



Strictly Private and Confidential

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Ref: [REDACTED]

Dear Mr Appleton,

Inquest into the death of Margaret Huntley

Regulation 28 – Report to prevent future deaths

I am writing in my role as Chief Executive of North East Ambulance Service NHS Foundation Trust ("NEAS") in response to the Regulation 28 report for the prevention of future deaths dated 13th August 2024 as issued by you following the inquest into the tragic death of Margaret Huntley. I am sorry that you have had to raise concerns with NEAS following the inquest and would like to take this opportunity to pass my sincere condolences to the family of Margaret.

I am aware that the report was also issued to NHS England, Association of Ambulance Chief Executives and Royal College of General Practitioners. My team have liaised with colleagues within Association of Ambulance Chief Executives in drafting our response to ensure a consistent response from the ambulance sector.

The matters of concern listed in your report are: -

1. There is a lack of understanding amongst (non-clinical and clinical) Ambulance Service staff as to the importance of steroid medication and the steps to be taken should a patient (a) report that they are prescribed steroid medication and/or (b) present with symptoms potentially consistent with steroid insufficiency/Addison's Crisis.
2. There is not, within the NHS Pathways system or otherwise, guidance or processes for Ambulance Service staff triaging calls, including non-clinically qualified staff, to follow regarding (a) the importance of steroid medication and the need to establish, if a patient raises during a call that they are prescribed steroid medication, detailed information regarding that prescription to include the type of prescription and the reasons for it; (b) actions to be taken or processes to follow should a patient raise during a call that they are prescribed steroid medication.

3. It is unclear as to whether Margaret Huntley had been issued with a Steroid Emergency Card and/or information around use of such a Card. I am concerned that there needs to be improved usage, and awareness, of Steroid Emergency Cards.
4. It was confirmed in evidence that it is possible for GPs to request that an alert is placed on to the Ambulance Service's system(s) to alert Ambulance Service staff to specific patient health conditions, such as steroid insufficiency. I am concerned that (a) there is inadequate awareness of this ability amongst GP's; (b) this action is not routinely being taken by GPs.

I will address each point you have raised in your matters of concern below: -

1. **There is a lack of understanding amongst (non-clinical and clinical) Ambulance Service staff as to the importance of steroid medication and the steps to be taken should a patient (a) report that they are prescribed steroid medication and/or (b) present with symptoms potentially consistent with steroid insufficiency/Addison's Crisis.**

In respect to emergency ambulance clinicians (Paramedics), it may be helpful to explain the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) guidance before I answer this specific concern. The JRCALC guidelines have evolved from many locally derived protocols to systematically developed national clinical practice guidelines based on current best evidence. The ongoing continuous updates are supported via the JRCALC Guideline Development Group (JRCALC-GDG), led by Dr Simon Brown, have over the years been responsible for developing and reviewing the national clinical practice guidelines for NHS Paramedics. JRCALC guidelines are also an important part of clinical risk management and ensure uniformity in the delivery of high-quality patient care. As such, they form the basis for UK Paramedic training and education. JRCALC combines expert advice with practical guidance to help Paramedics in their challenging roles and supports them in providing patient care. The guidelines cover an extensive range of topics, from resuscitation, medical emergencies, trauma, obstetrics and medicines to major incidents and staff wellbeing.

The guidelines are now reviewed and updated on a rolling basis. Due to the rapidly developing evidence base and the emerging technological options for publication, the guidelines are developed, updated and made available in a variety of format options. Working closely with the National Ambulance Service Medical Directors (NASMeD), guideline development sub-groups will develop specific guidelines that conform to the AGREE II standard which can be accessed via the following link <https://www.jrcalc.org.uk/wp-content/uploads/2014/12/JRCALC-process.pdf>. I have also enclosed a copy of the JRCALC Standard for Guideline Development.

In 2017 there was an update in the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) guidance emphasising the increased usage of Hydrocortisone for patients with adrenal crisis, including a further note stating if in doubt administer Hydrocortisone.

In September 2020 the medical emergencies section of JRCALC was updated to highlight that a joint National Patient Safety Alert was issued by NHS Improvement and NHS England about Steroid Emergency Cards to support early recognition and treatment of adrenal crisis in adults. Small amendments were made in the guidelines to highlight the need to be alert for a patient having an emergency card for a specific condition. I have enclosed a copy of the alert which was issued.

In February 2022 JRCALC issued a new guideline titled steroid dependant patients, that provided greater information on the different classifications of adrenal insufficiency.

All NEAS clinicians are given access to the JRCALC guidelines through individual licenses for the JRCALC Plus app. JRCALC Plus allows individual ambulance services to combine the national guidelines with their regional information, this is achieved via individual login details linking with the specific Ambulance Trust. The app contains the following which is utilised by NEAS:

- Complete JRCALC Guidelines;
- Regional and local guidance specific to NEAS
- Clinical Notices/Bulletins
- Medications information including patient group directives.
- All updates and alerts are published in real time as new guidance is issued;
- The app works offline and is therefore accessible to our teams.

Emergency Ambulance crews can access the JRCALC Plus app via iPads which are now being transitioned to personal issue, with the rollout of personal issue devices commencing in August 2024, prior to this date the iPad (or previous electronic device) was part of the standard vehicle equipment. In addition, the clinicians have the option for the App to be downloaded on other devices such as personal smart phones if they so choose so. This allows clinicians to access the guidelines whilst at the patient side and/or when travelling to the case.

As well as the above several articles and education package have been developed and delivered within the NEAS. These include 2 clinical alerts, which are the primary way NEAS cascades information to its operational teams on matters of clinical practice:

- Medical Directorate alert – Steroid Dependent Patients - issued on the 7th August 2023
- Clinical Directorate alert – Adrenal Insufficient Patients – Issued on the 30th July 2024

I have enclosed copies of both the alerts detailed above.

NEAS will, as part of the learning from this tragic event, provide more educational opportunities for its staff including the following:

- Sharing the details of this training event:
<https://www.addisonsdisease.org.uk/adshg-paramedic-training-in-adrenal-crisis-management>
- Sharing some more resources on adrenal insufficiency and steroid dependency through our corporate communications channels.
- We have commenced the development of a training module on time critical medications (which will include Steroids) in our Statutory and Mandatory Training module. This will be included in the Statutory and Mandatory training delivered in 2025/2026.

Upon liaising with colleagues within the Association of Ambulance Chief Executives (AACE). I am aware that AACE colleagues are engaging with the Addison's Disease Self-Help Group and the Pituitary Foundation. This joint work is to help ensure that they can provide information to patients in regard to ensuring their health care record contains information that they are steroid dependent. In addition, explaining how people can be reassured about what happens and what can be done to ensure if emergency help is needed such as a 999 ambulance that they receive the best care possible.

Turning towards non-clinical colleagues, specifically Health Advisors, working within the Emergency Operations Centre (EOC) using the NHS Pathways system, currently version 45.2.0. The NHS Pathways system is a national system and has been designed to be used by non-clinicians who ask a series of evidence-based questions to reach an end point. That end point is not a diagnosis, it is just what care and in what timeframe the care is needed. This is then matched to the most appropriate local services who deliver that care. NHS Pathways is not a diagnostic tool, but instead works on the basis of 'ruling out'. This means that questions are asked in order to rule out possible reasons for the patient's symptoms, until a point where it is safe for the patient to manage their own symptoms with advice or further intervention is needed by a clinician to establish a possible cause.

Even though thorough training is provided, it is not within the remit of the Health Advisor to be trained in, or understand more complex medical elements, such as in this case. Indeed, such enquiry can add confusion and delays to the management of the case and triaging process. It is for these reasons that questions on past medical history or pharmacology are utilised sparingly across the system, and only where it is deemed that a clear understanding can be sought. This is further complicated due to the vast range of medication which patients may be prescribed or purchase over the counter, including highly specialised medication.

Due to the fact NHS Pathways is a national system, it is not possible for NEAS to implement a process where Health Advisors will ask the caller to share the details/names of medication, which in turn would need to input as notes for the attending ambulance crew. Based on the rationale above, the vast range of medication would lead onto errors in recording the name of medication and pose additional risks.

The current version of NHS Pathways does include supporting information for Health Advisors, in respect to adrenal insufficiency, however we do recognise that Health Advisors may benefit from further information about Addison's disease and specifically adrenal crisis. We are therefore in the process of rolling out a refresher training bulletin confirming the steps to take in these circumstances with some further information relating to the condition. This will be monitored to ensure it has been read and understood by all Health Advisors and those who receive calls via the 111 and/or 999 services. Linking with my response to your second concern, we will support any changes made in the NHS Pathways system alongside any requirements to provide additional information, instruction or training to our call handling teams.

- 2. There is not, within the NHS Pathways system or otherwise, guidance or processes for Ambulance Service staff triaging calls, including non-clinically qualified staff, to follow regarding (a) the importance of steroid medication and the need to establish, if a patient raises during a call that they are prescribed steroid medication, detailed information regarding that prescription to include the type of prescription and the reasons for it; (b) actions to be taken or processes to follow should a patient raise during a call that they are prescribed steroid medication.**

The computer programme and algorithm used by NEAS, and other ambulance services across the country, is the NHS Pathways telephone triage system which is a clinical decision support system (CDSS) supporting the remote assessment of callers to urgent and emergency services. The NHS Pathways system is widely used in the following settings:

- NHS 111 (ambulance services including NEAS)
- 999 (ambulance services, including NEAS)
- Integrated Urgent Care Clinical Assessment Services
- NHS 111 Online
- To assist in the management of patients presenting to urgent care or emergency departments

The system is owned by the Department for Health and Social Care and delivered by the Transformation Directorate of NHS England. NEAS, as a service commissioned by NHS England and host system suppliers enter into licences with the Secretary of State for Health and Social Care, allowing them to embed NHS Pathways within their products. The system is maintained by a group of experienced staff most with an urgent and emergency care background. All the clinical authoring team are registered, licensed practitioners.

To this extent NEAS have limited ability to fully respond to this specific concern and will defer to the response via NHS England. We will of course fully liaise with our colleagues in NHS England to provide any additional information that will aid their understanding of the concerns as a result of the inquest. NEAS are members of a national NHS Pathways User Group and feed concerns into an issues log which is used to consider learning and system development/improvement.

NHS Pathways also have a national governance group, which involves all healthcare professional and college representation, who assess the clinical evidence to develop new pathways or make changes to the established pathways. The NHS Pathways team are aware of this case and we have raised the matter via the NHS Pathways issues log and await their response.

- 3. It is unclear as to whether Margaret Huntley had been issued with a Steroid Emergency Card and/or information around use of such a Card. I am concerned that there needs to be improved usage, and awareness, of Steroid Emergency Cards.**

I am aware the Regulation 28 report for the prevention of future deaths was issued to other organisations including the Royal College of General Practitioners. In regard to the influence NEAS has upon this concern, this is not something an Ambulance Trust would issue nor can directly influence. My response to the fourth concern links in with the awareness of emergency ambulance crews and accessing/sharing such information with our crews. As an Ambulance Trust we do not prescribe or issue long-term steroids and therefore do not have reasonability for issuing steroid emergency cards. As part of the work I have explained in the response to the fourth concern, we will continue to liaise with system partners to ensure information is accessed and shared appropriately across organisations.

To ensure consistency with existing public messaging we have included a link to the Addisons Self Help Group website on the NEAS website and have undertaken an awareness campaign via our social media platforms.

- 4. It was confirmed in evidence that it is possible for GPs to request that an alert is placed on to the Ambulance Service's system(s) to alert Ambulance Service staff to specific patient health conditions, such as steroid insufficiency. I am concerned that (a) there is inadequate awareness of this ability amongst GP's; (b) this action is not routinely being taken by GPs.**

I am aware the Regulation 28 report for the prevention of future deaths was issued to other organisations including the Royal College of General Practitioners. In regard to the influence NEAS has upon this concern I can confirm that upon attending a patient and completing an electronic patient care record, these clinical records are securely transferred to the patients General Practice and uploaded to the Great North Care Record. This ensures that any emergency ambulance attendance is shared with the General Practice to assist with the continuity of care and update the patients' clinical records. These records would include the assessment and treatment of the attending NEAS emergency ambulance crews. Whilst this is the flow of information from NEAS into General Practice, it is important to know that attending emergency ambulance crews can access systems including GP Connect and Great North Care Record. This does however rely upon NEAS having awareness to check for such information if not already known and a 'flag' been shared with the attending crew.

During our review we have also considered the associated guidance from the Association of Ambulance Chief Executives (AACE), specifically the publication relating to 'red flagging' of patients with specific clinical conditions. Whilst we recognise and share the concerns around the additional overhead the maintenance of flagging and care plan management places on NEAS, we believe that until an automated regional based solution can be provided, we will continue to accept care plans and flags from our providers, in the interest of aiding our crews with the delivery of patient care.

Linked with the above, our records show that the majority of care plans and flags are created by our wider system partners, a North East and North Cumbria Integrated Care Board (ICB) wide group has been established and is now meeting regularly to improve the flagging challenges and a coordinated approach to standardise and centralise the production, storage, and access to care plans for consideration by the North East and North Cumbria ICB Digital Board.

It is important to mention that both information sharing platforms, GP Connect and Great North Care Record, do not presently have full patient details or care plan documents from all providers. The North East and North Cumbria Integrated Care Board is leading on a 'levelling up' project for all providers in our region. NEAS will continue to work with wider system partners to develop more effective centralised means of region wide flagging and care plan sharing.

I hope this response provides you and the family with the appropriate level of assurance that as a Trust we are dealing with the concerns highlighted within your report. If it would be helpful, we would gladly arrange a visit to our Emergency Operations Centre to show you the NHS Pathways system in operational use as well. May I once again pass on my sincere condolences to the family of Margaret. If we can be of any further assistance then please do not hesitate to contact [REDACTED], Head of Regulatory Services via email at [REDACTED] or telephone 07891 469571.

Yours sincerely,

[REDACTED]

[REDACTED]

Chief Executive

Enclosures:

JRCALC Standard for Guideline Development
National Patient Safety Alert - Steroid Emergency Cards
Medical Directorate Alert - MED/0142 Steroid Dependent Patients
Clinical Directorate Alert - Adrenal Insufficient Patients