

Lynch syndrome

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

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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