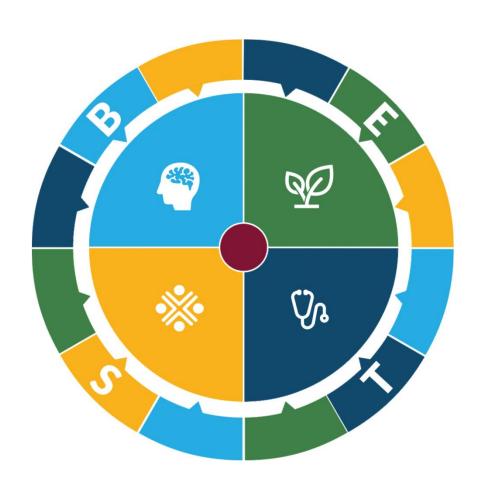
# NNN Conference Report – Dakar 2017





A global forum for nongovernmental organizations working together on NTDs

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#### Introduction

#### Introduction by the Chair, Wendy Harrison



It was a great honour to welcome 269 delegates from more than 100 organisations and 49 countries to the 8<sup>th</sup> annual conference of the NTD NGO Network, held 28-29 September 2017 in Dakar, Senegal.

Thank you to Mette Kjaer Kinoti from Helen Keller International for kindly hosting the meeting, and setting the stage for collaboration by reminding us that "alone we can do so little, together we can do so much."

We were also honoured to have the Secretary General for the Senegalese Ministry of Health, Dr Ibrahima Wone, address delegates in the opening plenary. We welcomed his emphasis of the government's commitment to find the resources to fight NTDs, as well as calls for support to bolster existing efforts.

The importance of cross-sector collaboration cannot be overstated when it comes to tackling the neglected tropical diseases that affect one billion of the world's poorest people. The diseases themselves may differ but there are many similarities and opportunities to collaborate in how the NTD community reaches and treats people affected, who often live in the hardest to reach communities.

That's why it is so vital that we come together to share our (often disease-specific) knowledge, skills and experience with others, and to identify ways to work together to increase our impact—in research, training of health workers, MDA programmes or education.

For this year's conference, we sought to build on the successes of previous meetings by placing an even greater focus on working together to generate solutions to the common challenges we face.

Themed around the BEST framework— an approach which encompasses Behaviour, Environmental factors, Social Inclusion and Equity, and Treatment and Care—we structured this conference around discussion-based workshops. The aim was to identify actions addressing a wide range of questions that are relevant beyond disease specific groups.

You'll find the key actions and outcomes of these 24 sessions, grouped by BEST category, summarised in this report. I hope these actions will provide a roadmap for even greater collaboration over the coming months as we build up to the NNN 2018 conference in Addis Ababa, Ethiopia, which the Federal Ministry of Health has kindly offered to host.

I now rotate to Past Chair, and welcome Tanya Wood as Chair, and Gail Davey as Vice Chair of NNN. I also welcome the election of Co-Chairs of the External Representation Committee, Virgina Sarah and Helen Hamilton, and Chair of the Conference Committee, Yaobi Zhang. They will work with other volunteers on the Steering Group to carry the excellent momentum generated in Dakar forward.

On behalf of the NNN team, we look forward to seeing you in Ethiopia.

Dr Wendy Harrison BVetMed MPH PhD MRCV

Chair of the NNN (2017) and Executive Director of Schistosomiasis Control Initiative at Imperial College London



## **Behaviour**

Eight presentations were made addressing physical behaviours, community attitudes, and institutional behaviours and actions to develop and implement comprehensive programmes to tackle NTDs.



Presentation & Workshop Leads	Action Points	How can the NNN support?
1. WASH and NTDs: developing barrier-busting solutions	-Support coordination and joint planning	-WASH working group: tools, dissemination, documentation, technical support
	-Operational research	-Continued forum for discussion,
Sophie Boisson, Fiona Fleming, Yael Velleman	-Mapping- tools, process and use	learning, celebrating success, community of practice
	-Monitoring to support joint action	
2. Are we building sustainable	-Individual: we can all reflect and act	-Sustainability task force
systems for NTD programmes?	in our daily work	
		-Sustainability tool kit
	-Organisation: long term vision (4	
	phase model)	-Using NNN platform as a
Carolyn Henry, Elizabeth		communication tool
Hololenberg	-Global: partnerships and	
	communication	
3. Help or Hindrance: can faith- based networks and institutions make a difference in the fight	-Explore opportunities for reaching scale with faith networks	-An informal group to explore and discuss progress
against STDs?	-Faith based and secular organisation to work together to address gaps	-For NNN members to reflect on how to connect with faith leaders
David Addiss, Gail Davey, Sarity Dodson, Stephen Omunyidde, Terver Anyor, Pete Garatt	-Seek to bring together all faith leaders (including traditional healers) for coordination with NGOs and government health systems.	-Share tools for engaging with faith networks that "speak their language"

Presentation	Action Points	How can the NNN support?
4. From Policy to Action: Engaging	-Need to raise awareness among	-Continue opening spaces for
the NTD community with the	the NTD community about the	capacity building and strategic
SDGs	SDGs, their principles and main	discussions on the SDGs during NNN
	routes for follow up at the national,	Conferences
Andrew Griffiths, Naiara Costa	regional and global levels	
		-Develop analysis about the
	-Need to promote further discussion	connection between the 2030
	on the interlinked and interrelated	Agenda, the SDGs and NTDs
	aspects of the 2030 Agenda and the	
	SDGs and how it connected to the	-Set up plans on how to make the
	NTDs	2030 Agenda a strategic framework
		for NTD policies and programmes
	-Need to draft plans to make the	
	implementation of the 2030 Agenda	
	a strategic framework for NTDs	
	policies and programmes	
5. The benefits of good community	-Select carefully community	-Raise fund to support training of
involvement in the control of	volunteers and train them	volunteers and community leaders
NTDs		
	-Find a good motivation system for	-Fund workshops and pilot projects
	volunteers	related to motivation of volunteers
Touré Loua, Aka N'Guetta, Akpa	-Include social rehab as a key	-Fund social rehabilitation
Amari, Konan N'Guessan	component of NTD projects	

GSA @elimin8schisto · Sep 30

Wrapping up #NNN2017 with excellent workshop posters e.g. bashing-barriers for #WASH & #NTDs with @fionaflemingSCI & @YaelVelleman





<u>Presentation</u>	Action Points	How can the NNN support?
6. Getting to Zero: Lessons for NTD Elimination from	-Increase advocacy	-Provide better guidance to categorise countries and describe strategies for
Successful STH Control Programs	-Improve Community engagement and BCC	intensified 5 <sup>th</sup> control
	-Mobilise funding	-Advocate for greater resources and coordination with WASH
Joe Amon		-Promote the use of BEST framework in NTD programmes
7. Integration of interventions for different NTDs; what does	-Share tools and best practices	-Collecting and sharing best practices
it mean for behavioural change?	-Desk review of best practices that came up	-Promoting integration
Michal Bruck, Mebiyu Negussu, Willemign Zaadnoordijk		
8. How can Policy and Partnerships Support Sustainable NTD	-Identified interested users to solicit further input	-Refer to NNN to develop a sustainability group
Programmes?	-Assess potential for further engagement and refinement for using	
Debra Bara, Sultani Hadley Matendechero	capability maturity model™ approach to assess implementation	

### **Environment**

Four presentations discussed the implementation of programs for environmental sanitation, infection prevention and control, universally accessible clean water, vector management and veterinary public health to prevent and minimize the impact of NTDs.

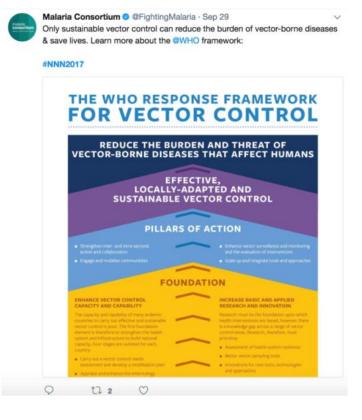
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<u>Presentation</u>	Action Points	How can the NNN support?
1. Skin related NTDs – an	-Need to understand if donors are willing	-By creating a cross-cutting group
untapped opportunity	to support wider programmes (flexible	dedicated to skin related diseases
for integration into the global health agenda	funding)	-By creating advocacy message on
Siobai nearth agenda	-Advocacy for more financial resources as well as at MOH, academic/research institutions	skin related diseases and identifying key messages for each specific audience or donor
	-Harmonised M&E indicators for capacity strengthening programmes (targets) and routine case recording	-By creating discussions via collaborating with other cross-cutting groups (e.g. morbidity management group/WASH group)
	-Discussion with other sectors, Ministry of Education, is needed to initiate awareness	
	-There is a need to establish cost effectiveness of integration of skin disease recognition and management	
Guiseppina Ortu, Kingsley Barnpoe Asiedu	-There is the need to understand the role of community engagement in disease surveillance	

<u>Presentation</u>	Action Points	How can the NNN Support?
2. The human-animal: How	-Foster collaboration between	-Create a collaborative steering committee
can we better engage the	different disciplines (including	on NTDs
Veterinary Public Health	veterinary and public health sector)	
Sector to strengthened		-Develop and promote advocacy agenda
health systems and tackle all	-Generate and share data on NTDs	on NTDs
NTDs	between different disciplines	
		-Develop Centre of Excellence on NTDs
Fekadu Abebe, Sarah Jayme,	-Plan, execute and eradicate NTDs	
Wendy Harrison	collaborative central programmes	
3. World NTD Day: Creating a	-Solicit feedback from additional	-Use network to solicit feedback from
Sustained, Impactful	partners, e.g. the private sector,	additional groups
Platform for NTD Advocacy	patient groups and country	-Help make decisions about World NTD
	governments	Day objectives and activities
	Dronosa samman massaging and	
	-Propose common messaging and activities	-If World NTD Day moves forward, use
Sang-Hee Min, Yacine Djibo,	activities	network to disseminate information to the
Harald Zimmer	-Agree on a date	NTD community
Tididid Zillillici	Agree on a date	



<u>Presentation</u>	Action Points	How can the NNN support?
4. Can vector control deliver a	-Create new career path and	-Create a cross-cutting vector
world free of vector-borne	jobs to encourage interest in	control NNN working group
diseases?	entomology and malacology and	
	adding these to other career	-Mapping existing evidence to
	paths e.g doctors and public	identify gaps in evidence and
	health specialists	capacity
	- Need to build capacity at	-Coordinate advocacy to
	country level in entomology and surveillance	mobilize resources, support capacity building and support the adoption and achievement
	- Increase political commitment at the country level to ensure sustainability	of the Global Vector Control Response
	- Create a pool of experts in regions that can be drawn upon for outbreak response	
Raman Velayudhan, Anouk Gourvas, Giuseppina Ortu, Oliver Williams	-Building on previous outbreak experience and create lessons learnt for future response	



## **Social Inclusion**

Four presentations discussed supporting programs for universal health coverage, addressing barriers to social integration, empowering disadvantaged communities, and eradicating stigma in NTD impacted areas.



<u>Presentation</u>	Action Points	How can the NNN support?
1. Stigma and the mental	-Understand the mental health needs of	-Join the Mental Wellbeing and
health of people affected	target populations as a first step to	Stigma Task Group
by NTDs: tools and	addressing them	
approaches for an		-Access relevant resources
appropriate response	-Integrate basic effective responses to	
	mental health needs into NTD	-www.infoNTD.org. Promote
	programmes, health services	consideration of stigma and
		mental health across all NTDs
	-Address stigma and exclusion through	and actors
Julian Eaton, Wim van Brakel,	evidence-based interventions to	
Jennifer Mangeard-Lourme	challenge common stigmatising	
	attitudes and discriminatory practices	
2. Accelerating progress	-NGOs to support development and	-Report outcomes and action to
towards gender equality in	implementation of data collection	scorecard stakeholders
NTDs	protocols with gender specific	
	indicators	-Working group
	-Report on impact and coverage data	-Provide platform to discuss
	disaggregated on gender and other	progress and hold network
	equality measures – feed into scorecard	organisations accountable for
	De alexante III i a contestado	progress
[	-Develop a toolkit or part of other	
Fiona Fleming	toolkits to support progression to	
	context specific programming	





<b>Presentation</b>	<b>Action Points</b>	How can the NNN support?
3. Increasing participation and	-We can only do it together –	-Collective advocacy
social inclusion of people	build capacities	
affected by NTDs using a		-Capacity development
human rights' approach	-Lead by example as NGO	
	community and track progress	-Increase participation of people affected
Martin Kollmann, Pradeep	-Participation and human rights	
Bagival, Rachna Kumari	are the two sides of the same	
	coin	
4. Reaching the unreached	-Individual – check personal work area/plans/activities	-Platform for communication
		-Promote sharing of knowledge
	-Organisation – revise	and experience
	organisational plans	
		-Providing framework – BEST
Birhan Mengistu	-Global – NNN inclusion	
5 5 5 5 5	committee	

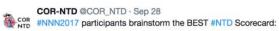
### **Treatment**

Eight presentations focused on improving comprehensive treatment through the inclusion of preventative chemotherapy, disease management and self-care, rehabilitation services, and disease surveillance to ensure proper recovery of those affected by NTDs.

<u>Presentation</u>	Action Points	How can the NNN support?
How do quality assurance programs for NTD diagnostics strengthen surveillance systems?	-QA should be a cross-cutting component of implementing an NTD programme	-Sharing the experience of effective QA programmes to demonstrate their value
,	-Training and supervision of QA programme roll-out can be an area where NGO's provide support	-Advocating for uptake of QA programmes for NTD diagnostic testing
Kelsey Barrett, Yakou Dieye	-At all levels, QA implementation feedback should be collected to refine QA processes	-Highlight QA within the NNN conceptual framework to build political and financial momentum for further QA programme development and adoption at local levels
2. Envisioning the best scorecard: How might the London Declaration	-Improve the visibility of the scorecard amongst NGO community	-Share future scorecard communications
scorecard evolve to meet the future needs of the NTD community	-Digest findings from workshop that will feed into the review	-Support additional requests for information from NNN partners
Joanna Pritchard, Molly Mort, Mariana Stephens, Victoria Skyes, Chelsea Toledo	-Follow up meetings and consultation with additional key stakeholders	-Continue to collaborate on next steps



<u>Presentation</u>	Action Points	How can the NNN support?
3. How to assess severity, select	-Expand the evidence base for	-Promote the cross NTD DMDI
appropriate DMDI	DMDI interventions by conducting	approach and working group
interventions and assess their	proof of concept studies	
outcome and impact?		-Promote the use of the available tools
	-Promote use of existing DMDI tools	in NTD programmes
	-Use the holistic BEST framework to	- Promote the use of BEST framework
Martin Kollmann, Wim van Brakel,	define outcomes and impact	in NTD programmes
Linda Faye Lehman		
4. Have the NTD programmes	-Develop simple messages for the	-NNN can be a presenter of messages
had a significant effect on	public, for funding agencies and	of success from each NTD, and could
disease and disability?	politician messages that emphasize	carry these on the website
	the impact programs have had on	
	patients, communities, caregivers,	-NNN could encourage disease groups
	and the economy of the local	to develop powerful impact messages
Charles Mackenzie	communities	that demonstrate the successes
		obtained by all our activities









<u>Presentation</u>	Action Points	How can the NNN support?
5. Tools and practices for data	-Advocate to convene forum for	- Use NNN as a platform and network
improvement for treatment	NGO and National Governments to	for discussion
and care	address the issue and challenges of	
	collecting and reporting NGO data	
	and working together to improve	
	coverage	
Dubing hosting Johin III Kaning	Adam DECT anation for the NA C. F.	
Rubina Imtiaz, Jahir-Ul Karim,	-Adopt BEST practices forum M & E	
Clayton Ajello, Daniel Irvine	to assess impact of deworming on	
	PSAC	
6. NTD Morbidity Cases: TT and	-Ensure standardized protocols are	-Sharing promising practices
LF case estimate	available and widely disseminated	
methodologies across 3		-Advocacy to start data collection now
countries	-Encourage morbidity data as part	
	of HM's	-Support national programmes to
Zeina Sifri, Molly Brady, Whitney		support locally specific solutions that
Goldman	-Use available data to model	align with preferred
	predicted burden	practises/guidelines
7. Life and Limb – better care for	-Further mapping of co-endemicity	-More evidence and research into
better life in Lymphatic	and required levels of care	effectiveness of joint approach
Filariasis, Leprosy and		
Podoconiosis	-Limb plus – develop holistic	-DMDI group to continue to promote
	approach to care	sharing of learning
Pete Garatt, Gail Davy, Tanny	-Use T.T and physical	
Hagens, Charles Mackenzie,	demonstration and supervision to	
Raphael Mulambo, Jerry Joshua	get knowledge and practice to community level	

### **Feedback**

All participants were invited to take part in an online survey following the conference. We have summarized the 86 responses we received below, which will help inform the conference planning for NNN 2018 in Ethiopia.

**Workshop format success:** The reduction of plenary time and increased number of interactive workshops was welcomed by most respondents. Most attendees enjoyed the new format and hope to continue the interactive nature of this year's conference. However, some say that the quality of individual workshops varied and suggest providing guidance to workshop leaders.

Increased opportunity to network at the next NNN conference was mentioned by several respondents. Others suggest the inclusion of more topical Q&A sessions, with questions collected beforehand and sorted to the appropriate experts on the topic.

Overall, attendees believe that there was a proper balance of interactive and lecture based sessions at the meeting and encourage the continuation of this format in future conferences.

**Senegal an appropriate location:** A majority of conference participants deemed Senegal as a reasonable place to travel to for this event. There was particular praise for hosting the conference in a country where NTDs are endemic. Many participants encourage continuing this idea, as it allows for those who are directly impacted to have a larger voice in the outcome of the conference. Some participants coming from further regions, particularly the Pacific, wish for a more centralized location.

**Strong support for NNN attendance fee:** Eighty-five percent of respondents (68 of the 80 participants who answered this question) stated that they would still attend if a logistics fee were to be charged. A majority of them (about 28) suggested a range between 50 and 100 USD or GBP, with some suggesting a higher amount. Of those who responded, 12 (15%) said they would not attend if a fee is imposed. Those who did not comment said that they could not as their attendance depends on various factors.

Language and Culture: The two most common comments from attendees included a yearning to engage more with the host country, and wanting increased access to translators during open discourse and poster sessions. Many were keen to participate in an excursion or learning opportunity to get a greater understanding of the culture of the area, as well as the burden of NTDs the local communities face. Additionally, while many deemed the translation services as effective, some wish for better translation in larger group settings, as well as the availability of translated material from all presentations after the conference completed.



A global forum for nongovernmental organizations working together on NTDs

#### NTD NGO Network Executive Committee

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- Vice Chair: Dr. Gail Davey (Brighton & Sussex Medical School)

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- External Representation Committee Co-Chair: Ms. Virginia Sarah (Fred Hollows Foundation) vsarah@hollows.org
- External Representation Committee Co-Chari: Ms. Helen Hamilton (WaterAid) HelenHamilton@wateraid.org
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Thank you and we look forward to seeing you in Addis Ababa, Ethiopia 2018