



## A clinical consensus on improving the colonoscopic screening and surveillance of people with Lynch syndrome in England

### Background

Lynch syndrome is an inherited condition which causes around 1,200 cases of colorectal cancer annually in the UK, as well as over 1,000 cancers in other sites. Unfortunately, Lynch syndrome is currently an under-recognised, under-diagnosed and under-managed condition. Fewer than 5% of gene carriers have been identified and so many do not receive the clinical management they need. This refers to colonoscopic screening and surveillance for people identified with Lynch syndrome following a diagnosis of bowel cancer, as well as family members who have been identified as gene carriers through cascade testing. It is crucial people with Lynch syndrome receive coordinated, timely and high quality care to reduce and manage their cancer risk throughout their lifetime, which can be as high as 80%. Whilst there is no cure for Lynch syndrome, research has proven that regular colonoscopy can reduce the risk of dying from colorectal cancer by 72% through detecting it early, when it is more treatable. Current British Society of Gastroenterology (BSG) guidelines<sup>1</sup> recommend that those with the condition should receive regular colonoscopy every 18 months to 2 years.

### An inconsistent service

Unfortunately, as it currently stands, there is an inconsistent approach in the management of Lynch syndrome across the country. This variability is a result of poor clinical awareness of the condition and/or BSG screening and surveillance guidelines, or with service organisation. Furthermore, many clinicians are unaware whose responsibility it is to manage these high risk patients. A national survey of hereditary bowel cancer services<sup>2</sup> found that:

- Many clinicians were not aware of the BSG guidelines on the screening and surveillance of people at increased risk of bowel cancer.
- More than 20% of clinicians did not think there was an adequate colonoscopic screening and surveillance service available for high risk patients within their trust.
- 64% of clinicians believed that someone else should be taking responsibility for monitoring this group.

The consequence of this is that too often people with the condition fail to receive adequate care, including:

- Waiting longer than recommended time intervals for their colonoscopy and;
- Incomplete or poor quality colonoscopy.

This variation across the country has led to an inequitable service and a postcode lottery of care.

A new approach to screening and surveillance is needed to address these issues and to ensure that everyone diagnosed with Lynch syndrome receives timely and high quality care. Unless urgent changes are made this variation in care will continue to undermine efforts to save lives from this treatable disease. This is even more urgent as the recent recommendation from the National Institute for Health and Care

Excellence (NICE)<sup>3</sup>, that everyone newly diagnosed with colorectal cancer is tested for molecular features of Lynch syndrome, will mean more people with the condition will be identified, and so services need to be ready to provide regular colonoscopy as outlined in BSG guidance.

## **A consensus: Developing a timely and high quality surveillance programme**

In July 2017, Bowel Cancer UK facilitated a clinical consensus meeting<sup>4</sup> with ten clinical experts in bowel cancer and genetics. The aim was to reach a consensus on the most effective model for delivering timely and high quality screening and surveillance for this high risk group.

**A consensus was agreed that for optimum effectiveness a national model is required to ensure a timely and high quality screening and surveillance service. This would necessitate effective call and recall capabilities, and strict standards and key performance indicators (KPIs).**

## **What is the most effective method to deliver national surveillance?**

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

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

- 1. The BCSP would ensure an efficient, consistent and streamlined approach to colonoscopic management across the country.** The current localised approach to the management of people with Lynch syndrome has resulted in an inequitable service and a postcode lottery of care. A national approach would reduce local disparity across the country and will help to improve the experience and outcomes for people with Lynch syndrome, regardless of where they live.
- 2. The BCSP has robust quality assurance mechanisms in place.** A poor quality colonoscopy or an incomplete procedure can lead to missed cancers and/or serious complications. By utilising the robust quality assurance system of the BCSP we can ensure that colonoscopic screening and surveillance for people with Lynch syndrome is conducted by an experienced and accredited colonoscopist, within a unit that is accredited by the Joint Advisory Group for Gastrointestinal Endoscopy (JAG). This would help to reduce the variation in quality of colonoscopy people with Lynch syndrome receive.
- 3. There are strict waiting times and Key Performance Indicators (KPIs) established in the BCSP.** Increasing demands on local endoscopy units to meet referral targets, mean many high risk patients are waiting unacceptable lengths of time for their routine appointments. A Bowel Cancer UK patient experience survey<sup>5</sup> reported that 49% of people with Lynch syndrome had experienced delays of more than six weeks to their planned colonoscopy appointment. Utilising the robust call and recall systems in place we can ensure people with Lynch syndrome are placed on par with screening and symptomatic patients and sent appointments promptly.
- 4. A precedent has already been set by the NHS Breast Cancer Screening Programme.** High risk BRCA1, BRCA 2 and TP53 gene carriers are routinely screened with annual MRI surveillance as part of the NHS Breast Cancer Screening Programme<sup>6</sup>. While it is acknowledged that the Breast Screening Programme has encountered problems with the risk criteria for inclusion in the Programme, Lynch syndrome gene carriers are a known cohort and a relatively small population. Inputting only identified gene carriers into the BCSP will ensure they are monitored efficiently and effectively. It is perverse that a robust and organised Programme is made available for people at average risk, but not for those at high risk of cancer.

## Recommendations

The increased risk of cancer and the development at a much younger age than the general population demands that only the highest standards should be set for this high risk group. We are calling for the following recommendations to be implemented as a matter of urgency:

- 1. The BCSP agrees to facilitate the colonoscopic screening and surveillance of people with Lynch syndrome.** This will help significantly to reduce the vast variation in access, quality and frequency of colonoscopy this high risk group currently face.
- 2. A linked national database of people identified as Lynch syndrome gene carriers should be developed to support the Bowel Cancer Screening Programme 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<sup>7</sup>. Furthermore, Bowel Cancer UK's patient experience survey found that 87% of its respondents with Lynch syndrome would consent to being part of a registry.
- 3. Additional 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.
- 4. A dedicated clinical champion for hereditary colorectal cancer 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.

## Conclusion

Currently, only approximately 5% of the likely prevalent population of Lynch syndrome gene carriers have been identified in the UK. NICE guidance recommending universal testing for molecular features of Lynch syndrome will likely result in this figure rising. It is essential that a plan is set in motion to provide an improved screening and surveillance service. This, however, will require additional infrastructure to accommodate an increased population. Through the BCSP we can ensure that, with its robust systems, all patients identified with Lynch syndrome and their families receive timely and high quality colonoscopy.

The UK has an opportunity to become a world leader for hereditary bowel cancer 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 bowel cancer, people with Lynch syndrome will continue to fall through the gap and lives will needlessly be lost.

### Members of the Clinical Working Group:

- Professor Sir John Burn, Professor of Clinical Genetics (Chair)
- Dr Kevin Monahan, Consultant Gastroenterologist
- Professor Huw Thomas, Consultant Gastroenterologist
- Professor Matt Rutter, Consultant Physician
- Professor Colin Rees, Consultant Gastroenterologist
- Miss Nicola Fearnhead, Consultant Colorectal Surgeon
- Professor Gareth Evans, Consultant of Medical Genetics and Cancer Epidemiology
- Dr Fiona Laloo, Consultant Clinical Geneticist
- Professor Wendy Atkin, Professor of Gastrointestinal Epidemiology

Supported and endorsed by the Association of Coloproctology of Great Britain and Ireland (ACPGBI), the British Society of Gastroenterology (BSG) and the UK Cancer Genetics Group (CGG).

## References

- <sup>1</sup> Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups British Society of Gastroenterology (update from 2002) [http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/endoscopy/ccs\\_10.pdf](http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/endoscopy/ccs_10.pdf)
- <sup>2</sup> A national survey of hereditary colorectal cancer services in the UK - Monahan K – <http://fg.bmj.com/content/early/2013/09/16/flgastro-2013-100362>
- <sup>3</sup> Molecular testing strategies for Lynch syndrome in people with colorectal cancer, National Institute for Health and Care Excellence, Diagnostics guidance [DG27], (2017) <https://www.nice.org.uk/guidance/dg27>
- <sup>4</sup> Urgent improvements needed to diagnose and manage Lynch syndrome, BMJ 2017; 356:J1388
- <sup>5</sup> Improving services for Lynch syndrome: who's responsible? Bowel Cancer UK (2016) [www.bowelcanceruk.org.uk/campaigning/never-too-young/lynch-syndrome/](http://www.bowelcanceruk.org.uk/campaigning/never-too-young/lynch-syndrome/)
- <sup>6</sup> National Breast Cancer Screening Programme <https://www.gov.uk/government/publications/breast-screening-screening-of-higher-risk-women>
- <sup>7</sup> 'Revised guidelines for the clinical management for Lynch syndrome (HNPCC) : recommendations by a group of European experts' The Mallorca Group, GUT 2013 62 (812-823) <https://www.ncbi.nlm.nih.gov/pubmed/23408351>

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