North Central London Integrated Care System

NHS North Central London Cancer Alliance

Lynch Syndrome Surveillance: Frequently Asked Questions

Age-specific surveillance:

Surveillance protocols vary by age, variant and cancer type; for example, patients with endometrial cancer linked to Lynch Syndrome begin treatment at age 35, whereas those with colorectal cancer can start at 25 or 35.

Accountability

The responsibility for the provision of genetic predicitve testing remains with specialist genomics services.

The lifelong care of people diagnosed with this condition remains with the survelliance hub.

National registry and coordinated screening:

The establishment of a national registry for Lynch Syndrome enhances the coordination and efficiency of screening programs, contributing to earlier detection and improved management of the condition.

Surveillance group classification:

1. **Newly diagnosed**: This group includes individuals newly identified with Lynch Syndrome and their immediate family members who have Lynch Syndrome.
2. **Ongoing surveillance**: Patients already identified with Lynch Syndrome who are under regular monitoring.
3. **Other**: Individuals who have been privately diagnosed with Lynch Syndrome, those who have not undergone genetic testing but are under surveillance, and those identified through alternative diagnostic methods.

Sources of Lynch Syndrome data:

- Data relevant to Lynch Syndrome can be sourced from specialised genetic hubs and public health records.
- Notably, new cancer diagnoses are documented in databases such as NHS England and other cancer statistics repositories, serving as valuable resources for understanding the prevalence and distribution of Lynch Syndrome and new cancer cases.

Addressing regional discrepancies:

The geographical coverage of genetic hubs often does not align with the boundaries of Cancer Alliances, leading to challenges in forecasting and managing Lynch Syndrome surveillance. Recognising and adapting to these regional differences is essential for effective healthcare planning and provision.

Estimating Lynch Syndrome prevalence:

To estimate the prevalence of Lynch Syndrome among patients, we can use NICE guidelines and consider age-related risks, supported by evidence from scientific literature.

This approach allows for a more accurate prediction of Lynch Syndrome cases, facilitating targeted interventions and support.

Sources

Monahan KJ, et al. BMJ Oncology 2023;2:e000124. doi:10.1136/bmjonc-2023-000124.

'Implementing Lynch syndrome testing and surveillance pathways' https:// www.england.nhs.uk/wp-content/uploads/2021/07/B0622-implementing-lynchsyndrome- testing-and-surveillance-pathways-may-2023.pdf