

Research Priority setting for Leprosy



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Summary

Background Leprosy is a neglected tropical disease and although there is a cure available, there are still many people in endemic countries infected by the disease or suffering from long-term complications, such as disabilities. In order to eliminate leprosy worldwide, health research is needed. In order for health research to be effective, the strengthening of health research systems is needed. A way of doing this is by defining research priorities. Furthermore, due to the limited resources and in order to effectively target the research and maximize the impact of health investments, it is important to define research priorities. Furthermore, a participatory way in which a wide range of stakeholders is involved in the research priority setting process is essential. The LRI, a combined venture of international NGOs working in the field of leprosy control, has developed a policy with research priorities in 2013. However, the field of leprosy is developing and it is unclear whether these priorities still cover the most important research topics in the field of leprosy. Therefore, the research question addressed in this report is: *“Which leprosy-related research topics are considered to be the most important and prioritized by stakeholders?”*

Methodology This study had a mixed methods design. Research topics in the field of leprosy that were considered to be important were gathered by the enquiry panel via mail. The topics that emerged from this enquiry panel were combined with research topics derived from the current LRI research priorities. Focus group discussions with researchers and a panel of leprosy affected persons and interviews with key informants were held to gather important research topics. During the FGD and interviews, advice to LRI and the entire leprosy research community was provided (e.g. which stakeholders to include in leprosy research, what type of research is needed and which research aspects deserve attention). All the FGD and interviews were analysed by thematic coding. All the topics of the enquiry panel, FGD and interviews were presented to a broader range of stakeholders during the e-survey. Participants of the e-survey were asked to rate these topics on importance and to add topics they felt were missing in the initial list. The importance ratings were analysed with SPSS. All the topics of the previous methods, including the e-survey, led to an extensive list of 84 topics which was categorized in three lists (Zero transmission, Zero disabilities and Zero discrimination) and presented to the participants of the Delphi process. They were asked to reduce and rank these topics in three rounds of online questionnaires. After each round, the data was analysed with SPSS and the topics with the highest medians were included in the next round. The group results, results of the e-survey and additional argumentations

were presented to the Delphi panel during the rounds and they were asked to reconsider their initial rankings on the base of these results. Consensus was analysed by the change in IQR of each topic in subsequent rounds.

Results During the FGD and interviews, reasons were provided why research topics were considered to be important, which were mostly practical issues they experienced in health care. Furthermore, participants mentioned that the LRI and the leprosy research community should pay specific attention to participation of leprosy affected persons, standardization of leprosy research (laboratory) outcome measurements and the dissemination and translation of research outcomes. Besides additional research topics that were gathered via the e-survey, the very importance ratings presented what the priorities of a broader range of stakeholders are. The outcomes of the Delphi process (and the end product of this study) lead to five research priorities in each Zero list. In the top five, in most of the topics an increased consensus was achieved after each round (a lower IQR). The top fives of the Delphi process and e-survey are for most topics similar.

Discussion and conclusion This study indicated that the established research topics are still considered important by a wide range of stakeholders in leprosy research field. Interestingly, a novel research priority that emerged from the project – was research into mental health of leprosy affected persons. Limitations of this study were that it was hard to include participants with a social science background and therefore, the research topic list included additional medical topics instead of social topics. During the Delphi process, some topics had to be shifted to another list, which lead to topics with a median ranking of another list in a new list. Strengths were that still a wide range of stakeholders was included in all stages of this study and leprosy affected persons were also included in the Delphi process. In this study, transparency was also achieved by comprehensively reporting all the results and reporting results back to the Delphi panel. Furthermore, the aim of this study was to identify research priorities in the field of leprosy, and not necessarily limited to LRI. Consequently, the results of this study contribute to the wider applicability of the research priorities. It is therefore recommended that (research) organisations working in the field of leprosy include these research priorities into their research agendas. Furthermore, these organisations (and specifically LRI) are recommended to make participation of leprosy affected persons in all decision-making processes (including scientific research) a reality, develop guidelines for standardization in leprosy (lab) research and invest in popular communication to disseminate and communicate leprosy research outcomes. This in order to effectively embed the defined research priorities into health research systems.