

Reference: FOI.ICB-2223/094

Subject: Epidermolysis Bullosa

I can confirm that the ICB does hold some of the information requested; please see responses below:

QUESTION	RESPONSE
<p>1. The number of people in your ICB/ICP area who have been diagnosed with Epidermolysis Bullosa during the past five years.</p>	<p>Hospital admissions and outpatients data has been used as a proxy to identify people with a diagnosis who live in BNSSG (Bristol, North Somerset and South Gloucestershire).</p> <p>To identify the cohort, ICD-10 codes Q81 and L123 were used.</p> <p>Over the past 5 years, 12 people were identified in the search.</p>
<p>2. The number of people with Epidermolysis Bullosa referred to one of the UK's specialist EB treatment centres in the past five years.</p> <p><i>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.</i></p>	<p>Bristol, North Somerset and South Gloucestershire Integrated Care Board (BNSSG ICB) does not have access to this information.</p> <p>The acute hospital trusts may hold this information, details of how to contact the trusts can be found via the following links:</p> <p>North Bristol NHS Trust (NBT) – https://www.nbt.nhs.uk/about-us/information-governance/freedom-information/request-information</p> <p>University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) – https://www.uhbw.nhs.uk/p/how-we-use-your-data/freedom-of-information-foi-requests</p>

<p>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.</p>	<p>The ICB does not hold this information. Epidermolysis Bullosa is not a diagnosis that would be made in Primary Care without a referral to Secondary Care. We advise you to contact the providers directly, who in this case would be the Acute Hospital Trusts; North Bristol NHS Trust (NBT) and University Hospitals Bristol and Weston NHS Foundation Trust (UHBW).</p> <p>NBT: https://www.nbt.nhs.uk/about-us/information-governance/freedom-information/request-information</p> <p>UHBW: https://www.uhbw.nhs.uk/p/how-we-use-your-data/freedom-of-information-foi-requests</p>
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The information provided in this response is accurate as of 31 October 2022 and has been approved for release by Sarah Truelove, Deputy Chief Executive and Chief Finance Officer for NHS Bristol, North Somerset and South Gloucestershire ICB.