Improving the early detection of cleft palate in the UK

In September 2017 the Royal College of Paediatrics and Child Health (RCPCH) launched its eLearning module *Cleft Palate: Examination in the Newborn*. Its aim is to improve the early identification of cleft palate which, despite a seemingly obvious appearance, is still missed during the newborn examination with significant impact on infant and family. The module highlights the importance of a proper examination to visualise the entire length of the palate using a torch and tongue depressor.

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Key points

McElroy H., Habel A., Jokinen M., Marsh C., Murphy G., Tuohy W. Improving the early detection of cleft palate in the UK. *Infant* 2017; 13(6): 223-27.
1. 30% of cleft palates are detected late.
2. The palate should be examined within 24 hours of birth using a torch and tongue depressor.
3. Introduction of an educational package will embed guidance in practice.

The Royal College of Paediatrics and Child Health (RCPCH) eLearning module *Cleft Palate: Examination in the Newborn* (**FIGURE 1**), provides a free educational resource for paediatricians, midwives, GPs and allied healthcare professionals.[1] The module highlights the importance of a proper examination to visualise the palate using a torch and tongue depressor; a method advocated in the 2014 RCPCH *Best Practice Guide* to facilitate an optimal view of the entire length of the palate from the gums to the uvula.[2]

Early detection of cleft palate: a national standard of care

Cleft palate is one of the most common congenital anomalies in the UK with an incidence of one in 1,500 births.[3] By its nature it can be readily identified by a thorough visual examination of the palate; diagnosis is therefore possible immediately after birth and is acknowledged as a national minimum standard of care by cleft services (**TABLE 1**), with referral to the local cleft team within 24 hours of diagnosis.[4] Diagnosis after 24 hours of age is considered delayed.
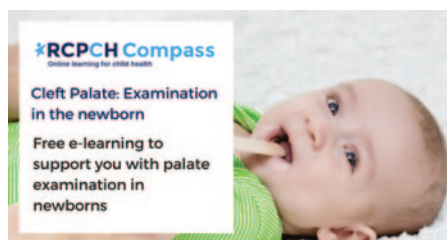

FIGURE 1 The RCPCH eLearning module.

These are the minimum standards of care that should be offered to families following the birth of a baby with cleft lip and/or palate:
- All babies born with a cleft lip and/or palate are to be diagnosed at birth
- All babies are to be referred by relevant professionals to the cleft team within 24 hours of diagnosis
- The clinical nurse should visit within 24 hours of receiving referral

TABLE 1 The national standards of care for a baby with cleft lip and/or palate.

Consequences of delayed detection

Most infants with a cleft palate experience immediate feeding difficulties including poor latching and nasal regurgitation of milk (**FIGURE 2**).[5,6] If the diagnosis is delayed even a few days after birth this may interrupt the establishment of feeding and contribute to distress for both mother and baby. The longer the delay in detection, the greater potential for faltering growth; there may be frequent readmissions to hospital because of poor feeding and poor weight gain. There is a risk of choking with aspiration and secondary pneumonia, and in the longer term, middle ear infections and hearing impairment. Older children with undiagnosed cleft palate experience problems with development of speech despite intensive therapy (**FIGURE 3**) and in some cases a cleft palate can remain undetected by the speech therapist during years of treatment.[5]

In infants with a syndromic cleft palate, failure to recognise the cleft may result in valuable time lost diagnosing the

syndrome complex. Delays in detection can lead to delays in surgery (usually performed between nine months to one year of age). This may affect the quality of the final repair and speech outcomes as articulation and resonance are recognised to be better for children who are younger and less lexically advanced at the time of surgery.[7]

In the past 15 years the NHS has paid out over £1 million in litigation claims for missed clefts.[8] The cost to families in the form of emotional and psychological distress remains with them throughout the years of follow-up and, where a diagnosis is delayed in the face of repeated concerns voiced to health professionals, there is an inevitable weakening of the doctor-patient relationship. Here are some quotes from parents:

"[I am] angry it was not diagnosed properly as baby struggled to feed for three days."

"I could see that J was not latching on and she was getting increasingly distressed."

"I knew something was wrong but I was reassured all was normal."

Extent of delayed detection

The national minimum standard that all cleft palates should be diagnosed at birth has never been achieved. A study of data from two UK centres between 1988-2001 revealed that 28% of clefts were detected after 24 hours of age.[9] The Cleft Registry and Audit Network (CRANE) collects information about all children born with cleft lip and/or cleft palate in England, Wales and Northern Ireland. Its annual reports for the last seven years show delayed detection running at 28-32% *annually*.[10] A telephone survey conducted in the Great Ormond Street Hospital study appeared to implicate the widespread use of palpation, but without definitive proof.[9]

Nasal regurgitation of milk during feeding

Frequent burping due to excessive intake of air

Fatigue due to excessive energy expenditure during feeding

Clicking sound during feeding

Poor latching, prolonged feeding time

Disorganised sucking pattern

Choking, gagging, coughing, increased respiratory rate

Poor weight gain due to inadequate nutritional intake

FIGURE 2 Signs of a cleft palate in the newborn.

A four-year-old child with delayed speech of a hypernasal quality was referred to the speech and language therapy team for assessment. After a number of sessions the team asked the GP to refer the child to audiology services to exclude a hearing impairment as cause for the speech delay. The GP visually inspected the child's mouth to reveal a large cleft of soft and hard palate.

FIGURE 3 A case study.

Concerns about the adequacy of the examination of the palate, with reference to the practice of palpation being substituted for visual inspection, continue to be raised by CRANE.[10]

In 2002, Armstrong and Simpson added to the growing body of disquiet.[11] They noted that palpation was being used as an adjunct to inspection with the expectation that by eliciting the gag reflex the examiner would be able to see the palate. After two babies with cleft palate had been incorrectly diagnosed with a normal palate in their region they investigated practice in 125 babies who received a routine newborn check by medical staff. If the baby spontaneously yawned or cried an attempt was made to visualise the palate, otherwise it was palpated with the little finger and an attempt made to view the palate if the baby gagged. Of the 20 babies who spontaneously opened their mouths the soft palate was clearly seen in 11 cases; 48 babies gagged and the soft palate was seen in seven, and in the remaining 57 babies there was an incomplete view of the soft palate.

The authors went on to demonstrate that by using a laryngoscope it was possible to clearly visualise the soft palate in all cases. This study confirmed suspicions that the examination method prevalent at that time was inadequate to reliably exclude a cleft palate. Understandably the laryngoscope did not enter routine use following this report, though a wooden spatula and torch would work equally well, and practices continued to vary between palpation and opportunistic visual inspection, usually with an ophthalmoscope.

RCPCH *Best Practice Guide*

In 2012 the continuing issue of delayed diagnosis was escalated to the RCPCH Clinical Standards Committee and a working group involving key partners was tasked with developing guidance. The *Best Practice Guide* was published in October 2014 with recommendations based on

consensus opinion from experts in the UK using Delphi methodology (a validated technique for achieving convergence of opinion) in the absence of evidence from observational studies.[2]

Recommendations for palate examination

The following is a list of the key messages from the *Best Practice Guide*:

- Healthcare professionals should examine a baby's hard and soft palate as part of the full newborn physical examination and record this in the child health record.
- Examination of the baby's palate should be carried out by visual inspection. A torch and method of depressing the tongue should be used to visualise the whole palate.
- Parents should be informed if the whole palate (including the full length of the soft palate) has not been visualised during the newborn examination. If the whole palate cannot be visually inspected at the first attempt then a further attempt should be made within 24 hours.
- Trusts should provide training on the correct method of visual inspection of the palate to all healthcare professionals required to carry out the newborn examination.

Visualising the palate: the gold standard

A key recommendation is the visual examination of the palate using a torch and tongue depressor. This enables a clear view of the whole length of the palate from gums to the uvula and is best performed with the help of an assistant, which can be either parent or a midwife (**FIGURE 4**). To comply with national standards of cleft palate care this should be done soon after birth.

FIGURE 4 The optimal examination technique using a tongue depressor and torch. The uvula is clearly seen at the tip of the wooden spatula.

In the event of failure to examine the whole palate, the result should be clearly recorded in the Child Health Record (the 'red book') and arrangements should be made for a repeat examination after explaining why to the family. The repeat can be either before the infant is discharged or at a follow-up clinic according with local arrangements.

National impact of the *Best Practice Guide*

In 2014 CRANE reported that 31.3% of cleft palates were diagnosed late, ie after 24 hours of age (**TABLE 2**).[12] The *Best Practice Guide* was published at the end of that year and would be expected to have significant impact on practice only after a latent period. The figure for 2015 reveals a small change with 28.3% diagnosed late; however in 2016, 32% were detected after 24 hours of age across the UK and Ireland (**FIGURE 5**) reiterating the need for greater awareness of the guidance and education of staff.[16]

Barriers to implementation

Properly developed guidelines can change clinical practice and patient outcome but this requires successful implementation

and sustained adherence.[13] Has the *Best Practice Guide* had sufficient time to become embedded in routine practice since the launch in 2014?

The authors regularly come across medical and midwifery staff, in training or senior positions, who are ignorant of the recommendation to visually inspect the palate. This may reflect ineffective dissemination of the guide, which was launched on key websites and presented at the RCPCH annual conference in 2015 and 2016, but may not have reached all health professionals in the workplace.

There may be concern about the use of a wooden tongue depressor, which has been associated with cutaneous fungal infection in preterm infants nursed in humid

incubators where it was used as a splint for cannulation sites.[14] Such concerns are unfounded in well term babies and single wrapped tongue depressors are readily available in wood or plastic.

Many practitioners who perform the newborn examination have never seen a cleft palate; indeed, knowledge of the normal is an essential prerequisite to recognising the abnormal.

Conflicting standards: cleft service versus NIPE

A potentially important and unaddressed factor is the conflict of standards on the timing of detection of cleft palate. Cleft services cite diagnosis at birth as a national standard whereas the NHS Newborn and

Year	Antenatal	At birth	≤ week	≤1 month	≤6 months	>6 months	All
2013	7 (1.6%)	300 (68%)	87 (19.7%)	23 (5.2%)	18 (4.1%)	6 (1.4%)	441
2014	4 (1%)	273 (67.7%)	72 (17.9%)	21 (5.2%)	27 (6.7%)	6 (1.5%)	403
2015	2 (0.5%)	287 (71.2%)	67 (16.6%)	19 (4.7%)	23 (5.7%)	5 (1.2%)	403

TABLE 2 The time of diagnosis of cleft palate in relation to birth (at birth includes up to 24 hours), data from England, Wales and Northern Ireland.[10] Note, the *Best Practice Guide* was published at the end of 2014.
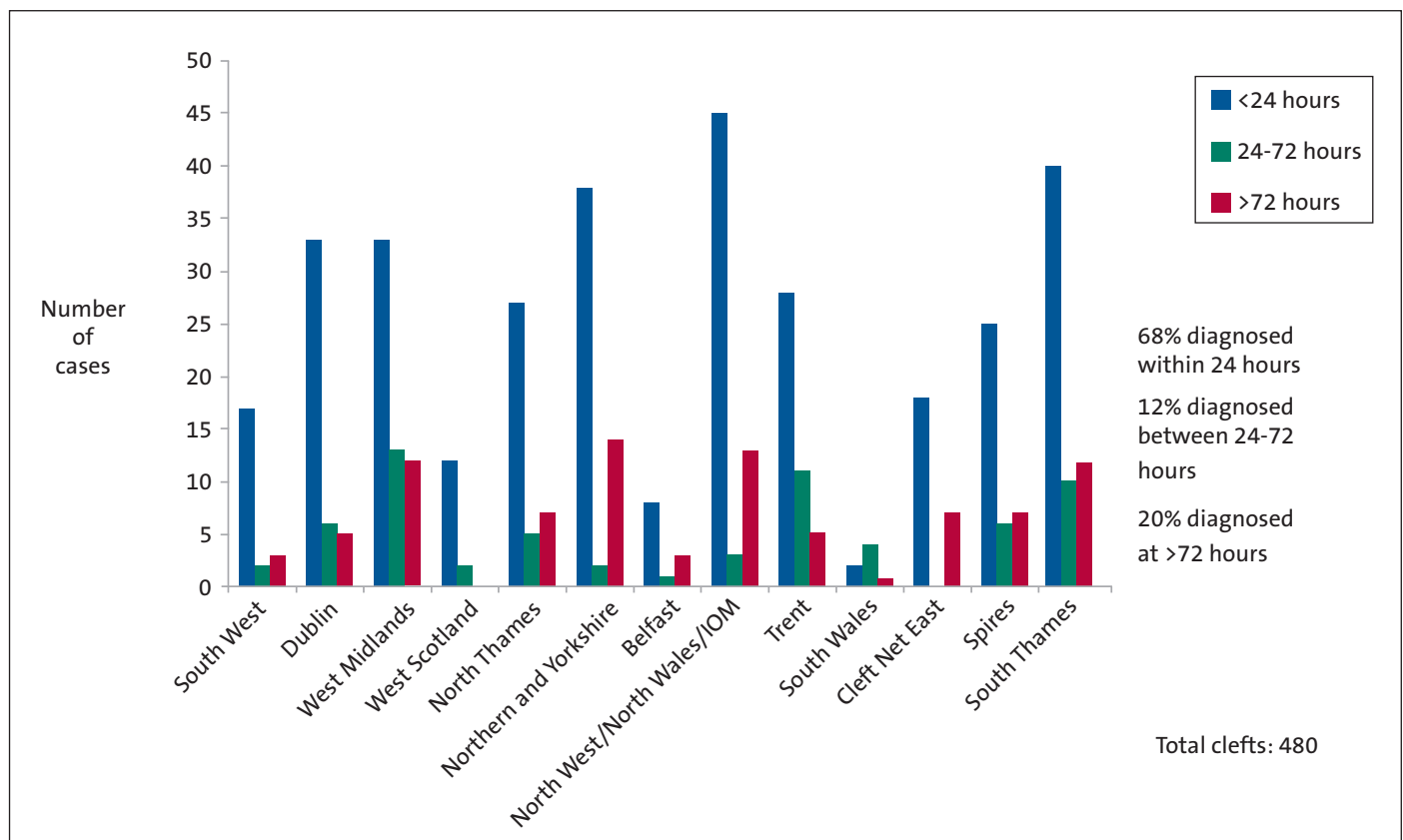

FIGURE 5 National data on timing of detection by cleft centres in the UK and Ireland for 2016. Data collected by the Cleft Specialist Nurses. Key: IOM = Isle of Man.

Infant Physical Examination Programme (NIPE), aims to detect anomalies within 72 hours.[15] The goalpost on timing of the newborn examination has moved over the years from being performed within the first 24 hours to an accepted 72 hours incorporating NIPE. Despite the extension in time, 18-20% of cleft palates were still not detected by 72 hours in 2015 and 2016.[16]

If a cleft palate is to be diagnosed at birth and referred within 24 hours then it must be examined earlier than the NIPE time frame. When is the ideal time? Should midwives be visualising the palate before the first feed; this is not current practice and is in juxtaposition with evidence-based recommendations on early skin-to-skin contact and initiation of breastfeeding.[17,18] However, examining the palate shortly after the first hour of skin-to-skin as part of an educational intervention has shown encouraging results.

Strategies for successful implementation

Successful implementation requires a coordinated systematic programme of instruction to existing and new practitioners performing the newborn examination. Educational interventions targeted at end users and employing local opinion leaders are more likely to change behaviour.[19] Clinical Nurse Specialists are the most obvious choice to encourage and monitor this; nationally the Clinical Nurse Specialists for Cleft Services have agreed to record both the 24 hour and 72 hour periods to provide feedback on the efficacy of efforts to reduce unnecessary delay (**FIGURE 5**).

■ Encourage midwifery staff to examine the palate after the first hour of skin-to-skin contact
■ Display reminders including posters in clinical areas and cards for staff
■ Have a notice alerting staff to the date of the last missed or delayed detection as an incentive to make this 'historical'
■ Highlight cases in structured teaching and morbidity meetings
■ Monitor and investigate all clefts missed at first examination or detected after 24 hours of age
■ Introduce the educational package.

The educational package

■ Incorporate the RCPCH eLearning module into trainee induction pro-

grammes for neonatology, paediatric and midwifery staff
■ Highlight the normal palate and cleft palate (**FIGURE 6**)
■ Use diagnostic models for 'hands on' experience of examining life-size orthodontic replicas of newborn clefts for a better understanding of why visualisation is superior to palpation (**FIGURE 7**).

Local impact at Medway Hospital

An educational package employing these strategies and led by a team of consultant neonatologist and regional clinical nurse specialists has been embedded in practice at Medway Hospital, Kent, since launch of the guidance. This has an added focus of monthly interactive teaching sessions with
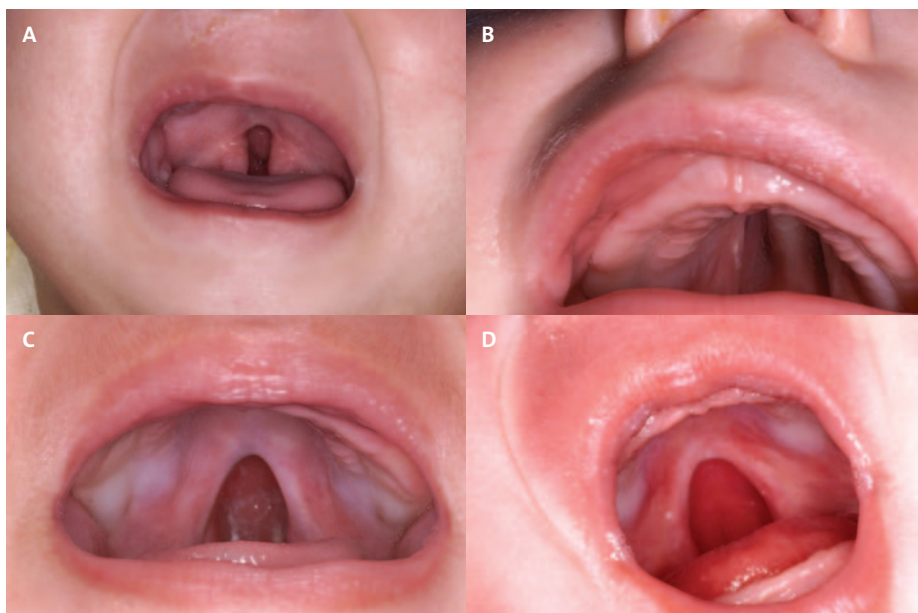

FIGURE 6 Examples of cleft palates. (A) a cleft of the soft palate, (B) a wide cleft of the hard palate – bony plates of the nasal septum are visible, (C) a narrow cleft of the hard palate, (D) a wide cleft of the hard palate.

FIGURE 7 Life-size silicone models of the palate. (A) Four normal and, (B) three sizes of cleft. *Photos courtesy of Marrbel Cleft Palate Diagnostic Models (mar-bel@mar-bel.co.uk).*

midwifery staff who are taught to examine the palate after the first hour of skin-to-skin contact. The collective intervention has shown a consistent reduction in the number of delayed clefts (**FIGURE 8**).[20]
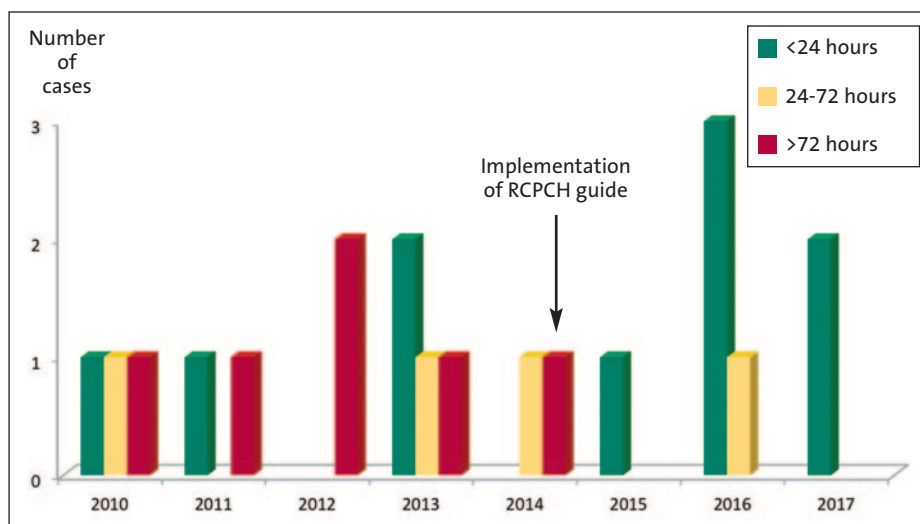

FIGURE 8 Time to detection of cleft palates at Medway Hospital.

Summary

Health professionals involved in the care of infants and young children should:

- examine the palate using a tongue depressor and torch
- encourage examination after the first hour of skin-to-skin contact and within 24 hours of age
- know the symptoms of a cleft palate
- implement a local educational package
- monitor and investigate delays in diagnosis.

Public Health England should consider the addition of palate as the fifth component of the NIPE: one in 1,500 babies has a cleft palate that requires treatment.

References

1. **RCPCH.** *Elearning.* Online at: http://rcpch.learningpool.com/course/view.php?id=291.
2. **RCPCH.** *Palate Examination: Identification of Cleft Palate in the Newborn.* 2014 Online at: www.rcpch.ac.uk/improving-child-health/clinical-guidelines-and-standards/published-rcpch/inspection-neonatal-palate [Accessed 31 October 2017].
3. **Stanier P., Moore G.** Genetics of cleft lip and palate: syndromic genes contribute to the incidence of non-syndromic clefts. *Hum Mol Genet* 2004;13: R73-R81.
4. **Bannister P.** Management of infants born with a cleft lip and palate. Part 1. *Infant* 2008;4:5-8.
5. **Masarei A.G., Sell D., Habel A. et al.** The nature of feeding in infants with unrepaired cleft lip and/or palate compared with healthy noncleft infants. *Cleft Palate Craniofac J* 2007;44:321-28.
6. **Hanny K.H., de Vries I.A., Haverkamp S.J. et al.** Late detection of cleft palate. *Eur J Pediatr* 2016;175: 71-80.
7. **Chapman K.L., Hardin-Jones M.A., Goldstein J.A. et al.** Timing of palatal surgery and speech outcome. *Cleft Palate Craniofac J* 2008;45:297-308.
8. Freedom of Information request 19.09.2017 (foi@resolution.nhs.uk).
9. **Habel A., Elhadi N., Sommerlad B., Powell J.** Delayed detection of cleft palate: an audit of newborn examination. *Arch Dis Child* 2006;91:238-40.
10. **Cleft Registry and Audit Network.** *Annual Reports on Cleft Lip and/or Palate 2009-2016.* Royal College of Surgeons, London. Online at: www.crane-database.org.uk.
11. **Armstrong H., Simpson R.M.** Examination of the neonatal palate. *Arch Dis Child Fetal Neonatal Ed* 2002;86:F210.
12. **Cleft Registry and Audit Network.** *Annual Report on Cleft Lip and/or Palate 2015.* Royal College of Surgeons, London. Online at: www.crane-database.org.uk
13. **Grimshaw J., Freemantle N., Wallace S.** Developing and implementing clinical practice guidelines. *Qual Health Care* 1995;4:55-64.
14. **Mitchel S.J., Gray J., Morgan M.E.** Nosocomial infection with *Rhizopus microsporus* in preterm infants: association with wooden tongue depressors. *Lancet* 1996;348:441-43.
15. **Public Health England.** *NHS Newborn and Infant Physical Examination (NIPE) screening programme.* Online at: www.gov.uk/topic/population-screening-programmes/newborn-infant-physical-examination [accessed 29 October 2017].
16. **Cathy Marsh.** Data from National Clinical Excellence Network for Cleft Specialist Nurses (personal communication).
17. **NICE.** *Postnatal Care up to 8 Weeks After Birth.* Clinical guideline [CG37] Published date: July 2006, last updated: February 2015.
18. **Lau Y., Tha P.H., Ho-Lim S.S.T. et al.** An analysis of the effects of intrapartum factors, neonatal characteristics, and skin-to-skin contact on early breastfeeding initiation. *Matern Child Nutr* 2017;e12492.
19. **Chauhan B.F., Jeyaraman M., Mann A.S. et al.** Behavior change interventions and policies influencing primary healthcare professionals' practice – an overview of reviews. *Implement Sci* 2017;12:3.
20. **McElroy H., Murphy G., Tuohy W.** G29(P) Implementing the RCPCH palate examination best practice guide leads to fewer delays in diagnosis of cleft palate. *Arch Dis Child* 2017;102:A13.