

NNN Conference Report

Addis Ababa 2018



NEGLECTED TROPICAL DISEASE NGO NETWORK

A global forum for nongovernmental organizations
working together on NTDs

With thanks to our national hosts and platinum sponsors:



FEDERAL DEMOCRATIC REPUBLIC OF
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Message from the Outgoing Chair, Tanya Wood

I am privileged to be the Chair of NNN 2018, the 9th NNN annual conference, for three reasons:

Partnership

NNN is a forum that has grown and expanded over the years, but the fundamental premise remains the same. It is built on a strong belief in partnerships:

Partnership between diseases - From the initial five founding diseases, NNN now has more than 70 members, representing a wide range of NTDs. This year we have welcomed the Chagas Coalition and the Rabies network.



Tanya Wood © NNN.

Partnership between cross cutting issues linked to our BEST framework –

Behaviour, Environment, Social inclusion and Treatment. We know the challenges in beating NTDs involve many overlapping factors but looking at these cross-cutting issues is central to the NNN. Our original two cross-cutting groups on disability, morbidity & inclusion (DMDI) and water & sanitation (WASH) have continued to be active, while this year, we were pleased to welcome groups on sustainability, vector control, skin NTD, conflict and zoonotics – as well as work on the London Declaration scorecard.

Partnership with Governments - While we are an NGO network, we understand that ending NTDs relies on partnership between governments and NGOs. What better way to see that than this year's NNN conference being hosted by the Ethiopian Federal Government. They have been an exceptional partner in hosting this event and working with NGOs here in Addis through our local organising committee.

Participation

This year it was amazing to see that we had more people trying to register than we could accommodate at the venue, which shows how much this community values the time together at the conference. I am also exceptionally pleased to see more participation from people affected by NTDs. This year a task team was launched through the DMDI group to progress this area of work, and we are very pleased to say we have increased the number of people affected attending tenfold this year.

Passion

Tackling NTDs is a story of passion and commitment - passion to tackle the inequity that sees more than one billion people impacted by these diseases that are not only a health issue but driven by many other factors, often related to the challenges of inequity and poverty. This passion drives the NNN. It is a network completely run by volunteers and I would like to express my thanks to the Executive Committee of the NNN. We have grown our Executive Committee this year, to reflect the leads of the disease networks as well as the cross-cutting groups. These people have given much time and energy throughout the year, have organised activities and worked tirelessly to bring this conference to life.

I would also like to express my thanks to the Ethiopian government for supporting this conference so whole heartedly, to Maximize Your Time for the logistical arrangements, to those organizations which sponsored travel awards, and of course to all of you joining us.

Tanya Wood

NNN Chair, Sept 2017- Sept 2018

Welcome from the Incoming Chair, Gail Davey

I am delighted to take up my role as chair of the NNN at this exciting time, as our network continues to grow in size and influence.

This year we welcomed more than 400 delegates from 54 countries to our 9th annual NNN conference in Addis Ababa, Ethiopia. Together, we represented 150 civil society organizations, as well as governments, funders and the private sector.

These are record numbers and reflect the commitment and energy of our voluntary NNN Executive Committee and of our passionate 70+ member organizations – many of whom generously sponsored this year's conference – as well as our hosts the Ethiopian Federal Ministry of Health.

It was an honour to have H. E. Dr Kebede Worku, State Minister of Health, speak at the opening of the conference to underscore his government's efforts to control NTDs and to stress the importance of government commitment, leadership and ownership in eliminating NTDs everywhere.

In a recorded video message, Dr Tedros, Director General of the WHO, told delegates: "This meeting is an important opportunity to highlight the urgent need to bring health equity to the remaining one billion people who continue to be affected by neglected tropical diseases."

This message aligned closely with the theme chosen for our conference - "Reaching the Last Billion: Setting BEST in Motion", a theme both ambitious and achievable.

Ambitious, because if we are to reach the more than one billion people living in remote and marginalized communities – those who are most affected by these diseases of poverty and under-development, and who typically lack access to health systems – then we need shared strategies and partnerships that reach beyond the global health sector.

Achievable, because we will do this through the NNN's BEST framework. This promotes multi-sector partnerships around Behaviour, Environment, Social inclusion and equity, and Treatment and care to realise our vision of a world free from NTDs. The vehicles for the multi-sector partnerships promoted through the BEST framework are the NNN Cross-Cutting Groups. We now have groups devoted to sustainability, conflict, vector control, skin NTDs and One Health, in addition to the WASH and DMDI groups. The 24 workshops selected this year – whose outputs are summarised earlier in this report - testify to this approach.

A highlight of the 9th conference was the active participation of people affected by NTDs. Rachna Kumari, from Lepra, spoke personally and powerfully about overcoming leprosy at the opening plenary.

"Only by partnering with people affected and involving us in the different stages of NTD programming will our community be able to make a real advance in social inclusion necessary for controlling and eliminating these diseases," she told delegates. "We won't reach the last billion without us."

I am already looking forward to our 10th anniversary celebrations from September 17th-19th 2019 in Liverpool, U.K. This will be a fitting time to reflect on our significant progress to date and reaffirm our commitment to working together to reach the last billion and to beat NTDs.

Professor Gail Davey

Brighton & Sussex Medical School & NNN Chair



Gail Davey speaking at the NNN 2018 press conference in Addis Ababa © NNN. Photo by Fitsum Alemayelu.



Young girls in the Oromia region of Ethiopia wash their hands and faces with clean water from a protected well, an activity key to eliminating trachoma. (c) ITI/ Steven Adams

Workshop

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Posters



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Setting **BEST** in Motion

1.1 Beyond Zero - Lesson for NTD elimination from transition planning in trachoma

WHO established 2020 as the target date for eliminating trachoma as a public health problem. NGO partners play an important role in assisting authorities prepare for this transition once elimination thresholds for TT and TF have been attained. "Transition planning is the process undertaken as districts work towards and reach their WHO elimination thresholds to ensure that successes are maintained, services are embedded within routine health care, water and sanitation services, and the health system is strengthened."

The objective of the workshop is to introduce countries and partners to tools that can assist them in developing transition plans for their NTD programmes - an integral part of successfully achieving and maintaining the elimination of NTDs.

Contact Information

Convener

Helen Bokea; Sightsavers

Rapporteur

Scott McPherson; ICTC

Speakers

1. *Michaela Kelly; Sightsavers*

2. *Leah Wohlgemuth;
Sightsavers*

3. *Stephen Mwatha;
Ministry of Health, NTD, Kenya*

4. *Innocent Mhango; Ministry of
Health, Malawi*

Main learning point:

Transition planning is an integral part of achieving and sustaining elimination of NTDs and should be planned for right from the outset of programmes.

Next steps – summary:

Draft trachoma transition planning guidelines to be presented at ICTC meeting and thereafter circulated for use.

Key action point:

Going forward Trachoma Action Planning to include a section on transition planning



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1.2 One Health - How to get the message across

A quarter of all NTDs are zoonotic but these are often not included in the broader discussions around NTDs. This workshop aims to identify the compelling messages that we can use to further strengthen essential linkages between the human and animal public health sectors.

The WHO recognises One Health as “an approach to designing and implementing programmes, policies, legislation and research in which multiple sectors communicate and work together to achieve better public health outcomes.” The One Health approach is particularly relevant to the control of zoonoses, including zoonotic NTDs (zNTD). To reach the WHO goals for the zNTDs, increased linkages with the veterinary public health sector must be fostered.

Contact Information

Convener

Wendy Harrison;
*Schistosomiasis Control
Initiative, Imperial College*

Rapporteur

Antonia Braus; *Veterinarians
San Frontier*

Speakers

1. Antonia Braus; *Veterinarians
San Frontier*

2. Gabrielle Laing; *House of
Lords UK Parliament*

3. Waqas Ahmad;
*University of Veterinary and
Animal Sciences, Jhang Campus*

Main learning point:

When did you last speak to a VET?

One Health has big potential for NTDs, Zoonoses, food safety, food security and food sovereignty

Next steps – summary:

One Health can help eliminate NTDs, meet the SDGs and complement work towards UHC, therefore we need to identify where to use it most effectively (use evaluation framework) and then we can combine resources and knowledge to maximise benefits vs costs

Key action point:

We propose a new cross cutting group for One Health at NNN



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1.3 Telling the NTDs story - what works?

Whether or not you have 'communications' in your job title, we all communicate about NTDs and the vital importance of our work to a variety of audiences on a regular basis. Ensuring that we tell the NTDs story in a compelling way through mass communications and media will contribute to achieving elimination faster. This workshop seeks to generate debate, share challenges and opportunities, and identify good practice in communicating about and telling the NTDs story in 2018 and beyond.

Hear from communications experts from within NGOs and the media about what works and what doesn't. Be part of discussions and activities that are designed to give practical tools to policy and programme experts, so they can further support people affected by NTDs and their comms teams to tell a compelling story and ensure NTDs are neglected no more.

Contact Information

Convener

*Rosa Argent; ILEP
Rebecca Mintrim; Sightsavers*

Speakers

- 1. Alison Hill; The Fred Hollows Foundation*
- 2. Eshetu Geletu, journalist*
- 3. Nikita Sarah; The Leprosy Mission - India*
- 4. Suresh Dhondge; Leprosy Mission*
- 5. Ashok Moloo; World Health Organization*
- 6. James Porter; END Fund*

Main learning point:

Positive media coverage can help to achieve NTD targets faster. It increases awareness and supports fundraising and advocacy efforts. However, NGOs must identify where NTDs fit within media agendas and plan media outreach accordingly. Developing relationships with journalists can increase media exposure and ensure stories include important context as well as personal stories of people affected, which are emotionally engaging and can, in turn, mobilise action.

Next steps – summary:

Working closely with persons affected by NTDs is vital in telling their stories authentically. NGOs should aim to include affected people in media outreach and also share media contacts with the NTD community to increase positive NTD stories. When good NTD stories are published, we all win. We should align language and identify shared objectives and opportunities for NTD communications.

Key action point:

NGOs to develop mechanisms for collaboration so that messaging can be aligned, opportunities identified and media contacts shared. Cross-sectoral communications working groups and task teams will support efforts to have media coverage represent the whole NTD community and increase amplification of communications outputs. Develop toolkit for programme staff with guidance and practical tips on working with people affected and gathering content in the field.



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1.4 Effective case finding and community mobilisation for trachoma control

As countries approach trachoma elimination, case finding has become significantly more challenging. Those left untreated are typically those in remote areas, the immobile, and those reluctant to participate in surgery. The need for a more intensive and proactive approach to case finding has been identified. This workshop will present a series of case studies of approaches adopted by different agencies, across different settings, to address this emerging challenge. A panel discussion will provide the audience an opportunity to engage in discussion and explore strategies, issues and opportunities within their own settings.

Contact Information

Convener

*Lizzy Jenkins; The Fred
Hollows Foundation*

Rapporteur

*Lazanya Weekes; The Fred
Hollows Foundation*

Speakers

*1. Eshetu Sata; The Carter
Center*

*2. Dr. Yeneneh Mulugeta; The
Fred Hollows Foundation*

*3. Scott McPherson;
RTI*

Main learning point:

Local trusted people (particularly women) are the most effective case finders, and can reach the most groups. Integration with other health workers/programmes is key to ensure cost efficiencies and to reach the furthest groups, as well as ensuring prioritisation among different levels of government. Budget for case finding will increase as cases decrease and strategies change, donors need to understand this.

Next steps – summary:

Notes from session will be summarised and shared.

Advocate to donors the importance of allocating sufficient resources to case finding, and promote understanding of why cost will change over time.

Key action point:

Organizations need to collect data and evidence that shows what strategies for case finding are working – when and why. Confirmed dialogue between groups/NGOs/NTDs to ensure this data is shared and informs programmes going forward.



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2.1 Designing Effective Behaviour Change Interventions for NTDs

Achievement of elimination and control targets requires coordinated effort at the beneficiary, community, national and international levels. The engagement of individuals and communities in sustained and widespread health behaviour change is critical to success but continues to prove difficult to achieve. The NTD sector needs to move towards being able to answer the question/s 'what works, in what circumstances and why?' for the behaviour change elements of programmes. To answer these questions, we need to move beyond reliance on personal experience and expert opinion. We must draw more effectively upon available theories, processes and conceptual frameworks, and develop interventions built on a foundation of adequate consideration of specific behavioural targets, context, and implementation constraints and opportunities.

This workshop aims to introduce participants to theory and evidence based approaches to the design, development and delivery of health behaviour change interventions. It will provide an overview of principles and approaches to the design, development and delivery of health behaviour change interventions. Design considerations and approaches will be introduced, and key tools and resources highlighted. The introductory presentation will be followed by presentation of a series of case studies, and group discussions.

Contact Information

Conveners

*Sarity Dodson (The Fred
Hollows Foundation)*

Rapporteur

*Lizzy Jenkins (The Fred
Hollows Foundation)*

Speakers

*Sarity Dodson
Helen Hamilton
(WaterAid)
Liat Rennet (NALA)*

Main learning point:

Stakeholder engagement throughout design, implementation, evaluation and dissemination is critical.
Designs should be evidence and theory based.
Strong M&E and common indicators will allow development of the evidence base.
We will accelerate achievement of end goals by sharing results of our evidence and theory based, well evaluated programmes.

Next steps – summary:

Disease logic model development.
Development of common indicators.
Synthesis of existing evidence – presented in accessible way.
WASH/NTD programme guidance - behaviour change programming focus.

Key action point:

NNN WASH/NTD – Behaviour Change, Task Team



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2.2 No More Neglected - Applying health equity to NTDs

Addressing equity in health is complex and is more than simply working in a disadvantaged geographical region. It means reaching the most disadvantaged within that region and making comparisons over time of health outcomes between disadvantaged and advantaged groups. Applying an equity lens to health care programming will help to further accelerate gains and bridge the gaps in access, quality and coverage of health care and its utilisation. The past couple of decades have witnessed significant advances in global public health efforts. Much of this can be attributed to advances in technology, increasing economic opportunities for people and efforts to scale up proven solutions. While progress is evident, stagnation in expedited results on critical health indicators continues to hamper the pace and the ability to consolidate achievements. Access, demand and utilisation of critical health services are often hampered by various forms of social exclusion.

Objectives of the Session: At the end of the workshop participants will: [1]. Gain an understanding on the perspectives and various forms of social exclusion in health. [2]. Become familiar with how social exclusion prevents vulnerable groups from engaging and benefitting from health programmes. [3]. Learn to apply social exclusion principles, tools and strategies in health programmes. [4]. Learn how to design programmes and measure social exclusion in health programmes (case study/small groups).

Contact Information

Convener

*Dennis Cherian; World
Vision*

Rapporteur

*Dennis Cherian; World
Vision*

Speakers

*1. Dennis Cherian; World
Vision*

*2. Yohannes
Chanyalewkassa; World
Vision*

Main learning point:

Scale up social exclusion concept and principles, tools and strategies.
Multi-sectoral approach is essential for the multi-dimensional challenge.
NTD programmes should learn from HIV, TB and leprosy, etc. programme responses.

Next steps – summary:

Form coalitions to explore opportunities to scale up social exclusion prevention, and for promotion of health equity approaches among actors, including amongst the NGO network.

Key action point:

Disseminate and promote the use of the social exclusion checklist for equity focussed NTD/health project design.
Explore opportunities for capacity building on social exclusion prevention approaches and strategies.



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2.3 NTDs in conflict and emergencies: What is happening, what can we do, what do we need to do?

The importance of NTD epidemiology, treatment and control in situations affected by conflict and humanitarian emergencies is increasingly recognised as an area that needs to be addressed in order to achieve control and elimination targets. This workshop will stimulate discussion and debate around key themes and share experiences and good practice through case studies exploring programme development in the field. Workshop outcomes will inform the work of the NNN cross cutting group on Conflict and Emergencies.

This workshop is designed to stimulate discussion and debate around key themes through the presentation of case studies and facilitation of table based sessions focused around the following:

- Identify programmes and initiatives currently being delivered or planned in conflict and humanitarian emergency settings to ensure populations effected by humanitarian emergencies or crisis are not left behind; identify good practice, share ideas, highlight issues
- Specify gaps we need to address as a community
- Identify potential mechanisms for leverage to develop this work

The table based discussion will be chaired by members of the group and managed to ensure maximum participation by participants and so that all perspectives are captured and fed into the work of the group.

Contact Information

Convener

Fiona Vincer; MENTOR

Rapporteur

*Fatima Ahmed;
MENTOR*

Speakers

*1. Joe Hollins;
MENTOR*

*2. Phil Downs;
Sightsavers*

*3. Angelia Sanders;
The Carter Centre*

Main learning point:

Conflict and emergency situations are significant barriers to achieving NTD goals. Delivery of health services in conflict and emergency situations is possible but solutions need to be shared and new ways of working advocated.

Next steps – summary:

Convene working group to take issues identified forward. Cross cutting group on conflict and emergencies to elaborate and agree a work plan.

Key action point:

Get involved.

Interested in joining / hearing about group contact: Fiona@mentor.iniative.net



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3.1 Behaviour Change: Practical education approaches, promotion strategies, and change interventions for improving the effectiveness of NTDs Programmes

This session will look at behaviour change education, promotion, and intervention approaches associated with community member collaboration, changing attitudes towards disease transmission, increasing health-seeking behaviours, and integrating multiple NTDs within a programme. The session will examine practical examples where behaviour change health education and promotion strategies have been used to strengthen community collaboration, strengthen the health system, increase health-seeking behaviours of community members, and modify attitudes around specific NTD issues.

The goal of the workshop is to provide insight into the practical application of behaviour change focussed education and interventions. We will present real world examples that have utilised community co-designed and other inclusive intervention strategies to enhance community prevention attitudes, strengthen community partnerships and increase adoption of health seeking behaviours associated with NTD programmes. The workshop promotes the necessity and feasibility of integrating practical, cross-cutting behaviour change education, intervention strategies, and promotion approaches for amplifying effective change messaging, integrating crosscutting diseases, and improving health seeking behaviors and compliance. This practice area is often overlooked despite the many lessons learned and empirical examples available to be shared with the NTD community.

Contact Information

Convener

*Anouk Gouvras; Global
Schistosomiasis
Alliance*

Rapporteur

*Anouk Gouvras; Global
Schistosomiasis
Alliance*

Speakers

*1. Bobbie Person;
Consultant SCORE*

*2. Michal Bruck; NALA
Foundation*

Main learning point:

Understanding the social-ecological context of your BC intervention and the perceptions, beliefs and habits of your community is key. Looking at access to infrastructure and services is also vital before designing BC interventions. Engaging and involving stakeholders, partner organizations and communities in the design and evaluation of interventions will make them more effective and sustainable. Creating demand through a suite of techniques will increase take up and sustainability.

Next steps – summary:

The learning points and ideas from this workshop will be shared with the GSA Behaviour Change Working Group and with the WASH NNN BC task group to feed into the development of the BC guiding document.

Key action point:

Feed into NNN WASH BC task group for BC guiding document.
Feed into GSA BC WG to share lessons learnt and provide support to those working in schistosomiasis.
Promote BC strategies and tools to implementing partners and national programmes.



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3.2 Joint Wash/NTDs planning in practice: can it work and how?

This sessions answers all the questions you have been asking yourself about how to plan together with the WASH sector (or at least makes a start!) Come and learn about how others have engaged in joint planning with WASH and NTDs and ways in which you and your programme can do the same!

The aim of this workshop is to provide participants with practical examples of how the forthcoming WASH/NTD planning toolkit can be used by programmes. There has been a lot of momentum gained around WASH and NTDs over the past years in terms of recognition of importance and joint collaboration. Based on this progresss there is now a recognised need for practical guidance on how to move from rhetoric to implementation. The WASH WG and WHO have developed a set of tools and resources to address this need. This toolkit is designed to help NTD programme managers and partners work with the WASH community by building partnerships, mobilising resources, and designing, implementing and evaluating interventions. This workshop will provide participants with examples of how some of the tools have been used in country contexts, lessons learned and what they can do in their countries and programmes. This workshop will play a key role in moving from discussing the importance of WASH and NTDs to showing how it can be done.

Contact Information

Convener

*Leah Wohlgemuth;
Sightsavers/WASH WG*

Rapporteur

Leah Wohlgemuth; Sightsavers

Speakers

- 1. Shyamala Anand; American
Leprosy Missions*
- 2. Jayaram Parasa; LEPRO
Society*
- 3. Suresh Munuswamy;
Indian Institute of Public Health*
- 4. Geordie Woods; Sightsavers*

Main learning point:

Collaboration is required at all levels to ensure joint WASH/NTD programmes are successful. This can be achieved given the right tools and supportive structures.

Next steps – summary:

Finalise and release WASH/NTD toolkit.

Key action point:

Engage countries and NGO partners to use the toolkit.
Document implementation and update toolkit as necessary.



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3.3 Increasing inclusion of hard-to-reach groups using lessons and strategies from within and outside the NTD community

NTDs disproportionately affect people living in poverty, many of whom may be difficult to reach via traditional mass drug administration channels. These may include children not enrolled in the public school system, women and girls, and people living in urban, geographically isolated, nomadic, and conflict-affected communities. Given the diverse needs of these hard-to-reach groups, there is no one-size-fits-all solution. While the vast majority of NTD programmes recognize the importance of equity and social inclusion, as indicated in the BEST framework, the complexities and additional resource requirements accompanying strategies to improve coverage of hard-to-reach groups can be daunting. Additional support, including widely applicable tools and resources, and learning from other programmes, especially polio immunization and vitamin A supplementation, will be required to enable countries to achieve treatment targets for the various NTDs.

This workshop will highlight the successes, challenges, and additional support, including evidence-based tools and resources, required for NTD and other health programmes' efforts to improve treatment coverage of hard-to-reach groups. Speakers will share experiences and lessons learned from within and outside the NTD community. Following speaker presentations, workshop participants and speakers will learn from each other's experiences and collaborate to brainstorm ideas for broader tools and resources to support efforts to improve NTD programme inclusivity. While several past conference sessions have covered NTD programme inclusivity, they have largely focussed on sharing experiences of individual programmes and organizations. This workshop aims to build on last year's sessions, broadening the conversation to supporting inclusivity across the NTD community.

Contact Information

Convener

*Katherine Williams;
Evidence Action*

Rapporteur

*Suzy Campbell; Evidence
Action*

Speakers

*1. Kaushlendra Kumar;
Evidence Action*

*2. Mary Hodges; Hellen
Keller International*

*3. Ellyn Ogden;
USAID*

*4. Fiona Fleming;
Schistosomiasis Control
Initiative*

Main learning point:

Work with both communities and government/programme leadership to identify the hard-to-reach groups in each geography or context. Successful strategies to reach these groups are tailor-made, context-specific and creatively build on local strengths.

Next steps – summary:

Organisers will write up the ideas shared in the workshop and send around to interested recipients, along with a summary of already existing tools/resources pertaining to including hard-to-reach groups in NTD programmes.

Key action point :

Did you miss the session?

Are you interested in receiving the tools/resources/notes?



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3.4 Cross-Sectoral Partnerships - Creating a roadmap for sustainable programmes

Cross-sectoral partnerships are a key strategy in reaching control and elimination in most NTD programmes. This workshop will look at successful strategies that bring in partners from different sectors and how these strategies can be applied in other countries. There will also be small group work to develop suggested strategies for different sectors so that organizations and countries can begin bridging new partnerships. We will review cross-sectoral work from community to international level.

There are two major challenges NTD country programmes are facing - reaching target MDA coverage consistently and how to sustain NTD gains after reaching the elimination goals and donors transitions. Cross-sectoral collaboration between government ministries and programmes like malaria, education, water and sanitation, maternal and child health, finance, to name a few, has often been proposed as the solution to these challenges. This session will explore the viability of such collaborations through a series of case studies from different countries in Africa and Asia.

The aim of this workshop is to identify what has worked in countries that have successfully achieved multi-sectoral collaborations, and thereafter develop and review strategies that countries can employ for successful cross-sectoral partnerships. At the end of the session, we aim to have developed a rough road map so that groups can begin working on developing necessary partnerships.

Contact Information

Convener

*Elizabeth Hollenberg;
Schistosomiasis Control
Initiative*

Speakers

*1. Edridah Tukahebwa;
Ministry of Health
Uganda*

*2. Fatma Kabole; Ministry
of Health Zanzibar*

*3. Helen Hamilton;
WaterAid*

*4. Jiptha Boiragee; The
Leprosy Mission
International Bangladesh*

Main learning point:

Partnerships, when created with clear roles and priorities, are integral for effective programmes and essential for sustained elimination.

Through effective coordination, successes can be increased, which will feedback into better partnerships.

It is essential that there are clear agreements, priorities, and roles within partnerships.

Stakeholders across all sectors should be engaged – take risks! Diversity and “piggy back” to increase the reach of programmes.

Next steps – summary:

The results of the workshop will be shared with the sustainability working group to develop further.

Key action point:

Based on the successes, opportunities and challenges or creating effective cross sector partnerships (as discussed in the workshop), we propose a partnership building guideline be developed to help programmes improve existing networks or to build new partnerships with the shared learning and experience of other programmes so that they are accelerated towards success.



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4.1 Setting BEST in Motion with Strategic Socio Behavioural Change Communication

Strategic health communication is a powerful tool for harnessing the power of communication to create social and behaviour change for promoting the adoption of healthy behaviours. This workshop shares innovative approaches for operationalising behaviour change interventions into the BEST framework. The workshop will discuss innovative approaches such as human centred design and behavioural economics, and successful health communication strategies such as gaming, infomercials, edutainment and short messaging services, and how to integrate behaviour-focussed interventions into NTD programmes and the BEST framework.

The aim of the workshop is to provide participants with ideas, tools, and resources for operationalising the BEST framework through a social and behaviour change lens.

Strategic socio behavioural change communication (SBCC) is a powerful approach for mobilising communities to understand, support, own, and be actively engaged in health promotion and treatment decisions, and the health programmes that can improve their lives. Prevention and health promotion are intricately linked, and are important to getting to the root causes of many global public health issues. Evidence also shows that strategic health communication can be an effective link between prevention and treatment interventions.

Contact Information

Convener

*Kuor Kumuji; Center for
Communication Programmes*

Rapporteur

*Leah Wohlgemuth and Geordie
Woods; Sightsavers*

Speakers

*1. Kuor Kumoji; Center for
Communication Programmes*

*2. Tsega Berhanu;
Communication for Health
Project, Ethiopia*

*3. Cheryl Lettenmaier;
center for Communication
Programmes*

*4. Habtamu Tamene;
Communication for Health
Project, Ethiopia*

Main learning point:

B – BCC can improve uptake of services, sanitation, and hygiene practices, and other preventive behaviours
E- BCC can trigger solutions for reducing environmental risk, including safe water sources, sanitation, hygiene structures and other preventive behaviours and separate animal and human spaces.
S – BCC can reach marginalised groups, and empower them to use services and reduce stigma and discrimination.
T – BCC can increase uptake of all treatment, improve health-seeking behaviours and facilitate a shift to facility-based care
BCC cuts across BEST and requires tailored, diversified approaches grounded in theory and based on evidence.

Next steps – summary:

Promote strategic communication in NTD programmes among stakeholders and funders.
Encourage increased use of SBCC guidelines, tools, frameworks in NTD programmes.
Prioritise behaviours for NTD disease groups.

Key action point:

Behaviour working groups to focus on integrating communications beyond B to E, S and T.
Shared evidence of effective SBCC programme approaches for NTDs, and evaluations.



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4.2 How do we build capacity of the health workforce to facilitate sustainable programmes?

This workshop will promote discussion and innovation of practical steps towards developing sustainable NTD programmes, focusing on the area of the health workforce as part of the WHO Health Systems Strengthening pillar. We will highlight a case study of a mentoring programme piloted in Ethiopia and examine different perspectives on how it is promoting sustainability. Group work will provide a platform for discussion and tangible next steps for all those involved.

The aim is to generate realistic approaches to building strong health workforces while delivering our NTD programmes to drive sustainability. Using a case study of a mentoring programme piloted in Ethiopia, this workshop will enable reflection on how mentoring can be utilised in our work and then allow for innovative approaches to be discovered. It will provide a platform for transparent and robust discussion on practical steps to delivering sustainable systems.

Contact Information

Convener

*Carolyn Henry; Imperial
College*

Rapporteur

Meron Seifu; SCI

Speakers

*1. Carolyn Henry; Imperial
College*

*2. Birhan Mengistu; Federal
Ministry of Health*

*3. Fikre Siefe;
Federal Ministry of Health,
Ethiopia*

Main learning point:

Shared challenges are: high turnover, being cost effective and quality control.
There are many great ideas and innovations!
We need to find space to share lessons and ideas and to collaborate.

Next steps – summary:

Taking the ideas we exchanged back to our programmes.
Sharing knowledge, findings, ideas through the NNN sustainability group
Test feasibility using technology and capacity building

Key action point:

SHARE IDEAS!!

We can move away from mass training only to training effective theory and practice models.



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4.3 Nothing about us without us; How to ensure the genuine participation of people affected by NTDs?

Participants will have the opportunity to discuss in details the added value of participation of people affected by NTDs in service delivery, decision making, advocacy and accountability, informed by personal experiences. We will look at opportunities and challenges, as well as identify good practice in the process of increasing participation of people affected. Tactics and strategies for increasing meaningful participation of people affected will be explored in small group settings with recommendations presented to plenary at the end of the session.

Participants will be able to understand the importance of people affected by NTDs' participation in effective service delivery and decision making, and identify practical actions the NTD community can take to ensure this happens.

Contact Information

Convener

Mathias Duck; The Fred Hollows Foundation, Hellen Keller International, CBM, TLMI and ILEP

Rapporteur

Nathalie Bonvin; ILEP

Speakers

1. Rachna Kumari; Lepra India

2. Mathias Duck; ILEP

3. Ujwala Kamalkishor Sharma; DPO

4. Suresh Dhondge; TIM Trust India

Main learning point:

Participation of people affected by NTDs makes our work more effective, efficient, equitable and sustainable. Barriers to participation include power inequity/awareness/accessibility and stigma and discrimination.

Next steps – summary:

Hold ourselves and others accountable for inclusion at all levels.
Advocacy and information sharing and engagement at all levels.
Foster active participation to give voice to people affected by NTDs.

Key action point:

Start where we have the power to start-

- Self-evaluation of participation in our organizations
- Ensure active and systematic participation through our work at all levels.
- Walk our talk – finance and prepare people affected to come to NNN and other events.
- Use the NNN DMDI working group as a platform for continuous engagement.



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4.4 Integrating detection, management and recording of NTDs into primary healthcare service delivery: policy and practice

Integration of NTD control into primary healthcare service delivery is a key component of the post-2020 agenda. However, the debate about effective ways of achieving integration is in its infancy and few interventions have been implemented and tested. This workshop aims to bring together policy makers, practitioners and researchers to discuss strategies, challenges and opportunities. Four presentations will inform the debate, each looking at the topic from a different angle: operational, policy and implementation research. "Historically, much of the global effort to reduce the burden of NTDs has focussed on transmission interruption by developing and distributing safe and effective drugs to affected populations, mainly through mass drug administration (MDA). While MDA remains a cost-effective strategy to achieve NTD roadmap targets in reducing disease burdens, there is growing recognition that the final stages of disease control will require alternative tools and approaches to eliminate remaining foci of the diseases and manage morbidity and the chronic disabilities caused by NTD infection, including those that are not treatable through MDA. This will require greater integration among health programmes, as well as integration of NTD control into broader health systems. It is well understood that this will not be an easy task, which will affect all health system building blocks.

This workshop addresses the Treatment and Care component of the BEST framework by exploring implications for policy and practice of strengthening primary healthcare for NTDs. It also touches on health worker behaviour and, in the context of strengthening universal health coverage, social inclusion.

Contact Information

Convener

Christian Rassi; Malaria Consortium

Rapporteur

*Dawit Getachew;
Malaria Consortium*

Speakers

*1. Giuseppina Ortu;
Malaria Consortium*

*2. Nebiyu Negussu;
Federal Ministry of
Health, Ethiopia*

*3. Esey Batisso;
Malaria Consortium*

4. Dawit Seyum; Orbis

Main learning point:

Vertical programmes can have value, but in the long-term, including transition scenarios, integration of NTD control into DHC can be a sustainable strategy.

Embed NTD control into existing systems, MOH should have ownership over setting priorities and M&E surveillance.

Interventions should include ensuring adequate capacity, resources, and quality of care.

Integration should extend to community –level, e.g.: to ensure equitable uptake of services, and support, prevention and community based management

Next steps – summary:

Countries to consider whether to adopt integration into PHC and define priorities and objectives

Evidence-base should be strengthened on what approaches work in different contexts.

Funding models should be developed to help partners to include implementation research within integration.

Key action point:

Governments should engage with practitioners and researchers to define a roadmap for integration, including the harmonisation of case definitions and developing consistent reference and training materials, and the creation of an implementation research platform to share learning, define priorities and create synergies.



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5.1 Communicating NTD Progress the BEST way

In 2012, pharmaceutical companies, donors, endemic countries and non-government organizations made a collective pledge to control, eliminate, or eradicate ten diseases by 2020. In the years since the London Declaration, considerable progress has been made in the global fight against NTDs. Today, we are at an important moment, with 2020 approaching and disease elimination being reached by some countries, while considerable efforts are still needed in others. How do we communicate current successes and challenges to advocate for continued investment? When and how do we switch our messaging toward 2030 or other goals? How can we support national NTD programmes to leverage their programmatic milestones to increase country ownership?

This session does not address just one element of the BEST framework. Rather, it focuses on the enabling environment necessary to support all elements of BEST implementation in the years to come. A key driver for the creation of the BEST framework was the need for a clearer message that would strengthen our collective advocacy efforts. We believe this conversation is both timely and crucial for sustaining the political and financial momentum to achieve global NTD goals and for exploring the challenges we face collectively when our messaging is not aligned. This session aims to engage NTD partners in critical discussions about the communications and advocacy needs for the road ahead. To do so, the session will draw in voices from across the NTD community - NGOs, donors, and host country governments. In line with NNN's mission, the focus will be on the role of NGOs in supporting global NTD advocacy and communications to meet our collective goals.

Contact Information

Convener

*Laura Cane; RTI
International*

Rapporteur

*Chelsea Toledo; Task Force
for Global Health*

Speakers

1. *Nebiyu Negussu, Federal
Ministry of Health,
Ethiopia*
2. *Aparna Barua Adams,
Project Manager,
International Coalition
for Trachoma Control*
3. *Scott McPherson, Senior
Programme Manager,
RTI / Vice Chair,
International Coalition
for Trachoma Control*
4. *Aryc Mosher, Senior
Technical Advisor, USAID*

Main learning point:

Need to evolve messaging over time / Communicate impacts achieved by 2020 through London Declaration, even if 2020 messaging shifts / Expand messaging beyond only MDA progress / value in linking with SDGs / voluntary national programme reviews / new partners, more global visibility / value in conveying economic impact (DALYs etc.)

Next steps – summary:

Work to develop better messaging on MMDP, WASH and other relevant issues.
Use messaging to communicate gaps, and challenges and to keep current partners and attract new ones.
Develop case studies that show “how to”.
Ensure messaging links with broader development communications and represents integrated approaches and multi-structural coordination.

Key action point:

Engage with relevant communications bodies to inform and update messaging.
Discuss sources of updated data and fact sheets.
Increase conversations/participation around SDGs.



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5.2 Tools and interventions to reduce stigma and improve mental wellbeing of persons affected by NTDs - evidence from community-based projects

In recent years, the DMDI Working Group has advocated for strategic attention for NTD-related stigma and its effects, which includes a major impact on the mental wellbeing of people affected by NTDs. The BEST framework has highlighted the need for a holistic view of and approach to NTD programming. Consequently, interest in these components is increasing. It is now important to demonstrate that tools and interventions exist that can be used effectively to address these issues that affect many millions of people living with the consequences of NTDs worldwide.

The overall aim of the workshop is to encourage NGOs working with NTDs and NTD programmes to incorporate stigma reduction interventions and interventions to improve the mental wellbeing of those affected in their programming. We will do this by demonstrating with evidence from field programmes that there is a need for this and that it is possible address NTD-related stigma effectively and to improve the mental wellbeing of persons affected by NTDs.

Specific Workshop objectives : [1] To understand how stigma and discrimination affect persons living with the consequences of NTDs and how this affects their mental wellbeing. [2] To present existing tools and interventions to address stigma and mental health consequences of NTDs and evidence of their effectiveness at community level. [3] To discuss how such tools and interventions could be incorporated in various NTD programme settings and what steps would be needed to make this happen.

Contact Information

Convener

*Wim H. van Brakel;
Netherlands Leprosy Relief*

Rapporteur

*Jennifer Mangeard-Lourme;
Lepra*

Speakers

1. *Arikonda Mohan; TLM
CREATE Project*
2. *Emeka Nwefo; CBM Nigeria*
3. *Maya Semrau;
Brighton and Sussex Medical
School*
4. *Gareth Shrubsole; The
Leprosy Mission England and
Wales*
5. *M. Mathanraj David, The
Leprosy Mission Trust India*

Main learning point:

Facilitation links between people affected and people not affected through direct (champions, films, comics etc.) and indirect contact is highly effective in reducing stigma in communities

Next steps – summary:

The testimony and interventions of champions (affected people who are trained in human rights and inclusions) is essential and powerful.

We need to build a network.

Force champions at local, national and international level.

Key action point:

Invest and strategically plan for raising the voice of champions in various platforms.

Acknowledge that this is a long-term strategy that needs to be implemented over many years, outside the usual 3/5 year project cycle management.

Something to be advocated by the NNN to funders?



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5.3 Leading the way: Collaboration between WASH and NTDs in Ethiopia

The need for stronger collaboration on WASH and NTDs is evident, although relatively little information exists on best-practices, practical approaches and aspects that contribute to program success. This panel session, based on a case study prepared for the NNN WASH-NTD WG will showcase models of coordination used in Ethiopia. It aims to share lessons learned from successful collaborations, to promote improved practices, illustrate opportunities both at policy level and implementation level, and identify challenges to address.

This workshop will review a case study prepared by the WASH-NTD Working Group in preparation for the NNN. The case study aims to show case successful collaboration, coordination and integration between WASH and NTDs programmes in Ethiopia to promote improved practices, illustrate opportunities both at policy level by federal and regional governments, and at implementation level by different NGOs, and identify challenges and shortcomings to address in the future.

The examples given in the case study will be as practical and as actionable as possible to allow replication in additional settings. The information will be used by partners in the NTDs NGO Network (NNN) and others to share experience on successes as well as challenges, to advance joint action. Different case studies and anecdotal evidence will be gathered to draw lessons for joint action across both WASH and NTD communities.

Contact Information

Convener

*Michal Bruck; NALA
Foundation*

Rapporteur

*Tim Jesudason;
International Coalition for
Trachoma Control (ICTC)*

Speakers

*1. Nebiyu Negussu; FMOH
Ethiopia*

*2. Kassahun Zewudie;
Emory Ethiopia*

*3. Gardachew Tiruneh;
CARE Ethiopia*

*4. Liat Rennert; NALA
Foundation*

Main learning point:

In order to achieve NTD targets there must be increased investment in intersectional collaboration and integration especially between health sectors such as WASH and NTDs. Great strides have been made towards collaborative action. The introduction of several platforms through which actors from both the WASH and NTD sectors can share knowledge of technical skills and work jointly is a great starting point from which organizations can collaborate.

Next steps – summary:

Understanding the challenges associated with WASH and NTD integration is the final step in creating more effective programmes and mitigating barriers to success. Key challenges include differing priorities between sectors, differences in funding, perceived benefits and lack of supporting evidence.

Key action point:

WASH / NTD integration task force meetings need to be held more regularly to overcome challenges. These are critical as they provide a platform to share experiences and best practices and coordinate the integration of NTDs/WASH. Creating joint indicators and planning platforms will enable inter-sectoral collaboration and guidance for programmes.



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6.1 Your NNN External Representation Group: Setting the communications and influencing agenda of the network

Established in 2017, the **External Representation Group** provides strategic guidance to the Executive Committee on policy influencing, advocacy and external relations opportunities for the NTD NGO Network.

A small group came together to:

- (i) Focus thinking on the priority influencing opportunities for the NNN for the next 18 months, including those linked with the tenth year anniversary of the NNN and the annual conference in Liverpool, United Kingdom
- (ii) Consider how the group might work together, including where possible to add value to member initiatives.

Contact Information

Convener

Co-Chairs: Helen Hamilton
(WaterAid) and Virginia
Sarah (The Fred Hollows
Foundation)

Members:

Rosa Argent (*ILEP and NNN
Comms*)

Aparna Barua Adams (*ICTC*)

Elisa Baring (*END Fund*)

Joni Lawrence (*MDP,
TFGH*)

Chelsea Toledo (*NTD
Support Centre, TFGH*)

Pradeep Bagival (*Leprosy
Mission*)

Main learning point:

Many groups are engaged in advocacy and influencing, harnessing rather than duplicating their efforts will be critical. Planning for influencing engagement in the next 18 months (including the WHO NTD Roadmap, NNN milestone anniversary, Women Deliver, Stockholm World Water Week, and the countdown to 2020) needs to begin early. Positioning the achievements of the NTD community towards a world free of NTDs requires specific communication materials and a language targeting the links between NTDs and the sustainable development agenda which ensures no one is left behind. Some of these materials/context need to be developed.

Next steps – summary:

Propose a range of conference themes for the NNN10, positioned to enable effective advocacy with key target audiences.
Survey members to inform updated key messages about impact of collective action.
Identify opportunities for exposure visits for key influencers ahead of the next NNN
Establish a comms/media plan for NNN10 – this may be undertaken as part of the Conference Committee (CoCo) activities

Key action point:

Develop a work plan of priority initiatives for the next 18 months.
Recruit active members of the ERG through promotion to the NNN membership.



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6.2 Mainstreaming NTDs to Strengthen Health Systems: A Multi-Sector Approach

Under the framework of social inclusion, mainstreaming of NTDs promotes the strengthening of health systems in order to ensure progress towards Universal Health Coverage. Though complimentary, the mainstreaming of NTDs and health systems strengthening have not historically been linked. Mainstreaming ensures that the control and treatment of NTDs are part of existing structures, which in the long run strengthen health systems through providing universal healthcare.

This workshop will focus on detailing examples of health systems strengthening work across country platforms and will allow for audience members to draw from experiences to shape future NTD programmes. The workshop will also allow audience members to develop preliminary planning for each of the WHO HSS building blocks, built on the WHO HSS Framework that was developed in 2010 as a blueprint to strengthen institutions that transform a country's health system and lead to improved health outcomes. As we move towards a more coordinated, global approach to control and elimination of NTDs, the discussion of mainstreaming and health systems will become necessary to ensure long-lasting transformations and to achieve the greatest impact.

The workshop hopes to provide tangible outputs and a framework that will foster future discussions surrounding the mainstreaming of NTDs within ministries and across sectors.

Contact Information

Convener

*Lauren Brown; RTI
International*

Rapporteur

*Lauren Brown; RTI
International*

Speakers

*1. Henok Gebramariam; RTI
International*

*2. Edridah Muheki; Ministry
of Health, Uganda*

*3. Leda Hernandez;
Division Chief – Infectious
Diseases, Disease
Prevention and Control
Bureau, Department of
Health, Philippines*

Main learning point:

Countries have different HSS in place to varying degrees of efficiency and functionality.
Countries know the importance of engaging different stakeholders.
HSS depends on both technical and financial commitment of government.

Next steps – summary:

For mainstreaming NTDs consider the challenges and opportunities across the six core elements of the health system and across sectors.

Key action point:

You cannot strengthen your system without a comprehensive understanding of the whole health system.



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6.3 Compassion is Essential for Quality Universal Health Coverage and for Effective Neglected Tropical Disease Programmes

As many NTD programmes, particularly lymphatic filariasis (LF), achieve their targets for interrupting transmission of infection, increased attention must be given to the quality of services delivered to disease management, disability, and inclusion (DMDI), and to integrating these services into national health systems. The role of compassion in motivating, sustaining, humanizing, and maintaining health worker competency in delivering DMDI services within health systems has been sorely neglected. The reasons for this are unclear. For some, the word compassion may mistakenly convey a sense of pity or superiority, which violates global health's core value of solidarity. For others, compassion may seem unscientific or too emotional. However, recent advances in the scientific study of compassion show how it lies at the heart of who we are as human beings and how deeply compassion is imbedded in our neural circuitry and our social support structures. Our inattention to compassion in NTD programmes has been costly at the individual, organizational, and national levels. It is time to bring compassion and person-centered care into our NTD discourse. This workshop will build on the growing momentum and evidence on compassion as an essential ingredient in health care; highlight the experience of Ethiopia in establishing compassion at the center of its strategy for health care quality; share recent experience on efforts to intentionally ground health services in compassion; and explore opportunities for workshop participants (NGOs and other stakeholders) to cultivate compassion at the individual and programme level. The NTD community has much to offer – and to receive from – the burgeoning movement to intentionally bring compassion into quality health care and UHC. This workshop will explore opportunities for NTD programmes and individuals to contribute to that effort and will identify next steps for engagement.

Contact Information

Convener

*David Addiss; Task
Force for Global
Health*

Rapporteur

*David Addiss; Task
Force for Global
Health*

Speakers

- 1. David Addiss; Task
Force for Global
Health*
- 2. Melissa Bingham;
World Health
Organization*
- 3. Daniel Burssa;
Ethiopia Ministry of
Health*
- 4. Asrat Mengiste;
NaPAN, Ethiopia*

Main learning point:

In order to provide compassionate health services, systems thinking and interpersonal skills are needed.
Modelling compassionate behaviour is key – this starts with leadership.
Rediscover compassion at the global leadership level for quality health care.
Compassion can be learned.

Next steps – summary:

Continue the conversation.
Incorporate lessons from recent experience and publications into health systems.
Develop and test metrics for compassionate care and compassionate organizations seven systems
Find ways to support health workers and health systems to be resilient and compassionate

Key action point:

Write and disseminate report.
Invite further discussion.
Disseminate materials – WHO, FMOH, Lancet articles.
Reconvene.



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6.4 ESPEN Portal: a platform designed to enable health ministries and stakeholders to share and exchange subnational programme data in support of the NTD control

ESPEN aims to equip all stakeholders with the evidence they need to successfully set targets, plan activities and mobilise resources more efficiently in order to tackle each disease.

Through this portal, ESPEN uses maps to illustrate site and district-level data that can be aggregated by disease and country. These maps, along with the downloadable underlying data, are tools to aid health officials and their partners in boosting and developing NTD interventions and strategies to reach key targeted communities.

Contact Information

Maria Rebollo Polo, WHO

Honorat Zoure, WHO

Uffe Poulsen, WHO

*Philip Downs, NTD
Technical Director,
Sightsavers*

Main learning point:

More than 4,400 maps with data sets are publicly available.
Used by countries and stakeholders for decision-making.

Next steps – summary:

Get the word out about ESPEN portal.
Get better data for the portal.

Key action point:

Validate some data working with country teams.
Make subnational level NTD teams use the portal.
Fill date gap when it exists in particular impact assessment data.

Rapid-Fire Workshops



Shelmel Terefa, a school teacher, demonstrates face washing to students at his school in Aware-Golje village in the North Shewa Zone, Oromia, Ethiopia. Face washing and environmental improvements are fundamental to eliminate trachoma. (c) ITI /Michael Amendolia



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RF 1.A

NTD SUSTAINABLE ASSESSMENT TOOL

Key challenges that limit NTDs from being addressed relate to sustainability of NTD programmes

There is an opportunity for NTD affected countries to assess the sustainability of their programmes.

This tool will ensure programmes are planned optimally.

Contact Information

Sara Mohamed,
Ciff
SMohamed@ciff.org

Speakers

Nejat Abdella, Dahlberg
Nejat.Abdella@dalberg.com

Sara Mohamed,
Ciff

Main learning point:

A sustainability assessment tool is a forward-looking tool that can enhance ongoing programmes.

Next steps – summary:

Contact Ciff (SMohamed@ciff.org) to obtain the user manual and tool. This tool is broadly applicable and can be used in different contexts.

Key action point:

Going forward, organizations working on NTDs should use this tool to assess levels of sustainability for their programmatic activities and use insights derived to plan way forward.



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RF 1.B Yaws Eradication Integrated with Case Management of NTDs

Yaws eradication is achievable by Mass Azithromycin Administration (MAA). During a WHO AFRO meeting, ten countries were oriented to jointly address three case management (CM) NTDs: Buruli ulcer, leprosy and yaws.

Two countries in West Africa (Cote d'Ivoire and Ghana) should implement MAA and Post-MAA surveillance in sentinel and spot-check sites (SSSS).

Four countries in Central Africa (Cameroon, CAR, Congo and DRC) should also implement MAA and Post-MAA SSSS in rainforest areas (autochthonous tribes and neighbouring Bantu communities).

In other areas and countries (Benin, Liberia, Nigeria and Togo), yaws endemic assessments and mapping should precede MAA or Total Community Treatment.

Contact Information

Alexandre TIENDREBEOGO

tiendrebeogoo@who.int

tialex57@hotmail.com

MO LEP, BU & YAWS
WHO-AFRO

CONTRIBUTORS:

Andrew S Korkor

Lamine DIAWARA

Didier BAKAJIKA

Kingsley ASIEDU

Daniel D ARGAW

WHO (AFRO and HQ)

Main learning point:

Joint active case finding and contact tracing of leprosy and Buruli ulcer cases during yaws assessment / mapping surveys. Combined Mass Azithromycin Administration and Mass Medicine Administration of PC-NTDs.

Next steps – summary:

The ten countries to finalise their 2018-19 implementation plans and mobilise domestic funding.
NTD NGOs and partners to provide technical and financial support to countries.
WHO to ensure Azithromycin donations and coordinate eradication, elimination and control efforts.

Key action point:

WHO and NNN to coordinate their support to the ten countries for implementation plans to eradicate yaws, eliminate leprosy and advance the control of Buruli ulcer and other CM-NTDs.



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Reaching the Last Billion:

Setting **BEST** in Motion

RF 1.D A comprehensive training package for establishing and strengthening LF

As countries are nearing the elimination goals for LF, there is a renewed focus on LF MMDP interventions. To support these efforts, WHO and partners developed a comprehensive training package on “Morbidity Management and Disability Prevention for LF” targeting national LF and MMDP Coordinators.

This presentation will describe the training package and its use in supporting national programmes to establish and strengthen MMDP aspects of their LF elimination efforts. It will include a quick overview of regional efforts conducted using this training package to orient countries to all components of a national LF MMDP program, leading to dossier submission.

Contact Information

Presenter:

*Zeina Sifri, zsifri@hki.org
Hellen Keller International*

Contributors:

*Jonathan King, kingj@who.org
World Health Organization*

*Didier Bakajika,
bakajikad@who.org
World Health Organization,*

Main learning point:

The WHO MMDP training package for LF is designed for capacity strengthening of national programmes in LF endemic countries to develop the MMDP component of their LF elimination programme.

Next steps – summary:

This comprehensive training is currently undergoing WHO clearance and will be available on the WHO website in English and French.

Key action point:

NGDOs and partners can use the training package with its theoretical and practical sessions in capacity building efforts for NTD, LF and/or MMDP coordinators/focal points in LF endemic countries.



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RF 1.E Progress in Addressing Post-operative Trichiasis

Post-operative trichiasis (PTT) is characterised as trichiatric eyelashes following surgery. It encompasses both surgical failure and recurrent trichiasis. Managing PTT is more challenging than treating initial trichiasis. The World Health Organization recommends that the highest skilled individuals available manage PTT; however, how best to manage PTT is still undetermined. Dr. Shannath Merbs developed a new surgical procedure aimed at improving PTT outcomes. Initial surgeries show promising results. However, more research is needed to determine whether this method improves outcomes compared to current procedures. To move progress forward, the MMDP project will be supporting an evaluation of 100 PTT surgeries.

Contact Information

Emily Gower
(egower@unc.edu)

Shannath Merbs
(smerbs@jhmi.edu)

Whitney Goldman
(wgoldman@hki.org)

Demissie Tadesse
(Demissie.tadesse@cbm.org)

University of North Carolina
Johns Hopkins University
Hellen Keller International
CBM

Main learning point:

To gain an understanding of the importance of managing PTT and what needs to be done to improve PTT management.

Next steps – summary:

Finalise research protocol
Initiate PTT surgeries through the research programme in Ethiopia.

Key action point:

Identify areas with high numbers of PTT patients
If possible, support additional PTT surgeries in this research setting



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RF 2.A How the NNN can address stronger advocacy for improved health care services for seasonal migrant workers, with a focus on Ethiopia

300,000 – 500,000 seasonal migrant workers descend to the Ethiopian lowlands of Tigray and Amhara particularly during harvesting and weeding seasons. Although there is legislation to protect migrant workers' rights to health care, shelter, clean water etc., most are not able to access these services and are at high risk of contracting diseases including malaria, leishmaniasis, TB, HIV and snakebite.

Malnutrition is common and there are known cases of migrants taking these infections back to their communities in the surrounding highlands, increasing the risk of outbreaks and with serious implications for the elimination agenda.

Contact Information

Cherinet Adera , AdS
cherinetadera@yahoo.com

Adamu Gelaw, RTI
agelaw@et-ntd.rti.org

Stefanie Meredith,
KalaCORE MM
Stefanie.Meredith-mm@mottmac.com

Margariet Den Boer,
KalaCORE, MSF
margrietdenboer@gmail.com

Sinead Rowan,
KalaCORE, MM
Sinead.Rowan@mottmac.com

Main learning point:

An intra -sectoral approach is needed to develop appropriate, targeted interventions to meet the needs of this under-prioritised and under- protected group.

Next steps – summary

Share lessons learnt to develop strategies aligning NTD cross-sectoral stakeholders to facilitate production and dissemination of advocacy tools and information for improving migrant workers access to health, shelter, clean water etc.

Key action point

Collaborative and targeted advocacy by the NTD community is needed to improve migrant workers' access to health care.



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RF 2.C Restoring Health Hope & Dignity - LEpra Experiences on Combined Approaches

Lymphatic filariasis (LF) and leprosy are classed as neglected tropical diseases (NTDs) and both disabilities have very similar characteristics such as irreversible disability, mobility restriction, participation limitation, social stigma and discrimination. Both can lead to mental health issues. Both disabilities affect the quality of daily life.

Women bear a double burden – these diseases limit their marriage prospects and make them a burden to their families. Persons with these disabilities need continuous care for the rest of their lives. Self-care (MMDP) is key to prevent worsening of impairments amongst people who have an irreversible impairment or secondary impairments.

Self-care is set of practices (5 pillars – skin care, wound care, exercise {active or passive}, protective footwear and counselling) performed by the affected persons by themselves to enhance and restore health and self-esteem. It requires active engagement by the persons affected by leprosy and lymphatic filariasis. Experience shows that such methods have significantly improved the quality of life of affected persons.

Contact Information

*Rajni Kant Singh,
State Coordinator,
Bihar Operations-India*

rajni@leprahealthinaction.in

LEpra Society



Main learning points:

Always provide all five components of MMDP to your beneficiaries such as skin care, wound care, exercise {active or passive}, protective footwear and counselling. Use local products and understand their circumstances. Learn the correct procedure and then train others.

Next steps – summary:

Common platform for learning and sharing – organise exposure visits.
Field study on satisfaction level of patients – pre MMDP and post MMDP.
Advocacy with policy makers to include disability (elephantiasis) under disability act in their country.

Key action point:

Always we tell in our routine life ‘something is better than nothing’ but in the case of prevention programmes we should follow “nothing is better than something”. Restore the hope and dignity and prevent ‘death before death’.



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RF 2.D Skin NTDs - One year later: achievements and urgent work ahead

The World Health Organization is promoting an integrated strategy for skin-related NTDs that require active detection, management and control, and is harnessing the experience of many experts involved in skin diseases to provide guidance to implement the integrated strategy in countries where skin related NTDs are a major burden.

WHO has developed a simple pictorial manual for community health workers and guidance documents to help national programmes in the operationalisation of this integrated strategy. Tools for economic evaluation of the integrated strategy have been developed.

Some countries in Africa have started to implement an integrated strategy and others are to follow.

Contact Information

Kingsley Asiedu
(asieduk@who.int)

Contributors

Daniel Argaw Dagne
Alex Tiendrebeogo
Giuseppina Ortu
Rod Hay

Main learning point:

Integration of skin diseases provides an opportunity to build the capacity of primary health care workers to detect and treat a number of diseases using the same resources.

Next steps – summary:

With the technical and financial support from WHO and partners, endemic countries should be supported to develop or adapt plans to integrate skin NTD management within primary health care

Key action point:

Advocacy for integration at national and international levels should be enhanced.
Flexibility of funding from donor's perspective needed to allow integration to succeed.



Conference

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Highlights



Reaching the last billion- setting BEST in motion

The NTD community recognises the important role it has to play in combatting inequity and contributing to improved health status and inclusion of people affected by NTDs.

We are committed to breaking down the barriers that hamper access to health and support services for people affected by NTDs.

NNN members are unified in the goal of reaching and empowering the most marginalised populations. We know that targeted approaches and prioritising equity and inclusion are critical to strengthening our work with women, people with disabilities, those affected by poor mental health and stigma, people in conflict-affected and fragile areas, migratory populations and out of school children. NNN members recommitted to action to reach these marginalised groups through enhancing the efforts of our existing disease-specific and cross-cutting groups and establishing new working groups on Sustainability, Conflict and Vector Control, Skin NTDs and One Health.

We recognise the agency and leadership of people affected by NTDs and the importance of ensuring that their voices are heard in NNN meetings and other relevant forums, and that their perspectives inform the work of the network.

We recognise the importance of cross-sectoral action on NTDs, including collaboration on WASH, education, veterinary public health and vector control, and call on all NTD funders and implementers to support such collaboration through suitable governance and financial mechanism. We will continue to advance progress on NTDs through development and sharing of best practices on joint monitoring, behaviour change and cross-sectoral partnership development.

In an effort to support NTD action for achievement of the Sustainable Development Goals, we will promote and implement practices that strengthen national health systems and secure sustainability of the impact of NTD interventions.

In the year ahead, the NNN community will continue its commitment to achieving progress on all components of the BEST (Behaviour, Environment, Social inclusion and equity, Treatment and Care) framework.

September 2018

Who's Who in the NNN



Steering Committee

- **Chair:** Gail Davey (Brighton & Sussex Medical School)
- **Vice Chair:** Yaobi Zhang (Helen Keller International)
- **Past Chair:** Wendy Harrison (Schistosomiasis Control Initiative)
- **External Representation Committee Co-Chair:** Helen Hamilton (WaterAid)
- **External Representation Committee Co-Chair:** Virginia Sarah (The Fred Hollows Foundation)
- **NNN Communications Lead:** Rosa Argent (ILEP)
- **NNN Administration Support:** Clare Callow (Brighton & Sussex Medical School)

Disease specific groups

International Coalition for Trachoma Control (ICTC)

- Chair: Serge Resnikoff (OPC)

Lymphatic Filariasis (LF) NGO Network

- Chair: Louise Kelly-Hope (Liverpool School of Tropical Medicine)

Onchocerciasis Elimination NGO Group

- Chair: Charles Mackenzie (Sightsavers)

Leprosy NGO Group

- Chair: Geoff Warne (ILEP)

Soil Transmitted Helminths/Schistosomiasis (STH/SCH) NGO Group

- Chair: Lynsey Blair (Imperial College London)

Cross-cutting groups

Disease Management Disability and Inclusion (DMDI) Working Group

- Chair: Martin Kollman (CBM International)

Water Sanitation and Hygiene (WASH) Working Group

- Chair: Leah Wohlgemuth (Sightsavers)

Vector Control Working Group

- Chair: Fiona Allen (Natural History Museum)

Skin NTDs Working Group

- Chair: TBC (Contact Claire Fuller or Liesbeth Mieras)

Conflict Working Group

- Chair: Fiona Vincer (Mentor Initiative)

Sustainability Working Group

- Co-Chair: Carolyn Henry (Imperial College London)
- Co-Chair: Liz Hollenberg (Imperial College London)

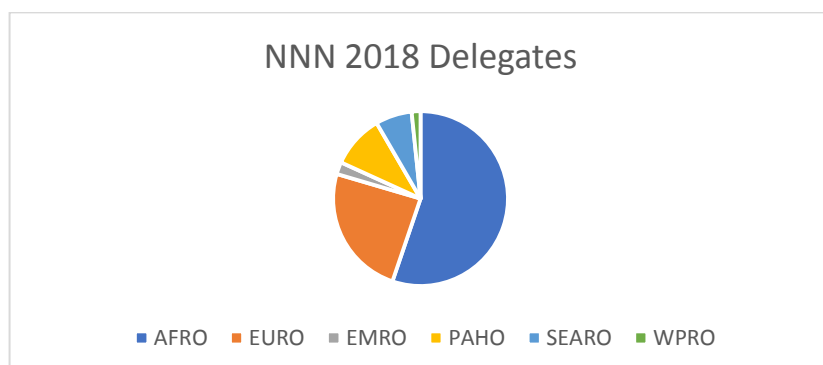
External Representation Group

- Co-chair: Helen Hamilton (WaterAid)
- Co-chair: Virginia Sarah (The Fred Hollows Foundation)

2018 Conference in Numbers

NNN2018 attendees by WHO region

This year, we had delegates from all 6 WHO regions attend the conference. The majority of these were from the African regional office, with the European regional office having the second highest representation.



Feedback received from the 2018 conference

A huge attempt was made to improve the workshop element of the conference in 2018, which seems to have been successful, with **81%** of respondents stating that the balance between workshops and plenaries was about right.

This year saw the introduction of the Attendify conference app, which was widely considered a positive development, with **over 90%** of people finding it easy to use and a useful tool for keeping track of the conference agenda, and receiving updates.

8% of respondents experienced or noticed others experiencing physical, language or other barriers to participation, some of which were around physical access to the venue. Next year we will ensure that information about accessibility provisions is made available on the conference app, and at the prior meeting for persons affected by NTDs.

64% of respondents said they would support a small logistics/registration fee to encourage attendance at the 2019 conference – in 2018 we had 500 registrations but only 410 attendees, therefore the 2019 NNN conference will see a sliding scale of registration fees introduced to aid planning and reduce costs.

We will also be moving the closing plenary to the third day of the conference in 2019, with the cross-cutting group meetings taking place on the second day of the conference, after receiving feedback that this would be a way of better signalling NNN ownership of the cross-cutting groups.

What does the NNN conference cost – and how are these costs covered?

Total expenditure*	£73,932.96
Sponsorship income – sponsors listed on back page	£64,494.90
Rolled over from NNN conference 2017	£14,899.18

*Includes use of the UN Conference Center including lunch and tea breaks, banners, posters and the App, two conference dinners, and the professional conference organisers' time.

By comparison, NNN 2017 cost £97,012.74.

We are enormously grateful to the thirteen organizations that supported NNN 2018 (see back page of report).

With thanks to our national host and generous sponsors...



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Federal Democratic Republic of Ethiopia Ministry of Health

