

BMJ Open Leprosy in England and Wales 1953–2012: surveillance and challenges in low incidence countries

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ABSTRACT

Objective: To review all notified cases of leprosy in England and Wales between 1953 and 2012.

Design: National surveillance study of all reported cases.

Setting: England and Wales.

Outcome: Number and characteristics of reported cases.

Results: During this period, a total of 1449 leprosy cases were notified. The incidence fell from 356 new cases notified between 1953 and 1962 to 139 new cases between 2003 and 2012. Where data were available, leprosy was more common in men, 15–45 year olds and those from the Indian subcontinent. There was considerable undernotification in 2001–2012.

Conclusions: The high level of under-reporting indicates a need for improved surveillance in the UK. Public Health England, in collaboration with the UK Panel of Leprosy opinion, has revised the UK Memorandum on Leprosy in order to provide updated guidance on diagnostic procedures, treatment, case management, contact tracing and notification.

INTRODUCTION

Leprosy is a curable infectious disease caused by the bacillus *Mycobacterium leprae*, which predominantly affects the skin and superficial nerves. It is a leading global cause of permanent disability from infectious disease.^{1 2} Although historically patients with leprosy have been subject to stigma based on exaggerated perceptions of infectiousness,³ leprosy is not a particularly infectious disease; only about 5% of spouses of lepromatous patients develop clinical leprosy.⁴

The WHO elimination target of less than one leprosy case per 10 000 population was met in 2000.¹ Since then the global prevalence of leprosy has decreased from approximately 600 000 cases in 2001⁵ to <200 000 in 2015.⁶ The significant decrease in prevalence since the late 1990s is due in part to the halving of the period required to complete

Strengths and limitations of this study

- National surveillance study including all notified cases; however, in recent years, there has been undernotification of cases.
- The extent of clinical information reported on each case is limited.
- First summary of leprosy epidemiology in the UK for over 15 years describing trends and characteristics of cases.

treatment for leprosy to 12 months,^{2 7 8} resulting in fewer people being treated at any one time. In 2014, the highest numbers of new cases were in India, Brazil and Indonesia, which reported more than 10 000 cases.⁷

In European Union countries, only a small number of leprosy cases are reported each year.^{9–11} Autochthonous transmission is infrequent; the last confirmed case of transmission within the UK was in 1954.¹² A report from France, however, suggests that transmission in a western European country can still occur.¹³ Leprosy has been a notifiable disease in England since 1951 but, due to low incidence, the importance of national surveillance has been perceived to be low and under-reporting is likely to have occurred.¹⁴ Notification of cases ensures that patients are referred to clinicians experienced in leprosy diagnosis and treatment (known as Consultant Advisors in Leprosy in the UK), and that timely contact tracing around infectious cases is carried out. Surveillance data are also important for monitoring the disease burden and epidemiology of UK leprosy to allow appropriate targeting of resources.

To improve leprosy case management and notification, Public Health England (PHE) has revised the Memorandum on Leprosy, which was previously published in 1997.¹⁵ This provides guidance updates on diagnosis and treatment of patients with leprosy,



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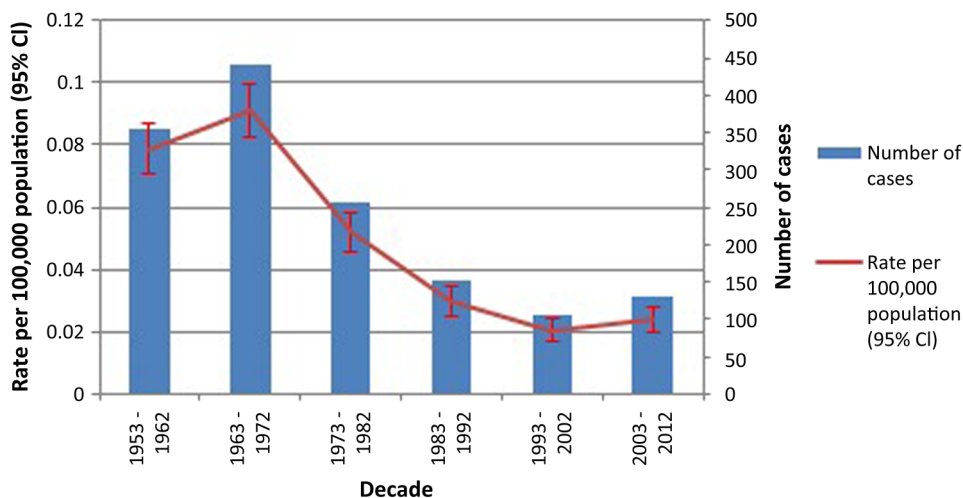
together with case notification procedures and surveillance.⁴ This report reviews the current epidemiology of leprosy in England and Wales, the shortcomings in recent surveillance and the measures implemented to strengthen surveillance and control of this rare infectious disease.

METHODS

All notified cases of leprosy in England and Wales between 1953 and 2012 were reviewed using national surveillance data held by PHE.¹⁴ Sociodemographic and clinical details are collected by PHE centres in close liaison with the managing clinician using the standardised leprosy notification form and include age, sex, country of birth and type of disease. An audit of data was carried out for the years 2001–2012 to determine completeness of case numbers, given concern about under-reporting during this period. This was done by cross-referencing the numbers reported in the national leprosy database with data from specialist leprosy centres. Additional cases identified from these centres were added to national surveillance if they had not originally been reported, but sociodemographic and clinical details were not available for these patients.

Incidence rates per 100 000 population were calculated using Office for National Statistics mid-year population estimates as denominators¹⁶ (2011 estimates were also used for 2012) and presented with 95% CIs. Proportions and numbers of cases reported between 1953 and 2012 were calculated. Figures by type of disease (tuberculoid/borderline tuberculoid (few skin lesions containing low numbers of bacilli) and lepromatous/borderline lepromatous (a more infectious form where numerous lesions and bacilli are present)) and demographic characteristics were presented for 1983–2012, where data were available. Significant changes in the number of leprosy notifications over time were examined using a χ^2 test for trend. *p* Values of less than 0.05 were considered statistically significant. Statistical analyses were performed using STATA V.12.0.

Figure 1 Case reports and rates reported to national leprosy surveillance, England and Wales, 1953–2012 (N=1449).



RESULTS

Between 1953 and 2012, a total of 1449 leprosy cases were notified in England and Wales. The incidence fell from 356 new cases notified between 1953 and 1962 compared with 139 new cases between 2003 and 2012 (χ^2 test for trend $p < 0.01$). Rates decreased from 0.079 (95% CI 0.071 to 0.087) new cases per 100 000 population in 1953–1962 to 0.024 (95% CI 0.02 to 0.028) new cases per 100 000 population in 2003–2012. The decline in rates and numbers of cases has slowed compared with the large decreases seen between 1963–1972 and 1983–1992 (figure 1). Of the 159 cases reported between 2001 and 2012, 57.8% (92/159) had not been notified and were identified as a result of the audit. Despite this, all of these patients were treated by a specialist leprosy clinician.

Between 1983 and 2012, 396 leprosy cases were reported in England and Wales. For cases with known clinical information, 44.7% (119/266) were diagnosed with lepromatous or borderline lepromatous leprosy (figure 2). For those with a recorded sex at notification, 63.9% (182/285) were male, and of those with a known age, 64.6% (148/229) were aged 15–44 years. Almost 60% (128/222) of cases with a recorded country of birth were born in South Asia, with the most common countries being India (72) and Bangladesh (24).

DISCUSSION

The decreasing global trend in leprosy rates and notifications since the 1950s has also been seen in England and Wales. Despite this, as with the global figures, England and Wales leprosy incidence reductions have slowed in the last decade.^{2–6} The slight increase in case report numbers seen in 2003–2012, compared with 1993–2002, probably reflects under-reporting in the earlier decade; 82.6% (76/92) of the cases identified in the 2001–2012 audit were 2003–2012 cases (making 54.7% (76/139) of the 2003–2012 cases). Therefore, the 1993–2002 period is likely to have under-reporting as it did not have the same level of correction for missing cases.

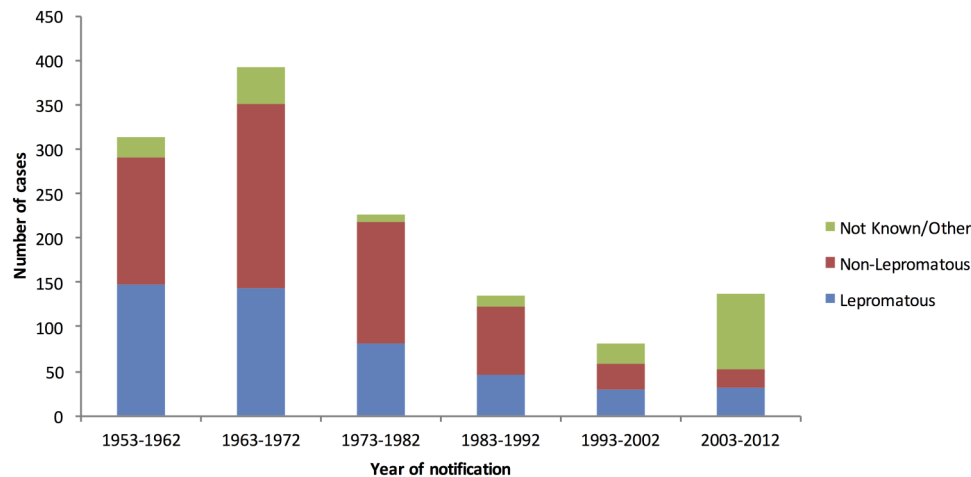


Figure 2 Number of leprosy cases by type, England and Wales, 1953–2012 (N=1449).

The high proportions of cases that were male and 15–44 years old may reflect the reported increased risk of leprosy in men after puberty,¹⁷ or alternatively the demographic features of immigrants to the UK from high incidence countries. The large proportion of UK patients with leprosy that were born in South Asia reflects the high levels of migration from this region compared with other world regions, together with the high leprosy burden in these countries.⁶

The significant level of under-reporting in 2001–2012 highlights the current shortfalls in leprosy surveillance and reporting systems in the UK. This may have implications for case management and resource distribution in the future, particularly if the lack of complete surveillance and clear protocols for leprosy cases contributes to low clinical expertise, and misdiagnosis/underdiagnosis of cases. Although not reported to PHE by the clinician making the initial diagnosis, the cases identified during the audit had been managed by a Consultant Advisor in Leprosy. This suggests that although diagnosing clinicians appeared to be aware that patients should be treated by a specialist physician, they were unaware of the requirement to notify or the notification procedure.

Owing to the rarity of leprosy in the UK, however, and consequent low clinical awareness, it is possible that further cases were not identified. These unidentified cases may not have received the highest standard of treatment, in view of the failure to refer to a Consultant Advisor in Leprosy, and appropriate contact tracing may not have been carried out.

In addition to a probable underestimate of total case numbers due to under-reporting, there is also a lack of UK data on key WHO indicators for assessing leprosy burden reduction, such as type of disease, and the presence of grade 2 disabilities (defined as visible damage to the hands and feet, such as wounds, claw hand and loss of tissue⁴). Despite surveillance data from the WHO indicating continued global decreases in leprosy prevalence and incidence, comprehensive surveillance on the key indicators from all world regions is also necessary to

monitor progress towards further burden reduction targets. Recent WHO reports indicate that leprosy data are not available for most of Europe, North America and numerous countries in Asia.¹⁸ This UK report and audit of cases will contribute to European figures for WHO assessment, and highlights the potential for other European countries to provide similar data. Complete case reporting in other parts of Europe will also enable a better understanding of the impact of changes in countries with the highest leprosy burden and shifting migration patterns over time on the epidemiology of leprosy in Europe.^{10 11 19}

As the incidence of leprosy further decreases, there is a risk that the number of clinicians with expertise in its management will diminish.²⁰ Future clinical training in leprosy management needs to be addressed in the UK and across Europe if a high standard of patient care is to be maintained.

As leprosy is rare in the UK, it is important to increase healthcare workers' awareness of the disease to ensure that patients do not experience stigma and delayed diagnosis.^{10 20 21} Increased clinical understanding will allow rapid diagnosis and appropriate treatment from, or in conjunction with, an experienced Consultant Advisor in Leprosy. This will help reduce the likelihood of severe neurological damage and grade 2 disabilities and ensure that timely contact tracing around infectious cases is carried out to prevent the possibility of onward transmission. Public and healthcare worker access to updated leprosy information, and clear guidance on public health action around leprosy, will enable an increased understanding of leprosy and its low infectiousness. This will help to consolidate efforts by leprosy organisations to dispel stigma around leprosy.^{10 22 23}

PHE, in collaboration with the UK Panel of Leprosy opinion, has revised the Memorandum on Leprosy⁴ in order to provide the most up to date national guidance on diagnostic procedures, treatment, case management, contact tracing and notification. In addition to a recommended code of practice for case management and

notification, it outlines the natural history of leprosy, and lists contact details of specialist Consultant Advisors in Leprosy and sources of further information. The Memorandum outlines steps that have been taken to strengthen and simplify national surveillance while safeguarding patient confidentiality. The Memorandum is published on the PHE website and revised as needed to keep abreast of changes in advice on clinical and public health management as well as relevant changes to the health service.

The prevalence of leprosy in high-income countries is extremely low. Nevertheless, national surveillance systems need to be robust and reliable so as to identify all cases and reduce the likelihood, however unexpected, of onward transmission. Health services in low prevalence parts of the world, such as Europe, should continue to support the maintenance of clinical and public health expertise, surveillance, and research into leprosy in order to contribute to further reducing the global burden of leprosy.

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