

### **Box 3: Brazil Case Study**

#### **Experience of *Rede-TB* in Brazil: development and impact evaluation of new health system intervention tools for TB control, with particular focus on TB/HIV and Drug-Resistant TB**

##### **Background**

During the period of 1980-2000, there were no NGO working on TB control in Brazil, and almost no interaction between the national TB control programme, academia and industry. Health Professionals did not perceive researchers as partners (and vice-versa), and further, development of policies for TB control was not driven by scientific evidence, and efficiency and impact of such policies was not monitored. The only available training of health professionals was limited to instruction in WHO Normative Guidance, without opportunity to participate in regional and global policy development, monitoring and evaluation. The lack of investment in efforts to build research capacity was reflected in the limited range and type of research conducted during this period.

##### **Multi-stakeholder partnership**

In response to the lack of systematic approach to development of research capacity in Brazil, a 'Foresight Seminar on TB Research and Control' was organised in Rio de Janeiro in March 2001. The aim of the Seminar was to identify strategies that would enable the development and evaluation of new products, technologies and strategies for TB control. A number of stakeholders were invited in order to mobilise political commitment and establish a systematic, sustainable system for research capacity development. These included representatives from National and Province TB Programmes; National and Province Aids Programmes; Public/Private laboratories; Research/Education institutions; Biomedical associations; Regulatory agency; Health Council / NGOs and the private sector.

##### **Promotion of information exchange between researchers and the TB programme:**

The Brazilian TB Research Network (*Rede-TB*) was created in April 2001 to spearhead the effort of developing TB control research capacity at the national level. The main objective of *Rede-TB* was to promote research and educational activities in an integrated manner in order to contribute to TB and TB/HIV control.

*Rede-TB* is a non-governmental organization initially constituted by a multi/interdisciplinary group of researchers and students from Health Sciences, Engineering and Education, later joined by Civil Society partners and Health Service

representatives from TB and AIDS branches in all levels (Federal, State, and Municipality). *Rede-TB* is a membership organization of 160 members from 47 institutions, including researchers, policy makers, AIDS and TB managers. The strategy was to establish a network with self-organizing nodes called 'Coordination Areas' or 'Working Groups' by research areas, linked to a common vision that formed the basis of a platform for membership engagement, identification of gaps and research partnership building.

*Rede-TB* played a key role in the creation of the first TB-NGO led by activists and of the Brazilian Partnership Against Tuberculosis (BPAT), respectively in 2003, and in 2004. *Rede-TB* researchers were invited by the Ministry of Health (MoH) to help in the definition of the National TB Research Agenda, in 2004, 2007, and 2010. It also led to the establishment of a number of research initiatives including the scientific and technological platform in TB diagnosis developed together with the Latin America Network (REACTB) for TB Control and WHO. Research Institutes and universities are now engaged in the implementation of TB [OR] research, with good interaction between basic and clinical research using several laboratories with standardized procedures. This has led to prominent interaction between governmental institutions (NTP, Central Laboratories, Sanitary Supervision Institutions) and industry.

### **Strategy for research capacity development: decentralized multi-level training in health systems research methods and operational research**

With an award from the Science Technology Department of the Ministry of Health, REDE-TB piloted research training in Rio de Janeiro Province (2004). Building on this experience, the International Collaborative Operational and Health System Research on TB and HIV/AIDS (ICOHRTA) Research Capacity project expanded training with key collaborating institutions in the US (Johns Hopkins University Center for TB Research, Weill Medical College of Cornell University and the School of Public Health of the University of California, Berkeley) and key collaborating institutions in Brazil (the Academic Program of TB / Medical School at Federal University of Rio de Janeiro, the Infectious Diseases Nucleus of the Federal University of Espírito Santo and the Adolpho Lutz Institute of São Paulo State) to five additional provinces using funding from NIH and MoH to implement research training on clinical, operational and health system sector.

Participants are invited to participate in research methodology courses of various duration and levels, according to their scientific background, and to develop their own research projects, based on their service experiences and issues. The best projects are supervised by REDE-TB researchers and funded by ICOHRTA and the MoH.

### **Strong emphasis on expansion of the academic output**

An evaluation of the trends of scientific articles about TB in Brazil published between 1986 and 2006 showed that among 1054 publications, only 6.8% were on operational research and 3.5% included qualitative evaluations<sup>9</sup>. The Rede TB contributed with the expansion of the academic output in TB in Brazil over the last years. Analysis of CAPES (the Brazilian agency for graduate studies) databank on thesis and dissertation on tuberculosis between 2004-2008 revealed that 42% of Ph.D. theses and 37.4% of M.Sc. dissertations were mentored by REDE-TB members.

### **A focus on results, translation into policy and practice**

Following development of broad consensus that any Guidelines modification should be seen as a new technology incorporation activity, TB and AIDS Program coordinators (at federal, state, and municipality levels) prioritized operational research to evaluate the effectiveness of existing tools used in TB control, and the impact of new tools before introduction into practice. Working in an integrated manner, *Rede-TB* researchers have received significant national and international funding for basic, clinical and operational research. Recently, Rede TB researchers with NTP, NAP, Helio Fraga Filho Reference Center-ENSP-Fiocruz, Management Science for Health (MSH), Bill Mellinda Gates Foundation and The UNION developed protocols and received funding to evaluate the impact of the introduction in the Public System of NAAT (like GeneXpert) pulmonary TB diagnosis and line-probe assays (like MTBDRplus) for DR-TB diagnosis, in different regions in Brazil. And more recently, Rede TB received funding to validate the molecular test for pulmonary TB diagnosis called DETECT TB developed by Brazilian scientists in collaboration with national industry that will be compared with new commercialized tests entered in the market.

In addition, *Rede-TB* conducted a nationwide qualitative study to map performance of health services in the diagnosis of tuberculosis in 10 metropolitan areas of Brazil from the perspectives of the patient, health professionals, managers of health units, and civil society organizations. The investigation found low effectiveness in care, verified by the low suspicion of TB by professionals (even those with high knowledge of TB disease), high number of referrals to the services of Hospital/Emergency and Primary Care, and the deficiency of communication flow and referring activities between the services (in all levels) (including the laboratory network).<sup>10,11,12,13</sup> Moreover, diagnostic tests were not performed routinely in the same health service initially sought by the TB patient. The number of times the patient had to travel for health services until effective diagnosis of the disease was established was a factor that contributed negatively to the time between symptoms onset and TB diagnosis. This scenario occurred even in those cities with more decentralized health system where health family program has received high priority.

TB operational research led to key changes in national policy and practice described in the last National Guidelines released in March 2010. This included: the creation of a TB control program for vulnerable citizens: indigenous, homeless, prison inmates; the development of tools to be used for TB infection control in health settings (hospitals, prisons, and primary health services, etc); the adoption of routine culture for mycobacteria for all HIV infected TB suspects, drug susceptibility testing for drug resistant TB suspects, and HIV testing for all TB suspects; a change of treatment regimens for newly TB patients (using fixed dose combination with four drugs); and standardized drug resistant TB treatment.

### **Challenges and lessons learned**

The creation of *Rede-TB* helped the building of a renewed bridge between the Academia and Health System and Civil Society. Academia served as a tool to strengthen the TB and AIDS managers, health professionals, health system users and the national Industry in the production of scientific knowledge that responds to local demands, through operational and health system research approaches.

*Rede-TB* is a unique example of NGO leadership and coordination of a national research capacity development process that has demonstrated significant measurable results. Challenges, however, remain. Sustainability of achievements will require continued investments in research capacity development; funding research through the established research coordination areas; training health care workers, managers, and community leaders towards a change in attitudes and practices to improve conditions of access, the continuity of care, and communication flow between the services (in all levels) and the civil society. In addition, ongoing confusion with monitoring and evaluation will need to be resolved, and processes strengthened to incorporate research into the national TB program.