Department of Health & Social Care

From Maria Caulfield MP
Parliamentary Under-Secretary of State for
Mental Health and Women's Health Strategy
Department of Health and Social Care

39 Victoria Street
London
SW1H 0EU

[redacted]

Carly Elizabeth Henley
Assistant Coroner
Newcastle upon Tyne and North Tyneside
Coroner's office
Lower Ground Floor
Block 1
Civic Centre
Barras Bridge
Newcastle upon Tyne
NE1 8QH

[redacted]

13 May 2024

Dear Miss Carly Elizabeth Henley,

Thank you for your Regulation 28 report to prevent future deaths dated 17th October 2023 about the death of Tyler Jay Ryan. I am replying as Minister with responsibility for Minister for Mental Health and Women's Health Strategy.

Firstly, I would like to say how saddened I was to read of the circumstances of Tyler, and I offer my sincere condolences to their family and loved ones. The circumstances your report describes are concerning and I am grateful to you for bringing these matters to my attention. Please accept my sincere apologies for the significant delay in responding to this matter.

The report raises concerns over workforce capacity, genetic screening (particularly in relation to molecular autopsies), and issues surrounding sudden death in childhood, all of which are matters I take extremely seriously.

In preparing this response, Departmental officials have made enquiries with NHS England and will continue to discuss these important issues with NHS England counterparts.

Workforce

The NHS Long Term Workforce Plan LTWP) published by NHS England in June 2023 sets out the steps the NHS and its partners need to take to deliver an NHS workforce that meets the changing needs of the population over the next 15 years. The plan outlines the action needed to ensure we train and retain more staff, and reform medical education and training to put the NHS workforce on a sustainable footing for the future.

Genetic screening

NHS England (NHSE) has published guidance for inherited cardiac conditions which requires services to investigate patients with previously undiagnosed cardiac disease, suggestive

symptoms or from families with sudden unexplained deaths. Where a genetic variation is identified, cascade testing is offered to relatives based on risk.

NHS England has undertaken a formal assessment and continues to review evidence for the potential merits of using genetic testing for certain heart conditions and heart disease through the National Genomic Test Directory. A robust and evidence-based process and policy is in place to ensure that genomic testing continues to be available for all patients for whom it would be of clinical benefit.

Genomic testing in the NHS in England is delivered through a national genomic testing network of seven NHS Genomic Laboratory Hubs (GLHs). The NHS GLHs deliver the testing outlined in the National Genomic Test Directory (the Test Directory) available here: NHS England » National genomic test directory, which sets out the eligibility criteria for patients to access testing as well as the genomic targets to be tested and the method that should be used, and is applicable nationally providing a standardised approach. The Test Directory currently includes 357 rare and inherited disease clinical indications (covering around 3200 rare diseases) and over 203 cancer clinical indications. The Test Directory is regularly updated to reflect the latest scientific and technological developments, including new clinical indications for rare disease, for example during the most recent update in October 2022, which included 150 changes to the directory.

Seven NHS Genomic Medicine Service (GMS) Alliances also play an important role in supporting the strategic systematic embedding of genomic medicine in end-to-end clinical pathways and clinical specialities, as well as raising awareness among clinicians and the public of the genomic testing available through the NHS. The NHS GMS Alliances are supporting several national and local transformation projects, including a national project with the NHS Inherited Cardiac Conditions services, British Heart Foundation and the country's coroners, who carry out inquests into sudden and unexplained deaths. The project will test DNA of people who died suddenly and unexpectedly at a young age from a cardiac arrest. Their surviving family can then also be offered genetic testing to see if they carry the same gene changes.

Sudden death in childhood

Research is on-going in many of the causes of Sudden Cardiac Death. There is an opportunity now with the implementation of Genomic Laboratory Hubs across England to explore the systematic introduction of post-mortem genetic testing.

In 2020 NHS England and the British Heart foundation launched the NHS-Coronial-Sudden Unexpected Death pilot, including the causes of SAD across 7 sites to develop the pathways necessary to ensure equitable access to a genomics driven clinical programme.

I hope this response is helpful. Thank you for bringing these concerns to my attention.

Best Wishes,

MARIA CAULFIELD