approach on NTDs. We need to recruit technical expertise in this area and build this function within our team.

On integration we have experience from the UK Department for International Development funded project in Nigeria. We need to ensure that the lessons from that integrated work is published and shared – we also need to ensure that those lessons are used throughout Sightsavers' NTD projects and do not just remain in Nigeria. Apart from our experience in Nigeria, most global expertise in integration comes from United States-funded activity. We need to be engaging more with USAID and its NTD partners (FHI360 and RTI). This has started with our engagement with RTI on NTDs and behaviour change.

Country teams

We need to support our country offices to set and deliver their targets by providing excellent technical advice and target setting, implementation support, monitoring and operational research opportunities.

Country teams must start broadening their disease contacts from the blinding ones (often resting with the national eye health programmes) to the other diseases (which are often hosted within the NTD directorate). We need to have national plans, policies, disease mapping and other data more easily available for proposals and we need to undertake an analysis of the data to ensure that we are meeting elimination targets every time. We must build capability in in our own offices to follow through with the above and deliver against our ambitious elimination strategy.

We have promoted the idea of having NTD managers in country (reporting to the country director/regional office) and a number of these positions are in place. We need to review if this structure has worked and also if capacity building/training is required in core areas of NTD work.

As the number of NTD programmes that have advocacy objectives increases, it may be necessary to explore whether it makes sense to have a dedicated advocacy role working across multiple programmes, rather than it being a proportion of various programme staff members' roles. This may be true for other areas as well (mHealth, behaviour change, research, etc).

Not business as usual

On the contractual management of donor funds, we have a structure that achieves excellence in project management that includes cost recovery of key posts. The number of staff in this area is lean – we need to check carefully that the structure in place is fit to deliver and adapt quickly with full cost recovery achieved.

More broadly, we must develop an agile business model for NTDs: the ‘coalition holding structure’. We should enable more consistent and standardised approaches to delivery in an effort to get faster and better results with available funding.

We can share with the NTD/development community what we’ve done (and why), what we’ve learned along the way, and what we recommend going forward with regard to a more efficient and effective business model for delivering at scale, on time and with

consistently high quality as we go into 2020-2025. Our biggest challenge will likely be the extent to which, as the coalition facilitator, our business model enables us to be both proactive and responsive in supporting our partners’ capacity for optimal return on investment to our donors (DFID/ the Trust and others.)

Finally, the bulk of our current NTD grants will end in 2019. We need to be thinking now about what NTD work will replace these activities, which must include surveillance.



Ladi, a volunteer Community Directed Distributor in Bugai community, Kaduna, Nigeria.

Summary

We need to be:

- Delivering against our NTD portfolio as industry leaders.
- Incorporating emerging areas like CATCH (Coordinated Approach to Eye Health), health system strengthening, social inclusion/ morbidity management, school health, mHealth and behaviour change.
- Reducing the amount of Sightsavers unrestricted funds being used to support the existing mass drug administration programmes but appreciating that we do need to use unrestricted funds, to develop our reputation as industry leaders in the areas identified above.
- Acknowledging that our ‘legacy’ NTD work (eg onchocerciasis and trachoma) will be entering into post-treatment surveillance stage and will stop distribution of Mectizan® and Zithromax®; success will mean fewer treatments and more activities around surveillance.
- Ensuring that our capacity to provide technical, fundraising and managerial support to the NTD portfolio is in place, with attention to a portfolio-wide approach enabled by a ‘community of practice’ ethos that also ensures NTDs and Sightsavers’ other programmes are mutually reinforcing.
- Operating in a more integrated manner. The current and planned set of portfolio projects/programmes are all a natural fit for this – technically, financially, and managerially.

Planned elimination milestones 2016-2025

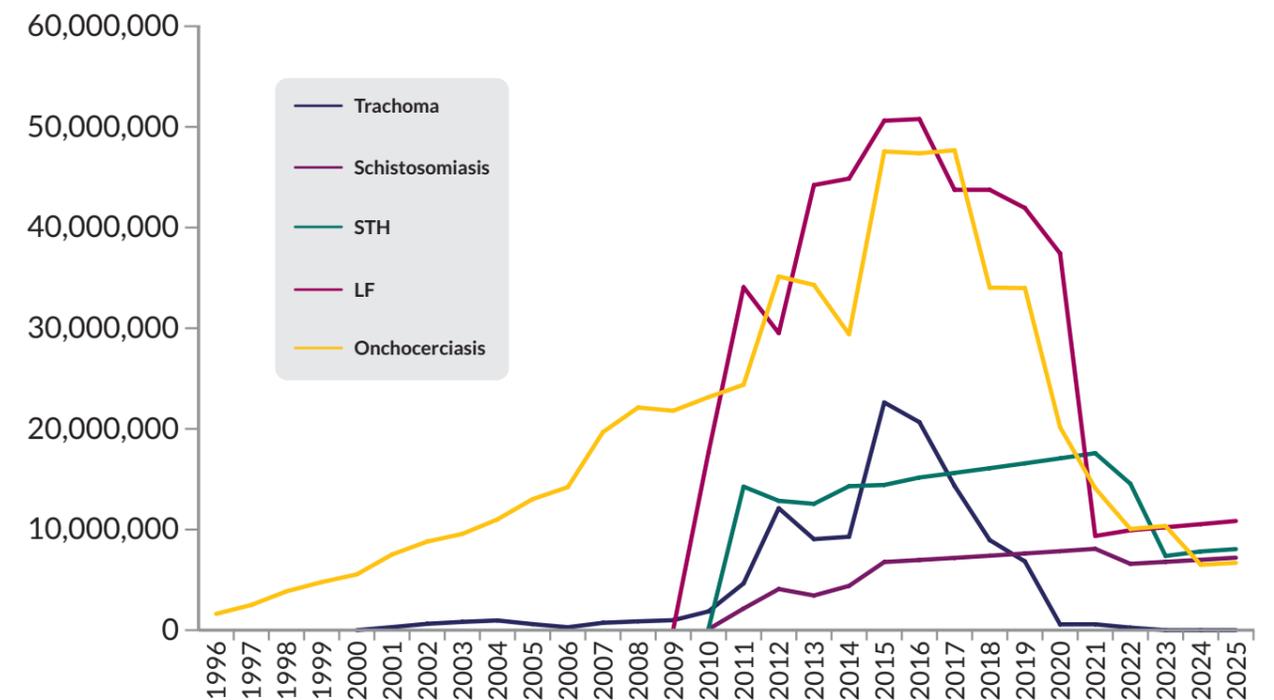
With surveillance properly undertaken, we aim to achieve the following in Sightsavers-supported projects by the year 2025

Country	Onchocerciasis			LF			Trachoma	
	UIG	PTS	Elim	UIG	PTS	Elim	UIG	PTS
Benin	2017	2017	2021	2019	2019	2023	2019	2021 ¹
Burkina Faso	2018	2018	2021	2016	2016	2020	2020	2022 ²
Cameroon	2023	2023	2025 ³	2019	2019	2023	2020	2022
CAR	N/A	N/A	N/A				2022	2024 ⁴
Chad	N/A	N/A	N/A	N/A	N/A	N/A	2019	2021 ⁵
Côte d'Ivoire	2020	2020	2025	2019	2019	2023	N/A	N/A
DRC	Beyond 2025	Beyond 2025	Beyond 2025	Beyond 2025	Beyond 2025	Beyond 2025	N/A	N/A
Ethiopia	N/A	N/A	N/A	N/A	N/A	N/A	2021	2023 ⁶
Ghana	2020	2020	2025	2018	2018	2020	2010	2014
Guinea (Conakry)	2017	2017	2025	Beyond 2025	Beyond 2025	Beyond 2025	2020	2022 ⁷
Guinea-Bissau	2020	2020	2025	2019	2019	2025	2020	2022
Kenya	N/A	N/A	N/A	N/A	N/A	N/A	2019	2021
Liberia	2021	2021	2025	2019	2019	2024	N/A	N/A
Malawi	2016	2016	2020	2014	2014	2017	2018	2020
Mali	2016	2016	2020	N/A	N/A	N/A	2020	2022 ⁸
Mozambique	N/A	N/A	N/A	N/A	N/A	N/A	2020	2024
Niger	2015	2015	2019	N/A	N/A	N/A	N/A	N/A
Nigeria	2019	2019	2022 ⁹	2020	2020	2026	2020	2022
Senegal	N/A	N/A	N/A	N/A	N/A	N/A	2019	2021 ¹⁰
Sierra Leone	2020	2020	2025	2020	2020	2026	N/A	N/A
South Sudan	Beyond 2025	Beyond 2025	Beyond 2025	Beyond 2025	Beyond 2025	Beyond 2025	2022	2024 ¹¹
Sudan	N/A	N/A	N/A	N/A	N/A	N/A	2019	2021 ¹²
Tanzania	N/A	N/A	N/A	N/A	N/A	N/A	2020	2022 ¹³
The Gambia	N/A	N/A	N/A	N/A	N/A	N/A	2018	2020
Togo	2017	2017	2020	2012	2012	2015	2018	2020
Uganda	2017	2017	2021 ¹⁴	N/A	N/A	N/A	2020	2022 ¹⁵
Zambia	N/A	N/A	N/A	N/A	N/A	N/A	2020	2023 ¹⁶

UIG Ultimate Intervention Goal
PTS Post-Treatment Surveillance
Elim Elimination verified or certified

Impact of reaching elimination on numbers of treatments

Actual (1996-2015) and estimated (2016-2025) treatment data for Sightsavers-supported NTD projects (all projects including DFID and The Queen Elizabeth Diamond Jubilee Trust funded activities)



Footnotes:

1. Benin needs partners to support clearing trichiasis backlog. If this is done early, then it could reach its UIG by 2019.
2. Some areas in Burkina Faso need support for TT surgery.
3. This represents the last supported onchocerciasis project to reach elimination – the timetable is: SW1 2023/SW2 2023/ NW 2022/Western 2022.
4. Current security issues may delay progress in programme implementation. CAR may not reach confirmation of elimination by 2025 if security issues are not resolved in good time.
5. The timelines given here are for the DFID SAFE supported programme areas only.
6. The timelines given here are for the DFID SAFE supported programme areas only.
7. Guinea Conakry needs more partners to help clear the TT backlog.
8. Mali may need additional years to complete work in the areas with security issues. We will however complete work in the Koulikoro region by 2022.
9. This represents the last supported project to reach elimination – the project-by-project timetable is: Kaduna 2016/Kebbi 2019/ Kogi 2021/Kwara 2019/Sokoto 2016/Zamfara 2016.
10. The trichiasis backlog in Senegal is large and may need a few more years to clear.
11. Security issues in South Sudan may affect progress of programme implementation.
12. Reaching elimination targets in Sudan is possible but there is a need to improve the rate of clearing the TT backlog. Working in Darfur may be challenging due to uncertainty of security.
13. Tanzania has many endemic districts and may need a few more years to clear the TT backlog as and conduct all surveys needed for confirmation of elimination.
14. This represents the last supported onchocerciasis project to reach elimination – the timetable is: Masindi 2019/Buliisa 2019/ Hoima 2019/Kibaale 2019.
15. Uganda has many endemic districts and may need an additional year to conduct the needed survey for confirmation of elimination.
16. Uncertainty in the burden of disease in Zambia – if there are areas with TF ≥ 30% then it may not reach their UIG by 2020.

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

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