ANNUAL REPORT

Leprosy Control Program 2022

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Directions for referring to this book:

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Annual Leprosy Control Program Report 2022.

Remarks

Minister of Health of the Republic of Indonesia

I am delighted by the completion of this Leprosy Control Program Report 2022.

Many people think that leprosy is part of history and has long disappeared from Indonesia. In fact, Indonesia is not yet free from leprosy, and the disease and the stigma surrounding it persist. Approximately 15,000 - 17,000 new cases of leprosy have been found every year in the last two decades, with about 10% occurring in children and approximately 4-6% being classified as Grade-2 Disability cases. A fact rarely known to the public is that Indonesia currently ranks third globally for the highest number of leprosy cases, following India and Brazil. This fact is a cause for great concern for all of us.

The Ministry of Health is aware of this situation and is determined to make Indonesia free of leprosy in this generation. This goal is ambitious, but we must strive for it, and the Ministry of Health is determined to achieve it through the formulation of the National Action Plan (NAP) for Leprosy Elimination 2023–2027. This plan outlines targets, strategies, budgets to eliminate leprosy, and expected contributions from various parties.

The Leprosy Control Program Report 2022 contains information, data, and the public's perspective regarding the dynamics of the national leprosy program in 2022. Lessons learned and recommendations for improvement are also conveyed in detail. I believe all stakeholders will gain a comprehensive understanding of our current status and the direction we are heading in the upcoming years toward a leprosy-free Indonesia.

Thank you to all those who participated in preparing this report.

Health Minister

BUDI G. SADIKIN

Foreword

Director General for Disease Prevention and Control

The transformation of the National Health System with its six pillars is the basis and reference for the implementation of all health programs in Indonesia. The results of it start to be seen. Several indicators have shown improvement, including in the national leprosy control program.

We realize that a few pillars of transformation still need to be strengthened in the leprosy control program, namely the first and fifth pillars: **transformation of primary services** and **transformation of human resources.** The Leprosy Control Program Report 2022 also confirms this. Therefore, we will give special attention to both pillars, specifically the role of primary service and human resources to carry out: *community education activities, early case detection, and provision of preventive drugs* with improved coverage and quality in years to come.

The Leprosy Control Program Report 2022 becomes more special because it does not only describe numbers, but also stories or experiences of the community and health workers when providing and accessing health services. Such stories are very touching and inspiring.

Finally, I would like to thank all those who have participated in writing this Report.

Director General of Disease Prevention and Control (DG of DPC)
Ministry of Health of the Republic of Indonesia

Dr. dr. Maxi Rein Rondonuwu, DHSM, MARS

Summary

The year of 2022 is a special year for the Leprosy Control Program because of two reasons. Firstly, 2022 was a period when the impact of the COVID-19 pandemic in Indonesia became sluggish that the implementation of the leprosy control program gradually returned to normal in the mid of the year. Secondly, 2022 was the last period for the implementation of the Ministry of Health Strategic Plan 2020 – 2024 prior to the implementation of a new National Action Plan (NAP) toward Leprosy Elimination 2023 – 2027. The accelerated renewal of the NAP was in line with the newly released global document of the WHO strategy, Towards Zero Leprosy 2021-2030.

In 2022, leprosy is still a public health problem in Indonesia with number of cases that is relatively the same as the situation for the last 2 decades. The number of new cases of leprosy each year is still around 15,000 – 17,000, with the proportion of cases in children 9-12%, the proportion of Grade-2 Disability (apparent disability) 5-8% and Grade-2 Disability in children 2-5%. The position of Indonesia as a country that contributes the most cases of leprosy in the world also remains in the third place after India and Brazil.

Efforts to eliminate leprosy in Indonesia have actually shown improvement from year to year, but the challenge is still quite numerous. Since Indonesia achieved leprosy elimination at the national level in 2000, number of leprosy-endemic provinces and districts/cities reporting elimination indeed increases. Nevertheless, Indonesia has failed to achieve its target for provincial-level elimination by 2019. At the end of 2022, 7 provinces and 113 districts/cities were still reported not achieved leprosy elimination, causing elimination at district/city level targeted in 2024 will not be achieved either.

The current national leprosy program and policy consist of four strategies, namely health promotion, surveillance, chemoprophylaxis, and leprosy case management. Evaluation of the program implementation shows that, in general, all of these strategies have not been implemented optimally due to the following factors: (i) coordination across sectors/programs between national and regional; (ii) capacity and number of human resources; (iii) national-regional funding scheme; and (iv) drug availability. A bigger proportion of attention needs to be given to the health promotion aspect, especially in addressing the problem of stigma which has been hindering the early detection and treatment of leprosy cases in the last few decades.

The Ministry of Health and development partners continue to make various efforts and program innovation to accelerate the achievement of leprosy elimination. These efforts have resulted in good practices in several areas which could be replicated to other areas.

One of the concrete manifestations of the commitment of the Ministry of Health for the elimination of leprosy is the preparation of the National Action Plan (NAP) toward Leprosy Elimination 2023 – 2027 which includes 4 new pillars of strategy. Trying to address the weaknesses of existing leprosy elimination program, the four pillars of the NAP are: community; acceleration; integration; and commitment, policy, and management, all of which are well aligned with the spirit of the transformation of the national health system.

Our dream is to achieve Indonesia free from leprosy and its consequences in this generation. To make it happened, technical policies regarding the availability of human resources and budget, including drugs, has been urgently required. Strengthening the cross-sectoral and cross-program collaboration among stakeholders is also critical. The NAP toward Leprosy Elimination 2023 -2027 has mentioned that the amount of budget needed for the program is one hundred times higher than the annual leprosy-budget of the last 5 years. To make this budget available is a big homework for all stakeholders, especially for the governments. The non-government actors are also expected and encouraged to support the implementation of this NAP. Program approach using conventional methods in health promotion need to be reviewed by considering the way of communication of people in the current digital era. All of these efforts need to be built on strong commitments from all involved parties. That way, Indonesia will be able to achieve leprosy-free by 2030.

Table of Content

Introduction

Included in the neglected tropical diseases (NTD), leprosy is a chronic infectious disease caused by Mycobacterium Leprae bacteria that attacks the peripheral nerves, skin, eyes and nasal mucosa. Even though it usually does not cause death, Leprosy that is handled late can cause functional damage of nerves even organ deformity (disability) (WHO 2023).

The impact of leprosy is multidimensional for it does not only impact on physical health aspects, but also on psychological, social and economic aspects of the persons affected by leprosy (Somar, Waltz & Van Brakel 2020). Therefore, the treatment of leprosy also requires a multidimensional approach. A globally known approach is called Triple Zero approach consisting of Zero Transmission, Zero Disability, and Zero Exclusion/Discrimination. This means that efforts to tackle leprosy are primarily aimed at preventing its transmission in the community. However, if the transmission is not possible to be prevented, then the next effort is aimed at preventing occurrence of disability in leprosy patients. If disability is also unavoidable, then the last resort is preventing discrimination against people with disabilities due to leprosy. In the last two decades, the national policy and program on leprosy control has been increasingly paying equal attention to these triple-zero aspects.

Zero Transmission

Zero Disabillity

Zero Exculusion

At national level, Indonesia has achieved Leprosy elimination in the year 2000 with number of cases less than 1 per 10,000 population. Although in the last 20 years the number of provinces and districts/cities that report elimination continue to increase, the elimination target at provincial level by 2019 was not achieved (Kemenkes RI 2023a). In 2010, for example, there were 14 provinces and 150 districts/cities that have not achieved leprosy elimination (Kemenkes RI 2010). By the end of 2022, this figure has decreased to 7 provinces and 113 districts/cities. With this situation, the national target for achieving leprosy elimination in all districts/cities by 2024 will not be achieved (Kemenkes RI 2022b).

Annually
15.000–17.000

90% Proportion of MB Type Leprosy

Woman cases
35% - 40%

Child cases
9% - 10%

Grade-2 Disability **5% - 8%**
In Childern **2% - 5%**

Data WHO 2022

Indonesia is also facing stagnation in the number of new cases of leprosy, which ranges from 15,000–17,000 annually with a proportion MB-type of around 90%. The proportion of women is around 35-40% and the proportion of children is around 9-10%. Grade-2 Disability rate is around 5-8% and Grade-2 Disability in children is around 2-5% (WHO 2022). This suggests that ongoing transmission is still high, and that it is not yet sufficiently coped with early case detection and treatment.

An overview of the implementation of the national leprosy control program, especially throughout 2022, will be described in this report: what has been going well; what has not gone well, and lessons learned that can be taken for improvement in the future. Through this report, stakeholders from government, non-government, community, academics and financing institutions are expected to sharpen their strategies and action plans for accelerating the achievement of leprosy elimination and making Indonesia free from leprosy and its consequences.

Our Voice

Restoration of Self-Dignity

Dasuki (male, 40) at first did not know what leprosy was. He only knew about this disease when he was diagnosed with leprosy at the Public Health Centre (Puskesmas) when he was 17 years old. Soon after being diagnosed with leprosy, Dasuki seeks as much information as possible about leprosy. "I finally know that leprosy is contagious and can cause disability if found late", said Dasuki who works as a seller of carpets and food in Subang District, Jawa Barat Province.

Suffering from leprosy made Dasuki despair. His zest for life gradually disappeared. Luckily, he soon found a community that helped him recover from self-stigma. Dasuki actively participated in activities with the community and eventually, slowly but surely, he was able to accept himself and regained his self-confidence. "I joined with the Self-Care Group (SCG). There, I met several persons affected by leprosy who turned out to be also having the same problem as me. In fact, they have more than me. I listened to stories from other peers and I can share my experiences. It makes me strong and motivated again."

Now Dasuki has recovered not only physically, but also mentally and socially. All of that happened because of activities that he participated in with his new community. What makes Dasuki happy is that he can now be useful for others through opportunities given to him. "NLR Indonesia often invited me to various peer counseling activities for persons who have leprosy," added the father of two children.

At the moment Dasuki serves as chairman of the Association of Persons with Disabilities, a big and very influential role. Although Dasuki now has many activities, he always makes himself available to provide peer counseling for other persons affected by leprosy.

My Anxiety Fruits Happiness

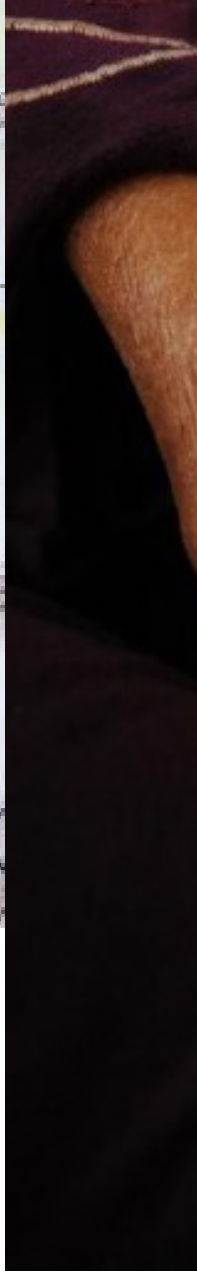
Taufik Rahman (male, 50) happily smiled when he found out that in recent years no cases of leprosy with grade-2 disability have been found in the village of Rancabango, a village where he lives and serves. Leprosy cases are indeed still found in the village, but the number has been very significantly decreased, i.e., from 30 cases per year in the early 1990s to 6 cases per year in 2021.

Taufik worked as a leprosy program staff for 27 years from 1991 to 2018 in Rancabango Health Center. The long service period made him very familiar with the situation of leprosy in the Rancabango area.

"After I was appointed a leprosy staff in 1991, I went to various places in the village of Rancabango and found many leprosy patients with grade-2 disability. This does not yet include those who were exiled or isolated themselves so they are not found," he said.

In the 1990s, people considered leprosy to be a common disease. They did not know the negative effects that can occur if leprosy is left without treatment. At that time, the stigma was very strong that leprosy was a disease caused by witchcraft and curses. This stigma made Taufik never feel comfortable to just sit still at the health center. Therefore, immediately after filling out the attendance list at his office, Taufik usually went "hunting" together with his team to look for leprosy patients who were invisible due to being estranged by their families or self-isolating. He was well aware that early case finding followed by early treatment of leprosy patients was the best way in such a society at that time. That's what made Taufik excited to find and take care of them intensively.

Supported by the health office, village officials and local community leaders, Taufik also provided regular counseling to the community through various opportunities, such as village meetings, village weekly, celebrations, and others. From NLR Indonesia, which was a partner of the Ministry of Health, he also received a capacity building on leprosy management, counseling materials, as well as transportation assistance to carry out visits to villages.



"Memang butuh kesabaran tinggi dan waktu yang panjang agar masyarakat paham tentang kusta. Dan, alhamdulillah, di awal tahun 2000 kasus kusta dan disabilitas tingkat dua mulai menurun. Masyarakat juga semakin antusias mengikuti kegiatan pemeriksaan bercak dan saling berbagi informasi," said Taufik who later became the Head of the Administration Subdivision Rancabango Health Center since 2019.

Taufik has done his best in dealing with leprosy in Rancabango. However, he was aware that leprosy transmission still occurred despite the cases of grade-2 disability has not been found any longer in recent years in this village. Taufik promised himself that he would continue to guard leprosy program at the Rancabango Health Center even though he is no longer working as a leprosy program staff.

Leprosy Situation in 2022

The situation of leprosy can be seen from several indicators used by WHO and the Ministry of Health, namely the **number of new cases and leprosy elimination status** at the regional level; **the proportion of child cases;** and **the proportion of cases with grade-2 disabilities.** The following will display annual data for the last 5 years for each indicator. In this report, the impact of the COVID-19 pandemic on countermeasures will also be discussed.

Leprosy new cases and Elimination Status

As per third quarter 2022

Leprosy cases: 15,052
(New cases: 12,095)

9,89%
Child cases

82.87%
Proportion of Grade-0 Disability

9.29%
Proportion of Grade-1 Disability

6,37%
Proportion of Grade-2 Disability

(Kemenkes RI 2022a)

34 Provinces

- **27** Provinces have reached leprosy elimination
- **7** Provinces have not reached leprosy elimination

  Sulawesi Utara, Gorontalo, Sulawesi Barat, Maluku Utara, Maluku, Maluku Utara, Papua dan Papua Barat (Figure 1).

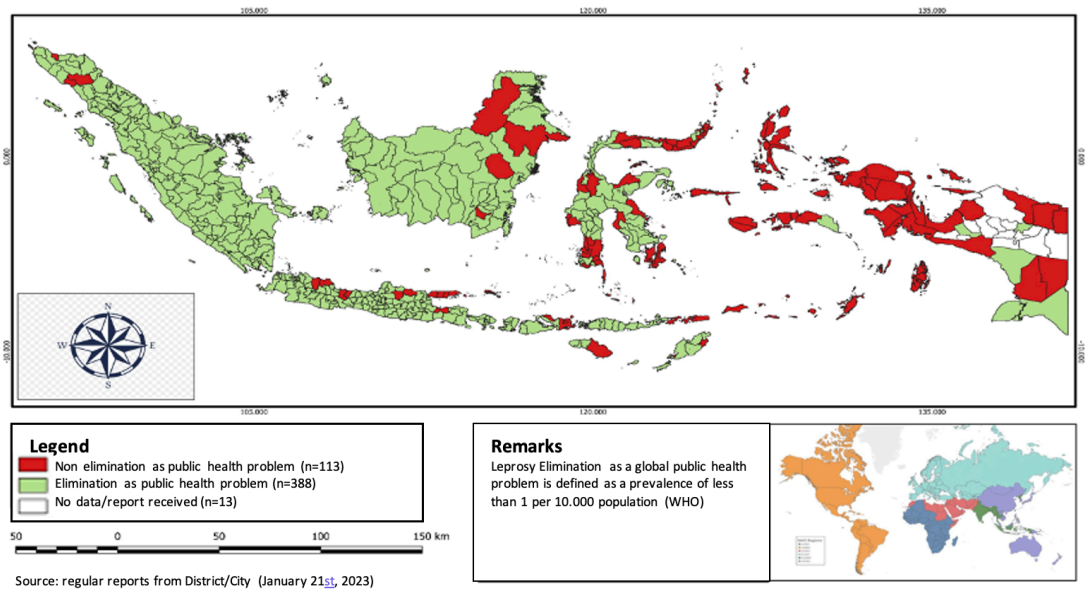
514 Districts/ Cities

- **501** districts/cities submitted reports
- **466** districts/cities reported new cases in their area
- **113** districts/cities have not reached elimination

(Kemenkes RI 2022a)

Nation-wide, the percentage of patients who have completed treatment or have been released from treatment (RFT) for PB-type leprosy is 87.46% and for MB-type leprosy is 86.57%. There are 2 provinces with RFT achievements above 95%, namely Sulawesi Tengah and Sulawesi Selatan; and 1 province with an RFT achievement of less than 75%, namely Papua Barat (first validation in January 2022) (Kemenkes RI 2022a).

Figure 1. Distribution of Districts and Cities based on Leprosy Prevalence (Source: Pambudi n.d.)

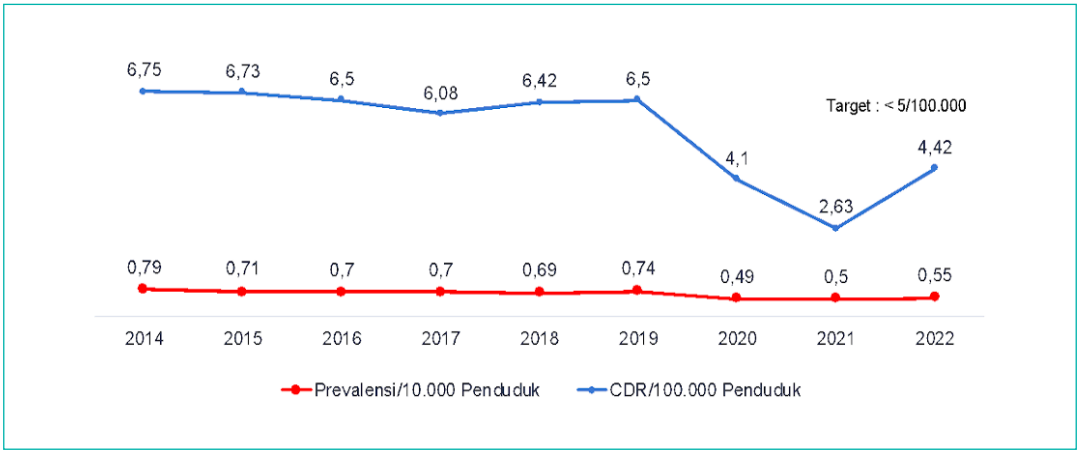


The high number of new leprosy cases is evidence of the high sources of transmission in the community.

In the period of 2014–2019, the number of new leprosy cases was relatively stagnant at the range of 15,000–17,000 per year, indicating that there are still sources of transmission in the community. Transmission of leprosy is known to originate from 2 main sources, namely (i) leprosy cases that are not diagnosed, and (ii) leprosy cases that are not completely treated. The group of people who are at high risk for contracting are the closest people to leprosy sufferers (close contacts) such as family members and colleges at work places, as well as people in the leprosy patient's social environment (social contact) such as neighbors and friends (World Health Organization 2023).

Still in the period of 2014–2019, the Case Detection Rate (CDR) was in the range of 6–7 per 100,000 population, higher than the national target of CDR<5 per 100,000 population (Graph 1). In 2020 and 2021, the number of new cases of leprosy decrease drastically due to reduced case finding activities during the COVID-19 pandemic.

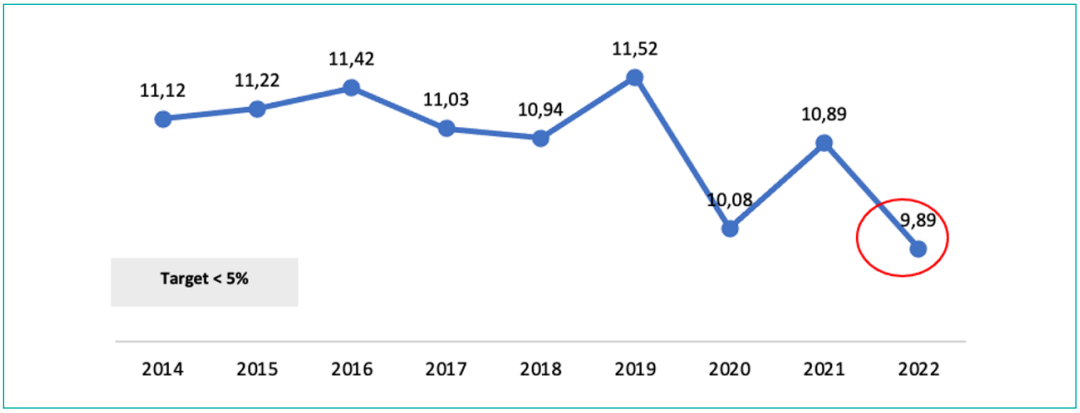
Graph 1. Prevalence Trend and New Leprosy Cases in Indonesia (2014 - 2022)
(Source: Pambudi 2023)



Leprosy Cases in Children

The existence of this source of transmission also causes vulnerable populations such as children to be infected by leprosy. Of all the new leprosy cases found in the 2014-2019, around 10-11% occurred in children under 15 years of age, far higher than the national target of under 5% (Graph 2).

Grafik 2. Tren Proporsi Kasus Kusta Pada Anak di Bawah Usia 15 Tahun (2014–2022)
(Sumber: Pambudi 2023)



Laela's story is an example of leprosy case in children. Laela is a 13-year-old girl who was included in the 10-11% cases of child leprosy. In 2021, when health workers collected family self-screening form through the Post-Exposure Prophylaxis Community (PEPCOM) activity at her village in Indramayu District, Jawa Barat, they visited Laela's family. At that time, Laela's parents reported in the screening form about white and reddish spots on Laela's body and face.

Laela was then put into the list of leprosy suspects for a re-examination. During the re-examination, three persons were confirmed as suspects, including Laela. The examiner then took and examined samples from the ear and from the spot at Laela's chest. After the examination, Laela was diagnosed with leprosy.

From further evaluation it is known that Laela village is a relatively dense environment and where chemoprophylaxis has never been administered in. Out of 21 cases of MB-type leprosy found in that village, Laela was the only child case found in the period of 2016-202.

Laela, who is now in grade 7 of her school, has completed the treatment of leprosy with MDT. Completeness of this treatment was contributed a lot by the supportive role of Laela's parents who always reminded Laela to take her drugs regularly. When still undergoing treatment, Laela remained enthusiastic to go to school even though she had to walk for 3 kilometers to arrive at her school.

Laela and family were so grateful that Laela was found and treated quickly so that she could finish her treatment without any disability.

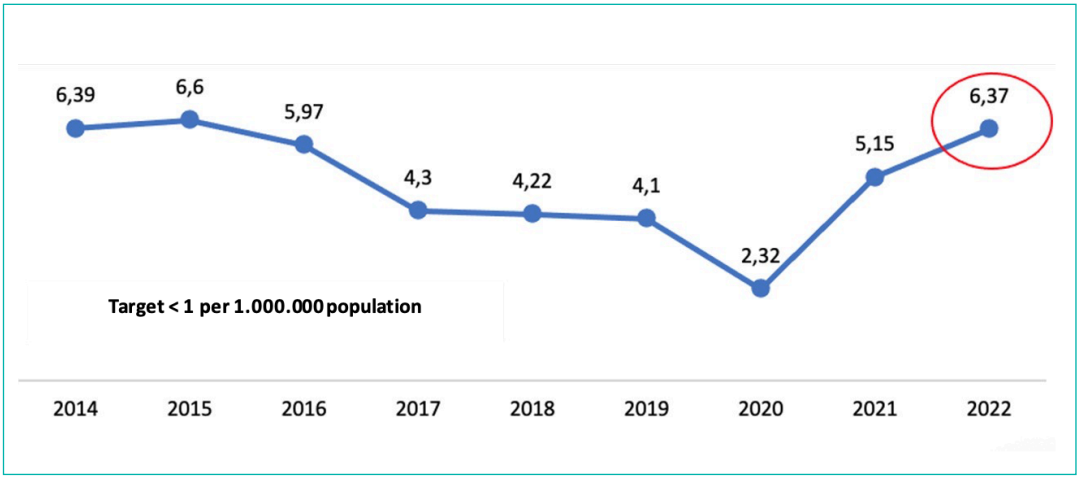
The existence of cases of leprosy in children as experienced by Laela above shows that transmission rate in the community is still high and that there are other factors that accelerate transmission such as poor environment condition and lack of child's immunity to infection (Narang & Kumar 2019)).

Leprosy cases in children shows the ongoing high transmission, poor environment condition and lack of child's immunity to infection.

Cases of Grade–2 Disability

Delays in case finding and treatment have also been high in recent years. The proportion of new leprosy cases with grade-2 disability ranges from 4-6% in the 2014-2019 with a decreasing trend in 2020 and increasing again in 2022 (Graph 3).

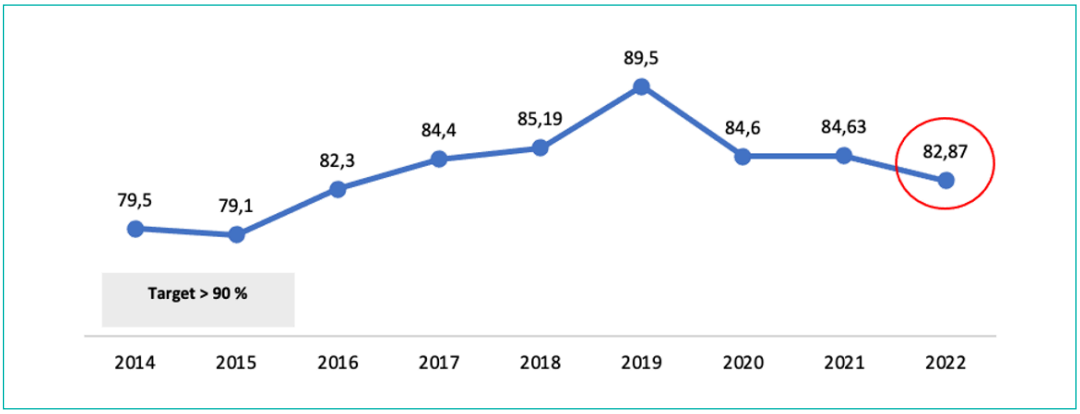
Graph 3. Trend of Leprosy Prevalence with Grade-2 Disability (2014–2022)
(Source: Pambudi 2023)



The cause of the delay in leprosy treatment could come from **the side of a patient** who is late in seeking and getting treatment from a health facility, or from **the side of a health worker** who is late in diagnosing or providing treatment. However, apart from delays in the case finding and treatment, the grade-2 disability is also caused by a lack of self-care and treatment of leprosy reactions (immune reactions) which can occur **before, during and after treatment** (Darlong 2021; Swarth 2001).

High proportion of leprosy cases with disabilities shows that many cases of leprosy are found and treated too late.

Graph 4. Proportion Trend of new cases without disability
(Source: Pambudi 2023)



Graph 4 indicates that the proportion of cases without disability is in the range of 82%, far less than the national target of >90%.

Delays in treatment can occur due to late diagnosis because the signs of leprosy are similar to signs of allergies. This was experienced by Siti Mutia (usually called as Mutia), an 8-year-old girl brought by her grandmother to a puskesmas in Halmahera Utara District, Maluku Utara Province, to examine her skin blotches.

Initially, the puskesmas health worker stated that Mutia had allergy. However, when Mutia experienced leprosy reaction, the doctor and the leprosy worker immediately realized that Mutia had leprosy.

"I didn't feel anything on my face, but the spots kept getting bigger," she said.

Neither Mutia nor her grandmother knew anything about leprosy at that time. All they know is that there are red blotches on Mutia's face, hands, fingers, toes and body. Because it was found and treated too late, a few of hand fingers of Mutia's right hand became weakened and show claw hand.

Little Mutia had a very high enthusiasm for going to school because of her aspiration to become a flight attendant in the future. It's the dream that drives Mutia return to school even though her schoolmates often made fun of her due to leprosy spots on the face.

Mutia has finished her treatment for 12 months. Now, patches of leprosy on her face, hands and body are still visible. Her fingers are still small and her ring finger still crooked, but Mutia was diligent to do the therapy and exercise on her fingers as advised by the health workers.

Stigma and Discrimination

Stigma is the main obstacle to leprosy treatment. This stigma includes self-stigma, stigma on health workers, and social stigma.

In addition to the high caseload and disability, the problem of leprosy is also complicated by the high self-stigma at the persons affected by leprosy, **stigma from health workers and stigma from the community.** Stigma can hinder treatment seeking and also impact treatment adherence. Furthermore, stigma can limit persons affected by leprosy from carrying out their daily activities. This could lead to decrease in their quality of life and participation, as well as impacting their mental health.

An assessment conducted by the Ministry of Health together with NLR Indonesia in Bone District Sulawesi Selatan regarding stigma shows that more than 30% of persons affected by leprosy feel inferior because of the illness they experienced and were embarrassed by their illness (NLR Indonesia 2022). Another assessment of the stigma of health workers against leprosy in Indramayu District, Jawa Barat in 2020 found that more than 50% of health worker, who participated in the assessment, were not willing to buy food or clothing from persons affected by leprosy and almost 74% of respondents said they were not willing to marry a person affected by leprosy (Muzir et al. 2022).

Stigma and discrimination from society were once experienced by a mother named In, who had leprosy when she was 16 years old and still attending high school. Because treated late, In experienced crooked or kiting fingers (claw handd).

As a single parent, In supports his two daughters, Novi (20) and Avril (17), by working multiple jobs as a stone seeker, broom maker, laundress and retail gasoline seller and also received financial support from her father. In's days were full of stigma and discrimination. Her neighbors often rushed in and closed the door of their houses when In passed in front of their houses.

At the place of worship, In also felt that the congregation of the church did not like her presence. Her house in Saparua must also be built far away from other houses.

"My children were often ridiculed, humiliated, shunned, and made to cry by his friends at school. In one instance, my child's bag was taken and the book was torn up," she said with a sad face.

At the campus where she studied administration in 2014 - 2017, In had never been given the opportunity to learn and operate computer because she was not allowed to enter computer room.

"I can't go in and use the computer there. As a result, I fell behind in class," she said.

Her meeting with dr. Teky, a Senior Technical Advisor at NLR Indonesia, in 2008 became a turning point in In's life. She was assisted to continue studying administration in Saparua in 2014. In 2020, In was offered to work at NLR Indonesia as a project officer for Maluku Province.

In feels happy because she has been considered a human being and given the opportunity to work in humanitarian organizations. She is happy because she can support her family. Now the woman who was born in 1983 is actively helping other persons affected by leprosy who experienced discrimination like her.

Financing and Human Resources

In the last 5-year period (2018 – 2022), the amount of budget for leprosy from the national budget (APBN) shows a downward with a sharp decline in 2020. The amount increased in 2021, and then the APBN budget for leprosy in 2022 has again fallen, sharply (Graph 5).

Graph 5. Trend of Leprosy and Frambusia Program Financing using APBN (Sumber: Subag Adum P2PM 2022)

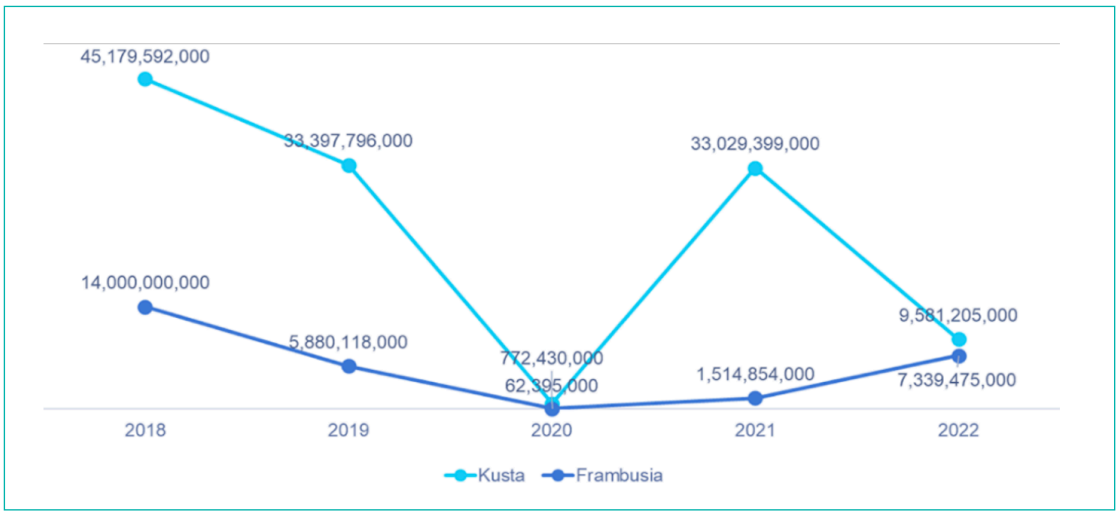


Table 1. Financing from DIPA APBN
(Source: Subag Adum P2PM 2022)

Year	Amount (Rupiah)
2018	45,179,592,000
2019	33,397,796,000
2020	772,430,000
2021	33,029,399,000
2022	9,581,205,000
Total	**121,960,422,000**

Table 1 shows the direct impact of the COVID-19 pandemic on the ability to finance the leprosy program in Indonesia. Except for 2020, most of the budget is channeled in the deconcentrating mechanism for strengthening provinces and districts/cities in the leprosy program management in accordance to the stipulated technical guidelines.

The decrease of budget at the start of the COVID-19 pandemic in 2020 occurred due to the transfer of funds for the pandemic control. The main cause for the reduction in the budget in 2022 is unknown.

Regarding the availability of health workers for the leprosy program, the classic problem, which is a shortage of number and capacity of health workers, is still the main obstacle. The continuous rotations and mutations of health workers without satisfactory risk mitigation plan also slows down the course of the program. In addition, provision of supervision and technical assistance by the province and district/city to the *puskesmas* health workers who are the key to program quality is still not running routinely.

Our Efforts

Policy and Program

The four national leprosy control strategies are: (i) Health Promotion, (ii) Surveillance, (iii) Chemoprophylaxis, and (iv) Management of Leprosy Patients

The Roadmap of Leprosy Elimination 2020-2024 of the Ministry of Health targets that by 2024 all regencies/cities have achieved leprosy elimination and that the grade-2 disability rate is less than 1.00 per 1,000,000 inhabitants. Another goal is 100% coverage of contact screened, with a minimum of 20 contacts per patient. In addition, the coverage of finding new cases without disabilities is above 95% (Kemenkes RI 2020).

To achieve this target, the Ministry of Health through regulation (Permenkes) No. 11 of 2019 concerning leprosy control has established four strategies to achieve leprosy elimination throughout the provinces by 2019 and throughout districts/cities in 2024 (Kemenkes RI 2019). The four strategies are then translated into several efforts, namely:

Health Promotion. The aim of this effort is to empower community to be able to play active roles in supporting behavior change and in maintaining and improving health through leprosy prevention and control. This health promotion activity is carried out by:

a Providing information to the public about early signs and symptoms of leprosy, as well as technical leprosy prevention activities.

b Raising awareness of individuals, families, and communities to eliminating stigma and eliminating discrimination against leprosy patients and persons affected by leprosy.

c Advocating for relevant stakeholders to gain support for leprosy prevention policies, especially elimination of stigma and discrimination, as well as financing.

d Encouraging individuals, families, and communities to play an active role in case finding and management of leprosy patients, implementation of chemoprophylaxis, and research and development activities.

Surveillance. The purpose of surveillance activities is to find Leprosy sufferers, early treatment and knowing the magnitude of the leprosy problem in an area. This surveillance activity is carried out by:

a Collection of data through the leprosy case finding:

- Actively (intensified case finding, examination of household, neighbor and social contacts).
- Passively (receiving data from health care facilities - followed by village rapid surveys or village rapid surveys - communities, and other data sources).

b Data processing, through data recording, codification, validation, and/or grouping by place, time, age, classification, and gender.

c Data analysis, through descriptive and/or analytic epidemiological methods to produce information suitable for surveillance purposes.

d Information dissemination, by conveying information to program managers and other units that require and provide feedback as needed.

Chemoprophylaxis. Prophylactic drug administration is intended to prevent transmission of leprosy to people who have contact with leprosy sufferers through administration of single dose of rifampicin (SDR). Chemoprophylaxis can be carried out using two approaches, namely contact approach and blanket approach.

Management of Leprosy Patients. This activity aims to early treatment for leprosy cases and to prevent disability due to leprosy.

Realization of Policy and Program

Since the publication of the MOH's regulation (Permenkes) regarding the prevention of leprosy, the implementation of the leprosy prevention program has become more focused. However, the number, frequency, and quality of implementation of activities in these four strategies are still not optimal due to various factors.

Health Promotion

Education or awareness raising about leprosy is carried out in activities that gathers community like Posyandu, School Health Unit (UKS) and other routine health promotion activities. This activity is usually done by the leprosy program holder alone, not yet done by other Puskesmas health workers such as health promotion staff, environmental health staff, etc. To support educational efforts for society, various Communication, Information, and Education (IEC) materials have also been produced for example hand fan, flipchart, etc.

Awareness raising activities have also been carried out through the Community's Movement for Healthy Life (Germas) with members of Commission IX of the Parliament (DPR) in the selected areas. Throughout the year 2022, this Germas activities have been carried out in 8 districts targeting the community. However, the number of such activities is still insufficient compared to the total number of areas which have not yet achieved leprosy elimination (113 districts/cities).

Extensive health promotion activities were usually done only in certain moments or events, for example the commemoration of leprosy day or NTD day and disability day. Activities such as workshops and series of webinars are usually targeting limited audiences, such as health workers, academics and leprosy observers. Whereas, a group of audience which is the main target in health promotion, namely families and communities, have still not been reached sufficiently.

Several advocacy activities have also been carried out by districts/cities of high burden of leprosy, such as Morotai and Toujo Una-una districts. This advocacy activity was very effective because it has succeeded in making districts heads release concrete leprosy-related policies and programs, for example the district-wide PEP implementation.

Surveillance

Data on leprosy cases are collected and reported through the Leprosy Program Information System (SIPK), which is tiered from the health center to the national levels. This surveillance data is evaluated at the provincial and national levels on a regular basis. Delay of submission and quality of data is still the main hindrance in the implementation of surveillance. Hence, the data often cannot be used as basis for program planning. The intensified case finding activity is also still weak that the number of cases reported still do not reflect the real burden of leprosy cases.

Chemoprophylaxis

Throughout 2022, the implementation of chemoprophylaxis shows an increasing trend in number of areas that have implemented. Reported by a development partner, NLR Indonesia, around 30 districts/cities in 10 provinces have implemented chemoprophylaxis using contact or blanket method. Regardless of implementation quality and coverage rates, which indeed still need to be improved for better impact, this trend of increasing activity is very exhilarating.

Management of Leprosy Patients

The forefront of the management of leprosy patients is the primary and referral health care facilities (puskesmas and referral hospitals). To ensure the quality of management of leprosy in these health care facilities, the Ministry of Health has compiled the National Guidelines for Medical Services (PNPK) for Leprosy. In general, completeness of patient treatment (RFT – Released from Treatment) is relatively good, with a default rate (not complete treatment) of 6%. But, in the absence of drugs in some areas in recent years, it is feared that this RFT number may decrease.

Challenges in the management of leprosy include the lack of quality in diagnosis and management based on standards, less optimal management of leprosy reactions before, during, and after treatment, and prevention of disability. In addition, leprosy cases handled by independent practicing doctors and clinics/hospitals in urban areas are often not reported to the puskesmas, making patients receive non-standard treatment. This is caused by the absence of leprosy referral system in urban areas.

Transformation of National Health System in Leprosy Program

As previously mentioned, achievements of leprosy prevention and program is still far below the target due to some drawbacks. If examined more deeply, the weakness is closely related to the not-yet-strong implementation of the national health transformation.

The Pillar of Primary Service in the national health transformation, namely puskesmas, have a crucial role in the leprosy prevention and control program covering prevention including health promotion, chemoprophylaxis and leprosy case management. The health center also has a key role in recording and reporting leprosy cases in leprosy information system (SIPK). However, the capacity and time availability of the *Puskesmas* to implement these functions are still inadequate causing routine programs are not running optimally. The availability of health workers with the number and adequate competence in diagnosing and treating leprosy as well as the implementation of leprosy prevention programs such as discovery cases, chemoprophylaxis, and health promotion is still low. Another cause is the low quality-assurance of program through monitoring and evaluation as well as supervision of the implementation of the leprosy program from the national to the districts level.

The underlying causes of these problems are the weakness of **the fifth pillar, health human resources,** namely the lack of numbers of manpower and high rotation or mutation of positions. This long-running rotation problem had not been resolved until now. If the problem of leprosy is indeed considered important to be resolved, there needs to be a breakthrough done by the national and district governments to concretize the reformation on the human resources.

Pilar second pillar, namely referral service for leprosy that are still needed strengthened. Currently, rehabilitation health services for leprosy are still not available sufficiently due to lack of expertise in leprosy rehabilitation. In addition, the coverage of health care insurance (BPJS) for rehabilitation is still limited.

The third pillar is the health resilience system, especially in pharmacy. In the last few years, leprosy programs often face problems of drug availability in the right quantity and type, at the right time and at the right place. A multi-party discussion which has been facilitated by the Ministry of Health and NLR Indonesia in 2022 indicated that there are administrative and technical issues that need to be addressed in the leprosy drug supply chain system, starting from the level of puskesmas, district/city, central/national, and international (WHO).

To ensure leprosy drugs are available on time in the right amount and at the right location, then the drug supply chain system from the puskesmas to WHO level needs to be addressed.

The last pillar is health financing for leprosy program. Decreased budget at the start of the COVID-19 pandemic in 2020 is indeed understandable because of the transfer of funds was directed to control the pandemic. But the downturn in 2022 keeps some parties questioning the government's commitment to end leprosy problem in Indonesia. Leprosy prevention and control program is very much relied on outreach activities, including active case finding. All these activities require an adequate budget, in particular with the geographical situation of leprosy endemic areas which is generally difficult and high cost to access

Another interesting thing related to this budget is the local budget (APBD). Some areas have implemented leprosy program using district APBD, but detailed data regarding the size of the budget and type activities are not yet available. This needs to be studied in the coming years.

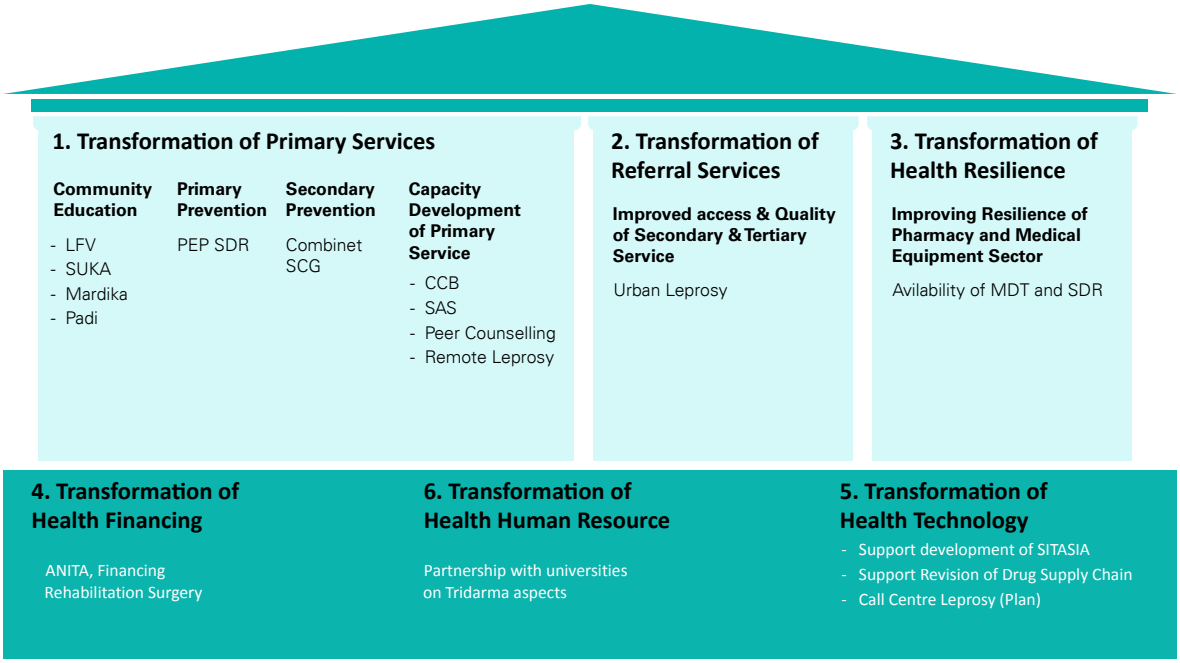
Fundings for the leprosy program from the state budget tend to decrease. This decrease is not reflecting the enthusiasm to achieve leprosy elimination.

Our Supports

National Action Plan toward Leprosy Elimination 2023 – 2027

Support provided by development partners for leprosy prevention programs throughout 2022 consists of 2 groups of activities, namely (i) preparation of a national road map or action plan (RAN) toward Leprosy Elimination 2023 – 2027, and (ii) implementation of innovations to fill gaps and encouraging the transformation of the national health system with its 6 pillars.

Graph 4. Transformation Diagram of National Health System 2021 - 2024 in Leprosy Program



Caption: LFV: Leprosy Friendly Village, SUKA: Voice for Indonesia Free from Leprosy, MARDIKA: Disability and Leprosy Friendly Community, PADI: Prioritizing Children with Disabilities and Leprosy, PEP-SDR: Post Exposure Prophylaxis- Single Dose Rifampicin, SCG: Self Care Group, CCB: Comprehensive Capacity Building, SAS: Semi Active Surveillance, ANITA: Advocacy for Zero Leprosy Indonesia

As illustrated by Figure 4, development partners' supports have been targeted to several layers of the building blocks of the transformation of the national health system. At the impact level, for example, supports have contributed to one of the impacts of the National Medium-Term Development Plan (RPJMN), namely "Improving Disease Control". This support was implemented in 2022 through the renewal of the **National Action Plan (NAP) toward Leprosy Elimination 2023 – 2027.** Apart from being designed to address the weaknesses in the implementation of the leprosy program so far, the NAP has also targeted a reduction in the number of new cases by 90%, reduce the number of child cases and grade-2 disability by 70% in 2030 (Kemenkes 2023b).

NAP toward Leprosy Elimination 2023 - 2027 specifically outlines strategy and efforts into four main strategies (which fits perfectly with the spirit of transformation of national health system) that are:	**1.**	Mobilizing the community by utilizing various resources **(Community)**;
	2.	Increase the capacity of service systems to do prevention, early detection, diagnosis, and management of leprosy **(Acceleration)**;
	3.	Improve integration and coordination among stakeholders and health facilities, both government and private sector **(Integration)**;
	4.	Strengthen commitment, policy and program management **(Commitment, policy, and management).**

(Kemenkes 2023b)

The NAP's first strategy, **Community**, is very much in line with the first pillar of health transformation, namely the transformation of primary health services that focus on promotive and preventive. The second strategy of the NAP, **acceleration of health services**, is very much aligned with the first and second pillars of health transformation, namely primary and secondary services. The other two strategies, namely **Integration and Commitment**, are closely aligned with the other pillars of the national health transformation.

Innovations

Several innovations to fill gaps, to overcome challenges and to accelerate achievements of elimination have been carried out by development partners together with the Ministry of Health.

Strengthening the Capacity of Health Workers

Health workers are the main actors whose capacities absolutely need to be strengthened in order for Indonesia to achieve leprosy elimination according to the target. The capacity referred to in this regard includes: knowledge, behavior/motivation and technical ability. With development partners, the Ministry of Health implements various low-cost and effective innovations to strengthen the capacity of the health workforce. The long-term goal is to produce more dedicated and competent health workers at work.

Strategic Partnership

Throughout 2021 - 2022, development partners with the Ministry of Health have started to promote multi-stakeholder collaboration, namely with government ministries/agencies, universities, media, private, and community (pentahelix). These efforts have shown significant results in the last 2 years in the form of a significantly growing spirit of collaboration. The national commission on human rights (*Komnas HAM*) and the National Commission on Disability (*Komnas Disabilitas*), for example, have taken this leprosy issue more seriously as an issue that they will work on in their action plans. Universities in areas that have not yet achieved elimination have also begin to be interested in bringing topic of leprosy in their Tri Dharma activities. The number of news and information about leprosy disseminated by the mainstream media and social media also increased significantly based on a survey conducted by development partners. In the coming years, development partners and the Ministry of Health will continue this effort to keep the spirits up, even strengthened to be able to produce collective and synergistic actions that have a bigger impact.

Initiatives to strengthen leprosy programs and management

In recent years, several innovations have been initiated and implemented, including:

1. Leprosy Friendly Village

   Leprosy Friendly Village is an innovation carried out in the villages which have high number of cases and stigma which aims to reduce the burden and stigma of leprosy by increasing the participation of influential groups in society. In this innovation, efforts were done to increase awareness of influential groups so that they are willing and able to play active roles in making the village free of leprosy and inclusive for persons affected by leprosy. In the end, it is expected that village community will also be willing and able to live side by side with leprosy patients and persons affected by leprosy. Leprosy Friendly Village initiative has started to be replicated in several districts with several adjustments based on learning in previous areas.

2. Assistance, Lobbying and Advocacy for PEP implementation

   Post-Exposure Prophylaxis (PEP) or leprosy chemoprophylaxis is the administration of Single Dose Rifampicin preventive drugs to reduce the risk of developing leprosy in at-risk community groups (contacts). PEP will only be successful if implemented by taking into account several conditions, namely (i) adequate coverage area, and (ii) adequate capacity of PEP implementing staff. Several regions have started to implement PEP,

however, was considered less successful because the 2 prerequisites above were not met. To answer this problem, assistance, and capacity building are provided to the implementing staff related to planning and implementation. Using behavior change communication approach, PEP conducted in several districts (contacts approach) and villages (blanket approach) have proven successful in increasing participation of village community, making the coverage of contacts who take preventive medicine increases. PEP in Morotai and Tojo Una Una districts are examples of PEP activities with assistance, as a result of lobby and advocacy in 2022. It is hoped that other districts are motivated and could learn from both areas.

3. Comprehensive Capacity Building (CCB) Activities

The ability of leprosy officers is very important in leprosy prevention programs. In CCB activities, development partners and the Ministry of Health improve the ability of program managers from provincial level, all the way to the health center through individual technical guidance activities and group technical guidance or cluster-based on the Job Training (OJT cluster). Technical guidance or mentoring was given using the principles of right-needs and right-way by using a participatory approach with individuals and groups. This learning method is felt very useful by the participants who take part in the activity because they can find appropriate solutions to their situations through group discussions.

4. Urban Leprosy Activities

Urban Leprosy Activities is an effort to overcome leprosy with a goal to improve accessibility and quality of health services in urban areas. Through Urban Leprosy, a network was formed between the government and the private sector such as private physicians, general practitioners, dermatologists, clinics, and private and government hospitals. With this network, it is hoped that a referral system from private physicians, clinics and hospitals to *puskesmas* in suspected areas or patient could be built. Urban Leprosy also seeks to increase the participation of health cadres including in the dissemination of leprosy information in the community, suspect screening, and medication assistance for leprosy patients.

5. Combined Self Care Group (SCG)

   The Self Care Group (SCG) is a group approach to self-care and education for persons affected by leprosy as an effort to prevent disability and eliminate self-stigma. This activity is initiated based on potentials that persons affected by leprosy and people who have filariasis could join in the same SCG. In this SCG, persons affected by leprosy and OYPMF together carry out self-care activities with assistance from the Community Health Center and influential community groups in their village.

6. Peer Counselling Activities

   This activity aims to prevent the occurrence or worsening of mental health problems in persons affected by leprosy who suffer from chronic reactions, chronic injuries or disabilities through peer counseling programs. In this activity, persons affected by leprosy was trained on leprosy, disability, stigma and mental health as well as in communication and counseling skills. After training and mentoring, they will provide regular counseling to fellow persons affected by leprosy who are vulnerable to experiencing this stigma and mental health problems. In addition, this activity also trains leprosy health workers and mental health workers in health centers.

7. SUKA (Voice for Indonesia free from leprosy and its consequences)

   SUKA initiative is motivated by the lack of public knowledge about leprosy and its consequences. Through SUKA, leprosy education with comprehensive material (triple zero) conducted every month using several communication platforms, namely radio, articles, and social media. This activity involves journalists and creative young people to produce educational materials (contents) in various forms (text, images, songs and videos) and disseminate them to society. This activity, which began in 2021, has shown significant positive results. Educational content published on social media has received positive reactions from millions of audiences. This SUKA innovation is very promising for improving health promotion and the eradication of stigma in society and therefore needs to be continued in the coming year.

Financing

The national leprosy program receives financial supports from 2 main partners of Ministry of Health, namely the WHO Representative Office in Indonesia and Yayasan NLR Indonesia.

Funding from WHO

Based on the 2018 – 2022 Budget Implementation Entry List (DIPA), WHO has provided the following support:

Table 2. Financing Support from WHO for Leprosy Program 2018-2022 (Source: WHO Indonesia)

Year	Activities	Drugs	Amount (Rupiah)
2018	634,810,664	11,519,870,551	12,154,681,215
2019	2,470,258,944	2,617,717,304	5,087,976,248
2020	1,206,493,898	6,309,056,251	7,515,550,149
2021	1,012,802,555	6,820,143,106	7,832,945,661
2022	1,070,946,808	1,082,126,691	2,153,073,499
Total	**6,395,312,869**	**28,348,913,903**	**34,744,226,772**

Funding from NLR Indonesia

Throughout 2018–2022, financing support prepared by NLR Indonesia in the form of programs (services) is Rp. 57 billion, with an annual average Rp. 11.4 billion and divided into 2 programs, namely the capacity development program and innovation program. Apart from the two forms of programs, NLR Indonesia also places this support in the form of incidental activities such as provision of personal protective equipment (PPE) during the COVID-19 pandemic, financing drug transportation to areas experiencing stock shortages, support for commemoration of leprosy day/ NTD, and support for program information system development management of leprosy and yaws (SITASIA).

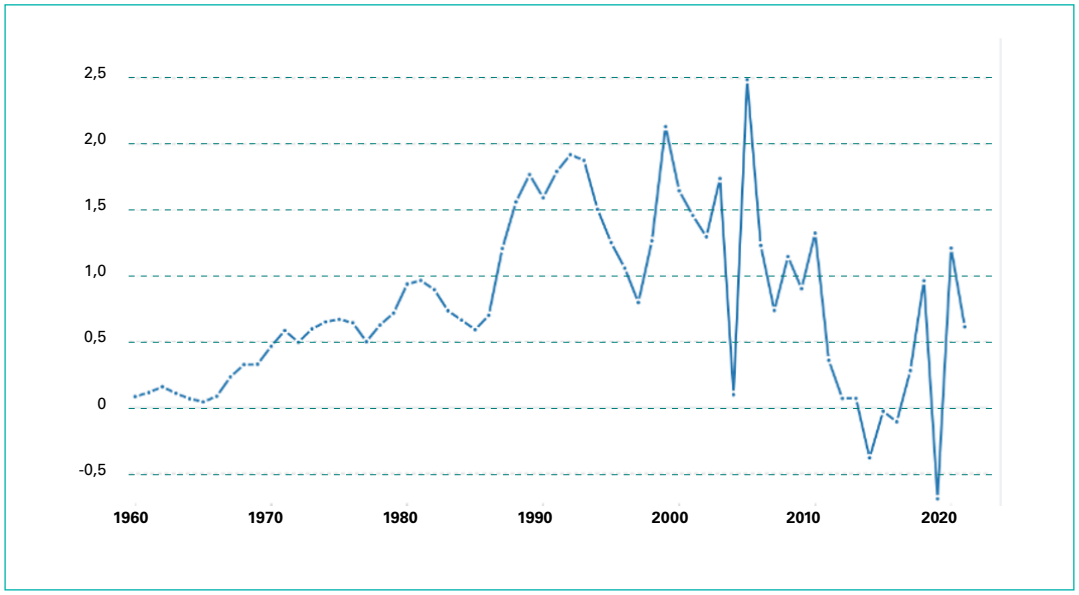
The average financing realization for the last 5 years is at 70%. Annual realization ranges from 50 – 90%. This annual realization difference was caused by several factors, including: (i) delayed signing of the Memorandum of Understanding (MOU), (ii) the existence of the COVID-19 pandemic in 2020-2021, and (iii) exclusion of programs managed by the Director of Non-Communicable Diseases from the Minutes of Handover (BAST).

Table 3. Financing Support from NLR IndonesiaMOH for Leprosy Program 2018 – 2022
(Source: BAST between NLR Indonesia and the MOH (P2P)2018 - 2022)

Year	Commitment (Rupiah)	Realization (Rupiah) BAST	Remarks
2018	11,465,266,277	7,113,587,634 **(62%)**	Lower realization due to late MOU signing
2019	11,465,266,277	9,326,415,557 **(81%)**	
2020	11,465,266,277	7,544,434,665 **(67%)**	Lower realization due to pandemic COVID-19
2021	11,465,266,277	10,204,599,645 **(90%)**	
2022	11,465,266,277	5,720,315,494 **(50%)**	Programs realization hosted by PTM (40%) is excluded from BAST
Total	**57,326,331,389**	**39,909,352,995 (70%)**	

Financing Challenges and Potentials for the Leprosy Program in Indonesia

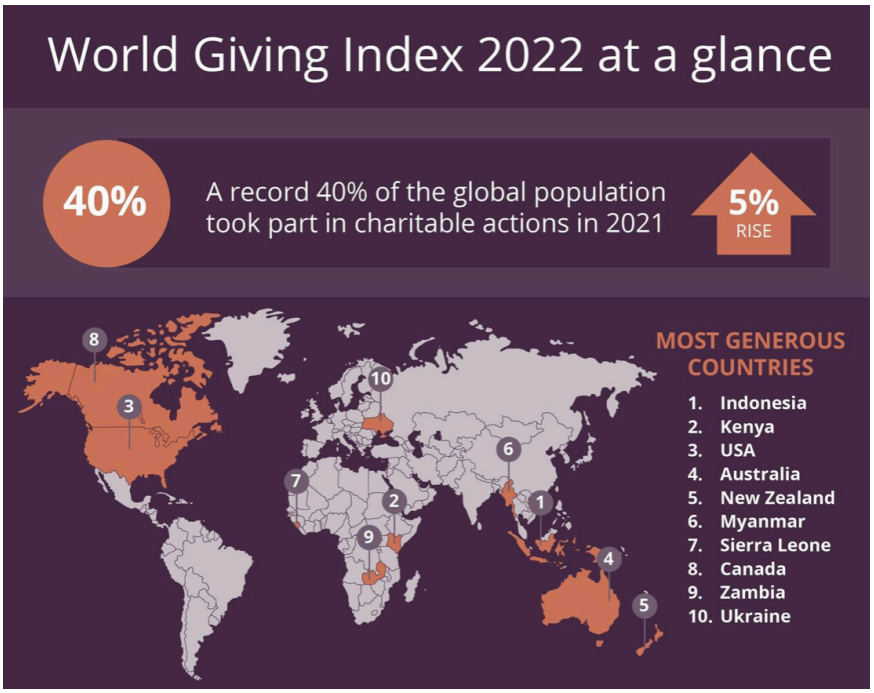
The budget sources for the National Leprosy Program in the last 5 years have been from the state budget and grants abroad through WHO and NLR Indonesia. If combined, the average annual budget available is Rp. 37 billion. Meanwhile, the NAP for Leprosy Elimination 2023–2027 estimates the annual budget need for 2023 – 2027 is IDR 6.43 trillion a year. This means leprosy control program requires an additional budget of Rp. 6.2 trillion a year. This high budget needs to be anticipated through, among other things, budget advocacy to the national and district governments as well as fundraising from donor agencies from within and outside the country.



Regarding financing sourced from abroad, World Bank data shows that the budget Official Development Assistance (ODA) for Indonesia has tended to decline since 2005. It is recorded that in 2005, for example, Indonesia received ODA of USD 2.49 billion which then decreased to USD 612 million in 2021 (The World Banks 2023). This decrease was due to the improving economic conditions in Indonesia. However, regardless the decline in ODA received by Indonesia, for the leprosy control program itself, this trend does not have a big effect because the leprosy program is indeed not a priority program of the ODA for a long time. Nonetheless, bearing in mind the NAP toward Leprosy Elimination 2023-2027 has stated that the budget for leprosy need a sharp increase to more than 100 times compared to the annual budget of previous years. Thereofre, ODA needs to be directed to support the leprosy prevention and control program through special approach to donor countries.

Donor agencies have the potential to stop providing support for the leprosy program in Indonesia because they are not aware that there are still many cases of leprosy in Indonesia.

Regarding the availability of financing or grants sourced domestically, the potential is very high. Indonesia is considered as a country with the most generous or giving people (Charities Aid Foundation 2023). This situation is also supported by a study which found that distribution of philanthropic funds has tended to increase in recent years and in 2020 reached the Rp. 15 trillion mark (Katadata 2023). This potential needs to be targeted by the Ministry of Health and development partners. NLR Indonesia's experience in fundraising activities in 2 the last decade has shown that philanthropists will only donate their funds to development issues that they know well. The issue of leprosy is rarely known by philanthropists, that is why the budget for leprosy is rarely or almost always non-existent. Ministry of Health and development partners need to make them aware of the leprosy situation in Indonesia and engage them to support the leprosy prevention program towards Indonesia that is free from leprosy and its consequences.



Closing

In general, the national leprosy elimination efforts have stagnated since the last 20 years, which is indicated by the relatively same number of new cases from year to year. Although leprosy has achieved national elimination with a prevalence of <1 per 10,000 population since 2000, data for 2022 shows that there are still 7 provinces and 113 districts/cities that have not yet achieved leprosy elimination. Throughout 2022, from four strategies of the national elimination program that has been set by the government in the road map for leprosy elimination, almost all strategies have not been implemented optimally. Weaknesses that stand out are in the health promotion strategy, meanwhile strategy that shows improvement is chemoprophylaxis.

Several inhibiting factors or weaknesses in program implementation known are: (i) coordination across sectors/central-regional programs; (ii) capacity and number of human resources; (iii) national-regional funding; (iv) availability of quantity and type of drugs; (v) health education and promotion; and (vi) management of leprosy cases. Those weaknesses have been targeted through the formulation of the National Action Plan toward Leprosy Elimination 2023 – 2027 and through innovation programs, which have been implemented in the last few years. The two attempts are aligned with national health system reform with its 6 pillars.

Several recommendations to be implemented in 2023 and upcoming years include:

1. Advocacy and socialization of the NAP toward Leprosy Elimination 2023-2027 to the regions and encourage the preparation of District Action Plans (RAD) and programs to accelerate elimination of leprosy, especially in areas with high burdens in leprosy.
2. The problem of removing stigma, covering self-stigma in leprosy patients and persons affected by leprosy, the stigma of health workers, as well as the stigma of the general public, needs more serious attention from all parties. It is suggested that this is handled through creative and innovative ways using appropriate communication platforms, including the use of social media professionally.
3. Efforts to grow a joint movement (partnership) towards leprosy elimination needs to be encouraged through collaboration and collective action of multi parties from the village to the national level.
4. The vacancies of leprosy officers due to high staff rotation and mutation must be solved by ensuring that the rotation or mutation may only be carried out if a replacement is already available or prepared by the official who decided the mutation and rotation. For this to happen, affirmative policies from national and district governments are needed.
5. Resilience in terms of the availability of leprosy drugs, chemoprophylaxis and consumables for the treatment of disabilities/chronic cases needs to be addressed immediately with the application of information system. In addition, the administrative and bureaucratic process of drug requests from health centers to WHO including import permits need to be simplified.
6. Implementation of chemoprophylaxis needs to be doubled in number and scope to stop transmission at the community level. In this case, there are 2 things that need to be improved in the implementation, namely lobbying and advocating to the regions for policies and budgeting, and adequate assistance to officers for doing blanket chemoprophylaxis. Meanwhile, for chemoprophylaxis with contact approach, its integration with case finding activities (active and passive) should not be delayed any longer. The integration of these two activities will make activities more effective and less expensive.
7. Trend of reduced funding from international donor agencies for the leprosy program and for Indonesia need to be anticipated immediately by communicating intensively with them. Potentials of financing from within the country is quite promising, but the government and development partners need to take a special approach to them.
8. Several local governments have allocated budgets (APBD) for leprosy in the last 5 years, but the details of the districts, amount of budget and types of activities still need to be studied. Budgeting potential of this APBD needs to be the target of advocacy by the government and development partners considering the budgetary needs for leprosy is very high in the coming years.

“Leprosy does not kill the body, but have killed millions of hopes and the dignity of persons experiencing it.”

— Asken Sinaga, Executive Director of NLR Indonesia —

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