

Terms of Reference

Leprosy Research Agenda Working Group

The Global Partnership for Zero Leprosy will convene two working groups in 2018. The Leprosy Research Agenda Working Group will develop an aligned research agenda for current and potential future innovations in diagnostics, strategies, and interventions to contribute to zero leprosy. The Operational Excellence Working Group will identify and foster the use, scale-up, monitoring, and evaluation of best practices and promising innovations in national leprosy control programs. Together, these working groups are a continuum that spans scientific research, field testing, monitoring and evaluation, and the scale-up of new tools, approaches, policies, and practices to achieve zero leprosy. Close collaboration and consultation between the two groups will be essential.

Purpose

The purpose of the Leprosy Research Agenda Working Group is to facilitate and stimulate scientific research to develop and evaluate diagnostic tests, strategies, and interventions that, based on emerging evidence, will contribute to zero leprosy.

Goal for 2018

A consensus leprosy research agenda or “roadmap” for research needed to achieve zero leprosy will be developed. This effort will build on recent work by the WHO Technical Advisory Group (TAG) and by scientists participating in a May 30, 2017 Novartis Foundation-convened meeting with the Oswaldo Cruz Foundation in Rio de Janeiro, Brazil on strategies to detect and interrupt transmission of leprosy. It will also build on ongoing research by several groups, including the Leprosy Research Initiative (LRI), R2STOP, the LPEP Project, and others.

Topics that the Working Group may consider include:

- Post-exposure chemoprophylaxis
- Diagnostic tests
- Vaccines and immunoprophylaxis
- Surveillance
- Case detection
- Assessing the population at risk and burden of leprosy
- Monitoring and evaluation
- Stigma as a barrier to efforts to reduce transmission

Milestones for 2018

Milestone	Activity	Dates	Output
1.1 Leprosy Research Agenda	Terms of reference for Research Agenda Work Group finalized	1/05/18	TOR
	Working Group members list finalized, approved by LT and invited	1/05/18	Working group
	2018 meeting dates/places finalized	1/06/18	Save the date note to invitees
	Online platform to foster the group's work established	1/06/18	Basecamp, google drive etc. platform
	Small group created to develop background materials	1/06/18	Background materials/meta research
	Drafting group convened to produce first draft of Research Agenda	16/07/18	Research Agenda draft 1
	Validation group convened to revise and approve Research Agenda	01/09/18	
	Input of others sought via various channels	01/10/18	Outline: formal research agenda
	Comment and revision period for LT	15/10/18	Revised drafts
	Formal report outlining Research Agenda completed	01/11/18	Research agenda report
	Paper in the scientific literature	01/12/18	Paper submitted
	Anticipated but outside the dates of this grant: Work Group continues to engage as community of practice with regular exchange through communications platform, teleconference and meetings at other venues (as feasible).	Quarterly through 2020	Feedback, discussions, information to support and advocate for Research Agenda
Leprosy Research Agenda becomes a key component of the advocacy/resource-mobilization strategy	01/12/18	Innovation and Implementation road map based on agreed-upon research priorities	

Duration of Service

For the period April 2018 – March 1, 2019, the Research Agenda Working group is envisioned by the Leadership Team as an ad-hoc group that is charged with producing a research agenda or roadmap. Beyond that time, the Leadership Team may decide to reconstitute the Research Working Group as an ongoing body to:

- provide guidance to the Global Partnership for Zero Leprosy on scientific and technical matters;
- ensure that the research agenda remains aligned with, and is informed by, ongoing research efforts
- develop, with support of the Secretariat and the Leadership Team, sources of support to expand necessary research to reach zero leprosy; and
- engage with the larger scientific community at scientific and technical meetings such as the Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD).

In this case, the Secretariat will draft terms of reference for a “permanent” Research Working Group for deliberation and approval by the Leadership Team.

Representation

Chair

The Novartis Foundation nominated Fareed Mirza as chair through 1 March 2019, and the Leadership Team approved this nomination in Colchester, UK on 23 March, 2018. The role of the chair is to facilitate the group’s goal and objectives through transparent and equitable discussion and consensus.

Members

The Working Group will include representation from:

- Leprosy researchers in the biological and social sciences, with representation from endemic countries
- Technical organizations and scientific initiatives:
 - The Leprosy Research Initiative (LRI)
 - R2STOP
 - World Health Organization
 - The WHO Technical Advisory Group (TAG)
 - The ILEP Technical Commission
 - The LPEP program
- Persons affected by leprosy
- National leprosy program managers
- Non-governmental organizations (NGOs)
- Implementation researchers in the biomedical, public health, behavioral, and social sciences
- Others as nominated by the Working Group Chair and approved by the Leadership Team

- The operational excellence working group (chair)
- Gender and regional representation
- The Leadership Team

Decision Making

Decision making will be by consensus. If a vote is required, each work group member will have one vote with a simple majority rule.

Approved by the GPZL Leadership Team

April 30, 2018