Pancreatic Cancer UK
National Cancer Plan call for evidence response

Background:

Pancreatic cancer is one of the least survivable cancers, with only 7.3% of people living 5 years or more beyond the date of their diagnosis. As of 2021, 80% of staged pancreatic cancers were diagnosed late. Over the last few years, there have been several pancreatic cancer health improvement programmes launched as well as national investment into early detection initiatives. The National Cancer Plan now presents a significant opportunity to develop a revised governance approach and set a clear central strategic vision for cancer, which can build on these existing programmes and implement the solutions needed to drastically improve pancreatic cancer diagnosis, treatment, and care.

This response to the national cancer plan call for evidence represents the view from Pancreatic Cancer UK, which has been built through insights developed from the Pancreatic Cancer UK Optimal Care Pathway (OCP) and National Pancreatic cancer Audit (NPaCA). The recommendations put forward for the cancer plan have also been developed with expert clinical input through a consensus building roundtable of pancreatic cancer healthcare professionals held on the 10th April 2025.

For more information about the policy recommendations put forward please contact peter@pancreaticcancer.org.uk.

Prevention and awareness:

While the causes of pancreatic cancer are not fully understood, some important risk factors have been identified and research suggests that 37% of pancreatic cancer cases in the UK are preventable. Modifiable risks for pancreatic cancer include smoking, being overweight or obese, and heavy alcohol use. Smoking is estimated to cause over one in five pancreatic cancers cases in the UK, while around one in eight may be linked to being overweight or obese. Non-modifiable risks include age, sex, race, blood group, and family history.

Meanwhile, some factors, like diabetes and pancreatitis, bridge modifiable and non-modifiable classification. Diabetes and pancreatitis are both long-term risk factors and can also be caused by an underlying pancreatic cancer. They can sometimes be prevented by addressing modifiable risks like obesity, diet, and heavy alcohol use. Lifestyle changes can help reduce the risk of acute or chronic pancreatitis, but hereditary pancreatitis cannot be prevented in this way and carries a high lifetime risk of pancreatic cancer.

Raising awareness of these risk factors empowers people to make informed choices that could reduce their risk. The Government should develop interventions, campaigns, and initiatives that raise awareness of all risk factors and encourage the public to reduce their exposure to modifiable ones. Given that many of the modifiable risk factors are higher in more underserved and disadvantaged communities, any public health campaigns should begin by focusing in areas of higher socio-economic deprivation.

There are also now opportunities to target people most at risk of developing pancreatic cancer, including people with hereditary risk factors and people with a recent diagnosis of diabetes. The Government should build on recent pilot initiatives and develop a more central strategic programmes to oversee case finding across multiple cancer types as well as surveillance for people with inherited cancer risk.

To achieve this, the National Cancer Plan should:

1. Develop interventions, campaigns, and initiatives that raise awareness of risk factors for cancer as well as encourage the public to reduce their exposure to modifiable risk factors. The should be integrated into broader public health initiatives that address smoking, alcohol use, and obesity, focusing first in areas of higher socio-economic deprivation.

2. Promote and fund further research and data collection to better understand the relationship between modifiable risk factors and pancreatic cancer, as well as the intersection with other socio demographic factors.

3. Develop a centralised, nationwide programme to oversee and drive surveillance for all individuals with inherited cancer risk. This should build on existing programmes for cancers with inherited risk and incorporate surveillance for people with a family history of pancreatic cancer and hereditary pancreatitis, utilising the risk assessment protocol from the EUROPAC study.

4. 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.

Early diagnosis and detection:

The wider issues with access to primary care across the NHS play out most significantly in complex and aggressive diseases such as pancreatic cancer. This is because the challenges facing primary care, like long GP waiting times and lack of capacity for diagnostic investigations, are compounded by specific issues that pancreatic cancer presents. The symptoms are often vague and there are no biomarkers or tests currently available. As a result, people often have multiple GP appointments before being referred, and 80% are diagnosed at a late stage, often via emergency admission. The latter is not only associated with worse survival outcomes and patient experience but is also more costly to the health system.

Over the last decade, there has been a range of important national programmes that have sought to improve patient access and referral through primary care. These include GP direct access, Non-Specific Symptom (NSS) pathways and the BPTPs. These are the right solutions; however, they have not been consistently implemented or commissioned across the country, with decisions left to local health bodies often without the funding to deliver and sustain them. For example, decisions about the future commissioning of the NSS pathways will now be left to Integrated Care Boards (ICBs). This could lead to significant variation in provision of these services and miss an opportunity to detect people with vague symptoms, including pancreatic cancer.

There are also now opportunities to target people most at risk of developing pancreatic cancer, including people with hereditary risk factors and people with a recent diagnosis of diabetes. The NHS has recently invested in a study undertaking surveillance of people with family history of pancreatic cancer and launched a case finding pilot in people with new onset diabetes. These programmes have been modelled to lead to a 10.8% stage shift for pancreatic cancer if implemented nationally. The National Cancer Plan is an important opportunity to build on these initiatives and develop a centralised nationwide programme to oversee case finding and surveillance for people with inherited cancer risk.

To deliver this, the National Cancer Plan should:

1. Ensure comprehensive commissioning and diagnostic capacity for multiple routes into the health system, to ensure we capture people presenting with high-risk cancer symptoms as well as vague lower risk symptoms. This should include GP direct access, NSS pathways and urgent suspected cancer pathways. This should be combined with professional training, integrated clinical decision support tools and include pilots to expand access and referral routes, including self-referral mechanisms and direct referrals from pharmacies.

2. Develop a centralised, nationwide programme to oversee and drive surveillance for all individuals with inherited cancer risk. This should build on existing programmes for cancers with inherited risk and incorporate surveillance for people with a family history of pancreatic cancer and hereditary pancreatitis, utilising the risk assessment protocol from the EUROPAC study. This programme should combine centralised clinical expertise and risk assessment, with more streamlined self-referral and registration systems, as have been piloted through the Family History Checker.

3. 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.

Improving patient pathways and treatment:

The NHS is not currently set up to provide high quality treatment and care quickly for people with complex health conditions, such as cancer. There are multiple barriers including significant variation in the pathways in place, lack of diagnostic capacity as well as oncology and supportive care workforce to enable people to tolerate treatment. The consequences of these challenges are felt most severely in aggressive conditions, such as pancreatic cancer - which are hard to diagnose, have rapid disease progression, and require specialised treatment and support. In this context, faster diagnosis and access to treatment are critical to improving patients' chances of survival.

Current metrics show the extent to which pathways are letting people with pancreatic cancer down. For example, the recent National Pancreatic Cancer Audit (NPaCA) highlighted that only 56% of people are diagnosed within the 21-day timeframe recommended by the HPB Best Practice Timed Pathway (BPTP). Furthermore, only 35% of people with pancreatic cancer were treated within 62 days of referral, with these treatment waiting times varying significantly across England. As a result, only 25% of people with metastatic and 55% of people with

non-metastatic disease received any treatment. This is the lowest treatment rate among all common cancers and all these factors are having a direct impact on patient outcomes.

Over the last few years, there have been several excellent pancreatic cancer health improvement programmes, including HPB BPTP, NPaCA, HPB service specification and Getting It Right First Time (GIRFT). Aligned with these programmes, our charity has built clinical consensus through the Optimal Care Pathway (OCP). We believe that together, these programmes contain the solutions needed to drastically improve pancreatic cancer treatment, which would lead to significant improvements in survival.

However, over the past few years responsibility for cancer care in England has become diffuse and fragmented, without unified strategic direction and long-term funding, which has made it difficult to implement local pathway improvements. This plan presents an opportunity to develop a revised governance approach and set a central strategic vision for cancer. We believe this should include developing an overarching national framework for specific conditions (like the National Service Framework), starting with the cancers with the poorest operational performance.

As part of this central strategic vision, the National Cancer Plan should:

1. Appoint a national role to support the implementation of urgently needed local pathway improvements for cancers with poor operational performance. For pancreatic cancer, these improvements should be based on the recommendations from GIRFT, NPaCA and BPTP.

2. Develop national, timed optimal pathways across the whole patient pathway, starting with the cancers with the poorest operational performance. For pancreatic cancer, this should be based on the OCP, GIRFT, NPaCA and HPB BPTP. This should provide a strategic, central vision for optimal treatment and care for local systems to commission and deliver.

3. These pathway improvements should be underpinned with funding for the specialist oncology and multi-disciplinary supportive care workforce. For pancreatic cancer, this should contain a commitment to increase workforce for HPB CNSs, HPB oncologists and cancer navigators.

Living with and beyond:

People with pancreatic cancer commonly experience complex, severe symptoms and poor performance status from the point of presentation. These result in people becoming too unwell to access or tolerate treatment and this has a significant impact on survival and quality of life. The NPaCA found a clear link between performance status (PS) and treatment rates for non-metastatic pancreatic cancer.

However, the NHS is not currently set up to provide the specialist symptom management needed to support people with such complex and chronic health conditions. Poor and inconsistent access to specialist symptom management can lead to rapid patient deterioration, avoidable emergency admissions and extended hospital stays.

Our charity's Optimal Care Pathway and the Getting It Right First Time (GIRFT) review have both identified several barriers to delivering comprehensive and integrated supportive care services. These barriers include insufficient local funding and prioritisation for supportive care services and workforce. For example, it can be challenging for Cancer Alliances and ICBs to prioritise business cases for enhanced supportive care services over improvements in operational performance. In addition, it is also currently difficult to measure any improvements in patient experience for pancreatic cancer, as the median survival is shorter than the survey reporting timeframes.

To support local commissioning and delivery of specialist supportive care services, there needs to be incentivised funding for local health systems to deliver supportive care services, as well as a national programme to evaluate the cost benefit for enhanced supportive care and prehabilitation services. These service improvements should be underpinned with funding for the specialist supportive care workforce as well as a new framework for measuring patient experience in people with rapidly progressing cancers.

To deliver this, the National Cancer Plan should:

1. Ensure local health systems should have incentivised funding to implement enhanced supportive care and prehabilitation services for all people with cancer. This should focus first on access for groups where there is a high symptom burden and currently low access to disease targeted treatment, such as pancreatic cancer. Funding for enhanced supportive care services should be based on the cost analysis undertaken by Dr Daniel Monnery and the NHS England Specialised Services Improving Value team.

2. Develop a national programme to evaluate the cost benefit for prehabilitation and enhanced recovery after surgery services, to support business cases for long term commissioning of supportive care and prehabilitation services.

3. Provide additional funding for the specialist, multi-disciplinary supportive cancer care workforce including CNSs, dietitians, palliative care specialists, diabetes specialists and patient administration and coordination support. For pancreatic cancer, this should contain a commitment to increase workforce for HPB CNSs and HPB dietitians.

4. Improve data collection on patient experiences of care and develop a new data collection framework for measuring patient experience. This framework should focus on rapidly progressing cancers that have a median survival shorter than the National Cancer Patient Experience Survey (NCPES) reporting timeframes.

5. Establish a pathway for direct NHS referrals into disease-specific charities that can offer wraparound information and support, to complement NHS services.

Research and Innovation:

Rare and less survivable cancers, including pancreatic cancer, have historically been left behind and often struggle to attract research funding and focus. As a result, there are limited treatments and clinical trials available – in turn leading to no significant improvements in survival and sustaining this as an unattractive area for investment.

Currently, clinical trials are often the only option for people with pancreatic cancer to receive any treatment. However, many are not offered the opportunity to participate and even where there are clinical trials available, rapid deterioration means people are often too unwell or ineligible. A recent Pancreatic Cancer UK survey found that 81% of people affected were not being given the opportunity to participate in a clinical trial.

One key barrier to improving research is consistency and standardisation of data collection, as well as reporting, within the NHS. In addition, we currently lack comprehensive access to genomic testing at the point of diagnosis. This could be transformative for pancreatic cancer because it would allow more patients to be eligible for targeted therapies through clinical trials and would expand access to new treatments.

The Rare Cancers Bill and National Cancer Plan provide a unique opportunity to deliver new initiatives to improve data collection, access to clinical trials and genomic profiling for people with rare and less survivable cancers, providing a platform for more and better research.

To deliver this, the National Cancer Plan should:

1. Ensure full implementation of the provisions of the Rare Cancers Bill, including appointing 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.

   Coordination can be strengthened by prioritising the following actions:

   a) Development of 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 would address original research question and support the development of clinical trials, acting as a readymade control arm for novel therapeutics trials from both investigators and industry. It could also provide infrastructure to increase clinical trial participation through a single, centralised, national data opt-out system.

   b) Prioritise and incentivise funding for genomic profiling at diagnosis, starting with a pilot for rare and less survivable cancers in a selected region via Genomic Laboratory Hubs. This would also help lay the groundwork for a future centralised system for storing and accessing genomic data nationally.

2. Direct the named lead to 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.

Health inequalities:

There are widening inequalities in provision, experience and outcomes and we know people face a postcode lottery of care depending on where they live. There are currently multiple reasons for these inequalities, including the lack of standardised pathways and significant differences in local areas' specialist cancer workforce, which leads to vastly different services being on offer.

As a result, there are significant inequalities in diagnosis, treatment, and care for people with pancreatic cancer. Treatment rates for pancreatic cancer range from 29.6% to 41.0% across Cancer Alliances and treatment waiting times vary from 57 days to 99 days. Variation is also driven by a lack of expertise within non-specialist care - leading to significant differences in outcomes between specialist and secondary care settings. For example, people with pancreatic cancer treated in specialised surgical centres have higher rates of Pancreatic Enzyme Replacement Therapy (PERT) prescription as compared to people treated in non-surgical settings.

The true extent and underlying reasons for the variation in experience and outcomes are also masked by significant gaps in data collected and reported. Data collection systems often fail to accurately record pancreatic cancer treatment modalities and care interventions. This is further complicated by non-integrated data systems and insufficient training for staff. The aggregation of data under broader groupings such as upper gastrointestinal (UGI) or hepatopancreatobiliary (HPB) also mean that healthcare teams are unable to track disease-specific issues in the pathway.

Health inequalities within the population also likely drive further variation in access and availability of healthcare services. However, we lack data to understand how other health inequalities interact with and exacerbate inequity of access to treatment and survival for people with pancreatic cancer.

To address this, the National Cancer Plan must:

1. Commit to reviewing all clinical cancer data collection, coding, and guidance to leverage data for service improvement with particular focus on cancers where national audit teams have identified data completeness as a significant issue, such as pancreatic cancer. This review should include:

    - Disaggregation of data for all cancer types.

    - A review of metrics needed to understand variations in pathways and outcomes by cancer type, identifying gaps in data collection and working with the clinical community to fill these.

- The linkage of clinical cancer data with protected characteristics where possible, so that inequalities can be identified.

2. Continue to fund the national clinical audits, including for pancreatic cancer, as these provide important insight to identify what improvements need to be made and track progress.

3. Based on this improved understanding of where inequalities exist across the pathway, there should be interventions to support standardisation of the pathway and address those health inequalities identified.

4. To reduce inequities in access and early diagnosis, any symptom awareness, case finding, and surveillance programmes should be pro-actively targeted in communities where there are existing inequalities, such as more deprived communities.

Overall priorities:

Over the last few years, there have been several excellent pancreatic cancer health improvement programmes launched, including HPB BPTP, NPaCA, HPB service specification and Getting It Right First Time (GIRFT). In addition, there has been recent investment into a surveillance study for people with a family history of pancreatic cancer, as well as a case finding pilot in people with new onset diabetes. All these programmes contain the right solutions to improve pancreatic cancer diagnosis, treatment, and care, which would lead to significant improvements in survival. However, over the past few years responsibility for cancer care in England has become diffuse and fragmented, without clear strategic direction and funding, which has made it difficult to implement local pathway improvements and drive forward these national early detection programmes.

The National Cancer Plan now presents a significant opportunity to develop a revised governance approach and set a clear central strategic vision for cancer, with rare and less survivable cancers at the centre of this. This new vision should include development of an overarching national framework for specific conditions (like the National Service Framework), starting with the cancers with the poorest operational performance. It is also an opportunity to build on the pilot initiatives already underway in early detection and develop central strategic programmes to oversee case finding across multiple cancer types as well as surveillance for people with inherited cancer risk.

Finally, the Rare Cancers Bill provides a unique opportunity to deliver new initiatives to improve data collection, access to clinical trials and genomic profiling for people with rare and less survivable cancers, providing a platform for more and better research for these cancers.

As part of this central strategic vision, the National Cancer Plan should:

1. Develop national, timed optimal pathways across the whole patient pathway, starting with the cancers with the poorest operational performance. For pancreatic cancer, this should be based on recommendations already developed from the OCP, GIRFT, NPaCA and HPB BPTP. This should provide a strategic, central vision for optimal treatment and care for local systems to commission and deliver.

2. Underpin these pathway improvements with funding for the specialist oncology and multi-disciplinary supportive care workforce. For pancreatic cancer, this should contain a commitment to increase workforce for HPB CNSs, HPB oncologists, HPB dietitians and cancer navigators.

3. Develop a centralised, nationwide programme to oversee and drive surveillance for all individuals with inherited cancer risk. This should build on existing programmes for cancers with inherited risk and incorporate surveillance for people with a family history of pancreatic cancer and hereditary pancreatitis, utilising the risk assessment protocol from the EUROPAC study.

4. 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.

5. Ensure full implementation of the provisions of the Rare Cancers Bill, including appointing a named lead in government and development of an observational cohort study for rare and less survivable cancers.