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The Global Trachoma Mapping Project

"Trachoma is both an ancient and a stubborn disease, slow to blind, and obviously hard to "cure" in a public health context. All through human history, in times of peace as in times of war, it has taken a steady toll of human sight. Against this persistent affliction, some of the best minds in public health ophthalmology have during the course of the last half century or so, been forging increasingly effective weapons to control and eliminate blinding trachoma. Not a decade has passed without some improvement in strategy or medication against this leading cause of preventable blindness."

—Mariotti et al., 2003

In August 2015, Sightsavers' Neglected Tropical Disease Operations Director Tom Millar and the World Health Organization's Anthony Solomon had four months left of managing the largest standardized global mapping project ever to take place for any disease. Over 60 partner agencies and organizations across six continents had worked together on the Global Trachoma Mapping Project (GTMP), a three-year, USD 16.5 million effort to map the prevalence of trachoma in endemic countries. The ultimate goal was to eliminate the detrimental health effects of trachoma by 2020.

Under the guidance of Millar, who had previously worked in the oil industry, and with Solomon's scientific and technical expertise, the partners had systematically sampled an area of over 1.2 billion people, including 1,469 districts across 22 countries, and directly examined 2.1 million individuals for trachoma.[1] Human disease eradication had been achieved only once before: in the case of smallpox, whose vaccination campaigns relied on the visible nature of the disease and many years of international collaboration. Even polio, another vaccine-preventable disease with decades of eradication campaigns and data collection behind it, had not been eradicated. The Guinea worm campaign that relied on community prevention efforts had missed its 2009 eradication target but seemed to be getting close. How could Millar and Solomon help maximize the return on investment in trachoma mapping so that the campaign could achieve its ultimate goal of global elimination of blinding trachoma? And what lessons could they extract to teach others about what it took to create an effective collaboration of this magnitude?

Patrick Brooks, Julie Rosenberg, and Rebecca Weintraub prepared this case with assistance from Amy Madore for the purposes of classroom discussion rather than to illustrate either effective or ineffective health care delivery practice.

Trachoma

Trachoma resulted from chronic infection with the bacterium *Chlamydia trachomatis* (*C. trachomatis*), which entered the human host in discharge from the eyes or nose of an infected individual. Transmission occurred through direct person-to-person contact, use of shared towels and clothing, or vectors such as flies.* Suboptimal hygiene and sanitation practices, common in settings of extreme poverty, facilitated the transmission.[2]

Over decades, the effects of the infection progressed: repeated episodes of active, inflammatory trachoma often manifested as "trachomatous inflammation–follicular (TF)" or "trachomatous inflammation–intense (TI) (see **Appendix I** for commonly used acronyms and abbreviations)." TF or TI could lead to trachomatous conjunctival scarring (TS), which, in some individuals, ultimately produced trachomatous trichiasis (TT) and corneal opacity (CO; see **Exhibits 1** and **2** for clinical characteristics of these signs of trachoma and **Appendix II** for key definitions).[3]

The immune system of a healthy, non-immunodeficient individual could clear a single *C. trachomatis* infection with very few, if any, long-lasting effects. However, in trachoma-endemic areas in Africa, Asia, the Middle East, Australia, and Central and South America, infection occurred over and over again in young children, with many being infected with new strains before they had cleared the existing one. In some communities, more than 50% of children ages 1–9 years had active trachoma (TF or TI) at any given time.[2] In 2006, over a million people had been blinded by trachoma and over 10 million more had TT and were in grave danger of incurring progressive visual impairment.[4]

Pre–school age children and their caregivers were most likely to acquire infection. Women were disproportionately exposed and 2.5 times more likely to develop TT than males.[5] Marrying young and having multiple childbirths increased the risk of mothers acquiring infection from children.[5]

In 2011, an estimated 325 million people lived in trachoma-endemic areas where the district-level prevalence of active trachoma was thought to be greater than 10%. The majority were in Ethiopia, Niger, Nigeria, Tanzania, and Uganda.[6] For almost half the suspected population at risk for trachoma, no specific district-level prevalence data existed. Vision problems from trachoma cost countries between USD 3 billion and USD 6 billion in productivity losses each year.[6]

Addressing Trachoma

While ophthalmologists documented evidence of blinding trachoma as far back as 8000 BCE, control measures were not identified until the early 19th century, and available treatments were ineffective or had detrimental side effects through the turn of the 20th century. Thanks to improvements in hygiene and sanitation that came with general socioeconomic progress, trachoma disappeared in much of the developed world by the mid-1900s[7] but continued contributing to visual impairment of hundreds of thousands of people in developing countries.[6]

In 1952, the American pharmaceutical company Pfizer Inc. ("Pfizer") developed tetracycline ointment and showed it was effective at treating active trachoma when applied to the eyelids twice a day for three to six weeks.[8] Many nongovernmental organizations (NGOs) provided tetracycline for active disease, but getting patients to adhere to the rigorous therapy regimen proved difficult.[9]

Unsuccessful vaccine trials in the 1960s and the lack of practical treatment options left trachoma largely neglected by public health programs in most countries for most of the twentieth century. In 1978, the World

* Vector-borne diseases are those that rely on organisms ("vectors"), such as mosquitoes and ticks, to play an active

Health Organization (WHO) made the Programme for the Prevention of Blindness and Deafness responsible for trachoma.[7,4]

In the 1980s, Pfizer and Croatian pharmaceutical company Pliva both filed patents for the antibiotic azithromycin, found to have enhanced antibacterial activity and a prolonged effect compared to other antibiotics. The two companies later entered a licensing marketing agreement. Pfizer would market azithromycin as Zithromax and begin conducting the trials needed to register azithromycin for trachoma.

During the same decade, a Rockefeller Foundation officer introduced the term "neglected diseases" to describe a host of conditions for which there was little funding; these included trachoma, onchocerciasis, and Guinea worm disease (see **Appendix III** for more on the latter diseases). The Edna McConnell Clark Foundation ("Clark Foundation"), which "took on orphan diseases when no one else would," according to one informant, was phasing out its schistosomiasis program starting in 1981 and turned to trachoma.[10] The Clark Foundation used similar strategies for trachoma as it had for schistosomiasis, such as "early co-option of leading scientists and workshops to develop a scientific agenda and encourage networking between bench and field researchers."[10] In addition to establishing overall scientific goals and strategies, the program invested in developing a simple system for paramedical staff to diagnose and grade signs of trachoma to enable an epidemiological survey. The Clark Foundation partnered with WHO on this,[10,11] and WHO endorsed the grading scheme in 1987 after confirming inter-observer agreement.[†,12,13] Around the same time, Pfizer, with the Clark Foundation and the National Institute of Allergy and Infectious Diseases[9], confirmed that a single dose of Zithromax was as effective as the standard six-week treatment of topical tetracycline ointment.

Evidence of the disappearance of trachoma from some endemic areas following improvement of socioeconomic factors also pointed to missing links in trachoma control efforts, such as behavioral and environmental interventions.[13]

The Clark Foundation and others supported the development of a new trachoma control strategy called SAFE, named for its four distinct components: *S*urgery to correct existing cases of TT; mass drug (*A*ntibiotic) administration (MDA) to clear infection;[‡] *F*acial cleanliness to minimize transmission; and *E*nvironmental improvement, including improved access to water, methods for appropriate disposal of human feces, and facilities to wash hands and faces.[14] No component of the strategy alone was believed to be sufficient.[4,13]

Surgical interventions, the first component of SAFE used to reverse existing eye damage, varied across programs and countries.[4] Many countries lacked the trained ophthalmologists or experienced eye nurses needed to perform the surgeries.[4] Programs continued to treat individual patients with antibiotics to limit scarring and infection of the patients' contacts[4], and to do MDA at the district level to slow transmission more widely.[4]

In November 1996, WHO, with support from the Clark Foundation and Pfizer, convened a meeting of NGOs in Geneva, Switzerland, to evaluate azithromycin study results.[15] Seeing promising evidence, WHO formally endorsed the SAFE strategy as the gold standard for trachoma control programs and recommended the use of oral azithromycin for MDA.[2,10,9,16,17]

[†] Inter-observer agreement is the degree to which two or more observers report the same values after measuring the same events. It is often used to validate a methodology.

[‡] In the 1990s and early 2000s, NTD elimination programs, including those for schistosomiasis and soil-transmitted helminthes, focused mainly on MDA; drugs for such diseases were readily available and inexpensive to manufacture.[7] Some involved in schistosomiasis and lymphatic filariasis campaigns believed the trachoma community should focus on MDA as well. Others argued that MDA was ineffective without simultaneous environmental improvement and health education.[14]

Initially, the lack of high-quality economic analyses of the SAFE strategy[18] led to uncertainty about the cost-effectiveness of MDA for trachoma. Azithromycin was much more expensive than other drugs used for MDA: one study found MDA for trachoma was three times more expensive than MDA for integrated neglected tropical disease (NTD) control (USD 1.50 per person compared with USD 0.50).[19] Some were concerned there was a potential conflict of interest given Pfizer's involvement. However, an estimated 400 million people were in need of antibiotic treatment, and the community agreed to move forward together.

Global Elimination

Various disease elimination and eradication efforts had failed over the previous century, starting with the Rockefeller Foundation's efforts to establish a commission to eradicate hookworm worldwide in 1907 and to eliminate yellow fever from the US in 1915. The failed campaigns diminished the popularity of eradication efforts until the mid- to late 1950s, when WHO began working toward global malaria and smallpox eradication. The elimination of malaria from specific regions and development of a stable vaccine for smallpox fueled the notion that disease eradication was possible. The smallpox eradication campaign concluded successfully in 1977, while the malaria eradication effort (having invested USD 1.4 billion over 10 years) failed due to a host of factors, including drug resistance, absence of a vaccine, lack of acquired immunity, and rising costs. Public health experts were again skeptical of whether eradication could be achieved for diseases other than smallpox (see **Appendix III** for more on select disease elimination efforts).

The Guinea worm eradication campaign began in 1980 at the US Centers for Disease Control and Prevention (CDC) with a target of elimination by 2009, relying primarily on prevention through safe water. WHO joined the effort in 1981. The Interagency Steering Committee for Cooperative Action for the International Drinking Water Supply and Sanitation Decade (1981–1990) proposed the elimination of Guinea worm disease as an indicator of success for the decade, and momentum increased. In 1986, the Carter Center joined the effort and became responsible for coordinating the Guinea Worm Eradication Program, working with WHO, CDC, UNICEF, and ministries of health (MOHs).[20] The campaign used a "village by village" approach and community leader guidance to detect the disease and decide where to focus.

In 1992, the International Taskforce for Disease Eradication determined that Guinea worm was a prime target for elimination. The following year, it developed definitions to differentiate eradication and elimination. Although both would be the result of deliberate efforts, elimination was defined as the reduction to zero of the incidence of a disease/infection in a defined area, and eradication as the permanent reduction to zero of the worldwide incidence of a specific agent.[21,§] In 1997, the task force evaluated over 90 diseases and identified 6 as having the potential for eradication, as well as an additional 6 that had the potential for elimination. Trachoma was a candidate for elimination.[21]

The WHO Programme for the Prevention of Blindness organized the first meeting of the Alliance for the Global Elimination of Trachoma (GET) for June 30–July 1, 1997. Participants included 12 NGOs, the World Bank, and WHO member states (see **Exhibit 3** for a full list of partners).[22] They set a target of eliminating trachoma by 2020. The target date was decades away, which seemed reasonable, and it promoted the idea of good vision for all ("20/20 vision"). The so-called GET2020 Alliance worked to: (1) advocate for integrating the SAFE strategy into trachoma control and prevention efforts, (2) connect member countries and organizations working to obtain prevalence estimates from countries with endemic

[§] The CDC notes elimination requires continued intervention measures. In the case of trachoma, true elimination would mean the correction and prevention of TT and CO due to the disease.

trachoma, (3) leverage resources to help governments build capacity and implement trachoma control programs, and (4) make treatment of trachoma a part of primary health care.[22]

In 1998, Pfizer and the Clark Foundation cofounded the International Trachoma Initiative (ITI), with a mission to advance the WHO goal of eliminating trachoma by 2020.[11] Pfizer had committed to ensuring ongoing access to Zithromax in clinical efficacy studies and promised over USD 60 million worth of Zithromax to ITI, along with financial and technical support. The Clark Foundation and ITI's other partners also provided significant technical and financial support worth millions of US dollars.[23]

The announcement of Pfizer's drug donation to ITI gave the organization a strong presence in the trachoma community. ITI joined the GET2020 Alliance, hired 27 technical and program support staff, and formed a Trachoma Expert Committee (TEC) tasked with providing technical and strategic direction for the organization, monitoring trachoma control programs, and reviewing country-level trachoma action plans.[23] The TEC was responsible for deciding where Zithromax would be distributed based on country applications (see **Exhibit 4** for application components).

ITI moved quickly to begin program implementation (see **Exhibit 5a** for a list of ITI partner projects by country), starting in areas where Pfizer had been conducting field trials on azithromycin. In 2000, Pfizer agreed to continue Zithromax donations for as long as ITI demonstrated progress toward the GET2020 goals. ITI brought in new partners involved in research, implementation, and advocacy (see **Exhibit 5b** for list of partners by activity).[23]

The Second Global Scientific Meeting

From 1997–2003, GET2020 Alliance membership grew rapidly to include academic institutions, more NGOs, and representatives from the MOHs of newly identified trachoma-endemic countries. By 2003, over 50 countries were represented.

NGOs and MOHs were using available trachoma prevalence and socioeconomic data to determine if they needed to take action and where to prioritize SAFE implementation.[22] National programs were also beginning to conduct outcome surveys to assess their progress, using various methods. Review of the first five years of ITI programs[24] demonstrated measurable short-term impact. Pfizer's support of research on the SAFE strategy through ITI led to more efficient implementation strategies.[25,26]

The WHO Programme for the Prevention of Blindness and Deafness convened the 2nd Global Scientific Meeting on trachoma in 2003. Working groups revealed that although prevalence mapping had been completed in many districts through NGO-MOH partnerships, "different surveys did not always use the same protocol … age groups [were] different in the various surveys and data on trachomatous trichiasis often provide[d] information only for women over 14 years," the meeting report explained.[27] Many endemic countries (including China, India, and Ethiopia) lacked data altogether. According to the meeting report, "a new assessment of the global burden of trachoma was sorely needed to plan for the work ahead."[27]

A working group at that meeting estimated that TF/TI affected over 84 million globally and TT affected 7.6 million, though these estimates were based on vastly incomplete data (see **Exhibit 6** for regional estimates of the burden of trachoma).[27] The Western Pacific region, followed by Africa and Southeast Asia, had the highest burdens, with the estimate for the Western Pacific dominated by numbers from China.

Using the African Programme for Onchocerciasis ("river blindness") Control as a model (see **Appendix III** for more on onchocerciasis efforts), another working group developed a tool called the Trachoma Rapid Assessment (TRA).[22] The TRA utilized a two-part assessment strategy to identify high-burden trachoma areas. Ministries of health and their partner organizations conducted the preliminary TRA, which included

collecting all available documented or anecdotal information on trachoma. The second phase involved field teams doing a rapid survey in communities identified in Phase 1 as most likely to have trachoma. Teams assessed for trichiasis in the adult population through a series of questions and visual recognition cards.[22]

It was clear to all the GET2020 Alliance members that more planning support was needed for trachoma initiatives. "WHO was the organization with the mandate to lead … However, WHO is a political organization, and political rules and processes bind it—it can't move quickly. With something as large as this, you needed more support than WHO could give," explained Paul Emerson, director of ITI and former director of the Carter Center's trachoma program.

Forming the ICTC

"The idea for a coalition started with that group of people who hang out together at the [GET2020] meetings—the ones who sit next to each other, exchange thoughts and ideas and then continue talking long after the meeting ends," Virginia Sarah, a Fred Hollows Foundation leader who later became chair of the group explained. Noting that other NTD groups, including those focusing on onchocerciasis and Guinea worm, had formed coalitions to oversee their disease elimination agendas, Sightsavers International, a UK-based NGO committed to eliminating preventable blindness globally, convened a meeting of six NGOs in July 2004 to examine lessons from the other coalitions.[28] Emerson noted, "The onchocerciasis program taught us a lot about going to scale quickly … The Guinea worm program had a lot to teach us about the importance of data-driven outputs and solid epidemiology" (see **Appendix III** for more on these elimination programs).

Sightsavers envisioned a group for trachoma that would share information and advocate for policy. Members named the group the International Coalition for Trachoma Control (ICTC) in October 2004 and set its mission: "to support trachoma control programs in endemic countries by acting as a catalyst for the implementation of the WHO SAFE strategy" (see **Exhibit 7** for a full description of ICTC goals).[28]

The ICTC general body included official member organizations and observing members (e.g., funding partners in trachoma), an executive group elected by members, working groups, a program advisory committee, and partnership grant managers. "It started with that group of people who hang out together at the [GET2020] meetings – the ones who sit next to each other, exchange thoughts and ideas and then continue talking long after the meeting ends," Virginia Sarah, 2015 chair of the group, said.

Members elected the executive group. A vice chair, a chair, and an immediate past chair served six-year terms—two years as vice chair, two as chair, and two as immediate past chair, consecutively, before moving off of the group.

Unlike other NTD coalitions, the ICTC was an unregistered membership organization. "The collective thinking at the time was that existing within legal regulations would detract from us getting the job done, that we'd spend time managing the business of having a business, rather than being able to provide technical and funding support," said Sarah. A vice chair, a chair, and an immediate past chair served six-year terms—two years as vice chair, two as chair, and two as immediate past chair. Members and officers (who were mainly leaders of NGOs implementing SAFE activities) participated in the group on top of fulfilling responsibilities at their home institutions. [29]

Moving ITI to The Task Force for Global Health

ITI's expansion of SAFE activities into 18 countries strained its financial and human resources.[30] In 2004, after investing USD 50 million in ITI, the Clark Foundation ended its financial support. The foundation was

wary of ITI's approach under its new leader, which required increasing donor commitments, and the tension ITI was starting to cause in the trachoma community. Pfizer was also looking to focus on other diseases and international health programs. Around the same time, trachoma was being classified as a NTD so that it could attract global health funding that was going primarily toward better-known diseases such as HIV/AIDS and TB.

In 2006, Pfizer and the ITI board of directors decided to find another organization that could take on ITI to improve management and financial decisions to meet the 2020 deadline.[29] Pfizer selected The Task Force for Global Health (The Task Force for Child Survival, at the time) in April 2009 from among the organizations that applied to steward ITI. The Task Force had experience building effective partnerships and working with trachoma, other NTDs, and MDA programs. It also had a reputation for thinking strategically.

Dr. Danny Haddad became ITI's new director. He was a medical doctor, previously on staff with Helen Keller International, and was then leading another Task Force program. ITI's team also included a deputy director, an associate director, and a supply chain and project manager.

With Task Force leadership and guidance from key stakeholders such as WHO, the Gates Foundation, and USAID, ITI decided to focus on three activities that would help it scale more efficiently: partnership building, trachoma knowledge management and dissemination, and management of Zithromax distribution, including supply chain capacity building.

Gaining 'INSight' for 2020

Pfizer knew more drugs would be needed to meet the 2020 goal, but it was hard to forecast just when and how much. Commenting on knowledge management, Haddad explained, "Before ITI moved to the Task Force, the drug donations were not being informed by concrete data—there wasn't really a clear process. But even when we started looking at district data, they were sparse, and quality was uncertain. Every time a new district would be up for approval, we would have to ask if we really trusted these data." According to Anthony Solomon, who became the WHO Medical Officer for Trachoma in 2014, "The history of trachoma is rife with instances where academics gathered data on trachoma, and then disappeared. In many cases, those data sat in cupboards or on hard drives and were forgotten about after they were published, or even without being published." The national trachoma program data were often lost with government staffing changes.

The new ITI team outlined a protocol for a web-based trachoma prevalence map. "We had a grant from the Bill & Melinda Gates Foundation that included training national coordinators from each country in GIS [geographic information systems]. As we didn't think that countries were going to use the skill that much themselves, and given that maps were something that everybody needed, we started thinking that it would be more useful for trachoma to put all the data online in one place for anyone to see," said Haddad. The tool was called the *Global Atlas of Trachoma* (available at www.trachomaatlas.org) and "aimed to consolidate published and unpublished data at the district-level and provide up-to-date country maps of trachoma distribution on an open-access forum."[31]

Throughout 2010, the ITI team dug through publications and inter-organizational documents that it requested from NGOs and MOHs to fill in the *Atlas*. According to Haddad, however, "It was glaringly obvious that there was a huge gap in what data were collected. So that's when we started meeting with national coordinators in Geneva, sitting them down, and just asking questions about their district-level data."

At the 2010 GET2020 Alliance meeting, countries presented their plans for trachoma control activity. Because of budget constraints, one country stated that it was planning to map trachoma in 1 or 2 out of 60 total districts each year. Haddad explained, "That's 30 years of mapping, which wasn't nearly good enough for the 2020 deadline ... It clicked with several of us that what we were doing was not planning towards elimination, but planning for what was as convenient as possible." An influential University of Melbourne physician and trachoma researcher from the GET2020 Alliance proposed ITI develop a template for countries to create individualized strategic plans for elimination by 2020.

Haddad and his deputy spent two days at the meeting interviewing national coordinators on their district-level trachoma prevalence to get a more complete picture. Most countries were hesitant to provide data, worried about how it would reflect on their national governments and their progress toward the Millennium Development Goals (MDGs). Some felt that previous researchers had, on occasions, published data "without regard for the country where they were collected," according to Solomon, "including data that cast a poor light on country programs." "I'm sure they felt like they'd been thrown in front of the inquisition," said Haddad. "We had to negotiate and reassure them that the data would not be used without their permission, would only be used for programmatic purposes, and would only show brackets of prevalence, not actual prevalence," he remarked.

While the *Atlas* revealed that 1,115 districts had been mapped for trachoma, ITI believed an additional 1,285 needed mapping given what they learned from MOH reports and interviews. "This was a huge realization. We didn't know anything at a global level, but we'd been trying to implement for years," said Haddad. "We wanted something that would identify the scope of the problem in each country, so we could focus activity and prioritize where implementation was most crucial."

In collaboration with a McKinsey & Company management consultant, the Carter Center, and Kenya's national trachoma program coordinators, ITI wrote a global strategic plan for trachoma elimination. The plan had three main goals: (1) sketch the current situation of trachoma and lay out what was left to be done, (2) describe milestones needed to reach global elimination of trachoma by the year 2020, and (3) convince donors and partners that a dollar spent on trachoma was a dollar well spent.[6] The plan, called *The End in Sight: 2020 INSight*, provided unit-based cost estimates for overall trachoma elimination and estimated that over 110 million people lived in areas that were proven to have trachoma as a public health problem, and another 210 million lived in districts needing trachoma mapping.

ITI presented the plan at the Trachoma Expert Committee meeting in June 2011. Some people external to the Committee did not think a global plan was additive and believed countries would get the work done using their own action plans. The Trachoma Expert Committee hoped to get WHO to adopt it, believing that without a coordinated global plan and unified data repository, the work ahead could not be fully understood.

Opposition to the global strategic plan within the GET2020 Alliance dampened WHO support. Realizing WHO's endorsement would require a formal review process and the approval of all member countries—a process that could have taken over two years—the ICTC published the global strategic plan for trachoma under its own name on the ICTC webpage.

The plan infused new energy into trachoma elimination efforts. "After *INSight 2020*, we realized we needed quality assurance, standardization, and huge scale up. That was when we decided to use some strategic reserve funds to kick-start the global mapping and standardization process," Haddad said. Solomon added, "To eliminate any disease, the critical step is knowing where the disease is—otherwise you're just shooting in the dark."

The Global Trachoma Mapping Project

In January 2012, the British government announced the London Declaration on Neglected Tropical Diseases, a collaborative disease elimination effort between the UK, US, United Arab Emirates, the Bill & Melinda Gates Foundation, 13 major pharmaceutical companies, and the World Bank that would provide funding for support and research on NTDs worldwide.[32] The Declaration targeted 10 NTDs,[32] with Iain Jones, economic adviser at the UK Department for International Development (DFID), in charge of managing the USD 76,522,500 allocated to trachoma.

Sightsavers' chief executive and its director of policy and strategic program support learned of the new fund and within a month mobilized a group from Sightsavers and ITI to go to London to discuss the idea of a global mapping project for trachoma with DFID. "When we pitched the idea to Iain, he loved it," said Haddad.

"I did have some requirements in mind before making a recommendation to our [UK] ministers," Jones explained. "I wanted the project to be ambitious in terms of timing; mapping had to be completed by 2015 to allow for up to five years of SAFE before the 2020 deadline. I also asked them to work with a range of partners across different sectors, and I asked them to be ambitious in terms of the [water, sanitation, and hygiene (WASH)] and NTD data" (see **Appendix IV** for more on WASH in trachoma control).

Haddad and the associate director from ITI, Sightsavers' directors of policy and advocacy and African alliances, and a few others "all got together in this tiny little hotel conference room in London and just drafted a plan," said Haddad. The result was the outline for the Global Trachoma Mapping Project (GTMP).

GTMP Structure

The group decided the project needed a chief scientist and asked Solomon, then an infectious diseases registrar at St. Mary's Hospital and an honorary lecturer at the London School of Hygiene & Tropical Medicine. "Sol was hardworking, modest, and incredibly bright," Haddad recalled. The GTMP consortium (ITI and Sightsavers) welcomed the London School into the fold with Solomon and created a steering committee of 12 experts to advise Solomon and oversee four working groups.[33] The steering committee would meet three times a year in coordination with GET2020 Alliance and ICTC formal meetings. The members of the committee included individuals working in trachoma control across much of Africa.

ICTC members were supportive of Sightsavers as the group that would lead the GTMP. As Virginia Sarah explained, "Sightsavers had DFID's support. They had the capacity and the relationships [to make it work]."

Sightsavers asked Neglected Tropical Disease Operations Director Tom Millar to oversee the project. Millar's professional experience was based in private sector energy development. Millar explained, "Any project is about joint ventures. If you dressed this project up in different clothes, it sounded like just as much a logistical challenge as it did a medical or a clinical challenge."

Millar was responsible for managing partner communications, reviewing and approving budget proposals, coordinating mapping activity timelines, ensuring timely delivery of project activities, and communicating with DFID. "My job was to make sure I had the right people with the right experience in the right place at the right time to serve the right market. [I was not] the technical, clinical advisor—that's your expert in health. But everything else is about delivery, and you need people who can provide delivery, regardless of where their previous experience is," Millar explained.[34]

With a Sightsavers colleague, Millar oversaw development of the DFID grant proposal, and Solomon and Haddad provided technical feedback. "It was a straightforward process, and like with most big grants,

the proposal did not have to be very specific on fine details," said Solomon. The proposal was a high-level picture of how the GTMP would look and function. Solomon worked "through the night, seven days a week" to build the technical parts of the project. He engaged others in the process by creating working groups that would develop specific protocols for internal use.

The final grant proposal budgeted the global mapping of the district-level prevalence of trachoma at £10,621,044 (USD 16.5 million) over three years, ending in April 2015.[35] The proposal laid out plans to estimate prevalence for 1,285 districts, map the distribution of other NTDs and of water and sanitation facilities, and train up to 1,100 field staff in disease mapping.[35] "I wasn't surprised when I saw the price tag," Jones said. "The INSight 2020 paper suggested that 1,285 districts needed mapping, at a cost of around USD 5,000 per district in 30 or so countries across Africa and Asia." In February 2012 the team submitted the final proposal to DFID. The goal of the GTMP was "100% completion of *The Global Atlas of Trachoma*."

To streamline the process, DFID had allowed only me of the ICTC —whose meetings Jones attended— to submit funding proposals, and Sightsavers was the only organization to submit. "DFID was able to go through a different kind of contracting procedure, which was lighter in touch when it came to evaluating the proposal," said Sarah (see **Exhibit 8** for the GTMP logical framework).

Developing GTMP Partnerships and Protocols

After submitting the grant, project leadership continued to work toward the development of specific GTMP protocols using funds from ITI's strategic reserves. They designed the GTMP as a consortium of separate projects that would use a standardized methodology. The consortium relied on two types of collaborating NGOs: coordinating and implementing partners. Partner selection for each region was an informal process that happened among ICTC members and the GTMP steering committee. The coordinating partner agencies worked closely with national health ministries and worked to build in-country NGO support for training and mapping. They also liaised with implementing partners with the MOH. Implementing agencies worked at a national or subnational level, collaborating with MOHs and, in some cases, local government health offices, to ensure that infrastructure, trained staff, transportation, and supervision were in place to deliver training and mapping. Implementing partners were responsible for creating budgets for mapping activity and for seeking budgetary approval from Millar and technical approval from Solomon. Sightsavers' head of finance and risk for NTDs assessed budgets on the basis of known and suspected levels of endemicity, national factors, cross-project comparisons, and local per diem values.

Soon after its conception, the Steering Committee was reconceived as an advisory committee to acknowledge its advocacy role on top of its technical responsibilities as the project awaited formal approval from DFID (see **Exhibit 9** for list of advisory committee members).

Solomon worked "through the night, seven days a week' to build the technical parts of the project. He tried to keep others engaged in the process by creating working groups to develop specific internal protocols.

Mapping Methodology

The Methodology Working Group aimed to produce guidelines for determining which sampling method should be used at various levels. It also selected indicators for WASH variables, determined how to integrate them into trachoma surveys, and solidified the details of data collection.

The GTMP selected a Population Based Prevalence Survey model for baseline trachoma mapping that WHO and others considered the "gold standard." Solomon and the working group figured out a sample

size (see **Exhibit 10** for formula).[33] Methods for household selection within the clusters varied by country, according to local population structures. There was a minimum of 20 clusters per evaluation unit, but overall number of households and the mean number of 1- to 9-year-olds per household factored into cluster size.[33]

There was some disagreement about which data to gather, including whether to collect information on the presence or absence of a "dirty face" or an individual with visible eye or nose discharge, or observing a fly touching the individual's face. Some Methodology Working Group members thought the question was too subjective and noted the irregular presence of flies. "If I am infected and you are not infected, and you have discharge, then flies are more likely to come to your face. It's not clear if examiners are measuring the effect of, or the risk of acquiring disease, or both," said Solomon.

The Methodology Working Group wanted a survey that could be completed in fewer than 10 minutes per household to maximize cost-effectiveness and scale-up potential. Solomon made the final decision to exclude the facial cleanliness indicator from the survey. Recording the presence or absence of trachomatous conjunctival scarring (TS) on the inner eyelid was another contentious issue. Members of the working group with a background in ophthalmology suggested that the presence of TS was a prelude to TT and should be assessed. Early TS was hard to identify consistently, however, and lacked a clear definition, so groups of graders (or even the same graders making multiple observations over time) tended to lack consistency in inter- (or intra-) observer agreement tests. Over 600 people would need to be trained to recognize its presence or absence reliably, and it occurred infrequently enough that it would be hard to show examples to trainees. Again, Solomon made the decision to exclude TS from the survey.

The final version of the survey included questions on drinking water sources, water sources for face washing, defecation practices, and observation-based questions on sanitary facilities, based on the WHO/UNICEF Joint Monitoring Program for Water and Sanitation methodologies (see **Exhibit 11** for a full list of GTMP WASH survey questions). The group planned for the survey data to be collected using an Android-based data collection application.

Graders finding individuals with active trachoma provided them with 1% tetracycline eye ointment and referred adults with TT to the district hospital.

Prioritization

The Prioritization Working Group collaborated with national programs to identify the countries with the largest burden of trachoma and the least data collected on its distribution, where mapping would take the longest. Ethiopia, with 434 districts in need of mapping, and Nigeria, with 239, were the highest priority in 2012 (see **Exhibit 12** for known and suspected trachoma burden by country).[6]

Tools

Members of the Tools Working Group were adamant about using electronic data capture tools for the project. The Carter Center and the London School had previously developed their own electronic data capture programs. The Carter Center's program, Swift Insights, was tablet-based (using personal digital assistants or PDAs) and had been shown to be 35% faster than pen-and-paper entry.[36]

Haddad and Solomon wanted a system that would upload data to a secure location and provide easy access for future data analysis, which Swift Insights did not offer. Alex Pavluck, senior information technology manager for the NTD Support Center at the Task Force for Global Health at the time, explained "The Swift model was more of a PDA style, where data would be collected and all the data collectors would come back to a central place—usually a laptop—and offload their data. So the data would stay very local to that pod [or device]."

Pavluck had developed an open source electronic data capture tool for the Task Force's NTD Support Center using Open Data Kit that he redesigned for the GTMP under working group guidance. The redesigned tool, named LINKS, needed to integrate GPS functionality to record the coordinates of the households surveyed within 10 feet using satellite connections. The GPS data would be important for assessing the validity and accuracy of the data points when compared to a map of the planned cluster.

To protect country interests, the GTMP agreed that the MOH in each country owned the data it collected and that the minister of health or other approved official would be the only one(s) allowed to access or disseminate the data after they were collected and approved. Solomon therefore wanted a two-layer approval system via a secure web-based user interface. The first layer allowed designated MOH officials to view summary statistics for the numbers of people examined, the locations of enrolled households, and so on, and to confirm that data collection looked correct for that area. The second layer allowed countries to view and approve prevalence values adjusted for age and sex.

District-level TF prevalence in 1- to 9-year-olds was categorized according to the WHO standards set during the 3rd Global Scientific Meeting on Trachoma, held in 2010: <5.0%, between 5.0–9.9%, between 10.0–29.9%, and >30.0%. These percentages correlated with a suggested action: Under 5.0% did not require intervention, 5.0-9.9% required one year of MDA (plus the S, F, and E components of the SAFE strategy) before impact survey; 10.0–29.9% required three years of MDA (plus S, F, and E) before impact survey, and over 30.0% required five-plus years of MDA (plus S, F, and E) before impact survey.[14] Once both levels were approved, a GTMP data manager based at the Task Force in Atlanta, Rebecca Willis, uploaded categorical data to the *Atlas*.

The Tools Working Group stored data on the phones' micro-SD cards to reduce the risk of data loss due to device damage and opted for a cloud-based data storage system to minimize the risk of loss or interruption of access to data after upload. They selected Android devices for data collection because of battery life, screen size, and price (approximately USD 100). They cleared phones of extraneous applications and set to a black background to preserve battery life. Task Force staff downloaded LINKS and installed the GTMP survey on the devices, then repacked and shipped the phones to sites.

International Air Transport Association regulations on lithium-ion batteries made shipping the devices and their spare batteries difficult. The Task Force applied for a license to ship hazardous materials and had to pack phones in small batches in specific packages to adhere to the relevant regulations.

Training

The Training Working Group was tasked with determining the composition of field teams and how to train them. The group reviewed as many materials produced by academic institutions and NGOs as they could find, and developed a standardized training manual with some room for local adaptation. The training pack included sets of training slides, kappa score calculators to assist with assessing accuracy of trachoma grader trainees, training session plans, and more. "It was a massive task," Solomon noted.

The group developed a three-level grader training cascade: master grader, grader trainer, and grader (see **Exhibit 13** for grader prerequisites). The grader trainer evaluation criteria included a slide-based inter-grader agreement (IGA) test and a live-subject IGA test on 50 children, ages 1–9. Graders would be evaluated using a kappa statistic** with a GTMP-certified grader trainer's grading as the baseline.[37] Similarly, recorders had to pass a test for accurate data entry. Both graders and recorders were expected to know the local languages and to understand the customs and practices of the villages being surveyed. In addition,

** Cohen's Kappa is a statistical coefficient that measures agreement between two individuals for categorical items. The statistic is considered useful because it takes into account agreement occurring by chance.

recorders had to be able to read and write and have a familiarity with smartphone devices; they did not need previous experience in health care.[33]

The First Year of the GTMP

Evaluation of the grant proposal took longer than Millar and Solomon hoped. The funds ITI provided were not sufficient to keep the project fully afloat throughout the approval process. Solomon and many others kept working independently, but working group activity was suspended in May 2012 until the grant was awarded in July.

With approval, Millar and Solomon quickly began working with The Fred Hollows Foundation and ITI, to convince Ethiopian health officials to participate in the project. The Fred Hollows Foundation was the implementing partner supporting the region with the highest mapping needs in Ethiopia at the time. Ethiopia had one of the largest and most active ophthalmologic communities of any country considered for GTMP activity and could have been resistant to adopting the GTMP approach. According to GTMP leadership, "Ethiopia has a proud history of never having been colonized. As a result, they're quite independent."

Ethiopian officials were cautious about the data management approach. Many were unfamiliar with the emerging concept of cloud-based computing. The GTMP leadership organized meetings with health officials to help ease any potential fears. After introducing the country to the project in full, Ethiopia agreed to be the first country in which GTMP activities would occur. The president announced the beginning of the mapping, which would occur in the Oromia region, one of the most trachoma-endemic regions in the world.

Oumer Shafi, former NTD program manager for the Ethiopia Federal Ministry of Health, explained that, once activities began, "Tom and Sol were in constant contact. I would receive multiple e-mails a day from them checking in, or they would come in person if there were issues, and that really spoke to the commitment we got from them."

Training Field Teams

The first developmental five-day training of field teams (of one grader and one recorder each) took place in October 2012. It was held in the Oromia region outside the capital city Addis Ababa, where the burden of trachoma, especially in children ages 1–9, was high. The Oromia Ministry of Health selected the teams to be trained and participated fully in the process, offering suggestions to improve the system. Local ophthalmologists and public health specialists worked in collaboration with an international training team (see **Exhibit 9** for a list of pilot team members in Ethiopia).

"Ethiopia effectively became an at-scale beta site for the GTMP system of training, survey methodology, and electronic data capture," said Millar. Sarah explained, "We were working through the final draft of the training manual during the pilot, and walking through it with the graders and recorders step-by-step and revising as we went. For example: Does the way this is described make sense to people? Is it translated correctly? What definitions do we need to include? Can people simply photocopy the pages and have the same quality?" Training and survey materials were originally produced in English, and local staff translated information sheets and survey questions into local languages for field use. Ultimately, the complete training package was also translated into French, Spanish, Portuguese, and Arabic.

In field training, a grader trainer took four grader candidates to the field to practice trachoma identification. Fully trained and, in some cases, world-renowned ophthalmologists supervised candidates.

Candidates had to achieve a kappa statistic ≥ 0.70 against a GTMP-certified grader trainer for the diagnosis of TF in live children ages 1 to 9 years to pass the test.[37]

About 25% of grader candidates failed. Though it created recruiting challenges for MOHs, the failure rate was "broadly perceived and indeed regularly pointed to as testimony to the GTMP's commitment to quality," a project evaluation noted. A GTMP partner insisted, "Quality has to come first. Even if the trainee is *just* under the required kappa score, we can't keep them. Data quality needs to be maintained over everything else." Subsequent trainings were held to fill the positions left by the trainees who did not pass the grader training.

Data recorders were trained on the mobile phones when graders were taking their field tests. According to Pavluck, "There were issues that we did not dream would come up. The swipe motion on most smartphones that we sort of take for granted seems intuitive, but it really isn't. It's [something learned] through exposure. So when we told [the candidates] to swipe, they would swipe up instead of right, or in some other way." Trainees were also unfamiliar with other basic phone functionalities, including charging, using the GPS function, and understanding how data would be transmitted wirelessly.

According to Shafi, "The graders were expected to know the difference between pit latrines and tube wells, and all of these different WASH variables, but there wasn't much time for that [in the training]." Training in these elements was reinforced as a result. The MOH had reservations about whether it was useful to collect the WASH variables at all. Shafi explained, "At the ministry, we knew that expecting to find certain types of latrines in districts was not possible—the people can barely sustain themselves, and they are supposed to have money for a clean latrine?"

During the last three days of the training session, graders and recorders paired up and learned about the GTMP goals, trachoma, SAFE strategy, and the survey and sampling methods. They also learned how to obtain individuals' consent, examination techniques, and how to select households in each village.

Teams went in groups of four with a local guide for one day to the field to practice grading and recording under the supervision of a trainer. Teams greeted the head of household and explained the purpose of the survey and the procedures in the local language. Though the goal was to collect data on the prevalence of signs in children ages 1–9 and adults over the age of 15, graders asked to examine all residents over one year old for the sake of simplifying the explanation and to prevent ages from being misrepresented by examinees.[37] Once the head of household consented to the examination, the data recorder captured the GPS coordinates of the household, asked the head of household the WASH survey questions, and inspected the latrines and hand-washing facilities, if present.

The grader examined all eligible individuals for signs of TT, TF, and TI using binocular loupes and sunlight, or a flashlight (see **Exhibit 14** for visual representations of examination tools).[37] Graders sanitized their hands with alcohol hand gel between examinations.

Grader trainers corrected errors during training and advised on how to increase efficiency. If some residents were not present at the time of the examination, households were reexamined at the end of the day. Graders offered 1% tetracycline eye ointment to individuals with TF or TI; those with TT received instructions on how to access surgery. Successful GTMP graders and recorders received certificates on the final day. Evaluation of data collected in the field would be the responsibility of Willis and Solomon, who reviewed and cleaned data prior to MOH approval. Field supervisors helped resolve questions about the data by phone or email.

Mapping Begins

After the training in Oromia, Solomon and colleagues updated the training package with lessons and feedback from the first training group, and continued preparing for mapping, including testing the mobile phone app and the GIS components to make sure they captured data accurately. They also had to purchase and ship binocular loupes, flashlights/headlamps, tetracycline ointment, phones, and other materials. GTMP leadership, ITI Ethiopia, and The Fred Hollows Foundation prepared staff to go into the field to oversee survey teams.

In each country, the coordinating agency—usually an NGO—facilitated a dialogue between the GTMP and the relevant program within the MOH to create a memorandum of understanding (MOU) and a scope of work (SOW) agreement identifying districts that needed to be mapped based upon existing knowledge and suspected trachoma. The SOW outlined the training needs and the relevant implementation partners.

The GTMP began mapping in Oromia in December 2012. Within two weeks, there were 15 teams mapping five days a week throughout the region. A trained ophthalmologist or senior ophthalmic nurse oversaw 7 to 10 teams and spent one day in the field with each team every two weeks.

Once deployed, teams uploaded data through Wi-Fi or cellular connection. Willis then cleaned and flagged data where necessary. Solomon reviewed and signed off on the data before it queued for MOH approval. Willis and Solomon examined data particularly carefully during the first weeks of surveying a new region to identify any unusual entries, patterns of household absence, or other emergent trends that could impact data validity. When the number of children evaluated was below the number required per EU, for example, Willis investigated and notified Solomon to take further action.

Once the MOH approved the data, prevalence was classified into the four action-based ranges and automatically uploaded to the *Atlas*.

GTMP leadership held calls with field supervisors at the end of each week. Calls focused on field team progress, including any obstacles teams faced. Teams and field supervisors would also suggest corrections to the methodology to increase mapping efficiency. Feedback was incorporated quickly, usually by the following week. In addition, Willis generated a weekly report that summarized issues addressed.

On December 25, 2012, Solomon realized that the evaluation unit and cluster code labeling system led teams to label data incorrectly, which resulted in what looked like repetitive data. Pavluck corrected the issue by changing the labeling protocol in the application.

The GPS functionality also presented initial challenges. In January 2013, Willis noticed that clusters of data were coming in with null or unrecorded GPS values. She notified Solomon, who found that the GPS functionality of the phones was not working. In addition, he found that the software was draining the phone battery by continuously looking for a connection or coordinate. To solve the problem, Pavluck reprogrammed LINKS to record the status at a given point in time and stop searching for coordinates.

The GTMP's First Year

From December 2012 to April 2013, the GTMP mapped 200 districts in the Oromia region of Ethiopia, meeting its first-year target within only four months. "It was extraordinary, and a real tribute to the hundreds of people in Ethiopia who pushed to reach this target much more quickly than they had initially thought might be possible," said Solomon. "The ministries of health in Ethiopia and elsewhere really owned and were critical to the process—technically, logistically, and in their provision of human resources."

The GTMP consortium grew to include more health ministries and partner organizations (see **Exhibit 15a** for list of partners). As the project moved into its second year, Sightsavers hired a project manager, Siobhain McCullagh, a previous management consultant, to reduce Millar's workload. "Siobhain had less program experience than we had ideally sought," Millar said, "but because I wasn't going anywhere, we thought that she brought strong program management and organization skills we could use for the project. It wasn't a kind of complete handoff, so we had time to manage the transition."

Little GTMP information had been documented. Solomon and Millar had most of it in their heads, including the processes for connecting with ministries, generating memoranda of understanding, and the way data flowed from field to storage, among other things. "Much of Siobhain McCullagh's role was to get the information from Sol and me and make sure that it was transparent for NGOs and funders," said Millar.

Project Midterm

By the end of the second year of GTMP implementation in 2014, mapping was complete in 8 of 30 countries, including 924 districts, each of which had a resident population of around 100,000–250,000. Of the 924 districts, 878 were mapped using the complete set of GTMP protocols. Trachoma prevalence for districts not mapped using GTMP protocols was estimated from existing methodologies and systems, collected by MOHs and NGOs before the GTMP was fully operational.

In addition to being ahead of schedule (see **Exhibit 15b** for the list of countries completed and in progress for the GTMP in 2014), the GTMP was spending less than it anticipated on mapping activities. The average incremental (per district) cost of mapping in 591 districts across three countries was USD 5,131, compared with an average of USD 5,849 in a comparable 2011 study of trachoma mapping in eight countries on which the budget was based. Multiplied by the number of districts, the costs were radically lower than previous efforts (see **Exhibit 16** for a breakdown of cost by region).

The costs varied region to region. For example, mapping cost an average of USD 13,407 per district in the Somali region of Ethiopia, while in Oromia the per-district cost was USD 2,412. Fieldwork was the main cost driver—almost 70% of the total per-district cost. Of fieldwork costs, 90% went to personnel[††] and transportation costs, including providing a car and driver to navigate in the field. Less accessible areas were also generally more expensive to map. While reflecting on work in the Tigray region of Ethiopia, Solomon stated, "If there was an Ethiopian space agency and they had colonized the moon, some communities in Tigray are what I would expect to be the result. There are these vaguely hilly areas of bare dirt with big lumps of rock, and people somehow eking out an existence." In addition to environmental factors, district mapping costs were impacted by climate, expected trachoma endemicity, country security, government capacity and commitment, NGO capacity, ethno-linguistic complexities, and the efficiency of field teams.

As the GTMP continued mapping districts, the scope of the project grew rapidly. In 2014, the GTMP's target had increased from 1,285 districts to 1,736 districts, and its timeline extended to the end of 2015 (see **Exhibit 17** for additional district estimates). MOHs and partners had come to perceive the GTMP as responsible for mapping all endemic trachoma. In addition, ministries saw the GTMP could be a valuable means to get Zithromax. "If they supported the mapping, and the prevalence fell into the relevant range, they felt that they were guaranteed Zithromax because ITI endorsed the GTMP's protocols. If [ministries] got the Zithromax, they looked good to their people," said Solomon. DFID agreed the initial £10.6 million (USD 16.5 million) it awarded would not be enough to cover the additional districts. According to Millar, "The conversation with DFID about expanding our goals was initiated at the GET2020 Alliance meeting in

[††]Personnel costs did not include the salaries of health-sector staff, whose time was contributed by MOHs.

April 2014. Sightsavers worked with USAID and DFID to set up a collaboration between the two funding agencies for trachoma mapping."

In early 2014, Iain Jones at DFID reached out to leaders at ENVISION—the United States Agency for International Development (USAID)'s program aimed at providing support to national programs to address seven NTDs, including trachoma, run by RTI International. ENVISION recognized that mapping was "essential for all NTD programs … to understand the country situation and guide a national program's decision making on program implementation and where treatments should be distributed."[38] Jones aimed to have USAID funds support trachoma mapping in Guinea, Mozambique, Nepal, and Indonesia as a part of its ENVISION project using GTMP methodologies.[39] RTI and its partners would serve as the implementing organizations. USAID and RTI enthusiastically agreed, and RTI subsequently joined the GTMP team.

As the GTMP experienced fewer problems and became streamlined, the advisory committee's role shifted from creating standards toward doing advocacy and planning future endeavors. The ICTC and GET2020 Alliance meetings provided a forum for implementing partners to exchange ideas and confirm methods.

With high-quality data on trachoma available, ITI was able to focus its efforts on supply chain management to ensure Zithromax was going to exactly where it was needed and that there was enough. With better forecasting capacity, ITI began "thinking much more about the last mile—getting the drug from the country stores into the people's mouths," CEO of ITI's parent organization, the Task Force for Global Health, Dr. Mark Rosenberg explained. "Most drug administration programs are content to get the drug into the hands of the Ministry of Health at the port of arrival."

The GTMP Midterm Evaluation

To better understand where the program could improve, Sightsavers commissioned an independent consultant to conduct a midterm evaluation of the GTMP. The 28-day evaluation included interviews with team members and field workers and reviewing activities in the office and on the ground.

The evaluation identified some ongoing problems with the validity of WASH data, reporting trainees were instructed in the use of the Android devices rather than in correct identification of water and sanitation types. Field supervisors also reported difficulty identifying and following up with absentees.

The evaluation noted that because of the speed of implementation, project management and monitoring tools were not fully developed when mapping began in Oromia, and they failed to develop further due to a "hit the ground running" mentality. The lack of documentation was related to an overreliance on project leadership, specifically Solomon and Millar. Program practices that had been essential to quick scale up were beginning to become burdensome. For example, new implementing partners often had to seek basic information directly from Solomon or Millar. According to the evaluation, "The loss … of these individuals would put the [project] at serious risk, as they carry with them enormous knowledge of the entire system as well as details on the status of mapping in a number of countries."

The evaluation also identified benefits of having a system where only a few individuals were at the helm. The close relationship between Sightsavers and the GTMP consortium allowed project leadership to find creative solutions to issues, especially when it came to funding. For example, Sightsavers had extended funds in advance of mapping to some NGOs. Sightsavers' willingness to take calculated risks, the evaluation noted, "was characteristic of the flexibility that Sightsavers has brought to the GTMP table." Other organizations had shared funds with partners to help continue mapping in areas with need as well.

Sightsavers and the GTMP took the midterm review seriously, "and really worked to change things. We put more emphasis on documenting our process, and put more emphasis on [McCullagh's] role as the project manager—we let her take the reins," said Solomon.

Following up with absent households also became a top priority for the GTMP and a focus of weekly survey team meetings. Because factors associated with follow up varied by region, an overarching solution was not possible; however, field supervisors stated that "close supervision in the first few days of a survey could encourage diligence in the recording and follow-up of absentees." At midterm, the GTMP had completed mapping in 924 districts.

Moving Past the GTMP

In 2014, a Zithromax production delay from Pfizer further highlighted the importance of having high-quality demand data; with an approximate 20% gap between Zithromax doses that had been requested versus what was immediately available, drug needed to be allocated carefully. Thanks to the GTMP, "[Pfizer] was able to work collaboratively with its partners using the GTMP data to keep countries on track toward their elimination targets," said Pfizer's Jenson. The scheduled end of the GTMP brought worries about the ability of countries to continue producing accurate data to inform the elimination goal and Zithromax applications and MDA support. According to one health official, "At the regional and national level, turnover happens so quickly, and doing things the exact same way as they have been done before isn't always possible—you lose documents or knowledge that people who leave take with them."

To mitigate this, ITI, Sightsavers, RTI, and WHO began collaborating on a new project called Tropical Data to support ministries with: impact surveys and surveillance surveys for 385 districts in 33 countries needed in 2015 or 2016; TT surveys; and baseline surveys where they had not been completed within the life of the GTMP (see **Exhibit 18** for the structure of the Tropical Data project).[39] Tropical Data was conceptualized as a "centralized, funded service that country programs could plug into free of charge to access scientific and technical guidance," said Millar.

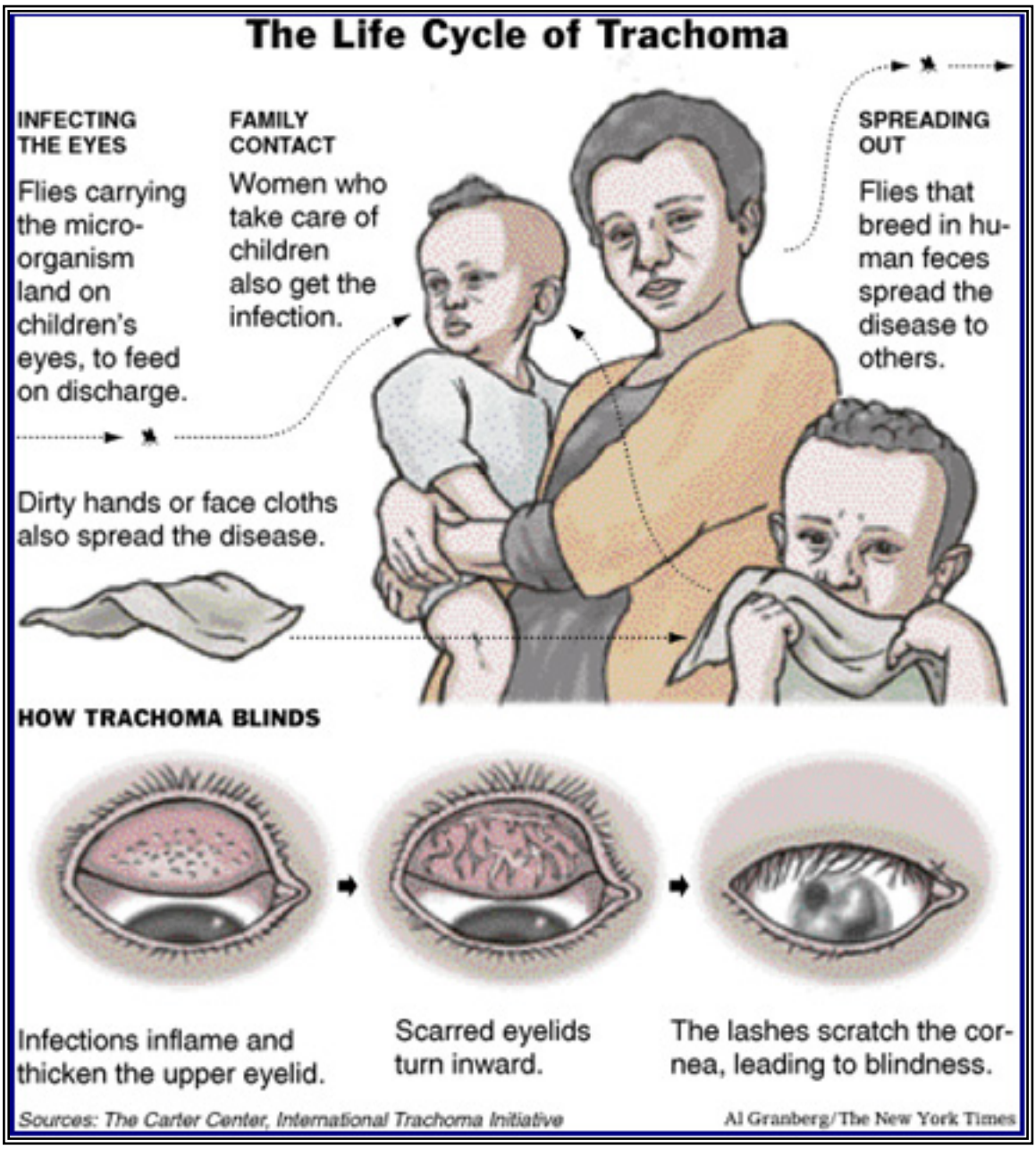
By October 2015, the GTMP had mapped 1,531 districts across 26 countries in Africa, Asia, and South America (95% of which were completed using full GTMP protocols; see **Exhibit 19** for results; see **Exhibit 20** for full list of partners involved). This represented examination of over 2.39 million people and informed the donation of over 466 million treatments of Zithromax.[1] Only 74 accessible districts in 10 countries had yet to be mapped by December 2015. Other districts were predicted to remain unmapped. According to Millar, the GTMP considered at least 96 districts inaccessible due to security concerns.

The Tropical Data consortium hoped to "avoid a situation in which impact and surveillance surveys are either not done at all, or are conducted using a variety of home-brew methodologies …[that] can be rejected by the Trachoma Exert Committee, resulting in the need for costly re-mapping," according to the proposal.[39] In addition, if the ITI Trachoma Expert Committee rejected data, Zithromax distribution could cease for the given region, which would be detrimental to the larger goal of trachoma elimination.[39]

Though still in the proposal phase in August 2015, Tropical Data represented an opportunity to ensure the GTMP's legacy. "The GTMP—standardized global disease mapping—is something that hasn't been done before. It's inspired countries and reminded them that they have the capacity to generate local solutions while meeting international benchmarks. It really goes beyond trachoma," said Millar.

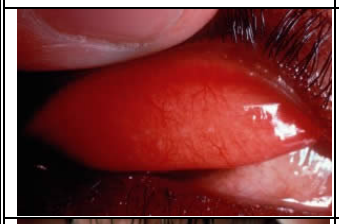
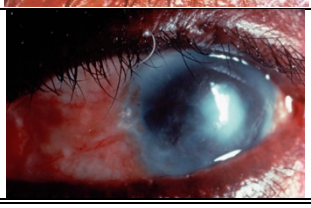
The GTMP was scheduled to end on December 31, 2015. According to Millar, "We have a long way to go to reach elimination and we have to stay focused to reach that deadline, or this will all have been for nothing."

Exhibit 1 *Life Cycle of Trachoma*



Source: The Carter Center/Al Granberg, International Trachoma Initiative. Available at http://www.neglecteddiseases.gov/target_diseases/trachoma/.

Exhibit 2 *Signs of Trachoma: WHO Simplified Grading Scheme*

Visual Example	Name/Definition	Clinical Characteristics
	**Trachomatous Inflammation – Follicular (TF)** Presence of five or more follicles in the central part of the eyelid.	**Average age**: 2–5 years old **Effects**: Asymptomatic
	**Trachomatous Inflammation – Intense (TI)** Pronounced inflammatory thickening of the conjunctiva that obscures more than half of the normal deep tarsal vessels.	**Average age**: 2–5 years old **Effects**: Asymptomatic or mild pain, possible discharge
	**Trachomatous Scarring (TS)** Presence of easily visible scarring in the tarsal conjunctiva.	**Average age**: 10+ years old **Effects**: Asymptomatic, or dry eye
	**Trachomatous Trichiasis (TT)** At least one eyelash rubs on the surface of the eye, or evidence of recent removal of inturned eyelashes.	**Average age**: 15+ years old **Effects**: Pain from eyelashes rubbing against cornea, photophobia, spasm of the eyelids
	**Corneal Opacity (CO)** Easily visible corneal opacity over the pupil.	**Average age:** 15+ years old **Effects:** Visual impairment, blindness

Source: Adapted from the Community Eye Health Journal. Available at: http://www.cehjournal.org/article/who-simplified-trachoma-grading-system/

Exhibit 3 *GET2020 Alliance Startup Members and Activities, 1997*

Organization	Regions of activity/support	Major activities
Al-Noor Foundation	Cairo, Egypt	Training programs for TT surgery
African Medical and Research Foundation	Southwest Kenya	Trachoma control
Christian Blind Mission	Western Pacific, Eastern Mediterranean, South East Asia, Africa, China, Vietnam, Afghanistan, Pakistan, India, Myanmar, Burkina Faso, Ethiopia, Ghana, Kenya, Niger, Nigeria, Tanzania, Uganda	Trachoma control, SAFE implementation
Edna McConnell Clark Foundation	Global	Financial support
French Ministry of Cooperation	Mauritania, Senegal, Mali, French Guinea, Côte d'Ivoire, Burkina Faso, Benin, Niger	Program support
Helen Keller International	Morocco, Tanzania, West Africa	Trachoma control
International Agency for the Prevention of Blindness	Oman, Morocco	Ministry coordination and advocacy
Internatioanl Eye Foundation	Guatemala, Guinea-Bissau, Malawi, Mozambique	Trachoma mapping
Organisation pour la Prévention de la Cécité	Africa, Southeast Asia	Trachoma control, surgical interventions
Sightsavers	Mali, The Gambia, Pakistan, Kenya	Program support
Swiss Red Cross	Nepal, Tibet, Ghana, Mali, and Burkina Faso	General eye care
University of Rome	Ethiopia	Trachoma control, trachoma mapping
The World Bank	Global	Financial support
WHO	Global	Promotion of SAFE, tools development, data management, setting of standards, representation of member states, secretary to the Alliance

Source: Adapted from WHO GET2020 Report, 1997. Available at: http://www.who.int/pbd/publications/trachoma/en/get_1997.pdf?

Exhibit 4 *Criteria the TEC Considers in Reviewing National Trachoma Programs' Zithromax Donation Applications*

1. The **prevalence** of trachoma based on existing information, recent population-based prevalence surveys.

2. An appropriate **treatment strategy** for the designated population group. The strategy for mass treatment is to administer Zithromax® to all eligible people in endemic areas (prevalence of TF > 10% in children 1–9 years of age).

3. The availability of **sufficient program resources** to continue treatment until such time as elimination is achieved. These resources may include:

- Competent and well-trained staff
- Transportation
- Appropriate Zithromax® storage facilities
- Plans for program monitoring and evaluation

4. The evidence of support for implementation of the **comprehensive SAFE strategy**. All components must be addressed in order to successfully apply for the drug donation and sustainably eliminate blindness from trachoma.

5. Making plans to inform and gain the **support of the community** to be treated through appropriate health education and social mobilization activities.

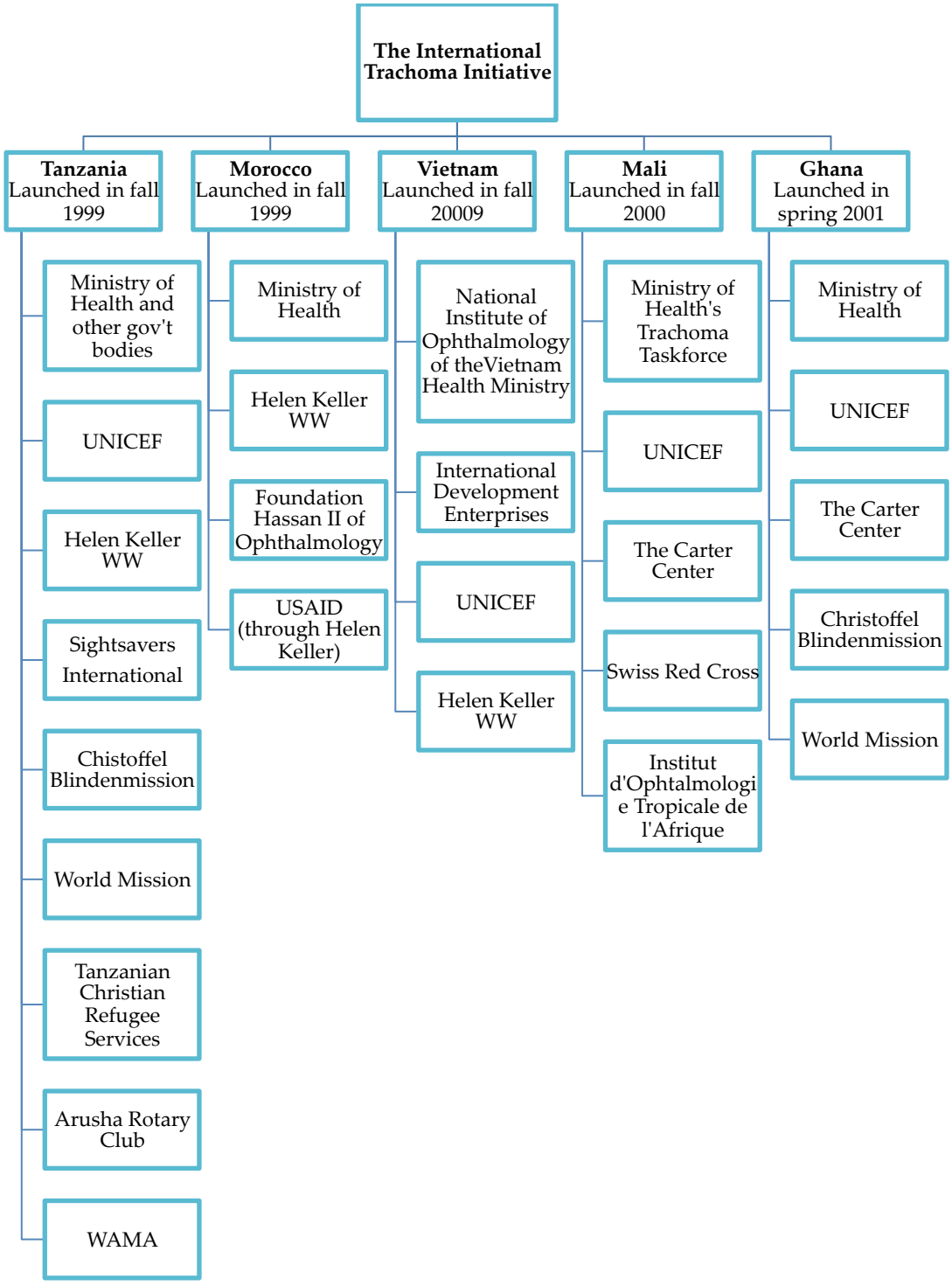
6. Ensuring that **health workers** and community-based drug distributors are **trained** and competent in such procedures as:

- Registering persons for treatment
- Identifying persons to be excluded from treatment
- Determining the correct Zithromax® dose based on weight or height
- Assuring that persons swallow the proper dose of the drug
- Providing adequate standby medical care for adverse drug experiences after treatment
- Monitoring for and reporting serious adverse experience

7. **Sustainability** and the possible integration of SAFE strategy activities within existing primary health care systems or other established health care activities.

Source: ITI. Available at: http://trachoma.org/applying-zithromax

Exhibit 5a *Proposed Partners for the International Trachoma Initiative, 1999*



Source: Barrett, D., J. Austin, and S. McCarthy. Cross-Sector Collaboration: Lessons from the International Trachoma Initiative. 1999.

Exhibit 5b *ITI Program Partners by Activity*

Implementation	Research	Advocacy
Christoffel Blindenmission Helen Keller Worldwide Ministries of health and other government sectors ORBIS International Sight Savers International The Carter Center UNICEF WaterAid WHO World Vision	Johns Hopkins University Worldwide Medical Research Council (UK) Children's Hospital Oakland Research Institute London School of Hygiene and Tropical Medicine Center for Educational Development in Health (Tanzania) University of California, San Francisco Health Research Unit (Ghana)	Global Health Council Vision 2020 International Development Enterprises BBC World Service Trust

Source: Adapted from Mecaskey J W, Knirsch C A, Kumaresan J A, Cook Dr J A. The possibility of eliminating blinding trachoma. The Lancet Infectious Diseases. November 2003; 3(11): 728–734. DOI: http://dx.doi.org/10.1016/S1473-3099(03)00807-7.

Exhibit 6 *Estimated Regional and Global Burden of Trachoma, 2003*

WHO Region	Population in 2000	Population living in endemic areas	TF/TI cases (all ages)	% Global burden of TF/TI cases
Western Pacific	1,404,434,386	688,897,001	28,601,516	33.7%
African	485,784,687	236,202,330	24,559,043	29%
South-East Asia	1,079,726,212	745,002,385	20,791,760	24.5%
Eastern Mediterranean	420,731,490	175,383,205	9,788,816	11.5%
The Americas	181,789,829	268,689	1,066,467	1.3%
TOTAL	3,572,466,604	1,845,753,610	84,807,602	100%

Source: Report of the 2nd Global Scientific Meeting on Trachoma. WHO, 2003. Available at http://www.who.int/entity/blindness/2nd%20GLOBAL%20SCIENTIFIC%20MEETING.pdf?ua=1

Exhibit 7 *Programmatic Goals and Activities of the International Coalition for Trachoma Control (ICTC)*

Our mission is to support trachoma control programs in endemic countries by acting as a catalyst for the implementation of the World Health Organization SAFE strategy.

Specifically, the ICTC:

1. Collects information on existing trachoma-related activities currently undertaken by International Non-governmental Development Organizations (INDGOs)
2. Promotes and supports coordination among INDGOs and partners to enable National Prevention of Blindness programs towards their Ultimate Intervention Goals
3. Shares information (programmatic and technical) about developments in trachoma control
4. Identifies, motivates and engages new partners in trachoma control efforts
5. Mobilizes resources, both individually and as a consortium, to support national programs in expanding the SAFE strategy
6. Advocates to raise awareness of the burden of trachoma and solutions available to address the problem at global, national, and local levels

Source: ICTC website. Available at: http://www.trachomacoalition.org/sites/default/files/ICTC-strategic-plan-2015-2020-FINAL.pdf

Exhibit 8 *Global Trachoma Mapping Project Logical Framework*

	Description	Indicators
Impact	Support the global elimination of trachoma by 2020	1. Percent TF in children ages 1–9 in all countries globally 2. TT cases per 1,000 population
Outcome	Trachoma globally mapped by 2015	1. Percentage completion of the *Global Atlas of Trachoma*
Inputs	Funds and support	1. USD 16.5 million, provided by DFID 2. DFID Advisor, Programme
Output 1	Baseline prevalence surveys completed in 1285 districts	1. Number of districts for which baseline mapping is completed 2. Technology tools developed for trachoma, trachoma and WASH, and NTD integrated mapping 3. Percentage of districts mapped with new tools
Output 2	1,100 surveyors and analysts trained	1. Number of surveyors and analysts trained for survey collection
Output 3	Effective programme management structure established and maintained	1. Number of steering committee members actively engaged in decision making 2. Number of implementing agencies actively mapping trachoma 3. M&E structures in place

Source: Allen, Nancy J. *Evaluation Report – Midterm Review of the GTMP*. June 2014.

Exhibit 9 *GTMP Advisory Committee and Working Group Members*

Advisory Committee	Allen Foster (Chair) Agatha Aboe Simon Brooker Paul Courtright Paul Emerson Danny Haddad Erik Harvey Silvio Mariotti Jeremiah Ngondi	Serge Resnikoff Anthony Solomon Sheila West ***Observers:*** Angela Weaver, USAID Nominee Iain Jones, DFID Nominee Tom Millar and Simon Bush, Sightsavers Nominees
Methodology Working Group	Simon Brooker Paul Emerson Katherine Gass Danny Haddad Jonathan King Chad MacArthur	Els Mathieu Beatriz Muñoz Erik Harvey Jeremiah Ngondi Stephanie Ogden Anthony Solomon
Prioritization working group	Simon Bush Paul Courtright Paul Emerson Allen Foster	Danny Haddad Richard Le Mesurier Silvio Mariotti Anthony Solomon
Tools Working Group	Erik Harvey Jonathan King Thomas Lietman	Joseph Pearce Anthony Solomon Sheila West
Training Working Group	Agatha Aboe Paul Courtright Jonathan King Susan Lewallen Chad MacArthur Silvio Mariotti	Els Mathieu Jeremiah Ngondi Anthony Solomon Jennifer Smith Sheila West
Ethiopia Pilot Team	Liknaw Adamu Wondu Alemayehu Menbere Alemu Berhanu Bero Paul Courtright Solomon Gadisa Teshome Gebre Zelalem Habtamu Amir Bello Kello	Richard Le Mesurier Susan Lewallen Addis Mekasha Tom Millar Alex Pavluck Virginia Sarah Alemayehu Sisay Anthony Solomon Jo Thomson

Exhibit 10 *Sample Size Calculations for the Global Trachoma Mapping Project*

Necessary Information

a) **The expected prevalence of TF in 1- to 9-year-old children**
b) **The desired precision of the estimate**
c) **Required alpha risk as z-score**
d) **Expected design effect multiplier**
e) **Nonresponse multiplier**

Calculation

Sample Size = =(a × (1-a) × c^2 × d × e)/b^2 = 1,222

Sources: (1) Kirkwood BR. Essentials of medical statistics. Oxford:Blackwell Science, 1988; (2) Solomon AW, Pavluck A, Courtright P, et al. The Global Trachoma Mapping Project: methodology of a 34-country population-based study. Ophthalmic Epidemiol 2015; 22(3): 214-225.

Exhibit 11 *Global Trachoma Mapping Project, Water, Sanitation, and Hygiene (WASH) Survey Question and Responses*

Question	**Possible responses**
In the dry season, what is the main source of drinking water for members of your household?	01=Piped water into dwelling 02=Piped water to yard/plot 03=Public tap/standpipe 04=Tube well/borehole 05=Protected dug well 06=Unprotected dug well 07=Protected spring 08=Unprotected spring 09=Rainwater collection 10=Water vendor 11=Surface water (e.g. river, dam, lake, canal) 99=Other (specify)
How long does it take to go there, get water, and come back?	1=Water source in the yard 2=Less than 30 minutes 3=Between 30 minutes and 1 hour 4=More than 1 hour

Source: Courtright P, Gass K, Lewallen S, et al. Global trachoma mapping project: training for mapping of trachoma (version 3). London: International Coalition for Trachoma Control; 2015.

Exhibit 12 *Estimated Trachoma-Endemic Districts and TT Burden by Country in 2011*

Country	Total number of districts	Confirmed endemic districts[1]	Suspected endemic districts[2]	TT burden: Best available estimates (# of cases)
Afghanistan	368	—	58	83,100
Algeria	1,544	1	51	86,700
Australia[3]	(See note)	—	—	1,100
Benin	77	—	—	7,600
Botswana	25	—	—	32,900
Burkina Faso	63	30	—	23,000
Burundi	45	4	—	746
Cambodia	183	—	74	7,559
Cameroon	178	13	23	47,200
CAR	51	—	21	1,000
Chad	14	—	8	34,300
Côte d'Ivoire	58	—	—	—
Djibouti	6	—	—	50—100
Egypt	26	2	3	35,400
Eritrea	58	8	11	15,238
Ethiopia	649	209	434	1,100,000
Fiji	—	—	—	800
Ghana	137	—	—	4,000
Guatemala	—	—	—	25,100
Guinea	38	15	—	25,528
Guinea Bissau	—	20	38	7,361
Iran	—	—	—	43,900
Iraq	102	—	—	43,900
Kenya	80	5	10	67,253
Kiribati	—	—	—	900
Laos	—	—	—	13,200
Libya	—	—	—	33,400
Malawi	27	2	5	33,400
Mali	61	10	—	37,943
Mauritania	53	3	—	1,017
Mexico	2,422	—	—	—
Morocco	46	—	—	—
Mozambique	131	3	72	60,500
Myanmar	65	1	—	65,800
Namibia	107	—	—	6,100
Nauru	—	—	—	—
Nepal	75	10	15	42,886
Niger	42	23	—	58,870
Nigeria	774	79	209	1,291,001

Oman	61	—	—	600
Pakistan	133	-	31	71,700
Papua New Guinea	—	—	—	—
Senegal	34	13	12	91,500
Solomon Islands	—	—	—	500
Somalia	74	—	—	10,300
South Sudan	80	26	28	91,245
Sudan	133	3	37	67,799
Tanzania	121	43	—	130,000
The Gambia	41	7	—	—
Togo	30	—	—	2,900
Uganda	80	22	6	167,538
Vanuatu	—	—	—	210,000
Viet Nam	659	—	—	100,000
Yemen	333	2	111	270,800
Zambia	72	5	36	8,500
Zimbabwe	59	—	—	—
Brazil	5,564	38	—	58,000
China	256	—	—	2,330,600
India	565	2	198	443,000

[1] >10% prevalence of TF from district-level population-based prevalence surveys.

[2] >10% prevalence of TF from district-level TRA/other survey type, >10% prevalence of TF from region-level surveys, or classified as suspected endemic by Ministry of Health.

[3] Indigenous populations in Australia are spread over 80 confirmed and 238 suspected communities; this is estimated to be the equivalent of 5 and 15 districts in cost and intervention.

Source: International Coalition for Trachoma Control, 2011. *The End in Sight 2020*.

Exhibit 13 *Three-Level Training Cascade for Global Trachoma Mapping Project Graders*

GTMP Master Grader	1. Experience teaching clinical delivery 2. Experience in trachoma surveys 3. Kappa ≥ 0.80 in inter-grader agreement test against the GTMP Chief Scientist 4. Participation in two grader workshops
GTMP Grader Trainer	1. Experience teaching clinical delivery 2. Kappa ≥ 0.80 in inter-grader agreement test against a GTMP Master Grader 3. Participation in one grader workshop
GTMP Grader	1. Background in medicine or nursing, or equivalent experience 2. Kappa ≥ 0.70 in inter-grader agreement test against a GTMP Grader Trainer 3. Participation in one grader workshop

Source: Created by case writers using interviews with GTMP leadership.

Exhibit 14 *Binocular Loupes and Light, as Used in the GTMP*

GTMP Grader Genemo Abdela examining a child for trachoma in Ethiopia.

Source: Courtright P, Gass K, Lewallen S, et al. Global trachoma mapping project: training for mapping of trachoma (version 3).London: International Coalition for Trachoma Control; 2015.

Exhibit 15a *Partners Involved at Midterm of the GTMP, February 2014*

Ethiopia partners	Nigeria implementing partners	Other implementing partners
The Fred Hollows Foundation* ITI Orbis Light for the World AMREF Johns Hopkins University	Helen Keller International Christian Blind Mission Sightsavers Mitosath	Malawi: BICO South Sudan: Light for the World Egypt: Al-Noor Foundation Mozambique: Sightsavers

*Coordinating partner

Source: Allen, Nancy J. Evaluation Report – Midterm Review of the GTMP. June 2014.

Exhibit 15b *Countries Involved in the GTMP by Mapping Stage, February 2014*

Completed regions	In progress and nearing completion	Training scheduled	Planning in progress
Ethiopia (10 Districts) Nigeria (9 states) Fiji* Cameroon Solomon Islands	Yemen (Phase 2) Malawi (Phase 2) Laos* (Phase 2) Mozambique** (Phase 2) Nepal* (Phase 1)	Senegal Eritrea Benin Guinea South Sudan Sudan Uganda Chad Cambodia	Egypt Côte d'Ivoire CAR DRC Eritrea Tanzania Zambia Afghanistan Algeria Vanuatu Colombia
Approximately 1,000 districts		Approximately 700 districts	
*USAID funded **Funded by USAID and DFID			

Source: Allen, Nancy J. Evaluation Report – Midterm Review of the GTMP, June 2014.

Exhibit 16 *Survey Cost per District at Midterm, February 2014*

Country	Region or state	Number of districts	Average cost per district (USD)
Ethiopia	Afar	25	6,150
	Oromia	151	2,412
	SNNPR	106	7,419
	Somali	27	13,407
	Tigray	34	5,894
Malawi	Southern & Central Region	12	5,894
Nigeria	Federal Capital Territory	6	8,750
	Jigawa	4	9,792
	Kaduno	23	5,347
	Kano	44	5,049
	Katsina	34	5,088
	Niger	25	4,977
Total/Average		**591**	**USD 5,131**

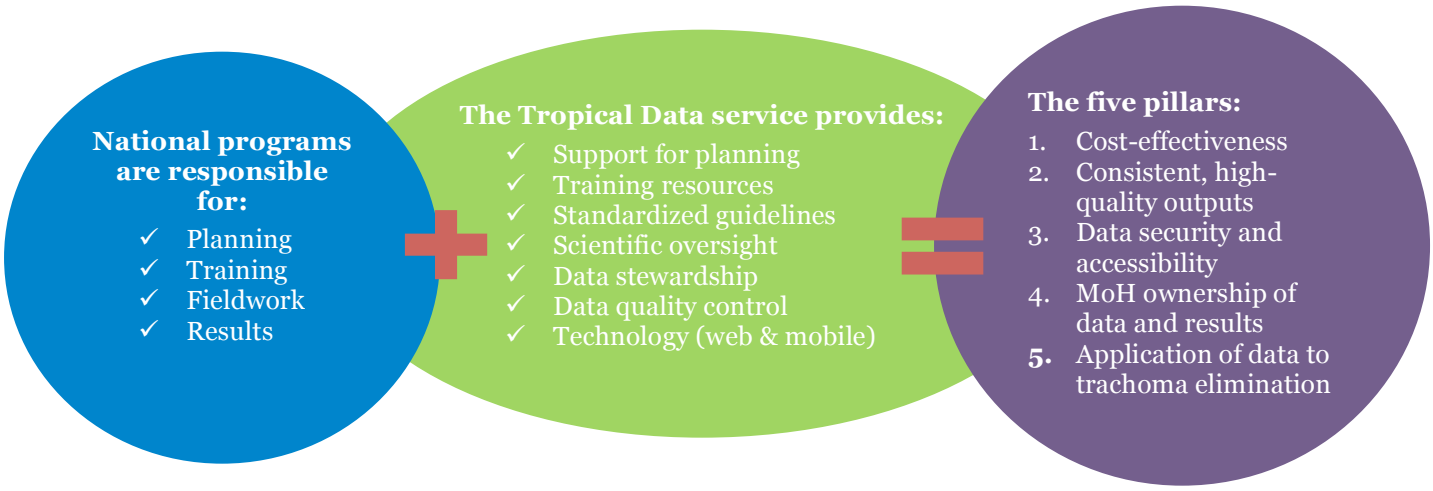
Source: Allen, Nancy J. Evaluation Report – Midterm Review of the GTMP. June 2014.

Exhibit 17 *Original and Expanded Scope of the Global Trachoma Mapping Project*

	Mapping goal (2013–2014): Total: 1,285 districts, 104.3 million		**Mapping goal (by 2015):** Total: 1,805 districts, 155.5 million	
	Mapping complete	**Mapping deemed not necessary**	**Mapping complete**	**Mapping deemed not necessary**
Districts	649	64	275	5
People (in millions)	81.20	6.41	32.12	0
	Total: 1,738 districts, 149.1 million people			

Source: Allen, Nancy J. *Evaluation Report – Midterm Review of the GTMP*. June 2014.

Exhibit 18 *Tropical Data Programmatic Design*



Source: Tropical Data proposal, 2015.

Exhibit 19 *Global Trachoma Mapping Project Results, October 2015*

Mapping Goal:
Total: 1,805 districts

	Mapping complete	Mapping incomplete due to insecurity
Total Districts	1531	296
Districts in Africa	1,176	153
Districts in Mediterranean, Asia, Pacific, and South America	355	143

Source: Global Trachoma Mapping Project.

Exhibit 20 *Global Trachoma Mapping Project Partners, Complete List*

Organizations	AMREF Barraqua Institute BICO Brien Holden Institute The Carter Center College of Ophthalmology & Allied Vision Sciences The Fred Hollows Foundation FHI 360 Helen Keller International International Coalition for Trachoma Control	International Trachoma Initiative (The Task Force for Global Health) Johns Hopkins University Kilimanjaro Centre for Community Ophthalmology Light for the World (Austria) Light for the World (Netherlands) London School of Hygiene & Tropical Medicine	Magrabi Foundation Mitosath ORBIS Organization for the Prevention of Blindness (OPC) Organización Panamericana de la Salud (PAHO) RTI Sightsavers World Health Organization
Ministries of Health	Benin Cambodia Chad Colombia Côte d' Ivoire Democratic Republic of Congo Egypt Eritrea Ethiopia Fiji Guinea Kiribati	Laos Malawi Mexico Mozambique Pakistan Papua New Guinea Nigeria Republic of Congo Senegal Solomon Islands Sudan Tanzania	Uganda Vanuatu Zambia Zanzibar Zimbabwe Yemen (In addition, ministries of health in Cameroon and Nepal conducted baseline mapping projects during the life of GTMP without the use of GTMP methods.)
Funders	DFID USAID		

Source: Sightsavers, International. Available at: http://www.sightsaversusa.org/about_us/press_center/Global_Trachoma_Mapping_Project.html

Appendix I *Commonly Used Acronyms and Abbreviations*

CDC	US Centers for Disease Control and Prevention
CO	corneal capacity
DFID	UK Department of International Development
GET	Global Elimination of Trachoma
GTMP	Global Trachoma Mapping Project
ICTC	International Coalition for Trachoma Control
IGA	inter-grader agreement
ITI	International Trachoma Initiative
MDA	mass drug administration
MOH	Ministry of Health
MOU	memorandum of understanding
NGO	nongovernmental organization
NTD	neglected tropical disease
SAFE	trachoma control strategy (*S*urgery/*A*ntibiotic/*F*acial cleanliness/*E*nvironmental improvement)
SOW	scope of work
TEC	Trachoma Expert Committee
TF	trachomatous inflammation–follicular
TI	trachomatous inflammation
TRA	Trachoma Rapid Assessment
TS	trachomatous conjunctival scarring–intense
TT	trachomatous trichiasis
UK	United Kingdom
UN	United Nations
US	United States
USD	United States Dollars
WASH	water, sanitation, and hygiene
WHO	World Health Organization

Appendix II *Key Definitions*

Azithromycin	An azalide antibiotic, often administered as a single dose to treat active trachoma. It is the WHO-recommended drug for treatment of active trachoma. Zithromax is the Pfizer brand name for azithromycin.
Cluster random sampling (CRS)	A type of population-based prevalence survey used for the Global Trachoma Mapping Project. In CRS, non-overlapping subpopulations (clusters) within geographical or political boundaries are selected, and then eligible participants are selected within each cluster.
Corneal opacity (CO)	Easily visible corneal opacity over the pupil.
Coordinating agency	The GTMP coordinating agencies worked closely with national health ministries and built an in-country NGO support network for training and mapping. They also acted as liaisons between implementing partners and the MOH.
District	The term "district" is often defined locally in different ways in different countries, but for trachoma elimination purposes it referred to the usual administrative unit for health care management (around 100,000–250,000 persons).
Elimination	Reduction to zero of the incidence of a specified disease in a defined geographical area as a result of deliberate efforts; continued intervention measures are required. In the case of trachoma, elimination would be the reduction of cases of blindness from trachoma to zero.
Endemic	Regularly found among particular people or in a certain area.
Eradication	Permanent reduction to zero of a specific pathogen, as a result of deliberate efforts, with no more risk of reintroduction.
Evaluation unit	The geographical and demographical unit in which a GTMP population-based prevalence survey was conducted.
GET2020	Global Elimination of Trachoma by the year 2020.
Grader	A health professional trained in grading trachoma using the WHO simplified trachoma grading scheme.
Implementing agency	Implementing agencies worked at national or subnational levels to ensure that the infrastructure, trained staff, transport and supervision were in place to deliver training and mapping. Implementing partners were responsible for creating budgets for mapping activity and seeking approval from Sightsavers and the technical team.
Indicator	A signal that shows an outcome or impact of interest has been reached.
Inter-grader agreement	The degree to which two or more graders report the same observed values after measuring the same events; used within the GTMP to validate training. It is most often calculated using a kappa statistic, with a value between –1 and +1 (–1 indicating complete disagreement, and +1 indicating perfect agreement).
Kappa statistic	Cohen's Kappa is a statistical coefficient that measures agreement between two sets of measurements for categorical items. The statistic is considered useful because it takes into account agreement occurring by chance.
LINKS	An android-based electronic data capture tool used by the Global Trachoma Mapping Project.

London Declaration on NTDs	A commitment statement to increase support for measures against neglected tropical diseases (NTDs) that was announced on January 30, 2012 in London. It was inspired by the World Health Organization 2020 roadmap to eradicate, eliminate, and control NTDs.
Mass drug administration (MDA)	The administration of drugs to entire populations to control, prevent, or eliminate a disease.
Millennium Development Goals (MDG)	The world's time-bound and quantified targets for addressing, by 2015, extreme poverty in its many dimensions—income poverty, hunger, disease, lack of adequate shelter, and exclusion—while promoting gender equality, education, and environmental sustainability.
Memorandum of understanding (MOU)	A formal agreement between two or more parties. Companies and organizations can use MOUs to establish official partnerships, as in the case of the GTMP and National Programs. MOUs are not legally binding but they promote commitment and mutual respect.
Neglected tropical disease (NTD)	A diverse group of diseases with distinct characteristics that thrive mainly among the poorest populations. The 17 NTDs prioritized by WHO are endemic in 149 countries and affect more than 1.4 billion people.
Population-based prevalence survey	The "gold standard" for estimating the prevalence of trachoma within a target population. The most commonly used population-based survey design for trachoma prevalence estimation is cluster random sampling.
Prevalence	Proportion of a population with a given disease or condition
SAFE strategy	The strategy recommended for trachoma elimination by WHO. It stands for *S*urgery, *A*ntibiotics, *F*acial cleanliness, and *E*nvironmental improvement, which are methods used in combination for trachoma elimination. It was developed in the 1990s by the Edna McConnell Clark Foundation, WHO, and other partners.
Scope of work agreement (SOW)	A formal document that specifies all the criteria of a contract between a service provider and the customer, in this case the GTMP, National Programs, and implementing agencies. It clearly documents the project requirements, milestones, deliverables, and end products that are expected.
Tarsal conjunctiva	The lining of the human eyelid.
Tetracycline	A broad-spectrum polyketide antibiotic, often administered as a topical ointment used to treat active trachoma. It was the drug of choice for treating active trachoma until the discovery of azithromycin.
Trachomatous inflammation – follicular (TF)	Presence of five or more follicles, each at least 0.5mm in diameter, in the central part of the upper tarsal conjunctiva
Trachomatous inflammation – intense (TI)	Pronounced inflammatory thickening of the tarsal conjunctiva that obscures more than half of the normal deep tarsal vessels.
Trachoma Action Plan (TAP)	A document that lists the steps country programs must take to eliminate the infectious eye disease that causes blindness. During a TAP workshop, participants analyze available trachoma data, including whether suspected endemic areas have been surveyed, what the prevalence levels are, and

	whether highly endemic areas are ready and able to distribute donated Zithromax.
Trachoma Atlas	The *Atlas* aims to consolidate published and unpublished data at the district level and provide up-to-date country maps of trachoma distribution on an open-access platform.
Trachomatous scarring (TS)	The presence of easily visible scarring in the tarsal conjunctiva.
Trachomatous trichiasis (TT)	At least one eyelash rubs on the eyeball, or there is evidence of recent removal of in-turned eyelashes.
Vector-borne transmission	Vectors are living organisms that can transmit infectious diseases between humans or from animals to humans.
WASH	*W*ater, *S*anitation, and *H*ygiene. See **Appendix IV** for a history of WASH.

Appendix III *Disease Elimination Efforts*

Smallpox

Smallpox was the only human disease to be eradicated as of 2015, and its eradication was the result of over 200 years of effort by governments and countless NGOs.

As early as 1796, physicians recognized the efficacy of using cowpox to protect against smallpox infection. Soon after in 1800, Dr. John Clinch introduced the smallpox vaccine in Trinity, a small coastal town in Newfoundland, Canada.[40] A heat-stable, one-dose vaccine was developed for smallpox and administered en masse cheaply and effectively.[41] The arrival of the vaccine heralded the beginning of worldwide vaccination and prevention efforts, but distrust in the vaccination and high indigenous population prevalence stifled coverage.[21]

By the turn of the 20th century, Britain, the US, and other European countries had enacted legislation that made vaccination for smallpox mandatory. As a result, smallpox was eradicated throughout much of the developed world, but pockets of the disease persisted in developing countries and in underserved populations, especially indigenous peoples.[42]

The first international eradication effort took place in 1950 with the Pan American Health Organization, which successfully eradicated smallpox in all American countries except for Argentina, Brazil, Colombia, and Ecuador.[21] In 1959, WHO undertook a global initiative to eradicate the disease in the remaining endemic regions, and intensified its efforts in 1967 by contributing USD 2.4 million annually toward mass vaccination and containment; by 1975, smallpox persisted only in the horn of Africa.[42] The last naturally occurring case of smallpox occurred on October 26, 1977.[41] The smallpox eradication campaign celebrated its eradication goal on May 8, 1980 at the 33rd World Health Assembly.

Surveillance was a key part of the containment strategy developed by Dr. William Foege. "Know the truth"—where the virus is, Foege insisted, "because that is the only way you can contain it." Dr. Mark Rosenberg, head of the Task Force for Global Health and former US assistant surgeon general, explained, "For smallpox, you didn't have to do [disease] mapping because you just look for people with the blisters. The disease declares itself, so it was easy to find the virus."

Onchocerciasis

Onchocerciasis, also called "river blindness," is caused by a parasitic filarial worm and commonly causes blindness in infected individuals.[43] It is the second leading infectious cause of blindness worldwide. In 1995, WHO estimated that 120 million people in Africa and the Americas were at risk for infection; 17.6 million were suspected to be infected.[44] Though onchocerciasis primarily affects rural populations, in Africa, the disease has "been found to cause serious socio-economic problems; populations have in the past abandoned fertile land along the rivers … whilst persons with unsightly lesions have been socially marginalized."[45]

The Onchocerciasis Control Program (OCP) was officially formed in 1974 as a collaboration between WHO, the World Bank, UNDP, and the Food and Agriculture Organisation, all groups nested within the United Nations (UN). After working exclusively on vector control for many years using larvicide (killing black flies that carry the parasite), in 1987 Merck & Co. donated Mectizan (ivermectin) to treat the disease. The control strategy shifted to larviciding combined with mass administration (MDA) of ivermectin treatment or mass ivermectin treatment alone.[46]

In 1992, the International Task Force for Disease Eradication concluded that onchocerciasis could not be eliminated. However, it determined the disease could be controlled to the point that it would not pose a risk to public health.[47] When WHO reevaluated the feasibility of onchocerciasis elimination in 2001, it concluded that while the situation in Africa remained the same, onchocerciasis could be eliminated in the Americas.[47] Following this announcement, WHO decided to focus on regional eradication of onchocerciasis and began garnering the support of partner organizations.[45]

Three regional programs worked toward elimination using vector control and MDA, using geographical features and sampling to plan interventions: the Onchocerciasis Control Program of West Africa, supported by the WHO; the African Programme for Onchocerciasis Control, supported by WHO and the Gates Foundation; and the Onchocerciasis Elimination Program for the Americas, supported by the Carter Center.[48]

Merck donated all the Mectizan needed.[1] The program relied on a tool called the Rapid Epidemiologic Mapping of Onchocerciasis (REMO) to inform drug distribution efforts.[49] As WHO described, "REMO uses geographical information—particularly the presence of river basins—to identify communities likely to be at high risk of infection. A sample, representing 2–4% of villages in the area, is then quickly assessed for the presence of onchocerciasis by feeling for the sub-cutaneous worm nodules in 50 adults per village."[49]

The OCP reduced the burden of onchocerciasis infection greatly. According to WHO, it prevented 600,000 cases of blindness, spared 18 million children from the risk of river blindness, and made 25 million hectares of land safe for cultivation and resettlement.[46]

With such strong initial success, the OCP lost some momentum by 2016. Little was invested in developing new tools for disease control, and heavy reliance was been placed on the distribution of Mectizan. According to Basanez et al, "annual [Mectizan] regimes are not considered sufficient to achieve local elimination of parasite populations, unless very high therapeutic coverage (more than 80 percent of the total population) is achieved for at least 25 years without loss of treatment efficacy."[44]

Guinea Worm

Guinea worm disease (dracunculiasis) is a disease caused by a parasitic round worm that can only be transmitted through contaminated drinking water. The disease is characterized by emergence of the worm, up to a meter long, from lesions on the legs or arms after a year of incubation and mating inside the abdomen.[50] Guinea worm disease usually is not fatal but causes extreme pain at the lesion site and, in some cases, permanent disability.[51]

While no vaccine or medication existed to treat Guinea worm, the International Task Force for Disease Eradication considered the disease a prime target for elimination.[51] Filtration of contaminated water and preventing infected individuals from entering water sources have proven to be extremely effective at preventing Guinea worm infection.[51] The Guinea Worm Eradication Program (GWEP) started at the Centers for Disease Control in 1980.[52] The eradication target for Guinea worm was set for 2009.

In 1981, the UN began its *International Drinking Water Supply and Sanitation Decade* and saw Guinea worm eradication as a prime indicator of success. The WHO released a 1982 Dracunculiasis Surveillance Report in 1982, and in 1986, the Carter Center took the lead for the Guinea worm eradication effort in partnership with the CDC, WHO, and UNICEF.[52] Their strategy was to work with ministries of health to prevent the spread of disease by providing health education and helping maintain political will in affected areas. Specific interventions "aimed at increasing access to safe drinking water … and health education and community-involvement."[50]

In 1986, the WHO estimated Guinea worm affected 3.5 million people a year in 20 countries across much of Africa and Asia. However, due to poor documentation, only 9,585 cases were recorded.[52]

To understand the burden of disease and where to focus efforts, a "village-by-village" assessment was necessary.[53] Searches were conducted throughout much of the late 1980s and early 1990s, and were undertaken in countries of suspected endemicity, as determined by the early WHO report.[53,51] The nationwide village searches took about 1–4 weeks, and utilized brief questionnaires and "recognition cards," which featured pictures of typical emerging worms.[53] After a village was identified to have Guinea worm, an individual was designated to supply monthly reports of Guinea worm cases.

In 2015, only 22 cases of Guinea worm were reported (in Chad, Ethiopia, Mali, and South Sudan).[51] Though the eradication goal was not met, reported cases have continued to decline. Insecurity continues to be a problem for the Guinea worm campaign in areas of South Sudan and Mali.[51]

Appendix IV *Water, Sanitation, and Hygiene (WASH) in Trachoma Elimination*

Water, sanitation, and hygiene (WASH) is a public health concept first developed in the mid-20th century. The three areas of focus are grouped under the acronym due to their interrelatedness and importance to international development and global health as a whole.[54] According to the WASH Advocates organization, "Access to WASH is a basic human right, and lack of access is not only an injustice but is detrimental to economic productivity, childhood survival, public health, education, environmental conservation, climate resilience, and much more."[55]

Throughout much of the 1980s and 1990s, governments and NGOs advocated for the importance of WASH in health and development, but they rarely addressed the individual services in an integrated and comprehensive way. Grouping the services together is a relatively recent practice.[54] In 1981, the UN established the "International Drinking Water Supply and Sanitation Decade" to focus on integrating water, sanitation, and hygiene interventions.[54] In 1990, the UN established the Water Supply and Sanitation Collaborative Council (WSSCC), devoted solely to the promotion of WASH activity.[54]

The 21st century saw WASH gain prominence as a universal issue and concept in global health and development.[56] WASH was noted in the UN's Millennium Development Goals in 2000, which shaped the agendas of international development and health interventions for many nations and organizations worldwide.[54] Under Goal 7 of the MDGs, the UN mandated that countries "halve, by 2015, the proportion of people without sustainable access to safe drinking water and basic sanitation."[57]

In 2016, many diseases were considered WASH-related, including waterborne diarrheal disease, neglected tropical diseases (NTDs), schistosomiasis, soil-transmitted helminthes, and trachoma.[32] WASH activity includes education on hygiene behavior and proper sanitation methods; environmental capacity building to ensure that clean, safe drinking and bathing water is used by vulnerable populations; and direct health intervention to build sanitation facilities, including latrines, hand-washing stations, and schools where WASH education can occur.[54]

WASH services and NTD incidence are highly correlated.[18] Despite this, integrating strategies to address both has proven difficult, as most organizations address only one of the two.[54]

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