

# **The ‘War on Cancer’ in England 10 Year Cancer Plan: Call for Evidence**

## **Response from Pancreatic Cancer UK**

**March 2022**

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### **Foreword**

This is Pancreatic Cancer UK’s organisational response to the Department for Health and Social Care’s Call for Evidence, to inform the development of a new 10 Year Cancer Plan for England.

Pancreatic cancer has been neglected for far too long. Half of people diagnosed with this cancer will die within three months, and three in four will die within a year. This makes it the deadliest common cancer in the UK. Yet multiple governments, cancer plans and strategies have missed the opportunity to give pancreatic cancer the attention it deserves and, as a result, the survival gap between pancreatic cancer and other cancers has continued to grow.

It’s essential that the deadliest common cancer is finally prioritised in the Government’s new cancer plan. We believe that, if the below suggestions are implemented – as a matter of urgency – thousand of lives will be saved. Together, we can make sure that in the future, pancreatic cancer is not the devastating diagnosis that it is today.

## **Our response to the Call for Evidence's key questions**

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### **1. Do you have any suggestions for how to raise awareness of the causes of cancer and how it can be prevented?**

We urge the Government to address low awareness about pancreatic cancer causes, and prevention, by taking the following actions:

#### **1. Ensure everyone at risk of hereditary pancreatic cancer has access to surveillance programmes on the NHS by 2024.**

About 10% of total pancreatic cancers are hereditary.<sup>1</sup> However, there is not currently provision for surveillance of those at risk of hereditary pancreatic cancer through the NHS. Surveillance is only given through research studies such as the EUROPAC study in Liverpool. This is a considerable limitation as not all people at risk across the country are offered screening, despite the recommendation included in the NICE guidance on diagnosis and management of pancreatic cancer in adults (NICE NG85).

As such, the Government should start working closely with EUROPAC to better understand the risk of familial pancreatic cancer, and must commit resource and funding to ensure that everyone at risk of familial pancreatic cancer has access to a surveillance service through the NHS, no matter where they live in England, by 2024.

#### **2. Government should commit to funding surveillance programmes and specific studies focussing on people at risk of pancreatic cancer, so that everyone at risk has access to surveillance by 2032.**

Emerging evidence demonstrates that a new diagnosis of pancreatitis with unknown cause, history of chronic pancreatitis with increasing pain, weight loss and jaundice, and New-Onset Diabetes, are also risk factors for developing pancreatic cancer.<sup>2</sup> Further funding commitments to surveillance programmes are needed for people at risk of pancreatic cancer so that everyone at risk has access to a surveillance service by 2032. Specific studies will

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<sup>1</sup> [https://www.thelancet.com/journals/ebiom/article/PIIS2352-3964\(20\)30050-5/fulltext](https://www.thelancet.com/journals/ebiom/article/PIIS2352-3964(20)30050-5/fulltext)

<sup>2</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7768873/>

also help us to understand the best approach to identifying and providing surveillance to at-risk groups, and should be undertaken by 2026, with full implementation of learnings by 2032.

## **2. Do you have any suggestions for how to raise awareness of the signs and symptoms of cancer?**

We urge the Government to undertake the following actions to raise awareness of the signs and symptoms of pancreatic cancer:

- 1. Invest in a dedicated public awareness campaign in the next 2-3 years to be rolled out from 2024 onwards, that will enable more people with pancreatic cancer to be identified at an earlier stage.**

Pancreatic cancer normally causes vague and non-specific symptoms, it lacks a simple test for detection and there is poor public awareness of the symptoms (two thirds of UK adults say that they are not aware of the symptoms<sup>3</sup>). As a result, it remains exceptionally difficult to diagnose at an early stage, making pancreatic cancer almost impossible to treat and survive for the majority. This leads to shocking outcomes: over half die within three months of diagnosis.

A campaign focussed on pancreatic cancer has the potential to save lives through earlier diagnosis and we urge Government to invest in this. Success has been seen in other cancer types: a national Be Clear on Cancer campaign in England for lung cancer symptoms increased the number of people diagnosed with lung cancer, increased the proportion of people diagnosed at an early stage and of people receiving surgery. Results show there were an estimated 700 additional cancers diagnosed in the months surrounding campaign activity, compared to the same period in the previous year.

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<sup>3</sup> Savanta ComRes interviewed 2,087 UK adults online from 3-5 September 2021. Data were weighted by age, sex, region and social grade. Savanta ComRes is a member of the British Polling Council and abides by its rules.

As well as this, the successful joint campaign between NHS England and Prostate Cancer UK to promote its prostate cancer risk checker is a good example of a campaign that focusses on changing behaviour and action as well as increasing awareness.

**2. Allocate sustainable resource to local health bodies such as Integrated Care Systems (ICSs) and Cancer Alliances (CAs) so that key healthcare professionals are aware of symptoms and risk factors for pancreatic cancer by 2025.**

Currently, there is a common delay between first presentation of pancreatic cancer symptoms at the GP, and referral for diagnostic tests leading to multiple visits to primary care and diagnosis at a late stage. People with pancreatic cancer present an average of three times with alarming symptoms in the two years prior to diagnosis. It has been shown that 91% of patients had relevant symptoms in the two years prior to their diagnosis.<sup>4</sup>

To address this, the Government must allocate sustainable resource on an annual basis starting from 2022 to ICSs and CAs to support healthcare professionals with understanding the key symptoms to be aware of which might indicate pancreatic cancer.<sup>5</sup> Pancreatic Cancer UK have designed training on pancreatic cancer for this purpose, which can be integrated into educational programmes delivered through the NHS.<sup>6</sup>

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<sup>4</sup> <https://bmjopen.bmj.com/content/4/11/e005720>

<sup>5</sup> <https://courses.pancreaticcancer.org.uk/courses/introduction-to-pancreatic-cancer-part-one-symptoms-risk-factors-and-diagnosis/>

### **3. Do you have any suggestions for how to get more people diagnosed quicker?**

Late diagnosis is one of the biggest factors causing poor survival for pancreatic cancer. The Government must invest in the following interventions to start driving earlier diagnosis, and thus improving outcomes:

- 1. Invest in the development of a triage biomarker test for pancreatic cancer in the next 2-3 years, so that by 2032 every patient with pancreatic cancer can receive a prompt referral to be diagnosed at an early symptomatic stage by the GP.**

Pancreatic cancer has the lowest early-stage diagnosis of all common cancers, with only 16% of people being diagnosed at stage one or two, lagging far behind NHS England's ambition for 75% of all cancers to be diagnosed at an early stage by 2028. Government must provide funding and work with the primary care cancer research community on refined versions of GP decision making tools such as the QCancer tool to better pick up those with suspected symptoms of pancreatic cancer for referral.<sup>7</sup> QCancer has been designed with the aim of developing machine learning tools to identify combinations of symptoms in health records which generate a risk score and a red flag for pancreatic cancer. We also need to see investment in innovative biomarker research to develop a triage test to help identify those who should be referred for investigation by 2026.

- 2. Increase research funding in the next two years to identify, image and monitor those at increased risk of pancreatic cancer with the aim of a pancreatic cancer screening programme to be nationally rolled out by 2032.**

This can be done through the development of machine learning tools and targeted interventions to identify people in GP records with a combination of symptoms, conditions and risk factors that are associated with a high risk of developing pancreatic cancer, which could then lead to a referral or follow up survey to further enrich these population data. This could start by targeting patients with new-onset diabetes (NOD), given the high risk associated with pancreatic cancer in people with NOD: it can be detected in the pre-

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<sup>7</sup> <https://www.qcancer.org/>

symptomatic phase and is one of the most promising risk factors that could enable earlier diagnosis. At the time of diagnosis, around 65% of people with pancreatic cancer have diabetes, with more than 50% having new-onset diabetes. People with defined high risk of pancreatic cancer, such as those with NOD, must be provided with established routes to easily access the GRAIL NHS England-Galleri national pilot. Pancreatic cancer should also be a priority in the aims, access and roll out of the Galleri pilot.

**3. Provide capacity and workforce to implement Best Practice Timed Pathways (BPTP) so that by 2027 everyone with pancreatic cancer is diagnosed within 21 days of referral, and ensure that the early diagnosis interventions mentioned above are adopted in the BPTP so that it delivers both faster and earlier diagnosis by 2032.**

NHS England are currently developing a Best Practice Timed Pathway for HPB cancers. This will provide a clinical framework for the optimal structure and sequencing of the diagnostic pathway for urgent suspected cancer referrals for pancreatic cancer. However, it is essential that the Government ensure there is sufficient investment in capacity and workforce to deliver the BPTP for pancreatic cancer across all regions of England as soon as this is published in summer 2022. Delivering and reporting pathology is widely considered to be one of the most difficult parts of the pathway to achieve in a timely manner, therefore, there needs to be additional workforce and capacity for pathology to ensure that the entire BPTP is deliverable. In addition to the BPTP Task and Finish Group, NHS England should also form an HPB Early Diagnosis Task and Finish Group to develop recommendations on early diagnosis.

**4. Expand the scope of the NICE NG12 criteria for pancreatic cancer.**

The central reason for the low early-stage diagnosis in England compared to other countries is the primary care 'gatekeeping' system, rather than differences in public awareness of symptoms across developed countries.<sup>8</sup> The propensity to refer from primary care is influenced by a combination of system-wide factors, including the NICE NG12 referral criteria. These referral criteria do not pick up people with pancreatic cancer quickly or effectively and they should be broadened to include:

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<sup>8</sup> <https://bmjopen.bmj.com/content/5/5/e007212>

- Consideration of referral with a broader combination of persistent unexplained symptoms, including but not dependent on weight loss
- Referring people for pancreatic cancer if they have jaundice at any age
- Broader and more flexible referral of people with new-onset diabetes in combination with another symptom.

#### **4. Do you have any suggestions for how to improve access to and experiences of cancer treatment?**

We need to see the following commitments in the new ten-year plan to remedy variation in pancreatic cancer outcomes:

##### **1. Implement the Optimal Care Pathway that Pancreatic Cancer UK are developing with the pancreatic cancer community to eliminate variations, and standardise clinical practice across England, by 2025.**

Pancreatic cancer treatment and care has unacceptable levels of variation. Currently, one-year survival for pancreatic cancer ranges from 21% to 29% and five-year survival ranges from 4.8% to 10.6% across Cancer Alliances.<sup>9</sup> Variation is further exemplified by data on chemotherapy, showing that the percentage of patients who have surgery who also undergo adjuvant chemotherapy from ranges 41% to 65% between Cancer Alliances (2013-2015).<sup>10</sup>

Pancreatic Cancer UK has developed an Optimal Care Pathway, from symptom presentation to diagnosis and access to best treatment and supportive care. The Government must ensure that this Optimal Care Pathway is adopted by NHS England so that everyone, from doctors and nurses to patients and their families, know what to expect and what should happen to give people the best possible chance of survival. Specific, regularly reported KPIs should also be adopted to track and reduce variation alongside the annual repetition of the planned NHSE pancreatic cancer audit.

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<sup>9</sup> CONCORD-3, 2018. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)33326-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)33326-3/fulltext)

<sup>10</sup> <http://www.ncin.org.uk/view?rid=3682>

**2. Cancer Waiting Time targets should be disaggregated and updated to reflect the urgency of each individual cancer.**

The current Cancer Waiting Time (CWT) standard between decision to treat and first treatment is 31 days, however, this is too slow for pancreatic cancer, given that one in four people will die within a month of diagnosis and pancreatic cancer progresses rapidly.

The Best Practice Timed Pathway (BPTP) for HPB will aim to deliver a pancreatic cancer diagnosis and treatment plan within 21 days from referral, however, the impact of a rapid diagnosis will be lost if people then have to wait a further 31 days for treatment from the decision-to-treat date.

As such, NHS England should have disaggregated CWT targets based on the clinical urgency of each cancer, rather than broad stroke targets across all cancers.

**3. Prehabilitation and rehabilitation should be made a standard of care for pancreatic cancer by 2025, with all patients having access to a personalised programme whether or not they receive treatment by 2032.**

Currently 70% of people with pancreatic cancer do not receive any type of active treatment such as surgery or chemotherapy – even those who are diagnosed early. A major factor driving poor treatment access in pancreatic cancer is the aggressive and fast deteriorating symptoms of the disease. This is why it is critical for people with pancreatic cancer to be assigned to pancreatic cancer-specific prehabilitation and rehabilitation programmes to optimise access and tolerance of treatment through a joint approach of physical activity, nutritional optimisation, symptom management and psychosocial support.

**4. Develop a dedicated national programme to increase prescription rates of Pancreatic Enzyme Replacement Therapy (PERT) from 50% to 75% across England by 2024. The Government must also ensure that no inequalities exist in PERT access between people with pancreatic cancer receiving surgery and those diagnosed late by 2032.**

PERT is a crucial treatment for people with pancreatic cancer and it is recommended by NICE NG85 for all pancreatic cancer patients. However, although widely available, currently only 50% of pancreatic cancer patients are being prescribed PERT with access more limited for people who are diagnosed late and not seen by pancreatic cancer clinical specialists. A



multidisciplinary approach is needed to increase prescription rates of PERT. National public health bodies and cancer data registries need to publish more and better data on PERT prescription in pancreatic cancer. NHS targets must then be created for PERT prescription, supported by clear and strong leadership from NHS England, ICS, CCGs and Cancer Alliances starting in 2022, so that everyone who needs PERT can access it from 2024 onwards.

**5. Ensure that all people with pancreatic cancer have access to molecular profiling, targeted treatments and clinical trials by 2032, in line with the NHS Genomic Medicine Service's commitments within the Long-Term Plan.**

We need to ensure that more people with pancreatic cancer are included in molecular profiling clinical studies, such as the Target National study. By 2032, everyone with pancreatic cancer should have access to molecular profiling through the NHS so that they can be given the best targeted treatment for their cancer type. Access to personalised medicines, such as Olaparib and initiatives such as Know Your Tumour in the USA, must be granted to give people the best chance of recovery.

People with pancreatic cancer have a very poor performance status, displaying significant symptom burden compared to other common cancers that are, essentially, asymptomatic at diagnosis. It is therefore incredibly difficult to recruit people with pancreatic cancer on to conventional trials that have strict inclusion and exclusion criteria. The NHS and Government must establish more pragmatic approaches to gathering treatment data from patients by establishing study framework infrastructure that allows all patients to have their treatment data collected as standard in a comprehensive and consistent way, across all levels of care, in all parts of England.

## **5. Do you have any suggestions for how to improve after-care and support services for cancer patients and their families?**

The Government must invest in a dedicated programme of continuous supportive care for people diagnosed with pancreatic cancer and their families. Two key principles of this programme should be:

- 1. Ensure Enhanced Recovery After Surgery (ERAS) principles are used as standard in the context of pancreatic surgery, and that systems have sufficient resource to enact them by 2032.**

ERAS principles have generated encouraging results in improving patient quality of life, post-operative complications, comorbidities and reducing lengths of hospital stays post-operation. However, we often hear from clinical specialists for pancreatic cancer that there is lack of capacity in the Intensive Care Unit (ICU) to provide this.

Clatterbridge Cancer Centre in Merseyside and the team at the University of Liverpool have developed a pancreatic cancer specific unit for better peri-operative management (pancreatic cancer ERAS), better nutritional optimisation (Dietitian and access to PERT) and greater physiological reserve of pancreatic cancer patients – the Pancreatic Enhanced Recovery Unit (PERU). This model is associated with reduced 30-day post-operative mortality, reduced length of stay in the hospital and has enabled 92% of surgical patients to receive adjuvant chemotherapy in 2017 (the national average based on 2015 data is 50%). We need to ensure that capacity for such interventions is increased so that everyone with pancreatic cancer who has surgery can benefit from ERAS by 2032.

- 2. Ensure that by 2032 everyone with pancreatic cancer receives tailored, holistic psychological support for pancreatic cancer patients, from the point of diagnosis.**

Recognising and managing psychological distress is particularly important for pancreatic cancer patients.<sup>11</sup> They are at higher risk of suicide than other cancer patients, especially in

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<sup>11</sup> Taylor AK, Chang D, Chew-Graham CA, et al. 'It's always in the back of my mind': understanding the psychological impact of recovery following pancreaticoduodenectomy for cancer: a qualitative study. *BMJ Open* 2021;11:e050016. doi:10.1136/bmjopen-2021-050016

the initial 6 months post-diagnosis but continuing up until 3 years post-diagnosis.<sup>12</sup> Given the progressive nature of the illness, all pancreatic cancer patients should be promptly assessed and provided with psychological support if required.

In settings where there is no access to a specialist psychological care MDT team, healthcare professionals should be provided with pragmatic guidance on making appropriate, safe and effective use of available resource, including both local and national charities. It is also important to support patient carers to understand that biological factors relating to pancreatic cancer can present as depression.

**3. The Government must ensure that by 2032, pancreatic cancer workforce numbers are stabilised and increased so that everyone with pancreatic cancer has access to specialist clinical and allied professional support.**

The resource-poor health system can limit CNS' opportunities to fully support patients psychologically, but where possible they should be encouraged to prioritise patients' welfare and engage in further training around managing patients' mental health. We need to retain and recruit more pancreatic cancer CNSs to ensure this support can be provided. Similar prioritisation needs to be done with other specialist members of the cancer workforce that provide supportive care, such as dieticians, who have the potential to have a significant impact on patients' quality of life. Greater dietician resource would also benefit other cancer patients, such as oesophageal, stomach, bowel and throat amongst others.

**4. Improve signposting of patients to patient support organisations such as Pancreatic Cancer UK.**

We need to ensure that the cancer system more effectively refers pancreatic and other cancer patients to relevant patient support organisations, such as Pancreatic Cancer UK, to make sure that what support is available is utilised. These organisations can provide expert, tailored support for patients in every step of dealing with diagnoses, symptoms, treatment and care, thus relieving significant pressure on the NHS workforce; yet only around 20% of

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<sup>12</sup> Henson KE, Brock R, Charnock J, Wickramasinghe B, Will O, Pitman A. Risk of Suicide After Cancer Diagnosis in England. *JAMA Psychiatry*. 2019;76(1):51–60. doi:10.1001/jamapsychiatry.2018.3181

people diagnosed with pancreatic cancer are currently being signposted to Pancreatic Cancer UK.

## **6. Do you have any suggestions for how can we maximise the impact of research and data regarding cancer and cancer services in England, including how we can translate research and data into practice sooner?**

The Government should commit to undertake the following actions:

### **1. Invest and sustain £35-40 million per year in research for pancreatic cancer.**

Successive governments, strategies and plans have consistently missed the opportunity to invest in pancreatic cancer research to the extent required to transform survival. Despite being the deadliest common cancer, pancreatic cancer receives only a fraction of the funding of cancers with similar case numbers, such as leukaemia (which has received four times the funding of pancreatic cancer since 2002).

This has created a precarious research environment for the disease, which inadvertently discourages researchers from undertaking innovative research – but this is essential if we are to make the breakthroughs we desperately need. Assuming research funding should be commensurate with the number of deaths in the population due to that cancer, we recommend investment should be between £35-40 million per year for pancreatic cancer, to bring spend in line with the other four biggest causes of cancer-related death (where, for example, spend per death for pancreatic cancer for 2019/20 was £2447 compared to £5402 for breast cancer).

### **2. Bring all patient health records and data under a centralised platform.**

This will create better opportunities for data analysis and research, and will enable clinical professionals to access patient records regardless of where the patient was seen.

**3. Invest in building partnerships between members of the detection research community in pancreatic cancer, and experts in the field of implementation research.**

This could be achieved through schemes that bring together and award funding specifically to multi-disciplinary research teams seeking to ensure that innovations in detection can be seamlessly adopted by NHS cancer pathways. These formats have already been used successfully in the cancer detection space. Additionally, the Government should provide the research community with networking and engagement opportunities with NHSE to ensure a balance in outcomes and economics of detection innovations, increasing the pace and efficiency of their transition out of the lab and into the clinic.

**4. Publish more and better data on pancreatic cancer, including via an annual NHSE pancreatic cancer audit from 2023 onwards.**

Improved data on pancreatic cancer is crucial – to understand people’s current experiences, what needs to be done to improve care and treatment, and how changes in care affect outcomes. More and better data will also give us the intelligence we need to improve our global standing – currently, England’s pancreatic cancer survival rates place it 28<sup>th</sup> out of 36 countries with comparable data.<sup>13</sup>

NHSE’s planned audit of pancreatic cancer services should be repeated annually from 2023 onwards, to ensure that no variations in care exist across England, by 2032.

UGI cancer waiting times operational standards (2WW, FDS, 31-day wait, 62-day wait) must be disaggregated to individual cancer types and also grouped by treatment intent such as active treatment (curative or palliative) and other care (e.g. supportive care). UGI cancer should be disaggregated to liver, pancreas, stomach and oesophageal, to determine what part of the pathway is underperforming and the delays for each cancer site. Additionally, having these data broken down by treatment intent group (including surgery, palliative chemotherapy, other care) will enable us to understand differences in operational standards between people who receive a type of active treatment and those who receive only supportive care.

Pancreatic cancer data should be broken down to exocrine PDAC and endocrine PNET, as part of the national cancer datasets routinely collected. This ask should be extended to

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<sup>13</sup> [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)33326-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)33326-3/fulltext)

international initiatives such as the CONCORD-3 programme as well as the International Cancer Benchmarking Partnership (ICBP).

We must ensure that any changes in the NCPES sampling method will also capture more and better data for individual less survivable cancers. If this is not possible, then NHSE must consider an improved methodology, or the commissioning of a separate survey for QoL and NCPES for pancreatic cancer and other less survivable cancers.

**5. Produce more and better data starting from 2023 to understand and tackle health inequalities in pancreatic cancer by 2032.**

We welcome the determination of the Secretary of State for Health and Social Care to tackle health inequalities, however we first need to understand health inequalities within this cancer in order to develop targeted strategies. Currently, data for pancreatic cancer health inequalities are very limited.

NHS England's planned audit of pancreatic cancer treatment and care should investigate and address inequalities in its data collection, as a key priority. Preliminary data suggest inequalities in the care and treatment between operable and inoperable patients; incidence rate is higher in black populations as opposed to white populations; and the risk of emergency diagnosis is higher in deprived communities. Moreover, current data imply variation in survival, diagnosis and access to treatment between Cancer Alliances, however these data are not adjusted to confounding factors and therefore any conclusions may be biased.