

Our Ref: PW/AKB/FOI-10-149

4th November 2022

Stafford Education & Enterprise Park
Weston Road
Stafford
ST18 0BF

Sent by email

Telephone: 0300 123 1461

Dear

FOI-10-149

Your request for information under the Freedom of Information Act 2000

Thank you for your request dated the 21st October 2022. We can confirm that the Staffordshire and Stoke-on-Trent Integrated Care Board does hold part of the information that you have requested. Please see our responses in blue below

I am writing to you under the Freedom of Information Act 2000 to request the following information from Staffordshire and Stoke-on Trent.

- 1. The number of people in your ICB/ICP area who have been diagnosed with Epidermolysis Bullosa during the past five years.**

The Staffordshire and Stoke-on-Trent Integrated Care Board (ICB) do not hold this information. Whilst the ICB received data of patients referred and treated at various hospitals we do not hold the diagnostic detail, nor the procedures undertaken. This information would be available from the providers themselves.

- 2. The number of people with Epidermolysis Bullosa referred to one of the UK's specialist EB treatment centres in the past five years.**

Note: Specialist centres include children's services at Birmingham Women's and Children's Hospital, Glasgow Royal Hospital for Children and GOSH and adult services at Glasgow Royal Infirmary, Guy's and Thomas' Hospital and Solihull Hospital.

The Staffordshire and Stoke-on-Trent Integrated Care Board (ICB) do not hold this information. Whilst the ICB received data of patients referred and treated at various hospitals we do not hold the diagnostic detail, nor the procedures undertaken. This information would be available from the providers themselves.

- 3. How many GPs and frontline healthcare professionals have received training on Epidermolysis Bullosa diagnosis and care within your area. Please refer to training undertaken where possible.**

A Protected Learning Time (PLT) event was held for GP practices on the 30th September 2022. This was a virtual training event held over Microsoft Teams with two Dermatology Consultants and a Plastic Surgeon Consultant from our local acute trust and local Community Service Provider. The session covered cancer two week wait skin and high risk Basal Cell Carcinoma, future pathways, e.g. tele-dermatology, diagnosis and management of dermatology conditions in primary care and not specific to Epidermolysis Bullosa diagnosis. 114 clinicians attended.

Right of Appeal

Should you require any further information or clarification regarding this response please do not hesitate to contact us. If you are dissatisfied with the response, you are entitled to request an internal review which should be formally requested in writing and must be within two calendar months from the date this response was issued.

To request an internal review

You can request an internal review by contacting the Staffordshire and Stoke-on-Trent Integrated Care Board FOI team by emailing the team at StaffsStokeFOI@staffsstoke.icb.nhs.uk or by post to the address at the top of this letter.

If you are not content with the outcome of your internal review, you may apply directly to the Information Commissioner's Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the Staffordshire and Stoke-on-Trent Integrated Care Board's FOI complaints procedure.

The ICO can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

www.ico.gov.uk

Yours sincerely

Paul Winter
Deputy Director of Corporate Governance,
Compliance & Data Protection/Data Protection