



Bwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board

Information Governance Team
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Bronllys Hospital
Bronllys
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Powys LD3 0LY
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Our ref: IG/FOI/23.R.092

11 April 2023

Sent via email to: [REDACTED]

Dear [REDACTED]

Request under the Freedom of Information Act 2000

I write further to your request for information which was received on 20 March 2023, to confirm, in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Teaching Health Board (PTHB) does hold the information that you require.

For ease of reference your request is set out below and our response follows:

Your Freedom of Information (FOI) Request:

When the Rare Disease Action Plan for Wales 2022-26 was published last summer, the Welsh Health Circular that accompanied the Plan (WHC-2022-017), set out clear expectations for Health Boards to facilitate and implement the priorities and actions in the Plan over its lifetime. The WHC said: "Health boards should take account of the priorities for rare diseases when planning their services and developing their Integrated Medium-Term Plans (IMTPs)".

Given that the Action Plan is still in its first year of implementation, it is extremely important that the Health Board embeds the Plan's four key priorities, both in financial and operational terms, into their IMTPs. Therefore, could you update me please on:

1. How is the Health Board implementing the Rare Disease Action Plan for Wales and what progress has been made on the four priorities to date, including identifying actions, delivery partners, timelines and outcome measures?
2. How many patients with X-linked hypophosphataemia (XLH) is the Health Board currently treating?
3. For those patients with XLH, how is the Health Board improving care coordination, as well as access to specialist care, treatment and medicines?

Pencadlys
Tŷ Glasbury, Ysbyty Bronllys,
Aberhonddu, Powys LD3 0LU
Ffôn: 01874 711661



Headquarters
Glasbury House, Bronllys Hospital
Brecon, Powys LD3 0LU
Tel: 01874 711661



Powys Response:

1. Powys Teaching Health Board has considered the actions required in the Rare Disease Action Plan for Wales 2022-26 in the development of its Integrated Plan. Please see Attachment 1.

PTHB's position in relation to the Rare Diseases Action plan is attached (Annex 1). Powys Teaching Health Board is not a provider of District General Hospital services, specialised services or clinical laboratory services. Most of the actions in the Rare Diseases Plan involving the health board are being taken forward through its participation in joint statutory Welsh Health Specialised Services Committee (WHSSC) through which specialised services are commissioned on behalf of the seven health boards in Wales. In addition, the health board is working to improve care co-ordination locally for children and adults with complex needs as set out in the Integrated Plan.

- 2&3. PTHB has scrutinised its database, with a public health consultant and made operational enquiries of those leading on primary care, children's services and adult services. In general terms Powys Teaching Health Board is working to improve access to specialised services and treatment via its participation in the Welsh Health Specialised Services Committee. PTHB is also working to improve care co-ordination locally as set out in its Integrated Plan.

PTHB is not able to provide these exact numbers due to the low numbers of individuals involved (5 or less). PTHB believes there is a potential risk of individuals being able to be identified, when considered with other information already available within the public domain, if this was disclosed. Therefore, the data is classed as personal data as defined under the UK General Data Protection Regulation (UK GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute unfair and unlawful processing in regard to Articles 5, 6, and 9 of UK GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.

Should you need any further assistance, please do not hesitate to contact me at the address below.

If you are dissatisfied, with the way your request has been dealt with by PTHB, you have the right to request a review in which case you should write to:

Chief Executive
Powys Teaching Health Board Headquarters
Glasbury House
Bronllys Hospital
Bronllys
Brecon

Powys LD3 0LY

If you are still dissatisfied at the end of the review, you may complain to the Information Commissioner, who can be contacted at the following address:

Information Commissioner's Office - Wales

2nd Floor,

Churchill House,

Churchill Way,

Cardiff, CF10 2HH

Tel: 029 2067 8400 Fax 029 2067 8399

www.ico.org.uk

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Rydym yn croesawu derbyn gohebiaeth yng Nghymraeg. Byddwn yn ateb y fath ohebiaeth yng Nghymraeg ac ni fydd hyn yn arwain at oedi. We welcome receiving correspondence in Welsh. We will reply to such correspondence in Welsh and this will not lead to a delay.

Yours sincerely



Carol Shillabeer
Chief Executive