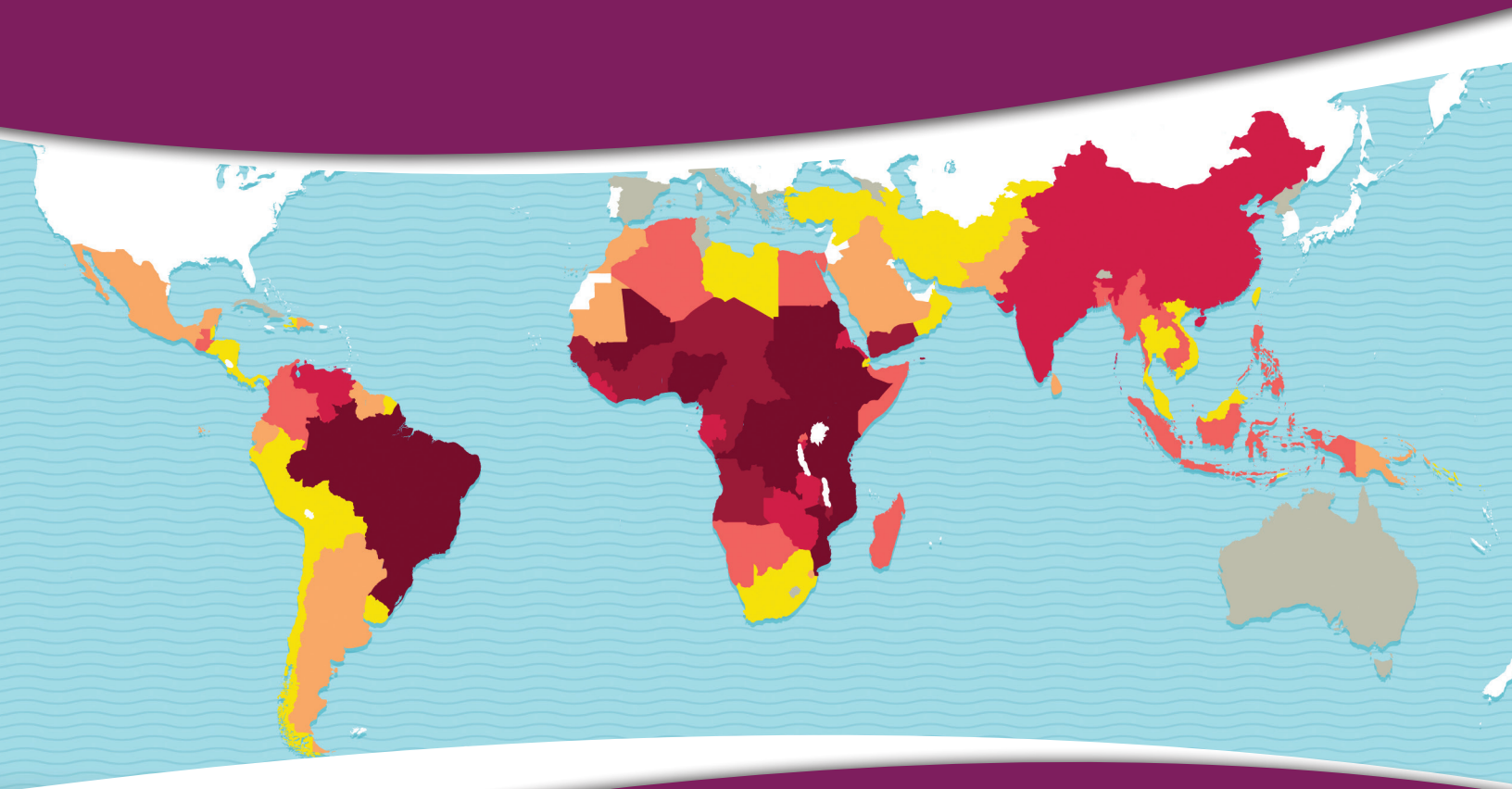


# UNITING TO COMBAT NEGLECTED TROPICAL DISEASES:

Translating the London Declaration  
into Action



**16-18 November 2012**

The World Bank  
Washington, D.C.

**MEETING REPORT**

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## OPENING LETTER

On behalf of the group of organizing partners, we would like to thank everyone who participated in *Uniting to Combat NTDs: Translating the London Declaration into Action* at the World Bank. For those of us who have been a part of the NTD community for years, it was remarkable to see such a diverse group committed to and enthusiastic about eliminating these devastating diseases.

As World Bank Group President Jim Yong Kim and others reminded us, NTDs are diseases of inequity and diseases of neglected people. Thus, it was fitting that the community came together at the World Bank, an institution that is tasked with reducing poverty and promoting development.



This meeting could not have taken place were it not for the unprecedented gathering of partners in London in January 2012 to announce new and extended commitments to control and eliminate 10 NTDs by 2020 as part of the London Declaration on Neglected Tropical Diseases. Representatives from many of the London partner organizations were present at the meeting, as were stakeholders from the dozens of additional organizations that have endorsed the declaration in the last year. Over 500 individuals signed up for the meeting from 65 different countries, a feat we could not have imagined possible even a few years ago.

As the title suggests, the focus of our discussions was to identify solutions and next steps that need to be taken to achieve the 2020 goals. While it is impossible to capture all of the important conversations that were held during the meeting, we hope that this report is a good record of the ideas that were offered. Moving forward, success requires taking these recommendations and turning them into action. Having seen the passion and dedication on display in Washington, we are confident that we can do this as we begin to move toward a world free from NTDs.

**Prof. Donald Bundy**  
*Coordinator*  
African Programme for  
Onchocerciasis Control  
The World Bank

**Dr. Julie Jacobson**  
*Senior Program Officer*  
Neglected Infectious  
Diseases  
Bill & Melinda Gates Foundation

# SETTING THE STAGE

## 1.1 Overview

On 16-18 November 2012, participants from 65 countries gathered at the World Bank in Washington, DC for *Uniting to Combat NTDs: Translating the London Declaration into Action*. This meeting was one of the most comprehensive gatherings of NTD stakeholders held to date. As the title suggests, the primary objective of the conference was identifying how to move from a broad set of commitments to sustainable impact.

To achieve this impact, a major focus of the meeting was the work being done in endemic countries by governments and NGOs. Importantly, endemic country governments are increasingly making commitments to fund Mass Drug Administration (MDA) and other NTD-related programs. To be successful, participants continually stressed the need for international organizations to work with governments as true partners as they implement these programs. As Dr. Charles Mwansambo, Malawi's Principal Secretary of Health, succinctly stated, "We have no other choice but to succeed."

## 1.2 NTDs in Context

In welcoming participants to the World Bank, President Jim Kim reminded attendees that protecting poor people from NTDs goes hand in hand with the bank's core mission to end poverty and promote human development.



"It's not that these diseases [NTDs] really have been neglected," said World Bank Group President Jim Yong Kim in his opening remarks. "It's the people who suffer from them who have been neglected."

If developing countries, and those in Africa in particular, are to benefit from the 'demographic dividend' and make the best use of their young populations, it is essential that their people are not held back by NTDs.

Efforts to control NTDs align with a number of other areas of development pursued by the World Bank and other agencies. The emphasis on service delivery, systems strengthening, and the need for multisectoral cooperation is the hallmark of effective development work everywhere, not just in health.

## 1.3 Key Conference Themes

Several central themes emerged from the opening speeches that were discussed throughout the meeting. The first of these was that drug supply for MDA is no longer a major bottleneck. Thanks to the commitments made in London, pharmaceutical companies are now providing the treatments needed. The focus within drug delivery must now shift to ensuring that the drugs we have reach the people who need them. This means improving support for delivery organizations and agencies, including the provision of resources and training.

Second, and perhaps most importantly, our implementation efforts need to be redoubled if we are to reach the 2020 goals. Great progress has been made and more people than ever are being reached; 710 million people received treatment in 2010. But an additional 1.2 billion people remain at risk and in need of treatment. Furthermore, the 710 million who received treatment did not all receive the full package they deserve — work must be done to ensure treatment programs are of high quality and have the broadest possible reach.

To fund this scale up, there is a substantial annual funding gap of approximately US\$300 million that must be filled. Despite important contributions from endemic country governments and international donors such as USAID and DFID, current levels of funding will not support the work that needs to be done. Without new commitments of funds, the 2020 goals for control, elimination and eradication will not be reached.

To use resources most effectively, important strides are being made in integrating NTD delivery programs in endemic countries. Increasingly, the community is moving away from single-disease vertical programs and toward models that seek to benefit from the synergies of combining drug administration and other programs. Increasingly, too, the NTD community is reaching out to the other sectors addressed by the London Declaration: Water, Sanitation and Hygiene (WASH), education and housing. Everyone working on NTDs must ensure that this effort continues and expands so that NTD control becomes a truly multisectoral, multidisciplinary endeavor.

Finally, we must consider the endgame for NTDs. As incidence decreases, new tools and approaches will be needed. Once areas eliminate transmission of certain

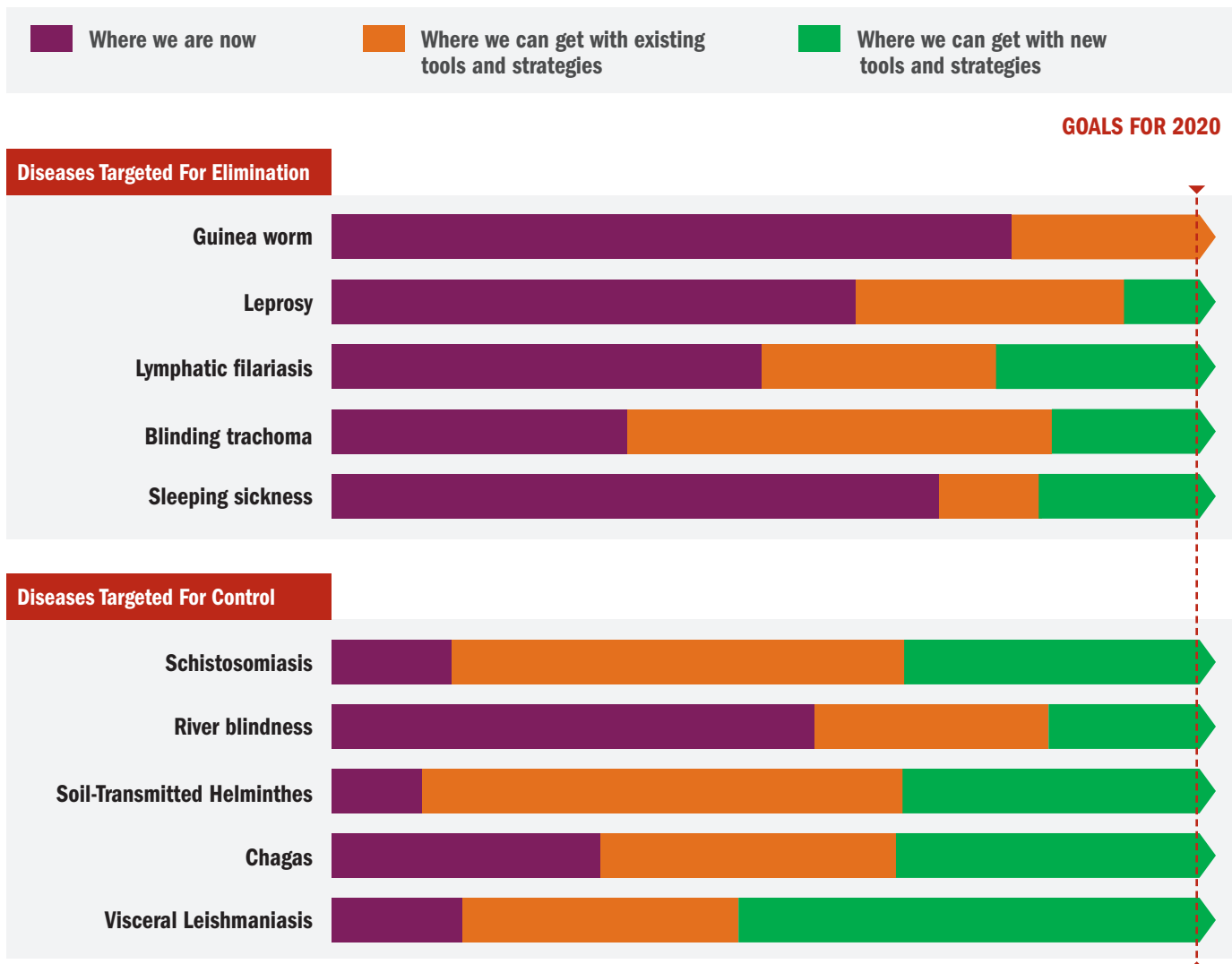
diseases, fewer people will need to be treated by MDA and screen and treat programs. In order to ensure that we are ready, we need to invest in the development of improved diagnostic tools and effective mapping so that we know where and when to target resources. Current tools will be able to take us close to achieving the 2020 goals but innovation, partnership and new tools will be required to make it all the way.

**“LET US NOT FORGET THAT BEHIND THE NUMBERS LIE PEOPLE, THE PATIENTS WHO ARE CENTRAL TO OUR CAUSE.”**

— Dr. Hussein Mwinyi, Minister of Health and Social Welfare, Tanzania

**FIGURE 1 | Measuring Our Progress to 2020**

As part of the London Declaration on NTDs, partners committed to controlling or eliminating the 10 NTDs shown in this figure. While much can be done by extending the reach with the tools and strategies we already have, new tools and strategies are needed to reach the ultimate goals for most NTDs. **Presented By Dr. Julie Jacobson.**



# MOBILIZING TO REACH THE 2020 GOALS

With a diversity of constituents present, *Uniting to Combat NTDs* afforded the community a chance to evaluate the resources available and discuss what is still needed to achieve the London Declaration goals. Many of these efforts were part of the ongoing process to create a scorecard to track delivery of London Declaration commitments and progress in achieving milestones. The full scorecard is available at [www.unitingtocombatntds.org](http://www.unitingtocombatntds.org).

**“EVERY ONE OF US NEEDS TO BE ACCOUNTABLE FOR THEIR PART OF THE STORY.”**

— Dr. Frédérique Santerre, Head, Global Government Affairs & Health Policy, Merck Serono

## 2.1 Drug Supply and Delivery

For the first time, the supply of drugs available to NTD programs is ahead of the capacity to deliver them. The major need now is to ensure the treatments reach those in need, through effective delivery programs. The need for scale-up is real: while great strides have been made, with over 700 million people receiving treatment in 2010, two-thirds of people who need treatment do not receive it. Mass treatment and screen and treat programs must reach more people, in increasingly remote settings, to remain on track to achieving 2020 goals.

This scale-up must begin now. While the number of people receiving treatment rose between 2008 and 2010, it did not rise quickly enough to remain on trajectory to achieve 2020 targets. To achieve this trajectory, roughly 50 percent of at-risk populations need to be treated in the year ahead [see Figure 2], which is a dramatic increase from the ~30 percent currently reached. Failing to scale up treatment soon will make it harder in the years ahead to get back on track.

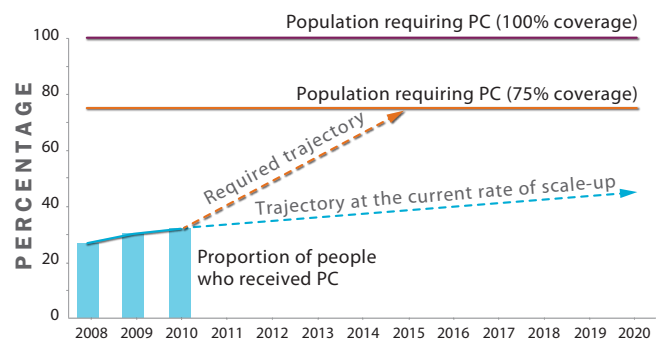
If we are to scale up access to treatment, it is essential to take a holistic view of supply. Pharmaceutical companies have committed to producing the necessary drugs and ensuring they are delivered to the countries that need them; once drugs are in the target countries, additional partners must ensure that they reach the patients before the drugs expire. Pharmaceutical companies can

contribute to training and support, but accountability must be shared and new partners and resources identified.

Commitment and resources from endemic country governments, frequently supported by NGOs and bilateral partners, are essential to effective distribution. Support must be provided to ensure that these delivery programs have sufficient capacity to reach people in need. This includes technical support in areas such as supply chain management, as well as logistical support in terms of upgrading storage facilities and delivery vehicles.

FIGURE 2 | **Expanding Access to Preventative Chemotherapy**

If MDA programs are to reach the levels required to achieve the 2020 goals, scale-up must accelerate now. Presented by Dr. Dirk Engels.



## 2.2 Research and Development

Scaling up research and development (R&D) is essential to increasing impact and measuring endpoints in the years ahead. Importantly, the research agenda must be driven by the needs identified by implementers and be guided by program milestones. These milestones are captured in the R&D component of the tracking scorecard. Research in the short term needs to focus on low-hanging fruit in three main areas: drug development, diagnostics and operations.

New drugs are urgently needed for Intensified Disease Management (IDM) disease programs and can improve existing MDA programs, particularly if resistance to existing drugs emerges. In addition to developing new treatments, existing drugs can be improved in many ways: they can be repurposed, made safer and more tolerable, or

reformulated for pediatric use. Capacity to conduct clinical trials needs to be upgraded if new or reformulated drugs are going to reach endemic communities.

Expanding the range of available diagnostics is essential to understanding the diseases we are fighting. As MDA programs begin to work and the incidence and prevalence of these diseases is reduced, high-quality, sensitive, low-cost diagnostics will become increasingly important. New diagnostics that can be used inexpensively in large remote populations will also support the targeting of resources in IDM programs. The pharmaceutical industry recognizes it can engage more to support development and commercialization of new diagnostics, as the barrier to product development for NTD diagnostics is often not only a scientific but also a commercial one. It is clear that existing platform technologies can be leveraged to develop new diagnostics.

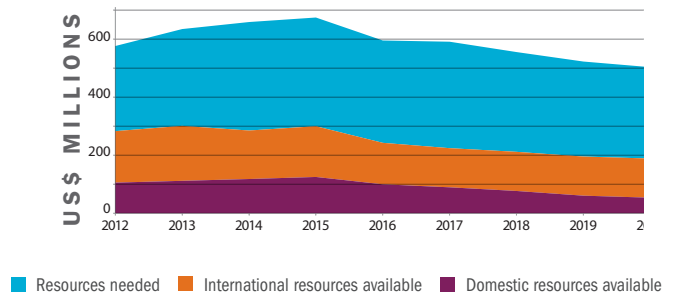
Finally, operational research must be appropriately funded and supported so that scale-up of interventions is done in the most efficient and effective way possible. Pat Lammie of the US Centers for Disease Control & Prevention reminded attendees that as NTD control moves away from single MDA programs, it will become particularly important to understand how interventions interact. Operational research can help identify what makes drug delivery programs successful in communities and how to overcome barriers to success. This essential research and innovation can only be achieved by close cooperation between researchers, NGOs, endemic country governments and communities.

### 2.3 Funding Gap

For any of the scale-up identified above to occur, it is essential that programs be adequately funded. The drugs to treat most NTDs are available, but the funding to implement delivery programs falls far short of what is needed. A preliminary evaluation carried out by the Bill & Melinda Gates Foundation estimated the total cost of implementation for these 10 diseases at approximately US\$600 million per year through 2020, with an estimate of the annual funding gap standing at approximately US\$300 million (see Figure 3). This gap represents only the shortfall for implementation funding and does not include the funding needed for non-donated drugs, diagnostics and research. To reach the goals of the London Declaration, the funding gap needs to be closed well in advance of 2020 to allow time for the resources to be put to use. Simultaneously, partners must actively work with programs to use funds more efficiently, looking for savings and synergies by integrating programs.

### FIGURE 3 | The Global NTD Funding Gap

Preliminary analysis of implementation funding identified an annual funding gap of approximately \$300 million that must be filled. Additional resources for R&D are also needed. **Presented by Dr. Daniel Kress.**



New sources of funding must be found to fill this gap. Some of it will have to come from increased commitments from new bilateral donors and endemic country governments as they take ownership of these campaigns. However, funding must also be sought from the private sector. One effort to secure private funding for NTD programming that was highlighted at the meeting was The END Fund's success in filling a funding gap for Mali's NTD programs in the aftermath of that country's coup d'état in March. This success demonstrated that it is possible with a focused and intense effort to mobilize substantial sums from a broader range of funders including those not usually involved in NTD work. Mining and oil companies, understanding that their workforce is vulnerable to NTDs, are good examples of private sector players getting involved in funding control programs. For such outreach to new donors to be successful, funding requests must be aligned both with national priorities and with the interests of potential donors. Improved cooperation between donors is essential, and priorities must be led by discussions with ministries of health and country NTD programs.

The NTD community is making enormous efforts to mobilize to ensure effective control, elimination and eradication programming. Major donors such as DFID, USAID and the Bill & Melinda Gates Foundation are delivering hundreds of millions of dollars to NTD programs each year. But there is considerably more work to be done to close the funding gap and provide implementers and researchers alike with the support they need. New sources of funding for programs must be identified and brought on board. Reliable, long-term funding streams for research must be available for diagnostics and operational research as well as for new drugs as they become available.

# WORKING TOGETHER

As previously noted, effective collaboration is essential if the 2020 goals for NTD control and elimination are to be reached. Partnership and collaboration can take many forms. Three areas in particular that received significant attention during the meeting were (1) improving coordination within governments to launch integrated, multi-disease NTD control programs, (2) fostering collaboration between organizations within the NTD community and (3) building new partnerships between the NTD community and other related sectors.

## 3.1 Improving Government Coordination Across Diseases

Coordination at the country level is the backbone of successful NTD programs. With numerous partners providing different sources of funding and technical support, it's important that there be coordination between and within governments and the various local and foreign organizations working to deliver services. This integration must extend horizontally and vertically within governments.



Speaker Dr. Juan Luis Manzur, Minister of Health of Argentina, explained how a public-private consortium in his country has led to an unprecedented scale-up of drugs to treat Chagas disease.

Many endemic countries are now using country-specific NTD master plans to ensure that programs operate in harmony with each other. Each plan provides a platform

for integrated programming, enhances synergies among NTD initiatives, strengthens partner coordination, and encourages linkages between health and other programs. WHO's AFRO office has supported these efforts by developing a joint reporting form, replacing the individual forms that previously had to be filled out for each disease.

**“WE KNOW THAT IF WE DO THIS TOGETHER, WE CAN MAKE A LOT MORE PROGRESS THAN WE’VE BEEN ABLE TO SO FAR.”**

— Lisa Schechtman, Head of Policy and Advocacy, WaterAid in America

Uganda was highlighted as one country that has recently seen the positive effects of collaborative programming firsthand by folding three vertical MDA platforms into one integrated plan, which allowed for pooling of resources and a greater ability to deliver interventions in an efficient and effective manner. This integration extends to vector elimination as well, a crucial tool in the fight against NTDs. To promote this type of success there must be support for best practices — providing technical support to countries seeking to develop NTD master plans, or to those attempting to integrate interventions with limited financial and technical resources.

## 3.2 Collaborating Within the NTD Community

Approaching NTD control in an integrated fashion is not just important for governments, but also for other donors, NGOs and implementing partners. Improving collaboration among these groups can help achieve greater results with constrained resources. In order to achieve this, the NTD community should establish a forum to facilitate coordination and communication among partners.

Better coordination within the NTD community can help improve advocacy efforts as well. While advocating for additional funds is critical, advocacy can also ensure effective engagement from government partners at the highest level. Political will from senior leadership in



various ministries (health, education, water, finance, etc.) is very important in ensuring sustainable policy change and real action (see Figure 4).

Advocates must work closely with implementers to identify success stories and gaps in need of support. Good data can be a very effective advocacy tool; evidence-based advocacy can highlight the efficacy and cost-effectiveness of well-designed and managed NTD interventions.

### 3.3 Partnering Across Sectors

Numerous opportunities exist to form partnerships between the NTD community and other sectors such as WASH and the education community. Defining best practices and working to provide a comprehensive, integrative package of interventions across sectors can significantly increase impact moving forward.

#### FIGURE 4 | Key Government Ministries Involved in NTDs

In order to combat NTDs on the ground, all sectors of the government must work together to implement effective and efficient programs.

Presented by Dr. Sarman Singh.



In the case of the WASH sector, for example, the evidence is clear: without proper hygiene and sanitation practices within a community, certain diseases such as trachoma, schistosomiasis, STH and Guinea worm remain prevalent. In the past year, the NTD community has rapidly increased its outreach to the WASH sector. A representative from WaterAid noted that the organization has attended five or six international meetings related to NTDs in 2012, whereas in 2011 they attended none.



Representatives from a broad range of sectors attended the global meeting in Washington, D.C. and reaffirmed their commitment to the London Declaration on Neglected Tropical Diseases.

It is very important, too, that the NTD community reaches out to those working in education. Although there are concerns about low attendance, school participation rates are increasing in many areas. Thus, integrating treatment programs into the education sector must form an important element of any strategy to eliminate NTDs, especially for the soil transmitted helminths (STH) and schistosomiasis.

Effective cooperation can be generated within governments through interdepartmental communication. For instance, improving coordination between education and health ministries will help reduce the current two-year delay in reporting program data to WHO. Cooperation can also be achieved by outside actors, such as NGOs, working with different government departments to generate support and funding from multiple sources.

The NTD community continues to come together as a cohesive group since releasing the London Declaration in January. As the momentum from the London Declaration builds, this partnership must continue to grow to reach the 2020 goals. As of publication, 73 organizations have endorsed the London Declaration. As Professor Moses Bockarie, Director of the Centre for Neglected Tropical Diseases at the Liverpool School of Tropical Medicine, said, "I think we have everything here, all the ingredients... for collaboration...I think we should take advantage of that."

# BRAINSTORMING SESSION RECOMMENDATIONS

*Uniting to Combat NTDs: Translating the London Declaration into Action* was designed to be a working meeting where participants actively discussed challenges and proposed solutions. Prior to the meeting, participants completed a questionnaire on the NTD landscape. During the meeting, attendees were divided by constituency to discuss their answers. Key points from the questionnaire and the group discussions are captured here.

Participants committed to continuing these important discussions in follow-up meetings and establishing new communication mechanisms to foster ongoing dialogue within the community. This will allow the community to follow progress and make course corrections along the way.

1. What are the most pressing challenges facing the NTD community?	2. What are the best opportunities to ensure success?
<b>Academia/Research</b>	
<ul style="list-style-type: none"> <li>• Obtaining reliable funding and increasing political commitment</li> <li>• Building consensus with countries on key research questions and the best use of tools for integrated programs</li> <li>• Ensuring research scorecard measures research progress linked to the 2020 goals</li> </ul>	<ul style="list-style-type: none"> <li>• Collaborating better with implementing partners and countries</li> <li>• Improving the integration of NTD health interventions with other health programs</li> <li>• Researching the impact of school-based treatment, and the use of triple therapy in appropriate countries</li> </ul>
<b>Advocacy</b>	
<ul style="list-style-type: none"> <li>• Scaling up implementation, including human resource and technical capacity, to reach 2020 targets</li> <li>• Ensuring donors and endemic country leadership are fully engaged on NTDs and developing appropriate policy resolutions</li> </ul>	<ul style="list-style-type: none"> <li>• Strengthening technical systems in endemic countries</li> <li>• Engaging in national level advocacy efforts, particularly with endemic country governments</li> <li>• Securing additional funding for NTD programs</li> </ul>
<b>Donor</b>	
<ul style="list-style-type: none"> <li>• Maintaining reliable funding, political commitment and community engagement</li> <li>• Expanding the funding base, including those supporting other relevant sectors</li> <li>• Aligning funders linked to diseases with countries that want to strengthen broader health systems</li> </ul>	<ul style="list-style-type: none"> <li>• Identifying the best opportunities for impact in order to channel funds, including operational research and integrated programs</li> <li>• Engaging new NTD donors</li> <li>• Enhancing collaboration at all levels of leadership</li> </ul>
<b>Endemic Country Government</b>	
<ul style="list-style-type: none"> <li>• Addressing lack of coordination and integration</li> <li>• Increasing supply chain and human resource capacity, especially the capacity of community health workers</li> <li>• Improving prioritization of NTDs by country leadership and donors</li> <li>• Identifying new sources of funding</li> </ul>	<ul style="list-style-type: none"> <li>• Integrating NTDs with other disease programs and sectors</li> <li>• Utilizing existing platforms to strengthen collaboration across countries and regions</li> <li>• Increasing medical education and local training</li> </ul>
<b>Industry</b>	
<ul style="list-style-type: none"> <li>• Developing new diagnostics to support case finding, surveillance and clinical trials</li> <li>• Preserving the efficacy of existing drugs against resistance</li> <li>• Expanding and coordinating with the London Declaration community</li> </ul>	<ul style="list-style-type: none"> <li>• Improving uptake and appropriate use of drugs in children and pregnant women</li> <li>• Engaging new industry partners and donors for creation of new tools, operational research and intersectoral collaboration</li> <li>• Working together to be more effective advocates with donors</li> </ul>
<b>Non-Governmental Organization</b>	
<ul style="list-style-type: none"> <li>• Aligning NGO work with NTD Country Master Plans, led by governments, to promote ownership and “buy-in”</li> <li>• Securing funding beyond MDA programs</li> <li>• Improving collaboration and coordination among all stakeholders and NGOs</li> </ul>	<ul style="list-style-type: none"> <li>• Coordinating governance structure at the country level via NTD Task Forces</li> <li>• Strengthening NGO networks to improve partnerships and better integrate NTD interventions with other health programs</li> </ul>

### 3. What does your constituency need to do?

### 4. What do you need from other partners? Are there new partners needed that are not currently engaged?

### 5. How do we keep the NTD community dialogue going and maintain momentum for 2020?

#### Academia/Research

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|---|---|--|
| <ul style="list-style-type: none"> <li>Identify key NTD research questions (building on previous efforts and reports, e.g., TDR and others)</li> <li>Engage with funders to ensure sustainable funding</li> <li>Work closely with the country programs</li> </ul> | <ul style="list-style-type: none"> <li>Inclusion of other sectors (e.g., ecology, engineering, WASH, immunology, development)</li> <li>Improve quality assurance on field data especially as we approach the 'end game'</li> <li>Identify research needs by country programs</li> </ul> | <ul style="list-style-type: none"> <li>Establish a network within the academic/research constituency</li> <li>Ensure there is a clear link between the NTD milestone table and the scorecard for research</li> </ul> |
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#### Advocacy

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| <ul style="list-style-type: none"> <li>Use evidence-based advocacy to show leaders and donors that success is possible</li> <li>Involve affected individuals in advocacy campaigns</li> <li>Develop an advocacy "tool kit"</li> </ul> | <ul style="list-style-type: none"> <li>New partners are needed, including the private sector, faith leaders, affected individuals and endemic country leaders</li> <li>Constructive collaboration is key with all stakeholders</li> </ul> | <ul style="list-style-type: none"> <li>Link endemic countries to the London Declaration through smart communications</li> <li>Raise awareness of existing commitments</li> <li>Humanize the NTD issue with tangible stories about how efforts are working to change lives</li> </ul> |
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#### Donor

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| <ul style="list-style-type: none"> <li>Map current donors and the remaining gaps via landscaping</li> <li>Engage additional donors and create funding syndicates that pool donors together to provide comprehensive resources</li> <li>Coordinate with countries to align with their priorities</li> </ul> | <ul style="list-style-type: none"> <li>Make sure that partners help put NTDs on the global agenda</li> <li>Encourage pharmaceutical companies to reach out to the bilateral donors of their countries to invest in NTDs</li> </ul> | <ul style="list-style-type: none"> <li>Improve coordination among donors and among other partners</li> <li>Determine an "NTD indicator" for post 2015 MDGs</li> <li>Highlight successes and make sure donors know they have an opportunity to invest in big targets like the elimination of diseases</li> </ul> |
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#### Endemic Country Government

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| <ul style="list-style-type: none"> <li>Exchange best practices and failures, and learn from the successes of other health programs</li> <li>Advocate for NTDs to ensure they are on the agendas of high-level political figures</li> </ul> | <ul style="list-style-type: none"> <li>Coordination with partners and regional organizations</li> <li>Use of a matching scheme and flexible funding by donors to encourage endemic country investment</li> <li>Private sector involvement at national levels</li> </ul> | <ul style="list-style-type: none"> <li>Continue conversations with donors</li> <li>Advocate for the inclusion of NTDs on the agenda of upcoming, high-level meetings – including the WHA resolution</li> <li>Determine how best to advocate for NTDs in the post-MDG era</li> </ul> |
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#### Industry

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| <ul style="list-style-type: none"> <li>Use voice to move diagnostics up on the NTD agenda and bring diagnostics companies to the table</li> <li>Review the threat of resistance with existing drugs</li> <li>Decrease the time lag between partnership agreements and initiative launches</li> </ul> | <ul style="list-style-type: none"> <li>Clear target product profiles are needed to support diagnostic development</li> <li>Specific requests from programs for trainings and support</li> <li>Guidance on monitoring resistance from global agencies</li> </ul> | <ul style="list-style-type: none"> <li>Hold a meeting to map out diagnostic development priorities</li> <li>Promote community-wide efforts to elevate NTDs on national health agendas.</li> <li>Communicate clearly on challenges/opportunities with pregnant women and children.</li> </ul> |
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#### Non-Governmental Organization

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|--|--|--|
| <ul style="list-style-type: none"> <li>Each individual NGO is responsible for promoting coordination and collaboration</li> <li>Establish and improve metrics to evaluate ourselves</li> </ul> | <ul style="list-style-type: none"> <li>Clarity of purpose and roles with transparency in order to gain mutual trust</li> <li>New partners are needed, including WASH, education, single disease programs, private companies and the research sector</li> </ul> | <ul style="list-style-type: none"> <li>Bring the issues from the field into the policy and research discussions</li> <li>Use community reach to generate demand and visibility for NTD services and interventions</li> </ul> |
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# APPENDIX 1: MEETING PROGRAM

16-18 November 2012

Friday, 16 November 2012

## EVENING WELCOME RECEPTION:

*Speakers: Jim Yong Kim, The World Bank; HRH Princess Alexandra, Sightsavers; Minister Sabine Ntakarutimana, Burundi Ministry of Health; Robert McMahon, Merck & Co.; Lance Gordon, Bill & Melinda Gates Foundation*

Saturday, 17 November 2012

## OPENING SESSION: SETTING THE STAGE

*Chair: Don Bundy (The World Bank)*

### Welcome and Context Setters

**World Bank Welcome:** Olusoji Adeyi, The World Bank

**The London Declaration: Uniting the Community:** Julie Jacobson, Bill & Melinda Gates Foundation

**The Path to 2020: Sustaining the Drive to Overcome the Global Impact of NTDs:** Dirk Engels on behalf of Lorenzo Savioli, WHO

**NTD NGDO Network Declaration of Support:** Simon Bush, NTD NGDO Network

**NTD Funding and Preliminary Gap Assessment:** Dan Kress, Bill & Melinda Gates Foundation

### Perspectives from Partners

**NTDs and Development:** Ritva Reinikka, The World Bank

**Regional Insights:** Jon Andrus, WHO PAHO & Adiele Onyeze, WHO AFRO

**The African Union Perspective:** Ambassador Amina Ali, AU

**Argentina's Commitment to NTDs:** Manager Juan Luis Manzur, Argentina Ministry of Health

*Video Remarks from Dr. Luis Sambo*

## SESSION 1: MOBILIZING

### Ensuring Adequate Drug Supply

*Moderator: Dirk Engels (WHO)*

**Where We Are: Pharma Scorecard:** Andy Wright, GlaxoSmithKline

**Industry: Ensuring Supply:** Frédérique Santerre, Merck Serono

**Implementers: Effective Delivery:** Francisca Olamiju, MITOSATH

**Endemic Countries: Matching Donation to Need:** Olga Amiel, Mozambique Ministry of Health

### Advancing Research for NTDs

*Moderator: Roy Anderson (Imperial College)*

**Where We Are: R&D Scorecard:** James Cheyne, HSL

**Drug Discovery: Accelerating the Pipeline:** Graeme Bilbe, DNDi

**Developing New NTD Diagnostics:** Rosanna Peeling, LSHTM

**Operational Research: Asking Hard Questions:** Pat Lammie, CDC

### Mobilizing Resources to Reach Our Goals

*Moderator: Shantayanan Devarajan (The World Bank)*

**Where We Are: Funding Scorecard:** Dan Kress, Bill & Melinda Gates Foundation

**Bringing Donors Together:** Ellen Agler, The END Fund

**Collaborative Funding:** Angela Weaver, USAID

**Partnering Across Sectors:** Maria Fernanda Garcia, Inter-American Development Bank

## SESSION 2: WORKING TOGETHER

*Moderator: Adiele Onyeze (WHO AFRO)*

### Creating Synergies Across NTDs

**MDA Perspective: Leveraging Shared Platforms:** Karsor Kollie, Liberia Ministry of Health

**Tri-Tryps and Other NTDs Requiring IDM: Challenges for Health Systems:** Julien Potet, MSF

**Endemic Countries: Strengthening Programs, Capitalizing on Synergies in NTD Control:** Edridah Muheki, Uganda Ministry of Health

**LF/Oncho: Reporting on New Opportunities for Synergy:** Paul Lusamba, APOC

Effective Collaboration

*Moderator: Lance Gordon (Bill & Melinda Gates Foundation)*

**WASH: Engaging Other Stakeholders:** Sarman Singh, All India Institute of Medical Sciences

**Vector Control: Advances with Shared Benefit:** Moses Bockarie, LSTM

**Communities: Effective Engagement:** Alison Krentel, DOLF Project

**Endemic Countries: Ensuring a Comprehensive Strategy:** Kesetebirhan Admasu Birhane, Ethiopia Ministry of Health

## BRAINSTORMING SESSIONS:

**Rapporteurs by Session:** *Industry:* Benedict Blayney, Sanofi; *NGO:* Simon Bush, Sightsavers & Adrian Hopkins, Mectizan Donation Program; *Academic/Research:* Johnny Gyapong, University of Ghana & Alice Norton, Wellcome Trust; *Endemic Country Government:* Mwele Malecela, NIMR-Tanzania; *Donor:* Iain Jones, DFID & Angela Weaver, USAID; *Advocacy:* Neeraj Mistry, GNNTD & Michelle Brooks, GNNTD

### Questions for all groups:

1. What are the most pressing challenges facing the NTD community?
2. What are the best opportunities to ensure success?
3. What does your constituency need to do?
4. What do you need from other partners? Are there new partners needed that are not currently engaged?
5. How do we keep the NTD community dialogue going, use the London Declaration NTD Milestone Table and maintain momentum for 2020?

## Sunday, 18 November 2012

## BREAKOUT SESSIONS:

**Overcoming Stigma: Lessons from Leprosy and LF:** Wim van Brakel, Netherlands Leprosy Relief

**Maximizing School-Based Health and WASH Programs:** Seung Lee, Save the Children & Lisa Schechtman, WaterAid

**NTDs and Maternal/Child Health/Nutrition:** Chad MacArthur, Helen Keller International

**Morbidity Management and Health Systems:** Pierre Brantus, Handicap International & Ann Varghese, IMA

**Speaking with One Voice: NTDs and Advocacy:** Richard Hatzfeld, GNNTD

**NTDs and the Poverty Reduction Movement:** Abdo Yazbeck, The World Bank

**NTD E-tools and Mapping:** Alex Pavluck, Task Force for Global Health

## SESSION 3: NEXT STEPS

*Moderator: Julie Jacobson (Bill & Melinda Gates Foundation)*

**Summary of Breakout Sessions and Brainstorming Sessions:** Neeraj Mistry, GNNTD and rapporteurs

**Roadmap Priorities for 2013:** Dirk Engels on behalf of Lorenzo Savioli, WHO

**Endemic Country Call to Action:** Minister Hussein Mwinyi, Tanzania Ministry of Health and Social Welfare

**Pulling It All Together: Final Thoughts from the Organizers:** Julie Jacobson, Bill & Melinda Gates Foundation

*Comments from participants, including François Marie Didier Zoundi, Burkina Faso Minister of Budget*

## APPENDIX 2: BREAKOUT SESSION SUMMARIES

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*Breakout Session:*

### **Speaking with One Voice: NTDs and Advocacy**

*Convener:*

**Richard Hatzfeld**, Global Network for NTDs

*Panelists:*

**Caroline Harper**, Sightsavers

**Jon Pender**, GlaxoSmithKline

**Ann Saybolt**, APCO Worldwide

**Mustapha Sonnie**, Hellen Keller International

**Neeraj Mistry**, Global Network for NTDs

The purpose of “Speaking with One Voice: NTDs and Advocacy” was to identify areas of advocacy that need improvement, showcase examples of storytelling and bring to light best practices.

#### *STORYTELLING*

Effective storytelling is at the heart of many advocacy campaigns. A critical first step to telling effective stories is identifying the audience and figuring out how to make the messages relevant to them. By including morbidity control in NTD advocacy efforts, organizations can empower those who suffer from NTDs to become advocates on the organization’s behalf.

#### *BEST PRACTICES*

Some of the main ideas that panelists shared on what we need for effective advocacy included:

- An effective message
- Research on that message or testing of the message
- A clear call to action
- Stories that give examples of the message and add to the urgency

#### *AREAS OF IMPROVEMENT*

Panelists noted that although the NGO community is competitive for funding, it can do more to work together in the advocacy space. Additionally, the NTD community should not focus on its perceived weaknesses (such as focusing on many diseases instead of one, or that the diseases are not big “killers”), but should turn these weaknesses into strengths.

A few successful examples from other global health and development advocacy campaigns were referenced, including “Living Below the Line,” “Shot at Life” and “#GivingTuesday.” These examples effectively engaged a wider audience by giving them the opportunity to experience the issue or subject matter.

Finally, by limiting the amount of time requested of partners, organizations will have a better chance of securing participation in their advocacy campaigns.

#### *LOOKING AHEAD*

Moving forward, the panelists discussed a need to come to a consensus in the community on what they are looking for in the post-MDG years with respect to NTD advocacy. In particular, aligning on what the community wants from policymakers and decision-makers is critical. By putting to use the strategies and tactics discussed above, advocates can secure the additional resources needed to control and eliminate NTDs.

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*Breakout Session:*

### **Morbidity Management and Health Systems**

*Convener:*

**Peter Ackland**, International Agency for the Prevention of Blindness

**Paul Courtwright**, Kilimanjaro Centre for Community Ophthalmology

**Amir Bedri Kello**, Light for the World

“Morbidity Management and Health Systems” focused primarily on the morbidity-related issues facing the trachoma, buruli ulcer and lymphatic filariasis (LF) communities. In particular, the participants aimed to: identify core problems affecting their communities; consider current strategies used to address morbidity, including areas for improvement; discuss how to place morbidity-reduction activities into national NTD plans and into the broader health system; and, identify potential areas for collaboration.

The session opened with a discussion of these issues as they relate to trachoma. Participants discussed the global trichiasis burden, and the ways in which it causes morbidity: vision loss, stigma, pain and reduced quality of life. Of particular note is the fact that women account for two thirds of all trichiasis infections globally and therefore suffer from a disproportionate amount of the disease burden.

Fortunately, some countries (such as Ethiopia) have developed a national trichiasis action plan as part of their overall trachoma plan. Participants discussed that practical plans such as this need to be supported elsewhere. The bottom line with trachoma is that the tools are available. What is needed now is the commitment of partners, governments, and others to see them implemented.

NTD programs in Benin were presented as a case study for LF and Buruli ulcer. The Benin example showed that it is possible to integrate several NTDs at various levels, and provided an opportunity to consider which health system levels are concerned with NTD control. These different levels include district hospitals, health centers and community-based home care.

Other key session outcomes include:

- All diseases should be considered of equal importance
- Disease-specific and general morbidity strategies and information need to be developed and shared
- NTDs need greater recognition within health systems; this should be achieved through advocacy at global and country levels
- Community based rehabilitation and community based care is needed for NTDs; this will require additional capacity building
- Funding for morbidity-related innovations and research should be increased

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*Breakout Session:*

## **NTDs and Maternal and Child Health/Nutrition**

*Convener:*

**Chad MacArthur**, Helen Keller International

The focus of “NTDs and Maternal and Child Health/Nutrition” was the impact of NTDs on maternal health, fetal health and on the health of children under five years. One of the clearest links demonstrated in this area is between STH infection and subsequent anemia. Among pregnant women, anemia leads to increased maternal mortality and may result in low birth weight and anemia in the newborn. Low birth weight is a major risk factor for many subsequent health problems including infant mortality. STH infection also leads to anemia and stunting in children under five years. Infection with the roundworm *Ascaris* is also linked to vitamin A deficiency, a critical contributor to elevated rates of child mortality.

Fortunately, treatment solutions exist to combat these challenges. Multiple deworming is associated with an overall 5-10 percent reduction in anemia in communities with high infection rates. Additionally, there is growing evidence of reduced overall child mortality due to community distribution of Zithromax in trachoma-endemic communities.

In order to deliver these solutions, the participants agreed that a greater effort was needed to break out of program silos and to take a more holistic approach to health issues that affect communities. It was suggested that a life-cycle approach would promote this; that is, identifying key integrated actions needed at each point of an individual’s life. A number of examples of countries where integration was taking place were cited, such as in Malawi and Peru. Broader partnerships would be needed to achieve this kind of integration.

Though most discussion focused on linkages within the health sector, it was also acknowledged that the NTD community must extend beyond health to the WASH community

and other sectors such as agriculture, education and social welfare. There was also a consensus that more research was needed to establish relationships that would not only contribute to a body of knowledge but also be essential for advocacy and policy development.

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*Breakout Session:*

### **Maximizing School-Based Health and WASH Programs**

*Convener:*

**Seung Lee**, Save the Children &  
**Ms. Lisa Schechtman**, WaterAid in America

*Panelists:*

**Jamal Abdul Naser Chowdry**, Ministry of Primary and Mass Education, Bangladesh  
**Raj Kumar Pokharel**, Department of Health Services, Ministry of Health and Population, Nepal  
**Margaret Thiongo**, Ministry of Education, Kenya  
**Solomon Shiferaw**, Federal Ministry of Education, Ethiopia

“Maximizing School-Based Health and WASH Programs” built off of previous discussions of the role of WASH and education partnerships in creating a comprehensive NTD program for school children and provided opportunities to learn from successful school-based programs to combine WASH, prevention of relevant NTDs, and MDA programs. The panelists spoke about their countries’ school-based deworming efforts which were an integral component of each country’s school health program. Specifically:

- Mr. Chowdry spoke about the school-based deworming that is conducted jointly by the Ministry of Health and Education in Bangladesh and health workers and teachers trained with assistance from Save the Children. These workers reach scale by working in both formal and informal educational settings.
- Mr. Pokharel spoke about the similar focus on collaboration among the various levels of

government. Currently, the government of Nepal is working to expand the School Health and Nutrition (SHN) program in collaboration with the Department of Water Supply and Sewerage, the water sector and NGOs.

- Ms. Thiongo highlighted the detailed joint planning required for the national deworming activity in Kenya. The activities being planned include extensive training of teachers to deliver albendazole with appropriate messages to school age children throughout Kenya.
- Mr. Solomon Shiferaw focused on how SHN is a cross-sectoral issue. As such, Ethiopia has coordinated across multiple ministries and donors to create and support a SHN strategy that is part of the overall education development plan. Ethiopia also has strategic plans to address the needs of children in emergencies and non-formal education who also have similar or greater need for services including NTD control activities.

Although all four panelists represented different programs at different stages of maturity, they spoke about some common themes:

1. Additional technical assistance, training and resources are needed to reach children at scale.
2. Good monitoring and evaluation of activities is essential to understand the progress being made and to improve programming.
3. Collaboration is needed among the different sectors, with clear roles and responsibilities outlined within policies – in particular within national SHN programs.
4. Coordination is critical all the way from national to community levels, especially among the teachers, parents and students.



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*Breakout Session:***Overcoming NTD-related Stigma***Convener:***Wim van Brakel**, Netherlands Leprosy Relief

Health-related stigma has many faces and affects people with a wide range of chronic conditions worldwide. It has a major psychosocial impact on those affected that is often worse than the physical effects of the condition itself. In addition to impacting those directly afflicted, stigma also negatively impacts disease control efforts in various ways, putting more people at risk.

Dr. Wim van Brakel began the session by presenting examples of work on leprosy, the archetype of stigma. ‘Leprosy’ is used as a curse word or synonym for exclusion in many societies and languages around the world. Many other NTDs are similarly stigmatized, including lymphatic filariasis (LF). Fortunately, qualitative and quantitative tools are now available to assess the types, severity and extent of stigma and to understand its dynamics and consequences. Dr. Margaret Baker of Georgetown University presented some of the deep and traumatic effects of LF-related stigma and discrimination documented in recent years in various LF-endemic countries while Prof. David Molyneux of the Liverpool School of Tropical Medicine presented on the mental health impact of NTDs.

Comparative research has indicated that, despite many differences in the reasons that conditions are stigmatized, the manifestations of stigma and its effects on affected people, their families, communities and public health programmes are remarkably similar across conditions and cultures worldwide. Several participants in the breakout session shared experiences relating to cysticercosis, schistosomiasis and onchocerciasis that illustrated this assertion. Importantly, the commonalities are true also for intervention strategies. It is therefore important that NTD-related stigma be addressed through combined strategic efforts that are sensitive to

differences, but that also capitalize on the cross-cutting aspects.

Participants emphasized the need to establish an evidence base of psychosocial issues related to NTDs and the need for evidence of the effectiveness of interventions addressing stigma and its psychosocial consequences. Several concrete proposals emerged from the meeting, including:

- Creating and funding of a cross-NTD platform for research and action against stigma which involves people affected by these conditions as priority stakeholders.
- Convening a conference with all who work on NTD-related stigma and other psychosocial issues to kick-off the cross-NTD platform.
- Including a strategy on addressing the psychosocial aspects of stigma on the WHO roadmap for implementation of strategies to overcome the impact of NTDs.

For additional resources on health-related stigma: see [www.leprosy-information.org/keytopic/stigma-guides](http://www.leprosy-information.org/keytopic/stigma-guides)

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*Breakout Session:***NTD E-Tools and Mapping***Convener:***Alex Pavluck**, Lymphatic Filariasis Support Center & International Trachoma Initiative, The Task Force for Global Health

“NTD E-Tools and Mapping” focused on identifying core concepts to be retained when considering the use of e-tools and next steps the NTD community should take in integrating e-tools into NTD programs.

If e-tools for data capture and management are to fulfill their promise and make a genuine difference to the design, administration and evaluation of NTD programs, certain important steps must be taken. Firstly, e-tools must be prioritized within NTD programs. The three

essential elements in these programs are drugs, diagnostics and data. Each of these elements must be supported for NTD programs to be effective, but data management has thus far lagged behind. Effective use of data will be increasingly important for capturing program impact and increasing efficiency.

Participants also discussed 'data ownership' and its relevance in the context of data gathered through the use of e-tools in global health. Control or 'ownership' of data should be considered in terms of "data stewardship." Sharing data on a common e-platform should not be viewed as a loss for an individual group, but as a gain in management efficiency and as a program enhancement. The use of e-tools can prompt a virtuous cycle: it not only builds technical capacity but also encourages the further use of efficient data capture and management approaches.

In order to ensure that the adoption of e-tools is as wide and effective as possible, we need to encourage the development of a standard, agreed platform. This effort should be led by WHO or another international body. Consultations must include current developers and users of e-tools. Finally, advocates for e-tools must promote linkages with partners in the NTD community and encourage dialogue to support the expansion of e-tools.

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*Breakout Session:*

### **NTDs and Poverty Reduction**

*Convener:*

**Abdo Yazbeck**, World Bank, Lead Health Economist, The World Bank

"NTDs and the Poverty Reduction Movement" focused on discussing the link between NTDs and poverty, identifying how to secure the necessary funds for NTDs, and ensuring that resources targeted for NTDs make it to the primary health care levels.

Overlays of NTD burden maps with poverty

maps show a strong association of the two. Participants acknowledged an unfortunate cycle: suffering from NTDs often traps people in poverty, which only increases their likelihood of acquiring additional NTDs. They recognized the value of existing best practices, but emphasized the need for approaches to be adapted to the contexts of each country. Poverty is persistent; the reasons for the persistence are different within each context, and must be accounted for in program planning.

Medically, outreach to reduce the burden of NTDs and to help lift people out of poverty is best conducted at two levels: the facility level and the community level. Responses at both of these levels must be demonstrably oriented toward the poor. This can be complex, and may require cooperation between the public and private sectors.

In order to help break the NTD and poverty cycle, participants discussed several recommendations during the session. In particular, the community should work to:

1. Establish a credible base of evidence: such a base provides credibility and coherence to the overlays placed on poverty mapping and helps in identifying appropriate responses. Developing reliable NTD-related overlays, such as for sanitation, water, outreach centers and the NTDs themselves, is very important. One mechanism would be to weave monitoring and data gathering mechanisms into projects and programs at the delivery and reporting levels.
2. Integrate vertical programs within countries' primary health systems.
3. Build sustainable approaches into the fabric of these integrated programs.

# The London Declaration on Neglected Tropical Diseases

For decades, partners including pharmaceutical companies, donors, endemic countries and non-government organisations have contributed technical knowledge, drugs, research, funding and other resources to treat and prevent Neglected Tropical Diseases (NTDs) among the world's poorest populations. Great progress has been made, and we are committed to build on these efforts.

Inspired by the World Health Organization's 2020 Roadmap on NTDs, we believe there is a tremendous opportunity to control or eliminate at least 10 of these devastating diseases by the end of the decade. But no one company, organization or government can do it alone. With the right commitment, coordination and collaboration, the public and private sectors will work together to enable the more than a billion people suffering from NTDs to lead healthier and more productive lives — helping the world's poorest build self-sufficiency. As partners, with our varied skills and contributions, we commit to doing our part to:

- Sustain, expand and extend programmes that ensure the necessary supply of drugs and other interventions to help eradicate Guinea worm disease, and help eliminate by 2020 lymphatic filariasis, leprosy, sleeping sickness (human African trypanosomiasis) and blinding trachoma.
- Sustain, expand and extend drug access programmes to ensure the necessary supply of drugs and other interventions to help control by 2020 schistosomiasis, soil-transmitted helminthes, Chagas disease, visceral leishmaniasis and river blindness (onchocerciasis).

- Advance R&D through partnerships and provision of funding to find next-generation treatments and interventions for neglected diseases.
- Enhance collaboration and coordination on NTDs at national and international levels through public and private multilateral organisations to work more efficiently and effectively together.
- Enable adequate funding with endemic countries to implement NTD programmes necessary to achieve these goals, supported by strong and committed health systems at the national level.
- Provide technical support, tools and resources to support NTD-endemic countries to evaluate and monitor NTD programmes.
- Provide regular updates on the progress in reaching the 2020 goals and identify remaining gaps.

To achieve this ambitious 2020 vision, we call on all endemic countries and the international community to join us in the above commitments to provide the resources necessary across sectors to remove the primary risk factors for NTDs — poverty and exposure — by ensuring access to clean water and basic sanitation, improved living conditions, vector control, health education, and stronger health systems in endemic areas.

We believe that, working together, we can meet our goals by 2020 and chart a new course toward health and sustainability among the world's poorest communities to a stronger, healthier future.

**To endorse the declaration, visit [www.unitingtocombatntds.org](http://www.unitingtocombatntds.org).**

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