

FOI 1670

16th August 2023

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

Question 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.

Answer 1:

Yes we follow the NICE guidelines but also that of the Royal College of Pathology.

Question 2:

Do you offer newly diagnosed bowel cancer patients in your Health and Social Care Trust 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.

Answer 2:

Yes – all newly diagnosed bowel cancer patients.

Question 2 (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.

Answer 2 (B):

N/A - All newly diagnosed bowel cancer patients are treated for molecular features of Lynch Syndrome.

Question 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.**

Answer 3:

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

Question 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).**

Answer 4:

N/A – No barriers – all newly diagnosed bowel cancer patients are tested for molecular features of Lynch syndrome.

Question 4 (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.

Answer 4 (B):

N/A – No barriers

Question 5:

Do you audit diagnostic outcomes within your Health and Social Care Trust 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.

Answer 5:

- Yes, as part of private audit.

Question 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.

Answer 6:

- Reflex.

Question 7:

Is there a named individual within each colorectal team in your Health and Social Care Trust 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.

Answer 7:

- Other – Histopathologist

Question 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.

Answer 8:

- Genetic counselling.

Question 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.

Answer 9:

- No.

Question 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.

Answer 10:

N/A

Question 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.

Answer 11 (A):

- Yes, at the recommended intervals (2-yearly).

Question 11 (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.

Answer 11(B)

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

Unfortunately we are unable to provide the information you have requested as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. It has been estimated that it would take more than 18 hours to locate and retrieve the requested information. In order to obtain this information and it would exceed the £450 limit and is therefore cost prohibitive.

Question 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.

Answer 12:

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