Bwrdd Iechyd Prifysgol Bae Abertawe
Swansea Bay University Health Board

Cadeirydd/Chair: **Emma Woollett**
Prif Weithredwr/Chief Executive: **Mark Hackett**

gofalu am ein gilydd, cydweithio, gwella bob amser
caring for each other, working together, always improving

Cais Rhyddid Gwybodaeth / Freedom of Information request
Ein Cyf / Our Ref: 23-E-012

You asked:

Please complete the attached Freedom of Information request on the use of mismatch repair (MMR) testing for molecular features of Lynch syndrome and sequential Lynch Syndrome clinical pathway measures.

Our response:

Please find below your completed questionnaire.

Freedom of Information request on the use of mismatch repair (MMR) testing for molecular features of Lynch syndrome and sequential Lynch Syndrome clinical pathway measures in Health Boards.

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 could you send acknowledgement of this information request via email. We look forward to receiving your response within the given 20 working days.

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.

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.

    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 2022/23, 98.9% of patients had MSI or MMR done (with remainder having insufficient tissue available for testing).

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).

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.

    N/a as 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. Timeliness pre-surgery remains an issue
    - Lynch Syndrome surveillance – e.g., 2 yearly colonoscopies. Lack of colonoscopy capacity remains a constraint

5. Do you audit diagnostic outcomes within your Health Board to ensure that patients are being tested for molecular features for Lynch syndrome?

    - Yes, and the data is publicly released. NBCA report

6. Is this test carried out as a reflex test i.e., automatically or upon referral?

    - 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?

    - Other (please explain).

    Histopathology consultant with support of MDT

    - 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.

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.

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.

    The proportion of predictive tests for close relatives of those diagnosed with Lynch is usually 2-3 predictive tests per confirmed diagnostic Lynch test.
    Genetic services aim to see most people for a predictive test within 6-12 weeks, unless they have chosen to defer their appointment, especially if they are of screening age at the time of referral.

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).

    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.

Current backlog of surveillance procedures exists with recovery measures in place to reset to full compliance pre-COVID-19.

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.

Automatic recall by endoscopy department with additional case tracking by colorectal genetic condition lead clinician.