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COMMENTARY

# How can the neglected tropical disease community be inclusive and equitable in programme delivery? Reaching refugees and internally displaced persons through integrating a 'leave no one behind' approach

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As directed by the Sustainable Development Goals, the principle of 'leave no one behind' is a pivotal approach to improving coverage and equity within neglected tropical disease (NTD) programme activities. Displaced populations are an at-risk group who are often excluded from treatment and services due to their mobility and marginalisation. This article reflects on the experiences of two countries within the Ascend programme, which responded to the need to strategise and implement approaches that lead to more inclusive and accessible programme activities for displaced populations. With the increasing rate of insecurity and the threat of natural disasters, which is resulting in the displacement of communities and persons eligible for NTD treatment, the 'leave no one behind' approach is needed to move closer towards the NTD elimination agenda and to ensure effective coverage thresholds are met.

**Keywords:** displacement, equity, IDPs, leave no one behind, NTDs, refugees.

## Introduction

Neglected tropical diseases (NTDs) have a devastating impact on the most marginalised communities globally where there are varying levels of vulnerability, exposure and access to services and treatment. 'Leave no one behind' (LNOB) is a commitment to ensure the equitable and inclusive delivery of services and treatments. It is a concept at the heart of the United Nations Sustainable Development Group,[1] reflects goal 10 (reduced inequalities) of the Sustainable Development Goals (SDGs), and the principle has been adopted by the WHO's 2030 NTD elimination road map.[2] In practical terms, LNOB means taking explicit steps to end extreme poverty, curb inequalities, confront discrimination and fast track progress for the furthest behind.

The Ascend West and Central Africa programme (hereafter called 'Ascend', or 'the programme'[3]) embedded a cross-cutting LNOB approach that was built into all NTD activities with the recognition that certain marginalised groups (e.g. people with disabilities and women) are at risk of exclusion in relation to treatment access and equitable health outcomes. This is also the reality for internally displaced people who are attempting to access NTD activities.[4]

Unprecedented levels of displacement caused by insecurity, conflict and violence have globally affected an estimated 82.4 million people during 2020.[5] The increasing influxes of displaced populations both within and across national borders are largely excluded from NTD programme activities for a myriad of reasons—including structural and logistical barriers[4]–and these populations are more at risk when residing in overcrowded settlements with inadequate sanitation. The continuous rise in population, conflict and political insecurity creates a question for national NTD programmes in how to navigate a response and be inclusive when conducting activities[6] if they are to strive towards universal health coverage targets as emphasised in the WHO road map 2030.[7]

**Table 1.** Main recommendations to support PC (preventative chemotherapy) treatment provision among refugees in Benue, Nigeria

| Key challenges | Recommendations |
|---|---|
| Information on IDP sites, population trends and distribution | (1) State NTD programmes will continue to strengthen coordination with UNHCR, Benue State Emergency Management Agency (SEMA) and community-based organisations for access to refugee camps, newly sited IDP camps and IDP population trends for MDA planning. |
| Accessibility to unsecured areas | (2) State NTD programmes will make use of community structures (self-monitors) who are resident within the displaced communities to support the monitoring of MDA and reporting to the NTD programme. |

This commentary will highlight two distinct examples from within the Ascend programme on improving and strategising for extended coverage and inclusion of displaced populations in Nigeria and Niger. Through strategising and implementing a LNOB approach to proactively consider those at risk, the Ascend programme has endeavoured to bridge the gap between NTD activities and displaced populations.

## Identifying and conducting activities for internally displaced people and refugees in Nigeria

Following the commitments of the London Declaration of 2012, Nigeria has prioritised the eradication and elimination of specific NTDs. This led to a countrywide disease mapping and scale-up of mass drug administration (MDA) in endemic communities. A WHO methodology, Community Directed Intervention, has been used to deliver MDA in Nigeria to leverage community structures and ownership to ensure the sustainability of MDA in endemic communities.[8]

Since November 2018, individuals being displaced from Cameroon have been seeking refuge in Nigeria due to ongoing conflict between the government of Cameroon and separatists from the Anglophone regions in the northwest region of the country. This undermines NTD MDA strategies and affects geographic and therapeutic coverage. The crisis has led to the establishment of camps for refugee and internally displaced persons (IDPs) across affected communities in Benue State, Nigeria.

Taking into consideration the WHO 2030 NTD elimination road map, the SDGs and the underlying principle of LNOB embedded within the programme's approach, the Ascend programme continued to target all eligible and marginalised populations—including IDPs and refugees—during MDA, to ensure that every individual who is eligible to receive NTD interventions has access to these interventions.

At its inception, the Ascend programme emphasised the need for everyone eligible for MDA treatment to be reached with the required intervention. The Benue State NTD team undertook an analysis of the groups of people who could potentially be left behind during MDA. As a result of the LNOB commitment of the Benue State NTD programme, the NTD programme consulted with the Benue State Emergency Management Agency,[a] and this led to the identification and mapping of all IDP and refugee camps. Consequently, IDPs and refugees were selected and trained as drug distributors. The NTD programme also trained State Emergency Management Agency officials who supervised MDA in all IDP camps and were overseen by health workers based in catchment areas where the camps are situated.

As a result of these actions, the programme has sustained MDA in all seven IDP camps since 2018 and one refugee camp since 2019 by involving the IDP camps as a regular part of the communities to be treated, and selecting representatives of the camps to be trained as community-directed distributors. In total, 29 576 IDPs and 2190 refugees have been treated across these camps since 2019. The population of IDPs in Benue State continues to vary as IDPs are mobile and seek new places to live depending on where the best healthcare is attainable.

Going forward, for enhanced MDA coordination and planning, the programme will continue to work with IDPs and refugee representatives to jointly plan for greater inclusiveness and accessibility to services and treatments at all levels, which will ensure that no individual is left behind. The LNOB strategy will continue to be sustained in subsequent NTD interventions post the Ascend programme as a way of ensuring that NTD treatment is available to all eligible treatment populations, irrespective of where they reside.

This experience garnered some recommendations on how to support treatment provision among refugees and IDPs within Benue, Nigeria (Table 1). There is a need for NTD programmes to better understand the impact of conflict situations, natural disasters and other emergency situations on the potential of marginalising vulnerable populations. As such, innovative approaches, tools and other creative adaptions to programming including opportunistic partnering[9] are opportunities for learning.

[a]Benue State Emergency Management Agency is the responsible body for disaster prevention, mitigation, and response within Benue State.

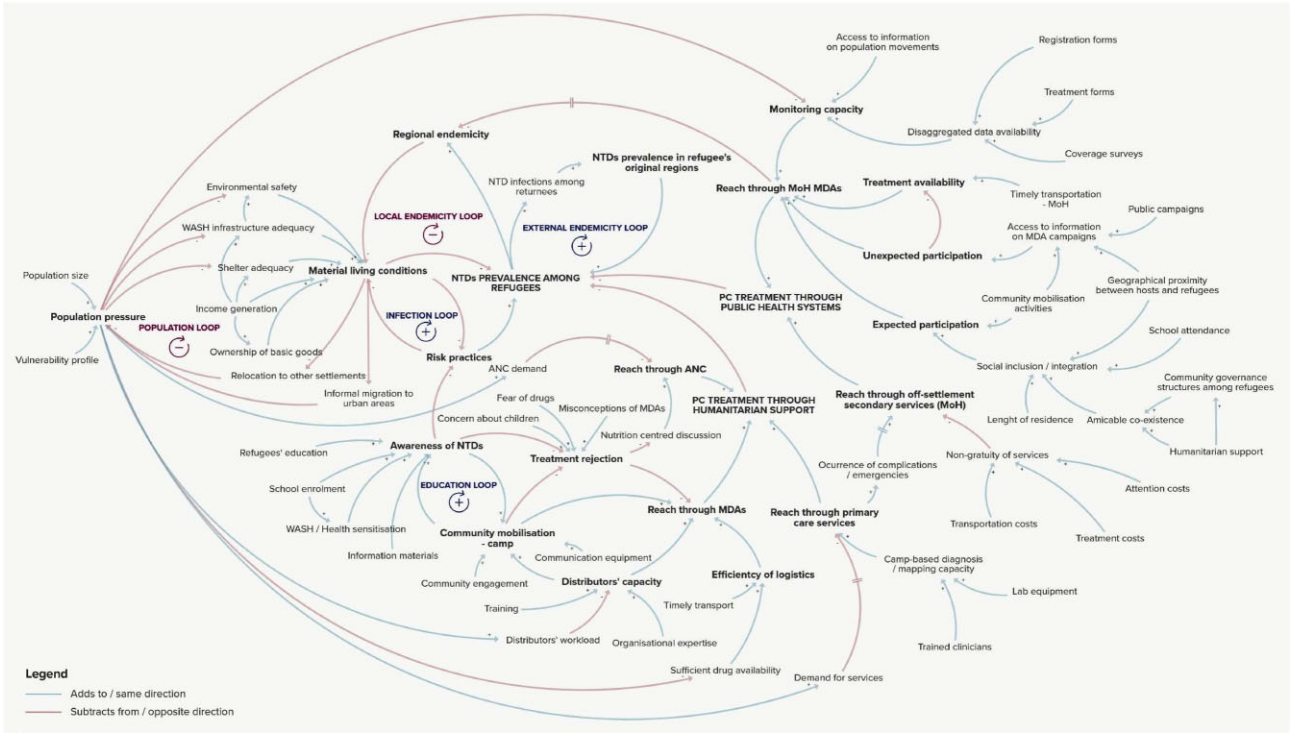


**Figure 1.** Complete causal loop diagram depicting the impacts and interactions shaping the system of PC provision for refugees in Niger.

## Strategising for improving access to services for refugees in Niger

As part of the Ascend Learning and Innovation Fund, which funds pioneering ideas to improve the quality of NTD programming, a research project led by the SCI Foundation was established to test the usage of systems-based modelling to explore strategies that may improve access to preventative chemotherapy for refugees in Niger.[b]

There are an estimated 245 000 refugees in Niger[10] and the volatile situation continues to escalate due to conflict within the Sahel and Lake Chad Basin regions. Refugees may reside in isolated areas with limited access to public health facilities and include various at-risk groups such as children, women, older people and people with disabilities. They are often forced to inhabit overcrowded settlements lacking suitable sanitation, which can heighten the risk of exposure to NTDs. There is also a further risk as the movement of people can introduce new NTDs where they were previously not prevalent.

From July 2020 to May 2021, a process of in-depth interviews was conducted with national-level and front-line stakeholders from the United Nations High Commissioner for Refugees (UNHCR), Ministry of Health and partner non-governmental organisations (NGOs), including health practitioners, water, sanitation and hygiene (WASH) experts and programme managers.[c] The project sought to identify the organisational, socioeconomic, informational and environmental factors that directly or indirectly impact refugees' access to preventive chemotherapy treatment through their multiple interactions. Data were systematised through a thematic analysis of described interactions and a modelling exercise utilising a causal loop diagram (Figure 1).

In the pilot camp visited, there was treatment provision through on-site annual MDAs, antenatal care services and primary care services. WASH-related community mobilisation and awareness-raising activities were reported but comparable NTD-focused activities appeared lacking. Diagnostics and mapping capacity was limited, while security concerns continuously threatened logistics for treatment provision. Treatment rejection was a barrier highlighted by informants, and in the public health system there is a lack of available disaggregated data that could serve to track this impact among refugees. Treatment registers did not record their participation.

The project outlined a series of recommendations on how to support preventive chemotherapy treatment among refugees in Niger (Table 2). Preparations are being made to share the model and recommendations with the relevant stakeholders involved to move towards validating the process through a knowledge exchange and to ensure the linkages are as precise as possible. This consultation process, to be conducted remotely, is expected to be conducted and completed by the end of 2021. This will be

[b]The full title of the research project led by the Schistosomiasis Control Initiative Foundation was "Promoting access to preventive chemotherapy for NTDs among refugees: a systems-based approach".

[c]In total, 23 national-level stakeholders and 32 front-line officers (including 16 health practitioners, 5 community-based agents, 5 WASH experts and 7 administrative staff) were interviewed.

**Table 2.** Main recommendations to support preventative chemotherapy treatment provision among refugees in Niger

| Key challenges | Recommendations |
|---|---|
| Information on population trends and distribution | (1) NTD programmes need to coordinate with the United Nations High Commissioner for Refugees (UNHCR) for access to the latest displaced population information and should reflect on obtaining disaggregated data on refugees within monitoring and evaluation (M&E) tools. |
| Endemicity | (2) Mapping surveys should be coordinated with the UNHCR in refugee settlements. Information on mapping surveys and treatment activities should be shared between NTD programmes in the Sahel and Lake Chad regions. |
| Supporting on-site treatment activities | (3) Humanitarian agencies can be supported through NTD programmes through sharing tested training modules with social inclusion embedded within, distributing sensitisation materials and utilising mass media tailored to the needs of the most vulnerable/at-risk. |
| Community-based humanitarian work | (4) Regional-level consultations with the UNHCR and partner NGOs (including participation from WASH and education sectors) should take place to share knowledge and resources on the participation of refugees in MDA campaigns. |
| Optimising frontline treatment activities | (5) District-level MDA planning should involve the UNHCR and partner NGOs to update the Ministry of Health on any ongoing activities and coordinate accordingly. Community distributors should be provided detailed guidance to manage the participation of refugees in MDAs. |

undertaken so that priority actions may be identified that can be taken forward in future NTD programme activities. Adopting a systems-thinking approach provides a more holistic oversight, which is useful in a dynamic context such as Niger.

## Key reflections for future programming

NTD interventions for displaced populations within national health systems are often not considered as public health priorities. This needs to be urgently changed within humanitarian contexts to ensure that displaced populations are not left behind. This also echoes the call for the integration of NTD programming into national health systems from the WHO 2030 road map.[2]

The Ascend programme has helped contribute to addressing issues of coverage and inclusion for IDPs and refugees by working within existing Ministry of Health structures and processes, and through fostering trust and collaboration. Although it has contributed to the development of innovative approaches to address inclusion issues, there is still a lot of progress that needs to be made to mitigate against low coverage in displaced populations. This is especially true in a global environment with the presence of COVID-19 and a reduced overseas development assistance budget. Embedding LNOB considerations into national NTD master plans could also provide both a foundation to encompass NTD activities within humanitarian frameworks, and act as an advocacy tool to mobilise financial resources. Some useful and valuable resources for delivering NTD interventions in humanitarian contexts are available such as the Neglected Tropical Disease NGO Network's resource guide for conflict and humanitarian emergencies[11] that collates global guidance to address these issues.

Overall, framing approaches to address the displaced population's participation in NTD activities through the lens of LNOB is imperative in placing a marked emphasis on being proactive in planning and implementation. Without a commitment to and action on LNOB, NTD elimination agendas may fall short of succeeding.

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