





08 July 2025

Dear Dr Henderson,

Re: RCPCH Response to the Inquest Touching the Death of Rose Annie Harfleet A Regulation 28 Report – Action to Prevent Future Deaths

Thank you for sharing your report with us regarding the tragic and untimely passing of Rose Annie Harfleet. I was very sorry to hear of Rose's death.

We have considered your report carefully and respond below to the four concerns noted.

1. The management of children with profound disabilities within a hospital setting

The RCPCH Facing the Future standards describe how paediatric care should be delivered to provide a safe and sustainable, high-quality service that meets the health needs of every child and young person. Our Facing the Future: Emergency Care Standards apply to all persons up until the age of 18. These standards aim to ensure that urgent and emergency care is fully integrated to ensure children are seen by the right people, at the right place and in the right setting. We are currently in the process of review, revision and update of our current standards, to be published in Autumn 2025.

Our currently available Facing the Future: Emergency Care Standards (2018) contain a dedicated chapter on children with complex medical needs. Three of these standards have particular relevance:

- Standard 49: Triage systems must consider the additional requirements of prioritising care for children with complex medical needs.
- Standard 50: When treating a child with complex medical needs, the need to consider early escalation for senior review should be included in all training and induction.
- Standard 51: When treating a child with complex medical needs, staff should ask to see the child's emergency care plan.

The revised standards are due to be published in Autumn 2025 and will be shared with all relevant professionals working in emergency care settings. I will share your report with the Chair of our Intercollegiate Committee for Emergency Care who is leading this work for their information.

2. Guidelines - consultation with parents and guardians of children with profound disabilities within a hospital setting

Good medical practice, produced by the General Medical Council, sets out the principles, values, and standards of professional behaviour expected of all doctors. This includes requirements that doctors must "treat all patients fairly and without discrimination, including those with disabilities" and that "doctors are required to consider and respond to the communication needs of all patients, including those with disabilities." RCPCH has no authority over provision of nursing care on wards but notes that the Nursing and Midwifery Council states how nurses "must take account of individual differences, capabilities and needs" and "use a range of communication skills and technologies to support person-centred care and enhance quality and safety".

3. Nursing and Medical care on the ward - the importance of listening and responding to Rose's mothers ongoing concerns

Our response to point 2 above recognises the responsibility of clinicians to listen and respond to patients and their families. All parents are experts in their own children, however this is often particularly the case in those children with complex needs.

RCPCH are actively supporting the role out of Martha's Rule. Martha's Rule is a patient safety initiative currently being piloted in England which aims to empower all staff, patients and their families to seek an independent medical review if they feel their concerns about a patient's care are not being adequately addressed. The rule is designed to give families the ability to directly request an expert review by a senior clinician not within the immediate care team, potentially identifying critical issues before they result in harm.

By establishing this right to an independent review, Martha's Rule improves ability to recognise and respond to deterioration by incorporating parents and families as part of the team. It formalises an escalation route for parents, carers and families to use to ensure their concerns are listened to and acted on and encourages transparency and collaboration.

RCPCH contributed to the early working groups for Martha's Rule, sharing our members expertise on the unique and complex paediatric environment, in particular highlighting the challenges associated with paediatric ICU availability, the need for workforce training and capacity building in order to implement this important patient safety initiative. We continue to engage with NHS England as data from the pilot sites emerge

In addition, RCPCH are committed to the introduction, embedding and appropriate standardisation of Paediatric Early Warning Systems (PEWS) within the four nations. PEWS are designed to effectively recognise and respond to the deterioration of children or young people in a healthcare environment. A parental escalation process is essential to any effectively PEWS. We have been collaborating with NHS England and the Royal College of Nursing to develop a single national PEWS for England since 2018 and are supportive of equivalent processes across the UK.

4. LeDeR Role

The RCPCH has no authority over provision of access to learning disability liaison nurse. We do make reference to the importance of the support of these professionals in our revised Facing the Future Standards for Emergency Care, which are due to be published in Autumn 2025.

It is my understanding that the revised standards will include the following standard:

 EDs should have a lead professional for CYP with complex medical needs, learning disability and or those who are neurodivergent and access to advice and support from a Learning Disability Liaison Nurse.

Thank you for seeking our views and reminding us of the importance of this work. Our sincere condolences are with Rose's family.

