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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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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

British Society of Gastroenterology is the speciality society of Registered Charity no: 1149074

gastroenterologists. It is one of the key partners leading the Audit.

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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.

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## 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](https://www.natcan.org.uk/resources/timeliness-of-the-national-cancer-registration-dataset-ncrd/) (“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](https://www.gov.uk/government/publications/ncras-statistical-publications-quality-and-methodology-information/data-collection-and-quality-assurance-of-administrative-data).

| 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]](#footnote-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 |
| 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" or5 "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) |
| 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 diagnosisdatebestSet 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 dateIn 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 surgeryNumerator: number of people with a record of an FDG-PET/CT prior to surgeryDenominator: 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 diagnosisNumerator: number of people with a record of an MDT meeting dateDenominator: number of people with a primary diagnosis of pancreatic cancerConstruction 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 surgeryNumerator: number of people with a record of biliary stent prior to Whipple procedure without record of SACT/RT before procedureDenominator: number of people who had a Whipple procedure without a record of SACT/RT before procedureConstruction 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 treatmentDenominator: N/AConstruction 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 diagnosisNumerator: 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 4Construction notes:* Dates of disease-targeted treatment were on or after diagnosis date
 |
| 6. Percentage of people with metastatic (stage 4) pancreatic cancer who received disease-targeted treatment |
| 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 procedureNumerator (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 procedureDenominator (after surgery): number of people who underwent Whipple procedureConstruction 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:**Definition: record of SACT and/or radiotherapy starting up to 6 months before any pancreatic surgery or starting up to 14 weeks after Whipple procedureBefore surgeryNumerator (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 After surgeryNumerator (after surgery): number of people who had a start date for SACT and/or radiotherapy up to 14 weeks after Whipple procedureDenominator (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 involvedDenominator: 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 PERTDenominator: number of people with a primary diagnosis of pancreatic cancerNote: * 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 cancerDenominator: 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 dataDenominator: 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”](https://www.hqip.org.uk/wp-content/uploads/2024/02/HQIP-NCAPOP-Outlier-Guidance_21022024.pdf). For more information, please refer to the [NATCAN FAQs](https://www.natcan.org.uk/faqs/faqs-for-professionals/), #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* |
| 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](https://icd.who.int/browse10/2019/en#/C25.0)

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) |
| 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/](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/](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 |
| REM | 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]](#footnote-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 Status3

|  |  |
| --- | --- |
| 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. |

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|  |  |  |
| --- | --- | --- |
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1. MB Amin, SB Edge, FL Greene, et al, eds. AJCC Cancer Staging Manual. 8th ed. New York: Springer; 2017. [↑](#footnote-ref-1)
2. 2 MB Amin, SB Edge, FL Greene, et al, eds. *AJCC Cancer Staging Manual*. 8th ed. New York: Springer; 2017

3Oken MM, Creech RH, Tormey DC, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. Am J Clin Oncol 1982; 5:649. [↑](#footnote-ref-2)