ISSN: 2755-6468

Research Article

Open Access Journal of Clinical Pathology Research

Prevention and Integrated Management of Noma and Maxillofacial Diseases in Burkina Faso, Mali, Madagascar and Togo (2018 – 2028) – Lessons Learnt and Challenges – Preliminary Results

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Received: September 10, 2025; **Accepted:** September 18, 2025; **Published:** September 25, 2025

ABSTRACT

Noma is a rapidly progressive, preventable orofacial gangrene affecting malnourished children in low-resource settings. La Chaîne de l'Espoir has implemented a multi-country programme on Noma and maxillofacial conditions (PMF) in three phases: 2018–2021 (phase 1), 2021–2024 (phase 2) in Burkina Faso and Mali, and 2025–2028 (phase 3) expanding to Togo and Madagascar. We synthesise phase-2 implementation (2021–2024) and report the 2024 mixedmethods endline evaluation.

Quantitative surveys included 454 respondents (227 patients; 227 caregivers). Qualitative enquiry comprised 162 interviews/focus groups with health workers, community relays, traditional healers, civil-society partners and officials. Quantitative data were analysed in IBM SPSS Statistics; qualitative data underwent thematic analysis.

The programme trained 659 community relays (219.7% of a 300person target), 613 health workers and 483 community health agents, and supported surgical care with postoperative follow-up. Knowledge increased by 38% among health workers and 35.5% among traditional healers. Overall, 87.2% of patients reported improved health and 72.2% of respondents reported increased awareness of Noma and maxillofacial conditions. Stakeholders described reduced stigma and stronger collaboration between traditional and biomedical providers. Key gaps included patient traceability and continuity of follow-up. In Mali, loss of funding in 2022 halted reconstructive surgery.

An integrated, communityanchored model linking prevention and awareness, early case-finding, and surgical care delivered meaningful health and system gains. Priorities are to standardise registries and longitudinal outcome tracking, secure multi-year financing (including for complex reconstruction), strengthen mentorship and decentralised skills, and restore interrupted services to sustain equitable, timely care.

Keywords: Noma, Maxillofacial Diseases, Integrated Care, Prevention, Early Casefinding, Reconstructive Surgery, Health Systems Strengthening, Postoperative Follow-up, Oral Health, Child Health, Surgical Mentorship

Introduction

The objective of this article is to present the lessons learnt and to analyse data, results and main challenges encountered in implementing the project for the prevention and integrated management of common oral–dental pathologies (PMF) and Noma in Burkina Faso, Mali, Togo and Madagascar [1].

Citation: Nicolas C, Martin L, Bunkembo Mampindu M, Basimage C, Gonter C, et al. Prevention and Integrated Management of Noma and Maxillofacial Diseases in Burkina Faso, Mali, Madagascar and Togo (2018 – 2028) – Lessons Learnt and Challenges – Preliminary Results. Open Access J Clin Path Res. 2025. 1(2): 1-7. DOI: doi.org/10.61440/OAJCPR.2025.v1.13

Noma, also known as "Cancrum Oris" is a neglected and devastating disease that primarily affects malnourished children in low-income settings. It constitutes a severe gangrenous disease of the mouth and face [2]. Its pathogenesis is linked with nonspecific polymicrobial organisms and a range of modifiable risk factors and underlying social determinants shared with other neglected tropical diseases (NTDs).

It mainly affects children aged 2 to 6 years old and is found mostly among those living in poor communities. Africa is the most affected continent, although cases have also been reported in Asia, the Americas and other regions.

Although there are no clear global statistics —owing to the neglected nature of the disease and its association with regions and contexts of low socioeconomic development— the WHO Director-General's 1998 report estimated an incidence of 140 000 cases and a prevalence of 770 000 cases. Case fatality is around 90%, with Noma responsible for the deaths of approximately 500 000 children each year worldwide, although empirical evidence shows it can be drastically reduced with early treatment [3, 4]. Although these figures are outdated and likely underestimate the true burden of the disease, they remain the most widely accepted —albeit obsolete— references, with the caveat of their uncertain current validity [5].

Accurately estimating the impact of Noma is difficult, since many cases go undiagnosed, untreated, or unreported due to the disease's rapid progression, high mortality, the weakness of local health systems (including epidemiological surveillance), the associated social stigma, and the lack of awareness of Noma among the general population, healthcare professionals, and caregivers.

Certain recent local estimates (for example, in northern Nigeria) have reported localised spikes in incidence [6]. This information has been useful for decision-making in the field, although it has not been possible to extrapolate it globally to inform and improve current statistics.

Children affected by Noma who survive the disease often suffer severe aesthetic and functional sequelae, including disfigurement and impairment of breathing, swallowing, speech, and vision. These consequences contribute to social stigmatisation and discrimination and, consequently, to violations of their human rights. In settings where Noma is prevalent, deeply rooted beliefs and superstitions further drive social exclusion, expulsion from the family, school dropout, and, in some cases, infanticide [7].

Materials and Methods

Between 2018 and 2021, CDE has implemented a programme in Burkina Faso to prevent and manage Noma and maxillofacial pathologies. The second phase (2021–2024) was executed in Burkina Faso and Mali. Third phase has been extended to Togo and Madagascar, and it will take place between 2025 and 2028.

A final evaluation of the programme's second phase was conducted between June and November 2024. In this study, a mixed-methods evaluation and data-collection approach was applied, combining quantitative assessments conducted with 454 participants -227 patients and 227 caregivers (Table 1)– and qualitative data gathered through interviews with 162 stakeholders. The results and information collected were analysed using SPSS (IBM SPSS Statistics) for the quantitative data and thematic content analysis for the qualitative findings [8].

Table 1: Distribution of surveyed patients by sex and country

Country / Sex		Female		Masculin		Total
Burkina Faso	59	41,5%	83	58,5%	142	62,6%
Mali	43	50,6%	42	49,4%	85	37,4%
Total	102	44,9%	125	55,1%	227	100,0%

The study took place on the following areas of intervention (Tables 2 and 3):

Table 2: Region of origin by patients' sex

Country	Region		Female		Male	Total	
Burkina Faso Mali	Cascades	2	40,0%	3	60,0%	5	100,0%
	Centre	30	44,8%	37	55,2%	67	100,0%
	Centre Est	8	72,7%	3	27,3%	11	100,0%
	Centre Ouest	4	36,4%	7	63,6%	11	100,0%
	Est	11	36,7%	19	63,3%	30	100,0%
	Plateau Central	4	22,2%	14	77,8%	18	100,0%
	Bamako	8	53,3%	7	46,7%	15	100,0%
	Kayes	6	54,5%	5	45,5%	11	100,0%
	Koulikoro	9	39,1%	14	60,9%	23	100,0%
	Mopti	4	40,0%	6	60,0%	10	100,0%
	Ségou	8	57,1%	6	42,9%	14	100,0%
	Sikasso	8	66,7%	4	33,3%	12	100,0%
Total		102	44,9%	125	55,1%	227	100,0%

Table 3: Distribution of patients' residence status by sex

Residence Status / Sex	Female		Male			Total
IDP	28	56%	24	44%	52	22,9%
Member of the Host Community	74	42,3%	101	57,7%	175	77,1%
Total	102	44,9%	125	55,1%	227	100,0%

Burkina Faso: The Boucle du Mouhoun, North, Centre-North, Plateau-Central, Centre-East, Centre-West, East, Cascades and Centre regions.

Mali: Mopti, Kayes, Koulikoro, Sikasso, Ségou and the district of Bamako.

Madagascar: Fianarantsoa and the Deep South (Androy, Anosy, Atsimo-Andrefana and Atsimo Atsinanana).

Togo: Greater Lomé, Savanes and Kara This programme —and the research subsequently undertaken using the entirety of the data collected— has been carried out by CDE and the following consortium of local Civil Society Organisations (CSO) partners, who have collaborated across the different countries of the region [9,10].

CDE: Coordination of the project, development of training in specialised paediatric surgery. Country offices (Mali, Burkina Faso, Togo and Madagascar) and headquarters (Paris).

Ensemble pour Eux (Burkina Faso): Swiss humanitarian association. It provides pre and postoperative care and coordinates surgical missions.

La Voix du Paysan (Burkina Faso): A Burkinabè community radio station created in 1996 targeting rural populations, for whom it aims to be a "voice". Community awareness-raising activities.

Bilaadga (Burkina Faso): A Burkinabè association that works to promote access to care for disadvantaged children. Training, community awareness-raising and pre- and postoperative patient follow-up.

Sentinelles (Burkina Faso): A Swiss foundation active in several African countries, in Colombia and in Switzerland, developing programmes for sick children or victims of violence. Established in Burkina Faso and involved in the fight against Noma since 1990. Training, community awareness-raising and pre and postoperative patient follow-up.

New Face (Mali): A Malian association aiming to eradicate Noma. Activities include awareness-raising, patient care and support for reintegration.

Vozama (Madagascar): A Malagasy CSO founded in 1997 that fights poverty by promoting children's literacy and the empowerment of vulnerable village communities. Actions to raise awareness among children, parents, teachers and community authorities about maxillofacial pathologies (PMF) and oral health.

Association Espoir pour Demain (AED Lidaw): A Togolese CSO founded in 2001, working on the care of people living with HIV, child protection, and sexual and reproductive health at the community level. With a strong territorial presence, notably in the Kara region through the mobilisation of community health workers, it engages in community awareness-raising, case identification and referral, as well as postoperative follow-up. The integration of the management of maxillofacial pathologies (PMF) and Noma into local mechanisms took place at several levels [11]. At community level, capacity-building for community relays, health workers and local authorities laid the foundations for prevention, awareness-raising and early case-finding. Patients were recruited or referred to through different mechanisms, depending on the country in which they were located (Table 10):

Table 10: Breakdown of the information channels used by accompanying caregivers regarding the project (multiple responses allowed)

Communication Channel	Burkina Faso (n=142)			Mali (n=85)		Total
Word of mouth	48	34%	35	41%	83	37%
Healthcare centre	61	43%	29	34%	90	40%
Schools	1	1%	1	1%	2	1%
Hospitals	28	20%	38	45%	66	29%
Radio	28	20%	4	5%	32	14%
Social media	4	3%	2	2%	6	3%
Television	3	2%	5	6%	8	4%
Other	4	3%	2	2%	6	3%
Total	142	100%	85	100%	227	100%

Mali: recruitment via health centres, traditional practitioners and previously treated patients, with support from CDE for social assessments and databases.

Burkina Faso: referral via hospitals, radio stations and former beneficiaries; contact with CSOs to compile and validate files before entry into a centralised database.

Togo: case-finding via hospitals, health centres, trained staff, radio campaigns and former beneficiaries; referral to the local centre and then to the reference university hospital according to severity, using a national form validated by CDE.

Madagascar: Community Health Workers (CHW) / Community-Based Health Workers (CBHW) identify children with symptoms and refer them to Basic Health Centres (BHC) for initial management [12].

We next describe how surgical care for affected patients was organised in each country. In Mali, surgeries are performed autonomously by local teams for standard cases, with La Chaîne de l'Espoir (CDE) supporting complex cases; in Burkina Faso, pre-operative tests are covered by civil society organisations, and surgery is undertaken on site or during international missions with full inmission follow-up and a final consultation; in Togo, patients are integrated into the local hospital circuit, ensuring continuity of care and inclusion in international missions under the same protocols; and in Madagascar, simple operations are carried out autonomously by the CHU Andrainjato team, while complex cases are co-managed with CDE surgical teams through mentorship missions [13]. Across Mali, Burkina Faso and Madagascar, average costs for surgical management fall within €1,500–€2,250 for Noma and €150–€950 for other PMF's such as cleft palate [14-16].

Postoperative follow-up was structured similarly across programme countries. In all settings, patients were hospitalised for 1–5 days according to clinical severity, then transferred to CSO's reception centres for convalescence, with scheduled follow-up until full recovery and prompt reevaluation in the event of complications. In Madagascar, children and their families additionally benefited from sessions with a psychology-trained resource person to support pain management, frustration, and adaptation to bodily changes; peer support groups brought together children awaiting surgery, families, and former patients to foster mutual support and experiencesharing.

Results

Preliminary results showed that among patients 70% were minors, with 43.7% under 13 years in Burkina Faso and 68.3% in Mali. Nearly 45% were female and 77% came from host communities (23% were internally displaced persons) – (Table 4). Illiteracy was high: 46% female, 44.8% male (Table 6). Caregivers were mainly farmers (38.3%) – (Table 7). The project trained 659 community health relays (219.7% above the initial target), 613 health workers, and 483 community health agents [17]. Reconstructive surgery missions achieved a high success rate, with full postoperative follow-up. Throughout postoperative follow-up and during the interviews, 87.2% of patients reported an improvement in their health status, while 72.2% of respondents stated that their knowledge and awareness of Noma and maxillofacial conditions had increased. Interviewees reported a reduction in stigmatisation, and collaboration between traditional healers and biomedical staff improved at the community level. However, the discontinuation of funding for this project in Mali in 2023 led to a halt in reconstructive surgical activity.

Table 4: Distribution of surveyed patients by age group and sex

Age / Gender Group		Female	Male			Total
0 à 5 years old	24	23,5%	30	24,0%	54	23,8%
6 à 12 ans	38	37,3%	28	22,4%	66	29,1%
13 à 17 ans	16	15,7%	23	18,4%	39	17,2%
18 à 24 ans	14	13,7%	13	10,4%	27	11,9%
25 à 35 ans	7	6,9%	18	14,4%	25	11,0%
36 ans et plus	3	2,9%	13	10,4%	16	7,0%
Total	102	100,0%	125	100,0%	227	100,0%

Table 5: Distribution of patients by age group and country

Groupe d'âge/sexe		Féminin	Masculin			Total
0 à 5 ans	24	23,5%	30	24,0%	54	23,8%
6 à 12 ans	38	37,3%	28	22,4%	66	29,1%
13 à 17 ans	16	15,7%	23	18,4%	39	17,2%
18 à 24 ans	14	13,7%	13	10,4%	27	11,9%
25 à 35 ans	7	6,9%	18	14,4%	25	11,0%
36 ans et plus	3	2,9%	13	10,4%	16	7,0%
Total	102	100,0%	125	100,0%	227	100,0%

Table 6: Distribution of patients by educational level and sex

Education Level / Gender	Female			Male		Total
None	47	46,1%	56	44,8%	103	45,4%
Preschool	5	4,9%	2	1,6%	7	3,1%
Prmary	42	41,2%	46	36,8%	88	38,8%
Highshool	8	7,8%	15	12,0%	23	10,1%
Other	0	0,0%	6	4,8%	6	2,6%
Total	102	100,0%	125	100,0%	227	100,0%

Table 7: Distribution of main occupation and gender of accompanying people

Main Occupation	Female		Male		Total	
None	1	100%	0	0%	1	0,44%
Farmer	14	16%	73	84%	87	38,33%
Craftperson	1	50%	1	50%	2	0,88%
Trader / Shopkeeper	15	41%	22	59%	37	16,30%
Student	4	40%	6	60%	10	4,41%
Civil servant	7	54%	6	46%	13	5,73%
Homemaker	29	104%		0%	28	12,33%
Salaried employee	0	0%	6	100%	6	2,64%
Self-employed worker (tailor, carpenter, etc)	11	28%	28	72%	39	17,18%
Other		0%	3	100%	3	1,32%
Total	82	36%	145	64%	227	100,00%

The project effectively improved prevention, detection, treatment, and community awareness of Noma and related conditions. Its integrated, multistakeholder approach proved relevant, coherent, and sustainable, which opens prospects and prepares the ground for conducting new studies and organising new prevention and treatment programs. Challenges remain in continuity of care, post-operative follow-up, and long-term financing.

The project achieved a satisfactory level of effectiveness, as evidenced by the degree of attainment of several outcome indicators (Tables 8 and 9). Indeed, based on the analysis of qualitative data, it can be concluded that the project contributed to improving knowledge of maxillofacial pathologies by 38% among health workers and by 35.5% among traditional practitioners, surpassing the planned target of 30%. Regarding strengthening civil society capacities, the project also achieved very satisfactory results: against a training target of 300 community relays, a total of 659 were trained, i.e., 219.7% above the initially envisaged objective. Those trained were able to apply the new knowledge acquired on these pathologies very rapidly by organising 3,314 community talks among members of the local population in the various localities of the countries where the project was implemented. As for understanding the pathologies, almost all awareness-raising activities (talks, forum theatre, microprogrammes, radio games and street interviews) helped improve the population's understanding of PMF, although not all radio stations were able to broadcast all the content produced (58%). Most children with PMF and Noma and their families benefited from postoperative follow-up, while 20.7% confirm the effectiveness of economic assistance on the ground.

Table 8: Level of achievement of the monitoring indicators for the results' activities

Activities	Indicators	Achieved	Target	Achievement Rate
Recruitment, referral and selection of patients for forthcoming surgical missions	Number of patients recorded in the database	931	700	133%
	Percentage of patients recorded in the database who received an initial medical opinion on the basis of file review	71%	100%	71%
Outpatient consultations and, where appropriate, operations delivered through surgical mentorship	Number of patients seen in consultation	701	589	119%
	Number of patients operated on	323	409	79%
Care at partner reception centres throughout the year and during surgical missions (pre- and postoperative stays) for referred patients with Noma (acute phase or sequelae) or any other maxillofacial pathology/malformation requiring medical monitoring and care	Number of patients staying in reception centres	842	409	206%
	Percentage of patients arriving at reception centres who required medical monitoring and care and who were managed	100%	100%	100%
Health education for patients and their accompanying persons at reception centres on basic oral, personal and environmental hygiene practices, as well as appropriate physiotherapy exercises	Percentage of patients and their accompanying people staying in reception centres who received hygiene education/promotion	100%	100%	100%
	Percentage of patients requiring physiotherapy who received it	100%	100%	100%
Pilot autonomous surgical activity (operations performed independently)	Number of cases operated autonomously	21	15	40%
Increase in the number of new cases referred to within the project each year by health workers and traditional practitioners		27,5%	30%	25%
At least 70% of people who are sensitized have improved knowledge of maxillofacial pathologies		90%	90%	90%

Table 9: Level of achievement of monitoring indicators

Indicators	Multicountry	Burkina Faso	Mali
At least 70% of health personnel trained in the targeted regions in Burkina Faso and Mali improved their knowledge of maxillofacial pathologies and Noma	81%	84%	78%
At least 90% of referred patients receive medical or surgical care	75%	100%	50%
Percentage of children and young people under care who were able to (re-)enter the school system or engage in a professional activity	106%	106%	

It should be noted that 90% of local medical teams improved their knowledge of specific techniques for reconstructive surgery of facial malformations and pathologies, thanks to the work of volunteer surgical teams who travelled on mission to the field.

An effective integrated strategy involving both health-sector and community actors was applied: the project's intervention strategy is based on a combination of community awareness-raising, case detection and medical care. Analysis of qualitative data obtained through interviews showed that stakeholders consider the intervention strategy effective, particularly in relation to awareness and prevention.

The integrated approach implemented in the project made it possible to mobilise a wide range of actors and to cover a substantial proportion of the target populations. Direct beneficiaries, who constitute the intervention's target population, were invited to assess the organisation put in place to provide them with holistic support. Thus, in their view, collaboration among consortium members is considered "good" by 67% of parents (60% men and 40% women) and "very good" by 23% (70% men and 30% women). However, 6% of respondents (64% men and 36% women) felt there was "weak collaboration". Good collaboration is crucial to achieving the project's objectives, and this positive result shows strong commitment from the actors and good synergy. Although their contribution was positive, several of them pointed to insufficient follow-up and ongoing collaboration with La CDE. Among the six traditional practitioners interviewed, one considered that the training received was insufficient and that collaboration with the project ceased after the initial meetings.

The partnership mechanism is considered generally effective, as it enables the referral of patients, the organisation of surgical missions, the facilitation of skills transfers through mentoring, the strengthening of local CSO capacities and outreach to certain regions. Local actors also view this collaboration positively.

The patient follow-up system needs to be strengthened. Several testimonies indicate shortcomings in patient care after interventions, particularly the lack of traceability of beneficiaries of the project's actions, which resulted in notable gaps in the creation and updating of the patient database.

Discussion

In the year 2007, La CDE started working in various African countries on PMFs through a program called "Les Sourires de l'Espoir" (Smiles of Hope"), with activities in prevention, surgery, strengthening of local teams, and structuring of care pathways. It also conducts regional advocacy.

In 2018, with financial support from French Agency for Development (Agence Française de Développement – AFD), CDE launched a pilot project on this theme with an integrated approach and the involvement of several partners. The present phase constitutes a first scale-up of this approach, incorporating the lessons learnt from the first phase.

This project, through awarenessraising, training, and comprehensive patient care (PEC) for children affected by Noma and for those with facial pathologies and malformations, primarily aims to contribute to the efforts of the health authorities by targeting areas and activities where public-sector interventions remain insufficient.

This project on the integrated management of PMF and Noma aims to optimise the quality of care for this group of pathologies in Togo and Madagascar by equipping maxillofacial services and training local health personnel, community health workers (CHW), and traditional practitioners to identify cases. It also seeks to improve access to care through mentorship missions and medical–surgical care, as well as psychosocial support for patients in Togo and Madagascar. Finally, it strengthens the capacities of community and institutional actors on PMF and Noma through awareness campaigns, the strengthening of local CSO partners in the project, and the dissemination of knowledge on PMF and Noma, notably via an epidemiological study in Togo and Madagascar. The intervention logic focuses on decentralising the care offer and on the process of enabling hospital structures to become autonomous in the management of these conditions.

Conclusion

This multi-country programme demonstrates that an integrated, community-anchored approach combining prevention and awareness, early case-finding and referral, reconstructive surgery, and psychosocial support— can deliver tangible gains for children affected by Noma and related maxillofacial conditions in West and Southern Africa. The intervention achieved substantial training outputs, strengthened local pathways for detection and care, and was associated with self-reported improvements in health and knowledge, while surfacing system gaps in patient traceability, continuity of follow-up, and predictable financing. These findings are consistent with contemporary evidence that Noma is largely preventable when recognised early and managed promptly, and that durable progress depends on embedding prevention and care within existing child- and oral-health platforms.

Recognition of Noma by WHO as a neglected tropical disease in December 2023 provides a timely policy window to institutionalise surveillance, integrate Noma indicators into routine information systems, and resource national action plans. Programmes like ours should be leveraged to (i) standardise patient registries and longitudinal outcome tracking; (ii) formalise surgical mentorship and step-wise decentralisation of competencies; and (iii) secure multi-year budgets that cover both community operations and the higher, episodic costs of complex reconstruction. Prioritising these elements will help convert short-term missions into sustained, locally owned services.

Future work should address three priorities. First, strengthen measurement: Align with WHO guidance to improve burden estimates and routinely capture functional outcomes and patient-reported measures after surgery. Second, deepen prevention: Scale proven community strategies (including collaboration with traditional healers and community radios) and embed oral-health promotion and acute Noma recognition within primary care. Third, advanced science: Support longitudinal, early-stage microbiological studies to clarify dysbiosis and inform targeted interventions alongside nutrition and oral-hygiene packages. Together, these steps would consolidate the programme's gains and accelerate progress towards timely prevention, equitable access to complex care, and social reintegration for survivors.

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