



Identifying and managing clinical risks in newborn babies

infant

PATIENT SAFETY

Working together

Edward Baker MD, FRCP, FCPCH Deputy Chief Inspector of Hospitals, Care Quality Commission
enquiries@cqc.org.uk

In England, one in every nine babies is born needing care from specialist neonatal services due to complications and this number is rising.¹ As babies with complex health needs require specialist care from different clinical teams, the journey of care for their families can be daunting, demanding and emotional as they navigate pathways of care between services. A lack of consistency in care and communication between staff and services themselves can result in poor outcomes for both babies and families.

Such concerns around inconsistent care and failures in communication are exemplified by the issues relating to the care and subsequent death of Elizabeth Dixon in 2001. Elizabeth was born prematurely and was cared for on a neonatal unit, but suffered brain damage after a failure to identify and manage her high blood pressure. Subsequently, Elizabeth had a tracheostomy tube to help her to breathe and she was discharged home. A package of care was commissioned locally to support Elizabeth's parents at home. Tragically, Elizabeth died shortly before her first birthday when there was a failure to correctly maintain her tracheostomy tube and to recognise that the tube was gradually occluding during the night.

In July 2016 the Care Quality Commission (CQC), the independent regulator of health and adult social care in England, published a thematic review into the areas of care that Elizabeth would have received. The review looked at the quality and variability of current care across the NHS, with the aim of identifying any gaps that need to be addressed as well as any opportunities for improvement.

The review, which focused on the management of newborn babies and infants with complex health conditions in hospital and in the community, examined three areas or 'pathways' of care:

1. Communicating and handing over fetal anomalies detected through screening
2. Diagnosing and managing newborn babies who may be at risk of deterioration (with a particular focus on high blood pressure)
3. Discharging and managing infants who need respiratory support (particularly tracheostomies) in the community.

Information for the review was collected from a range of sources; CQC worked with clinicians to review findings and identify themes and recommendations. Between September and December 2015, CQC inspectors discussed current practice with staff at 19 NHS acute hospital trusts and reviewed their clinical guidance documents. To help get a picture of the care for infants in the community who need long-term ventilation, CQC asked 16 clinical commissioning groups and eight long-term ventilation network leads about their current practice and challenges,

and spoke with 10 parents or guardians of children with respiratory support needs.

The review found that in the years since Elizabeth Dixon's death in 2001, there have been changes to the way neonatal services are provided and overseen, which suggest that they now operate in a very different environment.^{2,3} Reflecting this, CQC's review highlighted many examples of good practice but it also found variation between trusts, potentially due to the lack of national guidance about the management of at-risk babies and infants, and inconsistent processes to communicate information from one specialty team to another. CQC found that:

- Overall screening and referral processes are relatively effective with clear national guidance on screening for 11 specific physical and genetic anomalies and conditions as part of the NHS Fetal Anomaly Screening Programme.⁴ However, processes are less clear to guide staff when other anomalies are detected or suspected.
- There is no consistent process for transferring data from the mother's notes to the baby's notes at birth and the processes currently in use are often vulnerable to human error. A baby does not get an NHS identification number until he/she is born, which means that prenatal medical history must be stored within the mother's notes.
- Use of early warning observation systems such as the Newborn Early Warning Trigger and Track (NEWTT) tool⁵ varies across trusts. Some use these tools in a postnatal ward and some in a low-dependency neonatal unit, while others do not use any early warning tool at all.
- With one exception, the local guidelines reviewed at trusts focus solely on low blood pressure (hypotension), which could risk neonatal hypertension being overlooked. There are no national guidelines on how to identify hypertension in babies and children.
- Most trusts measure blood pressure routinely when a baby is admitted to a neonatal unit, but the frequency of measuring blood pressure after that is inconsistent, which could mean that problems associated with low or high blood pressure are missed.



- Some families whose children live at home and receive respiratory support in the community report a lack of confidence in care agency staff and are concerned that training for staff providing care in their homes has not been good enough. These findings are supported by comments from some long-term ventilation network leads and also echo findings of a report published in September 2014 by the Patient Experience Network.⁶
- There is variability among clinical commissioning groups and providers in: the expected timescales for discharge from hospital to home; what information is shared and with whom; the frequency of multidisciplinary team meetings and reviews of

home care packages; and the processes to receive feedback from parents or carers.

Based on the findings of this review, CQC made a number of recommendations to address inconsistencies in current practice (TABLE 1). These recommendations have been supported by the National Institute for Health and Care Excellence (NICE), the Royal College of Nursing, the Royal College of Paediatrics and Child Health, the Royal College of Midwives and the British Association of Perinatal Medicine, as well as a number of other organisations, all of whom have provided expertise and advice to CQC's review.

CQC's recommendations are aimed at encouraging appropriate organisations to work together, to further CQC's purpose of making sure that services continue to provide safe, effective, compassionate, high quality care and encouraging care services to improve the quality of care for patients.

1. There is need for guidance on the antenatal and postnatal identification and management of fetal anomalies, particularly focusing on recording, coordinating and communicating information between all stakeholders.
2. A fetus should be assigned a unique identification number linking medical data and other relevant information. This would resolve issues that arise when transferring data from the mother's notes to the baby's notes, and permit sharing of information about risks between specialist teams.
3. To help monitor newborn babies who are at risk, all trusts should use ongoing clinical judgement and assessment alongside a trigger tool (eg NEWTT).
4. There is need for guidance on assessment of blood pressure and management of hypertension in newborn babies and infants.
5. In its forthcoming guideline, NICE should include advice on the discharge pathway from hospital to home and caring for infants who need respiratory support in the home.
6. Commissioning of care should include the requirement that all staff providing care for infants needing long-term ventilation have appropriate training and competencies.
7. There is need for a good practice guideline on education and training to support nurses who provide care for infants with complex care needs, including those who need long-term ventilation at home.

TABLE 1 CQC's recommendations for additional guidance and clarity on practice to address inconsistencies identified in the review.

References

1. **Bliss.** *Bliss Baby Report 2015: Hanging in the Balance.* [Online]. Available at: www.bliss.org.uk/hanging-in-the-balance.
2. **Department of Health.** *Neonatal Intensive Care Review: Strategies for Improvement.* DH; 2003.
3. **National Audit Office.** *Caring for Vulnerable Babies: The Reorganisation of Neonatal Services in England.* [Online] 2007. Available at: www.nao.org.uk/press-releases/caring-for-vulnerable-babies-the-reorganisation-of-neonatal-services-in-england-2.
4. **Public Health England.** *NHS Fetal Anomaly Screening Programme.* [Online] Available at: www.gov.uk/government/collections/fetal-anomalies-screening-conditions-diagnosis-treatment.
5. **British Association of Perinatal Medicine.** *Newborn Early Warning Trigger and Track: A Framework for Practice.* 2015 [Online]. Available at: www.bapm.org/publications.
6. **Patient Experience Network.** *Children who are Long Term Ventilated.* NHS England; 2014.

To view the CQC report and the full list of recommendations visit: www.cqc.org.uk/sites/default/files/20160707_babyclinicalrisks_web.pdf

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