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[redacted]

Dr Dominic Bell
Assistant Coroner Hull and the East Riding of Yorkshire

By Email: [redacted]
Our reference: LT04121

26th July 2022

Dear Dr Bell

Inquest into the death of Esma Guzel

I am writing in response to the Regulation 28 report received from HM Senior Coroner, dated 1st June 2022. This follows the death of Esma Guzel who sadly passed away on 10th May 2019. This was followed by an investigation and inquest which concluded on 23rd March 2022, and which NHS Pathways gave evidence at. I am Dr [redacted] and am writing in my capacity as Chief Clinical Officer, NHS Pathways, NHS Digital.

NHS Pathways is the clinical decision support software (CDSS) used by all 111 service providers, and some 999 ambulance trusts in England. For information, we have included a short summary of the functions that NHS Pathways performs and the governance that underpins it (containing background information on NHS Pathways) in Appendix A.

I would like to reiterate my sincerest condolences to the family of Esma Guzel.

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

1. *The 111 algorithm has been subject to modification in the light of these events, but I remain concerned that there is*
    a. *no detailed assessment of the degree of parental concern,*
    b. *no accommodation of the prior direct review by a general practitioner,*
    c. *and no consideration of the timing of the request for advice, when reaching a disposition that does not involve referral to paediatric services: and*
2. *I have heard in evidence that an educational message on 'rare causes for common symptoms' could be circulated as a case report, but take the view that the lead professional bodies for both general practice and child health should consider how such information is effectively disseminated, and whether the algorithms and dispositions*

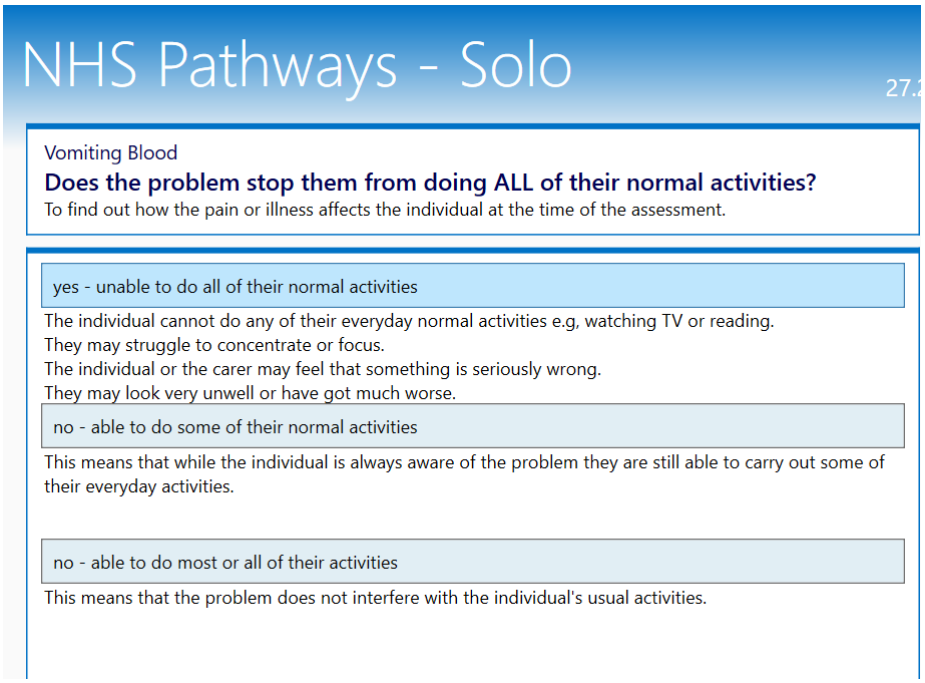
generated by the 111 service need further modification to maximise the chance of expedited optimal care for what is acknowledged to be an uncommon condition. I have heard in evidence that the 111 service is the default safety net arrangement in such circumstances, and this therefore requires endorsement by your professional bodies, if it is to command the confidence of patients, parents and practitioners as a definitive safety net.

NHS DIGITAL'S RESPONSE

To specifically address the concerns raised:

1) **The 111 algorithm has been subject to modification in the light of these events, but I remain concerned that there is:**
    a. **no detailed assessment of the degree of parental concern**

NHS Pathways currently has a question that considers parental concern within the context of other signs of general illness that result in an inability to perform normal activities (known as 'functional impairment'). The supporting information for this question (visible to health advisors) states, "The individual or the carer may feel that something is seriously wrong". Answering positively to this answer stem would be a positive response to functional impairment. This feature is included within the "vomiting blood pathway" for children aged over 5 and under 16 years old (as well as many other pathways). In this pathway the combination of the answers to the questions will result in a disposition which is mapped to either a Category 3 ambulance, 'Primary Care within 1 hour' or 'Primary Care within 2 hours'. The lowest level of care within the vomiting blood pathway for children aged over 5 and under 16 years old is mapped to 'Primary Care within 2 hours' for further assessment by a clinician. Please see below for a screenshot of the 'functional impairment' question.



Assessing parental concern through telephone triage is challenging as it is highly variable and subjective, with other discriminators such as physical signs of organ dysfunction provide stronger discriminatory accuracy for severe illness in most cases. NHS Pathways therefore assesses parental concern as described above and this, in the context of other symptoms also presenting, is taken account of in the disposition reached. It is critical that an Urgent and Emergency care triage system such as NHS Pathways ensures that patients' symptoms are assessed in a timely manner so that the appropriate level of care can be offered rapidly and safely. NHS Pathways considers that providing a more detailed assessment of parental concern at this stage of the triage would be challenging for a health advisor and may result in delays in signposting to the next level of care.

Esma's case was thoroughly reviewed by the NHS Pathways team to identify any potential learning and, following this, changes were made to the vomiting blood pathways to improve the identification of 'critical illness'. The potential critical illness triage assessment includes additional questions on breathlessness and confusion. These additional questions offer increased sensitivity to detect how unwell a child is and detect organ dysfunction and potential deterioration.

Had these critical illness triage assessment questions been asked as part of Esma's assessment, if symptoms of breathlessness and confusion were identified, the disposition reached would have been a Category 3 ambulance. A Category 3 ambulance means that 90% of incidents are responded to within 2 hours.

The above changes were approved by members of the National Clinical Governance Group (including The Royal College of Paediatrics and Child Health) as being a sensitive marker of critical illness in children and made within the system in Release 29 which was initially deployed through 'early adopter testing' on 1st November 2021, then widescale deployment from 24th November 2021.

b. no accommodation of the prior direct review by a general practitioner

NHS Pathways assesses symptoms at the time of the call. If all patients who had a previous encounter with a healthcare provider were automatically transferred to a clinician this would prevent the initial NHS Pathways assessment occurring which has the potential to prevent a timely generation of an urgent disposition such as an ambulance dispatch. It is also not possible to interrogate previous encounters as part of the NHS Pathways assessment such to only transfer some to a clinician, as this would require reliance on caller's recollection and knowledge, and health advisors to use discretion, neither of which is clinically safe or appropriate for telephone triage by non-clinical staff. Furthermore, previous direct review by a healthcare provider can represent a highly variable set of scenarios that has the potential to undermine the triage of the symptoms at the time of assessment and result in the wrong disposition with subsequent clinical risk. The fact of and details of these contacts may be

relevant to the assessment of symptoms at the time of a later call, but this is not always the case.

NHS Digital does not consider that all paediatric cases where there has been previous attendance to primary or secondary care should result in transfer of the call to a clinician. It considers that doing this could cause potential delays to assessing patients which could compromise patient safety. The system deals with a significant number of calls to 111 which have followed a previous assessment by a GP or other health care provider (or have also been previously assessed by a 111 or 999 service and advised to call back should a condition deteriorate). Providing a higher disposition than reached upon symptom-based-triage for those where there has been a previous contact with a healthcare provider may introduce delays to provision of care for individuals and across the population.

Recent prior contact with 111 service itself is taken account of as follows. The NHS 111 service specification (which can be found in full here:
https://www.england.nhs.uk/urgent-emergency-care/nhs-111/nhs-111-service-specification/
states:

"If a patient (or their carer) calls NHS 111 three times in 4 days, on the third call the patient must be assessed to determine whether or not an ambulance is required. If an ambulance is not required the call must be transferred to a clinician. The GP must complete a thorough reassessment of the patient's needs and have access to the details of all three calls".

This specification is set by NHS England and further questions regarding the rationale for setting this requirement would be best dealt with by NHS England.

c. and no consideration of the timing of the request for advice, when reaching a disposition that does not involve referral to paediatric services

NHS Pathways is a comprehensive decision support system, which assesses symptoms presented at the time of a call and signposts to next level of care. Therefore, assessment of time of day is not routinely considered as it would not be clinically safe to change level of care signposted to be based upon time of day as a discriminator alone. However, the functional impairment question identifies when the presenting problem is interfering with normal daily activities and that would include sleeping. This is an assessment against the patient's 'usual activities' so takes account of different patients having different baselines. In addition, NHS Pathways must consider differing daily routines encountered and 'usual activities' at different times of day may differ from person to person. For this reason utilising an objective standard against the individuals 'usual activities' is the preferred approach.

NHS Pathways assessments result in a disposition, but it is a local responsibility to match services to these. Therefore, services which are presented/returned from the Directory of Services for urgent primary care assessment (including Out of Hours referrals) are determined by local commissioners, and local decisions can be made not to make certain services or locations available in response to paediatric dispositions.

2) **I have heard in evidence that an educational message on 'rare causes for common symptoms' could be circulated as a case report, but take the view that the lead professional bodies for both general practice and child health should consider how such information is effectively disseminated, and whether the algorithms and dispositions generated by the 111 service need further modification to maximise the chance of expedited optimal care for what is acknowledged to be an uncommon condition. I have heard in evidence that the 111 service is the default safety net arrangement in such circumstances, and this therefore requires endorsement by your professional bodies, if it is to command the confidence of patients, parents and practitioners as a definitive safety net.**

RCPCH and RCGP have agreed to respond to this concern.

Conclusion

- NHS Pathways is not a diagnostic system; it assesses symptoms presented at the time of the call and signposts to the care skill set and time frame that a patient requires at that point in time. For this reason prior health care contacts are not taken into consideration other than repeat, recent 111 calls.
- Parental concern is taken account of in functional impairment assessment.
- It is not clinically safe or recommended to vary dispositions by time of day, but local decisions can be made in respect of the mapping of services to dispositions.
- The NHS Pathways content is continually under review to take account of clinical issues, user feedback, the latest available data and evidence, guidelines from Royal Colleges and other respected bodies and Coroner feedback. Any changes to NHS Pathways clinical content are overseen by the National Clinical Governance Group (NCGG) and Coroner referrals are submitted to NCGG as a standing agenda item.

NHS Digital takes its role in such enquiries and any PFD report received very seriously. NHS Digital wish to reassure the Coroner that it fully investigates and responds to PFD Reports accordingly. The matters that concerned the Coroner have been further assessed, and NHS Digital hopes this response assures that any changes that can be made to better the service and make this safer in respect of this points have been made. If I can be of any further assistance, please let me know.

I would like to take this opportunity again to offer my sincere condolence to Esma Guzel's family.

Yours sincerely

[redacted]

[redacted]
Chief Clinical Officer NHS Pathways
NHS Digital

Appendix A

Function of NHS Pathways

NHS Pathways is a telephone and digital triage Clinical Decision Support System (CDSS) that has been in use since 2005 within the Urgent and Emergency care setting. It is used in all NHS 111 and half of English ambulance services. This triage system supports the remote assessment of over 19 million calls per annum.

NHS Digital is the Health and Social Care Information Centre (a non-department public body) as detailed in Part 9, Chapter 2 of the Health and Social Care Act 2012. The NHS Pathways system is owned by the Department for Health and Social Care, commissioned by NHS England and developed and managed by NHS Digital; the NHS Pathways team is part of NHS Digital.

Calls using NHS Pathways are managed by non-clinical specially trained 'Health Advisors' who refer the patient into suitable services based on the patient's health needs at the time of the call. The Health Advisors are supported by clinicians who can 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 symptoms are assessed at the start of the call triggering ambulance responses, progressing through to less urgent symptoms which require a less urgent response (or disposition) in other settings. NHS Pathways is not a diagnostic system and only assesses symptoms presented at the time of the call and signposts to next level of care.

NHS Pathways is an interlinked series of algorithms, or pathways, that link questions and care advice leading to clinical endpoints known as "dispositions". The system presents a series of questions in order that the most appropriate clinical response or disposition may be determined based on the answers given. A disposition will specify the skill set and time frame that a patient requires. The system triages both injury and illness presentations for all age groups (neonate, infant, toddler, child, and adult). In addition, special populations are included where relevant to the triage e.g., pregnancy.

The NHS Pathways system was developed and maintained by a group of experienced NHS clinicians (clinical authors) with an Urgent and Emergency Care background. The NHS Pathways clinical authoring team come from a variety of clinical backgrounds and are either a paramedic, nurse or doctor who are registered, licensed practitioners.

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, an independent intercollegiate 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. The group considers all aspects of the triage process, including the impact on services, as well as the evidence base for changes to the clinical content. All changes to, and development of, the core telephone system and other platforms, are formally documented and presented for a critique by a group of authors. This includes both purely clinical elements, but also an appraisal of the operational impacts on NHS Pathways users and on providers' services.

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 clinical practice in the UK. This includes latest guidelines from:

a. NICE (National Institute for Health and Clinical Excellence);
b. The UK Resuscitation Council; and
c. The UK Sepsis Trust.

Safe and appropriate use of NHS Pathways by NHS care providers is governed by way of a 'Licence to Use'.

NHS Pathways welcomes user feedback to help improve the system. The License to Use details how serious incidents, near misses, requests for change, suggestions for enhancements and inquests or Prevention of Future Deaths Reports relevant to NHS Pathways should be reported to NHS Digital via the NHS Pathways authoring tool (in redacted form). Such clinical enquiries are given a priority grade and reviewed and responded to accordingly. All providers have access to the log and can see all enquiries raised.