



Framework for Engagement

Shaping the way forward in the fight against NTDs

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Executive Summary

NTDs are a group of treatable and preventable diseases that continue to affect over one billion of the world's most impoverished, marginalized people living in remote communities. Non-governmental organisations (NGOs) play a key role in the fight against these diseases.

The NTD NGO Network (NNN) is a global forum for NGOs to contribute to the global control, elimination, and management of consequences of NTDs outlined within the internationally agreed World Health Organisation (WHO) NTD Roadmap.¹

This framework for engagement was developed through a participatory approach with members and stakeholders to clarify the NNNs vision, purpose, objectives and values and ensure that the NNN had a governance structure to support its aims.

Our vision is a world free of NTDs.

Our purpose is to enhance the contribution of NGOs towards that vision.

Our objectives to achieve our vision and purpose are:

1. To be the unified NGO voice on common issues to achieve our NTD goals.
2. To enhance our community of practice through membership engagement, learning and sharing knowledge.

Our values of participation, legitimacy, creativity and independence guide our NNN community in achieving these objectives.

Our Membership is open to any NGO or academic institution² that is engaged in the fight against NTDs. Other organisations are welcome to join our work as active observers.

NNN is governed by an Executive Committee, comprised of representation of various NGO disease-specific groups and working groups that will enable the network to successfully meet the objectives of NNN.

¹ http://www.who.int/neglected_diseases/NTD_RoadMap_2012_Fullversion.pdf

² Based on the principle that most academic and research institutions are registered NGOs – they are welcome to become members based on the understanding of this principle

1. Introduction

NTDs are a group of treatable and preventable diseases that continue to affect over one billion of the world's most impoverished, marginalized people living in remote communities. NTDs are both a consequence and cause of poverty, thriving where access to clean water, sanitation, and healthcare are limited. The impact on individuals and communities can be devastating. Many NTDs cause severe disfigurement, disabilities and mental health problems and affect the life expectancy, education, and socio-economic opportunities of individuals, families and the communities they live in.

The NNN is a global forum for NGOs to contribute to the global control, elimination, and management of consequences of NTDs outlined within the internationally agreed WHO NTD Roadmap.³

The network started in 2009, when three groups: the NGO Group for Onchocerciasis Elimination; LF NGDO Network; and the International Coalition for Trachoma Control, came together to establish the NNN. Since then, the network has continued to grow with the addition of two more NGO Coordination Groups: the STH/Schistosomiasis NGO Coordination Group and ILEP. The annual conference is its flagship activity, along with advocacy and coordination activities throughout the year.

The growing number of organisations involved in the NTD community and increased potential of this Network has created an opportunity for the development of a clear framework for engagement for all stakeholders. This framework was developed in 2016 through extensive consultation with members and stakeholders and with the support of an external consultancy firm, Direct Impact Group. This framework provides a platform through which the community can work together more effectively to have a greater impact in combatting NTDs.

³ http://www.who.int/neglected_diseases/NTD_RoadMap_2012_Fullversion.pdf

2. Vision, Purpose and Objectives of the NNN

Our vision is a world free of NTDs

Our purpose is to enhance the contribution of NGOs towards that vision.

Our Objectives are

1. ***External facing:*** To be the unified NGO voice on common issues to achieve our NTD goals.

NNN will agree and prioritize issues of common concern. NNN will ensure relevant structures and skill sets are in place to lead advocacy, influencing and policy development and be able to respond to opportunities as and when they arise. In doing this, NNN will enhance existing contributions by the disease-specific groups and continue to build on the practical successes of the cross cutting working groups.

For NNN members, this will amplify messaging on issues of shared concern, avoid duplication of efforts, maximize efficiency of resources, and access new audiences for programming and partnership.

This will demonstrate the contribution of the NGO sector to the global effort to combat NTDs.

2. ***Internal facing:*** To enhance our community of practice through member engagement, learning and sharing knowledge.

NNN will further develop existing mechanisms to engage members, including the NNN annual conference, websites, email communications and through the disease-specific groups and working groups. NNN will continue to identify innovative opportunities to engage members and strengthen our community of practice, while avoiding duplication and effectively signposting available resources to members. The NNN will take account of the international nature of the community and varying levels of access to the internet and seek to find the most effective methods of engagement and communication for all.

This increased engagement within NNN will build momentum and a sense of urgency as we move towards the end game. The existing strong technical capacity of our members to support national programs will be enhanced by effectively networking and collaborating with other stakeholders leading to: increased synergies; shared learnings; more effective utilisation of

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existing resources; and greater exploration of innovative opportunities for collaboration and collective problem solving.

Through this engagement NNN members will benefit from further development of technical knowledge and awareness, access to best practice and leadership and the creation of a shared responsibility for outcomes.

3. Our values

The following values guide NNN. They influence our thinking and are used routinely in policy, priority setting, decision making and implementation of all aspects of our work.

Participation: We believe in creating opportunities for all stakeholders to engage in the fight against NTDs.

This value is reflected in the following principles:

- We create a dynamic and welcoming environment which stimulates and appreciates active participation by our members.
- We seek collective and collaborative engagement with other partners, working to combat NTDs.

Legitimacy: We seek to become a legitimate representative body with a clear mandate from our members to act.

This value is reflected in the following principles:

- We support an environment which includes two-way communication across the network and allows members to raise their voice and opinion on topics.
- We ensure a representative governance structure of the NNN which reflects the membership.

Creativity: We continuously search for better solutions in the fight against NTDs.

This value is reflected in the following principle:

- We provide platforms for promoting creative and innovative efforts, ideas and methods to continuously improve the fight against NTDs.

Independence: We are the independent voice of NGOs.

This value is reflected in the following principles:

- We promote the value of NGOs in the fight against NTDs.
- We exchange and collaborate in an atmosphere of respect, dignity, and inclusion.

4. Our Membership

The framework aims to foster NNN's identity as an NGO network, while ensuring that NNN's work is inclusive of all organisations that wish to make a valid contribution to the control and elimination of NTDs. This approach will also provide a foundation for establishing a legitimate voice of NGOs on areas of common concern across all NTDs.

The following principles will apply for the membership of NNN:

Members: Any NGO or academic institution⁴ with an interest in NTDs can apply for membership.

The process for applying for NNN membership is:

- a. Representatives from at least two NNN member organizations provide written letter of support for applicants.
- b. The Executive Committee reviews and determines whether the application is successful.
- c. Each member confirms its membership every five years.

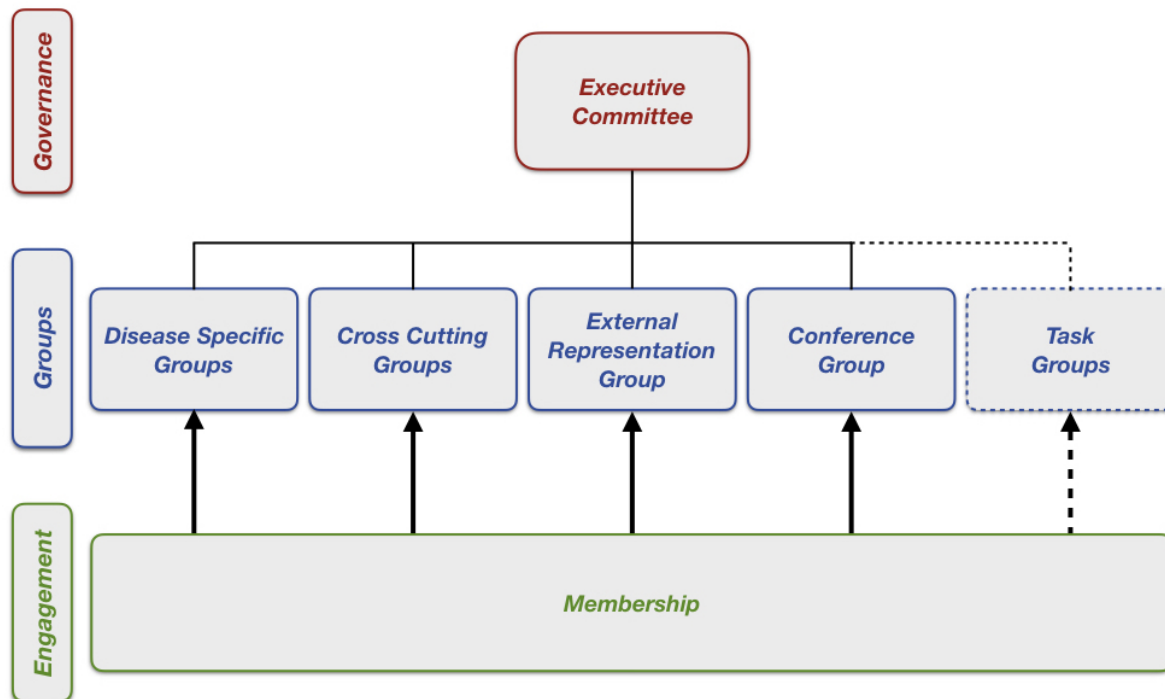
Active Observers: Any other organisation (e.g. WHO, donors, pharmaceutical companies, etc.) or networks are invited to interact with NNN as an active observer, participating and contributing in meetings when invited, but without the right to vote on organisational matters.

⁴ Based on the principle that most academic and research institutions are registered NGOs – they are welcome to become members based on the understanding of this principle

5. Governance and Structure of the NNN

5.1 The Structure of NNN

The following overview summarizes the structure of NNN:



- Disease Specific Groups***

The disease specific groups are groups already established independent of the NNN. The NNN provides a forum for these disease specific groups to come together to identify areas of common concern and integration opportunities.

A new disease specific group can join the NNN with the agreement of the Executive Committee. Each disease specific group has representation on the Executive Committee which is decided by the respective group.

- Cross Cutting Working Groups***

The cross cutting working groups focus on issues of common concern across disease groups or to the NTD community at large. They will have an action orientated approach identifying

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pertinent issues and working together to develop solutions that can be disseminated more widely.

A Cross Cutting Working Group can be established if there are five or more members willing to collaborate. Each Cross Cutting Working Group has representation on the Executive Committee. The membership, operations and representation on the Executive Committee is guided by a Terms of Reference agreed by the Executive Committee.

- ***External Representation Group***

This group provides strategic guidance to NNN executive committee on advocacy and external communications. It facilitates engagement with the wider NTD community in the creation of policy positions and influencing work. The group leads on external communication strategies and activities, providing guidance and support to groups where needed. It provides a platform for the growing number of national NTD coalitions and networks to coordinate their influencing activities and share information.

The membership, operations and representation on the Executive Committee is guided by a Terms of Reference agreed by the Executive Committee.

- ***Conference Group***

This group initiates, plans, conducts, and evaluates the annual conference and other opportunities for members and active observers to exchange and engage.

The membership, operations and representation on Executive Committee is guided by a Terms of Reference agreed by the Executive Committee.

- ***Task Groups (time limited)***

Task Groups work on specific time limited tasks which are not primarily addressed by any other group. Task groups are identified by the Executive Committee and operate in accordance with a Terms of Reference agreed by the Executive Committee.

5.2 Governance of NNN

NNN is governed by the NNN Executive Committee. The Executive Committee oversees the management of the network and ensures it is meeting its objectives in line with its terms of reference.

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The NNN is composed of the following representatives:

- Chair, Vice Chair and Immediate Past Chair
- 1 representative per Disease Specific Group
- 1 representative per Cross Cutting Working Group
- 1 representative from the External Representation Group
- 1 representative from the Conference Group

The members elect the Vice Chair who then becomes the Chair and then Immediate Past Chair.

Representation from each of the groups will be determined by the respective group as outlined in their Terms of Reference. Representatives from time limited task groups will be invited to join the Executive Committee meetings where relevant.