

Global Partnership for Zero Leprosy Leadership Team Meeting

11-12 October 2018

Brussels, Belgium

Meeting participants

Leadership Team Members or Delegates

1. Bill Simmons, President and CEO, American Leprosy Missions (Chair)
2. Arielle Cavaliero, Program Manager, Novartis Foundation
3. Roch Christian Johnson, President, International Leprosy Association
4. Taye Letta, Program Director for Leprosy and TB, Federal Democratic Republic of Ethiopia
5. Takahiro Nanri, Executive Director, Sasakawa Memorial Health Foundation
6. W. Cairns Smith, Emeritus Professor, University of Aberdeen
7. Geoff Warne, CEO, ILEP
8. Venkata Ranganadha Rao Pemmaraju, Technical Advisor, WHO Global Leprosy Program
9. Amar Timalina, President, IDEA Nepal

Advisors

10. Ann Aerts, Head, Novartis Foundation
11. Jan van Berkel, President, ILEP
12. Bart Vander Plaetse, FAIRMED (Chair of Operational Excellence Working Group)

Secretariat

13. Courtenay Dusenbury, Secretariat Director
14. Jessica Cook, Communications Director
15. Christine Fenenga, Coordinator, Operational Excellence Working Group

Invited but unable to attend

- José Ramirez, President IDEA
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Program
- Anil Kumar, Deputy Director General (Leprosy), Ministry of Health, India
- Erwin Cooreman, WHO Global Leprosy Program
- David Addiss, Coordinator, Research Agenda Working Group
- Fareed Mirza, Novartis Foundation, Chair of Research Agenda Working Group

Summary of Meeting Decisions

- Partners approved an Action Framework that lays out the Global Partnership for Global Leprosy's (GPZL) vision and goals through 2025; this will be regularly assessed and modified.
- The Action Framework provides a theory of change that will be used to describe the GPZL.
- Partners agreed to continue to try to structure and align their leprosy-related work around the GPZL in ways that add value and leverage the activities of each other. Examples include:
 - The World Health Organization (WHO) will work jointly with the GPZL on mid-term reviews, invite the GPZL to regional meetings and look for other ways to partner globally and within countries.
 - The GPZL will endorse the WHO Guidelines and Strategy, and include its training and modules in the GPZL toolkit.
 - WHO will work jointly with GPZL on its country assessment and toolkit. WHO will participate in GPZL site visits and planning activities in three pilot countries this year. WHO will also share information with national program directors on the GPZL's methods.
 - The GPZL will participate in WHO work to develop the WHO Leprosy Strategy post-2020.
 - The Nippon Foundation will consider funding country plans, including research.
 - The Novartis Foundation will provide a second year of support for the GPZL, and will support some of the research priorities coming out of the Research Agenda Working Group. They will also develop a manual on post-exposure prophylaxis (PEP), to be part of the GPZL toolkit.
 - International Federation of Anti-Leprosy Associations (ILEP) members will provide a second year of support for the GPZL. ILEP members will explore how to engage with GPZL at the global and country levels, including through communications and joint work
 - The International Leprosy Association (ILA) will explore how to promote the GPZL to its members, including a 2019 workshop.
 - International Association for Integration, Dignity and Economic Advancement (IDEA) will continue to be a strong participant and influencer in the GPZL.
 - Country directors will lead the development of the GPZL road map and toolkit and will be key experts on peer-to-peer assessment and visioning activities in 2019.

Day 1: Thursday, 11 October 2018

Group Discussion: What are the trends, opportunities and threats to the Global Partnership for Zero Leprosy?

Trends and Opportunities

New partners

Leprosy has been gaining traction in the NTD community, particularly at meetings like the NNN. United to Combat NTDs' new Leprosy Action Framework is another example. New audiences are coming together: persons affected by leprosy and national leprosy program directors are interested in the partnership. The team sees an opportunity to look beyond the leprosy community and partner with other NTD organizations.

Research and innovations

Many innovations are happening now. Examples: a diagnostic accelerator and GIS mapping are advancing, and a vaccine trial was recently completed. L-PEP has recently completed field activities and is included in the new WHO guidelines. Progress for the research agenda is good. An opportunity is to put more emphasis on morbidity to understand the true impact of the disease.

Funding opportunities

More donors are including leprosy in their portfolios. Some funders such as the World Bank are investing more in people versus infrastructure.

Threats

Country data and resources

Many threats are perceived at the country level, including lack of resources and countries that discontinue leprosy surveillance in a post-elimination era. WHO data may not show hidden cases, including countries who are not reporting. Gaps in overall public health capacity in countries are challenging to address. The team emphasized the need for a collaborative process with WHO and countries in creating GPZL products, especially since national program managers would find it difficult to manage multiple plans or strategies. Another comment was that we need more resources that address discrimination and stigma.

Other threats and needs

Other threats include lack of funding and lack of awareness of the partnership. A comment was that we need an investment plan for what the partnership wants to accomplish.

Progress to Date: Strategic Objectives 2018

Courtenay Dusenbury presented a brief summary of progress to date and requested feedback from the Leadership Team on its work.

Audiences and communications

The Secretariat should continue to focus on building trust and unity among the partners. Getting more people involved is critical, including national program managers and ILEP members. Different countries should be involved to ensure high/low endemicity and capacity are represented; each country is unique. A recommendation was to have new messaging that can address audience questions and expectations.

Data and best practices

The leadership team recommended that the partnership help reinforce WHO Guidelines and endorse innovations like PEP. The partnership needs to show data that reflects accomplishments across the leprosy field. Overall, the group sees a universal need for better reliable data. Publishing the research agenda will be critical.

Prioritization

The research agenda will need prioritization. We must ask: Is this list going to lead to good quality evidence and lead to new policy? What will accelerate the most progress?

For the Operational Excellence Working Group, the team will need to prioritize the tools that can lead to the most progress. Findings and identified gaps from this working group may go back to the Research Agenda Working Group for further study.

Action Framework: Strategic Objectives

Courtenay Dusenbury presented the Action Framework. The document has been discussed individually with leadership team members over the past two months. She noted that it will be important to align with WHO and ensure that components of WHO's work will be part of the toolkit.

Discussion question: Have we adequately addressed threats and opportunities in the previous discussion?

The group noted that quality assurance and prioritizing the research topics will be important for funding. Countries need support in implementing WHO guidelines. Power of consensus is important and perhaps small country-focused partnerships could be created. It will be important to show that country strategies should link to their own goals.

The group emphasized the GPZL strategy should align with WHO's strategy and not be parallel. National WHO mid-term reviews will take place in 10 countries—it will be useful for GPZL to collect more information and have case studies.

Discussion questions for the Action Framework: Does the Action Framework meet our goals? Does it move us toward Zero Leprosy fast enough? Is it realistic? How will it be received in countries?

Recommendations were to include low-endemic countries and that morbidity needs more attention. The group did not think we had a clear target for zero leprosy yet, but a suggestion was to highlight countries that do get to "zero." Working with WHO, national program managers and ILEP organizations will help make sure the framework is received in countries. Overall, the group felt it was a good way to frame our overall vision, and will need to be regularly updated.

Research Agenda Working Group Update

Arielle Cavaliero presented an update of the work of the Research Agenda Working Group.

Comments:

The team agreed that there should be a clear validation process for ranking the different sub-groups for prioritization. Other comments: (1) The COR-NTD meeting is a good opportunity to promote the research agenda. (2) The working groups do not have enough participants from African countries, Indonesia and Japan.

Discussion question: What will be the role of this working group after 2018?

- Raising funds for research areas will be important. Also, next discussions should include: (1) how sub-areas will be prioritized; and (2) LRI and ITC and how they will connect.
- Ensure that the research is applicable across different contexts and countries.
- The group should engage with other disease groups and on cross-cutting issues, and keep watch on innovations.

Operational Excellence Working Group Update

Christine Fenenga presented an update of the work of the Operational Excellence Working Group. She also presented the names of potential chairs (national program managers).

Comments:

- Establish criteria for selecting program managers.
- WHO will recommend that leprosy program managers join this working group. In addition, WHO will work jointly with GPZL assessment tool and may include it in the WHO mid-term reviews.
- Feedback from ILEP technical managers should be sought.
- Need to be inclusive; may include French-speaking and Portuguese-speaking groups.
- Open call for participants: Need a communications plan and everyone has to endorse this. Open call criteria and web page up in early November.
- After the toolkit is tested, the Nippon Foundation may be able to help fund implementation in some countries through country plans.

Advocacy and Resource Mobilization

The leadership team was divided into small discussion groups to provide feedback on the different focal areas of the Advocacy and Resource Mobilization Strategy. Suggestions made will be incorporated into the Strategy.

Day 2: Friday, 12 October 2018

Group Discussion: Reflections from Leadership Team Members

Power in a group

Many group members said they felt inspired and that the group has a common ground. A value is bringing people together. Isolation has been common in the leprosy community and the partnership can help change that. Working closely together may bring non-traditional donors. The new Action Framework shifts the thinking from an annual plan to a long-term visionary plan.

Audiences and communications

Key audiences include national program managers, persons affected by leprosy, and ILEP members. Leadership Team members can represent the GPZL when they are working in different countries. Leadership Team members also have a unique charge to disseminate information. The task of communications is large.

Local country involvement

Recommendations include bringing the partnership to a local country level to make everyone feel they belong. Some countries have local partnerships already. The GPZL can work closely with WHO on action plans for every country.

Time and commitment

Leadership Team members noted that it will take time to see results. The work of the Research Agenda Working Group may take five years to start seeing any results. Multidrug therapy was a major advance for leprosy, yet took years to be implemented at the country level. A Leadership Team member advised not to underestimate how hard implementation will be.

Communications and Membership

Jessica Cook presented the GPZL communications data, such as website visits and social media metrics. She also presented the membership structure and showed an analysis of who was joining the partnership. She stated that the current secretariat structure and resources are limited and it is challenging to implement all tactics.

Discussion question: What communications materials does the Leadership Team need to effectively communicate about the partnership?

Informational materials

A request was for a short elevator speech and new talking points. Materials should be in English, French and Portuguese. A recommendation was to include a concrete call-to-action: how people can get involved. Another request was for specific materials for the two working groups that show their purpose and vision.

Website and videos

A suggestion was to make the Google Translate button larger on the website. Video ideas included animating the Action Framework and creating various video interviews such as experts discussing why zero leprosy is possible. A suggestion was to link to other partners and include partners' news in the newsroom section of the website.

Other ideas

Other ideas included selecting an ambassador for the partnership, TED talks and celebrity videos.

Discussion question: What changes or additions are needed to membership policies?

The leadership team agreed that ILEP members can join as separate organizations and individual staff could join as affiliates. WHO will work with GPZL to target country program managers as members. It may be easier for country officials to join as individuals rather than countries.

Meeting adjourned