

The Rt Hon. Andrew Stephenson CBE MP
Minister of State

39 Victoria Street London SW1H 0EU

Mrs Heidi J Connor Senior Coroner for Berkshire Reading Town Hall Blagrave Street Reading RG1 0QG

3 April 2024

Dear Mrs Connor,

Thank you for your letter of 6 April 2023 about the death of Alexandra Briess. I am replying as Minister with responsibility for long-term conditions, including allergies, and I am grateful for the additional time in which to respond.

Firstly, I would like to say how saddened I was to read of the circumstances of Alexandra's death, and I offer my sincere condolences to her family and loved ones. Her loss at such a young age must be extremely distressing for them and I agree that it is essential that we learn from this tragic event to prevent future deaths.

The circumstances your report describes are very concerning and I am grateful to you for bringing these matters to my attention.

In preparing this response, Departmental officials have made enquiries with the organisations to which you issued your report to understand the system-wide response to the matters of concern. I am assured that your concerns have been carefully considered. I will not repeat the detail of the responses you have received, which are the responsibility of others. My response will focus on the matters of concern relating to the need for national leadership on allergy to oversee action to prevent similar deaths and register of deaths, as well as capturing and recording cases of fatal anaphylaxis.

National leadership on allergy services

In relation to national accountability for allergy services, following the reforms initiated by the Health and Social Care Act 2012, NHS England (NHSE) is responsible for clinical policy and strategy in the NHS in England (including for allergies) and is held to account through the annual NHS mandate.

While there is indeed currently no National Clinical Director (or 'Tsar') for allergy in England, NHSE has a clinical reference group (CRG) for Specialised Immunology and Allergy Services that provides advice on specialised services and commissioning policies and quality standards. The CRG is chaired by NHSE's National Specialty Advisor (NSA) for clinical immunology and allergy, Dr Claire Bethune, a clinical immunologist, and allergy clinical immunology expert clinicians are among the membership.

More generally, NSA and National Clinical Director (NCD) posts within NHSE are specifically aligned with its major clinical programmes of work, which in turn are aligned with the NHS Long Term Plan. NHSE keeps consideration of which areas would benefit from an NCD under review, and new NCDs are appointed as they reason is necessary.

An Expert Advisory Group for Allergy (EAGA) has recently been established, which brings together key stakeholders with the aim improving the quality-of-life of people with allergies. Chaired jointly by the Department of Health and Social Care and the National Allergy Strategy Group, the EAGA identifies priority areas for the Department, NHSE and other government department and agencies relating to allergy that require policy change or development and advises on how to best achieve improved outcomes.

Capturing and recording cases of anaphylaxis

As articulated in your report, recommendations refer to establishing a robust system of capturing and recording cases of anaphylaxis, both food and non-food related.

The Department of Health and Social Care notes the recommendation and concurs that it is essential that we learn from tragedies such as Alexandra. Data regarding all anaphylaxis-related deaths in England and Wales are documented by the Office of National Statistics. The British Society for Allergy and Clinical Immunology also holds a register, the UK Fatal Anaphylaxis Registry (UKFAR), referenced in your report, to capture and learn from fatal cases of anaphylaxis, which has been operational since 1992. A link to the register follows:

https://www.bsaci.org/professional-resources/bsaci-registries/ukfar/#:~:text=The%20UK%20Fatal%20Anaphylaxis%20Registry,order%20to%20influence%20clinical%20outcomes.

I understand that NHSE's National Patient Safety Team is working closely with the UKFAR to develop a mechanism for sharing relevant patient safety anaphylaxis incidents with them and this work is ongoing.

I hope this reply is helpful. Thank you for bringing these concerns to my attention. Kind regards,



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