

Reviewing Research Priorities of the Leprosy Research Initiative (LRI): A Stakeholder's Consultation

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For which topic were research priorities identified?

leprosy

In which location was the research priority setting conducted?

international

Why was it conducted at all?

Leprosy is a neglected tropical disease and although a cure is available, each year over 200,000 persons are newly diagnosed with leprosy and many more suffer from long-term complications, such as disabilities. The Leprosy Research Initiative (LRI) provides competitive research funding for research projects related to one of five research priorities. Five years after its launch in 2013 and with new developments in the field, the LRI consulted a wide range of stakeholders to evaluate its research priorities and to contribute to a wider research agenda.

What was the objective?

to evaluate the research priorities of the Leprosy Research Initiative and to contribute to the development of a wider research agenda for leprosy

What was the outcome?

a ranking list of 15 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

Delphi; focus group; interview; survey

How were the priorities for research identified exactly?

Step 1: collecting research priorities: by asking panel of experts, focus groups and key informant interviews, recordings transcribed and thematic analysis conducted, 55 topics emerged, additionally 16 topics added and 5 topics from previous survey added, 76 topics categorized into 11 sub-clusters. Step 2: survey and Delphi process: survey: participants were asked to rate one or two (sub-)clusters according to their perceived importance. Delphi: Delphi round 1: participants were asked to rank 50% of the topics, Delphi round 2: participants were asked to re-consider their initial ranking based on importance ratings of survey, participants were asked to re-rank, Delphi round 3: participants were asked again to re-rank based on round 2 ranking.

Which stakeholders took part?

Leprosy-affected persons, researchers, health professionals and policymakers. 124 participants overall. Expert panel: 17 participants. Focus groups: 29 participants. Key informant interviews: 6 participants. Survey: 80 participants. Delphi: 23 participants.

How were stakeholders recruited?

Purposive sampling was used to create a balance between clinical/public health and basic science researchers; social scientists; policymakers and people affected by leprosy. To reach a wide range of stakeholders the e-survey was translated in Portuguese, Bahasa Indonesia, Hindi and French and distributed in multiple ways: via the Leprosy Mailing List (LML), the ILEP monthly update and also via targeted invitations to organizations of persons affected by leprosy (IDEA, ENAPAL, Morhan and APAL India). Moreover, snowballing of the invitations was encouraged. For the Delphi process, experts were identified by the LRI Steering Committee. Eligibility considerations included county of origin, area of interest, and expertise. Purposive sampling was used to ensure a balance between clinical/public health and basic science researchers; social scientists and policymakers. Persons affected by leprosy were also invited to participate.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.