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Email: [ddicb.foi@nhs.net](mailto:ddicb.foi@nhs.net)

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Date: 15 November 2022

**FREEDOM OF INFORMATION – DECISION NOTICE**

Dear Sir / Madam,

**FOI Reference Number: 1692**

I refer to your email of 21 October 2022 requesting information in respect of Epidermolysis Bullosa.

I can confirm on behalf of Derby and Derbyshire Integrated Care Board (DDICB), and in accordance with S.1 (1) of the Freedom of Information Act 2000 (FOIA) that we do hold some of the information that you have requested. A response to each element of your request is detailed below:

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

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.*

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.

**Our response:**

Q1. and Q2. The table below contains the number of inpatient spells where the patient has a diagnosis of Epidermolysis bullosa, unspecified or Epidermolysis bullosa dystrophica. All this activity is at local or non-specialised providers. This is all the information that we are able to identify with regards to diagnoses of Epidermolysis Bullosa.

Please note that, in order to prevent identification of individuals where the numbers involved are 5 or fewer, we have withheld this information under the exemption permitted to us by Section 40 of the FOI Act: Personal information.

Please note also that the information for 2022/23 only contains activity up to financial month 5.

|  |  |
| --- | --- |
| **Financial Year** | **Patients** |
| 2018/19 | <5 |
| 2019/20 | 0 |
| 2020/21 | <5 |
| 2021/22 | 9 |
| 2022/23 | <5 |

Q3. We do not hold this information.

I hope that this answers your queries with the information we currently hold, but if I can be of any further assistance please do not hesitate to contact me.

If you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

NHS Derby and Derbyshire ICB  
FOI Team

First Floor

Cardinal Square

10 Nottingham Road

Derby

DE1 3QT

Or:

[ddicb.foi@nhs.net](mailto:ddicb.foi@nhs.net)

If you are not content with the outcome of our review, you may apply directly to the Information Commissioner for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by the ICB.

The Information Commissioner can be contacted at: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF, telephone 0303 123 1113, email [casework@ico.org.uk](mailto:casework@ico.org.uk).

Yours faithfully,

**Kathryn Jacklin**

**FOI Officer**

**Derby and Derbyshire Integrated Care Board**

*All information we have provided is subject to the provisions of the Re-use of Public Sector Information Regulations 2015. Accordingly, if the information has been made available for re-use under the* [*Open Government Licence*](http://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/) *(OGL) a request to re-use is not required, but the licence conditions must be met. You must not re-use any previously unreleased information without having the consent from the ICB. Should you wish to re-use previously unreleased information then you must make your request in writing (email will suffice) to the FOI Lead via*[*ddicb.foi@nhs.net*](mailto:ddicb.foi@nhs.net)*. All requests for re-use will be responded to within 20 working days of receipt.*