

Reference:	FOI 10097.22
Subject:	Epidermolysis Bullosa
Date of Request:	21 October 2022

Requested:

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.

Response:

1. & 2. Hywel Dda University Health Board (UHB) is unable to provide you with the exact number of patients due to the low numbers of cases (3 and under) during the whole five (5) year period, as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the Data Protection Act (DPA) 2018/ General Data Protection Regulations (GDPR) 2016, as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles 6 and 9 of the GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.

In reaching this decision, the Data Protection Act 2018/ General Data Protection Regulations 2016 define personal data as data which relates to a living individual who can be identified solely from that data or from that data and other information which is in the possession of the data controller.

3. The UHB is unable to provide you with the number of GPs and Frontline Health Workers who have received training on Epidermolysis Bullosa, as it is estimated that the cost of answering your request would exceed the "appropriate limit" as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. The "appropriate limit" represents the estimated cost of one person spending 18 hours (or 2 ½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

The training subject would form part of wider dermatological training programmes, and therefore, in order to identify the information requested, the UHB would first be required to identify each of the training courses which may contain this subject matter. Furthermore, not all training records and programmes are held centrally as some will be locally delivered training within the clinical setting. Thereafter, the UHB would need to collate the number of frontline clinical workers and GPs that have received the identified training programmes.

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000, which provides an exemption from a public authority's obligation to comply with a request for information where the cost of compliance is estimated to exceed the *appropriate limit*.

Under section 16 of the Freedom of Information Act, the UHB has a duty to provide advice and assistance. As such, the UHB must inform you that it does not hold all information relating to GP partners, as many GP Practices are independent of the UHB. Therefore, in order to access the requested information for GP Practices, it is recommended you redirect your request to the practices directly. Their contact details can be found at: [Health in Wales | GP Surgeries in Hywel Dda University Health Board](#)

The UHB had four (4) managed practices at the time of your request, whose information has been considered as part of the UHBs response, namely Meddyfga Minafon, Meddygfa'r Sarn, Tenby Surgery and Ash Grove Surgery.