

5th June 2023

**Our Ref:** RFI 50942

Dear

**Freedom of Information Act 2000  
Information in Relation to LyncheSyndrome**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to above which you requested on 9 May 2023.

A response to each of the questions raised has been provided by the Hospital Services Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital ([informationgovernance@setrust.hscni.net](mailto:informationgovernance@setrust.hscni.net)) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

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**Rebecca Manning  
Information Governance Manager (Interim)**

**Q1. Which nation is the Health and Social Care Trust or Health Board that you are answering this FOI request on behalf of in?**

A1. Northern Ireland.

**Q2. Which Health and Social Care Trust or Health Board are you answering this FOI request on behalf of?**

A2. South Eastern Health & Social Care Trust.

**Q3. 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

A3. Service please provide response.

**Q4. 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

A4. Yes, other.

**Q5. 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.**

A5. Service please provide response.

**Q6. 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.**

**A6. Service please provide response**

**Q7. 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**

**A7. Financial.**

**Q8. 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.**

**A8. Service please provide response**

**Q9. 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**

**A9. Service please provide response**

**Q10. 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.**

A10. Yes, as part of private audit.

**Q11. 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.**

A11. Service please provide response

**Q12. 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.**

A12. Yes, Gastroenterologist.

**Q13. 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.**

**A13. Service please provide response**

**Q14. 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**

**A14. Service please provide response**

**Q15. Over the last financial year, what proportion of close relatives of individuals identified to have Lynch Syndrome have been tested for Lynch Syndrome?**

**A15. Service please provide response**

**Q16. 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**

**A16. Service please provide response**

**Q17. 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?**

**A17. Service please provide response**

**Q18. 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.**

**A18. Service please provide response**