Freedom of Information Act 2000 - Request Reference FoI/23/246
Lynch Syndrome

Information Requested:

1. **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.**
    - **No.**
    - **Other, please specify.**

Yes

2. **Do you offer newly diagnosed bowel cancer patients in your Health Board 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 Board has agreed an implementation plan for this.**
    - **No.**
    - **Other.**

Yes – all newly diagnosed bowel cancer patients.

B) If this 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 type your response below. Please type N/A if no such testing is available.

In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual search through individual records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the Section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 18 hours, to comply with a request and the cost limit set within the fees' regulations for this amount of work (18 hours) is £450 for the UHB. The fees regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.

3. **If 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.**

Pre-treatment i.e., at diagnosis (on a biopsy of the tumour).

4. **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.**

    - **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 (please specify).**

Other (please specify). - No Barriers as this is already introduced

B) At what point in the clinical pathway are barriers having the greatest effect with regards to being able to adhere to NICE 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, please specify.**

Lynch Syndrome surveillance – e.g., 2 yearly colonoscopies.

5. **Do you audit diagnostic outcomes within your Health Board 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.**

Yes, as part of private audit. We are auditing parts of the pathway – we look at all those tested to see if the appropriate ones are then referred into clinical genetics.

6. **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.**

Reflex.

7. **Is there a named individual within each colorectal team in your Health Board who is responsible for ensuring testing for molecular features of Lynch syndrome take place?**

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

After considering your request, the UHB believes that the data requested is classed as personal data as defined under the General Data Protection Regulation (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 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.

8. **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.**

- Genetic counselling.
- Signposting to support groups.
- Provision of patient information resources.

9 Upon identification of individuals with Lynch Syndrome, do you offer to 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.**

Yes

10 Over the last financial year, what proportion of close relatives of individuals identified to have Lynch Syndrome have been tested for Lynch Syndrome? Please type your response below, or type N/A.

All those who have been referred in for testing have been seen within a reasonable timeframe.

11 A) Upon identification of individuals with Lynch Syndrome who do not currently have cancer, is regular colonoscopic surveillance offered?

- **Yes, at the recommended intervals (2-yearly).**
- **Yes, but at a different interval than recommended – Please specify interval length.**
- **No.**

Yes, at the recommended intervals (2-yearly). The team aim for the recommended intervals, however there are challenges to meet 100% compliance

B) 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? Please type your response below, or type N/A if no such surveillance is offered.

In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual search through individual records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the Section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 18 hours, to comply with a request and the cost limit set

within the fees' regulations for this amount of work (18 hours) is £450 for the UHB. The fees regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.

12 If such surveillance is offered how are patients called and recalled for these tests. Please type your response below, or type N/A if you do not offer such surveillance.

Surveillance patients are added to a waiting list with a target date and a RCS priority, set by the referring consultant. Patients are then seen in turn, depending on the RCS priority (4A, 4B & 4C). However, due to the CVOID pandemic, there is a backlog of overdue patients of which we are working our way through for the highest priority (4A & 4B) that are the most overdue.