

Nadia Persaud
The Coroner's Court
Queens Road
Walthamstow
E17 8QP

National Medical Director
NHS England
Wellington House
133-155 Waterloo Road
London
SE1 8UG

30 April 2024

Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Isaac Onyeka who died on 31st May 2023.

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 11th March 2024 concerning the death of Isaac Onyeka on 31st May 2023. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Isaac's family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Isaac's care have been listened to and reflected upon.

The first concern you raised was that there is a knowledge gap amongst the public (parents of children with Down's Syndrome in particular), and amongst some healthcare practitioners in relation to the immune deficiency associated with Down's Syndrome. NHS England manages the NHS website on behalf of the Department for Health and Social Care. The NHS website for England is the UK's biggest health website, with more than 50 million visits every month. The NHS website is subject to governance and assurance processes, ensuring content is regularly reviewed and represent current medical practice.

The NHS website has information for the public on many conditions, including [Down's syndrome](#). The pages contain summary information and also signpost patients, parents, and carers to third sector organisations, such as the [Down's Syndrome Association](#) and [Down Syndrome UK](#), for more comprehensive information about Down's syndrome, and associated health management. Both the Down's Syndrome Association and Down Syndrome UK publish public facing information about vulnerability to infection of people with Down's syndrome. These third-party websites are not managed by NHS England.

The NHS website has a page about [Other health conditions and Down's syndrome](#). This page signposts people to annual health checks and states "*People with Down's syndrome are more likely to become unwell through an infection...*" in the context of encouraging adherence with vaccination programmes. To support the public, the "*other health conditions*" page has been updated to make clearer the risks of increased susceptibility and consequences of infection. The '[Who's most likely to get sepsis](#)' section of our sepsis pages has also been updated to include genetic disorders such as Down's syndrome.

We agree that good understanding and awareness around sepsis amongst parents/ carers and clinicians' relation to children and young people is crucial. This is particularly important in respect to infants and young children. Children under five are at greater risk of sepsis than older children and those with compromised immune systems, including children with Down's Syndrome may be at an increased risk of complications from infections including sepsis.

NHS England's Learning Disability and Autism Programme will work with allied stakeholders so that they can help with raising awareness amongst parents/ carers of autistic children and young people and those with a learning disability or special educational needs and disabilities (SEND) families about the signs of sepsis as well as understanding that signs of sepsis may be easier to spot on the palms or feet amongst children and young people with black or darker skin.

[NICE Guidance](#) for varicella zoster chickenpox and complications includes information about complications that may arise in children as a result of having chickenpox.

Your second concern was that health advisers with NHS111 do not have access to GP electronic summaries and that they do not therefore have the background diagnoses of the patient concerned. The NHS Pathways triage system is a clinical decision support system (CDSS) supporting the assessment of patients presenting to urgent and emergency services. The system is owned by the Department for Health and Social Care and delivered by the Transformation Directorate of NHS England. NHS Pathways supports NHS 111 services nationally by providing a triage system to assess symptoms of patients over the telephone. It does not seek to diagnose patients but is instead built around a clinical hierarchy by presenting a series of questions in order for the most appropriate clinical response or disposition to be determined based on the presenting symptoms.

Health Advisers in NHS 111 telephone services are trained to use NHS Pathways by NHS 111 providers. These highly trained, non-clinical staff use the NHS Pathways system to support assessments so that cases can be triaged and directed to an appropriate service, within a suitable timeframe.

Where medical terms or diagnoses are volunteered by the caller, non-clinical Health Advisors are trained to identify these calls as "complex", being outside their scope of practice and for transfer to a clinician. This is so that the clinician can exercise clinical judgement.

GP electronic summaries contain clinical terms. Presenting such information to non-clinical Health Advisers would be outside the scope of practice for non-clinical staff. This is because they do not have the clinical training required to interpret the information held in these records, nor do they have a mandate to apply clinical judgement. It is the case, however, that Summary Care Records (SCRs) are visible to clinically trained staff in urgent and emergency care services. This is managed through local records sharing agreements.

Where appropriate, and in this case, the NHS Pathways system prompts Health Advisers to seek out from callers whether a pre-existing condition is present that can make infection very serious, as is the case for Down's syndrome. Sadly, in this instance, the question, though presented, was answered in the negative, meaning the opportunity to reach a higher disposition was missed.

Your third concern was that there is no central resource for assisting families to recognise signs of sepsis in patients with darker skin. It is well recognised and publicised that sepsis is hard to diagnose and over the years there have been numerous initiatives and solutions to try to improve the early recognition and prompt the treatment of sepsis to prevent complications including death.

Transformation and redesign of the sepsis pages of the NHS website was conducted in 2022. During this process the team consulted with stakeholders, including the [UK Sepsis Trust](#). They performed user research and tested the page with users, including parents of children that had not had sepsis. Based on the results of the testing and consultation, the team opted not to include any images on the page, but instead to emphasise the need to obtain emergency help from 999/Accident & Emergency (A&E) or urgent help from 111 if they/their child had any of the symptoms in the care card.

Care cards are visible on relevant pages of the NHS website, prompting further action by the reader in the presence of symptoms or findings. Based on the outcomes of the research, the page layout of the sepsis pages differs from those of other conditions. Because of the nature of this condition, the team found that the care cards - emergency care card (the red/black card) and an urgent card (red/white card) – should be located towards the beginning of the page, ahead of more detailed background information. On most other condition pages these care cards are included towards the end of the page after background information on the condition.

The NHS website has information for the public on [sepsis](#) which emphasises that sepsis can be hard to spot in babies, young children, and people with learning disabilities. The first section on the page is titled “Check if it's sepsis”. The first point on the emergency care card, highlighted in red and black, says “*Call 999 or go to A&E if:*”

“A baby or young child has any of these symptoms of sepsis:

- blue, grey, pale, or blotchy skin, lips, or tongue – on brown or black skin, this may be easier to see on the palms of the hands or soles of the feet”.*

Similarly, the emergency care card (“Call 999 or go to A&E if:”) on the [skin rash page](#) says:

“On brown and black skin, it may be easier to see the rash or colour changes on the soles of the feet, palms, lips, tongue and inside the eyelids.”

More generally, the NHS website Team are committed to include written content and (where appropriate) images of rashes and skin symptoms on a different range of skin tones. In 2020, user research interviews with people of colour with skin conditions were conducted and a skin tone survey was posted on conditions pages for cellulitis,

contact dermatitis and scarlet fever. The learnings around skin tone language were used to inform changes to the page on Chickenpox, which underwent user testing in 2021. This work continues across many areas of the NHS website.

As a result of your Report the Website Team will review whether to include images videos on the sepsis page to support identification of visible symptoms of sepsis.

I would also like to provide further assurances on national NHS England work taking place around the Reports to Prevent Future Deaths. All reports received are discussed by the Regulation 28 Working Group, comprising Regional Medical Directors, and other clinical and quality colleagues from across the regions. This ensures that key learnings and insights around preventable deaths are shared across the NHS at both a national and regional level and helps us pay close attention to any emerging trends that may require further review and action.

Thank you for bringing these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,



[Redacted text]

National Medical Director