

# Pancreatic Cancer UK

## The Optimal Care Pathway for pancreatic cancer

A guide to implementing better and fairer standards of care across the UK

**Foreword from Diana Jupp, CEO Pancreatic Cancer UK**

“I am incredibly proud that we at Pancreatic Cancer UK have brought together members of the pancreatic cancer community including people with lived experience, healthcare professionals and healthcare improvement experts to build consensus on pancreatic cancer care for the first time.

The survival rates for pancreatic cancer care are shockingly low in the UK. But we know it doesn't need to be this way. We know that over the next decade, research breakthroughs will drive change for this cancer, but in the meantime, there is a huge amount that can be done to improve survival and drastically improve quality of life too.

Over the past few years as Chief Executive of Pancreatic Cancer UK, I have heard first hand from so many people affected by pancreatic cancer about the significant challenges they've had in getting the timely, high-quality care they need. As it stands today, the quality and speed of diagnosis, treatment and care varies substantially depending on where people live.

We must and can do better, which is why we have developed the Optimal Care Pathway. This pathway sets out what good care should look like for someone, from the point of being referred to diagnosis, to treatment and care.

We have been able to agree as a community that the NHS needs to speed up how quickly people are diagnosed, treated and cared for to give them the best chance of survival and a good quality of life. We also need to see greater standardisation in terms of the support that is available across the UK.

But, to make this Optimal Care Pathway for pancreatic cancer a reality everywhere, we know that government action is desperately needed. The NHS is already hugely stretched coming out of the COVID-19 pandemic, and we know that improvements will require more funding and capacity. That is why we will call on governments in each nation of the UK to invest in bringing this to life.

At the same time, we are confident that there is a lot that can be done by local systems to make improvements now, and set out what these are in this report. We share examples of what is already happening in certain areas and make recommendations for how NHS systems can start implementing the Optimal Care Pathway.

We believe that by working together to deliver on the Optimal Care Pathway, we can drive a huge step change in pancreatic cancer over the coming years. And, ultimately, this will help us make significant headway on our target of doubling survival rates so that many more people with pancreatic cancer survive to live long and well.”

**Diana Jupp**

Chief Executive, Pancreatic Cancer UK



## **Foreword from Professor Paula Ghaneh**

“The odds facing people with a pancreatic cancer diagnosis in the UK today are stark - UK survival rates have improved, but still lag behind much of the rest of the world.

But with the right ambition and will, I believe that change is possible.

I've been honoured to chair Pancreatic Cancer UK's Optimal Care Pathway initiative. This has, for the first time ever, brought together people affected by pancreatic cancer and experts from across the UK to build consensus on what the best treatment and care looks like— and to agree action to transform outcomes.



This report sets out the recommendations that we believe will double treatment rates and improve survival and quality of life for people affected by pancreatic cancer.

Despite the challenges the NHS currently faces, appetite to improve health services is building across the UK to tackle this awful cancer – once and for all.

In the last year we've seen the introduction of a raft of national NHS programmes on pancreatic cancer across the UK. Combined with our recommendations, these initiatives have the potential to drastically improve the odds for people diagnosed with pancreatic cancer.

We now need the leadership of governments across the UK to unlock this potential – and position the UK as one of the best countries for pancreatic cancer survival.”

### **Paula Ghaneh**

Professor of Surgery and Honorary Consultant Surgeon, University of Liverpool  
Chair of Optimal Care Pathway Steering Committee

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## **Richard Murphy's experience**

“When my wife Lynda was diagnosed with pancreatic cancer on Christmas day in 2019, the first advice was not to google it.

With an average survival time of just three months and five-year rates that had barely changed in the last 50 years, it was a grim moment for us. The cancer was caught just in time for her to have surgery and, having been incredibly ill, she made an amazing recovery. Given what we had learned about this terrible disease and the need for improved diagnosis and treatment, we then started to volunteer with Pancreatic Cancer UK. Sadly, Lynda's cancer returned, and she died in December 2021, aged just 51.

Pancreatic Cancer UK asked me if I wanted to join the Optimal Care Pathway project as a patient/carer voice and I was delighted to be able to do so. For me, this meant there was a focused way to continue the work Lynda and I had done together.

It has been a privilege to be part of this project to put this report together, working with experts from so many different fields and with those, like me, who brought their personal experiences to the discussions. There are so many opportunities identified in this document which can improve the outcomes for other families facing this diagnosis in the future.

Whether your role is in providing cancer care directly or in the wider community, I hope that this report inspires you to play a part in delivering change.”

**Richard Murphy,**  
Optimal Care Pathway steering committee member



For too long, pancreatic cancer has been left behind. Survival rates have improved enormously for most cancers but sadly, for pancreatic cancer, this is not the case. Currently, more than half of people diagnosed with pancreatic cancer die within 3 months.

Pancreatic cancer is tough to detect. And even once it's spotted, people can go on to face potentially huge obstacles: from getting a diagnosed quickly, accessing treatment and having the support they need to manage symptoms. People face a postcode lottery of care depending on where they live in the UK and all these factors impact people with pancreatic cancer's quality of life and chance of survival.

This is why, in 2021 Pancreatic Cancer UK embarked on the Optimal Care Pathway initiative. As part of this, we have brought together a community of health professionals and people with lived experience across the UK to understand the obstacles people face, and agree what needs to happen to improve diagnosis, treatment and care.

Based on this, as one unified voice we have worked together to develop **what an Optimal Care Pathway for pancreatic cancer should look like**. As part of this, we have agreed three crucial areas in which we need to see improvements for people with pancreatic cancer:

<b>1. Fairer Care:</b> Everyone should get advice, care and support from dedicated expert professionals from diagnosis.
<b>2. Faster Diagnosis:</b> Everyone should have their diagnosis confirmed or ruled out within 21 days of being sent for tests.
<b>3. Faster Treatment:</b> Everyone should start treatment within 21 days of diagnosis.

For each of these three areas, this guide outlines in detail:

- What high-quality **diagnosis, treatment and care** looks like for people with pancreatic cancer and healthcare systems,
- The **impact** better and fairer standards of care would have for people with pancreatic cancer and their loved ones,
- What **NHS systems** and **healthcare professionals** across the UK can do to implement better and fairer standards of care,
- Any **gaps in evidence and research that still exist** in some areas.

**Recommendations for NHS systems to implement the Optimal Care Pathway for pancreatic cancer**

As a community, we have agreed that **NHS systems and healthcare professionals across the UK** can drive implementation of the Optimal Care Pathway by committing to delivering on **6 key recommendations**, as laid out below, and expanded on throughout this report:

**Recommendation 1**

NHS systems should ensure that from the point of diagnosis and throughout a patient’s care, everyone with pancreatic cancer should be pro-actively offered support and care tailored to their needs. This includes ensuring:

- Access to prehabilitation and rehabilitation services,
- Access to better nutritional management and specialist dietetic services,
- Access to better psycho-social support services,
- Access to better post-resection follow up care for people living beyond pancreatic cancer.

**Recommendation 2**

NHS systems should ensure that everyone with pancreatic cancer has access to a 24/7 rapid access enhanced care service to get support with the symptoms and side effects of their cancer. This model should be a service delivery and rapid referral hub with close links to other specialist, secondary and local healthcare teams.

**Recommendation 3**

NHS systems should ensure that everyone with pancreatic cancer, regardless of where they are treated or cared for, has a hepato-pancreato-biliary or upper gastrointestinal clinical nurse specialist (HPB/UGI CNS) as their lead point of contact to oversee their care.

**Recommendation 4**

NHS systems should ensure that everyone with pancreatic cancer is diagnosed within 21 days of referral for suspected cancer.

**Recommendation 5**

NHS systems should ensure that treatment pathways are standardised depending on tumour classification and staging, so that everyone with pancreatic cancer has a fair chance of accessing life extending, or life-saving treatment.

**Recommendation 6**

NHS systems should ensure that treatment should be initiated within 21 days from confirmed diagnosis (and 42 days from referral) where appropriate, for people with pancreatic cancer.

We recognise that for the Optimal Care Pathway to be fully implemented across the country, NHS systems will require sustained, additional funding from governments and national NHS organisations. **That’s why in parallel we will be calling on governments and national NHS organisations to make this happen.**

## Introduction and our case for change

### 1.1 Pancreatic cancer is the deadliest common cancer

Pancreatic cancer affects 10,000 people a year in the UK and is the deadliest common cancer, with shocking five-year survival rates of just 7%, which have barely changed in the last fifty years <sup>1</sup>.

More than half of people with pancreatic cancer die within 3 months, while around 75% die within one year of diagnosis <sup>2</sup>. This makes pancreatic cancer eight times more deadly than other common cancers.

Although pancreatic cancer is the least survivable cancer globally, the UK lags far behind the rest of the world. Figure 1 outlines the UK’s survival ranking amongst other countries – it ranks 26<sup>th</sup> out of 33 countries with reliable data and similar economies to the UK <sup>3</sup>. This means that the UK has the potential to make significant improvements in survival and – over time - become a world leader.

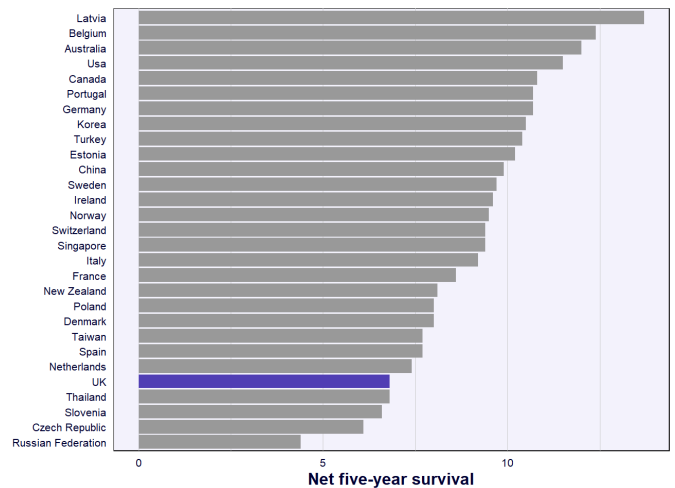


Figure 1: Survival rates for pancreatic cancer

**Table 1: Pancreatic cancer statistics by UK nation (to note, the data captured by each nations’ registries varies)**

<p><b>England:</b></p> <ul style="list-style-type: none"> <li>• Five-year survival (data to 2015): 6.6%</li> <li>• One year survival (2017-2019): 23.2%</li> <li>• Emergency admission rate (2013-2019): 55.8%</li> <li>• Incidence per 100000 (2018-2020): 17.3</li> <li>• Incidence per 100000 (2018-2020): 15.2</li> </ul>	<p><b>Wales:</b></p> <ul style="list-style-type: none"> <li>• Five-year survival (2015-2019): 9.3%</li> <li>• One-year survival (2015-2019): 25.9%</li> <li>• Incidence per 100000 (2015-2019): 16.4%</li> </ul>
<p><b>Scotland:</b></p> <ul style="list-style-type: none"> <li>• Five-year survival rate (2010-2014): 7.3%</li> <li>• One-year survival (males, 2013-2017): 21.9%</li> <li>• One-year survival (females, 2013-2017): 22.5%</li> <li>• Incidence per 100000 (2021): 16.4</li> </ul>	<p><b>Northern Ireland:</b></p> <ul style="list-style-type: none"> <li>• Five-year survival (2019-2020): 8%</li> <li>• One-year survival (2016-2020): 24.1%</li> <li>• Emergency admission rate (2015-2019): 42.6%</li> <li>• Incidence per 100000 (2016-2020): 16.6</li> <li>• Mortality per 100000 (2016-2020): 15.6</li> </ul>

<sup>1</sup> [Pancreatic cancer statistics](#), Cancer Research UK. Accessed October 2023.

<sup>2</sup> [Cancer survival in England, 2015-2019](#), National Cancer Registration and Analysis Service (NCRAS). Accessed October 2023.

<sup>3</sup> Allemanni *et al.*, 2018 Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries *Lancet* 17;391(10125):1023-1075. doi: [10.1016/S0140-6736\(17\)33326-3](https://doi.org/10.1016/S0140-6736(17)33326-3)



## 1.2 Our Optimal Care Pathway initiative to improve pancreatic cancer services

We believe everyone should be able to access high quality treatment and care no matter where they live. But we know from national datasets on pancreatic cancer, as well as from experiences shared with our Specialist Nurses who run our Support Line, that there is considerable variation in people's access to care. While formal clinical guidelines to improve diagnosis, treatment and care of people with pancreatic cancer exist across the UK, we know that these are not implemented consistently.

We know there are several drivers of poor outcomes and variations in care. These include the following:

- The fact that national and NHS systems are under-resourced, including the cancer workforce, which makes it challenging to fully implement clinical guidelines,
- There has been a lack of consensus amongst expert pancreatic cancer health professionals on how to implement formal guidelines, which contributes to inconsistency in care for people with pancreatic cancer,
- Clinical guidelines do not cover all aspects of care in detail. For example, the National Institute for Health and Care Excellence (NICE) guidelines do not provide detailed recommendations for prehabilitation and rehabilitation pathways,
- Formal guidelines do not always reflect the latest clinical evidence, as advances often develop at a rapid pace.

That's why in September 2021 our charity launched a UK-wide initiative known as the Optimal Care Pathway. In this, we have brought together expert health professionals, healthcare service improvement experts and people affected by pancreatic cancer from across the UK. Together, we have worked to better understand the issues people face and achieve a consensus on what better care looks like. Our initiative has drawn on national and international evidence and is looking to build on existing guidelines and resources<sup>4</sup>. It seeks to:

- Offer evidence-based, clinically supported recommendations,
- Support national policy development, such as the design and delivery of national clinical audits and faster diagnosis pathways for pancreatic cancer. We are working in tandem with and feeding into other national initiatives, to ensure they are aligned and deliver effective results: See **Appendix 1** to find out more on health improvement programmes taking place across the UK.

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<sup>4</sup> - [Pancreatic cancer in adults: diagnosis and management](#) 2018. NICE guideline NG85. Accessed October 2023

- [National Optimal Pathway for Pancreatic Cancer](#) 2020. NHS Wales Health Collaborative. Accessed October 2023

- [HepatoPancreatoBiliary Cancers National Follow-up Guidelines](#) 2016 National Scottish Guidelines. Accessed October 2023

- Khorana *et al.*, 2019 Potentially Curable Pancreatic Adenocarcinoma: ASCO Clinical Practice Guideline Update *J Clin Oncol* 37(23):2082-2088 doi: [10.1200/JCO.19.00946](#)

- Sohal *et al.*, 2020 Metastatic Pancreatic Cancer: ASCO Guideline Update *J Clin Oncol* 38(27):3217-3230 doi: [10.1200/JCO.20.01364](#)

- Tempero *et al.* 2021 National Comprehensive Cancer Network (NCCN) Pancreatic Adenocarcinoma guideline *J Clin Oncol* 37 (23): 2082-2088 doi: [10.1200/JCO.19.00946](#)

- [Optimal care pathway for people with pancreatic cancer](#) 2021. Cancer Council, Australia. Accessed October 2023

**1.3 Key issues facing people with pancreatic cancer**

By working together as a community and through wider consultation and engagement with people affected by pancreatic cancer, we have identified key issues in pancreatic cancer care. In the following sections, we summarise what these are.

*1.3.1 Many people do not receive joined up care*

One of the most common challenges people told us they face is in getting the joined up care they need. Too often, people struggle to navigate the healthcare system and are not offered clear information about their pathway or emotional support to help them through their journey.

Poor communication between different healthcare teams was also seen as a significant issue for people when trying to access the right care. Related to this, many report being discharged from hospital without a support plan in place, or without vital help to manage their symptoms to be able to live longer and well.

‘[He was] passed around like a rugby ball. 6 hospitals for 6 procedures’  
**Jo, Pancreatic Cancer UK Transforming Care workshop participant**

*1.3.2 Many people face delays in getting a diagnosis*

Pancreatic cancer is tough to detect and often diagnosed late. Only 20% are diagnosed early (stage 1 and stage 2), while 80% of people are diagnosed late, at stage 3 and 4. This is one of the quickest killing cancers – it progresses rapidly, often becoming incurable within months, yet the vague presenting symptoms and need for multiple tests make it tough to diagnose.

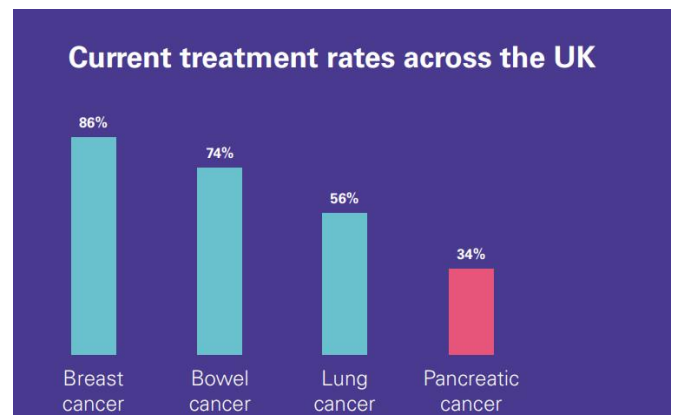
Delays in processes and decision-making when carrying out, chasing and reviewing diagnostic tests and results mean that diagnosis often comes too late. This can result in people losing out on the opportunity to access treatment and care options available to them to live longer and well.

‘Continually chasing test results and telling story over and over’  
**Anon, Pancreatic Cancer UK Transforming Care Workshop participant**

*1.3.3 The vast majority do not receive treatment*

Currently, 70% of people with pancreatic cancer do not receive any form of active treatment. This is the lowest proportion of treatment access of all cancers. For example, as shown in Figure 2, breast cancer has an 86% access to treatment rate<sup>5</sup>.

Surgery, followed by adjuvant therapy (or neo-adjuvant therapy followed by surgery when clinically indicated), is the only potentially curative treatment for people with



**Figure 2:** Access to treatment rates for common cancers

<sup>5</sup> [Chemotherapy, Radiotherapy and Surgical Tumour Resections in England, 2013 – 2020](#), National Cancer Registration and Analysis Service (NCRAS). Accessed October 2023

pancreatic cancer. However, only 10% of people with pancreatic cancer currently have surgery.

For those not eligible for surgery, chemotherapy and radiotherapy are potential treatments to improve their quality of life and often extend or increase their chances of survival. However, only 20% of people with pancreatic cancer will receive any form of palliative chemotherapy and/or radiotherapy.

Current NHS targets call for treatment to be started within 62 days of referral<sup>6</sup>. We believe this is too long to wait in the case of pancreatic cancer as the disease progresses rapidly, with over half of people dying within three months.

“Our dad, Clive, was always a very fit and healthy man. His passion was walking, and he loved the great outdoors. He was a very involved, loving grandparent.

In summer 2019 he started to feel like something wasn't right – but he just wasn't a priority. After going to his doctor multiple times over the course of a year, he was finally sent for a scan.

That's when Dad was told “it is your pancreas, prepare for the worst”. But he heard nothing and was left in limbo. He had to keep chasing the scan results. Then he was given his diagnosis: stage four pancreatic cancer.

Dad was told he could have six to 12 months to live with chemo and three to six without. He signed himself up straight away. He was still fit and healthy, and he was told he was “the perfect chemo candidate”.

But after being given his chemo schedule, dad waited and waited – and then it felt like he was dropped. Dad was still healthy when he was diagnosed, but his treatment didn't come fast enough. He started to have issues digesting food and was beginning to lose weight, and then he really went downhill. He had no support to manage these symptoms. Everything seemed so slow and the communication non-existent.

Finally, he was told that chemo was now no longer an option for him. Dad died on 8 November 2020 aged 67, just 12 weeks after diagnosis. He spent seven of these weeks waiting for his treatment to start. If his chemo had started earlier, maybe we would have had a chance to do more things with him. Just a bit more time.”

**Nicola Allen, 43, Kent**



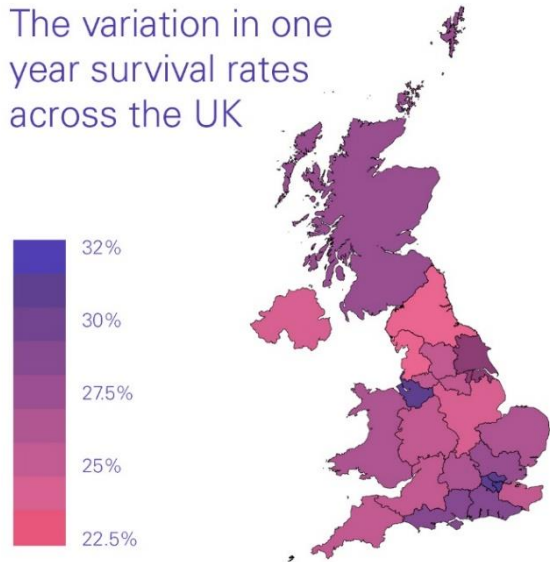
**Figure 3:** Clive with his granddaughter Grace and grandson Joe

<sup>6</sup> Cancer Waiting Times. [NHS England](#), [N Ireland Department of Health](#), [Public Health Scotland](#), [Wales Parliament](#). Accessed October 2023

**1.3.4 People’s chances for one-year survival vary significantly across the UK**

Challenges in getting a diagnosis, treatment and care are compounded by variations in pathways and access to services that exist across the UK. This contributes to a variation in people’s chance of survival depending on where they live. Currently, one-year survival for pancreatic cancer across the UK ranges from 21.3% to 29.1% (see Figure 4) <sup>7</sup>.

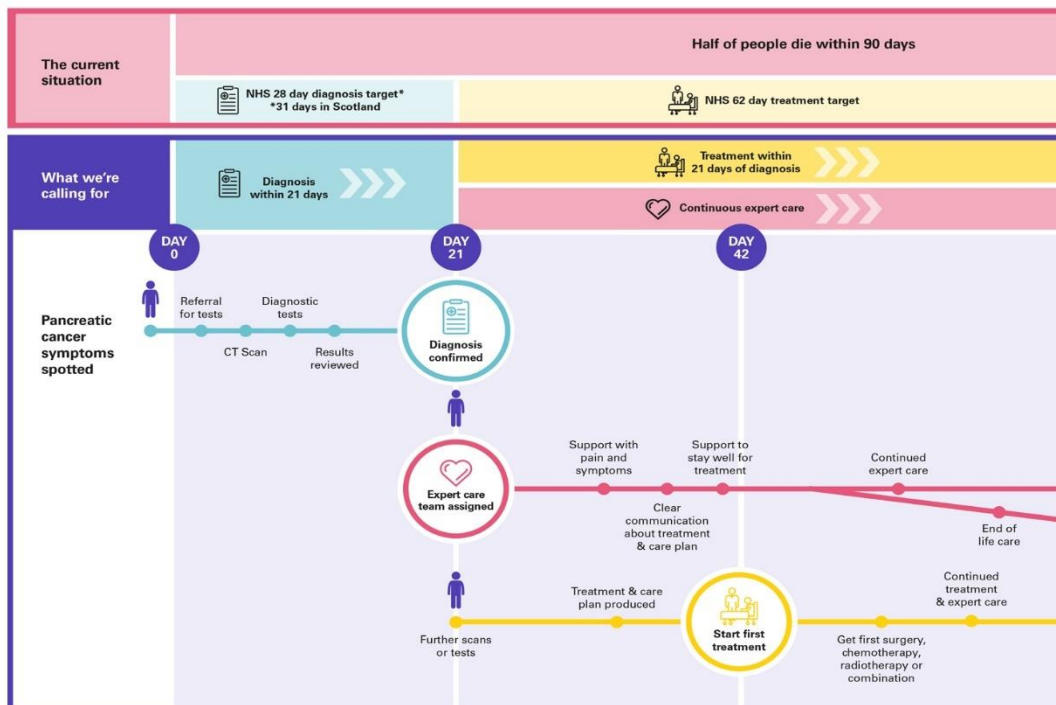
The variation in one year survival rates across the UK



**Figure 4:** Map showing variation in survival rates across the UK

We know that there are many contributing factors to the existence of variation, including a lack of agreement amongst health professionals about what good standards of care look like, and differences in the capacity and expertise of the workforce.

**1.4 Our solution: A UK-wide Optimal Care Pathway to improve people with pancreatic cancer’s chance of survival and quality of life**



**Figure 5:** Schematic of the Optimal Care Pathway

<sup>7</sup> [Cancer survival in England 2015-2019](#). National Cancer Registration and Analysis Service (NCRAS). Accessed October 2023

People with pancreatic cancer urgently need a **faster, fairer and funded** care pathway through their diagnosis, treatment and care. To see this realised, we have developed a guide for NHS systems and healthcare professionals on how to implement this. Figure 5 outlines what our Optimal Care Pathway guide calls for.

We know improvements in pancreatic cancer care are possible, as this has been realised in other cancer types like lung cancer, over the past 20 years. Moreover, the Australian Government endorsed an Optimal Care Pathway for pancreatic cancer<sup>8</sup> that was developed by patients, health professionals and patient organisations and in 2022 the government provided funding to roll this out<sup>9</sup>. Now, Australia that has one of the best survival rates for pancreatic cancer (and cancer overall) in the world. However, we cannot do this alone. We need governments and NHS systems to prioritise implementing much needed changes in pancreatic cancer care. To do this, we need to see:

- **Governments and NHS organisations across the UK invest funding** needed for the Optimal Care Pathway to be implemented everywhere in the UK.
- **Healthcare professionals and NHS health systems** work together to improve pancreatic cancer care in their area now by committing to implement the recommendations we set out in this guide.

## Lung cancer: a case study

Over the last 20 years, lung cancer has seen governments commit to many national initiatives that have started to turn the tide on survival, more than doubling five-year survival from 7% to 16%.

- In 2005, the first National Lung Cancer Audit kickstarted the spread of national improvements in England so that the number of people receiving surgery more than doubled from 3,000 in 2005 to over 8,000 in 2022.
- In 2017, the first National Optimal Lung Cancer Pathway was published, providing a road map for the best care and treatment for people with lung cancer.
- In 2019, NHS England's Long Term Plan called for the roll-out of targeted lung cancer screening, as a part of the ambition to diagnose 75% of cancers at an early stage.
- Now, other nations are following this example. The Scottish Government recently invested £3 million in an Optimal Lung Cancer Diagnostic Pathway with the aim that all people with lung cancer should be diagnosed by day 21, and start treatment by day 42 – which is what we're now demanding for pancreatic cancer.

## 1.5 The impact of a fully implemented Optimal Care Pathway for people with pancreatic cancer and health systems

Our modelling shows that if the Optimal Care Pathway is implemented everywhere, the UK could become a global leader in improving outcomes and survival rates for pancreatic cancer (Figure 6)<sup>10</sup>. If the pathway becomes a reality across the UK, we believe the following would happen:

<sup>8</sup> [Optimal care pathway for people with pancreatic cancer](#), June 2021. Accessed October 2023

<sup>9</sup> [New hope for Australians affected by pancreatic cancer](#). Announcement by Australian Government 1<sup>st</sup> April 2022

<sup>10</sup> **Modelling methodology:**

- **Datasets used:** [Office for National Statistics at population projections for England, England detailed statistics for pancreatic cancer](#). Accessed October 2023, Exarchakou *et al.*, 2020 Pancreatic cancer incidence and survival and the role of specialist centres in resection rates in England, 2000 to 2014: A population-based study *Pancreatology* 20(3):454-461 doi: [10.1016/j.pan.2020.01.012](#)
- **Methodology and assumptions made:** The Optimal Care Pathway will double treatment rates by 2028. The Optimal Care Pathway rollout begins in 2023 and increase in treatment rate is linear up to 2028. All patients diagnosed with pancreatic ductal adenocarcinoma (PDAC) in stage 1 or stage 2 are eligible for resection and adjuvant chemotherapy. All patients diagnosed with PDAC in stage 3 are eligible for neoadjuvant chemotherapy, and 10% of those patients will become resectable. The stage breakdown of the unknown stage category reflects the overall pattern of staging. Survival rates of resected and non-resected patients follow the results presented in Exarchakou *et al* 2020 (*Pancreatology* 20:454-461), which were estimated based on row-level data from the NCRAS registry.

1. People with pancreatic cancer and their loved ones' quality of life would improve because:
  - They would know what to expect from their care and feel confident and supported by their healthcare team,
  - They would be given the right care at the right time.
  
2. People with pancreatic cancer would have better access to treatment and a greater chance of survival because:
  - They would be diagnosed fast enough to receive treatment such as surgery, chemotherapy, and radiotherapy,
  - Through this, 1 year survival would increase from 25% to 33%, meaning 842 more people with pancreatic cancer every year will live longer than 1 year. In addition, 5 year survival would increase from 7% to 10%, which would equate to 265 more people with pancreatic cancer every year living longer.
  
3. Capacity and efficiency of the wider healthcare system would improve, which would mean:
  - More people get the right care at the right time, meaning fewer hospital and emergency admissions and readmissions.



**Figure 6:** How treatment and survival rates could be transformed with a fully implemented Optimal Care Pathway.

**Mary's story: showing what's possible**

**In October 2020 Mary Farley was walking home from work when she was struck with extreme tiredness. She also experiencing an itchiness all over, but explained it away. Later, when two people noticed her eyes were yellow, she rang her doctor.**

**“My symptoms were spotted right away”**

“At the appointment, my doctor looked at my eyes and the palm of my hand and told me to go to the hospital right away. When I told her I finish work at 3.30, she said “No, I want you to go now. I'm sending through the details to your hospital.”

**“I was given my diagnosis of pancreatic cancer within 48 hours of being sent to hospital”.**

“At the hospital they took my bloods, and the next day for my ultrasound. The day after they did a CT scan. The doctor told me they had found a mass – and that I had pancreatic cancer. I'd never really heard of pancreatic cancer, but I was sitting on the side of the bed and the tears were hitting my hands. I asked him how big the mass was, and he said about the size of a peanut.”

**“10 days later I had my surgery to remove the cancer.”**

“The doctor reassured me that they believed they had caught me in time. He talked through the Whipple's operation, but he said we had a lot of steps to go through first before we could get there.”

“The first one was to put a stent in the bile duct to drain it. Then I had another CT scan to make sure it hadn't spread anywhere else. Thankfully this came back clear.”

“It wasn't long before they came in to tell me they could do the operation. When I had my operation, I was on the table for about eight hours.”

**“I've never once felt alone.”**

“My medical team kept me informed throughout and told me what to expect. I was surrounded by people that were straightforward and helpful. If I had any worry, I just had to ask a question and it was answered truthfully.”

“As I recovered, they talked me through why I had to have Pancreatic Enzyme Replacement Therapy tablets. At first, the food was going straight through me, but they worked with me, chopping, and changing what I was eating and how many tablets I should take until we found something that worked for me.”

“After five months of chemotherapy, I was told I was cancer-free. It's now been two years and I'm still receiving amazing support. I know if I've got any kind of worry or something comes up, I can just pick that phone up and ask for my clinical nurse.”



**Figure 7:** Mary holding Lylah, her granddaughter.

**Mary Farley, London**

## Our guide to what a better and fairer care should look like

Based on available evidence and clinical consensus from our expert community, this chapter outlines the standards of better and fairer care that we want everyone with pancreatic cancer to receive from the point of diagnosis and throughout the pathway. This is the standard we believe everyone with pancreatic cancer should receive, regardless of where they live, their disease stage or what healthcare setting their diagnosis, treatment and care is given.

### 2.1 What we mean by better and fairer care in pancreatic cancer

**Table 2: Defining ‘care’ in this report**

#### What do we mean by ‘care’?

We define care using Fitch’s (2008) model of care which defines the following Need Categories <sup>11</sup>:

- Physical e.g. pain, fatigue, early satiety, nausea/vomiting,
- Informational e.g. communication with patients and caregivers, help with decision-making,
- Emotional e.g. fear, distress,
- Psychological e.g. changes in lifestyle, major depression or anxiety disorders,
- Social e.g. social relationships, interpersonal communication,
- Spiritual e.g. examine personal values and priorities,
- Practical e.g. daily home help, transportation.

In this report, the above categories are packaged in three wider areas; **high-quality care, support and personalised information** to live longer and well.

#### Staging of tumour definitions

Throughout this chapter and report, we refer to the care that everyone with pancreatic cancer should receive, regardless of their staging at diagnosis. Where appropriate, we also reference any specific care someone should receive based on the staging of their tumour.

**Table 3: Tumour staging definitions**

Tumour staging	Definition
Resectable at diagnosis	The tumour is contained inside your pancreas. This is early, localised pancreatic cancer. It is also called operable or resectable cancer because surgery may be possible.
Borderline resectable at diagnosis	The tumour that has grown very close to the major blood vessels near the pancreas (it has some vascular involvement). This classification is contested by health professionals both in terms of the definition itself and due to variation in reporting. The adoption of standardised radiology reporting tools would help to minimise variation in approach to staging a tumour <sup>12</sup> .
Locally advanced at diagnosis	The tumour is touching a vein or artery at an angle that is 180 degrees or it has spread to a number of lymph nodes.
Metastatic at diagnosis	The tumour has spread to other parts of the body, such as the liver, lungs or peritoneum.

<sup>11</sup> Fitch 2008 Supportive Care Framework *Can Oncol Nurs J* 18(1):6-24 doi: [10.5737/1181912x181614](https://doi.org/10.5737/1181912x181614).

<sup>12</sup> Please see Chapter 4 for more information about standardised radiology reporting tools



## 2.2 The current problems in accessing care

A pancreatic cancer diagnosis can be devastating and, alongside the complex range of severe symptoms that come with this disease, the impact on quality of life for people with pancreatic cancer can be significant<sup>13</sup>. High-quality care and personalised information throughout the pathway are essential to ensure that people with pancreatic cancer get the right support they need to manage their symptoms and stay well.

In 2022, we ran a series of consultation activities with 123 people affected by pancreatic cancer. This exercise found that on average, the most common challenges people faced in getting help with their pancreatic cancer were:

- Feeling like they were ‘fighting the system’ e.g. having to chase test results/follow up,
- Facing long delays to diagnosis due to misdiagnosis or inconclusive investigations,
- A lack of joined up care including poor communication between different departments and/or no one taking ‘ownership’ of care plans,
- A lack of emotional support for people with pancreatic cancer and their families.

These findings reflect the most recent results from NHS England’s 2022 Cancer Patient Experience Survey (CPES). This found people with pancreatic cancer gave a significantly lower score than the national average for multiple questions in the survey, including the average overall rating of care<sup>14</sup>.

People with pancreatic cancer commonly experience a complex range of often severe symptoms and poor performance status from the point of being referred for a diagnosis. These symptoms can play a significant role in survivability and quality of life, as they can increase and result in people becoming too unwell and frail to access and/or tolerate stronger treatment, clinical trials or any treatment at all<sup>15 16 17</sup>.

Within this context, many people told us they struggle to navigate the healthcare system to get the care and support they need to stay as well as possible. We heard that many feel left in the dark about their options and do not know where to turn for support - they are left chasing test results and information about the next steps in their care. Or, if their cancer is unresectable (the cancer can’t be removed by surgery), people have told us they feel abandoned by the system, struggling to find out what their options for treatment and support are. In turn, this leaves too many feeling ill-informed and disempowered about their choices.

Due to the complex symptoms associated with the disease and the poor disease prognosis, people with pancreatic cancer often experience high levels of psychological distress. People with pancreatic cancer are more likely to be at risk of suicide than people with other cancer types (2<sup>nd</sup> highest risk after mesothelioma); suicide risk was highest in the first 6 months following diagnosis<sup>18</sup>.

The fact that many people with pancreatic cancer and their loved ones are struggling to get the joined up and coordinated care they need is – overall – contributing to higher levels of distress and poorer quality of life.

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<sup>13</sup> Watson *et al.*, 2019 Experiences and supportive care needs of UK patients with pancreatic cancer: a cross-sectional questionnaire survey *BMJ Open* 9:e032681. doi:[10.1136/bmjopen-2019-032681](https://doi.org/10.1136/bmjopen-2019-032681)

<sup>14</sup> [National Patient Experience Survey England 2022](#) NHS England. Accessed August 2023.

<sup>15</sup> Tas *et al.*, 2013 Performance status of patients is the major prognostic factor at all stages of pancreatic cancer. *Int J Clin Oncol* 18(5):839-46 doi: [10.1007/s10147-012-0474-9](https://doi.org/10.1007/s10147-012-0474-9)

<sup>16</sup> Catalano M *et al.*, 2022 The impact of age, performance status and comorbidities on nab-paclitaxel plus gemcitabine effectiveness in patients with metastatic pancreatic cancer. *Sci Rep* 12, 8244 doi: [s41598-022-12214-4](https://doi.org/10.1038/s41598-022-12214-4)

<sup>17</sup> Dominik *et al.*, 2019 Chemotherapy of pancreatic cancer in patients with poor performance *Chinese Clin Oncol* 8:Suppl 1 doi: [10.21037/cco.2019.08.01](https://doi.org/10.21037/cco.2019.08.01)

<sup>18</sup> Henson *et al.*, 2019 Risk of suicide after cancer diagnosis in England *JAMA Psychiatry* 76(1):51–60 doi: [10.1001/jamapsychiatry.2018.3181](https://doi.org/10.1001/jamapsychiatry.2018.3181)

<b>Table 4: Recommendations for health professionals and NHS systems to improve care for people with pancreatic cancer</b>	
<b>Recommendation 1:</b>	<i>NHS systems should ensure that from the point of diagnosis and throughout people’s pathway, everyone with pancreatic cancer should be pro-actively offered support and care tailored to their needs. This includes ensuring:</i> <ul style="list-style-type: none"> <li>• <i>Access to prehabilitation and rehabilitation services,</i></li> <li>• <i>Access to better nutritional management and specialist dietetic services,</i></li> <li>• <i>Access to better psycho-social support services,</i></li> <li>• <i>Access to better post-resection follow up care for people living beyond pancreatic cancer.</i></li> </ul>
<b>Recommendation 2:</b>	<i>NHS systems should ensure that everyone with pancreatic cancer has access to 24/7 rapid access enhanced care so they can get support with the symptoms and side effects of their cancer. This should be a service delivery and rapid referral hub with close links to other specialist, secondary and local healthcare teams.</i>
<b>Recommendation 3:</b>	<i>NHS systems should ensure that everyone with pancreatic cancer, regardless of where they are treated or cared for, has a hepato-pancreato-biliary or upper gastrointestinal clinical nurse specialist (HPB/UGI CNS) as their lead point of contact to oversee their care.</i>

**2.3.1 Recommendation 1: Improved proactive support and care for everyone with pancreatic cancer**

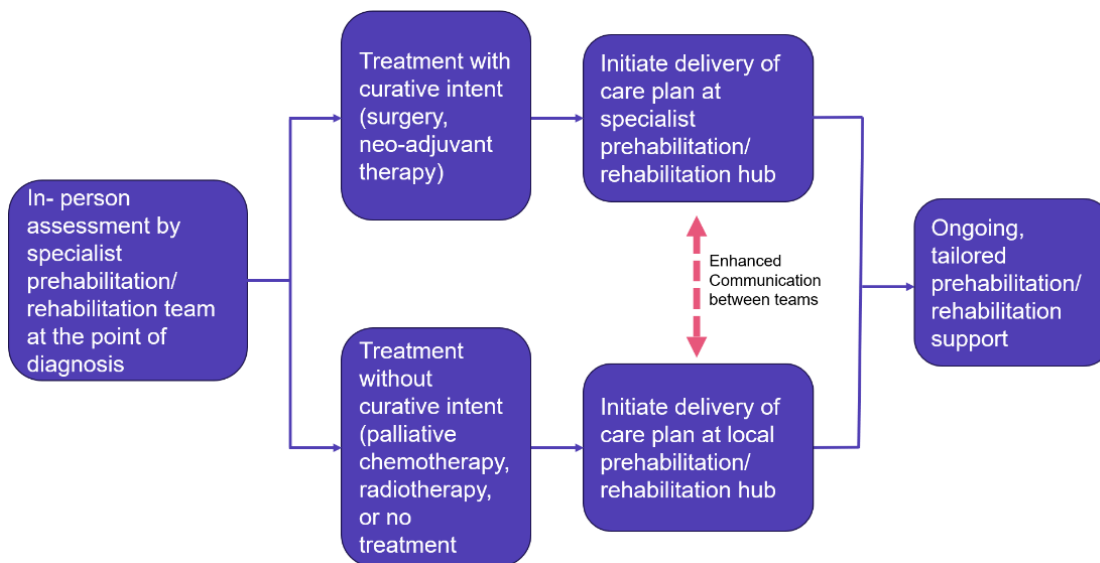
At the point of diagnosis - and often while waiting for a diagnosis - people with pancreatic cancer are commonly already experiencing poor performance status, nutritional deficiency and weight loss, pain, fatigue and high levels of psychological distress. As a result, people quickly become too unwell to access and tolerate treatment for pancreatic cancer.

The below sections outline how we want to see recommendation 1 delivered across the areas we set out, as this is a crucial element in enabling people to maintain good physical and mental health.

1. Access to prehabilitation and rehabilitation services

A **multidisciplinary prehabilitation and rehabilitation service** combines exercise, nutrition and psychological strategies to improve a person’s performance status, ability to tolerate treatment, recovery time after treatment and general health and wellbeing. These services have traditionally been offered to people accessing active anti-cancer treatment, but we believe everyone with pancreatic cancer should be offered access to these too.

Below, we outline the prehabilitation and rehabilitation pathway we believe needs to be established for pancreatic cancer, based on whether a person is being supported on a pathway with curative or non-curative intent.



**Figure 8:** Prehabilitation and rehabilitation pathways based on curative or non-curative intent

We have also agreed as a community – based on the evidence - what a prehabilitation and rehabilitation service should involve to ensure that it meets people with pancreatic cancer’s needs.

**Table 5: Further details on how local health systems and health professionals can offer better prehabilitation and rehabilitation services for pancreatic cancer**

Service characteristics	Overview
<b>Holistic assessment</b>	<p>This should be undertaken in-person at the point of diagnosis. It should involve a hepato-pancreato-biliary or upper gastrointestinal clinical nurse specialist CNS (HPB/UGI CNS) who should assess psychological, nutritional, and physical impact and refer to relevant support such as:</p> <ul style="list-style-type: none"> <li>• Specialist - ideally HPB, or alternatively specialist oncology/prehabilitation dietitian to assess nutritional status and advise on use of Pancreatic Enzyme Replacement Therapy (PERT),</li> <li>• Physiotherapist to assess physical fitness,</li> <li>• Psychological services to address psychological impact.</li> </ul>

<p><b>Delivery format</b></p>	<p>People receiving treatment and care, or care only, with no curative intent have different support and care needs from those suitable for treatment with curative intent. This should be considered when developing prehabilitation and rehabilitation services.</p> <p>Enhanced communication and rapid access referrals between prehabilitation and rehabilitation services are crucial to ensure that people with pancreatic cancer can be given the right support at the right time. For example, if someone stops receiving curative treatment, they are referred to a non-curative prehabilitation/rehabilitation team.</p> <p>Flexibility in service delivery is essential. Ideally, when a prehabilitation and rehabilitation service is in-person, it should be delivered locally. Many people with pancreatic cancer, particularly those who live in rural areas, may not be able to travel due to their health. If a person is unable to travel to get support, home visits or transfers to a specialist centre should also be made available.</p> <p>The following delivery formats should be offered and agreed with the person with pancreatic cancer:</p> <ul style="list-style-type: none"> <li>• One-to-one support,</li> <li>• In-person groups,</li> <li>• Online support,</li> <li>• Information videos,</li> <li>• Weekly telephone calls.</li> </ul>
<p><b>Support covered</b></p>	<p>The following types of support should be covered:</p> <ul style="list-style-type: none"> <li>• Exercise,</li> <li>• Nutritional aspects of care; calories and protein intake,</li> <li>• Psychosocial support,</li> <li>• Peer support,</li> <li>• Pain and fatigue management,</li> <li>• Financial advice,</li> <li>• Signposting to wider support including complementary therapies,</li> <li>• Peer support,</li> <li>• Smoking cessation.</li> </ul>
<p><b>Team membership</b></p>	<p>A number of specialisms should be covered as part of the prehabilitation and rehabilitation service to meet the needs of people with pancreatic cancer:</p> <ul style="list-style-type: none"> <li>• Physiotherapist and exercise instructor,</li> <li>• Occupational therapist,</li> <li>• Complementary therapies,</li> <li>• Welfare rights,</li> <li>• Hub coordinator,</li> <li>• Administration support.</li> </ul>

	<p>In addition, people who are suitable for active anti-cancer treatment with curative intent should have access to a HPB/UGI CNS and specialist HPB dietitian as part of a prehabilitation/rehabilitation service.</p> <p>People who are suitable for anti-cancer treatment with no curative intent and people who are not suitable for any anti-cancer treatment should have access to a community/district general/general practitioner nurse and local oncology specialist dietitian.</p>
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## 2. Better access to nutritional management

Weight loss is a very common symptom for people with pancreatic cancer - 80% of those with cancer located in the head of the pancreas present with weight loss at diagnosis<sup>19</sup>. A contributing factor is pancreatic exocrine insufficiency (PEI)<sup>20</sup>. The pancreas plays a vital role in digesting food, as it produces enzymes that break down food. Pancreatic cancer can affect this process, meaning people with pancreatic cancer don't get all the nutrients they need from food.

This can cause symptoms including weight loss and malnutrition, as well as indigestion, nausea, bloating, diarrhoea, erratic blood glucose levels and acid reflux<sup>21</sup>. Poor nutritional status can also affect a person's ability to tolerate treatment, increase the risk of poor wound healing, hospital readmissions, pancreatic fistula and chest infection, as well as lead to increased length of hospital stay<sup>22</sup>.

Anti-cancer treatments (for pancreatic cancer) have many implications on nutritional status, including delayed gastric emptying resulting in nausea, reflux and early satiety, poorly controlled diabetes, malabsorption due to PEI and/or external biliary drains or jaundice, side effects of chemotherapy causing diarrhoea, constipation, taste changes, sore mouth and physical barriers to eating such as peripheral neuropathy<sup>23</sup>. Pancreatic surgery also predisposes people to other predominantly nutritionally managed conditions, such as bile acid malabsorption and micronutrient deficiency which impact on quality of life with high prevalence of anaemia and increased risk of osteoporosis<sup>24</sup>.

Therefore, specialist dietetic support and access to pancreatic enzyme replacement therapy (PERT) are essential for people with pancreatic cancer. This enables them to get the tailored information they need to manage the impact of pancreatic cancer on their body, improve their general health and improve their eligibility for treatment as well as the success of the treatment they have.

However, access to a HPB specialist dietitian particularly for people not undergoing pancreatic cancer resection, is poor, and only 50% of people with pancreatic cancer are prescribed PERT<sup>25</sup>. This does vary for people with pancreatic cancer, with people whose cancer is resectable being more likely to be

<sup>19</sup> Olson *et al*, 2015 Weight loss, diabetes, fatigue, and depression preceding pancreatic cancer *Pancreas* 7:103–113 doi: [10.1097/MPA.0000000000000590](https://doi.org/10.1097/MPA.0000000000000590),

Sikkens *et al*, 2013 Prospective assessment of the influence of pancreatic cancer resection on exocrine pancreatic function *Br J Surg* 2014;101:109–113

doi: [10.1002/bjs.9342](https://doi.org/10.1002/bjs.9342), Hackert *et al*, 2014 The pancreas: Causes for malabsorption *Visz Gastrointest Med Surg* 2014;30:190–197 doi: [10.1159/000363778](https://doi.org/10.1159/000363778)

<sup>20</sup> Iglesia *et al*, 2020 Pancreatic exocrine insufficiency, and pancreatic enzyme replacement therapy in patients with advanced pancreatic cancer: A systematic review and meta-analysis. *United Europ Gastroenterol J* Nov;8(9):1115–1125. doi: [10.1177/2050640620938987](https://doi.org/10.1177/2050640620938987)

<sup>21</sup> Phillips *et al* 2021 Consensus for the management of pancreatic exocrine insufficiency: UK practical guidelines *BMJ Open Gastroenterol* 8:e000643. doi: [10.1136/bmjgast-2021-000643](https://doi.org/10.1136/bmjgast-2021-000643)

<sup>22</sup> Gupta and Ihmaidat, 2003 Nutritional effects of oesophageal, gastric and pancreatic carcinoma *Eur J Surg Oncol* Oct;29(8):634–43. doi: [10.1016/s0748-7983\(03\)00124-0](https://doi.org/10.1016/s0748-7983(03)00124-0), Hari and Rosenzweig, 2012 Incidence of preventable postoperative readmissions following pancreaticoduodenectomy: implications for patient education *Oncol Nurs Forum* Jul;39(4):408–12 doi: [10.1188/12.ONF.408-412](https://doi.org/10.1188/12.ONF.408-412), Kanda *et al*, 2011 Nutritional predictors of postoperative outcome in pancreatic cancer, *Br J Surgery* 98(2): 268–274 doi: [10.1002/bjs.7305](https://doi.org/10.1002/bjs.7305), Crucitti *et al*, 1998 Assessment of risk factors for pancreatic resection for cancer *World J Surg* 22: 241–247 doi: [10.1007/s002689900377](https://doi.org/10.1007/s002689900377), Garth *et al*, 2010 Nutritional status, nutrition practices and post-operative complications in patients with gastrointestinal cancer *J Human Nutr Diet* 23(4): 393–401 doi:[10.1111/j.1365-277X.2010.01058.x](https://doi.org/10.1111/j.1365-277X.2010.01058.x)

<sup>23</sup> [FOLFIRINOX](https://www.folfirinox.com/). Cancer Research UK. Accessed October 2023.

<sup>24</sup> Phillips 2015 Pancreatic exocrine insufficiency following pancreatic resection *Pancreatolgy* 15(5):449–455 doi: [10.1016/j.pan.2015.06.003](https://doi.org/10.1016/j.pan.2015.06.003), Phillips *et al*, 2023 Do patients benefit from micronutrient supplementation following pancreatoco-duodenectomy? *Nutrients* 15(12):2804 doi: [10.3390/nu15122804](https://doi.org/10.3390/nu15122804)

<sup>25</sup> RICOCHET Study Group on behalf of the West Midlands Research Collaborative 2021 Pancreatic enzyme replacement therapy in patients with pancreatic cancer: A national prospective study *Pancreatolgy* S1424–3903(21)00469-5. doi: [10.1016/j.pan.2021.05.299](https://doi.org/10.1016/j.pan.2021.05.299)

prescribed PERT than those whose cancer is unresectable. PERT is also more likely to be prescribed in specialist surgical centres than in non-specialist care.

**Table 6: How NHS health systems and health professionals can improve nutritional management (These complement nutritional management as part of a prehabilitation/rehabilitation service as laid out in section 2.3.1 Recommendation 1)**

Service characteristics	Overview
<b>Better nutritional management and support</b>	<ul style="list-style-type: none"> <li>Based on a person’s needs, or through access to a multi-disciplinary prehabilitation and rehabilitation team, nutritional support and access to a specialist dietitian should be offered at the point of diagnosis and throughout the patient pathway.</li> </ul>
<b>Increase of PERT prescription rates</b>	<ul style="list-style-type: none"> <li>PERT should be prescribed by day 5 after referral, if clinically indicated. For example, if a person’s tumour is in the head of the pancreas, they have a dilated pancreatic duct, there is presence of jaundice, weight loss or change in bowel habit,</li> <li>At the point of discharged from specialist care, a standard PERT letter should be given to primary care by a HPB/UGI CNS, which outlines the way in which PERT should be taken and the contact details of the CNS who has held responsibility for the person.</li> </ul>

### 3. Better access to psycho-social support

In the context of pancreatic cancer, people very often experience an acute and direct threat to life and severe and complex symptoms. It is therefore highly likely that people with pancreatic cancer and their loved ones will experience psychological distress, ranging from time-limited distress to ongoing, clinically significant mental health difficulties. These include:

- Anxiety, including acute / traumatic stress reactions, adjustment disorders, generalised anxiety, phobias,
- Depression, ranging from adjustment disorders to severe clinical depression,
- Problems with interpersonal relationships, within families and with healthcare professionals,
- Psychosexual and body image difficulties,
- Organic brain syndromes (delirium) and cognitive impairment.

Several observational studies support the argument that pancreatic cancer has a significant psychological impact on people with this disease<sup>26 27</sup>. Despite this, many people with pancreatic cancer report being offered no support to deal with the psychosocial impact of pancreatic cancer. A recent survey run in 2018 that included 274 people living with pancreatic cancer, identified that 87% of patients had one or more physical or psychological unmet needs<sup>28</sup>.

We have developed a guide of best practice on how to implement psychosocial support for people with pancreatic cancer and their loved ones, setting out what they should be able to expect and access. This

<sup>26</sup> Dengsø et al, 2020 Increased psychological symptom burden in patients with pancreatic cancer: a populationbased cohort study *Pancreatology* 20:511–21 doi: [10.1016/j.pan.2020.01.001](https://doi.org/10.1016/j.pan.2020.01.001)

<sup>27</sup> Akizuki et al, 2016 Prevalence and predictive factors of depression and anxiety in patients with pancreatic cancer: a longitudinal study *Jpn J Clin Oncol* 46:71–7 doi: [10.1093/jjco/hyv169](https://doi.org/10.1093/jjco/hyv169)

<sup>28</sup> Watson et al, 2019 How does the public conceptualise the quality of care and its measurement in community pharmacies in the UK: a qualitative interview study *BMJ Open* 9:e032681 doi:[10.1136/bmjopen-2018-027198](https://doi.org/10.1136/bmjopen-2018-027198)

guide applies the 2020 London Integrated Pathway for cancer psychosocial support as a basis for recommendations for delivering psychosocial support for people with pancreatic cancer <sup>29</sup>.

The London Integrated Pathway is designed to provide personalised psychosocial care for all adults affected by cancer and is based on the NICE 2004 guidance on improving supportive and palliative care for adults with cancer <sup>30</sup>. It consists of 3 levels of support, which are as follows:

- **Level 1 Universal support:** all people affected by cancer will have access to universal support. The whole healthcare team should be trained to deliver universal support to people with pancreatic cancer and their loved ones.
- **Level 2 Enhanced support:** a substantial proportion will require enhanced support episodically or throughout their cancer experience. This level of support should be delivered by a palliative/enhanced supportive care team, a counsellor, community mental health teams, the charity sector and/or hospice support.
- **Level 3 Specialist support:** a smaller proportion will require specialist support at one or more time points. This level of support should be delivered by a psycho-oncologist.

In the context of pancreatic cancer, we recognise people and their loved ones may need different or multiple support interventions at different times. There is no assumption that people proceed through universal, enhanced, and specialist support in a linear or predictable fashion, so access to services must be flexible.

All members of a prehabilitation and rehabilitation team should be trained to deliver universal (level 1) psychosocial support.

**Table 7: Further details on how local health systems and health professionals can offer better psycho-social support for people affected by pancreatic cancer**

Service characteristics	Overview
<b>Better access to psycho-social support</b>	<ul style="list-style-type: none"> <li>• Information about psychosocial support and signposting to support groups should be provided at the point of diagnosis,</li> <li>• Psychosocial support should be monitored by everyone in a person's healthcare team but overall responsibility for coordinating this aspect of care should lie with a HPB/UGI CNS with the support of a cancer care coordinator.</li> </ul>

4. Access to better post-resection follow up care for people living beyond pancreatic cancer

People who undergo a pancreatic cancer resection and are living beyond pancreatic cancer can experience a wide range of side effects including digestive issues, a particular type of diabetes called type 3c diabetes, fatigue, pain, nutritional challenges, PEI and weight management difficulties. In addition, people often experience emotional and psychological effects of having had pancreatic cancer, managing the side effects of living beyond it, and managing the fear and anxiety of a recurrence.

In 2021, a qualitative study of 20 participants who had undergone a pancreatic-duodenectomy (a type of surgery to remove a pancreatic cancer tumour) was undertaken. It found participants reported 'struggling with physical symptoms such as fatigue...' and reflected that they would have valued more emotional

<sup>29</sup> [Psychosocial support for people affected by cancer](#) 2020 Healthy London Partnership. Accessed October 2023

<sup>30</sup> [Improving Supportive and Palliative Care for Adults with Cancer](#) 2004 NICE Cancer service guideline CSG4. Accessed October 2023

support, particularly following treatment <sup>31</sup>. More widely, there is a lack of research about the impact these side effects have on people with pancreatic cancer.

**Table 8: Further details on how local health systems and health professionals can offer better care for people living beyond pancreatic cancer**

Service characteristics	Overview
<b>Living beyond follow up care</b>	<ul style="list-style-type: none"> <li>• Everyone living beyond pancreatic cancer should be offered the following specialist post-surgery follow up support on an ongoing basis:               <ul style="list-style-type: none"> <li>○ Diabetes support and management,</li> <li>○ Psychosocial support,</li> <li>○ Specialist nutritional management support,</li> <li>○ A direct telephone line to their HPB/UGI CNS, to contact if they are having difficulties accessing the right support to manage the symptoms post-surgery.</li> </ul> </li>   <li>• When discharged back into primary care, a treatment summary letter with information about the side effects of living with or beyond pancreatic cancer should be provided to the General Practitioner (GP).</li> </ul>

**2.3.2 Recommendation 2: Improved access to a 24/7 rapid access enhanced care service to get support with the symptoms and side effects of their cancer.**

People with pancreatic cancer commonly experience a range of symptoms including pain, nausea, vomiting, bloating, reflux, altered bowel habits, fatigue, cachexia and psychological distress. They can also commonly experience venous thromboembolism, gastric occlusion or outflow obstruction, infection and ascites.

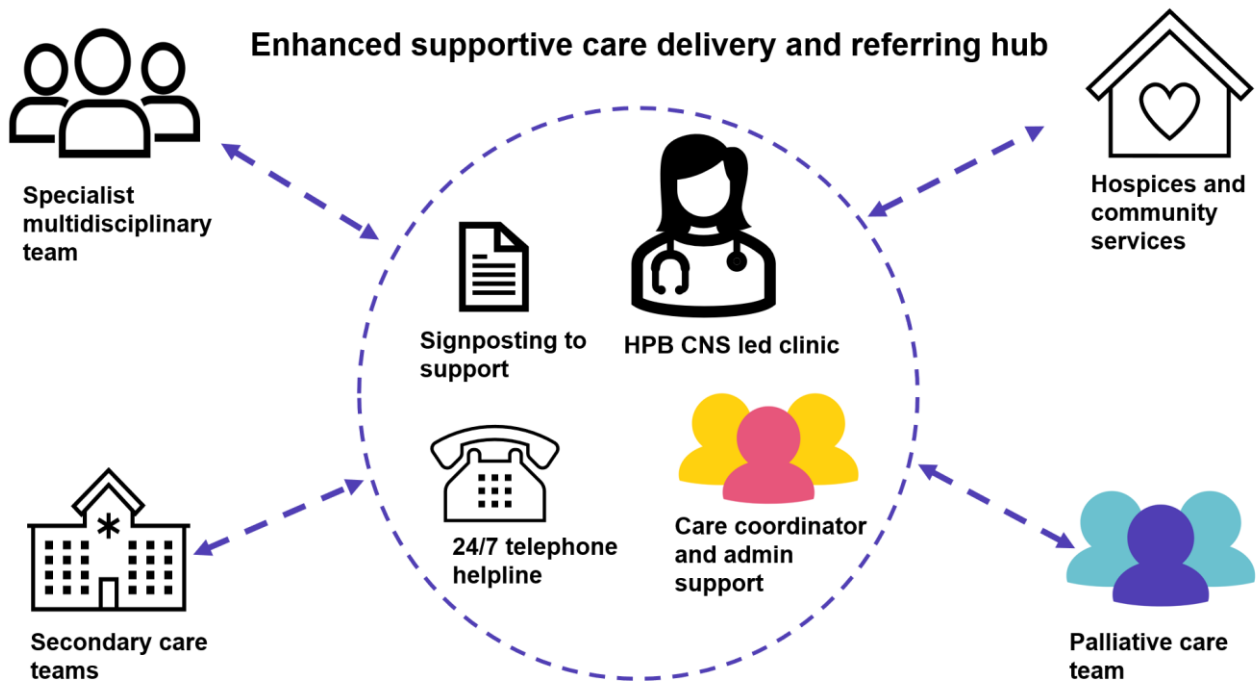
People with pancreatic cancer can experience varying symptoms at different stages of their cancer. These can cause extreme discomfort and pain, impacting a person and their loved ones' quality of life. When certain acute symptoms are left untreated, this can also impact a person's chance of survival.

From hearing from people affected by pancreatic cancer through our Support Services and other engagement work, and through our work with health professionals, we know that that people with pancreatic cancer often report not knowing where to go or who to ask for help. They often struggle to access the rapid support they need to manage and treat severe symptoms and side effects of pancreatic cancer. Without the right support, people with pancreatic cancer can experience the following outcomes, which can affect their ability to tolerate and ultimately live longer:

- Their condition deteriorates, sometimes so much that they require hospitalisation,
- They end up accessing support through emergency healthcare services,
- Sometimes, untreated symptoms can be life limiting.

<sup>31</sup> Taylor *et al*, 2021 It's always in the back of my mind: understanding the psychological impact of recovery following pancreaticoduodenectomy for cancer: a qualitative study *BMJ Open* 11:e050016. doi: [11/12/e050016](https://doi.org/10.1136/bmjopen-2021-028016)





**Figure 8:** Enhanced supportive care delivery and referring hub for people with pancreatic cancer

**Table 9: Further details on how local health systems and health professionals can deliver a better enhanced supportive and palliative care service for people with pancreatic cancer**

Service characteristics	Overview
<b>Clear service ownership</b>	<ul style="list-style-type: none"> <li>HPB/UGI CNS-led service, with substantial cancer care coordinator and administration support.</li> </ul>
<b>Coordination with other healthcare teams</b>	<ul style="list-style-type: none"> <li>Enhanced communication with other healthcare teams and streamlined palliative treatment referral pathways.</li> </ul>
<b>Timely access</b>	<ul style="list-style-type: none"> <li>Commissioned for people to be seen within 48 hours of reporting symptoms.</li> </ul>
<b>Person centred communication</b>	<ul style="list-style-type: none"> <li>Open, honest communication with people with pancreatic cancer and their loved ones about their options and the support different teams can provide so that they feel educated, informed and empowered to make decisions about their care.</li> </ul>
<b>Flexible service delivery</b>	<ul style="list-style-type: none"> <li>This service should be commissioned to ensure flexibility in service delivery. Many people with pancreatic cancer may not be able to travel due to their general health, particularly those who live in rural areas. If a patient is unable to travel to get support, home visits or transfers to a specialist centre should also be available.</li> </ul>

**2.3.3. Recommendation 3: Improved access to a HPB/UGI CNS as a single point of contact**

People who are treated at a specialist centre will often have access to a HPB CNS. However, people who receive no treatment, or receive treatment in secondary care, often do not have the opportunity to access this specialist support.

There is a lack of consistent data on access to a HPB/UGI CNS. However, we know from speaking to people affected by pancreatic cancer that many do not have access to this kind of support. This is reflected in results of the most recent National Cancer Patient Experience Survey (NCPES) in England which found that people with pancreatic cancer rated the ease of contacting their main contact person significantly lower than the national average <sup>32</sup>.

Everyone with pancreatic cancer should be given access to a HPB/UGI CNS with expertise in pancreatic cancer. This would help to ensure the care they receive is high quality, consistent and coordinated, because a HPB/UGI CNS holds the right level of expertise and knowledge of other teams and services available, to guide someone through their care. A HPB/UGI CNS should be supported by a cancer care coordinator, who can act as the first point of contact for people with pancreatic cancer and their loved ones when a HPB/UGI CNS is unavailable. They can support with referrals, signposting and coordinating of other healthcare teams.

<b>Table 10: Further details on how local health systems and health professionals can improve communication between healthcare teams and people with pancreatic cancer</b>	
<b>Service characteristics</b>	<b>Overview</b>
<b>HPB/UGI CNS as single point of contact</b>	<p>A HPB/UGI CNS, with support from a cancer care coordinator, should be given the capacity to:</p> <ul style="list-style-type: none"> <li>• Provide people with pancreatic cancer and their loved ones with personalised, open and honest communication, including undertaking regular holistic support assessments which incorporate person-centred questions,</li> <li>• Be an information, signposting and referral hub for people with pancreatic cancer,</li> <li>• Provide information at the point of diagnosis about a person’s cancer, signpost to other support such as charities like Pancreatic Cancer UK and provide any additional tailored information about their cancer.</li> </ul>
<b>HPB/UGI CNS responsible to coordinate care across NHS teams</b>	<p>A HPB/UGI CNS, with support from a cancer care coordinator and administration team, should be given the capacity to:</p> <ul style="list-style-type: none"> <li>• Be a key point of contact for other healthcare teams and oversee enhanced communication with primary (general practitioners and pharmacy), secondary and community care teams,</li> <li>• Oversee referrals for tests and to other healthcare teams, ensuring they are made in a timely manner and that other healthcare teams follow up on referrals quickly,</li> <li>• Advocate for people with pancreatic cancer in clinical settings, such as at HPB specialist multidisciplinary team meetings (HPB MDT meetings).</li> </ul>

<sup>32</sup> [National Patient Experience Survey England 2022 NHS England](#). Accessed August 2023

### **St Helens & Knowsley model of personalised care for upper gastrointestinal (UGI) cancers**

In partnership and with financial support from Macmillan, St Helens & Knowsley Teaching Hospitals had an opportunity to undertake a scoping exercise into their service as the team felt there was room for improvement in the care they were providing to their patients. Findings from this scoping exercise highlighted numerous challenges in patient pathways and coordination of care:

1. Diagnosis and treatment pathways were slow and inconsistent

Diagnostic pathways were prolonged and complex, with 64% of people were presenting in emergency settings. There were also inconsistencies in the provision of oncology services.

2. There were challenges in delivering high-quality care

People experienced unreliable communication, disjointed care and difficulties in accessing palliative care services. Health professionals experienced challenges in providing holistic needs assessments (HNA), and in providing Specialist Nurse support from the point of diagnosis and throughout the pathway.

3. There was poor access to reliable data and a lack of patient feedback

These challenges were found to have a significant impact on people with pancreatic cancer. Together, these factors were contributing to poor outcomes for patients, which included:

- The majority presenting with advanced disease – 79% were palliative,
- 28% of patients died within less than one month and 47% of palliative patients died within 3 month,
- Only 30% of palliative patients were appropriate for palliative chemotherapy,
- 64% of patients experienced at least one further hospital admission, with 34% of those dying during that admission.

#### **What was done to improve the situation**

To address these significant challenges, the team put forward a business case and was successful in securing two years of funding from Macmillan Cancer Support to support two band 6 and 1 band 7 clinical nurse specialist roles.

With this investment, the service has been remodelled to provide improved support to those with the greatest need and has been successful in creating working partnerships with Hospital Specialist Palliative Care Services, the local hospice and community services. The team now deliver a wide range of clinics and services to patients and their families, such as:

- Access to a clinical nurse specialist and dietetic support and monitoring, from the point of suspected cancer diagnosis and throughout their cancer journey,
- A post Nurse Led MDT clinic, which provides patients with timely, up-to-date information,
- Twice weekly holistic needs assessment clinics and a daily telephone clinic,
- A joint weekly multi-professional clinic for all palliative patients to support those undergoing palliative chemotherapy with symptom management,
- Fortnightly health and wellbeing clinics ('Tea with the team') in partnership with the local hospice which provides support for patients, families and carers, and includes guest speakers, tools to prepare patients for the challenges of end of life, mindfulness, yoga sessions and practical and financial help.

#### **The impact of this service**

This new service model has made a significant difference to patients, families, carers and the healthcare team. Through these improvements, the following changes have been identified;

1. Fewer people require emergency support or hospitalisation

The service has seen a 54% reduction in crisis calls to the UGI team and hospital readmissions post-diagnosis have reduced from 64% to 33%.

2. People are experiencing better quality of life and end of life care

85% of patients are now prescribed PERT, over 90% of patients appropriate for HNA were approached with 74% completing a HNA and 55% of patients who were in their last 12 months of life and approached to complete an advance care plan accepted.

In addition, 70% of those completed an advance care plan, and 81% of patients who engaged in a preferred place of care/death conversation and documented their preference, achieved their preferred place of death.

**Feedback from patients**

Patient feedback has been very positive, and the team reports regularly receiving phone calls from families following the death of their loved ones to thank them for all they have done to ease this difficult time and commend them on the support they have provided.

Overall, patients and their loved ones report being given the vital support and care they need to live well. One family member said in July: “he was made to feel like he was the ‘only patient we had’ and the ‘most important person under our care’”.

***All the data in this case study was collected by the local healthcare team***



**Figure 10:** The UGI CNS team at St Helens and Knowsley



**Figure 11:** The dietetics team at St Helens and Knowsley

## Our guide to what faster diagnosis should look like

This chapter outlines the standards that **everyone** with pancreatic cancer should expect from the point of referral to their confirmed diagnosis. We set out our key recommendations to improve diagnostic pathways so that people with suspected pancreatic cancer can be diagnosed more quickly than they are today, which we believe is crucial in increasing survival and quality of life for people with pancreatic cancer.

### **Recommendation 4**

NHS systems should ensure that everyone with pancreatic cancer is diagnosed within 21 days of referral for suspected cancer.

### 3.1 The current problems people with pancreatic cancer face during their diagnosis

Pancreatic cancer is the quickest killing cancer – it progresses rapidly and quickly becomes incurable. The disease is tough to diagnose due to vague symptoms and the need for multiple tests. Pancreatic cancer has the lowest proportion of early-stage diagnosis of all common cancers, early stage diagnosis is critical as one-year survival rates are 6 times higher for those diagnosed at early stage compared to people diagnosed at stage four.

Too many people are left waiting months for their diagnosis to be confirmed, with many likely to experience multiple appointments before referral, often re-attending with the same symptoms.

The fact that the symptoms of this cancer type are vague and there is no simple test to detect pancreatic cancer can make referring someone for further tests difficult. To address this, our charity is investing in research to develop tools and tests to more easily detect pancreatic cancer at an earlier stage.

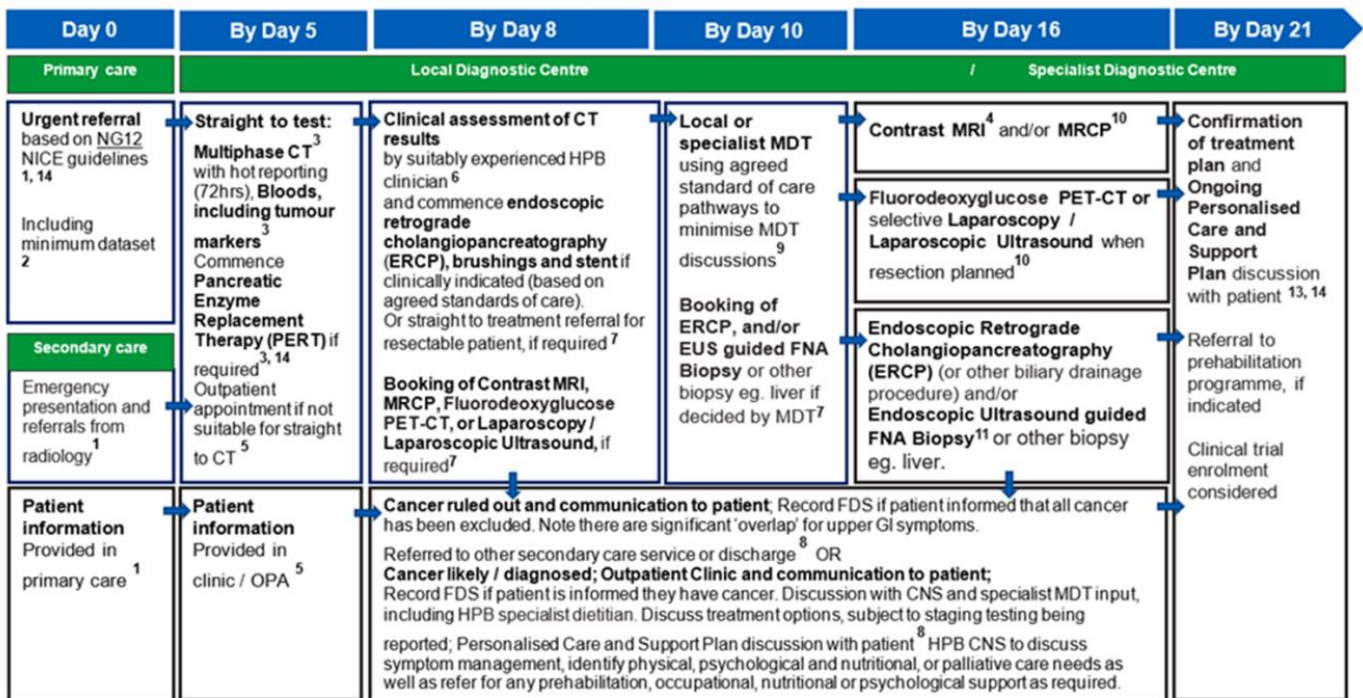
However, once suspected pancreatic cancer has been identified and a referral is made, the need for multiple tests, and slow processes in decision-making and test results can still mean that a person's diagnosis often comes too late. Delays from a referral to a confirmed diagnosis occur because:

- Multiple scans and tests (that can often be indeterminate and need repeating) are required due to the complexity of pancreatic cancer,
- There is a lack of diagnostic administration and coordination capacity which means tests and investigations are not always booked in a timely manner or coordinated with MDT meetings. This often delays MDT decision-making.

### 3.2 Our solution to implement a faster diagnosis pathway

In England, we have worked with NHS England and other pancreatic cancer specialists to develop a framework of how people with pancreatic cancer should be diagnosed - within 21 days. We believe this provides sufficient time for local and specialist tests to be undertaken, while speeding up the overall diagnostic timeframe. Figure 9 shows the 21-day diagnostic and early holistic support pathway we recommend and how it can be implemented by local health systems and health professionals. It outlines the tests and investigations and when they should be undertaken, as required.

See Appendix 1 of this report for details of how this pathway was developed, and the other faster pancreatic cancer diagnostic pathways which are being delivered across the UK.



**Figure 9:** 21-day diagnostic pathway for pancreatic cancer. Taken from NHS England Faster Diagnosis pathway for HPB cancers following permission (due to be formally published by the end of 2023)

To note, while most people with pancreatic cancer should be offered this 21-day pathway, some may not be fit enough for multiple tests and investigations, may have a very short prognosis and/or multiple comorbidities meaning they are not be able to access treatment. For this group, this pathway may not be appropriate.

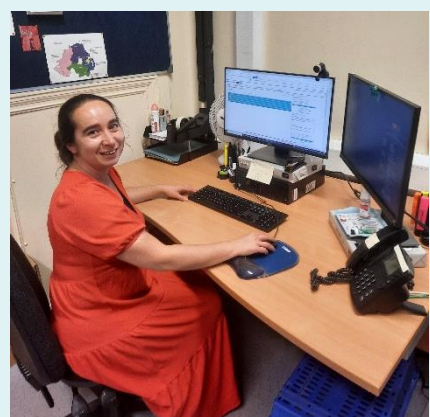
**Table 11: Further details on how local health systems and health professionals can deliver a 21-day referral to diagnosis pathway for people with pancreatic cancer**

Service characteristics	Overview
<b>Faster decision-making</b>	<ul style="list-style-type: none"> <li>Where a GP refers a person for a direct access test and the CT or ultrasound is abnormal and suspicious of cancer, a person should be followed up directly by secondary care, without the need for an urgent referral from their GP,</li> <li>Similarly, where a person receives initial tests in A&amp;E and they are still suspicious of cancer, they should be upgraded onto the pathway after the relevant test(s) undertaken under the care of A&amp;E,</li> <li>A minimum dataset should accompany the referral for further tests for suspected cancer and facilitate straight-to-clinic and immediate diagnostics.</li> <li>Whilst initial diagnostics can be undertaken at local units, additional staging investigations require specialist management and decision-making,</li> <li>A triple phase pancreas protocol CT of the abdomen and pelvis for people with suspected pancreatic cancer should be undertaken,</li> <li>The abdominal CT should always be performed prior to any endoscopic procedure, which can in some instances lead to complications that can mask the site and extent of the tumour,</li> <li>Bloods should include checking for full blood counts (FBC), urea and electrolytes (U&amp;E), liver functional test (LFT), clotting, HbA1c and CA 19-9 tumour marker.</li> </ul>

<p><b>Patient centred, holistic care</b></p>	<ul style="list-style-type: none"> <li>• Information should be provided by primary care to people with pancreatic cancer including information about the pathway they are on and expected timelines, including that the person should be available within the next 14 days for appointments and tests,</li> <li>• Information touchpoints should be provided throughout,</li> <li>• Preferences for the amount of information and when it is provided will vary, and therefore it will help to provide a cancer care coordinator telephone contact details who will be able to provide support throughout the pathway and outside of clinic times,</li> <li>• Everyone with pancreatic cancer should be prescribed PERT by day 5 of the pathway, if clinically indicated – for example if a person’s tumour is in the head of the pancreas, they have a dilated pancreatic duct, there is presence of jaundice, weight loss or change in bowel habit,</li> <li>• Everyone with pancreatic cancer should be offered an in-person prehabilitation assessment within a week of diagnosis. Please see Chapter 2 for details of what this assessment entails,</li> <li>• People with locally advanced and metastatic pancreatic cancer and people who are not suitable for anti cancer treatment, should be given information about local palliative care services and hospices and onward referral to these services, where clinically indicated,</li> <li>• If someone diagnosed with pancreatic cancer also has a family history of pancreatic cancer, consider referring family members to the EUROPAC trial for at risk surveillance,</li> <li>• Provide information at the point of diagnosis about other support such as charities like Pancreatic Cancer UK.</li> </ul>
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**The role of Belfast Health and Social Care Trust’s Patient Navigator and Multidisciplinary Meeting Coordinator in improving the diagnostic pathway**

The combined role of the Patient Navigator and Multidisciplinary Meeting (MDM) Coordinator, Helen, for the HPB regional service in Belfast Health and Social Care Trust is integral to proactively ensuring people with either a new pancreatic cancer or a suspected cancer, receive a timely diagnosis. Often multiple tests are required to diagnose and stage pancreatic cancer. Helen’s role is crucial to ensuring that tests are undertaken quickly and the patient’s case is coordinated. Helen achieves this by:



**Figure 12:** Helen, Belfast Health and Social Care Trust’s Patient Navigator and MDM Coordinator

- Working with members of the Multi-Disciplinary Team (MDT) to ensure all people with a new primary cancer or suspected cancer are discussed in a timely manner,
- Ensuring that all the relevant imaging and histology is available for review by Pathology and Radiology teams prior to the meeting of the MDT, so that a full and informed discussion can take place and a decision is made,
- Recording outcomes in live time during the Multi-Disciplinary Meeting (MDM) and circulating these to the MDT members,
- Ensuring all referrals, appointments or diagnostic tests for each person discussed at the MDM are scheduled for the first available appointment slot. For example, Endoscopic Ultrasound, percutaneous biopsy or PETCT,

- When necessary, liaising with services across the cancer pathway to negotiate quicker access for people awaiting further investigations,
- Identifying and highlighting delays/bottlenecks in the patient pathway and escalating these to the appropriate manager,
- Running Lab Reports on a weekly basis to ensure no new cancer diagnosis is missed and that if possible these are added to the MDM and discussed the same week.

What this means for the MDM and for patients:

- MDM time is used effectively and efficiently. Tests results are ready for meetings so that decisions can be made quickly,
- Specialist health professionals are given vital time back to focus on their clinical priorities rather than spending time chasing test results,
- Patient care is coordinated. Helen ensures that local and specialist care is joined up and all relevant healthcare teams are updated. Helen ensures that appointments are booked and the patient is aware of what's happening.

An example of how this works in practice for patients:

Patient A

- **Day 0** – Patient was admitted into Antrim Area Hospital with painless, obstructive jaundice. The patient was given an ultrasound scan which identified a mass on the head of the pancreas,
- **Day 1** – Patient was given a CT scan which found a like neoplastic lesion on the head of the pancreas the pancreatic head,
- **Day 7** – Belfast Trust HPB multi disciplinary meeting discussion and potential diagnosis and treatment plan agreed with a decision made to do further investigations (ERCP & brushings, PET-CT and outpatient appointment with consultant surgeon).

Immediately after the meeting, Helen took the following actions:

- Ensured the consultant from local Hospital, who requested the MDM discussion, knew to arrange ERCP locally,
- PETCT - request completed by Consultant at the MDM and submitted by Helen that same day.
- Helen liaised with Appointment staff to organise outpatient appointment at surgical clinic for the following week,
- **Day 12 - Patient attended Belfast Trust Surgical Clinic, met the HPB nurse, was given confirmed diagnosis and discussed diagnosis and care plan.**



## Chapter 4:

### Our guide to what faster treatment should look like

This chapter outlines the standards we believe **everyone** with pancreatic cancer should be able to expect across their treatment pathway, which we define as any active anti-cancer treatment. We set out our key recommendations to achieve this, which include the following components:

- Standardising the treatment options available depending on the staging and classification of a tumour, and
- By initiating treatment faster - within 21 days of confirmed diagnosis.

#### **Recommendation 5**

NHS systems should ensure that treatment pathways are standardised depending on tumour classification and staging, so that everyone with pancreatic cancer has a fair chance of accessing life extending, or life-saving treatment.

#### **Recommendation 6**

NHS systems should ensure that treatment should be initiated within 21 days from confirmed diagnosis (and 42 days from referral) where appropriate, for people with pancreatic cancer.

### 4.1 The current problems people with pancreatic cancer face in accessing and receiving treatment

As mentioned in Chapter 1, **only 30% of people with pancreatic cancer receive treatment**<sup>33</sup>. Surgery (or neo-adjuvant therapy followed by surgery when clinically indicated) followed by adjuvant therapy is the only potentially curative treatment for people with pancreatic cancer. However, as it stands only 10% of people with pancreatic cancer currently have potentially curative surgery.

For those not eligible for surgery, chemotherapy and radiotherapy are potential treatments to improve their quality of life and extend or increase their chances of survival. But, unfortunately, only 20% of people with pancreatic cancer will receive any form of palliative chemotherapy and/or radiotherapy.

#### 4.1.1 The lack of clarity on what constitutes treatment

Currently, there is not sufficient clarity on what constitutes ‘treatment’ for pancreatic cancer.

For example, NHS England operational standards guidance includes endoscopic stent placement (stenting) as ‘day 1 of initiating treatment’, when this intervention is seen as necessary for a patient to access active treatment (for example, neo-adjuvant therapy)<sup>34</sup>. However, it is often assumed by health professionals that stenting can always be considered a first definitive treatment.

In addition, NHS Scotland, NHS Wales and Health and Social Care Northern Ireland incorporate supportive and palliative care interventions as a first definitive treatment<sup>35</sup>. We believe this should be redefined because supportive and palliative care interventions do not address the tumour itself and are therefore not

<sup>33</sup> In the context of this report, treatment is defined as any active, anti-cancer treatment such as surgery, chemotherapy or radiotherapy.

<sup>34</sup> [Cancer Waiting Times Data Collection \(CWT\)](#) April 2023, NHS England. Accessed October 2023

<sup>35</sup> Cancer Waiting Times. [N Ireland Department of Health](#), [Public Health Scotland](#), [Wales Parliament](#). Accessed October 2023

necessarily life extending or curative, but can ‘stop the clock’ and cause delays in accessing anti-cancer treatments.

#### **4.1.2 Very few people with pancreatic cancer access curative or life-extending treatment**

Pancreatic cancer is a challenging disease to treat, and we need more research to help us improve current treatments and find new and more effective treatments going forward. As it stands, available treatments for this cancer are limited and can be toxic, which makes it difficult for people to tolerate the associated side effects. However, our community has also identified other factors contributing to the very low treatments rates. We have identified three key main barriers to improving treatment access:

##### 1. Delays in decision-making about treatment

Through our initiative, we have heard that there are often delays in making decisions about what treatment – if any – to offer people. This means that many people who could potentially be eligible for treatment upon diagnosis become ineligible for this because they become too unwell while they are waiting (either because the tumour develops, their symptoms worsen or both).

##### 2. Variation in the delivery of treatment, as well as treatment pathways

We have also identified a lack of consistency in the delivery of treatment, which is based on several factors:

- Where people live,
- What stage people are diagnosed at,
- The state of people’s health,
- Whether they receive treatment in a specialist centre or in local NHS and community services.

Those who are eligible for potentially curative surgery – currently around 10% of people with pancreatic cancer – are usually treated by a team of pancreatic cancer specialists at a HPB specialist centre. However, those who are not able to have potentially curative surgery are often treated in their local hospital or by community teams.

Differences in treatment and care settings can often lead to unwarranted variations in access to treatment. This is a key contributor to variation in access to treatment across the UK and we believe that to address this, clinical practice should be standardised and consider gaps in treatment in both specialist centres and local NHS and community services.

##### 3. Poor performance status and a lack of support to manage symptoms

People with pancreatic cancer often experience severe symptoms and poor performance status<sup>36</sup>. If people have become very weak due to the symptoms and side effects of pancreatic cancer and a lack of support to manage these, they may not be able to access treatment.

In addition, people who are given surgery to remove the tumour may not be given the support they need to receive and tolerate adjuvant chemotherapy, which is concerning because having this gives people with pancreatic cancer the best possible chances of survival<sup>37</sup>. As it stands, only 50% of those who receive

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<sup>36</sup> Watson *et al.*, 2019 Experiences and supportive care needs of UK patients with pancreatic cancer: a cross-sectional questionnaire survey *BMJ Open* 9:e032681. doi:

<sup>37</sup> Neoptolemos *et al.*, 2001 Adjuvant chemoradiotherapy and chemotherapy in resectable pancreatic cancer: a randomised controlled trial *The Lancet* 358(9293): 1576-1585 doi: [https://doi.org/10.1016/S0140-6736\(01\)06651-X](https://doi.org/10.1016/S0140-6736(01)06651-X) Neoptolemos *et al.*, 2017 Comparison of adjuvant gemcitabine and capecitabine with gemcitabine monotherapy in patients with resected pancreatic cancer (ESPAC-4): a multicentre, open-label, randomised, phase 3 trial *The Lancet* 389(10073):1011-1024 doi: [10.1016/S0140-6736\(16\)32409-6](https://doi.org/10.1016/S0140-6736(16)32409-6)

surgery undergo adjuvant chemotherapy, often because they are not given the support to manage the side effects of surgery which result in them being too unwell to tolerate chemotherapy <sup>38</sup>.

#### 4.2. Our recommendations to improve treatment for people with pancreatic cancer

In this section, we set out the recommendations we believe will help to increase access to and standardise treatment for people with pancreatic cancer.

##### 4.2.1 Recommendation 5: Standardise treatment pathways depending on tumour classification and staging

Until we have the research breakthroughs we desperately need in pancreatic cancer treatment, it is important to ensure as many people as possible who are diagnosed now can benefit from existing treatment options. The treatments currently available on the NHS for pancreatic cancer are:

- Surgery to remove the tumour (curative intent - pancreatico-duodenectomy, distal pancreatectomy, total pancreatectomy, central pancreatectomy),
- Palliative systemic anticancer treatment (SACT), often referred to as chemotherapy,
- Traditional radiotherapy,
- Stereotactic ablative body radiotherapy (SABR).

Currently, treatments such as SABR are not available everywhere in the UK because they need to be delivered by specialised oncologists.

**Table 12: Treatment pathways by staging and classification of pancreatic cancer tumour which should be implemented and followed by local health systems and health professionals**

Tumour staging	Treatment management
<b>Resectable at diagnosis</b>	<ul style="list-style-type: none"> <li>• A biopsy is not needed before surgery,</li> <li>• In line with the NICE NG85 guidelines, if clinically indicated, straight to surgery to remove the tumour should be a priority <sup>39</sup>,</li> <li>• Everyone with pancreatic cancer should have access to enhanced recovery after surgery (ERAS),</li> <li>• In line with NICE NG85 guidelines, all patients who are fit enough should be offered adjuvant therapy after resection – this should be the standard of care and anyone not fit enough should be given support to be able to have it,</li> <li>• If appropriate, every patient should be given the option to be involved in a clinical trial.</li> </ul>
<b>Borderline resectable at diagnosis</b>	<ul style="list-style-type: none"> <li>• Regular and detailed scans, a biopsy and coordinated and clearly defined HPB MDT reviews are needed to understand how the tumour is responding to treatment and whether a person should be offered a resection after neo-adjuvant therapy,</li> <li>• Individuals should be offered regular reviews and discussions about their treatment plan,</li> <li>• If appropriate, every person with pancreatic cancer should be given the option to be involved in a clinical trial.</li> </ul>

<sup>38</sup> [Chemotherapy, Radiotherapy and Surgical Tumour Resections in England, 2013 – 2020](#), National Cancer Registration and Analysis Service (NCRAS). Accessed October 2023

<sup>39</sup> [Pancreatic cancer in adults: diagnosis and management](#) 2018. NICE guideline NG85. Accessed October 2023

<b>Locally advanced at diagnosis</b>	<ul style="list-style-type: none"> <li>• Chemoradiotherapy or SABR should be offered, where clinically indicated,</li> <li>• Regular, detailed scans, a biopsy and HPB MDT reviews are needed to understand how the tumour is responding to treatment,</li> <li>• Regular reviews and discussions of a treatment plan should be undertaken with the individual as well as open discussions about the potential of the tumour becoming resectable,</li> <li>• If appropriate, every person with pancreatic cancer should be given the option to be involved in a clinical trial.</li> </ul>
<b>Metastatic at diagnosis</b>	<ul style="list-style-type: none"> <li>• In line with NICE NG85 guidelines, if deemed fit enough after assessment by HPB specialists, everyone with locally advanced and metastatic pancreatic cancer should be offered palliative systematic anticancer therapy (such as chemotherapy),</li> <li>• If appropriate, every person should be given the option to be involved in a clinical trial.</li> </ul>

**4.2.2 Recommendation 6: Initiating treatment within 21 days from confirmed diagnosis (and 42 days from referral)**

The current UK-wide standard recommends treatment within 62 days from the point of referral (or suspicion for Wales). Through our engagement as part of this initiative, we have come to agree that this is too slow for people with pancreatic cancer.

We instead are advocating for a timeline of 21 days between diagnosis and treatment. This would ensure more people become eligible for treatment, while giving enough time for health professionals to develop the right treatment plan. It also gives people with pancreatic cancer time to consider their options and build up their health and general wellness for treatment.

To make this deliverable, local systems will need to ensure effective decision-making so that people are reviewed by healthcare teams with the right expertise, and that they're staged consistently and accurately from the start. This is crucial in ensuring people have the best chance of accessing the right treatment and/or care. In addition, the principles of patient-centred care should be followed throughout this process.

<b>Table 13: How local health systems and health professionals can achieve a faster access to treatment standard</b>	
<b>Service characteristics</b>	<b>Overview</b>
<b>Timely and standardised radiology reporting</b>	<ul style="list-style-type: none"> <li>• PACT-UK radiology reporting template should be used to ensure standardised classification of tumours,</li> <li>• Fast-track radiology reporting (the next working day) should be undertaken.</li> </ul>
<b>Timely and consistent review of all people with suspected or confirmed diagnosis by HPB MDT</b>	<ul style="list-style-type: none"> <li>• In line with NICE NG85 guidelines, a HPB MDT should hold overall responsibility for the assessment, treatment planning and management of all people with pancreatic cancer.</li> </ul>
<b>Comprehensive HPB MDT specialty representation</b>	<p>HPB MDT membership should cover all core specialties to bring a range of expertise to the decision-making and patient management process. Members should include:</p> <ul style="list-style-type: none"> <li>• Pancreas/HPB surgeon,</li> <li>• A clinical representative with responsibility for systemic anti-cancer therapy and radiotherapy,</li> <li>• HPB radiologist,</li> <li>• HPB pathologist,</li> <li>• HPB endoscopist,</li> </ul>

	<ul style="list-style-type: none"> <li>• Pancreas/HPB specialist dietitian,</li> <li>• HPB CNS,</li> <li>• Palliative care specialist,</li> <li>• MDT coordinator.</li> </ul> <p>An MDT coordinator should manage referrals and follow-up on scans and ensure that HPB MDT meetings are utilised for effective decision-making. An MDT coordinator should also be responsible for collecting data and outcomes of every person with pancreatic cancer treated in the specialist centre or the district hospitals that the specialist centre serves.</p>
<p><b>A HPB CNS should be the lead point of contact for people with pancreatic cancer and their loved ones.</b></p>	<p>A HPB/UGI CNS, with the support of a cancer care coordinator, should ensure that people with pancreatic cancer and their loved ones:</p> <ul style="list-style-type: none"> <li>• Understand the decision-making timeframes and where they are in the pathway,</li> <li>• Are given information about other support available,</li> <li>• Are given space for informed discussions about their treatment options including the risks and side effects of different treatments and potential impact on performance status.</li> </ul>
<p><b>A member of the specialist multidisciplinary team should discuss treatment options with people with pancreatic cancer and loved ones</b></p>	<p>A member of the specialist MDT should discuss treatment options with people with pancreatic cancer and loved ones, which cover:</p> <ul style="list-style-type: none"> <li>• The treatment intent and expected outcomes,</li> <li>• Side effects and risks of different treatment options and no treatment and the impact on performance status,</li> <li>• Be open to discussing the impact of alternative treatment options raised by a person with pancreatic cancer and their loved ones,</li> <li>• Provide a written copy of the plan and any referrals.</li> </ul>

**The impact of implementing the Pancreatic Cancer Reporting Template - UK (PACT-UK) on treatment decision making**

**Dr Raneem Albazaz, Consultant Radiologist, Leeds Teaching Hospitals NHS Trust**

“The PACT-UK project is the first ever UK-wide multi-speciality consensus development initiative to produce a standardised and structured pancreatic cancer radiological reporting template for use across the NHS.

PACT-UK aims to improve the consistency in documentation of tumour stage/classification. In this way, it facilitates MDT efficiency, guaranteeing documented evidence of disease relevant to surgical planning and oncological treatment response. It also optimises research trial protocols. The template ensures consistent reporting of all relevant information to allow rapid and appropriate decision making.

The Leeds Pancreas Unit was one of the first pancreatic centres to adopt PACT-UK, where it has been transformative



**Figure 13:** Dr Raneem Albazaz, Consultant Radiologist, Leeds Teaching Hospitals NHS Trust

and is now firmly embedded into MDT practice. The Pancreas MDT is more confident with decision-making and surgery is now safer due to consistent documentation of anatomical variants and vascular issues which may complicate surgery.

The national implementation of PACT-UK is underway and is being facilitated through practical workshops, with the support of national organisations such as Pancreatic Cancer UK and the British Society of Gastrointestinal and Abdominal Radiology. The ultimate hope is that it will successfully deliver improved clinical care to pancreatic cancer patients.

Our pancreatic cancer expert group agrees that the PACT-UK proforma has the potential to speed up initiation of treatment if consistently implemented across the UK. We are working with a team of experts to evaluate the impact of the report more formally.”



**Figure 14:** The Pancreas specialist MDT at Leeds Teaching Hospitals NHS Trust.

## Next steps in driving implementation of the Optimal Care Pathway

For the first time, we have come together as one voice to agree on and develop a guide on how to improve diagnosis, treatment and care for people with pancreatic cancer. Now, this pathway must be implemented in every corner of the UK and to do so, we all need to play our part in making this a reality.

This chapter lays out the actions we are calling on healthcare professionals, local health systems, national NHS bodies and governments across the UK to take to ensure that the Optimal Care Pathway for pancreatic cancer is embedded within cancer services.

### 5.1 How local health systems and healthcare professionals can drive implementation of the Optimal Care Pathway

Pancreatic Cancer UK and the Optimal Care Pathway expert community would like to work with **local systems** (e.g. Cancer Alliances, integrated care boards, cancer networks and health boards) and **health professionals** to embed our 6 recommendations for improvement - as laid out in this report.

**Table 14: Local health systems and health professionals should work together to:**

Develop business cases for local commissioners and national decision-makers to receive funding to implement improvements in pancreatic cancer care. Funding may include to increase workforce, dedicated expertise and resource for people with pancreatic cancer.

Increase awareness and educate healthcare teams to implement better and fairer standards of care for people with pancreatic cancer as laid out in this report.

Engage with existing and future national health improvement programmes in pancreatic cancer, such as the Getting It Right First Time for pancreatic cancer, the National Pancreatic Cancer Audit, the NIPANC/Queen's University Belfast pancreatic cancer audit and future pancreatic cancer audits and health improvement programmes such as Prehabilitation for Scotland in Scotland.

### 5.2 What governments and the NHS across the UK must do now to implement an Optimal Care Pathway for pancreatic cancer

Governments and NHS must act to fund a faster and fairer pathway for people with pancreatic cancer. Our calls to action for decision-makers in governments and NHS across the UK to implement at Optimal Care Pathway by UK nation are outlined in figure 15.

## Our calls to action across the UK

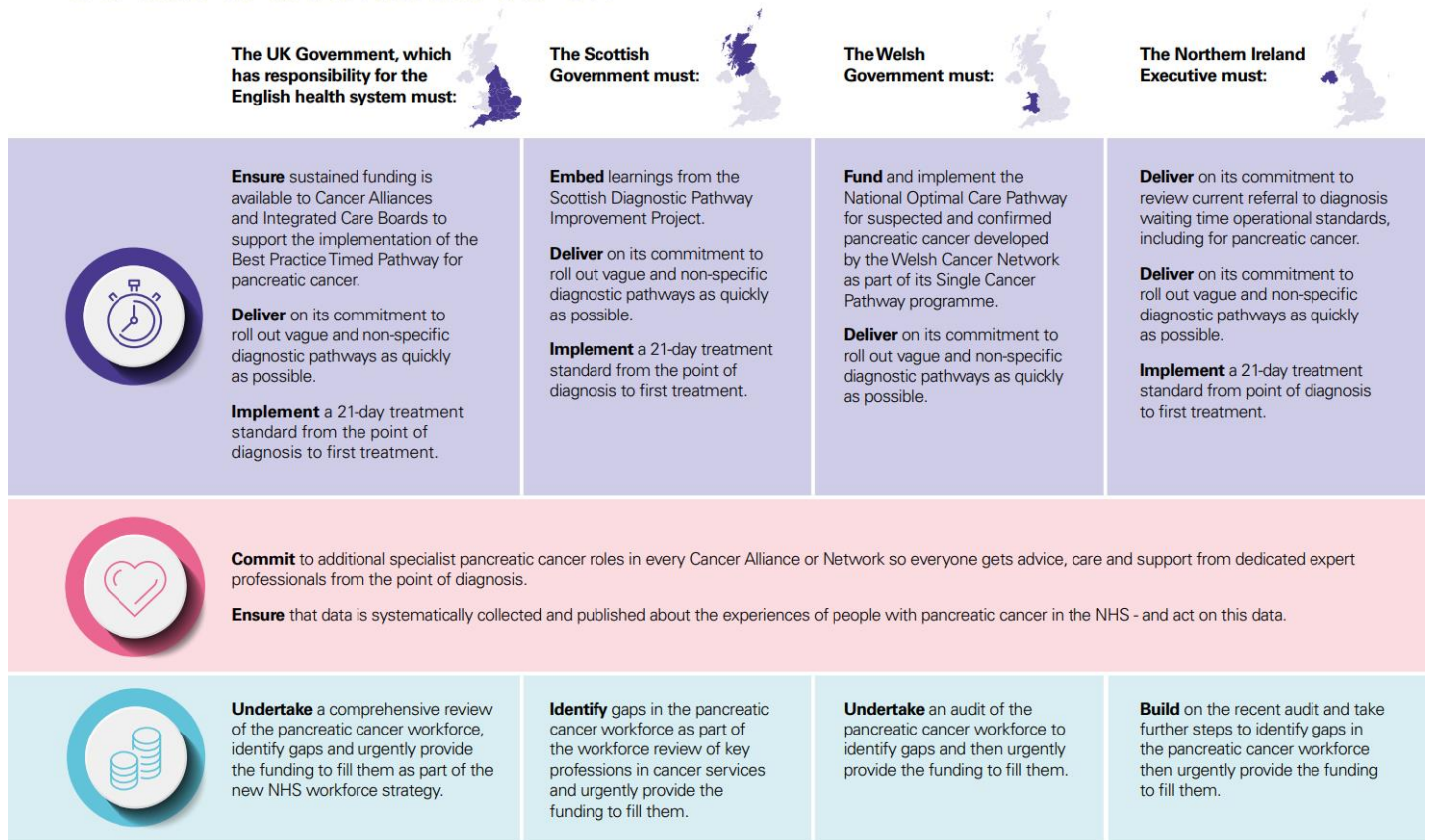


Figure 15: Our calls to action to implement an Optimal Care Pathway by UK nation

### 5.3 Next steps for our initiative

As a community, we will continue to develop our evidence base and build on this report. We will focus on two key areas, including developing evidence in areas of care that lack data (as set out below) and driving implementation of the Optimal Care Pathway across the UK.

#### 5.3.1 Develop evidence in areas of care that currently lack data

Table 15: Areas of care where we currently lack evidence and/or research, and will work with relevant research and national NHS teams to better understand	
Area of care	Additional evidence and/or research needed to understand what better standards of care look like
Treatment pathways for people with resectable pancreatic cancer	<ul style="list-style-type: none"> <li>While there is clear evidence that the right treatment pathway for people with borderline resectable disease is neo-adjuvant therapy followed by resection where clinically indicated, we need to better understand whether this or a straight to surgery model gives the best outcomes for people who are resectable at diagnosis,</li> <li>We need to better understand the impact of biliary drainage versus a straight to surgery model and how and when pre-operative biliary drainage should be given. We need to develop a specific pathway to ensure that when pre-operative drainage is given, it does not lead to long delays in accessing surgery.</li> </ul>



<p><b>Neo-adjuvant treatment pathways for people with borderline resectable pancreatic cancer</b></p>	<p>There is a strong evidence base for a neo-adjuvant therapy approach for people with borderline resectable pancreatic cancer. However, we need to better understand:</p> <ul style="list-style-type: none"> <li>• Which people within this cohort are most likely to benefit from neo-adjuvant programmes to predict onward management,</li> <li>• The optimal neo-adjuvant treatment regime, and when and what tests should be used to determine whether resection should be considered. For example, if a biological response (CA-19-9/PET avidity reduction) as well as anatomical stability or response are needed.</li> </ul>
<p><b>Active treatment options</b></p>	<ul style="list-style-type: none"> <li>• Currently, the optimal adjuvant chemotherapy approach is FOLFIRINOX for people who are deemed fit and gemcitabine capecitabine (GemCap) combination for people who are less well. However, there is a need for further research in the adjuvant setting and further research into Gem/Abiraxane and other chemotherapy options,</li> <li>• We need to understand whether people who have received neo-adjuvant therapy and a resection would benefit from receiving adjuvant therapy,</li> <li>• We need to optimise the role of precision radiation into the systemic treatment paradigm, including the role of drug – precision radiotherapy options in the preoperative setting and drug – radiotherapy such as SABR the locally advanced and (oligo) metastatic setting,</li> <li>• We need more evidence to understand the optimal length of chemotherapy treatment, and how to take a fully personalised and tailored approach,</li> <li>• We need more research into better treatment options for people with locally advanced and metastatic pancreatic cancer.</li> </ul>
<p><b>Alternative therapies</b></p>	<ul style="list-style-type: none"> <li>• We need to better understand the evidence about the impact of alternative therapies and repurposed drugs. We need to understand whether people affected by pancreatic cancer feel we should prioritise this area of care.</li> </ul>
<p><b>Post resection follow up surveillance</b></p>	<ul style="list-style-type: none"> <li>• Currently approaches to postoperative tumour surveillance vary considerably regionally and nationally. We need more evidence to understand the impact of post-operative follow up surveillance, which considers rates of recurrence and the ability to spot recurrence at an early stage, a person’s wishes, and a review of current practices to understand the best model for this aspect of the pathway.</li> </ul>
<p><b>Supportive care</b></p>	<ul style="list-style-type: none"> <li>• We need to establish and standardise management and investigations of people with jaundice and people with biliary obstruction,</li> <li>• We need to understand the optimal second line management of people who require biliary drainage, when endoscopic retrograde cholangiopancreatography (ERCP) fails,</li> <li>• We need more evidence to support the case for the impact of good nutritional management during treatment for people with pancreatic cancer,</li> <li>• We need more investment in research to understand how best to prevent, manage and treat cachexia in pancreatic cancer.</li> </ul>

Some of the above evidence gaps may be addressed through the national audits across the UK as well as the Getting It Right First Time review on pancreatic cancer in England. We will also identify what gaps – if any - constitute research questions which can be explored through our charity’s Research Strategy <sup>40</sup>.

<sup>40</sup> [Our research strategy](#) 2023 Detect early. Treat better. Save lives. Pancreatic Cancer UK

### *5.3.2 Drive implementation of the Optimal Care Pathway across the UK*

We will support national and local systems to make our Optimal Care Pathway for pancreatic cancer a reality by driving national policy development in pancreatic cancer, as well as informing and educating health professionals through our health professional programme of work. Furthermore, we are aiming to work with NHS officials and frontline health professionals to test elements of the pathway, share and disseminate examples of best practice and develop service development and improvement proposals.

## 1. National healthcare improvement initiatives in pancreatic cancer

Nations across the UK are undertaking national health improvement programmes to improve pancreatic cancer care. Below we outline these programmes and how the Optimal Care Pathway has fed into and continues to align with them.

### *Health improvement programmes on pancreatic cancer in England*

Area of care	Health Improvement Programme	Programme detail	Alignment with Optimal Care Pathway
Improving diagnosis	<b>NHS England Best Practice Timed Pathway for HPB Cancers.</b>	<ul style="list-style-type: none"> <li>The Pathway was developed by NHS England in partnership with a multi-disciplinary consensus group of clinical leaders from local and specialist services across England, expert advice from Cancer Alliances, charities, and people with lived experience.</li> <li><b>Aims:</b> <ul style="list-style-type: none"> <li>To improve and shorten diagnosis pathways,</li> <li>Reduce variation,</li> <li>Provide early holistic support,</li> <li>Meet the Faster Diagnosis Standard.</li> </ul> </li> <li>The pathway proposes a 21-day referral to diagnosis standard for people with pancreatic cancer. The pathway has been published on the NHS England Cancer Alliance portal.</li> </ul>	Evidence and recommendations developed through the Optimal Care Pathway initiative fed into the design of this pathway, including a recommendation of a <b>21-day diagnostic pathway.</b>
Improving treatment and care	<b>National Pancreatic Cancer Audit (NPaCA) in England and Wales</b>	<ul style="list-style-type: none"> <li>Commissioned by the NHS England cancer programme team and the Welsh Government, the audit will be delivered by the National Cancer Audit Collaborating Centre (NATCAN) at the Royal College of Surgeons,</li> <li>It will gather real world information from databases across England and Wales,</li> <li>It will measure a set of clinical indicators and provide an overview of patient outcomes on a local, regional and national level.</li> </ul>	Through the evidence of the Optimal Care Pathway, we have proposed priority areas for the NPaCA to address. There is an aim to fill some of the key gaps in evidence and data that have been identified through the Optimal Care Pathway initiative.  NPaCA can potentially act as a key auditing tool for evaluating the success of the implementation of

		<ul style="list-style-type: none"> <li>• <b>Aims:</b> <ul style="list-style-type: none"> <li>○ Understand variation in outcomes for people with pancreatic cancer,</li> <li>○ Allow better comparisons to be made,</li> <li>○ Revealing where shortfalls need to be addressed.</li> </ul> </li> <li>• The first report is due in autumn 2024.</li> </ul>	better standards of care for people with pancreatic cancer.
	<b>Getting It Right First Time (GIRFT) for pancreatic cancer in England</b>	<ul style="list-style-type: none"> <li>• Launched in August 2023, this programme will use available data as well as data driven deep dives at all specialist centres and their referring hospitals in England to review service provision across England,</li> <li>• It will highlight good examples and issues across England,</li> <li>• The national report is due in summer 2024.</li> </ul>	<p>This programme will identify the progress of specialist centres against the recommendations in the Optimal Care Pathway.</p> <p>It will map service provision to understand what is needed to implement the Optimal Care Pathway.</p>
	<b>Hepato-pancreato-biliary (HPB) specialist service specification in England.</b>	The specification review was set up to ensure that the treatment and care that people with pancreatic cancer receive is aligned with formal national guidelines and the most up-to-date clinical practice. A specialist HPB centre is defined as a centre with a team of health professionals who specialise in pancreatic cancer (and other HPB cancers) deliver treatment and care. Expected to be published by NHS England early 2024.	Evidence and recommendations through the Optimal Care Pathway initiative has supported the development of the specification – in terms of recommendations and quality metrics.
	<b>Improving psychosocial support for people affected by cancer implementation toolkit for Cancer Alliances in England</b>	Evidence and recommendations through the Optimal Care Pathway initiative has supported the development of the specification – in terms of recommendations and quality metrics.	The Optimal Care Pathway developed a best practice psychosocial support for people with pancreatic cancer guide which was incorporated into this toolkit.

**Health improvement programmes on pancreatic cancer in Scotland**

<b>Table 17: Health improvement programmes in Scotland</b>			
<b>Area of care</b>	<b>Health Improvement programme</b>	<b>Further details of programme</b>	<b>Alignment with Optimal Care Pathway</b>
Improving diagnosis and treatment	<b>6-week Pathway Improvement Project.</b>	<p>This programme is overseen by the Scottish Hepato-pancreato-biliary (SHPBN) network. A baseline audit was initially undertaken to develop project performance indicators. A new fast track diagnostic pathway has been implemented and is currently being audited to understand improvements in pathways and patient outcomes.</p> <p><b>Aims:</b></p> <ul style="list-style-type: none"> <li>• To enhance care alongside existing pathways utilising the existing local and regional care teams,</li> <li>• Facilitate early specialist review of radiology findings to enable efficient, patient-specific staging investigations prior to presentation at the regional MDT,</li> <li>• Facilitate early involvement of a “key worker” (local CNS team) to act as a single point of contact for the patient,</li> <li>• Initiate Early Holistic Care to prevent deconditioning and coordinate communication between the patient, CNS, primary/secondary / regional care teams and involved Allied Health Professionals (AHPs) <sup>41</sup>.</li> </ul> <p>An evaluation of initial phase of the pilot will be released soon.</p>	We are working with the SHPBN Pathway Improvement Project team to understand the impact the new 6-week pathway has had on patient experiences and outcomes.
Improving care	<b>Prehabilitation for Scotland.</b>	The Scottish Government has developed the following frameworks for implementing prehabilitation services across Scotland:	Evidence gathered through the Optimal Care Pathway initiative has fed into the development of implementation plans for prehabilitation services.

<sup>41</sup> [The Pancreatic and Hepatocellular Cancer Pathway Improvement Project](#). Scottish Government. Accessed October 2023

		<ul style="list-style-type: none"> <li>• Key Principles for Implementing Cancer Prehabilitation across Scotland<sup>42</sup>,</li> <li>• Nutrition Framework for People with Cancer<sup>43</sup>,</li> <li>• Psychological Therapies and Support Framework for people affected by cancer patients<sup>44</sup>.</li> </ul> <p>These frameworks have been published and additional investment has been provided to roll out a prehabilitation service across all 5 cancer networks.</p>	
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**Health improvement programmes on pancreatic cancer in Northern Ireland**

<b>Table 18: Health improvement programmes in Northern Ireland</b>			
<b>Area of care</b>	<b>Health Improvement programme</b>	<b>Further detail of programme</b>	<b>Alignment with Optimal Care Pathway</b>
Improving diagnosis	<b>Cancer Strategy commitment to review waiting time targets.</b>	As part of its work to ensure equity across the patient pathway, in its recently published 10-year Cancer Strategy, the Northern Ireland Assembly committed to reviewing current waiting time targets.	We would like the opportunity to feed our evidence into this review, to ensure the needs of people with pancreatic cancer are met.
Improving care	<b>Prehabilitation service development.</b>	In partnership with Macmillan, prehabilitation Leads have been appointed in each of the five Health and Social Care Trusts to oversee the development of multi-disciplinary prehabilitation services. Three tumour sites (colorectal, lung & haematology) are being piloted to begin with the plan to extend to other tumour sites.  The aims are to improve clinical outcomes and general well-being for people with cancer.	We would like the opportunity to feed our evidence into this health improvement programme, to ensure the needs of people with pancreatic cancer are met.

<sup>42</sup> [Cancer prehabilitation survey: findings report](#). Scottish Government. Accessed October 2023

<sup>43</sup> [Nutrition Framework for People Affected by Cancer](#). Scottish Government. Accessed October 2023

<sup>44</sup> [Psychological therapies and support framework for people affected by cancer](#). Scottish Government. Accessed October 2023

<b>Table 19: Health improvement programmes in Wales</b>			
<b>Area of care</b>	<b>Health care improvement programme</b>	<b>Further detail of programme</b>	<b>Alignment with the Optimal Care Pathway</b>
Improving treatment and care	<b>National Pancreatic Cancer Audit (NPaCA) in England and Wales.</b>	<ul style="list-style-type: none"> <li>• Commissioned by the NHS England cancer programme team and the Welsh Government, the audit will be delivered by the National Cancer Audit Collaborating Centre (NATCAN) at the Royal College of Surgeons,</li> <li>• It will gather real world information from databases across England and Wales,</li> <li>• It will measure a set of clinical indicators and provide an overview of patient outcomes on a local, regional and national level.</li> <li>• <b>Aims:</b> <ul style="list-style-type: none"> <li>○ Understand variation in outcomes for people with pancreatic cancer,</li> <li>○ Allow better comparisons to be made,</li> <li>○ Revealing where shortfalls need to be addressed.</li> </ul> </li> <li>• The first report is due in autumn 2024.</li> </ul>	<p>Through the evidence of the Optimal Care Pathway, we have proposed priority areas for the NPaCA to address. There is an aim to fill some of the key gaps in evidence and data that have been identified through the Optimal Care Pathway initiative.</p> <p>NPaCA can potentially act as a key auditing tool for evaluating the success of the implementation of better standards of care for people with pancreatic cancer.</p>
Entire pathway	<b>The Wales National Optimal Pathway for suspected and confirmed pancreatic cancer.</b>	NHS Wales has developed the Wales National Optimal Pathway for pancreatic cancer, as part of the Single Cancer Pathway (SCP) programme of work. The Wales National Optimal Pathway for pancreatic cancer outlines better standards of care across diagnosis, treatment and care for people with pancreatic cancer. The pathway has been published.	Many of the recommendations in this pathway broadly align with the Optimal Care Pathway diagnosis and treatment recommendations.

## Appendix 2: Our Approach

The following section outlines our approach to reviewing, collating and analysing evidence to build our Optimal Care Pathway guide.

### Existing Literature

In 2021, we undertook a review of existing literature on optimal care pathways in pancreatic cancer, and other cancer types. Table 20 outlines the national and international guidelines which were reviewed to support the development of the Optimal Care Pathway.

**Table 20: Key resources used to inform the draft Optimal Care Pathway for pancreatic cancer<sup>45</sup>**

#### Key resources used to inform the draft Optimal Care Pathway for pancreatic cancer

**NICE NG85 guideline: Pancreatic cancer in adults: diagnosis and management.** This guideline covers diagnosing and managing pancreatic cancer in adults aged 18 and over. It aims to improve care by ensuring quicker and more accurate diagnosis, and by specifying the most effective treatments for people depending on how advanced their cancer is (2018).

**Wales National Optimal Pathway (NOP) for Pancreatic Cancer.** This pathway covers the diagnosis, treatment and care of people with pancreatic cancer (2020).

**North, South East and West of Scotland Cancer Networks. HepatoPancreatoBiliary Cancers National Follow-up Guidelines** (2016)

**Australian optimal care pathway for people with pancreatic cancer.** This pathway describes the standard of care that should be available to all cancer patients treated in Australia (2021).

**American Society of Clinical Oncology (ASCO): Potentially Curable Pancreatic Adenocarcinoma: ASCO Clinical Practice Guideline Update.** This document outlines practice-changing evidence into ASCO's recommendations on potentially curable pancreatic adenocarcinoma (2019).

**American Society of Clinical Oncology (ASCO): Metastatic Pancreatic Cancer: American Society of Clinical Oncology Clinical Practice Guideline.**  
ASCO guideline on metastatic pancreatic cancer pertaining to recommendations for therapy options after first-line treatment (2020).

**National Comprehensive Cancer Network (NCCN) Pancreatic Adenocarcinoma guideline.**  
In the NCCN Guidelines for Pancreatic Adenocarcinoma, the diagnosis and management of adenocarcinomas of the exocrine pancreas are discussed. These NCCN Guidelines are intended to assist with clinical decision-making (2021).

<sup>45</sup> - [Pancreatic cancer in adults: diagnosis and management](#) 2018. NICE guideline NG85. Accessed October 2023

- [National Optimal Pathway for Pancreatic Cancer](#) 2020. NHS Wales Health Collaborative. Accessed October 2023

- [HepatoPancreatoBiliary Cancers National Follow-up Guidelines](#) 2016 National Scottish Guidelines. Accessed October 2023

- [Optimal care pathway for people with pancreatic cancer](#) 2021. Cancer Council, Australia. Accessed October 2023

- Khorana *et al.*, 2019 Potentially Curable Pancreatic Adenocarcinoma: ASCO Clinical Practice Guideline Update J Clin Oncol 37(23):2082-2088 doi: [10.1200/JCO.19.00946](https://doi.org/10.1200/JCO.19.00946)

- Sohal *et al.*, 2020 Metastatic Pancreatic Cancer: ASCO Guideline Update J Clin Oncol 38(27):3217-3230 doi: [10.1200/JCO.20.01364](https://doi.org/10.1200/JCO.20.01364)

- Tempero *et al.* 2021 National Comprehensive Cancer Network (NCCN) Pancreatic Adenocarcinoma guideline J Clin Oncol 37 (23): 2082-2088 doi: [10.1200/JCO.19.00946](https://doi.org/10.1200/JCO.19.00946)



The review revealed a lack of data, evidence and research on what better and fairer standards of care for people with pancreatic cancer should look like, particularly within the context of UK health systems.

Furthermore, we found that the experiences and quality of life of people with pancreatic cancer and their loved ones are not captured effectively. NHS systems across the UK disseminate multiple annual patient surveys including the Cancer Patient Experience Survey (CPES) and Quality of Life survey. However, due to the rapid progression of pancreatic cancer and high mortality rate, these surveys have a strong survivor bias and do not give us a full picture of the state of pancreatic cancer services in the UK.

To build our evidence base, we brought together the clinical experience and authoritative expertise of a Steering Committee, as well as consulting with wider pancreatic cancer stakeholders (300 people in total). We used a range of consensus building activities such as polls and roundtables to gather qualitative and quantitative data. We used 70% as consensus threshold while developing our recommendations and calls to action.

### **Expert Steering Committee**

The expert Steering Committee was established in September 2021 and brought together leading health professionals, representing all levels of NHS, NHS health care service improvement experts and patient and carer representatives across the UK. The Committee is led by a Chair, Professor Paula Ghaneh, Honorary Consultant Surgeon and Professor of Surgery at the University of Liverpool, and a Vice Chair, Mary Phillips, Advanced Clinical Practitioner (Hepato-pancreatico-biliary dietetics) at Royal Surrey County Hospital and post graduate researcher at the University of Surrey. The Steering Committee is facilitated by Pancreatic Cancer UK. The Steering Committee has met formally six times to discuss each area of the pancreatic cancer pathway, to build clinical consensus on what better standards of care should look like and to agree on how this can be implemented across the UK.

### **Wider NHS and health professional stakeholder engagement**

In addition to the expert Steering Committee, Pancreatic Cancer UK disseminated a survey to understand the gaps in care and key priority areas for the Optimal Care Pathway. The survey received around 50 responses from a range of health professionals across the UK.

Pancreatic Cancer UK also held additional workshops in 2022 and 2023 and brought together wider stakeholders from across the NHS including health professionals and policy experts, to build consensus on specific areas of care and to agree on the changes needed to implement the pathway recommendations.

### **Wider engagement with people affected by pancreatic cancer**

Pancreatic Cancer UK held two workshops in 2022 and disseminated a survey to a wider pool of people affected by pancreatic cancer to better understand the key challenges in pancreatic cancer care delivery and the impact on people with pancreatic cancer and their loved ones. Over 150 people with a personal connection to pancreatic cancer engaged with these activities.

### **Developing this report**

This report is a culmination of the evidence gathered and consensus built over the past 2 years. This report was developed by the Optimal Care Pathway expert community (over 300 people were consulted and contributed).

### **Strengths and limitations**

Engagement participants were self-selecting and may not be representative of all people with pancreatic cancer and their loved ones, and health professionals. Furthermore, whilst a wide range of stakeholders were involved in the evidence development process, the majority of the health professional stakeholders were HPB specialists. However, we have ensured that we have representation of healthcare professionals who were not specifically pancreatic cancer specialists – e.g. palliative medicine specialists and psycho-oncologists. We will continue to work to engage wider specialties in this work.

A lack of UK data on pancreatic cancer pathways and outcomes has meant recommendations are based on the evidence and views of an expert community. To strengthen our case for change, standardised pancreatic cancer pathways must be funded, implemented, measured and evaluated.

These limitations aside, the initiative brought together a wide range of stakeholders, facilitated discussions between health professionals and people affected by pancreatic cancer, and it brought together a fragmented community to build a case for change, as one voice. It is the first time that a cross-UK Optimal Care Pathway for pancreatic cancer has been developed – as a community, we are leading the way in driving improvements across the whole pathway, across the UK.

The work does not end here. As national initiatives and government plans progress, and research breakthroughs are adopted into NHS practice, we will continue to work together to build our evidence of what better and fairer standards of care should look like and how these can be implemented, driving forward progress in pancreatic cancer care.

**Thank you to the health professionals, NHS improvement experts and patient representatives from across UK who developed these recommendations:**

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