

## Leadership Team Meeting Teleconference

5 June 2019

### Participants

#### Leadership team members

- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Arielle Cavaliero, Leprosy Project Manager, Novartis Foundation
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)
- Erwin Cooreman, Team Leader, Global Leprosy Programme, WHO (observer)
- José Ramirez, President, International Association for Integration, Dignity and Economic Advancement (IDEA)
- Zaahira Gani, Project Manager, Novartis Foundation
- Jan van Berkel, Chair Executives Group, Leprosy Research Initiative
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana

#### Secretariat

- Jessica Cook, Communications Director, Global Partnership for Zero Leprosy
- Courtenay Dusenbury, Secretariat Director, Global Partnership for Zero Leprosy
- Christine Fenenga, Operational Excellence Coordinator, Global Partnership for Zero Leprosy
- Andie Tucker, Communications Specialist, Global Partnership for Zero Leprosy

#### Invited but unable to attend

- Alice Cruz, UN Special Rapporteur (observer)
- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health and Family Welfare, Government of India
- Roch Christian Johnson, President, International Leprosy Association (ILA)
- Bart Vander Plaetse, Deputy Director FAIRMED; member of ILEP ITC (Chair, Operational Excellence working group)
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen

**I. Welcome from Leadership Team Chair Bill Simmons****II. Communications update (Jessica Cook, Andie Tucker)**

- Webinar: We planned last week's webinar to introduce the country model, and our audience for this webinar was ILEP members. The Country Model Webinar was a successful debut of the concept. We had lower attendance than we were anticipating based on the amount of people that signed up, but we've talked through strategies we can employ for the next webinar to increase attendance. The next one will likely be held around October and will focus on country model implementation with the target audience being national leprosy programme managers.
  - Arielle: What topics of interest came up in the webinar?
  - Andie: Many of the questions we received ahead of time had to do with contextualization—how will the country model be applied differently to a variety of different countries and settings?
  - Jessica: There were also many questions about who's participating in the country model, particularly about people who experience leprosy.
  - Christine: I received questions during the presentation about the roadmap.
- Upcoming events: We're working right now to arrange a side event at the WHO AFRO NTD Bi-Annual Programme Managers Meeting, from 15-19 July 2019 in Addis Ababa, Ethiopia. Benedict and Geoff will attend this meeting and have already graciously offered to lead a presentation about the partnership in this proposed side event, and we're talking with a few other potential speakers. We'll keep you posted on the status of this event, but I would like to open the floor to everyone to share any other upcoming events that would be good opportunities for the partnership to be represented. Beyond the WHO AFRO NTD meeting, are there any others that should be on our radar?
  - Geoff: No other meetings come to mind that we're not already aware of.
- Messaging update: Based on feedback from leadership team members and Julie Jacobson, who's advising GPZL, the key messaging documents have been updated. These include expanded messaging, talking points and elevator speeches. Jessica will send them to the leadership team separately and they are also available on the leadership team Google drive. Please also send comment to Courtenay re. the Leprosy Review commentary.

**III. Research Agenda Manuscript (Arielle Cavaliero)**

- Arielle: Last month we talked about trying to explore publishing in the Lancet. Based on level of interest, we spent the past month trying to connect with someone we've worked with in the past who's offered input on how to engage with the Lancet and offered guidance on writing styles. This person is interested, but there is a question of timing before going into further discussions with him. Working with him means we would publish more toward the end of the year. Is this something we still want to explore? Do we want to publish now, or is there a sense of flexibility from a time standpoint?
  - Bill: The main objective is to have a clear roadmap to when that publication would be. We would prefer to have clarity, even if it's deferred. That was a general agreement of our last conversation about this. We want it published in a major publication, even if it means we publish in November.

- Jan: Do we have a Plan B? Is there another publication platform?
- Arielle: We've had discussions around publishing in PLOS NTDs or Leprosy Review. It's a question of if we want to try to publish in this high impact journal, weighing in the fact that it will take longer.
- Geoff: I agree with publishing in Lancet, the higher impact journal. Is the delay because of Lancet's timeline, or is it the person you've asked to do the work? December seems a long way away.
- Arielle: It's both. There's a certain format and way of engaging with Lancet and a formality of how to write the piece in a way that the Lancet would receive it. Because this ambition was not underway in parallel with the writing, there may be need to redress the format of the paper to make it suitable for the journal.
- Bill: In 30 days can we have clarity on the timeline?
- Arielle: By next leadership team meeting we can have an idea of what it will take to move forward with Lancet.
- Bill: Next month we can talk about whether this is the best option.
- Geoff: Does the non-publication between now and November prevent us from mobilizing resources for elements of the agenda?
- Courtenay: I don't think so. We're using completed sections to prepare materials for donors. We're able to move forward with donor discussions without a formal paper having been published yet.
- Bill: Let's revisit this next month.

#### V. **Resource Mobilization Update (Courtenay Dusenbury)**

- Dr. Mwele Malecela: Julie is talking with Dr. Malecela about promoting the partnership at WHO Headquarters. Dr. Malecela is landscaping where WHO programs are located, how they're operating, and where's the best location. It's possible at some time that we may be consulted on the where the leprosy programme should be located.
  - Geoff: Are we clear what the partnership's view would be on this? ILEP's view would be Geneva.
  - Erwin: WHO will now commission an external evaluation about this. They will consult major partners, but it will take time to initiate that evaluation.
  - Courtenay: We likely will be contacted during the evaluation. The secretariat should put together a process to think about the position of the WHO office.
  - Taka: Do you have a timeline for this evaluation?
  - Erwin: No, this is out of my hands. It will be conducted by an external evaluation unit in Geneva. We will not lead this initiative.
- MacArthur 100 Million & Change: We sent around information last week about this proposal. It is due August 6<sup>th</sup>. The initial proposal is not very complex. It only requires brief statements about what we would do with 100 million over 5 years, however, we want to make it as comprehensive as possible and give it a good effort to move forward to the next round. If we are selected to move to the next round we would then put together a full proposal. Julie Jacobson knows one of the

reviewers and she's reached to to get feedback on our key concepts: PEP implementation and a human rights component, focused on building capacity of persons affected. We're putting together a logic model with these basic components of the proposal. Next week we're meeting in London with our proposal partnership for a technical conversation about PEP implementation: what it would cost, and to come up with a protocol. Once we conclude that meeting, we'll be coming back to you with the logic model. We will need guidance from you to make sure this gets developed into a more comprehensive effort.

- Julie Jacobson activities and next steps: A list of potential donors is being prepared by Julie. We're working on contacting all these identified organizations to understand what types of things they're funding, and if they'd be interested in our work. We're looking for additional partners to support country work and the research agenda. We're not seeking sources of funding that are already going to partnership members. [Courtenay shares list of potential partners]. We intend to connect ILEP members with donor sources in country. We're going to work to connect these groups with sources either with us or alone to get funding. We've been talking with LRI about hosting a meeting to bring together researchers to come up with big ideas we can plug into these grand challenges.
- Next steps: Economic modeling. Novartis has funded this in the past. A model would show the impact of our proposal and could be slotted into any of these opportunities. We're working on a case study of our work, what the country model is, and how we think it could transform conversation about leprosy. We're going to narrow down this list and look for leads from our more focused list.
  - José: The episcopal church in Texas has put 1 million dollars toward mental health issues. The catholic church has US conference of Bishops. We need funding to stipend persons who experience leprosy. This money could help these people share their experience and lead us to zero leprosy. We can't just fund research, we need to help persons affected.
  - Courtenay: Half of the McArthur proposal is about dignity and empowerment. We can work together to come up with activities to put into the proposal in this area. LRI would also like to work on this issue.

#### **IV. Operational Excellence Working Group (Christine Fenenga, Bart Vander Plaetse)**

- Concept paper on the Country Model: The objective of this concept paper is to have a comprehensive description of the Model, and it is in progress. The leadership team should read it and send comments or suggestions to Christine. In particular, the last chapter on the roadmap and the targets will need careful consideration and more work. We are sure that we will also learn from the first country review and roadmap planning in Nepal in July.
- The country model will be first applied to Nepal. The review and roadmap planning mission is currently being prepared by Nepal MoH in close collaboration with the GPZL and WHO. We received the definite terms of reference, developed with input from stakeholders, and we have almost defined the team. From the GPZL we have paid particular attention to the zero leprosy goal, with its different components. We realize this is something most ministries are not very used to, so we need to create awareness of the need to include issues beyond disease and transmission, also considering disability, human rights, etc. At the same time, we have to ensure country leadership and ownership. Our team has now a good mix of people including Courtenay Dusenbury and Andie Tucker, who will be working on communicating the successes and lessons learned from implementation. We have also engaged Sasakawa Foundation and Novartis to come up with suitable team members from their side.

- Taka: Do you have estimation of a budget for the Nepal trip?
- Christine: No, we're only looking at the review, roadmap, and how much money we're getting from partners. Based on the roadmap we'll develop a budget. We'll develop a budget from the review.
- Erwin: Leprosy programmes can't always report their budget because they have monies that come from different places. This review could come up with a recommendation to make a consolidated budgeting plan, covering all funding from all partners.
- Arielle: Nepal is one of the LPEP countries. You could use this experience to get their view on taking LPEP forward and going to scale.
- Other potential countries for the country model are Morocco and Bangladesh. Discussions with the WHO/GLP revealed that the number of country requests is high and we determined that some of them are minor missions and other are comprehensive reviews. GPZL is carefully considering the requests and has planned to carry out 2-3 this year in order to have time to improve the country model approach and tools, with the intention of scaling up next year. Countries can express interest in a review on our website. This was also mentioned in our recently held webinar.
  - José: Is Morocco still on the list?
  - Christine: Yes. I hope the potential side event AFRO meeting will create more interest and awareness among African partners.
- The toolkit is now being prepared for testing and the first best practice formats (format B) have been reviewed and will be uploaded soon. This summer we expect that around 30 best practices will be uploaded, ensuring we will have substantial content for the launch in Manila.
- Although the collection and reviewing of best practices will continue, we also realize that the weight of work will shift from this process to technical support in the help desk and participation in reviews and roadmap planning as we look ahead. We are in the process of filing CVs of members that are available for the technical support to allow us to easily consult this pool when needed. WHO and ILEP can also consult this pool. In the next steering team meeting we will also discuss whether the 10 subgroups can be consolidated, resulting in fewer groups, which will be easier to manage.

#### **VI. Updates and comments from Leadership Team members**

- José: We should bear in mind the importance of economic empowerment enhancement models in our work, and we should use words like stipend instead of remuneration. Also, the publication of The Star is coming out next week and the secretariat can forward it to you.
- Arielle: There is a lot of momentum and I'd like to recognize all the work that's being done and all the contributions that are underway from leadership team members and the greater network. I am officially on maternity leave until January, but may be able to join for these calls. In the meantime, my colleague Zaahira is joining these calls for the next six months.
- Benedict: Could we hold this meeting an hour later? I've been talking to Christine and will provide her with comments on her documents and the toolkit. I haven't received communication from the WHO about the WHO AFRO NTD Meeting.
- Erwin: I haven't received an invitation for that meeting either. That invitation comes from the African regional office.

- Jan: I am happy to note the progress we're making. I am feeling encouraged by our conversation and proud to be part of the Leadership Team.
- Taka: It's hard for me to attend these calls because of my schedule and the time difference, but I am carefully reviewing all documents sent from the secretariat.
- Geoff: There is planning going on for the side event at the upcoming Human Rights Council meeting where Alice will be speaking. The ILEP office is assisting with the coordination of this, and at the end of June, Alice gives her annual report to the Human Rights Council.