

### **A Framework for Engaged Research to Reach Zero Leprosy**

**Session Date:** Saturday, October 27

**Session Time:** 9:00am – 12:00pm

**Session Location:** Conde, 3<sup>rd</sup> Floor

**Session Description:** After the introduction of multi-drug therapy (MDT) 30 years ago, the reported number of new cases of Hansen's disease, or leprosy, decreased dramatically. However, >200,000 cases have been reported annually for the past decade, suggesting that current approaches are inadequate to achieve the World Health Organization (WHO) goal of zero leprosy. The Global Partnership for Zero Leprosy was established in 2018 to harmonize efforts and accelerate progress toward zero leprosy. A key objective is to develop new tools and approaches for diagnosis, treatment, and prevention of leprosy. To this end, a Research Working Group was convened in August 2018, with broad participation of the leprosy community and sub-groups on diagnostic tests, vaccines, post-exposure prophylaxis, operational research, stigma, disability, and epidemiologic modeling, among others. In this session, Research Working Group members will present initial recommendations and seek input from the COR-NTD research community before finalizing a framework for engaged research to reach zero leprosy.

**Session Chairs:** David Addiss, The Task Force for Global Health  
Fareed Mirza, Novartis Foundation

**Session Rapporteur:** Liesbeth Mieras

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#### **KEY DISCUSSION POINTS**

The Research Working Group of the Global Partnership of Zero Leprosy (GPZL) came together to discuss the draft agendas that were formulated in the eight sub-groups that had been formed to enable the process. A short introduction was given on the GPZL:

The GPZL was established in 2018 to catalyze and coordinate action toward the goal of zero leprosy. The Research Agenda Working Group is one of the three working groups that will work on the Global Partnership's strategic objectives. The second group is on Operational Excellence and will identify and promote best practices to achieve zero leprosy and help facilitate the uptake of best practices and new interventions into national leprosy programmes. A third group to be formed early 2019, on Resource Mobilization and Advocacy, will take these initiatives forward to potential donors and partners.

The Research Agenda Working Group is chaired by Dr. Fareed Mirza. Eight scientists from around the world are facilitating eight subgroups. Each group focuses on a specific area of research related to zero leprosy. Membership and participation in these subgroups is open to all interested persons.

Several scientific advisors have been appointed to provide overall guidance and support to the Research Agenda Working Group.

### ➤ Presentations

The following draft research agendas were presented:

1. Diagnostic and screening tests	Malcolm Duthie on behalf of Milton Moraes
2. Vaccines	Steve Reed
3. PEP and Transmission	Peter Steinmann on behalf of Christa Kasang
4. Stigma	Wim van Brakel
5. Disability	Liesbeth Mieras
6. Operational Research	Paul Saunderson
7. Epidemiologic modelling and economics	David Blok
8. Digital Health	Fareed Mirza on behalf of David Heard

### ➤ Discussions

- A suggestion was given to the Diagnostics group to look at the experience with microbiopsies used for diagnosis in the field of leishmaniasis. In areas where the diseases overlap, for example in some areas in India, this technique could be used.
- The quality of immunotherapeutics needs to be guaranteed. This is part of the development process. WHO requirements for a leprosy vaccine should also be taken into account.
- The Child Health and Mortality Prevention Surveillance (CHAMPS) network, developed by the Task Force for Global Health, was mentioned as an example of a data system that can be used to capture and disseminate surveillance information to scientists and policy makers.
- Another example from the leishmaniasis field is the technique of sampling around an index patient to study transmission. It was suggested to the Operational Research group to see in how far this technique could be useful for the leprosy field.
- Complete, disaggregated, and good quality data are very important for modelling. Including geographical information into modelling is possible but would require more advanced modelling tools.
- The importance of basic science, in the form of molecular biology, was discussed – as a way to get more in-depth knowledge on leprosy reactions and also to study transmission.
- There is a lot to learn from other disease areas. The leprosy field also has lessons to share, for example on human rights approaches and the involvement of people affected.

- Integrated approaches provide an opportunity for increased (cost-) effectiveness, cross-learning, and health systems strengthening. This is however an area that is more related to the Operational Excellence Working Group.

#### KNOWLEDGE GAPS IDENTIFIED

- Elimination as a Public Health problem has been achieved at national level in most countries, while transmission is still ongoing. How do we address this?
- How do we ensure continued support for leprosy control? What should be our next target?
- One of the main challenges of the Global Partnership is to come to action at national level. Undoing the elimination message is an important part of that. How can the research agenda be best formulated in order to get maximum support to work towards zero leprosy?

#### RECOMMENDED NEXT STEPS

- It was suggested to **identify which of the issues of the Research Agenda would need to be addressed first**, before addressing others. A framework as was presented by Emily Wainwright during the plenary session showing the steps needed and indicating with green, orange, and red which steps have to be taken next when working towards the elimination of a disease.
- When formulating the research agenda, it is important to **keep in mind who it will be presented to**. The Global programme to Eliminate Lymphatic Filariasis has also gone through a process of formulating the research agenda. The agenda was collapsed into five key questions. This enabled the communication with major donors.