

# River blindness and lymphatic filariasis

Working in partnership to protect millions of people from these painful, debilitating diseases

Brief



Sightsavers

Now is the time to say goodbye to neglected tropical diseases



Former hydrocele patient Muhammed Umar 35, with his family outside his house in Raha, Bunza.

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## Cover image

Safiatou photographed 30 days after she began treatment. She reported feeling better and said her skin had improved significantly.

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Black flies that transmit the parasitic worm that causes river blindness.

## Introduction

River blindness (also called onchocerciasis) and lymphatic filariasis are neglected tropical diseases (NTDs).<sup>1</sup> They mainly affect people living in low-income, often remote, rural areas with limited access to clean water, sanitation and health facilities. If left untreated, the painful symptoms of both diseases can stop adults from going to work. In severe cases, there is no other choice but for children to drop out of school to take care of ill relatives or to take on the responsibility of financially providing for the family. This traps individuals, families and whole communities in a cycle of poverty.

**River blindness** is caused by the parasite *Onchocerca volvulus*, a worm that is transmitted to humans by black flies. These flies breed near fast-flowing rivers, hence the disease's name. Many communities rely heavily on river water for drinking, washing and agriculture, increasing the spread of the disease.

River blindness causes severe skin irritation and itching and can lead to irreversible blindness. It can also force people to move away from fertile river valleys, where the disease is found, to areas that are less suitable for farming. This can push families and communities further into poverty.

**Lymphatic filariasis** is caused by three parasites (*Wuchereria bancrofti*, *Brugia malayi* and *Brugia timori*) that are transmitted to humans by mosquitoes. People living in at-risk areas are usually first infected during childhood.

Lymphatic filariasis can result in an altered lymphatic system and the abnormal enlargement of body parts. This is painful and leads to permanent physical changes – a condition called lymphoedema – and is highly stigmatised. In men, the disease causes hydrocele, a form of lymphoedema that causes the scrotum to swell, leading to pain and disability.

People with advanced lymphoedema cannot be cured but the symptoms can be eased through care. Hydrocele, however, can be cured through surgery, transforming the lives of men affected.

### Integrated treatment

Although river blindness is transmitted by black flies and lymphatic filariasis by mosquitoes, they can be treated in similar ways because both diseases are caused by a filarial worm. As a result, the World Health Organization (WHO) recommends

coordinating treatment for the two diseases.

A single dose of two medicines (ivermectin for river blindness with the addition of albendazole for lymphatic filariasis) is provided to at-risk populations through mass drug administrations (MDAs). Local volunteers – often known as community drug distributors – are central to this process, which provides entire communities with treatment to stop transmission.

Sightsavers works in partnership with ministries of health and NTD programme coordinators in 16 countries to target river blindness and/or lymphatic filariasis. Where both diseases occur together in co-endemic areas an integrated approach is used.<sup>2</sup> These programmes go further than simply providing two treatments at once. They put the person receiving the medicines at the very centre, and include a range of interventions to treat and relieve symptoms, such as teaching people to manage the painful, swollen limbs caused by lymphatic filariasis.

In recent years, many countries have made huge progress in tackling both diseases, protecting people's sight, and improving their health and livelihoods. National and international milestones on the journey towards eliminating river blindness and lymphatic filariasis are being met, and best practices are being shared to further the global NTD elimination agenda.

### Country-led programmes

NTD programmes are run by ministries of health in countries where these diseases are endemic. The ministries set the elimination agenda and country-specific targets based on national priorities. There is considerable expertise within each country on controlling and eliminating NTDs and our role is to build on this by strengthening political and financial commitment and technical capacity to reach NTD targets and milestones.

The technical support we provide comes in various forms. It includes supporting ministries to strengthen or create platforms to plan, manage, implement and evaluate a country's NTDs services. We also support ministries to integrate NTD programmes into national health systems. Another key area is providing technical support to enable ministries to unite the different entities that work on NTDs. These include multiple sectors within governments, donors, multilateral organisations, research institutions, non-governmental development organisations, community-based organisations and the private sector.



Marie Claire Mwika, who has lymphoedema, has her leg washed by nurse Lokoto Samengoy at a government clinic in the village of Makulo, Democratic Republic of Congo.

# NTDs: facts and figures

Correct as of September 2020



## River blindness<sup>3</sup>

**217.5 million people**

globally are at risk of river blindness

**20.9 million people**

are actively infected

**14.6 million people**

are affected by the skin disease

**1.1 million people**

are living with blindness or visual loss caused by river blindness

More than **99% of people** infected by river blindness live in 31 African countries. The disease is also present in remote parts of Latin America and in Yemen.



## Lymphatic filariasis<sup>4</sup>

**893 million people**

globally are at risk of lymphatic filariasis

**120 million people**

are currently infected

**40 million people**

have symptoms

**49 countries**

are endemic for lymphatic filariasis

**151.8 million people**

were treated globally for river blindness in 2018.

**1 out of every 4 people**

who received treatment did so through a NTD programme working with Sightsavers' support.

In 2018, country-led NTD programmes worked in partnership with Sightsavers to:



Provide more than **45 million** lymphatic filariasis treatments



Train **218,000 local volunteers** to distribute medication



Clécio Siteo stands for a portrait after finishing a day of surveys for the Onchocerciasis Elimination Mapping (OEM) project in Cemente, Mozambique.

## Mapping river blindness

In Ghana, Nigeria and Mozambique an innovative research project is enabling health ministries to determine whether communities not previously treated for river blindness need to be included in elimination programmes.

The Onchocerciasis Elimination Mapping (OEM) Project works by collecting data and blood samples from people who may be at risk of the disease. Mappers work in two-person teams: a technician takes finger-prick blood samples, which are then sent for laboratory testing, while a recorder collects patient data on a mobile phone application, using barcodes to link participants with their test results.

Not only is the project mapping the presence of river blindness in previously untreated communities, it is also helping to standardise the way data on the disease is recorded and stored. This is helping government officials make informed decisions on where mass treatment campaigns will be most effective.

OEM is led by ministries of health working in collaboration with Sightsavers, local communities, the WHO, the Task Force for Global Health, the Bill and Melinda Gates Foundation and other partners.

“

This project will have a positive impact... the impact will be huge as we can help many people. With this mapping we will know what steps to take next. If the disease is found, we can follow it up with treatment.”

OEM technician Clécio, from Cemente in Mozambique

## The four steps to identifying who is at risk of river blindness



**1**

**Establish which communities should be screened for the disease**

A mapping survey identifies communities that have not been treated for river blindness before and are located near potential vector breeding sites.



**2**

**Record participant information in the mobile app and take blood spot samples**

The survey team go out to the community where the recorder collects participant information in the secure mobile app, ESPEN Collect. The technician conducts the test by pricking the participant's finger for blood and applying this to special filter paper. Survey participants must be over the age of 20 and have lived in the community for at least 10 years.



**3**

**Examine blood spot samples in a laboratory**

The dry blood spot samples are sent to a laboratory to test for exposure to the parasites that cause the disease. A barcode attached to the blood spot sample links participants to their test results.



**4**

**Plan next steps**

Test results are used to determine next steps, including whether communities are at risk of river blindness and require mass drug administration.





Edwina Kona, who has lymphoedema, and her son, Modeste Chola, speak to Dr Diana Joana Kaningini at a Catholic clinic in Zambwa, Democratic Republic of Congo.

## Working in challenging environments

In 2018, around 50 million people (over half the population) in the Democratic Republic of Congo (DRC) needed treatment for lymphatic filariasis.<sup>5</sup> On top of extreme poverty, people living in remote regions of DRC face ongoing armed conflict and are still recovering from the devastating Ebola outbreak of 2014/15.

Dr Diana Joana Kaningini, from DRC's Ministry of Health, says: "In our country we have extreme poverty and that comes with a lot of disease. That's why we really need to eliminate NTDs like lymphatic filariasis... when people can't work they go even deeper into poverty."

The NTD programme in DRC has been partnering with Sightsavers to treat lymphatic filariasis since 2016. This was initially supported through the UK Aid Match Onchocerciasis and Lymphatic Filariasis Elimination programme, which ended in 2019. Our contribution to the ministry of health's ongoing NTD programme is now part of UK aid's flagship NTD initiative, Ascend West and Central Africa (see page 15). Through this work, the country's ministry of health aims to reach more than 32 million people and provide an estimated 5,500 surgeries for lymphatic filariasis in three years.



## The impact of Ebola on river blindness work

When Ebola broke out in Liberia, we supported the country's ministry of health to suspend its river blindness work and use the systems and personnel that were in place to respond to the outbreak.

"When we heard the news about the Ebola outbreak, we stopped everything we were doing [on river blindness]," explains Lincoln Gankpala, a health technician from Liberia's Ministry of Health.

"We were afraid because we knew what Ebola was. Examining people for river blindness means dealing with blood... and medical tests. People could get infected and we couldn't take those kinds of risks."

"Along with Sightsavers colleagues, during the outbreak I worked with international medical teams screening for Ebola. One year later, we went back to treat river blindness... when we returned people were afraid of us. We had to hold community meetings before we could regain trust.

"Eventually it was safe to continue the work we had started before the outbreak. Now everyone is excited to see us."



Anthony Kollie, an entomologist, and Kenuma Kerkula, a community researcher, both from the Liberian Ministry of Health, during mosquito collection in a suburb of Monrovia.

# The road to eliminating river blindness

The first steps to defeat river blindness were taken more than 20 years ago. In 1987, the pharmaceutical company Merck & Co committed to donating river blindness treatment across the world for as long as it takes to eliminate the disease, through a mechanism that would eventually be known as the Mectizan® Donation Programme (MDP).

With other partners, Sightsavers supported governments to participate in multi-country research to develop the best method for providing mass treatment to communities over a number of years. This resulted in the CDTi approach, which now forms the bedrock of river blindness control and elimination work.

CDTi stands for 'community-directed treatment with ivermectin' (ivermectin is the generic name for Mectizan®). It has been successful because it enables at-risk communities to distribute treatment at a time and with a method that suits them. **The CDTi approach works because it puts people in control of their own health, enabling those from at-risk communities to be instrumental in distributing and monitoring treatment.** Because communities have ownership of the process, treatment distribution is more likely to continue and be effective, enabling progress to be sustained. The approach is also low-cost, which contributes to its sustainability.

As CDTi began to take off it became apparent there was a need to ensure mass drug administrations were well-coordinated and that best practice was shared. This led to the NGDO Coordination Group for the Control of Onchocerciasis, of which Sightsavers was a founding member, being established in 1991 to assist national programmes. In 2013 the group's name was changed – the word 'control' replaced

with 'elimination' – indicating just how far efforts have come in the 20 years since its inception.

In 2013, Colombia became the first country to be declared free of river blindness by the WHO, followed by Ecuador in 2014, Mexico in 2015, and Guatemala in 2016.

Other countries are making important progress. For example, in 2019 Nigeria – home to around one quarter of all those at-risk of river blindness in the world – eliminated the disease from Kaduna, Nassarawa and Plateau states, where 4.2 million people had previously been vulnerable. In 2020, two additional states, Kebbi and Zamfara, reduced prevalence to such a low level that mass treatment could be stopped.

Sightsavers Nigeria country director Sunday Isiyaku said: **"When we first started working in Kaduna there were so many people suffering. Just over 20 years later, we couldn't find one single case. Just think if we can make that happen anywhere."**

“

**Kaduna was one of the most endemic areas in the most endemic country in the world. If we can remove river blindness here, we should be able to remove it anywhere."**

Sunday Isiyaku, Sightsavers  
Nigeria country director

# Lymphatic filariasis: tackling stigma through patient-centred care

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Symptoms relating to lymphatic filariasis cause obvious physical changes and are highly stigmatised as a result.

As hydrocele causes the scrotum to swell, personal and societal sensitivities around sexual and reproductive health means the condition is particularly stigmatised and mythologised – it can be seen as both a curse and a sign of virility. People's beliefs that the disease might be spiritual rather than physical leads some to seek alternative treatments for its symptoms rather than medical care.

The only way to overcome such barriers is to enlist the help of people from affected communities who are well-known and trusted. Work to address lymphatic filariasis would not be possible without an army of local volunteers who have been trained to identify people in their communities who have lymphoedema or hydrocele.

Volunteer case finders are on the front line as they identify people in need of assistance. They help people begin their care and recovery journey by putting them in touch with the health services that can treat and care for them.

## Person-centred care

Health programmes are helping people with lymphoedema understand how to care for their limbs and reduce the debilitating, acutely painful attacks they experience,

which can often last for days. For men affected by hydrocele, these programmes provide surgery and after care.

The most successful way to care for people with lymphoedema is to put them, not the disease, at the centre. That's why the lymphoedema activities we help countries deliver are designed to support someone throughout their diagnosis, treatment and recovery. Support can come in many forms, including guidance on how to cope with and reduce symptoms, money to cover the cost of transport to visit clinics, and reminders about follow-up appointments.

This is not just effective for the person concerned, as focusing on someone's journey from start to finish, and strengthening every step in that process, also strengthens health systems. This is because, for treatments to work, every link in the health system chain has to function, from outreach through to clinical services and after care.

## Ambassadors for change

Many men who have hydrocele surgery go on to become ambassadors for change, successfully convincing other men who are affected to have surgery and encouraging community members to accept mass drug treatment.



Hassana Dadi Ibrahim has lymphatic filariasis. She stays with her family in Lokoja, Nigeria



## Mohammed's story

Mohammed Umar, a 35-year-old father-of-three from Kebbi in Nigeria, works as a construction worker, farmer and a community drug distributor (CDD).

Mohammed was a 15-year-old schoolboy when he first experienced swelling in one side of his scrotal sac. At the time it was not visible, neither was it causing him discomfort, so he did not seek treatment. But as the years went on the swelling increased, and he began to experience fever and pain.

Mohammed sought help from a local health facility where he was examined and given medication. But after a while his scrotum began to swell on the other side. At this point he decided to try traditional healers who took his money but offered very little.

At this time Mohammed was working in construction and had a family, but the condition was making it increasingly difficult for him to work and take care

of his loved ones. He could not walk or sit for long and often had a fever. The fear of what people would say made him stay at home.

In 2019, Mohammed discovered that free lymphoedema screenings and surgery were being offered in a nearby medical centre. He went along and was operated on successfully.

**“I’m now able to take care of my family and go to the farm. I’m looking forward to the possibility of having a fourth child,”** says Mohammed. **“I’m also looking forward to resuming work as a community volunteer and ensuring that people are sensitised and offered albendazole [treatment] to prevent them from going through this painful experience.”**



Mohammed Umar, 35, underwent surgery for hydrocele.



Ngarba, who is 30 years old, is having his height measured to receive the correct dose of Mectizan.

## Delivering large-scale integrated programmes: Ascend West and Central Africa

Ascend West and Central Africa is Sightsavers' largest multiple disease programme and is part of UK aid's flagship NTD programme.

The three-year programme, which started in 2019, aims to support health ministries in 13 countries to make major progress towards eliminating five NTDs, including river blindness and lymphatic filariasis.

Ascend West and Central Africa is managed by a consortium, which Sightsavers leads alongside Mott Macdonald, the SCI Foundation and the Liverpool School of Tropical Medicine. The programme works directly with ministries of health, in partnership with affected communities and international bodies such as the WHO, to deliver one of the most significant NTD programmes in history.

Through the programme, health ministries will deliver treatments and carry out elimination activities for river blindness in

Chad, DRC, Ghana, Guinea, Guinea-Bissau, Liberia, and Nigeria as well as support elimination activities in Sierra Leone.

A further 10 health ministries are tackling lymphatic filariasis by delivering treatments, performing hydrocele surgeries, carrying out elimination activities, and training people with lymphoedema to manage their symptoms. This work is happening in Benin, Chad, DRC, Ghana, Guinea, Guinea-Bissau, Liberia, Niger, Nigeria and Sierra Leone.

In its first year, Ascend West and Central Africa supported countries to provide 19.5 million people with combined river blindness and lymphatic filariasis treatments, plus 21.9 million treatments for lymphatic filariasis and 7.9 million treatments for river blindness.



Bopda Jean tests skin snips in Yaounde's laboratory.

## The importance of research

### Finding new ways to fight river blindness in Cameroon

Sightsavers is supporting Cameroon to conduct vital research on why river blindness is persisting in some parts of the country.

In 2018, researchers carried out a comprehensive study in the country's West Region. This included an evaluation of infection in flies and humans in the Massangam district, where many people had river blindness.

The research identified the following key reasons why the disease was so prevalent:

- The presence of several fast-flowing rivers where flies breed all year round
- Nomadic communities missing out on preventative medication and potentially being a source of continued infection

- Large numbers of people fishing from the rivers, exposing them to the flies that carry the disease.

Once researchers had established why the disease was such a problem in the area, health officials were able to start working with the local community to discuss new ways of treating it. The previous approach had been to treat as many people as possible through mass drug administrations, whether they were infected or not.

But through this work, they agreed to treat only people who tested positive. As of 2020, all treatments have been distributed using this new approach and the impact this is having is being monitored.



## Gathering evidence on the mosquitoes that spread lymphatic filariasis

Sightsavers-supported research on mosquitoes is helping to establish whether lymphatic filariasis is being spread in densely populated urban areas.

Understanding disease transmission and prevalence in cities can be challenging. This is because the parasitic worms that cause lymphatic filariasis can live in humans for years, so if people in urban areas test positive it is not necessarily an indication that lymphatic filariasis transmission is happening in that area, as they may have already been carrying these worms when they arrived.

In 2018, researchers began to examine whether mosquitoes in the Nigerian cities of Kaduna and Minna, rather than people, were carrying the parasite. Mosquitoes have short lives and tend to stay in the same place, so if they test positive it is an indication that transmission is happening in that area.

The first phase of this research was used to trial various ways of catching two different types of mosquitoes (*Culex* and *Anopheles*) that can spread the disease.

## The importance of community researchers

The study required some of the traps to be set up in people's houses. This meant researchers needed people to provide regular access to their homes during unsociable hours. Recruiting local volunteers to work as community researchers was crucial for this aspect of the study as they could help households understand what the researchers were doing and why, meaning people were more likely to agree to take part. During their rounds, the community researchers had conversations with people from participating households, answering questions or listening to their concerns.

This work has established the optimum methods for catching the mosquitoes that spread lymphatic filariasis.<sup>6</sup> Findings on whether the disease is being transmitted in both cities will be published shortly.



Children washing themselves in a stream after school.

# Looking to the future

In 2019, the WHO highlighted several priority areas that, if addressed, will help speed up the elimination of river blindness.<sup>7</sup> We have used this guidance, plus our expertise in supporting countries to tackle river blindness and lymphatic filariasis, to work with health ministries to define a set of strategic approaches to achieve their elimination goals. These are aligned with the WHO's NTD roadmap, the sustainable development goals and the move towards universal health coverage.

Priorities include improving access to field and laboratory-based diagnostics and monitoring, ensuring people with

lymphoedema and hydrocele receive quality care and treatment – expanding these services in countries where they are needed – and working with schools and communities on prevention. Providing support for areas where MDAs have not started, and ensuring coverage targets are met everywhere through coverage evaluation surveys, are also key focuses.

Central to all of this is our commitment to achieving elimination in a sustainable and equitable manner – ensuring countries are supported to carry out NTD activities within national health systems in ways that serve to strengthen and sustain them.

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Community health worker Jean Kanku, in Kamafesa, Democratic Republic of Congo, measures a woman's height to find out the correct treatment dosage.

# References

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1. Neglected tropical diseases are a group of parasitic and bacterial infections that affect more than one billion people worldwide. They became known as 'neglected' because historically they did not spark the same public attention or investment as other diseases such as malaria. They also affect some of the most marginalised and neglected communities in the world.
2. The NTD programmes that Sightsavers supports do not provide treatments for both diseases in all 16 countries. In some, we provide health ministries with technical support only, in others we support ministries to treat lymphatic filariasis or river blindness, and in some we support the treatment of both diseases. The level of support we provide is based on national NTD plans, Ministry of Health priorities, and the different context and settings present in each country.
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6. For the full research findings, see Rogers, N et al. (2020) 'Testing a method of sampling for entomological determination of transmission of Wuchereria bancrofti to inform [parasitesandvectors.biomedcentral.com/articles/10.1186/s13071-020-3905-x](https://parasitesandvectors.biomedcentral.com/articles/10.1186/s13071-020-3905-x)
7. Ibid.

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

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