

## Leadership Team Meeting

3 June 2021

### Participants

#### Leadership team members and guests

- Benedict Quao, Program Manager, National Leprosy Elimination Program of Ghana
- Deanna Hagge, Senior Research Advisor, The Leprosy Mission (TLM)
- Gangadhar Sunkara, Senior Global Program Clinical Head, Novartis
- Geoff Warne, CEO, International Federation of Anti-Leprosy Associations (ILEP)
- Linda Hummel, Chair of Executive Group, Leprosy Research Initiative (LRI)
- Maarten van Cleeff, Former Director of Challenge TB project, KNCV
- Mauricio Lisboa Nobre, Consultant to Brazilian Leprosy Programme
- Nienke Veldhuijzen, Technical Officer, Leprosy Research Initiative (LRI)
- Takahiro Nanri, Executive Director, Sasakawa Health Foundation
- Wim van Brakel, Chair, ILEP Technical Commission (ITC)

#### Secretariat

- Andie Tucker, Project Manager, Global Partnership for Zero Leprosy
- Bill Gallo, Secretariat Director, Global Partnership for Zero Leprosy
- Caroline Cassard, Communications Specialist, Global Partnership for Zero Leprosy
- Mondie Tharp, Project Manager, Global Partnership for Zero Leprosy

#### Invited but unable to attend

- Alice Cruz, UN Special Rapporteur
- Amar Timalina, President, International Association for Integration, Dignity and Economic Advancement (IDEA) Nepal
- Arielle Cavaliero, Global Franchise Lead, Leprosy, Novartis
- Bill Simmons (Chair), President & CEO, American Leprosy Missions
- Erwin Cooreman, Team Leader, WHO Global Leprosy Programme
- Rao Pemmaraju, Technical Officer, WHO Global Leprosy Programme
- Rekha Shukla, Joint Secretary, Ministry of Health and Family Welfare, India
- Roch Christian Johnson, President, International Leprosy Association

## I. Research Landscaping and Gap Analysis Presentation

*Nienke Veldhuijzen shares findings from the landscaping and gap analysis.*

- **Wim van Brakel:** In the WHO document, mental wellbeing and mental health is a medical topic, classified under disability, and not under social aspects. We can group stigma and mental wellbeing, but we have to be careful that they are different aspects.

Regarding the workshops, how will we decide who will be invited? A mix of researchers and implementers?

- **Nienke Veldhuijzen:** We have discussed inviting people from the field. Whether we will organize it as two separate groups is still open. We want to involve a range of stakeholders.
- **Gangadhar Sunkara:** What is the next step after the workshops?
  - **Nienke Veldhuijzen:** The outcome of the workshops will be concept notes. The resource mobilization team will then look for potential sources of funding for the concept notes. Then they will be developed into concrete proposals, depending on the funders.
- **Gangadhar Sunkara:** Often, someone has to own the research and GPZL does not own any research responsibility.
  - **Nienke Veldhuijzen:** I envision that if one workshop leads to 5 concept notes, then some of the researchers will take ownership and take the concept note forward. Identifying the funding opportunities falls under GPZL.
- **Linda Hummel:** If the end goal of the workshops is to develop concept notes and then full proposals, what is your thought about involving the target groups of these notes/proposals in this wide range of stakeholders? I would like to advise involving (institutional) fundraisers and perhaps even potential donors from the beginning, not after the workshops.
- **Maarten van Cleeff:** Looking at the top 10 priorities, I suggest clarifying for each topic, what is the deliverable? Secondly, is it a country-specific deliverable or a global tool? If we look for funding, country-specific tools will require country-specific funding.

- **Nienke Veldhuijzen:** Prioritisation was done from a global perspective. Once we start working on these concept notes, I agree that we need to be very specific.

To respond to Wim's first question: I don't have an immediate answer. When we started with the Research Agenda, stigma and mental wellbeing were still combined in one of the "zeros." Before, they were in the same group. We have to be pragmatic about which is the best grouping for mental wellbeing: with disability or with stigma?

- **Geoff Warne:** When you consider how many people were involved in the Research Agenda at the beginning, I think it's the resource mobilization that's the weak link here. Petra was talking about the value of bringing potential funders into the picture very early on. The challenge is, the researchers do an immense amount of work, and then it's hard to find a funder. I'd rather bring the funder in before the work is done.

- **Andie Tucker:** For your awareness, that's a conversation that Nienke and I have been having. We are balancing the priorities to reach zero leprosy with the priorities of funders. That will require some flexibility with the development of concept notes and research questions.

To tease out the differences between this process and the TPP group: The TPP was developed under the guidance of the WHO DTAG group. There were external offices that we were working under with that group. TPPs are not written to answer questions now, but to serve for the future, because the technologies needed for that product may not yet be available. TPPs are highly specific: the exact requirements we would need for a practical tool that is effective in reaching zero leprosy.

- **Nienke Veldhuijzen:** We often see with research funders that they want to have an impact pathway: what will the research accomplish and what is the longer goal that we are working towards? I will give it some more thought and look at the TPP document.
- **Geoff Warne:** I take Andie's point that these are different things. With the TPP development, we had the Bill and Melinda Gates Foundation team-member involved. If we have the right person, it seems there are advantages to engaging potential funders from the beginning.
- **Wim van Brakel:** I want to endorse the need to ask for more specific research outputs from the start. We need to ask for more specific work products.

- **Mauricio Nobre:** I think the question in the early diagnostic is too complex. One workshop like this is a good opportunity to bring people from different fields (education, psychology, sociology), not only the scientists who have worked in leprosy.
- **Nienke Veldhuijzen:** We need to focus on certain topics, which was the whole reason to do the prioritization. The challenge will be to keep focused and not drift away to the other areas.

II. Proposed topics for research workshops

*All endorse the proposed topics.*

III. Discussion: Escalation of COVID-19 pandemic in India and Brazil

- **Gangadhar Sunkara:** As you know, India has been going through a damaging second wave. Novartis was working with the tertiary care hospital to collect skin images for an artificial intelligence project. Usually, an investigator collects this information from patients when they do national medical camps for leprosy detection in endemic districts. But these camps have not been happening for almost 18 months. There is no progress on these camps. During the second wave, there is no case detection. I'm not sure how the primary health care centers are doing with MDT distribution. Novartis has an initiative called Healthy Families. India and Brazil have high numbers of COVID cases. I see the stress that India is going through. I think 2-3 years from now, we may end up seeing many cases of leprosy, especially due to close living conditions. I want to bring this to GPZL's attention because I think we can do more.
- **Mauricio Nobre:** We have in Brazil about 16 million cases since the beginning of the pandemic and nearly a half-million deaths. We are in the second wave and it is stable, not decreasing as expected. We have 100,000 new cases a day and 2,000 deaths a day. The number of deaths has decreased, but in many areas the number of new cases is stable. The second wave did not decrease as expected. Only 20% of our population have received the first dose and 10% have received a second dose.

With the leprosy programme, things are better than last year since we solved the issue of access to medication. Health posts are seeing patients. But case detection efforts are not sufficient. Linked with COVID, poverty, and hunger are increasing. People go to the streets to protest the government, and this makes people more vulnerable in the middle of a pandemic. Yesterday we

had a meeting with MORHAN, which asked for the prioritization of a vaccine for people suffering from leprosy.

- **Bill Gallo:** I have ongoing concerns about our country work. We continue to forge ahead and Mondie is doing extraordinary work managing these reviews and road-mapping exercises. I have ethical concerns about doing work on the ground that could expose people to COVID. We spoke with two CDC persons in Tanzania. The old president was in denial about COVID, and the new president is moving the country toward understanding COVID. Meanwhile, we are convening stakeholder meetings. We are asking those involved to take the necessary precautions. But are we taking enough precautions by simply asking others to follow guidelines?
- **Geoff Warne:** The Neglected Tropical Diseases NGO Network (NNN) has been working to find a good balance between the risk to health staff and patients versus the risk of not carrying out those interventions. We can learn from their work. **Mauricio:** We understand that in India, the new case detection last year was 60% less than normal. Do you get the sense of the new case detection in 2020 versus the previous year?
  - **Mauricio Nobre:** We detected about 40% of what would be expected.
- **Deanna Hagge:** In Nepal, it was also at about 50% of the expected case detection. Patients who were diagnosed in 2020 typically had more problems. A lot of the research staff were also pulled into testing for COVID. Hospital staff and their families were prioritized for vaccination.

Research is there, but there's not a lot of ability to do much right now. They're not going to put patients or their families at risk. If anything was said, it would be encouragement, solidarity, and understanding.

- **Wim van Brakel:** In response to Ganga's comments about what NGOs can do, I want to say that NGOs are already doing a lot. We don't always see that easily. And the impact of NGOs is not reflected in maintaining case detection, which is the responsibility of the government. Teams reached out by mobile phones to hundreds of patients and counseling them about medication. From a public health perspective, it's not all about COVID. From a human rights perspective, people are asking, why is someone with COVID more important than someone with another serious condition? We need to take every possible precaution. But whatever can be done with the available precautions should be done.

- **Gangadhar Sunkara:** In the next monthly meeting, we should have someone from India or Brazil share the challenges. So when we work with WHO in the future when COVID is under control, we will better understand the issues on the ground.
  - **Benedict Quao:** In Ghana, a decision was made to restore other essential services. So we have gotten back on track more or less.
- **Takahiro Nanri:** Thank you everyone for staying for a few extra minutes.