

## GPZL working group assesses challenges and a path forward for leprosy during COVID-19

### Leprosy Emergency Operations Committee

#### Authors

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#### Introduction

On 4 March 2020, as a rapidly increasing number of COVID-19 infections were beginning to be reported around the globe, the Global Partnership for Zero Leprosy (GPZL) Leadership Team held a strategy session to discuss the potential impact of the pandemic on member organizations and GPZL's 2020 Strategic Outline.

Three urgent areas of focus were identified:

1. Assessing and resolving the pandemic-related challenges of national leprosy programs.
2. Understanding and amplifying the humanitarian needs of persons affected by leprosy and their families.
3. Preparing for the resumption of regular activities following COVID-19.

Working groups were proposed for each of these focal areas. The first of these, the Leprosy Emergency Operations Committee (LEOC) was formed to assess and take action on the emergency situations being reported by national programs.

The LEOC included representatives from many GPZL member organizations, along with new members from Novartis and WHO with anti-leprosy drug supply expertise. It was the first time these partners had worked together in a coordinated manner. The LEOC was chaired by Arielle Cavaliero (Leprosy Flagship, Novartis) and Benedict Quao (National Leprosy Programme, Ghana). It included Maarten van Cleeff (consultant expert), Erwin Cooreman and Rao Pemmaraju (WHO Global Leprosy Programme), Dmitry Esin (WHO HQ, NTD strategic operations); Simon Hoos and Lorenz Yeboah (Novartis Global Health

Process Governance and Value Chain Management); Roch Christian Johnson (International Leprosy Association); Rodrigo Ramos de Sena (Ministry of Health, Brazil); Aya Tobiki (Sasakawa Health Foundation); Geoff Warne (International Federation of Anti-Leprosy Associations - ILEP); and Sunday Udo (The Leprosy Mission Nigeria). Coordination was provided by Christine Fenenga and Jessica Cook of the GPZL secretariat office.

The LEOC's terms of reference included developing a platform for enhancing information sharing, assessing and monitoring the situation in national leprosy programs, and facilitating the resolution of operational challenges generated or aggravated by the current situation. Key issues to be addressed and resolved were the supply of drugs for treatment of leprosy and reactions and issues with access to leprosy care. The LEOC also wished to link experts to address potential needs, as feasible; assess how to support information needs of national program managers; and liaise with the other two GPZL working groups to exchange information and avoid duplication.

## Methodology

The LEOC launched in April and began a series of virtual meetings, initially meeting twice a month and then once a month. The group held 8 meetings April through August 2020.

### *Survey to National Leprosy Program Managers*

The LEOC members expected the pandemic would have major implications for national leprosy programs, especially around the supply and distribution of drugs due to travel restrictions. The members prepared a survey for national leprosy program managers to understand their immediate needs and to assess their familiarity with and adaptation of a WHO-GPZL-ILEP guidance document on leprosy-related activities during the first months of the COVID-19 pandemic. (1) The survey was emailed to 222 countries and territories by the WHO Global Leprosy Programme on 21 April. A total of 34 unique country responses were received, primarily from African and Asian countries. Twenty-six were from national program directors and 8 were from WHO staff in countries. Considering that only 56 countries reported over 100 cases of leprosy in 2018, LEOC members felt the response rate was high.(2)

### *Survey to CSOs and NGOs*

The LEOC augmented the information received from national program managers and WHO representatives with a survey of non-governmental organizations (NGOs) and civil society organizations (CSOs) working in countries. A survey was prepared by the LEOC and sent to all ILEP members working in endemic countries with a request to send it on to CSOs in countries.

A total of 26 organizations from 12 countries responded to the NGO/CSO survey. LEOC members analysed and summarized results on a shared document. Notable results are summarized below.

## Key Outcomes and Discussion

### *Survey to National Leprosy Program Managers*

An analysis of survey responses indicates that COVID-19 was having a direct impact on the majority of countries. Seventy-six percent of respondents (26 countries) said the outbreak was impacting their program. Their responses varied from clinics and offices being completely closed, to open clinics with limited case finding and community-based activities.

#### 1. *Supply of drugs*

Twenty programs reported that MDT supply had not been affected. However, concerns about the supply of MDT were mentioned by respondents from 13 countries (1 country responded “other”), who reported delays in in-country supply, distribution and/or shortages in facilities. Seven countries also said that while the drugs were available at the health facility level, patient access had been hampered due to travel restrictions. These countries were supplying patients with more than a one-month supply of MDT as much as possible. One program reported that the MDT supply in country was severely impacted. Also noted were issues with the availability of drugs for reactions and challenges in providing continuity of care for ulcers and disabilities.

#### 2. *Supportive services (wound, disability and social care)*

One country reported that delays in wound and disability care due to COVID-19 resulted in a large backlog of leprosy patients. Access to treatment was being negatively affected by limitations on travel in another country. In a third country, clinics were closed and MDT supply was an issue. Some countries noted issues with the monitoring of leprosy reactions. Ensuring continuity of disability care at all levels, and starting community activities as soon as possible, were mentioned as challenges. The monitoring of nerve function impairments in some districts and countries was mentioned as a problem. One respondent noted that there is a general need for health system strengthening, while another noted the serious impact of the pandemic on access to such basic needs as food and essential goods.

#### 3. *General support for the work of national leprosy programs*

Several respondents suggested that additional guidance would be helpful, including how to maintain disability services, disability care and self-care groups.

LEOC members discussed these survey results, identified the countries most affected and followed up with the program managers of those countries, to find out the actual situation and type of support that may be needed.

### *Survey of NGOs and CSOs*

Common themes included the discontinuation of outreach and community activities, a reduction or elimination of active case finding or screening, and sharp reductions in nerve function tests, disability services and ulcer care. Respondents noted that the MDT supply was usually available, though varied in areas, but patient access was limited. They commented they were unsure of who was affected by COVID-19 in the leprosy community. Because of lockdowns, travel restrictions and program closures, NGOs and CSOs reported becoming involved in humanitarian aid, including providing food, water, and hand hygiene.

### **Key Outcomes and Findings**

1. Bringing all the major players in the MDT supply chain onto the same platform to quickly assess and take action on national program needs has been a major outcome and can be the basis for further streamlining of the MDT supply chain in the future. Ten countries required additional follow-up for MDT supply issues. LEOC members from Novartis and WHO were able to resolve these issues and/or determine why there was a delay, often because of COVID-19 travel restrictions. The supply of drugs has mainly been resolved and communication is open and functioning well—relationships are in place to address future issues.
2. Creativity and innovation will be needed to overcome the limitations imposed by travel bans, which make the provision of services challenging. Travel bans have had an adverse impact on diagnosis and treatment, self-care groups, disability care, ulcer care and the production and fitting of disability appliances/devices. Such bans also hamper active case finding, contact tracing and preventive chemotherapy. Potential innovations include:
  - Engaging family members to take an active role, including examining household contacts. Indonesia has been doing this for several years through its “family approach” (not only for leprosy) and the Indonesia Leprosy Post-Exposure Prophylaxis Program (2014-2018) used a self-screening tool.
  - Increasing the use of digital technology in daily leprosy control activities, such as SkinApp and LEARNS, both featured in the GPZL Research Agenda. Such tools are positioned for geographically hard-to-reach places or areas of low endemicity where workforce capacity is low. These tools could be increasingly helpful where COVID-19 restrictions remain and workforces are overstretched.
  - Use of mobile phones. In Rwanda the NLPM reported that patients were asked to send WhatsApp pictures of ulcers etc. to the clinic for receiving advice. In Ghana, patient

cards and calls are used for follow-up. The Maldives conducts an online consultation service.

3. More emphasis on mental health and well-being is needed as COVID-19 has exacerbated the stress and vulnerability of the leprosy community. In Nigeria, a COVID-19 call centre has been set up to receive calls and provide psychological support during this time. Boosting self-care groups with community group support could be considered. The German Leprosy Relief Association (GLRA) has successfully used mobile phone calls between patients and healthcare workers to manage complaints and mental health challenges. Pandemics also cause stress and disengagement for health care workers, perhaps requiring different approaches than for patients. (3)
4. When considering how to add value to countries during the COVID-19 response, it will not be sufficient for the GPZL and its members to only give guidance or develop suggested policies. National leprosy program managers are busy with multiple responsibilities and in some cases may need additional support to reach measurable outcomes at the country level. In some cases, technical assistance will be needed to support the implementation of guidance or guidelines.
5. Efforts that make such guidelines accessible and widely disseminated are also important. For example, in Bangladesh, WHO guidance was translated into the local language and taken to implementers. Dermatology associations have developed guidance and have referred to the WHO-GPZL-ILEP guidance document. The leprosy community could partner with organizations, such as dermatology associations, so that guidance documents reach more people.
6. Flexibility, and a long-term view, are important. COVID-19 is impacting each country, and districts within countries, differently and standard guidance or recommendations will not be completely effective. In some areas there are very limited restrictions while others are under complete lock-down. Situations have undoubtedly changed since this survey was conducted in April and will continue to change, particularly if countries experience a new wave of infections. This necessitates a plan for a longer-term, with flexible guidance or recommendations to account for different locations and contexts.
7. Providing humanitarian aid was a new role for organizations but likely will continue. Leprosy NGOs and CSOs had to broaden their mandate this year, by providing aid such as food and water. These organizations have had to rethink their roles and address the larger needs of poverty during a time of crisis. (4)

## Next Steps

The LEOC achieved its goals of developing a platform to enhance information sharing, assessing and monitoring the situation in national leprosy programs. It also addressed and resolved the supply of drugs for treatment of leprosy and reactions in many countries. Moving forward, the GPZL has established another COVID-19 working group to take forward learnings from the LEOC and incorporate them into strategies for working with program managers to build sustainable capacity to deliver leprosy services during the COVID-19 pandemic and beyond.

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