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Mr Ian Arrow
Senior Coroner for Plymouth, Torbay and South Devon
The Coroner's Office
Derriford Business Park
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Our reference: LT0519

6th August 2019

Dear Mr Arrow

Inquest into the death of Sebastian Zane Hibberd

I am writing in response to the Regulation 28 report received from HM Senior Coroner, dated 11th June 2019. This follows the death of Sebastian Hibberd who sadly passed away on 10th October 2015. This was followed by an investigation and inquest which concluded on 1st February 2019. NHS Pathways is the clinical decision support software used by all 111 service providers, and some 999 ambulance service providers including South West Ambulance Service. I am [redacted] and am writing in my capacity as Deputy Clinical Director, NHS Pathways, NHS Digital.

HM Coroner has raised the following matters of concern with regards to NHS Pathways:

I. At the conclusion of the inquest there was no question within the NHS Pathways questionnaire concerning colds hand and feet for children aged over five:
II. At the time of the conclusion of the inquest the question regarding green vomit, asked in respect of children over five, had an inappropriately high threshold (that is required severe pain for more than four hours before the question was engaged) and would not have been activated in Sebastian's case:
III. There has no indication NHS Pathways/NHS Digital have reviewed the support arrangements for non-clinically call advisors to refer unusual cases to clinically qualified colleagues:
IV. At the time of the conclusion of the inquest NHS Pathways did not allow a meaningful assessment of pain in a child; that is to say questions about severity of pain and ability of a child to communicate such pain should be reviewed at national governance level.

NHS DIGITAL'S RESPONSE

Firstly, I offer my sincerest condolences to the family of Sebastian Hibberd.

For information, I have provided below a short summary of the functions that NHS Pathways performs and the governance that underpins it.

Function of NHS Pathways

NHS Pathways is a programme providing the Clinical Decision Support System (CDSS) used in NHS 111 and half of English ambulance services. This triage system supports the remote assessment of over 16.4 million calls per annum. These calls are managed by non-clinical specially trained call handlers who refer the patient into suitable services based on the patient's health needs at the time of the call. These call handlers are supported by clinicians who are able to provide advice and guidance or who can take over the call if the situation requires it. The system is built around a clinical hierarchy, meaning that life-threatening problems assessed at the start of the call trigger ambulance responses, progressing through to less urgent conditions which require a less urgent response (or disposition) in other settings.

Please note that where an NHS Pathways question is answered in such a manner as to prompt the asking of a further question along the same pathway this is referred to as a 'negative' answer. Where a response (in most cases indicative of more serious clinical symptoms) to a question or string of questions is such that it prompts different questions or a clinical endpoint ('disposition') being reached this is generally referred to as a 'positive' answer.

Governance of NHS Pathways

The safety of the clinical triage process endpoints resulting from a 111 or 999 assessment using NHS Pathways, is overseen by the National Clinical Governance Group, hosted by the Royal College of General Practitioners. This group is made up of representatives from the relevant Medical Royal Colleges. Senior clinicians from the Colleges provide independent oversight and scrutiny of the NHS Pathways clinical content. Changes to the NHS Pathways clinical content cannot be made unless there is a majority agreement at NCGG.

Alongside this independent oversight, NHS Pathways ensures its clinical content and assessment protocols are consistent with the latest advice from respected bodies that provide evidence and guidance for medical practice in the UK. In particular, we are consistent with the latest guidelines from

- NICE (National Institute for Health and Clinical Excellence)
- The UK Resuscitation Council
- The UK Sepsis Trust

To specifically address the concerns raised:

1) At the conclusion of the inquest there was no question within the NHS Pathways questionnaire concerning colds hand and feet for children aged over five:

Historically, a question about whether a child has cold hands and/or feet has not been included within NHS Pathways. This was a deliberate decision not to include it after consideration of the available evidence of its accuracy as a discriminator of severe illness in a remote assessment setting. According to the National Institute for Health and Care Excellence (NICE) guideline for sepsis NG51, published in July 2016, cold hands and/or feet in the context of an unwell child is a moderate to high risk factor or an 'amber flag' considered during diagnosis in an unwell child with possible sepsis.

Underlying literature (used by NICE in preparation of NG51) about 'red flag' symptoms in children, identifies there is a very low likelihood of a positive ratio between cold hands and/or feet and a child being critically unwell. It is also acknowledged that it is very difficult to measure "coldness" over the phone as a caller's interpretation of coldness is likely to be very subjective.

However, in 2014, NHS Pathways were tasked by the Secretary of State to develop potential enhancements to identify septic children. A trial was undertaken as described below.

The trial initially consisted of adding a question about cold hands and/or feet to all illness pathways for children under 5 years. As this reflects the potential for clinical shock, the question used was:
'Are they severely ill AND do they have any of the following?'

The positive answer options were 'cold hands'; 'cold feet'; or 'cold hands and feet'.

If this question was answered positively, the disposition reached was "emergency ambulance within 30 minutes" which in 2016 was the national ambulance response standard for a "Green 2" ambulance category.

There were three trials of the additional question in 2016 at beta testing sites which established that the ambulance dispatch rate was higher than expected and the conveyance rate was very low, i.e. the children that were reported with cold hands and/or feet were not conveyed to hospital upon assessment by the ambulance crew as their illness did not require it. Consequently, it was not considered to be a useful discriminator of critical illness in this age group at the level of ambulance dispatch.

The low conveyance rate seen during the beta testing phase of the additional question about cold hands and/or feet in under 5's resulted in the disposition reached for an unwell child who also reported cold hands and/or feet being changed from an "emergency ambulance within 30 minutes" to a "speak to Primary Care within 1 hour" disposition.

This would allow for further expert remote triage to occur and determine whether a higher level of care is required, such as an ambulance or referral to the Emergency department, or whether a review by Primary Care would be acceptable.

The question about cold hands and/or feet with the amended disposition was finalised and included in Release 14 in all illness pathways for the under 5 years age group. Widescale deployment of release 14 to all providers of NHS111 and all ambulance services in England that use the NHS Pathways system was 2nd October 2017, with services then having an 8 week period to update their staff and deploy in their systems. This question is undergoing a formal evaluation of impact for the under 5 years age group before extension to the 5-16 years age group. However, other markers to identify critical illness are included across the clinical content.

In 2015 NHS Pathways, as part of its routine monitoring and evaluation process, took the opportunity to further enhance clinical triage to identify other markers for identifying a critically unwell person (both children over 5 and adults) for release 15 in line with the new NICE sepsis guidance (NG51).

These critical illness enhancements have involved discussions externally with the UK Sepsis Trust, the Royal College of Paediatrics & Child Health (RCPCH) and have also been discussed at the National Clinical Governance Group which introduced the inclusion of the qSOFA (quick Sepsis Related Organ Failure Assessment). The enhancements made in respect of over 5's and adults were:

- New questions added to identify functional impairment, and if functional impairment plus confusion plus breathless were all positive a category 3 emergency ambulance would be dispatched.
- Substituting the question 'Are they breathless now?' with a more objective question of 'are they breathing faster or harder when doing nothing at all' with a positive to this resulting in advice to attend an Emergency Treatment Centre within1 hour.
- If functionally impaired and confused but not breathless or breathing harder and faster caller would be advised to speak to primary care within 1 hour.
- If functionally impaired or confused in isolation would be advised to contact primary care service within 2 hours.

Different enhancement more suitable to the under 5 population and bearing in mind applicable / available evidence were made in respect of under 5's. Widescale deployment of release 15 to all providers of NHS111 and all ambulance services in England that use the NHS Pathways system was 4th May 2018, with services then having an 8 week period to update their staff and deploy in their systems.

It is important that the presumed illness/risk posed to a patient following triage is accurate in NHS Pathways, not only to ensure that patients receive the appropriate level of care when seriously ill, but also to ensure that patients are not over-referred.

When the questions within NHS Pathways are created, the authoring team must ensure that a careful balance between 'sensitivity' and 'specificity' is struck. By way of brief summary, the 'sensitivity of a test' is the ability to correctly identify those with a disease or condition (true positive rate), whereas 'specificity' is the ability to correctly identify those without the disease (true negative rate).

More than 16.4 million calls are triaged every year using NHS Pathways, so it is critically important that the content of the system has an appropriate and safe balance between sensitivity and specificity, since an imbalance in either direction carries significant risks.

In summary:
Having included a question about cold hands/feet in our content for children under 5, we have established this is not an accurate discriminator of critical illness requiring an ambulance response and is better being managed by a primary care review. These findings are consistent with other evidence that this symptom, in isolation, is a poor discriminator for critical illness.

A formal evaluation of the impact of this question is being completed before extending to other age groups.

NHS Pathways has specifically updated its questions to identify critical illness in children (age 5 and over) and adults that identify the 'red flag' symptoms described in the NICE guidelines for sepsis.

2) **At the time of the conclusion of the inquest the question regarding green vomit, asked in respect of children over five, had an inappropriately high threshold (that is required severe pain for more than four hours before the question was engaged) and would not have been activated in Sebastian's case:**

The question regarding the production of green vomit was not included in the abdominal pain pathway used for the over 5 years age group at the time of Sebastian's illness.

The clinical rationale for not including this question for this age group historically was because whilst it is indicative of intussusception (a rare cause of obstruction in children over 5 years), the other critical symptoms associated with the presentation of intussusception would be triaged for within NHS Pathways, including severe abdominal pain and/or breathlessness. This had been considered with external input from the Royal College of Paediatrics and Child Health on two previous occasions who accepted that asking only in the under 5's was appropriate.

Upon further consideration of this issue an additional question about the presence of green vomit in children aged 5 - 16 was implemented in Release 14. A positive response results in callers being referred to the emergency department within 1 hour. Widescale deployment of Release 14 to all providers of NHS111 and all ambulance services in England that use the NHS Pathways system was 2nd October 2017, with services then having an 8-week period to update their staff and deploy in their systems.

These changes were made in discussion with the National Clinical Governance Group (NCGG) Royal College of Paediatrics representative in post at that time. It was concluded that whilst there were no apparent deficiencies in the pathway due to the clinical rationale explained above, green vomit could be interrogated in children aged 5 to 16 years who presented with severe abdominal pain lasting for more than 4 hours. This approach was adopted to support call handlers in similar circumstances in the future and not as a result of believing there was a deficiency in the pathway.

NHS Pathways continually monitors and evaluates enhancements to the clinical content in any such release. There are several steps as part of the monitoring and evaluation process

following a new release of the NHS Pathways programme, including analysing the beta test data, live deployment data analysis, feedback from users and outcome data appraisal. The level of appraisal and evaluation required once a change is made is dependent on the nature of the change itself.

Outcome data is a new development in the armoury of data intelligence and has only become available in 2018. It is based on the analysis of anonymised patient-level data for each NHS 111/999 call in which the patient subsequently attended an emergency department (ED). NHS Digital is constantly developing data in this way to allow adaptations to the NHS Pathways system to be supported by a robust evidence base.

Since the additional question relating to green vomit was added to the child abdominal pain pathway in Release 14, we have analysed the data available to ensure that no cases of children presenting with green vomit had been overlooked. This work identified a very low proportion of potentially critically ill children identified through an NHS Pathways triage on the basis of these changes subsequently attended the emergency department or were admitted to a hospital ward.

In addition, the deployment data and feedback from the critical illness changes for Release 15 has suggested the critical illness questions are identifying the correct cohort.

As referrals to the ED are much lower than expected following the inclusion of the additional questions in Releases 14 and 15, it was identified that there was an opportunity to further enhance the interrogation of green vomit to support non-clinical call handlers without over referring children to the ED and impacting on services unnecessarily.

Following review of this data and discussion with National Clinical Governance Group (NCGG) Royal College of Paediatrics representative, it was concluded that the current question about dark green vomit is useful in identifying a cohort of unwell children, but the scope could be increased to have a wider sensitivity than those with severe abdominal pain and pain constant for more than 4 hours, whilst maintaining the specificity.

These changes set out below were made in Release 17. Widescale deployment of release 17 to all providers of NHS111 and all ambulance services in England that use the NHS Pathways system was 13th May 2019, with services then having an 8-week period to update their staff and deploy in their systems.

- Children over 5 years of age will be asked if they have 'green vomit' if they are vomiting and in **severe pain** regardless of how long that pain has been experienced (i.e. we have removed the question asking if the pain has lasted more than 4 hours) and if positive will be advised to attend an Emergency Treatment Centre within 1 hour.

- Children over 5 years of age will only be asked if they have 'green vomit' if they are vomiting and in **moderate pain** with symptoms of critical illness including being severely ill, confused or breathlessness, and if positive will be advised to attend an Emergency Treatment Centre within 1 hour.

The changes in Release 17 are intended to support call handlers by providing additional opportunities to identify potentially critically unwell children and not because any issues have been identified with the question sets in any of the pathways currently in use.
The data we have examined has not given any indication that the pathways are deficient nor that children presenting with green vomit are not being identified using the current question sets. We are simply expanding the range of scenarios in which green vomit may be

interrogated as a precautionary measure to avoid any potential human error and further develop an evidence base for telephone triage.

3) **There has no indication NHS Pathways/NHS Digital have reviewed the support arrangements for non-clinically call advisors to refer unusual cases to clinically qualified colleagues:**

The training and support materials provided to sites are also under continual review as part of the NHS Pathways governance processes. Individual providers are responsible for training and supporting their staff as required by NHS Pathways and as appropriate to their local operating procedures.

NHS Pathways provides system functionality called 'early exit' which enables call handlers to exit a call and transfer it to a clinician, this has been part of the system for 10 years. Creating the necessary infrastructure to enable successful transfers to a clinician is the responsibility of the organisation using NHS Pathways. This includes creating a culture where call handlers are empowered to recognise when a call is beyond their skills/abilities, as well as providing the clinical manpower to be able to accept these calls.

There are various reasons why a call handler might 'early exit' a call, including if they identify the call as 'complex'. A complex call is defined as *'any call which isn't straightforward and where the call handler determines that they are working at or beyond the limits of their knowledge'*.

This broad definition is necessary to create a culture where call handlers feel able to be honest about situations where they are struggling. This is vital from a clinical safety perspective. What one person finds challenging, another person may not, thus a defined list of what might make a call 'complex' is not helpful and may indeed be unsafe, if it encourages call handlers to try and manage a call they find difficult, just because it's 'not on the list'.

However, because call handlers are not qualified clinicians there are four situations that will ***always*** fall under the definition of a complex call. These are supported by the Early Exit functionality shown overleaf:

call audits against the NHS Pathways Competencies, using a structured audit tool. The requirements around complex calls are outlined below:

Competency 6: Practices According to Designated Role Requirements
'Where it is clear that the member of staff has recognised they are out of their depth, it is important that they seek support appropriately. This is an important part of operating within role boundaries.'

Competency 7: Skilled Use of Pathways Functionality
'It is vital that the correct route through the system is taken. This includes taking the trauma or non-trauma route appropriately, selecting the option for patients with an existing management plan where required, appropriate use of the declared questions in Module 0, appropriate pathway choice, whether early exit was used appropriately and so on.'

Actions in relation to complex calls following Sebastian's death

As outlined in the oral evidence during the inquest following Sebastian's tragic death, we facilitated a discussion with NHS 111 and 999 lead trainers about complex calls, and whether there was additional support that could be provided to call handlers. This discussion took place at our Training Stakeholder Group (TSG) on 18th July 2018. The group felt that the definitions and early exit routes are sound, but that staff needed a 'reminder'. The discussion led to the production of a set of 6 posters reminding staff of what constitutes a complex call and how they should respond. The rationale of having posters is to try and keep the notion of 'complexity' top of call handlers' minds, rather than relying on memory. The Hot Topic on complex calls was also updated and recirculated. This update included the following addition:

'Organisations must encourage a culture, where call handlers feel empowered to recognise their limits and are able to act appropriately on this. They need to be able to transfer calls complex calls to a clinician with minimal delay and fuss.'

This was added following discussion with the TSG members who reinforced the fact that sometimes there are cultural or operational barriers which can make it more challenging to transfer a call to a clinician.

Finally, we have developed a training session which focuses on how we can support call handlers to recognise complex calls. This was introduced to all organisations that use NHS Pathways at the Training and Quality Forum on 25th June 2019.

The training session is a workshop that builds on existing core training and learning materials around complex calls. It's been designed to explore and understand why some call handlers may have difficulty in recognising a complex call. During the session, we examine the complexity of issues that can arise during telephone triage, and how organisations can encourage a climate of multi-disciplinary support when the call handler is dealing with a call that they feel is at or beyond their level of knowledge or experience.

4) **At the time of the conclusion of the inquest NHS Pathways did not allow a meaningful assessment of pain in a child; that is to say questions about severity of pain and ability of a child to communicate such pain should be reviewed at national governance level:**

The way in which pain is assessed in children is best explained by the screen shot below of the question that would appear on the screen when a call is taken. The assessment is done by reference to whether certain activities are possible, which is more informative than simply asking what the level of pain is.

Vomiting and/or Nausea

How bad is the pain?

To find out if there are features that suggest there might be a serious underlying cause for the pain.

so bad that doing anything is impossible

This means any pain which is so bad that the individual cannot walk about normally.
They may be lying down and unable to move or be writhing around in agony.
They may be crying out with the pain.

bad enough to interfere with normal activity

This means the individual can walk about and continue to do things but feels uncomfortable.
The pain may be coming and going.
They will not be crying out with pain.

neither of the above

A telephone assessment of pain in any age group is challenging as pain can be binary in nature. It is acknowledged that asking how bad the pain is will likely generate a very subjective description. Therefore, the system supports call handlers to undertake a 'functional capacity' assessment by way of the question presented.

This involves asking a parent/carer to describe how the pain is affecting the normal everyday activities of the child. This allows for a comparison against the child's normal baseline. This comparison with 'normal' by the parent is a more objective and meaningful measure of severity than asking how bad the pain is. It also recognises the fact that parents are well placed to judge how the pain is affecting the child and includes an element of parental concern in the response.

It should also be noted that the triage questions asked in those with declared mild/moderate abdominal pain still aims to capture serious pathology by asking similar questions to those in the severe pain assessment. This ensures serious pathology is still identified and a reasonable disposition, in keeping with clinical scenarios, is reached.

It has also been confirmed during the inquest that the assessment of pain is difficult in children because they do not have the ability to explain it in detail. Pain is not part of the NEWS score (National Early Warning Score) used to assess acutely ill patients, but is discussed by references to smiley faces on a chart when children are examined face to face. Smiley faces cannot be used in a triage system where assessment is made over the phone.

The assessment of pain within NHS Pathways is as meaningful as it can be for a remote assessment and recognises the difficulties in assessment of pain in children.

As with all pathways and the training/support materials, the abdominal pain pathway is under constant review to ensure any enhancements required will be made as quickly and effectively as possible. The use of extensive data analysis, external oversight / clinical expertise from the National Clinical Governance Group and continually developing medical guidance is integral to the production of NHS Pathways to ensure it operates safely and effectively at all times, supporting the health care economy and members of the public.

We trust that this addresses your concerns but please let us know if we can answer any further enquiries from HM Coroner.

Yours sincerely

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NHS Pathways