Digital health

Using technology to tackle neglected tropical diseases

Brief

Sightsavers

Now is the time to say goodbye to neglected tropical diseases

A Sightsavers vehicle drives along a dirt road in Turkana, Kenya, ahead of a series of trachoma surgeries.

Contents

Cover image

Josina Mate (left) prepares to take a dry blood spot sample, while Américo Hunguana (right) enters a survey participant's information into the mobile phone data collection software.

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Anna Namoe at her home the day after bilateral trichiasis surgery in Napak, Northern Uganda.

Introduction

Neglected tropical diseases (NTDs) are preventable and treatable conditions that can cause blindness and physical disability. They most often affect people living in rural regions, poor urban areas and conflict zones.

Sightsavers is using digital technology to help eliminate a number of NTDs, and it is changing the way we work for the better. For example, understanding where NTD programmes will be most effective and how they are currently performing requires robust data, but until recently this has been missing. Technology is now addressing this gap by increasing the quality of data and the speed at which it can be accessed. Digital applications are enabling Sightsavers teams working in remote areas to collect information about people's eye health to improve their quality of care, while real-time monitoring software is keeping the mass distribution of NTD treatments on track.

Innovative digital health solutions are also helping to reduce healthcare costs in many countries in a diverse number of ways. For instance, by generating reliable, affordable and accurate health data, governments are now able to deliver more targeted and effective NTD programmes.

Our digital health work is also improving people's access to technology and their technology literacy. The skills and knowledge gained by those implementing our digital health programmes are also transferable to other development areas and sectors.

Collaboration plays an essential role in all our digital health initiatives. To be effective, a wide range of partners – including regional health bureaus, ministries of health, funders, academic bodies, international non-governmental organisations and community-based organisations – are working together to ensure technological solutions are being utilised. This saves time and resources and helps to improve the health and wellbeing of millions of people.

Digital health: the facts

More than one billion

people are affected by neglected tropical diseases[1]

5 billion people

use mobile phones[2]

Sightsavers' impact

8.6 million people

examined through Tropical Data and the Global Trachoma Mapping Project

26 countries

with digital health initiatives coordinated by Sightsavers

5.5 million

NTD treatments tracked in real-time

1.2 billion

treatments since our NTD work began

21,000

patients' treatment journeys monitored

Sightsavers

5

Zakari Abdou Loufaye (right) uses the TT Tracker mobile app to collect patient data from Dr Ammadou during trachoma surgeries in the Nikki region, Benin.

Improving health services: technology and trachoma

Digital technology has become an essential tool in the fight against trachoma, one of the world's most ancient diseases.

The advanced stage of trachoma, trachomatous trichiasis (TT), causes eyelashes to turn inwards and scrape the eyeball. Not only is this incredibly painful, it can lead to irreversible blindness.

The only way to treat TT is to operate, but people in need of surgery often live in remote places. This can make it challenging to monitor patients after they've had surgery, which is crucial for assessing how successful their operation has been and for identifying any additional care needs.

In 2015, the World Health Organization (WHO) convened a group of NTD experts to address this issue.[3] In response, Sightsavers developed a mobile app called the TT Tracker. This enables surgeons, assistants and supervisors to collect and analyse information about surgery and performance, and to determine when and where follow-up appointments are needed.

Patients' data is collected when they register, throughout their treatment journey, including on the day of surgery and during three follow-up appointments. Surgical team supervisors then receive online and email updates telling them which patients need to be followed up and when. The different stages of this care journey often occur in various locations with different medical teams, but by recording all of a patient's information through the app, the surgeon in charge of their care has easy access to it.

This centralised system also enables information on demographics, numbers of patients and surgeries, the status of follow-up appointments and surgical outcomes to be collated for reporting purposes, and analysed to inform future work. Under Accelerate, an ambitious trachoma elimination programme, the TT Tracker is being used in Benin, Ethiopia, Guinea, Nigeria and Senegal.

Ensuring advanced trachoma surgeries are on track in Benin

Zakari Abdou Loufaye is part of a mobile eye health team who in 2019 carried out the first sight-saving TT surgeries in Borgou, a remote area in northern Benin.

In just one day, the team saw nine people who needed to be operated. Zakari collected information about each person and the surgery they were due to have, which he then uploaded to the TT Tracker.

"It helps the surgeons, and beyond the surgeon [it helps] the whole system", Zakari explains. "It's very easy to use. When you work with many patients but you don't have their data in an app, it is hard to remember where exactly all the different pieces of information [are]. [This helps] a surgeon understand what has happened and make decisions about what needs to continue to be investigated."

> " It helps the surgeon, and beyond [it helps] the whole system.

trachoma patients following surgery in the Nikki region, Benin.

A typical pastoralist settlement in the Turkana region of northern Kenya.

Strengthening health management information systems

In countries where multiple NTDs are highly prevalent, and where there are many partners working to combat them, it is vital to have accurate, timely data from everyone working on NTDs.

Sightsavers is working with governments to integrate NTD programmes into national health information systems – otherwise known as 'mainstreaming'. Doing this will help to ensure NTDs are included when governments set health priorities and budgets. It should also help long-term disease surveillance of NTDs to become standard practice.

In order to do this, and in support of the WHO's NTD 2020 roadmap[4], in 2019 we assessed how NTD data was being collected, stored, and used in Benin, Burkina Faso, Cameroon, Côte d'Ivoire, Ethiopia, Guinea-Bissau, Guinea, Kenya, Nigeria, Senegal, Tanzania and Zimbabwe.

This assessment, carried out as part of the Accelerate programme, identified important gaps in how national NTD programmes store their data. We found that most NTD programmes collect routine NTD mass drug administration data through disease-specific channels, rather than through national health information systems.

With the exception of trachoma, we also found that epidemiological surveys, which record the distribution, patterns and determinants of a disease in a certain area or population group, were being recorded using either paper forms or a wide range of electronic data-collection platforms.

We are also working to strengthen in-country data warehouses to aggregate programmatic data, and provide support services so that non-trachoma epidemiological surveys can be standardised. A key part of this work is training people working in this area on how to manage, access, and use data to inform programmatic decision-making, ensuring that NTD programmes become as effective as possible.

Improving data management in Ethiopia

Sightsavers is supporting the Ethiopian government to develop a national NTD database. This will collate all NTD programmatic data and can be integrated with other national and global data systems.

This work began with an assessment of the way NTD data had previously been managed in the country, which indicated that dual reporting was occurring. International organisations were reporting NTD data to donors using one system, while the Ethiopian government was reporting the same NTD data to WHO on another. This siloed approach created a situation whereby any changes made to the data after it had been reported were only being communicated through one channel, making it harder to get an accurate picture.

From this, it became clear that there was a need to develop a central NTD database. This new database has been built using the same software as its national health information management system, a platform called DHIS2[5]. This was done to utilise DHIS2's wide range of functionality and take advantage of the fact that in-country staff were already trained to use this software. The goal now is to fully integrate the new national NTD database into the country's health management information system and other global NTD systems. When this happens, NTD data in Ethiopia will be accessible and nationally owned, and the project will have reached its aims.

This process has also helped the Ethiopian ministry of health agree a set of standardised indicators to track surgeries, treatments and access to water, sanitation and hygiene. In 2018, the decision to include these indicators in Ethiopia's health information management system was made, signalling a major step forward in mainstreaming NTDs.

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Staff from the command centre in action during the trachoma mass drug administration campaign in Zimbabwe.

Real-time monitoring of mass NTD treatment distribution

Many of our NTD programmes use mass drug administration, in which entire communities are treated with medication to stop infection from spreading. Due to their vast scale, MDAs require detailed logistical planning and monitoring – and this is where technology is invaluable.

After piloting different forms of MDA monitoring over the years, we have now embraced one software and process, DHIS2, which we have configured to meet the data needs of MDAs. Many ministries of health were already using this software to manage other health data (for example our case study in Ethiopia on page 9), which means the government officials we work with are already familiar with it.

Through this platform, targets can be set for drug distribution teams. The numbers of people who still need treatment in each area and who have already received it can be monitored. Teams can also track drug use and remaining stock. When an area is behind target, supervisors there will be contacted and we can rapidly investigate why this might be and address any issues that have arisen, ensuring an MDA stays on course.

This approach has significantly improved the quality of our data and it means far fewer drugs are being wasted. Due to the success of the work so far, digital MDA monitoring will continue to be rolled out in more countries to track treatment for a variety of NTDs.

Using technology to monitor NTD treatment in Zimbabwe

In Zimbabwe, a major breakthrough came in 2019 when digital technology was successfully used to guide the distribution of trachoma treatment to 1.4 million people in 10 districts over the space of a week through the Accelerate programme.

Sightsavers worked with Zimbabwe's Health Information and Surveillance Unit to configure the MDA digital monitoring platform and train field teams on how to use it.

Around 280 distribution teams were tasked with providing trachoma treatment to at-risk communities. Each team reported data on drug distribution and drug stocks every day. Information was entered on a daily basis to enable team progress to be tracked in real-time. The data was monitored by a central team, staffed by people from the country's Health Information and Surveillance Unit, the ministry of health and Sightsavers. This 'command centre' kept in touch with supervisors and teams throughout the campaign.

Rapid responses

The central team was able to spot issues as they arose and react quickly, solving problems and providing support as and when it was needed. The team then communicated any issues to province and district leads, creating an invaluable feedback loop.

Thanks to the monitoring platform, for the first time national and province-level workers were able to have a view of the whole MDA as it unfolded. District-level team leaders were also able to identify the distribution teams that needed additional support, which helped to encourage individual teams to reach the targets that had been set.

Two weeks after the MDA, the data indicated that 87 per cent of people in target communities had been reached. Not only does this mean the coverage target had been met – something that has previously proven challenging due to the logistical complexities of MDAs. Also the fact that the actual coverage level was already known was an important improvement; this can usually take months, which often hinders future activity planning.

87 per cent of people in target communities were reached

Yumba Ndumba Dyesse, data manager from the World Health Organization's Expanded Special Project for Elimination of Neglected Tropical Diseases (ESPEN).

Survey collection: mapping river blindness

Sightsavers has been working with partners to develop stronger, more efficient ways of mapping the spread and transmission of river blindness (otherwise known as onchocerciasis).

River blindness causes severe skin irritation and can lead to blindness, but if people who have the infection take a medicine called Mectizan®, there will be no lasting impact on their skin or eyesight. If those who are at risk of infection take this medication one or two times a year through an MDA they will also be protected. After repeated MDAs over many years, transmission of river blindness can be broken.

For MDAs to be effective, they have to reach the communities that are most at risk, and this is where the Onchocerciasis Elimination Mapping (OEM) project comes in.

The OEM project records where river blindness is prevalent and where MDAs would be most effective. Testing is carried out by two-person teams – a recorder and technician – who conduct finger-prick blood tests for adults who have lived in their community for at least 10 years. The blood tests are then sent to laboratories to be analysed while a secure mobile app uses barcodes to link participants with their test results.

In 2019, the OEM project was piloted in Ghana and Nigeria in areas that had not had access to Mectizan® before. The initial trial was used to test WHO's protocol for mapping river blindness and to develop technical expertise.

The insight for this trial has since been used to implement OEM in Mozambique. This is the first time river blindness has been mapped in the country using modern techniques. It is hoped these activities will help to establish best practices for data collection, data visualisation and decision-making to inform the scale-up of the OEM project in other countries. Countries and partners are being encouraged to prepare for OEM by reviewing their own data and identifying districts that have not yet been treated or mapped.

The mapping team in Mozambique

Meet some of the team who are mapping river blindness in Nampula, Mozambique, through the OEM project.

Dyesse

"My name is Dyesse Yumba and I'm the data manager of the OEM project. My job involves helping a country… use a data collection application [called the] ESPEN Collect for Onchocerciasis Elimination Mapping.

"The mobile phones are used to help collect data for the results during the survey and I will then look at the results and tell the team or the supervisor how the results are looking or if there are mistakes. We [then] work together to fix those mistakes. The OEM project is important because it will help the country to eliminate onchocerciasis. Because, after the mapping, we know what the status of the disease is in the country."

Isaque

"My name is Isaque Joaquim and I am a recorder for the OEM project. As a recorder I ensure the process is running smoothly and gain consent from the survey participants, which require me to fill in forms to send to the database.

"For my daily job I sell construction materials, but I was interested in being involved in this project because it is something new. I like to learn about different things than what I do daily. I feel confident, after the training, to go out into the communities and begin surveys…[and] positive and comfortable using the mobile phones to collect data.

"I believe the impact of this project will be the elimination of onchocerciasis. It will make things better and we can also help the population to understand how to avoid it, to protect themselves from the disease. This project is going to help many people and many communities. So in the long run it will be very helpful to Mozambique."

Isaque Joaquim (second from left) and other volunteers practise how to use a mobile phone to obtain GPS location and collect data during a three-day training for the Onchocerciasis Elimination Mapping project.

A trachoma grader checks a child's eyes for signs of the disease in a Maasai community during a Tropical Data Refresher Training in Meserani Juu, Monduli, Arusha, Tanzania.

The Global Trachoma Mapping Project and Tropical Data

One of our most successful digital projects to date has been the Global Trachoma Mapping Project (GTMP), the largest infectious disease survey ever undertaken.

Sightsavers led a 50-strong partnership that used smartphones to collect trachoma-related data on 2.6 million people in 29 countries. On average, one person was examined every 40 seconds.

Immediate results were captured, and this data was then cleaned and analysed before being reviewed and approved by ministries of health using a secure web-based portal. The data was used by each country to request medication donations and create action plans to control and eliminate trachoma.

The GTMP project came to an end in early 2016. But its legacy lives on in the WHO-led Tropical Data initiative, in which Sightsavers plays a key role alongside a consortium of partners.

Tropical Data uses the same approach and methodology as the GTMP. Since 2016 it has worked in 44 countries and has examined 6 million people in relation to trachoma. The service also provides support to countries to develop epidemiological surveys and provide standardised training.

Tropical Data is enabling numerous ministries of health to pinpoint exactly where to run trachoma treatment programmes, and understand when to stop treatment because interventions have been successful. It is also helping countries gather crucial evidence on trachoma elimination to submit to WHO.

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Using WASH data to combat NTDs

Clean water and good sanitation and hygiene are key to preventing the spread of certain NTDs, such as intestinal worms, schistosomiasis and trachoma. This is why joined-up working between NTD programmes and water, sanitation and hygiene (WASH) sectors is crucial.

Sightsavers is supporting a number of countries to merge WASH data with other information about NTDs. Data from both areas is then analysed together, turning this combined information into knowledge that will lead to more effective NTD and WASH programmes, and greater collaboration between key players. For instance, it will provide insight into which districts are co-endemic for WASH-related NTDs, and where behaviour change activities, such as hand-washing campaigns, will have the greatest impact.

The data merge was made possible by integrating databases from the WASH and NTD sectors to enable more effective planning and joint resource allocation. Support for this has been provided through the publication of a comprehensive WASH and NTD sector landscape analysis, and by implementing the WHO's 2019 WASH/NTD toolkit[6], which was published to encourage sustainable cross-sectoral collaboration.

By building the evidence to show that working together on WASH can control multiple diseases, it is hoped that more support for multi-sector initiatives will emerge, alongside increased investment to improve WASH-related infrastructures.

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Digital innovation beyond NTDs

Digital tools originally developed to tackle NTDs are now being adapted to respond to other health and eye care needs.

One example of this is CataTrack, a version of the TT Tracker, which is being piloted in our child cataract programme in Nigeria. The mobile app is being used in three states to ensure children who have had their eyesight corrected through cataract surgery are monitored and contacted so they can access essential aftercare in the six months after their operation. In the past, many children were not returning for post-surgery appointments, and the gains to their eyesight brought about by their operation were at risk of being lost. The app also helps surgeons access their performance by making it easy to view and understand surgical outcomes.

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Six-year-old cataract patient Khadijah Yahaya's eye is examined after surgery at the Ophthalmology Department of Usmanu Danfodiyo University Teaching Hospital in Sokoto, Nigeria.

(Right to left) Silvia Danga records survey participant information for Xavier Michovie and Rosalina Paulo into the mobile phone data collection software.

Our future plans for digital health

Since beginning work in digital health, Sightsavers has created the digital solutions that countries need to tackle NTDs.

These are user-driven in their design and implementation. At the heart of this approach is a commitment to listen to what NTD programmes need and innovating to address these gaps. As we continue work in this field we will remain committed to this philosophy.

In addition, we will continue working to create a culture of data use. We have embedded an understanding that it is not enough to simply collect data – the data must be accessible and be used at global, national, and sub-national levels to drive programmatic decision-making in all our current and future digital health work. We will remain committed to ensuring the data tools we support are integrated with national and global systems, and local capacity is built to ensure sustainability.

No one can say for sure where the exciting, rapidly changing field of digital technology will take us over the next few years, in our NTD programmes and our other work at Sightsavers. But we are ready for the challenge ahead.

References

1. WHO (2020) Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021–2030. **www.who.int/neglected_diseases/Revised-Draft-NTD-Roadmap-23Apr2020.pdf**

2. Pew Research Center (5 February 2019) 'Smartphone Ownership Is Growing Rapidly Around the World, but Not Always Equally' [online] **www.pewresearch.org/global/2019/02/05/smartphone-ownership-is-growing-rapidly-around-the-world-but-not-always-equally/. Accessed 28 April 2020.**

3. WHO (2015) Informal consultation on a tracking system for patients with trachomatous trichiasis. **www.who.int/trachoma/resources/9789241509640/en/**

4. WHO (2012) Accelerating work to overcome the global impact of neglected tropical diseases. A roadmap for implementation. **www.who.int/neglected_diseases/resources/WHO_HTM_NTD_2012.1/en/**

5. For more information see **www.dhis2.org**

6. WHO (2019) WASH & Health Working Together – a how to guide for Neglected Tropical Disease Programmes toolkit. **www.who.int/water_sanitation_health/publications/wash-health-toolkit/en/**

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

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