Department of Health & Social Care

[redacted]
Parliamentary Under-Secretary of State for
Patient Safety, Women's Health and Mental Health

39 Victoria Street
London
SW1H 0EU

[redacted]

HM Coroner Alison Mutch
Coroner's Court,
1 Mount Tabor Street,
Stockport,
SK1 3AG

[redacted]

15 August 2025

Dear Ms Mutch,

Thank you for the Regulation 28 report of 6 June sent to the Secretary of State for Health and Social Care regarding the tragic death of Esme Vera Louise Atkinson.

Firstly, I was saddened to read of the circumstances of Esme's death, and I offer my sincere condolences to Esme's family and loved ones. The circumstances your report describes are concerning and I am grateful to you for bringing them to my attention. In preparing this response, my officials have made enquiries with NHS England to ensure we adequately address your concerns. We recognise that several opportunities for the identification of Esme's heart defect were missed and that there needs to be improvement in the areas set out below. Our responses to your specific concerns are as follows:

The Inquest heard evidence that health visitors, midwives and GPs play a key role in the early identification of a heart defect, such as Esme's, at an early stage. They heard that such a defect will rarely be apparent at the 72-hour check, but symptoms will manifest subsequently. You raised concerns that training for community midwives, health visitors and GPs on early identification of heart defects needs to be improved, with good quality information sharing essential. You mentioned that this should include concerns around feeding and weight loss. You also flagged that it was important that health professionals involved in the care of a baby understood that the mother being diabetic increased the risk of a defect significantly and should increase the care taken in relation to presenting symptoms.

We agree that health visitors, midwives and GPs play a key role in identifying heart defects at an early stage, and that sharing of good quality information is essential in facilitating this. We also agree with the importance of healthcare professionals understanding what factors could increase the risk of heart defects in babies. We recognise that this could have been improved in Esme's case, as she was seen by GPs on three occasions and the community midwifery services.

To support the early identification of conditions, NHS England has put in place nationally-mandated, annual multi-professional training which includes training modules on diabetes in pregnancy, care during labour, the immediate postnatal period (including a focus on infant feeding), and practical simulations to recognise and escalate care for deteriorating mothers or babies. There is a compliance benchmark of >90% staff attendance, providing assurance that key competencies are being routinely reinforced across the workforce.

Screening of babies is routinely carried out both antenatally and postnatally through the Fetal Anomaly Screening Programme (FASP) and the Newborn and Infant Physical Screening Programme (NIPE). Further information about these programmes, and the training available to healthcare professionals to deliver them, is provided below.

Antenatal Screening

Antenatal screening is carried out by the FASP to screen for 11 physical conditions, one of which is congenital heart disease.

Screening through the FASP is conducted by midwives, who are supported with learning resources and local screening co-ordinators to enable up to date understanding of screening and conditions to enable discussions with families that support informed choice.

Providers are responsible for assessing the competence of each practitioner before they scan independently and are responsible for making sure staff receive sufficient time to complete minimum training requirements. They should ensure training is completed and recorded, and that there should be a system in place to assess ongoing competence.

Postnatal Screening

Postnatally, the NIPE recommends the offer of screening to all babies born in England for conditions relating to the eyes, heart, hips and testes (if applicable).

The NIPE newborn screening examination must be completed by a trained practitioner. This can be a midwife, neonatal nurse, a qualified doctor, or a health visitor who has successfully completed a university-accredited ‘examination of the newborn’ programme of study.

The NIPE handbook, which informs and supports best clinical practice for healthcare professionals, was updated in April 2024. This included an updated list of risk factors, categorisation of congenital heart disease, additional information on undertaking heart examinations (observation, palpation auscultation), and enhanced sections on the management of babies with screen negative and screen positive results.

We recognise the importance of practitioners establishing relevant information about the mother’s medical history and the baby’s family history as part of the NIPE, and recognise that this would have been particularly important in Esme’s case. Best practice sets out that practitioners should ask parents if they have any concerns about their baby’s breathing or colour when their baby is at rest or feeding or if their baby is not feeding well. Practitioners are also informed about the risk factors for Congenital Heart Disease and encouraged to have increased vigilance during the screening examination if the mother has type 1 diabetes.

Effective information sharing at the point of transfer of care - for example, from secondary to primary care, and from midwifery to health visitor care - is also essential. As set out in NICE

guidance, details such as pregnancy history, maternal conditions (e.g. diabetes), and any concerns about feeding or growth, should be shared to ensure continuity and safety in care.

You also flagged that the GP check at 6-8 weeks is a key checking point and that GPs must ask the right questions and have a good understanding of how to listen for a heart defect such as Esme's. We agree that the GP check at 6-8 weeks (also known as the newborn infant examination) is a key checking point, as it provides the opportunity to conduct a further physical examination to assess development and check for any possible conditions relating to the eyes, heart, hips and testes (if applicable). We likewise recognise how important this is, particularly in Esme's case, given that some conditions can develop or become apparent after the newborn screen described above.

While the 6–8-week check is not a formally-managed part of the NIPE programme, regional commissioners provide scrutiny, as required, to oversee this part of the examination. The NIPE screening programme also produces best practice guidance and recommended referral timescales in relation to the infant screening examination.

We recognise the importance of ensuring continued development and training for practitioners conducting the 6-8 week check. NHS England's Learning Hub provides relevant online training modules including 'Infant Feeding' and 'Diabetes in Pregnancy' to support safe, informed care across maternity and neonatal services.

You raised specific concerns that there is no routine echocardiogram of babies born to a mother with diabetes and that in Esme's case, although her mum's identical twin had a

heart defect, this did not trigger the protocol for a routine echocardiogram. NHS England encourages all trusts to follow the FASP criteria for offering screening for fetal anomalies. Additional screening for fetal anomalies may include a fetal medicine scan and/or a fetal echocardiogram for patients at higher risk of fetal anomalies for reasons such as maternal diabetes, or having a first degree relative with a congenital heart disease (for example an affected parent or sibling). We agree that additional screening for Esme would have been a reasonable course of action, given the increased risk associated with a genetically identical maternal aunt with a heart defect. However, this decision would have been down to individual risk assessment and the discretion of the treating clinician. In addition, Esme's postnatal course would have been a further opportunity to diagnose a congenital heart defect, and we recognise that this monitoring was not as rigorous as it should have been in her case.

You also raised concerns around the fact that the usual abnormality scan did not detect Esme's heart defect. The diagnosis of ventricular septal defects (VSD) is recognised as difficult on prenatal imaging especially without the use of colour Doppler, which is not a requirement of the cardiac protocol. We agree that this needs to be improved and NHS England is therefore working in collaboration with Fetal Cardiologists, a Congenital Heart

Disease Clinical Reference Group, and Congenital Heart Disease Operational Delivery

Networks to improve detection of congenital cardiac conditions that are defined in the FASP standards, by providing better feedback (including data) to ultrasound practitioners and education and training of the ultrasound workforce.

Your report also flagged that the cardiac part of an abnormality scan is not audited in England under national guidance and cardiac images are not stored, meaning they are not available for subsequent examination. Currently there is no NHS FASP requirement to archive images of the fetal cardiac protocol. We acknowledge your concern and NHS England are currently reviewing this and, if required, will revise current guidance on the storage of cardiac views at the 20-week screening scan.

There are two national audit data collections of antenatal congenital heart disease, the National Congenital Heart Disease Audit (NCHDA) and the National Congenital Anomaly and Rare Disease Registration Service (NCADRS). The NCHDA is a national data collection that produces an annual report of outcomes following congenital cardiovascular procedures. These reports include a proportion of patients undergoing surgery or intervention for a particular diagnosis that have an antenatal diagnosis. For 2023/24 this showed that 52% of infants requiring a procedure during the first year of life had an antenatal diagnosis. The NCADRS provides national surveillance for congenital anomalies ascertaining data from multiple pre and postnatal sources to evaluate detection rates.

You also flagged concerns around the fact that centile tracking was not seen as useful before 1 month of age. You also flagged concerns around the red book not being used to look at weight centile tracking in the early stages, even though tracking weight from an early point helps ascertain if there is a significant issue with feeding. We agree that weighing and measuring is an important part of monitoring a baby's health and development, and that this could have been improved in Esme's case. The Royal College of Paediatrics and Child Health has developed guidance for healthcare professionals on the use of growth charts and measuring and weighing babies. It is important that babies are weighed in their first week of life, as part of the assessment of feeding, and after that as needed. Once feeding is established, babies should usually be weighed at around 8, 12 and 16 weeks and 1 year at the time of routine immunisations. We recognise that the red book is an important tool for tracking and sharing information between healthcare professionals, and we are digitalising the red book to improve access to this data. Over time, we will add more information and create more functionality, including AI analytics, to ensure the best care is provided for the child, including detecting any anomalies in weight gain or feeding.

I hope this response is helpful. Thank you for bringing these concerns to my attention.

Yours sincerely,

[redacted]

PARLIAMENTARY UNDER-SECRETARY OF STATE FOR
PATIENT SAFETY, WOMEN'S HEALTH AND MENTAL HEALTH