

# NNN Conference 2021

Enabling a Paradigm Shift to a country-led response to deliver the NTD Road Map



**NEGLECTED TROPICAL DISEASE  
NGO NETWORK**

A global forum for nongovernmental organizations  
working together on NTDs

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# Welcome from Outgoing Chair, Dr Kisito Ogoussan

As the 2020/2021 chair, it was my utmost pleasure to welcome everyone to the 12th NNN annual conference.

I was delighted to note that we had over one thousand delegates registered representing over 300 organizations from 83 countries, including NGOs, donor agencies, Ministries of Health, academia, research, and individuals, particularly people living with NTDs, whom I would like to recognize and thank personally.

The agenda has been designed to suit our virtual platform and accommodate delegates and speakers from different time zones.



Dr Kisito Ogoussan, 2020/2021 Chair

We delivered a high-level panel during the opening plenary with notable speakers including Dr. Maria Flachsbarth, Dr. Mwele Malecela, Prof. Samba Sow and Ms. Jayashree Kunju. We had 16 Workshops and two Rapid-Fire sessions and welcomed the new NNN Chair, Arielle Dolegui of World Vision and Vice-Chair, Girija Sankar from CBM.

We hosted the third NTD Innovation Prize, in collaboration with the American Leprosy Missions. The 2021 Prize included two \$20,000 awards for winning proposals from two domains: data and analytics, and diagnostics. The application process drew 30 applicants from 15 countries, yielding three finalists in each domain. Dr. Amber Barton and Dr. Martin Holland from the London School of Hygiene and Tropical Medicine won the data and analytics award. The diagnostics domain winner was Dr. Temitope Agbana from Delft University of Technology in the Netherlands. Additionally, a \$1000 Popular Choice Award went to Dr. Anthony Ablordey from the University of Ghana's Noguchi Memorial Institute for Medical Research.

In 2021 we launched two new session types. The special plenary session was created to reflect on the need for a transformational approach to improving the health and wellbeing of people living in resource-limited contexts. Social networking hours were also introduced to ensure we can continue collaboration during these difficult, socially distanced times. In January 2021, under the leadership of the World Health Organization (WHO), NNN proudly participated in the highly anticipated launch of the 2021-2030 road map for neglected tropical diseases (NTDs), which will shape and define NTD control, elimination and eradication efforts for this decade.

The NNN is steadfast in its support of the new and ambitious goals of the road map in the global fight against NTDs. The NNN also recognizes the need for a new *modus operandi* to align with these ambitious goals set by the new road map to rid the world of NTDs. This was translated in the conference theme of this year "Enabling a Paradigm Shift to a country-led response to deliver the NTD Road Map". Regardless of your sector of work, area of expertise, or country of operation, the NNN as an inclusive global forum, hopes you found the discussions to be enriching in understanding the practical delivery of the new road map: accountability, cross-sectoral collaboration, sustainability, country-led decision making, with equity and inclusion at the core.

I would like to thank the volunteer interpreters, MYT staff, the NNN Executive Committee, the Conference Committee, and the Influencing Priorities Task Team for the work behind the scenes to put together the 2021 conference, and the NNN Communications Task Group for their invaluable support during the conference and in the development of this report. To all our sponsors, thank you very much for your generous contributions to enable this year's conference.

**Dr Kisito Ogoussan, NNN Chair 2020/2021**  
Implementation Management Lead,  
USAID's Act to End NTDs | West program (Act | West)  
FHI 360

A handwritten signature in blue ink that reads "Kisito Ogoussan". The signature is written in a cursive, flowing style.

# Special Session - Walking the talk on country ownership – towards a paradigm shift in global health operations

The NNN has a unique and crucial role to play in inviting member input into and developing a viable path forward for NTD NGO partners to advance the new NTD road map and to recommend measures to address the power imbalance inherent in global health dynamics and relationships between international and national stakeholders.

At the 2021 annual conference, the NNN's Influencing Priorities task team organized a special session titled, "Walking the talk on country ownership – towards a paradigm shift in global health operations" to understand the role that NNN members have played thus far in advancing health outcomes and underscore the need for a transformational approach to improving the health and wellbeing of people living in resource-challenged contexts. Over 520 conference delegates participated in the session which started with a presentation of an overview of NNN membership, followed by a panel discussion, and a breakout session.

A landscape analysis of the NNN membership noted that over 80% of the NNN members came from the Global North, and that 40% of the members focused their work on only one NTD.

The panel discussion featured Dr. Mwelecele Ntuli Malecela, Director, Department of Control of NTDs, WHO, Geneva, Dr. Horace Cox, Director, Vector Control Services, Ministry of Health, Guyana, Dr. Suma Krishnasastry, Professor of Internal Medicine & Director, Filariasis Research Unit, WHO Collaborating Center for MMDP in LF, Government TD Medical College, Kerala, India, and Ms. Arielle Dolegui, Incoming Chair, NNN & Technical Advisor, Health Systems Strengthening & Cross-Sector Coordination, World Vision. The panelists urged donors and implementing partners alike in being intentional about the need to decentralise decision-making and allow endemic country governments and leaders the opportunity to fully embrace local ownership of NTD programmes. For example, in the context of research, Dr. Krishnasastry encouraged all partners to , "to learn to work together and co-determine the knowledge as knowledge is power."

Following the panel discussion, breakout sessions encouraged participants to identify the key responsibilities and priorities of the NGO, Government, Research, & Donor communities in advancing country leadership and ownership in NTD interventions.

Participants suggested that retiring the language of "Global South/North" and replacing it with "NTD endemic/non endemic countries" would be useful to reinforce the purpose of the power shift.

Participants also provided suggestions for actionable next steps, including specific actions for the Donor, Research, and NGO communities. For the donor communities, for example, requiring local ownership of most aspects of programmes as a prerequisite for funding was offered as an actionable next step. Several suggestions were put forth for the research community, including that principal investigators be from endemic countries and the dissemination of research in local languages. Again, participants noted the inherent conflicts, citing for example that "global north academic career progression is in conflict with decolonizing global health....and that this requires a wider paradigm shift so we can walk the talk, not just talk the talk."

Finally, participants noted that NGOs would need to adapt their approach in working with government partners – if the government asks NGOs to take the lead, NGOs need to resist the urge or tendency to take over. Here too, participants noted the challenges in promoting the participation of smaller NGOs or community-based organizations.

In summary, the discussions centered on language, intentionality, and the willingness to change, with several actionable suggestions for the NGO, donor, and research communities to carry forward.



# Workshop summaries





### **1.1 Data integration: A game changer for NTD elimination**

#### **Overview of Session**

The WHO 2030 roadmap calls for neglected tropical diseases (NTDs) programmes to move from disease vertical programmes to be an integrated part of the national health system.

But, are the national systems up to the task? How does one even go about integration? What are the challenges to integration? And, does this even make sense given the elimination goal?

This session summarised the global rollout of DHIS2, the most common software platform for national health management information systems, as well as country level experience with integrating NTDs into national systems such as DHIS2 and IDSR.

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#### **Contact Information**

**Session lead**  
Alex Pavluck, Senior  
Technical Health  
Systems Director,  
Sightsavers

#### **Main learning points:**

WHO guidance, maturity of national information systems, and sustainability concerns are all pushing NTD programmes to move from disease vertical programmes to integrated national systems. However, we must consider what should be integrated, what risks and costs are associated with integration and what to do about programmatic data that cannot be integrated.

#### **Real world implications:**

Without additional guidance, support and funding, the progress of moving from disease vertical programmes to integrated programmes in the national health information system will continue to be ad hoc and uneven.

#### **Next steps and implementation:**

There needs to be more prescriptive guidance on how to move from disease vertical programmes to an integrated part of the national health system. This guidance could come in the form of how to define NTD programmatic activity as routine, what indicators and disaggregations should be proposed, and how to evaluate the readiness to move from disease vertical reporting flows to fully embrace national systems.

**1.2 'Do no harm': Supporting Country-led Programs for the Safe and Effective Delivery of NTD**

**Overview of Session**

'Do no harm' is a fundamental ethical principle. Although safety has long been a cornerstone of neglected tropical disease (NTD) programmes, further cross-sector coordination, planning, and systemic change are needed to improve safety in three key areas: the management, reporting, and prevention of serious adverse events (SAEs); addressing rumours and misinformation about SAEs; and preventing choking in young children during mass drug administration (MDA).

This session explored the critical role of NGOs in promoting a culture of NTD safety. As well as the key three areas highlighted previously, speakers also raised the new NTD safety guidance from the World Health Organization (WHO), collaborations between NTD programmes and pharmacovigilance (PV), and upcoming plans for NTD safety workshops in the Americas.

Several opportunities for NGOs to support country-led efforts were highlighted, including raising safety awareness; facilitating NTD-PV collaboration; conducting situational assessments; building capacity of drug distributors to ensure safety; facilitate safety communication; adapting WHO guidance; and providing financial support.

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**Contact information**

**Session lead**  
Scott McPherson, RTI  
**Speakers**  
Jonathan King, WHO  
David Addiss, FACE  
Jennifer Chukwumerjie,  
NASDAC, Nigeria  
Benjamin Nwobi, RTI  
Ana Lucianez, PAHO

**Rapporteurs**  
Kate McCracken,  
Evidence Action  
Laura Cane, RTI  
Emily Staub,  
The Carter Center  
Elizabeth Sutherland, RTI

**Main learning points:**

NGOs can play a vital role in supporting and improving the safety of NTD programmes – and they are already doing so.

**Real world implications:**

NGOs have a crucial role to play in ensuring and improving the safety of programmes, particularly in facilitating greater collaboration between NTD programmes and pharmacovigilance agencies; supporting the development of comprehensive communications plans and capacity for NTD programmes; and ensuring safe MDA at the point of delivery. These contributions will improve programme quality overall and facilitate integration of NTD programmes into national health systems – a primary goal of the NTD Road Map, 2021-2030.

**Next steps and implementation:**

- Recommendations from breakout groups will be shared with WHO regional offices and national NTD programs currently planning safety workshops, as well as with NGOs.
- Recommendations will be incorporated into work plans for several NGOs for the next fiscal year.
- NGOs will support national NTD safety workshops in at least two additional WHO regions during 2022.



### **1.3 Enhancing Resilience: Country led, people centred, holistic and inclusive approaches to NTD programming and livelihoods**

#### **Overview of Session**

A medical-only approach to neglected tropical disease (NTD) programming falls short of addressing equally contributing factors to poverty and disease. This workshop considered how more holistic and inclusive programming can address some of the multiple vulnerabilities experienced by people affected by NTDs.

Presentations from Nigeria, India and Kenya gave examples of the benefits of addressing intersectional issues and improving DMDI including economic empowerment, stigma reduction and improving mental health.

We heard from persons affected by NTDs how increased ownership and shared decision making is the only way to deliver the WHO NTD Roadmap 2021-2030.

During the group discussions, participants from different countries - with differing disease burdens and contexts - reflected on how they could adapt their programming to make it more holistic and inclusive.

Focus on the  
BEST Framework: **ALL**

#### **Contact Information**

##### **Session leads**

Theresa Baird, CBM Global  
Jannine Ebenso,  
The Leprosy Mission

##### **Speakers**

Kirsty Smith, CBM UK  
Suresh and Mangala Dhondge,  
TLM Trust India  
Chris Ogoshi, HANDS Nigeria  
Tolulope Afolaranmi, University of Jos,  
Nigeria  
Aphuid Njeru, Lucy Nkatha, Kenya Meru  
Inclusive Trachoma (MINT) Programme  
Victoria Bariu, CBM Kenya

#### **Main learning points:**

Donors and actors in non-endemic countries need to listen to persons affected by NTDs and 'let go' of power. Inclusive programming, with persons affected central to the planning process, increases sustainability, and enhances impact.

#### **Real world implications**

It is crucial to ensure active participation of persons affected at the design and development stage of programmes. There are existing tools that could be adapted for this. Programmes must consider all contributing factors, including the link between poverty and disease, and be country-led, people-centred, holistic and sustainable.

#### **Next steps and implementation:**

We will look at ideas suggested for adapting NTD programming and extract practical steps forward.



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## 1.4 Cross-Sector Coordination in Practice: Countries' Perspectives on Multisector Coordination to Advance the Fight against NTDs

### Overview of session

The 2030 WHO Roadmap calls for collective partnerships, innovative models of implementation, and cross-cutting interventions to accelerate programming to advance the fight against NTDs. This workshop provided an overview of the contextualized technical framework, consultation process, and country experiences in designing, establishing, and operationalizing a responsive and adaptive cross-sector coordination mechanism for NTDs.

Panelists from **Ghana, Senegal, and Sierra Leone** shared the role of country ownership in setting priorities forward; the approach to defining cross-sector priorities to respond to each country's individual needs for sustainability interventions; and approaches of the cross-sector coordination mechanism to monitoring and coordinating the country's sustainability interventions and priorities for NTD programming. Panelists highlighted the practical steps and systematic processes undertaken to institutionalize the cross-sector coordination mechanisms, lessons learned, and the outlook for these mechanisms in the sustainable control and elimination of NTDs.

Ghana Intra-Country Coordination Committee (ICCC)  
Sénégal Comité National de Lutte contre les MTN (CNLMTN)  
Sierra Leone Partners Network Forum (PNF)

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### Contact Information

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Sierra Leone  
Ministry of Health and  
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Dr. Hafez Adam Taher  
Ghana Ministry of Health

Dr. Rose Monteil  
FHI360 Senegal

Irene Dzathor  
World Vision Ghana

### Main learning points:

Participants (1) were introduced to the technical framework and systematic processes for establishing a cross-sector coordination mechanism which advocates for political commitment towards mainstreaming NTDs into the overall health system while ensuring the sustainability of NTD interventions and (2) reflected on how dedicated country ownership and commitment to cross-sector collaboration can effectively contribute to the long-term impact of a country's NTD programming interventions.

### Real world implications:

The WHO Roadmap for NTDs 2021-2030 calls for ambitious multisectoral action to achieve cross-cutting targets aligned with the SDGs and NTD control and elimination objectives. National NTD programs are increasingly focusing their efforts on programmatic coordination and integration with cross-sector activities for long-term sustainability. USAID's Act to End NTDs | West Program supported the Ghana, Sierra Leone, and Senegal Ministries of Health to establish cross-sector coordination mechanisms for NTDs through a country-owned, highly contextualized process. This workshop highlighted these experiences, lesson learned, and practical tools. Expert panelists from endemic countries discussed real-life examples of cross-sector coordination in practice.

### Next steps and implementation:

Development of a toolkit which provides frameworks, tools, and recommendations for revamping or establishing a cross-sector coordination mechanism. This is one facet in ensuring that the international NTD community has access to a framework and methodology in support of cross-sector coordination, multisector collaboration, and the WHO 2030 Roadmap for NTDs. Collation of shared experiences with cross-sector coordination and collaboration across countries and across contexts with the support of NNN cross-cutting and expert teams.



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## 1.5 Listening to communities and communicating for impact

### Overview of Session

**Presentation 1:** Under Ascend West, teams in Nigeria implemented beneficiary feedback mechanisms to ensure that activities respond and address the needs of communities. Feedback collected from 2,128 CDDs and 238 hydrocele patients will be included in programme microplanning going forward (closing the feedback loop) to improve programme quality.

**Presentation 2:** In Tanzania, some community groups had been identified as potentially missing from MDA campaigns. WI-HER worked with the MoH to conduct a pilot in four primary schools in Pangani district. Stakeholders from all levels targeted community influencers to address reasons of non-participation in previous MDAs in order to devise a solution to the issue of missed MDAs. This led to significantly improved coverage in pilot schools and a further understanding of how to improve access to, and use of, data.

**Presentation 3:** Barriers to accessing health services in Ghana were having a detrimental impact on the lives of persons with disabilities. The Ghana Federation of Disability Organisations highlighted that issues were largely centred around communication, inaccessibility to services, and data gaps. Key solutions to address this included training health workers on disability awareness and advocating for governmental policies on inclusive communication in healthcare.

**Presentation 4:** In collaboration with M&C Saatchi, Ascend West flexed support to 11 countries during the Covid-19 pandemic to reach over 130m people via mass media campaigns. Key takeaways include making campaigns culturally appropriate, visually accessible, inclusive, with a positive portrayal of people with disabilities, and using a combination of formats to maximise access.

Focus on the  
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### Contact Information

#### Moderator

Uche Amazigo, PACIEH

#### Speakers

Dauda Nurudeen,  
Sightsavers

Debam Mark, Benue State  
NTD Programme, Nigeria

Stella Kasindi Mwita, WI-  
HER

Rita Kusi Kyeremaa, Ghana  
Federation of Disability  
Organisations

Andrea Pregel, Sightsavers

### Main learning points:

To create impactful NTD programming, communities must be included in the activity design from the beginning and at every subsequent stage. Engaging communities will help to ensure programmes are relevant and contextually appropriate so that no-one is left behind, as encouraged in both the Universal Health Care agenda and the WHO 2030 NTD Road Map.

### Real world implications:

Equity in health cannot be achieved without formulating strategies for communities to take charge and be part of the solution to their own health problems. Beneficiary feedback mechanisms and inclusive communication campaigns are key approaches to engaging communities, leading to increased understanding and impact from activities.

### Next steps and implementation:

Prioritise obtaining feedback from communities to ensure sustainability.  
Continue to work with stakeholders in raising awareness and understanding of disability; listening to communities can strengthen community ownership of activities and lead to stronger programme outcomes.  
Design campaigns to be accessible from the start, to ensure no-one is left behind by using examples similar to the materials/resources that were shared in the presentation.



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### **2.1 Country-led approaches on planning and operationalizing the integration and mainstreaming of NTD programs for achieving NTD 2030 targets in India and Ethiopia.**

#### **Overview of session**

This workshop hosted by the Health Campaign Effective (HCE) program of the Task Force for Global Health, aims to align with the recommendations of the WHO 2021-2030 NTD roadmap to emphasize community-based research and country-driven efforts to eliminate NTDs. The focus of the workshop will be on integration and mainstreaming of NTDs. In the workshop, participants will be able to:

- Describe the decision factors and collaborative approaches used by two countries (Ethiopia and India) to **\*\*explore the integration\*\*** NTDs with other health programs and plan their mainstreaming with national health systems, and
- Identify opportunities to apply the lessons from these experiences to other country and local contexts, including health system readiness and community factors that may enable or hinder the integration or mainstreaming of NTDs.

**Full integration** involves the co-delivery of campaign-based health interventions with coordination of most or all typical campaign components.

**Transitioning or mainstreaming of campaign interventions** with the PHC system refers to the eventual assimilation of delivery of vertical health interventions into primary health care services with integrated governance, financing, planning, service delivery, and monitoring and evaluation mechanisms.

Focus on the **T**  
BEST Framework:

#### **Contact Information**

##### **Session Lead:**

Eva Bazant, DrPH, Health Campaign Effectiveness Coalition (HCEC), The Task Force for Global Health

##### **Moderator:**

Teshome Gebre, PhD International Trachoma Initiative, The Task Force for Global Health

##### **Speakers:**

Preetha GS, MBBS, International Institute of Health Management Research, India (New Delhi)

Fikre Seife, EYU Ethiopia  
Zewdie Birhanu, PhD,  
Jimma University,  
Ethiopia

#### **Main learning points:**

**India:** Coordination across stakeholder groups and integration of technology into health campaigns greatly improves effectiveness.

**Ethiopia:** (1) The NTD program should be fully integrated into the national health systems to ensure sustainable programming and long-lasting impact. (2) Ethiopian health systems and communities are well receptive to co-delivery of MDAs for onchocerciasis and soil-transmitted helminths along with complimentary educational health interventions; yet, in order to enhance acceptance of the co-administrations, potential concerns and barriers should be explored and addressed.

#### **Real world implications:**

Some of the key promising practices that emerged from this presentation were the following:

- Involve local government, especially young leaders, closely in the implementation of campaigns
- Conduct intersectoral coordination – at multiple levels and types of organizations – ahead of campaign implementation to maximize the chance of success
- Identify “role models” or leaders who can gain community trust for campaigns
- Provide monetary incentives for health workers and local volunteers
- Consider ways to converge with other health programs in order to more effectively provide community members with access to multiple health campaigns.

#### **Next steps and implementation:**

Complete case study on project from India will be available in late fall 2021. Final study results from Ethiopia will be available in mid-2022. HCE will continue discussions of integration and mainstreaming of campaigns at the HCEC Second Annual Coalition meeting (virtual) on **October 19 and 20, 2021 from 8 AM – 11AM EDT.**



## **2.2 Reaching the last mile: the importance of identifying and addressing gender equity and social inclusion in NTD programming**

### **Overview of Session**

This workshop offered a practical, country-led session that allowed participants to learn from MoH leadership in Tanzania and Uganda, who have led the institutionalization of GESI into NTD programs. Both country examples presented a process for GESI integration, which began with a targeted GESI assessment to identify GESI barriers and gaps to NTD program implementation and goals, followed by the integration of GESI into national policies and plans, and its integration into, and application of, training curricula for mass drug administration. Finally, presenters shared GESI integration experiences from the community level, whereby national, sub-national, and community stakeholders implemented GESI-integrated behaviour change activities to increase coverage and uptake of mass drug administration among vulnerable groups. By explaining this process, and the gaps, barriers and opportunities encountered throughout implementation, participants were able to learn first-hand how GESI integration looks in practice. Then, in breakout groups, participants were able to test their GESI integration skills, with the inputs and suggestions from the workshop presenters and facilitators.

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### **Contact Information**

Taroub Faramand, WI-  
HER

Sara Pappa, WI-HER

Amanda Ottosson, WI-  
HER

Stella Mwita, WI-HER

Mike Mukirane, RTI

Isaac Njau, TZNTDCP

Dr. Alfred Mubangizi,  
Uganda MOH

### **Main learning points:**

Gender equity and social inclusion (GESI) is context specific, critical, and should be integrated into NTD programming at all levels to help to reach those that are most vulnerable and hard to engage.

### **Real world implications:**

GESI approaches should be guided by country governments, program implementers and critically, communities. If GESI approaches are implemented with this mindset, they will be more successful and sustainable as they will be grounded in the local context and realities, and importantly, owned by the countries and communities the approaches are intended to serve.

### **Next steps and implementation:**

Connecting with participants to further explain and share GESI approaches, tools and learning. Within program implementation continue to apply, learn from, and adapt those approaches to reach the last mile.





## **2.4 Decentralized microplanning to accelerate elimination of schistosomiasis and soil-transmitted helminths in Kenya and Rwanda**

### **Overview of Session**

The Kenyan and Rwandan governments are introducing new, decentralized approaches in 2021 to accelerate elimination of two NTDs: schistosomiasis and soil-transmitted helminths, in line with their respective national NTD strategic plans.

In Kenya, the government uses the most recent national gazetted census data, with a growth rate applied, to set NTD mass drug administration (MDA) treatment targets down to ward level. Kenya showed several sub-county comparisons of 2009 to 2019 census data, showing that the ward population shifted considerably during that decade.

In Rwanda, 2-3 months before each NTD MDA campaign, the villages count the real target population per age group, and the health center aggregates and enters this data into HMIS. The NTD MDA treatment target coverage and drug quantifications are based on the real target population.

Akros has developed satellite maps with structure counts to further assist Kenya and Rwanda to plan where and how to reach these targeted populations with treatment. AIHD has identified targeted sub-sets of the population to reach with new social mobilization tools and approaches. Akros and AIHD are supporting each government with new tools for enumeration, microplanning and social mobilization. These activities are funded by the Gates Foundation through the END Fund. We will open with 2 presentations related to their integrated campaign planning. Kenya will share their process of enumerating their population to set targets, and Rwanda will share how

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### **Contact Information**

#### **Session lead:**

Akros

#### **Moderators:**

Elizabeth Jere, Akros  
Mary Nyamongo, AIHD

#### **Presenters:**

Florence Wakesho, MOH  
Kenya  
Jean Bosco Mbonigaba,  
Rwanda Biomedical  
Center  
Clare Amyunzu, AIHD  
Mercy Odhiambo, Akros

### **Main learning points:**

A reliable population source is required to reach every targeted population with NTD MDA interventions. Participants recommended that there should be transparency and triangulation in the selection of population data, with a review of the collected data against population estimates, and post-MDA communication with stakeholders about results.

### **Real world implications:**

During the workshop discussion, the majority of participants (89%) felt that the community counted population should be the preferred denominator for targeted NTD MDA interventions, and 65% of participants felt that the decision on what population is reliable should be determined at the decentralized government level, such as by a district team.

### **Next steps and implementation:**

In 2022, Rwanda and Kenya will have final microplanning and social mobilization packages, lessons learned, and recommendations from their decentralized NTD MDA campaigns. Participants recommended that information be shared through the Global Schistosomiasis Alliance, with the NNN STCH-CHW Group, and at infoNTD.org.

## 2.5 Operationalising One Health for the NTDs

### Overview of session

A One Health approach is crucial for the delivery of the WHO NTD 2021-30 road map, both on specific targets for zoonotic diseases and to support sustainability.

We held a participatory workshop on a One Health framework for action to accompany the road map.

The NTD road map 2021-2030 pillars were applied to One Health to form the basis for a One Health Framework for Action:

- Accelerate programmatic action:
  - Integrate One Health into NTD programme design and delivery
- Intensify cross-cutting approaches:
  - Coordinate and integrate action on NTDs across key sectors
- Change operating models and culture to facilitate country ownership:
  - Country-led One Health action

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### Contact Information

Wendy Harrison,  
SCI Foundation and Chair of NNN  
One Health CCG

### Speakers:

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Public Health Officer, Division of  
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Bernadette Abela-Ridder, WHO,  
Team leader, Neglected Zoonotic  
Diseases

Sithar Dorjee, Director and  
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### Main learning points:

The new NTD road map 2021-2030 describes the critical role of multi-sectoral One Health action in achieving its control, elimination, and eradication targets but One Health has not been sufficiently profiled on the NTD agenda to date. The roadmap describes the purpose of taking a One Health approach for NTDs is to *“ensure a coordinated approach to disease hosts and related environmental factors, with clear assignment of roles and responsibilities”*.

### Real world implications:

The [NNN's One Health Cross-cutting group](#) has supported the WHO to develop a companion document to the NTD road map 2021-2030 on One Health for NTDs, which is to launch in January 2022. This document sets out a framework for action to identify and operationalise key areas for application of One Health in NTDs (see summary box).

### Next steps and implementation:

**Join the NNN's One Health cross-cutting group!** Read more on the website:

<https://www.ntd-ngonetwork.org/cross-cutting-groups/one-health> or email [w.harrison@schisto.org.uk](mailto:w.harrison@schisto.org.uk)



### **3.1 De-mystifying implementation: bringing stakeholders together to operationalize the Global WASH and NTD Strategy**

#### **Overview of Session**

WHO has published a Global Strategy on WASH and NTDs to complement the NTD Road map 2021-2030 and share milestones on access to WASH services. A participatory, inclusive monitoring and accountability framework is needed to ensure the strategy delivers on its objectives. The aims of the workshop were to a) create a shared understanding of the new strategy and its role in delivering the NTD road map and b) initiate the process to develop a workable monitoring framework for the strategy to be implemented by WHO and partners. This will be inclusive of all stakeholder groups and geographical regions, will align with the road map milestones and the overall road map M&E Framework.

The workshop included an overview of the strategic objectives and the need for a monitoring framework; an interactive discussion on the current state of implementation; reflections on monitoring from two endemic countries (Kenya and Lao PDR); a discussion and vote on the desired type of monitoring framework; and breakout discussions on specific indicators for each of the objectives.

Focus on the  
BEST Framework: **B, E**

#### **Contact Information**

Sophie Boisson, WHO

Helen Hamilton, WaterAid

Gilbert Baayenda, Uganda  
MoH

Dauda Nurudeen,  
Sightsavers

Sultani Matendechero,  
Kenya NPHI

Souvanaly (Tock)  
Thammavong, WHO

#### **Main learning points:**

Much progress has been made so far but a monitoring framework is required that captures information regularly and that reflects activities across all regions.

#### **Real world implications:**

The monitoring framework should be a hybrid model that allows both self-reporting against stated commitments as well as objective progress measures in the form of a scorecard. While this may require more work from all stakeholders, this model will allow more accountability as well as recognition of all progress, however small.

#### **Next steps and implementation:**

Participants provided a set of indicators with which the monitoring framework will be populated. The WHO team and NNN WASH working group will collaborate to develop a workable framework and share this with all relevant stakeholders in the coming months.



### **3.2 Participation and involvement of persons affected by NTDs: How to keep the NNN membership committed?**

#### **Overview of Session**

This session introduced a concept version of the NTD Inclusion Score Card (NISC). The NISC is based on the Disability Inclusion Score Card (DISC) and is a self-assessment tool that helps NTD NGOs to assess to what extent these organisations actively involve and facilitate meaningful participation of persons affected by NTDs. The NISC focuses on governance, programme management, human resources, financial resources, accessibility, and external relations.

The session was facilitated by DMDI working group convenors Mathias Duck and Suresh Dhondge, introducing the importance of meaningful participation of persons affected by NTDs. During the NNN conference in 2020 this was supported by the NNN membership through the adoption of the NNN “Statement of commitment to the participation of persons affected by NTDs”. Nikita Sarah illustrated how TLM India facilitates meaningful participation of affected persons through concrete examples. At the end of the plenary Paulien Bruijn introduced the NISC tool. After the plenary, the group split up into five breakout sessions, discussing the dimensions of the NISC.

Focus on the  
BEST Framework:

**S**

#### **Contact Information**

Mathias Duck, TLM  
International

Suresh Dhondge, TLM  
India

Paulien Bruijn, Into  
Inclusion

Nikita Sarah, TLM India

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

The NISC tool approach was seen as very relevant for NNN member organisations. Different versions might be needed for coordinating/international organisations and implementing/locally based organisations.

#### **Real world implications:**

When further developing the tool, global as well as local situations, should be taken into account. Furthermore, the tool can be helpful as a supportive recourse when developing internal policies, such as HR policies, or annual strategies for the NNN NGOs. In addition, a toolbox could be developed that can support the NNN NGOs to improve their NISC score.

#### **Next steps and implementation:**

The NISC tool is still in a concept phase. The workshop participants were enthusiastic, and this has encouraged the DMDI CCG to continue its development. The DMDI CCG will be looking for NNN NGOs that are willing to participate in a pilot and report back to the NNN membership.



### 3.3 Embedding NTD sustainability into national structures

#### Overview of Session

In 2021, WHO launched “Ending the neglect to attain the sustainable development goals: a sustainability framework for action against neglected tropical diseases 2021-2030,” the first global document that provides guidance on embedding sustainability considerations into national health policies, strategies and plans. National programs undertaking such efforts have had varying degrees of success. ACT | East, ACT | West, and ASCEND programs are supporting multiple countries to embed sustainability into their NTD programs. This session showcased lessons on how NTD programs and the NGO community in Cote d’Ivoire, Ethiopia, and Ghana, mainstreamed NTD sustainability efforts into existing structures.

In Cote d’Ivoire, political validation of the NTD sustainability plan with a group of multisectoral stakeholders was key to successfully integrating NTDs into the 2030 National Health Strategy. Meanwhile, in Ethiopia, there was a need to align all stakeholders on a definition of sustainability prior to embedding priorities that emerged from their sustainability plan into the country’s NTD Master Plan. Finally, in Ghana, costing program services and developing investment cases for advocacy purposes—domestic and external alike—was used to spur national conversations around sustainable NTD program financing.

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

#### Contact Information

##### Presenters

Aboulaye Meite, Cote d’Ivoire  
MoH, NTD Program Manager

Fikre Gebretsadik, FMOH-  
Ethiopia, National NTD  
Program Team Leader  
Ethiopia MoH

Joseph Opare, Ghana MoH,  
NTDs Program Manager

Virginie Traore-Ettiegne,  
FHI360, Project Manager

Wangeci Thuo, RTI  
International, NTD Technical  
Advisor/ Advocacy Specialist

Berthine Njiemoun, Deloitte  
Consulting, Senior Consultant

#### Main learning points:

Each country responded to the challenge of embedding sustainability into existing national structures in different ways, based on national priorities, political opportunities, and country and national trends, including Universal Health Coverage. Driving each country’s effort was a sustainability plan, informed with epidemiologic, programmatic, and financial data, developed with strong multi sectoral coordination and commitment.

#### Real world implications:

A concerted effort is required from NTD Programs and the NGOs that support them to mainstream Programs into broader systems and existing structures, with a focus on sustainability. Such efforts are foundational to delivering on the WHO framework’s major pillars: accelerate programmatic action; intensify cross-cutting approaches; and change operating models and culture to facilitate country ownership.

#### Next steps and implementation:

As countries continue on the journey towards making the 2030 framework’s vision a reality, they will continue to generate useful evidence and lessons learned on improving NTD Program sustainability. The documentation and sharing of such information will help NTD Programs and supporting NGOs to strengthen their approaches, ultimately leading to improved implementation and sustainable Program outcomes.



### **3.4 Different diseases, same agenda: facilitating integration and country ownership to accelerate NTD elimination**

#### **Overview of Session**

The session began with an overview of the difference between eradication (the global absence of disease), elimination of transmission (the absence of disease in a defined geographic location) and elimination as a public health problem (disease does not significantly contribute to mortality/morbidity in a defined location). Next was an overview of the process Nigeria went through to write its National Onchocerciasis Elimination Plan, and how they were able to incorporate WHO guidelines whilst ensuring local voices were elevated and country-level experiences were centred. Following this, the real-world practicalities, opportunities and challenges of integration were discussed using the example of Sierra Leone's Integrated NTD Programme Model. Finally, the role of data in achieving elimination targets was explored through the lens of the national NTD programme in Bangladesh.

Focus on the  
BEST Framework:

**B**

#### **Contact Information**

B.E.B Nwoke, Imo State  
University

Fatu Yumkella, Sierra  
Leone NTD Programme  
Technical Advisory  
Committee

Abu Nayeem Mohammed  
Sohel, NKEP

Patrick Ndongmo,  
Sightsavers

Dieudonné Sankara, WHO

#### **Main learning points:**

While integration presents clear opportunities for streamlining, reduction of overlap and increases in efficiency, we must be mindful of each of the PC-NTDs' particular elimination needs if our efforts are to succeed. We must also carefully consider local contexts and make an active effort to centre in-country voices and expertise so that the desire to harness the benefits of integration does not lead to oversights that end up slowing progress.

#### **Real world implications:**

Having strong in-country leadership is key – not only to ensuring programmatic efficiency is optimised, but also in order to generate political will, galvanise coordination at all levels and ensure there is a central source of information and influence. Good data is also key, as without it, you are unable to do the meticulous planning needed to create integrated programmes that achieve their elimination goals. Finally, partnerships, as always, are key. Elimination cannot be achieved unless all actors in a given space have good relationships with clear communication.

#### **Next steps and implementation:**

Do we need to engage in specific efforts as a sector to coordinate advocacy and mobilise political will? Ensuring there are platforms available for deliberation and discussion regarding priorities, coordination, and more, requires greater focus. More opportunities to share specific challenges/successes in country integration efforts for learning purposes would be beneficial.



### **3.5 Reaching the last mile for trachoma elimination: ensuring equitable access and sustainable impact of interventions**

#### **Overview of Session**

To achieve and sustain the elimination of trachoma as a public health problem, it is essential that interventions be integrated into health systems so that incident trachoma cases can be identified and managed efficiently and effectively.

This workshop facilitated discussion and knowledge exchange in ‘reaching the last mile’ towards the elimination of trachoma as a public health problem.

The workshop included reflections from country programs on efforts to transition from elimination programs to sustainable integrated systems.

Focus on the  
BEST Framework: **ALL**

#### **Contact Information**

Scott McPherson, ICTC  
International  
George Kabona, MoH, Tanzania  
Dr Saleh Al-Habry, MoH, Oman  
Dr Abdullatif Al Raisi, MoH,  
Oman  
Sarjo Kanyi, NEHP  
Stephanie Palmer, FHI 360  
Jeremiah Ngondi, RTI  
International  
Grace Ajege, Sightsavers  
Michaela Kelly, Sightsavers  
Zahid Awan, CBM  
Juliana Amanyi-Enegla, CBM  
International

#### **Main learning points:**

It is recommended that ‘transition planning’ is incorporated during the development of the national Trachoma Action Plan. Countries that do not have a detailed transition plan should start the process of developing a plan as soon as possible. Involving the MoH eye care directorate/unit in planning is essential.

#### **Real world implications:**

Informed and increased country-led decision making is needed to ensure integration of NTD interventions. Strengthened domestically financed health systems is essential to ensure trachoma interventions are included in routine health services.

#### **Next steps and implementation:**

ICTC’s transition toolkits provides countries and implementing partners with tools to support the transition of trachoma activities into routine public services. Planning of transition should happen at the beginning of programs to ensure effective integration and sustainable action towards the elimination of trachoma as a public health problem.



### 3.6 Remote supervision: how can we build back better?

#### Overview of Session

In this session we heard about experiences from the field in adapting to the pandemic by using remote tools to carry out supervision of MDA and coverage surveys as part of NTD programme implementation. Christian Nwosu, explained how the use of the CommCare application in Nigeria has improved remote supervision by enabling health workers to feedback on implementation progress, with state coordinators receiving real time information and coordinating using phone calls and WhatsApp. Abdulmaleek Mohammed presented on the Nigeria Ministry of Health experience using CommCare, which has enabled real time monitoring and enabled timely feedback and adjustments. Nana Ama Tiwaa-Boateng outlined how Kobo Collect and WhatsApp were used in Ghana to address challenges related to the monitoring of MDA supervision. The use of these platforms improved data quality at subdistrict level, and enabled real time feedback of MDA supervision. Finally, Anthony Kerkula Bettee and Akinola Oluwole presented on the use of multiple media tools for remote supervision and support of primary care for Female Genital Schistosomiasis interventions in Liberia and Nigeria. Dr. Oluwole spoke about the use of WhatsApp to engage with implementing teams, which allowed for troubleshooting and for subnational and lower level implementors to be directly engaged with the national programme. Anthony Bettee spoke of the use of Microsoft Teams as a forum for intervention design and to review action plans, promoting local ownership of the intervention, whilst reducing the risk of COVID-19 infection.

Focus on the  
BEST Framework:

**T**

#### Contact Information

Dr John Amuasi, Executive  
Director, African Research  
Network for NTDs  
Dr Akinola Oluwole,  
Sightsavers, Research  
Officer

Christian Nwosu,  
Sightsavers, Digital Health  
and Innovations Advisor  
Anthony Kerkula Bettee,  
MPH, Ministry of Health,  
National Schistosomiasis  
Coordinator

Nana Ama Tiwaa-Boateng,  
Sightsavers, Project Officer  
Abdulmaleek Mohammed,  
Ministry of Health, Public  
Health Practitioner

#### Main learning points:

The use of digital remote supervision tools can improve data quality, whilst also improving communication and linkages between national NTD programmes and community health workers by allowing for real time data availability and monitoring; and providing consistent communication channels to address challenges.

#### Real world implications:

Innovation through the use of digital tools like CommCare, WhatsApp and Kobo Collect has provided opportunity for real time monitoring and supervision, enabling programmes to ensure that activities are carried out effectively, reaching all those that need to be reached. The implications of using these technologies are that interaction and collaboration between health workers and national and international stakeholders is enhanced, thus improving outcomes by ensuring effective avenues for communication, troubleshooting and supervision.

#### Next steps and implementation:

Some of the key challenges outlined during this session included the security of the tools used and the accessibility of technology. Going forward, programmes will need to continue to ensure they use the most secure tools, identifying which servers work best to ensure that data captured is secure. It will be important to ensure effective IT and data management as remote supervision tools will continue to be needed as the pandemic continues to change the way we work. This will include providing training for health workers on the use of the tools and seeking to engage users of the tools by gathering feedback on data use and challenges.



# Rapid fire session summaries





## ***RF1.A Integrating Scabies into Skin NTD Programs in Pacific Island Countries***

### **Overview of Session**

Scabies is one of the most common neglected tropical diseases (NTDs) affecting 450,000 million each year; mostly people living in crowded, impoverished conditions, and with the greatest impact on children. Scabies can lead to infected skin sores that can result in life-threatening conditions. In 2017 scabies was added to the WHO list of NTDs and now is included in the NTD roadmap. However, like many skin NTDs, scabies is often neglected and underfunded.

In 2019 a group of experts agreed on a framework for controlling scabies. The framework recommends mass drug administration in endemic areas, increased community awareness, strengthening case management and surveillance of scabies. Many components of this framework are common with other NTD programs providing many opportunities for integrating scabies with other NTD programs. In Solomon Islands and Fiji, the World Scabies Program is working with ministries of health to integrate scabies control strategies with activities for lymphatic filariasis and yaws. Examples of activities integrated include mass drug administration, community awareness campaigns and training for primary health care workers.

Focus on the  
BEST Framework: **T**

### **Contact Information:**

Sarah Andersson,  
Program Manager,  
World Scabies Program,  
Murdoch Children's  
Research Institute

### **Main learning points:**

Scabies affects some of the world's most disadvantaged people in the world and can result in life threatening complications. Countries with endemic scabies (>10%) can take up a public health approach to control scabies by integrating activities for scabies with other NTDs. Strategies include integrating mass drug administration, community awareness messaging with other diseases, training health care workers to detect and provide early treatment and enhancing surveillance through routine health information systems.

### **Real world implications:**

Scabies affects millions of people living in crowded, impoverished conditions, with the greatest impact on children. Reducing the burden of scabies will improve lives and reduce the number of infected skin sores that can result in life-threatening conditions.

### **Next steps and implementation:**

In areas where scabies is endemic, countries should consider integrating scabies control strategies with other NTD programs. As the World Scabies Program works with governments in Fiji and the Solomon Islands to implement national scabies control programs, the program is developing ready-to-implement materials and resources that can be shared with other countries and programs who wish to implement scabies control programs.



**RF1.B Promoting access to preventive chemotherapy for NTDs  
among refugees: A systems-based approach**

**Overview of Session**

The session discussed a systems-based examination of refugees' access to preventive chemotherapy against NTDs in Niger. Refugees are particularly vulnerable to NTDs due to their material deprivation, socio-demographic profile, precarious living conditions, and limited access to public health services. Complex security conditions and institutional landscape, involving humanitarian and NTD organisations, make responses to refugees' needs challenging.

A consultation with national and local level stakeholders served to generate a casual loop diagram to inform recommendations on the subject. Systems-thinking encourages decision-makers to examine the complex array of (in)direct and (non)linear linkages connecting factors influencing outcomes whilst promoting a shared understanding of problem-situations and solutions. By identifying critical drivers of results, it enables stakeholders to identify optimal intervention areas for positive change.

Focus on the BEST Framework: **T**

**Contact  
Information**

Carlos Torres-  
Vitolas, MER  
Advisor:  
Social Science,  
SCI Foundation

**Main learning points:**

- Substandard living conditions and location of settlements in endemic areas increase the need for NTD treatments.
- Growing refugee population affects the capacity of NTD and humanitarian actors to respond to treatment needs.
- Treatment and WASH sensitisation activities take place in camps. Mapping capacity is limited and saliency of NTDs in health education programmes appears limited.
- MDAs from the Ministry of Health is likely to reach refugees hosted in local villages. Existing reporting systems do not allow to identify the extent of reach.

**Real world implications:**

- Information on refugee population distribution should be shared across humanitarian and NTD actors.
- Mapping activities for NTDs are urgent among refugees, not only in camps but also in hosting villages.
- NTD actors have a wealth of expertise in community sensitisation and mobilisation activities that can be shared among humanitarian actors.
- Regional and local-level planning activities for MDAs should incorporate humanitarian organisations to confirm presence of refugee settlements, ongoing parallel control activities, and access to public education services.

**Next steps and implementation:**

Findings should be further disseminated to promote discussions on pathways to implement recommendations. Support is required to promote coordination and cooperation between humanitarian and NTD organisations. This includes policy-level (e.g., with United Nations institutions) and implementation-level discussions (NGOs). Mapping activities for NTDs, particularly in refugee settlements outside camps, are urgent. NTD organisations working in refugee areas across frontier countries should communicate to share solutions and strategies.



**RF1.C SAPIENS: A tool to conduct small area population evaluations**

**Overview of Session**

So much of NTD programmes are based on population figures. To name but a few, there is treatment targets, MDA planning, drug requests, reported coverages, with currently no formalised mechanism to assess or review the population figures used in these.

As National censuses occur infrequently, population figures used by a programme can be expected to be inaccurate or non-representative of current situations in the country.

[SAPIENS](#) tested and evaluated two methods of modelling population estimates developed by [WorldPop](#) and compared these modelled population data alongside those used in NTD programmes to create a method which would allow NTD programmes to evaluate their current official population figures.

Focus on the  
BEST Framework:

**T**

**Contact Information**

**Presenter**

Alexandra Carlin,  
Associate MER Advisor,  
SCI Foundation

**Main learning points:**

- Lack of up-to-date and standardised geographic data.
- A recommendation towards a single population figure for all NTD endeavours. The process of determination of the single population data source should be country-led.
- Research needed to create population data quality thresholds to assess the effects incorrect populations have on NTD programmes in terms of cost and progress towards NTD goals.

**Real world implications:**

As countries move to more targeted treatment in PC-NTDs, accurate populations will be more vital than ever to implement smaller targeted MDAs to key at-risk populations. However, currently doubts may be held in the population data used by an NTD programme, with no alternative than to use outdated census or survey data to inform their planning or drug requests. So following other sectors, SAPIENS aimed to create access to modelled population data by providing a step-by-step guide and automated tool, called the SAPIENS Guidance Document and Population Review Workbook, to enable NTD Programme Managers or Data Managers to use this modelled data to scrutinise a NTD programme's population data.

**Next steps and implementation:**

- **Disseminate** findings to the pilot countries MoH.
- **Trial** the SAPIENS Guidance Document and Population Review Workbook start to finish with a country MoH to improve the resources for further application. Templates can be found via SCI Foundation website.
- **Fund** gather for further research into integrating microcensuses alongside regular M&E surveys in the NTD Sector to supply population data necessary for the models mentioned.
- **Research** further to understand the possibilities of WorldPop modelled data to enable targeting of specific at-risk populations for treatment.

**RF1.D Ending the Neglected to Attain the Sustainable Development Goals: A Road Map for  
Neglected Tropical Diseases 2021-2030**

**Overview of Session**

A recent pilot study assessed the effectiveness of the integration of a Chronic Disease Self-Management (CDSM) Program into Hope Clubs, or social support groups, in Léogâne, Haiti in improving depression, disease self-management, self-rated health, social support and disability among persons living with lymphatic filariasis. Findings suggest that there is a potentially beneficial effect of the intervention on symptoms of depressive illness among participants. The session highlighted how this work can help elucidate the feasibility of the integration of mental health activities into national NTD strategies and the NTD roadmap, and the importance of incorporating mental health and well-being into NTD care systems.

Figure 1: Mean scores on depression symptom inventory from baseline to endpoint.

Figure 2: Hope Club participants attending a focus group.

Focus on the BEST Framework: **ALL**

**Contact Information**

Luccene Desir  
Program Manager,  
Hispaniola Initiative  
The Carter Center

Sadie Bazar-Leidy  
Senior Program  
Associate, Mental  
Health Program  
The Carter Center

**Main learning points:**

- Evidence from the pilot study suggests that the Chronic Disease Self-Management intervention may have a beneficial impact on symptoms of depressive illness among persons living with lymphatic filariasis.
- There is an increasing need to integrate mental health components into national NTD strategies and programming.

**Real world implications:**

The pilot study highlights the Chronic Disease Self-Management curriculum as a mental health intervention that was successfully integrated into an NTD care setting in Haiti. Understanding the mental health burden of persons affected by NTDs and exploring effective strategies paves the way for further conversations and learning around the feasibility and practicality of integrating mental health into national NTD programming.

**Next steps and implementation:**

Further research is required to better understand the effect of specific interventions on the mental health outcomes of persons living with NTDs. Findings from the study support the integration of mental health into NTD care and will be shared broadly with the NTD community to build on the current understanding of this programmatic nexus.



***RF1.E NTD Program Costing & Resource Allocation: How NGOs  
Can Amplify Country-level Advocacy Efforts to Fill the Funding Gap***

**Overview of Session**

One of the three major pillars of the [WHO Roadmap for NTDs 2021-2030](#) is Programme Ownership, which refers to country ownership and financing of NTD Programs (NTDPs), such as establishing government-funded budget lines for NTD activities. As NTDPs work to include NTD interventions into national health plans and budgets, their NGO partners must support their advocacy efforts around domestic resource mobilization.

Since 2018, USAID's Act to End NTDs | West (Act | West) has been building NTDPs' capacity to use the Tool for Integrated Planning and Costing (TIPAC). TIPAC allows users to estimate the cost of implementing activities, quantify existing resources, identify funding gaps, produce reports, and generate projected program costs and drug needs. Already, NTDPs have used TIPAC outputs to facilitate identification of integration opportunities and annual planning. As NGOs worldwide have rallied to support increased government commitment, programs, and financing of a range of health issues, from HIV/AIDS to family planning to tuberculosis, Act | West sought to solicit input from the NTD NGO community during this session on how to amplify the work of NTDPs and support advocacy and domestic resource mobilization efforts.

Focus on the  
BEST Framework **B**

**Contact  
Information**

**Presenter**  
Berthine Njiemoun,  
MPH  
Senior Consultant,  
Deloitte Consulting  
LLP

**Main learning points:**

Throughout Act | West's experience with NTDPs, TIPAC has helped NTDPs extract the underlying data that support advocacy efforts for critical, under-funded NTD activities. Gathering and leveraging these programmatic and financial data in NTDP-led advocacy efforts is one example of how NTDPs can engage relevant stakeholders as countries increasingly take on ownership of NTD activities.

**Real world implications:**

Participant input on NTD financing advocacy efforts indicated that NTD NGOs' involvement has been mostly through interacting with Ministry of Health decision-makers and lobbying policymakers. Others indicated that no role has been played in NTD advocacy around financing. Act | West's experience has underlined the need for NTD NGOs to play a strong supporting role in such advocacy efforts and to open the aperture and broaden their advocacy efforts to reach additional stakeholders, including Ministry of Finance and private sector actors.

**Next steps and implementation:**

The various avenues through which NTD NGO communities can support NTDP efforts in resource mobilization and funding gap reduction include sharing gap data through advocacy across a broad range of stakeholders beyond the Ministry of Health; financing social activities; providing technical assistance; and supporting educational initiatives that promote the expansion of NTD control activities.



***RF2.A Spatial Intelligence: Enabling new frontiers for equitable access***

**Overview of Session**

Spatial intelligence is the application of paper based and digital map technology to guide the planning and delivery of health interventions. This technology is increasingly being applied to improve the coverage of life-saving interventions, including mass drug administration for NTDs. This session provided a snapshot of Reveal, a leading spatial intelligence platform which uses satellite imagery to understand total population and population distribution. These data inform macro and microplanning and are put in the hands of field workers to navigate through their communities and deliver MDAs. Management staff use real time dashboards to monitor campaign coverage to ensure high coverage is achieved.

[Reveal](#) is a digital global good and is currently used in 10 countries. Use cases within the NTD sector include MDA for onchocerciasis, lymphatic filariasis, STH and schistosomiasis.

Focus on the  
BEST Framework:

**B**

**Contact Information**

Anna Winters, PhD  
Akros

**Main learning points:**

Spatial intelligence significantly improves impact through delivering reliable data on populations and ensuring health interventions reach the last mile.

**Real world implications:**

The global community has set ambitious disease elimination agendas. New innovative approaches are required to achieve these goals. Use of the spatial intelligence digital platform, Reveal, should be further explored, and expanded to deliver interventions at high coverage rates, and to the last mile.

**Next steps and implementation:**

Areas to explore and expand include:

- Delivery of end-to-end health campaigns integrated across multiple diseases and guided by spatial intelligence.
- Additional research and cost analysis reviewing the degree which spatial intelligence improves true coverage and impact of health campaigns.
- Costing analysis.



**RF2.B Social Science contribution towards NTD Programming in Sierra Leone**

**Overview of Session**

Four districts with high baseline prevalence for LF failed Pre-TAS in 2017 though they have reported therapeutic coverage of over 65%. The NNTDP and HKI with technical support from LSHTM conducted a rapid social science assessment with different age groups to find out why communities with ongoing LF Transmission are hesitant towards Mass Drug Administration (MDA) drugs and Disease Specific Assessments (DSAs).

Remote zoom training of researchers by the LSHTM was done on the following social science methods: Ethnography and participants observation, In-depth interviews, focus group discussions and participatory workshops on power mapping and rumour tracking. Pre-testing of tools done whilst observing COVID-19 regulations at all levels.

The findings from this rapid assessment is used to re-design and inform a responsive community engagement strategy: a paradigm shift from previous models that relied on messaging and information.

Focus on the  
BEST Framework:

**B**

**Contact Information**

**Lead Moderator**

Luisa Enria

**Speaker**

Gandi Kallon,  
Helen Keller INT'L

**Main learning points:**

The use of innovative social science approach that ensures community engagement is driven by evidence grounded upon people-experience.

**Real world implications:**

Given the challenges faced by the Sierra Leone NTD Program, a contextualized understanding of the social factors determining acceptance, hesitancy and refusal during MDA and DSAs will enable programmers to design a responsive community engagement strategy in the context of COVID-19.

**Next steps and implementation:**

Recognizing the role of communities and integrating their voices into NTD programming  
Integrating social science community –centred approach into NTD programming  
Enabling CHW to identify barriers, social exclusion and tackle mistrust.





**RF2.C MSF: Challenge of managing Innovative and Intensified Disease Management (IDM) NTD's in Africa**

**Overview of session**

IDM NTD's are difficult and costly to manage, their burden is poorly understood, there is a lack of appropriate control tools and relatively low investment in research and development. People affected often live in remote rural areas with poor health systems and limited access to diagnosis and treatment. MSF provides care for visceral leishmaniasis (VL) in Africa. There are multiple challenges, some of which are: persistent fever is the main symptom (unspecific); rapid test (IT-Leish, BioRad) production will be discontinued per May 2022; treatment and diagnosis are not decentralized. In South East Asia a regional VL elimination plan was initialized in 2005 and elimination is now almost achieved. In East Africa the VL burden has remained the same and is now the highest worldwide. Outbreaks are common. The main 2030 WHO Roadmap Goal for VL, <1% case fatality rate, is far from being reached. VL elimination in East Africa is feasible but the following is needed: 1) research for better tools for prevention, diagnosis and treatment 2) a regional approach, country leadership and political visibility in affected countries 3) long term donor support.

Focus on the  
BEST Framework:

**B**

**Contact Information**

Margriet den Boer  
Kala azar advisor,  
Médecins Sans  
Frontières/Doctors  
Without Borders (MSF) UK  
and Ireland

**Main learning points:**

To achieve the 2030 WHO roadmap goal for VL in East Africa a regional elimination plan is needed.

**Real world implications:**

A major effort must be made to develop a regional VL elimination plan in East Africa, establish country leadership and engage long term donor support.

**Next steps and implementation:**

In South East Asia, VL elimination has almost been reached. A successful regional approach was taken under strong leadership of the countries and WHO. Contributions of all stakeholders, including NGO's, pharma and donors were well coordinated. A similar approach can be taken in East Africa, starting with the establishment of a Technical Regional Advisory Group under WHO as was done in Asia.



***RF2.D London Centre for NTD Research rapid fires on stigma, discrimination and mental health***

**Overview of Session**

2021 has been a landmark year for those fighting for disability inclusion and a person-centred approach to NTDs. After decades of conceptualising, researching, and bringing the importance of this topic to the fore, the launch of the WHO road map 2021-2030 has delivered a paradigm shift in the way NTD programmes are being approached and delivered. The road map includes an emphasis on people-centred programmes, which is supported by new resources including the WHO Guide on Mental Health and NTDs.

This session, coordinated by the London Centre for NTD Research explored the theoretical underpinnings and systematic undervaluation of the burden of illness when using disability adjusted life years. It brought together researchers and implementing partners to strengthen the eco-system between academic and implementation to ensure that research around disability inclusion is reflected in NTD advocacy and programmes.

Focus on the  
BEST Framework:

**B**

**Contact Information**

David Molyneux, Liverpool  
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**Main learning points:**

Disability adjusted life years as a metric to measure the burden of disease underestimates the burden of NTDs, as it does not account for the significant levels of diminished mental health associated with people affected. NTD programs must take a holistic approach that includes care and wellbeing for people affected.

**Real world implications:**

The implications of underestimating the DALYs of NTD can result in reduced investment or programmes that to maximise the health of the world's most vulnerable people. If we do not mainstream the inclusion of people affected by NTDs, our programs risk leaving behind those most in need of care.

**Next steps and implementation:**

All programs should utilise resources including WHO and NNN's Mental Health of people with NTDs, Towards a Person-Centred Approach NNN and ILEPs Guides on Stigma and Wellbeing and work towards mainstreaming inclusion and mental health wellbeing into programs. Advocacy efforts should highlight the mental health impact of people with NTDs.

# Conference highlights



# Closing remarks from Incoming Vice-Chair, Girija Sankar

Before entering the world of NTDs, I led community-based programming in Haiti, facilitating training and technical support for community health workers who provided critical services to women and young children. I had the opportunity to learn from multiple actors within a health system - in working with community health workers, I learned about the importance of grounding development and health efforts where it matters most – at the community-level, centered around women and children. I learned that trust is the cornerstone of progress - between health workers and their communities, between community leaders and community members, and between NGOs and Ministries of Health.



Girija Sankar, 2021/2022 Vice-Chair

Since 2015, I have been privileged to support NTD elimination, first at the Task Force for Global Health, and more recently, at CBM. The NTD community has taught me valuable lessons in collaborative problem-solving. I've watched in fascination as members of the trachoma or STH or leprosy communities would set aside organizational differences to advance collective goals. I've admired your selflessness in sharing resources and facilitating knowledge transfer. It is these lessons that I bring with me in my role as Vice-Chair. Equipped with our learnings from the NNN 2021 special session titled, "walking the talk on country ownership – towards a paradigm shift in global health operations", we are keen to develop a new strategic framework to align the NNN with the new road map. Facilitating the development of this new strategic framework is one of my key priorities as incoming vice-chair.

This is the second year of virtual conferencing... two years in a row that we've missed out on shared meals, coffees, and hurried conversations in the hallways between sessions. I know we're a community of eternal optimists, so I know for sure that we will get back to meeting in-person soon. I do believe there is an upside to this virtual environment. If we do have decent internet connectivity, we are in a sense that much closer to each other. An opportunity then to be more intentional about promoting and encouraging peer-to-peer exchanges and networking within the NNN, and to strengthen the NNN as a more inclusive NGO forum. These are some of the initiatives that I am eager to carry forward in the coming years.

I look forward to working with Arielle, Kisito, and the NNN community to advance our vision of a world free of NTDs by upholding our values of participation, legitimacy, creativity, and independence.

**Girija Sankar, NNN Vice-Chair 2021/2022**

Head of NTDs - Inclusive Eye Health Initiative, Christian Blind Mission

# Closing remarks from Incoming Chair, Arielle Dolegui

Thank you to participants, delegates, friends, and colleagues for joining us at the 12th annual NNN conference with 3 days of engagement, networking, learning, sharing and just connecting with one another in our NTD community. For the second year now, we have been able to demonstrate our steadfast commitment and resilience in furthering our mission towards a world free of NTDs by hosting the conference virtually, despite the limitations imposed by the ongoing pandemic.



Arielle Dolegui, 2021/2022 Chair

This year's theme "Enabling a paradigm shift to a country-led response to deliver the NTD Road Map" calls us to collectively rethink our programmatic approaches on the heels of the 2021-2030 WHO road map launch. As we know, the road map calls for a radical acceleration of programmatic action, enhanced cross-sectoral collaborations and a shift to country-driven prioritization of interventions to reach its ambitious goals of disease control and elimination

The 2021 conference was exceptionally transformative. First, a diverse high-level panel of international leaders set the opening scene by sharing their vision and guidance for innovative approaches to fundamental shifts in NTD programming. This was followed by a special session dedicated to exploring Pillar 3 of the NTD road map which calls for a change in "operating models and culture by increasing country ownership, clarifying the roles of organizations, institutions and other stakeholders, their culture and perceptions and aligning them to meet the 2030 targets." This was a crucial conversation that generated a lot of engagement and excitement in our community. I am grateful for the NNN's openness and transparency to have such a critical introspective look as a community of practice that has independence and influence to assess its operational guiding principles, but also lead the way for its NGO members to follow suit in addressing imbalances in power dynamics for a true and effective collaboration with the common goal of advancing country ownership at all levels of implementation to beat NTDs.

In addition, with 16 full workshops, two rapid-fire, and numerous networking sessions, the conference was enriched by exciting knowledge sharing and research findings with recurring themes of resiliency, adaptability, and restorative practices to accelerate programming and implementation of the WHO road map. We have challenged ourselves and each other to think beyond normative approaches to designing new and innovative models of practice.

As mentioned by our Outgoing Chair Kisito Ogoussan, the NNN community is embarking together on this journey to 2030, and as such, we must keep our eyes on the target 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 to build resilient and sustainable health systems. As an NGO platform, we have a unique opportunity to cement our core value of implementing person-centered, cross-sectoral, and equitable interventions while striving to elevate our commitment to promote programmatic effectiveness driven by country-led decision making and alternative models of operations, requiring a heightened and intentional collaboration across the NTD community and with other sectors.

### **Call to action**

I am full of excitement for the new year ahead and our collective commitment to shift paradigms of operations and programming in rolling out the road map. I know that reimagining transfers of power is a daunting task, the process for redressing ingrained practices is slow and heavy, but I look forward to the positive changes we can bring about as the NNN community. A community of dedicated members to rid the world of NTDs, a unified voice of NGOs committed to enhance our community of practice and aligned towards inclusivity and equity in our partnerships to reach the goals of the road map. It is my hope that this momentum is maintained throughout the years and I encourage you to continue your involvement with the NNN through your participation in our cross-cutting groups and task teams. I also seek your support and guidance as I begin my tenure as Chair of this community and look forward to leaning on your unique experiences to strengthen our collaboration and partnerships.

### **Arielle Dolegui, NNN Chair 2021/2022**

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

# NNN Statement of Commitment to Hand Hygiene For All 2021

## Matching commitments to actions - the NNN way

In 2020, NNN made a [commitment to support the attainment of hand hygiene for all](#) through three focal areas; fostering cross-sectoral political leadership, creating enabling environment, and promoting sustainable and inclusive programming at scale.

One year after this commitment, we reflect on these commitments and share our progress:

### Political leadership

- The NNN supported the development of a new Global Strategy on WASH and NTDs to deliver the cross-cutting pillar, including a strong focus on hygiene and behaviour change overall, mainstreamed into all strategy actions.
- The NNN supported the development of national frameworks on WASH and NTDs coordination in Ethiopia, Uganda, Mozambique and Kenya, as well as national behaviour change strategies. NNN members have also supported several country-driven hygiene initiatives as part of COVID response efforts.

### Enabling environment

- The NNN co-organised a special session on Hand Hygiene for All at the ISNTD Connect held on 10 December 2020, with panellists from UNICEF and the Nigerian Federal Ministry of Health. The annual NNN conference also included a consultation on the development of a monitoring framework for the WASH and NTDs strategy and several case studies and blogs were published on WASH and hygiene on the NNN website and promoted on its social media channels. NNN also supported the launch activities for the Global Strategy on WASH and NTDs.
- The NNN supported a learning series on the WASH and NTDs toolkit for programme staff in East Africa (6 virtual 2-hour workshops organised through the Ascend East programme), as well as the development of an online learning course on WASH and NTDs organised by PAHO for programme staff in several countries in the region of the Americas.

### Sustainable, inclusive programming at scale

- NNN is in the final stages of developing a new guiding document on behaviour change for NTD control and elimination. The existing toolkit on WASH and NTDs will be updated to include a broader range of sectors and behaviours, including aspects related to vector management and One Health.
- Preliminary engagements have been held with WHO in relation to this priority area. Full implementation will commence in line with WHO timelines on the NTD Research & Development Blueprint.

# Conference in numbers

The 2021 NNN Conference was attended by a total of 881 delegates from 83 countries, representing over 320 organisations.

In the second year of the NNN Conference running as a virtual event, it was great to see that this year's delegate numbers and number of countries represented remained at similar levels as at the 2020 conference. This was thanks to the virtual format of the conference and the free registration fee.

While the United States and the United Kingdom each were represented by over 100 delegates, those attending from NTD-endemic countries were also represented in an encouraging number. Delegates from Nigeria, India and Ethiopia represented the largest number of delegates from NTD-endemic countries, with 139, 61 and 61 delegates, respectively. The largest increase in delegate numbers were for Kenya at 2.5-fold (12 delegates in 2020 to 32 delegates in 2021) and Nepal at almost 2-fold (9 delegates in 2020 to 17 delegates in 2021).

For the first time, at the NNN 2021 we introduced virtual networking sessions to ensure that those delegates who joined us from different time zones had a chance to engage with each other and network. At the two sessions, one conveniently timed for attendees from Asia Pacific and one for attendees from the Americas, we had a total of 394 registrants engaging on the virtual networking platform, Airmeet.

This year we also introduced a special session to allow all delegates to attend and discuss important aspects of the future of NNN and all NTD NGOs. The special session, titled "Walking the talk on country ownership – towards a paradigm shift in global health operations" had over 520 delegates participating.

These findings have implications for future NNN conferences that merit serious consideration. As noted by Arielle Dolegui, Incoming Chair, "The ongoing pandemic continues to challenge the NNN and other organizations to rethink ways to fully engage their delegates to maximize participation and access to future conferences and events. Despite the physical constraints we collectively face, these numbers have shown our community's desire to remain connected to uphold our tenet of enhancing our community of practice through membership engagement, learning and sharing knowledge to end the fight against NTDs. Moving forward, we will take a holistic approach and careful consideration of the implication of these statistics to design an innovative, responsive, and engaging conference format in 2022 and beyond, meeting the demands of our times while enabling equitable participation and representation across geographies."



# Who is who in the NNN

## 2021/2022 Steering Committee

The Steering Committee is the NNN's leadership team

Chair: Arielle Dolegui (World Vision)

Vice Chair: Girija Sankar (Christian Blind Mission)

Immediate Past Chair: Kisito Ogoussan (FHI 360)

NNN administrative support: Kyle Jacobson (World Vision)

## 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.

### Lymphatic Filariasis

Chair: Ernest Mensah (FHI 360)

### Leprosy

Chair: Geoff Warne (International Federation of Anti-Leprosy Associations - ILEP)

### Onchocerciasis

Chair: Louise Hamill (Sightsavers)

### SCH & STH

Chair: Anouk Gouvras (Global Schistosomiasis Alliance)

### Trachoma

Chair: Angelia Sanders (The Carter Center)  
Alternate representative: Michelle Taylor (International Coalition for Trachoma Control)

## Cross-Cutting Groups (CCG)

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

### Conflict & Humanitarian Emergencies

Chair: Angelia Sanders (The Carter Center)

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

Chair: Aparna Srikantam (Lepra Society India)

### Ensuring Sustainable Systems

Co-Chair: Wangeci Thuo (RTI International)

Co-Chair: Carolyn Henry (SCI Foundation)

### One Health

Chair: Wendy Harrison (SCI Foundation)

### Skin-related NTDs

Chair: Michelle Murdoch (International Foundation of Dermatology)

### Water, Sanitation and Hygiene

Chair: Sarity Dodson (The Fred Hollows Foundation)

## Task Groups

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

### COVID-19

Co-Chair: Angela Weaver (Helen Keller International)

Co-Chair: Simon Bush (Sightsavers)

### Knowledge Management

Chair: Sarity Dodson (The Fred Hollows Foundation)

### Safety

Chair: Virginia Sarah (The Fred Hollows Foundation)

### Communications

Co-Chair: Anna Georgeson (SCI Foundation)

Co-Chair: Kat Gulyas (Global Schistosomiasis Alliance)

## Task Teams

### Influencing Priorities

Chair: TBD

# With thanks to our generous sponsors



# Acknowledgements from NNN Chair, Arielle Dolegui

As we transition in the Steering Committee for the year 2021-2022, I would like to express my most heartfelt gratitude to Kisito Ogoossan, the Outgoing Chair and current Implementation Lead at FHI 360 for his thought leadership and unwavering support as he — what I call “graduates” — onto become the immediate past chair, and, in that position, will remain a member of the steering committee to continue to lend his support to the network.

In addition, with profound gratitude and appreciation, I would like to acknowledge the outgoing immediate past chair Yaobi Zhang, Senior Scientific Advisor at Helen Keller for his leadership, expertise, contributions, and continued support. I am sure we as a network and I, personally will continue to lean on his wealth of knowledge in this community. On behalf of the NNN members, thank you immensely.

In that same note, allow me to take a moment to individually thank the following past chairs who have completed their tenure this year.

- the Skin -related NTDs, Claire Fuller,
- the WASH working group, Yael Velleman,
- the Influencing Task Team, Chelsea Toledo and Joni Lawrence
- the Sustainability cross-cutting group, Aparna Barua Adams, and Girija Sankar
- NNN Representative to ESPEN, Margaret Baker
- DMDI, Wim van Brakel
- SCH/STH disease group, Suzy Campbell
- Communications Task Team, Kelly Bridges and Tim Je-su-da-son
- ICTC, Scott McPherson (Incoming Immediate past chair)
- LF Group, Paul Watson

The NNN thrives on the engagement and leadership of our various disease and cross cutting groups, tasks teams, and we thank you greatly for the expertise you bring to these groups and to the community overall.

Also, I would like to acknowledge the incredible support of Janine Lancaster, Hazel Dupont, Debbie Jackson-Cole and the entire Maximize Your Time or MYT team, for working your organizational magic to support this year’s conference. Really, thank you very much. We could not have done this without you.

To the volunteer translators who have supported the plenaries and workshop sessions: Rodolfo Garcia and Madelle Hatch, as well as Alice, Giorgia and Cristina. We are grateful for your support and thank you very much for your commitment to the NTD community.

To our three volunteer co-hosts, Dr. Íñigo Navarro Fernandez, Carolyn Henry, and Kyle Jacobsen, thank you for an extraordinary job supporting the smooth running of the conference behind the scenes.

I would also like to recognize the hard work and wonderful efforts of all the NNN Executive Committee, Conference Committee, cross-cutting groups and task teams who have contributed to the development, shaping and running of this year's conference. A special thanks to the Communications Task Group who have done a fantastic job before and during the conference with engaging social media content and ensuring equitable representation of the diversity of topics presented over the three days; and for delivering this conference report. Thank you very much!

To all our conference sponsors, my immense gratitude for your continued support in making this conference possible but also for your commitment towards a world free of NTDs. I am extending my congratulations to this year's NTD Innovation Prize Winners, and my sincere thanks to the ALM and Novartis teams for partnering with us in supporting innovation to advance programmatic effectiveness.

And finally, to all of those that attended, actively participated, and engaged with each other over the course of this conference, thank you. Thank you for your collaborative spirits, your hunger for change, and for your willingness to continue to learn with and from each other.

**Arielle Dolegui, NNN Chair 2021/2022**

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



\*The preparation of this report was led and coordinated by Kat Gulyas and Anna Georgeson,  
co-chairs of the NNN Communications Task Team.



**NEGLECTED TROPICAL DISEASE  
NGO NETWORK**  
A global forum for nongovernmental organizations  
working together on NTDs

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