

# Final Evaluation READY4PEP Project

## **Final Report**

### NLR – Until No Leprosy Remains (Leprastichting)



Photo credit Jan-Joseph Stok 1

Submitted by

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### Acronyms and abbreviations

CSCG	Combined Self-Care Group
FGD	Focus group discussion
HCW	Health care worker
IEC	Information, education and communication
ILEP	International Federation of anti-Leprosy Associations
KII	Key informant interview
LGA	Local government area
LTR-Nigeria	Leprosy and Tuberculosis Relief Initiative
MDT	Multi-drug therapy
МоН	Ministry of Health
MoHSW	Ministry of Health and Social Welfare
NLCP	National Leprosy Control Programme
NTBLCP	National TB and Leprosy Control Programme
NTD	Neglected tropical diseases
Ready4PEP	Preparing Mozambique and Nigeria for PEP
RiH	ResultsinHealth
SDR-PEP	Single-dose rifampicin as post-exposure prophylaxis
SoC	Story of Change
ТВ	Tuberculosis
TLM-Nigeria	The Leprosy Mission
ТоС	Theory of Change
WHO	World Health Organization

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#### Background of the Ready4PEP project

NLR is an alliance of non-governmental organisations committed to creating a world free from leprosy. Together with its partners – the Leprosy and Tuberculosis Relief Initiative (LTR-Nigeria), The Leprosy Mission (TLM-Nigeria) and RedAid in Nigeria, as well as NLR-Mozambique and TLM-Mozambique in Mozambique – NLR implemented the **Ready4PEP project** from 2020 to 2024. This project focuses on interrupting leprosy transmission and improving the care of individuals affected by the disease.

In close collaboration with each country's government health authorities and leprosy divisions, the project operates in 12 districts across 4 provinces in Mozambique, and 26 endemic local government areas (LGAs) across 6 states in Nigeria. The project's primary aim is the introduction of single-dose rifampicin post-exposure prophylaxis (SDR-PEP), a preventive post-exposure prophylactic antibiotic designed to lower the risk of developing leprosy and to stop its transmission. Ready4PEP addresses five critical components: active case finding, epidemiological mapping, capacity-building of health workers, SDR-PEP distribution and Combined Self-Care Groups (CSCGs).

Ready4PEP focuses on achieving three key outcomes:

- 1. **Inclusion of SDR-PEP in national strategies:** Ministries of Health (MoHs) in Mozambique and Nigeria formally adopt SDR-PEP as part of their national leprosy strategies.
- 2. **Fully functioning leprosy control programmes:** Project intervention areas in both countries have fully functioning leprosy control programmes, including SDR-PEP administration, with adequately trained staff, sufficient resources and sustained leprosy-related activities.
- 3. **Integration of CSCGs:** CSCGs become an integrated part of leprosy-related interventions in both Mozambique and Nigeria.

#### **Objectives of the final evaluation**

After nearly four years of implementation, NLR commissioned a final evaluation, with the following main objectives:

- analyse progress made towards key strategic outcomes and project targets, identify existing hurdles for their full achievement, and explore the necessary measures to overcome them and ensure sustainability;
- describe the main steps and mechanisms developed by the project within the health system for the implementation of leprosy control and SDR-PEP administration activities;
- document changes produced by the project among health care providers and health care managers at national and subnational levels;
- analyse the level of maturity and integration of the CSCGs within the health system, as well as the quality and sustainability of these groups;
- document and analyse changes in the perception of leprosy and related stigma in the communities where SDR-PEP was introduced;
- explore potential negative effects of the project; and
- consolidate best practices, lessons learned and main recommendations for future strategies and plans, identifying what has already been integrated into the leprosy control programmes and what can still be included.

**To achieve these objectives**, the evaluation used a mix of primary and secondary data collection methods. Secondary data was gathered through a comprehensive desk review of project documents and relevant datasets. Primary data collection methods included key informant interviews (KIIs), focus group discussions (FGDs), and the collection and editing of Stories of Change (SoCs) for each country. Quantitative data analysis was conducted using available datasets provided by the project.

A total of 28 KIIs were carried out: 12 respondents in Nigeria, 14 in Mozambique and 2 representatives from NLR International Office. A total of 12 FGDs (6 per country) were held with project participants, including leprosy patients, affected contacts, CSCG members, and trained health care workers (HCWs) and/or health care service providers. Additionally, the team collected 4 SoCs per country from health care providers and individuals affected by leprosy.

To reflect on project activities and collaboratively interpret the data, sense-making and validation workshops were held – one in Mozambique on 30 October 2024 and another in Nigeria on 4 November 2024.

#### **Main findings**

# Level of adoption of SDR-PEP within the health system, the national leprosy strategy and the sustainability of its continuous implementation

In Mozambique, integrating SDR-PEP into the national leprosy strategy and health system is still a work in progress. Most of the respondents viewed the adoption of SDR-PEP positively, though a few voiced caution about its broader integration and sustainability in the national health system. Key actors in leprosy control – including health workers and health care personnel, provincial supervisors and community leaders – recognised the benefits of SDR-PEP, particularly its role in improving contact tracing and its potential to reduce leprosy cases. Respondents also highlighted the project's contributions to enhancing HCWs' technical knowledge and stronger collaboration within the health districts as direct outcomes of the project.

While the administration of SDR-PEP was generally well received, some respondents expressed concerns about the potential for drug resistance among tuberculosis (TB) patients. Throughout the project, discussions with the MoH were ongoing, with NLR actively advocating for government approval of SDR-PEP. NLR presented evidence from other countries and expert opinions from TB specialists, emphasising that the risk of inducing rifampicin resistance in TB patients through SDR-PEP is negligible or non-existent.

Stakeholders identified several steps needed to secure full adoption of SDR-PEP in Mozambique. These include securing full government approval to integrate SDR-PEP into national leprosy control policies, improving logistics for SDR-PEP distribution to prevent distribution delays, and improving HCWs' skills, particularly for technicians in peripheral health units where diagnostic capacity remains limited. Additionally, continued engagement with community leaders, volunteers and activists is essential, along with leveraging existing self-care groups to ensure effective sensitisation and communication about the benefits of SDR-PEP.

In Nigeria, SDR-PEP is well accepted by the government at both national and LGA levels. Government officials recognised the positive impact of SDR-PEP on leprosy control efforts. In 2021, the Federal MoH, through the National TB and Leprosy Control Programme (NTBLCP), integrated both SDR-PEP and CSCGs into the National Leprosy Guidelines and the Zero Leprosy Roadmap for 2021–2030. This integration demonstrates a strong commitment to scaling up the intervention. Furthermore, the government developed standard operating procedures (SOPs) and included them in training manuals for HCWs.

The Nigerian government's commitment to SDR-PEP is further evidenced by the NTBLCP's engagement with the House of Representatives, advocating for the allocation of resources to expand SDR-PEP provision nationwide. State-level support has also been significant. For example, in Jigawa State, the Director of Public Health championed state funding to facilitate wider adoption of SDR-PEP. These successes were the result of targeted advocacy efforts aimed at national and state government stakeholders, raising awareness and building support for SDR-PEP since its inception.

LTR Nigeria and its government counterparts recognised that achieving a broader and sustainable integration of SDR-PEP into routine leprosy control would require steadfast government support. It would also require adequate financial resources, particularly to strengthen the capacity of health

workers, ensure the availability of drugs, and support for CSCGs. Additionally, it would need to continue to engage the community in discussions about the importance of leprosy treatment and providing a supportive environment for SDR-PEP, strengthening the trained health workers, and reaching out to more health workers on SDR-PEP.

## Main steps and mechanisms developed by the project within the health system for the implementation of leprosy control and SDR-PEP administration activities

In each country, partners contextualised SOPs for the identification of index cases and their contacts and developed capacity in the health system sub-national structures of the target areas to ensure their application. SOPs were then revised according to the experience developed in the framework of the project.

In both countries, SDR-PEP administration was combined with active case finding and community mobilisation activities. In consideration of the fact that the majority of the target population lives in remote villages in rural areas and that SDR-PEP was newly introduced, community-based approaches (door-to-door or mini-campaigns) for contact screening and SDR-PEP administration were preferred and contributed to successful results. Overall, leprosy control activities were primarily managed by district or LGA supervisors along with supervision at provincial or state-level. Support at the community level was provide through community activists/volunteers and leaders who participated in community mobilisation efforts, and the active involvement of community-based healthcare workers with monitoring conducted by healthcare personnel also through house-to-house visits. Community members and individuals affected by leprosy also played a pivotal role.

The index patient's identity was not always disclosed to social contacts. Retrospective leprosy cases from previous years were included to identify contacts.

Considering the available data until mid-2024, about 10-11 contacts per index case were listed. 97% in Mozambique and 99% in Nigeria of the contacts listed were screened. Very few contacts refused to be part of the process and a limited number were not found. Among the contacts screened around 93% in Mozambique and 92% in Nigeria received SDR-PEP. In both countries about 5% of the contacts screened could not receive SDR-PEP because under 2 or below 10 kg or pregnant. These contacts received a voucher that they can use to obtain SDR-PEP, once their situation changes. The remaining contacts were diagnosed with leprosy or had other conditions. These figures indicate a high level of acceptability of SDR-PEP and the feasibility of the intervention.

They also complement findings from a document review of baseline and follow-up studies in both Mozambique and Nigeria, with lower SDR-PEP refusals and testimony from contacts that prior to the introduction of SDR-PEP the fear of stigmatising their close contacts prevented them from seeking diagnosis and treatment. Now they are more willing to come forward because they know preventive therapy is available to their families free of charge. No adverse events related to SDR-PEP were reported in either country.

The project significantly improved HCWs' knowledge and skills in diagnosing and managing leprosy, administering SDR-PEP and conducting active case finding. This led to a notable increase in the detection of new cases in both Mozambique and Nigeria. Community involvement, particularly through community activists and CSCGs, also played a vital role in mobilising communities, promoting awareness, reducing stigma and supporting individuals affected by leprosy. In addition, integration of leprosy control into broader health services, such as TB and skin disease programmes, proved beneficial, though limited in scope.

Both countries faced challenges with consistent drug supply ofmulti-drug therapy (MDT) and loose rifampicin. Reliance on external funding also poses sustainability concerns. While Nigeria successfully integrated SDR-PEP and CSCGs into national policies, Mozambique's efforts were still ongoing, highlighting the need for continued advocacy and resource mobilisation to ensure long-term success.

# Level of maturity of CSCGs, their integration into the health system, and their quality and sustainability

In Mozambique, the integration of CSCGs into the health system continues to evolve. CSCGs are well connected with public health sector operations, with district health staff regularly visiting to provide treatment and support. The Ready4PEP project has significantly advanced the establishment of new CSCGs and revitalised those originally formed by the MoH. Over the past three years, the number of CSCGs has grown substantially. For instance, up to June 2024, the project surpassed its target of new groups registered, trained and equipped with necessary materials, as 39 groups were functioning in the target districts, compared to the original goal of 25. In addition to facilitating self-care and community-based physical rehabilitation through activists trained as community-based rehabilitation facilitators, the Ready4PEP project expanded CSCGs' roles. It enhanced social rehabilitation, advocacy and inclusion by engaging local government institutions and creating pressure groups within CSCGs to address the needs of persons affected by leprosy.

Respondents consistently highlighted the significant support that CSCG activities provide to individuals diagnosed with leprosy. These groups offer a safe environment where members can access medical, emotional and social supports. This, in turn, has helped reduce stigma and foster community acceptance. Most agreed that the CSCG activities effectively help members manage their condition, prevent further physical deterioration and improve mental well-being.

While the MoH recognises the important contributions of CSCGs to leprosy management – particularly in addressing social exclusion and promoting the inclusion of persons affected by leprosy and other neglected tropical diseases (NTDs) in the community – their formal inclusion in national leprosy policies remains limited. In particular, the combined approach between leprosy and other NTDs is underdeveloped. There is an opportunity to incorporate CSCGs into strategic documents such as the Roadmap for Leprosy Control. Furthermore, the MoH is currently in the process of securing a grant (approximately 90% guaranteed) to support associations of individuals affected by leprosy, signalling progress in strengthening these groups.

In Nigeria, in 2021, the Federal MoH, through the NTBLCP, included SDR-PEP and CSCGs in the National Leprosy Guidelines and the Zero Leprosy Roadmap 2021–2030. By 2023, 14 new CSCGs were established, bringing the total number of functioning CSCGs to 55 - 122% above the project target. This growth reflects a higher-than-anticipated demand for community-based rehabilitation through CSCGs.

Although CSCGs in Nigeria are still maturing, their members demonstrated commitment by holding regular meetings to discuss challenges, provide mutual encouragement and reinforce self-care practices. Through regular meetings, CSCGs offer essential resources such as hygiene materials, counselling and, in some cases, financial support, helping members manage their condition and feel included in the community. Participation in CSCGs has helped support individuals with leprosy by fostering community acceptance and providing a safe space to address their health and social needs. This structure has positively impacted members' self-esteem and helped them manage social interactions more confidently.

Overall, while stakeholders recognise CSCGs' vital role in supporting individuals affected by leprosy at the community level, their integration into broader national policies remains incomplete. Continued advocacy is needed to ensure these groups are fully incorporated into the country's health strategies, enabling them to sustain and expand their impact.

## Changes in the perception of leprosy and related stigma in the communities where SDR-PEP was implemented

In Mozambique, the introduction of SDR-PEP has reduced the stigma surrounding leprosy in the communities where it was implemented. Community members have become better informed about leprosy, which has led to greater acceptance of individuals affected by the disease. The administration

of preventive medicine, including screening and treatment programmes, initiated by the Ready4PEP project has helped communities to view leprosy as a treatable and preventable disease, further reducing fear and discrimination against those affected. The training sessions for HCWs, community volunteers, activists and leaders have been effective in addressing misconceptions about leprosy transmission and encouraging participants to reflect on their biases. In addition, community mobilisation efforts through radio announcements, engagement of local churches and door-to-door activities have played a crucial role in changing perceptions about leprosy. Also, the formation of CSCGs has been crucial in lessening stigma. These groups provide a safe, supportive space for people affected by leprosy to rebuild confidence and re-engage in community life. Finally, understanding that discrimination and isolation can affect mental health, NLR-Mozambique has partnered with the MOH and mental health departments to provide emotional support, including counselling sessions for leprosy patients.

In Nigeria, the data collected in this evaluation indicated that the implementation of SDR-PEP and accompanied education has led to increased knowledge of leprosy among patients, contacts and community members. Knowing that close contacts of leprosy patients can be protected through a single dose of rifampicin has alleviated much of the anxiety surrounding the transmission of leprosy. As a result, communities are beginning to view leprosy as a manageable and preventable condition rather than a threat to public health. Engaging with religious and community leaders, community activists and volunteers has been effective in delivering messages about leprosy-related stigma to their members. Involving these stakeholders has helped to normalise discussions about leprosy, reduce the taboo surrounding the disease, and view leprosy patients with empathy and understanding rather than fear and suspicion. In addition the trained CHWs and MDT staff conducted community sensitisation, using the social and behaviour change communication materials developed at the start of the project, helping to raise awareness and reduce misconceptions about leprosy. Finally, leveraging diverse media platforms, TLM-Nigeria conducted periodic public awareness-raising campaigns to engage a wide audience in addressing issues related to stigma.

#### Potential concerns for further scale-up of the project

In Mozambique, the respondents mentioned challenges with ensuring a consistent supply of rifampicin, as loose rifampicin was unavailable. The MoH clarified that the Ready4PEP project was primarily a pilot study designed to evaluate the acceptance and effectiveness of SDR-PEP in communities. This framework allowed NLR-Mozambique to import rifampicin, but the process faced difficulties, particularly due to medication shortages caused by the COVID-19 pandemic. To adopt SDR-PEP as part of routine leprosy control, it will be necessary to register rifampicin specifically for leprosy prevention or include it in the national medication guidelines. For long-term sustainability, establishing a clear and reliable supply chain is essential, as no such system existed during the project. The Stop TB/Global Drug Facility has expressed willingness to supply rifampicin for leprosy in the future, and a World Health Organization (WHO) rifampicin donation programme is also being developed, which promises to improve trust and ensure a sustainable supply chain. Collaboration with the TB programme could further strengthen supply logistics, as ordering loose rifampicin through the Stop TB/Global Drug Facility allows for shared medication shipments, reducing logistical costs.

In Nigeria, in addition to the WHO donation programme and Stop TB/Global Drug Facility, sourcing rifampicin from local producers with a proven track record of high-quality production could be a viable solution to enhance the supply chain and support sustainable distribution.

Another issue mentioned is the project's reliance on external funding and resources. It risks weakening critical components such as community activists and the availability of medicines once the initiative concludes. Also, the implementation and monitoring strategies were resource-intensive and heavily reliant on project funding, which the MoH, lacking a clear funding structure, is unlikely to sustain.

Further, stakeholders also mentioned that the global MDT programme relies solely on donations from the WHO, as MDT cannot be purchased independently by any country where leprosy is prevalent.

Challenges often arise when countries delay placing orders, fail to account for active case-finding efforts that increase patient demand, or underestimate long lead times for delivery. It is therefore important for MoH to be in close contact with the WHO, monitoring in-country medication stock, forecasting quantity needs, placing orders in time and optimising the medication import process to enhance efficiency and reduce delays. This is also important for when the WHO rifampicin donation programme is fully in place.

#### Best practice, lessons learned and recommendations

Based on the findings, several best practices, lessons learned and recommendations emerged to enhance future leprosy control efforts. Best practices include:

- Community engagement and ownership: The active involvement of community activists, leaders and CSCGs proved crucial for successful implementation and sustainability.
- Capacity-building and training: Targeted training programmes for HCWs, combined with supportive supervision, significantly strengthened leprosy management capabilities.
- Integrated health strategies: Integrating leprosy control with other health programmes optimised resources and facilitated a more comprehensive approach.
- Technological innovations: The use of the NLR SkinApp enhanced diagnostic accuracy, particularly in areas with limited access to dermatologists.

Lessons learned related to the use of innovative tools, the importance of community engagement and integrated health strategies, including the use of the NLR SkinApp, as well as task-shifting to empower HCWs and community-level workers to diagnose and manage leprosy effectively while bridging gaps in technical expertise. CSCGs emerged as a critical mechanism to reduce stigma, improve mental well-being and foster social inclusion for persons affected by leprosy and other diseases. In addition, community-centred approaches, including house-to-house administration of SDR-PEP, demand creation efforts and participatory decision-making enhanced awareness and acceptance of interventions.

Recommendations are broken down into the following six key themes.

#### Policy and advocacy

Mozambique: Advocate for the full approval and integration of SDR-PEP into national health policies, and secure a clear financing mechanism for its sustainability.

Nigeria: Continue advocating for the nationwide scale-up of SDR-PEP to all states and LGAs.

#### Capacity-building and community engagement

Both countries: Expand training programmes to ensure sufficient skilled personnel, and enhance community engagement efforts to promote awareness and reduce stigma.

#### Sustainability and expansion

Both countries: Ensure a consistent supply of MDT and SDR-PEP drugs, address logistical challenges, and secure long-term funding mechanisms for leprosy control activities.

Mozambique: Prioritise the integration of leprosy control efforts into the package provided by multipurpose health agents.

Nigeria: Formalise the role of CSCGs within the health system and provide increased resources for their activities.

#### Additional recommendations

Mozambique: Integrate psychosocial support into CSCGs to address mental health challenges and provide more comprehensive care.

#### Conclusions

The Ready4PEP project demonstrably strengthened leprosy control efforts in Mozambique and Nigeria and provided the two countries with the main tools to include SDR-PEP in their leprosy control programmes. Through a multi-pronged strategy encompassing capacity-building, community engagement and innovative technological tools, the project achieved significant progress in early case detection, SDR-PEP administration and stigma reduction. A key takeaway from this evaluation is the transformative power of community involvement and ownership in advancing leprosy control. In both countries, community activists and leaders emerged as crucial drivers of success, mobilising communities, fostering awareness and supporting individuals affected by leprosy. The creation and revitalisation of CSCGs further amplified this impact, providing vital support networks, promoting self-management and reducing stigma.

While the project encountered challenges, notably regarding consistent drug supply, logistical constraints and the need for sustained funding, the evaluation underscores a crucial lesson: comprehensive leprosy control requires a collaborative approach that integrates innovative strategies with existing health systems. The project's successes in integrating leprosy management with broader health services, such as TB, NTD and skin disease programmes, highlight the potential for maximising resource utilisation and achieving more holistic patient care. The adoption of technological innovations such as the NLR SkinApp (and in the future the WHO SkinApp) further strengthened diagnostic accuracy and facilitated early intervention.

Moving forward, ensuring the sustainability of these gains is paramount. Mozambique must prioritise the full integration of SDR-PEP into national health policies, securing a clear funding mechanism and addressing logistical bottlenecks to ensure consistent drug availability. Nigeria, having successfully integrated SDR-PEP and CSCGs into national policies, needs to focus on nationwide scale-up, maintaining a consistent drug supply and strengthening the role of CSCGs within the health system. Both countries must continue to invest in capacity-building, community engagement and the integration of mental health support into leprosy care to address the multifaceted challenges associated with the disease.

The lessons learned from the Ready4PEP project provide valuable insights for future leprosy control initiatives. The project's success in fostering community ownership, embracing technological advancements and championing integrated health strategies offers a roadmap for achieving a leprosy-free world. By embracing these lessons and addressing remaining challenges, Mozambique and Nigeria can build on the project's achievements and ensure lasting improvements in the lives of individuals affected by leprosy.

#### 1. Introduction

#### **1.1.** Background of the Ready4PEP project

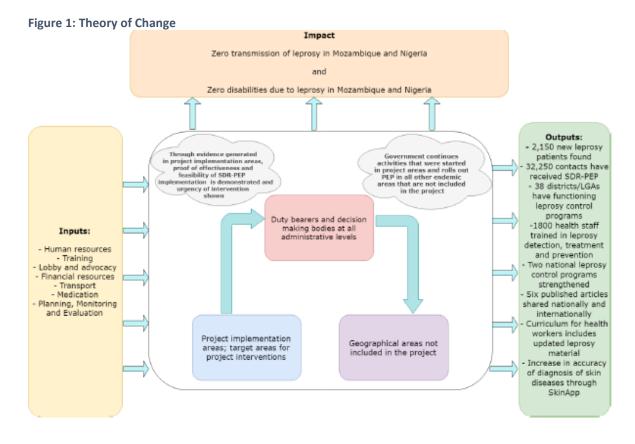
NLR is a non-governmental organisation dedicated to achieving a world free from leprosy. NLR and its partners in Mozambique and Nigeria implemented the **Ready4PEP project**, which focuses on interrupting leprosy transmission and improving the care of affected individuals in both countries. The project works closely with various stakeholders, particularly the National Leprosy Control Programmes (NLCPs) in Mozambique and Nigeria. The project's primary aim is the introduction of single-dose rifampicin post-exposure prophylaxis (SDR-PEP), a preventive post-exposure prophylaxis antibiotic meant to reduce the risk of developing leprosy and to stop its transmission. The project addresses five key components: active case finding, epidemiological mapping, capacity-building of health care workers (HCWs), SDR-PEP distribution and Combined Self-Care Groups (CSCGs).

The project launched on 1 January 2020 with funding from a foundation; it was extended, through two no-cost extensions, until the end of 2024. It was co-designed with local partners in Nigeria and Mozambique and implemented through the Leprosy and Tuberculosis Relief Initiative (LTR-Nigeria), The Leprosy Mission - Nigeria (TLM-Nigeria) and RedAid in Nigeria, and NLR-Mozambique and TLM-Mozambique in Mozambique. LTR-Nigeria and NLR-Mozambique lead the consortia, in collaboration with each government's health authorities and national leprosy divisions.

The project is focused on achieving three key outcomes:

- 1. **Inclusion of SDR-PEP in national strategies:** Ministries of Health (MoHs) in Mozambique and Nigeria formally adopt SDR-PEP as part of their national leprosy strategies.
- 2. **Fully functioning leprosy control programmes:** Project intervention areas in both countries have fully functioning leprosy control programmes, including SDR-PEP administration, with adequately trained staff, sufficient resources and sustained leprosy-related activities.
- 3. **Integration of CSCGs:** CSCGs become an integrated part of leprosy-related interventions in both Mozambique and Nigeria.

The Ready4PEP's Theory of Change (ToC) that underpins the project consolidates the impact, main outcomes, outputs and inputs into a single framework, as shown in **Figure 1**. The ToC is built on the assumption that project interventions, including the training of staff, provision of resources and preparation of local facilities for the administration of SDR-PEP in selected areas of Mozambique and Nigeria, will generate results that will persuade governments to implement SDR-PEP nationally, targeting areas that are not included in the project roll-out.



The project is active in 12 districts in Mozambique across 4 provinces, and 26 endemic local government areas (LGAs) across 6 states in Nigeria. **Table 1** lists the states/LGAs and provinces/districts covered by the project as of September 2024.

Table 1	: Geographic	coverage	of Ready4PEP
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States/Provinces	LGAs/Districts	
	Phase I up to 2022	Phase II from 2022
	Nigeria	
Cross Rivers	Ogoja	Ogoja
Implementing Partner (IP):	Yakurr	Yakurr
RedAid		Boki
		Obubra
Ebonyi	Ebonyi	Ebonyi
IP: RedAid	Ohaukwu	Ohaukwu
		Afikpo North
		Afikpo South
Bauchi	Misau	Misau
IP: LTR	Shira	Shira
		Alkaleri
		Katagum
Jigawa	Buji	Buji
IP: LTR	Ringim	Gwaram
		Ringim*
		Birniwa
		Kazaure

States/Provinces	LGAs,	/Districts
Kebbi	Bagudo	Bagudo
IP: TLMN	Yauri	Yauri
		Shanga
		Argungu
		Suru
Niger	Kontagora	Kontagora
IP: TLM	Mashegu	Mashegu
		Magama
		Paikoro
	Mozambique	
Cabo Delgado	Chiure	Chiure**
IP: TLM		Namuno***
		Montepuez****
Nampula	Rapale	Rapale
IP: NLR		Ribáuè
		Malema***
Zambezia	Molumbo Cuamba	Molumbo
IP: NLR		Milange
		Mulevala***
Niassa		Cuamba
IP: NLR		Mecanhelas
		Mandimba***

Note: The project targeted 26 LGAs in Nigeria.

\* Security is a factor in this location.

\*\* Started, but activities stopped due to insecurity.

\*\*\* Engaged in 2023 but started providing SDR-PEP in 2024 (total of 11 districts).

\*\*\*\* Targeted 12 districts; however, due to a growing security situation, could not expand to one district (Montepuez).

#### **1.2.** Purpose of the evaluation

After about four years of implementation, NLR International commissioned a final evaluation. According to the evaluation's Terms of Reference (ToR) provided by NLR, the main objectives of the evaluation were to:

- analyse progress made towards key strategic outcomes and project targets, identify existing hurdles for their full achievement, and explore the necessary measures to overcome them and ensure sustainability;
- describe the main steps and mechanisms developed by the project within the health system for the implementation of leprosy control and SDR-PEP administration activities;
- document changes produced by the project among health care providers and health care managers at national and subnational levels;
- analyse the level of maturity and integration of the CSCGs within the health system, as well as the quality and sustainability of these groups;
- document and analyse changes in the perception of leprosy and related stigma in the communities where SDR-PEP was introduced;
- explore potential negative effects of the project; and
- consolidate best practices, lessons learned and main recommendations for future strategies and plans, identifying what has already been integrated into the leprosy control programmes and what can still be included.

The evaluation aimed to assess progress towards achieving the project's key strategic outcomes and targets, guided by the evaluation questions outlined in the ToR and further refined during the inception phase. Additionally, it sought to identify barriers hindering the full realisation of the project and explored measures to overcome them and ensure long-term sustainability. The evaluation also documented best practices and lessons learned, where applicable, providing actionable recommendations to inform a potential project extension and gather insights for improvement.

#### 1.3. Users and uses

The final evaluation's primary audiences are the NLR's implementing partners and the MoH representatives at national and subnational levels in Mozambique and Nigeria. Useful information and insights from the evaluation will also feed into a meeting, planned for the end of 2024, with NLCP managers, the World Health Organization (WHO) Regional Office for Africa, and other relevant stakeholders from countries that are endemic for leprosy. Other target audiences for this final evaluation include the donor and the implementing partner's fundraising, communications, advocacy and research staff.

### 2. Final evaluation design and methodology

### 2.1. Evaluation questions

The evaluation aimed to address a number of questions and sub-questions, as listed in **Table 2**.

Table 2:	Evaluation	questions	and	sub-questions

Evaluation questions Sub-questions		
1. What is the level of adoption of SDR-PEP within	1a. How do the most important leprosy actors perceive SDR-PEP, and how committed are they to implementing SDR-PEP administration?	
the health system and the national leprosy strategy, and the sustainability of its	1b. Which steps are needed to ensure wider and sustained adoption of SDR- PEP in the two countries?	
continuous implementation?	1c. Does the MoH have the intention to ensure staff training and the use of information, education and communication (IEC) materials on leprosy, contact screening and SDR-PEP administration, based on the tools developed and the results achieved by the project?	
2. What are the main steps and mechanisms developed	2a. What changes were produced by the project among health care providers and health care managers at national and subnational levels?	
by the project within the health system for the implementation of leprosy control and SDR-PEP administration activities?	2b. How are leprosy control, active case finding and SDR-PEP administration activities planned, managed and monitored at the district and provincial/LGA levels? Who are the main actors? Which approaches are used? When are activities implemented?	
	2c. Has the project increased awareness and commitment regarding leprosy among health care providers and managers?	
	2d. Has the project improved the competencies and confidence of health care providers in the diagnosis and treatment of leprosy cases, as well as in the tracing, screening and SDR-PEP administration of their contacts? How? Are protocols and standard operating procedures (SOPs) well known and clear?	
	2e. What are the main challenges and concerns of health care providers and managers in conducting the activities?	
	2f. What is the level of integration of the leprosy programme with other health programmes and services?	
	2g. Are decision-makers at the subnational level allocating more resources (human, financial, logistics) towards the elimination of leprosy?	
	2h. How well established are the mechanisms related to the procurement and supply chain of drugs (rifampicin and MDT) within each country?	
3. Concerning the CSCGs, what is the level of maturity	3a. How extensively are the CSCGs included in leprosy policies and programmes?	
and integration within the health system, and the quality and sustainability of these	3b. How well has participation in CSCG activities helped and supported persons diagnosed with leprosy?	
groups?	3c. Have the participants in the groups improved their health condition and prevented the (further) development of disabilities?	
	3d. Have the groups contributed to the social participation and mental well- being of their members?	

Evaluation questions	Sub-questions
4. What are the changes in the perception of leprosy and related stigma in the communities where SDR-PEP was implemented?	N/A
5. What are the potential concerns of upscaling the project?	N/A
6. What are the consolidated best practices, lessons learned and main recommendations for future strategies and plans, identifying what has already been integrated in the leprosy control programmes and what can still be included?	N/A

A detailed matrix evaluation can be found in **Annex 1**, which shows the methods used to answer each question and sub-question.

### 2.2. Site selection

During inception meetings with NLR and country-level partners, a number of sites were selected for evaluation in each country, as shown in Table 3.

Table 3: Evaluation sites					
Country	State/Province	LGA/District			
Mozambique	Nampula Zambézia	Rapale and Nampula Milange and Quelimane			
Nigeria	Cross River Jigawa	Obubra and Yakurr Kazaure and Ringim			

This selection was guided by several factors, including the presence of implementing partners and the security situation.

### 2.3. Methodology

The evaluation employed a mix of primary and secondary data collection methods. Secondary data was gathered through a comprehensive desk review of project documents and relevant datasets. Key documents included the original project proposal, baseline evaluations in both countries, annual reports and other monitoring data. These materials were analysed in relation to the final set of evaluation questions, helping to design primary data collection tools and identify examples and quotes that illustrate common themes and findings.

Primary data collection methods included key informant interviews (KIIs), focus group discussions (FGDs) and Stories of Change (SoCs) collected/edited for each country. Quantitative data analysis was conducted using available datasets provided by the project.

During the evaluation kick-off meeting with NLR and implementing partners in Nigeria and Mozambique, it was agreed that this final evaluation would not replicate the baseline evaluation by

using identical tools or conducting a direct process comparison. The tools developed in 2020 were specifically designed to assess facilities in the target areas and to guide project implementation.

In August to September 2024, NLR Mozambique and LTR also conducted end-line data collection to provide evaluators with updated information on key indicators. As a result, this evaluation incorporated relevant insights and tools from multiple data collection points, including: 1) baseline evaluations in Mozambique and Nigeria; 2) a 2021 review conducted in Nigeria; and 3) the Mozambique and Nigeria end-line data collection reports provided during the evaluation's analysis stage.

KIIs with stakeholders primarily addressed evaluation questions 1–3 and 6, while FGDs focused on evaluation questions 3–5, particularly examining changes in the attitudes of health care personnel towards individuals affected by leprosy. Both the KII and FGD tools were designed to align with the evaluation objectives and are included in **Annexes 2 and 3**, respectively.

Finally, a sense-making and validation workshop took place in each country to allow Ready4PEP project partners to reflect on the project activities and actively engage in interpreting the collected data. The sessions focused on developing country-level lessons learned, findings and recommendations. The sense-making and validation workshops were held in Mozambique on 30 October 2024 and in Nigeria on 4 November 2024.

#### **2.3.1.** Ethical considerations

A key priority for both NLR and the evaluation team was ensuring inclusivity and adopting a participatory approach throughout the evaluation process. To achieve this, the individuals affected by leprosy were actively involved in two key stages: the KIIs, FGDs and SoCs, as well as the sense-making and validation workshops. Their participation provided an opportunity to voice their opinions and perspectives on project achievements. Their contributions also enriched the evaluation by offering deeper insights into the lived experiences of individuals affected by leprosy, highlighting its long-term impact on their lives. Each KII, FGD and SOC was recorded with the informed consent of the participants. Consent and release forms can be found in **Annex 5**.

#### 2.3.2. Desk review

A desk review was conducted to obtain information on the Ready4PEP project's context/situation and allow initial findings to be understood using the evaluation questions which would be explored, triangulated and validated during fieldwork. The results of this review also informed the tool development/review, data collection guidelines and fieldwork plan. The review included project monitoring data, project proposal, project reports, baseline and midterm review reports (Nigeria), harvested outcomes, collected SoCs and other relevant documents. The document review findings were used as preliminary secondary data to complement the primary data.

#### 2.3.3. Key informant interviews

Individuals and groups knowledgeable about, connected to or with experience of the project participated in KIIs. They included government representatives, staff from NLR and its partner organisations, and health care personnel. To ensure comprehensive insights into all aspects of the evaluation questions, an appropriate balance between NLR staff and external stakeholders was agreed on with NLR.

A total of 28 KIIs were carried out: 12 respondents in Nigeria, 14 in Mozambique and 2 representatives from NLR Global (as summarised in Table 4). The full list of interview participants is provided in **Annex 6**.

Role	Nu	Total	
	Nigeria	Mozambique	
National Ministry of Health	1	1	2
Provincial/state leprosy supervisors/focal points	2	3	5
District/LGA CMO/leprosy supervisors	3	2	5
Health care providers	3	3	6
Implementing partners	3	3	7
WHO or other civil society organisation	0	2	2
Total	12	14	26

#### Table 4: KII participants – Nigeria and Mozambique

#### 2.3.4. Focus group discussions

The FGDs were conducted with project participants, including leprosy patients, affected contacts, CSCG members and health care service providers. Three FGDs were carried out per site (six per country), for a total of 12 FGDs across both countries (see Table 5). All discussions were recorded with the informed consent of the participants.

The FGD instruments were prepared in English, translated into Portuguese and Hausa for use Mozambique and Nigeria, respectively, and piloted to ensure accuracy and cultural relevance.

Role		Number			
	Nig	Nigeria		Mozambique	
	М	F	М	F	All
Health care managers/providers	4	8	6	1	19
Community volunteers/leaders/contacts*	6	19	4	-	29
Community members/contacts	-	-	6	6	12
CSCGs	11	4	13	11	39
Tota	21	31	29	18	99

\* For Nigeria, the group was made up of contacts, community leprosy workers and patients. Therefore, contacts were included in a larger FGD with other community members in Nigeria. In Mozambique, they were interviewed separately.

#### 2.3.5. Stories of Change

In developing SoCs, the team made use of data and information collected during project implementation to illustrate key identified outcome results achieved by the project and to gain an indepth understanding of the process that lead to these changes. Additionally, the team collected four SoCs per country (a total of eight) – four from health care providers and four from individuals affected by leprosy. The SoC tool can be found in **Annex 4**. All the SoCs collected during this evaluation can be found in **Annex 7**.

Role	N	Total	
	Nigeria	Mozambique	
Health care providers	1	2	3
Persons affected by leprosy (leprosy patients/community leprosy workers)	3	2	5
Total	4	4	8

#### 2.3.6. Sense-making workshop

Two sense-making and validation workshops were conducted, one in each country. The workshop in Mozambique took place at the end of October, with participation from the MoH at national, provincial and district level (leprosy programme managers), the National Disease Control Programme, the National Tuberculosis (TB) Control Programme, primary health care nurses, members of the CSCGs, community leaders, implementing partners such as TLM-Mozambique, Associazione Italiana Amici de Raoul Follereau (AIFO) and the NLR-Mozambique team.

In Nigeria, the workshop was held at the beginning of November and was attended by representatives from the Federal Ministry of Health and Social Welfare (MoHSW), the National Tuberculosis, Leprosy and Buruli Ulcer Control Programme and the National TB and Leprosy Training Centre in Zaria. Participants also included state-level leprosy programme managers, Ready4PEP focal points, LGA TB and leprosy supervisors, implementing partners (LTR, TLMN and RedAid) and the chairman of IDEA Nigeria.

#### 2.4. Limitations of the final evaluation

The evaluation encountered several limitations:

- Selective reporting in KIIs: While KIIs open dialogue and can capture unexpected insights, they can also result in bias, as interviewees may selectively report information they wish to share.
- **Remote interviews:** Some interviews were conducted remotely, limiting the observation of non-verbal cues and contextual interactions that might have enriched the data.
- Unavailable WHO representative in Nigeria: It was not possible to interview the WHO representative in Nigeria, due to procedural requirements for obtaining approval from the country office. As a result, their perspective is not included in this report.
- **Project scope misalignment in Mozambique:** Misalignments between NLR, the MoH and the WHO in Mozambique regarding the scope of the project specifically its balance between implementation and research caused slight delays. These issues were ultimately resolved during the sense-making and validation workshop.
- **Cancelled FGD in Mozambique:** A second FGD with community contacts in Mozambique was cancelled due to adverse weather and road conditions, which delayed access to the community of Carico in Milange, Zambezia Province.

#### 3. Findings of the final evaluation

#### **3.1.** Demographic characteristics

Data was collected from 132 respondents in total: 65 in Mozambique, 65 in Nigeria and 2 at the global level.

At the country level, respondents for this evaluation included district and provincial stakeholders (such as leprosy supervisors), representatives from the Ministry of Health, healthcare providers, implementing partners, community members (including individuals affected by leprosy), civil society stakeholders, the WHO, and NLR representatives in each respective country. At the global level, respondents included NLR representatives.

#### Gender distribution of respondents

Overall, the evaluation respondents represented a balanced gender division with more males participating in Mozambique and more females in Nigeria respectively, as shown in the table below

Type of Mozambio		mbique	Nigeria		Global		Total
respondent	F	М	F	М	F	М	
KII	3	11	3	6	2	_	29
FGD	18	29	31	21	_	_	99
SoC	1	3	2	2	_	_	8
Total	22	43	36	29	2		132

# **3.2.** EQ1. What is the level of adoption of SDR-PEP within the health system and the national leprosy strategy, and the sustainability of its continuous implementation?

## **3.2.1.** EQ1a. How do the most important leprosy actors perceive SDR-PEP, and how committed are they to implement SDR-PEP administration?

#### Mozambique

The desk review and interviews with key stakeholders revealed that the integration of SDR-PEP into the national leprosy strategy and health system is a work in progress. While the Ready4PEP project achieved significant progress, its efforts primarily focused on specific geographic areas. Most of the respondents viewed the adoption of SDR-PEP positively, though some voiced caution about its broader integration into the national health system and its sustainability. Key actors in leprosy control – such as health technicians, provincial supervisors and community leaders – generally viewed SDR-PEP favourably, emphasising improvements in technical knowledge and stronger collaboration within the health districts as direct outcomes of the project. One respondent reflected on these changes as follows:

"It was a very good experience... we already have trained activists who get the medicines to the community; they can already take the patients to the health unit." – KII, government stakeholder

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Respondents acknowledged SDR-PEP's contribution to improving contact tracing and its potential to reduce leprosy cases. They also noted the strong commitment among key actors, and the proactive involvement of community volunteers and health professionals, in advancing its implementation.

While the administration of SDR-PEP was generally well received, some respondents expressed concerns, particularly about the potential for drug resistance among TB patients.<sup>1</sup> During the project's implementation, discussions within the MoH were ongoing. NLR actively advocated for SDR-PEP by providing evidence from other countries and expert opinions from TB experts, which indicated that the risk of resistance was negligible or non-existent. By the end of 2023, the National Directorate of Public Health expressed a willingness to discuss incorporating SDR-PEP into the NLCP.

For example, in March 2023, a Leprosy Task Force meeting facilitated by the National Director of Public Health addressed steps for including SDR-PEP in the NLCP, aligning with WHO recommendations. Additionally, a 2023 discussion of the National Roadmap to Zero Leprosy provided NLR with further opportunities to advocate for SDR-PEP adoption by the MoH.

Although discussions on national adoption are ongoing, leprosy control services in districts such as Milange, Molumbo, Ribáuè, Rapale and Chiúre successfully managed SDR-PEP distribution without direct oversight from NLR and TLM staff. This demonstrated a growing confidence and ownership in SDR-PEP administration. However, during the sense-making and validation workshop, participants highlighted a gender imbalance, with women demonstrating quicker acceptance of SDR-PEP, while a small number of men were more doubtful and needed longer to be convinced. However, just 19 refusals were reported among more than 10,000 people. Workshop participants recommended addressing these gender-related challenges to enhance programme inclusivity.

Respondents also voiced concerns about the sustainability of SDR-PEP if scaled nationwide. Key challenges include inconsistent funding and logistical support, which could hinder full commitment to the programme. Sustainability also depends on continuous training for health care professionals, requiring ongoing financial and institutional collaboration with the National Directorate of Training.

Since leprosy was eliminated as a public health problem in 2008, donor support for leprosy-specific programming has declined significantly. This funding gap has made it difficult to secure resources exclusively for leprosy-related initiatives. Workshop participants suggested that integrating leprosy control into other health initiatives, such as TB and neglected tropical diseases (NTDs), could provide a more sustainable and resource-efficient solution.

#### Nigeria

Document review and feedback from respondents highlighted that SDR-PEP is well accepted by the government at both the national and LGA levels. Officials recognised the positive impact of SDR-PEP on leprosy control efforts. There is no refusal reported in Nigeria on adoption of SDR-PEP. Before its introduction through the Ready4PEP project, the government focused solely on treating leprosy using multi-drug therapy (MDT). Respondents generally appreciated the innovation brought about by SDR-PEP, especially as it introduced a preventive treatment option that was previously unavailable in Nigeria.

<sup>&</sup>lt;sup>1</sup> An experts' meeting (pharmacologists, leprologists, TB experts and resistance experts) held in 2015 concluded that administering a single dose of rifampicin for leprosy prevention to selected contacts of leprosy patients, provided there are no symptoms of active TB, poses a negligible risk of inducing resistance in *Mycobacterium tuberculosis* at both individual and population levels. Consequently, the benefits of SDR prophylaxis in significantly reducing the risk of leprosy development among contacts of new leprosy patients greatly outweigh the potential risk of drug resistance in *M. tuberculosis* (Mieras et al.; doi: 10.1186/s40249-016-0140-y). A study investigating drug resistance of *Mycobacterium leprae* in Comoros also suggested that PEP had not selected rifampicin-resistant strains (Braet et al.; doi: 10.1016/S2666-5247(22)00117-3).

At the beginning of Ready4PEP, a series of advocacy initiatives targeted national and state government actors and other relevant stakeholders to promote adoption of SDR-PEP. Building on these efforts, the WHO convened a meeting with national stakeholders in Nigeria to further discuss the implementation of SDR-PEP, fostering greater awareness and support.

A noteworthy aspect of the project in Nigeria was the engagement of key stakeholders from its inception. For example, the National TB and Leprosy Control Programme (NTBLCP) was actively involved in critical activities, including the inception meetings, material development workshops, training of trainers, the project's kick-off event, stakeholder meetings and routine progress monitoring. These engagements enabled the NTBLCP to fully grasp the project's goals and objectives, and its critical role in ensuring its successful implementation.

As a result of these efforts, several respondents noted that the Ready4PEP project facilitated the integration of SDR-PEP into Nigeria's leprosy control strategy. This included formal inclusion in the national guidelines for leprosy control. Additionally, the government developed SOPs and incorporated them into training manuals for HCWs. One respondent shared their perspective on the inclusion of SDR-PEP in national strategies:

"The National Leprosy Control Programme has finally included SDR-PEP as part of the strategies for leprosy control in Nigeria...trigger[ing] scale-up [and] now being part of the national guidelines for leprosy control." – KII, NLR partner

Before the Ready4PEP project, CSCGs were limited to a few states/LGAs, and most of them were not operational. However, in 2021, the NTBLCP incorporated both SDR-PEP and CSCGs into the National Leprosy Guidelines and the Zero Leprosy Roadmap for 2021–2030. By 2023, MDT clinics in Ready4PEP LGAs were fully operational, staffed with trained professionals skilled in leprosy diagnosis, treatment, disability management and SDR-PEP administration. Additionally, a network of leprosy control experts was established across all 26 LGAs. This led to a notable increase in the detection of new leprosy cases, with fewer individuals presenting with visible disabilities at diagnosis, underscoring the success of early case detection, timely treatment and enhanced community awareness.

The Nigerian government's commitment to SDR-PEP is further evidenced by the NTBLCP's engagement with the House of Representatives, advocating for the allocation of resources to scale up the intervention nationwide. The project has gained strong support within the MoH, with the Department of Public Health demonstrating its commitment to integrating leprosy control with other public health programmes, such as TB. As one of the respondents stated:

"...there's more funding for TB than leprosy, but with commitment from the Director of Public Health, we are leveraging a lot on even TB activities...to include leprosy." – KII, government respondent

In addition, there was also evidence of commitment at the state level to support SDR-PEP interventions. For instance, in Jigawa, the Director of Public Health advocated for state funding to expand implementation of the SDR-PEP across the region.

These advances suggest that the health system is gradually adopting a more integrated approach to managing leprosy alongside other health priorities, such as TB, despite limited funding for leprosy programming. FGD participants emphasised a noticeable shift in HCWs' attitudes, driven by increased awareness of leprosy as a public health issue. They observed that HCWs demonstrated strong commitment to implementing SDR-PEP administration and carrying out related activities, including contact tracing and community sensitisation.

HCWs also reported successfully integrating leprosy diagnosis and treatment into their routine services, which also enhanced case detection and earlier intervention. Respondents mentioned that the training and resources provided through the Ready4PEP project empowered HCWs, boosting their confidence in diagnosing and managing leprosy cases. One respondent underscored this transformation, noting that the project strengthened their ability to handle leprosy within the broader framework of health care delivery:

"Before [Ready4PEP], none of them showed interest in managing leprosy... But during this [programme] they were trained, and they now know that leprosy is real... The activity has made them understand that deformity comes from negligence and lack of knowledge." – KII, service provider

## **3.2.2.** EQ1b. Which steps are needed to ensure wider and sustained adoption of SDR-PEP in the two countries?

#### Mozambique

As highlighted in Section 3.2.1, the full adoption of SDR-PEP and its integration into the health system in Mozambique is still a work in progress. Interviews with project stakeholders identified several steps required for its adoption. Many respondents stated that securing full government approval for integrating SDR-PEP into national leprosy control policies was a pivotal step, as the sustainability of its ongoing implementation relied heavily on its inclusion in national strategies. To expedite this process, some respondents underscored the need for intensive and continued engagement with MoH counterparts.

Some interviewees and participants in the sense-making and validation workshop also highlighted the need to improve logistics for SDR-PEP distribution to avoid delays, as well as the need for a robust and efficient supply chain:

"We are almost there... but it's more like a logistics thing that has to be solved quickly, because the medications are available in Mozambique." – KII, NLR partner

"Unlike the set of leprosy treatment medications [MDT] that WHO sends...and from there distributed to the provinces [provincial depots], then to the district, and then to the health units, therefore within the Ministry's structure... rifampicin [SDR-PEP] has a confusing flow." – KII, government respondent

Some respondents emphasised that enhancing the capacity of HCWs is a critical and generally positive step towards ensuring the sustained adoption of SDR-PEP. They expressed confidence that the knowledge and skills gained through the project are likely to endure beyond its duration. As one respondent shared:

"One of the things I noticed, which can still be beneficial to us even after the activities end, is the knowledge that the technicians acquired. Of the 13 health units in Chiúre, adding 3 more from Namuno, a total of 19 technicians were trained. I can say that the technicians' knowledge improved significantly. Even with the conclusion of the project, the technicians still carry this legacy, and this legacy was thanks to the training we had. They can diagnose patients and properly follow up with them. This was the greatest outcome of the activity." – KII, NLR partner However, targeted training was also highlighted as a necessary strategy, particularly for health unit technicians in peripheral health units where diagnostic capacity remains limited.

In addition, interviewees and FGD participants consistently highlighted the importance of continued engagement with community leaders, volunteers and activists, and leveraging existing CSCGs to ensure effective sensitisation and communication about the benefits of SDR-PEP. Several respondents noted that the education and campaigns about leprosy prevention organised by the project were positively received by communities, fostering greater awareness and acceptance of the initiative. One respondent described how information is spread through community-led initiatives:

"In the village, they are informed to search and raise awareness at the fairs and churches to go to the health centre early, for timely diagnosis." – FGD participant

Some respondents also suggested that awareness-raising and educational efforts warranted expansion, as these initiatives significantly contributed to further reducing stigma and discrimination.

#### Nigeria

As reported in the previous section, stakeholders in Nigeria demonstrated a strong commitment to implementing SDR-PEP. LTR-Nigeria and its government counterparts recognised that achieving broader and sustainable integration of SDR-PEP into routine leprosy control would require steadfast government support. An important milestone was the adoption of SDR-PEP administration in the National Leprosy Guidelines and the Zero Leprosy Roadmap 2021–2030. Building on this progress, NLR's partners in Nigeria continued their advocacy efforts, resulting in the approval of a Zero Leprosy and Buruli Ulcer Roadmap 2023–2030, which included the scale-up of SDR-PEP to additional states and LGAs.

While these approvals marked the success of the advocacy efforts, respondents highlighted that to ensure the implementation of SDR-PEP in all LGAs, firm commitments from the national and local governments would require adequate financial resources, particularly to strengthen the capacity of HCWs, ensure the availability of the drugs and support CSCGs. As mentioned before, in 2023, LTR-Nigeria and the NTBLCP started to advocate to the House of Representatives and state-level policymakers to allocate resources for the scale-up of SDR-PEP intervention across Nigeria in the coming years.

In addition to government support, it was noted that the project received support and appreciation from individuals affected by leprosy, as well as their communities. Participants in interviews and focus groups highlighted the importance of continuing to engage the community in discussions about the importance of leprosy treatment and providing a supportive environment for SDR-PEP. They observed that when communities are well informed, they are more likely to participate in screening and treatment. One FGD participant summarised this sentiment, emphasising the project's effectiveness in fostering participation through awareness-raising:

"Involving community members in understanding the dangers of leprosy is crucial... So when we give that information, whoever wants to come will come." – FGD participant, CSCG

Respondents also considered that ensuring the availability of the drug is crucial to sustain the adoption of SDR-PEP. They observed that without a steady drug supply, the programme would not be implemented effectively:

"The SDR-PEP drug should always be available. It should be available because if it is not available, there is no 'how' we are able to move." – KII, government stakeholder

Most of the respondents also mentioned that strengthening the training for HCWs and reaching out to more HCWs on SDR-PEP would be needed to ensure wider and sustained adoption. Some stakeholders further elaborated that the training provided by the Ready4PEP project has significantly enhanced the knowledge and skills of health care providers, enabling them to diagnose and manage leprosy cases effectively. They stated that there is an urgent need to scale up knowledge on SDR-PEP across all the LGAs and states involved, as many local governments are currently not engaged in the project. Virtual training and leveraging existing platforms, such as annual review meetings, and using existing HCW structures could help spread knowledge on SDR-PEP.

**3.2.3.** EQ1c. Does the MoH intend to ensure staff training and the use of information, education and communication (IEC) materials on leprosy, contact screening, and SDR-PEP administration, based on the tools developed and the results achieved by the project?

#### Mozambique

In Mozambique, the project has developed various IEC materials and training modules, such as diagnosing leprosy, leprosy treatment and complication follow-up, contact examination and the use of the Open Data Kit tool for data management. Using these training materials throughout project implementation, the Ready4PEP project has conducted a series of training activities. For example, at the beginning of the project, phased training was set up, starting with a Training of Trainers (ToT) and followed by training at the district level. Another training course was conducted for district leprosy supervisors and health staff at primary health centres in 2021. Similarly in 2022 and 2023, the Mozambique project team updated the ToT curriculum and conducted a refresher course that included all provincial and district leprosy supervisors, focusing on the clinical management of leprosy and SDR-PEP administration, and the use of the revised SOPs and the required forms. Participatory methods such as role-plays and practical exercises using the NLR SkinApp and Skin Games were applied during the training to make the learning more effective.

Interviews with project stakeholders indicated that the training enhanced their knowledge and skills on both leprosy and SDR-PEP, as shared by the following respondent:

"The project improved our knowledge about leprosy and allowed us to better understand the disease and how to treat it... enhancing diagnostic capacity and the use of rifampicin for single-dose prevention. Many of us did not know how to administer rifampicin or follow up on cases, but with the involvement of partners, there was training that helped greatly... Now, we have the capacity to diagnose, treat and prevent leprosy, which has improved the quality of life for patients and been a positive experience for us individually." – FGD with health care provider

In addition, the training has also been able to increase the number of maternal and child health practitioners and general practitioners with skills in leprosy diagnosis, treatment and follow-up, as well as to involve community leaders and activists in mobilisation and active case finding, as shared by one of the respondents:

"This increased human resources, with previously only one technician per district having diagnostic skills... Now Chiúre alone has 23 technicians covering 13 health units, compared to just 1 before, and Namuno now has 8 technicians for 6 health units, compared to only 2 initially. These technicians have no difficulty diagnosing, treating and following up on leprosy cases." – KII, provincial health care manager

In addition, the Mozambique project team has also employed various communication materials to reach its target groups. For example, in 2023, local radio stations broadcasting in the local language were used more regularly. A specific message was disseminated during contact tracing and SDR-PEP administration in two districts in Zambezia, resulting in an increase in the number of leprosy patients and contacts. Additionally, radio debates were organised to enhance public understanding of leprosy and raise awareness about this persistent public health issue, emphasising its curable and preventable nature.

Interviews with respondents indicated that the MoH has shown its intention to ensure staff training and the use of IEC materials on leprosy and SDR-PEP administration developed by the project. While the MoH recognises the need to continue staff training and the use of IEC materials, some of the respondents pointed out that there are no clear indications of a systematic plan to train staff or use IEC materials developed by the project. One of the respondents highlighted that the actual implementation of these intentions will depend on the availability of resources and ongoing support from external partners. They are concerned that, without further integration of SDR-PEP into the national strategy, the continuation of training and the use of IEC materials could not be guaranteed.

Further, the sense-making workshop highlighted the need to revise the outdated leprosy manual to align with current guidelines and to standardise training and IEC materials. These efforts aim to ensure consistency and alignment across all partners involved in leprosy control efforts. In response, the MoH asked NLR to collaborate with the Public Health Directorate and other partners by bringing its tools to support the standardisation of training and IEC materials. Additionally, NLR was advised to work with the National Directorate of Health Professional Training to institutionalise these tools and approaches, including by integrating them into pre-service training programmes at relevant institutes. This collaborative approach seeks to enhance the quality and sustainability of leprosy training and communication efforts.

#### Nigeria

It was reported that before the Ready4PEP project, leprosy and disability prevention, and leprosy treatment for individuals affected by leprosy in Nigeria had received minimal attention. In the past three years, significant improvements were made by training facilitators and coordinators across 22 of the 26 LGAs in disability prevention and management, CSCG management and stigma reduction. In addition, 263 community leprosy workers across all Ready4PEP project areas underwent training focused on recognising signs and symptoms of leprosy, referral pathways to more specialised leprosy care, and stigma reduction in communities, aiming to strengthen community participation in the delivery of leprosy services in Nigeria.

According to the document review, SDR-PEP administration and SkinApp implementation are integrated into the pre-service leprosy training curriculum of the National TB and Leprosy Training Centre in Zaria. There is also now a government-mandated two-week posting at International Federation of anti-Leprosy Associations (ILEP) offices for doctors undergoing dermatology residency training.

Conversations with the discussants and interviewees indicated that the MoH has shown an intention to ensure staff training and the use of IEC materials on leprosy and SDR-PEP administration developed

by the project. The MoH plans to include leprosy-related training, including SDR-PEP administration, in TB programmes as part of an integrated approach, leveraging existing resources.

"Part of the mandate ... is that whenever there is going to be TB training, leprosy also must be part of that agenda for training." – KII, LTR

While this approach aims to ensure that both leprosy contact screening and SDR-PEP administration remain sustainable and effective, some of the respondents considered that future plans depend on whether the national and state health authorities decide to continue these activities. While the training and materials have been beneficial, there is no guarantee that financial resources have been allocated for the continuation of the training and the use of the materials developed by the project.

# **3.3.** EQ2. What are the main steps and mechanisms developed by the project within the health system for the implementation of leprosy control and SDR-PEP administration activities?

The Ready4PEP project introduced several initiatives aimed at enhancing leprosy control and prevention efforts. These included a comprehensive training programme for health care personnel and the development of SOPs for managing and administering SDR-PEP. Emphasis was placed on early diagnosis, treatment and geo-mapping of contacts.

Community-based strategies were also central to the approach, with a focus on active case finding, contact screening, and the provision of treatment support through CSCGs linked to health care facilities. Household and extended contacts were screened for symptoms during active case finding, which also leveraged the NLR SkinApp, while offering home-based treatment options when needed. Additionally, the project facilitated community education campaigns and conducted regular supportive supervision visits with HCWs.

Ready4PEP also supported the integration of mental health support and assistance for individuals with other NTDs into the framework of CSCGs. Finally, to maintain thorough documentation, the project employed tools such as contact and index case registers, and the KOBO-collect application, part of the Open Data Kit tool, for data management.

# **3.3.1.** EQ2a. What changes were produced by the project among health care providers and health care managers at national and subnational levels?

#### Mozambique

Before the Ready4PEP intervention commenced in Mozambique, leprosy patients – particularly those seeking care at peripheral health centres – faced significant challenges in obtaining accurate diagnoses and timely treatment. Limited knowledge among HCWs often led to delays in case detection, exacerbating health issues and increasing stigma associated with the disease. Through capacity-building activities, Ready4PEP, along with the ongoing efforts of NLR-Mozambique, substantially strengthened the skills and knowledge of HCWs in active case finding and early intervention. According to the document review, training health care providers at the peripheral level, such as health technicians in local health centres, proved effective, as health technicians were able to diagnose leprosy patients without requiring the intervention of district supervisors. This reduced delays in diagnosis and treatment, contributing to early case detection. This expanded capacity is highlighted in the following three KII quotes:

"The training of health technicians was particularly transformative. Previously, leprosy diagnosis was solely the responsibility of the district supervisor. However, with the training provided, health technicians are now able to independently diagnose leprosy and determine the appropriate treatment for patients. This expansion of diagnostic capacity has significantly improved the programme's efficiency, as more trained individuals are now capable of diagnosing and managing patients, ensuring better follow-up and care." – KII, government stakeholder

"Regarding the health units, [the training] allowed for an improvement in technical capacity because, after the training, the knowledge didn't stop with us. We replicated it with colleagues in the health units, which, in turn, improved patient care as well as the technical skills of the staff. It provided support to the health units because it was different from other programmes... it was an experience." – FGD, health care professional

"The managers, the technicians in all districts that are considered endemic are aware of leprosy, and they have knowledge." – KII, implementing partner

The graph below shows the number of staff trained over the years vs. target, with more than 500 individuals trained as of mid-2024.

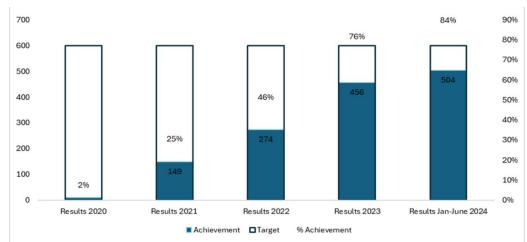
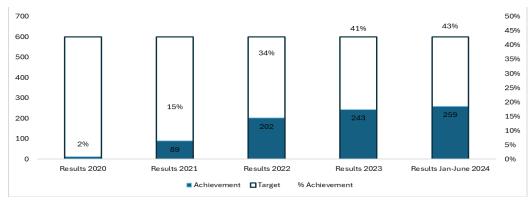


Figure 2: Mozambique: Number of health staff trained vs. target, 2020 to June 2024

Despite significant increase in trainings above and beyond targets, a smaller number of individuals were trained in the use of the NLR SkinApp – below the intended target. Programme staff indicated that the low numbers report may have been due to a technical glitch, which made downloads difficult to quantify.





The positive changes in knowledge and attitudes experienced by HCWs are reflected by a SoC with Gilson, a focal point at the Carico Health Centre in Milange District.

#### Gilson's journey with Ready4PEP: Empowering a community



Gilson, a dedicated health worker, has been pivotal to the Ready4PEP project since its introduction in 2022. As the focal point at Carico Health Centre in Milange District, his role is crucial in managing the project within the local health unit. Initially stationed at Sabelua Health Centre, his commitment remained unwavering even after his transfer. Gilson's involvement began with extensive training aimed at addressing the gaps in knowledge about leprosy, an NTD. "The training enhanced my skills significantly, transforming how I managed the disease," Gilson reflects. His training covered several crucial areas, including leprosy

*Photo credit Joao Vembane* management and SDR-PEP application, all of which culminated in certification that symbolised his enriched competence. The project provided Gilson with essential resources, such as medications and educational tools, which he used to educate and treat his community effectively. "The tokens and medicines were crucial in performing our duties more efficiently," he notes.

One of the most significant impacts Gilson observed was in the community's perception of leprosy. "Through the programme, knowledge about the disease improved, and the stigma associated with it decreased significantly," he says. His personal contributions, including community lectures and direct consultations, have been instrumental in this transformation. Gilson did not work alone; his efforts were supported by a network of activists, health professionals, programme supervisors and community leaders. This collaboration fostered stronger community links and enhanced the overall effectiveness of the interventions.

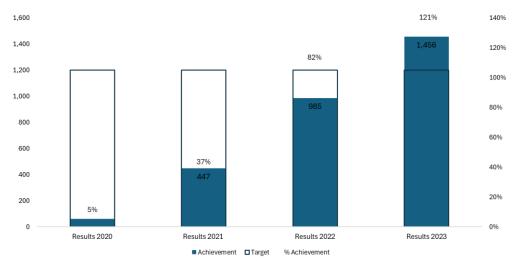
Addressing why behaviour change is crucial, Gilson emphasises the need to destigmatise leprosy due to its infectious nature. "Understanding that leprosy should not lead to isolation is vital. It's about embracing mutual aid beyond just leprosy but in all social situations," he asserts. If he were to visualise this change, it would be represented by a "global hug", symbolising the embrace of community support and understanding. Through his story, Gilson illustrates the profound impact of informed health care and community support in transforming attitudes and enhancing the quality of life for individuals affected by leprosy. His story is a testament to the power of education and collective effort in overcoming health challenges and fostering an inclusive environment.

#### Nigeria

In Nigeria (and similar to Mozambique), the Ready4PEP project created a positive impact on HCWs through increased awareness and capacity. According to the document review, a broad range of health care providers were trained, including general physicians, nurses, peripheral health workers and physical therapists/rehabilitation technicians. In addition, as mentioned by KII and FGD respondents, the initiative also fostered a supportive and respectful approach to treating leprosy patients with individualised and compassionate care. For example, focus group participants indicated that HCWs demonstrated greater attentiveness, respect and inclusivity – a marked improvement from the previous stigma and neglect that leprosy patients report facing. Providers also reported better health outcomes for patients, which in turn strengthened their commitment to leprosy management. These improvements were the result of training, regular group meetings and community awareness initiatives led by the Ready4PEP project, as described below:

"The project has increased the awareness and competence of health care providers in diagnosing and treating leprosy. MDT officers, previously unfamiliar with leprosy, now exhibit higher levels of confidence and competence in both diagnosis and treatment, including SDR-PEP administration. The project has also reduced stigma among health care workers and communities." – KII, TB and leprosy supervisor

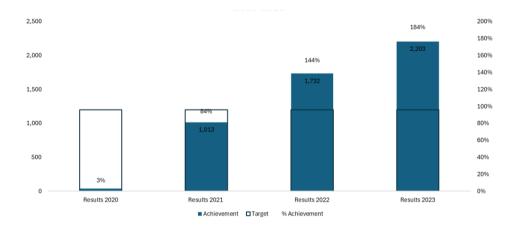
Figure 4 shows the number of staff trained over the years vs. target, with nearly 1,500 individuals trained as of mid-2024.



#### Figure 4: Nigeria: Number of health staff trained vs. target, 2020–2023

Similarly, Nigeria exceeded the intended target in the number of individuals trained in the use of the NLR SkinApp, as shown in Figure 5.

Figure 5: Nigeria: Number of health staff trained in the use of the SkinApp vs. target, 2020–2023



# **3.3.2.** EQ2b. How are leprosy control, active case finding and SDR-PEP administration activities planned, managed and monitored at the district and provincial/LGA level? Who are the main actors? Which approaches are used? When are activities implemented?

Before the start of the Ready4PEP project, a collaborative proposal development process was undertaken. This included a series of ToC workshops in each country, led by the NLR implementing organisation. These workshops actively engaged all relevant stakeholders and actors (MoH, non-governmental organisations, organisations of persons affected, etc.) to ensure an inclusive and participatory design, refining the project's objectives and strategies.

Prior to Ready4PEP in Mozambique, there was significant need at MoH level to re-establish the NLCP, as illustrated by the following quote:

"Starting in 2018, a review led to the creation of the Department of Prevention and Disease Control, and since 2013, leprosy was categorised under the group of neglected tropical diseases. However, this shift resulted in the absence of a dedicated programme representative at the central level. Consequently, the established information flow to the WHO was disrupted. [There was a]....breakdown in data collection from the provinces and two years of non-reporting to the WHO. This ultimately caused significant issues, including medication stock-outs." – KII, government stakeholder

After the ToC sessions, each NLR implementing organisation organised kick-off meetings in Mozambique and Nigeria. These meetings convened key stakeholders, including government officials, WHO representatives, ILEP partners, health care providers, dermatologists and local/provincial health authorities, to align project objectives and implementation strategies.

For both countries, inclusion in the development of the Roadmap to Zero Leprosy was also an important milestone, with both selected as partner countries within the Global Partnership for Zero Leprosy (GPZL) to develop a Roadmap to Zero Leprosy coordinated by the MoH, with ILEP partners closely involved and coordinating activities and particularly the budget for a country survey.<sup>2</sup> The roadmap incorporated contributions from Ready4PEP interventions and stakeholder insights as core components of the national leprosy control strategies.

<sup>&</sup>lt;sup>2</sup> ILEP is a consortium of international non-governmental organisations with a shared desire to see a world free from leprosy Through the programmes of its member associations, ILEP spans more than 60 countries and 1,000 project locations worldwide.

Overall, leprosy control activities were primarily managed by district or LGA supervisors as the main actors, along with supervision at provincial or state level. Support at the community level was provided by community activists/volunteers and leaders who participated in community mobilisation efforts, and the active involvement of community-based HCWs in monitoring conducted by health care personnel through house-to-house visits. Community members and individuals affected by leprosy also played a pivotal role, leading and participating in CSCGs. The following quote highlights gradual improvements in SDR-PEP administration and its role in raising awareness and giving hope to affected families:

"The level of adoption of SDR-PEP within the health system and the national leprosy strategy is gradually improving, with increased knowledge and capacity among health providers. The project has raised awareness about the possibility of cutting off transmission, which is crucial for sustainability. The project has raised the esteem of the patients themselves and their families. It made it known that it is possible...to cut off transmission." – FGD, health care provider

#### Mozambique – Main actors and approaches

Mozambique's main leprosy actors include the NLCP, which operates under the MoH, with oversight from the National Directorate of Public Health. The programme implements activities according to the *Manual Nacional de Lepra* (2008), which offers comprehensive guidance on leprosy management, including supervision protocols. The NLCP collaborates with other leprosy actors to implement strategies aligned with the WHO's Global Leprosy Strategy 2016–2020, the WHO's 'Towards zero leprosy. Global leprosy (Hansen's Disease) strategy 2021–2030' and the 'Zero Leprosy Strategy', focusing on prevention and early detection, health information system improvements, community-based rehabilitation initiatives and capacity-building.

According to the document review and interviews, leprosy management in Mozambique occurs at district and provincial levels and involves regular (monthly/quarterly) supervision by district and provincial health supervisors, supported by community volunteers. According to the document review, at the provincial level, the provincial leprosy supervisor is responsible for coordinating leprosy control activities. However, the provincial programme receives limited financial support from the national level, making it heavily reliant on ILEP partners for resources and implementation support. At the district level, the district leprosy supervisor is the key actor planning, managing and supervising leprosy-related activities. HCWs in health centres conduct leprosy diagnosis and treatment, and are involved in active case finding and SDR-PEP administration (if trained); they are assisted by community volunteers in terms of community mobilisation and contact tracing.

Screening and SDR-PEP administration are conducted only after mapping identified leprosy cases and contacts with digital tools enabled for real-time data tracking for case management and medication distribution, along with more systematic approaches, such as treatment tracking cards. The following quotes illustrate the main actors, the activities planned and managed, and monitoring:

"The main actors in leprosy control include community leaders, task force agents and health technicians. These actors manage activities like contact screening and SDR-PEP administration. Activities are planned around community mobilisation efforts in homes and public places such as fairs and churches, with the primary goal of raising awareness and identifying cases early." – FGD, contacts

"We start with the mapping of index cases, we list contacts, then... we go to the field to implement the programme." – FGD, contacts

#### "House-to-house administration of the prevention dose was more comprehensive." – KII, implementing partner

"[One] issue is the supervision of activities, which only occurred when provincial teams came here. Often, patients live very far away, and due to stigmatisation, they end up staying at home. Activists have to cover long distances, and given the problems with access roads, some places are unreachable by car. Because of the distance and lack of accessibility, activists might reach certain areas but have to turn back, leaving leprosy patients and their contacts without support. This weakens the programme." – KII, district health care manager

Figure 6 shows the total number of contacts listed from 2021 until mid-2024, the cascade of those located and screened (97%), and the proportion receiving SDR-PEP (nearly 93%).

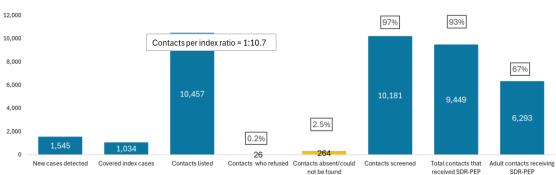


Figure 6: SDR-PEP cascade – Mozambique, 2021 to June 2024

Geographic variations in the identification of new cases can be seen in Figure 7, which shoes the number of new cases detected in Mozambique per year and by district. Though most locations (except Macanhelas and Ribaue) showed an increase in new cases detected from 2022 to 2023, both Milange and Molumbo stood out as nearly doubling the number of new cases detected in 2023. These improvements were likely attributable to Ready4PEP's active case finding approach, which helped to identify 'hidden cases' that would otherwise continue transmitting the disease. However, while this obvious increase in new cases was likely to continue in the short term (for example, in Rapale, where 67 new cases were diagnosed as of mid-2024), continued active case finding would likely result in fewer new cases, as well as further reductions through the provision of SDR-PEP.

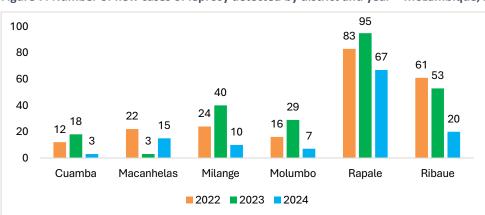
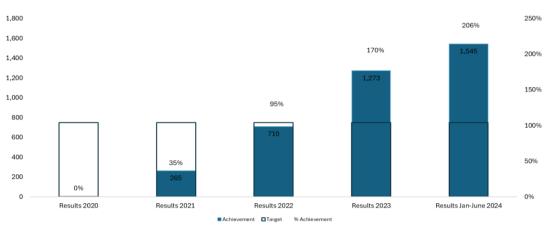


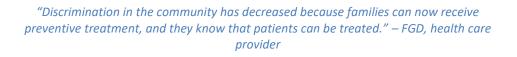
Figure 7: Number of new cases of leprosy detected by district and year – Mozambique, 2022 to June 2024

Figure 8 shows the number of new cases detected (cumulatively) vs. targets, with aggregated results for 2023 and the first half of 2024 significantly exceeding the targets set at the beginning of the project.



### Figure 8: Mozambique: Number of new leprosy patients registered and started on MDT vs. target, 2020 to June 2024

In the FGDs, health care providers noted that the Ready4PEP project has increased awareness and reduced community stigma. They highlighted that community members now understand that leprosy can be controlled and treated, which has improved acceptance and reduced discrimination against affected individuals. As one health care provider noted:



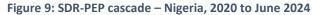
#### Nigeria – Main actors and approaches

In Nigeria, the State Tuberculosis and Leprosy Control Programme (STBLCP) is responsible for overseeing leprosy control activities at the state level. Leprosy management is led by the LGA TB and leprosy supervisor, with support from MDT officers. Monitoring is conducted regularly by these supervisors and Ready4PEP focal points (at state level). Though digital tools, such as Kobo Collect (Open Data Kit), are available for tracking cases and managing medicine distribution, some informants indicated that access to screening and diagnosis is limited in remote locations. Screening and SDR-PEP administration are conducted by MDT officers, who are front-line HCWs responsible for mapping leprosy cases, diagnosis/treatment, identifying contacts and SDR-PEP administration. At community level, community leprosy workers refer suspected cases for diagnosis and raise community awareness. Ready4PEP also introduced index and contact registers for monitoring and tracking purposes. While approaches were reported as consistent across geographies in Nigeria, informants working in difficult security settings indicated that their efforts require additional (and locally informed) vigilance for successful implementation.

Stakeholders in Nigeria mentioned their collaborative work to discuss and tailor both existing and new leprosy procedures, with informants noting that working group participation in Nigeria is particularly active due to high involvement of ILEP partners.

"The role of MDT workers is to go out, do the contact screening, identify patients that are eligible for single-dose rifampicin in accordance with their training." – KII, implementing partner

Figure 9 shows the total number of contacts listed, the cascade of those screened (99%), and the proportion receiving SDR-PEP (nearly 80%).



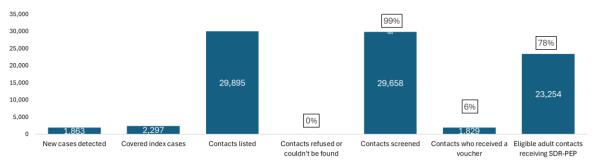




Figure 10 shows the number of cases detected by district per year, with a substantial increase in four out of six locations in 2022 and 2023, and maintenance or improvement in the number of new cases diagnosed in five out of six locations.

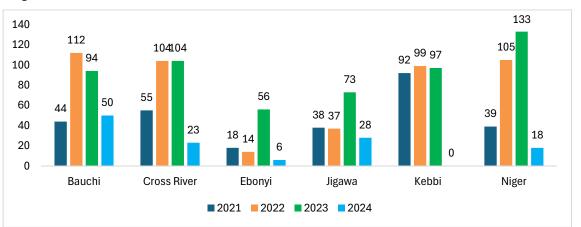


Figure 11 shows the number of new cases detected (cumulatively) vs. targets, with results for 2023 and the first half of 2024 significantly exceeding the targets set at the beginning of the project.

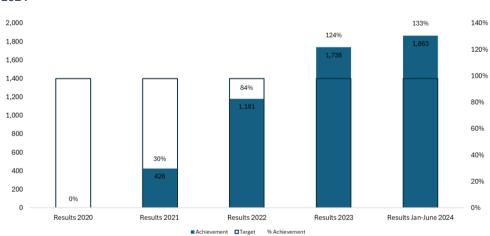


Figure 11: Nigeria: Number of new leprosy patients registered and started on MDT vs. target, 2020 to June 2024

In the FGDs, participants – particularly contacts – were clear that the Read4PEP project has shown its potential, with those who received SDR-PEP expressing newfound confidence in interacting with those affected by leprosy. They noted that the medication reduced their fear and changed their perceptions of the disease. There was also community support for continuing SDR-PEP. As one participant noted:

"If later in the future somebody asks you to go take this medication again, you go take it again... Yes, we go take it." – FGD, contacts

However, participants were aware that the government only supplies MDT and does not provide SDR-PEP or other preventive interventions. They expressed concern that, without ongoing project support, access to SDR-PEP could end, and they supported the need for advocacy to integrate SDR-PEP into the national health strategy. As one participant stated:

"We want the government to help us to progress... since it is they who are responsible for the prevention trial." – FGD, contacts

# **3.3.3.** EQ2c. Has the project increased awareness and commitment regarding leprosy among health care providers and managers?

#### Mozambique

The project successfully raised awareness and strengthened commitment among health care providers and managers by offering targeted training and involving health care personnel at various levels. This approach led to greater engagement, as reflected in the increase in the number of diagnosed leprosy cases. Through collaboration with local health officials, the project effectively integrated leprosy control measures into the broader health care system. For example, HCWs acquired essential knowledge on leprosy treatment, improved their diagnostic skills and gained competency in administering rifampicin.

The project has also enhanced diagnostic capacity, expanded understanding of prophylactic treatment and boosted HCWs' confidence in following up with leprosy patients. Respondents reported that this acquired knowledge was shared with colleagues, leading to an overall increase in capacity within health units. However, it was also noted that maintaining these improvements will require ongoing resource allocation and strong government support to ensure a sustained commitment to leprosy control efforts.

"The project opened our vision; we no longer wait for cases in the health unit. With the displacement, we diagnose more cases." – KII, government stakeholder

#### Nigeria

Key informants and focus group participants indicated that health care providers show significant improvements in awareness, knowledge and attitudes, demonstrating more confidence in diagnosing and treating leprosy cases, including administering SDR-PEP. Training and the involvement of health personnel across various levels have enhanced engagement, evidenced by an increase in the number of diagnosed cases. Additionally, collaboration with local health officials integrated leprosy control into the health care system.

The establishment of a pool of leprosy control experts across all 26 LGAs also reinforced confidence that contact screening and SDR-PEP strategies will continue beyond the Ready4PEP project. To maintain this progress, sustained resource allocation and government support will be essential.

"There is a big change... Health workers now call, 'Hello. How are you feeling? How is your health? Do you need your drugs? Should I send your drugs over to you?" – FGD, contacts

"The programme has created awareness...opening opportunities for awareness creation as well as accepting leprosy as a public health concern." – KII, implementing partner

**3.3.4.** EQ2d. Has the project improved the competencies and confidence of health care providers in the diagnosis and treatment of leprosy cases, as well as in the tracing, screening and SDR-PEP administration of their contacts? How? Are protocols and SOPs well known and clear?

#### Mozambique

The majority of respondents indicated that the project improved the skills of health care providers in diagnosing and treating leprosy, as well as in SDR-PEP administration. For example, HCWs are now better equipped to conduct contact tracing, screen contacts of leprosy patients and follow the necessary protocols. Even HCWs in peripheral districts in the target areas now have the capacity to diagnose leprosy patients without the involvement of the district supervisor, making the leprosy control programme more effective and preventing delays in diagnosis and treatment. However, informants indicated that there are still significant gaps in training, especially due to staff turnover, and the need for refresher training.

Informants in Mozambique mentioned that comprehensive knowledge of protocols and SOPs remains limited, as providers at the district level are still in the early stages of becoming familiar with them. This may be attributed to significant updates made to Mozambique's SOPs through the Ready4PEP project, which introduced new elements such as contact tracing and SDR-PEP administration – components previously absent from leprosy control activities. Informants also highlighted the extensive paperwork required for registering contacts and administering SDR-PEP, which posed a potential barrier to project implementation. This challenge was more pronounced in Mozambique, where Ready4PEP was classified as a research project, necessitating additional documentation. However, informants suggested that the paperwork burden would likely decrease if SDR-PEP were integrated into routine leprosy control programmes.<sup>3</sup>

#### Nigeria

One of the findings of the 2021 baseline survey was the insufficient capacity of the health care providers in the diagnosis and treatment of leprosy cases, as well as in the tracing, screening and SDR-PEP administration of their contacts. To address this situation, the project conducted a series of training activities and refresher training for various project stakeholders. These included: 1) Training of Trainers on recent leprosy innovations such as SDR-PEP administration and use of NLR's SkinApp for 31 NLCP staff members, including trainers of the National TB and Leprosy Training Centre in Zaria; 2) training of 29 LGA supervisors/NTD coordinators and 112 MDT officers on leprosy recognition, treatment and prevention; and 3) training for 280 community leprosy workers on the recognition of leprosy signs and symptoms and referral pathways. By the end of 2023, the end-of-year evaluation indicated strong functionality of the leprosy programme at state, LGA and facility level. This included

<sup>&</sup>lt;sup>3</sup> A minimal list of essential data to be registered in contact tracing and post-exposure prophylaxis administration is documented by the WHO and in a practical guide from Richardus et al. WHO Technical Guidance - Leprosy/Hansen disease: Contact tracing and post-exposure prophylaxis' Chapter 11 'Recording and reporting ' & annexes https://iris.who.int/bitstream/handle/10665/336679/9789290228073-eng.pdf?sequence=1 &

Richardus et al. 'Minimal essential data to document contact tracing and single dose rifampicin (SDR) for leprosy control in routine settings: A practical guide'

https://www.semanticscholar.org/paper/Minimal-essential-data-to-document-contact-tracing-Richardus-Kasang/a8f2e35ff15c8d2135fbb178429952f455359bb5

the number of staff trained, new MDT facilities established, the old ones revived, improvement in the supply of MDT drugs, availability of SDR-PEP, and the technical capacity of state and LGA staff.

Informants indicated leprosy control is now integrated into the daily activities of HCWs, including screening and managing contacts of index cases and administering SDR-PEP. With the training provided, HCWs reported increased confidence in identifying and managing skin diseases, including leprosy. This contrasts with the situation prior to the training, when HCWs often struggled to differentiate leprosy from other skin conditions and lacked the expertise to make an accurate diagnosis.

"Due to the project's capacity-building activities, the index of suspicion of HCWs...has increased. HCWs can now identify leprosy without the onset of pronounced symptoms." - KII, implementing partner

"I call it a teacher who is not physically present. In fact, the SkinApp really helps. It prevents us from wrong diagnosis. We always use it to screen contracts during household visits." – KII, LGA TB and leprosy supervisor

Protocols and procedures were developed to be simple, clear and user-friendly, with the national government involved in reviewing the SOPs to expand the programme's coverage to all states and LGAs. The inclusion of MDT officers and supervisors in meetings with high-level officials to share their observations and recommendations was also included as an effective practice in familiarising stakeholders with SOPs. The challenge noted was the limited understanding of SOPs due to language barriers, with HCWs expressing the desire to translate SOPs into local languages.

"We know the SOPs, but sometimes the language makes it difficult to understand them fully." – FGD, contacts

For both countries, respondents also pointed out that the global MDT programme relies solely on donations from WHO, as MDT cannot be purchased independently by any country. Challenges arise when countries delay placing orders, failing to account for active case finding efforts that increase patient demand, or underestimating long lead times for delivery. Additionally, import regulations, as observed in Nigeria, can also complicate the process of receiving donated medication. At national level, issues with stockkeeping and supply chain management further worsen these effects, highlighting the fragility of the supply chain and its potential impact on leprosy control efforts. This is not only important for the WHO MDT donation programme, but also for the future rifampicin donation programme from WHO which is now being set up.

# **3.3.5.** EQ2e. What are the main challenges and concerns of health care providers and managers in conducting the activities?

#### Mozambique

Some of the main challenges and concerns of HCWs and managers included turn-over issues due to frequent transfers of district supervisors and HCWs to other facilities – sometimes non-implementing facilities – hindering the continuity and consistency of leprosy management and supervision. Funding gaps were also mentioned, with a lack of sufficient funds limiting their ability to carry out supervision and implement leprosy control activities effectively.

The north of Mozambique, specifically Cabo Delgado Province, has been suffering from continuous terrorist attacks, resulting in a worrisome security situation and leading to one of the ILEP partners (TLM) moving its office to Nampula. Delays in the supply of medicines, including rifampicin, have been a recurring challenge in the country. Lastly, Mozambique has limited resources for community outreach, given the financial burden of related logistics.

"There were times when there were shortages of medicines, and it took one or even two months to access medicines." – KII, government stakeholder

"The problem is not the cost of the medicine; it is the cost to do the search and find the patients." – KII, national stakeholder

"We train people, but six months later, they move to another place or for further studies which creates a gap in knowledge and continuity." – KII, implementing partner

#### Nigeria

Nigeria faced similar challenges such as limited attention to leprosy compared with TB, and difficulties in patient/contact tracing and follow-up due to mobility issues. Supply chain challenges are common, with stock-outs of loose rifampicin and MDT, the latter due to policy changes regarding the import process, resulting in difficulties in locating some patients/contacts for follow-up after stock-outs.

Additionally, funding gaps are prevalent, with limited funding within state and LGA budgets for leprosy control services.

Rising insecurity in Nigeria led to limited movements, affecting routine implementation of the field activities in different regions, particularly in Ebonyi State and Niger State, where banditry and kidnappings limited access to beneficiaries. The Nigerian ILEP partners have adapted to working in a context of changing levels of security and have risk reduction strategies in place to direct their activities in the field.

"To keep the progress we have made, we need more support and recognition from the health system and the government." – FGD, CSCG

"The commitment to leprosy – just like the name 'neglected tropical disease' – is neglected in Nigeria. The focus is more on TB because that's where the money is going and a whole lot of people follow...sometimes when you go for review meetings, you talk more of TB than any other disease." – KII, implementing partner

"Limited challenge in accepting the single-dose rifampicin given you need to get consent from the index case that you're coming to the family, and you also need to get the consent of the contact. A plus is that a single-dose prophylaxis is easier to administer compared to other prevention prophylaxis like TB that requires a six-month regimen." – KII, implementing partner

# **3.3.6.** EQ2f. What is the level of integration of the leprosy programme with other health programmes and services?

#### Mozambique

The leprosy programme operates largely in isolation, with minimal integration with other health programmes. However, the MoH initiated the development of a National Integrated Plan for NTD

Control, while the Ministry of Gender, Child and Social Action started discussions on a new law on the promotion and protection of rights of persons with disabilities. NTD organisations, including NLR, were actively involved in this process, with NLR presenting its approach on morbidity management through CSCGs. The National Integrated Plan for NTD Control was approved and incorporated leprosy and morbidity management as innovations presented by NLR.

The leprosy programme is partially integrated with other health programmes, especially with the management of other NTDs, particularly TB. While there have been efforts to align leprosy activities with broader health initiatives, the lack of coordination and clear communication between different health programmes remains a significant barrier.

"There is some resistance to integrating fully with TB, as it is seen like a 'marriage' where one side might lose resources." – KII, implementing partner

#### Nigeria

Collaboration among stakeholders is rife, with the Federal MoH engaged by grant sub-recipients through the managers of 6 selected states, 26 community leaders and TB/leprosy survivors. The Federal MoH also involved the mental health department and members of NTD programmes to foster integration. One partner recently started an integrated project whereby trained community health workers called volunteer liaison officers (who receive a stipend) are engaged and trained on TB, leprosy and Buruli ulcers and are expected to manage all these diseases through outreach activities in communities.

"We carry out skin camps, where we check for leprosy, TB and other skin diseases." – KII, TB and leprosy supervisor

*"Integration occurs during meetings, where, as health workers, we discuss leprosy alongside other diseases like malaria and immunisation." – KII, TB and leprosy supervisor* 

# **3.3.7.** EQ2g. Are decision-makers at the subnational level allocating more resources (human, financial, logistics) towards the elimination of leprosy?

#### Mozambique

At the subnational level, informants shared the perception that there is limited resource allocation (human, financial and logistical) towards the elimination of leprosy. While some commitment from subnational decision-makers was acknowledged, there is significant government reliance on external partners for resources. Informants noted that more support from both national and international partners is needed to ensure that adequate resources are available to sustain leprosy control efforts:

"There has been some allocation of resources, but it remains limited. Decision-makers at the subnational level are waiting for stronger evidence from the project before committing significant resources to leprosy elimination." – KII, implementing partner

"The government is not putting up the resources for leprosy. Medicine is given through WHO and [others]...even if activities are implemented, it is partners implementing. The government is not putting in money." – KII, international partner

#### Nigeria

During interviews, informants noted the limited capacity of the government to support training for HCWs. To mitigate this, online webinars instead of physical meetings were introduced as a solution. Leprosy is also now integrated into the national curriculum for HCWs, with LGA leprosy staff receiving more support from state programmes, including improvements in the supply of MDT and clinical guidance materials. In addition, respondents noted that full integration in the future will be daunting, as SDR-PEP administration is currently limited only to epidemiologically mapped implementation areas. There is a large remaining gap, given that Nigeria has 80,000 facilities and Ready4PEP covers only 100 facilities.

# **3.3.8.** EQ2h. How well established are the mechanisms related to the procurement and supply chain of drugs (rifampicin and MDT) within each country?

#### Mozambique

The procurement and supply chain for drugs such as rifampicin and MDT continues to face challenges. Though loose rifampicin for provision of SRP-PEP was imported into Mozambique by NLR after consultation with the MoH, MDT was donated free of change by the WHO, with the government responsible for quantification and ordering. Informants highlighted multiple supply chain disruptions in the past, affecting the availability of both drugs at national and provincial levels. Logistical issues, particularly in distributing drugs from central warehouses to provincial and district levels, remain a concern and occasionally lead to stock-outs.

For MDT, these disruptions are especially problematic, since WHO guidelines and thus the protocol mandates that the identified index case must be on MDT before contact screening and SDR-PEP provision can occur, also to stop ongoing transmission. During the sense-making discussions, stakeholders emphasised the need for improved coordination with government counterparts to streamline the process for importing rifampicin for SDR-PEP. A WHO donation programme is also expected soon for loose rifampicin, similar to the MDT. But this does not rule out medication shortages as seen for MDT. Monitoring, proper stock management, accurate forecasting, timely ordering and a smooth import process for WHO-donated drugs are essential to ensure the consistent availability of both medications.

#### Nigeria

While respondents noted that the NLCP has demonstrated greater commitment and proactivity in addressing MDT stock-out issues compared to previous years, these improvements have also resulted in an excess of MDT drugs being redistributed from states with lower levels of new cases to project implementation states such as Bauchi, Kebbi and Jigawa. These transfers were efficiently coordinated by the leprosy programme's logistics unit. However, MDT availability remains an ongoing concern in Nigeria, particularly as more cases are now being detected, making it a critical issue for continued advocacy efforts, as multiple informants noted that the successful provision of SDR-PEP relies on the availability of MDT – that both drugs are linked – as illustrated in the following quote:

"As part of the SOP, what we do in the community, we have to have...cases on [MDT] treatment for at least two weeks and <u>then</u> follow up after they have consented for a visit to their household for contact investigation. One of the challenges that we have is because the SOP states that the client has to be on MDT treatment for two weeks, when we have a stock-

out of MDT those in contact with the index client will never be contacted and screened for eligibility for SDR-PEP." – KII, implementing partner<sup>4</sup>

# **3.4.** EQ3. Concerning the CSCGs, what is the level of maturity and integration within the health system, and the quality and sustainability of these groups?

#### 3.4.1. EQ3a. How extensively are the CSCGs included in leprosy policies and programmes?

#### Mozambique

The baseline report of the Ready4PEP project identified the existence of 'combined' self-care groups, which include individuals affected by leprosy, as well as those affected by other diseases and conditions such as lymphatic filariasis or *konzo*. On average, each CSCG consisted of 26 members who met either weekly or monthly. These groups were initially established by the MoH and later revitalised by the Ready4PEP project. Discussions with interviewees and focus group participants revealed that the integration of CSCGs within the health system was still evolving. While the MoH recognised the important contributions of CSCGs to leprosy management – particularly in addressing social exclusion and promoting the inclusion of persons affected by leprosy and other NTDs in the community – their formal inclusion in the national leprosy policies remained limited.

Respondents noted that CSCGs were well established within public health sector operations, with district health staff regularly visiting to provide treatment and support. However, their integration into broader national leprosy policies had not yet been formalised, particularly in terms of securing consistent financial and logistical resources.

CSCGs are currently involved in leprosy programmes mainly at the operational level, acting as essential points of contact between leprosy patients and the health system. While the groups are linked to health units, there is still a need for their full integration into official leprosy control policies, as highlighted by one of the respondents:

"We are empowering the health technicians to take more responsibility... but it's a process that is not yet fully formalised within national guidelines." – KII, NLR partner

Although the inclusion of CSCGs in national policies remains limited, the Ready4PEP project has made significant progress in both establishing new CSCGs and revitalising those originally formed by the MoH. Figure 12 provides information on the number of new self-care groups registered, trained, and provided with materials from 2020 to June 2024. It highlights a significant increase in the number of CSCGs established over the past three years, particularly between 2022 and 2023. This is due to the fact that the project made efforts to ensure that all targeted communities with new cases had a group to support leprosy-affected persons. The number of new cases was in fact much higher than originally predicted.

Figure 12: Mozambique: Number of new self-care groups registered, trained and provided with materials vs. target, 2020 to June 2024

<sup>&</sup>lt;sup>4</sup> According to WHO guidelines, SDR should be given to contacts only after the index case has received treatment for at least four weeks. However, if coverage with SDR would be significantly compromised by delaying administration, it can be given earlier.



Through the Ready4PEP project, health staff received training on setting up and supporting CSCGs. A practical guide for HCWs developed, which includes lessons learned on establishing and guiding these groups. Additionally, the Ready4PEP project created a comprehensive guide on CSCGs.

Interviews and the sense-making and validation workshop with project stakeholders revealed opportunities to incorporate CSCGs into strategic documents, such as the Roadmap for Leprosy Control. Furthermore, the MoH is currently in the process of securing a grant (approximately 90% guaranteed) to support associations of people affected by leprosy, signalling progress in strengthening these groups.

## Nigeria

As reported in the previous section, in 2021, the Federal MoH, through the NTBLCP, included SDR-PEP and CSCGs in the National Leprosy Guidelines and the Zero Leprosy Roadmap 2021–2030. By 2023, 14 new CSCGs were established, bringing the total number of functioning CSCGs to 55, exceeding the project target by 22%. This reflects a higher-than-expected demand for community-based rehabilitation through CSCGs. The inclusion of SDR-PEP and CSCGs as part of the national strategy is crucial for achieving zero leprosy in Nigeria and ensuring the sustainability and functionality of these groups.

Respondents noted that CSCGs are vital for individuals affected by NTDs such as leprosy, especially those who suffer from related disabilities or are at risk of developing them. Notably, the MoH collaborated with CSCGs to address leprosy, although only a few CSCGs existed in certain states and LGAs, and most were not operational. Many CSCGs became inactive due to a lack of trained facilitators or financial support. The baseline survey revealed that no functioning CSCGs were present in the 12 initial LGAs where the Ready4PEP project was planned for implementation. CSCGs have been introduced through the Ready4PEP project, as noted by one of the respondents:

"We added a few self-care groups in the states we implemented. Because of the Ready4PEP project, we were able to establish new self-care groups and also reactivate some of the groups within the state." – KII, government stakeholder

The baseline assessment conducted in the Bauchi, Ebonyi and Kebbi at the beginning of the project found that very few CSCGs existed in the communities where the Ready4PEP project was implemented, and none were functional. However, during the course of the project, there was noticeable progress, with at least one functioning CSCG established or reactivated in every participating LGA.

Figure 13 provides information on the number of new CSCGs that were registered, trained and supplied with materials from 2020 to 2023. It illustrates a significant increase in the number of CSCGs established over three years, particularly between 2021 and 2022.

Figure 13: Nigeria: Number of new self-care groups registered, trained and provided with materials vs. target, 2020–2023



Not all the respondents consulted for this evaluation were aware that CSCGs had been included in national policies and guidelines, with some noting that they were becoming increasingly recognised in leprosy policies and interventions, particularly as key vehicles for improving patient care and addressing stigma, mental health and social needs. They emphasised that CSCGs have strong connections to health facilities, with each group linked to a nearby health centre. This recognition has contributed to a greater understanding within communities, positioning CSCGs as vital components of the broader leprosy strategy.

However, some respondents were unaware that, in 2021, the Federal MoH, through the NTBLCP, had included SDR-PEP and CSCGs in the National Leprosy Guidelines and the Zero Leprosy Roadmap 2021–2030. While some interviewees acknowledged that CSCGs operate at the community level and play a significant role in supporting people with leprosy, they pointed out that their inclusion in broader national policies had not been fully established.

# **3.4.2.** Q3b. How well has the participation in CSCG activities helped and supported persons diagnosed with leprosy?

#### Mozambique

Respondents revealed that CSCG activities have provided substantial support to persons diagnosed with leprosy. These groups offer a safe space where members can access medical, emotional and social support. Most respondents agreed that the CSCG activities are effective in helping members manage their condition and prevent further physical deterioration. One discussant stated:

"We are taught to take care of our injuries and wounds... these groups have improved the lives of patients." – FGD, CSCG member

CSCG activities also supported members in advocating for their social and economic needs. Through the Ready4PEP project, NLR-Mozambique trained these groups to establish 'pressure groups' aimed at addressing specific member concerns. NLR facilitated connections between CSCGs and relevant stakeholders, such as district departments for agriculture and social action. For example, in 2023, four groups in Rapale, Milange, Molumbo and Ribáuè submitted requests to social services to enrol their members in social protection programmes. Additionally, two groups in Ribáuè and Milange successfully advocated for agricultural plots, receiving approval from the district administration to begin farming activities. The agricultural departments further instructed their extension workers to provide technical assistance to these groups. Other advocacy successes included constructing ramps in schools to enhance accessibility for teachers and students with disabilities, and enrolling affected individuals in cash-for-work social programmes.

Some respondents highlighted that participation in CSCGs fostered a sense of community among members, offering a supportive network that helps to reduce stigma and discrimination. Members of these groups have become advocates, promoting understanding of leprosy within their communities.

### Nigeria

While the CSCGs are still maturing in Nigeria, members demonstrated commitment by having regular meetings to discuss their problems, encourage each other and reinforce their skills in self-care practices. Through regular meetings, CSCGs offer essential resources such as hygiene materials, counselling and, in some cases, financial support, helping members manage their condition and feel included in the community.

Several respondents highlighted that tangible improvements have been noticed, particularly in wound healing. The CSCG activities positively impacted the health conditions of individuals diagnosed with leprosy. Members are trained to monitor their health conditions daily, which helps prevent complications. They also learned from others who have successfully managed similar conditions, which has helped in reducing disability. It was reported that improved self-care practices had reduced the number of hospitalisations of people affected because of complications.

"They reassure themselves on how to take a thorough check of their body every day... they soak their feet and hands if affected." – KII, MDT officer

Most of the respondents mentioned that CSCGs play a vital role in reducing stigma and increasing support within communities. CSCG members who participated in an FGD reported that group members feel better supported and accepted, as CSCGs foster an environment of mutual understanding and shared experiences. They also mentioned improved social engagement, better health outcomes and a notable reduction in stigma and discrimination.

Participation in CSCGs has helped support individuals with leprosy by fostering community acceptance and providing a safe space to address their health and social needs. The groups have positively impacted members' self-esteem and helped them manage social interactions more confidently.

> "The groups have improved their self-esteem by enabling them to have a good perspective of themselves...This has assisted reintegration into the community, whereas they were previously discriminated [against]." – KII, government official

In some groups, additional activities are incorporated that focus on personal development, improving the independence and resilience of the group members, such as reading/writing or sewing lessons.

# **3.4.3.** EQ3c. Have the participants in the groups improved their health conditions and prevented the (further) development of disabilities?

#### Mozambique

The SoCs collected by the Ready4PEP project and the data collected for this evaluation indicated that the CSCGs have played a critical role in improving the health conditions of their participants and preventing the development of disabilities. Members have been trained to handle personal hygiene

and wound management effectively, reducing the risk of deformities associated with leprosy, as shared by one of the health officials:

"We saw improvements in the deformities of the patients... there was a great improvement on the part of the patients." – KII, health official



Some of the respondents highlighted that by encouraging consistent self-care and following health advice, the CSCG members have shown improved health conditions. Members learn practical selfcare techniques that help manage complications such as ulcers, which are common in leprosy patients. This education, along with regular health monitoring within the groups, plays a significant role in preventing disabilities and improving overall health outcomes among CSCG members.

Photo credit NLR Mozambique

The SoC below provides an insight into how participation in a CSCG has helped one member improve his health.

#### The story of Estêvão Frigson



Photo credit NLR Mozambiaue

Estêvão Frigson, 55, lives in Carico village, Milange District, Zambézia Province. As a husband and father of nine, Estêvão was once a farmer until leprosy changed his life. He first noticed suspicious spots in 2007 and consulted a traditional healer on his uncle's advice but found no relief.

His condition was officially diagnosed as leprosy in 2008 following a health education session. Estêvão began treatment with MDT, but due to inconsistent medication availability, his treatment was sporadic between 2008 and 2009, and for years afterwards he struggled to obtain regular medication. The gaps in treatment led to significant physical deformities, forcing him to give up farming. "During the time I stayed without treatment, I started to feel my body heating up, and over time, I got deformities in my hands and foot," Estêvão explains, revealing the profound impact on his daily life and work.

The introduction of the Ready4PEP project in 2021 was a turning point. The project trained health technicians in leprosy management, ensuring a reliable supply of medication. "The nurse said, as a long time had passed without having completed medication, I should restart. I'm happy because I have now completed the treatment, thanks to the project," Estêvão gratefully recounts.

A member of the Kusaca Moio Self-Care Group, Estêvão benefited from training in the prevention and rehabilitation of deformities. His progress is a source of communal pride. Francisca Fernando, a hygiene leader within the group, observed his dedication: "Estêvão had a big ulcer, but with the correct care and follow-up, it healed, and we are all proud of the effort."

Through participation in the CSCG and self-care practices, Estêvão has regained some mobility, transforming his quality of life. "With the practice of self-care and rehabilitation, I can now move my fingers, which before I was unable to do," Estêvão shares, highlighting the personal and practical successes facilitated by community support and health initiatives.



Photo credit NLR Mozambique

#### Nigeria

The harvested outcomes and SoCs collected by the Ready4PEP project and the data collected for this evaluation indicated that through their participation in CSCGs, the individuals affected by leprosy have developed a more positive attitude towards dealing with leprosy. The groups' activities have supported their members in early detection and improving health management, which further helps them prevent the development of disabilities, as shared by one of the respondents:

"We were educated on the negative perception about the disease, as well as the means through which the disease spreads." – FGD participant

CSCGs have empowered their members to take ownership of their health by promoting awareness of the disease, encouraging adherence to treatment, and facilitating early detection of complications. It has also supported persons affected by leprosy to self-manage their wounds and build self-care into their daily lives. Group members were taught a daily routine of inspecting their bodies for signs of injury or infection, which are not felt because of nerve damage, and care for existing injuries, improving their health literacy.

In addition, they also practised exercises to prevent joint stiffness and follow-up, and shared instructions on soaking and oiling their skin to prevent skin damage or ulcerations due to dryness or injuries, as shared by one of the CSCG participants:

"Before now I used to tear a chunk of my blanket because of the condition [cracks and calluses]. I don't mingle with people. However, because of what we were taught in the group... I have seen a significant improvement. Even people within the community used to tell me that you are now getting better. All my colleagues have admitted a significant improvement in their condition. I am now happy with myself. In fact, I have gone back to my carpentry work, which I was unable to do in the past. Praise be to God! Praise be to God!! I think now even if the support we are getting is stopped, we will continue to take care of ourselves. We will encourage anyone with this condition." – outcome harvesting, CSCG member, Kazaure LGA, Jigawa State

Through participation in the group activities, this CSCG member was able to learn self-care, preventing further development of disabilities, which in turn helped him to integrate with people and return to his job.

Interviews with health facility staff highlighted that through the information session in the group, they are taught how to manage scars to prevent them from breaking down again.

# **3.4.4. EQ3d.** Have the groups contributed to the social participation and mental well-being of their members?

#### Mozambique

Conversations among respondents indicate that the groups have significantly enhanced social participation and mental well-being. The groups created a safe space for members to share experiences, reduce feelings of isolation and receive emotional support, which has helped reduce stigma and promote acceptance within communities. One CSCG member described how participating in the group restored their social ties:

"I am now with my family and the community... the situation has improved." – FGD participant

Also, the SoC provided by one of the respondents highlights how the targeted educational activities organised by his group have helped to shift the community's attitude to leprosy from fear and discrimination to understanding and support.

#### **Cipriano's story**

"At the core of Cipriano's mission was addressing the lack of awareness and discrimination surrounding leprosy. He discovered that many community members were unaware that leprosy medication was provided free at local health centres. Through targeted educational talks, Cipriano and his group were able to enlighten people about the disease and the available care options, significantly reducing the stigma associated with it. "The misunderstanding of patients has already been overcome," Cipriano reflects. "Everything is going according to plan." His efforts have shifted community perspectives from fear and discrimination to understanding and support. This change, he notes, is overwhelmingly positive because it dismantles the baseless myths surrounding transmission of the disease

The CSCGs have created a sense of community and belonging for people affected by leprosy, reducing stigma and discrimination. They have also helped to build self-esteem and provide a support network, which is crucial for the mental health of members. In addition, social participation was also encouraged through community events, such as World Leprosy Day, which are often held in the groups to further integrate these members into their communities and reinforce the positive impact of their participation.

# Nigeria

The harvested outcomes and SoCs, as well as interviews and discussions conducted for this evaluation show that the presence of CSCGs has offered a platform for individuals affected by leprosy to come together, share their experiences and find encouragement. The CSCGs have been instrumental in promoting social participation among their members. The group activities have helped members build a sense of belonging, self-worth and personal identity.

People diagnosed with leprosy often suffer stigma, including self-stigma, discrimination and isolation that could lead to mental health problems. CSCGs provide a platform for members to share their experiences and change their perceptions about their condition and self-worth. This peer support reduces feelings of isolation and offers emotional reassurance. The interactions have helped members develop social skills and build trust within the group.

FGD participants emphasised a shift in community acceptance:

"Before, people avoided us, but now we go to meetings together." - FGD, CSCG member

Another participant stated that before the project they were ashamed to go out, but now they feel free to interact within the community. This indicates that they have become more confident in participating in public life and no longer feel the need to hide their condition.

"Since joining the group, I feel more confident going out in the community and associating with others." – FGD participant

The activities of CSCGs have encouraged open dialogue and emotional sharing, which helps members process their experiences in a supportive and non-judgemental environment. Group discussions helped the members to release emotional burdens, confront internalised stigma and rebuild their self-esteem. A female member of a CSCG located at Mile 4 leprosy referral hospital in Ebonyi LGA said that her participation in the CSCG and interaction with other members have helped her to overcome the difficult consequences of her condition:

"Before now, I was always at home and thinking of life being worthless. But when I started attending this group meeting, I found some people with more terrible disabilities and life experiences, and this has changed my perception about my condition." SoC, CSCG member

CSCG members who participated in FGDs stated that their participation in the CSCG has contributed substantially to the social inclusion and mental well-being of their members. The groups provide a space where leprosy patients feel understood, accepted and supported, reducing stigma and encouraging positive interactions within the community. Members feel a sense of belonging and community support, which has been critical to improving their mental health and social participation.

# **3.5.** EQ4. What are the changes in the perception of leprosy and related stigma in the communities where SDR-PEP was implemented?

#### Mozambique

The stigma surrounding leprosy often stems from a lack of knowledge, leading to discriminatory attitudes within health care settings and communities. To address this, the Ready4PEP project aims to shift perceptions of leprosy and reduce associated stigma through multiple strategies. Insights from group discussions, interviews and the document review highlight the positive changes in attitudes and reductions in stigma achieved so far.

Most of the respondents considered that the introduction of SDR-PEP has reduced the stigma surrounding leprosy in the communities where it was implemented. Community members have become more informed about the disease, which has led to greater acceptance of individuals affected by leprosy. As one health care provider explained:

"In the community, stigmatisation has plummeted... Before starting treatment, people covered their noses because of the smell, but with the beginning of the project and treatment, it was possible to get rid of the wounds." – KII, health care provider

Individuals who previously might have avoided seeking help are now more willing to come forward for diagnosis and treatment. The administration of preventive medicine has helped communities view leprosy as a treatable and preventable disease, further reducing fear and discrimination against those affected. One of the respondents pointed out that the screening and treatment programmes initiated by the Ready4PEP project also contributed to changing the community's perception, as more people understood that leprosy is treatable, which led to an increase in the number of people seeking early diagnosis and treatment.

Interviews and discussions with the project stakeholders also offered insights into the strategies the project has used to reduce stigma. Most of the respondents felt that the training sessions for HCWs and community volunteers had been effective in addressing misconceptions about leprosy transmission and encouraging participants to reflect on their biases. The training has effectively raised awareness about leprosy, resulting in reduced fear and stigma. HCWs now show more empathy and attentiveness, creating a more inclusive health care environment.

Community leaders who received the training have also played a key role in raising awareness about leprosy within their communities. They have acted as advocates, informed their members that leprosy is curable and encouraged early treatment. This has helped to create a supportive environment that reduces fear and stigma. In addition, community mobilisation efforts through radio announcements, engagement of local churches and door-to-door activities have played a crucial role in changing perceptions about leprosy.

Some of the respondents also mentioned that the formation of CSCGs has been crucial in lessening stigma. These groups provide a safe, supportive space for people affected by leprosy to rebuild confidence and re-engage in community life. CSCGs also equip members with skills for incomegenerating activities, helping them achieve financial independence and recognition within their communities. As a provincial supervisor explained: "CSCGs have been essential in reducing discrimination and raising awareness. Many former leprosy patients have regained their self-esteem and are now participating in community activities, showing that they are valuable members of society." – KII, government stakeholder

Through these groups, individuals are not only supported in their recovery but are actively reintegrated into community life, positively influencing others' perceptions and further reducing stigma.

Understanding that discrimination and isolation can affect mental health, NLR-Mozambique has partnered with the MoH and mental health departments to provide emotional support for leprosy patients. Counselling sessions are available to help patients manage feelings of sadness or low self-worth due to stigma. One mental health provider shared:

"Patients affected by leprosy often face not only physical challenges but also emotional ones due to discrimination." – KII, health provider

The introduction of SDR-PEP, combined with ongoing training, community support, mental health care and advocacy through CSCGs, has brought about meaningful changes in reducing stigma and transforming perceptions of leprosy in Mozambique. Although full integration of SDR-PEP is still pending government approval, its positive impact on awareness and stigma reduction is evident, though some stigma persists, particularly in more isolated areas.

#### Nigeria

The perception of leprosy and the stigma associated with it have deep psychological, cultural, religious and social roots in many communities in Nigeria.<sup>5</sup> As a result, people affected by leprosy are afraid to disclose their status even when fully aware that they have leprosy. One of the objectives of the Ready4PEP project is to address the perception of leprosy and the stigma associated with it through several strategies, including the provision of capacity-building to HCWs who are in direct contact with patients, to train them not only on the physical signs and symptoms but also on their behaviour towards the patients. The project also includes setting up CSCGs and public health education at the community level.

The document review, discussions and interviews with the project stakeholders indicated that the implementation of SDR-PEP and accompanied education has led to increased knowledge on leprosy among patients, contacts and community members.

The following SoC captures the experiences of someone affected by leprosy and how she has changed since receiving SDR-PEP.

<sup>&</sup>lt;sup>5</sup> Tahir Dahiru, Zubairu Iliyasu, Aliyu T. Mande, Anna T. van 't Noordende and Muktar H. Aliyu, Community perspectives on leprosy and related stigma in northern Nigeria: a qualitative study, *Leprosy Review*; 2022; 93(1): 48–62. DOI: 10.47276/lr.93.1.48. <u>https://leprosyreview.org/article/93/1/20-21077</u>.

#### Mary's story



Photo credit Toyin Aderemi

Mary (not her real name) lives in Nko, Cross River State. She is a mother of three children and a businesswoman. She lived in Lagos for a long time before moving to her village to start a family.

During the birth of her last child at the health facility, the midwife observed a big patch on her shoulder. She explained to the midwife that she had more such patches on her back and buttocks. For a while, she had been experiencing dizziness, fatigue, weakness of the left hand, and heat sensations in her toes and fingers. She had no idea what it was, and had already given up on herself. The midwife asked her to return soon after the childbirth and referred her to the leprosy control unit, where she was diagnosed with leprosy.

She was placed on MDT. She doubted the efficacy of the medication and started pressurising the health workers. About three months into the treatment, she started noticing changes. Now, all the patches are gone, and she no longer feels the fatigue. She can also use her left hand again. Her husband, who abandoned her after the diagnosis, is back.

Mary draws on her success story to raise awareness on leprosy treatment and SDR-PEP. She also organises other leprosy patients in her village to fundraise for fuel, so that a health worker can deliver their MDT to them in the village, which is more economical for them and enhances treatment compliance.

Mary has regained her confidence. Unlike before the treatment, she freely socialises with friends and family members. She is happy that her children, husband and friends received SDR-PEP and were saved from contracting leprosy.

The evaluation conducted in the first year of project implementation found that the perceptions of community members towards persons affected by leprosy had started to change. The harvested outcomes and SoCs collected by Ready4PEP throughout the five-year project produced similar findings. The fear surrounding the disease and negative attitude towards those affected by leprosy began to reduce, shifting community perceptions towards greater understanding and acceptance. FGD participants noted this shift in perception:

"People used to be afraid of us, but now they know that leprosy can be treated, the stigma has reduced a lot." – FGD participant

Knowing that close contacts of leprosy patients can be protected through a single dose of rifampicin has alleviated much of the anxiety surrounding the transmission of leprosy. As a result, communities are beginning to view leprosy as a manageable and preventable condition rather than a threat to public health.

The document review, interviews and discussions with project stakeholders indicated several factors that contributed to these changes. Most of the respondents stated that the approach to engaging with religious and community leaders has helped to deliver messages about leprosy-related stigma to their members and encourages them to adopt more compassionate attitudes. The community leaders who received information about leprosy-related stigma and the use of SDR-PEP as a preventive measure played a vital role in motivating community members to support contact tracing and SDR-PEP administration. Involving community leaders has helped to normalise discussions about leprosy, reduce the taboo surrounding the disease, and view leprosy patients with empathy and understanding rather than fear and suspicion.

In addition, community awareness-raising activities conducted by trained community leprosy workers and MDT staff within their communities seemed to contribute to these changes. These community leprosy workers and MDT staff have participated in training sessions on leprosy-related stigma, equipping them with a deeper understanding of leprosy-related stigma and reducing misconceptions. With this knowledge, they conducted community sensitisation activities, using the social and behaviour change communication materials developed at the start of the project, helping to raise awareness and reduce misconceptions about leprosy. One HCW explained:

"We educate people that leprosy is not what they think it is, and people are more willing to come out for screening and treatment." – FGD, HCW

The reduction in stigma has also been evident during contact tracing, as families have become more accepting of preventive treatment for leprosy.

Also, TLM-Nigeria conducted periodic public awareness-raising campaigns, using events such as World Leprosy Day and National NTD Day celebrations to highlight the harmful effects of stigma and the continued fight against leprosy-related stigma, and celebrating the success of those who have been cured. Leveraging diverse media platforms, these campaigns effectively engage a wide audience, addressing issues related to stigma. For example, as a guest speaker for World Leprosy Day, the LTR Executive Director provided valuable insights into the remaining problem of stigma in Nigeria, drawing from experiences gained through the Ready4PEP project.

# **3.6.** EQ5. What are the potential concerns of upscaling the project?

The Ready4PEP programme has made significant progress in leprosy prevention and treatment in Mozambique and Nigeria, but it also faces potential concerns that threaten its long-term success. Key concerns include reliance on external funding, difficulties in sustaining community engagement and supervision, and logistical challenges in remote areas, all of which cast doubt on the programme's scalability and sustainability.

#### Mozambique

Ready4PEP was instrumental in advancing leprosy control efforts in Mozambique, particularly through the introduction and administration of SDR-PEP. Respondents consistently highlighted the project's progress, emphasising significant improvements in treatment opportunities for individuals affected by leprosy. When asked about potential challenges or barriers to project scale-up, many interviewees mentioning obstacles encountered during implementation. However, some also raised concerns about future risks. A recurring theme was the project's heavy reliance on external funding and resources, which threatens the sustainability of key elements such as community activists after the project concludes. One government stakeholder observed:

> "With the end of the project, in the short term, we will experience some vulnerabilities, particularly regarding the activists themselves... considering that they receive some form of incentive; from the moment they no longer have any incentive, there may be vulnerabilities..." – KII, government stakeholder

Additionally, the heavy reliance on external funding created challenges in sustaining supervision activities, which potentially led to the neglect of the leprosy programme:

"...the supervision of activities only occurred when provincial teams [with NLR's support] came here, and often patients live very far away..." – KII, government stakeholder

Another major concern was the absence of a clear funding mechanism to sustain SDR-PEP activities, which could undermine the project's long-term impact. Additionally, the reliance on monetary incentives for community engagement raised doubts about the sustainability of these efforts. Lastly, the limited integration of the leprosy programme with broader health initiatives – particularly beyond TB – was also noted as a missed opportunity to deliver more comprehensive care.

#### Nigeria

While the programme achieved significant progress in advancing leprosy prevention through the adoption of SDR-PEP, early detection and improved health management, potential negative effects or challenges to scale up persist. For example, the long-term sustainability of the SDR-PEP project faces risks due to resource constraints and inconsistent implementation. A lack of logistical support, particularly in remote regions, hindered the programme's ability to fully achieve its objectives. One participant underscored this concern, stating:

"The level of adoption of SDR-PEP within the health system remains inconsistent due to logistical challenges, particularly in remote areas." – KII, Ready4PEP focal point, Jigawa

# 3.7. EQ6. What are the consolidated best practices, lessons learned and main recommendations for future strategies and plans, identifying what has already been integrated into the leprosy control programmes and what can still be included?

#### 3.7.1 Best practice

The evaluation identified several best practices that significantly contributed to Ready4PEP's success:

#### Mozambique

- Involvement of community activists and leaders: Most respondents highlighted the critical role of community activists and leaders in community sensitisation activities. Their influence was pivotal in mobilising communities, reducing stigma and promoting adherence to health interventions. This involvement facilitated early diagnosis and increased treatment uptake. Additionally, their participation enhanced the acceptability of SDR-PEP administration.
- Creation and revitalisation of CSCGs: Respondents emphasised the importance of CSCGs in empowering patients with knowledge on managing their conditions and preventing further disabilities. These groups served dual purposes: providing support networks for leprosy patients and mobilising community-wide education and awareness-raising campaigns. Their efforts significantly improved diagnosis rates and reduced stigma.
- Training for HCWs: Training initiatives at the district and peripheral health unit levels enhanced health care providers' ability to diagnose and manage leprosy cases. Continuous supervision and on-the-job training further boosted their skills and confidence. Decentralised training reduced dependency on district supervisors, thereby increasing the efficiency of case detection and SDR-PEP administration.
- Approach to contact tracing: Multiple respondents noted the effectiveness of contact tracing and prophylaxis in reducing new leprosy cases. In addition, approaches to expanding screening

to include social contacts beyond household members was instrumental in early case detection, demonstrating an impact on disease control.

#### Nigeria

Similarly to Mozambique, the involvement of community activists and leaders in community sensitisation efforts played a critical role in identifying cases and reducing stigma. The Ready4PEP project effectively trained community health workers and community members on identifying symptoms, enabling early detection and prompt treatment. These individuals often served as the first point of contact for patients, and their training in suspecting and referring leprosy cases significantly improved case detection rates. Working with community stakeholders facilitated community engagement and strengthened the acceptance of SDR-PEP. Moreover, their ability to educate communities about leprosy, SDR-PEP and the benefits of early detection contributed to reducing stigma and improving treatment adherence. Incentives, such as transportation allowances and financial support, motivated community health workers to identify and refer leprosy patients, particularly in rural areas.

Stakeholders in Nigeria stated that establishing CSCGs created a strong support network for individuals affected by leprosy, contributing to both physical health and mental well-being and showing the importance of community-based approaches. The CSCGs successfully promoted self-management among patients and provided peer support. Integrating leprosy patients with those suffering from other conditions such as lymphatic filariasis was also effective in reducing stigma and improving care.

Respondents further highlighted the integration of leprosy diagnosis, treatment and SDR-PEP administration into broader health services, such as TB and skin disease programmes, as a best practice. This approach ensured that patients with various conditions were managed together, improving the efficiency of health services. The integration also enabled shared training and planning initiatives, which are essential for sustainability.

Capacity-building and supervision were also crucial in increasing the competence of HCWs, making them more confident in diagnosing and treating leprosy patients. FGD participants noted that the attitudes of trained HCWs towards leprosy patients evolved over time to where they treated leprosy patients with respect, confidentiality and personalised care, improving the quality of care and patient experience.

One government stakeholder particularly mentioned a best practice of establishing a "50-50 commitment by both government and partners" to ensure sustainability and a robust training system

#### 3.7.2 Lessons learned

During both sense-making and validation sessions, participants were asked to document lessons learned in Mozambique and Nigeria as part of group discussions. Innovative tools, community engagement and integrated health strategies were all mentioned, including the use of the NLR SkinApp, as well as task-shifting to empower HCWs and community-level workers to diagnose and manage leprosy effectively while bridging gaps in technical expertise. CSCGs emerged as a critical mechanism for reducing stigma, improving mental well-being and fostering social inclusion for persons affected by leprosy and other diseases. In addition, community-centred approaches, including house-to-house administration of SDR-PEP, demand creation efforts and participatory decision-making, enhanced the awareness and acceptance of interventions.

Sustained funding, consistent drug supply and robust data management systems also proved vital for programme success and building trust. Moreover, integration with broader health services, such as TB and dermatological care, optimised resource utilisation and patient outcomes. These combined lessons underscored the value of collaboration, innovation and sustainability in tackling leprosy while addressing broader health and social challenges.

#### Mozambique

#### Community mobilisation and engagement

- Volunteers play a pivotal role, identifying around 80% of leprosy cases despite limited resources, showcasing the power of community-level involvement.
- Community activists effectively reduced stigma and raised awareness through the CSCGs, which also facilitated dialogue about leprosy.
- House-to-house administration of SDR-PEP proved more effective than fixed-point distribution, highlighting the importance of meeting community members where they are.

### Technological tools and innovation

• Tools such as the NLR SkinApp (and in future the WHO Skin NTD App) were instrumental in areas with limited access to dermatologists, enabling technicians to detect early signs of leprosy more efficiently.

#### Monitoring and supervision

• Consistent supervisory support during programme execution allowed for immediate technical guidance and on-the-spot training, ensuring programme fidelity.

#### Programme integration

- NLR successfully introduced SDR-PEP to Mozambique, demonstrating resilience and innovation in a challenging context.
- Collaboration between partners and the MoH requires a structured strategy, beginning with engagement through the Department of Planning and Cooperation to ensure alignment and efficiency.

#### Data management and logistics

- Because the project was implemented under 'study conditions', contact investigation data could not be integrated into the MoH systems. In future, it will be helpful to avoid the inefficiency of creating a parallel system.
- Timely and accurate data is necessary for platforms such as SIMAM to ensure proper allocation of medicines, reinforcing the importance of robust logistics management.

#### Sustainability and trust

- Planning for sustainability from the outset is crucial to maintain momentum and long-term success.
- Ensuring timely drug availability is vital for maintaining community trust in health systems.

# Collaboration and stakeholder engagement

• A collaborative approach among stakeholders enhances programme effectiveness, fostering shared ownership and accountability across sectors.

#### Nigeria

#### Diagnosis and treatment innovations

- The NLR SkinApp was helpful in supporting the diagnosis of leprosy and other skin diseases, even by less technically trained staff.
- Task-shifting, which involved building the capacity of general HCWs and community-level workers to diagnose and manage leprosy, addressed a lack of leprosy expertise in the implementing states.

#### Community engagement and social inclusion

- The introduction of CSCGs was a novel initiative that significantly improved the mental wellbeing of leprosy patients and reduced stigma by fostering integration into the community alongside individuals with other diseases and disabilities. SDR-PEP indirectly reduced stigma within communities, while CSCGs offered a holistic approach by integrating mental health support alongside physical health interventions.
- Regular group meetings, community discussions and the involvement of leprosy patients in decision-making were pivotal in reducing stigma and improving community acceptance.

• Demand creation and social engagement, initiated through the Ready4PEP project, increased awareness and acceptance of SDR-PEP across implementation sites.

## Capacity-building and collaboration

- Task-shifting to MDT officers and community leprosy workers contributed to the success of the Ready4PEP project, ensuring more comprehensive service delivery.
- Involving MDT officers and community leprosy workers in review meetings helped gain valuable insights into project challenges and successes.
- Ongoing training and well-structured SOPs bolstered health care providers' competence and confidence in diagnosing and treating leprosy.

## Integration and sustainability

- Integrating leprosy diagnosis, treatment and SDR-PEP administration into broader health services, such as TB, NTD and skin disease programmes, enhanced efficiency and patient management.
- Collaborative approaches, involving stakeholders from various levels, strengthened the overall programme framework and sustainability.

## Logistical and financial sustainability

- A consistent drug supply was identified as critical, emphasising the need for robust procurement strategies and sustained funding from the subnational level to ensure continuity.
- Early detection efforts and continuous community engagement were essential in dispelling myths and reducing stigma about leprosy.

## **3.7.3 Recommendations**

Both Mozambique and Nigeria demonstrated significant progress in implementing the Ready4PEP project. To ensure sustainability and long-term impact, several key recommendations emerged during interviews, group discussions, and the sense-making and validation workshops. These recommendations were intended for the key stakeholders involved in the leprosy control programmes in Mozambique and Nigeria: NLR, ILEP partners, TLM and the MoH in both countries, and LTR and RedAid in Nigeria. The recommendations fall into four key areas: policy, capacity-building, community engagement and operational efficiency. Where appropriate, the 'owner' of the recommendation is suggested.

Overall, NLR partners in Mozambique must enhance strategic planning and integration, including an appropriately designed evaluation of future phases of the project to identify lessons and guide future interventions. Additional recommendations include enhancing and expanding training programmes, further integrating mental health support into leprosy care, and improving resource management, especially as the project scales to more endemic areas.

Similarly, for Nigeria a strong emphasis is placed on ensuring the consistent availability of MDT drugs and integrating leprosy control more comprehensively with other public health programmes, such as TB and NTDs. The further adoption of technological innovations, such as the NLR SkinApp/WHO Skin NTD App, is recommended to improve diagnosis and management practices. These measures aim to build on the project's successes and ensure a robust, sustainable framework for leprosy control into the future.

#### Mozambique

#### Strategic planning and integration

 Develop a new or follow-on project proposal for a second phase Ready4PEP project in alignment with strategies and guidelines already developed and used by the MoH and in consultation with key departments (e.g. Public Health, Medical Assistance, Health Promotion, etc.) that already have defined approaches and manuals for implementation. Ensure that lessons learned from prior planning, implementation and monitoring are incorporated for improvement and expansions. (NLR, TLM, ILEP members and MoH)

- Work with the NLCP to present the results of the evaluation to the National Directorate of Public Health. (NLR, TLM and MoH)
- Since it is expected that SDR-PEP administration and the CSCGs will be adopted by the MoH, provide accurate and detailed costing information to assist decision-making. (NLR and TLM)
- All actors should work together to ensure proper budget planning for medications (logistics) and collaboration with SIMAN to avoid stocks-outs or supply delays. (All)
- Prioritise the integration of leprosy control efforts into the package provided by multipurpose health agents. (MoH)
- To address the challenges encountered by health professionals who must travel long distances from the health facility to reach communities, consider providing (motor)cycles and tents to enhance performance in community activities. (MoH)
- Actors supporting CSCGs are recommended to integrate psychosocial support and use tools such as the MoH's *Fica Bem* instrument to address participants' mental health challenges. (NLR, TLM, ILEP partners and MoH)

# **Operational and policy development**

- Review issues that may hinder women's participation, striving for a gender balance among activists and community leaders. (NLR, TLM and MoH)
- Address any misunderstanding, such as confusion between the use of red cards and other IEC materials. (NLR and MoH)
- Strengthen the connection with the MoH's community health subsystem strategy, particularly the Health Promotion Directorate. (NLR, TLM and ILEP partners)
- Continue advocating for the full approval and integration of SDR-PEP into national health policies, as well as inclusion in the national leprosy strategy and broader public health plans. (NLR and TLM)

## Community and health care engagement

- Continue to advocate for strengthening the connection between leprosy control efforts and other public health programmes. (NLR and TLM)
- Expand training and supervision beyond the current districts to include more regions and health units, ensuring all HCWs, especially those in peripheral areas, are well equipped to diagnose and treat leprosy. (MoH)
- Renew efforts to engage health care managers at the provincial and district levels to foster greater involvement. (NLR)
- Enhance communication tools and materials, ensuring they are widely available and using neutral colours for identification cards to avoid political associations. (NLR and MoH)
- Given the high turnover of health staff, create standardised induction packages to quickly equip new HCWs with the necessary skills to manage leprosy cases and contact screening combined with SDR-PEP administration. (NLR, TLM and MOH)

#### Training, support and simplification

- If SDR-PEP is adopted by the MoH, simplify/adapt the SOPs for SDR-PEP administration, making them easier to use for routine leprosy control, as the current forms are a challenge for HCWs. (MoH)
- Any future intervention that establishes new CSCGs should always be linked to health facilities to ensure sustainability. (MOH)
- Cooperate with other organisations to support community-based income-generating activities and provide additional support for patients with severe deformities, including mobility aids, to enhance social inclusion and dignity. (MoH, TLM, ILEP partners)
- Build advocacy skills for community activists and health care providers in the second phase to increase engagement and support. (NLR, ILEP and TLM)
- Maintain and expand community engagement efforts to reduce stigma and increase acceptance of SDR-PEP. (NLR and TLM)

• Strengthen the capacity of CSCGs to continue their critical role in diagnosis, reducing stigma and mobilising community-wide education. (NLR, TLM, ILEP partners and MoH)

### Advocacy and partnerships

- Expedite the revision of leprosy guidelines and protocols, aiming to have them finalised by 2025, also including leprosy prevention with SDR-PEP. (MoH)
- Develop clear instruments or guidelines for the implementation of SDR-PEP, with a presentation on its cost and impact to assess the MoH's ability to sustain it. (NLR and TLM)
- Share the progress of SRD-PEP adoption during meetings organised by the NLCP and find local partnerships to assist with transporting medicines to patients. (NLR and TLM)
- Ensure the availability of MDT (donated by the WHO) and leprosy reaction medication for all leprosy patients. (MoH)
- Ensure the availability of rifampicin for patient contacts, especially if the WHO donation programme is in place (MoH).

#### Sustainability and expansion

- Consider the integration of SDR-PEP with TB activities, as both diseases often overlap. (MoH)
- Expand SDR-PEP to additional endemic areas to increase coverage and impact. (MoH and NLR and ILEP partners)
- Evaluate the need for additional staffing in the MoH leprosy programme, especially staff focused on data management. (MoH)
- Collaborate in the review and update of the National Manual on Leprosy, including elements introduced by the Ready4PEP manual. (NLR, TLM, ILEP partners and MoH)
- Standardise leprosy training packages and have them approved by the MoH training department to ensure consistency across all partners. (ILEP and MoH)
- Ensure regular and timely availability of MDT, as well as rifampicin and leprosy reaction medication, across the country, in collaboration with the NTBLCP and other relevant stakeholders. (MOH)

#### Nigeria

#### Policy advocacy and integration

- Continue to lobby the government to ensure the leprosy and other public health plans receive funds. (NLR, ILEP partners and LTR)
- Focus on scaling up SDR-PEP to all states and LGAs, and maintaining a consistent supply of MDT, SDR-PEP and leprosy reaction drugs. (MoHSW)
- Coordinate with the MoHSW on the necessary steps and activities for a next phase. (LTR and ILEP partners)

#### Drug supply, import, supply chain management and local manufacturing

• Ensure regular and timely availability of MDT, as well as rifampicin and leprosy reaction medication, across the country, in collaboration with the NTBLCP and other relevant stakeholders. (MoHSW)

# Capacity-building and community engagement

• Continue to involve the community in active case finding, contact tracing and health education as part of a strategy for early detection and stigma reduction. (All)

#### Training and skills development

 Expand and formalise the use of tools such as the NLR SkinApp (from 2025 or 2026 onwards the WHO Skin NTD App) to diagnose skin lesions and screen for other NTDs. Consider costeffective solutions to identify smartphones/tablets for some MDT and LGA supervisors, and consider integration with TB and other diseases to enhance efficiency. (All)

#### Mental health and psychosocial support

• Integrate mental health support for individuals affected by leprosy, to address stigma and improve overall well-being. (All)

# Self-care and community-led support

- Formalise the role of CSCGs within the health system to improve the sustainability and impact of community-based leprosy care. (MoHSW)
- Increase resources and supplies for wound care to support individuals with leprosy and other NTDs effectively. (All)

# Resource mobilisation and partnerships

- Build partnerships with local governments and at subnational level to ensure timely drug supplies and adequate resources, and to promote ownership at all levels. (ILEP)
- Advocate for financial and logistical support to ensure the sustainability of leprosy control efforts at the local level. (ILEP and MoHSW)
- Engage in efforts to develop income-generating activities within communities affected by leprosy, supporting both the economic and social inclusion of individuals impacted by the disease. (ILEP and LTR)

# Innovation and technological integration

- Explore innovative ways to integrate leprosy control efforts with the management of other NTDs, including using mobile technologies such as the NLR SkinApp. (NLR)
- Consider further integration of leprosy control with TB and other public health programmes to streamline resources and enhance efficiency. (NLR, LTR and MoHSW)