Global collaborations in leprosy research – the future is connected

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Collaboration between endemic and non-endemic partners has always been essential for leprosy research: patients and clinical knowledge are mainly found in endemic countries, whereas technical advances and opportunities are usually first available in non-endemic countries. During the period 1976–1995 the WHO IMMLEP and THELEP Special Programmes provided forums for the melding of basic and field research and resulted in great advances, particular in the application of immunological and molecular approaches to control of leprosy. However, nowadays the opportunities for leprosy researchers involved in more basic research to interact are few with a limited number of dedicated meetings. Even at the International Congresses held every 5 years, the balance is quite rightly in favour of leprosy control over basic research.

Meanwhile leprosy research has been facing two major challenges. Firstly, the decline in global leprosy case detection rates has had the same effect on leprosy research funding as on the provision of leprosy diagnostic services: dedicated leprosy research funding is thin on the ground, although invaluable support is still provided by the non-governmental anti-leprosy organisations represented in the International Federation of Anti-Leprosy Associations (ILEP). Secondly, there has been a huge increase in funding for tuberculosis research. With the similarities between Mycobacterium tuberculosis and Mycobacterium leprae, many researchers who previously worked exclusively on leprosy have found the balance of their research on mycobacteria tipping increasingly towards tuberculosis.

In the last 10 years there has been another change occurring in the funding of infectious diseases research. Smaller European Community-funded mycobacterial research networks...
of 3–6 partners have expanded into ‘networks of excellence’ and larger consortia, such as EU FP6 TB-VAC (http://www.tb-vac.org/) or MUVAPRED (http://www.mucosalimmunity/muvapred/). Such grants bring together much larger numbers of research groups, with 39 and 22 partners respectively, and fund not only research focussed into work packages but yearly or biannual meetings or workshops. This trend has been amplified by new funding, such as for the Gates Grand Challenges,1–3 which funds three tuberculosis consortia, with 7–15 partners each, work plans and deliverables, and meetings of all the partners (http://www.grandchallenges.org/NewVaccines/Challenges/LearnaboutImmunologicalResponses/Pages/Biomarkers.aspx; http://www.grandchallenges.org/CureInfection/Challenges/Therapies/Pages/Tuberculosis.aspx; http://www.grandchallenges.org/CureInfection/Challenges/ImmunologicalMethods/Pages/PostExposureTB.aspx), or for the Gates Malaria Partnership led by the London School of Hygiene & Tropical Medicine (http://www.lshtm.ac.uk/gmp/).4

In the USA context, NIH/NIAID have funded for many years contracts which support the mouse foot pad and armadillo colonies at Louisiana State University (Baton Rouge, LA) and the work at Colorado State University (Fort Collins, CO) largely for the purpose of generating viable and large quantities of Mycobacterium leprae and ensuing M. leprae reagents (http://www.cvmbs.colostate.edu/mip/leprosy/). NIAID also currently funds several investigator-initiated grants through their R01 mechanism. In the private sector, the Heiser Program is the most prominent (see below).

Three consortia are involved in leprosy-related research activities, namely ICRAAS, Synapse and IDEAL. The International Consortium for Research and Action Against health-related Stigma (ICRAAS) (http://www.kit.nl/smartsite.shtml?id = 7641) was established in 2004. Even though it has not yet obtained formal funding, ICRAAS are organising two stigma symposiums during the International Stigma Conference in London, UK in January 2009 at which leprosy will be high on the agenda. The Synapse consortium held an international workshop on neuropathology in leprosy in Soesterberg, the Netherlands in June 2007,5 but has currently no funding, even though a research proposal (TENLEP) has been developed.

The IDEAL Consortium grew out of a workshop held by the World Health Organization in Geneva in November 2002 to identify the research opportunities that the M. leprae genome sequence provided. This workshop identified the need for M. leprae-specific early diagnostic tools based on antigens capable of stimulating T cells, and for the development of tools using molecular epidemiology to track leprosy transmission. This led to another workshop in Amsterdam in October 2003, at which the Initiative for Diagnostic and Epidemiological Assays for Leprosy (IDEAL) Consortium was born, led by Dr. Patrick Brennan and Dr. Hazel Dockrell, IDEAL’s first co-chairs (http://www.ideal-leprosy.net). The plan was to exploit the M. leprae genome by coordinated research in leprosy endemic areas, and by bringing those still active in leprosy research together on a regular basis to retain this expertise, thus preventing a further brain drain towards tuberculosis and making optimal use of the scarce resources by avoiding duplication of activities.

This of course needed funding, and IDEAL has been generously supported by The Heiser Program for Research in Leprosy and Tuberculosis of the New York Community Trust (http://www.nycommunitytrust.org), and currently, the Netherlands Leprosy Relief (NLR) and the Turing Foundation. Almost 4 years since the start of activities, we can report scientific progress but also a deeper insight in the value and challenges of running such a consortium. IDEAL has held workshops in Ethiopia,6 Thailand, Brazil and India and in December 2008 in Cebu, The Philippines. The 30 partners have formed closer links, and, although many do much of their research outside the IDEAL grants, there is more information sharing, less competition, and
less likelihood of duplication of effort. Hopefully IDEAL is giving this small, dedicated leprosy research community a heart and an identity. Links to the northern partners in IDEAL are providing training and technical advancement opportunities for partners from leprosy-endemic areas and links to the endemic partners have given non-endemic partners sources of patients, samples and clinical expertise. Together, the partners are making progress.

This coordinated approach does provide its own challenges. Coordinating activities takes time and effort. Moreover, carrying out research in a coordinated way in different leprosy research centres requires preparation of, and agreement on, standard operating procedures (SOPs) that give details on how the work will be done. Starting from the premise that we wanted as many partners as possible to participate in the research inevitably resulted in slower progress than if more focussed research had been conducted in fewer sites, which the Consortium found a hard lesson to learn. But with the possibility that M. leprae itself may differ in different parts of the world and the certainty that different ethnic groups have differences in their genetic make-up that influence the immune response to infection and disease, to develop tools for leprosy diagnosis or transmission that would only work in certain parts of the world would be very short-sighted. For now, IDEAL is trying a middle way, doing things in more than one country but in less than the 5–7 countries that participated in our earliest studies.

There are both advantages and disadvantages in networks and consortia. Mutual support, training and just having more intellectual input into projects all bring benefits, in addition to the feeling of being a family. There may, however, be a danger that the coordination required to make consortia work can slow progress and that individuality in research is stifled. But we live in a connected society and the era in which any laboratory could work on its own without collaborations is long gone. So the future is connected, and these connections will hopefully help maintain and foster leprosy research, and help the development of new tools that would aid the ultimate goal of the elimination of leprosy.

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References