



# FIVE KEY LEARNINGS

*For how to strengthen co-ordination, collaboration and person-centred partnerships for more equitable early case detection of skin NTDs*



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Early case detection is known to improve outcomes for people affected by NTDs and to enhance NTD control. We know that people who are most disadvantaged and marginalised experience the greatest health inequities, encountering barriers to seeking and using health services. In consequence, they are more likely to be diagnosed and to start treatment later, by which time they may already have a chronic condition and/or disability. Community actors, including formal providers such as community health workers as well as informal providers, such as faith and traditional healers, play significant roles in identifying and managing people affected by skin conditions (including NTDs). Traditional medicine and healing practices are often the first source of care for people affected by NTDs, yet there is limited consideration of the best ways to collaborate with these health actors. There is therefore an opportunity to strengthen collaborations between formal and informal providers, patient advocates and other community and health systems actors to improve equitable early case detection for NTDs. Through the COR NTD breakout session held in Chicago, 16/10/23, we sought to understand more about ways to strengthen equitable early case detection of people affected by skin NTDs. In this brief we share our five key learnings from the session for how to strengthen co-ordination, collaboration and person-centred partnerships for more equitable early case detection.

## 1. A wide range of actors within the community and health system play a role in enabling early case detection

A wide range of actors may play a role in early case detection (McCollum et al. 2022). These actors were discussed in various presentations and throughout the session group work, reminding us that:

- Informal providers, such as traditional and faith healers play a critical role in shaping the journey of a person affected by skin NTDs due to the persisting health beliefs relating to the causation of these conditions.
- When appropriately trained and supported, community health workers (CHWs) can:
  - Improve knowledge and understanding about skin NTDs within their community by sharing information about skin NTD signs and symptoms. This can help challenge myths and stigma.
  - Conduct active case finding of persons affected by skin NTDs through home visits/during mass drug administration campaigns to strengthen case identification and links for referral, reduce delays in reaching care-seeking decisions, increase patient enrolment and reduce permanent impairment at diagnosis. Examples of the usefulness of this approach were provided from Kenya during discussion.
- Surveillance actors (such as district surveillance officers in Liberia), carry out active case finding and surveillance within NTD programmes to ensure no one is left behind (Godwin-Akpan et al. 2023).
- Patient advocates can play a critical role in building trust and strengthening pathways between persons affected and formal health actors.
- All health workers need knowledge & good communication skills to ensure patients understand their condition and future treatment.

Ways to balance workload and training, to avoid overburdening community level actors such as community health workers (including community drug distributors) was discussed as an important consideration. We should also consider learning from other disease control interventions, considering the frequent importance of teachers and school children as part of case detection efforts. Examples were shared from Brazil, where children learn about NTDs at school, followed by homework to search for any possible signs or symptoms among family members. Approaches such as this may provide a valuable addition to current case detection work, but would need to be implemented carefully to ensure those most marginalised, who are most at risk for NTDs, and yet also may be less likely to attend school, do not miss out on this pathway towards case detection.

## 2. Trust shapes a patient's care seeking pathway

Patient knowledge about skin NTDs and care-seeking pathways, and their trust and confidence in the health system all influence when and where a person will seek care. Trust was described by several presenters (including a person affected by a skin NTD) as critical to a patient's journey. People with symptoms of skin NTDs in the community often feel able to share their symptoms with a person with lived experience of an NTD, rather than other health workers. When a person affected shows community members their own healed wound, they gain trust that they too can receive similar healing. As a result, this encourages them to seek biomedical care from a local health facility.

Trust in the health system (and health worker) must be protected, with health workers trained in communication skills to better communicate with patients, and how to provide holistic care, given the mental health needs of people with skin NTDs (Dean, Tolhurst, et al. 2019) disability and inclusion (DMDI). Strong supply chains must be established alongside any activities to increase case detection, as trust can easily be lost if there are drug and supply stock outs. Where trust in the health system is lacking, patients frequently return to seeking care from informal providers.



Peer support group with persons affected

### 3. Involving traditional and faith healers can increase case detection

Supernatural beliefs and stigma play a critical role in influencing demand for health seeking from faith or traditional healers among people affected by skin NTDs in order to deal with the perceived underlying cause of these conditions (McCollum et al. 2022). Presenters shared that informal providers (traditional leaders and religious leaders) expressed feelings of empathy towards people affected by skin NTDs and often already provide their patients with a wide range of holistic care. Although lack of knowledge about skin NTDs, has previously led to delayed biomedical care seeking. Findings from Sierra Leone revealed that training and involving traditional healers to refer persons with suspected leprosy resulted in the discovery of more patients with leprosy in intervention areas, compared with control districts. In Liberia informal providers described willingness to collaborate with the health system, with many faith healers expressing the need to seek medical advice prior to praying for a patient, after taking part in training about skin NTDs. Across both Sierra Leone and Liberia, the need to avoid stigmatising people affected was emphasised.

More learning is required to understand how best to strengthen relationships between the formal and informal health system for the benefit of people affected by skin NTDs. Despite key successes, some informal providers still refuse to refer patients, due to their perceived 'spiritual responsibility' for their patient, as well as their own need to generate an income through treatment of patients. This was reflected in the group discussion with a range of operational research questions relating to how to motivate and/or incentivise informal providers to refer possible persons affected, given the potential loss to their income? To what extent can informal providers help to challenge stigma and discrimination towards people affected by skin NTDs?



### 4. A health systems strengthening approach is needed for successful case detection

Preventive chemotherapy of NTDs is often referred to as a 'litmus test' for Universal Health Coverage' (Dean, Ozano, et al. 2019) until now highly aggregated coverage data may have masked inequities in availability, accessibility and acceptability of medicines, slowing down the equitable achievement of elimination goals. Methods We conducted qualitative programmatic analysis across different country contexts through the novel application of the Tanahashi Coverage Framework enhanced by gendered intersectional theory to interrogate different components of programme coverage: availability, accessibility, acceptability, contact and effective. Drawing on communities and health implementers perspectives (using focus groups, interviews, and participatory methods. The early case detection and management of people with skin NTDs could be added as an indicator of UHC in the extent to which people who are most marginalised can access and benefit from quality health care. In order to achieve universal access for NTD care there needs to be more holistic collaboration and multi-sectoral approaches for the management of people affected by skin NTDs, as outlined in the WHO NTD 2021-2030 roadmap (WHO 2020).

The need for integration across disease programs and mainstreaming within the health system in Liberia was highlighted. Health systems building blocks relating to data quality and drug and supply chain have created challenges for the NTD programme, and will need addressing alongside other disease programs to ensure that gains made in disease control and elimination are not hindered by weaknesses in other systems areas. Cross-departmental and sectoral collaboration is essential to promote mainstreaming and local ownership for sustainability. This must be supported by equity in participation in planning and implementation with persons affected included and involved throughout. Group discussions highlighted suggestions and questions relating to how best to integrate NTD and mental health data within existing data management structures, such as HMIS?

### 5. Involving persons affected by NTDs makes a BIG difference to case detection and NTD programming

The role of persons with lived experience as advocates to raise awareness and improve understanding about skin NTDs within their local communities is less documented within the global literature. Persons affected can play a vital role within case detection, by nature of the trust placed in them by people with possible NTDs due to their own experience and recovery. People affected can also help to support health workers at community level by encouraging a person to take up referral if they are reluctant and then accompanying them to the health facility. They are also critically positioned to challenge stigma and discrimination within their communities.

Learnings across settings may be particularly valuable for the role of persons affected, with group discussions highlighting the role of persons affected in signposting others with possible symptoms to seek care, through their daily interactions at work and within the community. Formalised associations and national federations for persons affected in Colombia, where persons affected are trained and certificated to walk with newly diagnosed persons affected as they receive their diagnosis and throughout their treatment and care-seeking journey, can provide lessons in other contexts. Yet questions remain surrounding how best to remunerate persons affected adequately and sustainably for their time?

The COR NTD session provided space to discuss and share together about ways to strengthen equitable early case detection of people affected by skin NTDs through co-ordination, collaboration and partnership between formal and informal health actors. As well as highlighting the key operational research areas to move forward this important work.

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