

NNN conference 2019 – Key takeaways September 17th, 2019

Networks present

- 1.) African Research Network for NTDs
- 2.) Canadian Network for NTDs
- 3.) German Network against NTDs
- 4.) Japan Alliance on Global NTDs
- 5.) Réseau Francophone sur les MTN
- 6.) Swiss Alliance against NTDs
- 7.) Speak up Africa, African Regional NTD Network
- 8.) UK Coalition against NTDs

Summary

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.) Inputs from workshop session on research
 For some NTDs, mass drug administration will not be enough to reach elimination. The new WHO roadmap is an opportunity to distill and define the needs for im- proved/new diagnostics and drugs.
• We need to move beyond engaging only with health ministries. To promote an in- creased understanding of operational research and new tools, we need to also en- gage with ministries that work in scientific research, WASH, education, mother and child health and more. By presenting NTDs as an investment towards health, we can bring multiple ministries into the same conversation.
• The challenge of representation in the field of research needs to be tackled. Visa re- strictions and missing funds need to be addressed. To work equally and collabora- tively across Latin America, Asia and Africa, we need to ensure that there are enough resources available to give everyone an equal opportunity to participate in these discussions.
.) Inputs from workshop session on advocacy
 We did quite well with international advocacy for NTDs. If we want the new roadmap to be as successful as the last one, we need to focus on national advocacy in endemic countries. To facilitate that, we need to engage with local groups,



scientists and communities to influence decision makers. Inspiration could be drawn from the HIV movements and networks.

- In order to create demand from endemic countries and the field, we need to take NTDs out of the bio-medical space and make it a human rights issue. We need to make it an issue that the communities can understand and respond to.
- Youth activism could be the key to success. The power of youth activists in HIV is impressive, as they translate a complicated message into something that communities can understand and support.

4.) Summary of research panel

NGOs and research in a time of fake news, alternative realities and funding scarcity: can you highlight approaches to overcome the suspicion of governments and the population, and secure funding while retaining independence?

- Disconnects between our thinking and that of the general public need to be avoided. Researchers need to have their ears close to the ground and be ready to counter false information quickly.
- Ghana is countering fake news with immediate social media interactions that share verified information. Quelling the spread of misinformation at a very early stage has proven to be effective.
- Making the results of trials available publicly might not be enough to combat rumors; but it can give people solid grounds for forming an opinion.
- Researchers are striving to publish information that is verified and true. But they need to be aware that their findings and publications could be competing with false information.

What are your perspectives on the key challenges to be addressed/focus areas of research over the course of the next WHO NTD roadmap?

- If we are prioritizing the elimination of certain diseases, we will also have to come up with new tools to measure elimination. For diseases where we achieve elimination, we will need to explore what kinds of tools are needed to fully stop transmission.
- Eliminating diseases outside of a full mass drug administration approach will require diagnostics tools at the field level that allow us to safely administer treatment. Bringing gaming changing tools to the field will also change how health workers manage these diseases. Additionally, integration with other areas such as Malaria will also play an important role.
- At some point, we will also have to address the effects of NTDs on mental health. This area has been neglected, as finding tools was the main priority.



• The resources of networks and donors are limited. We need to follow an integrated approach that includes all aspect of the patient management, including treatment, diagnostics, vector control and more. A simple approach would be to test new diagnostics during the clinical trials for treatments. This has already been done for sleeping sickness. But to facilitate partnerships, we need to be aware of who is working on what.

The benefits of collaboration: how can non-NGO actors support the work of NGOs and make it more effective (except providing funding), and what role can national NTD alliances play to facilitate collaboration and thereby maximize impact?

- Many actors in the field of NTDs have been working independently. Forming NTD
 networks has helped the different actors to focus on shared tasks. It can be beneficial to bring together actors from R&D, access, delivery and community involvement. Combining that expertise into a shared project will be crucial for reach the
 2030 targets.
- By forming alliances and bringing together experts from various fields, networks can form an important focal point for politicians and governments.

5.) Summary of advocacy panel

How can advocacy help tackling a new WHO NTD Roadmap and facilitate the inclusion of NTDs in national development aid priorities? How do strategies differ between coalitions operating in donor governments vs those that operate within endemic countries?

- Advancing the roadmap is not just a question of investing more money into drug distribution and diagnostics. We also need to invest into basic research, capacity building, delivery services and more. This gives us different narratives to work with, as we are not only advocating for NTDs, but also for connected areas such as capacity building.
- Recognizing NTDs as a multi-dimensional, multi-disciplinary issue allows us to reach different parts of society and tap into different funding streams.
- National programs in endemic countries might be battling each other for resources. Even a presidential sign off cannot always create enough will to get people on the ground to change priorities. It is vital to acknowledge that realities on national and regional levels might be different. Networks must engage on both levels and build political will around NTD elimination.

Building political will: how do NTD advocacy networks reach politicians and can you share examples of national coalitions collaborating to build/maintain political commitment?



- The UK is working with an All-Party Parliamentary Group to bring together people from various parties around issues that they can all buy into. They hold technical meetings, organize country visits, support annual reports, etc.
- Building political will goes beyond working with parliamentarians and government departments; advocacy must also reach the public. We need to convince the public that NTDs and development in general are good investments; and motivate them to think beyond the domestic agenda.
- Advocacy is only the door opener, defining the "how" to address NTDs is the hard part: how can support be delivered, how can sustainability be achieved, how can it be linked with other parts of the aid system, etc. In the long run, it is about addressing NTDs within other parts of the aid system and embedding it into horizontal development in health programming.
- A new perspective is forming: NTDs in the service of the global development agenda. We need to demonstrate how investing in NTDs delivers health system strengthening, universal health coverage, improved global security and more.
- Our messages need to become more sophisticated. We have simplified our messages to a degree where they are no longer accurate. Dealing with NTDs might be cheap in the short term, but long term investments might no longer provide value for the money. We need to choose different narratives to explain why NTDs are good investments.
- NTD networks become "more difficult to ignore" if they represent a broad range of actors (universities, R&D, veterinarians, implementation, industry, etc.). Engaging with adjacent sectors such as WASH and nutrition could amplify that effect.
- NTD studies are usually only available in English. To engage with politicians on a national level, networks should consider translation relevant content to the national language(s).
- Offering country visits to selected parliamentarians can help build interest and political will. Additionally, networks can try to connect parliamentary groups from different countries to facilitate discussions among politicians.

Is there something that NTD networks can learn from current social movements such as the climate movement? While the long-term effect of some of these movements is unclear, they have managed to influence and set the political agenda in countries across Europe.

• Climate change movement shows that youth are interested in global issues; we should offer them an opportunity to learn about NTDs and give them platforms to get involved.



- The Canadian network has launched a contest for youth ambassadors by asking for 3 minute videos on why Canadians should be concerned about NTDs globally. The quality of the videos received was excellent.
- Building up youth as allies could help us reach forums that we would otherwise not interact with.