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# National Pancreatic Cancer Audit

## Quality Improvement Plan – September 2024



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**Citation for this document:**

National Pancreatic Cancer Audit (NPaCA) Quality Improvement Plan 2024 London:  
National Cancer Audit Collaborating Centre, Royal College of Surgeons of England, 2024.

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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), 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>

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# Executive Summary

The National Pancreatic Cancer Audit (NPaCA) has been commissioned to evaluate the quality and outcomes of care for patients diagnosed with pancreatic cancer in England and Wales. It aims to help NHS organisations to benchmark their pancreatic cancer care against measurable standards, to identify unwarranted variation in care, and to provide tools to help services improve quality of care for people with pancreatic cancer.

The NPaCA Quality Improvement Plan (QIP) sets out the scope, care pathway, five quality improvement goals and ten performance indicators for the Audit. To inform the development of this QIP, the NPaCA team carried out 1) a review of clinical guidelines, existing audits/registries and literature relevant to pancreatic care, and 2) consultations with key stakeholders, including clinical experts, allied health professionals, patient groups and charities, and representatives from NHS England and NHS Wales. These activities built on a feasibility study conducted by the National Oesophago-Gastric Cancer Audit in 2022, which comprised a stakeholder survey and review of potential performance indicators for an audit of pancreatic cancer.

Based on this work, the NPaCA proposes to include all adults diagnosed with exocrine pancreatic cancer in England and Wales, plus those with tumours of the extrahepatic bile duct and ampulla of Vater. The Audit will cover the care pathway from first diagnosis of pancreatic cancer to the end of primary treatment, including treatments with and without curative intent. Treatment pathways will be reported by intent, and type of treatment where appropriate.

The following quality improvement goals have been identified for the NPaCA:

1. Increase the percentage of people who have diagnostic procedures and a process of diagnosis consistent with national recommendations for pancreatic cancer
2. Optimise diagnostic and treatment pathways to reduce the time between referral and start of disease-targeted treatment
3. Increase the percentage of people with pancreatic cancer (who are fit enough for treatment) who receive disease-targeted treatment (surgery, chemotherapy, radiotherapy - both curative and palliative)
4. Increase the percentage of people with pancreatic cancer who receive supportive care (care that helps the person to live as well as possible with their cancer and its treatment) in line with national recommendations
5. Improve outcomes for people diagnosed with pancreatic cancer

The NPaCA has identified ten performance indicators, mapped to five quality improvement goals and clinical guidelines. This QIP sets out improvement methods, improvement activities and approaches to evaluation of these goals and activities.

# 1. Introduction

## 1.1 Aim and objectives of the Quality Improvement Plan

The National Pancreatic Cancer Audit (NPaCA) Quality Improvement Plan builds on its [Scoping Document](#), which set out the Audit's scope and coverage of the care pathway, and identified key quality improvement priorities.

The Quality Improvement Plan develops this further to define five quality improvement goals and identifies ten performance indicators which map to the goals, national guidelines and standards. These performance indicators will be used by NPaCA to monitor progress towards its quality improvement goals and to stimulate improvements in pancreatic cancer care.

The Quality Improvement Plan describes the development of the Audit's quality improvement goals and performance indicators. In addition, it aims to set out the improvement methods and activities that will support implementation of the plan, including strategies for reporting and disseminating results, in addition to describing the approaches to evaluation.

The NPaCA Quality Improvement Plan was developed in consultation with key stakeholders, including people with lived experience of pancreatic cancer, and will be reviewed on an annual basis.

## 1.2 The National Cancer Audit Collaborating Centre

The NPaCA is part of the [National Cancer Audit Collaborating Centre \(NATCAN\)](#), a new national centre of excellence which aims to strengthen NHS cancer services by looking at treatments and patient outcomes across the country. It was set up on 1<sup>st</sup> October 2022 to deliver six new national cancer audits, including ovarian, pancreatic, kidney, breast cancer (two separate audits in primary and metastatic disease) and non-Hodgkin Lymphoma. Existing audits in [prostate](#), [lung](#), [bowel](#), and [oesophago-gastric](#) cancers moved into NATCAN in 2023. The centre is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government.

The aims of the ten NATCAN audits are to:

1. Provide regular and timely evidence to cancer services of where patterns of care in England and Wales may vary.
2. Support NHS services to increase the consistency of access to treatments and help guide quality improvement initiatives.
3. Stimulate improvements in cancer detection, treatment and outcomes for patients, including survival rates.

Further information about NATCAN and key features of its approach to audit can be found in Appendix 1.

## 2. Background on pancreatic cancer

### 2.1 Main issues in pancreatic cancer care and outcomes

Patterns of care provided to people with pancreatic cancer have been reported to vary across England and Wales.<sup>1</sup>

In its 2020 report<sup>2</sup>, Pancreatic Cancer UK (PCUK) highlighted results from the global surveillance of trends in cancer survival 2000–14 (CONCORD-3)<sup>3</sup>, which demonstrated that the UK was ranked 29<sup>th</sup> out of 33 countries for five-year survival for pancreatic cancer and had a lower proportion of people diagnosed with early stage (1 or 2) disease than other countries. The PCUK report went on to highlight:

- regional variation in the distribution of disease stage,
- low rates of surgery with curative intent,
- regional variation in the proportion of patients who had chemotherapy after surgery, and
- regional variation in the proportion of patients who received palliative chemotherapy.

While these figures relate to care delivered before 2020, the evidence highlights various areas of concern.

The COVID-19 pandemic had a major impact on routine care pathways for people with cancer. Although there was not a reduction in the number of people diagnosed with pancreatic cancer during the pandemic, fewer people underwent a surgical resection (6 for every 100 people diagnosed) compared with the pre-pandemic period (8-9 per 100 people). (Lemanska et al.)<sup>4</sup>

Variation in prescribing of pancreatic enzyme replacement therapy (PERT), a treatment that is recommended for all people with unresectable pancreatic cancer to manage digestive problems caused by pancreatic cancer, has been found in two recently published studies. In a prospective study by the RICOCHET Study Group, rates of PERT prescribing in the UK were 74.4% in people with potentially resectable disease and 45.3% in those with unresectable disease in 2018.<sup>5</sup> A second study using a primary care prescribing database in England estimated prescribing rates in England were far below the expected 100% level, at only 48% nationally in December 2022.<sup>6</sup> Regional rates ranged from approximately 30 to 60%.

### 2.2 Care pathways

The management of pancreatic cancer involves a variable sequence of treatments which depend on the characteristics of the individual (Figure 1, overleaf). People who are diagnosed with a tumour that has not spread beyond the pancreas, and does not involve important local blood vessels, are considered to have resectable (operable) cancer, and if they are sufficiently fit will have surgery to remove the tumour. Following this, they may receive systemic anti-cancer therapy (such as chemotherapy) with or without radiotherapy. A tumour can be classified as borderline resectable if local arteries and veins are involved. In this scenario, individuals may receive systemic therapy with or without radiotherapy, with the aim of reducing the size of the tumour to enable surgical removal. People who have advanced pancreatic cancer (precluding surgery) may receive treatments aimed at extending life and/or managing symptoms caused by the cancer.

<sup>1</sup> Exarchakou A, et al. [Pancreatic cancer incidence and survival and the role of specialist centres in resection rates in England, 2000 to 2014: A population-based study](#) Pancreatolgy. 2020;20(3):454-61.

<sup>2</sup> Pancreatic Cancer UK [PCUK-Variation-Report-Aug-2020.pdf](#)

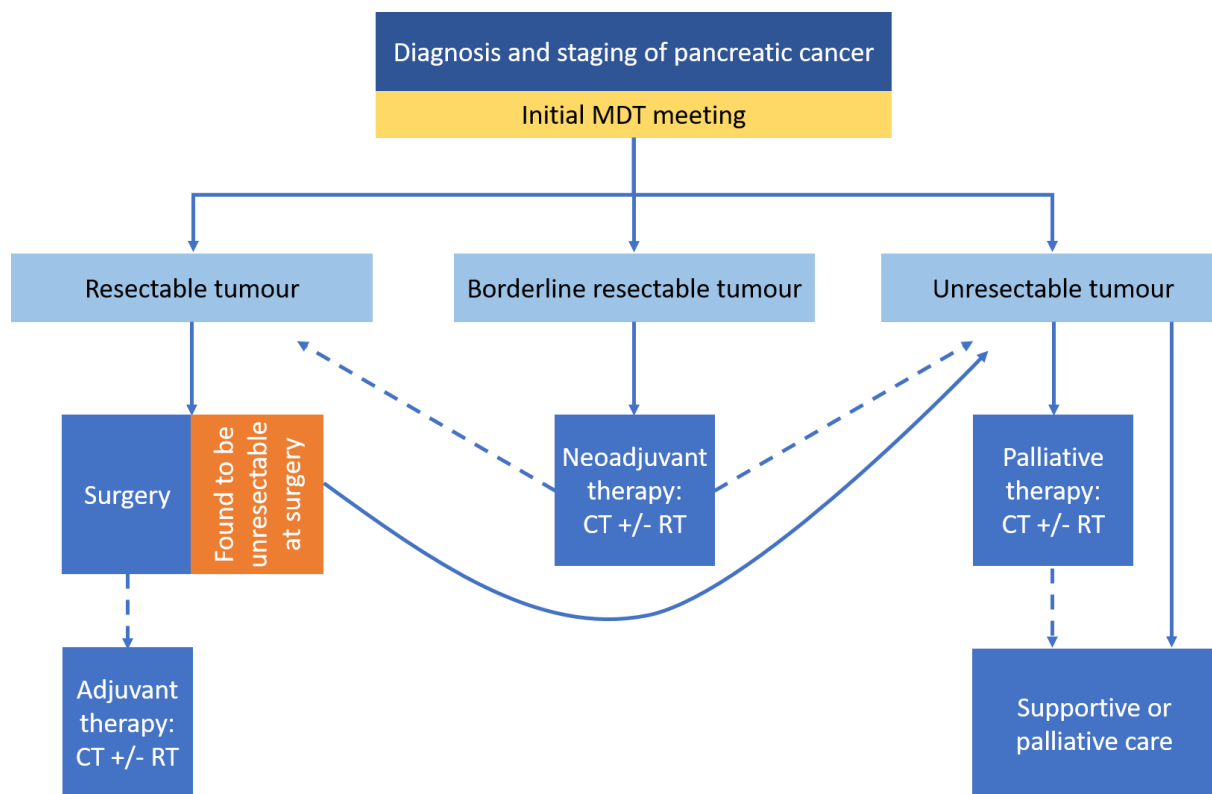
<sup>3</sup> Allemani C, et al. [Global surveillance of trends in cancer survival 2000-14 \(CONCORD-3\): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries](#) Lancet. 2018;391(10125):1023-75.

<sup>4</sup> Lemanska A, et al. [Healthcare in England was affected by the COVID-19 pandemic across the pancreatic cancer pathway: A cohort study](#) using OpenSAFELY-TPP. Elife. 2023;12.

<sup>5</sup> RICOCHET Study Group. [Pancreatic enzyme replacement therapy in patients with pancreatic cancer: A national prospective study](#). Pancreatolgy. 2021.

<sup>6</sup> Lemanska A, et al. [A national audit of pancreatic enzyme prescribing in pancreatic cancer from 2015 to 2023 in England using OpenSAFELY-TPP](#). medRxiv. 2023

Figure 1: Sequence of steps in common pancreatic cancer pathway, from diagnosis to treatment, in English and Welsh NHS organisations



CT: chemotherapy; MDT: Multi-disciplinary team; PS: performance status; RT: radiotherapy; *Supportive care: helps the person to cope with their cancer and its treatment; Palliative care: care towards the end of life that aims to provide relief from pain and other distressing symptoms.*

NOTE: Dashed lines indicate variations or alternative steps in pathways; some patients may not proceed along these routes

## 2.3 Guidelines on the management of pancreatic cancer

There are several UK-specific guidelines relevant to pancreatic cancer care, which were reviewed as part of the set-up of NPaCA and are referenced where applicable within the Audit's [scoping document](#):

- [NICE Guideline NG85](#): "Pancreatic cancer in adults: diagnosis and management"
- [NICE Quality Standard QS177](#): "Pancreatic cancer quality standard"
- [NICE Guideline NG12](#): "Suspected cancer: recognition and referral"
- [NHS England Clinical Commissioning Policy Statement](#): "Stereotactic ablative body radiotherapy for patients with locally advanced, inoperable, non-metastatic pancreatic carcinoma"
- [European Society for Medical Oncology \(ESMO\) clinical practice guideline](#): "Pancreatic cancer: ESMO Clinical Practice Guideline for diagnosis, treatment and follow-up"

radiotherapy, endoscopic treatments, and pancreatic enzyme replacement therapy (PERT). There are ongoing developments within each of the different modalities. For example, the range of available systemic anti-cancer therapies is expanding, along with research into the optimal timing for its use, with new targeted therapies being developed for individualised genetic and molecular tumour profiles. Other changes include an increasing use of neoadjuvant systemic anti-cancer therapy over the last decade.

Guidance is also available on the organisation of services. In Wales, the NHS Wales National Optimal Pathways (NOPs) programme produced [guidance to support pancreatic cancer services](#) in establishing an effective and efficient pancreatic cancer pathway. It covers the pathway from diagnosis, staging and the various treatment options, as well as highlighting when patients should receive information and support to meet their individual needs.

Pancreatic cancer care may involve a combination of treatment modalities: surgery, systemic anti-cancer therapy,

### 3. Approach to developing the Quality Improvement Plan

The NPaCA Quality Improvement Plan builds on the Audit's [Scoping Exercise](#), which set out the Audit's scope and coverage of the care pathway ([Section 4](#)), and identified key quality improvement priorities.

The Quality Improvement Plan outlines ten performance indicators that have been mapped to clinical guidelines and the five quality improvement goals ([Section 5](#)).

In [Sections 6 and 7](#), improvement methods and improvement methods and improvement activities are outlined. Finally, [Section 8](#) sets out the approaches to evaluation of the Quality Improvement Plan. This Quality Improvement Plan will be reviewed and updated on a regular basis.

#### 3.1 Approach to developing the audit scope

The scope of the NPaCA was developed in consultation with a range of stakeholders. The following approaches were taken:

- **A feasibility study** for an audit of pancreatic cancer was conducted in 2022 by the National Oesophago-gastric Cancer Audit (NOGCA) team. The study comprised an online stakeholder survey and review of potential performance indicators. Responses were received from a range of stakeholders including medical professionals and Pancreatic Cancer UK.
- **Consultation meeting with the Clinical Reference Group (CRG).** The stakeholder group was formed for NPaCA, with representation from surgery, medical oncology, clinical oncology, radiology, gastroenterology, palliative care, cancer nurse specialists, HPB specialist dietitians, patient groups, NHS England, and NHS Wales. The first meeting of this group was held in July 2023 and formed part of the Audit's scoping exercise.
- **Consultation with the patient charities** [Pancreatic Cancer UK](#) and [Pancreatic Cancer Action](#), to hear about the experience of their members and understand their priorities.

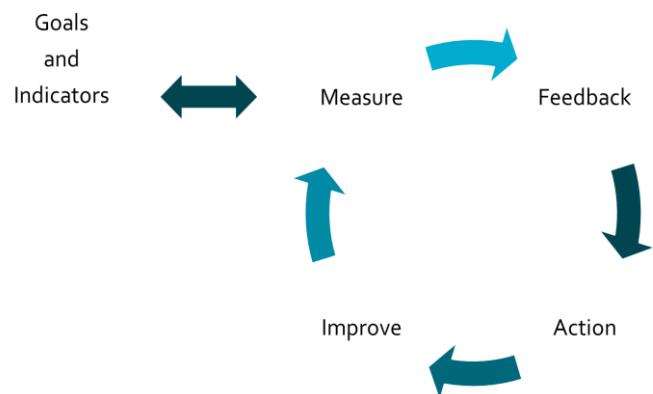
Details of the scoping exercise, including the results of the feasibility study and meeting discussion points, can be found in the [NPaCA Scoping Document](#).

<sup>7</sup> Brown B, Gude WT, Blakeman T, van der Veer SN, Ivers N, Francis JJ, et al. Clinical Performance Feedback Intervention Theory (CP-FIT): a new theory for designing, implementing, and evaluating feedback in health care based on a systematic review and meta-synthesis of qualitative research. *Implement Sci* 2019;14:40.

#### 3.2 Approach to prioritising performance indicators

Clinical Performance Feedback Intervention Theory (CP-FIT)<sup>7</sup> states that developing improvement goals and performance indicators are the first steps in the audit and feedback cycle (Figure 2).

Figure 2: The audit and feedback cycle



Based on the quality improvement priorities identified in the scoping exercise, the NPaCA developed a list of candidate performance indicators. Prioritisation of ten indicators from this list of candidates was informed by the following set of key principles.

The audit and feedback cycle is only as strong as its weakest link: to enhance the NPaCA's ability to inform improvements in care, its performance indicators must have three properties:

- **Measurable** so that they can be the basis of credible feedback about performance. This property means that the indicators can be defined with available data in a valid, reliable, and fair manner that allows performance to be attributed to a specific unit.<sup>8</sup>
- **Actionable** so that feedback translates into action to improve care. Indicators should therefore be important and address a specific pathway of care that is clear to all stakeholders. Stakeholders should understand the drivers of variation in performance within this pathway and control the levers for change. These changes should be evidence-based and address policy priorities.
- **Improvable** so that actions have the desired effect on patient care. There should therefore be clear scope for improvement (low baseline levels or large unwarranted variation) in a large population and a receptive context, with no unintended consequences. Some interventions may have demonstrated improvements to certain indicators in existing literature.

Some of these properties are difficult to know in advance of selecting and investigating a performance indicator (such as existing levels of performance, drivers of low performance, or

<sup>8</sup> Geary RS, Knight HE, Carroll FE, Gurol-Urganci I, Morris E, Cromwell DA, van der Meulen JH. A step-wise approach to developing indicators to compare the performance of maternity units using hospital administrative data. *BJOG* 2018;125:857-65.



interventions that can improve care). In addition, clinical practice and its context may change over time so that properties of indicators also change (such as whether they relate to a policy priority). Therefore, the NPaCA's goals and performance indicators are likely to evolve over time and recommendations will become more focused as the NPaCA learns through the audit and feedback cycle.

### 3.3 Data provision

The NPaCA utilises information from routine national health care datasets. These datasets capture details on the diagnosis, management and treatment of every person who is newly diagnosed with pancreatic cancer in England and Wales.

Further details on data acquisition can be found in the Appendix 2.

### 3.4 Data limitations

For accurate and timely benchmarking, it is essential that data used by the NPaCA:

1. Includes all the data items required to measure and risk-adjust performance indicators
2. Is timely
3. Has a high-level of case-ascertainment
4. Has high levels of data completeness
5. Is accurate.

For patients treated in England, Rapid Cancer Registration Data (RCRD) linked to other national healthcare datasets is used for quarterly reporting. This dataset is mainly compiled from Cancer Outcomes and Services Dataset (COSD) records and is made available more quickly than the gold standard National Cancer Registration Data (NCRD). The speed of production means that case ascertainment and data completeness are lower, and the range of data items in the RCRD is limited. This may restrict the extent to which risk adjustment can be applied to indicators used for quarterly reporting. For patients treated in Wales, no equivalent of RCRD is currently available.

The NCRD covering England is used for the annual State of the Nation Report. This dataset has a longer lag than RCRD, but higher case ascertainment and data completeness due to additional curation by NDRS and linkage to additional datasets such as the Medicines Prescribed in Primary Care. Similar national-level data will be provided for Wales via Wales Cancer Network (WCN)/Public Health Wales (PHW).

### 3.5 Stakeholder involvement

The NPaCA is provided through a partnership that combines clinical leadership, methodological expertise, project

management and a secure environment for data analysis, representing the following organisations: Association of Upper Gastrointestinal Surgery of Great Britain and Ireland (AUGIS), Royal College of Radiologists (RCR), British Society of Gastroenterology (BSG), and NATCAN.

The Audit team is supported by twice-yearly meetings of stakeholders in its Clinical Reference Group (CRG), which includes clinicians from across the patient pathway, patient representatives, commissioners and funder representatives. NPaCA has also established a Patient and Public Involvement (PPI) Forum that meets twice a year, whose members represent people with lived experience of pancreatic cancer and several patient organisations.

### 3.6 Service provision

Pancreatic cancer care in England and Wales is organised around specialist centres, where specialist multidisciplinary teams review new diagnoses of pancreatic cancer, plan treatment, and carry out surgical resections for people who are eligible. There are 23 specialist hepatopancreaticobiliary (HPB) centres in England, and one surgical and two oncology specialist centres in Wales<sup>9</sup>. This centralised service model was implemented following the publication of national guidance in 2001, which recommended that specialist teams for pancreatic cancer serve populations of two to four million, to ensure the teams reach minimum treatment volumes associated with improved outcomes<sup>10</sup>.

Preliminary analyses of Hospital Episode Statistics data by the NPaCA team confirmed that almost all pancreatic cancer surgeries in England (99.7%) take place at one of the 23 specialist centres.

<sup>9</sup> Pancreatic Cancer UK. Specialist centres 2022 [Available from: <https://www.pancreaticcancer.org.uk/support-for-you/your-care/your-local-pancreatic-cancerspecialist-centre/>]

<sup>10</sup> NHS Executive. Guidance on Commissioning Cancer Services: Improving Outcomes in Upper Gastro-intestinal Cancers, The Manual. 2001

## 4. Audit scope

### 4.1. Patient inclusion criteria

NPACA includes adults ( $\geq 18$  years of age) diagnosed and/or treated in England or Wales by NHS hospital services for pancreatic cancer, as defined using the ICD-10 codes listed in .

Patients are eligible if they have a radiologic or clinical diagnosis; eligibility is not limited to those with a histological diagnosis because a large proportion of people with pancreatic cancer are too unwell to undergo biopsy for histological diagnosis. Neuroendocrine tumours can be identified on imaging and are excluded.

### 4.2. Care pathway

The Audit covers the pathway from first diagnosis of pancreatic cancer through to the end of primary treatment.

Primary treatment includes planned treatments with, and without, curative intent. Treatments may be multimodal and include any of surgery, chemotherapy (CT), radiotherapy (RT), supportive or palliative care. Interventions aimed at relief of symptoms, such as a biliary drainage stent or PERT, will not be considered primary treatment unless they are part of best supportive care.

Surgical and non-surgical treatment pathways are reported separately. Non-surgical pathways may be further sub-categorised into 1) borderline resectable cancers treated with CT +/- RT and 2) metastatic disease treated with palliative CT +/- RT or best supportive care.

Compared to some other tumour types, pancreatic cancer has relatively few known biomarkers and targeted therapies. However, the Audit will monitor emerging personalised medicine approaches in pancreatic cancer and report on system factors that support personalisation.

**Table 1. ICD-10 diagnosis codes for defining people who are eligible for inclusion**

Inclusion criteria	Rationale
Diagnosis is one of the following: <ul style="list-style-type: none"><li>• C25.x Malignant neoplasm of pancreas</li><li>• C24.0 Extrahepatic bile duct</li><li>• C24.1 Malignant neoplasm of ampulla of Vater</li></ul>	The diagnostic and treatment pathways are very similar for people with pancreatic cancer, Ampulla of Vater, and (most) tumours covered by the code for extrahepatic bile duct tumours.
Exclusion criteria	Rationale
Diagnosis is one the following: <ul style="list-style-type: none"><li>• C25.4 Pancreatic neuroendocrine tumour</li><li>• C24.8 Overlapping lesion of biliary tract</li><li>• C24.9 Unspecified biliary tract tumours</li><li>• C23.x Gallbladder tumours</li><li>• C22.1 Intrahepatic bile duct tumours</li><li>• C17.0 Duodenal tumours</li></ul>	<ul style="list-style-type: none"><li>• Neuroendocrine tumours have a different treatment pathway from exocrine pancreatic cancers</li><li>• While people diagnosed with the other ICD-10 codes listed may receive some of the treatments received by those with pancreatic tumours, their inclusion may complicate the interpretation of results.</li></ul>

## 5. Quality Improvement Goals & Performance indicators

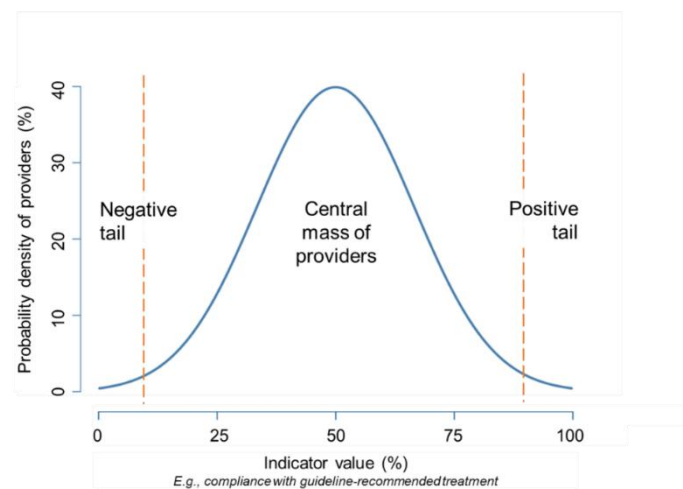
Quality improvement goal	Performance indicators*	National Guidance/standards
Increase the percentage of people who have diagnostic procedures and a process of diagnosis consistent with national recommendations for pancreatic cancer	Percentage of people with a diagnosis of pancreatic cancer who had a FDG-PET/CT prior to surgery	NICE Quality Statements ( <a href="#">QS 177 - Pancreatic cancer</a> ): 1. "Adults with suspected pancreatic cancer have their diagnosis and care agreed by a specialist pancreatic cancer multidisciplinary team (MDT)" (QS1) 2. "Adults with localised pancreatic cancer on CT have staging using FDG-PET/CT before they have surgery, radiotherapy, or systemic therapy" (QS2)
	Percentage of people with a diagnosis of pancreatic cancer who had a record of being discussed at an MDT meeting	
	Percentage of people with a diagnosis of pancreatic cancer undergoing surgery (no neo-adjuvant chemotherapy) who had a biliary stent prior to Whipple procedure	
Optimise diagnostic and treatment pathways to reduce the time between referral and start of disease-targeted treatment	Time from referral to first treatment (days) <i>Note: within this we will look at component parts of the pathway: median time (IQR) from referral to diagnosis and from diagnosis to first treatment, and percentages achieving cancer waiting time targets, including percentage of people treated within 62 days of urgent suspected cancer GP referral (England)</i>	NHS England has <a href="#">three core measures for cancer waiting times</a> : <a href="#">28-day Faster Diagnosis Standard</a> , 62-day referral to treatment standard and 31-day decision to treat to treatment standard. Furthermore, there is an NHS England <a href="#">Best Practice Timed Diagnostic Pathway for HPB cancer</a> that sets out a target 21 days from referral to diagnosis. Wales has a <a href="#">Suspected Cancer Pathway of 62 days from point of suspicion to start of treatment</a> .
Increase the percentage of people with pancreatic cancer (who are fit enough for treatment) who receive disease-targeted treatment (surgery, chemotherapy, radiotherapy - both curative and palliative)	Percentage of people with non-metastatic (stage 1-3) pancreatic cancer who received disease-targeted treatment**	<a href="#">Pancreatic Cancer UK</a> reports that only 3 out of 10 people with pancreatic cancer receive active treatment. Furthermore, expert clinical input believes current clinical practice has moved beyond the NICE guidelines for pancreatic cancer published in 2018, with greater use of CT/RT in practice than is recommended in the guidelines.
	Percentage of people with metastatic (stage 4) pancreatic cancer who received disease-targeted treatment**	
	Percentage of people with pancreatic cancer receiving CT/RT alongside surgery (Percentage who received CT/RT before any pancreatic surgery and percentage who received CT/RT after Whipple procedure)	
Increase the percentage of people with pancreatic cancer who receive supportive care (care that helps the person to live as well as possible with their cancer and its treatment) in line with national recommendations	Percentage of people with a diagnosis of pancreatic cancer who were seen by a CNS	NICE Quality Statement ( <a href="#">QS 177 - Pancreatic cancer</a> ): 1. "Adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin" (QS4) 2. "Effective interventions to address psychological needs" (QS5), but no guidance is currently available. The <a href="#">PCUK Optimal Care Pathway Policy Report</a> recommends an HPB CNS should be responsible for coordinating access to psycho-social support.
	Percentage of people with a diagnosis of pancreatic cancer who were prescribed pancreatic enzyme replacement therapy (PERT)	
Improve outcomes for people diagnosed with pancreatic cancer	30-, 90-day, 1- and 2-year survival rates after diagnosis, by intent and treatment modality	N/A

\* The NPpCA will publish initial performance indicators in the first State of the Nation Report published in September 2024. Additional indicators will be reported in quarterly reports and future State of the Nation reports. The publication of indicators is aligned with data availability and completion of robust, methodological development work including appropriate risk-adjustment models. \*\*"Disease-targeted treatment" includes surgery, chemotherapy and radiotherapy, and includes treatments with curative and palliative intent; this may include both treatments targeting the disease and symptom management.

## 6. Quality Improvement Framework

The figure below shows a hypothetical example of how the values of a performance indicator may be distributed across NHS providers nationally at a single time point. On this indicator, a lower value indicates worse performance. This distribution can be separated into three domains: the negative tail (suggestive of worse performance), the central mass (centred on the national average, for example), and the positive tail (suggestive of better performance).

**Figure 3. Hypothetical distribution of organisational values on a performance indicator across NHS providers**



Each domain is associated with a different set of methods for improving healthcare:

### Negative tail

*Example methods: Regulation and public reporting of outliers*

- Clinical audit has traditionally focused on the negative tail to improve healthcare. This approach implies that some NHS providers are doing something systematically worse than their peers that can be resolved through direct intervention. Such intervention may be necessary to assure minimum standards of care and to reduce distance between the best and worst performing NHS providers. Cancer audits that pre-date NATCAN have formally reported negative outliers (see Appendix 3).

### Central mass

*Example methods: Statistical process control and iterative testing of interventions*

Most providers have indicator values that lie in the central mass of the distribution. Efforts focused here may present the greatest scope for improving average levels of care nationally. Methods in this domain suggest that all providers can improve their performance, regardless of current levels. Local audits and evaluations can inform the iterative deployment of

interventions which incrementally raise standards.

Longitudinal monitoring by national clinical audits provides feedback about whether improvements occur or not.

### Positive tail

*Example methods: Positive deviance*

- Some NHS providers perform exceptionally well despite similar constraints to others, which presents opportunities to learn and share how this is achieved. 'Positive deviance' approaches assert that generalisable solutions to better performance already exist within the system. Such solutions are therefore likely to be acceptable and transferable within existing resources. These approaches aim to identify local innovations and spread them to other settings (see Appendix 3).

The NPaCA has selected methods to implement to improve pancreatic cancer care after investigating the distributions of its performance indicators (outlined in section 5). This includes the distribution of performance indicators between providers at a given time point and within providers over time.

## 7. Improvement activities

Improvement activities and outputs of NPpCA will be aligned to the QIP. The Audit will: (1) engage in key collaborations, (2) align with other initiatives in pancreatic cancer care, and (3) provide outputs to support quality improvement at the national, regional and local level.

The principal strategies for reporting NPpCA results include:

- A short 'State of the Nation' (SotN) report for NHS Trusts/Health Boards within England and Wales. This annual report includes five key recommendations highlighting where services should focus quality improvement activities. These recommendations are developed in collaboration with clinical reference groups and major national stakeholders.
- A quarterly dashboard, to facilitate benchmarking and the monitoring of performance at regular intervals so improvements can be tracked.

### 7.1 National and Regional

The NPpCA undertakes various activities that directly support national stakeholders and regional NHS organisations to tackle system-wide aspects related to the delivery of quality pancreatic cancer services. These include:

Stakeholder	NPpCA activity
<i>NATIONAL</i>	
NHS England / Welsh Cancer Network	Identify issues and make recommendations on the organisation and delivery of pancreatic cancer services which might involve large-scale investment, national leadership or service reorganisation.
Care Quality Commission	Provide Care Quality Commission CQC with information to support local inspections of NHS trusts and highlighting areas of concern identified after an organisation is flagged as a potential outlier on a NPpCA performance indicator.
Professional societies	Identify issues and make recommendations regarding the delivery of pancreatic cancer services that fall within the remit of the professional associations.
National programmes	Engage with national programmes such as the pancreatic cancer Getting Right First Time (GIRFT) peer review, to identify areas for coordination and shared learning.
<i>REGIONAL</i>	
Cancer Networks / Alliances / Vanguard	Support the monitoring role of Welsh Cancer Networks and the English Cancer Alliances / Vanguard by publishing results for their region/area.

At a national level, the NPpCA team also provides the National Cancer Registration and Analysis Service (NCRAS) Data Improvement Leads (in England), and the Wales Cancer Network with information to help them support their NHS organisations to improve the quality of their routine data submissions.

## 7.2 Local

The NPACA will support local NHS cancer services in the provision of quality care to people with pancreatic cancer in the following ways:

Feedback activity	Description
Annual State of the Nation Report	State of the Nation report that enables NHS organisations to benchmark themselves against clinical guideline recommendations and national performance.
Local Action Plan template	Template that allows NHS organisations to document how they will respond to the State of the Nation Report recommendations.
Slide sets summarising State of the Nation Report results	A slide set that allows NHS organisations to insert their own figures and present their results at local staff meetings.
Organisational Data Viewer	Results presented for individual NHS organisations using information from the State of the Nation data tables that allows the user to compare the results of selected providers.
Outlier reporting	In the future, NPACA will report NHS provider values that are more than three standard deviations from the expected level of performance (i.e. deemed a potential outlier). NPACA will support potential negative outliers to identify areas for improvement.
Web-based dashboard	Webpages that present organisational level information on the performance of the provider for different aspects of the care pathway.
Quarterly reports	Reports that describe patterns of care on a quarterly basis to enable tracking of performance.

## 7.3 Improvement tools

The NATCAN website includes a [Quality Improvement Resources page](#) with links to the RCSEng website and other web-based material that direct healthcare providers to various quality improvement tools including:

- ‘How to’ guides including quality improvement methodology
- Links to existing resources
- Links to training courses for quality improvement
- Good practice repository with contact information where possible.

In future cycles, the Audit will develop and implement an outlier process for select indicators, to identify organisations with performance outside of the expected range.

## 7.4 Improvement workshops

The NPACA will support a range of improvement activities that are aligned to national meetings and quality improvement initiatives of relevant professional bodies.

In 2023, members of the NPACA team presented at several events including: the Royal College of Radiologists Clinical Oncology Quality Improvement Audit Forum, the Royal College of Surgeons of England’s Pancreas Research Symposium, the Pancreatic Society of Great Britain and Ireland, Annual Scientific Meeting and the Pancreatic Cancer UK ‘Improving Pancreatic Cancer Care’ launch event. The Audit will continue to work with these organisations to host improvement workshops and other events linked to key national meetings.

## 7.5 Designing a National Quality Improvement Initiative

Based on analysis of rapid cancer registry data, NPACA will design a national Quality Improvement initiative aiming “to close the audit cycle” following an approach commonly referred to as the “plan-do-study-act” method.<sup>11</sup>

This will involve the identification of priority areas for quality improvement and working with stakeholders to develop appropriate design and methodology to underpin the initiative.

We will identify opportunities to link in with other initiatives, such as activities during National Pancreatic Cancer Awareness month. Further details about the initiative design and consultation process will be published in a future Audit output.

## 7.6 Patient and Public Involvement

Patient representatives are regularly consulted on the design of the Audit and the communication of its results, via the NPACA Patient and Public Involvement (PPI) Forum. The chair of the PPI Forum also acts as a patient representative on the Clinical Reference Group to advise on Audit priorities and participate in the development and review of key Audit outputs. The PPI Forum will:

- Undertake a key advisory role in developing content for the Audit webpages to ensure that patients and the public can easily access the information they are seeking,

<sup>11</sup> Taylor MJ, McNicholas C, Nicolay C, Darzi A, Bell D, Reed JE. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. *BMJ Qual Saf.* 2014 Apr;23(4):290-8. doi: 10.1136/bmjqs-2013-001862.

- Contribute to the design and content of patient information materials and NPaCA reports for the public,
- Provide input into the development of the Audit's quality improvement goals, activities and outputs to ensure they reflect priorities from the patient perspective, and
- Help to disseminate and publicise NPaCA and its outputs via their networks.

## 7.7 Communication & dissemination activities

NPaCA communicates regularly with stakeholders, providers, people with lived experience of pancreatic cancer and the public in several ways, including:

- Regular posts and interactions with the pancreatic cancer community on X (formerly Twitter)
- Regular distribution of quarterly newsletters
- Contribution of items for newsletters created by medical associations, patient associations
- Presentations at national conferences
- Publication of articles in medical journals and other media.

## 8. Evaluation

The NPaCA will report year-on-year progress against improvement goals to the Audit's Clinical Reference Group and in the State of the Nation reports on an annual basis. This will focus on describing how values of performance indicators have changed over time at a national level.

To evaluate the impact of specific NPaCA or other national interventions on the performance of NHS providers, quasi-experimental methods (when allocation of providers to certain groups cannot be controlled) or experimental methods (when group allocation can be controlled) will be used.

The NPaCA will examine the opportunities for, and strengths and limitations of, quasi-experimental and experimental evaluation methods once it is more fully established.

# Appendix

## 1. National Cancer Audit Collaborating Centre (NATCAN)

NPaCA is part of the National Cancer Audit Collaborating Centre ([NATCAN](#)), a national centre of excellence launched on 1<sup>st</sup> October 2022 to strengthen NHS cancer services by looking at treatments and patient outcomes in multiple cancer types across the country. The centre was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government with funding in place for an initial period of three years.

NATCAN is based within the Clinical Effectiveness Unit ([CEU](#)), the academic partnership between the Royal College of Surgeons of England (RCS Eng) and the London School of Hygiene & Tropical Medicine. The CEU is recognised as a national centre of expertise in analytic methodology and the development of administrative and logistic infrastructure for collating and handling large-scale data for assessment of health-care performance.

NATCAN was set up on 1<sup>st</sup> October 2022 to deliver six new national cancer audits, including kidney, ovarian, pancreatic, breast (two separate audits in primary and metastatic disease) and non-Hodgkin Lymphoma. Existing audits in [prostate](#), [lung](#), [bowel](#), and [oesophago-gastric](#) cancers moved into NATCAN in 2023. This critical mass of knowledge and expertise enable it to respond to the requirements of the funders and stakeholders.

The aim of the ten NATCAN audits is to:

1. Provide regular and timely evidence to cancer services of where patterns of care in England and Wales may vary.
2. Support NHS services to increase the consistency of access to treatments and help guide quality improvement initiatives.
3. Stimulate improvements in cancer detection, treatment and outcomes for patients, including survival rates.

Key features of NATCAN's audit approach

The design and delivery of the audits in NATCAN has been informed by the CEU's experience delivering national audits, built up since its inception in 1998. Key features of all audit projects within the CEU include:

- Close clinical-methodological collaboration
- Use of national existing linked datasets as much as possible
- Close collaboration with data providers in England (National Disease Registration Service [NDRS, NHSE] and

Wales (Wales Cancer Network [WCN], Public Health Wales [PHW])

- A clinical epidemiological approach, informing quality improvement activities.
- "Audit" informed by "research".

All these features will support NATCAN's focus on the three "Rs", ensuring that all its activities are clinically relevant, methodologically robust, and technically rigorous.

### Organisational structure of NATCAN

#### Centre Board

NATCAN has a multi-layered organisational structure. [NATCAN's Board](#) provides top-level governance and oversees all aspects of the delivery of the contract, ensuring that all audit deliverables are produced on time and within budget and meet the required quality criteria. The Board also provides the escalation route for key risks and issues. It will also consider NATCAN's strategic direction. The Board will meet at 6-monthly intervals and will receive regular strategic updates, programme plans, and progress reports for sign-off. Risks and issues will be reported to the NATCAN Board for discussion and advice.

#### Executive Team

[NATCAN's Executive Team](#) is chaired by the Director of Operations (Dr Julie Nossiter) and includes the Clinical Director (Prof Ajay Aggarwal), the Director of the CEU (Prof David Cromwell), the Senior Statistician (Prof Kate Walker), and the Senior Clinical Epidemiologist (Prof Jan van der Meulen) with support provided by NATCAN's project manager (Ms Verity Walker). This Executive Team is responsible for developing and implementing NATCAN's strategic direction, overseeing its day-to-day running, and coordinating all activities within each of cancer audits. This group meets monthly. The Executive Team will provide 6-monthly updates to NATCAN's Board.

#### Advisory groups

The Executive Team will be supported by two external groups. First, the Technical Advisory Group including external senior data scientists, statisticians, and epidemiologists as well as representatives of the data providers (NDRS, NHSD and WCN, PHW), co-chaired by NATCAN's Senior Statistician and Senior Epidemiologist, will advise on national cancer data collection, statistical methodology, development of relevant and robust performance indicators to stimulate QI, and communication to practitioners and lay audiences.

Second, the Quality Improvement Team includes national and international experts who have extensive experience in QI and implementation research. This team will provide guidance on the optimal approaches to change professional and organisational behaviour. It will be chaired by NATCAN's Clinical Director and managed by the Director of Operations.

This set up will provide a transparent and responsive management structure allowing each audit to cater for the individual attributes of the different cancer types, while also



providing an integrated and consistent approach across the NATCAN audits. The integrated approach will result in efficient production of results through sharing of skills and methods, a common “family” feel for users of audit outputs, and a shared framework for policy decisions and, project management.

#### *Audit Project Teams*

Audit development and delivery is the responsibility of each [Project Team](#). The Project Team works in partnership to deliver the objectives of the audit and is responsible for the day-to-day running of the audit and producing the deliverables. It will lead on the audit design, data collection, data quality monitoring, data analysis and reporting.

Each cancer audit Project Team is jointly led by Clinical Leads representing the most relevant professional organisations, and senior academics with a track record in health services research, statistics, data science and clinical epidemiology, affiliated to the London School of Hygiene and Tropical Medicine. In addition, each audit will have a clinical fellow, who contributes to all aspects of the audits, reinforcing the audits’ clinical orientation and contributing to capacity building.

The delivery of the audit is coordinated by an audit manager who is supported by NATCAN’s wider infrastructure. Data scientists with experience in data management and statistics and methodologists with experience in performance assessment and QI work across audits.

#### *Audit Clinical Reference Groups*

Each audit has a [Clinical Reference Group \(CRG\)](#) representing a wide range of stakeholders. This group will act as a consultative group to the Project Team on clinical issues related to setting audit priorities, study methodology, interpretation of audit results, reporting, QI, and implementation of recommendations.

Effective collaboration within the centre and across audits facilitates the sharing of expertise and skills in all aspects of the delivery process, notably: designing the audits, meeting information governance requirements, managing and analysing complex national cancer data to produce web-based performance indicator dashboards / state of the nation reports, and supporting quality improvement.

This organisation creates “critical mass” and audit capacity that is able to respond to the requirements of the funders (NHS England and Welsh Government) and the wider stakeholder “family”.

#### *Audit PPI Forums*

People with a diagnosis of pancreatic cancer and/or lived experience of pancreatic cancer and patient charities are involved in all aspects of the delivery of the cancer audits.

Each audit has a standalone Patient and Public Involvement (PPI) Forum to provide insight from a patient perspective on strategic aims and specific audit priorities. This will include shaping the development of each audit’s quality improvement initiatives by ensuring this work is relevant from a patient perspective. A key activity of the PPI Forums will be to actively participate in the production of patient-focussed audit outputs (including patient and public information, patient summaries of reports, infographics and design and function of the NATCAN website), guiding on how to make this information accessible.

## 2. Data provision

The NATCAN Executive Team has worked closely with data providers in England (NDRS, NHSE) and in Wales (WCN, PHW) to establish efficient “common data channels” for timely and frequent access to datasets, combining data needs for all cancers into a single request in each Nation and only using routinely collected data, thereby minimising the burden of data collection on provider teams.

#### *Annual and quarterly data*

NATCAN will utilise two types of routinely collected data in England. First, an annual “gold-standard” cancer registration dataset, released on an annual basis with a considerable delay between the last recorded episode and the data being available for analysis, and second, a “rapid” cancer registration dataset (RCRD), released at least quarterly with much shorter delays (3 months following diagnosis). The CEU’s recent experience with English rapid cancer registration data, in response to the COVID pandemic has demonstrated the latter’s huge potential,<sup>12</sup> despite a slightly lower case ascertainment and less complete staging information.

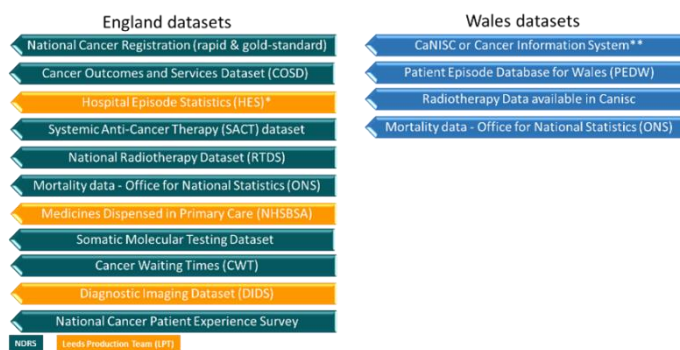
NATCAN will utilise these data across all cancers linked to administrative hospital data (Hospital Episode Statistics/Systemic Anti-Cancer Therapy/Radiotherapy Data Set/Office for National Statistics among other routinely collected datasets, see Figure 4) for describing diagnostic pathway patterns, treatments received and clinical outcomes.

An equivalent data request will be made to the Wales Cancer Network (WCN)/Public Health Wales (PHW).

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<sup>12</sup> Nossiter J, Morris M, Parry MG, Sujenthiran A, Cathcart P, van der Meulen J, Aggarwal A, Payne H, Clarke NW. Impact of the Covid-19 pandemic on the diagnosis and treatment of men with prostate cancer. *BJU Int.* 2022; doi: 10.1111/bju.15699

**Figure 4. National datasets available to NATCAN**



\* Includes inpatient and outpatient data and Emergency care Dataset (ECDS).

\*\* NHS Wales will use Welsh registry information for the initial years data for the audit. NATCAN submitted a request for historical data from the Welsh Cancer Registry in Q4 2023 (). From 2022 data submissions will be from either Canisc or the new cancer dataset forms.

### 3. Quality Improvement Framework – Supplementary information

#### Negative tail

##### *Regulation and public reporting of outliers*

National cancer audits that pre-date NATCAN have used a formal process for reporting outliers publicly. This process includes contacting outliers before publication to: (1) verify the data, (2) identify the reasons for the low level of performance identified, and (3) determine what corrective interventions have been put in place. The findings are reported publicly and may inform care practices in other NHS Trusts.

#### Central mass

##### *Statistical process control and iterative testing of interventions*

Most providers exist in the central mass of the distribution (by definition). Just because something is common it does not mean that it is alright: performance may be systematically below an achievable standard nationally for example (such as 75% of eligible patients receiving a particular treatment). We recommend that individual providers verify their performance data and undertake internal audits to assess areas for improvement and consider evaluation of their processes of care.

#### Positive tail

##### *Positive deviance*

Positive deviants may perform consistently better than comparators over time or demonstrate a clear upward trend in performance between two time points. It may be possible to learn from these providers to identify practices of care that have driven high levels of performance. This could include care protocols or factors related to system organisation which may

inform quality improvement amongst providers in the negative tail and central mass of performance.

#### Determinants of variation

To support targeting of improvement interventions and recommendations, the audit will analyse particular patient, hospital and regional factors associated with variation in processes and outcomes of care. For example, for the utilisation of a particular evidence-based treatment, factors associated with utilisation may include advanced age, social deprivation and frailty, clinician preferences, and regional policies. Findings may be reported at an aggregated national or regional (alliance) level and can support NHS Trusts to target interventions or evaluation at particular patient populations.