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LESS SURVIVABLE CANCERS

Inquiry into earlier detection and faster diagnosis

Final Report

June 2025

This report was researched by Pancreatic Cancer UK and funded by Less Survivable Cancers Taskforce.

Contents

About the APPG on Less Survivable Cancers

The APPG on Less Survivable Cancers is a new cross-party parliamentary group.

It is chaired by Paulette Hamilton MP and made up of more than 20 MPs and Peers who are passionate about tackling the issues affecting people with a less survivable cancer: brain, liver, lung, pancreatic, oesophageal, and stomach cancer. The group advocates for action to improve survival rates, as currently only 16% of people diagnosed survive five years.

The APPG on Less Survivable Cancers is calling for earlier and faster diagnosis, equitable access to the best treatments, and investment in vital research. The Group monitors government policies, provides evidence-based briefings to parliamentarians, and puts forward actions for the Government to take forward. Urgent action is needed to address this significant gap in cancer survival rates.

For more information about the APPG, please visit the Group's website.
lesssurvivablecancers.org.uk/all-party-parliamentary-group-on-less-survivable-cancers

Foreword by Paulette Hamilton MP

As Chair of the APPG on Less Survivable Cancers, I am proud to introduce our report on earlier detection and faster diagnosis of the less survivable cancers.

Our inquiry has revealed that we are at a pivotal moment for transforming patient outcomes and accelerating survival rates for the less survivable cancers. We're on the brink of research breakthroughs and in the midst of developing potentially game-changing Government health reforms. In this backdrop, achieving earlier detection and faster diagnosis is finally within reach.

Like many of my fellow APPG members, I have personally experienced the devastating impact that less survivable cancers have on individuals, their families and loved ones. Whilst there have been advancements in cancer survival and treatments, these cancers have alarmingly fallen behind. Today, these cancers have a collective five-year-survival rate of only 16%, compared to 54% for all other cancers. Enough is enough.

Historically, there has been a sense of hopelessness surrounding the less survivable cancers – but we are confident this can now change. This report sets out the APPG's practical, but urgent, recommendations the Government can take to improve early detection and faster diagnosis for the less survivable cancers. Inaction is simply not an option. Late diagnosis costs lives.

I want to thank everyone who submitted evidence to this inquiry. I have been inspired by the expertise and passion of our expert witnesses, as well as by the thoughtful written submissions we have received. Your insights have been invaluable in putting together this report, and have enabled us to make clear and evidence based recommendations for change.

I urge the Government and Department of Health and Social Care to consider our recommendations and take the vital steps needed to accelerate earlier detection and faster diagnosis of the less survivable cancers.

Paulette Hamilton MP
Chair of the All-Party Parliamentary Group on Less Survivable Cancers

Recommendations for government

The APPG on Less Survivable Cancers recommends the following actions for government to drive earlier and faster diagnosis for the less survivable cancers:

1. Invest in greater research into detection tests and tools to support GPs when identifying symptoms of the less survivable cancers.
2. Support the roll-out of innovative detection tests and develop a pilot to evaluate their use in diagnostic pathways.
3. Support campaigns to raise awareness of the symptoms of less survivable cancers.
4. Produce an overarching strategy for earlier and faster diagnosis of the less survivable cancers to ensure comprehensive commissioning and diagnostic capacity (including across Non-Specific Symptoms pathways, urgent suspected cancer pathways, and GP direct access).
    - This must include professional training around integrated clinical decision support tools to help GPs recognise vague symptoms and make appropriate referrals.
    - The Department for Health and Social Care (DHSC) should pilot programmes to expand access points and referral routes, including self-referral mechanisms and direct referrals from pharmacies. DHSC must work closely with Integrated Care Boards (ICBs) to ensure consistent implementation of services across regions.
    - DHSC should develop a full direct access pathway for brain tumours, given the current limitations of NSS pathways and urgent cancer referral pathways in detecting these.
5. Develop a centralised, nationwide case-finding programme to proactively identify high-risk individuals across multiple cancer types, building on the work already undertaken by the NHS in new-onset diabetes and weight loss.
6. Develop a centralised, nationwide programme to oversee and drive surveillance for individuals with inherited cancer risk.
    - This should include and build on existing programmes, such as those for BRCA in Jewish populations, Lynch Syndrome, and familial breast cancer. It should incorporate surveillance for people with a family history of pancreatic cancer and hereditary pancreatitis, utilising the risk assessment protocol from the EUROPAC study.
7. The Department for Health and Social Care should continue to support the rollout and expansion of testing for conditions that are precursors to the less survivable cancers (including NHSE's risk-stratified Community Liver Health Check programme and testing for HIV, Hep C and Hep B).
8. Develop an observational cohort study for rare and less survivable cancers to ensure that a standardised clinical dataset, from diagnosis and throughout treatment, is being routinely collected and to a high standard. This should include a process to facilitate genomic profiling and identify patients to participate in clinical trials.
9. Tackle capacity challenges impacting the rollout of Whole Genome Sequencing across NHS hospitals, including by investing in frozen tissue storage.
10. Appoint a named Government lead to both:
    a. Establish a strategic mission for rare and less survivable cancers.
    b. Support research and innovation for these cancers. This lead must coordinate with the new Health Data Research Service to ensure consistent, comprehensive data collection on rare and less survivable cancers.
11. Together with research and medical communities, establish Centres of Excellence for each of the less survivable cancers as key forums for knowledge sharing and collaboration.
    - Each discipline within the field would be represented to ensure there was some structure to research and treatment. Whilst Centres of Excellence would be their own entities, they could be built up from existing structures and tumour-specific associations (e.g. the Association of Upper Gastrointestinal Surgeons).
    - Whilst Centres of Excellence should be established by the national research community, they should be supported by the Department for Health and Social Care.
    - DHSC should work with Centres of Excellence to facilitate collaboration between different centres to avoid siloes.
12. Clinical trials should be incorporated as a performance metric within the NHS to incentivise clinicians to prioritise research.

Introduction

The less survivable cancers

The six less survivable cancers are cancers of the brain, liver, lungs, pancreas, oesophagus and stomach. Progress has been made to boost survival rates and improve patient outcomes for many cancers; however, these six cancers still lag behind. Tragically, the five-year survival rate for these cancers is just 16%, and they account for 67,000 deaths every year – around 42% of all cancer deaths in the UK.[1]

If early diagnosis was doubled across these six cancers, an additional 7,500 lives per year could be saved.

About the inquiry

The APPG on Less Survivable Cancers was formed in January 2025 and launched its inquiry into earlier detection and faster diagnosis in March 2025. The APPG chose this topic for its first area of focus having identified that accelerating earlier detection and faster diagnosis for those with a less survivable cancer is critical in improving people's access to treatment and ultimately their chance of survival.

Over the last 25 years, survival rates for these cancers have stayed largely static – and part of the reason is that it has been very challenging to diagnose people early. As it stands, just 28% of less survivable cancers are diagnosed at stage one or two, compared to 54% of all cancers.[2] However, recent advancements, including the development of innovative diagnostic tests and tools, the roll-out of new surveillance and screening programmes, and the potential for wider systemic transformation, provide opportunities to drive progress in early detection and faster diagnosis. **If early diagnosis was doubled across these six cancers, an additional 7,500 lives per year could be saved**.[3]

The APPG's inquiry focused on enhancing both earlier detection and faster diagnosis to capture improvements for all the six of the less survivable cancers, including brain. For brain tumours specifically, faster diagnosis is more pertinent than earlier detection, as brain tumours are not staged like other cancers. This is because they do not behave in the same way as other cancers: it is rare for primary brain tumours to spread outside of the brain or away from the central nervous system.[4]

To inform this report, the APPG held two oral evidence sessions in Parliament, in March and April 2025. The first session focused on the challenges facing earlier detection whilst the second explored next steps for innovating faster diagnosis. During these sessions, members heard from healthcare professionals, researchers and patients about what can be done to transform the diagnostic landscape. The APPG also issued a call for written evidence.

PART 01

Overcoming today's challenges in detecting less survivable cancers earlier

The challenges of vague symptoms

Identifying symptoms earlier

A fundamental challenge of detecting less survivable cancers early lies in their vague and non-specific symptoms. These symptoms may overlap with less serious health conditions, making it difficult to attribute these to cancer, especially since GPs may only see a small number of cases each year. For instance, a patient with oesophageal cancer may suffer from nausea and difficulty swallowing, but these symptoms could also be indicative of more common issues such as acid reflux or heartburn.

For years, these vague and non-specific symptoms have presented a seemingly unassailable barrier in accelerating earlier detection. A meagre 28% of less survivable cancers are diagnosed at stage one or two (of those that are staged), compared to an all-cancer average of 54% - and a large proportion of people with a less survivable cancer are diagnosed in emergency settings like A&E.[5]

However, increased development and faster adoption of diagnostic tools and tests can play an integral role in tackling late-stage diagnoses by equipping GPs with additional support to identify vague symptoms earlier. Researchers are already driving progress in creating innovative new diagnostic tests and tools, like Cytosponge/capsule sponge testing[6], Clinithink AI technology[7], the Galleri GRAIL test, and the VAPOR Breath Test[8], many of which are simple to use.

Empowering GPs through smarter diagnosis

As of November 2024, GPs had a record of 63.7 million registered patients, an increase of around 6.8 million since 2015.[10] As GPs handle growing numbers of cases, it is impractical for them to investigate every 'low-risk' symptom, which presents a barrier in diagnosing people with the less survivable cancers. For instance, patients with brain tumours often visit their GP multiple times before being referred for further diagnostic image screening.[11]

If we provide diagnostic tools and technologies to GPs and primary care that can triage patients with vague symptoms, this could change. They could help to address pressures on primary care and speed up diagnostic pathways. These can do this by enabling GPs and potentially other healthcare professionals working in primary care to make more informed decisions at first presentation – meaning people get rightly flagged as at risk of a less survivable cancer much quicker, as well as speeding up patient referrals that would enable them to be diagnosed much earlier.[12]

As GPs face continued capacity constraints,[13] witnesses also discussed the opportunities to embed innovative diagnostic tests and triage tools (as they become available) in different parts of community care.

Case Study: Galleri (GRAIL) Multi-Cancer Early Detection test

GRAIL has developed a Multi-Cancer Early Detection Test to screen for multiple cancer types. It is a simple blood test that assesses changes to DNA patterns in cell-free DNA in order to identify signals associated with cancer. If a cancer signal is detected, the test can help to predict where exactly in the body it may come from, supporting clinicians in their diagnostic investigations. It has wide application and could be used to improve earlier detection and faster diagnosis for several of the less survivable cancers including liver, stomach, oesophageal, lung and pancreatic. It is currently being trialled in England among 140,000 people aged 50-77 to assess its efficacy in reducing late-stage cancer diagnosis. Results are expected next year.[9]

For example, witnesses shared that the VAPOR Breath Test, currently being developed at Imperial College, could be made available at Community Diagnostic Centres or pharmacies. This could not only remove the initial requirement for a GP appointment, but once a person has an indication of possible cancer, they could present at their GP and be sent through to the right tests at first presentation. This would be a marked change from today's norm, in which people end up going backwards and forwards from their GP multiple times with non-specific symptoms.

> For years, I had lots of low-level symptoms that didn't seem that serious on their own and I kept going back to the GP because I knew something was wrong. I'd suffered from persistent tiredness and itchiness on my skin. I was tested for sleep apnoea, thyroid issues and iron deficiency but there were no answers.
>
> Then one weekend before Christmas (2019), […] I just felt really queasy and ill, I thought I'd eaten too much. Three days later my urine had changed colour, even though I knew I was really hydrated. I went to the doctor on Thursday, after not being able to eat anything since Sunday, and I was tested for a UTI [urinary tract infection]. On Saturday morning, I noticed my eyes were starting to go yellow so I called 111. They sent me to an out-of-office GP for more blood tests. The next morning, I was completely yellow and my stools had changed colour. So, I called 111 again and was taken to Southmead Hospital's acute medicine unit."
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> **Patient with pancreatic cancer**

Case Study: Dxcover PANORAMIC test

Dxcover has developed an innovative liquid biopsy test that uses AI to detect certain biomarkers in a patients' blood samples to test for brain tumours.[14] It has already had excellent results during its trial phases. During recent trials, the test was able to detect 96% of patients with brain tumours.[15] Witnesses noted that further research is now needed to explore how tools like the Dxcover blood test could be implemented into existing diagnostic pathways. Given the poor prognosis and rapid deterioration that patients with brain tumours face, faster diagnosis can improve treatment options, maximising chances of survival. In fact, new research from Dxcover has confirmed that there is a clear link between increased tumour size and mortality and that diagnosis even just one month earlier could reduce patients' mortality by 18-28%.[16]

GPs are on the front-line of symptoms detection as the first point of contact for many patients. Without the appropriate tests, GPs largely rely on what their patients tell them about their symptoms to decide whether to refer them on for further tests. However, with the average GP appointment lasting approximately nine minutes[17], GPs only have a short amount of time to conduct a holistic examination of a patient before deciding on next steps. This is further compounded by the fact that 40% of patients feel that they do not have enough time[18] to raise all concerns during this time which may limit GPs' ability to get the full picture.

Communication is key

Witnesses acknowledged the challenges patients face when communicating symptoms to GPs and emphasised the importance of ensuring GPs understand patients' fears, as this can significantly influence how symptoms are described in consultations.

Patients may feel embarrassed or reluctant to talk to their doctor about their symptoms, particularly when it comes to digestive issues[19], which are common for several less survivable cancers including stomach, pancreatic and liver. One witness noted that there can also be certain societal and personal stigmas surrounding the risks associated with liver cancer in particular (including alcohol harm, obesity and viral hepatitis)[20], which can impact how comfortable patients may feel about speaking to a healthcare professional. Many patients are also concerned about being seen as a 'burden' or as 'timewasters' because of the pressures facing the NHS.[21]

Furthermore, witnesses noted that the language used by GPs to question patients about their symptoms can vary greatly, creating barriers in communication and inhibiting timely referrals. A lack of consensus among clinicians on how to describe and discuss symptoms makes it harder for patients to have their concerns heard, as well as for GPs to correctly identify and test for the cancer in question. Many patients told us that they had been to the GP numerous times before being diagnosed due to such challenges around inconsistency of language. Diagnostic tools and technologies could provide GPs with a tool to help them more easily triage patients and ascertain when further tests are needed – helping to overcome the challenges of communication.

> I was 20 when I was diagnosed and that was the biggest barrier. It just wasn't expected by my GP… Though I didn't have many symptoms, those that I did have – headaches and sickness – were initially associated with the contraceptive pill I was taking. I was then told my headaches could be due to studying a very stressful degree. This went on for about 6 months."
>
> **Patient diagnosed with a brain tumour**

Improving public awareness

Public awareness of symptoms linked to the less survivable cancers remains staggeringly low. A study conducted by the Less Survivable Cancers Taskforce in 2021 revealed that only 11% of people were able to identify oesophageal cancer symptoms, only 10% could identify stomach cancer symptoms, 5% were able to identify liver cancer symptoms and only 4% were able to identify pancreatic cancer symptoms.[22] Given that symptoms across all six less survivable cancers are wide-ranging and vague, patients themselves may also feel that symptoms might be unrelated or not relevant.[23]

A recent survey by Cancer Research UK also found that a third of people in the UK waited around six months after spotting possible cancer symptoms, across all cancer types, before visiting their GP.[24] This is a particularly worrying trend for patients with a less survivable cancer given that symptoms only start to appear in the more advanced stages, when urgent treatment is essential. To improve early detection and ensure people visit their GP earlier, the Government must take steps to improve public awareness of symptoms associated with all six less survivable cancers.

> “I was annoyed with myself that I hadn’t been aware of the symptoms. Looking back my symptoms were all known so more needs to be done to make people aware of these terrible cancers.”
>
> **Patient living beyond oesophageal cancer**

Recommendations for government

- ✓ **Invest in greater research into detection tests and tools to support GPs when identifying symptoms of the less survivable cancers.**
- ✓ **Support the roll-out of innovative detection tests and develop a pilot to evaluate their use in diagnostic pathways.**
- ✓ **Support campaigns to raise awareness of the symptoms of less survivable cancers.**

Improving primary care capacity and access

To accelerate survival rates across the less survivable cancers, routes into primary care and diagnostic pathways must be expanded. As patients across the UK continue to face long waits to visit their GP, we need to improve and expand routes into the NHS so that people can be referred on for the right tests as quickly as possible. We have already seen efforts to address GPs acting as a barrier, including the expansion of pharmacies’ role since the COVID-19 pandemic and self-referral programmes.

However, even when people are able to see their GP, we know that they are often not getting referred on for the right tests. Many people who end up diagnosed at a late stage have seen their GP on several occasions, presenting with symptoms that have not been identified correctly. While this is partly due to the vague symptoms outlined earlier in this report, another significant factor is the current patchwork of diagnostic pathways available across the country.

NHS England has worked to develop programmes like the Non-Specific Symptoms (NSS) pathways, GP Direct Access and NHSE Best Practice Timed Pathways. If these programmes were all embedded in every area, we would capture many more people with less survivable cancers before an advanced stage. During the inquiry sessions, witnesses highlighted how the NSS pathways have provided a valuable route for GPs to quickly refer patients who have symptoms not easily attributable to a specific tumour. They have led to faster diagnoses, higher referral rates among harder-to-reach communities, and improved efficiency of pathways.

Whilst the NSS pathways have positively impacted cancers like pancreatic or stomach, witnesses did raise that more work needs to be done to ensure these diagnose brain tumours properly. This is because the common symptoms aren’t incorporated in the list of non-specific symptoms used for this pathway. According to research conducted by Ipsos Mori in 2024, 0.4% of patients with a brain tumour referred through the pathway were successfully diagnosed.[25]

To mitigate this challenge, it is vital that the list of NSS symptoms is widened to cover more symptoms of relevance to brain tumours, and that a full direct access pathway is implemented to support the diagnosis of brain tumours. The UK must also expand the number of alternative diagnostic pathways available and maximise opportunities for the use of Direct Access for all six less survivable cancers.

Case Study: GP Direct Access

Since 2022, GP Direct Access has provided a valuable route for GPs to refer patients for crucial diagnostic tests without the need for secondary care referral.[26] It provides GPs with access to vital tests including ultrasounds, CT scans, MRI scans and blood tests without the need to refer onto a hospital which often delays the process.[27]

Research conducted by The Brain Tumour Charity showed that there are several barriers that must be addressed to strengthen the impact of GP direct access. Their research focused specifically on GP Direct Access for brain tumours but highlights wider systemic challenges of relevance to all the six less survivable cancers: for example, 33% of GPs surveyed said that they were unaware of the guidance around how to directly request MRI imaging and 34% were unclear on next steps once a patient is referred. A lack of a clear pathway made GPs hesitant about referring a patient through direct access.

To encourage more GPs to use this route going forward, further efforts are needed by both Integrated Care Boards (ICBs) and DHSC to ensure that guidance on direct access is consistently implemented, to ensure GPs understand how to order the correct diagnostic tests and have a better understanding of how patients can benefit from this pathway.

Witnesses also emphasised the potential of data and new emerging AI technologies in supporting primary care to better detect cancer cases early. They highlighted the role of AI-enabled technologies in recognising patterns or combinations of symptoms as a powerful first step in tackling the issue of non-specific symptoms.

Case Study: The ERICA Trial

A team of clinical researchers at Exeter University, led by Professor Willie Hamilton, have developed new software called Skyline which can be linked up to patients' medical records to calculate their risks of developing six cancers (lung, oesophago-gastric, colorectal, kidney, bladder and ovarian cancers) based on key clinical indicators, including symptoms. The software detects when a patient has a 2+% risk of one or more of the cancers and will send an alert to the GP. [28]

Case Study: Optellum - AI powered lung cancer precision care

Optellum has developed AI-enabled technology to predict cases where patients may be at risk of developing lung cancer to fast-track earlier detection and enabling doctors to treatment patients before the disease has metastasised.[29] Optellum's technology has been used across more than 30 sites in the U.S. and in Germany and has led to a reduction in the number of missed cases of lung cancer, improved accuracy in assessing cancer risk and in the identification of benign nodules, avoiding the need for further imaging and diagnostic tests. It is being currently being piloted in the UK.[30]

To harness the full potential of the data available, we need data sharing practices to be improved. Witnesses warned that existing coding methods for classifying and collecting data on symptoms are often inconsistent, making it more challenging for primary care professionals to use records effectively for identifying symptom patterns. The Department of Health and Social Care must take action to centralise data coding and sharing in order to support earlier diagnosis.

Recommendations

- ✓ **Produce an overarching strategy for earlier and faster diagnosis of the less survivable cancers to ensure comprehensive commissioning and diagnostic capacity (including across NSS pathways, urgent suspected cancer pathways, and GP direct access).**
  - This must include provisions for professional training around integrated clinical decision support tools to help GPs recognise vague symptoms and make appropriate referrals.
  - The Department for Health and Social Care (DHSC) should pilot programmes to expand access points and referral routes, including self-referral mechanisms and direct referrals from pharmacies. DHSC must work closely with ICBs to ensure consistent implementation of services across regions.
  - The Department for Health and Social Care should develop a full direct access pathway for brain tumours, given the current limitations of NSS pathways and urgent cancer referral pathways in detecting these.

Detecting at-risk groups earlier

Screening and case finding

Witnesses spoke about the integral role of targeted screening programmes in accelerating earlier detection of the less survivable cancers, such as the NHS Lung Cancer Screening Programme. Witnesses noted that more needs to be done to accelerate efforts to roll-out existing programmes, as well as adopt new initiatives where there is evidenced risk, if we want to shift towards earlier diagnosis.[31]

Studies show that population-wide screening is currently inefficient and impractical for cancers with relatively low incidence and that this can cause additional delays for those who urgently require treatment for other diseases. However, when targeted at those who are at highest risk, it can be a powerful tool and increases the likelihood of a cancer being diagnosed at stage one or two.

Case finding, which involves proactively identifying and checking people at an evidenced high risk with the intention of identifying undiagnosed cancers, is another crucial tool in diagnosing less survivable cancers earlier and faster. Examples include the use of Community Liver Health Checks across high-risk communities, and the NHS's upcoming new-onset diabetes case-finding programme for pancreatic cancer. These types of programmes have the ability to find those with the disease who may not have otherwise known they could have a less survivable cancer. To ensure efficiency for the NHS, witnesses sighted that such programmes could be rolled out on a nationwide basis, to proactively identify those at high risk of multiple cancer types (that have similar risk factors).

Witnesses also discussed the importance of targeted screening among vulnerable and marginalised communities. One study revealed that patients experiencing social and economic disadvantages were more likely to be diagnosed with liver cancer in an emergency setting versus those who were economically stable.[32] There are a wide range of techniques that can be used to further target programmes to make them more accessible to these groups. For instance, mobile units are used for Community Liver Health Checks at a range of locations to ensure that those in underrepresented communities at highest risk can access services.

Case Study: The NHS Lung Cancer Screening Programme

Lung cancer is one of the deadliest forms of cancer, accounting for over 20% of cancer deaths every year in the UK.[33] The NHS Lung Cancer Screening Programme highlights the pivotal role that screening can play in detecting cancer earlier and improving survival outcomes. This programme is already delivering significant progress in transforming earlier detection and consequent survival rates for lung cancer. People aged between 55-75 with a history of smoking are eligible to attend a lung health check to answer questions about their health and lifestyle to assess whether they are at high risk of developing lung cancer. If they meet the risk threshold, they are then offered a CT scan and may be asked to return for further scans at three months and 12 months.[34]

The programme was first rolled out across the country's most deprived areas after studies showed that people living in these areas were four times more likely to smoke than those living in the least deprived areas. By August 2024, over 75% of the cancers detected by the programme were diagnosed at stage one or two compared to fewer than 30% of lung cancers diagnosed at the same stages prior to the programme's launch.[35] However, implementation has been slow and more needs to be done to boost its uptake among those eligible for tests.

Case Study: Community Liver Health Checks

Only 30% of liver cancer cases are currently diagnosed at stages one and two. The number of cancer deaths in the UK caused by liver cancer is rising significantly but community-based screening programmes such as fibroscans can play a valuable role in helping GPs to test for liver disease and liver problems in high-risk groups.[36] This programme is currently being piloted in 19 areas across England. Since 2022, over 93,500 fibroscans have been delivered, leading to 6,421 people being enrolled in liver cancer surveillance. The vans visit GP practices, recovery services, food banks, diabetes clinics, sexual health clinics and homeless shelters and offer free checks to those at highest risk.[37] When detected earlier, nearly 50% of patients with liver cancer survive five years or more compared to only 5% of those diagnosed at stage four. This highlights the importance of such programmes in driving earlier detection among high-risk groups, ultimately improving patient outcomes and driving up survival rates. Given the impact of these checks, the APPG calls on the Government to continue to support the rollout and expansion of this programme to maximise the number of people identified at a higher risk of developing liver cancer.

While targeted screening can be very impactful, witnesses also highlighted that developing many screening programmes for individual tumour types could result in a high cumulative rate of false positives - leading to undue stress for families and their loved ones, as well as unnecessary diagnostic procedures. They emphasised the value of finding ways to screen for multiple cancers simultaneously where there is evidence of risks for more than just one cancer type, in the future.

Surveillance

Surveillance is equally crucial in accelerating faster diagnosis for the less survivable cancers. This involves regularly monitoring people who are known to be at high risk of developing these cancers, often due to genetic factors or pre-existing conditions. Rolling out these programmes is a vital part of identifying many more cases at an earlier, more treatable stage.[38]

Whilst there are already several surveillance programmes across the UK, further work must be done to strengthen their rollout and ensure that eligible individuals are accessing these vital services. These include the EUROPAC study and Pancreatic Cancer UK's Family History Checker, and Best4 trial. The Government must continue to support the further rollout and expansion of such programmes for the less survivable cancers to maximise opportunities to detect these cancers at the earliest possible moment, even where an individual is asymptomatic.

Case Study: NHS England and Pancreatic Cancer UK Family History Checker

The Family History Checker was launched in September 2024 and aims to identify those with a hereditary risk of pancreatic cancer. 1 in 10 pancreatic cancers are currently inherited. This means that people who have had more than one family member diagnosed with pancreatic cancer or who have hereditary pancreatitis or a rare genetic condition such as Lynch Syndrome may be at higher risk. In three quick and easy questions, people can find out whether they are at high risk and may be given the option to participate in a research study known as EUROPAC. After sharing some additional background history with the EUROPAC team, individuals may then be invited to receive annual monitoring, including regular blood tests and scans.

Case Study: Capsule Sponge testing

A fifth of oesophageal cancer cases are diagnosed in an emergency setting, often at a later stage in the tumour's development when it is too late to treat. The 10 minute capsule sponge test, which can be conducted by a nurse, has the potential to revolutionise earlier detection of this deadly cancer. The sponge is contained within a pill on a string which is swallowed by the patient.[39] When the capsule dissolves, the sponge is released and drawn back through the oesophagus with the string. As it is pulled through, cells are collected for testing.[40]

Cells are then tested to check for protein TFF3, a key sign of Barrett's oesophagus, which often indicates that someone is at a significantly higher risk of developing oesophageal cancer.[41] Further testing can be done to detect biomarkers and evidence of adenocarcinoma, squamous cell carcinoma and other conditions.

The test is currently being trialled among 40,000 patients who have heartburn, indigestion or acid reflux. The aim is for the test to be rolled out more widely to detect signs of early oesophageal cancer as part of a National Screening Programme. If the Best4 trial is successful, it could be a powerful tool for driving up early diagnoses of oesophageal cancer.

Case Study: Opt-out emergency care testing for hepatitis B - a key risk factor of liver cancer

Liver cancer is often asymptomatic during the early stages with only 30% of cases being diagnosed at stage one and two. Identifying and monitoring those who are higher risk is therefore critical to detecting liver cancer earlier at a stage where there are more treatment options. Patients with chronic Hepatitis B (Hep B) are at higher risk of developing primary liver cancer (hepatocellular carcinoma).[42] Due to this, NICE guidelines state that patients with Hep B should be offered testing for primary liver cancer twice a year. Since April 2022, opt-out testing in emergency departments for Hep B, Hep C and HIV has led to the diagnosis of over 5,000 patients. Testing in emergency departments plays a crucial role in not only targeting hepatitis but also surveilling those at high risk of liver cancer. Funding for this service will be cut across a number of hospitals by the end of 2025, impacting over 3,000 people with Hep B and C and the number of people surveilled for liver cancer. The APPG recommends that the Government continues to roll-out testing for HIV, Hep B and Hep C as a crucial programme for surveilling those at highest-risk of developing liver cancer.

Recommendations for government

- ✓ **Develop a centralised, nationwide case-finding programme to proactively identify high-risk individuals across multiple cancer types, building on the work already undertaken by the NHS in new-onset diabetes and weight loss.**
- ✓ **Develop a centralised, nationwide programme to oversee and drive surveillance for individuals with inherited cancer risk.** This should include and build on existing programmes, such as those for BRCA in Jewish populations, Lynch Syndrome, and familial breast cancer. It should incorporate surveillance for people with a family history of pancreatic cancer and hereditary pancreatitis, utilising the risk assessment protocol from the EUROPAC study.
- ✓ **The Department for Health and Social Care should continue to support the rollout and expansion of testing for conditions that are precursors to the less survivable cancers** (including NHSE's risk-stratified Community Liver Health Check programme and testing for HIV, Hep C and Hep B).

Testing in emergency departments plays a crucial role in not only targeting hepatitis but also surveilling those at high risk of liver cancer.

PART 02

Driving research and innovation for less survivable cancers

The need for greater research into the less survivable cancers

A strategic focus on the less survivable cancers

Over the last 25 years, research into the less survivable cancers has faced a cycle of underfunding and a lack of national focus. As a result, there have been limited research breakthroughs to enable earlier and faster diagnosis for less survivable cancers, partly because this has continued to be seen as an unattractive area for investment. The poor survival of these diseases also presents specific challenges in undertaking research, including the recruitment and delivery of clinical trials as well as access to genomic testing at diagnosis.

To help transform the research landscape and drive strategic innovation in faster diagnosis, we believe the Government should appoint a named lead to support research and innovation for these cancers. This lead must work with the Government's new Health Data Research Service, which we understand will act as a central hub to streamline access to health data across the UK, to ensure consistent, comprehensive data collection on rare and less survivable cancers to support further research. Having this data would ensure that researchers have access to a standardised clinical dataset, from diagnosis and throughout treatment, to support the development of clinical trials and to address research questions.

Clinical trials and the less survivable cancers

Staggeringly low survival rates of these cancers are a major challenge for the design and rollout of clinical trials. Many patients are sadly diagnosed too late or become too unwell to be eligible to participate. In a recent survey conducted by Pancreatic Cancer UK, 81% of patients were not given the chance to participate in a clinical trial.[43] Witnesses emphasised that more needs to be done to tackle this going forward. Enhancing patient access to clinical trials for those with a less survivable cancer not only accelerates potential breakthroughs but also offers the possibility of new, cutting-edge treatments for these patients who may have exhausted all standard forms of treatment. Other challenges impacting the rollout of clinical trials into the less survivable cancers include inconsistency in clinical practice across the UK and a lack of data completeness, making it hard to define a standard of care control.

Potential of genomic profiling

Witnesses also emphasised the value of genomic profiling in transforming outcomes for patients with a less survivable cancer. Advancements in genomic profiling could lead to more precision treatments for these cancers and innovation in new technologies to speed up genomic profiling will lead to faster diagnosis and decisions about treatment.

However, currently genomic research into the less survivable cancers can be challenging, as it can be difficult to get enough patients with individual subtypes to adequately power studies, as many patients die very quickly or are too unwell. As a result, there are limited precision treatments available on the NHS for these cancers. For instance, for those with pancreatic cancer, the only test currently available on the NHS is used to test for BRCA1/BRCA2 genes, the presence of which may make someone eligible for a PARP inhibitor, a targeted cancer drug.

Witnesses also highlighted how genomic profiling should become the standard of care for patients with less survivable cancers – including brain tumours. However, they warned that more needs to be done to overcome some of the major challenges impacting the rollout and access to these services. Witnesses warned that patients also face significant delays when awaiting results for genomic testing, which could delay diagnosis and decisions on treatment. However, the development of new innovative techniques can offer a quicker, more efficient solution to this challenge – such as long-read sequencing developed by Oxford Nanopore Technologies.

Case Study: Use of genomic sequencing for glioblastomas

Whole Genome Sequencing (WGS) enables clinicians to analyse the genetic makeup of patients. It has already played an integral role in enhancing treatment for several cancers including breast, lung and melanoma, and is a valuable tool for treating patients with aggressive and less survivable cancers like glioblastoma (GBM). By identifying specific mutations and pathways driving tumour growth, WGS enables the development of more personalised treatment, can help to match patients up with the most relevant trials, and supports the development of innovative new drugs.

Despite its potential as a transformative diagnostic tool for glioblastoma and other less survivable cancers, WGS still remains a significantly underused form of testing in the UK. In 2024, only 10-15% of patients received WGS.

There are still several systemic challenges to the effective rollout of WGS. A report by the Tessa Jowell Brain Mission on Equity in Genomics revealed that many centres offering Whole Genome Sequencing lack the necessary equipment to carry out testing.[44] One of the major barriers is the lack of frozen tissue storage at NHS hospitals nationwide, an essential requirement for genomic analysis. An alarming 7 out of the 21 Tessa Jowell Centres of Excellence hospitals were only able to freeze fewer than 10 samples per year and 2 centres froze none.

A national prospective observational cohort study for rare and less survivable cancers

A solution that was highlighted as having the potential to start overcoming barriers to improving research and innovation is the development of a national prospective observational cohort study for rare and less survivable cancers. This study would enable all newly diagnosed patients across England with rare and less survivable cancers to be recruited and would provide the national infrastructure needed to collect clinical data, patient-reported data and biological samples.

As part of this, a process could be established to facilitate genomic profiling at diagnosis and ensure patients can be identified to participate in clinical trials, including through the NIHR Be Part of Research.[45] This would enhance opportunities for patients to access targeted treatments and therapies through clinical trials and strengthen datasets for further research into the different subtypes of these cancers. The study could be linked with the new Health Data Research Service to make it easier for researchers across the country to access national-scale health datasets. This would also help to ensure that the UK remains a highly attractive country for pharmaceutical and industry investment.

Recommendations for government

- ✓ **Appoint a named lead in government to support research and innovation for these cancers. This lead must coordinate with the new Health Data Research Service to ensure consistent, comprehensive data collection on rare and less survivable cancers.**
- ✓ **Develop an observational cohort study for rare and less survivable cancers to ensure that there is a standardised clinical dataset, from diagnosis and throughout treatment, being routinely collected and to a high standard. This should include a process to facilitate genomic profiling and identify patients to participate in clinical trials.**
- ✓ **Tackle capacity challenges impacting the rollout of Whole Genome Sequencing across NHS hospitals, including by investing in frozen tissue storage.**

Streamlining regulation and implementation of innovation

Removing regulatory framework barriers

Exciting progress is already being made in research into the less survivable cancers but there are several barriers in regulatory processes that are preventing and slowing down the roll-out of new innovations. In the inquiry sessions, witnesses highlighted the fact that the approval process for medical devices in the UK remains problematically slow and bureaucratic. They warned that researchers often face unclear timelines for approval processes, creating unexpected additional costs and undue complications in terms of getting these embedded into the NHS.

Witnesses set out that one way to address this is to do to more to empower researchers to embed regulatory thinking earlier into product development rather than waiting until trials are complete for this to begin. Witnesses called for research applications to receive a response from regulators within three months, and that in the longer-term, the Government should explore giving universities accreditation to simplify and speed up regulatory processes.

We are aware that to address regulatory barriers, which exist across health research, the MHRA launched the Innovative Devices Access Pathway Pilot. This is aimed at simplifying the process for integrating new medical technologies into the NHS.[46] The scheme, launched by the previous government in 2023, provided tailored regulatory and access support to eight technologies. Whilst the scheme has now closed, its learnings will have wider relevance for the future regulation of medical devices.[47]

It is encouraging that the new Government has also indicated its intention to simplify processes. Namely, the Government has committed to cutting the time taken to set up clinical trials by 100 days by March 2026, through reducing unnecessary bureaucracy and standardising NHS contracts. In April 2025, the Government also passed secondary legislation, the Medicines for Human Use (Clinical Trials) (Amendment) Regulations 2024, to achieve this goal.[48] Marking a significant overhaul of the existing regulatory framework for clinical trials, these reforms will come into force in April 2026 and will help to streamline approval processes and deliver a more proportionate approach to regulation. The MHRA and the HRA are currently drafting guidance on how the new requirements will impact those applying for clinical trials.

Case Study: Data algorithms

Data algorithms are a prescient example of where regulatory barriers and delays are hindering how quickly medical technologies can be implemented. Algorithms have the potential to analyse patient data to identify people most at risk and can support earlier diagnosis and detection.[49] Currently, they are classified as medical devices and follow the same regulatory approval process. Whilst witnesses recognised the need for stringent regulation to ensure their safe application, they noted that the current medical devices regulatory framework is not the appropriate route for these technologies.

Current regulation means algorithms face a delayed, very costly route to clinical adoption, and that without philanthropic funding, researchers struggle to cover the related costs. This in turn hampers the adoption of potentially life-saving technologies that could speed up diagnosis for the less survivable cancers. For example, the COLOFIT algorithm,[50] which could eliminate the need for approximately 17,000 colonoscopies annually at no clinical cost, risks being shelved due to a lack of funding and time.

Recommendations for government

- ✓ **A named government lead should establish a strategic mission for rare and less survivable cancers.**

This should include reviewing research funding, infrastructure needs and regulatory barriers that delay adoption of innovative medicines and technologies. The lead should work with MHRA, NICE, NIHR and UKRI to prioritise rare and less survivable cancers within regulatory frameworks. They should also work with NIHR to develop strategic funding opportunities, such as highlight notices or challenge calls.

Building closer engagement between research and clinical communities

Overcoming siloes in research

There are already many examples of positive collaboration between researchers and the medical community in the UK. However, there is variation in this across the country, due to a lack of collaboration between academic and medical communities. This can create major challenges for innovation and seeing products embedded into the health system, as new products may fail to fit into existing NHS structures or be too costly to integrate.

Engaging with clinical stakeholders from the early phases of research and product development is crucial in ensuring that innovations have real-world applicability and are good value for money to maximise the likelihood of clinical adoption. The Darzi report published in 2024 warned that there has been a decline in the number of clinical academics in the NHS[51], a worrying trend given their value in delivering research that is practical and patient-focused.[52]

Ensuring healthcare professionals have trust in new innovations that come through is key to their integration into clinical pathways.[53] Witnesses noted that, whilst a number of exciting innovative developments exist, healthcare professionals can be hesitant about them, which results in avoidable delays in patient access. However, studies have shown that involving clinicians in research boosts the likelihood of adoption for new treatments and tools.[54] As part of this, it is vital that clinicians are equipped to work with rapidly evolving technologies and are given the necessary training to implement these effectively.

Hesitancy around Whole Genome Sequencing illustrates the need for early engagement with clinicians. A report published by the Tessa Jowell Brain Cancer Mission last year warned that some clinicians do not recognise its value in shaping clinical outcomes, and fear that the admin and time pressures cannot be justified[55]. The report also noted that clinicians may delay the use of genomic analysis due to the lack of approved targeted treatments for glioblastoma.[56]

Case Study: Cancer Research UK (CRUK) Brain Tumour Centre of Excellence

Centres of Excellence for research into brain cancer have played an instrumental role in connecting specialists, bolstering knowledge-sharing efforts and improving collaboration. The CRUK Brain Tumour Centre of Excellence was established as a joint initiative between the University of Edinburgh (UoE) and University College London (UCL) to bring together academics and specialist clinicians. It aims to build a more connected neuro-oncology community to strengthen how brain cancer is understood, and to use both research and clinical insights to deliver evidence-led clinical advances and carry out cutting-edge clinical trials.[57]

Recommendations for government

- ✓ **The Government, together with research and medical communities, should establish Centres of Excellence for each of the less survivable cancers as key forums for knowledge sharing and collaboration.** Each discipline within the field would be represented to ensure there was some structure to research and treatment. Whilst Centres of Excellence would be their own entities, they could be built up from existing structures and tumour-specific associations (e.g. the Association of Upper Gastrointestinal Surgeons). Whilst Centres of Excellence should be established by the national research community, they should be supported by the Department for Health and Social Care and the Department for Science, Innovation and Technology.
- ✓ Clinical trials should be incorporated as a performance metric within the NHS to incentivise clinicians to prioritise research.

Conclusion

The evidence received during the APPG's inquiry has demonstrated the overwhelming need for greater action to improve earlier detection and faster diagnosis of the less survivable cancers to accelerate survival rates and improve patient outcomes.

For too long, the less survivable cancers have been left behind. The National Cancer Plan and Rare Cancers Bill offer a pivotal moment to strengthen these efforts going forward, tackle the systemic barriers affecting earlier and faster diagnosis and drive further progress for the less survivable cancers. We urge the Government to consider the recommendations made in this report and ensure that the less survivable cancers are prioritised in the National Cancer Plan. Decisive action is critical to achieve lasting impact for patients, their families and loved ones.

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