EDITORIALS

An evaluation of GAEL, the Global Alliance for the Elimination of Leprosy

KOMMER L. BRABER
Netherlands Leprosy Relief Association, Wibautstraat 137K
PO Box 95005 NL-1090 HA Amsterdam, Netherlands

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The Alliance

The Global Alliance for the Elimination of Leprosy (GAEL) was initiated by the World Health Organisation (WHO) in 1999, when it had become clear that the target set for the elimination of leprosy would not be reached by the year 2000. GAEL should facilitate the concerted effort of all parties involved to reach elimination at national level in all endemic countries by 2005. WHO labelled the campaign the ‘Final Push’. WHO invited the governments of the major endemic countries, the Japanese Nippon Foundation, the Novartis Foundation for Sustainable Development, the Danish Development Cooperation Agency Danida, the International Federation of Anti-Leprosy NGOs ILEP and others to join GAEL.

ILEP, whose members spend some $60 million annually on leprosy work, had always been critical of the WHO elimination campaign, but staying outside GAEL was considered to be not constructive so ILEP decided to participate but without signing a formal agreement.

WHO campaign to eliminate leprosy as a public health problem

In the beginning of the 1980s, multi-drug therapy (MDT) had been found to be a highly effective treatment and became the WHO recommended regimen. The success of MDT and the prospect of the elimination of leprosy must have encouraged WHO to take up the challenge. In 1991, the World Health Assembly passed a resolution to eliminate leprosy as a public health problem by the year 2000. The target was arbitrarily set at a ‘prevalence’ (number of patients on MDT at the end of the year) rate of less than 1 per 10,000 of the population. The underlying assumption was that at this prevalence rate the chain of transmission would be broken so leprosy would die out naturally.

Correspondence to: K. L. Braber (e-mail: k.braber@leprastichting.nl)
Achievements and major points of criticism

Achievements

Before MDT was introduced, over 12 million people had accumulated on dapsone monotherapy registers and leprosy appeared to be a major international health problem. In fact, leprosy is a relatively minor disease in terms of the global incidence. The elimination campaign of WHO has strongly promoted the worldwide fight against leprosy. It created enthusiasm and alerted governments of leprosy endemic countries and their ministries of health. During the 1990s, a lot of effort was put into the acceptance of MDT, which accelerated the implementation of the therapy.

Today’s statistics show that over 600,000 new patients are put on treatment every year and most of them are released from treatment and are off the register within a year. The ‘registered prevalence’, therefore, will be less than 600,000.

Who's motivation

One may wonder why WHO, without proper evaluation of the elimination campaign, decided to extend the campaign for an additional 5 years in 1999. By then, the criticism of the basic assumptions and the means used to reach the 1:10,000 target was very strong. A thorough review of the campaign could have either changed the strategy, or silenced the critics.

Some have wondered why the WHO is so deeply involved in leprosy at all. In terms of human suffering leprosy may be a high burden on individuals and the communities they live in, but in quantitative terms leprosy does not belong to the world’s major diseases. Therefore it is unlikely that without external financial support WHO would have been so active in the implementation of leprosy control programmes and the ‘elimination’ campaign. The donations from the Nippon Foundation have been crucial to the campaign. This Japanese NGO has sponsored the leprosy activities of WHO for almost 30 years now. Between 1975 and 2002, this support amounted to US $130,000,000.

Prevalence concept

One of the elements of the elimination campaign that has been seriously questioned is the definition of prevalence it had adopted. Prevalence is defined as the number of people who have leprosy at a given moment. WHO took the number of patients on the MDT registers instead. This definition ignores the large reservoir of leprosy patients who have not yet been diagnosed. This is an important reservoir if only because many of these patients are infecting their contacts without even knowing they have leprosy. In addition, hundreds of thousands of so-called ‘ex-patients’ are living with the consequences of nerve damage, deformities and handicaps. Even though they may not host any living leprosy bacilli, they will certainly be regarded as leprosy patients by their communities. Their ‘released from treatment’ card will not impress many of their contacts. This reinforces the leprosy stigma and thereby contributes to the late reporting. The above implies that reaching the 1 per 10,000 prevalence target has little epidemiological value and certainly does not mean that leprosy is eliminated.

ILEP’s questions

WHO kept on organizing large scale Leprosy Elimination Campaigns and other interventions. Apparently, the goal of bringing down the number of people on MDT was a justification for neglecting crucial aspects such as the prevention of disabilities.
ILEP has always tried to maintain an open dialogue with WHO. After ILEP decided to participate in GAEL, the federation and its technical advisory committee remained critical of ‘elimination’. Active ILEP members focus on the delivery of MDT, prevention of nerve function impairment, and on patient care during and after MDT. The ‘elimination’ campaign does not appeal to them and the year 2005 is irrelevant in their approach.

Most ILEP members would rather concentrate on early case detection and treatment, aiming at a reduction of the incidence of nerve damage and disabilities. They will also go on addressing the problems of the millions of so-called ex-leprosy patients, who have to live with handicaps and stigma. Most experts agree that leprosy control and care will be needed in the years after 2005 just as much as they are needed today.

Generally speaking, ILEP members receive their income from private donors. The press releases of WHO and its GAEL partners have made the fundraising activities of ILEP more difficult and potentially jeopardize the support of leprosy work after 2005. ILEP was expelled from GAEL in December 2001, probably because ILEP wanted a critical dialogue on key issues.

THE ILA CONGRESS

The ILA is the international professional association of leprosy experts. The ILA congress in August 2002 provided an opportunity to discuss the future of leprosy control and related issues. In preparation for the congress, the ILA organized a Technical Forum in February 2002. WHO declined to participate. A thorough review of all published and grey literature from 1966 onwards was carried out. The Forum discussed the major issues in leprosy and reviewed the evidence. The Forum questioned assumptions and the implementation of the WHO ‘elimination’ campaign. Similar voices were heard during the congress. At the end of the congress the ILA meeting of members adopted a resolution stating that a significant leprosy problem will continue to exist for many years to come and that leprosy control services must be sustained. The ILA called on all stakeholders to review their recommendations and guidelines in the light of the ILA Forum report. The WHO did not respond.

The GAEL evaluation

It came as a surprise that WHO invited an independent expert, Dr Richard Skolnik, to lead an independent evaluation of GAEL in the beginning of 2003. When I was interviewed by one of the team members, I was disappointed to learn that the effectiveness of the ‘elimination’ campaign was not formally included in the evaluation. Yet I was given ample opportunity to voice my concerns regarding ‘elimination’ campaign issues. The evaluation was done extremely thoroughly. The team interviewed over 100 persons worldwide, and did in fact also consider technical and policy aspects of the elimination campaign.

The evaluation report

In order to discuss the recommendations made by the evaluators I shall reproduce relevant parts of the report in italics and comment on them below.
A number of collaborators, and other experts working in leprosy, believe that WHO has acted too unilaterally on some important matters and that WHO has largely ignored their concerns, especially when it has developed policy through its Technical Advisory Group (TAG). These include questions about the validity of the data on prevalence, the apparent suggestion that the duration of treatment be universally shortened, and the perceived encouragement by WHO of accompanied multi-drug therapy, in circumstances many deem to be inappropriate. They also include suggestions by many of those working on leprosy that the protocols for diagnosis and treatment have been simplified too much. Many collaborators also believe that GAEL has had too exclusive a focus on targets for leprosy elimination.

The concept of ‘elimination’ suggests that after the goal has been met that there may not be important leprosy work to do. Related to this, the notion of ‘the final push’ is also one that can easily be misused and misunderstood. Second, the Alliance has appeared to many involved in leprosy activities to be promoting an approach in which multi-drug therapy is done almost to the exclusion of other leprosy related activities, such as rehabilitation. Third, the panel believes that integration will occur at a very different pace in different settings, with varying implications for what governments will need to do to ensure effective control of leprosy, and that all collaborators must take account of this.

It can be asked why the WHO Leprosy Unit sticks to a campaign, which meets such strong criticism from so many leprosy experts. Is it the commitment WHO has made towards Novartis and the Nippon Foundation? Or has WHO identified itself with ‘elimination’ so strongly that no re-evaluation is possible? Little criticism is heard from endemic countries, but this may be due to the importance of WHO for the ministries of health in other programmes and leprosy not being worth a confrontation with WHO.

Evaluations have to analyse the past, with the objective to improve future activities. In this sense, the GAEL evaluation meets expectations. I fully agree with the evaluation team, when they write:

It is already the middle of 2003 and the target date for ‘elimination’ is 2005. The panel believes, therefore, that measures to enhance collaborative work on leprosy and prepare for the period after 2005 must start immediately.

The panel also presumes that WHO will continue to play its traditional technical role in helping governments to address leprosy.

In addition, the panel believes that the main focus of leprosy efforts will have to be at the country level, but important contributions to leprosy activities will still need to be made at the global level.

The panel does not recommend the continuation of GAEL in its present form. They believe that the Alliance needs to be reconstituted and refined. The panel is not in favour of maintaining the ‘elimination’ of leprosy as the goal of future collaboration, and that the farewell to ‘elimination’ be done in such a way that no one would be able to draw the conclusion that leprosy is a thing of the past:

First, collaborators will have to work more openly, collegially, and inclusively. Refinements to the Alliance will not make any difference if collaborators cannot work in this way. If a lack of collegiality were to continue, the Alliance would do a major disservice to those who suffer from leprosy.

Second, the manner in which the achievement of the GAEL goals is handled ‘politically’ is extremely important. This will have to be done in a way that highlights the achievements to date and gives credit to all who worked to reach these goals. However, it must also be done in a way that makes clear to the world that this is not the end of leprosy. Rather, it must be made
clear that there will continue to be new cases and a need for health systems and trained people to work on leprosy.

The public health, clinical and rehabilitative aspects of leprosy work must be portrayed without hesitation as complementary matters that will be addressed by an inclusive alliance of partners who respect the work of others.

Leprosy control is to be the responsibility of endemic countries:

Second, and very fundamentally, all countries will need to ensure effective leadership and coordination of their leprosy activities and be firmly accountable for them.

The panel advises WHO to return to its original role:

WHO would focus largely on technical advice to country programs and on ensuring effective monitoring and evaluation of those activities.

NGOs, such as ILEP member organisations should initiate co-operation:

The panel recommends that NGOs and foundations involved in leprosy take the lead in organizing a ‘collaborators forum’. Such a forum would include any organization or government that works on leprosy that would wish to join and WHO. It would also include better representation than GAEL has had of people living with leprosy.

Country task forces would bind all parties working in a country together:

Governments and WHO should work closely within country task forces with the NGOs and foundations that are active in leprosy.

Monitoring the global anti-leprosy campaign should take place as follows:

The panel recommends strongly that the monitoring and evaluation group be chosen in an open manner, taking account of the views on possible candidates of key leprosy NGOs, foundations, and bi- and multilateral institutions that have worked on leprosy.

Funding is an important aspect:

It would be important to ensure that adequate funds are available for the monitoring and evaluation function, the work of the forum, and well focused operational research.

The evaluation panel, realizing that the era of ‘elimination’ will have to be rounded off in an elegant manner, advises the WHA to pass a new resolution:

Finally, the panel believes that it would be valuable for the World Health Assembly to pass a resolution that would take leprosy activities beyond 2005. Such a resolution would help move leprosy efforts towards an explicitly broad-based approach to the control of leprosy, the avoidance of nerve damage, and the rehabilitation of those in need.

The panel recommended:

It is already the middle of 2003 and the target date for ‘elimination’ is 2005. The panel believes, therefore, that measures to enhance collaborative work on leprosy and preparations for the period after 2005 must start immediately.

What is to be done now?

By now the middle of 2004 is already behind us and a major reason for writing this article is that there are few signs that any of the recommended measures are being implemented. The Nippon/Novartis funded elimination campaign rolls on as if no evaluation had taken place at
all. WHO still uses the old elimination rhetoric. Governments of endemic countries are still being urged to do their utmost to reach the 1 per 10,000 ‘elimination’ target in the year 2005. WHO pushes for ‘cleaning the registers’.

How can break the deadlock be broken? The evaluation team advises the leprosy NGOs to take initiatives and to facilitate a discussion among all stakeholders. This is a strong appeal to the NGOs, notably ILEP and including the Sasakawa Memorial Health Foundation, to invite the major players in the fight against leprosy for an open discussion of the evaluation’s consequences and to build new forms of collaboration along the lines sketched by the evaluation team. WHO, the Nippon Foundation and the Novartis Foundation will also have to make major steps.

Although Dr Endo, the head of WHO’s Department of Control, Prevention and Eradication, Communicable Diseases Programme, had a frank discussion with representatives of ILEP members in London in June 2004, there are no concrete signs of WHO being prepared to start new ways of dialogue. Dr Endo could not say much about the strategic and organizational changes WHO may be considering. We learned that a World Health Assembly resolution regarding the elimination campaign and the future of leprosy control may be postponed till May 2006, because the WHO Technical Advisory Committee on the Elimination of Leprosy would not be able to meet before February 2005. This could mean that the future leprosy strategy of WHO remains unclear for another 2 years.

I am sure that if the millions of handicapped ‘ex’-leprosy patients and the millions of future leprosy patients would have a vote, they would certainly support the idea of a new dialogue on responsible, integrated and sustained leprosy control and leprosy care in all the leprosy endemic areas of this world.