

# Final Evaluation READY4PEP Project

## Executive Summary

NLR – Until No Leprosy Remains (Leprastichting)



Photo credit Jan-Joseph Stok

Submitted by

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## Acronyms and abbreviations

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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
MoH	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
TB	Tuberculosis
TLM-Nigeria	The Leprosy Mission
ToC	Theory of Change
WHO	World Health Organization

## Acknowledgements

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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.



Photo credit NLR

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 provided 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.



*Photo credit LTR*

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 of multi-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.



*Photo credit NLR*

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.



*Photo credit LTR*

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.



*Photo credit NLR*

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.



*Photo credit LTR*



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.



*Photo credit LTR*



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.



Photo credit LTR

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.

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



Photo credit Joao Vembane

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 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.

## 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.