

## Issues:

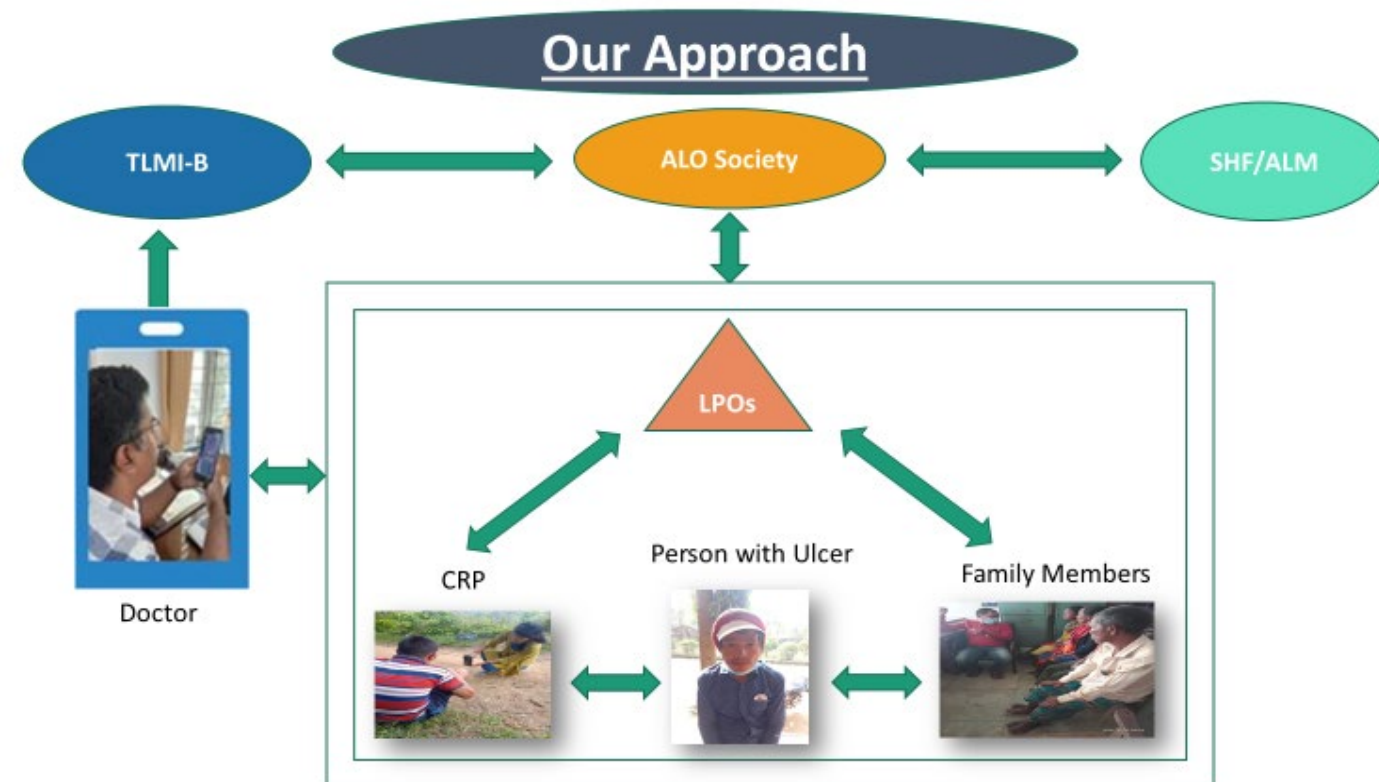
- Annually about 2,500 people suffer with leprosy complications and need hospital care in Bangladesh.
- The people suffering from leprosy complications, are mainly women, children, and senior citizens, and they are typically residing in inaccessible areas. These people often have mobility issues and don't receive quality care and timely service from service providers.
- Leprosy complication service centers are located only in certain areas. As a result, access to healthcare services is not easy from other geographic areas, posing a travel burden, daily income loss and family detachment risks.
- Hospital care is becoming more and more limited due to a lack of leprosy expertise, a difficulty in integrating the care with the general healthcare system, and several funding issues for both government and non-government leprosy hospitals.

ALO is a national level registered organization (reg no: S-13330 /2020), representing more than 100 federations and more than 1,500 Self-Help Groups (SHGs), formed with about 17,000 members in total.

- Patients are ignorant of doing regular self-care. Their relatives also don't feel the need about it and are therefore unable to provide regular care without external support and follow-up appointments. Again, there is huge skill gap for identifying complications in time, e.g. reaction, neuritis, etc.
- The role of people affected by leprosy and Leprosy Peoples Organizations (LPOs) in supporting and serving people affected by leprosy is not very prominent, but they could potentially have a very key role.
- The existing problem of accessing care for leprosy complications has worsened by the COVID-19 pandemic.

# Measures:

- Partnerships between TLMI-B, Funding Partner, ALO, and local Leprosy Peoples Organizations (LPOs) have been established.
- Community Resource Person (CRP- staff of LPO), leaders of LPOs and skilled project staff have prepared a list of people who live very far from hospitals and are unable to travel but continue to seek admission to leprosy hospitals for leprosy complication care service.
- CRPs, leaders, and field staff have been oriented on the digital service system, which ensures smart mobile device usage with reliable mobile data to allow for a better communication.



## Measures (cont.):

- CRP visited people with leprosy complications at their homes and used digital video calling platforms like WhatsApp and IMO to connect with doctors of TLMI-B.
- Doctors did consultation with patients and eligible family members. Doctor then provided prescriptions to distant patients with manageable conditions, and referred others to upgraded care if their condition were complicated and unmanageable.
- They have encouraged family members, LPOs leader, CRP to contact them for further information or follow-ups.



Training being conducted for CRPs



Ulcer care conducted by CRP

# Results:

Many lessons were learnt from pilot interventions in 11 districts between ALO and The Leprosy Mission International-Bangladesh TLMI-B during COVID-19 (7 months of 2020–2021), supported by Sasakawa Health Foundation (SHF). TLMI-B and ALO submitted an abstract for NTD Innovation Prize 2022. TLMI-B has also been awarded \$40,000 as NTD Innovation Prize from American Leprosy Missions (ALM) for scaling up Digital Complication Care.

The key results from the piloting interventions are:

- Within 7 months, 120 people with leprosy complications in remote areas have been served digitally, majority suffering from ulcers.
- 70% of the service receivers showed improvement of their health condition.
- The doctors received about 300 extra phone calls from service receivers asking questions and thanking them for their care. This indicates that the people with leprosy complications benefitted from the service.
- Increased follow-ups to patients by experts encouraged them to engage in self-care practices.



**Doctor digitally serving a patient**



**CRP connecting patient with doctor using digital platform**

# Results:

ALO started implementing this project from March 2023 after receiving a commitment from American Leprosy Missions (ALM). The results from this project are as shown below:

- ALO selected 20 LPOs from 12 districts and signed MOU with the LPOs.
- ALO trained 20 Community Resources Persons (CRP), specifically on leprosy, complication identification skills, techniques of care, using mobile (smartphone) devices and digital recording and reporting systems.
- The project aided 40 people suffering from leprosy. This service included complication care and follow-ups (1<sup>st</sup> follow-up to all 40 and 2<sup>nd</sup> follow-up to 12) with the support of TLMI-B doctors and physiotherapists. The target was to serve about 250 people.
- ALO provided complication care package to 21 vulnerable people suffering from leprosy complications.
- 1 patient has been referred to hospital for complication care service.
- 30% of family members of the served people are supporting them with ulcer care.



**Doctor digitally serving a patient**



**CRP providing ulcer care to a patient as per doctor's advice**

## Lessons Learnt:

- Utilizing modern digital platforms for complication care is a convenient approach to extend services to uncovered areas, lacking access to healthcare expertise.
- This service has played a significant role in promoting self-care among patients, leading to a positive shift in their mindset towards taking charge of their own health.
- Engaging the family members of patients and building a supportive environment is a crucial aspect of this approach. It helps to create a positive mindset and encourages family members to lend helping hands to patients in need, which therefore help make the patients more hopeful in a full recovery.



Daughter supporting her mother with ulcer care



Patient doing self-care

## Lessons Learnt (cont.):

- Regular consultations with leprosy experts and consistent follow-up care enable patients to develop expertise to overcome the barriers of complication care.
- The involvement of LPOs (Federations/Associations) in delivering services to people affected by leprosy has proven to be highly effective and greatly appreciated by those receiving the care.
- ALO's support to the LPOs has been well-received by the LPOs, local communities, and the government. This partnership strengthens the LPOs capacity and promotes ALO's campaigns. The LPOs are committed to fulfilling their social responsibility by continuing their leprosy-related work.



Ulcer size is improving



CRP doing ulcer dressings

## Next Steps:

- ALO wishes to work with more LPOs and in more remote districts to provide digital complication care to those in need.
- They are planning to engage government doctors for digital consultations to people suffering from leprosy complications.
- There are plans providing essential materials for complication care to ultra-poor patients.
- LPOs need more financial and management support to serve their members to improve their health and socio-economic condition.
- ALO is processing to get NGO bureau registration to receive foreign denotation into their accounts.

