



WHO/MMC/NOMA/98.1 ✓

Original: English

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# ***NOMA TODAY***

## **A PUBLIC HEALTH PROBLEM?**

### **Report of an expert consultation**

Organized by the Oral Health Unit  
of the World Health Organization  
using the Delphi method



**WORLD HEALTH ORGANIZATION**



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The present report was written by Mrs Leclercq on the basis of information and comments provided by the experts listed below who were involved in the consultation.

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(in alphabetical order)

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<sup>1</sup> Addresses at the time of the consultation (1994).

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## The context

There is no doubt that the form of noma occurring in the maxillo-facial complex - cancrum oris or oro-facial gangrene - results in death in a large percentage of cases and severe facial disfigurement and disability in most of the remainder. As with any disease leading to such serious outcomes those expert and lay persons who have become aware of the disease and its sequelae do not easily accept the prevailing lack of interest in tackling the problem at global, regional and national levels.

Since 1989, when the World Health Organization's (WHO) Oral Health Programme (ORH) organized the first information meeting on noma at the World Health Assembly, the problem of cancrum oris has been one of its areas of activities. ORH staff involved in this work, as in the case of concerned experts and lay persons, have felt a type of shock in relation to the juxtaposition of extreme gravity and widespread ignorance. Despite this natural emotion, the essential priorities and cost effectiveness by which public health programmes and activities are governed must be respected. In order to make an adequate evaluation by which to develop an appropriate and justified response it quickly became clear that further information and expert consultation were needed.

Bibliographical research (yielding 354 references, of which 328 have been published since the beginning of the twentieth century), the work of correspondents and that of several nongovernmental organizations have shown that this disease is a real public health issue and one for which answers and solutions should be found.

The epidemiological data was extremely patchy, but by assembling various pieces of data both from surveys and referral records, together with estimates of case-mortality, a possible incidence was calculated of two to four cases per annum for every 10 000 children between the ages of two and six in some regions of Africa. In Niger, from a national study of cases

referred between 1991 and 1992, it was assumed that there were between seven and 14 cases per annum for every 10 000 children up to the age of six.

In November 1992, during an international meeting in Paris, WHO put forward a strategy for action and an offer to coordinate what has continued to develop as an international network against noma.

Building upon acceptance of those proposals it was clear that consultation with a group of experts in the field was essential before any far-reaching decisions could be made.

## **Methods and objectives**

Accordingly, at the end of 1993, in order to come to a consensus of opinion on noma, a consultation of experts using the Delphi method was organized.

This method, developed between 1965 and 1975, is designed to improve the quality of judgements expressed in areas of relative uncertainty, and to provide an approach to quantifying them (bibliographical references in Annex 1).

The Delphi consultation method recommends that groups of between seven and 15 experts are used. It is organized by individual correspondence, without the experts knowing who else is in the group. A consultation consists of two to four stages and a questionnaire is sent out at each stage. The panel should possess the widest possible range of expertise to cover all important aspects of the subject under study.

The design team sets the questions and decides how many questions and questionnaires there are to be. This team should be as small as possible.

For this study a list of 15 experts was drawn up, and a preliminary protocol was sent to each of them in November 1993; 12 agreed to take part. Eleven were oral surgeons or specialists in oral medicine; the twelfth, an ophthalmologist and epidemiologist in charge of a regional centre in West Africa, was asked to participate in view of his great knowledge of Africa and the extra-disciplinary contribution he could make to the consultation. Five experts in the field were from Niger, Nigeria, Kenya and Sudan. The other six specialists were chosen for their extensive experience of the problem in the field (four were working in French-speaking African countries at the time) and their scientific knowledge of the matter, as demonstrated by their publications.

The design team consisted of only two people from WHO/ORH. In addition, advice was obtained from two WHO experts, an epidemiologist and a health scientist.

The consultation had three objectives:

1. To reach consensus on the main elements of understanding of the disease.
2. To test the parameters used in WHO for calculating possible annual incidence.
3. To obtain expert opinion on the control strategies proposed by WHO.

The consultation took place between November 1993 and February 1994. Analysis had to be postponed until the end of April 1994 because of preparations for World Health Day, for which oral health was the theme. There were two stages and two questionnaires. The first questionnaire contained 10 questions, and the second eight.

The second questionnaire was not finalized until the answers to the first had been analysed, so that answers would not be taken for granted, and

ill-phrased questions could be made more specific or complete - as was the case, for example, with question 10, on mortality.

In spite of the difficulties of communication with some countries, 11 replies (88%) were received for the first series, and 10 (83%) for the second. These levels of response are regarded as particularly high for this type of consultation.

## Results

Data are reproduced below, question by question, conforming to the actual wording used in the two questionnaires. Thus, where we recognized, subsequently, that the wording led to equivocal categorization, we have included a note which modifies or elaborates results according to explanations given by the respondents.

### A. STAGE 1 - First Questionnaire

#### 1. Is noma a tropical disease?

Yes	No	Other
5	6	0

Included in the "no" category are two affirmative replies where it was specified that the answer referred to cases which have been reported recently only in the tropics even though, historically, it could not be regarded as a tropical disease. Therefore, eight out of the 11 responses received did not consider noma as a tropical disease.

## 2. Is noma essentially a dental disease?

Yes	No	No, because there are other sites	Yes, if cancrum oris	No, because it is a multidisciplinary problem
7	1	1	1	1

The variety of negative replies and the comments made show that the question was not put precisely enough. Elements of the replies to this question related to the site of origin of the lesion, its extent and the consequent complexity of reconstructive care needed. It is accepted that, in this study, the subject is the oro-facial form of noma (cancrum oris) and that the essential feature is the intra-oral site of origin whatever reparative complexity is required. Therefore, we considered that positive responses actually numbered 10 out of 11.

## 3. What health/disease conditions favour the development of noma?

Malnutrition	Superimposed infections	Unspecified stress	Immuno-suppression
11	10	3	1

Of the superimposed infections mentioned, measles was cited 10 times, other tropical diseases four times, HIV once.

**4. What social/environmental conditions favour the development of noma?**

Poverty	Lack of hygiene and sanitation	Improper weaning	Cultural practices (unspecified)	Traditional medicine	Lack of access to the health network	Stress
7	4	2	1	1	1	2

**5. Which countries/regions are most affected?**

Africa	Asia	Latin America	Tropical or subtropical areas
11	5	5	3

The continent of Africa is mentioned 11 times, and countries where cases have been reported within the last two years are Sudan, Niger, Nigeria, Mali, Ethiopia, Djibouti, Kenya, Zambia, the Gambia and Malawi. Five experts mentioned countries in Asia and Latin America; three considered that no tropical or subtropical area was really free of the disease.

The subsequent questions dealt with prevalence, incidence, severity by age and sex, and presumed mortality.

**6. Which age groups are most affected by noma?**

0-6 years	6-12 years	0-18 years	All ages
7	2	1	1

The consensus (9) was that new cases occurred in children mostly in the age group 0-6 years.

**7. Are there significant differences in incidence between the sexes?**

Do not know	No difference	More girls	More boys
8	2	0	1

The "more boys" answer assumed that more boys were referred, but the reason for that assumption was not elaborated.

**8. Are there significant differences in prevalence between the sexes?**

Do not know	No difference	More girls	More boys
9	1	1	0

**9. Are there significant differences in severity between the sexes?**

Do not know	No difference	More girls	More boys
7	4	0	0

The answers to questions 7 to 9 show how poorly cancrum oris is documented by sex.

**10. What is the mortality rate related to noma?**

All experts realized that this question related to case-mortality.

Five people admitted they did not know. The six others differed depending on whether mortality occurred in the absence of treatment or after treatment.

Question 10 was therefore reformulated as question one of the second stage.

## B. STAGE 2 - Second Questionnaire

### 1. What is the mortality rate related to noma?

#### (a) In the absence of treatment?

Do not know	Very high	100%	90%	80%
4	1	3	1	1

Assuming that "very high" is of the order of the average magnitude indicated by the other five experts who gave a positive response, the case-mortality rate would be at least 90%.

#### (b) If treated?

Do not know	Very high	90%	50%	<15%	0%
4	1	1	1	1	2

Four experts said that they had evidence of a positive response to treatment. However, others commented that the mortality rate after treatment remained high, due to the weakness of the patient rather than to the disease itself.

### 2. Map of reported cases

World maps were provided to all experts who were requested to indicate for which countries they knew of reported cases in the last two

years. Six maps were sent. All included Africa and three of them also displayed countries in Asia or South America (see Annex 3).

- 3. What, in your opinion, would be the most reasonable estimate of the percentage of the total number of patients affected by noma who reach the care centre?**

20-30%	10-20%	5-10%	<5%	Do not know
1	3	2	1	3

- 4. In the last five years have you seen or known of more cases than before?**

No	Yes	Do not know	Not in the field
5	3	1	1

- 5. ANUG<sup>1</sup> is usually reported as the early stage of cancrum oris though apparently few cases of ANUG evolve into actual noma**

- (a) Are there specific clinical characteristics in ANUG precursor of noma?**

No	Yes	Do not know
6	3	1

The "do not know" reply was expected since it was given by the only physician of the group who is not a specialist in the field.

<sup>1</sup> ANUG: Acute Necrotizing Ulcerative Gingivitis.

- (b) Is the generally observed ANUG of the same nature (in microbiological terms) as the ANUG first stage of noma?

No	Yes	Do not know
2	6	2

Six people were of the opinion that the same pathogens were involved, though three expressed reservations as to their number and particular virulence. Two thought there were different, unidentified germs, but their "no" is likely to be more of a "perhaps".

6. Would you say that cancrum oris is a preventable disease?

Yes	Not sure
9	1

There was rare unanimity of the oral health experts.

7. What are the preventative steps at individual level?

Treatment of ANUG	Better hygiene	Proper nutrition	Measles vaccination
7	6	6	3

## 8. What are the preventative steps at public health level?

Public education/ information (hygiene and nutrition)	Training of health personnel	Food supplements for communities at risk	Vaccination
9	5	5	2

For prevention, the essential tasks are information, education and training. Three experts stressed the need to reach the groups at risk, the particularly vulnerable communities. One expert suggested a plan of action relevant to the village, regional, ministerial and WHO levels.

## Discussion and conclusion

As mentioned earlier, this type of consultation is recommended for areas where scientific certainty is lacking. This is clearly the case with epidemiology of cancrum oris, its etiology, and therefore, its dimension as a public health problem.

The emerging consensus covers both what is known or what is thought, and what is not known, which indicates two lines of action: immediate intervention, and further research to improve intervention.

### First Questionnaire

*Questions 1-4 deal with knowledge on which there is general consensus*

Noma is *not* a tropical disease, strictly speaking, and it is an oral disease, assuming we are referring to cancrum oris, which is the oro-facial form of noma. This is consistent with the history of the disease which has

been reported since ancient times in the Mediterranean region and afterwards, in all parts of the world: most of Europe in the 17th, 18th and 19th centuries and more recently in Germany during the second World War (concentration camps). It has been mentioned in North America (19th century) and nowadays in South and Central America, in South-East Asia and mostly in Africa.

The main causes recognized are malnutrition, superimposed infection and lack of hygiene. In social terms, economic factors such as poverty and lack of health infrastructure are predominant.

***Questions 5-10 concern epidemiology***

There is a clear consensus on the countries affected by noma. They are found mainly in Africa but none of the least developed countries of the world can be excluded. In view of the replies (Questions 3 and 4) to conditions and environments favouring the occurrence of noma, and comments to question 1, the geographical distribution of cases can be explained in socioeconomic terms.

It is mainly young people who are affected, and mortality is probably of the order of 80% to 90%.

**Second Questionnaire**

***Question 1(a) (Mortality without treatment)***

No study to date has been able to present adequate data to confirm statistics on prevalence, incidence or mortality estimates. Obviously, the experts were asked to give what they regarded as a reasonable figure in view of their experience in the field, their clinical knowledge and their common sense. Their responses have a profound effect on estimates of incidence (see presentation model by which to construct the estimates, on page 21) as case mortality rate was previously assumed to be about 70%, whereas the experts consensus is 90%.

**Question 1(b)** (Mortality if treated)

The divergence of opinion was surprising. Review of the literature led to expectation of a greater agreement on the success of treatment, especially with antibiotics and food supplements. Three experts thought that mortality would remain high or very high even after treatment. Explanations supplied suggest that post-treatment deaths are not directly attributable to cancrum oris, since gangrene can almost always be arrested, but to the extreme weakness of the young noma patients who contract secondary infections and especially pneumonia.

**Question 2** (Geographical distribution)

The aim was to compare the results of the actual experience of the experts with the maps made by WHO on the basis of bibliographical research. The consequence was that a number of other countries was added: Mali, Algeria, Libya, Togo, Pakistan, Chad, Central African Republic, Namibia, Angola, Botswana, Zambia, Cameroon, Egypt, Ethiopia, Argentina, Paraguay, Uruguay and South Africa.

*Nota bene:* This list refers purely to any observed cases; there is no quantification.

**Question 3** (Referred cases)

Again no scientific basis was given for positive assumptions of the percentage of referred cases. Three experts refused to advance any estimate. The other provided estimates which averaged just under 15%. These estimates are essential to calculation of incidence and are much more pessimistic than the prior estimations of about 30%.

**Question 4** (Re-emergence)

Question 4 was an attempt to identify any resurgence that might be occurring. The replies gave no evidence either way even though suggestions had been communicated of re-emergence. It is coherent to

expect resurgence in relation to aggravation of socioeconomic deprivation which increases the population at risk. Reports of increased incidence continue to be received.

**Question 5(a)** (Noma and ANUG)

The three affirmative replies included commentaries describing the particular signs.

These are involvement of the periosteum and the alveolar bone, abnormal severity of ulceration, and cheek or labial involvement adjacent to the gingival ulcer. One of the negative replies did, however, note a feature that could be indicative of noma - the fact that ANUG is found predominantly around primary teeth.

It may be concluded that, even in the absence of clinical certainty, special attention should be paid to the signs described. Any severe ulceration of the gingiva in a young child (especially when associated with exanthematous fevers and malnourishment) and particularly around primary teeth, should suggest a possible evolution to cancrum oris and lead to immediate therapeutic measures.

**Question 5(b)** (Noma and ANUG)

The replies confirmed the need for more etiological research.

**Questions 6-8** (Preventive action)

All oral experts agreed that noma is preventable. Replies advocate early detection and treatment combined with education, nutrition and vaccination against measles. They call for multisectoral activity targeting groups at risk.

## Did the consultation achieve its objectives?

### *First objective*

As regards the epidemiology of noma and its causal or promoting factors, the answers given confirm what had been understood and described previously. Although there is no new information on the possible incidence and prevalence at present, the information supplied substantiates previous estimates and adds to the map of reported cases of noma. This is important for drawing the attention of governments and the health professions in the countries affected to the urgent need to document the situation adequately so that an appropriate priority for action can be established.

### *Second objective*

The second objective was to test the method used for the calculation of the annual incidence.

Calculations have been based on the following considerations:

- the only data accessible (though not always) are the number of cases of noma referred to treatment centres during a given period. Even these data are dependent on the existence of a system of medical records for each patient;

- the number of cases referred to and reaching the treatment centres (R) constitute a certain percentage (x) of total surviving cases (S), which can thus be calculated by

$$S = \frac{R \times 100}{x}$$

- the number of surviving cases is itself a percentage of total incidence, dependent on the case survival rate (y/100). Therefore, the total incidence (I) is estimated by

$$I = \frac{S \times 100}{y}$$

This arithmetic depends on two assumptions. One concerns the ratio of referred cases to surviving cases, and the other concerns the case mortality rate. Original estimations were that one case in three reached treatment centres and that the mortality rate was about 70%. The experts consulted were more pessimistic on both figures.

Consensus on the logic for calculation of incidence has not been checked and must be discussed and verified. The whole process is based on a number of elements which are uncertain, such as the possibility of choosing at random a sample representative of the entire population or the population at risk from the treatment centres of a country or region. It also presupposes the existence of systems of access or recourse to treatment that are more or less comparable throughout a region, which is difficult to assess and to quantify.

Only population surveys adequately sampling risk groups and conducted in the largest possible number of countries would validate the approach or provide the basis for an alternative. However, the replies to the consultation eliminate the likelihood of a gross over-estimation in the statistics used, and support the need for intervention and research without further delay.

They emphasize the merit of an epidemiological approach, even if it is speculative, in that it offers a method of documentation on the basis of referred cases, which is the only realistic source of information when a survey of the entire population is unavailable and unlikely to become available in the near future.

### *Third objective*

This was to test the strategic proposals of WHO - the action envisaged depended on the possibility of early detection and prevention. The experts were almost unanimous on this point. The recommendation that vulnerable groups be targeted coincided with the intention to conduct pilot studies in networks of nutritional rehabilitation centres. The experts

stressed the need for capacity building programmes to inform and train health workers especially auxiliaries. All these points were approved and adopted at the meeting in Paris in November 1992.<sup>1</sup>

The advantages and limitations of the Delphi method have been analysed, especially in a critique comparing various methods of scientific consultation.<sup>2</sup>

The method is particularly appropriate (1) for the area defined, which is highly specialized and lacking in established scientific data; (2) given the time limits and financial limitations that ruled out an actual meeting of experts from all continents; (3) for the objectives that had been set.

The results obtained, though of course they do not give the final answers that only epidemiological and etiological research and feasibility studies could provide, do at least make possible the preparation of an intervention and research programme of work for the years to come with the greatest confidence in the options chosen, that can be attained with present knowledge.

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<sup>1</sup> Meeting on noma organized jointly by Aide Odontologique Internationale and the Oral Health Unit of WHO, also involving representatives from Niger, Burkina Faso, Côte d'Ivoire, Madagascar, Médecins du Monde, Chaîne de l'Espoir, Sentinelles, Geneva Cantonal Hospital, and the Health Service of the French Army.

<sup>2</sup> Joseph P. Martino, *Technological Forecasting for Decision Making*. New York: American Elsevier, 1972, pp. 18-64.

## ANNEX 1

September 1993

### **Delphi consultation on epidemiological aspects (features) of cancrum oris or noma**

#### **Main terms of the protocol**

A Delphi consultation protocol is being drawn up by the Oral Health unit of the World Health Organization.

**Purpose:** To obtain a consensus on the magnitude of cancrum oris in epidemiological terms to test the WHO model for constructing a global estimate of the incidence of cancrum oris/noma.

**Design team:** Mrs M.-H. Leclercq, Dr D.E. Barmes

**Expert group:** The design team will select a group of a minimum of seven recognized experts in the domain. The experts will be anonymous.

**Questionnaires:** The questionnaires will be prepared by the design team which will also be responsible for the analysis of the replies and the overall coordination of the consultation.

**Timing:** There will be three to four rounds of questions. The whole consultation will not last beyond 31 December 1993.

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## ANNEX 2

### ORAL HEALTH UNIT

#### Delphi consultation on noma

##### Questionnaire No. 1

10 November 1993

1. Is noma a tropical disease?
2. Is noma essentially a dental disease?
3. What health/disease conditions favour the development of noma?
4. What social/environmental conditions favour the development of noma?
5. Which countries/regions are most affected?
6. Which age groups are most affected by noma?
7. Are there significant differences in incidence between the sexes?
8. Are there significant differences in prevalence between the sexes?
9. Are there significant differences in severity between the sexes?
10. What is the mortality rate related to noma?

**Questionnaire No. 2****8 December 1993**

1. What is the mortality rate related to noma:
  - (a) In the absence of treatment?
  - (b) If treated?
2. Map of reported cases ("reported" meaning published, or seen by you, or reported to you by a reliable witness). The map in Annex 3 is not meant to give any quantitative information. Please simply indicate in which country or countries you *know* of a case(s) of noma which has(have) been reported since 1980. If you can specify a region within each country, please circle this.
3. Referred cases: What in your opinion would be the most reasonable estimate of the percentage of the *total number of patients affected* by noma (dead or alive) who reach the care centre?
 

<5%	5-10%	10-20%	20-30%	30-50%	>50%
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4. In the last five years have you seen or known of more cases than *before*?
5. ANUG is usually reported as the early stage of cancrum oris, though apparently few cases of ANUG evolve into actual noma.
  - (a) Are there specific clinical characteristics in the ANUG precursor of noma?
  - (b) Is the generally observed ANUG of the same nature (in microbiological terms) as the ANUG first stage of noma?
6. Would you say that cancrum oris is a preventable disease?
7. What are the preventative steps at individual level?
8. What are the preventative steps at public health level?

ANNEX 3

