# Navigating the Path to Elimination:

Lessons from Lymphatic Filariasis and Trachoma Dossiers

# CONTEXT

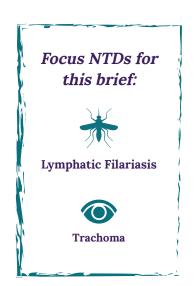
In the late 1990s, the World Health Assembly adopted resolutions targeting the global elimination of the diseases lymphatic filariasis (LF) and trachoma as public health problems. Tremendous progress has been made since then, with 19 countries eliminating LF and 18 countries eliminating trachoma.<sup>1,2</sup>

To validate elimination of a neglected tropical disease (NTD) as a public health problem, World Health Organization (WHO) Member States must follow a standardized five-step process to summarize their achievements in a dossier (Figure 1).

Since 2014, USAID has supported Ministries of Health (MOH) in the preparation and submission of dossiers. This support has resulted in dossier submission and validation of elimination by WHO in Bangladesh (LF), Cambodia (trachoma), Nepal (trachoma), People's Democratic Republic of Lao (LF and trachoma) and Viet Nam (LF). Act | East has also helped governments prepare draft dossiers for LF or trachoma in an additional 7 countries.

These countries' experiences developing and submitting dossiers underscore the importance of initiating data compilation early, strategizing to address remaining data gaps, and planning for government review and approval.

This brief provides a summary of best practices and common challenges for countries preparing dossiers—lessons gathered from dossier submission work in Act | East supported countries.





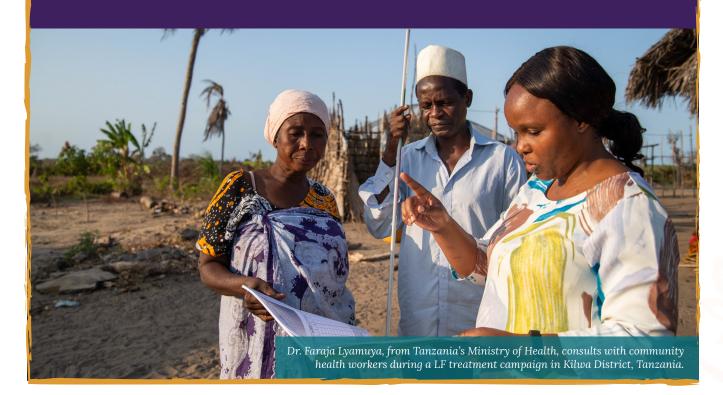




# **KEYS TO SUCCESSFUL DATA MANAGEMENT**

Preparing an elimination dossier involves gathering, synthesizing, and summarizing significant quantities of data. Some challenges to successful data management include:

- Data gathering: Gathering certain types of data can be involve more steps than others, especially when data must be obtained from outside trachoma or LF programs, e.g., facial cleanliness and environmental improvement (F & E) data for trachoma elimination. In decentralized countries, the task can be more challenging, because district or local data might not be available at national level. Countries with long-running programs may have data stored in multiple offsite locations like storage facilities or archives.
- **Data documentation:** Historical knowledge can be lost with changes in MOH personnel, so timely documentation of activities and outcomes (as they occur) must be prioritized.
- Data security and archiving: Data can be lost if not archived and stored correctly, e.g. data loss due to weather conditions degrading equipment and files.
- **Data review:** Compiling, reviewing, and cleaning historical data can be time-consuming, particularly for decades-long programs.
- Data gaps: If missing or incomplete data are identified, national programs need time to clarify or gather more data. Sometimes, districts previously classified as non-endemic, based on an absence of clinical cases or no historic evidence of transmission, may need to undergo further investigation. If these are found to be endemic, there could be a significant delay in dossier submission and validation while steps are taken to assess the suspected areas.



# APPROACHES FOR DEVELOPING DOSSIERS

The process of preparing a dossier is unique for each country and depends on the disease burden, the duration of program implementation, the status of data archiving, and MOH leadership. Dossier preparation can take from 1 to 10 years based on factors like how early a country begins, the quality of data storage, and internal government review processes.

Developing a draft dossier can involve **some or all** of the approaches below, depending on country context.

### Ministry of Health Working Group

- The MOH establishes a working group to oversee the writing of the dossier narrative and the compilation of dossier data.
- A 1-day or half-day meeting may be hosted with relevant government officials and partners at the beginning of the dossier development process to outline achievements and next steps. Follow-up meetings may be held annually.

### **Dossier Workshops**

- MOH personnel and partners host a 1- to 3-day workshop to introduce each section of the dossier and review the data needed to begin drafting the narrative dossier.
- A consultant or working group continues the process of drafting the dossier.

#### Champion

- A dossier champion can be someone within the MOH or a national or regional expert engaged through a consultancy, tasked with developing the draft dossier.
- Typically, the champion spends one to two weeks with the MOH, gathering data and collaborating with personnel, and one to two weeks drafting the dossier.
- MOH personnel review and update the draft dossier on an annual basis until it is ready for submission to WHO.

# FIGURE 1. PROCESS FOR VALIDATION OF ELIMINATION AS A PUBLIC HEALTH PROBLEM

Preparation of elimination dossier for submission, using WHO narrative and data

templates

Submission of the dossier from the Ministry of Health to WHO, through the WHO Country Representative

**Deliberation** of the dossier by an ad hoc reviewing authority (Dossier Review Group, [DRG]) convened by the WHO Regional Office

Generally takes 3-6 months, though can take longer

Recommendation to acknowledge the claim of elimination as a public health problem or postpone the

decision pending revisions

**Validation** is achieved, countries implement post-validation activities to ensure achievements are sustained, *i.e.*, continued surveillance and morbidity management

**⊗** 

Decision is postponed & dossier revised



.....

Claim is validated

# LESSONS FROM DEVELOPING DOSSIERS

We have compiled the following lessons from experience supporting elimination validation efforts, serving on Dossier Review Groups, and dossier development in African, South-East Asian, and Western Pacific Regions.

Although each dossier preparation process is unique, the following list of lessons and real-world examples may help others respond to common challenges.



# **START EARLY**

It is never too soon to start developing the dossier. The process of gathering, reviewing, and cleaning historical data—sometimes dating back more than 20 years—can be unwieldy. If the dossier process is started too late, staff turnover can mean loss of key historical knowledge. Historical program data may be stored in offsite facilities or archives and may take time to access. Most importantly, if data gaps are found, national programs need time to fill them.

Integrate activities, revisit regularly. To save time and resources, identify opportunities to integrate dossier preparation discussions into routine NTD program meetings or annual reviews. Take advantage of opportunities to inform key decision makers about the requirements and process. Plan to update the dossier draft and review annually.

**Be holistic.** Elimination of both LF and trachoma requires national programs to address aspects of morbidity and disability. Early dossier preparation can be a good reminder of all the required elements and may help garner the political will to start or advance these activities.



# **ALLOCATE RESOURCES**

**Identify a champion.** Determine who will lead the dossier preparation process to ensure it moves forward. Stakeholders, including the NTD Program Manager at the MOH, can help this champion be successful by providing local context and connections with technical experts.

**Think longer term.** The dossier preparation process is useful for long-term planning for surveys and post-validation surveillance activities. Countries are using this process to map the way to elimination and plan for the resources that will be required to ensure elimination is sustained.



# **FILL DATA GAPS**

Additional work is needed when data gaps are identified, especially where new guidance is available or where mapping results are unclear. The earlier the national program starts to look at the dossier requirements, the sooner it can take the necessary measures to clarify the data or gather more data.

**Integrate activities where possible.** When assessing facility readiness to manage existing clinical cases of

LF or trachoma, a Direct Inspection Protocol survey might be integrated into program evaluation surveys (TIS/TSS or TAS/IIS). Integrating these surveys can save financial and human resources and emphasize the connection between elimination activities and long-term support for patients affected by these diseases.





# **KEEP IT SHORT**

WHO dossier templates have page limits that should be adhered to. This helps reviewers assess the most relevant information and review dossiers in a timely manner. Where programs have extra data, context, or history to share, take advantage of the annexes.



# MAKE A PLAN FOR REVIEWS AND APPROVALS

Governments may require multiple levels of review or may require approvals to be made in national language versions. Make time early in the dossier development process to agree on clear steps and timelines for final reviews and internal government approvals.

Request an informal review. WHO technical experts can review a dosser draft once all data are included, prior to formal submission. Receiving WHO comments

prior to submission can help ensure that the final dossier includes the quality data needed for validation. This also helps WHO plan for the DRG review process.

Prepare to respond. Be ready to respond quickly to questions from the DRG as they review the dossier. This involves keeping data organized and having technical experts available to respond to questions.



# **COORDINATE ANNOUNCEMENT**

The elimination of LF or trachoma is an important opportunity to celebrate national achievements and global NTD progress. Ahead of pending eliminations, develop a press release, social media posts, photos, and blogs to cover the various activities that led to

elimination success. Collaboration with the WHO Regional Office, WHO Geneva, and all stakeholders is needed to coordinate timing and activities for the announcement. A press and social media kit can be shared with partners to amplify the success.

# **COUNTRY EXPERIENCES AND LESSONS**



LF

#### LAO PDR



- Lao People's Democratic Republic (PDR) MOH staff—with support from USAID, RTI, WHO, FHI 360, and a consultant—planned a 3-day workshop to introduce the dossier preparation process and the data needed to begin drafting the narrative sections. The workshop also provided an opportunity to advocate for and develop a cost-effective patient estimation strategy.
- WHO and Act | East worked together with the malaria program to identify opportunities to integrate LF post-validation surveillance into training for malaria program staff based at health centers.

#### **BANGLADESH**



- In Bangladesh, dossier development started in 2014 and brought suspected endemic districts to the attention of the MOH. Funding was obtained for remapping to confirm that these were not endemic districts.
- In 2021, Act | East supported a Direct Inspection Protocol survey in LF endemic districts. The survey showed that on the whole, local level clinics and health centers were prepared to support LF patients, but that some supplies and medicines were not regularly available. The results of the survey were discussed before the dossier was submitted to WHO and helped the MOH plan resources for post-validation patient care.

#### VIET NAM



- Viet Nam's LF dossier was started in 2015 with USAID support, with an initial scoping that identified gaps needing more data. The dossier was then updated annually and submitted in 2018.
- The WHO DRG had clarifying questions for the MOH following initial submission. Thanks to strong coordination with, the MOH responded within two days. This prevented a delay in the DRG's decision and the announcement of validation from WHO.
- The Viet Nam MOH and Act | East's predecessor, ENVISION, gathered stories, photos, and video documenting the impact of LF elimination. Through a coordinated effort led by the MOH with WHO, USAID, and RTI, press releases and media pieces were developed that raised the global profile of the elimination announcement.



#### VIET NAM



- Following the final MDA, Act | East and MOH partners held a dossier coordination meeting, in 2018, to plan and organize the final updates, review and fill data gaps and agree on the final rounds of review and approval for the dossier.
- Reviewing the dossier at this stage highlighted gaps that required strong coordination between partners and national and subnational level government administrations to fill.
- Laying out clear expectations on review and approvals with all relevant partners helped ensure a smoother process for internal review as the country prepares to submit the final dossier in 2024.

#### **UGANDA**



- From 2017, the Ugandan WHO NTD focal point championed dossier development and highlighted the need for timely preparation of the dossier.
- Uganda's NTD program included "dossier development" as a fixed agenda item for all trachoma review meetings and advocated for commitment of resources by program partners.
- A dossier task team of MOH staff and partners was created, and a series of dossier writing workshops resulted in the completion of a draft narrative and data templates.
- Dossier narrative and data appendix drafts are now updated annually to include new survey, MDA and F & E data.

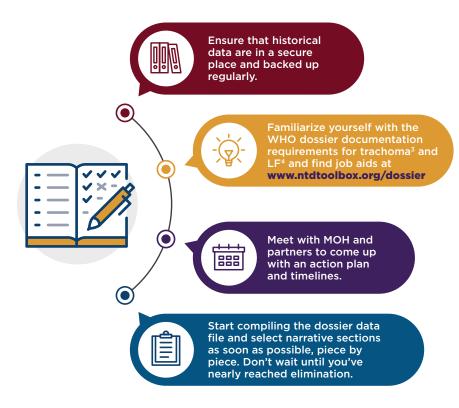
#### NEPAL



- In 2018, informal WHO reviews of Nepal's draft dossier brought to light that
  districts with low baseline Trachomatous Trichiasis (TT) prevalence needed
  further TT-only surveys. ENVISION, WHO and Nepal Netra Jyoti Sangh, a local
  NGO partner, supported surveys in 12 districts that were added to the dossier
  before formal submission.
- The WHO Country Office NTD focal point's involvement in the planning and preparation of the dossier facilitated communication and coordination with the WHO Regional Office before and after submission.
- The MOH and ENVISION gathered photos and interviews during the last trachoma surveys to be used in press releases and media articles to celebrate validation of elimination.

# **GETTING STARTED**

Ready to kick off the dossier preparation process? Apply the lessons above and start with these priorities:



#### To Learn More

Please contact Molly Brady (*mbrady@rti.org*) or Jeremiah Ngondi (*jngondi@rti.org*) with questions, and visit <u>www.ntdtoolbox.org/dossier</u> for job aids and more.

#### Sources

- 1. GPELF: progress report, 2022  $\underline{\text{https://www.who.int/publications/i/item/who-wer9841-489-502}$
- $2. \ \underline{https://www.who.int/news/item/31-07-2023-iraq-eliminates-trachoma-as-a-public-health-problem}$
- 3. Validation of elimination of trachoma as a public health problem:  $\frac{https://www.}{who.int/publications/i/item/who-htm-ntd-2016.8}$
- 4. Validation of elimination of lymphatic filariasis as a public health problem: <a href="https://www.who.int/publications/i/item/9789241511957">https://www.who.int/publications/i/item/9789241511957</a>

Photo credits: (page 1) RTI International/Nguyen Minh Duc, (page 2) RTI International/Roshni Lodhia, (page 5) RTI International/Oscar Siagian (page 8) RTI International/Damien Schumann



March 2024

#### **AUTHORS**

Molly Brady RTI International

Jeremiah Ngondi RTI International

Nandini Pillai

RTI International

Alexis Serna RTI International

We acknowledge the Ministries of Health in Bangladesh, Lao PDR, Nepal, Philippines, Uganda, and Viet Nam in leading their disease programs through the process of dossier development.

This brief was adapted from a previous version published by the USAID ENVISION project in 2019.

#### **CONTACT US**

701 13th Street, NW Suite 750 Washington, DC 20005 www.ActEast.org ActEast@rti.org

This publication is made possible by the generous support of the American People through the United States Agency for International Development (USAID). The contents are the responsibility of Act to End NTDs | East, led by RTI International in partnership with The Carter Center, Fred Hollows Foundation, Light for the World, Sightsavers, Results for Development, Save the Children, and WI-HER under cooperative agreement No. 7200AA18CA00040 and do not necessarily reflect the views of USAID or the United States Government.