Missed at Birth: *are current newborn screening guidelines helping to detect cleft palates?*

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BACKGROUND

👶 Every year, **~1 in 1000 babies worldwide** are born with a **cleft palate (CP)**[3] — a gap in the roof of the mouth that is not visible from the outside.

⚠️ Unlike cleft lip (CL), which is apparent on a baby's face, CP **can only be detected if a health worker examines inside the mouth.**

🍼 **If missed at birth**, babies with CP **struggle to breastfeed**, leading to **malnutrition**, **stunted growth**, and even **death** in the first weeks of life.

📋 Even though CP can be identified with a simple, low-cost intraoral exam, over 25% of cases still go undetected[1]

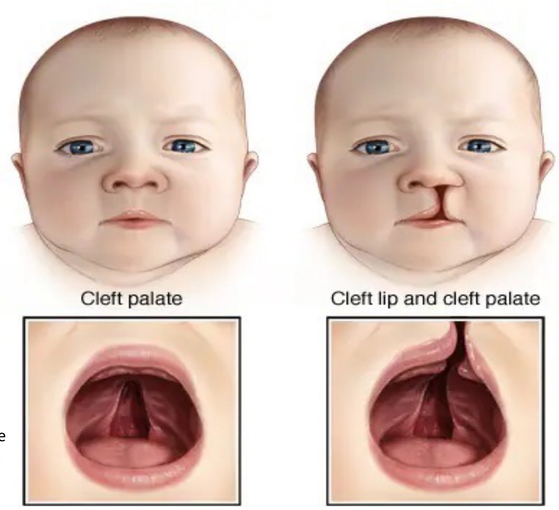


Figure 1. Comparison of CP (normal external appearance but intraoral defect visible + posterior cleft at the uvula) vs CL with CP (external lip and nasal involvement). Illustrations © Mayo Clinic.

OBJECTIVES

To *evaluate* current national and international newborn screening (NBS) guidelines, *assess* the extent, clarity, and consistency of CP screening recommendations, and *highlight* areas where recommendations may be insufficient for early detection.

METHODS

- **Sources:** PubMed, Google Scholar, health body websites, grey literature
- **Scope:** National and international NBS and CP-specific guidelines in English*
- **Data extracted:** Country, examiner, exam timing, CP mention, CP definition clarity, exam method, uvula visualisation

**Local or institution-specific guidelines were excluded.*

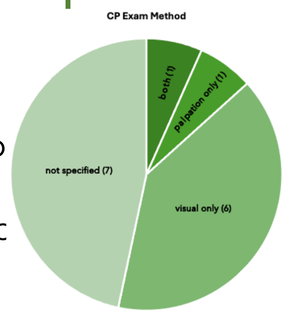
RESULTS

Guidelines identified:

- 15 NBS guidelines (12 national + 3 international from WHO, NICE and government health ministries)
- 1 CP-specific guideline (RCPCH[2])

Mention of CP:

- 11/15 guidelines mentioned CP (73%) however over half failed to distinguish it from CL (54%).
- Only 8/15 (53%) specified how tc examine for CP (see chart).



Documentation:

- **No guideline** specified how to document palate examination findings.

DISCUSSION

Early CP detection relies on the examiner *knowing* exactly what to look for. Many guidelines use vague terms like check *"mouth"* or *"face"* or even conflate CP with CL, perpetuating confusion. Without precise terminology, diagrams or steps, examiners may overlook CP, especially since it is not visible externally. This breeds complacency: you cannot diagnose what *you do not know to look for.*

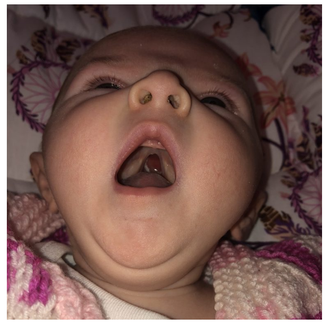


Figure 2. Baby with normal external appearance, but intraoral examination reveals a posterior cleft involving the uvula. Image from CLAPA.

A complete examination is essential and should state to visualise the entire palate, including the uvula – y*et only one guideline[2] specified this explicitly* – despite *all* clefts having similar feeding impacts[1].

CONCLUSION

Missed diagnoses of CP remain a preventable cause of global infant morbidity and mortality. Current NBS guidelines do not give healthcare workers the practical tools needed for reliable detection. Clear, standardised guidance — integrating ***intraoral visualisation and palpation*** — is urgently needed.

References:

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2. Royal College of Paediatrics and Child Health (2015). Palate examination: Identification of cleft palate in the newborn. *Royal College of Paediatrics and Child Health.* Available at: https://www.rcpch.ac.uk/resources/palate-examination-identification-cleft-palate-newborn-best-practice-guide
3. World Health Organization (2025). Oral health fact sheet. Available at: https://www.who.int/news-room/fact-sheets/detail/oral-health