



## National Pancreatic Cancer Audit

## State of the Nation Patient and Public Report 2024

An audit of care received by people diagnosed with pancreatic cancer in England (2020-2021) and Wales (2022)





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This document was prepared by members of the NPaCA project team and has been developed in close collaboration with NPaCA Patient and Public Involvement (PPI) forum members. Input was also received from our charity partners at Pancreatic Cancer UK (PCUK) and Pancreatic Cancer Action.



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The National Cancer Audit Collaborating Centre (NATCAN) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). NATCAN delivers national cancer audits in non-Hodgkin lymphoma, bowel, breast (primary and metastatic), oesophagogastric, ovarian, kidney, lung, pancreatic and prostate cancers. HQIP is led by a consortium of the Academy of Medical Royal Colleges and the Royal College of Nursing. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical, and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies. <u>https://www.hqip.org.uk/national-programmes</u>

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## 1. The National Pancreatic Cancer Audit (NPaCA)

The NPaCA is the first national clinical audit of pancreatic cancer services in England and Wales. The audit is delivered by the National Cancer Audit Collaborating Centre (NATCAN), a new national centre of excellence based within the Clinical Effectiveness Unit (CEU).

The overall aim of the NPaCA is to improve the quality of care for people with pancreatic cancer in England and Wales. The audit uses information collected by NHS hospitals about the care they provide for people with pancreatic cancer. This data is analysed to build a picture of what is happening across England and Wales to help drive improvements in these services. More information about the NPaCA can be found on our website: https://www.natcan.org.uk/audits/pancreatic.

We use national guidelines on the diagnosis and treatment of pancreatic cancer to assess the care provided. In this first year of reporting from the NPaCA, we give an overview of how pancreatic services function across England and Wales. Over time, the audit will be able to see which areas of pancreatic cancer care are getting better or worse compared to previous years.

This document is intended for people affected by pancreatic cancer and the general public to read, and summarises key findings from our 2024 "State of the Nation" report, which can be accessed via the <u>NPaCA web pages</u>.

#### A note on data 'quality'

The data used by the NPaCA is routinely collected within hospital systems.

We use different national sets of data to form a picture of the person's journey across the NHS. Whilst some information we receive is very complete (eg. People's sex or age at diagnosis), other information may be missing. The 'completeness' of data is an important element of *data quality*.



The proportions of records that contain complete information on three important data items in England. Ideally, levels of completeness would meet the target of 90%.

\*Clinical nurse specialist

## 2. Introduction to pancreatic cancer

The pancreas has two main roles in the body:

- i. Making enzymes to break down food ('exocrine' role)
- ii. Making hormones to control your blood sugar ('endocrine' role)

Pancreatic cancer develops when cells in the pancreas grow out of control, forming a lump. You might hear this called a tumour, lesion or mass. As these abnormal cells grow, they take up space in the pancreas, which can stop it functioning in its usual way. These cells can spread quickly to the areas around the pancreas (local spread of the tumour) and to other areas in the body (distant spread of the tumour, also known as 'metastatic' disease).

There are different types of pancreatic cancer based on the type of pancreatic cell affected:

- **Pancreatic ductal adenocarcinoma** (most common) formed when the cells which produce pancreatic <u>enzymes</u> grow abnormally
- **Neuroendocrine tumours (NETs)** formed when the cells which produce pancreatic <u>hormones</u> grow abnormally

These two cell types are different, and therefore the treatments for these tumours will also be different.

Most people are diagnosed with pancreatic ductal adenocarcinoma and we focus on these tumours in this audit.

#### Characteristics of people diagnosed with pancreatic cancer

Our audit included information about people diagnosed with pancreatic cancer over a two year period for England (2020-2021) and a one year period for Wales (2022).

The majority of people (59% in England and 63% in Wales) have stage 4 pancreatic cancer when they are diagnosed.

## 

Key findings from NPaCA 2024

## Characteristics of people diagnosed with pancreatic cancer in England (2020 - 2021)



Number of diagnoses

**19,308** people diagnosed in 2020-2021 (9,480 in 2020 and 9,828 in 2021)



 of people in the audit were diagnosed
 with a pancreatic tumour (code C25) excluding neuro-endocrine tumours (code C25.4)

12% of people were diagnosed with an extrahepatic bile duct (code C24.0) or ampulla of Vater (code C24.1) tumour.



# Age at diagnosis

Median age: 74	4 years
Under 60 years:	13%
60-69 years:	21%
70-79 years:	35%
80 years and over	: 31%

# Performance status (PS)

A measure of how 'fit' someone is, and how able they are to do tasks to look after themselves.

### Stage Stage Stage Stage

## Stage at diagnosis

Stage 1 (localised disease):12%Stage 2 (locally advanced):13%Stage 3 (locally advanced):16%Stage 4 (metastatic):59%

## 68% of people are performance status 0-1 at time of diagnosis.

PS 0 (most fit):	36%
PS 1:	32%
PS 2:	17%
PS 3:	12%
PS 4 (least fit):	3%

## Ethnicity

White:	
Asian or Asian British:	
Black or Black British:	
Mixed:	
Other ethnic group:	



3%	
3%	
2%	
<1%	
1%	

#### Affluence of areas



Division 1 (least affluent):	17%
Division 2:	19%
Division 3:	21%
Division 4:	22%
Division 5 (most affluent):	21%



## Characteristics of people diagnosed with pancreatic cancer in Wales (2022)



Number of diagnoses

**480** people diagnosed in 2002



94%

6%

63%

of people in the audit were diagnosed with a pancreatic tumour (code C25) excluding neuro-endocrine tumours (code C25.4)

50% male 50% female

of people were diagnosed with an extrahepatic bile duct (code C24.0) or ampulla of Vater (code C24.1) tumour.



# Age at diagnosis

 Under 60 years:
 13%

 60-69 years:
 23%

 70-79 years:
 37%

 80 years and over:
 26%

+

## Performance status (PS)

A measure of how 'fit' someone is, and how able they are to do tasks to look after themselves.

# Stage at diagnosis64% of people are performance<br/>status 0-1 at time of diagnosis.Stage 1 (localised disease): 14%

PS 0 (most fit):	34%
PS 1:	30%
PS 2:	17%
PS 3:	15%
PS 4 (least fit):	3%

## Affluence of areas

Stage 4 (metastatic):

Stage 2 (locally advanced): 10% Stage 3 (locally advanced): 13%

Division1 (least affluent):	21%
Division 2:	22%
Division 3:	22%
Division 4:	18%
Division 5 (most affluent):	17%



## 3. Diagnosing pancreatic cancer

#### 3.1 Review of waiting times

People are usually referred to pancreatic cancer services through these routes:

i. Urgent referral from a GP for suspected cancer

ii. 'Other' referral routes - usually through an emergency hospital admission

The NHS target for diagnosing cancer is 28 days from referral for a suspected cancer (in England, the target applies only to urgent GP referrals). However, because pancreatic cancer grows rapidly, a faster 21 day target has been recommended. For more information see: <u>NHS England:</u> <u>Implementing a timed HPB cancer diagnostic pathway, 2024.</u>

For people who go on to have treatment for their cancer, the target is for treatment to start within 62 days of referral.

#### England



#### Wales



## 3.2 Multi-disciplinary team (MDT) meetings

An MDT is a multi-disciplinary team formed of members of the pancreatic cancer healthcare team. They meet to discuss each person's cancer care, usually once a week. The team is usually made up of surgeons, gastroenterologists, oncologists, radiologists, specialist nurses, palliative care, dietitians and therapy staff.

The aims of these meetings are to confirm a person's diagnosis and agree on the next steps in their care plan. National guidelines recommend that every person with pancreatic cancer should have their care discussed at an MDT meeting, to ensure they receive specialist input from health professionals.

A member of the team will usually update the person on the outcome of this meeting either on the phone or during a face to face clinic appointment.

76% of people in England with pancreatic cancer had their care discussed at an MDT meeting.

Note: We did not have this information for people diagnosed in Wales.

Key findings from NPaCA 2024

## 4. Treating pancreatic cancer

### 4.1 All cancer treatments

Pancreatic cancer is treated using a combination of surgery to remove the cancer, chemotherapy and radiotherapy. The type of treatments offered will depend on a person's cancer stage, fitness levels and other health conditions.

In this audit, we separated people into two groups as they will be offered different forms of treatment:

- People diagnosed with stages 1, 2, or 3 pancreatic cancer: the cancer has not spread to other organs in the body
- People diagnosed with stage 4 pancreatic cancer: the cancer has spread into other organs of the body (metastatic disease)

Within these groups, we had a closer look into what types of treatment each group are receiving.





We found that people who were less fit (frail or very unwell) were less likely to receive treatment. For example, among people who had non-metastatic (stage 1, 2 or 3) cancer in England:

- If people were fit ('Performance status' of 0): 80% received treatment
- If people were less fit ('Performance status' of 3 or 4): only 6% received treatment

#### 4.2 Treatments before or after surgery

Surgery to remove the pancreatic tumour is the only way to potentially cure pancreatic cancer. The surgery involves removing parts of the pancreas, bile duct and the small intestine. It is known as a 'Whipple procedure'. Only people who are fit and whose cancer has not spread to other organs will be candidates for this major surgery.

Often, the pancreatic tumour may be too big to be fully removed by the surgical team. These people may have chemotherapy and/or radiotherapy in an attempt to shrink the tumour so that surgery may become an option (see Appendix 1).

Some people may have chemotherapy and/or radiotherapy after surgery to reduce the chances of the cancer coming back.



#### Chemotherapy with or without radiotherapy before surgery ('neo-adjuvant' treatment)

Please refer to Appendix 1 for a flow diagram on why people might be offered oncological treatments (chemotherapy / radiotherapy) before surgery.

#### Chemotherapy with or without radiotherapy after surgery ('adjuvant' treatment)

Surgery to remove pancreatic tumours is a big strain on the body and a person will need a good amount of time to rest and recover from this procedure. During this time, the pancreatic cancer MDT will look closely at the tumour which they have removed during the operation, including:

- The size of the tumour
- How many lymph nodes were found to have cancer in them
- Whether the surgeon was able to remove the tumour fully, or if there is cancer still remaining

After surgery, it is difficult to know if there are any of small cancer cells left behind as all cells, including cancer cells, are too small to see individually on scans. It is only when a cancer cell starts to grow and rapidly multiply in number to form a little lump of cells that we can detect it on imaging. If there are cancer cells still present after surgery, there is potential for these to grow and spread quickly. Therefore, if a person has not received chemotherapy before their operation, the MDT usually recommends a course of chemotherapy after surgery to kill any of these remaining cancer cells, in line with national guidance. The course of chemotherapy starts as soon as person is well enough after their surgical procedure and may be given with or without radiotherapy.

For a person that has received chemotherapy before their operation, there is no evidence to support additional chemotherapy after surgery. People may not receive adjuvant treatment if they are not fit enough after surgery.

## 5. Supporting people with pancreatic cancer

#### **5.1 Pancreatic enzyme replacement therapy (PERT)**

The pancreas plays an important role in digesting food, producing enzymes that help to break down food. When a person has a tumour in the pancreas, the pancreas may not produce enough of these enzymes to break down the food they eat. People can lose weight and become weak if they are not absorbing food properly.

Pancreatic enzyme replacement therapy (PERT) is a medication which replaces the digestive enzymes that your pancreas would normally make. The enzymes come in capsules that you take with food. Most people with pancreatic cancer will need to take PERT.

In England, 51% of people with pancreatic cancer were prescribed PERT. Those who had pancreatic surgery had a much higher proportion of PERT prescriptions (93%) compared to people who did not undergo any pancreatic surgery (46%).

Key findings from NPaCA 2024

#### **5.2 Clinical Nurse Specialists (CNS)**

Clinical nurse specialists (CNSs) are nurses who specialise in a particular area of healthcare. The NHS have cancer CNSs who support people during their cancer care.

Data on CNS involvement was missing for around half of people (54%). However, for those we did have data for, the audit found that 86% of people were seen by a CNS in England.

Key findings from NPaCA 2024

We do not have data on PERT prescriptions or CNS involvement for people with pancreatic cancer in Wales.

## 6. Survival

The audit has data on the survival of people diagnosed with pancreatic cancer in England (2020-21) and Wales (2022).

#### 6.1 Overall survival results



#### 6.2 Survival by cancer stage one year Stage 1-3 Stage 4 45-England 10% 50% Survival at one year was higher for those who had stage 1-3 cancer compared to those with stage 4 cancer. Wales 39% 9% 90 days after Whipple 6.3 Survival at 90 days after Whipple procedure procedure England For people who underwent a Whipple procedure, 97% of people in England and 100% of people in Wales survived for at least 3 months after their surgery. Wales

4 in 5 people survive to 30 days after diagnosis

Key findings from NPaCA 2024

## 7. Recommendations from the audit

The aim of the NPaCA is to improve the care of people with pancreatic cancer. In the 2024 State of the Nation report, we made five recommendations addressing these five areas of care:

- 1. Every person with a new diagnosis of pancreatic cancer should be discussed at an MDT meeting. Hospitals where diagnoses are made should look into their diagnosis pathways to make sure this happens.
- 2. Diagnosing pancreatic cancer can be a long process due to multiple investigations which need to take place. All hospitals should review their diagnostic process and ensure it is in line with the nationally recommended hepatopancreatobiliary (HPB) cancer pathway.
- 3. People need to be physically fit to receive and tolerate pancreatic cancer treatments. Specialist members of the pancreatic cancer team should work with people to get them as fit as possible, for example improving their nutrition, exercise capacity and stabilising other medical conditions.
- 4. All people with pancreatic cancer should be seen by a Clinical Nurse Specialist and, ideally, they should be available to help people from the time they receive their diagnosis.
- 5. All people with pancreatic cancer should be assessed to see if they would benefit from pancreatic enzyme replace treatment (PERT).

# Appendix 1 – Chemotherapy and radiotherapy before surgery

The diagram below outlines how doctors may decide that chemotherapy +/- radiotherapy is required before a person has pancreatic cancer surgery:



There is no national guidance on implementing this treatment; however, there are positive results from clinical trials which suggest this is a good strategy to be used for people whose tumours are too big to remove initially.

## **Appendix 2 - Glossary**

**Adjuvant therapy** – cancer treatment such as chemotherapy or radiotherapy that is given after primary treatment (typically surgery, for pancreatic cancer), to maximise effectiveness and reduce the chance of cancer recurrence.

**Ampulla of Vater** – a small structure within the wall of the duodenum (first part of the small bowel) where the common bile duct meets the pancreatic duct

**Bile duct** – a small tube-like structure that carries bile (digestive fluid) from the liver and gall bladder to the small bowel

Biliary drainage - a procedure that aids in clearing blockages from the bile ducts

**Biliary stent** – a small tube (either made from plastic or metal) that is placed into a bile duct to relieve obstruction or narrowing of the ducts, which keeps bile ducts open and allows bile to flow normally

**Clinical nurse specialist** – a registered nurse with an advanced nursing role to provide specialist care and advice to patients in a certain medical speciality

**Disease-targeted treatment** – various treatments given with the aim of killing or removing the cancerous tissue (such as surgery, chemotherapy, radiotherapy)

**Extrahepatic bile duct** – bile ducts (see above) which are located outside of the liver. They carry bile (digestive fluid) from the liver and gallbladder to the small bowel.

**FDG-PET/CT** – a Positron Emission Tomography (PET) scan combined with Computerised Tomography (CT) using 18F-fluorodeoxyglucose (FDG) as the tracer. A PET-CT scan is a type of imaging technique where a patient is injected with a small amount of radioactive tracer to assess metabolic activity in the body. Cancer cells have a very high metabolic rate, so show up brightly on this test. The images from a PET-CT scan give us a more detailed picture of tumour activity than a routine CT scan.

**Gy/F or Grays/Fractions** – External beam radiotherapy treatment is usually delivered over several treatment sessions. A course of radiotherapy is described as the full planned dose of radiation in Grays (Gy), and the number of treatment sessions (fractions, F) over which the dose is delivered. For example, 30Gy/15F would describe a course of 30 Grays of radiation delivered over 15 sessions.

**HES** – Hospital Episode Statistics is a database which contains data on all in-patients treated within NHS trusts in England. This includes details of admissions, diagnoses and treatments.

**HPB (hepatopancreatobiliary or hepatobiliary and pancreatic)** – a term used to collectively refer to some of the organs of the digestive system, namely the liver, pancreas, gallbladder, bile ducts and small intestine.

**ICD-10 – the 10<sup>th</sup> revision of the International Classification of Diseases** (a medical classification list). The list of medical codes in this comprehensive list is used to identify and categorise medical diagnoses.

**IMD (Index of Multiple Deprivation)** - a measure of relative deprivation in a particular small area (of ~1,500 residents or 650 households)

**Metastatic** – a term used to refer to the spread of disease from an initial or primary site to a different secondary site

**MDT (multi-disciplinary team)** – teams consisting of individuals drawn from various disciplines who come together to achieve a common goal: to meet and agree the diagnosis and treatment plan. These can be categorised as

- a. **specialist** (multi-disciplinary teams with particular expertise in certain areas, eg. Specialists in pancreatic cancer surgery who are often based in specialist cancer centres) or
- b. local (multi-disciplinary teams within local hospitals)

**MRI (Magnetic resonance imaging)** - a medical imaging technique used in radiology to form pictures of the body using strong magnetic fields.

**NATCAN** - The National Cancer Audit Collaborating Centre (NATCAN) is a national centre of excellence which will shine a spotlight on the care and treatment of patients who are diagnosed with cancer in England and Wales. It has been commissioned to deliver new cancer audits by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England and the Welsh Government. NATCAN is part of the Clinical Effectiveness Unit (CEU) in London – a collaboration between the Royal College of Surgeons of England (RCSEng) and the London School of Hygiene & Tropical Medicine (LSHTM).

**NCRD (National Cancer Registration Data)** - the "gold standard" cancer registration data for England. It contains information on all aspects of the cancer registration for everyone diagnosed with cancer in England. Undergoes extensive quality control by NDRS before release.

**National Disease Registration Service (NDRS)** – a service that collects and analyses data on cancer and rare diseases in the UK as part of NHS England

**Neoadjuvant therapy** – a term used to describe anti-cancer treatment (such as chemotherapy, hormones or radiation) given before the main treatment (such as surgery). The intent of this treatment is to reduce the size of the tumour, to improve the success of the main treatment or reduce the need for a more extensive procedure.

**Neuroendocrine tumours** – tumours that start from cells which produce hormones in the body. In pancreatic cancer this is very relevant as the pancreas has several cell types which produce hormones – these cells can become cancerous and the tumours will secrete hormones in an uncontrolled fashion. The treatments for these tumours are mainly hormone-based, and therefore they are managed quite differently from other pancreatic cancer tumour types.

NHS (National Health Service) - the publicly funded healthcare system in the UK

**NICE** – The National Institute for Health and Care Excellence is an independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

**Pancreas** – an organ in the human digestive system within the abdomen, which plays a major role in digesting food and regulating blood sugar

**PERT (Pancreatic Enzyme Replacement Therapy)** – medication used to replace enzymes which would normally be made within the pancreas. When patients have pancreatic cancer, or part of the pancreas is removed in a surgical procedure, the pancreas is unable to produce these enzymes which help to break down food, so PERT is required to aid digestion.

**Performance status** – a classification system to describe a patient's functional status whilst performing routine activities of daily living. Scores range from 0 (fully active with no restrictions) to 5 (dead). Note: only scores of 0-4 will be included in the audit.

**Radiotherapy**– a treatment that uses radiation to kill tumour cells and so shrink the tumour. It can be used together with surgery or chemotherapy to reduce disease.

**'Rapid' cancer registration dataset** – a dataset which provides a quicker source of cancer data compared to the gold standard registration process

**RCS** – The Royal College of Surgeons of England is an independent professional body committed to enabling surgeons to achieve and maintain the highest standards of surgical practice and patient care. As part of this it supports audit and the evaluation of clinical effectiveness for surgery.

**Stage / TNM (Tumour / Nodal / Metastatic) stage** – an international classification system to classify the extent of a cancer using information on the tumour size, lymph node status, and the presence or absence or metastatic disease. Overall cancer stages range from 1 (localised disease) to 4 (advanced disease) which is determined by the extent of the tumour size, the nodal disease burden and the presence or absence of metastatic disease.

**Supportive treatment** – a term used to refer to various treatments which can be given alongside medical treatment, or alone, to aid in managing treatment side effects or cancer-related symptoms

**Surgical resection** – a medical treatment that involves surgically removing all, or part, of a tissue, structure or organ

**Systemic anti-cancer therapy (Systemic Anti-Cancer Therapy)** – a term used to refer to medication given to treat cancer (eg. Chemotherapy or immunotherapy)

**Whipple procedure** – also known as pancreaticoduodenectomy – a complex surgical procedure whereby the head of the pancreas is removed (along with the gallbladder, bile duct the first part of the small intestine) most often performed to remove cancerous lesions located at the head of the pancreas