

Leadership Team Meeting Teleconference

30 August 2018

Participants

Leadership team members

- Arielle Cavaliero, Leprosy Project Manager, Novartis Foundation
- Erwin Cooreman, Team Leader, Global Leprosy Programme, WHO (observer)
- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)

Invited guests

- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)
- Jan van Berkel, President, International Federation of Anti-Leprosy Associations (ILEP)

Secretariat

- David Addiss, Senior Advisor, Global Partnership for Zero Leprosy
- Jessica Cook, Communications Director, Global Partnership for Zero Leprosy
- Courtenay Dusenbury, Secretariat Director, Global Partnership for Zero Leprosy
- Christine Fenenga, Global Partnership for Zero Leprosy, Coordinator, Operational Excellence working group
- Christine Jonesteller, Project Manager, Global Partnership for Zero Leprosy

Invited but unable to attend

- José Ramirez, Chair, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health and Family Welfare, Government of India
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Taye Letta, Leprosy Prevention and Control Manager, Ministry of Health, Ethiopia
- Fareed Mirza, Head of Research, Novartis Foundation (Chair, Research Agenda working group)
- Takahiro Nanri, Executive Director, Sasakawa Memorial Health Foundation
- Mauricio Lisboa Nobre, Technical Advisor, The Brazilian Leprosy Program, General Coordination of Leprosy and Diseases in Elimination (CGHDE)

I. Welcome and Update by Leadership Team Chair Bill Simmons

II. Secretariat update

Long-Term Milestones/Road Map update

- Progress on this document will continue and an updated version will be shared next week with the Leadership Team. This document will be shared with prospective donors and partners to explain the partnership's goals for the future.

Special Rapporteur Alice Cruz

- Courtenay Dusenbury previously outlined to the Leadership Team ways in which the Global Partnership could work with Alice Cruz, UN Special Rapporteur. She is exploring options for this and will report back to the Leadership Team next week.

Initial comments received from Leadership Team:

Two team members expressed strong support for the addition of Alice Cruz to the Leadership Team. Her mandate of Special Rapporteur has a limited time frame of three years, and this inclusion could support her efforts.

Communications

- Jessica Cook shared a progress report on communications. The monthly newsletter is receiving high open rates and engagement. Twitter has a growing audience, thanks to the support of the Leadership Team and partners. Facebook, while a small audience now, continues to be an effective channel to reach persons affected. The partnership video received over 2,700 views from 15-21 August.
- The new website (www.zeroleprosy.org) was launched in June. From June-August, the website received visits from 1,002 unique people. This is not a high number, however, the time spent on the site is high. The most popular page has been the call to join the Research Agenda Working Group. Jessica summarized that it takes time to build an audience and encouraged the Leadership Team to continue to promote the website.

III. Research Agenda Working Group

- Courtenay noted the spirit of excitement and collaboration at last week's Research Agenda Working Group meeting and thanked David Addiss for his facilitation. Courtenay also noted the high degree of collaboration during the Operational Excellence Working Group meeting, and an appreciation for the engagement and leadership of Christine Fenenga and Bart Vander Plaetse. As a result of these

meetings, strategies were developed to propel the organization's overall mission and activities forward.

- David Addiss provided a Research Agenda Working Group meeting summary, citing the draft report distributed prior to the call. He shared that it was encouraging with great engagement and collaboration. Six (of seven) sub-group facilitators and five of 12 advisors were in attendance, along with four members of the Operational Excellence working group, which provided cross fertilization of ideas and influences. This was a great opportunity to present initial thoughts related to the research priorities of the sub-group areas. David also reported that Cairns Smith did a great job of synthesizing research themes.
- The structure of the working group is an open membership with over 60 individuals signed up for participation at this time (deadline was extended through 7 September). These members will work with the facilitators and advisors over the next two months to deliberate and develop research agenda drafts.
- The facilitators are now charged with leading their sub-groups and an additional sub-group was added called Leprosy Digital Health and Technology.

Initial comments received from Leadership Team:

It is a positive start for this effort, with a sense of momentum, and the next few months will be critical, especially with facilitating the sub-groups. Although there is not yet a clear plan for the crucial synthesis of sub-group ideas in November, the need is recognized and will be specifically addressed in a face-to-face setting at the COR-NTD meeting 26-27 October.

The Basel meeting was excellent, and David Addiss managed it very well. With the Operational Research sub-group of the Research Agenda Working Group, a grey area exists between the two working groups which emphasizes the need for strong communication. The effort to do so began with the attendance overlap at the recent meetings in Basel.

Operational Excellence members are welcome to join the Research Agenda sub-groups. Teleconferences will be arranged to facilitate cross-communication between the working groups.

Appreciation was shared for the support provided by the Novartis Foundation and the facilitation by Fareed Mirza during the Research Agenda working group meeting last week in Basel.

IV. Operational Excellence Working Group

- Bart Vander Plaetse reported that the recent Operational Excellence Working Group meeting in Basel was open and constructive; a good start for the working group. The most important question at this time is how are we going to affect change? Also, how will this effort be different? The partnership and the working groups must create momentum and involve people who have the desire and belief to make change.

- Christine Fenenga presented on Basel meeting content and the working group structure. The key principles for the group are country ownership and alignment with WHO. The first meeting item for discussion was over current strategies, developing best practices, and how to exchange ideas with countries already doing well. The main theme will focus on the population at-risk, and cross-cutting themes like policy, monitoring and evaluation, and leadership will all be important to realize for zero leprosy. Separate conversations will be had with the country representatives already on the Leadership Team to help develop strategies.
- The structure of this group will encourage broad support through an open call, and will include the invitation of national country programme managers. It will be critical that this group include representation from different countries and expertise, as well as persons affected. Prior to this open call, the themes must first be clearly defined.
- Work will begin in early 2019 with the testing of the Zero Leprosy national evaluation tool in three countries. The results of such assessments can be used by countries to identify key strengths and gaps; a menu of tools for filling key gaps will be available from the Zero Leprosy Toolkit. These tools, with technical assistance and funding, will be the basis for the Partnership's operational excellence work.

Initial comments received from Leadership Team:

Leveraging insight from country programme managers and current country representatives on the Leadership Team will validate our process. Also, it's important to involve countries with varying levels of capacity.

Active involvement is needed from the three countries represented on the Leadership Team. It is a core principal that the countries need ownership, and now is the time for country involvement, in particular for roadmap engagement.

V. Updates and comments from Leadership Team members

Erwin Cooreman: WHO Guidelines

- The WHO Guidelines for the Diagnosis, Treatment, and Prevention of Leprosy are now in the public domain, and he expressed appreciation for the circulation of the document.
- The two main issues are: 1) the change of regimen for PB-leprosy with three drugs for six months (MB regimen is unchanged), 2) the recommendation of single-dose rifampicin (SDR) as prophylaxis for contacts.
- The next step is to put them into practice at the country level which will require change in national policy. More work will need to be done on behalf of the supplier, to ensure donations are getting to the local level. The Supplier (Novartis) will need to seek approval from the Swiss regulatory authority for changing the indication of clofazimin (to allow use for PB). In addition, the Supplier needs a transition not to waste the already produced PB blister and determine revised needs of raw

materials. Larger countries will take more time to implement this than smaller countries. Countries are enthusiastic about tools such as post-exposure prophylaxis, but while it will aid the burden, these tools are not 100% efficacious. Erwin reports that he will visit Novartis soon to discuss these guidelines.

- The guidelines are recommended but not binding to countries who do not want to adopt them.
- The translation of the guidelines is in progress.

Christine Fenenga: London Declaration Scorecard

- Christine shared a brief overview of the history and action items of the scorecard for the London Declaration on Neglected Tropical Diseases. An effort began in 2017 to redesign and improve effectiveness of the scorecard.
- A new tool has been developed with two additional objectives, 1) to mobilize resources from new and current partners, and 2) to create an action framework to identify gaps and bottlenecks. This action framework is now under consultation over the coming months, and will continue with dialogue in November for provisional introduction in 2019. The action framework has three pillars: environment, strategy and public health.
- The leprosy community, including the Global Partnership, WHO, the Novartis Foundation and persons affected, will meet in Amsterdam 5-6 September 2018, to consult on the action framework. The meeting is sponsored by United to Combat NTDs.

David Addiss: COR-NTD and NNN meetings

- The NNN meeting is 24-26 September 2018 in Addis Ababa, Ethiopia. A session called “Strategies for National Capacity Building and Partnership in Leprosy Programs” will include presentations on the WHO guidelines and preliminary results of the working groups. Participants include David Addiss, Erwin Cooreman, Pete Garratt, Taye Letta and Bart Van der Plaetse.
- The COR-NTD meeting will have two panels for leprosy: 1) Research recommendations and request for input, and 2) PEP strategies and updates by Arielle Cavaliero. There is a pending option for a plenary session, to be determined.

Leadership Team members

- Cairns Smith expressed the critical need to involve program managers and persons affected. The partnership needs to think creatively to get their involvement in its efforts.
- Geoff Warne supports the need for program manager involvement, which will be crucial to the success of the Operational Excellence Working Group.
- Erwin Cooreman shared that it is especially important to include program managers and researchers from India, in view of the fact that India represents two-thirds of the global leprosy burden.

- Arielle Cavaliero stated that good indicators are needed for ownership by program managers and the efforts need to start soon. It should be recognized that strong country leadership is important, but also that that individual is empowered to make the change management needed.
- Jan Van Berkel expressed excitement that it seems possible to structure the same questions for both working groups and on the four or five key questions to allow coordination.
- Courtenay Dusenbury reaffirmed that the Global Partnership is actively engaged with WHO and the Uniting to Combat NTDs (funding the London Declaration work) – not only to study their tools but to incorporate them in our work in a way that makes sure we are operating within and support existing global frameworks for leprosy. Great conversations have been had with Erwin over the influence of the Operational Excellence Working Group at the country level, and how it will link with the WHO guidelines. The scorecard may be influenced by the work of the Operational Excellence Working Group to be sure it is linked with the ideas of the Global Partnership.
- Jessica Cook provided a reminder to share the website, www.zeroleprosy.org, and to review the events listed on the site and let the secretariat know if any key leprosy or NTD meetings are missing.

Action Items for the Secretariat

- Share the updated version of the long term milestone/roadmap graphic
- Contact Leadership Team country representatives about how best to engage their insight and expertise for the Operational Excellence working group.
- Begin engagement and teleconference coordination with the facilitators of the Research Agenda working group.
- Continue to prepare for the next Leadership Team meeting in Brussels, 11-12 October 2018 (confirmation of attendance requested by Christine, cjonesteller@taskforce.org, by 10 September).
- Prepare and disseminate Leadership Team call meeting minutes (also available on team Google drive).
- Unless specifically requested, there will not be another Leadership Team conference call before the October 11-12 Leadership Team meeting in Brussels.