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- Feature: Neglected tropical diseases—Leprosy and the rhetoric of elimination (*BMJ* 2013;347:f6142)
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Hazards of targets to eliminate disease: lessons from the leprosy campaign

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

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.[1] 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 a global treatment programme in the 1980s around 230 000 cases are diagnosed annually, mainly in India and Brazil but also in 41 other countries.[2] Leprosy is caused by *Mycobacterium leprae* and is spread through droplets.[3] 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%.[4] The condition can be diagnosed clinically by recognising a range of characteristic skin lesions and palpating thickened peripheral nerves (box 2, bmj.com). Diagnosis can be confirmed through detection of acid fast bacilli in slit skin smears or through granulomatous inflammation in skin and nerve biopsy samples.[5] Up to 60% of patients have peripheral nerve damage at diagnosis, which requires treatment with steroids lasting several months.[6 7] 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.[7]

After a WHO expert committee on leprosy recommended fixed duration antibacterial multidrug therapy for leprosy patients in 1982,[8] 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."

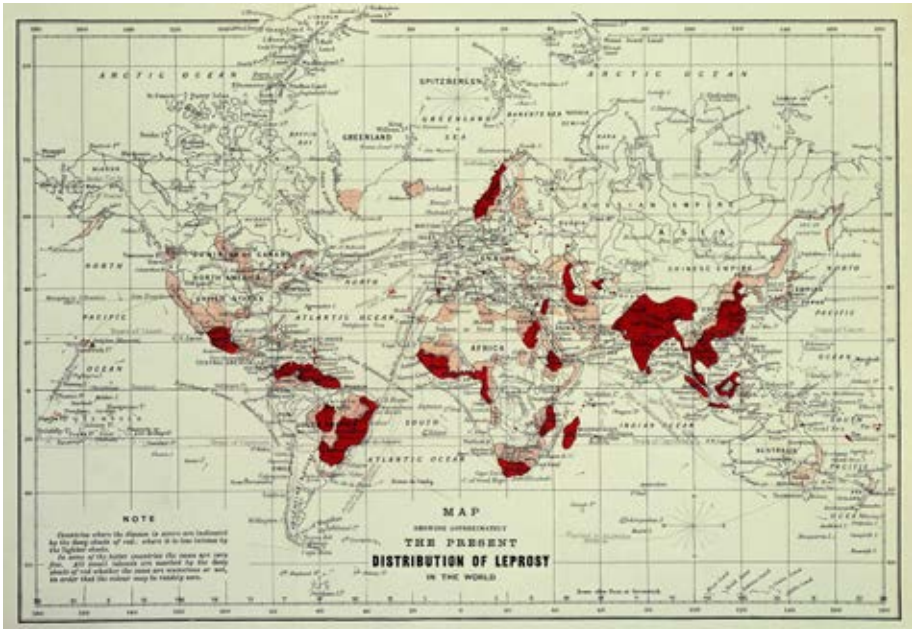
What does elimination mean?

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.[9] The selection of

Box 1 | Neglected tropical diseases identified by WHO for elimination[1]

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)



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Modern medicine has done much to tackle leprosy since this 1891 map of the geographical distribution of the disease. But recent obsession with elimination has caused schisms in the leprosy world

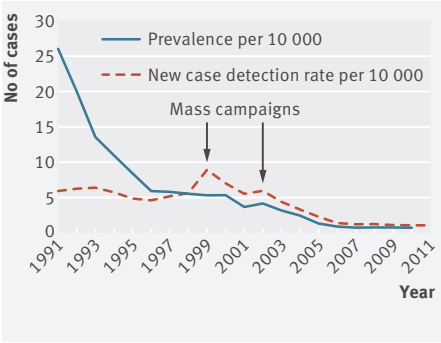
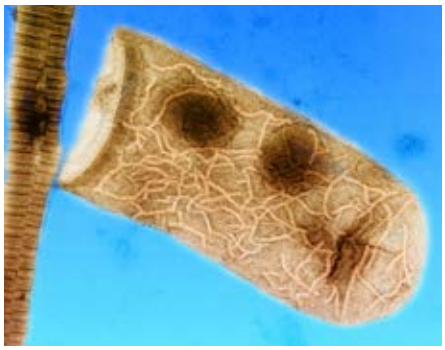


Fig 1 | Incidence and prevalence of leprosy in India, 1991-2011 (data from *Weekly Epidemiological Record*)



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***Mycobacterium leprae*: leprosy's biology means it is not suitable for elimination within 10 years**

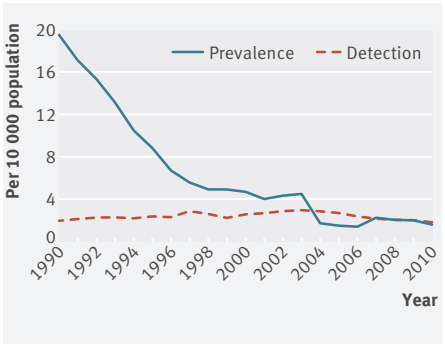

Fig 2 | Leprosy prevalence and detection rates in Brazil, 1990-2010 (data from Brazilian Ministry of Health)

this number was arbitrary and not supported by mathematical modelling of leprosy data.[10] 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[11] and facilitated free drug treatment.[12] Diagnosis was simplified with a straightforward field based classification based on counting the number of skin lesions[13] and new case detection was promoted with innovative approaches.[14] 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 target the country moved to voluntary reporting and stopped actively seeking new cases and screening contacts (box 3, bmj.com). Detection rates fell by 75% between 2003 and 2005 (fig 1).

Although India met the 2005 target, many players questioned the reported leprosy figures, and independent studies showed many undiagnosed patients. Leprosy patients petitioned the Indian parliament about post-elimination services. The government commissioned a national sample survey of 15 million people in 2010, which had a case detection rate of 2.57 per 10 000. The survey findings have not yet been published nor mentioned on the website. In 2011 India reported 127 509 new cases.[18] The difference between the reported and observed estimates suggests that up to half of India's leprosy cases are not being reported. India has been reporting about 130 000 new cases a year (fig 1), which keeps it safely in the eliminated leprosy category. There is therefore no incentive to find new cases.

After closing its leprosy colonies in the 1970s and integrating leprosy services into primary care, Brazil was already making progress in reducing the disease. It adopted the WHO multidrug treatment regimen in 1991 and established referral centres integrated with dermatological services.[19] A successful research programme was also set up, funded by the WHO Immunology of Leprosy Project. New case detection continued at a steady rate, and this should have been congratulated (fig 2).[20] However, the programme was under pressure to show progress towards elimination, and the 2004 returns omitted patients detected during October to December 2004 because they were not yet registered.[19] This enabled Brazil to achieve elimination in 2005, but this was retracted when the missing patients were reinstated (box 4, bmj.com).[18] The under-reporting of cases resulted in a shortage of drugs for treatment of new patients.

The country is again under pressure to reach the elimination target. Yohei Sasakawa, chairman of the Nippon Foundation, which funds the WHO elimination programme, announced that the country would reach the target at a Brazilian leprosy conference in October 2011.[21] Academics in Brazil felt that they were being pressured, and this announcement was widely discussed on the web based leprosy mailing list (http://leprosymailinglist.blogspot.co.uk/).

Box 5 | WHO definitions of elimination[1]

Control—Reduction of disease incidence to a locally acceptable level

Elimination—Reduction of the incidence of infection to zero

Eradication—Permanent worldwide reduction of infection to zero

Globally, the leprosy elimination campaign contained an inherent problem because it was assumed that transmission would drop when case detection and treatment were widened. The possibility that this might not happen in some countries was not considered. New case detection rates in both India and Brazil showed evidence of ongoing transmission into the 21st century (figs 1 and 2).[22] However, both programmes were pressed to meet the target of leprosy elimination by WHO and the Nippon Foundation. This could be done only by reporting fewer patients. The Indian programme adopted measures that ensured that fewer patients were registered, including not registering single lesion cases and no tracing of household contacts, even though this is not good public health practice.[16] These changes led to patients being undiagnosed[17] and experiencing important delays in starting treatment.[23]

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[3]—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.[24] 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.[25]

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.

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.[26] 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.[27] 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.[19]

Academic work on leprosy has declined; it rarely figures in medical school curriculums even in endemic countries, and research has declined.[28 29] 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.[30]

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).[31 32]

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

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.[33]

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 fulfils 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.[34] Targets need to be evidence based. Like a battle strategy, they need to be reviewed regularly and amended when inappropriate.

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We thank Doug Soutar, general secretary of ILEP (the International Federation of Anti-Leprosy Associations) and Maggie Armstrong for their help.

Contributors and sources: DNJL wrote the first version of the manuscript. VS contributed the data and analysis on India. GOP contributed the data and discussion on Brazil. All three authors have contributed to the subsequent versions and final version.

Competing interests: None declared.

Provenance and peer review: Not commissioned; externally peer reviewed.

References are in the version on bmj.com.

Cite this as: *BMJ* 2014;348:g1136

Online state of the art reviews Neuropathic pain: mechanisms and their clinical implications

This week we start a new online section called, "State of the Art Reviews." These evidence based reviews will cover topics that are relevant to all of our readers. Given their in depth analysis, however, specialists, academics, and clinical researchers may find them particularly useful.

The first in the series is "Neuropathic pain: mechanisms and their clinical implications." Most previous reviews of neuropathic pain have been directed at neuroscientists, but clinicians also need to understand the mechanisms because such an understanding will guide clinical practice and future research.

This review summarises the various mechanisms involved in neuropathic pain at different sites along the nociceptive pathway (figure). Although treatment based on underlying mechanisms is conceptually appealing, it yields poor results in clinical practice. The reasons for this and the sites of action of various analgesics is discussed.