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

**Final Scientific Report**

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DE GENÈVE**

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## ABOUT THE PROJECT

The collaborative research project *Noma, The Neglected Disease – An Interdisciplinary Exploration of Its Realities, Burden, and Framing* (hereafter, the Noma Project) commenced in October 2019 and formally concluded its work in March 2022.

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, the project was designed 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 aim 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).

This report discusses the findings of the research across its three analytical pillars: noma's epidemiology and global burden, the realities and lived experiences of individuals at risk of and survivors of noma, and noma's framing as a neglected tropical disease and human rights concern.

The report is based on substantive contributions and research by the project's coordinator Professor Emmanuel Kabengele Mpinga, co-coordinators Dr Mirko Winkler and Dr Ioana Cismas, principal research team members Marie-Solène Adamou Moussa-Pham, Dr Denise Baratti-Mayer, Dr Margaret Leila Srouf, Dr Peter Steinmann and Alice Trotter, and associate members Dr Gabriel Alcoba, Martin Bovay, Curdin Brugger, Anaïs Galli, Dr Emilien Jeannot, Dr Moubassira Kagone and Maïna Sani Malam Grema. Finally, we wish to acknowledge the contributions made by Dr Thomas Fürst to the project proposal and the initial stages of the project.

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The research team has relied on strong partnerships and collaborations with non-, inter-, governmental and academic key stakeholders. The project would have not been possible without their generous support. We extend special thanks to Fondation Sentinelles, Health Frontiers Laos, Hilfsaktion Noma e.V., Médecins Sans Frontières, SongES Niger, and the Winds of Hope Foundation & International No Noma Federation, and the Geneva Health Forum. We are also grateful to the United Nations Human Rights Council Advisory Committee, the United Nations Children's Fund in Niger, the World Health Organization, the Ministry of Health of Burkina Faso and the Programme National de lutte contre les maladies bucco-dentaires et le noma in Niger, the Centre Inter-facultaire en droits de l'enfant at the University of Geneva and the Centre de recherche en santé in Burkina Faso.

## THE WORK CONTINUES

Visit our webpage [www.thenomaproject.org](http://www.thenomaproject.org) and those of our partner organisations for updates on research and on-the-ground activities relating to noma.

## NOMA: THE NEED FOR DATA TO ENGENDER GLOBAL ACTION

Noma (*cancrum oris*) is a gangrenous disease that predominantly affects children aged 2-6 years living in extreme poverty. With an untreated mortality rate estimated at up to 90%,<sup>1</sup> noma leaves survivors with significant aesthetic and functional sequelae, suffering intense social isolation, stigmatisation and discrimination.<sup>2</sup>

The Noma Project is grounded in a literature review that has identified three interrelated **empirical and theoretical gaps in the current understanding of noma**, which in turn resulted in noma being trapped in a ‘vicious circle’ of neglect at institutional level. These analytical lacunae pertain to a) a lack of accurate, up to date empirical epidemiological data on noma, b) insufficient understanding about the experiences of individuals at risk and survivors of noma, and c) the absence of theoretical insights and empirical evidence concerning the utility of framing for noma’s advocacy.<sup>3</sup>

**Figure 1: Research packages and questions**

The Noma Project set out to address these gaps by answering the research questions listed in Figure 1 as part of three interdisciplinary research packages. All along our goal has been to build an evidence base for meaningful **inter-, non- and governmental policy interventions** aimed at the prevention and treatment of noma and the redress of human rights violations suffered by those at risk of noma and survivors. The inclusion of noma in the WHO list of NTDs is a first step of this process.

The present report presents our findings with reference to project activities, published outputs and forthcoming publications.

### **RP 1: Epidemiological evidence and global burden of noma**

- What is the current epidemiological evidence on noma in terms of geographic distribution, prevalence, incidence, mortality, remission/treatment/cure rates?
- What is the current global burden of noma in terms of DALYs?

### **RP 2: Experiences of individuals at risk of and survivors of noma**

- What are the key risk factors, social determinants and socio-economic costs of noma across the four case study contexts of the project (Burkina Faso, Niger, Laos, Europe & North America taken together)?
- How are the experiences of noma survivors impacting on the realisation of their human rights (health, food, housing, work, private and family life, and their right to equality and non-discrimination)?

### **RP 3: Framing of noma as a human rights issue and neglected tropical disease**

- Does the framing of noma as cause and effect of human rights violations contribute to greater awareness and action among stakeholders?
- Can the framing of noma as a WHO NTD contribute to better awareness and action among stakeholders?

## EPIDEMIOLOGICAL EVIDENCE AND GLOBAL BURDEN OF NOMA

To provide an accurate estimation of the epidemiological evidence and global burden of noma, the project sought to employ a mixed-method approach, comprising of: i) a systematic literature review; ii) an epidemiological analysis of existing patients’ records from the Sentinelles Care Centres in Burkina Faso and Niger; iii) a cross-sectional household survey in Burkina Faso and Niger; and iv) a prevalence and retrospective incidence analysis in Laos.

### *i) Systematic literature review of recent studies*

The comprehensive systematic review of existing literature was conducted in alignment with the requirements laid out in the PRISMA statement.<sup>4</sup> For the search of peer-reviewed and grey literature we accessed ten databases, including PubMed, ISI Web of Science and Scopus. To identify any additional literature, we hand-searched bibliographies of included studies and reference papers on noma and consulted experts. We did not apply any language, time, or study type restrictions for the searches. In the subsequent steps of the systematic literature review, we reviewed all documents and

<sup>1</sup> WHO, ‘Promoting Oral Health in Africa: Prevention and control of oral diseases and noma as part of essential noncommunicable disease interventions’ (Brazzaville, WHO Regional Office for Africa 2016).

<sup>2</sup> D Baratti-Mayer et al., ‘Noma: an “infectious” disease of unknown aetiology’ 3(7) *The Lancet Infectious Diseases* 419 (2003); ‘Study of the Human Rights Council Advisory Committee on severe malnutrition and childhood diseases with children affected by noma as an example’ (24 February 2012) UN. Doc. A/HRC/19/73 1 (Hereafter, HRCAC Study).

<sup>3</sup> See SNIS Full Proposal C19086, Noma, The Neglected Disease. An Interdisciplinary Exploration of Its Realities, Burden, and Framing, Research Plan, Geneva/Basel/York, May 2019, pp. 3-9; See also the ‘What We Do’ section on [www.thenomaproject.org](http://www.thenomaproject.org) website.

<sup>4</sup> ‘Preferred Reporting Items for Systematic Reviews and Meta-Analysis’ (PRISMA Statement Expert Group 2019), <http://www.prisma-statement.org/>

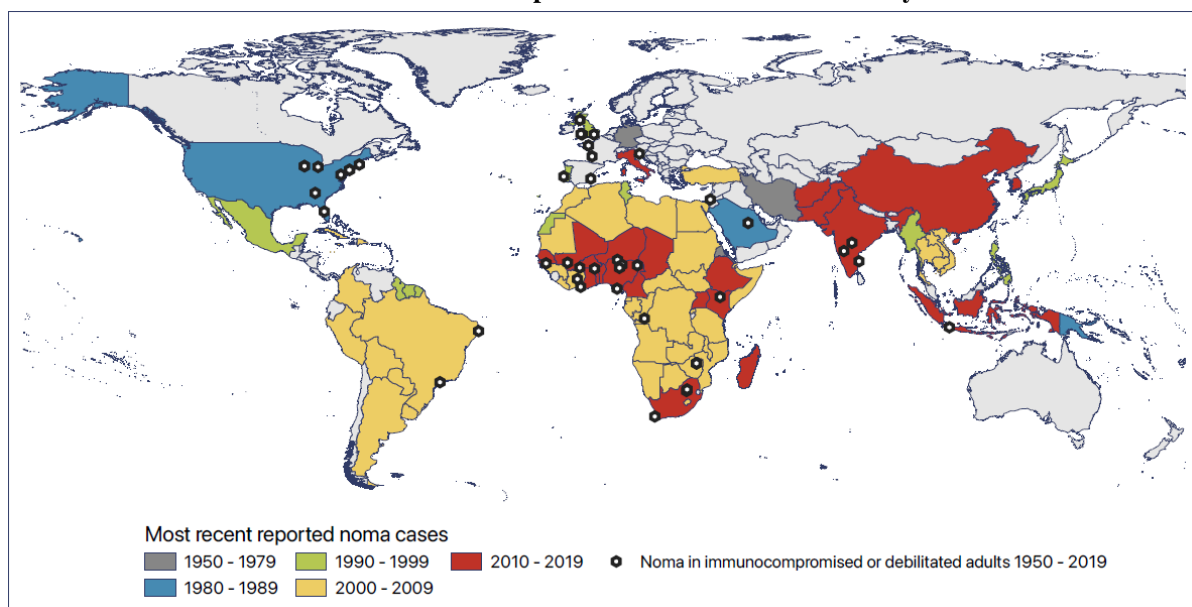


extracted the following characteristics: study type, study area, year of the study, study population, incidence, prevalence, mortality, sequelae, disease stage, treatment, remission/cure rates and diagnostic/verification techniques. In addition, we assessed the quality of the included case-control studies by applying the Newcastle-Ottawa Scale.<sup>5</sup> Based on the data extracted, we created world maps to visualize the reported global epidemiological information of noma, including a classification of endemic countries according to the time of the most recent reported noma case among children.

In this first systematic literature review focusing on the global incidence and prevalence of noma, which was published in *Lancet Infectious Diseases*,<sup>6</sup> we identified a total of 4238 unique documents by applying the search strategy to the different databases, and another 21 documents were identified by hand-searching reference lists and through recommendations of experts. Of those papers, 283 were eligible for producing world maps showing the occurrence of noma cases at global, national and sub-national levels.

We found that most noma cases have been reported in West Africa, where noma programs are in place (see Figure 2), and observed that the number of reported noma cases correlates with the volume of literature per country. In comparison with previous reports on global noma epidemiology, our systematic literature review identified new countries with noma incidence or prevalence, especially in Southeast Asia and Latin America.

**Figure 2: Reported global occurrence of noma cases from 1950 to 2019 based on the last reported noma case in each country<sup>7</sup>**



Another important finding of the study is that high-quality epidemiological data on noma is extremely scarce: most publications are case reports and case series, only one study used a randomised sampling strategy to assess noma prevalence,<sup>8</sup> and no population-representative mortality data could be identified. Although no new estimate of the global incidence and prevalence of noma could be calculated due to the differences in quality and the limited geographical range of the studies identified, our systematic literature review is an important new piece of evidence to promote the inclusion of noma in the WHO list of NTDs. It speaks directly to the fourth criteria set out in the Recommendations of the WHO Strategic and Technical Advisory Group for Neglected Tropical Diseases (STAG – NTDs):<sup>9</sup> noma is relatively neglected in global health research, with negative consequences on developing new diagnostics, medicines and control tools.

<sup>5</sup> G Wells et al., 'The Newcastle-Ottawa Scale (NOS) for assessing the quality of non-randomized studies in meta-analysis', 2000, [http://www.ohri.ca/programs/clinical\\_epidemiology/oxford.asp](http://www.ohri.ca/programs/clinical_epidemiology/oxford.asp).

<sup>6</sup> A Galli, C Brugger MSc, T Fürst, N Monnier, M S Winkler, P Steinmann, 'Prevalence, incidence and reported global distribution of noma: systematic review of recent studies', *Lancet Infectious Diseases* (2022). <sup>7</sup> Ibid

<sup>8</sup> E. Farley et al. 'The prevalence of noma in northwest Nigeria', *BMJ Glob Health* 5(4) (2020).

<sup>9</sup> WHO STAG – 'NTDs, Recommendations for the Adoption of Additional Diseases as Neglected Tropical Diseases', [https://www.who.int/neglected\\_diseases/diseases/Adoption\\_additional\\_NTDs.pdf](https://www.who.int/neglected_diseases/diseases/Adoption_additional_NTDs.pdf)

## ii) *Epidemiological analysis of existing patient records from Burkina Faso and Niger*

The Sentinelles Foundation has generously provided the Noma Project researchers with access to its archive of records of noma patients who had received treatment at their care centres in Burkina Faso and Niger since the 1990s. The archive consisted of over 1500 socio-medical surveys (370 for Burkina Faso and 1206 for Niger), of which 1134 files were inputted in a database designed by the researchers<sup>10</sup> – the remaining files were excluded because they were incomplete.

To estimate the retrospective incidence of noma, based on the rate of consultation at Sentinelles care centres in Burkina Faso and Niger, we included in the analysis the acute cases having consulted from 1997 to 2018. The yearly rate of consultation during this period runs from a minimum of 10 cases in 2015 to a maximum of 44 in 2013, and the mean is 27.7 cases/year. Taking into account that the mortality is 90%<sup>11</sup> and that only 12.5%<sup>12</sup> of survivors will consult a health centre, we can, by using the methodology described by WHO<sup>13</sup> estimate a yearly incidence of 2216 cases /100 000. This significantly high incidence can be explained by the fact that, unlike previous estimations, our sample takes in account noma stage 1, including therefore children who are at risk to develop noma if not taken in charge by health facilities. This rate is comparable or higher than the incidence of many other diseases formally recognised by the WHO as neglected.

## iii) *Cross-sectional household survey in Burkina Faso and Niger*

A cross-sectional household survey was conducted to establish the prevalence and incidence of noma in Burkina Faso and Niger. We owe a debt of gratitude to Sentinelles and Hilfsaktion Noma e.V. for supporting the research financially and logistically in Burkina Faso and Niger, respectively. Methodologically, the clusters' selection process began by selecting randomly 450 households (30 households from 15 different sanitary districts) in Burkina Faso and in Niger, based on three levels of random selection. Because of the delicate security situation in the Sahel region, we relied on the advice of country field experts, to identify sanitary districts considered safe for the implementation of the surveys. Pursuant to this, first we used [www.randomize.com](http://www.randomize.com) to select 15 'safe' sanitary districts per country, and in each of the districts one commune (town or village) and two additional back-up communes, should any problems occur during the fieldwork. Second, by using Google Earth Pro (GEP), a square grid was applied on each of the geographic locations of the 45 communes. Third, from each of the communes' grids, one square was randomly selected using again [randomize.com](http://www.randomize.com), and two back-up squares. If the initially selected square did not possess 30 households, the next square to the right was chosen until there were sufficient households to conduct the survey.

The surveys were conducted between June and July 2021 in Niger between October and November 2021 in Burkina Faso by priorly trained teams of four field surveyors. They used KoboTool on smartphones to fill in the predesigned database. District authorities and chiefs of communes in both countries gave their consent to the survey being conducted, and each household representative signed a free and informed consent form after having been briefed in detailed about the research, the purpose of the data collection, and their right to withdraw from the research. The field teams conducted 450 surveys in Burkina Faso and 452 in Niger for a total of 902 surveys, against a difficult security situation and logistical strains posed by the Covid-19 pandemic. The database thereby created is, to our knowledge, a unique achievement – we are hopeful that, once the data analysed and the results published in 2022, our research will provide significant information on the prevalence of acute noma and noma survivors, and the retrospective incidence for the last 10 years.

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<sup>10</sup> The database includes general information on the patient and the disease, health care access, family composition, diet, hygiene, family income, living conditions, education, marriage, work, impact of noma on the child's life and on the family and family dynamic.

<sup>11</sup> See WHO Afro, 'Evaluation of the WHO Africa Regional Programme on Noma Control (2013 - 2017)' (2019), <https://www.afro.who.int/publications/evaluation-who-africa-regional-programme-noma-control-2013-2017>

<sup>12</sup> See LM Srour et al., 'Noma: neglected, forgotten and a human rights issue', *International Health* 7(3) (2015).

<sup>13</sup> DM Bourgeois et al., 'Epidemiology of the incidence of oro-facial noma: a study of cases in Dakar, Senegal, 1981-1993', *The American Journal of tropical medicine and hygiene*, 61(6) (1999).

Some preliminary findings can already be reported. For example, the survey highlighted a regional noma prevalence of three per 100 people in Burkina Faso and seven per 100 people in Niger for the last five years. Furthermore, over 71.5% of the survey households indicated that they do not know the cause of the disease – if missing data is interpreted as ‘not knowing the cause’, then the percentage is even higher (89.1%). Figure 3 indicates that even among those respondents that had indicated that they know the possible risk factors of noma, misinformation persists. This will be a significant finding, which should inform programmes for the prevention of noma in endemic countries.

**Figure 3: Possible risk factors of noma as identified by survey respondents**

Lack of oral hygiene
General lack of hygiene
Promiscuity in combination with a lack of oral hygiene
Using water from the pond or river
Malnutrition
Evil bush spirits (‘wound is their way out of the body’)
Food debris and sugary foods
Transmission via saliva during eating from the same plate
Not sufficiently washed or cooked food
Smoking
Mother to child contamination
Using water that has been stored for too long

#### *iv) Prevalence and retrospective incidence analysis in Laos*

We conducted a retrospective review of data collected to monitor patient care from 50 noma patients in Laos who presented for care primarily at Mahosot Hospital from 2002-2020. The data includes sociodemographic characteristics, information on the patients’ acute illness, mouth opening before and approximately one year after surgery, the survivors’ quality of life prior to care being sought and after surgery, and the names that survivors and their families used to describe the disease. The patients were interviewed before and at least one year after their surgery.

At the stage of planning, we estimated that we may be able to calculate noma’s prevalence and retrospective incidence, and a burden of disease in Laos based on 10% survival and on the fact that only 10% of survivors present for treatment. This would have meant that each case might represent 100 cases of unreported noma. However, the below reflections on the spread of disease over five decades in Laos suggest that this estimate would be overly speculative.

The Lao noma survivors’ cohort may not be representative of the burden of noma in Laos for several reasons. First, the patients were identified opportunistically, when they came to the capital city in response to posters or social media offering free treatment. Since all survivors came from remote villages, it is unlikely that the news of treatment possibilities reached all of them. They were offered free care and reimbursed for transportation and food costs of the patient and caregiver; however, they needed to find the money to travel in the first place, which may have been impossible for some. The majority had waited decades from the time of acute disease in early childhood, before seeking care. Second, the noma survivors reported the onset of disease between 1962-2005, a time of tremendous changes, including the devastations of war, and significant economic growth in recent years, so the risk factors per year are not equal. Finally, determining noma incidence and prevalence is very challenging as the acute untreated mortality is estimated to be 80-90%; until 2008 and the first publication of noma in Lao, the Lao Ministry of Health reported no noma in the country and young children’s deaths from noma were not recorded as such.<sup>14</sup>

Despite these limitations, which prevented us from identifying a disease burden, this research is highly significant as the number of patients found opportunistically in Laos, including patients with acute disease in the 21<sup>st</sup> century, suggests noma’s endemicity in Laos. The dearth of data on noma outside the African continent is likely to be explainable due to the lack of sufficient research focus in Asia and Latin America, not due to noma’s absence from these regions.<sup>15</sup>

<sup>14</sup> See ML Srouf, et al ‘Noma in Laos: Stigma of Severe Poverty in Rural Asia’, *Am. J. Trop. Med. Hyg.*, 78(4) (2008).

<sup>15</sup> ML Srouf, E Farley, EK Empinga, ‘Lao noma survivors: a case series, 2002-2020’, *Am. J. Trop. Med. Hyg.* (2022).

## EXPERIENCES OF INDIVIDUALS AT RISK AND SURVIVORS OF NOMA

To explore the experiences of people at risk of developing noma and those who have survived the disease, this research package combined several different methods of investigation. These included: i) statistical analysis of patient files in Burkina Faso and Niger; ii) semi-structured interviews conducted with children, adults and families affected by noma in Niger and Burkina Faso; iii) analysis of patient files from Laos; iv) a legal analysis of the human rights vulnerabilised when children develop noma and the obligations states bear towards them; v) a socio-economic cost estimation of noma.

### *i) Statistical analysis of Sentinelles health centres' patient files*

As noted earlier, we created a database containing 1134 socio-medical files of patients that had been treated by Sentinelles health centres in Niger and Burkina Faso. Figure 4 provides general information about the patients' profile, family and living conditions. Statistical analysis performed on this data confirms, yet on a much larger scale, previous findings according to which noma overwhelmingly affects children who are part of large families that experience extreme poverty conditions.<sup>16</sup>

**Figure 4: General information, family and living conditions**

Country of origin	87.8% (Niger); 10.7% (Burkina Faso); 1.5% other countries (mostly, Nigeria)
Location	86.8% lived in a rural environment; 13.2% in an urban area
Gender	56% females; 44% males
Access to healthcare	Mean distance from home to first healthcare facility: 9.6 km (range 1-140) Mean distance from home to Sentinelles/ hospital: 132.5 km (range 1-1125)
Family profile	Mean number of persons in the family: 8.6 (range 1-52). Mean number of children/mother: 4.8 (range 1-14) with 1.6 children dead (range 0-9) Mean sibling's rank for children with noma is 4.7 (range 1-14) Main caretaker mother (71.3%); grandmother (18.2%); father (5.3%); someone else (5.1%)
Living conditions	Mean number of living spaces/rooms: 2.5 2.3% of families have direct access to electricity 17.2% have access to water directly at their home 69.3% share their living space with livestock

In what concerns the diagnosis, our data shows that the majority of cases are diagnosed late, on average with 10.3 years. This finding conceals significant negative impacts. Given noma's fulminant development and high mortality rate, the prospect of a late diagnosis is devastating for those who develop the disease. Those who survive must live a long time with sequelae and often face associated discrimination.

The results also show that 78.4% of parents seek help during the first week from the onset of the disease and among them 37.5% during the first 2 days, 13% consult at 2 weeks, 7.1% at 1 month and 1.5% more than two months and even years after the acute phase of the disease. Interestingly then, the vast majority of parents (78.4%) seek help for their children quite early on. Yet only 10.2% reach a specialised care centre for noma during the first week from the disease's onset, with the rest having consulted Sentinelles centres at stages 3-5.

This delay can be explained by the number of consultations of health facilities that had failed to identify and diagnose noma. In fact, before reaching Sentinelles, 45.9% of parents consult once, 34.6% twice, 17.6% three times and 2% 4 times other facilities. These include traditional healer (65.6%), *centre de santé intégré* (63.7%), regional hospitals (37%), district hospital (32.5%) and village-based *case de santé* (23.8%).

<sup>16</sup> D Baratti-Mayer et al, 'Risk factors for noma disease: a 6-year, prospective, matched case-control study in Niger' *Lancet Glob Health* (2013); E Farley et al, 'Noma (cancrum oris): A scoping literature review of a neglected disease (1843-2021)' 15(2) *PLoS Neglected Tropical Diseases* (2021).

**Figure 5: First signs/symptoms determining parents to seek help**

Gingival issue (57.9%)
Facial swelling (45.4%)
Fever (39%)
Poor general state (7.3%),
Facial/mouth necrosis (13.2%),
Facial hole (8.4%).
Other: halitosis, hypersalivation, oral aphthous lesions or diarrhoea

to notice them (36.9%), refusal to seek health care support by someone in the family (17.5%) (generally the father or the grandmother) and financial reasons (9.4%).

Similar to previous findings, malaria and malnutrition seem to be risk factors of noma.<sup>18</sup> Other health conditions reported by families and/or carers to have preceded noma are listed in figure 6.

**Figure 6: Health conditions reported to have preceded noma**

Malaria (37.6%)
Malnutrition (25%)
Fever (16.4%)
Measles (10.5%)
A gingival problem (8.7%)
Diarrhea (4.9%)
Whooping cough (4.1%)
A dental issue (2.6%)

The mortality in the sample was 5.6% or 63 cases. This is likely an underestimate as missing data are not excluded. It is also important to note that this reflects the mortality of noma children who have been taken in charge medically at Sentinelles health centre. Therefore, it does by no means reflect the mortality of noma itself. Mortality differed according to the stage of noma: very low at stage 1 (only one case), increases from stage 2 (11 cases or 17.5%) to stage 3 (28 cases or 44.4%) and decreases at stage 4 when the scarring process starts (19 cases or 30.2%) and stage 5 (2 cases or 3.2%), which is the stage of sequels, where mortality is probably due to other intercurrent reasons.

## ii) *Semi-structured interviews with survivors and families in Burkina Faso and Niger*

30 semi-structured interviews were conducted in Burkina Faso in December and March 2021 and 29 in Niger in April 2021. The majority of the research participants were randomly selected from patient databases of our project partner Sentinelles; these include patients with post-acute noma, children and adult patients awaiting surgery, children and adults who had been operated on, and family members whose children passed away from noma or associated illness. Additionally, a small number of healthcare workers, teachers, religious leaders, and municipal and community counsellors were also interviewed.

A thematic examination of the collected data in relation to the disease's first symptoms and consultation confirms and refines the understandings gained from the statistical analysis. In Burkina Faso, the knowledge of patients and their families about noma's causes and first signs is lacking; predominantly they thought that evil spirits are responsible for noma's onset. A similar pattern can be identified among the responses provided by research participants from Niger – 53.6% of the interviewees believed that noma is the result of a social transgression or an evil force, with a greater preponderance among interviewees from the rural areas. Interestingly, an interpretation of this finding, anchored in anthropological insights, suggests that the cultural beliefs on noma resulting from evil spirits or being God's will, may represent a means to building resilience for carrying the heavy (social) burden of the disease. In Burkina Faso, most patients have first sought help from a traditional healer. In Niger, the respondents noted that the first port of call was the grandmother, as the custodian of a family's tradition, followed by traditional healers, and medical centres when the disease evolves to later stages.

<sup>17</sup> For e.g., D Baratti-Mayer et al., 'Sociodemographic Characteristics of Traditional Healers and Their Knowledge of Noma: A Descriptive Survey in Three Regions of Mali', *Int J of Environmental Res and Public Health* 16(22) (2019).

<sup>18</sup> D Baratti-Mayer et al., supra note 16.



Another main finding of the semi-structured interviews relates to the stigmatisation and discrimination experienced by children and adults with noma. In Burkina Faso, respondents with visible noma sequelae recalled being cast away from social events, suffering insults, being unable to find a spouse or being verbally mistreated by their in-laws, and experiencing difficulties in their income generating activities. Those with pronounced noma sequela cover their face in public in an effort to avoid stigmatization. Some respondents mentioned having considered suicide due to social stigma – given that in many African cultures suicide is widely condemned at societal level, this shows how profound the impact of the experienced stigmatisation and rejection. In Niger, the interviews similarly revealed that noma sequelae will almost always result in the stigmatisation of the survivor, their rejection by their community and at times by their own family. Many respondents dropped out of school because other students would ridicule them or, in one case, because a teacher refused to teach them. 42% of interviewees (12 patients out of 28) mentioned being victims of violence because of their physical appearance. In conclusion, and as noted more in depth below, noma survivors experience direct and indirect discrimination transversally affecting an array of human rights.

### *iii) Retrospective review of data collected in Laos*

The study which focused on a cohort of Lao noma patients confirms findings relating to the age of noma's onset and the stigmatisation experienced by survivors. They were aged between 2 and 7 years when the first symptoms appeared and had to wait decades before being surgically treated. These decades of suffering from facial disfigurement during childhood and adolescence frequently led to stigma resulting in social isolation, excessive questions about their physical appearance, bullying, and self-consciousness. After surgery, patients reported significant improvements in the quality of their lives: acceptance in their communities, ability to socialize, get married and have families, and to seek employment.

The Laos study is uniquely important as it demonstrates that noma survivors on different continents experience very similar realities – the shared experiences range from the similar age range when the disease erupts, to difficulties in accessing adequate healthcare, to stigmatisation and discrimination in the absence of surgical treatment.

### *iv) Legal analysis of affected human rights & states obligations*

In 2020, we developed a legal doctrinal background study with focus on Burkina Faso, Niger and Laos in which we mapped the international and regional human rights framework relevant to the experiences of children at risk of noma, as well as children and adult survivors of the disease.<sup>19</sup> Our aim was to update and expand the Human Rights Council Advisory Committee (HRCAC) Study on severe malnutrition and childhood diseases with children affected by noma as an example, which was the first iteration of a human rights analysis of noma's implications.

Findings from the statistical analysis on Sentinelles patient files, semi-structured interviews conducted in Burkina Faso and Niger, and the Laos patients' study enable us to provide clear evidence of violations of a panoply of survivors' human rights and their right to non-discrimination. For example, the right to education has been identified as one of the human rights at risk in the context of noma.<sup>20</sup> Analysis of the Sentinelles patient files goes some way to providing statistical evidence for this conclusion. The percentage of children with sequelae of noma who did not attend school before reconstructive surgery decreased significantly once the surgery had been completed, from nearly 29% to just under 6%. Whilst it must be recognized that the children were not of school-age when they developed acute noma and that Sentinelles are active in the promotion of schooling to patients' families, these results nonetheless represent an illustration of the extent of the social stigma attached to noma. This is reinforced by qualitative data obtained from interviews conducted in Burkina Faso and Niger with survivors of noma. Another aspect which deserves mentioning is that

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<sup>19</sup> A Trotter & I Cismas, *Noma & Human Rights Law – A Doctrinal Legal Analysis with Focus on Burkina Faso, Niger and Laos, Background Study*, 2020, <https://static1.squarespace.com/static/5e624ea1b53d653768470cb6/t/6089546457c5ef56f07fc311/1619612778742/Noma+%26+Human+Rights+Law+background+study.pdf>

<sup>20</sup> See e.g., HRCAC Study; A Trotter & I Cismas, *supra* note 19.

discrimination is, at times, perpetuated by state actors (e.g. teacher in a public school), but often by non-state actors such as members of communities or the family. In this latter case, states have an obligation to protect against discrimination.

Notwithstanding the limitations imposed by the high non-response rate to discrimination-related questions in the patient files, their analysis alongside the findings of the legal mapping provides a unique insight into the importance of early intervention and education.

#### v) *Socio-economic cost estimation*

Three main approaches were used to calculate the socio-economic cost estimation of noma: an estimation of prevalence level drawing on the systematic literature review, an analysis of Sentinelles's patient database, whilst the estimation of indirect costs was carried out by using the human capital method and the cost component analysis technique.<sup>21</sup> The research to be published in a forthcoming article<sup>22</sup> has estimated that the direct costs of care and support for noma survivors amount to around 30 million USD per year in Burkina Faso compared to around 31 million USD in Niger. They mainly include the costs of medical treatment, physiological and psychological care, social assistance, schooling and professional training and care abroad. Indirect costs are estimated at around 20 million lost production costs in Burkina Faso and around 16 million in Niger. Those linked to premature deaths are estimated at more than 3.5 billion in Burkina Faso and 3 billion in Niger.

### FRAMING OF NOMA AS A HUMAN RIGHTS CONCERN AND AN NTD

Our research combined a review of the literature and 20 key-informant interviews with stakeholders in the noma agenda. Participants in the interview process were practitioners in the medical, human rights, and humanitarian fields, as well as representatives of non-, inter-, and governmental organizations working on noma. A series of conclusions have been formulated from the findings of this research package, which will be published in a forthcoming article.<sup>23</sup> These may be used to inform and enhance current and future advocacy around noma as a human rights issue and NTD.

When asked to describe their understanding of noma as a human rights issue, a majority of key informants engaged in a violations-based frame. This suggests that, in the decade following the publication of the HRCAC Study, a human rights-based understanding of noma is taking root amongst stakeholders in the international noma community. There was, however, consistent concern amongst participants about the political sensitivity with which some endemic states may perceive the human rights framing of noma. The following reflections point to several areas where the human rights frame may be enhanced. First, to effectively target national governments, there is a need to adjust the focus of the human rights framing of noma. Action on noma – whether it be case surveillance, community education or healthcare training – could be presented as states taking steps towards realizing their obligations under international human rights law. Interestingly, Nigeria has recently presented its work on noma in precisely such human rights terms.<sup>24</sup> Second, the responses of our participants indicated a need for training on human rights-based approaches (HRBAs) amongst actors in the international health and humanitarian fields themselves. Doing so may increase understanding of the importance of participation, ownership, and accountability – the principles of HRBAs – in programming and practice and centring those with experience of noma not only as victims, but also as agents of change. Finally, the violations-based frame of noma should not be discarded entirely. This became evident through our engagement with the reporting system of the UN treaty bodies, where the Committee on the Rights of the Child questioned Eritrea during its 2020 reporting cycle

<sup>21</sup> SD Grosse & KV Krueger, 'The Income-Based Human Capital Valuation Methods in Public Health Economics Used by Forensic Economics', *Journal of Forensic Economics*, 22(1) (2011); JM Kirigia, RDK Muthuri, NG Muthuri, 'The Monetary Value of Human Lives Lost to Suicide in the African Continent: Beating the African War Drums', *Healthcare* 8(2), (2020); JS Landefeld JS & EP Seskin, 'The Economic Value of Life: Linking Theory to Practice', *Am J Public Health*, 72(6) (1982).

<sup>22</sup> EK Mpinga, et al, 'Economic and Social Costs of Noma: Design and Application of an Estimation Model for Niger and Burkina Faso', *Tropical Medicine and Infectious Disease* (forthcoming 2022).

<sup>23</sup> A Trotter & I Cismas, 'Framing Noma: Human Rights & Neglected Tropical Diseases as Paths for Advocacy', *Tropical Medicine and Infectious Disease* (forthcoming 2022).

<sup>24</sup> COP 26 Satellite Conference 2022, 'Day 1 - Climate Change, Oral Health and Sustainability' (University of Glasgow, 2-4 November 2021).

about the national prevalence of noma. Whilst Eritrea did not recognize the existence of cases within its border, this example suggests that UN monitoring mechanisms have the ability to put a spotlight on noma when states are reluctant to acknowledge its existence and impacts on individuals.

Two main findings, which draw on desk-based research and key informant interviews, demonstrate that the NTD frame would (or rather does) undoubtedly contribute to enhancing awareness and action amongst stakeholders. First, securing recognition on the WHO list of NTDs was considered by participants to be an overwhelmingly positive prospective for the noma agenda – as one participant observed, this will likely secure ‘more visibility for the disease, more funding, and therefore [the involvement] of more actors.’ For several participants, a key factor in forming this opinion was the extent to which NTDs have been established as a global health ‘brand’. Securing access to the research, surveillance, and management infrastructure embedded at the WHO was considered highly beneficial to the noma agenda. It would also attract attention and increase action at the international, national, and local level. Second, when this research project began taking shape, from 2018 onwards, the NTD framing of noma was primarily being debated in academic scholarship and amongst NGOs. There was little evidence of these discussions taking place at the WHO or among states. At the conclusion of the project, some two and a half years later, we have found that the NTD framing of noma is on its way to becoming a reality. Through conversations with our interview participants, it became clear that unprecedented momentum is gathering behind the campaign for noma’s listing as an NTD by the WHO. This is being reflected in the wider narratives circulating through the international noma community. Noma was, for example, mentioned in a 2021 oral health resolution by the World Health Assembly, earmarked for potential inclusion in the next NTD roadmap.<sup>25</sup>

## CONCLUSION AND OUTLOOK FOR FURTHER EXPLORATION

This project, through its activities, outputs, and the present report has provided clear evidence that noma meets the criteria to be included in the WHO NTD list: whilst generally neglected by research, noma affects populations in tropical and sub-tropical areas in Africa, Asia and Latin America who experience extreme poverty conditions. It causes high mortality and morbidity rates, and results in significant socio-economic costs. Survivors experience significant stigma and discrimination. All the while, noma is amenable to integration into existing health structures and systems.

Equally, our research has revealed that further areas of exploration on noma include its disease burden and distribution, and targeted awareness raising and educational programmes, and public health interventions for its prevention. Noma’s listing as an NTD is a first step in the direction of a systematic and assumed effort to tackle these aspects. 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.

As the campaign for noma’s listing as an NTD 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. The political connotations of human rights, some of our research participants argued, would detract from the achievement of NTD status, as governments of affected states would be unwilling to buy-in into the narrative. However, the findings of this research indicate that this is not the case – much rather, the NTD and human rights frames of noma are complementary. Indeed, consistent incorporation of human rights-based approaches in health programming will not undermine the delivery of effective case surveillance and management. Rather, such incorporation will expand the capacity of interventions to also capture and address the social realities of noma. As our findings confirm, people affected by noma are likely to encounter instances of discrimination and social isolation, whilst also possessing unique insights on what and how change should happen. Applying a rights-based approach to programme design and implementation will, as one participant suggested, focus attention on ‘the social, economic, and cultural dynamics that are truly behind the stigma and discrimination’ of neglected diseases, including noma.

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<sup>25</sup> World Health Assembly (74<sup>th</sup> session) ‘Oral Health Resolution’ (Geneva, 13 May 2021) WHA 74.5, 3(6).