Research priorities for Leprosy

1. Background

- Leprosy: a disease of the ‘poor’
- Cure available, but still 215,000 new cases in 2016
- Health research is essential to eliminate leprosy
- In order for health research to be effective, defining research priorities in a participatory way is needed
- LRI has defined research priorities in 2013, but there have been developments in the field of leprosy

“Which leprosy-related research topics are considered to be the most important and prioritized by stakeholders?”

2. Conceptual framework

Research priorities were conceptualized as important research topics

Research topic: topics that correspond to five years research programmes and provide guidance, but still research questions can be derived from the topics

Criterion on which research topics were assessed was importance, which includes research topics that are considered to be in urgent need of research and will directly or indirectly benefit leprosy affected persons and persons ‘at risk’ for leprosy

3. Methods

- Enquiry panel (n=17)
- FGD (n=4) + interviews (n=6)
- E-survey (n=80)
- Delphi process (n=22)

4. Results

Zero Transmission

1. Defining and implementing optimal post-exposure prophylaxis strategies and regimens
2. Developing new assays for diagnosis and disease monitoring purpose
3. Research on strategies to improve the quality of services at different levels of the health care system, including identifying factors which hinder or facilitate case finding and management
4. Research on vaccines including the full spectrum from pre-clinical development to implementation research
5. Identification and mapping of infection and disease

Zero Disabilities

1. Identification of new treatment options and efficacy trials of novel drug treatment of nerve function impairment (NFI) and reactions
2. Research on mechanisms of Type 1 or Type 2 reactions and nerve damage in leprosy
3. Research on the feasibility, effectiveness and impact of prevention of disability strategies
4. Development and validation of diagnostic tools and validation of standardized tools for the detection and measurement of NFI and reactions
5. Assessing the impact of case finding/contact tracing strategies on the prevalence of leprosy-related disabilities among new cases

Zero Discrimination

1. Research into the effectiveness of stigma reduction interventions, including the feasibility, acceptability and impact of community involvement, and skills building and empowerment of persons affected
2. Studies on mental wellbeing of leprosy affected persons and associations between mental health, health care seeking behaviour and accessibility of services
3. Acceptability studies on medical interventions and leprosy services
4. Assessment of stigma prevalence and type and local validation of tools/questionnaires to determine stigma
5. Studies investigating the effect of the participation of leprosy affected persons in research and services and development of models/best practices

5. Conclusion and discussion

- Consensus and consistency research priorities with other methods in this study and current LRI priorities
- One truly novel research priority: mental health leprosy affected persons
  - Research topic list included predominantly medical topics
  - Wide involvement of stakeholders (incl. leprosy affected persons)

Future research: literature review

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