**Freedom of Information Request: Our Reference CTHB_04_18**

**You asked:**

Under the Freedom of Information Act 2000, we are requesting the following information relating to the implementation of NICE guidance DG27: *Molecular testing strategies for Lynch syndrome in people with colorectal cancer*, within your health board.
The guidance, published in February 2017, recommends that '*testing be offered to all people with colorectal cancer, when first diagnosed, using immunohistochemistry for mismatch repair proteins or microsatellite instability testing to identify tumours with deficient DNA mismatch repair, and to guide further sequential testing for Lynch syndrome*.'

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.

**FOI questions**

**Please see our responses highlighted where appropriate, as requested.**

1. Do you test newly diagnosed bowel cancer patients in your health board (either contracted or referred) for molecular features of Lynch syndrome using either immunohistochemistry or microsatellite instability testing?

    - Yes – all bowel cancer patients, as per DG 27 NICE guidance
    - Yes - everyone under the age of 70
    - Yes – everyone under the age of 50
    - Yes – according to family history of the disease
    - No
    - **Other - The All Wales Genetics Service has WHSSC funding for MSI analysis in (a) patients and families who meet our guidelines for Lynch syndrome, and (b) CRC when chemo is being considered. The department plans to introduce testing of all patients in line with the NICE guidance as soon as possible within the next few months.**

2. If yes, at what stage does this testing take 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

3. 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) - currently on referral from the Multi-Disciplinary Team. In the future it will be reflex tested.**
   - Not applicable

4. In their published adoption support resource NICE suggest identifying a named 'clinical champion' within each colorectal multidisciplinary team to effectively implement testing people for molecular features for Lynch syndrome. Is this established in your health board?

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

5. Do you audit diagnostic outcomes within your health board to ensure that every patient is tested for molecular features for Lynch syndrome?

   - Yes, as part of private audit
   - Yes, and the data is publicly released
   - **No**

6. Have you had to submit a business case for funding in order to effectively implement this new guidance?

   - Yes, and additional funding was provided fully/partially as requested. Please provide information.
   - Yes, but no additional funding was provided. Please provide information on why.

- **No please provide information on why - We are in the process of doing this to support the full introduction of the NICE guidance.**

7. If no such testing is in place, do you have information on whether there are any plans to introduce molecular testing for Lynch syndrome as per NICE guidance?

   **As above.**

8. What are the main barriers you have faced if no molecular testing or only selected testing is performed? Please specify.

   - **Financial**
   - Policy
   - Awareness of current guidance
   - **Staff resources**
   - Other (please specify)