Finding the missing 95%:

Unlocking the potential of Lynch syndrome services

Bowel Cancer UK
Beating bowel cancer together

Executive summary

Lynch syndrome is a genetic condition which increases a person's risk of developing bowel cancer by up to 80%, as well as increasing the risk of other cancers. Yet currently, less than 5% of people with Lynch syndrome have been diagnosed[1]. It is estimated that around 175,000–200,000 people across the UK have Lynch syndrome and are unaware they are at high risk of developing bowel, and other cancers[2]. Our 2018 report, Time to Test, found that this was due to a lack of routine testing across the UK for people diagnosed with bowel cancer, and for their families.

Identifying people with Lynch syndrome has important implications for the person affected, and their family members. It is also a crucial part of the puzzle to improve survival of bowel cancer, through increasing early detection in people with a high risk of developing the disease.

In 2017, national guidance recommended all bowel cancer patients are tested for Lynch syndrome, and testing be offered to the family members of those with the condition. Bowel cancer patients with Lynch syndrome can be offered drugs that are more likely to successfully treat their cancer and reduce the chances of having a serious reaction to chemotherapy drugs. People can be offered regular surveillance colonoscopies which can reduce their risk of dying from bowel cancer by up to 72% because it can detect cancer at earlier stages, when it is more treatable and curable.

To understand how well the national guidance on Lynch syndrome testing and surveillance has been implemented, we requested information from health services across the UK on the percentage of bowel cancer patients routinely tested for the condition, as well as the extent that family members were offered testing and if a surveillance colonoscopy was routinely offered to anyone with Lynch syndrome. This data helps to identify which geographical areas and parts of the pathway still require improvement.

Since 2018, considerable progress has been made, with 90% of UK bowel cancer patients being tested for Lynch syndrome in 2022/23. However, significant challenges with testing family members and offering routine surveillance colonoscopies still require urgent attention.

Testing all newly diagnosed bowel cancer patients for Lynch syndrome (also called universal testing) and routine surveillance are vital to meeting the early diagnosis ambitions set out by governments and health services across the UK.

To unlock the unrealised impact of Lynch syndrome testing and surveillance, we need:

- all bowel cancer patients to be tested for Lynch syndrome, at diagnosis, so that more effective treatments can be used
- cascade testing to be offered to all immediate family members, for patients who test positive, to allow for risk-reducing strategies to be deployed
- a high-quality colonoscopic surveillance programme delivered through each UK nation's bowel cancer screening programme to reduce variation in access, quality, and timeliness of surveillance colonoscopies
- a registry of people with Lynch syndrome in each UK nation to increase our understanding of the condition and highlight regional differences in treatment and care

If everyone with bowel cancer and their family members were tested for Lynch syndrome and enrolled into appropriate surveillance pathways by 2028, 300 lives could be saved annually in England alone[3].

"Understanding Lynch syndrome and the genetics of bowel cancer is no longer of academic interest alone. It's core to the modern management of cancer and therefore it's essential that all members of cancer Multidisciplinary Teams (MDTs) have a clear understanding of Lynch syndrome. Bowel cancer is preventable and curable. Patients and their families need to feel reassured that surveillance services and decision making is robust and sustainable. The Association of Coloproctology of Great Britain and Ireland (ACPGBI) welcomes this report and will work with all agencies across the UK and Ireland to support these goals."

Professor Jared Torkington,
Consultant Colorectal and General Surgeon,
Spire Cardiff Hospital

Glossary

Association of Coloproctology of Great Britain and Ireland (ACPGBI)
The Association of Coloproctology of Great Britain and Ireland (ACPGBI) is a group of 100+ health professionals who work to advance knowledge and treatment of bowel diseases in Britain and Ireland[4].

Bowel Cancer Screening Programme (BCSP)
The Bowel Cancer Screening Programme (BCSP) is run by the NHS to regularly check for bowel cancer. A home test kit called a faecal immunochemical test (FIT) is sent automatically to people eligible for screening every two years, to collect a small sample of poo and send it to a lab. This is checked for tiny amounts of hidden blood[5].

British Society of Gastroenterology (BSG)
The British Society of Gastroenterology is the professional body for health professionals working in gastroenterology in Britain and works to promote gastroenterology and hepatology.

Cancer Alliances (CA)
Cancer Alliances bring together clinical and managerial leaders from different integrated care systems and other health and social care organisations, to transform the diagnosis, treatment and care for cancer patients in their local area. These partnerships enable care to be effectively planned across local cancer pathways.

Cascade testing
Testing close relatives of people with Lynch syndrome for the condition.

Devolved nations
The devolved nations are Scotland, Wales, and Northern Ireland. These nations have separate executives and legislatures which are responsible for the funding and delivery of health services in their nation. As a result, each nation has a different health system.

Freedom of Information (FOI)
Freedom of Information is a right of access to official information held by public authorities. It is based on the principle that individuals and the public have the right to know what is happening in their interests.

Genomics Medicine Service Alliances (GMSA)
Genomics Medicine Service Alliances are networks of regional alliances created in January 2021 by the NHS Genomic Medicine Service (GMS) to oversee and coordinate the integration of genomics into routine healthcare across England[6].

Health Boards (HB)
Local Health Boards in Scotland and Wales are responsible for planning and delivering NHS services in their areas and for the protection and improvement of their population's health. There are 14 Health Boards in Scotland and seven in Wales.

Health and Social Care (HSC)
Health and Social Care is the publicly funded healthcare system in Northern Ireland. Although having been created separately to the NHS, it is still considered a part of the overall national health service in the UK.

Health and Social Care Trust (HSCT)
There are five Health and Social Care Trusts in Northern Ireland, which are the regional authorities that provide health and care services to the public in their regions.

Integrated Care Boards (ICBs)
There are 42 Integrated Care Boards across England, which are the statutory NHS organisations responsible for developing plans to meet the health needs of the population, manage the NHS budget and arrange for the provision of health services in the area.

Lynch champions
Lynch champions are local leads within cancer multidisciplinary teams (MDTs) responsible for ensuring patients who are eligible for genetic testing are identified and offered testing.

Mismatch repair (MMR)
Mismatch repair (MMR) genes are responsible for fixing DNA errors. If these genes have faults, DNA mistakes can accumulate and lead to cancer over time.

Multidisciplinary team (MDT)
When someone is diagnosed with bowel cancer, a team of healthcare professionals work together to plan their treatment. Teams can be made up of several different healthcare professionals, including pathologists, surgeons, oncologists, and clinical nurse specialists. This team is called a multidisciplinary team (MDT).

National Institute for Health and Care Excellence (NICE)
The National Institute for Health and Care Excellence (NICE) help medical practitioners and commissioners get the best care to patients, as quickly as possible, by assessing health technologies and issuing guidance on the diagnosis and treatment of different conditions[7].

Risk stratification
The process of dividing the eligible population for screening into groups based on their risk status to improve health outcomes[8].

Velindre University NHS Trust
The Velindre University NHS Trust provides specialist cancer services across South East Wales.

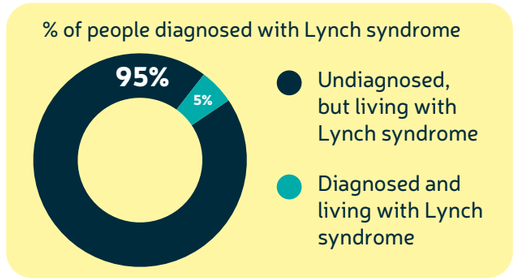
Introduction

In recent years, breakthroughs in genetics and DNA testing have revolutionised healthcare, especially in cancer diagnosis, treatment, and care. By examining a person's genes, we can now identify people at higher risk of developing certain cancers. This allows healthcare providers to detect cancers at an earlier stage and make informed decisions about cancer management and surveillance. Crucially, they can also offer more effective personalised treatments and prevention strategies based on the patient's genetic profile.

In this report, we investigate how this approach is being delivered for patients with Lynch syndrome across the UK. We found progress has been made in recent years, but the UK's health services are not currently fully delivering best practice, particularly on cascade testing, and there are worrying variations in Lynch syndrome services creating a postcode lottery of care.

Identifying people with Lynch syndrome will help improve early diagnosis of bowel cancer

Approximately 175,000-200,000[9] people in the UK are estimated to have Lynch syndrome, a genetic condition with no known cure, that increases a person's lifetime risk of bowel cancer by up to 80%[10]. It is estimated to cause around 3% of bowel cancer cases in the UK every year, many of them in people under the age of 50. It also raises the risk of endometrial, ovarian, brain, and other cancers[11]. People with Lynch syndrome have a 50% chance of passing the condition on to their children, meaning whole families can be devastated by the impact of bowel cancer. For Lynch syndrome, the evidence on what works and must be done has been available since 2017. Yet currently less than 5% of people with Lynch syndrome have been diagnosed[12]. The inability to offer people with the highest risk of bowel cancer effective care simply because we don't know who they are is unacceptable.



Early diagnosis has been recognised by governments and health services across the UK as the priority for cancer, because the earlier a cancer is detected, the greater the chance of survival. For bowel cancer, 9 in 10 people will survive their diagnosis for five years or more if diagnosed at the earliest stage. However, this drops significantly as the disease progresses.

If everyone with bowel cancer and their family members were tested for Lynch syndrome and enrolled into appropriate surveillance pathways by 2028, 300 lives could be saved annually in England alone[13].

Method and response rates

This report is based on Freedom of Information (FOI) data. Between April-July 2023, Bowel Cancer UK sent FOI requests to every Health Board in Scotland and Wales, each Health and Social Care Trust (HSCT) in Northern Ireland, and every Cancer Alliance in England. We asked about the extent to which they implemented national guidelines, cascade testing, wraparound care, and key barriers. The response rate was 62% in England and 100% across Northern Ireland, Scotland, and Wales.

Testing and management of Lynch syndrome

Diagnosing Lynch syndrome begins with molecular testing of tumours for specific genes related to DNA repair.

Mismatch repair (MMR) genes are responsible for fixing DNA errors in the body. If these genes have faults, DNA mistakes can build and lead to cancer over time. Around 15% of people with bowel cancer are estimated to have defects to these genes[14], and approximately 25% of those with MMR defects have Lynch syndrome[15]. Because these faults can happen in cancers unrelated to Lynch syndrome, two more tests are carried out. If no changes are found, further testing of DNA called germline testing is necessary to definitively diagnose Lynch syndrome[16].

Before getting a diagnosis, every patient must undergo genetic counselling. Counselling helps people to make informed decisions by providing information on the genetic condition, the implications of being diagnosed, and the measures that would be put in place to care for them after a Lynch syndrome diagnosis (also known as 'wraparound care').

Wraparound care consists of providing information, support, and the network needed to help patients through their Lynch syndrome journey. This can include genetic counselling, signposting to support groups and relevant charities, and providing information resources. It is essential that wraparound care is offered to all patients to ensure they have access to the best information and support, at the right time.

To find the missing 95% of undiagnosed people with Lynch syndrome, family members of patients who test positive for the condition should be offered the same genetic tests. This strategy of screening immediate family members helps to find those who carry the same genetic condition so lifesaving interventions can be offered, unlocking the true benefit of Lynch syndrome testing by saving more lives. Routine surveillance colonoscopy reduces the risk of dying of bowel cancer by as much as 72% because it can detect the disease at an earlier stage when it is treatable and curable, and in some cases, even prevent it from developing[17]. Some people with Lynch syndrome may benefit from other 'risk reducing strategies'; for example, women can be referred to obstetrics and gynaecology to be offered a hysterectomy to reduce their risk of developing endometrial cancer. Additionally, daily aspirin has been shown to reduce the chance of bowel cancer[18].

Guidelines on Lynch syndrome

In 2017, the National Institute for Health and Care Excellence (NICE) recommended that everyone diagnosed with bowel cancer is tested for Lynch syndrome, at the time of diagnosis. Since the initial guidance was published, NICE have also adopted the British Society of Gastroenterology (BSG) and Association of Coloproctology of Great Britain and Ireland's (ACPGBI) recommendations on routine surveillance colonoscopies for those with Lynch syndrome.

This guidance applies to England and Wales, and the guidelines have been endorsed in Scotland by the Molecular Pathology Consortium as well as in Northern Ireland by the Department of Health[19].

Unless this guidance is followed, across the UK people with Lynch syndrome will not have the best chance to avoid developing bowel cancer or catching it early – when it is much more treatable.

However, since NICE guidance was published, efforts have been made to improve the testing and care of people with Lynch syndrome to support early diagnosis ambitions.

> Lynch syndrome is one of the few conditions where a relatively simple test can make a huge difference to its diagnosis, particularly for younger patients. Testing for mutations in the DNA of colorectal tumours can identify patients that have a genetic condition, such as Lynch syndrome, which makes them prone to developing cancer at a younger age.
>
> This discovery can determine a more effective treatment pathway for the patient. It also allows family members to be screened for the condition so that they can be monitored, and preventative measures can be put in place to reduce their risk of bowel cancer.

Professor Malcolm G Dunlop
MRC Investigator, Institute of Genetics and Cancer

State of the nations - what's the picture for Lynch syndrome across the UK?

England

In 2021, NHS England established the National Lynch Syndrome Transformation Project through seven regional Genomics Medicine Service Alliances (GMSA) to improve the identification and management of Lynch syndrome[20]. This project was set up to[21]:

- develop regional expert networks to deliver standardised and equitable testing pathways for Lynch syndrome and monitor geographical differences in testing
- establish a Lynch champion within each colorectal and gynae cancer multidisciplinary team (MDT)
- upskill the workforce to identify eligible patients for testing and delivering genetic testing

The funding for this project ends in March 2024 so from April, Integrated Care Boards (ICBs) will take over responsibility for commissioning Lynch services. The biggest challenge will be ensuring that the progress from the Lynch Transformation Project is not lost. In January 2024 we wrote to ICBs, along with our key partners, highlighting the funding changes and recommending that they produce targeted business case planning and guidance in collaboration with GMSAs, to ensure that all aspects of the Lynch syndrome pathway continue to be funded in each of their areas.

In May 2023, colonoscopic surveillance for people living with Lynch syndrome became the responsibility of the Bowel Cancer Screening Programme (BCSP)[22]. We've campaigned for this change since 2017 and it now means people with the condition will automatically receive an invitation when their next surveillance colonoscopy is due. This change has standardised Lynch syndrome surveillance and ensures people are offered a high-quality colonoscopy, regardless of where they live.

Scotland

In November 2021, the Scottish Government published an 'Endoscopy and Urology Diagnostic Recovery and Renewal Plan'[23]. This document set out several actions needed to improve bowel cancer diagnosis. It included a commitment to creating a national framework to manage surveillance of patients, such as those with Lynch syndrome.

In March 2023, the Scottish Government published the first in a series of three genomics papers. The 'Genomics in Scotland: Building our Future' publication set out the strategic intent for genomics in Scotland and is to be followed by a broader genomics strategy[24]. It indicates the Scottish Government's intention to make genomic services a key part of cancer pathways to detect relapses earlier and considers the benefits for family members of patients with Lynch syndrome.

In June 2023, the Scottish Government published a ten-year strategy underpinned by an initial three-year action plan (2023-2026). The action plan included pledges to broaden the Scottish Genomic Test Directories, supporting the standardisation of genomic cancer testing as well as a promise to publish a genomics strategy for Scotland as outlined above.

Wales

In 2019, the Welsh Government established the National Endoscopy Programme and published a National Endoscopy Plan covering 2019-23 and was updated in 2020 to take account of the impact of COVID-19. Surveillance of high-risk patients was included within this important plan.

In 2021, interim guidance for risk stratification of patients in surveillance pathways stated: "We consider Lynch syndrome patients to be the highest risk category on the surveillance waiting list." In relation to the risk to Lynch syndrome patients from delays in colonoscopic surveillance, the paper states: "The implications for patients with Lynch syndrome being overdue for surveillance are far more adverse than almost any other category"[26].

In 2022, the Genomics Delivery Plan for Wales (2022-25) was published, containing several actions that would affect Lynch syndrome services, such as attracting, developing, and retaining a robust genomics workforce, and for 5,000 extensive genomics profiles to be offered to patients with newly diagnosed cancer each year[27].

A further commitment on the genomics workforce was included in the Wales Cancer Improvement Plan (February 2023) for Genomics Partnership Wales and Health Education and Improvement Wales to develop a Genomics Workforce Plan[28].

Northern Ireland

In March 2022, the Northern Ireland Executive launched the ten-year Cancer Strategy for Northern Ireland. This long-awaited plan stressed the importance to patients and their families of being well informed of the benefits and consequences of genomic testing. Action 27 called for the delivery of genetic and genomic testing in cancer pathways in line with NICE recommendations[29].

At the same time, the then Northern Ireland Health Minister announced plans to improve genomics services within a broader UK genomics landscape[30].

Unfortunately, since the publication of the Cancer Strategy for Northern Ireland, and following the May 2022 Stormont election, the Northern Ireland Assembly has been unable to sit, and no Executive has been formed. This has led to reduced budget allocations, including the health budget, and a lack of a full funding settlement to deliver on all the commitments within the strategy.

> It's estimated that 95% of people with Lynch syndrome remain undiagnosed, which amounts to around 200,000 people in the UK. Only by knowing who such people are can we offer the many benefits that will help to prevent cancer more effectively and improve their outcomes from a diagnosis of cancer. Through the National Lynch Syndrome Project, we have worked with cancer teams across England to ensure we can deliver these diagnoses and change the future for them and their families.
>
> **Dr Kevin Monahan,**
> **Consultant Gastroenterologist,**
> **St Mark's, The National Bowel Hospital**

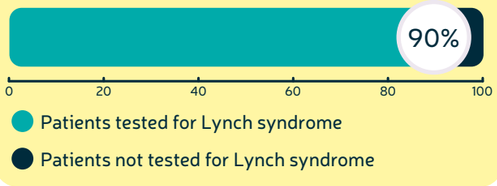
What we found

To understand how well the national guidance on Lynch syndrome testing and surveillance has been implemented, we sent Freedom of Information (FOI) requests to health authorities across the UK. This report has also helped to identify the areas which still require attention so universal testing and surveillance can be offered.

Our 2023 data found that, across the UK:

- 83% of health authorities reportedly implement NICE guidelines
- yet only 80% test at the time of diagnosis (pre-treatment) in line with NICE guidance
- 92% of health authorities test all newly diagnosed bowel cancer patients for Lynch syndrome
- on average, 90% of patients were tested over the last financial year

On average, 90% of all newly diagnosed bowel cancer patients were tested for Lynch syndrome over the last financial year (UK-wide figure)



Improvements in genetic testing for bowel cancer patients but workforce and capacity issues are still barriers

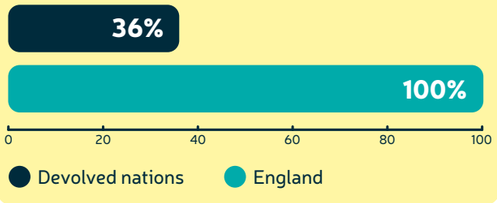
While there has been huge improvement in the overall proportion of bowel cancer patients offered genetic testing across the UK, a postcode lottery still exists for patients.

Difficulties with MMR testing were reported by 20% of health authorities across Wales, Scotland, and Northern Ireland. Resource and capacity constraints have prevented MMR testing from being carried out before surgery in some cases. For other health authorities, a lack of laboratory staff able to perform genetic testing is a significant barrier to universal testing.

Lynch champions within MDT's were reported by only 36% of health authorities across the devolved nations compared to 100% in England[31]. Lynch champions help identify someone accountable within MDT's to ensure patients are tested for Lynch syndrome, as well as signpost and refer patients to appropriate wraparound care and services.

Across the UK, 57% of health authorities reported barriers to implementing national guidelines. Health authorities cited a lack of resources and staffing as explanations for their failure to implement national guidelines fully. Reduced capacity of laboratories due to a shortage of staff also functioned as a barrier to universal testing.

% of health authorities with a Lynch champion in each cancer MDT



Lack of cascade testing is undermining early diagnosis ambitions

Worryingly, only 49% of UK health authorities provided family members with letters for their GP highlighting their risk of Lynch syndrome and requesting referral for genetic services. This is preventing the NHS from realising the true benefit of Lynch syndrome testing and management which is extremely frustrating as early diagnosis has been recognised by all governments across the UK as a priority for cancer care.

% of UK health authorities providing close relatives with letters for their GP

This situation is worse in the devolved nations with some health authorities reporting that they had difficulties in offering cascade testing at all. For instance, some health authorities in Scotland and Northern Ireland rely on patients to self-refer to genetic services and one Trust in Northern Ireland reporting testing 0% of close relatives for Lynch syndrome.

Postcode lottery for life-saving routine surveillance colonoscopy

Even when people are diagnosed with Lynch syndrome in the devolved nations, only 64% of health authorities offer routine surveillance colonoscopies in line with clinical guidelines. Although some health authorities said they intend to provide it in the future, waiting lists for colonoscopies have been worsened by the COVID-19 pandemic and this remains a significant barrier to introducing routine surveillance.

Alarmingly, others report that they don't provide any routine surveillance, raising significant concerns around the care and management of people with Lynch syndrome in these areas. This is a prime example of the postcode lottery of care people with the condition receive.

Colonoscopy surveillance is not a concern in England as this responsibility was moved under the Bowel Cancer Screening Programme in May 2023.

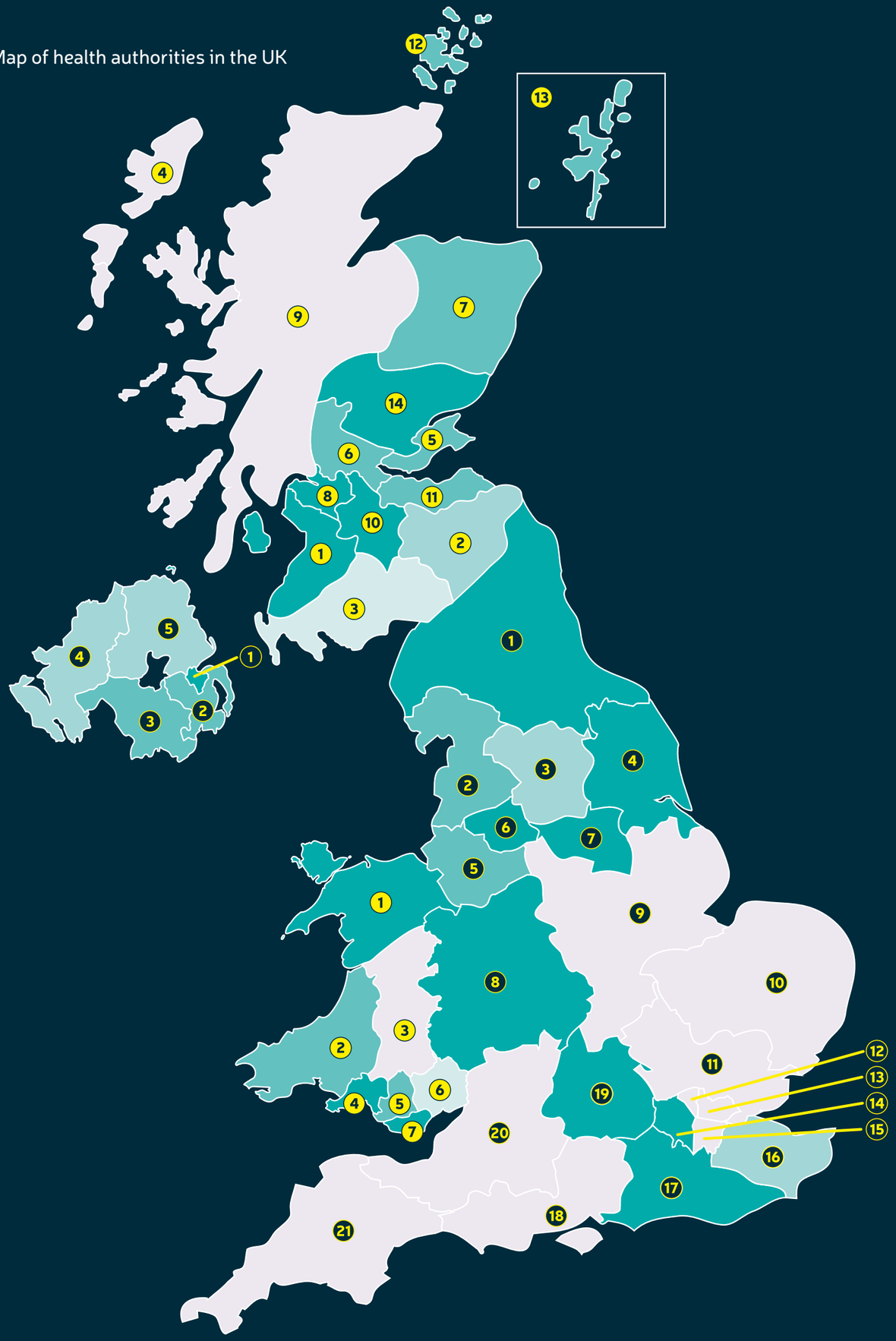
Data gaps are holding back care for people with Lynch syndrome

To monitor the effectiveness of Lynch syndrome testing and care, it is important that robust data is routinely collected and reported at a national level. This would help support local implementation of NICE guidance, provide national oversight for the NHS and help national teams to support local areas to remove barriers.

Our FOI requests found major gaps in data collection and reporting on Lynch syndrome guidance and services. For example, no Cancer Alliances in England could provide data for the proportion of close relatives offered cascade testing over the last financial year. If this data is not routinely collected and monitored, it is hard to understand how many people are being identified with Lynch syndrome each year and makes it difficult to plan services accordingly.

Even when data is collected, there is significant variation in where and how information is stored and accessed as some health authorities were unable to provide any data at all. For example, one Cancer Alliance did not hold information on the proportion of patients tested for Lynch syndrome, but rather this data was held at Trust level within the Cancer Alliance.

Map of health authorities in the UK



Health authorities have been scored based on their fulfilment of following criteria:

- Adherence to NICE/BSG guidelines
- Offering genetic counselling
- Providing regular colonoscopic surveillance
- Offering letters to close relatives of people with Lynch syndrome to take to their GP

4 of 4

3 of 4

2 of 4

1 of 4

Failed to respond or didn't hold the information required

Scotland Health Boards		Score
1	NHS Ayrshire and Arran	4
2	NHS Borders	2
3	NHS Dumfries and Galloway	1
4	NHS Western Isles	0
5	NHS Fife	3
6	NHS Forth Valley	3
7	NHS Grampian	3
8	NHS Greater Glasgow and Clyde	4
9	NHS Highland	0
10	NHS Lanarkshire	4
11	NHS Lothian	3
12	NHS Orkney	3
13	NHS Shetland	3
14	NHS Tayside	4
England Cancer Alliances		
1	Northern Cancer Alliance	4
2	Lancashire and South Cumbria Cancer Alliance	3
3	West Yorkshire and Harrogate Cancer Alliance	2
4	Humber, Coast and Vale Cancer Alliance	4
5	Cheshire and Merseyside Cancer Alliance	3
6	Greater Manchester Cancer Alliance	4
7	South Yorkshire and Bassetlaw Cancer Alliance	4
8	West Midlands Cancer Alliance	4
9	East Midlands Cancer Alliance	0
10	East of England - North Cancer Alliance	0
11	East of England - South Cancer Alliance	0
12	North Central London Cancer Alliance	0
13	North East London Cancer Alliance	0
14	RM Partners	4
15	South East London Cancer Alliance	0
16	Kent and Medway Cancer Alliance	2
17	Surrey and Sussex Cancer Alliance	4
18	Wessex Cancer Alliance	0
19	Thames Valley Cancer Alliance	4
20	Somerset, Wiltshire, Avon and Gloucestershire Cancer Alliance	0
21	Peninsula Cancer Alliance	0
Wales Health Boards		
1	Betsi Cadwaladr University Health Board	4
2	Hywel Dda University Health Board	3
3	Powys Teaching Health Board	0
4	Swansea Bay University Health Board	4
5	Cwm Taf Morgannwg University Health Board	3
6	Aneurin Bevan University Health Board	1
7	Cardiff and Vale University Health Board	4
Northern Ireland Health and Social Care Trusts		
1	Belfast Health and Social Care Trust	4
2	South Eastern Health and Social Care Trust	3
3	Southern Health and Social Care Trust	3
4	Western Health and Social Care Trust	2
5	Northern Health and Social Care Trust	2

> I was given the option of cascade testing by Oxford University Hospitals once it was confirmed that I had Lynch syndrome. I personally feel that it's an essential part of the support process for any patient with Lynch syndrome. It's a very difficult diagnosis to deal with and having to tell relatives that not only do you have this horrible disease, but they might have it also, is something that no-one should have to do without professional support. My sister was contacted directly by the geneticist and was able to talk through her options as part of a full and frank discussion. This is something which I will always be glad about as I would not have been able to do the conversation justice, and my sister certainly benefited from it.
>
> **Tom, bowel cancer patient**

Spotlight on England

There's been significant improvement in the testing and management of Lynch syndrome in England over the last five years. This can be attributed to NHS England's National Lynch Syndrome Transformation Project, which aims to deliver a comprehensive service for the detection of Lynch syndrome, and the movement of surveillance to the BCSP. If NICE guidelines were to be fully implemented, it is estimated that 300 lives could be saved every year in England[32].

Drastic improvements in genetic testing for bowel cancer patients

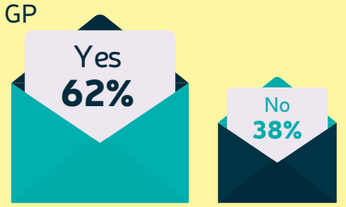
In England, 92% of Cancer Alliances reported use of NICE guidelines to offer all newly diagnosed bowel cancer patients testing for the molecular features of Lynch syndrome. However, our findings show that only 85% of Cancer Alliances tested at the time of diagnosis, in line with the guidelines. In 2018, 17% of hospitals tested at the time of diagnosis. Although these figures aren't directly comparable, a testing rate of 85% nevertheless illustrates a significant improvement. It is important that the incredible progress made by NHS England's National Lynch Syndrome Transformation Project is not lost when it comes to an end in March 2024, with Cancer Alliances maintaining a rate of over 90% for Lynch syndrome testing and continuing to work towards universal provision.

However, wraparound care is an area in desperate need of improvement in England. Only 69% of Cancer Alliances provide all wraparound care measures. It is essential that these measures are offered universally by Cancer Alliances to ensure patients have access to all the information and support that they require whilst navigating a possible Lynch syndrome diagnosis and considering what this means for themselves and their families.

Lack of cascade testing impacting ability to save lives

Cascade testing is another key area of concern. Only 62% of Cancer Alliances provide letters for at-risk family members to take to their GP requesting referral to genomic services. Cascade testing is essential in identifying the missing 95% of people with Lynch syndrome and making access to lifesaving interventions available to them and their families. It is where the most benefits, both cost-effective and clinical benefits are possible in Lynch syndrome care, and therefore essential we get this right.

% of Cancer Alliances providing letters for at-risk family members to take to their GP



In addition, no Cancer Alliances could provide the proportion of close relatives who received cascade genetic testing over the last financial year. Several Cancer Alliances stated that whilst cascade testing is offered, they do not audit the proportion of patients tested. The lack of data collection and reporting on the proportion of close relatives undermines efforts to maximise the effectiveness of Lynch syndrome care, and ultimately to save lives.

A new world-leading surveillance programme

Since May 2023, patients with Lynch syndrome are now offered surveillance colonoscopies via the Bowel Cancer Screening Programme. We've been campaigning for this since 2017 and it is the first programme of its kind in the world.

It will now ensure that patients are routinely invited to high-quality surveillance colonoscopy and help reduce the likelihood of someone with Lynch syndrome dying from bowel cancer.

Recommendations

- Integrated Care Boards (ICBs) should support providers to implement NICE DG27 guidance and must commission Lynch syndrome services once the National Lynch Syndrome Transformation Project comes to an end to ensure that progress is not lost
- ICBs must ensure local plans are in place across all providers to support full implementation of NICE DG27 guidance and should ensure metrics are in place locally to track progress
- ICBs must implement fully NICE and NHS England guidance (Lynch syndrome handbook, 2021) on Lynch syndrome testing and surveillance pathways, and commission the appropriate services including cascade testing of family members
- NHS England must continue to commission the National Bowel Cancer Screening Programme to provide colonoscopic surveillance for people with Lynch syndrome in line with national guidance
- NHS England must build on the Lynch Syndrome Monitoring Framework which measures implementation of Lynch syndrome testing pathways to include metrics on the management of patients with Lynch syndrome, to monitor the implementation of national guidance and identify local areas which require further support
- ICBs should develop reliable data metrics for monitoring the implementation of Lynch syndrome testing of all newly diagnosed bowel cancer patients, and cascade testing of family members to identify testing service providers where further support is required
- Clinical genetic services must report quarterly to the centralised database held by NHS England on the proportion of patients tested for Lynch syndrome including cascade testing of family members
- ICBs, Genomic Medicine Service Alliances and Cancer Alliances should routinely access the centralised Lynch syndrome database to understand their performance against national targets, and develop local plans for improvement
- ICBs, Genomic Medicine Service Alliances and Cancer Alliances should work together to develop an action plan to remove any barriers for universal testing of Lynch syndrome such as workforce and capacity barriers by reviewing resourcing requirements
- The Government must fully fund the NHS Long-Term Workforce Plan to address the staffing and financial barriers – especially in pathology - that restrict the provision of high-quality care for patients with Lynch syndrome
- ICBs should work closely with Cancer Alliances to monitor the provision of wraparound care, ensuring it is offered universally by genetic services to all patients with Lynch syndrome
- UK National Screening Committee should consider the evidence, benefit, and eligibility of Lynch syndrome screening in people with bowel cancer as a new targeted screening programme

> Identifying people in the population that have Lynch syndrome means that they can, hopefully, get appropriate surveillance which is key for prevention and early detection. We know that early diagnosis means a greater chance of survival and that's what we need for more people. Cascade testing allows us to identify those people, it balances the approach towards the preventative, a relative has been diagnosed, the risk can be identified and screening can be accessed. Then all we need is for the screening to be readily available equally across the country. We know that capacity is a challenge within the NHS. I would also say that cascade testing helps the individual, they know if they at risk and they can play an active part in minimising that risk rather than living with uncertainty.
>
> **Cara, bowel cancer patient**

Spotlight on Scotland

Three of Scotland's 14 Health Boards refer bowel cancer patients to other Health Boards, they are NHS Western Isles, NHS Orkney and NHS Shetland.

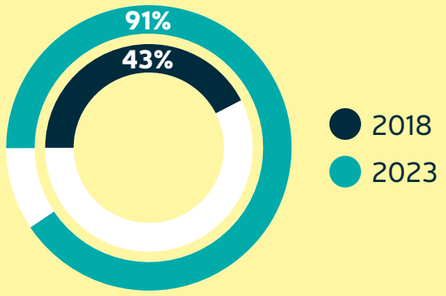
Since our last investigation of Lynch syndrome services, Scotland has made progress in some key areas, such as initial testing. However, the data shows there is a long way to go on surveillance of patients with Lynch syndrome, establishing Lynch champions, providing comprehensive wraparound care, capturing necessary data, and effective cascade testing of family members.

Improved genetic testing of newly diagnosed bowel cancer patients

Three of Scotland's island Health Boards refer elsewhere and of the remaining 11 Health Boards, five reported adopting NICE guidelines for the testing of newly diagnosed bowel cancer patients for Lynch syndrome, while a further five pointed to other guidance they follow (e.g. South and East of Scotland Cancer Network guidance or BSG/ACPGBI guidelines).

We found that 91% of responding Health Boards test at the time of diagnosis in line with NICE or other guidelines. This is a welcomed improvement on our previous report, where only 43% of Health Boards tested newly diagnosed bowel cancer patients.

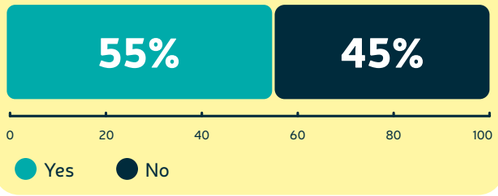
% of Health Boards testing for Lynch pre-treatment in line with NICE guidance



Tackling data gaps to improve surveillance of Lynch syndrome patients

Our research has found only 55% of Health Boards in Scotland are providing Lynch syndrome surveillance colonoscopies at the recommended two-year interval. Two Health Boards stated they wanted to deliver this level of service but said endoscopy capacity was a barrier to achieving this. Surveillance of patients with Lynch syndrome is key to early diagnosis and saving lives, therefore it is of vital importance that steps are taken to improve on this figure.

% of Health Boards providing colonoscopic surveillance at the recommended time intervals



Better data collection will be crucial to improving Lynch syndrome surveillance in Scotland. A framework to manage people who need surveillance was announced by the Scottish Government when establishing the Endoscopy and Urology Diagnostic Programme Board. A planned database, including Lynch syndrome patients, would be a useful first step in understanding the surveillance needs across the country. This database must include all known people with Lynch syndrome, with clear guidance on how often they should receive surveillance colonoscopies. The option to include surveillance of Lynch syndrome patients within the Scottish Bowel Cancer Screening Programme should be considered.

Lack of Lynch champions in Scotland

A designated individual in each cancer MDT, to drive forward improvements within Lynch syndrome services, can be of benefit to clinical teams as well as patients.

> "Screening the family of patients with Lynch syndrome to identify those who carry these mutations has been undertaken in South East Scotland Cancer Network (SCAN) since the genetic causes of Lynch syndrome were first discovered, allowing us to identify many families in the population."
>
> **Professor Malcolm G Dunlop**

Unfortunately in Scotland, only 36% of Health Boards were able to identify such an individual, while one Health Board indicated they share the responsibility across their MDTs. This compares to 100% in England. NHS Scotland should explore the benefits of establishing local Lynch champions, using information from Cancer Alliances in England to guide their decisions in this area.

Cascade testing can unlock the full benefits of Lynch syndrome testing

Only 64% of responding Health Boards provide letters for at-risk family members to take to their GP. Cascade testing is essential in identifying the missing 95% of people with the genetic condition and making access to lifesaving interventions available to them and their families. It is where the most cost savings and clinical benefits are possible in Lynch syndrome care.

Our inquiries found no Health Boards could provide the proportion of close relatives who received cascade genetic testing over the last financial year. The lack of data collection and reporting on the proportion of close relatives who receive cascade testing is a major concern that must be addressed.

Recommendations

- NHS Scotland must fulfil the commitment made in the Endoscopy and Urology Diagnostic Recovery and Renewal Plan to deliver a national framework for the management of endoscopic surveillance. Data concerning Lynch syndrome patients must be incorporated into any database that underpins this framework
- The Scottish Government and NHS Scotland should provide the necessary resources to populate a national database with accurate data for all endoscopic surveillance patients, especially high-risk groups like Lynch syndrome patients, with a view to this database being updated with new patient information in a 'live' format
- To ensure this data is of greatest value, the surveillance database should include information relating to the level of risk for each patient (as determined nationally) and the date of their next surveillance invitation
- Nationally agreed interval thresholds should be created to drive compliance with both Lynch syndrome surveillance interval targets and data capture requirements around high-risk groups
- The Scottish Government must continue to provide ongoing support to the training and recruitment of staff, via the Endoscopy and Urology Diagnostic Programme Board. Additional resources/staffing in endoscopy departments can deliver greater capacity for Lynch syndrome surveillance
- The Endoscopy and Urology Diagnostic Programme Board should work with Health Boards to develop reliable measures for cascade testing as this was an area where no data was available. These must be applied universally and the proportion of Health Boards providing letters to at risk family members must increase from 64% to 100% so family members can access referral to genetic services for genetic counselling and genomic testing
- The Scottish Government and NHS Scotland must develop and implement a Genomics Workforce Plan to underpin the anticipated Scottish Genomics Strategy. Without a clear plan to strengthen the genomics workforce and laboratories, the Scottish Genomics Strategy will struggle to realise its ambitions

Spotlight on Wales

Powys Teaching Health Board outsources bowel cancer treatment to 'neighbouring district general hospitals'. They didn't answer any questions as a result.

Major progress has been made in Wales since our last report with regards to the adoption of NICE guidance and offering initial Lynch syndrome testing for newly diagnosed bowel cancer patients. However, more work is required on data, cascade testing and establishing Lynch champions.

Progress on testing of newly diagnosed patients, but data gaps exist

A major shift in testing newly diagnosed bowel cancer patients for Lynch syndrome has happened in Wales since our last report was published. 100% of Health Boards said they have adopted NICE guidelines and moreover, 100% of areas also stated they offer the test in line with those guidelines. In our last report we found no Health Board in Wales offered testing to all newly diagnosed patients, with 40% offering only to under 50s and 60% offering the test based on family history alone.

While this change is significant, there are still areas of concern in Wales. When asked about auditing diagnostic outcomes, to ensure patients are being tested for Lynch syndrome, 50% of Health Boards replied that they conducted no audit. A further third conduct private audits and only one Health Board responded to say their data is collected and published in the National Bowel Cancer Audit each year. Health Boards in Wales must ensure auditing of this nature takes place, and this information should be provided to the National Bowel Cancer Audit.

Insufficient data hampers surveillance of Lynch syndrome patients

Alongside the lack of audit data to evidence initial testing of newly diagnosed patients, gaps in evidence exist that undermine efforts to detect bowel cancer early in people with Lynch syndrome.

While it is encouraging that 83% of Health Boards offer surveillance of Lynch syndrome patients, only one Health Board collects data to show surveillance takes place, and this Health Board stated they are still dealing with a backlog caused by service changes during the COVID-19 pandemic. This means 83% of Health Boards do not collect any data to monitor the performance of their Lynch syndrome surveillance pathways.

NHS Wales and the National Endoscopy Programme should establish data capture processes that help to monitor and evaluate Lynch syndrome testing of newly diagnosed patients as well as those on surveillance pathways.

Cascade testing is falling behind other parts of the pathway

Only 50% of responding Health Boards provide letters for at-risk family members to take to their GP, although one other did state they have plans to adopt this practice. Cascade testing is vital to find the missing 95% of people with Lynch syndrome and making access to lifesaving interventions available to them and their families. It is where the most cost and clinical benefits are possible in Lynch syndrome care.

% of Health Boards providing letters for at-risk family members to take to their GP

Recommendations

- Health Boards in Wales must ensure auditing of Lynch syndrome services takes place, and this information should be provided to the National Bowel Cancer Audit for annual reporting
- Data collection for Lynch syndrome surveillance is a key requirement. The National Endoscopy Programme should work with Health Boards to establish a Lynch syndrome register, learning from the creation of the Lynch Syndrome Registry Portal in England
- The development of this register should be seen as the first step in the process of integrating Lynch syndrome surveillance into the Bowel Screening Wales programme, the National Endoscopy Programme and the Welsh Government should agree on a process of integration to ensure patients identified as having Lynch syndrome can receive colonoscopic surveillance within the recommended intervals
- Health Boards should commit to identifying Lynch champions that can help to drive forward service improvements
- Wraparound services for Lynch syndrome care should be expanded with all Health Boards providing genetic counselling, as well as providing patient information and signposting to support groups and third sector organisations
- Improved awareness and understanding of Lynch syndrome within MDTs, and comprehensive provision of genetic counselling are key components in improving cascade testing of at-risk family members. Health Boards should provide enhanced training opportunities for members of MDTs
- Data collection and reporting is lacking in key areas. Health Boards should develop reliable nationally agreed measures for cascade testing, as this is a part of the service that requires attention if more lives are to be saved through early diagnosis of bowel cancer in Lynch syndrome patients

> Despite my clear family history of various cancers, including bowel cancer, none of my family members were tested for Lynch syndrome until I was diagnosed. If they were, my Lynch syndrome could have been identified through cascade testing. Instead I was diagnosed with bowel cancer after going to my GP and then received a Lynch syndrome diagnosis. Had I been diagnosed through cascade testing, like my children, then my cancer may have been prevented or picked up at the earliest stage through surveillance colonoscopies.

Tracy, bowel cancer patient

Spotlight on Northern Ireland

Northern Ireland has made great improvements in testing newly diagnosed bowel cancer patients for Lynch syndrome, but like other nations, there are aspects of Lynch syndrome services that require urgent improvement. Data, surveillance, wraparound care, and cascade testing show signs of variation across Northern Ireland.

Testing of newly diagnosed patients shows clear signs of improvement

Newly diagnosed bowel cancer patients are far more likely to be tested for Lynch syndrome in Northern Ireland than was the case in our previous report. 100% of Health and Social Care Trusts (HSCTs) have adopted NICE guidelines. A similar proportion offer genetic testing to newly diagnosed patients which is a substantial increase from the previous figure of 20%.

Not only do we see an increase in Trusts offering the test at this stage, but data provided by Northern Ireland's five HSCTs shows four areas are testing 100% of newly diagnosed bowel cancer patients, with the other area providing genetic testing to approximately 90% of patients.

Like other nations, there are data gaps that need to be filled. 60% of Trusts conduct a private audit of their services to ensure they are meeting NICE guidelines. Efforts must be made to deliver comprehensive auditing of services across Northern Ireland.

Data gaps undermine surveillance of patients with Lynch syndrome

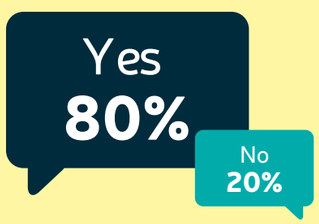
80% of Trusts have responded to our questions concerning colonoscopic surveillance of patients with Lynch syndrome stating they provide surveillance at recommended intervals. Unfortunately, as we see in other nations, no Trust can provide data on the proportion of patients who are entitled to surveillance and receiving their follow up within the agreed timelines.

Improving data collection and reporting will be crucial to ensure Northern Ireland can identify areas for improvement within the surveillance programme.

Wraparound care must be enhanced

HSCTs responses show 80% of areas provide genetic counselling, with the remaining Trust referring patients to a neighbouring Trust for this service. While this is a welcome development, only 20% of Trusts offer a more comprehensive wraparound Lynch syndrome care service by signposting to support groups and third sector organisations like Bowel Cancer UK, and offering patients information about Lynch syndrome.

% of HSCTs offering genetic counselling



25% of the 80% provide more comprehensive wraparound care

Our report also finds that Northern Ireland's Trusts have differing approaches to Lynch champions. Only two Trusts were able to identify a single champion, with another stating all members of the MDT share this responsibility. The other two Trusts were unable to identify a Lynch champion.

Cascade testing requires attention to save lives

When asked if at-risk family members of patients identified as having Lynch syndrome are provided letters to take to their GP, only one Trust stated they provide this service. Two Trusts responded that they refer to another area to provide this service and a further two do not provide letters at all.

Furthermore, only two Trusts could provide any data on the proportion of at-risk family members who are subsequently tested for Lynch syndrome. One area said all family members identified in the last year had been tested, while the other stated their figure was 0%.

The Department for Health alongside Trusts must address shortcomings in cascade testing as a priority. It is through cascade testing and regular colonoscopic surveillance that the greatest benefits of early diagnosis of bowel cancer can be realised and more lives saved.

Recommendations

- Health and Social Care (HSC) must ensure auditing of Lynch syndrome services takes place across Northern Ireland to monitor and evaluate services. An annual report capturing this data should be produced
- Data collection for Lynch syndrome surveillance is a key requirement. The Department of Health and HSC should establish a register of Lynch syndrome patients, learning from the approach taken in England with their Lynch Syndrome Registry Portal. The development of this register should be seen as the first step in the process of integrating Lynch syndrome surveillance into the bowel screening programme. The Department of Health, HSC and the Public Health Agency should agree on a process of integration to ensure patients identified as having Lynch syndrome can receive colonoscopic surveillance within the recommended intervals
- Trusts should commit to identifying Lynch champions that can help to drive forward service improvements
- Wraparound services for people with Lynch syndrome should be expanded with all Trusts providing genetic counselling, as well as providing patient information and signposting to support groups and third sector organisations
- Improved awareness and understanding of Lynch syndrome within MDTs, and comprehensive provision of genetic counselling are key components in improving cascade testing of at-risk family members. Trusts should provide enhanced training opportunities for members of MDTs
- Data collection and reporting is lacking in key areas. HSC should develop reliable nationally agreed measures for cascade testing, as this is a part of the service that requires attention if more lives are to be saved through early diagnosis of bowel cancer in Lynch syndrome patients

> In Northern Ireland, the introduction of testing for Lynch syndrome on all new cases of colorectal cancer was successfully introduced in November 2019. This is a vital first step in improving care for individuals with Lynch syndrome, but clinicians and researchers recognise that further work is urgently needed to improve surveillance and streamline care. The creation of a register of individuals with Lynch syndrome should be a key priority here, which will enable better monitoring, more effective prevention and earlier detection of cancer in this patient group.
>
> **Dr Ashleigh Hamilton,**
> **Academic Clinical Lecturer, Queen's University Belfast**

Conclusion

It is clear from the data provided in response to our FOI request, that significant and welcome progress has been made across all UK nations in providing initial testing of newly diagnosed bowel cancer patients for Lynch syndrome. However, it is alarming that there are several areas where services are far from the level patients should expect, and serious regional variations stubbornly exist.

While England has implemented relevant NICE guidelines to a high degree, the devolved nations are lagging, which creates a postcode lottery across the UK. England's adoption of colonoscopic surveillance of Lynch syndrome patients within the Bowel Cancer Screening Programme is a clear example of national variation. Scotland, Wales, and Northern Ireland must move quickly to develop robust surveillance pathways, underpinned by national Lynch syndrome registries, to close the surveillance gap with England.

Cascade testing falls short in all nations, which is worrying because truly realising the potential of Lynch syndrome testing and care requires universal provision of cascade testing of family members. It is through identification of all people with Lynch syndrome via cascade testing, followed by regular surveillance, that more lives can be saved from bowel cancer by detecting the disease early when it is treatable and curable, or in some cases prevent it from developing in the first place.

Local and national issues with data collection and monitoring are almost universal, which makes it difficult to understand the extent of national guidance implementation. Enhancing the management and publication of data must be prioritised by each nation so progress can be more closely monitored. In England, there must also be a commitment to build on the work of the Lynch Syndrome Transformation Project when funding responsibilities fall on ICBs from April 2024.

Protecting hard won progress on initial testing of bowel cancer patients, implementing best practice guidance across the entire Lynch syndrome pathway and improving routine data collection and monitoring are vital pillars to help eradicate the current postcode lottery of care for people with Lynch syndrome, and to help increase early diagnosis of bowel cancer. It is only then that the full potential of Lynch syndrome testing will be realised, which will ultimately save more lives.

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Bowel Cancer UK is the UK's leading bowel cancer charity. We're determined to save lives and improve the quality of life of everyone affected by the disease.

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