

Time to Test campaigner briefing

To help you feel confident talking about the issues relating to Lynch syndrome we've created this briefing to use, in conjunction with our three step [Campaigner Toolkit](#), with everything you need to know. Why not bring it along to meetings to remind you of the key points to discuss?

Three points to remember

- 1. Everyone diagnosed with bowel cancer should be tested for Lynch syndrome at the point of diagnosis.**
- 2. More than 80% of hospitals in England are failing to test all bowel cancer patients in line with clinical guidance.**
- 3. Health bodies must work together to ensure hospitals have the funding and staff resources to carry out this test.**

What is Lynch syndrome?

- Lynch syndrome is a genetic condition that can increase the risk of bowel cancer to up to 80%, as well as increase the risk of many other cancers.
- Each year approximately 1,200 cases of bowel cancer in the UK are caused by this genetic condition, making it the most common form of hereditary bowel cancer.
- There is a 50:50 chance of passing it on through generations, meaning whole families can be devastated by bowel cancer.

Testing for Lynch syndrome in England

- In February 2017, the National Institute for Health and Care Excellence (NICE) published guidance recommending that everyone diagnosed with bowel cancer is tested for Lynch syndrome automatically, at the time of diagnosis.
- It's estimated over 200,000 people in the UK have Lynch syndrome. Yet a staggering 95% of those affected don't know they have it because they simply aren't being tested.

How many hospitals are testing?

- Despite the clear advice given in clinical guidelines and the benefits of testing, Bowel Cancer UK found that there is still alarming variation in testing in hospitals in England.

- Hospitals aren't being given the funding and resources to pay for these tests by their local clinical commissioning group (CCG) – the local budget holders for health.
- Only 17% of hospitals test all bowel cancer patients for Lynch syndrome at the time of diagnosis (i.e. before treatment).
- Just 6% of CCGs fund their local hospital(s) to test in line with NICE guidance.
- Many hospitals report financial reasons as the biggest barrier to implementing the test.

Why is it important to test for Lynch syndrome?

- **Identifying more high risk individuals:** those at greater risk of developing further cancers can be identified and their family can be offered testing to identify their risk of developing cancer.
- **Enabling early diagnosis:** Once identified, individuals and their families can receive regular colonoscopy to detect cancer at the earliest stages, reducing the risk of dying from bowel cancer by 72%.
- **Informing treatment options and success:** The condition can affect treatment options for bowel cancer. Testing at the time of diagnosis is crucial, to ensure patients aren't offered treatment they won't respond to or may have adverse reactions to.
- **Value for money:** Detecting bowel cancer at an earlier stage reduces the need for costly treatments. The test costs just £200, less than half the price of a colonoscopy at £580, compared to an average cost of £25,000 for bowel cancer treatment.

Who is responsible?

- NHS England made it clear this test should be funded through local budgets by CCGs.
- The Department of Health and Social Care - The Health Minister believes that CCGs are best placed to take responsibility for services to meet the needs of local populations. This includes testing for Lynch syndrome.
- CCGs - 65% of CCGs don't fund these tests and nearly a third of these said that it's not their responsibility. Worryingly over half of these CCGs have no intention to pay for these tests.
- The lack of local responsibility and national leadership is incredibly concerning and is affecting hospitals ability to test in line with clinical guidelines, meaning patients lose out.

What's the solution?

- Local health bodies must work together to ensure hospitals have the funding and staff resources to carry out this test, so patients don't lose out.
- Ultimately so that testing is consistently taking place across the country, NHS England must step up and ensure testing for Lynch syndrome is funded in the NHS.

Don't forget we're here to support you if you need it, so please get in touch at campaigns@bowelcanceruk.org.uk if you have questions about the information in this briefing.