



# Opportunities and Challenges

## Establishing a Lynch Syndrome Surveillance Hub

### OPPORTUNITIES

- **Universal testing initiative:** Implementing comprehensive Lynch Syndrome testing to prevent diagnostic oversights and ensure at-risk individuals and family members are identified and managed appropriately.
- **Enhanced surveillance programs:** Initiating regular colonoscopy surveillance for patients and their immediate families diagnosed with Lynch Syndrome, reducing bowel cancer mortality by 72%. Addressing the nuances in gynaecological surveillance to prevent false reassurances and encourage timely preventative surgeries when necessary.
- **Cancer prevention impact:** According to NICE, proactive Lynch Syndrome testing has the potential to prevent over 300 bowel cancers each year, underscoring the value of widespread genetic screening.
- **Supportive counselling services:** Providing essential counselling for individuals undergoing Lynch Syndrome testing, offering psychological support and guidance through the diagnostic and treatment processes.
- **Personalised medicine approach:** Customising surveillance and management based on individual genetic risk profiles to optimise early detection, the ability to use immunotherapies and increase life expectancy.
- **Awareness and education:** Conducting educational campaigns to increase awareness and understanding of Lynch Syndrome among healthcare professionals and the general public, leading to earlier diagnosis and treatment.
- **Data-driven strategies:** Integrating AI and data analytics to sift through health data efficiently, improving the identification process for individuals at risk of Lynch Syndrome.
- **Focused research and development:** Encouraging more dedicated research into Lynch Syndrome potentially leading to increased funding, enhanced understanding, and better management of the syndrome.

### CHALLENGES

- **Healthcare disparities:** Ensuring equal access to testing and surveillance for all socio-economic groups.
- **Psychological impact:** The knowledge of carrying a genetic mutation can have substantial psychological effects on patients and their families.
- **Compliance:** Ensuring that patients adhere to surveillance schedules over the long term.
- **Complexity of care:** The management of Lynch Syndrome is inherently complex due to the involvement of multiple cancer types and the need for interdisciplinary care.
- **National NHSE Lynch Syndrome transformation project:** This project is set to end in March 2024, which may result in changes to how Lynch Syndrome care is delivered and funded.
- **Collaboration among multiple partners:** Effective management involves Trusts, clinical teams, NHS England Vaccination and Screening team bowel screening programs, and genomic services, each with different operational scopes.
- **Data management:** Accessing and utilising databases effectively for patient data is crucial for ongoing surveillance and research.
- **Surveillance vs. testing:** Determining the balance between testing for Lynch Syndrome and the subsequent surveillance poses operational and ethical questions.
- **Inclusive testing:** Not everyone at risk is currently being tested, potentially leaving gaps in surveillance and prevention. There is a need for clear strategies regarding germ-line and cascade testing of family members, which is essential for early detection and management.
- **Terminology consistency:** Standardising terminology across different clinical and operational teams is crucial for clarity and effective communication.