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Ms Veronica Hamilton-Deeley The Coroner's Office Woodvale Lewes Road Brighton BN3 2QB

Our reference: LT02005

Your reference: VHD/ST/00921-2018

1st May 2019

Dear Ms Hamilton-Deeley

Inquest into the death of John Scott

I am writing in response to a Regulation 28 report received from HM Senior Coroner, dated 14th February 2019. This follows the death of John Scott who sadly passed away on 27th September 2018. This was followed by an investigation and inquest which concluded on 8th February 2019. NHS Pathways is the clinical decision support software used by all 111 service providers, and some 999 ambulance service providers including South East Coast Ambulance Service. I am Service Service in Clinical Director, NHS Pathways, NHS Digital.

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

- (1) With regard to the questions asked when an emergency call is made to South East Coast Ambulance Service my view is that the additional questions should be asked:
 - 1. Is there anyone else with you or are you alone? If there is anyone else with you may I, please speak to them:
- 2. If the caller is alone: we will be asking you not to ring anybody because we need to consider the possibility that we will need to ring you back however, if you want to phone for somebody to come and bring you some support and company could you please do that within the next 15 minutes from now.
 - At the end of the call when the Pathways aspect of the call is ended why do you not explain to the person ringing you, about the likely timing of the ambulance at this stage and therefore, the estimated time of arrival. If at that stage the estimated time of arrival is two hours or more, why do you not suggest to the patient that they may like to make arrangements to get themselves to hospital without an ambulance?

- 3. With regards to pathways I understand that they have their particular questions but how can a person who is alone when they ring the ambulance service phone the ambulance service back if they become unresponsive? This is nonsense and may well confuse the patient ringing.
- 4. Since we were dealing at this inquest with a case of previously undiagnosed abdominal aortic aneurysm and since this is not an unusual scenario for Pathways and South East Coast Ambulance to come across, is it not possible to ask the patient whether they can feel anything at the site of the pain e.g. a pulsating mass. This if it is felt, could be a clear diagnostic sign.

NHS DIGITAL'S RESPONSE

For information, I have provided below a short summary of the functions that NHS Pathways performs and the governance that underpins it. I have also attached to this letter a Coroner's Information Pack which provides further details and may be useful for your future reference.

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 13 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.

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.

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 answer the concerns raised:

Is there anyone else with you or are you alone? If there is anyone else with you may I please speak to them:

Call handlers using NHS Pathways are always trained to speak directly with the patient when it is a 3rd party call, this ensures that the questions being asked are answered as accurately as possible to ensure both a safe outcome and that questions are not mis-interpreted through a 3rd party.

Call handlers are not trained to ask if there is someone else with a 1st party caller, however this is assessed on a case by case basis as there are certain situations where it may not be appropriate to speak with the patient including, but not limited to, children of certain ages, callers with communication difficulties, those with hearing disabilities or so ill they cannot speak.

The decision whether to ask call handlers to ask to speak to someone else if they are with the caller would be an operational decision for South East Coast Ambulance Service as NHS Pathways cannot mandate this.

If the caller is alone: we will be asking you not to ring anybody because we need to consider the possibility that we will need to ring you back however, if you want to phone for somebody to come and bring you some support and company could you please do that within the next 15 minutes from now.

Within NHS Pathways, where there is an ambulance dispatch in both 999 and 111, callers are advised to not to ring anybody else in case the ambulance service needs to call the patient back for example to confirm the address or any special requirements like entry information. This is especially important in calls generated from 111 as these are automatically sent through to the ambulance service and the service that has received the case may need to call back.

This script forms part of the closing instructions which were reviewed in 2016 by NHS Pathways and at the time with 6 ambulance service trusts using NHS Pathways. The agreement was for this instruction to remain for the reason outlined above.

NHS Pathways will review this instruction in line with its review process and consider adding in a statement to "call someone else" and work closely with all 999 services using NHS Pathways in this development. If changes are required these will be incorporated into release 19 (due for deployment May 2020) following NHS Pathways robust processes for authoring, assuring, testing and deployment of clinical content.

At the end of the call when the Pathways aspect of the call is ended why do you not explain to the person ringing you, about the likely timing of the ambulance at this stage and therefore, the estimated time of arrival. If at that stage the estimated time of arrival is two hours or more, why do you not suggest to the patient that they may like to make arrangements to get themselves to hospital without an ambulance.

Within NHS Pathway release 17 which is being deployed from 5th May 2019 call handlers will be provided with a script to advise callers that an ambulance aims to be with you within x minutes or hours. This was introduced to enable patients to make an informed decision as to whether to wait for that ambulance or, where safe, make their own way to hospital.

However, exact times cannot be given by NHS Pathways as this information can only be provided by South East Coast Ambulance Service based on their live operational position and so NHS Pathways cannot comment further on this point.

With regards to pathways I understand that they have their particular questions but how can a person who is alone when they ring the ambulance service phone the ambulance service back if they become unresponsive? This is nonsense and may well confuse the patient ringing:

For all calls that go through NHS Pathways, care advice and closing instruction are provided at the end of each call by the call handlers. This advice instructs the patient how to look after themselves either while waiting for an ambulance to arrive or another health care professional to contact them or what to do if there is any deterioration.

NHS Pathways constantly reviews all clinical content and is currently reviewing all aspects of the care advice given. One part of this review by NHS Pathways will be looking at the worsening advice which is currently given, this will include specifically reviewing the advice to call 999 if deterioration happens, such as for 1st party callers becoming unresponsive, as you suggest.

Any changes will be incorporated into release 19 (due for deployment May 2020) following NHS Pathways robust processes for authoring, assuring, testing and deployment of clinical content.

Since we are dealing at this inquest with a case of previously undiagnosed abdominal aortic aneurysm and since this is not an unusual scenario for Pathways and South East Coast Ambulance to come across, is it not possible to ask the patient whether they can feel anything at the site of the pain e.g. a pulsating mass. This if it is felt, could be a clear diagnostic sign.

Abdominal aortic aneurysms (AAA) represent an important diagnostic challenge. The majority of aortic aneurysms are asymptomatic, with the classic presentation for a ruptured aortic aneurysm being back pain with or without abdominal pain, and a pulsatile mass. However, this triad is present in only 25-50% of cases.

Most AAA rupture into the retroperitoneal cavity (the space at the back of the abdominal cavity). The precise site of the rupture will give rise to the different common and uncommon presentations.

Academic studies on abdominal palpation, by trained clinicians, for identifying the presence of AAA have shown not only poor diagnostic accuracy but also wide interobserver variability, affected by the size of both the aneurysm and the patients' abdomen.

Telephone symptom-based assessment presents significant challenges relating to eliciting clinical signs and in determining the reliability of the findings. This is especially so in relation to layperson palpation. Asking an individual or their carer to determine the presence of a possible 'pulsating mass' would be very difficult over the phone. This could lead to an increase in call length due to the need to articulate to a lay person what they are looking for and what palpation means. Call handlers often have to transfer the call to a clinician due to the difficulties in interpreting the responses, thereby resulting in further increases in call length. The end result is a significant delay to ambulance dispatch for a time critical condition.

NHS Pathways recognises the serious nature of a ruptured AAA. Within the current triage, symptoms relating to hypovolemia and critical illness are identified and give rise to an emergency ambulance dispatch. NHS Pathways is currently undertaking a detailed review to determine whether additional discriminators can be used over the phone to enhance the triage. These include utilising risk factors like the patients age together with specific questions to determine the onset and nature of the pain (including its location, nature and severity) and compounding these with symptoms relating to organ dysfunction. The presence of a pulsatile mass, even if it could be reliably identified, would not necessarily change the disposition given the seriousness of the symptoms already identified by the earlier questions. These changes will be incorporated into release 18 (due for deployment 7th October 2019) following NHS Pathways robust processes for authoring, assuring, testing and deployment of clinical content.

I am happy to answer any further enquiries from HM Coroner.

Yours sincerely

Deputy Clinical Director NHS Pathways