

# Identifying and managing clinical risks in newborn babies and providing care for infants in the community who need respiratory support



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**The Care Quality Commission is the independent regulator of health and adult social care in England.** We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

## Our role

- We register health and adult social care providers.
- We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- We use our legal powers to take action where we identify poor care.
- We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

## Our values

**Excellence** – being a high-performing organisation

**Caring** – treating everyone with dignity and respect

**Integrity** – doing the right thing

**Teamwork** – learning from each other to be the best we can



# Contents

FOREWORD .....	2
INTRODUCTION .....	7
FINDINGS AND RECOMMENDATIONS .....	9
<b>1. Detecting fetal anomalies and handing over care for babies with a suspected or known fetal anomaly between antenatal, obstetric and neonatal services .....</b>	<b>9</b>
Anomaly screening .....	9
Managing newborn babies with a fetal anomaly .....	13
Recommendations .....	15
<b>2. Identifying, and managing the care of, newborn babies whose condition could deteriorate (with a focus on diagnosing and managing hypertension) .....</b>	<b>16</b>
Managing newborn babies whose condition could deteriorate .....	16
Measurement and interpretation of blood pressure readings in newborn babies.....	18
Recommendations .....	20
<b>3. Managing care for infants in the community who need respiratory support (with a focus on managing respiratory support technologies, including tracheostomies) .....</b>	<b>21</b>
Discharge from hospital to home .....	22
Training and support for families .....	25
Skills and training for staff.....	29
Commissioning and supervision of home care .....	31
Recommendations .....	32
NEXT STEPS AND RECOMMENDATIONS .....	33
APPENDIX A: NHS FETAL ANOMALY SCREENING PROGRAMME CARE PATHWAY .....	35
APPENDIX B: LOCATIONS VISITED .....	36
APPENDIX C: LONG-TERM VENTILATION LEADS AND CLINICAL COMMISSIONING GROUPS CONTACTED .....	37
APPENDIX D: EXTERNAL STAKEHOLDERS CONSULTED .....	38
REFERENCES.....	39

# Foreword



Recent advances in technology have supported many improvements in care for newborn babies and infants who have complex health needs. Despite this, they remain a high risk and vulnerable group. In the NHS, teams of dedicated specialists provide care that affects not just the infant's life but the lives of their parents and wider families. The journey of care for families can be daunting, demanding and emotional – both physically and mentally – as they navigate pathways of care between services. Any lack of consistency in care or communication between staff and services can result in a poor outcome for both babies and families.

The focus of this review draws on one particular case that had a tragic outcome for a baby and her parents. Elizabeth Dixon was born prematurely but suffered brain damage as a result of missed high blood pressure. Because of these health needs, Elizabeth required support for her breathing, including a tracheostomy. She was discharged home with a package of care, but sadly died in 2001 shortly before her first birthday. There was a failure to correctly maintain her tracheostomy tube and to recognise that the tube was gradually occluding during the night. This meant that she slowly suffocated and was discovered dead in her cot.

While our review was not an investigation of the specific circumstances of Elizabeth's case, we did draw on this to examine current practice, systems and guidance used in three areas of neonatal care. There is no doubt about the dedication and skills of staff that provide this very specialist care – however we have found variable practice across the country, potentially because of an absence

of or lack of detailed national guidance.

Parents need to be confident that newborn babies who need the most complex care will receive the same high standards wherever they live. Similarly, families of children who need long-term ventilation at home need to be confident that they can rely on professional, well-trained staff to care for their child after they have left the secure and dependable surrounding of hospital. The safety of their children depends on it.

Throughout this review, we have worked closely with experts in neonatal and infant care and have observed current practice. We also listened to the experiences of families, and we thank them for providing this valuable human perspective. Our report makes recommendations to support improvements for infants and their families. We are grateful for the support of professional bodies and stakeholder organisations in considering and taking forward these recommendations.

**Professor Edward Baker**

Deputy Chief Inspector of Hospitals  
Care Quality Commission

# Summary

In England, one in every nine babies is born needing care from neonatal services and this number is rising.<sup>1</sup> Newborn babies may need extra care in a neonatal intensive care unit or special care baby unit if they were born prematurely or need care for a condition they were born with, or if their health deteriorates after birth. To detect anomalies during pregnancy (for example, congenital heart defects, neural tube defects or Down's syndrome) women are offered a range of tests to monitor progress and screen for specific conditions. After birth, hospitals provide neonatal care according to the needs of each baby.

Babies and infants who need long-term care can be transferred to a local unit or discharged to receive care in the community at home. However, the journey for a baby with complex health needs involves moving between distinct areas of care or 'pathways'. A lack of consistency in care and communication across a pathway can result in poor outcomes for both babies and parents.

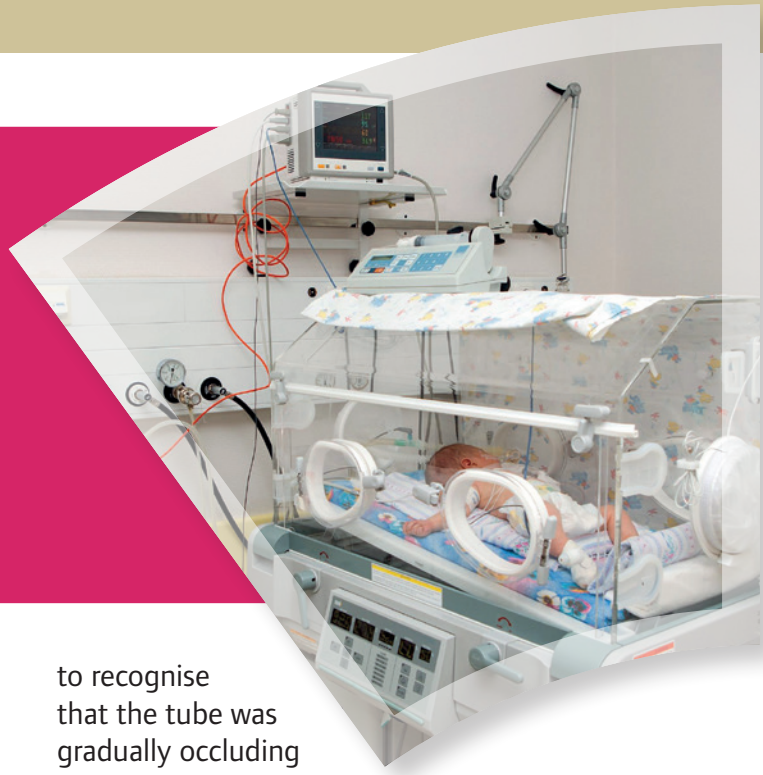
These concerns are exemplified by the issues relating to the care and subsequent death at home of Elizabeth Dixon in 2001. Elizabeth was born prematurely and was admitted and cared for on a neonatal unit, but suffered brain damage after a failure to identify and manage her high blood pressure. Subsequently, Elizabeth had a tracheostomy tube to help her to breathe and she was discharged from hospital to home. A package of care was commissioned 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. This meant that she slowly suffocated and died.

In 2014, the Care Quality Commission (CQC) offered to undertake a thematic review into the areas of care that Elizabeth would have received. CQC acknowledges the length of time since Elizabeth Dixon was cared for in the NHS, and this report is not part of an investigation into her death. We committed to undertake the review to focus on the quality and variability of **current** NHS care, to enable us to identify any gaps that need to be addressed. The aim of this review is to improve care for infants and their families by identifying opportunities for improvement and influencing the development of clear national guidelines. The detail in the report is of a technical clinical nature, as it is primarily intended for clinicians and policy-makers who shape these guidelines.

We looked at current practice in three different aspects of care that are associated with the care that Elizabeth would have received:

1. Detecting fetal anomalies and handing over care for babies with a suspected or known fetal anomaly between antenatal, obstetric and neonatal services.
2. Identifying, and managing the care of, newborn babies whose condition could deteriorate (with a focus on diagnosing and managing hypertension).



3. Managing care for infants in the community who need respiratory support (with a focus on managing respiratory support technologies, including tracheostomies).

Across England, NHS trusts are using a range of different processes to identify and manage clinical risk in newborn babies and infants. We believe that this inconsistency is partly a result of the limitations of the available national guidance, which is not sufficiently detailed for this area of care. There is a particular lack of:

- Detailed national guidance on managing fetal anomalies that may be detected prenatally, but which are not routinely screened for as part of the **NHS Fetal Anomaly Screening Programme (FASP)**.
- Best practice and benchmarking for the measurement of blood pressure in newborn babies and identification of hypertension.
- Commissioning standards or strategy around long-term ventilation for infants in the community.

For this review, CQC collected information from a range of sources followed by work with clinicians to review findings and identify themes and recommendations. This involved discussing current practice with staff at 19 NHS acute hospital trusts and reviewing their clinical guidance documents. To help us to get a picture of the care for infants in the community who need long-term ventilation, we obtained feedback from 16 clinical commissioning groups and eight long-term ventilation network leads. We also spoke with 10 parents or guardians of children with respiratory support needs, who belonged to long-term ventilation networks in Yorkshire & Humberside and the North East and South East of England. The experiences of these families provide an important perspective to this review. However, as we only spoke with a small number of families, their experiences may not be representative of care across England. Also, gathering evidence from care agencies was beyond the scope of the fieldwork for this review and we acknowledge this gap in our evidence.

## Our findings

We found that in the years since the death of Elizabeth Dixon 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. In many areas neonatal care is provided well, but national provision is inconsistent and there are still lessons that can be learned from Elizabeth's tragic death.

We found variability and inconsistent practice in each of the three aspects of care that we reviewed. The main reason for this may be the lack of national guidance about the best management of at-risk babies and infants and inconsistent local processes to communicate information from one specialty team to another.

### 1. Detecting fetal anomalies and handing over care for babies with a suspected or known fetal anomaly between antenatal, obstetric and neonatal services

- The overall screening and referral process is relatively robust, with clear national guidance on screening for 11 specific physical and genetic anomalies and conditions as part of the NHS Fetal Anomaly Screening Programme. However, clarity is needed for what happens when other anomalies are detected or suspected.
- The national guidance for NHS trusts on handling fetal anomalies, either prenatally or postnatally, and implementing transition between specialist teams is insufficient and could leave care open to inconsistency.
- There is no consistent process of transferring data from the mother's notes to the baby's notes and the current systems are vulnerable to human error. A baby does not get an identification (NHS) number until he/she is born, which means that prenatal medical history must be stored within the mother's notes.
- Hospital staff use different methods to communicate information about the fetus, including how they flag risks and who they share this information with.

Based on these findings, CQC recommends developing further guidelines to address the current lack of guidance on identifying and managing fetal anomalies, both before and after birth. We recommend that NHS England ask NICE to develop this. This would complement the guidance already available for the 11 anomalies that are routinely screened for by FASP.

We also recommend that a fetus should have a unique identification number that would link to its medical data and other relevant information. This would resolve issues in transferring this information from the mother's notes to the baby's notes when they are born, as this process is vulnerable to human error. Any fetal anomalies detected at or after birth that were missed by the screening midwives and sonographers could then be fed back to enable them to review and learn from them. In addition, any medical problems identified in later life would then have the potential to be more easily related back to antenatal factors.

## 2. Identifying, and managing the care of, newborn babies whose condition could deteriorate (with a focus on diagnosing and managing hypertension)

- Our visits found that use of the Newborn Early Warning Trigger and Track (NEWTT) tool varied across trusts as some used it in a postnatal ward and some in a low-dependency neonatal unit, while others did not use it or any early warning tool/trigger tool at all. To some extent, this variability is to be expected as the tool was only introduced in 2015. However, our findings from the review demonstrate that application of the tool is inconsistent.
- With one exception, the local guidelines reviewed at trusts focused solely on low blood pressure (hypotension), which could risk neonatal hypertension being overlooked. Most trusts measure blood pressure routinely when a baby is admitted to a neonatal unit, but the frequency of measuring blood pressure is not mandated and depends on the baby's condition.

- There are no national guidelines on how to identify hypertension in babies and children.

To address the inconsistency that we found around monitoring newborn babies who are at risk, CQC recommends that all trusts should use ongoing clinical judgement and assessment alongside a trigger tool such as NEWTT, or a similar tool. These tools should be validated and trusts should ensure that they are using them consistently in line with their intended use.

We also recognise the need for national guidance on which babies require blood pressure monitoring and the frequency of observations. CQC recommends that NHS England should ask the National Institute for Health and Care Excellence (NICE) to develop guidelines for assessing blood pressure and managing hypertension in newborn babies, infants and children, which should include the use of age-appropriate reference ranges.

## 3. Managing care for infants in the community who need respiratory support (with a focus on managing respiratory support technologies, including tracheostomies)

- In some clinical commissioning group (CCG) areas, specialist respiratory support and advice is not available to families 24 hours a day, seven days a week.
- Some families reported a lack of confidence in care agencies and spoke of their 'lack of faith' in agency care staff. A number of parents said agency care staff often seemed inexperienced and they felt the training for staff providing care in the home was inadequate. This was supported by comments from some long-term ventilation network leads.
- There is variability across CCGs and providers in the expected timescales for discharge from hospital to home; the information that is shared and who it is shared with; the frequency of multi-disciplinary team meetings and reviews of home care packages; and the processes to receive feedback from parents or carers.

NICE will be issuing a national guideline on neonatal services and CQC recommends that this should include both guidance on the discharge pathway from hospital to home and about caring for infants and children who need long-term ventilation in the home.

CQC also recommends that when commissioning care for infants who need long-term ventilation, commissioners should include the requirement that all staff providing the care have the appropriate training and competencies and do not work outside their sphere of practice. This area is also addressed by a recommendation for the Royal College of Nursing to consider developing a good practice guideline on education and training to support the competence of children's nurses who provide care for infants, children and young people who have complex care needs, including those who need long-term ventilation provided at home.

The full recommendations from this review are in the main body of this report.



# Introduction



In 2014, 661,496 live births were registered in England.<sup>2</sup> The NHS in England offers women a range of tests during pregnancy to monitor progress and screen for specific conditions (for example, congenital heart defects, neural tube defects or Down's syndrome). After birth, hospitals provide neonatal care according to the needs of each baby. In 2003, the Department of Health carried out a review of neonatal care and invested an additional £72 million between 2003 and 2006 into local neonatal networks to help implement the recommendations of the review.<sup>3</sup> These include providing specialist neonatal skills and expertise required to care for babies needing longer and more complex care when an anomaly has been detected, either during pregnancy or in a newborn baby. The National Audit Office (NAO) reviewed the implementation of the report's recommendations in 2007 and reported that the reorganisation of care into neonatal networks had improved the coordination, consistency and effectiveness of services, but that there were still capacity and staffing problems and a lack of clear data on outcomes.<sup>4</sup>

Babies and infants who need long-term care can be transferred to a local unit or discharged to receive care in the community at home. However, the journey for a baby with complex health needs involves moving between distinct areas of care or 'pathways'. A lack of consistency in care and communication across a pathway can result in poor outcomes for babies and parents.

These concerns are exemplified by the issues relating to the care and subsequent death at home of Elizabeth Dixon in 2001. Elizabeth was born prematurely and was admitted and cared

for on a neonatal unit but suffered brain damage after a failure to identify and manage her high blood pressure. Although this meant that Elizabeth needed a tracheostomy tube to breathe, she was able to be discharged home with a package of care to support her parents. 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. This meant that she slowly suffocated and died.

In 2014, the Care Quality Commission (CQC) offered to undertake a thematic review into the areas of care that Elizabeth would have received. CQC acknowledges the length of time since Elizabeth Dixon was cared for in the NHS, and this report is not part of an investigation into her death. We committed to undertake the review to focus on the quality and variability of **current** NHS care, to enable us to identify any gaps that need to be addressed.

We looked at current practice in three defined aspects of care that are associated with the care that Elizabeth would have received:

1. Detecting fetal anomalies and handing over care for babies with a suspected or known fetal anomaly between antenatal, obstetric and neonatal services.
2. Identifying, and managing the care of, newborn babies whose condition could deteriorate (with a focus on diagnosing and managing hypertension).

3. Managing care for infants in the community who need respiratory support (with a focus on managing respiratory support technologies, including tracheostomies).

Throughout this review, we consulted external stakeholders with relevant expertise and representatives from a range of bodies (see appendix D). These bodies have supported the focus and approach of the review, and advised on the findings and recommendations.

## How we carried out the review

To gather evidence for the first two aspects of care, we visited 19 NHS acute hospital trusts (see appendix B). The evidence for this was largely sourced by asking staff a set of questions and discussing the practice in their trust. In some cases, this was also supported by reviewing the trust's clinical guidance documents.

Few of the NHS sites we visited for this review were involved in transferring infants who need long-term ventilation from hospital to home. Therefore, to enable us to get a good picture of this third aspect of care, we used our powers under Section 48 of the Health and Social Care Act 2008, which enabled us to carry out a special review of how NHS health care services are provided in England. We contacted clinical commissioning groups (CCGs) as well as long-term ventilation network leads in the local areas that we visited and asked them about their processes for:

- Discharge from hospital to home
- Training for families
- Support for families
- Skills and training for staff
- Commissioning and supervision of home care.

We also asked long-term ventilation network leads to identify parents or guardians who would be willing to talk to us about their experiences of caring for their children at home using respiratory support technologies. We wanted to include these stories in our report to give their perspective. We received feedback from 16 CCGs, eight long-term ventilation network leads and spoke with 10 parents or guardians of children with respiratory support needs. We are grateful to the families who gave their time to talk to us about their experiences.

# Findings and recommendations



## 1. Detecting fetal anomalies and handing over care for babies with a suspected or known fetal anomaly between antenatal, obstetric and neonatal services

### KEY FINDINGS

- The overall screening and referral process is relatively robust, with clear national guidance on screening for 11 specific physical and genetic anomalies and conditions as part of the **NHS Fetal Anomaly Screening Programme**. However, clarity is needed for what happens when other anomalies are detected or suspected.
- The national guidance for NHS trusts on handling fetal anomalies, either prenatally or postnatally, and implementing transition between specialist teams is insufficient and could leave care open to inconsistency.
- There is no consistent process of transferring data from the mother's notes to the baby's notes and the current systems are vulnerable to human error. A baby does not get an identification (NHS) number until he/she is born, which means that prenatal medical history must be stored within the mother's notes.
- Hospital staff use different methods to communicate information about the fetus, including how they flag risks and who they share this information with.

### Anomaly screening

Since 2002, the British Isles Network of Congenital Anomaly Registers (**BINOCAR**) has collected data to provide epidemiological monitoring of the frequency, nature and outcomes of congenital anomalies for different regions within the British

Isles. Public Health England (PHE) took over the role of BINOCAR in April 2015 and will continue to expand the registers. Data is collected on all suspected and confirmed congenital anomalies identified before birth, at birth or in childhood.

From the BINOCAR data,<sup>a</sup> the total birth prevalence of congenital anomalies in 2012 was estimated to be 243 babies with one or more anomaly per 10,000 total births.<sup>5</sup> According to BINOCAR data, 61% of babies with a screened congenital anomaly were diagnosed through antenatal screening in 2012.<sup>b</sup> While this figure may be an overestimate<sup>c</sup>, there has nonetheless been a significant upwards trend in the efficacy of screening since 2007, when 44% of anomalies were detected antenatally.

### What should happen?

All eligible pregnant women in England are offered tests to screen for specific physical and genetic anomalies and conditions as part of the NHS Fetal Anomaly Screening Programme (FASP). This aims to ensure equal access to uniform and high-quality-assured screening and information so that women can make an informed choice about their screening and pregnancy options. FASP was established in 2003 and is now part of Public Health England. Women are offered a dating scan at around eight to 14 weeks and a mid-pregnancy scan between 18 and 21 weeks of pregnancy to assess the risk of the baby being born with Down's or Edward's/Patau's syndromes, or a number of other fetal anomalies (see appendix A).

The NHS sets out care pathways for the fetal anomaly scan, with specific guidelines for 11 audited diagnoses.<sup>6,7</sup> Although national guidance, including treatment options and a referral pathway, is available for these 11 screened congenital anomalies, there is a lack of guidance for other anomalies beyond the generic antenatal care pathway for mid-pregnancy scans (appendix A). Feedback from external stakeholders who provided advice for this review suggests that an area of concern is in the handover between

specialist teams along this referral pathway. For all anomalies detected before birth, communication across specialities is essential. Where major fetal anomalies are identified, there should be multi-disciplinary meetings that include staff from obstetrics, fetal medicine and neonatal specialists. In some hospitals this is routine, but the external stakeholders suggested there is variation in current practice.

A series of key documents identifies national standards and existing guidance that is in place, including:

- Fetal Anomaly Screening Programme (FASP) Handbook 2015, which covers the screening and referral pathway.
- FASP Standards 2014-2015, which include eight recommended standards along the screening and referral pathway.
- NHS FASP Failsafe Processes v1.1 2011, which identify failsafe points along the screening and referral pathway to help ensure quality assurance.
- FASP documents that describe conditions screened for, including diagnostic tests and treatment options.<sup>8</sup>

To direct the focus of our review, our inspection teams used a set of questions that relate to this specific aspect of care. The evidence was largely sourced from discussions with staff about the practice at trusts. In some cases, this was also supported by reviewing a trust's clinical guidance documents and patient case notes. The information that we were able to collect relating to the detection and handover of fetal anomalies was variable in detail and content, which limited our ability to quantify variation in practice.

### What we found in relation to anomaly screening

Among the trusts where information was available, it appeared to be normal practice to offer a 20-week anomaly scan to pregnant women, as required in the Fetal Anomaly Screening Programme. We were also able to obtain details of how some trusts followed up women who did not attend scanning appointments (referred to as 'DNAs'). These

a. BINOCAR does not currently have full coverage of all areas of England or the British Isles.

b. For cases where timing of diagnosis is known (86% of all cases).

c. The true proportion of anomalies detected through anomaly screening is likely to be lower because BINOCAR registers may not have been updated at the time of reporting to include anomalies that were diagnosed postnatally.

included having a designated role responsible for following up DNAs; creating dashboards to monitor DNAs; recording consent/decline of screening in handheld notes, and offering a second appointment to these women.

It was common practice across trusts to give written information about screening to women, such as the UK National Screening Committee's leaflet *Screening tests for You and Your Baby*. Some trusts also told us that interpreters were available during consultations for women who do not speak English as a first language.

In most trusts, we found evidence of how the screening and referral process was audited, although there was variation between trusts in

which elements of the screening and referral pathway were audited. In some cases, trusts were auditing compliance with, and effectiveness of, local or national guidelines for the screening process. One trust specified that its screening guidelines were audited in line with relevant standards from the NHSLA's Clinical Negligence Scheme for Trusts' Maternity Clinical Risk Management Standards. Several trusts audited the effectiveness of the screening programme by monitoring detection rates for specific anomalies against targets. A few trusts reviewed the findings from audits at meetings, and developed and monitored action plans. One trust had recently implemented a new electronic auditing system.

### GOOD PRACTICE IDENTIFIED ON OUR VISITS



On one visit, we noted a clear escalation process for women who did not attend scanning appointments. This was explained in written guidance, which included the process to follow for missed routine anomaly scans, other scan appointments and repeat nuchal scan appointments. Roles and responsibilities for following up were clearly designated depending on the circumstances. These involved antenatal clinic (ANC) clerks, ANC midwives, community midwives, GPs, sonographers, sonographer clerks, fetal medicine unit/day care midwives, and a vulnerabilities team. There was also a clear process for the documentation, with all hospital DNAs being recorded in hospital records along with arrangements for following up.

In some trusts, there was a dedicated 'screening coordinator' who monitored the screening process, arranged follow-up scans, facilitated communication between various teams and individuals (including community midwives) and was available to provide ongoing advice and support to women.

### RISKS IDENTIFIED ON OUR VISITS



Fetal medicine midwives from one trust raised the issue that they were often not made aware of the congenital anomalies that were only detected after postnatal discharge, and were therefore unable to feed back any potential learning into the screening process.

At the same trust, these midwives also identified issues with the Congenital Anomaly Register, in that it is a paper form that cannot be completed and submitted until the baby has been born and assigned an NHS number. They felt it would be more efficient and less prone to errors if there was an electronic system that could be updated in an ongoing way from detection of fetal anomaly, using an alternative identification number for the unborn baby.

## What we found in trusts when a suspected anomaly is identified

It was common practice for local hospitals to refer anomalies suspected at the 20-week scan to the fetal medicine unit (FMU) at a tertiary centre<sup>d</sup> (as per the FASP pathway for fetal anomaly scan). In tertiary centres, it was common practice for women to be referred to a fetal medicine specialist within the trust, or to other specialist centres where appropriate (for example, for cardiac anomalies). However, not all the trusts that we visited had written guidelines on the screening and referral pathways for fetal anomalies.

From the information that we collected, we saw that trusts aimed to refer to a FMU within the timeframes recommended by FASP (three to five days), although some trusts aimed to make referral appointments to the FMU within 24 to 48 hours.

There was limited evidence collected from local hospitals on further diagnostic testing before birth and further management, since this is mostly handled by the FMU at a tertiary centre. However, we did identify that some of the local hospitals we visited offered further investigation or second scans within the trust before referring to a FMU. Some tertiary centres confirmed that where a fetal anomaly is detected, the fetal medicine specialist will arrange an ongoing plan of care depending on the individual circumstances of the pregnancy. This may include referral for further specialist imaging, for example, an MRI scan and/or referral to neonatal, specialist paediatric services or to clinical genetics. We also saw that some trusts offered immediate or same day referral to on-call obstetric medical teams, antenatal clinics or paediatric consultants for initial reviews or counselling regarding the suspected anomaly. In several trusts, we were advised that midwife sonographers were trained in counselling and in giving bad news to enable them to meet the emotional needs of the mother, where required. In other trusts, consultants lead on breaking bad news to the mother.

d. Tertiary centres are usually larger or more specialised hospitals that receive referrals from another healthcare organisation, such as a local hospital or primary care service.

## Communication

Communication around the management plan for mother and baby was variable across the trusts we visited. Specifically, information sharing varied in relation to the means of communication, the way in which risks were highlighted and the various teams and individuals that had sight of the information.

Methods of communication included:

- Alert forms generated when a fetal anomaly was diagnosed. These forms included detailed care plans formulated by paediatric/neonatal consultants to notify the practitioners providing subsequent care.
- Multi-disciplinary team meetings to discuss current, challenging cases.
- Documenting the management plan and discussions relating to care in hospital and maternal handheld records.

## Highlighting risks

There was variability in the way that trusts flagged risks such as fetal anomalies in the maternal record. Some trusts used a sticker on the front of the maternal record. However, one tertiary centre identified this as a risky approach, since many cases involved risks and if there was a failure to use a sticker, staff may not check the record for risks. They decided it was safer to always check the detail within the maternal record.

Some trusts used uniquely coloured forms or folders to readily identify information from a particular source. For example, all communication from a tertiary centre was on yellow paper, or a neonatal alert form to share information across teams was always on green paper.

## Involving all required teams and people

We found variability across trusts in the different teams that would receive a copy of alert forms. We also found that the composition of multi-disciplinary teams varied across trusts, and that discussions and actions relating to care were not always copied into the maternal handheld records.

## GOOD PRACTICE IDENTIFIED ON OUR VISITS



A local hospital described a 'phone a friend' relationship with a tertiary centre, allowing consultants to contact specialist tertiary centre consultants if they had any concerns.

We found one trust that had built and maintained its own database of historical care plans for high-risk pregnancies or deliveries. The lead neonatal consultant referenced new cases against this and adapted them or got specialist advice where necessary. However, there was a risk as the maintenance and rigour of this database/process relied on one clinical lead, and this was not an embedded process.

## RISKS IDENTIFIED ON OUR VISITS



At one trust, we identified that women may receive a variable quality of care as the referral process was inconsistent, with some women being referred 'in-house' and others referred externally for a second scan for a suspected anomaly.

Another trust used a neonatal alert form that was an unstructured letter containing information deemed relevant by the neonatal consultant. The lack of an embedded process or structured form and the reliance on communication from a single consultant made this process vulnerable to errors.

In a couple of trusts, the delivery and postnatal care plans entered on the neonatal alert form were only shared a few weeks prior to the expected delivery date, which could cause problems if delivery was early.

Not all letters to the neonatal team in one trust were copied to the woman, her GP or the community midwives.

Staff in a couple of trusts highlighted a risk of poor communication regarding appointments with women or updates to care plans that come back from another trust or from the tertiary centre back to the local centre.

Our findings reflect those from published reports. The Perinatal Mortality Surveillance Report 2013 highlights the importance of providing complete data and also suggests information that is "readily available in the mother's notes" is not being transferred to the appropriate teams.<sup>9</sup>

The National Maternity Review, *Better Births*, also highlighted the need for "the NHS to make it much easier for health professionals to collect and share data with each other and with those for whom they care. This means... investing in electronic, interoperable maternity records, from which data can be inputted once and can feed the data demands made of the service from Trusts, CCGs and the Maternity Service Data".<sup>10</sup>

## Managing newborn babies with a fetal anomaly

### What should happen?

The majority of babies, with or without a detected fetal anomaly, will be born in hospital. In England and Wales, only 2.3% of pregnant women give birth at home.<sup>11</sup> Women expecting a multiple birth or babies in a breech position may be advised to give birth in hospital. However, there is currently no recommendation regarding place of delivery for women who continue with a pregnancy that has a fetal anomaly. These babies may therefore be delivered in hospital or at home. Before making a decision about where to give birth, women receive advice

about the distance and time it takes to travel to hospital. If a woman decides to give birth at home and additional medical help is needed during the delivery, the midwife will then make arrangements for transfer to hospital. Where a baby is born with an anomaly, handover from obstetrics or midwifery teams to the neonatal team should be prompt.

There are guidelines for the management of babies born with any of the 11 anomalies routinely screened for in NHS hospitals.<sup>7</sup> Where anomalies have not been detected before birth, they may be picked up as part of routine physical examinations undertaken at birth and when they are six to eight weeks old to detect major physical anomalies.<sup>12</sup> These include screening for congenital cardiac defects, developmental dysplasia of the hip, some ocular disorders (including congenital cataract) and undescended testes, as well as a general physical examination. The newborn physical examination is usually carried out in hospital before the mother and baby go home, but it can also be done at a hospital or community clinic, GP surgery, children's centre, or at home. The Newborn and Infant Physical Examination (NIPE) screening programme is currently being rolled out across the country. This is offered within 72 hours of birth and aims to detect less obvious adverse conditions or anomalies.

A series of key documents identifies the national standards and existing guidance that is in place. These include:

- NICE CG190 Recommendations for Initial Assessment of Newborn Baby 2014
- NIPE Programme Handbook.<sup>13, 14, 15</sup>

## What we found

The information that we collected on our visits to trusts showed that delivery wards would contact the neonatal unit when a woman was admitted with a known fetal anomaly and keep them informed of progress. It was common practice for neonatal units to hold a copy of the neonatal alert form, or the action plan for care of the baby, in their expected deliveries folder. This aimed to help the neonatal unit to prepare for new admissions and to facilitate the handover from obstetrics.

The evidence that we were able to gather on our visits to trusts showed that they are using immediate newborn examinations and NIPE.

Feedback from our external stakeholders who advised on this review suggests that an area of concern is the transfer of information from the maternal to the newborn baby's records, which is a key component of handover.

Our visits showed that different trusts are using a range of different processes to transfer information from the mother's notes to her baby's notes. These included:

- Ad hoc processes, for example, manually transcribing or photocopying relevant information from the mother's notes to the baby's notes.
- Prescribed processes, for example, duplicating a set form, such as a neonatal alert form, that contains all key information and placing a copy in the newborn baby's notes.
- Comprehensive processes, where all information relevant to the baby is stored in a separate pocket with the maternal notes. This folder is then transferred in its entirety to the newborn baby's record.
- Linking the newborn baby's notes to the mother's notes electronically, and keeping paper copies together physically.



## GOOD PRACTICE IDENTIFIED ON OUR VISITS



We identified good multi-disciplinary handover in one trust, which ensured timely communication between specialist teams around care for newborn babies with congenital anomalies. This involved:

- Daily morning meetings between the delivery suite coordinators and the consultant paediatrician or neonatal intensive care coordinator. This was to review the admission board and share information about clinical activity on the delivery suite and availability on the special care baby unit, to ensure that it was aware of potential transfers to the department. Schedules were then coordinated to ensure that specialist staff were available when required.
- A consultant-led multi-disciplinary handover meeting held every morning and evening on the central delivery suite. This ensured that all staff were aware of the treatment and care plans of women who needed care from obstetrics.

At another trust, staff used a separate coloured pocket within the mother's handheld notes to hold all information relevant to the baby before and after birth, including the neonatal alert. This was then transferred in its entirety into the newborn baby's folder to reduce the need to take the maternal notes away from the delivery suite, and also to reduce the problem of transcribing errors.

## RISKS IDENTIFIED ON OUR VISITS



On one visit, we identified a lack of any antenatal clinical notes within newborn babies' notes, including scans, as a potential safety risk.

Neonatal data have to be manually entered into the BadgerNet patient data management system, which is not electronically linked to maternity records. In one trust, the neonatal consultant stated that the task of entering this data is often only carried out when there is sufficient time, which could make it prone to error, such as omitting important information.

## RECOMMENDATIONS

1. NHS England should ask NICE to develop guidelines on the antenatal and postnatal identification and management of fetal anomalies to complement the guidance available for the 11 anomalies that are routinely screened for by FASP. This guidance should focus particularly on recording, coordinating and communicating information between all key stakeholders, including counselling for parents.
2. A fetus should be assigned a unique identification number, to which all its medical data and other relevant information are linked. This would resolve issues that arise when transferring data from the mother's notes to the baby's notes. It would also facilitate feedback to the screening midwives and sonographers where fetal anomalies are detected at or after birth so they can review any missed anomalies and learn from them. In addition, any medical problems identified in later life would then have the potential to be more easily related back to antenatal factors.

## 2. Identifying, and managing the care of, newborn babies whose condition could deteriorate (with a focus on diagnosing and managing hypertension)



### KEY FINDINGS

- Our visits found that use of the Newborn Early Warning Trigger and Track (NEWTT) tool varied across trusts as some used it in a postnatal ward and some in a low-dependency neonatal unit, while others did not use it or any early warning tool/trigger tool at all. To some extent this variability is to be expected given the tool was only introduced in 2015, however at present our findings demonstrate application of the tool is inconsistent.
- With one exception, the local guidelines reviewed at trusts focused solely on low blood pressure (hypotension), which could risk neonatal hypertension being overlooked. Most trusts measure blood pressure routinely when a baby is admitted to a neonatal unit, but the frequency of measuring blood pressure is not mandated and depends on the baby's condition.
- There are no national guidelines on how to identify hypertension in babies and children.

The World Health Organisation (WHO) defines the neonatal period as the first 28 days of life. Quality standards from the National Institute for Health and Care Excellence (NICE) provide clinicians, managers and people who use services with a description of what high-quality specialist care should look like and what they should be able to expect from the NHS. Quality Standard 4 (QS4) addresses the high-level care provided for babies in need of specialist neonatal services<sup>16</sup> and is endorsed by the British Association of Perinatal Medicine (BAPM), the Royal College of Obstetricians and Gynaecologists, the Royal College of Midwives, the Royal College of Paediatrics and Child Health and BLISS, the charity to support families of premature and sick babies. Providers of care can use this standard for self-assessment, for monitoring by commissioners of care and in inspection visits such as those made by CQC.

### Managing newborn babies whose condition could deteriorate

#### What should happen?

A series of key documents identifies the national standards or existing guidance for providers, including:

- NICE CG190 Recommendations for Initial Assessment of Newborn Baby 2014<sup>13</sup>
- NHS Newborn and Infant Physical Examination: Standards and Competencies 2008<sup>14</sup>
- British Association of Perinatal Medicine: Newborn Early Warning Trigger and Track (NEWTT) A Framework for Practice, April 2015.<sup>17</sup>

In addition, NHS England has developed a free online resource, **Re-ACT**, the Respond to Ailing Children Tool, which focuses on paediatric deterioration.<sup>18</sup>

The NEWTT framework is a new tool that has been developed to monitor the clinical progress of newborn babies that belong to ‘high risk’ groups (see risk factors below). It provides a standardised process of heightened surveillance to help staff primarily in maternity units to recognise and monitor babies at risk of clinical deterioration. It includes a traffic light system to aid visual identification of abnormal parameters and the appropriate escalation actions that should follow.

The tool is designed to be used in delivery suites and postnatal ward areas. In certain circumstances, it may be appropriate to use the tool in other settings such as special care units (SCU), transitional care units (TCU) and even community settings.

The following risk factors have the potential to put babies at risk of clinical deterioration following birth and therefore trigger the use of NEWTT:

- Sepsis
- Gestational diabetes
- Maternal beta blockers
- Birthweight  $\leq$  2nd centile
- Intrapartum compromise evidenced by meconium-stained liquor (requiring intervention), low APGAR scores, low cord pH or low base excess
- Intermittent positive pressure ventilation  $>$  5 minutes
- Maternal pethidine  $<$  6 hours before delivery
- $<$  37 weeks gestation.

Observation charts based on work by Roland et al enable staff to monitor the vital signs of newborn babies, refer to agreed acceptable values, track a baby’s progress and determine whether management needs to be escalated.<sup>19</sup> This requires a suitable number of staff who are able to make, record and interpret accurate observations and clear communication pathways with neonatal services to escalate care where appropriate.

The report of the Morecambe Bay Foundation Trust investigation highlights the importance of assessing risks properly.<sup>20</sup> The report referred to a ‘wait and see’ approach, whereby, “babies may be relatively well during the first hours of life

but then deteriorate rapidly to the point where highly intensive care is required: as a result of the ‘wait and see’ approach...”. This highlights the importance of NEWTT or a similar tool being used in all trusts alongside clinical judgement.

To direct the focus of our review, our inspection teams used a set of questions that relate specifically to this aspect of care. The evidence was largely sourced from discussions with staff about the practice at their trusts. In some cases, this was also supported by a review of the trust’s clinical guidance documents and patient case notes. The information that we were able to collect in relation to identifying newborn babies whose condition could deteriorate and managing their care, including the diagnosis and management of neonatal hypertension, was variable in detail and content. This presents a challenge to quantifying variation in practice.

### What we found

Trusts varied in their use of NEWTT (or other similar early warning score systems) to detect babies whose health is deteriorating. Where trusts were using NEWTT, or similar tools, it was commonly on postnatal wards or in low dependency neonatal units. Several trusts were trialling NEWTT, while others were planning to introduce it in the future. However, a few trusts said they did not use NEWTT or any other similar tool. To some extent this variability is to be expected as NEWTT was only introduced in 2015. However, there is a need to evaluate the tool in the future to ensure that trusts are using it consistently, in line with its intended use.

One trust described an alternative observation tool that they were trialling to detect deteriorating newborn babies, which was called the ‘First hour of care’ pathway. This trust was also using the ‘Neuroprotection Care Pathway’ (NCP-1) for diagnosis and initial management of hypoxic ischaemic encephalopathy (brain injury caused by oxygen deprivation to the brain). Where we were able to collect evidence, we saw that it was normal practice to have escalation and transfer policies for newborn babies who were seriously unwell.

## GOOD PRACTICE IDENTIFIED ON OUR VISITS



In one trust, we saw clear written guidelines on immediate care of newborn babies, which stated that a plan of care should be made soon after birth that takes into consideration any known risk factors and any highlighted in the initial assessment. It stated that the level of observations should be appropriate to the risk factors and that in some infants more than one risk factor may be identified. Where no risk factors have been identified, the midwife should carry out routine daily observations that include: colour, temperature, respirations, cord, eyes, urine and stools.

## RISKS IDENTIFIED ON OUR VISITS



In one trust, we saw that black and white photocopies of NEWTT were being used because the cost of colour photocopying was too expensive. The inspector identified that this renders the red and amber alert colouring as useless, and is therefore a safety risk.

## Measurement and interpretation of blood pressure readings in newborn babies

### What should happen

The definition of hypertension (high blood pressure) in children and adolescents is based on the normative distribution of blood pressure in healthy children. Hypertension is defined as average systolic blood pressure (SBP) or diastolic blood pressure (DBP) that is greater than the 95th percentile for gender, age, and height on at least three separate measurements.

Normal blood pressure in newborn babies depends on a variety of factors, including gestational age, postnatal age, and birth weight. Because the incidence of hypertension in healthy newborn babies is very low (estimated at one in 500 babies or 0.2%) routine screening is not recommended. However, hypertension is more common among 'at-risk' newborns, including babies admitted to NICUs, and ranges from 0.7% to 2.5%, which is equivalent to as many as one in every 40 babies who are deemed 'at risk'.<sup>21</sup>

While there is information on normal blood pressure in both premature and term babies, treatment criteria in infancy remain controversial. One study suggests that there should be

separate guidance on monitoring blood pressure in infants over three years and in those under three years of age.<sup>22</sup>

The gold standard technique for measuring blood pressure in newborn babies remains direct measurement by intra-arterial analysis (measuring blood pressure internally using a sensitive catheter inserted into an artery), but less invasive methods have also proved effective, are easy to use and allow blood pressure to be followed over time.<sup>23</sup>

The most common concurrent conditions in babies with raised blood pressure include the effects of using antenatal steroids, maternal hypertension, acute renal failure, and chronic lung disease.<sup>24</sup> In 2004, the USA National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents set recommendations for a defined group of infants below the age of three who should be screened for hypertension.<sup>25</sup> Although this guidance is being used in some local guidelines, there are currently no nationally endorsed guidelines for this area.

## CONDITIONS THAT SHOULD TRIGGER BLOOD PRESSURE MEASURING IN CHILDREN YOUNGER THAN THREE YEARS

- History of prematurity, very low birth weight, or other neonatal complication requiring intensive care
- Congenital heart disease (repaired or non-repaired)
- Recurrent urinary tract infections, haematuria, or proteinuria
- Known renal disease or urologic malformations
- Family history of congenital renal disease
- Solid-organ transplant
- Malignancy or bone marrow transplant
- Treatment with drugs known to raise blood pressure
- Other systemic illnesses associated with hypertension (such as neurofibromatosis, tuberous sclerosis).

### What we found

There is evidence of variation in the monitoring of blood pressure in newborn babies. A number of trusts noted that neonatal hypertension is rare and a couple of trusts told us they would not look to diagnose it in isolation, but rather it would be assessed in the context of other vital signs of the baby.

Only one trust that we visited had developed guidelines that specifically outlined diagnosing neonatal hypertension. In other trusts, the guidelines we reviewed around monitoring neonatal blood pressure most commonly related to identifying hypotension (low blood pressure), though these did include normal ranges for blood pressure that could enable hypertension to be identified.

Sources of guidance for best practice on diagnosing hypertension were variable, and ranged from: none; contacting a specialist trust (such as Great Ormond Street Hospital) for advice; contacting the trust's nephrology

consultants for advice; reading peer-reviewed clinical journal articles; transferring knowledge from experienced staff and referring to guidelines such as *A Manual of Neonatal Intensive Care and Neonatal Guidelines* (Robertson & Rennie); and *Neonatal Guidelines 2015-2017* (Staffordshire, Shropshire and Black Country Newborn and Maternity Network) and international guidelines such as the *Neonatal Handbook*.<sup>26</sup>

There was general recognition among clinicians at the trusts we visited that blood pressure varied according to gestational age and weight, and interpretation required 'within individual' comparisons.

Where blood pressure was being measured, it was routinely carried out on admission to the neonatal unit and was not measured in other wards. However, in a couple of trusts that had special care baby units or local neonatal units, blood pressure was not routinely measured on admission, even though in one of these cases it was the trust's policy to do so.

We saw that the frequency of recording blood pressure depended on the condition of the baby being monitored. For low-dependency cases, blood pressure was usually measured using non-invasive cuffs, while continuous monitoring was measured by an arterial line for babies in intensive care. One trust's nephrology<sup>e</sup> team used a sphygmometer and Doppler to give accurate systolic measurements.

We saw that any member of staff (registered nurse, doctor or midwife) who has completed the appropriate competencies is authorised to take and record blood pressure.

e. The branch of medicine that deals with the management of infants or children who have diseases affecting the kidneys.

## GOOD PRACTICE IDENTIFIED ON OUR VISITS



One trust had just developed a local guideline that emphasised recognising hypertension as well as hypotension. This included risk factors for hypertension and benchmarks for diagnosing hypertension in term and preterm newborn babies, as well as normal ranges by weight, gestation and age.

## RECOMMENDATIONS

1. To help monitor newborn babies who are at risk, all trusts should use ongoing clinical judgement and assessment alongside a trigger tool, for example NEWTT, or a similar tool. These tools should be validated and trusts should ensure that they are using them consistently in line with their intended use.
2. There is a need for national guidance on which babies require blood pressure monitoring and the frequency of observations. NHS England should ask NICE to develop guidelines on assessment of blood pressure and management of hypertension in newborn babies, infants and children, to include the use of age-appropriate reference ranges.

### 3. Managing care for infants in the community who need respiratory support (with a focus on managing respiratory support technologies, including tracheostomies)



#### KEY FINDINGS

- In some clinical commissioning group (CCG) areas, specialist respiratory support and advice is not available to families 24 hours a day, seven days a week.
- Some families reported a lack of confidence when using care agencies and spoke of their 'lack of faith' in agency care staff. A number of parents said agency care staff often seemed to be inexperienced and they felt the training for staff providing care in the home was inadequate. This was supported by comments from some long-term ventilation network leads.
- There is variability across CCGs and providers in the expected timescales for discharge from hospital to home; the information that is shared and who it is shared with; the frequency of multi-disciplinary team meetings and reviews of home care packages; and the processes to receive feedback from parents or carers.

Neuromuscular disease, airway disease, lung disease, thoracic insufficiency syndromes, central breathing disorders and spinal cord injuries may leave a child unable to maintain adequate breathing on their own and in need of long-term respiratory support. These children may require long-term ventilation. Assisted ventilation may be required 24 hours a day, such as in spinal cord injury, but where there is some respiratory reserve, such as in cases of neuromuscular disease, children may only need to be ventilated at night. This nocturnal assistance allows respiratory muscles to rest and can improve the child's daytime quality of life. Ventilation can be invasive, delivered through a tracheostomy, or non-invasive, delivered through a non-invasive interface such as a mask or through nasal prongs.

Ventilation needs have been defined by the National Framework for Children and Young People's Continuing Care on three levels:

- **High** (Level 1): Child is able to breathe unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm.
- **Severe** (Level 2): Child requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.
- **Priority** (Level 3): Children with no respiratory drive at all who are dependent on ventilation at all times, including those with no respiratory drive when asleep or unconscious who require ventilation and one-to-one support while asleep as disconnection would be fatal.<sup>27</sup>

Babies with a tracheostomy cannot correct their body position or manipulate a displaced tracheostomy tube themselves and so are a particularly vulnerable age group. Infants who

are tracheostomy-ventilated are generally under the lead care of a paediatric respiratory service in a tertiary hospital because of the complexity of care. Infants who have a tracheostomy but are not ventilated may also be managed by the paediatric respiratory service or by ear, nose and throat (ENT) specialists.

Children who need long-term ventilation have a comparatively poorer health-related quality of life<sup>28</sup>, but this can be improved by managing their ventilation needs at home rather than in hospital.

The NHS supports home care for children who need long-term ventilation. It is recognised that these children need some of the most complicated care that can be delivered outside of hospital, but the risks of home care must be balanced against the benefits of leading as normal a life as possible, at home with their parents and families.

There is currently no coordinated national data collection of the numbers of children requiring long-term ventilation support at home, and individual centres maintain their own patient databases. However, the Paediatric Critical Care Reference Group estimates that there are about 250-275 tracheostomy-ventilated children managed out of hospital in England, with a further 1,000-1,300 children requiring non-invasive ventilation managed under a specialist respiratory team.<sup>29</sup>

## Discharge from hospital to home

### What should happen?

The NHS England service specification for paediatric long-term ventilation sets a clear pathway for all long-term ventilated children whose pathways of care begin in paediatric or neonatal critical care. The specification states that all services should adhere to the service standards set out by the West Midlands Quality Review Service published in December 2013 and updated in April 2015.<sup>30</sup> The service specification states that every ventilator-dependent child who is an inpatient in hospital and needs a Complex Home Care Package (CHCP) should have:

- An identified Hospital Key Worker (HKW) or team of HKWs responsible for multi-disciplinary discharge planning.
- A weekly assessment of medical stability and readiness for discharge.
- Specialist review at three, six, and 12 months after hospital discharge.<sup>29</sup>

There are a number of discharge planning tools in use that are designed to increase the efficiency of the discharge planning process, including a web-based system developed by the Royal Brompton Hospital, which acts as a decision support tool.<sup>31</sup>

Before being discharged home, children on long-term ventilation can often remain in hospital for extended periods until they are medically fit for discharge and while they wait for a home care package to be arranged. While the NHS aims to provide home care for these children, the length of hospital stay from identification of the need for long-term ventilation to discharge averages at between seven and nine months – a figure that has barely improved over the last 20 years.<sup>32</sup>

There should be an assessment of the level of nursing support that will be required once the child is discharged into the community. A number of needs assessment tools are available nationally for the UK, which can be used to regularly review the nursing care package.<sup>33</sup> Community nursing and occupational therapy teams should risk assess the home environment and provide guidance to help children and families adapt to changes in everyday life. They should also ensure that families have access to support once the child is transferred into the community.

Staff who provide care to a child in the home – from both the NHS and those from a private care agency – should receive appropriate training and supervision.

The process of discharge planning and set-up at home may take several months for children in hospital who are medically fit for discharge but have complex care needs. Each case, and each family, is different and the transition to home care must be tailored to each child's ventilation needs and the ability of the parents to deliver those needs.



## What we found

The NHS antenatal, fetal medicine and neonatal services that we visited as part of this review were mostly not involved in transferring infants with long-term ventilation needs from hospital to home. Therefore, to develop a picture of the care for infants in the community who need long-term ventilation, we obtained feedback from 16 CCGs and eight long-term ventilation network leads. We also spoke with 10 parents or guardians of children with respiratory support needs who belonged to long-term ventilation networks in

Yorkshire & Humberside and the North East and South East of England. The families we spoke with provide an important perspective to this review (we have changed names to protect their identities). However, it should be noted that their views may not reflect experiences of care across England because of the small number of families we were able to speak with and their limited geographic representation. It is also important to note that gathering evidence from care agencies was beyond the scope of the fieldwork for this review and we acknowledge this gap in our evidence.

### FAMILY EXPERIENCE: MIA

Mia was born three weeks early with a complex cardiac condition and had multiple operations on her heart and lungs, culminating in one of her lungs being removed.

Mia was fitted with a tracheostomy when she was two and a half months old. Although she was originally expected to be in hospital for only six weeks, she ended up staying in hospital until she was 14 and a half months old when she had recovered sufficiently to be discharged home.

Mia's mother felt her discharge from hospital was managed well, as everything was put in place before she got home. A discharge planning meeting was held two weeks before she was due to go home and another one a week before discharge. All the equipment had been installed before she got home. The respiratory nurses from the tertiary centre organised a humidifier for bedtime, chargers, extra plug sockets and all the equipment that Mia needed during the night.

However, at the time of discharge, Mia's mother felt that she was being pushed to accept a care package, even though she wanted to care for Mia herself:

*"At first I did think they were trying to push us to have a care package and I thought it was being forced upon me, but then obviously I did sit and speak in front of everybody, and... as soon as I said 'she's my little girl, I've missed out on 14 months, it's now my turn', they sort of took a step back".*



The feedback received from CCGs and long-term ventilation leads revealed inconsistency in which guidelines different organisations use for the management of tracheostomies and patients on long-term ventilation. Many just referred to the guidelines of the local tertiary centre, while others mentioned use of the Royal Brompton and Harefield's Hospital to Home Long Term Ventilation Pathway and/or guidance produced by Great Ormond Street Hospital. A few CCGs mentioned use of the West Midlands Quality Standards for Long term Ventilation and the NHS England Service Specifications for Paediatric Long Term Ventilation.

All CCGs stated that multi-disciplinary team (MDT) meetings were coordinated by the tertiary centre before an infant was discharged. These meetings included the infant's parents, their lead community children's nurse, the lead consultant in paediatric respiratory medicine from the tertiary centre and a respiratory specialist nurse or physiotherapist. The picture was more mixed as to whether the infant's GP or the community paediatrician were invited to MDT meetings before they were discharged. In cases where the GP was not invited, CCGs told us that they were almost always informed of the discharge plans.

For the frequency of multi-disciplinary meetings before discharge, nearly all CCGs said they held them as and when necessary, although a couple of CCGs scheduled fixed monthly meetings.

Most CCGs said the tertiary centre's training programmes/packages for parents would assess their capability to care for their child. However, several CCGs indicated they were not aware of what risk assessment processes the tertiary centre had in place to assess the suitability of parents to manage a child with complex respiratory needs.

All CCGs that responded to us said that continuing care service assessments for the child included assessing the child's long-term ventilation needs in hospital, visits to the child's home in the day and at night, phased transition to home, provision of breathing equipment, drug therapies and medication, nutrition and hydration (including nasogastric gastrostomy and total parenteral nutrition (TPN) feeding arrangements) and mobility. All but one CCG said continuing care service assessments also covered

continence care, bathing, washing and hygiene and basic life support arrangements.

In most cases, CCGs said that multi-disciplinary reviews after discharge from hospital would take place as necessary. However, a few CCGs stated that there were no multi-disciplinary reviews once a child had been discharged.

There was variability in the expected timescales for discharge. Many CCGs stated that the length of time depended on the complexity of the case. Several CCGs cited the need for suitable housing, including making necessary adaptations, as a leading cause of delays. One of our external stakeholders suggested that another barrier to efficient, timely discharge is often the difficulty in the recruitment and training of nurses or carers to provide care in the child's home.

All but one CCG had a dedicated person to coordinate discharge, though the positions responsible for this function varied (for example, specialist nurse, children's community nurse, continuing care children's nurse).

## FAMILY EXPERIENCE: ISABEL



Isabel's mother described how Isabel was born with a congenital diaphragmatic hernia:

*"All the organs in her body were pushed up into her chest and crushed her lungs". She was put on a ventilator but had difficulty being weaned off it, so was given a tracheostomy when she was three weeks old. She re-herniated a few times and was in hospital for 10 months before being discharged.*

When it came to discharge planning, Isabel's mother told us: *"We didn't have a choice in what care we could have. [The community provider] took it to a board and decided that way... she has to be watched 24/7, but we only got awarded three nights. People in different areas get awarded different amounts. It does make a difference where you live."*

Isabel's mother did not think the discharge from hospital was managed very well: *"We could have been home a lot sooner; [the community provider] didn't really want to accept her at first. They were meant to come and inspect our home, and they didn't do that for months on end. They were very slow at doing what they were doing, it felt like they were not trying to get us home as quickly as we should have been, there wasn't enough staff [at the community provider] and they couldn't take us.*

*There was always something to stop us coming home. We were told we were going home at Christmas - we could have gone home at Christmas. Then it was January, and then it was February, March and I think then she re-herniated... then that stopped us going home but, obviously we could have been at home, it wouldn't matter if she re-herniated at home, she could have gone back to the hospital. But it was the fact that it took so long for them to do anything before moving, so we were very frustrated and upset about how it was handled."*

In most CCG areas, specialist respiratory support and advice was available to families 24 hours a day, seven days a week, once the infant was home. However, a few CCGs indicated that this level of support was not available. This raises questions as to which services families are expected to contact during those times when specialist care is not available.

### GOOD PRACTICE IDENTIFIED FROM CCGS



One CCG told us that it has worked with the Royal Brompton Long Term Ventilation Hospital to Home team to develop its pathway to include guidance on sharing information and advice to the local team about procuring equipment. This CCG has also carried out a research project to identify the experiences of families that care for a child with long-term ventilation needs, so that it can improve the experience of discharge for all families.

## Training and support for families

### What should happen?

Our external advisors to the review advised that there is an expectation for parents to be trained by staff at the tertiary centre before their child's discharge home and that they are expected to be competent in all of their child's ventilation needs. This is also a key outcome in the NHS Service Specification for paediatric long-term ventilation (E07/S/c), which states that appropriate training should be provided to parents and carers "to enable the child to be cared for safely in the home environment." Most centres will stipulate a number of competencies that need to be achieved, including, for example, airway suction, tracheostomy care, tracheostomy change, use of a humidifier, basic life support, bag and mask ventilation, and management of enteral tube feeding systems.

The West Midlands Quality Review Service standards state that each service that commissions or provides NHS-funded care for

children and young people needing long-term ventilation should offer information to children, young people and families that covers:

- What the service provides
- The staff and facilities available
- How to contact the service for help and advice, including during 'out of hours' periods.

The standards also state that children, young people and families should be offered discussion and access to written information about their long-term ventilation, including:

- A description of their condition and its impact.
- Equipment and a user guide or manual on how to use it, including guidance on preventing problems and what to do if they occur, maintenance and storage and how to return equipment when no longer needed.
- Medication and information on what it is for, when to take it, storage and possible side effects.
- Guidance on managing acute and chronic changes in health.
- Lifestyle advice, including nutrition, exercise and travel.
- Housing and housing adaptations.
- Emotional, spiritual and psychological support for children and young people and for their families, including siblings.
- Benefits advice, Personal Health Budgets and how to access charitable and voluntary sector resources.
- Transport and mobility.
- Other local services available for children and young people with complex care needs and how to access them.
- Advance Care Planning (if appropriate).
- Relevant voluntary organisations and support groups.
- Where to go for further information, including useful websites.
- A personalised care plan with names and contact details for their 'key worker'.<sup>30</sup>

## What we found

The training provided to families was largely consistent across CCGs. All CCGs indicated that there were mechanisms to ensure that family training is durable and kept up to date and that opportunities for retraining were available.

Most of the long-term ventilation leads told us that they felt the training and support

provided to families was adequate. However, a couple of leads felt that it was inadequate. One commented that this was as a result of only having one nurse to support the long-term ventilation service, while the other stated that they can only train and prepare parents while the child is an inpatient, and that any further training needed after discharge depends where the family lives and the resources and expertise available within services in their area.

### FAMILY EXPERIENCE: DYLAN



Dylan was born prematurely with two conditions: a diaphragmatic hernia and tracheoesophageal fistula and atresia, both of which affected his ability to breathe.

The first time he was discharged home from hospital was at 14 weeks when he was on nasal ventilation. However, Dylan had to return to hospital again at 19 weeks where he was in intensive care for six months until he was discharged home again with a tracheostomy just after his first birthday. Dylan's mother described two very different experiences of being trained and supported to care for Dylan at home in each case.

*"I don't think I was supported well enough when I went home... The first time we went home with nothing. Nobody came out, nobody assessed the home; nobody gave me any contacts to get back to anybody. We had open access to [the tertiary centre]. They hooked us up with our local community nursing team [but] I didn't even meet them before we got home, I met them once I was at home."*

*If you have a child who requires assistance in staying alive, I think that there should have been a support network [with] somebody to call on... I never met our community nursing team and didn't have a point of contact until I was already home."*

*The [oxygen company] came the day I got home... the guy showed me how to use the machine. That was it, and off he went. It was terrifying, really frightening. I didn't have any medical training and any insight."*

But the second time Dylan was discharged home was different: *"It was absolutely amazing. It was a bit intense but much better than the previous time. I got to meet [the lead nurse], before Dylan actually went on to [the specialist respiratory ward], bless her, she came to meet me and tell me what her role was, how she was going to help me on the ward and any questions, she was there for that, she was absolutely brilliant. They taught me how to do the suction and how to change the trachy... So they prepared me to go on to [the specialist respiratory ward], and then I would step up, I became Dylan's main carer, with the nurses as support."*

Dylan's mother spoke highly about the specialist respiratory ward: *"The nurses were fabulous, and they let me take over. The nurses never ever did anything with Dylan, they didn't need to do anything with his trachy, and they never suctioned him. "I administered all his meds... I took over – I was ready to do it, it was my child, I wanted Dylan to be with his mum."*

*Once I was home, [the respiratory nurses] were fabulous in keeping in touch. [They] were probably my support network and still are. I've got [their] numbers on my mobile phone... Last year Dylan had the chicken pox, but the first person I phoned wasn't my GP, who I have a fabulous relationship with as well, it was [the respiratory nurse]."*

The majority of CCGs that responded to us said that long-term ventilation and tracheostomy care plans were reviewed as necessary, with a couple stating this took place monthly and one saying it took place weekly initially. The frequency of reviews of home care packages was more variable, with most CCGs saying this took place as necessary but several others saying it took place on a more routine basis at three, six or 12-month intervals.

All the CCGs said that infants who needed long-term ventilation were provided with a key worker.

They also all said that they give information to families that covers:

- Agreed goals.
- The name and contact details of their community children's nurse.
- The name and contact details of their key worker.
- The name and contact details of the paediatric respiratory nurse or physiotherapy specialist.
- The name and contact details of the children's long-term ventilation service consultant at the tertiary centre.
- Contact details for the home support service.
- Escalation plans as well as emergency and advanced care planning.
- Information about equipment and medication.
- Information on how to manage acute and chronic changes in health.
- Options around short breaks.
- Therapeutic interventions (pharmacological and non-pharmacological).
- Information on weaning off ventilation (if applicable).
- Planned review date.

Most CCGs that responded also provided the following information to families:

- How to access 24/7 specialist respiratory support.
- Responsibilities and arrangements for staff while working in the family home.
- The name and contact details of the community paediatrician.
- Housing adaptations.
- Emotional and psychological support for the whole family.
- Lifestyle advice, including nutrition, exercise and travel.
- Religious, spiritual and cultural needs.
- Transport arrangements and transport needs.
- Benefits advice, personal health budgets and how to access charitable and voluntary sector resources.
- Relevant voluntary organisations and support groups.
- Where to go for further information, including useful websites.

## FAMILY EXPERIENCE: ISABEL



Isabel's mother told us about the information provided by the hospital about Isabel's condition.

*"I didn't find a lot out through the hospital as such; I found a group on the internet, a charity group [CDH UK] that really told more. There wasn't even a pamphlet to understand it or anything... It was just so hard to take in what people were trying to say. They do explain it a little bit, but not as much as they could.*

*They used a lot of words I didn't understand... they just said 'we believe she needs a tracheostomy', by then we didn't really know too much about the trachy to be honest. We hadn't seen anybody with a trachy, so we didn't really know too much about it. It was after she had it, we had more information... I didn't think there was enough beforehand.*

*We got a lot more information once we had actually met the respiratory nurse. She is very easy to talk to, you could drop her a message and she would be there straight away explaining it all. She was so good, she was around most days. She really, really knows her stuff, she was the one that went through everything with us because she went into, not technical terms, she put it simpler terms so we understood it."*

There was a mixed picture from CCGs as to whether the infant's GP was told about the information that families had been given.

CCGs used a variety of ways to enable families to provide feedback on care. Many CCGs said they did this through discussions between the care team and the family, but some used broader feedback systems such as patient advice and liaison service (PALS) and the Friends and Family test.

## GOOD PRACTICE



One parent that we spoke with identified peer-to-peer support for families as good practice:

*"When we were in hospital, there was a little one that was going to have a tracheostomy and the nurses had asked if I would talk to the mum, because she had wanted to speak to somebody else that had a trachy. And actually she found it really helpful to be able to ask some of the questions that maybe the nurses did not know the answers to. They prepare you as much as they can for coming home but actually they don't know what it is like at home. Whereas I could answer exactly what she was asking."*

## RISKS IDENTIFIED ON OUR VISITS



One long-term ventilation network lead identified that psychological support services were not automatically offered to families of children with complex ventilation needs. Some parents echoed this sentiment, saying that counselling was either not offered or not followed up:

*"I haven't been [offered counselling], which I do think I would have benefitted from. Now, I am actually seeing a counsellor and I have just been diagnosed with post-traumatic distress disorder, which is really difficult to talk about and go through and to actually accept. It has affected the way that I am capable of looking after [all my children]. I do feel quite anxious a lot of the time, but I think that it's only because I've realised that myself and asked my GP to be referred for some help, but I think in hospital, it should definitely be talked about because it wasn't one of the things that got talked to about."*

## Skills and training for staff

### What should happen?

According to the West Midlands Quality Review Service standards, anyone with professional caring responsibilities for children and young people on long-term ventilation should have, and should maintain, competencies appropriate to their role in a minimum of the following:

- Ventilation
- Resuscitation
- Transporting ventilated children<sup>f</sup>
- Professional boundaries
- Child safeguarding
- Working in the home environment (where applicable)
- Infection control and disposal of clinical waste.

All healthcare professionals should also be offered regular clinical supervision appropriate to

f. Some sections of the Standards apply only to children who have more complex needs (Level 2 and Level 3).

their role at least quarterly. This should include ‘safeguarding supervision’.

### What we found

Responsibility for training home care staff varied depending on how the care was commissioned and delivered. There were also different approaches to ensuring that training was comprehensive, delivered to the appropriate standard and kept up to date. Some CCGs suggested that training was under frequent review. Some stated that the details of training and updates or reviews were included within the agency contracts. Others provided more detailed responses on how they assured themselves that they delivered appropriate training and standards. One CCG used competent, qualified staff to deliver training who then performed a minimum of an annual review. This training included shadowing others in families’ homes and practising emergency scenarios every other month. Staff also undertook continuing professional development and had study days, with training records kept up to date and monitored.

### FAMILY EXPERIENCE: DANIEL



Daniel’s foster parents started caring for him when he was 18 months old. Daniel had been diagnosed with a cardiac condition, fetal alcohol syndrome and lung disease and had been cared for in hospital until that time. He has a tracheostomy and is on ventilation 24 hours a day and so needs continuous care. Daniel’s care package currently includes care every night and four part-time days in the week. His foster mother describes her experience of home care staff in their home:

*“We have had a lot of different carers. The first lot of carers we had was from the NHS and they were amazing. Very confident in them, and then they all got made redundant, now the [local hospital] don’t have carers... We had to go to an agency; I don’t feel as confident anymore in the agency as I did with the NHS. They’re not trained as well, they don’t know the equipment as well as they have not been in the job like the NHS.*

*What we have now done is put an emergency bell into our bedroom so the minute there’s the slightest problem they can ring the bell and we just go and deal with it... We have caught one asleep. It is really hard having carers; it’s not as easy as it sounds.*

*There are a couple of them that are absolutely brilliant with Daniel; but there’s a couple of them I don’t find are child friendly with him, they can be quite abrupt. I would expect them to be more friendly and child friendly with him and they’re not. I have commented on this with the agency about one of them. I never see her communicating with him or playing with him and he is an early riser. They’re here until 7:30 so if he’s up at 6am they need to be playing with him and they’re not. They’re just sitting in the chair really, doing their notes and he just sits in his cot.”*

Nearly all CCGs said clinical supervision is offered to staff who care for infants in need of long-term ventilation and tracheostomy, as well as supervision on safeguarding issues.

Half of the long-term ventilation leads who responded to our request for information felt that training provided to care staff was adequate, although one of these leads added that there were challenges due to high staff turnover. Another commented that, “the system works best where packages are closely overseen by our community nursing teams. In my experience, some commercial teams can be less robust in their practices.”

The remaining half of long-term ventilation leads responded that training was not adequate. In the context of care provided in the community, one lead noted:

“Community teams do not get the same training and experience as staff within a tertiary service. They do not see ventilated children very often and don’t often have enough staff to care for them in their local hospital. These children may be clinically stable but they often have high nursing need.”... “There is not enough study time to allow primary care staff to spend time in a tertiary service to get experience.”

Another LTV lead raised concerns around the training and competencies of private care agencies:

“I have reservations [about] the current system, whereby private agencies secure staff who have not had adequate high volume training in large respiratory centres with patients similar to what they are expected to look after in the community. It is clear that some of the staff have had the most rudimentary training (‘see one, do one’) and yet are expected to care for children that many non-respiratory paediatric wards with trained RSCN [registered sick children’s nurse] would refuse to take. In my opinion, the only way such staff could be deemed competent would be to undertake training within a large respiratory centre where they would repeatedly face genuine emergencies and learn to deal with them. This is how we train the parents where they effectively live in the hospital with their child learning under the direct supervision of trained staff.”

Long-term ventilation leads also noted concerns around staffing and training in tertiary centres and the impact of this on the provision of care within hospital and the ability to support training of community teams. One lead noted:

“There is a lack of long-term staff on the wards with long-term ventilation and non-invasive ventilation experience as there is a high turnover of staff.”... “As a tertiary service, we often do not have enough resources to do regular follow-up training in the community and support hands-on training to get people competent.”



## FAMILY EXPERIENCE: LILY



Lily was born with a diaphragmatic hernia and was given an emergency tracheostomy when she was two hours old. She was discharged home from hospital at 10 months old. Lily was given a care package that included nine hours of care every night. Lily's mother describes her impressions of the carers:

*"To begin with we had a few carers that weren't great; a few kept falling asleep on the night shift. It was very stressful at home to begin with, knowing who you can trust, and the care agency weren't amazing. They never covered a full week and we were always left short... Then we decided to make the decision to go to a personal budget and to get rid of the carers that were obviously making all the mistakes for Lily. Now her dad and my sister do it and it is much happier."*

*I don't feel like we were given enough information from the care agency... about the training of the carers. All they gave us was that they're tracheostomy-trained; well, there's different levels to be trained on a tracheostomy and how much knowledge you have behind it. But all they said is: 'yeah, they're tracheostomy-trained'; they didn't really go into much detail. Some of them weren't tracheostomy-trained. There was one that couldn't suction her tracheostomy properly to the point of where Lily nearly went blue and I had to run in and sort her out. We ended up saying that she wasn't coming back. And there was another one who had no training whatsoever, but the care agency had told us that she had."*

*[The care agency] said it's very hard to find carers that are trained in such specialist things, which sounds understandable... but we'd rather not be lied to about their training."*

The findings from our review concerning the training of home care staff echo those in a study conducted by the Patient Experience Network, which said "Finding, training and retaining good quality carers is an ongoing issue for all. Parents are looking for carers who are competent, confident and right for their child. One parent spoke of a carer who came to look after their baby and they had never even changed a nappy before."<sup>28</sup>

## Commissioning and supervision of home care

### What should happen?

A Network Care Package Review Board should offer multi-professional and multi-agency advice to local commissioners on decisions about care packages.

According to the West Midlands Quality Review Service standards, commissioners should regularly review the quality of services provided

by children's long-term ventilation services. Appropriate action should be taken to tackle any issues identified through quality monitoring.

### What we found

Most CCGs told us they ensured that the continuing care packages met the needs of the infant and their family through assessment or reviews, including multi-agency reviews in some cases. CCGs also said they asked the family for feedback to gauge whether care packages met their needs.

Most CCGs had their own local monitoring and reviewing processes in place to ensure that home care arrangements were delivered to a given standard.

Several long-term ventilation leads highlighted the disparity of services provided in the community across different areas, including disparity in the provision of equipment and in the number of days of home support provided per week to children with similar health needs.

A few long-term ventilation leads had concerns around the quality of commercial providers that were being commissioned to provide staff for care packages, with one lead noting that although they worked hard to highlight safety concerns, ultimately the CCGs made the decisions.

A couple of leads noted the lack of national standards to support management of these patients both in hospital and at home. One specifically noted that there didn't appear to be any standards for commissioners to follow when commissioning home support, and that commissioners, or their representatives, seemed to have very little experience in the management of this patient group.

Long-term ventilation leads also noted issues around ineffective collaboration between hospital and community services, and insufficient staffing and time to manage a growing patient group. One said, *“There is an apparent lack of a joined-up approach and usually individual care packages need to be bid for ad hoc. There is also a variability of community provision and reliance on a stretched hospital-based nursing team.”*

## RISKS IDENTIFIED BY CCGs



CCGs commonly cited the need for services to recruit and retain appropriate numbers of suitably trained staff as a key issue. One CCG acknowledged that recruiting staff for care packages may take some time and cause delays in discharging infants from hospital, but said there is a risk that “adhering to timescales becomes the focus rather than the safety of the child. Threats of delayed discharge cannot be more important than a safe discharge.”

A couple of CCGs also highlighted coordination of services as a challenge, including the need to have sufficient links between tertiary centres and local services in the community.

Other risks highlighted by CCGs included issues relating to funding and appropriate housing, provision of equipment, managing the diversity of cases and managing parental expectations.

## RECOMMENDATIONS

1. In its forthcoming guideline on neonatal services, NICE should include guidance on the discharge pathway from hospital to home and about caring for infants and children who need long-term ventilation in the home.
2. When commissioning care for infants needing long-term ventilation, commissioners should include the requirement that all staff providing the care have the appropriate training and competencies and do not work outside their sphere of practice.
3. The Royal College of Nursing should consider developing a good practice guideline on education and training to support the competence of children's nurses who provide care for infants, children and young people who have complex care needs, including those who need long-term ventilation provided at home.

# Next steps and recommendations



We have found variability in the way that different NHS trusts identify and manage clinical risk in newborn babies and infants in the areas of practice we considered in this review. We believe that this inconsistency is as a result of the limitations of available guidance and agreed best practice. We have identified specific areas where additional guidance and clarity on practice is needed. These include:

- The identification and management of fetal anomalies prenatally and postnatally.
- Information-sharing about risks between specialist teams, including how information is transferred from the mother's notes to the baby's notes.
- The measuring and benchmarking of blood pressure in newborn babies and identifying hypertension.
- The pathway of care for infants requiring long-term ventilation in the home.

To support improvements in these areas of care for infants and their families, we have discussed our findings and recommendations with relevant professional bodies and stakeholders to ensure that they are considered in developing future guidance.

We did not approach care agencies for this review, but in light of the issues raised, by both the case of Elizabeth Dixon and also by some of the parents we spoke to, there could be scope for another body to carry out a further, more detailed review of how care agencies manage infants in the community who are in need of respiratory support.

## Recommendations

### 1. Detecting fetal anomalies and handing over care for babies with a suspected or known fetal anomaly between antenatal, obstetric and neonatal services

1. NHS England should ask NICE to develop guidelines on the antenatal and postnatal identification and management of fetal anomalies to complement the guidance available for the 11 anomalies that are routinely screened for by FASP. This guidance should focus particularly on recording, coordinating and communicating information between all key stakeholders, including counselling for parents.
2. A fetus should be assigned a unique identification number, to which all its medical data and other relevant information are linked. This would resolve issues that arise when transferring data from the mother's notes to the baby's notes. It would also facilitate feedback to the screening midwives and sonographers where fetal anomalies are detected at or after birth so they can review any missed anomalies and learn from them. In addition, any medical problems identified in later life would then have the potential to be more easily related back to antenatal factors.

### 2. Identifying, and managing the care of, newborn babies whose condition could deteriorate (with a focus on diagnosing and managing hypertension)

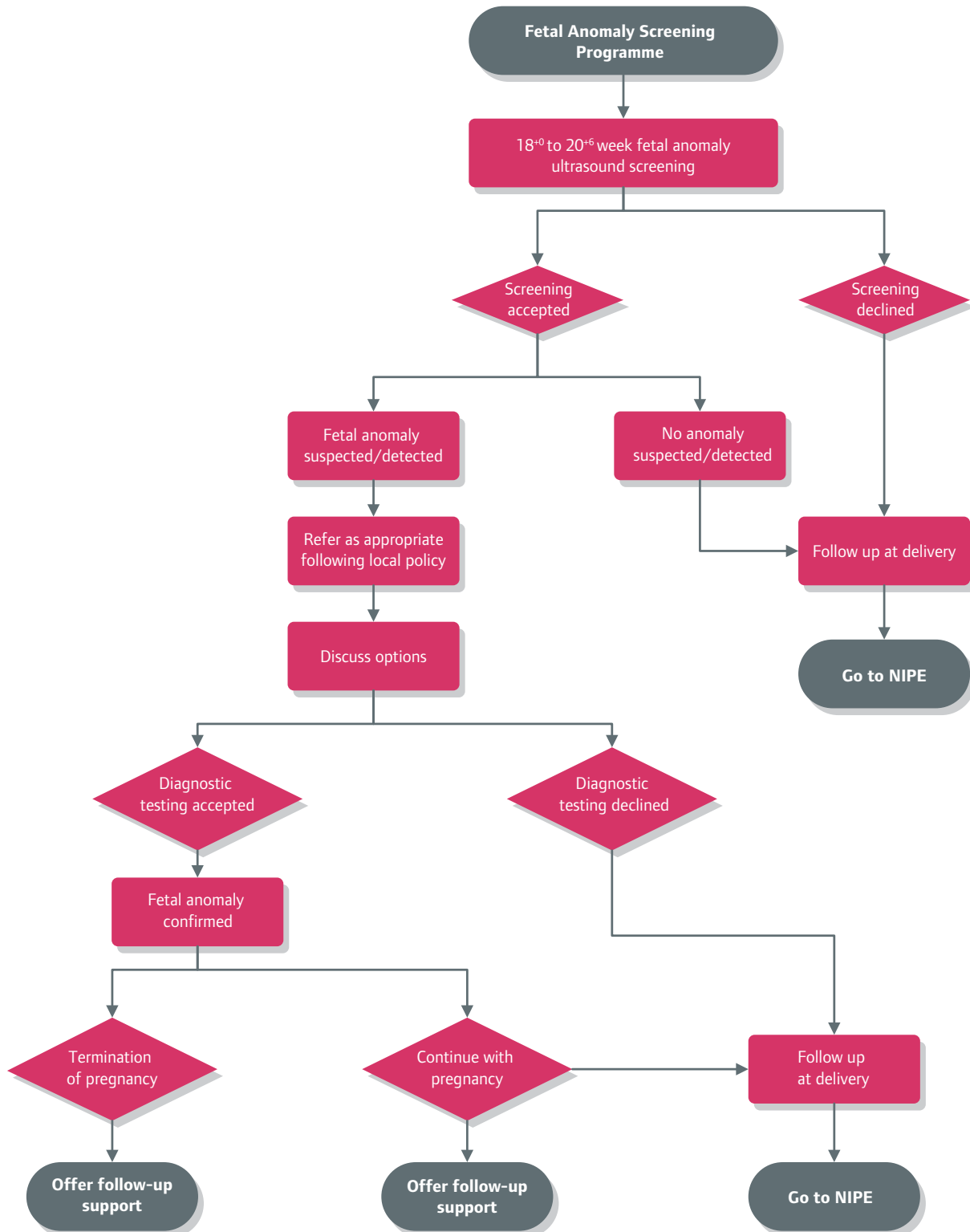
1. To help monitor newborn babies who are at risk, all trusts should use ongoing clinical judgement and assessment alongside a trigger tool, for example NEWTT, or a similar tool. These tools should be validated and trusts should ensure that they are using them consistently in line with their intended use.

2. There is a need for national guidance on which babies require blood pressure monitoring and the frequency of observations. NHS England should ask NICE to develop guidelines on assessment of blood pressure and management of hypertension in newborn babies, infants and children, to include the use of age-appropriate reference ranges.

### 3. Managing care for infants in the community who need respiratory support (with a focus on managing respiratory support technologies, including tracheostomies)

1. In its forthcoming guideline on neonatal services, NICE should include guidance on the discharge pathway from hospital to home and about caring for infants and children who need long-term ventilation in the home.
2. When commissioning care for infants needing long-term ventilation, commissioners should include the requirement that all staff providing the care have the appropriate training and competencies and do not work outside their sphere of practice.
3. The Royal College of Nursing should consider developing a good practice guideline on education and training to support the competence of children's nurses who provide care for infants, children and young people who have complex care needs, including those who need long-term ventilation provided at home.

# Appendix A: NHS Fetal Anomaly Screening Programme care pathway



Fetal anomaly ultrasound scan at 18+0 to 20+6 weeks pregnancy (from Public Health England)

## Appendix B: Locations visited

Location	Type: neonatal intensive care unit (NICU), special care baby unit (SCBU) or local neonatal unit (LNU)
Nottingham University Hospital	NICU
Wirral University Teaching Hospital NHS Foundation Trust	NICU
Central Manchester University Hospitals NHS Foundation Trust	NICU
Sheffield Teaching Hospitals NHS Foundation Trust	NICU
Guy's and St Thomas NHS Foundation Trust	NICU
Norfolk and Norwich University Hospitals NHS Foundation Trust	NICU
Salisbury NHS Foundation Trust	LNU
The Whittington Hospital NHS Trust	LNU
London North West Healthcare NHS Trust	LNU
East and North Hertfordshire NHS Trust	LNU
Royal Devon and Exeter NHS Foundation Trust	LNU
St Helen's and Knowsley Teaching Hospital NHS Trust	LNU
Wrightington, Wigan and Leigh NHS Foundation Trust	LNU
Wye Valley NHS Trust	SCBU
Gateshead Health NHS Foundation Trust	SCBU
Northumbria Healthcare NHS Foundation Trust	SCBU
Western Sussex Hospitals NHS Foundation Trust	SCBU
James Paget University Hospital Foundation Trust	SCBU
Great Western Hospitals NHS Foundation Trust	SCBU

## Appendix C: Long-term ventilation leads and clinical commissioning groups contacted

Long-term ventilation lead responses	Clinical commissioning group responses
South East	NHS Herefordshire CCG
East	NHS Wirral CCG
East Midlands	NHS Great Yarmouth and Waveney CCG
South West	NHS Central Manchester CCG
Yorkshire and Humberside	NHS Nottingham City CCG
Wessex	NHS North Tyneside CCG
North East	NHS Newcastle Gateshead CCG
London	NHS Brent CCG
	NHS East and North Hertfordshire
	NHS Wigan Borough CCG
	NHS Sheffield CCG
	NHS Sutton CCG
	NHS Swindon CCG
	NHS Wiltshire CCG
	NHS Lambeth CCG

## Appendix D: External stakeholders consulted

CQC is grateful for the time, support, advice and expertise given to the review by the following people and organisations.

Name and role	Organisation
<b>Doreen Crawford</b> , Senior Lecturer in Child Health	Royal College of Nursing, and De Montfort University, Leicester
<b>Dr Jan Dudley</b> , Consultant and Lead Paediatric Nephrologist	University Hospitals Bristol NHS Foundation Trust
<b>Sue Eardley</b> , Head of Invited Reviews	Royal College of Paediatrics and Child Health
<b>Alan Fenton</b> , President	British Association of Perinatal Medicine
<b>Dr Julian Forton</b> , Consultant in Paediatric Respiratory Medicine	Children's Hospital for Wales
<b>Susan Frost</b> , Lead Respiratory Nurse Specialist	National Paediatric Respiratory and Allergy Nursing Group
<b>Dr Anoo Jain</b> , Consultant in Neonatal Medicine	University Hospitals Bristol NHS Foundation Trust
<b>Tracey Jones</b> , Clinical Assurance Manager	Interserve Healthcare
<b>Dr David Millar</b> , Consultant Neonatologist	Belfast Health and Social Care Trust
<b>Jane Munro</b> , Quality and Audit Development Advisor	Royal College of Midwives
<b>Dr Christopher O'Brien</b> , Consultant Respiratory Paediatrician	Newcastle Upon Tyne Hospitals NHS Foundation Trust
<b>Andrew Rostron</b> , National Programmes Lead	Public Health England
<b>Dr Manish Sinha</b> , Consultant Paediatric Nephrologist	The Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust
<b>Fiona Smith</b> , Professional Lead for Children and Young People's Nursing	Royal College of Nursing
<b>Dr Carol Sullivan</b> , Consultant Neonatologist	Abertawe Bro Morgannwg University Health Board
<b>Mr Myles Taylor</b> , Consultant Obstetrician and Gynaecologist	Royal Devon and Exeter NHS Foundation Trust
<b>Michele Upton</b> , Maternity and Newborn Safety Lead	NHS England
<b>Shirley Vickers</b> , National Project Lead	Fetal Anomaly Screening Programme, Public Health England
<b>Cathy Warwick</b> , Chief Executive	Royal College of Midwives



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