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Hazards of setting targets to eliminate disease: lessons from the leprosy elimination campaign

Diana Lockwood and colleagues reflect on the global leprosy elimination programme and challenge the wisdom of WHO’s elimination strategies

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Elimination of a disease sounds attractive, but as the recent re-emergence of polio has shown, it is difficult to accomplish. As part of its roadmap for reducing the burden of neglected tropical diseases, the World Health Organization has identified five diseases for elimination by 2015 and a further eight by 2020. Although setting these ambitious targets has the potential to focus money and resources, unless the targets are realistic they can have unforeseen consequences. We use the experience of the 1991 campaign to eliminate leprosy to show how targets can end up causing harm to patients.

Why choose leprosy?

Leprosy is a stigmatising and potentially disabling disease. Despite the introduction of an global treatment programme in the 1980s around 230,000 cases are diagnosed annually, mainly in India and Brazil but also in 41 other countries. Leprosy is caused by *Mycobacterium leprae* and is spread through droplets. However, the disease can be treated with a six or 12 month course of multidrug therapy (rifampicin, dapsone, and clofazimine), which has a cure rate of 98%. The condition can be diagnosed clinically by recognising a range of characteristic skin lesions and palpating thickened peripheral nerves (box 2). Diagnosis can be confirmed through detection of acid fast bacilli in slit skin smears or through granulomatous inflammation in skin and nerve biopsy samples. Up to 60% of patients have peripheral nerve damage at diagnosis, which requires treatment with steroids lasting several months. Even after effective treatment long term morbidity can be problematic; immune mediated complications can occur for years and education and monitoring are needed to prevent damage to hands, feet and eyes in those with peripheral neuropathy.

After a WHO expert committee on leprosy recommended fixed duration antibacterial multidrug therapy for leprosy patients in 1982, it was postulated that effective treatment would interrupt transmission globally, and in 1991 the World Health Assembly passed a resolution to “eliminate leprosy as a public health problem by the year 2000.”

What does elimination mean?

The target for elimination of leprosy (and other diseases) as a public health problem did not mean achieving a prevalence or incidence of zero. For leprosy WHO set a target to achieve a prevalence of less than one case per 10,000 population at a global level. The selection of this number was arbitrary and not supported by mathematical modelling of leprosy data. WHO’s leprosy unit in Geneva monitored the elimination programme, with programme managers in endemic countries required to report annual leprosy figures for publication.

Reality of eliminating a disease

The leprosy elimination strategy had strengths. It committed governments, donors, and health workers to focus on leprosy and facilitated free drug treatment. Diagnosis was simplified with a straightforward field based classification based on counting the number of skin lesions and new case detection was promoted with innovative approaches. Mass detection campaigns were held to detect early cases and special programmes were set up to detect cases in nomadic populations. However, India and Brazil, two countries with high prevalences of leprosy, provide case studies of how the elimination target had unintended consequences. In India from 1983 there was an energetic campaign supported by the Indian government and leprosy non-governmental organisations, which had the initial effect of increasing detection rates. Despite efforts to clean the leprosy register by removing patients who had completed antibacterial treatment, many of whom had chronic complications, India failed to meet the 2000 target and the date for elimination was moved to 2005. In order to help meet this
Box 1: Neglected tropical diseases identified by WHO for elimination

By 2015
- Rabies in Latin America
- Chagas disease transmission through blood
- Human African trypanosomiasis in selected countries
- Onchocerciasis in Latin America
- Schistosomiasis in Eastern Mediterranean region, Caribbean, Indonesia, and Mekong river

By 2020
- Rabies in South East Asia and Western Pacific
- Blinding trachoma
- Leprosy
- Chagas in most Latin American countries
- Human African trypanosomiasis
- Visceral leishmaniasis in Indian subcontinent
- Lymphatic filariasis
- Endemic treponematoses (yaws)

Box 2: Case definition for leprosy (WHO, 2012)
Presence of one of the following:
- Loss of sensation in pale or reddish skin lesions
- Peripheral nerves with loss of sensation or weakness of the muscles supplied by that nerve
- Acid fast bacilli in a slit skin smear sample

Damage from chasing a target

Leprosy was an inappropriate disease to choose for elimination. The biology of leprosy means that it is not suitable for an elimination target within 10 years. The incubation period is long—2–15 years depending on the type of leprosy—so new patients can continue to present for many years after successful control campaigns have ended. South Africa attained elimination rates in 1926 but new cases still present today.

Modelling of the leprosy elimination strategy based on trends in case detection rates for 1995–8 predicts that it will slow transmission but that complete elimination will take decades to achieve.

Obsession with the leprosy target caused schisms in the leprosy world. Leprosy non-governmental organisations were asked to leave the Global Alliance for the Elimination of Leprosy, which meant that the organisations that lead work nationally had no input to global leprosy health policy.
Box 3: India: Strategies for leprosy control and elimination as a public health problem, 1983-2012

1983: Government establishes a national leprosy eradication programme with strategy of early detection of cases by surveys and contact examination and treatment with multidrug regimen
1996-7: Fixed duration treatment introduced with “cleaning” of registers and patients not on treatment removed from the list. New case detection rate 4.6/10 000
1997: Campaigns to reach undetected cases initiated
1999: Modified leprosy elimination campaigns launched emphasising public awareness and voluntary reporting of patients. One million new cases were detected in five campaigns
1999: New case detection peaked at 8.9/10 000
2000: India did not meet elimination target because the national prevalence was 5.2/10 000

Altered strategy to reach elimination target
2001: WHO proposes “final push” and moves target date to 2005
2002: National health policy set the goal for leprosy elimination by 2005 and national detection rate began to fall 25% a year (fig 1)
2004: Leprosy services moved into general healthcare services with large scale staff training. Voluntary reporting of patients became the main strategy
2005: WHO Kathmandu produced policy directives to reduce prevalence, which included the following:
  - Stop all active searches for new case detection.
  - New cases to be given multidrug treatment only after validation by authorities locally
  - Delete names of the patients from the register as they receive the last dose of treatment
  - Do not register single lesion leprosy cases
  - Cease screening household contacts
2005: India achieved elimination nationally
2006: Independent surveys in Maharashtra show cases levels of 2.96-9.52/10 000
2009: National Forum of Leprosy Patients petitioned parliament to investigate the numbers of leprosy patients
2010: National sample survey of 15 million people examined detects 2177 cases. Weighted new cases rate estimated at 2.5/10 000

In 2007 WHO abandoned the elimination target for leprosy programme and instead set a target based on disability rates with the aim of improving focus on prevention of disability. Despite the shift in emphasis WHO still reports global leprosy rates and which countries have achieved elimination. Political commitment to leprosy has been lost. Funding and support for leprosy agencies have been declining at 5% a year for the past five years (International Federation of Anti-Leprosy Associations, ILEP, personal communication). Skills in diagnosing and managing leprosy have also been lost as programmes have been left unsupported. This has also been accelerated by the transfer of diagnosis and management of leprosy to peripheral health workers in many countries, away from specialist centres. The rhetoric on elimination has discouraged dermatologists from engaging with leprosy programmes, even though they may be diagnosing cases in the private sector, because they believe leprosy is eliminated. Academic work on leprosy has declined; it rarely figures in medical school curriculums even in endemic countries, and research has declined. Young researchers perceive that the disease is eliminated. The International Journal of Leprosy ceased publication in 2005 with an editorial noting the absence of scientific evidence for the elimination policy.

Future of elimination
The terminology of leprosy elimination was confused and misleading. Many people, from policy makers to observers, understood the goal to be complete elimination rather than reduced prevalence. It is important in future that those involved in campaigns, politicians, funders, health services, and the wider media are clear about what elimination means. Although WHO has defined the terms “eradication,” “elimination,” and “elimination as a public health problem,” the possibility of confusion remains, and the terms could be misused for political purposes (box 5).

Elimination of any disease is a powerful target and sets high expectations. Targets used judiciously can energise programmes, and the leprosy campaign reached out to many countries and ensured that millions of patients were detected and cured and
gave leprosy a much higher profile. However, this achievement has been lost in the retrenching that has been required to take forward planning for a chronic disease. The lessons of leprosy show that monitoring of targets must be transparent. Workers strive to reach targets and find unexpected ways of doing so, particularly if incentives or pressure is exerted on them. This mirrors the use of targets elsewhere—for example, in the English NHS where targets can disrupt the focus of services.

A target to eliminate should be set only if it is realistic. The following conditions are needed: straightforward diagnosis, effective treatment, low transmissibility, and ability to differentiate between current and past infection. Of the diseases listed for elimination on the WHO roadmap only rabies in Latin America fulfills these conditions.

When it was clear that leprosy transmission continued in many countries the appropriate response should have been to redefine the campaign rather than cling on to it. It is important to learn the lessons from earlier elimination programmes. Targets need to be evidence based. Like a battle strategy, they need to strive to reach targets and find unexpected ways of doing so, particularly if incentives or pressure is exerted on them. This mirrors the use of targets elsewhere—for example, in the English NHS where targets can disrupt the focus of services.

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**Figures**

**Fig 1** Incidence and prevalence of leprosy in India, 1991-2011 (data from *Weekly Epidemiological Record*).

**Fig 2** Leprosy prevalence and detection rates in Brazil, 1990-2010 (data from Brazilian Ministry of Health).