Neglected Tropical Diseases Annual Report 2021

Resilience: Stories of collaboration and progress
Neglected tropical diseases (NTDs): a diverse group of communicable diseases that prevail in tropical and subtropical conditions in 149 countries – affecting more than one billion people and costing developing economies billions of dollars every year (WHO)

Acronyms

A P O C: African Programme for Onchocerciasis Control
A S C E N D: Accelerating Sustainable Control and Elimination of Neglected Diseases
A T C P: Amhara Trachoma Control Programme
C A R: Central African Republic
C B I D: Community Based Inclusive Development
C D D: Community Drug Distributor
C D T I: Community Directed Treatment with Ivermectin
D E C: Diethylcarbamazine
D F A T: Department of Foreign Affairs and Trade (Australia)
D I D: Disability Inclusive Development
D M D I: Disease Management, Disability and Inclusion
D R C: Democratic Republic of Congo
E S P E N: The Expanded Special Project for Elimination of Neglected Tropical Diseases
F & E: Facial Cleanliness and Environmental Improvements
F C T: Federal Capital Territory (Nigeria)
F C D O: Foreign and Commonwealth Development Office
F H F: Fred Hollows Foundation
G T M: Grarbet Tehadiso Mahber
G E T 2 0 2 0: WHO Alliance for the Global Elimination of Trachoma by the year 2020
H A N D S: Health And Development Support
I A D C: Italian Agency for Development Cooperation
I D P: Internally Displaced Persons
L F: Lymphatic Filariasis
L G A: Local Government Area (Nigeria)
M D A: Mass Drug Administration
M D P: Mectizan Donation Program
N N N: NTD NGO Network
O P D: Organisations of People with Disability
O R D A: Organization for Rehabilitation and Development of Amhara
P C T: Preventive Chemotherapy
S & A: Surgery and Antibiotics
S A F E: Surgery, Antibiotics, Facial Cleanliness and Environmental Improvements
S D G s: Sustainable Development Goals
S I O V S: Sindh Institute of Ophthalmology and Visual Sciences
T T: Trachomatous Trichiasis
W A S H: Water, Sanitation and Hygiene
W H O: World Health Organisation

First names rather than full names have been used in many instances in this report to protect the identities of the people involved.

CBM gratefully acknowledges financial support from the following organisations

Cover photograph: A child taking Albendazole® in Ikanlaga Village, Tshuapa Province, DRC © CBM
Foreword

I am proud to say that our CBM programmes have continued the fight against NTDs over the last year and made significant progress towards their elimination. This report illustrates the perseverance and adaptability of CBM and its partners in the countries in which we work, and the advances made in strengthening health systems and in designing and implementing inclusive programmes.

It’s been a tough time for those working in the field of neglected tropical diseases. The pandemic has had a detrimental impact on our ability both to deliver medicines to the right places and to administer them. Conflict has, as ever, added another layer of complexity. Throw government funding cuts into the mix, and the picture has seldom looked as challenging as it does now.

Despite all of this, we have remained resilient. The stories of the efforts made in DRC to reach communities in Tshuapa that can only be accessed by boat, our achievements in South Kapoeta and Unity State in South Sudan to treat new populations with preventative chemotherapy and our work in Nigeria to ensure that even those displaced by conflict are included in our programmes, show just how determined we are.

In the period from 2018 to 2020 we have treated 96 million people against NTDs and performed 74,000 TT operations, but perhaps just as importantly when it comes to fulfilling our goals of integration and sustainability, we have also trained 971,000 people across all NTDs and 26 million people have participated in health promotion and education.

We are at the half-way point of the Inclusive Eye Health Initiative that was launched in 2017 and we took this milestone as an opportunity to assess how we were doing and what still needs to be done. It seems that with a few adjustments, our strategy is still fit for purpose and is aligned to wider policy frameworks such as the NTD Road Map. There is still a way to go to achieve our joint endeavour of elimination and of ensuring that no one is left behind, but I feel we are on track and equipped to tackle the next ten years, and beyond.

We couldn’t do it without our donors, supporters and collaborators, and I would like to take this opportunity to thank you all for understanding the vision and for trusting us to make it happen.

Babar Qureshi
Director of the Inclusive Eye Health Initiative
CBM NTD Programmes 2020

**Nigeria**

**DISEASES COVERED:**
- Onchocerciasis
- Lymphatic Filariasis
- Schistosomiasis
- Soil Transmitted Helminth infections
- Trachoma

Integrated MDA: 3 states
TT surgery: 2 states
Partner: HANDS
Funding: Accelerate (Sightsavers), The END Fund

**CAR**

**DISEASES COVERED:**
- Onchocerciasis
- Lymphatic Filariasis
- Schistosomiasis
- Soil Transmitted Helminth infections

Integrated MDA: 29 districts, 12 provinces (not implemented in 2020 due to pandemic)
Funding: The END Fund, CBM

**DRC**

**DISEASES COVERED:**
- Onchocerciasis
- Lymphatic Filariasis
- Schistosomiasis
- Soil Transmitted Helminth infections
- Trachoma

Integrated MDA: 120 districts (limited implementation in 2020 due to pandemic)
TT surgery: 1 province
Funding: The End Fund, CBM
South Sudan

**DISEASES COVERED:**
- Onchocerciasis
- Lymphatic Filariasis

**Integrated MDA:**
- 44 counties, in 9 states

**MMDP services:**
- 2 states

**Funding:**
- The END Fund, FCDO (Crown Agents), Waldensian Church, CBM

Pakistan

**DISEASES COVERED:**
- Trachoma

**Trachoma surveillance, TT surgery, F&E:**
- 2 districts

**Partner:** SIOVS

**Funding:** FCDO & FHF

Ethiopia

**DISEASES COVERED:**
- Trachoma

**SAFE:**
- 11 districts in 4 woredas, Amhara Region

**Partner:** ORDA

**Funding:** IADC, DFAT, CBM

Burundi

**DISEASES COVERED:**
- Onchocerciasis
- Soil Transmitted Helminth infections
- Trachoma

**Integrated MDA:**
- 11 districts

**Trachoma surveillance:**
- 9 districts

**Funding:** The END Fund, CBM

CBM carries out additional TT surgeries under its Inclusive Eye Health programmes in these and other countries.
The WHO NTD Road Map for 2021-2030 recommends three major shifts in focus from its previous incarnation, can you tell us what these are?

Historically, NTD interventions have focused more on counting the number of medicines distributed and the number of surgeries. The new Road Map is calling for a greater emphasis on the tangible impact of NTD interventions on peoples' lives.

It also advocates for a less silo-based approach to disease interventions and renewed efforts to bring about cross-sectoral collaboration, which could mean better integration of NTD services with other public interventions such as immunisation campaigns, or stronger working partnerships with other sectors, such as social welfare or education.

The third call to action in the Road Map is a move away from donor and partner driven decision making to country ownership.

How is the work CBM is doing in NTDs aligning itself with these three new areas of emphasis?

We discussed this very question at our Inclusive Eye Health and NTDs midterm review earlier this year! For example, there is still a gap in understanding trachoma prevalence in DRC and so CBM is keen to support the national programme in identifying the remaining pockets of disease so that we can scale up trachoma elimination. There is a real need in many of the countries that we work in for improved data so that better decisions can be made.

When it comes to integration, CBM is already delivering integrated NTD services where possible. In three states in Nigeria, we provide training workshops at the state and district level for a package of NTD interventions.

Beyond this, our work is increasingly informed by community based inclusive development (CBID). We'd like to go beyond NTD interventions to fully address disabilities and morbidities caused by NTDs to ensure that people living with long-term disabilities have the support they need to lead productive lives.

The third shift in the Road Map is possibly the most challenging of all. Countries should be free to decide what they want to do, when they want to do it, and where they want to do it. In making an explicit call to action for countries to take charge of their own decision making, they are signalling a new way of working. The best and most sustainable way of delivering health care is for it to be led by the people who live closest to the communities.

How realistic do you think the target of 90% reduction in people with NTDs is?

It’s very ambitious, but if donors, partners, and countries are truly committed to the paradigm shift identified in the Road Map, then this goal is achievable.

We’d like to go beyond NTD interventions to fully address disabilities and morbidities caused by NTDs to ensure that people living with long-term disabilities have the support they need to lead productive lives.

Achievements 2018-2020

18.2 million people treated for soil transmitted helminths
Pakistan: Sometimes it’s the simple things

Many people who live in rural communities like the Kamber Shahdadkot district in Pakistan, have very little access to affordable, quality eye health services. What provision exists, can be out of the financial and geographical reach of many, with individuals having to travel long distances to access the care they need. Additionally, with no formal record keeping at the community level, there is no way of tracking who needs or who has accessed referral services.

The pandemic has further deepened the challenge, since COVID 19 restrictions have meant that people have been unable to seek medical help. With an imperative to set up mechanisms to treat those with conditions such as trachoma, an infection of the eye which can lead to blindness, it was necessary to think laterally about ways of delivering safe and affordable solutions.

The tele-trachoma pilot was developed as part of CBM’s Pakistan Trachoma Elimination Project which is implemented through the Sindh Institute of Ophthalmology & Visual Sciences, Pakistan, with funding from the Fred Hollows Foundation. The project uses mobile phones to take close-up photographs of the eye, and the images are shared on a WhatsApp channel monitored by trained ophthalmologists.

Implementation of the tele-trachoma strategy started in August 2020 with the training of volunteers done in collaboration with primary health care facilities and the People’s Primary Health Initiative Pakistan and backed up by Lady Health Workers who support health systems at the household and community levels.

With the success of this pilot, there is a possibility that it could be replicated in other CBM supported programmes. Working at the primary level and embedded in the existing government structure, this approach has the potential to strengthen inclusivity and sustainability in eye care in Pakistan and elsewhere.

Achievements 2018-2020

25.6 million people treated for trachoma

With the success of this pilot, there is a possibility that it could be replicated in other CBM supported programmes.
DRC: Treating the hard to reach – by river

Patient never learnt to ride a bicycle but his skills with a wooden pirogue are impressive. As if walking on the water, he balances perfectly, his paddle moving precisely through the slowly moving waters, propelling his small dug-out canoe forward quietly.

Today, he is assisting Eyanga Lonkonga – one of a small army of Community Drug Distributors – to travel between villages to conduct the annual round of treatment against neglected tropical diseases – supported by CBM and the END Fund.

There are no roads connecting Ngombe Malala village to Boende, the capital city of Tshuapa Province, just the river. Everything has to be taken by boat to reach the isolated communities that live on the river margins – including the drugs for the Ministry of Health’s annual mass drug distribution.
Accessing every one of these remote communities is a challenge, but if the treatment is to be effective, at least 80% of individuals need to take the drugs annually. In this way, transmission of onchocerciasis and lymphatic filariasis can be gradually reduced, and these disabling diseases can eventually be eliminated.

CBM and the END Fund recently provided boats and outboards to the NTD Programme in these provinces to assist with the organisation and supervision of the drug distribution.

More than 49 million people in the Democratic Republic of Congo are at risk from neglected tropical diseases. Community health workers supported by CBM help to distribute vital treatments every year in some of the hardest to reach communities.

‘I’m not paid but I love doing my job protecting my community and will do it for as long as I can.’

Tina Mboyo, a Community Drug Distributor in Boende
South Sudan

Kapoeta South

A programme for the treatment for lymphatic filariasis and onchocerciasis has reached parts of South Sudan which have not hitherto benefited from drug interventions.

CBM, in partnership with the national health authorities and supported by Crown Agents, through the Accelerating Sustainable Control and Elimination of Neglected Diseases programme (ASCEND) have implemented a mass drug administration in 29 counties, including Kapoeta South in Eastern Equatoria where the communities have, until now, remained vulnerable to the devastation wrought by these diseases.

The organisation of a drugs distribution and treatment campaign requires a lot of support from many people. At the East Equatoria States Health Department, health supervisors are trained in the distribution and administration of the drugs. They then recruit and train community health workers and drug distributors from the villages. This chain system provides a way of ensuring that those giving the drugs are trusted members of their communities and work in their own localities.

Moses Duku, CBM’s Monitoring and Evaluation Officer in Juba, explains the importance of the treatment campaigns:

“People suffering from lymphatic filariasis, or onchocerciasis are often unable to move around or to walk to the market, some cannot wear shoes or flipflops and have to wear loose garments to lessen the pain of their condition. They are sometimes unable to work and earn a living for their family or even to look after the children. This affects their relationships and social life. The fact that this mass drug administration has reached areas of the country which have never been reached before, is a big step forward.”

Above: Moses Duku CBM’s Monitoring and Evaluation Officer talking to CDDs during the 2021 MDA in Kapoeta © CBM
Unity State

The last time CBM and partners implemented a mass drug administration against Trachoma in Unity State was eleven years ago. The area is remote and riven by conflict and CBM is one of the few organisations with the necessary resources and expertise to train staff and oversee programmes.

With the support of ASCEND and working with the MOH, all but one district in the region have completed mass drug administrations this year and continue to implement the SAFE strategy that includes the distribution of drugs, surgery and targeted hygiene messaging. Ten surgeons have also been trained as part of CBM’s efforts to build surgery capacity.

Geoffrey Muchiri, CBM Regional Programme Manager (Africa East) says:

“Unity is not an easy state. Implementation of health interventions can be a logistical nightmare and some NGOs struggle. The prevalence of trachoma was so high that CBM decided to go ahead despite the difficulties. There have been challenges – delays in signing contracts, the slow procurement of equipment, insecurity in some of the counties and heavy rain, but the work has continued. In a sense we are starting the battle against trachoma all over again in this region and it is an on-going struggle. We need at least a further five rounds of treatment campaigns.”

Achievements 2018-2020

40.9 million people treated for lymphatic filariasis
Out of the shadows

Interview with Mr. Makoy Samuel Yibi
Director of the National NTD Programme in South Sudan

“The Ministry of Health worked with CBM in 2015 to control onchocerciasis but this programme went into limbo in 2016 because the situation in the country was so difficult. CBM then helped us to do a treatment campaign in the most endemic areas, and now 44 counties have been involved in successful campaigns. In the 2020-2021 cycle, 5 million people have been treated, and this success was built on the journey that started in 2015.

Few people believed anything could be done but we saw the opportunity and saw what was possible even in the context of a challenging situation. CBM has made a very important contribution to the Health Ministry and to the people of South Sudan. The programming of the treatment campaigns is right at the centre of all of this. All programmes are developed at county level, very close to the population. It puts the community at the heart of the work.
Research reveals that historically, only 50% of the population receive health care. People in the most rural areas are often left out, but the structure we are developing means that there are now strong links between communities and health institutions, ensuring universal access to health care. The training of health workers creates connections and networks within the community.

We are just embarking on a programme of support for people with hydrocele and lymphedema. These are people living in the shadows, discriminated against even by their families and often the last to hear that help is available. This will be the first time such people have been offered any hope because they haven’t been able to afford the treatment they need. We are in the process of building mechanisms to reach them and bring them out of the shadows. Even this venture is part of strengthening the health system because those that receive surgery and care are then able to live fuller lives and will act as ambassadors and encourage others to come forward for treatment. The fact that we are even able to start this work is incredible.

Everything that we have done and continue to do, has at its heart the idea of inclusivity. We are reaching the people in our communities who have been until now, excluded from health services and from being able to live a normal life. This is our driving agenda and informs all of the work that we do.”

Few people believed anything could be done but we saw the opportunity and saw what was possible even in the context of a challenging situation.
Nigeria: A comprehensive approach

“I believe this surgery will help me regain my confidence and hopefully, if God wills, I will have children again.”

Five of Abdulahi’s six children have died. He was screened and operated on for hydrocele in 2020, after living with the condition for many years. His surgery was vital for him to lead a full life, but he might not have received it without a pilot NTD project designed and implemented by CBM with the aim of improving access to comprehensive and inclusive services for those living with the effects of NTDs.

The eighteen-month project was implemented in Jigawa State, Nigeria and reached 400,000 people.

As part of the scheme, over 500 community volunteers were trained to identify and refer lymphedema and hydrocele patients to health facilities for verification and access to services. Forty-one of the confirmed hydrocele cases were operated on and forty-two people with lymphedema were trained in home-based limb care and infection management.

The mental health training provided to over sixty health workers also formed an important part of the project and almost two hundred people received mental health support in the form of counselling and referral for further support.

Despite the significant progress made towards the elimination of NTDs, there is currently little provision for those already affected by NTD morbidity which can result in disability and mental health problems. There is an urgent need for an holistic and inclusive approach to NTD programming; in addition to surgery, this CBM project incorporates protection against infection, reduction of stigma, management of morbidity and rehabilitation.

Achievements 2018-2020

74 thousand people had trachoma trichiasis operations

Leaving no one behind

The number of people displaced by conflict in Nigeria has continued to rise, taking a grim toll on peoples’ health and livelihoods.

Health systems and other administrative structures collapsed when people were driven from their homes and makeshift systems were put in place to support them.

The Federal Capital Territory (FCT) administration established five camps to cater to displaced people from Maiduguri. The FCT is endemic for four neglected tropical diseases (onchocerciasis, lymphatic filariasis, schistosomiasis and soil transmitted helminthiasis).

Mass drug administration for these diseases has been going on for more than 15 years, and recognising that it was important to include everyone, particularly displaced people who are not included in census data, CBM made great efforts during the 2020 treatment campaign to include the residents in two of the camps – Wasa and Waru, which are situated in the Abuja Municipal Council and have a combined population of about 1200 people, making good the goal to leave no one behind.
Up to 50 million people globally and 10 million in Africa are estimated to be infected with lymphatic filariasis. Amina is one of them and as a result she has developed lymphedema. Spread by infected mosquitoes, this disabling condition can have a life changing impact.
Ethiopia: Two trachoma prevention efforts

Game Changers

School children in the Amhara region of Ethiopia are taking a collective stand against trachoma. The potentially blinding disease affects 70% of the country and Ethiopia carries 50% of the overall global burden.

The CBM funded Amhara Trachoma Control Programme (ATCP) working with partner ORDA, has established 10 Anti-Trachoma School Clubs (ATSCs) to raise awareness of the disease, of which Silda Primary School has become a successful example.

CBM’s approach to trachoma prevention and control follows the World Health Organisation’s SAFE strategy which is made up of four components – surgery to address the infection in its final stage, antibiotic treatment, facial cleanliness and environmental improvements, including the provision of clean water. The children in the ATSCs learned about the importance of hygiene, and the role of safe water and latrines in preventing trachoma.

The school trained 5 children and 2 teachers in trachoma prevention and control. With the school Director, they promoted messages about trachoma among the other students and their communities.

As a result of their work, more than 175 students joined the ATSC in a year and more than 350 pit latrines were constructed by families.

The School Director, Mr. Fasil Amsalu, says: “We have seen a lot of changes, due to the Anti-Trachoma School Club member’s activities. Students are no longer suffering from communicable diseases and school attendance has increased. Moreover, club members are working on trachoma prevention and control activities outside the school compound when they return to their village... the club members are game-changers.”

Access to protection

Until recently, Emebet had to walk for two hours to fetch water, along with the other women in her village in Legehida district, South Wollo Zone. Drinking unsafe water was commonplace, as were the diseases that resulted from this.

CBM and partner ORDA constructed new, accessible water collection points. Now Emebet and her 250 neighbours no longer have to struggle during the region’s periods of drought.

“My family fetches at least four jerricans a day of water from the new source for personal hygiene, cooking, drinking and washing clothes. I’m no longer afraid of water-borne diseases or trachoma, because my daughter and I have clean water for bathing and know how to protect ourselves. The new water scheme means I have more time for work and for my household tasks.”
Trachoma programme timeline

Prior to the commencement of MDA over **27.6 million persons were at risk** of preventable blindness due to trachoma in 24 states.

**2002**
- **Start trachoma mapping** The trachoma mapping was conducted in a few Local Government Areas (LGA).

**2002-07**

**2010**
- **Mapping scaled-up to more LGAs.** In all, 449 LGAs were mapped out of which 122 were endemic.

**2013**
- **Implementation of large-scale SAFE** (Surgery, Antibiotics, Facial Cleanliness, Environmental Improvements) strategy in many states.

**2017**
- **2017-20 CBM has supported treatment in 39 districts** since 2017; 25 of these districts no longer require trachoma MDA.

**2020**
- **16 states are conducting surveillance** to confirm decrease in trachoma prevalence to below public health thresholds.

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**Trachoma Mapping**
Known to be endemic in neighbouring countries, mapping started in 2014

**DRC**

**2014**
- **Trachoma Mapping** Known to be endemic in neighbouring countries, mapping started in 2014

**2018**
- **2018-20 MDA** CBM supported 3 rounds of MDA in 12 districts with a further 15 districts planned in 2021. Nationally, 26 districts successfully completed impact surveys

**2019**
- **CBM TT training support** 5 national trainers trained in trachoma trichiasis surgery.

**2020**
- **Trachoma Trichiasis surgery** Estimated that >50,000 cases require surgery nationally. CBM to restart its TT programme in 2021 following delays due to the COVID pandemic.

In Nigeria in 2020, 5 million people in 38 districts were at risk for trachoma, with only 2 additional rounds of MDA left before impact surveillance. Nigeria is the fourth most endemic country for trachoma in the world.
COVID-19

2020 will be remembered for the global COVID-19 pandemic. For CBM’s NTD programmes, it brought significant challenges and greatly impacted workload and schedules.

The main difficulty was how to restart community-based services, without them becoming a vehicle to spread COVID-19. For MDA, every household needs to be visited by a local volunteer drug distributor – so the potential for spreading the virus was a real concern.

All activities were put on hold until a protocol for the safe distribution of drugs had been approved by the national Ministry of Health, in line with WHO guidance. Every meeting, training or interaction had to be safeguarded against spreading infection. All participants at training events were required to wear masks, maintain distancing and ensure good hand hygiene – all of which required an additional budget for supplies. Measures were also taken to avoid staff travelling between regions – particularly from areas that had higher infection rates.

Drug distributors were trained to follow the same precautions during their house-to-house visits – although maintaining a 1m distance was not an easy task. In temperatures of 30 degrees and above, wearing a mask all day could be very uncomfortable. The drug distributors were also trained to explain COVID-19 and how people could protect themselves.

In the early stages of the pandemic, many of the rural areas that make up much of our working area experienced very few cases of COVID-19 although news of the global pandemic spread quickly. In a study CBM carried out in Nigeria, all community members knew of the virus through mass media and friends, but no one knew of anyone who had had the infection. In some areas of western DRC where almost no cases had been recorded, the community was sceptical about the need for the precautions. Despite this, the drug distributors took their role seriously and there has been no evidence that the MDA for NTDs has contributed to the spread of COVID-19.

Achievements 2018-2020

26 million people participated in health promotions

The main difficulty was how to restart community-based services, without them becoming a vehicle to spread COVID-19.
The drug distributors were trained to explain COVID-19 and how people could protect themselves.
Community drug distributor measures a community member with the dosing pole to ascertain dosage, Terekeka, South Sudan. © CBM