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Noma as a neglected tropical disease: an opportunity to reconsider neglect in global health

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SUMMARY BOX

⇒ The rise of neglected tropical diseases (NTDs) as a global health category has undoubtedly increased awareness of hitherto unknown health problems; an example of this is the recent incorporation of noma, a severe gangrenous disease of the mouth and face, in the NTD list.
⇒ Yet, the sustained participation of those directly affected by NTDs has not always been a central feature of global health discourses.
⇒ This commentary draws insights from a workshop which brought together representatives from advocacy, humanitarian and academic organisations working on noma and leprosy to discuss the process and political dimensions of disease framing and the challenges of overcoming neglect in global health.
⇒ Here we outline important steps that must be taken to address neglect through a more inclusive and person-centred approach.

Noma (cancrum oris or gangrenous stomatitis) is a severe gangrenous disease of the mouth and face. It is a non-contagious, opportunistic infection mostly affecting children aged 2–6 years and is linked to malnutrition, poor oral hygiene and weakened immune systems.[1] It is most commonly found in deprived and marginalised communities in sub-Saharan Africa, although cases have been reported elsewhere.[2] It is difficult to accurately estimate the number of cases due to the stigma associated with the disease, its rapid progression and high (90%) case-fatality rate, and poor health and surveillance systems.[3]

Noma is the latest addition to the WHO's neglected tropical disease (NTDs) list.[4] The process leading to noma's inclusion was neither straightforward nor quick, reflecting the complexities of WHO's NTD designation process. Nigeria became the main governmental champion of the initiative, with 32 member states lending crucial support and survivors playing an essential role in advocacy efforts.[5] Following a recommendation by the 17th meeting of the Strategic and Technical Advisory Group for Neglected Tropical Diseases (STAG-NTD) in December 2023, the WHO announced the inclusion of noma as the 21st disease in the NTD list.[4]

In the wake of this announcement, in May 2024, a workshop held in Geneva, Switzerland, brought together representatives from advocacy, humanitarian and academic organisations to discuss the process for declaring NTDs, its strengths and limitations, as well as the ways in which its potentialities can be realised. This was done against the background of a broader discussion about the political dimensions of disease framing and the challenges of overcoming neglect in global health. Among the participants were the co-founders of Elysium, the 'Noma Survivors Association', as well as representatives of The Leprosy Mission. The main conclusions from this discussion are presented below.

NTD RECOGNITION AND THE GOVERNANCE OF NEGLECT

The recognition of noma marks a significant milestone in the global health community's efforts to address diseases that disproportionately affect marginalised populations. NTD recognition is an important step, which undoubtedly increases political and even public awareness of diseases like noma. Nonetheless, it is far from being enough to address the neglect of these diseases and of the populations impacted by them. Labelling

a disease as 'neglected' does not automatically translate into political priority or action.[6] Recognition as an NTD does not necessarily reflect, much less create, the required political will to effectively address neglect. While NTDs are now part of the global health agenda, they remain a largely peripheral concern, without sufficient resources being allocated. The NTD label can and does increase visibility, but without the political will to back action and priorities, this visibility may not result in necessary resources or decisive policy changes. Moreover, NTD recognition is not a *fait accompli*. There is a need to continually advocate for the prioritisation of NTDs in political agendas, particularly in the context of ongoing discussions about priority setting in global health.[7]

Also, importantly, the sustained participation of those directly affected by NTDs has not always been a central feature of the governance of these diseases, even after they are recognised as NTDs.[8] Although there are notable examples of people with lived experiences of NTDs leading and shaping the agenda—such as in leprosy advocacy, where affected individuals have become prominent voices—these instances remain exceptions rather than the rule.[9 10] More often than not, people affected by NTDs have found themselves largely at the receiving end of NTD planning, programming and interventions, rather than actively shaping the policies that affect their lives.

This situation reveals two intertwined challenges in the global health community's approach to addressing neglect. First, the institutional processes required for recognition as an NTD are often disconnected from the lived experiences of those who suffer from these diseases. The designation process remains largely disease centred, with the everyday realities of affected individuals often relegated to a peripheral concern.[11] The 21 conditions currently classified as NTDs are medically, socially, culturally and economically diverse. While these diseases share certain characteristics, the experiences of the people affected by them are not uniform, and it is crucial to recognise that these individuals do not always speak with a single voice. Second, there is a lack of understanding about the impact that NTD recognition has on the people who experience these diseases. The inclusion on the WHO's NTD list is intended to enhance its visibility locally, nationally and internationally, thereby reducing the extent of neglect.[12] However, the reality is more complex. The reframing of a condition as part of NTDs, while useful for advocacy, can also inadvertently reinforce a static categorisation that fails to account for the dynamic nature of neglect, its multiple dimensions and the ways in which it is experienced, challenged and eventually overcome.

A PEOPLE-CENTRED APPROACH

The recent inclusion of noma on the NTD list provides an opportunity to reflect on how a people-centred approach could enhance the global response to neglected diseases. Such an approach is urgently needed. The WHO itself has emphasised the importance of person-centred and integrated health services, particularly the need to prioritise the perspectives of people with lived experiences of NTDs.[13] As Mathias Duck, Global Advocacy Manager for The Leprosy Mission, pointed out, the term 'neglected tropical diseases' might be more accurately described as 'diseases of neglected people'.[8] Such a shift in focus from the disease to the people affected by it could lead to a deeper understanding of what neglect means and its social, economic and cultural dimensions. It can also provide important insights into how neglect can be effectively challenged and overcome.

The need for a people-centred approach ties with another theme that emerged from our discussions: the importance of supplementing medical and epidemiological research in addressing NTDs. While such work is critical, there is an equally important need to focus on the political, socioeconomic and cultural contexts in which diseases like noma emerge, are experienced and where their aftermath is felt. As the co-founders of Elysium, the 'Noma Survivors Association', observed in the workshop, the 'neglect' of noma was most acutely felt in the life *after* disease.[10] This consideration of broader contexts should also include the political and governance processes related to WHO's NTD designation. We need, therefore, to draw on a broad range of knowledge and expertise, including local and indigenous knowledge, that can adequately engage with the lived realities of NTDs.

One of the workshop's discussions focused on the concrete implications of labelling a disease as neglected, and the way it can influence how the public and the people affected perceive the issue—and themselves. Narratives around NTDs often centre on themes of victimhood, tragedy and charity.[6] These narratives, while compelling, can diminish the agency and autonomy of those affected, reducing them to mere recipients of assistance rather than active agents in their own health outcomes. The terms we use to describe diseases and the people who suffer from them can shape perceptions and, by extension, influence policy decisions.

If people are to be centred in the NTD agenda, then we must re-examine the way diseases have been named and represented. Here, the viewpoints of people who have been affected by NTDs, and particularly those who have since taken up advocacy and campaigning, should be given due importance. The co-founders of *Elysium* emphasised the centrality of terminology in shaping their identity and advocacy

efforts. They noted that the term 'noma victim' is typically reserved for those who did not survive the disease, while 'survivor' is a term that better captures both their experiences and their ambitions. This choice of language underscores the importance of allowing people with lived experience to define their own identities and narratives, rather than having these imposed on them by external actors.

EQUITABLE, NON-EXTRACTIVE PARTNERSHIPS

From the perspective of campaigners, practitioners and academics, there is tremendous potential to develop more equitable, non-extractive and sustainable relationships between people who have been affected by NTDs, researchers and policymakers. The WHO's *Framework for Meaningful Engagement of People Living with Non-Communicable Diseases* could be a basis to also ensure involvement of people affected by NTDs.[14] Similarly, drafting recommendations for best practices in representing the experiences of people with NTDs—whether that be visually or discursively—could help shift the narrative towards one that emphasises agency and empowerment.

However, it is crucial to recognise that building trustful and mutually beneficial partnerships takes time, and such timelines and priorities may not always align with the schedules of research and humanitarian practice. Non-extractive partnership building must follow the pace set by those affected by NTDs, even if this requires a rethinking of conventional approaches to research and intervention.

Workshop participants called for sustained and systematic participation of those directly affected at every stage of research, policymaking and implementation. While this process can begin with thoughtful language use, it must also include concrete actions. For instance, involving people with lived experiences in the WHO STAG-NTD could ensure that their voices are heard at the highest levels of decision-making. Similarly, their involvement in the delivery, monitoring and evaluation of policies could lead to more effective and responsive interventions.

In conclusion, NTD designation is not as an endpoint; it must rather be seen as the beginning of a collaborative process. Each time a disease is recognised as an NTD, it opens a window of opportunity to discuss what neglect means and how it might be challenged and overcome. For the NTD category to have substantive meaning and the capacity to drive policy change, it needs to be much more than just a label. The designation should serve as the starting point for a broad discussion about the lived experience of disease and the multifaceted nature of neglect. Recognising the distinct dimensions at play when a disease is classified as an NTD—and when it is experienced and addressed—requires bringing political considerations back into the discourse. This means acknowledging the importance of language and representation and ensuring that the voices of those most affected by NTDs are central to every aspect of the global health response. By doing so, we can move beyond the label of neglect and towards a more inclusive, people-centred approach that truly addresses the needs of those who have been marginalised in global health.

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