

## Terms of Reference for the Stakeholders Working Group

### Uniting to Combat NTDs

#### Introduction

In January 2012, the World Health Organization (WHO) published an ambitious “[Roadmap for Implementation](#)”, outlining bold targets for the control, elimination or eradication of 17 Neglected Tropical Diseases (NTDs). Inspired by this initiative, a coalition of diverse partners came together under the banner of [Uniting to Combat NTDs](#), pledging their commitment – set forth in the [London Declaration](#) – to provide support which will enable countries to attain the WHO goals for 10 NTDs<sup>1</sup>.

20 organizations endorsed the London Declaration at the January 2012 meeting; these included pharmaceutical companies, donors, NGOs, and several endemic country ministers of health. Since 2012, many more organizations and individuals have endorsed the Declaration and currently there are 80 endorsers listed on the site including a number of research institutions and individuals. Together they form an informal partnership called Uniting to Combat NTDs, committed to doing their part to support the achievement of the WHO NTD Roadmap as put forward in the London Declaration.

#### The purpose and added value of the Partnership

Through collaboration, information sharing, and aligned strategies, the diverse partners<sup>2</sup> of Uniting to Combat NTDs aim to complement the work of WHO to support national programs in their efforts to build and implement NTD programs. As the partners come from varied fields, they act as a coalition of voices to:

- Increase the visibility of NTDs on the global stage
- Improve collaboration and consistency of messaging for advocacy and resource mobilisation
- Monitor progress of stakeholder commitments towards the London Declaration through a scorecard and report on progress
- Promote NTD community collaboration
- Identify funding gaps and challenges to meeting the WHO goals for NTDs targeted by the London Declaration
- Advocate to bridge the identified gaps

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<sup>1</sup> Lymphatic Filariasis (LF), Onchocerciasis, Soil Transmitted Helminthiasis (STH), Schistosomiasis, Trachoma, Chagas disease, Guinea worm disease (GWD), Human African Trypanosomiasis (HAT), Leprosy, and Visceral Leishmaniasis (VL). For more information on why these 10 diseases were chosen, please see the Uniting to Combat NTDs website

<sup>2</sup> Partners in this document includes all those who have endorsed the London Declaration

This document sets out the terms of reference for the Stakeholders Working Group (SWG) which aims to provide direction and open communication with the various stakeholders contributing to the Uniting to Combat NTD partnership. Given the essentially informal nature of the Partnership and the dynamic nature of its development, both the ToR and the structure may need to be revised in future. However these ToR provide operational guidance within some overarching principles.

### Over-arching principles

- The Partnership includes all those who have [endorsed](#) the London Declaration on NTDs and is established to support, through diverse contributions and actions, the achievement of the WHO NTD goals for 10 NTDs.
- The Partnership is essentially informal and aims to maintain flexibility and agility
- The Partnership is a “partnership of the willing” who have endorsed the London Declaration and aims to achieve its goals by creating value through collaboration across stakeholders and sectors
- The SWG is drawn from the key constituencies and is accountable to the broader Partnership<sup>3</sup>
- The SWG monitors progress towards the London Declaration commitments through a scorecard
- The Partnership advocates to raise attention, commitments and resources for NTDs but the Partnership is not a funding body and the SWG is not a mechanism for resource allocation
- Key constituencies endorsing the London Declaration all have voice in the Partnership and in shaping its priorities through the SWG and their representative(s)
- SWG members are accountable for sharing information and in consulting with their constituencies in whatever ways are most effective for their constituency

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<sup>3</sup> For a full list of the endorsers please see <http://unitingtocombatntds.org/endorsements>

## 1. The role of the SWG

In order to drive progress towards achieving the WHO 2020 NTD goals, a Stakeholders Working Group (SWG), was set up in 2012 to guide the work of Uniting to Combat NTDs with representatives from the major stakeholder groups supporting the London Declaration including donors, industry partners, researchers, implementers, NGOs, advocacy agencies and WHO as an observer. The role of the SWG is:

- 1.1 To work in partnership with WHO in support of endemic countries to achieve the WHO Roadmap on NTD goals supported in the London Declaration
- 1.2 To monitor global progress on the London Declaration and produce a scorecard and a report on progress
- 1.3 To identify bottlenecks, gaps and seek strategic opportunities to address them
- 1.4 To facilitate opportunities for partner collaboration and coordination across the 10 London Declaration NTDs
- 1.5 To identify global and country resource needs and gaps with the purpose of advocating for additional resources

## 2. Structure

2.1 The SWG is supported in its role by the Uniting to Combat NTDs Support Centre (see the current operational model of the support centre below), which is jointly hosted by Sightsavers and the Task Force for Global Health with initial funding provided by the Bill & Melinda Gates Foundation. As currently structured, the Support Centre is tasked to do the following:

- Provide coordination and support to the cycle of activities needed to produce the Scorecard and report on progress towards London Declaration commitments
- Coordinate the implementation of the SWG work plan
- Provide support to the SWG and facilitative management of its business and meetings
- Provide support to the Uniting to Combat NTDs Working groups (including ensuring the development of work plans and ToRs)

The operational model of the support centre will be subject to regular review.

2.2 The Partnership is further strengthened by three working groups<sup>4</sup> as follows:

**The Advocacy and Resource Mobilization Working Group (ARM):** brings together key players to discuss, agree and coordinate the implementation of strategic advocacy priorities in support of the WHO, for the NTDs targeted through the London Declaration.

**The Disease Specific Working Group:** brings together representatives of the 10 NTDs disease communities to contribute to and help coordinate access to information that drives the Scorecard and progress reporting process. In addition, the group's members also provide a forum for technical and experiential input from implementing partners. The group identifies bottlenecks and challenges faced in meeting the WHO 2020 goals.

**The Extended Donors' Working Group:** provides a platform for coordination and collaboration among funders supporting the efforts of the global NTD community towards reaching the WHO 2020 goals. The Working Group enables contributors to share experiences, look for opportunities, and identify new donors to identified gaps in resources needs and mobilize new resources.

Additional working groups may be established, as relevant, to respond to specific needs and issues.

### **3. Membership of the SWG**

3.1 The SWG is made up of the following key constituencies that are critical to the achievement of the London Declaration as follows:

- The core donors: represented by BMGF, DFID, USAID and the World Bank
- Industry partners: represented by a nominated representative from the EXCO (CEO Roundtable) and the Drug donation programs represented by a representative of the Partnership for Disease Control Initiatives (PDCI)
- Research partners: (representing operational research and product development): operational research represented by a nominated representative from the Coalition for Operational Research on NTDs (COR-NTDs) and product development represented by a representative from the group. Currently, product development is represented by DNDI<sup>5</sup>
- Non Governmental Development Organizations: represented by the chair, the vice chair and the immediate past chair of the NTD NGDO Network (NNN).

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<sup>4</sup> The working groups are in various stages of development (2015) and ToR for each will be reviewed and agreed within the partnership

- Advocacy and Resource Mobilization: represented by a nominated representative from the Advocacy and Resource Mobilization Working Group
- Endemic countries: represented by a nominated representative from the chairs of the five regional programme review groups (RPRG)
- The Extended Donors Working Group: represented by a nominated representative from the group
- The Disease Specific Working Group: represented by a nominated representative from the group
- WHO: Observer Status

Membership of the SWG will be subject to regular review and additional constituencies will be brought in as necessary.

## **4. Chairs**

### **4.1 The role of the Chair**

The Chair of the SWG

- chairs the meetings of the SWG
- advises the Support Centre on the preparation of the meetings
- ensures that critical issues are brought to the attention of the SWG
- ensures that the Partnership is visible in key fora
- provides rapid response for the Partnership where needed and reaches out to the group to facilitate the rapid response
- ensures that SWG members are kept informed and up to date in between meetings
- Is the main contact person with the Support Centre and provides continuity of oversight between SWG meetings

The chair is supported in their role by a Vice-Chair and they agree between them how to share the tasks.

## 4.2 The election of the Chair

The Chair and Vice Chair are elected by the SWG from among the individual members. The individual is elected to serve as Chair rather than the organisation from which the individual comes.

The Chair and Vice Chair will be elected for a period of 2 years (If one of them leaves their position or moves organisation they can continue to serve in their capacity as Chair/Vice chair if they are still working towards the goals of the UTC and if the SWG so determines).

The Chair can be elected for a follow-up term if the SWG so determines.

The Vice Chair is not “de facto” Chair designate.

An election of Chair and Vice-chair will be held as soon as possible after approval of the terms of reference. The Chair and Vice-chair elections will be on alternate years to provide better consistency. The term for the first election of the Chair will be for one year to allow this alternation.

For elections to these two posts, nominations should be sought in advance and each SWG member will be entitled to vote. A voting mechanism will be established which enables every member to participate.

## **5. Stakeholder Working Group Members**

Stakeholder Working Group Members

- The Members represent their constituency group. They consult and report back to their respective constituencies.
- Represents the SWG on behalf of the Partnership as required
- Supports advocacy and shared messaging as appropriate
- Attends and contributes to SWG meetings and sends a delegate if appropriate
- Participates in the scoring of the scorecard and contribute to the progress report
- Supports the setting of priorities for the SWG and supportive activities as appropriate

## 6. Quorum

6.1. At least half of the constituencies will need to be represented at an SWG meeting for key decisions to hold and the business of Uniting to Combat NTDs to be progressed.

## **7. Observers**

- 7.1 Observers may attend meetings with prior approval of the chair. Requests for observer status should be submitted in advance of every meeting.
- 7.2 Observers shall not participate in the discussions unless invited to do so by the chair and have no voting status.

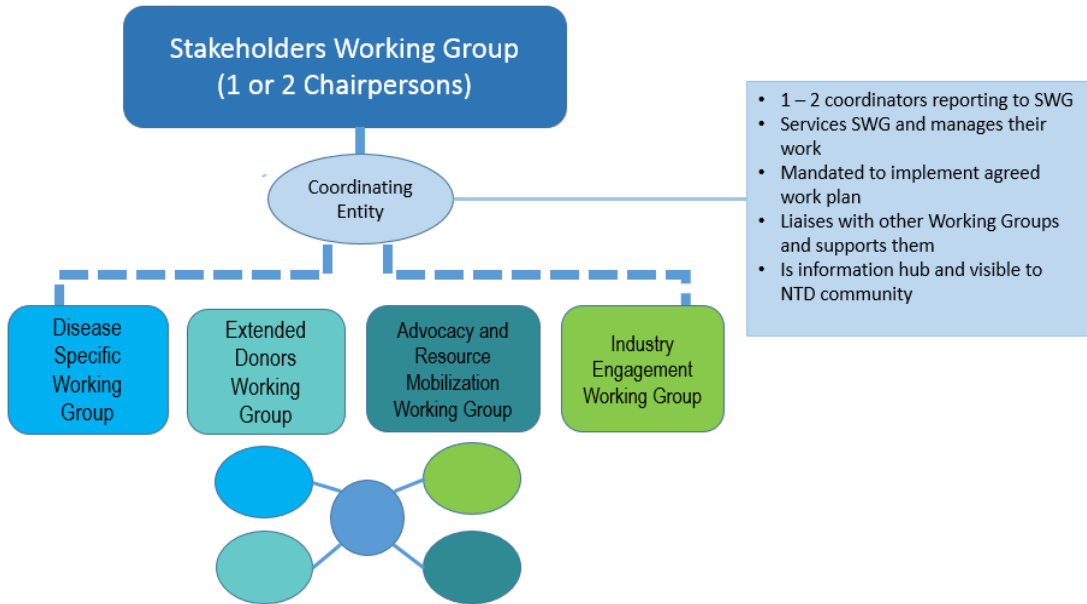
## **8. Frequency of Meetings**

- 8.1 Regular meetings of the SWG will take place on a quarterly basis by teleconference or video link. Other meetings will be organised as necessary.
- 8.2 The SWG will meet face to face at least twice a year. (For instance around the World Health Organisation Strategic, Technical and Advisory Group (STAG) meeting and the annual meeting of the American Society for Tropical Medicine and Hygiene (ASTMH), and in coordination with any of the working group meetings.
- 8.3 Once a year, (most likely ASTMH) the meeting of the SWG will involve the participation of endemic countries to allow for a broader discussion and contributions.
- 8.4 Once a year, the SWG meeting will involve the DSWG and this will be around the NNN.

## **9. Minutes of meetings**

- 9.1 Summary notes and action points from SWG meetings will be made available to partners and others on request, except in exceptional circumstances.

Scenario 2





## LONDON DECLARATION ON NEGLECTED TROPICAL DISEASES

For decades, partners including pharmaceutical companies, donors, endemic countries and non-government organisations have contributed technical knowledge, drugs, research, funding and other resources to treat and prevent Neglected Tropical Diseases (NTDs) among the world's poorest populations. Great progress has been made, and we are committed to build on these efforts.

Inspired by the World Health Organization's 2020 Roadmap on NTDs, we believe there is a tremendous opportunity to control or eliminate at least 10 of these devastating diseases by the end of the decade. But no one company, organization or government can do it alone. With the right commitment, coordination and collaboration, the public and private sectors will work together to enable the more than a billion people suffering from NTDs to lead healthier and more productive lives – helping the world's poorest build self-sufficiency. As partners, with our varied skills and contributions, we commit to doing our part to:

- Sustain, expand and extend programmes that ensure the necessary supply of drugs and other interventions to help eradicate Guinea worm disease, and help eliminate by 2020 lymphatic filariasis, leprosy, sleeping sickness (human African trypanosomiasis) and blinding trachoma.
- Sustain, expand and extend drug access programmes to ensure the necessary supply of drugs and other interventions to help control by 2020 schistosomiasis, soil-transmitted helminthes, Chagas disease, visceral leishmaniasis and river blindness (onchocerciasis).
- Advance R&D through partnerships and provision of funding to find next generation treatments and interventions for neglected diseases.
- Enhance collaboration and coordination on NTDs at national and international levels through public and private multilateral organisations to work more efficiently and effectively together.
- Enable adequate funding with endemic countries to implement NTD programmes necessary to achieve these goals, supported by strong and committed health systems at the national level.
- Provide technical support, tools and resources to support NTD-endemic countries to evaluate and monitor NTD programmes.
- Provide regular updates on the progress in reaching the 2020 goals and identify remaining gaps.

To achieve this ambitious 2020 vision, we call on all endemic countries and the international community to join us in the above commitments to provide the resources necessary across sectors to remove the primary risk factors for NTDs—poverty and exposure—by ensuring access to clean water and basic sanitation, improved living conditions, vector control, health education, and stronger health systems in endemic areas.

We believe that, working together; we can meet our goals by 2020 and chart a new course toward health and sustainability among the world's poorest communities to a stronger, healthier future.