Freedom of Information Request: Our Reference CTMUHB_203_23

You asked:

Under the Freedom of Information Act 2000, we are requesting the following information relating to the implementation of testing for molecular features of Lynch syndrome in your Health Board.

Please could you provide us with information on the following questions. We would appreciate it if you could select the answers to the written questions below by either highlighting the appropriate response or deleting the inapplicable.

Please see the Health Boards responses provided in bold below:

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.

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.

    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.

    98%

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.

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). ADMIN SUPPORT**

    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.

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. no time**

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.

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. But driven by the PATHOLOGIST**
- Other (please explain).
- No.

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.

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.**

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.

    We do not capture this information.

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). - We wait for the letter from the Genetics Team and book the surveillance clinic accordingly. Normally 2 yearly.**
    - Yes, but at a different interval than recommended – Please specify interval length.
    - No.

    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.

    The Health Board do not centrally record this data.

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.

Request is made by the CNS in the surveillance clinic for the colonoscopy and sent to the endoscopy department with the history of Lynch and the date requested.