

## **Project Summary:**

Improving Access to Healthcare and Support Services for People Living with Life-Long Morbidity and Disability Due to NTDs in Liberia During and Post COVID-19 Pandemic.

## Background to the study

People affected by long-term consequences of Neglected Tropical Diseases (NTDs) have difficulties in carrying out their activities or engaging in society. This is due to a range of physical impairment, stigma and social exclusion, poverty and poor access to healthcare. Liberia is endemic for NTDs with lifelong disabilities including Lymphatic Filariasis, Buruli ulcer and Leprosy. Treatment for these diseases is at health facility level, associated with the NTD programme. The recent Corona Virus Disease (COVID-19) pandemic which instilled high levels of sanitation and social distancing caused the WHO to suspend all NTD field activities. As such, NTD activities have been suspended in Liberia, with supply chains prioritized for COVID-19 response. With limited supply at health facilities, and physical distancing rules, access to care of this vulnerable group of people became increasingly difficult. Identifying strategies to cater for people with these morbidities/disabilities in times of health system shocks will improve wellbeing and support universal health coverage goal of no one is to be left behind.



Figure 1: Lymphatic Filariasis

Aim: To identify necessary strategies to improve access to healthcare and support services for people living with lifelong morbidities or disability due to Buruli Ulcer, Leprosy and Lymphatic Filariasis in the new COVID-19 era in Liberia.

## **Methods: Qualitative Research Methods**

This study drew on qualitative and participatory research methods to document current disease and access to care experiences and identify strategies to improve these for people living with lifelong morbidities and disabilities due to NTDs.

## In-depth Interview (IDIs) with people living with NTD morbidities and disabilities

A total of 21 IDIs were conducted with people living with NTD morbidities and disabilities including Buruli Ulcer, Leprosy and Lymphatic Filariasis to understand patient experience with disease and access to care prior to and during the COVID-19 pandemic, and to access patient needs and suggestions for improving their care.

## Body mapping participatory exercise

A participatory exercise including patients mapping sections on their body most affected by the disease and access to care was carried out to support patient interviews.

## Key Informant Interview with health system stakeholders

Semi-structured interviews were conducted with 10 health system stakeholders across all levels of the health system to understand current measures and strategies in place to care for people with morbidity/disability associated with NTDs, to document health system response to COVID-19 in relation to NTD morbidities and explore possible strategies to improve access to care and the wellbeing of people living with NTD morbidities and disabilities.

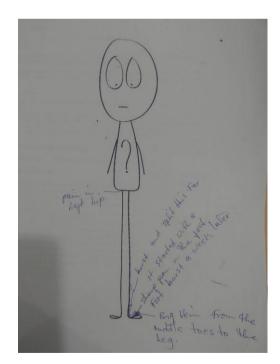


Figure 2: Body mapping exercise







## **Results and Findings**

#### Patient experience with disease and disability

Most patients felt uncomfortable with the disease due to the associated pain, multiple and extensive sores, loss of sensations and sleeplessness. In some cases, this has led to loss of livelihoods and social relationships through self-isolation, shame, social discrimination and abandonment. A few patients had experience of being suicidal and were referred to the rehabilitation centres for support.

"Well, since I get this sore here, I not feeling fine about myself because sometimes I go among my friends they will always hang (mockery) mouth on me. They will say how I rotting, I smelling then they will talk whole lot of things like that I will.....

(Bong, Male BU patient)

#### Access to care and support services prior to COVID-19

Prior to the COVID-19, most participants reported multiple means of seeking care, extending from the formal health system through roadside vendors and traditional healers for their disease. However, the majority reported using the health system because of available care services provided free of charge. This includes wound care, medications, home care kits and some laboratory investigations. Health workers also provided regular home visits to patients for follow-up and disease education.

"Some of the health facilities, some of the staffs were not going to work at all because of COVID-19. that also created a gap at the level of the health facility and affected the normal health delivery protocol at the facility" ...

(KII National Male)

#### Impact of COVID-19 on people living with NTD morbidities and disabilities and on the health system

Following the experience with Ebola, the Liberia government and health system was prompt to apply strict measures on hygiene and sanitation and social distancing due to COVID-19. All NTD community programmes were also stopped following recommendations from the WHO. As such, many patients experienced reduced source of livelihoods with increased cost of transportation to seek care. Furthermore, response to COVID-19 was prioritized over all other services, as such, supply of medications and care kits for NTDs was limited or absent at health facilities. Due to misinformation on COVID-19 being transmitted at health facilities, some patients and health workers abstained from health facilities. The result has been a default in medication and increased disease progression and/or complications.

## Strategies to improve access to care and support for people living with NTD disabilities

## Maintain supply of medications and care kits for people with NTD morbidities and disabilities

Across all cadres, participants stressed on the need for a constant supply of medications and care kits at health facilities. However, the was a high dependence on the government and partner support for these supplies. While the patients requested a constant supply of medications and care kits at the health facilities from the government, heath worker and partners suggested such a programme be supported by an external partner for continuous supply of needs for people with NTD morbidities and disabilities in times of crisis.

## In-service training of staff and community sensitization

Many participants suggested training more health workers on COVID-19 and NTDs will boost management of NTDs during this crisis. Likewise, community sensitization on COVID-19 will reduce myths and misinformation and boost health seeking attitude of populations for other diseases. Likewise, some patients and health system stakeholders suggested large scale sensitization of communities on existing rehabilitation centres for people with disabilities including those from NTDs. . One patient reported being catered for at a rehabilitation centre since the start of the COVID-19 with much improvement.

# Support and motivation of community cadre of health workers (community health volunteers and community health assistants)

Many health workers expressed the importance of close-to-community healthcare providers in NTD case identification and follow-up. As such, this cadre should be supported with transport means and personal protective equipment; and motivated financially to continue with NTD case identification and home care.

#### Health system and community strengthening

Some participants suggested strengthening of existing health structures to cater for people with NTD disabilities. For example, one participant suggested upgrading existing decentralised laboratories to carryout diagnostic confirmations for NTDs, such that samples will not be blocked by restricted movements as they will not need to be carried across counties. Another suggested key elements used to assemble care kits such as buckets be acquired locally such that cross-county transportations will not be required.









## **Impacts**

- ✓ Increased awareness amongst health system stakeholders on the effect of the COVID-19 on this neglected cadre of people living with morbidities and disabilities due to NTDs.
- ✓ Development of a policy brief for NTD and other health system stakeholders targeting care and support for people living with NTD morbidities and disabilities.

