Freedom of Information Request	FOI 23-250	6th June 2023

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

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

Aneurin Bevan University Health Board

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.**
   Yes P
   No.
   Other:

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. P

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.

   Approximately 100%

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) P *(if possible but post treatment otherwise)*
   Post treatment i.e., test is carried out on the tumour resection specimen only.P

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. P
Genetic counselling capacity.
Infrastructure P
Lack of Lynch Syndrome clinical champion/leadership.
Policy.
Awareness of current guidance.
Limited number of staffP
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.

Please refer to Q7.

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: No major barriers from laboratory side now that the service has been established

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 P as part of internal audit calendar
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. P
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) P Reporting pathologist
    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. Not applicable to Health Board
    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 Not applicable to Health Board

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

The Health Board does not record this information.

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 As per Q15

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?**
    Other As per Q15

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.

As per Q15