TE AHO O TE KAHU CANCER CONTROL AGENCY

New Zealand Government

# POTENTIAL PANCREATIC CANCER QUALITY PERFORMANCE INDICATORS

## Draft descriptions for feedback

**2021**

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# INTRODUCTION

**Tēnā koutou katoa**

**We are seeking your feedback on the potential quality performance indicators for pancreatic cancer described in this document.**

Te Aho o Te Kahu | the Cancer Control Agency (Te Aho o Te Kahu) and the National Pancreatic Cancer Working Group (the Working Group) have collaborated to develop a set of potential quality performance indicators (QPIs) for pancreatic cancer.

The Working Group has identified a potential set of 17 QPIs that, once calculated, will measure the quality of care and outcomes for people with pancreatic cancer in Aotearoa, New Zealand. The results will be used to target and support quality improvement in pancreatic cancer care.

Data from existing Ministry of Health National Collections will be used. If data are not available or of high enough quality to use, the QPI will not be calculated. Instead there will be further work to improve the data sources with the aim of calculating and reporting on that QPI in future.

### What feedback are we seeking?

We are providing an opportunity for all those involved in pancreatic cancer services to provide feedback on this set of 17 potential pancreatic cancer QPIs. We would like to know:

- if you think these QPIs are useful measures that can drive quality improvement for services provided to people diagnosed and treated for pancreatic cancer in Aotearoa, New Zealand
- if you have any feedback on the QPI descriptions and/or data descriptions.

### Who are we seeking feedback from?

Primarily we are seeking feedback from clinicians who provide diagnosis and treatment services for people with pancreatic cancer in Aotearoa, New Zealand. Feedback from other stakeholders is also welcome.

### How can you provide your feedback?

You can provide feedback to Te Aho o Te Kahu using the following email address:
**pancreaticqpiconsultation@teaho.govt.nz**

### When do we need feedback by?

Please complete your review of the QPIs and submit feedback by 27 September 2021.

Thank you.

# Background

## What is the Quality Performance Indicator programme?

Te Aho o Te Kahu | Cancer Control Agency (Te Aho o Te Kahu) has continued the Ministry of Health's cancer quality performance indicator (QPI) programme, which aims to improve the quality and reduce variation of cancer detection, diagnosis and treatment across Aotearoa, New Zealand.

Developing QPIs to measure performance with best practice clinical processes and outcomes is an internationally accepted approach to driving quality improvement in cancer care. Te Aho o Te Kahu, in partnership with sector-led working groups are developing national tumour-specific QPIs across multiple cancer types.

The QPIs that are selected will:

- address an area of clinical importance that could significantly impact on the quality and outcome of care delivered for people diagnosed with cancer
- support our goal of achieving Māori health gain and equity
- measurable with data in a national collection
- evidence with a clear rationale that this indicator can drive quality improvement

Addressing variation in the cancer services is pivotal to ensuring equitable care. In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Māori experience a disproportionate and inequitable burden in mortality from cancer in Aotearoa New Zealand.

By stratifying QPIs by ethnicity, including Māori and non-Māori, Te Aho o Te Kahu and district health boards will be able to identify specific areas of inequity and develop quality improvement initiatives to address these and monitor progress over time.

QPIs have already been developed for the diagnosis and treatment of bowel, lung and prostate cancers. The QPIs for these cancer types can be found on the Te Aho o Te Kahu website (**https://teaho.govt.nz/reports/publications**). QPIs for other cancer types will be calculated in the future.

## How did we come up with the proposed pancreatic cancer indicators?

The development process for pancreatic cancer QPIs is aligned with that used for the QPIs for the diagnosis and treatment of bowel, lung and prostate cancer.

A 'long list' of 39 pancreatic cancer QPIs was produced by the Working Group based on international/national literature and evidence. The Working Group then reviewed these indicators and considered which would be most valuable to drive quality improvements for pancreatic cancer care in Aotearoa, New Zealand. A 'short list' of 22 indicators was carried forward for further discussion by sub-work groups and initial assessment of measurability of data items required.

After consultation and further work by the sub-work groups, the final list of 17 potential QPIs, which are now being consulted on, was presented and endorsed by the Working Group on 17 May 2021.

The 17 QPIs are made up of 8 QPIs specific to pancreatic cancer, and 9 'common' QPIs identified as being both important and potentially relevant to other tumour streams.

## What will happen next?

Your feedback will be presented and considered at the next Working Group meeting. Feedback will be incorporated into an agreed set of potential QPIs. The calculations phase of the project then begins; this phase includes assessing the data, developing data specifications and developing the reporting requirements for each indicator.

Once the QPIs are calculated the results will be shared with DHBs for review and feedback. The final 'products' will be a Pancreatic Cancer QPI Monitoring Report (with associated description and specification documents) and a Pancreatic Cancer QPI Action Plan, both of which will be consulted on before being published on the Te Aho o Te Kahu website.

# National data for indicators

Data requirements have been considered for each indicator, and work to assess whether the data are available in existing national data collections is ongoing.

If the data are currently available, it will be used to further develop and report on the indicators.

National data improvement projects are underway to enable collection of robust data regarding clinical stage and clinically diagnosed cancers, and to develop structured pathology reporting. This data will enable ongoing development of the proposed QPIs described in this document.

QPIs for which the data are currently available or will be become available on the completion of the projects mentioned above, are considered currently 'measurable'.

QPIs for which the data are not currently available nationally are considered 'aspirational'. Te Aho o Te Kahu will work with their clinical advisory groups and service provider organisations (eg, DHBs) to develop technical solutions to ensure that these QPIs can be calculated and reported on in the future.

This document refers to the following national data sources.

- **Mortality Collection** – classifies the underlying cause of death for all deaths registered in New Zealand.
- **New Zealand Cancer Registry (NZCR)** – a population-based register of all primary malignant diseases diagnosed in New Zealand, excluding squamous and basal cell skin cancers.
- **National Minimum Dataset (NMDS)** – a collection of public and private hospital discharge information, including coded clinical data for inpatients and day patients.

- **National Non-Admitted Patients Collection (NNPAC)** – includes event-based purchase units that relate to medical and surgical outpatient events and emergency department events.
- **Pharmaceutical Collection (PHARMS)** – a data warehouse that supports the management of pharmaceutical subsidies and contains claim and payment information from pharmacists for subsidised dispensing.
- **Radiation Oncology Collection (ROC)** – a collection of radiation oncology treatment data, including both public and private providers.

More information on these data sources can be found on the Ministry of Health's website: **www.health.govt.nz**.

# Stratifying variables

The indicators will be stratified by the following variables where possible:

- DHB
- region
- age
- sex
- ethnicity (Māori, Pacific, Asian, European/Other)
- social deprivation
- rurality
- public/private provider.

# Glossary

| Term | Description |
|---|---|
| Adenocarcinoma | Cancer that begins in cells that line certain internal organs and that have gland-like (secretory) properties. |
| Advanced disease | Advanced pancreatic cancer means the cancer has spread from where it started or has come back some time after treatment (recurrence). Pancreatic cancer can be quite advanced when it is first diagnosed. |
| Biopsy | Removal of tissue to be looked at under a microscope to help in the diagnosis of a disease. |
| Carcinoma | The medical term for cancer. |
| Chemotherapy | Treatment aimed at destroying cancer cells using anti-cancer drugs, which are also called cytotoxic drugs. |
| Clavien-Dindo classification | Used to grade the severity of surgical complications. |
| Clinical trials | A type of research study that tests how well new medical approaches or medicines work. These studies test new methods of screening, prevention, diagnosis or treatment of a disease. |

| Term | Description |
|---|---|
| Common indicator | Indicator of quality of diagnosis and treatment (ie, service provision) applied to more than one tumour group. |
| Computerised tomography (CT) | An X-ray imaging technique, which allows detailed investigation of the internal organ of the body. |
| Curative intent | Treatment which is given with the aim of curing the cancer. |
| Diagnosis | The process of identifying a disease, such as cancer, from its signs and symptoms. |
| District health board (DHB) | An organisation responsible for ensuring publicly funded health and disability services are provided to people living in a geographical area. |
| ECOG | The scale was developed by the Eastern Cooperative Oncology Group (ECOG) used to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. |
| Emergency surgery | Unscheduled surgery performed promptly and often for lifesaving purposes. |
| Endoscopic retrograde cholangiopancreatography (ERCP) | A procedure combining upper gastrointestinal endoscopy and X-rays to diagnose and treat certain problems of the liver, gallbladder, bile ducts and pancreas. |
| Extensive stage disease | Cancer that has spread beyond the initial site of development and is not usually possible to cure by local measures alone. |
| Fistula | An abnormal or surgically made passage between a hollow or tubular organ and the body surface, or between two hollow or tubular organs. |
| Grade of cancer | A description of a tumour based on how abnormal the cancer cells and tissue look under a microscope and how quickly the cancer cells are likely to grow and spread. |
| Histology | The study of tissues and cells under a microscope. |
| Histological/histopathological | The study of the structure, composition and function of tissues under the microscope, and their abnormalities. |
| Inoperable | Describes a condition too extensive to be treated by surgery. |
| Interventional radiology | Involves delivery of precise, targeted treatment for complex diseases and conditions using minimally invasive image-guided techniques. |
| Jaundice | A condition in which the skin, whites of the eyes and mucous membranes turn yellow because of a high level of bilirubin, a yellow-orange bile pigment. |
| Lymph nodes | Small oval-shaped structures found in clusters throughout the lymphatic system. They form part of the immune system and are also known as lymph glands. |
| Malignancy | Cancerous. Malignant cells can invade and destroy nearby tissue and spread to other parts of the body. |
| Metastasis | The spread of cancer from the primary site (place where it started) to other places in the body via the bloodstream or the lymphatic system. |
| Morbidity | How much ill health a particular condition causes |

| Term | Description |
|---|---|
| Mortality | Either (1) the condition of being subject to death; or (2) the death rate, which reflects the number of deaths per unit of population in any specific region, age group, disease or other classification, usually expressed as deaths per 1000, 10,000 or 100,000. |
| Multidisciplinary | A treatment-planning approach or team that includes several doctors and other health care professionals who are experts in different specialties (disciplines). |
| Palliative care | Care given to improve the quality of life of patients who have a serious or life-threatening disease. |
| Palliative treatment | Anything which serves to alleviate symptoms due to the underlying cancer but is not expected to cure it. |
| Pancreatectomy | Partial or total surgical removal of the pancreas. |
| Pancreatoduodenectomy (Whipple procedure) | A complex surgical procedure that involves removal of the head of the pancreas, the first part of the small intestine (duodenum), the gallbladder and the bile duct. |
| Pathological stage | The stage of cancer (amount or spread of cancer in the body) that is based on how different from normal the cells in samples of tissue look under a microscope. |
| Performance status | A measure of how well a patient is able to perform ordinary tasks and carry out daily activities. For example, a WHO score of 0 = asymptomatic, 4 = bedridden; an Eastern Cooperative Oncology Group (ECOG) score of 0 = fully active, 5 = dead. |
| Platinum-based chemotherapy | Chemotherapy drugs that contain derivatives of the metal platinum. |
| Positron emission tomography / computed tomography (PET CT) | A specialised imaging technique which demonstrates uptake of tracer in areas of high cell metabolism and can help differentiate between benign and malignant masses. It is most frequently used to help stage pancreatic cancer by demonstrating or excluding distant metastases. |
| Primary tumour | Original site of the cancer – the mass of tumour cells at the original site of abnormal tissue growth. |
| Prognosis | An assessment of the expected future course and outcome of treatment. |
| Radical treatment | Treatment which is given with the aim of destroying cancer cells to attain cure. |
| Radiotherapy | Treatment using high energy X-rays to destroy cancer cells. |
| Recurrence | When new cancer cells are detected, at the site of original tumour or elsewhere in the body, following treatment. |
| Stage | A way of describing the size of a cancer and how far it has grown. Staging is important because it helps decide which treatments are required. |
| Stenting | Insertion of a plastic or wire mesh tube into a blocked duct or hollow organ to keep it open and restore the flow of bile, blood or other fluids. |
| Stratification | The separation of data into smaller, more defined groups based on a predetermined set of criteria. |
| Surgical margin | How close the cancer cells are to the edges of the whole area of tissue removed during surgery. |
| Surgical resection | Surgery to remove tissue or part or all an organ. |



| Term | Description |
|---|---|
| Synoptic reporting | A process for reporting specific data elements in a standardised and structured format in surgical pathology reports. |
| Systemic anti-cancer therapy (SACT) | Treatment of cancer using drugs which induce a reduction in tumour cell population, for example chemotherapy or hormone therapy. |
| Tissue | A group or layer of cells that work together to perform a specific function. |
| Tumour | An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumours may be benign (not cancer), or malignant (cancer). |
| TNM group stage | T stands for the original (primary) tumour. N stands for nodes (indicates whether the cancer has spread to the nearby lymph nodes). M stands for metastasis. It is often useful to combine TNM system categories into groups. Tumours localised to the organ of origin are generally staged as I or II depending on their extent; locally extensive spread to regional nodes is staged as III; and those with distant metastasis are classified as stage IV. While most Stage I tumours are curable, most Stage IV tumours are inoperable. |
| TNM system | T stands for the original (primary) tumour. N stands for nodes (indicates whether the cancer has spread to the nearby lymph nodes). M stands for metastasis. The TNM system is a global standard used to record the anatomical extent of disease. In the TNM system, each cancer is assigned a letter or number to describe the tumour, node and metastases. |
| Toxicity | The extent to which something is poisonous or harmful. |

# PANCREATIC CANCER QPIs

The table below lists each indicator, with a hyperlink to the detailed descriptions for each indicator on the following pages.

| ID | Indicator title | Indicator description |
|---|---|---|
| 1 | **Timeliness to Treatment** | Time from first histological diagnosis to first definitive treatment |
| 2 | **Radiological Staging** | Proportion of pancreatic cancer (PC) patients who have pancreatic protocol CT scan with synoptic reporting (determining resectability by agreed criteria) |
| 3 | **Resectability** | Proportion of patients who present with resectable, borderline, locally advanced and unresectable PC |
| 4 | **Multidisciplinary Discussion** | Proportion of patients with a working diagnosis of PC discussed at an MDM |
| 5 | **Pancreatic Resection** | Proportion of patients who had pancreatic resection |
| 6 | **Stenting and/or Drainage** | Proportion of jaundiced PC patients resected without stenting |
| 7 | **Tissue Diagnosis** | Proportion of PC patients with tissue diagnosis before treatment |
| 8 | **Medical Oncology Assessment** | Proportion of PC patients reviewed by medical oncologist |
| 9 | **Systemic Therapy** | Proportion of PC patients receiving systemic anti-cancer therapy, by stage and ECOG performance status |
| 10 | **Structured Pathology Reporting** | Proportion of resected PC patients with synoptic histopathology report |
| 11 | **Pancreatic Fistula** | Proportion of PC patients with post-operative pancreatic fistula |
| 12 | **Failure to Rescue** | In-hospital deaths from major complications after pancreatic resection for PC |
| 13 | **Days Alive and Out of Hospital** | Proportion of patients alive and out of hospital for at least 30 days |
| 14 | **Mortality** | Proportion of PC patients who died within 30 and 90 days of beginning treatment with curative intent (not palliative) |
| 15 | **Overall Survival** | Proportion of PC patients surviving at 1, 2, and 5 years from diagnosis |
| 16 | **Palliative Care** | Proportion of PC patients referred to palliative care services |
| 17 | **Clinical Trial Participation** | Proportion of PC patients participating in a clinical trial at any time after diagnosis |

# Indicator 1.
# Timeliness to treatment

| | |
|---|---|
| **Indicator description** | Time from first histological diagnosis to first definitive treatment. |
| **Rationale and evidence** | Timely treatment following diagnosis of cancer contributes to a better patient experience by reducing anxiety and uncertainty and minimising the risk of deterioration before treatment. |
| **Equity/Māori health gain** | No data available regarding equity.<br>Later presentations mean fewer resections for Māori and worse outcomes. |
| **Specifications** | |
| **Numerator** | Median time for pancreatic cancer (PC) patients from histological diagnosis to first definitive treatment. |
| **Denominator** | PC patients having treatment. |
| **Notes** | Definitive treatment includes chemotherapy (curative or palliative intent) or surgery.<br>The histology date currently available on the NZCR is most often the date of definitive histology following surgery, rather than the earlier biopsy date (ie, when diagnosis was first made).<br>Data from Lakes District Health Board (LDHB) shows that average time to review a patient from time of referral is 17 days (range: 0–40 days). |

## References


Camburn L, Dass PH. 2021. Patterns of presentation among New Zealand Māori with pancreatic cancer at Lakes District Health Board. J*ournal of Clinical Oncology* 39: 15_suppl, e18553–e18553.

Jooste V, Dejardin O, Bouvier V, et al. 2016. Pancreatic cancer: Wait times from presentation to treatment and survival in a population-based study. *International Journal of Cancer* 139: 1073–80.

Lukács G, Kovács Á, Csanádi M, et al. 2019. Benefits of Timely Care in Pancreatic Cancer: A systematic review to navigate through the contradictory evidence. *Cancer Management and Research* 11: 9849–61.

# Indicator 2.
# Radiological staging

| | |
|---|---|
| **Indicator description** | Proportion of PC patients who have pancreatic protocol CT scan with synoptic reporting (determining resectability by agreed criteria). |
| **Rationale and evidence** | Staging CT should be a pancreatic protocol and include chest, abdomen and pelvis.<br>Staging in practice means identifying metastatic disease and determining resectability status.<br>Synoptic reporting enables more complete capture of all-important data and assists useful data analysis.<br>Resectability is important because it determines whether the patient will be offered neoadjuvant chemotherapy and/or surgery. |
| **Equity/Māori health gain** | No data available. |
| **Specifications** | |
| **Numerator** | Number of PC patients who had pancreatic protocol CT with synoptic reporting. |
| **Denominator** | Number of PC patients. |
| **Notes** | It is recommended that radiological staging is recorded in the synoptic report and presented at the multidisciplinary meeting (MDM).<br>Radiological TNM staging is difficult based on CT imaging, as it does not accurately identify involved nodes, which is the reason why there is increasing use of PET-CT in PC patients. PET-CT gives more accurate staging information than CT alone. For approximately 20% of PC patients their management changes after PET-CT, usually because of occult metastatic disease.<br>Resectability is currently defined on anatomical criteria which do not necessarily reflect the biological behaviour of the PC. The international consensus criteria should be used (Isaji et al 2018) for reporting resectability status.<br>Data from LDHB shows that 84% of patients had a CT before or within 7 days of first presentation. |

## References


Al-Hawary MM, Francis IR, Chari ST, et al. 2014. Pancreatic ductal adenocarcinoma radiology reporting template: consensus statement of the Society of Abdominal Radiology and the American Pancreatic Association. *Gastroenterology* 146(1): 291–304.e1.

Camburn L, Dass PH. 2021. Patterns of presentation among New Zealand Māori with pancreatic cancer at Lakes District Health Board. *Journal of Clinical Oncology* 39: 15_suppl, e18553–e18553.

Isaji S, Mizuno S, Windsor JA, et al. 2018. International consensus on definition and criteria of borderline resectable pancreatic ductal adenocarcinoma. *Pancreatology* 18(1): 2–11.

# Indicator 3. Resectability

| | |
|---|---|
| **Indicator description** | Proportion of patients who present with resectable, borderline, locally advanced and unresectable PC. |
| **Rationale and evidence** | While the TNM staging of PC correlates with survival, it is not accurate or useful in deciding whether a patient has resectable disease. That decision is based on the anatomical relationship of the tumour to the portal/superior mesenteric, coeliac and common hepatic arteries.<br>Multiple criteria have been published, but the international consensus criteria by Isaji et al is recommended. This can be used to categorise patients into resectable, borderline, locally advanced or unresectable cancer.<br>Differences in the proportions of patients could reflect variation in criteria used, delays in presentations or different standards of reporting.<br>Resectability has a significant bearing on the next step in treatment. Patients with resectable disease are currently referred for surgery, in contrast to those with borderline resectable disease who are referred for neoadjuvant chemotherapy. Patients with locally advanced and unresectable disease are referred for palliative chemotherapy.<br>The resectability category should be ratified at the MDM. |
| **Equity/Māori health gain** | No data available. The suspicion is that later presentation by Māori results in a lower chance of resection and worse clinical outcomes. |
| **Specifications** | |
| **Numerator** | Number of patients with resectable PC, borderline resectable PC, locally advanced PC or unresectable PC. |
| **Denominator** | Number of PC patients. |
| **Notes** | TNM staging is not accurate for PC.<br>Currently focusing on A of ABC (Isaji et al 2018), which is anatomy. Biology markers (B) and fitness for surgery (C) are also important considerations in determining whether a patient with PC is resectable or not. |

## References

Isaji S, Mizuno S, Windsor JA, et al. 2018. International consensus on definition and criteria of borderline resectable pancreatic ductal adenocarcinoma. *Pancreatology* 18(1): 2–11.

# Indicator 4.
# Multidisciplinary discussion

| | |
|---|---|
| **Indicator description** | Proportion of patients with a working diagnosis of PC discussed at an MDM. |
| **Rationale and evidence** | International evidence shows that multidisciplinary care is a key aspect to providing best-practice treatment and care for people with cancer. Effective MDMs result in positive outcomes for people receiving the care. The benefits of MDMs include improvements in treatment planning, communication between care services, use of time and resources, equitable access to care, patient outcomes, satisfaction with care and participation in clinical trials.<br>An experienced multidisciplinary team is important in reaching consensus with complex multimodality treatment decision-making, including the role of surgery. |
| **Equity/Māori health gain** | No data available. Māori have worse outcomes from PC, but it is not known whether this is reflected in variations in the proportion of patients who are registered and discussed at an MDM. |
| **Specifications** | |
| **Numerator** | Number of patients with PC discussed at an MDM. |
| **Denominator** | Number of PC patients. |
| **Notes** | National data are not available to calculate this indicator because the numerator is not measured. Therefore, this QPI cannot be reported in 2021. The QPI will initially be the number of people who were discussed at an MDM (numerator alone).<br>The MDM is an important opportunity for data capture, and a standardised national reporting format for MDM should be developed as an urgent priority.<br>There is concern that there is insufficient time and resource to discuss all patients at an MDM. Not all patients require a detailed discussion, and the development of agreed treatment pathways would allow for efficient decision-making for most patients.<br>An MDM requires participation by appropriate specialties including Med Onc, Rad Onc, Radiology, Pathology, Gastro/Endoscopy, Palliative Care and Surgery.<br>Data needs to be reported by DHB even though Hepatobiliary and Pancreatic (HBP) MDMs do not exist in each DHB. |

## References


Camburn L, Dass PH. 2021. Patterns of presentation among New Zealand Māori with pancreatic cancer at Lakes District Health Board. *Journal of Clinical Oncology* 39: 15_suppl, e18553–e18553.

Phillips AR, Lawes CM, Cooper GJ, et al. 2002. Ethnic disparity of pancreatic cancer in New Zealand. *International Journal of Gastrointestinal Cancer* 31(1-3): 137–45.

Te Aho o Te Kahu Cancer Control Agency. 2021. *HISO 10038. 4: 2021 Cancer Multidisciplinary Meeting Data Standard*. Wellington: Te Aho o Te Kahu.

# Indicator 5.
# Pancreatic resection

| | |
|---|---|
| **Indicator description** | Proportion of patients who had pancreatic resection. |
| **Rationale and evidence** | It is important to know whether everyone with resectable disease is being resected.<br>Pancreatic resection combined with adjuvant therapy is the historical standard of treatment for resectable PC (Takaori et al 2016). But this 'surgery-first' approach to the treatment of PC is being challenged. Neoadjuvant multimodal chemotherapy is now established for borderline resectable PC and is being offered more frequently for resectable PC but rarely for locally advanced PC (Versteijne et al 2018).<br>Resectability can be difficult to predict by staging CT scanning after neoadjuvant chemotherapy (Barreto et al 2019). Thus a 'trial dissection' to determine resectability usually precedes resection.<br>There is no role for pancreatic resection in the presence of distant metastatic disease. |
| **Equity/Māori health gain** | Accessibility and number of people offered resection may vary by ethnicity.<br>Whether Māori are as likely to be offered potentially curative pancreatic resection needs to be determined.<br>Māori have worse outcomes from PC (Phillips et al 2002; Gurney et al 2020). |
| **Specifications** | |
| **Numerator** | Number of patients who had pancreatic resection with curative intent. |
| **Denominator** | Number of patients with PC. |
| **Notes** | It is not known how complete the Cancer Registry data are and therefore how accurate the number of people with PC is. The Cancer Registry includes data from death certificates, diagnostic coding from medical records, and minimum data set from discharge.<br>It would be helpful to report resection rates in resectable, borderline resectable, and locally advanced categories. This would require recording at the MDM, based on an agreed method (Isaji et al 2018) and for national reporting of MDM.<br>No distinction is made between pancreatoduodenectomy or distal pancreatectomy, and both should be included.<br>Given that there is a limited number of PC MDMs, the data should be reported for the service and domicile DHBs. |

## References


Barreto G, Loveday B, Windsor JA, et al. 2019. Detecting tumour response and predicting resectability after neoadjuvant therapy for borderline resectable and locally advanced pancreatic adenocarcinoma. *ANZ Journal of Surgery* 89(5): 481–7.

Gurney J, Stanley J, McLeod M et al. 2020. Disparities in cancer-specific survival between Māori and non-Māori New Zealanders, 2007–2016. *JCO Global Oncology* 6: 766–74.

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Phillips AR, Lawes CM, Cooper GJ, et al. 2002. Ethnic disparity of pancreatic cancer in New Zealand. *International Journal of Gastrointestinal Cancer* 31(1–3): 137–45.

Takaori K, Bassi C, Biankin A, et al. 2016. International Association of Pancreatology (IAP)/European Pancreatic Club (EPC) consensus review of guidelines for the treatment of pancreatic cancer. *Pancreatology* Jan–Feb 16(1): 14–27.

Versteijne E, Vogel JA, Besselink MG, et al. 2018. Meta-analysis comparing upfront surgery with neoadjuvant treatment in patients with resectable or borderline resectable pancreatic cancer. *British Journal of Surgery* Jul 105(8): 946–58.

Wylie N, Hider P, Armstrong D, et al. 2018. The volume, cost and outcomes of pancreatic resection a regional centre in New Zealand. *ANZ Journal of Surgery* 88(12): 1258–62.

# Indicator 6. Stenting/drainage

| | |
|---|---|
| **Indicator description** | Proportion of jaundiced PC patients resected without stenting. |
| **Rationale and evidence** | There is evidence that bile colonisation occurs with biliary stenting and that this is associated with an increased risk of infection after pancreatic resection.<br>Patients who do not have pruritus or cholangitis need stenting only if they are being referred for neoadjuvant chemotherapy.<br>Sometimes stenting is offered because of a long-anticipated delay to treatment.<br>Most patients have ERCP for stenting, but occasionally percutaneous transhepatic access is required. |
| **Equity/Māori health gain** | It is not known whether there is a difference in the stenting rates for Māori and non-Māori. |
| **Specifications** | |
| **Numerator** | Number of jaundiced PC patients resected without stenting. |
| **Denominator** | Number of jaundiced PC patients resected. |
| **Notes** | Stenting is best achieved by ERCP.<br>Complications of ERCP can delay definitive treatment, and these include pancreatitis, bleeding, cholangitis and perforation, all of which might require readmission, prolong hospital stay and delay definitive treatment.<br>Metal stents are preferred to plastic, as they allow prolonged drainage and reduce the need for repeat procedures (elective or urgent) and are associated with a lower risk of cholangitis.<br>Comparison between providers should be made with caution where the denominator is the number of PC patients who received treatment. This is due to variations in case complexity. Centres that perform fewer pancreatic resections are likely to treat those with better prognoses and higher volume centres are likely to treat those with patients with a range of prognoses (due to the availability of facilities and expertise). Therefore, higher volume centre outcome data may be skewed differently compared to lower volume centres. The two should not necessarily be compared without taking case mix into consideration. |

## References


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Thomaidis T, Kallimanis G, May G, et al. 2020. Advances in the endoscopic management of malignant biliary obstruction. *Annals of Gastroenterology* 33(4): 338–47.

# Indicator 7.
# Tissue diagnosis

| | |
|---|---|
| **Indicator description** | Proportion of PC patients with tissue diagnosis before treatment. |
| **Rationale and evidence** | Definitive treatment should be based on a histopathological diagnosis.<br>This can be obtained from the primary or secondary tumours, which typically means Endoscopic ultrasound (EUS) biopsy and ultrasound (U/S) or CT guided percutaneous biopsy, respectively. |
| **Equity/Māori health gain** | It is not known whether there is a difference in the tissue diagnosis rates for Māori and non-Māori. |
| **Specifications** | |
| **Numerator** | Number of PC patients who had EUS-based diagnosis before treatment. |
| **Denominator** | Number of PC patients treated. |
| **Notes** | EUS fine needle core biopsy (for histopathology) is preferred to fine needle aspiration (for cytology).<br>Histopathology is preferred to cytology as it allows for tissue architecture, immunohistochemistry and genetic profiling.<br>Combined EUS/ERCP is best practice and preferred at the same time to allow both tissue diagnosis and stenting, if required.<br>EUS is frequently used to provide additional information (eg, vascular staging, resectability, nodal status).<br>Interventional radiology should be available as back-up for tissue diagnosis by percutaneous biopsy. |

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Thomaidis T, Kallimanis G, May G, et al. 2020. Advances in the endoscopic management of malignant biliary obstruction. *Annals of Gastroenterology* 33(4): 338–47.

# Indicator 8.
# Medical oncology assessment

| | |
|---|---|
| **Indicator description** | Proportion of PC patients reviewed by a medical oncologist. |
| **Rationale and evidence** | Most PC patients present with locally advanced or metastatic disease, which means that medical management of PC and the complications of their malignancy will be the mainstay of treatment for the majority of patients.<br>Medical oncologists are experts in systemic therapy for malignancy. Improved survival has been demonstrated in those who meet a medical oncologist and particularly those who receive systemic therapy in a timely fashion. |
| **Equity/Māori health gain** | PIPER study (Presentations, Investigations, Pathways, Evaluation and Rx) data indicates that Māori referrals, recommendations and receipt of systemic therapy are lower than for non-Māori. |
| **Specifications** | |
| **Numerator** | Number of PC patients assessed by medical oncologist via FSA. |
| **Denominator** | Number of patients diagnosed with PC. |
| **Notes** | That these data are not routinely and consistently collected across all DHBs is a concern in itself. Without it, inequities cannot be improved. There is recognised inequity in access to medical oncologist review and subsequent therapies.<br>From the limited data available and reported by LDHB, 42% patients (of the 55% referred) were reviewed by medical oncology. |

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Mavros MN, Coburn NG, Davis LE, et al. 2019. Low rates of specialised cancer consultation and cancer-directed therapy for non-curable pancreatic adenocarcinoma: a population-based analysis. *Canadian Medical Association Journal* 191: 574–80.

Von Hoff D, Thomas E, Francis P, et al. 2013. Increased survival in pancreatic cancer with nab-paclitaxel plus gemcitabine. *The New England Journal of Medicine* 369 (18): 1691–703.

# Indicator 9.
# Systemic therapy

| | |
|---|---|
| **Indicator description** | Proportion of PC patients receiving systemic anti-cancer therapy, by stage and ECOG performance status. |
| **Rationale and evidence** | All PC patients, regardless of stage, have proven survival benefit from receipt of systemic therapy for their malignancy. Indications for chemotherapy include neoadjuvant and adjuvant (in the setting of potentially resectable and resectable disease, respectively) and palliative chemotherapy in those with advanced disease. |
| **Equity/Māori health gain** | PIPER data indicates that Māori referrals, recommendations, and receipt of systemic therapy are lower than for non-Māori. |
| **Specifications** | |
| **Numerator** | Number of PC patients who receive systemic anti-cancer therapy. |
| **Denominator** | All patients diagnosed with PC. |
| **Notes** | None. |

## References


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Conroy T, Desseigne F, Ychou M, et al. 2011. FOLFIRINOX versus Gemcitabine for metastatic pancreatic cancer. *The New England Journal of Medicine* 364(19): 1817–25.

Mavros MN, Coburn NG, Davis LE, et al. 2019. Low rates of specialised cancer consultation and cancer-directed therapy for non-curable pancreatic adenocarcinoma: a population-based analysis. *Canadian Medical Association Journal* 191: 574–80.

Von Hoff D, Thomas E, Francis P, et al. 2013. Increased survival in pancreatic cancer with nab-paclitaxel plus gemcitabine. *The New England Journal of Medicine* 369(18): 1691–703.

# Indicator 10.
# Structured pathology reporting

| | |
|---|---|
| **Indicator description** | Proportion of resected PC patients with synoptic histopathology report. |
| **Rationale and evidence** | Pathology reports of PC resection specimens provide important information which guides post-operative management and informs prognosis.<br>Synoptic reporting improves the completeness of pathology reports. |
| **Equity/Māori health gain** | No data available. |
| **Specifications** | |
| **Numerator** | Number of resected PC patients with synoptic histopathology report. |
| **Denominator** | Number of resected PC patients. |
| **Notes** | The use of the Royal College of Pathologists of Australasia structured reporting protocol is recommended. |

## References


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# Indicator 11.
# Pancreatic fistula

| | |
|---|---|
| **Indicator description** | Proportion of PC patients with post-operative pancreatic fistula. |
| **Rationale and evidence** | A post-operative pancreatic fistula represents failure of healing/sealing of a pancreatic-enteric anastomosis, or it may represent a parenchymal leak not directly related to an anastomosis, such as one originating from the raw pancreatic surface (eg, left or central pancreatectomy, enucleation, and/or trauma). This involves a leak from pancreatic ductal system into and around the pancreas and not necessarily to another epithelialised surface (eg, via a surgical drain). |
| **Equity/Māori health gain** | Case volumes and clinical outcomes, including pancreatic fistula, need to be reported by ethnicity. |
| **Specifications** | |
| **Numerator** | Number of PC patients with clinically relevant post-operative pancreatic fistula (Clavien-Dindo 3/4/5) after pancreatic resection. |
| **Denominator** | Number of PC patients who had pancreatic resection. |
| **Notes** | There is an expectation that units that perform pancreatic resections for PC will maintain audit data on pancreatic fistula.<br>Given the number of centres (15 centres) this data could be collected with an annual survey or alternative data collection method.<br>Centres performing surgery should also capture data for the Fistula Risk Score (Vollmer et al) so the data can be risk-adjusted as necessary. A higher fistula risk score is associated with increased risk of clinically relevant post-operative pancreatic fistula (FRS ≥4.9).<br>Comparison between providers should be made with caution where the denominator is the number of PC patients who received treatment. This is due to variations in case complexity. Centres that perform fewer pancreatic resections are likely to treat those with better prognoses and higher volume centres are likely to treat those with patients with a range of prognoses (due to the availability of facilities and expertise). Therefore, higher volume centre outcome data may be skewed differently compared to lower volume centres. The two should not necessarily be compared without taking case mix into consideration. |

## References


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Isaji S, Mizuno S, Windsor JA, et al. 2018. International consensus on definition and criteria of borderline resectable pancreatic ductal adenocarcinoma. *Pancreatology* 18(1): 2–11.

# Indicator 12.
# Failure to rescue

| | |
|---|---|
| **Indicator description** | In-hospital deaths from major complications after pancreatic resection for PC. |
| **Rationale and evidence** | This reflects the ability to make an early diagnosis of major complications and deliver prompt and appropriate treatment. It involves the availability of equipment and services (eg, interventional radiology and interventional endoscopy) and is related to the quality of clinical decision-making. |
| **Equity/Māori health gain** | No definitive data are available on whether there is inequity for Māori, but the suspicion is that post-operative outcomes, including outcomes after major complications, are worse for Māori. |
| **Specifications** | |
| **Numerator** | Number of patients who died due to major post-operative complications of PC. |
| **Denominator** | Number of patients who developed major post-operative complications of PC. |
| **Notes** | Major complications are defined as Clavien-Dindo category III, IV and V.<br>These complications include deep vein thrombosis/pulmonary embolism, pneumonia, sepsis, shock/cardiac arrest, or gastrointestinal haemorrhage/acute ulcer. Ideally the incidence of each of these complications would be recorded and reported by ethnicity.<br>Comparison between providers should be made with caution where the denominator is the number of PC patients who received treatment. This is due to variations in case complexity. Centres that perform fewer pancreatic resections are likely to treat those with better prognoses and higher volume centres are likely to treat those with patients with a range of prognoses (due to the availability of facilities and expertise). Therefore, higher volume centre outcome data may be skewed differently compared to lower volume centres. The two should not necessarily be compared without taking case mix into consideration. |

## References

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# Indicator 13.
# Days alive and out of hospital

| | |
|---|---|
| **Indicator description** | Proportion of patients alive and out of hospital for at least 30 days after pancreatic resection. |
| **Rationale and evidence** | This patient-centred metric demonstrates greater sensitivity to patient and surgery level characteristics than differences in hospital characteristics.<br>'Out of hospital' means the patient has been discharged. |
| **Equity/Māori health gain** | Data may highlight inequities in outcomes. |
| **Specifications** | |
| **Numerator** | Number of patients alive and out of hospital for at least 30 days after pancreatic resection. |
| **Denominator** | Total number of patients who had a pancreatic resection. |
| **Notes** | This has not been used previously.<br>Comparison between providers should be made with caution where the denominator is the number of PC patients who received treatment. This is due to variations in case complexity. Centres that perform fewer pancreatic resections are likely to treat those with better prognoses and higher volume centres are likely to treat those with patients with a range of prognoses (due to the availability of facilities and expertise). Therefore, higher volume centre outcome data may be skewed differently compared to lower volume centres. The two should not necessarily be compared without taking case mix into consideration. |

## References

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# Indicator 14. Mortality

| | |
|---|---|
| **Indicator description** | Proportion of PC patients who died within 30 and 90 days of beginning treatment with curative intent (not palliative). |
| **Rationale and evidence** | While crude mortality is available, it is important to calculate risk-adjusted perioperative mortality for pancreatic resection and other treatments. |
| **Equity/Māori health gain** | Later presentations mean fewer resections for Māori. This is particularly important as Māori have a higher rate of mortality following resection. |
| **Specifications** | |
| **Numerator** | Number of PC patients who died within 30 and 90 days of treatment with curative intent. |
| **Denominator** | Number of PC patients who had treatment with curative intent. |
| **Notes** | An annual audit of risk-adjusted mortality after pancreatic resection may be possible due to small case volumes and number of surgeons.<br>Comparison between providers should be made with caution where the denominator is the number of PC patients who received treatment. This is due to variations in case complexity. Centres that perform fewer pancreatic resections are likely to treat those with better prognoses and higher volume centres are likely to treat those with patients with a range of prognoses (due to the availability of facilities and expertise). Therefore, higher volume centre outcome data may be skewed differently compared to lower volume centres. The two should not necessarily be compared without taking case mix into consideration. |

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Wylie N, Hider P, Armstrong D, et al. 2018. The volume, cost and outcomes of pancreatic resection in a regional centre in New Zealand. *ANZ Journal of Surgery* 88: 1258–62.

# Indicator 15.
# Overall survival

| | |
|---|---|
| **Indicator description** | Proportion of PC patients surviving at 1, 2, and 5 years from diagnosis. |
| **Rationale and evidence** | For the majority of cancers, the survival at 5 years after diagnosis is generally accepted as an indication of cure.<br>As PC has a poor prognosis, 1-year survival time is also included as an indicator of effectiveness of care. |
| **Equity/Māori health gain** | Māori have similar rates of pancreatic cancer up until around 45 years of age, after which the groups diverge and Māori appear to have higher age-specific rates.<br>Overall, incidence of PC is significantly higher for Māori (10.4/100,000) compared with non-Māori (6.7/100,000).<br>Māori have disproportionately poor survival outcomes: median overall survival is 41 days for Māori and 90 days for NZ Europeans. The 1-year survival is 16% overall (Māori 14%, NZE 20%). |
| **Specifications** | |
| **Numerator** | Number of PC patients surviving at 1, 2, and 5 years from diagnosis. |
| **Denominator** | Number of patients diagnosed with PC. |
| **Notes** | PC is an increasing cause of cancer deaths and New Zealand's 1, 2 and 5-year survival rates are the lowest among comparable countries.<br>Data from LDHB shows that median overall survival is 71 days – 41 days for Māori compared to 90 days for NZ European. For patients who received palliative chemotherapy, overall survival was 240 days compared to 34 days for patients who only received palliative care.<br>Data on overall survival for resectable PC was not obtained. Patients who had borderline resectable PC had a median overall survival of 167 days compared to 157 days in those who presented with locally advanced PC, and 43 days in those with metastatic PC.<br>Numerator and denominator data are likely to be inaccurate as PC diagnosis is generally obtained from death certificates, and advanced patients don't necessarily get a biopsy or formal diagnosis. |

## References


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Phillips AR, Lawes CM, Cooper GJ, et al. 2002. Ethnic disparity of pancreatic cancer in New Zealand. *International Journal of Gastrointestinal Cancer* 31(1–3): 137–45.

# Indicator 16.
# Palliative care

| | |
|---|---|
| **Indicator description** | Proportion of advanced PC patients referred to palliative care services. |
| **Rationale and evidence** | Palliative care has a major role to play in the care of PC patients as >70% are not offered definitive 'curative' treatment at the time of presentation. Furthermore, >90% patients overall will ultimately die of PC. All of these patients have the potential to benefit from specialist palliative services.<br>Palliative care referral is associated with significant reduction in use of chemotherapy near death, multiple ED visits and hospitalisations. |
| **Equity/Māori health gain** | Accessibility is an issue, due to a lack of palliative care services in remote regions.<br>Underutilisation of palliative care is associated with socioeconomic disparities. |
| **Specifications** | |
| **Numerator** | (i) Number of PC patients referred for palliative care services (as indicated in hospital, at advice of MDM, discharge from hospital or by GP).<br>(ii) Number of PC patients with advanced disease referred for palliative care services. |
| **Denominator** | Number of PC patients with advanced disease. |
| **Notes** | Despite being relevant to the majority of PC patients, there is great variability in access across the regions.<br>As a result, there are limited data (with data from LDHB reporting an average of 14 days from oncologic review to palliative treatment) on palliative care services for patients with PC, especially in the community.<br>The vast majority of patients are managed in the community (at home and in hospice) and it is not clear whether data collection is possible (eg, number of patients referred to palliative care with PC).<br>The need to make inferences about palliative care based on numerators and denominators listed, further highlights the need to capture this data and have this as a measurable QPI. |

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Michael N, Beale G, O'Callaghan C, et al. 2019. Timing of palliative care referral and aggressive cancer care toward end-of-life in pancreatic cancer: a retrospective, single centre observational study. *BMC Palliative Care* 18: 13(2019).

# Indicator 17.
# Clinical trial participation

| | |
|---|---|
| **Indicator description** | Proportion of PC patients participating in a clinical trial at any time after diagnosis. |
| **Rationale and evidence** | Progress in preventing, diagnosing and treating cancer predominantly comes from scientific research. This includes the testing of new, potentially more effective medications and procedures through clinical trials.<br>People who participate in these trials gain access to the very latest advances in cancer care developed by cancer specialists. |
| **Equity/Māori health gain** | No New Zealand data.<br>However, Māori and other minority ethnicities are under-represented in clinical trial participation. |
| **Specifications** | |
| **Numerator** | Number of PC patients treated on a clinical trial at any time after diagnosis. |
| **Denominator** | Number of PC patients. |
| **Notes** | PC trials are rare and difficult to recruit to.<br>Keeping a national database would increase awareness of what is available. For example, PURPLE: a prospective database of anonymised clinical outcomes collected in real-time with the hope for future tissue banking and correlation. |

## References


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# APPENDIX 1: WORKING GROUP MEMBERS

The National Pancreatic Cancer Working Group members in 2020 were:

## Chair

Professor John Windsor, Surgeon, Auckland DHB/University of Auckland

## Members

Associate Professor Adam Bartlett, Surgeon, Auckland DHB
Dr Andrew McCormick, Surgeon, Counties Manukau DHB
Dr Andrew Miller, Pathologist, Canterbury Health Laboratories
Dr Andrew Wilson, Anaesthetist, Auckland DHB
Dr Anna Wojtacha, Medical Oncologist, Nelson Marlborough DHB
Dr Chris McKee, Radiologist, Waitemata DHB
Dr Colleen Van Der Vyver, Palliative Medicine Specialist, Midcentral DHB
Dr Daniel Cookson, Interventional Radiologist, Counties Manukau DHB
Dr David Orr, Hepato/gastroenterologist, Auckland DHB
Dr David Rowbotham, Hepato/gastroenterologist, Auckland DHB
Dr Dean Harris, Medical Oncologist, Canterbury DHB
Dr Frank Weilert, Gastroenterologist, Waikato DHB
Dr Gabriel Lau, Radiologist, Southland DHB
Grant Middleton, Consumer
Helen Brown, Dietitian, Nurse Maude Canterbury
Dr Hermann Van der Vyver, Radiation Oncologist, Midcentral DHB
Dr Janet Hayward, General Practitioner, Nelson-Marlborough
Dr Jeremy Rossaak, Surgeon, Bay of Plenty DHB
Professor Jonathan Koea, Surgeon, Waitemata DHB
Professor John McCall, Surgeon, Southern DHB/Dunedin School of Medicine
Juliet Ireland, Clinical Psychologist and Clinical Advisor Te Aho o Te Kahu
Dr Kate Clarke, Medical Oncologist, Capital and Coast DHB
Dr Matthew Drake, Anatomical Pathologist, Canterbury DHB
Dr Michael Rogers, Surgeon, Waitemata DHB
Nadine Peake, Cancer Nurse Coordinator, Canterbury DHB
Dr Paul Restall, Histopathologist, Auckland DHB
Petro Nel, Clinical Nurse Specialist
Dr Saxon Connor, Surgeon, Canterbury DHB
Dr Simon Bann, Surgeon, Capital & Coast DHB
Sue Lodge, Palliative Care Nurse, Mary Potter Hospice, Kapiti
Dr Sam Wall, Anaesthetist, Auckland DHB