



Bwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board

Information Governance Team
Monnow Ward
Bronllys Hospital
Bronllys
Brecon
Powys LD3 0LY
Email: Powys.FOI@wales.nhs.uk
Tel: 01686 252159/01874 442071

Our ref: IG/FOI/23.R.151

30 May 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 9 May 2023, to confirm, in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Teaching Health Board (PTHB) partly holds 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:

Freedom of Information request on Lynch Syndrome

1. Which nation is the Health and Social Care Trust or Health Board that you are answering this FOI request on behalf of in?

<input type="checkbox"/>	Scotland
<input type="checkbox"/>	Northern Ireland
<input type="checkbox"/>	Wales

2. Which Health and Social Care Trust or Health Board are you answering this FOI request on behalf of?

3. Do you use NICE guidelines to inform measures related to a Lynch Syndrome Clinical Pathway? If you use another set of relevant national guidelines, please specify this in the 'Other' box.

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
<input type="checkbox"/>	Other

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



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



4. Do you offer newly diagnosed bowel cancer patients in your health authority a test for molecular features of Lynch syndrome e.g., using either immunohistochemistry or microsatellite instability testing?

	Yes - all newly diagnosed bowel cancer patients.
	Yes - all newly diagnosed bowel cancer patients under the age of 70.
	Yes - all newly diagnosed bowel cancer patients under the age of 60.
	Yes - all newly diagnosed bowel cancer patients under the age of 50.
	Yes - according to family history of the disease.
	No - but our trust has agreed an implementation plan for this.
	No.
	Other

5.If such testing is offered, over the last financial year what proportion of newly diagnosed patients have had a test carried out for the molecular features of Lynch Syndrome? Please enter N/A if such testing is not available.

6.If such testing measures are in place, at what stage is it aimed that this testing takes place?

	Pre-treatment i.e., at diagnosis (on a biopsy of the tumour).
	Post treatment i.e., test is carried out on the tumour resection specimen only.
	Not applicable.

7.What are the main barriers you face to introducing testing for molecular features of Lynch syndrome in all newly diagnosed bowel cancer patients? Please select all that apply, and where possible specify why in the following free text box.

	Financial.
	Laboratory capacity.
	Genetic counselling capacity.
	Infrastructure
	Lack of Lynch Syndrome clinical champion/leadership.
	Policy.
	Awareness of current guidance.
	Limited number of staff.
	Lack of training for current staff.
	Other

8.Where possible, please use the below free text box to explain why the above barriers present difficulty to your health authority in introducing testing for molecular features of Lynch syndrome in all newly diagnosed bowel cancer patients.

9. At what point in the clinical pathway are the above barriers having the greatest effect with regards to being able to adhere to NICE or relevant national guidelines associated with Lynch Syndrome?

	Initial MMR tumour testing.
	Sequential germline testing.
	Cascade testing for close relatives of identified individuals with Lynch Syndrome.
	Lynch Syndrome surveillance – e.g., 2 yearly colonoscopies.
	Wraparound care measures such as genetic counselling.
	Other

10. Do you audit diagnostic outcomes within your health authority to ensure that patients are being tested for molecular features for Lynch syndrome?

	Yes, as part of private audit.
	Yes, as part of a private audit that is sent to a relevant organisation for national reporting.
	Yes, and the data is publicly released.
	No.

11. Is this test carried out as a reflex test i.e., automatically or upon referral?

	Reflex.
	Referral via MDT.
	Referral via Genetics Centre.
	Referral via GP.
	Other (please explain).
	Not applicable.

12. Is there a named individual within each colorectal team in your health authority who is responsible for ensuring testing for molecular features of Lynch syndrome take place?

	Yes, Gastroenterologist.
	Yes, Colorectal Surgeon.
	Yes, Oncologist.
	Yes, Nurse Specialist.
	Yes, Clinical Geneticist.
	Other (please explain).
	No.

13. What wraparound care measures are in place for those that are confirmed to have Lynch Syndrome? Please select all that apply.

	Genetic counselling.
	Referral to psychological services.
	Signposting to support groups.
	Signposting to third sector organisations such as Bowel Cancer UK.

	Provision of patient information resources.
	Other, please specify.
	None.

14. Upon identification of individuals with Lynch Syndrome, do you suggest that you provide letters for at risk family members to take to their GP that highlight their risk of Lynch Syndrome and request referral to genomic services for germline testing?

	Yes.
	No, but there are plans to introduce this.
	No.
	Other

15. Over the last financial year, what proportion of close relatives of individuals identified to have Lynch Syndrome have been tested for Lynch Syndrome?

16. Upon identification of individuals with Lynch Syndrome who do not currently have cancer, is regular colonoscopic surveillance provided?

	Yes, at the recommended intervals (2-yearly).
	No, we do not follow recommended interval lengths.
	Other

17. Over the last financial year, what proportion of individuals identified to have Lynch Syndrome who are offered regular colonoscopic surveillance are provided regular colonoscopies within the timelines selected above?

18. If such surveillance is offered how are patients called and recalled for these tests? Please enter N/A if you do not offer such surveillance.

Powys Response:

Q 1 Wales

Q 2 Powys Teaching Health Board

Q3 – 18 PTHB can confirm that colorectal treatment is undertaken at neighbouring district general hospitals. Please see the table below for contact details should you wish to contact them directly:

Health Board/Organisation	FOI Contact Details
Aneurin Bevan University Health Board	FOI.ABB@wales.nhs.uk
Betsi Cadwaladr University Health Board	bcu.foi@wales.nhs.uk
Cardiff & Vale University Health Board	FOI.Requests@wales.nhs.uk
Cwm Taf Morgannwg University Health Board	Freedomofinformation@wales.nhs.uk
Hywel Dda University Health Board	FOI.hyweldda@wales.nhs.uk
Swansea Bay University Health Board	FOIA.Requests@wales.nhs.uk

NHS Providers (England)	Contact Details
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Shrewsbury & Telford NHS Trust	info@sath.nhs.uk
Robert Jones & Agnes Hunt NHS Trust	foi@rjah.nhs.uk
Gloucester NHS Trust	https://foi.glosnhs.net/secureforms/infomationrequestform/
Wye Valley NHS Trust	freedom.information@wvt.nhs.uk

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 twitter.com/iconews

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



Joy Garfitt
Interim Director of Operations/Director of Community & Mental Health