

BMJ Rapid Response: A clinical consensus on improving the colonoscopic screening and surveillance of people with Lynch syndrome in England

In March 2016 a clinical expert meeting was held at which it was recommended that a quality assured surveillance programme for individuals with Lynch syndrome (LS) should be established to reduce variation in access, quality and frequency of colonoscopic screening.

Addressing this variation and improving services for this group is vital. We know LS is an incurable genetic condition that increases the risk of bowel cancer by up to 80%, but access to regular colonoscopy screening can reduce the chance of dying from the disease as much as 72%. However, Bowel Cancer UK research¹ shows many people experience unacceptable waiting times and poor levels of care. That's why a new approach to screening this high risk group is desperately needed to address these issues and ensure everyone diagnosed with Lynch syndrome receives timely and high quality colonoscopy.

To explore this recommendation a further clinical meeting was held to reach a consensus on the most effective model for providing an improved service.

We agree and recommend that for optimum effectiveness a national model is required to ensure a timely and high quality screening and surveillance service for people with Lynch syndrome. This would necessitate effective call and recall capabilities, and strict standards and key performance indicators (KPIs) to ensure quality and consistency.

We believe that the most efficient and effective method to deliver a national programme is through the Bowel Cancer Screening Programme (BCSP), utilising existing infrastructure provided for screening the asymptomatic population. The BCSP is delivered to a very high standard with robust quality assurance mechanisms for colonoscopy and a good call and recall system.

The consensus reached is supported and endorsed by the Association of Coloproctology of Great Britain and Ireland (ACPGBI), the British Society of Gastroenterology (BSG), and the Cancer Genetics Group.

The statements below set out why delivering this service through the BCSP would significantly reduce the vast variation in access, quality and frequency of colonoscopic screening:

- **The BCSP would ensure an efficient, consistent and streamlined approach to colonoscopic management across the country.** This will help to reduce local disparity and improve the experience and outcomes for people with LS, regardless of where they live.
- **The BCSP has robust quality assurance mechanisms in place.** This would help to reduce the variation in quality people with LS face as colonoscopy appointments will be conducted by an accredited colonoscopist and take place within a Joint Advisory Group for Gastrointestinal Endoscopy (JAG) accredited unit.

- **There are strict waiting times and Key Performance Indicators (KPIs) established in the BCSP.** Bowel Cancer UKⁱⁱ reported that 49% of their LS survey respondents had experienced delays of more than six weeks to their planned colonoscopy appointment. Utilising the BCSP's robust call and recall systems and strict waiting time targets we can ensure people with LS are placed on par with screening and symptomatic patients and are seen on time.
- **A precedent has already been set by the NHS Breast Cancer Screening Programme.** The Programme which routinely tests healthy women for risk of cancer also manages the screening of those with a known genetic mutation (*BRCA 1 or 2*) that increases the risk of breast cancer. LS carriers are a relatively small, known population. By inputting only identified gene carriers into the BCSP we can ensure we do not encounter the same problems the NHS Breast Cancer Screening Programme faced with risk criteria in providing MRI surveillance.

Our recommendations:

The frequency and heightened risk of cancer demands only the highest standards for this group. To ensure a national programme can be implemented we are calling for the following recommendations to be implemented as a matter of urgency:

- **The BCSP agrees to facilitate the screening and surveillance of people with LS.** This will help significantly to reduce the vast variation in access, quality and frequency of colonoscopy this high risk group currently face.
- **A linked national database of people identified as LS gene carriers should be developed to support the BCSP to facilitate the call and recall of these patients.** Both clinicians and patients have come forward in favour of the development of a national registry, including the Mallorca Group.
- **Investment must be made available to increase the capacity of endoscopy centres and cellular and molecular pathology laboratories, as well as genetic services.** This is to enable units to deliver an efficient and effective high quality screening and surveillance programme.
- **A dedicated clinical champion for hereditary CRC must be established in each colorectal multidisciplinary team** to oversee service coordination and to ensure patient pathways are instituted. This is essential to ensure referral pathways are adhered to and patients experience a seamless service.

It is essential that a plan is set in motion to provide national screening and surveillance for people with LS, especially with the likely increased population identified through the new NICE guidance. Utilising the BCSP's available robust systems and infrastructure we can ensure that, all patients identified, and their families, receive timely and high quality colonoscopic surveillance, consistently,

regardless of location. It is incomprehensible this robust and organised system is not already available to those at high risk of CRC.

This also provides a unique opportunity for England to become a world leader for hereditary CRC screening and surveillance and set a precedent, as there is currently no international comparison. The reality is that until there is clear national leadership and a firm commitment from Public Health England to improve the services for people at high risk of developing CRC, people with LS will continue to fall through the gap and lives will needlessly be lost.

(956 words)

ⁱ *Improving services for Lynch syndrome: who's responsible? Bowel Cancer UK (2016)*
www.bowelcanceruk.org.uk/campaigning/never-too-young/lynch-syndrome/

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