

Leprosy Research Initiative joint policy for support to scientific research

1 Introduction

The Leprosy Research Initiative (LRI) is a combined venture of the Netherlands Leprosy Relief (NLR), American Leprosy Missions (ALM), German Leprosy and Tuberculosis Relief Association (GLRA) and Effect:hope (The Leprosy Mission Canada) and The Leprosy Mission International (TLMI). Guided by an allied policy with clearly defined research priorities, the partners decided to establish a joint fund to support leprosy research and to establish a mechanism to access external funding also.

The joint fund will be reserved for research that has a focus on leprosy. Additional resources will be actively sought for research aimed at different diseases (e.g. other NTDs, TB and diabetes) or issues that relate closely to leprosy.

Co-funding will be sought from organisations such as the Turing Foundation (TF), which may focus their support on specific areas of leprosy research. In the case of the TF, these are early diagnosis and transmission of leprosy, nerve damage and leprosy reactions. The continuation of this co-funding is an important pillar of our research funding, as TF is prepared to match the funds the coalition raises for research in these areas.

2 Monitoring of supported research via the SRC

In 1987, NLR established a Scientific Review Committee (SCR), comprising a number of independent experts, each of whom monitors a particular field of research (see Annex 1). The composition of the Committee reflects the portfolio of projects that is supported. In the coming period a gradual shift in portfolio is expected (see 3.1), which should be reflected in the composition of the Committee. The Committee meets face-to-face at least twice yearly.

Since 1992, NLR has periodically commissioned independent reviews (audits) of the quality and relevance of its research. These reviews are carried every 5 years.

3 Research agenda

The coalition is of the opinion that for research to have impact on leprosy control and on the lives of persons affected by leprosy, it is important that these beneficiaries (staff of leprosy control programmes and persons affected by leprosy) are involved in studies and can develop a sense of ownership. Consequently, it is the intention to further develop the involvement of organisations of people affected by leprosy in determining topics for research through active consultation, and, if possible, through involvement in planning and implementation of research, and dissemination and application of results.

3.1 Calls for proposals

To arrive at a balanced research portfolio across the priority areas, the coalition may issue calls for proposals for particular research topics, asking initially for a letter of intent outlining the envisaged approach and an indication of budget and time. In dialogue between the coalition, the field partners, the concerned institutes and potential users of the results, more detailed proposals can then be developed.

3.2 Current research priorities

In 2011, the ILEP Technical Commission produced a research agenda of 20 topics for leprosy. On the basis of this agenda and results from a survey among field partners (including persons affected by leprosy) 5 research areas were selected as main priorities. The projects should aim to:

1. Promote and enable early detection of leprosy
Early detection is important to reduce further transmission, but particularly because it reduces the risk of permanent impairments. The LRI will support studies that examine approaches, methods or tools to improve early case detection. This will include health systems approaches to promote community awareness, appropriate health-seeking behaviour of patients and access to services, as well as the testing of lab-based tools for subclinical infection or disease. It may also include interventions to reduce community stigma, if this is a barrier to early detection in a given setting.
2. Promote prevention, early detection and effective treatment of nerve function impairment (NFI) and reactions
Neural and ocular impairments and disabilities are the main causes behind the many problems persons affected by leprosy may experience. The LRI will therefore support studies of approaches and interventions for primary prevention of nerve or ocular damage, methods to improve detection and interventions and treatment regimen to improve the prognosis of NFI and leprosy reactions.
3. Promote inclusion of persons affected by leprosy in society
Exclusion from society is the most feared and severe consequence of leprosy. This may happen overtly, as when people are sent away from their home or faced divorce, or in much more subtle ways, such as loss of status, gossip, avoidance, etc. The LRI will support research that promotes inclusion and participation of persons affected by leprosy in any aspect of society. Important aspects are relationships, including marriage and promotion of the sexual and reproductive health and rights of affected persons, livelihoods and labour participation, education, and participation in civil organisations, such as disabled people's organisations. Participation of affected persons in leprosy services in the broadest sense is another aspect that deserves specific attention.
4. Improve the coverage of prevention of disability activities and their integration in national programmes and integrated wound and limb care programmes
Prevention of disabilities (POD) is a core component of leprosy services. Appropriate methods and tools are already available, but often they are not used and not used adequately. Examples are nerve function assessment and self-care training. Usually, POD interventions or activities are carried out in a leprosy-only mode, while there are many people with similar problems who would also benefit from such interventions and activities (e.g. people with diabetic neuropathy). The LRI will support implementation research that explores or provides ways to improve the use of existing methods and tools for POD, the integration of POD interventions in national leprosy policies and programmes, and the integration of leprosy-related POD in general wound and limb care programmes (or vice versa).
5. Test methods and tools to interrupt the transmission and incidence of leprosy, including increasing the coverage of effective contact management and chemoprophylaxis
The ultimate goal of leprosy control services is to interrupt the transmission of leprosy. Current approaches to case detection and treatment with MDT have not led to a sufficient decrease in incidence of leprosy in many countries or areas within countries. Recent research has shown that strategies aim at contacts of leprosy patients are the most promising and cost-effective options to further reduce the incidence of leprosy. Therefore, the LRI will support implementation research aimed at introducing or scaling up effective contact management or chemoprophylaxis interventions. Testing of additional contact examination interventions, chemoprophylaxis regimen or other prophylaxis approaches, such as immune-prophylaxis, would be eligible for support. Studies aimed at reducing or removing barriers to the effective use of contact-based interventions are also eligible for support.

4 Procedures

4.1 For new project proposals

- An Expression of Interest may be submitted at any time during the year, using the format available on the LRI site. These will be screened by the LRI Steering Committee. They will invite research groups that have submitted potentially eligible proposals to develop a full proposal for submission to the SRC. For large multi-year studies, the SC may require that this be done through a multi-stakeholder workshop during which a project proposal is developed in collaboration with other partners, such as field projects, organisations of persons affected by leprosy and users of the intended results of the research.
- Full research proposals should be submitted to the SRC Secretariat in time for the Committee's autumn meeting, permitting adequate time for review by external experts and rebuttal by the researchers. In practice this means a submission deadline of June 1st.
- The SRC will assess the proposal, the external assessments and rebuttal (when applicable) and advise the coalition whether or not to fund the proposal.

4.2 For ongoing projects

- A plan of activities and budget should be submitted to the SRC Secretariat on an annual basis (in August), containing also a brief report of achievements in the first 6 months of the current year and a plan of activities for the following year, if relevant. a budget request stating the originally requested budget for the coming calendar year and an updated version. Any differences should be indicated and justified.
- The SRC assesses submitted project proposals and advises the coalition regarding the progress of the ongoing projects.

4.3 General procedures

- Each LRI partner will commit an annual contribution to the joint LRI research fund. This commitment is made for at least 3 years, so that continuity of project funding can be guaranteed.
- Annually, the coalition will decide on a budget reserved for new proposals.
- The coalition will require principal investigators to submit a final summary report to the SRC secretariat within 6 months of completion of the project. The report will be assessed by the SRC and the LRI SC.

5 Selection criteria for proposals

The following criteria will be used to determine the eligibility of research project applications:

- The main topic of the study should fall within one of the agreed priority areas.
- Research results should be directly applicable to leprosy services or to the wellbeing of persons affected by leprosy.
- Preference will be given to proposals from or in close collaboration with institutions or organisations in endemic countries.
- For research related to disability, proposals should clearly state how persons with disabilities will be involved in the various stages and levels of the project planning, execution and management.
- Project duration should not exceed four years (48 months).

6 Open access publication

Open access publication of research results is encouraged. Papers based on publicly funded research should be free for anyone to read. Therefore, articles based on coalition-funded research should be published in a scientific, peer-reviewed open access journal.

Last updated: 25 August 2015 (ND)

7 Annex 1

Composition of the Scientific Research Committee (SRC; formerly called 'CWO')

Name	Function	Background information
Prof. Dr. W.R. Faber	Chairman	Emeritus Professor of Tropical Dermatology (Academic Medical Center, University of Amsterdam). Expertise; Tropical dermatology; in particular Leprosy. Specific interest in neuropathic foot complications, leprosy reactions and other aspects of prevention of disabilities.
Prof. G.J. Ebenezer	Member	Assistant Professor, Neurology Department, Johns Hopkins School of Medicine, USA. Previously, Head, Histopathology Department, Schieffelin Leprosy Research and Training Center (SLRTC), India.
Dr. B.E. Ebenso	Member	Research Fellow, Leeds, Institute of Health Science, United Kingdom. Public health specialist and interdisciplinary researcher focusing on health policy and systems research in lower income countries. Many years of experience in international health, 15 years of which were in management positions in TB and leprosy control programmes in Nigeria and Niger Republic.
Dr. F. van Dijk	Member	Rehabilitation Physician at the Rehabilitation Centre Het Roessingh in the Netherlands. Tropical Medicine work experience in Kenya; Med Director Alupe Leprosy Hospital and Training Unit, West Kenya leprosy and TB control program.
Prof. Dr. V.P.M.G. Rutten	Member	Associate Professor at Department of Infectious Diseases and Immunology, University of Utrecht and Extraordinary Professor at Department of Veterinary Tropical Diseases, University of Pretoria. Expertise: Bovine Immunology, specifically immunology of mycobacterial diseases like tuberculosis and paratuberculosis. The impact of NTM in pathogenesis, diagnosis and vaccination of mycobacterial infections. Mycobacterial infections in wildlife species. Canine immunology, specifically immunology of atopic dermatitis.
Dr. P.A.M. Schreuder	Member	Medical doctor/leprologist (retired) with long leprosy control field work experience in Thailand, Indonesia and Brazil. PhD in epidemiology of reactions and impairments in leprosy. Broad grasp of leprosy-related medical and public health issues.
Prof. Dr. T.S. van der Werf	Member	Pulmonologist, Head of the Infectious diseases Service & Tuberculosis unit at the University Medical Centre Groningen. Great affinity for tropical medicine, expert in the area of mycobacterial infections. Focus on: Buruli ulcer. Field work experience in Kenya and Ghana.