



# Global consultation of National Leprosy Programme managers, partners and affected persons on Global Leprosy Strategy 2021–2030

Report of the virtual meeting  
26-30 October 2020



World Health  
Organization

Global consultation of National Leprosy Programme managers, partners and affected persons on Global Leprosy Strategy 2021–2030: Report of the virtual meeting 26-30 October 2020.

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## Abbreviations

AFR	WHO African Region
ALC	Anti-Leprosy Campaign (Sri Lanka)
ALM	American Leprosy Missions
ALO	Advancing Leprosy and disadvantaged peoples Opportunities Society (Bangladesh)
AMR	anti-microbial resistance
AMR	WHO Americas Region
APAL	Association of People Affected by Leprosy (India)
ASHA	accredited social health activist
BCG	<i>bacille Calmette-Guérin</i>
COVID-19	coronavirus disease 2019
DNA	deoxyribonucleic acid
DR Congo	Democratic Republic of the Congo
EMR	WHO Eastern-Mediterranean Region
ENAPAL	Ethiopian National Association of Persons Affected by Leprosy
EUR	WHO European Region
G2D	grade-2 disability
GLP	Global Leprosy Programme
GLRA	German Tuberculosis and Leprosy Relief Association
GPZL	Global Partnership for Zero Leprosy
HQ	headquarters
IDEA	Integration, Dignity and Economic Advancement
IEC	information, education, communication
ILEP	International Federation of Anti-Leprosy Associations
LEPRA	British Leprosy Relief Association
LRI	Leprosy Research Initiative
MB	multi-bacillary
MDT	multidrug therapy
MORHAN	Movement of Reintegration of Persons Afflicted by Hansen's Disease (Brazil)
NGO	nongovernmental organization
NTD	neglected tropical disease
NLP	national leprosy programme
NLR	Until No Leprosy Remains
PAHO	Pan-American Health Organization
PB	pauci-bacillary

PCR	polymerase chain reaction
PEP	post-exposure prophylaxis
PLF	Pacific Leprosy Foundation
SDG	sustainable development goal
SDR	single-dose rifampicin
SEAR	WHO South-East Asia Region
SHF	Sasakawa Health Foundation
TAG	Technical and Advisory Group
TB	tuberculosis
TFCEL	Task Force on definitions, criteria and indicators for transmission and elimination of leprosy
TLM	The Leprosy Mission
TLMTI	The Leprosy Mission Trust India
TNF	The Nippon Foundation
UHC	universal health coverage
UN	United Nations
WASH	water, sanitation and hygiene
WHO	World Health Organization
WPR	WHO Western Pacific Region





## 1. Inaugural session

No fewer than 450 participants, representing the vast majority of Member States of the World Health Organization (WHO) and nongovernmental organizations, experts and persons who have experienced leprosy, attended the virtual *Global consultation with National Leprosy Programme (NLP) managers, partners and persons affected by leprosy on Global Leprosy Strategy 2021–2030*. The meeting started with a welcome note by Dr Erwin Cooreman, Team Leader of the Global Leprosy Programme (GLP) of WHO. The consultation was held virtually due to travel restrictions caused by the coronavirus disease (COVID-19) pandemic. The consultation was split in two groups. The ‘East’ session mainly covered participants in the WHO South-East Asia and Western Pacific Regions; while the ‘West’ session covered participants from the WHO African, Americas, Eastern Mediterranean and European Regions. The two sessions followed the same agenda but took place at a different time. Each session lasted for 2.5 to 3 hours for four consecutive days. Translation into English, French, Spanish, Portuguese and Russian was provided for the ‘West’ session; while the ‘East’ session was conducted in English only. Due to time constraint and the limitations of the virtual meeting, participants were requested to make comments through the zoom chat box or send comments by email. All comments and feedback received would be taken into consideration while finalizing the strategy.

### 1.1. Inaugural address by the Regional Director, WHO South-East Asia Region



In her opening address, which can be viewed [here](#), Dr **Poonam Khetrapal Singh**, Regional Director, welcomed all stakeholders to the consultation on the draft Global Leprosy Strategy. She commended the success in progress made towards a leprosy-free world by all stakeholders. A steady decline in total new cases and new cases with visible deformities has been observed over the past ten years; while the stigma also appears to have reduced. Well-organized leprosy programmes, donation of multidrug therapy (MDT) medicines, sustained funding by donors, active participation of partners and persons who have experienced leprosy has led to this success.

The draft Global Leprosy Strategy covering the period 2021-2030 was aligned with the global Neglected Tropical Diseases (NTDs) Roadmap covering the same period. It was developed following numerous consultations over one and half year. She acknowledged the inputs provided by all stakeholders.

The strategy is more ambitious, shifting the paradigm towards “zero leprosy”, which includes zero leprosy-related disability and zero discrimination. The impact of COVID-19 also is considered along with several new ways to sustain programme implementation and inclusion of persons affected by leprosy. Participants were urged to consider evidence-based solutions, adapt innovations and promote the dignity of persons affected by leprosy while implementing the strategy.

## 1.2. Message by the WHO Goodwill Ambassador for Leprosy Elimination



In his recorded [message](#), Mr **Yohei Sasakawa**, WHO Goodwill Ambassador for Leprosy Elimination, commended the current draft of the Global Leprosy Strategy. He welcomed the concrete and ambitious target of a 70% reduction in annual number of new cases detected by 2030.

Mr Sasakawa has been engaged in the fight against leprosy for over 40 years, visiting endemic countries in order to convince them to allocate highest priority possible for leprosy. He has engaged with heads of state and governments, ministers for health and NLP managers. He visited hospitals as well as health facilities in remote areas and made it a point to always enter into a dialogue with patients, persons who have experienced leprosy, their families and the communities they live in. He cautioned for false optimism in so-called ‘silent zones’ where leprosy may remain undiagnosed for various reasons.

He welcomed this consultation as a forum for stakeholders to provide further inputs in the Strategy. He wished leprosy to be clearly linked to each country’s infectious disease control strategy and to efforts to strengthen the health sector to attain universal health coverage (UHC), covering the full spectrum from diagnosis to treatment and rehabilitation.

He urged all participants to work together to make this strategy a success.

## 2. Global leprosy situation

### 2.1. Overview of current global situation

Dr **VRR Pemmaraju**, Technical Officer GLP, provided an overview of the current global leprosy situation. His presentation, which can be accessed [here](#), was largely based on most recent data provided by Member countries covering the year 2019.



The 2019 annual leprosy data report was published in the WHO Weekly epidemiological record of 1 September 2020. It contains data submitted by 160 Member States, including all priority countries. A significant improvement in data quality has been observed since 2013.

Forty-five countries reported zero cases and 33 reported less than 10 cases. On the other end of the spectrum, 16 countries reported more than 1000 new cases. India accounts for more than half of the 202 189 new cases detected globally, followed by Brazil (14%) and Indonesia (9%). Table 1 provides an overview of key leprosy indicators, by WHO Region. These indicators are also available in the Global Health Observatory.

Following discussions with NLP managers, experts and the Technical and Advisory Group (TAG) on leprosy, the population-based rates (i.e. prevalence rate, new case detection rate and grade-2 disability (G2D) rate among new cases) are now calculated per million population; while the child case detection rate is expressed per million children.

Trend analysis shows a clear decrease in number of new cases: from 299 036 cases in 2005 to 202 189 in 2019. The new case detection rate decreased from 46 per million to 26 per million during the same period. The trends of new case detection are not uniform in all regions. A heavy focus on active case detection in recent years has flattened or even reversed the declining trend in several regions. The proportion of cases with multibacillary (MB) disease has shown a slight increase over the past years. The proportion of female cases remains more or less at the same level, around 40%. The proportion and rates of children and G2D among new cases shows a consistent decline. The latter two indicators will be monitored closely through the next ten years to see reduction in transmission of infection.

**Table 1:** key leprosy indicators, by WHO Region, 2019

Indicator	AFR	AMR	EMR	EUR	SEAR	WPR	World
Prevalence	22,701	35,231	4,894	18	109,956	4,381	<b>177,181</b>
Prevalence rate (*)	20.3	34.7	6.7	<0.1	53.8	2.3	<b>22.8</b>
New case detection	20,209	29,936	4,211	42	143,787	4,004	<b>202,189</b>
New case detection rate (*)	18.0	29.5	5.8	<0.1	70.4	2.1	<b>26.0</b>
MB proportion (%)	81.4	78.8	66.2	73.8	58.2	85.6	<b>64.5</b>
Female proportion (%)	29.6	44.0	40.9	40.5	39.2	33.1	<b>39.6</b>
Child proportion (%)	10.6	5.4	3.5	0	7.4	10.2	<b>7.4</b>
Child rate (**)	5.2	7.1	0.7	0	20.4	1.1	<b>7.9</b>
G2D proportion (%)	15.3	8.5	6.1	9.5	3.4	6.6	<b>5.4</b>
G2D rate (*)	2.6	2.5	0.3	<0.1	2.4	0.1	<b>1.4</b>
Children with G2D	195	51	4	0	106	14	<b>370</b>

(\*) per million population    (\*\*) per million child population

Information about foreign-born (proxy for non-autochthonous cases) was asked since 2015. In 2019, 133 out of 160 countries responded. Globally there were 887 new foreign-born cases. An outlier is Nepal with 562 cases while Malaysia and the United Arab Emirates reported more than 50 foreign-born cases each. Twelve – mostly developed – countries reported only foreign-born cases while the share of foreign born-cases was more than 50% in an additional four countries.

As part of additional information, data on reactions was also sought. Globally, 13 602 type-1 reactions (reversal reactions) and 5277 type-2 reactions (*erythema nodosum leprosum*) were treated during 2019.

Following points also were identified from analysis of global leprosy situation:

- Sub-optimal treatment completion rates are reported by some countries. Consequently, a greater number of retreatment cases is also reported: almost 20 000, including 3897 relapses. These retreatment numbers will also need to be considered when forecasting MDT requirements.
- There are still 127 discriminatory laws while 111 instances of discrimination were reported. This calls for more concerted efforts to combat stigma at all levels and inclusion of persons affected by leprosy.

- Data management is improving but needs to be expanded to cover sub-national areas to ensure operationalization of strong disease surveillance system.
- COVID-19 has impacted all health programmes and leprosy control is no exception with re-purposing of staff, allocation of more local resources to the pandemic and travel restrictions imposed for most part of 2020. It is predicted that that the pandemic will continue to impact service delivery, MDT supply, care-after-cure and programme management.

The global leprosy situation calls for renewed efforts to bend the curve of new case detection, improve ownership by countries and include persons affected by leprosy.

## 2.2. Challenges faced in countries

Six NLP managers provided a presentation on the main challenges faced with leprosy control in their countries. They were: Brazil, Ethiopia, India, the Federated States of Micronesia, the Philippines and Somalia.

### 2.2.1. Challenges in implementation: Brazil

Dr **Gerson Fernando**, Director of the Department of Chronic Conditions and Sexually Transmitted Infections, Ministry of Health, shared the challenges faced by his country through a presentation which can be accessed [here](#).



Brazil's strategy to fight Hansen's disease is aligned with the WHO Global Leprosy Strategy. After comparing some epidemiological data on its specific context, Dr Gerson highlighted one key challenge: the development of a mathematical model that provides an estimate of undetected incident cases, which approximates reality, based on the list of variables available in the country's Notifiable Diseases Information System.

He also commented the on-going scientific efforts to strengthen diagnostics by developing and incorporating new serological methods as a promising method of screening and defining priority areas for preventive actions.

He further highlighted the challenge it faces in implementing an algorithm for periodic evaluation of contacts.

Finally, he shared the challenges faced in trying to implement a permanent and regular strategic stock of medicines for treatment to attend the national demand without depending on external factors and facing stockouts as it experienced several times.

### 2.2.2. Challenges in implementation: Ethiopia

Dr **Taye Letta**, Head of Ethiopia's National Tuberculosis and Leprosy Control Programme, made a presentation (accessible [here](#)) highlighting the main challenges in his country.



One of the high burden countries for leprosy, Ethiopia reported 3426 leprosy cases in 2012 financial year (Ethiopian calendar (corresponding to 8 July 2018 to 7 July 2019) which comprises: new cases (96%), MB cases (69%), children (15%) and G2D (14%). The disease trend in the country remains much stagnant during the last 20 years, after achieving the elimination of leprosy as a public health problem at the national level despite, though leprosy is increasingly confined to few pocket areas. The increasing trends in the G2D and child proportions, observed since 2013, are worrisome for NLP.

The country conducted an external end-term Tuberculosis/Leprosy programme review and stakeholder analysis using a people-centred framework. The following challenges and gaps were observed:

- ✓ Stagnation in the number of leprosy cases for the past two decades;
- ✓ Increasing trends in G2D rate among new cases and in the proportion of childhood leprosy cases since 2013;
- ✓ The quality of leprosy services is suboptimal due to inadequate funding;
- ✓ The COVID-19 pandemic is also negatively impacting leprosy control;
- ✓ Poor health seeking behavior
- ✓ Poor contact tracing activity and lack of prophylaxis;
- ✓ Inadequate capacity of health care providers to diagnose, manage and follow up of leprosy and its complications;
- ✓ Poor documentation on leprosy cases, disabilities due to leprosy and contact tracing in the routine health information system;
- ✓ High rate of retreatment cases due to treatment interruptions and misclassification or misdiagnosis.

### 2.2.3. Challenges in implementation: India

Dr **Sunil Gitte**, Joint Director, Central Leprosy Division, Ministry of Health and Family Welfare, gave an overview of the key challenges faced by India. His presentation can be accessed [here](#).



He briefly presented the goals of the National Leprosy Eradication Programme, epidemiological trends, status, programme activities, response related to COVID-19 in the context of leprosy and the challenges in implementation. For the financial year April 2019-March 2020, India reported a case detection rate of 81.3 per million

population. The proportion of children was 6.8% and of G2D among new cases 2.4%, the latter one corresponding to a rate of 2.0 per million. On 31 March 2020, the prevalence rate was 57 per million.

Challenges in leprosy control include continued emergence of new cases, late detection and quality of care. The country is confronted with a weak infrastructure and programme management, limited capacity and motivation of human resources and poor referral linkages. The programme continues to face remaining challenges of health seeking behavior of the population, access to health care services, stigma and integrating persons affected by leprosy in the mainstream of society.

#### **2.2.4. Challenges in implementation: Federated States of Micronesia**

The Federated States of Micronesia is yet to achieve the global target of 'elimination as a public health problem'. The [presentation](#) made by Dr **Mayleen Ekiek**, Medical Director National Communicable Diseases, Department of Health and Social Affairs, provided an overview of several challenges faced by the country. Micronesia is a country in the Pacific Ocean comprising more than 600 islands grouped in four states (Chuuk, Kosrae, Pohnpei and Yap). The population was estimated around 115 000 in 2020. In 2019, the country had a case detection rate of 1250 per million population and prevalence rate of 420 per million, witnessing one of the highest transmission rates in the world.



The country relies mainly on clinical findings to diagnose leprosy. Slit-skin smear services are fragmented and new staff are yet to be trained in this. Leprosy is managed together with tuberculosis (TB). The turnover of staff is also very high, resulting in a constant training gap.

The government funding for the programme is directed to four states and central staff relies on this funding for their monitoring activities. Additional funding is made available by the Sasakawa Health Foundation (SHF) and WHO while MDT drugs are donated. There are no nongovernmental organizations (NGOs) supporting leprosy control in the country.

Active case finding is especially challenging in the outer Islands due to very high transport cost (sea or air). Traditional beliefs and stigma lead to delay in diagnosis in many cases. The proportion of child cases is consistently high at over 25%. G2D is not high: only three cases have been reported from two states. There is no dedicated programme for rehabilitation. Recording and reporting is also challenging due to turn over of staff.

#### **2.2.5. Challenges in implementation: the Philippines**



The Philippines accounts for roughly half of all new leprosy cases in the WHO Western Pacific Region. The country faces particular challenges, which were elaborated by Dr **Julie Rubite**, NLP Manager, in a presentation which can be accessed [here](#).

The National Leprosy Control Programme is one of the oldest programmes of the Department of Health. Leprosy control got shaped by laws (e.g. *Republic Act*),



proclamations, presidential decrees and administrative orders. In 1998, the Philippines eliminated leprosy as public health problem. The targets of the *Global Leprosy Strategy 2016-2020* – zero new child cases with G2D, a G2D rate of less than 1 per million population and zero laws or legislations in place that allow discrimination on the basis of leprosy – have been achieved by the country. Though this is good news, it poses a challenge as the country did not formulate more ambitious targets in its *Medium-Term Plan 2017–2022*; the guiding principles of this plan are based on the objectives of the *Global Leprosy strategy 2016–2020*. The country has updated its national guidelines in line with the *WHO Guidelines for the diagnosis, treatment and prevention of leprosy (2018)*.

Leprosy is increasingly focalized in hot spots. Leprosy also continues to be diagnosed in children. ‘Elimination as a public health problem’ is yet to be achieved in several provinces and cities.

The presentation contained an analysis of the barriers along the patient’s pathway, resulting in delayed diagnosis and late treatment. To address this, active case detection is encouraged, especially contact tracing. It is, however, hampered by the low priority this receives by health care workers who have to handle multiple programmes and considering the fact that leprosy is not life-threatening.

While there are sufficient drugs in the country to treat all cases, local drug stock-outs happen, typically due to faulty forecasting and planning.

The country has an *Integrated Leprosy Information System*. Some areas, however, cannot yet be linked to this due to poor or unavailable internet connectivity, even though data entry can be done in an offline fashion; submission of paper-based reports is often delayed. Tracing patients who are transferred is also problematic. The NLP has issued *Guidelines on the Institutionalization of the Leprosy Alert and Response Network System*.

Leprosy services are provided by general health care workers, which are part of a system characterized by a high turnover. This requires frequent training or orientation of health care workers. The programme often depends on retired experts to facilitate such training courses.

Research in leprosy is also very limited, partly by lack of or limited funding. There is only one (nongovernmental) facility that conducts studies for antimicrobial resistance (AMR).

As in other countries, COVID-19 is also serious hampering leprosy services, for which *Interim Guidelines on National Leprosy Control Program during COVID-19* has been issued.

### **2.2.6. Challenges in implementation: Somalia**

Dr **Abdu Aziz Ahmed Adam**, National NTD Manager, Ministry of Health and Human Services, made a presentation on the recent development of leprosy control in Somalia and the challenges the country needs to overcome. His presentation can be accessed [here](#).



Somalia has been experiencing a protracted conflict (since 1991). In this context, the country could revive its NLP.

While prior to the conflict, leprosy cases were mainly found in pockets in the southern regions of the country, cases are increasingly reported from previously non-endemic regions. Population movement was believed to be the main reason behind this spread, due to conflict but also famine and drought.

In 2015, an NTD unit was established which includes also leprosy. During 2016 and 2017, five active screening activities were implemented during which 635 and 1576 new cases were detected, respectively. During 2017-2019, screening activities were expanded, resulting in a further increase in case detection to more than 2000 in 2019. All detected cases were treated with MDT. Activities were carried out in camps for internally displaced people. These included skin camps and community awareness sessions (e.g. media debates) to increase knowledge of leprosy among the community and reassure that treatment is readily available.

Before 2014, challenges were mainly related to the lack of a functional government agency responsible for programme. This also led to a lack of drugs, poor level of awareness among health care workers, poor community awareness, and a high level of stigma in the community. There is a general fear of leprosy cases with folk stories still being told. This fear also leads to cases hiding and reduced health seeking behavior.

After the re-establishment of the national programme in 2014, the main problem was the absence of national/central treatment center. The low level of knowledge of the disease and its management is still an issue among health workers, which is believed to be the reason behind misdiagnosis and poor care. Apart from medicines (which are donated), no preventative equipment is available such as protective wear. There is shortage of trained and dedicated staff for facility-based and outreach activities. The majority of the staff work on a voluntary basis. Domestic resources are very scant. Stigma remains high.

## 3. Global Leprosy Strategy 2021–2030

### 3.1. Current draft of the Global Leprosy Strategy 2021–2030



The presentation, made by Dr **Erwin Cooreman** and accessible [here](#), consisted of two parts: the process of development; and the draft strategy itself.

Though the *NTD Roadmap 2021–2030* covers well each of the 20 NTDs (including leprosy), WHO was advised to still develop a ‘stand-alone’ Global Leprosy Strategy. This was to be in line with the NTD Roadmap but extracts and magnifies what is relevant for leprosy. As such it increases the visibility for leprosy and will be useful for NLP managers, including those leprosy programmes which are combined with TB or diseases other than NTDs. Leprosy control contributes to at least three sustainable development goals (SDGs): SDG 3 (good health and well-being for people, which includes UHC or “leaving no one behind”), SDG 10 (reduced inequalities) and SDG 17 (partnerships for the goals).

The current draft was developed over the past 1.5 years. It started by soliciting potential targets to be reached by 2030, following which interventions were proposed. The work-in-progress has been shared



at several events, including WHO meetings and trainings as well as leprosy or NTD events organized by partners. Inputs were also received from TAG-Leprosy.

The strategy starts with providing an overview of achievements and describing the current situation (most recent epidemiological data are of 2019). Major challenges are also highlighted.

The vision is “zero leprosy”, which includes zero infection and disease, zero disability and zero stigma and discrimination. Over the next ten years, this strategy is expected to make a meaningful contribution towards this vision. Under goal, there is a paradigm shift from ‘elimination as a public health problem’ to ‘elimination’ (interruption of transmission or absence of new disease).

Key targets are: (i) 120 countries report zero new autochthonous cases; (ii) 70% reduction in annual number of new cases detected; (iii) 90% reduction in rate (per million) of new cases with G2D; and (iv) 90% reduction in rate (per million children) of new child cases with leprosy. These are global targets which several countries are expected to overshoot and other countries making significant progress towards. Reaching these targets globally will depend on optimizing the use of existing tools (especially in the first half of the strategy period) while new tools (e.g. diagnostic tests, vaccine) still need to be developed.

The strategy is built along four main pillars, which were elaborated during his presentation:

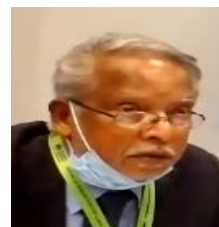
- Implement integrated, country-owned zero leprosy roadmaps in all endemic countries
- Scale up leprosy prevention alongside integrated active case detection
- Manage leprosy and its complications and prevent new disability
- Combat stigma and ensure human rights are respected

Key research areas have also been defined. Reference is made to Chapter 9 of this report.

In summary, the *Global Leprosy Strategy 2021–2030* provides basic directions, goals, challenges and strategic pillars at a global level. Countries – both high and low-burden – should adopt the strategy and then adapt its targets and strategic pillars to their specific national and subnational contexts.

### 3.2. General comments by the Technical and Advisory Group on Leprosy

TAG-Leprosy is the principal mechanism to advise the Regional Director of the WHO South-East Asia Region, who is the Head of WHO’s Global Leprosy Programme. In its meetings in June 2018 and November 2019 TAG reviewed the then iterations of the strategy and commended the progress made. Since then, members of TAG-Leprosy have continued to provide comments. Dr **Vijay Kumar Pannikar**, chair of TAG-Leprosy, summarized the group’s current position, as follows:



- The Strategy is in-line with the *Roadmap for NTDs 2021–2030*. Attaining the targets of the NTD roadmap will contribute significantly to the SDGs and UHC. TAG welcomes the integration

with skin NTDs and other disability NTDs, which may include combined TB/leprosy programmes.

- The strategic vision includes zero new cases, zero G2D, zero new child cases and zero stigma and discrimination against affected persons and their families.
- Leprosy control is now moving from “Elimination of leprosy as a public health problem” to “elimination or interruption of transmission”. TAG believes that the new status of leprosy as a disease marked for elimination of transmission will increase political commitment, increase donor support and motivate programmes to accelerate their efforts. In addition, mechanisms for verification of interruption of transmission which are already reporting zero new cases. This will require a post-elimination plan.
- TAG suggests prioritizing countries into two groups: (i) high endemic countries and (ii) countries which have already interrupted transmission or are close to reaching it.
- Addition of the new pillar on “prevention of leprosy” using the recommended tool for post-exposure prophylaxis (PEP) of leprosy among household and social contacts, is a significant supplement to the leprosy control, which was based, so far, solely on case detection and treatment with MDT. TAG is aware that there are ongoing studies on more effective preventive chemotherapy tools and leprosy vaccines, which may become available during the course of the strategy period and these would be incorporated during the reviews planned in 2023 and 2025.
- TAG believes that research on finding an effective and affordable diagnostic test is essential to achieve the 2030 targets and go beyond to eliminate leprosy and its transmission. Access to diagnostics can reduce morbidity by early detection and management to reduce progression and disability (both during and after antibiotic treatment) and reduce programme costs.
- TAG supports actions required to improve laboratory capacity, including capability for microbiological diagnosis (sampling, microscopy, networking for molecular diagnosis and drug resistance testing, histopathology) to be maintained to support clinical diagnosis.
- TAG recommends inclusion of leprosy in the global AMR and adverse drug reaction agenda for drugs used in the management of leprosy, leprosy reactions, preventive chemotherapy and anti-leprosy vaccines.
- TAG recognizes that eradication of leprosy is not feasible at this point in time due to presence of zoonotic reservoirs in some areas. Improved understanding of the mode of zoonotic transmission and its overall epidemiological significance will be important.

## 4. Global normative guidance documents

Two important global documents were presented as they have the potential to impact on global leprosy control in the next decade: (i) *Roadmap for Neglected Tropical Diseases (NTDs), 2021–2030*; and (ii) the *Global Framework for Multi-Disease Elimination*.

## 4.1. Roadmap for NTDs, 2021–2030

Dr **Gautam Biswas**, Head of the Strategic Information and Analytics unit in the Department of Control of NTDs, WHO-HQ, presented the *Roadmap for NTDs, 2021–2030*. His presentation can be accessed [here](#).



As the current NTD roadmap will end in 2020, there was a need to develop a new NTD roadmap to set overall direction to fight against NTDs until 2030. The roadmap can be accessed [here](#). The roadmap has been developed through an extensive consultative process, incorporating feedback from various stakeholder groups. It will be reviewed at the World Health Assembly in November 2020. Upon endorsement by Member States, it will become a solid document setting a high-level strategy giving the overall direction to fight against NTDs over the next decade.

The NTD roadmap encourages three fundamental shifts in the approach to tackling NTDs: (i) increase accountability by measuring impact on patients and communities; (ii) move away from siloed, disease-specific programmes by mainstreaming programmes into national health systems and intensifying cross-cutting approaches; and (iii) change operating models and culture to facilitate greater ownership of programmes by countries. The roadmap sets specific and measurable targets: four are overarching, ten cross-cutting and 56 disease-specific. Achieving these will contribute towards reaching SDG3.

The roadmap is an aid to policy and advocacy efforts that draw attention to key challenges across the 20 diseases and conditions. A gap assessment has been conducted for each NTD along three components and 11 dimensions to identify bottlenecks which require action if we want to achieve the 2030 targets. Looking at this 'heat map' enables to identify key critical cross-cutting areas. There is a strong focus on cross-cutting approaches, built on three pillars: (i) accelerate programmatic actions; (ii) intensify cross-cutting approaches; and (iii) change operating models and culture to facilitate country ownership. The NTD road map is a tool to facilitate alignment of efforts across stakeholder groups over the next decade. The role of stakeholders at all levels and in all sectors will be clarified.

Five companion documents are under development to help countries to implement the NTD roadmap; they are: *Sustainability Framework for Action*; *Investment Case*; *Monitoring and Evaluation Framework*; *Updated Strategy on Water, Sanitation and Hygiene (WASH) and NTDs*; and *NTD Research Portfolio*. The NTD roadmap is the overarching document for the Global leprosy strategy.

## 4.2. Global Framework for Multi-Disease Elimination

Dr **Richard Carr**, Adviser to the Assistant Director General for UHC and Communicable and Noncommunicable Diseases, WHO-HQ, presented the current draft of the document *Global Framework for Multi-Disease Elimination*. His presentation can be accessed [here](#).



More than 30 diseases have been targeted for elimination (including 13 NTDs, human immune-deficiency virus infection, hepatitis B and C and sexually transmitted infections) and four diseases have been targeted for eradication. Each disease area has

typically developed its own targets, strategies and processes according to the specific needs of each individual disease. This has led to a proliferation of elimination terminology, evidence requirements and confirmation processes (i.e. validation, verification, certification) that are used inconsistently or in contradictory ways across disease programmes. Additionally, many countries have multiple diseases targeted for elimination.

Without proper guidance, countries risk setting up a series of vertical elimination programmes. This represents a missed opportunity to identify and capitalize on synergies between programmes to address multiple diseases in a more coherent, holistic, people-centred approach in the context of UHC.

Recognizing some of these challenges, the Pan-American Health Organization (PAHO) adopted in 2019 a Regional framework to harmonize regional disease elimination approaches and targets. Based on the PAHO experience, WHO is now developing a *Global Framework for Multi-Disease Elimination*. This framework could be used for both communicable and some non-communicable diseases and conditions, including those not currently targeted for elimination. The framework would aim to guide actions at country, regional and global levels to facilitate and accelerate disease elimination efforts across multiple diseases at the same time.

The objectives of the Framework would be to:

- guide countries or regional organizations to develop integrated multi-disease elimination strategies, through a people-centred approach in the framework of UHC, based on global commitments and standards and adapted to the local context;
- identify programme synergies and optimize effectiveness, efficiency and impact through integrated approaches to multi-disease elimination that also address other health priorities;
- guide countries on how best to integrate elimination of multiple diseases or health conditions into broader national health and development strategies and plans according to local contexts, disease burden and other considerations – and to subsequently develop a locally appropriate ‘pathway to multi-disease elimination’;
- harmonize disease elimination definitions, governance structures and validation processes globally;
- provide an overview of all diseases currently targeted for elimination or eradication through WHO or other United Nations (UN) commitments or processes; and
- outline the potential roles and responsibilities of countries, WHO and partners to support multi-disease elimination efforts in countries and regions.

## 5. Contact tracing and post-exposure prophylaxis

### 5.1. WHO guidance and next steps

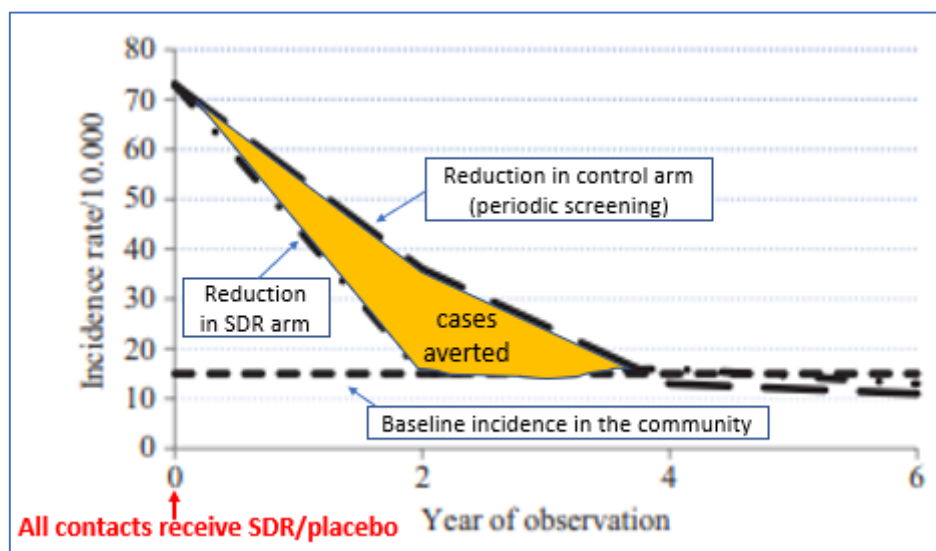
Dr **Erwin Cooreman** in his presentation (accessible [here](#)) clarified WHO’s position with regard to both contact tracing and post-exposure prophylaxis.

Contact tracing is a recognized form of undertaking active case detection in a group which is significantly more likely to have leprosy than the general population in both high and low-endemic countries. Among different types of contacts, household contacts have 3.5 more likelihood of having leprosy than social contacts and almost double that of neighbours. But even social contacts are 2.5 to 3 times more likely to have leprosy than the general population.

With regard to chemoprophylaxis, the *WHO Guidelines for the diagnosis, treatment and prevention of leprosy (2018)* recommends single-dose rifampicin (SDR) for contacts (adults and children above two years) after excluding leprosy and TB and in the absence of other contra-indications. This builds on adequate management of contacts and on the consent of the index case to disclose his or her disease. The guidelines were developed after a careful assessment of all available published evidence. WHO keeps on monitoring new evidence since its publication. Till date, no new evidence has emerged with the power to override the published guidance.

He highlighted the efficacy of SDR, based on the randomized controlled trial which led to the conclusion that SDR reduces the occurrence of leprosy among contacts and does so much faster than a scenario where only periodic screening and treatment of cases with MDT is undertaken (Figure 1).

*Fig. 1: Effect over time on incidence of SDR vs placebo given once*



Subsequent feasibility studies undertaken in several countries have demonstrated that PEP with SDR can be undertaken as a routine programme component. The intervention is considered as safe (so far no side effects have been reported); while the risk for resistance is also considered negligible. A collateral benefit was that it rejuvenated the entire leprosy programme in several settings.

WHO will publish a technical guidance document on contact tracing and chemoprophylaxis. This document will elaborate *how* to operationalize both interventions on a routine programme. It will cover the following chapters: counselling and obtaining consent; identification of index cases; listing, tracing and screening of contacts; administration of SDR; supply chain management; recording and reporting; implementation, monitoring and supervision; information, education and communication.

Chemoprophylaxis with SDR has the potential to accelerate reducing the incidence and will be more effective when combined with other interventions including early diagnosis (where contact tracing can help) as well as BCG vaccination.

## 5.2. Country perspectives on contact tracing and PEP

Representatives from NLPs from six countries presented their perspectives on contact tracing, PEP with single-dose rifampicin or both: Colombia, Ghana, India, Indonesia, Kiribati and the United Republic of Tanzania.

### 5.2.1. Country perspectives on contact tracing and PEP: Colombia

A presentation, which can be accessed [here](#), was made by Dr **Yesinia Castro**, NLP manager of Colombia.



Colombia has reduced the leprosy burden, leading to a case detection rate of around 7 per million population since 2015. In 2019, 319 new cases were reported. The highest endemicity is found in the eastern and north eastern parts of the country.

Colombia has a ten-year Strategic Plan for Leprosy, covering the period 2016-2025. Its goals are aligned with those of the *Global Leprosy Strategy 2016–2020*. The goal of zero new child cases with G2D has been reached.

For contact tracing and follow up, following are the main actions undertaken: (1) collection of additional information; (2) identification of close contacts; (3) identification of risk factors; (4) complete physical examination (dermatological, neurological and ophthalmological examination); (5) verification of BCG vaccination status and referral for vaccination if indicated. A single dose of BCG is given to contacts with a BCG scar, two doses with a 6-month interval is given if there is no BCG scar; (6) referral to health care provider if necessary.

After the initial visit, contacts will be visited after 6 and 12 months and then annually for five years (contacts of pauci-bacillary (PB) index cases) and seven years (contacts of MB index cases).

Achievements include: identification of weaknesses in the process; nominal registry of close contacts of index cases; standardization and implementation of national tools and forms; and timely diagnosis of leprosy among contacts.

Post-exposure prophylaxis is currently not done but is planned to start in 2021.

Other programmatic monitoring actions include: (1) follow up of progress towards the goals of the 2016-2025 National Plan; (2) strengthening follow up of contacts; (3) standardization of PEP procedures; (4) strengthening patient detection and provision of integral health care for patients; and (5) maintaining the necessary funding.



### 5.2.2. Country perspectives on contact tracing and PEP: Ghana



In his presentation, which can be accessed [here](#), Dr **Benedict Quao**, NLP Manager, first introduced the leprosy control programme of Ghana. Since its very inception in the late 1940s, the Ghana Leprosy Service aimed to reduce transmission as well as leprosy-associated disabilities. Ghana reached elimination as a public health problem in 1998 at the national level and in 2005 in all regions of the country. Leprosy services were gradually integrated into general health care services.

Passive case detection is the predominant mode of detection. Assuming that many cases remained undetected, the country implemented strategies to enhance case detection: enhance the index of suspicion among frontline health workers, increased public awareness and focused active case detection (population-based as well as contact tracing).

Case detection was hampered by absence of clear guidelines, non-systematic way of implementation, no dedicated fund. Following the publication of the *WHO Guidelines for the diagnosis, treatment and prevention of leprosy* in 2018, contact tracing got a boost, especially with the prospect of offering chemoprophylaxis to contacts who did not have disease. Other global events added to the momentum created.

Recording and reporting tools were adapted so that they captured activities related to contact tracing and chemoprophylaxis.

Dr Quao concluded that the yield of contact tracing increases with increasing coverage; much of contact tracing is done by focal persons with limited involvement of general staff; the case detection rate among contacts is significantly greater compared to active case detection at population level. He further mentioned that the public health interventions surrounding COVID-19 has offered an opportunity to train different cadres of staff on techniques of contact tracing, which could also be applied to leprosy.

### 5.2.3. Country perspectives on contact tracing and PEP: India

A [presentation](#) was made by Dr **Megha Khobragade**, Assistant Director General (Leprosy), Ministry of Health and Family Welfare.



India introduced chemoprophylaxis after satisfactory results of the PEP feasibility study conducted in the Union Territory of Dadra and Nagar Haveli with support of Until No Leprosy Remains (NLR, formerly known as Netherlands Leprosy Relief). Operational guidelines were developed in 2019. A minimum of 20 contacts are screened by the local accredited social health activist (ASHA). Any person who has been living/working/having social activities with a newly detected case of leprosy for 20 hours per week for more than three months in the last one year is considered a contact.

From 2018 to August of 2020, a total of 1.3 million contacts were identified. Of them, 65% were given SDR. The challenges in implementation of chemoprophylaxis are ensuring availability of rifampicin, training of field staff to identify the contacts, follow up of contacts of all newly registered cases. Contact tracing and PEP is particularly challenging in hilly and tribal areas due to logistic constraints,

non-availability of contacts at one time (and thus need to undertake repeated visits) or refusal to consume drugs (especially by social contacts).

SDR is considered a highly cost-effective intervention towards leprosy control in the Indian context. The country is making great efforts to streamline procurement of rifampicin and strengthen the PEP activity.

#### **5.2.4. Country perspectives on contact tracing and PEP: Indonesia**



On behalf of Dr **Prima Yosephine**, NLP Manager, Dr **Naufal Azhari**, National Professional Officer (NTDs), WHO Country Office for Indonesia, presented Indonesia's viewpoint related to contact tracing and PEP, which you can find [here](#).

Though contacts are known to be most at risk for developing leprosy, contact tracing was not well managed. Since 2012, Indonesia has undertaken multiple pilot projects with different approaches and is now in the process of mainstreaming contact tracing and chemoprophylaxis. Both index-based and blanket approach have been undertaken. A third approach builds on community participation where villages are counselled and asked to do self-screening, following which leprosy is confirmed or ruled out and SDR provided. This approach does not require revealing of the index case.

Best practices included accurate mapping of index cases. This makes it easier to track the contacts, resulting in an increased coverage of routine contact examination. The community approach reduces the workload of the health staff while attention for self-screening increases public awareness. The blanket approach is most suitable for remote or isolated areas. Integration with routine screening for other disease will add value and efficiency.

Following challenges need to be addressed: health workers need to be prepared in technical and programme management; community acceptance and support from key stakeholders at the local level needs to be strengthened; management of drugs and post-treatment monitoring; and integration with other programmes at primary care level.

Dr Yosephine concluded that chemoprophylaxis is one of the approaches for accelerating elimination of leprosy. Lessons learnt from several areas with different approaches can be the basis for innovative and tailored implementation. The next step will include mainstreaming the various approaches as part of routine leprosy activities.

#### **5.2.5. Country perspectives on contact tracing and PEP: Kiribati**

Ms **Erei Rimon**, NLP manager of Kiribati, made a presentation, accessible [here](#), on the country's efforts to roll out contact tracing and PEP.

Kiribati is a Pacific Island nation with a population of 119 000 and area of 811 km<sup>2</sup>. The population is very unequally distributed with South Tarawa counting almost 4000 persons per km<sup>2</sup>. The NLP has four staff (one dermatologist, one programme manager and two nurses).



With on average 150 new cases detected annually over the past ten years, Kiribati witnesses one of the highest detection rates in the world. Especially the high proportion of children (between 33% and 50%) points to unabated transmission.



Contact tracing is a routine programme activity undertaken in annual drives. Focus is on household contacts. With support of the Pacific Leprosy Foundation (PLF), *SDR-MDT Plus* – rifampicin given as prophylaxis twice with a one-year interval – chemoprophylaxis has been rolled out in South Tarawa since 2018. The intervention requires proper planning, advocacy and awareness raising, training, piloting and scaling up. It is important to educate the health workers and the communities on the merits as well as the limitations of chemoprophylaxis. As it is a new strategy, careful monitoring is important, for which additional forms have been developed.

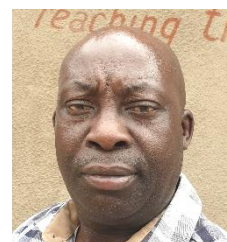
Challenges faced include: proper timing to fit in the schedule of multipurpose health workers as well as achieving high coverage (evening or early morning to maximize coverage); migration of the index case and his/her family; incorrect address; detection of new cases among persons who have received SDR; poor recording.

Positive results of the intervention include a closer involvement of health staff in leprosy outreach activities, especially in the follow up of cases; improved compliance with MDT; nil side-effects of rifampicin observed; high acceptance in the community; high participation of and support by clinic staff; increased willingness of defaulters to restart treatment with MDT.

In conclusion, SDR appears very safe; high coverage of chemoprophylaxis can be reached; the annual drives of contact tracing and chemoprophylaxis are now considered as routine programme components. Last but not least, the innovative approaches have reinvigorated overall leprosy control.

### **5.2.6. Country perspectives on contact tracing and PEP: United Republic of Tanzania**

Dr **Deuseddit Kamara** from the National Tuberculosis and Leprosy Programme, Ministry of Health, Community Development, Gender, Elderly and Children of Tanzania, made a presentation which can be accessed [here](#).



Tanzania has been implementing its *Fourth TB and Leprosy Strategic Plan, 2015–2020*. The primary approach for disease elimination has been passive case finding.

In-line with new lessons, partnered programmes, the WHO *Global Leprosy Strategy* and WHO *Guidelines for the diagnosis, treatment and prevention of leprosy (2018)*, the country has made active case finding and PEP a national policy. SDR-PEP has been included as a standard approach for control under the new *National Tuberculosis and Leprosy Strategy 2021–2025*. Contact tracing and PEP have been given a great emphasis in the revised and updated disease management manuals to improve early case finding and treatment primarily. Key approaches include the participation of local leaders, Health Management Teams, local coordinators, community health workers and volunteers. To ensure quality, the manuals have also stipulated training, transport to ensure reaching all in need and close

monitoring at all levels. Other supportive elements include the availability of screening and data collection tools and drugs (MDT and rifampicin).

The country is currently implementing three separate projects, covering different districts in or close to known high burden areas; unfortunately, not all regions and districts in need could be covered. One of the projects will also end in December 2020. The country is looking for opportunities to mainstream its operations as part of regular leprosy control activities in all endemic areas.

Table 2 shows some achievements of the projects.

**Table 2:** Key achievements in SDR implementation, Tanzania

Project	Households visited	Persons given SDR
LPEP	933	6,275
PEP4LEP	252	1,170
BDSF	612	1,327

Under the different projects, the following new tools were developed:

- ✓ The new Patient Treatment Card includes a list of all contacts requiring screening and PEP. The index patient is requested to provide names of his/her close contacts. All contacts are invited to the facility or are screened by community volunteers or index cases themselves.
- ✓ Home Register. This paper-based tool is used to take detailed information of all home contacts, including their physical assessment.
- ✓ Tool for reporting home visits.
- ✓ Summary form for household contact tracing.
- ✓ Indicators for effective programme monitoring.

### 5.3. Perspectives of persons affected by leprosy on contact tracing and post-exposure prophylaxis

Three members from organizations representing persons who have experienced leprosy made comments on the issue of the contact tracing and PEP. These patient organizations are: the Ethiopian National Associations of Persons Affected by Leprosy (ENAPAL), the Nepalese chapter of the International Association for Integration, Dignity and Economic Advancement (IDEA) and the Movement of Reintegration of Persons Afflicted by Hansen's Disease (MORHAN) in Brazil. A short video was also recorded in the (hyper-endemic) leprosy village of Hula in Papua New Guinea where a community leader and health volunteer provided their views.

### ***5.3.1. Perspectives of affected persons on contact tracing and PEP: ENAPAL***

Mr **Tadesse Tesfaye**, Managing Director of ENAPAL, made a presentation, accessible [here](#), on the views of ENAPAL on contact tracing and PEP.



ENAPAL is a member-based organization, established in 1996, to advocate for participation and equal opportunity of leprosy-affected persons and to create awareness in the community. The organization works in partnership with the government and NGOs.

As an organization of persons affected by leprosy, ENAPAL has observed that new cases continue to occur: around 3500 to 4000 per year; more than 10% of them are children and 15% of them presented with G2D. Introducing a preventive intervention is the need of the hour to reduce new cases in the country and particularly among children. Having learnt about the recommendation from the WHO guidelines that SDR may be used as preventive treatment for contacts of leprosy (adults and children aged two years and above), ENAPAL views chemoprophylaxis as an opportunity to accelerate leprosy control. As this is an evidence-based recommendation, ENAPAL advocates that NLP should introduce SDR for the prevention of leprosy.

ENAPAL appreciates the idea of contact tracing and prophylaxis as means to reduce transmission and the number of new cases of leprosy.

### ***5.3.2. Perspectives of affected persons on contact tracing and PEP: IDEA Nepal***



Mr **Amal Timalisina**, President of IDEA-Nepal, made a [presentation](#) on the position of affected persons vis-à-vis contact tracing and PEP.

Acceptability and perception of PEP needs to be looked through socio-cultural and psychological aspects of the contact tracing and implementation of the intervention programme. The programme faces significant problems. Literacy rate is generally low. Willingness of index case and contact case needs better understanding. Screening of contacts and administration of SDR is easier among family contacts. The screening of contacts in the neighbourhood is more complex as patients are hesitant to expose their disease status outside their family; neighbours are also reluctant to accept any contact with the index case. Stigma puts a heavy burden on the person affected by leprosy.

IDEA observed so far that, though contact tracing and PEP is from an epidemiological viewpoint helpful to interrupt transmission, its administering is very difficult in the community. Apart from medical, social and psychological angles, PEP needs to be considered from legal and economical point of view of patients and their contacts. More efforts are required to make the interventions also socially acceptable.

### 5.3.3. *Perspectives of affected persons on contact tracing and PEP: MORHAN*

In her [presentation](#), Ms **Paula Brandão**, nurse and volunteer for MORHAN, highlighted the views of affected persons in Brazil on the issue of contact tracing and PEP. The following were the salient points of her presentation:



- ✓ There is a need for a robust health information system, either to identify problems by location, gender, age group, income and education level in order to plan the right activities for the particular context;
- ✓ The type of data collected and their use should be clearly communicated so that affected persons can exercise their right to autonomy. Channels for listening to and counselling of persons with Hansen's disease should be established. This should help in identifying and addressing stigma and discrimination as well as providing access to psychological support services.
- ✓ Training should cover the entire patient pathway, including extensions to contacts, family and community members. It should contribute to make affected persons self-reliant as well as recognize their potential contributions.
- ✓ Health staff should recognize how patients perceive their body and take any complaint seriously.
- ✓ Persons affected by Hansen's disease should be involved in the formulation, implementation, monitoring and evaluation of leprosy strategies, including active case search, contact investigation, and chemo- and immuno-prophylaxis.
- ✓ Access to health services should be universal, and in particular not deprive vulnerable people (including those most stigmatized for whatever reason).

She emphasized that, to break with tradition, future strategies should be duly consulted with persons affected by Hansen's disease, i.e. through a truly participatory process.

### 5.3.4. *Perspectives of affected persons on contact tracing and PEP: Papua New Guinea*



Mr **Rawali Ila**, former leprosy patient from Hula, and Mr **Marie Vekwa**, community volunteer, were earlier interviewed. They highlighted the demand from the community to roll out PEP with SDR in order to further reduce the leprosy burden in their hyper-endemic village. The video recording of the interview can be accessed [here](#).



## 5.4. Partner perspectives on contact tracing and/or PEP

Interventions in support of contact tracing and/or PEP were made by three partner agencies: American Leprosy Missions (ALM), the German Tuberculosis and Leprosy Relief Association (GLRA) and PLF. The

latter NGO provides support to leprosy control in few Pacific Island countries (including Samoa and Kiribati) while the former two are members of the International Federation of Anti-Leprosy Associations (ILEP).

#### ***5.4.1. Partner perspectives on contact tracing and/or PEP: ALM***

Dr **Paul Saunderson**, Medical Director of ALM and member of the ILEP Technical Commission, provided his views on contact tracing and PEP in a presentation which can be accessed [here](#).



Contact management is the key to leprosy control in the next ten years. This will need to be based on actively tracing of contacts for up to five years after leprosy is diagnosed in an index case. This can be supplemented by health education and promotion of self-examination.

In settings where stigma is a major issue, this can be partially mitigated by conducting focal surveys or skin camps so that index cases need not be identified. Skin camps have the advantage that they can address common skin problems including other NTDs (e.g. yaws, Buruli ulcer, cutaneous leishmaniasis, onchocerciasis, scabies) where there are geographic overlaps. A blanket approach may be applied in defined hyper-endemic areas (with many index cases, where there is likely to be significant overlap in contacts). In low-endemic areas, contact examination is very cost-effective.

Contact tracing is an ideal platform for administering PEP. He mentioned that more evidence is becoming available that confirms the protective effect of SDR. Improved prophylactic regimens will also become available in the future, which will even have a greater effect on transmission. Drug resistance should also be monitored. Although vaccines are in trial phase, it will take several years to prove efficacy.

#### ***5.4.2. Partner perspectives on contact tracing and/or PEP: GLRA***



The presentation made by Dr **Blasdus Njako** from GLRA-Tanzania and accessible [here](#), complemented the [presentation](#) made by the representative of Tanzania's National Tuberculosis and Leprosy Programme.

The presentation highlighted the support provided by GLRA to implement the Leprosy Post-Exposure Prophylaxis (LPEP) study project, conducted in seven countries including Tanzania. The purpose of the multi-country study was to assess the feasibility, effectiveness and impact of contact tracing and PEP with SDR to contacts of leprosy patients. In Tanzania, the project is being implemented in three highly endemic districts.

Best practices and lessons emanating from the ongoing LPEP project in Tanzania and other countries have been resourceful in guiding the expansion of PEP to other countries.

Salient points of the presentation include:

- LPEP administration to household contacts was very much feasible. Patients' acceptance to participate has been high: 98.5% of 5894 listed contacts of 617 index cases were screened. Of them, 93 were diagnosed as new leprosy cases while 4691 (81%) received SDR. The project subsequently extended services to more households (up to 20 surrounding neighbouring families) and social contacts. Contact tracing was carried out retrospectively including index cases diagnosed over the past year.
- SDR-PEP opened doors for disclosure and prevention. Contact tracing managed to reduce stigma, provide prophylaxis preventing contacts from developing the disease. Patients were delighted to see their contacts not only screened but also given SDR to reduce their chances of developing leprosy. PEP contributed positively to the decision of leprosy patients to disclose their status.
- LPEP invigorated active case finding. Having active case finding for leprosy as part of LPEP programme implementation, this initiative enhanced early case detection and may thus contribute in disrupting the chain of transmission.
- The combination of active case finding and PEP was a right mix for identifying hidden cases. In this project, for every 63 contacts identified, one new leprosy case was detected. This indicates the possibility of a high number of unreported cases in these areas.
- Increased capacity to diagnose/suspect leprosy by frontline health facilities and community volunteers: 401 health care workers were trained and 5969 community members sensitized on transmission, signs and symptoms of leprosy. This has enhanced community and facilities' capacity to timely suspect and diagnose the disease.

Dr Blasdus also shared updates on integrated skin screening of contacts and administering SDR, work implemented through an ongoing cluster-randomized implementation trial (PEP4LEP). Through skin camps specialized health care was brought closer to communities. There was no need for the index patients to disclose their disease to the community as contacts were listed and subsequently invited to take part in these camps. At least 100 contacts have so far received SDR for every index case.

#### **5.4.3. Partner perspectives on contact tracing and/or PEP: PLF**



Dr **Jill Tomlinson**, General Manager of PLF, provided the perspective of PLF on PEP based on the NGO's experience in Samoa and Kiribati where it is partnering with the Ministries of Health to support leprosy control. Her presentation, focusing mostly on Kiribati, can be accessed [here](#). She explained the rationale for piloting chemoprophylaxis in Kiribati, mainly as it has the potential to accelerate reducing the leprosy burden in the medium term.

She presented the results of modelling studies undertaken which compared different single and combination of approaches. Introducing a new strategy involves four phases: (i) planning and design; (ii) intensive case finding and contact tracing; (iii) pilot; and (iv) nationwide scale up. Involvement of the community is crucial at each stage.



She highlighted results achieved to date. They include:

- ✓ Household contacts constitute more than 10% of the total population;
- ✓ Over 12 000 contacts have been enumerated, unevenly spread;
- ✓ SDR has been widely accepted with coverage in excess of 90% in six months' time;
- ✓ No adverse events have been reported;
- ✓ PEP has contributed to improving leprosy control and enhancing the effectiveness of the control programme (improved diagnostic skills, improved communication between the Central Leprosy Unit and peripheral clinics; and between the health services and the community; increase attention for leprosy control at national level; increased public awareness; improved treatment outcomes).

Finally, she had some take-home messages for partners in other countries:

- ✓ PEP should not be seen as a one-off project, but is most effective when fully integrated into the overall NLP activity plan;
- ✓ The opportunity of introducing PEP should be used to review the entire programme;
- ✓ The added value should be highlighted in terms of increased community awareness and reduction in stigma.

## 6. Disability care

### 6.1. Country perspectives on disability care in leprosy

Representatives from six countries provided inputs in this session of the Global consultation. These countries were: Bangladesh, the People's Republic of China, the Democratic Republic of the Congo (DR Congo), the Republic of the Union of Myanmar, Paraguay and the Russian Federation.

#### 6.1.1. Country perspectives on disability care in leprosy: Bangladesh



Dr **Rahat Chowdhury**, NLP Manager, made a presentation (accessible [here](#)) of disability care for leprosy affected persons in Bangladesh.

The Bangladesh Parliament repealed the *Lepers Act (1898)* on 26 November 2011 and proclaimed the *Persons with Disabilities' Rights and Protection Act (2013)* two years later. The latter act includes compensation in case of discrimination. Access to welfare schemes was facilitated by the Department for Social Welfare through the issuance of a "Disability Card" to beneficiaries.

The *Bangladesh Leprosy Control Strategy 2016–2020* specifically includes strengthening of all measures aimed at preventing and addressing complications as well as strengthening care-after-cure programme. Various information-education-communication (IEC) materials have been developed for disability prevention. Disability care is provided in dedicated hospitals (including NGO facilities) as well

as at community level (e.g. through self-care groups). Protective footwear and assistive devices are provided. Reconstructive surgery is conducted for selected patients. Counselling and ulcer care are being offered in general hospitals. Investments in self-care at the community level focuses on promoting regular, simple interventions which prevent disabilities, reduces the need for hospitalization and improves the quality of life. Mental support is provided through peer motivators who are specially trained for this purpose.

Dr Chowdhury further elaborated on the impact of COVID-19 on leprosy control and how measures are implemented to continue essential services and minimize negative effects.

He further highlighted current challenges as well as opportunities. Integration of medical services as well as merging of social services for leprosy affected persons with similar services for persons with disabilities with other causes is pursued. Critical to success is the involvement of affected communities.

The *National Leprosy Conference*, held in December 2019, was an important event where the honourable Prime Minister inaugurated the country's "Zero leprosy initiative by 2030"

### **6.1.2. Country perspectives on disability care in leprosy: China**

Professor **Hong-Sheng Wang**, Executive Director General of the National Center for Leprosy Control, China Centers for Disease Control, elaborated on the role of prevention of disabilities in China. His presentation can be accessed [here](#).



New leprosy cases – and consequently also registered prevalence – have been reducing fast, almost in a linear fashion: in 2010, the country reported 1324 new cases, which went down to 464 cases in 2019. New cases with G2D were around 100-150 annually, or about 20% of all new cases, pointing to delays in case detection and challenges with finding the remaining cases in a huge population. There is further room for improving early detection of reactions and neuritis as well as rehabilitation services.

Primary prevention focuses on early case detection, with three key approaches identified: monitoring of leprosy suspects; contact screening and spot surveys. A mobile app has hereto been developed. A laboratory test – ELISPOT – is also used which recognized leprosy specific antigens that activated memory T-cells, especially in patients with PB disease. A nested PCR test was also developed to amplify DNA, which is used in skin lesions of patients with very few bacteria.

Secondary prevention (prevention of new or worsening of existing disabilities) focuses on adequate case management: treatment with MDT; early detection and treatment of neuritis with prednisolone; chemoprophylaxis with prednisolone for nerve impairment. Vaseline, self-care kit, footwear and wound dressing kit is also provided. Wound and ulcer care is undertaken through self-care and as part of community-based rehabilitation. Reconstructive surgery services are also available for selected patients.



### 6.1.3. Country perspectives on disability care in leprosy: DR Congo

Dr **Florent Ngandu**, Director-Coordinator of NLP, highlighted in his [presentation](#) the leprosy-related disability burden and what is done to alleviate this. There are currently more than 20 000 persons affected with leprosy and disabilities. Each year, more than 10% of new leprosy cases show visible deformities at the time of diagnosis.



The role of the national level includes coordination and evaluation of activities conducted in the provinces and increasingly in the peripheral facilities (health zone level). Programmatic interventions include capacity building, issuance of guidelines, facilitate activities to make patients self-reliant, improve community participation, footwear provision and disability management. Where possible, efforts are done to integrate with disability care related to other causes (including Buruli ulcer and diabetes)

Special activities are also supported by NGOs to rehabilitate persons with disabilities. These including housing and education.

In the future, the programme will further promote integration of prevention of disability and physical rehabilitation services, for which technical support and also more sustainable funding will need to be identified.

### 6.1.4. Country perspectives on disability care in leprosy: Myanmar



Dr **Myo Ko Ko Zaw**, NLP Manager, presented data on leprosy and disabilities. His presentation is accessible [here](#). Though gradually reducing, the G2D rate remains pretty high: it was 5.5 per million population in 2019. Also, seven children diagnosed with leprosy showed visible deformities.

Disability care services are provided through both institutional and field approaches while rehabilitation services are also available. These services are provided in an integrated fashion (i.e. through the regular health services) with NLP providing technical support. The field approaches include primary, secondary and tertiary prevention packages as well as socio-economic support packages. Primary prevention consists of awareness raising, chemoprophylaxis and BCG vaccination; secondary prevention includes diagnosis and treatment of leprosy, nerve function assessment, management of nerve function impairment, reaction management. It also includes self-care packages for persons with grade-1 and grade-2 disabilities as well as provision of assistive devices. Tertiary prevention includes physical rehabilitation as well as surgery. Socio-economic support measures include access to micro-credit schemes, vocational training, community-based rehabilitation. Additional financial support is provided for persons with G2D during the COVID-19 pandemic.

### 6.1.5. *Country perspectives on disability care in leprosy: Paraguay*

Dr **Olga Aldama**, NLP manager of Paraguay, presented her country's perspective on disability care in leprosy in a presentation which can be accessed [here](#).



The proportion of new cases with G2D is around 12% among newly detected cases, though recently none of such cases occurs in children. Grade-1 disability is recorded in both new adult and child leprosy cases. *Erythema nodosum leprosum*, reversal reaction, Lucio phenomenon, neuritis as well as ulcers are common.

The goals of the current strategy have not been met in full. The current G2D rate is 6 per million population.

The National Strategic Plan is built along four main strategies: (i) passive and active surveillance (including contact tracing); (ii) capacity building (including laboratory), training (pre- and in-service) and supervision down to the Family Health Units (primary health care); (iii) assistance and education; and (iv) health promotion. These four approaches should lead to early case detection, prompt treatment and ultimately nil disabilities.

Several documents are being developed, including: National Strategic Plan; Surveillance Protocol; updated guidelines on diagnosis and treatment; and training and educational materials.

A strategic partner is the Mennonite Hospital Km 81, which is the country's apex centre for surgery, provision of adapted footwear and education on self-care. District and specialized hospitals are also designated for referral of complications.

Weaknesses of the programme include: delayed diagnosis, loss to follow up, low proportion of contacts traced (around 60%), leprosy among migrants.

The country's programme is working with a vision of zero leprosy among children, zero new adult cases with G2D and improving access to social welfare and inclusion schemes.

The NLP has formulated the following objectives for the next ten years:

- Early case detection, accurate diagnosis and timely treatment;
- Access to comprehensive and well-organized referral facilities;
- Proper diagnosis and management of reactions, neuritis and disabilities;
- Monitoring, support and training in self-care;
- Mental well-being through psychological first aid and therapeutic counselling.

### 6.1.6. *Country perspectives on disability care in leprosy: Russian Federation*

The Russian Federation has very few new leprosy cases. However, the country still counts a good number of old patients, many of them with lifelong disabilities. Many also continue to reside in sanatoria. Dr **Victor Duiko** from the Astrakhan Research Institute on Leprosy of the Ministry of Health made a [presentation](#) focusing on the rehabilitation of leprosy patients in the Russian Federation.

The state program to combat leprosy started in 1923. Due to the implementation of a set of practical anti-leprosy measures, the primary morbidity is sporadic. As of 1 January 2020, there were 202 persons who have experienced leprosy in the country; 30% of them have disabilities, while 15 were considered as “active” (under treatment). Most disabilities are old as during the last ten years, there were no new patients with severe complications leading to disabilities. The last child with leprosy was diagnosed in 1970. Most patients (60%) are found in the Astrakhan Region.



Infrastructure-wise, the country has one apex institute (the Astrakhan Research Institute on Leprosy), a branch of the Central Dermato-Venereal Institute of Russia (catering for the Moscow region) and the leprosaria in Abinsk (Krasnodar Territory) and Tersky (Stavropol Territory).

Rehabilitation of leprosy patients begins on the first day of hospitalization. In order to prevent disabilities, a combination of physiotherapeutic and medical measures is applied. These were further elaborated in his presentation. Assistive devices to make users self-reliant for activities of daily life are also provided.

Leprosy control in the Russian Federation continues to focus on providing medical and surgical services as well as undertaking research into new tools (including for diagnosis, management and prevention of disabilities). Surveillance is also maintained to capture the sporadic new cases early.

## 6.2. Perspective of persons affected on disability care in leprosy

Four persons who have experienced leprosy provided their views on disability care in leprosy. They spoke on behalf of the organizations they belong to: Association of People Affected by Leprosy (APAL, India), HANDA Rehabilitation and Welfare Association (HANDA, China) and MORHAN (Brazil).

### 6.2.1. Perspective of affected persons on disability care: APAL India



Mr **V. Narsappa**, President, and Mr **Venu Gopal**, Vice-President, Association of People Affected by Leprosy in India, made a joint presentation on behalf of leprosy-affected persons in India. The presentation can be accessed [here](#).



They highlighted the minimum services that should be provided at the primary care level: disability assessment by doctors; periodic nerve assessment; continuous supply of medicines (including steroids); access to expert services, including provision of splints and physiotherapy services; counseling; proper referral to hospitals when required (including for reconstructive surgery).

With regard to prevention of disabilities, they mentioned that services for ulcer care are not always available; and that provision of adequate footwear is rather irregular. They worried about the risk of worsening of disabilities if a trained doctor is not present. Patients with disabilities require special

attention as many of them are old. COVID-19 impacts people who have experienced leprosy more than others.

With regard to reconstructive surgery, physiotherapy needs must be taken into account, on top of the surgical needs. Reconstructive surgery requires proper preparation (before surgery) and follow-up (after surgery).

### ***6.2.2. Perspective of affected persons on disability care: HANDA China***



Ms **Sally Qi** from HANDA Rehabilitation and Welfare Association, People's Republic of China, presented her organization's perspectives. Her presentation can be accessed [here](#).

The number of new leprosy cases in China is now less than 1000 per year. The number of persons who have experienced leprosy in the country is estimated to be around 230 000 of whom approximately 160 000 have disabilities. Twenty thousand persons affected by leprosy live in 593 leprosy villages. The main challenges persons affected by leprosy are confronted with include physical disabilities, geographic isolation, discrimination and economic deprivation.

HANDA is the first organization of people affected by leprosy in China. Its mission is to promote the dignity and respect of persons affected by leprosy. It empowers members to participate in organizational governance, rendering leprosy-related services, undertake social activities and mobilize resources. HANDA's strategic approach focuses on persons affected by leprosy but also on the general public, to promote social integration. A holistic approach is pursued, including physical, psychological and socio-economic rehabilitation.

Critical challenges are of demographic nature with limits of participation of elderly people, affected persons typically living alone (without family support) and, as their number dwindles, they have less visibility and, therefore, it becomes more difficult to attract attention from the public.

### ***6.2.3. Perspective of affected persons on disability care: MORHAN Brazil***

Ms **Patrícia Soares**, Programme Coordinator of MORHAN in Brazil, made an intervention on behalf of MORHAN. Her presentation can be accessed [here](#). She highlighted the following key points:



- 1) Not to blame persons affected by Hansen's disease for their situation, but provide conditions for improving their health condition, because often people are blamed by professionals for developing some kind of sequelae;
- 2) Provide access and comprehensive healthcare to persons affected by Hansen's disease even after treatment in order to prevent worsening of existing conditions or emergence of new sequelae;

- 3) Have a clear, objective definition of rehabilitation to avoid institutional prejudice;
- 4) Empower persons affected by Hansen’s disease for self-care; as well as for knowing their rights and how to ensure that they can enjoy these rights;
- 5) Access to comprehensive health care with priority for women and girls affected by Hansen’s disease, especially those with G2D; seeking to stabilize the sequelae and disabilities already present, with special attention for underlying or concurrent medical conditions affecting particularly women;
- 6) Ensure access to persons affected by Hansen’s disease to orthoses, prostheses, reconstructive surgery, timely and appropriate hospital treatment at all stages of their treatment, and also screening for potential relapse or resistance;
- 7) Define operational models that comply with official and recommended guidelines, ensuring comprehensive care to persons affected by Hansen’s disease, including monitoring and evaluation of services offered to targeted population;
- 8) Consider rehabilitation comprehensively, beyond the biological aspects. Rehabilitation must be physical, mental and social, ensuring a multidisciplinary team qualified to attend all aspects of this demand.

### 6.3. Partner perspectives on disability care in leprosy

Four partners, including one non-ILEP disability agency, provided their perspectives on care for persons with leprosy-related disabilities. They are: ANESVAD, the British Leprosy Relief Association (LEPRA), NLR and The Leprosy Mission (TLM).

#### 6.3.1. Partner perspectives on disability care in leprosy: ANESVAD



ANESVAD is an international NGO promoting the right to health and supporting primary health care. Dr **Gabriel Diez**, Head of ANESVAD’s Political Advocacy and External Relations Department, made a presentation (accessible [here](#)) He focused on the NGO’s role in control of NTDs (Buruli ulcer, leprosy, lymphatic filariasis and yaws) among the most vulnerable populations of sub-Saharan Africa.

The NGO promotes integration of disease control, in collaboration with strategic partners and the host country’s health authorities. Prevention and inclusion of disability is one of the cross-cutting areas it supports (others are gender, environmental protection and intercultural respect); it also addresses social determinants that have an impact on health. It addresses the needs of disabled persons from a human rights perspective. Medical care is focused on prevention as well as restoring physical functionality.

Reasons to promote integration include: skin NTDs are relatively easy to recognize; importance to maintain surveillance and expertise (e.g. for Buruli ulcer and leprosy); efficiency gains in programme delivery; increased staff motivation; co-endemicity; diseases of poverty. Cross-cutting interventions by ANESVAD can be grouped as follows: early detection and integrated management of skin NTDs;

prevention and inclusive management of disabilities; ulcer care and self-help; and water, sanitation and hygiene.

ANESVAD applies a holistic approach, i.e. it addresses physical impairments, functional limitations, participation restrictions as well as environmental and personal factors.

In the future, ANESVAD wants to contribute to evidence-based policy formulation by analyzing available data disaggregated by gender; it will capitalize on good care practices; it will improve the perception of affected persons and promote their social reintegration. Challenges on the path hereto include the need to inform decisions makers about the correct disability situation; scaling up of pilot projects; incorporating lessons learnt into normative work; capacity building; behaviour change communication; sustainability (which can be best ensured if there is a strong involvement of affected communities).

### *6.3.2. Partner perspectives on disability care in leprosy: LEPR Bangladesh*



**Md. Mijanur Rahman** from LEPR-Bangladesh highlighted his organization's work on disability care for leprosy. His presentation, accessible [here](#), focused much on the mental health problems faced by persons affected by leprosy.

Research has shown that more than half of persons affected by leprosy suffer from severe depression. Mental health problems are more common among leprosy patients with disabilities, female patients (though anxiety and depression were more common in men in Bangladesh), low education and economic dependence.

Based on these findings, the person-centred, holistic approach includes addressing mental health in addition to morbidity management and disability prevention, both at the individual and at the programme level. Mental motivators – typically female peers – have been specifically trained; they keep in touch with beneficiaries through regular mobile phone communication and home visits. They are key in providing counseling and disability care services. Mental health is also included in awareness programmes involving self-help groups and the larger community.

### *6.3.3. Partner perspectives on disability care in leprosy: NLR India Foundation*

Dr **Ashok Agarwal**, Country Representative of NLR India Foundation, highlighted the contributions of NLR in India with regard to disability care in leprosy. His presentation (accessible [here](#)) focused on self-care. The approach encourages the formation of self-care groups, promotes practices for prevention and management of disabilities, collectively and independently. The self-care practices are in principle easy to perform (e.g. soaking of anesthetic feet, active and passive exercises to prevent contractures, covering of eyes during sleep). Self-care is organized in three models: (i) self-care groups in colonies, formed by NLR; (ii) self-care groups in open communities, formed at the primary health care level with involvement of ASHAs and health facility staff; and (iii) home-base care, on individual basis but with regular follow-up by trained ASHAs and





health staff. The three models will be evaluated, but it is already clear that the colony-based model results in better healing of ulcers and wounds.

#### 6.3.4. *Partner perspectives on disability care in leprosy: TLM*

Ms **Jannine Ebenso**, Head of Quality Assurance and based in TLM's International Office, elaborated through a presentation, which can be accessed [here](#), the support that TLM is providing in the care of leprosy-related disabilities throughout its projects worldwide. Prevention starts with early and accurate diagnosis and prompt treatment with MDT; as well as diagnosis and management of lepra reactions and neuritis. Self-care is important. She presented the concept "Journey through Care" with the physical, social and emotional dimensions. Access to quality services is necessary at home, at primary care level but also when referral is required to higher levels of care, with proper bi-directional referral mechanisms and follow-up. This should be designed for both disease management as well as disability care (including provision of assistive devices).



Self-care can be individualized, though a family-centred approach may show greater impact, especially when this is done for multiple diseases.

Mental well-being is also taken care of through psychological first aid at all points of care; while therapeutic counselling may have to be accessible at a more specialized level of mental health care. She highlighted some of the challenges implementation poses at all points of care, especially for obtaining necessary resources: financial, human, skills and guidance in order to ensure that vulnerable people are safeguarded. The WHO guidance document *Mental health of people with NTDs* is a commendable document towards a person-centred approach.

## 7. Interruption of transmission, elimination of disease

### 7.1. Task force on definitions, criteria and indicators for transmission and elimination of leprosy

#### 7.1.1. *Concepts, definitions and criteria to ascertain elimination of leprosy*



Several countries have requested verification of achieving milestones in the elimination of leprosy. Criteria, indicators and milestones are therefore needed for such a verification process and for defining a dossier for leprosy elimination. To start this process, WHO organized an informal consultation in Mexico City in February 2020. To continue work on the output of this meeting, a *Task Force on definitions, criteria and indicators for transmission and elimination of leprosy* (TFCEL) was constituted by WHO. This task force is led by Dr **Wim van Brakel** whose presentation can be accessed [here](#).

The main objectives of TFCEL are to define criteria for countries to be ascertained for having made significant progress towards interruption of transmission and elimination of disease; and to establish

criteria and indicators that best define interruption of transmission of *M. leprae* and elimination in terms of zero disease incidence.

The key concepts defined by TFCEL include ‘autochthonous case’, ‘elimination as a public health problem’, ‘elimination of transmission’, ‘elimination of disease’ and ‘eradication’. A definition for each has been proposed, usually based on the *Global Leprosy Strategy 2016–2020 Monitoring and Evaluation Guide* or other WHO publications.

TFCEL has also proposed five endemicity levels: high endemic, moderately endemic, low endemic, sporadic cases and non-endemic, with a criterion defined for each in terms of the rate or number of new autochthonous cases detected.

Three phases have been proposed (Figure 2): (i) Phase 1: up to elimination as a public health problem; (ii) Phase 2: up to elimination of disease; and (iii) Phase 3 or post-elimination phase. Milestones indicating when a country or area would move to the next phase have been proposed. Phase 2 is conceptually divided into a Phase 2A: up to elimination of transmission; and a Phase 2B: up to elimination of disease. TFCEL proposes that verification of elimination of disease be done after Phase 2B since this is – with current tools – more easily ascertained.

Fig. 2: Phases in the elimination of leprosy

	Elimination of leprosy			
	Phase 1	Phase 2		Phase 3
		Phase 2A	Phase 2B	
Description	Up to elimination as a public health problem	From elimination as a public health problem until elimination of transmission	From elimination of transmission until elimination of disease	Post-elimination Surveillance
Endemicity level	High => Moderate	Moderate => Low	Low => Sporadic cases	Sporadic cases only (often foreign-born)
Milestone to move to next phase	<1 per 10 000 registered cases	New case rate among children = 0 for at least 5 years	No new autochthonous cases in past 3 years	No new autochthonous cases for ≥ 10 years

Verification of elimination of leprosy disease

A matrix of criteria across the above phases has been designed. The matrix comprises nine key criteria to be included in a ‘readiness assessment tool’ and/or a country roadmap for zero leprosy. Some are potential core components of a *Dossier for Leprosy Elimination*. The latter would include participation of persons affected in all aspects of leprosy services, adequate training of relevant staff, a good surveillance and response system and availability of services for leprosy treatment and management, disability management, rehabilitation and mental health care.

### 7.1.2. Indicators and post-elimination surveillance

Dr **Vivek Lal**, member of TFCEL, described a set of indicators currently under discussion for use in the ascertainment of interruption of transmission or elimination of diseases. His presentation can be accessed [here](#).



Indicators relevant to the interruption of transmission and elimination of disease were discussed. The definitions and formulas were taken or adapted from the *Global Leprosy Strategy 2016–2020 Monitoring and Evaluation Guide*. It was strongly advised to look at trend data over at least ten years, both when conducting situational analyses and when interpreting year-to-year changes.



Indicators relevant to interruption of transmission included child-based indicators (absolute number of new autochthonous child (<15 years of age) cases; child proportion among new cases (expressed as a percentage); and new case rate among children (expressed per million children). Leprosy in children generally reflect recent transmission. Absolute number (of child cases) can be used to calculate MDT requirements and are a more suitable indicator when denominators are very small. The rate of new child cases in the child population provides a more stable indicator, especially when the number of new cases is small; it also allows comparing jurisdictions even if their population distribution is different.

Other relevant indicators include age at detection and its trend; proportion or rate of MB leprosy among new cases and its trend; and proportion of new autochthonous cases with a known leprosy contact in the family. Trend in age at detection is important as an increase in mean age at detection, a shift in the mode towards older age groups and a decreasing proportion of children among new cases (or child rate) may all suggest that a country has achieved or is moving towards elimination of transmission. An increase in MB proportion among new cases may support that transmission is declining or may already have been interrupted.

The indicators relevant to elimination of disease include: absolute number of new autochthonous cases; new case detection rate (expressed per million population); proportion of foreign-born among total new cases (proxy indicator for infection acquired elsewhere); and rate of new cases with G2D. The absolute number of new autochthonous cases directly relates to the target of elimination of disease and is especially useful when new case numbers become very small. If in a country all new cases are foreign-born (or in a province all cases come from outside the province), elimination of leprosy disease may already have been achieved. The rate of new cases with G2D would decrease as case detection improves, e.g. through active case detection, and as the incidence of overall leprosy decreases.

During the post-elimination phase, monitoring the absolute number of cases would be more relevant. Contacts of such cases would need to be screened (preferably annually for five years). Access to few centres (in the country or abroad) and maintenance of their leprosy expertise will need to be ensured since sporadic cases can be expected to occur for many years after this phase has started. It is also important to be mindful of the fact that, besides such sporadic autochthonous cases, there may be imported cases also.

## 7.2. Interruption of transmission, elimination of disease: country experiences

Representatives from Ministries of Health of four countries that have already reached elimination or that report only small numbers annually shared their experience in reaching this point. These countries are: Cuba, Japan, Maldives and Morocco.

### 7.2.1. Experience in interruption of transmission or disease elimination: Cuba

Dr Raisa Rumbaut, National Director Leprosy, shared Cuba's experience in further reducing the leprosy burden in a presentation which can be accessed [here](#). Care is taken through the general health system, which is decentralized and free-of-cost. The country reports about 200 new leprosy cases annually. Though the total number is declining slowly, the decline is much more visible among children (less than five cases annually) since 2016 while before there were around 10 cases annually.



The country is redesigning its surveillance system by incorporating sentinel processes. This applies to leprosy suspects, zero reporting, new cases in children and diagnostic delays. Sentinel populations include contacts and people residing in high-risk areas. Active search is conducted in such settings.

Routine leprosy control activities include: supervised treatment at the health centre level; contact tracing; post-exposure prophylaxis among contacts; stratification of new cases detected in four groups: linked to known index case diagnosed in last five years; index case diagnosed six to ten years ago; index case diagnosed more than ten years ago; and no link to another case possible. The referral network to specialist doctors is maintained and innovations are introduced (especially in digital health). Stigma is also identified among patients, in the community and among health personnel. Further investments are made for strengthening of the diagnostic capacity and increase health promotion activities. Technical advisory committees are also active at provincial level. The programme is also undertaking an annual evaluation of which the results are shared with the health authorities.

### 7.2.2. Experience in interruption of transmission or disease elimination: Japan



Dr **Mariko Mikami**, from the West Yokohama Sugawar Dermatology Clinic and the Department of Clinical Laboratory Science of the Teikyo University, highlighted the elimination process of leprosy in Japan in a presentation which can be accessed [here](#).

Japan was once a leprosy endemic country but has only sporadic autochthonous cases now and not even every year. Since 2010, all autochthonous cases are over 60 years old; no child cases have been detected for more than 20 years. There is also a geographic shift from north to south with the last cases being reported from the Okinawa island prefecture (most southwestern tip of Japan).

The bulk of cases are now found among immigrants from leprosy-endemic countries, mostly Brazil, the Philippines and Nepal. Leprosy is also reducing among migrants, but older age groups tend to have larger share over the years. There is a parallel between the decline in leprosy in migrants from Brazil and the declining detection rate in the State of São Paulo from where most Brazilian migrants originate.

Current leprosy control efforts focus on: (i) surveillance; (ii) laboratory diagnosis; (iii) treatment; and (iv) rehabilitation and disability management. The National Sanatorium Tamazenshoen and Leprosy Research Centre of the National Institute of Infectious Diseases functions provide the national coordination for leprosy. Training of health staff and awareness raising in the community continue to be undertaken.

Japan is in a position to share its expertise in leprosy to other countries across the globe.

### *7.2.3. Experience in interruption of transmission or disease elimination: Maldives*

Ms **Sana Saleem**, Public Health Programme Manager, Health Protection Agency of the Maldives presented the country's experience related to interruption of transmission and elimination of leprosy. Her presentation can be accessed [here](#).



Maldives consists of 1190 islands, out of which 186 are inhabited; they are grouped into 20 atolls. Every island has a health facility with doctors, nurses and other healthcare providers for preventive and curative healthcare.

Leprosy has a long history in the Maldives with segregation and isolation in the 1920s. With the introduction of treatment for leprosy patients in 1959, the affected persons from across the country were moved to two designated islands closer to the capital. The NLP was established in 1974 at which point the prevalence was 70 per 10 000 population. MDT was introduced in 1982. Elimination as a public health problem was achieved in 1997. No new case with G2D has been reported since then. Maldives has reported less than 10 new cases annually since 2008. The last new child case was reported in 2012.

The NLP is benefitting from a well-established referral system, supported by dermatologists who closely monitor every case. Health facilities in the island can refer any leprosy suspect for confirmation to the nearest hospital with a dermatologist. Leprosy is a notifiable disease under the Health Protection Act. Recording, reporting and surveillance of leprosy is computerized.

After observing no registered case in most islands in the past 20 years, the government took the initiative of planning for a zero-leprosy roadmap. Zero leprosy has been defined as 'interruption of transmission of leprosy with no new cases in the autochthonous population for a period of ten years' (twice the average incubation period), in the presence of a strong surveillance system able to detect any new case.

Despite of the remarkable success seen towards interruption of leprosy transmission, Maldives also notes multiple challenges. Improving resilience of health system to the effects of climate change has been highlighted as an area that needs strengthening. High mobility between the islands, with one-

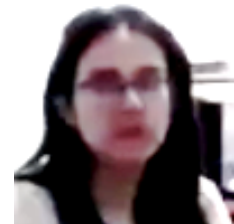
third of the population residing in the capital, poses not only renewed risk of transmission between islands, but also makes identifying and tracing contacts difficult. A large migrant population coming from leprosy endemic countries poses a risk of importing leprosy. Sustaining commitment to zero-leprosy for over a decade from all stakeholders, with changes in government every five years, has also been identified a challenge. Being an upper middle-income country, Maldives struggles to attract partner organizations to provide technical or financial support.

Despite these challenges, and highlighting the need for strong political support, Maldives believes that achieving zero-leprosy is possible. Presence of a strong health system, universal health insurance, a high health expenditure, and access to health services in every inhabited island are noted as strengths that would contribute to this goal. Moreover, the country has experience in eliminating other diseases such as polio, malaria, lymphatic filariasis, measles as well as mother-to-child transmission of HIV and syphilis.

The zero-leprosy roadmap identifies five milestones with introduction of SDR chemoprophylaxis as an important addition. Maldives has a strong commitment to implement the zero-leprosy plan and monitor the progress.

#### **7.2.4. Experience in interruption of transmission or disease elimination: Morocco**

Dr **Asma Saadi** presented the dwindling case burden as seen in Morocco over the past decades. Her presentation can be accessed [here](#). The country has maintained a central leprosy data base since 1950. Morocco eliminated leprosy as a public health problem in 1991. A final push is needed in order to eliminate leprosy by 2030. In 2000, the case detection rate was 2 per million, further decreasing to 0.4 per million in 2019. The prevalence rate has declined significantly after introduction of MDT and the decentralization of leprosy services in 2006. 68% of all new cases are reported from three endemic regions: Tanger-Tétouan-Al Hoceima, Fès-Meknès and Rabat-Salé-Kénitra. Since 2002, the majority of new cases are classified as MB (73%), 61% of the cases were males, 40% of the cases were in the age group of 16-39 years while children made up 7%. The number of new cases with G2D has declined since 2012 and only 1 G2D case was detected in 2020.



A National Leprosy Control Programme was established in 1981. Initially it was centrally operated with 11 regional units. In 2006 health services were decentralized including leprosy care. In 2019 an in-depth external review of the leprosy control programme was conducted. Based on the review findings and recommendations, NLP has developed its *Roadmap towards zero leprosy by 2030*.

Chemoprophylaxis with SDR was introduced in 2012 in four pilot areas and subsequently scaled up nationwide. Implementation of PEP demonstrated a significant reduction in new case detection. During 2012-2019, 80% of all contacts were screened. Among them 91% received SDR while 8% had a contra-indication for rifampicin, 1% refused and 1% was suspected of having leprosy disease.

## 7.3. Country roadmaps for zero leprosy: country perspectives

Four NLP managers shared the roadmaps or strategic plans developed for their countries, with a specific aim to move towards elimination of leprosy. These countries are: Mexico, Nepal, South Sudan and Viet Nam.

### 7.3.1. Country roadmaps for zero leprosy: Mexico



Dr **Fatima Luna**, Director Mycobacterial Disease Control, presented the country's [presentation](#) on behalf of Dr **Marta García**, NLP manager. The presentation was titled: "Let's make history... for a Mexico free of leprosy, without stigma or discrimination".

The number of new cases has reduced a lot compared to 20 years ago, though appears to stagnate in more recent years around 180-200 annually. Leprosy is increasingly confined to few states. The majority of cases occur in the older age groups. The registered prevalence has also declined and six states show nil cases on treatment. 18 municipalities in 9 states report a prevalence rate of more than 100 per million population.

The objectives of the country's 2019-2024 Specific Action Plan for Mycobacterial Disease Control are: (i) Strengthen person-centred prevention and care, with emphasis on vulnerable groups; (ii) Consolidate the leadership of the national programme, ensuring the resources to care for persons affected by mycobacterial diseases; (iii) Promote the participation of civil society and all health care providers in the care of people affected by mycobacterial diseases; (iv) Promote research that allows the implementation of innovative actions in mycobacterial disease control.

Active case detection is undertaken in municipalities that are yet to achieve the benchmark of elimination as a public health problem. Contact tracing is also systematically done, including for index cases in post-treatment surveillance. Priority is given to areas that have reported new cases in the past five years.

Mexico has defined a '2030 Roadmap to Zero Leprosy'. Rather than scaling down leprosy control, the programme is realigning its strategies to the changing needs of low numbers during the end-game. It focuses on national ownership and accountability. It includes curative and preventive approaches, with continuous training of health staff. Integrated care focuses on family and communities. Leprosy research remains important. Investments are also made in strengthening the data management system. Advocacy, health literacy and empowerment at all management and care levels is further intensified. Strategic inter-institutional alliances and linkages with civil society are promoted.

### 7.3.2. Country roadmaps for zero leprosy: Nepal

Dr **Basudev Pandey**, Director of the Epidemiology and Disease Control Division, Ministry of Health, presented the country's roadmap to zero leprosy. His presentation can be accessed [here](#).



Dr Pandey first provided a background on leprosy situation in the country. Some key highlights were:

- Elimination of leprosy as a public health problem at the national level in 2010; subnational elimination is yet to be achieved in 17 (out of 77) districts;
- The prevalence rate shows an increasing trend, due to active case detection undertaken in recent years and thereby almost crossing the elimination threshold;
- Approximately 3000 new leprosy cases are reported each year

The country has a national leprosy strategy covering the period 2016-2020. It aims to reduce the prevalence rate at district level to below the elimination threshold; it also targets for zero G2D among children and a reduction in the G2D rate to less than one case per million population.

Dr Pandey presented the key outcomes of the 'in-depth review of NLP and envisioning *Roadmap to zero leprosy*' which was conducted in July 2019. Some key recommendations were to:

- Pursue high level advocacy;
- Improve the surveillance system;
- Intensify active case detection;
- Implement IEC activities for raising community awareness/reducing stigma;
- Ensure universal contact screening chemoprophylaxis;
- Increase the number of technically qualified staff;
- Ensure adequate allocation and distribution of funds and explore partnerships for complementary funding;
- Strengthen the supply chain management;
- Expand access and coverage of comprehensive disability care;
- Actively engage persons affected by leprosy in planning and implementation.

Dr Pandey lastly briefed on the stakeholders meeting where the participants identified challenges, formulated recommendations and drafted a roadmap to stimulate further discussion and come to an agreement on a final version to guide Nepal's effort towards zero leprosy. The recommended next steps from the meeting were to align the draft roadmap with other relevant strategic plans, such as the *Nepal Strategic Health Plan*, the *WHO NTD Roadmap 2021–2030*, and formation of a smaller working to develop the detailed roadmap.

He also shared the way forward in terms of roadmap to zero leprosy and national leprosy strategy. The country plans to develop a new national leprosy strategy and a roadmap to zero leprosy based on

the recommendations from the national review and aligned with the *Global Leprosy Strategy 2021–2030* and *NTD Roadmap 2021–2030*.

### 7.3.3. Country roadmaps for zero leprosy: South Sudan

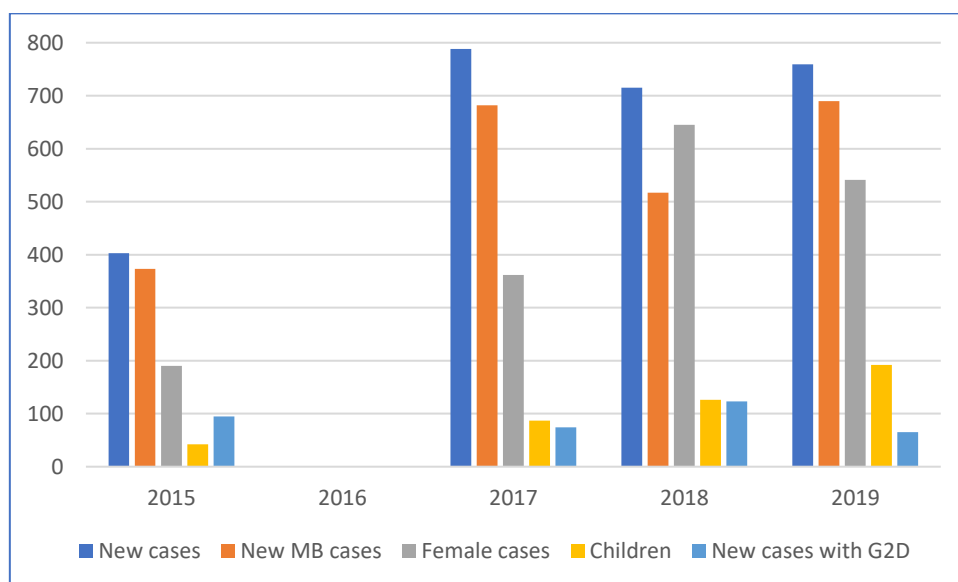


On behalf of Dr **Martin Likambo**, NLP Manager, Dr **Joseph Mogga** from the WHO Country Office for South Sudan presented the country’s Framework for the elimination of leprosy. The presentation can be accessed [here](#).

The goal of the current National Leprosy Strategy of South Sudan is to reduce the leprosy disease burden and to sustain the provision of high-quality services for all affected communities by ensuring the principles of equity and social justice. The country’s NLP faces several challenges in implementing the strategy including competing priorities, recurrent disease outbreaks, inadequate funding, poor health systems and weak surveillance systems. In addition, the country is experiencing a protracted humanitarian crisis and insecurity. Lack of awareness and high levels of stigma also prevail at community level. The states in the western part of the country reported more cases and this is likely related to better availability of services and better security.

During the period 2015-2019, most leprosy indicators worsened in the country due to the conflict (Figure 3). Women appear disproportionately affected: female patients accounted for 90% and 71% in 2018 and 2019, respectively.

**Fig. 3:** Trends in key leprosy indicators, South Sudan, 2015-2016



Taking into account the global initiative and the challenges faced by the country in the implementation of the leprosy programme, a framework for elimination of leprosy was drafted aiming to: (i) strengthen leadership and coordination to improve ownership and partnership; (ii) mainstreaming and integration of leprosy into primary health care package for improved service delivery and data management; and (iii) accelerate programme action for case finding and management, promote social



welfare and community-based rehabilitation of persons affected by leprosy and scale up and strengthen access to underserved and hard-to-reach areas.

#### 7.3.4. Country roadmaps for zero leprosy: Viet Nam



On behalf of Dr **Nguyen Van Thuong**, NLP Manager, Dr **Quang Hieu Vu** from the WHO Country Office for Viet Nam presented the country's National Action Plan for prevention and control of leprosy. The presentation can be accessed [here](#).

Viet Nam has achieved elimination of leprosy as a public health problem in mid-1990s. Since then, leprosy continues to reduce. New cases were (only) 81 in 2019, down from 138 in 2016. Almost 90% of all new cases in 2019 were MB cases and since last two years, country is not reporting any case in children. However, 17 cases presented with G2D in 2019. With the reduction of cases, the programme is losing priority and resources. Capacity of health care workers as well general awareness is dwindling while stigma remains a challenge.

Considering the epidemiology and current challenges, the programme has drafted a National Action Plan 2021–2025 to prevent and control leprosy. This plan aims to maintain 100% care and rehabilitation services to disabled persons. The plan also aims to reach four criteria of elimination in at least 50% of the districts; detection of 100% cases with disability and provision of treatment to all detected cases.

In addition, the programme also aims to eliminate stereotypes, stigma and discrimination, maintain awareness, strengthen communication, advocacy and capacity of local levels. There are some specific indicators set for achieving the ultimate goal of zero leprosy in Viet Nam.

### 7.4. Country roadmaps for zero leprosy: perspective of the Global Partnership for Zero Leprosy



Dr **Bill Gallo**, Director, and Ms **Mondie Tharp**, Project Manager, Secretariat of Global Partnership for Zero Leprosy (GPZL) highlighted the viewpoint of GPZL in a presentation which can be accessed [here](#).



GPZL was launched in 2018 with a purpose to facilitate alignment of the leprosy community and accelerate effective collaborative action towards zero leprosy (no disease, no disability, no discrimination and no stigma). Members aligned to achieve global targets in three ways: (i) aligned research agenda; (ii) country-led planning and capacity building (GPZL model and tools); and (iii) advocacy and fundraising. The Partnership's role is to coordinate strategies and innovations; facilitate the adoption of best practices; be a voice for advocacy and fundraising; and serve as a community of practice.

The Action Framework was presented as a tangible plan what the Partnership intends to do over the next ten years.

GPZL has developed a *Country model* to support NLPs. There are three types of inputs: (i) an online toolkit of best practices with helpdesk; (ii) joint country reviews of leprosy control in the broad sense (medical, epidemiological, programmatic, but also human rights, stigma and discrimination); and (iii) country roadmap, i.e. a medium-to long-term plan that will guide the country towards zero leprosy but can also be used as an advocacy document for funding. This should lead to country-level action planning and implementation.

The toolkit is a collection of field-tested best practices. Some tools are scientifically underpinned while others are practice-based. The different examples are grouped in the following groups: early detection and prompt treatment; PEP, people at-risk; disability prevention and management; reducing stigma, discrimination and exclusion; operational capacity; health workforce; service delivery and medical products; health information; leadership and governance; and health finance.

Success depends on a broad group of partners in each country being closely aligned, through a National Partnership for Zero Leprosy and with a common vision that zero leprosy is achievable.

## 7.5. Country roadmaps for zero leprosy: comments by expert



Dr **Rie Yotsu**, member of TAG-Leprosy, provided her perspective on the adoption of the Global Leprosy Strategy by Member countries and its adaptation to the national and subnational context in each country. Her presentation can be accessed [here](#).

She cautioned that this is a global and generic strategy. Member countries can use it as an important guidance document but need to tailor it to their particular country situation. This situation should be carefully assessed through a challenge and gap analysis. The proposed indicators and especially the global targets should be adapted. Some countries should be more ambitious than what the world wants to achieve while other countries can aim for significant progress towards reaching global targets even if they cannot reach the global target. Each major indicator of the draft Global Leprosy Strategy was projected against different country scenarios.

She urged countries to formulate ‘smart’ objectives:

- Specific: simple, sensible, significant;
- Measurable: meaningful, motivating;
- Achievable: agreed, attainable;
- Relevant: reasonable, realistic, resources, results-based;
- Time-bound: time-based, time-limited, timely, time sensitive.

For each of the four pillars, she recommended that countries establish a baseline and plan accordingly for the future.

Partnerships will be key to success, both within countries (government, NGOs, referral system, private sector, traditional healers, affected persons, etc.) as well as international.

Integration should also be pursued when there is a chance to capitalize on joint interventions and when there is geographic overlap, e.g. with other skin NTDs, wound-causing diseases (such as diabetes), noncommunicable chronic diseases, tuberculosis, water, sanitation and hygiene, etc.

## 8. Stigma and discrimination

### 8.1. Stigma and discrimination: country perspectives

Managers from NLPs in four Member countries commented on the section in the draft Global Leprosy Strategy related to stigma and discrimination. These countries are: Brazil, Malaysia, Senegal and Sri Lanka.

#### 8.1.1. Country perspectives on stigma and discrimination: Brazil



Ms **Carmelita Ribeiro**, General Coordinator for Surveillance of Diseases in Elimination, Ministry of Health, made a presentation which can be accessed [here](#).

She emphasized the role of several historical legal actions taken by the government to ban the use of the word “leprosy” and related terminology, as well as to grant compensation and act in defense of discriminated patients. As per the 2019–2022 National Strategic Plan, programmatic actions are implemented in the three tiers of the country’s administrative structure: federal, state and municipality.

There are established mechanisms to register discriminatory practices through several lines of reporting: ombudsman for the national Unified Health System, monitoring of information collected within communities, specific trainings of health professionals implemented with printed training materials but also online course on stigma prevention.

Supportive actions are considered as a programmatic priority to facilitate access to existing social protection schemes, including joint work with the Ministry of Citizenship, public and private partnerships to extend this protection and awareness within work places, reinforce the national guidelines on stigma prevention and support the expansion of self-care groups within communities, with special efforts to strengthen the capacity and participation of affected population within health services, guaranteeing access to socio-economic support and active inclusion into social control initiatives.

Further perspectives are to create a Hansen’s disease parliamentary caucus in the National Assembly, to develop national campaigns and involve religious leaders and schools in communities, focus on dissemination of informative materials on patient’s rights and protection to continue to empower affected population on the fight against stigma and discrimination.

### 8.1.2. Country perspectives on stigma and discrimination: Malaysia



Dr **Thilaka Chinnayah**, NLP manager, made a [presentation](#) on behalf of Dr **Rafidah binti Baharuddin**, Senior Principal Assistant Director (Leprosy), Ministry of Health.

Malaysia has made significant progress in reducing the leprosy burden and reached elimination as a public health problem in 1994 with further reduction in burden continuing since then. In 2019, 195 leprosy cases were detected with less than 3% children and also less than 3% G2D among them. Any stigma is specifically attached to disability.

With regard to discriminatory laws, in 1926 the *Leper Act* was enacted by the then colonial government in Malaya requiring compulsory notification of all leprosy patients and mandatory isolation and hospitalization. In 1930, Sungai Buloh Leprosarium, officially known as the National Leprosy Control Centre, was opened; it was then one of the largest in Asia. Compulsory isolation of leprosy cases resulted in society's rejection and stigma. The NLP was established in 1969 and promoted ambulatory treatment. This resulted in gradual decline in number of admissions and consequently social inclusion.

Leprosy with G2D, in children and in indigenous communities or migrants attracts higher stigma and results more in discrimination. More than 60% of all new cases occur among migrant or foreign-born persons, a quarter of them remain illegally in the country.

The country has taken several measures to combat stigma. They include: (i) free diagnosis and treatment for all, including migrants; (ii) social protection to persons affected by leprosy; (iii) equal opportunity for employment, training, education, housing benefits and shelter; (iv) disability benefits; (v) indigenous welfare and development; (vi) use of support groups; (vii) training of staff. Several awareness campaigns have been conducted. The 2015 National Health and Morbidity Survey reported high leprosy awareness among community. Several studies have been conducted and published on stigma.

In conclusion, early detection, treatment, prevention and rehabilitation of disability and inclusion of persons affected by leprosy are effective approaches to fight against stigma and discrimination.

### 8.1.3. Country perspectives on stigma and discrimination: Senegal

Dr **Louis Zoubi**, NLP Coordinator, shared his country's experience in addressing stigma and discrimination. His presentation can be accessed [here](#).



He presented the history of leprosy control in his country, starting with the forceful isolation during the colonial time, based on the then prevailing idea that leprosy was incurable. This policy was partially reversed in 1976 and 1978, though the change in legislation still allowed for discrimination.

In Senegal, the stigma remains very strong. Thus, in collaboration with the General Directorate of Social Action and the Senegalese Association of Leprosy Patients, the Ministry of Health and Social Welfare has set up an action plan to combat stigma and discrimination through: militant, educational

actions, as well as actions based on individual contact with people affected by this disease. Action points addressed (i) insufficient awareness and knowledge on stigma and discrimination; (ii) fear for contracting leprosy; and (iii) pluralistic approaches to address stigma and discrimination.

Future work will focus on inclusion of non-discrimination in policy making and in the work and educational places; support to organizations of affected families; use of media.

#### ***8.1.4. Country perspectives on stigma and discrimination: Sri Lanka***

Dr **Champa Aluthweera**, Director of the country's Anti-Leprosy Campaign (ALC), presented on the country's perspective on stigma and discrimination. Her presentation can be accessed [here](#).



She provided an update on the leprosy status in Sri Lanka which achieved elimination as a public health problem in 1995. In 2019, 1660 new cases were reported. Among them, 58% were MB, 40% women, 11% children and 6% presented with G2D at the time of diagnosis; 27% of all cases were reported as 'late presentation'. There are geographic differences with 38% of all cases coming from the Western Province, 16% from the Eastern Province and 12% came from Southern Province. The G2D proportion fluctuated over the years, ranging between 10% in 2015 and 6% in 2006 and 2019.

In 2017 and 2018, ALC undertook research including patients and their families, general public, and health staff, to better understand the status of leprosy in the country. The survey revealed low levels of awareness about leprosy, delay in seeking treatment, considerable level of wrong diagnosis, and high stigma associated with leprosy among all categories of people included in the survey. Dr Aluthweera highlighted the consequences of stigma and discrimination and how it affects the patients, their family and country.

Sri Lanka has been undertaking several activities to avoid stigma and discrimination. Key activities include stopping the separate leprosy clinics that provided leprosy services and integrating the services in the general healthcare system; increasing awareness of leprosy among general public, media and health staff; advocacy among policy makers and religious leaders who are key stakeholder in changing societal perspectives; and are working on amending the old leprosy ordinance. Sri Lanka has also been providing strong support to persons affected by leprosy through the social security system. The ALC has also been organizing public exhibitions to increase public awareness and minimize stigma and discrimination.

Dr Aluthweera noted that main reason for stigma attached to leprosy is deformities and subsequent disability which could be minimized by raising awareness, capacity building, early detection and treatment. Special recreational programmes (including dancing and musical therapy) are organized in leprosy hospitals as part of the activities to reduce stigma and discrimination, where persons affected by leprosy and the hospital staff take part.

## 8.2. Stigma and discrimination: viewpoint of the UN Special Rapporteur



Professor **Alice Cruz**, UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, provided her viewpoint on the issue of stigma and discrimination of persons affected by leprosy. Her statement can be accessed [here](#).

She called on governments and partners to fully implement the Global Leprosy Strategy, thereby providing adequate funding and with participation of organizations of persons affected by leprosy. Implementation of Pillar 4 – related to human rights, stigma and discrimination – is required in order to also successfully implement the other three pillars, based on the inherent interaction between biology, culture and society. In order to be effective, public health strategies need to be comprehensive and act on the social determinants of health and illness.

There is a need to move beyond the medical and charity models that have dominated both public and private interventions on leprosy and leprosy-related stigmatization and truly embrace a human rights approach that recognizes persons affected by leprosy as right holders.

She made several recommendations, including:

- (i) the Global Leprosy Strategy should acknowledge the status of the Principles and Guidelines;
- (ii) The Strategy should advise States to consider the policy framework for rights-based action plans;
- (iii) Leprosy should be mainstreamed into government bodies other than Ministries of Health, such as the ones regarding education, work, justice, but also those created for protecting the rights of more vulnerable groups;
- (iv) In order to eliminate discrimination on the grounds of leprosy, collection of data and monitoring of discrimination requires significant improvement.
- (v) It is mandatory to put in place a robust human rights education strategy directed at different groups
- (vi) Goals need to aim at people-centred health systems
- (vii) As challenges will be mostly felt at the level of national implementation, pillar 1, particularly in what concerns “political commitment with adequate resources for leprosy in integrated context”, is key.

She further recommended to include an explicit reference to Guideline 14 of the Principles and Guidelines on “development, implementation and follow-up to States’ activities”, guiding States to designate a committee to address activities relating to the human rights of persons affected by leprosy and their family members, which should include representatives of organizations of persons affected by leprosy.



### 8.3. Stigma and discrimination: perspective of partners

Three partners based in four countries made an intervention on the topic of stigma and discrimination. They are: GLRA (Colombia), NLR (Indonesia) and TLM (India and Niger).

#### 8.3.1. *Perspective of partners on stigma and discrimination: GLRA Colombia*

Mr **Alberto Rivera** shared the experience of GLRA in a presentation (accessible [here](#)) on the role played by GLRA in Colombia in addressing stigma and discrimination. GLRA is building capacity of organizations and networks of persons affected by leprosy. The agency is also developing systems to monitor stigma reduction at community level.



Organizations of affected persons are set up based on geographic area as well as personal characteristics. Leaders are identified. Group members are empowered through training and mentoring. An action plan is hereto developed, allowing proper monitoring during implementation. Felehansen is the national umbrella organization of local associations of leprosy-affected persons.

In 2018, a study was carried out to monitor the stigma reduction in communities. It focused on mental distress, participation restriction and stigma in persons affected by leprosy, Chagas disease or cutaneous leishmaniasis. Mental distress was common among leprosy patients (nearly 50%), more so in those with low education level; a quarter had participation restriction, especially among women while more than half of the patients reported significant stigma, in the community, by health and education service providers but also self-stigma. A holistic approach can tackle medical, mental and social problems related to stigma. When such approaches are combined for multiple stigmatizing diseases, they can be more effective.

#### 8.3.2. *Perspective of partners on stigma and discrimination: NLR Indonesia*



Dr Mimi Lusli from the Mimi Institute in Indonesia has been working with NLR on issues related to leprosy and stigma. Her perspectives were shared in a presentation which can be accessed [here](#).

As stigma cannot be avoided, it should be embraced by building knowledge, enjoying rights, involving peers and realizing inclusion. Knowledge has the power to make people change (from negative to positive, from exclusion to inclusion). Rights are inherent attached to people; they are widely regarded as the basis of laws, which are aimed at ensuring and protecting these rights. Discrimination on the basis of disability is a violation of the inherent dignity of the human person. In the case of leprosy and disability, peers can contribute much: the person who has experienced (and overcome) stigma is well placed to further reduced stigma against others. Involving them provides added value. An inclusive community is open to persons affected by leprosy and offers them an opportunity to be part of the human diversity, thereby accepting their existence and recognizing their contributions. It is important to mainstream leprosy and disability into policies,



programmes and services. Empowerment of affected persons is of utmost importance, e.g. through counseling and psychological support, educational support and affirmative actions.

She summarized the findings of the *Stigma Assessment and Reduction of Impact* project, which was a research project probing into leprosy-related stigma.

### 8.3.3. *Perspective of partners on stigma and discrimination: TLM India*

Ms **Nikita Sarah**, Head Advocacy and Communication, The Leprosy Mission Trust India (TLMTI), provided the perspective of her organization through a presentation that can be accessed [here](#).



There are a number of plans and documents (national and global) with which TLMTI is aligning its strategies and plans.

She presented the *problem tree*, analyzing the causes (root), the problem (stem) and its effects (branches and leaves). They include: unclear concept of stigma; negative historical perception of leprosy; traditional medical model of care; complicated terminologies and definitions; lack of evidence of discrimination (because of lack of understanding of the concept and rights); discrimination perceived as *karma* (way of life).

She highlighted the next steps to be undertaken to address the problems. They include: simplified definitions; demystification of concept of stigma and discrimination; development of training materials; stakeholder mapping (including peoples' organizations); identification of champions and change agents; IEC; media involvement. A particular project is titled *WACA*, where women affected by leprosy participate meaningfully as change agents in active governance and leadership roles and find dignity in living.

She further elaborated on the impact of COVID-19 on leprosy, especially on health (double stigma, reduced accessibility because of lockdown, treatment interruption, fear); livelihood (income loss, no safety net); education (no smart phones to take part in online education); and isolation.

The way forward includes: mass awareness on rights; convergence of redressal mechanisms existing in states and awareness on how to access these; revision of disability/leprosy pension; states should remove discriminatory language and laws; all organizations to be mindful of images used.

### 8.3.4. *Perspective of partners on stigma and discrimination: TLM Niger*



Mr **Abdou Yohanna**, Programme Manager, TLM Niger, shared the contribution of his NGO with regard to fighting stigma and discrimination against leprosy. His presentation can be accessed [here](#). He elaborated on the work of TLM in Niger, the overall leprosy situation in the country and the work undertaken by partners of TLM (including *Fondation Raoul Follereau*, Danja Serving-in-Mission Leprosy Hospital and IDEA Niger).

TLM works as official partner with both the Ministry of Public Health and the Ministry of Community Development. It is active in six regions in the country. Every year, more than 300 new leprosy cases are detected in Niger. In 2019, 16 health centres reported leprosy.

Stigma against leprosy has been widespread and is linked to ignorance, traditional beliefs and fear, poverty, disabling conditions, and low priority for health workers. Leprosy affected persons were often forced to move to the outskirts of cities; if a leprosy patient could marry, it was typically with another patient. Persons affected by leprosy are the most disadvantaged groups among disabling conditions.

The work of TLM in Niger is in direct support of disease control (including active case detection and training, hospital care) as well as community-based rehabilitation (self-care, income generation and housing). Support is also provided to children of leprosy patients, for formal education and vocational training.

TLM further supports IDEA Niger, established as an organization of persons who have experienced leprosy. Its members contribute in disease control, counseling, awareness creation and integration of persons with disabilities (jointly with the Niger Federation of Disabled Persons).

## 8.4. Stigma and discrimination: perspective of affected persons

Three persons made interventions on behalf of persons who have experienced leprosy. They belong to the following organizations: APAL, the ILEP Panel of Women and Men Affected by Leprosy; and MORHAN.

### 8.4.1. Perspective of affected persons on stigma and discrimination: APAL India

Mr **V. Narsappa**, Mr **Venu Gopal** and Mrs **Maya Ranavare**, Treasure of APAL, made a joint presentation, accessible [here](#), by expressing their gratitude to the Government of India for providing basic leprosy services and for involving persons who have experience leprosy in decision making.



Unfortunately, derogatory words are still commonly used to describe the disease as well as patients and affected persons (including children of cured patients). They concurred with the need to identify “leprosy champions”.

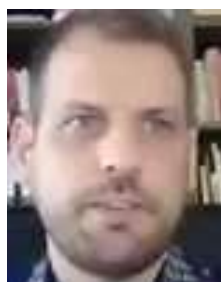
Female leprosy patients are even more negatively affected, reducing their chances of getting married or even being taken away their rights to raise their children. Dwellers of colonies remain excluded from the mainstream society. Affected boys and girls seldomly can study beyond primary school, which affects their chances of getting better job opportunities. Reserved or preferential employment opportunities (in government, private sector and even NGOs) are much less than the demand. People affected by leprosy are also excluded from credit schemes for self-employment.

Stigma and discrimination are very common: at home, but also in hospitals and even in burial places. Stigma reduces access to sanitation, housing, education and work. Leprosy patients are often denied their civil, political, social and cultural rights. Though there is progressing in repealing discriminatory

legislation, there is stiff competition to access benefits while designated government offices remain off-limits for patients to submit requests.

As a result, mental health issues (e.g. depression, anxiety) are very common among leprosy affected persons. Any improvement will only be successful if actions start at the grassroots level.

#### **8.4.2. Perspective of affected persons on stigma and discrimination: ILEP Panel of Women and Men Affected by Leprosy**



The statement, accessible [here](#) and made by Mr Mathias Duck, based in Paraguay, was formulated with contributions from the following organizations of affected persons: *Association Sénégalaise de Lutte contre la Lèpre et les Maladies tropicales négligées* (Senegal), ENAPAL (Ethiopia), Felehansen (Colombia), IDEA (Kenya, Niger, Nepal), NAPAL (Sierra Leone), the Organization of Persons Affected by Leprosy in the Democratic Republic of the Congo and Purple Hope Initiative (Nigeria).

He commended the fact that the draft Global Leprosy Strategy recognizes the crucial role played by organizations of persons affected.

Persons affected by leprosy are often disadvantaged in comparison to other people with disabilities. Many of them continue to live in sub-human conditions in colonies, in spite of these colonies giving some sense of protection against stigma and discrimination. There are many good examples of projects that results in improving the lives of leprosy affected persons. Patient organization have also given evidence that they can have a meaningful contribution in disease control: case detection, psychosocial support, awareness raising, advocacy, etc. These efforts can be increased if more technical, logistical and financial support is made available. More accountability from all stakeholders, including governments, is also required.

He further lauded the role played by the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members and recommended to consider her reports when finalizing the Global Leprosy Strategy. Her latest report refers to binding documents that need to be applied to guarantee the rights of persons affected; while the *Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members* – though important – remains a non-binding document.

#### **8.4.3. Perspective of affected persons on stigma and discrimination: MORHAN**

Mr **Francisco Pinto** spoke on behalf of MORHAN. He shared a series of personal experiences and compelling stories, reflecting in a profound humanitarian tone on the conditions of being a persons affected by Hansen’s disease who had to deal with stigma and discrimination. He expressed the face of social injustice as well as the need to maintain vivid the debate on Hansen’s disease and human rights and to make the voices of affected persons heard. He emphasized that



governments should enforce what is already defined by law. He expressed the urgency to see all suggestions and statements written in various documents by organizations from around the world as well as WHO recommendations becoming tangible actions for better quality healthcare services and promote a life with more dignity.

MORHAN proposes the following actions on a global scale:

- To change the terminology from “leprosy” to “Hansen’s disease” within the scope of governmental and NGOs; and adapt the medical terminology with a more dignifying vocabulary
- To respecting the culture of each individual; through clear and objective information to fight against discriminatory nomenclatures that cause social exclusion.
- To promote the inclusion and guarantee the participation of affected persons in projects, as active participants in the planning, execution and monitoring of activities.
- To fully implement supportive healthcare guidelines and regulations that already exist in each country.
- To provide lectures, seminars, training about stigma with the purpose of improving the quality of the services offered to persons affected by Hansen’s disease.
- To better monitoring and evaluate the services offered to persons affected by Hansen’s disease.
- To make available educational materials including newspaper articles, leaflets and folders that addresses stigma through listening to those affected by Hansen’s disease and respecting their image and dignity.

## 9. Research in leprosy



The draft Global Leprosy Strategy identifies several research gaps, which will need to be addressed in order to reach the 2030 targets. Dr **Nienke Veldhuijzen** from the Leprosy Research Initiative (LRI) gave an overview of how the global community is currently gearing up to streamline the research agenda and facilitates its implementation. Her presentation can be accessed [here](#).

To identify the research gaps and to develop a consensus on the overall research agenda, GPZL established a ‘Research Agenda Working Group’ in 2018. Through a wide consultation process with NLPs and partners, this resulted in a broad agenda where a multitude of research topics were categorized in eight groups.

Prioritization of this research agenda was carried out in 2020 by a panel of 39 experts based on various criteria and an e-survey on importance rating. Delphi panel was used to reach agreement on the ranking. The prioritization exercise considered the draft *NTD Roadmap 2021–2030* and GPZL Action Framework. Main criteria used for prioritization were urgency, impact, translational potential, feasibility, cost, timeliness and novelty of the topics. The exercise led to the following results:

- ✓ 40 topics were prioritized. Topics around operational research and health system research considered of higher priority than topics related to basic science.
- ✓ Topics were then triangulated and categorized along the three main LRI priorities: zero transmission (10); zero stigma and discrimination (7); and zero disability (8).
- ✓ Cross-cutting topics were related to health systems research, digital tools, data quality and modelling.

The prioritization exercise was published in several journals including *Leprosy Review*. The next steps would include involvement of persons affected by leprosy and broader engagement in the following phase.

The formulation of a multiple stakeholder-driven prioritized research agenda was acknowledged as a successful endeavour which, while focusing on operational research, includes topics ranging from fundamental to applied research and is well aligned with the vision of the *Global Leprosy Strategy 2021–2030* and includes cross-cutting topics.

The next steps would be to carry out a mapping of ongoing research in order to identify any unmet priorities, plan for resource mobilization, coordination and implementation while liaising with all stakeholders including NLPs, GPZL, LRI, ILEP, WHO and persons affected with leprosy.

## 10. Concluding session

### 10.1. Statements by partners

Statements of support were made by the following partners: The Nippon Foundation (TNF)/SHF, GPZL, ILEP, Novartis and two statements on behalf of leprosy-affected communities. A summary of the statements is provided below, in alphabetical order.

#### 10.1.1. Affected persons



Ms **Zoica Barkivtzief de Silva Pereira**, representative of IDEA in Brazil, formulated some key elements of support for the *Global Leprosy Strategy 2021–2030* in the ‘West’ session. These comments are given by persons who have experienced leprosy. “Nothing about us without us” has been rightfully applied throughout the development of the Strategy and she praised the way persons affected by leprosy have been truly involved from the initial stages of the development of the Strategy. The rights of leprosy patients and persons with disabilities are well covered as are the duties and responsibilities of health care providers. She appreciated the emphasis on counseling and obtaining informed consent, especially when it comes to contact tracing. She further commended the holistic approach advocated throughout diagnosis, treatment and care, also after cure. She further cautioned to remain vigilant for ensuring that the dignity of the persons remains guaranteed. She trusts that the voice of affected persons will continue to be heard by governments and partners when it comes to implementing the Strategy.

**Md. Kamal Uddin** is the Chairperson of the patient organization *Advancing Leprosy and disadvantaged peoples Opportunities Society* in Bangladesh. He provided a statement in capacity of a person who has experienced leprosy. His statement can be accessed [here](#).



His organization – known by its acronym ‘ALO’ – is the apex body of an 89-member subdistrict federation, itself constituted by 1554 self-help groups. ALO represents the voice of affected person nationally and internationally. It contributed to the country review report on the United Nations Convention on the Rights of Persons with Disabilities.

He specifically requested WHO to consider the following when finalizing the Global Leprosy Strategy:

- mass awareness, early case detection, disability care, complication management need to be integrated with the government health system in all aspects; in relation to, government ownership needs to be enhanced.
- Integrate leprosy related disability care within the wider movement for rights, stigma reduction and disability services
- Leprosy people’s organizations should be recognized and partnerships with them fostered by government as well as funding agencies;
- NLP needs to be a holistic program in order to respond to all the needs of persons affected by leprosy
- Leprosy people’s Organizations can support the following activities under the Global Leprosy Strategy: stigma reduction through awareness creation among self-help group members; identification and referral of leprosy suspects by self-help group members; advocacy for the rights and entitlements of leprosy-affected and disability-affected persons; support the livelihood of persons affected by leprosy or persons with disabilities.

### 10.1.2. GPZL



On behalf of GPZL, **Bill Simmons**, Chairperson of the GPZL Leadership Team, provided a statement of support in the ‘West’ session while **Bill Gallo** provided a similar statement in the ‘East’ session. They emphasized the role of country partnerships, country-owned roadmaps and the readiness of GPZL to support resource mobilize and provide technical and operational assistance. He reminded about the Partnership’s ‘toolkit of best practices’ which can facilitate implementation of especially pillars 2 and 3. The presence of NLP managers and affected persons in the GPZL’s Leadership Team are an expression of the Partnership’s drive to work with and for countries and persons who have experienced leprosy and enhance their voices. The Partnership is also adjusting itself to new realities imposed by COVID-19. It further supports conducting research to broaden the evidence base for policy formulation as well as introduce more effective tools. The goal of the Partnership is to increase alignment among all stakeholders and assist national programmes as they do the hard work of reaching all of those whose lives are impacted by this disease.



### 10.1.3. ILEP



**Brent Morgan**, CEO-elect from ILEP, provided a statement in the 'West' session while **Geoff Warne**, current CEO of ILEP, did the same in the 'East' session. ILEP and its members share the desire for a world free of leprosy. ILEP works in partnership with persons affected by leprosy, with governments, WHO, GPZL and other NGOs and donors. Its



members operate more than 700 projects in 60 countries. ILEP lends its expertise to support all aspects of leprosy control. ILEP fully supports the WHO Global Leprosy/Hansen's disease Strategy for 2021–2030. The 2030 targets are ambitious and will push for more focused action, better integration, innovation, alignment of partners and best use of available resources. ILEP would also welcome further guidance on how to implement the strategy. ILEP and its members will continue to work closely with WHO, countries and partners and support the adoption and adaptation of the strategy to the particular circumstances for effective implementation.

### 10.1.4. Novartis



Dr **Gangadhar Sunkara**, Senior Global Programme Clinical Head, provided Novartis' statement of support in the 'West' session while **Arielle Cavaliero**, Global Franchise Lead (Leprosy), did so in the 'East' session. For 20 years, Novartis has been donating MDT drugs, which has proven to be a cornerstone of many leprosy control programmes. Novartis



(and earlier the Novartis Foundation) is also proud of having partnered in establishing the effectiveness of chemoprophylaxis. Novartis values the *Global Leprosy Strategy 2021–2030* very much and will align its own strategy alongside it. Novartis is keen to work with partners in the journey of leprosy elimination, both scientifically and medically. One of its focus areas will be the support to logistics management, so that end users can benefit from an uninterrupted supply of high-quality medicines. Novartis also supports digital health and is working with Microsoft Artificial Intelligence for designing a screening tool for skin diseases, which may become a point-of-care diagnostic test. He committed the support of Novartis, especially in endemic countries where the company has a physical presence. Being a member of GPZL, Novartis will continue to support global leprosy control in the spirit of collaboration and transparency.

### 10.1.5. The Nippon Foundation/Sasakawa Health Foundation



Professor **Takahiro Nanri** made a statement on behalf of Sasakawa Hansen disease Initiative, which is a strategic alliance between the WHO Goodwill Ambassador for Leprosy Elimination, SHF and TNF. He highlighted three points in particular: (i) the inclusion of practical indicators based on trends following elimination as a public health problem; (ii) comprehensive scale-up of leprosy-related health services to include new initiatives; and (iii) the emphasis on stigma



and discrimination. He further suggested to provide a clear link to UHC, to identify actors responsible for implementing the strategy and to bear in mind what ‘zero leprosy’ means for countries that pursue integration. He further recommended to investigate ‘silent zones’ and to cost the strategy. He ensured the support of his agency.

## 10.2. Conclusions and recommendations

During the course of the four-day consultation, GLP has summarized the key conclusions and recommendations that emanated from the discussions but also from the comments received in the chat box as well as communication sent by email. These were presented by Dr **VK Pannikar**.

As a preamble or background, he stated the following: “The virtual Global Consultation with NLP managers, partners, affected persons and their organizations on the draft Global Leprosy Strategy 2021–2030 started with opening message from the Regional Director. In her message, she stressed the importance of national ownership, commitment and provision of evidence-based guidance and technical support from WHO. There are visible signs that leprosy transmission is decreasing, the number of new cases, child cases and cases with G2D are on the decline. More importantly, stigma and discrimination towards persons and families affected by leprosy are reducing. Leprosy is now more seen as a skin disease which can be easily cured. The new approved tool to prevent leprosy, with a single dose of rifampicin is a wonderful addition to our armaments against leprosy. In the times of COVID-19 pandemic, innovative approaches like e-learning, m-health, telemedicine etc. are finding new roles. Most importantly, promoting dignity of persons affected by leprosy and respecting their human rights will be crucial to make a leprosy-free world. Mr Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, has been supporting WHO’s leprosy work for more than 40 years. He visited more than 120 leprosy endemic countries to motivate political leaders and policy makers to pay attention to leprosy. In his message he welcomed the global target of 70% reduction of new cases by 2030. He stressed the need to reach difficult to reach areas to attain UHC. More than 70 NLP managers, partners, affected persons and experts spoke during the four-day consultation and shared their perspectives and experiences. In addition, several hundred individuals participated and many of them provided inputs, comments, suggestions and feedback through the chat-box and email communications.”

The following conclusions and recommendations were made:

- The participants generally agreed with the draft *Global Leprosy Strategy 2021–2030*.
- The new pillar ‘Scale up leprosy prevention alongside integrated active case detection’ is overwhelmingly supported by NLP managers, partners and persons affected by leprosy and their organizations.
- Contact tracing and chemoprophylaxis combination has the potential to be a game changer in elimination of leprosy. Many endemic countries have embarked on or plan to implement post-exposure prophylaxis. India and Indonesia are already scaling up this new intervention.
- Innovative approaches such as e-learning, distance education and tele-medicine will be needed for capacity building and maintaining leprosy expertise.

- Countries should develop National Leprosy Strategies with activities and targets adjusted to the local context at national and sub-national level, including duration of their strategy.
- Integrated/combined leprosy services with other disease/NTD programmes will improve effectiveness and efficiency.
- There is a need to keep watch on new scientific developments in chemotherapy, chemoprophylaxis, vaccines and diagnostics and their incorporation into the leprosy elimination strategies.
- Brazil and China are taking the lead in development of new molecular tests to diagnose early leprosy disease and infection. There is a need to explore networking with other countries.
- Establishing a strong and effective surveillance and response system to capture new cases, sporadic new cases, relapses, new cases among children and foreign-born/migrant individuals will still be needed for many years after elimination has been achieved.
- Integrated surveillance systems can capture information in several diseases/conditions and keep the relevant disease programme informed, for example, skin NTDs.
- ‘People requiring interventions’ should include persons requiring MDT, care during and after treatment (disabilities, reactions), mental health support, rehabilitation, and persons who can benefit from prophylactic interventions.
- Mental health issues are becoming very important, as depression and anxiety among persons affected by leprosy are more frequent than previously thought. There is a need to provide supportive services for counselling and psychological first-aid at the point of care.
- It is noted that WHO is currently developing mechanisms for verification of elimination of leprosy and interruption of transmission, which could be applied to national and sub-national level.
- It is recognized that eradication of leprosy is not feasible at this point of time due to presence of a zoonotic reservoir in some areas. Studies to understand the mode of zoonotic transmission and its overall epidemiological significance will be needed.
- Participants suggested WHO to support activities required to improve and maintain laboratory capacity at referral levels (including microscopy and histopathology) for diagnosis, confirmation of relapse cases and drug resistance testing.
- UHC will help in reaching the targets of the leprosy strategy and NTD roadmap, which will contribute to achieving the SDGs.
- Implementation of the *Global Leprosy Strategy 2021–2030* will be reviewed periodically to assess progress and make any course correction.
- Monitoring of resistance to drugs used in the treatment of leprosy, leprosy reactions and prevention of leprosy; and monitoring adverse drug reactions should be part of core leprosy programme activities.
- Prevention of disability; and disability care during and after treatment are very important to prevent socio-economic disruption and hardships suffered by persons affected by leprosy and their families.

- The UN Special Rapporteur appreciated WHO for including ‘combatting stigma and discrimination and making a reference to UN Principles and Guidelines in the draft Global Leprosy Strategy.
- The year 2020 has seen unimaginable disruption to health programmes, including leprosy programmes, due to the COVID-19 pandemic. It will be necessary to adjust the data reported during 2020 to use as the baseline for 2021–2030 strategy.
- As this pandemic will continue to affect for considerable time, leprosy control will need to adjust to the ‘new-normal’.

### 10.3. Closing remarks

Closing remarks were made by Dr **Erwin Cooreman**. On average, there were between 350 and 400 participants in the east and west sessions, every day, from a variety of countries, including all priority countries, and partners, affected persons and other stakeholders. Presentations were delivered by more than 70 speakers. The interventions were very rich and informative and have confirmed that the draft Global Leprosy Strategy is generally well conceived. Some new and sometimes unexpected but very valuable contributions were also made and deserve to be incorporated in the final version. Uncountable comments were received through the chat box as well as by email and these will also be considered when finalizing the strategy.

Initially it was thought that COVID-19 would take away the opportunity for consulting with stakeholders but this was turned into an opportunity and many more stakeholders were in a position to take part and contribute in this consultation than would otherwise have been the case in a face-to-face meeting.

A strategy is as valuable as it gets implemented. The onus is now on all stakeholders to translate this document into action so that we can truly make a leap forward towards zero leprosy.

On behalf of WHO, Dr Cooreman sincerely thanked all participants, NLP managers, persons affected by leprosy, partners, experts and fellow WHO colleagues in headquarters, regional and country offices and also the translators who have done great efforts to make the interventions available in English, French, Spanish, Portuguese and Russian.

## Annex 1: Programme

‘West’ AFR AMR EMR EUR	‘East’ SEAR WPR	Agenda item [presenter]					
		‘West’	‘East’				
<b>26 Oct (IST)</b>	<b>27 Oct (IST)</b>	<b>Day 1</b>					
18:00-18:30	09:30-10:00	Inaugural session - 01. Inaugural address by RD SEARO [Poonam K Singh] - 02. Message by WHO Goodwill Ambassador for Leprosy Elimination [Yohei Sasakawa] - 03. Objectives and expected outcomes [Erwin Cooreman]					
18:30-18:45	10:00-10:15	04. Global leprosy situation: current situation [VRR Pemmaraju]					
18:45-19:15	10:15-10:45	05. Challenges in implementation - Ethiopia [Taye Letta] - Brazil [Gerson Fernando] - Somalia [Abdul Aziz] <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none;">- India [Sunil V. Gitte]</td> <td style="width: 50%; border: none;">- Philippines [Julie Rubite]</td> </tr> <tr> <td style="border: none;">- Micronesia [Mayleen Ekiek]</td> <td style="border: none;"></td> </tr> </table>		- India [Sunil V. Gitte]	- Philippines [Julie Rubite]	- Micronesia [Mayleen Ekiek]	
- India [Sunil V. Gitte]	- Philippines [Julie Rubite]						
- Micronesia [Mayleen Ekiek]							
19:15-19:20	10:45-10:50	<b>Comfort break</b>					
19:20-19:50	10:50-11:20	06. Draft Global Leprosy Strategy 2021–2030 [Erwin Cooreman]					
19:50-20:10	11:20-11:40	07. Roadmap for NTDs, 2021–2030 [Gautam Biswas] 08. Global architecture for elimination of multiple diseases [Richard Carr]					
20:10-20:30	11:40-12:00	09. General comments from TAG-Leprosy [VK Pannikar]					
<b>27 Oct (IST)</b>	<b>28 Oct (IST)</b>	<b>Day 2</b>					
18:00-18:15	09:30-09:45	10. Contact tracing and post-exposure prophylaxis: WHO guidance and next steps [Erwin Cooreman]					
18:15-18:45	09:45-10:15	11. Contact tracing and/or post-exposure prophylaxis: country perspectives - Tanzania [Deusdedit Kamara] - Colombia [Yessenia Castro] - Ghana [Benedict Quao] <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none;">- India [Megha Khobragade]</td> <td style="width: 50%; border: none;">- Indonesia [Naufal Azhari on behalf of Prima Yosephine]</td> </tr> <tr> <td style="border: none;">- Kiribati [Erei Rimon]</td> <td style="border: none;"></td> </tr> </table>		- India [Megha Khobragade]	- Indonesia [Naufal Azhari on behalf of Prima Yosephine]	- Kiribati [Erei Rimon]	
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- Kiribati [Erei Rimon]							
18:45-19:00	10:15-10:30	12. Contact tracing and/or PEP: perspective of persons affected - ENAPAL [Tadesse Tesfaye] - MORHAN [Paula Brandão] <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none;">- IDEA Nepal [Amar Timalisina]</td> <td style="width: 50%; border: none;">- Papua New Guinea [Rawali Ila, Marie Vekwa]</td> </tr> </table>		- IDEA Nepal [Amar Timalisina]	- Papua New Guinea [Rawali Ila, Marie Vekwa]		
- IDEA Nepal [Amar Timalisina]	- Papua New Guinea [Rawali Ila, Marie Vekwa]						
19:00-19:15	10:30-10:45	13. Contact tracing and/or PEP: perspective of partners - ALM [Paul Saunderson] - GLRA Tanzania [Blasdus Njako] <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none;">- PLF [Jill Tomlinson]</td> <td style="width: 50%; border: none;"></td> </tr> </table>		- PLF [Jill Tomlinson]			
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19:15-19:20	10:45-10:50	<b>Comfort break</b>					
19:20-19:50	10:50-11:20	14. Disability care: country perspectives - Russian Federation [Victor Duiko] - Paraguay [Olga Aldama] - DR Congo [Florent Ngondou] <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none;">- Bangladesh [Rahat Chowdhury]</td> <td style="width: 50%; border: none;">- China [Hong-Sheng Wang]</td> </tr> <tr> <td style="border: none;">- Myanmar [Myo Ko Ko Zaw]</td> <td style="border: none;"></td> </tr> </table>		- Bangladesh [Rahat Chowdhury]	- China [Hong-Sheng Wang]	- Myanmar [Myo Ko Ko Zaw]	
- Bangladesh [Rahat Chowdhury]	- China [Hong-Sheng Wang]						
- Myanmar [Myo Ko Ko Zaw]							
19:50-20:10	11:20-11:40	15. Disability care: perspective of persons affected by leprosy - MORHAN [Patrícia Soares] <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none;">- APAL [V Narsappa, Venu Gopal]</td> <td style="width: 50%; border: none;">- HANDA [Sally Qi]</td> </tr> </table>		- APAL [V Narsappa, Venu Gopal]	- HANDA [Sally Qi]		
- APAL [V Narsappa, Venu Gopal]	- HANDA [Sally Qi]						

'West' AFR AMR EMR EUR	'East' SEAR WPR	Agenda item [presenter]	
		'West'	'East'
20:10-20:30	11:40-12:00	16. Disability care: perspective from partners <ul style="list-style-type: none"> <li>- TLM [Jannine Ebenso]</li> <li>- ANESVAD [Gabriel Diez]</li> </ul>	
		<ul style="list-style-type: none"> <li>- NLR India Foundation [Ashok Agarwal]</li> <li>- LEPR Bangladesh [Md. Mijanur Rahman]</li> </ul>	
<b>28 Oct (IST)</b>	<b>29 Oct (IST)</b>	<b>Day 3</b>	
18:00-18:25	09:30-09:55	17. Interruption of transmission, elimination of disease: Interim report of Task force [Wim van Brakel]	
18:25-18:50	09:55-10:20	18. Leprosy elimination: indicators to be monitored [Vivek Lal]	
18:50-19:20	10:20-10:50	19. Interruption of transmission, elimination of disease: country experiences <ul style="list-style-type: none"> <li>- Morocco [Asma Saadi]</li> <li>- Cuba [Raisa Rumbaut]</li> </ul>	
		<ul style="list-style-type: none"> <li>- Maldives [Sana Saleem]</li> <li>- Japan [Mariko Mikami]</li> </ul>	
19:20-19:30	10:50-11:00	<b>Comfort break</b>	
19:30-20:00	11:00-11:30	20. Country roadmaps for zero leprosy: country perspectives: <ul style="list-style-type: none"> <li>- Mexico [Fatima Luna on behalf of Marta A. García]</li> <li>- South Sudan [Joseph Mogga on behalf of Martin Likambo]</li> </ul>	
		<ul style="list-style-type: none"> <li>- Nepal [Basudev Pandey]</li> <li>- Viet Nam [Quang Hieu Vu on behalf of Nguyen Van Thuong]</li> </ul>	
20:00-20:15	11:30-11:45	21. Country roadmaps for zero leprosy: perspective from partners [Bill Gallo, Mondie Tharp]	
20:15-20:30	11:45-12:00	22. Country roadmaps for zero leprosy: comments by expert [Rie Yotsu]	
<b>29 Oct (IST)</b>	<b>30 Oct (IST)</b>	<b>Day 4</b>	
18:00-18:30	09:30-10:00	23. Stigma and discrimination: country perspectives <ul style="list-style-type: none"> <li>- Senegal [Louis Zoubi]</li> <li>- Brazil [Carmelita Ribeiro]</li> </ul>	
		<ul style="list-style-type: none"> <li>- Sri Lanka [Champa Aluthweera]</li> <li>- Malaysia [Thilaka Chinnayah]</li> </ul>	
18:30-18:40	10:00-10:10	24. Stigma and discrimination: viewpoint of UN Special Rapporteur [Alice Cruz]	
18:40-18:55	10:10-10:25	25. Stigma and discrimination: perspective of partners <ul style="list-style-type: none"> <li>- GLRA Colombia [Alberto Rivera]</li> <li>- TLM Niger [Yohanna Abdou]</li> </ul>	
		<ul style="list-style-type: none"> <li>- NLR Indonesia [Mimi Lusli]</li> <li>- TLM Trust India [Nikita Sarah]</li> </ul>	
18:55-19:10	10:25-10:40	26. Stigma and discrimination: perspective of persons affected by leprosy <ul style="list-style-type: none"> <li>- MORHAN [Francisco Pinto]</li> <li>- ILEP Panel [Mathias Duck]</li> </ul>	
		<ul style="list-style-type: none"> <li>- APAL [V Narsappa, Venu Gopal, Maya Ranavare]</li> </ul>	
19:10-19:30	10:40-11:00	27. Research [Nienke Veldhuijzen]	
19:30-19:40	11:00-11:10	<b>Comfort break</b>	
19:40-20:05	11:10-11:35	28. Statements by partners <ul style="list-style-type: none"> <li>- TNF/SHF [Takahiro Nanri]</li> <li>- GPZL [Bill Simmons]</li> <li>- ILEP [Brent Morgan]</li> <li>- Novartis [Gangadhar Sunkara]</li> <li>- Affected person [Zoica Barkivtzief de Silva Pereira, IDEA]</li> </ul>	
		<ul style="list-style-type: none"> <li>- TNF/SHF [Takahiro Nanri]</li> <li>- GPZL [Bill Gallo]</li> <li>- ILEP [Geoff Warne]</li> <li>- Novartis [Arielle Cavaliero]</li> <li>- Affected persons [Md. Kamal Uddin, ALO Bangladesh]</li> </ul>	
20:05-20:20	11:35-11:50	29. Conclusions and recommendations [VK Pannikar]	
20:20-20:30	11:50-12:00	30. Closing session [Erwin Cooreman]	

## Annex 2: List of participants

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The World Health Organization organized a Consultation of National Leprosy Programme managers, partners and affected persons to discuss the draft Global Leprosy Strategy, 2021–2030. This virtual event took place from 26 to 30 October 2020. It was attended by more than 450 stakeholders. Contributions were shared through 70 presentations made by stakeholders from all Regions. The presentations covered the key strategic approaches: global context, challenges in countries, contact tracing and post-exposure prophylaxis, disability care, interruption of transmission and elimination of disease, stigma and discrimination, research. In addition to numerous comments received through the chat box and by email, the conclusions and recommendations of this Consultation will guide finalizing the post-2020 Global Leprosy Strategy.