

# NNN conference report

Liverpool, UK

2019



**NEGLECTED TROPICAL DISEASE  
NGO NETWORK**

A global forum for nongovernmental organizations  
working together on NTDs

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## Welcome from the Outgoing Chair, Professor Gail Davey

It has been an honour to serve as NNN Chair for 2018/2019. Over the last year NNN members have been wonderfully active, drawing in new stakeholders, strengthening partnerships and facilitating knowledge sharing in support of our shared vision. The diversity of members was evident at this year's conference, which drew over 400 individuals from 49 countries, including 22 Sightsavers sponsored NNN Travel Awardees from 14 countries. This year also featured several notable guest speakers, including Baroness Elizabeth Sugg, Dan Carden Member of the UK Parliament and Dr Mwele Malecela, Director of the WHO Department of Control of NTDs, who gave a motivating keynote speech at the opening plenary, calling for stakeholders to "further strengthen our partnerships with the wider health sector in all the countries we work with, to embed NTD control as part of a stronger and more resilient health system."



*L-R: Baroness Sugg, Parliamentary Under-Secretary of State, UK Department for International Development, Professor Gail Davey, NNN Chair 2018/2019, Dr Mwele Malecela Director, WHO Department of Control of NTDs, at the opening plenary of the NNN 2019 conference. Photo Credit: NNN/Patrick Bannon*

There are many highlights that deserve mention over the past year. In 2018, the NNN and WHO published 'WASH and health working together: A 'how-to' guide for neglected tropical disease programmes' and during the 2019 NNN conference, "Collecting stories about NTDs: A beginner's guide to field communications" was launched to support partners to collect authentic stories about NTDs and the people they affect. 2019 also saw the launch of the new NNN website. I encourage you to visit the new website and wish to share my thanks to Footwork, Helen Keller International, International Foundation for Dermatology, Liverpool School of Tropical Medicine, Mentor Initiative, Plan:G, RTI International and Sightsavers International and for their financial support in bringing it to life.

The 2019 NNN conference hosted for the first annual NTD Innovation Prize. A project of American Leprosy Mission, we were delighted to award the US\$25,000 prize to Dr. Tito Trésor Melachio and Mr. Joseph Pryce for their project, "Exploring the viability of excreta sampling for monitoring Human African Trypanosomiasis (sleeping sickness)". This project will develop new tools for tracking the spread of sleeping sickness as cases become rarer.

At the conclusion of the conference, I was proud to announce two NNN statements of commitment. The first on patient safety to highlight our joint responsibility for delivering health benefits and minimising harm, published to mark World Patient Safety Day on September 17th. Secondly the NNN statement on sustainability, carefully crafted by the NNN Cross-Cutting Group on Ensuring Sustainable Systems, informed by an in-depth survey shared with NNN members, NTD stakeholders and health ministries.

As we look to the year ahead, it is important we recognise the value and impact of 10 years of collaboration through the network in bringing many partners together with one voice. Significant progress has been made across NTDs with the support of increased political will, mobilised resources, defining research questions and increased partnerships within and outside the NTD sector. However, key challenges remain and a renewed focus on cross-cutting approaches and strengthened health systems for universal health coverage, will guide our work as NTD implementers to support a new WHO NTD Roadmap 2021 - 2030. The NNN looks forward to continuing to work with health ministries, WHO and all NTD stakeholders in our shared vision of a world free of NTDs.

### **Professor Gail Davey, NNN Chair 2018/2019**

Research Lead for the Department of Global Health and Infection  
Co-Director, BSMS-NIHR Brighton and Sussex Centre for Global Health  
Research / Professor of Global Health Epidemiology



# Workshop summaries





## NEGLECTED TROPICAL DISEASE NGO NETWORK

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NNN Annual Conference  
**Our Vision Beyond 2020:  
Many Partners, One Voice**  
17-19 September 2019  
Liverpool, United Kingdom

### 1.1 From problem to solution – learning to use the WASH/NTD Toolkit to find solutions for integrating WASH in NTD programmes and vice versa

#### Abstract

The [Water, Sanitation and Hygiene \(WASH\) and Neglected Tropical Disease \(NTD\) Toolkit](#), launched in January 2019 by the WHO and NNN, delivers the best principles for integrating WASH in NTD programmes (and vice versa). The toolkit has been widely disseminated, BUT how many have actually explored and appreciated its full potential? WASH is the key to PREVENTION, TREATMENT and CARE of a number of NTDs which, by their very nature, impact the poorest and most vulnerable marginalised people. The toolkit explains how NTDs trap the poor in a cycle of poverty and disease:

- Poor people lack access to basic WASH infrastructure
- This forces a dependence on unprotected, distant, unaffordable, unsuitable and limited water resources, and unsafe or non-existent sanitation services
- Because of the contaminated environment and poor hygiene, they are exposed to infection
- Infection leads to disability, medical costs, and further deepening of poverty.

The WASH and NTDs sectors share clear common goals. Both sectors aim to sustainably improve the health and prosperity of people living in poverty, as outlined in the Sustainable Development Goals. Success for both sectors relies heavily on creating access to water and sanitation and ensuring sustainable usage for hygiene and disease prevention. By unlocking the practical templates and tools, you will find out how to convene productive and sustainable joint meetings, understand each other's priorities, identify common geographical areas and utilise available budgets effectively.

Focus on the  
BEST Framework: **All**

#### Convenor

Theresa Baird, CBM

#### Moderators

Helen Hamilton,  
WaterAid

Theresa Baird, CBM

#### Rapporteur

Angelia Sanders,  
The Carter Center

#### Speakers

Yael Velleman, SCI  
Foundation

Geordie Woods,  
Sightsavers

Dejene Minliku  
Mekoya,

ORDA Ethiopia  
Liat Rennert – NALA  
Foundation

#### Main learning point:

The WASH NTDs toolkit provides tools for NTD partners to engage and work collaboratively with the WASH community to achieve and sustain positive health outcomes. The toolkit was developed using real world experiences. The tools are adaptable and can be applied to different country contexts to support all stages of NTD programmes, from setting a programme vision, building partnerships (including advocacy), situation analyses, planning and designing programmes, implementation and monitoring.

#### Next steps – summary:

Organisations and countries need to begin implementing the toolkit, bringing it to meetings and using the tools when challenges arise. Workshop attendees have agreed to dive deeper into the toolkit and discover how each section can resolve challenges in their country context. Others have agreed to share the toolkit in their organisations and most importantly, use the toolkit!

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

This year's conference theme lies at the heart of the WASH NTD toolkit. It is designed from WASH/NTD experiences and will be updated regularly based on community feedback on WASH/NTD experiences. To help achieve a unified voice however, we ask that WASH and NTD partners provide direct feedback about what works, what doesn't or what else would be useful via the [interactive toolkit online](#).



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### 1.3 Participation of people affected by NTDs - best practices

#### Abstract

This workshop showcases successful experiences of participation of people affected by NTDs in service delivery, decision making, advocacy and accountability. Discussion will include opportunities, challenges and good practices for increasing participation of people affected, and strategies for increasing meaningful participation. People affected by NTDs often experience marginalisation, discrimination and exclusion due to associated stigma and disabilities. There is a strong bi-directional link between poverty and NTDs and they often exacerbate each other. Participation of people affected by NTD is still a challenge, and their rights— especially of women and children who are disproportionately affected – is severely compromised. Restrictions on the expression of their civil and political rights, across health, education, employment and social security hinder their full and effective participation in society. This has stimulated efforts to measure the impact of NTDs on human rights of those affected. Human rights-based approaches to NTDs emphasise that any intervention process related to NTDs should be based on human rights principles such as ‘Participation, Non-Discrimination and Accountability’. The participation of people affected by NTD’s in decision making, advocacy, service delivery and other interventions that directly affect themselves and their communities is sporadic. Some disease specific communities including leprosy and Chagas disease have been including people affected and building their capacity for several years. There are also lessons to be learned from the disability and HIV communities in this regard. Participation of people affected has shown to improve services, add energy, passion and insight to programmes and empower communities. The aim of this workshop is to look at these successful experiences and learn from them.

Focus on the  
BEST Framework:

**S**

#### Convenors

Mathias Duck Enns, ILEP  
John Arpon Samaddar,  
The Leprosy Mission  
Suresh Ramkrushna  
Dhondge,  
The Leprosy Mission

#### Moderators

Martin Kollmann, CBM

#### Rapporteur

Geoff Warne, ILEP

#### Speakers

Suresh Ramkrushna  
Dhondge,  
The Leprosy Mission  
Jannine Ebenso, TLMI  
Mathias Duck Enns, ILEP

#### Main learning point:

1. ‘No equity without inclusion and no inclusion without participation’. Participation includes striving to hear the voice of persons affected by NTDs at all levels, going past wishful thinking into active listening and engagement.

2. We will not achieve participation unless we are intentional in working towards removing the barriers. Methods may vary, but participation must be seen as a right, and a serious intent.

3. At field level, group formation is one effective way of building capacity, from ground up, to engage in genuine participation. A twin-trade approach is needed, working with both rights-holders and duty-bearers.

#### Next steps – summary:

NTD member organisations should think through how they will build the capacity of persons affected by NTDs to engage meaningfully, which level on the ‘participation ladder’ they strive to reach and how – feasibly – they will get there. Then, incorporate commitments to authentic participation in organisational policy, budgets and timeframes. Organisations should recognise that reaching the desired level of participation is likely to be a multi-year process.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

1. Develop this thinking further into sample policy framework and checklists for members
2. Mandate a minimum of one ‘seat’ on the NNN ExCo for persons affected by NTDs
3. Lobby at UTC, WHO-NTD Stag and other influential forums for inclusion of persons affected by NTDs on decision-making group
4. Encourage members to start now to identify and build capacity of persons affected by NTDs to attend NNN conferences in 2020/2021
5. Consider participation as theme of NNN Conference in 2020 or 2021



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### 2.1 Scaling up MDA campaigns: delivering health benefits and doing no harm

#### Abstract

17 September 2019 is World Patient Safety Day [#PatientSafety]

Global health programmes have a dual obligation to provide benefits to populations and minimise harm to individuals. For the past decade, national programmes have scaled up MDA to eliminate NTDs with more than one billion people receiving MDA annually for all NTDs since 2016. Although infrequent, young children have died from choking on tablets. Not enough is known about safety practices and messaging to prevent these tragic events. As we strive to support national NTD programmes to achieve higher coverage we must not lose sight of our responsibility to do no harm.

This workshop took place at a time when interest in safety is gathering momentum in the NTD community. Participants joined discussions and committed to change the outcome.

Focus on the  
BEST Framework: **ALL**

#### Convenors

David Addiss  
Task Force for Global Health  
([daddiss@taskforce.org](mailto:daddiss@taskforce.org))  
Virginia Sarah  
The Fred Hollows  
Foundation  
([vsarah@hollows.org](mailto:vsarah@hollows.org))

#### Speakers

Mwele Malecela, WHO  
Tijana Williams, GSK  
Leta Damessa, FHF Ethiopia  
Fiona Campbell, University  
of Sheffield

#### Main learning point:

- Healthcare is complex and prone to errors – better data and a no blame culture improves practice. Achieving treatment coverage targets and the pursuit of safety in NTDs are not mutually exclusive outcomes.
- There is limited understanding of the right to refuse treatment and implications for programming.
- As we seek a world free of NTDs, we have responsibilities to do no harm.

#### Next steps – summary:

1. Develop identified/prioritised tools and resources to support safety planning and messaging
2. For MDA (i) refine an observational assessment protocol (ii) identify and prioritise a list of operational research
3. Develop and socialise key indicators for safety for use by NTD stakeholders
4. Form an NNN Cross Cutting Group on Safety.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

*The Liverpool Commitment to Safety in NTDs and a plan of action*





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### 2.2 Data-driven decision making: Developing a blueprint for globally standardised data collection, access and use

#### Abstract

As NTD control programmes evaluate ongoing impacts of current intervention strategies and define achievable targets and milestones post-2020, it is vital there is universal access to a single reliable source of up-to-date, high quality subnational data for decision-making. Ensuring this requires a commitment both to collecting high quality data, and to ensuring accessible rapid reporting. The Global Trachoma Mapping Project (GTMP) established a globally standardised methodology for epidemiological surveys, supporting countries from start to end of the survey process, collecting high-quality trachoma prevalence data that conform to WHO recommendations. The GTMP system has been used and refined by others, including Tropical Data and the Onchocerciasis Elimination Mapping (OEM) Project under ESPEN Collect, and could be an essential component in supporting other NTDs on "The Road to 2030". The ESPEN Portal established by WHO provides an open access repository and platform for data from such globally standardised projects, and for other monitoring and evaluation data from AFRO and EMRO regions. The ESPEN Portal supports countries and partners to share programmatic data and make data-driven decisions addressing NTD control and elimination goals. The overall aim of this workshop is to provide the NNN community with an opportunity to listen to global, regional and country experiences of collecting high-quality standardised data and how the ESPEN Portal will be the principle platform through which these data can be used for data-driven decisions. This session will engage the NNN participants to use their experiences to:

1. Inform a cross-NTD action plan to develop a globally standardised survey design, implementation and reporting blueprint;
2. Explore opportunities to streamline countries and partners' workflows to facilitate completion and submission of the Joint Application Package to the WHO;
3. Develop a draft partner plan and commitment (and institutions where they are based) to (i) adopt the survey process blueprint (ii) ensure high-quality epidemiological and programmatic data are submitted to ESPEN and uploaded on the portal (iii) use these data for decision-making.

Focus on the  
BEST Framework:

**T**

#### Convenor

Fiona Fleming, SCI  
Foundation

#### Moderators

Fiona Fleming, SCI  
Foundation  
Rachel Pullan, LSHTM

#### Rapporteur

Ana Bakhtiari,  
International  
Trachoma Initiative

#### Speakers

Anthony Solomon,  
WHO  
Gilbert Baayenda,  
Ministry of Health,  
Uganda  
Maria Rebollo Polo,  
.....

#### Main learning point:

Three critical components are required to ensure reliable data for decision-making: evidence-based standardisation; transparency; partnership

#### Next steps – summary:

- COR-NTD Workshop in November 2019 which will continue this discussion with those involved in operational research
- ESPEN to engage NNN partners to develop and pilot automatised JAP process
- NNN task team (time limited) formed to achieve the below commitment

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

Commitment from WHO, NGOs to three critical components above to ensure reliable data & processes for decision-making.



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### 2.3 Conflict, crisis and the control of neglected tropical diseases: practical approaches for implementing safe and effective mapping and intervention strategies

#### Abstract

This workshop will explore successes and challenges in mapping NTDs in conflict and emergency settings and build confidence of the NNN community to deliver in these settings. Case studies will highlight how effective mapping is possible. A new **practical decision tool developed by the NNN Conflict and Humanitarian Emergency Working Group** will be presented and discussed. Participants will be invited to contribute to identifying shared guidelines and best practice, and road test the tool to refine and finalise for sharing with the NNN community. Conflict and humanitarian emergencies and population movements (planned/unplanned), present specific barriers to determining transmission and prevalence of NTDs. This impedes effective planning, delivery of treatment and management of NTDs.

**Case study 1:** HKI provided support to the FMOH to conduct baseline trachoma surveys in 15 out of 29 previously unmapped districts of Borno and Adamawa states in Northeast Nigeria with displaced communities, and roads and schools destroyed due to years of insurgency. **Case study 2:** MENTOR conducted mapping of leishmaniasis to track the development of disease and direct treatment to effected populations.

The Mapping tool offers a mechanism to assess mapping strategy and action by overlapping and stratifying endemicity, conflict and partnerships to develop new risk combinations to inform action. This workshop discussion will directly contribute to the further development of NTD work in conflict and emergency settings through the NNN cross-cutting Conflict and Humanitarian Emergency Working Group.

Focus on the **T**  
BEST Framework:

#### Convenors

Fiona Vincer, The  
MENTOR Initiative  
Aliyu Mohammed,  
HKI

#### Moderator

Emma Harding-Esch,  
LSHTM  
Yaobi Zhang, HKI

#### Rapporteur

Fatima Ahmed,  
The MENTOR  
Initiative

#### Speakers

Dr. Louise Kelly-Hope,  
CNTD/LSTM  
Dr. Thomas Stewart,  
The MENTOR  
Initiative  
Aliyu Mohammed,  
HKI

#### Main learning point:

The mapping algorithm is a useful tool for high level decision-making identifying partners and next steps.

#### Next steps – summary:

Feed into the Conflict and Humanitarian Emergency Working Group to finalise and publish the tool.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

Share our learning. Share our good practice.



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### 2.4 National NTD advocacy networks: uniting forces in support of the 2021-2030 NTD road map

#### Abstract

NTD networks have formed in several prominent donor countries and endemic countries to step up advocacy and research efforts for NTDs. This workshop intends to present those networks, showcase how they influence policy development, research agendas and practice, and solicit contributions from the NNN audience and endemic country participants to enhance the impact of their efforts to support a new WHO 2021-2030 roadmap.

At the beginning of a new decade and a new ambitious NTD roadmap for all 20 WHO recognised NTDs, it is imperative to step up efforts to ensure enough resources become available to achieve success by 2030. This is true for the entire spectrum of activities, including research, novel product development and implementation. Actors in those fields need to engage more intensely with each other and with NTD actors in and from endemic countries to identify global advocacy goals and build political will.

Taking advantage of the joint presence of all actors at NNN/ECTMIH, this workshop is an opportunity to strengthen networking between actors in NTD endemic countries and national, global advocacy actors, in view of enhanced commitments towards NTDs. The workshop will highlight and promote the relative unique strengths of individual networks as well as articulate their specific interest areas to contribute to a new NTD roadmap.

Focus on the  
BEST Framework:

**All**

#### Convenor

David Maurer, SANTD

#### Moderators

Dirk Engels,

Uniting to Combat NTDs

Stuart Mackie,

Direct Impact Group

Aparna Barua Adams, ICTC

#### Rapporteurs

David Maurer, SANTD

Johan Willems, DNTDs

#### Speakers

Dr. John Amuasi, ARNTD

Maelle Ba, Speak Up Africa

Yael Velleman, SCI

Foundation/UKCNTD

Mary Ellen Sellers, CNNTD

Nathalie Strub-Wourgaft,

RFMTN

Harald Zimmer, DNTDs

Kenji Hirayama, JAGntd

Peter Steinmann, SANTD

#### Main learning point:

Panel discussions on research and advocacy recognised the importance of communications strategies and public engagement to combat 'fake news' that impact NTD initiatives. As we prioritise the elimination new and improved tools will be needed as well as strategies to better manage the psychosocial impact of NTDs. NTD networks have demonstrated how bringing together different constituents across influencing, programmes and research (operational and new tools) can collaborate to build political will. The session also highlighted ongoing challenges in ensuring empowered participation of stakeholders from endemic countries in advocacy efforts.

#### Next steps – summary:

NTD advocacy messaging needs to evolve and become more sophisticated to support the delivery of a new WHO roadmap that emphasises the need and value of cross-sectoral collaboration. Articulate messaging that demonstrates how NTD investments support health systems strengthening and broader development goals, including 'health as a human right'.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

Taking lessons from the climate change and HIV/AIDS movements, explore opportunities to engage, empower and mobilise young people as agents of change, and actively forge closer advocacy relationships between NTD networks



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### 3.1 Our behaviour change programming 'failures' - lessons learned the hard way

#### Abstract

Facilitating more effective community engagement in sanitation and hygiene behaviours is critical to the success of NTD programmes. NNN participants will come together in this highly interactive workshop to share their experiences designing and implementing behaviour change programmes - in particular, the lessons they have learned the hard way. Teams will convene around a current programmatic challenge and work together to identify potential solutions.

The workshop aims to support NNN participants engage effectively with their peers around the common challenges of developing and implementing behaviour change programmes. The interactive and team focused approach to the workshop will support participants to draw on the collective expertise of the participant group to identify practical solutions and tools they can apply to their own programmatic challenges.

Focus on the  
BEST Framework: **B**

#### Convenor & Moderator

Dr. Sarity Dodson,  
The Fred Hollows  
Foundation

#### Rapporteurs

Lizzy Jenkins,  
The Fred Hollows  
Foundation

#### Speakers

Yael Velleman, SCI  
Foundation  
Kimberly Kamara,  
The END Fund  
Kuor Kumoji,  
John Hopkins Centre for  
Communication Programs  
Alexandra Czerniewska,  
London School Hygiene  
and Tropical Medicine

#### Main learning point:

1. Understanding context is critical
2. Community engagement is critical
3. Respond to local needs
4. Donor awareness of programme complexity
5. Solid planning is critical
6. Ongoing review and learning are important

#### Next steps – summary:

NNN WASH Working Group to develop preferred practice guidance for designing and implementing behaviour change programmes for NTDs

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

Collaborate to produce preferred practice guidance, tools and training





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### 3.2 Developing tools to support an integrated dermatological approach to NTD interventions

#### Abstract

Many NTDs have significant skin manifestations which contribute to the morbidity and economic hardship experienced by those affected. New skin NTDs continue to be identified with significant overlap among populations affected, requiring updated and integrated diagnostic capacity. Opportunities for integration around a dermatological focus range across diagnosis, aetiology and disease mapping, to mass drug administration and morbidity management.

This workshop will bring together examples of effective integration work and develop a suite of best practice tools to assist in bringing an integrated dermatological focus to NTD interventions to increase case finding, case management and cost effectiveness. It is expected that integrated skin NTD survey would increase new case detection especially of NTDs with social fear and stigma (e.g. leprosy). Additionally, skin related NTDs with funding limitations (e.g. mycetoma, scabies etc) may benefit due to sharing of activities. Promote integrated approaches to detect and treat skin-NTDs to reduce morbidities and socio-economic burden.

Focus on the  
BEST Framework: **All**

#### Convenors

Liesbeth Mieras,  
International Foundation  
for Dermatology  
Kebede Deribe, BSMS

#### Moderators

Liesbeth Mieras,  
International Foundation  
for Dermatology  
Michele Murdoch, NHS

#### Rapporteur

Benita Jansen, NLR

#### Speakers

Rie Yotsu, National Center  
for Global Health and  
Medicine, Japan  
Wendy Van de Sande,  
Erasmus  
Kebede Deribe, BSMS

#### Main learning point:

Skin-NTDs' needs are best addressed within a wider framework of general skin diseases.

#### Next steps – summary:

1. To develop a relevant community in order to consolidate the new Skin-NTD cross-cutting group.
2. To pool our existing experiences and tools, including digital health tools.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

Future pooling of existing disease-specific resources & vertical programmes into horizontal skin-NTDs strategy



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### 3.3 Beyond 2020 – national and global perspectives on progress towards sustainable NTD programming

#### Abstract

Looking to 2020 and beyond, there is a recognised need to ensure national NTD programmes can identify and leverage financial, and technical resources required for continuous NTDs services provision.

This session will discuss: (i) health system strengthening (ii) mainstreaming NTD programming as part of a sustainability strategy and (iii) country capacity to leverage existing and new resources. The session will also explore lessons learned from national programmes that have made progress toward sustaining their NTD programmes.

The global NTD community has worked to advance thinking around sustainability in the context of NTD programmes, and assessing national capacity for programme scale-down and integration into larger health systems. The NNN Sustainability Working Group, national programmes, several donors and implementing organisations are among the thought leaders in the NTD community who are working towards defining and operationalising sustainability within the NTD community. This workshop allows for concepts and ideas to be presented to the broader NTD community including NGOs, donors, policy makers, and national governments who could take this conversation forward.

Focus on the  
BEST Framework: **All**

#### Convenors & Moderators

Karen Palacio, The End Fund  
Wangeci Thuo, RTI  
NNN Sustainability WG

#### Rapporteur

Katherine Williams,  
Evidence Action; NNN  
Sustainability Working Group

#### Speakers

Justin Tine, FHI360  
Nebiyu Negussu,  
Ethiopia Federal Ministry of  
Health  
Dr. Wilfrid Batcho,  
Benin National NTD Program  
Co-ordinator  
Rubina Imtiaz,  
Children Without Worms

#### Main learning point:

The definition and operationalisation of sustainability differs among partners. Countries also have different experiences when it comes to NTD sustainability. There are many lessons to be learned from sharing and among them is how to measure sustainability.

#### Next steps – summary:

Group discussion on measuring sustainability; developing national programme's capacity for sustainability; challenges of NTD integration into health and education policies; and the desirable level of inclusion of NTD activities into the health system revealed new ideas that can/ should be further explored. Examples from Ethiopia, Benin and Guinea were

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

Commitment to continue dialogue on sustainability.



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### 4.1 Reporting from the field: how programme staff can effectively communicate NTD stories (toolkit launch)

#### Abstract

“Collecting stories about neglected tropical diseases: A guide to field communications” is a new sector wide and NNN endorsed story gathering toolkit. It has been created using insights and experiences from last year’s workshop and with input from other professionals in the sector. The ‘Telling the NTD story’ workshop in 2018, generated discussion about NTD communications and highlighted enthusiasm of field staff to acquire new skills to effectively tell the NTD story to diverse audiences. In response, a Task Team was created to design a new toolkit to support non-communications staff to collect content that member organisations can use for external communications activities.

The session will open a dialogue about the role of communications in NTD programmes and highlight best practices for collecting content. The workshop will include interactive group work to introduce key elements from the communications toolkit such as: how to identify an opportunity and prepare, how to get good quotes, how to take photos and videos. Overall we aim to help build workshop participants’ confidence, enthusiasm and practical skills in communications, story gathering and being NTD ambassadors.

With 2020 fast approaching the workshop could also consider how we can collect stories from the field to feature at the next NNN. We encourage workshop participants to share photos, quotes and reflections on the workshop via social media using #NNN2019 and #NTDStories

Focus on the  
BEST Framework: **All**

#### Convenor

Rebecca Mintrim,  
Sightsavers

#### Moderators

Rebecca Mintrim,  
Sightsavers  
Alison Hill,  
The Fred Hollows  
Foundation

#### Rapporteur

Tim Jesudason,  
International Coalition for  
Trachoma Control

#### Speakers

James Porter, The END Fund  
Rebecca Mintrim,  
Sightsavers  
Alison Hill,  
The Fred Hollows  
Foundation

#### Main learning points:

People affected by NTDs have a voice but no platform or audience to hear them. Helping to share their stories should be a priority to all people working to empower marginalised people. The communications toolkit aims to strengthen capacity among non-communications staff with skills to tell stories from the field, while respecting the dignity of affected people.

#### Next steps – summary

The toolkit has been launched and is available on the NNN website. Please read and share it among your organisations. It is an important document that will help ensure that we protect the people we serve by capturing their stories authentically. It will also help us to continue to raise awareness of NTDs.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

1. Download, read and use the toolkit.
2. Send in one photo, quote or story to Tim at LCTC comms.
3. Communications staff to hold a workshop to share information from the toolkit with their organisations.
4. Send feedback to Tim – [lctccomms@gmail.com](mailto:lctccomms@gmail.com)



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### 4.2 Improving the impact of NTD interventions through inclusive, integrated, community approaches in our programmes

#### Abstract

The Sustainable Development Goals aim for inclusive, equitable and sustainable development, including universal access to key services. The commitment to leave no one behind requires us to ensure equitable access across health and other sectors to sustain NTD programme efforts.

This interactive workshop, hosted by the Disease Management, Disability and Inclusion (DMDI) Working Group, will identify challenges and solutions for successful inclusive, integrated, community-based NTD programmes. Best-practices will be shared from Africa and Asia.

Focus on the  
BEST Framework:

**T**

#### Convenors

Saskia Kreibich, DAHW  
Jannine Ebenso, TLM

#### Moderators

Kirsty Smith, CBM  
Denis Gadah, DAHW Togo

#### Rapporteur

Jannine Ebenso TLM

#### Speakers

Vivek Lal, GLRA India  
Chinwe Eze, DAHW Nigeria  
Kirsty Smith, CBM  
Dr Paul Saunderson, ALM  
Julian Eaton, CBM  
Chris Ogoshi, HANDS Nigeria  
Mongala Diaondge, TLM  
India

#### Main learning point:

1. Lack of integration limits the impact of our programmes. Integration done well makes better use of resources (money, time, people etc). Integrated not just across NTDs but across all sectors (e.g. mental health)
2. Persons affected by NTDs are first and foremost people, not patients. Listen to them and find out what matters most.
3. Be intentional and deliberate to ensure all NTD programmes are inclusive (of all marginalised groups) throughout the continuum of care – from prevention onwards.

#### Next steps - summary

1. Join the DMDI working group!
2. DMDI working group to reflect on learning from workshop and build into action plan.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

1. Individuals and members to move from our own agendas and work deliberately towards our joint agenda of integrated, inclusive approaches – by improved partnership and collaboration.
2. Mindset shift – create and encourage platforms and exchange in order to listen to and respond to the voices of persons affected.





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### 4.3 A One Health approach to NTDs

#### Abstract

The session drew on results of a high-level consultation on integration between veterinary public health and NTD programmes conducted by the One Health cross cutting working group. Participants were asked to reflect on a set of emerging issues including:

1. Reaching the unreachable through integrated services
2. Practical implications of integration
3. Successes (and challenges) in integration
4. Health systems benefits

The One Health approach acknowledges that human, animal and environmental health are interconnected, interdependent and of equal importance. It refers to a “collaborative, multisectoral, and transdisciplinary approach with the goal of achieving optimal health outcomes recognising the interconnection between people, animals, plants, and their shared environment” (CDC). It is rooted in growing acknowledgement that infectious disease control will not be possible without due emphasis on animal and the environment and essential to the impact and sustainability of NTD programmes. Additionally, linking NTD programmes with animal health and livelihood programmes offers new and exciting opportunities to increase the reach and uptake of NTD interventions.

For programmes to be able to capitalise on these links, clearly articulated policy recommendations developed and translated into programme solutions are needed; however, given the multiple sectors and stakeholders involved, this is a significant challenge. The NNN plays an important role in driving the development and implementation of new programming approaches; therefore, this workshop offered an opportunity for participants to contribute creative ideas and experiences for an NNN One Health approach.

Focus on the  
BEST Framework: **All**

#### Convenors

Wendy Harrison, SCI  
Foundation  
Yael Velleman, SCI  
Foundation

#### Speakers

Sarah Cleaveland,  
University of Glasgow  
Aya Yajima, WHO  
WPRO  
Eric Fevre, University of  
Liverpool

#### Main learning point:

People aren't silos; they live one-health lives. One-health offers an opportunity to leave no one behind!

#### Next steps – summary:

Working Group Action Plan – including advocacy messages, case studies, tools/resources

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

Broaden and convene a community of practice on one-health. Engage other stakeholders to support country action.



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### 4.4 Understanding and evaluating successful drivers for partnership to achieve the 2030 NTD goals

#### Abstract

To achieve our collective ambitions tied to a new WHO NTD Roadmap and the SDGs, the NTD community must build effective partnerships to deliver targeted strategies. How do we define partnership and evaluate key learnings of what works? How do we measure impact and make the case for working together, within the NTD community and with other stakeholders across WASH, education, disability and humanitarian emergency to achieve a world free of NTDs.

This workshop seeks to develop a shared understanding of the concept and language of partnership to ensure alignment of the ways of working and to define a better distinction between a choice to work in partnership. In addition, when collaborative working is spread between a wide range of stakeholders, how do we recognise and utilise the unique strengths and contributions of stakeholders towards the same shared objective at a national, regional and global level. By demonstrating the value add of partnership we hope to identify how to grow the saleability of investing in collaborative efforts and coalitions themselves (paid staff, project activities etc), and ensure investments into partnerships continue to be valued, measured and sustained. Our panel will share their perspectives of lessons from different partnership models, challenges and opportunities to strengthen current partnership models through a series of questions through moderated Q&A and small group work.

Focus on the  
BEST Framework: **All**

#### Convenor

Aparna Barua Adams,  
International Coalition for  
Trachoma Control

#### Moderator

Girija Sankar,  
Children Without Worms

#### Rapporteur

Anouk Gouvras,  
Global Schistosomiasis  
Alliance

#### Speakers

Maelle Ba, Speak Up  
Africa

Stuart Mackie, Direct  
Impact Group

Geoff Warne, ILEP/  
Global Partnership for  
Zero Leprosy

#### Main points:

Partnerships convene a broad range of stakeholders that increase influence and skillset to achieve a shared vision, shifting from a resource-limited focus to a need/vision focus. In order to be effective, partnerships must have common values, and vision, clear transparent operational structures and equally value contributing partners and members. Two main measurements of the 'health of partnerships' is evidenced by continual active member engagement and the ability and willingness to adapt and manage when needed.

#### Next steps - summary

- A checklist to measure the health of a collaborative partnership and measure the impact and value of ways of working.
- A briefing paper that identifies and shares lessons learned, celebrates the success of partnerships and guidance on 'trouble shooting' challenges.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

As organisations we commit to making collaborative partnerships work a central ethos;/guiding principal to our way of working.

# Rapid fire sessions



Photo credit: RTI International/Nguyen Minh



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#### **RF1.B Realising the potential of technology to support high-quality NTD programmes**

##### **Highlights**

Evidence Action works with the national Government of India and 11 states to deworm >260 million preschool and school-age children through a biannual National Deworming Day (NDD).

Progressive technological innovation has helped the programme digitise data collection, enable real-time data availability, improve monitoring efficiency and increase programme quality. This rapid-fire session shared an overview of several applications and tools used in NDD:

- Customised NDD mobile app used at scale for coverage reporting
- Survey application to collect monitoring & evaluation data
- Automated tele-calling for process monitoring and to assess preparation for MDA
- Management Information System (MIS) with modules for programme management, data archives, and analytics
- Adapting Google Forms for monitoring

These tools have enabled faster, higher quality data which in turn enhances programme delivery, coverage results, and helps relevant stakeholders to be more accountable for the programme.

##### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice**

- Continue to explore further use of technology to improve programme quality and reach to the hundreds of millions of children treated by the NDD programme in India.
- Learnings from India can serve as a model for others to replicate or adapt to their programme contexts, specifically for those at scale.

##### **Contact Information**

Subhash Khatri: [Subhash.khatri@evidenceaction.org](mailto:Subhash.khatri@evidenceaction.org)  
Katherine Williams: [Katherine.williams@evidenceaction.org](mailto:Katherine.williams@evidenceaction.org)

Contact us for more information about the design, implementation, successes and lessons learned from using a range of tech tools to support large-scale MDA programmes in India.





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### RF1.C Using a network approach to build NTD laboratory capacity

#### Highlights

Limited laboratory capacity is becoming an increasingly significant bottleneck in achieving global control and elimination targets as programmes move into the post-2020 agenda. In an effort to address this gap, a NTD Laboratory Network has been developed to maximise use of existing resources and expand lab capacity in endemic countries. The fully functioning lab network will provide the following services to the NTD community:

1. Ensure availability of standardised lab protocols
2. Implement and maintain a qualitative assurance system
3. Develop a communication system to share experiences, protocols, and laboratory derived data
4. Work with partners to coordinate sample processing when local lab capacity is limited

This session will provide an update on the status of the lab network and information on the services available to NGO community and other NTD partners.

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice**

The NTD Lab Network will ensure availability of the laboratory capacity needed to support NTD programmes as they transition into the post-2020 agenda. The laboratory network is clear example of a NTD initiative that supports all partners and eventually all NTDs.

#### **Contact Information**

Ashley Souza, Task Force for Global Health  
Charles Mackenzie, Task Force for Global Health

## RF 1.D Snakebite: challenges to reduce mortality and morbidity in sub-Saharan Africa

Prof. Rob Harrison LSTM  
Dr. Gabriel Alcoba MSF-HUG



### Global & African burden of Snakebite

#### Globally

- 4.5-5.4 million victims bitten,
- 1.8-2.7 million envenomed
- 81,000-136,000 die, due to shock, respiratory paralysis, hemorrhage
- 400,000+ disabled/amputated.

#### In Sub-Saharan Africa

- 0.5-1 million victims
- ½ million envenomed ± 32,000+ deaths (up to 50-70,000)
- 95% in rural areas, 68% victims consult traditional healers rather than hospital
- Children : at higher risk of dying

### Three collaborations

**MSF & partners** in **South-Sudan, CAR, Ethiopia, and Yemen** treat about ~3000 snakebite victims each year. Huge challenges & complexity : From **antivenom to skin grafts** → Example: <https://www.msf.org/antivenom-not-frogs-needed-cure-snakebite-south-sudan>



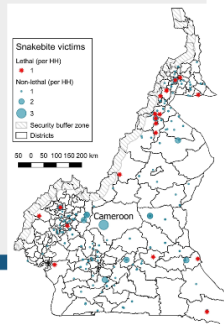
**Antivenom, not frogs, needed to cure snakebite**

**The African Snakebite Research Group Kenya-Nigeria (LSTM).** What is more medically- and cost-effective - motorcycle ambulances? - community education? - both?  
→ Community and hospital surveys in:  
- Gombe State, **Nigeria** AND Kitui County, **Kenya**



### The Snake-byte group in Cameroon & Nepal (UniGE, HUG)

Spatial Epidemiology 250 areas  
N=64.000 per country,  
Random GPS points  
True community incidence  
Nation-wide  
One-health and economic impact



### Conclusions

#### Snakebite victims need

- **Community awareness** to reduce incidence and to improve health seeking behaviour
- **Rapid access to effective, affordable antivenom & respiratory support, wound and foot care, surgery**
- Integration with other NTDs (eg emergencies & foot care) and prevention (shoes, nets, habitat)
- We welcome the **WHO NTD 2019 strategy !**



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### **RF1.E Trachoma elimination in Africa: lessons from two multi-country initiatives**

#### **Highlights**

A recently published learning paper, [‘Trachoma Elimination in Africa, Lessons from Two Multi-Country Initiatives’](#) showcases 10 lessons from two International Coalition for Trachoma Control (ICTC) partnership initiatives: The Queen Elizabeth Diamond Jubilee Trust’s Trachoma Initiative and the DFID SAFE Program.

With a combined investment of £80 million over 5 years these programmes have brought together 82 partners including international donors, government ministries, ICTC members including Sightsavers as the grant manager, local NGO partners and international bodies to further support countries to achieve the elimination of trachoma as a public health problem.

These lessons offer direct examples of partnership, impact and challenges to be considered as the trachoma and NTD community makes progress towards cross-sectoral approaches and strengthening of health systems to achieve the 2030 Sustainable Development Goals and a new WHO NTD Roadmap.

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice**

We hope these lessons will contribute to global discussions to advance NTD strategies, cross sectoral collaborations with the WASH sector, and planning for sustainability through integration with national health systems.

#### **Contact Information**

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Aparna Barua Adams, Project Manager, International Coalition for Trachoma Control  
([trachomacoalition@gmail.com](mailto:trachomacoalition@gmail.com))



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### **RF1.F The role of modelling towards 2030 goals: tell us which question to answer first!**

#### **Highlights**

Mathematical modelling of the transmission dynamics of NTDs plays a role in informing policies on the roll out of interventions, assessments of impact and sampling strategies.

However, challenges still remain in both communicating and understanding the impact of modelling outputs to those implementing the programmes.

As we move to new targets for control and elimination of NTDs in the next 10 years, it is an opportunity how can modelling provide a programmatically grounded evidence base for effective decision making?

We aim to improve partnership between researchers in transmission modelling and other members of NNN community in plotting the pathway to 2030.

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice**

Working with partners at NNN to understand how modelling insights are better communicated and ensure that future modelling analysis are used to guide immediate interventions as well as longer-term strategy.

#### **Contact Information**

Andreia Vasconcelos, University of Oxford; NTD Modelling Consortium



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### **RF1.I Early childhood habit creation for disease prevention, the case of trachoma**

#### **Highlights**

Light for the World has implemented school and community programmes that specifically target children below the age of 7. Since young children are at the highest risk of contracting trachoma, a specially designed curriculum for early childhood (aged 7 and below) has been developed. It includes the use of a puppet called “Toto” to build an emotional connection with the children and teach about trachoma prevention. In addition, hand and face charts, eye drawings, games and songs, and art activities were also a part of the programme.

The programme was unique in that school staff, Parent Teacher Association members, and Health Development Armies and Health extension workers all participated together.

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice**

Light For The World is pleased to work with all the NTD partners who strive to realise a better world specifically for children, women and people with disabilities.

#### **Contact Information**

Aduagna Amin - Light for the World





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### RF1.J Can data reuse fast-track developments in NTD treatment?

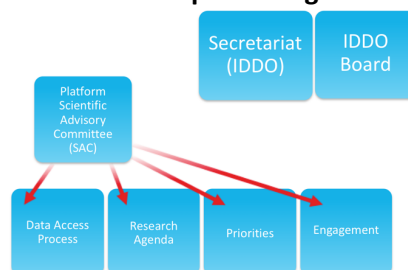
#### Highlights

The Infectious Diseases Data Observatory (IDDO) is pioneering data sharing & reuse to improve treatment outcomes for people suffering from the poverty related infectious diseases including Chagas disease, schistosomiasis, soil-transmitted helminthiasis, visceral leishmaniasis & mycetoma. IDDO builds on and incorporates the successes of the WorldWide Antimalarial Resistance Network (WWARN)

#### What is the value of data platforms?

- Improve data reproducibility, reuse & accessibility
- Improve data quality & interoperability
- Uphold ethical imperative to protect human health data

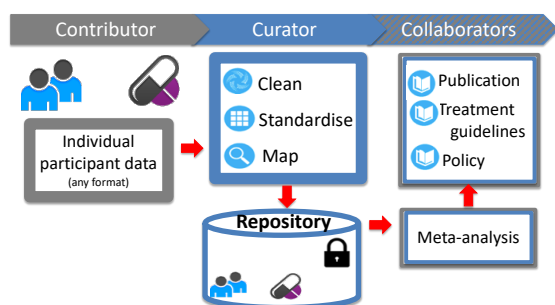
#### How is an IDDO platform governed?



#### Guiding principles of an IDDO platform

- Collaboration & engagement with stakeholders
- Incentivise data contribution
- Recognise value of contributor involvement

#### What does an ID



#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice

IDDO aims to improve treatment outcomes for people suffering from NTDs through ethical & equitable data sharing. Our NTD platforms are guided by principles of collaboration, inclusivity & transparency.

#### Contact Information

Dr Martin Walker, Lecturer in Epidemiology, Royal Veterinary College & Senior Scientist, IDDO  
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### **RF1.K National level progress report on WASH interventions for the sustainable control of NTDs, the case of Ethiopia**

#### **Highlights**

- Current status of Ethiopia : 97% of urban households have access to improved sources of drinking water, compared to 57% of rural.
- To clarify what to do and how to do parts of the WASH NTD integration, the following strategic documents and different tools were developed, just to list the few :
  - National and regional WASH-NTD TOR and MOUs
  - National WASH-NTD toolkits
  - The message harmonisation guide
  - The WASH-NTD framework and many more that can be downloaded and read from the FMOH (Ethiopian Federal Ministry of Health website)
- Ethiopian Government is taking the lead and different actors from both WASH and NTD sections collaborating to bring impact
- The establishment and strengthening of technical working groups both at regional and national level must be sustainable
- The good opportunities that we have regarding WASH-NTD joint programmes include :
  - Government and partners attention on the subject matter
  - One WASH national programme
  - Global attention on the sustainability of WASH interventions

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice**

- (i) Expanded hygiene and sanitation approach to bring the interruption of transmission among highly endemic communities
- (ii) Activities should be harmonised, aligned and could be supported with funds for both WASH and NTD actors
- (iii) Activities related to advocacy, social mobilisation and community sensitisation must be strengthened at all levels
- (iv) Existing tools, strategies and other documents must be implemented

#### **Contact Information**

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### RF2.A Assessment and screening tools

#### Highlights

Assessment and screening tools play essential roles in identifying the need with regards to NTDs. Be it physical health, mental health condition and socio-economic conditions and demography factors. Assessment tools play an important role in finding problems that require interventions. In addition, these tools can also measure changes in a person or communities over a time in a response to interventions. Furthermore, these tools can support the development of interventions and assess the effectiveness of such interventions.

Despite the importance of these tools, people involved in the implementation of NTDs programme in low resource settings do not have sufficient access, knowledge and skills to administer appropriate tools.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice

Using multimedia, after this conference, I commit myself to share resources and knowledge to my colleagues and organisations to address NTD related issues in Nepal and elsewhere.

#### Contact Information

Chiranjivi Sharma, The Leprosy Mission Nepal



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### **RF2.B Equitable access to STH interventions – reaching preschool-age children to achieve WHO goals of elimination of STH morbidity by 2030**

#### **Highlights**

- WHO soil-transmitted helminthiasis control targets >75% coverage of deworming for preschool-age children (PSAC).
- 265 million PSAC require Preventive Chemotherapy (PC): over 104 million live in countries that are not treating PSAC.<sup>1</sup>
- 45% of countries treat PSAC, but only 3.6% reported consistent PC over a consecutive 3-year period.<sup>1</sup>
- Our combined deworming and vitamin A supplementation project addresses gender equality barriers to reach all PSAC with treatment every 6 months.
- Challenges for sustainability are inconsistent drug supply and fragmented and/or lack of deworming data.
- Without equitable and consistent PC, impact of STH control programmes is lost by allowing reinfection through intermittent treatments.

<sup>1</sup> Children Without Worms PSAC Analysis (source: WHO 2017 PCT data)

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice**

Increased collaboration between WHO, governments, pharma donors and NGOs to ensure a sustainable drug supply and consistent service delivery (for at least 3 consecutive years) that reaches all preschool children.

#### **Contact Information**

Sara Marshall, effect:hope



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### **RF2.C Improving MDA coverage through effective social mobilisation - the Kenya IDA experience**

#### **Highlights**

In November 2018, Kenya implemented the new triple drug therapy with ivermectin, diethylcarbamazine citrate and albendazole (IDA) against lymphatic filariasis. In spite of fears over compliance, 82% coverage was achieved.

Among the innovative approaches employed, effective social mobilisation stands out as the major driver of success alongside:

- Deliberate efforts were made to win over support of all stakeholders at both national and county levels.
- More community drug distributors were recruited, more supervisors deployed.
- The training cascade was shortened and duration of distribution increased.
- Development of specific messages for specific groups and utilisation of multiple innovative dissemination platforms contributed significantly to the success of the MDA experience in Kenya.

#### **Actions and commitments towards our vision beyond 2020: Many partners, one voice**

Strong and effective partnerships were leveraged for maximum effect. Frequent calls and engagement ensured synergy between multiple partners including donors, funders, implementing partners, research institutions, WHO and government agencies.

#### **Contact information**

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### RF2.D Best practices in foot care in NTDs and NCDs – experiences from the field in India

#### Highlights

A person walks about 115,000 miles during an average lifetime and three-quarters of people have foot problems at some point in time. People with leprosy and lymphatic filariasis are 20 times more likely to have foot problems than the general population, affecting their social, personal and economic lives. Affected people often do not attend social functions and mingle within their communities. One of the reasons cited is shame and embarrassment and a resulting lack of confidence.

***“Protective footwear should be worn by all patients with abnormal foot function, whether or not they have sole wounds, throughout their lifetime. MCR/EVA cushioned insole will distribute walking pressure more widely over the sole and thus minimise the risk of wounds at pressure sites.”***

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice

Five pillars of foot care must be implemented:

- (i) skin care
- (ii) wound care
- (iii) exercises (active and passive)
- (iv) protective footwear (MCR/EVA)
- (v) counselling and health education

We constantly need to modify our footwear as per our client needs and around their choice if they are not satisfied. Otherwise this will lead to non-compliance, and risk of ulcers and lead to amputation.

#### Contact Information

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## NEGLECTED TROPICAL DISEASE NGO NETWORK

A global forum for nongovernmental organizations  
working together on NTDs

NNN Annual Conference  
**Our Vision Beyond 2020:  
Many Partners, One Voice**  
17-19 September 2019  
Liverpool, United Kingdom

### RF2.G Noma, a neglected tropical disease

#### Highlights

Noma, a rapidly progressing oral infection, has a reported 90% mortality rate and mostly occurs in low resource settings.

The WHO estimates that 140,000 new cases of noma occur annually. Noma cases are frequently reported in Nigeria.

The Nigerian Ministry of Health and Médecins Sans Frontières, implement clinical programmes for the treatment of noma at the Noma Children's Hospital in Sokoto, northwest Nigeria.

To combat noma, input is needed from health ministries in endemic countries, the NGO community and the WHO. Noma is a neglected condition and should be included in the WHO neglected tropical diseases list.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice

We commit to advocate for noma to be included on the WHO neglected tropical diseases list and to collaborate with the Nigerian Ministry of Health on prevention and treatment programmes.

#### Contact Details

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### **RF2.J Real time LQAS monitoring of medication coverage improves district management of preventive mass medication campaigns and ensure progress towards elimination of lymphatic filariasis**

#### **Highlights**

- Mozambique is endemic in 115 of its 161 districts for lymphatic filariasis (LF).
- Campaigns for LF elimination started in 2009 and reached 100% geographical coverage in 2014.
- Since 2014, LQAS surveys verify coverage of campaigns.
- In 2018, LQAS survey indicated that two very endemic areas had not reached coverage.
- For the recovery campaign, we applied LQAS to conduct daily real time monitoring of medication coverage.
- Teams checked daily medication intake in areas treated the day before, to identify people not treated.
- Communities not treated were visited and re-treated.
- The strategy provided independent information to district management teams and ensured optimum coverage.

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice**

Real time LQAS daily monitoring of medication intake provided information of the progress of the campaign and allowed district management teams to ensure campaign coverage and no one left behind.

#### **Contact Information**

Carmen Maroto Camino, Liverpool School of Tropical Medicine  
Xavier Badia Rius, Liverpool School of Tropical Medicine

# Cross-cutting groups





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### Conflict and Humanitarian Emergencies Cross-Cutting Group

#### Agenda

Review of the year, assessing progress against initial objectives. Presentation of the work of the cross-cutting task teams.

#### Cross cutting work groups sessions:

- Communications case study template
- Policy advocacy briefing paper
- Mapping tools

#### Discussion and sharing:

- (1) Identification of ongoing needs and challenges
- (2) How the working group can meet these identified issues
- (3) Planning for the year and sign up of new members
- (4) Admin and next steps.

#### Co-Chairs

Angelia Sanders, The  
Carter Center  
Fiona Vincer, The  
MENTOR Initiative

#### Vice Chair

Sharone Backers, RTI  
International

#### Speakers

Aparna Barua Adams,  
International Coalition for  
Trachoma Control  
Rebecca Hill, Sightsavers  
Mohammed Aliyu, Helen  
Keller International

Plus other group members

#### Main learning point:

Members are becoming increasingly involved in C&HE environments and therefore more experiences and lessons learned are occurring. Documenting and sharing experiences and lessons learned will benefit partners. Developing a mapping tool and system to collect data in C&HE settings remains a high priority. Active engagement within the C&HE task teams will continue to be important to further the work of the group.

#### Next steps – summary:

1. Develop checklist to help partners think through needs when implementing in C&HE environments; 2) Develop a case study template; 3) Complete mapping tool; 4) Complete an advocacy paper; 5) Expand the advocacy paper to include sub-section; 6) Develop C&HE webpage on NNN and infoNTD sites





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### Disease Management, Disability and Inclusion Cross-Cutting Group

What is required to integrate DMDI essential care into NTD programmes and other government health services?

#### Agenda

##### **Open session 14.00-16.00**

WHO NTD Roadmap 2021-2030 update with special reference to Disease Management, Disability and Inclusion (DMDI)

- Journey through Care concept
- DMDI Theory of Change update
- **Panel discussion** with WHO, National Programme Managers and Investors: **“What is required to integrate DMDI essential care into NTD programmes and other government health services?”**

##### **Members only session 16.00-17.30**

- Membership update
- Vice Chair election and handover
- Theory of Change: completion and prioritisation of interventions
- Task group structure review
- Next steps

#### Chair & Moderator

Martin Kollmann, CBM

#### Speakers

Dr Mwelecele Malecela, WHO

Maneesh Phillip, effect:Hope  
Wim van Brakel, NLR

#### Panelists

**WHO:** Dr Mwelecele Malecela

**MOH Liberia:** Karsor Kolie

**MOH Kenya:** Dr Sultani  
Matendechero

**Investors/funders:** Gretchen  
Stoddard, Izumi Foundation,

Warren Lancaster, The END  
Fund

Kiyomi Takahashi, Sasakawa  
Health Foundation

#### **Outcomes and main learning point:**

Agreed common understanding and commitment to enhance support for cross cutting and holistic DMDI approaches as part of comprehensive, inclusive NTD work, integrated into health and other systems.

#### **Next steps – summary:**

(1) Continue a partnership-based discussion process amongst key stakeholder groups on how to enhance support for DMDI (2) Based on session learnings and stakeholder commitment, develop a compelling rationale for investment in DMDI that includes support for essential care packages at IU level.

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:**

- (1) Work with WHO, national programmes, investors and partners to develop and support essential care packages for DMDI (2) Continue advocacy for inclusion of DMDI interventions in NTD programmes, in both health and social services.



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### Ensuring Sustainable Systems Cross-Cutting Group

#### Agenda

- Overview of the Sustainability Working Group and its objectives
- Review of progress from the groups three task teams:
  - Sustainability statement
  - Knowledge review
  - Indicators/tools
- Discussion: Collating or developing sustainability indicators, in coordination with stakeholders
  - Informal updates on existing tools or ongoing work among partners such as STH Coalition, World Bank, USAID, and others
  - Drug forecasting as a resource for sustainability planning
- Refreshing our commitments
  - Setting goals for the coming 6-9 months
  - Working group leadership roles

#### Chair

Katherine Williams,  
Evidence Action

#### Immediate Past Chair

Carolyn Henry, SCI  
Foundation

#### Speakers

Rubina Imtiaz, Children  
Without Worms  
Justin Tine, USAID  
Chiara Marocco, Graduate  
student

#### **Main learning point:**

Sustainability is context-specific and very complex! We need to be collaborative and flexible in our approaches to support future progress.

#### **Next steps – summary:**

Select short/mid/long term priorities for our workplan; gather and share tools and resources for promoting programme sustainability.

#### **Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:**

Sharing (and continuing to refine/get buy-in for) our working definition of sustainability.



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### WASH Cross-Cutting Group

#### Agenda

- Welcome and celebration of the group's five year anniversary
- Update on WG Work: communications, monitoring, behaviour change, policy
- Group Work:
  - Challenges, messages and platforms for communications on WASH & NTDs
  - Developing behaviour change best practice
- Consultation: Updating the WHO global strategy on WASH & NTDs
  - Review of Strategic Objectives:
    - Awareness
    - Monitoring
    - Evidence
    - Planning
  - Definition of key actions for WHO, countries and partners
- Wrap Up, next steps and call to join the Working Group
  - } Are the objectives still relevant?
  - } Should they be revised & how?
  - } Any new objectives

**Happy 5 Year Anniversary!**

#### Co-Chairs

Angelia Sanders  
[Angelia.sanders@carterceter.org](mailto:Angelia.sanders@carterceter.org)  
Yael Velleman  
[y.velleman@schisto.org.uk](mailto:y.velleman@schisto.org.uk)

#### Task Team Leads

1.Communications  
Kelly Bridges  
[kbridges@globalwater2020.org](mailto:kbridges@globalwater2020.org)  
Tim Jesudason  
[ictcommms@gmail.com](mailto:ictcommms@gmail.com)

2.Behaviour Change  
Sarity Dodson  
[sdodson@hollows.org](mailto:sdodson@hollows.org)  
Geordie Woods  
[gwoods@sightsavers.org](mailto:gwoods@sightsavers.org)

3.Policy  
Helen Hamilton  
[Helenhamilton@wateraid.org](mailto:Helenhamilton@wateraid.org)

#### Main learning point:

1) There are many exciting platforms for WASH & NTD engagement, sharing lessons and practices 2) An effort is needed to develop BCC best practices within the NTD community 3) The strategic objectives of the global strategy need alignment with 2030 roadmap targets, accompanied by a similar monitorable action plan.

#### Next steps – summary:

1) Communications plan to be developed further 2) Development of resource on strategies for effective behavior change 3) Summary of key strategy feedback to WHO

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

1) Expand and effectively facilitate the WG 2) Collaborate with WHO

# Disease specific posters



Photo credit: RTI International/ Muhammad Fadli



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### Leprosy session: WHO targets and the Global Partnership for Zero Leprosy Framework

#### Agenda

**Topic 1: WHO targets and NTD strategy** 9:00-10:00 a.m. *Presentation:*  
*Erwin Cooreman (20 minutes)*  
*Discussion: (40 minutes)*

**Topic 2: GPZL Action Framework** 10:00-10:30 a.m.  
*Presentation: Christine Fenenga (10 minutes)*  
*Discussion: (20 minutes)*

**Break** 10:30 a.m.-11:00 a.m.

**Topic 3: GPZL Country Model** 11:00 a.m.-12:00 p.m.  
*Presentation: Christine Fenenga (20 minutes)*  
*Discussion: Facilitated by Geoff Warne (40 minutes)*

**Topic 4: Open discussion time** 12:00 p.m. – 12:30 p.m.  
*Facilitated by Christine Fenenga, Erwin Cooreman and Geoff Warne*

#### Speakers

Erwin Cooreman  
Team Leader, Global  
Leprosy Programme,  
WHO

Christine Fenenga  
Operational Excellence  
Coordinator, Global  
Partnership for Zero  
Leprosy (GPZL)

Geoff Warne  
CEO, ILEP

#### Main learning point:

Learn more about WHO targets and NTD strategy; GPZL framework and country model.  
Discuss alignment and future activities.

#### Next steps – summary:

**WHO NTD strategy and WHO global leprosy strategy** – attendees asked that the following be included or highlighted: (1) leprosy complications and reactions (2) human rights issues (3) chemoprophylaxis and percentage of people at risk (4) the role of media in awareness-raising of NTDs and leprosy.

**GPZL Action Framework and Country Model** – By 2020, 5 countries will develop partnerships around fundable plans for ending leprosy. By 2025, the number of countries will increase to 15, and 25 by 2030.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

The GPZL is a global community of persons affected by leprosy, researchers, clinicians, country programme managers, ministry of health officials, and scientists. The GPZL, with WHO partnership, focuses on building national partnerships within countries. Our collective 2030 goal is that 25 priority countries for leprosy have national partnerships and clear roadmaps for ending leprosy.





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### Onchocerciasis NGO Group for Elimination

#### Agenda

TIME		
2:00-2:10	Chair's Report Update, session outline, website	Charles Mackenzie
2:15-2:20	Summary of group outputs over the past year: shared data presentation	Louise Hamill
2:20-3:30	Information updates from: <ul style="list-style-type: none"><li>• Camilla Ducker- WHO diagnostics lead</li><li>• Charles – NLCB/labs</li><li>• Stamping out oncho</li></ul> Member's reports: 5 min presentation, 2 mins discussion <ul style="list-style-type: none"><li>• CBM</li><li>• FHI 360</li><li>• HKI</li><li>• Light of the World</li><li>• MITOSATH</li></ul>	Member Organisations
3:30-4:00	BREAK	
4:00-4:30	Updates continued: <ul style="list-style-type: none"><li>• Sightsavers</li><li>• The Carter Center</li><li>• UFAR</li><li>• Open forum – additional member updates, discussion</li></ul>	Member Organisations
4:30-5:30	ONVGO Group planning session	Chair, vice-chair and members
5:30	CLOSE	

#### Contact Information

Charles MacKenzie  
[Cmackenzie@taskforce.org](mailto:Cmackenzie@taskforce.org)

Louise Hamill  
[LHamill@sightsavers.org](mailto:LHamill@sightsavers.org)

#### Main learning point:

NGOs have supported significant progress towards onchocerciasis elimination: millions of treatments delivered, surveys conducted, MDA no longer needed.

#### Next steps – summary:

Group will have a re-vamp. New name, voting on new issues.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

We are stronger as a group working together. We commit to participate and communicate to drive the success of this group.



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### STH SCH Disease Specific Group

#### Agenda

An opportunity to hear updates on global strategic direction and information sharing on tools and ongoing work in the SCH and STH space.  
Presentations:

- WHO Roadmap for NTDs towards 2030
- Update from STH Coalition
- Update from the Global Schistosomiasis Alliance
- ESPEN SCH analysis toolkit for PCQ for costing at the sub-district level *Anouk Gavroas (on behalf of ESPEN)*
- NT Deliver: monitoring the drug supply chain *Ashley Sara (NTD-SC)*
- Equitable access to STH interventions – reaching pre-SAC to achieve WHO goals of elimination of STH morbidity by 2030 *Sara Marshall (effect:hope)*
- Paediatric Praziquantel – reaching pre-SAC for SCH treatment *Nadia Ben Meriem (SCI Foundation)*
- Acting for Health: increasing community engagement *Kamran Rafiq and Alex Dover (Acting for Health)*

Group discussions: Mainstreaming STH and SCH. Are there commonalities we could leverage for a combined platform – based approach?

#### Contact Information

##### Chair

Lynsey Blair (SCI Foundation)

##### Vice Chair

Michael French (RTI International)

##### Past Chair

Yaobi Zhang (Helen Keller International)

##### Speakers

**Antonio Montessoro**  
(WHO HQ NTD Dept)

**Girija Sankar**  
(STH Coalition)

**Anouk Gouvras**  
(Global Schistosomiasis Alliance)

#### Main learning points:

(1) Wide variety of work taking place across partner organisations to encompass the multi-faceted approaches needed for SCH and STH control and elimination. There is an exciting new tool available and on the horizon! (2) WHO Roadmap is welcomed for SCH and STH targets but community recognises that country programmes will need support in the measurement of achieving targets.

#### Next steps – summary:

(1) Continue to advocate through GSA, STH Coalition and partner organisations for evidence-based decision making for SCH/STH interventions (2) Continue to identify and address reaching underserved at risk populations for SCH/STH, particularly in context of sustainable programming and integration into existing health systems.

#### Actions or commitments towards Our Vision Beyond 2020: Many Partners, One Voice:

ALIGNMENT:	Of STH/SCH programmes with routine health services as programmes progress	IMPERATIVE:	SCH/STH programmes need to be adaptable, evidence-based and progressive
EVIDENCE:	Develop appropriate standardised impact assessment methodologies	PARTNERSHIPS:	Multi-sector collaboration is essential

# Conference highlights



## Closing remarks from the Incoming Chair, Yaobi Zhang

The 2019 NNN conference represents a significant moment in the history of the NNN as we celebrate 10 years of partnership and collaboration, in support of our shared vision of a world free of NTDs. I am delighted to share that this year's conference was attended by over 400 participants from 49 countries, eager to discuss challenges and share lessons across a diverse range of cross-cutting issues. In light of this, I can think of no better theme for the 10-year anniversary than **'Our Vision Beyond 2020: many partners, one voice'**.

Since 2009, the world has witnessed a seismic shift in the NTD landscape, including 31 countries achieving elimination of at least one NTD. Progress has been supported by increased political will through international agreements, including WHA resolutions, the 2012 London Declaration on NTDs and the Sustainable Development Goals (SDGs). This increase in political will was demonstrated at this year's annual conference, by the attendance of UK Parliamentary Under Secretary of State for the Department of International Development, Baroness Sugg, CBE. At the opening ceremony Baroness Sugg spoke passionately about the UK's commitment to alleviating the burden of NTDs for 200 million people through the UK Department for International Development's new Ascend programme. Similarly, at the closing ceremony, Labour member of the UK Parliament and Shadow Secretary of State for International Development Dan Carden, showed that political will for NTDs exists across the political spectrum. In his speech during the closing ceremony he spoke about his commitment to the world's most marginalised people and the achievement of universal health coverage.



*Incoming Chair, Dr Yaobi Zhang*

The UK's commitment to NTDs is reassuring and as the new NNN Chair, I thank the UK Government for its work towards NTD elimination and its collaboration with international donors including USAID, the private sector and the philanthropic sector. Sustained investments in integrated programmes that strengthen health systems and respond to the needs of hard to reach communities will be essential to achieve global goals.

2020 will be an important year for the NNN as a new WHO NTD Roadmap is launched. The 2021-2030 roadmap will be a key guiding document for the global response to NTDs over the next decade in alignment with the Sustainable Development Goals. Additionally, 2020 brings a new WHO WASH and NTD strategy that will inform continued cross-sectoral collaboration between WASH, health and other sectors.

It is a great privilege to assume the role of NNN Chair. The NNN has established itself as the global forum for NGOs to contribute to the global control and elimination of NTDs and I am honoured to contribute to the continued work to enhance our community of practice through membership engagement, learning and sharing knowledge so that the NNN remains a unified NGO voice on common issues to achieve NTD goals.

A handwritten signature in blue ink, appearing to be 'Yaobi Zhang', on a light blue background.

**Dr. Yaobi Zhang, NNN Chair 2019/2020**

Senior Scientific Advisor, Neglected Tropical Diseases  
Helen Keller International

# NNN 2019 communiqué

## Our vision beyond 2020: many partners, one voice

### A decade of partnership

Ten years ago, the Neglected Tropical Disease NGO Network (NNN) was established to enhance the contribution of NGOs towards a vision of a world free of neglected tropical diseases. The NNN is a dynamic and diverse network bringing together over 80 NGO members worldwide to speak with a unified NGO voice. The network has grown into an established forum for collaboration, developing a community of practice and partnerships to overcome barriers to beating NTDs.

Over the last decade, NNN members have worked together to make significant contributions to global progress on combating NTDs. The NNN successfully championed the inclusion of an indicator on NTDs in the SDG framework. In 2016 the NNN launched its BEST (Behaviour, Environment, Social inclusion, Treatment & Care) framework, which sets out the NTD community's commitment to forging new partnerships and working across sectors to ensure equity and inclusion in efforts needed to reach control, elimination, and eradication targets for NTDs. In 2019, the NNN's WASH working group partnered with the World Health Organization to publish a collaboration toolkit, [WASH and health working together: A 'how-to' guide for Neglected Tropical Disease Programmes](#). It provides NTD programme managers and partners with practical guidance to build and deliver multi-sectoral partnerships and action.

### 2020: Year of action on NTDs

2020 is a defining year for the next, bolder phase of efforts to combat NTDs. During the opening plenary session, Dr. Mwele Malecela, WHO NTD Director stated "I was asked to speak today about WHO's vision post-2020...but my main aim today is to talk of our shared vision. We would not be where we are today and would not have made the significant progress we have without the spirit of collaboration which I believe defines our NTD community." In 2020, NNN members will champion a new ambitious WHO NTD Roadmap 2021 - 2030, underpinned by cross-cutting approaches.

### Our commitment

This year the NNN launched two statements on sustainability and our commitment to safety, highlighting its alignment with the global health and development agenda. In the year ahead, the NNN community commits to expanding and strengthening existing and new partnerships between NTDs and across sectors inclusive of WASH, disability, education, one health and humanitarian aid. Through cross-cutting approaches codified through the BEST framework, we will contribute to strengthening health systems, ensure the sustainability of control and elimination efforts and amplify the voices of people affected by NTDs and those working on the front lines.



# NNN Statement of Commitment to Safety

## Background

Global health programs have a dual obligation to provide benefits to populations and to minimize harm to individuals. During the past 15 years, neglected tropical disease (NTD) control and elimination programs have delivered health and social benefits to hundreds of millions of people around the world. More than one billion people are treated through mass drug administration (MDA) for at least one NTD every year. Millions more experience improved health through clinical care, surgery, and health education messaging on NTD prevention.

As with all health interventions, however, unintended harm and error in delivery sometimes occur. For example, during MDA, incorrect administration of tablets to young children has resulted in fatal choking, and persons with *Loa loa* infection have developed encephalopathy and coma when receiving ivermectin for onchocerciasis elimination.

In general, though, NTD interventions have a high degree of safety, by which we mean protection from injury or harm. NTD programs have been implemented with a strong emphasis on safety, for example, to minimize adverse drug reactions. At times this emphasis has been explicit, and at times implicit.

As NTD programs mature, scale up to full capacity at the global level, and become more fully integrated into national health systems, it is appropriate for the NTD community to recommit itself with even greater vigilance to safety, minimizing harm, and safeguarding health; and to align with World Health Assembly Resolution 72.6 Global Action on Patient Safety adopted in May 2019. Attention to safety is particularly timely as we approach the release of the WHO 2030 NTD Roadmap.



## Our Commitment

We care about the women, men and children living with neglected tropical diseases. To achieve a world free of NTDs, on World Patient Safety Day 2019, the NNN community commits to:

## The BEST approach to safety and safeguarding health



### Behaviour

Promoting risk-reducing behaviours, NTD programs can be further strengthened by understanding the cultural context and community attitudes towards health and safety; by rapid reporting, prompt investigation, and



- **Safety first in scale up.** Our commitment to safeguarding the communities we serve includes a priority to do no harm while scaling up services to reach those in need.
- **Shared learning and evidence-based planning.** Sharing our experiences of promoting safety and embedding cross-sectoral approaches and systems thinking to inform the development of integrated work plans and preferred programming practices.
- **Continuous improvement to strengthen health systems.** Monitoring and measuring safety risks, collecting and analysing safety data, and conducting operational research to strengthen practice and take remedial action.
- **Messaging the importance of safety.** Reviewing key messaging and reinforcing the rights of individuals to consent to treatment.
- **Empowering community health workers.** Providing frontline staff with the skills they need to identify health and safety risks and manage challenging situations.
- **The bigger picture.** Understanding how safety planning incorporates principles from the field of medical errors and local cultural norms.

## Our Call to Action

As many partners with one voice, we call on NTD stakeholders to emphasize safety in their 2030 work plans and ongoing activities.

- For WHO: Highlight the importance of safety for NTD programs in the 2030 NTD Roadmap
- For member states: Monitor for programmatic safety; establish or enhance safety processes/protocols, including reporting and response; collect and routinely analyse safety data for continuous improvement
- For implementing partners: Include safety in training modules and microplanning
- For NTD donors: Support efforts to maintain and improve safety.

timely analysis of serious adverse events; by revising guidelines to prioritise safety; and by ensuring safety in program design and microplanning and training activities.



## Environment

Incorporating a robust understanding of the physical, biological, and social environments in which NTD interventions are delivered – whether MDA, surgery, or clinical care – can have a marked effect on patient safety and infection control, and on the uptake of facility-based treatment and care. NTD safety depends on improved Water, Sanitation and Hygiene (WASH) in healthcare facilities and communities.



## Social Inclusion

Participation in NTD interventions is limited by stigma, social exclusion, and other barriers. Empowering and safeguarding the psychological and social health of vulnerable community members and ensuring the safety of persons with disabilities is essential for achieving NTD program coverage.



## Treatment and care

Achieving progress towards Universal Health Coverage (UHC) means strengthening health and other systems so they are equipped to deliver comprehensive large-scale treatment interventions safely, and in response to the needs of individuals and communities. Access to WASH in health facilities is crucial to safeguard health against microbial threats. The broad spectrum of NTD interventions – ranging from MDA to surgery, to medical and clinical care, as well as public health measures, including strong NTD-WASH partnerships – positions NTD programs to play a lead role in ensuring safety and safeguarding health within UHC.

-- **BEST** evidence -- **BEST** access to treatment and care -- **BEST** outcomes for the individuals we support and the communities we serve --

# NNN statement on sustainability



## Background: Need and Purpose

Over the last several years, the global fight against neglected tropical diseases (NTD) has seen immense progress towards important shared goals. While much of this has been driven by productive country- and disease-specific partnerships, there is now an increasing need to focus on our longer-term collective impact to advance critical objectives such as *sustainability*.

To date partners have not had a shared definition of sustainability, resulting in disparate ideas about what the concept means and how it should be operationalised to achieve a world free of NTDs.

Developed following extensive consultations by the NNN Sustainable Systems Working Group, this statement provides the NNN community with a starting point to speak the same language about sustainability, to articulate potential differences in opinions or approaches, and to identify ways we will work together to promote sustainable elimination and control of NTDs.

This is a working definition of *sustainability*, which will evolve as we continue to refine and realign with learnings and evidence generated through programme implementation in endemic countries.

## Working definition of Sustainability

Sustainability, for NTD programming, is realised when the intended result is achieved for as long as required. Sustainability is not a binary achievement that either exists or doesn't; rather, it is a spectrum comprised of multiple context-specific factors.

A central theme of sustainability is a national government's long-term commitment to a goal or result with **multi-level, local ownership**<sup>1</sup>. Sustainability and ownership are further characterised by the three components of **domestic commitment, resource mobilisation, and accountability**. The three components are closely linked and may not always be completely independent of one another.

1. *Domestic commitment* to NTD programming is multifaceted: it requires high-level political will and dynamic leadership at national, regional, and sub-regional levels. An effective, impactful programme will ideally be driven by community demand for continued services and may have shared goals with health systems strengthening<sup>2</sup> and universal health coverage efforts (i.e., those Sustainable Development Goal 3)<sup>3,4</sup>.
2. *Responsive resource mobilisation* means that countries are engaged in determining and mobilising the inputs required to reach their NTD goals and are taking initiative to quantify and fill the resource gaps. Sustainable resourcing involves leveraging domestic investments alongside partner contributions<sup>5</sup>, as local ownership tends to be limited when a programme is financially dependent on external sources.
3. *Accountability* is outcome-oriented, coupled with task-oriented responsibility to deliver high-quality results.

The NNN Executive Committee endorsed this Sustainability statement on September 18<sup>th</sup>, 2019.

Professor Gail Davey, NNN Chair (2018-2019)

## References

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## BACKGROUND NOTES

### 1. Proposed use of this sustainability statement

The statement serves as a shared, working definition of sustainability. It is not perfect or static, and should continue to evolve over time along with the dynamic NTD landscape; for instance, working group and NNN community members may review the statement in concurrence with the periodic milestone timelines of the upcoming WHO NTD Roadmap (i.e., 2023, 2025, 2030). NNN members are encouraged to use the scope of this practical working definition during strategic planning discussions, partnership development or operational work planning meetings to foster a shared approach and embed the key components of sustainability. To accompany this working definition, the Ensuring Sustainable Systems Cross Cutting Group plans to collate and/or develop complementary tools and resources to support partner contributions to sustainable NTD programmes. For any feedback to these plans or to offer support to the cross cutting group, please find contact information on the NNN website.

### 2. Developing this sustainability statement

The NNN Ensuring Sustainable Systems cross cutting group has undertaken the following activities to develop this statement for NNN endorsement:

- Between July and September 2018, the working group surveyed over 50 NNN affiliates (NGOs, academia, government, WHO) about the most important components of sustainability and what the term and concept mean to them.
- At the NNN conference in Addis Ababa, Ethiopia in September 2018, the working group reviewed a qualitative / thematic analysis of the survey findings and developed more specific and focused definitions of the most commonly emerging key concepts.
- Following the NNN conference, a smaller team of working group members drafted the first version of the statement, which was reviewed by the full group prior to circulation to a wider audience of NGOs, government officials and academia for iterative development.
- The working group coordinated their work with WHO and disease coalitions with similar sustainability focused discussions to ensure efforts would be aligned and not duplicative.
- A final draft of the working definition and context for sustainability was agreed by the working group for circulation to 18 reviewers from the WHO and national NTD programmes in different regions in March 2019; reviewers were nominated by working group members and their feedback was discussed and incorporated to the statement during a regular working group call.
- In June 2019, the NNN Executive Committee reviewed the draft statement and agreed to endorse it as an NNN working definition, recognising alignment with its other collaborative efforts towards a world free of NTDs

# Who's who in the NNN

## 2019/2020 Steering Committee

The Steering Committee is the NNN's leadership team.

Chair: Yaobi Zhang (Helen Keller International)

Vice Chair: Kisito Ogooussan (FHI360)

Immediate Past Chair: Professor Gail Davey  
(Footwork/ Brighton & Sussex Medical School)

NNN administrative support:

Clare Callow (Brighton & Sussex Medical School)

Cleo Stern (Helen Keller International)

## Executive Committee

NNN is governed by the Executive Committee. The Executive Committee oversees the management of the network and ensures it is meeting its objectives in line with its terms of reference. The Executive Committee is composed of the Steering Committee, representatives from disease-specific groups and cross-cutting groups.

## Disease - Specific Groups

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

### International Coalition for Trachoma Control (ICTC)

Chair: Scott McPherson (RTI International)

### Leprosy NGO Group

Chair: Geoff Warne (ILEP)

### Lymphatic Filariasis (LF) NGO Network

Chair: Paul Watson (Lepra)

### Onchocerciasis Elimination NGO Group

Chair: Charles Mackenzie (Sightsavers)

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

Chair: Mike French (RTI International)

## Cross-Cutting Groups (CCG)

CCGs focus on issues of common concern to the NTD community at large. They have an action-orientated approach and work together to identify challenges, develop solutions, advocate/socialise them widely.

### Conflict and Humanitarian Emergencies

Co-Chair: Angelia Sanders (The Carter Center)

### Disease Management, Disability and Inclusion (DMDI)

Chair: Wim van Brakel (Netherlands Leprosy Relief)

### Ensuring Sustainable Systems

Co-Chair: Aparna Barua Adams (ICTC)

Co-Chair: Girija Sankar (Children Without Worms)

### One Health

Chair: Wendy Harrison (SCI Foundation)

### Skin-related NTDs

Chairs: Claire Fuller (International Federation for Dermatology); Michele Murdoch (West Hertfordshire Hospital); Rie Yotsu (Nagasaki University)

### Water Sanitation and Hygiene

Co-Chair: Yael Velleman (SCI Foundation)

Co-Chair: Leah Wohlegemuth (Sightsavers)

## 2020 Task Groups

Task Groups work on specific time-limited tasks which are not primarily addressed by CCGs.

### External Representation

Co-Chair: Virginia Sarah (The Fred Hollows Foundation)

Co-Chair: Helen Hamilton (WaterAid)

### Communications

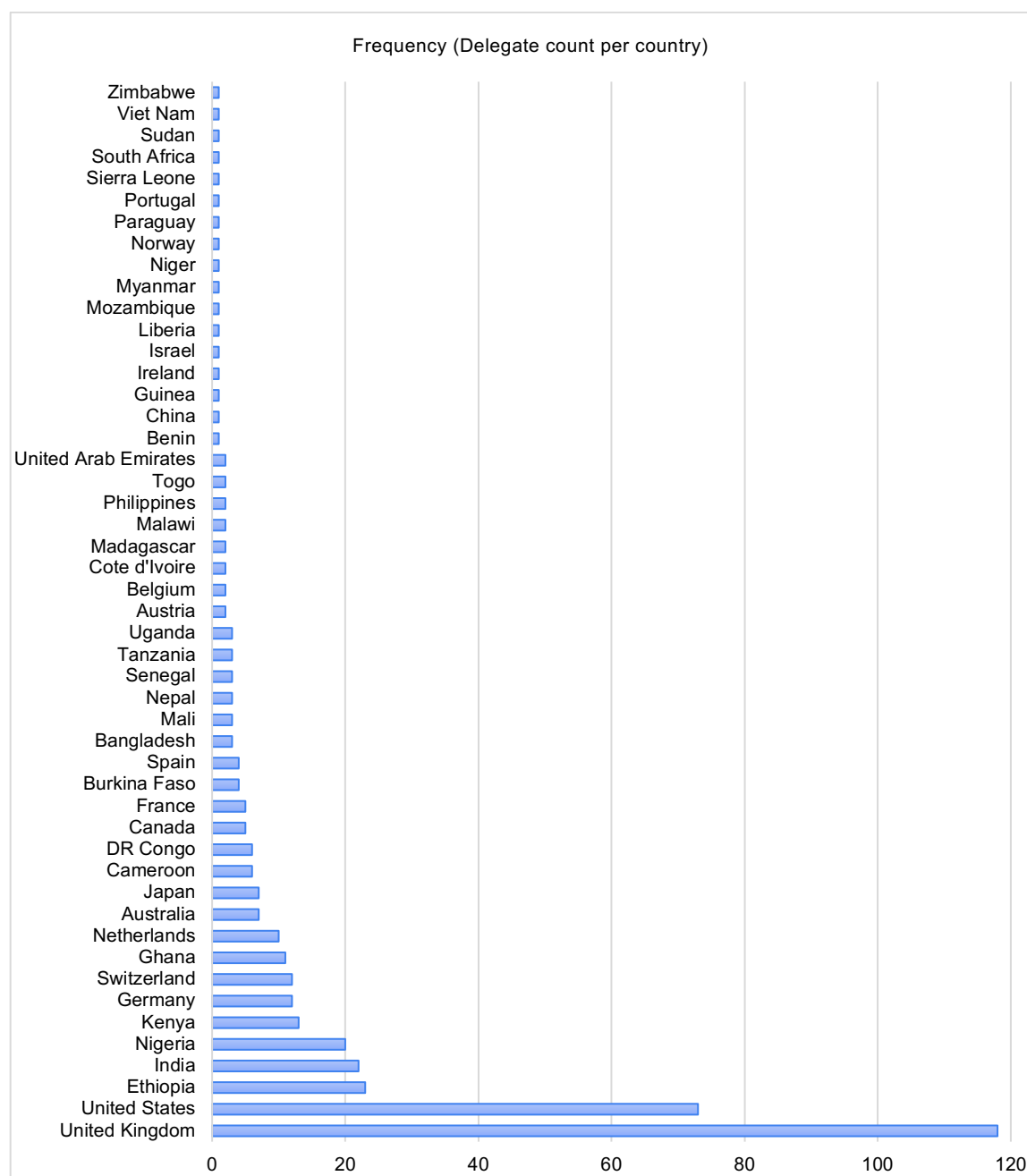
Co-Chair: Kelly Bridges (Global Water 2020)

Co-Chair: Tim Jesudason (ICTC)

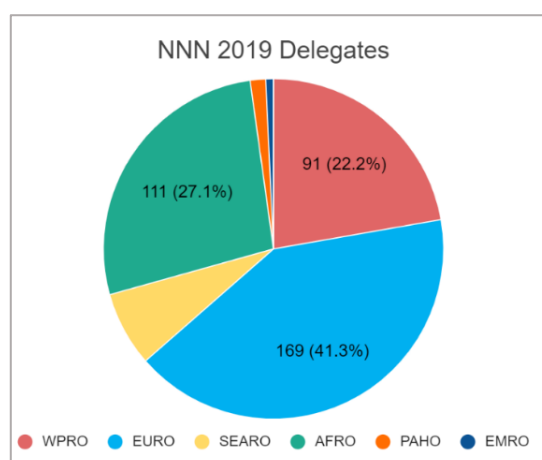
## 2019 conference in numbers

### NNN Attendees by Country

A total of 409 delegates attended the 2019 NNN conference in Liverpool, UK, from 49 countries across all six WHO regions. With the conference hosted in the UK many delegates came from the UK itself (118) accounting for just over 28% of all delegates, followed by attendees from the USA (73) and Ethiopia (23). Among NTD endemic countries, Ethiopia had the highest number of attendees, followed by India (22) and Nigeria (20).

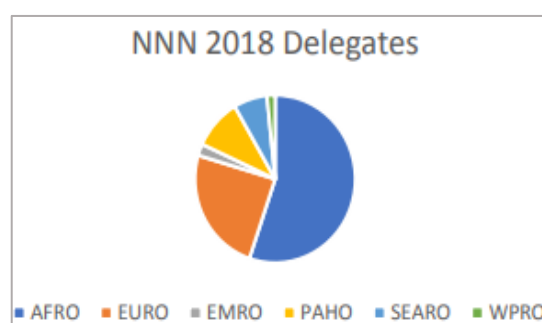


## NNN Attendees by WHO Region



The 2019 annual conference received delegates from all WHO regions. The majority of delegates were from the EURO region accounting for 41% of all delegates overall, followed by attendees from the AFRO region at 27% and WPRO at 22% having the highest representation. The high representation of conference participants from the EURO region coincides with the annual conference taking place in the UK and the ease of travel for attendees in the region.

A similar trend was observed during the 2018 annual conference in Ethiopia, where over 55% of conference attendees came from the AFRO region and almost a quarter from the EURO region.



Data from 2019 and 2018 indicates that conference location plays a role in the proportions and accessibility of the annual conference to delegates from different regions. With this in mind, the NNN Executive Committee put out a call to members in late 2019 to share ideas on future conference locations. The NNN looks forward to its first annual conference in the SEARO region in 2020, which will take place 8 – 10 September 2020 in Kathmandu, Nepal.

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

	2019 (UK)	2018 (Ethiopia)	2017 (Senegal)
Total expenditure*	£111,248.03	£73,932.96	£97,012.74
Total income – sponsors + PayPal donations + registration fees	£131,423.58	£64,494.90 (sponsors only)	
Rolled over from previous year NNN conference	£5,461.12	£14,899.18	

\*Includes conference centre including lunch and tea breaks, banners, posters, the App; and professional conference organisers' time.

In 2019 for the first time, the NNN implemented a tiered registration fee for conference attendees to support the overall costs associated with the annual conference. The NNN generated £49,344.90 from registration fees and £75,696.23 from sponsors. The significant growth of the NNN in membership over recent years has resulted in a much larger conference compared to those in the early years of the NNN and the 2019 registration fees have ensured the conference is able to grow and be inclusive of the wide range of stakeholders that attend. The NNN is enormously grateful to the 11 organisations that supported NNN 2019 through hosting support, financing and travel awards, highlighted at the end of this report.

## 2019 NNN conference photos

All photos of the 2019 conference can be found [here](#). These photos are available for all members to use freely. Please credit all photos as NNN/Patrick Bannon.



## NNN 2019 conference – national host



## Platinum sponsors



## Other sponsors

### Gold sponsor:



### Silver sponsors:



### Bronze sponsors:





2019 NNN conference, Liverpool, UK

### **Acknowledgements:**

The 2019 NNN conference report was prepared by Aparna Barua Adams, Tim Jesudason and Jessica Rodgers. Thanks goes to the Maximise Your Time for their assistance in bringing together digital posters for the conference report and support in organising the conference logistics. Thanks is also shared with all members part of the 2019 NNN Conference Committee in shaping the 2019 annual conference, agenda, plenaries and workshops. The NNN would also like to recognise the Royal Society of Tropical Medicine and Hygiene for serving as national host for the 2019 annual conference in the UK, and to all conference sponsors for their support. Finally thank you to all the workshop leads, guest speakers and attendees for their active participation to inform ongoing dialogue on ending neglected tropical diseases.