

### 10 Year Health Plan Pancreatic Cancer UK organisational response 2 December 2024

The government has promised to put in place a 10-Year Health Plan to fix the NHS in England. We want to hear what your priorities are for this plan as interested organisations. Tell us what your organisation wants to see in the 10 Year Health Plan, and why this is important.

# Question 1: What does your organisation want to see included in the 10-Year Health Plan and why?

We welcomed the report of the Lord Darzi investigation into NHS performance this year, as it highlighted the key challenges presenting our health system and the barriers to providing the right care to people diagnosed with cancer.

Our charity believes that many of the issues drawn out, including blockages in access to primary care, long waiting times for diagnostic assessments and treatment, as well as significant variation, are felt most severely in complex health conditions like pancreatic cancer. As it stands today, this cancer type has the lowest treatment and survival rates of all common cancers in the UK, with half of people diagnosed with pancreatic cancer dying within three months.

Over five years, only 7% of people survive. Most diagnoses of pancreatic cancer are currently made at a late stage (80% are diagnosed at stages 3 and 4), there is rapid progression of the disease and people are not getting access to the specialised treatment and support they need.

The government's new 10 Year Plan presents a significant opportunity to finally bring change for this long overlooked and underfunded cancer, and we believe there is much that can be done to achieve this. Currently, we are lagging significantly behind other countries when it comes to survival and are ranked 29<sup>th</sup> out of 33 OECD countries for pancreatic cancer survival; demonstrating that the situation we face is not inevitable.

We agree with much of what the government has proposed to date in terms of changes to how the health system should work going forwards, including moving healthcare back into the community and improving capacity. We urge the government to look at these systemic changes specifically through the lens of pancreatic cancer, where the impact of system failures is particularly acute. This is due to the complex biology of this cancer, the vagueness of its symptoms, which make it difficult to diagnose, as well as its fast progression rate.

Below, we highlight how the system is currently failing people with pancreatic cancer and outline the comprehensive set of actions the government must take to finally turn the tide on this cancer. We set out both immediate actions needed in the first five years, as well as actions to transform pancreatic cancer treatment and care over the next 5 – 10 years. By implementing our recommendations, the UK could match the survival rates of leading OECD countries by the end of this plan.

We have split these actions out by the three strategic priority areas we believe will transform pancreatic cancer outcomes and experience over the next decade:

- 1. Securing earlier diagnosis and detection
- 2. Delivering optimal pancreatic cancer treatment and care
- 3. Driving more research breakthroughs

#### 1. Securing earlier diagnosis and detection

The poor and varied access to primary care highlighted by Lord Darzi is felt particularly acutely by people with pancreatic cancer. This is because the challenges that present across the board in primary care, like long waiting times and lack of access to GP appointments, are compounded by specific issues that this disease presents. The symptoms of pancreatic cancer are vague, and there are no national screening programmes, biomarkers or easy-to-use tests available today.

This makes it very challenging to identify the signs of pancreatic cancer at an early stage. Currently, 80% receive a late-stage diagnosis (at stages three or four), and people with pancreatic are more likely to require 3 or more GP visits before referral than other cancers. For comparison, people with breast cancer or testicular cancer are more likely to be referred after only one or two consultations.

Unfortunately, these challenges result in over 50% of people with pancreatic cancer getting diagnosed in an emergency setting. In contrast, just 4% of people with breast cancer are diagnosed through an emergency route, which is associated with worse survival, outcomes and increased healthcare costs.

In the first 5 years of the NHS plan, the government must take the following actions to transform earlier diagnosis and detection of pancreatic cancer:

# Investment and roll-out of surveillance for those at the highest risk of developing pancreatic cancer:

There are currently no national screening programmes available for pancreatic cancer. However, there are pilot initiatives underway to detect people at higher risk, which the government must invest in and implement nationally over the next five years. These include:

- Investment in and roll-out of a surveillance programme for people with family history of pancreatic cancer and hereditary pancreatitis. This should build on NHS England investment into the European Registry of Familial Pancreatic Cancer and Hereditary Pancreatitis (EUROPAC) and the Pancreatic Cancer UK Family History Checker, which is a new self-referral tool. NHS England modelling has shown that this will help increase the early-stage pancreatic cancer diagnosis by 6.1% from 24%, with 1050 cancers prevented or caught early.
- Investment in and roll-out of new-onset diabetes case finding: Around half of people diagnosed with pancreatic cancer have new onset diabetes, making this a high-risk group for pancreatic cancer. NHS England have launched a new case-finding pilot focused on people with new onset diabetes and weight loss. Based on the findings of this pilot the government should expand this case finding programme for pancreatic cancer nationally. NHS England modelling has shown that this will help increase the early-stage pancreatic cancer diagnosis by 6.1% from 24%.

# Enabling faster access and referral through primary care for further investigations:

Currently, people with pancreatic cancer present to their GP multiple times before being referred on for the right investigations and experience long delays within primary care. This is due to both poor and varied access into diagnostic investigations from primary care, as well as restrictive referral criteria for further investigations for suspected pancreatic cancer. This results in many presenting via emergency routes, which associated with worse survival, outcomes and increased healthcare costs.

To ensure more people can get referred earlier and more quickly, we believe that:

- NICE must review the guidelines for suspected cancer recognition and referral (NG12) to ensure that more people presenting with symptoms can be recognised and referred earlier, based on new evidence commissioned by Pancreatic Cancer UK.
- DHSC should undertake a comprehensive review of the wider cancer diagnostic workforce and available routes into diagnostic investigations for pancreatic cancer, including direct access and community diagnostic hubs.

# In the next 5 – 10 years, the government must take the following actions to transform earlier diagnosis and detection of pancreatic cancer:

#### Adopt and roll out new pancreatic cancer detection tests:

The development and implementation of reliable biomarkers and diagnostic tests presents a crucial opportunity to transform early detection of pancreatic cancer. Investing in these tools would help clinicians identify the disease earlier despite its vague symptoms, potentially also reducing diagnostic costs. There is already work underway in this area, and we want the government to:

• Invest in the roll-out and implementation of new blood, urine or breath biomarker tests within suspected cancer pathways, based on the outcome of latest clinical trials and evidence, such as the Imperial VAPOR breath test for suspected Upper Gastro-intestinal (UGI) cancer.

#### Implement new surveillance strategies for people at high risk:

In addition to new onset diabetes and family history, we need to identify and refine new surveillance strategies for people at high risk of pancreatic cancer, as there is much that remains unknown. Furthermore, we need to see the development of new risk stratification models for modifiable and non-modifiable risk factors for pancreatic cancer so we can better target interventions. To achieve this, the government must:

- Invest in the development of new risk models and surveillance strategies for people with known modifiable and non-modifiable risk factors for pancreatic cancer.
- Undertake a review of the NICE NG85 guidance on the routine monitoring of pre-cancerous lesions in the pancreas and risk stratification for surgery. There is research ongoing to better identify and

- stratify the highest risk pre-cancerous lesions for surgical intervention and this represents the next best opportunity to expand surveillance.
- Following this the **government should invest and roll-out a surveillance programme for people with pre-cancerous** lesions based on the emerging evidence and NICE NG85 guidance.

# Implement routine use of clinical decision support tools to help GPs make suspected cancer referrals:

Currently, people diagnosed with pancreatic cancer frequently re-attend primary care with the same symptoms and are not referred quickly. And, as it stands, NHS patient and primary care medical records are underutilised as a source to support clinical decision making. These primary care patient datasets present an opportunity to support GPs to automatically flag pancreatic cancer. There are excellent examples of these clinical decision support tools (such as QCancer or C the Signs) available and the government should:

• **Provide funding to embed clinical decision support tools** to help GPs make referrals to suspected cancer and explore their potential for proactive case finding.

#### 2. Achieving optimal treatment and care

As highlighted in the Darzi review, people across the country are waiting too long for their NHS treatment and receiving inconsistent care. We believe this has a particular impact on people with pancreatic cancer.

Today, 70% of people with pancreatic cancer receive no treatment – the worst statistic for all cancers in the UK. Part of the reason for this is that people are experiencing long waits for treatment, with only 35% getting this within the 62 day-NHS operational treatment standard. This is driven by significant variation in the pathways in existence across the country, as well as gaps in the workforce.

Because pancreatic cancer progresses so rapidly, even if the current standards were met far too many would still miss out on the chance of treatment. In addition, the treatment options for this cancer type are very limited and toxic, and people have to be well enough to tolerate them. As a result, we need the government to adopt and invest in a pathway that is faster, more standardised and can support people through to possible treatment.

# In the first 5 years, the government must take the following actions to improve treatment and care for people with pancreatic cancer:

#### Implementation of a fast, standardised pancreatic cancer pathway:

To improve people's ability to access treatment and thereby give them a better chance at survival, the government needs to adopt a fast standardised pancreatic cancer pathway and fund the specialist workforce to deliver this. To achieve this, the government must:

- Adopt an optimal treatment pathway for pancreatic cancer and invest the funding required for local systems to deliver this. This should be based on the clinical consensus and recommendations developed through the <u>Pancreatic Cancer UK Optimal Care Pathway initiative</u> and the National Pancreatic Cancer Audit (NPaCA).
- Provide investment to enable Cancer Alliances to implement the NHSE Best Practice Timed Pathways (BPTP) for HPB cancers. This guidance is a positive step forward and sets out best practice to diagnose people with pancreatic cancer within 21 days. However, local healthcare systems currently lack the funding to implement these changes effectively. With proper investment, these pathways could help get people diagnosed much faster and give them a better chance at treatment.
- Audit the specialist treatment and care workforce for pancreatic cancer. This is important in addressing the capacity challenges we know exist in the workforce, which in turn are contributing towards avoidable delays that have significant consequences for a rapidly progressing cancer like pancreatic cancer.
- Develop and implement a dedicated faster treatment waiting time standard for cancers with fast progression, such as pancreatic cancer, so that people can receive earlier supportive care so more people can tolerate treatment and are fit enough for clinical trials.

#### Improving collection and publication of pancreatic cancer data:

There are significant gaps in data collected and reported on pancreatic cancer. Current datasets fail to capture critical metrics around diagnosis routes, treatment access, and patient outcomes, masking significant regional variations in care quality. To drive meaningful improvements in outcomes and reduce unwarranted inequalities, the government must work with NHSE to prioritise comprehensive data collecting and reporting going forwards. To make this happen, we need to see:

- A comprehensive review of the pancreatic cancer data published within routine NHS statistical publications and datasets, and an action plan to improve this.
- Continued funding for the National Pancreatic Cancer Audit programme in England and Wales: this will ensure the government and NHS England can identify and drive key improvements in pancreatic cancer care and measure progress annually.
- Better collection of data to better understand the experience and outcomes of people from diverse groups for individual cancer types.
   This is important in helping inform targeted strategies to resolve any specific challenges.

#### 3. More research breakthroughs:

The stark lack of treatment breakthroughs in pancreatic cancer is the result of the chronic under-investment in research we have seen over the last few decades. As it stands, pancreatic cancer receives just 3% of the UK cancer research budget. With this cancer set to become the UK's fourth biggest cancer killer in the next few years, there is an urgent need to act now.

We know from cancers like breast, prostate and leukaemia that the right level of ambition and funding into research can change everything. In the last two decades alone, leukaemia has received over £522 million in funding – four times the amount invested in pancreatic cancer research over the same period. This sustained research funding has led to a quadrupling of the five-year survival rate for leukaemia over the past 50 years. With similar annual case rates to pancreatic cancer, leukaemia serves as a clear example of what can be achieved with proper investment.

# In the first 5 years, the government must take the following actions to bring forward treatment breakthroughs for pancreatic cancer:

• Increase investment to at least £35 million every year for the next 20 years to deliver the vital improvements needed to transform survival. Ensuring this is sustained is essential because meaningful research breakthroughs require continuous, reliable investment over

many years to support the full cycle of research; from lab studies through to clinical trials and implementing new treatments in the health system.

- Centralise patient data, images, bio-samples, tissue and health episode statistics into one platform to both improve clinical decision-making and improve researchers' ability to access these. This would enable researchers to analyse larger data sets more efficiently, identifying potential patterns and breakthroughs that could currently be missed.
- Working with the research and development industry, as well as pharmaceutical companies, undertake a review of the barriers to developing new treatments, clinical trials and genomic testing for pancreatic cancer.

#### The three 'shifts'

The next questions relate to 3 'shifts' – big changes to the way health and care services work – that doctors, nurses, patient charities, academics and politicians from all parties broadly agree are necessary to improve health and care services in England.

#### Shift 1: moving more care from hospitals to communities

This means delivering more tests, scans, treatments and therapies nearer to where people live. This could help people lead healthier and more independent lives, reducing the likelihood of serious illness and long hospital stays. This would allow hospitals to focus on the most serious illnesses and emergencies.

More health services would be provided at places like GP clinics, pharmacies, local health centres, and in people's homes.

This may involve adapting or extending clinics, surgeries and other facilities in our neighbourhoods, so that they can provide things that are mostly delivered in hospitals at the moment.

#### Examples might include:

- urgent treatment for minor emergencies
- · diagnostic scans and tests
- · ongoing treatments and therapies.

### Question two: What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

While pancreatic cancer is a complex condition that does require a combination of hospital specialist-based decision-making and provision of care, moving more care to the community and improving primary care could make a substantial difference for people with pancreatic cancer.

In addition to the more systemic challenges in moving care to communities, like gaps in the NHS workforce, infrastructure challenges and funding flows, we see three key challenges in moving pancreatic cancer care from hospitals to communities:

#### 1. Pancreatic cancer is being missed in primary care

There is currently a lack of access to primary care as well as lack of streamlined and rapid onward referral routes. As a result, 80% of people with pancreatic cancer are diagnosed at a late stage, and over 50% are diagnosed in A&E, putting strain on emergency hospital settings. This results in worse clinical outcomes, poor patient experience and higher costs to the health system.

#### 2. Insufficient supportive care provision

There is insufficient capacity within the specialist cancer workforce to ensure people with pancreatic cancer have timely access to the necessary specialist support, treatment and care where and when they need it. As a result, people with pancreatic cancer deteriorate rapidly and often forced to access emergency healthcare services and are hospitalised to manage debilitating symptoms and complications.

#### 3. Expertise gaps in non-specialist settings

Outside of the specialist care setting within primary, secondary and community care services, there is a lack of clinical expertise and knowledge to effectively manage and support people with pancreatic cancer, which often results in poorer provision of care outside of specialist settings.

To overcome these three challenges, we need to see the **following enabling** actions:

### 1. To start to shift pancreatic cancer presentation away from emergency hospital settings we must see the following actions:

 Investment and implementation for Cancer Alliances to implement the NHSE Best Practice Timed Pathways (BPTP) for HPB cancers to streamline diagnostic pathways and investigations so that people are

- referred and diagnosed quickly and do not present within emergency care.
- Investment and implementation of **new proactive surveillance interventions** to detect pancreatic cancer earlier within primary care and community care settings, including new onset diabetes case finding and family history of pancreatic cancer surveillance programmes.
- NICE to revise the suspected cancer recognition and referral guidelines (NG12) to ensure that more people presenting with symptoms can be recognised and referred earlier, based on new evidence commissioned by Pancreatic Cancer UK.

### 2. To reduce unnecessary hospitalisations to manage debilitating symptoms and complications we must see the following actions:

- DHSC and Cancer Alliances should audit the specialist treatment and care workforce for pancreatic cancer, to identify where gaps in workforce exist. Based on the outcomes of the review, the government must commit the funding for the specialist roles needed. This would ensure patients have earlier and more localised access to supportive, dietetic and psychosocial support, which would prevent patients reaching crisis point multiple times across their patient journey and being forced to access emergency healthcare services.
- Implement and provide the funding for the pancreatic cancer workforce recommendations set out within the Getting It Right First Time (GIRFT) pancreatic cancer programme.
- Development of national standardised optimal treatment pathway for pancreatic cancer and funding provided for local systems to deliver this, based on the clinical consensus and recommendations developed through the Pancreatic Cancer UK Optimal Care Pathway initiative, National Pancreatic Cancer Audit (NPaCA) and GIRFT programme. This will ensure that everyone have access to the best treatment, care and support and reduce unnecessary hospitalisations to manage symptoms and complications.
- Development and support for **new digital tools which give people agency** to manage their own conditions and self-report symptoms, embedded within routine outpatient management. This will help healthcare professionals to provide earlier supportive care interventions and prevent unnecessary hospitalisations.
- The 10 Year Plan should consider how healthcare charities can support the NHS to ensure patients can access high-quality and effective care, through a standard signposting pathway. Pancreatic Cancer UK is a member of the Healthcare Charity Collective, a group of charities exploring the design of a new standardised pathway from the NHS directly into condition-specific charities that can offer specialist information and support, with the aim of improving health outcomes and quality of life. The Charity Collective has modelled how charity support services can reduce healthcare costs and

demand on NHS resources, and improved individual health-related quality of life.

### 3. To increase expertise and knowledge outside of specialist care settings we must see the following actions:

- Investment and additional capacity to enable specialist pancreatic cancer healthcare teams to engage, support and upskill their non-specialist colleagues. This would ensure that more health professionals outside specialist care settings could have the support and expertise they need to properly treat and care for people with pancreatic cancer.
- The 10 Year Plan should consider **how healthcare charities can support the NHS to ensure patients can access high-quality and effective care**,
  through a standard signposting pathway. This would provide people with
  tailored and expert information and support to better manage their
  condition, symptoms, and complications. This may be particularly
  important when people are treated outside of the specialist care settings,
  where there is less clinical expertise and knowledge about pancreatic
  cancer.

#### Shift 2: Making better use of technology in health and care

Improving how we use technology across health and care could have a big impact on our health and care services in the future.

Examples might include better computer systems so patients only have to tell their story once; video appointments; AI scanners that can identify disease more quickly and accurately; and more advanced robotics enabling ever more effective surgery.

### Question three: What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

There are four key challenges to making better use of technology in health and care:

- 1. **Poor data:** The low quality of pancreatic cancer datasets, as well as access to that data and incompatible datasets across the NHS all present barriers to monitoring and driving improvements in pancreatic cancer care.
- 2. **Underutilised data:** NHS patient data, including self-reported data, is currently underutilised as a source of potential research and technological innovation, for example in early detection and monitoring of pancreatic cancer.

- 3. **Outdated systems:** Outdated digital systems and slow processes impede decision-making and coordination within the NHS. As a result, patients with pancreatic cancer are deteriorating while waiting for diagnosis and treatment.
- 4. **Lack of patient empowerment:** Patients currently struggle to navigate their healthcare journey and advocate for their needs, in large part due to the complex systems and lack of coordination. Many report feeling that they don't have control over or feel empowered to make decisions about their care.

To overcome these four challenges, we need to see the following enabling actions:

- 1. To improve the quality of data and drive improvements in pancreatic cancer care the government must undertake the following actions:
- A comprehensive review of the pancreatic cancer data published within routine NHS statistical publications and datasets, and an action plan to improve this.
- Continued funding for the National Pancreatic Cancer Audit
  programme in England and Wales to ensure we continue to measure
  progress and drive improvements in pancreatic cancer treatment and
  care.
- **Better data collection** to understand the experience and outcomes of people from diverse groups for individual cancer types.
- An audit into the specialist treatment and care workforce for individual cancer types, including pancreatic cancer.
- Improve access for third sector and research organisations to **NHS patient** data to ensure more research and innovation can happen.
- 2. To better use data and technology to improve clinical decision making and empower patients the government must:
- Provide funding to **embed clinical decision support tools** to help GPs make referrals to suspected cancer and explore their potential for proactive case finding.
- Centralise and **digitise all patient health records** and data under one platform to enable clinical professionals to access records across different settings. This should be routinely used to speed up diagnosis confirmation and treatment decisions, by improving the pathway to scanning and enabling faster access to results.
- As part of efforts to digitise these records, the government should work with the third sector on tools to **empower patients to have control and agency over their care.** As part of this, the government should support

new digital tools which gives people agency to manage their own conditions and self-report symptoms, embedded within routine outpatient management. This will help healthcare professionals to provide earlier supportive care interventions and prevent unnecessary hospitalisations.

#### Shift 3: Focussing on preventing sickness, not just treating it

Spotting illness earlier and tackling the causes of ill health could help people stay healthy and independent for longer, and take pressure off health and care services.

# Question four: What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

#### Risk factors and causes of ill health:

Pancreatic cancer **risk factors are both modifiable and non-modifiable.** Modifiable risks include smoking, obesity, diet, and heavy alcohol use, while non-modifiable risks include age, sex, race, and blood type. Some factors, like type 2 diabetes and pancreatitis, fall in between, as these conditions can sometimes be prevented by addressing modifiable risks like obesity, diet, and heavy alcohol use.

To both prevent and detect more pancreatic cancer cases earlier:

- The government must increase investment in interventions, campaigns, and initiatives that raise awareness of all known pancreatic cancer risk factors and encourage the public to reduce their exposure to modifiable risk factors.
- The government must invest in the development of new risk models and surveillance strategies for people with known modifiable and nonmodifiable risk factors for pancreatic cancer and work with the clinical community and NHS bodies to improve early detection in these higherrisk groups.

#### **Earlier diagnosis and detection:**

Achieving earlier diagnosis of pancreatic cancer presents the biggest opportunity to improve long term survival. Currently, only 24% of pancreatic cancer cases were diagnosed at stage 1 or 2 from 2019 - 2021, compared to an all-cancer average of 54% over the same period. There are currently no national screening programmes available, no biomarkers or tests available and the symptoms with which people present are vague.

There are **four key challenges** to detecting pancreatic cancer earlier:

- Despite the existence of known modifiable and non-modifiable risk factors for pancreatic cancer, there is currently no comprehensive screening programme for most people at a higher risk of developing pancreatic cancer.
- 2. **Primary care does not effectively refer and diagnose people** with conditions where the symptoms are vague and non-specific. As a result, people with pancreatic cancer visit their GP on average three times before an onward referral.
- 3. There is not the necessary capacity, workforce and streamlined diagnostic pathways to **rapidly investigate and diagnose cancer quickly** following referral.
- 4. There are currently **no effective tools or biomarkers tests** to detect pancreatic cancer earlier or triage people for further investigations.

To overcome these **four challenges**, we need to see the following enabling actions:

- 1. To improve the early detection of people at higher risk for pancreatic cancer the government must undertake the following actions:
  - Investment and **implementation of surveillance interventions** to detect pancreatic cancer earlier, including new onset diabetes case finding and family history of pancreatic cancer surveillance programmes.
  - Invest in the **development of new risk models and surveillance strategies** for people with known modifiable and non-modifiable risk factors for pancreatic cancer.
  - Undertake a review of the NICE NG85 guidance on the routine monitoring of pre-cancerous lesions in the pancreas and risk stratification for surgery. There is research ongoing to better identify and stratify the highest risk pre-cancerous lesions for surgical intervention and this represents the next best opportunity to expand surveillance.
  - Following this the government should **invest and roll-out a surveillance programme for people with pre-cancerous lesions** based on the based on emerging evidence and NICE NG85 guidance.
- 2. To ensure earlier and faster referral for people presenting with symptoms within primary care the government must undertake the following actions:

- NICE must review the guidelines for suspected cancer recognition and referral (NG12) to ensure that more people presenting with symptoms can be recognised and referred earlier, based on new evidence commissioned by Pancreatic Cancer UK.
- Provide funding to **embed clinical decision support tools** to help GPs make referrals to suspected cancer and explore their potential for proactive case finding.

# 3. To fast-track development and adoption of new tools and tests to detect pancreatic cancer earlier we need to see:

- Investment in the roll-out and **implementation of new blood, urine or breath biomarker tests** within suspected cancer pathways, based on the outcome of latest clinical trials and evidence, such as the Imperial VAPOR breath test for suspected Upper Gastro-intestinal (UGI) cancer.
- Commitment to **increasing investment to at least £35 million every year** for the next 20 years to drive development in early diagnosis and detection tools for pancreatic cancer.

# 4. To improve the diagnostic capacity and streamline cancer referral pathways:

 DHSC should undertake a comprehensive review of the wider cancer diagnostic workforce and available routes into diagnostic investigations for pancreatic cancer, including direct access and community diagnostic hubs.

#### Ideas for change

We're inviting everyone to share their ideas on what needs to change across the health and care system. These could be:

- · Ideas about how the NHS could change to deliver high quality care more effectively.
- · Ideas about how other parts of the health and care system and other organisations in society could change to promote better health and/or improve the way health and care services work together.
- · Ideas about how individuals and communities could do things differently in the future to improve people's health.

#### Question five: Please use this box to share specific policy ideas for change.

In addition to the specific policy actions described above for pancreatic cancer, we believe the 10-Year Health Plan provides a unique opportunity to refocus on improving care and addressing inequalities in provision for people with less survivable cancer, such as pancreatic cancer.

The Less Survivable Cancers Taskforce (LSCT) is a coalition of cancer charities - Action Against Heartburn (oesophageal lead), Guts UK (stomach lead), Liver Cancer UK (liver lead), Pancreatic Cancer UK (pancreatic lead), Roy Castle Lung Cancer Foundation (lung lead), and The Brain Tumour Charity (brain lead) - seeking to improve experiences and outcomes for people diagnosed with one of the six least survivable common cancers in the UK: lung, liver, brain, oesophageal, pancreatic, and stomach cancers. People diagnosed with these cancers have a shockingly low life expectancy. Today, on average, the chance of someone surviving for five years after being diagnosed with one of these cancers is only 16%.

To ensure the 10-Year Health Plan addresses the needs of people with the six less survivable cancers, **we want to see a specific focus on these cancers** and a commitment to doubling survival rates.

• Commit to a dedicated focus and plan to tackle less survivable cancers in the upcoming cancer strategy.

Central to any future cancer strategy, there needs to be a **plan to improve outcomes for less survivable cancers.** These cancers are often diagnosed late, have low survival rates, and require tailored approaches that prioritise early detection, faster treatment pathways, and comprehensive care.

It will be extremely challenging to improve overall cancer survival rates without a focus on them, as although these six cancers only account for 20% of cases, they are responsible for 42% of all cancer deaths in the UK. **This plan should include a commitment to doubling survival rates for these cancers.** 

• Specific targets to improve outcomes for less survivable cancers.

The current generic targets for cancer diagnosis and treatment fail to address the disparities faced by less survivable cancers, and the particular challenges they present. 54% of all cancers are diagnosed at stages 1 or 2, whereas only 28% of less survivable cancers are diagnosed at these

stages. This means there is a danger that targets such as the Long Term Plan commitment - that by 2028 75% of people with cancer by 2028 will be diagnosed at an early stage - could be met without any improvements for the less survivable cancers. The rapid progression of these cancers also means that it is crucial to get people into the system quickly to ensure they can receive treatment and improve survival - the current 62 day referral to treatment time target is insufficient to do this.

This is why there needs to be specific and differentiated targets for the less survivable cancers. These should include a commitment to a dedicated faster treatment waiting time standard, and targets for survival focused on these cancer types. These targets should not just focus on increasing diagnosis at stage one and two but also shifting diagnosis from stage four to three, to open up more options for treatment. These targets should also not just be based on staging, as brain cancer is unable to be staged.

#### • Commit to a sustained increase in research funding.

The less survivable cancers are trapped in a vicious cycle of research underfunding. Poor survival outcomes result in fewer patients taking part in research studies, which in turn contributes to fewer positive breakthroughs and less research investment. This perpetuates low survival rates, and the cycle continues. Strategic, transformative action from Government and national funding bodies is needed to break this cycle and provide the step change in research we need to see.

For this reason, we want to see a commitment to a sustained increase in ringfenced funding for the less survivable cancers, with a strategy in place to ensure this is used to achieve maximum impact - making the most of existing infrastructure.

Pancreatic Cancer UK 2 December 2024