

Global Partnership for Zero Leprosy Leadership Team Inaugural Meeting

20-22 March 2018
Lepra, Colchester, UK

Meeting Participants

Leadership team members

- Arielle Cavaliero, Leprosy Project Manager, Novartis Foundation
- Erwin Cooreman, Team Leader, Global Leprosy Programme, WHO (observer)
- Mauricio Lisboa Nobre, Technical Advisor, The Brazilian Leprosy Program, CGHDE
- José Ramirez, Board Member, International Association for Integration, Dignity and Economic Advancement (IDEA)
- W. Cairns Smith, Emeritus Professor of Public Health, University of Aberdeen
- Takahiro Nanri, Executive Director, Sasakawa Memorial Health Foundation
- Tanya Wood, International Federation of Anti-Leprosy Associations (ILEP)
- Bill Simmons (Chair), President & CEO, American Leprosy Missions

Invited guests

- Jan van Berkel, President, International Federation of Anti-Leprosy Associations, (ILEP)
- Fared Mirza, Head of Healthcare Outcomes and Research, Novartis Foundation

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 Jonesteller, Program Manager, Global Partnership for Zero Leprosy

Invited but unable to attend

- Taye Letta, Leprosy Prevention and Control Manager, Ministry of Health, Ethiopia
- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health and Family Welfare, India
- Carmelita Ribeiro Filha, Secretariat of Health Surveillance, Ministry of Health, Brazil

Day 1, 21 March 2018

Welcome and Introductions: Global Partnership for Zero Leprosy (GPZL)

Topic 1: Planning

Values and 2018 project plan: The leadership team (LT) outlined key words to describe the partnership's values: transparency, inclusivity, self-determination, dignity/respect, perseverance, a historical and futuristic perspective, commitment, inquisitively and a desire to learn, hard-working, passionate, open-minded, innovative, bold thinking, embracing and driving change, optimistic, united, honest, impactful, evidence-based, a safe environment for differing perspectives, serious about results.

The secretariat presented a draft project plan, based upon the October 2017 prospectus and the GPZL's steering committee deliberations in 2017. This project plan is the basis for the budget, which will be revised based on the decisions made by the LT during this meeting and sent to them for review.

Getting to zero: visioning for long-term objectives: A modified logic model was presented and discussed. The LT was asked to define the meaning of success for the long, intermediate and short terms. This included:

Topic 2: Governance

Leadership team and definitions of membership: The LT voted to invite the President of the International Leprosy Association to join the GPZL leadership team. It defined membership as follows:

Partners: Organizations working in leprosy research, policy, clinical care, advocacy, human rights, funding or other fields. Partners are asked to support the Global Partnership for Zero Leprosy's mission and key objectives, to share logos and link websites, to participate in working groups and meetings (as feasible), to vote on leadership matters and to provide feedback to policy, partnership and implementation issues.

Affiliates: Persons with an interest in leprosy (including affected persons and their families) and/or working in leprosy research, policy, clinical care, advocacy, human rights, funding or other fields. Affiliates are asked to support the Global Partnership for Zero Leprosy's mission and key objectives, to provide feedback and/or participate in working groups and meetings (as feasible).

Responsibilities of the Leadership Team, Chair and Secretariat: Responsibilities proposed by the chair include advocating with stakeholders (along with the secretariat director and the leadership team), representing the leadership team externally, leading leadership team meetings, helping to mobilize resources and helping to bring alignment within the partnership.

Additional meetings for the leadership team: A second meeting will be held in 2018 at a date and time convenient for leadership team members (potentially at the same time as an ILEP or similar meeting). A monthly teleconference be scheduled.

Topic 3: Working Groups (purview, TORs and milestones)

Working Group One (Research)

The intent of this working group is to be forward-looking, developing a research agenda and roadmap for the future. To do so, an understanding of the current status of leprosy research on transmission (in

the broadest sense) is needed to avoid duplicating research currently underway or planned by other groups. It will be crucial within this first year to develop a research agenda, or “roadmap” (to be approved by the leadership team), and to engage with the scientific community. Other key points raised include:

- A literature review on diagnostics, treatment and prevention has been done and will be part of the forthcoming WHO guidelines.
- Important considerations for the working group include:
 - Recommendations of the working group will need to be “validated” or endorsed
 - The purview of the working group will be broad in scope, and include social issues (this should be reflected in the TOR)
 - Will need to have a good knowledge of current research activities
 - Will need to coordinate closely with the implementation working group
- A background document summarizing current research could be ready within a month, especially if the WHO guidelines are released.
- The research working group should also consider research related to economic considerations, case detection, surveillance, drug resistance, and contact tracing.
- The working group members will articulate the details of how they will work; alignment with existing research groups and work is crucial.
- The research working group agenda should focus on three key areas: diagnostic tests, strategies, and interventions.
- Researchers should be representative of various disciplines, including: immunology, molecular science, epidemiology, clinical trials, statistics, economics, behavioral science, research methods, NTDs, TB, monitoring and evaluation, field studies, and operational research approaches, and could include representatives from the digital health or biotech sectors.

Working Group Two (Implementation or Operations)

This working group will be formed in parallel with the research working group. Options for the exact name of this working group include: effectiveness, operational effectiveness, and program implementation. The name will be proposed by the working group itself.

- The purview of this working group is very broad and needs to be more clearly articulated.
- National country programs should be involved at every step; the roadmap that the working group is tasked with developing should be a resource document to improve program effectiveness.
- It is envisioned that individual countries will develop their own roadmaps for zero leprosy, if they haven’t already.
- ILEP will nominate a working group chair and hire a full-time coordinator.
- Communication and collaboration between this working group and WHO will be essential.

Day 2, 22 March 2018

Topic 5: Communications

A stakeholder mapping exercise was conducted to solicit input on key potential partners and audiences. The LT discussed audience types and levels of influence and interest.

Highlights from the communications plan were discussed, including goals, messaging considerations and communications tactics. Options for a GPZL logo were presented, with a final logo approved by the 2018 Global Partnership for Zero Leprosy Leadership Team Inaugural Meeting

leadership team. The layout and sections of the website were presented, revised and approved. The secretariat and LT agreed that key documents will be available in English, French, Portuguese and Spanish, and Google Translate functionality will be available on the new website. The secretariat will create a style guide for consistency. A recommendation was made to focus on data and progress towards goals. WHO data could be available to aid this process.

Topic 6: Fundraising/Resource Mobilization and Advocacy

The leadership team discussed various points related to this topic. An economic analysis and business case for leprosy funding would be powerful for advocacy and fundraising. Clarity is needed on what the partnership will/will not raise money for; something for working group two to consider for each country program. The partnership needs to ensure that money for leprosy work increases, even if these funds don't go to the partnership. It is too early to determine an expectation for amount to be raised, however, it's important that there is enough to fund the secretariat and working groups. An annual partnership meeting is a priority for other NTDs for sharing best practices and creating cohesion.

A third working group, focusing on fundraising, was originally envisioned. The LT felt that it may be too early in the process for this working group at present. The secretariat will work on funding options along with the leadership team and see if it needs to create a committee to assist. There is recognition that advocacy will be an important function of the partnership, especially as it relates to policies at the national level. This should be recognized, along with resource-mobilization, as an area of focus.

Topic 7: Envisioning the Future

The modified logic model for long-term objectives was further discussed and refined.

End of Meeting

Participants expressed gratitude for this meeting and for the progress that was made as a result of robust discussion and cooperation.

Appendix A: Agenda

Tuesday, March 20:

6:00 p.m. – 8:00 p.m.: Welcome reception with ILEP members – Lepra premises

Wednesday, March 21:

Time	Topic	Presenter	Outcomes/outputs
9:00 a.m. – 9:30 a.m.	Welcome and introductions Overview of the meeting agenda and proposed outcomes	Bill Simmons	<ul style="list-style-type: none"> Agreement on agenda, outcomes and outputs
9:30 a.m. – 10:30 a.m.	Topic 1: Planning Short-term objectives and 2018 program plan: What will success look like on December 31, 2018? Getting to Zero: Logic Model for the Global Partnership: Visioning for long-term objectives	Courtenay Dusenbury	<ul style="list-style-type: none"> Agreement on 2018 program plan Discussion on strategic outline for key milestones: What will be the impact of these over the next 10 years and beyond?
10:30 a.m. – 11:00 a.m.	Coffee/tea break		
11:00 a.m. – 1:00 p.m.	Topic 2: Governance Remaining issues to decide for the charter: Presentation on secretariat recommendations, group discussion and decisions	Courtenay Dusenbury	Finalization of charter: <ul style="list-style-type: none"> Definition of membership levels and roles Roles of leadership team and chair Election process for chair, scientific member, additional members and country representatives Meeting frequency: Leadership team, membership
1:00 p.m. – 2:00 p.m.	Lunch		
2:00 p.m. – 4:00 p.m.	Topic 3: Terms of Reference: Research Agenda working group and Innovation and Implementation Roadmap working group	David Addiss	<ul style="list-style-type: none"> Terms of Reference for two working groups including content, purview, milestones and how they relate to each other
4:00 p.m.– 4:30 p.m.	Summary of key decisions/next steps and adjourn for the day	Bill Simmons	<ul style="list-style-type: none"> List of key decisions and next steps
6:30 p.m.	Dinner hosted by Lepra		

Thursday, March 22

Time	Topic	Presenter	Outcomes/outputs
9:00 a.m. – 10:30 a.m.	Topic 4: Nominations for Research Agenda and Innovation and Implementation Roadmap working groups	David Addiss	Outline of potential working group members and formal nomination process and timeline for selecting these

10:30 a.m. – 11:00 p.m.	Coffee/tea break		
11:00 a.m. – 12:00 p.m.	Topic 5: Communications, partnership and advocacy	Jessica Cook	Stakeholder mapping exercise Communications: <ul style="list-style-type: none"> • Logo • Goals, audiences • Website • Messaging
12:00 noon – 1:00 p.m.	Lunch		
1:00 p.m.– 2:00 p.m.	Topic 6: Fundraising working group	Courtenay Dusenbury	Fundraising/advocacy working group: <ul style="list-style-type: none"> • Vision for this working group • Goal/objectives • Members • What are our core values for raising funds? • How can we raise funds without negatively impacting fundraising for partners?
2:00 p.m. – 2:30 p.m.	Topic 7: Envisioning the future	Courtenay Dusenbury	Getting to Zero: Discussion and finalization of draft strategic outline
2:30 p.m. – 3:00 p.m.	Open discussion	Bill Simmons	<ul style="list-style-type: none"> • Unaddressed topics • Reflections on the past year and movement forward • Other items as suggested
3:00 p.m.	Closing of the meeting	Bill Simmons	
3:30 p.m.	For those whose flights depart the next morning: Walk to Colchester Castle for a guided tour; informal dinner at a local restaurant.		