

Reviewing Research Priorities of the Leprosy Research Initiative (LRI): a stakeholder's consultation

ZAHRA KHAZAI*, WIM VAN BRAKEL**,
DIRK ESSINK***, TOM GILLIS****,
CHRISTA KASANG*****, PIM KUIPERS*****,
PAUL SAUNDERSON*****, DAVID SCOLLARD*
& NIENKE VELDHUIJZEN*

**Leprosy Research Initiative*

***Netherlands Leprosy Relief*

****VU University*

*****effect:hope*

******The German Leprosy and Relief Association*

******Independent Consultant*

******American Leprosy Mission*

Accepted for publication 13 March 2019

Summary

Introduction: 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.

Material & Methods: A mixed methods approach was used in which qualitative methods (enquiry panel, focus group discussions (FGD) and key informant interviews) were followed by quantitative methods (e-survey and Delphi process). The Delphi process was the final phase of the study with the aim to reach consensus on the priority ranking of the research topics.

Results: In total, 124 people contributed to the study. Stakeholders consulted included leprosy-affected persons, researchers, health professionals and policy makers. 50% of the participants came from Africa, Asia or Latin America (endemic areas). In total, 84 research topics were identified. The Delphi process resulted in three top five lists of research topics in the categories Zero Transmission, Zero Disability and Zero Discrimination.

Discussion: In conclusion, 15 research priorities categorised in Zero transmission, Zero disabilities and Zero discrimination were prioritised in this study. A research

priority new to LRI was research into the mental health of persons affected by leprosy. These findings are not only relevant for the LRI – but may also contribute to research agenda setting by others, most notably the Global Partnership for Zero Leprosy.

Keywords: leprosy, research priorities

Introduction

Leprosy is caused by an infection with *Mycobacterium leprae*, which primarily infects the peripheral nerves. Although leprosy is curable with multidrug therapy (MDT), reactions and nerve function impairment often occur before, during or after the treatment and may lead to impairments and disability which, depending on social, attitudinal and other factors, may lead to stigmatisation and socioeconomic isolation of those affected.¹ Since the introduction of MDT in 1981, the prevalence of leprosy worldwide has declined significantly. However, the incidence has plateaued in the last decade at over 200,000 new cases per year. Brazil, India and Indonesia together account for 80% of new cases globally.² New developments are promising, especially with regard to chemo- and immuno-prophylaxis. However, implementation may prove challenging in many settings, requiring research into the most feasible and acceptable ways to incorporate them into current programmes. Other challenges include finding means to facilitate early diagnosis, to prevent or treat reactions and nerve function impairment and to reduce stigma and discrimination. Health research is considered to be an essential tool for addressing health challenges and improving public health and health equity.³ In order for health research to be effectively targeted, research priorities should be defined.⁴

The Leprosy Research Initiative (LRI) is a combined venture of members of the International Federation of Anti-Leprosy Associations (ILEP) and closely associated partners. The LRI was launched in 2013 with the aim of contributing to the goal of zero leprosy by promoting, facilitating and funding high-quality research; strengthening research capacity in endemic countries, and facilitating the translation of research results into policy and practice (www.leprosyresearch.org). Prior to its launch, the LRI partners formulated a joint policy that defined research priorities and procedures for selection and monitoring of projects. These research priorities included (1) early detection, (2) nerve function impairment and reactions, (3) inclusion, (4) prevention of disability and (5) tools and methods to interrupt transmission. Five years after its launch and with new developments such as the R2STOP initiative,⁵ the new WHO Global Leprosy Strategy 2016–2020,⁶ the publication of the WHO Guidelines for the diagnosis, treatment and prevention of leprosy,⁷ and the launch of the Global Partnership for Zero Leprosy (GPZL)⁸ as a platform for coordination, the LRI conducted a wide-ranging stakeholder's consultation to evaluate its research priorities. The present work was done in the context of the LRI. However, our broader aim is also to contribute to the development of a wider research agenda for leprosy.

Methodology

A mixed methods approach was used in which qualitative methods (enquiry panel, focus group discussions (FGD) and key informant interviews) were followed by quantitative methods (e-survey and Delphi process).

QUALITATIVE PHASE

The aim of the qualitative phase was to develop a comprehensive list of research topics which could be used in the quantitative phase. The qualitative phase consisted of three parts: (1) an enquiry panel of experts identified by the LRI Steering Committee (consisting of the research coordinators of LRI partner organisations); (2) Three FGDs among LRI 2018 Spring Meeting^a attendees and one FGD with the ILEP panel of affected persons; (3) Key informant interviews.

All three parts used purposive sampling trying to ensure a balance between clinical/public health and basic science researchers; social scientists; policymakers and people affected by leprosy.

The enquiry panel consisted of a direct mailing to selected experts inviting them to list the research issues they considered most important. The cumulative list of topics was checked for duplicates and categorised according to a predefined classification system. This classification system was based on the Health Research Classification system of the UK Clinical Research Council and consisted of five clusters and 8 sub-clusters (Annex 1).⁹

The FGDs and key informant interviews both used a semi-structured interview guide. The recordings were transcribed and a thematic analysis was conducted using a predefined coding scheme based on the same classification system. Any new topics that were identified were added to the categorised list.

QUANTITATIVE PHASE

The quantitative phase consisted of two separate parts: (1) an e-survey and (2) a Delphi process. The e-survey was designed with Google forms and consisted of the categorised list resulting from the qualitative phase. 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 organisations of persons affected by leprosy (IDEA, ENAPAL, Morhan and APAL India). Moreover, snowballing of the invitations was encouraged. The respondents were asked to rate one or two (sub-) clusters according to their perceived importance, using a four point Likert scale (not important at all, somewhat important, important, and very important). In addition, a 'no opinion' option was included. Respondents were also invited to suggest topics they considered missing from the list. Overall importance rates and stratified rates by respondent type were calculated for each topic using IBM SPSS Statistics 24.0.

The aim of the Delphi process was to reach consensus on the most important research topics by a group of expert stakeholders and to rank these according to perceived priority. 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.

The topics were reclassified according to the well-established ILEP Triple Zero Campaign classification, to contribute to the wider applicability of the research priorities for

^a The LRI Spring meeting is an annual event organised by the LRI Scientific Review Committee during which (mostly) senior researchers of LRI-funded research present progress updates. Other regular attendees include the LRI Steering Committee, LRI (associate) partners, Novartis Foundation, and the Turing Foundation.

purposes outside the LRI. This resulted in three questionnaires: Zero Transmission, Zero Disability and Zero Discrimination. New topics arising from the e-survey were checked for duplicates and included if not yet listed. The Delphi process consisted of three rounds of ranking; questionnaires were sent via e-mail. During the first round participants were asked to rank 50% of the topics (with a minimum of 10 topics) based on perceived priority, thereby reducing the total number of topics. During the second round, participants were asked to reconsider their initial ranking based on the overall important rates from the e-survey and the results of the first round of the Delphi process. Participants were also given the opportunity to provide an explanation of their ranking to a maximum of 300 words. During the third round, participants were asked again to reconsider their ranking based on the results of the second round and the provided explanations.

After each round, the results of the rankings were imported into SPSS and the median (Interquartile range (IQR)) and mean ranking (standard deviation (SD)) were calculated. Research topics were ranked according to the median of the assigned scores. Higher scores indicated higher perceived priority. Research topics with the same median were ranked according to the mean. For purposes of analysis, unscored topics received the score 0 when estimating the mean and median. After ranking the data of the first and second rounds, some topics were combined and the new topic was ranked in the subsequent round according to the original topic with the highest median. Moreover, after receiving feedback from participants, some topics were moved to another list. Topics which were moved, always figured on the topic list of the subsequent round – irrespective of their ranking position. After the third round, consensus was interpreted by assessing the change in IQR between rounds. Consensus was considered increased if the IQR of a topic was reduced in round three as compared to round one and two. No statistical testing was performed.

Results

In total, 124 persons contributed to the study. Of the five parts included in the overall study (enquiry panel, FGD, key informant interviews, e-survey and the Delphi panel), the majority (80%) participated in one part only, 16% participated in two parts and 4% in three or more. Overall, 39% was female and 52% of the participants came from Africa, Asia or Latin America (endemic countries*). The distribution by gender and origin, across phases can be found in Table 1.

Table 1. Gender and origin of study participants

Phase	Parts	N =	Female	High burden countries*
Qualitative	Enquiry panel	17	29%	35%
	FGD	29	41%	62%
	Key informants	6	33%	17%
Quantitative	E-survey	80	35%	53%
	Delphi panel	23	48%	26%
Overall			34%	50%

[*Includes countries in Africa, Asia and Latin America. Non-endemic areas include Australia and the United States and countries in Europe. The United States is considered non-endemic for the purpose of this study, despite the low prevalence of (zoonotic) leprosy.]

QUALITATIVE PHASE

Participants

The enquiry panel was consulted via e-mail. 41 experts were invited to participate, 20 experts from endemic countries and 21 from non-endemic countries. The response rate was 35% and 48% among experts from endemic countries and non-endemic countries, respectively. In total 17 experts responded positively.

The FGD were held at the time of the LRI Spring Meeting, an annual event for mostly (senior) researchers of LRI-funded research and other partners. Three FGDs were held, each one lasting 1.5 hour: one focusing on social science topics (n = 8), one focusing on clinical and public health topics (n = 9) and one focusing on laboratory/basic science topics (n = 8). Five members of the ILEP Panel of persons affected by leprosy participated in the FGD at an earlier occasion. Key informant interviews were held with the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members and with representatives of the WHO Global Leprosy Programme, Novartis Foundation, Netherlands Leprosy Relief, American Leprosy Missions and ILEP's Panel of persons affected by leprosy.

Results of the thematic analysis

From the enquiry panel, 55 topics emerged. In addition, 16 research topics from the FGD and interviews which were not mentioned during the enquiry, were added to the topic list. Finally, five topics from a previous survey from 2012 which were not mentioned during the enquiry, were included because the current LRI priorities are based on this survey. In Annex 2 the categorised topic list is presented.

QUANTITATIVE PHASE

Participants

The e-survey was completed by 80 respondents. The respondents self-identified with the following stakeholder categories: (1) persons affected by leprosy (including members of organisations of persons affected by leprosy); (2) researchers; and (3) health professionals, NGO staff and policy makers. In case someone self-identified with multiple stakeholder groups, self-identifications with the first stakeholder group (leprosy-affected persons) overruled the second and third group, and self-identification with the second stakeholder group (researchers) overruled the third group.

The Delphi panel was consulted via e-mail. 34 experts were invited to participate in the Delphi process – 23 accepted (68%). The response rate was 57% and 75% among experts from endemic and non-endemic countries respectively. The number of Delphi panellists in each round is shown in Figure 1. Based on established professional expertise of the Delphi panellists - it was possible to classify them according to the same stakeholder categories. The

e-survey consisted of equal proportions of researchers and health professionals/NGO staff or policy makers (43% and 41% respectively); while in the Delphi panel researchers were the largest group (65%). 16% and 17% of respondents were persons affected by leprosy or members of persons affected organisations in the e-survey and Delphi panel, respectively. Table 2 further reports the origin of the participants in the e-survey and Delphi panel, by stakeholder group.

Table 2. The origin of stakeholders of e-survey respondents and Delphi panellists

Stakeholder	Origin	E-survey participants N = 80 (n)	Delphi panel N = 23 (n)
Persons affected by leprosy	High burden countries	11	3
	Low burden countries/Non-endemic	2	1
Researchers	High burden countries	15	4
	Low burden countries/Non-endemic	19	10
Health professionals/NGO staff/policy makers	High burden countries	18	3
	Low burden countries/Non-endemic	15	2

E-survey results

The 76 topics were categorised into five different clusters – two clusters were further subdivided into five and three sub-clusters respectively, resulting in 11 different (sub-) clusters (Table 3). Respondents were asked to complete one or two (sub-) clusters. The sub-cluster

Table 3. Number of respondents per (sub-) cluster

Cluster	Sub-cluster	Respondents (N = 80)	Stakeholder group		
			1 (N = 13)	2 (N = 34)	3 (N = 33)
Mapping, modelling and surveillance		14	1	8	5
Leprosy					
	Aetiology and epidemiology	12	0	9	3
	Prevention	17	1	10	6
	Detection/diagnosis	21	2	10	9
	Treatment and management	15	2	7	6
	Health system aspects	18	2	10	6
Reactions, nerve damage and impairments					
	Aetiology and determinants	14	3	9	2
	Prevention, detection/diagnosis and treatment and management	30	3	15	12
	Health system aspects	13	3	7	3
Stigma, discrimination and inclusion		30	7	9	14
Rehabilitation		26	7	9	10

Stakeholder group: (1) persons affected by leprosy (including members of organisations of persons affected by leprosy); (2) researchers; and (3) health professionals, NGO staff and policy makers. Column totals do not reflect total number of respondents because respondents were allowed to complete more than one (sub-) cluster.

‘Leprosy: aetiology and epidemiology’ had the lowest overall response rate (15%). Sub-clusters with the highest overall response rates (both 38%) were ‘Reactions, nerve damage and impairments: prevention, detection/diagnosis and treatment and management’ and ‘Stigma, discrimination and inclusion’. The (sub-) cluster-specific response rate differed per stakeholder group. Persons affected by leprosy most frequently completed the cluster ‘Stigma, discrimination and inclusion’ (7/13) and ‘Rehabilitation’ (7/13). The highest response rate among researchers was for the cluster ‘Reactions, nerve damage and impairments: prevention, diagnosis and treatment’ (15/34). The highest response rate among health professionals/NGO staff/policy makers was for the cluster ‘Stigma, discrimination and inclusion’ (13/33). Results of the importance ratings are presented together with the complete Delphi results (Annex 3).

Stakeholder group: (1) persons affected by leprosy (including members of organisations of persons affected by leprosy); (2) researchers; and (3) health professionals, NGO staff and policy makers. Column totals do not reflect total number of respondents because respondents were allowed to complete more than one (sub-) cluster.

36 additional topics were suggested by the e-survey participants. Of these topics, seven topics were truly novel topics and these were included in the final topic list for the Delphi panel.

Results Delphi process

Figure 1 shows how topics were excluded, moved or merged throughout the rounds. It furthermore shows the number of Delphi panellists in each round and Zero group. Slight

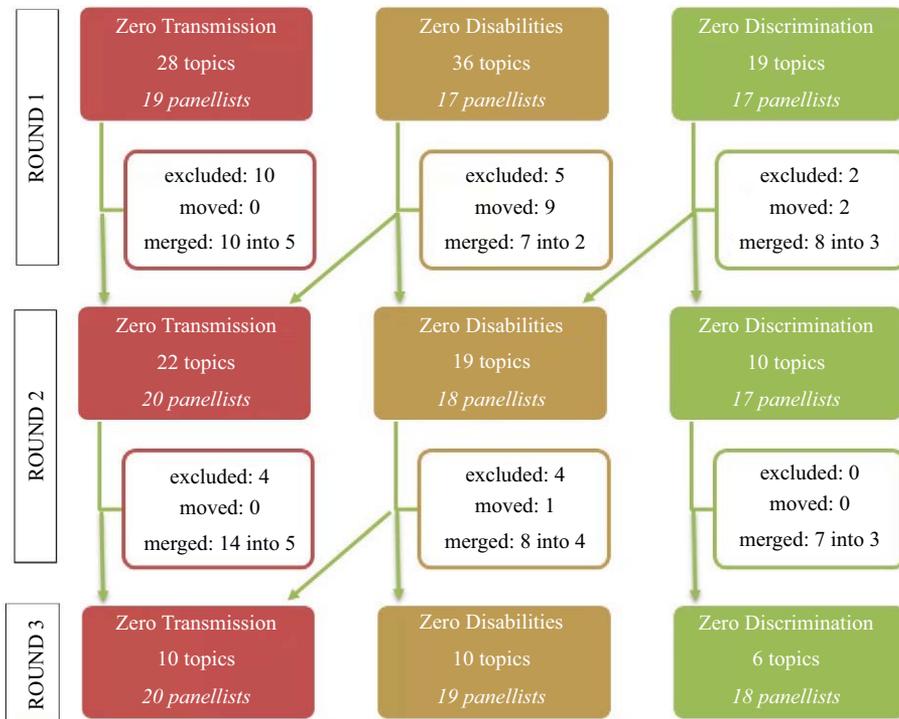


Figure 1. Flow diagram Delphi process.

changes in the number of Delphi panellist between rounds are explained by one exclusion of results because of incorrect rankings (round one) and lack of time reported by two panellists during some of the rounds.

Table 4 shows the top five research priorities in each Zero group ordered according to the highest median score during the final Delphi round. The median score (IQR) for the first and second round are also shown. The IQRs of all research topics remained similar or decreased after round two and three.

Table 4. Top five research priorities ordered according to the highest median scores in round 3

		Round 1		Round 2		Round 3	
		Median	IQR	Median	IQR	Median	IQR
Zero transmission							
1	Defining and implementing optimal post-exposure prophylaxis strategies and regimens (chemoprophylaxis/immunoprophylaxis).	4	13	5.5	7	8.5	4
2	Developing new (laboratory) assays for diagnosis and disease monitoring purpose (incl. point-of-care tests and <i>M. leprae</i> viability assays)	8	10	5	9	8	4
3	Research on (the effectiveness, feasibility, impact of) strategies to improve the quality of leprosy services at different levels of the health care system, including identifying factors which hinder or facilitate case finding and management	5	9	5.5	8	7.5	4
4	Research on leprosy vaccines (prophylactic or therapeutic) - including the full spectrum from pre-clinical development to implementation research	7	11	3.5	9	7	5
5	Identification and mapping of infection and disease (incl prevalence studies and geo-spatial studies)	5	12	4	8	6	4
Zero disabilities							
1	Identification of new treatment options and efficacy trials of novel drug treatment of NFI and reactions (including monitoring of treatment and thus steroid complications)	10	10	9	6	10	2
2	Research on pathophysiological/immunological mechanisms of Type 1 or Type 2 reactions and nerve damage in leprosy - including identifying factors associated with increased risk of reactions and nerve function impairment	7	10	6	6	8	5
3	Research on the feasibility, effectiveness and impact of prevention of disability strategies (incl self-care, physiotherapy and combined approaches)	7	11	4	7	7	3
4	Development and validation of diagnostic tools and validation standardized tools for the detection and measurement of nerve function impairment and reactions	7	15	6	4	7	4

Table 4. *Continued*

		Round 1		Round 2		Round 3	
		Median	IQR	Median	IQR	Median	IQR
Zero transmission							
5	Assessing the impact of case finding/contact tracing strategies on the prevalence of leprosy-related disabilities among new cases.	4	11	3-5	6	6	4
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	3	8	9	2	9	2
2	Studies on mental wellbeing of persons affected by leprosy and associations between mental health, health care seeking behaviour and accessibility of services (e.g. diagnostic or treatment delay, treatment compliance, participation in self-care groups)	1	7	5	5	8	2
3	Acceptability studies (from a patient's perspective) on medical interventions and leprosy services.	3	6	7	4	8	3
4	Assessment of stigma prevalence and type (attitudes, enacted, experienced, anticipated and internalized) and local validation of tools/questionnaires to determine stigma in communities and health services	4	6	7	5	7	2
5	Studies investigating the effect of the participation of persons affected by leprosy in research and services and development of models/best practices in how persons affected by leprosy can participate in research and services	1	6	5	4	6	3

The tables in Annex 3 show the scores (median and IQR) for all the research priorities as given during the third round of the Delphi process. Topics are ordered (ranked) according to the highest (median) score. Topics, which were excluded in previous rounds, are also shown. In addition, the corresponding topics in the e-survey are listed including the number of valid responses, the overall 'very important' rates (%) and the absolute number of different stakeholders rating topics as 'very important'.

Discussion

We identified the top five research priorities for the categories Zero Transmission, Zero Disability and Zero Discrimination, indicating what a broad range of stakeholders currently consider to be important as topics for leprosy research.

When comparing the prioritised topics with the current LRI research priorities – one new topic was evident- namely research into mental health of persons affected by leprosy.¹⁰ This topic ranked second in the final Zero Discrimination list. Moreover, the perceived priority of this topic increased from round one up to round three, while the IQR reduced indicating an

increase in consensus about the perceived priority of this topic. This finding is in line with a recently published report by WHO which addressed the hidden problem of mental health issues among persons affected by leprosy and the lack of research in this area.¹¹ The relevance of the topic was furthermore reported by a recent modelling study showing that lymphatic filariasis and other neglected tropical disease (NTDs), including leprosy, cause significant mental health related morbidity.¹²

One other issue was evident in the results, namely, enhancing the participation of persons affected by leprosy; in research, and in service delivery, and in particular researching models for enhancing participation and exploring the effect of such participation. While the LRI has historically encouraged applicants to include/consult persons affected from the early stages of protocol development, determining best practice for achieving genuine participation in many types of research has yet to be explored. The ILEP Panel of persons affected strongly advocated for meaningful involvement of persons affected in all stages of research. This is consistent with trends in leprosy services in general, and particularly with shifts towards greater consumer participation in research, across many conditions and disease groups globally. It has also been addressed in the 'WHO Guidelines for strengthening participation of persons affected by leprosy in leprosy services'¹³ and the 'UN report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members'¹⁴ that involvement of persons affected – can help to reduce stigma and discrimination.

There are a few remarks which needs to be considered when interpreting these results. First of all, we used a different classification system for the e-survey as compared to the Delphi panel – which makes it difficult to directly compare the findings. For the e-survey we used a classification which was less disease specific to stimulate out of the box thinking. For the Delphi process we chose to categorise the topics according to the ILEP Triple Zero campaign (Zero Transmission, Zero Discrimination and Zero Disability) to keep it manageable for the panellists and to contribute to the wider applicability of the research priorities. These three broad categories of the ILEP Triple Zero campaign are not mutually exclusive and therefore the classification of some topics led to discussions. This resulted in a number of reclassifications after round one and two. In order to minimise the impact of shifting topics, the topics were shifted after analysing the average rankings and topics that were shifted were still included in the following round of the Delphi process irrespective of their rank. This gave the panellist the opportunity to rank them again according to the relative relevance of the list in which they appeared. Furthermore, not all stakeholders, origins or areas of expertise are equally represented in this study and selection bias may have occurred by design (e-survey, FGD, interviews) or by self-selection (enquiry panel, Delphi panel). Despite the translation of the e-survey in Bahasa, French, Hindi and Portuguese – the invitation was sent via e-mail or mailing lists which may have limited the participation of stakeholders from endemic areas. Moreover, among the researchers, social scientists may have been underrepresented. However, there were several opportunities to contribute to the study and despite the possible underrepresentation of social scientists, a wide range of stakeholders was still included. Researchers, health professionals, policy makers and the direct beneficiaries (persons affected by leprosy) were involved in both the qualitative and quantitative part of the study. This inclusive approach contributes to the comprehensiveness, relevance and acceptability of our findings.^{15–18}

A final remark which needs to be considered when interpreting these results – is that the present work was done in the context of how the LRI operates – with a strong focus on clinical and operational research. In particular, topics extending to the social and community

dimensions (including for example issues such as system readiness and methods of introducing change in services, systems and communities) may be under-emphasised. Finally, while stakeholders will advocate their own interests when asked about priorities, it may be argued that this is more so when a funding organisation is asking the question.

In conclusion, 15 research priorities categorised in Zero transmission, Zero disabilities and Zero discrimination were identified in this study. Research into the mental health of persons affected by leprosy was identified as a novel topic. These findings contribute to a novel inclusive agenda for leprosy and therefore, are not only relevant for the LRI – but may also contribute to research agenda setting by others, most notably the Global Partnership for Zero Leprosy.

Conflicts of interests

This stakeholder’s consultation was an internal LRI project. Two authors (ZK and NV) are employed by LRI and five authors are employed by organisations that fund LRI.

Acknowledgements

We would like to express our sincere gratitude to Mathias Duck (The chair of the ILEP panel of affected persons) for his efforts to include persons affected by leprosy in this study, the translators of the e-survey and the participants of this study.

Authors’ contributions

All authors contributed to the planning, conducting and reporting the work.

References

- ¹ White C, Franco-Paredes C. Leprosy in the 21st century. *Clin Microbiol Rev*, 2015; **28**: 80–94.
- ² World Health Organization. Global Leprosy update. *Weekly Epidemiological Record*, 2017; **35**(90): 501–520.
- ³ McGregor S, Henderson KJ, Kaldor JM. How are health research priorities set in low and middle income countries? A systematic review of published reports. *PLoS One*, 2014; **9**: e108787.
- ⁴ Dye C, Reeder JC, Terry RF. Research for universal health coverage. *Sci Transl Med*, 2013; **5**: 199ed13.
- ⁵ Research to stop neglected tropical disease transmission (R2Stop). 2016. Available at: <http://r2stop.org/> [last accessed 1 September 2018].
- ⁶ World Health Organization. Global Leprosy Strategy 2016–2020: Accelerating towards a leprosy-free world. 2016. Available at: http://apps.who.int/iris/bitstream/10665/208824/1/9789290225096_Eng.pdf?ua=1
- ⁷ World Health Organization. Guidelines for the diagnosis, treatment and prevention of leprosy. 2018. Available at: http://www.searo.who.int/entity/global_leprosy_programme/approved-guidelines-leprosy-executives-summary.pdf?ua=1. [last accessed 1 September 2018].
- ⁸ Global Partnership for Zero Leprosy. 2018. Available at: <https://zeroleprosy.org/>. [last accessed 1 September 2018].
- ⁹ UK Clinical Research Collaboration. Health Research Classification System. 2018. Available at: <https://hrcsonline.net/> [last accessed 1 April 2018].
- ¹⁰ Leprosy Research Initiative joint policy for support to scientific research. Leprosy Research Initiative. 2013. Available at: https://www.leprosyresearch.org/images/Joint_Research_Policy_2013-2015_250815.pdf [last accessed 1 September 2018].
- ¹¹ World Health Organization. Report of the informal consultation on stopping discrimination and promotion inclusion of persons affected by Leprosy, New Delhi, 14–16 Nov 2017. World Health Organization. Regional Office for South-East Asia; 2018.

- ¹² Ton TG, Mackenzie C, Molyneux DH. The burden of mental health in lymphatic filariasis. *Infect Dis Poverty*, 2015; **4**: 34.
- ¹³ World Health Organization. Guidelines for strengthening participation of persons affected by leprosy in leprosy service. 2011. Available at: <http://www.who.int/iris/handle/10665/205169>. [last accessed 1 September 2018]
- ¹⁴ UN Human Rights Council. Study on the implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members. 2017. Available at: <http://www.refworld.org/docid/593a9e874.html>. [last accessed 1 September 2018]
- ¹⁵ Nuyens Y. Setting priorities for health research: lessons from low-and middle-income countries. *Bull World Health Organ*, 2007; **85**: 319–321.
- ¹⁶ Kapiriri L, Tomlinson M, Gibson J *et al*. Setting priorities in global child health research investments: addressing values of stakeholders. *Croat Med J*, 2007; **48**: 618–627.
- ¹⁷ Monk JM, Rowley KG, Anderson IP. Setting and meeting priorities in Indigenous health research in Australia and its application in the Cooperative Research Centre for Aboriginal Health. *Health Res Policy Syst*, 2009; **7**: 25.
- ¹⁸ Viergever RF, Olifson S, Ghaffar A, Terry RF. A checklist for health research priority setting: nine common themes of good practice. *Health Res Policy Syst*, 2010; **8**: 36.

Annex 1: classification system for e-survey

Cluster A: Mapping, modelling and surveillance	
Includes studies mapping the disease burden and surveillance tools as well as mathematical modelling studies.	
Cluster B: Clinical leprosy	
<i>Aetiology and epidemiology</i>	Includes research into the identification and characterisation of determinants that are involved in the cause, risk and development of infection and/or disease, as well as research into incidence and prevalence of leprosy
<i>Prevention</i>	Includes research into means for primary prevention of diseases among people without leprosy. Secondary prevention of reactions and impairments belong to Cluster C.
<i>Detection/diagnosis</i>	Includes research where the main aim is to develop diagnostic or prognostic tests for clinical use as well as operational research for targeted approaches for early detection.
<i>Treatment and management</i>	Includes research where the main aim is to discover and develop new therapeutic interventions in preclinical settings; to test and evaluate therapeutic interventions in clinical, community or applied settings; as well as research into individual care needs.
<i>Health system aspects</i>	Encompasses all research on the provision and delivery of health and social care services, including cost-effectiveness analyses. It includes health care delivery and organisation from a health service perspective.
Cluster C: Reactions, nerve damage and impairments	
<i>Aetiology and epidemiology</i>	<i>[uses the same themes as Cluster B above]</i>
<i>Prevention, detection/diagnosis and treatment and management</i>	
<i>Health system aspects</i>	
Cluster D: Stigma, discrimination and inclusion	
This cluster focuses on all forms of stigma and discrimination, both on the individual level (perceived, experienced and enacted stigma), the community level and the national level (policies). Furthermore, this cluster includes the participation and inclusion of leprosy affected persons in society.	
Cluster E: Rehabilitation	
This cluster focuses on physical (medical) rehabilitation (incl. surgery, physiotherapy and occupational therapy, assistive devices); socio-economic rehabilitation; as well as vocational rehabilitation.	

Annex 2: categorised list with topics resulting from the qualitative phase

MAPPING, MODELLING AND SURVEILLANCE

1. Mapping studies (using geographic information systems).
2. Developing electronic data collection and surveillance tools.
3. Developing targeted surveillance tools for marginalised populations.
4. Developing and applying mathematical models to support data analysis and policy decision making in leprosy control (country level).
5. Modelling studies to predict and map the effect and impact of PEP interventions.

LEPROSY: AETIOLOGY AND EPIDEMIOLOGY

1. (Basic) research into the pathogenesis of disease and host-pathogen interactions.
2. Research into genetic susceptibility for leprosy.
3. Research into the molecular epidemiology of leprosy.
4. Identifying reservoirs of viable *M. Leprae* and the associated transmission potential to humans.
5. Identifying the hidden prevalence of leprosy in endemic areas.
6. Estimating the burden of morbidity due to leprosy and other neglected tropical diseases (NTDs) or other diseases that share cross-cutting issues with leprosy.

LEPROSY: PREVENTION

1. Defining and implementing optimal post-exposure prophylaxis strategies and regimens (chemoprophylactic/immunoprophylaxis).
2. (Further) identification and pre-clinical development of new leprosy vaccines.
3. Randomised controlled clinical trials to determine the safety and efficacy of potential new leprosy vaccines.
4. Implementation research (field studies) on leprosy vaccines or TB vaccines providing partial protection against *M. leprae* infection.

LEPROSY: DETECTION/DIAGNOSIS

1. (Further) development of immunological and molecular markers for infection with *M. leprae* and disease.
2. (Further) development of a field-friendly point-of-care test for leprosy infection or sub-clinical disease.
3. (Further) development of *M. leprae* viability assays (explanation: such assays may for example be used to monitor treatment outcome/success).
4. Development of markers to detect relapse.
5. Developing and field-testing of strategies to improve case finding among children.
6. Operational research to establish the coverage of and to identify factors limiting or facilitating case finding strategies (incl contact tracing).

7. Studies into health seeking behaviour of families and contacts of persons affected by leprosy.
8. Development of novel and alternative diagnostics (innovative ideas, e.g. artificial intelligence).

LEPROSY: TREATMENT AND MANAGEMENT

1. Studies assessing the prevalence of rifampicin resistance.
2. Research into the prevalence of relapse in field settings.
3. Development and field testing of alternative MDT regimens.
4. Operational or intervention research into strategies to assess and improve treatment adherence.
5. Research into the effectiveness of immunotherapy for highly positive patients (borderline lepromatous leprosy (BL) and lepromatous leprosy (LL)).
6. Studies assessing the effectiveness, feasibility and impact of reducing MDT treatment duration (e.g. uniform-MDT).
7. Studies in patient education with regard to UMDT.
8. Research into aspects of dapsone hypersensitivity syndrome (susceptibility, detection, prevalence).

LEPROSY: HEALTH SYSTEM ASPECTS

1. Research on the (effectiveness, feasibility, impact of) strategies integrating high quality leprosy services into primary health care, or into dermatology services or NTD programmes.
2. Identifying effective and feasible strategies for leprosy services in low endemic areas – including cost-effectiveness analyses.
3. Operational research to identify health provider-associated factors that facilitate or hinder early detection of leprosy patients.
4. Defining and testing of strategies to improve the capacity in the health services for leprosy case detection and management.
5. Operational research into education, communication and information strategies targeting the general population.
6. Assessing the impact of existing leprosy control/elimination strategies on the continuum of care and on national health systems.
7. Acceptability studies (from a patient's perspective) on medical interventions and leprosy services.
8. Cost-effectiveness studies for evaluation of leprosy programmes and development of a core set for economic evaluation.
9. Studying associations between mental health and health care seeking behaviour and accessibility of services (e.g. diagnostic or treatment delay, treatment compliance, participation in self-care groups).

REACTIONS, NERVE DAMAGE AND IMPAIRMENTS: AETIOLOGY AND DETERMINANTS

1. (Further) identifying pathophysiological/immunological mechanisms of nerve injury in leprosy and type 1 or type 2 reactions.
2. Research into genetic susceptibility for the development of reactions and impairments.
3. Identifying risk factors for the development of reactions and impairments.

REACTIONS, NERVE DAMAGE AND IMPAIRMENTS: PREVENTION, DETECTION/DIAGNOSIS AND TREATMENT AND MANAGEMENT

1. Defining, implementing and assessing optimal strategies for the prevention of disabilities.
2. Operational research to determine best practices for post-MDT surveillance.
3. Operation research into the feasibility and effectiveness of self-monitoring/self-care on early nerve damage.
4. (Further) development of diagnostic tools for the detection of nerve function impairment and reactions.
5. Assessing the impact of case finding/contact tracing strategies on the prevalence of leprosy-related disabilities among new cases.
6. Testing the diagnostic accuracy of monofilaments tests in different settings – and means to improve the accuracy.
7. Assessing the role and impact of (involving) traditional healers in case detection activities.
8. Operational research into combined approaches for prevention of disabilities (POD) in leprosy, diabetes and other skin conditions (e.g. self-care groups for leprosy and diabetes).
9. Developing and validation standardised tools to measure nerve damage/nerve function impairment and Type 1 reactions.
10. Identification and efficacy trials of novel drug treatment of NFI and reactions.
11. Research into innovative approaches for the treatment of secondary consequences by ophthalmologist and reconstructive surgeons.
12. Research on the effectiveness, feasibility and acceptability of new orthopaedic methods.
13. Identifying and testing novel treatment approaches for ulcers.
14. Monitoring studies on steroid complications.

REACTIONS, NERVE DAMAGE AND IMPAIRMENTS: HEALTH SYSTEM ASPECTS

1. Research on the (effectiveness, feasibility, impact of) strategies integrating high quality prevention of disability (POD) activities at primary health level care.
2. Identifying effective and feasible strategies for self-care programmes in low endemic areas.
3. Research into the financial burden of reactions.

STIGMA, DISCRIMINATION AND INCLUSION

1. Designing and implementation research of community empowerment and awareness interventions.
2. Local validation of tools/questionnaires to determine stigma.
3. Assessment of prevalence of stigma and type of stigma in communities and health services.
4. Identifying prevalence of enacted, anticipated and internalised stigma.
5. Operational research into the feasibility, acceptability and impact of stigma reduction activities.
6. Assessing the role of community/religious leaders in generating or maintaining stigma and in stigma reduction activities.
7. Assess the (local) implementation and impact of the UN guidelines on leprosy discrimination.
8. Test charter approach (develop and promote a charter for people affected by leprosy in which they describe minimum quality standard for key aspects of leprosy services).
9. Evidence studies in what the effect is of the participation of persons affected by leprosy in research and services and development of models/best practices in how persons affected by leprosy can participate in research and services.
10. Studies into approaches on capacity building/empowerment for persons affected by leprosy.
11. Studies on mental health and wellbeing of persons affected by leprosy.
12. Research into patient explanatory models of disease (personal conceptualisation of the cause, course, and consequences of leprosy).
13. Studies into the attitudes of families and contacts of persons affected by leprosy.
14. Studies into the perceptions and behaviour of health staff towards leprosy.

REHABILITATION

1. Research on the effectiveness, feasibility, impact of community-based rehabilitation (CBR) programmes.
2. Assessing the effectiveness of physical rehabilitation services for persons with leprosy related disabilities within health system context.

Annex 3

Annex 3		By respondent type			
Topics Delphi - Round 3		Very important rate overall	(very important (n)/total (N)) ³		
Zero Transmission	Median	Number of valid responses ²	Leprosy affected ⁴		
IQR ¹	Corresponding E-survey topics	n/N	Researchers n/N		
Health professionals ⁵			n/N		
1	Defining and implementing optimal post-exposure prophylaxis strategies and regimens (chemoprophylactic/immunoprophylaxis).	17	1/1	7/10	3/6
2	Developing new (laboratory) assays for diagnosis and disease monitoring purpose (incl point-of-care tests and <i>M. Leprae</i> viability assays).	22	2/2	8/10	5/10
3	Research on (the effectiveness, feasibility, impact of) strategies to improve the quality of leprosy services at different levels of the health care system, including identifying factors which hinder or facilitate case finding and management.	20	1/2	7/10	0/8
		18	2/2	7/10	4/6
		30	1/3	3/15	4/12
		16	2/2	4/8	4/6
		17	2/2	6/9	5/6

Annex 3		Number of valid responses ²		Very important rate overall		By respondent type (very important (n/total (N))) ³			
Topics Delphi - Round 3 Zero Transmission		Median	IQR ¹	Corresponding E-survey topics	Leprosy affected ⁴ n/N	Researchers n/N	Health professionals ⁵ n/N		
4	Research on leprosy vaccines (prophylactic or therapeutic) - including the full spectrum from pre-clinical development to implementation research.	7	5	primary health care, or into dermatology services or NTD programmes. Developing and field-testing of strategies to improve case finding among children. Operational or intervention research into strategies to assess and improve treatment adherence. Randomized controlled clinical trials to determine the safety and efficacy of potential new leprosy vaccines. (Further) identification and pre-clinical development of new leprosy vaccines. Implementation research (field studies) on leprosy vaccines or TB vaccines providing partial protection against <i>M. leprae</i> infection. Research into the effectiveness of immunotherapy for highly positive patients (borderline lepromatous leprosy (BL) and lepromatous leprosy (LL)).	23	57%	2/2	6/10	5/11
5	Identification and mapping of infection and disease (incl prevalence studies and geo-spatial studies).	6	4	Identifying the hidden prevalence of leprosy in endemic areas. Mapping studies (using geographic information systems).	14	57%	1/2	4/7	3/5
4	Research on leprosy vaccines (prophylactic or therapeutic) - including the full spectrum from pre-clinical development to implementation research.	7	5	primary health care, or into dermatology services or NTD programmes. Developing and field-testing of strategies to improve case finding among children. Operational or intervention research into strategies to assess and improve treatment adherence. Randomized controlled clinical trials to determine the safety and efficacy of potential new leprosy vaccines. (Further) identification and pre-clinical development of new leprosy vaccines. Implementation research (field studies) on leprosy vaccines or TB vaccines providing partial protection against <i>M. leprae</i> infection. Research into the effectiveness of immunotherapy for highly positive patients (borderline lepromatous leprosy (BL) and lepromatous leprosy (LL)).	17	29%	0/1	4/10	1/6
					17	41%	1/1	3/10	3/6
					17	35%	0/1	5/10	1/6
					14	29%	0/2	3/7	1/5
5	Identification and mapping of infection and disease (incl prevalence studies and geo-spatial studies).	6	4	Identifying the hidden prevalence of leprosy in endemic areas. Mapping studies (using geographic information systems).	12	58%	-	6/9	1/3
					14	79%	1/1	7/8	3/5

Annex 3		By respondent type (very important (n)/total (N)) ³	
Topics Delphi - Round 3 Zero Transmission		Very important rate overall	Number of valid responses ²
Median	IQR ¹	Corresponding E-survey topics	Leprosy affected ⁴ n/N
Median	IQR ¹	Corresponding E-survey topics	Health professionals ⁵ n/N
6	5	4	Not in e-survey
6	5	4	Not in e-survey
7	4.5	8	15
7	4.5	8	15
8	4	3	15
8	4	3	29
9	4	4	15
9	4	4	11
10	2	4	14
10	2	4	13
			18

Annex 3		Median		IQR ¹		Corresponding E-survey topics		Number of valid responses ²		Very important rate overall		By respondent type (very important (n)/total (N)) ³	
Topics Delphi - Round 3		Zero Transmission						Leprosy affected ⁴		Researchers		Health professionals ⁵	
								n/N		n/N		n/N	
endemic areas – including cost-effectiveness analyses.				endemic areas – including cost-effectiveness analyses.									
11	Research into the molecular epidemiology of leprosy.	<i>Excluded in earlier rounds</i>		Research into the molecular epidemiology of leprosy.				10	40%	-	4/9	0/1	
12	Cost-effectiveness studies for evaluation of leprosy programmes and development of a core set for economic evaluation.	<i>Excluded in earlier rounds</i>		Cost-effectiveness studies for evaluation of leprosy programmes and development of a core set for economic evaluation.				15	47%	2/2	4/8	1/5	
13	Development of novel and alternative diagnostics (innovative ideas, e.g. artificial intelligence).	<i>Excluded in earlier rounds</i>		Development of novel and alternative diagnostics (innovative ideas, e.g. artificial intelligence).				21	48%	1/2	7/10	2/9	
14	Developing and applying mathematical models to support data analysis and policy decision making in leprosy control (country level).	<i>Excluded in earlier rounds</i>		Developing and applying mathematical models to support data analysis and policy decision making in leprosy control (country level).				14	57%	0/1	6/8	2/5	
15	Modelling studies to predict and map the effect and impact of PEP interventions.	<i>Excluded in earlier rounds</i>		Modelling studies to predict and map the effect and impact of PEP interventions.				12	67%	1/1	6/8	1/3	
16	(Basic) research into the pathogenesis of disease and host-pathogen interactions.	<i>Excluded in earlier rounds</i>		(Basic) research into the pathogenesis of disease and host-pathogen interactions.				12	58%	-	7/9	0/3	
17	Studies on mechanisms of natural protection in leprosy patients.	<i>Excluded in earlier rounds</i>		Studies on mechanisms of natural protection in leprosy patients.				Not in e-survey					
18	Research into genetic susceptibility for leprosy.	<i>Excluded in earlier rounds</i>		Research into genetic susceptibility for leprosy.				10	20%	-	2/7	0/3	

Annex 3		By respondent type (very important (n)/total (N)) ³	
Topics Delphi - Round 3 Zero Transmission		Very important rate overall	Leprosy affected ⁴ n/N
Median	IQR ¹	Number of valid responses ²	Researchers n/N
Corresponding E-survey topics		Health professionals ⁵ n/N	
19	(Further) development of immunological and molecular markers for infection with <i>M. leprae</i> and disease. <i>Excluded in earlier rounds</i>	21	9/10
20	Studies on the field diagnostic accuracy and relative importance of slit skin smear examinations. <i>Excluded in earlier rounds</i>	62%	1/2
21	Assessing the impact of existing leprosy control/elimination strategies on the continuum of care and on national health systems. <i>Excluded in earlier rounds</i>	61%	1/2
22	Studies into health seeking behaviour of families and contacts of persons affected by leprosy. <i>Excluded in earlier rounds</i>	43%	0/2
		Not in e-survey	6/10
			6/10
			3/9
			4/6
			3/10

Annex 3		Topics Delphi - Round 3 Zero Disability		Median	IQR ¹	Corresponding E-survey topics	Number of valid responses ²	Very important rate overall	By respondent type (very important (n)/total (N)) ³		
									Leprosy affected ⁴ n/N	Researchers n/N	Health professionals ⁵ n/N
1	Identification of new treatment options and efficacy trials of novel drug treatment of NFI and reactions (including monitoring of treatment and thus steroid complications).	10	2	Identification and efficacy trials of novel drug treatment of NFI and reactions. Monitoring studies on steroid complications.	30	60%	1/3	11/15	6/12		
2	Research on pathophysiological/immunological mechanisms of Type 1 or Type 2 reactions and nerve damage in leprosy - including identifying factors associated with increased risk of reactions and nerve function impairment.	8	5	Identifying risk factors for the development of reactions and impairments. Research into genetic susceptibility for the development of reactions and impairments. (Further) identifying pathophysiological/immunological mechanisms of nerve injury in leprosy and Type 1 or Type 2 reactions.	14	86%	3/3	8/9	1/2		
3	Research on the feasibility, effectiveness and impact of prevention of disability strategies (incl self-care, physiotherapy and combined approaches).	7	3	Operation research into the feasibility and effectiveness of self-monitoring / self-care on early nerve damage.	29	38%	1/3	7/15	3/11		

Annex 3 Topics Delphi - Round 3 Zero Disability		Median	IQR ¹	Corresponding E-survey topics	Number of valid responses ²	Very important rate overall	By respondent type (very important (n)/total (N)) ³
					Leprosy affected ⁴ n/N	Researchers n/N	Health professionals ⁵ n/N
				Operational research into combined approaches for prevention of disabilities (POD) in leprosy, diabetes and other skin conditions (e.g. self-care groups for leprosy and diabetes).	29	38%	Leprosy affected 1/3 7/15 3/11
				Defining, implementing and assessing optimal strategies for the prevention of disabilities.	29	72%	Leprosy affected 2/3 10/15 9/11
				Research on the (effectiveness, feasibility, impact of) strategies integrating high quality prevention of disability (POD) activities at primary health level care.	13	85%	Leprosy affected 3/3 5/7 3/3
				Identifying effective and feasible strategies for self-care programmes in low endemic areas.	13	62%	Leprosy affected 3/3 4/7 1/3
				Role and impact of physiotherapy as early intervention for impairments.	Not in e-survey		
4 Development and validation of diagnostic tools and validation standardized tools for the detection and		7	4	(Further) development of diagnostic tools for the detection of nerve function impairment and reactions.	28	68%	Leprosy affected 1/3 10/14 8/11

Annex 3 Topics Delphi - Round 3 Zero Disability		Median	IQR ¹	Corresponding E-survey topics	Number of valid responses ²	Very important rate overall	By respondent type (very important (n)/total (N)) ³		
							Leprosy affected ⁴ n/N	Researchers n/N	Health professionals ⁵ n/N
	measurement of nerve function impairment and reactions.			Developing and validation standardized tools to measure nerve damage/nerve function impairment and Type 1 reactions.	29	59%	1/3	9/15	7/11
5	Assessing the impact of case finding/contact tracing strategies on the prevalence of leprosy-related disabilities among new cases.	6	4	Assessing the impact of case finding/contact tracing strategies on the prevalence of leprosy-related disabilities among new cases.	29	38%	1/3	5/14	5/12
6	Research into the financial burden of reactions.	4	5	Research into the financial burden of reactions.	13	62%	3/3	4/7	1/3
7	Research on the effectiveness, feasibility, social and economic impact of community-based rehabilitation (CBR) programmes.	4	2	Research on the effectiveness, feasibility, social and economic impact of community-based rehabilitation (CBR) programmes.	26	65%	7/7	6/9	4/10
8	Assessing the effectiveness of physical rehabilitation services for persons with leprosy-related disabilities within health system context.	3	4	Assessing the effectiveness of physical rehabilitation services for persons with leprosy-related disabilities within health system context.	26	65%	6/7	3/9	8/10
9	Estimating the burden of morbidity due to leprosy and other neglected tropical diseases (NTDs) or other diseases that share cross-cutting issues with leprosy.	3	4	Estimating the burden of morbidity due to leprosy and other neglected tropical diseases (NTDs) or other diseases that share cross-cutting issues with leprosy.	12	50%	-	6/9	0/3

Annex 3				By respondent type (very important (n)/total (N)) ³			
Topics Delphi - Round 3 Zero Disability		Median	IQR ¹	Corresponding E-survey topics	Very Important rate overall		
Number of valid responses ²	Leprosy affected ⁴ n/N	Researchers n/N	Health professionals ⁵ n/N				
10	Identifying and testing novel treatment approaches for ulcers.	3	6	Identifying and testing novel treatment approaches for ulcers.	48%	5/14	7/10
11	Evaluation studies in new approaches of peripheral nerve surgery.	<i>Excluded in earlier rounds</i>		Evaluation studies in new approaches of peripheral nerve surgery.	Not in e-survey		
12	Testing the diagnostic accuracy of monofilaments tests in different settings - and means to improve the accuracy.	<i>Excluded in earlier rounds</i>		Testing the diagnostic accuracy of monofilaments tests in different settings - and means to improve the accuracy.	31%	6/15	3/11
13	Research into innovative approaches for the treatment of secondary consequences by ophthalmologist and reconstructive surgeons.	<i>Excluded in earlier rounds</i>		Research into innovative approaches for the treatment of secondary consequences by ophthalmologist and reconstructive surgeons.	42%	5/14	5/9
14	Research on the effectiveness, feasibility and acceptability of new orthopaedic methods.	<i>Excluded in earlier rounds</i>		Research on the effectiveness, feasibility and acceptability of new orthopaedic methods.	19%	2/15	3/9
15	Development of markers to detect relapse.	<i>Excluded in earlier rounds</i>		Development of markers to detect relapse.	48%	4/9	5/10
16	Research into the prevalence of relapse in field settings.	<i>Excluded in earlier rounds</i>		Research into the prevalence of relapse in field settings.	47%	4/7	1/6

Annex 3		Median		IQR		Corresponding E-survey topics		Very important		By respondent type (very important (n)/total (N)) ³		
Topics Delphi - Round 3 Zero Discrimination								number of valid responses ²	Very important overall	Leprosy affected ⁴ n/N	Researchers n/N	Health professionals ⁵ n/N
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.	9	2			Operational research into the feasibility, acceptability and impact of stigma reduction activities.		29	72%	5/7	7/8	9/14
						Designing and implementation research of community empowerment and awareness interventions.		29	59%	6/7	6/9	5/13
						Operational research into education, communication and information strategies targeting the general population.		16	69%	2/2	5/9	4/5
						Assessing the role of community/religious leaders in generating or maintaining stigma and in stigma reduction activities.		30	53%	5/7	5/9	6/14
						Studies into approaches on capacity building/empowerment for persons affected by leprosy.		28	54%	5/7	5/9	5/12
2	Studies on mental wellbeing of persons affected by leprosy and associations between mental health, health care	8	2			Studies on mental health and wellbeing of persons affected by leprosy.		29	69%	5/7	7/9	8/13

Annex 3		By respondent type (very important (n)/total (N)) ³	
Topics Delphi - Round 3 Zero Discrimination		Very important rate overall	Health professionals ⁵ n/N
Median	IQR ¹	Number of valid responses ²	Leprosy affected ⁴ n/N
Corresponding E-survey topics		Researchers n/N	Health professionals ⁵ n/N
seeking behaviour and accessibility of services (e.g. diagnostic or treatment delay, treatment compliance, participation in self-care groups).		16	1/2
3 Acceptability studies (from a patient's perspective) on medical interventions and leprosy services.	8	17	2/2
4 Assessment of stigma prevalence and type (attitudes, enacted, experienced, anticipated and internalized) and local validation of tools/questionnaires to determine stigma in communities and health services.	7	30	3/7
	3	17	2/2
	2	30	3/7
		30	4/7
		29	5/7
		29	4/7
		29	5/7
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	6/9
		29	6/9
		16	5/8
		17	5/9
		30	7/9
		30	7/9
		29	6/8
		29	

Annex 3			By respondent type (very important (n)/total (N)) ³			
Topics Delphi - Round 3 Zero Discrimination			Very important rate overall	Leprosy affected ⁴ n/N	Researchers n/N	Health professionals ⁵ n/N
Number of valid responses ²	Corresponding E-survey topics	Median IQR ¹				
5	Studies investigating the effect of the participation of persons affected by leprosy in research and services and development of models/best practices in how persons affected by leprosy can participate in research and services.	6 3	48%	4/7	4/9	6/13
6	Assess the (local) implementation and impact of the UN guidelines on leprosy discrimination.	5 1	34%	4/7	3/9	3/13
7	Test charter approach (develop and promote a charter for people affected by leprosy in which they describe minimum quality standard for key aspects of leprosy services).	<i>Excluded in earlier rounds</i>	56%	6/7	3/8	6/12
8	Research into patient explanatory models of disease (personal conceptualization of the cause, course, and consequences of leprosy).	<i>Excluded in earlier rounds</i>	38%	3/7	4/9	4/13