NPaCA
National Pancreatic Cancer Audit

NATCAN
National Cancer Audit Collaborating Centre

National Pancreatic Cancer Audit

State of the Nation Report 2024

Methodological supplement for the National Pancreatic Cancer Audit for patients diagnosed in England (2020-2021) and in Wales in 2022

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HQIP
Healthcare Quality Improvement Partnership

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), oesophago-gastric, 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. https://www.hqip.org.uk/national-programmes

AUGIS
ASSOCIATION OF UPPER GASTROINTESTINAL SURGERY OF GREAT BRITAIN AND IRELAND

Association of Upper Gastrointestinal Surgery of Great Britain and Ireland is the speciality society that represents upper gastrointestinal surgeons. It is one of the key partners leading the Audit. Registered Charity no: 1093090

bsg BRITISH SOCIETY OF GASTROENTEROLOGY

British Society of Gastroenterology is the speciality society of gastroenterologists. It is one of the key partners leading the Audit. Registered Charity no: 1149074

The Royal College of Radiologists

Royal College of Radiologists is the professional body for clinical radiologists and clinical oncologists. It is one of the key partners leading the Audit. Registered Charity no: 211540

This work uses data that has been provided by patients and collected by the NHS as part of their care and support. For patients diagnosed in England, the data is collated, maintained and quality assured by the National Disease Registration Service (NDRS), which is part of NHS England. Access to the data was facilitated by the NHS England Data Access Request Service.

NHS Wales is implementing a new cancer informatics system. As a result, the quality and completeness of data from Wales is likely to have been impacted due to implementation of this new system across multiple NHS organisations (Health Boards), which has resulted in data being supplied by both old and new systems. Additionally, and reflecting the uncertainty of data quality, the data submitted to the audit may not have undergone routine clinical validation prior to submission to the Wales Cancer Network (WCN), Public Health Wales.

Contents

Introduction

This document accompanies the NPaCA 2024 State of the Nation report. The purpose of this document is to provide detail on the data sources and methods used to manage and analyse the data.

Data sources

The State of the Nation Report uses National Cancer Registration Data ("gold standard" registration data) for England, which is currently available for people diagnosed up to the end of 2021. The "gold standard" data has better case ascertainment and completeness of key variables compared to more recent registration data. However, to further support quality improvement activities, NPaCA publishes quarterly reports of data quality metrics and a subset of performance indicators (from October 2024, England only), which use more timely Rapid Cancer Registration Data (time lag 4-6 months).

The NPaCA's data collection partner in Wales is the Wales Cancer Network (WCN), Public Health Wales. The NPaCA dataset is captured through a national system, Cancer Information System Cymru (CaNISC), after identification by hospital cancer services and uploaded via electronic MDT data collection systems.

Completeness of cancer registrations

As with cancer registries in other countries, cancer registrations in England can take up to 5 years after the end of a given calendar year to reach 100% completeness and stability. NDRS uses an active system of gathering information on cancer diagnoses from multiple sources across the patient pathway. Completeness varies by tumour type because different patient pathways provide different opportunities for data flows into NDRS. The 'Gold standard' cancer registration dataset that is used in cancer statistics bulletins and available for analysis outside of NDRS contains over 98% of all the people that will eventually be found by the registration process, and the completeness for a calendar year of data increases over time. More information about the cancer registration process can be found here.

Country	Data source	Content
England	NCRD	The National Cancer Registration Dataset (NCRD) contains information on all cancers diagnosed and registered in England, including information from hospital pathology systems
England	COSD	The Cancer Outcomes and Services dataset (COSD) provides the national standard for information that is required to support cancer registration and other national activities, including cancer audit programmes. COSD items are submitted routinely by service providers via multidisciplinary team (MDT) electronic data collection systems
England	SACT	The Systemic Anti-Cancer Therapy (SACT) dataset contains information on disease modifying cancer therapies, such as chemotherapy and immunotherapy, delivered by NHS providers. It provides information on regimen(s), dose, and dates of treatment
England	RTDS	The Radiotherapy dataset (RTDS) contains information on radiotherapy delivered by NHS providers, and includes information on dates, prescription region, dose, and fractionation
England	HES - APC	Hospital Episode Statistics – Admitted patient care (HES-APC) is the administrative database of all NHS hospital admissions in England; the Audit uses information on hospital care both before and after cancer diagnosis
England	CWT	Cancer Waiting Times (CWT) contains data on dates of referrals, diagnoses, and treatments, as well as source of referrals. This information is uploaded monthly by NHS providers and is used to monitor cancer waiting times
England	Medicines prescribed in primary care	Contains data on prescriptions from primary care prescribers
England	DIDs	The Diagnostic Imaging Dataset (DID) contains detailed information about diagnostic imaging tests carried out on NHS patients, including details of the test (type of test and body site) and date of imaging. Information is extracted from local radiology information systems.
Wales	Cancer Cohort data	The cohort dataset contains data on all cancers diagnosed and registered in Wales. It includes information on all aspects of the registration, including investigations, and treatments (including chemotherapy and radiotherapy treatment information).
Wales	PEDW	The Patient Episode Database for Wales (PEDW) is an administrative database that contains information on all NHS hospital admissions in Wales.
Wales	ONS	Office for National Statistics dataset contains information on the date of death
Wales	LSOA	Lower-layer Super Output Areas (LSOA) dataset contains information on deprivation in small areas (LSOAs) across Wales

The data sources for England were merged based on pseudo patient ID (and pseudo tumour ID, where available). The data sources for Wales were merged based on person ID.

Data for England and Wales were managed and analysed separately.

Key data item sources

Data item	Source variable / approach to deriving variable	
	England	**Wales**
Patient characteristics (at time of diagnosis)		
Age	age (NCRD)	Derived using the age at the start of the hospital episode closest to the date of diagnosis (episodestartdate and patientepisodestartageyears, from PEDW).
Index of multiple deprivation	imd19_quintile_lsoas (NCRD)	Deprivationquintile (LSOA)
Performance status	performancestatus (COSD)	PERFORMANCE_STATUS (Cohort data)
Sex	gender (NCRD)	GENDER (Cohort data)
Stage	stage_best (NCRD)	Derived using 3 variables (from Cohort data): T_STAGE_Final_Pretreatment, N_STAGE_Final_Pretreatment and M_STAGE_Final_Pretreatment to generate overall stage using the AJCC (American Joint Committee on Cancer staging) staging for pancreatic cancer version 8 [1].
Tumour site	site_icd10 (NCRD)	TUMOUR_SITE_ICD10_CODE (Cohort data)
Diagnosis, staging, and treatment planning		
Biliary stent	Derived by searching variables opertn_1 – opertn_24 in HES for biliary stent codes listed in Table 5	Derived by searching variables operation01 – operation12 in PEDW for biliary stent codes listed in Table 5. Corresponding procedure dates taken from operation01datestyleddmmyyy - operation12datestyle
Imaging	Derived by searching variable imagingcodesnomedct in DIDs for imaging codes listed in Table 3	Patients who had a relevant scan were identified by the presence of a date in the variables: Imaging__MRI, Imaging__PET (Cohort data)
Imaging date	diagnostictestdate (DIDs) associated with imaging	Imaging__MRI, Imaging__PET (Cohort data)
MDT meeting record / date	firstmdtmeetingdate (COSD)	Data not provided

[1] MB Amin, SB Edge, FL Greene, et al, eds. AJCC Cancer Staging Manual. 8th ed. New York: Springer; 2017.

Data item	Source variable / approach to deriving variable	
	England	**Wales**
Organisation of diagnosis (Trust or local health board)	diag_trust (NCRD)	ORGANISATION_CODE (Cohort data)
Time from referral to start of treatment		
Diagnosis date	diagnosisdatebest (NCRD)	DIAGNOSIS_DATE (Cohort data)
Referral date	crtp_date (CWT)	DATE_OF_REFERRAL (Cohort data)
Referral source	ref_source (CWT) Grouped as follows: *GP referral:* 3 - "General medical practitioner" or 12 - "General practitioner with extended role" *Emergency:* 1 "Following emerg admission" or 4 "Emergency Care Department" or 10 "Following an Emergency Care Attendance" *Other Consultant:* 2 "Following Consultant domiciliary consultation" or 5 "CONSULTANT - not emergency care" or 11 "Consultant initiated - other" *Other:* all other options	Data not provided
Referral priority	priority_type (CWT): Grouped as follows: *Urgent referral:* 2 – Urgent or 3 – Two Week Wait	
Treatment date	Derived as date of first record of disease-targeted treatment (see below)	Derived as date of first record of disease-targeted treatment (see below)
Disease-targeted treatment		
Surgery record	Derived by searching variable opcs4_code (NCRD) for surgery codes listed in Table 4	Derived by searching the variables operation01 – operation12 in PEDW for surgery codes listed in Table 4
Surgery date	eventdate (NCRD) associated with surgery record	operation01datestyleddmmyyy – operation12datestyle (PEDW)
SACT (Systemic Anti-Cancer Treatment)	Derived based on any record of anti-cancer treatment in SACT (except exclusions in Table 6)	Derived based on the presence of a value in the variable START_DATE_OF_CHEMOTHERAPY (Cohort data)
SACT date	start_date_of_cycle associated with SACT treatment	START_DATE_OF_CHEMOTHERAPY (Cohort data)
Radiotherapy treatment	Derived based on any record of radiotherapy in RTDS (excluding brachytherapy (rttreatmentmodality=06))	Derived based on the presence of a value in the variable START_DATE_OF_RADIOTHERAPY (Cohort data)

Data item	Source variable / approach to deriving variable	
	England	**Wales**
Radiotherapy date	apptdate associated with radiotherapy treatment	START_DATE_OF_RADIOTHERAPY (Cohort data)
Chemoradiotherapy treatment	Derived based on record of SACT and radiotherapy	PROTOCOL_FOR_CHEMOTHERAPY (Cohort data)
Disease-targeted treatment	Derived as any record of surgery, SACT, or radiotherapy	Derived as any record of surgery, SACT, or radiotherapy
First treatment date	Earliest of surgery date, SACT date, and radiotherapy date	Earliest of surgery date, SACT date, and radiotherapy date
Supportive care for pancreatic cancer		
CNS (Clinical Nurse Specialist) involved	Derived using clinicalnursespecialist (COSD), counting any "Yes" response option as CNS involved	Data not provided
PERT (Pancreatic Enzyme Replacement Treatment prescription)	Derived based on prescribedbnfcode=0109040 or prescribedbnfname of "Creon", "Pancrease", "Nutrizym", or "Pancrex" (primary care prescribing data)	Data not provided
Survival outcomes		
Survival at specific time points post-diagnosis	Calculated using vitalstatus and vitalstatusdate (NCRD) and diagnosisdatebest Set vitalstatusdate to equal deathdatebest in instances where former was missing	Calculated using time between DIAGNOSIS_DATE (Cohort data) and the date of death. Date of death derived from the earliest date of two variables: DATE_OF_DEATH (Cohort data) and date_of_death (ONS).

Audit inclusion and exclusion criteria

Note: if practices differ between the analysis of English and Welsh data, these have been noted separately

Criteria	Operationalisation in data sources **See variable table for details on each variable**
Inclusion	
Malignant neoplasm of the pancreas	Tumour site is one of the pancreatic cancer diagnosis codes listed in Table 1
Malignant neoplasm of the extrahepatic bile duct or ampulla of Vater	Tumour site is one of the pancreatic cancer diagnosis codes listed in Table 1
Adults	Age >=18
First diagnosis of primary pancreatic cancer	Kept records associated with earliest diagnosis date In instances of multiple pancreatic cancer diagnoses on the same day, prioritised records based on:

	• Worst stage, then • Record with most complete information across variables *Note: For Wales, information on only one diagnosis per patient was provided*
Exclusion	
Neuroendocrine tumours of the pancreas	**For English data:** Using NCRD: Tumour site = C254 (Endocrine pancreas) *and/or* histology_coded_desc contains word "neuroendocrine" *and/or* morph_icd10_o2 or morph_coded contain neuroendocrine morphology codes specified in Table 2 Using linked SACT data: morphology_clean contains neuroendocrine morphology codes specified in Table 2 *and/or* benchmark_group = lanreotide or octreotide *and/or* drug_group = lanreotide or octreotide **For Welsh data:** Using Cohort data: if MORPHOLOGY_DESCRIPTION contains word "Carcinoid" or "Neuroendocrine" *and/or* TUMOUR_SITE_ICD10_CODE (Cohort data) = C25.4 *and/or* MORPHOLOGY_CODE contains neuroendocrine morphology codes specified in Table 2
Diagnosis via death certificate only	**For English data:** Using NCRD: final_route = DCO (Death Certificate Only) *and/or* basisofdiagnosis = 0 (Death certificate) *and/or* dco = Y (tumour registered from a death certificate only) *and/or* diagnosisdatebest = deathdatebest **For Welsh data:** DIAGNOSIS_DATE (Cohort data) = date of death. Note: Date of death derived from the earliest date of two variables: DATE_OF_DEATH (Cohort data) and date_of_death (ONS).
Not diagnosed or treated in England	Trust of diagnosis was a Welsh health board (code starting with 7) *and* No record of pathway event via trust_code in England* *and*

	No record of org_code_of_drug_provider in England* in SACT *And* No record of orgcodeprovider in England* in RTDS *Trust code starting with "R" is in England

Indicator definitions & construction notes

Indicator	Definition & construction notes
1. Percentage of people who had an FDG-PET/CT scan prior to surgery	Definition: record of an FDG-PET/CT scan up to six months prior to any pancreatic surgery Numerator: number of people with a record of an FDG-PET/CT prior to surgery Denominator: number of people with a record of any pancreatic surgery Construction notes: • Time restriction: only count imaging records on or before date of pancreatic surgery, and no more than 183 days (6 months) prior to date of pancreatic surgery • Liver MRI reported separately as additional information, but not included within the indicator
2. Percentage of people who had a record of being discussed at an MDT (Multidisciplinary Team) meeting (England only)	Definition: record of an MDT meeting date within 60 days before or after date of diagnosis Numerator: number of people with a record of an MDT meeting date Denominator: number of people with a primary diagnosis of pancreatic cancer Construction notes: • Time restriction: MDT meeting date is within 60 days before or after diagnosis date
3. Percentage of people undergoing surgery (no neo-adjuvant chemotherapy) who had a biliary stent prior to a Whipple procedure	Definition: record of a biliary stent before first Whipple procedure date and up to 30 days before diagnosis date, without a record of SACT/RT prior to surgery Numerator: number of people with a record of biliary stent prior to Whipple procedure without record of SACT/RT before procedure Denominator: number of people who had a Whipple procedure without a record of SACT/RT before procedure Construction notes:

Indicator	Definition & construction notes
	• Neo-adjuvant chemotherapy: see approach as part of indicator #7

4. Time from referral to first treatment (days)	Numerator: Median time (days) from urgent suspected cancer GP referral to first treatment
	
	Denominator: N/A
	
	Construction notes:
	• Data cleaning: replaced to missing any referral dates more than 183 days (6 months) before diagnosis date or more than 7 days after diagnosis date
	• In instances of multiple records per patient, executed the following steps to select referral date:
	  ○ Dropped records if duplicates in terms of: patient ID, referral date, referral source, priority type, and site ICD10 code
	  ○ Sorted records based on patient ID and referral date. In instances of duplicates in terms of referral date, prioritised records in the order of:
	  ▪ Containing a pancreatic-specific or non-site specific (C76-C80) tumour site ICD-10 code
	  ▪ Complete data on referral source and priority type
	  ▪ GP referral source
	  ▪ Urgent priority referral
	  ○ Selected record with earliest referral date, dropping other records for the patient
	• Urgent GP referral defined as a referral with a priority type of "Urgent" or "TWW"
	Note for Wales: information on referral source not provided

5. Percentage of people with non-metastatic (stage 1-3) pancreatic cancer who received disease-targeted treatment	Definition: record of surgery, systemic anti-cancer therapy, and/or radiotherapy at any point on or after the date of diagnosis Numerator: number of people who undergo surgery, SACT, and/or radiotherapy Denominator: number of people diagnosed with pancreatic cancer, split into groups of stage 1-3 and stage 4

Indicator	Definition & construction notes
6. Percentage of people with metastatic (stage 4) pancreatic cancer who received disease-targeted treatment	Construction notes: • Dates of disease-targeted treatment were on or after diagnosis date

7. Percentage of people with pancreatic cancer who received chemotherapy and/or radiotherapy alongside surgery	**For English data:**
	Definition: record of SACT and/or radiotherapy up to 14 weeks before any pancreatic surgery or up to 14 weeks after Whipple procedure
	
	Numerator (before surgery): number of people who received SACT and/or radiotherapy up to 14 weeks before any pancreatic surgery
	Denominator (before surgery): number of people who underwent any pancreatic surgery
	
	Numerator (after surgery): number of people who received SACT and/or radiotherapy up to 14 weeks after Whipple procedure
	Denominator (after surgery): number of people who underwent Whipple procedure
	
	Construction notes:
	• CT/RT before surgery: count when at least one of the following is recorded
	  ○ Any SACT treatment when SACT date <=98 days before pancreatic surgery date
	  ○ Any radiotherapy treatment when radiotherapy date <=98 days before pancreatic surgery date
	• CT/RT after Whipple: count when at least one of the following is recorded:
	  ○ Any SACT treatment when SACT date <= 98 days after Whipple procedure date
	  ○ Any radiotherapy treatment, excluding palliative doses**, when radiotherapy date <=98 days after Whipple procedure date
	
	** Following combinations of rtprescribeddose & prescribedfractions considered palliative:
	30Gy/15 fractions; 26Gy/5 fractions; 20Gy/5 fractions; 8Gy/1 fractions
	
	For Welsh data:

Indicator	Definition & construction notes
	Definition: record of SACT and/or radiotherapy starting up to 6 months before any pancreatic surgery or starting up to 14 weeks after Whipple procedure <u>Before surgery</u> Numerator (before surgery): number of people who had a start date of chemotherapy or radiotherapy up to 6 months before any pancreatic surgery *Note for Wales: a different period was used to identify preoperative treatment (vs for English data). This is because, for Wales, the date of only the very first SACT cycle was provided, and SACT and radiotherapy treatment may have started several months prior to the surgery.* Denominator (before surgery): number of people who underwent any pancreatic surgery <u>After surgery</u> Numerator (after surgery): number of people who had a start date for SACT and/or radiotherapy up to 14 weeks after Whipple procedure Denominator (after surgery): number of people who underwent Whipple procedure minus the number of patients who had SACT or radiotherapy before surgery. *Note for Wales: only the date of the first cycle of SACT or first radiotherapy session was provided, therefore we were unable to determine whether the patients who received pre-operative treatment went on to have any treatment after surgery. Therefore, patients who received pre-operative treatment were removed from the denominator.*
8. Percentage of people with a new diagnosis of pancreatic cancer who were seen by a CNS (England only)	Numerator: number of people with CNS involved Denominator: number of people with a primary diagnosis of pancreatic cancer with complete information related to CNS
9. Percentage of people who were prescribed pancreatic enzyme replacement therapy (PERT) (England only)	Numerator: number of people with a prescription of PERT Denominator: number of people with a primary diagnosis of pancreatic cancer Note: • Primary care prescribing data only available from 1 April 2018
10. 30-, 90-day, 1- and 2-year survival rates after diagnosis, by intent and treatment modality	**For English data:** Numerator: number of people alive more than 30 days, 90 days, 1 year, and 2 years after diagnosis of pancreatic cancer

Indicator	Definition & construction notes
	Denominator: number of people with a primary diagnosis of pancreatic cancer and a vital status date **For Welsh data:** Numerator: number of people alive more than 30 days, 90 days and 1 year after diagnosis of pancreatic cancer. Note: we don't have sufficient follow up to do 2 year survival for the Welsh data Denominator: number of people with diagnosis of pancreatic cancer

Statistical analyses

Audit period

The audit periods used in analyses were as follows:

- England: diagnoses between 1 January 2020 – 31 December 2021 (2-year period)
    - Except for surgical indicators, where the period of analysis was 1 January 2019 – 31 December 2021 (3-year period), to enable a larger sample size given the relatively low number of people undergoing surgery for pancreatic cancer
- Wales: diagnoses between 1 January 2022 – 31 December 2022 (1-year period)

Organisation-level allocation and analyses

The analyses in the State of the Nation Report focussed on national-level results, with exploration of variation by trust or health board of diagnosis or (in England) HPB specialist centre, as appropriate to the indicator. Generally, we reported at the level of HPB specialist centre for indicators concerned with surgery as nearly all pancreatic surgeries in England take place at these specialist centres.

The trust of diagnosis was identified using the organisation recorded in the NCRD. HPB specialist centres were flagged via the trust codes listed in Table 7. For Wales, the local health board of diagnosis was identified using the organisation codes listed in Table *8*.

A minimum of five diagnoses in the audit period were required for reporting at trust or health board level. This was to ensure only trusts providing cancer services were included and also to avoid very small numbers which can lead to unreliable estimates and increase the risk of potential data disclosure.

Analyses of indicators

All analyses were carried out in STATA version 17.

The values of the various process and outcome indicators are typically expressed as proportions and are presented as percentages. Survival rates are presented with 95% confidence intervals (CI) to describe their level of precision.

In descriptive analyses of continuous variables, the distribution of values is described using appropriate statistics (e.g. mean and standard deviation or median and interquartile range). Categorical data items are described using percentages (%). The denominator of these proportions (presented as percentages) is the number of patients for whom the value of the data item was not missing, unless otherwise stated.

Risk adjustment
Risk-adjusted figures for NHS organisations are presented for 90-day and 1-year survival indicators. The survival rates have been adjusted to take into account differences in the case mix of patients treated at each organisation. Multivariable logistic regression models have been used to estimate the likelihood of survival for each individual diagnosed with pancreatic cancer (based on their characteristics), and these probabilities have been summed to calculate the predicted number of people surviving for each organisation. The regression models include the following patient characteristics: age, sex, deprivation (IMD quintile), stage, performance status, tumour site (C24 or C25), receipt of disease targeted treatment, RCS Charlson score (calculated using HES-APC or PEDW), and diagnosis year (for England only). Data for England and Wales were analysed separately.

Missing values for stage, performance status, and IMD quintile (for Wales only) were imputed with multiple imputation using chained equations, creating ten data sets and pooling model estimates using Rubin's Rules. The imputation models included all the variables in the analysis models.

Risk adjusted rates are presented only for organisations with at least 10 people diagnosed during the relevant period.

Reporting of small numbers
We follow the Office for National Statistics policy on the publication of small numbers to minimise the risk of patient identification from these aggregate results.

Given the focus on national-level results in this report, there was not an issue of small number reporting. In general, we suppress cell values of counts <5.

Reporting of statistical outliers
For the first State of the Nation report, NPaCA will not implement a formal "outlier process". For more information, please refer to the NATCAN FAQs, #17.

Code lists

Table 1. ICD-10 codes used to define pancreatic cancer audit cohort

Code	Description
Malignant neoplasm of pancreas	
C25.0	Head of pancreas
C25.1	Body of pancreas
C25.2	Tail of pancreas
C25.3	Pancreatic duct
C25.7	Other parts of pancreas: neck of pancreas
C25.8	Overlapping lesion of pancreas
C25.9	Pancreas, unspecified
Malignant neoplasm of other and unspecified parts of biliary tract	

Code	Description
C24.0	Extrahepatic bile duct: biliary duct or passage NOS, common bile duct, cystic duct, hepatic duct
C24.1	Ampulla of Vater

Source of ICD-10 codes: https://icd.who.int/browse10/2019

Table 2. Morphology codes for identification of neuroendocrine tumours

Code	Description
8013	Large cell neuroendocrine carcinoma
8041	Small cell carcinoma, NOS
8042	Oat cell carcinoma
8043	Small cell carcinoma, fusiform cell
8044	Small cell carcinoma, intermediate cell
8045	Combined small cell carcinoma
8150	Islet cell carcinoma
8151	Insulinoma
8152	Glucagonoma
8153	Gastrinoma
8154	Mixed islet cell & exocrine adenocarcinoma
8155	Vipoma
8156	Somatostatinoma
8157	Enteroglucagonoma
8158	ACTH-producing tumor
8240	Carcinoid tumour
8241	Enterochromaffin cell carcinoid
8242	Enterochromaffin-like cell tumour
8243	Goblet cell carcinoid
8244	Composite carcinoid
8245	Adenocarcinoid tumour
8246	Neuroendocrine carcinoma
8247	Merkel cell carcinoma
8249	Atypical carcinoid tumour
9091	Strumal carcinoid

Source of morphology codes: https://biobank.ndph.ox.ac.uk/ukb/ukb/docs/ICDcancermorph.pdf
Reference publication on neuroendocrine tumour morphology codes:
https://www.nature.com/articles/s41416-019-0606-3

Table 3. SNOMED codes used to identify scans

SNOMED-CT ID	Description
FDG-PET/CT	
725928006	Positron emission tomography with computed tomography fluorodeoxyglucose F18 imaging of base of brain to mid-thigh (procedure)

SNOMED-CT ID	Description
443271005	Positron emission tomography with computed tomography using fluorodeoxyglucose (18-F) (procedure)
432675001	Positron emission tomography fluorodeoxyglucose imaging of whole body (procedure)
1097781000000108	Positron emission tomography with computed tomography 18F fluorodeoxyglucose imaging of cranial vertex to mid-thigh (procedure)
Liver MRI	
910561000000103	Diffusion weighted magnetic resonance imaging of liver (procedure)
432551009	Magnetic resonance imaging of liver and spleen (procedure)
431839003	Magnetic resonance imaging of liver with contrast (procedure)
432633002	Magnetic resonance imaging of liver and biliary tract with contrast (procedure)
764569004	Magnetic resonance imaging of liver and spleen with contrast (procedure)
1065681000000100	Magnetic resonance imaging of liver and spleen with contrast (procedure)
911811000000107	Magnetic resonance imaging of transplanted liver (procedure)
241622002	Magnetic resonance imaging of liver (procedure)

Source of SNOMED-CT codes for diagnostic imaging (Annex 5):
https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/

Table 4. OPCS-4 codes used to identify pancreatic surgery

OPCS-4 code	Description
Whipple procedure	
J56.1	Pancreaticoduodenectomy and excision of surrounding tissue
J56.2	Pancreaticoduodenectomy and resection of antrum of stomach
J56.3	Pancreaticoduodenectomy NEC
J56.4	Subtotal excision of head of pancreas with preservation of duodenum and drainage HFQ
All other pancreatic surgeries	
J55.1	Total pancreatectomy and excision of surrounding tissue
J55.2	Total pancreatectomy NEC
J55.8	Total excision of pancreas, other specified
J55.9	Total excision of pancreas, unspecified
J56.8	Excision of head of pancreas, other specified
J56.9	Excision of head of pancreas, unspecified
J57.1	Subtotal pancreatectomy
J57.2	Left pancreatectomy and drainage of pancreatic duct
J57.3	Left pancreatectomy NEC
J57.4	Excision of tail of pancreas and drainage of pancreatic duct
J57.5	Excision of tail of pancreas NEC
J57.8	Other partial excision of pancreas, other specified
J57.9	Other partial excision of pancreas, unspecified

Source of OPCS-4 codes: https://classbrowser.nhs.uk/#/book/OPCS-4.10/

Table 5. OPCS-4 codes used to identify biliary stents

OPCS-4 code	Description
J382	Endoscopic sphincterotomy of sphincter of Oddi and insertion of tubal prosthesis into bile duct
J401	Endoscopic retrograde insertion of tubal prosthesis into both hepatic ducts
J402	Endoscopic retrograde insertion of tubal prosthesis into bile duct NEC
J403	Endoscopic retrograde renewal of tubal prosthesis in bile duct NEC
J405	Endoscopic retrograde insertion of expanding covered metal stent into bile duct
J406	Endoscopic retrograde insertion of expanding metal stent into bile duct NEC
J407	Endoscopic retrograde renewal of expanding metal stent in bile duct
J408	Other specified endoscopic retrograde placement of prosthesis in bile duct
J409	Unspecified endoscopic retrograde placement of prosthesis in bile duct
J418	Other specified other therapeutic endoscopic retrograde operations on bile duct
J431	Endoscopic retrograde cholangiopancreatography and biopsy of lesion of ampulla of Vater
J432	Endoscopic retrograde cholangiopancreatography and biopsy of lesion of biliary or pancreatic system NEC
J433	Endoscopic retrograde cholangiopancreatography and collection of bile
J438	Other specified diagnostic endoscopic retrograde examination of bile duct and pancreatic duct
J439	Unspecified diagnostic endoscopic retrograde examination of bile duct and pancreatic duct
J441	Endoscopic retrograde cholangiography and biopsy of lesion of bile duct
J448	Other specified diagnostic endoscopic retrograde examination of bile duct
J449	Unspecified diagnostic endoscopic retrograde examination of bile duct
J471	Percutaneous insertion of tubal prosthesis into both hepatic ducts
J472	Percutaneous insertion of tubal prosthesis into right hepatic duct NEC
J473	Percutaneous insertion of tubal prosthesis into left hepatic duct NEC
J474	Percutaneous insertion of tubal prosthesis into hepatic duct NEC
J475	Percutaneous insertion of tubal prosthesis into common bile duct
J478	Other specified therapeutic percutaneous insertion of prosthesis into bile duct
J479	Unspecified therapeutic percutaneous insertion of prosthesis into bile duct
J481	Renewal of percutaneously inserted tubal prosthesis in bile duct
J483	Attention to percutaneously inserted tubal prosthesis in bile duct NEC
J485	Percutaneous transhepatic biliary drainage multiple
J486	Percutaneous transhepatic biliary drainage single
J488	Other specified other therapeutic percutaneous operations on bile duct
J489	Unspecified other therapeutic percutaneous operations on bile duct
J502	Percutaneous cholangiography NEC
J505	Percutaneous transhepatic cholangiography

Source of OPCS-4 codes: https://classbrowser.nhs.uk/#/book/OPCS-4.10/

Table 6. Excluded regimens in Systemic Anti-Cancer Therapy (SACT) dataset

Regimens excluded from SACT analyses

Benchmark_group= “NOT CHEMO”
benchmark_group= "LUTETIUM-177"
benchmark_group= "ZOLEDRONIC ACID" & none in drug_group are systemic anti-cancer treatments
benchmark_group= "DENOSUMAB" & none in drug_group are systemic anti-cancer treatments
benchmark_group= "HORMONES" & drug_group contains “hormones”
benchmark_group= "PAMIDRONATE" & no other drugs listed in drug_group
benchmark_group= "STREPTOZOCIN" & none in drug_group are systemic anti-cancer treatments

Table 7. Trust codes for HPB specialist centres

Trust code	Trust name
RTD	The Newcastle Upon Tyne Hospitals NHS Foundation Trust
Trust	Liverpool University Hospitals NHS Foundation Trust
RJE	University Hospitals of North Midlands NHS Trust
RKB	University Hospitals Coventry and Warwickshire NHS Trust
RRK	University Hospitals Birmingham NHS Foundation Trust
RJZ	King’s College Hospital NHS Foundation Trust
RA2	Royal Surrey County Hospital NHS Foundation Trust
RTH	Oxford University Hospitals NHS Foundation Trust
RK9	University Hospitals Plymouth NHS Trust
RA7	University Hospitals Bristol and Weston NHS Foundation Trust
RHM	University Hospital Southampton NHS Foundation Trust
RXR	East Lancashire Hospitals NHS Trust
ROA	Manchester University NHS Foundation Trust
RPY	The Royal Marsden NHS Foundation Trust
RYJ	Imperial College Healthcare NHS Trust
RGT	Cambridge University Hospitals NHS Foundation Trust
RWE	University Hospitals of Leicester NHS Trust
RX1	Nottingham University Hospitals NHS Trust
RHQ	Sheffield Teaching Hospitals NHS Foundation Trust
RWA	Hull University teaching Hospitals NHS Trust
RAL	Royal Free London NHS Foundation Trust
R1H	Barts Health NHS Trust
RR8	Leeds Teaching Hospitals NHS Trust

Source: https://www.pancreaticcancer.org.uk/support-for-you/your-care/your-local-pancreatic-cancer-specialist-centre/

Table 8. Organisation codes for Wales Health Boards

Organisation code	Hospital code	Trust name
7A1	7A1A1	Glan Clwyd Hospital
7A1	7A1A4	Wrexham Maelor Hospital
7A1	7A1AU	Ysbyty Gwynedd
7A2	7A2AG	Glangwili General Hospital
7A2	7A2AJ	Bronglais General Hospital
7A2	7A2AL	Prince Philip Hospital

7A2	7A2BL	Withybush General Hospital
7A3	7A3C4	Singleton Hospital
7A3	7A3C7	Morriston Hospital
7A3	7A3CJ	Neath Port Talbot Hospital
7A4	7A4BV	University Hospital of Wales
7A4	7A4C1	University Hospital Llandough
7A5	7A3B7	Princess of Wales Hospital
7A5	7A5B1	Royal Glamorgan Hospital
7A5	7A5B3	Prince Charles Hospital
7A6	7A6AM	Nevill Hall Hospital
7A6	7A6AR	Royal Gwent Hospital
7A6	7A6G9	The Grange University Hospital

Table 9. AJCC TNM staging of (exocrine) pancreatic cancer[2]

Stage	T	N	M
1	1	0	0
	2	0	0
2	3	0	0
	1-3	1	0
3	4	0-2	0
	1-4	2	0
4	1-4	0-2	1

Table 10. Eastern Cooperative Oncology Group (ECOG) Performance Status[3]

Performance status	**Definition**
0	Fully active; no performance restrictions.
1	Strenuous physical activity restricted; fully ambulatory and able to carry out light work.
2	Capable of all self-care but unable to carry out any work activities. Up and about >50% of waking hours.
3	Capable of only limited self-care; confined to bed or chair >50% of waking hours.
4	Completely disabled; cannot carry out any self-care; totally confined to bed or chair.

[2] MB Amin, SB Edge, FL Greene, et al, eds. *AJCC Cancer Staging Manual*. 8th ed. New York: Springer; 2017
[3] Oken MM, Creech RH, Tormey DC, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. Am J Clin Oncol 1982; 5:649.

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