NHS Digital

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Your Reference: AJC/LJB
Our reference: LT02238

22 nd August 2019

Dear Mr Cox

Inquest into the death of Jennifer Mary Withey

I am writing in response to a Regulation 28 report received from HM Senior Coroner, dated 3rd July 2019 and addressed to NHS England and NHS Pathways, and a subsequent letter dated 24 July 2019 addressed to NHS Digital. This follows the death of Jennifer Mary Withey who sadly passed away on 10th September 2017. This was followed by an investigation and inquest which concluded on 26th June 2019. NHS Pathways is the clinical decision support software used by all 111 service providers, and some 999 ambulance service providers including South Western Ambulance 111 Service. I am Darren Worwood, RGN, RSCN, BSc, SPQ and am writing in my capacity as Deputy Clinical Director, NHS Pathways, NHS Digital.

HM Coroner has raised the following matters of concern in the Regulation 28 report:

1. The free text box could be set up so that identified symptoms, where appropriate, could generate an automatic red flag. By way of illustration, a non-blanching rash could automatically justify immediate hospital admission by ambulance in a case of suspected meningitis. Similarly, in this case, where a number of sepsis indicators were present, a red flag could have been raised requiring the call advisor specifically to consider a sepsis pathway. This would act as a second level of security, the first step being to allocate a patient to a correct pathway in the first instance: and
2. Is it possible to establish a single patient orientated pathway with a key performance indicator of, for example, 'patient to be seen within two hours' rather than separate time limits for two or more organisations (here, 111 and Cornwall Health) which cumulatively introduces unnecessary and avoidable delay into the process.

HM Coroner asked for confirmation in the letter dated 24 July 2019 that NHS Digital is the organisation with authority, where it is felt to be appropriate, to make changes to all or the relevant NHS pathway(s), and, on that basis, confirmed that NHS Digital should respond to paragraph 5A of the Regulation 28 Report (concern 1 above). HM Coroner also sought confirmation that NHS England was the organisation with responsibility for setting key performance indicators, and, on that basis, suggested that NHS England should respond to paragraph 5B of the Regulation 28 Report (concern 2 above).

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. We also provided a Coroner's Information Pack on 18 July 2019 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 16.5 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. 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 answer the points raised with regards to NHS Pathways:

1) **HM Coroner asked for confirmation that NHS Digital is the organisation with authority, where it is felt to be appropriate, to make changes to all or the relevant NHS pathway(s).**

The NHS Pathways system is owned by the Department for Health and Social Care and managed by NHS Digital; the NHS Pathways team is part of NHS Digital. Therefore, it is correct that NHS Digital manages, develops and makes changes to NHS Pathways, subject to the governance processes described above.

2) **HM Coroner stated in paragraph 5A of the Regulation 28 Report: The free text box could be set up so that identified symptoms, where appropriate, could generate an automatic red flag. By way of illustration, a non-blanching rash could automatically justify immediate hospital admission by ambulance in a case of suspected meningitis. Similarly, in this case, where a number of sepsis indicators were present, a red flag could have been raised requiring the call advisor specifically to consider a sepsis pathway. This would act as a second level of security, the first step being to allocate a patient to a correct pathway in the first instance.**

In responding to the concerns raised we would like to address three separate elements:

1. The use and risks of the free text facility within NHS Pathways
2. The recognition of complex calls, and transfer to clinicians
3. The inclusion of current best practice guidance for the recognition of critical illness (including sepsis) within our question algorithms

1) The use and risks of the free text facility within NHS Pathways

The free text box is built into NHS Pathways to allow users (whether non-clinical call handlers or clinicians)to add any relevant additional information that may have bearing on the call, for example the patient had seen a doctor last week, or volunteered information about specific medication. Any free text entered into the free text box is displayed in the full report generated at the end of any assessment in red, which can be seen in the picture below highlighted with the green box. This is transferred onwards to the health care professional seeing or speaking with the caller.

Wording entered into the free text box does not have any bearing on the NHS Pathways disposition reached but is to inform onward local care providers. In many cases call handlers will not record any free text information. Therefore, each individual 111 and 999 provider produces their own guidance on what information could or should be recorded in the free text box by call handlers and clinicians, based on local operating procedures.

The structured and hierarchical nature of the NHS Pathways questions enables non-clinical call handlers to move through the assessment in a logical order and at an appropriate speed bearing in mind the clinical risks of various symptoms and need to trigger the fastest dispositions for the most urgent needs.

CONSULTATION SUMMARY PRINTED ON 10/08/2019 06:28:00
CASE ID: a1df4dba-52ab-4427-a600-0cc0ead59128
NHS PATHWAYS R18.5.0

PATIENT: Joe Bloggs
TELEPHONE:
AGE GROUP: Adult
GENDER: Female
PARTY: 1
POSTCODE: DH1 2HP
NOTES:

SKILLSET: 111 Call Handler
CALL HANDLER USER ID: TEST_USER1
PATHWAY: PW516 - Abdominal Pain
SYMPTOM GROUP: 1004 - Abdominal Pain
SYMPTOM DISCRIMINATOR:
DISPOSITION: Dx32 - I'll connect you with a clinician from our service now.
SELECTED CARE SERVICE: No care service selected

CONSULTATION SUMMARY:

Illness - TEST
Warm to touch
Assessment ended: call transferred to clinician
Clinician transfer, other complex call - test

PATHWAYS ASSESSMENT:

An injury or health problem was the reason for the contact.
Heavy bleeding had not occurred in the previous 2 hours.
An illness or health problem was the main problem. - TEST
The individual was not fighting for breath. - Demonstartion Text
The main reason for the assessment was not a heart attack, chest/upper back pain, probable stroke, recent fit/seizure or suicide attempt.
The main reason for contact was not new confusion, declared diabetic hypo/hyperglycaemia, a probable allergic reaction or ICD shock.
The skin on the torso felt normal, warm or hot.
Pathway Selected: PW516, Abdominal Pain
Vomiting, diarrhoea, rectal bleeding, groin pain or groin swelling could not be confirmed.
There was no vaginal bleeding, discharge or swelling.
Assessment ended because transfer to a clinician was required.
The call was transferred to a clinician for further exploration. - test

ADVICE GIVEN:

No worsening instructions given as direct transfer to clinician

NHS Pathways considers that introducing use of the free text box to record symptoms and trigger dispositions would create the following risks and issues:

- If there was conflict between the questions/answers and the free text this would result in a disposition being unclear and create a situation which non-clinical call handlers were not able to manage (thus requiring transfer to a clinician, as detailed in the complex call procedure below);

- 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;

- The questions and range of answers are developed by clinical authors and assured by the National Clinical Governance Group to achieve the above and ensure an accurate assessment is carried out. Relying on non-clinical call handlers to enter accurate symptom descriptions on a free-text basis introduces risks of incorrect or irrelevant information being used. An accurate free text description of symptoms requires knowledge and discretion that non-clinical call handlers are not expected to have, and that a training programme for individuals who are not medical professionals could not deliver;
- It may be in time that technology, natural language processing and artificial intelligence develop such that free text analysis of this nature can successfully be deployed but NHS Pathways do not consider that sufficient expertise or evidence exists currently to safely introduce such a feature. Use of developing technology is something that remains under constant review in NHS Pathways.

2) The recognition of complex calls, and transfer to clinicians

In NHS Pathways there are a number of aspects which support the identification of seriously unwell patients and resolution of any uncertainty experienced by non-clinical call handlers as detailed below.

When using NHS Pathways call handlers should be guided by the triage questions presented during the assessment, however if there is any doubt the complex call process can be used which enables the call handler to transfer the call to an in-house clinician. The definition and explanation of complex call is defined below:

Complex Call Definition and Categories

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 calls 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:

1. Multiple symptoms that don't threaten a patient's airway/breathing/circulation but where the patient/caller can't prioritise a main symptom

If any of the symptoms have the potential to compromise a patient's airway, breathing or circulation, the call handler would treat this as the priority and would continue triage. In some cases, a Pathway will cater for multiple symptoms (such as the Colds and Flu Pathway),

however, where this is not the case, the patient/caller would be asked to prioritise their most troubling/worrying/pressing symptom. If they were unable to do so, the call handler should Early Exit and transfer to a clinician.

2. Difficulty Obtaining Adequate Information

Clearly safe triage depends on getting the right information from the patient at the right time. If a call handler is struggling to obtain this information for any reason, the call should be Early Exited and transferred to a clinician. The clinician may or may not be able to obtain more information, however within the scope of their professional registration, accountability structure and clinical expertise, they are better placed to make a professional decision about how best to manage the situation.

3. Medication or Medical Procedure Enquiry

It is not within the remit of a call handler to give information or advice relating to medication or medical procedures since this can require a significant breadth and depth of clinical knowledge, so these calls are Early Exited and transferred to a clinician.

4. Declared Medical History

It is not reasonable to expect a call handler to understand the wide range of diagnoses a patient might declare, or to be able to understand every piece of medical terminology presented to them. If the caller declares a medical history or uses medical terminology that the call handler feels complicates or ***might*** complicate the situation, they should Early Exit and transfer to a clinician.

In addition to these four pre-defined categories of complex call, there is also the option to select 'other'. This facility allows call handlers to transfer any other call where they are working at or beyond the limits of their knowledge.

Examples of where this might be used include:

- Where there are complex social circumstances complicating the problem.
- Where lots of information has been volunteered and it is not clear what is relevant and what isn't.
- ANY other situation where they are unsure about how best to handle the call.

The five categories outlined and the option to select 'other' are shown in the Early Exit Pathway below.

Note that 'Caller refuses disposition' is not defined as a complex call but is the route for a call handler to early exit and pass the call to a clinician for further assessment as to why the disposition was refused.

Early Exit
WHAT IS THE REASON FOR TRANSFER TO A CLINICIAN?

To find out why the call needs to be transferred to a clinician.

caller refuses disposition (specify)

This means that the caller refuses to accept the recommended disposition.

caller unable to prioritise a main symptom

This means the caller has difficulty deciding which symptom is troubling them the most.

difficulty obtaining adequate information (specify)

This means, for example, a caller who seems very vague, or unable to focus on the questions being asked.
This may also mean a caller who is incoherent or extremely difficult to communicate with.

medication or medical procedure enquiry (details not required)

This means that the call relates to medication or a medical procedure.
This does not mean a call about an individual with symptoms that need to be assessed.
This also does not mean a call about an overdose/toxic ingestion.

declared medical history (details not required)

This means a call where a diagnosed condition or medical language used complicates the situation.

other (specify)

3) The inclusion of current best practice guidance for the recognition of critical illness (including sepsis) within our question algorithms

NHS Pathways, as part of its routine monitoring and evaluation process, made enhancements to better identify those who are critically ill and at risk of sepsis in release 15. 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.

These critical illness enhancements have involved the UK Sepsis Trust and the National Clinical Governance Group and led to the inclusion of the qSOFA (quick Sepsis Related Organ Failure Assessment). The current algorithms are compliant with the NICE guidance (NG51) on Sepsis: recognition, diagnosis and early management. These enhancements include the specific feature of functional impairment (as was demonstrated in this unfortunate case) which we ask about with the question:

Difficulty Passing Urine

Are they so ill that they have stopped doing ALL of their usual activities?

To find out if the individual has symptoms which suggests they have become seriously ill.

yes - so ill they have stopped doing ALL normal activities

This means the individual is so ill they are unable to carry out any of their usual activities.
Usual activities means anything that they would normally do, e.g. watching TV or reading.
They may not respond or react normally to other people.
The individual or the carer may feel that something is seriously wrong.

no - unwell but able to do SOME normal activities

This means that the individual is able to carry out some of their everyday activities.

no - well enough to do MOST or all activities

This means that the individual can do most or all of their usual activities.

In addition to the above critical ill enhancements across all our relevant symptom algorithms, NHS Pathways has always asked the following questions in the relevant pathways (as these are potentially indicative of septicaemia rash and meningitis). These questions are asked if a positive answer has already indicated that the caller is functionally impaired:

Abdominal Pain

Have you developed one or more new marks, like bruising or bleeding under the skin?

To find out if the individual has developed symptoms suggestive of serious illness.

yes

This ONLY means new skin mark(s). It does not mean a bruise or mark(s) that were present before the individual began to feel ill.
There may be small red-blue, purple or brown mark(s) or pinprick spot(s) or larger purple blotch(es) or blood blister(s). On dark skin it is easier to see in paler areas, e.g. the mouth, palms and soles. The mark(s) do not go white or disappear when pressed BUT there is no need to ask the caller to check for this.

not sure

no

A 'positive' or 'not sure' answer to the above question would result in dispatch of an emergency ambulance (Category 2).

Have you got either of the following?
To find out if the individual has other symptoms suggestive of meningitis.

completely unable to put the chin to the chest

This means the individual cannot bend their head forward and put their chin onto their chest because the back of the neck is extremely stiff. It may also be painful.
This does not mean just pain or stiffness when turning the head from side to side.

completely unable to bear any light

This means the individual cannot bear any light, including daylight.
They will want to be in a darkened room, and will not be able to look at television or computer screens.
This does not mean just sore eyes.

not sure

no

A positive answer to 'completely unable to put the chin to the chest' or 'completely unable to bear any light' would result in dispatch of an emergency ambulance (Category 3).

In respect of the concern raised at paragraph 5B of the Regulation 28 Report I can confirm that NHS Digital cannot comment on national or locally commissioned performance indicators and this concern should be addressed to NHS England.

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

Yours sincerely

Darren Worwood
Deputy Clinical Director
NHS Pathways