The South East Regional Lynch Syndrome Patient Experience Report

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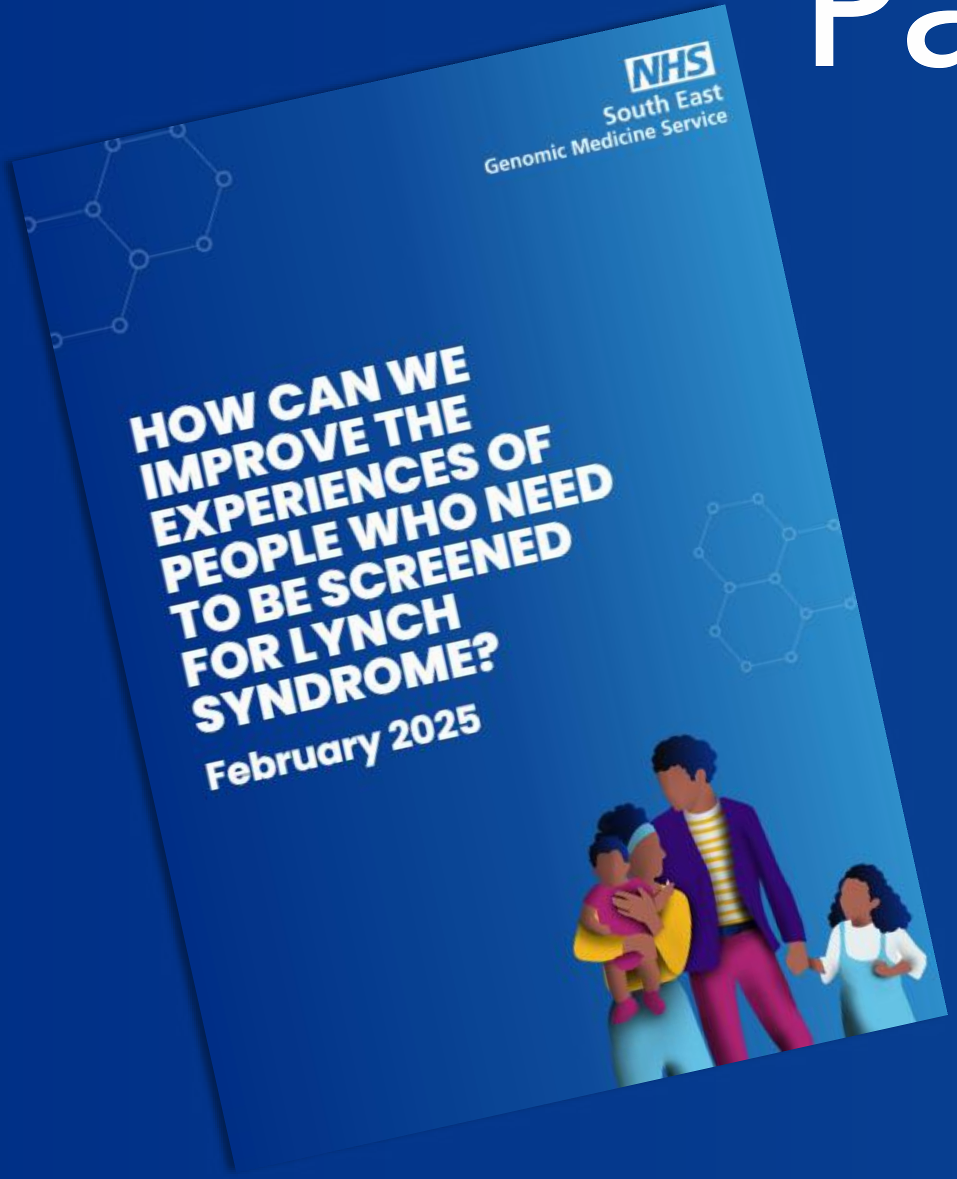

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HOW CAN WE IMPROVE THE EXPERIENCES OF PEOPLE WHO NEED TO BE SCREENED FOR LYNCH SYNDROME?

February 2025

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SE GMSA 24/25
Lynch Syndrome Project

Pathway Improvement

Mainstreaming

Business Case Delivery

SE Expert Network

Additional

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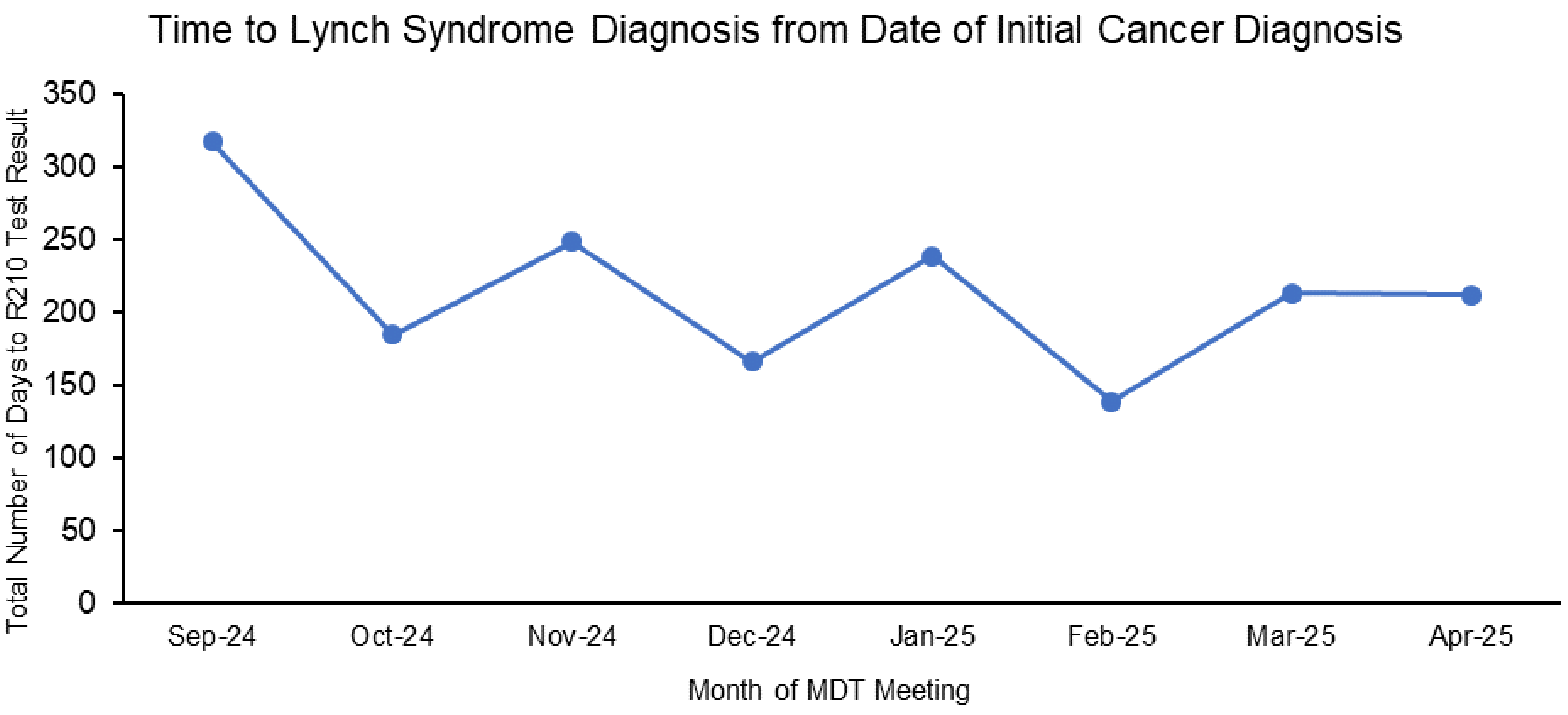
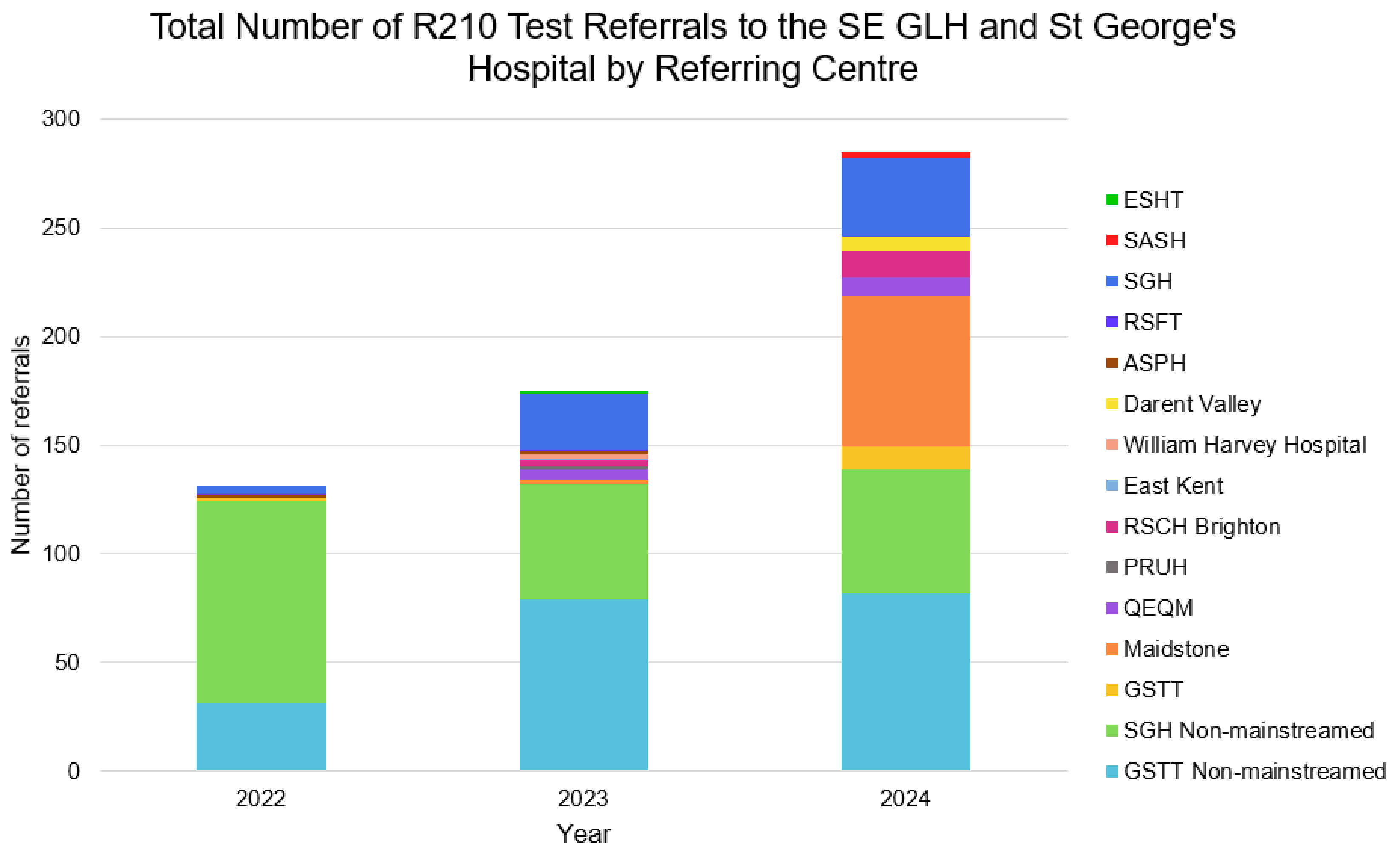
Lynch Syndrome Project Benefits


Time to Lynch Syndrome Diagnosis from Date of Initial Cancer Diagnosis


Total Number of R210 Test Referrals to the SE GLH and St George's Hospital by Referring Centre

33% reduction in time to Lynch syndrome diagnosis

from August 2024 to April 2025 based on MDT referrals

Number of mainstreamed R210 test referrals has tripled

since 2023

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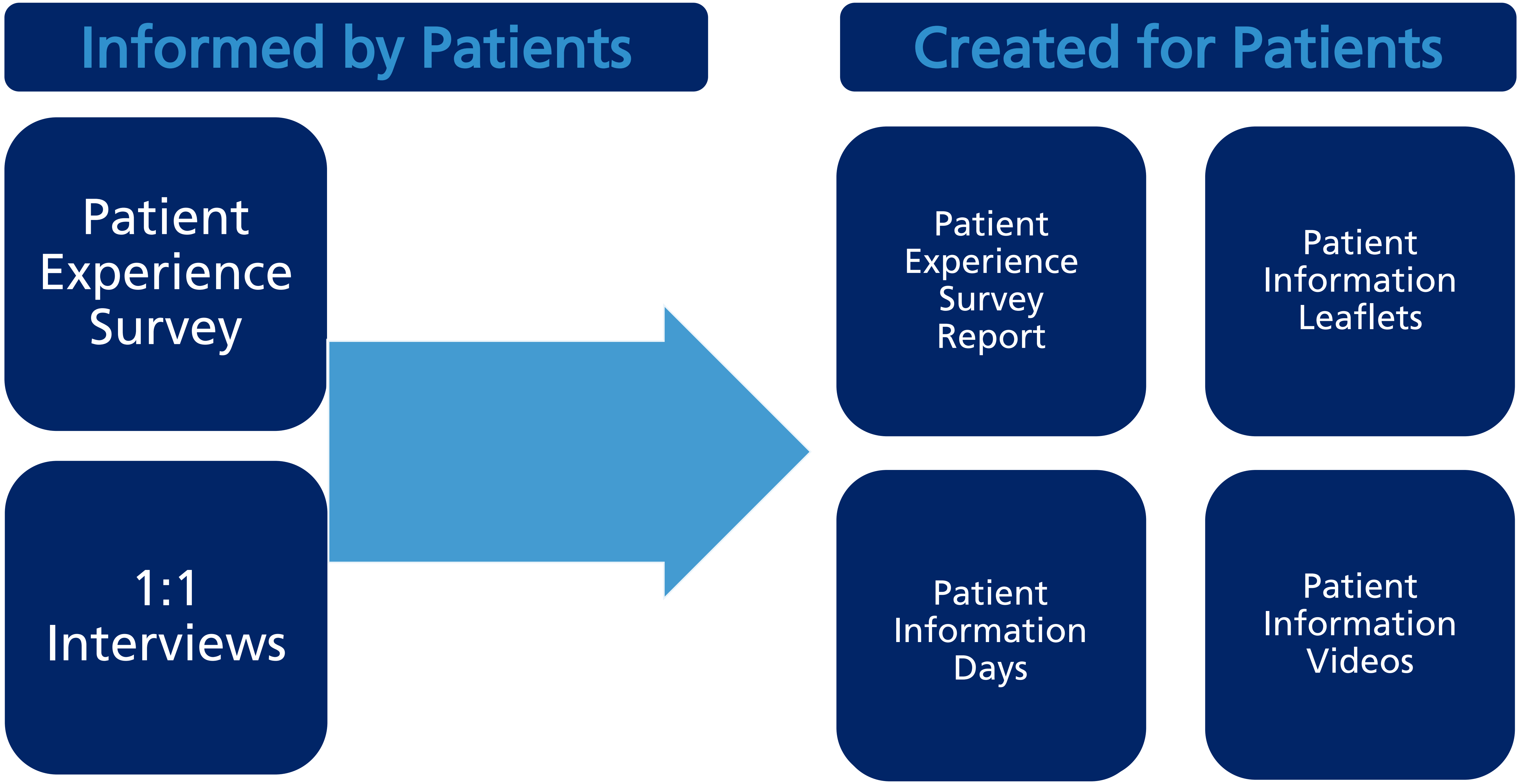
Our Patient Experience Approach



Informed by Patients

- Patient Experience Survey
- 1:1 Interviews

Created for Patients

- Patient Experience Survey Report
- Patient Information Leaflets
- Patient Information Days
- Patient Information Videos

How did we do it?

- Eligibility criteria as broad as possible
- Distribution was varied
  - Direct outreach via Lynch Champions and clinical colleagues
  - Charities patient involvement sites
  - Social media
- Encourage people from sources they feel comfortable and familiar with

MACMILLAN CANCER SUPPORT

NHS
Cancer Alliances

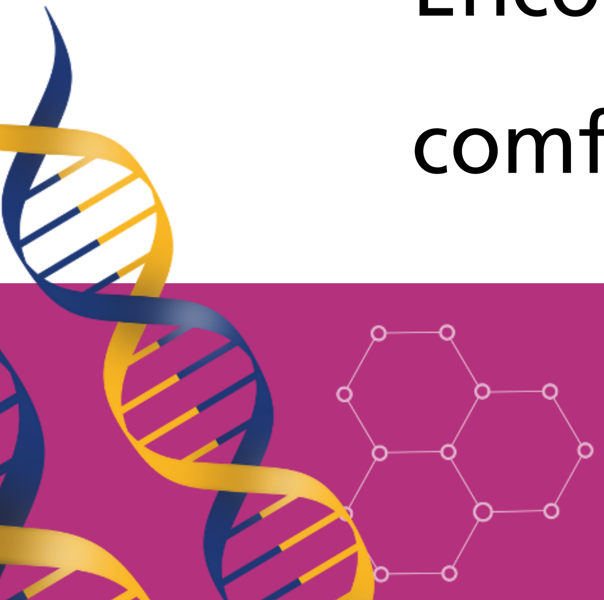
PEACHES
WOMB CANCER TRUST

the eve appeal

Bowel Cancer UK
Beating bowel cancer together

CANCER RESEARCH UK

Lynch Syndrome UK



How did we do it?

- Invited participants for further one-to-one conversations about their experience via video or phone
- Allow them to share what they felt was important rather than making assumptions
- Aimed to create a safe environment & had support available on hand from Lynch Syndrome Specialist Nurse
- Gained valuable insight about patients' journeys and what could be improved
- Identified six key themes that describe the patients' experience and perspectives

What did we hear?

Thematic analysis of qualitative survey responses and interview conversations identified six key themes that describe patients' experiences, needs and perspectives.

These themes are explored in detail in the report to highlight key areas of success and improvement throughout the patient journey.

Key Themes

Lack of Integrated Care

Shared Experiences within Families

Experiences with Clinical Genetics Services and Hospital Care

Psychological and Emotional Support

'Knowledge is Power'

Providing an Inclusive and Accessible Experience

Lack of Integrated Care

What we heard:

Respondents shared that their experiences with multiple different care providers impacted upon their overall experience.

Patients expressed a worry regarding “slipping through the net.”

> “I went in for something else and asked about the letter – the GP had filed it because they thought they didn’t have to do anything with it.”
>
> “The GP surgery did not think they could do the test.”

Recommendations:

1. Training for GPs and cancer teams should be prioritised
2. Improved communication between services about the Lynch syndrome pathway
3. Taking a person-centred approach to Lynch syndrome.

‘Knowledge is Power’

What we heard:

Many patients said that their results gave them a greater sense of control, understanding and peace of mind.

Respondents talked about the need for clear, accessible information for themselves and their family members.

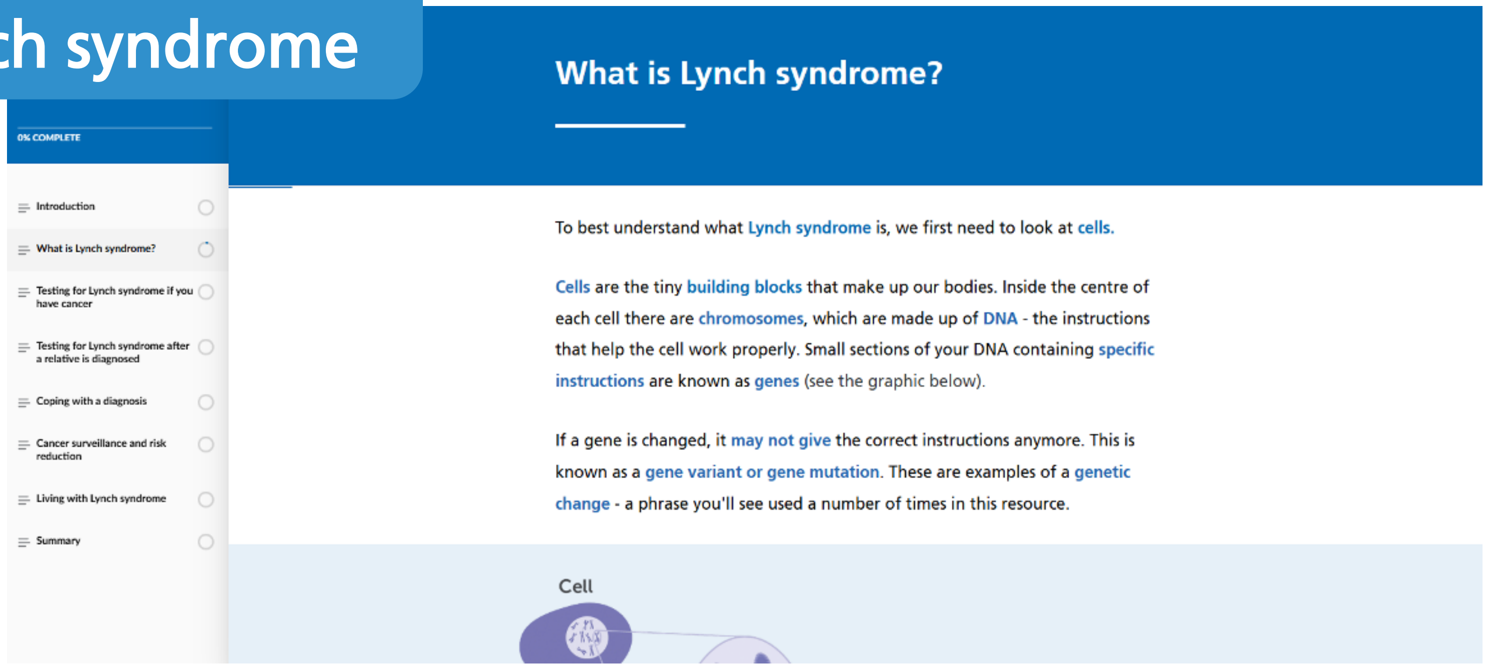
> “I wish I had known earlier, maybe I would have been Stage 1 instead of Stage 3b.”
>
> “If I had known I had Lynch syndrome earlier, I would have been monitored and might not have incurable endometrial cancer now.”

Recommendations:

1. Standardised patient information should be created and utilised across all regions and NHS providers
2. Lynch Syndrome App should be widely promoted
3. Everyone diagnosed with Lynch syndrome should be given information about Lynch Syndrome UK and other support groups

Coming Soon – Lynch Syndrome Patient Information Module

The basics of Lynch syndrome



What is Lynch syndrome?

To best understand what Lynch syndrome is, we first need to look at cells.

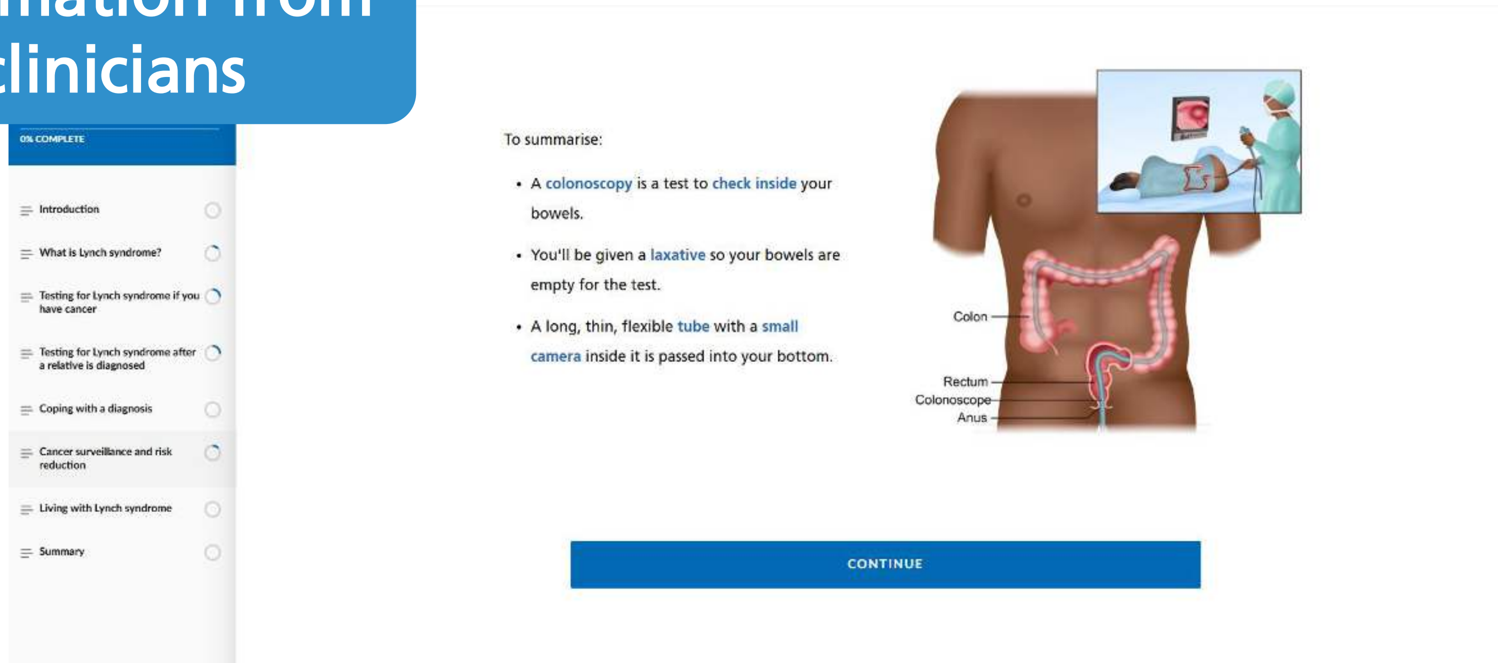
Cells are the tiny building blocks that make up our bodies. Inside the centre of each cell there are chromosomes, which are made up of DNA - the instructions that help the cell work properly. Small sections of your DNA containing specific instructions are known as genes (see the graphic below).

If a gene is changed, it may not give the correct instructions anymore. This is known as a gene variant or gene mutation. These are examples of a genetic change - a phrase you'll see used a number of times in this resource.

Patient stories

Here's Emma outlining her considerations about whether or not to be tested for Lynch syndrome, and the reasons behind her eventual decision.

Information from clinicians



To summarise:

- A colonoscopy is a test to check inside your bowels.
- You'll be given a laxative so your bowels are empty for the test.
- A long, thin, flexible tube with a small camera inside it is passed into your bottom.

Living with Lynch syndrome

Living a healthy lifestyle

As Adam says, if you have Lynch syndrome it's particularly important to live a healthy lifestyle.

The gallery below highlights some of the key ways in which you can do this.

Eat more fibres such as wholemeal and wholegrain foods, legumes, fruit and vegetables.

Eat less red and processed meat such as bacon and sausages. Instead have lean proteins like fish, poultry, and plant-based alternatives.

Aim for at least five portions of a variety of fruits and vegetables a day to ensure you're getting enough essential vitamins and minerals.

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In conclusion…

- More needs to be done to support healthcare providers that do not have knowledge of Lynch syndrome through increased education.
- There is a strong desire for knowledgeable and accessible points of contact.
- This report has clarified that there is a great need to reduce inequity and to increase integration of care.
- There is a need for increased psychological support.

Patient Feedback

The final version of the report was shared with the patients who responded to the survey and took part in interviews.

Here is what some of them said:

‘The survey, interview and the final release of this report and it's recommendations, on behalf of people with Lynch Syndrome and their families, is really welcome and greatly appreciated.’

‘I can't see anything I would question or suggest to change, great work!’

‘Thank you for sharing the results, very interesting!’

Thank you!

Please scan the QR code below to access the report.

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