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## SKIN RELATED NEGLECTED TROPICAL DISEASE CROSS CUTTING GROUP

### TERMS OF REFERENCE

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#### Background

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 organizations (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 Organization (WHO) NTD Roadmap<sup>1</sup>.

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 institution<sup>2</sup> 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 from various NGO disease-specific groups and cross cutting groups, the External Representation Committee and the Conference Committee that will enable the network to successfully meet the objectives of NNN.

Cross Cutting Groups focus on issues of common concern across disease groups or for the NTD community at large. A Cross Cutting Group (CCG) can be established if there are five or more members willing to collaborate and with agreement and periodic review by the

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<sup>1</sup> [http://www.who.int/neglected\\_diseases/NTD\\_RoadMap\\_2012\\_Fullversion.pdf](http://www.who.int/neglected_diseases/NTD_RoadMap_2012_Fullversion.pdf)

<sup>2</sup> 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

Executive committee. Each Cross Cutting Group has representation on the Executive Committee.

### **Purpose of the cross cutting NNN “Skin related NTDs” Group (SkinNTDs)**

The recent debates on how to address NTDs that are not treatable with blanket administrations (non PCT NTDs) and the urgent need to develop strategies that would answer multiple challenges in prevention, control, management and surveillance of these diseases, has led to the recognition of other specific operational and technical aspects of the non-PCT NTDs that have not been discussed so far, yet are an important component of the NTD roadmap. For instance, several diseases such as those that have in common **skin lesions as initial signs of infection** (Buruli ulcer, cutaneous leishmaniasis, mycetoma and yaws, for instance), have been somehow neglected as **difficult to map or involving complex treatment**. Meanwhile, in a post-MDA phase in which drugs such as ivermectin or azithromycin are not administered anymore as blanket administration, diseases such as scabies and yaws, treatable and kept under control with these drugs, are suddenly increasing or reoccurring.

To move forward the elimination agenda also for these diseases that haven't been adequately addressed and included in the public health priorities, the World Health Organization (WHO) has recently started to promote an integrated strategy for **skin-related NTDs** that **require active detection, treatment and control**. The integration of management of these diseases that have skin problems as commonality creates an opportunity to tackle many conditions at once in a cost-effective way, and may open up more financial opportunities to finally address them and aim at their elimination in those countries where they are endemic.

The awareness of the current challenges on treating skin related diseases, and the poor knowledge about how to detect and manage them, has prompted several organizations to start focusing on this topic, for instance, by developing new tools to map skin related NTDs and guidelines to support health staff in differential diagnosis of skin diseases.

As well as the need to **improve knowledge and awareness of these diseases** that have been forgotten by the international community, the absence of necessary financial support has also been recognized as one of the main challenges. Greater advocacy efforts are needed in order to increase the international support for skin related NTDs.

In view of the above, several organizations have agreed to create a new CCG called “Skin NTDs” to ensure that these neglected diseases receive adequate attention and financial support within the NTD Roadmap.

### **Functions of this group**

This Group comprises of NNN members with an interest in learning and advocating on skin related NTDs as a guide to fighting NTDs.

The key functions are:

1. To drive the development and implementation of the Network's strategy on this cross cutting topic.
2. To align with and contribute to the NNN Framework for Engagement and its objectives
3. To ensure the Network's support to the WHO NTD Roadmap is aligned with NNN objectives.
4. To ensure that NNN is represented in relevant forums related to skin related NTDs and sharing relevant information with NNN membership
5. To identify, and plan for, an annual programme of activities that deliver, or enable the Network to deliver on, on the NNN strategy for skin related NTDs
6. To report back to the Members at the Annual Conference on progress

Other functions – policy, advocacy, information sharing and fundraising:

1. To **create a platform** that gathers non-governmental organizations, scientists, academics, and advocacy groups interested in tackling skin related NTDs, and helps the discussion of technical, policy, advocacy and research aspects of skin NTDs
2. To **share experiences**, challenges and lessons learned for improving prevention, detection, treatment and management of skin related NTDs, including new tools that may be useful and possibly found effective in improving disease detection and management.
3. To **push forward already accepted strategies** for preventing, detecting, treating and managing skin related NTDs, either via supporting the drafting of international policies or where necessary, advocating for them
4. To use this platform **to raise awareness** amongst the general public about this group of NTDs and increase international recognition of the urgent need to address these diseases
5. To **increase awareness and knowledge about these diseases among donors**, in order to create the opportunity for the funding of skin related NTDs
6. To **advocate for the mapping** of NTDs in countries where the disease burden is not yet known, as the precursor for control, treatment and management interventions
7. To **build the evidence base and business case** for donors and endemic countries to invest in interventions targeting skin based NTDs
8. To help **promote the most cost effective approaches** available, **and** support the development of more **sustainable solutions** for controlling skin related NTDs.

Other functions - technical support:

1. To **identify potential gaps** in disease burden and current state-of-the-art in management of skin related NTDs
2. To discuss and **promote new approaches to effectively map** skin related NTDs in countries where the disease burden is not yet known

3. To **support capacity building** within the remit of skin related NTDs in countries where these diseases are a public health priority, especially at the community and primary health care level to improve early detection and management
4. To **identify new methods** and processes **for disease surveillance** and reporting after mapping is done, and in post-elimination phase
5. To help in understanding where effort should be targeted to **ensure cost effective interventions**

#### Scope of engagement

- I. To **technically support governments** and international health organizations such as the WHO in gathering scientific evidence in identifying what works and what does not work in terms of disease detection, management and follow up
- II. To **enhance discussions** and information sharing among all those that are trying new integrated approaches **to detect skin conditions other than skin related NTDs**, but equally important, such as podoconiosis and tungiasis, and those emerging in post-MDA context (e.g. scabies)
- III. To **collaborate with the WHO in providing evidence based approaches**, monitor and evaluate current strategies already in use in endemic countries, and support in the drafting and finalization of guidelines, policies, and work plans that would guide NTD endemic countries in their NTD national plan

### **3. Membership of the CCG**

Membership is open to any NNN member who can contribute to the learning and advocacy of skin related NTDs in the fight against NTDs.

There is no maximum number of members; every organization that is interested in and working on these diseases is welcome to join as long as it adheres to the NNN NGDO framework and to the principles represented by these ToRs.

The adherence to this CCG does not limit members to adhere to other disease based or CCGs, if their remit of work includes other areas of engagement beyond skin related NTDs.

Members need to submit their names to Skin NTDs to join the group via sending their request to join to the CCG secretary via email. The request should contain a statement about the work on skin related NTDs the organization is currently engaged with, and the reasons for joining. Requests of membership will be assessed by the Chair and Vice Chair and acceptance confirmed via email. The new organization member will have then, to propose a representative that would fulfil the attributes as expressed below. The CCG will maintain an up to date mailing list, which will be reviewed annually.

### **4. Elections / Appointments**

- The Chair  
Elected by the CCG (based on a list of people expressing their interest of covering this role) and will serve a two year term.
- Vice chair

Elected by the CCG (based on a list of people expressing their interest of covering this role) and will serve a two year term.

- Advocacy & secretary person

Appointed by the group Chair and Vice-chair, based on a list of people expressing their interest of covering this role

- Representatives of the organizations that are members of this CCG

Elected by the organization members

*Attributes and criteria applying to individual representatives:*

- Technical skills and experience to a) report to the group NTD activities that currently ongoing within the organization, ideas and any technical work that is relevant for this group, and b) be able to provide input to the working group from the technical, policy and/or advocacy points of view.
- Willingness and support from individual's employer to enable them to contribute actively and on a voluntary basis without compensation.

The above roles will be reviewed every two years.

*Note: Chair and Vice Chair should belong to two different organizations of the CCG. It would be also preferred to have an advocacy/administrative support belonging to members different from those of the Chair and Vice Chair.*

## **5. Roles and Responsibilities**

### Applicable to all

- All members of the CCG should adhere to the values of the NNN in all their efforts and decision making
- All members should actively contribute to the CCG and attend the regular meetings
- All positions are voluntary and non-remunerated

### The Chair (and Vice Chair):

*Note: the Vice Chair has the same responsibilities of the Chair; group activities and annual plan have to be discussed and decided in terms of role/representation in advance.*

- Sits on the NNN ExCo and will act as the liaison between the wider NNN community and this CCG
- Drafts agenda and chairs the CCG meetings
- Oversees the CCG annual plan
- Reports back to the members after the annual NNN NGDO conference
- Appoints a CCG advocacy/administrative support
- Reviews membership applications, and approve membership when applicable
- Acts as a link to CCG observers

### Advocacy /administrative support

- Develops newsletters, statements and other public documents representing ideas and positions of the CCG, if needed, and when needed
- Liaises with other NTD advocacy groups within the NNN NGDO and outside this coalition
- Support in organizing skype call and other CCG events, if any

- Participates to the routine CCG calls, takes and circulates minutes of these calls, to CCG members
- Forwards the request of membership to Chair/Vice chair
- Supports the CCG in any other advocacy/administrative duty

#### Representatives of CCG members

- Participate to skype calls, webinars, meetings and other activities that may be needed and decided by the CCG

#### **6. Meetings & activities**

Routine skype calls, webinars, and/or global calls (via international dial/in numbers), would be organized every two months to provide updates, propose new ideas, collaborate for new projects and proposals, share tools, present data and discuss about any topic relevant to this CCG.

Other activities would be decided based on the agenda and minutes of the skype calls, needs of the CCG members, requests of the NNN NGDO executive committee and possibly, based on specific request of observer members.

Face to face meetings will be preferred where possible. Additional communication amongst members will be done by email, or other electronic means.

Participation in meetings, calls or activities of the CCG, by non-NNN and non - Skin NTDs members, can be requested to the secretary and approved by the Chair/Vice Chair, if applicable.

#### **List of members (organization, contact person, email address)**

1. Malaria Consortium - Giuseppina Ortu, g.ortu@malariaconsortium.org
2. Footwork: The International Podoconiosis Initiative - Wendy Santis, wsantis@podo.org
3. Lepra - Geoff Prescott, GeoffP@lepra.org.uk
4. International Alliance for the Control of Scabies, Murdoch Children's Research Institute (Melbourne, Australia) - Daniel Engelman, dengelman@gmail.com
5. Leprosy Research Center, National Institute of Infectious Diseases (Tokyo, Japan), Norihisa Ishii, norishii@niid.go.jp & Rie Yotsu, yotsurie@hotmail.com
6. London School of Hygiene and Tropical Medicine, Michael Marks, Michael.Marks@lshtm.ac.uk
7. Leprastichting / Netherlands Leprosy Relief (NLR), Liesbeth Mieras,

8. L.Mieras@Leprastichting.NL
9. ISGlobal, Laia Bertran, laia.bertran@isglobal.org
10. International Foundation for Dermatology, Claire Fuller, claire.fuller@nhs.net

**Observers:**

World Health Organization:

RUIZ POSTIGO, Jose Antonio, postigoj@who.int

ASIEDU, Kingsley Bampoe, asieduk@who.int