

Freedom of Information Request: Our Reference CTMUHB_417_22

You asked:

I am writing to you under the Freedom of Information Act 2000 to request the following information from Cwm Taf Morgannwg Health Board.

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

As the diagnosis of a patient can occur at differing levels: outpatient consultation, the result of a diagnostic test, inpatient/daycase admission, for example and we only record diagnoses via clinical coding at the inpatient stage, we are unable to provide the number of patients diagnosed with Epidermolysis Bullosa.

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

Epidermolysis Bullosa services are considered specialist and are commissioned on an All Wales basis by the [Welsh Health Specialised Services Committee](#) (WHSSC). We can confirm that the Health Board does not hold this data.

For information relating to this service, you may wish to contact WHSSC directly.

Their contact details can be found via the following link:

[Contact Us - Welsh Health Specialised Services Committee \(nhs.wales\)](#)

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.

GPs - We can confirm that the Health Board does not hold this information. GPs are independent contractors. Therefore, you may wish to contact them directly.

A list of practices that fall under the CTMUHB is available via the following link: [Health in Wales | GP Surgeries in Cwm Taf Morgannwg University Health Board](#)

Frontline Healthcare Professionals – The Health Board does not hold this data centrally or in a format that would enable us to respond to your request to the level of detail required.

As this is not information that the Health Board routinely compiles, we would have to carry out a specific exercise to collate this data. From our preliminary assessment, we estimate that to comply with your particular request would significantly exceed the 18 hours time and £450 cost limit set out within Section 12 of the Freedom of Information Act.