

Pancreatic
Cancer
UK

DON'T WRITE
ME OFF



**Faster.
Fairer.
Funded.**

People with pancreatic cancer urgently need a faster, fairer, funded pathway throughout their diagnosis, treatment and care.

Foreword

Paula Ghaneh

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



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 Europe, and the world.

However, with the right will and ambition, we believe that change is possible.

I've been honoured to chair Pancreatic Cancer UK's Optimal Care Pathway initiative. For the first time ever, we've brought together people affected by pancreatic cancer and experts from across the UK to build consensus on the action that needs to be taken 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 is building across the UK to tackle this challenging 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 hugely improve the outcomes for people diagnosed with pancreatic cancer.

Now, governments across the UK need to unlock this potential – and position the UK as one of the best countries for pancreatic cancer survival.

Introduction

Pancreatic cancer is tough to detect. And even once it's spotted, people face huge obstacles in getting the care they need.

They struggle with getting their diagnosis, receiving timely treatment and getting the support they need to have the best possible quality of life.

People feel left in the dark, and in some cases written off - with no options and no hope.

This is unacceptable. But it doesn't have to be this way.



7 in 10 people with pancreatic cancer never receive treatment - not even chemotherapy



More than half of people die within three months of diagnosis

More than 300 patient representatives and health professionals from across the UK have joined our charity to lay out what needs to change to transform diagnosis, treatment and care for everyone facing pancreatic cancer.



People with pancreatic cancer urgently need a faster, fairer and funded pathway through their diagnosis, treatment and care.

With this pathway, more people would have a chance to survive.

Our report sets out what governments and the NHS must do to achieve this. **Now, we urge them to act.**



Richard Murphy
Patient Representative,
Optimal Care Pathway
Steering Committee



My wife Lynda died of this terrible disease in 2021, aged just 51. Sharing my personal experiences as part of this project gave me a focused way to improve the outcomes for other families facing this diagnosis in the future. It's my hope that this report inspires decision-makers across the UK to play their part in delivering change.



Nicola's dad waited so long that treatment became impossible



Nicola Allen, 43,
Kent



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.

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. Written off.

Dad was still strong 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.

We need things to change if patients are going to stand a chance of living longer.



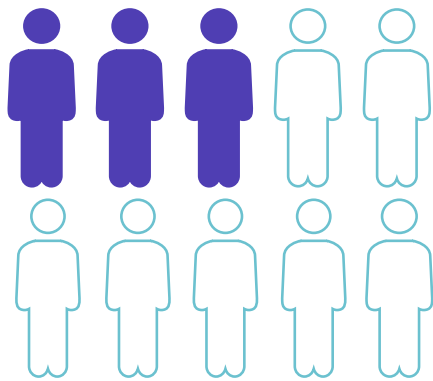
If his chemo had started earlier, maybe we would have had a chance to do more things with him. Just a bit more time.



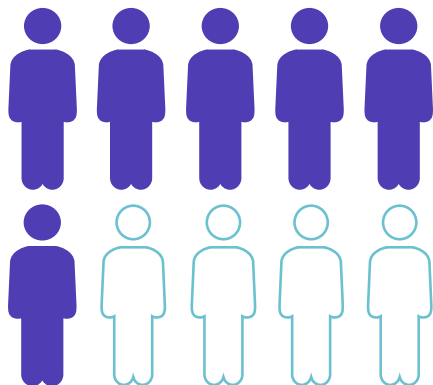
Clive with his granddaughter Grace and grandson Joe

If a faster, fairer, funded pathway was implemented now:

▶▶▶▶ Treatment rates could double



Treatments rates now



Treatments rates by 2028



UK ranking for 5 year survival rates could move up 10 places

Latvia
Belgium
Portugal
Germany
Estonia
Sweden
Ireland
Norway
Switzerland
France
Poland
Denmark
Spain
Netherlands
UK
Czechia

Survival now

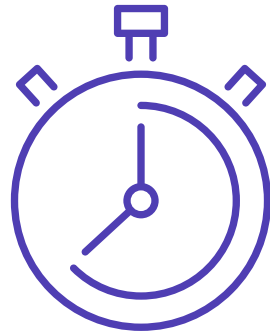


Latvia
Belgium
Portugal
Germany
UK
Estonia
Sweden
Ireland
Norway
Switzerland
France
Poland
Denmark
Spain
Netherlands
Czechia

Survival by 2028

Comparison with 15 countries in Europe with comparable and reliable data.

Why do we need to act now?



Diagnosis is taking too long



People are waiting far too long for pancreatic cancer to be confirmed or ruled out. **Slow processes and the need for multiple tests leave people in the dark, often chasing results.** Because of this, many people quickly become too weak to receive any treatment.

Treatment comes too late



Once diagnosed, **only three out of 10 people get any treatment, the lowest proportion of all cancer types.** This cancer progresses rapidly, and many people who were operable at diagnosis become incurable. Half of people die within three months of diagnosis.

Care is inconsistent



People struggle to navigate the health system. They feel like they're fighting to be heard and to get the information and care they need to be well enough to have treatment. **Many people feel written off with no support plan in place, and no help to manage their symptoms.**

Care also varies throughout the UK, meaning that the chance of someone surviving varies depending on where they live.

This isn't fair.



Our calls to action

Governments across the UK must act now to implement a pathway for the diagnosis, treatment and care of everyone facing pancreatic cancer.

If this becomes a reality, everyone with pancreatic cancer will have a better quality of life, and more people will survive.

This pathway must be:



Faster.

Everyone should be diagnosed within 21 days of being sent for tests, and start treatment within 21 days of receiving a diagnosis.



Fairer.


Everyone should get the best support and care from expert professionals, regardless of where they live, or their chance of survival.




Funded.

Governments must provide the sustained funding to make these changes possible.


The current situation


 **NHS 28 day diagnosis target***
*31 days in Scotland


 **NHS 62 day treatment target**

Half of people die within 90 days

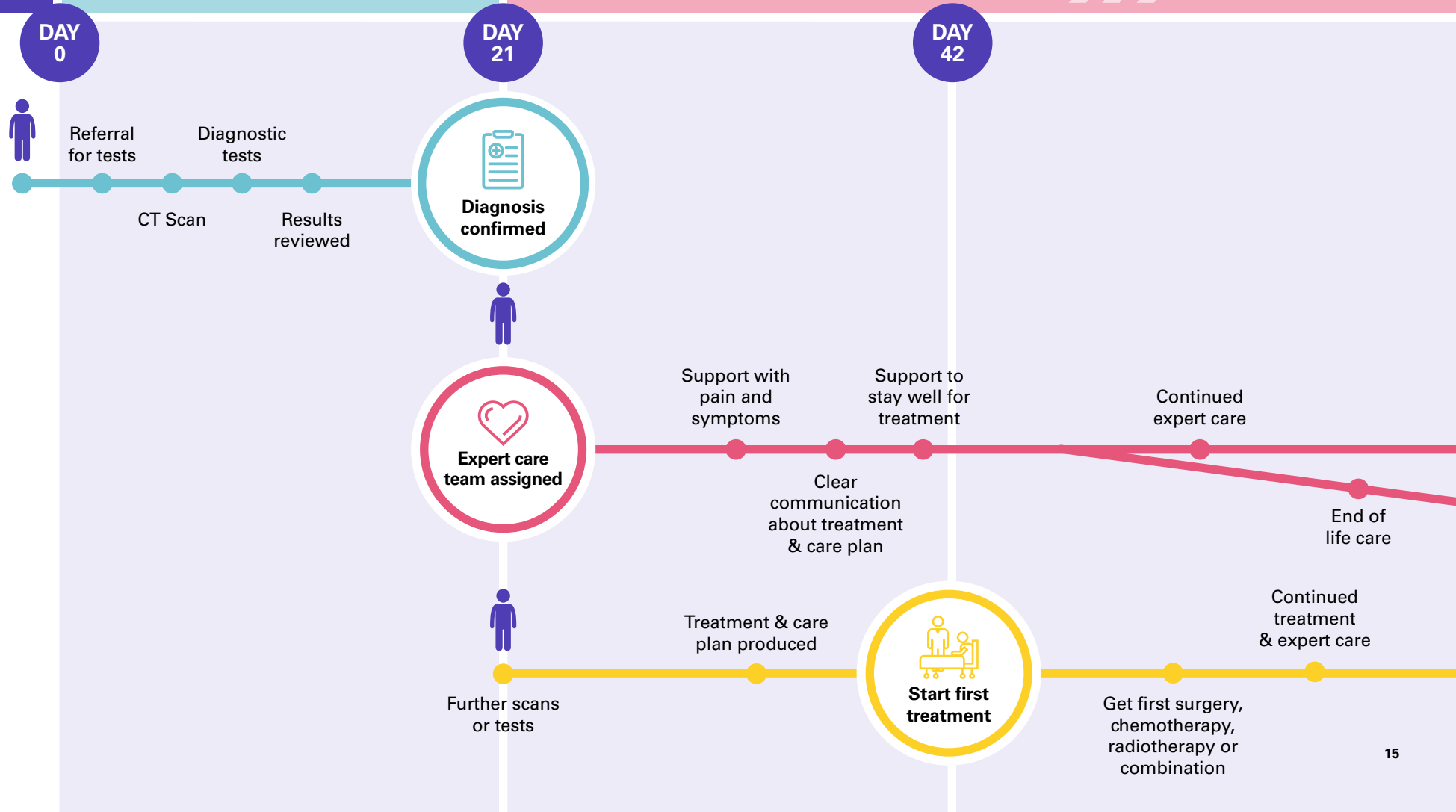
What we're calling for

 **Diagnosis within 21 days** >>>>

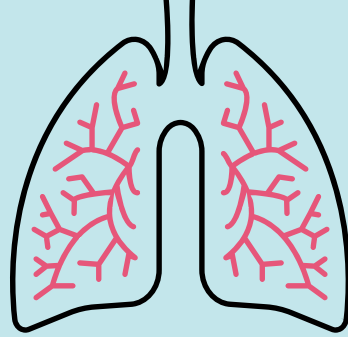
 **Treatment within 21 days of diagnosis** >>>>

 **Continuous expert care** >>>>

Pancreatic cancer symptoms spotted



Lung cancer: showing what's possible



With the right focus and investment, we can improve outcomes for pancreatic cancer— just like we've seen for lung cancer.

Over the last 20 years governments have committed to many national initiatives that have started to transform lung cancer survival. **This has more than doubled five-year survival from 7% to 16%.**

Now it's time for governments across the UK to apply the same bold approach to pancreatic cancer.

On the next pages we show how.

2005

Evidence from the first National Lung Cancer Audit kickstarted service improvements in England that led to the number of people receiving surgery more than doubling from 3,000 in 2005 to over 8,000 in 2022.

The first National Optimal Lung Cancer Pathway was published, providing a road map for the best care and treatment for people with lung cancer.

2017

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.

Other nations are following suit. For example, the Scottish Government recently invested £3 million in an Optimal Lung Cancer Diagnostic Pathway to help patients get their diagnosis within 21 days and start treatment by day 42.

2023



Faster. Faster diagnosis

Right now, people are left waiting far too long for pancreatic cancer to be either confirmed or ruled out. In this time, the disease often progresses quickly and becomes incurable.

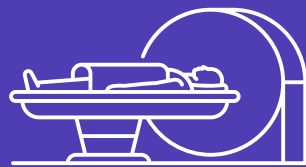
It can take multiple tests to confirm the diagnosis. Slow processes and decision-making in an under-resourced NHS worsen the situation.

That's why **it's vital that people get diagnosed within 21 days.** This would give them the best chance of getting the treatment they need to live better and longer.



1 in 2

people with pancreatic cancer are diagnosed in an emergency setting



40%

of the people in this situation had already been sent for tests for suspected cancer



Everyone should have their diagnosis confirmed or ruled out within 21 days of being sent for tests

This provides enough time for the NHS to complete all the tests required, while speeding up the overall diagnosis for people who desperately need it.



To achieve this, we need decision-makers in governments and the NHS across the UK to deliver:

- better and faster decision-making processes and access to scans, so clinicians can act quickly to confirm a diagnosis
- centralised, digital patient record management
- investment in the diagnostic workforce so results can be provided more quickly
- the continued roll-out of faster diagnostic routes for pancreatic cancer across the UK including vague and non-specific symptom pathways.

Faster diagnosis would mean more people could:

- be diagnosed when they are well enough to have treatment – such as surgery or chemotherapy
- get early support to manage severe symptoms and improve their quality of life
- live longer and have the best chance of survival.

Fast diagnosis is possible

Belfast Health and Social Care Trust's HPB team employs Helen in the unique dual role of patient navigator and MDT coordinator, which has resulted in faster diagnosis for patients.



Helen Smyth,
HepatoPancreaticoBiliary (HPB)
and Neuroendocrine Tumours
(NET) Patient Navigator and MDT
Coordinator, Belfast Health and
Social Care Trust



My job is to make sure that the Multi-Disciplinary Team (MDTs) members have the information at their fingertips to make fast decisions. I then accelerate everything to get patients diagnosed quickly, while guiding them through every step.

- Radiology and pathology teams receive all the test results ahead of the MDT – so decisions can be made quickly.
- All referrals, appointments or diagnostic tests agreed at the MDT are scheduled quickly so that a patient's care is coordinated, and patients get their diagnosis faster.
- Helen negotiates quicker access for people waiting for further investigations and highlights delays or bottlenecks – because people with pancreatic cancer have no time to wait.
- Thanks to this additional workforce resource, patients are often diagnosed much sooner, reducing some of the stress and worry they face.

What governments across the UK need to do now

England

- Provide the long-term funding needed by Integrated Care Boards and Cancer Alliances to implement and sustain the Best Practice Timed Pathway for HPB cancers, including pancreatic cancer, across England.
- Deliver on its commitment to roll out vague and non-specific diagnostic pathways as quickly as possible.

Scotland

- Provide the long-term funding needed to embed learnings from the Scottish Diagnostic Pathway Improvement Project.
- Deliver on its commitment to roll out vague and non-specific diagnostic pathways as quickly as possible.

Wales

- Fund and implement the National Optimal Care Pathway for suspected pancreatic cancer developed by the Welsh Cancer Network as part of its Single Cancer Pathway programme.
- Deliver on its commitment to roll out vague and non-specific diagnostic pathways as quickly as possible.

Northern Ireland

- Deliver on its commitment to review current referral to diagnosis waiting time operational standards, including for pancreatic cancer.
- Deliver on its commitment to roll out vague and non-specific diagnostic pathways as quickly as possible.

Faster.

Faster treatment

Even once people get a diagnosis, valuable time is often lost.

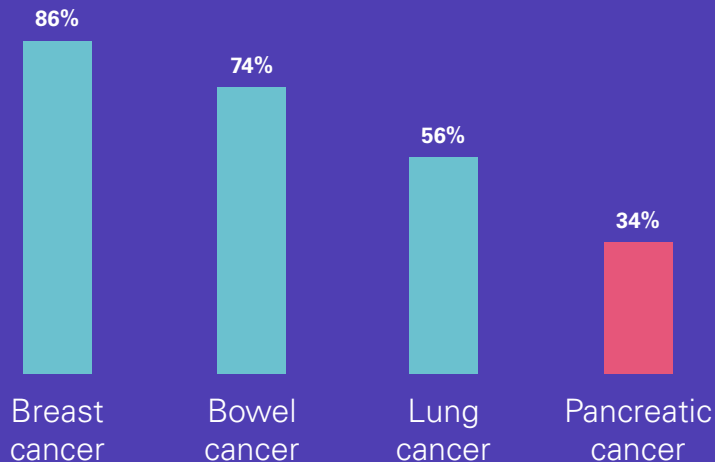
While someone with pancreatic cancer waits to have treatment, their disease often advances to the stage that chemotherapy or surgery are no longer an option.

People who were expecting treatment can no longer receive it.

Faster and more effective NHS decision-making processes, and more expertise in the treatment workforce are needed.

This would mean that more people could be fast tracked into treatment – whether that’s life-saving surgery, or chemotherapy or radiotherapy, to give them more time with their loved ones.

Current treatment rates across the UK



Everyone should start treatment within 21 days of getting their diagnosis

This would ensure more people are eligible for treatment, whilst giving health professionals enough time to develop the right treatment plan. It would also give people with pancreatic cancer time to consider their options and build up their health.



To achieve this, decision-makers in governments and the NHS across the UK must deliver:

- faster and more effective decision-making tools to help clinicians develop treatment plans
- investment in the cancer treatment workforce so everyone can get treated by dedicated oncology teams with pancreatic cancer expertise.

Faster diagnosis would mean more people could:

- be treated before their cancer becomes incurable
- be well enough to receive treatment such as chemotherapy, radiotherapy and surgery
- live longer and better.

Fast forward Faster treatment is possible

Special pancreatic cancer units in the UK have begun to trial a new standardised radiology reporting template called Pancreatic Cancer Reporting Template (PACT UK). This has the potential to get more people into treatment quicker by speeding up decision-making. The Pancreas Unit at Leeds NHS Trust has become one of the first centres in the UK to implement this new tool.



Raneem Albazaz,
Leeds Teaching Hospitals
NHS Trust



The PACT UK pro-forma has standardised radiology reporting, so results can be shared in a clear and consistent format between clinical teams. This helps us make better, faster decisions with more confidence. It's now become embedded as a decision-making tool within our Multi Disciplinary Team.

This has resulted in:

- faster, better informed decision-making
- safer surgery due to consistent and more detailed information about potential complications (e.g. vascular issues)
- clearer information for patients about their options.

PACT UK was developed through a UK-wide consensus building initiative supported by Pancreatic Cancer UK.

What governments across the UK need to do now

England, Scotland and Northern Ireland

Governments must implement a 21-day treatment standard from the point of diagnosis of pancreatic cancer to first treatment.

Wales

The Welsh Government must implement the Welsh National Cancer Pathway for suspected and confirmed pancreatic cancer.

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.



**Shannon
(Mary's daughter)
and Mary**

// **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"

Fast diagnosis

// **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 an 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.



Fast treatment

// **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.



Fairer care

// **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 specialist.**





Fairer.

Fairer care

A pancreatic cancer diagnosis can be devastating – and high-quality care and support is essential, regardless of someone's chance of survival.

Experts such as specialist nurses, dietitians, palliative care professionals and cancer care coordinators are specifically trained to provide this care.

They can help with managing pain and symptoms, fitness and nutrition, and provide emotional support – as well as a friendly face to guide people through their care, including for those at the end of their life.

When available, this support gives people a better quality of life and can even help them build up their strength for potentially lifesaving treatment.

But many people never get access to this type of support. Without this they feel like they're fighting the system and are left in the dark about their options - with no one to turn to, and no hope.



50%

of people with pancreatic cancer are never prescribed Pancreatic Enzyme Replacement Therapy (PERT).

PERT is a simple tablet, readily available on prescription, that replaces enzymes so food can be digested, reducing debilitating symptoms, and helping build strength for treatment.



Everyone should get advice, care and support from dedicated expert professionals from the point of diagnosis.

People with pancreatic cancer need to access a team of dedicated specialists who can oversee their treatment and care plan and provide clear and timely information.



To achieve this, decision-makers in governments and the NHS across the UK must:

- identify the gaps in resource and workforce standing in the way of fairer care
- invest in expert roles within the cancer workforce to fill these gaps.

Fairer care would mean more people could:

- feel confident in and supported by their healthcare team
- get the right support at the right time, improving their symptoms and quality of life
- receive more joined-up care – and a fairer chance of living longer and surviving.

Fairer.

A fairer chance of survival

The chance of someone surviving varies depending on where they live. This demonstrates that pancreatic cancer care is not consistent across the UK.

This is unacceptable.



Everyone should have a chance to live longer, regardless of where they live.

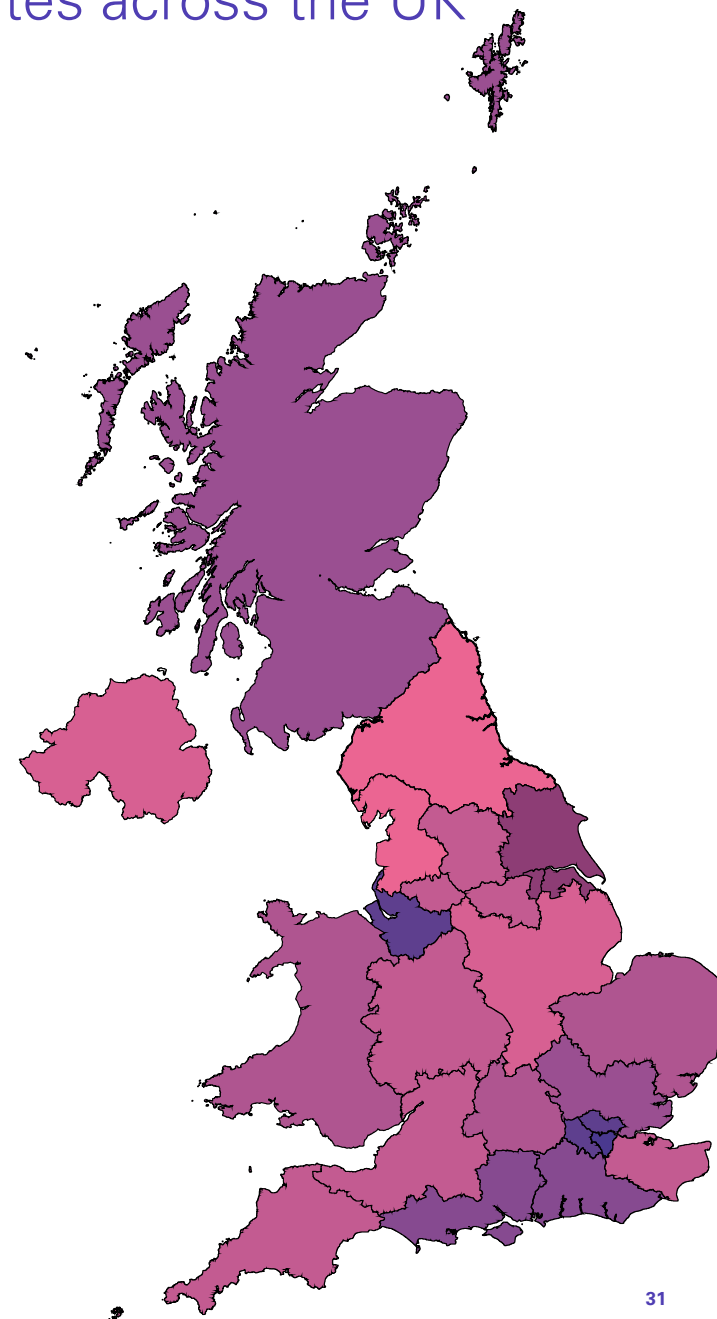
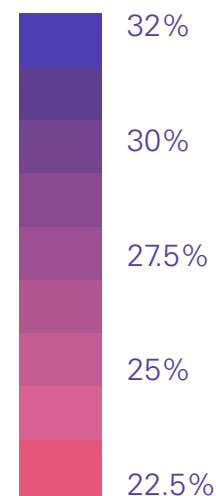
They should also feel confident they will get the best possible care.



To achieve this, decision-makers in governments and the NHS across the UK must now:

- fund and implement a faster, fairer pathway for everyone with pancreatic cancer
- ensure that data is systematically collected and published about the experiences of people with pancreatic cancer in the NHS - and act on this data.

The variation in one year survival rates across the UK



Fairer care is possible

After carrying out a review of its care for pancreatic cancer patients, St Helens & Knowsley NHS Trust urgently remodelled its service to provide people with timely information, joined up care and a better quality of life.



Barbara Ashall
(second from left) with her Upper Gastrointestinal Cancer Services Team



We secured funding for two new Clinical Nurse Specialist roles, with expertise in pancreatic cancer care, and have created partnerships with specialist palliative care services, the local hospice and community service that is giving patients better care.

They can now offer:

- access to a Clinical Nurse Specialist and dietetic support from the point of suspected diagnosis
- a weekly nurse led, multi-disciplinary team clinic to keep patients updated
- holistic needs assessment clinics twice a week and a daily telephone clinic for patients
- a weekly clinic for all palliative patients to help build their strength for palliative chemotherapy and support those receiving chemotherapy with side effects of their treatment.

As a result:

- crisis calls to the Upper GI team reduced by over 50%
- hospital readmissions post-diagnosis halved from 64% to 33%
- 85% of patients are now prescribed PERT
- patients have provided excellent feedback on the service.



He was made to feel like he was the 'only patient we had' and the 'most important person under our care'.

Family member



The team's dietitians
Naomi Chalmers
and **Fiona Bangs**

What governments across the UK need to do now

England, Scotland, Wales and Northern Ireland

- All governments must commit to funding additional specialist pancreatic cancer roles in every Cancer Alliance and Network across the UK so everyone gets advice, care and support from dedicated expert professionals from the point of diagnosis.
- All governments must ensure that data is systematically collected and published about the experiences of people with pancreatic cancer in the NHS - and act on this data.



Funded.

This report has outlined the action that is needed from governments across the UK to transform diagnosis, treatment and care for everyone facing pancreatic cancer.

But years of NHS underfunding mean that we do not currently have the sufficient workforce in place to fully deliver this care.



Governments must provide the sustained funding needed to make change possible

People with pancreatic cancer have no time to wait for their care, and we have shown how current workforce shortages are directly impacting on their chances of survival.



By 2030 we expect to have a **shortage of**

4,000

cancer nurses
across the UK.

To make a faster, fairer pathway a reality, governments need to have a fuller understanding of the extent of gaps in the pancreatic cancer workforce across diagnosis, treatment and care, and report on these gaps.

Governments must then prioritise investing in the workforce needed to implement a faster, fairer pathway for everyone with pancreatic cancer.

What governments across the UK need to do now

England

As part of the new NHS workforce strategy, carry out a comprehensive review of the pancreatic cancer workforce, identify gaps and urgently provide the funding to fill them.

Scotland

As part of the workforce review of key professions in cancer services, identify gaps in the pancreatic cancer workforce and urgently provide the funding to fill them.

Wales

Undertake an audit of the pancreatic cancer workforce to identify gaps and then urgently provide the funding to fill them.

Northern Ireland

Building on the recent audit, take further steps to identify gaps in the pancreatic cancer workforce and then urgently provide the funding to fill them.

Our calls to action across the UK

The UK Government, which has responsibility for the English health system must:



The Scottish Government must:



The Welsh Government must:



The Northern Ireland Executive must:



Ensure sustained funding is available to Cancer Alliances and Integrated Care Boards to support the implementation of the Best Practice Timed Pathway for pancreatic cancer.

Deliver on its commitment to roll out vague and non-specific diagnostic pathways as quickly as possible.

Implement a 21-day treatment standard from the point of diagnosis to first treatment.

Embed learnings from the Scottish Diagnostic Pathway Improvement Project.

Deliver on its commitment to roll out vague and non-specific diagnostic pathways as quickly as possible.

Implement a 21-day treatment standard from the point of diagnosis to first treatment.

Fund and implement the National Optimal Care Pathway for suspected and confirmed pancreatic cancer developed by the Welsh Cancer Network as part of its Single Cancer Pathway programme.

Deliver on its commitment to roll out vague and non-specific diagnostic pathways as quickly as possible.

Deliver on its commitment to review current referral to diagnosis waiting time operational standards, including for pancreatic cancer.

Deliver on its commitment to roll out vague and non-specific diagnostic pathways as quickly as possible.

Implement a 21-day treatment standard from point of diagnosis to first treatment.



Commit to additional specialist pancreatic cancer roles in every Cancer Alliance or Network so everyone gets advice, care and support from dedicated expert professionals from the point of diagnosis.

Ensure that data is systematically collected and published about the experiences of people with pancreatic cancer in the NHS - and act on this data.



Undertake a comprehensive review of the pancreatic cancer workforce, identify gaps and urgently provide the funding to fill them as part of the new NHS workforce strategy.

Identify gaps in the pancreatic cancer workforce as part of the workforce review of key professions in cancer services and urgently provide the funding to fill them.

Undertake an audit of the pancreatic cancer workforce to identify gaps and then urgently provide the funding to fill them.

Build on the recent audit and take further steps to identify gaps in the pancreatic cancer workforce then urgently provide the funding to fill them.

Thank you to the patient representatives and health professionals across the UK who fed into the development of this report and recommendations, including members of the Optimal Care Pathway steering committee:

Dr Raneem Albazaz

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Dr Victoria Allen

GP with specialist interest in HPB Medical Oncology at The Christie NHS Foundation Trust, Manchester

Seema Arif

Consultant Clinical Oncologist, Velindre University NHS Trust at Velindre University NHS Trust, Cardiff

Anna Beretta

Patient and carer representative, Belfast

Dr Margred Capel

Consultant in Palliative Medicine and Clinical Director City Hospice at Cardiff University, Cardiff

Professor David K. Chang

Professor of Surgical Oncology and Consultant Pancreatic Surgeon at University of Glasgow and Glasgow Royal Infirmary, Glasgow

Anthony Cunliffe

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Di Dobson

Specialist Nurse at Pancreatic Cancer UK

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Professor Paula Ghaneh

Pancreas Surgeon and Professor of Surgery at University of Liverpool, Liverpool

Lesley Goodburn

Chair of Pancreatic Cancer UK's Patient and Carer Advisory Board, Stoke

Professor Nigel Jamieson

Professor of HPB Surgery, Consultant Hepatobiliary and Pancreatic Surgeon and CRUK Clinician Scientist at University of Glasgow and Glasgow Royal Infirmary, Glasgow

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Myranda Leleu

Patient and carer representative, London

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HPB Clinical Nurse Specialist at Belfast City Hospital, Belfast

Laura McGeeney

Pancreatic Specialist Dietitian at Addenbrooke's Hospital, Cambridge

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