The Global Trachoma Mapping Project: Determining Prevalence to Help Eliminate Trachoma by 2020

The Task Force for Global Health is committed to the idea of health equity, that all lives have equal value and everyone should have equal access to the means for good health. One of its priorities is to control and eliminate a group of disabling infectious diseases called the neglected tropical diseases (NTDs) that primarily affect people living in poverty. The Task Force supports large-scale programs to address these diseases, including managing billions of dollars in donations from pharmaceutical companies and driving a robust operational research portfolio.

One NTD that The Task Force is working to eliminate is trachoma, a painful bacterial infection that causes blindness in later stages. Trachoma remains the world’s leading cause of infectious blindness. Trachoma is generally found in areas of the world with poor hygiene and sanitation. The disease spreads through contact with the eyes or nose of an infected individual. It can also be spread through shared towels and clothing or vectors such as flies. Children who don’t wash their face are most likely to be infected, and they, in turn, spread the bacteria to their caregivers and other children. Repeated infections cause scarring and result in the eyelashes turning inward and scratching the cornea. In later stages, trachoma can lead to blindness. About 1.9 million people in 42 countries are currently blind or visually impaired as a result of trachoma.

Efforts to address trachoma began in the 1990s after the pharmaceutical company Pfizer showed the antibiotic azithromycin, or Zithromax, could treat the infection. In 1996, the World Health Organization (WHO) endorsed a comprehensive strategy known as SAFE for trachoma control programs that incorporated the use of azithromycin, environmental and behavioral changes, and surgery. With new tools at hand, WHO set the goal of eliminating the disease by 2020 and called this initiative GET2020.

In 1998, several groups, including Pfizer, united to create a nonprofit called the International Trachoma Initiative (ITI) to bridge their efforts and work towards the 2020 elimination goal. Pfizer committed to providing ITI initially $60-million worth of Zithromax for mass drug administration in countries affected by the disease. ITI formed an expert committee responsible for reviewing country applications and deciding where Zithromax would be distributed. ITI began supporting partners around the globe implementing the SAFE strategy. In 2000, Pfizer agreed to continue Zithromax donations for as long as ITI demonstrated progress towards the 2020 elimination goal.
The Challenge

In 2009, after ITI became a program of The Task Force for Global Health, the team recognized the need for better information about the prevalence of trachoma in countries where the disease was endemic. This information would inform decisions about where to implement the SAFE strategy. It also would be needed to ensure that countries prioritized trachoma elimination.

ITI saw that countries were using different tools to measure the prevalence of trachoma and that some countries lacked data altogether. Many countries were not measuring trachoma prevalence because diagnosing the disease was difficult. In addition, the conventional surveillance method involved paper-based systems, which were labor intensive and inefficient. Data and files were often lost each time national program managers turned over. Most countries were also hesitant to share what data they had with international partners, worried that reporting high levels of trachoma would reflect poorly on their public health systems. This reluctance to share data made it challenging for ITI to know where to allocate Zithromax. “Every time a new district would apply for Zithromax, we would have to ask if we really trusted these data,” ITI’s director said.

The Opportunity

In January 2012, the UK’s Department for International Affairs (DFID) announced the largest coordinated effort to date to combat NTDs, including trachoma. ITI teamed up with several collaborators to propose the Global Trachoma Mapping Project (GTMP) to DFID. ITI proposed to work with a consortium to complete The Global Atlas of Trachoma by mapping global trachoma prevalence within three years. A total of 600 field staff would be trained to collect the necessary data to complete the atlas. An initiative on this scale had never been attempted previously, and it would give program implementers in countries a blueprint for the work ahead to reach the 2020 elimination goal.

The Strategy

The GTMP consortium worked quickly to develop a plan, structure, and scientific protocol for its ambitious effort. The mapping effort would encompass thousands of remote districts around the world with distinct languages and geographies.

ITI took the lead on developing the technology that would be needed for data collection and management. Field teams would use mobile devices to record findings of trachoma infection at each household. The data management software would convert the household-level findings to maps that would show trachoma prevalence at the village and district levels. This information would inform the drug applications that were reviewed by the expert committee. An electronic data capture and management tool called LINKS that had been piloted for another NTD was adapted for GTMP. The
interface was designed to be basic enough for field staff to understand and secure enough to prevent accidental data loss or breaches.

GTMP leadership worked to ease national concerns and explain the intricacies of how the data would be collected, stored, and shared. They also visited with local leaders to explain the data collection process. Ministries of health in each country were permitted to review and own all the data the project collected within their borders. In order to ensure data quality, the technology had a two-layer approval system—requiring both countries and the GTMP group to certify the data. Once reviewed, the district-level data would be classified into four categories based on what needed to be done to address the disease. The suggested actions were all shared online through the Atlas. This allowed aid groups, advocates, funders, program managers, and others to see where and what help was needed.

The GTMP field teams began in the Oromia region of Ethiopia, where they believed there was the highest burden of unmapped trachoma in the world. Field teams administering the GTMP survey uploaded findings through Wi-Fi or cellular connections to a central server in the Cloud. ITI reviewed the information in real time to check for any irregularities and ensure a seamless flow of information.

The Impact

The GTMP finished ahead of schedule and under budget. Critical to the success were ministries of health and 50 partner organizations that undertook the mapping process. By January 2016, more than 2.6 million people had been surveyed for trachoma to create prevalence maps of 29 countries, which became the largest infectious disease map ever created.

The availability of high-quality data on trachoma had an impact at many levels. The Atlas helped informed the scale-up of the global trachoma elimination program. With the availability of prevalence, ITI was able to make better decisions about where to allocate Zithromax and to inform Pfizer about demand to ensure the right amount of Zithromax was produced each year. In 2016, ITI reached scale when Pfizer donated 120 million treatments to 32 countries, bringing the cumulative program total to 627 million azithromycin treatments.

With the availability of robust prevalence data, civil society and international advocacy groups had new data to support their work to eliminate trachoma. With greater understanding of trachoma prevalence in their country, ministries of health were able to prioritize trachoma elimination. They used the information to apply for Zithromax donations and allocate resources to the most affected districts. Household-level prevalence data also helped countries understand local risk factors for trachoma infection and tailor their prevention and treatment activities. Finally, GTMP revealed
lower levels of trachoma prevalence than had originally been determined in some countries, which allowed mass drug administration to be stopped in these countries. In some areas of Mozambique, for example, GTMP determined the prevalence was only 5 percent rather than 35 percent as originally thought.

The Future

GTMP has helped inform the world about where trachoma exists, but eliminating trachoma by 2020 remains a persistent challenge. ITI continues to work diligently to support the distribution of antibiotics where they are needed. It also has begun collaborating with many GTMP partners on a new WHO-led initiative called Tropical Data that will support ministries of health in ongoing impact assessments and surveillance surveys of trachoma prevalence. The initiative will help countries assess how effective their SAFE activities are and how close they are to reaching the 2020 elimination goal.

Tropical Data also plans to adapt its approach to trachoma mapping to other NTDs that are targeted for elimination. This will include implementing surveys that are standardized across countries using WHO-approved methodologies to ensure high-quality outputs and allow ministries of health to maintain full ownership of their data. These important characteristics of GTMP will continue to define the path ahead. GTMP disrupted the science of disease elimination and has set the stage for success with other disease elimination programs.