

Towards zero leprosy

**Global Leprosy (Hansen's disease)
Strategy 2021–2030**



**World Health
Organization**

Towards zero leprosy

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Foreword



Over the past decade the world has made considerable progress in the battle against leprosy, also known as Hansen's disease. In 2019, just over 200 000 cases of leprosy were detected from 118 countries globally. Around 5% of cases had visible deformities at the time of diagnosis, equating to 1.4 per million population – a 40% reduction on the 2014 figure. Globally, the new child case detection rate was 7.9 per million children, marking a significant improvement on the 2014 rate of 10.1. Virtually all new cases can now be cured within six to twelve months.



The WHO Global Leprosy Strategy 2021–2030, which was developed through a consultative process with all major stakeholders, reflects these epidemiological changes. Whereas previous strategies focused on the “elimination of leprosy as a public health problem”, defined as less than one case on treatment per 10 000 population, the new strategy focuses on interrupting transmission and achieving zero autochthonous cases. In doing so, the Strategy aims to motivate high-burden countries to accelerate activities while compelling low-burden countries to complete the unfinished task of making leprosy history.

Notably, the Strategy is aligned with broader global health trends, including the move towards multi-disease service integration, digitalization and accountability, and addresses key challenges, such as human resource capacity, surveillance and antimicrobial resistance. The Strategy promotes innovative approaches such as the use of targeted active case detection and the potential introduction of a safe and effective vaccine, and calls on countries to develop “zero-leprosy roadmaps” and provide chemoprophylaxis to all contacts of confirmed cases. Crucially, the Strategy redefines the burden of leprosy to not only include persons in need of physical treatment and socioeconomic rehabilitation, but also persons suffering from the mental health impact of leprosy.

The implementation of the Global Leprosy Strategy 2021–2030 will drive rapid and sustained progress in all leprosy-endemic countries, advancing progress on the WHO Roadmap for Neglected Tropical Diseases 2021–2030 and the Sustainable Development Goal targets. A world with zero leprosy infection and disease, zero disability, and zero leprosy-related stigma and discrimination, is possible. Together we must act.

Dr Poonam Khetrapal Singh
Regional Director
WHO South-East Asia Region

Abbreviations

| | |
|-------------------------|---|
| AMR | antimicrobial resistance |
| BCG | <i>bacille Calmette-Guérin</i> |
| G2D | grade-2 disability |
| GPZL | Global Partnership for Zero Leprosy |
| ILEP | International Federation of Anti-Leprosy Associations |
| MB | multi-bacillary |
| MDT | multidrug therapy |
| <i>M. leprae</i> | <i>Mycobacterium leprae</i> |
| NGO | nongovernmental organization |
| NLP | national leprosy programme |
| NNN | NTD NGO Network |
| NTD | neglected tropical disease |
| SDG | sustainable development goal |
| TAG | Technical Advisory Group |
| WHA | World Health Assembly |
| WHO | World Health Organization |

Strategy at a glance

Long term vision: Zero leprosy: zero infection and disease, zero disability, zero stigma and discrimination

Goal: Elimination of leprosy (defined as interruption of transmission)

Global targets for 2030:

120

countries
with zero new
autochthonous
cases

70%

Reduction in
annual number
of new cases
detected

90%

Reduction in rate per
million population of
new cases with grade-2
disability (G2D)

90%

Reduction in rate
per million children
of new child cases
with leprosy

Strategic pillars and key components

1 Implement integrated, country-owned zero leprosy roadmaps in all endemic countries

- Political commitment with adequate resources for leprosy in integrated context
- National partnerships for zero leprosy and zero leprosy roadmaps engaging all stakeholders
- Capacity building in the healthcare system for quality services
- Effective surveillance and improved data management systems
- Monitoring of antimicrobial resistance (AMR) and adverse drug reactions

2 Scale up leprosy prevention alongside integrated active case detection

- Contact tracing for all new cases
- Preventive chemotherapy scaled up
- Integrated active case-finding in targeted populations
- Existing and potential new vaccines

3 Manage leprosy and its complications and prevent new disability

- Early case detection, accurate diagnosis and prompt treatment
- Access to comprehensive, well-organised referral facilities
- Diagnosis and management of leprosy reactions, neuritis and disabilities
- Monitoring, support and training in self-care
- Mental well-being through psychological care and therapeutic counselling

4 Combat stigma and ensure human rights are respected

- Adoption of the United Nations *Principles and Guidelines for elimination of discrimination against persons affected by leprosy and their family members*
- Inclusion of organisations and networks of persons affected by leprosy
- Amendment of discriminatory laws
- Interventions and processes to reduce and monitor leprosy-related stigma in communities
- Access to social support and rehabilitation

Research

The strategy includes a set of research priorities of key importance for this strategic period. Global and national investment in research are essential to achieving zero leprosy.

Development

November 2018: Request for input on 2030 targets for 2021–2030 NTD Roadmap and Global Leprosy Strategy sent to the WHO Technical Advisory Group (TAG) on leprosy and partners

February 2019: Online survey of National Leprosy Programmes (NLPs) and partners on possible 2030 targets

April 2019: WHO Global training of NLP managers from priority leprosy-endemic countries, Bangkok, Thailand

June 2019: International Leprosy Training Programme for Developing Countries, Tai'an, China

September 2019: Symposium "Innovations in Leprosy Control", Twentieth International Leprosy Congress, Manila, the Philippines

November 2019: WHO Training of NLP managers from hyper-endemic island countries, Pohnpei, Federated States of Micronesia

December 2019: National Conference on Zero Leprosy Initiative 2030, Dhaka, Bangladesh

April 2020: Set up of WHO Task force on definitions, criteria and indicators for transmission and elimination of leprosy

October 2020: Global consultation with NLP managers, partners, and affected persons on Global Leprosy Strategy 2021–2030

December 2020: Finalization of Global Leprosy Strategy 2021–2030

January 2019: First International Dermacon and 47th National Conference of the Indian Association of Dermatologists, Venereologists and Leprologists, Bengaluru, India

April 2019: Twelfth meeting of the WHO Strategic and Technical Advisory Group on Neglected Tropical Diseases (NTDs), Geneva, Switzerland

April-May 2019: E-mail feed-back on first draft strategy from technical experts in leprosy

July-September 2019: Leprosy chapter finalized in NTD Roadmap 2021–2030

September 2019: WHO side meeting in the Tenth NTD NGO Network (NNN) Conference, Liverpool, United Kingdom

November 2019: Sixteenth meeting of TAG-Leprosy, New Delhi, India

February 2020: WHO Informal consultation on defining criteria to declare elimination of transmission of leprosy, Mexico City, Mexico

June-August 2020: Consolidation of full document of Global Leprosy Strategy 2021–2030

November 2020: World Health Assembly (WHA) endorsement of the document Ending the Neglect to Attain the Sustainable Development Goals: A Road Map for Neglected Tropical Diseases 2021–2030

Overview and context

Leprosy is classified by WHO as one of twenty NTDs¹. Like other NTDs, its occurrence is often related to poor socio-economic conditions. It is a communicable disease, caused by *Mycobacterium leprae* (*M. leprae*)², with a long incubation period. Leprosy is likely transmitted by droplets from the nose and mouth during prolonged and close contact with untreated leprosy patients. It affects the skin and peripheral nerves and, if untreated, can progress to permanent impairments to the skin, nerves, face, hands and feet, and to disabilities and social exclusion. Stigma and discrimination have played a major role in leprosy for millennia; overcoming them is important to reach zero leprosy.

Following the successful introduction of multidrug therapy (MDT) in 1981, WHO strategies focused on reducing prevalence, initially to below 1 per 10 000 population, and then on further reducing new case detection, disability (especially among children), and stigma and discrimination³. Some countries have achieved very low case numbers and may have interrupted community transmission. In recent years, a single dose of rifampicin as preventive chemotherapy has proven effective in reducing the risk of leprosy in contacts of leprosy patients⁴. These developments have encouraged WHO to reset the target for leprosy as elimination, defined as no new autochthonous cases as a result of interruption of transmission¹. WHO is developing standard operating procedures to verify elimination of transmission, in which a key element will be a commitment to post-elimination surveillance. Incorporating the goals of zero disability and zero discrimination, this strategy is boldly entitled ***Towards Zero Leprosy***.

The ***Global Leprosy Strategy 2021–2030*** is one of the disease-specific strategies underpinning the WHO *Road map for NTDs 2021–2030*. The leprosy profile from the NTD Road map is attached in Annex 1. The road map, its companion documents and the related strategies are a significant contribution to the Sustainable Development Goals (SDGs), especially SDG 3 (healthy lives and wellbeing, including the goal of universal health coverage), SDG 10 (reduced inequalities) and SDG 17 (partnerships). The commitments of the SDGs are to leave no one behind and to endeavour to reach the furthest behind first⁵. Through the combination of disability and stigma, persons affected by leprosy are consistently among the most left behind. This strategy sets out to challenge and change that.

The role of partners, at global and country level, is significant. The formation in 2018 of the Global Partnership for Zero Leprosy (GPZL)⁶ has been a major step forward in aligning the efforts and priorities of partners and stakeholders throughout the leprosy world. Its Leadership Team includes representatives of NLPs, the private sector, nongovernmental organisations (NGOs), donors, academia, organisations of persons affected by leprosy, and WHO's Global Leprosy Programme (as observer). The emergence of networks of persons affected, supported in recent years by the United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, has given them greater confidence and a stronger voice⁷.



Fundamental gaps in knowledge continue to impede progress. After a comprehensive review involving national programmes and scientists worldwide, GPZL and the Leprosy Research Initiative have developed a consensus set of research priorities⁸ which the wider leprosy community is urged to support.

This *Global Leprosy Strategy 2021–2030* presents the basic direction, goals, challenges and strategic pillars at a global level. National NTD and leprosy programmes in both high-incidence and low-incidence settings should adopt the global strategy, adapt its strategic pillars to the country context, and select targets and indicators appropriate to the country.

Achievements and current situation

In four decades since the introduction of MDT, 18 million people have been treated, bringing down the registered prevalence by more than 95%. In line with World Health Assembly Resolution WHA 44.9 (1991)⁹, global leprosy strategies focused initially on elimination of leprosy as a public health problem (defined as a registered prevalence of less than 1 case per 10 000 population). This was achieved at the global level in 2000. Subsequent five-year strategies focused on further reducing the disease burden through early detection and prompt treatment in the sustainable context of integrated services.

By 2015, the target of elimination as a public health problem had been achieved in almost all countries, at least at the national level. Factors underlying this achievement included political commitment, collaboration with major partners, and the free availability of MDT drugs. But the very slight downward trend in new case numbers was showing the limitations of a strategy reliant solely on case finding and treatment with MDT, and successive strategies had some (albeit limited) impact in reducing the physical, mental, social and economic consequences of leprosy on affected individuals and their families.

The WHO *Global Leprosy Strategy 2016–2020*³ sought to redefine disease burden in terms other than registered prevalence and the often misinterpreted ‘elimination as a public health problem’. New targets emphasised a decrease in child cases and new cases with G2D, thereby promoting early detection and reduction of transmission, and reduction in the stigma and discrimination experienced by persons affected by leprosy and their families. Table 1 shows the progress made towards the 2020 targets in the strategy.

Table 1: Progress towards the 2020 global targets

| Impact indicator | 2020 target | 2019 status |
|--|---|---|
| G2D rate in newly detected cases | < 1/million population | 1.4/million population |
| Newly detected child cases with G2D | Zero | Reported: 370 Estimated: 400-500 |
| Number of laws allowing discrimination on the basis of leprosy | Zero countries with discriminatory laws | 127 discriminatory laws in 22 countries ¹⁰ |

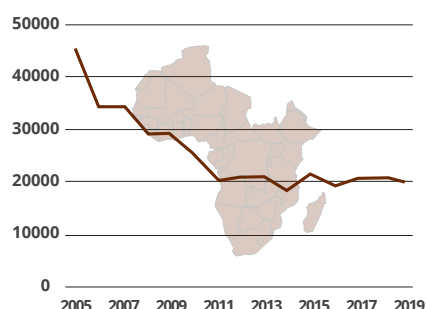
Leprosy data were reported by 161 countries in 2019¹¹. A total of 202 256 new cases were detected in 118 countries (26.0 per million population). Of them, 96% were reported by the 23 global priority countries¹², including 79% in India, Brazil and Indonesia. Sixty-six countries reported fewer than 100 cases.

Table 2: New case detection, by WHO Region, 2019

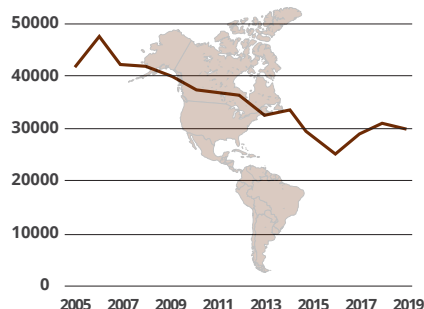
| Region | Countries reporting ≥ 1 case | New cases reported | | New child cases | | New cases with G2D | |
|-----------------------|------------------------------|--------------------|-------------------------------|-----------------|-----------------------------|--------------------|-------------------------------|
| | | Number | Rate (per million population) | Number | Rate (per million children) | Number | Rate (per million population) |
| Africa | 38 | 20,209 | 18.0 | 2,150 | 5.2 | 2,933 | 2.6 |
| Americas | 24 | 29,936 | 29.5 | 1,612 | 7.1 | 2,544 | 2.5 |
| Eastern Mediterranean | 15 | 4,271 | 5.8 | 149 | 0.68 | 254 | 0.35 |
| Europe | 6 | 42 | <0.1 | 0 | 0 | 4 | 0 |
| South-East Asia | 10 | 143,787 | 70.4 | 10,661 | 20.4 | 4,817 | 2.4 |
| Western Pacific | 25 | 4,011 | 2.1 | 411 | 1.1 | 264 | 0.14 |
| Total world | 118 | 202,256 | 26.0 | 14,983 | 7.9 | 10,816 | 1.4 |

Regional case detection, 2009-2019

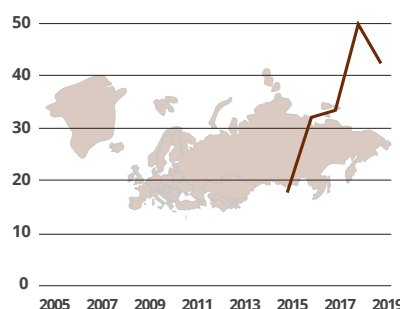
Africa



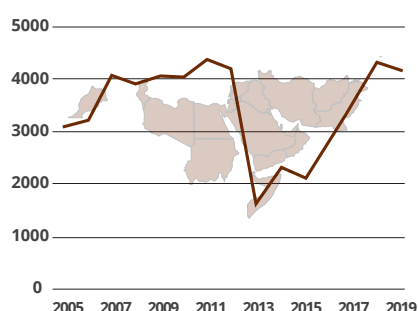
Americas



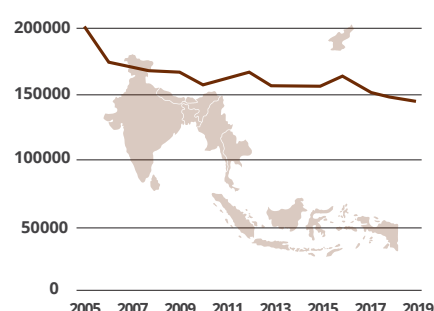
Europe



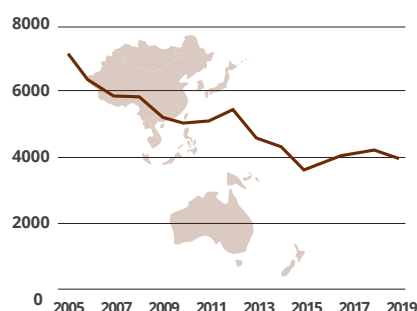
Eastern Mediterranean



South-East Asia



Western Pacific



In total 10 816 new cases in 94 countries, including 370 children, presented with G2D at the time of diagnosis, an indication of late diagnosis and lack of community awareness. The number of children is likely to be significantly higher, as some countries did not report data on G2D in children. The overall G2D rate was 1.4 per million population (down from 2.0 in 2014).

Of the new cases, 38.9% were female, and 7.4% were children. Detection of cases in children is considered an indicator of recent transmission of infection in the community. Globally, the new case detection rate for those aged 0 to 14 years was 7.9 per million children (down from 10.1 in 2014).

Only 47 countries reported treatment completion rates above 85%. Furthermore, 3897 relapses were reported by 54 countries – 44% of them in Brazil – up from 1175 in 2014. The increase may be attributed to better reporting though there are still weaknesses in diagnosing relapse. The relapse rate in leprosy appears low at around 1% over 5-10 years. Reports of AMR are rare. As there is limited availability of second-line drugs for leprosy, vigilance is needed to avert amplification of drug resistance.

In the absence of verifiable data, it is estimated that 3-4 million people are living with visible impairments or deformities due to leprosy. Because both the 'label' of leprosy and the disability it causes result in social exclusion in many communities, the number of people experiencing leprosy-related stigma is likely to be even greater. There are ongoing efforts to reduce discrimination, including to repeal all discriminatory laws and regulations in force. Fifty-six countries (35%) reported the availability of counselling services, an important provision because of the known mental health consequences of leprosy diagnosis, disability, stigma and social exclusion.

In 2018, WHO published evidence-based *Guidelines for the diagnosis, treatment and prevention of leprosy*¹³. This document recommends preventive treatment for contacts with a single dose of rifampicin. Subsequently WHO has published *Technical guidance on contact tracing and preventive chemotherapy* in 2020¹⁴. It is estimated that 25 million people can benefit from prophylactic interventions, initially with chemoprophylaxis. The Guidelines also address several areas of clinical uncertainty in the diagnosis, treatment and prevention of leprosy. In 2020, WHO published updated guidance on the management of leprosy reactions and neuritis¹⁵, and the *Guide for surveillance of antimicrobial resistance in leprosy* was updated in 2017¹⁶.

Leprosy and other NTD programmes need to be managed within the new reality of pandemics like COVID-19. Alongside WHO guidance¹⁷ on how to mitigate such situations, countries are advised to place more emphasis on e-learning, telemedicine, m-health and other innovative approaches to drive improvements to services whilst protecting staff and patients from risk.

Major challenges



Delay in detection is evidenced by the relatively high proportion of new cases with G2D. Causes may include lack of capacity to diagnose, lack of a point-of-care diagnostic test to detect leprosy infection or disease¹⁸, weak case finding and contact tracing programmes, lack of community awareness, and the stigma associated with leprosy.



Limited or dwindling capacity and leprosy expertise, especially clinical skills at all levels, are an issue in almost every endemic country, associated with loss of political attention and inadequate domestic funding. Inadequate laboratory services are also a risk to programmes.



Meaningful engagement of relevant stakeholders is still limited. There is often political apathy and lack of a comprehensive approach between government ministries. Organisations of persons affected by leprosy, a vital stakeholder, are still in their infancy in many countries. Greater interaction is needed with dermatologists, other private practitioners, and traditional healers.



Stigma and discrimination are deeply embedded in many communities, including healthcare settings, and result in exclusion and denial of human rights. Knowledge-based leprosy awareness programmes have proven insufficient to change community attitudes. The *Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members*, adopted by the United Nations, are seldomly incorporated into national policy frameworks.



There remain significant **research gaps**. The consensus research agenda published in 2019 by GPZL⁸ is a crucial contribution in terms of the evidence that needs to be generated towards the goal of zero leprosy. Ongoing interest and investment in research are essential.



There is **limited access or referral to essential care services** for leprosy complications including reaction management, reconstructive surgery, assistive devices, wound care and self-care training, physical and socio-economic rehabilitation, and counselling and psychological care services.



Routine surveillance systems are yet to be put in place by most countries, both for sparse or hidden cases and for post-treatment monitoring of nerve damage and other disabling complications.



Weak health information systems, including paper-based systems at the periphery, lead to poor data quality and gaps in recording and reporting of information on which decisions should be based.



Laboratories in several leprosy endemic countries monitor **antimicrobial resistance** (AMR). Resistance to first-line drugs appears low, but expansion of AMR monitoring is essential especially as post-exposure prophylaxis is scaled up.



Adverse drug reactions such as dapsone hypersensitivity are rare but potentially serious. Pharmacovigilance systems should monitor adverse reactions to anti-leprosy drugs, reaction treatments, post-exposure prophylaxis and potential vaccines.



Health emergencies such as epidemics, pandemics, conflicts or wars can overwhelm entire health systems and negatively affect leprosy services.



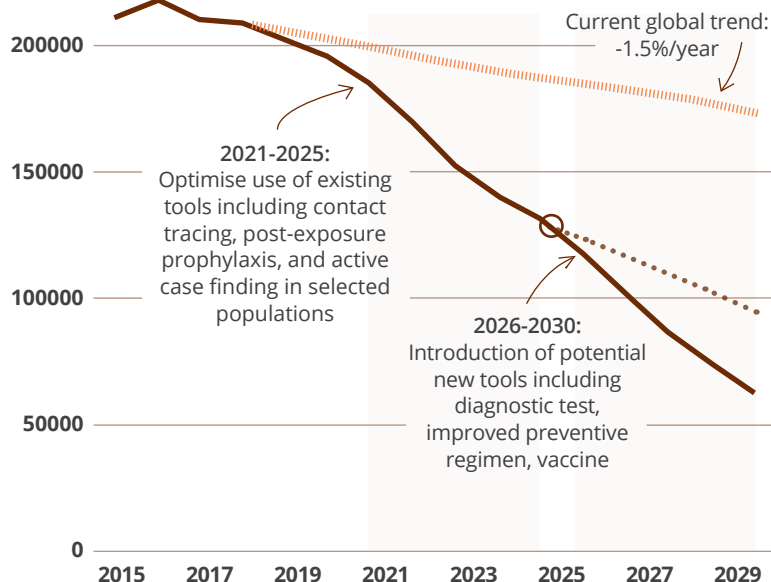
Zoonotic transmission of *M. leprae* by the nine-banded armadillo (*Dasypus novemcinctus*) has been demonstrated²⁰ but until now the risk appears low and highly localized. There is no evidence of transmission from other known animal reservoirs.



Migration has meant that some countries with no or no more autochthonous cases are reporting leprosy as an imported disease, with the potential risk of sub-sequent transmission.

Vision, goal, targets and pillars

Leprosy new case detection



Long term vision

Zero leprosy: zero infection and disease, zero disability, zero stigma and discrimination

Goal

Elimination of leprosy (defined as interruption of transmission/absence of disease)²¹

Global targets for 2030

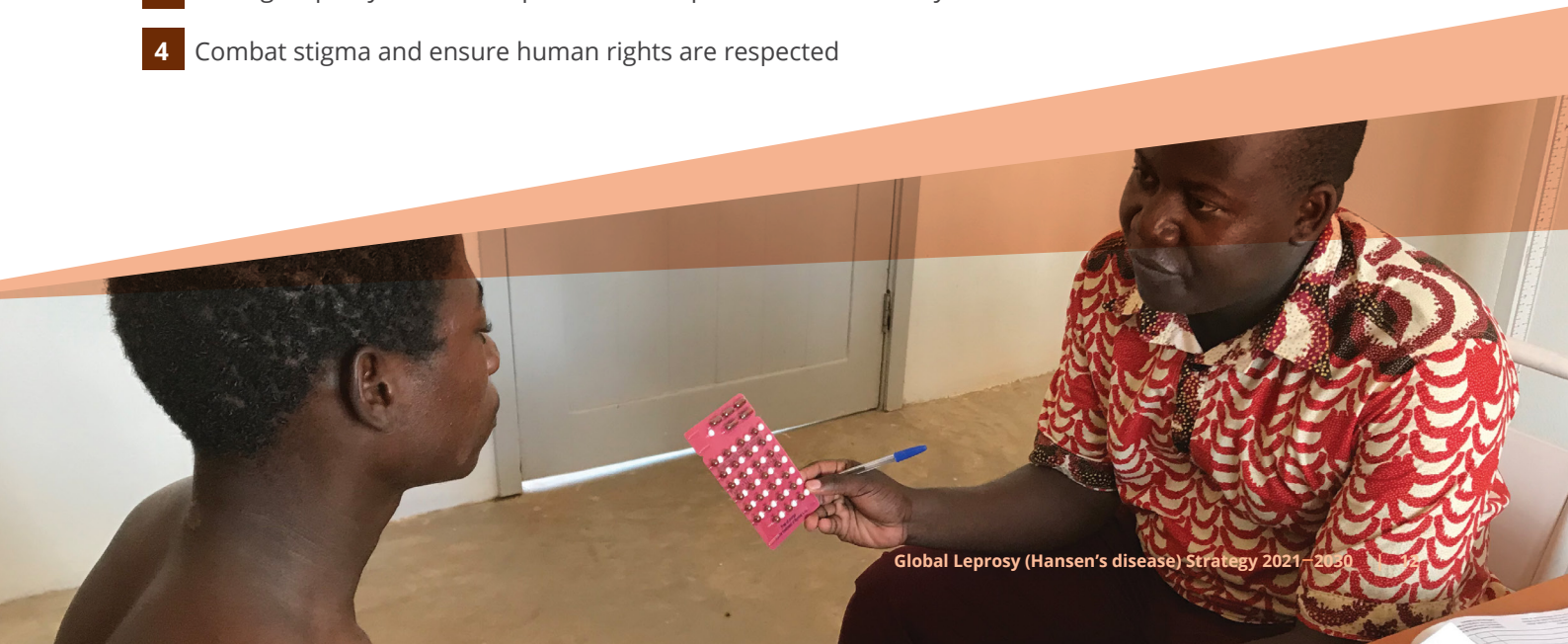
- 120 countries reporting zero new autochthonous cases
- 70% reduction* in annual number of new cases detected
- 90% reduction* in rate per million population of new cases with G2D
- 90% reduction* in rate per million children of new child cases with leprosy

* from 2020 projected baseline

These are global targets. Countries will set targets relevant to their own leprosy situation and baseline data in order to contribute to the achievement of global targets. Strategic evaluations will be undertaken by WHO after 2023 and 2025 to assess progress and consider the need for course corrections or amended targets.

Strategic pillars

- 1 Implement integrated, country-owned zero leprosy road maps in all endemic countries
- 2 Scale up leprosy prevention alongside integrated active case detection
- 3 Manage leprosy and its complications and prevent new disability
- 4 Combat stigma and ensure human rights are respected





Key research areas

Research topics considered to be of key importance for this strategic period:

- More effective approaches to active case detection in different contexts and levels of endemicity
- Innovative approaches to building capacity of health workers
- Tools for geospatial distribution of leprosy and surveillance mapping
- Improved preventive approaches including chemotherapy regimen and vaccines
- Tools for epidemiological and programme monitoring
- Diagnostic tests, including at community and point-of-care level, for disease and infection
- Impact of case finding and contact tracing strategies on the number of new cases with disabilities
- Optimized and new treatment options for reactions and nerve function impairment
- Diagnostic tools for detection and monitoring of nerve function impairment and reactions
- Improved understanding of the mechanism of leprosy reactions
- More effective drugs or drug combinations, or shorter regimens, to treat leprosy
- Improved understanding of transmission including host, agent and environmental factors and zoonotic transmission
- More effective drugs or drug combinations, or shorter regimens, to treat leprosy
- Effective models of care throughout the patient journey
- Digital health applications in leprosy
- Inclusive approaches in community-based rehabilitation and stigma reduction
- New technologies for wound care, orthosis, prosthesis and materials for footwear

Measuring progress and impact

Table 3 shows the high-level impact indicators for leprosy in the NTD Roadmap 2021–2030.

Table 4 is a list of indicators to monitor progress and impact in implementing the strategic pillars.

Table 3: Overall impact indicators

| Indicator | 2019 (Reported) | 2020 (Projected) | 2023 (Milestone) | 2025 (Milestone) | 2030 (Target) |
|---|--------------------|---------------------|---------------------|---------------------|------------------|
| Number of countries with zero new autochthonous cases | 34 | 50 (26%) | 75 (39%) | 95 (49%) | 120 (62%) |
| Number of new cases detected (disaggregated by sex and age) | 202,256 | 184,000 | 148,000 | 123,500 | 62,500 |
| Rate (per million population) of new cases with G2D | 1.40 | 1.30 | 0.92 | 0.68 | 0.12 |
| Rate (per million children) of new child cases with leprosy | 7.83 | 7.81 | 5.66 | 4.24 | 0.77 |

Table 4: Progress and key indicators for strategic pillars*Numerical person-based data should be disaggregated by gender*

| Key action | Indicator |
|--|--|
| PILLAR 1: Implement integrated, country-owned zero leprosy road maps in all endemic countries | |
| Political commitment | <ul style="list-style-type: none"> • Countries with established national partnerships for zero leprosy, incorporating government, development partners and persons affected by leprosy • Increasing share of leprosy budget financed by domestic sources |
| Zero leprosy roadmaps | <ul style="list-style-type: none"> • Countries implementing integrated, multi-stakeholder zero leprosy roadmaps • Countries including persons affected by leprosy in planning and implementation of leprosy programmes |
| Capacity building | <ul style="list-style-type: none"> • Strategy in operation to build and sustain leprosy capacity among health staff |
| Surveillance and data management | <ul style="list-style-type: none"> • Effective epidemiological and post-treatment surveillance systems functioning • Proportion of districts/municipalities that use digital mapping • Proportion of districts/municipalities using digital case-based data reporting system • Accurate data of patients with disabilities and of those at-risk at the end of treatment |
| Monitoring of AMR and adverse drug reactions | <ul style="list-style-type: none"> • System in place to test for possible drug resistance • Pharmacovigilance system in place to report on adverse drug reactions |
| PILLAR 2: Scale up leprosy prevention alongside integrated active case detection | |
| Contact tracing | <ul style="list-style-type: none"> • Proportion of new cases for which contact tracing and screening has been applied • Average number of contacts screened per index case |
| Preventive chemotherapy | <ul style="list-style-type: none"> • Proportion of screened contacts who received preventive chemotherapy |
| Active case-finding | <ul style="list-style-type: none"> • Active case-finding programmes in target populations |
| PILLAR 3: Manage leprosy and its complications and prevent new disability | |
| Early detection, diagnosis and treatment | <ul style="list-style-type: none"> • Number and proportion of new cases with G2D at the time of diagnosis • Number of new child cases, and number of new child cases with G2D • Number of relapses • Number of retreatments other than relapse • Number of multi-bacillary (MB) cases and proportion among new cases • MDT completion rate: MB cases, pauci-bacillary cases • Number of new non-autochthonous cases |
| Access to referral facilities | <ul style="list-style-type: none"> • Proportion of patients having access to referral services for diagnosis and treatment (where not available at primary level), management of complications and reconstructive surgery |
| Management of reactions, neuritis and disabilities | <ul style="list-style-type: none"> • Number of patients with worsening of disability grade during MDT treatment • Number of patients with worsening of disability grade after completion of MDT treatment • Number of patients in need of assistive devices |
| Self-care | <ul style="list-style-type: none"> • Proportion of patients given self-care counselling and information • Self-care groups implementing disability care activities • Number of patients that need hospitalization for ulcer care |
| Mental well-being | <ul style="list-style-type: none"> • Availability of psychological support at points of care • Availability of therapeutic counselling • Referral services to address mental health needs |
| PILLAR 4: Combat stigma and ensure human rights are respected | |
| Adoption of <i>Principles and Guidelines</i> | <ul style="list-style-type: none"> • Absence of legislation or regulations allowing discrimination on the basis of leprosy • Existence of positive norms or regulations facilitating social inclusion of persons affected by leprosy |
| Inclusion of persons affected by leprosy | <ul style="list-style-type: none"> • Existence of national or regional associations of persons affected by leprosy for self-help and advocacy |
| Stigma reduction | <ul style="list-style-type: none"> • Evidence of reduced stigma and increased social participation of persons affected by leprosy in the community (by using relevant tools) • Absence of reports of exclusion of persons affected by leprosy or their family members from health facilities, schools or other public services on account of leprosy |
| Social support and rehabilitation | <ul style="list-style-type: none"> • Access by persons affected by leprosy to social entitlements and community-based rehabilitation services |

Strategic pillar 1

Implement integrated, country-owned zero leprosy roadmaps in all endemic countries

Key components

- Political commitment with adequate resources for leprosy in integrated context
- National partnerships for zero leprosy and zero leprosy roadmaps engaging all stakeholders
- Capacity building in the healthcare system for quality services
- Effective surveillance and improved data management systems
- Monitoring of AMR and adverse drug reactions

Government ownership, national policies and strategies are the essential foundation for progress towards zero leprosy. Health, education, social development and law ministries may all share responsibility for leprosy activities, so continuous advocacy and communication within and across ministries are essential to the wellbeing of persons affected by leprosy during and after treatment. Cross-border collaboration may also be needed to ensure continuity of care and the interruption of transmission.

Attaining all SDGs and NTD goals is founded on strong partnerships initiated by governments with WHO, academic institutions, the private sector, local and international NGOs, community leaders and civil society organizations including organisations of persons affected by leprosy. Mechanisms such as national partnerships for zero leprosy should be established to ensure effective coordination between partners. Such structures will also enable ongoing focus on leprosy when it is mainstreamed into national health systems and integrated with other health conditions, such as skin NTDs and NTDs associated with ongoing disease management, disability and social exclusion. Partners and academia should collaborate on basic and operational research, in participation with persons affected by leprosy, to build the evidence base for better policies, strategies and programmes.

Zero leprosy roadmaps, integrated into national healthcare strategies, operate as a focus for the action of all stakeholders, in higher- and lower-endemic countries. They should be developed within a thorough, well-structured, government-led process supported by WHO and GPZL. The process involves an independent, in-depth situation analysis to identify gaps and priorities, development of a roadmap containing the steps and appropriate strategies and tools to reach zero leprosy in integrated contexts, and a monitoring and evaluation framework to enable progress to be measured. The national partnerships for zero leprosy should be involved in all stages of roadmap formulation, implementation and monitoring and evaluation. Leprosy, like other NTDs, must be included in budgets for domestic funding, sometimes supplemented through contributions by partners. Because leprosy incidence is not uniform across all subnational areas, roadmaps should incorporate a variety of strategic approaches relevant to sectors of the country with high, medium and low incidence.

Staff capacity is, for many countries, the severest obstacle to achieving zero leprosy. Strategies are needed to build and sustain the capacity of integrated public health and clinical services staff in all aspects of leprosy prevention, screening, diagnosis, treatment, management of complications, self-care, rights of persons affected by leprosy and their families, and programme management. Innovative, e-health approaches should be considered for training and capacity-building. Organisations of persons affected by leprosy, involved as partners, may encourage early identification of leprosy and improve treatment adherence. Laboratory capacity for microbiological analysis, including slit-skin smears, needs to be built up and maintained to support clinical diagnosis.

Routine surveillance systems need to be put in place in all countries to detect hidden cases and endemic clusters, and to monitor nerve damage, physical impairments and mental health issues during and after treatment. Effective data management, ideally based on digital, restricted-access, case-based health information systems including geolocation data, is needed to accurately record and report progress towards zero leprosy and enable sound, evidence-based programmatic decisions.

In line with WHO recommendations¹⁶, testing for AMR should be undertaken for all relapses and a sample of new and other retreatment MB cases, with the collaboration of expert laboratories in-country or elsewhere.

Integrated with other pharmacovigilance systems, data should be collected and reported on adverse reactions to drugs used in leprosy prevention, treatment and reaction management, as well as potential vaccines.

Strategic pillar 2

Scale up leprosy prevention alongside integrated active case detection

Key components

- Contact tracing for all new cases
- Preventive chemotherapy scaled up
- Integrated active case-finding in targeted populations
- Existing and potential new vaccines

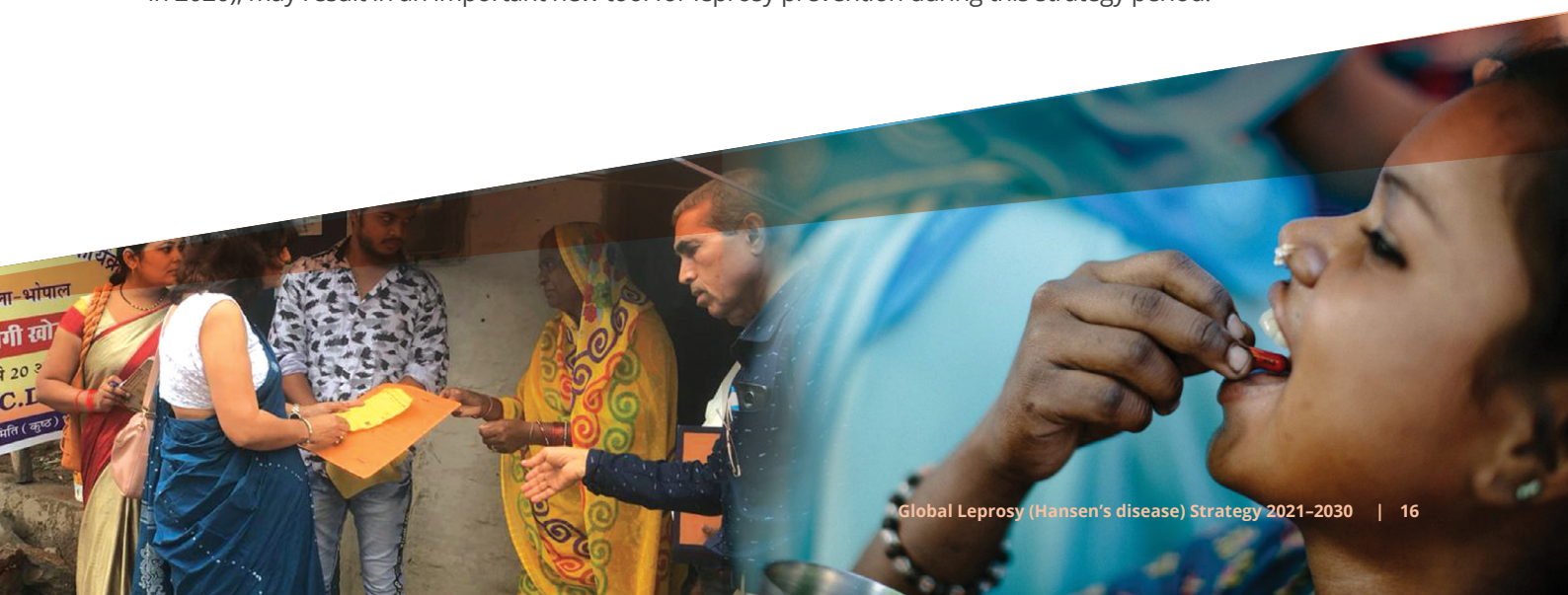
Passive case detection and treatment with MDT alone have proven insufficient to interrupt transmission. To boost the prevention of leprosy, with the consent of the index case, WHO recommends tracing household contacts along with 25-50 neighbours and social contacts of each patient, accompanied by the offer of a single dose of rifampicin as preventive chemotherapy¹⁴. Ongoing research may produce a more effective regimen during the period of the strategy. Up to five years' retrospective contact tracing will boost opportunities for case finding and prevention. Defined populations (such as islands, institutions, urban slums, villages or even districts) with known high transmission may benefit from 'blanket' preventive chemotherapy. Introduction of SDR chemoprophylaxis has proven to strengthen several routine programme components such as counselling, training, supervision, contact tracing etc.

Alongside its role in the prevention of leprosy, contact tracing is the most productive tool for finding new cases, and may be the key to leprosy control in the next ten years. In addition, active case-finding campaigns should be implemented in targeted populations such as areas of higher endemicity, 'silent' areas that are difficult to reach, or among at-risk groups. Where possible, contact tracing and case-finding should be undertaken in combination with other skin NTDs or other relevant diseases and accompanied by training for peripheral health workers. Effective case-finding may result in an initial rise in new case numbers.

Case-finding campaigns should be accompanied by innovative and well-targeted community information and awareness activities that combat myths and encourage early self-referral and positive attitudes towards persons affected by leprosy. Ideally, opinion leaders and persons affected by leprosy should be involved in these activities. Special attention should be given to ensuring that information and programmes are reaching women and girls, who may have reduced access to diagnosis and treatment due to cultural and other barriers. Data should be disaggregated by gender to verify this.

Countries reporting fewer than 100 new cases per year, and countries with low-incidence areas, need effective surveillance systems to respond to and investigate every new case. Contact screening, with the offer of preventive chemotherapy, should be routinely undertaken in these settings, and active case-finding may be considered in any clusters. These measures will enable low-incidence countries and areas to achieve and sustain the goal of zero transmission.

WHO recommends BCG vaccination at birth as an effective tool for reducing the risk of leprosy. Its use should be maintained, at least in countries or areas with a high leprosy burden. Repeat BCG vaccination for leprosy is not recommended²². Trials of other existing and potential new vaccines, including LepVax (which is in human trial phase in 2020), may result in an important new tool for leprosy prevention during this strategy period.



Strategic pillar 3

Manage leprosy and its complications and prevent new disability

Key components

- Early case detection, accurate diagnosis and prompt treatment with MDT
- Access to comprehensive, well-organised referral facilities
- Diagnosis and management of leprosy reactions, neuritis and disabilities
- Monitoring, support and training in self-care
- Mental wellbeing through basic psychological care and therapeutic counselling

Early case detection and prompt treatment with 6-12 months' MDT (dapsone, clofazimine and rifampicin) continue to be the mainstay of effective leprosy control. Countries have varying approaches to the integration of leprosy into healthcare systems. WHO recommends integrated skin NTD strategies where feasible²³, with active coordination in all relevant aspects of planning, management, programme implementation and monitoring and evaluation. In line with goals related to universal health coverage, mapping tools should be used, and surveillance systems developed, at sub-national as well as national level, to ensure detection of sporadic and hidden cases and monitor progress. Leprosy programme managers should engage with dermatologists, private practitioners and traditional healers and capture also their contribution when collating data. Close attention is needed to the supply chain, especially last-mile delivery, for MDT, prophylactic drugs, second-line drugs and drugs to treat leprosy reactions.

During MDT treatment, a significant proportion of patients experience complications such as leprosy reactions and nerve damage leading to new grade-1 (loss of sensation) and/or grade-2 disability (visible impairments). Health staff need training in nerve function assessment to recognise and treat or promptly refer signs and symptoms of leprosy reactions and neuritis. Well-organised referral systems should provide access to suitably resourced facilities that can manage reactions, offer wound care, deal with other complications such as damage to the eye, supply assistive devices such as tailor-made footwear along with training and advice on self-care, and offer reconstructive surgery with associated physiotherapy services. Careful attention should be given to ensuring equitable access to services by women and girls and, where necessary, supporting the costs of travel to the referral centre. A good understanding of referral pathways is essential, along with efficient communication between primary health units and referral services.

Major events that may occur after completion of treatment include leprosy reaction, neuropathic pain, recurrence of disease (relapse) and worsening of disabilities or occurrence of new disabilities. Although relapse is relatively rare, laboratory facilities are needed to confirm it and track relapse trends. Reactions, worsening of disabilities and new disabilities (particularly grade-1 progressing to grade-2) are relatively common, and negatively affect the quality of life and social participation of persons affected by leprosy. Thorough examinations including nerve function assessments and eye-hand-foot scores should be undertaken at the beginning and end of MDT treatment, followed by post-treatment surveillance, to identify, record, monitor and provide customised support for persons who at higher risk of developing reactions or worsening disability and need ongoing care and access to referral facilities¹⁵.

Ideally, prevention of disabilities should start with maintaining grade-0 (no disability) status by early recognition and treatment of leprosy reactions and neuritis. Nerve function impairment (grade-1) often manifests in eyes, hands and feet which are most used in daily activities of life and are prone to injuries and ulcer formations. These, if neglected, lead to infection, tissue loss and disfigurement. Persons at risk, and their family members, need to be informed about the signs of nerve involvement, trained in self-care and lifestyle modifications to prevent injuries and protect limbs and eyes, and encouraged to report to health facilities if required. These interventions may be integrated with similar services for other disabling NTDs. Access to clean water is important for routine self-care including daily soaking of hands and feet to prevent secondary disabilities.

Leprosy frequently causes emotional distress in affected persons and their family members and carers, and this can sometimes lead to more severe mental, neurological and social problems. Psychological care²⁴ should be available at all points of care, supported by referral to therapeutic counselling and other services promoting mental wellbeing²⁵. These services play a crucial role in enabling persons affected by leprosy and their family and community members to better understand the diagnosis and its impact, cope with stigma-related events and provide a supportive environment.

Strategic pillar 4

Combat stigma and ensure human rights are respected

Key components

- Adoption of *Principles and Guidelines for elimination of discrimination against persons affected by leprosy and their family members*
- Inclusion of organisations and networks of persons affected by leprosy
- Repeal or amendment of discriminatory laws
- Interventions and processes to reduce and monitor leprosy-related stigma in communities
- Access to social support and rehabilitation

Stigma and discrimination against persons affected by leprosy and their families are almost as old as recorded history. Effects may include social exclusion, loss of income, reduced access to healthcare and education, and reduced mental well-being. Changing beliefs and prejudices is not easy, though school children may be more receptive than adults to messages about changing behaviour and attitudes. Reduction in community prejudice promotes early detection of leprosy and improves acceptance of diagnosis and adherence to treatment and self-care practices.

The document *Principles and Guidelines for elimination of discrimination against persons affected by leprosy and their family members*¹⁹ was adopted by the United Nations General Assembly in 2011 and is shown in Annex 2. It provides a road map for states to meet and clarify their obligations under international human rights law through policy frameworks²⁶ that protect the rights of persons affected by leprosy. These policy frameworks should stimulate actions to combat prejudice and discrimination, including initiatives to improve the knowledge and attitudes of community and religious leaders and people employed in healthcare, education and social services. Facilitating contact between advocates among persons affected by leprosy and community members can be effective in reducing negative attitudes. There should be zero cases of persons affected by leprosy or their family members being excluded from health facilities, schools or other public services on account of leprosy.

Persons affected by leprosy should be encouraged and supported to form self-help groups, ideally including other persons with disabilities or facing social exclusion, for mutual support and resilience, advocacy, and the development of livelihoods and socioeconomic advancement. Initiatives should also be taken to nurture, support and strengthen the capacity of regional and national community-based organisations and networks of persons affected by leprosy, so that they can provide meaningful engagement on issues relevant to them at all decision-making levels^{27,28}. Financial provision may be needed to enable persons affected by leprosy to be active participants.

Laws and regulations allowing discrimination against persons affected by leprosy should be repealed or amended without delay and replaced with positive regulations and policy frameworks that facilitate the inclusion of persons affected in the community. Countries should use the available tools to collect data on the level of social exclusion in selected communities, and monitor over time to assess the impact of stigma reduction strategies which may be focused not only on leprosy but also on other stigmatised NTDs²⁹. Official processes should be in place to register and take action on reports of discriminatory behaviour. Special attention should be given to vulnerable populations including women, children, immigrants, refugees, the elderly, the homeless, residents of deprived leprosy 'colonies' and those living in geographically inaccessible areas.

An estimated 3-4 million people live with physical disabilities caused by leprosy, and potentially a greater number suffer stigmatisation and social exclusion. The social, emotional and economic impacts of leprosy are arguably a greater burden than the disease itself. Persons affected by leprosy need access to mainstreamed, community-based rehabilitation services focused on mitigating the effect of impairments, enabling livelihoods and optimising inclusion in the community³⁰. Access to a country's social entitlements and other welfare measures is also essential to reduce adverse socio-economic consequences, and to ensure appropriate care for older persons living with disabilities.





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Annex 1

WHO Road map for NTDs 2021–2030: leprosy profile

Leprosy (Hansen's disease)

Leprosy (Hansen's disease) is a communicable disease caused by the bacillus *Mycobacterium leprae*; the incubation period is long (average of 5 or more years). Untreated leprosy can lead to impairment, disabilities and exclusion.

Disease and epidemiology

- Leprosy (Hansen's disease) is a communicable disease caused by the bacillus *Mycobacterium leprae*; the incubation period is long (average of 5 or more years).
- The disease affects the skin and peripheral nerves and can cause permanent damage to the skin, nerves, face, hands and feet; untreated leprosy can lead to impairment, disabilities and exclusion.
- Infection is likely transmitted by droplets from the nose and mouth during prolonged close contact with untreated leprosy patients.¹
- Diagnosis of leprosy is mainly clinical.
- Stigma and discrimination play a major role in leprosy; overcoming them is important to reach zero leprosy.
- As with other NTDs, the occurrence of leprosy is often related to poor socioeconomic conditions.

Progress against WHO 2020 targets

| Impact indicator | 2020 target | Current status (2019) |
|--|---|--|
| Rate of grade 2 disabilities in newly detected cases/million | Below 1/million | 1.5/million |
| Rate of new grade 2 disabilities in new paediatric cases | Zero | 350 ³ |
| Number of laws allowing discrimination on the basis of leprosy | Zero countries with discriminatory laws | 39 discriminatory laws in 17 countries |

Core strategic interventions

| | |
|---------------------------------|---|
| Preventive chemotherapy | <ul style="list-style-type: none"> Post-exposure prophylaxis administered to all contacts of detected and consenting cases (single-dose rifampicin reduces the risk of leprosy among contacts by 60%²) |
| WASH | <ul style="list-style-type: none"> Access to clean water for wound care and routine self-care including daily soaking of hands and feet to prevent secondary disabilities; ensure hygiene, water and sanitation in health care facilities |
| Vector control | N/A |
| Veterinary public health | N/A |
| Case management | <ul style="list-style-type: none"> Early detection of cases is important to contain the spread of infection and prevent disabilities Multidrug therapy (MDT) lasting 6 to 12 months combines dapson, rifampicin and clofazimine Periodic monitoring, detection and treatment of immunological reactions (Type 1 and 2) and nerve damage Management of adverse drug reactions Counselling and psychological first aid Prevention of disability, wound care and management of disability including self-care Rehabilitation to optimize functioning of the individual in the community |
| Other | <ul style="list-style-type: none"> Early detection by active cases search (including contact screening), and prompt treatment with MDT or post-exposure prophylaxis, is important to contain the spread of infection and prevent disabilities Interventions addressing stigmatization and discrimination help to reduce their unfavourable consequences and promote inclusion of people affected or impacted into society Counselling and health education are essential to help leprosy patients, their families and communities to complete treatment and cope with physical and mental consequences |

WHO 2030 target, sub-targets and milestones

| Indicator | 2020 (provisional estimate) | 2023 | 2025 | 2030 |
|--|-----------------------------|----------|----------|-----------|
| Number of countries with zero new autochthonous leprosy cases | 50 (26%) | 75 (39%) | 95 (49%) | 120 (62%) |
| Annual number of new leprosy cases detected | 184 000 | 148 000 | 123 500 | 62 500 |
| Rate (per million population) of new cases with grade 2 disability | 1.3 | 0.92 | 0.68 | 0.12 |
| Rate (per million children) of new paediatric cases with leprosy | 7.81 | 5.66 | 4.24 | 0.77 |

¹ Up to 95% of the world's population has some immunity

² Single-dose rifampicin as a blanket approach can be used in areas characterized by small populations and hyper transmission

³ Figure based on incomplete data; estimate including all countries is 400–500 cases

SOURCE: All data sourced from WHO unless otherwise indicated

Burden of disease

202 256

new leprosy patients
diagnosed globally in 2019

14 983

new paediatric cases
diagnosed with leprosy
in 2019

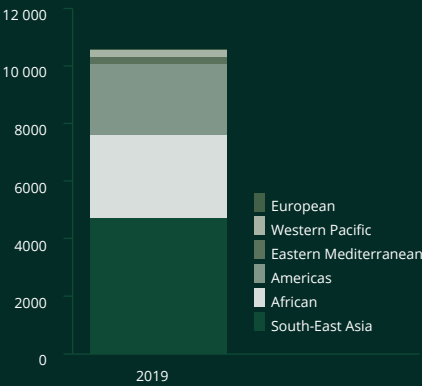
10 816

new leprosy patients with
grade 2 disability in 2019

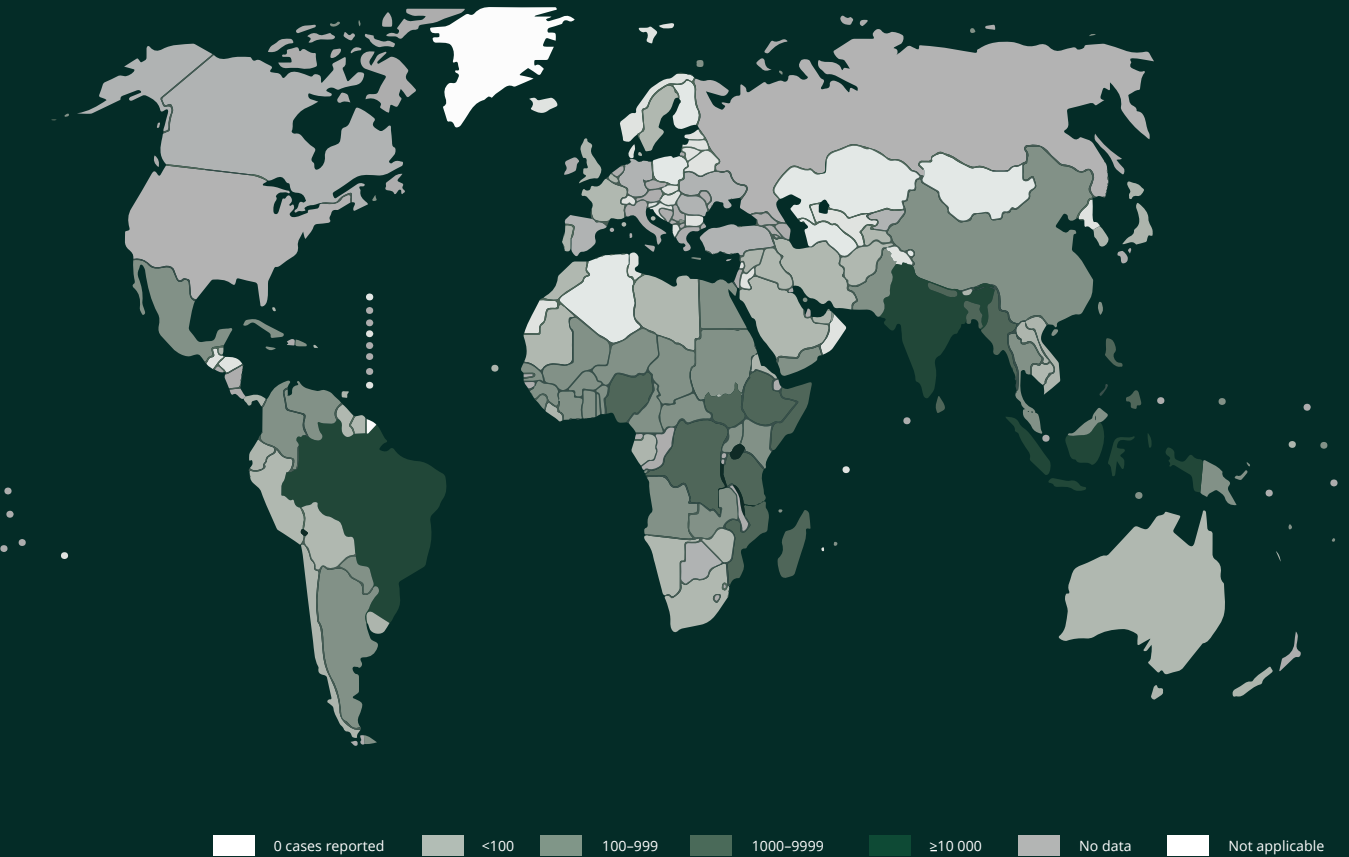
In 2019, leprosy was reported from 118 countries (including imported cases); 79% of the burden is in India, Brazil and Indonesia; 82 countries reported new cases with grade 2 disabilities.

About 30 million: estimated population at risk that needs to be treated with chemoprophylaxis to reach a 70% reduction in incidence by 2030.

Number of new leprosy patients with grade 2 disability (visible deformities) by WHO region, 2019



Number of new cases reported, 2019






Leprosy (Hansen's disease): assessment of actions required to meet 2030 sub-targets



Summary of critical actions to achieve targets

- Update country guidelines to include use of single-dose rifampicin for post-exposure prophylaxis for contacts; advance research on new preventive approaches.
- Continue investment into research for diagnostics for disease and infection; develop surveillance strategies, systems and guidelines for case-finding and treatment; ensure resources for validation.
- Ensure medicines supply, including access to MDT, prophylactic drugs, second-line treatments and medicines to treat reactions; monitor adverse events (pharmacovigilance) and resistance.
- Ensure capacity for case-finding (screening, diagnosis), treatment and surveillance; integrate with primary care, skin and other NTDs, TB and/or other programmes where appropriate.
- Combat stigmatization and discrimination to ensure access to services and inclusion in society; ensure human rights of leprosy-affected persons are respected.

| Category and current assessment | Current status | Actions required |
|---|--|--|
| Technical progress | | |
|  Scientific understanding | <ul style="list-style-type: none"> • Limited understanding of host, agent, and environmental factors • Mechanism of leprosy reactions not fully understood | <ul style="list-style-type: none"> • Improve understanding of transmission including transmission from animals to humans • Improve understanding of reaction development |
|  Diagnostics | <ul style="list-style-type: none"> • Mainly clinical diagnosis • Slit-skin smear available for some cases (limited access) • PCR is useful for diagnosis and surveillance of drug resistance • Serology allows detection of infection but its utility to predict disease progression is limited • Inadequate diagnosis of relapses | <ul style="list-style-type: none"> • Maintain and strengthen capacity for clinical diagnosis • Maintain access to and capacity for slit-skin smear • Develop a point-of-care test to confirm diagnosis and detect infection in the population at risk • Improve diagnosis of relapses |
|  Effective intervention | <ul style="list-style-type: none"> • MDT (a combination of rifampicin, dapsone and clofazimine) used as first-line treatment • Single-dose rifampicin to contacts of new patients provides ~60% protection but is not yet globally implemented • Limited information on antimicrobial resistance in leprosy; resistance of first-line medicines appears low • Tools exist to diagnose and manage nerve function impairment | <ul style="list-style-type: none"> • Explore more effective medicines or combinations of medicines to treat leprosy and leprosy reactions • Conduct research on other preventive approaches (e.g. improved chemotherapy and vaccines) • Swiftly implement new post-exposure chemoprophylaxis (rifampicin) • Expand active case detection in targeted populations • Include diagnosis and treatment of nerve function impairment as routine programme components • Encourage access to WASH |



For more details, please visit:
www.who.int/lep/en

No hindrance towards target

Critical action required to reach target

Target: elimination (interruption of transmission)

| Category and current assessment | Current status | Actions required |
|---|---|---|
| Strategy and service delivery | | |
|  Operational and normative guidance | <ul style="list-style-type: none"> Guidelines for the diagnosis, treatment and prevention of leprosy published (2018) Guide for surveillance of antimicrobial resistance in leprosy updated (2017) Global leprosy strategy (2016), operational manual (2016), monitoring and evaluation guide (2017) with strategies identified based on burden of disease Technical guidance on management of reactions and prevention of disabilities issued (2020) | <ul style="list-style-type: none"> Create surveillance strategies and guidelines for varied endemicity settings Develop validation/verification guidelines Update country guidelines where appropriate; integrate with WASH, skin NTDs and other programmes |
|  Planning, governance and programme implementation | <ul style="list-style-type: none"> Global Partnership for Zero Leprosy (2018) formed as a coalition committed to ending leprosy Countries are integrating leprosy with skin NTD programmes and into universal health coverage Ongoing efforts to reduce discrimination including abolition of discriminatory laws Countries have varying approaches to integration of leprosy | <ul style="list-style-type: none"> Development of global leprosy elimination plan While integration is occurring, ensure leprosy services continue regardless of the platform or approach used Reduce stigma to improve case-finding and treatment outcomes Enhance coverage of medical and social rehabilitation Support countries as they transition to low-burden stages |
|  Monitoring and evaluation | <ul style="list-style-type: none"> Roll-out digitalized case-based data management system is ongoing Mapping of cases is being introduced Integrated programme reviews are occurring, with focus on reviewing progress in reaching the leprosy programme targets Periodic monitoring for reactions is weak | <ul style="list-style-type: none"> Utilize mapping tools and strong surveillance system to ensure detection of sporadic and hidden cases and to monitor progress; improve notification systems Develop mechanisms to monitor adverse events Expand monitoring of antimicrobial resistance |
|  Access and logistics | <ul style="list-style-type: none"> Novartis donates MDT medicines and clofazimine for reactions; current commitment is until 2020 Limited availability of second-line medicines Limited availability of medicines to manage reactions Assistive devices to improve quality of life of persons affected by disabilities due to leprosy are mostly available but often with poor access | <ul style="list-style-type: none"> Bring drug supply chain systems in line with annual leprosy data Ensure supply of MDT, prophylactic medicines, second-line drugs and drugs to treat leprosy reactions Ensure availability of wound dressing materials Ensure access to assistive devices including tailor-made footwear Ensure unrestricted access to leprosy services for women and girls |
|  Health care infrastructure and workforce | <ul style="list-style-type: none"> Weak capacity of health care staff for diagnosis and management of leprosy, reactions, and morbidity and disability prevention Inadequate capacity of laboratories for diagnostic services Limited corrective surgery, wound care and disability care for persons with disabilities due to leprosy Limited access to mental health care services, counselling and psychological support | <ul style="list-style-type: none"> Increase capacity for diagnosis, treatment and management Increase laboratory capacity to support clinical diagnosis and resistance monitoring Increase capacity to conduct active case-finding and post-exposure prophylaxis Ensure access to wound care, reconstructive surgery and rehabilitation Offer counselling and mental health care services |
| Enablers | | |
|  Advocacy and funding | <ul style="list-style-type: none"> Despite increased domestic funding in several countries, many countries still depend on external sources of funding High-level advocacy to sustain interest in elimination of leprosy Ongoing promotion of interest and investment in research: clinical, basic and operational research | <ul style="list-style-type: none"> Advocate with central and local governments to sustain and increase domestic funding even in the post-elimination era Continue periodic evaluation and high-level advocacy to inform ministries on progress and gaps and to increase engagement Advocate for policy based on evidence from research Ensure the human rights of leprosy affected persons are respected |
|  Collaboration and multisectoral action | <ul style="list-style-type: none"> Global Partnership for Zero Leprosy (2018) coordinates and advocates for the leprosy community Variable collaboration with other ministries (e.g. social welfare, justice, education) Involvement of organizations of affected persons in many countries Collaboration with donors and partners in implementing programme Collaboration with communities to address stigmatization and discrimination Integration of leprosy programme with other health programmes is ongoing in specific countries | <ul style="list-style-type: none"> Closely integrate with universal health coverage/primary health care and community health worker efforts; coordinate with other relevant programmes for case detection, management and surveillance Optimize collaboration with other relevant sectors to increase reach of services and promote anti-discrimination measures Optimize involvement of organizations of leprosy affected persons Engage specialists including dermatologists and reconstructive surgeons Engage with private sector and traditional healers Engage with communities to combat stigmatization and discrimination |
|  Capacity and awareness building | <ul style="list-style-type: none"> Clinical expertise among frontline health workers is often insufficient Limited managerial capacity in the context of transition to low burden or decentralization | <ul style="list-style-type: none"> Ensure capacity of front-line and referral-level staff in screening, case-finding and treatment Strengthen the capacity of persons affected by leprosy Improve capacity to promote social inclusion and access to services Develop and disseminate e-learning modules Engage media in awareness raising |

Annex 2

Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members

Principles

1

Persons affected by leprosy and their family members **should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms** proclaimed in the Universal Declaration of Human Rights, as well as in other relevant international human rights instruments to which their respective States are parties, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.

2

Persons affected by leprosy and their family members **should not be discriminated against on the grounds of having or having had leprosy.**

3

Persons affected by leprosy and their family members **should have the same rights as everyone else with respect to marriage, family and parenthood.** To this end:

- No one should be denied the right to marry on the grounds of leprosy
- Leprosy should not constitute a ground for divorce
- A child should not be separated from his or her parents on the grounds of leprosy.

4

Persons affected by leprosy and their family members **should have the same rights as everyone else in relation to full citizenship and obtaining identity documents.**

5

Persons affected by leprosy and their family members **should have the right to serve the public, on an equal basis with others,** including the right to stand for elections and to hold office at all levels of government.

6

Persons affected by leprosy and their family members **should have the right to work in an environment that is inclusive and to be treated on an equal basis with others** in all policies and processes related to recruitment, hiring, promotion, salary, continuance of employment and career advancement.

7

Persons affected by leprosy and their family members **should not be denied admission to or be expelled from schools or training programmes on the grounds of leprosy.**

8

Persons affected by leprosy and their family members **are entitled to develop their human potential to the fullest extent, and to fully realize their dignity and self-worth.** Persons affected by leprosy and their family members who have been empowered and who have had the opportunity to develop their abilities can be powerful agents of social change.

9

Persons affected by leprosy and their family members **have the right to be, and should be, actively involved in decision-making processes regarding policies and programmes that directly concern their lives.**



Guidelines



1. General

- 1.1 States should promote, protect and ensure the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy. To this end, States should:
 - Take all appropriate legislative, administrative and other measures to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members, or that forcefully or compulsorily segregate and isolate persons on the grounds of leprosy in the context of such discrimination.
 - Ensure that all authorities and institutions take measures to eliminate discrimination on the grounds of leprosy by any person, organization or private enterprise.
- 1.2 States should take all appropriate measures to achieve for persons affected by leprosy and their family members the full realization of all the rights enshrined in the Universal Declaration of Human Rights and the international human rights instruments to which they are party, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities.
- 1.3 In the development and implementation of legislation and policies and in other decision-making processes concerning issues relating to persons affected by leprosy and their family members, States should consult closely with and actively involve persons affected by leprosy and their family members, individually or through their respective local and national organizations.



2. Equality and non-discrimination

- 2.1 States should recognize that all persons are equal before and under the law and are entitled, without any discrimination, to the equal protection and equal benefit of the law.
- 2.2 States should prohibit all discrimination on the grounds of a person having or having had leprosy, and should guarantee equal and effective legal protection to persons affected by leprosy and their family members.
- 2.3 Specific measures which are necessary to achieve de facto equality of persons affected by leprosy and their family members shall not be considered as discrimination.



3. Women, children and other vulnerable groups

- 3.1 In many societies, leprosy has a significantly adverse impact on women, children and other vulnerable groups. States should therefore pay special attention to the promotion and protection of the human rights of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.
- 3.2 States should promote the full development, advancement and empowerment of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.



4. Home and family

- 4.1 States should, where possible, support the reunification of families separated in the past as a result of policies and practices relating to persons diagnosed with leprosy.



5. Living in the community and housing

- 5.1 States should promote the enjoyment of the same rights for persons affected by leprosy and their family members as for everyone else, allowing their full inclusion and participation in the community.
- 5.2 States should identify persons affected by leprosy and their family members living in isolation or segregated from their community because of their disease, and should give them social support.
- 5.3 States should enable persons affected by leprosy and their family members to choose their place of residence and should ensure that they are not obliged to accept a particular living arrangement because of their disease.
- 5.4 States should allow any persons affected by leprosy and their family members who were once forcibly isolated by State policies in effect at the time to continue to live in the leprosariums and hospitals that have become their homes, if they so desire. In the event that relocation is unavoidable, the residents of these places should be active participants in decisions concerning their future. States should, however, improve living conditions in those leprosariums and hospitals. With due regard to the wishes of the persons affected by leprosy and their family members, and with their full participation, States should also design, promote and implement plans for the gradual integration of the residents of such places in the community and for the gradual phasing out of such leprosariums and hospitals.



6. Participation in political life

States should ensure that persons affected by leprosy, and their family members, enjoy voting rights, the right to stand for election and the right to hold public office at all levels of government, on an equal basis with others. Voting procedures must be accessible, easy to use and adapted to accommodate any individuals physically affected by leprosy.



7. Occupation

States should encourage and support opportunities for self-employment, the formation of cooperatives and vocational training for persons affected by leprosy and their family members, as well as their employment in regular labour markets.



8. Education

States should promote equal access to education for persons affected by leprosy and their family members.



9. Discriminatory language

States should remove discriminatory language, including the derogatory use of the term “*leper*” or its equivalent in any language or dialect, from governmental publications and should revise expeditiously, where possible, existing publications containing such language.



10. Participation in public, cultural and recreational activities

- 10.1 States should promote the equal enjoyment of the rights and freedoms of persons affected by leprosy and their family members, as enshrined in the Universal Declaration of Human Rights and the international human rights instruments to which they are party, including, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities.
- 10.2 States should promote access on an equal basis with others to public places, including hotels, restaurants and buses, trains and other forms of public transport for persons affected by leprosy and their family members.
- 10.3 States should promote access on an equal basis with others to cultural and recreational facilities for persons affected by leprosy and their family members.
- 10.4 States should promote access on an equal basis with others to places of worship for persons affected by leprosy and their family members.



11. Health care

- 11.1** States should provide persons affected by leprosy at least with the same range, quality and standard of free or affordable health care as that provided for persons with other diseases. In addition, States should provide for early detection programmes and ensure prompt treatment of leprosy, including treatment for any reactions and nerve damage that may occur, in order to prevent the development of stigmatic consequences.
- 11.2** States should include psychological and social counselling as standard care offered to persons affected by leprosy who are undergoing diagnosis and treatment, and as needed after the completion of treatment.
- 11.3** States should ensure that persons affected by leprosy have access to free medication for leprosy, as well as appropriate health care.



12. Standard of living

- 12.1** States should recognize the right of persons affected by leprosy and their family members to an adequate standard of living, and should take appropriate steps to safeguard and promote that right, without discrimination on the grounds of leprosy, with regard to food, clothing, housing, drinking water, sewage systems and other living conditions. States should:
- Promote collaborative programmes involving the Government, civil society and private institutions to raise funds and develop programmes to improve the standard of living
 - Provide or ensure the provision of education to children whose families are living in poverty by means of scholarships and other programmes sponsored by the Government and/or civil society
 - Ensure that persons living in poverty have access to vocational training programmes, microcredit and other means to improve their standard of living.
- 12.2** States should promote the realization of this right through financial measures, such as the following:
- Persons affected by leprosy and their family members who are not able to work because of their age, illness or disability should be provided with a government pension
 - Persons affected by leprosy and their family members who are living in poverty should be provided with financial assistance for housing and health care.



13. Awareness raising

States, working with human rights institutions, nongovernmental organizations, civil society and the media, should formulate policies and plans of action to raise awareness throughout society and to foster respect for the rights and dignity of persons affected by leprosy and their family members. These policies and plans of action may include the following goals:

- To provide information about leprosy at all levels of the education system, beginning with early childhood education affirming, inter alia, that leprosy is curable and should not be used as grounds for discrimination against persons who have or have had leprosy and their families
- To promote the production and dissemination of “know your rights” material to give to all persons recently diagnosed with leprosy
- To encourage the media to portray persons affected by leprosy and their family members with dignified images and terminology
- To recognize the skills, merits and abilities of persons affected by leprosy and their contribution to society and, where possible, to support exhibitions of their artistic, cultural and scientific talents
- To encourage creative persons, including artists, poets, musicians and writers, particularly those who have personally faced the challenges of leprosy, to make a contribution to awareness-raising through their specific talents
- To provide information to social leaders, including religious leaders, on how addressing leprosy in their teachings or written materials may contribute to the elimination of discrimination against persons affected by the disease and their family members

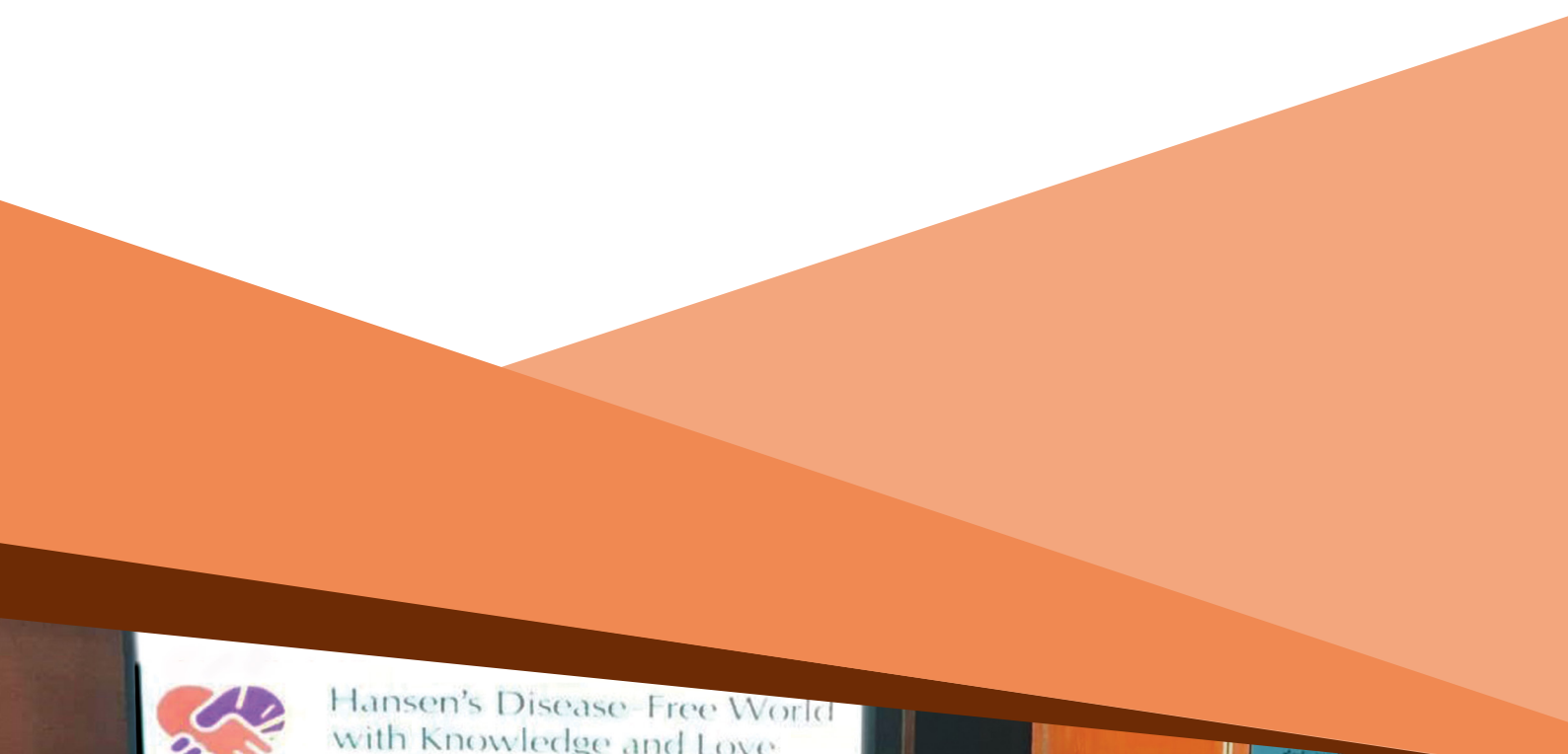
- To encourage higher education institutions, including medical schools and nursing schools, to include information about leprosy in their curricula, and to develop and implement a “train the trainer” programme and targeted educational materials
- To promote implementation of the World Programme for Human Rights Education and to incorporate the human rights of persons affected by leprosy and their family members into the national human rights education programme of each State
- To identify ways to recognize, honour and learn from the lives of individuals forcibly isolated by their Governments for having been diagnosed with leprosy, including oral history programmes, museums, monuments and publications
- To support grass-roots awareness efforts to reach communities without access to traditional media.



14. Development, implementation and follow-up to States' activities

- 14.1** States should consider creating or designating a committee to address activities relating to the human rights of persons affected by leprosy and their family members. The committee should ideally include individuals affected by leprosy and their family members, representatives of organizations of persons affected by leprosy, human rights experts, representatives from the human rights field and related fields, and representatives of government.
- 14.2** States are encouraged to include in their State party reports to the relevant treaty bodies the policies and measures that they have adopted and/or implemented with regard to the elimination of discrimination against persons affected by leprosy and their family members.





The Global Leprosy Strategy 2021–2030 “Towards zero leprosy” was developed through a broad consultative process with all major stakeholders during 2019 and 2020. Valuable inputs were provided by national leprosy programme managers, technical agencies, public health and leprosy experts, funding agencies and persons or members of communities directly affected by leprosy.

The Strategy aims to contribute to achieving the Sustainable Development Goals. It is structured along four pillars: (i) implement integrated, country-owned zero leprosy road maps in all endemic countries; (ii) scale up leprosy prevention alongside integrated active case detection; (iii) manage leprosy and its complications and prevent new disability; and (iv) combat stigma and ensure human rights are respected.

Interruption of transmission and elimination of disease are at the core of the Strategy.