

**NOMA, THE NEGLECTED DISEASE –
AN INTERDISCIPLINARY EXPLORATION OF ITS
REALITIES, BURDEN, AND FRAMING**

Abstract of the Executive Summary & Executive Summary

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ABSTRACT

Noma is a gangrenous disease that predominantly affects small children living in extreme poverty. With an untreated mortality rate of up to 90%, noma leaves survivors with significant aesthetic and functional sequelae. This collaborative, interdisciplinary research project aimed to achieve greater understanding of noma across three dimensions: its epidemiology, the realities and lived experiences of individuals at risk of and survivors of noma, and the utility for advocacy of its framing as a neglected tropical disease (NTD) and human rights concern. The project findings provide clear evidence that noma meets the formal criteria to be included in the World Health Organization (WHO) list of NTDs. Such formal inclusion would be a first step towards systematic and assumed action to prevent, detect and treat noma and redress the human rights violations suffered by survivors.

EXECUTIVE SUMMARY

Noma (*cancrum oris*) is a gangrenous disease that predominantly affects children aged 2-6 years living in extreme poverty. With a high untreated mortality rate estimated at up to 90%, noma leaves survivors with significant aesthetic and functional sequelae, suffering intense social isolation, stigmatisation and discrimination.

The interdisciplinary research project *Noma, The Neglected Disease – An Interdisciplinary Exploration of Its Realities, Burden, and Framing* (2019-2022) was led by the Global Health Institute of the University of Geneva, the Swiss Tropical and Public Health Institute in Basel and the York Law School & Centre for Applied Human Rights at the University of York and developed in close [partnership](#) with non-, inter- and governmental organisations and academic collaborators in Burkina Faso and Niger. The project's overarching aim was to achieve greater understanding of noma and engender action to prevent, detect and treat the disease and redress the human rights violations suffered by survivors. Our specific objective was to contribute, through research activities and outputs, to the inclusion of noma in the World Health Organization (WHO) list of Neglected Tropical Diseases (NTDs).

The project drew on three country case studies and employed a mix-method approach to research. It combined a systematic literature review, archival research of patient files from Burkina Faso, Niger and Laos, primary data-collection through a cross-sectional household surveys and semi-structured interviews with noma survivors and their families in Burkina Faso and Niger, doctrinal and socio-legal analysis and elite interviews with stakeholders in the noma agenda. The following findings, across the project's three analytical pillars, deserve emphasis.

Noma's epidemiology & global burden

- The systematic literature review confirms that most noma cases have been reported in West Africa, where noma programs are in place; it indicates a positive correlation between reported noma cases and the volume of literature per country. New countries with noma incidence or prevalence have been identified, especially, in Southeast Asia and Latin America. The global burden of noma could not be calculated due to the differences in quality and the limited geographical range of the studies identified.
- The number of patients found opportunistically in Laos, including patients with acute disease in the 21st century, suggests noma's endemicity in this country. The dearth of data on noma outside the African continent is likely due to the lack of sufficient research focus in Asia and Latin America, not due to noma's absence from these regions.
- In Burkina Faso and Niger, a yearly incidence of 2216 cases /100 000 could be estimated based on archival research of patient files of Sentinelles health centres. This rate is comparable or higher than the incidence of many other diseases formally recognised by the WHO as neglected.

Realities & lived experiences of individuals at risk of and survivors of noma

- Statistical analysis performed on 1134 socio-medical files of noma patients from Burkina Faso and Niger confirms, on much larger scale compared to previous findings, that noma overwhelmingly affects children who are part of large families that experience extreme poverty conditions. Similar to previous findings, malaria and malnutrition appear to be among the main risk factors of noma.
- In what concerns the diagnosis of noma, the data shows that, although 78.4% of parents/caretakers seek help during the first week from the onset of the disease, the majority of cases are diagnosed late (on average with 10.3 years). This delay in diagnosis can be explained by the failure of the actors consulted first to identify and diagnose noma, or differently put, by the lack of access to adequate healthcare. The analysed archival and

interview data, identify traditional healers and local health centres as the first points of call for families of children with noma. Hence, inter-, non- and governmental intervention should prioritise raising awareness among these actors.

- The multi-case study research has shown that the lived experiences of noma survivors are tragically universal, in that their lives are marked by stigmatisation, social exclusion and discrimination. Stigma is initially occasioned by a lack of awareness about the disease, sought to be caused by evil spirits or social transgressions; this morphs into action or inaction by state and non-state actors that in turn can amount to violations of an array of survivors' human rights. Our legal mapping has identified nine key human rights at stake – ranging from the right to life to the right to education –, whilst also emphasising possible corrective interventions consistent with the obligations of states under international and regional human rights law.
- The socio-economic costs of noma are staggering. Our analysis estimated direct costs of care and support for noma survivors to be around 30 million USD per year in Burkina Faso and 31 million USD in Niger; indirect costs to represent around 20 million of lost production in Burkina Faso and 16 million in Niger; and costs linked to premature deaths to account for more than 3.5 billion in Burkina Faso and 3 billion in Niger.

Noma's framing as a neglected tropical disease & human rights concern

- Since their emergence in a 2012 Study of the Human Rights Council's Advisory Committee, two main framings of noma have been used to advance advocacy around the disease: noma as an NTD and as a human rights concern.
- Literature and interviewed key informants have, overwhelmingly, emphasised the positive consequences of securing the inclusion of noma on the WHO list of NTDs across various dimensions: visibility, funding for research, access to existing surveillance and management infrastructure embedded at the WHO, and involvement of a variety of actors. When this research project began taking shape, the NTD framing of noma was primarily being debated in academic scholarship and amongst NGOs. Today, unprecedented momentum is gathering behind the campaign for noma's listing as an NTD by the WHO.
- The human rights framing of noma has also taken root amongst stakeholders in the international noma community, yet its embrace is tempered by concerns due to perceived political sensitivity. Our analysis includes reflections on enhancing noma's human rights framing. On the one hand, we observe that this framing can be presented in a less adversarial mode – affected states that choose to recognise and tackle noma are ultimately progressing the realisation of their obligations under international and regional human rights law. On the other hand, it becomes apparent that training on human rights-based approaches amongst actors in the international health and humanitarian fields could be useful. This may increase understanding of the importance of participation, ownership, and accountability – the principles underpinning human rights-based approaches – in noma programming design and implementation, and of centring those with experience of noma not only as victims, but also as agents of change.

Drawing on the work of, and in collaboration with, project partners and other stakeholders in the noma agenda, our research has provided clear evidence that noma meets the formal criteria to be included in the WHO NTD list. It would be particularly cruel to argue that the absence of perfect data in relation to a neglected disease makes it ineligible to be included in the list of neglected diseases. Noma's listing as an NTD is a first step in the direction of a systematic and assumed effort to tackle these gaps. As the campaign for this first goal progresses, we also need to consider what comes after. This research suggests that we must explore the complementarities between the NTD frame and the human rights frame.