

Lynch syndrome

Lynch syndrome can increase the risk of bowel cancer by 80%

50:50

CHANCE



chance of passing on the condition leading to whole families being devastated by cancer

An estimated 175,000 people in the UK have Lynch syndrome, but most people don't know they have it because of a lack of systematic testing

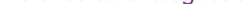
We carried out a nationwide survey of people with Lynch syndrome. This is what they told us:



waited 4 months to over a year to have their diagnosis confirmed

Lynch syndrome can affect treatment options for bowel cancer. But only 9 people were tested at diagnosis

Almost **30%** weren't offered a follow up appointment with a genetic counsellor





78% waited more than 6 weeks for their planned colonoscopy appointment

Regular colonoscopy can detect bowel cancer early and reduce chance of dying by 72%

70% weren't offered a written personalised care plan but 95% would have wanted one

43% did not get enough relevant information about their condition

The current identification and management of Lynch syndrome is unacceptable. We're calling for:

- A national registry of people with Lynch syndrome. This will increase our understanding of the condition and highlight regional differences in treatment and care. 87% told us they would consent to be part of a registry
- A national surveillance programme to reduce the vast variation in access, quality and timeliness of regular colonoscopy
- Comprehensive UK guidelines that set out best practice for the clinical management of people with Lynch syndrome

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