2018 Action Framework Report

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2018 Action Framework Executive Summary

Highlights

For the first time, stakeholders from all ten London Declaration Neglected Tropical Disease communities collaborated to develop a common framework for assessing progress and applied it across all ten diseases in 2018. This pushed the partnership beyond its former scoring approach to a model that fosters dialogue and catalyses action and cross-disease learning. Below are some of the outcomes as well as some of the concerns.

Positive outcomes

- Stakeholders are taking the lead on areas spotlighted as warranting collective action
- Disease communities uncovered new opportunities to share learning and felt empowered by the process
- Dialogue within and across diseases and stakeholder groups is stronger and presented an important opportunity to achieve consensus within disease-specific communities on critical priorities
- Conflicting assessments provided an opportunity to discuss differences of opinions
- One disease program is using the Action Framework to develop a national-level assessment tool
- Partners endorsed the transparency and participatory nature of the new process.

Concerns and questions

- The process generated more value for some disease programs and stakeholders than others
- More participation in the disease-specific information gathering would strengthen the results
- Participants are uncertain how the efforts will be fully leveraged
- Input from national programs is limited
- Input from WHO should be sought on how to optimize their engagement in this process.

Project Background and Description

Inspired by the World Health Organization’s 2020 Roadmap on NTDs, there has been tremendous progress in the control or elimination of these devastating diseases since 2012. From 2013 to 2017, the Uniting to Combat Neglected Tropical Diseases (“Uniting”) partnership has produced an annual scorecard and report to celebrate progress and highlight the principal challenges.

The Uniting partnership reviewed the scorecard approach in 2017. The initial scoring process was associated with several challenges in terms of inconsistent indicators across diseases and the number of subjective judgements required to arrive at a final score. The scorecard review resulted in a transition from a scoring approach to a collaborative assessment of progress, gaps and priorities, and identification of areas for collective action. Two new tools replaced the scorecard: the Action Framework and the Impact Dashboard.

The Action Framework is a standardized gap analysis tool. It uses qualitative input from stakeholders across the NTD community and fosters dialogue and collective action among a broad set of stakeholders.

The Impact Dashboards display quantitative data sourced from WHO and pharmaceutical companies, with standardized indicators across the PC and IDM diseases, to provide a high-level view of impact and gaps at the global level.

The purpose of these two new tools is to strengthen partnership, coordination and collaboration between
the public and private sectors, in order to accelerate global NTD efforts enabling the more than a billion people suffering from NTDs to lead healthier and more self-sufficient lives. The scope of the project is specific to the London Declaration and includes the ten London Declaration diseases, regardless of countries, regions, available partners or funding. This report focuses on the Action Framework.

Requirements for the new scorecard
Specific requirements resulting from the 2017 review of the London Declaration Scorecard determined the design of the Action Framework and Impact Dashboards:

<table>
<thead>
<tr>
<th>Tool</th>
<th>Requirement</th>
</tr>
</thead>
</table>
| Action Framework | • Assessment of key gaps and challenges across the ten diseases  
|               | • Qualitative data inputs from a broad range of stakeholders in each disease  
|               | • Standardized, transparent and comparable process and data inputs  
|               | • Program priorities defined through consensus  
|               | • Acceptable to the NTD community and WHO. |
| Impact Dashboards | • Standardized indicators that can be followed annually  
|               | • Standardization specific to IDM and PC diseases respectively  
|               | • Quantitative, objective data from WHO and pharmaceutical companies  
|               | • Brief mention of priorities for the upcoming year  
|               | • Two views: one for current partners and one for potential new partners |

Action Framework Process
Framework development
Many NTD stakeholders generously contributed to collective brainstorming in 2017 on what a new framework should look like. Potential concepts came from various approaches such as the theory of change, balanced scorecards, and other NTD and global health planning tools. These concepts provided the building blocks of a preliminary framework.

To finalize the framework, Uniting collaborated with the Neglected Tropical Disease NGO Network (NNN) to form a temporary working group, the NNN London Declaration Scorecard Working Group (WG). Leveraging the NNN’s established community of NTD disease and crosscutting groups, it included a representative from each disease and from the DMDI and WASH crosscutting group. During a two-day workshop hosted by the Chagas Coalition and ISGlobal in May 2018, the WG developed the preliminary version into a framework consisting of 3 pillars, 11 components and 33 requirements applicable to all ten diseases.

Implementation
Disease-specific input
The WG then engaged stakeholders of various constituencies of their respective disease programs (donors, pharma, researchers, NGOs, WHO, country programs, etc.), to comment on the challenges and priorities of each sub-component. The method varied by disease community: some collected contributions remotely via an online platform and others organized in-person meetings.

Disease-specific dialogue
Once individuals had contributed, the WG members consolidated the input into single disease-specific forms and circulated them for approval within their disease community. In this first pilot round, the timeline for data collection and consolidation was short (approximately two months), resulting in a heavy lift for those leading the effort. It also limited the breadth of stakeholder input. As a result, the number of contributors was lower than desired, varying from two to fifteen. A detailed report on participation in the process was shared at the Action Framework Meeting in October 2018 and is included in the full report.

Cross-disease dialogue
The Uniting team then compiled the consolidated information from each disease into cross-disease views
to help identify components representing common challenges, opportunities to leverage success stories for cross-disease learning, or both. The WG analysed the cross-disease views at a side meeting of the NNN conference in September 2018 and identified themes meeting these criteria, which became agenda items for the Action Framework Meeting on October 10-11, 2018 at WHO HQ in Geneva.

Figure 1. Annual Action Framework Process

Forty-five participants from WHO, the NNN-UTC WG, and the SWG (which represents pharmaceutical companies, donors, researchers and NGOs) participated in the Action Framework Meeting. They reviewed disease progress, discussed the cross-disease themes, and agreed on priority areas for collective action in 2019.

On October 28, 2018, in New Orleans, the outcomes from the Action Framework Meeting were shared with the full SWG, as some members were not able to participate in the October 10-11 meeting.

Outcomes of the 2018 Action Framework

Cross-disease outcomes

The process focused attention on the cross-disease themes that were identified to be the most important across the diseases. Below are the seven themes discussed at the Action Framework Meeting. These themes presented common challenges across the diseases, or opportunities to leverage success stories for cross-disease learning, or in some cases, both. In some cases, they reconfirm recognized priorities and in others they identify new ones.

During the discussion of each theme, the group captured high-level actions already in progress and identified areas where new collective action is required. Organizations from one or more constituency volunteered to take the lead on prioritizing how the partnership should collectively address each theme in 2019. Actions may be supported by existing partner resources or may need additional resources.

<table>
<thead>
<tr>
<th>THEME</th>
<th>LEAD PARTNERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal Health Coverage</td>
<td>WHO, SWG</td>
</tr>
<tr>
<td>Equitable access to quality service delivery</td>
<td>NNN, WHO</td>
</tr>
<tr>
<td>Availability and quality of disease data</td>
<td>WHO, BMGF, USAID</td>
</tr>
<tr>
<td>Diagnostics</td>
<td>COR-NTD</td>
</tr>
<tr>
<td>WASH</td>
<td>NNN, STH Coalition</td>
</tr>
<tr>
<td>Global stakeholder coordination networks</td>
<td>WHO, Uniting</td>
</tr>
<tr>
<td>Resource mobilization planning</td>
<td>SWG, WHO</td>
</tr>
</tbody>
</table>
Disease-specific outcomes

At the disease-specific level, the Action Framework process resulted in a comprehensive overview of the status of each global disease program. While there were clearly limitations due to the newness of the tool and the short time for completion, the final documents were generally perceived as useful analyses, which will facilitate identification of priorities to focus on in the next year and beyond, both in terms of program actions and broader advocacy. Due to varying planning cycles and competing priorities, a few of the disease communities were not able to engage fully in the process. In some cases, the number of contributors was limited due to time constraints and in others, key strategy meetings within the disease community had not taken place prior to the Action Framework meeting.

The best outcomes appear to have resulted from two methods: (1) an in-person meeting among key stakeholder groups and (2) a targeted virtual data collection phase with key stakeholders followed by an in-person meeting to finalize the content. The optimal timing of the process was difficult to standardize as program cycles and meeting schedules varied.

Perceived value of the Action Framework process varied by disease community. For example, some disease communities already conduct regular, comprehensive internal gap analyses and found that this activity added limited value; for others, the timing did not match well with their calendar of priority-setting activities. On the other hand, for most disease communities, the process provided a valuable new perspective on program status and important actionable observations, and useful insights into successful practices in other disease communities. Some disease programs are considering adaptation of the tool for use in assessing country programs; one such tool is already under development for use in 2019.

Other outcomes

The Action Framework process has generated other positive outcomes across the partnership. It strengthened dialogue and created new relationships within and between diseases, increased the NTD community’s understanding of common challenges shared by diseases, increased awareness of and alignment across diseases and diverse stakeholder groups, provided an opportunity to discuss different opinions, and was generally well-received as a more transparent and participatory process.

The ratings and comments on all 33 requirements in the framework are included in the full report appendix. The hope is that sharing these outputs with the NTD community will facilitate identification of other areas of common interest and initiate further dialogue and action.

Evaluation of the Action Framework

Uniting obtained feedback from participants via several methods: the NNN-UTC Scorecard WG members gathered feedback during data collection, an online survey was sent out after the Action Framework Meeting (garnering 78 responses), and additional feedback was received via further discussions.

The main messages from the evaluation are presented later in this report and the detailed survey responses are included in the appendix. The real impact of the process depends on the community’s capacity to carry out the identified actions and to continue strengthening collaboration, communication and the sharing of lessons learned.

Next steps

The future of the Action Framework is under discussion as part of the Uniting to Combat NTDs partnership-wide review, which is currently ongoing in collaboration with WHO. The next steps will be communicated over the upcoming months once this process is complete. For more information on the 2018 Action Framework process or the follow-up in 2019, please contact info@combatntds.org.
2018 Action Framework Participation Summary

The process for completing the Action Framework varied by disease community. Disease representatives on the NNN Scorecard Working Group were asked to solicit input from all constituencies of their disease communities (i.e. NGOs, donors, pharmaceutical companies, researchers, WHO, etc.). However, the specific process for gathering input was left to be defined by each disease community; for example, most diseases used online web forms to collect individual input and then summarized these and others completed the Action Framework via in-person meetings. The table below summarizes participation by disease. Some representatives also put out an open call for input at stakeholder meetings, but the numbers invited via this mechanism were not tracked.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Number invited to contribute</th>
<th>Constituencies invited to contribute</th>
<th>Number of actual contributors</th>
<th>Constituencies that contributed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chagas Disease</td>
<td>27</td>
<td>Affected persons, Donor, NGO, Pharma Research, Vector control, WHO</td>
<td>11</td>
<td>Donor, NGO, Pharma Research, Vector control, WHO</td>
</tr>
<tr>
<td>Guinea Worm Disease</td>
<td>2</td>
<td>NGO, WHO</td>
<td>2</td>
<td>NGO, WHO</td>
</tr>
<tr>
<td>Human African Trypanosomiasis</td>
<td>2</td>
<td>WHO</td>
<td>2</td>
<td>WHO, on behalf of global stakeholder networks</td>
</tr>
<tr>
<td>Leprosy</td>
<td>16</td>
<td>Affected persons, Donor, NGO, Pharma Research, WHO</td>
<td>16</td>
<td>Affected persons, Donor, NGO, Pharma Research, WHO</td>
</tr>
<tr>
<td>Lymphatic Filariasis</td>
<td>46</td>
<td>Donor, NGO, Pharma Research, WHO</td>
<td>12</td>
<td>Donor, NGO, Pharma Research, WHO</td>
</tr>
<tr>
<td>Onchocerciasis</td>
<td>48</td>
<td>Donor National program managers, NGO, Pharma Research, WHO</td>
<td>16</td>
<td>National program managers, NGO, Pharma Research, WHO</td>
</tr>
<tr>
<td>Schistosomiasis</td>
<td>22</td>
<td>Coalition, Donor Implementer/NGO Pharma Research, WASH, WHO</td>
<td>12</td>
<td>Coalition, Donor Implementer/NGO Pharma Research, WASH, WHO</td>
</tr>
<tr>
<td>Soil-transmitted Helminths</td>
<td>27</td>
<td>Donor, NGO, Pharma Research, WASH, WHO</td>
<td>10</td>
<td>Donor, NGO, Pharma Research, WASH, WHO</td>
</tr>
<tr>
<td></td>
<td>50 Coalition Donor NGO Pharma Research WASH WHO</td>
<td>9 Coalition Donor NGO Pharma Research WASH</td>
<td></td>
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<tr>
<td><strong>Trachoma</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Visceral Leishmaniasis</strong></td>
<td>24 Diagnostics Donor NGO National implementers Pharma Research Vector control WHO</td>
<td>10 Donor NGO National implementers Research Vector control WHO</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

By the end of the 2018 Action Framework process, the total number of individual invitations to contribute to all ten disease-specific action frameworks was 264, and the number of actual individual contributions was 100. These totals are not adjusted to account for individuals who were invited to contribute to more than one disease framework. Approximately 15 additional people did not contribute to a disease-specific action framework but participated by attending the Action Framework Meeting on October 9-10 at WHO Headquarters.

Disclaimer: The information contained in the Action Framework represents the consolidated views of the organizations and individuals who participated in the 2018 Action Framework process, as of February 2019. The number of participating individuals and organizations varied by disease. As in some cases, the input was from a small number of individuals and organizations, the information cannot be assumed to be representative of all disease communities. Most disease-specific Action Frameworks include input from the respective disease-specific WHO medical officer(s). Input from WHO, however, does not imply official endorsement by WHO.
Overview of collective action themes

The Action Framework process was developed jointly by Uniting to Combat NTDs Support Center and the NNN London Declaration Scorecard Working Group (NNN LDS WG) as a tool for gap analysis and action-oriented dialogue both within and across the ten NTDs of the London Declaration. The analytical framework has three pillars: enabling environment, strategy, and public health intervention. These divide into 11 components and 33 requirements. This structure facilitated a cross-disease analysis to identify programmatic areas that represent opportunities for progress through collective action and shared learning. The status of each requirement was numerically rated by the disease communities as follows: 1 = substantial challenges and delays, 2 = moderate challenges and delays, 3 = minor challenges and delays, 4 = no challenges or delays.

A heat map displaying the numerical status rating across all ten diseases was created to show which requirements had low status ratings in all or most of the diseases and therefore represented common challenges across the diseases. It also highlighted potential opportunities to leverage successes, where status ratings were low for some diseases, but high for others.

The NNN LD Scorecard WG reviewed the ratings heat map and selected areas of the framework that best represented areas for collective action based on the following criteria:

- Relative importance to the disease communities, as reflected in the status ratings
- Realistic potential for progress through collective action
- Recognized need for new linkages or outside engagement to promote progress

Based on these discussions, the following six themes were identified to be the focus of UTC collective action efforts for 2019:

- Equitable access to quality service delivery
- Availability and quality of disease data
- Resource mobilization planning
- Diagnostics
- Global stakeholder coordination networks
- WASH

These themes formed the core agenda for the 2018 Action Framework meeting among stakeholders, which took place in October, 2018 at WHO Headquarters. In addition to these six topics, WHO requested that the group also discuss the topic of Universal Health Coverage at the meeting. The goal of this meeting was to better define the themes, identify actions, and identify organizations that would take the lead. Below is a brief overview of each theme, the identified action items, and organizations who volunteered to take the lead.

1. Equitable access to quality service delivery

Equitable access to quality service delivery was assessed in three key intervention areas: (1) disease prevention, (2) disease management and disability prevention, and 3) rehabilitation and inclusion. Systematic equity data are lacking but many gaps are apparent. In terms of prevention, access to PC was generally good except for STH and leprosy (PC was only recently introduced in the latter). Geographic coverage was poor or not yet started in some countries, particularly insecure states, and among mobile populations (voluntary and involuntary, cross-border and internal). Access to WASH and vector control services was generally poor. For
disease management and disability prevention, access to treatment varied widely by disease and by intervention. Gaps in guidelines, donor support and mental health care were especially notable. In terms of rehabilitation and inclusion, access to services is a universal challenge. Awareness of the needs and opportunities for these services is poor and they are frequently excluded from NTD programs. This is a large, multi-faceted topic but there is potential for quick wins by sharing what is already being done across the diseases. There is synergy with crosscutting work of the NNN in these areas, and NNN agreed to take the lead in prioritizing and catalyzing follow-up actions.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identify two (or more) individuals to look at needs, linkages and areas for collective action on reaching special populations, program scale up, and mainstreaming</td>
<td>• NNN</td>
</tr>
<tr>
<td>• Work with broader community to decide on priority area(s), action items and advocacy messaging</td>
<td>• WHO</td>
</tr>
</tbody>
</table>

2. Availability and quality of disease data

Issues in data timeliness, quality, completeness and availability affect every NTD program. Data systems and data management resources vary by disease program and by country, leading to inefficiencies and limited data use at the national level. Data requirements vary by disease, causing challenges to integration and use of national health management information systems. There was a call for standardization, via the completion of the WHO NTD indicator compendium, and a request to track data standardization within the Action Framework. In addition, the partnership should prioritize the integration of key indicators with HMIS and supporting improved data ownership, reporting and use of data by countries. Multiple partners are addressing various data challenges and this could be strengthened through collaboration across and beyond NTDs.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead Organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identify individuals within lead organizations to</td>
<td>• WHO</td>
</tr>
<tr>
<td>o Support the WHO NTD indicator compendium</td>
<td>• BMGF</td>
</tr>
<tr>
<td>o Develop an NTD indicator framework for HMIS</td>
<td>• USAID</td>
</tr>
</tbody>
</table>

3. Diagnostics

The need for new or improved diagnostics is a universal challenge, which is growing more acute as NTD programs approach their control or elimination targets. Both PC and IDM diseases have acute diagnostic challenges. Concerns included availability, performance, and cost. Diagnostics must be developed and selected based on programmatic use cases and M&E frameworks, to guarantee field performance and the ability to guide programmatic decisions, including low prevalence settings. Integration and innovation will be essential. There is also a need to strengthen supply chain for most of the currently available diagnostics and the manufacturing issues require new approaches. There was a call for greater collaboration and harmonization between partners and across diseases with regard to investments and efforts.

<table>
<thead>
<tr>
<th>Action</th>
<th>Lead Organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identify how current opportunities may meet needs and what additional gaps exist in:</td>
<td>• BMGF</td>
</tr>
<tr>
<td>o Diagnostic tool development and optimization</td>
<td>• USAID</td>
</tr>
<tr>
<td>o Supply and manufacturing issues</td>
<td>• COR NTD</td>
</tr>
<tr>
<td>o Logistics and forecasting</td>
<td>• WHO</td>
</tr>
</tbody>
</table>
4. WASH
Integration and closer collaboration between WASH and NTDs is a priority for several diseases. Challenges exist such as clarity of disease-specific WASH interventions, uncertainty on the threshold for WASH impact on prevalence, and lack of consistency in the NTD sector on including WASH interventions and use of WASH-related indicators. A WASH NTD toolkit jointly developed by WHO and NNN will soon to be launched, and this will address many of these challenges. Over the next year, the WASH-NTD community will focus on dissemination of this toolkit and uptake of the practices included.

<table>
<thead>
<tr>
<th>Action</th>
<th>Lead Organizations</th>
</tr>
</thead>
</table>
| ● STH Coalition will partner with the NNN WASH Working Group to move implementation of the WHO toolkit forward | ● STH Coalition  
● NNN WASH Working Group  
● WHO? |

5. Global stakeholder coordination networks
These networks play a critical role in accelerating progress. The structure, scope and strength of disease-specific coordination networks vary greatly by disease. There is an opportunity to look across diseases at the existing structures and models to share lessons learned and develop solutions for existing limitations.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead Organizations</th>
</tr>
</thead>
</table>
| ● Clarify WHO management position on global NTD alliance  
● Exchange knowledge on current models of disease-specific coordination networks  
● Follow up after UTC partnership evaluation | ● WHO  
● UTC |

6. Resource mobilization planning
Resource mobilization planning is a common challenge across the diseases. Some programs lack global planning in this area, while others are hindered by lack of alignment between global and national level planning. Ongoing needs for funding gap analyses or cost estimates create difficulty in effective resource mobilization planning, and the “end game” presents new funding challenges. There are also some successful strategies that can be shared more widely. Fundamentally, there is a critical need to shift the conversation across all the programs towards domestic ownership and financing. This will require a unified approach across the NTD community, especially among donors. This transition should be linked with UHC and the minimum basic package of interventions to be provided by countries. There is a need to define the most useful role for the Uniting to Combat NTDs partnership in this and to look at best practices among endemic countries, global NTD programs, and in other global health programs.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead Organizations</th>
</tr>
</thead>
</table>
| ● Collaborate and coordinate on principles of domestic resource mobilization  
● Determine the appropriate role of the UTC partnership in this work  
● Exchange knowledge on planned and ongoing funding gap analyses | ● SWG  
● WHO NTD team  
● Donors |
7. Universal Health Coverage

Universal Health Coverage (UHC) is one of three WHO strategic priorities over the next five years, with a focus on measurable impact targets and an integrated health systems approach. NTDs must therefore be understood and advanced within this context. WHO is developing a UHC menu of interventions that will shape national UHC agendas. WHO is launching a pilot project to integrate essential communicable disease (CDS) services (including NTDs) into UHC health benefit packages in 14 countries. Opportunities exist to include NTDs in the UHC menu in a way that allows CDS programs to leverage each other towards success.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead Organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Engage partners working in the 14 pilot countries of the WHO UHC-CDS Flagship Accelerator Initiative to coordinate on supporting NTDs within the UHC context</td>
<td>● WHO NTD team</td>
</tr>
<tr>
<td>● WHO NTD team and partners to align on the minimum package to be included at country level under the umbrella of UHC</td>
<td>● SWG</td>
</tr>
</tbody>
</table>

Other topics for follow up

In addition to the themes outlined above, the qualitative assessments in the Action Frameworks highlighted several other prominent topics of cross-disease importance, such as program sustainability, populations affected by conflict and insecurity, drug and diagnostic supply chains, training for entomologic assessments, and MMDP/DMDI data and services. Action Framework information on these topics will be shared with NTD crosscutting working groups, such as those hosted by WHO and the NNN. Suggestions and questions regarding disseminating and leveraging topics for collective action and shared learning are most welcome.

The ratings and comments on all 33 requirements in the framework are included in the full report appendix. The hope is that sharing these outputs with the NTD community will facilitate identification of other areas of common interest and initiate further dialogue and action.

Next steps

Follow-up on the Action Framework is under discussion as part of the Uniting to Combat NTDs partnership-wide review, which is currently ongoing at the time of this report in collaboration with WHO. Next steps will be addressed over the upcoming months, once this process is complete. For any questions, suggestions or other comments on the 2018 Action Framework process or the follow-up in 2019, please contact info@combatntds.org.
Evaluation of the 2018 Action Framework

Feedback was gathered via three mechanisms: comments collected during input gathering, online survey after the Action Framework Meeting, and through in-person discussions with participants.

Action Framework input-gathering process

The NNN Scorecard Working Group members collected contributors’ comments during the 2018 input-gathering process and presented them at the October 2018 Action Framework meeting in a “Pros vs Cons” format. Key points are below.

**Pros**
- The input process was inclusive and encouraged community cohesion
- The process provided a snapshot of community sentiments
- Incorporation of HSS building blocks made it relevant to a wider audience
- Action-orientated, prospective approach is more useful than the previous scorecard
- The framework provided a common language for cross disease analysis

**Cons**
- It was very time consuming to complete
- There was a low response rate
- Did not allow for country-specific comments
- Some requirements need to be restructured
- The timeline was too short and competed with other priorities
- The cross-sectoral element was lacking
- There was uncertainty about the return on time investment

Online survey

A 37-question online survey was sent to all who were invited to contribute to disease-specific action frameworks, and all Action Framework meeting attendees. Seventy-eight individuals responded to the survey. The full list of responses is in the appendix and the main findings are listed below.

- The audience and outcomes/uses of the activity require further definition and clearer articulation
- The process could be implemented every 2-3 years instead of every year
- The process requires more time for disease-specific input and consultations
- The process requires more participation to generate greater confidence in the results
- The framework must be revised and streamlined to reduce the time burden and increase clarity on the definitions, while also maintaining the necessary level of detail for a productive discussion
- The disease-specific process was useful for most disease communities, very useful for some diseases and not useful for a few
- There was strong support for the cross-disease dialogue on common challenges
- There was strong support for the identified themes for collective action and shared learning
- Future iterations should include country input, and countries should be represented at the Acton Framework meeting, although more thought is needed on how to accomplish this
- At the Action Framework meeting, the discussion of the crosscutting topics, and proposed actions to address them, was too brief.

Other feedback

Other discussions during and after the 2018 Action Framework process provided valuable feedback and helped shape the survey questions. Additional points were:

- In-person meetings and interviews are likely the most effective ways to gather community input
- Communities with newer, less formally structured networks experienced more positive outcomes
- The process was more democratic and transparent than the previous scorecard
- The stakeholder landscaping aspect of the process was a useful exercise
- Guidance from WHO is needed on how to optimize WHO engagement in this process.

Next steps

The above feedback will inform revisions to the process and framework in 2019, prior to future iterations.
Acknowledgments

UTCNTD gratefully acknowledges the below contributions to the development and implementation of the Action Framework:

- The more than 100 individuals who participated in the 2018 Action Framework process as contributors to the disease frameworks and/or participants at the 2018 Action Framework meeting in Geneva;
- The Department for Control of Neglected Tropical Diseases at the World Health Organization for providing input to the disease-specific frameworks, hosting the 2018 Action Framework meeting, and providing feedback on the framework and process;
- The NNTD NGO Network (NNN) for shaping the Action Framework via the NNN London Declaration Scorecard Working Group (see below) and for encouraging and supporting members to contribute data to the individual disease Action Frameworks;
- The Bill & Melinda Gates Foundation (BMGF) for technical advice and funding to support this work through the Uniting to Combat NTDs Support Centre.

The Action Framework process and conceptual framework were developed through the collaborative efforts of many individuals and organizations. These include participants of the 2017 Scorecard Monitoring and Evaluation Workshops in Dakar and Baltimore; the NTD department at the Bill & Melinda Gates Foundation who developed the London Declaration Action Plans approach, which strongly shaped the final framework; and Instituto de Salud Global de Barcelona (ISGlobal) and the Chagas Coalition, who hosted the 2018 Action Framework Workshop in Barcelona, Spain. Special thanks are due to the NNN London Declaration Scorecard Working Group members and their home institutions, who thoroughly revised the draft framework into the final 2018 version and defined the implementation process. They also managed input gathering and consolidation, identified the priority collective action themes and led discussions at the Action Framework Meeting. Participants are below:

<table>
<thead>
<tr>
<th>Disease or crosscutting topic</th>
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## Appendix 1

Structure of 2018 Action Framework: pillars, components, requirements and input requested from contributors

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### Appendix 3
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### Appendix 4

#### 2018 Action Framework: 2019 Priority Ratings

<table>
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<tr>
<th>COMPONENTS &amp; REQUIREMENTS</th>
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### 1.0.0. ENABLING ENVIRONMENT

#### 1.1.0. Healthcare financing

1. **Needs of political will to provide more relevance to NTDs program, access to more funding for scaling up of diagnosis and treatments**

   - If additional research is needed to reach the endgame, this will require additional funding.

   - Funding is not sufficient. It is crucial to ensure funds for long term approach.

   - More funds needed for both early detection and PEP (post-exposure prophylaxis) programme. DMDI related activity mainly funded by NGO sector, globally inconsistent.

   - Limited funds for countries scaling up and shortage of funds for MMDP.

   - The shift in target has created a funding gap for endemic countries. There is no clear funding stream for national elimination committees and elimination related surveys which are key to the elimination process. Countries suffering from ongoing civil conflict do not have adequate funding. Other countries that would like to eliminate onchocercal often find themselves with insufficient funding to do so. Unclear where funding for OEM will come from, particularly in loa endemic areas.

   - Significant gaps persist in scaling up SCH treatment to all at-risk populations, including adults and pre-SAC. Financing for drug procurement for non-SAC populations is needed.

   - Where funding exists for programme implementation, funds for comprehensive M&E and WASH should be included.

   - There is a need to identify long-term funding for SCH programming as there is no guarantee that current funding levels will be sustained indefinitely. Additionally, due to the variable frequency of SCH treatment, it is not clear exactly what the treatment gap and funding requirements are on an annual or longer term basis.

   - Domestic investment is linked to health priorities, and strategies to increase domestic financing have been met with insufficient funding to do so. Unclear where funding for OEM will continue funding in the medium/long term.

   - Variable access to funding across countries; - Inability to utilize existing funds in some countries due to insecurity and other challenges

   - Leprosy has received less priority and inadequate budget in most countries due to 1) having reached previous WHO elimination targets 2) small numbers compared to other programmes or compared to before 3) poor understanding that leprosy is a disease targeted for elimination, hence small numbers are important and funding should not have been reduced based on numbers only and 4) leprosy is a disease of poor and marginalized who generally have less voice.

   - Different funding cycles between donors and countries. Integration of funding sources can pose challenges.

   - Many countries are insufficiently funded to carry out all integrated MDA activities. Domestic resource mobilization and/or new donors are required to ensure all countries have adequate resources to achieve high coverage necessary to eliminate onchocerciasis. Sometimes delays with funding certain activities for one disease can delay the procedure. This is particularly true if yearly treatment is indicated.

   - Where funding is available, challenges arise where multiple organizations support the same country and different timelines and processes are in place.

   - For international resource timeliness, no challenge. As domestic resources increase, the timeliness of their availability will be increasingly important to the sustainability of national programs.

   - There is a potential funding gap in 2019. In India, the transfer of funds from central to state level can be slow. There is a need for follow-up mechanism to check for appropriate utilization of funds.

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### 2018 Action Framework Challenges Summary

<table>
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<tr>
<th>Chagas Disease</th>
<th>Guinea Worm Disease</th>
<th>Human African Trypanosomiasis</th>
<th>Leprosy</th>
<th>Lymphatic Filariasis</th>
<th>Onchocerciasis</th>
<th>Schistosomiasis</th>
<th>Soil-transmitted Helminths</th>
<th>Trachoma</th>
<th>Visceral Leishmaniasis</th>
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<tr>
<td>To improve public health information related to Chagas disease to achieve the level of attention required at political and health level</td>
<td>Availability of funding</td>
<td>To improve coverage of control activities to better cover population at risk</td>
<td>Low monitoring, lack of systematic analysis</td>
<td>Limited capacity in countries for forecasting with surveillance and MMDP activities not clearly costed</td>
<td>Country level gap analyses led by National Oncho Elimination Committees are needed. Funding is needed to support underserved and conflict areas. Mapping for onchoc is incomplete, so the there may be needs that are not yet known. The scale of those needs is also unknown. Furthermore, funding gaps created by the shift from control to elimination need to be addressed. Funding for epidemiological and entomological surveys is unknown. Other funding gaps include: underserved areas, conflict zones, programmatic M&amp;E. In general, as the disease becomes less physically noticeable in a population, the priority for donor and national support lowers.</td>
<td>There is a lack of clarity on the specific needs for SCH which hinders the ability to identify and calculate funding gaps. Updated estimates will be needed in line with updated recommendations in the new WHO SCH guidelines currently under development. Estimates will also change as strategies for treatment are adjusted over time.</td>
<td>Tools that exist to analyze/quantify funding gaps in the national program (ex: TIPAC) are not often used or updated.</td>
<td>Limited understanding of the funding gaps relating to F&amp;E components</td>
<td>- Limited understanding of the funding gaps relating to F&amp;E components - Need for additional discussions and coordination around addressing the surgical backlog.</td>
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<tr>
<td>Building an adapted plan to enhance scaling up on diagnosis and treatment</td>
<td>Availability of funding</td>
<td>Important funding is guaranteed for next 2-3 years but extension for long term support is required</td>
<td>Clear resource plans and leads needed. Lack of human resources impede this.</td>
<td>Resources should be mobilized based on needs, however, the needs and scale of needs is only partially understood due to incomplete mapping activities. The cost of lab analysis and surveys is not well understood. A coordinated approach to funding across stakeholders using an evidence-based decision making approach is needed.</td>
<td>No tangible fundraising advocacy outside dialogue with traditional donors Limited agreement on programme goals and strategies leading to an absence of clarity on funding gaps Uncertainty on how this links with domestic resource mobilisation</td>
<td>Need to better share information across donors/partners, particularly as new donors are investing in trachoma.</td>
<td>A resource mobilization plan must be worked out on the national level and should include a commitment to provide domestic funding.</td>
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#### 1.1.3. Clear identification of the funding gaps

- To improve public health information related to Chagas disease to achieve the level of attention required at political and health level
- Low monitoring, lack of systematic analysis
- Limited capacity in countries for forecasting with surveillance and MMDP activities not clearly costed
- Donors less willing to support assessments than PC
- Country level gap analyses led by National Oncho Elimination Committees are needed. Funding is needed to support underserved and conflict areas. Mapping for onchoc is incomplete, so the there may be needs that are not yet known. The scale of those needs is also unknown. Furthermore, funding gaps created by the shift from control to elimination need to be addressed. Funding for epidemiological and entomological surveys is unknown. Other funding gaps include: underserved areas, conflict zones, programmatic M&E. In general, as the disease becomes less physically noticeable in a population, the priority for donor and national support lowers.
- There is a lack of clarity on the specific needs for SCH which hinders the ability to identify and calculate funding gaps. Updated estimates will be needed in line with updated recommendations in the new WHO SCH guidelines currently under development. Estimates will also change as strategies for treatment are adjusted over time.
- Tools that exist to analyze/quantify funding gaps in the national program (ex: TIPAC) are not often used or updated.

#### 1.1.4. Resource mobilization plan for meeting identified funding gaps is in place

- Important funding is guaranteed for next 2-3 years but extension for long term support is required
- Resources should be mobilized based on needs, however, the needs and scale of needs is only partially understood due to incomplete mapping activities. The cost of lab analysis and surveys is not well understood. A coordinated approach to funding across stakeholders using an evidence-based decision making approach is needed.
- No tangible fundraising advocacy outside dialogue with traditional donors Limited agreement on programme goals and strategies leading to an absence of clarity on funding gaps Uncertainty on how this links with domestic resource mobilisation
- Need to better share information across donors/partners, particularly as new donors are investing in trachoma.
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### Appendix 5
2018 Action Framework Challenges Summary

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<tr>
<td><strong>1.2.0. Health information systems</strong></td>
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<tr>
<td>Need standardized data collection systems and compulsory report of cases as well as the establishment of a follow-up system of populations under risk. Need of information sharing at national and local level</td>
<td>- Improved methods to enhance active and passive case-finding strategies are still required - Better understanding of the coverage of the populations screened is desired to help focus on the populations at highest risk - The use of data management and case mapping tools can critically help to better target case-finding activities - Surveillance has weakened in a few countries, mainly owing to security constraints (e.g. Central African Republic and South Sudan) - With rhodesiense HAT, adoption of malaria RDTs (instead of microscopic examination), decrease in HAT-skilled staff, and the acute clinical progression may cause under-detection</td>
<td>Assessment of disability is not followed up. There is no surveillance system post-MDT, while the risk of of worsening of disability continues for a significant minority of patients. Reporting of cohort data is poor. Desire for concealment leads to underreporting. Target-driven reporting results in misleading data. Quite a few endemic countries are not reporting cases (while it is known they exist).</td>
<td>Accessibility and quality vary by country with few able to access historical data (stored correctly)</td>
<td>There is insufficient funding, time, and personnel for assessment validation. Onchocerelation mapping must be completed to fully understand the scope of the problem. Data is likely to be housed in different data capturing systems.</td>
<td>Mapping and testing not consistently done and not standardised. There is a lack of data across age groups, with SAC having some data but others lacking. The reliability of coverage data is questioned, but this seems to be an issue with reporting and sharing.</td>
<td>Limited epidemiological data. Lack of support for surveys, lack of incentive to report data, lack of clear guidelines on measuring intensity. Data are old and localized to specific geographic areas. Minimal data on all age groups (outside of PSAC and SAC).</td>
<td>Insecurity, special populations, historical data is of variable quality which may cause challenges during dossier development.</td>
<td>Countries are not using consistent formats for data collection, even in the reporting for WHO. There is a lack in standardization. In India, data collection is limited to few facilities with unreliable communications. In Ethiopia, diagnostics to check relapse and/or re-infection are only available at higher institutions, therefore, there is limited data on relapse/re-infection of VL. Data is currently collected through a manual, monthly process which can result in delays and errors in reporting.</td>
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#### 1.2.1. Availability and quality of epidemiological data (ex. completeness, age of data, and accuracy)

| Need tools and models for a comprehensive view of the disease burden for a better planning and forecast. | Timely response to outbreaks of disease | Limited access to diagnostic tools limits the program’s ability to improve interventions | Need disaggregated data and analysis. Feedback loops not always in place. Mapping should be an integral part of the health information system (HIS) for leprosy from national down to local levels (example: trachoma). Capacity for mapping needs to be built. | Unclear what data is needed in certain areas (persistent transmissions) and issues around data quality cause challenges as programmes progress (e.g. TASS). Data usage can be improved at national and local levels to improve programmes. Programmes are not always supported for mop-up | Harmonization of data, data sources, and collection methods between WHO/ESPenn, NGOs, and government is needed to ensure the same data is used to produce action. Harmonization in data between diseases may be a challenge, as onchocerain data is by focus or village, while other diseases use district level data. Foci boundaries do not necessarily align with district boundaries. | Schistosomiasis is focal and needs high-resolution mapping and improved diagnostics for detecting and quantifying low intensity infections. Accurate estimates of endemicity are needed at sub-district level to guide interventions. Data should be disaggregated and disease-specific challenges & preferred practices integrated into control programmes | There is very little effort to measure burden of disease outside of school-age children. Of the countries undertaking impact evaluations, further information on how they are using these results to guide decision-making is required, and should be disseminated to assist other countries. There are currently few examples of what countries do when they arrive at a point where WHO decision tree cut points for STH may warrant a reduction in treatment frequency. It is not clear how much these data are independently validated, or whether/how countries are using these data to drive programmatic improvements (for example monitoring at lower-order administrative levels to determine areas where compliance may be problematic). | - Minimal to no funding available at the national level for data management and analysis. - Use of trachoma data for increased targeting of WASH infrastructure and joint planning. | Limited capacity means that there is no monitoring and promotion of effective use of data. In India, timely entry of VL cases into KAMIS continues to be a challenge and use at state level is limited. In Ethiopia, data is only collected from health facilities passively, rather than through active surveillance. |

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1.2.3. Extent of integration of essential NTD data collection and monitoring activities into national health information systems

Need awareness and friendly and agile models of integration of NTD activities into National Health Information systems

- Need for continual validation of data reported in the national health information system to align with the National GWEPs’ data.
- Lack of formal integration structure with regard to the adhoc case searches.

More efforts from countries are needed to integrate control and surveillance into strengthened national health systems

Pilot studies needed to determine how all the data elements needed to monitor the effectiveness of leprosy programmes can be collected within an integrated NTD framework, where relevant, possibly in association with other skin NTDs.

Unclear on what needs to be captured in HMIS/DHIS2 vs separate systems. Monitoring indicators for MDA are good but there is a clear gap for MMDP which most countries do not report on.

The difference between foci and district boundaries makes a national health information system challenging because existing data is likely at the district and sub-district level. In general, NTDs are not well integrated into national health information systems, where countries lack interest in integrating oncho data into NHS.

The data management, standardization, quality and sharing needs to be strengthened at both international and national level for it to enter into national health systems.

There are parallel M&E systems within national ministries of health. Utility and ability to integrate with national/sub-national HMIS systems vary by country.

Child health cards/distribution registers/tracking sheets do not differentiate between NGO and government contributions.

National health information systems, where available, do not always contain NTD data. Where they do, the data are of variable completeness and quality. Current data captured within national health information systems is not robust enough to meet the criteria for completing the Trachoma Elimination Monitoring Framework (TEMPF), trachoma impact survey data, dossier development, Zithromax donation applications, or trichiasis surgery goals tracking.

Implementing a uniform information system is challenging. Some countries have invested resources in their own systems and object to adopting a different system. Agreement on indicators is lacking.

There is lack of standardization in definitions relating to disease progression that can impact, making data collection.

Need to facilitate the supply chain of nifurtimox and benznidazol either from PAHO strategic fund or from National Health Systems.

The registration of drugs, and to reduce the time for diagnosis and treatment and the bureaucracy in acquisition should help to improve the supply delays or gaps.

No vaccine or treatment is currently available

Non responsiveness of GW to anti-helminthic drugs, thus far

Dependence upon external funders to purchase existing diagnostic tools and the shortage of companies willing to engage in their production at costs compatible with available resources of concern. Efforts and contributions to emulate the previous success in assuring access to medicines or diagnostic tools offer a potential way forward.

New vector control tools are more affordable but unstable funding is available

Reaction-specific drugs and disability aids not easily available. Disability aids generally provided by NGOs, and/or in a disease-specific way, resulting in long-term sustainability issues. It would be more sustainable if services for disabilities were available and leprosy patients could be referred to them.

Issues continue with diagnostic assay and need validated Ab R/T. Countries need support/guidance regarding ordering of FTS, especially if they have limited experience.

Some countries need improved supply chains to manage drug donations once they arrive in country. Many are challenging in some countries. Vector trapping technology for testing is needed. There is a strong need to strengthen non-MDA supply chains. Diagnostics need to be verified. Clarity is needed on the recommended ELISA protocol to use, and labs need to receive training on SOPs for ELISAs.

The manufacture lag time and import requirements in endemic countries create supply chain issues with regards to PZQ RDTs, ELISAs, and PCR reagents. The ESPEN lab in Ouaga is a huge opportunity for the global oncho program. It has the potential to act as the logistics hub (housing the diagnostic tests and ancillary supplies so that they can then be shipped to countries via WHO office to WHO office).

Current challenges with annual and long-term forecasting and last mile visibility. Delayed treatment reporting and inventory management of remaining stock prevents proper planning and estimation of needs for subsequent year. Import procedures leading to retention of drugs at port of entry can lead to delays impacting utilisation downstream.

Varies by country (issues of internal logistics, health delivery systems, capacity to manage supply chain, forecasting, data timeliness and completeness)

Supply chain is often influenced by outside factors that cannot always be accounted for. The disbursement of drugs and diagnostics does not match the requests due to stock rupture and lack of integrated supply chain management. Also, different treatment protocols (single dose albendazole vs 3 days) affect forecasting.
### 1.3.3. Availability of required physical assets and infrastructure (ex. lab and clinical capacity, etc)

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<tr>
<td>Need more resources and training to improve diagnosis capacities</td>
<td>HAT programmes cannot be in the driving seat of the reinforcement of the peripheral health system.</td>
<td>Retention of these skills within the workforce is the issue.</td>
<td>Not a requirement for current GPELF M&amp;E, but limited impact on MMDD capacity at health facility level.</td>
<td>Currently, existing lab and clinical capacity is insufficient.</td>
<td>Due to lack of the infrastructure, training will be required at a decentralised level to allow routine monitoring.</td>
<td>Technical capacity in many countries isn’t sufficient. Training for microscopists needed. New technologies are needed.</td>
<td>In-country supply chain infrastructure and capacity varies by country in the ability to process drugs upon arrive and deliver them to distribution points.</td>
<td>- Involvement by and coordination with multiple country institutions is required.</td>
<td>Both diagnosis and treatment require specialized equipment. Remote areas and conflict zones suffer from weak infrastructure and limited clinical and lab capacity.</td>
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<td><strong>1.4.0. Health workforce</strong></td>
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<td><strong>Clear need for specific awareness and training of health staff on Chagas disease</strong></td>
<td>Skilled human resource are not always readily available.</td>
<td>The decrease in HAT-skilled staff is a widespread challenge as the number of cases dwindles. More efforts from countries are needed to ensure continued staff training and motivation.</td>
<td>Lack of standardized on-job training for TAS. Limited pre and post-education training (critical). Retention of CDUs for MDA is challenging. Limited surgical staff resulting in backlog for MMDD. Some countries lack trained professionals for M&amp;E (entomologists, molecular experts, etc).</td>
<td>Programme relies on volunteers who are trained on an annual basis and influenced by high turn-over rates. Currently not enough trained personnel to effectively monitor programme impact.</td>
<td>Health worker fatigue. Lack of national capacity for M&amp;E.</td>
<td>There is a shortage of personnel to identify triachiasis cases, provide surgery, and conduct follow up. - Identifying and retaining skilled TT surgeons is an ongoing challenge. - There is a shortage of graders and resources needed to conduct surveys in a timely manner to provide vital program data for decision making.</td>
<td>Retention of trained health workers is challenging. There is high turn over in trained staff.</td>
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<tr>
<td><strong>1.4.1. Availability of health workers with requisite skills and support</strong></td>
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<td>Integration is training already overburdened CDUs. Treating in previously assumed hypoendemic areas will likely increase the need for health workers. Many countries lack personnel adequately trained on the available diagnostics. Programme fatigue is likely to be a major problem. More black fly entomologists able to assist in the renewed mapping activities are needed, along with a cadre of trainers for onch mapping (and ultimately stopping MDA) surveys.</td>
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<tr>
<td>Need for a unified and comprehensive training package to standardize training protocols. Once developed, training materials must be tested. Entomology skills are not being passed along to new workers at a sufficient rate to meet the needs created by WHO recommended entomological surveys. Maintaining skills when the surveys are not regularly performed is challenging. There is no plan or framework in place to train the next generation as the current generation retires.</td>
<td>Programme fatigue is likely to be a major problem. More black fly entomologists able to assist in the renewed mapping activities are needed, along with a cadre of trainers for onch mapping (and ultimately stopping MDA) surveys.</td>
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<td><strong>1.4.2. Access to quality training programs and materials for health workers for the transfer and maintenance of essential skills</strong></td>
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<td>Access to appropriate training for all levels is limited by funding and by the decrease in prevalence which makes it difficult to gain experience.</td>
<td>Medical skills not sufficient with existing training.</td>
<td>Leprosy does not fit into the training curricula. Medical skills not sufficient with existing training.</td>
<td>Limited dissemination of materials; partners (all) need to ensure they use and follow WHO guidelines. Clear limitation regarding MMDD materials.</td>
<td>There is a need for a unified training package to standardize training protocols. Once developed, training materials must be tested. Entomology skills are not being passed along to new workers at a sufficient rate to meet the needs created by WHO recommended entomological surveys. Maintaining skills when the surveys are not regularly performed is challenging. There is no plan or framework in place to train the next generation as the current generation retires.</td>
<td>Lack of standardisation of training programmes and supporting material. Quality control of trainings undertaken by health professionals to unskilled health workers, e.g. teachers. SCH training not included in pre-training curricular for health workers (or not always)</td>
<td>NTD programs require fairly straightforward training materials/curriculum. Retention of these skills within the workforce is the issue.</td>
<td>Human and financial resource challenges exist, particularly for TT surgeons and graders. Current training programs are largely dependent upon external resources (including finances and international trainers). National programs need locally-based trainers. Because of the successes experienced in trachoma programs, maintaining skilled TT surgery workforce and graders becomes difficult as cases become less common. Limited to no training on IWASH and hygiene or behavior change for healthcare personnel in trachoma.</td>
<td>Training is depending on available funding, which is not always available. This issue is compounded by the high turn over of skilled health workers.</td>
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Diagnostics for prepatent GW are difficult to develop. Research is fragmented and no clear shared agenda with common goals in mind among VL research community. There are a lot of unanswered questions in the natural history of the disease which need to be answered. There is a lack of funding for vector research and lack of funding for PKDL. For East Africa, the main challenge lies in understanding the transmission pathway.

Improvement of diagnosis capacities and earlier diagnosis. Need resources for lab capacities. The continued occurrence of dog infections (with guinea worm) points to an alternative modality of transmission (transport or paratenic host). The roles of asymptomatic human carriers and animal reservoirs of the disease in epidemiology require further attention. Epidemiological modelling could help to frame these roles. The skin may be an underappreciated site of trypanosome infection. Addressing the problem of refugees moving from endemic to non-endemic areas also requires attention. Methods to define the targeting of vector control activities need to be clarified. The very long incubation period, the lack of a test of infection, and the inability to culture leprosy on artificial culture media is a major challenge to transmission research.

Recrudescence, vector control, and animal reservoirs. OR is needed to assess the threat of recrudescence. Epidemiological conditions in some foci may need more investigation. Persistent hot spots are not well understood. Investigations into the impact of hypoenemic areas are needed. Vector control strategies should be more thoroughly integrated with MDA activities. M&E diagnostic and data sharing challenge for impact of intervention and recrudescence modelling. Lack of investment in snall vector identification, impact on local epidemiology and cost-effective snall-focused control/intervention options. Lack of investment and clarity on Behaviour Change - WASH strategies, M&E indicators and reporting.

Threshold for WASH to impact disease prevalence is unknown. Further scientific understanding needs to be developed - particularly regarding recrudescence - and additional challenges may emerge post-elimination.

1.5.1. Understanding of transmission pathways, vectors, reservoirs, and recrudescence

1.5.2. Ability and feasibility of current diagnostics to provide accurate view of disease epidemiology to inform decision making

1.5.3. Ability of survey methodology or other tools to provide accurate view of disease epidemiology to inform decision making

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2018 Action Framework Challenges Summary

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<td>Need more understanding of vector behaviour in certain contexts and under certain conditions as well as the interaction with humans. Mapping of risk areas.</td>
<td>- Dependence upon external funders to purchase existing diagnostic tools and the shortage of companies willing to engage in their production at costs compatible with available resources is of concern. Companies contributing to emulate the previous success in assuring access to medicines or diagnostic tools offer a potential way forward. - Improved diagnostic tools and screening protocols are still in development - The skin may be an underappreciated site of trypanosome infection, and may have a role to play in diagnosis.</td>
<td>Understanding of disease markers during the latency period is necessary for the development of a diagnostic test.</td>
<td>No rapid diagnostic test validated to measure antibodies</td>
<td>The diagnostic needs are poorly met. Available ELISA and RDTs have not been validated. There is a need for standardization in diagnostics, protocols and cutoffs. Available diagnostics are not able to distinguish between active and past infections. New diagnostics (preferably antigen-based tests) are needed, as the RDT is insufficient, while the ELISA is expensive and difficult to procure and receive in-country in a timely manner. Then there is the lack of high-functioning, high-quality labs. There is a lot of work underway to improve all of these, but at present they are a bottleneck for the programs.</td>
<td>The available diagnostics do not perform equally in all countries. There is a need for more sensitive diagnostics as programs move beyond &quot;control&quot; goals. KK lacks sensitivity, is time-consuming, and relies on skilled manpower.</td>
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<td>More resources needed to improve the epidemiological understanding of the disease in many areas</td>
<td>- Improved methods to enhance active and passive case-finding strategies are still required - Better understanding of the coverage of the populations screened is desired to help focus on the populations at highest risk. - The use of data management and case-mapping tools can critically help to better target case-finding activities.</td>
<td>Data on new case detection is available, so the incentive to conduct surveys is low.</td>
<td>Need to understand importance of &quot;hot spots&quot; - how to find and respond to them. Need post-validation surveillance and (potentially) verification methodologies.</td>
<td>There is a lack of standardization in epidemiological assessments. Thresholds and correlations across indicators are not well understood. The geographical domain is not well defined. There is a need for consistent guidelines. Funding for evaluation of new survey methodology is needed.</td>
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### 1.5.4. Existence of effective tools and intervention(s) capable of achieving Roadmap targets

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<td>Need to mark clear targets on access to diagnosis and treatments; to dedicate more resources at national levels with building an expert consensus; to enhance diagnosis and treatments tools.</td>
<td>Tools available are imperfect but they have been applied successfully</td>
<td>To implement PEP, contacts need to be identified. Stigma can interfere with willingness of index patients to disclose their status to their contacts.</td>
<td>Areas with persistent transmission require special attention. Issues exist regarding compliance and quality implementation</td>
<td>There is a need for an effective macrofilaricide. Low coverage is an obstacle to elimination. More data on hypoenemic and low co-endemic areas is needed.</td>
<td>There is a need to clarify and build the evidence-base for which WASH, snail control and behaviour change interventions/tools can effectively be used to achieve roadmap targets. There is also a need to properly define morbidity control and elimination targets. Work also needs to be done on how to effectively integrate different tools and interventions into a holistic NTD-WASH programme. MDA/PC needs to be properly targeted and morbidity control indicators and targets need more defining.</td>
<td>New strategy and guidelines are needed for program managers to make informed decisions</td>
<td>- Need more collaboration to implement F&amp;E in all areas in collaboration with other NTD communities; - How to address special populations (i.e., refugees, IDPs, indigenous and nomadic populations)?</td>
<td>Effective implementation of the road map is challenging. Further operational research in this area is required. Development of vector control tools is necessary.</td>
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</table>

### 1.5.5. Understanding of interventions required to prevent recrudescence

| Need to strengthen community health activities and knowledge sharing among experts, health staff and communities at risk. | Maintenance of an effective surveillance system | In very low endemic settings, secondary cases appear to be rare, so the risk of recrudescence is low, probably because transmission has actually stopped. | What is the effect of hot spots or migration on recrudescence? There are still new cases reported from few districts at northern part of Bangladesh | CCD and country programs need sensitization on the threat of recrudescence. Persistent hot spots challenge current understanding. Few areas have reached elimination, so there is little opportunity to evaluate the risk of recrudescence or study the mechanisms behind it. | Progress has been made on clarifying the implementation of other interventions beyond PC/MDA such as the operational manual for field use of molluscicides and the NTD-WASH toolkit. There is a need for better diagnostic and survey/impact assessment methodologies in order to collect the evidence and evaluate these interventions. | This aspect has been inadequately focused on with emphasis on PC. Environmental and non-treatment cohort reservoirs require emphasis. Research on which types of WASH interventions can impact disease burden is needed. | - Lack of definition of recrudescence for trachoma. - Limited understanding of what behavior change interventions are most effective for sustained hygiene practices. | Fragmented research groups and agendas limits progress towards answering key questions. More funding for research is needed. |

### 1.5.6. Understanding of interventions required to address disability and stigma

| Need to identify stigma and disability factors in treatment and prevention failures as well as implementation of a people-centered health care model for Chagas Disease | Early case detection and education of community | The nerve impairments in leprosy are life-long and the affected person therefore needs to manage these for the rest of their life. New nerve damage can also occur after patients have completed MDT successfully. Stigma also often continues after release from treatment. The concept of 'cure' and the experience of the person affected is often different. | Little evidence about feasibility and cost of national-level interventions. Poor implementation of activities | There is little agreement, interest, or discussion on how oncho interventions can be made more inclusive to ensure stigmatized populations or those with disabilities are reached, and on how to ensure the needs of those who have onchocerciasis-mediated life long conditions such as blindness, visual impairment of chronic skin conditions, are provided for in the health system. Guidelines are needed to support capacity building. | There is a difficulty in associating SCH with disability and stigma. The damage to organs is dependent on the schistosome species and can vary. Local health facilities do not necessarily link disability and damage to SCH or NTD disease managements. Diagnosis of FGS is very difficult and relies on local health centers knowing about FGS. Schistosomiasis is not considered a IDM/MMDP disease. | - Other than surgery to reduce pain, there is a lack of access to support services for those suffering from end-stage trichiasis and other causes of blindness. - While trachoma interventions are designed to reach the most vulnerable populations, there are no specific indicators tracking whether all individuals with disabilities and stigma are able to access interventions. | unitingtocombatntds.org | 2018 Action Framework Report p.24 of 57 | @combatNTDs |
### 2.0.0 STRATEGY

#### 2.1.0. Leadership & governance

<table>
<thead>
<tr>
<th>Need a clear and adapted Access Plan with the participation of main stakeholders</th>
<th>Improved understanding of transmission dynamics resulting in dog infections</th>
<th>Strategic plans need to be adapted to different epidemiological settings</th>
<th>Current roadmap targets not routinely focused on at international forums, as considered non-realistic. May be discussed in regional-level National Program Managers meetings. A new quantitative target is needed reflecting the second infection point towards true elimination (zero transmission)</th>
<th>GPELF behind on milestones, plans need to update for post-2020</th>
<th>There is a need for a global roadmap for oncho elimination to be collectively developed by multiple stakeholders. Additional guidance details and expansion are needed in several key areas, including: protocols and sampling strategies for conducting routine M &amp; E surveys, pre-stop MDA surveys, stop MDA surveys, and elimination verification surveys. Guidance on treatment priorities in loa loa endemic areas, areas in need of elimination mapping, and endemic areas not yet undergoing MDA is urgently needed.</th>
<th>Although high level morbidity control and elimination targets have been set in the NTD roadmap, there is a lack of clarity on how to assess the achievement of those targets and set new targets for post-2020.</th>
<th>There is a lack of alignment between Roadmap targets and STH strategic plan.</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Does not address all trachoma community challenges, including interventions targeting special populations;</td>
<td>- Funding is not fully available to meet the planned timescale set forth in Accelerating Towards 2020</td>
<td>- Funding challenges limit by availability and timeliness of data</td>
<td>- Lack of global alignment and political commitment.</td>
<td>- Request to evaluate current roadmap achievement as SCH risks being left behind in setting realistic post-2020 roadmap goals</td>
<td>- Lack of monitoring impact sub-nationally</td>
<td>- Lack of validated coverage data</td>
<td>- Insufficient funding for leprosy. Chemoprophylaxis is a new element in the 2018 Guidelines, so adoption will take time.</td>
</tr>
</tbody>
</table>

#### 2.1.1. Existence of global strategic plan for achieving Roadmap targets

| A global strategy should be aligned and implemented | Previous efforts never ended up in alignment planning. Not enough funding for a coordinated action plan at global level. Insufficient funding and capacity to implement at country level | MMDP tools needed | There is fragmented alignment with current guidance and a funding gap caused by the shift from control to elimination which causes challenges in supporting elimination activities | Request to evaluate current roadmap achievement as SCH risks being left behind in setting realistic post-2020 roadmap goals | Lack of knowledge and political commitment. | None |

#### 2.1.2. Extent of global alignment on strategic plan

| New indicators and progress monitoring methodology should contribute to better follow up and planning. | Criteria for verification of full elimination in 2030 need to be developed | Insufficient guidelines on monitoring of stigma and other DMDI issues. There are credibility issues in data reporting (eg. transparency in active case finding coverage). | Lack of reporting from countries, especially for MMDP. | For monitoring coverage targets, mechanisms are reasonably clear and transparent but mechanisms to monitor progress towards elimination need definition and improvement in timeliness of reporting. | For monitoring coverage targets, mechanisms are reasonably clear and transparent but mechanisms to monitor progress towards elimination need definition and improvement in timeliness of reporting. | None |

#### 2.1.3. Effectiveness and transparency of mechanisms to monitor global progress against stated goals

| New indicators and progress monitoring methodology should contribute to better follow up and planning. | Criteria for verification of full elimination in 2030 need to be developed | Insufficient guidelines on monitoring of stigma and other DMDI issues. There are credibility issues in data reporting (eg. transparency in active case finding coverage). | Lack of reporting from countries, especially for MMDP. | For monitoring coverage targets, mechanisms are reasonably clear and transparent but mechanisms to monitor progress towards elimination need definition and improvement in timeliness of reporting. | For monitoring coverage targets, mechanisms are reasonably clear and transparent but mechanisms to monitor progress towards elimination need definition and improvement in timeliness of reporting. | None |

#### 2.1.4. Extent of adoption of global NTD control/elimination guidance by national programs and partners

<table>
<thead>
<tr>
<th>To implement and adapt WHO/PAHO guidelines in each country under technical and advisory supervision</th>
<th>Increased resources are needed to accompany countries for the validation and verification of elimination process</th>
<th>Insufficient funding for leprosy. Chemoprophylaxis is a new element in the 2018 Guidelines, so adoption will take time.</th>
<th>MMDP tools and guidance needed. Funding challenges limit programmes maintaining standard</th>
<th>More detailed guidance is needed to ensure global guidance is adopted in a uniform way. NOECs are needed to promote adoption within national programmes.</th>
<th>Guidelines often adapted on the basis of funding availability and country context resulting in populations being missed by interventions. Very limited approaches to snail control and WASH. Guidelines require updating in line with identifying better defined targets for SCH.</th>
<th>STH control seems to have been well adopted by NTD programme managers as evidenced by the numbers of countries regularly contributing data to the PCT databank. Fewer countries have no guidance in place as programs have been developed</th>
<th>- Lack of adequate financial resources to implement all guidance</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Challenges in establishing partnerships with broader, non-health actors in the development space. This is a key component of integrating trachoma services and interventions into the broader health system.</td>
<td>- Adoption of elimination guidance by national programmes in Asia is strong. No relevant guidance for control in Africa.</td>
<td>- Adoption of elimination guidance by national programmes in Asia is strong. No relevant guidance for control in Africa.</td>
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<tr>
<td><strong>2.1.5. Evidence of commitment at national level to the goals of NTD control/elimination</strong></td>
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<tr>
<td>Strengthening planning and implementing capacities and commitment of local and national Health authorities (with the support of an expert committee, e.g.)</td>
<td>- More efforts from countries are needed to increase the level of commitment to support HAT control and surveillance. - If awareness of the disease wanes and there is an insufficient country ownership of the elimination process and goals, there could be a risk of deceleration of control and surveillance activities. The consequences of such deceleration have already been painfully experienced in the recent history of HAT.</td>
<td>Questionable commitment in countries that haven't started or scaled MDA; likewise, questionable commitment to MMDP</td>
<td>Though commitment may be high, funding is not always a priority. Advocacy is needed to educate ministries of low performing or low resource countries. There is a risk of overburdening the national system through uncoordinated or duplicated efforts and poor integration.</td>
<td>Donor-dependence with commitment not translated into domestic funding which undermines country programme ownership. Lack of clear control/elimination targets can undermine commitment resulting in SCH programmes considered an add-on to other PC-NTDs or conversely, over-amplification of what is feasible either epidemiologically or within the envelope of available funding. Long-term investment to reach elimination/interruption of transmission goals can be a deterrent.</td>
<td>Generally strong commitment in the context of many competing health priorities. Difficult for many countries to provide financing support.</td>
<td>Demonstrated fulfilment of country budget line items.</td>
<td>Varying levels of commitment and capacity of national health systems and competing donor funded programmes.</td>
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<tr>
<td><strong>2.2.0. Operational &amp; normative guidelines</strong></td>
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<tr>
<td><strong>2.2.1. Clear understanding of end points and operational approach to achieve goals</strong></td>
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<tr>
<td>A clearer view on the strategies to achieve the SDG and roadmap goals (as the vertical transmission control, e.g.) should be considered. Chagas should progress towards elimination of disease as a global health problem. The total control of transmission as well as the scaling up of access to all those affected are key.</td>
<td>Operational approach needs to be adapted to different settings and changes</td>
<td>Leprosy needs a clear, globally agreed, credible statement of endpoints and operational approaches to reach them.</td>
<td>Need for stakeholder consensus of whether or not to support elimination of transmission</td>
<td>There is a need for intermediate milestones and clarity around the operational approach to reach the endpoints. There is ongoing debate about sample size and methods for verification of elimination. MDA in loiasis areas needs clearer guidelines.</td>
<td>There is a lack of consensus that the current targets are meaningful based on the complexity of the transmission pathway. Updated definitions of targets are required to align with new, more sensitive diagnostic tests and based on strong evidence. There is no agreed target for interruption of transmission which likely requires a sampling approach in humans, probably snails, and perhaps zoonotic reservoirs.</td>
<td>This is a major challenge for STH control programme sustainability. WHO 2020 targets may be met, however there is no end date that can be set without risking resurgence. It is widely understood that PC needs to be augmented with other interventions and economic improvement, however experimental evidence on many aspects has been difficult to compile. This does lead to lack of clarity and ultimately-deprivation of supportive activities/policies, especially WASH. There are major opportunities to work with the WASH sector as the sector is making its own progress towards SDG goals - this requires clear operational guidance.</td>
<td>Clearer endpoints for control targets are necessary</td>
</tr>
<tr>
<td><strong>2.2.2. Clear process to certify/validate/etc. achievement of Roadmap goals</strong></td>
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<tr>
<td>A comprehensive standardized process of accountability and validation should help with the contribution of all private and public stakeholders</td>
<td>Criteria for validation of rhodesiense HAT elimination as public health problem need to be defined</td>
<td>Leprosy has no clear, globally agreed, credible statement of endpoints or goals and how they are to be assessed</td>
<td>Some continued misunderstandings regarding MMDP data needed, particularly among some supporting partners or other disease communities</td>
<td>Dossier guidance needs additional detail to guide programs and countries as to what data to collect at each stage of the elimination effort in order to have elimination verified. Understanding at the national level is not uniformly high.</td>
<td>A process to verify elimination as a public health problem and interruption of transmission is needed.</td>
<td>Coverage reported to PCT; however ongoing rounds of MDA required to sustain this. No certification of achievement.</td>
<td>- Level of evidence required to demonstrate achievement of trichiasis goals; - Variable quality and availability of historical data that is necessary for the dossier.</td>
</tr>
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</table>

**2.3.0. Agile collaboration & innovation**

2.3.1. Existence and effectiveness of global coordination body that facilitates communication and synergy between stakeholders

Global networks on Chagas must have a stronger voice to achieve a better awareness of health systems, civil society collaboration and political actions in favor of the affected populations. Good steps in general agreement in mother-to-child transmission control initiatives.

<table>
<thead>
<tr>
<th>Strength of GWEP varies with country</th>
<th>Social stability and insecurity are the main challenges in some areas</th>
<th>Focus on short term goals and lack of project cycle management approach</th>
</tr>
</thead>
</table>

- More efforts from countries are needed to enhance cross-border collaboration.
- Low global coordination between associations of people affected. GPZL is still in its infancy. Resources are critical to support its strategies for an aligned global research agenda and capacity development and zero-leprosy toolbox at country level.

If GAELF aims to increase advocacy activities, need specific staff with these skills.

- Improvement is needed in communication, collaboration and sharing of results and approaches between stakeholders at all levels. Countries are not well represented in global spaces. Clarity is needed about roles and messaging.

The GSA has strengthened its presence and acts as a convening body for many in the community. It is still growing and needs to continue to strengthen. Many topics identified to address to accelerate progress therefore robust coordination will be required.

Communication is acceptable; coordination and commitment to results could use improvement. Regular and substantive engagement of STH stakeholders is necessary to make progress.

The annual GET2020 Alliance meeting, which has been instrumental in bringing the trachoma community together since the beginning of the program, builds consensus, and ensures consistency in approach across programs, was not held in 2018. This creates challenges for effective resource coordination and shared problem solving. The trachoma community needs to continue to bring in more WASH stakeholders as transition to elimination draws closer.

The challenge is to increase the cost-effectiveness of the full range of interventions for leprosy and other NTDs by interfacing with the One Health interface between human and animal African trypanosomiasis is desired. Enhanced community awareness in disease transmission areas is required to facilitate referrals of suspected cases to passive screening facilities.

- Interventions that also interface with control of animal trypanosomosis and possible synergy at the One Health interface for leprosy and other NTDs by combining them, without losing focus on leprosy. WHO Global Leprosy Program based in Delhi and not within NTD Geneva: this positions GLP closer to 75% of global leprosy, but weakens sectoral communication and coordination.

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- Limited support for WASH activities, hence, few interested and committed stakeholders. Need for development and use of educational materials for lymphedema management. Need improvement in coordination between LF and onchoceriasis and STH.

Oncho benefits from capitalizing on close collaboration with LF. Collaboration and coordination between PC and IDM diseases needs to be improved. Collaboration in data use and sharing could use improvement. Relationships with WASH and Education could be strengthened.

WASH is likely of critical importance for elimination goals but operates in silo from treatment programmes. Lack of multi-sectoral SCH action plans inclusive of WASH and behavioural change interventions.

Intersectoral collaboration is complex. There is generally strong collaboration with ministries of education. Good integration with schisto control programs but less ideal with other NTDs.

- Both the funding and delivery of trichiasis surgeries are typically vertical programs within the Ministries of Health, which makes them less sustainable within the national infrastructure. More work is needed to integrate trichiasis surgeries within the general eye health system.

The trachoma community’s collaboration with the other NTD programs needs more work, particularly at the international level, in areas like best practice and knowledge sharing.

The trachoma community needs work on joint planning and coordination with WASH and education.

2.3.2. Adaptability of approach and plans in case of intervention failures or other programmatic challenges

An expert advisory committee could help to develop flexible plans to be adapted to program failures or unexpected events.

- Interventions that also interface with control of animal trypanosomosis and possible synergy at the One Health interface for leprosy and other NTDs by combining them, without losing focus on leprosy. WHO Global Leprosy Program based in Delhi and not within NTD Geneva: this positions GLP closer to 75% of global leprosy, but weakens sectoral communication and coordination.

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The trachoma community needs work on joint planning and coordination with WASH and education.

Transition of responsibilities for maintaining elimination of trachoma post-validation falls on national programs, but there is not yet guidance in place to define (recrudescence or the methodologies appropriate for monitoring for it).

2.3.3. Effectiveness of collaboration with other NTD programs, and sectors such as WASH and education.

A model of people and community-centered approach should integrate NTDs for which affected communities are at risk of infection.

Formal integration of activities to ensure GW is discussed during other program training and to allow integration of sensitization activities is not always evident.

- Interactions that also interface with control of animal trypanosomosis and possible synergy at the One Health interface for leprosy and other NTDs by combining them, without losing focus on leprosy. WHO Global Leprosy Program based in Delhi and not within NTD Geneva: this positions GLP closer to 75% of global leprosy, but weakens sectoral communication and coordination.

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The trachoma community needs work on joint planning and coordination with WASH and education.
### 2.4.0. Integration into national health systems

**2.4.1. Extent of guidance and planning at global and national levels to integrate NTD programs into existing national systems (e.g. health, education, water), including for delivery of interventions required after reaching Roadmap goals.**

Lack of resources and implementation mechanisms for the planning and integration of NTDs programs in health systems. There is no formal integration plan within some Ministries of Health for Guinea Worm.

Integration of HAT control activities into general health system is essential but very challenging in peripheral rural areas where the disease is entrenched and the health system is weak. HAT programmes cannot be in the driver seat of the reinforcement of the peripheral health system.

Stigma is perceived to be a barrier for integration, but in reality, integration has been shown to have a destigmatising effect. Leishmaniasis stand-alone services can also be a barrier for integration.

Need more examples to inform WHO policy guidance for post-validation surveillance and sustainability. LF interventions largely donor dependent.

There is no need for more domestic funding to maximize integration. More documentation is needed to fully assess the situation.

Moving towards integration of SCH strategies into existing systems needs to be reflected in updated roadmap goals. It will require a significant conceptual and organizational shift to move to integrating into existing national systems and operate cross-sectorally.

Integration is inconsistent and country-specific solutions are needed.

Guidance needed for post-validation surveillance.

Not all countries are yet fully transitioning their trichiasis programs into existing health infrastructures.

### 3.0.0. PUBLIC HEALTH INTERVENTION

### 3.1.0. Service delivery

- **Basic development infrastructure varies considerably across all risk areas.**

  Basic development infrastructure varies considerably across all risk areas. Limited evidence base and subsequent lack of investment in non-PC interventions and a lack of coordination at the programme level. Access to veterinary public health services is variable and important where zoonotic interventions play a role in transmission but is becoming increasingly important outside areas where hybridization is occurring.

  Geographic coverage remains poor. WASH interventions still has major gaps. Limited behavior change focus on hygiene practices.

- **Obstacles to access due to stigma/discrimination.**

  Stigma is perceived to be a barrier for integration, but in reality, integration has been shown to have a destigmatising effect. LF interventions largely donor dependent.

- **Not much data about availability at global level. Lack of dissemination of guidance.**

  Not much data about availability at global level. Lack of dissemination of guidance. Lack of donor support.

- **Limited evidence base and subsequent lack of investment in non-PC interventions and a lack of coordination at the programme level.**

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- **Geographic coverage remains poor. WASH interventions still has major gaps. Limited behavior change focus on hygiene practices.**

### 3.1.2. Equitable access to quality individual disease management and disability prevention interventions

- **Access is not equitable.**

  Access is not equitable.

  While access to trichiasis surgery is improving, major gaps still exist.

- **Reaching vulnerable groups such as migrants and marginalized populations is challenging.**

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More data on disability are needed. Chronic patients should be included in all interventions. Adapted prevention measures and disease management guidelines should be implemented in remote areas with access barriers.

Basic development infrastructure varies considerably across all risk areas.

- **Control and surveillance have weakened in a few countries, mainly owing to security constraints (e.g. Central African Republic and South Sudan).**

  Control and surveillance have weakened in a few countries, mainly owing to security constraints.

- **Enhanced community awareness in disease transmission areas is required to facilitate referrals of suspected cases to passive screening facilities, especially if active screening campaigns are scaled-back and focused interventions are targeted to the highest risk areas.**

  Enhanced community awareness in disease transmission areas is required to facilitate referrals of suspected cases to passive screening facilities, especially if active screening campaigns are scaled-back and focused interventions are targeted to the highest risk areas.

- **Addressing the problem of refugees moving from endemic to non-endemic areas requires attention.**

  Addressing the problem of refugees moving from endemic to non-endemic areas requires attention.

Multiple barriers: long duration of MDT, stigma, very equitable, access by women, other vulnerable groups. Weaknesses in health system structure, low capacity in wound care, managing complications, etc. Due to limited resources and stigma, rates of depression and anxiety are known to be high among persons affected by lympho and their families.

Not much data about availability at global level. Lack of dissemination of guidance. Lack of donor support.

Increased disease management around onchocerciasis is needed. Improving services depends on understanding patient behaviors and statuses, but this can be challenging.

Investments are dominated by SAC morbidity control which limits outreach to other at risk groups, particularly those at risk of developing genitalic SCH. Control measures are focused on prevention but there is no case management guidance or visibility for those with advanced morbidity.

- **Reaching vulnerable groups such as migrants and marginalized populations is challenging.**

  Reaching vulnerable groups such as migrants and marginalized populations is challenging.
## Appendix 5
### 2018 Action Framework Challenges Summary

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<th>Trachoma</th>
<th>Visceral Leishmaniasis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Improvement and change of priorities; vulnerability approach to population at risk.</strong></td>
<td>Basic development infrastructure varies considerably across all risk areas.</td>
<td>Multiple methods and approaches are needed to tackle stigma, not only specific services (e.g., advocacy, education, etc.). Physical distance, lack of ID cards, awareness/access barriers in receiving entitlements. Advocacy is normally required for DPOs to accept people affected by leprosy. Limited evidence of intervention effectiveness</td>
<td>How to balance scaling up basic package everywhere vs. including full package (with rehab and inclusion)? How to affect services available outside of remit of LF NPs? Little to no current support outside of demonstration projects.</td>
<td>Rehab and inclusion are not monitored for oncho. Such services are not generally included in implementation programs.</td>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
<td>Other than surgery to reduce pain, there is a lack of access to support services for those suffering from end-stage trichiasis and other causes of blindness. While trachoma interventions are designed to reach the most vulnerable populations, there are no specific indicators tracking whether all individuals with disabilities and stigma are able to access interventions.</td>
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</table>

### 3.1.3. Equitable access to quality rehabilitation and inclusion interventions

| Program monitoring and surveillance at local level is challenging. Improved prevalence data quality is necessary to determine where to scale up interventions. Turnover of technical personnel is a barrier to maintaining commitments. | Maintaining surveillance and intervention activities in insecure areas, and those with limited access during the rainy season. | The sustainable elimination of HAT requires the reinforcement of the peripheral health system, but HAT programmes cannot be in the driving seat of this process. | Reinforcement of ownership of the elimination process and targets by endemic countries is required. | Development of improved tools is required. Retention of knowledge and skills at the peripheral health system is a challenge as the number of cases falls. | Maintaining the capacity of existing services within the health system and relevant sectors. Roadmap goals are not agreed. End-game scenarios not yet defined. | Need more data on cost-effective post-validation surveillance methodologies. Need more evidence on how best to ensure health systems continue providing hydrocele surgery and lymphedema management services. | Post treatment surveillance plans and resources for M&E are needed. | No defined surveillance and intervention activities once the roadmap goals have been achieved. A new/revised diagnostic approach will be needed for elimination certification. | The end point is unclear and there are major sustainability issues. Surveillance systems are not well-developed. |

### 3.1.4. Coverage of post-roadmap-goal surveillance and interventions activities

| Improvements needed | Hydrogeology in some high risk areas is not conducive for the harvest of potable water. | Impacts of socioeconomic and security conditions are extremely critical but outside the scope of the HAT program | Socioeconomic growth does not necessarily translate into better leprosy services and has little impact on stigma | Few resources available or plans to address | Such activities are frequently outside of national program activities. | A stronger link needs to be established between the impact of SCH and socioeconomic conditions through evidence generation that will help inform the balance of effort in investing in environmental interventions or continuing a focus on morbidity control while awaiting secular socioeconomic improvements | - Inability to understand the improvement of access to WASH over time and measure its impact on trachoma prevention. - Most resources are being dedicated to elimination activities, leaving less availability of funding from the NTD donor community for direct investment into overall development and WASH implementation. |

### 3.1.5. Sustaining impact

| 3.2.0. Sustaining impact | | | | | | | | As elimination is achieved in countries, donor funding and commitment will necessarily reduce. Countries and partners need to consider post-validation approaches early. | Integrating surveillance with other diseases is necessary to sustain the gains. |

### 3.2.1. Coverage of post-roadmap-goal surveillance and interventions activities

| 3.2.2. Improvement in socioeconomic and environmental conditions required to prevent recrudescence | | | | | | | | This is a multisectoral issue and requires advocacy at all levels | | | | |
1.1.0. ENABLING ENVIRONMENT

1.1.1. Healthcare financing

- Advocate for domestic financing in national Chagas programs and interventions at all levels (including community health work and additional resources for local authorities). More efficient resource planning must be done and campaigns to stimulate the demand and attract more donors to the cause
- Identify additional funders and partners
- Conduct fundraising through a combination of international donors (and where possible domestic funding)

No new action needed in 2019

- Evaluate best practices for national programmes and any synergies in the end-game and beyond

- Advocate for improved domestic funding, new donors, and increased funding from current funders. Focus needed for MNDP

- Advocate for donor/implementer partnerships
- Enhance global and regional advocacy

1) Advocate for domestic funding
2) Advocate for donor/implementer partnerships
3) Enhance global and regional advocacy

1) Advocate for domestic funding

- Pipeline analysis of global treatment requirements and financing gaps to estimate funding need

- Strengthen national advocacy and communication links to engage central government to allocate fiscal space to effectively manage STH within the health delivery system

- Coordinate of multiple funding sources where overlaps occur

- Achieve better donor coordination (e.g. between programs for STH, SAs, and adults) to improve effectiveness and efficiency

2) Advocate for funds to encourage allocation of domestic resources

- Continue to encourage national programs to determine how to include a budget line for trachoma within their national budgets

1) Complete a funding gap analysis
2) Monitor availability of existing funds to ensure that there is sufficient support to complete programmatic activities
3) WHO will continue producing financial country profiles

1.1.2. Timeliness of funding for program requirements

- Pipeline analysis of global treatment requirements and financing gaps to estimate funding need

- Strengthen national advocacy and communication links to engage central government to allocate fiscal space to effectively manage STH within the health delivery system

- Increase engagement from affected people in the role of supporting the timeliness of responses. To incorporate in national and local level additional resources to leave no people behind

- Advocate for domestic financing
- Advocate for donor/implementer partnerships
- Enhance global and regional advocacy

A coordinated effort among STH stakeholders is required to make progress. Information sharing needs to increase and be more transparent

- Achieve better donor coordination (e.g. between programs for STH, SAs, and adults) to improve effectiveness and efficiency

1) Advocate for domestic funding
2) Advocate for donor/implementer partnerships
3) Enhance global and regional advocacy

- Funding gap analysis to define the scale of the needs across endemic countries

- Work with stakeholders to develop a Global Business Plan incorporating disease burden, value for money of interventions to encourage allocation of domestic resources

- Strengthen advocacy with donors and Governments through GSA

1.1.3. Clear identification of the funding gaps

- Advocate for domestic financing in national Chagas programs and interventions at all levels (including community health work and additional resources for local authorities). More efficient resource planning must be done and campaigns to stimulate the demand and attract more donors to the cause

- Identify additional funders and partners
- Conduct fundraising through a combination of international donors (and where possible domestic funding)

No new action needed in 2019

- Gaps are identified but budget sources and disaggregated allocation. Undertake gap analysis. Align budgets with the goals of zero leprosy

- Partners to improve costing for surveillance and MMDP activities while further advocating for domestic and international funding

1) Advocate for funds to support National Oncho Elimination Committees in each endemic country
2) Conduct NOEC-led funding gap analyses in endemic countries
3) Advocate for assessment costs to be included in MDA budgets
4) Advocate for funding to support underserved areas (e.g. Conflict zones)
5) Develop a detailed cost analysis for laboratory component and surveys
6) Determine how support for lab analysis will be provided

- Development of a robust SCH gap analysis disaggregated to implementation level

- Strengthen engagement with national and international stakeholders to focus investment on STH as a basic human right and a means to achieve UHC.

- Prioritize identification of funding gaps especially during pivotal stages in program development, during the redesign/updates of master plans, at the beginning of the establishment of a deworming program

- As more countries begin transitioning, additional data needs to be collected to prepare donors for the increase in costs to find and operate on trichiasis cases.

- Increased continued funding for F&E (i.e. WASH and hygiene interventions)

1) Complete a funding gap analysis
2) Monitor availability of existing funds to ensure that there is sufficient support to complete programmatic activities
3) WHO will continue producing financial country profiles

1.1.4. Resource mobilization plan for meeting identified funding gaps is in place

- Put in place elements of Access Plan designed to attract the interest of new funding sources
- Continued coordination with key partners and stakeholders
- Develop a long term funding plan, including a quantification of the needs and a campaign to mobilize resources to meet needs.
- GP2L (Global Partnership for Zero Leprosy) focusing in 2019 on identifying gaps at global level in research and leprosy toolkit and promoting to funders

- Improve cost estimates for activities (surveillance and MMDP, etc) with increased advocacy and planning for post 2020

- Funding gap analysis to define the scale of the needs across endemic countries

- Work with stakeholders to develop a Global Business Plan incorporating disease burden, value for money of interventions to encourage allocation of domestic resources

- Strengthen advocacy with donors and Governments through GSA

- A coordinated effort among STH stakeholders is required to make progress. Information sharing needs to increase and be more transparent

- Update Cost Calculator and Blueprint for Action to better inform resource mobilization efforts

- Develop resource mobilization plan with multiple stakeholders.
## 1.2.0. Health information systems

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### 1.2.1. Availability and quality of epidemiological data (ex. completeness, age, data, and accuracy)

- Promote collection of prevalence data by countries in order to understand the real burden and distribution of disease as a basis for cost estimates and scale-up of programs. - Encourage countries to contribute Chagas data into new WHO data system. - Establish compulsory reporting of chronic cases in all endemic countries. - Scale up screening of women of reproductive age, pregnant women and newborns. - Advocate for primary health care systems to include screening for Chagas among populations at risk of Chagas.

### 1.2.2. Data for action: effective use of data to identify challenges and improve interventions

- Continue to advocate with MoH Angola to formally insert GW in the national health information and surveillance system. - Collaborate with partners and national ministries of health to formalize integration of GW activities into redundant outreach or surveillance activities.

## 1.2.3. Extent of integration of essential NTD data collection and monitoring activities into national health information systems

- Address Chagas data quality issues in national health reports (e.g. standardized indicators, complete reporting at all levels of government and all subnational regions). - Continue to advocate with MoH Angola to formally insert GW in the national health information and surveillance system. - Collaborate with partners and national ministries of health to formalize integration of GW activities into redundant outreach or surveillance activities.

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### 1.3.0 Access to medical products and technologies

#### 1.3.1. Supply of drugs, products and technologies required for diagnosis and intervention (ex. drugs, vector control tools, RDTs and aids for people with disabilities)

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<td>- Improve supply chain management of BNZ and Nifurtimox (address delays and shortages)</td>
<td>- Ensure that Drugs are widely registered</td>
<td>- Generate awareness in decision makers of all areas to increase budgets for the prevention, diagnosis and treatment of Chagas disease</td>
<td>- Quantify and address shortages of essential diagnostic supplies at national level</td>
<td>- Robust research agenda employed to identify, new technologies (vaccines), and other interventions</td>
<td>- Establish a new access model for HAT diagnostic tools similar to access to medicines approach.</td>
<td>- Organise and mobilise funds for allocation of PEP drugs. Improve availability of drug supplies to manage disease complications. Prioritize access to disability aids which are not seen in some programmes.</td>
<td>- Partners to advocate for strengthening of in-country supply chains. Further training and support for awareness of tools and processes. Increased OR for RTDs to fill existing gaps</td>
<td>- Work with WHO, ESPEN, Standard Diagnostics, and other key stakeholders to streamline the RDT procurement process and provide increased support to country programs.</td>
<td>- Advocate for clarity around ELISA methodology and for accelerated training of labs to use standard ELISA protocols.</td>
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<td>- Train health personnel and municipal governments in planning and management of logistics of materials, supplies and medicines necessary for the program</td>
<td>- Analyze systematic distribution issues and develop a plan to address them integrated with national health systems.</td>
<td>- Find solutions to maintaining stock in low endemic areas. Include mapping/links to HIS</td>
<td>- National partners to submit applications earlier; working with NP to improve logistical challenges.</td>
<td>- 1) Work with WHO, ESPEN, SD, and other key stakeholders to streamline the RDT procurement process and provide increased support to country programs 2) Advocate for clarity around ELISA methodology and for accelerated training of labs to use standard ELISA protocols 3) Advocate for integrated supply chain</td>
<td>- Support for review of supply chain and reverse logistics where required.</td>
<td>- Implement tool for short-term forecasting (1-3 year) Support countries to provide complete, quality, and timely information Improve last mile supply chain and inventory management</td>
<td>- The assumption is that the existing systems will be maintained. No additional actions required in 2019. This remains of critical importance.</td>
<td>1) Capacity building at national level 2) Develop proper supply chain and inventory management procedures</td>
<td></td>
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#### 1.3.2. Effectiveness of the allocation system, supply chain and logistics for the above

| - Advocate for antenatal screening capacity in key regions | - N/A | - Participate in efforts advocating for UHC, providing examples from HAT program | - Geographical gap analysis. Advocate for integrated wound care services. | - Advocate for uniform MMDP implementation with partners increasing technical support and assistance (including clinical capacity building in budgets.) | - Advocate for funding to be directed towards increasing lab infrastructure and personnel and building clinical capacity 2) Establish test sources and lab system for oncho testing | - Develop training programs and new diagnostics. | - Focus on providing in-country supply chain capacity development trainings. - Include in budget a line item to support effective infrastructure. | - 1) Capacity building, especially in remote areas and conflict zones 2) Promote infrastructure and equipment maintenance |

#### 1.3.3. Availability of required physical assets and infrastructure (ex. lab and clinical capacity, etc.)

| - Advocate for antenatal screening capacity in key regions | - N/A | - Participate in efforts advocating for UHC, providing examples from HAT program | - Geographical gap analysis. Advocate for integrated wound care services. | - Advocate for uniform MMDP implementation with partners increasing technical support and assistance (including clinical capacity building in budgets.) | - Advocate for funding to be directed towards increasing lab infrastructure and personnel and building clinical capacity 2) Establish test sources and lab system for oncho testing | - Develop training programs and new diagnostics. | - Focus on providing in-country supply chain capacity development trainings. - Include in budget a line item to support effective infrastructure. | - 1) Capacity building, especially in remote areas and conflict zones 2) Promote infrastructure and equipment maintenance |
### 1.4.0. Health workforce

**1.4.1. Availability of health workers with requisite skills and support**

- Hold clinical training seminars for healthcare worker groups.
- Increase training and development of educational tools.
- Enhance national level human resources in Chagas management.

**NSSCPs to develop national plans for staff training, awareness and motivation within the national health systems.**

- Promote digital knowledge to maintain staff trained. Pilot digital diagnosis platform (e.g. sending pictures to national/global diagnostic centre). Creative approaches to formal training (e.g. online continuous medical education, incentivizing credits, etc.). Skilled persons affected by leprosy empowered to have a health role.

**Integration of NTDs into core pre-service curriculum for all HW.**

- Continue support and training of CDDs to ensure coverage and increase in low coverage areas.
- Expand training of surgeons and staff for MMDP.

**1.4.2. Access to quality training programs and materials for healthworkers for the transfer and maintenance of essential skills**

- Develop and disseminate protocols/SOPs to train workers and encourage integration into health curricula.

**More support for frontline health workers (include deworming activities in job descriptions of community health workers, teachers, etc.; provide compensation).**

- Build capacity to implement M&E activities in country (for example, include training for FELTP with NTD programs, support national programs to implement M&E activities).

**1.5.0. Scientific understanding**

**1.5.1. Understanding of transmission pathways, vectors, reservoirs, and recrudescence**

- Develop and distribute locally-appropriate training materials via websites and in person.
- Improve training strategy, including promoting the implementation of continuous training programs.

**Formalize collaboration during training meetings.**

- Include specific training into the curricula, enhancing destigmatising attitude to leprosy.
- Training of trainers.

**Innovative methods.**

- Advocate for research funding into the epidemiological role of asymptomatic human carriers, parasites in the skin, and possible animal reservoirs. Follow up on COR-NTD session.

**Priority - Dissemination of WHO MMDP toolkit to national programmes.**

- Partners to support and aid in-country training.
- Continual review, and updating of material.

**1.5.2. Ability and feasibility of current diagnostics to provide accurate view of disease epidemiology to inform decision making**

- Conduct operational research where needed.

**Support for review and standardisation of training materials.**

- Provide quality training opportunities to improve competency.

**Identify countries doing this well and showcase lessons learned.**

- Train master TT surgeon trainers at the country level.
- Train adequate numbers of graders to meet large number of impact and surveillance surveys planned for 2019, balancing against other program requirements.
- Identify adequate numbers of ophthalmologists to address recurrence and post-op TT complications. This will require highly specialized trainers and materials.

**1.6.0. Policy and systems**

**Appendix 6**

- Robust research agenda in place to determine precise pathways of transmission so as to guide interventions.
- Advocate for research funding into the epidemiological role of asymptomatic human carriers, parasites in the skin, and possible animal reservoirs. Follow up on COR-NTD session.

**Continued support for modelling and ensure correct documentation of survey results.**

- Continue research and development for a more specific diagnostic test suitable for low burden setting.

**Research into diagnostic test is on workplan of GP2L research group.**

- OR support needed for RDT trails with manufacturers supporting investigation into problems and improvements.

**1.3.0. Policy and systems**

- Work with maternity services in high risk areas to implement screening.
- Reinforce the host-parasite interaction research pathway.

**Robust research agenda in place to determine precise pathways of transmission so as to guide interventions.**

- Advocate for research funding into the epidemiological role of asymptomatic human carriers, parasites in the skin, and possible animal reservoirs. Follow up on COR-NTD session.

**Continued support for modelling and ensure correct documentation of survey results.**

- Contribute to the development of a more precise diagnostic test for low burden settings.

**Research into diagnostic test is on workplan of GP2L research group.**

- OR support needed for RDT trails with manufacturers supporting investigation into problems and improvements.

**1.3.1. Epidemiology**

**Standardization of diagnostics and accompanying protocols.**

- Continue research to develop new diagnostics.

**Create use definitions for approved tests.**

- Improve use and validation of existing rapid diagnostic techniques such as POC-CCA, and support development of POC diagnostic techniques in the pipeline such as CAA.

**1.3.2. Monitoring and Evaluation**

**Conduct operational research where needed.**

- Conduct operational research where needed.

**Support for review and standardisation of training materials.**

- Provide quality training opportunities to improve competency.

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- Train master TT surgeon trainers at the country level.
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### 1.5.3. Ability of survey methodology or other tools to provide accurate view of disease epidemiology to inform decision making

- Advocate for research funding
- Advocate for alignment around research agenda

- Need to define recrudescence for trachoma;
- Once defined, need to demonstrate that the TT thresholds have been reached for the dossier.
- Continue to collect and analyse results from Stronger SAFE

#### 1.5.4. Existence of effective tools and intervention(s) capable of achieving Roadmap targets

1) Advocate for research in this area, and for examples, case studies, training and supporting materials to be developed.
2) Countries should be encouraged to plan the transition from treatment to verification and surveillance as early as possible.
3) Assessments should be conducted in countries that have reached their targets

#### 1.5.5. Understanding of interventions required to prevent recrudescence

- Mobilize resources for research on disease progression and responsiveness to treatment
- Adapt active and passive case-finding strategies and methods to low burden setting.
- Design effective community sensitization tools informed by social science research.

- Identify clear targets on access to diagnosis and treatments
- Carry out operational research to test new tools (e.g. drones)
- Redesign/refine current strategies (as defined elsewhere in this table) to adapt to low burden setting.

- Research on increasing community adoption of vector control measures and a culture of prevention
- See actions defined elsewhere
- Implement WHO guidelines in countries, including PEP

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<td>Mapping efforts need to be expanded to produce data on endemic pockets</td>
<td>Focus needed on OR and analysis of results. Development of new protocols and standardized methods</td>
<td>1) Advocate for and contribute towards training and guidance for RDT use and survey design 2) Standardize use of epidemiological diagnostics 3) Finalize guidelines 4) Test new approaches as needed. 1) Highlight roadmap progress and achievements 2) Complete desk reviews to assess the epidemiological situation of each endemic country 3) Roll-out of new approaches to Loa mapping</td>
<td>Develop M&amp;E preferred practices that are better at accounting for focal nature of schistosome infections. i.e Precision/micro mapping protocols and methodologies. Work on morbidity indicators and targets. Define/designed evidence based targets for morbidity &amp; elimination and develop methodology to reach at-risk groups Develop/implement/feld test toolkit for integrated approach (e.g. field test of WASH-NTD toolkit) New guidance critically needed.</td>
<td>Programs to continue collecting data on TT case finders and document their lessons learned; Clarify the level of evidence needed to demonstrate that the TT thresholds have been reached for the dossier. Continue to collect and analyse results from Stronger SAFE</td>
<td>1) Organize regional workshops with policy makers to adopt optimum vectors and transmission surveillance strategies and provide technical and financial support for these programmes. Identify centres of excellence that can develop climate-based models for prediction of VL outbreaks and monitoring of control programmes. Advocate for funding to support development of standardized survey methodology.</td>
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<td>1.5.6. Understanding of interventions required to address disability and stigma</td>
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<td>Mobilize resources for interventions and monitoring and evaluation, provide training to health workers in nerve function assessment, diagnosis and management of reactions and methods to reduce stigma.</td>
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<td>Link with other programmes (mental health and disability services). Evaluate and explore cost effective scale up for sustainable intervention.</td>
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<td>1) Advocate for disability and stigma to be explicitly addressed in national elimination plans. 2) Integrate and use lessons learned from leprosy, LF and podoconiosis. 3) Support implementation of DMDI activities 4) Encourage more clinical interest in onchocerciasis patients</td>
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<td>Promote operational research for the IDA/MMDP aspect of schistosomiasis for established severe morbidity cases and for FGS cases.</td>
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<td>- Strengthen the referral system to ensure that those identified with trichiasis who don't accept surgical services have future opportunities for services when and if desired. - Link individuals suffering from blindness to disability support services and eye health services.</td>
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2.0.0. STRATEGY

2.1.0. Leadership & governance

2.1.1. Existence of global strategic plan for achieving Roadmap targets

Define a clear, agreed Access Plan with WHO/PAHO and participation of main stakeholders, and country level targets

Integrate scientific learning into the current suite of interventions. No new action needed in 2019

New achievable targets and agreed operational plans should be made at both global and country levels. WHO to update plan

1) Advocate for and work with stakeholders to promote the development of guidelines and protocols to support strategic plans to achieve roadmap targets 2) Maximize use of "Stamp Out Oncho" campaign 3) WHO definition needed

Evaluate the achievement of the current roadmap targets and based on the evidence, define and agree updated realistic targets for SCH. Develop a SCH action plan to progress priorities

Define and communicate the post-2020 strategy. Continue the working group on special populations; - Transparent conversations between donors for coordination; - Provide concentrated advocacy efforts to support countries behind the timeline

2.1.2. Extent of global alignment on strategic plan

- Global strategic plan has to be defined transparently and with representation of stakeholders WHO, TCC and CDC to continue to keep alignment, coordination and roll out of strategic interventions No new action needed in 2019

Investment needed to operationalize GP2L and other stakeholders to the WHO monitoring missions could be one approach. Prioritization of existing indicators and define new ones according to identified gaps. Continued involvement of GAELF in disseminating/collating feedback from community

1) Coordinate with NGOs and other stakeholders and encourage greater coordination and information sharing Support development of an SCH strategic plan Define and communicate the post-2020 strategy. Where possible, continued search for new partnerships

2.1.3. Effectiveness and transparency of mechanisms to monitor global progress against stated goals

Disseminate validation procedures to country programs Independent evaluation of country programmes; adding GP2L and other stakeholders to the WHO monitoring missions could be one approach. Prioritization of existing indicators and define new ones according to identified gaps. Improve reporting from NP and partners, especially for MMDP

1) Coordinate with NGOs and other stakeholders and encourage greater coordination and information sharing Develop protocols to determine whether targets for elimination have been met; Strengthen reporting. Continue to encourage data quality and sharing of sub-national data at a regional level Maintaining an annual Alliance for GET2020 meeting provides a crucial forum for transparency and progress monitoring for the trachoma community Support WHO in providing data.

2.1.4. Extent of adoption of global NTD control/elimination guidance by national programs and partners

Advocate for increased government commitment to fight Chagas in affected countries through support of National disease programs - Work with endemic countries to accelerate adoption of WHO/PAHO guidelines

Secure financial and technical support for validation and verification process by countries Better coordination between GLP and NTD Geneva is needed; high-level training and training of trainers regarding the new WHO Guidelines should be organised. Establishing national task forces for IDA planning and implementation WHO to disseminate MMDP tools WHO plan to support governments to achieve this

1) Raise awareness about existing guidance and the gaps that exist, alongside advocating these gaps be filled as detailed above 2) Increase government ownership of plans through development of functioning NOECs Update SCH guidelines Promote SCH coverage within the countries whose SCH programs haven't started. Define and communicate the post-2020 strategy once developed.

Continue supporting the development of National Trachoma Task Forces to support the dissemination of best practices
### 2018 Action Framework: 2019 Priority Actions Summary

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<td>- Advocate/empower decision-makers to increase Chagas funding</td>
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<td>- Reinforce ownership of the elimination process and targets by endemic countries, in the context of falling case counts</td>
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<td>- Increase advocacy for scale up and start of MDA in targeted countries</td>
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<td>- Incorporation of goals into national strategies</td>
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<td>- Support for leadership and HR skills into activity plans</td>
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<td>1) Encourage national programs to lobby within their own countries to secure funding for NTDs as well as from external donor sources</td>
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<td>- Increased focus on long-term sustainability and country ownership required. Increased advocacy for domestic resource mobilisation.</td>
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<td>- Finalize and disseminate STH policy assessment. Encourage countries to complete or finalize NTD Master Plans or STH Action Plans.</td>
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<td>- For countries transitioning, ensure integration of necessary interventions within national eye health care plans.</td>
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<td>- Use programme data as evidence for policies.</td>
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| **2.2.0. Operational & normative guidelines** |
| **2.2.1. Clear understanding of end points and operational approach to achieve goals** |
| - Update and complement PAHO guideline including recommendations to stop congenital transmission (e.g. mandatory screening of pregnant women/women of childbearing age) and screening at blood banks and guidelines regarding treatment of chronic patients |
| - Operational approach needs to be adapted to different settings and changes |
| - In consultation with GPZL, WHO should develop clear endpoints and workable action plans |
| - Propose targets and milestones for post-2020 agenda and plan on which stakeholders will support national programs to achieve this |
| - Identify priority research areas in collaboration with key stakeholders, and ways in which these could be funded |
| 2) Clarify and agree on milestones, indicators, and approaches |
| - Development of evidence-based programme targets |
| - Partners meeting to agree on different phases of STH programs, sharing of key issues. |
| - Continue to ensure that new countries beginning trachoma programs have early access to all relevant guidance and consultation with WHO. |
| - Ensure all partners are clear on the GET 2020 trachoma road map for elimination |

| **2.2.2. Clear process to certify/validate/etc. achievement of Roadmap goal** |
| - Continue development of criteria for validation of modense HAT elimination as public health problem |
| - GPZL to build consensus to define 'zero leprosy' goals and pathway to achievement |
| - WHO, NGOs continue dissemination and capacity building on dossier requirements. Processes could be modified if target changes. |
| 1) Advocate for clear guidance on dossier content, preparation and submission |
| 2) Support national programs to increase understanding of process |
| 3) Clarify procedures where necessary |
| - Once targets have been well-defined, it will be necessary to develop and test strategies to achieve them. |
| - Continue to encourage and support national programs to begin preparing their validation dossiers as early as possible. |

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### 2.3.0. Agile collaboration & innovation

2.3.1. Existence and effectiveness of global coordination body that facilitates communication and synergy between stakeholders

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<td>WHO, TCC and CDC to continue to keep alignment and coordination of key messages to MOH and PAHO</td>
<td>Mobilize resources in GPZL for its collaboratively-developed Framework for Action to Zero Leprosy, including an aligned Global Research Agenda and a Zero Leprosy Road Map and Toolkit, to support country-specific capacity mapping and capacity-building that leads to Zero Leprosy.</td>
<td>GAELF and NNN to advocate for more support for countries</td>
<td>1) Advocate for funding to support coordinating body</td>
<td>2) Increase country involvement</td>
<td>3) Create a more cohesive onchocerciasis community</td>
<td>Continue to increase Q&amp;A capacity.</td>
<td>Strengthen relationship between STH Advisory Committee and WHO. The STH Coalition could drive the development of a new strategic plan.</td>
<td>Hold the annual GE2020 Alliance meeting; Continue stakeholder coordination through ICTC and TSIW.</td>
<td>Discussions between WHO and other stakeholders on funding for coordination meetings. Define how the VL community will organize and plan itself for an effective and better 2019 at two meetings organized by KalaCORE in February 2019.</td>
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2.3.2. Adaptability of approach and plans in case of intervention failures or other programmatic challenges

| GWEP should continue to improve its reach to other programs to make the most of these programs’ field presence | Continue ongoing activities | Analyze opportunities and the effect of (a) enhancing collaboration and coordination of leprosy with other NTD programmes including at the WHO level (b) new forms of collaboration | Engage more WASH partners | 1) Maximize coordination with LF | 2) Advocate for integration within national health systems | 3) Capitalize on existing opportunities for collaboration such as NNN and COR-NTD | Develop case studies of collaboration between SCH and other sectors. Advocate for the inclusion of other sectors into Expert Committees to bring actors together at global and national levels | Foster behavior change through advocacy to country governments. Finalize STH-WASH indicators (NNN WASH working group). Investigate mechanisms for improving LF-STH integration. | Stronger collaboration with the WASH sector |

- Greater engagement with the general eye health community, both at the international and country levels; 
- More aggressively pursue participation by experts from the other NTD communities in existing trachoma coordination platforms to discuss opportunities for integration 
- Dissemination and use of the WHO WASH/NTD toolkit

2.3.3. Effectiveness of collaboration with other NTD programs, and sectors such as WASH and education.

| Continue current efforts to adapt | Develop a toolbox for countries to be able to select appropriate interventions. Implement an annual learning system based on results | WHO, NGOs, PMs quickly share information on failures and response and engage more stakeholders. Share lessons learned about what worked and didn't work. | 1) Encourage and support countries to develop contingency plans that are well embedded within national elimination plans | 2) Increase awareness of need for adaptable approach at global level | Define intervention failure tools for assessment including protocols, checklists to identify programmatic challenges. | Ongoing research; also more detailed consideration of implementation scenarios. | The community should work with WHO to develop a plan for defining recrudescence and suggest tools and methodologies for post-validation surveillance. This may require operational research into the accuracy, feasibility, and cost of such methodologies. | Develop course correction strategies.

[Ongoing research; also more detailed consideration of implementation scenarios.](#)
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<td><strong>2.4.0. Integration into national health systems</strong></td>
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<td><strong>2.4.1. Extent of guidance and planning at global and national levels to integrate NTD programs into existing national systems (e.g. health, education, water), including for delivery of interventions required after reaching Roadmap goals.</strong></td>
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- Strengthen voice of global Chagas networks to inform health systems and civil society on Chagas Disease
- More efforts from countries are needed to integrate control and surveillance into strengthened national health systems
- Enhanced community awareness in disease transmission areas is required to facilitate referrals of suspected cases to passive screening facilities
- Analyze opportunities to improve collaboration with other programs not related to leprosy (e.g. mental health, rehabilitation and diabetes).
- OR, WHO, NPs continue to explore sustainable surveillance methodologies and collect data on feasibility and cost. National programs and district budgets need to set aside funds for LF elimination.
- OR, WHO, NPs continue to advocate for integration of NTD programs with relevant sectors on the national level.
- 1) Advocate for integration of NTD programs with relevant sectors on the national level. 2) Use NOEC as platform for integrated activities 3) Promote integration of M&E activities
- Seek opportunities to engage cross-sectoral engagement in USAID, DFID and the World Bank
- Countries should continue to provide trichiasis surgeries for incident cases through the national eye care services post-validation.
- The trachoma community must develop a definition of recrudescence and guidance on methodologies for post-validation surveillance.
- Analyze opportunities to improve collaboration with other programs not related to leprosy (e.g. mental health, rehabilitation and diabetes).
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| **3.0.6. PUBLIC HEALTH INTERVENTION** |
| **3.1.6. Service delivery** |
| **3.1.1. Equitable access to quality disease prevention interventions (PC, WASH, vector control, veterinary public health services)** |

- Conduct community-based awareness activities
- Adapted prevention measures should be implemented in remote areas with access barriers.
- Focus more effort on reaching the most geographically inaccessible areas with screening and treatment activities.
- Mobilize resources for advocating and training for effective PEP implementation. Stigma reduction interventions should be implemented alongside PEP. Promote additional research to improve PEP regimen, and operational research to test implementation approaches not requiring disclosure of the identity of the index patients. Mobilize resources for the vaccine’s field trials.
- WHO, GAELF, NGOs, donors need to raise awareness of and provide special support for countries that have not started or fully scaled up MDA
- WHO, GAELF, NGOs, donors need to raise awareness of and provide special support for countries that have not started or fully scaled up MDA
- 1) Advocate for and further develop methods to measure and improve equity and access 2) Advocate for NOECs as platform to promote equity 3) Investigate equity issues on the national level
- Clearly define and advocate for equitable access to all prevention interventions beyond PC
- Collect age and sex disaggregated data at a local level.
- ICTC has developed a Special Populations Working Group, designed to provide guidance to national programs and implementing partners on how best to address these groups.
- - Uptake and use of WHO WASH/ NTD toolkit
- Use programme data to advocate for strategies for vulnerable groups inclusion.

| **3.1.2. Equitable access to quality individual disease management and disability prevention interventions.** |

- WHO to develop the concept and manage the roll out of the Global Cash Reward scheme.
- Focus more effort on reaching the most geographically inaccessible areas with screening and treatment activities.
- Develop effective shorter-duration treatment. Engage people affected and NGO sector in decision making processes. Improve access to prevention of disability. Undertake research to generate evidence on managing d tinyson hyper-sensitivity. Investigate ways to strengthen availability of skilled personnel in woundcare. Provide or facilitate links to services for mental health care for persons affected by leprosy and their families.
- WHO, NPs, NGOs, provide guidance/lessons learned on implementing these activities at scale, provide support to training and roll out of services. National programs include MMSP services in UHC essential services packages. Donors advocate for greater MMSP contributions.
- 1) Advocate for the urgent development of guidance relating to disease management for oncho 2) Advocate for NOECs as platform to promote equity 3) Increase awareness of patients needs in care aspects of oncho
- Development of morbidity management and disability prevention (MMDP) approaches. Advocate for inclusion of MMDP into SCH control and elimination programming. Further operational research to determine the effect of PC on FGS
- Cleared guidance needed for trichiasis case finding, particularly in low endemic areas.
- Continuation of activities.
### Appendix 6

2018 Action Framework: 2019 Priority Actions Summary

<table>
<thead>
<tr>
<th>Disease</th>
<th>2018 Action Framework: 2019 Priority Actions Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chagas Disease</td>
<td>- Advocate for better primary healthcare in rural areas. - Disease management guidelines should be implemented in remote areas with access barriers.</td>
</tr>
<tr>
<td>Guinea Worm Disease</td>
<td>N/A</td>
</tr>
<tr>
<td>Human Africa Trypanosomiasis</td>
<td>Mobilize resources to scale up evidence-based rehabilitation and inclusion services. Assess coverage of persons affected by leprosy under CBIR programmes. Conduct awareness campaigns of available services and provisions. Implement stigma-reduction programmes. Ensure participation of people affected in all decision making processes. Advocate for the inclusion of assistive devices under health insurance schemes. Collaborate with UN departments.</td>
</tr>
<tr>
<td>Leprosy</td>
<td>NPs link NTDs to mental health and disability services/programs. OR, NPs, NGOs document promising practices in achieving equitable access in order to influence WHO guidance and guide NPs.</td>
</tr>
<tr>
<td>Lymphatic Filariasis</td>
<td>1) Advocate for the urgent development of guidance relating to disease management for onchocerciasis 2) Advocate for NOECs as platform to promote equity 3) Establish care for those in need</td>
</tr>
<tr>
<td>Onchocerciasis</td>
<td>Not applicable for 2019</td>
</tr>
<tr>
<td>Schistosomiasis</td>
<td>Link individuals suffering from blindness to disability support services and eye health services.</td>
</tr>
<tr>
<td>Soil Transmitted Helminths</td>
<td>- Encourage MOH and National Institute of Health to increase their commitment even though there is progress. - Improve prevalence data to understand where to scale up interventions. - Empower communities and leaders to understand the disease and implement appropriate prevention and treatment.</td>
</tr>
<tr>
<td>Trachoma</td>
<td>Advocate for greater political involvement and support to access insecure areas for sustained surveillance and intervention activities.</td>
</tr>
<tr>
<td>Visceral Leishmaniasis</td>
<td>More efforts from countries are needed to integrate control and surveillance into strengthened national health systems. - Enhanced community awareness in disease transmission areas is required to facilitate referrals of suspected cases to passive screening facilities.</td>
</tr>
<tr>
<td></td>
<td>Evaluate best practices for national programmes nearing the end-game and beyond.</td>
</tr>
<tr>
<td></td>
<td>Propose targets and milestones for post-2020 agenda. OR, NPs, NGOs, WHO need to continue to collect data now in order to inform guidance that will become more important as more NPs reach validation stage.</td>
</tr>
<tr>
<td></td>
<td>Collaborate with WHO and partners to develop guidelines for these activities.</td>
</tr>
<tr>
<td></td>
<td>Develop tools and prepare plan to define and monitor successful elimination and surveillance.</td>
</tr>
<tr>
<td></td>
<td>The trachoma community must develop a definition of recrudescence and guidance on methodologies and data collection needs for post-validation surveillance. - Consider need for operational research to monitor for recrudescence over time. - Clearer guidance needed for trichiasis case finding, particularly in low endemic areas. - Advocate with WASH partners to ensure validated areas are covered by F&amp;E activities. Use specific tools in the WHO WASH/NTD toolkit to generate advocacy messages.</td>
</tr>
<tr>
<td></td>
<td>Collaborate with key stakeholders.</td>
</tr>
</tbody>
</table>

#### 3.2.0. Sustaining impact

##### 3.2.1. Coverage of post-roadmap-goal surveillance and interventions activities

- More efforts from countries are needed to integrate control and surveillance into strengthened national health systems. - Enhanced community awareness in disease transmission areas is required to facilitate referrals of suspected cases to passive screening facilities.

| No action included | Continue advocacy role for the provision of potable water through traditional and alternative means. |
| Critical challenges but out of program scope | Evaluate best practices for national programmes nearing the end-game and beyond. |
| | Propose targets and milestones for post-2020 agenda. OR, NPs, NGOs, WHO need to continue to collect data now in order to inform guidance that will become more important as more NPs reach validation stage. |
| | Collaborate with WHO and partners to develop guidelines for these activities. |
| | Develop tools and prepare plan to define and monitor successful elimination and surveillance. |
| | The trachoma community must develop a definition of recrudescence and guidance on methodologies and data collection needs for post-validation surveillance. - Consider need for operational research to monitor for recrudescence over time. - Clearer guidance needed for trichiasis case finding, particularly in low endemic areas. - Advocate with WASH partners to ensure validated areas are covered by F&E activities. Use specific tools in the WHO WASH/NTD toolkit to generate advocacy messages. |
| | Collaborate with key stakeholders. |

#### 3.2.2. Improvement in socioeconomic and environmental conditions required to prevent recrudescence

- Increase awareness of the threat of recrudescence and advocate for inclusion of such activities into national programs.

| No action included | Continue advocacy role for the provision of potable water through traditional and alternative means. |
| Critical challenges but out of program scope | Evaluate best practices for national programmes nearing the end-game and beyond. |
| | Propose targets and milestones for post-2020 agenda. OR, NPs, NGOs, WHO need to continue to collect data now in order to inform guidance that will become more important as more NPs reach validation stage. |
| | Collaborate with WHO and partners to develop guidelines for these activities. |
| | Develop tools and prepare plan to define and monitor successful elimination and surveillance. |
| | The trachoma community must develop a definition of recrudescence and guidance on methodologies and data collection needs for post-validation surveillance. - Consider need for operational research to monitor for recrudescence over time. - Clearer guidance needed for trichiasis case finding, particularly in low endemic areas. - Advocate with WASH partners to ensure validated areas are covered by F&E activities. Use specific tools in the WHO WASH/NTD toolkit to generate advocacy messages. |
| | Collaborate with key stakeholders. |

- Ensure better convergence between SDG targets: 3.2 (end preventable deaths in newborns and children under 5; looking at the collateral benefit of annual azithromycin in preventing child mortality from malaria, upper respiratory tract infections and diarrhoea); 3.3 (end NTDs); 3.8 (achieve universal health coverage); 6.2 (by 2030, achieve access to adequate and equitable sanitation and hygiene for all).
Appendix 7: 2018 Action Framework online evaluation survey results

A 37-question online survey was sent to the NNN Scorecard Working Group, all who were invited to contribute to disease-specific action frameworks, and Action Framework meeting attendees. The survey was sent one week after the October 10-11 Action Framework meeting and was kept open for one week. Seventy-eight individuals responded and the responses to each question are below.

1. Involvement in the 2018 Action Framework

Q1: Which of the following best describes your involvement in the 2018 Action Framework process?

- Also put in work to the AF creation
- Was not involved in developing framework, but was present during presentations and will definitely use it
- Member of the Trachoma Action Framework working group
- Worked on earlier development and engagement through the trachoma community input into the AF
- I collaborated as a Chagas Initiative coordinator, invited by the Chagas Coalition
- Member of NTD programs and projects
- Guided additional team members during earlier phases/process (Barcelona & Ethiopia meetings, etc.)

Other responses:

- Leprosy Action Framework Meeting Attendee (Amsterdam) (5 responses)
- Assisted NNN Scorecard Working Group Representative in collecting feedback from contributors

Q2: Please rate your level of familiarity with the new Action Framework.
Q3: Were you contacted (via Smartsheet or personal communication) to provide input into one or more Action Framework(s)?

- Yes: 44
- No: 5
- Unsure: 1

Answered: 50, Skipped: 28

Q4: Did you contribute to the Action Framework?

- Yes: 34
- No, but I was at the Action Framework Meeting (Geneva): 8
- No and I was not at the Action Framework Meeting: 8
- I was not asked to provide input, but I was at the Meeting: 8

Answered: 50, Skipped: 28
Q5: If you were contacted for input, but did not respond, please select or explain the main barrier to contributing

Other responses

- I did not provide input in writing, as the framework was too long/extensive, but I participated in a conference call facilitated by a TFGH staff member for the disease-specific group that I am part of.
- Only minimal input due to time
- There was less than one week provided to give feedback.
- I had nothing else to add to what was already provided by the disease community

- It was a combination of not understanding what was being asked. I had provided feedback on the overall framework earlier and thought this was a repeat request and by the time I learned that it was a new disease-specific request for input I did not have time to reply before the deadline.
- It was a mix of not understanding what was for, the framework being long and not having the availability at that time to investigate what was being requested.
- I wasn't contacted, just joined the program recently

2. Feedback from the NNN London Declaration Scorecard Working Group

Q6: Please rate the following:

- My comments and feedback during the Action Framework development process (pillars, components, etc) were incorporated
- The final product serves as an effective gap analysis tool for my community

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Appendix 7
2018 Action Framework online evaluation survey results

Q7: If this process is repeated, how can the UTC team better support you in your role as representative?

- More face to face meetings if possible
- It is so detail and labor intensive and it is better if enough time is given for completing it.
- The UTC team was very supportive, and I was impressed at all they were able to accomplish. I realize it was the first year for this tool so there were unexpected barriers, but if the team could keep the number of meetings down to one or two that would make this process a bit more feasible given time/work constraints.
- Clear articulation of how this serves the community and what value it has for the constituent - most people did not see the value of spending time on this for them or their organization
- Given us more inputs in terms of better focused the responses, and information in how the answer will be integrated after, in order to send you more accurate answers
- UTC team provided great support, but the process was still very intensive. Next time should be iterative, building off what has been said before.
- The review meeting had to be organized at very short notice this time. More advance warning and perhaps some support in the organizing would be great.

Q8: Would you be willing to serve as a disease/cross-cutting representative for this process again?

I split this role with another person from the community so I would defer this position to that individual in future years. However, if the need arose, I'd be willing to serve in this function again if the time commitment were reduced and, most importantly, this year's process yielded actual results towards the London Declaration goals (i.e.- more funding, demonstrable examples of policy change, etc.)
Appendix 7
2018 Action Framework online evaluation survey results

Q9: Please provide any additional comments about being on the NNN Scorecard Working Group.

- Meeting in person to develop the tool made it easier to work on. If it had been done via Skype or conference calls it would have been more difficult.
- I don't think it’s worth the time to re-do the entire Action Framework every year. Things move slowly, so we either need to do it less frequently, or just focus on a few key areas each year.
- It was a great learning experience. The open atmosphere and participatory nature gave ample opportunity to share our experience (leprosy community) and to infuse cross-cutting aspects (DMDI-related).
- Need to avoid duplication of effort with other initiatives and ensure alignment with them
- There was great team spirit and commitment
- Valuable chance to discuss disease progress and approaches across the different disease groups

3. Effectiveness as a tool for dialogue and priority-setting

Q10: How many disease-specific Action Framework(s) were you asked to contribute to?

- 1 (25 responses)
- 2 (4 responses)
- 3 (2 responses)

Q11: Which disease/cross-cutting Action Framework(s) did you respond to?

- Chagas (2 response)
- Leprosy (7 responses)
- VL (2 responses)
- LF (7 responses)
- Oncho (2 responses)
- SCH (5 responses)
- STH (4 responses)
- Trachoma (6 responses)

Q12/13: To what extent did the Action Framework facilitate a meaningful conversation within your disease community? (1 = not at all useful, 5 = extremely useful).

Answered: 41  Skipped: 37
Appendix 7
2018 Action Framework online evaluation survey results

Q14/15: How useful is the disease-specific Action Framework to your disease/cross-cutting community? (1 = not at all useful, 5 = extremely useful).

Q16/17: Rate the extent to which you feel that the Action Framework helped identify issues, priorities, and opportunities in your disease/cross-cutting community? (1 = not at all useful, 5 = extremely useful).
Appendix 7
2018 Action Framework online evaluation survey results

Q18: Are country voices adequately represented by NGOs/WHO participation in the Action Framework process?

Other responses:

- It depends on the disease. Some disease communities had difficulty organizing themselves to provide input.
- I think it would have been better if other regional health bureaus are also involved.
- I hope so. More emphasis probably could be given to this.
- No idea, little was shared around the Action Framework apart the survey to complete.
- For those of us not in the Action Framework group it's difficult to see which country voices are represented.
- It is important to capture country issues, these are not all the same across countries. NGOs will talk about their overall priorities but in the current format AF NGO's will struggle to summarize difficulties/opportunities specific to each country. Countries themselves can talk about their respective issues/opportunities/priorities.
- Not sure, definitely people affected voices are inadequately represented.
- It's really hard to know the answer to this question because we don't really have direct country input.
- I think we would try to involve some national programme reps next time.
- N/A (5 responses)

- There could have been better representation from endemic countries in SE Asia, it did not seem sufficient.
- No, but I'm not sure how such a thing would be possible. Countries would only be able to comment on their own progress and the metrics would be vastly different.
- Don't know. I do know that in the ICTC, country voices (at the NNN meeting in Ethiopia) emphasized a lack of attention to prevention, however this is not strongly represented in the AF template.
- I think this very much depends on the questions asked and the level of detail is required by the Action Framework. A particular challenge experienced during this process was the extremely short consultation time, recognizing that many stakeholders are juggling multiple priorities. Had the consultation time be more appropriately longer we could have ensured country voices were adequately included in key areas.
- It would be nice to have more representatives from different endemic countries taking part at the meeting.
- I think this is highly variable and depends on the type of country voice (affected people? implementers? MOHs?) as well as the disease. Some WHO teams and some NGOs are much closer to endemic countries than others.
Q19: Should direct country input be sought for contributions to the Action Framework?

- As a strategic document it is necessary for us to avoid duplication of work at the country level and be able to have a ‘birds eye view’ of progress, challenges, gaps and priority areas in order to ensure alignment between country level activity, with regional and global ambitions and goals. It is important that the Action Framework not get lost in the weeds of what happens programmatically or policy wise and should serve as a strategic document to help partners focus efforts at country level.
- Only if people can contribute to a face to face discussion. It would be too difficult to summarize country-specific comments using the current format.
- N/A
- In a modified version
- This would be up to the WHO and liaisons to the SWG to decide.

Other responses:

- If this approach is taken, it’s important to make the process of collecting the input an easier one. Many MOHs would have difficulty responding to a request of this sort - with a lengthy, complex form to fill. It would be important to specify more clearly how the responses will be used - this was not entirely clear.
- Plus people affected by the NTDs
- Where those already contributing to the AF identify this as lacking.

Q20: Please estimate the total amount of time spent filling in each framework.

- 1 hour (2 responses)
- 4 hours (2 responses)
- 2 days (3 responses)
- 2 hours
- 3.5 hours
- Approx 2-4 hours
- 8 hrs
- OV - 2-4 (it involved a conference call, which sped the process). LF - 5 in all, aggregating info from multiple individuals?
- 1.5 days
- More than 2 days
- 3 days
- 1 hour plus for the first and 45 mins for the second
- it was long but don’t remember the time spent (2 responses)
- Personal time 6 hours
- 16 working hours (including meeting together, getting community feedback, etc.)
- One day (approx 12 participants). Preparation and follow up by 2, or 3 for one day.
- our group discussed a lot many different points, then it was not only a question of filling the framework. Thus, I could not estimate the time needed just to fill it
- 5 hs and some more, participating in meetings, phone calls etc
- 4-5 hours
- I was involved in both surveys and meetings. The surveys perhaps one hour each (x2), the meetings 6 days (2 x 3)
- Personally, probably 4-5 hours Two working days in the face-to-face meeting (i.e. 16 hours) 2 hours in editing the final version
- Consultation - 3 hours; filling - 1.5 hours.
- More than 10 hours
Appendix 7
2018 Action Framework online evaluation survey results

Q21: From the feedback received so far, it is clear that the Action Framework in its existing form is very labor intensive. Would the same level of usefulness be achieved by a less detailed framework?

Other responses

- A less detailed framework would likely receive responses from a greater number of parties. It's a balance between completeness and representativeness.
- Difficult to determine at this stage (4 responses)
- Not sure. It is labour intensive mainly because the WHO system strengthening blocks are a bit unclear and can not be used by NGOs working in diverse countries, these are more useful for the countries themselves to report on. However, it can capture a lot of info.
- A less detailed framework would be better only because I'm still unclear how we are defining "usefulness" and therefore have trouble justifying the time required to complete it. The process fostered a really interesting dialogue, but the outcomes that resulted from the process are still unclear.
- A less detailed framework may well still achieve the same level of usefulness. However this will be governed by a clear and exact understanding of the purpose, use of this tool at what level, and who the target audience for this is. So far this has only been communicated in very basic and vague terms.
- Some of the information is cross cutting and should not be for each disease
- Not sure but likely that a less detailed framework may lose some of its usefulness
- Difficult to say, because it would depend on what is left out. However, quite a few of the current requirements/status remarks would not change much over time, so a next version could omit those that are unlikely to change within a year.
- Probably but if oversimplified might not be specific enough. What would be really useful is easily obtained country information.
- Potentially - we haven't see the full benefit of this year's process yet.
- Probably not, and I think we will all get quicker at completing them with practice.
Q22: Should Action Frameworks be posted online?

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>Yes, but only after a round of editing</td>
<td>8</td>
</tr>
<tr>
<td>It should be left to the discretion of the disease</td>
<td>3</td>
</tr>
<tr>
<td>No, they should serve as internal documents</td>
<td>7</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

Answered: 33  Skipped: 45

Other responses

- It would need to be clearer whose opinions they represent, and what purpose they serve, before doing so.
- If it is online topics and figures will be set differently compared to when it is used as an internal document only.
- I think it is a useful document for programs managers and others involved in disease’s control, but it can be improved and I think it needs good translation for different languages. I also suggest it can be published together with a kind of helpdesk.
- Countries should have a say in this.
- Editing should be done to ensure quality objective language is used.
- I think yes but there needs to be input and engagement with disease specific communities. Some disease communities and cross-country groups already have action plans, we must make sure effort is not duplicated.
Q23: How often should the Action Framework process be repeated?

- Every three years at the most. Perhaps not even that much. Or a much lighter touch update
- Depends if it's the full Action Framework or a pared-down version.
- N/A
- Probably once more next year, to get a better process going, using a more user-friendly version (e.g. not Excel-based); after that perhaps every other year
- If it is as time consuming as this year, every other year - if it can be streamlines, ever year
- I would say every three years across the board OR allow the individual disease communities to decide based on where they are in the progress towards their goals. If leprosy or HAT find this process incredibly valuable towards their goals, put them on a yearly cycle whereas LF and Trachoma could be on a two or three year track. An important caveat to this would be that it would need to made clear that it is all a deliberate strategy: diseases weren't 'opting out' by not participating yearly but instead were deliberately put on specific evaluation tracks.
4. Online Smartsheet platform for input gathering

**Q24:** Please rate your experience using the Smartsheet online input collection tool. (1 = extremely difficult to use, 5 = very easy to use)

![Bar chart showing responses to Q24]

**Q25:** Should the Smartsheet platform be used again for future Action Frameworks?

![Bar chart showing responses to Q25]

Other responses

- Smartsheet itself is quite easy to use
- I think it can be used pretty easily with some simple training. Bear in mind that older generation may struggle though they can delegate. Also if collecting country contributions then it is important to check it is easy to use when the internet is slow or weak!
- For me is a good tool but quite complex for users
- N/A
- I prefer sharing a regular excel sheet
- Only if the sheet could be simplified
Q26: Please provide other comments regarding the Smartsheet tool.

- Having a qualified person capture the responses through a conference call is an effective approach. Difficult for individuals to fill themselves.
- It is so detail. I think it is possible to prepare a summarized form.
- It is a good tool
- Time consuming to fill out and sometimes difficult to read through the small letters
- Smartsheet is a good tool. It was just the extent of the questions asked.
- I could not find an simple way to export into excel so that I could share/send
- It is important to have disease specific tools
- The areas/questions should be edited and shortened to prevent repetition and add clarity
- A menu with FAQ should be very helpful
- Too many incidents to solve before sending it
- Editing in a spreadsheet is a pain in the neck for non-numerical data. Also the fact that you can't track changes very easily makes it difficult.
- As with all spreadsheets when you get too many columns it easy to lose track within the form.

Q27: Do you have recommendations for other online platforms?

- Frequent follow-up of the participants is essential until the data collection is completed.
- Online Word or Google docs would be much easier. The platform should be geared towards handling text, instead of numbers as in a Smartsheet.

5. Action Framework Meeting: process & outcomes

Q28: Noting that there were some unavoidable absences, was the appropriate spectrum of partners represented at the 2018 Action Framework Meeting in Geneva?

- It was unclear who the audience for the presentations was and what would come out of the meeting
- Country programs were not represented and neither were the private sector large deworming organizations
- Broadly, yes, though a pity DFID were unable to attend.
- People affected by different NTDs: Leprosy, BU, LF, Chagas, etc
- N/A (17 responses)

Other responses

- There was some confusion over disease specific representatives. If NNN scorecard reps were going were they representing disease specific coalitions or their specific organization or the NNN disease specific group. Probably something that can be clarified internally.
Q29: Was the size of the meeting appropriate (Approx. 45 people)?

Answered: 38  Skipped: 40

- Yes 13
- The meeting was too large 1
- The meeting was too small 2
- Other (please specify) 22

Other responses

- I was unclear about the meeting objective
- If the agenda was more focused, the participant group could/should have been smaller and the outcomes clearer. However, for a first, exploratory (?) meeting, it was ok
- Not clear. Since the purpose of the Framework for the future isn't clear it is hard to know who should be in the room.

Q30: Was the length of the meeting appropriate (2 days)?

Answered: 37  Skipped: 41

- Yes 13
- No 1
- Other (please specify) 23

Other responses

- N/A (17 responses)
- Not clear. Since the purpose of the Framework for the future isn't clear it is hard to know if the amount of time was sufficient to review the data.
- A third day to flush out some of the discussions may have been useful.

- I'm still trying to decide what was gained from individual disease presenting their framework results on the first day in terms of that audience/forum. I found it incredibly interesting as a person interested in NTDs, but I'm having trouble quantifying what was achieved exactly given that we already knew what "concordant" and 'dissonant' issues were across the diseases. I felt like were presenting to an audience, but I never really understood who the target audience was supposed to be on that first day (WHO high brass, each other, donors??).
- As mentioned, I do not think that the collected information was representative of the situation. So in this situation a meeting of whatever number of days is not appropriate.
Q31: What aspects of the meeting should be changed?

- N/A (14 responses)
- More discussion and getting into the actions that could be done.
- Not clear as the original purpose of the meeting seems to be overtaken by the framework.
- I think it was excellent having the representation of the WHO and the NNN disease specific leads. I think that if we could think of other ways of presenting each disease in a more succinct way that would be helpful although appreciate that it is challenging
- The meeting will evolve as the process evolves.
- More discussion of use of the framework and how it will be used outside of the sector.
- The summaries on the first day were too long - the second day with the discussion was really where the productivity was so that should have been longer.
- as mentioned, we need to have more opinions from different actors in the PC programs and not only from NGO or financial partners. We need to understand the point of view of different group involved. In my opinion we can not judge these programs without the opinion of the implementers, managers in endemic countries MoH...
- If the idea is to identify cross cutting themes there may have been a more efficient way to do it - either through NNN or existing WHO meetings
- Needs more focus; clearer objectives and expected outcomes can achieve that
- Involve country NTD managers of a couple of countries.
- Perhaps fewer cross-cutting topics, with more time for each. Or dividing them in 2-3 groups and then give participants the opportunity to choose which ones they want to attend.
- Good on my side

Q32: Was the selection process for identifying the 7 cross-cutting themes discussed on day 2 sufficient?

![Bar chart](image)

Other responses

- It was a bit rushed, but the themes that emerged were useful to discuss in a cross-cutting way
- The seven topics are important and relevant. The way information was collected on those topics is not appropriate in my opinion. For example how only 6 or 7 individuals (no one of which directly involved in control activity) can decide on the “Degree to which available funding is sufficient for program requirements”? I think the question should (1) be addressed to the control managers (2) asked more directly for example “do you have sufficient fund for control of LF?” then to be significative the replies of at least 30 (out of 54 endemic countries) should be collected and analysed.
- N/A (7 responses)
Appendix 7

2018 Action Framework online evaluation survey results

Q33: The following seven topics were identified as areas for collective action and sharing lessons learned over the upcoming year. In your opinion, is it valuable for the UTC Partnership to facilitate collective action and/or shared learning in these areas.

![Graph showing survey results]

- Universal Health Coverage
- Equitable access to service delivery
- Diagnostics
- Availability and quality of data
- Resource mobilization and planning
- Global coordination Networks
- WASH

Answered: 36    Skipped: 42

Q34: What aspects of the meeting worked best?

- N/A (11 responses)
- The fact that the results of the AF feedback agreed with gaps shared by WHO focal persons.
- The sharing across diseases was interesting and people learned things from each other. In the cross cutting it was interesting to learn more about what is being done.
- Sharing approaches during the cross-sector meetings. More time for individual diseases to talk about what they've done creatively, etc. to address those would have been nice.
- The facilitation was excellent and there for the most part was enough time for discussion.
- The cross-cutting discussions were very well led.
- updates and trends
- The session format (summary then discussion) worked well
- Having the WHO input from each disease. Having the collated disease specific spreadsheet and also the individual disease sheets
- good representation from WHO
- Learning about the various individual NTDs and how these are set up, challenges and best practices, etc.
- Disease-specific presentations; presentations of the cross-cutting aspects
- Achievable equitable access to quality service delivery
- WHO participation was crucial. I think it is important to recognize that the meeting was scheduled too soon to see the full benefit of the process. It definitely important to separate the output of the AF meeting from the process that it should stimulate.
- Seeing where there was direct action to be taken and where partners could hold each other accountable.
Q35: Please rate the following aspects pertaining to the cross-cutting topics discussed on day 2:

![Graph showing survey results]

Answered: 24  Skipped: 54

- The topics are relevant and either reconfirm known priorities or identify new topics
- The topics represent realistic areas for cross-disease/sector collaboration
- Opportunities for collaboration in these areas should be discussed further
- It was beneficial to discuss these topics in a cross-disease setting

Q36: Are these topics being adequately addressed elsewhere? If so, please provide comments.

- No, otherwise they would not still be flagged as issues.
- N/A
- Most of the activities/actions identified don't seem to be within the mandate of the UTC SWG. The priorities would seem to be advocacy and resource mobilization.
- I think that WASH aspects are being very well covered by the NNN WASH working group
- I think that it is important to have started this process in order to better coordinate efforts among different NTDs, and I think the framework include very accurate directions in order to address some important points.
- Somehow yes
- To a limited degree.
- Yes there are multiple forums
- There is overlap with other forums but then participation may be different
- To some extent at the NNN meeting, but with little involvement of WHO. In other settings we do discuss issues like this, but not in a cross-NTD manner.
- Some - like WASH and perhaps some of the more technical things are being handled at the NNN Level.
- Several are being addressed by UTC partners (e.g. NNN and COR), but there is room to support these.
- the NNN also discusses these so it would be good to find a way to make sure discussions can be in enough depth to be meaningful - perhaps by dividing
- Nowhere else in such a broad way - however it’s important that these tasks are taken forward.
Q37: What is the most appropriate way to share outputs from the Action Framework meeting?

- N/A
- Publish and use internally by NNN mainly to drive actions by partners the next 3 years
- Dissemination via disease and cross-cutting communities, newsletter/weblink.
- Presentations, e-mail correspondence and online access
- There will need to be a report but further discussion at upcoming meetings would be valuable.
- News bulletin
- Through the NNN, individual Coalition networks, WHO website, etc.
- Succinct report
- An online, downloadable report. However, facilitating active follow-up will make the output much more meaningful. I'm afraid that with the not-so-well-defined actions, little collective action would happen.
- Web
- Brief (max 2-side) summary, focusing mostly on the cross-cutting area discussion
- e mail?
- Email them to disease focal persons
- email through representative members of the NNN
- Meeting report to capture the quality of discussion. And an infographic would be helpful tool to summarize key points, decisions.
- Not clear and the actual utility of the document isn't clear.
- Sharing the collated versions and the disease specific frameworks with the stakeholders and a very short narrative around the collective action items. These should be kept as working documents and not published as a formal report
- Global virtual debriefings, to reach country-level stakeholders.
- Through meetings
- Through the web
- 1) Sharing outputs with the disease communities. 2) through action
- Town-hall type calls, check in calls, webinars.
- A summary framework provided to all partners
- Each partner group should have a way of sharing.