

NNN Conference report

Virtual conference 2020



Sightsavers/Graeme Robertson



Task Force for Global Health/Billy Weeks



RTI International/Nabin Baral



HANDA



International Trachoma Initiative/Brent Stirton



SCI Foundation



**NEGLECTED TROPICAL DISEASE
NGO NETWORK**

A global forum for nongovernmental organizations
working together on NTDs

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Welcome from the Outgoing Chair, Dr. Yaobi Zhang

It has been an honour to lead the NTD NGO Network (NNN) as Chair 2019-2020. When I became Chair in 2019, I could not have imagined how quickly the world would change as a result of COVID-19 and that the 11th annual NNN conference would be held virtually to comply with important social distancing public health measures. Despite the challenges posed by COVID-19, it has been reassuring to see the NTD community adapt and participate in an engaging and motivating three-day virtual conference.

The virtual platform used for the 2020 conference provided several benefits. It enabled greater access existing partners to participate across time zones, in addition to inviting new stakeholders from across sectors to join in critical discussions. This is evidenced by the conference receiving over one thousand registered participants from more than 300 organisations across over 80 countries, representing NGOs, donor agencies, health ministries, academia, research and individuals, including people affected by NTDs.



Dr. Yaobi Zhang, NNN Chair 2019/2020

The conference boasted an exciting and interactive agenda which facilitated discussions on ways to support the drive towards improved impact, cross-sectoral partnership and enhanced country ownership – pillars of the upcoming World Health Organization 2021-2030 road map for NTDs. The conference also featured a high-level panel discussion with notable speakers including Dr Mwele Malecela, Margarita Focas Licht, Kelly Saldana, Githinji Gitahi, Paula Brandão, and Alice Cruz. The panellists highlighted the challenges ahead in reaching the NTD targets, not only in making the shifts needed to create sustainable and resilient health systems, but also in managing resources both human and financial, and in driving inclusivity with affected communities.

This year, the NNN hosted its second NTD Innovation Prize, with support from American Leprosy Missions. The first prize of \$20,000 went to Hugues Nana Djeunga and M. Arnauld Efon Ekangouo to explore the potential of cell-free DNA as a biomarker to diagnose onchocerciasis. The second prize of \$15,000 was awarded to Deanna Hagge, Suwash Baral, Arie de Kruijff and Janis Spigulis to create and test a spectral imaging diagnosis process as a way to identify leprosy lesions.

NNN 2020 provided an opportunity to highlight several important new resources for the NTD community, including the ILEP/NNN Guides on Stigma and Mental Wellbeing and an NNN Resource Guide for Conflict and Humanitarian Emergencies. It was also an opportunity to launch the NNN statement of commitment to the participation of people affected by NTDs.

Despite the challenges associated with COVID-19, the 2020 NNN conference has left me confident that that we can achieve sustained progress for NTDs, while strengthening the resilience of health systems to overcome any global health crisis. The upcoming WHO road map for NTDs will provide an important blueprint to achieve our shared vision, through innovative and cross-sectoral partnerships.

As I pass the torch on to our new Chair, Kisito Ogoussan, FHI 360, I thank all NNN members for their commitment to and knowledge exchange and creating a unified NGO voice and a community of practice on challenges and solutions to reach the global NTD goals.

Dr. Yaobi Zhang, NNN Chair 2019/2020

Senior Scientific Advisor, Neglected Tropical Diseases
Helen Keller International

A handwritten signature in blue ink, appearing to read 'Yaobi Zhang', written in a cursive style.

Workshop summaries



The Carter Center/Catalin Marin



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8-10 September 2020

1.1 Collective action in the face of COVID-19

Abstract

The devastating impact of COVID-19 has transcended international borders and sectors and has severely impacted universal coverage against neglected tropical diseases. In the face of this unprecedented global challenge come opportunities to leverage NTD platforms, harness the collective reach of the NTD community and support country preparedness and response.

This is not about suspending national NTD programmes but acting responsibly to prioritise the public health needs of endemic countries. This includes assessing where opportunities to flex support exist, where appropriate and feasible, and enhancing coordinated approaches to international humanitarian responses, particularly in the area of social behaviour change communication.

We need to examine mechanisms for flexing NTD control as a critical element of our response to disease outbreaks/global pandemics. These efforts represent fundamental humanitarian assistance, which is consistent with 2030 Roadmap's emphasis on equity and inclusion.

Focus on the
BEST Framework:

B

Contact Information

Lead

Becks Hill, Sightsavers

Co-Lead

Leah Wohlgemuth,
Sightsavers

Workshop Lead

Heather Burgess,
Sightsavers

Moderator

Geordie Woods, Sightsavers

Rapporteur

Ioasia Radvan, Sightsavers

Speakers

Andy Wright, M&C Saatchi

David Agyemang,
Sightsavers

Dr. Joy Shu'aibu,
Sightsavers

Main learning point:

COVID-19 offers the opportunity for us to change, an opportunity to reframe our approach to NTDs. We have opened doors and we can improve our impact as we resume activities—this has to be one of our key lessons learnt and a positive outcome of our responses.

Next steps – summary:

Taking lessons learnt from our COVID-19 responses to implement effective mass media campaigns. For example, through working with M&C Saatchi, we have utilised their broad network of advertising and media agencies in this way. There is a need for NTD programmes to look beyond traditional fliers and posters for behaviour change activities that reach people impactfully and at scale.



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1.2 Mainstreaming GESI into health system strengthening for NTDs: case studies in Nepal, Tanzania and Uganda

Abstract

Gender dynamics, norms, and behaviours are underlying drivers of inequality. Gender and social issues impact NTD programming as well as morbidity and mortality rates for the men and women affected by these diseases. The intersectionality of vulnerability further disadvantages some populations and influences access to treatment. Poverty, profession, location, sex, and age affect NTD programme outcomes, hence these and other socio-demographic factors should be considered when designing and implementing NTD programmes. This workshop enhanced understanding on how gender equity and social inclusion (GESI) integration in the health systems could accelerate individual country NTD elimination goals in alignment with the new WHO 2030 NTD roadmap. Gender analysis research in Tanzania found that Tanzanian men are less likely than women to be reached by MDA because they are less likely to be home during the day and in the evening due to business, fishing, farming and leisure activities such as watching football or visiting bars. In Uganda, women and children may not be able to access health services as a result of distant health facilities; they are also more vulnerable to poverty and social exclusion. Men face greater barriers to treatment due to distrust of preventive treatment and medications and their likelihood of being away from home during MDA. However, alcohol consumption was the most cited reason why men do not take preventive chemotherapy. Nepal has made significant efforts to develop and enforce laws and policies that reduce the cultural and historical barriers to inclusion embedded in its social fabric. Still, lack of participation from specific ethnic and religious communities hinders progress toward LF elimination goals in Nepal. The Government of Nepal has started to record and will eventually report service statistics disaggregated by caste, ethnicity, and gender.

Focus on the
BEST Framework:

S

Contact Information

Dr. Taroub Harb
Faramand, WI-HER

Teshale Yadeta, Act |
East Ethiopia

Mike B. Mukirane, Act |
East Uganda

Wemaeli Anderson
Mweteneni, Act | East
Tanzania

Dharmpal Prasad Raman,
Act | East Nepal

Paula Majumdar, WI-
HER, Act | East USAID's
Act to End Neglected
Tropical Diseases | East
Program

Main learning point:

To reach the last mile, we must ensure that the most vulnerable and marginalised populations have equitable access to NTD services by shifting gender, social, and cultural norms that influence and further contribute to vulnerability to NTDs.

Next steps – summary:

In order to have a sustainable impact on MDA programmes and overall elimination and control of NTDs, GESI must be integrated and institutionalised at all levels of the health system, from national to district levels.



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1.3 Building on the evidence base for addressing the mental health burden of NTDs: programmatic examples of integrated care

Abstract

Persons with NTDs experience a disproportionate burden of mental health concerns due, in part, to physical disability, stigma, and discrimination. It is well documented that mental health disorders can lead to reduced access to treatment seeking and adherence. The relationship between mental health and NTDs is growing increasingly clear, but interventions that take an integrated approach are still far and few between.

The workshop illustrated the importance of addressing mental wellbeing and NTD prevention and management together. It promoted the NNN Conference's 2020 theme, "Accelerating to 2030: Building Resilient NTD Programs in a Changing World," and the new WHO 2030 NTD roadmap's emphasis on the need for cross-cutting approaches, including mental health care, social support structures, and stigma reduction.

The session showcased different project approaches to assessing or addressing mental health and psychosocial wellbeing using existing NTD care structures. These include embedding mental health screening and interventions in social support clubs, or "Hope Clubs," for persons with lymphatic filariasis and sharing ongoing work in Ethiopia that aims to demonstrate the importance of mental health considerations for persons with trachomatous trichiasis. The discussion focused on possible entry points for incorporating mental health in the NTD agenda, weaving compassion into that process, and strengthening the evidence base.

Focus on the
BEST Framework:

B,S,T

Contact Information

Lead: Sadie Bazur-Leidy,
MPH, The Carter Center

Rapporteur: Mary Ottley,
The Carter Center

Speakers: Esmael Ali, PhD,
London School of Hygiene
and Tropical Medicine
John Umaru, The Carter
Center

Luccene Desir, MD, The
Carter Center

Martha Desir, Lymphatic
Filariasis Clinical and
Reference Center

Kelly Callahan, MPH, The
Carter Center

Gregory Noland, PhD, MPH,
The Carter Center

Eve Byrd, DNP, MPH, The
Carter Center

David Addiss, MD, MPH,
Task Force for Global

Main learning point:

There is a unique need to integrate people-centred mental health interventions into NTD care. If we work towards mitigating mental health issues linked with preventable diseases, compassion will grow, and suffering will lessen.

Next steps – summary:

- Continue integration of mental health into other health priorities.
- Continue to take action and measure and demonstrate impact of interventions.
- Appeal to new donors through incorporation of psychosocial aspects.



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1.4 Applying gender equality and inclusion in NTD interventions to achieve equitable health

Abstract

The WHO 2030 NTD roadmap encourages the NTD community to intensify cross-cutting approaches and work across sectors beyond health, while also strengthening national health systems and mainstreaming NTD interventions into these health systems to achieve NTD goals and the SDGs, including universal health coverage and gender equality. Ministries of health and NGOs need to consider gender differences in their responses to NTDs and make interventions more equitable by looking at health services through a gender lens.

This workshop shared examples from Every Child Thrives, a deworming and nutrition project for preschool children that contributed to the integration and mainstreaming of gender equality and inclusion into health services. Discussion of key achievements, lessons and challenges encountered enriched the understanding of gender equality, its importance in NTD interventions, and how gender equality integration and mainstreaming can be applied in NTD programs to promote equitable access to health services for all girls, boys, women and men.

Focus on the
BEST Framework:

S

Contact Information

Co-leads

Sara Marshall, effect:hope

Dr. Julien Ake, Coptiment

Speakers

Karen Craggs-Milne,
Conscious Equality Inc.
(www.KarenCraggs.com)

Dr. Oka Kouamé, Director
of National Nutrition

Programme, Côte d'Ivoire
Joseph Anyango, Public
Health Professional

Main learning point:

- Gender-based analysis is critical for identifying barriers to gender equality and equity.
- Multi-sectoral partnership with gender and disability groups improves gender mainstreaming.
- Strong community engagement is needed to address cultural and structural barriers to equity.

Next steps – summary:

- Consider barriers specific to women and men and tailor program approaches to community contexts.
- Engage both women and men strategically in addressing causes of inequalities.
- Improve evidence on effective approaches for achieving sustainable gender transformation.



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1.5 Strengthening the connection between research and programming to beat NTDs

Abstract

This workshop shared recent advances in scientific research for NTD control by LCNTDR member institutions and their collaborators. It highlighted the wide range of work being undertaken by the LCNTDR towards achieving the Sustainable Development Goals as well as supporting the objectives in the WHO NTD Road Map.

New research from the forthcoming LCNTDR Collection in *Parasites & Vectors* was presented, followed by discussions about the implications of the research towards WHO Road Map targets, how research can be used by implementing partners to strengthen health systems, and what further research is required to achieve shared goals.

The session featured the following short presentations:

- Can deworming at pre-natal clinics prevent morbidity from infections with soil-transmitted helminths in women of reproductive age? (Dr Carolin Vegvari)
- Evaluating the impact of biannual school-based and community-wide treatment on urogenital schistosomiasis in Niger (Dr Anna Phillips)
- What tools are needed for schistosomiasis transmission monitoring as we move towards elimination? (Dr Bonnie Webster)
- Patient pathways and barriers to treatment for kala-azar: findings from cross-sectional surveys and in-depth interviews in Bangladesh, India, Ethiopia and Sudan (Lucy Paintain)

Focus on the
BEST Framework:

B

Contact Information Organisers

Professor Sir Roy
Anderson and
Justine Marshall,
London Centre for NTD
Research (LCNTDR)
(info@londonntd.org)

Rapporteur

Lucy Paintain, London
School of Hygiene &
Tropical Medicine

Speakers

Dr. Carolin Vegvari,
Imperial College London

Dr. Anna Phillips, Imperial
College London

Dr. Bonnie Webster,
Natural History Museum,
London

Main learning point:

- To maximise relevance and uptake, research should be driven by country priorities.
- The use of standardised study designs and reporting based on stakeholder consensus would facilitate evidence synthesis across countries.

Next steps – summary:

- **Coordination:** WHO to coordinate the development of standardised, transparent and accessible data for national and international needs, including identification of research gaps.
- **Integration:** As we move towards elimination, research on how to integrate NTDs into health systems is going to become ever more important to promptly diagnose and manage the smaller number of cases.



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2.1 Adopting the WHO framework on sustainability relating to NTD programmes - what does it mean for implementers and health ministries?

Abstract

This workshop facilitated a deeper understanding of the *WHO Sustainability Framework for Action*, launching early 2021, with the broader NNN community and provided an opportunity to work through the adoption of the framework and significance for NTD programmes, cross sectoral collaborations and expanded partnerships to deliver on sustainable impacts of NTD programmes.

Workshop included:

- Presentation by WHO on the draft WHO Sustainability Framework for Action
- Reflections on the complimentary 2019 [NNN sustainability statement](#)
- Panel discussion including health ministry, WHO, NGO and donor representatives on considerations for the contribution of sectors to support a sustainability agenda for the benefit of achieving goals of the new road map and beyond.
- Group exercise to share ideas on measurables for sustainability

Focus on the
BEST Framework:

ALL

Contact Information

Co-leads

Carolyn Henry, SCI
Foundation

Aparna Barua Adams,
International Coalition for
Trachoma Control

Speakers

Fikre Seife, FMOH Ethiopia
Gautam Biswas, WHO

Karen Palacio, The END
Fund

Richard Killian, RTI
International

Main learning point:

Sustainability within NTD programming is a spectrum, and we are all at different points of understanding what this means and entails within NTD programmes at present. Having measurables, shared language and common understanding, and collective goals will support all stakeholders to move towards sustainable NTD interventions that ultimately support resilient and strengthened health systems and cross-sectoral public services that support good health.

Next steps – summary:

The NNN CCG on Sustainability will continue to support transparent community wide discussions and learning across key WHO resources and tools for the new roadmap. The CCG will take the points raised from this workshop forward through a deeper discussion to continue the process of creating principles and common understanding on measurables for sustainable programming in NTDs



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2.2 Making the most of evidence and learning in NTDs: defining a knowledge management approach for the NNN

Abstract

A focus on Knowledge Management (KM) has the potential to amplify influence and impact of the NNN network and contribute to achieving the goals set out in the *WHO 2030 NTD Roadmap*. An introduction to the NNN KM Task Team provided an overview of the importance of KM in enhancing cross-collaboration and promoting an NTD Learning Culture. Knowledge management can be defined in simple terms as “the process of capturing, distributing, and effectively using knowledge”.

Findings from a recently conducted survey has shown that over 50% of the NNN membership do not have dedicated resources for KM. Reliability of information sources was found to be critical, and trust in the organisation generating information was seen as more important than the channel providing it. The NNN is well positioned as a KM facilitator, however there are opportunities to strengthen its approach (especially with identifying funding opportunities and producing relevant guidance).

The Task team will support the NNN EXCo to understand the NNN's KM strengths and opportunities for improvement, generate a set of recommended actions for improving KM capability, and produce best practice briefings.

Focus on the
BEST Framework:

ALL

Contact Information Co-chairs

Amy Clark, Sightsavers

Sarity Dodson, The Fred
Hollows Foundation

Speakers

Laura Ulanowski, Sightsavers

Katie Fantaguzzi, SCI
Foundation

Roos Geutjus, NLR

Main learning point:

Knowledge management is not just about storing documents, but it a life cycle that involves various components - most importantly it is about ‘people’, and thinking about who holds NTD knowledge, and how it gets transferred and applied in a way that is inclusive and collaborative.

Next steps – summary:

- Collate inputs on planning the design, production & dissemination of WASH behaviour change guidance to share with NNN WASH WG
- Induct new members to KM Task team
- Update principles of knowledge management, review additional survey responses and continue to progress work of the Task Team.



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2.3 Enhancing national NTD programmes: approaches to empowering local teams

Abstract

The purpose of this workshop was to understand better the needs of endemic country NTD programmes as they move to implement and lead their health programmes. The session was divided into three major themes: (i) Programme infrastructure development, (ii) Personnel development, and (iii) Personal aspects of running NTD programmes. It explored pertinent questions such as, “What are the skills your teams need to be successful?” and “What are major stresses you face as a leader in your health programme?”.

The session was moderated by Charles Mackenzie (The END Fund/TFGH) and Daniel Boakye (The END Fund). Panellists included Adamou Salissou (Niger Ministry of Health), Massitan Dembele (Mali Ministry of Health), Makoy Yibi logora (South Sudan Ministry of Health), and Mamoun Homeida (Kartoum University of Medical Sciences and Technology), who provided thoughtful and thought-provoking commentary.

Focus on the
BEST Framework:

B

Contact Information

Charles Mackenzie, The
END Fund/TFGH
(cmackenzie@end.org)
Daniel Boakye, The END
Fund (dboakye@end.org)
Massitan Dembele, Mali
Ministry of Health
(masdembele1@gmail.com
)
Mamoun Homeida,
Khartoum University of
Medical Sciences and
Technology
(amst33@hotmail.com)
Makoy Yibi logora, South
Sudan Ministry of Health
(morrelogora@yahoo.com)
Adamou Salissou, Niger
Ministry of Health

Main learning point:

Enhancing national NTD programmes and empowering local teams necessitates significant investments in infrastructure (e.g., office space, communication, transportation) and personnel development (e.g., training in data collection and analysis, epidemiology, etc.). There should be greater recognition of the stress NTD programme management and implementation has on the lives of the individual team members.

Next steps – summary:

The END Fund is collaborating with panellists Massitan Dembele, Mamoun Homeida, Makoy Yibi logora, and Adamou Salissou to co-author an opinion piece identifying barriers to enhancing national NTD Programmes and recommendations for empowering local teams.



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2.4 Applying a quality improvement model to neglected tropical diseases programme implementation: supporting programs in identifying keys for sustaining operations

Abstract

The workshop presented two key issues that quality improvement can address for NTD programs: Low preventive chemotherapy coverage of at-risk populations at the sub-district level and poor disease-specific assessment quality. It included presentations on FHI 360's quality improvement (QI) model and two country examples: Sierra Leone's experience with planning for the use of the QI model and Ghana's experience with the results of using the QI model. The session covered how the QI model is used in improving healthcare services and performance, how countries are integrating the model into MDA and impact assessment, targeting specific steps in each for quality-enhancing changes, and testing and evaluating the changes.

After the presentations, session presenters and participants delved into the complexities of integrating QI into NTD programme campaigns, and discussed how NTD programmes can measure the effects of the changes they implement using the model and how researchers can test the validity and measure the added value of QI for NTD programmes.

Focus on the
BEST Framework: **ALL**

Contact Information

Lead

Dr. Kisito Ogoussan, FHI
360

Rapporteur

Kathy Sanchez, FHI 360

Speakers

Dr. Bruno Bouchet, FHI 360
(Moderator)

Dr. Ibrahim Kargbo-Labour,
NTD Program Manager,
Sierra Leone

Dr. Benjamin Marfo, NTD
Program Manager, Ghana

Main learning point:

Quality improvement can help NTD programs resolve persistent challenges including low MDA coverage and impact assessment failures by uncovering root causes and identifying and testing potential new solutions

Next steps – summary:

- NTD programs and partners should consider using QI to identify causes of persistent problems and test and evaluate innovative solutions. Solutions that have led to improvement should be institutionalised as best practices.
- Continue to use QI model to test new ideas of change



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3.1 Preferred practices of participation, inclusion and human rights of people affected by NTDs

Abstract

Persons affected by NTDs currently face a significant representational gap. It is well established that administrative and organisational levels of NGOs have striven to adequately represent the needs of people affected. This workshop aimed to show how such representations can be better targeted in order to increase the participation of people affected in its working strategies.

The recommendations of this workshop include i) building the capacity of health workers and persons affected, ii) building and developing the capacity of associations of persons affected by NTDs, and iii) including persons affected in decision making and not simply consultation. Further recommendations include applying basic elements of human rights and community based inclusive development, such as gender equity, empowerment and accessibility to the development of groups of persons affected by NTDs as well as people with disabilities.

The present situation of COVID-19 has left many development efforts at a disadvantage due to operations not being possible in the pandemic. Other methods of linking people and networking need to be found.

Focus on the
BEST Framework:

S

Contact Information Lead

Mathias Duck, ILEP

Moderator

Martin Kollmann, CBM

Rapporteur

Geoff Warne, ILEP

Speakers

Jenny Sanchez, Findechagas
Javier Sancho, Global Chagas
Disease Coalition
Gail Davey, Podo Network
Fikre Hailekiros, NaPan
Suresh Dhonge, TLM India
Trust
Alice Cruz, UN special
rapporteur

Main learning points:

- True participation and inclusion of persons affected intentionally involves them in the working strategies of NGOs that work with NTDs and people with disabilities. NGOs must support or enable persons affected by creating or reinforcing structures through which people can advocate for themselves.
- Participation is not consultation.

Next steps – summary:

- Build capacity of health workers (governments and NGOs) and persons affected.
- Build up organisations of persons affected.
- Include persons affected in the development of intentional strategies.



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3.2 People are neglected, not diseases

Abstract

Discrimination is often implicit rather than planned, either because it has been overlooked or it is embedded in existing socio-cultural structures. Ascend's leave no one behind (LNOB) group are making sure that those who are most vulnerable and disadvantaged, the poorest and those most excluded, including disabled people, will be prioritised, ensuring they benefit from prevention, diagnosis and treatment activities for NTDs. The group is ensuring that this is embedded throughout each part of Ascend's NTD activities including but not limited to health system strengthening, mass drug administration, morbidity management and disability prevention, water, sanitation and hygiene and behaviour change communications.

The workshop focused on: i) examining the operational and contextual challenges in LNOB in NTD programmes; ii) sharing examples from the three-year FCDO-funded Ascend West and Central Africa programme; iii) Identifying potential solutions to advance the LNOB approach and maintaining the prioritisation and fast-tracking of actions for the poorest and most marginalised people; iv) going beyond an anti-discrimination agenda.

Focus on the
BEST Framework:

B

Contact Information

Tracy Vaughan Gough,
Sightsavers

Dr. Carlos A Torres Vitolas,
SCI Foundation

Anita Gwom, Sightsavers

Dr. Peter Mpoma Mikobi,
Liverpool School of Tropical
Medicine

David Agyemang,
Sightsavers

Main learning points:

- Explicit and pro-active attempts are needed to ensure populations at risk of being left behind are included from the start of activities.
- Awareness of the importance of embedding LNOB approach in NTD programming to achieve elimination goals and contribute to SDGs needs to be improved.
- Knowledge of the successes and challenges in operationalising a LNOB approach in integrated NTD programming need to be shared.

Next steps – summary:

Going forward we need to identify champions, including people with disabilities and people receiving MDA for NTDs, to lead the LNOB work and consciously make efforts to implement LNOB principles in every aspect of the programming.



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3.3 Road to resilience: building sustainable public health capacity within national NTD programs

Abstract

The overall aim of the workshop was to share lessons learned from piloting a model for building epidemiological capacity at the national level for sustainable NTD programming. The Kenya NTD programme has worked with the Kenya national field epidemiology and laboratory training program (FELTP) to train field epidemiologists in NTD programme monitoring and evaluation. FELTP programmes typically train health officials over two years through placement in disease control departments for hands-on, experiential learning. With support from Children Without Worms (an NNN member) and several local and regional partners, the Kenya NTD Programme invested in the assignment of one FELTP field epidemiologist to work on NTD surveillance activities. An operational cascade training model was developed to build STH and SCH surveillance capacity. This model was officially piloted in 2019 with the community-wide survey of one county, with plans for two additional counties. Additionally, the NTD programme and Kenya FELTP programme developed an NTD training module to incorporate NTD-specific learning into the FELTP curriculum. In the initial stages of this project, the CWW team was actively involved in protocol development, training, planning, and survey implementation. As the in-country (Kenya FELTP) team gained more experience, they were able to lead the planning, implementation, and after-action reviews. Workshop participants heard detailed accounts highlighting gains in building national monitoring and evaluation capacity with regards to NTDs, which are widely applicable and highly relevant to the NNN community. Participants also discussed key considerations and potential barriers to replicating capacity building models for NTD monitoring and evaluation in different contexts.

Focus on the
BEST Framework: **ALL**

Contact Information Lead

Dr. Sultani Hadley
Matendechero, Division of
Vector Borne and Neglected
Tropical Diseases (DVBNTD),
Kenya MoH

Rapporteur

Girija Sankar, Children
Without Worms (CWW)

Speakers

Dr. Stephen Mwatha,
DVBNTD, Kenya MoH

Dr. Wyckliff Omondi,
DVBNTD, Kenya MoH

Dr. Denver Mariga, Kenya
FELTP Resident, DVBNTD,
Kenya MoH

Dr. Ben Masiira, AFENET

Cara Tupps, CWW

Main learning point:

By drawing on global, national and regional partners, this innovative epidemiological capacity building project in Kenya has paved the way for similar models to be replicated in other East African countries. Additionally, integrating NTD programmes into broader health systems necessitates integration of NTD data systems into national health systems, increased capacity building for health care workers, and building on existing health platforms for delivering NTDs.

Next steps – summary:

- Integrating and scaling up epidemiological capacity building for NTD surveillance requires increased capacity building for health care workers
- Integration of NTDs into broader health systems requires alignment of donor and partner priorities: opportunities exist within the 2030 NTD Roadmap and related dialogue across donors/partners.
- Integration of NTDs into broader health systems require careful consideration of data compatibility with existing national health data systems.



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3.4 Behaviour change programming for NTDs: new guidance and case studies

Abstract

The NNN WASH Working Group's Behaviour Change Task Team is developing guidance and practical tools to support NNN member organisations enhance the impact of their behaviour change programmes, and generate and use related evidence more effectively.

This interactive session provided participants with a first opportunity to engage with the new guidance, and provide critical input to shape its development going forward.

Focus on the
BEST Framework:

B

Contact Information Lead

Sarity Dodson, The Fred
Hollows Foundation

Rapporteur

Lauren Abrams, The Task
Force for Global Health

Speakers

Sarity Dodson, The Fred
Hollows Foundation

Geordie Woods, Sightsavers

Main learning point:

Taking into account the different audiences that will use this resource is key – languages it is translated into, terminology used, the format it is presented in, etc. must all consider how users will engage with the toolkit.

Next steps – summary:

- Responding to the suggestions and comments during the workshop, the toolkit content will be developed further over the coming months
- A communications and engagement plan for the toolkit will be developed and reviewed to ensure effectively strategies for reaching and engaging key audiences



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4.2 From evidence to practice and back again: transforming WASH and NTDs programming

Abstract

The purpose of this workshop was to understand how to translate the evidence behind the link between WASH and NTDs into practice and how to document practice to inform programming. Strategies for enhancing access to and use of available evidence, including strengths and limitations, were explored to help understand how to strengthen WASH programmes and their impact on NTDs.

WASH interventions are complex due to multiple disease transmission routes, contextual transmission risk, and multiple technological and behaviour change approaches. Evidence into practice, ideas and approaches were presented from Kenya, Uganda, and Vanuatu. Some key lessons were (1) importance of multisectoral data sharing, (2) promotion of evidence at all levels, (3) strong partnerships across sectors. WHO guidelines on sanitation and health have identified important gaps – although studies have assessed the impact of sanitation on health outcomes, evidence is sparse on which interventions are most appropriate for a given setting/disease.

Finally, opportunities for effective collaboration between NTD and WASH programmes and funders were discussed. Overall, the NNN is considered a useful platform for sharing templates, SOPs, toolkits, and publications with country examples. The NNN platform enables country programmes, researchers, and donors to access evidence in multiple languages.

Focus on the
BEST Framework: **ALL**

Contact Information

Leads

Yael Velleman, SCI
Foundation
Leah Wohlgemuth,
Sightsavers

Moderator

Helen Hamilton, WaterAid

Rapporteur

Anna Phillips, Imperial
College

Speakers

Jaki Adams-Barton, The
Fred Hollows Foundation
Gilbert Baayenda, MoH
Uganda
Sophie Boisson, WHO
Agnes Mbuki Kithinji, MoH
Kenya
Sarity Dodson, The Fred
Hollows Foundation

Main learning point:

Evidence plays a significant role in decision making for WASH NTD advocacy and resource allocation. A key limitation in current WASH NTD programming is the absence of a systematic approach to evidence generation and use in the programmatic context. The NNN has a key role in addressing this gap.

Next steps – summary:

The NNN WASH working group and WHO are developing an integrated NTD and WASH research and innovation agenda to:

- (1) Encourage coordination and prioritisation of research activities
- (2) Enable effective targeting of NTD/WASH investments
- (3) Identify critical gaps in investment



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4.3 Innovate to accelerate- how to apply innovative thinking and design innovative projects to accelerate progress against NTDs

Abstract

Innovation is critical to accelerate our progress, adapt to a changing world, build resilience and achieve our 2030 targets for NTDs.

Overall aim: This interactive workshop was designed to help participants increase the quality of their innovative designs.

Outcomes:

1. Gain deeper understanding of innovation and how it can advance goals to control/eliminate NTDs
2. Improve innovation thinking and design skills through breakout session activities using design thinking tools
3. Learn about funding opportunities and additional resources to enable innovation

Innovation practitioners and funders from American Leprosy Missions, Sightsavers, The END Fund and Accenture Development Program will highlight the need for innovation within the NTD space, and help participants increase the effectiveness of their innovation thinking and design with activities and resources.

Focus on the
BEST Framework:

ALL

Contact Information

Amy Clark, Sightsavers
(aclark@sightsavers.org)

Amberren Baig, Accenture
(ambereen.baig@accenture.com)

Claire Chaumont, The END
Fund
(cchaumont@endfund.org)

Melissa Edmiston,
American Leprosy Missions
(Medmiston@leprosy.org)

Main learning point:

Innovation is needed to achieve the targets of the 2030 WHO Roadmap. A number of tools and activities exist that can help foster innovation and design thinking.

Next steps – summary:

1. Participants apply design thinking activities in their own organizations
2. Workshop team sends additional resources and materials
3. Workshop team sends a survey for feedback on continued innovation discussions



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4.4 The end-to-end supply chain – working together towards a successful supply chain strategy to beat NTDs

Abstract

The end-to-end supply chain is the backbone of NTD programmes. This session sought to identify key strategies and best practices to improve the NTD supply chain and to working together NNN participants to make improvements that will cascade across the entire system.

For eight years, the NTD Supply Chain Forum (Forum) has promoted awareness of the end-to-end supply chain. While our primary focus is around the PC NTD supply chain, benefits can extend to other supply chains. In this session, knowledge was shared on the first-mile— ordering treatments for in-country delivery—and the last-mile— receipt of treatments by in-country medical stores and delivery for mass drug administrations. Available first-mile and last-mile tools were also shared.

The session aim was to expand understanding of the end-to-end supply chain across the NTD landscape. The NTD community needs basic knowledge of first-mile and last-mile supply chain processes to help promote improvements that will benefit the entire supply chain. This workshop built on the Forum's current knowledge base and engaged NNN participants to identify key strategies and best practices for the end-to-end supply chain. Building on this knowledge, we hope to promote supply chain improvements that can be shared throughout the NTD community.

Focus on the
BEST Framework:

B

Contact Information

Lead

Cassandra Holloway, Children
Without Worms, TFGH

Rapporteur

Ashley Souza,
NTD Support Center, TFGH

Speakers

Dr. Afework Hailemariam
TEKLE, WHO Dept. of NTD

Tijana Williams,
GlaxoSmithKline (GSK)

Modeste Tezembong,
WHO ESPEN | AFRO

Main learning point:

This session brought to the forefront that the last-mile NTD supply chain has many challenges whereas the first mile is better understood. Also, countries with strong supply chain practices welcome sharing their knowledge. The session lead will work with WHO to identify ways to share the best practices with the NTD supply chain community.

Next steps – summary:

- Review best practices shared during the session to include in an update report.
- Provide link for available tools of the first-mile (Now)
 - www.NTDdeliver.com/country - Tracks first-mile donated medicines (ALB, DEC, MEB, and PZQ)
 - The Zithromax® Shipment Tracker (www.trachoma.org/node/2281)
- Provide information for the last-mile tools as they become available.
 - SOP Toolkit for Supply Chain Management to be released in 2021.
 - Stock Management Tool (SMT) to be released in 2020/2021.



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4.5 Enhancing the NTD toolkit – practical approaches to addressing mental wellbeing and stigma

Abstract

Mental wellbeing and stigma are increasingly core considerations for NTD prevention and morbidity management, as evidenced by their integration into the WHO NTD Roadmap and increase in partnerships between the NTD and mental health communities. However, there is a dearth of available tools that effectively address mental wellbeing and stigma tied to NTDs. Filling this gap is a growing collection of approaches wherein diagnostic tools or interventions have been developed, adapted or utilised to respond to and alleviate the burden of debilitating and stigmatising NTDs.

In this session, panellists shared approaches that vary by NTD focus and country context, highlighting globally relevant tools and programmatic or research experiences from India, Haiti and Nigeria. By showcasing efforts for assessing and addressing mental wellbeing and stigma that have applicability to numerous diseases and contexts, the session flagged entry points and opportunities for cross-cutting approaches and collaborations within the NTD community as well as with broader health and sustainable development efforts. The activities showcased are newly researched and tested, bringing the most recent evidence, successes, and challenges to the forefront of the discussion.

Focus on the
BEST Framework: **B,S,T**

Contact Information

Lead

Dr Maya Semrau, Brighton
and Sussex Medical School,
UK

Co-Lead

Dr Wim van Brakel,
NLR International

Rapporteur

Dr Bahadir Celiktemur,
TLMEW

Speakers

Dr Ashok Agarwal, NLR
India

Samhita Kumar,
The Carter Center, USA

Dr Emeka Nwefoh,
CBM Nigeria

Dr Joydeepa Darlong and
Dr Rajeev Nathan, The
Leprosy Mission Trust India
Roos Geuties, InfoNTD

Main learning point:

In the absence of adequate tried-and-tested tools for the integration of mental wellbeing and stigma reduction into NTD prevention and morbidity management programmes, it is vital that an evidence base is developed through operational research embedded in NTD programmes.

Next steps – summary:

Facilitate and foster collaboration and dialogue across groups, organisations and programmes. As part of this, encourage further engagement with the NNN Disease Management, Disability and Inclusion (DMDI) Cross-Cutting Group.

Rapid fire session summaries



International Coalition for Trachoma Control



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RF1.A Telling the NTD Story: Using the NNN Beginners Guide to field communications and how it can help in a challenging global environment

Highlights

Neglected tropical diseases (NTDs) affect more than one billion people and cost developing economies billions of dollars every year. Stories by, and about, people affected by NTDs are essential to raise public awareness. Also, these stories help bring people involved in NTD programmes closer to people affected by NTDs. This workshop was centred on how all of us can continue to tell the stories of our work during the COVID-19 pandemic and beyond.

To support NNN members to communicate more effectively, a communications toolkit was developed. The toolkit provides a practical guide to help people collect content and tell the stories of those affected by NTDs. Since the toolkit was launched last year, the COVID-19 pandemic has significantly changed the global health landscape, with many NTD activities, including communications efforts, interrupted. As domestic and international travel are increasingly limited, many communications teams are unable to collect content to successfully tell the NTD story, making this toolkit more important than ever.

This session focussed on the importance of securing information from beneficiaries, collecting photographs and ensuring information is available about people affected by NTDs, particularly in the current COVID-19 environment.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

- All NNN members are encouraged to use the NNN Beginners Guide to Field Communications to strengthen storytelling in a COVID-19 climate and beyond.
- Participants asked about whether technology would play a role in storytelling in the future and sought more information about how they could better collect stories. The NNN Communications Group will support on-going online training for members and could consider further training should NNN members desire.

Contact Information

Alison Hill, The Fred Hollows Foundation (alisonhill@hollows.org)
Tim Jesudason, ICTC (ictcomms@gmail.com)



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RF1.C Supporting girls and building resilient communities for NTD elimination

Highlights

The burden of NTDs is higher in women and girls. Girls are held back due to care and house duties, which increase their exposure to NTDs, make them miss school days and may lead to early marriages and early pregnancies. Girls are the key to building resilient communities, thus successful NTD programmes must empower girls to promote resilience and sustainability.

CIFF follows six key strategies to empower girls and their communities through NTD programmes:

- **Layered interventions:** delivering linked interventions for NTDs, WASH, SRH, nutrition, climate & environment; the Geshiyaro programme in Ethiopia is building gender-segregated school latrines to improve WASH and providing separate rooms for menstrual health management.
- **Integrated efforts:** delivering combined, concerted messages to increase their efficacy; the Ethiopian FMOH delivers integrated handwashing and face-washing messages—also relevant for prevention of Covid-19—through the integrated NTD programme.
- **Local ownership:** supporting locally designed solutions to locally identified problems and ensuring women's participation; during the pandemic, Geshiyaro's WASH Business Centres increased soap production in response to increased community demand.
- **Tailored interventions:** training female surgeons under the AccelerateTE programme through Sightsavers to increase reach of TT surgeries in northern Kenya to women who would otherwise not see a doctor, thus increasing programme reach and equity.
- **Sustainable solutions:** building capacity for long-term sustainability; the strong local capacity of the Carter Center-led Guinea Worm Eradication (GWE) programme ensured most activities could carry on in endemic countries during the pandemic.
- **Problem-solving:** tackling the root causes of problems and amping up the ambition; the GWE programme is tethering dogs and tracking baboons to stop animal-to-human GW transmission, while the Geshiyaro programme aims to break STH/SCH transmission, going beyond business-as-usual.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

CIFF is committed to support NTD programmes to reach the 2030 goals through innovative strategies to accelerate progress toward elimination and promoting increased sustainability and equity.

Contact Information

For more information about the work CIFF is supporting on NTDs, please contact Rita Oliveira, Programme Officer, Africa (roliveira@ciff.org)



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RF1.D Cross-country approaches for service delivery integration with education and health for sustainable NTD programming

Highlights

This rapid-fire presentation explored collaboration between the health and education sectors, highlighting examples of service delivery integration from Ghana, Senegal, and Sierra Leone. Coordination with Ministries of Education provide a unique opportunity for NTD service delivery and sustainability beyond mass drug administration (MDA), leveraging the decentralised school system, the interdisciplinary role of teachers, and the infrastructure with established platforms for health education and linkages to related health services.

In **Ghana**, the NTDP collaborates with Ghana Education Service's School Health Education Program (SHEP) to plan, monitor, and evaluate school-based MDA, train teachers, and sensitise the community. SHEP effectively links NTDs with WASH promotion in schools, thereby sustaining the gains from treatment with protective environmental and behavioural changes. GHS provides the policy guidance and training on environmental health and technical assistance for materials development while SHEP mainstreams hygiene promotion in curricula, sets up school health clubs, monitors environmental health, and implements awareness-raising and advocacy on WASH in schools. The NTDP and SHEP have developed WASH materials with integrated NTD messaging, although the materials have not yet been rolled out.

In **Senegal**, the national education sector plan (PAQUET-EF) requires school curricula to contain a health education component, including information on NTDs and their prevention. The Ministry of National Education's *Division du Contrôle Médical Scolaire* (DCMS) is a strategic partner for school-based MDA and NTD-related health promotion through integrated behaviour change communication, awareness-raising, and teacher mobilisation. The collaboration is notable in that education, through the DCMS, is the only sector consistently represented at all NTDP coordination meetings.

In **Sierra Leone**, the School Health Program is under the Directorate of Primary Health Care in the Ministry of Health and Sanitation rather than the Ministry of Basic and Senior Secondary Education (MBSSE). SCH and STH control programs began as school-based deworming programs, with Directors of Education and regional and district leaders jointly declaring their support. The NTDP engages the MBSSE through the School Feeding Program for collaboration on school-based MDA, surveys, and community mobilisation, as well as ensuring adherence to school feeding practices during MDA. District Directors of Education and Community Teacher Associations participate in the planning for the deworming campaigns.

Overall, the aforementioned collaboration strategies highlight paths towards long-term NTD service delivery and sustainability. However, sustainable NTD control programming requires coordination and collaboration beyond MDAs to developing joint, targeted action plans for integrated services and cross-sector collaboration. Collectively, there is a need to advocate for integration of NTD and education priorities into sector policies and strategies to formalise this collaboration. Furthermore, integrating NTD prevention messages into the existing health and WASH education materials will maximise the impact of the school-based platform.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

- Formalise the collaboration between NTDPs and the Education sector: Develop a joint and targeted action plan for cross-sector collaboration
- Integrate both NTD and Education cross-sector priorities within sector policies and strategies
- Leverage existing health, WASH, and Education SBCC materials to integrate NTD messages

Contact Information

Arielle Dolegui, Health Technical Advisor - World Vision US
(adolegui@worldvision.org)



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RF1.E What works for people affected by chronic oedema?

Highlights

This rapid-fire session reported on a survey of NNN members who have experience in field settings with people affected by chronic oedema.

Responses to the survey were compared with current research or expert opinion and evidence for the benefits of each activity were discussed. Preliminary results on 53 responses collected up to August 30 were presented to the meeting. Respondents were largely working in NGO settings (64%) and with people affected by lymphatic filariasis (72%).

Regarding skin care, whilst the majority of members believe there is a benefit in using antibacterial soap over plain soap this is not supported in the literature. The pH of the soap is more important and many antibacterial soaps have a very high pH which can be damaging with long term use. Recommending plain and locally made soaps will reduce the barrier of expense or inaccessibility to performing the daily hygiene which is essential to chronic oedema self-care.

Limb elevation during the day was considered beneficial but again the literature does not support this. It was also erroneously believed that elevation improves lymphatic removal, however elevation assists venous resorption and only when the body part is above the level of the heart. Day time elevation may be at best useless and at worst harmful and may prevent exercise which is important in lymphedema self-care. Furthermore only early lymphedema has enough free fluid to benefit from elevation and guidelines should be refocused toward earlier stages of lymphedema and overnight only.

Exercise was generally considered beneficial and in other lymphedema populations deep abdominal breathing is routinely encouraged to clear the central parts of the system. This was recommended for people affected by filariasis-related lymphedema as early as 2003 but has not yet been included in the guidelines. Exercises to activate proximal skeletal muscle pumps and self-massage add no expense to people affected by chronic oedema and should be further investigated for their benefits in resource-poor settings.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

Research on each component of these interventions is needed to ensure that endemic countries spend their limited resources on the most beneficial activities. It is hoped that the survey results and rapid-fire presentation will spark further research on individual components of lymphedema management to maximise the benefits of self-care for affected persons.

Contact Information

Jan Douglass
(jan.douglass@jcu.edu.au)



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RF1.F Kenya NTD partner mapping: harmonising programme interventions and impact measurement at the county-level in Kenya

Highlights

Kenya has made notable progress towards controlling several NTDs using evidence-based strategies. However, mass drug administration activities are often not as well coordinated as they could be, and depending on the disease, different disease surveillance methodologies have been used by different implementing partners, producing epidemiological data that are not comparable across counties. Even if there is a greater recognition of the need for coordination at the national level, this is not reflected at the county-level where the actual implementation of activities take place. In order to address these challenges, Children Without Worms (CWW), a program of the Task Force for Global Health and facilitator of the STH Coalition, worked with the Kenya NTD programme since early 2020 to conduct a stakeholder analysis, map partner activities and improve data and information sharing between partners. In February 2020, CWW helped facilitate a meeting of NTD implementing partners at the SCH and STH technical advisory group meeting in Nairobi, Kenya. In March, CWW set up an online platform for information sharing and established a Google group. Between February and April 2020, CWW worked with the national NTD program to identify NTD partners, identify partner specific activity, geographical focus, the surveillance methods used, and organisational capacity and capabilities. In April, CWW produced a stakeholder analysis guide that provided a time-stamped overview of partner activity at the county-level in Kenya. And, over the last couple of months, CWW has worked with the national NTD programme to improve information sharing between partners, particularly with respect to harmonising disease surveillance methods for SCH and STH. As far as next steps, CWW would like use this forum to track COVID related contingency preparedness at the county-level, as countries and counties begin to think about resuming NTD activities, including MDA and surveillance. In the coming months, CWW will continue to work with the national programme to harmonise surveillance methods and eventually be able to facilitate information exchange on programme implementation and disease prevalence data under the leadership of the NTD programme.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

- National NTD programs and implementing partners commit to harmonising NTD activities at national, regional, and local levels.
- National NTD programs and partners commit to knowledge sharing at all levels to exploit economies of scale, pool limited resources, and avoid duplication of efforts.

Contact Information

Girija Sankar, Children Without Worms
(gsankar@taskforce.org)



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RF1.G Guidelines for the management of post-operative trichomatous trichiasis (PTT)

Highlights

- Definition of PTT: Presence of ≥ 1 eyelashes touching the eyeball or evidence of recent epilation of in-turned eyelashes from the upper eyelid that has had trichiasis correction surgery in the past.
- Magnitude: Overall, 20% - 40% PTT at one-year.
- Challenge: There is no standard protocol for PTT management at international or national levels to guide programs and ophthalmic practitioners.
- Ethiopia PTT management guidelines: PTT grading developed; defined appropriate management procedures for each level of PTT; and identified training needs for ophthalmic practitioners.
- Grading of PTT: Four grades developed mainly based on the number of eyelashes touching the eyeball, evidence of epilation, degree of entropion and postoperative complications.
- PTT management: Practical management approaches developed for each grade of PTT:
 - PTT0/None: Advice for follow-up.
 - PTT1/Minor: **Epilation**, epilation training and provision of epilation forceps by integrated eye care worker/TT surgeon at primary eye care unit, and epilation by patient or caretaker at home.
 - PTT2/Major PTT: **Corrective repeat surgery** using the PLTR procedure by specially trained IECWs or ophthalmic nurses.
 - PTT3/Complicated PTT: **Surgical correction** performed by an oculoplastic surgeon or specially trained ophthalmologist; **Electrolysis** if the patient is not going to benefit from surgery or refuses surgery.
 - For all cases: (a) Pre- and post-service counselling, and (b) Regular follow-up to assess outcomes.
- Skills: Training of eye care cadres to manage PTT:
 - IECWs: Epilation technique.
 - Selected IECWs, ophthalmic nurses and ophthalmologists: enhanced surgical training for PTT3 management.
 - All: Counselling techniques.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

- Consider developing a standard post-operative TT management protocol at global level to guide national trachoma programs.
- Ensure quality training and supportive supervision for both cadres managing TT and PTT.
- Research to develop evidence-based management intervention(s).

Contact Information

Dr Fikreab Kebede, Ministry of Health, Ethiopia
(fikreabk@yahoo.com)



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RF2.A NTD supply chain: A call for integration

Highlights

The Ascend West and Central Africa (WCA) programme supports health systems strengthening across 13 countries. Our specialised team for supply chain is working with ministries of health to build capacity in the last mile of the NTD supply chain. Integration into national healthy supply systems is our key approach to build resilient NTD programmes in a changing world. The session highlighted key findings based on our work in seven countries – Chad, DRC, Ghana, Guinea Bissau, Nigeria, Liberia, and Sierra Leone:

- 1. Planning and forecasting** are the first steps in the NTD supply chain. Most countries use a simple formula to quantify preventative chemotherapy (PCT) drug needs for target populations in endemic areas. However, this information is often outdated and does not account for actual population changes, cross border movements, or internal migration for seasonal work. Further, accounting for leftover stock from previous MDAs is a necessary requirement for drug applications, yet quick visibility of stock in country is lacking.
- 2. Delivery of drugs** is a year-long process. The first mile is complex, yet well-coordinated. The last mile is complex and highly challenging: countries lack integrated and reliable systems for **stock management**, tracking and reporting, and consequently the process is resource intensive if done properly. Countries are at varying stages of implementing logistics management systems (LMIS)
- 3. Last mile distribution and reverse logistics** is a challenge without a sustainable solution. It relies on resource capacity before, during and after MDA. Retrieval of leftover stock is an issue of geography, budget, and human resources. Integrating the NTD supply chain into the national supply system and/or with other disease programmes is an effective means of improvement.
- 4. Human resources and training** are overarching challenges. In most countries NTD supply chain responsibilities may be designated amongst NTD team members, rather than allocated as a separate role to a trained person. In some countries the national NTD team includes a pharmacist, which we see as beneficial to the programme. There are pharmacists and pharmacists' technicians across the health system who are not fully involved in NTD programmes, which we see as a missed opportunity.

From an informed position we developed targeted plans with NTD programmes in each country. Our initial focus is developing standard operating procedures (SOPs) and enhancing cascade training for MDA. We are working individually with each country and contributing at the global level through partnerships such as the NTD Supply Chain Forum and the technical working group led by ESPEN and USAID Act to End.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

- Delivering Supply Chain capacity building activities in the Ascend West Central countries
- Contributing to publications and case studies about NTD supply chain
- Working closely with ESPEN and the NTD Supply Chain Forum

Contact Information

Rocio Villacorta Linaza, Liverpool School of Tropical Medicine
(Rocio.villacortalinaza@lstm.ac.uk)



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8-10 September 2020

RF2.B Spatial Intelligence and precise, impactful NTD interventions in low-resource settings

Highlights

This Rapid Fire session, presented by Akros, introduced the concept of spatial intelligence and demonstrated how geospatial tools can be combined and applied to solve challenges routinely experienced in NTD surveillance and intervention management. This included the impact it has had in terms of improving the efficiency and effectiveness of various field-based public health campaigns.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

Committed to building and supporting resilient NTD programmes, by enabling campaign managers and field workers to effectively plan, navigate and deliver health interventions, in a targeted and precise way, through the use of appropriate technology platforms and innovations in service delivery models.

Contact Information

Anna Winters, CEO (awinters@akros.com)
Kyle Hutchinson, Reveal Coordinator (khutchinson@akros.com)



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RF2.C Providing analytical tools to understand the impact of MDA delays due to COVID19 and help plan resumption of NTD programmes

Highlights

The spread of coronavirus (COVID-19) to Africa will impact the progress of neglected tropical disease (NTD) programmes in different ways: how much delay can programmes tolerate before they start seeing a negative effect in the progress towards the 2030 goals? In which setting will the impact of delays be greatest? What remedial strategies can be implemented to mitigate the delays? Mathematical modelling provides insight into these questions and further support countries' decisions once programmes resume.

The analysis suggests that for some NTDs the mean delay to the targets is less or equal to the MDA interruption duration. Amongst the diseases studied, trachoma and schistosomiasis are likely to see the quickest rate of resurgence particularly in high transmission settings. And more intensive remedial strategies are therefore required for these programmes.

These analyses will be made available to programme managers through a web-based user-friendly interface to therefore increase the utility of model predictions. The interface allows users to change the starting assumptions of the model adapting analysis to local knowledge. And to use the models to explore different scenarios, such as the remedial strategies modelled.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

- Demonstrate how mathematical modelling can support national programme decisions by engaging with programme managers throughout the development of the interface.
- Facilitate partnership between researchers in transmission modelling and other members of the NNN community in accelerating the path to 2030.

Contact Information

Andreia Vasconcelos
(andreia.vasconcelos@bdi.ox.ac.uk)



NEGLECTED TROPICAL DISEASE NGO NETWORK

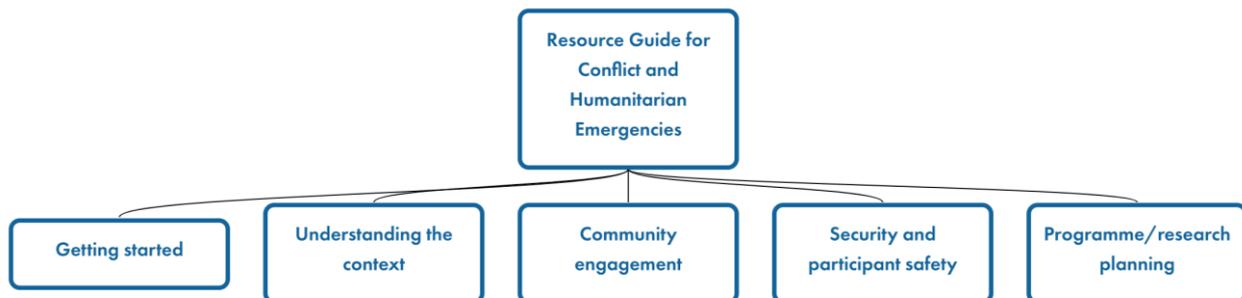
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RF2.D Creating resilient NTD programmes in settings affected by conflict and humanitarian emergencies (C&HE): piloting a C&HE tool

Highlights

- The Conflict and Humanitarian Emergencies (C&HE) Cross Cutting Group developed a resource guide to support organisations *working in* or who *would consider* working in areas affected by conflict and/or humanitarian emergencies.
- The guide can be found on the NNN Conflict and Humanitarian Cross Cutting Group page of the NNN website or by visiting <https://bit.ly/NNN-CHE-Resources>
- Information is divided into 5 thematic areas (shown below) with insights and links to external resources provided for each.



Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

Conflict and humanitarian emergencies (C&HE) represent a significant challenge for countries to achieve targets set in the draft WHO road map for NTDs. Resilient NTD programmes are critical in these settings and must be thoroughly planned and implemented to ensure they are both safe and effective. Moving forward the C&HE Cross Cutting Group will:

- Update the resource guide quarterly
- Collect and disseminate case studies from NGOs implementing NTDs in areas affected by Conflict and Humanitarian Emergencies
- Continue to advocate about the importance of NTD programming in areas impacted by C&HE

Contact Information

Angelia Sanders (Angelia.sanders@cartercenter.org)
Tim Jesudason: (ictcomms@gmail.com)



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RF2.F The challenges of managing innovative and intensified disease management (IDM) NTDs in the field in Africa

Highlights

IDM NTDs are difficult and costly to manage, their burden is poorly understood, and there are few appropriate control tools and relatively little investment in research and development. People affected often live in remote rural areas with poor health systems and have limited access to diagnosis and treatment. MSF provides care for visceral leishmaniasis (VL) and Human African Trypanosomiasis (HAT) in Africa. Since 1988, MSF has treated 130,098 patients for VL in 6 countries, and since 1986, it has screened almost 3.5 million people and treated over 50,000 people for HAT in 7 countries.

For both VL and HAT, diagnosis is complex, but for HAT, promising rapid tests are under evaluation. For VL, first-line treatment is 17 days of painful injections with sodium stibogluconate and paromomycin, provided in a hospital, and treatment with AmBisome is needed for vulnerable patients who do not tolerate the first-line treatment. For HAT, recent advances have been made through DNDi. An oral 10-day treatment, fexinidazole, is now available and a single dose treatment (acoziborole) is under development.

HAT is now a low prevalence disease occurring mainly in extremely remote areas (< 1000 cases in 2019). MSF has shown that active case finding is no longer cost-effective. But integrated diagnosis and treatment with simplified diagnostic and treatment tools may soon be possible at the community level. African VL is still endemic in many areas and outbreaks occur regularly.

MSF has shown that active case finding is not cost-effective except in certain outbreak scenarios. Better tools for decentralising diagnosis and treatment are needed. Access to treatment is poor, and many cases remain undiagnosed.

Early detection and treatment at the community level in all endemic areas is essential to reach the WHO's 2030 NTD roadmaps goals. Partners need to maintain the 'momentum' during and after the COVID crisis to avoid a re-emergence of VL & HAT, with emphasis on access, supply, training, community awareness and early detection of emerging outbreaks.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

MSF will continue working in VL in Ethiopia and South Sudan, treating patients and conducting operational research in collaboration with other institutions. This includes evaluating existing and new treatments, developing a special approach for HIV-VL co-infected patients, epidemiological research and evaluating decentralisation of diagnosis to the primary health care level as an approach to improve case detection.

MSF stopped vertical HAT programs because of the worldwide decline in cases but will pilot the integration of HAT diagnosis and treatment at the primary health care level in HAT-endemic regions.

Contact Information

Margriet den Boer, MSF
(Margriet.den.Boer@london.msf.org)



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RF2.G Understanding, applying and evaluating One Health to achieve the goals of WHO's NTD roadmap for 2030

Highlights

One Health - a collaborative, multisectoral, and transdisciplinary approach at the local, regional, national and global levels to achieve optimal health and wellbeing outcomes, recognizing the interconnections among people, animals, plants and their shared environment.

- One Health is still sparsely implemented in the field, yet it is especially needed in development and humanitarian contexts and in NTD-endemic countries.
- More than 50% of NTD-causing parasites use animals as vectors or / and an animal reservoir
- As NNN members, we must acknowledge, recognise and address the interconnections among diseases and people, animals, plants, water and their shared environment.

The lack of coordination between veterinary public health, the public health sector and the environmental sector is addressed in the WHO's 2030 NTD roadmap, which recommends:

→ **Developing a One Health strategy for NTDs**, including case definition, common targets, and strategies and mechanisms for collaboration among ministries of agriculture, livestock, wildlife, environment, food safety, health and others.

→ **Integrating NTDs into existing One Health platforms** and ensuring that they are considered and included in local strategies and plans.

→ **Creating national operational plans to deliver NTD interventions with a human– animal– environment interface and clear attribution of roles and responsibilities**, e.g., a coordinated plan outlining stakeholder accountability for human-, animal-, food- and ecosystem-related actions.

Actions or commitments towards Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

- **Share data on occurrence of NTDs** in humans and animal hosts among sectors to guide activities, e.g., surveillance in animals as a proxy for humans.
- **Develop plans for coordinated disease control**, e.g., simultaneous interventions for both humans and animals in a geographical area.

Contact Information

Christian Griebenow, Managing Director, Vétérinaires Sans Frontières Germany
(christian.griebenow@toge.de)

Antonia Braus, Desk Officer One Health, Vétérinaires Sans Frontières Germany (antonia.braus@toge.de)

Dr. Gabrielle Laing BVSc PhD MRCVS, SCI Foundation (g.laing@schisto.org.uk)

Conference highlights



The Fred Hollows Foundation/Michael Amendolia

Closing remarks from the Incoming Vice Chair, Arielle Dolegui

It is a tremendous honour and privilege to serve as the NNN 2020-2021 Vice Chair and to bring forth my contributions, leadership, and expertise to this incredible network of NGO partners and colleagues dedicated to the elimination and control of NTDs worldwide.

I am excited to contribute to this community a wealth of experience in strengthening the capacity of local governance bodies, setting up structures and systems for communities' resilience, as well as successfully building networks and partnerships across geographical areas.



Incoming Vice Chair, Arielle Dolegui

This year's conference theme, 'Accelerating to 2030: Building Resilient Health Systems in a Changing World,' has guided us at a critical time for the fight against NTDs. We're faced with technical and programmatic challenges in delivering our interventions during a pandemic. A pandemic that has further strained the livelihoods and access to health services in communities affected by NTDs. Throughout the conference, there were recurring themes of social inclusion, gender equity, quality improvement of programming, all referring to sustainability approaches to strengthen health systems and delivery of services. A call to action for multisectoral coordinated interventions has been overstated by the various panellists, and the contributions have been made clear that the road ahead requires in paradigm shift in the transfer of local skills and the onus on building solutions that responds to contextual needs.

We have understood collectively as a network of partners and practitioners that that there is an expressed and pronounced need for our efforts to focus on innovative approaches for sustainability that will truly ensure country ownership and strong local leadership. These complementary approaches are what I look forward to contributing to the NNN community and legacy.

I look forward to learning and working with you, and to truly further the vision of the NNN in ensuring that no one is left behind in a world free of NTDs.

Thank you,

Arielle Dolegui, NNN Vice Chair 2020/2021

Technical Advisor, Health Systems Strengthening and Cross-Sector Coordination
World Vision

Closing remarks from the Incoming Chair, Dr. Kisito Ogoussan

Thank you to all who participated and actively engaged in the first ever virtual NNN conference. I have been highly moved and motivated by the agility of the NTD community to adapt to our new circumstances and continue the engagement and knowledge sharing that makes our community of practice unique.



Incoming Chair, Dr. Kisito Ogoussan

I am greatly honoured to serve as the NNN Chair 2020-2021. Despite the challenges posed by COVID-19, the year ahead stands to be a formative year, with the expected launch of the World Health Organization road map for neglected tropical diseases 2021-2030. The draft road map provides a shared vision of country ownership, cross-sectoral collaborations and a shift from vertical disease programs to horizontal holistic, impact orientated approaches to ending NTDs.

The COVID-19 pandemic has shone a light on the importance of cross-sectoral comprehensive approaches to tackle public health challenges. The interventions required to tackle COVID-19 has required strong collaboration between a range of stakeholders including health, education, finance, water, sanitation and hygiene, and more. To beat NTDs, we must follow this example.

2020 has required all of us to adapt and approach our work with a renewed sense of empathy. In light of this, I was humbled during the opening plenary, which emphasised that person-centred approaches must govern our thinking and that we can never forget that it is the people affected by NTDs that we serve.

Since 2009, the NNN has made great progress towards unifying NGO voices and enhancing our community of practice. We recognise the need for person-centred, cross-sectoral approaches, and we strive to ensure progress for NTDs contributes to the achievement of universal health coverage and resilient and sustainable health systems.

As the incoming Chair, I ask us all to challenge ourselves as NGOs, and other NTD stakeholders across health ministries, donors, industry, and research to think more strategically about how we can support the vision of the upcoming WHO road map for NTDs, develop and strengthen partnerships, and ensure that no one is left behind.

As we embark on our journey to 2030, we must keep our eyes on our targets while striving to overcome the challenges ahead, foreseen and unforeseen. We must actively pursue and engage with all stakeholders within and outside the NNN to achieve our collective goals of a world free of NTDs.

Dr. Kisito Ogoussan, NNN Chair 2020/2021

Implementation Management Lead on USAID's Act to End NTDs | West program (Act | West)
FHI 360

NNN 2020 Communiqué

Accelerating to 2030: Building Resilient NTD Programmes in a Changing World

Operating under the COVID-19 pandemic

The COVID-19 pandemic is testing how we work together to address critical challenges at home and across borders. Support for international cooperation hangs in the balance at precisely the moment when robust collaboration is needed most. In 2020 the importance of resilience and sustainability have never been more relevant to global discussion than they are today, as a fractured global community tackles the evolving human tragedy, the stark inequalities within and between countries, and an economic crisis that COVID-19 forced to centre stage.

The ongoing pandemic challenges the global NTD community to confront the long overdue paradigm shifts at the core of the soon to be released *World Health Organization (WHO) [road map for NTDs, 2021 – 2030](#)*: strong, accountable local and national leadership; integration and cross-sectoral collaboration; equity and impact.

Accelerating to 2030

Within the context of this year's conference theme the High-level Panel and workshop discussions have made it abundantly clear that success is not inevitable and nor is it guaranteed. We must endeavour to challenge ourselves to do better and to work together within and outside of NTDs in order to support WHO and countries to 'build back better,' and work to cement the foundations for the resilient and strong health systems which all communities deserve and which will enable a world free from NTDs for all.

More than 1,000 participants representing nearly 300 organisations across 80 countries came together virtually to explore [innovative ideas](#) and catalytic opportunities to accelerate NTD progress with partners from other sectors, in service to the new NTD road map and Sustainable Development Goals.

Our commitment

- The NNN is committed to supporting endemic countries and communities by ensuring our support to the WHO road map for NTDs 2021 – 2030 and doing what we do [BEST](#): identify gaps, mobilise to understand them and develop approaches to learn and improve NTD programming and collaboration.
- We understand the need to see individuals in the context of their communities and not only their diseases, focusing our attention on people-centred strategies through holistic and inclusive programmes. During this annual conference, the NGO community adopted a new [statement of commitment to the participation of persons affected by NTDs](#). We recognise that we still have work ahead of us in putting this commitment to action, and that this is a journey we will take together.
- The pandemic has emphasized the critical importance of a multi-sector approach across education, clean water, decent sanitation and access to hygiene services in the prevention, treatment and care of diseases. We must broaden and deepen our partnerships to implement NTD programs, that will contribute to strengthened health systems and ultimately support equitable access to all through universal health coverage
- NNN members recognised the additional burden that conflict and humanitarian emergencies place on fragile health systems, with the NNN launching a [new resource guide for these emergencies](#) to better support members implementing NTD programs in these environments. The NNN offers our gratitude to community health workers and other key workers for their unfailing commitment to the health of their communities.

The NNN 2020 conference galvanised the NTD NGO community's commitment to resilience, sustainability, cross-sectoral collaboration, and inclusion as principles that will guide our actions over the next decade. On the final day of the conference WHO announced Myanmar was validated for eliminating trachoma as a public health problem—a case example for how the cross-sectoral principles of the NNN BEST framework come into play to achieve the goals set forth by the road map, and what can be done when we work effectively together.

Dr Mwele Malecela, the Director of the Department of Control of Neglected Tropical Diseases at the World Health Organization, acknowledged, **"We all have our roles to play for the road map to succeed, and we all need each other."**

ILEP/NNN Guides on Stigma and Mental Wellbeing

Background

Many people affected by Neglected Tropical Diseases (NTDs) are not treated in time or are not treated at all and suffer from severe complications, impairments and disabilities. These complications can often lead to stigma and discrimination. A significant proportion may develop poor mental wellbeing, or mental conditions such as depression and / or anxiety, which is often compounded by experiences of exclusion and discrimination.

These Guides on Stigma and Mental Wellbeing are a co-production of the International Federation of Anti-Leprosy Associations (ILEP) and the Neglected Tropical Disease NGO Network (NNN). They were comprehensively rewritten during 2019 to incorporate improved insights, align with current evidence, and make mental wellbeing an integral component of the series. The writers include specialist researchers, NGO staff, mental health professionals, policy makers, programme managers and people personally affected by NTDs.

The Guides provide best practice information and recommendations from various disciplines on how stigma manifests, how it can be reduced, and the tools available to assess the experience of stigma and mental wellbeing. Although written with a focus on NTDs, the content is relevant for people working to address all forms of health-related stigma and promote mental wellbeing in their interventions, policies, trainings, care packages, evaluations, or other services. Health and Social Welfare departments, development programmes and other agencies can use these Guides to promote access and inclusion of people affected by NTD-related disabilities into their services, activities and facilities. The Guides are also a useful resource for those responsible for training people working in services where clients may experience stigma and poor mental wellbeing. The other intended audience is people who have experienced or are at risk of experiencing stigma and may be distressed as a result, along with their family members and carers.



The Guides

The first Guide, *What are health-related stigma?*, provides basic information about stigma, its causes and manifestations. The second Guide, *How to reduce the impact of stigma*, provides coping mechanisms for individuals and families at risk of stigma and practical tools for those who are working with them. The third Guide, *How to reduce sources of stigma*, focuses on interventions that can tackle the different sources of stigma, for instance on interventions in the community, health sector, service providers, institutions, law and policies, and the media. The fourth Guide, *How to assess health-related stigma and mental wellbeing*, explains why it is important to assess stigma and mental wellbeing and describes qualitative and quantitative assessment methods and instruments. This Guide also explains how to interpret and report the assessment findings.

Each Guide provides exercise sheets and tips for use in education and training. Look out for web links provided in dialogue boxes throughout each Guide. A simple click will open the corresponding annex with training exercises and tips. The ILEP/NNN Guides on Stigma and Mental Wellbeing can be accessed [here](#).

NNN Statement of commitment to the participation of persons affected by NTDs

Background

The involvement of communities and persons affected is not a new concept in primary health care and disease programmes. However, the active participation of persons affected by NTDs is not always a reality. Human rights-based approaches to neglected tropical diseases (NTDs) emphasise that any interventions should be based on the principles of participation, non-discrimination and accountability¹. Participatory and human rights-based approaches, such as Disease Management, Disability and Inclusion (DMDI), address participation, non-discrimination and accountability as cross-cutting themes in NTD work. They are guided by the principle that engaging persons affected by NTDs is essential to the success of programmes. Having experienced the disease, disability and associated discrimination, persons affected by NTDs have a unique voice and perspective, they bring expertise and passion to the work and take the programmes closer to the communities they are designed to benefit. Aligning with these approaches helps to develop the Social Inclusion aspect of the NNN BEST Framework.

Call to action: the EASI strategy for participation of persons affected

To enable the active engagement of persons affected by NTDs, the NNN DMDI-Cross Cutting Group encourages all member organisations, partners and other stakeholders in the NTD community to adopt the EASI strategy to ensure that persons affected by NTDs have the space and the support for meaningful and effective participation.



Our commitment

- **Policymaking:** Persons affected by NTDs are supported to participate in the development, monitoring and evaluation of NTD-related policies, guidelines and preferred practices at all levels.
- **Comprehensive and inclusive NTD programmes:** Persons affected by NTDs systematically participate in all stages of inclusive NTD programmes from planning, to implementation, monitoring and evaluation.
- **Leadership, networking and sharing:** Persons affected by NTDs are supported to take on leadership roles in self-care groups, support groups and other relevant local, national and international networks; to seek resources and build local capacity; to encourage participation of new members; and to share their experience with others.
- **Advocacy:** Persons affected by NTDs actively participate in NTD advocacy for the promotion of universal access to comprehensive and inclusive services that are fully integrated into strengthened local health systems.
- **Public representation:** Persons affected by NTDs are supported to actively participate at local, regional and global NTD fora and to become spokespersons in NTD campaigns or speakers at public events.

¹ From "A human rights-based approach to neglected tropical diseases."
<https://www.who.int/gender-equity-rights/knowledge/ntd-information-sheet/en/>
World Health Organization, 2010

NNN Resource Guide for Conflict and Humanitarian Emergencies

Background

The NNN resource guide for conflict and humanitarian emergencies was developed by the NNN Conflict and Humanitarian Emergency Cross Cutting Group to support NGOs to learn more about neglected tropical disease (NTD) programming in areas affected by conflict and humanitarian emergencies.

The NNN resource guide for conflict and humanitarian emergencies aims to highlight the challenges and risks associated with working in areas affected by conflict and humanitarian emergencies and to make resources on this topic more accessible.

The resources included in this guide specifically relate to conflict and humanitarian emergency settings and were compiled by the NNN Conflict and Humanitarian Cross Cutting Group. The resource guide is not comprehensive and other resources, including the [NNN beginner's guide to field communications](#), [ILEP/NNN stigma guides](#) and [WHO/NNN WASH/NTD toolkit](#) will also benefit organisations working in these settings and should be used.

Five key thematic areas



Within each thematic area, users can expand subsections to learn more information and access additional resources.

1. Getting started

Working in areas affected by conflict and humanitarian emergencies requires tailored and targeted approaches that are often considered to be a major hurdle for NGOs. Settings can vary significantly across refugee camps, internally displaced persons camps, protection of civilian camps, unofficial camps and other post conflict or emergency situations. When getting started, organisations should identify the setting and its physical and health system structures, conduct a situational analysis, contact key stakeholders, and identify what formal agreements are required to work in the targeted setting.

- + Identify the setting you are considering working in
- + Conduct a situational analysis
- + Engage key stakeholders
- + Identify formal agreements needed to work in each setting

+ Resources for getting started

The guide can be found on the NNN website or by clicking [here](#). This resource guide will be updated periodically by the NNN Conflict and Humanitarian Emergency Cross Cutting Group. If you have any questions or would like to add resources to this resource guide please contact Angelia Sanders (angelia.sanders@cartercenter.org) or Tim Jesudason (ictccomms@gmail.com).

Who's who in the NNN

2019/2020 Steering Committee

The Steering Committee is the NNN's leadership team.

Chair: Kisito Ogooussan (FHI 360)

Vice Chair: Arielle Dolegui (World Vision)

Immediate Past Chair: Yaobi Zhang (Helen Keller International)

NNN administrative support: Tara King (FHI 360)

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 (International Federation of Anti-Leprosy Associations - ILEP)

Lymphatic Filariasis (LF) NGO Network

Chair: Ernest Mensah (FHI 360)

NGDO Coordination Group for Onchocerciasis Elimination

Chair: Louise Hamill (Sightsavers)

Soil Transmitted Helminths/Schistosomiasis (STH/SCH) Group

Chair: Michael 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

Chair: Angelia Sanders (The Carter Center)

Disease Management, Disability and Inclusion (DMDI)

Chair: Wim van Brakel (NLR – until No Leprosy Remains)

Ensuring Sustainable Systems

Co-Chair: Carolyn Henry (SCI Foundation)

Co-Chair: Wangeci Thuo (RTI International)

One Health

Chair: Wendy Harrison (SCI Foundation)

Skin-related NTDs

Chair: Claire Fuller (International Federation for Dermatology)

Water Sanitation and Hygiene

Chair: Yael Velleman (SCI Foundation)

2021 Task Groups

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

Influencing Priorities

Chair: Chelsea Toledo

Communications

Co-Chair: TBD

Co-Chair: TBD

2020 Conference in numbers

NNN Delegates by country

A total of 886 delegates from 81 countries attended the 2020 NNN Conference. This translated to a greater than 2-fold increase in the number of delegates, and 1.5-fold increase in countries represented, compared to the 2019 conference in Liverpool, UK (409 delegates and 49 countries, respectively). Key factors driving this increase in participation were the virtual conference format and free registration fee.

Doing a deeper dive into the data compared to the 2019 conference, ten countries saw an increase by 11+ delegates at NNN 2020, as shown below.

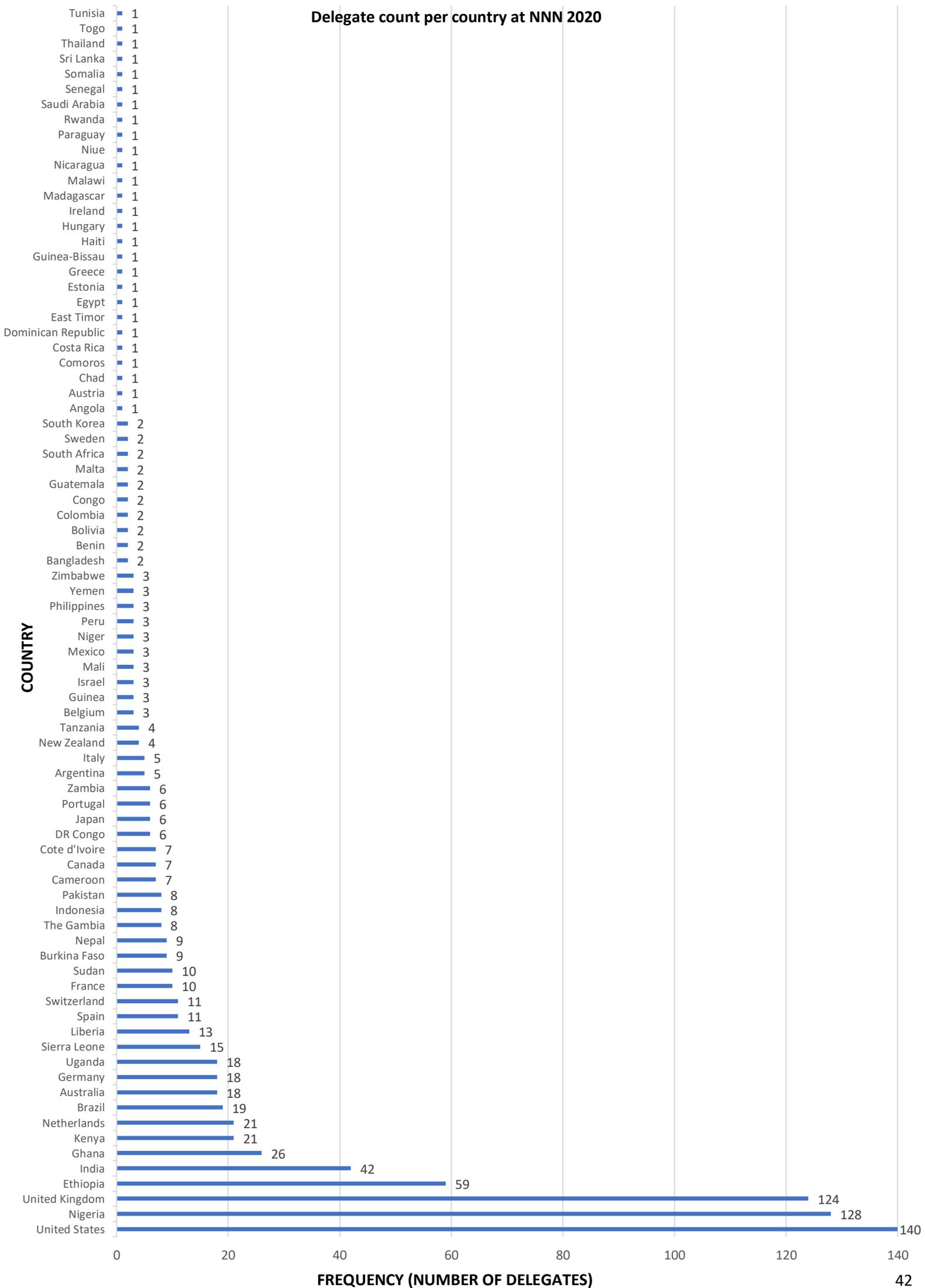
Country of residence	2019 Delegates	2020 Delegates	Delegate # difference
Nigeria	20	128	+108
United States	73	140	+67
Ethiopia	23	59	+36
India	22	42	+20
Brazil	0	19	+19
Ghana	11	26	+15
Uganda	3	18	+15
Sierra Leone	1	15	+14
Australia	7	18	+11
Netherlands	10	21	+11

Most notably, the number of delegates from Nigeria increased 6.4-fold, translating to 128 Nigerian delegates at NNN 2020, up from 20 delegates at NNN 2019. A similar fold increase was observed from Uganda, albeit on a smaller scale (from 3 to 18 delegates). The next largest increase came from the United States, which added 67 delegates at NNN 2020, for a total of 140 (roughly a 2-fold increase). The countries of Ethiopia, Ghana, and Australia all saw increases of approximately 2.5-fold, while India and the Netherlands saw increases of approximately 2-fold. Last, but not least, Brazil and Sierra Leone are two countries that saw major increases in representation at NNN 2020 compared to NNN 2019, from 0 to 19 delegates and 1 to 15 delegates, respectively.

In addition to the countries discussed above, nine countries saw an increase of 5-9 delegates: Burkina Faso, Cote d'Ivoire, France, Kenya, Nepal, Portugal, Spain, Sudan, and the United Kingdom. Importantly, six countries that had zero delegates at NNN 2019 had 5 or more delegates at NNN 2020, including Argentina (5 delegates at NNN 2020), The Gambia (8), Indonesia (8), Italy (5), Pakistan (8), and Zambia (6). Many other countries saw increases of 1-4 delegates, including some countries that had zero delegates at NNN 2019. Overall, these numbers translated to a median increase of 2 delegates, and a mean increase of 6 delegates, per country at NNN 2020.

Six countries represented at NNN 2019 were not represented at NNN 2020, including China (1 delegate at NNN 2019), Mozambique (1), Myanmar (1), Norway (1), the United Arab Emirates (2), and Vietnam (1). On the other hand, 38 new countries were represented. In total, 81 countries were represented. The complete graph of delegate count per country at NNN 2020 can be seen on the next page.

Delegate count per country at NNN 2020



NNN Delegates by WHO region

A key takeaway from the 2019 and 2018 conferences was that locale plays a role in the proportions of delegates, and accessibility of the annual conference to delegates, from the six WHO regions². For example, the 2019 conference in Liverpool, UK, had 41% of delegates from EURO, 27% from AFRO and 22% from WPRO. Similarly, the 2018 Conference in Addis Ababa, Ethiopia, had 55% of delegates from AFRO and roughly 25% from EURO. With the 2020 conference being virtual and free, the question became how would this format impact representation? Below is the breakdown of NNN 2020 conference attendees by WHO region.

WHO Region	2020 Delegates	Percentage of total 2020 delegates
African (AFRO)	354	40%
European (EURO)	221	25%
Americas (PAHO)	188	21%
South-East Asia (SEARO)	64	7%
Western Pacific (WPRO)	34	4%
Eastern Mediterranean Region (EMRO)	25	3%
	886	100%

Major percentage increases occurred in the AFRO and PAHO regions. The SEARO and EMRO regions stayed roughly the same. Interestingly, a marked decrease in participation was seen from the EURO region—25%, down from 41% in 2019. Furthermore, a decrease in participation from the WPRO region was evident, from 22% of total delegates in 2019 to 4% in 2020. This decrease is likely due to the time zone difference, as 2020 conference sessions ran from 11:00-14:30 GMT daily. Normally, time zone would not be a factor as all conference participants are at the conference venue, in-person. However, in a virtual setting, as was the case for NNN 2020, this difference in time zones could have hindered participation from delegates in the WPRO region. Although these differences are important to note, they should be put in the context of greater conference participation overall, as reflected by the 886 total delegates, from 300+ organisations, representing 81 countries.

In conclusion, these findings have implications for future NNN conferences that merit serious consideration (the same could be said for other organisations' international conferences as well). As noted by Dr. Yaobi Zhang, NNN Immediate Past Chair, "The virtual platform used for the 2020 conference provided several benefits. It enabled greater access existing partners to participate across time zones, in addition to inviting new stakeholders from across sectors to join in critical discussions..." Going forward, weight should be given to the conference format—in-person or virtual—and the conference fee (or lack thereof). Perhaps a rotating cycle of formats could be implemented (e.g., conferences being in-person every 2-3 years, or conferences being virtual every other year, conferences with different fee structures, etc.) to ensure the greatest participation from, and access to, all NNN members. It takes all of us working together to end neglected tropical diseases.

NNN 2020 conference recordings and NNN 2021

Recordings of the workshop, rapid fire, and plenary sessions from NNN 2020 can be accessed for free on [this page](#) (presentation slides are also available for download for free). Session recordings can also be found on the [NNN YouTube channel](#). In 2021, the NNN looks forward to its first conference in the South-East Asia Region (SEARO), which will take place in Kathmandu, Nepal, COVID-19 permitting (Nepal was the originally planned country location for the 2020 conference before the COVID-19 pandemic broke out). We hope that you'll join us and that we'll see you there.

² African (AFRO), Region of the Americas (PAHO), Eastern Mediterranean (EMRO), European (EURO), South-East Asia (SEARO), and Western Pacific (WPRO)

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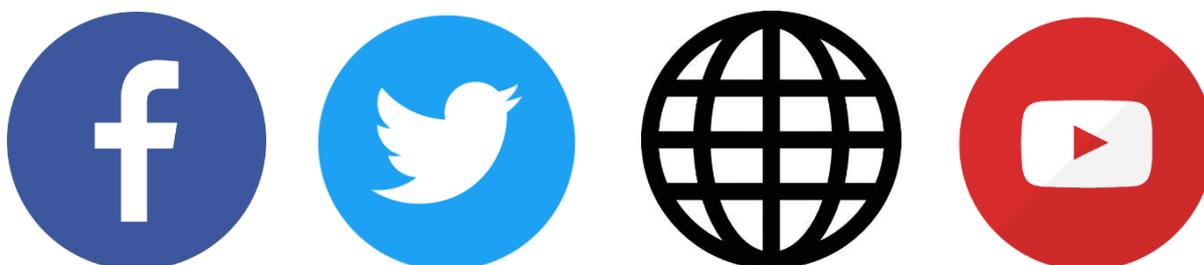
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